BEFORE THE
ACCESSIBILITY AND AFFORDABILITY WORKING GROUP
OF THE
INDEPENDENT CITIZENS' OVERSIGHT COMMITTEE
TO THE
CALIFORNIA INSTITUTE FOR REGENERATIVE MEDICINE
ORGANIZED PURSUANT TO THE
CALIFORNIA STEM CELL RESEARCH AND CURES ACT

REGULAR MEETING

LOCATION: VIA ZOOM

DATE: FEBRUARY 7, 2023
1 P.M.

REPORTER: BETH C. DRAIN, CA CSR
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I N D E X

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FEBRUARY 7, 2023; 1 P.M.

CHAIRPERSON BONNEVILLE: WELCOME TO THE MEETING, EVERYONE. MY NAME IS MARIA BONNEVILLE. AND I'M THE NEW CHAIR OF THE ACCESSIBILITY AND AFFORDABILITY WORKING GROUP. MARIANNE, WILL YOU PLEASE TAKE ROLL.

MS. DEQUINA-VILLABLANCA: DAN BERNAL.

MR. BERNAL: PRESENT.

MS. DEQUINA-VILLABLANCA: MARIA BONNEVILLE.

CHAIRPERSON BONNEVILLE: PRESENT.

MS. DEQUINA-VILLABLANCA: ANN BOYNTON.

MS. BOYNTON: PRESENT.

MS. DEQUINA-VILLABLANCA: JAMES BENEDETTI.

MR. BENEDETTI: HERE.

MS. DEQUINA-VILLABLANCA: DANA DORNSIFE.

DR. DORNSIFE: PRESENT.

MS. DEQUINA-VILLABLANCA: DANA GOLDMAN. TED GOLDSTEIN.

DR. GOLDSTEIN: PRESENT.

MS. DEQUINA-VILLABLANCA: DAVID HIGGINS.

DR. HIGGINS: HERE.

MS. DEQUINA-VILLABLANCA: HARLAN LEVINE.

DR. LEVIN: HERE.

MS. DEQUINA-VILLABLANCA: PAT LEVITT.

DR. LEVITT: HERE.

MS. DEQUINA-VILLABLANCA: ADRIANA PADILLA. AMMAR QADAN. AL ROWLETT.

MR. ROWLETT: PRESENT.

MS. DEQUINA-VILLABLANCA: DAVID SERRANO-SEWELL. MAHESWARI SENTIL.

DR. SENTIL: PRESENT.

MS. DEQUINA-VILLABLANCA: ADRIENNE SHAPIRO.

MS. SHAPIRO: PRESENT.

MS. DEQUINA-VILLABLANCA: JONATHAN THOMAS.

CHAIRMAN TORRES: HERE.

CHAIRPERSON BONNEVILLE: THANK YOU, MARIANNE.

I WANTED TO START OFF BY SAYING THAT I'M REALLY HONORED TO CHAIR THIS WORKING GROUP OF THE BOARD WHOSE MISSION IS SO VITAL TO THE PEOPLE OF CALIFORNIA. THE ICOC AND INDEED ALL CALIFORNIANS ARE GREATLY BENEFITED BY THE DEDICATION OF THE MEMBERS OF THIS WORKING GROUP WHO VOLUNTEER THEIR TIME TO SERVE ON THIS PANEL AND PROVIDE THEIR HARD EARNED EXPERTISE TO HELP GUIDE THE INSTITUTE IN ACHIEVING ITS MISSION TO ENHANCE ACCESSIBILITY AND AFFORDABILITY OF THE TREATMENTS AND CARES ARISING

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FROM CIRM FUNDING.

I CANNOT SAY THANK YOU ENOUGH FOR YOUR TIME AND EFFORT. I WANT TO ENSURE THAT YOUR VALUABLE TIME IS RESPECTED AND YOUR ABILITY TO MEANINGFULLY PARTICIPATE IN THE DEVELOPMENT OF OUR PROGRAMS IS ASSURED.

SO THAT END, I'VE BEEN WORKING WITH THE INTERNAL TEAM TO BRING TO THIS WORKING GROUP A PLAN THAT COVERS THE NEXT THREE TO FIVE YEARS OF ITS WORK. IT IS IMPORTANT THAT WE HAVE CLEAR, A CLEAR UNDERSTANDING OF WHAT THE TEAM IS FOCUSED ON, PLANS TO ACHIEVE, AND THE STEPS REQUIRED TO GET THERE. I'M LOOKING FORWARD TO MORE IN-DEPTH CONVERSATIONS AROUND PRICING AND THE CHALLENGES WE FACE IN THIS AREA AND HOW TO MAKE CLINICAL TRIALS AND THERAPIES AVAILABLE TO THOSE WHO OTHERWISE MIGHT NOT HAVE THAT OPPORTUNITY.

I'D BE GLAD TO HEAR FROM ALL OF YOU ON THIS WORKING GROUP ON ISSUES YOU BELIEVE ARE IMPORTANT TO DISCUSS AND ADDRESS DURING OUR TIME TOGETHER.

A CLEAR PATH GIVES US THE OPPORTUNITY TO MEASURE OUR PROGRESS AND SUCCESS AND REFLECT ON THINGS THAT DIDN'T WORK OUT QUITE AS WE EXPECTED. IT HELPS FOCUS OUR EFFORTS ON WHAT'S CRITICAL TO

ACHIEVING REDEFINED GOALS AND AVOIDING UNNECESSARY DISTRACTIONS. IN THIS WAY WE WILL ASSURE THAT THE WORKING GROUP ACHIEVES ITS POTENTIAL TO PROVIDE INVALUABLE ASSISTANCE IN ENSURING ACCESS AND AFFORDABILITY TO CALIFORNIA PATIENTS.

THIS IS NOT TO SAY WE HAVEN'T BEEN DOING ANYTHING. WE RECOGNIZE WE'VE ALREADY MADE SUCH GREAT PROGRESS IN THE PATIENT SUPPORT SERVICES PROGRAM, LISTENING SESSIONS FOR THE COMMUNITY CARE CENTERS OF EXCELLENCE THAT ARE UNDER WAY, FOR THE CONCEPT PLAN COMING TO YOU LATER THIS YEAR, AND THE ALPHA CLINICS PROGRAM WITH ITS NEW FOCUS ON COMMUNITY OUTREACH AND ENGAGEMENT. THESE INITIATIVES ARE CRITICAL TO OUR SUCCESS, AND I LOOK FORWARD TO WORKING WITH ALL OF YOU AND THE MED AFFAIRS TEAM IN DEVELOPING A PLAN THAT INCLUDES THESE INITIATIVES AMONG OTHERS IN A COMPREHENSIVE AND THOUGHTFUL LONGER TERM PLAN.

AND WITH THAT, I'D LIKE TO TURN THIS OVER TO SEAN.

DR. TURBEVILLE: THANK YOU, MARIA, NEWLY ELECTED VICE CHAIRMAN. THANK YOU FOR THE OPPORTUNITY.

TODAY WE'RE GOING TO BE GIVING AN UPDATE ON THE AAWG. AND I WILL LET MARIANNE SHOW THE

SLIDES AND WE'LL KICK THIS OFF.

ALL RIGHT. WELL, THANK YOU AGAIN FOR YOUR TIME TODAY. THE PURPOSE OF TODAY'S MEETING IS TWOFOLD. ONE, TO PROVIDE AN UPDATE ON THE MOST RECENT INLAND EMPIRE COMMUNITY CE LISTENING SESSION, WHICH TOOK PLACE AT UNIVERSITY OF CALIFORNIA RIVERSIDE. MANY OF YOU ATTENDED. AND THEN, TWO, WE'RE GOING TO TRANSITION BACK OVER TO THE ROAD MAP TO GIVE AN UPDATE ON A NUMBER OF POLICY ISSUES THAT WE THINK ARE PERTINENT TO OUR JOURNEY ON THE ROAD MAP TO ACCESS AND AFFORDABILITY.

SO FIRST, GEOFF IS GOING TO GIVE AN UPDATE. BEFORE I DO THAT, I WANT TO REORIENT EVERYBODY TO THE NEXT SLIDE. SO I KNOW EVERYBODY IS TERRIBLY BUSY, BUT THIS IS JUST TO REORIENT EVERYBODY TO OUR ROAD MAP TO ACCESS AND AFFORDABILITY. THIS IS SORT OF OUR WORKING SLIDE THAT HAS A NUMBER OF STRATEGIES. AND MANY OF YOU HAVE SEEN THIS BEFORE. TODAY RIGHT OUT OF THE GATE, WE'RE GOING TO TALK ABOUT THE ALPHA CLINICS AND THE COMMUNITY CARE CENTERS OF EXCELLENCE, SPECIFICALLY THE CCCP. AND THAT, AGAIN, I'LL GO INTO POLICY THAT'S IMPORTANT TO CALIFORNIA PARTICULARLY IN THE CANCER SETTING.

SO WITH THAT, LET ME GO AHEAD AND PUNT IT

OVER TO GEOFF TO GIVE AN UPDATE ON THE COMMUNITY CARE CENTERS OF EXCELLENCE.

DR. LOMAX: THANK YOU, SEAN. COULD I GET THE NEXT SLIDE PLEASE.

SO AS A REMINDER, AS PART OF THE CIRM PROCESS FOR DEVELOPING ANY NEW INITIATIVE, THERE'S A PHASE WHICH I'M GOING TO CALL THE ASSESSMENT PHASE. WE HAVE A SORT OF GENERAL SENSE OF THE SCOPE OF THE PROGRAM. IN THIS CASE IT'S TO BRING RESEARCH PLATFORMS OUT INTO COMMUNITIES, PARTICULARLY THOSE COMMUNITIES WHERE THERE'S BEEN LESS ACTIVITY IN TERMS OF CLINICAL TRIALS, CLINICAL RESEARCH, ET CETERA. AND THE AIMS OF THE NEEDS ASSESSMENT IS TO, AS IN THE TITLE, IS TO GET A BETTER SENSE OF THE NEEDS AND HOW THE NEEDS OF THOSE COMMUNITIES RELATE TO WHAT CIRM HAS TO OFFER IN TERMS OF CLINICAL RESEARCH.

AND SO WE ARE TRYING TO -- IN THAT VEIN WE'RE TRYING TO UNDERSTAND THE CAPACITIES WITHIN THOSE REGIONS TO SUPPORT CLINICAL RESEARCH BECAUSE THAT'S WHAT CIRM'S MANDATE IS IS TO PROVIDE THOSE OPPORTUNITIES.

IN ADDITION, AS WITH ANY CIRM INITIATIVE, WE ARE LOOKING AT THE WORKFORCE DEVELOPMENT AND TRAINING NEEDS IN THOSE AREAS BECAUSE IT'S REALLY

THE PEOPLE THAT ARE GOING TO SUPPORT THE SUSTAINABILITY OF THESE EFFORTS. AND IN PARTICULAR, PARTICULARLY WITH THIS PROGRAM, WE REALLY SEE THERE'S AN OPPORTUNITY TO ENGAGE IN PARTNERSHIPS WITH COMMUNITY-BASED ORGANIZATIONS. AND A NUMBER OF BOARD MEMBERS HAVE BEEN ENCOURAGING US TO REALLY USE THIS AS AN OPPORTUNITY TO FORGE THOSE RELATIONSHIPS IN THE CONCEPTUALIZATION OF THIS PROGRAM.

