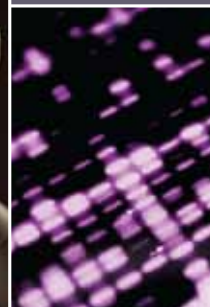


CENTER FOR  
GENETICS  
AND SOCIETY



2013 REPORT ON ACTIVITIES

# CENTER FOR GENETICS AND SOCIETY

2013 REPORT ON ACTIVITIES

2013

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## I. Introduction

This year saw a major staff transition at the Center for Genetics and Society, with founding Executive Director Richard Hayes retiring at the end of 2012 and former Associate Executive Director Marcy Darnovsky taking the helm as the new Executive Director. 2013 was also a transition year in terms of program focus, after the successful conclusion in 2012 of our three-year Tarrytown Meetings initiative.

Throughout these transitions, we continued to work toward building a “new biopolitics” to meet the social justice and public interest challenges raised by human biotechnologies. We maintained our three-pronged strategic approach, and have successes to report in all three areas. CGS organized, hosted, and presented at key events on biopolitical issues; celebrated significant wins in state and national policy interventions; and exceeded our expectations in our communications and media efforts.

## II.

## Events and Network Building

### THE CALIFORNIA EUGENICS INITIATIVE

#### *Future Past: Disability, Eugenics and Brave New Worlds*, November 1, 2013

Following the highly successful August 2012 public symposium and invitational meeting at Berkeley Law School, members of the California eugenics initiative decided to focus in 2013 on *Future Past: Disability, Eugenics and Brave New Worlds*. CGS co-organized this full-day public symposium at San Francisco State University with the Paul K. Longmore Institute on Disability, Living Archives on Eugenics in Western Canada, and Facing History and Ourselves. Interest was so strong that we were forced to close registration five weeks in advance, when we reached the 135-person capacity of the venue.

### CGS “TALKING BIOPOLITICS” WEBINAR SERIES

In 2013, CGS continued our online interview series, highlighting the thought-provoking work of colleagues. The year’s *Talking Biopolitics* events were:

- May 21: Miriam Zoll, author of *Cracked Open: Liberty, Fertility and the Pursuit of High Tech Babies*, interviewed by Diane Tober
- June 3: George Estreich, author of *The Shape of the Eye: A Memoir*, interviewed by Emily Smith Beitiks, Longmore Institute on Disability
- June 25: Ruha Benjamin, author of *People’s Science: Bodies and Rights on the Stem Cell Frontier*, interviewed by Marcy Darnovsky
- July 16: Donna Dickenson, author of *Me Medicine vs. We Medicine: Reclaiming Biotechnology for the Common Good*, interviewed by Osagie Obasogie
- October 3: Regan Brashear, producer and director of *FIXED: The Science/Fiction of Human Enhancement*, interviewed by Gina Maranto, Abess Center for Ecosystem Science and Policy
- November 14: Alexandra Minna Stern, author of *Eugenic Nation: Faults and Frontiers of Better Breeding in America*, and Corey G. Johnson, Center for Investigative Reporting, interviewed by Marcy Darnovsky.

### EAST BAY CONVERSATIONS

In 2013, CGS joined SynBioWatch, a consortium of organizations including Friends of the Earth, International Center for Technology Assessment, Alliance for Humane Biotechnology, Movement Generation Justice and Ecology Project, and ETC Group. *East Bay Conversations* consisted of four public events on synthetic biology and human biotechnology, all held at the David Brower Center in Berkeley:

- March 21: “When Green Tech Isn’t Clean Tech,” Jim Thomas, Rebecca Burgess, and Gopal Dayaneni
- June 6: “Genetically Modified Humans,” Stuart Newman and Milton Reynolds
- September 11: “Seeding Labs, Ceding Seeds: Regional And Global Impacts of the Biotech Bonanza,” Vandana Shiva and Gopal Dayaneni
- October 16: “Biosafety by the Bay,” Becky McClain, Ed Hammond, and Gopal Dayaneni



## Events and Network Building

*continued*

All four were streamed live, and are available on the SynBioWatch website. The event featuring environmental activist and philosopher Vandana Shiva drew a sold-out standing-room only audience.

