

**FRED FRIENDLY SEMINARS, INC.  
OUR GENES/OUR CHOICES  
PROGRAM 2: MAKING BETTER BABIES  
TRT: 56:46  
MODERATOR: JOHN HOCKENBERRY**

**INTRO TO PANEL**

01:01:06;21

**ROBERT KRULWICH:**

I'm Robert Krulwich, ABC News. This is Eric Lander ...professor at MIT and at the Whitehead Institute. Let's suppose my wife and I.....discover we're going to have a baby.

01:01:14;05

**ERIC LANDER:**

Congratulations.

01:01:16;01

**ROBERT KRULWICH:**

Well, thank you very much. And so we go to the doctor and he gives us-- you know-- it's just genetic testing. We say, "Okay." And then he comes back and he says, "You know, we've turned up some abnormalities." I hear "abnormalities" and right away I'm thinking... (Deep breath.)

*01:01:29;08*

***ROBERT KRULWICH Cont...(animation in)***

*"Oh my God." Genes are destiny like some terrible curse, like a lightning bolt. And one day this gene or whatever it is, is gonna kick in and my baby will be shorter or sicker or slower than all the other children. It's fated now. It's in her genes. ...(animation out)*

01:01:48;23

**ROBERT KRULWICH (Cont.):**

You recognize this situation?

01:01:49;10

**ERIC LANDER:**

People often think this way.

01:01:51;20

**ROBERT KRULWICH:**

Now, let me ask you. I'm gonna make it easier. I'm gonna give you my baby. Oh, she made a little cry. (NOISE)

01:01:56;29

**ERIC LANDER:**

Ah, it's a cutie, yeah.

01:01:58;03

**ROBERT KRULWICH: (NEW VOICEOVER)**

Now when you hear the phrase...

*01:01:59;20*

***ROBERT KRULWICH (Cont.): (animation in)***

*..."Bad Gene"...do you hear "Inevitable Disease"? "Destiny"? Or do you hear "Maybe"? "Possibly" ...(animation out)*

01:02:08;06

**ERIC LANDER:**

Look, there are a small number of things that are destiny. A small number of genetic certainties where you can say the baby, God forbid is, gonna have some terrible disease that we can't do anything about. But most of the genetic information that's encoded in the human DNA is not about certainty.

01:02:25;10

It's about the fact that perhaps when she grows up she'll have twice the risk of diabetes. That's not good but it's not a disaster. I think, as a parent, that you have to add this long list of maybe's that genetics is gonna potentially give you to a much longer list of worries that every parent has had since there were parents.

01:02:45;20

**ROBERT KRULWICH:**

Like what?

01:02:46;10

**ERIC LANDER:**

Is your child gonna grow up happy? Are they gonna marry well or marry unhappy and get divorced? Are they gonna have an unsatisfying career? Are they gonna get hit by a bus?

01:02:56;00

**ROBERT KRULWICH:**

So then against that string of maybes, maybe the bad bus, maybe the bad husband, you just add another string of maybes?

01:03:03;07

**ERIC LANDER:**

I think that's largely what it is. And if anything, there may be some maybes that maybe we can do something about. If you know you're at risk for diabetes you might be able to do something about it in the future.

01:03:14;28

**ROBERT KRULWICH:**

And knowing then that we're gonna live in a world where there's a much longer list of maybe's, not certainties, we're now ready to consider some of the surprising problems that might arise. Which means we are now ready for my friend and NBC correspondent, John Hockenberry, and his Fred Friendly Seminar panelists. \_ AUDIO OUT:  
01:03:30;25  
VIDEO OUT: 01:03:29;10

**PANEL STARTS**

01:03:32;02

**[LOWER THIRD: Videotaped February 23rd 2002]**

01:03:32;09

**JOHN HOCKENBERRY:**

Let's meet Lee and Meredith...and Adrienne. Adrienne is a friend of Meredith. Lee and Meredith are a married couple who are gonna have a child and were thrilled. Adrienne particularly is thrilled about that. First child.

01:03:53;16

As someone who is 35, you're going to have amniocentesis. You're going to get tested. It's something to do just to be on the safe side for women who are

35 years old. Um..Adrienne,  
a conversation develops around the test and around this joyful  
event in this family. What's the conversation?

