June 6, 2005 ICOC Meeting Minutes

Sacramento Convention Center Room 202 1400 J Street Sacramento, CA 95814

David Baltimore	Present
David Baitimore	Flesent
Robert Birgeneau	Present
Surrogate: Robert Price	1 TOSCIII
Keith L. Black	Present
Surrogate: David Meyer	
Susan V. Bryant	Present
Michael A. Friedman	Present
Michael Goldberg	Absent
Brian E. Henderson	Present
Edward W. Holmes	Absent
David A. Kessler	Present
Robert Klein	Present
Sherry Lansing	Absent
Gerald S. Levey	Present
Ted W. Love	Present
Richard A. Dr. Murphy	Absent
Tina S. Nova	Absent
Ed Penhoet	Present
Philip A. Pizzo	Present
Claire Pomeroy	Present
Francisco J. Prieto	Present
John C. Reed	Present
Joan Samuelson	Present
David Serrano Sewell	Present
Jeff Sheehy	Present
Jonathan Shestack	Absent
Oswald Steward	Present
Leon J. Thal	Present
Gayle Wilson	Present
Janet S. Wright	Present

Agenda Item #4 Consideration of and update on SCA 13 (Ortiz/Runner) and other legislation.

Chairman Klein: we moved this item up on the agenda so Senator Ortiz could be here.

When this board voted May 23 to oppose SCA 13, this was based on the then current language. We share the same goals with Senator Ortiz that this bill has. It is the language that keeps us apart and creates major problems in implementation.

The institute on that date committed itself to working with the legislature to advance stem cell research, to ensure transparency, to prevent conflicts of interest, to provide an outstanding peer review system, and to provide a strong and effective intellectual property program to protect the interest of the state of California and its citizens.

The members of this board take this commitment very seriously. Since May 23, Zach Hall, our President, James Harrison, our counsel, and I have met personally with Senator Ortiz, her staff and with staff of Senator Perata. A number of board members have also participated in these discussions, including David Serrano Sewell, Ed Penhoet, Jeff Sheehy, Dr. Claire Pomeroy, Dr. Prieto and others.

It is my intent during this meeting to establish a board legislative task force to proactively examine which policy enhancements can be recommended to our board for adoption.

This is a partnership. We're listening and we want to proactively work with the legislature. We want the legislature to have the message that the legislation really isn't necessary.

Countless people in California and around the world are depending on the Institute to begin work on finding cures for life-threatening diseases through groundbreaking stem cell therapy. We cannot afford to allow this critical work to be hindered and delayed.

It is also vitally important that the board needs to function in a much broader group than the small task force we've been working with day to day.

James Harrison: We've had some very productive meetings with Senator Ortiz and her staff, Senator Perata's staff, as well as the Treasurer and bond counsel to address some of the concerns the board expressed about SCA 13 at the last board meeting.

Senator Ortiz has promised in connection with those meetings to make revised language available to us sometime early this week. Because SCA 13 is a constitutional amendment, of course, each sentence is critical because it can only be amended by another constitutional amendment and a vote of the people.

Let me briefly take you through the document entitled "Proposed Policies for Consideration of Legislative Subcommittee of the ICOC." I'll start by explaining what the current law is, what SCA 13 would do, and then what proposed policy enhancement the subcommittee might consider.

Under current law, Proposition 71 requires board members and CIRM staff to file economic disclosure statements under the Political Reform Act. You've all filed these – they're known as Form 700. In addition, the board has adopted a policy that requires board members to recuse themselves from participating in any decision in which a board member has an interest in an applicant or decision that might benefit the member or institution that employs the member.

SCA 13 would require you to divest yourselves or put in blind trust any income of \$5000 or more from applicant or in an entity that devotes at least 5 percent of its current annual research budget to stem cell therapy.

We've suggested as a proposed policy enhancement to the legislative subcommittee would be to require board members to divest or place in blind trust any investment or real property interest, not income, of \$2,000 or more in any organization that applies for funding from the Institute or in any organization that allocates more than 5 percent of the organizations total annual budget to stem cell therapy.

