# CENTER FOR GENETICS AND SOCIETY

## 2008 REPORT ON ACTIVITIES













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## **CGS REPORT ON ACTIVITIES - 2008**

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#### I. CONFERENCES, MEETINGS, PRESENTATIONS AND SYMPOSIA

November 13-15: CGS Senior Fellow and Hastings Law School Associate Professor Osagie Obasogie presented on *DNA Databases: Impacts for Racial Justice* at the <u>Facing Race National Conference</u>, held in Oakland, California.

November 13: Marcy Darnovsky was a panelist at the teach-in on synthetic biology sponsored by the ETC Group, Friends of the Earth, and others, held in San Francisco, CA.

#### II. LEGISLATIVE AND REGULATORY INITIATIVES

June 19: CGS Executive Director Richard Hayes testified at the US House Foreign Affairs Committee Subcommittee on Terrorism, Nonproliferation and Trade hearing on "Genetics and Other Human Modification Technologies: Sensible International Regulation or a New Kind of Arms Race."

November 20: CGS policy analyst Jesse Reynolds testified at a hearing on the California Institute for Regenerative Medicine held by the "Little Hoover" Commission on California State Government Organization and Economy.

#### III. PUBLICATIONS AND REPORTS

January 15: *Geneticizing Disease: Implications for Racial Health Disparities* by Jamie D. Brooks (Center for Genetics and Society) and Meredith L. King (Center for American Progress).

June 19: "Is there an emerging international consensus on the proper uses of the new human genetic technologies?" by Richard Hayes: testimony before the US House Subcommittee on Terrorism, Nonproliferation and Trade

#### IV. ARTICLES AND OP-EDS

Richard Hayes, "Self-Made Man: Review of Babies by Design," *The American Interest* (January-February)

Marcy Darnovsky and Stuart Newman, "Time to Reconsider? What patient deaths mean for gene therapy trials," *GeneWatch* (Winter)

Jesse Reynolds, "New Book Makes Dangerous Claim That Inequality Is Genetic," *AlterNet.org* (January 18)

Jamie Brooks and Meredith L. King, "Blaming Your Genes for Your Health Problems? Not so Fast," *AlterNet.org* (January 18)

Marcy Darnovsky and Judy Norsigian, "Response to Rosemarie Tong on stem cells" [letter to the editor] *Conscience* (Winter)

Marcy Darnovsky, "Female Sperm and Gay Guinea Pigs," San Francisco Chronicle (March 12)

Marcy Darnovsky, "Are We Headed for a Sci-Fi Dystopia?," AlterNet.org (March 22)

Jesse Reynolds, "How to Break the Stem Cell Logjam," Bioethics Forum (April 4)

Richard Hayes, "Genetically Modified Humans? No Thanks," *Washington Post* website (April 15)

Osagie K. Obasogie and David E. Winickoff, "Race-specific drugs: regulatory trends and public policy," *Trends in Pharmacological Sciences* (April 29)

Marcy Darnovsky, "Crossing an Ethical Boundary," *The Journal of the Life Sciences* website (May 19)

Marcy Darnovsky, "Red flags over consumer genetics," San Diego Union Tribune (May 22)

Marcy Darnovsky, "Germline modification carries risk of major social harm," [letter to editor] *Nature* (June 5)

Marcy Darnovsky, "Homo Genesis: Techno enthusiasts are marketing extreme reproductive technologies to gay families," *Bitch Magazine* (June 6)

Osagie K. Obasogie, "Back From the Dead: What Dog Cloning Means for Our Human Future," *AlterNet.org* (June 16)

Osagie K. Obasogie, "Beyond Best Practices: Strict Scrutiny as a Regulatory Model for Race-Specific Medicines," *Journal of Law, Medicine and Ethics* (Fall)

Marcy Darnovsky, "All in the Genes" [letter to the editor], *Democracy: A Journal of Ideas* (Fall)

Richard Hayes, "The Vanishing Republican Voter" [letter to the editor], *New York Times Magazine* (September 21)

Marcy Darnovsky and Judy Norsigian, "Of Stem Cells and Politics" [letter to the editor], *RH Reality Check* (September 24)

