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This Editorial Is Not About Designer Babies

A procedure called mitochondrial replacement therapy could eliminate devastating diseases. It would not enable parents to 'design' their children.

By The Editorial Board

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Leigh syndrome is a terrible disease. In the worst cases, it emerges shortly after birth and claims one major organ after another. Movement becomes difficult, and then impossible. A tracheotomy and feeding tube are often necessary by toddlerhood, and as the disease progresses, lungs frequently have to be suctioned manually. Most children with the condition die by the age of 5 or 6.

Leigh syndrome is one of hundreds of so-called mitochondrial diseases, which are caused by defects in the specialized cellular compartments — called mitochondria — that produce 90 percent of the body's energy. These disorders are rare; about 1,000 to 4,000 babies in the United States are born with one every year. But they are devastating. They can result in grave impairment of nearly any bodily system. They are largely untreatable, uniformly incurable and very difficult to screen for.

Some might also be preventable. Scientists have devised a procedure called mitochondrial replacement therapy (M.R.T.) that involves transplanting the nucleus of an affected egg — mitochondrial diseases are passed down from the mother's side — into an unaffected one whose nucleus has been removed. (The procedure is sometimes called "three-parent I.V.F." — in vitro fertilization — because mitochondria contain a minuscule amount of DNA; any resulting embryo would have mitochondrial DNA from the donor egg and nuclear DNA from each of its parents.)

After decades of careful study in petri dishes, flies, rodents and primates, M.R.T. is finally being tested in human clinical trials by doctors in Britain. (Officials there have yet to confirm any births.) In the United States, however, the procedure is effectively illegal.

In 2015, members of Congress quietly attached a two-sentence rider to an enormous appropriations bill, prohibiting the clinical use of any technology that would produce a genetically modified baby. Just two months later, a report from the National Academies of Science, Engineering and Medicine concluded that human trials of M.R.T. would be ethically permissible as long as several key safeguards were in place.

On Wednesday, the Petrie-Flom Center at Harvard Law School will host a round-table discussion, during which the scientists, ethicists and families at the center of this issue will make the first significant attempt to reconcile the federal ban with the federally commissioned report.

The participants will have much to discuss. For starters, proponents of M.R.T. have long held that the procedure should be exempted from the current prohibition, in part because it does not involve altering any genetic code. Defective mitochondria are swapped out for healthy ones, but mitochondrial DNA governs only a handful of basic cellular functions. It is separate from nuclear DNA, which helps determine individual traits like physical appearance, intelligence and personality. That means M.R.T. cannot be used to produce the genetically enhanced "designer babies" that so many people are concerned about.

That's not to say that the procedure is risk-free. There's no way to know how safe or effective M.R.T. is until doctors test it in humans. Clinical trials and the American regulatory apparatus were designed for exactly this purpose: to minimize risk without forgoing medical progress. But opponents of mitochondrial replacement therapy say that in this case, to proceed with such trials would be to subject future humans to an experiment that they are powerless to oppose.

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Though that's true, the same might be said of any birth, whether it's assisted by technology or not. New life is always a risky proposition in which the life itself has no say. And parents have always tried to tip the odds toward success with deliberate actions — from prenatal nutrition to choice of school district — that can echo down through generations.

Some members of Congress have indicated that the 2015 clinical ban could be lifted — or amended to exclude M.R.T. — once such ethical questions are resolved. But they've already reauthorized it three times without any further public discussion.

They might look to their British counterparts for a template on moving forward. Before officials in the United Kingdom approved mitochondrial replacement therapy, they held multiple parliamentary debates on the issue. They also hosted public workshops and

conducted in-person interviews and surveys that thousands of citizens participated in. When it became clear that there was broad support for moving forward, the British government established protocols for licensing clinics that wanted to try the procedure, and for monitoring the health of any resulting children.

There's no telling how things will play out in the United States. When the Food and Drug Administration held a forum on M.R.T. in 2014, the agency received hundreds of letters opposing the idea; but a good portion of those letters were form emails, and many of them indicated a poor understanding of mitochondrial DNA and of the replacement therapies in question. Surveys have consistently shown that most Americans support the use of technology that modifies the human genome, as long as it's to eliminate diseases.

The coming round table offers a good start to a long-overdue public dialogue. The group's conclusions about if, when and how to proceed with human trials of M.R.T. are not foregone. But one hopes that as they talk, the nation's leaders will listen.

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