## Scientific and Medical Accountability Standards Working Group INFORMATION FORM FOR POTENTIAL MEMBERS

Pursuant to California Health and Safety Code [125290.55] the Independent Citizens' Oversight Committee of the California Institute for Regenerative Medicine shall have a Scientific and Medical Accountability Standards Working Group to recommend to the ICOC scientific, medical, and ethical standards. The Standards Working Group shall have 19 members: Five ICOC members from the10 groups that focus on disease-specific areas, nine scientists and clinicians nationally recognized in the field of pluripotent and progenitor cell research, four medical ethicists, and the chairman of the ICOC. "Medical ethicist" is defined [125292.10 (p)] as "an individual with advanced training in ethics who holds a Ph.D., M.A., or equivalent training and who spends or has spent substantial time (1) researching and writing on ethical issues related to medicine, and (2) administering ethical safeguards during the clinical trial process, particularly through service on institutional review boards.

XMr. \_\_Ms. \_\_ Dr. \_\_Mrs. \_\_Other\_\_\_\_ MARK BARNES Middle Initial Last Name Partner, Ropest Gray LLP ecturer, yale Univ. School of Medicine University, Company or Organization 45 Rockefeller Plaza Business Addres New York, NY City/State/Zip 10013 2-12 497 3635 Work Number mbarnes@ropesgray.com 1. What position in the Standards Working Group are you applying for? □ Scientist/clinician A Medical ethicist □ ICOC 2. Please indicate whether or not you are an expert in the following subjects using a "Y" for yes and an "N" for no. Please use the blank lines to list any other areas of your expertise that you feel might be relevant to serving on the working group.

The Biomedical Ethics of Stem Cell Research

Controls on research involving human subjects

Patient privacy laws and regulations

National Institutes of Health standards for research

National Academies' standards for biomedical research

*Compliance* for medical ethics, health and safety requirements

Expertise in medical regulatory agencies (such as the FDA)

 $\mathbf{v}^{\mathsf{T}}$  Expertise in the creation of public scientific resources

 $\underbrace{\searrow}$  Expertise in health disparities

3. The Working Group will develop draft interim standards. At the point that interim standards are adopted by the ICOC, a 270-day public hearing period begins, all subject to the California Administrative Procedure Act (APA). Working Group members will consider public comment as guidance in revising interim standards and procedures. Working Group members may also be asked to serve on subcommittees that may meet to develop standards or determine compliance in specific areas. At least 4 meetings per year are required for the Working Group; the specific meetings schedule and length of each meeting will be set by the membership, but in the first few months will likely be a few meetings to establish interim standards. Do you anticipate making such a time commitment?

No Ves

Please describe any constraints\_

4. Please attach a resume or CV.

5. Please be aware that Working Group members will be required to comply with conflict of interest standards determined by the Independent Citizens' Oversight Committee based on standards applicable to members of scientific review committees of the National Institutes of Health. The guidelines are under development.

Please send your completed information sheet and resume or CV by email (preferred) or mail with "Attn: Standards WG Search" to either:

- info@cirm.ca.gov or
- CIRM, 5858 Horton St., Ste. 455, Emeryville, CA 94608

#### PLEASE NOTE: THIS APPLICATION, TOGETHER WITH ANY ATTACHED MATERIALS, MAY BE SUBJECT TO DISCLOSURE PURSUANT TO THE CALIFORNIA PUBLIC RECORDS ACT.

#### MARK BARNES, J.D., LL.M.

Ropes & Gray LLP 45 Rockefeller Plaza New York, New York 10111 mbarnes@ropesgray.com (212) 497-3635

#### EXPERIENCE:

## **ROPES & GRAY LLP**

Partner, 2001-Present

Representation of hospitals, universities, medical schools, health care associations, physicians, and related organizations, in regulatory, reimbursement, research, compliance, privacy and litigation matters.

#### HARVARD UNIVERSITY

Interim Executive Director, Harvard AIDS in Africa, August 2004-January 2005

Seconded from Ropes & Gray to serve as first executive director for start-up of Harvard University's AIDS/HIV treatment programs in Nigeria, Tanzania and Botswana, funded under the President's Emergency Program for AIDS Relief (PEPFAR).

#### **PROSKAUER ROSE LLP**

Partner, Health Care Department, 1998-2001 Senior Counsel for Health Care, 1994-1998 <u>Pro bono</u> coordinator for corporate law matters. Editor-in-Chief, <u>Health Law Report</u>.

#### AIDS ACTION COUNCIL

#### AIDS ACTION FOUNDATION

Executive Director, February 1995- April 1996. Director of largest national AIDS lobbying and advocacy organization and supervisor of professional lobbyists, policy analysts and media/press officers. Responsible for lobbying and advocacy before Congress, federal agencies and the Office of the President on issues related to health care, Medicare/Medicaid, NIH research policy, and public health funding.

### NEW YORK CITY DEPARTMENT OF HEALTH

Associate Commissioner for Medical and Legal Policy, 1992-1994.

Responsibility for oversight and supervision of major policy, political, and organizational issues within the Department of Health relating to strategic planning, budget and finance, tuberculosis, AIDS/HIV, sexually transmitted disease control, clinical laboratory regulation, disease surveillance, lead poisoning control, and policy/program coordination with New York State Department of Health and United States Department of Health and Human Services. Direct supervision of Ryan White CARE Services program, a \$100 million health and social service delivery program for persons with HIV/AIDS in New York City.

## THE WHITE HOUSE

## NATIONAL HEALTH CARE REFORM TASK FORCE

Consultant and member of 10-person final legal/policy review committee for the President's national health care reform proposal; 1993.

# NEW YORK STATE DEPARTMENT OF HEALTH AIDS INSTITUTE

Director of Policy, 1989-1991.

Responsibility for formulation of public policy statements and position papers; drafting of legislation and health care regulations; coordination and oversight of State-funded HIV prevention, primary care, long-term care, and legal services programs; liaison with federal and State agencies; and supervision of enforcement staff for medical confidentiality laws and regulations.

#### **EDUCATION:** COLUMBIA UNIVERSITY SCHOOL OF LAW

LL.M., 1991; concentrations in public health law, employment law, and constitutional law.

#### YALE LAW SCHOOL

J.D., 1984 Joseph Parker Prize for Roman Law Yale-A.B.A. Prize for Property Law Class of '84 Co-Secretary, 1994-2009.

#### **BENNINGTON COLLEGE**

B.A., 1981; concentrations in Greek, Latin and political theory.

## <u>ACADEMIC</u> <u>APPOINTMENTS</u>: YALE UNIVERSITY SCHOOL OF MEDICINE

Lecturer, Department of Internal Medicine, 2004-present. Subjects: Informed consent, research law and regulations, law and medicine.

## CARDOZO LAW SCHOOL

Adjunct Professor of Law, 2004-present. Subject: Health law.

## **BROOKLYN LAW SCHOOL**

Adjunct Professor of Law, 2001-present. Subjects: health care transactions and managed care law; health care law, law of human subjects research.

## NEW YORK UNIVERSITY SCHOOL OF LAW

Adjunct Professor of Law, 1999-2000. Subject: health care law.

## PACE UNIVERSITY LAW SCHOOL

Adjunct Professor of Law, 1996-present. Subjects: public health law, occupational safety and health law.

#### COLUMBIA UNIVERSITY SCHOOL OF PUBLIC HEALTH

Lecturer in Public Health, 1995-1997.

#### **NEW YORK LAW SCHOOL**

Adjunct Professor of Law, 1992-present. Adjunct Associate Professor of Law, 1990-1992. Subjects: public health law, health care law and finance, AIDS and the law.

## COLUMBIA UNIVERSITY SCHOOL OF LAW

Assistant Clinical Professor of Law, 1989. Founder and Co-Director, AIDS Law Clinic, 1987-89; supervision of trial advocacy/legal services program staffed by Columbia Law School students. Lecturer in Law, 1988-89.

Associate in Law and Finkelstein Fellow, 1986-88.

## RECENT PROFESSIONAL ACTIVITIES:

## SECRETARY'S ADVISORY COMMITTEE ON HUMAN RESEARCH PROTECTIONS, UNITED STATES DEPARTMENT OF HEALTH AND HUMAN SERVICES

Committee Member, 2003-present.

Co-Chair, Committee on Human Subjects Research in Correctional Settings, 2003-2005.

## NATIONAL HUMAN RESEARCH PROTECTIONS ADVISORY COMMITTEE, UNITED STATES DEPARTMENT OF HEALTH AND HUMAN SERVICES

Committee member, 2000-2003. Chair, Working Group on Conflicts of Interest in Research.

# **PARTNERSHIP FOR HUMAN RESEARCH PROTECTIONS, INC.** (HCQA-JCAHO partnership for IRB accreditation)

Board member and Executive Committee member, 2003-present. Chair, Finance and Audit Committee

## NEW YORK STATE BAR ASSOCIATION, HEALTH LAW

## SECTION

Chair-elect, 2006-2007. Executive Committee Member, 2002-present Vice-Chair, 2004-2005. Treasurer, Health Law Section, 2003-2004. Secretary, Health Law Section, 2002-2003. Chair, Committee on Health Care Providers, 2000-2002

#### **DOCTORS OF THE WORLD**

Board Member and Executive Committee Member, 1997-2002. Chair, Nominations and Governance Committee, 1997-2002.

## AIDS ACTION FOUNDATION

Board Member, 1996-1998.

## NEW YORK STATE AIDS ADVISORY COUNCIL COMMITTEE ON ETHICAL ISSUES REGARDING ACCESS TO HIV TREATMENTS

Committee Member, 1997.

Other consulting work with the Institute of Medicine; Open Society Institute; National Commission on AIDS; Health Resources and Services Administration, Centers for Disease Control and Prevention, and Agency for Health Care Policy and Research, U.S. Department of Health and Human Services; New York State AIDS Advisory Council; and U.S. Congress Office of Technology Assessment.

## CURRENT EDITORIAL BOARDS:

FDA News IRB: Ethics and Human Research BNA Medical Research Law and Policy

Peer review of articles in the Journal of the American Medical Association, American Journal of Public Health, and Journal of Law, Medicine and Ethics

#### <u>RECENT</u> <u>PUBLICATIONS</u>:

<u>Multimedia Presentations in the Age of HIPAA</u>, Surgical Endoscopy 2004 (with K. Goodell, K. Heffernan and S. Schwaitzberg).

<u>Can Informed Consent be Tailored for the Critical Care Unit?</u>, 25 Health L. Canada 10 (September 2004) (with P. Florencio and B. Wyatt).

The "Future Uses" Dilemma: Secondary Uses of Data and Materials by <u>Researchers and Commercial Research Sponsors</u>, BNA Med. Research Law & Pol'y Rep. 440 (June 2, 2004) (with K. Gallin Heffernan).

<u>Auditing for Human Subjects Research Compliance:</u> Informed Consent, New Perspectives on Healthcare Auditing 23 (Spring 2004) (with K. Gallin Heffernan)

<u>Recent Developments in Research Compliance</u>, 22 New Perspectives on Healthcare Auditing 22 (Fall 2003) (with K. Gallin).

<u>HHS Draft Guidance on Financial Conflicts of Interest</u>, 25 IRB: Ethics and Human Research 15 (September-October 2003) (with K. Gallin).

<u>"Exempt" Research after the Privacy Rule</u>, 25 IRB: Ethics and Human Research 5 (July-August 2003) (with K. Gallin).

Conflict of Interest in Human Subjects Research, 31 Critical Care Med. 5137 (March 2003) (with J. Groeger).

HIPAA and Human Subjects Research: A Question and Answer Reference Guide, (March 2003) (with J. Kulynych). <u>Chevron v. Echazaba: Public Health Issues Raised by the "Threat of Self"</u> <u>Defense to Adverse Employment Actions</u>, 93 Amer. J. Pub. Health. 536 (April 2003) (with P. Florencio).

<u>HIPAA Compliance Steps for Commercial Research Sponsors</u>, BNA Med. Research Law & Pol'y Rep. 152 (February 19, 2003) (with C. Hermes and G. Glover).

<u>Restoring Balance to Industry-Academia Relationships in an Era of</u> <u>Institutional Conflicts of Interest: Promoting Research While Maintaining</u> <u>Trust</u>, 289 J. Amer. Med. Ass'n 741 (February 12, 2003) (with M.E. Johns and P. Florencio).

<u>Clinical Trial Agreements between Medical Schools and Industry</u> (letter), 348 New Eng. J. Med. 476 (Jan 30, 2003) (with K. Gallin).

Investigator, IRB and Institutional Financial Conflicts of Interest in <u>Human Subjects Research: Past, Present and Future</u>, 32 Seton Hall L. Rev. 525 (2002) (with P. Florencio).

<u>HIPAA-Related Liability for Employers</u>, FDLI Update 4 (Nov.-Dec. 2002) (with B. Wyatt and P. Florencio).

<u>Financial Conflicts of Interest in Human Subjects Research: The Problem</u> <u>of Institutional Conflicts</u>, 30 J. Law Med. & Ethics 390 (Fall 2002) (with P. Florencio).

<u>Clinical Research After the August 2000 Privacy Rule Amendments</u>, BNA Med. Research Law & Pol'y 406 (Sept. 18, 2002) (with C. Hermes).

Health Care Privacy, Bioterroism Preparedness and Other Challenge for Health Care Providers in the Post-September 11<sup>th</sup> World, BNA Health Care Pol'y 964 (July 15, 2002) and BNA Health Law Reporter 1125 (August 1, 2002) (with B. Wyatt, C. Hermes and K. Cleaveland).

<u>The HIPAA Privacy Rule: A Guide to Conducting State Law Preemption</u> <u>Analysis</u>, BNA Health Law Reporter 659 (May 2, 2002) (with M. Garvin, P. Florencio, K. Gallin and B. Wyatt).

<u>The Effect of the Proposed HIPAA Amendments on Human Subjects</u> <u>Research</u>, BNA Med. Research Law & Pol'y 81 (April 17, 2002) (with C. Hermes).

<u>The Effect of HIPAA on Human Subjects Research</u>, BNA Health Law Reporter 1026 (June 28, 2001) (with S. Krauss).

<u>The Health Insurance Portability and Accountability Act: Privacy and</u> <u>Security in Cyberspace</u>, in E. Kornreich, <u>The Health Care E-Commerce</u> <u>Revolution</u> (Practicing Law Institute, 2001).

<u>The HIPAA Compliance Challenge</u>, Metropolitan Corporate Counsel (March 2001) (with S. Krauss and B. Wyatt).

<u>IRBs Tend to Grow Short of Needed Skills</u>, National Law Journal (Sept. 4, 2000) (with S. Krauss).

<u>Conflicts of Interest in Human Research: The Risks and Pitfalls of "Easy</u> <u>Money" in Research Funding</u>, BNA Health Law Reporter 1378 (August 31, 2000) (with S. Krauss).

In Research, Follow the Money: The Rise of Private Funding Creates Conflicts That Could Be Deadly, Legal Times (June 19, 2000).

Evidence of Race-Based Discrimination Triggers New Legal and Ethical Scrutiny, BNA Health Law Reporter 1984 (December 16, 1999) (with E. Weiner).

<u>Research Issues Take Center Stage in Compliance Process</u>, BNA Health Law Reporter 1344 (August 12, 1999) (with S. Krauss).

Legal and Ethical Issues in Revising Human Immunodeficiency Virus Postexposure Protocols, 102 (5B) Amer. J. Med. 111 (May 19, 1997).

<u>Medicaid Managed Care and the Survival of TB, HIV/AIDS and STD</u> <u>Programs in Georgia</u>, Georgia Association for Primary Health Care, August 1996.

<u>Medicaid Reform and Managed Care:</u> Implications for People with HIV and the Organizations That Serve Them, AIDS Action Foundation, 1996.

<u>Bloodborne Pathogen Transmission From Health-Care Worker to Patients:</u> <u>Legal Issues and Provider Perspectives</u>, 75 Surgical Clinics of North America 1205 (Dec. 1995).

<u>Public Health and Individual Rights: Tuberculosis Control and Detention</u> <u>Procedures in New York City</u>, 12 Yale Law & Pol'y Rev. 38 (1994) (with C. Ball). Mandatory HIV Testing of Immigration Applicants: New York Responds with an Educational Program for INS Civil Surgeons, 6 AIDS & Pub. Pol'y J. 64 (1991) (with G. Cairns, M. Gourlay-Doyle, S. Perryman, A. Stern and G. Stern).

The HIV-Infected Health Care Worker: Employment Policies and Public Health, 18 Law, Med. & Health Care 311 (1990).

Access to Health Care, Education and Public Accommodations, in <u>AIDS</u> <u>Legal Practice Guide</u> (1990).

Providing High-Quality, Low-Cost Legal Services to People with AIDS: An Antidiscrimination Law Project, AIDS Care 297 (1989).

<u>Neuropsychological Impairment of HIV-Infected Persons: Implications</u> for the Workplace, presented at V International Conference on AIDS, Montreal, Canada, June 1989.

Legal and Ethical Issues in the Management of HIV-Infected Children, 1989 Renata and Allen Hunter Lecture in Law and Ethics, Albert Einstein College of Medicine, March 1989.

<u>Control and Prevention of HIV Infection in Intravenous Drug Users</u>, 110 Annals Internal Med. 833 (May 15, 1989) (with P. Brickner, A. Torres, R. Newman, D. DesJarlais, D. Whalen and Dr. Rogers).

Toward Ghastly Death: The Censorship of AIDS Education, 89 Colum. L. Rev. 698 (1989).

Education of Intravenous Drug Users in Report to the New York State AIDS Advisory Council, Committee on Management of Intravenous Drug Use and HIV Infection (April 1988).

<u>Confidentiality of Medical Information</u>, Chapter 4 of <u>AIDS Legal Guide</u> (A. Rubenfeld, ed. 1988).

Comments of the American Civil Liberties Union on Proposed Regulation for Adding HIV Infection to the List of Dangerous Contagious Diseases of the Immigration and Nationality Act (August 1987).

<u>AIDS and Mr. Korematsu: Minorities at Times of Crisis</u>, 7 St. Louis U. Pub. L. Rev. 35 (1988).

EDITORIALS:	"The Whistleblower Culture," Metropolitan Corporate Counsel, March 2001.		
	"A Lesson in 'Pure' State Control," Chicago Tribune, January 31, 1996.		
	"AIDS Shows Flaws In Block Grant Plan," Dallas Morning News, January 29, 1996.		
	"Losers In Budget Battle Could Be Persons With AIDS," Miami Herald, December 26, 1995.		
	"Poor and Sick Need Medicaid," Bangor Daily News, December 6, 1995.		
	"Local AIDS Patients Need Medicaid," Greensboro (N.C.) News & Record, November 19, 1995.		
	"But Beware The Cuts In Medicaid," Richmond Times-Dispatch, October 28, 1995.		
<u>BAR</u> ADMISSIONS:	Connecticut and New York		
PROFESSIONAL ASSOCIATIONS:	New York State Bar Association, Health Law Section American Public Health Association American Society of Law, Medicine and Ethics American Association for the History of Medicine		

# Scientific and Medical Accountability Standards Working Group INFORMATION FORM FOR POTENTIAL MEMBERS

Pursuant to California Health and Safety Code [125290.55] the Independent Citizens' Oversight Committee of the California Institute for Regenerative Medicine shall have a Scientific and Medical Accountability Standards Working Group to recommend to the ICOC scientific, medical, and ethical standards. The Standards Working Group shall have 19 members: Five ICOC members from the10 groups that focus on disease-specific areas, nine scientists and clinicans nationally recognized in the field of pluripotent andprogenitor cell research, four medical ethicists, and the chairman of the ICOC. "Medical ethicist" is defined [125292.10 (p)] as "an individual with advanced training in ethics who holds a Ph.D., M.A., or equivalent training and who spends or has spent substantial time (1) researching and writing on ethical issues related to medicine, and (2) administering ethical safeguards during the clinical trial process, particularly through service on institutional review boards.

\_\_Mr. \_\_Ms. \_X\_Dr. \_\_Mrs. \_\_Other\_\_\_\_

Norman Fost First Name

Middle Initial

Last Name

<u>Professor, Pediatrics and Bioethics; Director, Program in Bioethics</u> Title

<u>University of Wisconsin – Madison</u> University, Company or Organization

600 Highland Ave, Department of Pediatrics Business Address

Madison, Wisconsin 53792 City/State/ Zip

608-263-8562 608-218-9155 Work Number Home number

ncfost@wisc.edu Email

 1. What position in the Standards Working Group are you applying for?

 □ ICOC
 □ Scientist/clinician
 X Medical ethicist

2. Please indicate whether or not you are an expert in the following subjects using a "Y" for yes and an "N" for no. Please use the blank lines to list any other areas of your expertise that you feel might be relevant to serving on the working group.

- Y The Biomedical Ethics of Stem Cell Research
- Y \_ Informed Consent

- Y Controls on research involving human subjects
- Y\_ Patient privacy laws and regulations
- Y National Institutes of Health standards for research
- Y\_ National Academies' standards for (stem cell) biomedical research
- Y\_Compliance for medical ethics, health and safety requirements
- Y\_Expertise in medical regulatory agencies (such as the FDA)
- N\_Expertise in the creation of public scientific resources
- N\_Expertise in health disparities

I have chaired the Health Sciences IRB at the University of Wisconsin for 28 years and played a leadership role in developing the guidelines followed by Prof. James Thomson in his derivation of human embryonic stem cells. I also chair the University of Wisconsin Bioethics Advisory Committee, which developed guidelines for stem cell research at the University. I was a member of the AAAS Working Group on Stem Cell Research I am a member of the National Academy of Sciences Committee on Guidelines for Human Embryonic Stem Cell Research.

3. The Working Group will develop draft interim standards. At the point that interim standards are adopted by the ICOC, a 270-day public hearing period begins, all subject to the California Administrative Procedure Act (APA). Working Group members will consider public comment as guidance in revising interim standards and procedures. Working Group members may also be asked to serve on subcommittees that may meet to develop standards or determine compliance in specific areas. At least 4 meetings per year are required for the Working Group; the specific meetings schedule and length of each meeting will be set by the membership, but in the first 12 months will likely be 6 - 8 meetings. Do you anticipate making such a time commitment?

Yes X No\_\_\_\_

Please describe any constraints: I assume there will be compensation for travel expenses. It would be helpful to know if there will also be compensation for time.

4. Please attach a resume or CV. Attached

5. Please be aware that Working Group members will be required to comply with conflict of interest standards determined by the Independent Citizens' Oversight Committee based on standards applicable to members of scientific review committees of the National Institutes of Health. The guidelines are under development.

Please send your completed information sheet and resume or CV by email (preferred) or mail with "Attn: Standards WG Search" to either:

- <u>info@cirm.ca.gov</u> or
- CIRM, 5858 Horton St., Ste. 455, Emeryville, CA 94608

Forms are due postmarked or emailed by midnight Tuesday February 22, 2005.

PLEASE NOTE: THIS APPLICATION, TOGETHER WITH ANY ATTACHED MATERIALS, MAY BE SUBJECT TO DISCLOSURE PURSUANT TO THE CALIFORNIA PUBLIC RECORDS ACT.

## CURRICULUM VITAE

Name:	Norman Fost, M.D., M.P.H.
Date of Birth:	January 6, 1939
Place of Birth:	Newark, New Jersey
EDUCATION:	
1960	Princeton University, A.B.
1964	Yale University, M.D.
1973	Harvard University, M.P.H.
POSTGRADUATE TRAINING:	
1964-1967	Internship and Residency Department of Pediatrics Johns Hopkins Hospital
1969-1970	Chief Resident, Outpatient Department Johns Hopkins Hospital
1970-1971	Chief Resident Department of Pediatrics Johns Hopkins Hospital
MILITARY SERVICE:	
1967-1969	Captain to Major U.S. Army Medical Corps Pediatric Service, U.S. Army Hospital Fort Jackson, South Carolina
PROFESSIONAL APPOINTMENTS:	
1971-1972	Chief of Professional Services Edwards A. Park Building Johns Hopkins Hospital
1971-1973	Assistant Professor Department of Pediatrics Johns Hopkins Hospital
1972-1973	Fellow, Joseph P. Kennedy, Jr. Foundation Program in Law, Medicine, and Ethics Harvard University

1973-1977

Assistant Professor University of Wisconsin

#### PROFESSIONAL APPOINTMENTS (cont'd):

	1973-1994	Director, Residency Training Program Department of Pediatrics University of Wisconsin Hospital
	1973-Present	Director, Program in Bioethics University of Wisconsin
	1973-Present 1977-present	Health Sciences Institutional Review Board University of Wisconsin Chairman
	1975-Present	Director, Child Protection Team University of Wisconsin Children's Hospital
	1977-1982	Associate Professor University of Wisconsin
	1982-Present	Professor, Department of Pediatrics Professor, Department of Medical History & Bioethics University of Wisconsin
	1984-Present	Chairman, Hospital Ethics Committee University of Wisconsin Hospital
	1985-1994	Vice Chairman, Department of Pediatrics University of Wisconsin
	1996-1997	DeCamp Visiting Professor of Pediatrics, Princeton University
	1998 - present	Chairman, Bioethics Advisory Committee University of Wisconsin – Madison
	2002	Harvard University Course on International Research Ethics Faculty
	2004- present	Vice Chairman, Department of Medical History and Bioethics
	2004- present	Professor, Department of Population Health Sciences
HONO	<u>RS:</u>	
	1994-1998	Princeton University, Board of Trustees (Elected)
	1997	Nellie Westerman Prize for Research Ethics

American Academy of Pediatrics, Section on Bioethics: William G. Bartholome Award for Ethical Excellence

PROFESSIONAL ACTIVITIES (SELECTED):

2003

## NATIONAL:

	National Academy of Sciences
1973-1975	National Research Council
	Committee for the Study of Inborn Errors
	of Metabolism, Consultant
1988	Workshop on Children's Catastrophic Health Care
1900	Institute of Medicine
1983	Workshop on Ethics Commissions
1990	Committee on Perinatal HIV Screening
1991-1992	Committee on Assessing Genetic Risks
2002	Conference on Smallpox Vaccine Policy
2004-2005	Committee on Guidelines for Human Embryonic Stem Cell Research
2001 2000	
	American Academy of Pediatrics
1981-1990	Committee on Bioethics
1986-1990	Chairman
1984	Task Force on Guidelines for Infant Bioethics Committees
1988-1993	Task Force on Pediatric AIDS
1995-1999	Section on Bioethics Executive Board (Elected)
2003	William G Bartholome Award for Excellence in Ethics
	US Congress Office of Technology Assessment
1986	Technology and Child Health Advisory Panel
1991	Chairman, Workshop on Cystic Fibrosis
	Genetic Screening and Insurance
	National Institutes of Health
1990	Workshop on Heterozygote Screening for Cystic Fibrosis
1002 1002	Data Safaty and Manitaring Paarda
1992-1993	Data Safety and Monitoring Boards
1995-	Turner Syndrome - Growth Hormone Study Enalapril After Anthracyclines Study
1994-2003	Prostate Cancer Prevention Trial (SWOG)
2004- present	Best Pharmaceuticals for Children Act
2004- present	Dest Filamaceuticals for Children Act
1998-Present	Hyperaccelerated Award Special Review Group
1990-1 199611	Hyperaccelerated Award Opecial Neview Oroup
1973-1979	National Center for Law and the Handicapped
	South Bend, Indiana, Consultant
1974-1975	National Commission for the Protection of Human
	Subjects of Biomedical and Behavioral Research
	Fetal Research Study Group
1974-1985	National Endowment for the Humanities
	Fellowships in Science and Humanities
	Consultant
1981	
1501	President's Commission for the Study of Ethical
	Problems in Medicine, Invited Testimony
1985	Problems in Medicine, Invited Testimony

	Working Group on Stress in Residency Training
1988-1989	Medical Task Force on Anencephaly Representative from American Academy of Pediatrics
1991	American Association of Bioethics Original Planning Group
1991	Access to Treatment with Human Growth Hormone National Conference, Madison WI Organized (with Dr. David Allen)
1991-1992	Women Judges Fund for Justice Consultant and speaker for judicial education conferences
1991-1992	American Society of Human Genetics
1991-1992	Co-Chairman, Committee on Insurance Issues Committee on CF Population Screening
	Editorial Boards
1978-2000	IRB: A Review of Human Subjects Research
1991-1998 1992-1995	Politics, Ethics and the Life Sciences Current Problems in Pediatrics (co-editor)
2002-	American Journal of Law, Medicine and Ethics
1993	Clinton Health Care Task Force Ethics Working Group
1993	Annual Bioethics Retreat (Meeting of 120 leading bioethicists) Conference Organizer
1993	FDA Consultant on "Waived consent for emergency research"
1994, 1995	Food and Drug Administration Staff College, 8-session course on "Ethical Issues in Human Experimentation"
1994-1996	National Center for State Courts Committee on Guidelines for "End of Life Decisions"
1994- 2003	Southwest Oncology Group
	Data Safety Monitoring Board
	Finasteride Prostate Cancer Prevention Trial
1995	American Medical Association Task Force on Quality Care at the End of Life Consultant
1996	US Department of HHS
	Centers for Disease Control and Prevention
	Consultant on Newborn Screening for Cystic Fibrosis
1999	American Association for the Advancement of Science Working Group on Stem Cell Research

2000- present	Food and Drug Administration Pediatric Drug Advisory Subcommittee
2004- 2005	National Academy of Sciences Committee on Guidelines for Human Embryonic Stem Cell Research
STATE:	
1976-Present	Invited Testimony before Wisconsin Legislature -Genetic screening -Euthanasia -Malpractice -Baby Doe legislation -New genetic technology -Living Will bill -Brain death bills -AIDS confidentiality bill -Organ transplantation
1983	Arizona Legislature Consultation on "Baby Doe" Legislation
1983-1984	Wisconsin Office of Judicial Education Seminars on Child Abuse for Judges
PROFESSIONAL ACTIVITIES (SELECTED)	(conťd):
1985	Public Health Task Force on AIDS Wisconsin Department of Health and Social Services
1992	Appleton Consensus Conference on International Guidelines for Withholding Life Support
1993-	Wisconsin Department of Health and Human Services Newborn Screening Committee
OTHER INSTITUTIONS:	
1971-1973	Ethics Study Group Johns Hopkins Hospital
1974	National Cystic Fibrosis Research Foundation Conference on - "Ethical Problems in Heterozygote Screening in Cystic Fibrosis", Consultant and Organizer
1974-1985	Joseph P. Kennedy, Jr. Foundation Fellowships in Medical Ethics Reviewer and Interviewer
1976-1978	Kennedy Institute "Total Immersion Course" in Medical Ethics 20

	Washington, D.C. Faculty Member
1980-1985	Cystic Fibrosis Foundation Working Group on Heterozygote Detection Chairman
1981-1984	St. Mary's Hospital, Madison, Wisconsin Formation of Hospital Ethics Committee Consultant and Series of Six Seminars
1982-1998	Agracetus Corporation, Middleton, Wisconsin Institutional Biosafety Committee; IACUC Committee
1983-Present	Exchange Club Project for Prevention of Child Abuse Founding Member, Board of Directors
1984-1985	WHA Radio Bi-weekly commentaries on medical ethics Madison, Wisconsin
1987-Present	The Hastings Center, Fellow
1989	American Medical Association Expert Panelist, DATTA Project (Diagnostic and Therapeutic Technology Assessment)
1993	NYU Law School, Appellate Judges Seminar

## PROFESSIONAL ACTIVITIES (SELECTED) (cont'd):

1994, 1995, 1999-2005	Johns Hopkins Medical Institutions Graduate Program in Clinical Trials 8-session course on "Ethical and Regulatory Issues in Clinical Trials"
1994-1998	Princeton University, Board of Trustees
1995-Present	Promega Corporation, Consultant to help establish an Institutional Review Board
1998-	Powderject Company, IACUC (Community Member)
2000	Ethical Issues in Access to Growth Hormone 2 <sup>nd</sup> National Conference, Madison WI Organized (With Dr. David Allen)

## UNIVERSITY OF WISCONSIN:

1973-Present	All-Campus Committee on Clinical Research University of Wisconsin
1974-1983	Pharmacy and Therapeutics Committee University of Wisconsin Center for Health Sciences
1975-1979	Faculty Advisor/Mentor for 11 medical students University of Wisconsin School of Medicine
1975-1994	Post-Graduate Advisory Committee University of Wisconsin School of Medicine
(1984-1993)	Chairman
1977-1979	Faculty Rights and Responsibilities Committee University of Wisconsin
1978-Present	Child Protection Team University of Wisconsin Hospital Director
1993	University of Wisconsin 1-day conference on Fraud and Integrity in Science Principal Organizer
1993-1996	UW Medical School Chairman, Committee on Conflicts of Interest
1993-1996	University of Wisconsin Graduate School Committee on Graduate Training in Scientific Ethics

#### REVIEWER (approximately 10 articles per year):

New England Journal of Medicine Pediatrics University of Wisconsin Press Pharmacy in History Journal of American Medical Association March of Dimes Reprint Series Journal of Pediatrics Journal of Medicine and Philosophy Child Abuse and Neglect **Prenatal Diagnosis** Hastings Center Report Milbank Memorial Quarterly Politics and the Life Sciences Am J Human Genetics J Clinical Ethics Social Science and Medicine

#### **MEMBERSHIPS:**

American Academy of Pediatrics American Society of Human Genetics American Society of Bioethics and Humanities

#### **CERTIFICATION AND LICENSURE:**

Diplomate, National Board of Medical Examiners Diplomate, American Board of Pediatrics Wisconsin Medical License

#### TEACHING RESPONSIBILITIES:

Courses:	
1973-1990	Ethical Issues in Medicine, Fourth-Year Students University of Wisconsin Medical School (given twice each academic year)
1973-Present	Pediatric Clerkship, University of Wisconsin Medical School. Attending Rounds (1-3 months per year), Grand Rounds, Lectures and Conferences
1973-Present	Ethics Rounds Monthly case conferences on current cases
1974-Present	Ethical Problems Raised by New Biomedical Technologies University of Wisconsin College of Letters and Sciences (undergraduate) 3-credit course
1974-Present	Introduction to Medical Ethics, First-Year Students, University of Wisconsin Medical School 3-6 hours Lectures/discussion, as part of CMP I, II
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	(Clinical Medicine and Practice), now PDS (Patient, Doctor and Society)
1974-1995	Ethics Forums Monthly panel discussions on current controversies in health care
1993-2001	Department of Preventive Medicine Non-residential Program in Administrative Medicine Ethics Module: organizer, teach 4 hour session 2-3 times/year
1995-1997	Child Abuse Case Conference Monthly teaching conference reviewing abuse and neglect cases

## TEACHING RESPONSIBILITIES (cont'd):

1995-Present	Pediatric Ethics Case Discussions Med III students, 24 1-hour sessions (Organize and teach with other Ethics Program Faculty)
1995	Ways of Knowing (Undergraduate 1 credit Honors Course) Discussion group, met 6 times (with R Schapiro); Lecture on "Growth Hormone for Non GH Deficient Children"

Guest Lectures in numerous University of Wisconsin Programs and Courses (10-20 hours/year) including:

1974-Present	Law School Nursing School Institute for Environmental Studies School of Veterinary Medicine School of Allied Health Sciences School of Family Resources Physician Assistants Program Summer Genetics Institute for High School Biology Administrative Medicine Masters Program Most clinical departments
Graduate Students and Fellows:	
1975-1980	Natalie Rudolph, Ph.D., in Genetics Minor in Medical Ethics
1977-1978	Linda Besch, Candidate Masters in Nursing, Research thesis on "Quality of consent by physicians vs non-physicians"
1980-1981	Kathy Morris, Masters in Social Work (Genetic Associate) "Informed consent in mass genetic screening: A study of parental knowledge in Wisconsin"
1983-1984	JoEllyn Taylor, Masters in Social Work (Genetic Associate). "Applicability of computer-assisted instruction to genetic counseling"
1986-1992	Natalie Dahl, RN Ph.D. Candidate in Family Studies
1987-1990	Charles Williams, AB, MD U.W. Medical Scholars Program Special major in medical ethics
1988-1992	Larry Halversen, Ph.D. Environmental Studies Minor in Ethical Issues in Regulation of Biotechnology
1990-1994	Tim Richer A.B., Special major in medical ethics
1999-2001	Nicole Collins, Undergraduate Bioethics Major 25

#### PUBLICATIONS:

- 1. Fost NC. Successful treatment of juvenile hemangiomas with prednisone. <u>J. Peds</u>, 72:351, 1968.
- 2. Fost NC and Kaback MM. Why do sickle screening in children? <u>Pediatrics</u>, 51:742, 1973.
- 3. Fost NC. Intrauterine diagnosis for sickle-cell disease. (letter). <u>Pediatrics</u>, 52:463, 1973.
- 4. Fost NC. Our curious attitude toward the fetus. <u>Hastings Reports</u>, 4:2, 1974.
- 5. Fost NC. A surrogate system for informed consent. <u>JAMA</u>, 233:800, 1975.
- 6. Fost NC. Ethical considerations. In: <u>Genetic Screening: Programs, Principles, and Research</u>, Report of the Committee for the Study of Inborn Errors of Metabolism, National Academy of Sciences National Research Council, 1975.
- 7. Fost NC. Ethical problems in pediatrics. (monograph). In: Current Problems in Pediatrics, 6(12), Oct. 1976.
  - Fost NC and Cohen S. Ethical issues regarding case reports: to publish or perish the thought. <u>Clinical Research</u>, 24:269, 1976. (Nellie

Westerman Prize for research in ethics, Am Fed Clin Res, Honorable Mention).

- Robertson JA and Fost NC. Passive euthanasia of defective newborns: legal considerations. <u>J Peds</u>, 88:883, 1976.
- 10. Fost NC and Robertson JA. Care of hopelessly ill. (letter). <u>New Engl J Med</u>, 295:1142, 1976.
- 11. Fost NC. Teaching medical ethics to undergraduates. In: <u>Teaching Biomedical and Health Care Ethics to Liberal</u> <u>Arts Undergraduates</u>, Published by Associated Colleges of the Midwest, Chicago, 1977.
- 12. Fost NC. Children as kidney donors. <u>New Engl J Med</u>, 296:363, 1977.
- 13. Fost NC. Ethical issues in management of spina bifida: a physician's view. In: Swinyard CA(ed), <u>Decision</u> <u>Making and the Defective Newborn</u>. Springfield, Illinois; Charles C. Thomas, 1977.
- 14. Fost NC. Proxy consent for seriously ill newborns. In: Smith DH (ed), <u>No Rush to Judgment</u>. Bloomington, Indiana; The Poynter Center, 1977.
- 15. Fost NC. Children. In: Reich W (ed), <u>Encyclopedia of Bioethics</u>. Detroit, Michigan; Free Press, 1978.
- 16. Fost NC. Informed consent. In: Gellis S, Kagan B (eds), <u>Current Pediatric Therapy</u>. 8th edition. Philadelphia, PA; Saunders, 1978.
- 17. Fost NC. Consent as a barrier to research. <u>New Engl J Med</u>, 300:1271, 1979.
- 18. Fost NC. Prenatal diagnosis for Down Syndrome. JAMA, 242:2326, 1979.
- 19. Fost NC. Ethical problems in pediatric pharmacology: The Steroid-surfactant study. In: <u>Safe Drugs for</u> <u>Canadian Children</u>, 3rd Canadian Ross Conference, 1979.
- 20. Fost NC and Robertson JA. Deferring consent with incompetent patients in an intensive care unit. <u>IRB: A</u> <u>Review of Human Subjects Research</u>, 2:5, Aug. 1980.

- 21. Fost NC. Practicing procedures on dying children. <u>Hastings Center Report</u>, 10:12, 1980.
- 22. Fost NC, Chudwin D and Wikler D. The limited moral significance of fetal viability. <u>Hastings Center Report</u>, 10:10, 1980.
- 23. Fost NC. Research on the brain dead. <u>J Peds</u>, 96:54, 1980.
- 24. Fost NC. Counseling parents who have a child with a severe congenital anomaly. <u>Pediatrics</u>, 67:321, 1981.
- 25. Fost NC. Life and death decisions. In: Basson M (ed), <u>Rights and Responsibilities in Modern Medicine</u>. New York, NY; Alan R. Liss, 1981.
- 26. Fost NC. Ethical and psychosocial issues in prenatal diagnosis. <u>Pediatric Basics</u>, No. 29, 1981.
- 27. Fost NC. Ethical issues involving the care of critically ill newborns. <u>Pediatric Annals</u>, 10:16-22, 1981.
- 28. Fost NC. The rights of emotionally abused children. <u>J Peds</u>, 101:215-216, 1982.
- 29. Fost NC. Putting hospitals on notice. <u>Hastings Center Report</u>, 12:5-8, 1982.
- 30. Fost NC. Passive euthanasia of patients with Down's Syndrome. <u>Archives Int Med</u>, 142:2295-2296, 1982.
- 31. Fost NC. The new body snatchers. <u>Amer Bar Fnd Res J</u>, 718-732, Summer, 1983.
- 32. Fost NC. Let'em take steroids. <u>New York Times</u>, September 9, 1983.
- 33. Fost NC. Parental control over children. <u>J Peds</u>, 103:571-572, 1983.
- 34. Fost NC. Food for thought: Dresser on anorexia. <u>Wisconsin Law Review</u>, 375-384, 1984.
- 35. Fost NC. Ethical issues in the care of handicapped, chronically ill and dying children. <u>Pediatrics in Review</u>, 6:291-296, 1985.
- 36. Fost NC and Cranford R. Hospital ethics committees: administrative aspects. <u>J Am Med Assn</u>, 253(18):2687-2692, 1985.
- 37. Fost NC. Regulating genetic technology: values in conflict. In: Milunsky A, Annas G (eds), <u>Genetics and the Law-III</u>. New York, NY; Plenum Press, 1985.
- 38. Fost NC. Treatment of seriously ill and handicapped infants. In: Orlowski J (ed), <u>Ethical Moments in Critical</u> <u>Care Medicine</u>. Philadelphia, PA; WB Saunders, Critical Care Clinics, 2(1):149-159, January, 1986.
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- 41. Fost NC. Parents as decision makers for children. <u>Primary Care Clinics of North America</u>, Vol. 13, No. 2, June 1986.

- 42. Fost N. Human subjects in CPR research. In: Iserson KV, Sanders AB, Mathieu DR, Buchanan AE (eds.), <u>Ethics in Emergency Medicine</u>. Williams and Wilkins, Baltimore, 1986.
- 43. Oski F, Fost NC, et al. How far can confidentiality stretch? <u>Contemporary Pediatrics</u>, Jan, 1987.
- 44. Fost NC. What can a hospital ethics committee do for you? <u>Contemporary Pediatrics</u>, 119-129, Feb. 1987.
- 45. Fost N. Ethical issues in joint ventures. In: Burns L, Mancino DM (eds.). <u>Joint Ventures Between Hospital and</u> <u>Physicians</u>. Dow Jones-Irwin, Homewood, IL, 1987.
- 46. Oski F, Fost NC, et al. Should organs be taken from this patient? <u>Contemporary Pediatrics</u>, 110-17, Feb. 1987.
- 47. Fost NC. Ethical, social and legal issues in genetic medicine. In: Kaback M, Shapiro L, <u>Frontiers in Genetic</u> <u>Medicine</u>. 92nd Ross Conference on Pediatric Research, Ross Laboratories, Columbus OH, 1987.
- 48. Oski FO, Fost NC, Freeman J, et al. The needlestick incident: is this boy HIV positive? <u>Contemporary</u> <u>Pediatrics</u>, 4(7):48, July 1988.
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- 59. Farrell PM and Fost NC. Long-term mechanical ventilation in pediatric respiratory failure: medical and ethical considerations. <u>Am Rev Resp Dis</u>, 136:S36-S40, 1989.
- 60. Fleming MF, Bruno M, Barry K, Fost N. Informed consent, deception, and the use of disguised alcohol questionnaires. <u>American Journal of Drug & Alcohol Abuse</u>. 15(3):309-19, 1989.

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- 62. Fost NC. Removing organs from anencephalic infants: ethical and legal considerations. In: Volpe JJ (ed), <u>Clinics in Perinatology</u> (special issue on Neonatal Neurology). In press 1989.
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- 65. Allen D, Fost NC. Growth hormone therapy for short stature: panacea or pandora's box? <u>J Ped</u>, 117:16-21, 1990.
- 66. Ryan TJ, Graham TP, Annas GJ, DeMaria AN, Fost NC et al. Perspectives on the allocation of limited resourses in cardiovascular medicine. Task Force III, 21st Bethesda Conference: Ethics n Cardiovascular Medicine. <u>J Am</u> <u>Coll Cardiology</u>, 16(1):1-36, July, 1990.
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- 68. Fost NC. Discussion of case by Ragnar Nesbakken. In: Stanley J, <u>International Medical Ethics</u>, John Wiley, 1990.
- 69. Fost NC. I was "like whoa": a commentary on Michael Shapiro's "Performance Enhancement and the Control of Attributes." <u>So Calif Law Rev</u>, 65(1):115-120, Nov. 1991
- 70. Committee on Prenatal and Newborn Screening for HIV Infection. Hardy L (ed) <u>HIV Screening of Pregnant</u> <u>Women and Newborns</u>. Washington DC; National Academy Press, 1991.
- 71. Farrell PM, Mischler EH, Fost NC et al. Current issues in neonatal screening for cystic fibrosis and implications of the CF gene discovery. <u>Pediatric Pulmonology</u> (Supp) 7:11-18, 1991.
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- 73. Tluczek A, Mischler EH, Bowers B, Peterson N, Morris ME, Farrell PM, Bruns WT, Colby H, McCarthy C, Fost N, Carey P. Psychological impact of false-positive results when screening for cystic fibrosis. <u>Pediatric Pulmonology</u> <u>Supp</u>, 7:29-37, 1991.
- 74. Bloomberg J, Wozniak J, Fost N, Medearis D and Herzog D. Ethical dilemmas in child and adolescent consultation psychiatry. <u>J Amer Acad Child & Adol Psych</u>, 31(3):557-561, May, 1992.
- 75. Fost N. Ethical issues in genetics. In: Hall J, (ed.). <u>Pediatric Clinics of N America</u>, 39 (1): 79-89, 1992. (Feb).
- 76. Fost NC. Ethical implications of screening asymptomatic individuals. <u>The FASEB Journal</u> 6(10):2813-2817, July 1992.
- 77. Kling P, Fost N. A faculty-housestaff retreat. <u>Am J Dis Child</u>, 146:243-248, 1992. (Feb).

- 78. Fost N. Infant Care Review Committees in the Aftermath of Baby Doe. In: Caplan A, Blank R, Merrick J (eds.). <u>Compelled Compassion : Public Policy and the Care of Handicapped Newborns</u>. Humana Press, 1992.
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- 82. Fost N. The baby in the body. <u>Hastings Center Report</u>, Jan-Feb:31-32, 1994. (Jan-Feb).
- 83. Fost N. Ten bad reasons for not treating Baby K. <u>Trends in Health Care, Law and Ethics</u>, 9(1): 17-18, 22, 1994. (Winter).
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- 85. Ad Hoc Committee on Genetic Testing/Insurance Issues (Co-chair). Background Statement: Genetic Testing and Insurance. <u>Am J Hum Genet</u> 56:327-331, 1995.
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- 87. Green M, Fost N. Seven reasons for Wisconsin physicians to oppose proposed legislation to legalize physicianassisted suicide. <u>Wisc Med J</u> Dec 693-695, 1995.
- 88. Fost N. What's wrong with genetic engineering? Nothing new under the sun. <u>American J of Ethics and Medicine</u>, Spring 14-17, 1996.
- 89. Green MJ, Fost N. Genetic Education for Inherited Breast Cancer. An interactive CD-ROM 1996, University of Wisconsin.
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- 91. Gold S, Fost N. Survival Skills. <u>The New Physician</u> 46(9):37-38,1997.
- 92. Fost N. Bioethics of the Mother, Fetus and Newborn, in Fanaroff AA and Martin RJ (eds), <u>Neonatal-Perinatal</u> <u>Medicine</u> (6th edition), Mosby, St Louis, 1997.
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- 107. Green MJ, Fost N. Genetic Education for Inherited Breast Cancer. An interactive CD-ROM 1996, University of Wisconsin. (Reviewed in JAMA 281(17):1652, 1999 (May 5).
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- Wilfond B, Fost N. The introduction of cystic fibrosis carrier screening into clinical practice: policy considerations. <u>Milbank Quarterly</u>, 70 (4): 629-659, 1992. Reprinted in Arras J (ed), Ethical Issues in Modern Medicine, Mayfield Publishing Co.
- 11. Fost N. Death and Dying. In Fuhrman B, Zimmerman J (eds), <u>Pediatric Critical Care</u> (2nd edition), Mosby, St Louis MO, 1998.
- 12. Fost N. Ethics in Pediatric Care. In Behrman RE, Kliegman RM, Jensen HB. Nelson's <u>Textbook of Pediatrics</u>, 16th edition, Saunders, Philadelphia, 2000.

