









2010 REPORT ON ACTIVITIES

Center for Genetics and Society 2010 Report on Activities

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I. CONFERENCES, MEETINGS, PRESENTATIONS AND SYMPOSIA

January 7: CGS speaks at the "Progress in Bioethics" symposium convened by the Center for American Progress and *Democracy* in Washington, D.C. The event marked the publication by MIT Press of the anthology *Progress in Bioethics: Science, Policy, and Politics*, which includes a chapter authored by CGS associate director Marcy Darnovsky, "Biopolitics, Mythic Science, and Progressive Values."

January 22–24: CGS speaks at the New Delhi conference, "<u>Unraveling the Fertility Industry</u>: Challenges and Strategies for Movement Building, an International Consultation on Commercial, Economic and Ethical Aspects of Assisted Reproductive Technologies (ARTs)," organized by SAMA: Resource Group for Women and Health. The conference gathered over 100 experts from 13 different countries to discuss the social impacts, public health concerns and other issues connected with the industry.

February 15: CGS presents at the Hastings Women's Law Journal annual symposium, "Choice in the 21st Century? Regulating Reproductive Technologies" held at the University of California Hastings School of Law. Marcy Darnovsky was part of the panel, moderated by Osagie K. Obasogie, considering "Framing the Questions."

April 16–19: CGS speaks at the conference "Challenging Robotic Warfare and Social Control" [PDF] in Hood River, Oregon. The conference explored what the development of robotic technologies means for both modern warfare and civilian social control.



July 27–29: CGS hosts the inaugural <u>Tarrytown Meeting</u>, the first of three planned annual events. More than 100 invited advocates, scholars and others meet to consider what can be done to ensure that human biotechnologies support rather than undermine social justice, human rights, ecological integrity and the common good. The Tarrytown Meetings, and the network of individuals and organizations participating in them, grew out of a series of strategy consultations with colleagues and allies conducted over the previous year.

September 16: CGS appeared on a Panel to discuss "<u>Direct-to-Consumer DNA Testing</u>," at the University of California, Berkeley, along with faculty members, representatives of the industry and other experts. This followed several months of controversy about a campus initiative involving the proposed testing of freshmen for a few genetic variants, in which CGS played a prominent role (see below).

II. LEGISLATIVE AND REGULATORY INITIATIVES

During the spring and summer of 2010, CGS and several other groups and individuals (including a number who participated in the Tarrytown Meeting) played a key role in a controversy that resulted in UC Berkeley revamping a problematic gene-testing program for entering students. The panel discussion referenced above, and several media appearances listed below, arose from this issue.

In May, President Obama asked his newly formed Presidential Commission for the Study of Bioethical Issues to study, as its first order of business, the implications of synthetic biology, in light of an announcement that scientists had replaced all the genes in a bacterial cell with synthetic versions. CGS submitted comments to the President's Bioethics Commission, and later joined with 58 organizations from 22 countries to critique the Commission's recommendations.

III. ARTICLES AND OP-EDS



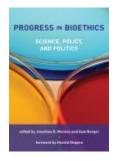
"Moral Questions of an Altogether Different Kind":

Progressive Politics in the Biotech Age [PDF]

by Marcy Darnovsky

Harvard Law and Policy Review, February 23rd, 2010

Human genetic, reproductive and biomedical technologies are taking us into uncharted moral and political waters.



Biopolitics, Mythic Science, and Progressive Values by Marcy Darnovsky A chapter in *Progress in Bioethics: Science, Policy, and Politics*, edited by Jonathan D. Moreno and Sam Berger. MIT Press, January 29th, 2010.



<u>Commercialisation of Reproductive and Genetic Technologies: What Lessons for Biotech Developments around the Globe?</u>

by Marcy Darnovsky

in *Unravelling the Fertility Industry: Challenges and Strategies for Movement Building* [PDF], a Report on the "International Consultation on Commercial, Economic and Ethical Aspects of Assisted Reproductive Technologies (ARTs)" held in New Delhi on January 22–24, 2010. New Delhi: Sama, 2010.



Human subjects research with prisoners: putting the ethical question in context

by Osagie K. Obasogie and Keramet A. Reiter

Bioethics, December 16th, 2010

Further dialogue is needed about the Institute of Medicine's recommendations to reform current standards for prisoners' participation as human subjects.



Democrats and DNA Databases

by Osagie K. Obasogie

The Huffington Post, September 24th, 2010

A new bill means that the federal government would pay states to engage in a practice that will likely lead innocent people's DNA to be stored alongside convicted criminals.

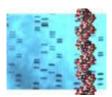


"Reports of My Death Have Been Greatly Exaggerated":
Race and Genetics Ten Years After the Human Genome Project

by Osagie K. Obasogie,

The Huffington Post, June 18th, 2010

Instead of closing the door on the historically misleading notion of race-asbiology, the ten-year-old Human Genome Project has drawn new attention toward biology's role in racial categories.



