

Meeting Report

Toward Fair Cures: Integrating the Benefits of Diversity in California Stem Cell Program

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INTRODUCTION

On October 14th, 2006, the Greenlining Institute, the UC Berkeley Project on Stem Cells and Society and the Children's Hospital Oakland Research Institute partnered to host a conference on minority health disparities and the promises of stem cell research.¹ The conference was entitled, "Toward Fair Cures: *Integrating the Benefits of Diversity in California Stem Cell Research Program*." The purpose of this report is to summarize the conference themes and recommendations in order to broadly disseminate and help address the issues identified as the most pertinent to underserved populations in stem cell research.

Adapted as state law in 2004, the California Stem Cell Research and Cures Act directs \$3 billion of state monies toward stem cell research. This investment into California's biotech industry is also predicted to create up to 22,000 jobs on average a year.² With such an investment into healthcare and employment opportunities, the underserved and minority communities of California must ensure that their stem cell program serves the state's diverse population. As Keith Wailoo, professor at Rutgers University, stressed in his presentation, fairness, equity, recognition, and equality depend on broader political currents outside of medicine. Even when high-profile programs such as stem cell research emerge, the general public must not lose sight of the broader issues of racial and ethnic health disparities. As Sujatha Jesudason of the Center for Genetics and Society elaborated further, the general public and the scientific community needs a paradigm shift. Stem cell research is at the crux of a highly politicized debate in reproductive rights where narrow lines are drawn over those who oppose and those who promote research. However, this view must be expanded to include a broader range of populations and platforms addressing issues of social justice as this conference attempts to exemplify.

CONFERENCE OBJECTIVES

The purpose of the conference was to unite leaders from minority communities, academia and the sciences to discuss the importance of ethnic diversity at all levels of stem cell research in California. Conference participants considered strategies for increasing the understanding of the economic and medical potential of stem cell research among historically underserved minority communities to ensure that California's stem cell research efforts serve the state's diverse community. All conference participants were asked to provide recommendations to California Institute for Regenerative Medicine (CIRM), community leaders, private industry, and the legislature to best coordinate their efforts toward developing a scientific program inclusive of diverse needs.

CONFERENCE THEMES

Institutional barriers to diversity. Conference participants agreed that there were a myriad of institutional and social barriers facing underserved communities in accessing science education. John Matsui, Director of the Biology Scholars Program at UC Berkeley, highlighted the key question: "How important is diversity in producing good science?" Matsui's answer to this question focused on cultivating the next generation of scientists from diverse backgrounds and highlighting the unique contributions that culturally diverse students bring. These contributions take the form of bringing an increased breadth of experience to scientific research and development. Indeed, the way in which one's cultural background consequently influences the overall research agenda was a major theme echoed throughout the meeting. Matsui's success in working with underserved college students at UC Berkeley demonstrates that "students are often not the problem. They do not need to be made 'better.' Rather it is our programs and institutions that must change for the better." Conference participants agreed that California is in a unique position to change its scientific institutions with \$3 billion of the state's money investing into the training of the next generation of biomedical researchers.

Career pipeline opportunities. Yesenia Valenzuela, a graduate and current staff member of the Oakland-based FACES for the Future, used her personal testimony to stress the importance of outreach projects that seek to help bridge disparities in access to science education, career guidance, and mentors in the sciences. Illustrating an alternative form of pipeline program, Dr. José Ramón Fernández-Peña, professor at San Francisco State University and director of the Welcome Back Initiative, emphasized the value of immigrant health professionals in bridging gaps between the stem cell research workforce and a pool of diverse professionals. Fernández-Peña stressed the potential for immigrant health professionals to fill the need for future employment positions in the biotech industry resulting from the \$3 billion investment into biomedical research. Both Valenzuela and Fernández-Peña illustrated the importance of pipeline programs that guide students as well as immigrant professionals to create a more diverse scientific workforce. This will be crucial for filling the projected thousands of employment opportunities in the sciences to be developed with the state's investment into stem cell research.

Science outreach and communication. According to Jennifer Reardon, professor at the University of California at Santa Cruz, conference participants must begin to expand the narrow

biomedical framing of the issues around stem cell research to focus also on understanding the structure of a community and its needs when involving disadvantaged peoples in the stem cell debate. Reardon also emphasized the important role of “translational players”—people in academia, government agencies, and community leaders to adapt complex and technical information involved in stem cell research. In essence, the process of becoming a participant in stem cell research should not be a burden for the communities that need to be involved. Conference participants agreed that there needs to be a greater understanding of the demands on communities of color for inclusion in California’s stem cell program. Addressing outreach plans in such a way would recognize the historic exclusion of underserved groups in the guidance of scientific research. Ortensia Lopez and Alberto Perez Rendon from El Concilio of San Mateo presented a model for community-based outreach in their program called *Nuestro Canto de Salud*. Aside from educating and screening tens of thousands of at-risked individuals for chronic diseases, *Nuestro Canto de Salud* educates community members in the benefits of clinical research. *Nuestro Canto de Salud* does this by partnering with biotech and pharmaceutical companies who provide the financial resources to train community health workers who in turn educate and encourage their own communities to participate in clinical research.

