



2004 ANNUAL REPORT



INTRODUCTION

The Center for Genetics and Society is pleased to present its Annual Report for 2004. This year has been our most active to date, and displayed an important new level of policy engagement.

Most significantly, CGS initiated discussions with pro-choice and other progressive organizations in California concerning the serious flaws inherent in Proposition 71, the \$3 billion Stem Cell Research and Cures Initiative, and went on to provide key leadership in opposing the measure. It was clear from the beginning that the measure was likely to pass, but we knew that its flaws would soon come to light and could serve to demonstrate why greater public oversight of the biotech industry is urgently needed.

In May CGS held the ground-breaking conference, *Gender and Justice in the Gene Age*, at the Ford Foundation in New York City. This conference led to the establishment two months later of CGS's Gender, Justice and Human Genetics Program.

In addition, we organized a series of wellattended symposia addressing the need for a broad civil society initiative addressing the new human genetic technologies, culminating in December with the symposium in New York City on *The Next Four Years, the Biotech Agenda, and the Human Future,* which attracted over 400 participants.

Our press and media presence continued to expand this year, as did traffic on our website.

We look forward to 2005, fully aware of the magnitude of the task before us, yet confident that a human future will prevail.

OUR MISSION

The Center for Genetics and Society is a nonprofit information and public affairs organization working to encourage responsible uses and effective societal governance of the new human genetic and reproductive technologies. We support benign and beneficent medical applications of these technologies, and oppose those applications that objectify and commodify human life and threaten to divide human society. We work in a context of support for the equitable provision of health technologies domestically and internationally; for women's health and reproductive rights; for the protection of our children; for the rights of the disabled; and for precaution in the use of powerful new technologies.

OUR HISTORY

After several years of exploratory activity the Center for Genetics and Society formally opened its doors in October 2001. It was founded by socially concerned academics, civil society leaders and others in Northern California. The Center focused its early work on alerting key civil society constituencies to the challenges posed by the new human genetic technologies. We subsequently became active in the policy arena, working with state elected officials, members of Congress and United Nations delegates, in support of responsible policies.

POLICY ENGAGEMENT AND SPECIAL INITIATIVES

During 2004 the Center launched a major policy initiative opposing California's Proposition 71 and working for responsible implementation of it; established our program on Gender, Justice and Human Genetics; and continued our work to "reframe the debate" over human genetic technologies.

PROPOSITION 71, THE CALIFORNIA STEM CELL INITIATIVE

In 2004 the Center for Genetics and Society played the leading role in organizing pro-choice and progressive supporters of embryonic stem cell research in opposition to California Ballot Proposition 71, the Stem Cell Research and Cures Initiative. Although, as widely expected, the measure passed, our active opposition alerted many people to the need to pay closer attention to human biotechnology issues, and established CGS as a leading authoritative voice.

In the course of our campaign activities, CGS:

- Prepared and publicized the first detailed critical analysis of Proposition 71. Our webpage containing the analysis received over 1300 visits during the campaign, and received 1200 more before the end of 2004.
- Assisted in the organization of the Pro-Choice Alliance Against Proposition 71, the statewide progressive network opposing the initiative.
- Recruited and helped place op-eds in opposition to Proposition 71 in the *San Francisco Chronicle*, the *Los Angeles Times*, the *San Diego Union-Tribune*, and the *Wall Street Journal*.
- Was cited in over sixty news articles, and debated Proposition 71 supporters on radio, on television, and at public events.
- Organized a telephone press conference with leading experts that drew reporters from outlets including the *New York Times*, the *Los Angeles Times*, USA Today, Newsday, the Wall Street Journal, and the Sacramento Bee.
- Worked with professional campaign consultants to send 66,000 email messages and place 175,000 phone calls to targeted registered Democrats in the final days of the campaign.

After passage of the initiative on November 2, CGS announced that it would begin organizing to hold the newly established stem cell program accountable to the public interest. In December, public interest attorney and CGS colleague Charles Halpern notified the California Attorney General that the agenda announced for the first meeting of the stem cell governing board was in violation of California's Open Meeting Act. On the advice of the Attorney General, the governing board directed that all agenda items but one—election of the new chair—be suspended pending adequate public notice. CGS representatives testified during the course of the meeting and were quoted in reports by the *New York Times, Reuters, AP*, the *San Francisco Chronicle* and *Wired*.

