

# Genetic Justice From Start to Summit

## February 27, 2023

This two-part online CGS event centers social justice and human rights, presenting voices and perspectives from feminist, disability rights, reproductive rights and justice, racial justice, environmental, and human rights movements and scholars, who will question whether heritable genome editing has any place in a fair and inclusive future. The first day of the symposium included **Marcy Darnovsky** discussing the “History and context of the Summit process” and a panel conversation featuring **Dorothy Roberts, Rosemarie Garland-Thomson, and George Annas** and moderated by **Silvia Yee** on “The social justice case against heritable genome editing.” Live captions and transcript provided by Ellen and Lee of AI-Live [minimal edits made for clarity].

KATIE HASSON:

Welcome everyone, thank you so much for joining us on the first day of Genetic Justice from Start to Summit.

I am Katie Hasson, the Associate Director of CGS, I’m a white woman in my 40s with curly red hair. I’m wearing glasses, a green sweater, and a dark blue scarf with tiny silver stars on it.

We would like to acknowledge that CGS sits on the ancestral and un-ceded land of the Chochoenyospeaking Ohlone people. This land was and continues to be of great importance to the Muwekma Ohlone Tribe.

Our panels today and tomorrow will focus on heritable genome editing. That is, attempts to alter the genes and traits of future children and generations by using gene editing techniques like CRISPR to edit early embryos, sperm or eggs and produce a genetically modified child. Doing so has long been seen as crossing a red line. Heritable genome editing is prohibited in over 70 countries. It is opposed by many scientists, civil society advocates and much of the public because it is unsafe, with thin medical justification, and likely to lead to a new form of eugenics, exacerbating existing inequalities and creating new ones.

It is important to note that heritable genome editing is very different from the promising gene editing therapies being developed to treat existing patients with conditions like sickle cell disease. Somatic gene therapies raise important concerns about their sky-high costs and who will be able to access them, but they are much more widely supported than heritable genome editing, with its unacceptable safety and societal risks.

But there are advocates for pursuing heritable genome editing, and potential moves toward making it possible to do so in places like the UK. With consequential decisions and high-profile discussions, like next week’s Summit on Human Genome Editing, on the way it is a crucial time to have these conversations.

Some of you joining us today have been involved with these issues for years, decades even. For others, it may be brand new. We are glad you are all here, and we think each of you will find something new to engage with in the conversations we've put together. You'll hear more about the summit from our next speaker, but the conversation we want to have at this symposium is different than what we are expecting at the summit itself.

Instead of starting from questions about the science, or abstract bioethical discussions of risks and benefits, we want to start with a focus on social context and consequences, and with questions about how to build a just and inclusive future.

In 2021, CGS launched our Missing Voices Initiative to bring into the conversation on heritable genome editing the essential voices of civil society advocates and socially engaged scholars, committed to social justice and human rights. These voices are rarely sought out or heard, despite widespread agreement on the need for broad and inclusive public deliberations.

We insist that putting different voices at the forefront fundamentally changes the conversation. People who think and care deeply about the unjust effects of power structures, and are committed to changing them, are exactly the people who can see the dire consequences down the road if we introduce a powerful technology like heritable genome editing into a society rife with inequalities.

We have organized two Missing Voices webinars so far, which you can find on the CGS website and links to them are in the chat now. And the speakers you will hear over the next two days are members of our Missing Voices Working Group and Gender Justice and Disability Rights Coalition.

In today's sessions, you will hear a discussion of reasons to oppose heritable genome editing from the perspectives of racial justice, reproductive justice, disability rights and human rights. First we will start with background for understanding the summit process and its significance. For that, I'll turn things over to CGS cofounder and Executive Director, Marcy Darnovsky.

MARCY DARNOVSKY:

Thank you so much, Katie. And thank you in advance to the stellar speakers that we will hear from today and tomorrow. And thanks to everyone who is joining us. I am Marcy Darnovsky, as Katie said, I have long, silver brown hair and pale skin. I am wearing a maroon colored sweater over a light gray sweater. Trying to keep warm.

As many of you know, next week the national science academies of the US and the UK will cohost the Third International Summit on Human Genome Editing. This convening is part of a series of high-profile events that began in 2015. But that first summit meeting was not by any means the start of public and policy controversy about applying genetic modification to human reproduction.

For at least several decades before that, scientists, scholars, policymakers, writers, filmmakers, and advocates for human rights and social justice were aware that tools to genetically try to improve our offspring were on the horizon, as were temptations to use them.

Today, the genetic engineering tool we hear most about, is CRISPR. And that has brought the prospect of reproductive genetic modification much closer. CRISPR was developed during the first decade of the 21st century. And patents on it were filed and commercialization began by about 2012. In early 2015, a research team at Sun Yat-Sen University used CRISPR to alter the genes of human embryos. These were nonviable embryos in a lab dish, and the experiment actually revealed significant technical hurdles that have yet to be overcome, but the study was seen as crossing a line, a significant line, and word about it did spread quickly.

So in that year, the beginning of that year, March and April, two different commentaries, each co-authored by a group of prominent scientists, appeared in *Science* and in *Nature*. The titles of these two articles, actually laid out the controversy that continues to this day, and had preceded it, laid it out pretty clearly. The *Nature* article was titled “Don’t Edit the Human Germline.” The one in *Science* was called “A Prudent Path Forward for Genomic Engineering and Germline Gene Modification.”

These events really put the prospect of heritable genome editing into the public view, and all over the mainstream media. Numerous magazine covers featured blonde-haired, blue-eyed, pale-skinned so-called designer babies. And some magazines splashed the word “eugenics” in their headlines.