Conflict of Interest policies for Working Groups: the ICOC has adopted strict conflict of interest policies for each of the three working groups, and for the grant making working groups – the Grants Working Group and the Facilities Working Group – requires non-ICOC members to file, under penalty of perjury, pre- and post-certification disclosure statements guaranteeing a Working Group Member has not participated in a decision in which he or she has a conflict of interest.

SCA 13 would require all Working Group members to file Form 700, a public document disclosing all of their investments, sources of income, and real property interests.

We suggest a proposed policy enhancement requiring non-ICOC members of the Grants Working Group to disclose, confidentially and under penalty of perjury, whether or not they hold specific financial interests that represent a conflict of interest. We suggest similar disclosure provisions for the Facilities Working Group.

Mr. Harrison provided further information on aspects of SCA 13 and the CIRM's recommended policy enhancements, regarding issues including:

- SCA 13's requirement for an annual review by State Auditor of disclosure statements filed by Working Group members to determine whether any had participated in a conflict of interest, defined by SCA 13 as an interest held by the member, a close relative, or a professional colleague amounting to \$5,000 or more in an applicant for funding.
 - The proposed policy enhancement would have the CIRM make the confidential disclosure statements available to an independent auditor to examine whether or not any of the members had participated in a decision in which they had financial interest and then report to the legislature on an annual basis to state whether or not there were any conflicts, and to report on any corrective actions taken.
- SCA 13's requirement that the Grants Working Group hold a public meeting prior to making its recommendations available to the ICOC and also report publicly the reasons why applications were recommended for funding and the reasons why applications were not recommended for funding.
 - The proposed policy enhancement would address the concern expressed by the legislature by requiring the Institute to submit annually to the legislature a report identifying the recipients of research, training and facilities grants, loans and contracts, the disease or injury, if applicable, to which the grant loan or contract relates, and for applications that were not funded, the disease or injury, if applicable, to which the application relates.
- Meeting Procedures: SCA 13 would impose the Bagley-Keene open meeting act on the ICOC – the ICOC is already subject to Bagley-Keene. SCA 13 would also impose Bagley-Keene on the Working Groups.
 - o The ICOC adopted in April and May meetings policies that would open the meetings of the Standards Working Group and the Facilities Working Group to the public. The Grants Working Group, however, would continue to meet in closed session to conduct scientific peer review, evaluation of applications, to rank applications, and to conduct oversight grantees.
 - The proposed policy enhancement suggested would be to require the Grants Working Group to consider criteria and standards in an open public meeting.
- SCA 13 would open the records of the Working Group
- On Intellectual Property. Under current law, Board members are required to adopt a policy that governs intellectual property agreements—and that balances the state's interest in benefiting from the research that [you] fund with the need to find critical medical research and to avoid having intellectual property agreements unduly hinder the advancement of that research.

 SCA 13, as currently drafted, would impose a number of preconditions on the institutions' award of grants, several of which relate to intellectual property and would require the Board to make a determination, in advance, that a particular grant, loan, or award would permit the state to recoup its development costs and would also require that grants, loans, and awards, would be made available, at cost, to participants in Medi-Cal and Healthy Families.

Chairman Klein: Could you comment generally on the concern about having lots of new language in the constitutional amendment and your evaluation of the litigation risk related to that?

James Harrison: Every sentence in a Constitutional Amendment is critical and would need to be evaluated by Bond Council. Ambiguous wording invites litigation. This is a concern and needs to be looked at in terms of looking at the bill as a whole.

Chairman Klein: Proposals that came out of meetings of staff of the Institute are going to a new Legislative Subcommittee. (Bob read names of volunteers)

Michael Goldberg; Dr. Claire Pomeroy, Dr. Francisco Prieto; Dr. Janet Wright; Dr. Tina Nova (confirming her schedule); Dr. Richard Murphy, Dr. Sue Bryant; Dr. John Reed.

This is a very strong and committed task force to give immediate feedback on a cooperative partnership with the legislature to try to enhance [SCA 13] although June 30 may be an impossible time frame.