Questions and concerns about the new stem cell program continued to mount, even among those who originally supported the initiative. Democratic legislators have introduced bills addressing the initiative's flaws, key newspapers have editorialized about their reservations, and news headlines critical of the initiative have become routine.

Even as the flaws in Proposition 71 became evident, however, biotech and biomedical interests in other states—including New York, Massachusetts, Wisconsin, Illinois, Pennsylvania and New Jersey began lobbying for public funding of their own stem cell research programs. In response, CGS and allied organizations began laying the groundwork for a national campaign for responsible governance of stem cell research and other new genetic technologies.

CGS wants to acknowledge the many others who worked hard on this effort, including Loni Andrews, George Annas, Diane Beeson, Paul Billings, Deborah Burger, Daniel Callahan, Francine Coeytaux, Chris Desser, Alexander Gaguine, Charles Halpern, Greg Fawcett, Susan Berke Fogel, Terry Francke, Debra Greenfield, Mitch Kapor, Freda Kapor Klein, Doug Linney, Vicki Michel, Stuart Newman, Michael Nolan, Judy Norsigian, Adrienne Pine, Daniel Sarewitz, Pete Shanks, Susan Stephenson, Tina Stevens, and David Winickoff.

GENDER, JUSTICE AND HUMAN GENETICS

n August 2004 CGS initiated its program on Gender, Justice and Human Genetics (GJHG) and hired its first director, Sujatha Jesudason. The purpose of the program is to build and deepen the capacity of feminist and social justice constituencies, nationally and internationally, to frame, advocate for and win policies that protect and expand the human rights and health of women, children and communities of color as they are affected by the new human genetic and reproductive technologies.

The seeds for this program were sown at a historic meeting of feminists and social justice activists in May 2004 in New York, Gender and Justice in the Gene Age. Working in collaboration with Our Bodies Ourselves and the Committee on Women, Population and the Environment, CGS hosted a meeting of 65 feminist leaders to grapple with the tensions and contradictions of the new reproductive and genetic technologies, and to chart a path that will protect women's health, access to abortion and uncoerced reproductive options, and allow for responsible social governance. Out of the rich debate, discussion and exchange of ideas that occurred at this meeting, it was decided that GJHG will focus initially on four areas of activism: Sex Selection, Eugenics, Human Rights, and Reproductive Health.

The *Sex Selection* initiative will campaign to stop the current use and marketing of sex selection in the United States and internationally. During 2004 CGS convened the first meetings of our initial collaborative partners in this effort: the National Asian Pacific American Women's Forum, the Committee



CGS opposes marketing of "sex selection" technologies, such as this ad in the New York Times.

on Women, Population and the Environment, and Manavi, a South Asian domestic violence prevention organization.

The *Eugenics Past, Present and Future* initiative will demonstrate the connection between eugenic and genocidal practices and ideologies in the past, current discriminatory practices, and proposals for the creation of "superior humans" through genetic modification. In 2004 CGS held the first planning meetings with our collaborative partners in this initiative: SisterSong, a national women of color reproductive and sexual health and rights organization, and the World Institute on Disability.

Preliminary discussions were held regarding the *Human Rights* initiative, which will work with human rights activists to develop a human rights framework for evaluating applications of new human genetic technologies.



May 2004: Feminist and social justice leaders gather for "Gender and Justice in the Gene Age" at the Ford Foundation, New York City.

In the area of *reproductive bealtb*, CGS will continue its work with pro-choice, feminist and women's health organizations. Marcy Darnovsky and Sujatha Jesudason briefed the California Coalition for Reproductive Freedom on the pro-choice and women's health implications of the new technologies. They assisted the coalition in forming a new Reproductive Technologies subcommittee to inform their understanding of the challenges faced with the new developments of these technologies. As an Advisory Committee member, Sujatha assisted in the formation of an Assisted Reproduction/Technologies section at the upcoming *Reproductive Justice for All: A US Policy Conference* hosted by Smith College and Planned Parenthood Federation of America. Additionally, Sujatha and Marcy briefed key leadership of Planned Parenthood of New York City on upcoming challenges of these technologies to prochoice organizations in the near future.

