



CENTER FOR GENETICS AND SOCIETY

2003 ANNUAL REPORT

INTRODUCTION

The Center for Genetics and Society is pleased to present its Annual Report for 2003.

During this year we initiated and co-sponsored, with the Heinrich Boell Foundation and the Institut Mensch, Ethik und Wissenschaft, the first international NGO conference focused on the social and political implications of new human genetic technologies. In addition, we held our first major public outreach event – an evening symposium in San Francisco featuring Bill McKibben, author of the critically acclaimed book *Enough: Staying Human in an Engineered Age*. We increased our press and media presence this year as well, and continued our core work of alerting and engaging leaders of key civil society constituencies to the challenges raised by the new human genetic technologies.

We are encouraged by the results of our efforts to date. But the challenges are great and we have far to go. We need to build on the work accomplished thus far, by ourselves and others, to reach additional leaders and constituencies as rapidly as possible. A sense of urgency is called for.

CGS PROGRAM INITIATIVES

During 2003 CGS engaged in a full program of leadership meetings and briefings, public symposia and workshops, communications and other activities.

LEADERSHIP MEETINGS AND PUBLIC SYMPOSIA

January 23-28: At the World Social Forum in Porto Alegre, Brazil, CGS and two Brazilian women's organizations – Ser Mulher and CRIOLA – organized the workshop “Genetics and Social Justice: The Global Politics of the New Human Genetic and Reproductive Technologies.” Speakers were CGS Associate Director Marcy Darnovsky, CGS International Associate Rosario Isasi, Ser Mulher Executive Director Alejandra Rotania, CRIOLA Coordinator Jurema Werneck, and Adelphi University professor Marsha Darling. Marcy Darnovsky presented on two additional panels: “Genetics in the Context of Health,” organized by Dr. Laura Jardim, Hospital de Clinicas de Porto Alegre, and the

Ecology / Sustainability panel of the “Life After Capitalism” series organized by *Z Magazine*.

February 10-23: CGS Executive Director Richard Hayes and Global Academy Genome Institute President Walter Link spent two weeks in Europe meeting with activist, civil society, governmental and other leaders concerning the need for responsible national and global governance of the new human genetic technologies. Meetings were held with officials at UNESCO, the UN High Commission on Human Rights, the Council of Europe, the European Union, the French and German Foreign Ministries, the World Council of Churches, the German Bundestag, Friends of the Earth, Human Rights Watch and the Club of Rome, among others.

February 24: CGS briefed the Washington, DC-based Center for Public Integrity (CPI) as background for their new initiative focused on human genetic technologies.

February 25: CGS, the Worldwatch Institute and the Heinrich Boell Foundation co-sponsored “Human Cloning and Genetic Modification: The Challenge to Social Justice, Human Rights and the Environment,” a symposium held at the Carnegie Endowment for Peace in Washington DC. Speakers were CGS Executive Director Richard Hayes, Jurema Werneck of the Afro-Brazilian women’s organization CRIOLA, author Gina Maranto of Miami University, Greenpeace USA executive director John Passacantando, and World Watch Senior Researcher Brian Halweil.

March 5: Rosario Isasi presented at the University of Toronto Faculty of Law, Feminism and Law Workshop Series the talk “The UN Process for Creating an International Convention against Human Reproductive Cloning” in Toronto, Canada. On **March 18** Rosario Isasi presented at the University of Alberta’s Health Law Institute Lectures Series, “Human Cloning and Future Policy,” held in Edmonton, Canada.

March 11: CGS co-sponsored a presentation by University of Virginia School of Medicine professor Paul Lombardo on the history of state support for eugenic practices in California before the California State Senate Select Committee on Genetics, Genetic Technology and Public Policy. Within three hours of the broadcast of his comments, official statements of apology were issued both by California Governor Gray Davis and Attorney General Bill Lockyer.

April 14: Richard Hayes briefed key leaders of the National Council of Churches USA, in support of their exploratory project on human genetic technologies.

April 23: CGS held a briefing via conference call and web-based display for foundation executives, addressing social justice implications of the new human genetic technologies.

April 28: Rosario Isasi presented at the Human Genome Organization Annual Meeting held in Cancun, Mexico on “The United Nations and the International Human Cloning Convention.”

