CENTER FOR GENETICS AND SOCIETY





2014 REPORT ON ACTIVITIES



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Ι.

Introduction

In 2014, the Center for Genetics and Society expanded our efforts to build a new biopolitics grounded in social justice and the public interest. We organized landmark conferences, spoke at key symposia, took advantage of increased opportunities to present our views in the media, broadened our online presence, played an active role in US and UK policy developments regarding human inheritable genetic modification, undertook several advocacy-oriented research projects, and expanded our Fellows Program.

II. Events and Presentations

During 2014, the Center for Genetics and Society co-organized events including a landmark international symposium in The Hague, Netherlands that addressed cross-border surrogacy, and a celebration of the life and work of eminent sociologist Troy Duster in Berkeley, California. We organized two series of online events, *Talking Biopolitics* and the invitational Assisted Reproductive Technologies Working Group. In addition, CGS staff gave invited presentations at venues including the Aspen Ideas Festival and the Disability Rights Leadership Institute on Bioethics.

INTERNATIONAL FORUM ON INTERCOUNTRY ADOPTION AND GLOBAL SURROGACY

In August, CGS co-organized and chaired the surrogacy "track" of this international forum in The Hague, Netherlands. The three-day event brought together nearly 100 scholars, women's health and human rights advocates, and policymakers from 27 countries at the International Institute of Social Studies of Erasmus University. *Global Surrogacy Practices*, a report on participants' deliberations co-authored by Marcy Darnovsky and Diane Beeson, was published in December. The forum and report were developed in part to help inform the exploratory work of The Hague Conference on Private International Law about a possible international agreement on cross-border surrogacy.

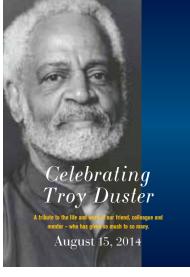
CELEBRATING TROY DUSTER

On August 15, CGS co-sponsored a day-long celebration of Troy Duster's scholarship, public engagement, and commitment to social justice, including in areas related to human genetic technologies. The event was also sponsored by the Haas Institute for a Fair and Inclusive Society at UC Berkeley. Other sponsors included the Institute for the Study of Societal Issues, UC Berkeley Department of Sociology, Berkeley Law School's Thelton E. Henderson Center for Social Justice, and Berkeley Law School's Center for the Study of Law and Society. Video of the event as well as a printable program are available on the CGS website.

TALKING BIOPOLITICS

Talking Biopolitics, our ongoing series of live web-based conversations with cuttingedge thinkers about the social meaning of human biotechnologies, featured:

- October 2: Charis Thompson, author of *Good Science: The Ethical Choreography of Stem Cell Research*, interviewed by David Winickoff.
- November 12: Dorothy Roberts and Jonathan Marks who assessed reactions to former *New York Times* reporter Nicholas Wade's new book, *A Troublesome Inheritance: Genes, Race, and Human History,* which argues that genetic variation between races could underlie global economic, political, and social differences.



Events and Presentations

continued

ASSISTED REPRODUCTIVE TECHNOLOGIES WORKING GROUP

The Assisted Reproductive Technologies Working Group is a collaborative project of CGS and the Pro-Choice Alliance for Responsible Research. It provides a forum for reproductive rights, health, and justice advocates to track, discuss, and confront developments in the fertility industry. In 2014, the ART Working Group held online sessions on US anti-choice efforts to pass sex-selective abortion bans, and on the highlights of the International Forum on Intercountry Adoption and Global Surrogacy in The Hague.

DEBATING "DESIGNER BABIES" AT THE ASPEN IDEAS FESTIVAL

Marcy Darnovsky was invited to speak in July at the Aspen Ideas Festival, which describes itself as "the nation's premier, public gathering place for leaders from around the globe and across many disciplines." She debated the question "Should We Design Our Babies?" with Nita Farahany, professor of law at Duke University and member of the Presidential Commission for the Study of Bioethical Issues. The debate was moderated by James Bennet, editor–in–chief at *The Atlantic*.