When this all happened in 2015, it followed years in which scores of countries had thought about these developments, anticipated them, and done so clearly enough that by 2015 they had already put in place policy prohibitions on heritable genome editing. That was not the case in the United States, at this time. In the United States, it was unclear how policy would be set, or who would be in charge of it.

So that was the moment when the US National Academy of Sciences and Medicine stepped in. The president of that organization went to Capitol Hill and testified at a congressional committee in June 2015. In essence, he told the elected officials there that they should not worry about it, that the scientists that he represented would take care of the issue, and the Academies announced what they called a major initiative to guide decision-making about heritable genome editing and said they would organize a summit and issue a report.

The advisory group for this initiative should have been, and was in fact a clue to what was coming. That advisory group included six of the authors of the *Science* article that called for a prudent path forward, and included none of the authors of the *Nature* article that argued for keeping germline modification off-limits.

So the National Academies and its advisory group went ahead. They organized a Summit that took place in December 2015. That first Summit was co-sponsored by the UK Royal Society and the Chinese Academy of Sciences. It drew 500 people to Washington DC over three days.

Even though the organizing committee of this Summit was dominated by scientists who were inclined towards moving forward with heritable genome editing, a few committee members were skeptical, and the Summit roster of speakers reflected that. They reflected that skepticism.

So at that first Summit, there were speakers that were nonscientists, there was a historian of eugenics, a philosopher critical of human genome editing, a scholar of race and racism, another focusing on disability and the social model thereof. I was invited to speak, but I was the only representative of a public interest organization. So critical scientists were also included amongst the presenters.

One prominent geneticist gave a talk, demonstrating in great detail why there is no unmet medical need for heritable genetic modification. And that is a point that had been largely absent from the conversation, and media coverage up until then, and is still under-emphasized in fact.

Also at that meeting, several CRISPR startup companies issued statements that they would not take part, they wanted to stay away from developing clinical applications for germline editing, and at the end of the summit the organizing committee issued a statement saying, "It would be irresponsible to proceed without evidence of safety and efficacy. Or, they said, without what they called "broad societal consensus."

That phrase, "broad societal consensus" seemed hopeful and promising at the time. And it is also one that proponents of heritable gene editing came to regret. In 2017, two years later, when the National Academies issued their report, the report ditched the phrase completely. Instead, it called for "public engagement" and it defined what public engagement meant, as being limited to questions about what kinds of genes and traits should be permitted to be altered and how we should go about this, not public engagement over whether reproductive genome editing was acceptable at all.

In fact, the report actually came out and said that "Clinical trials," that is, clinical trials using heritable genome editing, "should be permitted as long as they were limited to specified uses."

So, many people said at the time that this was essentially a green light for heritable genome editing, and that was definitely how an ambitious Chinese researcher saw it, and that brings us to the Second International Summit on Human Genome Editing which was held in 2018 in Hong Kong. It was another multi-day, multi-100 person meeting, and during the run-up to it, it was noted that this time, the Summit's organizing committee, its agenda and speaker roster, included very few public interest figures or social scientists or humanists or indeed scientists critical of heritable genome editing.

But, as it turned out, the 2018 summit was completely overshadowed by the revelation that Chinese scientist He Jiankui had presided over the genetic alteration of human embryos, their transfers to initiate pregnancies, and the birth of twin girls.

The meeting was really waylaid, and a frenzy of headlines about CRISPR babies and a rogue scientist ensued. Condemnation of He Jiankui was very swift to come, and was nearly universal, with the summit organizers joining in on this criticism of He Jiankui and what he did. But then, a strange thing happened. More or less in their next breath, the summit organizers pivoted. They declared “It is time to define a rigorous, responsible, translational pathway toward the clinical use of heritable genome editing.”

A few weeks later, the presidents of the national science committees, national science academies, co-authored an editorial in *Science* that drove the point home. The editorial conspicuously jettisoned the standard of “broad societal consensus” in favor of what they called “broad scientific consensus,” a very different thing.

And then the National Academies moved to set up a carefully selected commission to issue the next report, and the mandate of that commission was to map the logistical details of how to the designer baby technology could be brought to the fertility clinic.

So we now come to September 2020, a few months into the pandemic, when the commission issued its report, the second report about heritable genome editing. And that report did acknowledge the significant scientific and technical hurdles that heritable genetic modification would entail.

It also acknowledged the fact that all but a tiny number of people at risk for transmitting a serious genetic condition to their children can accomplish that, without messing around in their future children’s genomes. And the report recommended that heritable genome editing be allowed, initially, for those exceedingly rare cases.

The 2020 report did refer frequently to ethical and societal challenges. But it did not address them in any detail. It did include an entire chapter on governance and policy issues, but you would never know, if you read that report, that 70 countries prohibit heritable genome editing, which is a policy agreement that is remarkable for its global extent.

The Oviedo Convention, which is a binding international treaty that prohibits heritable genome editing that is signed and ratified by 29 European nations was mentioned in the report, but once. In a footnote. The report’s authors claim that they were not endorsing heritable genome editing. They were merely constructing maps of the technological path in case the country should wish to use those maps. Of course, doing it this way puts the cart before the horse, and it sends both the cart and the horse down a one-way road.

The Third Summit, originally planned for 2022, was postponed for a year due to the pandemic, and here we are now, it is getting underway next week. But as that happens, it is really

important to recognize that the summit process is not the first word and isn't the last word on heritable genome editing.

However, it is also important to recognize that the Summit is supported by huge resources. And it does take up a lot of oxygen. It is dominated by a small group of scientists, who do not represent the views of all their colleagues by any stretch. But who have put themselves in charge of a high-profile set of deliberations about a choice, a very consequential societal choice. And even they acknowledge that this choice will affect all of human society.