SO WE HELD THE FIRST ONE IN FRESNO AND GAVE YOU A REPORT BACK, AND I'M GOING TO TALK A LITTLE BIT NOW ABOUT OUR INLAND EMPIRE LISTENING SESSION.

AND, AGAIN, JUST A SHOUT-OUT TO EMILY AND MARIVEL, THE TWO PROJECT MANAGERS THAT REALLY MAKE THESE SESSIONS HAPPEN. THERE'S A LOT OF ORGANIZING. WE'RE GOING OUT INTO AREAS WHERE WE DON'T HAVE AS MATURE CONTACTS. AND THEY MAKE FRIENDS AND MAKE THESE SESSIONS HAPPEN. SO THANKS SO MUCH FOR THEIR EFFORT TO MAKE THIS HAPPEN.

WE HAD A SESSION -- THIS FIRST ONE, WE'RE GOING TO HAVE ANOTHER ONE -- WE'RE GOING TO HAVE A SECOND SESSION IN THE INLAND EMPIRE, BUT THE FIRST ONE WAS ON THE UC RIVERSIDE CAMPUS. I WOULD SAY THE GROUP WAS A COMBINATION OF ACADEMICS FROM THE UC RIVERSIDE CAMPUS, SOME COMMUNITY-BASED GROUPS THAT

FOCUS ON HEALTH NEEDS ASSESSMENT, AND THEN A FEW PATIENTS AND CLINICIANS FROM THE AREA.

AND SOME OF THE SORT OF OVERARCHING THEMES THAT REALLY STUCK IN TERMS OF THIS SESSION WAS, FIRST OF ALL, THE IDEA THAT YOU'RE GOING TO DO AN EXPERIMENTAL TREATMENT ON A POPULATION THAT HAS PRIMARY CARE DEFICIT REPRESENTS A REAL CHALLENGE. I THINK WE KNOW THAT, BUT WE ARE NOW HEARING THAT WITH SOME FREQUENCY IN THESE SESSIONS. SO IT KIND OF ELEVATES IT AS THIS IS A RECURRING THEME.

DR. LEVINE: COULD YOU GO DEEPER ON THAT THEME AND EXPLAIN? IS IT THEY'RE SAYING THAT WE SHOULD BE FOCUSING MORE ON PRIMARY CARE AND WORRY LESS ABOUT EXPERIMENTAL? OR WHAT'S THE POINT THAT'S BEING MADE IN THAT BULLET?

DR. LOMAX: SO I THINK THAT'S RIGHT. I MEAN WE ARE CHALLENGED. WE ARE A RESEARCH ORGANIZATION. WE DO RESEARCH. I THINK WHEN YOU START TALKING ABOUT HEALTH NEEDS IN THESE COMMUNITIES, THE VERY FIRST THING YOU'RE GOING TO HEAR IS, WELL, THAT SOUNDS LIKE A REALLY INTERESTING PROGRAM, BUT WE NEED THE BASIC CARE. THERE'S A BASIC CARE DEFICIT.

DR. LEVINE: I'VE HEARD THAT FOR YEARS, AND I UNDERSTAND THAT THERE ARE PREGNANT WOMEN

WITHOUT NUTRITION AND WE HAVE A DRUG PROBLEM. SO I JUST WANTED TO MAKE SURE I UNDERSTOOD THE POINT THAT WAS BEING MADE. SO THANK YOU.

DR. LOMAX: AND WE TRY TO -- WE UNDERSTAND THAT POINT, AND WE ALSO TRY TO BE CLEAR IN TERMS OF WHAT SORT OF ISN'T ABLE TO DO IN THAT CONTEXT. AND I THINK THAT -- AGAIN, THAT'S PART OF THE ENGAGEMENT PROCESS IS COMING TO THAT UNDERSTANDING.

THE OTHER PIECE IS I THOUGHT IT WAS REALLY SUMMED UP NICELY. AS WE ENGAGE, MEDICAL PROFESSIONALS CAN ALWAYS COME OFF AS KIND OF AGENDA DRIVEN. BUT THERE REALLY NEEDS TO BE -- IT'S A RELATIONSHIP BUILDING PROCESS AND NOT A TRANSACTIONAL PROCESS TRYING TO GET PEOPLE INTO TRIALS. SO THERE'S -- WHATEVER THAT INFRASTRUCTURE LOOKS LIKE, IT HAS TO HAVE THE CAPACITY TO TRULY DO ENGAGEMENT AS OPPOSED TO RECRUITMENT OR JUST SIGNING PEOPLE UP.

I THINK ONE OF THE MOST ANIMATED PARTS OF THIS DISCUSSION, AND THIS HAS HAPPENED BOTH TIMES NOW, IS A REAL DESIRE AND INTEREST IN HOW DO WE CREATE INNOVATIVE COMMUNICATION OPPORTUNITIES WITHIN THESE PROGRAMS. AND PARTICULARLY HOW DO WE DRAW ON YOUNG PEOPLE, BOTH BECAUSE THEY HAVE THE CREATIVE ENERGY, BUT ALSO FOR A NUMBER OF THESE POPULATIONS,

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PARTICULARLY POPULATIONS THAT MIGHT HAVE -- IMMIGRANT POPULATION OR ENGLISH AS A SECOND LANGUAGE, OFTEN THE YOUNGER GENERATIONS ARE ABLE TO BRING NEW INFORMATION TO THE HOME, SERVE AS TRANSLATORS.

THEY JUST SORT OF HAVE A CONNECTIVITY THAT, AGAIN, WAS SORT OF VIEWED AS VALUABLE. AND THERE WERE A NUMBER OF EXAMPLES ACTUALLY, PARTICULARLY IN THE PUBLIC HEALTH AND HEALTH EDUCATION SETTING, WHERE THESE SORTS OF MODELS WORKED, WHETHER IT WAS AN ARTS PROJECT OR, AGAIN, SOMETHING THAT ENGAGED CLUBS, COMMUNITIES, AND YOUTH TO THEN DEVELOP A MESSAGE AND DISSEMINATE IT WITHIN THE COMMUNITY.

AND THEN, FINALLY, I TOUCHED ON THE CLUBS AND THEN ALSO THE COMMUNITY-BASED ORGANIZATIONS, THAT, AGAIN, WE REALLY NEED THOSE SORT OF -- FIND WAYS TO REALLY CULTIVATE THOSE RELATIONSHIPS AND BUILD THEM INTO THIS PROGRAM.

SO I'LL PAUSE THERE. ARE THERE ANY ADDITIONAL THOUGHTS, QUESTIONS? OTHERWISE I'LL GET INTO A BIT MORE DETAIL. OKAY. NEXT SLIDE.

AND THIS IS AS A REMINDER OF JUST SORT OF HOW WE ARE SORT OF ORGANIZING THE INFORMATION WE ARE COLLECTING. I'M GOING TO GO THROUGH SORT OF THREE

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BINS WHERE WE ARE COLLECTING INFORMATION. THE FIRST IS KIND OF CLINICAL READINESS. AND THAT SPEAKS TOWARDS WHAT SORT OF INFRASTRUCTURE CAPACITIES ARE IN THE REGIONS THAT CAN SUPPORT THIS SORT OF EFFORT.

AS A REMINDER, FRESNO, WE WERE IN A LITTLE BIT MORE -- WE WERE IN A SLIGHTLY MORE CLINICALLY FOCUSED AREA WHERE WE WERE IN A CANCER CENTER; WHEREAS, RIVERSIDE WAS REALLY INTERESTING BECAUSE IT WAS A CENTER FOR HEALTHY COMMUNITIES. SO THEIR WORK TENDED TO BE A BIT MORE ON THE COMMUNITY-BASED RESEARCH AND MORE INTERVENTION WITH COMMUNITIES AT THE EDUCATION AND ENGAGEMENT LEVEL AS OPPOSED TO A CLINICAL CANCER CENTER.

THEY HAD A VERY HIGH CAPACITY TO DO COMMUNITY-BASED RESEARCH. AS CAME IN THE LEAD-UP TO THESE DISCUSSIONS, WE LEARNED A LOT ABOUT EFFORTS THEY HAD MADE WITH A LOT POPULATIONS OF THE REGION, CERTAINLY IN PUBLIC HEALTH, BUT ALSO IN CLINICAL WORK, PARTICULARLY MOST RECENTLY IN THE VACCINATION AREA. SO THERE'S KIND OF A RICH HISTORY NOW OF THE VACCINE AND COVID EFFORTS, THAT THERE ARE SORT OF CAPACITIES THERE THAT WE MIGHT WANT TO, AGAIN, POTENTIALLY LEVERAGE INTO THE FUTURE EFFORTS IN THE COMMUNITY CARE CENTERS OF EXCELLENCE.

AGAIN, I MENTIONED INTERFACE WITH

PARTICIPATORY RESEARCH AND THEN, AGAIN, THE ROLE OF COMMUNITY-BASED ORGANIZATIONS. A LOT OF THE WORK THAT UC RIVERSIDE'S CENTER HAD DONE IN COMMUNITIES WAS MEDIATED BY COMMUNITY-BASED ORGANIZATIONS IN THE VACCINE PROGRAM. SO, AGAIN, THAT CONNECTION WAS BOTH CONCEPTUAL AND VERY SPECIFIC IN TERMS OF COVID.

ONE INTERESTING SORT OF VERY SPECIFIC POINT ALSO WAS, TO THE EXTENT THAT WE EXPECT POTENTIAL PARTICIPANTS TO -- THEIR FIRST OF POINT CONTACT WOULD BE THEIR PHYSICIAN. SOME WAY A RESOURCE THAT -- BECAUSE AS WE ARE WELL AWARE, OFTEN EVEN YOUR FACE TIME WITH PHYSICIANS THESE DAYS CAN BE INCREDIBLY LIMITED. SO HOW DO WE ALLOW THAT CONVERSATION TO HAPPEN IN A SORT OF SENSITIVE WAY WITH THE APPROPRIATE TIME, AND IS THERE SOME WAY TO RESOURCE THE PHYSICIAN INTERACTION WITH POTENTIAL PARTICIPANTS SO THAT THERE'S A QUALITY INTERACTION THAT'S A TRUE ENGAGEMENT. IT'S NOT SORT OF JUST POINTING SOMEONE TO A TRIAL AND THEN THEY LEAVE WITH NO CONTEXT OR NO UNDERSTANDING. NEXT SLIDE PLEASE.