DISABILITY RIGHTS LEADERSHIP INSTITUTE ON BIOETHICS

In April, Marcy Darnovsky spoke at the first-ever "Disability Rights Leadership Institute on Bioethics," a groundbreaking event for advocates to advance a disability rights perspective on bioethics issues in Arlington, Virginia. Together with Silvia Yee of the Disability Rights Education & Defense Fund, Marcy presented on "Key Issues in Reproductive Technologies."

Other Presentations and Workshops

- In February, CGS organized a screening of the award-winning documentary *DNA Dreams,* followed by a discussion with director Bregtje van der Haak.
- In March, Jessica Cussins spoke on the implications of human genetic engineering on Issues Day at Saint Mary's Hall High School in San Antonio, Texas.
- In April, Marcy Darnovsky and Enola Aird of Mothers for a Human Future gave a presentation titled "Genetically Modified Babies? Human Biotechnologies, Immediate Threats to Children, How We Can Save Childhood" at the Global Summit on Childhood in Vancouver, Canada.
- In September, Marcy Darnovsky spoke at the University of San Francisco 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.

• In November, Marcy Darnovsky spoke at "The Future of Reproduction," a public symposium organized by Future Tense in Washington, DC, on a panel titled "In the *Gattaca-Family* Way: How Far is Too Far?"



III.

Policy, Legislative, and Regulatory Initiatives

In 2014, the CGS participated in policy debates on mitochondrial DNA transfer, a technique that would alter the human germline; advocated that the US prohibit human reproductive cloning; raised concerns about Silicon Valley companies' offer to cover costs for female employees to freeze their eggs in order to postpone family formation; and supported efforts to prohibit coercive sterilizations in California state prisons.

"THREE-PERSON IVF" (GERMLINE MITOCHONDRIAL MANIPULATION)

In 2014, CGS participated in policy debates on mitochondrial DNA transfer or "three-person IVF," a set of risky techniques that would alter the human germline and that could undermine the international near-consensus against human germline modification. We organized sign-on letters to the US Food and Drug Administration and the UK Human Fertilisation and Embryology Authority, authored articles and commentaries including an op-ed in *The New York Times*, issued several press statements, and were cited in dozens of media outlets.

Highlights include:

• In preparation for the U.S. Food and Drug Administration meeting to discuss "three-person IVF" in February, CGS sent the FDA committee a letter urging the agency to preserve the international near-consensus against human germline modifications. Additionally, CGS sent a sign-on letter with more than 250 signatures calling on the FDA not to allow this biologically radical procedure that would combine genetic material from three people. Marcy Darnovsky testified at the meeting on February 25 and wrote an op-ed for *The New York Times* on the issue, published on February 23.

• On March 21, CGS sent a letter signed by 53 prominent scholars and advocates to the UK's Human Fertilisation and Embryology Authority in response to its "Call for evidence: Update to scientific review of the methods to avoid mitochondrial disease."

• On June 3, CGS issued a press statement titled "UK Agency's Update on 'Three-Person IVF' Leaves Safety Questions Unresolved" in response to the HFEA's third update on the safety and efficacy of these techniques.

• In May, CGS submitted a response to the UK Department of Health's threemonth open consultation on draft regulations to permit the use of "mitochondrial donation." In July, the department published the results of its consultation, and CGS issued a press statement titled "UK Move Toward '3-Person IVF' is Risky and Premature, Says Public Interest Group."

• In October, CGS submitted comments to the UK House of Commons Science and Technology Committee evidence hearing.



Policy, Legislative, and Regulatory Initiatives *continued*

• CGS staff commented on germline mitchondrial manipulation more than 65 times on radio and television news programs and in media outlets including *Associated Press, The New York Times, Washington Post, NPR, Scientific American, Slate, Reuters* and many more.

• Staff, fellows, and longtime consultants published articles on "mitochondrial replacement" in *The New York Times* (February), *RH Reality Check* (March), *New Scientist* (June), *The Huffington Post* (June), *CNBC* (August) and *GeneWatch* (November).

