

CENTER FOR
GENETICS
AND SOCIETY

2012 REPORT ON ACTIVITIES



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2012

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I. Introduction

During 2012 the Center for Genetics and Society moved toward the objective of building a “new biopolitics” that confronts the social justice and public interest challenges raised by a range of human biotechnologies.

The year saw the successful completion of our major three-year Tarrytown Meetings Initiative, which established a robust network of scholars and advocates who are engaged with one or more of the issues raised by human biotechnologies and who look to CGS as a leader, coordinator and partner. In addition, CGS organized, hosted and presented at key events addressing priority biopolitical issues; collaborated with colleagues in high-profile advocacy efforts; appeared repeatedly in print, electronic and online media outlets; and significantly increased our web, blog and social media visibility.

Introduction

continued

The challenges raised by human genetic and reproductive technologies remain as stark as ever, but we are confident that the ongoing efforts to ensure that values of social justice, human rights, ecological integrity, democratic accountability and the common good inform their development and use will prevail.

II. Third Annual Tarrytown Meeting

THE TARRYTOWN MEETINGS were envisioned as a major initiative intended to begin building a network of individuals and organizations committed to responsible policies and practices regarding human biotechnologies and related emerging technologies. In July 2012, 101 invited colleagues convened for the third Tarrytown Meeting, held once more at the Tarrytown House Estate and Conference Center in Tarrytown, New York. Topics addressed included markets and assisted reproduction, genetic technologies and racial justice, synthetic biology, bioethics and political ideology, bioweapons and biowarfare, international regulation of human biotechnology, the legacy of eugenics in the United States, strategies for communicating about biotechnology challenges, human biotechnology and the arts, and much more.

Together the three Tarrytown Meetings, held in 2010, 2011 and 2012, brought together some 211 colleagues from over 130 academic, advocacy, policy, cultural and other institutions. A full report on the issues discussed, perspectives considered, participants involved, collaborations agreed upon, and more, is in preparation. The Tarrytown Meetings website can be accessed with a guest username and password. Although we had agreed at the outset that we would conclude this initiative with the third Tarrytown Meeting, participants suggested that regional follow-up convenings be held in late 2013 or early 2014. Specific proposals for these are now under discussion.

III. Convenings, Presentations, Symposia

THE CALIFORNIA EUGENICS INITIATIVE

On August 28, CGS, in collaboration with the UC Berkeley Haas Diversity Research Center, the UC Berkeley School of Law, and other groups, hosted an important two-part event addressing the legacies of eugenics in California. The first part was a day-long invitational strategy session in which some 30 key advocates and scholars, most from California, focused on the past, present and future implications of eugenic practices and ideologies. The second part of the event was a public symposium titled “Eugenics in California: A Legacy of the Past?” It drew over 200 participants, and was webcast and recorded. The strategy meeting produced a number of suggestions for an ongoing initiative, including the possibility of a larger conference in California in 2013.



Convenings, Presentations, Symposia

continued

A distinguished advisory committee is engaged with this effort. The committee members are Troy Duster, Professor of Sociology Emeritus, University of California, Berkeley and New York University; Alexandra Minna Stern, Associate Professor of Obstetrics and Gynecology, History, and American Culture, University of Michigan; Susan Schweik, Professor of English and Associate Dean of Arts and Humanities, University of California, Berkeley; Tony Platt, Professor Justice Studies, San Jose State University; and Miroslava Chavez-Garcia, Associate Professor and Chair, Chicana/o Studies Program, University of California, Davis; Milton Reynolds, Senior Program Associate, Facing History and Ourselves; and Emily Beitiks, Assistant Director, Paul K. Longmore Institute on Disability, San Francisco State University (and former CGS staff).

CGS “TALKING BIOPOLITICS” WEBINAR SERIES

In 2012 CGS inaugurated its online webinar series of interviews with three noted colleagues:

March 2: Bill McKibben, author of *Enough: Staying Human in an Engineered World* and founder of 350.org, was interviewed by Marcy Darnovsky.

April 10: Dorothy Roberts, author of *Fatal Invention: How Science, Politics, and Big Business Re-create Race in the Twenty-first Century*, was interviewed by UC Berkeley Associate Professor of Bioethics and Society David Winickoff.

May 8: Harriet Washington, author of *Deadly Monopolies: The Shocking Corporate Takeover of Life Itself – And the Consequences for Your Health and Our Medical Future*, was interviewed by UC Davis Professor of Law Lisa Ikemoto.

