

Human Rights and Human Gene Editing Webinar
Thursday, October 4, 2018
Transcript

NOTE: This transcript has been edited for clarity.

KATIE HASSON

Welcome to today's webinar on gene editing and human rights. I'm Katie Hasson, Program Director at the Center for Genetics and Society. We'll start the video in just a minute. I'll start off by describing the slide on the screen for those on the phone and anyone with a vision impairment. The slide has a blue geometric background with multi-colored DNA strands. At the top is the webinar title, "Human Rights and Human Gene Editing" and today's date, October 4th, 2018. The slide shows the photos, names, and affiliations of our featured speakers, Alicia Ely Yamin and Roberto Andorno.

You'll also find the hash tag we'll use for joining in the conversation on Twitter. #geneeditinghumanrights. To the right of the image area are two boxes, one labeled Q&A and the other labeled chat. We invite you to type your questions and comments at any time throughout the hour in either place. Submissions in the Q&A box go just to the moderator and speakers. The chat box will be visible to all participants. You can also use the chat box to ask about any technical issues. Below the image area is the live captioning box. Let me take this opportunity to thank our captioner, Shanna Baker.

This event is being recorded. The recording and transcript will be available on the websites of the two host organizations and on CGS' YouTube channel.

Next, I'd like to introduce the host and cosponsors of today's webinar, OpenGlobalRights and Center for Genetics and Society or CGS. This next slide continues the DNA strands on a blue background with the CGS and OpenGlobalRights logos at the bottom. OpenGlobalRights is a global, multi-lingual online forum for debating critical human rights issues. They publish short op-ed style articles by scholars and activists in all corners of the globe. Their website is openglobalrights.org.

The Center for Genetics and Society and is a public interest organization working to bring social justice and human rights perspectives to the social challenges raised by human genetic and assistive reproductive technologies. Their website is geneticsandsociety.org.

Today's conversation explores the intersection of human rights with techniques used to alter the human genome. The recent development of CRISPR, a molecular tool that allows DNA to be altered more precisely and inexpensively than previous techniques, has sped up the pace of scientific developments. This is a critical moment for public engagement and deliberation about the potential social consequences of gene editing, particularly given our current context of growing nationalism, populism, and associated threats to human rights in many parts of the world.

For more background, three resources are linked to aqua ovals on this titled: “What is Gene editing?” and “Reproductive Gene Editing Imperils Universal Human Rights.”

Now I’d like to briefly go over a few key points that will be important for the discussion that follows. First, it’s important to distinguish between two uses of human gene editing: somatic gene editing, or gene therapy, can be used to develop treatments for patients – for example, altering blood cells using CRISPR in order to treat sickle cell disease. Gene therapies hold real medical promise; as with other medical innovations, we need to ensure they are safe, effective, and not prohibitively expensive.

A very different use of human gene editing, often referred to as heritable or germline gene editing, is the one we’ll focus on today. It would alter genes in eggs, sperm, or early embryos, and these changes would be passed down to offspring and future generations. Often justified as a way to prevent passing on serious genetic diseases, it does not provide advantages over the embryo screening techniques we already use.

Germline gene editing poses not only serious safety risks but also a range of unacceptable societal consequences, notably the potential to increase already vast social inequalities and introduce new ones. We hope the webinar today will promote discussion of these societal consequences, highlighting the necessity of a human rights perspective on human gene editing.

And now I’d like to hand things over to our moderator, David Petrasek, Senior Editor at OpenGlobalRights and Associate Professor of Public and International Affairs at University of Ottawa, who will introduce you to today’s featured speakers.

DAVID PETRASEK

Hello, and welcome to the webinar. I’m David Petrasek, Associate Professor at the University of Ottawa and Senior Editor at OpenGlobalRights. It’s a great pleasure to be with you today. I’ll moderate the discussion. I’ll briefly introduce our two panelists and then ask each of them to make some short introductory remarks. We’ll follow this with a question and answer session. I hope those of you following the webcast will send in your questions.

Our panelists today are professors Alicia Ely Yamin and Roberto Andorno. You have links, I think, to their full biographies. Alicia is Visiting Professor of Law at the Georgetown University Law Centre and the Program director there of the health and human rights initiative. She has held posts at Harvard and Colombia universities, and has worked as an activist, researcher and scholar at the intersection of health and human rights issues for over 20 years, and indeed is widely regarded as one of the leading experts in that field.