**ADRIENNE ASCH:**

01:04:10;13 Well, I think it's great that you're pregnant. I don't necessarily know why  
you wanna get tested. [LOWER THIRD: Adrienne Asch/Prof of  
Bioethics/Wellesley College]

**MEREDITH VIERA:**

01:04:15;15 Well, I've been told I should get tested actually because I'm 35 and there are  
all these questions. I had the same doubts in my mind, because I've had  
miscarriages, three of them, coming into this. So, I'm a little hesitant. But  
my husband felt it was important that we had the test.

**LEE SILVER:**

01:04:29;00 I thought it was very important to have the test, because it's clear that at-- at  
this age, as you know, there's a higher risk of having a-- an extra  
chromosome in-- in the fetus that could bring about Down's Syndrome.  
[LOWER THIRD: Lee M Silver/Prof of Biology & Public Affairs/Princeton  
University]

**JOHN HOCKENBERRY:**

01:04:41;29 Well, there's a whole lot of things that they can test for. Adrienne?

**ADRIENNE ASCH:**

01:04:44;02 Alright..I've known you a long time. You wanna have a child.  
So what difference does it make what your child is?

**MEREDITH VIERA:**

01:04:50;18 Well, I mean in theory I guess it doesn't make a difference. Obviously, I  
want a baby desperately. But because of that, would I allow myself to give  
birth to a baby that may have tremendous trouble to satisfy some need in me  
and not really caring about the baby. That's the dilemma I'm in. I think  
that's why I agreed to go through with the amnio even though I don't know  
how to process the information, if it's not good. I don't know whether I'm  
thinking for myself in selfish terms or whether I'm really thinking about this  
baby. [LOWER THIRD: Meredith Vieira/Co-Host, The View/ABC News]

**LEE SILVER:**

01:05:16;12 It's a fact that some children are born with-- with health problems. And if  
we can avoid those problems, I think that that would be best for the child.

**ADRIENNE ASCH:**

01:05:24;28 Well, you can't make any conditional statement about what's best for a child.  
Health problems are-- are only one kind of thing that people have.

**LEE SILVER:**

01:05:33;09 That's-- I would agree with you completely. But for example I'm an  
asthmatic. There's nothing positive about being an asthmatic. If I could  
make sure that my son--

**MEREDITH VIERA:**

01:05:40;20 I love you. You wheeze all the time, and I love you. (LAUGHTER)

**LEE SILVER:**  
That's right. And--

**MEREDITH VIERA:**  
So--

01:05:45; **LEE SILVER:**  
You know I have to take medicine every day and night. And if I could have a daughter or son that didn't have to depend upon medicine to stay in good health, I think everybody would agree that's a positive.

01:05:56;10 **MEREDITH VIERA:**  
But I think because you're an asthmatic, you're more sensitive about this. And-- And I look at it from the other side. So what if you're asthmatic? So what if this baby has some sort of genetic probably? We'll deal with that.

01:06:05;25 **LEE SILVER:**  
Of-- Of course, if the-- if the child is here, of course we would deal with it. We would love the child, but if we can avoid this problem--

01:06:12; **JOHN HOCKENBERRY:**  
But-- But, Lee -- What-- What do you mean when you say "avoid this problem?" That's a euphemism for what?

01:06:18; **LEE SILVER:**  
Well, a euphemism for if-- in-- in the-- in the case of a-- of an amniocentesis diagnosis, if it was possible to identify genes that predispose the child towards asthma, then we would have to make a decision of whether to abort. I don't think I would abort the fetus.

01:06:32; **JOHN HOCKENBERRY:**  
So, "avoid this problem" is abort and try again.

01:06:35; **LEE SILVER:**  
Yes. I think asthma is not a serious enough condition--

**MEREDITH VIERA:**  
Right.

**LEE SILVER:**  
-- to-- to abort. I would want to have the child. The child can use medicine and lead a normal life.

01:06:46; **ADRIENNE ASCH:**  
You know I-- So, what's the difference between asthma and Down's Syndrome in your view?

01:06:50; **MEREDITH VIERA:**  
Well, I think there's a difference. I mean, I would agree with my husband on that. But I'm not sure if that's still reason to abort. I mean, I-- we have a-- a nephew who has Down's. And every Christmas, we go to visit, and I watch

him. He's now 12, and I see his mother is still treating him as if he's two, because that's really developmentally as far as he's ever gonna go. And I think-- Sometimes I hate myself for thinking it, but I look at her and go, "I wouldn't want her life." I wouldn't want that. And I look at this little boy, and I think, "What-- What quality of life does he have?" Then I'm not sure whether it's fair to bring this child into the world.

