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New Report Presents Options for Oversight of Genetic Testing of Human Embryos

A new report by the Genetics and Public Policy Center at Johns Hopkins University outlines policy options to address the scientific and ethical challenges raised by genetic testing of human embryos. The report will be released at a public forum, “Custom Kids?” Genetic Testing of Embryos, to be held on January 8 in Washington, DC. At the forum, an independent panel including former House Speaker Newt Gingrich, Former Clinton White House Chief of Staff John Podesta and former National Institutes of Health Director Bernadine Healy will discuss the issues raised by genetic testing of embryos.

“New biomedical technologies have a tendency to sneak up on us”, said Kathy Hudson, Director of the Genetics and Public Policy Center. “This report and the Policy Forum are tools to catalyze broad public discussion about this profound use of genetic testing and aid decisionmakers as they consider what policies can best keep pace with the rapid advances in reproductive genetics” she said.

The confluence of advances in human genetics and reproductive science has resulted in the ability to perform genetic tests on embryos produced by in vitro fertilization. This type of testing, known as preimplantation genetic diagnosis, involves the removal of one or two cells from the fertilized egg or embryo and analysis of the genetic material. Test results are then used to select the embryos to transfer to a woman’s womb to initiate a pregnancy.

Preimplantation genetic diagnosis (PGD) is used currently by families seeking to have a child free from a specific inherited genetic disease or, less often, to have a child with specific genetic characteristics. By testing embryos before a pregnancy has begun, PGD can reduce the need to terminate a pregnancy in which a fetus is found to have a genetic mutation. PGD has been used to test for dozens of inherited diseases, to select embryos that will be a matched tissue donor for an ailing sibling and to select embryos based on sex.

PGD raises a number of scientific, ethical and policy issues. First, there are questions about the safety of the in vitro fertilization and embryo manipulation required for PGD and about the accuracy of the genetic tests that are used. Second, some find PGD, or its uses, morally unacceptable because it involves the creation, selection and destruction of human embryos. Third, there are questions of equity: many cannot afford PGD and it is not clear whether and to what extent health insurers will cover it. Finally, there are broad ethical questions about the impact of PGD on family relationships, people living with disabilities, and society as a whole.

The Center's report, Preimplantation Genetic Diagnosis: A Discussion of Challenges, Concerns, and Preliminary Policy Options Related to the Genetic Testing of Human Embryos, details the concerns in each of these areas and presents an array of possible policy options. These options include leaving decisions about PGD to individuals and their health care providers, government restrictions on PGD's use and availability, voluntary regulation by professional groups, and an outright ban on PGD.

PGD sits at the intersection of two technologies with a confusing regulatory status: assisted reproduction and genetic testing. In the United States oversight of assisted reproductive technologies (ART) has been left primarily in the hands of the individual physicians and there is no uniform and comprehensive system to assure the accuracy and reliability of new genetic tests before they are offered in the clinic. Although there have been calls for heightened oversight of PGD, this report is the first to outline the full range of policy alternatives and consider the potential effects, good and bad, of distinctly different choices.

The report is designed to catalyze informed public discussion about PGD, its implications and what, if any, policy process should be put in place to guide the development and use of this potent technology. Over the coming months, the Center will organize meetings across the country to discuss PGD and actively seek out the informed attitudes and policy preferences of a representative sample of Americans. The Center will also convene meetings of stakeholders and experts in order to gain their feedback and input. The Center will then use input from all these sources to refine our PGD policy options and issue a complete set of options and public opinion data for consideration by policy makers.

The Center does not advocate for or against preimplantation genetic diagnosis or a particular policy approach. Instead, the Center is committed to providing objective information and analysis and encouraging an informed dialogue among a diverse array of interests. The goal is to ensure that policy decisions, even decisions to maintain the status quo, have been undertaken with a clear-eyed understanding of their potential impact.

In developing the options, the Center was aided by its Reproductive Genetics Advisory Committee.

To register to attend the public forum “Custom Kids?” Genetic Testing of Embryos, to be held January 8, 2004, in Washington, DC, go to www.dnapolicy.org. The [report](#) will be available online January 8.

The Genetics and Public Policy Center is a part of the Phoebe R. Berman Bioethics Institute at Johns Hopkins University and is funded by The Pew Charitable Trusts. The mission of the Genetics and Public Policy Center is to create the environment and the tools needed by decision makers in both the private and public sectors to carefully consider and respond to the challenges and opportunities that arise from scientific advances in genetics.

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