



2021_April 15_The Dark Future of CRISPR

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SPEAKERS

Rosemarie Garland-Thomson, Tim Leberecht, Monika Jiang, Sandy Sufian



Monika Jiang 00:00

Welcome to Beautiful Business Live, the weekly room by the House of Beautiful Business on "The Dark Future of CRISPR." I'm Monika, head of content and community. I'm based in Berlin and am joined today by my colleague Tim.



Tim Leberecht 00:17

Hi, I'm Tim Leberecht. I'm a co founder of the House of Beautiful Business. I'm actually currently in Lisbon, Portugal, which is the city where we hold our annual festival. We've done so since 2018, here in beautiful Lisbon, and will do so this year as well. The House of Beautiful Business is a global community with a mission to make humans more human, and business more beautiful. We create brave new spaces for discussions about this brave new world that we live in, partly or to a great degree enabled by the kind of technology that we'll be discussing here today. We host online and offline events, monthly, yearly events, we publish in the form of articles, books, and a weekly newsletter called Beauty Shot that you can subscribe to. And we work with organizations who want to lead the shift from business-as-usual to business that is beautiful. Just one housekeeping item: we are recording this session here today and we will make it available in audio and in the transcribed version.

M

Monika Jiang 01:27

This week, we dedicated our Beauty Shot newsletter to the topic of ethics. From vaccine passports to profit making as a kid influencer, the moral education of big tech engineers, the yet unknown of physiological, cognitive, and behavioral effects of extended reality technologies (we're actually hosting a Living Room Session on that very topic tomorrow on good old Zoom), and gene editing. More precisely, CRISPR, arguably gene-tech's most remarkable and thus highly disputable tool. This is what we want to discuss with you today. What is really the core ethical concern with CRISPR? Where does the common understanding of good and bad genes come from? And how can we start making the decision for embracing multiplicity rather than altering cutting weight parts of our humanity? To help us make sense of all of this, we're thrilled to be joined today by two guests who you can see here on stage of their first Clubhouse room. Rosemary Garland Thomson, a bioethicist and humanities scholar, who also recently co-edited the book "About us: Essays from the Disability Series," which began as a weekly series in the New York Times. And Sandy Sufian, who is an associate professor of health, humanities and history at the School of Medicine at the University of Chicago, and is currently working on a book about the history of disability and adoption in America in the 20th century. So first of all, let me welcome you both Rosemary and Sandy!

S

Sandy Sufian 03:19

Thank you so much for having us, that's number number one. Number two is that I'm dying to go to Lisbon. So we have a visitor soon!

R

Rosemarie Garland-Thomson 03:43

Well, thank you for inviting us. I'm delighted to be here as well. And looking forward to being able to talk about some of these really important ethical, but also public issues with you.

M

Monika Jiang 04:02

Thank you so much, Rosemary and Sandy, it's great to have you. First off, before we dive into all these really complicated and important questions: can one of you explain what CRISPR is? Just so we're all on the same page here in this room. What makes it so remarkable?

R

Rosemarie Garland-Thomson 04:22

I can actually speak a little bit to that because even though I'm an English teacher, not a scientist, but as a bioethicist I've been writing a bit about CRISPR and I've been asked a lot about CRISPR. Sandy also knows a great deal about it. But CRISPR is talked about as being a tool. It's a tool that can be used to cut and paste and edit genes in order to change the genetic makeup of either an individual or the human germline or the human gene line. So there are two types of uses for CRISPR. And they they differ a great deal in their ethical implications. One is what we call somatic gene editing. And that is using this tool, this scientific and medical tool. And I'll talk a little bit about that later, in order to change the genetic profile of an individual. And this is sometimes called somatic gene therapy. That is not as controversial, because the changes take place to an individual and the individual gives consent, in other words, exercises, autonomy, patient autonomy, in making decisions about what happens to their own bodies. So that is, as I said, much less controversial ethically. The other kind of use of CRISPR for gene editing is to edit the reproductive cells, in other words, to edit people so that the edits or the changes will be heritable, that is to say, they'll be passed on to future generations. So this is a really important, as I suggested, ethical and even moral distinction, because a somatic change in someone's genetics ends when they die. A heritable change to someone's genetic condition or situation can be then passed on for ever, in future generations, that that altered person, in genders into the world. And so this is one of the main concerns about using CRISPR is, there are worries about things. And this is an unsettling term, about off target effects. Because it's a metaphor, the idea of cutting and pasting and editing. It's not a computer, it's not word and, you know, a document in this way that can be edited and changed. It's actually a piece of biology. And so one of the criticisms of, of CRISPR is that it creates a kind of confidence that we've seen a lot in human endeavor, that there won't be any mistakes that this is easy to do that this is safe. And this is effective, kind of like the invention of plastic, or nuclear energy that we thought was going to be entirely swell in making humanity better. And we discovered that there are all sorts of problems, unintended consequences, off target effects of any of these really progressive technology developments. And so part of what bioethicists want to do is to call attention to the optimism, if you will, and the possible effects that could be engendered literally by using CRISPR to edit the heritable German human gene line. That's a long answer.