Marcy Darnovsky, "The Spitterati and Trickle-Down Genomics, Parts 1 and 2," *Mother Jones Blue Marble Blog* (November 3 and 4); also *The Cutting Edge News* (December 8)

Richard Hayes, "An Emerging Consensus: Human Biotechnology Policies Around the World," *Science Progress* (November 6)

Marcy Darnovsky, "Obama and the future of stem cell politics," *Science Blogs: What's new in life science research* (November 26)

Marcy Darnovsky, "Time to put research cloning on the back burner," *Science Blogs: What's new in life science research* (December 4)

Marcy Darnovsky, "Bizarre cloners and serious questions," *Science Blogs: What's new in life science research* (December 9)

Marcy Darnovsky, "Genetically Modified Humans? No Thanks.," *Science Blogs: What's new in life science research* (December 10)

Marcy Darnovsky, "Avoiding the unthinkable?," *Science Blogs: What's new in life science research* (December 14)

Marcy Darnovsky, "Next Steps for Progressive Stem Cell Politics: Research and Values Together at Last," *Science Progress* (December 16)

Richard Hayes, "TITLE," *The Cutting Edge News* (December 22?)

## V. CGS IN THE NEWS

## In print and on the web:

Marcy Darnovsky was cited in "As human cloning advances, ethics debate gets louder," Sandi Dolbee, *San Diego Union Tribune* (January 17)

Marcy Darnovsky was cited in "Human embryos cloned from adult cells," David Cyranoski, *Nature News* (January 17)

Marcy Darnovsky was cited in "Biotech Stemagen fused skin and egg to clone embryo," Terri Somers, *San Diego Union Tribune* (January 18)

Marcy Darnovsky was cited in "Mature Human Embryos Created From Adult Skin Cells," Rick Weiss, *Washington Post* (January 18)

Jesse Reynolds was cited in "The Bullet Missed" (unsigned editorial), *Investor's Business Daily* (January 18)

Marcy Darnovsky was cited in "U.S. Firm Clones Human Embryos," Jennifer LeClaire, *Sci-Tech Today* (January 18)

Marcy Darnovsky was cited in "Critics decry, downplay cloning report," Tom Strode, *Baptist Press* (January 18)

Marcy Darnovsky was cited in "Are male eggs and female sperm on the horizon?," Peter Aldhous, *New Scientist* (February 2)

Richard Hayes was cited in "Cloning Critics Split," Neil Munro, National Journal (February 2)

Marcy Darnovsky was cited in "Experts fear potential abuses of genetic screening," Beth Whitehouse, *Newsday* (March 6)

Marcy Darnovsky was cited in "Would you deposit to 'biobank'?," Lisa Krieger, *San Jose Mercury News* (March 11)

Jesse Reynolds was cited in "Identigene Offers Off-the-Shelf DNA Paternity Test," Mike Antonucci, San Jose Mercury News (April 4)

Jesse Reynolds was cited in "State Probes 6 Online DNA-Testing Firms," Victoria Colliver, San Francisco Chronicle (April 24)

Marcy Darnovsky was cited in "Outsourcing Labor," Joann Klimkiewicz, *Hartford Courant* (April 24)

Jesse Reynolds was cited in "\$227 million in grants going to build California stem cell labs," Mary Engel, *Los Angeles Times* (May 7)

Jesse Reynolds was cited in "\$271 Million for Research on Stem Cells in California," Andrew Pollack, *New York Times* (May 8)

Marcy Darnovsky was cited in "Genetically modified human embryo stirs criticism," Malcolm Ritter, *Associated Press* (May 12)

Marcy Darnovsky was cited in "Engineering by Scientists on Embryo Stirs Criticism," Andrew Pollack, *New York Times* (May 13)

Marcy Darnovsky was cited in "US group questions human embryo research, calls for rules," *Deutsche Presse-Agentur* (May 14)

Marcy Darnovsky was cited in "The Smiling Heretic," Daniel S. Levine, *The Journal of Life Sciences* (May 16)

Marcy Darnovsky was cited in "Company offers to clone dogs of highest bidders in auction," Marcus Wohlsen, *Associated Press* (May 21)

Marcy Darnovsky was cited in "Is Sex Necessary for Reproduction?," Bernadette Tansey, San Francisco Chronicle (June 1)