Affordability. The issue of how Californians will be able to afford future therapies and diagnostics was a major concern for all conference participants. As affordability is directly connected with questions of how to arrange intellectual property regulations, Pilar Ossorio explained how current patent laws would likely limit the accessibility of medical treatments. While the purpose of patents is to promote the common good by maximizing the dissemination of new and useful information and products, there is no distributive element to patent law. As a result, researchers and firms that obtain patents on health care technology, such as stem cell advancements, have virtually no incentive or authorization to ensure fair access to innovations in medical treatment. Without an adjustment in patent law, the cost of patent licenses in the stem cell industry will impact costs of any potential products. Because researchers have to recoup the costs of licenses, prices are driven up, with the greatest burden ultimately falling on disadvantaged communities of color. The CIRM currently includes provisions for affordability in their intellectual property policies that may be used as models for future state-funded research programs.³

Employment opportunities. Conference participants also voiced their concerns over how the tens of thousands of employment opportunities to be created with the state’s investment into stem cell research will be distributed fairly among all Californians. These jobs take the form of research positions, CIRM career staff, and supplier contracts. In his presentation, Joe Tayag from the Greenlining Institute showed

that there were over 60 different types of supplier services used by a large biotech company. These jobs range from advertising, to catering, to furniture manufacturing. Audience members such as Ernie Baker from the Covenant on Health in San Francisco stressed that these jobs may empower economically underserved communities if employment rates reflect the diversity of the state. Conference participants agreed that these jobs need to be recognized as essential to stem cell research and should be accounted for in any discussion of the fair implementation of stem cell research.

Community Reinvestment. Joe Tayag of the Greenlining Institute also focused on public-private partnerships as a manner of bringing fairness to the stem cell research and treatment debate. A balance must be achieved between private industry’s desire to profit, which often is the indirect impetus for technological innovation, and the public’s need to access future therapies. Tayag cited successful community reinvestment models in other arenas that have been employed—such as the Community Reinvestment Act of 1977—as possible models for upholding corporate leadership in the biotechnology industry. As discussed throughout the meeting, community reinvestment takes the form of investing in science pipeline programs, community outreach, science education, and making commitments to increase diversity in the biotech workforce. The crux of Tayag’s message was that advocates for fairness in the industry must convince private sector leaders and researchers to see community leaders and members as a resource. Benefits for the biotech industry include bettering public relations, investing in the next generation of diverse workforce, new ideas, as well as facilitating the participation of underserved populations in clinical research.

Protecting and including women in stem cell research. Lisa Ikemoto, professor of law at the University of California at Davis, aptly issued a reminder that institutions supporting health care research are dominated by Caucasian males. In explaining how gender inequities exist in the California stem cell research program, Ikemoto used evidence from the CIRM project. The requirements for CIRM researchers are as follows: possessing a Ph.D., M.D., or equivalent, as well as a “full-time, faculty-level position” with “his/her own dedicated laboratory.” Data from the National Science Foundation reveals the imbalance: 70.13% of researchers currently employed are male, while less than 10% are minority women. This is institutionally grounded as demonstrated by the low numbers of women in the sciences with these credentials: according to the National Academies of Science, women comprise only 30% of natural science Ph.D.’s, and only 15% of professional science faculty.⁴ Ikemoto also noted that the lack in gender diversity may jeopardize the effectiveness of the process of recruiting women as egg donors in avoiding the potential exploitation and coercion of women.

The Politics of Disability. Since its campaigning, Proposition 71 has featured an image of the disabled population as one in need of the therapies promised by stem cell research. Responding to this, Patricia Berne, Director of the Project on Race, Disability, and Eugenics at the Center for Genetics and Society, brought the perspective of a disability rights advocate. Berne cautions against the danger of discussing future stem cell therapies in a manner that promotes a pessimistic and disempowering image of people with disabilities, rather than a problem created by social perceptions of disability. The social model of disability refutes the implication that people have distinct abilities and limits. In essence, the social model addresses the fact that a disabled person is a *person* first and foremost, and not a *disabled* person.

RECOMMENDATIONS

Set clear and measure goals for increasing diversity. Representatives from the CIRM, including Gilberto Sambrano, urged the public to attend the CIRM's public meetings and participate in the governance of stem cell research in California. On the issue of public participation in the implementation of stem cell research, conference participants noted the key distinction between communities of color playing a central role in setting the research agenda versus being asked to play an advisory role once that agenda has been set. To address this, the CIRM should oversee that potential grantees set clear and measure goals to increase the diversity of personnel in their programs. The CIRM should also set a leadership example by establishing their own diversity goals in the recruitment of the institute's career staff. The CIRM should use the state's \$3 billion toward the biotech industry to leverage for equitable policies in supplier contracts going to minority and women owned small businesses. Biotech companies should set goals for increasing the percentage of their contract dollars to go toward minority and women owned small businesses as well.

