Stanford eCorner

Dissecting Sci-Fi Fears

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Anne Wojcicki, co-founder and CEO of 23andMe, talks about how ethical concerns over genetic research sometimes stem from science fiction. She uses the example of recent breakthroughs in gene editing, and how, despite existing knowledge about genetic disorders, we still can't use innovations like "CRISPR" to cure them. That, Wojcicki says, fuels her passion to completely understand the human genome.

Transcript

- I think there's a Gattaca world that is more science fiction than the reality.. So we know CRISPR, I know cystic fibrosis but I can't cure people yet with cystic fibrosis.. So there's a long world before I'm gonna like, have a homogenous society of everyone's choosing this one set of phenotypes.. That said, I think this is the ethical discussion.. As I look at 23 me, part of our mission, I wanna understand the genome.. What keeps me up at night is we have this code in us and we don't understand it.. How can everybody sleep? It's just, I really wanna understand.. It's so interesting.. And the fact that it goes back to the beginning of time.. That's so cool..

And so I want us to be the ones who are understanding and deciphering the genome.. There's all kinds of ethical questions about CRISPR and how you're gonna use this information and there are realistic issues that need to be discussed.. But I look at our job, it's like, I want to understand it.. - [Interviewer] So I wanna build on that because one of the concerns I've had early, early, in the early days, I was offered to participate in and get my genome done, which I have not done yet.. - We'll give you a kit.. - [Interviewer] Oh good.. Well here was, the issue is I'm concerned that do we actually really understand it enough to be giving meaningful data.. The rate of knowledge, increase of them in this world is super fast and we still are quite far from really understanding it.. I mean, you're saying, how can we sleep at night 'cause we don't understand it, and that's, my concern is we don't understand it and am I getting information that is really accurate.. - There's information we toggle in some ways..

Like this was a regulatory question in some.. We toggle between, "Oh my God, your data "is so actionable and so scary, "how could you give it to people?" And then like, "Oh my God, you know nothing "and it's meaningless." Well, I was like, pick and argument, people.. Either we're too scary or we're meaningless.. The reality is like, it's their early days.. We know cystic fibrosis mutations.. And I know BROCA mutations, and I know some of the familial hypercholesterolemia mutations.. There's certain mutations, we feel really good about.. There's an entire world in the whole genome sequencing department that makes me nervous.. And there's variance of unknown significance.. So I might, I used to give this talk that it was called deleterious me..

Like all, when I got my whole genome.. Like all the different ways, I should be dead, but I'm not.. And so you start to follow my mutations.. Like I had this mutation and I'd look, and you can look in some of the genetic databases online and be like, wow, there's like all these really terrifying diseases associated with this mutation.. So to me, the fact that we don't know everything is symbolic of life.. We don't know everything about everything.. But it doesn't mean we shouldn't have it.. To me, the journey to actually starting to understand what the genome means.. That's only gonna come by starting to actually explore it.. And I really have this belief like everyone can be a scientist..

My dad, my number one takeaway from the particle physicist is that in 1991, 1992, my dad ran something called the superconducting supercollider, and it got shut down by the government.. And it was gonna be the largest, giant accelerator, smasher ever.. And part of the reason why it got shut down was because the physicist couldn't articulate what the value proposition was.. And all the scientist, I repeat all the time, you hurt yourself by wearing the white coat and using big words and talking down to people.. Of course the average population believes more in Gwyneth Paltrow than they do at anyone in Stanford because she speaks their language.. And it drives me crazy.. We have to empower people and be like, you know what, be honest.. We don't understand most the genome.. But you can all still understand it and it's beautiful and it's

fascinating and the whole journey of science is the fact that we don't know.. That is what inspires all of us to be scientist..

It's like to figure it out.. There's nothing better, my two great moments are the birth of my children and the results of an experiment.. Did it work? Like same thing with my children, did they work? (crowd laughing) But I just think for me, the fact that's an unknown is the beauty of it and we're all gonna solve it.. And all of us, every single person on this planet should be interested in it.. It's about them, and I really, I really, I so want scientist to embrace this idea of everyone could be a scientist.. You don't need a degree.. We can all learn.. And the more that we actually get, the person stocking shelves at Walmart to understand CRISPR and what's happening and gravitational waves.. The more we're gonna get funding, the more we're all gonna be connected.. The more we're gonna actually advance society..

So I really like, to me, that's an opportunity.. We don't know.. And I think medicine and healthcare in general would be so much better if people actually just admit it.. Like, we just don't know most these things...