- 13. Buchanan A, Fost N. Ethical issues in screening for hemochromatosis. In Barton JC, Edwards CQ (editors), Hemochromatosis: Genetics, Pathophysiology, Diagnosis and Treatment. Cambridge University Press, Cambridge UK, 2000.
- 14. Ross LF, Fost N. Ethical Issues in Pediatric Genetics. In Feetham SL, Miller SM, McDaniel SM, Rolland JS (eds), *Individuals, Families and the New Genetics*. WW Norton & Co, New York, 2002 (in press).
- 15. Nelson RM, Fost N. Ethics in Pediatric Care. In Behrman RE, Kliegman RM, Jenson HB (editors), Nelsons Textbook of Pediatrics, 17th edition. Saunders, Philadelphia, 2003.

#### CHAPTERS (cont'd):

16. Fost N. Developing Hospital Policy: The University of Wisconsin Experience. In Youngner SJ, Anderson MW, Schapiro R. Transplanting Human Tissue:Ethics Policy and Practice. In press, Oxford Press, 2003.

#### AMERICAN ACADEMY OF PEDIATRICS STATEMENTS:

- 1. Committee on Bioethics, American Academy of Pediatrics. Religious exemptions from child abuse statutes. <u>Pediatrics</u>, 81:169-171, Jan. 1988.
- 2. Plotkin SA, Evans HE, Fost NC, et al. Task Force on Pediatric AIDS. Pediatric guidelines for infection control of human immunodeficiency virus (acquired immunodeficiency virus) in hospitals, medical offices, schools and other settings. <u>Pediatrics</u>, 82:801-807, Nov. 1988.
- 3. Perinatal HIV Infection. <u>Pediatrics</u>, 82:941-944, 1988.
- 4. Co-author. Infants and Children with AIDS: Placement in Adoption and Foster Care. <u>Pediatrics</u>, 83:609-612, April 1989.
- American Academy of Pediatrics, Committee on Adolescence, Committee on Bioethics, and Provisional Committee on Substance Abuse. Screening for drugs of abuse in children and adolescents. <u>Pediatrics</u>, 84(2):396-398, August 1989 (Principal author with K Schonberg).

#### TELEVISION APPEARANCES (selected list):

ABC Nightline (5) ABC "Good Morning America" CNN Crossfire Donahue Oprah NBC Today CBS Morning and Evening News Baby Doe issues; medical neglect; Christian Science Prosecution of Christian Scientists Christian Science Baby Doe Faith Healing Christian Science; Dr. Kevorkian Discovery of the CF gene; Baby Doe

#### VISITING PROFESSOR/ INVITED LECTURES (selected list):

1985	National Association of Children's Hospitals
1986	Conference of Chief Justices
1986	Johns Hopkins Hospital
1987	Hospital for Sick Children, Toronto
1987	Downstate Medical Center, Brooklyn
1988	University of Washington
1988	Mayo Clinic
1988	St. Louis Children's Hospital
1989	University of Pittsburgh
1989	University of Utah
1989	University of Tennessee
1990	Children's Hospital, National Medical Center
1990	Massachusetts General Hospital
1991	University of California, San Diego
1991	University of Virginia, Birdsong Lecture
1991	Society for Pediatric Research (President's Invited Lecture)

1991	University of Southern California Law School
1991	New Jersey Judicial College
1991	Cincinnati Children's Hospital
1991	Carleton College
1992	University of Medicine and Dentistry of New Jersey
1992	DePaul College of Law
1993	UCLA Department of Pediatrics
1993	University of Alabama Medical School
1993	Vanderbilt University, James Overall Visiting Professor
1993	University of Arizona, Vincent A Fulginiti Lectureship in Medical Education
1994	University of Pittsburgh Medical School, AOA Lecture
1994	Boston Children's Hospital, Harvard Medical School
1995	Emory University
1995	NYU Medical School
1995	Univ S Florida (AOA Lecture)
1995	New York Hospital- Cornell (Goldberg Lecture)
1996	North Shore University Hospital, NY (Boas Lecture)
1996	Dana Farber Cancer Center, Harvard Medical School
1999	Dartmouth Medical School
1999	Cleveland Clinic
2000	Johns Hopkins Medical Institutions
2000	Dartmouth College
2000	Princeton University
2000	Sloan Kettering Cancer Ctr, DeBeaumont Lecture
2001	Lyndon B Johnson Memorial Library
2001	Johns Hopkins Medical Institutions
2003	University of Tokyo
2003	University of Pittsburgh, Don Medearis Memorial Lecture
2004	Boston Childrens' Hospital
1975-2004	American Academy of Pediatrics Annual Meeting
	(Numerous lectures/workshops)

# Scientific and Medical Accountability Standards Working Group INFORMATION FORM FOR POTENTIAL MEMBERS

Pursuant to California Health and Safety Code [125290.55] the Independent Citizens' Oversight Committee of the California Institute for Regenerative Medicine shall have a Scientific and Medical Accountability Standards Working Group to recommend to the ICOC scientific, medical, and ethical standards. The Standards Working Group shall have 19 members: Five ICOC members from the10 groups that focus on disease-specific areas, nine scientists and clinicans nationally recognized in the field of pluripotent andprogenitor cell research, four medical ethicists, and the chairman of the ICOC. "Medical ethicist" is defined [125292.10 (p)] as "an individual with advanced training in ethics who holds a Ph.D., M.A., or equivalent training and who spends or has spent substantial time (1) researching and writing on ethical issues related to medicine, and (2) administering ethical safeguards during the clinical trial process, particularly through service on institutional review boards.

Mr. (or Prof.)

Henry First Name T. Middle Initial Greely Last Name

Dean F. and Kate Edelman Johnson Professor of Law; Professor, by courtesy, of Genetics Title

Stanford University University, Company or Organization

Stanford Law School, 559 Nathan Abbott Way. Business Address

Stanford, Ca. 94305-8610 City/State/ Zip

(650) 723.2517 Work Number (650) 279.9614 Cell Phone

hgreely@stanford.edu Email

2. What position in the Standards Working Group are you applying for?

Medical ethicist

2. Please indicate whether or not you are an expert in the following subjects using a "Y" for yes and an "N" for no. Please use the blank lines to list any other areas of your expertise that you feel might be relevant to serving on the working group.

(I'll use "S" means "some knowledge" – less than "an expert" but non-trivial) Y The Biomedical Ethics of Stem Cell Research Y Informed Consent Y Controls on research involving human subjects S Patient privacy laws and regulations S National Institutes of Health standards for research N National Academies' standards for biomedical research S *Compliance* for medical ethics, health and safety requirements Y Expertise in medical regulatory agencies (such as the FDA) N Expertise in the creation of public scientific resources N Expertise in health disparities

I also have substantial expertise in the area of "human/non-human chimeras," which may be an issue for the CIRM.

3. The Working Group will develop draft interim standards. At the point that interim standards are adopted by the ICOC, a 270-day public hearing period begins, all subject to the California Administrative Procedure Act (APA). Working Group members will consider public comment as guidance in revising interim standards and procedures. Working Group members may also be asked to serve on subcommittees that may meet to develop standards or determine compliance in specific areas. At least 4 meetings per year are required for the Working Group; the specific meetings schedule and length of each meeting will be set by the membership, but in the first 12 months will likely be 6 - 8 meetings. Do you anticipate making such a time commitment?

Yes\_\_\_\_\_

Please describe any constraints: My main constraint is an active teaching schedule, but I can almost always reschedule occasional classes. I would not expect major difficulties in attending 6 to 8 meetings in California in the first 12 months.

4. Please attach a resume or CV.

5. Please be aware that Working Group members will be required to comply with conflict of interest standards determined by the Independent Citizens' Oversight Committee based on standards applicable to members of scientific review committees of the National Institutes of Health. The guidelines are under development.

I would have no concerns about disclosing information to meet the broadest conceivable financial disclosure standards. Apart from our house and our retirement accounts (which are invested in mutual funds), my wife and I have no other significant assets.

Please send your completed information sheet and resume or CV by email (preferred) or mail with "Attn: Standards WG Search" to either:

- <u>info@cirm.ca.gov</u> or
- CIRM, 5858 Horton St., Ste. 455, Emeryville, CA 94608

Forms are due postmarked or emailed by midnight Tuesday February 22, 2005.

PLEASE NOTE: THIS APPLICATION, TOGETHER WITH ANY ATTACHED MATERIALS, MAY BE SUBJECT TO DISCLOSURE PURSUANT TO THE CALIFORNIA PUBLIC RECORDS ACT. HENRY T. GREELY Deane F. and Kate Edelman Johnson Professor of Law Professor, by courtesy, of Genetics Director, Center for Law and the Biosciences Co-Director, Program in Genomics, Ethics, and Society Stanford University

## Training

A.B., Political Science, Stanford Univ., 1974

J.D., Yale Law School, 1977

Law Clerk, Hon. John Minor Wisdom, U.S. Court of Appeals for the Fifth Circuit, 1977-1978

Law Clerk, Hon. Potter Stewart, U.S. Supreme Court, 1978-79

## Employment

Special Assistant, Deanne C. Siemer, General Counsel, Department of Defense, Aug. - Oct. 1979

Staff Assistant Charles W. Duncan, Jr., Secretary of Energy, Oct. 1979- Jan. 1981

Litigation attorney Tuttle & Taylor Inc., Los Angeles, 1981-1985 (partner from 1984)

Associate Professor and Professor Stanford Law School since 1985 (full professor from 1992)

### **Selected Memberships**

California Advisory Committee on Human Cloning Member (Jan. 1999 to Jan. 2002)

Ethics Advisory Committee, Scientific Advisory Committee, Genetic Tissue Banking Initiative, Cooperative Studies Program (CSP) Coordinating Center, U. S. Department of Veterans Affairs Member (1999 to present)

Ethics Advisory Committee, BEST study, U. S. Department of Veterans Affairs Member (1997 to present) Human Genome Diversity Project

Member, North American Regional Committee (Sept. 1993 to present) Chair, Ethics Subcommittee of N. Am. Regional Comm. (Sept. 1993 to present) Member, International Executive Committee (March 1997 to present)

World Cell Line Collection 1 (Collaboration between the Human Genome Diversity Project and the Centre de l'Etude de Polymorphism Humain) Ethics Officer (2000 to present)

National Academy of Sciences Committee on the Use of Third Party Toxicity Research with Human Research Participants Member (Dec. 2002 to Feb. 2004)

Ethics Advisory Committee, NIH Program Project on Human Genetic Variation (Cavalli-Sforza and Feldman, principal investigators)

Chair (1999 to present)

WHO Expert Advisory Committee, Report on Human Cloning Chair (1998)

Ad Hoc Study Section on Ethical, Legal, and Social Implications, National Institutes of Health Member (July 1999)

Stanford Center for Law and the Biosciences Founding Director, 2003 to present

Stanford Faculty Senate Member, winter 2000 through spring 2004 Vice chair, 2001-2002 Chair, 2002-2003

Stanford Planning and Policy Board Member, fall 2002 through spring 2004

Stanford University Center for Biomedical Ethics, Member, Steering Committee, (1991 to present); chair since fall 1995

Stanford Program in Genomics, Ethics, and Society, Co-Director (fall 1995 to present)

Leadership Council, Bio-X Program, Stanford University Member (May 2002 to present)

Executive Committee, Stanford Program in Regenerative Medicine

Member (December 2004 to present)

- Executive Committee, Stanford Center for Clinical Informatics Member (September 2004 to present)
- Stanford Program in Law, Science, and Technology Co-Director (fall 1998 to present), director (fall 1999 to 2001)

Organizer, Bay Area Academics Interested in Law and Bioscience (summer 2004 to now)

Ethics Advisory Board, Affymetrix Member (1997 to present)

## **Publications**

## Articles

Henry T. Greely, Seeking More Goodly Creatures, Cerebrum, Vol. 6, no. 4 49-57 (fall 2004)

Henry T. Greely, *Disabilities, Enhancements, and the Meanings of Sport*, 15 STANFORD LAW AND POLICY REVIEW 15:99-132 (2004)

Henry T. Greely, Defining Chimeras . . . and Chimeric Concerns, AMERICAN JOURNAL OF BIOETHICS, 3:No.

3, 17-20 (Summer 2003)

California Advisory Committee on Human Cloning, CLONING CALIFORNIANS? (Sacramento, CA. 2002)

(principal author), also published in the HASTINGS L. J., HASTINGS L. J. 53:1143-1203 (July 2002)

Henry T. Greely, *Cloning and Government Regulation*, HASTINGS L. J. 53:1085-96 (July 2002)

Philip W. Lavori, Heidi Krause-Steinrauf, Mary Brophy, Joel Buxbaum, Jennifer Cockroft, David R. Cox, Louis Fiore, Henry T. Greely, Harry Greenberg, Edward W. Holmes, Lorene M. Nelson, and Jeremy Sugarman, *Principles, Organization, and Operation of a DNA Bank for Clinical Trials: A Department of Veterans Affairs Cooperative Study*, Controlled Clinical Trials, 23:222-239 (2002)

Henry T. Greely, *Pharmacogenomics: Promise, Prospects, and Potential Problems*, MEDICAL ETHICS, vol. 9, issue 1, 1-2, 8 (Winter 2002)

Henry T. Greely, Informed Consent and Other Ethical Issues in Population Genetics, ANN. REV. GEN. 35:785.800 (2001)

Henry T. Greely, "Genotype Discrimination": The Complex Case for Some Legislative Protection, PENN. L. REV, 149:1483-1505 (May 2001)

Henry T. Greely, *Human Genomics Research: New Challenges for Research Ethics*, Perspectives in Biology and Medicine 44(2):221-229 (spring 2001)

Simon N. Whitney, Byron W. Brown, Howard Brody, Kirstein Alcser, Jerald Bachman, Henry T. Greely, *Views of United States Physicians and Members of the American Medical Association House of Delegates Toward Physician-Assisted Suicide*, J. GEN. INT. MED. 16(5):290-296 (May 2001)

Henry T. Greely, *Human Genome Diversity: What About the Other Human Genome Project?*, NAT. REV. GEN. 222-227 (March 2001)

Henry T. Greely, *The Revolution in Human Genetics: Implications for Human Societies*, SO. CAR. L. REV. 52:377-390 (winter 2001)

Henry T. Greely, Genes and Liberty: Commentary on Dr. Jacobs, PHAROS 64:20-22 (winter 2001)

Henry T. Greely, *Trusted Systems and Medical Records: Lowering Expectations*, 52 STANFORD L. REV. 1585-1593 (2000)

Henry T. Greely, *Iceland's Plan for Genomics Research: Facts and Implications*, 40 JURIMETRICS 153-191 (Winter 2000)

Henry T. Greely, *The Overlooked Ethics of the Human Genome Diversity Project*, POLITICS AND THE LIFE SCIENCES, (Sept. 1999)

Henry T. Greely, Breaking the Stalemate: A Prospective Regulatory Framework for Unforeseen Research Uses of Human Tissue Samples and Health Information, 34 WAKE FOREST L. REV. 737-766 (fall 1999)

Laura McConnell, Barbara A. Koenig, Henry T. Greely, and Thomas A. Raffin, co-editors, *Genetic Testing and Alzheimer Disease*, 3 GENETIC TESTING, issue 1 (May 1999)(special issue of 18 articles stemming from PGES 1997 project)

Henry T. Greely, *Special Problems in Genetic Testing for Alzheimer Disease*, GENETIC TESTING 3:115-119 (May 1999)

Laura McConnell, Barbara A. Koenig, Henry T. Greely, and Thomas A. Raffin, *Genetic Testing and Alzheimer Disease: PGES Recommendations*, GENETIC TESTING 3:3-12 (May 1999)

Henry T. Greely, Richard Epstein's MORTAL PERIL: Ebenezer Scrooge Meets the American Health Care System, U. ILL. L. REV. 1998:727:756

Henry T. Greely, *Banning "Human Cloning": A Study in the Difficulties of Defining Science*, SO. CAL. INTERDISC. L. J. 8:131-152 (1998)

Henry T. Greely, *Legal, Ethical, and Social Issues in Human Genome Research*, ANNUAL REVIEW OF ANTHROPOLOGY 27:473-502 (Oct. 1998)

Barbara A. Koenig, Henry T. Greely, Laura McConnell, Heather Silverberg, and Thomas A. Raffin, *PGES Recommendations on Genetic Testing for Breast Cancer Susceptibility*, JOURNAL OF WOMEN'S HEALTH 7:531-545 (June 1998)

Laura McConnell, Barbara A. Koenig, Henry T. Greely, and Thomas A. Raffin, *Genetic Testing and Alzheimer Disease: Has the Time Come?* NATURE MEDICINE 4:757-759.(July 1998)

Henry T. Greely, *Genetic Testing for Cancer Susceptibility: Challenges for Creators of Practice Guidelines*, 11 ONCOLOGY 171 (Nov. 1997)

Henry T. Greely, *The Control of Genetic Research: Involving the Groups Between*, HOUS. L. REV. 33:1397-1430 (1997)

North American Regional Committee, Human Genome Diversity Project, *Proposed Model Ethical Protocol* for Collecting DNA Samples, HOUS. L. REV. 33:1431-1473 (1997) (principal author)

Henry T. Greely, *Direct Financial Incentives in Managed Care: Unanswered Questions*, HEALTH MATRIX 6:53-88 (1996)

Henry T. Greely, *Quantitative Analysis of a Judicial Career: A Case Study of Judge John Minor Wisdom*, WASH. & LEE L. REV. 53:99-157 (1996)

Henry T. Greely, *Conflicts in the Biotechnology Industry*, 23 JOURNAL OF LAW, MEDICINE, AND ETHICS 354-359 (winter 1996)

Henry T. Greely, *Policy Issues in Health Alliances: Of Efficiency, Monopsony, and Equity*, 5 HEALTH MATRIX 37 (1995)

Henry T. Greely, *The Future of the American Health Care System: An Introduction to the Health Symposium*, 3 Stan. L. & Pol. Rev. 1 (1991)

Henry T. Greely, AIDS and the American Health Care Financing System, 51 Univ. Pitt. L. Rev. 73 (Fall 1989)

Henry T. Greely, A Footnote to "Penumbra" in <u>Griswold v. Connecticut</u>, 6 Const. Comm. 251 (Summer 1989)

Henry T. Greely, *The Ethical Use of Human Fetal Tissue in Medicine*, 320 N. Eng. J. Med. 1093 (April 20, 1989)(principal author)

Henry T. Greely, Contracts as Commodities: The Influence of Secondary Purchasers on the Form of Contracts, 42 Vand. L. Rev. 133 (Jan. 1989)

Henry T. Greely, The Equality of Allocation by Lot, 12 Harv. Civ. R. - Civ. Lib. L. Rev. 113 (1977)

#### Books or Book-Length Reports

Committee on the Use of Third Party Toxicity Research with Human Research Participants, INTENTIONAL HUMAN DOSING STUDIES FOR EPA REGULATORY PURPOSES: SCIENTIFIC AND ETHICAL ISSUES (National Academies Press, Washington, D.C. 2004)(principal author of chapter 6)

California Advisory Committee on Human Cloning, CLONING CALIFORNIANS? (Sacramento, CA. 2002) (principal author)

#### Book Chapters

Henry T. Greely, *The Social Consequences of Advances in Neuroethics: Legal Problems; Legal Perspectives*, In: NEUROETHICS (Judy Illes, ed., Oxford University Press, forthcoming 2005)

Henry T. Greely, *Prediction, Litigation, Privacy, and Property: Some Possible Legal and Social Implications of Advances in Neuroscience,* In: NEUROSCIENCE AND THE LAW: BRAIN, MIND, AND THE SCALES OF JUSTICE (Brent Garland, ed., The Dana Press 2004)

Henry T. Greely, *Genome Research and Minorities*, chapter 4, pp. 67-82 in PHARMACOGENOMICS: SOCIAL, ETHICAL, AND CLINICAL DIMENSIONS (Mark A. Rothstein, ed., John Wiley & Sons, 2003)

Henry T. Greely, *Neuroethics and ELSI: Some Comparisons and Considerations*, 83-94 in NEUROETHICS: MAPPING THE FIELD (ed. Steven J. Markus, The Dana Press, 2002).

Henry T. Greely, *Genome Research and Minorities*, chapter 4, pp. 67-82 in PHARMACOGENOMICS: SOCIAL, ETHICAL, AND CLINICAL DIMENSIONS (Mark A. Rothstein, ed., John Wiley & Sons, 2003)

Henry T. Greely, *Ethical Issues in "the New Genetics,"* in THE INTERNATIONAL ENCYCLOPEDIA OF SOCIAL AND BEHAVIORAL SCIENCES (3<sup>rd</sup> ed. 2001)

Henry T. Greely, *Ethical Issues in the Human Genome Diversity Project*, in THE ENCYCLOPEDIA OF ETHICAL, LEGAL, AND SOCIAL ISSUES IN BIOTECHNOLOGY 552-566(2000)

Henry T. Greely, *Individualizing Medicine Through PharamacoGenomics – Are There Ethical Concerns?* In THE BUSINESS CASE FOR PHARMACOGENOMICS 229-243 (ed. N.S. Rudolph, Woburn, Mass. 2000)

Henry T. Greely, Informed Consent, Stored Tissue Samples, and the Human Genome Diversity Project: Protecting the Rights of Research Participants, in ETHICAL ISSUES IN STORED TISSUE SAMPLES (ed. R. Weir, Univ. Iowa press, 1998)

Henry T. Greely, *The Human Genome Diversity Project: Ethical, Legal, and Social Issues,* in GENETICS: ISSUES OF SOCIAL JUSTICE 71-81 (ed. T. Peters, Pilgrim Press, 1998)

Henry T. Greely, *Introduction*, American Cancer Society, CANCER AND GENETICS: ANSWERING YOUR PATIENTS' QUESTIONS (1997)

Henry T. Greely, *The Ethics of the Human Genome Diversity Project: The North American Regional Committee's Proposal Model Ethical Protocol* in HUMAN DNA SAMPLING: LAW AND POLICY – INTERNATIONAL AND COMPARATIVE PERSPECTIVES 239-256 (ed. B. M. Knoppers, Kluwer Law Int'l, 1997)

Henry T. Greely, *Baby Doe and Beyond: The Past and Future of Government Regulation in the United States*, in PERINATOLOGY AND ETHICS (Amnon Goldworth, ed., Oxford University Press, 1994)

Henry T. Greely, *The Regulation of Private Health Insurance*, in HEALTH CARE CORPORATE LAW (Mark Hall, ed., Little Brown & Co. 1993, and regular supplements)

Henry T. Greely, *Health Insurance, Employment Discrimination, and the Genetics Revolution* in THE CODE OF CODES: SCIENTIFIC AND SOCIAL ISSUES IN THE HUMAN GENOME PROJECT (Daniel Kevles and Leroy Hood, eds. Harvard University Press, 1992)

Henry T. Greely, *Defining Basic Benefits Through Clinical Guidelines: Problems of Implementation*, in BASIC BENEFITS AND CLINICAL GUIDELINES (ed. David Hadorn, Westview Press, 1992)

Henry T. Greely, *AIDS and the U.S. Health Care Financing System*, in LE COUT MONDIAL DU SIDA: 1980-2000 (ed. D-C Lambert, CNRS Edition, Paris, 1992)

### **Book Reviews**

Henry T. Greely, *Genetic Modification*, review of DESIGNING OUR DESCENDANTS: THE PROMISES AND PERILS OF GENETIC MODIFICATIONS, Audry R. Chapman, Mark S. Frankel, ed., J. AM. MED. ASS'N 292:1374-75 (Sept. 15, 2004)

Henry T. Greely, *Human Genetic Enhancement : A Lawyer's View*, Review of *Wondergenes: Genetic Enhancement and the Future of Society* by Maxwell J. Mehlman, MEDICAL HUMANITIES REVIEW 17, no. 2, 42-46 (fall 2003)

Henry T. Greely, Book Review, *Conflicts of Interest in Clinical Practice and Research*, N. Eng. J. Med. (Feb. 13, 1997)

Henry T. Greely, Book Review, Money, Morals, and Medicine, J. Am. Med. Ass'n (June 22-29, 1994)

Henry T. Greely, Book Review, *The Sierra Club Legal Defense Fund and Environment Litigation*, 10 Stan. Env. L. J. 228 (1991)

Henry T. Greely, Book Review, *Revolution in the World Petroleum Market*, by Mary Tétrault, 22 Stan. J. Int'l L. 195 (Spring 1986)

## **Other Published Work**

Henry T. Greely, (2003) *The Human Genome Diversity Project, a personal view* (box), In: HUMAN EVOLUTIONARY GENETICS: ORIGINS, PEOPLES & DISEASE, M.A. Jobling, M.E. Hurles, C. Tyler-Smith (Garland Science, New York.)

Henry T. Greely, *Neuroethics?*, HEALTH LAW NEWS 5 (July 2002)

Howard M. Cann, et al., A Human Genome Diversity Cell Line Panel, 296:261-62 (April 12, 2002)

Working Group on Homeowner–University Relations, Report to the President and Provost (March 2002)

Henry T. Greely, *A Revolution in Understanding How Life Works*, SAN DIEGO UNION TRIBUNE, G-1 (June 24, 2001)

Henry T. Greely, Court's Intervention Breaks the Faith, SAN JOSE MERCURY NEWS, 7B (Dec. 15, 2000)

Henry T. Greely, *Out Here on the Frontier*, STANFORD LAWYER (2000)

Henry T. Greely, Biographical entries for *Judge John Minor Wisdom*, *Judge Elbert Tuttle*, and *Judge John R*. *Brown*, CIVIL RIGHTS IN THE UNITED STATES (1999)

Henry T. Greely, *Commentary: Do Physicians Have A Duty to Disclose Mistakes?*, WESTERN J. OF MED., 171:82-83 (August 1999)

Henry T. Greely, *Genväger kan bli senvägar*, DAGENS NYHETER (newspaper) (Stockholm, Sweden) (September 17, 1999)

Henry T. Greely, *Bragdon v. Abbott, The Americans with Disabilities Act, and HIV Infection* (Letter to the Editor), NEW ENGLAND JOURNAL OF MEDICINE 340:1213 (April 15, 1999)

Henry T. Greely, *Genetic Testing for Cancers: The Surgeons' Critical Role* (remarks), J. AM. COL. SURGEONS 188:86-89 (Jan. 1999)

Henry T. Greely, Editorial, Genomics Research and Human Subjects, SCIENCE 282:625 (Oct. 23, 1998)

Henry T. Greely, Letter to the Editor, NATURE (May 22, 1998) (on Swiss biotechnology referendum)

Henry T. Greely, *Information I Can Use*, STANFORD MEDICINE (Spring 1997)

Henry T. Greely, *Genes, Patents, and Indigenous Peoples*, CULTURAL SURVIVAL QUARTERLY 54-58 (Summer 1996)

Henry T. Greely, *Mapping the Genome*, THE UTNE READER 74:87 (Mar. 1996)

Henry T. Greely and Leigh S. Goodmark, *The Debate Over Abortion Coverage: A Compromise*, NEW YORK TIMES, op/ed page, July 22, 1994

## Selected Presentations (Since January 2002 – full list available on request)

The Revolution in Neuroscience: Legal Issues, Socio-Economics Section, Association of American Law Schools annual meeting, Jan. 6, 2005, San Francisco

Legal and Policy Issues in the Research with Embryonic Stem Cells: United States, Joint California/U.K. Symposium on Stem Cells, Tissue Engineering, Regenerative Medicine, Dec. 6, 2004, San Francisco

Human Cloning, Class discussion at Menlo School, Dec. 3, 2004, Menlo Park

<u>Discussion of Problem in Return of Information to Research Subjects</u> and <u>Discussion of Problem in</u> <u>Community Genetics Research</u>, Education in Genetics and Ethics (EDGE), Nov. 11-12, 2004, Salt Lake City

Law and Genetics: Seminar for the Federal Judicial Center, organized 2 1/2 day session, lectured for 9 hours on various topics involving law and genetics and law and neuroscience, October 28-30, 2004, Stanford

Legal Implications of the Revolution in Neuroscience, Society for Neuroscience Annual Meeting, October 27, 2004, San Diego

Bioscience and the California Ballot: Propositions 69 and 71, Center for Law and the Biosciences lecture, October 25, 2004, Stanford

<u>Neuroethics: How Neuroscience May Change Our World</u>, Classes Without Quizzes, Homecoming, October 23, 2004, Stanford

<u>The Future of Genetic Testing:</u> From Prenatal Genetic Diagnosis to Pharmacogenomics, University of Chicago, October 20, 2004, Chicago

Ethical and Policy Issues in Human Stem Cell Research, Community Connections, October 17, 2004, Los Altos

<u>Ethical Issues in Human/Non-Human Chimeras</u>, National Academies Workshop on Guidelines for Human Embryonic Stem Cell Research, October 13, 2004, Washington, D.C.

Ethical Issues in Human Embryonic Stem Cell Research (panel), Willie Brown Institute Workshop on Human Embryonic Stem Cells, October 12, 2004, San Francisco

<u>Legislative Issues in Human Embryonic Stem Cell Research (panel)</u>, Willie Brown Institute Workshop on Human Embryonic Stem Cells, October 12, 2004, San Francisco

Human Stem Cell Research: Science, Ethics, Policy, and Politics, Knight Fellows Seminar, October 6, 2004, Stanford

Race and Genetics: Why We Should Care, Stanford Genetics Department Retreat, Sept. 27, 2004, Monterey, Ca.

Law and the Revolution in Neuroscience, Law, Science, and Technology Colloquium, September 23, 2004, Stanford

Legal and Ethical Issues in Human Stem Cell Research, Los Altos League of Women Voters, August 10, 2004, Los Altos

<u>Neuroethics:</u> How Neuroscience May Change the Future, Program in English for Foreign Students, July 27, 2004, Stanford

<u>Genetic Testing and Cardiovascular Research and Practice</u>, Cardiovascular Fellows seminar, July 21, 2004, Stanford

<u>"Enhancement": Medical Possibilities; Ethical Quandries</u>, Stanford Medical Youth Science Program, July 9, 2004, Stanford

<u>Unnatural Selection: The Ethical and Policy Issues of Choosing our Children by Preimplantation Genetic</u> <u>Diagnosis</u>, California Senate Select Committee on Genetics, Genetic Technologies and Public Policy 2004 Lecture Series, June 30, 2004, Sacramento.

Biotech Enhancement - Improving "Normal" People, Quest Program, June 29, 2004, Stanford

<u>The True Facts of the Strange Tale of John Moore's Spleen</u>, American Association of Law School's Mid-Year Meeting, Property Law Teachers Conference, June 16, 2004, Portland, Ore.

Forensic DNA and Family Connections, Stanford Human Genome Center Seminar, June 9, 2004, Palo Alto

<u>Genetics and Society</u>, Retreat of the Stanford Center Human Genetics and Population Sciences, June 8, 2004, Stanford

Human Cloning, Stem Cells, and Enhancement, Medical Ethics, Philosophy 78, Mark Collier, June 1, 2004

Genetic Testing, Genetic Enhancement, Medical Ethics, Philosophy 78, Mark Collier, May 27, 2004

Transplantation of Human Neural Tissue into Non-Human Primates, Working Group on Interspecific Chimeric Brains, May 24, 2004, Johns Hopkins, Baltimore

<u>Ethical and Legal Issues in Biotechnology</u>, Introduction to Biotechnology, Chemical Engineering 450, Camilla Kao, May 25, 2004, Stanford Law School

<u>Issues In Genetic Testing</u>, Genes and Environment in Disease Causation: Implications for the Practice of Medicine and Public Health Instructors:, Human Biology 138, Lorene Nelson and Rita Popat, May 20, 2004, Stanford

<u>Genetic Enhancement: "Designer Babies"?</u>, Doug Brutlag, Genomics, Bioinformatics, and Medicine, Biochemistry 118Q, Sophomore Seminar, May 18, 2004, Stanford

Embryonic Stem Cells: Science, Law, Policy, and Politics, Stanford Student Biodesign Bioethics Symposium, May 12, 2004, Stanford

Preimplantation Genetic Diagnosis - Savior Sibs, Human Genetics Journal Club, May 11, 2004, Stanford

Forensic DNA and Family Connections, Current Issues in Genetics, Stanford Genetics Department, May 7, 2004, Stanford

Neuroethics, Retreat, Neuroscience Institute at Stanford, May 3, 2004, Asilomar

Biotechnologies and the Futures of our Society, Stanford Oregon Alumni Club, May 1, 2004, Beaverton, Ore.

<u>What Does the Future Hold?</u>, panel, Third Annual International Bioethics Forum, BioPharmaceutical Technology Center, April 23, 2004, Madison, Wisc.

<u>Genetic Testing: A Global View</u>, Third Annual International Bioethics Forum, BioPharmaceutical Technology Center, April 22, 2004, Madison, Wisc.

Genetics and Society, U. Wisconsin Program in Biotechnology, April 22, 2004, Madison, Wisc.

Managing Conflicts of Interest in Bioethics?, Markkula Center for Applied Ethics, Santa Clara University, April 20, 2004, Santa Clara

<u>Neuroethics:</u> The Neuroscience Revolution, Ethics, and Law, Regan Lecture, Markkula Center for Applied Ethics, Santa Clara University, April 20, 2004, Santa Clara

<u>Genetic Enhancement</u>, Biotechnology Law class, Phil McGarrigle and Vern Norviel, Santa Clara Law School, April 20, 2004, Santa Clara

Ethical Issues in Neuroscience: Incidental Findings, Prediction, and Enhancement, Advanced Topics in Clinical/Abnormal Psychology, Prof. Tom Plante (undergrad class), Santa Clara University, April 20, 2004, Santa Clara

Advances in Neuroscience and the Future of Litigation, Health Law and Policy Forum, Suffolk University Law School, April 14, 2004, Boston

Law and Neuroscience, Prof. Marc Rodwin's Health Law Class, Suffolk Law School, April 14, 2004, Boston

<u>A Revolution in the Neurosciences:</u> Challenges for the Law, Stanford Law School Boston Alumni Club, April 13, 2004, Boston

Medical Malpractice, Professional Ethics, Deborah Rhode, April 12, Stanford Law School

"Enhancement" in Sports, Toxic Torts Seminar, Bob Rabin, March 30, 2004, Stanford Law School

<u>Against Genetic Determinism</u>, part of a panel on Legal, Ethical, and Social Aspects of Human Genetics, Tech Museum Panel (organized, moderated, and spoke), March 27, 2004, San Jose

Should California Regulate PGD? California Prenatal Diagnostic Center Directors Meeting, March 26, 2004, Richmond, Ca.

Neuroethics: How Neuroscience May Change Our World, Alumni Day, March 6, 2004 (two talks), Stanford

Human Cloning, Philosophy Talk, KALW, 91.7 fm, March 2, 2004, San Francisco

Preliminary Conclusions on Regulating PGD, BioLaw Conference, Brave New Law, February 28, 2004, Stanford

Introduction to the Issues, Center for Law and the Biosciences Conference, Unnatural Selection: Should California Regulate Preimplantation Genetic Diagnosis?, February 27, 2004, Stanford

Legal and Ethical Issues in Genetics Research, EDGE (Education in Genetic Ethics) program, February 20, 21, 2004, San Francisco (gave one session alone, led one panel)

Law, Ethics, and the Biosciences, USF Law Review Annual Symposium, February 11, 2004, San Francisco

Legal and Social Issues Arising from Advances in Neuroscience, LSU Law School Faculty Lunch Seminar, Feb. 6, 2004, Baton Rouge, La.

Population Participation and Other Factors that Impact the Compilation and the Utility of Resulting Databases (not *my* choice of title!), Conference, Genomics Revolution, jointly hosted by LSU and U. Montréal, February 5, 2004, Baton Rouge, La.

Preimplantation Genetic Diagnosis and "Designer Babies", Serra House, January 13, 2004, Stanford

Ethical Issues in Genetic Database Research, January 7, 2003, Fairmont Orchid, Kohala Coast, Hawai'i

Legal Issues in Chimeras, Working Group on Interspecific Chimeric Brains, November 21, 2003, Johns Hopkins, Baltimore

Legal and Social Issues Arising from Neuroscience, Law, Science, and Technology Colloquium, Roland Vogl, November 13, 2003, Stanford Law School

<u>The Genetics Revolution</u>, Biotechnology Seminar, Alumni Seminar, Graduate School of Business, November 4, 2003, Stanford

Race and Genetics, Workshop moderator, Stanford Humanities Center, October 31, 2003, Stanford

<u>Neuroethics:</u> Legal and Social Issues Arising from Neuroscience, Santa Clara University High Technology Seminar, October 30, 2003, Santa Clara

Genetic Testing: Legal and Ethical Issues, City of Hope Annual Symposium, October 29, 2003, Duarte, Ca.

<u>"Benchside Consultations": Bioethics Advice to Researchers</u>, American Society for Bioethics and Humanities Annual Meeting, October 26, 2003, Montréal

Law, Bioethics, and Bioscience at Stanford, Stanford Club of Montréal, October 25, 2003, Montréal

Neuroethics, Human Biology House Seminar, Storey House, October 23, 2003, Stanford

<u>Neuroethics:</u> How Neuroscience May Change Our World, Stanford Homecoming Classes Without Quizzes, October 19, 2003, Stanford

Legal and Ethical Issues in Genetics Research, EDGE (Education in Genetic Ethics) program, October 18, 19, 2003, Seattle, Wa. (gave one session alone, led one panel)

"Neurolaw?: An Overview of Some Likely Legal Issues Emerging from Advances in Neuroscience," Stanford Brain Research Institute Neuroethics Seminar, October 16, 2003, Stanford

Neuroethics, Ethics at Noon, October 10, 2003, Stanford

Informed Consent and Other Physician Duties, The Physician in Society, David Magnus, October 3, 2003, Stanford Medical School

Panel: Cloning Policy and Politics: US and Canada, Annual Meeting, Canadian Stem Cell Network, September 20, 2003, Vancouver, B.C.

Embryonic Stem Cells in the United States: Science, Law, Policy, and Politics, Annual Meeting, Canadian Stem Cell Network, September 20, 2003, Vancouver, B.C.

Disabilities, Enhancements, and the Meanings of Sports, Stanford Conference on Sports Law, Sept. 18, 2003, Stanford

<u>Selected Legal Issues Raised by Neuroscience</u>, AAAS/Dana Foundation Workshop on Neuroscience and the Law, September 12-13, 2003, Washington, D.C.

Legal and Social Issues in Advances in Human Neuroscience, Stanford Law Faculty Lunch Seminar, Sept. 3, 2003

Chimeras and Chimeric Concerns, Workshop on Language and Bioscience, Linda Hogle, July 28, 2003, Stanford

Human Cloning: Science, Law, Policy, and Politics, QUEST program, July 24, 2003, Stanford

Chimeras and Chimeric Concerns, Law Faculty Lunch Seminar, July 23, 2003, Stanford

<u>"Hi, I'm Mickey:</u>" <u>Ethical Issues in the Human Neuron Mouse</u>, Intensive English and Academic Orientation for Foreign Graduate Students, July 22, 2003, Stanford

Law, Bioethics, and Bioscience at Stanford, Stanford Japan Association Annual Meeting, July 9, 2003, Tokyo

Bioethics, Law, and Bioscience, Toin University Symposium, July 5, 2003, Yokohama

Race and Genetics, Workshop moderator, Stanford Humanities Center, June 9, 2003, Stanford

<u>Cloning and Stem Cell Research</u>, Stanford Continuing Education seminar, Ethics, Society, and Technology, MLA 96, Blair Beebe, June 1, 2003, Portola Valley

Genetics and the Law, Federal Judicial Center, Stanford, May 24, 2003

Ethical Issues in Biotechnology, Chemical Engineering 430, Stanford, May 20, 2003

Philosophy Talk: Morality, Immortality, and Bioscience in the 21st Century, Stanford Alumni Day, Stanford, May 17, 2003

<u>Issues in the Control of Scientific Misconduct</u>, Meeting with Delegation from the Chinese Academy of Sciences, Stanford, May 8, 2003

Legal and Ethical Issues in Human Genetics, Biochem 118Q (Doug Brutlag), May 8, 2003

Legal and Ethical Issues in Genetics Research, UCSF/Avon Foundation Conference on Genetic Promise Versus Privacy, San Francisco, April 25, 2003

"Hi, I'm Mickey": Ethical and Social Issues Raised by the Human Neuron Mouse, Workshop on Interspecific Chimeras, Dalhousie University, Halifax, Nova Scotia, April 11, 2003

Medical Malpractice: A Debate (with Richard Epstein), Federalist Society, Stanford, February 27, 2003

"Hi, I'm Mickey": Ethical and Social Issues Raised by the Human Neuron Mouse, Parents Weekend, Stanford, February 22, 2003

What Matters to Me and Why?, Office for Religious Life, Stanford, February 12, 2003

Issues in Human Population Genetics Research, Santa Clara High Tech Law Review Biotechnology Symposium, Santa Clara, February 7, 2003

Cloning: An Update, Stanford Law and Technology Association, Stanford, February 3, 2003

Stem Cells: Ethics, Policy, and Politics, Ethics at Noon, Stanford, January 31, 2003

Stem Cells: Ethics, Policy, and Politics, Serra House seminar, Stanford, January 16, 2003

## Law and the Biosciences, BioLaw, Stanford, December 5, 2002

<u>Current Ethical and Legal issues in Genetics</u>, Current Issues in Genetics Seminar, Department of Genetics, Stanford, October 25, 2002

Human Stem Cells: Science, Ethics, Policy, and Politics, Stanford Interdisciplinary Seminar, Stanford, October 23, 2002

## Human Cloning and Human Stem Cells: Science, Policy, and Politics, San Francisco Stanford Women's Club, October 23, 2002

Morality and Immortality, Homecoming Classes Without Quizzes, Stanford, October 20, 2002

Genetic Discrimination?, Cancer Genetics Program Seminar, Stanford, October 11, 2002

Ethical Issues in the Use of Human Brain Stem Cells in Mouse Models, Biomedical Ethics Grand Rounds, Stanford, Oct. 3, 2002

Genetics and Ethics, Global Business Network Forum, Stanford, October 2, 2002

Human Cloning and Stem Cell Research: Science, Policy, and Politics, Staff Retreat, Stanford Vice Provost for Undergraduate Education, Half Moon Bay, Calif., August 13, 2002,

<u>The Revolution in Human Genetics: Social and Legal Issues</u>, Foundation for Reseach on Environment and Economics, Gallatin Gateway, Montana, July 27, 2002

<u>Global Issues in Genetics Research</u>, Foundation for Reseach on Environment and Economics, Gallatin Gateway, Montana, July 26, 2002

Human Cloning and Stem Cell Research: Science, Policy, and Politics, Ninth Circuit Judicial Conference, San Diego, July 18, 2002

Human Cloning and Stem Cell Research: Science, Policy, and Politics: Foreign Graduate Student Orientation, Stanford, July 16, 2002

Human Cloning, QUEST program, Stanford, July 10, 2002

Ethical, Legal, and Social Issues in Pharmacogenomics, Endocrine Society, San Francisco, June 20, 2002

Ethical, Social, and Legal Issues Arising from the Revolution in Human Biological Sciences, Molecular Biology in Medicine – A Study Tour for the Norwegian Research Council, San Francisco, May 31, 2002

Patents and Genetics: The Current Status and its Consequences, Human Genetics Journal Club, Stanford, May 14, 2002

Brain Science and Social Policy, Neuroethics: Mapping the Field, San Francisco, May 13, 2002

Stem Cell Transplants and Other Legal Issues that Affect Eye Research, Low Vision Seminar 2002, Peninsula Center for the Blind and Visually Impaired, Stanford, May 10, 2002

Morality and Immortality, Stanford Think Again program, Chicago, May 4, 2002

Human Cloning: Science, Policy, and Politics, Stanford Alumni Club of Sonoma, Santa Rosa, CA., April 27, 2002

Morality and Immortality, Stanford Think Again program, New York, April 20, 2002

Biowarfare and Vaccination, (moderator) SLATA minisymposium, Stanford, April 11, 2002

<u>Commercialization of Human Genetics in Newfoundland</u>, Public Forum, Memorial University of Newfoundland, St. John's, Newfoundland and Labrador, March 27, 2002

<u>Special Issues in Human Population Genetics Research</u>, Division of Community Health Seminar Series, Memorial University of Newfoundland, St. John's, Newfoundland and Labrador, March 27, 2002

Ethical and Social Issues in Human Genetics: An Overview, Libra Foundation Lecture in Bioethics, University of Maine – Machias, March 25, 2002

Legal and Social Issues in Human Genetics, Education Conference 2002, Illinois Judiciary, Chicago, March 22, 2002

Regulation of Human Cloning, Hearing, Calfornia Senate Committee on Health, Sacramento, March 20, 2002

Social Implications of a Revolution in Human Neuroscience: An Early Survey from 2025, Neuroscience Future conference, London,, March 14, 2002

Stem Cells and California Law, Hearing, California Senate Committee on Health, Stanford, March 8, 2002

Stem Cells, Human Cloning, and Public Policy, Parents' Weekend, Stanford, February 23, 2002

Morality and Immortality, Stanford Think Again program, Dallas, February 9, 2002

Legal and Social Issues in Human Genetics, Education Conference 2002, Illinois Judiciary, Chicago, February 8, 2002

Hearing on Human Cloning, U.S. Senate Judiciary Committee, Washington, D.C., February 5, 2002

Human Cloning: Science, Policy, and Politics, SLATA Pizza with the Profs, February 4, 2002

<u>Cloning and Government Regulation</u>, Hastings Law Journal Symposium on Human Cloning, Hastings College of Law, San Francisco, January 26, 2002

The Stanford Center for Biomedical Ethics: Past and Future, Stanford Medical School, January 17, 2002

Report of the California Advisory Committee on Human Cloning, Hearings, California Senate Committee on Appropriations, January 15, 2002

Morality and Immortality, Stanford Think Again program, Seattle, January 12, 2002

Stem Cells and Human Cloning: Policy and Politics, Serra House Seminar, Stanford, January 10, 2002

# Scientific and Medical Accountability Standards Working Group INFORMATION FORM FOR POTENTIAL MEMBERS

Pursuant to California Health and Safety Code [125290.55] the Independent Citizens' Oversight Committee of the California Institute for Regenerative Medicine shall have a Scientific and Medical Accountability Standards Working Group to recommend to the ICOC scientific, medical, and ethical standards. The Standards Working Group shall have 19 members: Five ICOC members from the10 groups that focus on disease-specific areas, nine scientists and clinicans nationally recognized in the field of pluripotent andprogenitor cell research, four medical ethicists, and the chairman of the ICOC. "Medical ethicist" is defined [125292.10 (p)] as "an individual with advanced training in ethics who holds a Ph.D., M.A., or equivalent training and who spends or has spent substantial time (1) researching and writing on ethical issues related to medicine, and (2) administering ethical safeguards during the clinical trial process, particularly through service on institutional review boards.

MrMs <u>x</u> _2	DrMrsOther	
Jeffrey	<u>P.</u>	Kahn
First Name	Middle Initial	Last Name
<u>Maas Family Endov</u> Title	wed Chair in Bioethics, and Director	
_Center for Bioethics	s, University of Minnesota	
University, Company	or Organization	
<u>N504 Boynton, 410</u> Business Address <u>Minneapolis, MN 5</u> City/State/ Zip		
612-624-9440		612-802-8954
Work Number		ell Phone
_ <u>kahnx009@umn.ed</u> Email	<u>u</u>	
3. What position	n in the Standards Working Group are	e you applying for?

 $\Box$  ICOC  $\Box$  Scientist/clinician x $\Box$ x Medical ethicist

2. Please indicate whether or not you are an expert in the following subjects using a "Y" for yes and an "N" for no. Please use the blank lines to list any other areas of your expertise that you feel might be relevant to serving on the working group.

- \_Y\_\_ The Biomedical Ethics of Stem Cell Research
- <u>Y</u> Informed Consent
- Y Controls on research involving human subjects

<u>N</u> Patient privacy laws and regulations

 $\underline{Y}$  National Institutes of Health standards for research

Y\_\_\_National Academies' standards for biomedical research

<u>N</u> *Compliance* for medical ethics, health and safety requirements

<u>N</u> Expertise in medical regulatory agencies (such as the FDA)

<u>N</u> Expertise in the creation of public scientific resources

<u>N</u> Expertise in health disparities

3. The Working Group will develop draft interim standards. At the point that interim standards are adopted by the ICOC, a 270-day public hearing period begins, all subject to the California Administrative Procedure Act (APA). Working Group members will consider public comment as guidance in revising interim standards and procedures. Working Group members may also be asked to serve on subcommittees that may meet to develop standards or determine compliance in specific areas. At least 4 meetings per year are required for the Working Group; the specific meetings schedule and length of each meeting will be set by the membership, but in the first 12 months will likely be 6 - 8 meetings. Do you anticipate making such a time commitment?