CLONING AND EGG RETRIEVAL

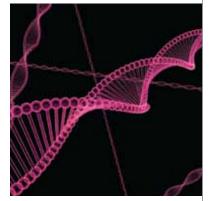
In April, researchers produced stem cell lines using somatic cell nuclear transfer (SCNT) from cells taken from two adult men. The aim of this research is to produce patient-specific stem cells for medical treatments. But unlike induced pluripotent stem cells created from ordinary somatic cells, which can also be patient-specific, SCNT makes human reproductive cloning more technically feasible and requires large numbers of women's eggs. CGS issued a press statement that underscores the need for the US to prohibit reproductive cloning. The statement also questions the risks to women who provide eggs and implications for health equity.

SOCIAL EGG FREEZING

After the decision by Facebook and Apple to offer their female employees a \$20,000 benefit to freeze their eggs for later use with in vitro fertilization in October, CGS released a press statement addressing the risks of egg freezing and advising women against the procedure. CGS was cited eleven times in media outlets including *Elle*, *Medical News Today*, *CBC*, *NPR*, *Our Bodies Our Blog*, *The Today Show*, and *Lexology*. Additionally, CGS published articles on egg freezing in *The Weekly Wonk*, *The Huffington Post*, and *RH Reality Check*.

STERILIZATION ABUSE IN CALIFORNIA PRISONS

CGS played a supporting role in the passage of California legislation (SB 1135) to prohibit coercive sterilizations in state prisons. We sent letters of support to the Senate Committee on Public Safety in April and to Governor Brown in September, and publicized the issue on our blog and social media.



IV.

Advocacy-Oriented Research

CGS selects research projects that aim to fill key gaps in knowledge about the societal implications of human biotechnologies and that support our strategic communications, policy, and networking activities. In 2014, our research work focused on commercial egg retrieval and cross-border surrogacy, and was funded by a generous grant from the John D. and Catherine T. MacArthur Foundation in support of a set of collaborative projects with the pioneering women's health organization Our Bodies Ourselves.

ATTITUDES ABOUT EGG RETRIEVAL

CGS Fellow Gina Maranto is conducting an online survey to explore American women's knowledge of and participation in egg harvesting, and their perception of its risks. To the best of our knowledge, this will be the first large-scale survey of its kind.

CROSS-BORDER SURROGACY

CGS is collaborating with Our Bodies Ourselves on an investigation of the availability and quality of information about cross-border surrogacy arrangements. Our research has explored both online sources (primarily websites of fertility clinics and surrogacy brokers and agents) and a range of media sources. This work will guide our planned development of an online alternative to the skewed information that dominates what is currently available.

BIOPOLICY WIKI

CGS is updating the sections of our compilation of country-level policies on surrogacy, egg retrieval for fertility purposes, and egg retrieval for research.

V.

Media and Communications

CGS's media profile continued to expand in 2014. Through our communications efforts, we aim to increase public, policymaker, and media understanding of bio-political issues; build CGS's reputation as a thought leader and go-to source for information and commentary; and provide information resources for colleagues, journalists, and students. Our work includes original writing from books to blog posts, frequent appearances by our staff in a range of media outlets, and a robust online presence.



Publications

PUBLICATIONS

Book and report

• Marcy Darnovsky and Osagie Obasogie's edited anthology, *Beyond Bioethics: Towards a New Biopolitics,* is forthcoming from University of California Press.

• *Global Surrogacy Practices*, a 54-page report co-authored by Marcy Darnovsky and CGS Fellow Diane Beeson and published by the International Institute of Social Studies in December 2014, summarizes the deliberations at the International Forum on Intercountry Adoption and Global Surrogacy.