T

Tim Leberecht 08:41

On that note, before we we really delve further into the, you know, the ethical complexities and the concerns that the two of you have in terms of the future of CRISPR. Can we just get excited about CRISPR for for a moment, and the possibilities and the

opportunities that it presents? I mean, even with, you know, a nuanced view of a bioethicists could could you just share with us what makes people so excited about CRISPR? In terms of like the benefits, for example, eradicating or curing genetic diseases, potentially producing more healthy or healthier food? Would you mind just kind of go going through that really quickly? I think that might be helpful.

R

Rosemarie Garland-Thomson 09:24

Well, I don't want to push Sandy's opinions out of the way. But just briefly, this is exactly right. With any kind of technology, there are benefits, and there are potential harms. And I'd like to simply concentrate on using CRISPR for humans to improve humans. And the benefits, of course, would be that we could do two things. We could eliminate what I call the human variations we think of as diseases disability defects, and to make human beings healthier, both present human beings and future human beings. So that's a really wonderful and important promise. And all we have to do is look at the history of medical technology for one second, and realize that the development of things like vaccinations, or which we're thinking a lot about now, and that's different from CRISPR. But these kinds of health improvements will make life better for all of humanity. So that's a really positive promise. And we need to pay a lot of attention to that.

S

Sandy Sufian 10:45

I add something here? And that is something that we talk about in our op ed a little bit, I think, the promise of CRISPR. And one of the things that people get excited about is the potential for eradicating human suffering. So Rosemarie and I take that up: What is suffering? Do people with disabilities always suffer all the time? But it is a critique that we're trying to make in response to the argument that CRISPR is so exciting, because it it can create potentially the sort of the end of human suffering for people with genetic illnesses or populations, and genetic illness.

T

Tim Leberecht 11:41

And, and maybe just one last round of level setting, because I think what is probably closest to layman like myself, right now, of course, are the COVID-19 vaccines, especially the messenger RNA vaccines by Moderna and Pfize and BioNTech. So I think some people think that is actually a case of genetic editing. But it is not right. Could you just sort of shed some light on that? What is the relationship between gene editing and these mRNA vaccines that we're now seeing?

R Rosemarie Garland-Thomson 12:15

I am not able to address that, other than to say anything more than you said. And that is, it's it's a different process? Because I am not a scientist, or, or do I have any medical training? Sandy, you might, you're a historian, you might know a little bit more about that.

S Sandy Sufian 12:40

I think just I have a superficial understanding, and that is that there has been some discussion about editing the virus itself, of COVID-19, either attenuated or change, you know, somehow change it so that it's not as deadly now mRNA vaccine. And Pfizer uses sort of your internal, your RNA to and I don't know enough about the technology, but uses is sort of activates a response, an internal cellular response to the virus. As far as I know, it doesn't involve editing now, but I could be wrong.

T Tim Leberecht 13:44

I think I read somewhere as well, that it does indeed not alter the DNA. So it doesn't add it right. It basically prompts the RNA to respond, but it doesn't it doesn't add it.

S Sandy Sufian 13:59

Yeah, that's what I know about these vaccines is that it's, it doesn't edit it, it activates. Whereas the use of CRISPR for for COVID-19 is about editing the virus, just like the beginnings of CRISPR has to do with editing bacteria to address multi resistant bacteria concerns.