Marcy Darnovsky was cited in "Egg shortage hits race to clone human stem cells: Researchers back bid to pay donors," Brendan Maher, *Nature* (June 11)

Richard Hayes was cited in "The Modified Man," Carl T. Hall, California (July/August)

Jesse Reynolds was cited in "California State Senator Vows to Push Life-Sci Bill without More Stem-Cell Amendments," Alex Philippidis, *BioRegion News* (July 21)

CGS was cited in "Egg Shortages Stalling Stem Cell Research," Darryn Bennett, *Voice of San Diego* (Aug 7)

Jesse Reynolds was cited in "McCain Equates Embryos and Fetuses in Stem Cell Statement," Brandon Kein, *Wired Science Blog* (September 19)

Jesse Reynolds and Marcy Darnovsky were cited in "Stem cell promises, obstacles remain four years after bill's approval," Sandy Kleffman, *San Jose Mercury News* (October 12)

Richard Hayes was cited in "Designer babies: Creating the perfect child," Mike Steere, *CNN.com* (October 30)

Richard Hayes was cited in "Fetal tests testing us," in *The Arizona Republic* (October 31)

Marcy Darnovsky was cited in "Build Your Own Cell: Local Scientists Work to Engineer Life," Lisa Krieger, *San Jose Mercury News* (November 14)

Jesse Reynolds was quoted in "Obama policy a lift for stem cells," Bernadette Tansey, in *San Francisco Chronicle* (November 29)

Jesse Reynolds was quoted in "Stem Cell dispatches from the Struggling State of Michigan" by Alexandra Stern, in *Science Blogs* (December 1)

#### On television and radio:

Marcy Darnovsky was interviewed about Stemagen's cloning announcement on ABC7 News (January 17)

Marcy Darnovsky was interviewed about Stemagen's cloning announcement on KNX Radio (January 18)

Marcy Darnovsky was interviewed about gene tests on KTVU Channel 2 (May 1)

Marcy Darnovsky debated Ronald Greene about his book "Designing Babies," hosted by Neal Conan, *NPR Talk of the Nation* (April 15)

Jamie Brooks was interviewed for "House Approves Genetic Test Law" by Farai Chideya, NPR News & Notes (May 6)

Marcy Darnovsky was interviewed about genetically modified human embryos on *The Troy Johnson Show* (May 15)

Marcy Darnovsky appeared on CNN's *The Glen Beck Show* and was interviewed about human-animal cybrids (May 21)

Marcy Darnovsky was interviewed for "Mill Valley Firm To Clone Dogs In Online Auction" on KPIX CBS News (May 21)

Marcy Darnovsky appeared on ABC News *Good Morning America* for "Cloning Man's Best Friend: How Far Would You Go to Keep Fido?" (May 21)

Marcy Darnovsky was interviewed about the California Health Department's challenge to direct-to-consumer genetic test companies on KQED Radio (June 30)

Marcy Darnovsky appeared on SBS TV (Korea) in a program about dog cloning and Hwang Woo Suk (July 12)

Marcy Darnovsky appeared on KPFA Terra Verde in a program on synthetic biology hosted by Michelle Chan (November 14)

#### **CGS Press Advisories:**

Press statement: Center for Genetics and Society's Executive Director to Testify before Congress on International Governance of Human Biotechnologies (June 17)

Press release: GINA may encourage problematic direct-to-consumer gene tests: Public interest group welcomes Genetic Information Non-discrimination Act as good first step (May 21)

Press release: Commercial dog cloning is more than just cute puppies: Public interest groups cite concerns about potential human reproductive cloning and involvement of disgraced cloning researcher Woo Suk Hwang (May 21)

Press release: Public interest group criticizes creation of first genetically modified human embryo Center for Genetics and Society calls for effective regulation (May 12)

Press release: California firm's cloning results are disturbing; may violate state law: Public interest group cites three key concerns (January 17)

Press release: Center for Genetics and Society launches online database of human biotechnology policies (September 15)

Press release: Center for Genetics and Society to Testify on Governance of California's Stem Cell Agency (November 19)

