



# Miller School Expert Co-authors New Ethics Guidelines for Gene Editing

On August 3, *The American Journal of Human Genetics* published the American Society for Human Genetics' policy statement on germline gene editing in humans. It recommends against gene editing that culminates in human pregnancy, supports publicly funded in vitro research into its potential clinical applications, and outlines scientific and societal steps necessary before implementation of these clinical applications is considered. The policy statement was developed by a task force of representatives from 11 organizations with genetics expertise, including the University of Miami Miller School of Medicine.



The science of gene editing has been advancing more rapidly than have ethical guidelines for its use, say experts.

Representing the Miller School on the task force was Rosario Isasi, J.D., M.P.H., a bioethicist and lawyer whose work focuses on the regulation of human genetic technologies.



Isasi, who joined the Miller School faculty in 2016 as a research assistant professor, holds appointments in the Dr. John T. Macdonald Foundation Department of Human Genetics, the Institute for Bioethics and Health Policy, the John P. Hussman Institute for Human Genomics, and the Interdisciplinary Stem Cell Institute. She has built an international reputation as a scholar with particular expertise in the area of comparative law and ethics regarding genomics and regenerative medicine.

“It is crucial that we get the ethics of gene editing right,” said Kenneth W. Goodman, Ph.D., director of the Institute for Bioethics and Health Policy. “This statement will shape policy, prevent abuses and foster progress. Professor Isasi gives UM’s bioethics and genetics teams a seat at this very important table.”

We asked Isasi to discuss the policy statement and its broad implications.

### **What is gene editing?**

Gene editing is a technique that enables targeted changes – editing, adding, replacing or modifying – to the DNA of a cell or an organism. There are different methods, but the procedure involves using an enzyme to cut the specific DNA sequence, and then repairing it by adding or replacing the deleted sequence.

### **What are the promises of gene editing?**

The biggest promise is the ability to “rewrite” the code of life – our DNA. Gene editing holds great promises, if safe and effective. It could give us a better understanding of genetic diseases in order to develop therapies – such as eradicating or correcting genes that cause inherited diseases – and even curing or eliminating them.



### **What are the concerns about gene editing?**

The main concerns are misuse of the technology and engaging in premature applications before we know they are safe and effective. Should we, for example, be trying to enhance certain traits, such as intelligence, to create designer humans? And what might be the result of passing these changes on to subsequent generations?

### **How real are these concerns?**

Some of the concerns are very real, because the science of gene editing has been advancing more rapidly than have ethical guidelines for its use. There is a growing sentiment for the need for scientific and ethical guidance. That is why we wrote the policy statement now. We have the fundamental human right to benefit from scientific progress and its applications, but we also have a duty to ensure that progress is achieved responsibly, reflecting our social and moral values as the human community. Policy statements by professional organizations are valuable because they set a precedent.

### **What comes next?**

We hope to continue encouraging societal debate regarding ethical guidance of scientific progress. This will not be an easy task, as advances in gene editing applications will continue to raise complex scientific, ethical and policy concerns.