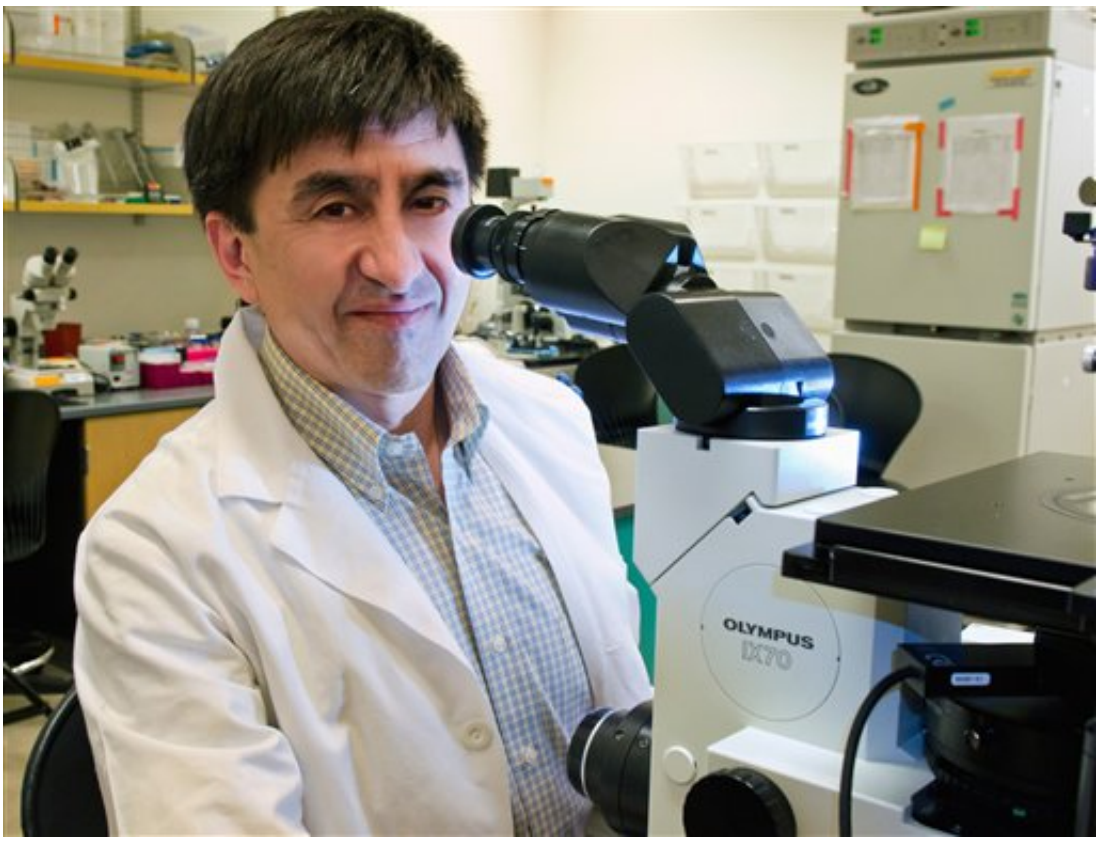
Medical Xpress

Report: It's ethical to test embryos from DNA of 3 people (Update)

February 3 2016, byLauran Neergaard



This photo provided by Oregon Health & Science University Photography shows Dr. Shoukhrat Mitalipov of the Oregon Health & Science University in Portland, Ore. Mitalipov hopes to test a technique that will use the DNA of three people, one man and two women, to create embryos, in the quest to prevent mothers from passing debilitating genetic diseases to their babies. (Oregon Health & Science University Photography via AP)

It's ethical to test a provocative new fertility technique that would prevent mothers from passing on rare but devastating diseases by creating embryos from the DNA of three people—dad, mom and an egg donor—advisers to the government said Wednesday.

But don't expect studies to begin anytime soon. It's not clear that such research can overcome political hurdles.

At issue is a kind of DNA that children can inherit only from their mother: genes that are inside the mitochondria, the energy factories in cells. Britain last year became the first country to approve creation of embryos that swap a mother's defective mitochondrial DNA with healthy genetic material from a donor egg.

The Food and Drug Administration has been considering whether to allow that replacement technique to be tested in the U.S. But it's controversial, in part because such alterations could be passed to future generations.

In a report requested by the FDA, the Institute of Medicine said Wednesday that it is ethical to do such research if initial experiments follow certain strict safety steps. They must target women at high risk of passing on a severe disease, and in the first attempts at pregnancy researchers should implant only male embryos. That's because when they grow up, those men couldn't pass on mitochondrial alterations to their own children.

Such research won't happen this year. While the FDA said it would be "carefully reviewing the report and recommendations," it noted that when Congress passed the agency's 2016 budget, it prohibited using any of the money to review applications involving inheritable genetic modification of embryos.

Jeffrey Kahn, a bioethicist at Johns Hopkins University who led the Institute of Medicine panel, said, "It is ethically acceptable to go forward, but go slowly and with great caution."

"Mitochondrial DNA disease can be extremely devastating, and for the women who are at risk of passing it on to their children, they have no other option by which to pursue having a child that's genetically related to them," he said.

The genes that give us our hair and eye color, our height and other family traits—and some common diseases such as cancer—come from DNA in the nucleus of cells, the kind we inherit from both mom and dad.

But only mothers pass on mitochondrial DNA, to both daughters and sons. It encodes a mere 37 genes, but defects can leave cells without enough energy and can lead to blindness, seizures, muscle degeneration, developmental disorders, even death. Severity varies widely, and researchers estimate 1 in 5,000 children may inherit some degree of mitochondrial disease.

"It's unlikely we'll find any cure once the child is born already with these mutations," said Dr. Shoukhrat Mitalipov of Oregon Health & Sciences University, who produced five healthy monkeys using the technique and approached FDA about starting human studies. "The best way is to prevent it."

Amy Hall of Boulder, Colorado, didn't know she carried such a mutation when her now 4-year-old daughter Nina was born. As a toddler, Nina began losing the ability to talk, eat, even sit up unassisted, and eventually was diagnosed with a deadly mitochondrial condition called Leigh's disease.

"Part of you dies when you figure out your child is dying, and then you can't continue your family," Hall said. "If there's technology available, which now there is, we should be able to utilize it."

It's a twist on regular in vitro fertilization: Remove the nucleus from a donor egg with healthy mitochondria. Take the nucleus from a prospective mother's egg and stick it in the prepared donor egg. After fertilization, the resulting embryo has nucleus DNA from mom and dad but mitochondrial DNA from the egg donor.

Critics have argued that the first such births would have to be tracked for decades to be sure they're really healthy, and that families could try adoption or standard IVF with a donated egg instead. And they say it crosses a fundamental scientific boundary by altering what's called the germline—eggs, sperm or embryos—in a way that could affect future generations.

"It is reckless to proceed with this form of germline modification," said Marcy Darnovsky of the Center for Genetics and Society, an advocacy group.

But the IOM panel argued that restricting initial pregnancies to sons takes away that concern. "This ensures that if there are adverse events, they will not be reverberating down the generations," said bioethicist R. Alta Charo of the University of Wisconsin at Madison.

"It's safer to do that," agreed Dr. Michio Hirano, a neurologist at Columbia University Medical Center who has patients ask about the technique. "The problem is, we're kicking the can down the street a little bit," as far as learning whether daughters, too, would benefit.