[If other Board members would like to volunteer for the Legislative task force, they are invited to do so.]

Resolution to form this task force and examine these proposals and come back to the Board on July 12th to move forward in this partnership with the Legislature.

Motion

- Brian Henderson moves
- Dr. Reed seconds

Others invited to join this Legislative Subcommittee on an ad-hoc basis.

Ms. Samuelson: we have a couple patient advocates...

Chairman Klein: David Serrano-Sewell is willing to join. Jeff Sheehy? (Yes). AS Joan points out, patient advocacy is critical to our insight. [Joan Samuelson is also asked to join and accepts.]

Dr. Prieto: what would the role of this Subcommittee be given SCA 13 is up for a vote sooner than July 12.

Chairman Klein. Both for the benefit of the Senate and for our benefit, we can't vote on something that's not in print. The key is to work proactively as soon as we language to be able to respond. We cannot take a final decision, but can indicate what our recommendations might be to the Board. So the task force could also make recommendations to the Board based on its experience with the legislature, to enhance our policies.

Dr. Pomeroy: I'm supportive of this committee. However, we need written charges of the Subcommittees we're forming, with an outline of the responsibilities and authority and deliverables. There are a number of subcommittees for whom we have not done this. That should be part of our procedure.

Chairman Klein: Agreed. There will be announcement to make today regarding funding to get additional staff so that we move beyond skeletal staff

Call for a vote on question of forming a Legislative subcommittee.

Vote:

- All in favor
- No oppositions
- Motion carries

Chairman Klein: Invites Senator Ortiz to the floor. Ortiz deferred the floor.

Senator Jackie Speier is here from San Mateo. She sent staff person to NAS event for 2 full days.

Senator Jackie Speier:

Recalled Pres. Jack Kennedy statement with members of arts at White House – "[N]ever have so many remarkable people gathered since Thomas Jefferson dined alone.

I know it has been challenging and will continue to be challenging, but that is what pioneers are all about.

Mr. Klein, in bringing Prop 71 to the public, did what Legislature couldn't do. I use you as an example of how one person really can make a difference.

The extent to which SCA 13 or any other bill is placed before legislature, which has a bad report card on trying to get anything of this magnitude through, we have to be very careful.

We spend as much money on prisons as students at UC. Much of the research we've become accustomed to bringing us accolades may not happen in the future. We're starting to starve the entity which brought us so much.

We have 3 new inventions coming out UC every day. We're not new in this business of trying to forge openness or conflict of interest – we've been doing it for decades.

Things that you can do to maximize openness to make sure there is no taint on anyone engaged in this process within the ICOC or within the Working Groups—I would encourage you to do. But I don't think it's right for any of us standing out her to impose stricter standards than are imposed by the NIH and the University of California. I stand ready to work with you and help make sure you can move forward effectively. I hope you will call upon all of us in the Legislature who are very interested in supporting the work that you do and helping you achieve those goals. The ICOC embracing and endorsing standards the NIH and UC have in effect and have worked historically, will work respectively. To expand on that — should only be done in this state if it is for all institutions in this state.

You are under a microscope and there are people who want to bring you down. You have to do what you can to keep that from happening.

We're investing \$3 billion in SCR because we believe in it.

Chairman Klein: Every individual on this board has made a great difference, for years before I was able to address this area.

It's our responsibility to work with you and others in the legislature to continue developing our standards so they're the best they can be.

We've adopted a model for the nation other states are looking to adopt. We have the best and the brightest working on this.

Senator Joe Dunn:

3 quick comments:

- 1. Echoes Senator Speier comments thanking each one of you for dedicating yourself and reputations to attacking this critical issue.
- 2. Why I have concerns with SCA 13: Committed to Senator Ortiz I would not do into details and honored this, but this is what is motivating me: Senator Ortiz referred to me as one of the chief critics of SCA 13. That is probably

correct—only one of---there are a handful of others. I encourage the ICOC to continue discussions with Senator Ortiz. She comes to that table with good faith. What drives my concern is: If we put any single obstacle in the way of this research, particularly now under the bond in its infancy, there are those among us who will use this to their advantage to bring about an end or dramatic slowing of this process. That cannot happen under ANY set of circumstances.