Yes<u>x</u> No\_\_\_\_

Please describe any constraints\_\_\_\_\_

4. Please attach a resume or CV.

5. Please be aware that Working Group members will be required to comply with conflict of interest standards determined by the Independent Citizens' Oversight Committee based on standards applicable to members of scientific review committees of the National Institutes of Health. The guidelines are under development.

Please send your completed information sheet and resume or CV by email (preferred) or mail with "Attn: Standards WG Search" to either:

- <u>info@cirm.ca.gov</u> or
- CIRM, 5858 Horton St., Ste. 455, Emeryville, CA 94608

Forms are due postmarked or emailed by midnight Tuesday February 22, 2005.

## PLEASE NOTE: THIS APPLICATION, TOGETHER WITH ANY ATTACHED MATERIALS, MAY BE SUBJECT TO DISCLOSURE PURSUANT TO THE CALIFORNIA PUBLIC RECORDS ACT.

#### JEFFREY P. KAHN

#### Curriculum Vitae

Director and Maas Family Endowed Chair in Bioethics Center for Bioethics University of Minnesota Suite N504 Boynton 410 Church Street SE Minneapolis, MN 55455-0346

Voice: (612) 624-9440, Fax: (612) 624-9108 Email: kahnx009@umn.edu

Born: Santa Monica, California; October 12, 1960

#### EDUCATIONAL BACKGROUND

1989	Ph.D.	Georgetown University (Philosophy/Bioethics)
1988	M.P.H.	Johns Hopkins University School of Hygiene and Public Health (Health Policy)
1983	B.A.	University of California, Los Angeles (Microbiology)

#### AREAS OF SPECIALIZATION

Bioethics, including ethics of human subject research, ethics and genetics, ethics and biotechnology, ethics and public health.

#### EXPERIENCE

October 2003-present	Maas Family Endowed Chair in Bioethics, University of Minnesota
Aug 1996-present	Director, Center for Bioethics, University of Minnesota.
July 2001-present	<i>Professor</i> , Department of Medicine, University of Minnesota Medical School.
Aug 1996-July 2001	Associate Professor, Department of Medicine, University of Minnesota Medical School.
May 1992-July 1996	<i>Director, Graduate Program in Bioethics, and Assistant Professor</i> Center for the Study of Bioethics, Medical College of Wisconsin. Duties included initial development and ongoing administration of graduate program and its curriculum leading to a Masters degree in Bioethics, teaching and administration of graduate and medical school courses in bioethics and health policy, preparation of large center grant applications, and

organizational responsibility for Midwestern Intensive Bioethics Course (MIBC).

Apr 1994-Oct 1995	Associate Director, White House Advisory Committee on Human Radiation Experiments. Appointed as Associate Director of staff of Committee charged with analysis of the ethical issues of government-sponsored human radiation experiments from 1944 to 1974. Committee's mandate was to provide President Clinton and the Human Radiation Interagency Working Group a report and recommendations regarding the ethical and scientific standards applicable to human radiation experiments carried out or sponsored by the U.S. Government. Final Report issued October 3, 1995 and published as <i>The Human Radiation Experiments: Final Report of the</i> <i>Advisory Committee on Human Radiation Experiments</i> (NY: Oxford University Press, 1996).
July 1989-Apr 1992	Assistant Professor, Department of Medical Humanities, East Carolina University School of Medicine. Duties included the development and teaching of first- and second-year medical school Philosophy and Medicine courses, third-year medical school ethics components of four clinical rotations, fourth-year medical school elective "Policy Issues in Health Care Delivery," and clinical ethics consultations in residency programs and for house staff as needed.

#### **OTHER FACULTY APPOINTMENTS**

October 2001-present	Faculty Fellow, Law School, University of Minnesota
Nov 1999-present	<i>Adjunct Faculty</i> , Hubert H. Humphrey Institute of Public Affairs University of Minnesota
May 1999-present	Associate Faculty, Clinical Research Graduate Program, University of Minnesota
Aug 1996-present	<i>Adjunct Faculty</i> , Division of Health Services Policy Research, School of Public Health, University of Minnesota
Aug 1996-present	Graduate Faculty, Department of Philosophy, University of Minnesota

## AWARDS, HONORS, AND ELECTED OFFICES

Dec 2004-present	<i>Member-at-large</i> , American Association for the Advancement of Science Section Committee of the Section on Societal Impacts of Science and Engineering
Sept 2003-present	Fellow, The Hastings Center
Jan 1998-present	Faculty Ambassador, University of Minnesota

Oct 1993-July 1996 *Elected Member*, Milwaukee Academy of Medicine

# **GRANT PARTICIPATION**

July 2003-Oct 2004	<i>Principal Investigator</i> , "Would Your Decision on Competing Interest Pass Public Scrutiny," supported by thy Office of Research Integrity.
Feb 2003-June 2004	<i>Principal Investigator</i> , "Towards Guidelines for Conflicts of Interest for Centers and Programs in Bioethics," supported by the Greenwall Foundation, Presidential Grant.
Sept 2002-August 2006 supported by the Nationa	<i>Consultant</i> , "Genetic and Environmental Determinants of Triglycerides," al Institutes of Health/NHLBI, Grant #U01 HL72524-01
Sept 2002-May 2004 Bioethics Education and #TW06071	<i>Consultant</i> , "Science Education Partnership Award: International Career Development", supported by the National Institutes of Health, Grant
	<i>sultant</i> , "USDA Agriculture and Food Systems Initiative: Consortium to ic, and Ethical Aspects of Biotechnology," supported by the USDA, Grant 100-9617.
Oct 2000-Dec 2004	<i>Principal Investigator</i> , "Genetics and Disability Insurance: Ethics, Law and Policy," supported by the National Institutes of Health, Grant #R01HG02089-01A1.
April 2000-Aug 2003	<i>Working Group Chair</i> , Association of Schools of Public Health – HRSA Curriculum Development Project In Ethics and Public Health
Feb 2000-2001	Member, Working Group, "Pilot Project on Ethical Issues in Public Health," supported by The Greenwall Foundation
June 1999-Aug 2004	<i>Primary Mentor</i> , "An Ethnographic Study of Institutional Review Boards," National Institutes of Health Mentored Scientist Development Award in Research Ethics, Awardee: Ray DeVries, Ph.D., St. Olaf College
April 1999-Mar 2002	Faculty Coordinator for Ethics Component, "NSF Research Experiences for Undergraduates," REU Site for Molecular Biology
July 1998-June 1999	<i>Co-Investigator</i> , "New Initiatives in Interdisciplinary Research and Postbaccalaureate Education," Center of Excellence in Critical Care Medicine, a program grant from the University of Minnesota

Sept 1998-Aug 2001 Advisor, "Research Ethics: Instruction in the Clinical, Biomedical and Public Health Sciences," University of Illinois - Chicago, College of Medicine

#### NATIONAL COMMITTEE AND PANEL APPOINTMENTS

January 2005-present	Member, NIH/NIAID HIV Trials Data and Safety Monitoring Board
Feb 2004-present	Member, NHGRI SBER Scientific Advisory Panel
Feb-Nov 2004	Member, ASBH Task Force on Ethics Consultation Liability
Jan 2004-present	<i>Member</i> , "Bank on a Cure" Advisory Board, International Myeloma Foundation
May 2003-present	<i>Member</i> , Data Safety and Monitoring Board, The Environmental Determinants of Diabetes in the Young Study (TEDDY), NHLBI, NIH
March 2003	<i>Chair</i> , NHGRI Special Emphasis Panel: Ethical, Legal, and Social Implications of Genetics, NIH
July 2002	<i>Member</i> , National Institute of Environmental Health Sciences Special Emphasis Panel on Ethical Challenges in Environmental Health, NIH
March 2002	<i>Member</i> , Center for Scientific Review Special Emphasis Panel on International Research Ethics (SSS-G), Fogarty International Center, NIH
Dec 2001-present	Member, National Children's Study Ethics Working Group
Aug 2001	<i>Chair</i> , Special Emphasis Study Section on Informed Consent in Research, NIH
Aug 2001-present	<i>Member</i> , American Medical Association-Health Resources and Services Administration (HRSA) Advisory Committee on Organ Donation
Jun 2001-present	Member, Ethics Committee, United Network of Organ Sharing (UNOS)
Mar 2001-June 2003	<i>Member</i> , Association of American Medical Colleges Task Force on Financial Conflicts of Interest
Jan 2001-present	<i>Member</i> , International Health Care Worker Safety Center Commission on Legal, Ethical, and Medical Issues of Transmission of Bloodborne Pathogens, University of Virginia

May 1992-June 1996Advisor, "Genetic Counselors as Educators on Human Genome Issues,"<br/>ELSI Program grant from the National Center for Human Genome<br/>Research, Northwestern University

Sep 2000-Dec 2003	<i>Member</i> , Board of Directors, American Society of Law, Medicine and Ethics
May 2000	<i>Co-Chair</i> , Donor Source Workgroup, National Kidney Foundation and American Transplant Society Living Donor Consensus Conference
Jan 2000-present	<i>Member</i> , Oversight Committee for the Geographic Information System (GIS) for the Long Island Breast Cancer Study Project (LIBCSP), NCI
Oct 1999-Oct 2001	<i>Member</i> , Board of Directors, American Society for Bioethics and Humanities
Oct 1999-Dec 2003	<i>Member</i> , Board of Directors, National Marrow Donor Program (Jan 2001-March 2004: Nominating Committee)
Jan 1999	<i>Consultant</i> , National Bioethics Advisory Commission, regarding ethics of embryonic stem cell research
Jan 1999-present	<i>Member</i> (ex officio), American College of Epidemiology Ethics Standards and Practice Committee
Dec 1998-2000	<i>Member</i> , Environmental Protection Agency Science Advisory Board Subcommittee on Data From Testing of Human Subjects
Nov 1998-2001	Member, American Public Health Association Governing Council
Sept 1998-present	<i>Member</i> , Liaison Board, HuGE (Human Genome Epidemiology) Net (CDC), representing the American Public Health Association
Aug 1997-March 2004	<i>Member</i> , Data and Safety Monitoring Board (DSMB) of the Sudden Cardiac Death in Heart Failure Trail (SCD-HeFT), National Institutes of Health (NIH)
July 1997	<i>Member</i> , Study Section on Informed Consent in Research Involving Human Participants study section, NIH
June 1997	<i>Invited participant,</i> National Policy Forum on Marrow Donation and Transplantation, Division of Transplantation, Health Resources and Services Administration
June 1997	<i>Invited participant,</i> National Action Plan on Breast Cancer (NAPBC) and the National Human Genome Research Institute (NHGRI) workshop
Jan 1997-present	Member, LifeSource (OPO) Medical Ethics Advisory Committee
Sept 1995-July 1996	<i>Member</i> , Monitoring and Advisory Panel (MAP) for the Prostate, Colon, Colorectal, and Ovarian Cancer Screening Trial (PLCO), Division of Cancer Prevention and Control, National Cancer Institute (NCI)

## STATE COMMITTEE AND PANEL APPOINTMENTS

Jan 1999-present	<i>Member</i> , Minnesota Department of Human Services Transplant Advisory Committee
Oct 1996-Feb 1997	<i>Member</i> , Technical Advisory Work Group, Minnesota State Department of Health for the Birth Defects Information System
Sept 1996-present	<i>Member</i> , Ad Hoc Advisory Committee on Genetics, Minnesota Department of Health

# UNIVERSITY COMMITTEE AND PANEL APPOINTMENTS

August 2005-present	<i>Chair</i> , Task Force on Faculty Culture (task force for the University's Strategic Positioning effort)
September 2004-June 2005	<i>Member</i> , University of Minnesota Director of Health Sciences Library Search Committee
August 2004-present	<i>Member</i> , University of Minnesota Faculty Senate Committee on Committees
March 2003-present	<i>Member</i> , University of Minnesota Center for Global Health Executive Committee
March 2003	<i>Member</i> , Expanding Authority to Prescribe and/or Dispense Drugs, University of Minnesota Academic Health Care Legislative Project
July 2001-present	Chair, Stem Cell Ethics Advisory Board
Sept 2000-present	<i>Membe</i> r, Governing Committee, Joint Degree Program in Law, Health, and the Life Sciences
August 2000-Jan 2003	Member, Center for Microbial and Plant Genomics Steering Committee
June 2000 to present	<i>Member</i> , Consortium on Law and Values in Health, Environment & the Life Sciences (member, Executive Committee June 2003-present)
May 2000-present	Member, MD/PhD Steering Committee, University of Minnesota
	Medical School
Mar 2000-present	<i>Member</i> , Blood-Borne Disease Policy, University of Minnesota Medical School
Nov 1999-present	Member, Clinical Research Panel, University of Minnesota Graduate School

May 1999-present	<i>Member</i> , Steering Committee and lecturing faculty, On Doctoring Program $(3^{rd} \text{ and } 4^{th} \text{ year medical students})$
Feb 1999-present	<i>Applicant Reviewer</i> , University of Minnesota Genetic Counseling Graduate Program Admissions Committee
Sep 1998-present	<i>Member</i> , Faculty Education Advisory Committee (Research Ethics), University of Minnesota (Chair, 1999-2001)
Apr 1998-present	<i>Member</i> , The University of Minnesota Center for Holocaust and Genocide Studies Advisory Board
Jan 1996-July 1996	<i>Member</i> , Medical College of Wisconsin Clinical Research Center (CRC) Review Committee
Jan 1994-July 1996	<i>Member</i> , Medical College of Wisconsin IAIMS Steering Committee (for preparation and administration of IAIMS Center Grant)
Nov 1993-July 1996	<i>Member</i> , Froedtert Memorial Lutheran Hospital/John Doyne Hospital Ethics Committee
Aug1993-July 1996	Member, Medical College of Wisconsin Recombinant DNA Committee
Dec 1992-July 1996	Member, Wisconsin Ethics Committee Network (WECN) Advisory Board
Oct 1992-July 1996	<i>Member</i> , Medical College of Wisconsin Human Research Review Committee (IRB)
May 1992-July 1996	Member, Medical College of Wisconsin Graduate Studies Council
May 1992-May 1994	Member, St. Francis Hospital (Milwaukee) Ethics Committee
Aug 1990-April 1992	<i>Member</i> , East Carolina University Policy and Review Committee on Human Research (IRB)
Aug 1989-April 1992	<i>Member</i> , East Carolina University Animal Care and Use Committee (Medical and Basic Sciences uses)
Aug 1989-April 1992	<i>Member</i> , East Carolina University School of Medicine Basic Sciences Computer Use and Education Committee

## EDITORIAL BOARD MEMBERSHIPS

July 2002-present	Journal of Law, Medicine and Ethics
Oct 1999-present	American Journal of Bioethics

## PROFESSIONAL ASSOCIATIONS

American Association for the Advancement of Science

American Philosophical Association American Public Health Association *Program co-chair*, Forum on Bioethics, 1997 *Forum co-chair*, Forum on Bioethics, 1998 *Member*, Governing Council, 1998-2001 American Society for Bioethics and Humanities *Member*, Board of Directors, 1999-2001 The American Society of Law, Medicine and Ethics *Member*, Board of Directors, 2000-present

#### REVIEWER

Agency for Health Care Policy Research (AHCPR) Archives of Internal Medicine American Journal of Bioethics *Community Genetics* **Cornell University Press** Genetics in Medicine Hastings Center Report Health Affairs Japan Foundation Journal of the American Medical Association Journal of American Geriatrics Society Journal of Clinical Ethics Journal of Law, Medicine and Ethics Kennedy Institute of Ethics Journal Lancet MacArthur Foundation Medical Research Council of Canada National Academy of Sciences, Institute of Medicine (IOM) National Human Genome Research Institute (NIH) National Research Council

#### New England Journal of Medicine

**Oxford University Press** 

#### **Perspectives in Biology and Medicine**

Political Psychology Research Council of Canada

Science

#### PUBLICATIONS

Books

- 1. Kahn JP, Mastroianni AC, and Sugarman J, eds., *Beyond Consent: Seeking Justice in Research*, (New York: Oxford University Press, 1998).
- 2. Sugarman J, Mastroianni AC, and Kahn JP, eds., *Policies for Human Subjects Research*, (Frederick, MD: University Publishing Group, 1998).

#### **Editorships**

- 1. Kahn JP, Mastroianni AC, guest editors, Issue devoted to the future of bioethics, *Journal of Law, Medicine and Ethics*, 32(2):2004.
- 2. Kahn JP, Mastroianni AC, guest editors, Issue devoted to research on specific populations, *Accountability in Research*, 7(1):1999.
- 3. Kahn JP, section editor, Bioethics and Law Forum, Journal of Andrology, 1998-2002.
- 4. Mastroianni AC, Kahn JP, guest editors, Issue devoted to the work of the Advisory Committee on Human Radiation Experiments, *Kennedy Institute of Ethics Journal* 6(3); September 1996.

#### Articles and Book Chapters

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- 2. "The Business of Medical Research," Oct 28, 2002.

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- 5. "Adoption of Frozen Embryos a Loaded Term," Sept 17,2002.
- 6. "Tainted Gifts of Life," Sept 4, 2002.
- 7. "Should We Be Able to Choose Our Children?" Aug 20, 2002.
- 8. "West Nile Virus: Far Away or Close to Home?" Aug 6, 2002.
- 9. "The Pros and Cons of Halting Research," July 22, 2002.
- 10. "Medicine in Your Junk Mail," July 9, 2002.
- 11. "Making Organ Donation a Better Deal," June 26, 2002.
- 12. "The Value of Vaccination," June 11, 2002.
- 13. "New Ways to Play with Your Food," May 29, 2002.
- 14. "Implanting Ideas to Store Medical History," May 13, 2002.
- 15. "Building Public Trust in Research," Apr 30, 2002.
- 16. "What's at Stake in the 'Cloning Wars'?" Apr 16, 2002.
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- 18. "The New Personal Code," Mar 19, 2002.
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- 20. "The Questionable Future of Unrelated Reproduction," Feb 18, 2002.
- 21. "Prisoners and Transplants," Feb 4, 2002.
- 22. "Dying to Donate" Jan 21, 2002.
- 23. "Cloning Pigs for Parts," Jan 7, 2002.
- 24. "If it Looks Like a Clone and Acts Like a Clone, isn't it a Clone?" Dec 10, 2001.
- 25. "On the Path to Cloning?" Nov 26, 2001.
- 26. "Don't Ask, Don't Tell?" Nov 12, 2001.
- 27. "High-Tech Sex Selection," Oct 1, 2001.
- 28. "Parents From Prison," Sept 17, 2001.
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- 33. "Listening to the Tin Man," July 9, 2001.
- 34. "Looking for Middle Ground in a Minefield," June 25, 2001.
- 35. "Choosing what Kind of People there Should be," June 11, 2001.
- 36. "ISO Healthy Kidney; Top Dollar Paid," May 29, 2001.
- 37. "Three Parents and a Baby," May 14, 2001.
- 38. "Where Have all the Organs Gone," Apr 30, 2001.
- 39. "You, Me and Foot-and-Mouth Disease," Apr 2, 2001.
- 40. "Transplanting Risk," Mar 19, 2001.
- 41. "Transplants and Personal Responsibility," Mar 5, 2001.
- 42. "Your Boss May be Looking Inside Your Genes," Feb 19, 2001.
- 43. "Whose Twins are they Anyway?" Jan 22, 2001.
- 44. "The Gift of Life Doesn't Have to Hurt," Jan 8, 2001.
- 45. "Protected to Death," Dec 25, 2000.
- 46. "Cloning Man's Best Friend," Dec 11, 2000.
- 47. "Placebos: Deceptive Benefits," Nov 27, 2000.
- 48. "The President's Science Policy," Nov 14, 2000.
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- 54. "Genetic Testing is all in the Family," July 25, 2000.
- 55. "Over the Counter or Over-Regulated," July 3, 2000.
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- 65. "Patience for Practice?" Jan 25, 2000.
- 66. "Too Old to Benefit? Why are so Few Seniors in Cancer Research?" Jan 10,2000.
- 67. "Bioethics for the New Millennium," Dec 27, 1999.
- 68. "Back Seat Doctors," Dec 13, 1999.
- 69. "Genetic Fixes and Future Generations," Dec 6, 1999.
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- 71. "Genetic Fixes and Future Generations," Nov 15, 1999.
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- 73. "Giving 'Til it Hurts: How Far to Go in Living Organ Donation," Oct 18, 1999.
- 74. "Good News, Bad News: The Mixed Bag of Research Advances," Oct 4, 1999.
- 75. "The Littlest Patients," Sept 20, 1999.
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- 77. "Turning a Blind Eye," Aug 23,1999.
- 78. "The Double-Edged Sword of Drug Marketing," Aug 9, 1999.
- 79. "Who Needs Bionics? Recycled Humans Are Here," July 26,1999.
- 80. "Risky Business: Helping the HIV-Infected Have Babies," July 12, 1999.
- 81. "We'll Pay You Not To Have Kids," June 28, 1999.
- 82. "Choosing Sides in the Sperm Race," June 15, 1999.
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- 84. "In Research We Trust?" May 18, 1999.
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- 86. "Riskier, Costlier, No Better And We Want It," Apr 20, 1999.
- 87. "Forced Fatherhood," Apr 6, 1999.
- 88. "Blinded by Hope, Dazzled by Detail," Mar 23, 1999.
- 89. "No Free Lunch: Managing Care, Paying for Research," Mar 9, 1999.
- 90. "Attention Shoppers: Special Today—Iceland's DNA," Feb 23, 1999.
- 91. "Dying to Know," Feb 9, 1999.
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- 94. "Eight is Enough," Dec 28, 1998-Jan 10, 1999.
- 95. "Whose Cord Blood is it Anyway?" Dec 14, 1998.
- 96. "Dr. Kevorkian's Latest Release: Death, Crimes and Videotape," Nov 30, 1998.
- 97. "Doctor Knows Best? The Ethics of Self-Prescription," Nov 16, 1998.
- 98. "And This Little Piggy Went to the OR," Nov 2, 1998.
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- 104. "Genetic Testing: The Future is Here," Aug 10, 1998.
- 105. "National Health Identifier: Big Help of Big Brother?," July 27, 1998.
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## **Book Reviews**

1. Kahn JP, "Transplant Policy with a Market Flavor," review of *Organ Transplantation Policy: Issues and Prospects*, edited by JF Blumstein and FA Sloan (Durham, NC: Duke University Press, 1989); *Bioethics Books* 2(1):11-13; 1991.

## Proceedings

- 1. Kahn JP, "Ethics of Allocation: Should Increasing Waiting Times Change the Allocation? Should We "Ration"?, *Selected Highlights: Transplant Immunosuppression 2001 The Compleat Care of the Transplant Recipient* (Minneapolis, MN: University of Minnesota Medical School).
- 2. Kahn JP, "Ethical Issues in Genetic Testing by Life Insurers," *Medical Section Proceedings*, Seventeenth Annual Meeting of the Medical Section of the American Council of Life Insurance (Washington, DC: American Council of Life Insurance, 1992).

## Abstracts

- 1. Weed DL, Kahn JP, McKeown R, Stoto M, "American College of Epidemiology Ethics Guidelines: Foundations and Dissemination," *Abstracts of the American Association for the Advancement of Science Conference on the Role and Activities of Scientific Societies in Promoting Research Integrity*, (Washington, DC, April 10-11, 2000).
- Kahn JP, "The Ethics of Art," Abstracts of the Society for the Study of Reproduction (Center for Reproductive Biology – Washington State University/University of Idaho, 32<sup>nd</sup> Annual Meeting, Pullman, WA, August 3, 1999).
- 3. Kahn JP, "Ethical Issues in Clinical Research: Lessons of Hope and Opportunity," *Abstracts of the Critical Reviews in Biomedical Engineering*, (Transactions of the First International Conference on Bioengineering, Clemson, SC, September 28, 1997), pp. 83-84.
- 4. Sugarman J, Kahn JP, Mastroianni AC, "Practical Clinical Research Ethics," *Abstracts of the Journal of General Internal Medicine*, (Society of General Internal Medicine, 20th Annual Meeting, Washington, DC, May 1-3, 1997).
- 5. Sugarman J, Kahn JP, Mastroianni AC, "Staff Report from the Advisory Committee on Human Radiation Experiments: Implications for Human Subjects Research," *Abstracts of the American*

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- Coughlin SS, Kahn JP, Goodman KW, Weed DL, "Practical Methods for Ethical Decision-Making in Public Health," *Abstracts of the American Public Health Association 123rd Annual Meeting and Exhibition*, (Washington: American Public Health Association, October 29-November 2, 1995), p. 163.
- 7. Kahn JP, "Moral Issues in the Use of Excise Taxes on Tobacco," *Abstracts of the American Public Health Association 122nd Annual Meeting and Exhibition*, (Washington: American Public Health Association, October 30-November 3, 1994).
- 8. Kahn JP, "The Shift from Autonomy to Community: Implications for Geriatrics," *Abstracts of the American Public Health Association 121st Annual Meeting and Exhibition*, (Washington: American Public Health Association, October 24-28, 1993), p. 368.
- 9. Wertz DC, Glantz LH, Juengst E, Kahn JP, "Ethical Issues in Predictive Genetic Screening," *Abstracts of the American Public Health Association 119th Annual Meeting and Exhibit, World Federation of Public Health Associations Sixth International Congress*, (Washington: American Public Health Association, November 10-14, 1991), p. 109.
- Kahn JP, "International Issues in Justice, Health, and Tobacco Policy," *Abstracts of the 118th Annual Meeting of the American Public Health Association and Related Organizations*, (Washington: American Public Health Association, September 30-October 4, 1990), p. 135.
- Kahn JP, "Decision Analysis and HIV Seropositive Pregnancy," *American Public Health Association* 117th Annual Meeting Abstracts, (Washington: American Public Health Association, October 22-26, 1989), p. 88.

## SELECTED PROFESSIONAL PAPERS AND LECTURES

## **Visiting Professorships**

- 1. University of Toronto Joint Centre for Bioethics, Toronto, Ontario, Canada, April 23-24, 1996.
- 2. University of Pittsburgh Medical Center, Center for Medical Ethics, Pittsburgh, PA, February 7-8, 1996.

## **Papers and Lectures**

- 1. "Accountability and Leading Edge Biotechnology: The Ethics of Creating Stem Cell Donors," invited lectures, Research Ethics Day, University of Washington, and Fred Hutchinson Cancer Institute, Seattle, WA. July 14, 2005.
- 2. "Ethics of Living Organ Donation," and "Ethical Issues in Human Embryonic Stem Cell Research," invited lectures, Keio University School of Medicine, Tokyo, Japan. June 27-28, 2005.

- 3. "Ethics of Research on Vulnerable Subjects," and "Use of PGD in Creating Stem Cell Donors," lectures at Sino-US Conference on Research Ethics, hosted by Peking University Health Sciences Center, Xi'an, China. June 23-34, 2005.
- 4. "Beyond Bioethics: Thinking about Ethics in Public Health," keynote presentation, Teaching Public Health Ethics Symposium, University of Washington School of Public Health and Community Medicine, Seattle, WA. May 12, 2005.
- 5. "Ethical Issues in Emerging Technologies--The Case of Creating a Stem Cell Donor," invited speaker, University of Louisville Medical School, Louisville, KY. April 29, 2005.
- 6. "Maimonides and Contemporary Research Ethics," invited speaker, The first International Maimonides Conference on Medicine and Ethics, Tiberius, Israel. March 23, 2005.
- 7. "Cutting Edge Debate: Organ Sales," invited speaker, University of Minnesota Transplant Conference, Minneapolis, MN. March 16, 2005.
- 8. "Organ Donation: Updating the AMA Code of Ethics," invited panelist, AMA Ethics Seminar, Georgetown University Medical Center, Washington, DC. March 14, 2005.
- 9. "Ethical Issues in Emerging Technologies," keynote presentation at University of Nebraska Research Fair, University of Nebraska, Lincoln. March 10, 2005.
- 10. "Ethical Issues Surrounding Cellular Therapy," invited presentation for United Resource Networks Spring Conference, Miami, FL. March 2, 2005.
- 11. "Exploiting Digital Technology for Practical Ethics: Report of Scholarly Communication Institute Projects," invited panelist, Association of Practical and Professional Ethics Annual Meeting, San Antonio, TX. February 26, 2005.
- 12. "The Stem Cell Research Debate: What it Means for Ethics and Public Health Policy," invited presentation, National Bioethics Center, Tuskegee University, Tuskegee, AL. February 14, 2005.
- 13. "Recent Developments in Research on Human Subjects,"," invited presentation, National Bioethics Center, Tuskegee University, Tuskegee, AL. February 15, 2005.
- 14. "At the Tipping Point: Public Trust and the Ethics of Clinical Research," invited presentation, Society of Clinical Research Associates Seminar. Minneapolis, MN. February 8, 2005.
- 15. "Ethical Issues Pertaining to Stem Cell Research," invited presentation, Minnesota Medical Association Committee on Ethics and Medical-Legal Affairs. Minneapolis, MN. February 7, 2005.
- 16. "Bioethics in the National Spotlight," invited presentation with President Bob Bruininks, "Great Conversations on the Road." Naples, FL. January 29-30, 2005.
- "Ethical Issues Raised By Advances in Genetics as they Relate to Disability and Disability Policy," Panel Moderator, "University of Minnesota Ethics, Genetics and Disability Conference." Minneapolis, MN. January 20, 2005.

- 18. "Ethical Issues in Embryonic Stem Cell Research," invited presentation, Medical Alley Clinical Studies SIG Conference. St. Louis Park, MN. December 15, 2004.
- 19. "Embryonic Stem Cell Research: The US Policy Context", invited presentation, University of Tasmania Faculty of Law. Hobart, Tasmania, Australia. November 16, 2004.
- 20. "Ethics and the Protection of Vulnerable Research Subjects," and "The Ethics of Creating a Stem Cell Donor," invited presentations, China Medical Board Project. Chengdu, China. November 5, 2004.
- 21. "Ethics and the Disclosure of Genetic Research Results," panel presentation, Annual Meeting of the American Society of Bioethics and Humanities. Philadelphia, PA. October 31, 2004.
- 22. "Promise and Controversy: Ethical Issues and the Future of Medicine," invited presentation, Minnesota Medical Foundation Heritage Society Banquet. Minneapolis, MN. May 20, 2004.
- 23. "Commentary from an Ethicist," invited panelist, WORLD Lysosomal Disease Clinical Research Network Annual Symposium. Minneapolis, MN. May 14, 2004.
- 24. "Little Cells, Big Issues: Ethics of Stem Cell Research," invited keynote presentation, University of Minnesota Elder Learning Institute. Minneapolis, MN. May 13, 2004.
- 25. "The Ethics of Creating Stem Cell Donors," invited keynote presentation, Pediatric Grand Rounds, Memorial Sloan-Kettering Cancer Center, Department of Pediatrics. New York, NY. May 6, 2004.
- 26. "Caring or Conflict at the End of Life? The Case of Proxy Consent for Organ Donation" invited keynote presentation, 7<sup>th</sup> Annual Florence Schorske Wald Lectureship, University of Minnesota School of Nursing. Minneapolis, MN. May 3, 2004.
- 27. "Ethics and the Use of PGD: From Avoiding Disease to Creating Donors," invited keynote presentation, Third Annual International Bioethics Forum: Who Knows? Who Needs to Know? Madison, WI. April 23, 2004.
- 28. "Ethics and Research Protections: Where We've Been and Where We're Going," invited presentation, Federation of American Societies For Experimental Biology Annual Meeting "Translating the Genome." Washington, DC. April 19, 2004.
- 29. "Bioethics in the National Spotlight," invited presentation, University of Minnesota's College of Continuing Education's "Great Conversations." Minneapolis, MN. March 23, 2004.
- 30. "Stem Cell Research: The State of Policy Debate," invited presentation, 10<sup>th</sup> Annual Kansas Health Ethics Conference. Wichita, KS. March 19, 2004.
- 31. "Little Cells, Big Issues--The Ethics of Stem Cell Research," invited keynote, Wisconsin Society of Science Teachers 2004 Convention "Building New Avenues." Appleton, WI. March13, 2004.
- 32. "What are the Boundaries of Artistic and Scientific Freedom?" Panel Moderator, Gene(sis): Contemporary Art Explores Human Genomics Town Hall Meeting. Minneapolis, MN. February 28, 2004.

- 33. "Primum Non Nocere: Medical Errors and Improving Quality Care," invited panelist, University of Minnesota Medical School On Doctoring Program. Minneapolis, MN. February 26, 2004.
- 34. "Ethics and the Protection of Vulnerable Research Subjects," invited presentation, China Medical Board Project. Beijing, China. February 13-22, 2004.
- 35. "Ethical Issues and Living Organ Donation," invited presentation, United Resource Networks 5<sup>th</sup> Annual Emerging Technologies and Innovative Approaches for Managing Patients with Complex Medical Conditions Conference. New Orleans, LA. February 4, 2004.
- 36. "Ethics of Creating a Stem Cell Donor," invited presentation, 44<sup>th</sup> Annual Meeting of the American Society of Hematology. San Diego, CA. December 7, 2003.
- 37. "Ethics and Public Health Curriculum Development Project: Use and Dissemination of Teaching Methods," invited presentation, American Public Health Association 131<sup>st</sup> Annual Meeting and Exposition. San Francisco, CA. November 17, 2003.
- 38. "Ethics of cloning and embryonic stem cell research," invited presentation, Minneapolis-University Rotary Club. Minneapolis, MN. November12, 2003.
- 39. "Ethical Issues in Emerging Technologies," invited presentation, University of Michigan Medical School. Ann Arbor, MI. November 7, 2003.
- 40. "Human Embryo Research: Examining the Policy Environment," invited panel presentation, Joint American Society of Bioethics and Humanities/Canadian Bioethics Society Conference: Bioethics Across the Borders. Montreal, Canada. October 24, 2003.
- 41. "Bioethics in the New Millennium," invited keynote presentation, St. Joseph's Hospital 150<sup>th</sup> Anniversary Event. St. Paul, MN. October 9, 2003.
- 42. "The Human Cloning Controversy and the Law," invited presentation, American Bar Association/Section of Science and Technology Law "Working at the Frontier of Law and Science: Applications for the Human Genome" Conference. Chapel Hill, NC. October 3, 2003.
- 43. "At the Tipping Point: Public Trust and the Ethics of Clinical Research," invited co-keynote presentation, Society of Clinical Research Associates 12<sup>th</sup> Annual Conference. Rancho Mirage, CA. Sept 19, 2003.
- 44. "Ethics of Creating a Stem Cell Donor: A Case Study in the New Genetics," invited presentation, Minneapolis Society of Internal Medicine Fall Event. Minneapolis, MN. September 17, 2003.
- 45. "Organ Allocation: What is Justice?" invited presentation, United Resource Networks 12<sup>th</sup> Annual National Clinical Conference. Minneapolis, MN. September 15, 2003.
- 46. "Cutting Edge Issues in Human Subject Research," invited presentation, Law, Health and the Life Sciences: Joint Degree Program Pro-seminar Series. Minneapolis, MN. Sept 10, 2003.
- 47. "Ethics, Law and Policy in Cancer Prevention and Control Module," invited presentation, National Institutes of Health/National Cancer Institute NCI Summer Curriculum in Cancer Prevention. Rockville, MD. July 28, 2003.

- 48. "Ethics, Human Pesticide Testing, and EPA Policy," invited presentation, Minnesota Department of Health Brown Bag Lunch Series. St. Paul, MN. July 24, 2003.
- 49. "Post Market Issues: Engaging the Physicians and Patients in Continuous Data Collection and Analysis," invited presentation, Medical Technology Leadership Forum. Minneapolis, MN. July 18, 2003.
- 50. "The Shift From Protection to Access in Clinical Research," and "Ethics, Policy and Stem Cell Research," invited presentations, University of Iowa Human Subjects Office Seminar Series. Iowa City, IA. June 23, 2003.
- "Little Cells, Big Issues: Ethics and Stem Cell Research and Therapy," invited presentation, Minnesota Medical Foundation Medical School Alumni Day. University of Minnesota. Minneapolis, MN. June 6, 2003.
- 52. "Ethical Issues in Emerging Technologies" invited presentation, 9<sup>th</sup> Annual Teaching Survival Skills and Ethics Conference. Snowmass, CO. June 4, 2003.
- 53. "Ethics, Pharmacogenetics and DNA Banking," invited presentation, Minneapolis VA Medical Center Seminar Series. Minneapolis, MN. May 27, 2003.
- 54. "Bioethics and Pharmacogenetics," invited presentation, Saint Luke's Hospital and the University of Minnesota—Duluth School of Medicine. Duluth, MN. May 23, 2003.
- 55. "Protection vs. Access: Navigating the Ethical Tensions in Clinical Research," invited keynote presentation, Contemporary Issues in Clinical Research, Park Nicollet Institute. St. Louis Park, MN. May 16, 2003.
- 56. "Ethical Issues: Lessons from Pharmacogenetics," invited presentation, National Academy of Sciences Food Forum Symposium. Washington, DC. May 6, 2003.
- 57. "Biomedical Ethics in the 21<sup>st</sup> Century," invited presentation, Program in Ethical Reflection at Carleton, Carleton College. Northfield, MN. April 28, 2003.
- "Ethical Issues in Preimplantation Genetic Diagnosis," invited presentation, International Symposium on Umbilical Cord Blood Transplantation: New Insights and Future Directions. City of Hope National Medical Center, Monrovia, CA. April 26, 2003.
- 59. "Ethics, Policy, and the Challenges of the New Biology" invited presentation, San Diego Science and Technology Council UCSD. San Diego, CA. April 10, 2003.
- 60. "Ethical Issues in Adolescent Health: Considerations for the Clinician," University of Minnesota Medical School "On Doctoring" Program. Minneapolis, MN. April 8, 2003.
- 61. "Ethics and Pharmacogenetics," visiting professor at Greenwall Fellowship Program, Phoebe Berman Bioethics Institute, Johns Hopkins University, Baltimore, MD. March 31, 2003.
- 62. "Ethics of Using PGD to Create Stem Cell Donors," Bioethics Interest Group, Phoebe Berman Bioethics Institute, Johns Hopkins University, Baltimore, MD. March 31, 2003.

- 63. "Ethics and Institutional Advancement: What are the Issues You Face," invited presentation, Group on Institutional Advancement National Professional Development Conference, (Association of American Medical Colleges). Memphis, TN. March 28, 2003.
- 64. "Ethical Issues Associated with Intentional Dosing of Human Research Participants with Toxicants," invited panelist, Third Meeting of the Committee on the Use of Third Party Toxicity Research with Human Participants, Science, Technology and Law Program of the National Academies. Washington, DC. March 19, 2003.
- 65. "Ethical Issues in Research Involving Communities," invited presentation, University of Illinois— Chicago International Center for Health Leadership Development Workshop. Chicago, IL. March 18, 2003.
- 66. "Ethical Issues in Stem Cell Transplant and Gene Therapy," invited presentation, 5<sup>th</sup> Annual Evolving Science of Blood/Marrow Transplantation Conference, sponsored by United Resource Networks. New Orleans, LA. March 12, 2003.
- 67. "Cover the Uninsured Week University of Minnesota Medical School Seminar," invited moderator, Cover the Uninsured Week, sponsored by the Robert Wood Johnson Foundation. Minneapolis, MN. March 11, 2003.
- 68. "Stem Cell Research and the Current Policy Environment," invited presentation, Bone Marrow Transplantation Seminar, University of Minnesota Cancer Center. Minneapolis, MN. March 10, 2003.
- 69. "Cover the Uninsured Week Town Hall Meeting," invited panelist, Cover the Uninsured Week, sponsored by the Robert Wood Johnson Foundation. St. Paul, MN. March 10, 2003.
- 70. "Ethics in Clinical Research," invited presentation, PubH 5550, School of Public Health, University of Minnesota. Minneapolis, MN. February 24, 2003.
- "Stem Cell Research and the Current Policy Climate," invited presentation, Medical Grand Rounds, Department of Medicine, University of Minnesota Medical School. Minneapolis, MN. February 13, 2003.
- "Sources and Stem Cells: Ethics and the Future of BMT," invited keynote speaker, American Society for Blood and Marrow Transplantation Society Annual Conference. Keystone, CO. January 31, 2003.
- 73. "Bioethics and Politics The Current Climate," University of Minnesota Student Committee on Bioethics Seminar. Minneapolis, MN. January 30, 2003.
- 74. "Driven to Excel: Performance Enhancing Drugs and Sports, Evidence, Practice and Ethics," invited moderator, University of Minnesota Medical School On Doctoring Series: Science, Medicine and the Social Fabric. Minneapolis, MN. January 15, 2003.
- 75. "Ethics and Stem Cell Research," invited presentation, Elder Learning Institute, University of Minnesota. Minneapolis, MN. January 9, 2003.

- 76. "Inclusion: Policy, Ethics, or Justice? Is it Time to Re-examine the Guidelines?" invited panelist, Office of Research on Women's Health, National Institutes of Health Scientific Workshop. Washington, DC. January 7, 2003.
- 77. "Teaching Ethics in Public Health: A New Curriculum," invited panelist, American Public Health Association 130<sup>th</sup> Annual Meeting. Philadelphia, PA. November 12, 2002.
- "Payment for Living Kidney Donation: The Pros and Cons," invited presentation, Transplantation Conference Debate, Department of Surgery, University of Minnesota Medical School. Minneapolis, MN. November 6, 2002.
- 79. "Ethics in Public Health: A New Curriculum," invited presentation, American Society for Bioethics and Humanities 5<sup>th</sup> Annual Meeting. Baltimore, MD. October 24, 2002.
- 80. "Ethics, Genetics and Public Policy for the Future," invited presentation, National Council of Women Judges Conference on Genome Justice: The Disparate Impacts of Genetic Testing on Women and Vulnerable Populations. Minneapolis, MN. October 17, 2002.
- 81. "Future of Molecular Genetic Testing and Bioethical Issues," invited presentation, 3M Corporation, Seminar on Biotechnology. St. Paul, MN. October 16, 2002.
- 82. "Ethics of Stem Cell Research," invited presentation, Lawrence University, Program in Biomedical Ethics. Appleton, WI. October 9, 2002.
- 83. "Institutional Environments for RCR Education and Training: The University of Minnesota Experience," invited presentation, Office of Research Integrity: The Role of Institutional Rules, Guidelines, and Education in Promoting the Responsible Conduct of Research Conference. Philadelphia, PA. September 24, 2002.
- 84. "Ethics of Living Organ Donation," invited presentation, 5<sup>th</sup> International Congress on Lung Transplantation. Paris, France. September 20, 2002.
- 85. "Biomedical Ethics of Genetic Testing and Pharmacogenetics," invited presentation, Spang Lectureship, St. Mary's/Duluth Clinic Health System Division of Education and Research. Duluth, MN. September 13, 2002.
- 86. "The Ethics of Conceiving a Stem Cell Donor," invited presentation, Department of Medical Humanities, East Carolina University Brody School of Medicine Perspectives Lecture Series. Greenville, NC. September 10, 2002.
- 87. "Ethical Issues in Transfusion Medicine," invited presentation, 27<sup>th</sup> Congress of the International Society of Blood Transfusion. Vancouver, Canada. August 26, 2002.
- 88. "Ethics, The Human Genome and Stem Cell Research: Where We Are and Where We're Going," invited presentation, 18<sup>th</sup> Annual ROSE Seminar. St. Paul, MN. July 30, 2002.
- 89. "Little Cells, Big Issues: The Ethics of Stem Cell Research," invited presentation, Aspen Allergy Conference 2002. Aspen, CO. July 27, 2002.

- 90. "Ethics and Public Health Research," invited presentation, Center for Bioethics Exploring Ethics and Public Health Intensive Workshop. Ruttgers Bay, MN. July 14-17, 2002.
- "Ethics and Conflict of Interest in Clinical Research A Policy Context," invited presentation, National Association of College and University Attorneys (NACUA) 42<sup>nd</sup> Annual Conference. Boston, MA. June 29, 2002.
- 92. "Ethical Issues In Radiation Research," invited presentation, American Radiation Safety Conference and Exposition. Tampa, FL. June 18, 2002.
- 93. "Ethical Issues In Stem Cell Research," invited presentation, American Diabetes Association 62<sup>nd</sup> Scientific Sessions. San Francisco, CA. June 15, 2002.
- 94. "Little Cells, Big Issues: Ethics and Stem Cell Research," invited presentation, Medical Alley Clinical Studies Conference. Minneapolis, MN. May 15, 2002.
- 95. "Innovations and IRB Challenges: Stem Cell Research," invited presentation, Innovation, Inclusiveness, and Informed Consent: Current Challenges for Institutional Review Boards and Researchers, Office of Human Research Protections, DHHS. Minneapolis, MN. May 13, 2002.
- 96. "Identifying and Managing Conflicts of Interest in Clinical Research," invited presentation, Promoting Integrity in Clinical Research, Office of Research Integrity and the Cleveland Clinic Foundation. Cleveland, OH. May 3, 2002.
- 97. "Living Donation How Far Should We Go?" invited presentation, Issues in Transplantation and Organ Procurement 2002, National Kidney Foundation of Middle Tennessee and Vanderbuilt University. Nashville, TN. May 2, 2002.
- 98. "Is Payment for Organ Donation Ethical?" invited presentation, American Transplant Congress: Transplant 2002. Washington, DC. April 29, 2002.
- 99. "Too Many Masters? Ethics and Conflicts of Interest in Clinical Research," invited presentation, Accountability in Clinical Research: Balancing Risk and Benefit, Annenberg Center for Health Sciences at Eisenhower. Indianapolis, IN. April 26, 2002.
- 100. "Little Cells, Big Issues: Ethics of Stem Cell Research", invited presentation, Elder Learning Institute, University of Minnesota. Minneapolis, MN. April 18, 2002.
- 101. "Ethics and Conflicts of Interest in Clinical Research," invited presentation, Conflicts of Interest and Research Integrity Conference, Washington University in St. Louis. St. Louis, MO. April 17, 2002.
- 102. "Pre-implantation Genetic Diagnosis and the Ethics of the New Genetics," invited presentation, Middlebury College, Middlebury, VT. April 15, 2002.
- 103. "Little Cells, Big Issues: Ethics of Embryonic Stem Cell Research," invited presentation, Hennepin Medical Society Physicians Association. Minneapolis, MN. April 9, 2002.
- 104. "Multi-cultural Issues: Health Care Policy and Bioethics," invited presentation, United Theological Seminary. St. Paul, MN. March 26, 2002.

- 105. "The Regulatory Challenges Testing, Approval, Labeling, and Post-Marketing Surveillance," invited panelist, Pharmacogenomics: the Legal, Ethical and Clinical Challenges, University of Minnesota Joint Degree Program in Law, Health, and the Life Sciences. Minneapolis, MN. February 26, 2002.
- 106. "Case Presentation: An Unethical Clinical Trial for Hepatitis C," invited panelist, The St. Francis International Center for Healthcare Ethics. Honolulu, HI. February 14, 2002.
- 107. "Stem Cells, Embryos, and Ethics in Research," invited presentation, The St. Francis International Center for Healthcare Ethics. Honolulu, HI. February 14, 2002.
- 108. "Ethics, Genetics and the Challenges of New Medical Technologies," invited presentation, The St. Francis International Center for Healthcare Ethics. Honolulu, HI. February 14, 2002.
- 109. "Ethical Issues in Cancer Clinical Trials," invited presentation, Metro Minnesota Chapter of the Oncology Nursing Society. Minneapolis, MN. February 12, 2002.
- 110. "Experimental Treatments in Stroke: Research Protocol or Off-Label Use," invited presentation, American Stroke Association's 27<sup>th</sup> International Stroke Conference. San Antonio, TX. February 8, 2002.
- 111. "Bioethics in the 21<sup>st</sup> Century," invited presentations, Rice Memorial Hospital Ethics Committee and Hospital Staff. Willmar, MN. February 4, 2002.
- 112. "Ethics, Public Health and Medical Practice," invited panelist, University of Minnesota Law and Ethics of Public Health: Responses to Bioterrorism. Minneapolis, MN. January 29, 2002.
- 113. "Ethics, Genetics and the Challenges of New Medical Technologies," invited presentation, Minnesota Hospital and Healthcare Partnership 10<sup>th</sup> Annual Trustee Conference. Plymouth, MN. January 18, 2002.
- 114. "Stem Cells, Human Subjects, Conflict of Interest and Cloning: Examining the Frontiers of the Implications of these Front Burner Ethical Issues for Universities, and Hearing how Campuses Have Handled Them," Association of American Universities Council on Federal Relations Annual Retreat. Tucson, AZ. January 14, 2002.
- 115. "Ethical Considerations in Covering Bioterrorism," invited panelist, Journalism and Bioterrorism Conference. Minneapolis, MN. December 10, 2001.
- 116. "Ethics and Consent Issues," invited panelist, National Institute of Drug Abuse (NIDA) Genetics Consortium. Rockville, MD. December 4-5, 2001.
- 117. "Ethical Issues in Stem Cell Therapies," invited presentation, Annenberg Center for Health Sciences Islet Transplantation 2001 and Beyond: From Research to Clinical Application. Rancho Mirage, CA. December 1, 2001.
- 118. "Little Cells, Big Issues: The Ethics of Stem Cell Research," University of Minnesota Cancer Biology and Therapy Seminar Series 2001-2002. Minneapolis, MN. November 16, 2001.

