

**Testimony of CTA Executive Director Andrew Kimbrell at a Hearing on Science,
Policy, and Ethics of Prenatal Genetic Testing**

The Senate Committee on Commerce, Science, and Transportation
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History does not repeat itself, but it does rhyme—Mark Twain

Preimplantation Genetic Diagnosis (PGD) is only one of many emerging genetic and reproductive technologies in need of broad public discussion and regulation, but we view PGD as a gateway technology. PGD, if permitted to continue unregulated, could pave the way to new eugenics, where children are literally selected and eventually designed according to a parent's desires and fears.

Recent rapid developments in PGD indicate that we are stumbling down a slippery slope toward this future rendering a policy response an urgent matter. Finally, unfettered developments of PGD applications in the US attest to the general failure of the US policy regarding genetic and reproductive technologies. This policy failure must be corrected if we are to prevent a new eugenics in the US and abroad.

Germany, Austria, Ireland, Switzerland, and Southwest Australia have banned PGD outright. Other nations, including the United Kingdom, France, the Netherlands, Belgium, Italy, and Greece have limited the use of PGD. Even in the US, until recently, PGD was used exclusively for medical purposes.

Today, two thirds of the 50 or so fertility clinics in the world offering PGD are in the US. Some clinics are blatantly performing PGD for selection.¹ Many other clinics have used PGD to avoid late-onset diseases like Alzheimer's. A growing number of couples are using PGD to select an embryo that would grow into a child intended to be a tissue match for its sibling. None of these applications were subject to formal regulatory review or public deliberation prior to their use. In the case of sex selection, the practice specifically violates the voluntary guidelines of the American Society of Reproductive Medicine.²

The US lack of regulation has resulted in advocates of expanded PGD in other countries to push for more permissiveness abroad. Some of the advocates, including Robert Edwards, who 25 years ago performed the first successful IVF procedure in humans, explicitly promote the new eugenic approach. Edwards has predicted that "Soon it will be a sin for parents to have a child which carries the heavy burden of genetic disease. We are entering a world where we have to consider the quality of our children."³

In the United Kingdom groups have already organized protests against this new eugenics. People Against Eugenics⁴ organized a September 30, 2004 protest at a British pro-eugenics conference at the Royal Society in London. The press release denounced the eugenics conference organizer, the pioneer of IVF, Robert Edwards as the link between the old-fashioned state sanctioned eugenics and the new

free-market version. It notes that Edwards, who 25 years ago, performed the first successful IVF procedure in humans is the former President and a leading member of the British eugenics society.⁵

Today, twenty-five years after the birth of Louis Brown from Edward's IVF technique, some one million children have been born from the process of IVF. The paralleled development of genetic testing has resulted into the merger of genetic testing and assisted reproduction into preimplantation genetic diagnosis (PGD). Parents can now choose which of their embryos to implant in the mother's womb based on the outcome of more than 1000 genetic tests that potentially could be performed on the embryos.

At birth, Chloe O'Brien seemed no different than any other healthy baby, but Chloe was the pioneer product of the new technology of PGD. Born in March 1992, she was the first baby to be genetically screened as an embryo for a genetic defect, cystic fibrosis (CF), before being implanted into her mother's womb.⁶

In the 12 years since Chloe's birth, up to 10,000⁷ children have been born after a preimplantation genetic screening. Chromosome abnormalities such Down syndrome and single gene defects including CF, Tay Sachs, muscular dystrophy and sickle cell anemia have been screened with PGD.

These tests screen for some diseases like Tay Sachs, that result in short brutal lives for the children with the diseases, but also for diseases like Downs where children can live into their 50s or later. Genetic testing for these diseases is not new in that many of them are already tested for through amniocentesis.