R Rosemarie Garland-Thomson 14:27

And one important thing, of course, about CRISPR as a tool, is that it can be used as Sandy suggesting and as we're talking about now on a variety of different objects or different living things, plants, we have genetically modified food. But there are other ways that medical science imagines, eradicating, or at least reducing human suffering, through reducing what we think of as disease and disability. And that is by, here's a good example. There's a lot of conversation about developing a heritable or inherited gene therapy for a disease such as sickle cell. But there are also other approaches. For example, one use of CRISPR that is proposed, and I haven't followed this recently, but I think it's really interesting is to address malaria by editing the genes of mosquitoes. And so that would be a way of doing something with it, which is what they call a gene drive, which is to change the mosquitoes, which, of course, are the carriers of malaria in order to, again reduce

human suffering, and to cure human disease. But that's very controversial too, because, again, there's the difficulty of these off target effects. If you do X to mosquitoes, like for example, make them sterile, so they can't reproduce. There may be again, unintended consequences, like bringing in kudzu, for example. That's always a good, you know, a good example of trying to change the environment in order to solve a problem and then creating other problems that weren't anticipated with the kudzu as an invasive species, which was thought to solve problem a, but it created Of course, problem B.

M

Monika Jiang 16:36

I want to come to humans again, and gene editing in humans specifically. So there's a book out currently, that probably a lot of you have heard of in the audience as well, which is the codebreaker by Walter Isaacson, which sort of chronicles the scientific discovery and the work of Jennifer Doudna. And the author, Walter Isaacson said, the distribution of the technology and the fear of so called "capitalist eugenics" So the idea that he refers to is basically a "genetic supermarket." Imagine that, and the fact that we can only buy, obviously, what we can afford. So companies can can market, different things that you can get when you go to the fertility clinic, and they'll say something like, Okay, so what do you want? Like, what kind of skin color do you want? What was sexual orientation? What height? What IQ should your child have? And then you can get what you can afford, I guess, or not. So just to unpack this a little bit and start with eugenics as a term. Sandy, can you maybe give some context around the linguistics and the history of eugenics?

S

Sandy Sufian 17:59

I can try. It's a huge field, the history of eugenics. In the 19th century, and early 20th century, eugenics was the science of improving the race. And so there were many different ways to do that. Meaning you could do positive eugenics, which would be to promote marriage, and pronatalist policies for white people, wealthy people usually. And or do net negative eugenic measures, which would be something like what Hitler did, which is, I mean, that's the most extreme would be genocide, or, you know, other kinds of anti, for example, anti immigration policies, because immigrants, people of color, disabled people, these were people who were deemed inferior versus white upper class, people who were deemed superior. And so this is what we call scientific racism. It starts sort of, you know, scientific racism is about sort of the ladder, so to speak, the hierarchy of races and eugenics are takes that and puts it into policy all different kinds It's a policy, educational policy, medical policy, immigration policy, etc. Now, it starts really, a lot of people who were a lot of scientists who were working in eugenics actually are starting with plants and animals, and ants, and Adam, you know, other other kinds of species. But then they bring these ideas about human sorry, breeding into human breeding. So that's a very, it was

quite common and very considered quite serious field in the late 19th, century, early 20th century, it then takes on different kinds of modalities in the post World War Two period, where you have a lot of marital counseling, and things like that. So in the 30s, it declines geneticists sort of distance themselves from eugenics, but it's still kind of there and takes on different ways of being in the post World War Two period. There are many, many, many books around the history of eugenics. So I was just trying to give you a synopsis, let's say. Rosemary, do you want to add anything to that?