REFRAMING THE DEBATE

To date most debate over policies concerning new human genetic technologies has been dominated by two polarized constituencies: religious fundamentalists, who generally want across-the-board bans on research involving human embryos, and the biotech industry and biomedical community, which resists even reasonable social oversight and control. Struggles over human genetic research have come to be seen as surrogates for struggles over abortion rights. This polarization has resulted in policy gridlock at many levels of government.

In 2004 CGS initiated a series of events designed to promote an alternative position on human genetic technology issues, one that does not reject these technologies in principle, but that calls for strong restrictions on their socially unacceptable applications.

These events included a July 12 symposium at The Century Foundation in New York City attended by nearly 130 people, a September 28 public colloquium sponsored by the U.C. Berkeley School of Journalism that attracted nearly 100 people, and a major December 9 symposium at the City University of New York Graduate Center attended by over 400.

These events were co-sponsored by noted liberal organizations, and organized with special regard to reaching liberal audiences. We are planning an expanded series of activities designed to "reframe the debate" during 2005.



CONFERENCES, MEETINGS, WORKSHOPS, SYMPOSIA

The Center's initial focus on alerting key civil society constituencies to the challenges posed by the new human genetic technologies remains a key element of our work. Major conferences, meetings, workshops, symposia and other events which we initiated, or in which we played key roles, are shown below.

January 17-20: In cooperation with Friends of the Earth and the Association for Women's Rights in Development, CGS Program Director Jesse Reynolds organized three workshops presenting seven speakers at the 3rd Annual World Social Forum held in Mumbai, India. The workshops addressed a full range of issues, including sex selection, gender equality, the biotech industry and globalization, and international governance of genetic technologies.

February 2-6: CGS International Associate Rosario Isasi conducted a **round of meetings in Peru**, including a presentation to the Peruvian Bioethics Association, meetings with the Peruvian Office of Social Research and the Andean Interdisciplinary Studies Seminar, and radio interviews. Plans were discussed for a subsequent lecture series in Peru, and other activities.

March 13: CGS Associate Executive Director Marcy Darnovsky was invited to organize and speak on a panel at *Boundaries in Question: New Feminist Perspectives on Biotechnology and Bioethics,* held at the University of California at Berkeley.

April 27-29: Rosario Isasi represented CGS at the Extraordinary Session Towards a Declaration on Universal Norms on Bioethics convened by the

UNESCO International Bioethics Committee, in Paris. She was joined by colleagues from the Heinrich Böll Foundation, the Institut Mensch, Ethik und Wissenschaft, and Disability Rights International, among others.

May 6-7: Gender and Justice in the Gene Age: A Feminist Meeting on New Reproductive and Genetic Technologies. Some sixty-five people—feminist, social justice, women's health, disability, and human rights activists, academics, writers and others—met in New York City at the Ford Foundation to work toward a framework for assessing new reproductive and genetic technologies from a social justice perspective. The event was co-sponsored by CGS, the Committee on Women, Population and the Environment, and Our Bodies Ourselves.

May 20: Marcy Darnovsky presented an overview of our perspectives at a meeting of the **National** Advisory Board, a coalition of women's groups working against religious restrictions on healthcare and medical research, in Los Angeles, California.

June 1: CGS Executive Director Richard Hayes presented and discussed our perspectives at a meeting of bioethics scholars at the **Institute for Advanced Study** in Princeton, New Jersey.



CGS Project Director Jesse Reynolds presenting at the World Social Forum, Mumbai, India, January 17-20.



CGS Associate Director Marcy Darnovsky speaking at the Next Four Years symposium, New York City, December 9.

June 4-5: Jesse Reynolds and Marcy Darnovsky were speakers at the *Reclaiming the Commons* Teach-In in San Francisco held in conjunction with the Annual Convention of the Biotechnology Industry Organization (BIO). Issues they addressed included biotech barriers to medical justice, feminism and reproductive rights, and the politics of the new human genetic technologies.

July 9: Marcy Darnovsky spoke on the panel What is Wrong with Remaking Human Nature? at the Communitarian Summit held in Washington DC, along with George Annas (Boston University), Arthur Caplan (University of Pennsylvania) and Ezekiel Emmanuel (National Institutes of Health), with Amitai Etzioni (George Washington University) as host and moderator.