### OTHER EVENTS

*The Tarrytown Meetings.* This year we converted the Tarrytown Meetings website into a publicly accessible version, and published a final report on the Tarrytown Meetings initiative.

#### *Presentations and workshops.*

- In April, Marcy Darnovsky gave an invited presentation at the symposium “Technologies of Imagination: Fifty Years Beyond *Man and His Future*” at Arizona State University.
- In September, Marcy Darnovsky gave an invited lecture at Wellesley College Women’s and Gender Studies Department titled “Gender and Genetics: The Biopolitics of Eggs and Wombs.”
- In September, Marcy Darnovsky and Francine Coeytaux spoke and led an invited workshop at The California Wellness Foundation’s annual grantee conference. The workshop was titled “The politics of genes, eggs and wombs: Challenges for reproductive justice and women’s health.”
- In December, Marcy Darnovsky spoke at the East Bay premiere of the award-winning documentary *FIXED: The Science/Fiction of Human Enhancement*, in which she is interviewed.
- In December, Marcy Darnovsky spoke on “The Case for a New Biopolitics” at Leonardo Art/Science Evening Rendezvous (LASER), a national program of evening gatherings that bring artists and scientists together for informal presentations and conversation with an audience.

## Policy, Legislative and Regulatory Initiatives

The Center for Genetics and Society addresses carefully selected state, national and international policy issues, bringing our perspectives to bear via invited testimony and submitted letters to regulatory, legislative and professional bodies; commentary in media interviews and published articles; and “friend of the court” briefs. In 2013, we celebrated a victory on gene patents at the Supreme Court, and a veto by California Governor Jerry Brown of a fertility industry-sponsored bill that would have expanded the market in women’s eggs. We continue to face an effort to gain regulatory approval in the US and the UK for clinical trials of germline “mitochondrial replacement” techniques.

**“Mitochondrial replacement.”** Throughout the year, we worked to oppose approval of human trials of controversial “mitochondrial replacement,” a set of risky techniques that would constitute human inheritable genetic modification. In 2013, CGS

- issued press statements on germline “mitochondrial replacement” in March and June
- sent a letter to the U.S. Food and Drug Administration signed by over 250 people in preparation for a scheduled public meeting of the Cellular, Tissue and Gene Therapies Advisory Committee



III.



## Policy, Legislative and Regulatory Initiatives

*continued*



- signed a Letter to the Editor of *The Guardian*
- wrote to the President of the Parliamentary Assembly of the Council of Europe; two weeks later, a statement from 34 members of the Parliamentary Assembly was released stating that this technique “is incompatible with human dignity and international law”
- appeared on radio and television news (NPR, CBS San Francisco, CBS New York, CCTV America, KPIX) and was cited in media outlets including *Nature*, *Forbes*, *Wired*, *Medical News Today*, *Health Medicine Network*, *BioEdge*, *Science For The Future*, and *Ottawa Citizen* about this issue
- published articles about “mitochondrial replacement” in *Nature*, *The European*, and *The Huffington Post*.

**A California bill on expanding the market for women’s eggs.** CGS successfully defeated a state bill sponsored by the fertility industry that would have permitted researchers to pay women for providing eggs and undermined protections for egg providers. We worked to organize a network of opposition among women’s health, reproductive justice and public interest groups, and spoke and wrote on the issue. Diane Tober provided expert testimony at the California Senate Health Committee Hearing. Although the bill was passed by both houses of the state legislature, our arguments convinced Governor Brown to veto it. His veto message began, “Not everything in life is for sale, nor should it be.”

**Human gene patents.** In June, the US Supreme Court ruled unanimously that naturally occurring human genes cannot be patented. CGS had submitted an amicus brief to the Supreme Court, and participated in conference calls with ACLU staff, plaintiffs, and other organizations. Since the lawsuit began in 2009, we have written several other briefs for lower courts and several articles about gene patents. In 2013 our writing about the issue included a co-authored op-ed in the *Los Angeles Times* with the executive director of Breast Cancer Action, one of the plaintiffs in the lawsuit. In our work on gene patents, we encouraged an understanding of the human genome as part of the “common heritage of humanity.”