TRAINING, AGAIN, I MENTIONED FRESNO. TO SORT OF BROADEN FRESNO, IT TENDED TO FOCUS VERY MUCH MORE ON TRADITIONAL CLINICAL GRAND ROUNDS, NETWORKS, RESIDENCY, THE SORT OF MEDICAL TRAINING. WHEREAS, IT'S INTERESTING IN RIVERSIDE WE GOT A BROADER

PERSPECTIVE AROUND CAREER PATHS THAT WOULD BE MORE AT THE COMMUNITY ENGAGER LEVEL OR THE PROMOTORES LEVEL. AND, AGAIN, THE FOCUS THERE WAS THAT THERE NEEDS TO BE CLEAR AND COMPELLING MESSAGES, WHICH WILL BE A CHALLENGE FOR THE TYPES OF PROGRAMS THAT WE ARE TRYING TO INTRODUCE PEOPLE TO.

AND THERE WAS, AGAIN, A VERY STRONG FOCUS ON LITERACY AND UNDERSTANDING FOR YOUNGER AUDIENCES, WHETHER IT'S DOWN TO SORT OF ELEMENTARY SCHOOL LEVEL. AGAIN, THE PROMOTORES. AND ULTIMATELY THAT THAT WORKFORCE SHOULD BE A REFLECTION OF THE POPULATION WHICH, AGAIN, IS CONSISTENT WITH THE LITERATURE.

OBVIOUSLY WE ARE ASKING PEOPLE TO ENGAGE IN AN ACTIVITY WHERE THERE NEEDS TO BE A HIGH DEGREE OF TRUST. AND IN ORDER TO HAVE THAT DEGREE OF TRUST, HAVING SORT OF CULTURALLY SENSITIVE MESSENGERS IS OBVIOUSLY GOING TO BE VERY IMPORTANT IN TERMS OF THAT TRUST-BUILDING EXERCISE.

SO, AGAIN, YOU CAN SEE IT WAS A LITTLE BIT -- IT WAS VERY INTERESTING TO GET THIS BROADER PERSPECTIVE. HOW WE SORT OF THEN MELD THAT INTO FUNDING PROGRAM IS GOING TO BE, I THINK, CHALLENGING, BUT EXCITING.

I THINK THAT'S -- IS THERE ONE MORE SLIDE?

I'M JUST LOSING TRACK OF WHERE I AM IN THE DECK. YEAH. ACCESS AND ENGAGEMENT.

SO THIS IS THE FINAL BIN. HOW DO WE BETTER ENGAGE WITH THE COMMUNITY? IN THIS CASE THE CONVERSATIONS WERE PRETTY SIMILAR, QUITE OBVIOUSLY, AGAIN, THIS FOCUS ON YOUNG PROFESSIONALS. AND THEN IT WAS A VERY -- THE AUDIENCE MADE A VERY STRONG PLEA THAT TRADITIONALLY FUNDERS -- FUNDERS LIKE US THAT FUND PROGRAMS, IT'S OFTEN CHALLENGING TO GET THOSE RESOURCES DOWN TO THE REAL COMMUNITY LEVEL, THE CLUBS, THE YOUTH ORGANIZATIONS, THE GROUPS THAT REALLY CAN HELP IN TERMS OF DEVELOPING THIS PROGRAM. SO THE BASIC MESSAGE IS WE NEED FUNDING.

AND THEN WE NEED TO MAKE THE ENGAGEMENT ACTIVITIES REWARDING FOR THE MESSENGERS. AND I THINK THAT'S ACTUALLY REALLY EASY BECAUSE WE HEARD FROM A LOT OF AREAS. WE HAD SOME BRIDGES STUDENTS, AND THEY REALLY TALKED ABOUT HOW EXCITING IT WAS FOR THEM TO GO OUT AND TALK ABOUT THESE OPPORTUNITIES. AND THEY WANT TO DO MORE OF IT. THEY FIND IT REWARDING. THEY WERE DOING IT ON THEIR OWN TIME, BUT OBVIOUSLY THAT'S NOT SUSTAINABLE. SO THEY STEP BACK AND BE A SUSTAINABLE ACTIVITY THROUGH, SAY, SOMETHING LIKE A BRIDGES PROGRAM. THAT WAS THE MESSAGE WE HEARD.

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AGAIN, I'M GETTING A LITTLE BIT REDUNDANT HERE, BUT WHEN YOU HEAR THINGS REPEATED, THAT'S IMPORTANT. THAT'S INFORMATION, FOSTERING INNOVATION IN THE COMMUNICATION, MULTIMEDIA, THOSE SORTS OF ACTIVITIES. AND, AGAIN, TAILOR THE MESSAGE AND SEGMENT YOUR AUDIENCE. WE KNOW OBVIOUSLY WITH THE HIGHLY DIVERSE POPULATIONS IN CALIFORNIA, THERE NEEDS TO BE SOME SEGMENTING OF THAT MESSAGE SO THAT IT'S CULTURALLY APPROPRIATE.

SO I THINK THAT COVERS IT.

CHAIRPERSON BONNEVILLE: GEOFF, CAN YOU TELL -- CAN YOU MENTION TO THE GROUP WHEN THE NEXT MEETINGS ARE, LIKE WHERE THEY ARE, AND THEN THE BIG ONE, AND WHETHER OR NOT ANY OF THE WORKING GROUP MEMBERS WOULD LIKE TO JOIN BY ZOOM AND LISTEN.

DR. LOMAX: SURE. SO WE ARE VERY CLOSE TO FINALIZING A SECOND MEETING IN THE INLAND EMPIRE. THE AIM OF THAT MEETING IS TO -- WE ARE WORKING DIRECTLY WITH A NONPROFIT IN THE REGION. I SPENT A BIT OF TIME DESCRIBING THIS AUDIENCE. IT WAS TILTED A LITTLE BIT TOWARDS SORT OF ACADEMICS AND PROFESSIONALS IN THE COMMUNITY. THIS MEETING WILL BE VERY MUCH FOCUSED ON COMMUNITY-BASED ORGANIZATIONS THAT WORK DIRECTLY WITH THE DIFFERENT POPULATIONS IN THE COMMUNITY. SO WE'RE GOING TO GET

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AWAY FROM THE ACADEMIC SIDE AND MORE TOWARDS THAT HEALTH INTERVENTION TYPE OF ORGANIZATION THAT'S OUT IN THESE COMMUNITIES WORKING WITH DIVERSE POPULATIONS.

THAT'S SCHEDULED FOR EARLY MARCH. I DON'T KNOW IF WE HAVE THE EXACT DATE, BUT WE'LL GET IT TO YOU. WE ARE JUST IN THE PROCESS OF SETTLING IT. AND IT WILL BE IN PALM DESERT.

CHAIRPERSON BONNEVILLE: IT'S PALM DESERT.

DR. LOMAX: PALM DESERT. SO WE'RE GOING TO BE HAVING THE DESERT COMMUNITY.

AND THEN THE AIM FROM THERE IS TO PULL EVERYTHING TOGETHER THAT WE'VE DONE. THAT WILL THEN BE OUR THIRD SESSION. AND WE'RE GOING TO SCHEDULE A STATEWIDE MEETING, AND I THINK RIGHT NOW WE ARE TARGETING EARLY MAY FOR SACRAMENTO. IT WILL BE ON THE UC DAVIS MEDICAL CENTER CAMPUS IN SACRAMENTO. AND THAT WILL BE OPPORTUNITY FOR REALLY ANYONE AND EVERYONE WHO'S SORT OF CONNECTED UP WITH THESE PROGRAMS. WE'LL HAVE THE ALPHA CLINICS THERE, WE'LL HAVE POTENTIAL APPLICANTS, OBVIOUSLY BOARD MEMBERS, AND MEMBERS OF THIS WORKING GROUP WILL BE LOBBIED TO ATTEND.

AND THAT'S WHERE WE REALLY WANT TO TRY TO WALK THROUGH BOTH REPORTING BACK ON THE RESULTS.

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AND THEN TYPICALLY WHAT WE'VE BEEN ABLE TO DO IN SESSIONS LIKE THAT IS THEN BREAK PEOPLE BACK OUT AGAIN AND REALLY GET THEM TO SORT OF MAP OUT WHAT A POTENTIAL RFA WOULD LOOK LIKE. WHAT ARE THE COMPONENTS?

NOW, BASED ON EVERYTHING WE'VE HEARD, WHAT ARE THE COMPONENTS WITHIN THAT RFA THAT WE NEED TO CREATE A FUNDING SPACE FOR TO MAKE THIS PROGRAM A SUCCESS? DOES THAT COVER YOUR QUESTION?

CHAIRPERSON BONNEVILLE: YES. THANK YOU. J.T.

DR. THOMAS: SO JUST FOR MEMBERS OF THE WORKING GROUP, THESE SESSIONS ARE THREE PLUS HOURS EACH. GEOFF DOES A GREAT JOB OF RUNNING THE DISCUSSION AND SORT OF MANAGING THE EBB AND FLOW OF THE TOPICS THAT ARE BROUGHT UP AND SEGUEING INTO VARIOUS THINGS THAT WE WANT TO DISCUSS. BUT SORT OF THE OVERWHELMING TAKEAWAY WE WANT TO CONVEY TO FOLKS ON THE WORKING GROUP IS THIS OBVIOUSLY IS ALL ABOUT THE ACCESSIBILITY PART OF THE AAWG'S WORK. AND THESE SESSIONS HAVE, WHAT WOULD YOU SAY, 30 TO 50 THE ATTENDEES, SOMETHING LIKE THAT.

DR. LOMAX: CLOSER TO 30, YEAH.

DR. THOMAS: AND THEY'RE FROM ALL DIFFERENT STAKEHOLDER GROUPS AND PERSPECTIVES. AND

EACH PERSON BRINGS A LOT TO THE TABLE, AND THEY'RE VERY ENGAGED. THE COMMUNICATIONS ARE ROBUST. THEY'RE HIGHLY PARTICIPATORY.

THE LEVEL OF ENTHUSIASM FOR THE CONCEPT FOR THE COMMUNITY CARE CENTER OF EXCELLENCE IN AREAS SUCH AS FRESNO, SUCH AS RIVERSIDE IS HIGHLY PRONOUNCED. THEY WANT ACCESS. THEY WANT TO BE -- THE COMMUNITIES ALL WANT TO BE A PART OF THIS. AND THIS IS REALLY AN INVALUABLE WAY OF NOT ONLY TEEING UP THE COMMUNITY CARE CONCEPT, BUT OF GETTING CIRM'S MESSAGE IN GENERAL OUT TO PARTS OF THE STATE THAT MAY NOT BE AS FAMILIAR AS THOSE WITH THE ACADEMIC CENTERS THAT HAVE ALPHA CLINICS, FOR EXAMPLE.

SO I THINK THAT THESE ARE HIGHLY VALUABLE MEETINGS AND I THINK WILL PAY REAL DIVIDENDS DOWN THE ROAD AS THE COMMUNITY CARE CENTERS OF EXCELLENCE CONCEPT IS TROTTED OUT FORMALLY AND PEOPLE CAN APPLY. THERE IS NO QUESTION THAT THESE AREAS WILL BE FRONT AND CENTER IN THE APPLICANT POOL ONCE THIS PROGRAM IS INITIATED.