I rarely, if ever, get into partisan comments. I don't think they serve the process well. I am greatly disturbed that in the Senate, all [15] republicans are in favor of SCA 13 as it is currently written.

Just this year, we have tried to toughen conflict of interest rules on Boards and Commissions throughout the state and all 15 republicans have stood in opposition to those proposals. Here we are today, at least in its current form, they all enthusiastically embrace SCA 13. I can only believe, unfortunately that this is driven to slow this process that you have embarked on and stop it We have heard their comments about instituting good government processes to what the voters did last fall, but some of those across the hall have stood against ALL good government suggestions in the past, on environment or water. Yet here we are today, at least its current form, they all enthusiastically embrace SCA 13. That is driven by an effort to slow this process you are embarked on, and if luck is on their side, to stop it — end it.

This research must get under way ASAP; process must be sped, not slowed.

3. Last comment is a request: all those sitting at table with Senator Ortiz do so with utmost speed. This body needs to ensure it speaks with one voice just as Ortiz has. I do hope differences remaining can be resolved on a consensus basis, but my position will not change. If there is any slowing of this process at all, I am not willing to let that happen.

Mr. Serrano-Sewell: Senator Dunn, Spier and Ortiz, thank you for coming today. I have a question for you, will ask same question of Senator Ortiz. Prop 71 specifies we have 3 years to get up and running before any legislative interference occurs. Why the rush job with SCA 13? Why can't we wait until June?

Senator Dunn: Due to t3 year moratorium: I haven't done research on whether SCA 13 or any other legislation would stand in violation of this moratorium. We're all in agreement about why that 3 year language was in Prop 71 – so you can get up and running, move forward. There are always errors with something so cutting edge and critical. There won't be perfection by this committee or anyone involved in the research over the next 3 years. My preference is to move this process

forward, avoid the death knell of the opposition. They will exploit weakness to put an end to the research in its entirety.

Dr. Pomeroy: do you have any thoughts on a mechanism other than SCA 13 to make adjustments? We have some proposed adjustments.

Senator Dunn: I'll refrain from doing that as per my pledge to Senator Ortiz.

Chairman Klein: question -

Senator Speier: that would be a great signal to the legislature. Also you're adopting NAS guidelines. We couldn't ask for better.

Dr. Henderson: passage of Prop 71 has led to enthusiastic new beginning within this area of research. There is no doubt about what it's launched in the way of enthusiastic approach to doing this research, something we were not doing before. This has widespread affect across this country and beyond. We need to recruit the talent we need to do this research. None of this would have happened without Prop 71. People are on the move to CA for this. Anything that slows this down would be terrible – it would be hard to get the momentum going again.

Dr. Levey: Thanks to previous speakers for your support. This has caused UCLA to commit to a stem cell research institute now up and running.

Dr. Bryant: We've all experience resurgence in this area. Seeing possibilities SCR can offer to humans is stunning. Prop 71 coming along has revitalized our institutions; we've gotten commitments from our leaderships, etc. Our ability to recruit some of the people from around the world who have experience that we are lacking is in clear jeopardy.

Chairman Klein: Dr. Pomeroy's institution has some plans as well in this area. State of MA overturned Romney's veto. Little Connecticut committed \$100 million.

Dr. Pomeroy: We all want to get on with this. My responsibility as an ICOC member is to make sure we do it right. [Question] if we were to find any other way to make adjustments than SCA 13, what would assure you that, after we committed to these as a board, we wouldn't go change them in 6 months?

Senator Spier: it's a valid question, but you're all people of good will. Also the public would be able to comment, etc. Legislature will have the opportunity to weigh in if necessary. We have to start from the principal you are all people of good will, the electorate put this in place, and want it to move forward. You are complying with all the rules and regulations set forth by the NIH and the UC, and

if you accept additional ones, you go beyond that. We can't ask any more if we really want the research to move forward and cures to be found.