- 119. "Little Cells, Big Issues: The Ethics of Stem Cell Research," invited presentation, The 19<sup>th</sup> Annual Terry C. Shackelford, MD, Memorial Lecture. Plymouth, MN. November 15, 2001.
- 120. "Ethics, Genetics and Stem Cells: Where we are and Where we're Going", invited presentation, MNBIO Conference on Biotech to the Future: How Biotech will Change our Lives. Bloomington, MN. November 15, 2001.
- 121. "Ethical Issues Surrounding Adult Volunteer Stem Cell Donors", invited presentation, National Marrow Donor Program 14<sup>th</sup> Annual Council Meeting. Minneapolis, MN. November 11, 2001.
- 122. "Ethical Challenges to Fulfilling the Promise of Stem Cells", invited presentation, AAMC Group on Institutional Advancement (GIA) 2001 Annual Meeting. Washington, DC. November 3, 2001.
- 123. "Ethics, Genetics and the Challenges of New Medical Technologies", invited presentation, St. Louis Park Rotary Club, St. Louis Park, MN. October 29, 2001.
- 124. "Ethical Issues in Schizophrenia Research", invited presentation, Second Annual Psychiatry Review Schizophrenia, sponsored by the University of Minnesota's Department of Psychiatry and the Medical School. Minneapolis, MN. October 29, 2001.
- 125. "Preimplantation Genetic Diagnosis and the Ethics of Creating Donors", invited panelist, American Society for Bioethics and Humanities 4<sup>th</sup> Annual Meeting, Nashville, TN. October 25, 2001.
- 126. "Bioethics as Policy: Experiences from Federal Advisory Committees", invited panelist, American Society for Bioethics and Humanities 4<sup>th</sup> Annual Meeting, Nashville, TN. October 25, 2001.
- 127. "Ethics of Allocation: Should the Increasing Waiting Time Change the Allocation? Should We Ration?", invited presentation, Transplant Immunosuppression 2001: the Compleat Care of the Transplant Recipient Conference, sponsored by the University of Minnesota Department of Surgery and the Medical School. Minneapolis, MN. October 24, 2001.
- 128. "Conflicts of Interest in Clinical Research: Ethical and Policy Issues", invited presentation, Sino-U.S. Conference on the Protection of Human Subjects in Clinical Trials and Biomedical Research. Kunming, China. October 21, 2001.
- 129. "Pre-implantation Genetic Diagnosis and the Ethics of the New Genetics", invited presentation, Salzburg Seminar Session 392: Biotechnology: Ethical, Legal, and Social Issues, Salzburg, Austria. October 14-21, 2001.
- 130. "Creation of a Donor", invited presentation, Medical College of Wisconsin Research Day. Milwaukee, WI. October 5, 2001.
- 131. "Creation of a Donor," invited Keynote presentation, United Resource Networks 10<sup>th</sup> Annual National Clinical Conference: Beyond the Horizon: Exploring Scientific Advances in Transplantation. Minneapolis, MN. September 10, 2001.
- 132. "Little Cells, Big Issues: Stem Cells, Embryos, and Ethics in Research," invited presentation, National Jewish Medical Center. Denver, CO. September 7, 2001.

- 133. "Public Policy and Ethical Concerns and Debate over Cloning and stem Cell Research and the Use of Personal Genetic/Genomic Sequence Information," invited panelist, Aventis Pharmaceuticals. Bridgewater, NJ. August 15, 2001.
- 134. "Designer Babies: Reproduction in the Genomic Age," invited panelist, National Conference of State Legislatures. San Antonio, TX. August 14, 2001.
- 135. "Ethical Issues in Emerging Technologies," invited presentation, University of Pittsburgh 7<sup>th</sup> Annual Workshop on Teaching Survival Skills and Ethics. Snowmass, CO. June 5, 2001.
- 136. "Research Ethics," invited presentation, Iowa State University Biotechnology Conference, Iowa State University Bioethics Institute. Ames, IA. May 30, 2001.
- 137. "Bioethical Issues Associated with Stem Cell Research," invited presentation, University of Minnesota Stem Cell Institute Executive Briefing. Minneapolis, MN. May 16, 2001.
- 138. "Bioethics and Policy of Biotechnology Roundtable Discussion," invited moderator, Dept. of Agronomy and Plant Genetics, University of Minnesota. St. Paul, MN. May 16, 2001.
- 139. "Ethics of Pre-Implantation Genetic Diagnosis and Creating Stem Cell Donors," invited presentation, HealthPartners Ob/Gyn Update 2001. Bloomington, MN. April 6, 2001.
- 140. "Ethical Issues in Living Donation," invited presentation, United Resource Networks 2<sup>nd</sup> Annual Conference: Exploring Organ Transplantation – Current Issues, Emerging Technologies and Innovative Approaches. Scottsdale, AZ. March 29, 2001.
- 141. "Justice: Thinking About Benefits and Burdens," invited presentation, Short Course on Racial and Ethnic Minorities as Research Subjects: Challenges for Research Ethics. Gallaudet University, Washington, DC. March 16, 2001.
- 142. "Bioethics in the 21<sup>st</sup> Century," invited presentation, Committee on Institutional Cooperation (CIC) Academic Leadership Program Spring Seminar. University of Iowa, Iowa City, IA. March 14, 2001.
- 143. "Ethics, Genetics and the Challenges of New Medical Technologies," invited panelist, Minnesota Hospital and Healthcare Partnership (MHHP) 53rd Annual Healthcare Executives' Institute. Plymouth, MN. March 8, 2001.
- 144. "Reconciling the Irreconcilable," invited panelist, "Irreconcilable Differences: Profits, Conflicts and Best Therapies – A Guide for Health Professionals' Interactions with the Pharmaceutical Industry," sponsored by the On Doctoring: Science, Medicine and the Social Fabric Series, University of Minnesota. Minneapolis, MN. February 15, 2001.
- 145. "Governing Genetically Modified Organisms (GMOs): Developing Policy in the Face of Scientific and Public Debate," invited panelist, co-sponsored by the Consortium on Law and Values in Health, Environment and the Life Sciences, the Joint Degree Program in Law, Health and the Life Sciences, and the College of Agricultural, Food and Environmental Sciences. Minneapolis, MN. February 1, 2001.

- 146. "Stem Cells and Genomics," invited panelist, CASE Media Fellowship on Genomics,, University of Minnesota News Service. Minneapolis, MN. January 25, 2001.
- 147. "PGD and Creating Stem Cell Donors: Ethical Implications," invited keynote address, United Resource Networks 3<sup>rd</sup> Annual Evolving Blood/Marrow Transplantation Conference. Naples, FL. January 22, 2001.
- 148. "The Human Genome, Stem Cells and Embryos," invited presentation, Women's Division of the Minneapolis Jewish Federation. Minnetonka, MN. February 5, 2000.
- 149. "Stem Cells, Embryos, and Ethics in Research," invited presentation, JDP Proseminar, University of Minnesota Law School. Minneapolis, MN. November 22, 2000.
- 150. "Fostering Research Integrity Through Educational Programs," invited panelist, "Lessons Learned at the University of Minnesota," Office of Research Integrity, Research Conference on Research Integrity. Bethesda, MD. November 18-20, 2000.
- 151. "Assessing Training Efforts in the Responsible Conduct of Research: Status, Challenges, and Future Directions," invited presentation, Office of Research Integrity, Research Conference on Research Integrity. Bethesda, MD. November 18-20, 2000.
- 152. "Ethical and Policy Issues in Development and Use of GMOs: The Evolution of the Debate," invited presentation, Plant Molecular Genetics Institute Annual Retreat, Minneapolis, MN. November 11, 2000.
- 153. "Ethical Issues Related to Mapping the Human Genome," invited presentation, 21<sup>st</sup> Annual St. Luke's Biomedical Ethics Seminar, St. Luke's Hospital, Duluth, MN. November 1, 2000.
- 154. "Ethical Issues in Assisted Reproductive Technologies," invited presentation, American Society for Reproductive Medicine Conference. San Diego, CA. October 21, 2000.
- 155. "Preimplantation Genetic Diagnosis and Creating Stem Cell Donors: Ethical Implications," invited presentation, University of Minnesota Pediatric Grand Rounds. Minneapolis, MN. October 18, 2000.
- 156. "Ethical Issues in Clinical Research: Moving from Protection to Access," invited presentation, University of Minnesota Cancer Center Seminar Series. Minneapolis, MN. September 26, 2000.
- 157. "Live Donation: An Innovative Approach to the Organ Donor Shortage," invited keynote presentation, 9<sup>th</sup> Annual National Clinical Conference. Minneapolis, MN. September 11, 2000.
- 158. "Beyond Consent Forms: Looking to the Future in Protecting Human Subjects," invited presentation, National Jewish Medical and Research Center: Protection of Human Subjects Seminar. Denver, CO. September 7, 2000.
- 159. "Ethics and Human Subjects Research," invited panelist, U.S. EPA Children's Health Protection Advisory Committee, Science and Research Work Group (RESOLVE). Washington, DC. August 24, 2000.

- 160. "Food Production will be Revolutionized by Biotechnology," invited presentation, Allen D. Leman Swine Conference, College of Veterinary Medicine, University of Minnesota. Minneapolis, MN. August 15, 2000.
- 161. "Overview: The Ethics of Human Subject Research," invited presentation, Veterans Affairs Intensive Ethics Training Program. Park City, UT. July 26, 2000.
- 162. "Ethics and Genetics Privacy and Healthcare Policy," invited presentation, HealthPartners Institute for Medical Education Conference: Genetics and the Future. St. Paul, MN. June 13, 2000.
- 163. "How Far Should We Go? The Ethical Limits of Living Organ Donation," invited presentation, British Columbia Transplant Society Annual Provincial Renal Transplant Day. Vancouver, British Columbia, Canada, June 9, 2000.
- 164. "Responsible Research in the Age of Biotechnology," invited presentation, Samuel G. Dunn Lectureship for the Humanities in the Practice of Medicine. University of Texas Medical Branch at Galveston. Galveston, TX, May 23, 2000.
- 165. "Clinical Research Ethics: The Move from Protection to Access," invited presentation, HealthSystem Minnesota Conference on Ethics and the Patient Experience in Clinical Research. St. Louis Park, MN, May 19, 2000.
- 166. "Deciding for Others: the Ethics of Research in Emergency Settings," invited keynote presentation, Medical Alley's Clinical Studies Special Interest Group. St. Louis Park, MN, May 17, 2000.
- 167. "Living Donation," invited panelist, Transplant 2000: First Joint Meeting of the American Society of Transplant Surgeons and American Society of Transplantation. Chicago, IL, May 13, 2000.
- 168. "Justice and the Transplant Organ Distribution System," invited presentation, Children's Hospitals and Clinics Ethics Committee Recognition Event. Edina, MN, May 11, 2000.
- 169. "Ethics in Healthcare and their Role in Quality of Life Products," invited presentation, Medical Alley Seminar on Ethics in Healthcare. St. Louis Park, MN, May 3, 2000.
- 170. "Bioethics in the New Millennium," invited presentation, Minneapolis Branch American Association of University Women. Minneapolis, MN, April 24, 2000.
- 171. "How Will the Science of Biotechnology Develop in response to growing public concern," invited panelist, Biotechnology and Genomics Extension Conference, University of Minnesota. St. Paul, MN, April 3, 2000.
- 172. "Ethics, Genetics and the Challenges of New Medical Technologies," invited keynote presentation for Ethics Week at The Minnesota Academy of Mathematics and Science. Winona, MN, March 27, 2000.
- 173. "Frankenstein Food or Better Living Through Chemistry? The Ethics of Genetically Modified Plants," invited keynote presentation, 2000 Kermit A. Olson Memorial Lecture, University of Minnesota. St. Paul, MN, March 23, 2000.

- 174. "Ethical Issues in 'Creating' a Transplant Donor," Mentor Connection Seminar Speaker Series. Plymouth, MN, March 6, 2000.
- 175. "Iceland DNA Project," invited presentation, Dept. of Biochemistry, Molecular Biology and Biophysics, College of Biological Sciences, University of Minnesota. Minneapolis, MN, February 29, 2000.
- 176. "Ethical Issues in Biotechnology," invited presentation, Minnesota Agri-Growth Council Annual Meeting. Bloomington, MN, November 9, 1999.
- 177. "Hot Topics in Bioethics," invited presentation, House of Hope Presbyterian Church Adult Education Group. St. Paul, MN, November 7, 1999.
- 178. "New Millennium Issues in Ethics," keynote speaker and panelist, United Theological Seminary of the Twin Cities Annual Benefit. St. Paul, MN, November 5, 1999.
- 179. "Bioethics and the Law: Oil and Water or Vinaigrette," keynote address, Law, Medicine and Biomedical Ethics in Patient Care Decisions Conference, St. Luke's Hospital and Regional Trauma Center. Duluth, MN, November 3, 1999.
- 180. "Ethical Implications of Gene Patenting," invited panelist, American Society for Bioethics and Humanities Second Annual Meeting. Philadelphia, PA, October 28-31, 1999.
- 181. "Current Controversies and Future Directions in Contemporary Research," invited presentation, Conference on Research Ethics: Confronting Challenges in the Next Millennium. University of Illinois at Chicago. Chicago, IL, October 15, 1999.
- 182. "Attention Shoppers: Special Today Iceland's DNA." invited presentation, Fall 1999 Health Informatics Seminar Series, University of Minnesota. Minneapolis, MN, October 7, 1999.
- 183. "Ethical Issues in 'Creating' a Transplant Donor," invited presentation, United Resource Network National Conference. Bloomington, MN, October 5, 1999.
- 184. "Current Ethical Challenges in Clinical Research," invited presentation, Veterans Health Administration Ethics Center Conference on Ethical Issues Within the Continuum. Minneapolis, MN, September 10, 1999.
- 185. "The Ethics of Art," invited presentation, 32<sup>nd</sup> Annual Meeting of the Society for the Study of Reproduction, Center for Reproductive Biology – Washington State University/University of Idaho. Pullman, WA, August 3, 1999.
- 186. "Is Managed Care an Oxymoron? Ethical Issues in the Changing Healthcare System," invited presentation, 46<sup>th</sup> Annual Meeting of the Society of Nuclear Medicine. Los Angeles, CA, June 7, 1999.
- 187. "Ethical Issues in Organ Transplantation," invited presentation, On Doctoring: Science, Medicine and the Social Fabric, University of Minnesota Medical School. Minneapolis, MN, May 4, 1999.
- 188. "How Far Should We Go? Public Policy and Human Cloning," invited presentation, Andrews University. Berrien Springs, MI, April 8, 1999.

- 189. "Toward a Better Death: End-of-Life Care Issues," invited panelist, Covering Health Care for Older Americans conference, Co-sponsored by the Minnesota Journalism Center, Journalists' Exchange on Aging and the Association of Health Care Journalists and the American Society on Aging. Minneapolis, MN, March 12, 1999.
- 190. "Of Cowboys and Embryos: Ethics and Embryonic Stem Cells," invited presentation, CHIP Winter Lecture Series, University of Minnesota. Minneapolis, MN, March 11, 1999.
- 191. "Assisted Reproductive Technologies: Septuplets, Octuplets, and the Problem of Multiple Births," invited panelist, Law & Medicine Society's Law, Medicine, and Bioethics Awareness Week. University of Minnesota Law School. Minneapolis, MN, March 10, 1999.
- 192. "Ethical Issues in Human Subject Research," invited presentation, Division of Epidemiology, School of Public Health, University of Minnesota. Minneapolis, MN, March 9, 1999.
- 193. "Genetic Testing for Breast Cancer: Implications for Jewish Women," invited presentation, Minneapolis Jewish Federation Women's Political Awareness lecture. Minneapolis, MN, February 16, 1999.
- 194. "Ethics & AIDS: Risks in the Changing Epidemic," invited presentation, Third in the Series On Doctoring: Science, Medicine and the Social Fabric, University of Minnesota Medical School. Minneapolis, MN. February 12, 1999.
- 195. "Ethical Issues in Genetic Epidemiology Research," invited presentation, University of Washington School of Public Health. Seattle, WA, January 27, 1999.
- 196. "Medicating the Media," invited presentation, Program in Clinical, Biomedical, and Public Health Ethics, College of Medicine, University of Illinois at Chicago. Chicago, IL, January 13, 1999.
- 197. "Ethical Issues in the New Reproductive Technologies from Jewish and secular perspectives," invited presentation, Minneapolis/St. Paul Chapter of Brandeis University Women. St. Paul, MN, December 3, 1998.
- 198. "Teaching Research Ethics: A Status Report," invited presentation, American Public Health Association 126<sup>th</sup> Annual Meeting and Exposition. Washington, DC, November 16, 1998.
- 199. "Decision Making Capacity and the Equipoise of Research Subjects," invited presentation, Friends Research Institute, Inc. 2<sup>nd</sup> National Ethics Conference. Baltimore, MD, November 14, 1998.
- 200. "Promoting Patient Confidentiality," invited presentation, Third District Nurses Continuing Education Program. St. Louis Park, MN, November 5, 1998.
- 201. "Brave New World or Same Old Song? Confronting Ethical Issues in Medicine in the 21<sup>st</sup> Century," invited presentation, Minnesota Medical Foundation Annual Dinner Meeting. Minneapolis, MN, October 26, 1998.
- 202. "Introduction: What Responsibilities, Whose Ethics?" invited presentation, On Doctoring: Science, Medicine and the Social Fabric, University of Minnesota. Minneapolis, MN, October 16, 1998.

- 203. "AIDS Vaccine: Is It For You?," invited presentation, A Minnesota AIDS Project Lifeline Forum, Minnesota AIDS Project. Minneapolis, MN, October 15, 1998.
- 204. "End of Life Care Issues," invited presentation, University of South Dakota School of Medicine Board of Visitors Meeting. Sioux Falls, SD, October 10, 1998.
- 205. "The Limits of Altruism: The Ethics of Encouraging Donation," invited presentation, National Marrow Donor Annual Council Meeting. Minneapolis, MN, September 18, 1998.
- 206. "Ethical, Legal and Public Policy Issues of Tissue Engineering and Genomics," invited presentation, Institute of Technology's Fall 1998 Management of Technology Program, University of Minnesota Center for the Development of Technological Leadership. Chaska, MN, September 11, 1998.
- 207. "The Ethics of Emergency Research," invited presentation, Department of Surgery, ICU conference, University of Minnesota. Minneapolis, MN, September 8, 1998.
- 208. "Science and Ethics at a Crossroads: Basic and Applied Science in Cloning," invited panelist, 1998 Life Sciences Summer Undergraduate Research Programs, University of Minnesota. Minneapolis, MN, July 23, 1998.
- 209. "Current Ethical Issues in Organ Transplantation," invited presentation, Second Chance for Life Foundation Scientific Session. St. Louis Park, MN, July 17, 1998.
- 210. "Traumatic Birth Injuries," invited presentation, Minnesota Law and Politics Medical Malpractice Seminar. Minneapolis, MN, June 29, 1998.
- 211. "Why Public Health Needs Bioethics," Commencement Address, School of Public Health, University of Minnesota. St. Paul, MN, June 12, 1998.
- 212. "Ethics of Managed Care," invited panelist, Shalom Home West. St. Louis Park, MN, May 21, 1998.
- 213. "Ethics and Managed Care," invited presentation, Back to Basic Sciences, Program for 3<sup>rd</sup> and 4<sup>th</sup> Year Medical Students, University of Minnesota Medical School. Minneapolis, MN, May 21, 1998.
- 214. "The Promise and Pitfalls of Genetic Testing: Confidentiality, Discrimination, and Informed Consent," invited lecture, University of Minnesota, Duluth, Medical School. Duluth, MN, May 12, 1998.
- 215. "Justice in Research and the Limits of Informed Consent," invited presentation to the St. Mary's/Duluth Clinic Health System Institutional Review Board. Duluth, MN, May 12, 1998.
- 216. "Animal Research Ethics Issues," invited presentation, Animal Science and Veterinary Medicine, University of Minnesota. St. Paul, MN, May 6, 1998.
- 217. "Dealing with Today's Bioethical Issues," invited presentation, Annual Initiation and Recognition Banquet of the Honor Society of Agriculture, University of Minnesota Chapter. St. Paul, MN, April 30, 1998.

- 218. "Future Horizons in Public Sector Health Insurance-Ethical and Policy Issues," invited keynote address, Setting the Course: Health Care Purchasing for year 2000 and beyond symposium, Minnesota Department of Employee Relations. Bloomington, MN, April 29, 1998.
- 219. "Genetics, Identity and Justice," invited panelist, 21<sup>st</sup> Century Trust Conference, Merton College, Oxford, England. March 27-April 4, 1998.
- 220. "A Healing Journey," invited panelist, Jewish Community Center of the Greater St. Paul Area. St. Paul, MN, March 20, 1998.
- 221. "Withholding and Withdrawing Treatment: Implications for Organizational Management," "From Protection to Access: Evolving Issues in the Ethics of Research in Human Subjects," and "Individual Rights and the Public Good: Ethical Issues in Public Health," invited presentations, Critical Issues in Bioethics Conference and Public Lectures, University of Minnesota—Crookston. Crookston, MN, March 8-13, 1998.
- 222. "Bioethics: Where we've been & where we're going," invited presentation, Biology Seminars at the University of St. Thomas. St. Paul, MN, February 20, 1998.
- 223. "Where Marketing and Medicine Meet," invited presentation, Department of Medicine Grand Rounds, University of Minnesota. Minneapolis, MN, February 19, 1998.
- 224. "From Protection to Access: Rethinking Justice in the Context of Human Subjects Research," invited presentation, Studies of Science and Technology, University of Minnesota Colloquium. Minneapolis, MN, February 13, 1998.
- 225. "Ethics in Health Care," invited presentation, Leadership Minneapolis Health Care Day, Greater Minneapolis Chamber of Commerce. Minneapolis, MN, February 12, 1998.
- 226. "Governments Role in Bioethics," invited presentation, National Conference on Catholic & Jewish Perspectives on Bioethics. Saint Leo, FL, February 10, 1998.
- 227. "How Close Is the Brave New World?: Ethical Issues in Reproduction," invited presentation, Minneapolis Jewish Federation Political Awareness Study Series, Shalom Home West. St. Louis Park, MN, January 20, 1998.
- 228. "Ethics Considerations," invited presentation, White Coat Ceremony, University of Minnesota Medical School. Minneapolis, MN, January 10, 1998.
- 229. "Ethics of Clinical Residents: Past and Present Lessons," invited presentation, University of Minnesota ICU conference. Minneapolis, MN, December 12, 1997.
- 230. "Genetic Testing," invited presentation, Science Museum of Minnesota. St. Paul, MN, November 18, 1997.
- 231. "Assisted Suicide," invited presentation, Orono High School. Orono, MN, November 18, 1997.
- 232. "Human Radiation Studies," invited presentation, International Partners Workshop Human Research Multilateral Review Board, Center for Advanced Studies, NASA. Houston, TX,

November 13, 1997.

- 233. "The Unkindest Cuts: The History of Radiation Research on Children and Lessons for Clinical Research," invited presentation, Pediatric Grand Rounds, University of Minnesota Medical School. Minneapolis, MN, October 29, 1997.
- 234. "Past and Present Lessons in the Ethics of Clinical Research," invited presentation, Millard Fillmore Health Center. Buffalo, NY, October 24, 1997.
- 235. "Ethical Issues in Managed Care: Lessons from Minnesota," invited presentation, Millard Fillmore Health Center. Buffalo, NY, October 24, 1997.
- 236. "Ethical Issues in Clinical Research: Lessons of Hope and Opportunity," invited presentation, The First International Conference on Ethical Issues in Biomedical Engineering, Clemson University. Clemson, SC, September 28, 1997.
- 237. "Bioethics Consequences of ART," invited presentation, A Foundation for the Next Millennium: Principles for Nurses Specializing in Reproductive Medicine and the ARTs, Medical Education Collaborative. New Orleans, LA, September 11-13, 1997.
- 238. "Informed Consent: Past, Present and Future," invited presentation, Unity Hospital. Fridley, MN, September 9, 1997.
- 239. "Ethical Issues in the Development and Testing of New Medical Technology," invited presentation, Medical Alley. St. Louis Park, MN, August 20, 1997.
- 240. "The Moral, Ethical & Technological Complications session," invited presentation, Confidentiality of Substance Abuse Patient Records, Medical Educational Services, Inc., June 18, 1997.
- 241. "Practical Clinical Research Ethics," presentation-workshop, Society of General Internal Medicine. Washington, DC, May 1-3, 1997.
- 242. "Ethical Issues in Genetic Testing for Alzheimer's Disease," invited presentation, Geriatric Research, Education, & Clinical Center (GRECC). Minneapolis, MN, April 28, 1997.
- 243. "Ethical Issues, Assisted Suicide and Disability," invited presentation, Minnesota State Council on Disability Annual Conference. St. Paul, MN, April 5, 1997.
- 244. "The Lessons of Hope and Opportunity: Past and Future Issues in the Ethics of Clinical Research," invited presentation, 1997 General Clinical Research Centers (GCRC) Annual Meeting. Washington, DC, March 7, 1997.
- 245. "Research Ethics and a Crisis of Trust: Black and Blue at the University of Minnesota," invited presentation, East Carolina University School of Medicine, Duke University Medical Center. Durham, NC, February 20, 1997 and Greenville, NC, February 21, 1997.
- 246. "The Unkindest Cuts: Radiation Experiments on Children During the Cold War," invited Grand Rounds, Children's Healthcare. St. Paul, MN, February 13, 1997 and Minneapolis, MN, December 10, 1996.

- 247. "Ethics of Reproductive Medicine: A Discussion of the Money Back Guarantee," invited presentation, Annual Meeting of the Minnesota Chapter of the American College of Obstetricians and Gynecologists. Minneapolis, MN, December 7, 1996.
- 248. "Strategies for Addressing the IRB's Current Obstacles: Holding it Together and Measuring Our Success" and "The Responsible Conduct of Research: A Commitment for All Scientists," invited panelist, Annual Meeting of Public Responsibility in Medicine and Research (PRIM&R). San Diego, CA, November 11-14, 1996.
- 249. "Vulnerability and the Public Good: Government Radiation Experiments and the Cold War," invited presentation, Minnesota Academy of Medicine. St. Paul, MN, November 5, 1996.
- 250. "Issues in Assisted Reproductive Technology," invited presentation to the Hoping and Coping Conference, Midwest Center for Reproductive Health, PA and North Memorial Health Care. St. Louis Park, MN, October 26, 1996.
- 251. "Report of the Findings and Recommendations of the Advisory Committee on Human Radiation Experiments," invited speaker, and "Contemporary Legal Issues and Actions in Human Subject Research," invited panelist, OPRR and FDA sponsored IRB conference on the Role of the IRB in Collaborative Research, University of Illinois College of Medicine. Peoria, IL, September 26, 1996.

*Updated* 2.16.05

## Scientific and Medical Accountability Standards Working Group INFORMATION FORM FOR POTENTIAL MEMBERS

Pursuant to California Health and Safety Code [125290.55] the Independent Citizens' Oversight Committee of the California Institute for Regenerative Medicine shall have a Scientific and Medical Accountability Standards Working Group to recommend to the ICOC scientific, medical, and ethical standards. The Standards Working Group shall have 19 members: Five ICOC members from the10 groups that focus on disease-specific areas, nine scientists and clinicians nationally recognized in the field of pluripotent and progenitor cell research, four medical ethicists, and the chairman of the ICOC. "Medical ethicist" is defined [125292.10 (p)] as "an individual with advanced training in ethics who holds a Ph.D., M.A., or equivalent training and who spends or has spent substantial time (1) researching and writing on ethical issues related to medicine, and (2) administering ethical safeguards during the clinicul trial process, particularly through service on institutional review boards.

\_\_Mr. <u>X</u>Ms. \_\_Dr. \_\_Mrs. \_\_Other\_\_\_\_

Patricia	А.	King
First Name	Middle Initial	Last Name
Carmack Waterhouse F Title	Professor of Law, Medicine, Et	hics & Public Policy
Georgetown University	/ Law School	
University, Company or Orga	inization	
600 New Jersev Avenu Business Address	<u>e, NW</u>	
Washington, DC 20001 City/State/ Zip		
202.662.9085 Work Number	Cell	I Phone
<u>kingp@law.georgetow</u> Email	1.edu	
<ol> <li>What position in the S ICOC</li> </ol>	Standards Working Group are y Scientist/clinician	ou applying for?

2. Please indicate whether or not you are an expert in the following subjects using a "Y" for yes and an "N" for no. Please use the blank lines to list any other areas of your expertise that you feel might be relevant to serving on the working group.

X The Biomedical Ethics of Stem Cell Research

Informed Consent

X Controls on research involving human subjects

\_\_\_\_ Patient privacy laws and regulations

X National Institutes of Health standards for research

X National Academies' standards for biomedical research

Compliance for medical ethics, health and safety requirements

Expertise in medical regulatory agencies (such as the FDA)

Expertise in the creation of public scientific resources

Expertise in health disparities

3. The Working Group will develop draft interim standards. At the point that interim standards are adopted by the ICOC, a 270-day public hearing period begins, all subject to the California Administrative Procedure Act (APA). Working Group members will consider public comment as guidance in revising interim standards and procedures. Working Group members may also be asked to serve on subcommittees that may meet to develop standards or determine compliance in specific areas. At least 4 meetings per year are required for the Working Group; the specific meetings schedule and length of each meeting will be set by the membership, but in the first few months will likely be a few meetings to establish interim standards. Do you anticipate making such a time commitment?

Yes\_\_\_\_\_ No\_\_\_\_

Please describe any constraints <u>I am committed but given the distance and my existing</u> commitments I will not have much flexibility until January 2006. During the summer of 2005 I will be in Italy. During the fall academic semester I teach Mondav – Wednesdav.

4. Please attach a resume or CV.

5. Please be aware that Working Group members will be required to comply with conflict of interest standards determined by the Independent Citizens' Oversight Committee based on standards applicable to members of scientific review committees of the National Institutes of Health. The guidelines are under development.

Please send your completed information sheet and resume or CV by email (preferred) or mail with "Attn: Standards WG Search" to either:

- info@cirm.ca.gov or
- CIRM, 5858 Horton St., Ste. 455, Emeryville, CA 94608

#### PLEASE NOTE: THIS APPLICATION, TOGETHER WITH ANY ATTACHED MATERIALS, MAY BE SUBJECT TO DISCLOSURE PURSUANT TO THE CALIFORNIA PUBLIC RECORDS ACT.

TOTAL P.03

## **CURRICULUM VITAE**

## PATRICIA A. KING

## PERSONAL DATA

Georgetown University Law Center 600 New Jersey Avenue, NW Washington, D.C. 20001 202.662-9085 202.662-9495 (FAX) Kingp@law.georgetown.edu

## **EDUCATION AND TRAINING**

J.D. 1969 Harvard Law School

Admitted to practice District of Columbia Bar November 4, 1969

Admitted to practice U.S. Supreme Court June 30, 1980

#### **PROFESSIONAL EXPERIENCE**

Carmack Waterhouse Professor of Law, Medicine, Ethics and Public Policy, 1996 - present, Georgetown University Law Center

Professor of Law, 1988-1996, Georgetown University Law Center

Associate Professor of Law, 1974-1988, Georgetown University Law Center

Adjunct Professor, 1990 - present, Dept. of Health Policy and Management, Bloomberg School of Public Health, Johns Hopkins University

Deputy Assistant Attorney General, 1980-1981, Civil Division, Department of Justice

Deputy Director, 1971-1974, Office of Civil Rights, Department of Health, Education & Welfare

Special Assistant to the Chair, 1969-1971, Equal Employment Opportunity Commission

9/1/04

## **PROFESSIONAL ACTIVITIES**

## **Current:**

Faculty Affiliate, Kennedy Institute of Ethics, Georgetown University, 2001-

Institute of Medicine, National Academy of Sciences, 1992-

Fellow, Hastings Center, 1977 -

American Law Institute 1988-

District of Columbia Bar (unified)

Member, Advisory Board, Genetics and Public Policy Center, Berman Bioethics Institute, Johns Hopkins University, 2002 -

Member, National Academies Committee on Ethical Issues in Housing Intervention Research Involving Children, Youth and Families, 2004-

Member, Ethics Research Consortium on Smoking and Genetics, Institute for Health Care Research and Policy, Georgetown University, 2001

Vice-Chair, Board of Henry J. Kaiser Family Foundation, 1999 -

Chair, Board of Trustees, Wheaton College, 2000-

Member, Board of National Partnership of Women and Families, 1987-

Director, Mathematica Policy Research Inc., 1991-

Director, Golden West Financial Corporation, 1994-

## Past:

Member, Working Group on the Criteria for Cell-Based Therapies, Phoebe R. Berman Bioethics Institute, Johns Hopkins University, 2002 - 2003

Member, Board of the Hospice Foundation, 1994-2003

Member, AAAS & Hastings Center Project, Tools for Public Conversation About Behavioral Genetics, 2000 -

Member, IOM Committee On Assessing the System for Protecting Human Research Subjects, 2001-

Member, NRC/IOM Committee on Biological and Biomedical Application of Stem Cells, 2001

Member, Council, Institute of Medicine 1998-2001

Member, Advisory Board, Pew Fellowships in International Jouralism, 1998-2001

Fellow, Kennedy Institute of Ethics, 1977 -2001

Member, Board of Advisors, American Board of Internal Medicine, 1995 - 1999

Member, Working Group to Advise the ACD (NIH) on Guidelines and Oversight of Human Pluripotent Stem Cell Research, 1999

Member, IOM Committee on Organ Procurement & Transplantation Policy, 1999

Member, IOM Committee on Perinatal Transmission of HIV, 1997 - 1998

Chair, Committee on the Assessment of Family Violence Interventions, National Research Council, 1994 - 1998

Member, Pew Global Stewardship Initiative Advisory Board, 1993 - 1996

Member, National Advisory Board of Ethics in Reproduction, 1991 - 1996

Member, President's Advisory Committee on Human Radiation Experiments, 1994-1995

Member, Board of General Services Foundation, 1990-1994

Co-Chair for Policy, Embryo Research Panel, NIH, 1994

Member, Commission on Behavioral and Social Sciences and Education, National Research Council, 1992-1995

Member, Advisory Board on Health Sciences Policy, Institute of Medicine, 1989-1994 Member, Ethics, Legal and Social Issues (ELSI) Working Group, Human Genome Center, NIH, 1989-1995 Member, Board of The Center for Reproductive Law & Policy, 1993-1994

Member, Board of Directors, American Society of Law & Medicine, 1990-1993

Member, Ethics Cluster, President Clinton's Health Care Taskforce, 1993

Member, Advisory Committee to the Director of the National Institutes of Health, 1990-1994

Member, Board of Trustees, Russell Sage Foundation, 1981-1991; Vice Chair 1987-1990

Member, Institute of Medicine, Committee to Study Decision Making with Respect to the Acceptance by the Public of Advances in Biology and Technology, 1989-1990

Member, Committee on Contraceptive Development, National Academy of Sciences, 1987-89

Member, Human Fetal Tissue Transplantation Research Panel, NIH, 1988

Member, Clinical Research Subpanel for National Institute of Aging, Clinical Center, NIH, 1984-1988

Member, Recombinant DNA Advisory Committee, 1979-1981

Member, National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1974-1978

Member, Health Advisory Committee, Office of Technology Assessment, U.S. Congress, 1979-1986

Member, National ACLU Special Committee on Receiving and Withholding of Medical Treatment, 1984-1988

Member, Medical Operating Committee, Whitman-Walker Clinic, 1987-1989

Member, Office of Technology Advisory Panel on Infertility Prevention and Treatment, 1986-1988

Member, Panel on Protection of Human Subjects at the Addiction Research Center, National Institute on Drug Abuse, 1987 Member, Office of Technology Assessment Panel on Technologies and Child Health, 1985-1987

Member, Office of Technology Assessment Panel on Indian Health Care, 1986

Member, Office of Technology Assessment Panel on Technology and Children's Mental Health, 1987

Member, Office of Technology Assessment Panel on Agent Orange Studies, 1980-1988

Member, Office of Technology Assessment, Workshop on Human Biological Materials, 1987

Member, Board of Directors, Wheaton College Alumni Association, 1982-1985

Member, Consensus Development Conference on Infantile Apnea and Home Monitoring, National Institute of Child Health and Human Development, 1985-1986

Member, Board of American Civil Liberties Union of the National Capital Area, 1984-86

Member, Minority Affairs Committee, Law School Admission Council/Law School Admission Services, 1986

Treasurer, Harvard Law School Association of D.C., 1983-1984 Governor, District of Columbia Bar Association (unified), 1973-76; 1982-85

Seminar Leader, Aspen Institute, Executive Seminar, 1984

Member, Council of the Harvard Law School Association, 1979-1983

Member, President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, 1980

Member, Board of the Center for Women's Policy Studies, 1980

Member, Joint Commission on Prescription Drug Use, 1976-1980

Member, Policy and Data Safety Monitoring Board, National Heart, Lung and Blood Institute, National Institutes of Health, 1977-1980 Member, Ad Hoc Committee on FDA Legislation and Policies Affecting Anti-Cancer Drugs, Institute of Medicine, National Academy of Sciences, 1979-1980

Member, United States Circuit Judge Nominating Commission, 1977-1980

Member, Board of the Institute for Public Interest Representation, Georgetown University, Washington, D.C., 1978-1980

Member and Chairperson, Redevelopment Land Agency of the District of Columbia, Washington, D.C., 1976-1980

Member, Visiting Committee for Law, Harvard University Law School, 1975-1981

Member, Committee on Academic Freedom and Tenure, American Association of Law Schools, 1976-1979

Member, Accreditation Committee, ABA Section on Legal Education and Admission to the Bar, 1975-1976

Member, ABA Council, Section on Legal Education & Admission to the Bar, 1976-77

Member, President's Advisory Committee, Wheaton College, 1972-1975

Member, Department of Defense Task Force on the Administration of Justice in the Armed Forces, 1972

Consultant, Women Judges' Fund for Justice, 1988-1991

## **Testified Before:**

House Subcommittee on Science and Technology; "Ethical Issues in Science Research," September 7, 1977

House Subcommittee on Science and Technology; "Social Policy Issues in Genetic Engineering" November 18, 1982

Senate Committee on Commerce, Science, and Transportation, Subcommittee on Science, Technology, and space, "Mapping the Human Genome: The Promise and the Problems," November 9, 1989

Senate Judiciary Committee, Clarence Thomas Nomination, September 17, 1991

CURRICULUM VITAE Patricia A. King Page 104

## **EDITORIAL ACTIVITIES**

Series Editor, Ethics, Health and Public Policy Series, Georgetown University Press, 2004-

Area Editor, Encyclopedia of Bioethics, Revised Edition, 1990-1994

Member, Council of Advisory Editors, Medical Humanities Review, 1986-

Member, Editorial Board of BioLaw Reporter, 1982-

## HONORS AND AWARDS

Honorary Doctor of Laws, Wheaton College, 1992

Distinguished Service Award HEW, 1973

Secretary's Special Citation (Elliott Richardson), 1973

John Hay Whitney Fellow, 1967-1968

## PUBLICATIONS

## Articles & Books

CASES AND MATERIALS ON LAW, SCIENCE AND MEDICINE, 3<sup>RD</sup> Edition (Co-Author), forthcoming 2005

Reflections On Race and Bioethics in the United States, 14 Health Matrix 149 (2004)

Ruth Faden, Liza Dawson, Alison Bateman-House et al., <u>Public Stem Cell Banks:</u> <u>Considerations of Justice in Stem Cell Research and Therapy</u>, Hastings Center Report 33, no.6 (2003): 13-27. Liza Dawson, Alison Bateman-House et. al., <u>Safety Issues in Cell-Based Intervention</u> <u>Trials</u>, Fertility and Sterility 80, no.5 (2003): 1077-1085.

Embryo Research: The Challenge for Public Policy, Journal of Philosophy and Medicine 22(5) (October 1997): 441-455.

<u>Helping Women Helping Children</u>, 69 <u>The Milbank Quarterly</u>, 595 (1991); In revised form in CONFRONTING DRUG POLICY, (R. Bayer and G. Oppenheimer eds.) Cambridge University Press 1993.

<u>Special Considerations for Minority Participation in Prenatal Diagnosis</u>, 243 J.A.M.A. 1254 (1980) (co-author)

CASES AND MATERIALS ON LAW, SCIENCE AND MEDICINE, (Co-Author) 1984.

CASES AND MATERIALS ON LAW, SCIENCE AND MEDICINE, 2nd Edition, (Co-Author) 1996.

SUPPLEMENTS, CASES AND MATERIALS ON LAW, SCIENCE AND MEDICINE, (Co-Author) 1987, 1989, 1999

Empowering and Protecting Patients: Lessons for Physician-Assisted Suicide from the African-American Experience, (with Leslie Wolf) 82 Minn. L. Rev. 1015 (1998)

Harms of Excluding Pregnant Women from Clinical Research: The Case of HIV-Infected Pregnant Women, (N. Kass, H. Taylor & P. King) 24 J. of Law, Med. & Ethics 36 (1996).

The Dangers of Difference, 22 Hastings Center Report 35 1992).

Against Clarence Thomas, 1 Reconstruction 58 (1992).

The Authority of Families to Make Medical Decisions for Incompetent Patients After the Cruzan Decision, 19 Law, Med. & Health Care 76 (1991)

Legal Issues Affecting Pregnant Women and Newborn HIV Testing, 4 AIDS Patient Care 3 (1990)

Legal Regulation of Human Gene Therapy, (with J. Areen), 1 Human Gene Therapy 151-161 (1990)

<u>Reproductive Technologies: The Legal and Ethical Issues</u>: <u>Update</u>, BioLaw, 1989 <u>Legal Regulation of Fetal Tissue Transplantation</u>, (with Areen), 36 Clinical Research 205 (April 1988)

Reproductive Technologies: The Legal and Ethical Issues, 1 BioLaw 113 (1986)

"New" Reproductive Techniques and the Need to Legislate for Parenthood in the Modern Era - Commentary on Cases, 1985 Bioethics Rptr. 1 (court Cases) (with Mandler)

Ethics Committees: A Concept Whose Time Has Come? -- Commentary on Cases, 1984 Bioethics Reporter 471

Rights of the Fetus: Case Notes, 1984 Bioethics Rptr. 393 (Court Cases) (with Areen)

Treatment and Minors: Issues Not Involving Lifesaving Treatment, 23 J. of Fam. Law. 241 (1984)

<u>The Juridical Status of the Fetus</u>: <u>A Proposal for Legal Protection for the Unborn</u>, 77 Mich. L. Rev. 1647 (1979), reprinted in THE LAW AND POLITICS OF ABORTION (C. Schneider and A. Vinovskis eds. 1980) and ABORTION: MORAL AND LEGAL PERSPECTIVES 57 (J. Garfield and P. Hennessey eds. 1984)

## **Book Chapters**

Justice Beyond Belmont. Forthcoming Georgetown University Press, 2004

<u>The Dangers of Difference Re-Visited</u>, THE STORY OF BIOETHICS: FROM SEMINAL WORKS TO CONTEMPORARY EXPLORATIONS, (Eran Klein & Jennifer Walters, eds.) Georgetown University Press, 2003.

<u>Race, Justice and Research</u>, BEYOND CONSENT: SEEKING JUSTICE IN RESEARCH, (Jeffrey Kahn, Anna Mastroianni & Jeremy Sugarman eds.) Oxford University Press 1998.

Lessons for Physician-Assisted Suicide From the African-American Experience, PHYSICIAN ASSISTED SUICIDE: EXPANDING THE DEBATE, (Margaret P. Battin, Rosamond Rhodes & Anita Silvers eds.) Routledge, 1998

<u>Reproductive Choices of Adolescent Females with HIV/AIDS</u>, HIV, AIDS AND CHILDBEARING: PUBLIC POLICY PRIVATE LIVES, (R. Faden & N. Kass eds.) Oxford University Press 1996. <u>Commentary:</u> The Need to Understand the Parent-Child Relationship. WOMEN AND REPRODUCTIVE GENETIC TESTING: OPTIONS, OBLIGATIONS AND OBSTACLES, Ohio State University Press 1994.

<u>The Past as Prologue</u>: <u>Race, Class and Gene Discrimination</u>, USING ETHICS AND LAW AS GUIDES (G. Annas and S. Elias eds.) Oxford University Press 1992.

Ethical and Legal Constraints on Research, SCIENCE IN THE 21ST CENTURY, (D. Harrison, M. Osterweis, and E. Rubin eds.) Association of Academic Health Centers (1991).

Legal Issues in Voluntary Screening for HIV Infection in Pregnant Women, AIDS, WOMEN AND THE NEXT GENERATION, (R. Faden, M. Powers & G. Geller eds.) Oxford University Press 1991.

The Lawyer's Role in Dax's Case, DAX'S CASE: ESSAYS IN MEDICAL ETHICS AND HUMAN MEANING (L. Kliever eds.) 1988

Adoption and Artificial Insemination, in GENETIC DISORDERS & BIRTH EFFECTS IN FAMILIES AND SOCIETY (J. Weirs, B. Bernhardt and N. Paul eds. 1984) (with R. Black)

Searching for Consensus, 2 Med. Hum. Rev. 36 (1988), Book Review

<u>BY NO EXTRAORDINARY MEANS</u>, 28 Jurimetrics, Journal of Law, Science and Technology 115 (1987), Book Review

She Broke the Law, Op-Ed Page, Washington Post, January 19, 1993 A-21.

Shackled to a Shadow of Doubt, Op-Ed Page, Los Angeles Times, Oct. 8, 1991 B-7.

# Scientific and Medical Accountability Standards Working Group INFORMATION FORM FOR POTENTIAL MEMBERS

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Pursuant to California Health and Safety Code [125290.55] the Independent Citizens' Oversight Committee of the California Institute for Regenerative Medicine shall have a Scientific and Medical Accountability Standards Working Group to recommend to the ICOC scientific, medical, and ethical standards. The Standards Working Group shall have 19 members: Five ICOC members from the10 groups that focus on disease-specific areas, nine scientists and clinicians nationally recognized in the field of pluripotent and progenitor cell research, four medical ethicists, and the chairman of the ICOC. "Medical ethicist" is defined [125292.10 (p)] as "an individual with advanced training in ethics who holds a Ph.D., M.A., or equivalent training and who spends or has spent substantial time (1) researching and writing on ethical issues related to medicine, and (2) administering ethical safeguards during the clinical trial process, particularly through service on institutional review boards.

Karen		Lebacqz_
First Name	Middle Initial	Last Name
<b>Bioethicist in Residence</b>	and Professor of Religious Ethics	
Title		
Yale University		
University, Company or C	rganization	
89 Trumbull St.		
Business Address		
New Haven, Ct. 06520		
City/State/ Zip		
203 432-2726	707 604 0160	
Work Number	_ Cell Pho	one
<b>karen.lebacqz@yale.e</b> Email	lu	
4. What position in th □ ICOC	e Standards Working Group are you a	

2. Please indicate whether or not you are an expert in the following subjects using a "Y" for yes and an "N" for no. Please use the blank lines to list any other areas of your expertise that you feel might be relevant to serving on the working group.

- \_\_y\_ The Biomedical Ethics of Stem Cell Research
- \_\_y\_ Informed Consent
- \_\_\_y\_ Controls on research involving human subjects
- \_\_n\_ Patient privacy laws and regulations
- \_\_\_y\_National Institutes of Health standards for research
- \_\_\_n\_ National Academies' standards for biomedical research
- \_\_n\_ Compliance for medical ethics, health and safety requirements
- \_\_n\_Expertise in medical regulatory agencies (such as the FDA)
- \_\_n\_Expertise in the creation of public scientific resources
- \_\_\_y\_Expertise in health disparities

3. The Working Group will develop draft interim standards. At the point that interim standards are adopted by the ICOC, a 270-day public hearing period begins, all subject to the California Administrative Procedure Act (APA). Working Group members will consider public comment as guidance in revising interim standards and procedures. Working Group members may also be asked to serve on subcommittees that may meet to develop standards or determine compliance in specific areas. At least 4 meetings per year are required for the Working Group; the specific meetings schedule and length of each meeting will be set by the membership, but in the first few months will likely be a few meetings to establish interim standards. Do you anticipate making such a time commitment?