Roberto is Associate Professor at the Faculty of Law, at the University of Zurich, and a Research Associate at the university's Institute of Biomedical Ethics. He has lectured in bioethics at universities in Argentina, Germany and Switzerland, and is widely published, including his book Principles of International Bio-law – Seeking common ground at the intersection of bioethics and human rights. Roberto was a Member of the UNESCO International Bioethics Committee for several years, and a member of its drafting group which prepared the 2005 Universal Declaration on Bioethics and Human Rights.

A very big thank you to both of you for joining us today. I'll begin by asking both of you to make short remarks by way of introduction to our topic, gene editing and human rights. Roberto, let's begin with you.

ROBERTO ANDORNO

Thank you for the kind invitation. The point I would like to stress here is that by the end of the 1990s, most bioethicists, governments and international organizations had agreed that it would be wrong to introduce inheritable alterations into the genome of human beings. This was regarded as a red line that should never be crossed. I think it's important to remind us of this because it's often forgotten, even if this took place only 20 years ago. At the time, there was a serious concern for the integrity of future generations. There was a concern about the risk of causing irreversible harm to future people and there was disquiet about the commodification of children, about the risk of opening the door to a new and much more radical form of eugenics than those we have known in the past.

I would say the underlining idea of these agreements was that we don't have the right to design our descendants according to our wishes and our preferences, even if we have the best of intentions. I mean, even if the gene alterations were initially focused on improving health and preventing the transmission of diseases, the risk is too high that we will then gradually start to make genetic changes for the non-therapeutic design of our children.

Also, as we know, the boundaries between therapy and enhancement are very difficult to define. Actually, the use of the term "therapy" is misleading here in my opinion. Because we're not dealing with existing patients who are sick and can be treated, but with future people, potential people, with people who do not exist yet. So this is a totally different situation than with any therapy.

So we are dealing more with wishes than with treating a sick person. In fact, gene editing does nothing to cure anyone, but only aims to satisfy the wish of potential parents to have a genetically related child, a child who has been genetically modified. All this is just to stress that for various reasons, germline alterations were regarded 20 years ago as morally wrong. Even from a merely utilitarian perspective this procedure was regarded as having in the long run a much greater potential to do harm than good.

I will now say a few words about the two main international documents dealing with this topic. One is the Universal Declaration of the Human Genome and Human Rights adopted by unanimity by representatives of virtually all countries gathered at the UNESCO headquarters in Paris in 1997. The declaration, first of all, labels the human genome as “the heritage of humanity” (Article 1) and therefore as something that deserves to be protected against manipulations and be preserved for future generations. And second, it stipulates that germline alterations can be regarded as “contrary to human dignity” (Article 24).

In 1998, the General Assembly of United Nations formally endorsed this Declaration.

The other important document is the European Convention on Human Rights and Biomedicine (also known as the Oviedo Convention), which prohibits interventions that “aim to introduce any modifications in the genome of any descendants” (Article 13). So the distinction is made between somatic and germline modification. While the first ones are permitted, the second ones are prohibited. I must mention that the Oviedo Convention is today binding for 29 European States.

Well, there are many other domestic laws, there are other international recommendations, regulations and domestic laws in several countries that also prohibit germline alterations. But the main point I wanted to emphasize is this: the international community has already agreed on the need to prevent alteration of the human germline. These agreements are still valid. In other words, the international community is still committed to prevent alterations of the human germline.

The fact that a new technique like CRISPR-Cas9 makes it easier and cheaper to cut and paste genes does not change anything about the ethical question. On the contrary, I would argue that this new development makes it more urgent than ever to adopt appropriate measures to enforce those international agreements and prevent the creation of genetically modified human beings.

To conclude, I will say we are faced here with a really crucial issue for us and for our descendants. It's not just a bioethical topic among others. And I think we'll need great wisdom to address this issue and take appropriate measures. We need really a long-term perspective to take into account the common good of humankind, not just immediate individual wishes. So the challenge cannot be greater, and I hope we'll have the wisdom to deal with this. Thank you.

DAVID PETRASEK:

Thank you, Roberto. Alicia?