OTHER EVENTS

March 28: CGS hosted a press briefing on synthetic biology organized by Friends of the Earth, International Center for Technology Assessment, Movement Generation, and the Alliance for Humane Biotechnology. In conjunction with the public event being announced, CGS senior staff associate Emily Beitiks authored an op-ed in the *San Jose Mercury News* titled “Bay Area may be at Risk from Synthetic Biology Research Labs” (March 27)

May 22: Marcy Darnovsky, along with CGS Advisory Board member Francine Coeytaux and colleagues Sunita Puri and Susan Fogel, presented a panel titled “Emerging Human Biotechnologies: Beyond Perceived Ideological Divides on New Reproductive and Genetic Technologies” at the Psychosocial Workshop, an annual gathering of psychological and social scientists and related health professionals held in conjunction with the Population Association of America.

September 11: Marcy Darnovsky spoke about CGS’s work at Professor David Winickoff’s bioethics class at the University of California at Berkeley.



Convenings, Presentations, Symposia

continued

October 8: Marcy Darnovsky was a featured speaker at the 2012 Applied Brilliance conference in Sonoma, CA, presenting on “Balancing Acts in an Open Source World: The Case for a New Biopolitics.”

November 2, Baltimore, Maryland: Richard Hayes participated in the “Biopolitical Constitution Roundtable” at the University of Maryland, organized by Tarrytown Meetings participant Michele Goodwin.

IV. Policy, Legislative and Regulatory Initiatives

January: CGS signed an *amicus curiae* brief to the United States Supreme Court with five other public interest and women’s health organizations to argue against the right of Myriad Genetics, Inc. to patent the BRCA 1 and 2 human genes.

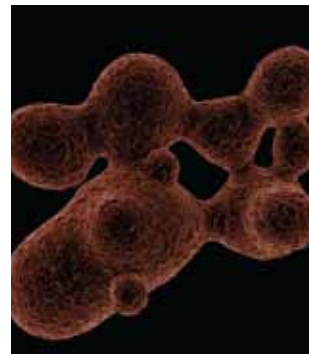
March: CGS, along with 110 other civil society organizations, signed the *Principles for the Oversight of Synthetic Biology*, a declaration calling for precautionary oversight of the emerging field.

April 10: Marcy Darnovsky delivered invited comments to the Institute of Medicine (IOM) Committee on a Review of the California Institute for Regenerative Medicine (CIRM), meeting in Irvine, CA. The IOM committee reviewed CIRM’s initial processes, programmatic and scientific scope, organizational and management systems, funding model, and intellectual property policies. The IOM released a report on December 6, 2012 echoing the longstanding concerns voiced by CGS and calling for stronger protections for the interests of Californians. CGS put out a press statement the same day, applauding the recommendations and calling for additional changes.

June: CGS joined five other public interest and women’s health organizations in an *amicus curiae* brief with the U.S. Federal Circuit Court of Appeals in Washington, D.C. in the landmark case on human gene patents filed by the ACLU and Public Patent Foundation against Myriad Genetics and the US Patent and Trade Office.

October: CGS signed an *amicus curiae* brief to the Supreme Court of the United States along with six other public interest and women’s health organizations, as well as several notable medical professionals, in the *Association for Molecular Pathology v. Myriad Genetics, Inc.* case in support of the petition for writ of certiorari to be granted and Myriad’s patents on human genes to be invalidated.

November 15: CGS sent a letter to the Human Fertilisation and Embryology Authority and the Secretary of State for Health in the UK in regard to their public consultation on the social and ethical implications of a technique known as mitochondria replacement. The technique is currently illegal in the UK because it results in inheritable genetic modification, but research teams are pushing to change the law in hopes of moving to human clinical trial. CGS organized 24 noted scholars and advocates from the U.S., the UK, Scotland, Germany, Canada, and Israel to send letters/consultation responses voicing their concerns.



Policy, Legislative and Regulatory Initiatives

continued

December 19: In response to the release of a study involving similar mitochondrial replacement techniques by scientists associated with the New York Stem Cell Foundation (NYSCF) and Columbia University Medical Center, CGS release a press statement titled “Public interest group calls on FDA to rule “nuclear genome transfer” unacceptable: “Nuclear genome transfer” would mean uncontrolled human experimentation on future children and their offspring.”



V.