Chairman Klein: correct, once we adopt something, we have 270-day public hearing in place and can't change it without going through Admin Procedures process, etc. First approach: do you trust the people's mandate and the board's ability to carry it out.

Senator Dunn: if this committee gave the legislature an assurance to do X and breached that assurance, there would be 15 Republicans and at least 11 Democrats to sign on to a bill.

Ms. Samuelson: comments: Senator Ortiz has been a huge friend and champion to us. Concept of Prop 71 was your idea. We owe you a debt of gratitude. She's been a huge champion of the Parkinson's Community as well. I think the fact SCA 13 had to be brought to the legislature is perhaps our failure because we had so many things to do, and we've been working as hard as we can, but we didn't think of a way to have the legislature be part of our processes.

Questions: it's important we as public servants obey COI guidelines and adhere to requirements of Prop 71. Our top priority is not the toughest guidelines or standards, it's to get cures. We need to make sure we keep our eye on the ball. Is there any way that any of these provisions in SCA 13 could undermine us? Will we discourage WG members from coming to work with us? Will we dampen the enthusiasm of our President when we find one? Will scientists we want to recruit go to Kentucky or Connecticut instead? Are we doing something that could delay the full implementation of our mission?

David Serrano-Sewell: all the issues raised by Joan are very important. I think we should now hear from Senator Ortiz.

Senator Ortiz: my number one concern will be if it hampers ability to issue the bonds. I am being guided by bond counsel – Treasurer's Office.

Same bond counsel I worked with when our legislature passed first SCR bill in country.

I suggested we go to the ballot. I would not have done \$3 billion, with all due respect.

I've shared with you a mock up: we propose to drop the divestment provision. On COI policies.

New request to add another layer on public records act. I don't want to further create an exception to existing law. We'll have to work out that provision.

The heart of my concern:

Whether or not this measure has been fairly debated in the legislature – heard in committees, there were no "no" votes. Every democrat in these committees voted.

Allegations this is partnership with right wing – I wear as a badge of honor the right wing will never consider me a partner.

This was the first legislature in the nation to pass bill authorizing SCR.

My willingness to stand up to the far right became the foundation for Prop 71. The legislature has been a friend to SCR. I challenge my colleagues to be part of the solution. Sit down with me and the bond council, as I sit down with the bond council.

Want to assure treatments for all Californians.

Join me in a complex area of bond law that NIH and NAS doesn't have. We're tied to public bonds that are tax exempt. You can't have a private activity with private business.

Boiler plate policy needs to be put in place by this board – every contract entered into should reflect that.

General allegations that this will slow down the release of bonds: I'm committed to work with bond counsel to figure this out.

Can we deliver to the Californians who so deserve the treatments and therapies? Or do we go to a broader policy – taxable bonds – cost far more.

I think we have an opportunity – you have someone who has been a partner and will always be a partner.

Chairman Klein: Thank you, Senator

Dr. Levey: where do you stand with regard to IP? It's critical to get to the point where advances can be applied to patients. Where specifically in this legislation do you stand on this issue? Bayh-Dole is in place, it works, etc.

Senator Ortiz: Royalty streams and revenue run afoul of your ability to sell bonds. Bayh-Dole doesn't address tax issues. Government Issue tax exempt bonds can't be given to public or private institutions if goes into revenue stream. Have to structure contracts in a way they don't run afoul of this law. Prop 71 can't deliver money to fund return to CA's needy. Move away from revenue streams,

move to broad policy. Has to pass muster with bond council. Will it hamper participation by private sector? Want to have good faith discussion on this.

Dr. Baltimore: Back to Joan Samuelson's question: is what's going on now, here today and a lot of other things, discouraging to research scientists, members of the ICOC, to the view that CA was going to lead the nation forward in SCR? The answer is YES. It is distinctly discouraging. We have accepted – the ICOC – a set of policies for doing our business that are defined by the state of CA, but go so far beyond anything we ordinarily do in our lives as we make decisions about carrying out research, and it is discouraging the lack of confidence that is represented by this process today.