Yes\_x\_\_\_ No\_\_\_\_

Please describe any constraints\_\_(I am currently living in New Haven; at the end of this academic year, I will return to California )

4. Please attach a resume or CV.

5. Please be aware that Working Group members will be required to comply with conflict of interest standards determined by the Independent Citizens' Oversight Committee based on standards applicable to members of scientific review committees of the National Institutes of Health. The guidelines are under development.

Please send your completed information sheet and resume or CV by email (preferred) or mail with "Attn: Standards WG Search" to either:

- <u>info@cirm.ca.gov</u> or
- CIRM, 5858 Horton St., Ste. 455, Emeryville, CA 94608

PLEASE NOTE: THIS APPLICATION, TOGETHER WITH ANY ATTACHED MATERIALS, MAY BE SUBJECT TO DISCLOSURE PURSUANT TO THE CALIFORNIA PUBLIC RECORDS ACT.

# **KAREN LEBACQZ<sup>1</sup>**

Robert Gordon Sproul Professor of Theological Ethics Pacific School of Religion, Emerita Currently: Bioethicist in Residence and Visiting Professor Of Religious Ethics, Yale University

89 Trumbull St. New Haven, CT. 06520, USA (203) 432-2726 (office) (707) 684-0168 (cell) P.O. Box 2413 Mendocino, CA 95460 SS#: 014-40-8762

#### **EDUCATION**

Ph.D. Harvard University 1974 Religion and Society(Dissertation: "Prenatal Diagnosis: Distributive Justice and the Quality of Life")M.A. Harvard University 1969 Religion and SocietyB.A. Wellesley College 1966 Biblical History

#### **PROFESSIONAL POSITIONS**

Bioethicist in Residence and Visiting Professor, Yale University	2005-2006
Prof. Social Ethics, McGill University, Montreal	1994-96
Prof. Theological Ethics, Pacific School of Religion	1982-2004
Associate Professor 1977-1982	
Assistant Professor 1972-1976	
Member, Geron Ethics Advisory Board	1997-2003
President, Society of Christian Ethics	1989
Chair of the Board, Park Ridge Center for the Study of Health, Faith, and Ethics	1988-1990
Acting Director, Center for Ethics and Social Policy,	
Graduate Theological Union	1984-1985
Director, Professional Ethics Group, Center for Ethics and Social Policy	1985-1991
Consultant in Bioethics, Calif. Dept. Health	1976-1977
Commissioner: National Commission for the Protection of Human Subjects of	
Biomedical & Behavioral Research	1974-1978
Instructor and Consultant, Center for Law and Health Sciences	
Boston University	1970-1972

#### **PROFESSIONAL MEMBERSHIPS / AWARDS**

<sup>&</sup>lt;sup>1</sup> Please note: because I am officially retired and have had no secretary for several years, this C.V. is hopelessly out of date. I am too busy doing things to spend time recording them! However, this will give you a basic understanding of my professional inclinations.

Phi Beta Kappa Society of Christian Ethics	1966- 1972-
Member of the Board 1981-1986	
President 1989	
Fellow, Hastings Center	1973-
Center for Ethics and Social Policy, GTU: Board Member	1974-1990
Outstanding Young Women of America	1976
Member, National Faculty Seminar on Congregational Education	1984-87
Association of Theological Schools Grant Recipient	1976 and 1985
Nattional Endowment for the Humanities Grant Recipient 1980 and 1984	
Director, Summer Humanities Seminar	1980
Co-Director, project on "Equal Worth and the Forms of Justice,"	1984
Lilly Endowment grant for work in professional ethics,	1985-1988
Recipient of GTU Newhall award for development of Practicum in Bioethics	1989
Recipient of GTU Newhall award for study of Asian-American women's literature	1991
Recipient of GTU Luce grant scholarship for study of Asian women's theology	1991
Member, Women's Research Group, Program for Theology and Cultures in Asia	1990-1993
Member, Center for Theology and the Natural Sciences, Genome Project	1991-1994

#### PUBLICATIONS

**Books:** 

- Karen Lebacqz, Suzanne Holland, and Laurie Zoloth, eds. *The Human Embryonic Stem Cell Debate*. Syracuse, NY: MIT, 2001.
- Karen Lebacqz and Joseph D. Driskill. *Ethics and Spiritual Care : A Guide for Pastors, Chaplains, and Spiritual Directors*. Nashville, TN: Abingdon, 2000.

Karen Lebacqz, Word, Worship, World and Wonder: Reflections on Christian Living, Abingdon, 1997.

- Karen Lebacqz & Ronald G. Barton, Sex in the Parish, Westminster Press, 1991.
- Karen Lebacqz, Justice in an Unjust World: Foundations for a Christian Approach to Justice, Minneapolis: Augsburg, 1987.
- Karen Lebacqz, Six Theories of Justice: Perspectives from Philosophical and Theological Ethics, Minneapolis: Augsburg, 1986.

Karen Lebacqz, Professional Ethics: Power and Paradox, Nashville: Abingdon Press, 1985.

Karen Lebacqz, ed., Genetics, Ethics and Parenthood, NY: Pilgrim Press, 1983.

#### **Articles/Chapters**

"Choosing Our Children: The Uneasy Alliance of Law and Ethics John Robertson's Thought." In *Ethics and Law in Biomedicine*, edited by Edward Keyserlingk. Montreal, [forthcoming].

- "Twenty Years Older but Are We Wiser?" In *Belmont Revisited [Tentative Title]*, edited by James Childress. Washington, DC: Georgetown University, 2003.
- "The Many Faces of Virtue." In *Proceedings of the Tenri Yamato Culture Congress*, edited by Cheryl Kirk-Duggan and Akio Inoue, 2001?
- "The Elusive Nature of Respect." In *The Human Embryonic Stem Cell Debate*, edited by Karen Lebacqz Suzanne Holland, and Laurie Zoloth. Cambridge, MA: MIT, 2001. Articles/Chapters (continued)
- "The Tarnished Temple: Sex and Difference in Christian Ethics." In *Love and Gender in the World Religions*, edited by Joseph Runzo and Nancy M. Martin. Oxford: One World, 2000.
- "Ambiguites of 'Therapy' and Their Implications for the Place of Women and the Disabled in a Gene-Focused Society." In *Gene Therapy: Ethical, Legal, and Social Perspectives*, edited by Anders Nordgren. Stockholm: Elandes Gotab, 1999.
- "Vicious Virtue? Patience, Justice, and Salaries in the Church," in James F. Keenan, S.J., and Joseph Kotva, Jr., eds., *Practice What you Preach: Virtues, Ethics, and Power in the Lives of Pastoral Ministers and Their Congregations* (Franklin, WI: Sheed and Ward, 1999), with Shirley Macemon.
- "Three Sisters, Three Theological Lessons." In *Ethical Boundaries in Cancer Genetics.*, edited by M.D Arthur W. Nienhuis, 1998.
  - "On (Non-)Reversible Living," in Soul to Soul, Cheryl Kirk-Dugan.
  - "Time to Die?", *Biomedical Ethics* (newsletter of the European Network for Biomedical Ethics) v. 4, no. 1, 1999, pp. 16-18.
  - "Religious Studies in Bioethics: No Room at the Table?" in Dena S. Davis and Laurie Zoloth-Dorfman, eds., *Notes from a Narrow Ridge: Religion and Bioethics* (Frederick, MD: University Publishing Group, 1998).
  - "Change, as in 'How I've...' or They Don't Make Pants the Way They Used To," *Journal of Religious Ethics*, 25:1, pp. 25-32.
  - "Fair Shares: Genes and Justice," in Ted Peters, ed., Genetics, Pilgrim Press, 1998.
  - "Genetic Privacy: No Deal for the Poor," in Ted Peters, ed., Genetics, Pilgrim Press, 1998.
  - "Difficult Difference," Cambridge Quarterly of Healthcare Ethics, v. 7:1, 1998, pp. 17-26.
  - "Justice," in Bernard Hoose, ed., Basic Christian Ethics: An Introduction (London: Cassell, 1998).
  - "Genes, Justice, and Clones" in Ron Cole-Turner, ed., *Human Cloning: Religious Responses* (Louisville: Westminster/John Knox Press, 1997), pp. 49-57.

- "Difference or Defect: Intersexuality and the Politics of Difference," Annual of the Society of Christian Ethics, v 17, 1997, pp. 213-229.
- "Justice," in Letty M. Russell and J. Shannon Clarkson, eds., *Dictionary of Feminist Theologies*, (Louisville, KY: Westminister/John Knox Press, 1996.)
- "Structuring the Review of Human Genetics Protocols: Gene Localization and Identification Studies," in *IRB, A Review of Human Subjects Research*, Vol. 18, No. 4, July August, 1996.
- "The Weeping Womb: Why Beneficence Needs the still Small Voice of Compassion in E.E. Shelp ed., *Secular Bioethics in Theological Perspective*, Kluwer Academic Publishers, Printed in the Netherlands, 1996, 85-96.
- "Diversity, Disability, and Designer Genes: on What it Means to be Human," in *Studia Theologica: An international journal of Nordic theology*, Scandinavian University Press, Norway, Vol. 50, No.1 1996, 3-14.
- "Alien Dignity: The Legacy of Helmut Thielicke for Bioethics." in Allen Verhey, ed., *Religion and Medical Ethics: Looking Back, Looking Forward*, volume celebrating the 25th Anniversary of the First International Conference on Bioethics, Houston, Wm B. Eerdmans Publishing Co., Grand Rapids, 1996, 44-60.
- "Boundaries, Mutuality, and Professional Ethics," with Ronald G. Barton in Katherine Hancock Ragsdale, *Boundary Wars: Intimacy and Distance in Healing Relationships*, The Pilgrim Press, Cleveland, Ohio, 1996, 96-110.
- "The 'Fridge:' Health Care and the Disembodiment of Women," in *Embodiment, Morality, and Medicine*, L. Sowle Cahill and M.A. Farley, eds. Kluwer Academic Publishers, Printed in the Netherlands, 1995, 155-167.
- "Justice & Sexual Harassment," Capitol University Law Review, Spring 1994.
- "A Tale of Truth: Story Theology and Ethical Analysis," in John C. England & Archie C. C. Lee, *Doing Theology with Asian Resources*, Auckland, New Zealand: Pace Publishing, 1993.
- "Fair Shares: Is the Genome Project Just?" CTNS Bulletin, Autumn 1993.
- "Bridging the Gap: Pain and Compassion," in John and Denise Carmody, eds., *The Challenge of Prophetic Christianity: Essays in Honor of Robert McAfee Brown*, Orbis, 1993.
- "Feminism," Encyclopedia of Bioethics, Warren Reich, ed., revised edition, Macmillan.
- "Sexual Ethics: A Theological View," Dialog: Journal of Theology, Winter 1993.
- "Sexual Ethics and Professional Standards," *Encyclopedia of Bioethics*, Warren Reich, ed., revised edition, Macmillan.
- "Empowerment in the Clinical Setting," in *Theology and Medicine*, vol. 3, 1993.

"Humility in Health Care," in Journal of Medicine and Philosophy, 17:291-307, 1992.

"Sexual Harassment in the Church," Claiming Our Gifts, Spring, 1991.

- "A Moral Justification for Voluntary Euthanasia," in *Active Euthanasia, Religion and the Public Debate*, The Park Ridge Center, 1991.
- "Justice as Norm for the Delivery of Health Care," in *Proceedings of the Conference on Ethics at Work: Issues in the Workplace and in Education*, Auckland Institute of Technology, June 1991.

"Feminism and Bioethics," in Second Opinion. October, 1991.

- "Power, Intimacy, and Supervision," with Ronald G. Barton, *Journal of Supervision and Training in Ministry*, vol. 12, 1990.
- "Avoiding Sexual Misconduct in Ministry," with Ronald G. Barton, a pamphlet produced by the Office of Church Life and Leadership of the United Church of Christ, 1990.
- "Love Your Enemy: Sex, Power, and Christian Ethics," *Annual of the Society of Christian Ethics*, 1990 (Presidential Address).
- "Power in the Supervisory Relationship," for the *Journal of Supervision and Training in Ministry* (coauthored with Ronald G. Barton; March 1990).
- "Paul Revere and the Holiday Inn: A Case Study in Hospitality," in Nelle Slater, ed., proceedings of the *National Faculty Seminar on Religious Education*, NY: Pilgrim Press, 1989.
- "A Modest Proposal: Pedagogy for Oppressors," in Mary C. Boys, ed., Citizenship and Discipleship,. NY: Pilgrim Press, 1989.
- "Protestant Statements on Economic Justice," in Robert McAfee Brown and Sydney Thompson Brown, *A Cry for Justice*, NY: Paulist Press, 1989.
- "Getting Our Priorities Straight," in Dieter Hessel, ed., *Theological Education for Social Ministry*, N.Y.: Pilgrim Press, 1988.
- "Sex, AIDS, and Ethics," with Deborah Blake, Religious Education, Fall 1987.
- "Christian Faith and Economic Life': Resources on Economic Justice," Prism v.2, no.2, Fall 1987.
- "Appropriate Vulnerability: A Sexual Ethic for Singles," The Christian Century, May 6, 1987.
- "Pastor-Parishioner Sexuality: An Ethical Analysis," *Explore*, Fall 1987.
- "Sex and the Single Pastor," Ethics and Policy, Fall 1987.

"Faith Dimensions in Medical Practice," in Michael Victoroff, ed., Primary Care, v.13, No.2, June 1986.

- "Justice, Economics and the Uncomfortable Kingdom: Reflections on Mt. 20:1-16," Annual of the Society of Christian Ethics, 1983.
- "Ethical Aspects of Clinical Trials," in Stanley Shapiro and Thomas A. Louis, *Clinical Trials: Issues and Approaches* (Marcel Dekker, 1983).
- "The Virtuous Patient," *Philosophy and Medicine* v.9: *Virtue and Health Care*,: Earl E. Shelp, ed., Boston: Reidel, 1983.
- Getting the Ethics Straight," Logos, Spring 1982.
- "Preferential Treatment," Religious Studies Review v.7(2): 97-107, Apr. 1981.
- "Justice and Human Research," *Philosophy and Medicine* v.8: *Justice and Health Care*,: Earl E. Shelp, ed., Boston: Reidel, 1981.
- "Ramsey on Research: Conceptual Confusion," *IRB: A Review of Human Subjects Research*, v.2(10):10-11, Dec. 1980.
- "Bioethics: Some Challenges from a Liberation Perspective," in Paul Abrecht (ed), *Faith and Science in an Unjust World*, proceedings of the World Council of Churches Conference on Faith, Science and the Future, v.1, 1980.
- "The Ethicist in Policy-Making" in Helen B. Holmes et.al., *Birth Control and Controlling Birth: Woman-Centered Perspectives*, Clifton, N.J.: The Humana Press, 1980, pp.283-287.
- "Controlled Clinical Trials— Some Ethical Issues," *Journal of Controlled Clinical Trials*, v.1:29-36, 1980.
- "Suicide," (with H. Tristram Engelhardt, Jr., Ph.D., M.D.) in David J. Mall, ed., *Death, Dying and Euthanasia* Washington, D.C.: University Publications of America, 1977, pp.669-705; reprinted as "Suicide and Covenant" in M. Pabst Battin and David J. Mayo, eds., *Suicide: The Philosophical Issues*, NY: St. Martin's Press, 1980.
- "Fetal Research: A Commissioner's Reflection," *IRB: A Review of Human Subjects Research*, v.1 (no.4), June/July 1979.
- "Some Ethical Considerations in Clinical Trials" (with Robert J. Levine, M.D.), *Clinical Pharmacology* and Therapeutics, v.25 (no.5): 728-741, May 1979.
- "Pediatric Drug Investigation: Current Ethical Guidelines," in B. Mirkin, ed., *Clinical Pharmacology and Therapeutics: A Pediatric Perspective*, Year Book Medical Publishers, 1977, pp. 279-297.
- "The National Commission and Research in Pharmacology: An Overview," *The Federation of American* Societies of Experimental Biology, 1977.
- "Respect for Persons and Informed Consent to Participate in Research," (with Robert J. Levine, M.D.), *Clinical Research* v.25 (no.3), Spring 1977.

"Sterilization: Ethical Aspects," Encyclopedia of Bioethics, Warren Reich, ed., 1977.

- "Suicide" (with H. Tristram Engelhardt, Jr., Ph.D., M.D.) in David J. Mall, ed., *Death, Dying and Euthanasia*, Washington, D.C.: University Publications of America, 1977, pp.669-705; reprinted as "Suicide and Covenant," in M. Pabst Battin and David J. Mayo, eds., *Suicide: The Philosophical Issues*, NY: St. Martin's Press, 1980.
- "Jesus, Feminism, and other Enigmas of Mental Health." *Philosophy and Medicine* v.4: *Mental Health: Philosophical Perspectives*,: H. Tristram Engelhardt and Stuart F. Spicker, eds., (Boston: Reidel Press, 1977, pp.275-280).
- "The History and Future of Ethical Issues in Research in Neuropsychopharmacology," in Donald Gallant and Robert Force, eds., *Ethical and Legal Issues in Psychopharmacologic Research and Treatment*, NY: Halstead Press, 1977, pp.113-132.
- "Informed Consent to Research" (with Robert J. Levine, M.D.), Encyclopedia of Bioethics, Warren Reich, ed., 1977.
- "Some Reflections on the Commission's Report and Recommendations: Fetal Research," *Villanova Law Review*, January 1977.
- "Reproductive Research and the Image of Woman," in Clare Fischer, et.al., eds., *Women in a Strange Land*, Fortress Press, 1975.

"Peter and His Doctor," Journal of Current Social Issues, Fall 1975.

"Prenatal Diagnosis and Selective Abortion," Linacre Quarterly, May 1973.

#### Media

- *Power Issues in Pastoral Relationships*. Sound recording 1audio cassette. New York, N.Y.: General Theological Seminary, 13 November, 1990. 1 audio cassette.
- Alice Walker. *Three Fates*. (Sound Recording). Graduate Theological Union Convocation. Berkeley, CA, 1997 September. 1 videocassette : sd., col. ; 1/2 in.

#### **Group Reports**

Geron Ethics Advisory Board, Karen Lebacqz (chair), Michael Mendiola, Ted Peters, Ernlé W. D. Young, and Laurie Zoloth-Dorfman, "Reasearch with Human Embryonic Stem Cells: Ethical Considerations," *Hastings Center Report* 29, no. 2 (1999): 31-36.

Reports issued by the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research: Research on the Fetus (1976) Research Involving Prisoners (1976) Psychosurgery (1977) Disclosure of Research Information (1977) Research Involving Children (1977) Research Involving Those Institutionalized as Mentally Infirm (1978) Institutional Review Boards (1978) Ethical Guidelines for the Delivery of Health Services by DHEW (1978) The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research (1978)

Human Life and the New Genetics, (National Council of Churches Task Force; see esp ch 5), 1980.

- *The Teaching of Bioethics,* (Hastings Center Commission on the teaching of bioethics; see esp. "Teaching Bioethics in Non-Medical Professional Schools"), 1976.
- "Ethical and Social Issues in Screening for Genetic Disease," *New England Journal of Medicine* 286:1129, May 1982 (Hastings Center Task Force on genetic counselling).

#### **Speeches/Workshops** (selected)

Response to panel on Violence & Gender, American Academy of Religion, November 21, 1992

School of Ministry, Florida Conference, United Methodist Church, Oct 5-7, 1992 (with Ronald G. Barton).

Spring Convocation lectures, Eden Theological Seminary, April 21-23, 1992.

Chidwick Memorial lectures, Good Samaritan Hospital, Corvallis, Oregon, Feb 27-28, 1992.

University Convocation, Willamette University, Feb 27, 1992.

Pastoral Conference faculty class on Theological Bioethics, Pacific School of Religion, Jan 27-29, 1992.

Pastors School, Southwest Conference, United Methodist Church, Jan 13-14, 1992 (with Ronald G. Barton).

Fellowship of Learning, Nebraska Conference, United Methodist Church, Jan 7-9, 1992.

- "Reinhold Niebuhr A Critical Appreciation," Society of Christian Ethics, January 1992.
- "Rediscovery of the Institutional Soul," the National Meeting of the Association of Clinical Pastoral Educators, Breckenridge, Colorado, Nov. 22, 1991.
- Newcombe Family Lectures on Religion and the Human Condition, University of Winnipeg, Sept. 30-Oct. 1, 1992.
- "The Teaching of Professional Ethics in the United States," for the Auckland Institute of Technology Conference on Ethics at Work, June 20-22, 1991.
- "Ethical Issues in Prenatal Diagnosis," the George R. Dunlop Symposium in Medical Ethics, The Medical Center of Central Massachusetts, May 22, 1991.

- "Abortion: the Wrong Questions," Faith in Action Seminar at Christian Theological Seminary, Indianapolis, IN, April 15, 1991.
- Workshop on sexual ethics, team-led with Stephen Breck Reid, "Families 2000" Conference, National Council of Churches, Chicago, IL, April 11-14, 1991.
- Harrell Lecture, Middle Tennessee State University, Murfreesboro, TN, April 4, 1991.
- "Humility in Health Care," Stanford University Center for Biomedical Ethics, February 21, 1991.
- Smyth Lectures, Blacksburg, VA. February 24-26, 1991.
- Lectures on Professional Ethics, Rocky Mountain Synod Theological Convocation, Evangelical Lutheran Church in America, Jan 28-31, 1991.
- Workshop on Clergy Sexual Ethics, Synod of The Rocky Mountains, Presbyterian Church, USA, January 27, 1991.
- "Ethics and AIDS: A New Challenge in Ministry," Northern California Conference United Church of Christ AIDS Luncheon, January, 22, 1991.
- "Power and Pastoral Relationships," General Seminary, New York, November 13, 1990.
- "Professional Power," Graduate Theological Union Women Faculty Retreat, October 12, 1990.
- Workshop on Ministerial Ethics for the Board of Ordained Ministry, Desert Southwest Conference, United Methodist Church, Phoenix, AZ, September 26, 1990.
- "Story Theology: Some Dilemmas," Program for Theology and Cultures in Asia, Seoul, Korea, July 1990.
- "Integrity of the Person: Sexual Ethics," keynote address to the Witherspoon Society National Gathering II, April 18, 1990.
- Consultation on clergy professional ethics, St. Paul School of Theology, February 18-20, 1990.
- "Protestant Views on Abortion,"- Symposium of Center for Jewish Studies, GTU, May 16, 1990.
- Catholic Health Association Conference on "Justice and Healthcare for All," St. Louis, Missouri, May 16-19, 1990.
- Witherspoon Society Conference, San Francisco, April 18-21, 1990.
- Workshop on Clergy Ethics, Saint Paul School of Theology, February 18-20, 1990.
- Workshop on Clergy Ethics, Ohio Pastor's Convocation, January, 28-31, 1990.

"Sex in the Parish." Workshop at Rocky Mountain Pastor's School, Iliff, Denver, Co., January 22, 1990.

- "Love Your Enemy': Sex, Power, & Christian Ethics," Presidential Address to the Society of Christian Ethics, January, 19, 1990.
- "Jubilee Justice; Justice in Health Care; Justice in Employment," January 24, 25, 26, 1989; Pastoral Conference Seminar at PSR.
- "Justice," Presidential Address to the Western Section of the Society of Christian Ethics, February 24, 1989.

"Professional Ethics," Omer E. Robbins Lecture in Religious Studies at U. of Redlands, March 14, 1989.

The Professional Ethics Group has completed a 5 year study of "Intimacy in the Parish." My colleague Ron Barton and I have given lectures on the topics to: The Association of Theological Field Educators (Toronto) The Center for the Ministry (Oakland) The Center for Abuse Prevention (San Mateo) Union Theological Seminary (New York) The National Consultation on Clergy Violence of the United Church of Christ (New York) The Western Region CPE supervisors (Burlingame) Several GTU schools. Field Education supervisors in the Chicago area.

"Professional Ethics," The Association of Theological Educators," Workshop, Chicago, Friday, April 21, 1989.

"Professional Ethics," Plenary Address to Minister's Council of American Baptist Church, June 20, 1989.

- "The Nature of Community," Address to the Reconciling Conference Committee and Affirmation group of the California-Nevada Conference, United Methodist Church.
- "Justice," July 27-31, 1989 a course for the Yellowstone Conference Pastors' School, United Methodist Church, Livingston, MT.
- "Professional Ethics," August 3-14, 1989 a summer course at Iliff School of Theology, Denver, Co.
- "Who Speaks for the Voiceless," Pastoral Care Symposium, Atlanta, GA, September 18, 1989.
- "Faith Dimensions in Medical Care," Madden Seminar, New Orleans, LA, October 20, 1989.
- "Sex in the Parish," M & M Board of the American Baptist Church, Monterey, CA, December 9, 1989.
- "The Potter Box: Elements for Ethical Analysis," Sept 4, 1986—guest lecture to class at University of San Francisco.
- "Ethics and Deterrence Policy," Oct 31, 1986—to the Bishop's colloquium on nuclear weapons.
- "Professional Ethics," Nov 3-5, 1986—three lectures to Duke University pastors' school (Hickman Lecturer).

"Justice," Dec 3, 1986—First Congregational Church, Berkeley.

"Professional Ethics," Jan 27-29, 1987—lectures to the Pastoral Conference of Pacific School of Religion.

"Justice," Mar 28, 1987—a television show for "Mosaic" focusing on Six Theories of Justice.

"The Frontiers of our Society," May 27, 1987—for "Frontiers: A National Consultation on Theological Education for Laity" sponsored by the Vesper Society, Santa Barbara, CA.

"Intimacy in the Parish"—the Palmer Lectures, Seattle, WA., October 1987.

"AIDS: Images, Feelings, and Fears"—National Consultation on AIDS Ministries, United Methodist Church, Milbrae, CA. Nov 1987, (Available on tape from Pacific School of Religion).

#### SERMONS

"A Rainbow to Live By" – a series of six sermons delivered at Chautauqua, August 2005.

"Walking Humbly in the Court," Peace Church, Oakland, CA, February 10, 1991.

"Walking Humbly in the Court," 1st Presbyterian Church, Blacksburg, VA, February 23, 1991.

"You Must Not Tell': The Story of the Unnamed Aunt," Alameda Congregational Church, Alameda, CA, August 18, 1991.

"You Must Not Tell': The Story of the Unnamed Aunt," Peace Church, Oakland, CA, September 8, 1991.

"Reconciliation," a worship service published in Words of Faith, National Council of Churches, 1991.

"Bread and Roses," Sermon at Alameda UCC, Ordination Service, September 10, 1989.

"The Unlikely Disciple," Preacher, Memorial Church, Stanford, April 9, 1989.

"Re-membering." sermon delivered at Society of Christian Ethics, 1988.

#### **BOOK REVIEWS/COMMENTS**

- Review of Eric Mount, Professional Ethics in Context: Institutions, Images, and Empathy, for Interpretation, Oct 1992.
- Review of Margaret P. Battin, *Ethics in the Sanctuary: Examining the Practices of Organized Religion* and Eric Mount, *Professional Ethics in Context: Institutions, Images and Empathy*, for *The Journal of Religion*, July 1992
- Review of Edmund G. Pellegrino, *Catholic Perspectives on Medical Morals*, for *Bioethics Books*, v. 2. no.2, Winter 1991.

Review of Warren R. Copeland and Roger D. Hatch, *Issues of Justice: Social Sources and Religious Meanings*, for the *Journal of the American Academy of Religion*, 1991.

Comment on the Presbyterian Task Force Report on *Human Sexuality*, for *Christianity and Crisis*, v 51, no. 8, May 27, 1991.

Review of John F. Kilner, *Who Lives? Who Dies? Ethical Criteria in Patient Selection*, for *The Christian Century*, January 30, 1991.

Review of Nel Noddings, Women and Evil, for Theological Studies, April 1990.

Review of Marie Fortune, Keeping the Faith, for Pacific Theological Review, Fall, 1987.

COURSES: [a selection of courses taught] Introduction to Christian Ethics Theories of Justice Bioethics Professional Ethics Decisive Cases for Ethical Theory (e.g. preferential treatment, abortion, land ownership) Sexual Ethics Feminist Perspectives in Ethics Methods in Ethics History of Western Social Thought II (Locke to R. Niebuhr)

# Scientific and Medical Accountability Standards Working Group INFORMATION FORM FOR POTENTIAL MEMBERS

Pursuant to California Health and Safety Code [125290.55] the Independent Citizens' Oversight Committee of the California Institute for Regenerative Medicine shall have a Scientific and Medical Accountability Standards Working Group to recommend to the ICOC scientific, medical, and ethical standards. The Standards Working Group shall have 19 members: Five ICOC members from the10 groups that focus on disease-specific areas, nine scientists and clinicians nationally recognized in the field of pluripotent and progenitor cell research, four medical ethicists, and the chairman of the ICOC. "Medical ethicist" is defined [125292.10 (p)] as "an individual with advanced training in ethics who holds a Ph.D., M.A., or equivalent training and who spends or has spent substantial time (1) researching and writing on ethical issues related to medicine, and (2) administering ethical safeguards during the clinical trial process, particularly through service on institutional review boards.

_Ben	A		Rich
First Name	Middle Initial		Last Name
Associate Professor of	f		
Title			
	alifornia, Davis School of		
Medicine University, Company or	Organization		
emversity, company or	orgunization		
4150 V. Street, Suite			
2400 Business Address			
Dusiness Address			
Sacramento, CA			
95817			
City/State/ Zip			
(916) 734-6010		-	
Work Number		Cell Phone	
	edu		
Email			

□ ICOC □ Scientist/clinician □X Medical ethicist

2. Please indicate whether or not you are an expert in the following subjects using a "Y" for yes and an "N" for no. Please use the blank lines to list any other areas of your expertise that you feel might be relevant to serving on the working group.

- \_Y\_\_ The Biomedical Ethics of Stem Cell Research
- \_Y\_\_ Informed Consent
- \_Y\_\_ Controls on research involving human subjects
- \_Y\_\_ Patient privacy laws and regulations
- \_N\_\_ National Institutes of Health standards for research
- \_N\_\_ National Academies' standards for biomedical research
- \_N\_\_ Compliance for medical ethics, health and safety requirements
- \_N\_\_ Expertise in medical regulatory agencies (such as the FDA)
- \_N\_\_ Expertise in the creation of public scientific resources

\_\_\_\_\_

\_N\_\_ Expertise in health disparities

3. The Working Group will develop draft interim standards. At the point that interim standards are adopted by the ICOC, a 270-day public hearing period begins, all subject to the California Administrative Procedure Act (APA). Working Group members will consider public comment as guidance in revising interim standards and procedures. Working Group members may also be asked to serve on subcommittees that may meet to develop standards or determine compliance in specific areas. At least 4 meetings per year are required for the Working Group; the specific meetings schedule and length of each meeting will be set by the membership, but in the first few months will likely be a few meetings to establish interim standards. Do you anticipate making such a time commitment?

Yes\_X\_\_\_ No\_\_\_\_

Please describe any constraints\_\_NA\_\_\_\_\_

4. Please attach a resume or CV.

5. Please be aware that Working Group members will be required to comply with conflict of interest standards determined by the Independent Citizens' Oversight Committee based on standards applicable to members of scientific review committees of the National Institutes of Health. The guidelines are under development.

Please send your completed information sheet and resume or CV by email (preferred) or mail with "Attn: Standards WG Search" to either:

• <u>info@cirm.ca.gov</u> or

• CIRM, 5858 Horton St., Ste. 455, Emeryville, CA 94608

### PLEASE NOTE: THIS APPLICATION, TOGETHER WITH ANY ATTACHED MATERIALS, MAY BE SUBJECT TO DISCLOSURE PURSUANT TO THE CALIFORNIA PUBLIC RECORDS ACT.

#### Curriculum Vita of Ben A. Rich, J.D., Ph.D.

Current Position:University of California, Davis<br/>Associate Professor, Division of Bioethics<br/>Department of Internal Medicine<br/>School of Medicine<br/>Sacramento, CA (since February, 2000)

University of California, Davis Associate Professor, Division of Pain Medicine Department of Anesthesiology and Pain Medicine School of Medicine Sacramento, CA (since October, 2002)

University of California, Davis Visiting Professor School of Law

# Davis, CA (2000-present)

Work Address: University of California, Davis Health System 4150 V Street, Suite 2400 Sacramento, CA 95817 Area Code: 916 Tel. 734-6010; Fax 734-1531 E-mail: barich@ucdavis.edu

Home Address: **4905 Ridgeline Lane** Fair Oaks, CA 95628

## Education: University of Colorado, Boulder (1992-1995)

# Department of Philosophy

M.A., 1994

Ph.D., 1995

Washington University School of Law St. Louis, Missouri (1970-1973) J.D., 1973

The University of St. Andrews (1967-1968) St. Andrews, Scotland

economy)	Full-time independent study (history and political
	DePauw University, Greencastle, Indiana (1965-1967, 1968-1969) B.A., History, 1969
Professional Experience:	Assistant Director, Center for Bioethics and Humanities, and Assistant Professor, Department of Preventive Medicine and Biometrics, School of Medicine, University of Colorado Health Sciences Center, 1995-2000 Denver, CO
	Assistant and Associate Clinical Professor, Department of Preventive Medicine and Biometrics, School of Medicine, University of Colorado Health Sciences Center, 1991-1995 Denver, CO
	Visiting Associate Professor, 1990-1991 Affiliate Professor, 1988-1990, 1994-1999 University of Colorado School of Law Boulder, CO
	University Counsel (General Counsel) 1986-1990 University of Colorado System Boulder, CO
	Associate University Counsel (Sr. Resident Counsel) 1984- 1986 University of Colorado Health Sciences Center Denver, CO
	Legal Counsel 1982-1984 The University of North Carolina Hospitals and Clinics Chapel Hill, NC
	Deputy Commissioner (Administrative Law Judge) 1980- 1982 North Carolina Industrial Commission Raleigh, NC
	Attorney (principal) 1976-1980 Hollowell, Silverstein, Rich & Brady, P.A. Raleigh, NC
	Attorney (professional staff) 1974-1976

National Association of Attorneys General Raleigh, NC Research Associate 1973-1974 Office of Environmental and Planning Studies University of Illinois College of Law Champaign, IL

Awards and Honors: Marquis Who's Who in The West (1991-present)

Marquis Who's Who in American Law (1991-present) Marquis Who's Who in America (1992-present) American Society of Law, Medicine and Ethics Mayday Faculty Scholar (1997-1998) Hamilton Davis Award, UCDMC Department of Anesthesiology and Pain Medicine (2001)

#### **University Service:** UC Davis School of Medicine Alumni Association Board of Directors – ex officio member (2000-present)

West Coast Center for Palliative Care Education and Research (2000-present)

Faculty member, Center for Health Services Research in Primary Care (2000-present)

Chair, Education Committee, UC Davis School of Medicine Center for Perinatal Medicine and the Law (2002-2004)

Chair, UC Davis School of Medicine Judicial Board (2002present)

Committee on Educational Policy, UC Davis School of Medicine (2001-present) Doctoring Curriculum Task Force (2002-present)

Advisory Committee, VA/UC-Davis General Clinical Research Center (2003-2004)

Selection committee member, Nelson Medical Lecture in the Humanities (2004)

Liaison Committee on Medical Education, Committee I (Institutional Setting; 2004-present); and Committee III (Medical Students; 2004-present) Faculty Executive Committee Task Force on Professionalism (2005)

UCDMC Palliative Care Service Committee (2005)

#### **Professional Activities:**

#### **Professional Licensure (Law)**

Illinois (1973), North Carolina (1975), Colorado (1984)

#### California

California Coalition for Compassionate Care (2000present) Steering Committee and Professional Education Committee (2000-present)

Barrister, Milton L. Schwartz American Inn of Court (2001-2003)

Board of Directors, CA Hospice & Palliative Care Association (2001-2004) Education Committee (2002-2004) Advocacy Committee (2002-present) Quality Task Force (2003 - 2004)

Northern California Pain Initiative Advisory Council (2003 - present)

California Commission on Aging – Palliative/End-of-Life Care Task Group (2004-present)

California Department of Health Services – Influenza Advisory Group (2004-present)

#### Colorado

AMC Cancer Research Center Institutional Review Board (1994-1998)

Boulder County Hospice Ethics Committee (1995-97)

University of Colorado Hospital Ethics Committee (1995-2000)

Governor's Commission on Life and the Law (1995-2000) Chair of Committee on Pain Management Committee on Physician-Assisted Suicide

Interdisciplinary Task Force on Intractable Pain Colorado General Assembly (1996-1997)

Colorado Multiple Institutional Review Board (1996-1998)

Colorado Professional Liability Insurance Corporation Pain Management Consortium (1997-2000)

Boulder Community Hospital Bioethics Advisory Board, Vice Chair (1997) Chair (1998)

Donor Alliance Ethics Committee (1998-2000)

#### National

Association of Trial Lawyers of America – National College of Advocacy, Advanced Programs in Trial Advocacy (1976)

National Institute for Trial Advocacy – Advanced Program (1983)

National Association of College and University Attorneys Co-Chair, Section on Liability, Risk Management and Insurance (1986-1990) Vice Chair, Annual Meeting Site Selection Committee (1988) Committee on Publications (1990-1991)

American College of Legal Medicine (Associate in Law 1987 - present) Ethics Committee (1999 - present)

American Society of Law, Medicine & Ethics Member, Health Law Teachers Section (1988present)

American Philosophical Association (1992-present)

Committee on Philosophy and Medicine (2004-2007)

Society for Health and Human Values (1993-1997)

Society for Bioethics Consultation (1995-1997)

American Association of Bioethics (1995-1997)

American Health Lawyers Association (1999-2004)

American Society for Bioethics and Humanities (1998-present)

Law and Bioethics Special Interest Group (2000-

#### present)

American Academy of Pain Medicine Ethics Consultant (2003)

American Pain Society (2003-present) Ethics Committee (2003-present)

American Academy of Pain Medicine Council on Ethics (2005)

#### **Scholarly and Professional Journals**

Editor: Ethical Issues in Health Care, Center for Bioethics and Humanities, University of Colorado (1996-1998)

Editorial Board: *Theoretical Medicine and Bioethics* (1999 to 2003)

Section Editor: Caduceus in Court, *Cambridge Quarterly of Healthcare Ethics* (2000-present)

Editorial Board: *Journal of Pain and Palliative Care Pharmacotherapy* (2001-present)

Section Editorial Board: Forensic Pain Medicine, *Pain Medicine* (2002-present); Section Editor effective 06/2005

Department Editor: Pain and the Law, *American Pain* Society Bulletin (2004-present) Manuscript Reviewer: *MIT Press*; *Ethics*; *Theoretical Medicine and Bioethics*; *Cambridge Quarterly of Healthcare Ethics*; *The Journal of Law, Medicine and Ethics*; *Annals of Internal Medicine*; *Pain Medicine*; *Southern Medical Journal*; *Western Journal of Medicine*; *The American Journal of Managed Care.*  **Visiting Professorships** 

# *Mar.* 1998 Shaping the Standard of Medical Care UC Davis School of Medicine

# The Influence of Law on Medical Ethics Responsibilities of Medical Practice

Sacramento, CA

# **The Current Legal and Ethical Status**

of Physician-Assisted Suicide

## Is There A Right to Health Care?

Legal and Ethical Considerations

Speaker/Discussion Facilitator

Apr. 2001 Organizational Ethics Conference University of Colorado Health Sciences Center Denver, CO

#### **Community Service (Since 2001)**

Apr. 2001 to	Testimony before California Assembly Health Committee on AB487 (bill
	require mandatory CME for pain management)
July 2001 AB487	Testimony before California Business and Professions Committee on
July 2001	Panel Presentation on Ethics of Pain Management at Public Hearing on AB487, Berkeley, CA
Oct. 2001-	California Mediated Dialogue on Physician-Assisted Suicide and End-of- Life
Jun 2002	Issues, convened in cooperation with the California State Assembly Select Committee on Palliative Care.
Nov. 2001-	California Mediated Dialogue on Physician-Assisted Suicide and End-of- Life
Mar. 2002	Care, California Assembly Select Committee on Palliative Care.
Feb. 2005	Testimony before Joint Hearing of the Assembly Committee on Aging and Long-Term Care and Assembly Judiciary Committee regarding AB 1592 (Death with Dignity Act)

#### Selection of Courses Taught at the University of California, Davis (Since 2000)

2000 – 2001 Health Law (28	86A, Law School)
----------------------------	------------------

- 2000 2001 Responsibilities of Medical Practice (MDS 440, Medical School)
- 2000 2001 Topics in Medical Ethics (MDS 414, Medical School)
- 2001 2002 Advanced Health Law (286B, Law School)
- 2001 2003 Family Nurse Practitioner/Physician Assistant Program (FAP 350, Medical School)
- 2001 2004 Applied Medical Principles (MDS400B, Medical School)
- 2002 2005 Doctoring 3 (MDS430B, Medical School) Co-facilitator
- 2002 2004 Health Care Ethics (GMD 470, Medical School)
- 2003 2004 Doctoring 2 (MDS400C, Medical School) Co-facilitator
- 2003 Freshman Seminar (001E, undergraduate) *Litigating the Right to Die*
- 2004 Freshman Seminar (002D, undergraduate) Famous Trials: History, Law and The Dramatic Arts
- 2004 Topical Issues in Health Law Law 286/Medicine and the Law IMD 450
- 2005 Topical Issues in Health Law Law 286/Medicine and the Law IMD 450
- 2005 Philosophy 15 Bioethics (Department of Philosophy)

#### **Publications**

- 1. 1974 <u>Rich, B. A.</u> Managing recreation rivers. University of Akron Law Review 8:43-56.
- 2. 1975 <u>Rich, B. A</u>. State regulation and the antitrust laws: conflicting roles for Attorneys General. National Association of Attorneys General 1-25.
- 3. 1976 <u>Rich, B. A</u>. Antitrust manual (Ed.), National Association of Attorneys General.
- 4. 1986 <u>Rich, B. A.</u> Minimizing the risk of obstetrical malpractice. Hospital Risk Management 8:107.
- 1987 <u>Rich, B. A.</u> Malpractice issues in the academic medical center. Journal of College and University Law 13:149-177. Reprinted at Defense Law Journal 36:641-675 (1988).
- 6. 1991 <u>Rich, B. A.</u> The assault on privacy in healthcare decision making. Denver University Law Review 68:1-55.

- 7. 1991 <u>Rich, B. A.</u> The values history: a new standard of care. Emory Law Journal 40:1109-1181.
- 8. 1993 <u>Rich, B. A.</u> Postmodern medicine: deconstructing the Hippocratic Oath. University of Colorado Law Review 65:77-136.
- 9. 1996 <u>Rich, B. A.</u> Pain management: legal risks and ethical responsibilities. Journal of Pharmaceutical Care in Pain & Symptom Management 5:5-19.
- 10. 1996 <u>Rich, B. A.</u> The values history: restoring narrative identity to long term care. The Journal of Ethics, Law and Aging 2:75-84.

 11. 1997 <u>Rich, B. A.</u> Prospective autonomy and critical interest: a narrative defense of the moral authority of advance directives. Cambridge Quarterly of Health Care Ethics 6:138-147.

- 12. 1997 <u>Rich, B. A.</u> Postmodern personhood: a matter of consciousness. Special Issue: Bioethics 11:206-216.
- 13. 1997 <u>Rich, B. A.</u> A Legacy of silence: bioethics and the culture of pain. Journal of Medical Humanities 18:233-259.
- 14. 1998 <u>Rich, B. A.</u> Pain Management: The Emerging Standard of Care. Colorado Medicine 95:88-89.
- 15. 1998 <u>Rich, B. A.</u> Advance directives: the next generation. Journal of Legal Medicine 19:63-97. Excerpts reprinted in Tom Beauchamp and LeRoy Walters (eds.) <u>Contemporary Issues in Bioethics</u> (6<sup>th</sup> ed. 2003) Belmont, CA: Wadsworth Publishing Co.
- 16. 1998 <u>Rich, B. A.</u> Pain management: an age old ethic seeks modern standards. Today's Internist 39:37-39.
- 17. 1998 <u>Rich, B. A.</u> Personhood, patienthood, and clinical practice: reassessing advance directives. Psychology, Public Policy, and Law 4:610-628.
- 18. 1999 Nelson-Marten, P., <u>B. A. Rich.</u> An historical perspective of informed consent in clinical practice and research. Seminars in Oncology Nursing 15:81-88.
- 19. 2000 <u>Rich, B. A.</u> An ethical analysis of the barriers to effective pain management. Cambridge Quarterly of Healthcare Ethics 9:54-70.
- 20. 2000 <u>Rich, B. A.</u> Pain management and the goals of health care: ethical and legal considerations. Journal of Pharmaceutical Care in Pain and Symptom

Control

8:43-64.

- 21. 2000 <u>Rich, B. A.</u> A prescription for the pain: the emerging standard of care for pain management. William Mitchell Law Review 26:1-91.
- 22. 2001 <u>Rich, B. A.</u> Defining and delineating a duty to prognosticate. Theoretical Medicine 22:177-192.
- 23. 2002 <u>Rich, B. A.</u> Moral lessons from the jury box. Journal of Pain & Palliative Care Pharmacotherapy 16: 81-92.
- 24. 2002 <u>Rich, B. A.</u> The ethics of surrogate decision making. Western Journal of Medicine 176: 127-129.
- 25. 2002 <u>Rich, B. A.</u> Moral conundrums in the courtroom: reflections on a decade in the culture of pain. Cambridge Quarterly of Healthcare Ethics 11: 180-190.
- 26. 2002 <u>Rich, B. A.</u> The tyranny of judicial formalism: oral directives and the clear and convincing evidence standard. Cambridge Quarterly of Healthcare Ethics 11: 292-302.
- 27. 2002 <u>Rich, B. A.</u> Prognostication in clinical medicine: prophecy or professional responsibility? The Journal of Legal Medicine 23: 297-358.
- 28. 2002 <u>Rich, B. A.</u> Oregon versus Ashcroft: pain relief, physician-assisted suicide, and the controlled substances act. Pain Medicine 3: 353-360.
- 29. 2003 <u>Rich, B. A.</u> Oregon versus Ashcroft: the battle over the soul of medicine. Cambridge Quarterly of Healthcare Ethics 12: 310-321.
- 30. 2003 <u>Rich, B. A.</u> A placebo for the pain: a medico-legal case analysis. Pain Medicine 4: 366-372.
- 31. 2004 <u>Rich, B. A.</u> Current legal status of advance directives in the United States. Wiener Klinische Wochenschrift, The Middle European Journal of Medicine 116/13: 420-426.
- 32. 2004 <u>Rich, B. A.</u> A brief introduction to pain and the law. American Pain Society Bulletin 14:6.
- 33. 2005 <u>Rich, B. A.</u> Medical custom and medical ethics: rethinking the standard of care. Cambridge Quarterly of Healthcare Ethics 14: 27-39.
- 34. 2005 <u>Rich, B. A.</u> Overcoming legal barriers to competent and compassionate pain relief for the dying patient. American Pain Society Bulletin 15:1, 6, 9-10.

35. 2005 Sullivan, M., G.W. Terman, B. Peck, D. Correll, <u>B.A. Rich</u>, W. C. Clark, K. Latta, A. Lebovits, G. Gebhart. American Pain Society position statement on the use of placebos in pain management. The Journal of Pain, 6:215-217.

# **Books and Book Chapters**

1. 1975	<u>Rich, B. A.</u> The Office of Attorney General (Editor). National Association of Attorneys General (1975).
2. 1975 officials,	<u>Rich, B. A</u> . Sovereign immunity: the liability of government and its National Association of Attorneys General 1-71.
3. 1974	<u>Rich, B. A.</u> A water law for Illinois, p. 93-125. <u>In</u> Illinois Economic and Fiscal Commission, <u>Water Resources Management in Illinois Program</u> <u>Review</u> , Springfield, Illinois.
4. 1986	Gilbert, B., <u>B. A. Rich</u> . Informed consent to gynecologic surgery, p. 13-28. <u>In</u> H. A. Buchsbaum and L. A. Walton (Ed.), <u>Strategies in Gynecologic</u> <u>Surgery</u> , Springer-Verlag, New York.
5. 1996	<u>Rich, B. A.</u> Elements compromising the autonomy of the elderly, p. 57-90. <u>In</u> R. Cebik (Ed.), <u>Violence, Neglect and the Elderly</u> . JAI Press, Greenwich, CT.
6. 2001	<u>Rich, B. A.</u> The old ethics and the new economics of health care: are they compatible? p. 113-126. <u>In</u> E. H. Loewy and R. S. Loewy (Eds.), <u>Changing Health Care Systems From Ethical, Economic and Cross-Cultural Perspectives</u> , Kluwer Academic/Plenum Publishers, New York.
	Rich, B. A. Strange Bedfellows: how medical jurisprudence has influenced medical ethics and medical practice, Kluwer Academic/Plenum Publishers, New York.
8. 2002	<u>Rich, B. A</u> . Pain in society: ethical and legal perspectives, p. 27-38. <u>In</u> T. S. Jensen, P. R. Wilson, A. S. C. Rice (Eds.), <u>Clinical Pain Management</u> – <u>Chronic Pain</u> , Arnold Publishers, London, GB.

