Emily: I'm Emily Kumler and this is Empowered Health. This week we're going to talk about CRISPR[1], which is a sort of gene editing technology that you probably have heard a lot about but maybe don't completely understand. That's sort of where we started this, but actually what we're interested in this week is the morality behind using DNA editing to make babies. So in China there were two babies that were born[2], two baby girls, and they were born with their genes edited to prevent them from developing HIV. That was the goal. But what we know is that when you edit the genes of an embryo, you're not just editing the genes of that person to be born. You are also editing the genes of every future generation that will come from that person. So her babies, her grandbabies, her great grandbabies will all be impacted. We also know that oftentimes when you change one gene, you are indirectly changing all kinds of others. So there's great concern that by turning off the ability or creating an immunity, so to speak, to HIV, you could potentially be turning on the gene for cancer or other very harmful things. So we wanted to call up somebody who was very well versed in what had happened in China and could break it down for us in terms of is this the future, is this good, is it bad? What are we learning? If we can prevent certain illnesses, diseases, you know, crippling effects on shortening someone's life. That sounds great. However, the idea of sort of creating babies that are genetically modified, there is no way that doesn't come without huge risk and consequences. So we're going to get into this. We're going to talk about the idea of sort of like futurism and like what if we could alter our genes so we can see at night so we could live on other planets as well as what does this look like today? Like this is already happening despite the fact that consensus science said we weren't ready for it yet.

Francoise: I'm Francoise Baylis[3], I'm a philosopher by training. I work in a faculty of medicine and my title is university research professor at Dalhousie University.

Emily: I thought the best place to start might be to just sort of give an overview of what CRISPR is.

Francoise: So CRISPR is a relatively new technology discovered in 2012[4] and what it does is improve upon existing strategies for what is now called gene editing, has been called gene transfer, gene surgery, et cetera. But people are sort of settling on the metaphor of editing because what the technology does in very simple terms is a cut and paste function with respect to genes. So if you imagine your DNA, what this is able to do is to send in what we call molecular scissors, that will go and make a cut in the two strands of DNA. And then it basically harnesses the cell's repair mechanism so that it will then either on its own rejoin those two pieces, or you may have sent in a new piece of DNA that you hope will get inserted where the cut was. Alternatively, you may be actually cutting out a piece of the DNA. In theory, this can happen in patients who are alive and not so well. It could in theory happen in utero in the fetus. And the area that's most controversial right now is actually making this change inside the human embryo. So very generally, we have two broad categories of genome editing. One is called somatic cell

[1] https://ghr.nlm.nih.gov/primer/genomicresearch/genomeediting
[2] https://www.statnews.com/2018/11/28/chinese-scientist-defends-creating-gene-edited-babies/
[3] https://medicine.dal.ca/research-dal-med/people/research-chairs/francoise-baylis.html
[4] https://www.ncbi.nlm.nih.gov/pubmed/22745249?dopt=Abstract&holding=npg

genome editing[5], and those are edits in any of the body cells. So [?} are live patients. And then we have what's called germline editing[6]. And that's when you're actually manipulating the reproductive cells. So your gametes, your sperm, your egg, or the very early stage human embryo.

Emily: And I think that's what we're gonna focus on in trying to talk to you a little bit about some of the morality behind that kind of editing of beginning cells.

Francoise: Right. So I think the thing that's really important for people to understand is colloquially, meaning in the general press, people talk about this as being able to treat newborns and people then sometimes imagine that you're making these changes is in a little baby that's just been born. Or some people imagine that you're making these changes in the fetus while the woman is pregnant. But the most important thing for people to appreciate is that this controversial area of science is in fact happening in the lab. And so what is happening is you have scientists that are manipulating the very early stage embryo to try to change its genetics. And the reason that they want to do it at this stage in development is then it's easy for you to imagine that as the cells divide and you go from one to two to four to eight, et cetera. It's the same change to the genetics that's being passed on to every single cell. And so that's the context in which people want to make changes to the embryo.

Emily: So as the cells are growing and they're doubling, you don't have to make the change to quite so many because the pattern has already been established and it'll replicate the same pattern over and over. Is that an accurate way of explaining that?

Francoise: Yes. In fact, many people refer to this as one and done because you make the change once and then that change gets replicated over and over and over again. And so you could appreciate that some people are saying, well that's going to be a whole lot easier than trying to fix a particular problem in a live person because then you've got to change how many millions of cells. And so that's the context in which people imagine going into a one cell embryo and making a change once and then just allowing the cellular development to happen naturally. And for this change to be replicated in all the DNA, all of the cells.

Emily: And so just from a, again, like a very sort of like kindergarten approach into genetics, I want to make sure that this is clear. So when you are changing something in a gene that is then going to be replicated, that affects the other genes as well. Correct? So like the pattern of gene replication is identical, but there could be unintended consequences that come from that replication pattern we don't even realize yet. Correct?

