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CENTER FOR
GENETICS
AND SOCIETY



2011 REPORT ON ACTIVITIES

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2011

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DURING 2011 THE CENTER FOR GENETICS AND SOCIETY successfully organized the Second Annual Tarrytown Meeting, hosted and presented at a variety of fora on cutting-edge biopolitical topics, joined with numerous coalitional partners in significant advocacy initiatives, appeared in print, electronic and online media outlets on almost a weekly basis, and significantly ramped up our website, blog and social media presence. Although the challenges raised by human genetic and reproductive technologies remain as formidable as ever, we are confident that their development and use, both domestically and world-wide, will increasingly and effectively be informed by deeply held and widely shared values of social justice, human rights, ecological integrity, democratic accountability and the common good.

I.

Second Annual Tarrytown Meeting, July 25-27

THE TARRYTOWN MEETINGS ARE CGS'S MAJOR THREE-YEAR INITIATIVE, intended to begin building a dynamic network of people and organizations working to ensure responsible policies and practices regarding new human biotechnologies and related emerging technologies. Some 121 invited advocates, scholars, scientists, creative artists and others convened for the second annual Tarrytown Meeting at the Tarrytown House Estate and Conference Center in Tarrytown, New York for three days of presentations, working sessions, special sessions, conviviality and more. Major topics included global governance of human biotechnologies, communicating effectively about biopolitical concerns, design of instructional curricula, DNA forensics and biobanks, assisted reproductive technologies and reproductive tourism, new techniques for prenatal genetic testing, genetics and racial justice, synthetic biology, cloning and human genetic enhancement, and much more. The 2011 Tarrytown Meeting concluded with discussion of activities to be undertaken in preparation for the third and final Tarrytown Meeting in July 2012.

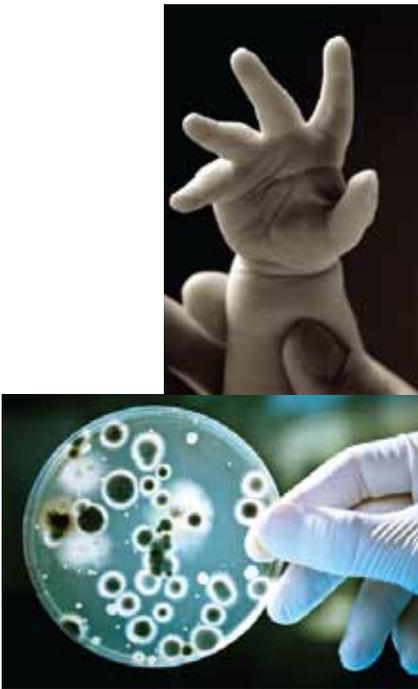
II.

Conferences, Meetings, Presentations and Symposia

January 25: CGS hosted an invitational forum with Helen Wallace, Executive Director of GeneWatch UK, a policy research and public interest group. Dr. Wallace, who holds degrees in physics and applied mathematics, and has worked as an environmental scientist in academia and industry, spoke about medical and forensic DNA databases and the challenges they pose for privacy, justice and human rights.

June 24: CGS hosted an invitational forum with Mara Hvistendahl, China-based correspondent for *Science* magazine, about her widely reviewed book on sex selection, *Unnatural Selection: Choosing Boys over Girls, and the Consequences of a World Full of Men*. Ms. Hvistendahl has emerged as a leading pro-choice voice in the increasingly heated controversies about sex selection in the United States.

- CGS organized two public symposia by noted legal scholar and author Dorothy Roberts about her important new book on race and genetics, *Fatal Invention: How Science, Politics, and Big Business Re-create Race in the Twenty-first Century*. The first, held on September 20 in Berkeley, was co-sponsored by Generations Ahead; the second, on September 22 in Los Angeles, was co-sponsored by Ms. Magazine.
- CGS staff gave invited presentations at venues including the Annual General Medical Staff Meeting of Sutter Davis Hospital, where Associate Executive Director Marcy Darnovsky discussed physicians' concerns about sex selection, direct-to-consumer genetic testing, gene tests that purport to measure children's athleticism, and fetal gene testing; and at Planned Parenthood Advocates, Mar Monte-Sacramento Region, where she discussed commercial surrogacy and reproductive tourism.