So, the voices we will be hearing over the next hour, and on two panels tomorrow, will bring a rich taste of a different type of conversation than what we are expecting to hear at the summit proceedings. Our collective challenge is to make sure that the wide agreement about the need for meaningful democratic public engagement is more than lip service. To make sure that the commitment to broad, societal consensus is honored. And that means bringing voices and perspectives grounded in social justice and human rights to the center of the debate. It means refocusing the conversation away from narrow, technical considerations and putting the spotlight on matters of human rights, equity and social justice. And it means making the time and finding the resources to support that kind of careful deliberation.

We need to foreground questions about the social, commercial and eugenic dynamics that would come into play if heritable genome editing is permitted. These are questions about what assumptions would possibly guide any choice of good genes to be inserted, or bad genes to be deleted. Questions about the inevitable commercial and cultural pressures to upgrade your offspring, and how would parents possibly navigate them? And questions about whether even the perception that gene-edited children were superior, no matter whether those genetic modifications do anything at all, that these perceptions would exacerbate the obscene levels of inequality and discrimination that we already live with.

I feel very sure that if social justice and human rights questions are put when they belong – at the heart of the debate – it will be very clear that heritable genome editing has no place in the future that we want to build. Thank you.

KATIE HASSON:

Thank you so much, Marcy. As we move into our next panel, we are going to share a very short video featuring quotes from our colleagues on why they oppose this type of heritable genome editing.

KATIE HASSON:

We are now going to hear from Dorothy Roberts, Rosemarie Garland-Thompson, and George Annas, who will discuss the social justice case against heritable genome editing. Silvia Yee from the Disability Rights Education and Defense Fund will moderate, so over to you, Silvia.

SILVIA YEE:

Thank you very much, Katie. We will have our three speakers present some initial remarks, in order of Dorothy, and then Rosemarie, and then George. Each will describe themselves, and I am just going to quickly get into that. Because I am sure we are all eager to hear them.

And, there will be an opportunity for them to respond to one another at the end of those initial remarks. Thank you.

DOROTHY ROBERTS:

Shall I begin? Thank you. And thanks to CGS for organizing this series of conversations on a truly existential and urgent issue. I am really honored to be in a conversation with George and Rosemarie, and Sylvia, all collaborators of mine for decades on this issue! It is good to be back together again.

I am speaking from Philadelphia, on the land of the Lenape people. I am a woman with light brown skin and medium length locks, and I am wearing a blue top, and bluish-green eyeglasses.

Now, before discussing the social justice concerns about human genetic modification, I want to point out how the question of social justice gets erased in the dominant scientific debates. The promoters of genetic modification argue that selection of human traits, and that is what it is, eliminating undesirable traits and amplifying those that are deemed desirable, can benefit human societies. But they act as if the benefit to society is unquestionable.

The main ethical debates they engage in have focused on the safety, and misuse of, gene editing technologies. For example, the influential 2015 article in *Science*, by key scientists and bioethicists in this field that Marcy just mentioned, called for research to “manage the risks arising from the use of CRISPR-Cas9 technology.” Which they identified as “the possibility of off-target alterations, as well as on-target events that have unintended consequences.”

So, in their view the risks of gene editing have to do with potential safety and efficacy. Not social justice. And managing those risks means weighing them against the potential benefits of gene editing. And those benefits are completely assumed.

As Marcy summarized, the ethical issues raised at the 2015 international Summit were somewhat broader. But, since that there seems to be a return to asking how to move forward with heritable human genetic modification, not whether it should be permitted at all. And all of these ethical concerns center on the risks of using gene editing technology in the wrong way. Even when justice concerns have been mentioned by these dominant voices, their framing accepts that genomic modification will make human beings better off, as long as no one is physically harmed and the technology is done safely, effectively and widely.

This approach fails to question the claim that human well-being will be furthered if the editing procedures achieve what they are designed to do, and are distributed to everyone. According to this view, as long as the technologies improve and the risk of so-called undesirable side

effects or off-target alterations diminishes, gene editing can ethically proceed because it will undeniably improve the quality of human lives.

The meaning of human well-being is left out of the debate entirely. Which is focused on safety, efficacy, and access. And that is not because it is ignored, it is because it is assumed, that we can all agree, that gene editing will improve human lives.

This argument, that having certain genetic traits, and not having others, that it increases well-being, whether in individuals or as a species, assumes an understanding of what it means for human beings to live well. But the meaning of human flourishing, embraced by these advocates, is not objective or universally accepted. And it is important to dig deeper, to see that the concept of living well undergirding their claims imports socially biased assumptions about what that means.

Now some bioethicists predict that gene editing will create a new social hierarchy of genetic have's and have-nots. And I do think that is a realistic concern given our already grossly unequal healthcare and other systems. But even if there is widespread access to gene editing, we should still be concerned about how heritable gene editing will increase social injustice.

Centering social justice, and not just individual choices that we might have access to, is essential to the reproductive-justice framework. Gene editing inevitably incorporates the social devaluation of certain group traits, and it distracts attention from ways of increasing human well-being that address current unjust social hierarchies.

We do not have to predict a future genetic social hierarchy, we are living with an abominable one right now! These unspoken assumptions have been determined by what improves the lives of the most privileged people in our society. And in a way that legitimizes their privileged position. The most socially privileged people have a vested interest in supporting a definition and means of increasing well-being that focus on individual enhancement rather than on social change.

And they blame lack of well-being on individual deficits, rather than on unjust social structures. The practice of genetic selection has long been characterized by confusing unjust social hierarchies with inherited traits. It attributes the disadvantaged status of politically subordinated groups to their supposedly inherited deficiencies.