ALICIA ELY YAMIN

Thanks very much, David. I want to pick up where Roberto left off, and take a step back and make some basic points about how we would see this from a human rights perspective. Because not everybody may be steeped in human rights. And I want

to emphasize first that there is no inherent conflict, as both Roberto and Katie suggested, between technological innovation and human rights. But the incorporation of any kind of innovation, including genetic therapies, has inexorably moral and ethical interventions. For example, because we can print a 3D gun on a printer does not necessarily mean that that's something that our society wants to allow that is consistent with commitments.

And in this area, especially technological innovation has far outstripped laws and political institutions that we use to make those judgments about what is socially and morally appropriate. So the three points I want to make are about how we understand human identity in human rights, about how we understand health and health systems in particular, and then the core commitments to equality and dignity which are fundamental in human rights.

So first point is that, in human rights, the axes of our identity have both biological and social dimensions. So race, for example, is a social construct on the one hand, but discrimination in law and practice against people with different skin colors is also a very real factor in constraining people's life choices and chances. Similarly, sex differences are based on biological difference, which means that women and men have distinct reproductive capacities and needs, but gender is also a social construct which means that our aspirations, our identities, our capabilities are inexorably defined by power relations in society.

Likewise, disability has biological dimensions and social dimensions. What we define as disability is structured by different norms and context, as are the penalties imposed by certain biological disabilities, whether it's physical or intellectual or psychiatric. So in a human rights framework, discrimination against persons with disabilities is prohibited, but there are also measures to be taken so persons with disabilities can effectively enjoy their rights and participate fully in society. So in health, one example would be sign language interpretation, for example in health facilities.

The second point I want to make is about the right to health and health systems. There are lots of ways about thinking about health and it's not always as a right. But if we think about it as a right, as closely connected with human dignity, then it's not just something we buy and sell like any other commodity in the market. It's something that can't just be allocated according to how much money certain people have or don't have. So it's considered a fundamental matter of justice for which the State has an obligation to somehow level the playing field; not equalize every outcome, but level the playing field and, address or mitigate the natural inequalities that occur because health systems and other institutions are the ways in which we can mitigate or exacerbate natural inequalities.

So when health systems are based around rights, they require fair financing, fair priority settings so we all agree that everybody, including marginalized people, have a voice, have a say in what is included in health systems; and there needs to be

effective oversight and regulation by the State, including of the private sector and including of private companies that are marketing genetic tools.

But finally, the third thing I want to say is the core commitment to equal dignity in human rights. The Universal Declaration of Human Rights, the founding document, says we are born equal in dignity and rights. In human rights, equality has two dimensions. Formal equality, which means treating people who are similarly situated or have a similar condition, in the same way. So that, again, it's not a matter of whether somebody can pay for somebody, but similarly situated people should be treated the same way. And also a substantive dimension, in that people who need different things should have access to effectively enjoy their rights on an equal basis.

But it's also true that income inequalities and wealth inequalities affects people's chances to enjoy health, not just whether they are of a certain race or a certain gender, et cetera. So the social gradient itself in health is a major, major factor in how people can enjoy their lives and their well-being. And, as Roberto suggested, this isn't just about people living today. It's not just about whether the wealthy co-op the technology where poor people are really exponentially further behind the wealthy within and across countries, but it's also about future generations. And that's the part about dignity, the part about equal indignity, that human beings are capable of self-governance and, as a result of that, we have an ability to collectively deliberate about life plans, and we want to sustain that across generations. We want to allow future generations how best to decide how best to arrange their institutions and social orders to expand people's rights and human flourishing.

And I want to, in conclusion, quote a South African constitutional court justice, who himself was citing Ronald Dworkin, Albie Sachs, who said "If people are to retain self-consciousness and self-respect, that is the greatest achievement of our species, they will let neither science nor nature simply take its course, but will struggle to express in the laws they make as citizens and the choices they make as people, the best understanding they can reach of why human life is sacred. And the proper place of freedom in its dominion."

DAVID PETRASEK

Thank you, Alicia. Thank you to both of you for those introductions.

Maybe I'll just kick off with a few questions. I would encourage those who are following the webcast to post your questions in either the Q&A or the chat box and we'll select those and put them to our two panelists.

Roberto, you spoke at the very beginning about a consensus in these two documents, the UNESCO document and the Council of Europe document, which seem to clearly prohibit germline modification. I take it from your remarks that this consensus is unraveling. We read about research that actually a number of countries have proceeded in this area. Given your experience and participation in some of the debates back then, what would you say is the main reason for the unraveling of this consensus?