The dangers of growing DNA databases

by Osagie K. Obasogie

Los Angeles Times, April 9th, 2010

The practice of retaining genetic samples from people arrested for a crime but not convicted is growing in the U.S. It has serious human rights implications.



When Scientists Pick a Fight with the Law

by Osagie K. Obasogie

Science Progress, April 7th, 2010

Researchers are calling for the FBI to allow independent scientists to look under the hood of their sizable DNA forensics database.



UC Berkeley should drop gene-test program

by Jesse Reynolds

San Francisco Chronicle, June 7th, 2010

UC Berkeley plans to send cotton swabs to thousands of freshmen and transfer students, for samples for DNA analysis. This plan is problematic for several reasons.

IV. CGS IN THE NEWS

In print and on the web:

Jesse Reynolds was cited in "Judge Invalidates Human Gene Patent," Marilyn Marchione, *Associated Press* (March 29)

Jesse Reynolds was cited in "It Ain't 'Brave New World' Yet: Federal Court Strikes Down Human Gene Patents," Peter Jamison, *San Francisco Weekly* (March 31)

Jesse Reynolds and Marcy Darnovsky was cited in "Court Rules Isolated and Purified Breast Cancer Genes Unpatentable Under Section 101," Tony Dutra, *Bureau of National Affairs* (March 31)

Jesse Reynolds was cited in "Gene Patenting Issue not settled despite ruling," Deborah Shelton, *Chicago Tribune* (April 1)

Marcy Darnovsky was cited in "3-parent Embryos Could Prevents Disease but Raise Ethical Issues," Brandon Keim, *Wired Science* (April 14)

Jesse Reynolds was cited in "PTO Finds Stem Cell Patent Anticipated, Obvious in Light of 'Significant Guideposts'," Tony Dutra and Joyce Cutler, *Bureau of National Affairs* (May 12)



Jesse Reynolds was cited in "California: DNA Tests Criticized," Tamar Lewin, *New York Times* (May 20)

Jesse Reynolds was cited in "Welcome Freshman! Swab your cheek! Go Bears!," Janet Fang, *Nature* blog (May 20)

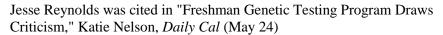
Jesse Reynolds was cited in "Ethics of UC Berkeley's gene testing questioned," Victoria Colliver, *San Francisco Chronicle* (May 21)

Jesse Reynolds was cited in "UC Berkeley Plan to test freshman criticized," Marcus Wohlsen, *Associated Press* (May 21)

Jesse Reynolds was cited in "Geno-Luddites and Berkeley's On the Same Page Program," Michael Eisen, *The Berkeley Blog* (May 21)

CGS was cited in "Daily Debriefing," Laura Bryn Sisson, *The Dartmouth* (May 24)

CGS was cited in "Cal's DNA testing Idea that took on a life of its own," Tracey Taylor, *Berkeleyside* (May 24)



CGS was cited in "UC Berkeley Fends off DTC Genomics Critics; Other Schools Mull Genetic Tests as Educational Tools," Turna Ray, *GenomeWeb* (May 25)

Jesse Reynolds was cited in "Don't attack UC Berkeley's Pursuit of Science," Asad Ramzanali, *The Daily Bruin* (May 26)

Jesse Reynolds was cited in "Do-It-Yourself Genetic Tests," Donna Dickenson, *ProjectSyndicate* (May 26)

Jesse Reynolds was cited in "Backlash to Freshman Gene Testing: We Saw Gattaca; We're not stupid," Alex Bigman, *The Daily Clog* (May 27)

CGS was cited in "Welcome, Freshman. DNA Swabs, Please," Troy Duster, *Chronicle of Higher Education* (May 28)

Jesse Reynolds was cited in "Federal Judge Invalidate Human BRCA Gene Patents," *The Tech Transfer Blog* (May 31)

CGS was cited in "Unwinding Berkeley's DNA Test," Jennifer Epstein, Inside Higher Ed (May 28)

CGS was cited in "UC Berkeley offer to test DNA of incoming students sparks debate," Larry Gordon, Los Angeles Times (June 1)

Jesse Reynolds was cited in "From genetic Tests to Tailored Care: Decoding a field with big potential - and even bigger implications," Kelly Bothum, *Delaware Online* (June 1)

Jesse Reynolds was cited in "Incoming Freshman Genetically Tested at UC Berkeley," Kelley Rees, *The Aggie* (June 3)

CGS was cited in "Skirting Laws Against Egg Payments," Susanne Schultz, *Hastings Bioethics Forum* (June 7)

CGS was cited in "Personal Genomics goes to school," Alla Katnelson, *Nature* blog (June 9)