July 15: Inequality, Democracy, and the New Human Biotechnologies. Nearly 130 participants gathered for this symposium at the **The Century Foundation** in New York City to hear Marsha Darling (Adelphi University), Sheldon Krimsky (Tufts University), Susan Lindee (University of Pennsylvania) and Richard Hayes (CGS) discuss the challenges to equality and democracy posed by new human biotechnologies. The event was co-sponsored by CGS, Demos, and The Century Foundation.

August 14: CGS convened a side meeting of participants at the annual meeting of the American Sociology Association in San Francisco to explore their interest in furthering debate over the social consequences of the new human genetic technologies. September 28: Humans 2.0: Will Your Grandchildren Be Genetically Modified? A Conversation on the Social and Political Implications of the New Human Biotechnologies. Author Bill McKibben and Marcy Darnovsky were joined by host Michael Pollan, Director of U.C. Berkeley's Knight Program in Science and Environmental Journalism, to consider the impact that the new human genetic and reproductive technologies could have on human society. Nearly 100 people attended. The event was later aired on KPFA radio.

October 22: CGS held a half-day meeting of New York City scholars and activists to discuss ways to bring issues concerning the new human genetic technology to the attention of liberals and progressives.

October 22-23: Sujatha Jesudason was a speaker in Mexico City at the Heinrich Böll Foundation's Conferencia Sobre Biopolitica 2004—Privatización de la Naturaleza y del Conocimiento—Bajo el signo BIOS: tecnología, ética, diversidad y derechos. She briefed reporters on social justice and feminist concerns with cloning, human genetic modification and reproductive and genetic technologies, and presented on issues of "Justice in the Gene Age."

October 27: CGS held a **press conference** on prochoice opposition to Proposition 71. Participants were Marcy Darnovsky (CGS), Paul Billings (U.C. Berkeley), Deborah Burger (California Nurses Association), and Francine Coeytaux (Pro-Choice Alliance Against Proposition 71).



Over 400 participants at the December 9 symposium in New York.



Dorothy Roberts of Northwestern University speaking at the December 9 symposium.



CGS Executive Director Richard Hayes.

November 8-11: CGS, in cooperation with the Heinrich Böll Foundation, presented a Special Symposium and a workshop, and held several side meetings, collectively titled New Voices, New Perspectives: Towards a Global Consensus on the New Human Genetic Technologies, at the meetings of the World Congress of Bioethics and Feminist Approaches to Bioethics in Sydney Australia. Over eighty people attended the various CGS/HBS events. Presenters at the events were George Annas (USA), Marsha Tyson Darling (USA), Anita Ghai (India), Richard Hayes (USA), Emilia Ianeva (Bulgaria/USA), Rosario Isasi (Peru/Canada), Sujatha Jesudason (USA), Rupsa Mallik (India), Roxanne Mykitiuk (Canada), Merry Osemwegie (Nigeria/UK), Andreas Poltermann (Germany), and René Segbenou (Benin).

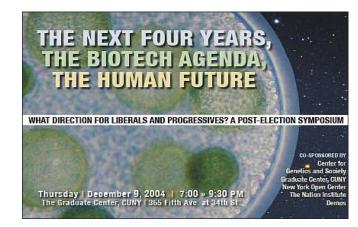
November 30: Marcy Darnovsky and Sujatha Jesudason briefed the Reproductive Technologies Committee (formed this year at their suggestion) of the **California Coalition for Reproductive Freedom** on the "New Science, Politics and Policies of Reproductive and Genetic Technologies." **December 8:** Sujatha Jesudason organized the first leadership meeting, in New York City, of the developing **campaign against sex selection**. Collaborative members include: National Asian Pacific American Women's Forum, Committee on Women, Population and the Environment, and Manavi, a South Asian domestic violence prevention organization.

December 9: Over 400 attendees heard Sheldon Krimsky (Tufts University), Dorothy Roberts (Northwestern University), William Saletan (Slate), Stuart Newman (NY Medical College) and Marcy Darnovsky (CGS) make the case for socially responsible policies governing the new human genetic technologies at *The Next Four Years, the Biotech Agenda* and the Human Future: What Direction for Liberal and Progressives? The symposium was held at the Graduate Center of the City University of New York, and co-sponsored by CGS, the Graduate Center CUNY, the Nation Institute, Demos, and the New York Open Center.

December 10: At the request of **Planned Parenthood NYC**, Marcy Darnovsky and Sujatha Jesudason presented and discussed our perspectives at a leadership briefing there.