April 30: CGS organized a special evening symposium in San Francisco featuring author Bill McKibben speaking on the subject of his new book, *Enough: Staying Human in an*

Engineered Age. McKibben was joined by Marc Lappé of the Center for Ethics and Toxics, Anuradha Mittal of Food First, and CGS Associate Director Marcy Darnovsky. The event was preceded by an author's reception and attracted an overflow crowd.

May 16-18: CGS Program Director Jesse Reynolds hosted a workshop on human genetics policies at the Biodevastation 2003 conference held in St. Louis, Missouri, and was a panelist at the conference workshop on growing ties between university research programs and the biotechnology industry.

June: CGS associate Dr. Emilia Ianeva spent three days in Moscow meeting with Russian scientists, scholars and human rights leaders to discuss the state of policy in Russia and Eastern Europe concerning human genetic and reproductive technologies, and to discuss on-going collaboration.

June 20: CGS held a strategy meeting at our Oakland headquarters with civil society leaders and activists. Activities discussed included an intensive series of briefings and strategy meetings for civil society leaders, scientists, foundation executives and others, and efforts to connect current attention regarding the history of eugenic sterilizations in California and elsewhere to present neo-eugenic initiatives.

June 21: CGS Associate Executive Director Marcy Darnovsky briefed leaders of the Committee on Women, Population and the Environment (CWPE) on recent political and policy developments regarding human genetic technologies, in preparation for the feminist leadership conference to be held in May 2004.

July: Richard Hayes and Rosario Isasi spent three days in Toronto, Ottawa and Montreal meeting with Canadian academics, activists, feminists and others to discuss mutual concerns, including the need for support for Bill C-13, the assisted reproductive technologies act.

September 19-20: Richard Hayes was a plenary speaker at the conference "The Face of the Future: Technosapiens?" sponsored by the Center for Bioethics and Culture in Oakland, California.

September 24: Richard Hayes was featured presenter at the University of California at Berkeley Energy & Resources Colloquium, speaking on "The New Technologies of Human Genetic Modification: A Threshold Challenge for Global Civil Society."

September 26-27: author Bill McKibben spoke in Vancouver, B.C. at the University of British Columbia and at the Vancouver Institute, at sessions initiated by CGS.

October 12-15: Marcy Darnovsky was a plenary speaker at the international conference *Within and Beyond the Limits to Human Nature: The Threshold Challenge of the New Human Genetic Technologies* in Berlin, Germany.

October 15-17: Rosario Isasi attended the United Nations sessions in New York City on the proposed treaty banning human cloning, and distributed copies of the CGS survey of national policies on cloning and inheritable genetic modification to delegates.

October 29: Richard Hayes was featured speaker at a seminar hosted by DEMOS in New York City, addressing the challenges to democratic institutions and values presented by the new human genetic technologies.

November 5: Richard Hayes spoke at a workshop and plenary session at the National Council of Churches-USA General Assembly meeting in Jackson, Mississippi. The NCC subsequently voted to establish an ongoing program to address the new human genetic technologies.

November 7: Marcy Darnovsky co-led a workshop on “Sex Selection Goes High-Tech: From Female Infanticide to ‘Family Balancing’” at the 14th Annual Meeting of the California Sociological Association, in Berkeley, CA.

November 13-15: Marcy Darnovsky co-organized, with the Committee on Women, Population and the Environment, and spoke at a workshop on the new genetic and reproductive technologies at the SisterSong Women of Color Reproductive Health Collective National Conference in Atlanta, GA.

December 11: Marcy Darnovsky spoke as a panelist at the annual staff retreat of the Public Interest Research Group (PIRG), in Denver, Colorado. PIRG has been active in opposing GE foods and is considering possible involvement in human genetic technologies issues as well

MEDIA AND PRESS

[for links see www.genetics-and-society.org/resources/cgs]

Jan. 6: *San Francisco Chronicle* op-ed: “The Misstep of Human Cloning,” by CGS Associate Director Marcy Darnovsky

Feb. 10: City Visions Radio featuring Marcy Darnovsky debating human genetics policies with Hoover Institute fellow Henry I. Miller and David Gollaher of the California Health Institute

April: *Z Magazine*, “Human Biotechnology: Responding to Emerging Dangerous New Human Genetics,” by CGS Program Director Jesse Reynolds

