

CENTER FOR
GENETICS
AND SOCIETY



09

2009 REPORT ON ACTIVITIES



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I. CONFERENCES, MEETINGS, PRESENTATIONS AND SYMPOSIA

January 2: CGS staff met in person and by phone with Dr. Francis Collins (now head of the National Institutes of Health, former Director of the Human Genome Project) and other members of the **Obama administration transition team** to discuss policies related to stem cell research and other human biotechnologies. We were gratified at the congruence of the President's later recommendations on stem cell and cloning policy and our own longstanding positions.

November 4: CGS held an invitational briefing in Washington DC on **the state of international policies** addressing human biotechnologies, in collaboration with the Johns Hopkins School of Advanced International Studies and Consortium for Science, Policy and Outcomes. Leading speakers included Francis Fukuyama of Johns Hopkins, Congressman Brad Sherman (D-Los Angeles), Chamudeenswari Kuppuswamy of Sheffield University, United Kingdom, George Annas of Boston University School of Public Health, and Richard Hayes of the Center for Genetics and Society.

II. LEGISLATIVE AND REGULATORY INITIATIVES

January: CGS published a set of **policy recommendations for the Obama administration**, titled *Responsible Federal Oversight of the New Human Biotechnologies*, covering a range of policy challenges that the new administration will have opportunities to address. Some 25 colleagues contributed to the document.



February-March: CGS helped to **derail an unprecedented offer by a Los Angeles fertility clinic** to screen embryos for the purpose of pre-determining eye, hair and skin color. CGS staff were consulted for and quoted in the *Wall Street Journal* article that broke the story, and appeared in coverage of it in major print, radio and television outlets. The clinic then announced it was “suspending” its offer, citing “negative societal impacts.” In reaction to this controversy and the near-simultaneous attention to the **birth of IVF octuplets**, CGS called for **Congressional hearings and federal oversight of the fertility industry**.

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March-April: CGS welcomed President Obama’s executive order and the NIH guidelines on expansion of funding for embryonic stem cell research and the exclusion of cloning techniques. **Staff were cited in the *New York Times* and elsewhere.**

September 1: CGS and other public interest groups filed **an amicus curiae brief in support of a lawsuit challenging the constitutionality of patents on human genes** by the American Civil Liberties and the Public Patent Foundation. The brief was filed in coordination with the National Women’s Health Network, Pro-Choice Alliance for Responsible Research, Asian Communities for Reproductive Justice, and Generations Ahead. An invited article on human gene patents by CGS staff was published in the September-October 2009 issue of *The American Interest*.

January-December: CGS continued to work to ensure that **policies adopted by the California stem cell agency** adequately protect the public interest. In July, the "Little Hoover" Commission on California State Government Organization and Economy, the state’s official "good government" agency, issued its legislature-requested report on CIRM, which reflected a number of the concerns raised in the invited testimony given to them by CGS policy analyst Jesse Reynolds in November 2008. CGS also worked with women’s health advocates to monitor CIRM’s policies on acquisition of women’s eggs for stem cell research.

III. PUBLICATIONS AND REPORTS

January 9: [Human Embryonic Stem Cell Research: Frequently Asked Questions and Fact Sheet](#) [PDF] by The Center for Genetics and Society (a briefing document to assist reporters and others in preparation of the expected announcement of a new federal policy).



January 14: [Responsible Federal Oversight of the New Human Biotechnologies: Opportunities for the New Administration](#) [PDF] by the Center for Genetics and Society (recommendations for the Obama Administration concerning the new human biotechnologies).



January 28: [Playing the Gene Card? A Report on Race and Human Biotechnology](#) by Osagie Obasogie (a 95-page report focusing on three biotech applications that pose particular risks for African American and other minority communities).