Other activities

In 2004 CGS staff participated in a number of key conferences and events. Rosario Isasi attended the Sept. 30-Oct. 1 *First Annual Conference on Ethics, Science and Moral Philosophy of Assisted Human Reproduction*; the October 12-13 National Academies of Science workshop in Washington, DC on *Guidelines for Human Embryonic Stem Cell Research: A Public Workshop*; and the October 16-17 meeting of the United Nations Sixth Committee addressing the UN cloning declaration process. Richard Hayes participated in the December 16 meeting on *Babies by Design*, sponsored by the Genetics and Public Policy Center, in Washington, DC.





COMMUNICATIONS

Publications and Resources

CGS's electronic newsletter, *Genetic Crossroads*, is delivered approximately every other month to over 3500 subscribers. Subscriptions are up 10% from 2003, mostly due to more than 300 voluntary on-line subscriptions. In 2004 the newsletter underwent a significant redesign, improving both visual impact and readability.

Unique visitors to the CGS website now typically number approximately 50,000 per month. On average, each month in 2004 saw a 29% increase in the number of unique visitors over the same month in 2003. Our home page was redesigned, and sections on the California stem cell initiative and related topics were added, as were versions of key documents in Russian.

CGS produced two high-quality CDs, containing

Published Articles, 2004

- Jesse Reynolds, "Stem Cell Cronyism," San Francisco Bay Guardian (December 29, 2004)
- Richard Hayes, "Breaking the policy deadlock on cloning and assisted reproduction," *San Francisco Chronicle* (April 4, 2004)



hundreds of pages of resource materials each, for distribution at the World Congress of Bioethics / Feminist Approaches to Bioethics, and at the Dec. 9 NYC symposium on *The Next Four Years, the Biotech Agenda, and the Human Future.*

- Richard Hayes, "Selective Science," *TomPaine.Com* (February 12, 2004)
- Marcy Darnovsky, "High-Tech Sex Selection: A New Chapter in the Debate," *GeneWatch* (Vol. 17, No. 1, January 2004)

Other Press and Media Appearances by CGS, 2004

CGS staff were quoted, cited, or interviewed on over seventy occasions during 2004, in the following outlets (parentheses = number of different stories):

ABC7 Evening News Associated Press (4) Christian Science Monitor (2) Cimac Noticias (2) Contra Costa Times (2) Criterios.com East Bay Express Grupo Reforma KGO TV Beyond the Headlines KPFA Morning Show KPFA Sunday Salon KQED Forum (2) KWMR America Off-Line

Los Angeles Times (3) Mujeres Hoy Nature New York Times Newsday North County Times Oakland Tribune group (4 papers) (5) Osgood Files Pacific Sun Red Herring Reuters (2) Sacramento Bee (5) San Diego Union Tribune (6) San Francisco Bay Guardian San Francisco Business Times (2) San Francisco Chronicle (8) San Francisco Examiner San Jose Mercury News (4) Science SFSU Xpress Silicon Valley Metro Slate Stanford Medicine Magazine USA Today WBAI Wake Up Call Wired

STAFF

CGS currently has six staff:

- Executive Director Richard Hayes, Ph.D., served for many years on the national staff of the Sierra Club and as a political organizer with the Democratic Party and a wide range of social justice organizations.
- Associate Executive Director Marcy Darnovsky, Ph.D., has taught courses on the politics of science and technology at the Hutchins School of Liberal Studies at California State University, Sonoma, and has long been active on social justice and environmental issues in California.
- Program Director Sujatha Jesudason, M.A., is a doctoral candidate at the University of California, Berkeley, and worked for many years in behalf of the rights of immigrants, people of color and working women.
- Project Director Jesse Reynolds, M.S., served as a US EPA Fellow and helped organize Students for Responsible Research at the University of California, Berkeley, focused on corporate-university relations.
- International Associate Rosario Isasi, J.D., M.P.H., has worked on international human rights,



CGS staff: Marcy Darnovsky, Sujatha Jesudason, Richard Hayes, Jasmine Gonzales, Jesse Reynolds. Insert: Rosario Isasi.

mental health and anti-torture initiatives, and is currently a post-doctoral fellow at the University of Montreal's Program on Genetics and Society.

• Administrative Assistant Jasmine Gonzales, B.A., has worked for immigrant and refugee rights and other social and economic justice concerns.