R

Rosemarie Garland-Thomson 21:39

Well, thanks. I think the term genetic supermarket is terrific, because it really captures through a metaphor. The problem, or really the ethical issue with making people according to some kind of a value system, that is extremely current to a particular time and a particular place. When in fact, you know, what counts as a useful trait, or a valuable trait changes over time and over place. And so the genetic supermarket, which makes so much sense, in a way, in terms of parents, giving their kids the best that they can give them can also end up creating, again, problems for kids, or for future generations that we hadn't imagined. Just as, you know, Hitler's always a touchstone for these sorts of things. Because Hitler had an idea or Nazis in general, had an idea that the best way to be the best traits, the best kind of person, the healthiest, the happiest, the best, or ariens, because those were very valued traits at the time. And we saw what was wrong with that, quite clearly, it wasn't so much that the traits that the ariens supposedly had were not beneficial traits, but rather, that the people who didn't have those traits ended up basically in the gas chambers. And so the whole Holocaust is, is a cautionary tale, in balancing the benefits and the harms of any kind of medical and scientific endeavor. And also, the idea of a genetic supermarket, I think, is great because it it introduces the idea of of commerce, and, and how commerce creates incentives to do things that we may end up not wanting to do like selling too much oxy cotton to people, or, you know, building too many automobiles that that ruin the, you know, the the environment. And so, it's a very vivid, very vivid term.

T

Tim Leberecht 24:35

Rosemary, just to kind of double down on that: I was listening to a podcast of Ezra Klein, with Walter Isaacson, the author of "The Codebreaker" that Monika mentioned, and his argument or his main concern is very much one of distributive justice, the ethics of distribution of CRISPR technology and the the socialist equity that it might create. There are two other I understand ethical concerns. One is, I guess the right to manipulate the human genome to begin with to play golf, right? That is an ethically challenging question.

Then you mentioned the unintended consequences, the off target effects. That was also worth considering, obviously, and then there are the ethics of distribution. So in your article in the Scientific American and in your work, is it correct that the ethics of distribution is sort of your primary concern? And wouldn't that suggest that the issue is capitalism or a free market distribution of technology rather than the technology itself?

R

Rosemarie Garland-Thomson 25:46

There are two ethical problems that are prominent one of them is exactly what you're talking about. And that is, the increasing inequalities that occur which already occur. And that is where you create, like, like the movie Gattaca, you create permanent embodied genetic classes of people that are understood as inferior. And that's, that's one problem. And also, I mean, that comes from unequal access to medical and scientific resources, which is a problem that we have in general, in the democracy that's supposed to be based on everyone having equal opportunity and equal access to the benefits of a society. But the other problem at which I think, gets less attention, which is really important is the tendency for a genetic supermarket to reduce human diversity. We know that in the plant and animal world. Biodiversity conservation is a really important principle and ethical principle. It's a practical principle that we want to have as much diversity as possible. But we don't do that very much in considering human beings. In fact, in truth, we're working toward reducing diversity in human beings, even though we speak a lot about racial diversity and gender diversity, and diversity in terms of sexual orientation. Biological diversity is, is important, but that is not what something like a genetic supermarket would end up creating.

S

Sandy Sufian 27:43

When you when you say genetic supermarket, what comes to mind is like, are some traits going to cost more than other traits, like with in the supermarket, they're probably I would think, would be a range of prices, as well, that would reflect that hierarchy of what is inferior superior. And so in the end, you might I mean, distributive justice, or, or you know, who can afford what isn't it? It would be an important thing to think about, not only just having a genetic marketplace, but also internally the economy of that genetic marketplace.

M

Monika Jiang 28:32

That's exactly right, and just reset the room quickly, for those who are joining: we're in the middle of discussing the ethical concerns with CRISPR and have just explored what Walter

Isaacson published the book, *The Code Breaker*, on the work of Jennifer Doudna, the scientist who discovered first discovered CRISPR, with Emmanuelle Charpentier calls it a genetic supermarket, as we're discussing about the access to it and how much capitalism as an underlying system, of course, plays a role here as well. Rosemary and Sandy, you and your your article that we brought up already in the *Scientific American*, you share a ride that you both have genetic conditions that many people would consider serious enough to eliminate from the human gene pool. You describe how medical treatments and social progress and also political equality movements have elevated your quality of life in a way that maybe prior generations would have not imagined. And you touched on this briefly, Rosemary as well that yet despite all of this progress, and the cultural assumption and the language specifically is one that associates disabilities and people with disabilities with "suffering" that is automatically gives you a sense of something negative, something unwanted and unwanted condition that diminishes sort of the the perfect life, or we understand His perfect life and you bring up the term common sense ableism by James L. Attorney. Can you explain what's meant by that? Exactly?