Francoise: Right. So what you're alluding to is the potential things that can go wrong. So I've made it sound very simple, right? So we have DNA inside of the cell. You send in your molecular scissors. It makes a cut. And the cell repairs itself using a couple of different strategies and you're absolutely right, a number of things can go wrong. So one of the things that can go wrong is called an off target effect, which means that it actually went

[5] https://ncats.nih.gov/somatic
[6] https://www.geneticsandsociety.org/internal-content/about-human-germline-gene-editing

and made a cut in the wrong place. So you've then got a serious problem. Alternatively, you can have what's called an on-target with an unwanted side effect, which means the cut was made in the right place, but you've actually had a side effect you didn't expect, anticipate, want. For example, you've turned on a cancer gene. Another thing that could go wrong is something called a genome wide effect, which means you've actually made the correction that you thought or hoped or wanted to make, but you actually at the same time had an impact somewhere else. So for example, you were trying to have an impact on muscle cells, but at the same time you had an impact on skin cells, which you didn't intend to do. And the last thing that can go wrong is something called mosaicism, which means that you tried to change all of the cells but it actually didn't quite work and you change some and not others. So mosaicism is when you end up with some cells that are gene edited and some that are not.

Emily: And the twins that were edited in China, one of them did have that, correct?

Francoise: That's correct. And so what that probably means is that if the first one was successful and what he was trying to do in that particular case was to give these infants resistance to HIV. So it was actually a preventive maneuver and we can have a comment about that in a minute. But the point that he did is that if he was successful and we don't really know, it probably will not be the case that both were similarly effected because he knew even before he transferred these embryos that they had not both been properly, in quotation marks, gene edited.

Emily: The potential problems are realized early?

Francoise: Not necessarily because we don't know what all the potential problems could be. So for example, you know, you could have a newborn that appears healthy and then later on developed a particular problem. In this case, we've only just recently learned that the babies were born in October, not in November, which is what most people believed until recently. And they were in what's called the NICU, which the neonatal intensive care unit, because they were born premature. So no matter what, they will probably have some of the complications of prematurity. Nothing to do necessarily with the genome editing. But the point is that when you go into the DNA and you start quite frankly messing about, you could have all kinds of possible consequences and you have no idea when in their lifetime those consequences will show up. A classic example is something called DES[7] which is a drug that women took while they were pregnant and they had what looked like healthy newborns. Except when those female newborns went on to reproduce, they couldn't. And so you don't know what the long-term effects of this will be, which is why many, many people are deeply concerned to say, really, why are you doing this? You really ought to have a very good reason to do this. And many people, myself included, are skeptical that there is such a good reason.

Emily: Well, and so when we look about sort of the idea of regulating medical practices, right? Like we often think of the FDA and the, you know how clinical trials, like the phase one is animals and it's about safety. But when we're talking about stuff like this and it has to do with the international community rather than something the United States can

[7] https://www.cdc.gov/des/consumers/about/history.html

theoretically control. I mean unless we were really to get into like sanctions and other kinds of things, which I guess is what we have done with nuclear energy. How do you see this being controlled? Is the sort of plea to morality? What is going to win out overall? Because it sort of feels like there are these rogue scientists who are just kind of doing it on their own.

Francoise: I mean at the end of the day, we're 7.7 billion people on this planet. Are you going to find one person of 7.7 billion that's going to say, I don't care what the rest of you think, I'm gonna do it anyways. Yes. I mean, I can't imagine that you know, that the world would be– that you would have 7.7 billion people agree to anything. However, I think we are in a very interesting and controversial morally difficult time. Where quite frankly, we are careening towards our own destruction. We are busy destroying our habitat. You know, you can think that we're doing that actively or you can think that we're doing it passively, but I think it's impossible to ignore the science with respect to climate change. And so as we do that, you know, we're probably already on a path to ensuring the demise of our species. Now the interesting thing is will we allow this technology to further contribute to that demise. Or as you might listen to some transhumanists or some futurists, they imagine using this technology to get us off this planet because by the time, you know, we're able to do that, this planet will not be habitable for us in our current shape. So you can really start even thinking in terms of science fiction, we've got to get off this planet because we're busy destroying it. Now please understand I'm of the view, well, if you actually think that's the future, why don't you just stop destroying this planet? But it's kind of how we work, right? We have one technology and it starts ruining something and instead of stopping using that technology, we just assume we'll find another technology somewhere down the road that'll fix the technology that's really hurting us right now. And some people imagine that that's what genome editing will do. We'll just change ourselves. We'll change our DNA so that we can breathe something other than oxygen maybe. You know, we'll change our eyesight so that we can work in the dark so that if we, you know, have nuclear darkness, we can still see somehow, I mean, people have all kinds of strange ideas in terms of, of science fiction. What I'd like to do is to come back to your idea of the rogue scientist. And the reason I want to do that is said that's become really trendy language. In light of what happened last November with the announcement by Doctor He that he had in fact created these genome edited twins. Very quickly, he was condemned and the condemnation was almost uniform. Meaning there were some people who did not, but by and large, it was a negative response to what he had done.