IV. ARTICLES AND OP-EDS

Pete Shanks, "Will Candidates' DNA Play a Role in Future Elections?," *AlterNet* (January 20)

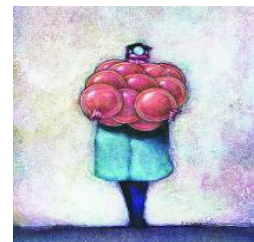
Jesse Reynolds, "NY stem cell research nears dangerous line," *Newsday* (January 23)

Jesse Reynolds, "Custom-Designed Kids: How Darwin's Legacy Is Being Abused," *AlterNet* (February 12)

Jesse Reynolds, "Preventing the Next Fertility Clinic Scandal," *Bioethics Forum* (March 13)

Jesse Reynolds, "Obama's stem cell policy is welcome change, but ethics are permanent feature of debate," *The Jurist* online (March 14)

Marcy Darnovsky, "Fertility Overload: Legislators should tame the 'Wild West' of assisted reproduction," *Riverside Press-Enterprise* (March 15)



Marcy Darnovsky, "Voluntary isn't working," *Modern Healthcare* (April 13)

Jesse Reynolds, "Obama cools the stem-cell debate," *San Francisco Chronicle* (April 27)

Marcy Darnovsky, "The Baby Business and Public Policy: Regulation Can Ensure Well-being and Protect Reproductive Rights," *Science Progress* (May 5)

Osagie Obasogie, "The Color of Our Genes," *Science Progress* (June 15)

Osagie Obasogie, "Return of the Race Myth?," *New Scientist* (July 1)

Marcy Darnovsky, "Political Science," *Democracy* (Summer)

Osagie Obasogie, "The Color of Our Genes," *GeneWatch* (July-August)



Marcy Darnovsky and Jesse Reynolds, "The Battle to Patent Your Genes: The Meaning of the Myriad Case," *The American Interest* (Sept-Oct)

Marcy Darnovsky, "What Kind of Bioethics Council Do We Need?," *Science Progress* (August 17)

Jesse Reynolds, "Monkeys, Mitochondria, and the Human Germline," *Bioethics Forum* (September 18)

Marcy Darnovsky, Letter to the Editor regarding "At Birth, Tales of Joy and Heartbreak," *New York Times* (October 14)

Osagie Obasogie, "Ten Years Later: Jesse Gelsinger's Death and Human Subjects Protection," *Bioethics Forum* (October 22)

Jesse Reynolds, "Symbol over Substance," *GeneWatch* (Sep-Oct)

Pete Shanks, "Cloning for Kicks," *GeneWatch* (Sep-Oct)



Marcy Darnovsky, "Biopolitics for the 21st Century," *2020 Science* (December 14)

V. CGS IN THE NEWS

In print and on the web:

Richard Hayes was cited in "Immortality 2.0: A Silicon Valley Insider Looks at California's Transhumanist Movement," David Gelles, *The Futurist* (January 1)



Richard Hayes was cited in "Designer Babies: Ethical? Inevitable?," Robert Roy Britt, *LiveScience* blog (January 11)

Marcy Darnovsky was cited in "The Burden of Knowing," Catherine Elton, *Boston Magazine* (January)

Marcy Darnovsky was cited in "Choose Your Child's Gender?," ClickOnDetroit.com (January 30)

Jesse Reynolds was cited in "Politics enters state's stem cell research program," Eric Bailey, *Los Angeles Times* (January 30)

Marcy Darnovsky was cited in "Unnatural selection: How far will parents go?," Marlowe Hood, Agence France Presse (printed in about 25 outlets) (February 5)

CGS was cited in "Group calls for action against octuplets clinic," Associated Press (printed in about 40 outlets) (February 11)

Marcy Darnovsky was cited in "A Baby, Please. Blond, Freckles -- Hold the Colic," Gautam Naik, *Wall Street Journal* (February 12)

Marcy Darnovsky was cited in "Color ID: Screening embryos for eye, hair, and skin color," Will Saletan, *Slate* (February 17)

Richard Hayes was cited in "Data Bank: U.S. Reproductive Biotechnology Regulation Falls Behind," Justin Masterman, *Science Progress* (February 18)