R

Rosemarie Garland-Thomson 30:28

I think that what's important is to think about the context of a whole life. Part of what Sandy and I and many people who work in this area, who are people with disabilities put forward is that, you know, a disability is, is one part of, of who we are. And the effects of our disabilities on our lives are one part of a whole life. And so what determines quality of life, and what determines levels of acceptable and unacceptable human suffering, very often are bigger and don't necessarily turn on the presence or absence of a specific kind of disability. And part of the problem when we look at the human condition is, it's it's kind of a problem that has to do with with time in a way. So if you say to anybody, do you would you rather? Here's an example. So I have six fingers, and the people say to me things like, what would you rather have 10 fingers than six fingers? And my answer to that is, Well, sort of. because it'd be nice to have 10 fingers, it would be nice to you know, wear rings on every one of them, it would be nice to be able to use a keyboard in the way that people attempt fingers use a keyboard. On the other hand, the real question is, What? How has that affected your life? The real question is, what would you want to give up in order to get that 10 fingers? And there's a kind of border about where these questions are? And I can sometimes ask a question back to someone who says something like that. And that is, what would you rather be? six foot 10? And that they can think a little bit about that? And what would you give to be six foot 10? And the other part of the answer is how has, you know, having six fingers shaped my life and other sorts of ways. And the point is at the beginning of life, if you say to a prospective parent, would you like to have your child have six fingers or 10 fingers? Of course, they're gonna say 10. And so what it is, is that there's a kind of bias, I guess, built into the idea of normal, the belief that if you're

normal, if you have all these advantages that we think of as normal, that you will have a better life. And in fact, it's simply more complicated than that. And I think that's what's counterintuitive about the kinds of arguments that Sandy and I make about our lives. I don't know, Sandy, you might want to say more about that.

S

Sandy Sufian 33:57

I just want to speak to the term itself common sense. ableism, I think it gets at the of course, right? Of course, you don't want to have suffering, of course, you would want to be in perfect health. And so it's common sense that you would want to cure everyone, it should be common sense that we don't want to have future generations with X, Y, or Z genetic illness. So it's the assumptions around the value of certain people's lives. That is what we mean by common sense ableism or what, what the scholar meant, and then what we take up and so what we're trying to do is question those assumptions right? to question what is your I'm about to question what a human a good human life is. You know, even Tim to question, we want humans to be better humans, like, what is better? What do we mean by that? So to sort of not take this as a common sense thing that we should all just accept without questioning, that's what we're trying to take up here by talking about common sense ableism. And so what CRISPR, sort of the discourse around CRISPR often gets into exactly the first question we talked about, which is, you know, of course, we should want everybody to be cured. And without thinking, like, does everyone want to be cured? Who is who's the one asking that question? versus who's the one receiving that question? And what kinds of messages are underneath that? Those sorts of questions and ideas?

R

Rosemarie Garland-Thomson 36:09

There is the step. And just let me add one more thing. What what are the important things that Sandy's suggesting, of course, is what's the cost of these changes? And what could that investment of resources do elsewhere? How could it be used to improve lives in other ways, our lives and the lives of many other people. So resource distribution, and resource to equity is a really important factor in thinking about curing all diseases and disabilities.

T

Tim Leberecht 36:50

The opportunity cost that you bring up, Rosemarie, you were talking about this, this question of like, what makes a better life, which is probably a question of optimization, or enhancing performance in many ways in in a competitive market society. But there's also this question of what makes a life worth living. And I guess what I'm referring to is a

practices such as genetic screening of embryos, with research showing that, for example, if parents detect through genetic screening that their unborn child has Down syndrome, for example, that, you know, there are more abortions. And I guess we've seen, at least in Western societies over the past few years or decades, a shift to delegate in power over, you know, the decision power over what what life is worth living to parents, right to the individual away from the government from the state. What is your position on that? Because I mean, in those cases, we do make decisions right, on what life is worth living and which life is not worth living, which is, of course, a form of, you know, passive eugenics, if you will, as well.