Publications

BOOK AND REPORT

- Marcy Darnovsky and Osagie Obasogie signed a contract with University of California Press for CGS’s first book, *Beyond Bioethics: Towards a New Biopolitics* (working title), an anthology with contributions by some 35 noted CGS colleagues. It will be published in 2014.

- *Values for a New Biopolitics* (working title), a report drawing on discussions held at the 2011 and 2012 Tarrytown Meetings, is in preparation for publication in 2013. Lead authors are Emily Beitiks; David Winickoff, Associate Professor of Bioethics and Society, University of California, Berkeley and CGS Advisory Board member; and Mark Brown, Associate Professor, Department of Government, California State University, Sacramento.

OP-EDS AND ARTICLES

- **Make Me a Baby As Fast As You Can**, an investigative report by CGS senior staff associate Doug Pet about conditions in the commercial cross-border surrogacy industry was published in *Slate* (January 9).

- **Should You be Able to Clone Your Pet?** a debate on the ethics of cloning animals including Biopolitical Times contributor Pete Shanks was published in *Junior Scholastic* (February 27)

- **Egg Freezing: Taking a Closer Look at the Experimental Label**, a report on the social consequences of moving egg freezing into the mainstream by CGS staff associate Sona Makker was published in *RH Reality Check* (March 22)

- **Bay Area may be at risk from synthetic biology research labs**, an op-ed reporting on the environmental and human health risks of the proposed synthetic biology lab in Richmond, CA by CGS senior program associate Emily Smith Beitiks was published in *San Jose Mercury News* (March 27)

- **The end of race history? Not yet**, an op-ed on the review of two books and their discussion of the conflict between ideas of a post-racial world and the continuing use of race in science and medicine by CGS senior fellow Osagie Obasogie was published in *New Scientist* (December 14)



Publications

continued



Psychology Today (Genetic Crossroads)

CGS's group blog at *Psychology Today* is called *Genetic Crossroads*.

Genetic Discrimination and Ron Paul by Emily Smith Beitiks (January 12)

Dog Cloning Infomercial on TV by Pete Shanks (January 19)

Flap Over Designer Sperm in India, “tall and fair” sperm donors only need apply by Marcy Darnovsky (February 2)

Too Posh for Pregnancy? by Marcy Darnovsky (February 8)

Assisted Reproduction Technologies on *Glee* and *Modern Family*
by Emily Smith Beitiks (February 29)

Illegal Surrogacy Operation the “Tip of the Iceberg”
by Emily Smith Beitiks (March 7)

Another Anti-Abortion Sting by Marcy Darnovsky (May 25)

DNA Donors Should be Aware of Privacy Risks by Pete Shanks (May 28)

Race Under the Microscope, a video featuring CGS colleagues on the biological misunderstandings of race by Emily Smith Beitiks (June 5)

Madonna's DNA – Want Some? by Pete Shanks (July 3)

Survival of the Fastest: Did the descendents of slaves inherit athletic talent? by Pete Shanks (July 11)

Ethics Schmethics Says Ethicist by Pete Shanks (July 3)

Stop and Swab: Dramatic Increases in DNA Police Databases
by Jessica Cussins (August 22)

The Dangers of Fetal Engineering: Intersex Babies and Risky Drugs
by Emily Smith Beitiks (August 24)

Politics in our Genes? Yet another study claims genetics as source of political identity by Jessica Cussins (September 12)

Will Joseph Merrick, aka the Elephant Man, Ever Rest in Peace?
by Emily Smith Beitiks (September 12)

Race-Based Medicine: Déjà vu all over again? by Osagie Obasogie (September 14)

Feel Good Surrogacy? by Jessica Cussins (September 17)

Frozen Egg Banks: A “Paradigm Shift” for the Fertility Industry?
by Jessica Cussins (November 6)

Embryos for Sale? When you want them, how you want them, or your money back by Jessica Cussins (November 29)



Publications

continued

Biopolitical Times Blog

144 blog posts by 15 different contributors were published in *Biopolitical Times* in 2012. They reported on a broad range of topics including stem cell research, synthetic biology, assisted reproduction, racialized medicine, arts and culture, and genetic testing.

VI. CGS In The News

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

IN PRINT AND ONLINE

Print and online outlets included *The New York Times*, *Associated Press*, *San Francisco Chronicle*, *San Francisco Business Times*, *Seattle Times*, *The Globe and Mail*, *Le Monde*, *Slate*, *The Week*, *Nature* and *Forbes*.