FINANCES

During 2004 CGS received \$609,500 in income, spent \$539,899 on program and administrative activities, and augmented its cash reserve. CGS has income of \$650,000 committed for 2005 and hopes to raise at least another \$250,000. CGS' funding history is shown here:

	CGS Funding History
Year	Total Funds Raised/ Committed
2000	\$165,700
2001	\$329,500
2002	\$392,400
2003	\$620,000
2004	\$609,500
2005	\$650,000 *
	* committe∂

CGS gratefully acknowledges its past and current donors:

Appleton Foundation, CS Fund/Warsh-Mott Legacy, Changing Horizons Fund, Foundation for Deep Ecology, Marisla Foundation, StarFire Fund, Aurora Foundation, Jennifer Altman Foundation, French American Charitable Trust, Pettus-Crowe Foundation, Heinrich Böll Foundation, Ahimsa Fund, Tides Foundation, Ms Foundation, and individual and anonymous donors. In-kind support has been provided by Public Media Center.

Organizational Status

CGS is currently a project of the Tides Center. We are in the process of forming a board of directors and plan to incorporate as an independent 501(c)3 organization during 2005.

2005 AND BEYOND

e anticipate that 2005 will be even more intense than 2004 has been. Controversies concerning the new human genetic technologies are coming to public attention with increasing frequency, and financial and corporate forces are playing a steadily greater role. During 2005 we intend to build a solid base of activism in the three program areas of Biotech Accountability, Gender and Justice, and Reframing the Debate. Senior staff will devote special attention to fundraising, to ensuring a smooth transition to our status as an independent 501(c)3, and to recruiting allies among national and international organizations and individuals. CGS activities already confirmed for 2005 include:

Jan. 26-31:

World Social Forum, Porto Alegre, Brazil. Program Director Sujatha Jesudason is invited by the Brazil Office of the Heinrich Böll Foundation to present at a workshop on the "The Biopolitics of Life: The Privatization of Life and Knowledge." She will be speaking on "(Re)creating Life—Ethical, Social and Gender Aspects about New Human Genetic Technologies."

Feb 25-27:

Women Coming Together: Claiming the Law for Social Change, at the University of Cincinnati and sponsored by the Ford Foundation. Sujatha Jesudason will present on a panel on "Emerging Issues in Reproductive Health: Impact of Ideology and Technology on Women's Access and Rights."

March 11-12:

Incite! Color of Violence 3: Stopping the War on Women of Color Conference, New Orleans. Sujatha Jesudason will be presenting a workshop on "Gender Based Violence of Biotechnology and Sex Selection," with collaborative partners Rajani Bhatia from the Committee on Women, Population, and the Environment, and Shamita Das Dasgupta of Manavi, a South Asian domestic violence prevention organization.

April 2-3:

From Abortion Rights to Social Justice: Building the Movement for Reproductive Freedom, Hampshire

College, Amherst, MA. Marcy Darnovsky will be speaking at a workshop and plenary session on the new eugenics at this annual conference sponsored by the Civil Liberties and Public Policy Program and the Population and Development Program.

May:

Publication of *Rights and Liberties in the Biotech Age: Why We Need a Genetic Bill of Rights* (Rowman & Littlefield Publishers, Inc.), Sheldon Krimsky and Peter Shorett, eds., including Marcy Darnovsky's chapter on "A Human Rights Framework for Understanding the New Human Genetic Technologies."

Sept. 21-25:

Health Rights, Women's Lives: Challenges & Strategies for Movement Building, the 10th

International Women and Health Meeting, New Delhi, India. Sujatha Jesudason and colleagues will present on their campaign to regulate and stop the marketing and use of sex selection in the U.S., and their work with collaborative partners in India and China.

Oct 27-30:

How Does Change Happen? The 10th Association of Women's Rights in Development International Forum, Bangkok, Thailand. Sujatha Jesudason and collaborative partners will discuss their campaign addressing social sex selection in the U.S., and their work with other organizations in India and China.

Nov. 10-13:

Reproductive Justice for All: Designing Policies to Secure Equality in the U.S., a conference organized by Planned Parenthood Federation of America and Smith College. Sujatha Jesudason will speak at a plenary about the policy challenges and opportunities of regulating reproductive and genetic technologies.

CENTER FOR GENETICS AND SOCIETY

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