ROBERTO ANDORNO

I couldn't say the consensus is unraveling. So formally, these international agreements are still in force and, as far as I know, no government has withdrawn from them. So technically speaking, from a legal point of view, we still have this global consensus. What we have seen in recent years is just some groups of scientists doing these kinds of experiments. For instance, in China two years ago, a group of researchers reported having produced genetically modified embryos to make them resistant to the HIV virus. But I'm not sure this is done with the formal support of governments. Maybe there's a kind of *laissez faire* policy from some governments, but that's all for the moment...

DAVID PETRASEK

Just to follow up on that, the advancements we're talking about, this research you just mentioned, how likely is it actually going to lead to the real possibility of individuals actually having these treatments in the near future. Is this something that's facing us in a couple of years or something that's decades away?

ROBERTO ANDORNO

That's difficult for me to say. It's very likely that this will happen sooner or later and we'll have some genetically modified embryos and children. But I don't like the argument saying: "Well, why set limits if this will happen anyway?". I think this is a misleading argument because we know that things that are prohibited happen anyway. We have criminal laws that prohibit murder or rape and many other crimes, and they happen, of course, and we know that they will continue to happen. The goal of the law is not to make those crimes disappear, because that's impossible, but to reduce them to the minimum, to deter crime, that's the goal of the law. So to answer your question: I think this probably will happen, I don't know when. But this not a reason to withdraw or to abandon the commitment to prevent, to reduce this risk as far as possible.

DAVID PETRASEK

On that point, to Alicia, you spoke about the three ways in which you saw the human rights framework as directly relevant to this debate. Maybe speaking more in terms of the emotive power, the compelling nature of human rights, we've seen other health issues or issues that were defined solely as medical problems, HIV/AIDS, maternal mortality, we've seen how applying a human rights framework to those as dramatically changed the debate and, in fact, many would argue advanced efforts to address those problems. How do you see that human rights framework then potentially impacting on the research that Roberto is talking about and the kind of inevitability of this proceeding? What do you think the real power of human rights will be?

ALICIA ELY YAMIN

I think that we're just beginning to have these conversations. The way we talked about HIV really was completely transformed by turning it into a human rights issue and the right to health into a human rights issue. So I think that potentially, while I am in

complete agreement that if laws are broken, that doesn't undermine their legitimacy, I think that now is the time to raise consciousness and mobilize awareness in terms of human rights and equity and equal dignity of what this would mean among broad, broad constituencies. It could be something that could mobilize more law reform and certainly new norms and reactions to this technology.

DAVID PETRASEK

Just to follow up Alicia, you've spoken about equality and non-discrimination, but of course freedom is a key human right as well, and some might say the human rights framework, which supports individual freedom, may argue in favor of allowing germline modification, because an individual freely chooses to undergo that. The question then is about a clash of rights. On the one hand, equality and non-discrimination, and on the other individual freedom. Do you see that as a clash of rights? And if so, why privilege non-discrimination and equality over freedom in this debate?

ALICIA ELY YAMIN

Well, the key issue here is that it's not, as was already stated, it's not the individual's decisional autonomy about treating an already existing condition or disease or, et cetera. This is about changing a germline that could affect generations to come. And we don't have that kind of freedom in human rights precisely because it would conflict with the idea of sustaining the conditions for other people to make decisions.

DAVID PETRASEK

Roberto do you want to comment on that?

ROBERTO ANDORNO

I would say most of these documents adopt a human rights approach. Even in the title you'll see a reference to human rights. Still, I wonder how we can apply the traditional notion of human rights to future people. That's a very tricky legal, philosophical question. I find interesting that the UNESCO Declaration on the human genome and human rights, when it refers to germline, mentions the notion of human dignity, not human rights. I think the idea is that these alterations in the human germline are not so much seen as contrary to human rights because these people don't exist yet, but it is the dignity of humankind as such which is at stake here. So the integrity of future human beings, of the human species, is jeopardized by this technology. So we need probably new legal concepts to protect this integrity of our own species. There are some strategies that have been advanced. Professor George Annas from Boston, for instance, has proposed to extend the notion of crimes against humanity to this kind of practice; the concept of "heritage of humanity" applicable to the human genome is another new concept.

DAVID PETRASEK

There's questions coming in from people who are listening in, and I'm going to go to those very soon.