Marcy Darnovsky was cited in “Unnatural Selection: Is Evolving Reproductive Technology Ushering in a New Age of Eugenics?,” Carolyn Abrahams, *The Globe and Mail* (January 7)

Center for Genetics and Society was cited in “Myriad Cert Petition Now Fully Briefed; Supreme Court May Decide by Feb. 20,” Tony Dutra, *Bloomberg BNA* (February 2)

Marcy Darnovsky was cited in “The Politics Of Biology: Bioprogressives vs. Bioconservatives,” Erik Kain, *Forbes* (February 22)

Marcy Darnovsky was cited in “At a Crossroads, California’s Stem Cell Agency Ponders a Future Without Taxpayer Support,” Alicia Chang, *Associated Press* (March 18)

Marcy Darnovsky was cited in “Bay Area Biotech Labs May Bring Unforeseen Risks, Says Civil Society Coalition,” Global Justice Ecology Project, *Climate Connections* (March 28)

CGS was cited in “Plan to merge labs for biofuel research criticized,” David Pearlman, *San Francisco Chronicle* (March 29)

Marcy Darnovsky was cited in “Center for Genetics and Society: ‘Wrong’ to Ask for More Billions for Stem Cell Agency,” David Jensen, *California Stem Cell Report* (April 10)

Marcy Darnovsky was cited in “\$3B question: Will stem cell bets pay off?,” Ron Leuty, *San Francisco Business Times* (April 13)

Marcy Darnovsky was cited in “Critics of California Stem-Cell Agency Address Institute of Medicine Panel,” Erika Check Hayden, *Nature* (April 13)

Marcy Darnovsky was cited in “Will Gattaca Come True?” Mara Hvistendahl, *Slate* (April 27)



CGS in the News

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Marcy Darnovsky was cited in conversation with David Winickoff, *Breakthroughs* (Spring 2012)

Marcy Darnovsky was cited in “DNA Blueprint for Fetus Built Using Tests of Parents,” Andrew Pollack, *The New York Times* (June 6)

Marcy Darnovsky was cited in “Will fetal DNA scans allow parents to tailor their offspring?,” Sandi Doughton, *The Seattle Times* (June 6)

Marcy Darnovsky was cited in “La fin de l’amniocentèse,” *Slate.fr* (June 7)

Marcy Darnovsky was cited in “Une méthode de dépistage des maladies génétiques plus performante et sans risques,” Valentine Pasquesoone, *Le Monde* (June 7)

Marcy Darnovsky was cited in “Researchers sequence fetus’ entire genome from mom’s blood and dad’s saliva,” Ryan Jaslow, *CBS News* (June 7)

Marcy Darnovsky was cited in “Genom przed urodzeniem,” Piotr Kościelniak, *Rzeczpospolita* (June 7)

Marcy Darnovsky was cited in “Would Easy In-Utero Genetic Testing Encourage Abortions?” *The Week* (June 8)

Marcy Darnovsky was cited in “Your Unborn Baby’s Genetic Code: Do You Want to Know?,” Kristina Chew, *Care2* (June 8)

Marcy Darnovsky was cited in “High Doses of Hormones Faulted in Fertility Care,” Jacqueline Mroz, *The New York Times* (July 16)

Marcy Darnovsky was cited in “Girl or Boy? Science can help you make the choice,” Bridgette Springer, *Parenting New Hampshire* (July 18)

Marcy Darnovsky was cited in “New Stanford fetal DNA test adds to ethical issues,” Stephanie M. Lee, *San Francisco Chronicle* (July 26)

Center for Genetics and Society was cited in “Weird Science: The Promise and Peril of Synthetic Biology,” Jeff Conant, *Earth Island Journal* (Autumn)

Marcy Darnovsky was cited in “How To Buy a Daughter: Choosing the sex of your baby has become a multimillion-dollar industry,” Jasmeet Sidhu, *Slate* (September 14)

Marcy Darnovsky was cited in “Gender Selection Obsessed ‘Girl-Mommys’ Are Insulting To Girls – And Boys,” Koa Beck, *Mommy-ish* (September 17)

Marcy Darnovsky was cited in “Human Genetic Modification Experiment in Oregon Shows Promise, Risks, Experts Say,” Nick Budnick, *The Oregonian* (October 24)

Marcy Darnovsky was cited in “Comment S’acheter Une Fille,” Jerry Lampen, *Slate.fr* (October 24)