Emily: Was it a negative response in China?

Francoise: That's complicated because on the one hand, there were early indications of celebration as this was an important breakthrough. But that changed very quickly. I would say probably within 24 hours. In large part not only because of what was being said in other parts of the world, but a number of Chinese scientists signed a letter[8] very forcefully condemning the work that had been done and I think that part of what you see is that science has become an international activity and scientists want to be part of that international club. And certainly, in that context, a number of people, including

[8] http://www.sohu.com/a/277918194_114760

scientists from China, were very quick to say this was not a responsible use of this technology. Now, some people believe it was not responsible because it was premature and that more science needed to happen first. Other people believe it was not responsible because it should never have been done. So even though you had uniform condemnation; the motivation, the perspective behind that was different. And so people are still differently situated. But the point I want to make is I really believe it's wrong to say that he was a rogue scientist. He is exactly the product of contemporary science. He was trained in the United States. He was brought up in a culture that says you've got to not only be the best, but you've got to be first. We don't give out Nobel prizes to whoever came second. We don't give out all the patents to whoever comes second. If you want to win and win big, you got to push the envelope. He was brought up in that context. He was also brought up in a context which privileges secrecy. We are now learning that a number of American scientists knew about this work.[9] They not only knew about the work, they knew when he had to pregnancy. Did they say anything? Did the rest of the world learn about this before it got announced with the births? No. So there's sort of a complicity in terms of silence.

Emily: Well that's not new either though. I mean that kind of competition seems to be, has been par for the course.

Francoise: Absolutely, but we're on track to say that's par for the course. And all that happens is whether somebody decides to celebrate it or condemn it. So you don't get to be called a rogue after the fact because you were doing exactly what you were trained to do. Right. it is not the case that this is one bad apple is where I'm trying to go. So what I'm saying, lots of people knew about this and said nothing. It's because of the people who said nothing that we actually know so far that we have at least one other pregnancy. Right? So he admitted that he has another ongoing pregnancy.[10] Well, it's quite possible that if somebody had sent off the alarms, right, that we wouldn't have a second pregnancy. And nobody's focusing on that, they're sort of saying, oh, they didn't know what to do. And so now the next person to do this only has to prove that they can do it better than him. So somebody else has gone out front taken the flak. And now for some people this is going to mean, well I can do it. I can just do it better than him. I'll take a few extra years, but then I'm not going to take this same kind of criticism. And I think, you know, one of the things that I think becomes really important around this is all of the debate that we've been having about the idea of whether or not there was, should have been, should be a moratorium on this science. And I think that that's really critically important. And then you can just trace the history. So in 2015 you had this international summit and at the end of the summit– and you know, exposure, conflict of interest, I was a member of the planning committee– so I signed this document[11]. We said very clearly that it would be irresponsible to do this work in the human embryo for the purpose of reproduction unless and until and we had two conditions. The first condition was safety and efficacy. Safety meaning you're not going to hurt people. Efficacy, meaning it's going to work. So you're not putting people through all of this and it's not even going to be effective. And the second one was broad societal consensus. And we talked about the

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[9] https://www.nature.com/articles/d41586-019-01274-8
[10] https://www.wired.com/story/he-jiankui-gene-editing-crispr-second-pregnancy/
[11] https://www8.nationalacademies.org/onpinews/newsitem.aspx?RecordID=12032015a

importance of starting a global discussion to understand this technology and how it might be used for good or for evil. And how did we want to imagine using this technology that was widely and quickly reported in the media as a call for a moratorium. The word moratorium was actually never used in the 2015 document, but that certainly what was meant and understood by many of the people who signed that document, including myself. However, in 2017 the National Academy of Science and Engineering and Medicine in the United States issued a report.[12] And in that report they did something very critical, which is they changed the starting assumption. Instead of saying that it would be irresponsible unless and until they said it would be permissible, provided that. And so what you've done now is you've changed the starting assumption, the starting assumption is you can't do it unless, and now the starting assumption is you can do it provided that. And this becomes extremely important because they then set out the criteria that they believe need to be met and you now have a scientist who says, okay, I can meet those criteria. Now you and I can decide that he didn't really meet those criteria and I would agree with that assessment. But you've put the scientific community now in a place where they can say, okay, there are rules for going forward. I'm going to follow those rules and I'm going to go forward. And we know that Jiankui He believed that because he actually submitted that document as part of the support for him moving forward when he went to get ethics approval. Now again, we can dispute whether he met those criteria. I would certainly argue he did not meet those criteria, but many people who know him better than I do have said that had there been a real moratorium that he probably would not have gone forward.