SO JUST WANT ALL OF YOU GUYS TO KNOW THAT THIS IS REALLY DOING A MAJOR PART IN ADVANCING THE GOALS AND MISSION OF THE AAWG. AND I WOULD ECHO WHAT MARIA AND GEOFF SAID, WHICH IS AT A FUTURE

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MEETING OF THIS SORT, I THINK, IF YOU CAN TAKE THE TIME TO ATTEND EITHER ON ZOOM OR EVEN BETTER IN PERSON TO GET A REAL FEEL FOR THE DYNAMICS OF THESE DISCUSSIONS, IT WOULD BE WELL WORTH YOUR TIME. SO THANK YOU.

DR. TURBEVILLE: THANK YOU. WE'LL MOVE ON, MARIANNE, TO THE NEXT SLIDE. I DON'T WANT TO MOVE TO THE POLICY SECTION YET. I STILL WANT TO KEEP THIS OPEN BECAUSE I'M NOT SURE IF OTHER PEOPLE HAVE HAD THE OPPORTUNITY TO OPINE ON THE COMMUNITY CARE CENTERS OF EXCELLENCE. THIS IS A BIG AND IMPORTANT COMPONENT OF OUR STRATEGIC ROAD MAP. THERE ARE LOTS OF TOUCHPOINTS WITH COMMUNITY CARE CENTERS OF EXCELLENCE. THIS IS ONLY OUR THIRD PRESENTATION FOR THE AAWG ON THE ROAD MAP. SO WE DO VISUALIZE A LOT OF DIFFERENT OUTGOING AND INBOUND PARTICIPATION WITH THE CCCE ON THE RESEARCH SIDE ALL THE WAY TO POTENTIAL INFUSION OF COMMERCIALIZED THERAPIES.

SO LET ME PAUSE HERE JUST FOR A SEC JUST TO SEE IF ANYBODY, THE COMMITTEE MEMBERS, HAVE ADDITIONAL COMMENTS OR QUESTIONS. OKAY. VERY GOOD.

SO WHAT WE'RE GOING TO DO NOW IS TRANSITION TO ANOTHER TOPIC. THIS IS, OF COURSE, VERY IMPORTANT AND ACTUALLY LEADS INTO OUR ROAD MAP.

AND THIS IS ADDRESSING MORE OF THE STATE POLICY. INTERESTING ENOUGH, I'M GOING TO TALK ABOUT THE POLICY THAT IS NOW ACTUALLY A LAW -- NEXT SLIDE -- THAT CIRM HAS SUPPORTED.

AND THIS IS THE CALIFORNIA CANCER CARE EQUITY ACT, MORE KNOWN AS CCCEA. IT'S A MOUTHFUL.

BUT FOR BACKGROUND, THE CALIFORNIA CANCER EQUITY ACT TOOK EFFECT THIS YEAR, ENABLING THE MOST VULNERABLE CANCER PATIENTS THE OPTION TO SEEK OPTIMAL CARE MORE EASILY IN AN NCI-DESIGNATED CENTER. AS YOU KNOW, THERE ARE TEN DESIGNATED CENTERS IN CALIFORNIA. THEY PROVIDE A NUMBER OF OPPORTUNITIES. ONE IS TO CONSULT WITH ONE OF THE CENTERS ALL THE WAY FROM GENOMIC TESTING TO PRECISION-BASED CARE, SUBSPECIALTY EXPERTISE, AND, MORE IMPORTANTLY, CLINICAL TRIALS.

NOW, AS I HAVE LEARNED, THIS LAW IS INTENDED FOR PATIENTS WHO HAVE EXHAUSTED ALL FDA APPROVED TREATMENTS FOR THEIR TUMOR TYPE. SO WHAT THEY'RE UP AGAINST IS BASICALLY THREE OPTIONS. ONE IS A POTENTIAL CLINICAL TRIAL AT ONE OF THE NCI SITES. THE SECOND IS THE HOSPICE ROUTE. AND THE THIRD POTENTIALLY IS COMPASSIONATE USE.

THERE ARE A NUMBER OF OPPORTUNITIES FOR US HERE AT CIRM TO HELP WITH THIS INITIATIVE. SO THIS

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HAS JUST KICKED OFF. I SPOKE TO MANY SUBJECT MATTER EXPERTS WHO HELPED WRITE PART OF THIS. AND THE FIRST THING THAT WE'VE IDENTIFIED IS THAT THERE'S ABSOLUTELY FROM THE EDUCATIONAL STANDPOINT OUT IN THE COMMUNITY IN TERMS OF EDUCATING WHAT THE CALIFORNIA CANCER CARE EQUITY ACT IS. COMMUNITY ONCOLOGISTS THAT I SPOKE WITH WERE NOT FAMILIAR WITH IT. THEY WERE WAITING FOR SOMETHING TO BE KICKED OFF. MANY OF THE NURSES AND STAFF WERE NOT FAMILIAR WITH IT. SO THERE'S A GREAT OPPORTUNITY FOR US, CIRM, TO PARTNER WITH OTHER ORGANIZATIONS THAT ARE OUT THERE FOR SORT OF AN OUTBOUND EDUCATIONAL INITIATIVE EITHER ON THE CME SIDE FOR HEALTHCARE PROVIDERS, BUT EVEN MORE IMPORTANTLY FOR PATIENTS.

THE OTHER THING THAT'S IMPORTANT, AND I'LL COME BACK TO THIS COMMENT IN A FEW MINUTES, SECOND, NOT ALL THE MEDI-CAL PROVIDERS UNDER THIS PROGRAM HAVE NCI-DESIGNATED TREATMENT CENTERS. SO THAT'S ONE OF THE OBSTACLES. SO THERE'S MULTIPLE MEDI-CAL PROVIDERS, RIGHT, AND MANY OF THEM DON'T HAVE AN NCI IN THEIR PORTFOLIO. SO THAT'S SOMETHING ELSE THAT WE SHOULD THINK ABOUT, CONSIDERING HOW WE CAN HAVE AN IMPACT MAYBE EVEN AT THE STATE LEVEL AT MEDI-CAL.

AND THE OTHER THING, LIKE ANY PIECE OF LEGISLATION, THERE'S A REGRESSION TO THE MEETING.

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SO IT'S A GOOD-FAITH EFFORT BY THE PLANS TO GO OUT THERE AND EDUCATE THE COMMUNITY, THE HEALTHCARE PROVIDERS ABOUT THIS PROGRAM. AND SO THERE'S NO REAL SORT OF MEAT, IF YOU WILL, BEHIND IT TO MANDATE THAT THE PLANS GO OUT THERE AND BE PROACTIVE.

SO THERE'S A NUMBER OF OPPORTUNITIES FOR US, CIRM, AND FOR AAWG TO CONSIDER MOVING FORWARD TO POTENTIAL EDUCATIONAL PROGRAMS, BUT EVEN SOME MORE ROBUST OPPORTUNITIES IF, IN FACT, THERE'S AN ADDITIONAL LEGISLATION MAYBE TWO TO THREE YEARS DOWN THE ROAD THAT MIGHT OPEN UP SOME MORE AGGRESSIVE, IF YOU WILL, OPPORTUNITIES FOR PATIENTS TO GET ACCESS TO THESE SITES.

SO, FINALLY, THERE'S ALSO A POTENTIAL PHARMACOECONOMIC OPTION HERE. THIS ACTUALLY JUST CAME UP LAST NIGHT. AND THERE IS A HYPOTHESIS THAT THE ECONOMICS, PHARMACOECONOMICS WOULD BE IN THE STATE'S FAVOR IF, IN FACT, THESE SITES OPENED UP MORE FOR PATIENTS WHO ARE AT THE TERMINAL STAGE. THAT IS, GENERALLY THEY'RE OFFERED THE TRADITIONAL COMMERCIAL THERAPIES, WHICH ARE TERRIBLY EXPENSIVE, AND AT THE SAME TIME THEY'RE NOT GIVEN THE OPTION FOR A POTENTIAL NOVEL CLINICAL TRIAL.

AND SO THERE'S AN OPTION FOR US TO WRAP IN OUR HEOR HERE. THIS IS SORT OF DOWNSTREAM, BUT

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REALLY STARTING TO THINK THROUGH HOW CIRM CAN PLAY A ROLE IN THIS INITIATIVE. AND LET ME PAUSE THERE AND SEE IF ANYBODY HAS ANY QUESTIONS OR HOW THAT RESONATES WITH THE AAWG WITH RESPECT TO THIS PARTICULAR POLICY.

CHAIRPERSON BONNEVILLE: DANA HAS A QUESTION.

DR. DORNSIFE: I REALLY JUST THINK IT'S MORE OF A NUANCE OF VERBIAGE. WHEN WE SAY MOST VULNERABLE, MANY PEOPLE ASSOCIATE THAT WITH SOCIOECONOMIC STANDING. BUT I BELIEVE, BECAUSE LAZAREX ALSO SUPPORTED THIS ACT, I BELIEVE WHEN THEY SAY MOST VULNERABLE, THEY'RE REFERRING TO THE COMPLEXITY OF A CANCER DIAGNOSIS. SO I JUST WANTED TO MAKE THAT NUANCE.

DR. LEVINE: YEAH. I CAN SPEAK TO THAT, DANA. YOU'RE CORRECT, BUT IT'S ACTUALLY -- THIS IS AN ADDITIONAL LAYER OF NUANCE. SO MOST VULNERABLE MEANT THAT IT WAS APPLIED TO MEDI-CAL PATIENTS WHO HAVE THE MOST SOCIAL DETERMINANTS OF HEALTH ISSUES. SO THIS DOESN'T APPLY TO THE EXCHANGE, DOESN'T APPLY TO PRIVATE INSURANCE OR MEDICARE. AND THEN WITHIN THE MEDI-CAL POPULATION, IT IS THE MOST COMPLEX CANCERS. AND THEN AMONG THE MOST COMPLEX CANCERS IS THOSE THAT HAVE EXHAUSTED TRADITIONAL APPROVED

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THERAPIES.

SO IT IS A FIRST STEP, BUT IT IS VERY TARGETED AS YOU SUGGESTED. AND I THINK SUBSEQUENT STEPS ARE GOING TO BE NEEDED, BUT THIS WAS A HEROIC ACT TO GET PEOPLE TO SAY PEOPLE SHOULD BE ABLE TO GO OUTSIDE THEIR NARROW NETWORKS OR THEIR HMO NETWORKS IF THERE'S LIFESAVING OPPORTUNITIES AT THESE NCI OR OTHER. THERE ARE OTHER CRITERIA THAT ACADEMIC MEDICAL CENTERS COULD QUALIFY TO BE ON THAT LIST.

DR. DORNSIFE: AND WE CERTAINLY AGREE, WHICH IS WHY WE ABSOLUTELY ENDORSED IT. SO THANK YOU FOR THAT, HARLAN.