That is an essential principle of eugenics and white supremacy. This way of thinking devalues the traits of socially disadvantaged groups, as if these traits diminish a universally accepted understanding of human well-being. And conversely, it values the traits of socially advantaged groups, as if they objectively enhance human well-being.

This way of thinking is profoundly shaped by the deeply embedded history of dividing human beings into supposedly biological races and sexes that are seen as evolving separately, having inherently distinguishable traits, and naturally belonging to different human communities.



In much the same way, a history of discrimination against disabled people has fueled the idea that disabilities are departures from some ideal human nature. And that is why popular images of genetic perfection in advertising, news media and movies routinely exclude people with disabilities and people of color.

As Marcy mentioned, the phrase “the perfect baby,” associated with assisted reproductive technologies, or this image of human genome modification, they are typically accompanied by a photo of a white baby, usually with blonde hair and blue eyes and something signifying that they are super intelligent, as if to highlight their racial purity and the biological nature, or genetic nature, of intelligence.

In short, the dominant ethical framework promotes the traits of socially advantaged groups, and it promotes individual enhancement, rather than social change. By assuming a concept of human well-being that privileges these interests, and discounts the importance of social change, arguments in favor of gene editing will reinforce socially unjust hierarchies, even if the technologies are so-called safe and accurate and widely distributed.

The idea that gene editing can improve human well-being distracts us from what we know are actually the most powerful predictors of well-being, and that is equality and justice in a society. For individuals to flourish, they have to live in societies that promote their flourishing. And people who are enthusiastic about gene editing either assume that those social conditions are already in place, so they fixate on what remains to be improved, which they see as their genomes, or they have great faith in the power of changing the biology of individual human beings but little faith in changing the unjust structure of the societies in which human beings live.

We need a full and equitable deliberation of the ethics of human genetic modification that includes this foundational question of the very meaning of human well-being, and its relationship to social inequality and social change.

That means it has to include the perspectives of groups, and center them, that are disadvantaged most by social hierarchies and inequalities. The public discussion so far has been just the opposite, it has narrowly included scientists, bioethicists and patient-advocacy groups, what some people call professional elites.

Their argument in favor of genome modification is based on false assumptions of scientific objectivity, and a universal concept of human well-being, that not only neglect other perspectives, but also affirmatively exclude them from view. People with disabilities, poor people, queer people, Indigenous people, people of color, Black people and others at various intersections of these social positions must be centered and have power, real power, in defining the very meaning of human flourishing, so we can democratically and justly determine what role gene editing technology should play or not play in promoting well-being for all of us.

And as Marcy suggested at the end of her introduction, the answers from people who have the greatest stake in radical social change, I too am assured will be very different from those who have a stake in the inequitable, and unjust, status quo. Thank you.

SILVIA YEE:

Thank you so much Dorothy, this is Sylvia again, brief description of myself, I have short dark hair, dark eyes, I am wearing glasses and earrings and a blue blazer. You have just heard from Dorothy Roberts, who is an internationally recognized scholar, public intellectual and social justice advocate. She has written and lectured extensively on the interplay of gender, race and class and legal issues, and has been a leader in transforming public thinking and policy on reproductive health, child welfare and bioethics.

Now, we will hear from Rosemarie Garland-Thomson, a professor emerita of English and bioethics at Emory University, and a senior advisor and fellow at the Hastings Center, and a fellow at the Center for Genetics and Society. Thank you, Rosemarie.

ROSEMARIE GARLAND-THOMSON:

Thank you, CGS and everyone involved, for organizing this really important event. And I am honored to be included. I am Rosemarie Garland-Thomson, I am a womanly person with pale skin, chin length straight silver hair, dark glasses, and a black shirt. And I'm joining you today from my home office in San Francisco.

I would like to begin by echoing and affirming everything that my esteemed colleague, Dorothy Roberts, just said. And to frame my own remarks today as an extension of what Dorothy said. I will focus though on some of the particular points that Dorothy made in her really eloquent and important explication of why we should not do heritable gene editing, and why we should not devote resources, both economic and human, in order to carry out that project.

What I would like to focus on is the concept of selection, which Dorothy mentioned. I would like to elaborate the idea of selection, in relation to how it operates, not just in gene editing, or heritable gene editing, but in the entire enterprise of making human beings better, ostensibly, through medical and scientific development of technologies and the carrying out and use of those technologies.

So that is a very big statement. Let me back up a little bit there, and say that selection in the process that Dorothy described and that I just briefly described, why it is wrong is that it violates the fundamental principle of human equality. That is the basis of liberal, modern, democratic social orders.

So this requires me to talk a little bit about what it means to be human. And also a little bit about what it means to be a person or a citizen, if you will, of modern, liberal, democratic societies.

To get to selection, let me rephrase Dorothy statement in the way I want to emphasize it. I want to say, again, we should not carry out or devote resources to medical and scientific technologies that select for or against human traits that we value, or devalue. And these human traits that we value or devalue, that is what I want to emphasize, these are human traits, or what I call human variations, that we, meaning medical science, has defined as disease or disability.

There are many human traits that we consider to be socially and culturally neutral. But there are many human traits that we consider to be disease or disability. And these are the traits or the characteristics that gene editing, or medicine in general works to eliminate. And I want to be clear that there is a difference between eliminating human traits, both individually and on a population level, and ameliorating through medical treatment, the negative effects, or perhaps the suffering if we want to talk about it that way, that are associated with these conditions.

But all of these assumptions become very perilous when we start thinking about the idea that having a disease or an illness or a disability is something that reduces human capability, reduces human value, and is something that needs to be expunged from the human community.