Emily: So wait, let's just go back for one second because I think there's something really important in terms of the iteration of how this went down. Right? Is there overlap in terms of those two scientific boards?

Francoise: Absolutely. Yes there is.

Emily: And so how does something like that happen? I mean the language gets completely flipped right from a basically like a pause to a go if, and that seems really stark. I mean, and I don't know how much detail the first document went into, but I would imagine that safety is something that needs to be defined in and of itself, right? Because the repercussions for future generations are significant.

Francoise: What happens is in the first iteration or the first sort of international document, which is December of 2015, there's no agreement as to what would be a reasonable, sufficient motivation for using this technology in an embryo. And what you have later on is people introducing hypotheticals that they believe would make it worthwhile to use this technology. And the typical hypothetical that they present is a couple who would like to have healthy genetically related childrens, not just any child. So they don't want to adopt. They don't want to use donor gametes. They don't want to use donor embryos. They don't want to be foster parents. They want to have their own genetically related children. They want them to be healthy and because of their own biology, they can't do this. There's no way they can accomplish their goal. So some people, myself included say, well, I'm actually really sorry that you can't accomplish your goal, but we have a lot

[12] https://www8.nationalacademies.org/onpinews/newsitem.aspx?RecordID=24623

of very safe technologies that will allow you to become parents. And yes, it's true. The child might not be genetically related to both of you, but we live in a modern world where we have used reproductive technologies with donor gametes for a very long time. We live in a world that has a very long history of adoption. We live in a world where lots of divorce happens and we have lots of blended families and we will help you to become a parent. We're just not going to use some very risky, very expensive technology. Some people, myself, are prepared to say that. Other people are prepared to say absolutely not. We're going to use all of the science that we can to help you achieve your particular wish.

Emily: But actually at this stage, we can't say going to be safe. That's the part that I get stuck on.

Francoise: No, we certainly can't say it's going to be safe.

Emily: Well you can't say they're going to be healthy. If one of the stipulations is healthy babies that are of the same genetic makeup as the parents. That is not a guarantee. Right?

Francoise: Absolutely not. It's not a guarantee. But that would be true of any research projects. So if you want to get involved in the research, and that's the thing that gets lost along the way. People assume that you can just make this on offer. What's really gonna happen if you were to go down this path is that several people will participate in a research project and we don't know what will happen. So they may not get what they think they're getting or asking for. The other thing we haven't talked about, and I don't want to go into detail here, but right now, any genome editing that we've had available in the context of gene transfer right now for patients costs about a million bucks a patient. Right? So this is not a technology we're developing to help the world, number one. Number two, if you actually look at patients that fall in this category, I'll remind you, we're 7.7 billion people on this planet. You might be finding maybe 300 couples that might meet the criteria for this technology. And I'm thinking, really, you want to spend your time, talent, energy doing that? I'm not prepared to invest my tax dollars in that kind of research. I can think of a lot better things to invest in. For example, dealing with climate change so that all of us can survive on this planet. Or alternatively, if you want to stay with genome editing, actually developing therapies for existing patients, there are many better uses of the money. But that's my personal view. So if we go back to the other people's view, what they're saying is we have a couple, for example, who has an underlying illness. The illness they typically give as an example is Huntington's disease[13] and the genetics are such that no matter what they do, all of the embryos they would create would have Huntington's disease. And that's the classic example that's given. There are other examples where that would be true, but my point is those are so few cases. How many times are you going to have people that have gotten together that are still healthy in their reproductive years and that want to have children where it's only going to be the case that all of them would be effected. That's just not the norm in many cases. What would happen in more often than not is you would have an underlying illness. You could still take Huntington's disease, but where for example, only one person has the illness, the other person does not and so only 50% of their embryos

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[13] https://www.nature.com/articles/d41586-018-05177-y

would have this genetic disorder. We have technology that will allow us to find the embryos that do not have the illness and we can transfer those embryos. So if you are a parent or a potential parent, you want to have healthy genetically related children and I say to you, look, let's use IVF, which is in vitro fertilization where we make the embryo outside the human body. Let's do a tap just called preimplantation genetic diagnosis on those embryos where I look for which ones have Huntington's disease and which ones don't and we'll just put the ones that don't have Huntington's disease back into you now. I would think that's a way better choice than saying, nah, I don't want those healthy embryos. Can we pick the faulty embryos and can you do some fancy technology and fix those faulty embroyos those are the ones I want you to put back in me. Well I'm starting to think like what kind of parent are you really?

Emily: Here's the thing that I think in listening to you a little bit, it seems like to play devil's advocate anyway, they're kind of two things at play here. One is finding the parents who justify the treatment, right? The other is the scientist who's really curious about if this is possible and so they want to know if they can make it work or not. Right? Which is sort of in of itself separate from the humanity that you are giving it by addressing it with the parents. Right? So like the parents might be the motivation for doing it in some way, but I think the scientist just wants to know if they can prove their theory right.