S

Sandy Sufian 38:05

Rosemary and I have actually had conversations about this. And maybe Rosemary can speak more to this, I think we are, we are proponents of autonomy. And so, you know, it's a, it is a tricky question, because we would want people to make choices to be able to make choices about their families. On the other hand, just like CRISPR making those decisions, let's say, to selectively abort, a fetus with down syndrome doesn't account for changes in treatments, changes in life, life expectancy, or age of mirta, average age of mortality, which, of course, is just an average age anyway, I get those kinds of decisions are based upon the moment in time and the status of technology and medicine at the time, rather than like in my life with CF. I mean, our treatments have extended our lives considerably since when I was born. And we now have new medicines that will even extend them. Way beyond anyone's previous imagination now, CRISPR and even pre implantation genetic screening would never account for those kinds of changes. So I think it's very complicated.

R

Rosemarie Garland-Thomson 39:47

Yeah, and it's really important to think about, as Sandy suggested, how prospects for a good life change over time. Not Just in terms of medical treatment, but also in terms of the political and social context. So, you know, the disability rights movement, and the laws that came out of that, primarily, the Americans with Disabilities Act in 1990, changed everything for people with disabilities and people with what we think of as genetic illnesses. In that it, it changed us from being, if you will, patients, to being full citizens. So that, for example, back to the, you know, six finger problem, like in the 1960s, or 70s, somebody with six fingers who couldn't type would just, you know, not get a job, or not be able to go to school. Or you could say, well, this person can't do something, therefore, they can't be included into the society. Well, after the logic, and the policies and the practices of the civil rights movement, and the Americans with Disabilities Act takes place. somebody like me can use dictation technology, somebody like me can say, I can do this

job, I need to request an accommodation. And then I can do this job. So, you know, in a way before the Civil Rights Movement, somebody with a disability was just so well, they could be discriminated against at will, they could be excluded. There wasn't. There wasn't Free and Equal Education available. It was a time of segregation enforced segregation. When people with disabilities were not imagined as having any rights, because they weren't imagined as a political group, post ADA, post civil rights, we have a whole new world open to us, people like Sandy, and I would never, ever have been able to go to school in a way that would have led us to the jobs that we have as professors. I mean, that's a miracle. And it's a miracle that takes place through political and social transformation.

M

Monika Jiang 42:36

And that is so much happening right now. Right is specifically I mean, we'll look at society, but also in business specifically, there's so much happening in terms of multiplicity and diversity, from gender from neurodiversity, and all of these topics are being addressed. And initiatives are being started. Isn't that counter what is the perceived conformity? What is the perceived what we think of us as normal? Where are we on a bigger picture?

R

Rosemarie Garland-Thomson 43:19

Well, I'd like to use the example that Sandy brought forward about people with Down syndrome, because it's a classic example of how of the kind of the irony if you will, the paradox that people with Down syndrome born now have an extremely high quality of life. people with Down syndrome born as recently as the 1960s, and 70s. And I don't know this, exactly the dates of you know, it was recommended that they would be institutionalized. They had very, very often they had very low quality of life. And, and yet we put in place the genetic testing for Down syndrome is kind of the the number one test it was the first test to be used in the reproductive clinic, and ironically now, in the United States, and pretty much everywhere in the world. Well, in the Western world, I might say, people down syndrome have the best quality of life they've ever had in all of human history. At the same time, that the people with fetuses and embryos with down syndrome are being eliminated at extremely high rates. And so it this irony kind of stands as the difficulty that the disability rights movement and the advancement medical technology and treatment kind of need to work out together as to really important initiatives in, in liberal democratic orders.

S

Sandy Sufian 45:14

I would add also for business, right? So how do we thread the needle between diversity and inclusion initiatives in in the business field while then also having initiative initiatives like germline CRISPR, which whose message is, you know, we don't want, we don't, we don't want this group of people, or we think this group of people should have no place in the future in future generations. So it's a very paradoxical kind of messaging. The same as what raspberry saying about Down syndrome? You know, how do you have both of those things sort of exist at the same time.