And the tricky part of this – and it is very counterintuitive – is that you really cannot separate the disease, the illness, the characteristic, from the whole person who bears that characteristic. So, again, this is very counterintuitive. And I think the best thing for us to do to try to think about this is, as I suggested, to bring into the conversation the idea of what justice might be.

Because of course, we are talking about genetic justice here today, together. And I will need a prompt so I do not go too far, so please help me with that, Marcy, as you promised.

So, justice, I want to suggest, in egalitarian modern societies, revolves around the concept of equality. Human equality. Now, that doesn't mean equality of capability. It doesn't even really mean equality of situation. I want to say that equality means equality of worth, or equality of moral worth, to invoke an ethical sense of these kinds of conversations.

Now, it is very difficult in application to imagine all human beings as being equal because we are not equal in capability, as I suggested. We are not equal in situation. But we need to be equal in worth, equal in moral worth, and in political and social worth.

It is very difficult to think that the person on the lowest rung, let's say, of the social order, and the person on the highest rung of the social order, the way they are, the way they are positioned in the world, the way they carry out their lives doesn't appear to be very equal. And that is a narrative that we have to be careful not to embrace. When we think about medical, and technological, treatments and enterprises that select for and against certain traits and select for and against certain kinds of people, in the distribution of resources that we call government, and the civic life together.

So, I want to talk in conclusion, a little bit, about disability. So, as I have suggested – I am sorry, Marcy, what do all those fingers mean? Six minutes. Eight minutes. I am at eight minutes, OK. Thank you.

So, what I want to do is conclude by talking a little bit about what we think of as disability. And the complexities of selecting for and against disability. And selecting for and against the conditions or what we think of as the human variations that medical science calls disease.

Let me start with some examples. Let's start with the genetic condition that we think of as cystic fibrosis. And, let's also start with the disease that we think of as Tay-Sachs. These are thought of as extreme cases, as – in some cases – incontestable examples of conditions that we don't want to have any more in the human community, and the human germline.

This seems very intuitive, it seems very ... unconditional. I have been involved in a few conversations with the philosopher Peter Singer – and it's not just Peter Singer, many people bring this up, when you talk about selection and when you talk about genetic editing, people always say "What about Tay-Sachs? What about Tay-Sachs?" Because it seems as if it is a question that is, as I suggested, incontestable.

But there are people who would argue that we need to allow people born with genetic conditions to live out the lives that they have been given. And as counterintuitive as that may seem, it is a perspective that needs to be brought forward when we have these conversations, about what seems to be an incontestable, intuitive, decision about which lives and which people matter. And should be conserved. And which lives don't matter, and should be eliminated, in future generations.

Cystic fibrosis is another condition, a condition that could be eliminated from the human genome through heritable genome editing. There are many people who live with cystic fibrosis who say something like this:

"I don't ... I am more than my condition. My condition cannot be separated from who I am. And if I had to choose life again, I would live a life with cystic fibrosis. There are treatments, there are ameliorations, that can make my quality of life worth living. And I would oppose, then, a gene editing therapy that would eliminate cystic fibrosis from the human condition. And the human community."

Those testimonies are not very widespread and they are very counterintuitive but these are the kinds of conversations that I think we need to call for when we call for broad public conversation, broad public participation, in these conversations. These personal testimonies about living with the conditions that we so unanimously say are conditions that should be removed from the human community. So, thank you.

SILVIA YEE:

Now we will hear from George Annas, our final panelist, who is William Fairfield Warren Distinguished Professor at Boston University and Director of the Center for Health Law, Ethics & Human Rights at Boston University School of Public Health. George is also a member of the Department of Health Law, Policy and Management at the School of Public Health. George?

GEORGE ANNAS:

Thank you, it is a pleasure and a privilege to be on this panel with my distinguished panelists. I am the token white old man on this panel today, and I have been told I look a little bit like Steven Spielberg but I am sure he would not want to acknowledge that.

I want to talk about human rights today for two reasons. One, because, I think they are really, really important but two, because many of the people on the side of enabling habitable genome editing have made the point that they do not think human rights matter anymore. That human rights have nothing to do with humans per se. And therefore we should not worry about human rights affecting how we treat each other. We should just go ahead and do the science, as long as we can say at some level “The risks are outweighed by the benefits.”

So what are human rights? If we don’t understand them, we can’t really use them in debate or in decision-making. And, perhaps the easiest way to think about human rights is that they are, number one, summarized in a document called the Universal Declaration of Human Rights, which was put together after World War II.

It was based almost entirely on the horrors of World War II. And the wish never, ever, to have those things happen again. And, the entire field can be summed up in article 1 of the Universal Declaration of Human Rights, which says that “All human beings are born free, and equal, in dignity and rights.” All human beings are born free and equal in dignity and rights.

Article 2 goes on to say “Everyone is entitled to all the rights and freedoms set forth in this declaration, without distinction of any kind. So you get the idea. If you are a human, you are equal to everybody else. There is no such thing as a subhuman, even though there was in World War II and you can argue that there still is in our society. There still is a long way to go to adopt human rights in reality.

But, there are four words there that I want to spend a couple of minutes on: free, equal, dignity and rights.

“Free” is pretty clear, and in a genomic setting means that your genome was not predetermined by another individual who had total control over it. So, we have to figure that one out. How did we get a statement or consent from the embryo, to be edited?

“Equal is of course the problem of the better baby. Can we all be equal when we have made a decision that certain genetic traits make us better than what the average, the mean, anyway, that is a challenge. Especially in the era of what has been called “Neo-eugenics.” There is no

way around it, we have to adopt some form of eugenics if we are going to start modifying genes to create better babies. That is part of the deal.

Dignity has been a term that has been very difficult for a lot of people. And with good reason, it still can be vague. But for a typical human rights person, dignity is another way to say that that you cannot to treat people like nonhumans. Or subhumans. They have to be treated equally. We know that. In fact, you can make a list of things that you cannot do to other human beings pretty easily.