I just have one more question, Roberto, for you. You're speaking here about the potential need to expand our frameworks to grasp this. But there are two frameworks at play here, the bioethics framework and the human rights framework. If you like, two ethical, moral frameworks. Do you see contradiction between the two frameworks, are both aligned in saying that germline modification should be prohibited or are there some distinctions between those two frameworks?

ROBERTO ANDORNO

Well, in general, I would say bioethics and human rights overlap to some extent, which is not surprising because both tend to protect similar basic human interests, life, integrity, privacy, etcetera. Now, they have a different status. Bioethics or ethics is not binding by itself. It's just the result of deliberation and practical reasoning, while law is by definition composed by binding norms. But it's difficult to put a clear limit between both. Generally, law is regarded as the minimum of ethics that we need in society. I would say biomedical law is to some extent the minimum of bioethics we need in society. But a clear limit or clear distinction is very difficult.

DAVID PETRASEK

I'm going to put out some questions that have come in from people who are listening in.

A question asks about disabilities: some people believe that genetic differences we call disabilities are valuable and should not be eliminated from the human genome. They say that these mutations are evolutions and a way of preparing for the unexpected and prepare all of us for the inevitable disabilities we suffer as we age. What are your thoughts on the elimination of disability? Should we allow for the elimination of congenital blindness or deafness, for example?

Roberto, you might want to start, but Alicia, feel free to jump in.

ROBERTO ANDORNO

Well, of course, the purpose of medicine has always been the fight against disease. There's no doubt about that. If we could reduce or even eliminate disease from earth, of course that would be great. The problem here is that we're not dealing with existing patients who can be treated. We're talking about germline alterations. It would be different with somatic gene therapy. But in the case of germline, the question is totally different. It means creating people with particular features that we think would be good for them, good for the future of humanity, but I'm afraid we may not be able to foresee all the harmful effects that the supposed cure will have, and we can become aware of them only after several generations, when it is too late to do something about this. More fundamentally, this would imply exerting disproportionate, excessive power over future people. The German philosopher Jürgen Habermas, for instance, has strongly argued against this possibility, which would be a kind of intergenerational tyranny. We have to ensure equality not only between individuals, but also between generations.

DAVID PETRASEK

Alicia, do you have a comment on that?

ALICIA ELY YAMIN

I think I would just complement what he said. It's not just Habermas, I was referring to Amartya Sen, those philosophers who argue that something that makes human beings unique is our capacity to reason and have conscience, believe that we should sustain that ability for future generations and not arrogate that power to ourselves. So I think that's really all I would add. There are a lot of questions in the queue. I can comment later on other things.

DAVID PETRASEK

There's a couple of questions on this point, phrased like this: Aren't parents always making decisions about future generations when they terminate a pregnancy? How does that differ from other ways of deciding the state of future generations as in germline editing? Alicia?

ALICIA ELY YAMIN

Sure. I anticipated that this question might come up. There's a very big distinction between this and the issues involved in abortion rights. Forcing a woman to carry a fetus to term is an obligation on that woman that is unparalleled in our society to support another life within her own body. Those kinds of negotiations and choices are different, not just in degree, but also in kind, from choices about designing future babies where you're not looking at one fetus inside your body and specific characteristics that it may or may not have.

DAVID PETRASEK

Roberto?

ROBERTO ANDORNO

I agree with Alicia. So it's a totally different situation. In one case, in the debate about abortion, we are confronted with a conflict between the mother, the pregnant woman, and the unborn baby, and we have to balance these two interests. In germline alteration, we have future people. In reality, there's no absolute need to create anyone. It's a totally different situation. So there's no conflict at all. Of course, the interest of prospective parents to have a child who's genetically related to them, and prevent the transmission of serious diseases is understandable, but this is not enough to justify this practice. So we have to balance these individual wishes with the general common good of society and future generations because a wish is not itself a right.

ALICIA ELY YAMIN

We're talking about germline editing, not other kinds of editing where it would be possible to affect an embryo already in existence.

DAVID PETRASEK

There's a very brief question here about whether the 1989 UN Convention on the Rights of the Child adds anything to this debate. I suppose, Alicia, you said it supports the right to health. Is there anything else you would like to add on that?

ALICIA ELY YAMIN

I think actually the conventions that Roberto has cited are more specifically addressed to this, and this is a topic that will invariably come up increasingly in human rights in more sort of conventional human rights law.