III.



Policy, Legislative and Regulatory Initiatives

CGS signed the [Principles for the Oversight of Synthetic Biology](#), organized by Friends of the Earth U.S., International Center for Technology Assessment, and ETC Group (released March 2012). Signed by 114 civil society groups from around the world, the declaration calls for precautionary oversight of the emerging field and outlines principles that should serve as the basis for its governance.

CGS joined several women's health and reproductive justice organizations in an [amicus brief](#) filed before the Supreme Court in the lawsuit challenging Myriad Genetics' patent on human genes associated with elevated risk of breast cancer. The outcome of this high-profile lawsuit may redefine the financial and scientific dynamics of a great deal of genetic research and product development.

CGS was an institutional signator to the [Petition for Human Egg Extraction Health Registry & for Warnings on Ads and Notices Seeking Egg Donors](#), sponsored by the Alliance for Humane Biotechnology. The petition calls for the creation of a widely-publicized, privacy-ensured national registry to facilitate long-term tracking and long-term studies to better understand the risks of egg extraction, and urges that advertisements and notices seeking women to supply eggs be required to state that long-term health risks of egg harvesting procedures are unknown.

CGS signed a [letter from the reproductive justice community](#) to the House Judiciary Committee Subcommittee on the Constitution opposing the Susan B. Anthony and Frederick Douglass Prenatal Nondiscrimination Act of 2011 (H.R. 3541), arguing that restricting abortion rights is not the way to address sex selection. The bill, known as PRENDA, was sponsored by long-time opponents of reproductive rights, and exploits concerns about sex selection in an effort to undermine those rights.

CGS joined Bay Area public interest, social justice and labor organizations in signing a letter to the City Councils of six Bay Area cities about the Lawrence Berkeley National Laboratory's push for a second campus in the East Bay. The letter expresses concerns about the health and safety risks of the synthetic biology experiments planned for the proposed facility.

CGS joined a gene patent coalition in signing a letter opposing the Wasserman-Schultz gene patent amendment as an isolated and weak legislative work-around that would threaten the goals of the ongoing lawsuit against gene patents. Other signators included the American Civil Liberties Union, Friends of the Earth, Breast Cancer Action, Our Bodies Ourselves, National Women's Health Network, International Center for Technology Assessment, and United Methodist Church-General Board of Church and Society.

IV.

Articles and Op-Eds

Op-eds and articles by CGS staff, fellows and consultants appeared in numerous professional journals, edited volumes, popular magazines and major blogs.

Cloning Technology: Control the Bonanza for Research Eggs

[Letter to the editor]

by Marcy Darnovsky, Susan Berke Fogel and Judy Norsigian

Nature, December 1st, 2011

The demand for women's eggs for research could soar alarmingly following a report of a new cloning technique.

Life, Monetized

Review of Harriet Washington's *Deadly Monopolies: The Shocking Corporate Takeover of Life Itself — And the Consequences for Your Health and Our Medical Future*

by Osagie K. Obasogie

The American Prospect, November 17th, 2011

Harriet Washington's new book examines the ways in which the "medical-industrial complex" benefits research industries at the expense of both consumers and human research subjects.

All That Glitters Isn't Gold

by Osagie K. Obasogie and Troy Duster

The Hastings Center Report, October 12th, 2011

Expanded uses of DNA forensics suggest new ethical, legal, and social implications, but the National Research Council's 2009 report obscured these concerns.