Murder, torture, enslavement, those have all become, after World War II, crimes against humanity, a whole different category of crimes. And the notion of calling them crimes against humanity is that they are not just crimes against individuals, but they are crimes against the entire species. And this is where we need to talk some more as well. Does it matter that you are committing a crime against the species, you could actually destroy the species?

And there are people, we should acknowledge, who no longer believe that is true. Not just the post-humans, but mostly the post-humans, who think that it is time that we got rid of humanity and got a new species. And I actually think that, rather than a risk of germline genetics, I think that is a goal.

So I would just say that I disagree with them. I am willing to argue this out, and hopefully they will not get to make the decision. I won't either, but that is the hardest part of thinking about this. Who gets to make the decision?

The final term is "Human" and that just tells us that ultimately, human rights are going to be determined by a political process, involving all humans.

The most studied human rights are human rights in war. That is a paradox, obviously. And we are living at a time when our own government has just accused the Russian government of committing war crimes and crimes against humanity in the Ukraine. And there seems to be no doubt about that. And that is both the good part of human rights, and the part where we still have a lot of work to do.

The good part, you can define things that you cannot do. The bad part, if you do them we still do not have an effective mechanism to stop you from doing them. Except to go to war, and the whole point of human rights is to prevent war! Not to go to war, even to fight about human rights.

The other big area of human rights, for historical purposes, is medical research. And that is what brings us to genetic research as well. After World War II, the doctors' trial at Nuremberg was probably the most famous trial, and physicians were tried for crimes against humanity, and war crimes, for murder and torture, in the name of science. High-altitude experiments, freezing experiments, Mengele's twins experiments, things you should never do to another human being. We actually have a lot of law on that, and a lot of decisions on that, and the question has

to be asked directly, is heritable genetic editing, can that ever be thought of as a crime against humanity? Can that ever be thought of as something you should never do?

I have made an argument, I will not make it today, but that a new category, which I call species-endangering experiments should never be done. Or at least if they are going to be done, they should never be done until a representative body of the world studies them in public, and comes to a conclusion that yes, this is worth a try.

It's just a decision that no group can make, certainly not a self-selected, self-appointed group from the National Academy of Medicine, as much as I love my colleagues there, they should be the first to acknowledge that they do not get to make the rules for the rest of the world, just because they are very distinguished physicians and scientists.

So I want to close with a quote from my favorite author, Kurt Vonnegut. At the end of his novel, *Breakfast of Champions*, his character, Kilgore Trout, who is a science fiction writer, is asked by the Secretary-General of the United Nations whether he is afraid of the future. Many of you have been asked that I am sure. Afraid of the future. To which Kilgore Trout responds, "No, Mr. Secretary-General. It is the past that scares the bejesus out of me." That is where human rights came from. Thank you very much.

SILVIA YEE:

Thank you so much to George and all of our panelists for their opening thoughts and the richness of those thoughts. I wanted to give each of you, and this is Sylvia, I am sorry, I did not identify myself when I first spoke. I wanted to give each of you an opportunity to actually respond to what you have heard from the others. I am sure that these remarks have triggered additional thoughts in your own mind.

So I'm going to call in each of you in turn, just to give you an opportunity to do that. Dorothy, we will begin with you.

DOROTHY ROBERTS:

OK thanks, and thanks to Rosemarie and George for their important comments. I do have lots of thoughts, I will try to contain them. Just immediately, I think it is so important how George ended with the acknowledgment that we already can see from past uses of technologies with similar ideologies behind them, the ideology I was mentioning in my talk, the pretense that socially disadvantaged people are disadvantaged because of some innate trait they have, as opposed to being oppressed by social structures in our society.

That idea has led to the most horrific, horrific, abominable violences against other human beings. We know that. We know that from recent past. And so we should be extremely concerned that a technology that promotes the same idea, that the way to improve human beings is to change genetic traits, and ignores how social structures are actually the greatest

harm to human beings, that social change is the greatest need for improving human well-being. We should be very concerned about that.

I am very grateful to Rosemarie for pointing out that the essence of selection, which is what heritable genome modification centers on, is the idea that there are certain traits that need to be expunged from the human community. And I would just emphasize that the determination of what those traits are that need to be expunged, does not depend on some kind of universal or obvious, or natural norm of what improves human well-being. Or what it means to live well. It is based on an unjust political hierarchy, and the people who are the most elite in that unjust hierarchy have been deciding what are the traits that need to be expunged.

So just a reflection on the example of cystic fibrosis, where it may seem like the answer to that is to expunge this trait from the human community. That idea ignores the way in which the lives of people with cystic fibrosis have been improved dramatically because of social changes, because of getting to those people medical care and social care. That helps to reduce any suffering and improve their well-being. And so we could contrast that with how people living with sickle cell anemia, because of racism, and the false pretense that it is a Black disease, have been ignored, largely, when it comes to social structures and medical care, that would improve their lives.

So we can see that it is racism that has been a major factor in the harms, denying them for example, pain treatment, based on stereotypes that Black people are prone to drug addiction, another false racist, biological idea. These false racist biological ideas are going to be imported into decisions about what are the traits that should be expunged from the human community.

I just want to emphasize again how focusing on gene editing, based on these political value judgments, about which traits should be removed, distracts us from the most important thing for improving human lives, and that is radically changing our society, to be more equal, humane and caring. I will end there, thanks again to Rosemary and George for your wonderful comments. And remarks.

SILVIA YEE:

Thank you so much Dorothy, this is Silvia again. I will give Rosemarie an opportunity to respond to the remarks of her fellow panelists.