DR. LEVINE: YEAH. WE APPRECIATED THE SUPPORT.

CHAIRPERSON BONNEVILLE: SEAN, I HAVE A QUESTION. I ALSO JUST WANT TO MAKE SURE. THIS IS SOMETHING THAT WOULD BE IN ADDITION TO THE PATIENT SUPPORT SERVICES THAT WE ARE PLANNING ON ROLLING OUT. SO IT WOULD BE AN ADD-ON AS MORE -- JUST ADDED SUPPORT FOR PATIENTS THAT ARE ENROLLED IN OUR TRIALS. SO I JUST WANT TO MAKE SURE THAT WE REORIENT OURSELVES BECAUSE THIS IS OBVIOUSLY A VERY BROAD INITIATIVE THAT COVERS A LOT. BUT IN THE CONTEXT OF US, THIS IS SOMETHING THAT IS A SUPPLEMENT OR ADDED ONTO AND HOPEFULLY SOMETHING

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THAT WE CAN GET EDUCATION OUT ABOUT WHEN SOMEBODY CALLS OR PATIENT SUPPORT SERVICES AND SAYS I WANT TO ENROLL IN THIS TRIAL. IS THERE SOMETHING THAT YOU KNOW OF? WE HOOK THEM UP WITH SOMETHING THAT'S GOING ON THAT CIRM IS FUNDING, AND THEN THIS IS SOMETHING THAT THEY CAN ALSO REFER BACK TO.

DR. TURBEVILLE: YEAH, ABSOLUTELY. IT KIND OF LEADS INTO THE NEXT SLIDE ABOUT POTENTIAL OPPORTUNITIES WE WANT TO STRESS TEST WITH THE TEAM HERE, OF COURSE.

ONE, OF COURSE, IS GRANTS WITH RESPECT TO A FUNDING MECHANISM, AS I MENTIONED EARLIER. ANOTHER OPPORTUNITY IS WORK DIRECTLY WITH THE STATE AND MEDI-CAL IN TERMS OF MAKING SURE THAT WE'RE AT LEAST PROVIDING SOME SERVICE OR ASSISTANCE ON THE EDUCATIONAL PLATFORM.

THE ALPHA CLINICS CAN ALSO PLAY A ROLE POTENTIALLY IN THE COVERAGE ANALYSIS AND PATIENT TREATMENT OR AT LEAST SORT OF NAVIGATION, BUT THAT LEADS DIRECTLY INTO WHAT LEVINE MENTIONED. THAT IS, HOW PATIENT SUPPORT SERVICES COULD PROVIDE THE HEAVY LIFT HERE. AND THIS IS IN THEIR SWEET SPOT FOR THE MOST PART, EDUCATING, NAVIGATING PATIENTS TO CLINICAL TRIALS, BUT MORE IMPORTANTLY JUST PROVIDING FAIR AND BALANCED INFORMATION ABOUT SOMETHING. SO

IT COULD BE A REAL SORT OF BOLT-ON, REAL EASY TURNKEY FOR THE PATIENT SUPPORT SERVICES, ABSOLUTELY.

CHAIRPERSON BONNEVILLE: ANYONE HAVE ANY QUESTIONS?

DR. TURBEVILLE: SO NO QUESTIONS OR COMMENTS. ANY INITIATIVES OR ANY THINGS THAT PERHAPS WE ARE MISSING THAT WE SHOULD CONSIDER WITH RESPECT TO THIS ACT AND THE LAW?

DR. GOLDSTEIN: THIS IS TED GOLDSTEIN. SO ONE OF THE THINGS THAT THIS ACT, AS I UNDERSTOOD WHEN IT WAS BEING PREPARED, I DON'T KNOW HOW IT FINALLY ENDED UP, IS TO PROVIDE ACCESS TO PRECISION MEDICINE, GENOMIC TESTING, AND TARGETED THERAPY FOR MEDI-CAL PATIENTS. AND IT WAS ALWAYS AMBIGUOUS ABOUT HOW THAT WOULD BE PROVIDED AND THE DEGREE TO WHICH IT WOULD GET REIMBURSED AND APPROVED AND SO ON. AND I BELIEVE THAT WHAT THIS INITIATIVE WAS WAS TO PROVIDE EQUITY WITH PRIVATE PLANS; IS THAT CORRECT? IS THAT WHERE IT ENDED UP AS PART OF WHAT THE LEGISLATION IS ABOUT?

DR. TURBEVILLE: YEAH, THAT'S CORRECT. HARLAN, DO YOU WANT TO OPINE ON ANY OF THIS?

DR. LEVINE: YEAH. I THINK IT'S A REALLY GREAT QUESTION THAT TED'S ASKING BECAUSE I THINK

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SOME OF THAT CLARITY IS GOING TO HAVE TO COME OVER TIME. SO I THINK WHAT IT ALLOWS IS THAT FOR PATIENTS WITH COMPLEX DISEASE, UNFORTUNATELY, NEAR THE END OF THEIR JOURNEY, THEY CAN THEN SEEK CARE AND ALL OF THOSE SERVICES, INCLUDING PRECISION MEDICINE, TESTING, AND ALL THAT, WILL BE INCLUDED IN THE PACKAGE, IN THE CARE PLAN THAT WOULD BE ALLOWED AT THESE ACADEMIC CENTERS, NCI OR A FEW OF THE OTHER DESIGNATED CENTERS.

IT IS NOT OPENING THE APERTURE FOR CANCER PATIENTS IN MEDI-CAL EARLIER IN THEIR STAGE. YOU DON'T MEET THAT MOST VULNERABLE STATUS THAT WE WERE DISCUSSING EARLIER. IT DOES NOT OPEN THE DOOR FOR THEM TO GET GENOMIC TESTING OR TARGETED THERAPY BEYOND WHAT THEY GET TODAY. SO IT DID NOT FULLY ADDRESS WHAT YOU HAD HOPED IT WOULD. I INFERRED YOU WOULD HAVE HOPED IT WOULD FROM THE BEGINNING AND IT GOT PEELED BACK. AGAIN, I THINK WE SHOULD LOOK AT THIS AS A FIRST STEP BECAUSE IT REALLY IS JUST TIP-OF-THE-ICEBERG TYPE OF SUPPORT.

DR. GOLDSTEIN: YEAH. THE BIG ISSUE, AND EVERYONE WHO'S BEEN ON 2 HEARTS KNOWS, THAT BY THE TIME YOU GET THE DATA ABOUT WHAT MIGHT BE USEFUL TARGETED THERAPY AND PRECISION MEDICINE, THE PATIENT HAS ALREADY PROGRESSED PAST THE POINT WHERE THE

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THERAPIES ARE USEFUL. AND SO IT STRIKES ME THAT THE VERY PURPOSE THAT WEALTHY PEOPLE CAN STILL GO OUT AND GET GENOMICALLY TESTED AT THE FIRST SIGN OF CANCER AND TO FIND OUT WHAT IS THE BEST TARGETED THERAPY FOR THEM. SO THIS IS STILL AN INEQUITY THAT EXISTS. SO I'M NOT QUITE SURE THE GREAT BENEFIT THAT YOU WOULD HOPE IS PRESENT YET.

MR. ROWLETT: I HAVE A QUESTION, AND I'LL ACKNOWLEDGE MY OWN NAIVETE AS I ASK THE QUESTION, BUT IT SPEAKS TO WHAT TED AND HARLAN JUST SAID ABOUT TARGETED THERAPY. AS AN EXAMPLE, I HAVE THE PRIVILEGE OF BEING IN CHARGE OF A COMMUNITY-BASED ORGANIZATION THAT SERVES THESE PATIENTS. AND WE DISCOVER, AS HARLAN DESCRIBED IT, UNFORTUNATELY AT A POINT WHEN THEY'RE AT THE END OF THEIR OPTIONS, ALBEIT THAT THEY HAVE A DISEASE LIKE CANCER, NOT THROUGH PRIMARY CARE A SUPPORT BULLET MIGHT SUGGEST, AND I'M GOING TO HONE IN ON MY QUESTION. BUT THROUGH THE EMERGENCY ROOM DOCTOR WHO IS UNFORTUNATELY THE PLACE WHERE A LOT OF THESE PATIENTS GO TO GET THEIR PRIMARY CARE BECAUSE OF ALL THE ENCUMBRANCES AND CHALLENGES ASSOCIATED WITH MEDI-CAL.

THAT SAID, I JUST WANT TO MAKE SURE THAT WHEN WE THINK ABOUT PRIMARY CARE DOCTORS, AGAIN, I'M

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REPEATING MYSELF, A LOT OF THE PATIENTS THAT I ADVOCATE FOR, THESE KINDS OF EXPERIENCES HAPPEN IN THE EMERGENCY ROOM WHERE THEY ARE UNFORTUNATELY TOLD, HEY, WHAT YOU'RE EXPERIENCING IS SOMETHING, QUITE FRANKLY, THAT MAY END YOUR LIFE BECAUSE IT'S BEEN UNTREATED FOR YEARS. AND IT'S A CONDITION THAT WE, QUITE FRANKLY, DON'T HAVE AN OPTION FOR YOU TODAY. AND THAT HAPPENS ALL TOO OFTEN FOR BEHAVIORAL HEALTH PATIENTS.

DR. LEVINE: AL, I DON'T THINK THIS GROUP CAN ADDRESS AND FIX THE PROBLEM, BUT I REALLY WANT TO PICK UP ON WHAT YOU JUST SAID BECAUSE IT'S REALLY FUNDAMENTAL. AND BY THE WAY, JUST AS AN ASIDE, FREQUENTLY THOSE PATIENTS THAT SHOW UP IN THE ER PROBABLY HAVE SOME SORT OF REFERRAL TO AN ONCOLOGIST IN THE SYSTEM GETTING WORKED THROUGH, BUT NEVER GETTING EXECUTED ON.

MR. ROWLETT: NEVER.

DR. LEVINE: BUT THE BIGGER POINT I WOULD ADD TO YOUR COMMENT IS THAT THERE'S JUST -- SO I'M A MANAGED CARE GUY, BY THE WAY. MOST OF MY CAREER BEFORE COMING TO CITY OF HOPE HAS BEEN ON THE MANAGED CARE SIDE. SO I THINK I KNOW THE BUSINESS PRETTY WELL. THERE'S JUST THIS FUNDAMENTAL BELIEF THAT THINGS HAVE TO BE ABSOLUTELY PROVEN BY

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CASE-CONTROLLED STUDIES AND RESEARCH IS SORT OF LIKE AN ADD-ON AND A PRIVILEGE. AND THERE'S A LACK OF RECOGNITION THAT FOR CANCER, THINGS ARE CHANGING SO FAST, THAT RESEARCH ACTUALLY MAY BE YOUR BEST OPTION. AND BY CUTTING OUT OR MAKING IT HARDER FOR THESE UNDERSERVED POPULATIONS TO GET TO RESEARCH, YOU'RE ACTUALLY -- IT'S AN INEQUITY BEYOND JUST THE FACT THAT WE ARE NOT LEARNING ENOUGH ABOUT AFRICAN-AMERICAN OR HISPANIC POPULATIONS.