**The California stem cell agency.** In 2013, we engaged the California Institute of Regenerative Medicine (CIRM) around two issues:

- In July, we organized a successful effort, working with women’s health and public interest colleagues, to persuade CIRM’s Standards Working Group, to reject a proposal that would have reversed current agency policy and expanded the market in women’s eggs. Similar proposals have been floated over the years by the agency’s leadership, but each time so far, our sustained and informed objections have convinced the Standards Working Group to reject them.
- In December 2012, the Institute of Medicine (IOM) issued a commissioned report on CIRM, concluding that the stem cell agency suffers from built-in conflicts of interest. The IOM’s conclusion closely echoed the critique of CIRM that CGS has been making since the campaign for the 2004 ballot measure that established the agency, and about which we had given invited testimony to the IOM earlier in the year.





## Policy, Legislative and Regulatory Initiatives

*continued*

**BioPolicyWiki.** We began work to update CGS's BioPolicyWiki, our compendium of laws and policies governing the use of human genetic and reproductive technologies throughout the world. Sharone Assa, a graduate of the University of Wisconsin Law School, conducted research on global surrogacy policies during a three-month internship with CGS arranged through Law Students for Reproductive Justice's Legal Research Initiative.

## IV.

## Media and Communications

One of our 2013 goals was to expand CGS's media profile and exposure, and to increase the impact of our perspective on biopolitical issues. We succeeded beyond our expectations.

### PUBLICATIONS

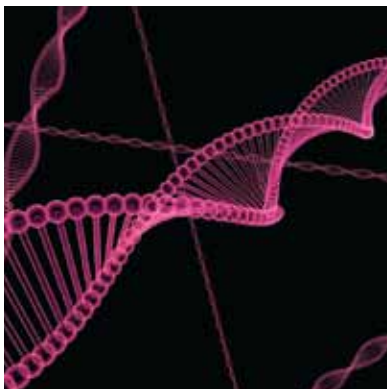
#### Book

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.

#### Op-eds and articles

CGS staff, along with Senior Fellow Osagie Obasogie and regular blog contributor Pete Shanks, published 16 commentaries and articles in 2013, three times as many as in 2012. Several were in top-tier newspapers and journals, including *The New York Times*, *Nature*, *Wall Street Journal*, *Los Angeles Times*, and *Scientific American*. Pete Shanks and Jessica Cussins have also recently been granted regular publishing access at *The Huffington Post*.

- "Should We Be Trying to Bring Extinct Species Back to Life?," Pete Shanks, *AlterNet* (April 8)
- "Who should own DNA? All of us," Marcy Darnovsky and Karuna Jaggar, *Los Angeles Times* (April 12)
- "The Bleak New World of Prenatal Genetics," Marcy Darnovsky and Alexandra Minna Stern, *The Wall Street Journal* (June 12)
- "Democratizing Creation' With Glowing Plants," Pete Shanks, *GeneWatch* (June)
- "Lieber Adoptieren," Marcy Darnovsky, *The European* (June 26)
- "A slippery slope to human germline modification," Marcy Darnovsky, *Nature* (July 9)
- "Viewpoints: Risks are many in paying women to donate eggs," Diane Tober and Nancy Scheper-Hughes, *The Sacramento Bee* (July 16)
- "High-Tech, High-Risk Forensics," Osagie K. Obasogie, *The New York Times* (July 24)
- "California Controversy: Let's Not Expand the Market in Women's Eggs," Marcy Darnovsky and Susan Berke Fogel, *The Huffington Post* (September 3)
- "Eggs for Cash: Pitting Choice Against Risk," Diane Tober and Francine Coeytaux, *RH Reality Check* (September 4)
- "Your Body, Their Property," Osagie K. Obasogie, *Boston Review* (September 30)



## Publications

*continued*

- “Google vs. Death? Really?,” Pete Shanks, *The Huffington Post* (October 3)
- “Commentary: The Eugenics Legacy of the Nobelist Who Fathered IVF,” Osagie K. Obasogie, *Scientific American* (October 4)
- “A Former IVF Baby on ‘Three-Parent IVF,’” Jessica Cussins, *The Huffington Post* (October 24)
- “Advocating Eugenics in the UK Department of Education,” Pete Shanks, *The Huffington Post* (October 28)