ROSEMARIE GARLAND-THOMSON:

Yes, thank you Silvia, thank you Dorothy and thank you George. I would like to echo again and follow up on George's invocation of history and the history of eugenics as it was practiced especially in the first three decades of the 20th century.

And to think about what we now sometimes called the difference between the old eugenics and the new eugenics. And that is a historical narrative which suggests that the development of eugenics in the first part of the 20th century, which was a scientific practice that was devoted



to the idea of improving humanity by encouraging the right kind of people, or the preferred kind of people, to reproduce. And to discourage the people that were understood as the wrong kind of people, or the inferior kind of people, to not reproduce. That is what eugenic science worked towards. And the kinds of political and social policies that came forward as a result of eugenic science.

So part of the history that George is invoking here is that eugenics was a very positive, it was a very progressive, we call that the progressive era, those first several decades of the 20th century. But as George suggested, what we think of as the Holocaust, and the practice of eugenics, and eugenic sterilization, and eugenic euthanasia, that was carried out against ethnic groups, and a whole variety of people that were understood as inferior, who were understood as having a low quality of life, who were understood as having lives not worth living, were the targets of that eugenic enterprise.

The human rights initiative and the kinds of covenants and laws and policies that came out of that, as George has suggested, came directly out of the lessons of the Holocaust, and the medical and scientific involvement in eliminating, killing, murdering hundreds of thousands, millions of people. Under the idea, the justification, that these people were biologically inferior.

So we have before us a set of ideas, covenants I like to call them, all of the stuff that the United Nations has done, but many other laws, that come from our own Declaration of Independence, if you will. The concept that everyone is created equal. That apparatus is there, and I think what we need to do is to try to bring forward the logic and the regulation that is in those covenants, and the legal and policy apparatuses that come from them. To put forward the concepts and the ideas, the logic of what we are talking about here, the three of us today. Thank you.

SILVIA YEE:

Thank you so much, Rosemarie. This is Silvia again. And I will turn it over to George for his thoughts on the remarks of his fellow panelists.

GEORGE ANNAS:

First I would like to thank both my copanelists for picking up on the idea of World War II and what we do to each other, what humans can do to other humans. I understand why nobody wants to talk about that anymore. It was horrible! But it is not over, the ideas are not dead.

And in genetics, you have to deal with them. Genetics was at the heart of a lot of the medical work, if you can call it that, in the concentration camps. Lives unworthy of life, as they were called, useless eaters. We do not use those terms anymore, but I have spent a lot of time, a lot of my career working with obstetricians, terrific ones, I have learned a lot from them. One of the projects, I was an advisor to, was trying to figure out, if you are going to screen for hundreds of conditions, prenatally, in the fetus, and you can now, which ones should you screen for? Are there conditions that every fetus should be screened for?

Of course, to be in one of those conditions, it has to mean that you think it is reasonable for the women to terminate the pregnancy based on the fact that her fetus has XYZ characteristics. One of my colleagues and I spent years and years trying to answer this question. We all agreed that, if you had a serious medical condition, you should screen for that. The question is, what is a serious medical condition?

I guess I would've said Tay-Sachs qualified, but I am taken with Rosemarie's discussion of moral worth there. Why should we get the decision that Tay-Sachs is always better off terminated immediately than lived through? In any event, that is a decision that a physician should not make. If anybody gets to make that decision, it is the pregnant woman.

Who is the decision-maker, that question is also at the heart of our discussion here. None of us would say that the decision-maker has to be the scientist who came up with the prenatal test, or who came up with the gene editing technique. The public has to be directly involved.

SILVIA YEE:

Thank you very much, George. This is Sylvia again, I have been looking at the questions that have come, in the questions and answers. I think that after the event, we cannot get to them all, but there are individual questions, questions for resources, messages directed at individual speakers, I think that you will all have the chance to see those and respond to them.

What I have gotten from some of them is an underlying question about how we, as panelists who are opposing the use of germline genetic engineering, how we speak. On the other side, on those in favor of germ editing, there is a lot of assumptions made. Dorothy highlighted that. Assumptions about what is best for human beings, for our future, should we not also be very careful then about making assumptions and how we speak? For example, Dorothy speaks a lot about how white supremacy underlies, and criticizes Democratic social orders, liberal democracies. Rosemarie talks about the universality and appropriateness of liberal democratic social arrangements.

Is there a contradiction there about what we are using to support our arguments? Can we actually speak in universal terms? And for George, that applies also potentially to cultural views of human rights, is there a universal human rights that applies in ways that we can speak of? That we can marshal for our arguments? I am going to ask Dorothy to speak first, and then we will turn to Rosemarie and then to George.

DOROTHY ROBERTS:

Well, I do think that we need to have a critique of liberal democracy that centers on white supremacy, liberal capitalism, ableism, patriarchy. All of those hierarchies and political inequities exist in liberal democracy. And so in fact, what we have been talking about, eugenics, eugenics was developed and promoted in liberal democracies!

The United States was the biggest promoter of eugenics, and continues to be. And I would emphasize that eugenicist thinking is behind many social policies today. It was behind the mass sterilization of black women, indigenous women, women in Puerto Rico, and other women of color. And it continues to fuel a lot of policies we have today.

So, I think that this is part of, you know how I ended my talk, that we need to include or center... It is more than inclusion, center the perspective, the voices, the activism of the most socially and politically marginalized people who are marginalized in liberal democracies like – or so-called liberal democracies – like the United States.

I am not saying that we cannot have principles that might be associated with democracy and liberalism. We may want other principles that are not associated with those as well. Like sovereignty, you know, and socialism. But, not to say that they are not necessarily associated with those other principles.