9. 2004 <u>Rich, B.A.</u> The process of dying, p. 308-314. <u>In</u> S. Sandy Sanbar (Ed.), <u>Textbook of Legal Medicine</u> (6<sup>th</sup> edition), Philadelphia: Mosby.

10. 2004 <u>Rich, B. A.</u> and P. G. Fine. Ethical and legal issues in pain management, p. 281-299. <u>In</u> Lipman, A. G. (Ed.) <u>Pain Management and Primary Care</u> <u>Clinicians</u>, ASHP, Bethesda, MD.

#### **Commentaries and Guest Editorials**

- 1. 1973 <u>Rich, B. A.</u> Commentary: Equal protection as a means of securing adequate municipal services. Urban Law Annual, 277-282.
- 2. 1992 <u>Rich, B. A.</u> Letter: Irrational and pregnant. Hastings Center Report, May-June; 22:44-45.
- 3. 1999 <u>Rich, B.A.</u> Editorial: Better late than never: the federation of state medical boards model guidelines for the use of controlled substances for the treatment of pain. Journal of Pharmaceutical Care in Pain & Symptom Control 7:1-5.
- 4. 2000 <u>Rich, B. A.</u> Case Commentary: Omit the mistake. Student British Medical Journal 8:449-450.
- 5. 2001 <u>Rich, B. A.</u> Case commentary: Pain and sickle cell anemia. Hastings Center Report May-Jun; 31:29-30.
- 2001 <u>Rich, B. A.</u> Case commentary: Omissions, p. 84-87. Commissions, p. 94-95. Mistreating patients, p. 224-225. <u>In</u> T. K. Kushner and D. C. Thomasma (Eds.) <u>Ward ethics: Dilemmas for medical students and doctors in training</u>, Cambridge University Press, United Kingdom.
- 7. 2001 <u>Rich, B. A.</u> Op-ed: Physicians' legal duty to relieve suffering. Western Journal of Medicine; 175:151-152.
- 8. 2001 <u>Rich, B. A.</u> Guest editorial: Prioritizing pain management in patient care. Postgraduate Medicine; 110:15-17.
- 9. 2003 <u>Rich, B. A.</u> Medico-legal commentary. Pain Medicine 4:202-205.

10. 2004 <u>Rich, B. A.</u> Commentary: Possible limits to the surrogate's role: when a

patient lacks decision-making capacity, is the surrogate's role absolute? Cambridge Quarterly of Health Care Ethics 13: 96-104.

11. 2004 Rich, B. A. Commentary: Background on refusal of treatment. Cambridge Quarterly of Healthcare Ethics 13:100-104.

- 12. 2004 Rich, B. A. Ethics Forum Commentary: Patients' rights in the academic medical center. Pain Medicine 5:207-209.
- 13. 2004 Rich, B. A. Commentary: Thinking the unthinkable: the clinician as perpetrator of elder abuse of patients in pain. Journal of Pain & Palliative Care Pharmacotherapy18:63-74.

#### **Book Reviews**

6. 2003

1. 1998	<u>Rich, B. A.</u> Book review of <u>Limits – The Role of the Law in Bioethical</u> <u>Decision Making</u> , by R. Dworkin. Cambridge Quarterly of Healthcare Ethics 7:108-109.
2. 1999	<u>Rich, B. A.</u> Book review of <u>The Problematics of Moral and Legal Theory</u> , by R. Dworkin, Cambridge Quarterly of Healthcare Ethics, 9:429-434.
3. 2000	<u>Rich, B. A.</u> Book review of <u>Advance Directives and Surrogate Decision</u> <u>Making in Health Care</u> , by H. M. Sass, R. M. Veatch, and R. Kimura (Eds.) Theoretical Medicine and Bioethics 21:367-373.
4. 2000	<u>Rich, B. A.</u> Book review of <u>Illness and Culture in the Postmodern Age</u> , by D. B. Morris, Journal of Medical Humanities, 21:118-120.
5. 2001	<u>Rich, B. A.</u> Book review of <u>Death Foretold: Prophecy and Prognosis in</u> <u>Medical Care</u> , by N. A. Christakis. Journal of Medical Humanities, 22:245- 247.
<u>Rich, B. A.</u>	Reflections on the social construction of death. Book review essay on <u>Death is that Man Taking Names: Intersections of American</u> <u>Medicine, Law,</u>
and the Rei	and Culture by R. A. Burt and <u>Twice Dead: Organ Transplants</u> <u>nvention of Death</u> by M. Lock, The Journal of Legal Medicine, 24: 233-290.

#### **Publications in Press**

- 1. 2005 <u>Rich, B.A.</u> Bioethics in court. The Journal of Law, Medicine & Ethics.
- 2. 2005 Rich, B.A. Patient values and medical indications. In Keller, R, McConnell, W. (Eds.), Kultur und Erkenntnis (Culture and Discovery), Francke Verlag, Tubingen and Basel.

3. 2005 <u>Rich, B. A.</u> The politics of pain: rhetoric or reform. DePaul University Journal of Health Care Law.

#### Works in Progress

- 1. <u>Rich, B. A.</u> An ethical analysis of punitive damages in professional liability litigation.
- 2. <u>*Rich, B. A.</u>* Fashioning a realistic and rational medical ethics.</u>
- *<u>Rich, B. A.</u> The enduring tension between medical paternalism and patient autonomy.*
- 4. Ballard, D. W., R. W. Derlet, <u>B. A. Rich</u>, R. A. Lowe. EMTALA, Two decades later: a descriptive review of EMTALA violations.
- 5. <u>*Rich, B. A.*</u> *Litigating the right to pain relief: law, ethics, and public policy.*
- 6. <u>Rich, B. A.</u> Pain the fifth vital sign: catch phrase or paradigm shift?
- 7. <u>Rich, B. A.</u> The process of dying. Revised and updated chapter in Sanbar, S. S. (Ed.) <u>Textbook of Legal Medicine</u> (7<sup>th</sup> edition). Mosby, Philadelphia.

#### Grants, Contracts, Research Activities

1996 President's Fund for the Humanities award for a colloquium series entitled "The Humanistic Dimensions of Pain and Suffering in the Clinical Setting," Grant award: \$5000.

1997 President's Fund for the Humanities award for a colloquium series entitled "Health Care, Law and the Life Cycle," Grant award: \$5000.

1997 - Mayday Scholars Award, Grand award: \$8000. 1998

2004

1998 - University of Colorado Hospital Authority Grants Program, Assessing and

*1999* Improving the Quality of Care for Dying Patients at University Hospital. *Grant award:* \$25,000.

2002 National Institute of Mental Health, Enhancing Mental Health Services to Children with Autism (*co-investigator*). Grant award: \$375,000.

*National Cancer Institute*, Overcoming the Barriers to Early Phase Clinical Trials, (*co-investigator*). *Grant award:* \$1,132,226.

2004 National Human Genome Research Institute, *Interactive ELSI Curriculum* for Primary Care Residents, (co-investigator). Grant award: \$473,132.

2004 National Institute of Mental Health, *Interdisciplinary Training for Autism Researchers*, (associated program faculty). Grant award: \$1,500,000.

2005 National Cancer Institute, *Statewide Initiative to Disseminate End-of-Life Education*, (ethics consultant). Grant award: \$4,000,000 (final budget in process at NCI).

#### Lectures and Presentations (1985 to present) Medical Malpractice Defense Apr. 1985 National Health Lawyers Legal Problems of Academic Association Seminar Medical Centers New Orleans, LA May 1985Issues and Trends in Obstetrical Colorado **Hospital Association** Malpractice of Risk Managers Denver, CO Sept. 1985 Legal and Ethical Issues in Clinical Fitzsimmons Army Medical **Practice** (Co-presenter) Center Seminar Denver, CO Dec. 1985 Professional Liability Insurance Association of Academic For Academic Health Centers Health Centers Washington, DC June 1986 Creating and Managing Risk Protection National Association of College and Programs University Attorneys Conference Baltimore, MD Sept. 1986 Medical-legal Aspects of Medical Practice Ciba-Geigy Seminar on Medical **Practice Management** Aspen, CO Apr. 1987 Managing the In-House Legal Office American Society of Law and Medicine Conference New York. NY June 1987 Student Drug Testing: The University National Association of College and of Colorado Experience University Attorneys Conference

Albuquerque, NM

Apr. 1988	Graduate Medical Education: Legal Considerations for Medical Schools and Teaching Hospitals	American Society of Law and Medicine Conference Washington, DC
Nov. 1989 College	Malpractice and Indemnification Issues	National Association of
Conce	in the Academic Health Sciences Center	and University Attorneys Washington, DC

Mar. 1990	In Search of a Legal Ethic of Personhood	University of Colorado
		Health Sciences Center Center for Human Caring Denver, CO
Apr. 1990 Law	The Assault on Privacy in Healthcare	Loyola University School of
Law	Decision Making	Chicago, IL

# Feb. 1991 The Legal and Political Realities ofColoradoNurses Association

	Rationing	Denver, CO
Mar. 1991 Boulder	Escape From the Twilight Zone:	University of Colorado,
Doulder	Living Wills and Other Advance Directives	Staff Development Series Boulder, CO
Apr. 1991	<i>The Values History: A New Standard of Care?</i>	University of Colorado School of Law Faculty Colloquium Boulder, CO
May 1991	The Values History: A New Standard of Care?	University of Colorado Health Sciences Center Center for Human Caring
Seminar		Denver, CO
June 1991	Confidentiality of Alcohol and Drug Abuse Patient Records	Medical Educational Services Seminar Denver, CO
Jan. 1992	Advance Directives	University of Colorado Health Sciences Center Department of Medicine Grand Rounds Denver, CO
May 1993	Postmodern Medicine: Deconstructing The Hippocratic Oath	University of Oregon Practicing Postmodernisms Conference

Eugene, OR

### July 1993 Current Ethical and Legal Issues in University of Colorado

	Medical Practice	School of Medicine 29 <sup>th</sup> Annual Internal Medicine Program, Estes Park, CO
Oct. 1994	Elements Compromising the AutonomyUn of the Elderly	iversity of Tennessee National Institute on Ag

National Institute on Aging, Center for Applied and Professional Ethics Violence, Neglect and the Elderly Conference Knoxville, TN

Sept. 1995 Consultation	Designing and Implementing an	Society for Bioethics
	Institutional Ethics Audit	Ethics Consultation:
Reflections		on Practice Conference
	An Ethics of Authenticity for the Care of the Elderly	Cleveland, OH
Sept. 1995	Postmodern Personhood: H. Tristram Youn	•

Engelhart's Vision of Human Personal Ethics, Medicine and Health Care: Life An Appraisal of the Thought

of H.

Conference

Tristram Englehart, Jr.

#### Youngstown, OH

### *Dec.* 1995 Legal Issues in Genetic Counseling University of Colorado Health

Sciences Center Denver, CO

Mar. 1996	Decision-making in Cases of Grave	University of Colorado
	or Terminal Illness	Health Sciences Center Panel Presentation in
	Frontiers	

*of Medical Sciences* Series Denver, CO

Apr. 1996 Human	Prospective Autonomy and Critical	Society for Health and
	Interests: A Narrative Defense of the Moral Authority of Advance Directives	Values Knoxville, TN
May 1996	Physician-Assisted Suicide: Ethical and Legal Issues	University of Colorado School of Medicine <i>Challenges in Pain</i>
Management	t	
	<i>The Alleviation of Pain: Ethical and Legal Issues</i>	Conference Denver, CO
May 1996 Health	Shaking the Foundation of Bioethics:	Colorado Bar Association
	Ethical Issues in Managed Care	Law Section Denver, CO
May 1996 Health	Physician-Assisted Suicide: Legal	University of Colorado
Presentation	Developments and Their Clinical	Sciences Center Panel

#### Implications

#### Denver, CO

### Sept. 1996 Physician-Assisted Suicide: Where the of Colorado and the

e University

Given Biomedical

Aspen, CO

Courts are Taking Us

Davis

Institute

Meeting of

Pain

Nov. 1996 Liability Issues in Pain Relief

American Society of Law, Medicine

& Ethics, The National

University of California,

The Project on Regulating

Relief

Boston, MA

Nov. 1996The Painful Prescription: The ClinicalUniversity of Colorado<br/>Failure to Relieve SufferingHealth Sciences Center<br/>Humanistic Dimensions of

Pain

149

#### Setting

and Suffering in the Clinical

Conference Denver, CO

Nov. 1996 Bioethics	Postmodern Personhood: A Matter	3 <sup>rd</sup> World Congress of
	Of Consciousness	San Francisco, CA
Jan. 1997	Pain Relief and Clinical Practice: The Penros Emerging Standard of Care	se Hospital Penrose, CO
Feb. 1997	Ethical and Legal Issues in Pain Alleviation	University of Colorado School of Medicine Midwinter Continuing Medical Education Seminar Denver, CO
Mar. 1997	Advance Directives: The Next Generation	American College of Legal Medicine Annual Conference Ft. Lauderdale, FL

Mar. 1997 Davis	The Riddle: Reconciling the Goals of	University of California,
	Medicine with the Needs of Patients - School	l of Medicine
Practice CA	Law, Ethics and Medical Malpractice	Responsibilities of Medical Sacramento,
Apr. 1997 Davis	The Next Generation of Advance	University of California,
	Directives	Health System
		Department of Internal
Medicine		Grand Rounds Sacramento, CA

# *Apr. 1997* Strange Bedfellows: Medical Ethics and University of California, Davis

	Medical Jurisprudence	Health System Department of Internal Medicine Grand Rounds Sacramento, CA
May 1997	Human Cloning: How Should the Law Phi Be Respond?	eta Kappa Colloquium University of Colorado Boulder, CO
May 1997 Health <i>Life</i> Series	Advance Directives and the Demented Elderly: The Personal Identity Prob	University of Colorado <i>blem</i> Sciences Center <i>Health Care, Law and the</i> <i>Cycle</i> , Colloquium Denver, CO
June 1997 Series	Medical Ethics and Medical Technology: An Uneasy Alliance	Chatauqua Summer Lecture Boulder, CO
Aug. 1997	The Supreme Court Physician-Assisted Hemlo Suicide Decision: Interpretations and Denve Implications	
Aug. 1997	The Supreme Court and Physician- Assisted Suicide: Lessons for Bioethics	Denver Community Bioethics Committee Denver, CO

Aug. 1997 Center	Transforming Medicine's Culture of	Columbia Rose Medical
of	Pain	The Role and Responsibility
0)		Institutional Ethics
Committ	ees	Conference
		Denver, CO
Sept. 1997	The Doctrine of Double Effect	Visiting Nurses Association Denver, CO
Sept. 1997	Informed Consent: The Patient's Right	University of Colorado

Hospital's *To Know* 

# Sept. 1997 The Supreme Court and Physician- University

Best of the Evenings at 7

Lecture Series Denver, CO

of Color	ado Health	·····
Lootuno	Assisted Suicide: Interpretations and	Sciences Center Noon
Lecture	Implications	Denver, CO
Oct. 1997 Davis	Last Acts: The Physician's	University of California,
Davis	Responsibility To Dying Patients	Health System
		Department of Internal Medicine Grand Rounds Sacramento, CA
Oct. 1997	Managed Care and Quality Care:	University of California,
Davis	Ethical And Legal Issues	Health System Department of Internal
Medicine		Grand Rounds Sacramento, CA
Oct. 1997	Long-Term Care and the Law	American College of Legal

#### **Medicine Intensive**

Low		Legal Medicine and Health	
Law		Chicago, IL	
Nov. 1997	Physician-Assisted Suicide: Ethics, Law	Colorado Guardianship	
Alliance	and Clinical Practice	Denver, CO	
	Pain and Public Health: Ethical, Legal	American Public Health	
Association	And Regulatory Considerations	Indianapolis, IN	

#### Nov. 1997 The Doctrine of Informed Consent: University of Colorado

Medical Ethics Meets Medical	Health Sciences Center
Jurisprudence	Healthcare, Law and the Life
	Cycle Colloquium Series

#### Denver, CO

Feb. 1998	End-of-Life Care and Decision-makingSt. Mary-Corwin Hospital
<b>51</b>	Continuing Medical

Education

Course in

Pueblo, CO

Feb. 1998 End-of-Life Care and Decision-makingMontrose Memorial Hospital Continuing Medical

Education

#### Montrose, CO

Feb. 1998 Series	Talking With Your Doctor about End-	AHEC Community Lecture
Berres	Of-Life Care	Montrose, CO
Eab 1009	End of Life Cane and Desirion making Date	Hognital

Feb. 1998 End-of-Life Care and Decision-makingDelta Hospital Continuing Medical

Education

Delta, CO

Feb. 1998 Series	Talking With Your Doctor about End-	AHEC Community Lecture
	of-Life Care	Delta, CO
Mar. 1998	Pain Management and Clinical Practice: Legal, Ethical and Regulatory Considerations (written material appeared in conference proceedings, oral presentation was not delivered due to flight cancellation)	American College of Legal Medicine Annual Conference Las Vegas, NV
	Postmodern Medicine: Toward a	American Society for
Bioethics an	d	
	Narrative Bioethics	Humanities Spring
Conference		
		East Carolina School

of Medicine

Greenville, NC

Dallas, TX

### Mar. 1998 The Role of State Medical Licensing Federation of State Medical

#### Boards in Improving Pain Management *Licensing Boards Conference*

		,
Apr. 1998 <i>Life</i>	The U.S. Supreme Court Decisions on	Improving Care at the End of
5	Physician-Assisted Suicide and Medical	Conference
	Care at the End of Life	Las Vegas, NV
Apr. 1998 <i>Life</i>	Legal Considerations in End-of-Life	Improving Care at the End of
Lije	Care	Conference
		Las Vegas, NV
Apr. 1998	The Supreme Court and Physician-	University of Colorado

#### Assisted Suicide (panel presentation President's Fund for the

## *in conjunction with performance of* A *Humanities Program*

Question of Mercy.)

Boulder, CO

May 1998	See No Evil, Speak No Evil: Bioethics University of Connecticut and the Under-treatment of Pain Health Center	
		Farmington, CT
May 1998	Medical Jurisprudence and Palliative	St. Louis University School
of Law,	Medicine: A Prescription for the Pain	Mayday Scholars Workshop
		St. Louis, MO
Aug. 1998 Retreat	Breaking the Silence of the Lambs:	National Summer Bioethics
nouou	<i>The Role of Bioethics in Transforming Medicine's Culture of Pain</i>	Cape Cod, MA
Sept. 1998	Pain Management and the Goals of Health Care	Memorial Hospital Pain Management Update: Strategies that Work Continuing Professional
Education		

#### СО

Sept. 1998 on	The Ethicist in Court: Reconfiguring	XII <sup>th</sup> European Conference
	The Relationship Between Law and	The Philosophy of Medicine
and	Morality	Health Care Marburg, Germany

# Oct. 1998Distinguishing Aggressive Palliative Colorado Prescription Drug Abuse

Colorado Springs,

Biannua	Medicine from Voluntary Active <i>Meeting</i>	Task Force
	Euthanasia: A Question of Intent	Denver, CO
Nov. 1998 Bioethics	The Ethicist in Court: Expanding the	American Society of
Meeting	Influence of Bioethics on Law	and Humanities Annual

### Houston, TX

Feb. 1999	Pain Management and Public Policy:	Annual Public Policy
Conference	of	
	Rhetoric Without Reform	the Colorado Chapter of the American Association of University Women Denver, CO
Feb. 1999 and	Empowering Physicians to Provide	Colorado Medical Society
	Appropriate End-of-Life Care: The Convergence of Ethics, Law and Public Policy	Colorado Bar Association, Bioethics Forum Pueblo, CO

Mar. 1999 Davis	The Prosecutor at the Bedside:	University of California,
Davis	Tensions Between the Ethics of Palliative Medicine and the Criminal LawHeal	th System Sacramento, CA
Mar. 1999 Davis	Orchestrating the End of Life: Is It	University of California,
Davis	Aggressive Palliative Medicine or Euthanasia?	Health System Department of Internal Medicine Grand Rounds Sacramento, CA
Apr. 1999	The Ethics of Pain Management	Penrose-St. Francis Centura Health Services Grand
Rounds		Colorado Springs, CO
Apr. 1999	Bioethics in the New Millennium	MENSA Denver, CO
May 1999 Organization	Ethical and Legal Dimensions of	Colorado Hospice
organization	End-of-Life Care	Annual Spring Conference Colorado Springs, CO
Oct. 1999	Patient Rights: Moral, Legal and Humanistic Dimensions	American Assoc. of Nurse Attorneys National Conference Denver, CO
Nov. 1999	<i>The Riddle of How We Die: The Case</i> Com <i>of Hazel Welch</i>	munity Bioethics Forum Denver, CO
Jan. 2000	The Old Ethics and the New Economics	University of California, Davis
	of Health Care: Are They Compatible?	Health System Health-Care Systems: Ethical and Economic Considerations Conference Sacramento, CA

*Feb. 2000* Advance Care Planning: Important *Colorado Medical Society* 

Legal Doctrines

Education for Physicians on Endof-Life Care

Denver, CO

*Feb. 2000* Common Legal Issues in End-of-Life Care *Colorado Medical Society* 

Education for Physicians on Endof-Life Care

Denver, CO

*Mar.* 2000 Legal and Ethical Issues in Primary Care University of California, Davis

Health System

Department of Family and

University

Community Medicine

**Grand Rounds** 

Sacramento, CA

*Mar. 2000* Who Will Own Our DNA? – Ethical of California, Davis

And Legal Issues

Leadership Council

Milton L. Schwartz American

and

(Panel discussant)

Inn of Co	ourt
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Sacramento, CA

<i>June 2000</i> The Pain Relief Promotio Association	n Act:	Colorado Bar
The Ambiguity of Clinical Committee on Law and	Intentions	Joint
Revisited Seminar		Medicine
	Denver	, CO
June 2000 Redrawing the Ethics Ma Summer Bioethics Retre		National
Organizational Ethics, Inst Conference Center	titutional Ethi	cs Asilomar
and Corporate Compliance	Pacific	Grove, CA
June 2000 Through a Glass Darkly: of California, Davis	Ethical and	University
Legal Perspectives on Pain Management	School of Medi	icine Alumni
		tion Annual onal Program
	Davis	, CA
Sept. 2000 Legal and Ethical Issues Administration Hospital,	in Patient Ca	re Veterans
	Mather Rancho	Cordova, CA

Sept. 2000 I Davis Semi	Deconstructing the Culture of Pain		sity of California, of Law Faculty CA
Sept. 200 Colorado	00 Legal Issues in the War on Pain 6 <i>Health</i>	:	University of
Center	Over-regulation and Under-Medic	ation	Sciences
Center		Denver	, CO
	Physician-Assisted Suicide: and Palliative		California
Associat	A Facilitated Discussion ion Board of Directors		Care
		Las Ve	gas, NV
<i>Oct.</i> 2000	Ethics, Professionalism and the Medically	Univer	sity of California,
Davis	Under-served	Annual	Medical Student
Retreat			Lake Tahoe, CA
Oct. 2000 California	Ethical Perspectives on Pain and a, Davis		University of
Medicine	Suffering		School of
meanome			on of Pain Medicine nento, CA

### *Oct. 2000*Ethical and Legal Issues in Pain Relief *University of California, Davis*

School of Medicine Roxane Palliative Care Scholars

<i>Oct. 2000</i> A War on Pain?: Prospects and <i>California Davis</i>	University of
Possibilities for Health Services Health Services Research	Center for
	in Primary Care Sacramento, CA
Oct. 2000Legal Dimensions of the Physicia of California, Davis	n- <i>University</i>
Patient Relationship Medicine	School of
	Department of
Internal Medicine	
	Noon Conference Sacramento, CA
Oct. 2000The Quality of Mercy: Ethical and of California, Davis	l University
Legal Issues in Pain Management	Health System
	<i>Department of Family and Community Medicine</i>
	<b>Grand Rounds</b> Sacramento, CA
Nov. 2000 Ethical and Legal Aspects of Pain Davis	University of California,
Management for the Elderly	School of Law

Elder Law Seminar Davis, CA

Sacramento, CA

Nov. 2000 *Autonomy in Health Care* Davis

University of California, School of Medicine

Faculty Training Seminar Sacramento, CA

### *Nov. 2000* Litigating Life and Death *California, Davis*

Seminar

#### University of

School of Medicine AMA/CMA Medical Ethics

Sacramento, CA

### Dec. 2000 Culture, Law & Ethics California, Davis

Dec. 2000 Under-treated Pain: Analyses of Cases Davis

### Dec. 2000 Law, Medicine and Ethics California, Davis

#### University of

Multi-Cultural Conference Sacramento, CA

University of California, Medical School

Division of Pain Medicine Sacramento, CA

#### University of

School of Medicine Faculty Training Seminar Sacramento, CA

### Feb. 2001 A Placebo for the Pain of California, Davis

#### University

School of Medicine Division of Pain Medicine Sacramento, CA

Feb. 2001 An Introduction to Bioethics Medical

Sierra Sacramento Valley

Society, Community and Environmental Health Committee

#### Sacramento, CA

University of California,

Feb. 2001 *Prognostication: Prophecy or* Davis

#### **Professional Responsibility?**

System

#### Department of Internal Medicine Grand Rounds Sacramento, CA

# *Feb. 2001* The Role of Advance Directives in of California, Davis

Patient Care

Internal Medicine

Medical School

University

Health

#### Department of

Noon Conference Sacramento, CA

### *Mar. 2001* Pain and Public Policy: *California, Davis*

*Framing the Debate about the* Medicine

Ethical Treatment of Pain

#### American

#### University of

Bioethics, the Law and

Leadership Council

#### Milton L. Schwartz

Inn of Court Sacramento, CA

#### ralient Gare

nent of

*Mar.* 2001 Pain, Ethics and the Law: Is It Safe *Academic Geriatric Resource* 

to Treat?

Mar. 2001 Personal Identity

**Philosophical Association** 

VP for

Managing Pain

#### Program, Office of

Health Affairs -

And Suffering in the Elderly Los Angeles, CA

American

(Session chair)

#### **Pacific Division**

San Francisco, CA

Mar. 2001 Physician-Assisted Suicide	American
Medical Association	

**EPEC** Program

**Advance Care Planning** 

San Jose,

CA

#### Legal Issues at the End-of-Life

Apr. 2001 Davis	Legislating Competencies in Pain	University of California,
	Medicine	School of Medicine Division of Pain
Medicine		Sacramento, CA
May 2001 Davis	Legal and Ethical Issues in Primary Care	University of California,
2		Family Practice Nurse Practitioner
Program		Sacramento, CA

UC

May 2001 Davis	Transforming the Culture of Pain	University of California,
Anesthesiolog	Hamilton Davis Award Lecture gy	Department of & Pain Medicine Sacramento, CA
June 2001 Davis	Law vs. the Ethics of Pain Keynote Address	University of California, 10 <sup>th</sup> Annual Review &
Management		Update of Pain Yosemite National
Park, CA June 2001 California, D	Opioids and Addiction:	University of
Management	Law and Ethics	10 <sup>th</sup> Annual Review & Update of Pain
Park, CA		Yosemite National
June 2001 Davis	The Interface between Law, Ethics and Medicine	University of California, Department of
Internal Medi		Ambulatory Care
Workshop		Sacramento, CA
June 2001	Pain Management and Palliative Medicine: Perspectives of Medical Ethics and Medical Jurisprudence	Laguna Honda Hospital Medical Staff Lecture San Francisco, CA
June 2001 Davis	Bergman vs. Chin: An Introduction	University of California,
	to the Case	School of Medicine Division of Pain
Medicine		Sacramento, CA
July 2001 California, D	The Interface Between Law & Ethics <i>avis</i>	University of

		in Medicine Department of Radiology and Pathology Residency Program Sacramento, CA
July 2001 Davis	The Interface Between Law & Ethics	University of California,
Otolaryngolog	in Medicine	Department of
		Residency Program Sacramento, CA
July 2001	Pain: The 5 <sup>th</sup> Vital Sign	Public Forum on AB487 Legislative Hearing Berkeley, CA
July 2001 Davis	A Proposed Solution to the Problem of	University of California,
Duvis	Undertreating Pain	Health System SICU Nursing staff Sacramento, CA
Aug. 2001 Davis	Support of End-of-Life Care and Ethical	University of California,
Duvis	Perspectives	Health System SICU Nursing staff Sacramento, CA
Sept. 2001 California, Do	From Medical Etiquette to Biomedical avis	University of
		Ethics – the Evolution of Ethics in the School of Medicine Health Professions Department of Obstetrics and Gynecology Residency Sacramento, CA
Sept. 2001 Davis	Bergman vs. Chin Revisited	University of California,
L'arm		Health System

Department of Anesthesiology and Pain Medicine Sacramento, CA

Oct. 2 of Bioethics	2001 Bioethics Expert Testimony	American Association
of Biocinics		and
Humanities A	nnual Conference	
		Nashville, TN
Nov. 2001 Palliative	The Ethics of Surrogate Decision-making	California Hospice and
		Care Association
Conference		Sacramento, CA
Jan. 2002 Davis	Prognostication: Prophecy or Professional Responsibility?	University of California, Health System Department of
Internal Medi	icine	Department of
		Grand Rounds Sacramento, CA
Jan. 2002 Conference	Ethical and Legal Issues in	Pain Resource Nurse
conjerence	Pain Management	Laguna Honda Hospital San Francisco, CA
Feb. 2002 Research	Ethical Issues in Transplantation	University-wide AIDS
Conference		Program – 5 <sup>th</sup> Annual
Ū		On AIDS Research in
California		Sacramento, CA
Feb. 2002	Current Issues in Health Care Ethics	16 <sup>th</sup> National Conference on Chronic Disease
Prevention		
		and Control Atlanta, GA
Feb. 2002 Palliative	Withholding and Withdrawing Life-	California Hospice and

Spring	Sustaining Treatment and	Care Association Annual
Spring	Medical Futility <i>Modules of</i> <i>Education for Physicians on End-of-</i> <i>Life Care (EPEC) training program</i>	Conference Sacramento, CA
Mar. 2002 Rounds	Ethical and Legal Issues In	St. Luke's Hospital Grand
	Pain Management	San Francisco, CA
Mar. 2002	Ethical and Legal Issues In Pain Management	San Mateo General Hospital San Mateo, CA
Mar. 2002 American	Ethical Issues in the Response	Milton L. Schwartz
American		To Bioterrorism (panel presentation) Inn of Court/UC Davis Health System Leadership
Council		Annual Bioethics and
Law Program		Sacramento, CA
Mar. 2002	Law, Medicine and Ethics	Travis Air Force Base Medical Center Fairfield, CA
Apr. 2002	Ethical and Legal Issues in	University of California,
Davis	Pain Management	School of Medicine Department of
	Physical Medicine	and Rehabilitation
Grand Rounds		Sacramento, CA
Apr. 2002 Davis	Aging and Old Age:	University of California,
	Ethical Considerations	Caring for Older
People - Cond	cepts,	Structures and
Changes		Sacramento, CA

Apr. 2002 Hospital	Law, Medicine and Ethics	San Joaquin General Stockton, CA
May 2002	Ethical, Legal and Regulatory Issues in Pain Management and End-of-Life Care	St. Helena Hospital St. Helena, CA

May 2002 Abuse	The Bioethics of Pain Management		Colorado Prescription Drug
nouse			Task Force Conference Fallacies & Phobias about Pain Management and Addiction Denver, CO
June 2002	Ethical and Legal Issues in Pain Management		Seton Medical Center Daly City, CA
June 2002 for	Reflections on a Decade in The Cult	ure	Rutgers University Institute
of Pair	n	Health	Care Policy and Aging Research Conference
The Problem			Of Pain: Medicine,
Culture, and			Public Policy New Brunswick, NJ
June 2002 Pain	Learning From History: Legal and		American Alliance of Cancer
1 am	Ethical Mandates For Improved Pain Management		Initiatives Annual Conference Richmond, VA
June 2002	Moral Lessons from the Jury Box		Kaiser Permanente Bioethics Conference Panorama City, CA
Aug. 2002	Ethical and Legal Perspectives		Pharmacia Managed Care
Working	on the Pain Management Problem		Group Newport, RI
Aug. 2002 Hospital of	Withholding and Withdrawing		Community Memorial
Hospital of	Life-Sustaining Treatment		San Buenaventura, CA
Aug. 2002 Marshall	Ethical and Legal Issues at the		Snowline Hospice and
mui situit	End-of-Life		Hospital of Placerville, CA

Sept. 2002 Davis	Current Ethical and Legal Issues	University of California,
Duvis	in Neurology	Health System Department of
Neurology		Grand Rounds Sacramento, CA
Sept. 2002	Informed Consent and Refusal of Treatment	Annenberg Center for Health Sciences at Eisenhower
Medical		Center
<i>Oct. 2002</i> Expert	The Management of Chronic Pain: Ethical and Legal Implications	Rancho Mirage, CA New Perspectives in Pain Management – An
Lapent		Summit Conference Henderson, NV
Oct.2002 Davis	Strange Bedfellows: Precedent-	University of California,
and Update of	Setting Legal Cases Involving	11 <sup>th</sup> Annual Review
	Pain Control	Pain Management San Francisco, CA
Oct. 2002 Conference	Ethical, Legal, and Regulatory	New Mexico Pain
Conjerence	Issues in Pain Management	and Summit Albuquerque, NM
Oct. 2 California, Do Symposium	002 Patient Values vs. Medical avis Indications: The Role of Law	University of International
Symposium	in Resolving Conflict	Values and Evaluating Davis, CA
Nov. 2002 Palliative	Making Tough Decisions: Tools for	California Hospice and
		the Hospice Administrator <i>Care</i> <i>Association Annual</i>
		Conference Las Vegas, NV

Nov. 2002		Emerging Issues in Law and Bioethics California Hospice and Palliative Care Association Annual Conference Las Vegas, NV
Nov. 2002 Davis	Emerging Informed Consent Issues	University of California, in Anesthesiology Health System 14 <sup>th</sup> Annual Anesthesiology Update Monterey, CA
Dec. 2002 Davis	Informed Consent in Anesthesiology	University of California, Health System Department of Anesthesiology and Pain Medicine Grand Rounds Sacramento, CA
Dec. 2002	Between A Rock and a Hard Place? Medical, Legal, and Ethical Aspects of Pain Treatment	Mt. Diablo Medical Center Concord, CA
Jan. 2003	The Politics of Pain	San Francisco Medical Society San Francisco, CA
History	Fashioning a Realistic and Rational cal Ethic: Insights From Scheffler's <i>and</i> AN MORALITY	University of Washington Department of Medical Ethics School of Medicine Seattle, WA
Jan. 2003	Physician Paternalism and Respect For Patient Autonomy: The More Things Change the More They Stay The Same	University of Washington Department of Philosophy Seattle, WA
Jan. 2003	Pain Relief and Patient Care: The Emerging Ethical Paradigm	Mercy Medical Center Redding, CA

Feb. 2003 Palliative	Making the Tough Decisions:	California Hospice and
Conference	Ethical Considerations	Care Association
		San Francisco, CA
Feb. 2003 Palliative	Education for Physicians on	California Hospice and
	End-of-Life Care ( <i>EPEC</i> ) Modules On Legal Issues, Withholding and Withdrawing Treatment, Physician- Assisted Suicide and Medical Futility	Care Association Conference San Francisco, CA
Mar. 2003 Annual	Pain and the Law	American Pain Society
		Scientific Meeting Chicago, IL
Apr. 2003 Hospital	Emerging Ethical and Legal Issues	Veterans Administration
	In Patient Care	Mather Rancho Cordova, CA
Sept. 2003 Initiative	Transforming the Culture of Pain: Ethical,	Ninth Annual Maine Pain
	Legal, and Public Policy Perspectives	Symposium Rockport, ME
Sept. 2003	Law and Bioethics at the End of Life	Community Hospice, Inc. and Kaiser Permanente
Stockton		Modesto, CA
Oct. 2003 Davis	Palliative Medicine: A View from Bioethics and the Law	University of California, Medical School Department of
Anesthesiolog	and and a second s	Division of Pain Medicine 12 <sup>th</sup> Annual Review of Pain and Palliative Medicine Napa, CA
Oct. 2003 Davis	Law, Bioethics, and Professionalism	University of California,
		Health System

		Department of Obstetrics and Gynecology Grand Rounds Sacramento, CA
Oct. 2003 Bioethics and	Undertreating Pain: A Simulated Medical	American Society of
Dioennes ana		Disciplinary Board Hearing <i>Humanities</i> and the Canadian Bioethics Society Montreal, Canada
Nov. 2003	Ethical and Legal Dimensions of Neuro-	University of California,
Davis		logic Practice: Cases and Analysis Health System Department of Neurology Grand Rounds Sacramento, CA
Nov. 2003 Staff	The Riddle: Reconciling the Goals of	Hanford Hospital Medical
Siujj	Medicine with the Needs of Patients	Hanford, CA
Nov. 2003	Transforming the Culture of Pain: An Institutional Perspective	Catholic Healthcare West Board/Medical Staff Retreat Ashland, OR
Jan. 2004 Davis	Malpractice Litigation: Settlement	University of California,
Duvis		and Allocation (panel member) Health System Center for Perinatal Medicine and Law System-Wide Grand Rounds Sacramento, CA
Jan. 2004 California, Da	Informed Consent Issues in the avis	University of

		Decisionally Incapacitated Patient Health System Department of Otolaryngology Grand
	hical and Legal Issues in Palliative Co t the End of Life	Rounds Sacramento, CA ommunity Hospital of the Monterey Peninsula Monterey, CA
Feb. 2004 of	Medical Quality and Medical Ethics:	Shands Health Care System
	Rethinking the Standard of Care	the University of Florida Gainesville, FL
Feb. 2004 of	Ethical Dimensions of Pain and	Shands Health Care System
	Suffering: The Role of the Ethics Committee	the University of Florida Gainesville, FL
Feb. 2004 System of	Prognostication in Clinical Medicine:	Shands Health Care
	Prophecy or Professional Responsibility?	the University of Florida Gainesville, FL
Feb. 2004 of	Ethics Cases for Analysis from the SICU	Shands Health Care System
	and NICU	the University of Florida Gainesville, FL
Feb. 2004	Legal Issues in Pain and Palliative	University of California,
Davis		Medicine Department of Obstetrics and Gynecology, Continuing Medical Education Program Lake Tahoe, NV
Mar. 2004	Emerging Care Standards in Pain	American College of Legal Management
Medicine Ann	ual Conference	management
Las Vegas, N	7	

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*Mar. 2004* in America:

#### СМЕ

*Mar. 2004* Environment in the

Control and Research

SC

*Mar. 2004* Pain

Surgery

*Mar. 2004* and

Apr. 2004 Management Davis

Apr. 2004 Care at the Legal and Regulatory Issues The Reality of Pain in

Pain Management Facts & Fiction – *Pharmcon* 

San Diego, CA

Managing the Legal American Society of Pain Decade of Pain Management Nurses Annual Conference Myrtle Beach,

Ethical and Legal Issues in Seton Medical Center Management Department of Orthopedic

Daly City, CA

Legal Perspectives on Pain Catholic Healthcare West Palliative Medicine Sacramento, CA

Legal Issues in Pain University of California,

Department of Anesthesiology and Pain Medicine Continuing Medical Education Program Kona, HI

Ethical and Legal Issues in Marshall Hospital End-of-Life Placerville, CA Apr. 2004 Ethical Issues in Chronic Pain The Reality of Pain in America: Management Facts & Fiction Pharmcon Continuing Medical Education Program Portland, OR May 2004 Commentary on Medico-Legal Practice American Pain Society Annual Standards and Ethical Guidelines for Scientific Meeting – Forensic the Pain Specialist Special Interest Group Vancouver, BC Canada May 2004 Informed Refusal of Care: Cases in University of California, Davis Perinatal Medicine Health System Center for Perinatal Medicine and the Law Sacramento, CA May 2004 Pain Policy and Pain Relief: Illinois Hospice & Palliative Care Rhetoric or Reform? **Organization Annual** Conference Naperville, IL May 2004 **Bioethics Expert Testimony:** Seton Hall University An Introduction to the Issues School of Law Newark, NJ May 2004 Health Care Providers: Are You Really PriMed West

Annual Conference

in Jeopardy? Anaheim, CA

Aug. 2004	Does the Controlled Substances Act Society for the Study of Social Preclude Physician- Assisted Suicide?: <i>Problems Annual</i> Conference The Case of Oregon v. Ashcroft San Francisco, CA
Sept. 2004 from Bioethics Davis	Palliative Medicine: A View University of California,
System	and the Law Health
	Department of Family and Community Medicine Grand Rounds Sacra
	mento, CA
Sept. 2004	Will I Receive Competent Care? Consumer Protection and End-of-Life Care in Maine - A Listening Conference Rockport, ME
Sept. 2004	The Elusive Standard of Care in Pain Maine Pain Initiative 10 <sup>th</sup> and Palliative Medicine Anniversary Symposium Rockport, ME
Oct. 2004	Meeting the Ethical Challenges of End-of- <i>California Hospice</i> and Palliative

Oct. 2004 Palliative Davis

Update of

Dec. 2004 of Pain Chicago

Setting

Medical Education

Feb. 2005 Consent Davis

Medical Honor

Mar. 2005 Standard of

Apr. 2005 Stories Life Care Care Association Pre-Conference Program Bioethical Principles and Approaches to Las Vegas, NV Case Analysis

Legal Issues in Pain and University of California,

Medicine *Review and* 

Pain and Palliative Medicine Modesto, CA

The Humanistic Dimensions University of Illinois at

and Suffering in the Clinical College of Medicine Department of

Chicago, IL

The History of Informed University of California,

School of Medicine Alpha Omega Alpha Society

History and Ethics of Medicine Series Sacramento, CA

Clinical Guidelines and the American College of Legal Care for Pain Management Medicine Annual Conference San Diego, CA

Pain Relief and the Law: The American Society of Pain Behind the Cases Management Nurses

Albuquerque, NM

Apr.	2005		Renaissance Society of California State University Sacramento, CA
May	2005	Ethical, Legal, and Policy Issues in End-of-Life Care – A Workshop	Marshall Hospital Placerville, CA
May	2005	The Strange Case of Theresa Marie Schiavo: Ethical, Legal, and Public Policy Implications	UC- Davis Center for Health Services Research In Primary Care Davis, CA
May	2005	Ethical, Legal, and Regulatory Issues in Pain Management	Physicians' Medical Foundation Oakland, CA
May	2005	The Case of Terri Schiavo and the Challenge For the Medical Humanities	University of Texas Medical Branch Galveston Institute for the Medical Humanities
June	2005	The Politics of Pain: Legal and Regulatory Issues	Kaiser Permanente Central Valley Stockton, CA
June		From Schiavo to Howe: Advance Directives and the Illusion Clarity in End-of-Life Decisions (co-presenter with Sarah Shannon, University of Washington School of Nursin	17 <sup>th</sup> Annual Summer Bioethics Retreat Pacific Grove, CA <i>ng</i> )

# Scientific and Medical Accountability Standards Working Group INFORMATION FORM FOR POTENTIAL MEMBERS

Pursuant to California Health and Safety Code [125290.55] the Independent Citizens' Oversight Committee of the California Institute for Regenerative Medicine shall have a Scientific and Medical Accountability Standards Working Group to recommend to the ICOC scientific, medical, and ethical standards. The Standards Working Group shall have 19 members: Five ICOC members from the10 groups that focus on disease-specific areas, nine scientists and clinicians nationally recognized in the field of pluripotent and progenitor cell research, four medical ethicists, and the chairman of the ICOC. "Medical ethicist" is defined [125292.10 (p)] as "an individual with advanced training in ethics who holds a Ph.D., M.A., or equivalent training and who spends or has spent substantial time (1) researching and writing on ethical issues related to medicine, and (2) administering ethical safeguards during the clinical trial process, particularly through service on institutional review boards.

\_\_Mr. \_\_Ms. \_\_Dr. \_\_Mrs. \_\_Other\_Professor\_\_\_

# MARJORIE M SHULTZ.

First Name Professor of Law Middle Initial

Last Name

Title Boalt Hall School of Law

University, Company or Organization University of California

Business Address Berkeley, CA 94720

City/State/ Zip (510) 642-1921

(510) 691-7008

Work Number m\_shultz@law.berkeley.edu Cell Phone

Email

6. What position in the Standards Working Group are you applying for?
 □ ICOC
 □ Scientist/clinician
 X Medical ethicist

2. Please indicate whether or not you are an expert in the following subjects using a "Y" for yes and an "N" for no. Please use the blank lines to list any other areas of your expertise that you feel might be relevant to serving on the working group.

- X\_\_\_\_ The Biomedical Ethics of Stem Cell Research
- X\_\_\_\_ Informed Consent
- X\_\_\_\_ Controls on research involving human subjects

X(some) Patient privacy laws and regulations

- X\_\_\_\_ National Institutes of Health standards for research
- \_\_\_\_ National Academies' standards for biomedical research
- X\_\_\_\_ Compliance for medical ethics, health and safety requirements
- X\_\_\_\_ Expertise in medical regulatory agencies (such as the FDA)
- \_\_\_\_ Expertise in the creation of public scientific resources
- X\_\_\_\_ Expertise in health disparities
- X\_\_\_\_ Expertise in legal/ethical issues in women's health, reproductive technology
- X\_\_\_\_ Expertise in Conflict of Interest in Medical/ BioScience Research
- X \_\_\_\_Expertise in Patient Advocacy, Perspectives and Rights
- X\_\_\_\_Expertise in Health Policy and Law

X\_\_\_\_Comparative conceptual, regulatory and institutional issues and relationships between legal and medical professions, including work on professional ethics in both fields..

3. The Working Group will develop draft interim standards. At the point that interim standards are adopted by the ICOC, a 270-day public hearing period begins, all subject to the California Administrative Procedure Act (APA). Working Group members will consider public comment as guidance in revising interim standards and procedures. Working Group members may also be asked to serve on subcommittees that may meet to develop standards or determine compliance in specific areas. At least 4 meetings per year are required for the Working Group; the specific meetings schedule and length of each meeting will be set by the membership, but in the first few months will likely be a few meetings to establish interim standards. Do you anticipate making such a time commitment?

Yes\_X\_\_\_ No\_\_\_\_

Please describe any constraints\_\_\_\_\_

4. Please attach a resume or CV.

5. Please be aware that Working Group members will be required to comply with conflict of interest standards determined by the Independent Citizens' Oversight Committee based on standards applicable to members of scientific review committees of the National Institutes of Health. The guidelines are under development.

Please send your completed information sheet and resume or CV by email (preferred) or mail with "Attn: Standards WG Search" to either:

- <u>info@cirm.ca.gov</u> or
- CIRM, 5858 Horton St., Ste. 455, Emeryville, CA 94608

## PLEASE NOTE: THIS APPLICATION, TOGETHER WITH ANY ATTACHED MATERIALS, MAY BE SUBJECT TO DISCLOSURE PURSUANT TO THE CALIFORNIA PUBLIC RECORDS ACT.

#### MARJORIE M. SHULTZ Professor of Law

Boalt Hall School of Law University of California Berkeley, California 94720 Telephone: (510) 642-1921 Fax: (510) 642-3856 m\_shultz@law.berkeley.edu

#### EDUCATION

1976 J.D., Boalt Hall, University of California at Berkeley (Law Review; Order of the Coif)

1964 M.A.T., University of Chicago (History)

1962 B.A., College of Wooster, Wooster, Ohio

2000 Certification, Mediator Training, American Health Lawyers Association

#### EMPLOYMENT

1976 - Present Professor of Law, Boalt Hall, University of California, Berkeley. (Fields: Contracts, Health Law, Gender and Race Law, Legal Ethics/ Profession).

1992 Visiting Professor, Program in Medical Ethics, University of California Medical School, San Francisco, California

#### SELECTED PROFESSIONAL SERVICE AND CONSULTATIVE ROLES:

Scientific Editorial Board, Gender Medicine: The Official Journal of the Partnership for Gender Specific Medicine at Columbia University, 2004- present

Advisory Committee, Center for Medicine, Humanities and Law, University of California at Berkeley (1999 - present).

Member, University of California, Task Force on Policy Governing Conflict of Interest in Research (2003 - 2004).

Member, UCSF Academic Senate Task Force on Policy Governing Conflict of Interest and Clinical Research, UCSF Medical School (2001 - 2004).

