A conversation on disability justice & human genetic engineering

CGS will be co-sponsoring a webinar, "A conversation on disability justice and human genetic engineering" with the Disability Visibility Project, the Longmore Institute on Disability, and Disability Rights Education & Defense Fund on April 24 at 1 pm Pacific Daylight Time (rescheduled from an earlier date). Find more on this accessible event, including registration and speakers you won't want to miss, on Facebook.

[Watch] 3-person IVF technique’s ethical & political implications: A discussion

CGS Program Manager Leah Lowthorp and consultant Jessica Cussins led a dynamic discussion about the policy developments surrounding 3-person IVF. Find a complete recording of their March 23 remarks on YouTube.

3-Person IVF: Putting the First Legal Genetic Modification of Babies in Context
by Jessica Cussins, Biopolitical Times guest contributor
This blog will look back at some of the history that led to this point, discuss global policy developments, and provide a rough framework for thinking about the ethical considerations.

3-person IVF and exploiting a “no rules” global South
by Leah Lowthorps
Both Powledge and We need to stop and consider the negative social implications of this type of rogue science, and its likely effects on both public trust of science and public health worldwide.
De-extinction is fake news
by Pete Shanks
Both Powledge and Hawks righteously rubbish the idea of de-extinction on environmental, ethical, and technical grounds, and specifically the fantasy of bringing back the wooly mammoth.

Blinded by Bad Science and Bad Oversight
by Pete Shanks
There is something very wrong with using payoffs to hinder expert analysis of a scientific failure. Sadly, the cover-up of deaths and other serious injuries in medical experimentation has a long history.

AI OK? WTF! LOL
by Pete Shanks
There are genuine issues to discuss but sometimes the best way to handle outrageous fear-mongering is to laugh at it.

NEWS

Genomics | Human Genetic Modification | Stem Cells
Assisted Reproduction | Governance | Eugenics | Various

GENOMICS

▶ Don't allow genetic stop-and-frisk
by Allison Lewis, Newsday
A New York forensic oversight agency wants to unilaterally expand the use of the offender DNA database to convert relatives of those on file into default suspects.

▶ Don't discriminate against mutants like me
by Louise Aronson, The New York Times
Mutations only signal increased risk; they don't tell you who will get cancer, what type or when.

▶ Germany considers wider use of DNA evidence in criminal cases
by Editorial, Nature
Is Germany's new push for wider usages of forensic DNA analysis linked to
Collecting DNA From Sex Workers to One Day Identify Their Bodies
by Sarah Zhang, The Atlantic
Bioethicists are concerned about a program in Dallas where law enforcement are collecting DNA from sex workers to identify their bodies if they are murdered in the future.

Familial DNA testing OK’d by state forensics sub-panel
by Anthony O'Reilly, Queens Chronicle
The DNA subcommittee of the state Commission on Forensic Science unanimously approved the use of familial testing in New York and recommended the full body authorize the method.

This company wants to analyze your saliva—to predict when you’ll die
by Rebecca Robbins, STAT
The sales pitch: We’ll pay you up front for your policy. We’ll pay your premiums for the rest of your life. And when you die, we get the insurance money.

How your ancestors’ environment determines the shape of your nose
by Carolyn Gregoire, Huffington Post
It’s not just genetics that influences whether your nose turns out short and wide or tall and narrow.

Questions raised over 3-parent baby procedure last year
by Andy Cochran, New Scientist
Ethical and safety concerns continue to loom, including procedural practices of obtaining consent and the 5% of mitochondrial DNA that was passed on to the baby.

Mitochondrial replacement techniques and Mexico
by César Palacios-González and María de Jesús Medina-Arellano, Oxford University Press
We reached the conclusion that Zhang’s team broke Mexican federal regulations, specifically the Regulations of the General Health Law on Health Research.

British scientists get approval to create babies using DNA from 3 people
by Maria Cheng, Associated Press
Britain's Newcastle University says its scientists have received a license to create babies using DNA from three people — the first time such approval has been granted.

Customized babies are closer than you think
[Cites CGS’s Marcy Darnovsky]
by Bonnie Rochman, Boston Globe
As this technology improves, which it inevitably will, we need to guard against becoming enclaves of finely tuned aristocratic offspring, an oligarchy of genetic haves and have-nots.