Egg Freezing: Risks to Women and Children Unknown

by Marcy Darnovsky

RH Reality Check, August 29th, 2011

Recent media accounts of egg freezing typically acknowledge the inadequate follow-up studies of children born after the procedure. But they neglect to mention the known – though also under-studied – risks of egg retrieval for women.

Surrogacy and Baby-Selling: Latest Fertility Industry Scandal

by Marcy Darnovsky

RH Reality Check, August 19th, 2011

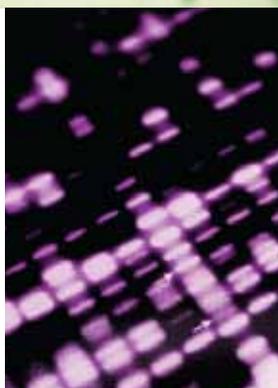
Prominent surrogacy lawyers plead guilty to setting up a baby-selling ring centered in California and the Ukraine, lying to clients and surrogates, and defrauding the state of California.

The Consequence of Unnatural Selection: 160 Million Missing Girls

by Marcy Darnovsky

Ms. Magazine Blog, June 6th, 2011

Mara Hvistendahl's new book provides a deeper understanding of sex selection around the world and makes an urgent case for confronting it.



Articles and Op-Eds

continued

Axing Gamete Donor Anonymity: British Columbia Ruling Reflects Growing Global Conversation

by Jillian Theil

RH Reality Check, May 26th, 2011

A British Columbia judge has ruled that anonymity for gamete donors in the Canadian province is unconstitutional.

One Step Closer to Designer Babies: New Noninvasive Prenatal Genetic Testing Could Change Human Pregnancy Forever

by Marcy Darnovsky

Science Progress, April 22nd, 2011

A new approach to testing the genes of early-stage fetuses could radically alter the experience of pregnancy and parenting from as early as five weeks, leading to a potentially dangerous moral quandary.

Black Salt

by Osagie K. Obasogie

Slate, April 18th, 2011

Should the government single out African-Americans for low-sodium diets?

Clinical Trials on Trial

by Osagie Obasogie

The New Scientist, January 22nd, 2011

Vulnerable people are increasingly targeted as subjects for clinical research. Have we forgotten the lessons of past abuses?

Prisoners as Human Subjects: A Closer Look at the Institute of Medicine's Recommendations to Loosen Current Restrictions on Using Prisoners in Scientific Research

by Osagie K. Obasogie

Stanford Journal of Civil Rights and Civil Liberties, January 18th, 2011

Greater attention must be paid to prisoners' heightened vulnerability as human subjects, and the relevance of human rights to research ethics.

Assisted Reproduction and Choice in the Biotech Age: Recommendations for a Way Forward

[Editorial] by Francine Coeytaux, Marcy Darnovsky and Susan Berke Fogel

Contraception, January 1st, 2011

An editorial in the journal of the Association of Reproductive Health Professionals.



V.

CGS in the News

IN PRINT AND ONLINE

CGS staff members were quoted on a nearly weekly basis by print, radio, television and on-line media on a diverse range of topics.

CGS was cited in “Genes and Health,” *CG Researcher* (January 21)

Doug Pet was cited in “Is Forced Sterilization Ever Ok?,” Tracy Clark-Flory, *Salon* (January 18)

Marcy Darnovsky was cited in “State stem cell firm uses tax dollars for nonpublic campuses,” Katie Worth, *San Francisco Examiner* (February 20)

Doug Pet was cited in “India moves toward regulating assisted reproduction and surrogacy,” Jared Yee, *BioEdge* (February 18)

Richard Hayes was cited in “Down with Gene Tyranny!,” Ron Bailey, *Reason Magazine* (February 22)

Marcy Darnovsky was cited in “Progress in Bioethics: Science, Policy and Politics,” Andrew Barnovsky, *Journal of the American Medical Association* (March 10)

CGS was cited in “The Troubling Rehabilitation of Eugenics,” Michael Cook, *Spero News* (March 8)