## **Editorial board meetings:**

## **Press Briefings:**

## VI. AWARDS / RECOGNITION

## VII. INTERNET COMMUNICATIONS

# A. CGS Blog: BioPolitical Times

| Month | Number of | Number of | # of posts w | Number of |
|-------|-----------|-----------|--------------|-----------|
|       | Posts     | Visits    | comments     | Comments  |
| Jan   | 14        | 1750      | 0            | 0         |
| Feb   | 18        | 2160      | 4            | 6         |
| Mar   | 11        | 2230      | 1            | 1         |
| Apr   | 20        | 2530      | 2            | 4         |
| May   | 12        | 2690      | 0            | 0         |
| Jun   | 14        | 2120      | 1            | 1         |
| Jul   | 13        | 2320      | 0            | 0         |
| Aug   | 16        | 2430      | 3            | 4         |
| Sep   | 13        | 2800      | 1            | 1         |
| Oct   | 15        | 3360      | 0            | 0         |
| Nov   | 17        | 4040      | 2            | 3         |
| Dec   | 18        | 3300      | 0            | 0         |

TOTALS 181 31,730 14 21

Ave posts/week: 3.4 Ave visits/post: 176

Percent of posts with comments: 8%

## **B.** CGS Website Visits Per Month

| Month | 2007 | 2008   | %<br>Increase |
|-------|------|--------|---------------|
|       |      |        | '07 to '08    |
| Jan   | _    | 18,100 |               |
| Feb   | -    | 20,200 |               |
| Mar   | -    | 20,700 |               |
| Apr   | -    | 22,600 |               |
| May   | -    | 20,500 |               |
| June  | -    | 13,400 |               |
| July  | -    | 11,700 |               |

| Aug             | -      | 11,200 |          |
|-----------------|--------|--------|----------|
| Sept            | 15,500 | 15,300 | -0.01 %  |
| Oct             | 24,200 | 22,600 | - 0.07 % |
| Nov             | 25,300 | 25,300 | 0        |
| Dec             | 18,200 | 18,400 | - 0.01 % |
| monthly average | 20,800 | 18,300 | - 0.11 % |

## C. CGS Newsletters and other mailings

### CGS Monthly News and Views.

In 2008 the CGS monthly Genetics Crossroads was graphically redesigned and changed its name to Monthly Views and News. Key statistics:

Average number of subscribers: 2790

623 (22 %)

Average number who open the email: Average number who click on a link: 216 (35 % of those who open; 8 % of subscribers)

## CGS Weekly News and Views.

This began in November. At the end of the year it had 100 subscribers.

CGS also publishes the *Report to Colleagues*, which goes to 342 selected close colleagues no more than three times each year.

### **D.** Social Networking Sites

September: CGS BioPolicyWiki went on-line on Sept 18. Between Oct 1 and Dec. 31 it received 894 visits, for an average of about 69 visits per week.

CGS YouTube.com channel went on-line July:

August: CGS Facebook.com went on-line December: CGS LinkedIn.com went on-line December: CGS Change.org went on-line

#### VIII. OTHER ACTIVITIES

Between January and April CGS held five invitational strategy sessions involving key colleagues in five cities. Dates, locations and number of participants are:

January 31: New York City, NY; Jessie Smith Noyes Foundation; 10

February 6: Washington, DC; Friends of the Earth; 12 February 12: Cambridge, MA; Harvard Faculty Club; 11 Berkeley, CA; UC Berkeley Faculty Club; 14 March 27: April 1: San Francisco, CA; The Commonwealth Club; 15

#### VIII. CGS STAFF

As of Jan 31, 2009, CGS had 5 staff (5.0 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
Jenna Burton, Administrative Associate
Osagie Obasogie, Senior Fellow for Bioethics, Law and Society

### IX. BUDGET AND FUNDING

CGS's adjusted budget for 2008, is \$598,000. Current funding for CGS comes from Appleton Foundation, Changing Horizons, the Marisla Foundation., and several small individual donors.

## **CGS FUNDING HISTORY**

| Year | <b>Total Funds Raised</b> |
|------|---------------------------|
| 2000 | \$165,700                 |
| 2001 | \$329,500                 |
| 2002 | \$392,400                 |
| 2003 | \$620,000                 |
| 2004 | \$609,500                 |
| 2005 | \$885,000                 |
| 2006 | \$882,600                 |
| 2007 | \$1,005,000               |
| 2008 | \$ 578,000                |

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