April 7: *The Nation*, “Germline Warfare,” by CGS associate Ralph Brave

April 30: Salon.com, “Human Beings, As Currently Constituted, Are Good Enough,” by Ralph Brave

May 28: Alternet.org, “James Watson Wants to Build a Better Human,” by Ralph Brave

June 26: Tompaine.com article, “21st Century Eugenics,” by Jesse Reynolds

July 24: *San Jose Mercury News* op-ed, “There’s a Line to Be Drawn – Before We Get to ‘Enhanced’ People,” by CGS associate Pete Shanks

July 27: *San Francisco Chronicle* op-ed, “Time to Act on Biotech’s Human Repercussions,” by Pete Shanks

Aug. 26: transfert.net, “Choisir le sexe de son enfant devient un acte de consommation,” interview with Marcy Darnovsky

Sept. 25: AlterNet.org, “Sex Selection Goes Mainstream,” by Marcy Darnovsky

Oct. 16: *Utne Reader* online, “Choose the Gender of Your Child,” by Marcy Darnovsky

Oct. 30: *Toronto Globe and Mail* Letter: “Support Bill C-23,” by Richard Hayes and Marcy Darnovsky

Nov. 7: *Wall Street Journal*, “UN Votes to Delay Cloning Ban,” cites CGS Report on National Policies

SPECIAL INITIATIVE:

WITHIN AND BEYOND THE LIMITS TO HUMAN NATURE

In late 2002 CGS approached the Heinrich Boell Foundation (HBS) about the possibility of organizing a major international conference to address the new human genetic technologies. HBS is an important German foundation affiliated with the Green Party, and is a major supporter of progressive political and social change. After phone conversations and meetings in early 2003, planning for the invitational working conference began.

On October 12-15 some 90 civil society leaders from 70 organizations and 30 countries gathered for three days in Berlin, Germany, for the conference. To our knowledge this was the first major international conference of its kind. It was widely judged to be a solid success. Issues addressed included the geneticization of biomedical research and the international public health agenda; human cloning and genetic alteration; sex selection and disability deselection; the prospects for meaningful national and international controls; biopiracy, biobanks, gene patenting, and the biotech industry; military uses of human genetic technology; philosophical foundations for proper use of genetic science; and others.

By the conclusion of the conference, proposals for follow-on conferences and other initiatives had been put forth by participants from Africa, Brazil, China, India, Canada, New Zealand, Eastern Europe and Iraq. Collaborative efforts were initiated by subsets of participants concerning sex selection, biobanks, the upcoming World Social Forum in India, the prospect of an international feminist network, and more.

The conference website, containing texts of presentations, working group reports, an archive of supporting documents and other materials is available at <http://www.biopolitics-Berlin2003.org>.

PUBLICATIONS

Genetic Crossroads, CGS' monthly newsletter, has a new format (see <http://www.genetics-and-society.org/newsletter/>). By the end of the year subscriptions totaled 3150, an increase of nearly 50% over estimated subscriptions of 2200 at the beginning of the year.

Use of the CGS website has grown dramatically. In November 2003 website visits averaged 1500 per day, an increase of 120% over the 680 visits per day in November 2002. Sections in Portuguese and Russian were added, our Spanish section was expanded, and a "news wire" feature was added to the website homepage.

During 2003 CGS prepared several new Fact Sheets and Resource Packets including:

- Fact sheets on "Implications of the New Genetic and Reproductive Technologies for the GLBT Community," "Social Justice and the New Human Genetic Technologies," and "Responsible Governance and the New Human Genetic Technologies."
- "Background Packet on Sex Selection" – articles and documents compiled for the *Within and Beyond the Limits of Human Nature* conference by CGS, the Committee on Women, Population and the Environment, the Center for Health and Gender Equity, and Manvani.
- "Background Packet on Race, Gender and Justice in the Gene Age" – articles and documents compiled for the SisterSong Women of Color Reproductive Health and Sexual Rights National Conference by CGS, the Committee on Women, Population and the Environment, Our Bodies Ourselves, and Communities against Rape and Abuse.