The lack of confidence that's shown by the bill that was presented and now much of it taken back by you because you say the committees passed this bill – they passed something that looks very different than this one with all the lines through it. It has taken a lot of effort of members on this board and Bob Klein to get it here. You are trying to burden this bill with a huge social problem in America – the disparity of the availability of health care to the poor. If you burden an initiative for research with that problem, it is a snare and a delusion to believe the resources that come from this research will pay for the needs of the poor. This history of the value of research is that is valuable in giving directions to companies, but it isn't that valuable monetarily. We're talking about something that won't exist. Research isn't about financial return.

I wish someone with your obvious sympathy with the need for this research would cheer on this group rather than tying us up so we are unable to carry out the function provided for us in Prop 71.

Senator Ortiz: I'm not asking for revenue stream for the poor to get treatments. The initiative as drafted suggests that.

As for a revenue stream, I understand that if at all, it's remote. But to finance these bonds, at the same time as we're decimating these programs, it is a value judgment I made as a legislator...I want a broad policy statement.

Chairman Klein: according to the NAS guidelines were adopted by this committee on May 23 – we're ensuring clinical trials are needs blind. Everyone can participate – all costs are paid for, for everyone in the trial.

Dr. Kessler: I share your values, Senator. Dr. Friedman and I spent a good part of our careers trying to figure out how you discover cures and make them accessible. We've lived this for several decades. Your values, I agree with. How you do this is exceptionally hard. We have found replacement therapies for certain diseases. What if we do this and there are no royalties? Let me give you a hypothetical: We develop a particular therapy. The cost of developing and producing the therapy costs \$100K per year per patient. There is no return on

investment. How do I ENSURE, as per your provision (a) in Section 9 of your bill, that these "therapies, products, inventions are accessible and affordable to low-income residents?" How do I do this?

Senator Ortiz: There are models. I'm in talks with bond counsel. You might be worried about liability too.

Dr. Kessler: this is not just about what passes bond council/counsel. It's not about liability. It's about getting cures and therapies created and out there.

Susan Bryant: SCCR – Task Force on IP – working on this. Goal of affordable pricing is outstanding. I don't know how we can accomplish this through our efforts. When you get to R&D, companies have to know they are going to be able to recoup their costs. It's not in our control to enforce anything in this area.

Senator Ortiz: these are recommendations. I hope you adopt policies you can adhere to. I'm not saying they won't be effective policies, but don't work within the law.

Dr. Friedman: Senator, your dedication to this is apparent. These are complicated issues – complicated financial issues, complicated IP implications, clinical care and other medical issues. They're all complicated and vexing. If we as a body publicly commit to working on these things, the issues you raise here, making that public commitment, without the force of law, then why move forward in a hurry to codify something that may be flawed and cause more difficulties than we can foresee? This is a committed group of people. These are really complicated things. If we're rushing toward a calendar deadline, I fear they will be flawed.

What does it take to demonstrate that good faith, confidence in you that we will have the discussions and come up with the best policies for the moment? Don't hastily rush toward a calendar date. Let's give ourselves the opportunity to have this discussion and work them out over the long term.

Senator Ortiz: if I have a level of confidence these policies will be adopted and their maintenance is assured...door is open. I am moving forward with the legislation. That is a reasonable recommendation

Dr. Friedman: What does it take to demonstrate good faith and confidence?

Dr. Prieto: We've come very close on these issues, between the enhancements written by Mr. Harrison and the current language of SCA 13. Senator Ortiz has moved considerably on these issues.

Mr. Sheehy: When do you plan to bring SCA 13 onto the Senate floor? We have a week or 10 days?

Senator Ortiz: A week, no more than that due to the June 30th deadline.

Mr. Serrano-Sewell: We don't want to hamper our efforts. Don't want to hamper the scientists, the good people we will fund. I appreciate the good faith you've made, but for me, when we started with SCA 13 and what we have today are 2 different documents. It evidences in my mind the need to give this much more time for consideration. I have to question anything that would impede our efforts. Something on the ballot would be a distraction.