Op-eds and articles

CGS-associated writers published 19 commentaries and articles in 2014 in media outlets including *The New York Times, New Scientist, CNBC, The Huffington Post,* and *RH Reality Check.*

• "Genetically Modified Babies," Marcy Darnovsky, *The New York Times* (February 23)

• "FDA halts 23andMe personal genetic tests," Marcy Darnovsky and Jessica Cussins, *Medical Laboratory Observer* (March)

• "What We Know About Three-Parent In Vitro Fertilization," Jessica Cussins, *RH Reality Check* (March 13)

• "Do the Blind Perceive Race?," Osagie K. Obasogie, *The Chronicle of Higher Education* (March 31)

• "Invoking 'Choice' When Discussing Surrogacy as a Feminist Concern Is a Mistake," Marcy Darnovsky, *RH Reality Check* (April 23)

• "Is the UK being too hasty over three-parent babies?," Marcy Darnovsky and Donna Dickenson, *New Scientist* (June 3)

• "Three-Person IVF' Update Reveals How Little We Know," Jessica Cussins, *The Huffington Post* (June 6)

- "A Troublesome Controversy," Pete Shanks, The Huffington Post (June 9)
- "Selling Stem Cells Honestly," Pete Shanks, The Huffington Post (July 7)

• "Rethinking 21st Century Racism On The Way Home," Victoria Massie, *GeneWatch* (July 17)

• "Tuskegee Today," Jessica Cussins, The Huffington Post (August 8)

• "Should we open the door to genetically modified babies?," Jessica Cussins, *CNBC* (August 11)

• "Evolution Right Now Is in the Marketplace," Pete Shanks, *The Huffington Post* (September 12)



Publications

continued



• "'The Stupidity of the 'Smart Gene'," Jessica Cussins, *The Huffington Post* (September 25)

• "Frozen II: The Tech Industry's Eggs," Marcy Darnovsky, *The Weekly Wonk* (October 16)

• "Dear Facebook, Please Don't Tell Women to Lean In to Egg Freezing," Jessica Cussins, *The Huffington Post* (October 16)

• "Silicon Valley's Egg-Freezing Perk Is Bad for People Across the Board," Marcy Darnovsky, *RH Reality Check* (October 20)

• "Why Worry About Genetically Modified Babies?," Marcy Darnovsky and Jessica Cussins, *GeneWatch* (November 24)

In interviews with reporters and in the articles written by our staff and fellows, we commented on topics including race and genetics, early fetal gene tests, surrogacy, the history of eugenics, egg freezing, cloning-based stem cell research, 23andMe and other personal genomic testing companies, "mitochondrial replacement" or "three-person IVF," and human germline modification in general.

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 2014 that had particularly high view counts:

- "Genetically Engineered Monkeys Born, Could Humans Be Next?," Jessica Cussins (February 7)
- "Americans Still Oppose 'Playing God' With Genetics," Pete Shanks (February 10)
- "Love Is in Your Genes," Jessica Cussins (February 14)
- "Whole Genome Sequencing Only Halfway There," Jessica Cussins (March 14)
- "Transcendence," Jessica Cussins (May 2)
- "Nicholas Wade: Genes, Race and Anthropology," Pete Shanks (May 12)
- "Orphan Black: The Best Show You've Never Seen," Jessica Cussins (May 29)
- "Selling the Next False Hope?," Jessica Cussins (June 25)
- "The Perfect 46: A Science Fiction Film About Our Near Future," Jessica Cussins (July 11)
- "Making Sense of the Brain," Jessica Cussins (July 25)
- "Disability Will Never Be Immoral," Jessica Cussins (September 12)
- "Breaking from Our Eugenic Past," Jessica Cussins (December 12)

Publications

continued

Biopolitical Times blog

CGS staff writers and guest contributors post 2-3 articles per week to the CGS blog *Biopolitical Times*, which receives approximately 4,000 visits per month. There were 107 blogs posted at *Biopolitical Times* in 2014.

Some of our favorites include:

• "Chinese Scientists, 'Genius Genes,' and the Future of Genomics," Jessica Cussins (January 7)

- "Hit-and-Miss Genetic Testing," Pete Shanks (January 20)
- "Human Longevity, Inc.," Pete Shanks (March 6)
- "Nicholas Wade: Genes, Race and Anthropology," Pete Shanks (May 8)
- "Scientists, Stem Cells and Self-Delusion?," Pete Shanks (May 10)
- "Orphan Black: The Best Show You've Never Seen," Jessica Cussins (May 29)
- "A Paragraph in Slow Motion: Three-Person IVF in *The New York Times*," George Estreich (July 10)
- "Data Yearning to Become Expensive Information," Pete Shanks (August 6)
- "Dear Facebook, Please Don't Tell Women to Lean In to Egg Freezing," Jessica Cussins (October 15)
- "A Season of Surrogacy Scandals," Marcy Darnovsky (October 16)
- "What Good is a Scientific Meeting If You Dismiss the Science?," Jessica Cussins (October 29)