And that means, again, centering the people who have been the most oppressed and disadvantaged and marginalized within liberal democracies like the United States. And, it is that, this is what I was trying to get across in my talk, that it is that political hierarchy and classification of human beings by the elite, which is a white male elite – George, you are the one who identified yourself – that has been controlling the very meaning of what human flourishing is. And that is what we need to challenge.

I am not sure if I completely answered that question but I would just say that at the center – I would not put at the center the principles of liberal democracy, I would put at the center the reality of unjust, unequal, social and political hierarchies that continue to dominate people's ability to live full, free lives. And that is what we should be challenging, and I would also point out that eugenics, white supremacy, and other forms of inequality and oppression that have caused the worst harms, you know, in human history, were promoted within liberal democracies.

In fact, you might say that the liberal democracies have the most, that those in power have the greatest need to come up with false ideas about humanity, like race, in order to excuse the violence and injustice that they promote within a nation that is supposedly premised on liberal democratic principles.

So again, I am not sure if I answered the question but that is my response to the question.

SILVIA YEE:

Thank you so much, Dorothy, you did address the question. And I would love to hear Rosemarie's thoughts next.

ROSEMARIE GARLAND:

Thank you. Someone in the chat brought up the question of what about the parents in relation to what we are talking about here in terms of reproductive policy and practice and intervention. And these are really good questions that invoke the problem of application, in policy and practice, of what we are all talking about here today.

And what that requires, of course, is ... I don't... a lot of thinking, a lot of conversation, about the difficulty of balancing the conflict between harms and benefits that exist in any kind of action, whether it is the action of the distribution of resources, whether it is the action of carrying out a policy, carrying out a medical or a scientific application, or carrying out specific healthcare initiatives. That balancing who gets harmed, and who gets benefited, from these actions, is really difficult.

Let's take an example, of the kind of situation that I have been talking about, and that is the situation of the genetic condition that we call Down syndrome. So, very briefly, that human variation or way of being in the world, that is how I like to talk about it, is a way of being that scientific medicine started testing for by developing a test in the mid-1960s, that would identify embryos and fetuses that had the genetic condition that we labelled Down syndrome, that collection of characteristics.

And the reason for the testing was to assess whether that kind of person should be brought into the world, or whether families wanted that kind of person to be brought into their families. And this is a very reasonable premise, based on the idea of liberty. Of the right for every person, and every family, to determine how their family is, who comes into their family.

This is a benefit. This is a good. This is in some sense an inherent right for every person to have. And so at that time, in the mid-1960s, a life lived with Down syndrome was not a very good life. People didn't do very well, they were often institutionalized, there was a short lifespan. And so we began testing for this condition that we think of as Down syndrome, with the premise that it could be selected against in the interest of reproductive freedom, and reproductive liberty. And the right to family making.

This makes a lot of sense. In 2023, the situation, the life conditions, the quality of life for people born in rich countries with Down syndrome, is completely different from what it was in the 1960s. And yet, that condition is still tested for. And fetuses and embryos with Down syndrome in the United States and worldwide are eliminated at a rate of about 80 to 95%.

This is emblematic of the ethical problem that we have been talking about here today. That people with Down syndrome and other genetic conditions are imagined as having low quality of life, using up more resources than they ought to, and that they will bring suffering into the world and into various families.

And those narratives, if you will, those sets of assumptions are the ones that I think we need to bring forward, not necessarily put together policies and laws, about reproductive practice. I mean, we already have those. But, what we need to do I think is focus on how to come up with

resource distribution that addresses the issues fairly, in terms of equality and justice, that we have all been talking about here today. So, thank you.

SILVIA YEE:

Thank you, Rosemarie. And George, I am so sorry, I don't mean to be cutting off your time to respond but I do think we're very close to the end. Is there one sentence that you wanted to raise, with regards to this?

GEORGE ANNAS:

Yes, I just would say that human rights is a work in progress. It is not final yet. It is based on treaties and legislation and it's an ongoing process that we, the community of human beings, get to define and get to say whether it should be taken seriously or not.

SILVIA YEE:

Thank you so much, George, that was very eloquently said. And all of you as panelists, I have so enjoyed this conversation. And I would love to pick your brains more, and I have the privilege, maybe, of sending you emails to do that. But knowing we are at the end of our time today I am going to turn it back to Katie just to close up our time together.

KATIE HASSON:

Thank you so much, Silvia, for such great moderation, great questions. Thank you Dorothy, Rosemarie, George, and Marcy for all that you shared. And I want to thank everyone who was watching, commenting, submitting questions, and connecting. Final thanks as well to our ASL interpreters, Sharon Neumann Solo and Holly Newstead, and our captioners, Ellen and Lee. And to our CGS crew, especially Emma McDonald and Emily Galpern.

I do want to let you know about a couple of things before we go. What is an international declaration against legalization of habitable genetic modification that is open for signatures. It is being organized by a public interest coalition of which CGS is a part. Also, there are several other Summit-related events that you can attend: An in-person conference if you are in London, and a hybrid teach-in are both taking place this coming weekend. And there is another hybrid convening next Tuesday evening. All that information is on the intro page for this symposium. And the link for that is in the chat.

If you are feeling inspired to make your voice heard after these events, we encourage you to participate online in the international Summit next week, March 6 to March 8. You can also follow CGS on Twitter, Facebook or LinkedIn for the latest on the happenings at the summit.

And finally, we have a third webinar in our Missing Voices series coming up on March 28: Feminist Intersections, Heritable Genome Editing at a Crossroads. Registration is open, I believe you have the link in the chat and we will include that information in our follow-up email.

Thank you so much everyone, we will see you tomorrow for day two of Genetic Justice from Start to Summit. Goodbye.