Science Editorial Board and Department Editor, Journal of Gender-Specific Medicine (1998 - 2003).

Advisory Committee, Berkeley Women=s Law Journal (1986 - present).

Advisory Committee, Partnership of Women=s Health, Columbia College of Physicians and Surgeons (1998 - 2003).

Board of Directors, Equal Rights Advocates, San Francisco, California. (2002 - 2004).

Consultant, Genome (Public) Radio Project (NSF/DOE public education series) 1998.

Member and Consultant, Alta Bates-Herrick Hospital Ethics Committee (1989 - 2001).

Study Sections (Grant Reviewer), NIH Ethics of Health Research, Office of Scientific Review Advisor (2002, 2004); National Cancer Institute, Rockville, MD (1998).

(First) Advisory Committee, Office of Women's Health Research, NIH, (1995-1997).

Member, Legal Review Group, White House Health Security Act (Wash, D.C., 1993).

Member, Advisory Committee, UC Systemwide Biotechnology Research and Education Program (1993 - 2000).

Faculty Program Consultant on Bioethics, Women Judges' Fund for Justice (1992 - 1995)

#### HONORS AND AWARDS:

Teacher of the Year Award, Society of American Law Teachers, 2000

Alum of the Year, California Law Review, 1996

Outstanding Dedication Award, Joint UCB-UCSF Medical Program, 1988

Berkeley Campus Distinguished Teaching Award, 1983

#### PUBLICATIONS:

The Problematic Law of Parenthood When ARTs Are Used: A Troubling Dispute in California (Washington University Journal of Law and Policy, forthcoming, August 2005).

Brown, Carnoy, Currie, Duster, Oppenheimer, Shultz and Wellman, Whitewashing Race: The Myth of A Color- Blind Society (University of California Press, 2003).

Briefs for Respondent and Appellant, Robert B. v. Susan B., 109 Cal. App. 4th 1109 Cal. App. 6th Dist. 2003 (Briefed in District Court of Appeal and California Supreme Court (2003 - 2004).

Insuring Fairness: Gender Inequity in Health Insurance, 6 Journal of Gender-Specific Medicine 7 (August 2003).

Amicus Filing, Greenberg v. Reuben Matalon and Miami Childrens Hospital, Federal District Court of Southern Florida, June 2003.

(With Stephanie Bornstein), Balancing Acts: Work and Care under the FMLA, 5 Journal of Gender-Specific Medicine 12 (May-June 2002).

[From Informed Consent to Patient Choice, in Sheila McLean, ed., Essays in Law and Legal (2d series): Medical Ethics (2001)(reprinted from 95 Yale Jaw Journal 219 (1985)].

Charleston, Cocaine, and Consent, 4 Journal of Gender-Specific Medicine 14 (May-June 2001).

We Are What We Say, 4 Journal of Gender-Specific Medicine 16 (March-April, 2001).

Conflict of Interest and the Law=s Role in Medical Research Ethics, in L=Ethique et Le

Droit, ed. Martin Kilias, (Editions Universitaires Fribourg Suisse, 2000), 287-297.

Gender and Race Bias in Medical Treatment, 2 Journal of Gender-Specific Medicine 27 (July-August 1999) (with David B. Oppenheimer).

Death Does Us Part, 2 Journal of Gender-Specific Medicine 23 (Jan-Feb. 1999).

Genetic Diagnosis and the Abortion Paradigm, 1 Journal of Gender Specific Medicine 20 (December 1998).

Protection of Women By Exclusion or Inclusion, 1 Journal of Gender Specific Medicine 18 (Oct.-Nov 1998).

The Value of Legal Perspectives in Medicine, 1 Journal of Gender-Specific Medicine 12 (September 1998).

Excellence Lost, 13 Berkeley Women=s Law Journal 26 (1998).

Questioning Commodification, (Review of Margaret J. Radin, Contested Commodities, Harvard University Press, 1996) 85 California Law Review 1841 (1997).

Legal and Ethical Issues of Consent to Epidemiologic Research in Steven Coughlin and Tom L.Beauchamp, eds. Ethics and Epidemiology (Oxford University Press, 1996).

Legislative Regulation of Surrogacy and Reproductive Technology, 28 U.S.F. Law Review 613 (1994).

Restoring Informed Consent: State High Court Has Chance to Clarify Doctors' Duty to Disclose, San Francisco Daily Journal p. 4 (September 8, 1993).

A(nother) `Critique of Pure Reason' (with Angela Harris) 45 Stanford Law Review 1773 (1993).

Contract, Intent, and the Formation of Families, in Proceedings of the National Conference on Bioethics, Family and Law, Women Judges Fund for Justice, 49 (1992).

Abortion and Maternal-Fetal Conflict: Broadening Our Concerns, 1 Southern California Review of Law and Women's Studies 79 (1992).

Reasons for Doubt: Legal Issues in Use of DNA Fingerprint Identification Techniques, in Paul Billings, ed., DNA and Crime: Applications of Molecular Biology in Forensics pp. 19-59 (Cold Spring Harbor Laboratory Press, 1992).

Reproductive Health Hazards in The Workplace: Policy Options for California (one of twelve authors as members of California Policy Seminar's Workplace Reproductive Hazards Policy Group) (1992).

Can Dialogue Succeed Where Liberal Legalism Failed? The Reach Exceeds the Grasp Review of Joel Handler's, Law and the Search for Community, 38 U.C.L.A. Law Review 1325 (1991).

The Gendered Curriculum: Of Contracts and Careers, 77 Iowa Law Review 55 (1991).

Debating P.C. on 'PC', 41 Journal of Legal Education 387 (1991).

Study Sends Message to Law Firms, National Law Journal, November 26, 1990, pp. 22-23.

Reproductive Technology and Intent-Based Parenthood: An Opportunity for Gender Neutrality, 1990 Wisconsin Law Review 297.

Amicus Curiae Brief (with Lori Andrews) in support of plaintiff in Moore v. U.C.Regents 51 Cal.3d (1990).

Detachment is Not Enough (Graduation Speech) 2 Berkeley Women's Law Journal 1 (1986).

Review: Ruth Faden and Tom L. Beauchamp, A History and Theory of Informed Consent, 17 Hastings Center Report 24 (June 1987).

From Informed Consent to Patient Choice: A New Protected Interest, 95 Yale Law Journal 219 (1985).

Marriage in Transition, 124 Trusts and Estates 8 (April, 1985).

Review: Kelly Weisberg, ed., Women and the Law: The Social and Historical Perspective (Vol. 2) 34 J. Leg. Educ. 540 (1984).

Contractual Ordering of Marriage: A New Model for State Policy, 70 California Law Review 204 (1982).

#### SELECTED PROFESSIONAL PRESENTATIONS:

APredicting Lawyering Competence for Purposes of Law School Admissions, @ University of Missouri (Columbia) Faculty Workshop, March 2005.

AOld Wine and New Wineskins: Parentage Law and ARTs Reproduction, @ Washington University Public Interest Law Speaker Series, St. Louis March 2005

AAuthor Meets Reader@ Panel on Brown, Carnoy, Shultz et al, Whitewashing Race: The Myth of A Color Blind Society. Law and Society Annual Meeting. Chicago, May, 2004.

AAlternatives to High Stakes Standardized Testing for Admissions, @ Society for Industrial and Organizational Psychology Annual Meeting. Chicago, April, 2004.

Aldentification and Development of Job Oriented Criteria for Law School Admissions@. Presentation, ABA Section on Legal Education, San Francisco, August 2003.

The Mind as A Site of Treatment and Therapy," Annual Northern California Kaiser Ethics Conference, April 2003.

ALife and Death: Technology and Conflict@ ABA Appellate Judges Seminar, Berkeley, California, October 2002.

AIssues of Race in Health Care, @ In Critical Condition: Conference on Women=s Health sponsored by the Berkeley Women=s Law Journal, (September, 2001).

ALegal and Ethical Issues in Stem Cell Research,@ German - American Lawyers Society, Cologne, Germany (May 2001).

ASynergy and Contrast in Defining Life and Death in American Law, Institute for Study of International and Comparative Law, University of Cologne, Germany (May 2001).

AThe Law and Ethics of Consent to Medical Research,@ Annual Training Retreat, Institutional Review Board, Alta Bates Medical Center (February, 2001).

Testimony on Hiring of Women Faculty at the University of California, at Hearing before the Government Oversight Committee, California State Senate (January 2001).

AIntimacy and Commodification,@ (Invited Workshop Participant), American University Law School (June 2000).

ABringing the Patient from Periphery to Center,@ A Complex Sorrow: The Management of Medical Error, University of California at Berkeley (May, 2000).

AThe Fate of Traditional Ethics Under Managed Care, @ California Society of Health Lawyers, Annual Conference (March, 2000).

AReflections on Contracts and Labor Law, @ Employment Law Section Annual Retreat, San Francisco Bar Association (February, 2000).

ACan Medical Ethics Survive Managed Care?@ Yale University Institution for Social and Policy Studies (Scholars in Health Policy Program Seminar and Workshop) (October, 1999).

ALegal Issues and Ethical Issues in Consent to Medical Research,@ University of Lausanne, Switzerland, (September, 1999).

AEthics in Managed Care, @ AAHP/ABA 10th Annual Managed Care Law Conference, Tucson, Arizona (April, 1999).

AGender and Contract Remedies, @ National Association of Women Judges, Annual Conference, Salt Lake City (September, 1997).

ALegal Issues in Care of Chronically Ill Children in the Home,@ Annual Conference of the American Society of Law, Medicine & Ethics (Boston, September , 1997).

ALegal Issues in Access to Data Banks, @ at Joint Meeting of the Public Health Conference on Records and Statistics and the Data Users Conference (Washington, D.C., July, 1997).

ALegal Issues of Consent in Regard to Retained Tissue Data Banks@ at conference AFrom Science to Practice: The Role of Research in Public Health@ (Sponsored by CDC, OPRR of HHS, Emory University School of Medicine, Morehouse School of Medicine). (April, 1997).

"Reproductive Technology and the Timing of Life Cycles," McGeorge School of Law, University of the Pacific (March, 1995)..

"An Intentionalist Approach to Reproductive Technology and the Feminist Critique of Liberty," Law and Society Association Annual Meeting (Phoenix, June, 1994).

"Ethical Issues in Health Care Reform," Symposium on Health Care Reform, Yale Law School (April, 1994).

"Legal Issues in Reproduction: The Need for a Conceptual Map," Institute for Health Policy Studies (San Francisco, March, 1994).

"Legal and Ethical Issues in Human Subjects Research," AIDS Research Faculty at San

Francisco General Hospital/ UCSF- Medical School (November, 1992).

- "Responsibility and Choice: Reproductive Issues and the Genome Project," Section of Science and Technology, ABA Annual Meeting (August, 1992).
- "Legal, Ethical and Social Issues in Health Policy: the Example of the Human Genome Project," Institute of Medicine and Pew Fellowship Annual Meeting, (May, 1992).
- "Legal Issues in the Use of DNA Identification Techniques, American Academy for the Advancement of Science Annual Meeting (February, 1991).

# Scientific and Medical Accountability Standards Working Group INFORMATION FORM FOR POTENTIAL MEMBERS

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_ <b>x</b> _MrMs.	DrMrsOther	
David	Е.	Winickoff
First Name	Middle Initial	Last Name
Assistant Professor of	Bioethics and Society, U.C. Berkeley	
Title		
University of Californ	ia, Berkeley	
University, Company o	r Organization	
115 Giannini Hall		
Business Address		
Berkeley, CA 94720-3	312	
City/State/ Zip		
510-643-0319	<b>n</b> /	a
Work Number	Cell Ph	none
David_Winickoff@na	ture.berkeley.edu	
Email		
7. What position in	n the Standards Working Group are you	applying for?

2. Please indicate whether or not you are an expert in the following subjects using a "Y" for yes and an "N" for no. Please use the blank lines to list any other areas of your expertise that you feel might be relevant to serving on the working group.

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- \_\_x\_Informed Consent
- \_\_x\_ Controls on research involving human subjects
- \_\_\_\_x\_ Patient privacy laws and regulations
- \_\_\_x\_National Institutes of Health standards for research
- \_\_\_x\_National Academies' standards for biomedical research
- \_\_x\_ Compliance for medical ethics, health and safety requirements
- \_\_x\_Expertise in medical regulatory agencies (such as the FDA)
- \_\_x\_Expertise in the creation of public scientific resources
- \_\_\_x\_Expertise in health disparities

3. The Working Group will develop draft interim standards. At the point that interim standards are adopted by the ICOC, a 270-day public hearing period begins, all subject to the California Administrative Procedure Act (APA). Working Group members will consider public comment as guidance in revising interim standards and procedures. Working Group members may also be asked to serve on subcommittees that may meet to develop standards or determine compliance in specific areas. At least 4 meetings per year are required for the Working Group; the specific meetings schedule and length of each meeting will be set by the membership, but in the first few months will likely be a few meetings to establish interim standards. Do you anticipate making such a time commitment?

Yes\_x\_\_\_ No\_\_\_\_

Please describe any constraints \_\_\_\_\_\_n/a\_\_\_\_\_

\_\_\_\_

4. Please attach a resume or CV.

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• <u>info@cirm.ca.gov</u> or

• CIRM, 5858 Horton St., Ste. 455, Emeryville, CA 94608

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# David E. Winickoff, J.D., M.A.

Assistant Professor of Bioethics and Society Dept. of Environmental Science, Policy & Management University of California, Berkeley

Division of Society & Environment 115 Giannini Hall Berkeley, CA 94720-3312 Tel: 510-643-0319 Fax: 510-643-2504 email: david\_winickoff@nature.berkeley.edu

# **RESEARCH AND TEACHING INTERESTS AT BERKELEY**

Research on the interaction of science, law, and political structure in the governance of biotechnology. Research on processes and practices through which rules and rights are constructed, decisions exerted, and power exercised in regulatory domains involving the life sciences, e.g., intellectual property, environmental protection, food safety, human research subject protection, and public health.

# EDUCATION

J.F.K. School of Government, Harvard Post-doctoral Fellow, Science & Technology Studies

Harvard Law School J.D.

Cambridge University B.A., M.A., English First-class honors

Yale University B.A., History Summa Cum Laude, Phi Beta Kappa

## FELLOWSHIPS, HONORS AND AFFILIATIONS

2005-2006	Visiting Professorial Fellow, <i>Genomics Policy and Research Forum</i> , UK Economic and Social Research Council (ESRC), Edinburgh, Scotland.
2005	
2005-	Faculty Advisor, Center for Law, Business and the Economy, Boalt Law School
2004-	Faculty Affiliate, Center for the Study of Law and Society, Boalt Law School
2004-	Faculty Affiliate, Energy and Resources Group (ERG), U.C. Berkeley
2002-2004	Post-Doctoral Fellowship, JFK School of Government, Harvard University
2003	Derek Bok Certificate of Distinction in Teaching, Harvard University
2000-2002	Founder and President, Ethics, Law and Biotechnology Society, Harvard Law School
1998	Newnes Prize, Cambridge University (U.K.), top award in English, Clare College
1996-1998	Paul Mellon Fellowship, full tuition and expenses at Cambridge University (U.K.)
1997	Phi Beta Kappa, Yale University
1995	Bates Traveling Fellow, from Yale University for environmental research in Borneo.

# **PUBLICATIONS**

Cambridge, MA 2002-2004

Cambridge, MA June, 2002

Cambridge, United Kingdom June, 1998

> New Haven, CT May, 1996

D. Winickoff, et al., Adjudicating the GM Food Wars: Science, Risk, and Democracy in World Trade Law, 30 YALE JOURNAL OF INTERNATIONAL LAW 81-123 (2005)

D. Winickoff, Prop. 71 a Risky Experiment in Squandering Public Monies, SAN FRANCISCO CHRONICLE, E3 (18 October 2004)

D. Winickoff (with L. Busch, R. Grove-White, S. Jasanoff, B. Wynne), amicus curiae brief submitted to the Dispute Settlement Panel of World Trade Organization, in the case of EC: Measures Affecting the Approval and Marketing of Biotech Products (28 April 2004). Available at <<u>http://www.lancs.ac.uk/fss/ieppp/wtoamicus/</u>>.

J. Otten, H.R. Wyle, G.D. Phelps, **D. Winickoff**, R. Winickoff, The Charitable Trust as a Model for Genomic Biobanks, Correspondence, NEW ENGLAND JOURNAL OF MEDICINE 350;1: 85-86 (1 January 2004)

D. Winickoff, R. Winickoff, The Charitable Trust as a Model for Genomic Biobanks, NEW ENGLAND JOURNAL OF MEDICINE 349;12: 1180-1184 (18 September 2003)

D. Winickoff, Governing Population Genomics: Law, Bioethics, and Biopolitics in Three Case Studies, 43 JURIMETRICS 187-228 (2003)

D. Winickoff (with Sheila Jasanoff), Hard facts and soft law: what's the evidence?, OPENDEMOCRACY.NET (18 November 2002)

D. Winickoff, Biosamples, Genomics, and Human Rights: Context and Content of Iceland's Biobanks Act, JOURNAL OF BIOLAW AND BUSINESS 4:2 (January 2001). Reprinted in POLITEIA 62:157 (2001)

D. Winickoff, E. Arnason, J.R. Gulcher, K. Stefansson, The Icelandic Healthcare Database, Correspondence, NEW ENGLAND JOURNAL OF MEDICINE, 343;23: 1734-1735 (7 December 2000)

D. Winickoff, Rhetoric Equals Cold Cash in Iceland, GENEWATCH (November 2000)

D. Berwick, D. Winickoff, *The Truth About Doctors' Handwriting: a Prospective Study*, BRITISH MEDICAL JOURNAL 313:1657-1658 (21 December 1996)

## INVITED ACADEMIC TALKS AND DELIVERED PAPERS

Shaping Cohort Genomics in Utah: Ethical, Legal and Social Issues, invited lecture, University of Utah and Huntsman Cancer Institute, Salt Lake City (19 August 2005)

*The International Politics of Agricultural Biotechnology*, U.C. Berkeley panelist invited by the California Agricultural Leadership Foundation (6 August 2005)

Asbestos, Risk and the World Trade Constitution, Harvard University, invited paper for 2005 conference of the "Science and Democracy Network" (25 June 2005)

*Genetics and Democracy: The Recombinant DNA Controversy*, U.C. Berkeley, invited talk, Molecular & Cell Biology 140, General Genetics (9 May 2005)

WTO, GMOs and the Environment, U.C. Berkeley, Global Environmental Seminar, invited guest lecturer (28 April 2005)

International Patent Law and Access to Drugs, U.C. Berkeley School of Public Health, invited lecture in "Health and Human Rights" seminar, Prof. Weinstein (21 April 2005)

Proposition 71 and the Challenge of Science and Democracy, U.C. Berkeley, invited guest lecture for Science, Technology and Values in the Global Arena, ISF 60, Dr. Urs Cipolat, Lecturer (19 April 2005)

*Governing Population Genomics: A Comparative Study with a Proposal for Policy*, Committee on Health Law of the Business Law Section of the California Bar Association (8 April 2005)

*Reframing the Human Participant in Genetics Research*, Boalt Hall (U.C. Berkeley law school), invited guest lecture in "Topics in Bioethics and Health Law Seminar," Professor Marjorie Shultz (5 April 2005)

*Politics of the Science/Policy Interface,* invited Panel Discussant, 2005 Breslauer Symposium at U.C. Berkeley: An Interdisciplinary Look at a Global Problem: Social and Scientific Aspects of Climate Change (25 February 2005)

*Bioethics, Biotechnology, and Society: Putting the Public Back Into Policy,* U.C. Berkeley, invited speaker for the annual meeting of the U.C. Berkeley College of Natural Resources Advisory Board (19 November 2004)

Settling the Trans-Atlantic Food Fight: Science, Risk and Democracy at the WTO, U.C. Berkeley, invited speaker for Environmental Science, Policy and Management Colloquium Seminar (25 October 2004)

From Subject to Citizen: Property Rights and Governance in Genomic Biobanking, Arizona State University, Tempe, invited speaker for conference entitled, "Bioethics, Genetics, and Group Rights" (14-15 October 2004)

Ruling the Unruly: The Case of CODIS and the Fourth Amendment, *Harvard University, Kennedy School of Government, invited presentation of a working paper for planned edited volume entitled,* Reframing Rights: Constitutional Implications of Technological Change (19 April 2004)

So You Want to Build A Biobank?: Ethical, Legal, and Social Issues, *Boston Veterans Administration* Health Care System, featured speaker at 1<sup>st</sup> Planning Meeting for the Veterans Affairs Biorepository (12 April 2004)

An Introduction to Patents, IP Licensing, and Public Health, Harvard University School of Public Health, invited guest lecture for course entitled "Pharmaceuticals and Public Health" (1 March 2004)

What is Sustainable Development?, *Harvard College, invited lecture for course on "Environmental Politics" (15 December 2003)* 

Democracy and the WTO: Law, Science and Regulation in Asbestos, *Harvard University, invited* commentary for Program on STS colloquium (21 November 2003)

The Charitable Trust Model for a Children's Biobank, Massachusetts General Hospital, Boston, invited speaker for lecture series at the Center for Child and Adolescent Health Policy (20 October 2003)

The Human Genome Diversity Project: Ethical, Legal, and Social Dimensions, Arizona State University School of Law, invited speaker for course entitled, "Bioethics and Genetics in an Interdisciplinary Context" (1 October 2003) Grammars of Globalization: Technoscience, Democracy and Legal Rules at the WTO, *Cornell University*, *invited speaker for conference entitled "Connecting Science and Technology Studies: The Academy, the Polity, and the World" (28 September 2003)* 

A New Model for Genomic Biobanks, University of Iceland, Reykjavík. Invited speaker (21 August 2003)

Collectivizing Genomes: Socio-legal Aspects of Bioethics, Property, and Power, *Harvard University, invited speaker in conference entitled, "Governing Biotechnology: From Regulation to Regime" (1 November 2002)* 

Our Bodies, Our Cells: Rethinking the Autonomous Subject in the Biotech Era, *Harvard University*, *invited speaker in the Horblit Colloquium in the History of Science (25 September 2001)* 

A Case Study of Informed Consent in the Age of Genetic Property, Kennedy School of Government, Harvard University, invited speaker for conference entitled, "Owning Up: Bodies, Selves, and the New Genetic Property" (5 May 2001)

Genetic Privacy and Iceland's DNA Database, *Reykjavik Academy, Iceland, invited colloquium speaker* (27 July 2000)

# **COURSES TAUGHT**

cases.

#### Currently teaching at U.C. Berkeley

ESPM 162 – Bioethics and Society ESPM 24 – Biotechnology: Ethics and Politics ESPM 254 – Science, Technology and the Politics of Nature (~ 100-student undergraduate lecture course)

(~ 17-person freshman seminar course)

(~ 17-person graduate seminar course)

#### Previously taught at Harvard

*Bioethics, Law and the Life Sciences* (with S. Jasanoff) JFK School of Government (2003) *Bioethics and Biotechnology* (with C. Nesson and B. Leicher) Harvard Law School (2002)

### **PROFESSIONAL EXPERIENCE AND CONSULTING**

University of California, Berkeley (2004- )

• Assistant Professor of Bioethics and Society (tenure-track) College of Natural Resources Dept. of Environmental Science, Policy and Management Full-time, tenure-track teaching and research position.

Harvard University, Kennedy School of Government

• *Adjunct Lecturer in Public Policy* (2003-2004) Taught graduate seminar entitled, "Bioethics, Law and the Life Sciences," organized colloquia on the ethical, legal and social implications of new biotechnologies, wrote articles, and submitted amicus briefs in legal

• *Post-Doctoral Fellow* (2002-2004)

Under Professor Sheila Jasanoff, pursued research at intersection of science, technology, law and public policy, especially in the areas of int'l trade law, health, intellectual property, biotech, and bioethics. Received Harvard's Certificate of Distinction in Teaching for work as a teaching fellow for Harvard courses in environmental studies and bioethics. Helped design, organize and conduct conferences for the program.

Cambridge, MA

Berkeley, CA

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# Harvard Law School

• Founder and Director, Ethics, Law, and Biotech Society (E.LaB) (2000-2002) While in law school, built a student organization from scratch: 8-member executive board, 50-person membership, and close partnership with Boston biotech and law firms. Developed program of research and activities (currently ongoing) with an \$8,000 endowment. Served on the Interfaculty Group on Genetics and Society, Harvard University

# Harvard College

• Teaching Fellow (1998-1999)

Taught sections for three large lecture courses: The Science and Politics of Global Climate Change (for Professor Michael McElroy), Science and Society in the 20th Century (for Professor Everett Mendelsohn), and Tragic Drama and Human Conflict (for Dr. Bennett Simon)

# Morrison & Foerster LLP

Summer Associate (Summer 2001)

Prepared legal letters, memoranda, and contracts for firm attorneys and firm clients. Worked in a number of law areas, including health care and privacy law, intellectual property licensing and litigation, general commercial litigation

# Mannvernd (Icelandic Bioethics Society)

• *Consultant* (Summer 2000)

Published article on the Icelandic Biobanks Law (see below) that was used by the Icelandic Medical Association to make regulation policy recommendations to the Icelandic Ministry of Health. Generated legal theories for right-to-privacy litigation against the Icelandic Government regarding a law mandating citizen participation in a national private-sector genetics project

# INSTITUTIONAL REVIEW BOARD (IRB) MEMBERSHIP

- Brigham and Women's Hospital (2003-2004) •
- *Veterans Administration Biorepository Ethics Oversight Committee (2004 )*

# **DEPARTMENTAL SERVICE (2004-2005)**

- Admissions Committee
- Undergraduate Program Committee

Cambridge, MA

Cambridge, MA

Reykjavík, Iceland

# Boston. MA Palo Alto, CA

San Francisco, CA

# Scientific and Medical Accountability Standards Working Group INFORMATION FORM FOR POTENTIAL MEMBERS

Pursuant to California Health and Safety Code [125290.55] the Independent Citizens' Oversight Committee of the California Institute for Regenerative Medicine shall have a Scientific and Medical Accountability Standards Working Group to recommend to the ICOC scientific, medical, and ethical standards. The Standards Working Group shall have 19 members: Five ICOC members from the10 groups that focus on disease-specific areas, nine scientists and clinicans nationally recognized in the field of pluripotent andprogenitor cell research, four medical ethicists, and the chairman of the ICOC. "Medical ethicist" is defined [125292.10 (p)] as "an individual with advanced training in ethics who holds a Ph.D., M.A., or equivalent training and who spends or has spent substantial time (1) researching and writing on ethical issues related to medicine, and (2) administering ethical safeguards during the clinical trial process, particularly through service on institutional review boards.

\_\_Mr. \_\_Ms. \_x\_ Dr. (Ph.D.)\_\_Mrs. \_\_Other\_\_\_\_

LaurieSZolothFirst NameMiddle InitialLast Name

Professor of Medical Humanities and Bioethics and of Religion and Director of Bioethics at the Center for Genetic Medicine, Feinberg School of Medicine Northwestern University

Title

Northwestern University, Feinberg School of Medicine, and Weinberg College of Arts and Sciences

University, Company or Organization

# 750 North Lakeshore Drive, Suite 634

**Business Address** 

## Chicago, Illinois, 60611

City/State/ Zip

**1312-503-4621** Work Number **1510-410-2265** Cell Phone

lzoloth@northwestern.edu\_\_\_\_\_ Email

8. What position in the Standards Working Group are you applying for?
□ ICOC
□ Scientist/clinician
X Medical ethicist

2. Please indicate whether or not you are an expert in the following subjects using a "Y" for yes and an "N" for no. Please use the blank lines to list any other areas of your expertise that you feel might be relevant to serving on the working group.

- Y The Biomedical Ethics of Stem Cell Research
- Y Informed Consent
- Y Controls on research involving human subjects
- N Patient privacy laws and regulations
- Y National Institutes of Health standards for research
- Y National Academies' standards for biomedical research
- N Compliance for medical ethics, health and safety requirements
- N Expertise in medical regulatory agencies (such as the FDA)
- Y Expertise in the creation of public scientific resources
- Y Expertise in health disparities
- Y Clinical ethics
- Y Ethics of nursing practice (California RN active license)
- Y ICUC and IRB theory and practice
- **Y** Regulation of private bioethics companies
- Y Conflict of interest standards
- **Y** Justice Theory
- **Y** Feminist Theory
- Y Comparable Religious Ethics
- Y International and national standards for basic research

3. The Working Group will develop draft interim standards. At the point that interim standards are adopted by the ICOC, a 270-day public hearing period begins, all subject to the California Administrative Procedure Act (APA). Working Group members will consider public comment as guidance in revising interim standards and procedures. Working Group members may also be asked to serve on subcommittees that may meet to develop standards or determine compliance in specific areas. At least 4 meetings per year are required for the Working Group; the specific meetings schedule and length of each meeting will be set by the membership, but in the first 12 months will likely be 6 - 8 meetings. Do you anticipate making such a time commitment?

Yes\_X\_\_\_ No\_\_\_\_

Please describe any constraints\_\_\_\_

I am an Orthodox Jew. If the committee meets during the 25 hours of the Sabbath (*i.e.*, between sunset Friday and one hour after sunset Saturday), I could participate fully, but would need to walk to the meetings and could not take written notes. I cannot travel to or from meetings from Friday evening to Saturday nightfall, and would have to travel prior to our meetings.

4. Please attach a resume or CV.

# See enclosed

5. Please be aware that Working Group members will be required to comply with conflict of interest standards determined by the Independent Citizens' Oversight Committee based on standards applicable to members of scientific review committees of the National Institutes of Health. The guidelines are under development.

Please send your completed information sheet and resume or CV by email (preferred) or mail with "Attn: Standards WG Search" to either:

- <u>info@cirm.ca.gov</u> or
- CIRM, 5858 Horton St., Ste. 455, Emeryville, CA 94608

Forms are due postmarked or emailed by midnight Tuesday February 22, 2005.

# PLEASE NOTE: THIS APPLICATION, TOGETHER WITH ANY ATTACHED MATERIALS, MAY BE SUBJECT TO DISCLOSURE PURSUANT TO THE CALIFORNIA PUBLIC RECORDS ACT.

# LAURIE ZOLOTH, PH.D.

#### FEINBERG SCHOOL OF MEDICINE AT NORTHWESTERN UNIVERSITY 750 North Lake Shore Drive :: Chicago, IL 60611 :: 312-503-4621 :: Lzoloth@Northwestern.Edu

#### PRESENT POSITIONS

Director of Bioethics, Center for Genetic Medicine Professor, Medical Humanities and Bioethics Program of Medical Humanities and Bioethics, Feinberg School of Medicine Professor of Religion at the Weinberg School of Arts and Sciences, Northwestern University Chicago, Illinois January 2003-present

#### PAST POSITIONS

Director of the Jewish Studies Program Professor of Social Ethics and Jewish Philosophy College of Humanities San Francisco State University September 2000 to January 2003

Director of the Jewish Studies Program Associate Professor of Social Ethics and Jewish Philosophy College of Humanities San Francisco State University January 1996 to September 2000

Lecturer, Social Ethics Graduate Theological Union Spring 1994

Co-founder, The Ethics Practice Research, Education and Consultation in Clinical Bioethics June 1993 to January 2003

Visiting Professor, University of Virginia Spring 2000

#### FIELD

Bioethics Jewish Social Ethics and Moral Philosophy Basic Research Ethics Clinical Ethics Justice Theory

#### ACADEMIC BACKGROUND

Tenured and Promoted to Full Professor, September 2000.
Ph.D., Social Ethics, Graduate Theological Union, May 1993.
M.A., Jewish Studies, Graduate Theological Union, The Center for Jewish Studies, May 1993.
M.A., English, California State University (San Francisco State), 1991.
B.S.N., University of the State of New York, 1982.
B.A., Women's Studies, University of California, Berkeley, Phi Beta Kappa, Cum Laude, 1974.
Certificate in Vocational Nursing (LVN), 1971, James Martin Vocational Trade School, Philade Pennsylvania, 1971.
Swarthmore College, 1968-1970.

#### ACADEMIC TEACHING EXPERIENCE

**Professor,** Northwestern University, Feinberg School of Medicine. **Professor,** Northwestern University, Weinberg School of Arts and Sciences.

**Director and Professor**, San Francisco State University. Administered the university-wide program in Jewish Studies, directing 2 full time and eleven part-time faculty, overseeing all grant projects, managing the graduate program, community development and community relations. January 2000 to 2003. **Director and Associate Professor**, 1996-2000.

**Visiting Professor,** University of Virginia, Department of Religious Studies, (Judaism) and **Visiting Fellowship** at the Center for Bioethics, University of Virginia. Spring 2000.

Visiting Research Professor, Graduate Theological Union, Berkeley, California

Lecturer, Program in Bioethics, Graduate Theological Union, Berkeley, California. Spring 1994. Served on M.A. Committee, Center for Jewish Studies, 1994-1995.

**COURSES TAUGHT:** Justice in an Unjust World; Genetics and Meaning; Religion and Bioethics; Topics in Public Health: History, Values and Ethics; The Moral of the Story: Biblical Ethics; Good and Evil: Contemporary Jewish Social Ethics; Internship in Community Service; Facing Each Other: Blacks and Jews in the Popular Media; Jews and Judaism in the Modern World; Jewish Bioethics: Text and Tradition; Last Chance for Philosophy.

#### **CLINICAL ETHICS TEACHING AND CONSULTATION**

**Co-Founder,** The Ethics Practice, Berkeley, California. In this capacity, co-directed the education, consultation, and research projects as noted below:

- Ethicist, Washington Hospital Healthcare System, Alameda County, California. With partner, Sue Rubin, provided ongoing Bioethics education and consultation services to the Bioethics committee and the medical center, including a comprehensive ethics curriculum, Bioethics rounds, case consultation, and policy review and analysis. 1991-1993, January 1995-2003.
- **Ethicist,** Mt. Diablo Hospital, Concord, California, and John Muir Medical Center, Walnut Creek, California. With partner, Sue Rubin, provided ongoing Bioethics education and Consultation services to the Bioethics committee and medical center. 1996-1997.
- Ethicist, Northern California Presbyterian Homes, San Francisco, California. With partner, Sue Rubin, provided ongoing Bioethics education and consultation services to the

Ethicist, The Children's Hospital, Oakland, California. Primary Ethicist for both the Medical

Ethics Committee and the Nursing Ethics Forum. Organized training and on-going

education to the committees, the staff, and the Pediatric Residency Program in Bioethics. Facilitated case consultation and served as consultant to the Medical Center, 1988-1997.

- **Consulting Ethicist,** National Kaiser Permanente Health Maintenance Organization. Trained and continued to educate the Institutional and Regional Ethics Committees, developed policy and procedures and served as consulting clinical ethicist in the Northern California Region (15 medical centers), the Southern Region (10 medical centers), the Denver Region, the Hawaii Region, the Ohio Region, the Pacific Northwest Region, and the Kansas/Missouri Region 1987-1996 (continuing with selected clients 1996-2001).
- **Consulting Ethicist,** California State Hospice Association. Board retreats and consultation, 1992-1993.
- **Consulting Ethicist,** Valley Memorial Hospital, Livermore, California. Trained and staffed Committee, 1989-1993
- Staff Ethicist, Bioethics Consultation Group, Berkeley, California. Consulting Ethicist to all clients and projects of the Group, faculty at all BCG Intensive Seminars and National Ethics Seminars jointly sponsored with the Kaiser Permanente Program. Developed methodology, teaching, case reviews, teaching tools, research resources, and programs in ethics committee development for the Group. Developed special programs in: justice theory, cultural diversity, basic legal and ethical training, feminist ethics, hospice, neonatology, and with colleague Susan Rubin, issues in futility and care, nursing, and community building, 1987-1993.
- **Consulting Ethicist,** Mt. Zion Hospital, San Francisco, California. Worked as Ethics Consultant to the Nursing Administration and as facilitator in the merger program with the University of California, San Francisco Hospital, 1989-1990.
- **Consulting Ethicist,** The UNOS (United Network for Organ Sharing), Northern California. Organized and taught Northern California Program Directors in "Ethics and Methodology" and lectured in "Ethics in Transplantation," as series of workshops throughout the northern state for hospital personnel and the lay community "Current Trends in Transplantation" developed by the UNOS. 1989.

#### CLINICAL NURSING

RN License, State of California, Current.

Staff Nurse (RN), Infant Intensive Care Unit, Kaiser Hospital, Oakland, California, 1982-1989. Coordinator, Parent Prenatal Education Program, Alta Bates Hospital, Berkeley, California, 1975-1981.

Staff Nurse (LVN), Neonatal Unit, Alta Bates Hospital, Berkeley, California, 1975-1981. Staff Nurse, Women's Health Collective (Berkeley Free Clinic), Berkeley California, 1972-1974. Staff Nurse (LPN), Neonatal Unit, Episcopal Hospital, Philadelphia, Pennsylvania, 1971-1972.

#### FEDERAL COUNCILS AND COMMITTEES

- National Aeronautics and Space Administration (NASA), National Advisory Council, 2001 to present
- NASA Planetary Protection National Advisory Board, 2002-present
- NASA National Institutional Animal Care and Use Committees (IACUC) and Flight IACUC, 1999 to present.
- California Stem Cell Research Advisory Panel of the State Legislature, appointed 2003.
- NASA Research Maximization and Prioritization Task Force (ReMAP), National Commission, 2002.
- National Institutes of Health (NIH), Division of AIDS Adult Clinical Trials Group Data Safety Monitoring Board, member 2000 to 2003.

National Institutes of Health, National Human Genome Research Institute, Ethical, Social, and Legal Implications of the Human Genome (ELSI) Policy Planning Group (EPPG), The Future of Human Genomics, 2002. NIH ELSI Section Chair, Ethical Boundaries of Genetic Research, 2002. NASA Extravehicular Activity, (EVA) Data Safety and Monitoring Board, 2000.

#### EXPERT TESTIMONY FOR NATIONAL or STATE COMMISSIONS

Testimony on Stem Cell Research at the Texas State Legislature, Austin, TX, January 26, 2005. Testimony on the "Ethics of Stem Cell Research" at the NAS Guidelines for Human Embryonic Stem Cell Research Workshop, National Academies, Washington, DC, October 13, 2004. Expert Testimony on Stem Cell Research before the United States Senate Subcommittee on Science, Technology, and Space, Washington, DC, September 29, 2004. Testimony to the NIH National Planning Commission on Ethical, Social and Legal Implications to the Human Genome Project Planning and Assessment Process, Section on Ethical Barriers "Ethical and Policy Implications in Stem Cell Research," Washington, DC, July 2002. Testimony and Response, California State Commission on Cloning Final Report (Religious Response Panel) 2001 The National Bioethics Advisory Committee Hearings: Religious Perspectives on Human Stem Cell Research, May 1999. Consultant to the National Institutes of Health, Septic Shock Protocols, February 1999. Consultant to the NASA Committee on National Standards for the Treatment of Animals as Research Subjects resulting in the Sundowner Report on The Use of Animals as Research Subjects, October 1996.

#### PROFESSIONAL AND ACADEMIC MEMBERSHIPS

#### LEADERSHIP POSITIONS:

American Society for Bioethics and Humanities, President for 2001. International Society for Stem Cell Research, Ethics Committee, Co-Chair, 2003 to present. Howard Hughes Medical Institute Bioethics Advisory Board, Chair, 2000 to present. Society for Jewish Ethics, Vice President, 2001 and 2002. Fellow of the Hastings Center, elected, 2000.

#### RESEARCH AND ACADEMIC BOARD SERVICE:

Howard Hughes Medical Institute, Bioethics Advisory Board, 2000 to present. Society for Women's Health Research, National Board of Directors, 2004 to present. International Society for Stem Cell Research, Founding Board, 2001 to present. National Hadassah Health Advisory Council, 2005

American Society for Bioethics and Humanities (ASBH), Founding Board Member, 1998-2002. Boston Children's Hospital Stem Cell Advisory Panel, 2004.

Society for Jewish Ethics, Founding Board Member, 2000 to present.

Religious Consultation on Ethics, Reproduction, and Women's Health, 2000-present.

American Society for Bioethics and Humanities (ASBH) Clinical Ethics Task Force, 2003present.

American Society for Bioethics and Humanities (ASBH) Conflict of Interest and Health Care Policy Task Force, 2003.

American Academy of Religion Steering Committee, Consultation on Religion and Childhood, 2003 to present.

American Academy of Religion, Women and Religions Steering Committee, 2000 to

present.

Genetics Policy Institute, Legal and Policy Advisory Board, 2004.

Scriptural Reasoning, International Advisory Founding Board Member, 2003 to present. The Louis Finkelstein Institute for Religious and Social Studies at the Jewish Theological

Seminary of America, National Advisory Board, 1998 to present.

Robert Wood Johnson Foundation, Promoting Excellence at the End of Life, National Advisory Board 1997 to 2004.

Textual Reasonings: Post-Modern Jewish Philosophy, National Board, 1997 to present.

California State University Jewish Studies, State Steering Committee, 1996-2003.

Academic Consortium of the Jewish Studies Program of Northern California, Executive Board Steering Committee 1996-2003.

Columbia University Institute for the Study of Science and Religion, Board, 1999-2003.

American Academy of Religion, Ethics Section, Steering Committee, 1997-2002.

The Park Ridge Center for Health, Faith and Ethics, The Project on Jewish Ethics, National Advisory Board, 1999 – 2001.

Geron Corporation, Ethics Advisory Board, 1998 to 2003.

Western Jewish Studies Association, National Board, 1998-2001.

American Society for Bioethics and Humanities, National Program Committee, 1998, 1999.

American Association for the Advancement of Science, Program of Dialogue between Science and Religion (DoSER), National Board, 1998-2004.

American Association of Bioethics, National Nominating Committee, 1995-1996.

#### EDITORIAL BOARDS:

Editorial Board: Stem Cells. 2004 to present.

Editorial Board: <u>A Journal of Bioethics</u>. 2000 to present.

Editorial Board: The Journal of Clinical Ethics. 1994 to present.

Editorial Board: Journal of Law, Medicine, and Ethics. 2003 to present.

Contributing Editor, National Board: <u>The Park Ridge Center: A Journal of Health, Faith and</u> <u>Ethics</u>. 1999.

Editorial Advisory Board: <u>Center for Medical Ethics and Health Policy</u>, for the project "Limited Access to Medical Treatment in an Age of Medical Progress: Developing a Christian Consensus." 1998.

Editorial Board: <u>Shofar: The Journal of the Western/Midwestern Jewish Studies Association</u>. 1997-2003.

#### **REVIEWER FOR PUBLISHERS:**

Journal of the American Medical Association (JAMA) Journal of Clinical Ethics Annuals of Internal Medicine Georgetown University Press The Hastings Center Report Johns Hopkins University Press MIT Press Routledge Press

#### COMMUNITY SERVICE

COMMUNITY BOARDS SERVED:

Hadassah Illinois State Planning Committee on Stem Cell Research, 2005. Jewish United Fund of Metropolitan Chicago, Faculty Advisory Committee, 2004. Chicago Museum of Science and Industry Advisory Board, "Body Worlds" Exhibit, 2004-2005. Judaism and Health Care Ethics Steering Committee, Chicago, 2004 Chicago's Museum of Science and Industry's 21st Century Initiative Exploration Task Force, 2003-2004. San Francisco Mayor W. Brown's Host Committee, the Jewish Film Festival, National Premiere of "Blacks and Jews," 1997. Alumni Council, Graduate Theological Union, 1995-1996. Commission On Jewish Continuity, Jewish Community Federation, 1993-1994. Dean's Advisory Board, Graduate Theological Union, 1991-1992. Member, Chevra Kadisha (Jewish Burial Society) of the Greater East Bay, 1985-1992. Board of Directors, Jewish Community Relations Council of the Greater East Bay, 1985-1990. Board of Directors, Congregation Beth Israel, Berkelev, 1985-1990. Commissioner, City of Berkeley Peace and Justice Commission, 1985-1990. Volunteer of the Year Award, Jewish Community Relations Council of the Greater East Bay, 1988. Board of Directors, B'nai B'rith Hillel Foundation, University of California, Berkeley, 1985-198 Nurse Representative, California Nurses Association, Oakland Kaiser, 1982-1988. Graduate Student Representative, Board of Trustees, Graduate Theological Union, 1985-1986. Chief Shop Steward, Service Employees International Union, Local 250: Hospital Workers, Alta Bates Hospital, 1975-1981.

#### UNIVERSITY SERVICE

Faculty Advisor, Northwestern University, Feinberg School of Medicine, Jewish Students Medical Organization, 2005.

Member, Northwestern University Committee for Jewish Studies, 2004-5.

Member, Northwestern University IRB Special Review Committee, 2004.

Member, SFSU University Human Relations Committee, 1996-2003.

Member, SFSU College of Humanities Dean's Council, 1996-2003.

Member, Academic Senate Faculty Affairs Committee, 1999-2000.

Member, University Academic Senate, 1997-2000.

Member, Academic Senate Student Affairs Committee, 1997-1999.

Member, SFSU University Interdisciplinary Council, 1998.

Mentor Professor, SFSU, 1998.

Co-Director, SFSU/Hillel/Hadassah Conference on Women and Jewish Life, 1998.

Faculty Advisor, Panel Chair, SFSU History Department Conference, "Passing on the Truthful," 1997.

Member, Woman and Embodiment Conference SFSU Planning Committee, 1996-1997. Advisor to SFSU Student Organizations: Hillel/Jewish Student Organization. Advisor to SFSU Student Organizations: New Russian Immigrant Association.

#### ACADEMIC HONORS AND AWARDS

Boyarsky Lectureship in Law, Medicine, and Ethics, Duke University, October 19, 2004. John P. McGovern Award Lectureship in the Art and Science of Medicine, March

31, 2004.

Hastings Fellow, elected 2000.

Benjamin Freedman Lectureship, McGill University, 2000

San Francisco State Professional Merit Award, 2000.

San Francisco State Professional Merit Award, 1999.

San Francisco State University Recognition Award for Outstanding Contribution to Community Service, 1998-1999.

San Francisco State University: The President's Research Award and Sabbatical, 1998. Korngold Annual Lecturer, San Francisco, California, May 1998.

San Francisco State University Recognition Award for Outstanding Contribution to Teaching, 1997-1998.

 San Francisco State University Professional Performance Merit Award, 1997.
 San Francisco State University Recognition Award for Outstanding Contribution to Research, 1996.
 National Nursing Honor Society, inducted, 1991.
 Phi Beta Kappa, University of California at Berkeley, 1974.

#### GRANT AWARDS FOR INDIVIDUAL ACADEMIC RESEARCH

American Academy of Religion Researchers Fellowship, 1999. San Francisco State University Faculty Research Grant, Summer 1997. Graduate Theological Union, American Academy of Religion/Society for Biblical Literature Scholarship, 1992.

#### GRANTS AUTHORED AND DIRECTED

Co-PI: "Family, Identity, Ethnicity, and Citizenship after the Human Genome Project." National Institutes of Health, the Program on Ethical, Legal, and Social Implications of the Human Genome, (NIH-ELSI) SFSU and the University of Minnesota Bioethics Center, 1999-2005.

Principal Investigator: International Jewish Discourse Project: On Religion and Ethics at the Frontier of Genetic Medicine, SFSU and the American Association for the Advancement of Science, 2001-2004.

Primary Author: "Haas Family Fund for the Chair in Jewish Community Service," 1999-2002.

"Koret Challenge Grant I, II, and III" and Koret Three Year Grant for Jewish Studies, with Carol Hayashino. 1997-2000.

Primary Investigator: San Francisco State University Centennial Project Grant, 1999.

Primary Investigator: San Francisco State University Assessment Project Grant, 1999.

Co-author and Director of the National Endowment for the Humanities Grant: The San Francisco State Jewish Studies Program, 1998. (Funded for matching at \$396,000)

Primary author: Der Arbeiter Ring Library Donation (Yiddish and Judaica Library donated to the SFSU program.) 1998.

Primary Author: "Teaching the Holocaust: Different Voices," from the Jewish Community Endowment Fund, Fall 1997.

Co-author: "The Richard and Rhoda Goldman Chair in Jewish Ethics and Social Responsibility," with Paul Fonteyn, (funded for one million dollars), 1996. (SFSU's first endowed chair)

#### **GRANT PARTICIPATION**

Scriptural Reasoning Theory Group, David Ford and Dan Hardy, (Cambridge University) directing, 2003 to present.

Program on Biotechnology, Religion, and Ethics, Andrew Lustig, directing. (Ford Foundation) Coordinator of Hybridization Section, 2003 to 2004.

NIH Ethical Legal and Social Implications of the Human Genome Project, the University of Health Sciences, Portland, Oregon, (NIH) "Family Notification and Breast Cancer Testing,"2000-2003.

