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**Human® Rights in the Age of Human Biotechnology**

**Wednesday, January 26, 2011, 9:30 – 10:30am**

*Facilitator:*

**Francine Coeytaux, Co-founder/Program Consultant and Director, Emergency Contraception Initiative,  
Pro-Choice Alliance for Responsible Research/Compton Foundation**



*Panelists:*

**Osagie Obasogie, Senior Fellow/Associate Professor of La, Center for Genetics and Society at  
University of California-Hastings College of Law**

**Hellen Wallace, Executive Director, GeneWatch UK**



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How can we ensure that new powerful technologies promote, rather than undermine, human rights? DNA collection raises questions about privacy. Egg donation has health and rights implications for the women who donate. Embryo selection affects diversity and pluralism in society. Science has largely been allowed to develop outside of the policy context – it is time to take proactive critical analysis of safety concerns and ethical dilemmas associated with these technologies. The political framing of these issues is critical; the debate needs to be shaped so that policies adhere to a human rights framework. This session has three primary goals:

- Make a compelling case for the need to address implications of technologies;
- Help funders understand how to introduce these issues to their boards and trustees;
- Outline concrete steps NGO and funder practitioners can take to address these issues.

**Helen Wallace** explained that the United Kingdom maintains the largest DNA database globally, which stores the DNA of persons found innocent, even though the retention of innocent peoples' DNA has been declared illegal by the European Court of Human Rights. The UK collects DNA upon arrest, either via mouth swab or hair on children aged 10 or older. DNA does not have to be relevant to the crime the individual is accused of and it is stored after the individual is found innocent.

Human rights issues inherent in this practice:

- Bio-surveillance: tracking of citizens and families (including non-paternity)
- Categorization based on genetics or other data
- Discrimination based on categorization of individuals as 'risky' (ethnic appearance, etc)

Through her work, Wallace has been documenting the expansion of DNA databases around the world. She concludes that the use of DNA can bring many benefits, but that sequencing DNA of populations is not justifiable and that safeguards to this practice are essential.

**Osagie Obasogie** shared an example of a drug targeted specifically to African-Americans to treat heart failure. This drug, BiDil, marks a shift in several ways:

- 1<sup>st</sup> drug patented as race specific – makes a legal claim about race and biology;
- 1<sup>st</sup> drug to receive FDA approval as race specific – makes a regulatory claim about race and biology;
- 1<sup>st</sup> to be marketed as race specific – makes an economic claim about race and biology.

The eugenics movement is premised on the idea that some races are biologically inferior, a dangerous premise. Bioethics usually addresses this but with the scale of technological change, we need to use a human rights frame. We must demand accountability for the failure to address the causes of health disparities; it cannot be based on 'race difference science'. Race is being emphasized at the molecular level, while people say that it doesn't matter at the social level.

**Coeytaux** screened a trailer of *Google Baby*, a film that explores the burgeoning global surrogacy market. Surrogacy is currently a greater than \$3 billion a year industry in the U.S. and is growing rapidly.

She then laid out several fertility practices that have human rights implications:

- Surrogacy. Often this practice involves poor and socially marginalized women serving as surrogates, agreeing to contracts that restrict their movement with minimal informed consent. How can ethical and legal standards be created that account for both the desire for biologically-related children and the risks for surrogates?
- Egg extraction. Extraction is invasive with significant risks for the egg donor, with long terms risks that have not yet been fully determined. Given this lack of adequate safety information, can egg donors truly provide informed consent?
- Embryo screening. This practice involves screening embryos for certain characteristics, including sex and disability. What are the long term effects on society if this practice serves to limit diversity?

## Question & Answer

It has been established that race is a social construction and that it is not biologically significant. However, there has been an increase over the past few years in the significance attributed to race within biology. Scientific research is developing in a way that portrays race not solely as a social construct. This leads to not addressing race as a social and political problem and instead 'blaming' it on biology.

Q: Could you further explain the use of DNA in the UK to investigate criminal activity? What is the relationship between the UK database and the suspected terrorist lists that the US maintains?

A: Research has shown that the expansion of the UK's database to retain DNA of innocent individuals has not helped to solve crimes. Monitoring is a key issue and GeneWatch UK is currently part of advocacy efforts lobbying for the establishment of an independent monitoring organization. The UK is the first country ever to actually consider rolling back its DNA database.

Q: When a woman is a surrogate in a different country from where the mother is located, how is the citizenship of the child determined?

A: The answer to that question has not been fully determined yet.

The audience then discussed the following questions:

- What issues resonate most strongly with you?
- What key questions would you like answered?
- What opportunities do you see for civil society and funder interventions?

Several funders expressed interest in these issues, but that they lay outside of their current funding priorities.

A: The individuals currently working on these issues represent a very diverse array of disciplines and foci. This is as challenge, as both funders and NGOs are struggling to 'add' these issues to the work that they already do. However there is one unifying tool needed to address this – a human rights framework. One critical action that funders can take is provide support for public communications on these issues. The public should have access to critical analysis of media depictions of these technologies.

Another opportunity for NGOs and funders is to support a proposal at the UN level for a global treaty that will establish a process for assessing emerging technologies. There is a group leading this effort and the movement is gaining traction. Groups cannot keep fighting these issues as individual battles after the fact, new technologies need to be critiqued in advance of their introduction into society.

The panelists encouraged the audience to attend a series of meetings being held in Tarrytown, New York. These meetings bring together practitioners from many disciplines to analyze these issues and discuss potential solutions. The next meeting will be in July 2011. If interested contact Francine Coeytaux.