In our interviews with reporters and in the articles written by our staff, fellow, and contributors, we commented on topics including human gene patents, proposals to clone Neanderthals and extinct animals, synthetic biology, early fetal gene tests, expanding the market for women’s eggs, misuses of police DNA databases, “mitochondrial replacement” (risky embryo manipulation techniques that would constitute inheritable genetic modification), the history of eugenics, egg freezing, cloning-based stem cell research, 23andMe’s “designer baby” patent, the FDA’s warning letter to 23andMe, and direct-to-consumer genetic testing in general. We put out six press statements this year.

### *Psychology Today (Genetic Crossroads)*

CGS writers post several times a month at *Genetic Crossroads*, our group blog at the *Psychology Today* website. Here is a selection of *Genetic Crossroads* posts from 2013 that had particularly high view counts:

- “Native American DNA Testing,” Jessica Cussins (January 3)
- “Sweden Repeals Forced Sterilization for Transgender People,” Jessica Cussins (January 25)
- “Would You Genetically Modify Your Baby?,” Jessica Cussins (March 6)
- “Predicting the IQ of Future People,” Pete Shanks (May 20)
- “Today’s Healthy Baby, Tomorrow’s Designer Baby?,” Jessica Cussins (July 31)
- “Involuntary Sterilization Then and Now,” Jessica Cussins (September 5)
- “The Politics of Sex Selective Abortion Bans,” Pete Shanks (September 14)



### *Biopolitical Times Blog*

CGS staff writers and contributors post 2–3 articles per week to the CGS blog *Biopolitical Times*. Eleven guest contributors wrote for *Biopolitical Times* in 2013. Some of our favorite blog posts of the year include:

- “Gene-ism and Mass Murder,” Marcy Darnovsky (January 22)
- “Selling the Story: Down Syndrome, Fetal Gene Testing, and *The Today Show*,” George Estreich (February 28)
- “Meet the New Eugenics, Same as the Old Eugenics,” Gina Maranto (March 4)
- “Sofia Vergara Freezing Her [Perfect, Perfect, Perfect] Eggs,” Diane Tober (April 4)



## Publications

*continued*

- “‘World’s First GM Babies Born’: 12-Year-Old Article Continues to Cause Confusion,” Jessica Cussins (April 25)
- “Predicting the IQ of Future People,” Pete Shanks (May 15)
- “Eight Misconceptions about ‘Three-Parent Babies,’” Jessica Cussins (July 9)
- “Big Business in Babies: First IVF Company Now Being Traded on the Stock Market,” Judy Norsigian and Miriam Zoll (August 6)
- “Involuntary Sterilization Then and Now,” Jessica Cussins (August 28)
- “More Concerns Over Familial DNA Searching,” Osagie K. Obasogie (August 28)
- “Advocating Eugenics in the UK Department of Education,” Pete Shanks (October 24)

## CGS IN THE NEWS

CGS staff members were quoted frequently by print, radio, television and online media on a diverse range of topics. In 2013, our staff appeared in more than 130 news stories, well more than twice as many as in 2012.

High-profile and high-circulation print and online outlets that cited or interviewed us included *Associated Press*, *Los Angeles Times*, *BBC News*, *Forbes*, *The Atlantic*, *Nature*, *MIT Technology Review*, *The Scientist*, *The Telegraph*, and *CBC News*. Notable radio and TV outlets included *The Diane Rehm Show*, *NPR News*, *KQED Forum*, *Oregon Public Radio*, *CBS News (New York)*, *CCTV America*, *Al Jazeera English*, and top Bay Area television news shows.