LET ME GIVE YOU AN EXAMPLE, AND THEN I PROMISE TO BE QUIET AT LEAST FOR A FEW MINUTES. BUT IF YOU HAD NON-SMALL CELL LUNG CANCER TEN YEARS AGO, IF YOU DIDN'T GET TO A RESEARCH CENTER, YOU WERE GOING TO DIE IN SIX MONTHS. BUT THERE WAS, LIKE, A SEVERAL YEAR LEAD IN THESE TARGETED THERAPIES THAT WERE IN TRIALS THAT WERE PRETTY WELL PROVEN, BUT JUST NOT FDA APPROVED, THAT IF YOU GOT ON THEM, YOU'D BE ALIVE TODAY. AND EVEN AFTER FDA APPROVAL, THERE WERE SEVERAL MORE YEARS BEFORE DOCTORS KIND OF FELT COMFORTABLE USING THEM OR HEALTHPLANS ALLOWED THEM. SO THERE WAS THIS DEATH GAP OF FIVE TO SIX YEARS BECAUSE PEOPLE COULDN'T GET ON TRIALS, AND THOSE PEOPLE THAT COULDN'T GET ON TRIALS WERE DISPROPORTIONATELY FROM UNDERSERVED AND MINORITY POPULATIONS.

SO WE HAVE TO, LIKE, REORIENT OUR ENTIRE THINKING AROUND RESEARCH AND WHAT CIRM BRINGS TO THE TABLE. IT'S NOT A NICE TO HAVE. FOR MANY PEOPLE WITH THESE DIFFICULT CONDITIONS WHERE PATHWAY OR GUIDELINE MEDICINE GIVES YOU A 15-PERCENT SURVIVAL RATE OF FIVE YEARS, THIS IS THE BEST WAY TO GO FOR THESE PATIENTS. IT'S NOT AN ELECTIVE.

MR. ROWLETT: AND I APPRECIATE, HARLAN, YOU BUILDING A BRIDGE BETWEEN MY LACK OF UNDERSTANDING OF THIS CANCER CARE EQUITY ACT. AND I'LL BE THE FIRST TO ACKNOWLEDGE THIS IS MY FIRST TIME BEING INTRODUCED TO THIS AND THE PATIENTS THAT I ADVOCATE FOR. THANK YOU.

DR. GOLDSTEIN: SO THIS IS ALL EXTREMELY IMPORTANT AND VERY RELEVANT. AND ONE OF THE THINGS WHICH I'M VERY FOCUSED ON IN MY OWN WORK IS IN PROSTATE CANCER, THE INTRINSIC INEQUITIES THAT RACE BRINGS. BUT THIS IS NOT THE MOST TOP-OF-MIND THING ABOUT STEM CELL WORK AND THE WORK OF THE INSTITUTE. AND I JUST WANT TO MAKE SURE THAT WE USE THE MISSION THAT THE STATE OF CALIFORNIA HAS CHARTERED CIRM WITH AND OUR COMMITTEE, WHICH IS TO BRING OUR FOCUS ON STEM CELL RESEARCH AND PROJECTS THAT WE ARE SUPPORTING CAN AND MAKE SURE THAT THE DOTS ARE CONNECTED BETWEEN THE INEQUITIES THAT WE SEE AND THE

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TARGETS OF THE THERAPIES THAT WE ARE STEWARDS OF.

TO ME THAT -- WE ARE DOING MANY THINGS IN MANY AREAS AS PART OF THE STATE AND THEY'RE REALLY IMPORTANT, AND I'M REALLY GLAD AND HAPPY THAT THIS PROGRESS, THAT THERE IS SOME ATTENTION TO THIS EVEN IF IT'S NOT EVERYTHING WE WANT IT TO BE.

SO I WANT TO BRING BACK TO WHAT DO WE SEE AS THE THERAPEUTIC CONNECTIONS, THE ACTUAL MEDICAL APPLICATIONS THAT WE THINK WE CAN ADDRESS THAT OVERLAP WITH THE DOMAIN OF THIS LEGISLATION?

DR. TURBEVILLE: MAYBE I CAN OPINE AND THEN PUNT IT TO MARIA IF YOU WANT TO GO FIRST.

DR. MILLAN: CHAIR.

CHAIRPERSON BONNEVILLE: THANK YOU.

DR. MILLAN: SO, TED, I THINK THAT'S A REALLY IMPORTANT QUESTION. AND AT THE LAST MEETING, DR. ABLA CREASEY GAVE JUST KIND OF AN OVERVIEW OF OUR PORTFOLIO THAT I WANTED TO JUST REMIND THIS BODY, THAT WE DO HAVE CAR-T PROGRAMS AND NEXT GENERATION CAR-T PROGRAMS IN SOLID CANCER. WE HAVE A CAR-T PROGRAM ACTUALLY FOR PROSTATE CANCER AS A MATTER OF FACT. SO WE DO FUND KIND OF SOME OF THESE RARE SUBSETS OF CANCERS THAT WOULD FIT INTO THAT CATEGORY OF THIRD LINE, NO OTHER OPTION THAT WOULD IMPACT THE STEPS THAT THIS PARTICULAR ACT IS

ADDRESSING IN THE FIRST INSTANCE.

SO I JUST WANTED TO POINT OUT THERE IS A RELEVANT OPPORTUNITY. AND THEN, AGAIN, LINKING TO WHAT MARIA SAID EARLIER, WHICH IS THAT IT'S FUNDED BY CIRM. SO BY ADDRESSING THAT, IT ADDRESSES SPECIFIC PROGRAMS, BUT IT CREATES KIND OF THE USE CASE AND THE DEMONSTRATION CASES FOR HOW THIS ACT COULD BE SUPPORTED TO BRING ACCESS TO CALIFORNIA PATIENTS FOR CUTTING-EDGE TRIALS, THAT HARLAN HAD SO ELOQUENTLY PUT, COULD BE THE BEST TREATMENT OPTION EVEN THOUGH THEY HADN'T WORKED THEIR WAY ALL THE WAY THROUGH APPROVAL AND ALL OF THE THINGS TO ADOPTION.

SO ANYWAY, I'M SORRY, SEAN, TO CUT IN FRONT. I THINK IT'S SUCH AN IMPORTANT TOPIC THAT I KNOW, SEAN, YOU'VE BEEN KIND OF TALKING TO THE TEAM ABOUT.

DR. TURBEVILLE: YEAH. CERTAINLY. DR. MILLAN IS SPOT ON. SO FROM A POLICY STANDPOINT, AS WE START LOOKING AT FOUR- OR FIVE-YEAR PROJECTIONS IN TERMS OF WHAT OUR IMPACT FACTOR COULD BE, THIS IS ONE THAT'S SORT OF LOW HANGING FRUIT THAT WE COULD REALLY MEASURE THE IMPACT IF WE GO OUT THERE AND HELP GET THE EDUCATION OUT THERE TO COMMUNITY DOCS.

AS HARLAN MENTIONED, MANY OF THE PATIENTS DOESN'T PAY FOR, LET'S SAY, MULTIPLE MYELOMA AND

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WOULD BE LOOKING TO EXPERIMENTAL MEDICATION AT ONE OF THOSE SORT OF NCI SITES, WHICH, LO AND BEHOLD, THERE ARE A NUMBER OF CAR-T THERAPIES THAT WE ARE SUPPORTING IN OUR PORTFOLIO. AND SO THESE PATIENTS MAY BE ABLE TO QUALIFY FOR THAT.

SO THERE'S A NUMBER OF TOUCHPOINTS FROM AN ACCESS STANDPOINT AND, MORE IMPORTANTLY, PROBABLY FROM AN IMMEDIATE ACCESS STANDPOINT, SOMETHING THAT WE CAN MEASURE, QUITE FRANKLY, IF, IN FACT, WE COULD PUT SOMETHING TOGETHER.

DR. GOLDSTEIN: NOT TO BELABOR THE POINT, BUT IT SOUNDS LIKE THIS IS JUST ONE MORE TOOL IN OUR PATIENT ADVOCACY TOOLBOX. IT'S NOT GOING TO REALLY CHANGE ANYTHING WE ARE DOING IN THIS, IN THE AAWG, ANYWAY, END OF THINGS.

DR. TURBEVILLE: I WOULD ACTUALLY PROPOSE THAT WE BE A LITTLE BIT MORE PROACTIVE AND PUT SOMETHING IN PLAY. SO IT DOES HAVE TOUCHPOINTS WITH WHAT'S GOING ON WITH THE PATIENT ADVOCACY. I THINK THIS WOULD BE, IF IT WAS APPROVED BY THIS GROUP, IN AAWG, WE COULD COME BACK TO YOU WITH A PROPOSAL ON A VERY AGGRESSIVE PROPOSAL ON HOW WE CAN GET THE WORD OUT, COLLABORATING POTENTIALLY WITH A NUMBER OF OTHER STATE ORGANIZATIONS, OUT TO THE COMMUNITY. THE COMMUNITY CARE CENTERS OF EXCELLENCE IS NOT

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GOING TO BE UP AND RUNNING FOR SOME TIME. SO I THINK THIS WOULD BE POTENTIALLY A MISSED OPPORTUNITY IF WE DIDN'T GET OUT THERE NOW AND START PUTTING SOME THINGS WITH REGARD TO AN EDUCATIONAL STANDPOINT. I'M OPEN FOR PUSHBACK FROM YOU ON THAT, HARLAN.

CHAIRPERSON BONNEVILLE: DANA, YOU HAD A QUESTION?

DR. DORNSIFE: JUST FROM OUR EXPERIENCE AT LAZAREX, I MEAN WE ARE 17 YEARS IN, AND ENGAGING AT THE COMMUNITY LEVEL WITH COMMUNITY PHYSICIANS IS, IF THEY'RE NOT ASSOCIATED WITH A RESEARCH INSTITUTION, IT'S NOT AS EASY AS YOU MIGHT THINK. I MEAN WE THOUGHT INITIALLY, OKAY, WE'LL JUST GO OUT THERE AND INTRODUCE THEM TO OUR CLINICAL TRIAL NAVIGATION AND TRAVEL REIMBURSEMENT FOR PATIENTS TO PARTICIPATE IN TRIALS. BUT IF THEY'RE NOT FAMILIAR WITH THE TRIALS, THEY'RE NOT FAMILIAR WITH THE TECHNOLOGY, THERE'S A HESITATION FOR THESE DOCTORS TO ENGAGE IN CONVERSATION WITH THEIR PATIENTS AROUND THOSE TOPICS BECAUSE, A, THEY HAVE LIMITED TIME, 11 MINUTES FROM THE START TO STOP OF AN APPOINTMENT; B, THEY DON'T NECESSARILY POSSESS THE KNOWLEDGE REQUIRED TO HAVE A CONVERSATION AND ANSWER ALL THE QUESTIONS; AND, C, THEY THEN BECOME THE CONDUIT OF INFORMATION FOR THAT

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INDIVIDUAL, WHICH REQUIRES A SERIOUS TIME SYNC FROM THEIR PERSPECTIVE.