Chairman Klein: Haste could be a train wreck.

Senator Ortiz: I am running the IP provisions through my office, with CHI and BIOCOM. Please consider I've given my assurance nothing will hamper the bond issuance. We've been told the language as written will not hamper the sale of bonds. I hope we can have a meeting of the minds – I would do nothing to delay cures. I was drawn to this fascinating policy area due to my mother's death. I will do nothing to hamper the future of SCR. I ask you to work with me.

[Public comment]

Don Reed: Don't move too hastily. Greatness takes time to grow. The world is watching us. Prop 71 brings hope.

Mr. Joseph Alioto: This suggestion of yours is a clear impediment and obstacle to the work of this committee. Any attorney who looks at this knows that from its start, is trouble. You are subject to injunctions and those can last more than a year. If you're interested, Senator, in not hampering this, you should WITHDRAW it.

Laurel Barchas/MoBio major at UCB: member of Cal chapter for SCR. We the students want access to the best training available to fight disease. I aspire to do SCR for my career. I'm disturbed this proposed amendment jeopardizes my career, critically needed funds for my lab. SCA 13 is a step backward.

Aja Kumar: UCB Opposed to SCA 13. It would be devastating. SCA 13 will delay the search for cures. Why is such important legislation being rushed?

Elizabeth Swaney: UCB: SC therapy is most important...SCA 13 would hinder.

Denise Reynolds: friend paralyzed – Chris Trappel. A cure is possible, but SCA 13 may keep research like this from being funded because it's not profitable. What keeps him going is knowing the cure is already out there. How long does

he have to wait? Let us not become greedy and demand more from companies which will already bring great wealth to CA. it is redundant and restricts the institute

Davis Brown: I received this badge in Washington earlier this year; it says "keep your politics off our stem cells"

John Strong: I have Parkinson's. Supporting Parkinson's group. If Ortiz bill goes through it will cause problems. If I were a politician I would have said what Mr. Alioto said. California is at the fore front-- What we are doing will affect millions of people.

Bud Suiter: [Wife has Parkinson's, cancer 15 years ago. Later got Parkinson's]. Let's get this going

Karen Miner: with several groups. Not representing any today because I'm going to be blunt. Shocked, frustrated, and now angry. Time is of essence. My condition is not degenerative, but Chris Reeve thought that too. We don't' have time to wait. I'm mystified as to why we are here to talk about this in the first place. The initiative people signed and read. There was 3 years the organization had to set this up. Why is this happening? Why is one persons' opinion halting why I'm sitting in this chair? I wanted to jump up if I could when I heard people say this is about research.

Steve Elliot: [Santa Rosa, CA.] I have Parkinson's. A research player can't be concerned whether it is profitable. Let's talk about the baby boomers are going to be faced with Parkinson's. We can't afford to not do stem cell research and find these cures. Where is seen. Ortiz, maybe not interested in comments

Barbara Cross: I am counting on stem cell research. [Has 2 children with diabetes]

Mark Siegel: President of Americans Parkinson's' assoc. I want to encourage you to stay on track you are on. Keep your eyes focused on finding cures and making treatments available to all people. Work with office to make sure measure doesn't get on the ballot. The incentives are great. Find answers to the rest of her questions

Ann Mead: Senator Ortiz not here. Consider that she and ICOC share same idea. I request that she consider taking you on your good faith and as soon as possible withdraw the amendment because in the larger picture. I am so proud as a California resident that we passed this initiative. It's groundbreaking fro the whole world. The whole country is looking at this and emulating it.

Agenda Item #7

Consideration of bridge financing and other finance and charitable donation actions.

Chairman Klein: SCA 13 had blocked current efforts to move forward with bridge financing.

Need legal issues removed. Working with Senator Ortiz, etc.

Critical to grants: have a staff available to manage evaluation. Within budget we had, working with skeletal staff.

Dolby Family came to us and said they believe full staffing is critical immediately. They have provided us with \$5 million as a GIFT, not a loan. Allows us to staff up, have high quality people.