Engineering consensus in the development of genome editing
policy
by Katherine Drabiak, The Hastings Center
Although the lengthy report suggests extensive deliberation, it glosses over troubling scientific evidence pertaining to risks of gene editing and stands in stark contrast to the current widely held view in many countries against human germline modifications.

Paper on 1st use of CRISPR in normal human embryos: Problems remain
by Paul Knoepfler, The Niche
I see it mainly as a tool for doing human developmental biology studies and even there it must be done in an ethical, transparent, institutionally approved, and cautious manner with bioethical training in advance.

UC Berkeley receives CRISPR patent in Europe
by Jef Akst, The Scientist
The European Patent Office will grant patent rights over the use of CRISPR in all cell types to a University of California team, contrasting with a recent decision in the U.S.

An experiment that blinded three women unearths the murky world of stem cell clinics
by Peter Aldhous, Buzzfeed
A look at the shadowy ethics review board that approved a stem cell clinical trial that left three people blind.

The stem cell therapies offered by this La Jolla clinic aren’t FDA approved, may not work — and cost $15,000
by Michael Hiltzik, Los Angeles Times
The lawsuit, which seeks class-action status, claims that StemGenex has made its money by “targeting the ill and the elderly” with “false, fabricated and purposefully misleading” claims about patient satisfaction.

Harvard scientists call for better rules to guide research on ‘embryoids’
by Rob Stein, NPR
New developments in synthetic biology are causing Harvard geneticists to push for international guidelines on this area of research.

Scientists have created the first artificial embryo without using an egg or sperm
by Kristen V. Brown, Gizmodo
Using stem cells in grown-on 3D scaffolding in a laboratory petri dish, scientists have for the first time created an embryo made entirely from stem cells.

A new form of stem-cell engineering raises ethical questions
by Carl Zimmer, The New York Times
Synthetic embryos, also known as “sheefs,” could develop into complex forms, raising concerns that “are just too big” to ignore.

Japanese man is first to receive ‘reprogrammed’ stem cells from another person
by David Cyranoski, Nature News
The world’s first induced pluripotent stem cell transplant, used to treat macular degeneration, represents a major step forward in movement to create banks of ready-made stem cells.
As Mexican state limits surrogacy, global system is further strained
by Victoria Burnett, The New York Times
The model in which would-be parents from wealthy countries hire surrogates in poorer — and less regulated — nations is "not sustainable."

Woman Guilty of Smuggling Woman for Surrogacy, Forced Labor
Associated Press
According to the plea agreement, [47-year-old Esthela] Clark paid $3,000 to have the victim smuggled into the U.S. and assured her the surrogacy would be medically supervised.

IVF treatment promoted as more 'natural' fails in 90% of cases despite costing £3,000, expert warns
by Jo MacFarlane, Daily Mail
[Professor Simon Fishel] said, "I'd be concerned that some clinics might use the natural method as a hook, and that patients will eventually need conventional IVF later."

The crazy plan to restore a woman’s fertility—and defy the limits of nature
by Kristen V. Brown, Gizmodo
Inovium and Genesis are offering women that are desperate for children and willing to pay a very high price treatment for which they still have published no peer-reviewed data, have done very small studies, and have little more than untested theories to explain how it all actually works.

Seattle fertility doctor says twins are trending, and that’s risky
by Gabe Cohen, KOMO News
More patients are asking for twins because of Beyoncé and George Clooney, though doctors are steering them away due to dangers.

Menopausal women become pregnant with their own eggs
by Jessica Hamzelou, New Scientist
A new technique is being developed to rejuvenate egg cells that may exploit women desperate to have children using a treatment that hasn't yet undergone peer review.

Mini reproductive organs in a dish mimic 28-day menstrual cycle
by Clare Wilson, New Scientist
Linking different organoids together enables researchers to study complex organ systems in miniature, an approach that could lead to new insights and less animal testing.

In a world first, Singapore’s highest court rules that parents deserve kids with their genes
by G. Owen Schaefer, The Conversation
Genetic affinity is an entirely new legal standard. It has no clear precedent in any jurisdiction. But the court made a compelling argument that it has a sound basis in the way we value family and heredity.

Tax breaks for infertility treatments broadened under new budget
by Angela Mulholland, CTV News
A retroactive tax break may be in store for Canadians who have used assisted reproductive technologies over the past decade.