Increase community outreach and education. Conference participants agreed that community members need who are asked to participate in research must have a basic understanding of human genetics and the social, legal, and regulatory issues embedded in that research. In addition, scientific institutes must encourage that their researchers uphold the highest standards of cultural competency toward diverse communities to best communicate the stakes of stem cell research. Specific recommendations to cultivate mutual understanding include:

- Using a model similar to El Concilio of San Mateo's Nuestro Canto de Salud program
- Using "translational" players such as academics and community leaders to bring information to the general public

Government agencies like the CIRM, scientists, academia, and community organizations need to deliver the proper resources

to underserved communities to enable them to participate in this debate.

Institute a community reinvestment model. Because Proposition 71 was an initiative, it cannot be touched by the legislature until 2008. In the meantime, an informal community reinvestment model mediated by a community contract would promote the flow of capital into formerly disenfranchised communities. Community investment may take several forms such as:

- creating opportunities for more jobs and contracts to underserved populations
- setting goals for philanthropic giving to community projects and initiatives
- allocating resources to youth education and outreach programs in the sciences
- increasing public education on the biotech industry's purpose and role in California's economy and community

This would empower underserved communities and address disparities in genetic literacy. Such a model would also benefit the biotech industry by cultivating a diverse pool of potential employees. Having closer connections with the general public would also help biotech in dealing with public perceptions of an industry rife with ethical quandaries.

Direct resources to pipeline programs. The CIRM's training grant programs should include grants to develop the workforce that will be a crucial part of California's stem cell research infrastructure. Pipeline programs help to address institutional barriers to scientific professions by outreaching and supporting underserved populations. This would help to diversify the pool of potential recipients of stem cell grants and foster future leadership among minorities in the sciences. These programs should be given the necessary financial and institutional support in the form of multi-year funding and partnerships with prestigious research institutes to best cultivate the potential in diverse populations. Ken Taymor, an attorney with MBV Law LLP emphasized the importance of investing in the Cal State System. After basic research comes the equally difficult task of refining inventions into commercially useful therapies, tools and diagnostics. This generally takes many people with training at the bachelor's and master's levels to support the work of Ph.D.s, post-docs and PIs. The CSU system has a training pipeline in place that is unparalleled in the state for purposes of training the workforce needed for biotech commercial development and therapy delivery. Investing resources to the CSU system would help create a more diverse pool of leaders in stem cell research

Protect women egg donors. Increasing the cultural competency among researchers could help to ensure that women of color participating in research (who are less likely to have access to quality health care) are informed of the risks.

Ikemoto proposed the following donor protection measures to protect female stem cell donors:

- Ban on payment for gametes, embryos, somatic cells, or tissue
- Reimburse “permissible expenses” involved in donations for stem cell research
- Require that institutions assume the cost of any medical care required when procurement of oocytes are required for derivation

Build partnerships. Following the leadership of Robert Birgeneau,⁵ John Gamboa,⁶ and Bertram Lubin,⁷ conference participants agreed that strategies to strengthen relationships between researchers, community members, the CIRM, and the private biotech industry are crucial for the success of stem cell research in California. Specific recommendations include:

- Encourage researchers to participate in community events in meaningful ways
- Reward the sharing knowledge of reports, articles, and findings of research among community members
- Advocate for the training of and education for the community in the potential for stem cell research and biomedical research

Several participants noted that community groups are often overburdened with responsibilities. Participants felt that partnerships with academic institutions do not come with adequate compensation or that community contributions are undervalued. Community partnerships should be viewed as important resources for ensuring that all benefit in California.

CONCLUDING REMARKS

As Evelyn Hammonds of Harvard University noted, diversity in stem cell research policies is not necessarily measured in the number of ethnicities represented; rather, it is in the diversity of backgrounds and experiences that a person considers in the guidance of such policies. California has the opportunity to develop new forms of scientific governance that is inclusive of underserved and minority populations. While it may take decades to end racial and ethnic disparities in access to care, science education, and access to health professions; California has the opportunity to begin bridging this divide by raising awareness of the issues and recommendations articulated in this report. As such, all parties involved in stem cell research must partner together to bring these recommendations into fruition.

REFERENCES

¹ Other conference sponsors include: The UC Berkeley Science, Technology, and Society Center, UC Berkeley’s International and Area Studies Department, Berkeley Diversity Research Initiative.

² Baker, Laurence, and Bruce Deal. Economic Impact Analysis Proposition 71 California Stem Cell Research Initiative. Analysis Group, Inc. Analysis Group, 2004.

³ California. California Institute for Regenerative Medicine. Intellectual Property for Non-Profit Organizations. 10 Feb. 2006. 31 Oct. 2006

<<http://www.cirm.ca.gov/policies/pdf/IPPNPO.pdf>>.

⁴ National Science Foundation, Employed S&E doctorate holders, by occupation, race/ethnicity and sex. 2001. 31 Oct. 2006 <<http://www.nsf.gov/statistics/wmpd>>.

⁵ Chancellor of the University of California, Berkeley

⁶ Executive Director of the Greenlining Institute

⁷ President of the Children’s Hospital Oakland Research Institute (CHORI)