Doug Pet was cited in “A Future with 3-month Pregnancies,” Michael Cook, *BioEdge* (March 26)

Richard Hayes was cited in “The Case for Enhancing People,” Ron Bailey, *The New Atlantis* (April)

Marcy Darnovsky was cited in “Could prenatal DNA testing open Pandora’s box?,” Malcolm Ritter, *Associated Press* (many outlets) (June 12)

Osagie Obasogie was cited in “Addressing Race and Genetics: Health Disparities in the Age of Personalized Medicine,” Michael J. Rugnetta and Khusboo Desai, *Center for American Progress* (June 13)

CGS was cited in “More Boys than Girls - A Growing Problem,” *EmpowerHER* (June 9)

Marcy Darnovsky was cited in “Tests prénataux : gare à la boîte de Pandore,” *La Republicain Lorraine* (June 18)

Marcy Darnovsky was cited in “Hypocrisy or Irony? Right-Wing Media and Abortion,” Cynthia Dill, *Huffington Post* (July 10)

Marcy Darnovsky was cited in “Unnatural Selection: Is Prenatal Testing A Triumph for Reproductive Freedom—or Brazen Discrimination?,” Ilana Yurkiewicz, *Science Progress* (July 18)

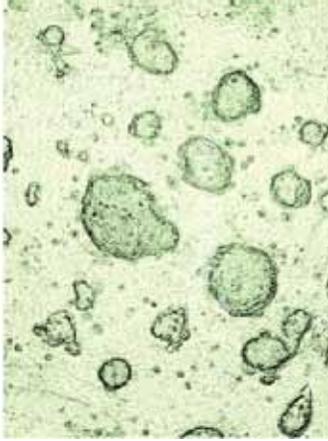
Marcy Darnovsky was cited in “The Abortion Trap,” Mara Hvistendahl, *Foreign Policy* (July 26)

CGS was interviewed in “Interview with the Center for Genetics and Society,” *What’s Happening Magazine* (August 1)



CGS in the News

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Marcy Darnovsky was cited in “Boy or Girl? Down Syndrome? What to Expect When You’re Testing,” Susan Gilbert, *Bioethics Forum* (August 11)

Emily Beitiks was cited in “Book Hits Human Fertilization ‘Market,’” Tom Abate, *Forbes* (August 26)

Pete Shanks was cited in “Of Dogs, Clones and Rick Perry,” John Farrell, *Forbes* (September 30)

Marcy Darnovsky was cited in “Stem Cell Research Used Cloning Technique, Paid Women for Eggs,” Eryn Brown, *Los Angeles Times* (October 6)

Marcy Darnovsky was cited in “Fresh (Human) Eggs for Sale,” Ron Bailey, *Reason Magazine* (October 11)

Marcy Darnovsky was cited in “Richmond bioscience company makes strides in HIV research,” Hasan Dudar, *Richmond Confidential* (October 18)

Marcy Darnovsky was cited in “California stem cell agency needs to study itself,” Michael Hiltzik, *Los Angeles Times* (December 7)

ON TELEVISION AND RADIO

Marcy Darnovsky was interviewed on a segment about non-invasive prenatal diagnosis on America’s Radio News Network (April 27)

Marcy Darnovsky was interviewed by Enola Aird, Mothers for a Human Future Radio in “A conversation about the latest developments in new human genetic and reproductive technologies and their implications for mothers and children” (June 15)

Marcy Darnovsky was interviewed on “Sex Selection in Asia,” Michelle Chen, WBAI 99.5 FM NYC (July 11)

Marcy Darnovsky was interviewed on “Concerns about fetal gene tests for sex and trait selection,” Al Jazeera (August 12)

Marcy Darnovsky was interviewed on “The Economics of Stem Cell Research,” Stephanie O’Neill, The Madeleine Brand Show (89.3 KPCC) (November 16)



CGS PRESS ADVISORIES

Women’s health and public interest groups warn against putting women’s health at risk in new kind of research cloning

October 5th, 2011 “We should not put the health of young women at risk, especially to get raw materials for such exploratory investigations.”