SO THERE ARE OTHER ISSUES, I THINK, THAT I WOULD HOPE WE WOULD JUST KEEP IN MIND GOING FORWARD AROUND SOME OF THOSE CHALLENGES.

CHAIRPERSON BONNEVILLE: THANK YOU, DANA.

DR. LEVINE: I THINK IT'S A REALLY GOOD POINT, AND WE WRESTLED WITH THAT AS WE THOUGHT ABOUT THE ACT. AND SO THIS IS NOT A SNAPSHOT. THIS IS GOING TO BE A MOVIE BECAUSE IT'S GOING TO TAKE TIME TO CHANGE THE MIND SHARE, THE MINDSET OF PEOPLE. I GUESS WHERE I WOULD SUPPORT SEAN IN DOING THIS IS THAT I THINK, AT THE END OF THE DAY, IF WE DON'T INCULCATE INTO THE SYSTEM THE IDEA THAT LOOKING FOR RESEARCH OPPORTUNITIES IS JUST PART OF THE NORM, IT'S NEVER GOING TO HAPPEN. AND DANA'S POINT IS NOT GOING TO HAPPEN WITH THE INDIVIDUAL DOCTOR LIKE BEING THEIR HERO.

BUT I DO THINK WE SHOULD TAKE ADVANTAGE OF THE FACT THAT MEDI-CAL HERE IS MANAGED, AND THERE ARE GROUPS AND THERE ARE MEDICAL DIRECTORS AND THERE ARE LEADERS. AND IF WE CAN FIGURE OUT HOW TO EDUCATE THOSE GROUPS AND HOLD THEM ACCOUNTABLE TO EDUCATE THEIR NETWORKS, THEIR DOCTORS, AND THEIR CASE MANAGERS AND UTILIZATION MANAGEMENT TEAM SO

THAT EVERY ONE IS LOOKING FOR THE OPPORTUNITY TO HELP PEOPLE, IT TAKES TIME. IT'S NOT HOW WE OPERATE AT ALL TODAY, BUT I THINK WE NEED TO MAKE THIS AS A FIRST STEP AND CHANGE, AGAIN, CHANGE THE MINDSET OF HOW WE LOOK AT PUTTING PEOPLE INTO RESEARCH TRIALS.

AND BY THE WAY, UNDERSERVED PEOPLE, MINORITIES, AREN'T ONLY IN MEDI-CAL. THEY'RE IN EXCHANGE PRODUCTS AND OTHER HMO PRODUCTS. I THINK WHAT I GOT EXCITED ABOUT HEARING SEAN'S PROPOSAL IS THIS IS SORT OF A FIRST STEP OF TRYING TO RAISE THE LEVEL, RAISE THE CONSCIOUSNESS OF THESE GROUPS. AND I DON'T THINK IT CAN BE AN INDIVIDUAL DOCTOR LEVEL. I THINK IT HAS TO BE THE GROUP LEVEL AND MEDICAL DIRECTOR LEVEL. IT'S A HEAVY LIFT. IT MAY BE A PIPE DREAM, BUT THAT'S WHERE I SEE THE OPPORTUNITY TO TRY TO LIFT UP THE STATE.

CHAIRPERSON BONNEVILLE: I'D LIKE TO INTERJECT REALLY QUICKLY. I THINK WHERE THIS MAKES THE MOST SENSE IS APPROACHING IT FROM WHERE OUR CLINICAL TRIALS ARE BEING ADMINISTERED. SO THE ALPHA CLINICS AND THEN THROUGH THE TRIAL SPONSOR DIRECTLY. I THINK THAT THAT'S SORT OF WHAT TED WAS GETTING TO IS WE HAVE TO FOCUS IN ON WHAT CIRM IS, WHERE OUR MISSION IS, WHAT WE ARE FUNDING, AND WHERE WE CAN PLAY -- WHERE WE CAN MAKE THE MOST DIRECT

IMPACT. WHAT I DON'T WANT TO DO IS TAKE ON A PROJECT OR A PLAN THAT'S OVER SCOPE OF WHAT WE DO BECAUSE I LOOK AT THAT AS DISTRACTIONS. THIS GROUP HAS A LOT THAT THEY NEED TO ACCOMPLISH IN THE COURSE OF THE NEXT THREE TO FIVE YEARS. SO UNLESS IT IS DIRECTLY RELATED TO SOMETHING THAT CIRM IS DIRECTLY INVOLVED WITH, I DON'T KNOW THAT -- I THINK IT WOULD WORK BEST IF THAT'S SORT OF YOUR APPROACH THERE; THAT IS, GOING THROUGH WHERE OUR TRIALS ARE ADMINISTERED, THE TRIAL SPONSORS, EDUCATING AROUND THERE.

DR. GOLDSTEIN: ONE OF THE THINGS, FOR EXAMPLE, WHICH I THINK -- I'M SORRY. YOU HAVE A BOARD IN FRONT OF YOU.

CHAIRPERSON BONNEVILLE: GO AHEAD, TED. AND THEN ADRIENNE IS NEXT AND THEN DAN.

DR. GOLDSTEIN: OKAY. THANK YOU. SO JUST BY WAY OF CONTRAST, IN CANCER IT IS WHAT I'VE SPENT THE LAST DECADE OF MY LIFE STUDYING AND WORKING ON. BUT DIRECTLY RELEVANT TO THE CIRM MISSION OF STEM CELL AND THE THERAPY THAT I THINK IS UNIQUE IS FOR SICKLE CELL ANEMIA. AND THERE IS AN OPPORTUNITY WHERE WE SHOULD BE LOOKING FOR HOW DO WE MAKE DIRECT CONTACT WITH PATIENTS WHO ARE MOST VULNERABLE. IT'S NOT AN ANSWER, BUT IT IS SOMETHING WHICH POINT OF

CONTACT IS GOING TO BE THE EMERGENCY ROOMS AND THE CLINICS WHERE PEOPLE GO TO GET AID. AND HOW DO WE MAKE THAT CONNECTION AS QUICKLY AS POSSIBLE TO CLINICAL TRIALS AND THERAPEUTIC USE.

I THINK THAT'S A MEDICAL PATHWAY THAT, IF WE CAN FIND EQUIVALENT ONES IN CANCER, THAT THE STEM CELL THERAPY IS BOTH UNIQUE AND DIRECTLY APPLICABLE TO THE CIRM MISSION, THEN WE SHOULD ADDRESS IT IN AS WIDE A FASHION AS POSSIBLE.

CHAIRPERSON BONNEVILLE: ADRIENNE.

MS. SHAPIRO: SO I WAS GOING TO SAY IN SICKLE, WE HAVE OFTEN LOOKED AT WHAT THEY'VE DONE IN CANCER AND FOR CANCER TO FIND WHAT IS POSSIBLE AND THEN TRY TO GET THOSE THINGS OFFERED TO US IN THE SICKLE WORLD. SO BECAUSE IT'S SO BIG AND SO MANY, RIGHT, FOR US, OUR HELP IS DONE BY HEMATOLOGISTS. THE IDEA OF CIRM MAYBE DOING SOME HANDOUTS OR WHATEVER FOR CANCER IN THAT SENSE IS REALLY GREAT.

BUT I WANT TO SAY TWO THINGS. ONE IS I WOULD LIKE FOR US TO THINK A LITTLE BIT OUTSIDE THE BOX AS WE LOOK AT THINGS LIKE PATIENT SUPPORT SERVICES. WHAT WE FOUND IS WE HAD CREATED POINT-OF-CARE ADVOCATES, AND OUR POINT-OF-CARE ADVOCATES GO EITHER TO VIRTUALLY OR PHYSICALLY TO APPOINTMENTS WITH PATIENTS, ALSO ON THE HOSPITAL

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FLOOR, ANY PLACE WHERE THEY'RE HAVING CONTACT. AND OUR ADVOCATES ARE TRAINED NOT ONLY TO SPEAK ABOUT SICKLE CELL, BUT ALSO TO SPEAK ABOUT THINGS LIKE CLINICAL TRIALS.

AND SO I'D LIKE FOR US TO KIND OF LOOK AT MAYBE ROLES OUTSIDE OF THE TRADITIONAL ROLES OF I WANT TO SAY A PROVIDER ROLE OR ALSO, I DON'T WANT TO SAY ADVOCATE, BUT JUST THE TRADITIONAL WAY. IN ORDER FOR US TO DO THIS AND GET THE TYPE OF SUPPORT PATIENTS ARE GOING TO NEED, WE'RE GOING TO HAVE TO LOOK FOR THINGS OUTSIDE OF A DOCTOR, OUTSIDE OF A NURSE, OUTSIDE OF A PSYCHOLOGIST. WE'RE GOING TO HAVE TO CREATE SOME NEW ROLES IN ORDER TO SUPPORT PATIENTS THROUGH THIS.

AND ONE OF THE THINGS WE'VE FOUND IS THAT THE DOCTORS, EVEN IF THERE ARE THREE DOCTORS IN AN AREA, ONCE THEY GET TO KNOW A POINT-OF-CARE HEALTHCARE ADVOCATE AND THEY'VE PROVEN THEMSELVES, FOR LACK OF A BETTER TERM, THAT THEY ARE MUCH MORE LIKELY TO HEAR US AND ENGAGE IN CONVERSATION ABOUT POSSIBILITIES OF NEW TREATMENTS AND CURATIVES.

AND THEN THE OTHER THING IS WE'VE BEEN TRYING REALLY HARD TO GET INFORMATION INTO ER'S BECAUSE THERE WAS A MAJORITY OF THE SICKLE COMMUNITY WHO GOES TO ER'S FOR THEIR HEALTHCARE. AND ONE OF

THE ROADBLOCKS WE HAVE THERE IS THE FACT THAT THE ER DOCS DON'T HAVE MATERIALS THAT HAVE BEEN APPROVED BY THE HOSPITAL TO ACTUALLY HAND OUT TO THE PATIENTS. SO MAYBE US LOOKING AT THINGS LIKE THAT, MAYBE HAVING CIRM BEHIND HOW TO GET INFORMATION OUT TO PATIENTS NO MATTER WHERE THEY ARE AT THEIR POINT OF CARE COULD COME UNDER US BOTH. THANK YOU.

CHAIRPERSON BONNEVILLE: THANK YOU, ADRIENNE. DAN.