Jesse Reynolds was cited in "DNA testing controversy a teachable moment," Mark Schlissel, San Francisco Chronicle (June 9)

Jesse Reynolds was cited in "Gene test mix-up brings scrutiny to industry," Alejandro Martinez-Cabrera, *San Francisco Chronicle* (June 11)

Jesse Reynolds was cited in "FDA to monitor genetic testing," Steve Johnson, San Jose Mercury News (June 12)

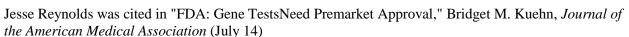
Jesse Reynolds was cited in "FDA Calls for genetic tests crackdown," David Gelles, *Financial Times* (June 13)

Jesse Reynolds was cited in "Students' DNA on curriculum at Stanford Medical School," Karen Kaplan, *LA Times Booster Shots Blog* (June 14)

Marcy Darnovsky was cited in "Interview with Marcy Darnovsky, Center for Genetics and Society," Susanne Schutlz, *Gen-ethischer Informationsdiesnst* (June)

Jesse Reynolds was cited in "Universities Bank on Stem Cell Research," Robert A. Guth, *Wall Street Journal* (July 1)

Jesse Reynolds was cited in "Medicine agency stays immune to budget cuts," Katie Worth, *San Francisco Examiner* (July 11)



CGS was cited in "UC Official to explain DNA testing program for freshman," Laurel Rosenhall, *Sacramento Bee* (August 10)

Jesse Reynolds was cited in "UC Berkeley Drops Part of Gene-scanning program," Marcus Wohlsen, *Associated Press* (August 12)

Jesse Reynolds was cited in "Campus DNA Testing Program Will not release individual results," Emma Anderson, *Daily Cal* (August 12)

Jesse Reynolds was cited in "UC Berkeley drops plans to release personal genetic information to incoming freshman," Lisa Krieger, *San Jose Mercury News* (August 12)

Jesse Reynolds was cited in "UC Berkeley waters down DNA testing," Victoria Colliver, *San Francisco Chronicle* (August 13)



Jesse Reynolds was cited in "Under Pressure, UC Berkeley Won't Tell Students Gene Test Results," Scott Hensley, *NPR Blog* (August 13)

CGS was cited in "A Slight Change in Plans," GenomeWeb (August 13)



Richard Hayes and Jesse Reynolds were cited in "UCal Berkeley Pulls Back Freshman Gene Tests," *GenomeWeb* (August 13)

Pete Shanks was cited in "Medicine, not food, may have more gain from cloning," Rick Barrett, *Milwaukee Journal Sentinel* (August 14)

Jesse Reynolds was cited in "UC Berkeley's Stillborn Gene-Testing Project Could Hold Lessons for Clinical Labs," Kirell Lakhman, *GenomeWeb* (August 18)

Jesse Reynolds was cited in "Marin Voice: Student Guinea Pigs at Cal?," Alan Miller, *Marin Independent Journal* (August 23)

Doug Pet was cited in "DNA Booth: A New Fair Favorite?," Jeremy Olson, *Minneapolis Star Tribune* (August 27)

Marcy Darnovsky was cited in "DNA Test Flip Flop Stirs Debate at UC," Victoria Colliver, San Francisco Chronicle (August 28)

Marcy Darnovsky was cited in "What Should You Ask Before You Give Up DNA? (At a State Fair or Elsewhere)," Katherine Hobson, *Wall Street Journal Health Blog* (August 30)

Marcy Darnovsky was cited in "Oh, No, It's a Girl! South Asians Flock to Sex-Selection Clinics in the US," Viji Sundaram, *New America Media* (August 31)

Marcy Darnovsky was cited in "Kids swap DNA for fairground rides," Ewen Callaway, *Nature.news* (September 1)

CGS was cited in "Tempest in a spit cup," Robert Sanders, *UC Berkeley News* (September 10)

Marcy Darnovsky was cited in "How reliable is personal DNA testing?," Gregory M. Lamb, *Christian Science Monitor* (September 15)

Marcy Darnovsky was cited in "U of M's 'DNA on a stick' study becomes platform for debate on genetic-research ethics," Sharon Schmickle, *MinnPost.com* (September 22)

Marcy Darnovsky was cited in "Genomes Mapped, Hope Elusive," Tracy Sutherland, *Australian Financial Review* (September 29)



Jesse Reynolds was cited in "On the Bridge: A conversation between a pro-lifer and an embryonic stem cell researcher," Christine A Scheller, *Huffington Post* (October 5)

Marcy Darnovsky was cited in "Nobel Prize reflects IVF's acceptance as medical procedure," Kevin B. O'Reilly, *American Medical News* (October 18)

On television and radio:

Marcy Darnovsky was interviewed about "Genetic Gender Selection," Hana Baba, *KALW Crosscurrents* (January 12)