Francoise: It's possible, but you don't do that at the expense of live human beings and that's what you would be looking at here, right? We are talking about taking a human embryo, genetically manipulating it, putting it back into a woman, hoping that a child will be born and then we'll look and see if it was safe and effective. You're talking about putting human beings at risk. We typically don't do that with research, right? We typically try to make sure that you have what's called a favorable harm benefit ratio[14] and this is a context in which you can't know that for the individual human that you are creating, right? This is not going into a human who has an illness where you're saying to them, look, this is your illness. These are the things that are likely to go wrong with you. Would you like to participate in a clinical trial where maybe we'll be able to make things better? We might not because I'm a scientist, I'm trying, I'm hoping to make things better for you. It may not work. That's a very different situation. And so what happens in the scenario we're talking about is the research participant is both the embryo that you're going to manipulate and the parents or the perspective parents who are participating in this trial. And I think we really need to say at some point do scientists just get to do whatever they want just because they have a question? I mean, you know, without getting too dramatic, we have had some horrific things happen throughout history because scientists should have just had questions that they wanted to ask. Right? And I'm not going to mention the most notorious example which happened in World War II, right? We don't do that typically to human beings. We do some pretty horrible things quite frankly, to nonhuman animals. But we don't typically do those horrible things to human beings.

Emily: So if we look at He as an example of, you know, sort of taking this and running with it a little bit, I mean like as you made the point, not as a, you know, outlier really like as just the first person to actually execute on this. But in terms of thinking of the alternatives

[14] https://clinicalcenter.nih.gov/recruit/ethics.html#4

which you've just provided a, you know, a number of examples of like if this, if the outcome is the ultimate goal, then in a lot of these cases there are other avenues to pursue that are safer. That we know are safer, right? That have been proven, that have been tested and all that stuff. And the example that you know, that he provides is this idea of becoming HIV resistant. And my understanding is that there are drugs that do that[15], right? Aren't there a lot of drugs that moms can take so that they don't pass HIV on to there?

Francoise: So there's a couple of things to think about there. First of all, you're absolutely right. There were alternatives that would be considered safer and the alternatives actually occur in two contexts. First of all, it's highly unlikely that the offspring would have had HIV through the mother. The mother was not HIV infected, the male partner was HIV infected. And in that context, what you could do or what would happen in a North American situation is they would be probably using in vitro fertilization. So making the embryo outside of the body, the sperm would have been treated and washed, etc. And you would've been able to have a child without HIV. So in the abstract, probably not in China, probably not for these couples because they would not have had the money to get access to the technology. And it's also my understanding that there's cultural constraints on the idea of whether or not you can have children if you are HIV positive. So probably not in China that it was an option, but certainly in other parts of the world, affluent parts of the world such as North America, you would have had alternative ways of making children that would not have put them at risk of HIV transmission in the first instance.

Emily: But if your point earlier about that it's $1 million dollars per baby and they did have HIV and they were able to have a baby in China. I mean, I feel like that sort of seems contradictory now.

Francoise: Well, there's two different things. So first of all, access to HIV, access to the in vitro fertilization to wash the sperm, etc. would more be in the lines of maybe $20,000. There are people in China that would be in that bracket. Probably not these couples that came forward. So these couples who participated had IVF provided to them for free and in fact they were also paid. So there are many financial incentives that would have made it possible for people to choose to participate in that research. And just to be clear for listeners, when I gave the figure of $1 million, that's extrapolating from the cost that we have now for gene therapies that are being offered to patients. And so I have no idea what it would really cost in the context of any future world in which we might offer this particular technology in the context of reproduction. I am just saying that in the context of right now, treating patients, it's already extremely expensive. So this is not for the masses, this technology. Now going back to this particular case, I think it's also important to appreciate that aside from whether or not the children would have received HIV in the context of the birth situation, one of the claims is this would protect them from later on as an adult or a young adult acquiring HIV. And the issue there is again, there are safer alternatives. You teach people about safe sex. You teach them about other behaviors that they shouldn't participate in if they wish to avoid HIV. And then you get to the stage that if you are unfortunate and you still acquire HIV, we do

[15] https://aidsinfo.nih.gov/understanding-hiv-aids/fact-sheets/21/58/fda-approved-hiv-medicines

have a number of medications that we can offer and people now, you know, it's not a death sentence the way it was some 20, 30 years ago.

Francoise: So I think in that context, there are many ways in which you could legitimately say there were alternatives. Now Doctor He has said in response that that perspective is not a culturally attentive to the realities in China and that in that particular country, the views and the attitudes and the quality of life for persons with HIV is very different than in North America. And I can't comment on that. But the point is he was saying, I'm actually developing a preventive technology and that that preventive technology, if it works, could be available to the world. And so that's his perspective at the time.