Marcy Darnovsky was cited in “Belief Blog’s Morning Speed Read for Friday, October 26th,” Arielle Hawkins, *CNN Belief Blog* (October 26)

CGS in the News

continued

Marcy Darnovsky was cited in “Leaning left or right? Red or blue? Answer may be in your genes,” Stephen Dinan, *The Washington Times* (November 5)

Center for Genetics and Society was cited in “Amici File Seven Briefs Supporting ACLU Challenge to Isolated DNA Patent Eligibility,” Tony Dutra, *Bloomberg BNA* (November 13)

Center for Genetics and Society was cited in “Gattaca Alert? Or Should We Welcome the New Age of Eugenics?,” Jon Entine, *Forbes* (November 26)

Marcy Darnovsky was cited in “Selecting Against Disease,” Urmila Ramakrishnan, *Fin Magazine* (November 26)

Marcy Darnovsky was cited in “Report says California’s taxpayer-funded stem cell agency needs a reorganization,” Alicia Chang, Associated Press, *The Washington Post* (December 6)

Marcy Darnovsky was cited in “Report recommends changes to California stem cell agency’s board,” Ron Leuty, *San Francisco Business Times* (December 6)

Marcy Darnovsky was cited in “IOM Proposals for Overhaul at CIRM Win High Marks,” David Jensen, *California Stem Cell Report* (December 7)

Marcy Darnovsky was cited in “More women turn to frozen eggs for help with infertility,” Andrea Walker, *The Baltimore Sun* (December 8)

Marcy Darnovsky was cited in “Why your DNA is a goldmine for marketers,” Carolyn Abraham, *The Globe and Mail* (December 12)

Marcy Darnovsky was cited in “Universities with Connections Win Most Stem Cell Money,” Melody Peterson, *The Orange County Register* (December 14)

Marcy Darnovsky was cited in “Why China is a genetic powerhouse with a problem,” Carolyn Abraham and Carolynne Wheeler, *The Globe and Mail* (December 15)

ON TELEVISION, RADIO AND WEBCAST

Television and radio appearances included *CBS News*, *ABC News Radio*, *PBS News Hour*, *NPR*, *HuffPost Live*, and *Southern California Public Radio*.

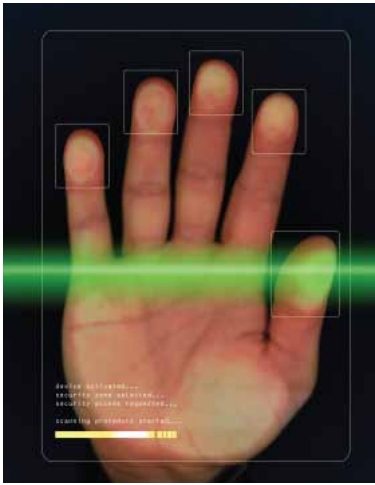
Marcy Darnovsky was interviewed for “The ethics of pre-natal DNA testing,” Madeleine Brand, *The Madeleine Brand Show* (89.3 KPCC) (June 7)

Marcy Darnovsky was interviewed for “New Fetus Testing Shows Promise, Raises Ethical Questions,” Joshua Cohan, *ABC News Radio* (June 8)

Marcy Darnovsky was interviewed for “How To Buy a Daughter,” *HuffPost Live* (September 18)

Marcy Darnovsky was interviewed for “My Three Parents, Coming Soon?” *HuffPost Live* (September 27)





Marcy Darnovsky was interviewed for “ASRM removes “experimental” label from egg freezing,” Jasmin Tuffaha, *KPCC* (October 19)

Marcy Darnovsky was interviewed for “Freezing Human Eggs for In Vitro Fertilization No Longer Experimental Procedure,” Margaret Warner, *PBS NewsHour* (October 19)

Biopolitical Times was cited in “Law Lags as Aussies Employ Overseas Surrogate Mums,” Damien Carrick, *ABC RadioNational* (October 23)

Marcy Darnovsky was interviewed for “Geneticists Breach Ethical Taboo By Changing Genes Across Generations,” Rob Stein, *NPR All Things Considered* (October 24)

Marcy Darnovsky was interviewed for “Frozen Eggs,” Stefano H. Kotsonis, *On Point (NPR)* (October 26)

Marcy Darnovsky was interviewed for “Genetic Breathrough at OHSU,” Allison Frost, *Oregon Public Radio* (October 29)

Marcy Darnovsky was interviewed for “Auf dem Weg zur umstrittenen Keimbahntherapie?,” Von Lucian Haas, *Deutschlandfunk* (November 20)

Marcy Darnovsky was interviewed for “Health Watch: More Parents Deciding Sex of Children,” Kim Mulvihill, *CBS San Francisco* (December 28)

VII.