ROBERTO ANDORNO

The Convention of the Rights of the Child does not have any provision related to germline alterations, but it includes the principle of the best interest of the child, which maybe could be interpreted or used with the purpose of preventing psychological or physical harm to future children.

DAVID PETRASEK

Roberto, there was a comment earlier when you were speaking about the researchers who are active in this field. We spoke about a consensus amongst governments. What degree of consensus is there amongst the scientific community, both in the bioethics and genetic fields, concerning the risks of germline modification? Are your concerns widely shared? Is there a minority view? Can you give us some sense of the discussion in these fields?

ROBERTO ANDORNO

It's hard to say where the majority of opinion among scientists is. There have been some reports over the last two years by academies of science and medicine from the U.S., from France, and also a report by the Nuffield Bioethics Council in the UK. They go more in the direction of authorizing germline interventions. But it's difficult to say if they are really representative of the whole worldwide scientific community. There have been also some recommendations or statements by scientists claiming that we have to introduce a moratorium on germline, and focus more on somatic gene therapy and not on germline because the risk is too high. I remember, for example, a paper in Nature with the title "Don't Edit the Human Germline" with a number of convincing arguments. But, again, it's difficult to say where the majority is.

DAVID PETRASEK

Someone's made an interesting suggestion, one of the people who's listening in; it's a question, but I think also a suggestion. Is there any role for the patent law system in this regard, perhaps prohibiting the grant of patents on inventions related to reproductive gene editing? Do either of you have a thought on that?

ROBERTO ANDORNO

I'm not an expert patent law. Your question is?

DAVID PETRASEK

Somebody is suggesting perhaps one way of putting a halt to research in this area is in fact by preventing the granting of patents in this area.

ROBERTO ANDORNO

Yes certainly. Well, in Europe, for instance, you cannot of course patent a genetically modified embryo. There are explicit norms on this. And to get a European Union research project approved, one of the conditions is also that it does not involve research on embryos.

DAVID PETRASEK

Alicia, I want to go back to something you said in the beginning. In your opening remarks, you spoke briefly about the right to health. In your previous work, you've written that it's more than about an individual right to health; in order to think about the right to health, we have to think about institutions and questions of power. I wonder, with that in mind, how you think those broader questions, those broader issues of the right to health points to, would impact on the gene editing debate.

ALICIA ELY YAMIN

Well, to be somewhat simplistic about it, there are many things in the world where we think that what is fair, means what we can pay for. So, I have no right to complain that I'm not going business class or that I don't have a Porsche or whatever because I can't pay for that. But there's certain things in life that are so closely related to what it means to be a human capable of living a life with dignity that we consider those things to be special, of special moral importance, and dependent upon institutional arrangements. And health in a human rights framework is one of those things because it is both the reflection of dignity and also necessary to live a life of dignity.

So if you think of health that way, then there needs to be some kind of equalization, some kind of intervention from the State, just as the State protects other rights in many ways. And that intervention can involve ensuring financing. It also requires—and this goes back to, I think, something that you were speaking to Roberto about—a broader inclusive legitimate democratic process. So these decisions are not to be taken by individual corporations getting patents or by small groups of scientists coming up with a declaration, but there needs to be broader democratic conversations about what the consequences could be, including from people who could be affected or who are marginalized in society. So I think the human rights perspective provides something of substance in terms of equality and not letting people who have a lot of money just buy whatever they want while other people are left behind, but also in terms of process and in equalizing the asymmetries of power in that process for decision-making as well.

DAVID PETRASEK

Thank you. There's another question that's come up. It's a big question. What's needed to resolve the germline debate globally and to determine what the majority and minority views might be? I suppose that's pointing to we have these two conventions; is there a need to bring them up to date, to have a protocol, or is there a need for some

kind of global gathering, a conference? What's the way forward to bring a common view on this?

ROBERTO ANDORNO

Well, first of all, I think we have to activate again the debate on this from the political scene, in the political domain. In the last year, we have mainly heard statements by scientists, many of whom are involved in this same practice. I am afraid there is an issue of conflicts of interest here. We need the involvement of governments, of international organizations, such as UNESCO, the World Health Organization, Human Rights Commission, etc. and try to discuss this again in the context of this new technique CRISPR/Cas9.

DAVID PETRASEK

Roberto, do you think giving your previous involvement with UNESCO, just to follow-up on that, do you think that's the right venue to proceed with this debate or perhaps it needs to come into something which has a broader, a more visible [scope]. I'm not suggesting UNESCO is invisible, but it certainly doesn't get the attention you would get through debates in the Human Rights Council or the UN General Assembly.