Emily: Again though, I sort of go back to if you were going to prevent one thing, would it be HIV or would it be cancer? Right. Or heart disease or something else. And I had heard that there was also another CRISPR baby who was a PCSK9 for so like to try to decrease the LDLC production. I dunno if you're familiar with this at all, but that's another one where I feel like that's a little, I mean heart disease is obviously a huge killer.

Francoise: Well, I would say that all of the areas in which people are currently working in human embryos and that's because of the way in which we do science, which really circles back to something that you said, which is that a scientist has a question. They want to know if it can work. They don't actually sit down and I know this is going to be hard to believe, but they don't actually sit down and say, what's the biggest problem we have in the world and let's try and fix it. And they don't even say, what's the second biggest problem we have in the world and how can I use my talents to fix it? They don't even say the third, the fourth, the fifth. They don't prioritize what are the big problems for the world. They basically look at their skillset and they say, what is it that I know how to do and that's what I'm going to do. And that's one of the things that I think people need to start thinking about. Do we identify what are our big problems and then put all of our talent and our treasure and our energy behind solving those problems? Or do we just say to the scientific community, hey, any question you have, go about finding any answer you want. Now, when I say that, please understand that is extremely controversial. Most people are going to defend the view that scientists should be able to ask and answer every question that's of interest to them. Everybody will probably say something like, you shouldn't micromanage science. Everybody is going to say serendipity. You can never know what are the benefits of what's going to happen once you start asking questions, and I have sympathy for all of those claims, but if we just take this one example, why wouldn't you pick a genetic condition that affects more people? Why wouldn't you pick a genetic condition that has the most devastating consequences? Right, and that's not the way in which we do science. And I can say often I have said to my colleagues, if we really listened to CRISPR, if we watch what happens with CRISPR, it will teach us all the things that we do wrong in how we manage science.

Emily: Tell me a little more about that.

Francoise: Well, I think that what we really need to be thinking about is what is it that would benefit humanity. And I actually think if we can find uses of this technology that will benefit humanity, then that's a whole lot better than finding a technology that's going to meet the needs, wishes, wants of some 300 couples that have decided that for them a non-genetically related child is just not good enough. And I think, you know, I understand that there's this kind of visceral drive and this energy to think it's really important to have genetically related children, but we have to decide are we going to support that or are we going to say, yeah, but you know what, we're mistaken about that view. That's what's important. What's really important about a family is loving and caring and nurturing those children. That's what makes a family not whether or not you've got some blood tie. We could invest in helping people to understand what's important about families, or we can say, no, no, you're right. All that matters is the genetics and your genetics are the best in the world. So we're going to help you to pass on your genetics. I mean, what we really need to do is look at the world in which we live and figure out what would it mean to help the world and here's one of the ironies. One of the things that would help the world are in fact preventions, prophylaxis. The exact kind of thing that in theory Dr. He was trying to do, he was trying to say, look, why don't I find a technology that can help the whole world? Well, if you had something that would prevent HIV, in theory, you could make that available to the whole world because the whole world would not want to have HIV. And yet what's interesting is everybody has come down really hard to say this was a terrible use of the technology. And then they highlight other uses of the technology that are gonna help a fraction of the population of the world. And during all of this, they forget that even Nobel laureates had at one time suggested that using genome editing for HIV prevention would be a good goal. We actually have in print, several scientists making this kind of claim some 20 years ago when it wasn't possible.

Emily: This is just symptomatic of the ambiguity that we're in right now about whether this is good or not, right? I mean, I think when people are talking about things, and in theory it's real easy to say like, wouldn't that be great? But then when it starts happening, I mean, just historically, this is what happens with humans, right? We all sort of take a step back and become more skeptical when we realize it's a reality.

Francoise: I think that's absolutely true. And I think, you know, there's quite frankly also the politics of science and we haven't really talked about that, but there is the equivalent of a race going on that's no different from what was the Sputnik of the 19, what was it, sixties, seventies, et cetera. And I think that where gene editing and gene transfer technology is concerned. That's what we have going on. There's a competition to see who's going to be first, who's going to be the best. And quite frankly, a number of American scientists have said that they're quite frustrated by the fact that China is able to forge ahead because from their perspective, they have a different regulatory system that allows them to move more quickly than in the United States. And so just recently we had the news that the University of Pennsylvania is going to be moving forward with genome editing technology in the context of treating patients for cancers[16]. And they're frustrated that Chinese scientists were able to get there sooner, get into the clinical trials sooner. And Dr. June described this as Sputnik II[17]. So, you know, we also need to think about what happens in science. And there's a kind of nationalism involved in

[16] https://www.thedp.com/article/2019/04/crispr-clinical-trial-penn-research

[17] https://www.nature.com/polopoly_fs/1.20988.1479924656!/menu/main/topColumns/topLeftColumn/pdf/nature.2016.20988.pdf?origin=ppub

science. There's a personal sense of accomplishment, wanting to be the first, wanting to get the Nobel prize, et Cetera. People don't share information in science. That's what I mean when I say CRISPR could teach us what we do wrong. If you really wanted to help people, you would want to reframe science so that it was more collegial and not competitive. That's my view. Other people think competition's great and that that's how you actually spur people on to be successful. I guess I have a different view about what makes for a better world.