Marcy Darnovsky was cited in "Most fertility clinics break the rules," Stephanie Nano, Associated Press (printed in about 150 outlets) (February 20)



Marcy Darnovsky was cited in "Designer baby row over clinic that offers eye, skin and hair colour," Philip Sherwell, *The Telegraph* (UK) (February 28)

Marcy Darnovsky was cited in "Fertility clinic rules often disregarded," Suzanne Bohan, *Oakland Tribune* (Bay Area News Group of 9 papers) (March 1)

Marcy Darnovsky was cited in "Fertility clinics said to lack regulation," UPI (printed in 5 outlets) (March 2)

Marcy Darnovsky was cited in "California fertility doctor's offer of trait selection stirs ethical questions," Laura Bauer, *Kansas City Star* (March 3)

Marcy Darnovsky was cited in "Forget Designer Baby Bags—Now There's Designer Babies," Madeline Ellis, *Health News* (March 4)

Marcy Darnovsky was cited in "Octuplets case prompts calls for fertility regulations," Kimi Yoshino, *Los Angeles Times* blog (March 4)

Jesse Reynolds was cited in "'OctoMom' inspires bill to regulate fertility clinics," Malcolm Maclachlan, *Capitol Weekly* (March 5)

Jesse Reynolds was cited in "Stricter rules on fertility industry debated," Kimi Yoshino and Jessica Garrison, *Los Angeles Times* (March 6)



CGS was cited in "The IVF Battlefield," Will Saletan, *Slate* (March 8)

Marcy Darnovsky was cited in "Designer Babies: A Right to Choose?," Brandon Keim, *Wired Science* (March 9)



Marcy Darnovsky was cited in "Supporters of hESC Research Ecstatic with President Obama's Executive Order," Debbie Strickland, *Genetic Engineering & Biotechnology News* (March 10)

Marcy Darnovsky was cited in "Obama's Pledge to Science," Scott Jaschik, *Inside Higher Ed* (March 10)

Jesse Reynolds was cited in "Stem Cell Decision Worries Some Scientists," Andrew Pollack, *New York Times* (March 11)

Jesse Reynolds was cited in "Family decisions prove risky business," editorial, *The Tennessean* (March 17)

Jesse Reynolds was cited in "Reversal on stem cell research calls state funding into question," Ambika Kandasamy, *The Public Press* (March 16)

Jesse Reynolds was cited in "Canadian-US scientists forecast stem cell research collaboration," Sarah Khalil, *The Manitoban* (March 19)

CGS was cited in "Billion Dollar Babies: The brave new world of designer children," Greg Beato, *Reason* online (March 24)

CGS was cited in "CIRM Close-Hauled, Seeks Bonds to Sustain Headway," Constance Holden, *Science* (March 27)

CGS was cited in "California would remain on cutting edge under new U.S. stem cell policy," Lisa Krieger, *San Jose Mercury News* (April 17)

Jesse Reynolds was cited in "NIH releases stem cell guidelines for public comment," LuLaine Compere, *Biotechniques* (April 24)

Marcy Darnovsky was cited in "Birth of Octoplets Raises Questions about Fertility Industry," Elayne Clift, *OpEdNews.com* (April 28)

Marcy Darnovsky was cited in "Reproductive Ethics: Should fertility medicine be regulated more tightly?," Marcia Clemmitt, *CQ Researcher* (May 15)

Marcy Darnovsky was cited in "The fight for our genes heads to court," editorial, *San Francisco Chronicle* (May 23)

Marcy Darnovsky was cited in "Monkey see, monkey glow: Altered primates bring inherited genetic modification closer to man," Tom Abate, *GlobalPost* (June 2)



Marcy Darnovsky was cited in "Progressive Science Values," Andrew Plemmons Pratt, *Science Progress* (June 22)

Center for Genetics and Society was cited in "RH Reality Check Interviews Donna Dickenson, Author of *Body Shopping*," Mandy Van Deven, *RH Reality Check* (June 25)

