

ISSUE BRIEF

Diversity in Stem Cell Research # 1

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**What stake do diverse
communities have in
stem cell research?**

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Toward Fair Cures: Diversity Policies in Stem Cell Research

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Introduction

What if a cure existed for cancer, diabetes, heart disease, blindness, HIV/AIDS, and many other debilitating diseases and illnesses? Adapted into state law in 2004, the California Stem Cell Research and Cures Act directs \$3 billion of state monies toward stem cell research to make such cures a reality. Also, the investment into biotech is predicted to create up to 22,000 jobs on average a year.¹

Despite such large economic and medical potential, these funds are currently managed by a governing board whose representation falls short of the diversity of the state. With such an investment into healthcare and employment opportunities, the underserved and minority communities of California must take action and voice their concerns in order to claim their share of the benefits promised by stem cell research.

To facilitate active and informed participation, this brief raises important policy issues related to stem cell research such as: *What stake do diverse communities have in California's stem cell research program? What is the medical potential of stem cells? What policy examples can communities set to guarantee fairness in the future?*

Diverse Communities and Stem Cell Research

In November of 2004, Proposition 71, the California Stem Cell Research and Cures Act, became California law with an overwhelming 59 percent of the electorate voting in favor of the initiative. The act established the California Institute for Regenerative Medicine (CIRM) to allocate \$3 billion derived from the sale of state bonds to be paid back with interest from the state's general fund. With interest, the bond measure is predicted to cost the state an estimated \$6 billion—the largest investment into stem cell research in the nation.²

With billions of dollars being directed toward such new and uncertain biomedical research, it is crucial for the state's minority communities to be informed of the prospects, issues, and limitations of stem cell research to best participate in the implementation California's stem cell research program.

Because the Proposition 71 passed as an initiative, it cannot be changed by the legislature until 2008. While people need to advocate for fair policies to be developed by the CIRM, minority communities must also plan for 2008 as a manner of making changes at the

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legislative level.

Minority communities must play an active role in practicing their right to be a part of this research at all levels. The following questions must be answered:

Diversity and the CIRM: Recipients of the \$3 billion

Who will receive the \$3 billion in grants to be paid for by the state? Given that Proposition 71 was largely supported by California’s ethnic minorities, how will these communities be represented in the employment and contract opportunities to arise with the huge state investment in biotechnology?

Affordability and the Economic Potential in Stem Cell Research

How will affordability and access to treatments benefits to the state be guaranteed to voters? How will the state benefit economically from their investment into the biotechnology industry? What are alternative models for ensuring financial returns to the state’s underserved and minority communities?

Ensuring Medical Access

How will questions linking science with race and ethnicity affect stem cell research? What are the issues involved in collecting the biological materials needed for the creation of stem cells? What issues are involved in protecting minorities participating in the research process?

According to Los Angeles Times exits polls, 44 percent of those voting in favor of the proposition were from minority communities.³ Considering the historic lack of minorities at the ballots, having such a large number of minorities voting in favor of the proposition demonstrates their desire to reap the benefits of stem cell research as a way to address their health disparities. With Proposition 71, minority communities, who have been underrepresented in positions of leadership in medical professions, now have the prime opportunity to contribute to the direction of research that seeks to cure human illness.

Since its creation, the CIRM has proceeded to conduct regular board meetings, set key policies, and has dispersed the first \$12 million in training grants. These actions set the example that states, such as Illinois, Maryland, New Jersey, New York, and Washington, are using as models for their own stem cell research programs. Because California’s stem cell research agenda will be used to define programs across the nation—and the world—those concerned with minority health and patients in California have the opportunity to make enormous impacts.⁴

The California Stem Cell Research and Cures Act establishes:

- A state institution to allocate grants and loans for stem cell research in California: The California Institute for Regenerative Medicine (CIRM)
- This institute will be funded by the sale of \$3 billion in state bonds, \$300 million each year for 10 years
- The CIRM to offer grants for the training of new stem cell researchers, the construction of new laboratories, and scientific research pro-

Understanding Stem Cell Science

Being a big stakeholder in this research, minorities have a legitimate right to be involved and informed about what is involved in stem cell research. The science of stem cell research is very complex; but the basic process can be simplified to a few principles. In general, stem cells are cells that are capable of renewing themselves for long periods of time. Stem cells are capable of turning into the specific cells that are found in blood, the brain, tissues such as muscle and bone, as well as whole organs. Harnessing this potential for stem cells to regrow various parts of the body may help replace depleted or damaged cells and tissues.

Scientists indicate that there are many ways in which human stem cells can be used in basic and clinical research. Stem cell research may provide information on the complex events that occur during human development that lead to serious medical conditions like cancer and birth defects. Human stem cells could be used to test the safety of drugs. Also, researchers indicate that stem cells offer the possibility of treating diseases such as Parkinson's, Alzheimer's, heart disease, or diabetes, or to treat spinal cord injuries.

Setting Policies for the Health of All

The California Institute for Regenerative Medicine (CIRM)'s principal mandate is to fund a statewide scientific program to research the potential for new biotechnologies to alleviate human health. Thus, the California Stem Cell Research and Cures Act provides the opportunity to set policy examples governing scientific research that includes input from minority communities. However, if minorities do not advocate on their behalf, they may never see the benefits of their investment.

This is in contrast to the historically exclusive policy making procedures governing scientific research without much consideration for the low-income and minority populations who face barriers to positions of leadership in the sciences.⁵ While the CIRM needs to outreach and educate the public to collect input, this dialogue will only succeed if those concerned with minority health also act soon to educate themselves about the issue and advocate for their concerns in this new and exciting research.

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“If minorities do not advocate on their behalf, they may never see the benefits of their investment.”



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ENDNOTES:

1. Baker, Laurence, and Bruce Deal. Economic Impact Analysis Proposition 71 California Stem Cell Research Initiative. Analysis Group, Inc. Analysis Group, 2004.
2. California. Legislative Analyst Office. Proposition 71. July 2004. 6 Sept. 2006 <http://www.lao.ca.gov/ballot/2004/71_11_2004.htm>.
3. In addition, according to Los Angeles Times exits polls, 72% of Asian, 68% of African American, and 61% of Latinos voted in support of Proposition 71.
4. "International Stem Cell Forum Welcomes California Institute for Regenerative Medicine." Press Release 10 Feb. 2006. 5 Sept. 2006 <<http://www.cirm.ca.gov/pressreleases/pdf/2006/02-10-06.pdf>>.
5. This is illustrated by the fact that only 3 percent of tenured life sciences faculty in the University of California is from underrepresented minority populations.