Emily: Well, and when you paint the picture from the sort of futurist perspective as this almost becomes a national defense kind of issue, right? Like if you can, if China is able to alter the genetic makeup of its citizens in a way that allows them to see at night and not breathe oxygen anymore, right. Or something really unbelievable, that certainly puts them at a great advantage for the future. So we're going way beyond like what do parents want in that when you put it in that framework?

Francoise: No, absolutely. And I think we have a term for that and we call that dual use research, which is we know when we go into this arena that we might have very good intentions about how we'd like to use this technology, but we can already see, you know, that other people with different values, different goals, different beliefs might want to use this technology differently. And you know, certainly in this arena people have talked about its use, for example, with the military. I mean the example of eyesight like that would be really great instead of having to wear all this technology on your head to be able to see, you know, in the dark and infrared, et cetera. What if you could just change people's eyes? Right. So, you know, it's not, I mean, it is science fiction, but it's not inconceivable in terms of the science fiction, if you know what I mean. But I think it's especially because that's possible, that what you want to do is you want to make a different world, right? You want to change the way in which we think about each other and learn to understand what we have in common. And the most interesting thing is that what we all have in common is our genome, right? Metaphorically speaking. I mean we don't all have the same genome, but we all have the human genome, right?

Emily: Well, when we share like 99% of our genes[18], right? I mean like it's a huge amount of–

Francoise: RIght, but the point there is that typically in the context of aggression and wars and things that are negative, it's because we're able to sort of have this divided us and them. And basically we then sort of see solidarity with those that are like us. And typically we've understood that narrowly in terms of the nation state or in terms of geography or in terms of race or ethnicity or culture. And what I'm imagining is a quite frankly, utopian world in which we break down this idea of us and them and that where we have the solidarity is with us all. Now, again, I know that people who disagree with me think I'm kind pollyannish you know, it's been said to me, you know, oh well if you want to know how 100,000 flowers bloom, go talk to Francoise. But if you want action, come see me. And I understand that at some level it may seem, you know, like this kind of strange euphoria, but I want to say back to you that if we do not get to finding a way to see that we're all in this together, we will, we have absolutely will just destroy ourselves. And that's why, go back to what I was saying at the beginning about the fact that we are

[18] https://www.genome.gov/about-genomics/fact-sheets/Genetics-vs-Genomics

destroying our planet. And if you think about it, everything we know right now talks about gene environment interaction. And when we talk about that, we're thinking about the gene in its environment. Well we are the gene and this is our environment. And the two interact. And if we don't start understanding that we have something in common, it's all of us in this together, which is what climate should be teaching us, right? I mean, if the air is polluted, it's going to be starting in one place. But eventually all of us will suffer. If the waters are rising, yes, it'll first attack some parts of the world, but we will eventually all suffer, right? If we lose, you know, all the fish species, we will all suffer. We need to start understanding that we're all in this together and we need to break down this mentality. And right now we're doing the exact opposite. We are bolstering the competition and we are saying, you know, we've got to be first and you know, we need to pay attention to those facets of how we do science.

Emily: I started thinking about this topic in the sense of just sort of homeostasis inside the body, right? And that when you mess with one thing, you are most often messing with more than you realize and that the body has a profound way of staying in balance. But I think what you're bringing me to in a way that I hadn't thought of it all before was the idea of environmental balance as our outside biology or however you want to call it, outside environment versus inside environment. And that those two things need to be in balance in order to have sort of optimal health. And so this idea that you're tinkering with something on the inside and not having any other impact seems just illogical, it seems like everything that I've ever learned about the way the body works is that there are always ways that the body compensates that balance out. Right. And so, and I think what you're saying is that the outside, like the how we're interacting as a human race, all of these things are being messed with when we're doing this kind of work.