MR. BERNAL: THANKS FOR THE GREAT PRESENTATION. JUST PUNTING ON MAYBE SOME OF WHAT ADRIENNE TALKED ABOUT AND ALSO WHAT AL TALKED ABOUT, I'M LOOKING AT THE CALIFORNIA CANCER CARE EQUITY ACT, I FELT THAT OPPORTUNITIES IN THAT CAME ABOUT BY ACCIDENT. I'M SURE IT INVOLVED SOME ADVOCACY FROM FORMER VICE CHAIR SENATOR TORRES AND OTHERS. I'M WONDERING IF THERE ARE OTHER OPPORTUNITIES ON THE HORIZON FOR MOVING LEGISLATION AT THE STATE OR EVEN THE FEDERAL LEVEL TO LOOK AT CARVING OUT CONSIDERATION LIKE WE ARE SEEING HERE THAT REQUIRES FRONT-LINE CLINICAL STAFF TO REALLY BE WELL VERSED IN AND ABLE TO DIRECT PEOPLE TO TRIALS AND OTHER THINGS.

DR. TURBEVILLE: WELL, I CERTAINLY KNOW THERE'S A LOT OF TALK ABOUT UPDATING THE

LEGISLATION. THAT'S NOT MY AREA OF EXPERTISE, BUT CERTAINLY IT'S SOMETHING WE CAN KEEP ON OUR RADAR. AND IF THERE'S AN OPPORTUNITY, THIS MIGHT BE A FIRST FOR CIRM, I'LL JUST THROW THIS OUT HERE, TO PARTICIPATE IN THAT. THERE'S A LOT OF HEAVY WEIGHTS HERE THAT HAVE LOTS OF TOUCHPOINTS. CERTAINLY THAT MAY BE A SECOND EDITION. I DON'T KNOW IF HARLAN HAS ANY INPUT ON THAT OR IF THAT'S BEING DISCUSSED EXTERNALLY.

DR. LEVINE: I FEEL LIKE WE HAVE A LOT TO ADD TO THAT, AND I THINK IT'S A GREAT IDEA. SENATOR PORTANTINO WAS A CHAMPION BEHIND THIS. A YEAR BEFORE SENATOR RUBIO WAS SUPPORTIVE OF THE CANCER PATIENT BILL OF RIGHTS. IT TOOK A COALITION TO DO THIS, BUT I THINK IF THIS GROUP WANTED TO ADD ITS WEIGHT TO THE COALITION TO EXPAND BEYOND CANCER AND ADDRESS THE ISSUES OF SICKLE AND OTHER TARGETS FOR REGENERATIVE MEDICINE, I THINK IT WOULD GO A LONG WAY. I DON'T KNOW WHAT ABILITY THIS GROUP HAS TO BECOME POLITICAL LIKE THAT, BUT IT WAS A HIGHLY POLITICAL PROCESS, BUT I THINK DAN IS ENTIRELY RIGHT.

WITHOUT TAKING UP TOO MUCH MORE TIME HERE, I HAVE TO SAY THAT CITY OF HOPE IS LOOKING AT EXPANDING IN CALIFORNIA. AND WHILE IT'S HARD, WE

ARE INITIATING SOME CONTACTS IN WASHINGTON RIGHT NOW TO GET US EITHER TO THE CONGRESS OR TO THE WHITE HOUSE TO DISCUSS THIS REALLY IMPORTANT ISSUE.

I THINK WE ALL NEED TO BAND TOGETHER AND WORK ON THIS. AND MY POINT I WAS TRYING TO MAKE EARLIER WAS IT'S NOT -- CANCER CAN'T BE ISOLATED. THE WHOLE IDEA OF PUTTING SOMEONE IN A TRIAL, WHETHER IT'S IN AN ALPHA CLINIC OR A RESEARCH CENTER, IT HAS TO BE PART OF A MIND-SET BECAUSE IT'S PART OF PATIENT FLOW. BECAUSE THERE WILL BE SOME PATIENTS WHERE RESEARCH AT A UCLA OR CITY OF HOPE IS MORE APPROPRIATE THAN JUST THE ALPHA CLINIC.

THERE WILL NEED TO BE SOME CLINICAL DECISION-MAKING. AND I THINK WE JUST NEED TO MAKE IT PART OF THE SYSTEM. AND RIGHT NOW MANAGED MEDI-CAL AND MANAGE EXCHANGES, IT'S JUST NOT PART OF THE SYSTEM. AND THAT'S WHAT WE NEED TO DO IS RAISE -- LEVERAGE LEGISLATION TO CHANGE THE CONSCIOUSNESS OF THE HEALTHCARE DELIVERY SYSTEM.

SO I'M WITH DAN. I ALSO NOMINATE DAN TO LEAD THE CHARGE.

MR. ROWLETT: CHAIR, LET'S CALL THE ROLL PLEASE.

CHAIRPERSON BONNEVILLE: NO GOOD DEED GOES UNPUNISHED, DAN. SO THANK YOU.

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MR. BERNAL: DON'T FORGET WE HAVE A CURRENT VICE CHAIR WITH EXTENSIVE LEGISLATIVE EXPERIENCE AS WELL. BUT HAPPY TO PARTNER ON THAT.

DR. TURBEVILLE: WELL, I WANT TO THANK EVERYBODY FOR YOUR INPUT. THANK YOU TO GEOFF FOR BRINGING EVERYBODY UP TO SPEED ON THE COMMUNITY CARE CENTERS OF EXCELLENCE. THAT WORKSTREAM IS KICKING OFF REALLY QUICKLY. SO WE ARE TRACKING FOR A CONCEPT PLAN THIS YEAR. I DO WANT TO THANK YOU FOR LISTENING IN ON THE OPPORTUNITIES FROM THE CANCER CARE EQUITY ACT. I'M SURE I'LL RECEIVE EMAILS FROM YOU FOR FOLLOW-UP, AND I ENCOURAGE YOU TO DO THAT. AND MAYBE WE WILL REGROUP INTERNALLY AND CONSIDER THIS FOR DISCUSSION AND ALSO PREPARE FOR THE NEXT AAWG, WHICH WE HAVE A LOT OF USEFUL INFORMATION ALL THE WAY FROM REAL-WORLD DATA COLLECTION TO POST SURVEILLANCE. SO LOTS OF IDEAS COMING YOUR WAY.

CHAIRPERSON BONNEVILLE: THANKS. REALLY QUICKLY, DOES ANYONE HAVE ANY OTHER COMMENTS? AND THEN WE HAVE PUBLIC COMMENT. I KNOW THERE'S SOMETHING TO READ INTO THE RECORD. ARE THERE ANY OTHER COMMENTS FROM THE GROUP? OKAY, MARIANNE.

MS. DEQUINA-VILLABLANCA: THIS PUBLIC COMMENT IS FROM DON C. REED.

"CIRM, AND THE FIGHT TO MAKE CURES

AFFORDABLE. SIXTY PERCENT OF AMERICAN ADULTS NOW LIVE WITH AT LEAST ONE CHRONIC CONDITION. FORTY-TWO PERCENT HAVE MORE THAN ONE. NEARLY 30 MILLION HAVE FIVE OR MORE.

"THESE ACCOUNT FOR MORE THAN FOR 40 PERCENT OF U.S. HEALTH SPENDING.

"30 CONDITIONS CLUSTER TOGETHER; FOR EXAMPLE, DEPRESSION IS ASSOCIATED WITH STROKE AND ALZHEIMER'S WHILE TB AND HIV/AIDS ARE ASSOCIATED WITH DIABETES AND CARDIOVASCULAR DISEASE.

"CLUSTER MAY BE AMENABLE TO IMPROVEMENTS IN HEALTH AND COST OUTCOMES THROUGH SHIFTS IN HEALTHCARE DELIVERY. THIS MAY BE IMPORTANT.

"BUT IS OUR COUNTRY EQUIPPED TO DEAL WITH A HUGE NUMBER OF PATIENTS, EACH WITH MULTIPLE DISEASES? IN A WORD NO.

"LIKE WATERLESS DESERTS, AMERICA HAS VAST AREAS LACKING ADEQUATE MEDICAL CARE.

"IN 2021, 8.3 PERCENT OF PEOPLE HAD NO HEALTH INSURANCE.

"THE NUMBER OF PEOPLE WITHOUT HEALTH INSURANCE VARIES. AT 3 PERCENT, MASSACHUSETTS HAS THE FEWEST UNINSURED WHILE TEXAS AT 18.4 PERCENT HAS THE MOST LACKING INSURANCE.

"THIS IS WHY THE WORK OF CIRM'S

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ACCESSIBILITY AND AFFORDABILITY COMMITTEE IS SO IMPORTANT.

"CIRM MUST HAVE A DOUBLE GOAL. WE NEED TO NOT ONLY COME UP WITH A CURE FOR CANCER AND VARIOUS OTHER CHRONIC DISEASES, BUT ALSO MAKE IT CHEAP AND AFFORDABLE.

"BECAUSE IF SCIENTISTS COME UP WITH A CURE FOR CANCER, BUT IT COSTS 20 MILLION FOR EACH PATIENT, IT ALMOST WOULD NOT MATTER BECAUSE WHO COULD AFFORD IT?

"MOST OF US EXPECT THAT THE PRICE OF THERAPIES WILL BE HIGH AT FIRST, BUT THEN GO DOWN, JUST AS COMPUTERS WERE UNAFFORDABLE AT FIRST, BUT TODAY ARE CHEAP AS CHILDREN'S TOYS.

"SIMILARLY, I BELIEVE OUR ULTIMATE RESULT WILL BE TO BRING THE REMEDIAL THERAPIES WITHIN THE REACH OF EVERYONE. IT WILL TAKE TIME AND EFFORT, OF COURSE, BUT THAT IS WHY YOU ARE HERE.

"SO THANK YOU. FOR EVERY HOUR YOU SPEND, EVERY DAY YOU WORK TOWARD THAT INCREDIBLE GOAL. THE FAMILIES OF CHILDREN YET UNBORN WILL HAVE REASON TO BLESS CIRM'S NAME."

CHAIRPERSON BONNEVILLE: THANK YOU, DON REED, FOR THAT. IF THERE'S NOTHING ELSE, I THINK WE STAND ADJOURNED. AND WE WILL SEE YOU NEXT MONTH.

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THANKS, EVERYONE.

(THE MEETING WAS THEN CONCLUDED.)

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REPORTER'S CERTIFICATE

I, BETH C. DRAIN, A CERTIFIED SHORTHAND REPORTER IN AND FOR THE STATE OF CALIFORNIA, HEREBY CERTIFY THAT THE FOREGOING TRANSCRIPT OF THE VIRTUAL PROCEEDINGS BEFORE THE ACCESSIBILITY AND AFFORDABILITY WORKING GROUP OF THE INDEPENDENT CITIZEN'S OVERSIGHT COMMITTEE OF THE CALIFORNIA INSTITUTE FOR REGENERATIVE MEDICINE IN THE MATTER OF ITS REGULAR MEETING HELD ON FEBRUARY 7, 2023, WAS HELD AS HEREIN APPEARS AND THAT THIS IS THE ORIGINAL TRANSCRIPT THEREOF AND THAT THE STATEMENTS THAT APPEAR IN THIS TRANSCRIPT WERE REPORTED STENOGRAPHICALLY BY ME AND TRANSCRIBED BY ME. I ALSO CERTIFY THAT THIS TRANSCRIPT IS A TRUE AND ACCURATE RECORD OF THE PROCEEDING.

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