Pro-choice women’s health and public interest advocates voice concerns regarding fetal gene tests for sex and trait selection

August 22nd, 2011 “These tests raise concerns about the well-being of children, women and families and the prospect of testing for additional traits other than sex.”



VI.

Internet Communications

WEBSITE. Traffic on the CGS website during 2011 averaged 31,342 unique visitors per month, an increase of 13.2% over 2010.

BLOGS. CGS staff writers and several regular guest contributors drawn from the Tarrytown Meetings network add 3–4 posts per week to *Biopolitical Times*, CGS’s blog on our website. CGS staff writers add several posts per month to *Genetic Crossroads*, the CGS blog at the website of *Psychology Today*.

NEWSLETTERS. We currently have 3,750 subscribers to our weekly newsletter.

SOCIAL MEDIA. CGS blog entries are posted on Twitter (1160 followers) and Facebook (475 fans). Videos are posted on the CGS YouTube Channel.

VII.

CGS Staff and Leadership

As of December 31, 2011, CGS had five regular staff (4.0 FTE), one Senior Fellow and one regular contributor to our Biopolitical Times blog. They are:

- > Richard Hayes, Executive Director
- > Marcy Darnovsky, Associate Executive Director
- > Charles Garzón, Director of Finance and Administration
- > Emily Smith Beitiks, Senior Program Associate
- > Osagie K. Obasogie, Senior Fellow for Bioethics, Law and Society
- > Pete Shanks, Biopolitical Times contributor
- > Douglas Pet, Staff Associate

The work of CGS, and in particular our work in support of the July 2011 Tarrytown Meeting, was greatly enhanced by our exemplary corps of CGS summer staff associates:

- > Brendan Parent (Georgetown Law)
- > Jillian Theil (University of California, Los Angeles)
- > Emily Stehr (University of California Hastings College of the Law)
- > Emily Smith Beitiks (University of Minnesota)
- > Spencer McFarlane (Washington University St. Louis)

CGS is honored to have a distinguished Advisory Board to help guide our work. Current members are:

- > Francine Coeytaux, founder, California Institute for Women’s Health
- > Dorothy Roberts, Professor of Law, Northwestern University School of Law
- > David Winickoff, Professor of Bioethics, University of California at Berkeley



CGS Staff and Leadership

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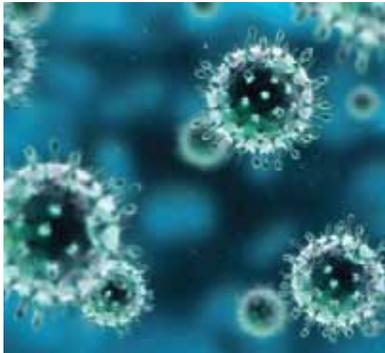
CGS's three-year Tarrytown Meetings Initiative is guided by an active Steering Committee. Members for the 2011 Tarrytown Meeting are:

- > Jaydee Hanson, Policy Director, International Center for Technology Assessment
- > Richard Hayes, Executive Director, Center for Genetics and Society (Coordinator)
- > Eric Hoffman, Biotechnology Campaigner, Friends of the Earth
- > Lisa Ikemoto, Professor of Law, University of California at Davis
- > Stuart Newman, Professor of Cell Biology and Anatomy, New York Medical College
- > Judy Norsigian, Executive Director, Our Bodies Ourselves
- > Osagie K. Obasogie, Associate Professor, University of California Hastings College of the Law
- > Dorothy Roberts, Professor of Law, Northwestern University

VIII.

Budget and Funding

CGS's adjusted budget for 2011 is \$740,793. Current funding for CGS comes from the Appleton Foundation, the Marisla Foundation and several individual donors. Complete financial reports are available on request.



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