• "The Vagina Bio-Hack That Wasn't: How Two 'Startup Bros' Twisted and Took Credit for a Young Woman's Company," Jessica Cussins (November 25)

CGS IN THE NEWS

CGS staff members were quoted frequently by print, radio, television, and online media on a diverse range of topics. In 2014, we issued five press statements on three-person IVF, cloning research, and egg freezing. CGS staff members appeared in more than 140 news stories in a wide variety of outlets, including:

• high-circulation newspapers and news agencies (*The New York Times, Boston Globe, Washington Post, Wall Street Journal, San Francisco Chronicle, USA Today, Newsday, Associated Press, Reuters, Agence France-Presse*)

• print and online magazines (The Atlantic, Slate, Daily Beast, Forbes, US News)



CGS in the News *continued*

• science and popular science outlets (*Scientific American, New Scientist, The Scientist, Nature Biotechnology, Medical News Today, Genetic Engineering News, MedPage Today*)

• radio and television shows (NBC News, The Today Show, ABC News, NPR On Point, NPR Here and Now, NPR Marketplace, CBS This Morning, BBC News, Al Jazeera America)

The following sections show selected CGS citations on various topics.

Mitochondrial DNA replacement ("three-person IVF") and human inheritable genetic modification

• Marcy Darnovsky was cited in "FDA weighs risks of 3-person embryo fertilization," Matthew Perrone, *Associated Press* (February 24)

• Marcy Darnovsky was cited in "FDA panel debates technique that would create embryos with three genetic parents," Ariana Eunjung Cha and Sandhya Somashekhar, *The Washington Post* (February 25)

• Marcy Darnovsky was cited in "Making Babies with 3 Genetic Parents Gets FDA Hearing," Dina Fine Maron, *Scientific American* (February 25)

• Marcy Darnovsky was cited in "The New Science Of Three-Parent Babies," Tom Ashbrook, *NPR On Point* (February 26)

• Marcy Darnovsky was cited in "U.S. FDA weighs evidence on producing 'three-parent' embryos," Sharon Begley, *Reuters* (February 26)

• Marcy Darnovsky was cited in "FDA Considers Allowing Scientists To Alter Human Genome," Meghna Chakrabarti, *NPR Here & Now* (February 26)

• Marcy Darnovsky was cited in "US panel debates three-parent embryos," Jean-Louis Santini, *Agence France-Presse* (February 26)

• Marcy Darnovsky was cited in "La era de los bebés a la carta estaría a la vuelta de la esquina," *Vanguardia* (March 1)

• Marcy Darnovsky was cited in "Un embrione con tre genitori: anche negli Usa si cerca l'autorizzazione," Germana Carillo, *NextMe* (March 4)

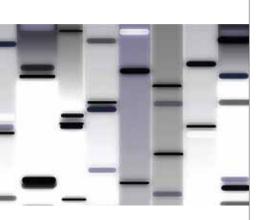
• Richard Hayes was cited in "La génétique permet de créer des bébés presque parfaits," *Canoe* (March 12)

• Marcy Darnovsky was cited in "His Fertility Advance Draws Ire," Sabrina Tavernise, *The New York Times* (March 17)

• Jessica Cussins was cited in "UK Govt Says Testing Three-Parent Embryos Wrong in Animals, Okay in Humans," Rebecca Taylor, *LifeNews.com* (June 10)

• Marcy Darnovsky was cited in "The Brave New World of Three-Parent I.V.F.," Kim Tingley, *The New York Times* (June 27)

• Marcy Darnovsky was cited in "Huntington man deals with mitochondrial disease as preventive measures debated," Kathleen Kerr, *Newsday* (August 1)