R

Rosemarie Garland-Thomson 46:10

I'd like to put a plug in for a book that is written by a colleague and friend of mine, her name is Kat Holmes. Kat is a computer engineer and designer, who's worked in technology companies for a number of years. And the name of her book is *Missmatch*. And it's a book for computer engineers and designers. So it's about technology, about technology companies. And it's an argument for why technology companies or businesses in general ought to have dissent, disability, disabled people and disability as a kind of concept, a diversity concept and diversity, equity and inclusion concept in their companies. And I think it's a terrific book. And it might be something that the House of Beautiful Business may want to pay attention to and feature a little bit, because it's it's not an academic book, it's written for tech companies

T

Tim Leberecht 47:23

That's great, we'll definitely take a look at that rosemary, just to kind of reset the room. So we're talking about the "Dark Future of CRISPR." As I think we've sort of learned over the past 15 minutes or so that it's, it's maybe gray. It's not entirely dark. It's very complicated. It's very ambiguous. We started by learning more about what CRISPR actually is, we got excited about the possibilities in terms of curing diseases, and also producing healthier food and making other big changes in the world in this brave new world. Then we talked about though, I think, what is your main concern, your main ethical concern rosemary, Sandy, which is the risk and the fear that we might in the wrong hands, right, we might use CRISPR, particularly combined with the forces of a capitalist market society to create a genetic supermarket, which might, in fact, lead to a reduction as, you know, humankind, right, where there is a common denominator that actually deprives us of the full range of identity and genetic expression, which would be really dehumanizing. But then you also pointed out that, you know, and you're putting out several examples, and Monika mentioned that as well, that we've seen major social transformations, new norms, new values, right, that that have really come to pass and then have really entered mainstream, particularly in the past few years as well. So I guess my question is, if CRISPR, the

technology per se, is not good or bad, right? It's a matter of our values and how we design it and how we use it and how we distributed? Who holds the power to help us become aware of those values to help us align on those values. Is it is it pop culture? Do you see Hollywood entertainment, education, or social media? Is are those sort of the big forces of the big values drivers? Or is it different entities? Is it governments? Is it supranational institutions? Is it people like yourselves academics, who has the biggest power and thus the biggest responsibility in Yeah, and educating us on those values that then define the future use of CRISPR.

S

Sandy Sufian 49:42

I like to just quickly go back a little bit and that is to say, I don't think that that this is limited to capitalist societies. I think even socialist or communist societies, right? In the state could say, you know, these people must have, we must have CRISPR to get rid of these kinds of people. So I'm not sure I think the marketplace is a capitalist marketplace in the way that we're talking about it, but it's not necessarily limited by capitalism. And that gets to like, who holds the power? Right? And what if it's in the wrong hands? So I would say it's, the onus is on all of us. It's a cultural illness. It's a governmental, educational, medical, public health. I mean, it's no, that's sort of a not very focused answer to your question, Tim, but I think it has to be multi pronged, I think the the impetus to not question and to pursue common sense ableism is so strong. This idea of normality is so strong in our society, that it must be a multi pronged sort of educational initiative to think about and think through these these issues.

M

Monika Jiang 51:35

Rosemarie, did you want to say something to that? Let me just take the chance, actually, to invite you all, if you like, or if you have something to say this to challenge another question that you have. And just raise your hand and we'll we'll invite you up up here. You know how it works. So there's someone here in the audience, you can you can do that.

T

Tim Leberecht 52:27

The concerns that we talked about are not limited to a capitalist market societies. Like in terms of like system? How would you envision a societal system to look like that would best accommodate or best account for the concerns that he issued? I mean, I'll be looking for Do we need something like an equivalent of universal basic income? does there need to be a government mandate to ensure that there is universal access to the genetic supermarket to a suite of, of tools for everybody? So maybe help us help us imagine what

a society might look like that that is socially just in terms of access to CRISPR? And and use of CRISPR? technology?

S

Sandy Sufian 53:15

I'm speechless, I have to think through this. I mean, in America, the first, my first concern is universal access to health care. So just to have access to any sort of treatments, or physicians, or that, to me, is, is more important than access to CRISPR. Especially germline CRISPR. You know, I think, for me, the somatic cancer treatment based CRISPR technologies are would be part of this universal access to healthcare, which we don't have. So that would be number one in America at least. And then, yes, I mean, I think universal access to an income, universal income would be very important. But that I would want that having nothing to do with crisper an improvement in education improvement in just equity in general. So, I guess, for me, I'm, I, I can't really think about access to CRISPR before I think about just access and equity, broadly speaking, as a social justice, culture and economy.