Marcy Darnovsky was cited in "An Ethical and Progressive Scientific Policy," Bennett Gordon, *Utne Reader* politics blog (July 7)

Osagie Obasogie was cited in "The science and myth of race," Michelle Chen, *RaceWire* (July 22)

Marcy Darnovsky was cited in "New York OKs paying women who donate eggs for research," Kevin O'Reilly, *American Medical News* (July 27)

Marcy Darnovsky was cited in "The Gene Hunt: Should Finders Be Keepers?," Lynne Peeples, *Scientific American* online (July 29)

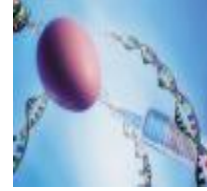
Marcy Darnovsky was cited in "The President's Council on Bioethics, Take Two," Ron Bailey, *Reason Online* (August 25)

Marcy Darnovsky was cited in "Lab Produces Monkeys with 2 Mothers," Rob Stein, *Washington Post* (August 27)

Marcy Darnovsky was cited in "Hooray for Frankenbabies," Ron Bailey, *Reason Online* (August 27)

Marcy Darnovsky was cited in "The Pros and Cons of Gender Prediction Kits," Shannon McKelden, *iparenting.com* (summer [undated])

Jesse Reynolds was cited in "Good Science and Good Ethics: Why we should discourage payment for eggs for stem cell research," Donna Dickenson, *Nature Reviews Genetics* (October 7)



Marcy Darnovsky was cited in "Fertility doctors tighten guidelines in wake of "octomom" controversy," Kevin O'Reilly, *American Medical News* (November 9)

Marcy Darnovsky was cited in "Argentina forces dirty war orphans to provide DNA," Mayra Pertossi, *Associated Press* (November 20)

On television and radio:



Marcy Darnovsky was interviewed on sex selection, CNN (January 29)

Marcy Darnovsky was cited in a story about octuplets, KNX radio, Los Angeles (February 11)

Osagie Obasogie was interviewed on race and biotechnology, WVON radio, Chicago (February 12)

Marcy Darnovsky was interviewed on octuplets, NBC Bay Area News (February 12)

Marcy Darnovsky was cited in a story about octuplets, KCSN radio, Northridge (February 12)

Marcy Darnovsky was cited in a story about designer babies, *The Albert Mohler Program*, Salem Radio Network (February 16)

Marcy Darnovsky was interviewed in a debate with Ron Green, Vermont Public Radio (February 26)

Marcy Darnovsky was cited in "Special deliveries: Are designer babies arriving?," *The Today Show* (March 3)

Marcy Darnovsky was interviewed on designer babies, Fox News (March 3)

Marcy Darnovsky was cited in "Your Own Personal Genomics," Rori Gallagher, *Crosscurrents Radio* (March 3)

Marcy Darnovsky was interviewed on designer babies, *The Ride Home*, KOA radio, Denver (March 3)



Marcy Darnovsky was interviewed on designer babies, CNN Headline News (March 3)

Marcy Darnovsky was interviewed in "Anger over 'Octomom'," *Lou Dobbs Tonight*, CNN (March 5)

Jesse Reynolds was featured on a panel on stem cells, *Which Way LA*, KCRW radio Los Angeles (March 9)

Osagie Obasogie was featured on a panel on designer babies, *KQED Forum*, KQED radio, San Francisco (March 9)

Osagie Obasogie was interviewed on race and biotechnology, *The Jeff Farias Show*, KXXT radio, Phoenix (March 10)

Marcy Darnovsky was cited in "How spit test can screen your genes," *BBC News* (April 9)

Marcy Darnovsky was cited in "New Genetic Therapy," Emily Harris and David Miller (hosts), *Think Out Loud*, Oregon Public Broadcasting (September 1)

Marcy Darnovsky was cited in "Send in the Clones," Mark Maley, producer, *Sunday Night* (Australia Channel 4) (October 11)

Marcy Darnovsky was cited in "Fertility doctors tighten guidelines in wake of 'octomom' controversy," *American Medical News* on XM Radio Channel 160 (November 9)