Marcy Darnovsky was interviewed on "Against the Grain: Progressive Bioethics," C.S.Soong, *KPFA Radio* (April 19)

Osagie Obasagie was interviewed on "Three O'clock Report with Roy Ulrich," Roy Ulrich, *KPFK Radio* (April 23)

Osagie Obasagie was interviewed about "Responsible Genetics," Radio New Zealand Nights (May 12)

Jesse Reynolds was interviewed about "DNA Testing Kits," Stephanie Martin, *KQED California Money* (May 12)

Marcy Darnovsky was interviewed about "Berkeley Offers Free DNA Testing to Students," Kim Carollo, *ABC News* (May 20)

Marcy Darnovsky was interviewed about "At-Home Genetic Tests," Dave Iverson, *KQED Forum* (May 21)

Jesse Reynolds was interviewed about "Scientists create first synthetic living cell, ethics questioned," Kellia Ramared, *Free Speech Radio News* (May 21)

Jesse Reynolds was cited in "UC Berkeley asks students for more than SAT scores - DNA," Patt Morrison, The Patt Morrison Show (June 1)

Marcy Darnovsky was interviewed about "DIY DNA," Brian Lehrer, *Brian Lehrer Live* (June 2)



Jesse Reynolds was cited in "FDA Seeks to regulate home gene tests," Gregory Warner, *American Public Radio Marketplace* (June 11)

Marcy Darnovsky was interviewed about "UCB Genetic Testing Program Altered After Decision by State Officials," KTVU Bay City News (August 12)

Jesse Reynolds was interviewed about "UC Berkeley Drops Part of DNA testing Program," Sarah Varney, NPR Morning Edition (August 13)

Marcy Darnovsky was interviewed about "Investigative Report: "Bring Your Genes to Cal," *Cal TV* (September 24)

CGS Press Advisories:



March 30: <u>Public Interest Group Praises Court Decision that Human Genes Cannot Be Patented</u>: Center for Genetics and Society Calls Ruling a Victory for Patients, Consumers and Responsible Research

CGS welcomed yesterday's District Court decision invalidating patents on genes associated with breast and ovarian cancer, which ruled that human genes cannot be patented because they are products of nature



May 5: How Far Would You Go? Public Interest Collaborative Announces First-Ever Web Series for Parents on Technologies that Could Alter Human Nature: Mother's Day launch to spark grassroots discussions about new reproductive and genetic technologies. A new website and series of short videos on the complex challenges of new reproductive and genetic technologies.



May 19: Public interest group calls for UC Berkeley to suspend controversial gene tests for incoming students: CGS is calling for the suspension of a project at the University of California, Berkeley in which incoming freshmen will be asked to provide samples of their own DNA for genetic analysis.



June 11: <u>Public interest group welcomes regulation of direct-to-consumer genetic tests</u>: The Center for Genetics and Society says FDA letters will help protect consumers. "Along with other observers, we've long said that some of these tests are tantamount to practicing medicine."



August 12: <u>Public Interest Group Applauds End of UC Berkeley's Controversial Genetic Testing of Incoming Students</u>: Center for Genetics and Society, others previously raised concerns, called for the program's halt. The University says its researchers will now use students' genetic samples provided for aggregate analysis only, and will not provide results to individual students.

V. INTERNET COMMUNICATIONS

Website. Traffic to the CGS website is approximately 21,000 unique visitors per month.

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

Newsletters. CGS Weekly News and Views has approximately 3500 subscribers.

Social media. CGS blog entries are posted on Twitter (more than 700 followers) and Facebook (approximately 3100 views a month). Videos are posted on the CGS YouTube Channel.

Video collaboration. <u>BioConversations</u> is a series of short videos meant to stimulate public conversations about assisted reproductive technologies. *BioConversations* is a collaborative effort of CGS, Mothers for a Human Future, Jamestown Project and Public Conversation Project.

VI. CGS STAFF

As of December 31, 2010, CGS had six staff (4.5 FTE), one Senior Fellow and one regular contributor to our *Biopolitical Times* blog. They are:

- Richard Hayes, Executive Director
- Marcy Darnovsky, Associate Executive Director
- Charles Garzon, Director of Finance and Administration
- Jesse Reynolds, Project Director, Biotech Accountability (through August 2010)

- Osagie K. Obasogie, Senior Fellow for Bioethics, Law and Society
- Pete Shanks, Biopolitical Times contributor
- Douglas Pet, Staff Associate (beginning May 2010)
- Jillian Theil, Staff Associate (beginning June 2010)

Summer staff associates (summer 2010)

- Molly Maguire
- Brendan Parent

VII. BUDGET AND FUNDING

CGS's adjusted budget for 2010 is \$\$697,797. Current funding for CGS comes from Appleton Foundation, Changing Horizons, the Marisla Foundation, and several individual donors.