CGS in the News

continued

Egg freezing

• Marcy Darnovsky was cited in "Why Egg Freezing Might Not Be the Answer for Women in Tech," Allison Yarrow, *Elle* (October 16)

• Jessica Cussins and Marcy Darnovsky were cited in "Silicon Valley offers egg freezing to employees - but is it safe?," David McNamee, *Medical News Today* (October 17)

• Center for Genetics and Society was cited in "Four things to think about before freezing your eggs," Brent Bambury, *CBC* (October 17)

• Marcy Darnovsky was cited in "Silicon Valley Companies Add New Benefit For Women: Egg-Freezing," Laura Sydell, *NPR* (October 17)

• Jessica Cussins was cited in "Egg freezing: controversial new benefit in the US workplace," Fabienne Faur, *Agence France Presse* (October 18)

• Jessica Cussins was cited in "Facebook Inc's 'egg freezing' offer sparks debate on female work force," Anthony Pittman, *WallStreet.org* (October 20)

• Marcy Darnovsky was cited in "Why egg-freezing parties are gaining popularity for women," Hallie Jackson, *The Today Show* (November 11)

• Jessica Cussins was cited in "Putting all your eggs in one frozen basket," Eleanor Wilson-Holt, *Lexology* (December 2)

"Digital embryos"

- Marcy Darnovsky was cited in "Meet your unborn child before it's even conceived," Catherine de Lange, *New Scientist* (April 9)
- Marcy Darnovsky was cited in "Startup offering DNA screening of 'hypothetical babies' raises fears over designer children," Catherine de Lange, *The Guardian* (April 5)
- Marcy Darnovsky was cited in "New service creates virtual babies for worried mothers," Michael Cook, *BioEdge* (April 11)
- Marcy Darnovsky was cited in "Embrioni digitali: come 'progettare' il bimbo su misura," Federica Vitale, *NextMe* (April 15)
- Marcy Darnovsky was cited in "New service creates digital embryos by virtually mixing two people's DNA," Bryan Nelson, *Bradenton Herald* (May 19)

DNA forensics

• Jessica Cussins was cited in "Racial profiling police DNA databases?," Devon G. Peña, *mexmigration* (April 4)

• Osagie Obasogie was cited in "Open Society Foundations Award Fellowships to 14 Visionaries Working to Reform Criminal Justice in the United States," *PR Newswire* (May 14)



CGS in the News

continued



Personal genomics and genetic testing

• Marcy Darnovsky was cited in "Genetic Testing Sparks Ethics Debate," Mark Niu, *CCTV America* (January 5)

- Osagie Obasogie was cited in "To Catch a Killer Gene: Sisters Race to Stop Mystery Disease," Tony Dokoupil, *NBC News* (February 6)
- Marcy Darnovsky was cited in "Why Family Caregivers Should Care for their Families' Genetic Inheritance Data," Dr. Gordon Atherley, *Voice America* (February 10)
- Pete Shanks was cited in "Can You Pass the (Deoxyribonucleic) Acid Test?," *Center for Environmental Health* (March 17)
- Richard Hayes was cited in "Embryo Screening and the Ethics of Human Genetic Engineering," Leslie A. Pray, *Indian Defense* (April 8)
- Marcy Darnovsky was cited in "Counsyl gets funding for new genetic tests," Stephanie M. Lee, *San Francisco Chronicle* (May 8)
- Marcy Darnovsky was cited in "Controversial DNA test comes to UK," Michelle Roberts and Paul Rincon, *BBC* (December 2)

• Marcy Darnovsky was cited in "23andMe: why have DNA kits been approved in the UK?," *The Week* (December 2)

• Marcy Darnovsky was cited in "£125 genetic test kit backed by Google arrives in Britain – with a health warning," Charlie Cooper, *The Independent* (December 2)