PGD accelerates trends begun through prenatal testing

While in the US there are no national data on how many pregnancies are terminated as the result of prenatal testing, some regional results may highlight what decisions are being made through pre-natal diagnosis. Interestingly, some data suggest that more women may be carrying Down syndrome babies to term. A study at Harvard-Pilgrim Health Care found that while the incidence of pregnancies with Down syndrome in the HMO had increased from 2 per 1000 in 1992 to 6 per 1000 in 1996, there was a significant trend toward carrying fetuses with Down syndrome to term. In 1992, almost 100 percent of fetuses prenatally diagnosed with Down syndrome at the HMO were terminated; in 1994-95, this figure was 65%.⁸

Rates of pregnancy termination for Down syndrome vary considerably between hospitals and between ethnic and religious groups. A 2004 study by the CDC of Down syndrome in Atlanta women found a lower portion of elective termination among black women as compared to white women.⁹

A study of pregnancy terminations for Downs in Boston in 1996 found that rates of termination varied widely between the north and south shores of Boston even though both groups of women received genetic counseling from the same people. Apparently women with deeply held beliefs about abortion decided to terminate the Down syndrome fetus at a much lower rate than women who did not have the same beliefs. Improvements in societal attitudes and support services for children with Downs also seemed to change the numbers of women choosing not to terminate their pregnancies. Women who are better prepared for their child's condition may also be more willing to carry a pregnancy to term. Some

researchers report, however, that most women carrying fetuses whose disorders are usually fatal at in early infancy choose to terminate those pregnancies.¹⁰

Many parents of children with Down syndrome consider them to be special children. A United Methodist minister from New England and his wife have a child with Down syndrome that he considers a gift from God.

“We fluctuated between accepting and rejecting the Downs diagnosis... That day we also got word that the chromosomal test confirmed the Downs condition; by now the news was expected and absorbed...almost exactly a week after birth, we had our exit interview with our nurse in charge, wrapped baby up and buckled her into our inspected car seat, and gingerly drove back to our apartment and began the awe-some process of becoming full time parents.

She is lovely. (She) is made in God’s image. She is a letter from God that says, “I love you.” As I began jotting down notes for today late at night, she was lying first on my shoulder, then on my lap, then on the bed between (her mother) and I. Her touch is wonderful. Her face testifies to God’s glory.”¹¹

Unlike prenatal diagnosis, that might be used by a couple to prepare for child that has a genetic disease, preimplantation genetic diagnosis is likely to result in a decisions to exclude from implantation ANY embryo that has a suspected genetic disease or trait that might lead to disease in later generations. In this respect, preimplantation diagnosis, even more than prenatal diagnosis is a eugenics practice. By excluding individuals that might live with genetic diseases for many years, PGD is a form of negative

eugenics. The designer baby wherein “positive” characteristics are selected for is not yet here, but it is a short step away.

PGD promotes both genetic discrimination and more IVF procedures

If we fail to pass legislation to prohibit all forms of genetic discrimination, parents may feel even more pressure not to have children with known genetic diseases. In these cases, they may choose to have IVF combined with PGD to avoid having a child with “avoidable” genetic diseases. If that happens, the brave new world of free market eugenics will have arrived.

Some argue that PGD should be a standard part of IVF practice. PGD is now performed routinely at one of the world's leading IVF clinics, the Reproductive Genetics Institute in Chicago. "It should be done for every IVF cycle, in my view," says Yury Verlinsky, the institute's director. "It doubles or triples the implantation rate, while decreasing dramatically the miscarriage rate." The overall effect, says Verlinsky, is to more than double the average success rate per IVF cycle, so that couples have a greater chance of conceiving a child and to do so sooner.¹²

PGD is still an experimental procedure. We do not know what long term health damage is caused to the early embryo as a result of removing one of its cells for genetic analysis. Furthermore, it requires a woman to use IVF, burdensome and risky procedure in order to have a child. Hormonal treatments required for egg extraction have caused long-term health problems in women. Low implantation rates and the high costs of the procedure¹³ encourage fertility specialists to implant multiple embryos at the same time, resulting in high rates of multiple births. IVF infants moreover have twice the risk of major

birth defects than those conceived naturally. Ironically, by encouraging more women to undergo IVF as a strategy to avoid birth defects, the fertilization industry may be producing more birth defects.

Nonetheless, fertility clinics are promoting PGD for more than just the most awful birth defects.