The following are a selection of notable CGS citations organized by topic:

### Human inheritable genetic modification

- Marcy Darnovsky was interviewed on “HealthWatch: Britain Considers Allowing Babies From 3 Parents,” Kim Mulvihill, *CBS San Francisco* (March 20)
- Marcy Darnovsky was cited in “UK May Be Close To Approving Nuclear Transfer Technique for IVF,” John Farrell, *Forbes* (March 28)
- Marcy Darnovsky was interviewed on “The Baby Blueprint,” *Al Jazeera English* (April 22)
- Marcy Darnovsky was interviewed on “Expert Panel Debates the Manipulation of Human Genetics,” Elaine Reyes, *CCTV America* (June 30)
- Marcy Darnovsky was interviewed on “Designer Babies,” Stephanie Robinson, *Blog Talk Radio* (September 12)
- Marcy Darnovsky was cited in “Proposed Treatment To Fix Genetic Diseases Raises Ethical Issues,” Rob Stein, *NPR* (October 9)
- Marcy Darnovsky was interviewed on “Designer Babies,” Arlene Bynon, *Arlene Bynon Show (Sirius)* (October 10)
- Marcy Darnovsky was cited in “Regulators weigh benefits of ‘three-parent’ fertilization,” Erika Check Hayden, *Nature* (October 15)
- Center for Genetics and Society was cited in “Are Three Parents One Too Many?,” Stephen L. Carter, *Bloomberg* (November 27)





## CGS in the News

continued

### Assisted reproductive technologies

- Marcy Darnovsky was cited in “Which Comes First: The Woman or Her Eggs?,” Ruha Benjamin, *The Huffington Post* (April 17)
- Diane Tober was cited in “There's More to Life Than Freezing Your Eggs,” Jacoba Urist, *The Atlantic* (May 14)
- Diane Tober was interviewed on “Motherhood Deferred: Freezing Your Eggs,” Judy Campbell, *KQED Forum* (May 31)
- Marcy Darnovsky was cited in “More Rights, More Inclusion, Better Country: Argentina Approves IVF for All,” Alex Stern, *The Huffington Post* (June 20)
- Center for Genetics and Society was cited in “California Legislation, Human Egg Sales and Profits,” David Jensen, *California Stem Cell Report* (July 1)
- Diane Tober was interviewed on “California Bill Would Lift Restrictions on Egg Donation,” Elaine Korry, *KQED* (July 16)
- Diane Tober was cited in “Assisted Reproductive Technologies: Blessing? Curse? Both?,” Eleanor J Bader, *Truthout* (July 28)
- Diane Tober was cited in “California governor vetoes proposed egg payment law,” *Nature* (August 14)
- Marcy Darnovsky was cited in “Scant surrogacy regulations mean uncertainty, risks,” Stephanie M. Lee, *San Francisco Chronicle* (September 30)
- Osagie Obasogie was cited in “The eugenicist sympathies of IVF pioneer Robert Edwards,” Xavier Symons, *BioEdge* (October 12)
- Marcy Darnovsky was cited in “Reproductive Rights and Responsibilities,” Mirah Riben, *Dissident Voice* (October 17)

### Gene and genetic testing patents

- Marcy Darnovsky was interviewed on “Supreme Court Tackles Genes,” *CCTV* (April 16)
- Marcy Darnovsky was cited in “Angelina Jolie and the fate of breast cancer genes,” Alexandra Le Tellier, *Los Angeles Times* (May 14)
- Marcy Darnovsky was cited in “23andMe’s ‘build-a-baby’ patent criticised,” *BBC News* (October 3)
- Marcy Darnovsky was cited in “Company's 'Designer Baby' Patent Divides Bioethicists,” Eliot Marshall, *Science* (October 3)
- Marcy Darnovsky was cited in “Critics fear new 23andMe patent will breed ‘designer babies,’” Michelle Castillo, *CBS News* (October 4)

### DNA forensics

- Center for Genetics and Society was cited in “DNA, Race and Public Safety,” Michael Corbin, *Open Society Institute—Baltimore* (February 9)
- Osagie Obasogie was cited in “Is DNA infallible proof? Contamination, stats can lead to injustice, prof says,” Debra Cassens Weiss, *ABA Journal* (July 29)
- Marcy Darnovsky was cited in “Supreme Court Backs DNA Collection in Arrests,” Michael Fitzhugh, *The Burrill Report* (July)