POLICY ENGAGEMENT

In February and again in October CGS supported efforts by Human Genetics Alert in the United Kingdom to oppose sex selection in that country, by writing and helping to generate individual and organizational letters to the Human Fertilisation and Embryology Authority (HFEA). On November 12, the HFEA recommended that sex selection for social reasons be prohibited. In May CGS helped generate statements of support from European and U.S. colleagues for the effort by GE Free New Zealand to secure changes in that country's proposed Human Assisted Reproductive Technologies (HART) bill, now under review by the New Zealand Parliament. In September CGS issued statements of support for Canadian bill C-13, the assisted reproductive technologies act. Decisions on the HART bill and C-13 are expected in 2004.

ADMINISTRATION AND FINANCE

STAFF

CGS currently has five staff: Executive Director Richard Hayes, Associate Director Marcy Darnovsky, Program Director and Operations Manager Jesse Reynolds, International Associate Rosario Isasi, and Administrative Assistant Jasmine Gonzales. During 2004 we plan to hire additional staff to handle increased activities across the board.

FINANCES

During 2003 CGS received \$620,000 in income and spent \$530,000 on program and administrative activities, including establishment of an operating surplus. CGS has income of \$ 425,000 committed for 2004 and hopes to raise another \$250,000. CGS' funding history is shown here:

CGS Funding History

Year	Total Funds Raised/*Committed
1999	\$ 25,000
2000	\$ 165,700
2001	\$ 329,500
2002	\$ 392,400
2003	\$ 620,000
2004	\$ 425,000*

CGS gratefully acknowledges its past and current donors: The Appleton Foundation, CS Fund/Warsh-Mott Legacy, Changing Horizons Fund, Foundation for Deep Ecology, Homeland Foundation, StarFire Fund, Aurora Foundation, Jennifer Altman Foundation, French American Charitable Trust, Pettus-Crowe Foundation, Heinrich Boell Foundation, Ahimsa Fund, the Tides 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 hope to move towards incorporation as an independent 501(c)3 organization during 2004. CGS is in the process of formally establishing our advisory board.

2004 AND BEYOND

In 2004 CGS will continue to emphasize our efforts in the two major areas of Civil Society Engagement, which focuses on specific critical constituencies, and Public Communications, which focuses on reports, articles, conferences and other events intended

for a broad audience. These efforts are intended to alert key individuals and constituencies to the challenges posed by the new human genetic technologies, and to identify those who wish to be part of an organized civil society response. We want to initiate an ambitious series of such public engagement events beginning in Spring 2004 and expect that these will extend into mid-2005.

Key CGS activities already confirmed for 2004 include:

- **January 17-20: *World Social Forum***, Mumbai, India. CGS is organizing three workshops at this important progressive gathering: “The Challenges of the New Human Genetic Technologies: An Overview,” “Genetic Technologies, Corporate Power, and Globalization,” and “Sex Selection and Disability Deselection.” Speakers include CGS Program Director Jesse Reynolds, Association for Women in Development (AWID) Gender and Technology Director Ann Elisabeth Samson, Anita Ghai of Jesus and Mary College, Sabu George of the Centre for Enquiry into Health, Pat Mooney of the ETC Group, and Vandana Shiva of the Research Foundation for Science, Technology and Ecology.
- **May 6-7: *Gender and Justice in the Gene Age: A Feminist Leadership Meeting on the New Human Reproductive and Genetic Technologies***. CGS is co-sponsoring this important conference, to be held in New York City at the Ford Foundation headquarters, with the Committee on Women, Population and the Environment and Our Bodies, Ourselves.
- **June 6-7: *Biodevastation/Biojustice 2004***, San Francisco, CA. CGS will be organizing a panel addressing the challenges of the new human genetic technologies.

Discussions are underway regarding additional initiatives, including a symposium on “Eugenics Past, Present and Future” in Washington, DC; working conferences with activists and experts in Asia, Africa, Latin America and Europe; public symposia in New York City with leading cultural and academic institutions; and more.

In 2004 CGS also plans to begin developing a comprehensive framework of social justice values within which to communicate the full implications of the new human genetic technologies to critical constituencies and the general public. Such a vision and program will likely address the heightened dangers of genetic discrimination, enclosure of the genetic commons through patents and intellectual property rights, exacerbation of global health inequities, corporate control and privatization of biomedical research, and other concerns, in addition to topics such as human cloning, assisted reproduction technologies, and the prospect of a new high-tech eugenics, that CGS has highlighted to date. Our first book, tentatively titled *Liberty and Justice in the Gene Age* and planned for publication in mid-2005, is intended to develop these themes.

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