- **House Republicans would let employers demand workers' genetic test results**
  by Sharon Begley, STAT
  Amidst health care debate, House GOP members are silently pushing a bill that would allow employers to demand workers’ genetic test results.

- **Saving GINA: Is genetic privacy imperiled**
  by Ricki Lewis, Public Library of Science
  H.R.1313, the “Preserving Employee Wellness Programs Act,” might instead be called the “telling on relatives” ruling.

- **Making US workers pass genetic data to employers is wrong**
  by Martina Cornel, New Scientist
  Many of the risk-reducing options for those few genetic conditions where testing is considered a good guide to the chance of serious illness are highly personal decisions. These should have nothing to do with an employer.

- **Canada’s new genetic discrimination law will prevent a ‘Gattaca’ future**
  by Jordan Pearson, VICE Motherboard
  The Canadian parliament bucked the Prime Minister to pass a law that makes it illegal for employers or insurance companies to discriminate against people based on their DNA.

- **Can a new model help governance keep up with synthetic biology?**
  by Aaron Dy, Public Library of Science
  Two researchers from North Carolina State University are creating a new model of governance to better address the concerns raised by synthetic biology.

- **Texas Considers GM Mosquitoes**
  by Kerry Grens, The Scientist
  In an effort to prevent the spread of Zika virus, Harris County officials are in discussions with Oxitec to release insects engineered to produce short-lived offspring.

- **Trump Leaves Science Jobs Vacant, Troubling Critics**
  Scores of departures by scientists and Silicon Valley technology experts who advised President Trump’s predecessor have all but wiped out the White House Office of Science and Technology Policy.

- **EU nations vote against GM crops, but not enough to block them**
  by Philip Blenkinsop, Reuters
  The votes against were not decisive in blocking their introduction because the opposition did not represent a “qualified majority” - also including countries that make up at least 65 percent of the EU population.

**EUGENICS**

- **“Scientific racism” is on the rise on the right. But it’s been lurking there for years.**
  by Nicole Hemmer, Vox
These ideas about an outside cultural threat and an internal genetic threat to white America were in circulation well before the emergence of the alt-right or the Trump campaign.

**Vermont's eugenics history demands public reckoning**
by Steve May, *VT Digger*
While we as Americans tend to associate eugenics with Hitler and the Nazis, it is actually a cadre of American researchers who actually created the field as an area of medical and scientific inquiry.

**Palo Alto: Two schools named after eugenics advocates to get new names**
by Jacqueline Lee, *Mercury News*
Board members agreed that the district’s schools must incorporate a unit about California and Palo Alto’s role in the eugenics movement into the history curriculum of secondary schools by next school year.

**6 Realities of growing up the product of a eugenics scam**
by Ryan Menezes, *Cracked*
Many donor children born from the 1970’s “Nobel Prize sperm bank” now report “genetic bewilderment.”

**Sex selection leads to dangerous gender imbalance; new programme to tackle root causes**
United Nations Population Fund
With funding from the European Union, the programme will work with the governments of Armenia, Azerbaijan, Bangladesh, Georgia, Nepal and Viet Nam to gather information about gender-biased sex selection and to raise up the value of girls and women.

**Reflections on reactions to the [Nuffield] Council's report on NIPT**
by Catherine Joynson, *Nuffield Blog*
This article attempts to continue the conversation, respond to some of the specific comments that have been aired, and describe how we came to our conclusions and recommendations.

**South Africa’s San people issue ethics code to scientists**
by Ewen Callaway, *Nature*
Now, after more than a century of being scrutinized by science, the San are demanding something back. Earlier this month the group unveiled a code of ethics for researchers wishing to study their culture, genes, or heritage.

**Scientists closer to creating a fully synthetic yeast genome**
by Rob Stein, *NPR*
In a series of seven papers published in the journal *Science*, the group reports it is on track to having a fully synthetic yeast genome finished by the end of the year.

**Backyard gene editing risks creating a monster**
by Editorial, *New Scientist*
Most biohackers are motivated by curiosity or altruism. But clearly this is not enough of a safeguard. Quite apart from the prospect of bad actors, US intelligence has also warned of “unintentional misuse.”
Animal gene sequencing project aims to assemble a comprehensive genomic zoo
by Luke Dormehl, Digital Trends
The purpose of the Genome 10K project is to assemble a genomic zoo of DNA sequences representing the full diversity of vertebrate animals.