## CGS in the News

*continued*



### Personal genomics

- Center for Genetics and Society was cited in “Is Eugenics ever OK?,” Nathaniel Comfort, *Genotopia* (July 26)
- Marcy Darnovsky was interviewed on “The Science and Ethics of Personal Genetic Testing,” Diane Rehm, *The Diane Rehm Show (NPR)* (October 28)
- Marcy Darnovsky was cited in “FDA bans 23andme personal genetic tests,” *BBC News* (November 26)
- Marcy Darnovsky was cited in “Genetic jungle: Trying to make sense of FDA’s 23andMe warning,” Ron Leuty, *San Francisco Business Times* (November 26)
- Marcy Darnovsky was cited in “Singularity: Reading our genes like computer code,” Jane Wakefield, *BBC News* (December 9)

### Stem cell research and cloning techniques

- Marcy Darnovsky was cited in “Stem cell research center needs overhaul, IOM panel says,” Marcia Frellick, *American Medical News* (January 8)
- Marcy Darnovsky was cited in “Stem cells recovered from cloned human embryos,” Malcolm Ritter, *Associated Press* (May 15)
- Marcy Darnovsky was interviewed on “Cloning, Stem Cells Long Mired In Legislative Gridlock,” Julie Rovner, *NPR* (May 16)
- Marcy Darnovsky was interviewed on “Panel on the Ethics of New Stem Cell Cloning Method,” Anand Naidoo, *CCTV* (May 23)

### Animal cloning and environmentalism

- Pete Shanks was cited in “Neanderthal Cloning Comments Spark Controversy in Scientific Community,” Jason Koebler, *US News* (January 25)
- Pete Shanks was interviewed on “Neo Neanderthal,” Alyona Minkovski, *HuffPost Live* (January 25)
- Center for Genetics and Society was cited in “The Chemical Industry’s Political Machinations,” Michael Green, *The Huffington Post* (March 18)
- Pete Shanks was cited in “Earth’s Life-Forms Collected to Aid in Genetic Research,” Donald E. Hurlbert, *National Geographic* (August 5)

### CGS ONLINE

**Website and blogs:** In 2013, there were over 181,400 visits to the CGS website, and an additional 66,650 visits to the CGS blog. Guest contributors to *Biopolitical Times* in 2013 were Abby Lippman, George Estreich, Gina Maranto, Emily Smith Beitiks, Nanibaa’ A. Garrison, Rori V. Rohlf’s, Stephanie M. Fullerton, Grant Shoffstall, Judy Norsigian, Miriam Zoll, and J. P. Harpignies. CGS writers added several posts per month to *Genetic Crossroads*, the CGS blog at the website of *Psychology Today*.

**Newsletter and News Scan:** In 2013, CGS’s twice-monthly newsletter *Biopolitical Views & News* had approximately 3,700 domestic and international subscribers. CGS also produces a twice-weekly digest of important news items that informs our press, media and other work, and is shared with close colleagues worldwide.

**Social Media:** At the close of 2013, CGS had some 3,500 followers on Twitter, up approximately 50% since January 1 (@C\_G\_S). CGS's YouTube Channel has received more than 50,000 views since it went online four years ago. The CGS Facebook page has more than 1,100 likes, up 37% since January 1.

## V. CGS Staff and Leadership

As of December 31, 2013, CGS had four full-time staff members, one Senior Fellow, and one regular contributor to our *Biopolitical Times* blog. They are:

- Marcy Darnovsky, PhD, Executive Director
- Diane Tober, PhD, Associate Executive Director
- Charles Garzon, MA, Director of Finance and Administration
- Jessica Cussins, BA, Program Associate
- Osagie K. Obasogie, PhD, JD, Senior Fellow for Bioethics, Law and Society
- Pete Shanks, MA, *Biopolitical Times* contributor

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, Professor of Bioethics and Society, University of California, Berkeley

### ORGANIZATIONAL STATUS

The Center for Genetics and Society is a project of Tides Center, a 501(c)3 organization funded by individual contributions and philanthropic foundations.

## VI. Budget and Funding

CGS's adjusted expenses for 2013 were \$529,032. Current funding for CGS comes from the Appleton Foundation; the Marisla Foundation; the Lyman B. Brainerd, Jr. Family Foundation; the Heimbinder Family Foundation; the Winiarski Family Foundation; and individual donors. Complete financial reports are available on request.



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