Francoise: I think that that's one of the things that's very unfortunate about the science, which is that I think it is doing something that I refer to as reification of the gene. And what I mean by that, I mean, it's just a fancy word to say that we're overvaluing the gene to the point that we're actually making the mistake of falling into this notion of genetic determinism where we think that the genes control, right? And you know, you can see in the media all the time, the gene for this, the gene for that we found the gene for obesity. We found the gene for whatever, you know, we're going to fix the intelligence gene, we're going to fix the sporting gene. And I think that one of the things that happens is we sort of narrow down and we're focusing on the inside of this little cell, this little strand of DNA, and we're going to cut and we're going to fix things. We're not understanding the bigger context in which as you change your cells, you're changing our cells, right? And here, I mean it both ways our cells and ourselves, right? Ourselves in the world. And the way in which that will happen is if you start manipulating some people and you're only going to manipulate those who have the money to pay for whatever those fancy manipulations are going to be, it's already been predicted that you're going to actually have a bifurcation in the species between the haves and the have nots. And people anticipate that this is going to lead again to a fair number of problems. And I think that, you know, that to me on one level ois science fiction, but the, the core example of issues of access and who will have access to the technology, well that's not science fiction and we live that right now, right? Some people have access to life saving technology, other people do not. And so you really need to think about what does it mean to develop technology that people will be able to use to inscribe their privilege. Their social privilege, their financial, economic, political privilege in their DNA. What does that mean when you've taken that and you're the only one to have access to this technology? So what becomes really important to think about is the quality of life that you have while you are alive. And the fact is that we've made a number of assumptions that say people with these genetic conditions have a terrible quality of life. And so we want to fix it. And one of the things that we haven't talked about yet, or the number of people who are living with different genetic conditions who say to us, this isn't so terrible as you think, and I quite like my life. And I don't see it in the way that you perceive it. And I think that, you know, that's one of the voices that we haven't listened to very well. The classic example that's given here is around deafness. We have scientists who have said they want to use genome editing technology to correct deafness and people who are part of the deaf community say, we don't have a problem. Like what are you trying to fix? We have a wonderful community. We just have a different way of communicating. And so I think, you know, that's one of the things we haven't talked about here is that who actually wants which technology and for which ends? Is that the people that have those conditions or is it the parents of people who might have those conditions who have different assumptions about the quality of life for themselves and or for their children. I think that's a really important thing to be aware of and to think about. And the other most important thing for people to think about is the following. When you make a genetic manipulation to an embryo, you are not treating a person. Not only are you not treating a person, the person that might be born is a completely different person than the person who would otherwise have existed. This is about wanting a particular kind of child. It's not about having a child in and of itself. And I think that that's a hard thing for people to grasp. If you are born with an illness, you have a particular life story and it may not be the terrible life story that you imagine. It may be, I'm not trying to say it's going to be a wonderful life story. I'm just saying it's going to be a completely different trajectory. And we know throughout history of many things, people who have made wonderful contributions to society who did die young but who had an amazing life while they lived. And in part they had an amazing life because of some of the adversity that they had, but they had great creativity and they managed to do something. So I mean, let's take Stephen Hawking[19] who just recently passed away. Everybody will admit and agree that he made tremendous contributions. He himself said he had a great life. Many people who look at his condition would say, wouldn't it be better if you know a baby had been born without that condition? What would he have been Stephen Hawking, the Stephen Hawking that we know that made all the amazing contributions?

Emily: I think that's such a great question. I mean, and so I think in some ways that brings me back and to this idea of social acceptance and how do we create a consensus about these kinds of things. When it really is, I mean both, it's a minority who would be experiencing, we could say benefiting or not depending on how you look at it. But the decision rests with, you know, a very small minority compared to the world population. Right? So how do you foresee any ability to have any kind of broad social acceptance?

Francoise: So,I think that one of the things that becomes really important is for people to buy into the idea. And what does that mean? It first of all means that everybody accepts. I'm

[19] http://www.hawking.org.uk/

actually not a luddite. I don't actually need to know as much as these important big thing scientists to engage with the question: what kind of world do I want to live in? Because that's what the science is about. It's about creating a world. It's about creating a future world. And so everybody on this planet has a right to think about what kind of world do I want to live in? It's not about a majority and I'll go even further. It's not about a minority holding veto power and stopping the rest of the world moving forward. I want to suggest that if we really changed the way we approach questions, we're in it together. What we're going to start looking to find ways to compromise and it's really a much more organic kind of shifting and what's going to matter at the end of the day is probably the journey more so than the destination. We're actually going to start treating each other differently. We're actually going to start prioritizing different kinds of questions. We're actually going to look for solutions to problems that we didn't think were the ones we were going to address. And so what I really asking for when I talk about broad societal consensus is I'm asking us to valorize each and every one of us to engage as many people as we can in the conversation. Because what we're talking about doing is changing the species and we have a right all of us to engage in that conversation. We've never done anything like that before, so it's wild and wonderful, but why can't we do that in the 21st century? What can't we find a way to talk meaningfully about something that affects us all?

Emily: I'm Emily Kumler, and that was in Empowered Health. Thanks for joining us. Don't forget to check out our website at empoweredhealthshow.com for all the show notes, links to everything that was mentioned in the episode, as well as a chance to to sign up for our newsletter and get some extra fun tidbits. See you next week.