ROBERTO ANDORNO

It's not either/or. The advantage of UNESCO is that you have representatives of virtually all countries in the world, and UNESCO has a long tradition of philosophical debate at the intersection of human rights, ethics and science. So, I think it would be a good platform for that. And in fact, we don't have many other organizations dealing with these kinds of interdisciplinary issues.

ALICIA ELY YAMIN

David, can I just add something?

DAVID PETRASEK

Please do.

ALICIA ELY YAMIN

I don't think it's either/or, but I think UNESCO is insufficient. So I think it needs to be brought to broader audiences; and to be effective, legislation needs to be on the national level as well as these international conventions, and with intellectual property, it could be global as well. But I think it needs to be really brought not just to the Human Rights Council, but to schools and students and made part of a broader human rights conversation. Because it's not really on the radar screen yet. Many times in the past, there have been things, like HIV/AIDS, where people thought it was impossible to do what was then done, and things can be done when ordinary people mobilize.

DAVID PETRASEK

There's a question that's come up which often underlies human rights debates, and that's the idea of one set of views being imposed on another. The question is: Is it permitted or the responsibility of one country to impose their views on human rights and

dignity on other countries? What if a society favors not a democratic process over, for example, a greater good or community-first argument? Alicia, would you have a thought on that?

ALICIA ELY YAMIN

The universal declaration of human rights talks about a social order and a global order in which everyone can realize these rights. So if you believe that being human means that each person has some dignity, that that identity is not constructed in autonomous isolation from society and community, but if you that believe human beings have dignity and capacity for self-governance and therefore rights, then there very clearly is a preference for democratic orders where power asymmetries are checked and the majority doesn't just rule or ride roughshod over minorities' rights or marginalized people's rights.

DAVID PETRASEK

Roberto, did you have a thought on that?

ROBERTO ANDORNO

Yes, it's true that international law is not strong enough. We don't have a global State. Probably we don't need a global State, but we don't have a global police. International law is always difficult to implement, not only in this domain. We have at the level of the United Nations the Security Council which can impose sanctions or take measures against States that do not respect these international agreements or human rights. But yes, we don't have any ideal, optimal solution at present.

DAVID PETRASEK

We only have a couple of minutes left. There's a few other questions, but unfortunately I'm not going to have time to go to them. I'm going to give each of you a chance, just in a minute or so, to have a last word on this, based on the discussion so far. Alicia, do you want to go first?

ALICIA ELY YAMIN

I'm really delighted. I feel privileged to be part of this conversation. And I hope this fosters a great deal of other conversations around, at schools and in human rights forums, because it is an issue that is very under-discussed in human rights, and I think it's a fundamental question of democracy as well. So I very much hope that this is the first conversation of many.

DAVID PETRASEK

Thank you. Roberto?

ROBERTO ANDORNO

I think it's important in this debate not to reduce the issues raised by germline to just a question of risk, or risk assessment in a very narrow technical sense. Because generally, these reports from scientific academies that I have mentioned tend to focus on the risk issue and they say: maybe in some years, we will be able to reduce the risk

of off-target effects and everything will be okay. But that's not the main point. I think what is at stake here is a much broader issue than simply the potential side effects of a new technique. The debate around germline alterations concerns the kind of society that we want for us and for our descendants. And I think we want to preserve a society in which people's features have not been predetermined by those who preceded them, a society in which children are not designed by their parents like mere commodities. So I think, ultimately, it's a matter of freedom that is at stake in this debate. Thank you.

DAVID PETRASEK

Thank you to both our panelists. I should apologize first off because there are questions that have come in that we haven't had time to address, but we only had an hour. As Alicia said, this is the beginning of a discussion, by no means the conclusion. I want to thank both of you for participating and for your thoughts and for putting forth ideas and also questions that we'll have to address in future discussions. I want to thank everyone who's been listening. And, again, apologies to those of you who posed questions that we didn't have time to reply to.

By way of closing, I think I would just say as we go off the screen, there will be a link that comes up and there will be an opportunity for those of you who have been listening, there's a survey, and there will be an opportunity for you to click on that and very briefly give us your thoughts on the webinar and how it's run and how it can be improved in the future. Thank you very much to everyone, and with that I'll close the discussion. Good-bye.