M

Monika Jiang 55:01

I was hoping that maybe Rosemary would find her way back to this clubhouse world. But maybe not. Maybe not today, maybe another time. So I have actually one one last question, Sandy, before we wrap up, because we talked a lot about this, ever since we even touched on this topic of CRISPR, and disability justice. And when I first started looking into this for our beauty shop, newsletter this week, it triggered a lot of fundamental questions, when I started to think about it. So the question that I have for you is, what is it that that makes a life worth living, to you personally?

S

Sandy Sufian 55:51

Great question. I think for, for me, what makes a life worth living is supportive relationships. So, we were talking about, you know, what kinds of jobs earlier and have been able to have a job but, but a lie a whole life isn't just that it's about first and foremost to me, you know, having the ability to have fulfilling relationships, having the ability to pursue certain things within every I mean, everyone has limitations as to what their talents are and what they can pursue, or afford to pursue, but at least having that opportunity to pursue what they have in mind, or what they love to do. And contributing in some way to society, making a mark on the world in a way, you know, not not necessarily to become famous, or, you know, make some huge discovery, but, but to contribute in some way to things outside of yourself. And so, I think that would be my way

of saying that's a life worth living.

T Tim Leberecht 57:26

And we got Rosemary back. Welcome back, Rosemary!

R Rosemarie Garland-Thomson 57:32

Sure, yes. It's you know, these in home internet situations that we're all facing these days, where the signal comes and goes. Yes, thanks.

T Tim Leberecht 57:43

So maybe after we just ask Sandy about her definition of a life worth living? Maybe one final question for you. Rosemary is, you know, if you dream big, a positive vision of a crisper, and abled world or a world in which CRISPR plays a major role. Given all your concerns and considerations, what might that world look like in 10 years? That the most positive vision you can think of?

R Rosemarie Garland-Thomson 58:16

Thanks for that question. I think that the most positive version of what the world might look like in 10 years, and we'd want to think a little bit about what the world means, but let me just say, the world we know, in other words, you know, like American society, the world of rich countries, because it gets really complicated when we try to think about income disparities and economic inequality, but, but the promise of liberal democracies, I think, really has is being fulfilled, as I suggested through, you know, the slow closure of the gap between aspiration and actuality, when it comes to the civil and human rights movement. And, and what that world would look like is the world that that we're trying to aim toward, in our best version. And this is in business a lot our best version of diversity, inclusion and equality or diversity, equity, and inclusion. And that is, you know, a world where everyone has the equal opportunity for employment. Everyone has equal opportunity for education. Everyone has equal opportunity for access to good health care, and that everyone has equal opportunity. To to get access to economic resources and the goods, the moral and social goods that are available. And that's, that's a very, very well, it's very aspirational. But I think, you know, government has done a great deal toward it, which I suggested a little bit about talking about the, you know, the civil and human rights movements and those laws, like the Americans with Disabilities Act and other civil rights legislation. But, but, you know, the business community is nimble, and it has money, and when it puts itself

on to an imperative, if you will. And if this imperative is diversity, equity and inclusion, it can change a lot of things. And I think that's a very positive goal. And and there's a very positive notion of, of what a diverse and inclusive world might look like. out there. So business and capitalism is not the enemy in this. It's actually a friend of, of equity in this way and can be

M Monika Jiang 1:01:36

Thank you, rosemary. Thank you, Sandy. Thank you all for for your presence here and for sharing, and questioning, and all of these really tough but fascinating questions.

T Tim Leberecht 1:02:48

Thank you so much. And thank you for raising awareness of the new social fault lines and the new social divisions that these exponential technologies from community passports, which is what we heard from Francois Baylis last week, to CRISPR might might present us worse. I think this is a really, really important conversation. And tomorrow we'll continue with XR and what extent reality might do to our notions of identity and to our concept of what it means to be human. So I thank you all very much for joining us today. On Beautiful Business Live, our weekly clubhouse session. Thank you so much, Sandy and Rosemary!

R Rosemarie Garland-Thomson 1:03:28
for having us. Thank you, Tim and Monika

T Tim Leberecht 1:03:33

and, Mark, let's see if we can hear you now, as you Usher us out with a piece of music. Thank you and good night.