Stem cell research and cloning techniques

- Marcy Darnovsky was cited in "Scientists Make First Embryo Clones From Adults," Gautam Naik, *Wall Street Journal* (April 17)
- Marcy Darnovsky was cited in "Cloning advance using stem cells from human adult reopens ethical questions," Ariana Eunjung Cha, *Washington Post* (April 17)
- Marcy Darnovsky was cited in "New personalized stem cells could offer hope in battling diseases," *CBS This Morning* (April 18)
- Center for Genetics and Society was cited in "Stem cell research fuels more debate on cloning," Karen Weintraub, USA Today (April 19)
- Marcy Darnovsky was cited in "Adult-to-Stem Cells," Rina Shaikh-Lesko, *The Scientist* (April 21)
- Marcy Darnovsky was cited in "State stem cell agency hasn't lived up to its hype," Editorial, *San Francisco Chronicle* (May 2)

CGS in the News

continued

• Marcy Darnovsky was cited in "Renewed Concerns For Women As Cloning Technology Advances," John Farrell, *Forbes* (May 23)

• Pete Shanks was cited in "Hype and Hope: Illuminating the Reality of Stem Cell Treatments," David Jensen, *California Stem Cell Report* (June 27)

• Marcy Darnovsky was cited in "We're Already Designing Babies," Olga Khazan, *The Atlantic* (July 3)

• Center for Genetics and Society was cited in "Building a superhuman: Stem cell advances are leading to dangers and ethical problems few have considered," Joseph Brean, *National Post* (October 3)

• Pete Shanks was cited in "Korean stem cell fraud in technicolour," Michael Cook, *BioEdge* (October 11)

• Pete Shanks was cited in "Can Human Embryonic Stem Cell Research Escape Its Troubled History?," Lisa Ikemoto, *The Hastings Center Report* (December)

Race and genetics

• Osagie Obasogie was interviewed in "Is Race Visual? An Interview with Osagie Obasogie," *2 Paragraphs* (January 2)

• Osagie Obasogie was interviewed in "How blind people see race," Francie Latour, *The Boston Globe* (January 19)

• Osagie Obasogie was interviewed in "Osagie K. Obasogie speaks with Skip Gates about colorblindness and race," Henry Louis Gates, Jr., *Oxford University Press Blog* (February 18)

• Osagie Obasogie was cited in "Blind people perceive race the same as sighted people, collegiate research shows," Evan Belanger, *AL.com* (April 1)

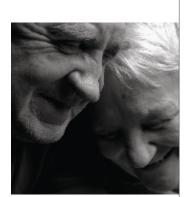
• Center for Genetics and Society was cited in "Legitimizing Racist Science, Naturalizing Health Disparities," Hannah Emple, *hannahemple.com* (August 26)

Synthetic biology

• Pete Shanks was cited in "Can the same regulatory systems that now oversee GMOs work for synthetic biology as well?," Kenrick Vezina, *Genetic Literacy Project* (June 19)

• Pete Shanks was cited in "First CRISPR-Cas patent opens race to stake out intellectual property," Cormac Sheridan, *Nature Biotechnology* (July 8)

• Pete Shanks was cited in "Editing DNA could be genetic medicine breakthrough," Stephanie M. Lee, *San Francisco Chronicle* (September 7)



CGS Online

Eugenics

• Center for Genetics and Society was cited in "Eugenics Round-up," Nathaniel Comfort, *Genotopia* (May 7)

• Jessica Cussins was cited in "Forced Sterilization in North Carolina," Hakeem Smith, *Medium* (August 21)

• Marcy Darnovsky was cited in "At What Point Does Preventing Disease Turn Into Eugenics?," Sonia Arrison, *Slate* (August 22)

• Center for Genetics and Society was cited in "Let's (Cautiously) Celebrate the 'New Eugenics," Jon Entine, *The Huffington Post* (October 30)

• Marcy Darnovsky was cited in "North Carolina compensates victims of eugenic sterilization," Lily Lou, *The Guilfordian* (November 7)

• Jessica Cussins was cited in "Are We In Danger of a New Wave of Eugenics?," Rob Wipond, *Mad in America* (November 25)

CGS ONLINE

Website and blogs: In 2014, the CGS website received just under 240,000 visits. Our blog, *Biopolitical Times*, received about 50,000 additional visits. Guest contributors to *Biopolitical Times* in 2014 were George Estreich, Gina Maranto, Carmel Shalev, Victoria Massie, Sonia Allan, Amy Richards, Diane Beeson, and Miriam Zoll. CGS staff writers added several posts per month to *Genetic Crossroads*, the CGS blog at the website of *Psychology Today*.