Marcy Darnovsky was cited in "Beauty, Brains & Eggs," Saul Gonzalez, producer; Judy Muller, reporter, *SoCal Connected*, KCET (PBS Los Angeles) (December 18)

CGS Press Advisories:

"New stem cell research backgrounder for reporters in anticipation of new policy under President Obama" (January 9)

"Federal Biotechnology Policy: Stem Cells and Beyond - Center for Genetics and Society releases policy brief for the Obama Administration" (January 14)

"Could genetic technologies set back efforts toward racial justice?" (January 28)

“Public interest group calls for disciplinary action against octuplets' fertility program - Flagrant violation of guidelines warrants revocation of membership and demonstrates need for regulation” (February 10)

“Embryo screening for "complexion" advertised by controversial fertility clinic - IVF octuplets and abuses of embryo screening highlight need for oversight” (February 12)

“Public interest groups calls for Congressional hearings on fertility industry - In wake of octuplets and “designer babies” controversies, Center for Genetics and Society says oversight is overdue.” (March 3)



“Public interest group responds to postponement of ‘designer baby’ service - Center for Genetics and Society calls for federal oversight, hearings” (March 4)

“Beyond stem cells: Public interest group urges strong regulation and oversight of reproductive and genetic biotechnologies - Center for Genetics and Society welcomes stem cell policy shift” (March 9)

“Federal stem cell guidelines welcomed by public interest group - Center for Genetics and Society says NIH is drawing appropriate lines (April 17)

“Public interest group urges caution in response to genetically modified primates - Center for Genetics and Society calls for scientists, policymakers to reject human inheritable genetic modification” (May 27)

“Final federal stem cell rules welcomed by public interest group - Center for Genetics and Society applauds expansion of funding; exclusion of cloning techniques” (July 6)

“Live mice and sperm - both from stem cells - create new social and ethical challenges - Public interest group calls for federal oversight of reproductive uses” (July 26)



“Public interest groups support groundbreaking challenge to human gene patents: Center for Genetics and Society, Pro-Choice Alliance for Responsible Research, other organizations file brief backing lawsuit” (September 1)

VI. INTERNET COMMUNICATIONS

Website. Traffic to the CGS website has grown to approximately 21,500 unique visitors per month.

Blogs. We add 3-4 posts per week to *Biopolitical Times*, CGS’s blog on our website. CGS was invited to establish a blog at the website of *Psychology Today*. The group blog, called *Genetic Crossroads*, began publication in May. Typical posts get between 1000 and 4000 reads.

Newsletters. CGS publishes a monthly and weekly newsletter, *Monthly Views and News* with close to 4000 subscribers at the end of 2009. *Weekly News and Views* was launched in November 2008.

Social media. CGS on Twitter, established in February, had 350 followers at the end of the year. CGS on Facebook had 86 fans at the end of the year. The CGS YouTube Channel had 43 subscribers and 2,170 channel views.

VII. OTHER ACTIVITIES

CGS undertook a major initiative in 2009 to organize an annual invitational meeting of individuals and organizations working to ensure that human biotechnologies and related emerging technologies support rather than undermine social justice and equality, human rights, and a sustainable future. A steering committee and working committees were established. Three events, called the Tarrytown Meetings, are planned for 2010, 2011 and 2012.

VIII. CGS STAFF

As of December 31, 2009, CGS had 4 staff (4.0 FTE) and 1 Senior Fellow. They are:

- Richard Hayes, Executive Director
- Marcy Darnovsky, Associate Executive Director
- Charles Garzon, Director of Finance and Administration
- Jesse Reynolds, Project Director, Biotech Accountability
- Osagie Obasogie, Senior Fellow for Bioethics, Law and Society

IX. BUDGET AND FUNDING

CGS's adjusted budget for 2009 is \$621,772. Current funding for CGS comes from Appleton Foundation, Changing Horizons, the Marisla Foundation, and several small individual donors.