CGS Online

WEBSITE & BLOGS: There were more than 300,000 visits to the CGS website and blog, *Biopolitical Times*. Guest contributors to *Biopolitical Times* in 2012 were Mike Beitiks, Jeff Conant, George Estreich, Anna Hamilton, Abby Lippman, and Gina Maranto. CGS staff writers add several posts per week to *Biopolitical Times*, and several per month to *Genetic Crossroads*, the CGS blog at the website of *Psychology Today*.

NEWSLETTERS & NEWS SCAN: In 2012 CGS’s newsletter *Views & News* averaged approximately 3500 subscribers. CGS also produces a twice-weekly digest of important news items that informs our press, media and other work, and is shared with about 80 close colleagues worldwide.

SOCIAL MEDIA: At the close of 2012 CGS had some 2300 followers on Twitter (@C_G_S). CGS’s YouTube Channel has received more than 43,000 views since it went online three years ago. We are currently revamping our CGS Facebook page, and have set up but not yet publicized a Tarrytown YouTube Channel.

VIII.

CGS Staff and Leadership

As of December 31, 2012, CGS had three full-time regular staff one Senior Fellow, two Staff Associates and one regular contributor to our blog, *Biopolitical Times*. They are:

- Richard Hayes, Executive Director
- Marcy Darnovsky, Associate Executive Director
- Charles Garzon, Director of Finance and Administration
- Osagie K. Obasogie, Senior Fellow for Bioethics, Law and Society
- Jessica Cussins, Staff Associate
- Emily Stehr, Staff Associate
- Pete Shanks, *Biopolitical Times* contributor

The work of CGS, and in particular our work in support of the July 2012 Tarrytown Meeting, was greatly enhanced by our outstanding roster of 2012 CGS staff associates:

- Jessica Cussins (University of California, Berkeley)
- Sona Makker (University of California, Berkeley)
- Jake Orr (University of Denver)
- Daniel Sharp (University of California, Berkeley)

Others who played key staff, consulting and staff associate roles at CGS in 2012 included Emily Galpern, Karthik Sonty, Anne Rumberger and Doug Pet.

On a bittersweet note, in September 2012 CGS Senior Program Associate Emily Beitiks accepted an offer to serve as Assistant Director of the newly-formed Paul Longmore Institute on Disability at San Francisco State University. Emily was dearly loved by everyone at CGS, and she will be greatly missed.

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

- Francine Coeytaux, public health specialist and founder, Pacific Institute for Women's Health
- Dorothy Roberts, George A. Weiss University Professor of Law and Sociology and Raymond Pace and Sadie Tanner Mossell Alexander Professor of Civil Rights, University of Pennsylvania Law School and Department of Sociology
- David Winickoff, Associate Professor of Bioethics and Society, University of California, Berkeley

CGS's three-year Tarrytown Meetings Initiative has been guided by an active Steering Committee. Members for the 2012 Meeting were:

- 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
- Gina Maranto, Director, Ecosystem Science and Policy Program, University of Miami
- 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 and Sociology, University of Pennsylvania



IX. Transition Planning

After twelve years as CGS founding executive director, Richard Hayes announced in May that he would step down from that position at the end of 2012. Beginning in January 2013 he will be a visiting scholar at the University of California at Berkeley College of Natural Resources. In January 2013, the CGS Advisory Board announced that after a national search, Marcy Darnovsky was selected as the new Executive Director. A new Associate Executive Director, Diane Tober, joined CGS in mid-January.

X. Budget and Funding

CGS's adjusted expenses for 2012 were \$683,879. Current funding for CGS comes from the Appleton Foundation; the Marisla Foundation; the Lyman B. Brainerd, Jr. Family Foundation; the Heimbinder Family Foundation; and individual donors. Complete financial reports are available on request.



CENTER FOR GENETICS AND SOCIETY

1936 University Avenue, Suite 350
Berkeley, CA 94704

info@geneticsandsociety.org
www.geneticsandsociety.org
land: 1-510-625-0819