American Society for Bioethics and Humanities and American Society for Law, Medicine, and Ethics, task force on conflicts of interests in consultation, Brody and Dubler, directing, (Greenwall Foundation,) 2001.

American Society for Bioethics and Humanities, Status of the Field committee report, Rothenberg, directing, (Greenwall Foundation,) 2001.

California Health Technology Assessment Panel, Human Stem Cells, (California State)2001. Hastings Center, Expanding Hospice Care Project, 2000-2001.

American Association for the Advancement of Science National Board for the Dialogue

between Religion and Science, and Project on the Ethical, Religious, and Social

Implications of Germ Line Intervention, 1998-2001.

- Invited participant, Liberty Fund Conferences on "Genes and Responsibility," 2001; "Locke, Pierre Bayle, and The Freedom of Conscience," March 1999; Pre-Commitment Contracts and Individual Liberty," Houston, 1999; ""The Practice of Medicine in a Free Society," Houston, 1998; "Hayak, Civil Order, and Society," Eric Mack, Grant Director, Albuquerque, March 1998. "Free Choices of Individuals in Society: Health Care," Baruch Brody, Grant Director, Houston, April 1997.
- American Association for the Advancement of Science, National Board for the Dialogue between Religion and Science, Stem Cell Research Project, 1999-2000.

University of California, Humanities Center Project on Error in Medicine, 1999-2000. University of California, San Francisco and Berkeley Project on the Moral Education of

Physicians, Bolinas, 1999.

- Religious Consultation on Reproduction, Health, Population, and Ethics, International Grants (Pew Foundation) "Abortion," 1999. "What Men Owe to Women," 1998.
- Summer Seminars in Jewish Studies, Web Training and Curriculum Development: San Jose State, 1998 and Chico State University, 1999.
- University of California, School of Public Health, Ethics and Reproductive Incentives Project, 1998.
- Textual Reasonings, Drew University, New Jersey, funded by the National Endowment for the Humanities, 1997.
- Planning Committee, "The Children's Hospital of Oakland Sickle Cell Project Grant, "Ethics and the Community in Sickle Cell Disease," National Institutes of Health, 1997.
- Stanford University Joint Conference on Model State Guidelines for Ethical Standards for Physician-Assisted Suicide, Dr. Barbara Koenig, directing, September 1996. Editorial Board for Project, 1997.
- University of Victoria, The Centre for Religion and Society/Ford Foundation, Religious Conversations on Population, Consumption, and Ecology, Jewish Ethics sources offered, Professor Harold Coward, directing, 1995-1997.
- Veteran's Administration New Technology Assessment Project, Served as faculty ethicist at National Conference, Mitchell Sugerman, directing, 1995.
- Pew Health Professions Commission, Project on Curriculum Development for the Managed Care Provider. Served as Ethicist on the California Curriculum Development Team, Drs. Keith Marton and Lucia Sommers, directing, 1995.
- NIH Ethical Social and Legal Implications of the Human Genome Project, National Advisory Committee, Project on Theological and Ethical Questions of Justice, Ted Peters, directing, 1995.

Hastings Center, National Report on Bioethics Education, 1991.

#### INVITED PRESENTATIONS IN THE MEDIA

"Science and Religion," NPR Science Friday, January 21, 2005.
"Embryonic Stem Cell Research in Illinois," Chicago Public Radio's Eight Forty-Eight, November 24, 2004.
"Stem Cell Research," NPR Science Friday, October 15, 2004.
"Genetics," Chicago Public Radio, September, 2004
"Speaking of Faith," NPR, Spring, 2003
"Space Research and Exploration," January, 2004, Chicago Public Television

"Space Tragedy and Exploration," February, 2003, Chicago Public Television

#### EXPERT WITNESS

William Thomas O'Conner v. Division of Medical Quality Medical Board of California Department of Consumer Affairs State of California, (for the defense) 2000. Monica Rochlin v. Health Net (Informed consent, marketing practices, for the plaintiff;

Michael Bidard, Esq.) 199	7.
	Linda Schneider (Treatment withdrawal, informed consent, for the defense; Randy
Andrada,	
	Esq.) 1997.
	Robert Wendland (Treatment withdrawal, surrogate decision making, for the
defense;,	
	W. Stephen Scott, Esq.) 1996-1997.
	Norcal Insurance Company (Medical Malpractice, Jehovah's Witness, truth telling,
informed	
	consent, for the defense; Norcal Research Staff), 1995.

# PUBLICATIONS\_

#### BOOKS AUTHORED:

Health Care and the Ethics of Encounter: A Jewish Discussion of Social Justice, University of North Carolina Press (1999).

Second Text: Essays toward a Feminist Jewish Bioethics (ms complete ).

#### Not Yet Borne: Response and Responsibilities to the New Genetics (ms complete )

#### BOOKS EDITED:

Human Embryonic Stem Cell Research: Science, Ethics and Policy, edited with Karen Lebacqz and Suzanne Holland, MIT Press (2001).

Margin of Error: The Inevitability and Ethics of Mistakes in Bioethics and Medicine, edited with Susan Rubin, University Press Publishing (2000).

Notes from a Narrow Ridge: Religion and Bioethics, edited with Dena Davis, University Press Publishing (1999).

<u>Riding on Faith: Disneyland and Religion in America</u>, edited with Simon Harek, (ms submitted to Duke University Press, 2004)

Letters of Fire: Jewish Thought and Genetic Research, edited with Elliott Dorff, (ms submitted to Jewish Publication Society and MIT Press for joint consideration, 2005)

#### BOOK CHAPTERS:

"Being in the World: Neuroethics and Moral Agency", in Neuroethics, edited by Judith

Illes,

Oxford University Press, forthcoming, 2005.

"Immortal Cells, Moral Selves," <u>Essentials of Stem Cell Biology</u>, edited by Robert Lanza, et al, Academic Press, forthcoming 2005

"Care of the Dying in America," <u>Prozac and Enhancement</u>, edited by Carl Elliott and Tod Chambers, University of North Carolina Press, 2004.

	"Immortal Cells, Moral Selves," <u>Handbook of Stem Cells, Volume 1</u> , edited by Robert Lanza, et al, Academic Press, 2004, pp 747-757.
	"Into the Woods: Women and the Problem of Evil," <u>Women and Gender in Jewish</u> <u>Philosophy</u> edited by Hava Tirosh-Samuelson, Indiana University Press, 2004.
	"Uncountable as the Stars: A Jewish View of Inheritable Genetics Interventions," <u>Designing Our Descendants: The Promises and Perils of Genetic Modification</u> , edited by Marc Frankel, and Audtey Chapman, Johns Hopkins Press, 2003.
	"Taking His Hand, He Raised Him From The Bed: Judaism, Healing and the Pursuit of Justice," The Ethics of Health, edited by Barry D. Cytron, Liturgical Press, 2003.
	"Freedoms, Duties, and Limits: The Ethics of Stem Cell Research," <u>God and the Embryo: Religious Voices on Stem Cells and Cloning</u> , edited by Brent Waters and Ronald Cole-Turner, Georgetown University Press, 2003, pp. 141-151.
Narrative	"Reflections in the Darkest Mirror: Burial Ritual in the Jewish Community, and the
	Of Care," Care and Narrative in Bioethics, edited by Paul Laritzen and Diana Fritz
Cates,	Georgetown University Press, 2002.
	"Like an Open Book: Reliability, Intersubjectivity and Textuality In Bioethics," with Rita Charon, <u>Stories Matter: The Role of Narrative in Medical Ethics</u> , edited by Rita Charon and Martha Montello, Routledge Press, 2002.
	"Each One a World: Family Planning, a Jewish View," <u>Ten World Religions: Family</u> <u>Planning</u> , edited by Daniel McQuire, Oxford, 2002.
	"Seeing the Doubting Judge: Post-Modernity and the Ethical Task," <u>Textual</u> <u>Reasonings</u> , edited by Peter Ochs and Stanley Hauerwas, Fortress Press, 2002.
	"A Walk in the Park" and "When You Wish Upon a Star, Makes No Difference Who You Are: Disneyland and the Illness Pilgrimage" <u>Riding on Faith: Disneyland,</u> <u>Religion, and Popular Culture</u> , edited by Laurie Zoloth and Simon Harek, Duke (submitted, 2002).
	"The Ethics of the Eighth Day: Jewish Bioethics and Research on Human Embryonic Stem Cells" and "Jordan's Banks: A View from the First Years of Human Embryonic Stem Cell Research," <u>The Human Embryonic Stem Cell Debate</u> , MIT Press, 2001.
	"Locations in Jazz and Gender," <u>Jewish Locations</u> , edited by Lisa Tessman and Bat- Ami Bar On, Rowman and Littlefield, 2001.
	"Responding to Limiting Access to Medical Treatment in an Age of Medical Progress:
	Developing a Catholic Consensus from a Jewish Perspective," <u>Limiting Access</u> to Medical Treatment in an Age of Medical Progress: Developing a Catholic <u>Consensus</u> , Tris Engleheardt, editor, Kluwer Press, 2001.
	Born Again: Cloning, Death and Rebirth," <u>Cloning and the Future of Human Embryo</u> <u>Research</u> , edited by Paul Lauritzen, Oxford University Press, 2001.

"Job Openings for Philosophers in Oregon: Philosophers and Physician Assisted Suicide," <u>The Series in Medicine and Philosophy: Physician Assisted Suicide</u>, edited by Loretta Koppelman, Kleuer Press, 2001.

"Out of the Depths I Call to You: Sin, Redemption and the Conversation," <u>Christianity in Jewish Terms</u>, edited by David Sandmel, Westview Press/Perseus, 2000.

"Nursing as the Existential Messenger: Ethics and Pain at the End of Life," with Karen Stanley, <u>Textbook of Palliative Nursing Care</u>, edited by Betty Ferrell and Nessa Coyle, Oxford Press, 2000.

"Faith and Reasoning(s): Bioethics, Religion and the Post-Modern Discourse" and "Articles of Faith," <u>Notes From a Narrow Ridge: Religion and Bioethics</u>, edited with Dena Davis, University Press Publishing, 1999.

"Dead Wrong" and "In the Margins of the Margins," <u>Margin of Error: The</u> <u>Inevitability and Ethics of Mistakes in Bioethics and Medicine</u>, edited by Laurie Zoloth and Susan Rubin, University Press Publishing, 1999.

"Now You are One of Us: Gender, Reversibility and The Good Read," <u>Walker Percy</u> and the Last Physician, edited by Carl Elliott and John Lantos, Duke University Press, 1999.

"Promises of Exiles," <u>Religious Conversations on Population, Consumption and</u> <u>Ecology</u>, edited by Harold Coward, State University of New York Press, 1999.

"Managing Care for Seriously and Chronically Ill Children" and "Choice of Venue and Provider Under Capitation," with Susan Rubin, <u>Ethical Challenges in Managed Care: A</u> <u>Casebook</u>, Georgetown University Press, 1999.

"A Jewish Perspective: Stewards of the Earth," The Family Handbook, The Family, Religion, and Culture Series, edited by Don S. Browning, et al, Westminster John Knox Press, 1998.

"The Befallen Community: The Ethical and Spiritual Dimensions of Pain," <u>Evaluation</u> <u>and Treatment of Pain</u>, 3rd Edition, edited by Gerald M. Aronoff, Williams and Wilkins, 1998.

"Just Managing: Ethical Obligations and Managed Care," <u>Current Issues in Nursing</u>, edited by Joanne McCloskey and Helen Grace, Mosby, 5<sup>th</sup> ed., 1997 and 6<sup>th</sup> ed., 2000.

"Mapping the Normal Human Self: The Jew and the Mark of Otherness," <u>Genetics</u>, edited by Ted Peters, Pilgrim Press, 1997.

"The Ethics of Encounter: Public Choices and Private Acts," <u>Contemporary Jewish</u> <u>Ethics and Morality</u>, edited by Louis Newman and Elliott Dorff, Oxford University

#### 1995.

Press,

"Community and Conscience," <u>Health Care Crisis? The Search for Answers</u>, edited by Robert Misbin, University Publishing Group (a Hastings Center Project), 1995.

"Methodology," Making Moral Community, Bioethics Consultation Group, 1992.

"Jewish Ethics," with Samuel Wineburg, <u>A Bibliographic Guide to the Comparative</u> <u>Study of Ethics</u>, edited by Mark Jurgensmeyer, Cambridge University Press, 1991.

#### ENCYCLOPEDIA ARTICLES:

"Genetics and Meaning," <u>Encyclopedia of Religion</u>, Macmillan Publishing Co., December 2004.

"Genetics and Human Self-Understanding," <u>The Encyclopedia of Bioethics</u>, Macmillan Publishing Co., 2004.

"Abortion – Religious Traditions: Jewish Perspectives," <u>The Encyclopedia of Bioethics</u>, Macmillan Publishing Co., 2004.

"Judaism, Contemporary Issues in Science and Religion," <u>Encyclopedia of Science and Religion</u>, <u>Macmillan Publishing</u>, 2003.

"Bioethics" and "Abortion," <u>The Encyclopedia of Contemporary American Religions</u>, Macmillan Publishing, 1999.

"Ethics: An Overview," <u>Encyclopedia of Women and World Religions</u>, Serenity Young, Editor-in-Chief, Macmillian Publishing, 1998.

#### JOURNAL ARTICLES:

D (22 1	"Clinical Ethics and the Road Less Taken: Mapping the Future by Tracking the
Present," with	Susan Rubin, Journal of Law, Medicine, and Ethics 32 (Summer 2004): 218-225.
	"Taking the Stem Cell Debate to the Public," with Leonard Zon and Suzanne
Kadereit in PloS	Biology, June 2004, Vol. 2, Issue 6, p. 0730, <u>http://biology.plosjournals.org</u> .
	"Yearning for the Long Lost Home: Jewish Genetics Communities Found in Africa," <u>Developing World Bioethics</u> , Volume 3, Number 2, 2003.
	"Double Talk and Double Vision: Creating a Science Research Policy on Human Cloning," <u>Health Affairs</u> , Volume 22, Number 1, January/February 2003.
	"Reasonable Magic: Ethics and Limits in Human Embryonic Stem Cell Research, The Franck Memorial Lecture, 2001," <u>Kennedy Institute Journal of Bioethics</u> , March 2002.
	"Conflicts of Interest in Consultation: a Task Force Report," with Baruch Brody,
Nancy Dubler,	Jeffrery Berger, Jeffrey Kahn, Jeremy Sugarman, Arthur Caplan, Bernand Lo, and
Nancy Kass,	Hastings Center Report, February 2002.
	"Just Bioethics in an Unjust World," <u>The Hastings Center Report</u> , January 2002.
	"Keeping Company: Bioethics and the Talk in The Commons," <u>Cambridge Quarterly</u> of Healthcare Ethics, Winter, 2002.
	"Stem Cell Research: a Target Article, Part I. Jordan's Banks," <u>A Journal of Bioethics</u> , Winter, 2002.
	"Justice as Cardiovascular Therapy," <u>A Journal of Bioethics</u> , Fall, 2001.

"Giving Credit Where Credit is Due," The Howard Hughes Bulletin, September 2001.

"Seeing the Duties to All: Conflicts of Interest in Bioethics Consultation,	" <u>The</u>
Hastings Center Report, March 2001.	

"Nursing Fathers and Nursing Mothers: Toward a Distinctively Jewish View of Reproductive Ethics," <u>Annual of the Society of Christian Ethics</u>, 21, 2001.

"Making the Things of the World: Narrative and the Project of Bioethics," <u>A Journal of Bioethics</u>, Spring, 2001.

"Her Work Sings Her Praise: A Feminist Jewish Business Ethics," <u>The Journal of</u> <u>Business Ethics, Special Edition: Religion and Business Ethics</u>, editor, Stewart Herman, Fall 2000.

"Religion and Bioethics," The Laney-Hitchcock Journal, Fall, 1999.

"The Best Laid Plans: The History and the Promise of Managed Care Medicine," <u>The</u> <u>Journal of Medicine and Philosophy</u>, Fall, 1999.

"The Nature of the Self in Judaism," Dialog: A Journal of Theology, Summer, 1999.

"Passing Through: The International Sweethearts of Rhythm," <u>The Magazine: The</u> Journal of the College of Humanities, San Francisco State University, Spring, 1999.

"The Ethics of Experimentation with Human Embryonic Stem Cells," with Karen LeBacqz, Ted Peters, and Michael Mendiola, a Report of the Steering Committee of the Geron Ethics Advisory Board, <u>Hastings Center Report</u>, Spring, 1999.

"Reading Like a Girl: Is There a Jewish Bioethics for Women?" Judaism, Spring, 1999.

"VaErah," Torah Aura, December 1998.

1998.

Rubin,

"The Concern for the Poor in Judaism," Vedanta Kesari, Bombay, India, December

"Dying the Good Death: Ethical Considerations at the End of Life: The Physician and the Inevitably Dying Patient," <u>Annals of Long Term Care</u>, November 1998.

"Our Bodies, Our Cells: Feminist Ethics and the New Reproductive Technology," <u>Feminist Collections</u>, University of Wisconsin, Summer, 1998.

"Insider Trading: Conscience and Critique in Bioethics," with Susan Rubin, <u>Healthcare</u> <u>Ethics Committee Journal</u> (HEC), Spring, 1998.

"Navigators and Captains: Expertise in Clinical Ethics Consultation," with Susan

Theoretical Medicine, Spring, 1998.

"Futility is in the Eye of the Beholder: Ethical Decisions in the Face of Despair," <u>Healthcare Forum</u>, December 1997.

"Imagining Perfection: Making Limits on the Reproduction of the Self," <u>Medical Humanities Review</u>, Summer, 1997.

	"Why We Can't Just Say No," with Susan Rubin, <u>Futility: Module 7</u> , The Decisions at The End of Life Project, Educational Consultants, Boston, 1997 and the Hastings Center, New York, 1997.
	"Audience and Authority: The Story in Front of the Story," <u>The Journal of Clinical</u> <u>Ethics</u> , Spring, 1997.
	"Facing Each Other: Teaching About Black-Jewish Relations and the Media," <u>Diversity Digest</u> , Association of American Colleges and Universities, Spring, 1997.
	"Medical Futility and Ethics in Managed Care," with Susan Rubin, <u>Healthcare Forum</u> , March/April 1997.
Dubie	"She Said/He Said: Ethics Consultation and the Gendered Discourse," with Susan
Rubin,	The Journal of Clinical Ethics, Winter, 1997.
	"The Silence in the Public Square: Universal Coverage and Social Responsibility," <u>Ethical Alternatives and Managed Care</u> , National Council of Churches, New York, December 1996.
	"What it Takes to Make a Just Society," <u>Tikkun</u> , September 1996.
	"Healthcare Consolidation Raises Ethical Questions," with Susan Rubin, <u>Modern</u> <u>Healthcare</u> , August 1996.
	"Moralities of Scale: Mergers and Medical Ethics," with Susan Rubin, <u>Modern</u> <u>Healthcare</u> , August 1996.
	"The Patient as Commodity: Managed Care and the Question of Ethics," with Susan Rubin, <u>Gilfix Elderlaw NewsAlert</u> , adapted from <u>The Journal of Clinical Ethics</u> article with a focus on Elderlaw, February 1996.
Rubin,	"The Patient as Commodity: Managed Care and the Question of Ethics," with Susan <u>The Journal of Clinical Ethics</u> , Winter, 1996.
<u>of</u>	"Face To Face, Not Eye to Eye: Further Discussions in Jewish Bioethics," <u>The Journal</u> <u>Clinical Ethics</u> , Fall, 1995.
	"Travels with Children: Ethics of Ordinary Life," <u>Tikkun</u> , June 1995.
	"Reading and <u>Reading Ruth</u> ," <u>Tikkun</u> , April 1995.
	"HIV and Pregnancy: A Call for Informed Refusal for all Pregnant Women," <u>1995</u> <u>Yearbook of Neonatal and Perinatal Medicine</u> , Klaus and Fanaroff, editors, Mosby Press, 1995.
	"Don't Ask, Don't Tell: Retrospective Analysis of Population Based Genetic Screening Programs," <u>1995 Yearbook of Neonatal and Perinatal Medicine</u> , Klaus and Fanaroff, editors, Mosby Press, 1995.
Prophetic	"One of These Mornings I'm Going to Rise Up Singing: The Necessity of the Voice in Jewish Bioethics," <u>The Journal of Clinical Ethics</u> , 1995.
	"Postmodernism and the Feminist Construct," <u>Sh'ma</u> , February 1995.
	"Standing At the Gate: Managed Care and Daily Ethical Choices," Managed Care

	Medicine, Haavi Morreim, Guest Editor, November-December 1994.
Rubin,	"First Person Plural: Community and Method in Ethics Consultation," with Susan
Kubiii,	The Journal of Clinical Ethics, Spring, 1994.
	"Survival of the Fittest: Health Care Meets Competition," <u>The Bulletin of the Center</u> for Ethics and Social Policy, Winter 1993.
	"Abortion: a Response," <u>Tikkun</u> , September 1993.
	"Notes on the Aladdin Problem: Genetic Counseling and Pre-natal Diagnosis," a review article in <u>1993 Yearbook of Neonatal and Perinatal Medicine</u> , Klaus and Fanaroff, editors, Mosby Press, 1993.
	"First Make Meaning: The Ethics of Encounter in Health Care Reform," <u>Tikkun,</u> July 1993.
	"Dilemmas in Pediatric AIDS" and "Decisionmaking in the NICU," two review articles
	in <u>1992 Yearbook of Neonatal and Perinatal Medicine</u> , Klaus and Fanaroff, editors, Mosby Press, 1992.
	"The AIDS Patient and the Last ICU Bed: Scarcity, Medical Futility, and Ethics," <u>Quality Review Bulletin</u> , Joint Commission of Hospital Accreditation of Health Care Organizations, June 1991.
	"Ethics: A Response," <u>1989 Yearbook of Neonatal and Perinatal Medicine</u> , Klaus and Fanaroff, editors, Mosby Press, 1989.

### PEER JURIED ACADEMIC PAPERS

	"Living Under the Fallen Sky: Biotechnology, Eschatology and Forbidden
Knowledge,"	American Academy of Religion, San Antonio, TX, November 2004.
	Respondent to Scriptural Reasoning Panel on "Poverty and Debt Release: Scriptural
and Social	Scientific Reasoning," San Antonio, TX, November 2004.
Droppe "	"The Care of Dying in America: The Ethics and Theology of Hair Dye, Botox, and
Prozac,"	American Academy of Religion, San Antonio, TX, November 2004.
Ortobar	"Just Beyond Our Reach: a Plenary Response to the Work of the President's Bioethics Commission," American Society for Bioethics and Humanities, Philadelphia, PA,
October	2004.
Martina	"Breaking News in Bioethics," American Society for Bioethics and Humanities, Spring
Meeting,	Plenary Panel. Houston, TX, March 12, 2004.
to Find	"The Cousins Club: The Yearning for the Lost Tribes and the Use of Human Genetics

	Them" American Academy of Religion, Atlanta, GA, November 2003.
Annual Meeting	"Jewish Studies and Israel," Society for Jewish Ethics/Society for Christian Ethics
	January 2003.
Toronto Conada	Stem Cells and Public Policy," American Academy of Religion Annual Meeting,
Toronto, Canada,	November 2002.
Policion Annual	"Gender and Genocide: Subjects, Objects, and Agency," American Academy of
Religion Annual	Meeting, Toronto, Canada, November 2002.
	"Pragmatism: Broken Text, Broken World," Academy for Jewish Studies Annual Meeting, Los Angeles, December 2002.
	"The Ethics of Space Travel," American Society for Bioethics and Humanities, Baltimore, 2002.
	"A New Religious American in a New America," American Academy of Religion Annual Meeting, Denver, 2001.
	"We Have Found the Book of Life: Ethics and Promise in Science Education Films 1956-2001, American Academy of Religion Annual Meeting, Denver, 2001.
	"Each One an Entire World: Jewish Views on Family Planning," American Academy of Religion Annual Meeting, Denver, 2001.
	"Talk in the Commons: Can We Have Consensus in Bioethics?" American Society for Bioethics and Humanities Annual Meeting, Nashville, 2001.
Christian Ethics	"Close Textual Reading of the Talmudic Text, Sanhedrin 75a," The Society of
Christian Ethics	Annual Meeting, Chicago, IL 2001.
Annual Meeting,	"A Distinctive Jewish Ethics of Reproduction," The Society of Christian Ethics
Annual Weeting,	Chicago, IL, 2001.
	"Social Ethics and Popular Culture: The Case of Dr. Laura," Bioethics Summer Conference, Asilomar, 2000.
	"Just Bioethics in an Unjust World," the Presidential Address, American Society for Bioethics and Humanities Annual Meeting, Salt Lake City, 2000.
	"Conflicts of Interest in Bioethics Consultation," American Society for Bioethics and Humanities Annual Meeting, Salt Lake City, 2000.
	"Ethics, Religion and Popular Culture: the Case of Disneyland," SFSU Asilomar Faculty Conference, 2000.
	"The History of Managed Care," American Society for Bioethics and Humanities Annual Meeting, Salt Lake City, 2000.
	"Exit, Voice and Loyalty: the Meaning of Covenant in Jewish Thought," American Academy of Religion Annual Meeting, Nashville, 2000.

	Gendered Reading/Gendered Text: Feminism and Jewish Bioethics," American Association of Jewish Studies Annual Meeting, Chicago, 1999.
	"The Ethics of the Eighth Day: a Jewish Perspective on Stem Cells," American Academy of Religion Annual Meeting, Boston, 1999.
	"Reasoning, Text and Case: Germ-line Intervention and Jewish Textual Recourse," American Academy of Religion Annual Meeting, Boston, 1999.
	"The Theory and Practice of Clinical Ethics," and "Buyers Remorse: When an Untrustworthy Agent Speaks for a Transformed Self," both with Susan Rubin, American Association for Bioethics and Humanities Annual Meeting, Philadelphia, 1999.
-	"Fidelity and Responsibility: The Sundowner Report – The United State
Interagency	Ethical Principles in Animal Research," with Joseph Bieletski, American
Association	for Bioethics and Humanities Annual Meeting, Philadelphia, 1999.
	"Root and Branch: Emerging Ethical Issues in Stem Cell Research," American Association for Bioethics and Humanities Annual Meeting, Philadelphia, 1999.
	"Judaism and Healing," at Annual Conference, Jay Phillips Center for Jewish-
Christian	Learning, Minnesota, October 1999.
	"A Jewish Perspective on Cancer Genetics," National Conference on Cancer Genetics, Memphis, St. Jude Children's Hospital and Research Center, May 1999.
A	"Perfect Strangers: Cloning and Jewish Bioethics," McElmury Lectureship,
Andrews	University, Michigan, April 9, 1999.
	"Spiritual Dimensions of Pain" and "Ethics and the New Medical Dilemma," as Scholar-in-Residence, University of North Carolina, February 8-11, 1999.
1999.	"Jews and Blacks and Jazz," SFSU Annual University Retreat, Asilomar, January
	"When You Wish Upon a Star, It Makes No Difference Who You Are: Disneyland and the Illness Pilgrimage," American Academy of Religion Annual Meeting,
Orlando,	November 1998.
12 1' 1 22	"Doubled in the Darkest Mirror: The Ritual and the Practices of the Chevra
Kadisha,"	American Academy of Religion Annual Meeting, Orlando, November 1998.
Maating	"Expanding the Borders of Bioethics Concern – Is the Issue of War an Issue for Bioethicists?" American Society for Bioethics and Humanities First Annual
Meeting,	Houston, November 1998.
	"Articles of Faith," American Society for Bioethics and Humanities First Annual Meeting, Houston, November 1998.

	"Notes From a Narrow Ridge, Religion and Bioethics," American Academy of Religion Annual Meeting, Orlando, November 1998.
and	"It's Not What You Know, It's Who you Know: Shifting from Epistemological Concerns to Ontological Ones in our Consideration about Genetic Interventions
and	the Practice of Clinical Medicine," Stanford Conference on Genetics and Ethics, October 1998.
at	"Duty Bound: Moral Translations and the Process of Bioethics Consultation," and "Here is the Perfect Baby Girl: Ethics and New Technology," both plenary papers
at	the First International Conference of Jewish Bioethics, Philadelphia, May 1998.
	"Jewish Views on Justice in Managed Care," Plenary Speaker at the Duquesne University Annual Bioethics Conference, May 1998.
	"The Necessity of the Stranger," keynote speech, and "Women and the Jewish Experience: Dreams, Politics, and Jewish Culture," Conference on the 50 <sup>th</sup> Anniversary of the State of Israel, West Coast Regional Hadassah, Hillel and San Francisco State University, April 1998.
Francisco	"Risking All: The Obligation to the Stranger: What is the Meaning of Service to the Community?" Truth or Dare Conference on Women and Jewish Life, San
Francisco	State University, April 1998.
	Philosophers and Physician Assisted Suicide," Plenary Speaker at the 25 <sup>th</sup> Anniversary of the University of North Carolina Bioethics Program and Spring Meeting of the Society for Health and Human Values, 1998.
	"Faith and Reasoning," American Association of Bioethics, Philadelphia, PA 1995.
V. h	"The Eye of the Beholder: The Outcomes Movement, Health Care Limits, and the Management of Belief," with Susan Rubin, The Society for Health and Human
Values	Annual Meeting, October 1995.
	"Funding for Ethics Education and Research," with Susan Rubin, The Society for Health and Human Values Annual Meeting, October 1995.
	"Thirty Years of Schooling and They Put You on the Day Shift: The Bioethicist and the
Marketplace," wi	ith Susan Rubin, The Society for Bioethics Consultation Annual
Meeting, October	· 1995.

"Girl Talk: Bioethics Consultation and the Gendered Discourse," with Susan Rubin, The Society for Bioethics Consultation Annual Meeting, October 1995.

"On Mapping the Normal Human Self: Jews, Genes, and the Mark of Difference," The American Jewish Studies Association Annual Meeting, December 1994. "On Seeing a Case: Religious Ethics and the Question of Futility," Faculty Panel and Workshops, The Society for Bioethics Consultation, Fall, 1994.

"Community and Conscience: A Jewish View of Health Care Reform," The Society

for Health and Human Values Annual Conference, Fall, 1994.

"Truth and the Embodied Listener," with Susan Rubin, The Society for Bioethics Consultation Annual Meeting, Fall, 1994.

"The Ethics of the Common Good: Health Care Reform, Public Policy, and the Religious Imperative," American Academy of Religion, Fall, 1994.

"The Ethics of the Ordinary World: Mothering, Daughtering, Religious Scholarship, and Spiritual Journey," American Academy of Religion, Fall, 1994.

"Just Choices: the Genome Project and the Embodied Gaze," The International Bioethics Institute Annual Conference: "Genes and Justice," April 1994.

"AIDS and the Common Good: Plague in the Jewish Tradition," with Mary Pinkerson, American Academy of Religion Annual Meeting, November 1993.

"Mapping the Normal Human Self: Reflections on Otherness, Eugenics, Jews, and the Genome Project," American Academy of Religion Annual Meeting, November 1993.

"Family Matters: Hearing Every Voice in the Consultation Process," with Susan Rubin, Society for Bioethics Consultation Annual Meeting, September 1993.

"Politics and Prophecy: Ethics and Partisanship," with Joel Frader, The Society for Bioethics Consultation Annual Meeting, September 1993.

"Is Consent Possible?" Faculty at the LDS/University of Utah Division of Bioethics Fourth Annual InterMountain Health Care Conference: "The Physician Provider Relationship," June 1993.

"Claiming Our Bodies: the Epistemology of Lived Experience," Keynote Speech, The

Jewish Women's Body: a Conference on Women and Health, San Francisco, May

1993.

"Jewish Tradition and Medical Ethics: Setting Limits," American Academy of Religion National Conference, Health and Religion Section, November 1992.

"Making Moral Community, Finding Moral Location: Using the Community as Text in the Story," Faculty, The Society for Bioethics Consultation, 6th Annual Meeting: "The Future of Bioethics Consultation." Also co-chaired and facilitated the Society's first meeting of women who are ethics consultants, both with Susan Rubin, September 1992.

"Ethical Issues in the Oregon Health Care Process," Fourth International Conference of Medical Ethics, Jerusalem, Israel, October 1991.

"Futility and Community," Faculty, LDS Hospital/University of Utah Bioethics Division, InterMountain Third Annual Conference on Ethics, March 1991.

"Nursing Ethics and The Covert Dynamic: Race, Gender, and Class," Faculty, The Society for Bioethics Consultation, Fourth Annual Meeting, September 1990.

# SELECTED INVITED SPEECHES, LECTURES, AND PRESENTATIONS\_\_\_\_\_

	2005
	"Faith, Science and the Future," University of Southern California, February 1,
2005.	
	"Health Care, the Budget and Morality: A Discussion of National Priorities," The Center for American Progress, Washington, DC, January 25, 2005.
	"Politics, Faith and the Public Imagination in Science," University of California,
	San Francisco,
	CA, January 10, 2005.
	2004
	"Living Under the Fallen Sky: Biotechnology, Eschatology, and Forbidden
Knowledge,"	
	American Academy of Religion, San Antonio, TX, November 22, 2004. "The Public, Faith, and the Press: Why did Stem Cells Make It to the Convention
Floor?"	
	Center for Medical Humanities & Ethics, University of Texas Health
Science Center,	
	San Antonio, TX, November 11, 2004.
	"Living Under the Fallen Sky: Bioethics and Stem Cell Research," The Inaugural
Annual	
	Myron Zinn Memorial Maimonides Lecture, San Antonio, TX, November
10, 2004.	
	"Whither Science after the Presidential Election?" American Heart Association's
Council on	
	Arteriosclerosis, Thrombosis, and Vascular Biology Women's Leadership
Committee	
	Luncheon, New Orleans, LA, November 8, 2004.
	"The Theory and Practice of Classical Ethics: Charting the Course for Effective
	Ethics," Workshop at the American Society for Bioethics and Humanities
	Conference, Philadelphia, PA, October 28-31, 2004.
	"Playing God or Playing Politics? How Stem Cells Came to the Convention Floor,"
	Northwestern University, October 22, 2004.
	"Is the Future Fair? Basic Research and the Question of Social Justice" at Duke

	University Medical School, Raleigh, NC, October 20, 2004. "Living Under the Fallen Sky: Bioethics and Stem Cell Research," Boyarsky Lecture
at	
	Duke University, Raleigh, NC, October 19, 2004. Scholar in Residence, Philadelphia Children's Hospital, Philadelphia, PA, October
14,	
	2003.
	"On Ethics and Morals" at the Willie Brown Institute Stem Cell Symposium, San
	Francisco, CA, October 12, 2004. "Ethics "Sume asium on Storm Calls Science, Ethics and Politics at the
	"Ethics," Symposium on Stem Cells: Science, Ethics and Politics at the Crossroads, Sponsored by The Science Network, Salk Institute, La Jolla,
CA,	Crossroads, Sponsored by The Science Network, Saik Histitute, La Joha,
,	October 2, 2004.
	"Religion, Science, and Public Policy: How Should We Frame Public Policy Issues such as Abortion, Stem Cell Research, Creation Theory and Same Sex Marriage?" at Religion, Politics and Public Policy Colloquium, Annenberg School of Communication, Los Angeles, September 20-23, 2004.
Faith"	"The Ethics of Research with Human Stem Cells: Issues of Policy, Science, and
	at Seoul Symposium on Stem Cell Research, Seoul, Korea, September 1-2,
2004.	at beout by inpostant on been research, beout, ribrea, beptember 12,
	"Freedoms, Duties, and Limits: The Ethics of Research in Human Stem Cells" at
the	
I. M	International Conference on Stem Cells, Universidad Nacional Autonome
de Mexico,	Mexico City, Mexico, August 15, 2004.
	"Ethical Considerations in the Organization of Research in Pluripotent Cells," Stem
Cell	
	Conference and Training for Investigators, Cold Spring Harbor, NY, August
	2004.
C	"Is the Future Fair? Basic Research and the Question of Social Justice," University
of	California, San Diego Medical School lecture, San Diego, CA, July 15,
2004.	Camorina, San Diego Medical School Reture, San Diego, CA, July 15,
	"Is it Possible to Say When Human Life Begins – Can Ethical, Legal, and Biological Conceptions of the Human Embryo Converge?" Symposium in
	Embryonic Stem Cell Research, San Diego, CA, July 14, 2004.
	"The Ultimate Reality Show: Jewish Bioethics For a Changing World," Annual
Hadassah	
	National Convention, Phoenix, AZ, July 12-13,2004.
	"May We Make the World: Ethics of Stem Cell Research," Plenary Speaker,
International	
	Society for Stem Cell Research, Boston, MA, June 10-13, 2004. Commencement Address to Biology Department Graduates, University of
California,	Commencement Address to Blology Department Oradiates, University of
Guirrorring	Berkeley, Berkeley, CA, May 21, 2004.
	"Firebell in the Night," Seminar on Campus Anti-Semitism, sponsored by
University of	
	Illinois, Chicago and the Chicago Jewish Federation, May 17, 2004.
2004	"Bioethics and Religious Traditions: Judaism." University of Chicago, May 12,
2004.	"Tales from the Front" in "The (II)legitimacy of Israel: Ancient to Modern,"
Crown	rates from the Front in Frite (in)regulinacy of Israel. And that to would lift,
	Family Center for Jewish Studies, Northwestern University, May 10, 2004.
	"The Ethics of Basic Research: the Public, the Press and Faith Communities,"
Hebrew	

2004	University, Jerusalem, May 4, 2004. "Biotechnology and Ethics," Lake Forest College, Lake Forest, Illinois, April 21,
2004.	"Stem Cell and Public Voice," Chicago American Medical Association, April 20,
2004.	"What is Quality of Life?" Plenary Speaker at Academic Coalition for Jewish
Bioethics,	February 2004.
Medicine,	"Abortion and Ethics" for Genetics Counseling Program, Feinberg School of
Line	February 26, 2004. Bioethicist's Response to "Evidence of a Pluripotent Human Embryonic Stem Cell
Advancement	Derived from a Cloned Blastocyte," American Association for the
	of Science National Annual Meeting. Seattle, Washington, February 12,
2004.	Textual Study, Society for Jewish Ethics, Chicago, IL, January 2004.
	<i>2003</i> "Nanoscience and Nanotechnology: The Next Big Idea is Really Small,"
respondent at	public lecture series of the Program of Dialogue on Science, Ethics, and
Religion	
2003.	of the American Association for the Advancement of Science, December
Prozac,"	"The Care of Dying in America: The Ethics and Theology of Hair Dye, Botox, and
Genetics to Find	American Academy of Religion, Atlanta, GA, November 2003. "The Cousins Club: The Yearning for the Lost Tribes and the Use of Human
Genetics to Find	Them," American Academy of Religion, Atlanta, GA, November 2003. "Duties and Freedoms in Stem Cell Research," Duquesne University Stem Cell
	Conference, Pittsburgh, PA, November 7-8, 2003. Scholar-in-Residence, Providence Hospital System, Portland, Oregon, November
3-5,	2003.
	"We Have Found the Book of Life: Genetics and Popular Science Films, 1950-1999, American Society for Bioethics and Humanities Conference, Montreal,
Canada, October	2003.
	Clinical Ethics Workshop, American Society for Bioethics and Humanities Conference, Montreal, Canada, October 2003. "Seeing the Blackbird: The Ethics of Neuroscience," Jane Coffin Childs Memorial
Fund	Symposium, Lakeville, CN, October 10-12, 2003. "Ethical Considerations in the Organization of Research in Pluripotent Cells," Cold
	Spring Harbor, NY, October 2003. Scholar-in-Residence, Philadelphia Children's Hospital, Philadelphia, Pennsylvania, September 17-18, 2003.
Montana,	"Religion and The New Reproductive Medicine," Planned Parenthood, Bozeman,
<b>-</b>	July 2003. "Conflicts of Interest in Medicine," Annual NIH Ethics Course, July 2003.

"Bioethics, Religion and Stem Cells," 6th Annual Fred Hutchinson Bioethics

Colloquium,

July 2003.

- "Doubled in the Darkest Mirror: Practice and Retold Narrative of the Jewish Burial Society, June 2003.
- "Ethics of Human Embryonic Stem Cell Research," Keynote Speaker,

International

- Society of Stem Cell Research, Seattle, Washington, June 2003. Scholar-in-Residence, Children's Medical Hospital, Chicago, Illinois, May 16, 2003. "Social, Ethical and Privacy Issues and Genetic Testing," Silverstein Lecture for the
- Center for Genetic Medicine, Northwestern University, May 13-14, 2003. "Justice and Healthcare Reform," Plenary Speaker at Mennonite National Meeting, March 2003.
- "Difficult Freedoms in Genetic Medicine," Invited Distinguished Lecture Series, University of California, Irvine, February 2003.
- "Truth Telling and the Clinical Context," University of California, Irvine, School of Medicine, February 2003.
- "Anti-Semitism and the Academy" International Meeting on Anti-Semitism, American Jewish

Congress, February 2003.

"Perfect Strangers," Bresnahan Colloquium, Feinberg School of Medicine, Northwestern

University, January 2003.

"Firebell in the Night: Anti-Semitism on American Campuses," Society for Jewish Ethics, Pittsburgh, Pennsylvania, January 10-12, 2003

"Text Study," Society for Jewish Ethics, Pittsburgh, Pennsylvania, January 10-12, 2003.

## 2002

"Ethics and Research," DARPA Annual Lecture Series, Washington, DC, December

2002.

National Human Genome Research Institute Retreat, November 2002.

"Justice and Health Care Access," Shearith Israel, San Francisco, California, November 14, 2002.

"Stem Cell Research Ethics," DARPA Project on Human Tissue Engineering, Florida,

October 2002.

"A Fireball in the Night," Simon Wiesenthal Center, Los Angeles, California, October 2002

Scholar in Residence, Annual Genetics Departmental Retreat, University of Washington,

September 2002.

"Israel on Campus," Distinguished Lecturer, Jewish Studies Department, York University, September, 2002.

"Must We Always Tell the Truth?" University of California, Los Angeles, August 2002.

"Stem Cell Policy and Ethics," <u>Frontiers in Ethics</u> Meeting, NIH ELSI Ten Year Planning and Review, Washington, D.C., July 2002.

Chair, Bioethics and Worldview, NIH ELSI Ten Year Planning and Review, Washington,

D.C., July 2002.

"Liberty and Responsibility in Robert Nozick's Anarchy, State, and Utopia," Liberty Fund

Colloquium, Bozeman, Montana, May 30-June 2, 2002.

"Healing in the Jewish Tradition," Plenary Speaker at Duke University, Institute for Care at the End of Life and School of Theology, May 2002.

"An Embarrassment of Riches: Health Care and Pediatric Medicine Series," Distinguished

Lectureship and Scholar-in-Residence, Johns Hopkins School of Public Health, Baltimore, Maryland, April 2002.

"Freedoms, Duties and Responsibilities in Stem Cell Research," Northwestern University, Center for Genetic Medicine Annual Lectureship, April 2002.

"Justice in Health Care," National Conference on Health Care Justice, Georgetown University, Washington DC, April 2002.

"Ethics and Stem Cell Research," National Press Club, Washington DC, March 2002.

"History of Anti-Semitism," Simon Wiesenthal Center, Los Angeles, CA, March 2002.

"Justice and Access," Plenary Speaker at National Coalition on Jewish Bioethics, New York, NY, February 2002.

## 2001:

"Who An I?: Identity and the Human Genome," the Becoming Human Conference, the AAAS and The Field Museum, Chicago, Illinois, November 2001.

"Introduction to Clinical Ethics," Preconference Workshop with Susan Rubin, American Society for Bioethics and Humanities, October 2000.

"The Ethics of Stem Cells," invited speaker with Bridget Hogan, Vanderbilt University, Nashville, TN, October 2001.

"Women and Genetics," University Women's Studies Lecture Series, San Francisco State University, October 2001.

"A Perspective on Stem Cells," Women in Business, San Francisco, CA, October 2001.

"Ethics and Genetics," Scholar-in-Residence, Congregation Rodef Shalom, Marin, CA, October 2001.

"A Jewish View of Reproductive and Therapeutic Cloning," Plenary Respondent, California State Commission on Cloning and the Markkula Center for Ethics, Santa Clara University, October 2001.

"Conflict of Interest in University Research," Keynote, University of California, Chancellor's Office Statewide Academic Research Committees on Conflict of Interest in Research Annual Meeting, October 2001.

CBS Religion and Science Panel on Stem Cells, September 7, 2001.

"Ethics of Clinical Trials," Genentech, April, August, and September 2001.

"Ethics and Stem Cells," Scholar-in-Residence, Congregation Beth Israel, Berkeley, CA August 2001.

"The DNA Files," National Public Radio, July 2001.

"Ethics and Stem Cells," Plenary Speaking, The International Teratology Annual Meeting, Montreal, June 2001.

"Identity after the Genome," Bioethics Lecture Series, Stanford University, June 2001.

"Reasonable Magic: Ethics and Responsibilities in Stem Cell Research," The Franck Lecture, Georgetown University, June 2001.

"The Ethics of Space Exploration," the NASA 40<sup>th</sup> Birthday Commemoration Plenary Lecture, the NASA Division of History, George Washington University, May 2001.

Invited Scholar, College of Health and Human Services, Northeastern University, May 2001.

"Philosophic Questions on the Future of Genetics," Panelist, Division of Ethics and History of Medicine, Harvard University, May 2001. "Leaving and Taking," Phi Beta Kappa Keynote Address, San Francisco State University, May 2001. "Voices of the Rescuers Project," with Deborah Lipstadt, San Francisco, CA, April 2001. "Jewish Heal Care Ethics and Justice," Park Ridge Center, Chicago, IL, April 2001. Keynote Address, Ethics and Nursing Annual Conference, University of California, Los Angeles, March 2001. "Perfect Strangers: The Ethics of Cloning and Jewish Thought," Benjamin Freedman Memorial Lecture, Montreal, March 2001. "Women and Evil," National Conference on Jewish Feminist Philosophy, Arizona State University, Phoenix, AZ, February 2001. Scholar-in-Residence, Congregation Beth Am, Saratoga, CA, February 2001. "Science, Religion, and the Ethics of the New Genetics," Center for Theology and the Natural Sciences and AAAS, San Francisco, CA, February 2001. "Conflicts of Interest in Research," Bresnahan Lecture, Feinberg School of Medicine, Northwestern University, Chicago, IL, February 2001. "The Sermon on the Mount Reconsidered," Earle Lecture Panel, Pacific School of

Religion, Berkeley, CA, January 2001.

## 2000:

"Introduction to Clinical Ethics," Preconference Workshop with Susan Rubin,

American Society for Bioethics and Humanities, Philadelphia, October 2000.

Whitehead Institute and the American Society for Law, Medicine and Ethics, Boston, Massachusetts, May 2000.

University of Virginia, Belief and Bioethics Conference, Charlottesville, Virginia, March 2000.

National Undergraduate Bioethics Conference, Charlottesville, Virginia, April 2000.

Silbert Lectureship Speaker: Cedars-Sinai Medical Center, Los Angeles, California, January 2000.

## *1999:*

"Ethical Issues in Pediatrics," Lucille Packard Children's Hospital, Stanford University Medical Center, November 1999.

"Faithful Justice: Jewish Ethics and The Discourse of Bioethics," Plenary Speech, Conference on Religion and Ethics, Santa Clara University, November 1999.

- "Jewish Perspectives on Genetic Medicine," 1st Annual Conference on Jewish Medical Ethics, Union of American Hebrew Congregations, San Francisco, October 1999.
- "Introduction to Clinical Ethics," Preconference Workshop with Susan Rubin, American Society for Bioethics and Humanities, Houston, October 1999.

"The Ethics of Managed Care," East Bay Rotary Club, Berkeley, October 1999.

"The Ethics of Pain," Ethical Choices Conference, City of Hope National Medical Center, September 1999.

- "Ethical Issues in Animal Research," Tulerik Laboratories, San Francisco, California, September 1999.
- "Diversity, Culture, and Ethnicity, and the Ethics of Nursing Care," Los Angeles Kaiser Joint Nursing-Management Seminar Series, with Susan Rubin, Los Angeles, California, June 1999.
- "The Ethics of Memory," City Wide Jewish Community Study, Berkeley, California, June 1999.
- "The Illness Pilgrimage," 11th Annual Bioethics Summer Institute, Virginia, June 1999.
- "Perfect Strangers: Human Cloning from a Jewish Perspective," The MeElmurry Ethics and Society Lectureship, Andrews University, Michigan, April 1999.
- "Jewish Healing and Ethical Considerations," Keynote, National Association of Jewish Chaplains Annual Meeting, San Francisco, California, February 1999.
- Scholar-in-Residence, Bioethics Consortium, University of North Carolina, Charlotte, North Carolina, February 1999.

(Prior lectures for 1987-1998 available on request)

(detailed account of University teaching and administration available)