Mohammed Taranissi, who runs the Assisted Reproduction and Gynaecology Centre in London, says that the industry is considering promoting other kinds of PGD even more. It is possible to test embryos for the genes that will cause certain "late onset" diseases, such as a form of Alzheimer's, which can occur in middle age and some cancers. Doctors could identify and select embryos that would have a healthy childhood and youth, but are destined to die prematurely. "Is this something that we should do? That to me is a very important issue," said Mr. Taranissi.¹⁴

If IVF becomes still more common and more health insurers begin paying for IVF, the combination of IVF and PGD will likely mean the exclusion from the genetic pool of families having IVF any of the genes that we are able to test for.

The absence of any real federal regulation in this area will make it likely that parents will have to make difficult decisions with little guidance. There are only about 1000 genetic counselors in the entire country, too few to effectively counsel an increased number of families seeking to use genetic testing. Moreover, only three states currently license genetic counselors and many health plans have dropped coverage for genetic counseling. Without independent counseling, the very people that have a financial interest in testing embryos will be advising couples on which embryos should be kept.

The New Eugenics as a form of “Cold Evil”

The fertilization industry has become like many of our other massive corporate and government bureaucracies wherein evil no longer requires evil people to purvey it. We are witnessing the “technification” of evil. Unfortunately, we have utterly failed to register the appropriate recognition and abhorrence of this new form of institutional evil brought about through our economic and technological systems. The tragic result of this failure is that this technological “cold” evil flourishes. If a totalitarian state were to propose eliminating all of its differently abled residents, we would rightly denounce that as the “hot” evil of genocide. If our society embarks on technological strategy of eliminating its future disabled members through a free-market technology should we be silent in the face of this “cold” evil of eugenics?

Recommendations for Regulatory Guidelines for PGD:

Limit genetic testing of embryos to those conditions that result in early and painful death of children, such as anencephaly, Tay Sachs, Lech Nyan’s Disease.

Prohibit negative eugenics in the case of all other genetic conditions.

Prohibit the use of PGD for selecting for non-disease characteristics such as height, weight, intelligence, personality traits, behavior or gender.

Implement a complete ban on the genetic modification of human embryos, including the introduction of synthetic genes or chromosomes.

¹ Aron Zitner, "A girl or a boy, you pick," Los Angeles Times, July 23, 2002, A1

² American Society of Reproductive Medicine, 1999, "Sex selection and preimplantation genetic diagnosis," Fertility and Sterility 72(4):595-598

³ Edwards speaking at European Society of Human Reproduction and Embryology as reported in Metro, July 5, 1999

⁴ Email from peopleagainsteugenics@hotmail.com on September 30, 2004

⁵ The Eugenics Society founded in 1907, changed its name to the Galton Institute in 1989.

⁶ Larry Thompson, "Cell Test Before Implant Helps Insure Healthy "Test-Tube" Baby," Washington Post, April 27, 1992, A1

⁷ The President's Council on Bioethics, Beyond Therapy: Biotechnology and the Pursuit of Happiness, October 2003, p.53

⁸ M.D. Macmillin and S.P. Parker at the American Society of Human Genetics, November 1, 1996

⁹ C. Siffel, A Correa, J Cragan, CJ Alverson, Prenatal diagnosis, pregnancy terminations and prevalence of Down syndrome in Atlanta. Birth Defects Res Part A Clinical Mol. Teratol. Sept. 2004; 70(9): 565-71.

¹⁰ The Impact of Prenatal Diagnosis on Down Syndrome, Anencephaly, and Spina Bifida, Gene Letter, March 1, 1997 in [www.genesage.com/professionals/geneletter/archives/theimpact](http://www.genesage.com/professionals/geneletter/archives/theimpact.html).html

¹¹ letter from Rev. Tim Atwater to Jaydee Hanson, Nov. 2, 2002

¹² Philip Hunter, Preimplantation Genetic Diagnosis: Studies begin to assess how screening might improve IVF success rates, The Scientist Jun. 21, 2004

¹³ M. Hansen, J.J. Kurinczuk, C. Brower, and S. Webb, "The risk of major birth defects after intracytoplasmic sperm injection and in vitro fertilization," New England Journal of Medicine (2002) 346:731-737.

¹⁴ Sarah Boseley, Are we on the genetic slippery slope? The Guardian, July 22, 2004