Newsletter and News Scan: In 2014, CGS's twice-monthly newsletter, *Biopolitical Views & News*, had approximately 4,718 subscribers. CGS also produces a twice-weekly digest of important news items that facilitates our press, media, and other work, and is shared with close colleagues worldwide.

Social Media: At the close of 2014, CGS had some 4,500 followers on Twitter, up approximately 29% since January 1 (@C_G_S). CGS's YouTube Channel has received more than 60,000 views since it went online four years ago. The CGS Facebook page has more than 1,600 likes, up 45% since January 1.



Who We Are

VI.

Who We Are

The work of the Center for Genetics and Society is carried out by regular staff, summer associates, Fellows, an Advisory Board, regular consultants, and contributors to our *Biopolitical Times* blog.

STAFF

As of December 31, CGS had three full-time regular staff:

- Marcy Darnovsky, Executive Director
- Charles Garzon, Director of Finance and Administration
- Jessica Cussins, Project Associate

FELLOWS PROGRAM

In November, CGS announced the expansion of our Fellows Program. Three exceptional scholars will work with us in 2015 and 2016 on issues related to commercial surrogacy and egg retrieval, and advise CGS and Our Bodies Ourselves on our work on these issues that is being generously supported by the John D. and Catherine T. MacArthur Foundation. CGS's longtime Senior Fellow Osagie Obasogie continues to play a key role in our organizational strategic thinking and our work. Current CGS Fellows are:

• Osagie K. Obasogie, Senior Fellow for Bioethics, Law and Society, is Professor of Law at the University of California, Hastings College of Law in San Francisco with a joint appointment at the University of California, San Francisco (UCSF) Department of Social and Behavioral Sciences.

• Diane Beeson is Professor Emerita of Sociology, California State University, East Bay and co-founder and Associate Director of the Alliance for Humane Biotechnology.

• Lisa Ikemoto is Professor at the University of California, Davis School of Law, a Bioethics Associate of the UC Davis Health System Bioethics Program, and a Faculty Associate of the UC Davis Center for Science and Innovation Studies.

• Gina Maranto is Director of the Ecosystem Science and Policy undergraduate program and coordinator of the graduate program in Environmental Science and Policy at the University of Miami's Leonard and Jayne Abess Center.



Who We Are continued

ADVISORY BOARD

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

• Francine Coeytaux, MPH (Advisory Board chair), reproductive and public health expert; founder, Pacific Institute for Women's Health

• Dorothy Roberts, JD, 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, JD, Associate Professor of Bioethics and Society, University of California, Berkeley

SUMMER AND PART-TIME ASSOCIATES

CGS's work in 2014 was ably supported by several summer and part-time staff associates:

- Jonathan Chernogouz, part-time staff associate
- Victoria Massie, summer associate
- Victoria Nichols, summer associate
- Kate Darling, summer associate

CONSULTANTS AND CONTRIBUTORS

A number of consultants play key roles in CGS's work. Several other colleagues contribute to the CGS blog, *Biopolitical Times:*

- Pete Shanks, CGS consultant and Biopolitical Times contributor
- Emily Galpern, CGS consultant
- Sonia Allan, CGS consultant
- George Estreich, Biopolitical Times contributor
- Amy Richards, Biopolitical Times contributor
- Carmel Shalev, Biopolitical Times contributor
- Miriam Zoll, Biopolitical Times contributor



Budget and Funding

VII. Budget and Funding

CGS's adjusted expenses for 2014 were \$498,026. Current funding for CGS comes from the Appleton Foundation; the Marisla Foundation; the John D. and Catherine T. MacArthur Foundation; the Lyman B. Brainerd, Jr. Family Foundation; the Heimbinder Family Foundation; and individual donors. Complete financial reports are available on request.



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