Mayor Gavin Newsom and city of San Francisco were instrumental in bringing Bob together with Dolby family which has long history of contributing to Community, to medical research, to women's right to choose, etc.

Request for the Board to accept gift from Dolby family.

Dr. Baltimore: the gift is to the CIRM?

Chairman Klein: yes, to the CIRM – a state agency with tax exempt status. Our attorneys reviewed it.

Dr. Pomeroy: we're grateful for this generous donation. Have a Q which I though the donors would have had. We haven't seen a budget. I learned about \$1 million being given out in consulting contracts which I don't know about.

Chairman Klein: we worked on a budget for this year. Walter Barnes presented it to budget committee at state. Presented it to this board 5/6 in Fresno. Walter Barnes has detailed budget to show you. We'll have a budget subcommittee as part of a governance subcommittee which we hope to create in July. Clarification: we have not given out \$1 million on consulting contracts. If legal issues played out with litigation, projections assumed expenditures

Motion to accept Dolby gift

- Dr. Friedman moves acceptance of Dolby gift and providing letter of thanks to Dolby family.
- Dr. Reed seconds

Vote

- All in favor
- No opposition
- Motion carries

Jessie Reynolds: I have concerns about bringing in loans...would members of the ICOC be actively engaged in fundraising? Would information be public? Would any donations to philanthropic donors be public information?

Chairman Klein: we'll consider this as an agendized item at July meeting again as an update. I believe there should be public information here.

Agenda Item #8

Consideration of status report from Facilities Working Group Search Subcommittee, including but not limited to consideration of appointment of members (ICOC Patient Advocates and Real-Estate Specialists) to the Facilities Working Group.

Dr. Friedman: recommend 5 Patient Advocates for Facilities Working Group

Dr. Henderson: move to approve everyone except Patient Advocates

Vote:

All in favor

Motion:

- Dr. Henderson moves to approve patient advocate members
- Dr. Prieto: Second

Vote:

- All in favor
- No opposition
- Motion carries

Motion:

- Chair recommendation: Rusty Doms as Chair and DSS as Vice-Chair
- Second: Dr. Wright

Vote:

- All in favor
- No opposition
- Motion carries

Agenda Item # 9

Consideration of meetings policy and procedures for Standards Working Group.

Dr. Hall: at April meeting, we discussed whether Working Groups should hold open or closed meetings, and agreed to revisit meeting policy and procedures for Standards WG

(See document provided for summary)

These are the recommendations we have. All recommendations from the Standards WG are subject to review by the ICOC at a public meeting. I ask for action on this item.

Ms. Samuelson: are you satisfied that these procedures provide enough flexibility for the process to work effectively?

Dr. Hall: I believe they do. This is consistent with the task of the Working Group and will allow its work to be done in a reasonable way.

Mr. Harrison: they do provide the flexibility to have this committee work effectively.

Motion:

- Jeff Sheehy moves
- Dr. Pizzo Seconds

Vote:

- All in favor
- No opposition
- Motion carries

Agenda Item # 10

Consideration of Alternates for Grants Working Group.

Alternates for Grants Working Group presented.

Motion to approve alternates

- Dr. Reed Moves
- Dr. Prieto Seconds

Vote:

All in favor

- No opposition
- Motion passes

Dr. Love: we are clear that we are in opposition to SCA 13.

Chairman Klein: we have not changed the position.

Dr. Henderson: I don't think it's the intent of any of us to say we're not committed to treating the poor. We just don't think we can represent it within the scope of our work on the ICOC.

Chairman Klein: cannot issue bonds for which you can't guarantee.

Ms. Samuelson: seemed to me the mere fact a new version of SCA 13 will provoke another round of litigation. Isn't that a reason in and of itself to reject this?

Dr. Pizzo: do you think the senator is aware of that?

Chairman Klein: if she would at least give us until December...

If this body with its goodwill makes a commitment and then doesn't keep it, as Senator Dunn said, you'd have legislation in 15 minutes.

[Kirk Kleinschmidt offered guidance on legislative meetings and information packets provided for ICOC members]

Adjourn.