**JOHN HOCKENBERRY:**

01:07:22; Is that their right, Adrienne?

**ADRIENNE ASCH:**

01:07:25; Oh, it's certainly their right. I'm not sure it's a very-- terrific attitude to have about being a prospective parent, because if you work so hard to avoid whatever set of characteristics, how-- how do you really know in your heart that you'll deal with the surprises that any child is gonna give you?

**MEREDITH VIERA:**

01:07:46;15 Well, then why did they come up with the stupid test in the first place?

**ADRIENNE ASCH:**

Well--

**MEREDITH VIERA:**

Because all this does is provoke anxiety.

**JOHN HOCKENBERRY:**

01:07:53; Well, let's go out into the community and see what other questions there are. Mr. Miller, you are friend's of Meredith and Lee.

**PAUL MILLER:**

01:07:56; Well, I-- I can understand your anxiety about that. Ultimately, it's your call and your very personal and difficult call what to do. But I guess the question that I wonder if you would ask your nephew is would he rather be living his life and be here than never have been born at all. [**LOWER THIRD: Paul Steven Miller/Commissioner/Equal Employment Opportunity Comm**]

**JOHN HOCKENBERRY:**

01: 08:22; Are you advising them to take the test and worry about all that later or are you suggesting they perhaps even avoid it?

**PAUL MILLER:**

01:08:28; I'm suggesting what I would think is not to take the test lightly, because the test is gonna give you information that's gonna force you to make a decision one way or the other and even not acting is making a decision.

**MEREDITH VIERA:**

01:08:44; Yeah, but we weren't even thinking about a test before. We were just thinking about finally having a baby.

**JOHN HOCKENBERRY:**

01:08:48; Does the community have a stake in this? And what would you advise these folks who are just trying to take a simple test, get some basic information?

01:08:54; **RICK LAZIO:**  
It's a very personal decision, and of course, the community's gotta stake in making sure that people are empowered to make decisions. if you have the test and you found out that the child had-- a probability of having a-- a serious disability, how would you feel-- how would you feel. **[LOWER THIRD: Rick Lazio/Fmr US Representative (R-NY)]**

01:09:14; **JOHN HOCKENBERRY:**  
You'd take the test, right? You'd take the test, right, (UNINTEL)?

**RICK LAZIO:**  
-- afterwards? Yeah, I-- I would-- I would say take the test, but be prepared

01:09:19;20 **FAYE WATTLETON:**  
Did you think about taking-- what the risks were for getting pregnant at 35 before you got pregnant?

01:09:24; **MEREDITH VIERA:**  
Our head wasn't even there. It was just about getting pregnant. That's ignorance, and I-- and I cop to that. But we really weren't thinking about the repercussions of the test.

01:09:32; **FAYE WATTLETON:**  
No, it wasn't about ignorance. It was about clearly you have a conflict now about to test or not to test. But I was just wondering if before you get pregnant if-- if that conversation had taken place? **[LOWER THIRD: Faye Wattleton/President, Center for Gender Equality]**

01:09:41;15 **LEE SILVER:**  
Well, I think but-- I think the-- the-- the important thing about the conflict is this is a conflict between the two of us. We have to--

01:09:47; **JOHN HOCKENBERRY:**  
What do you mean? It's involving this house over here--

**LEE SILVER:**  
We have to resolve that--

**JOHN HOCKENBERRY:**  
-- this Congressman down the street over here.

**LEE SILVER:**  
Well, I think that he can-- he can--

**JOHN HOCKENBERRY:**  
Adrienne, the college friend.

01:09:52;10 **LEE SILVER:**  
He can make sure that we are informed. And I certainly agree that we need to have all of the information. But in the end, it's a decision that the two of us have to make alone.

**JOHN HOCKENBERRY:**  
01:10:03; What I wanna focus on here is you have said that somehow it reflects on the parenting of these two people, if they were to make a decision going in to a test like amniocentesis that there were certain outcomes that would result in termination. [**LOWER THIRD: John Hockenberry/NBC News**]

**ADRIENNE ASCH:**  
01:10:19;25 I want to see my friends be the best parents that they can be. I think that a child with a disability can be as gratifying a child as any other child. But if they don't, that has to be the decision that they make for all kinds of reasons.

**LEE SILVER:**  
01:10:33; But our goal is to have a child. I mean, if it's not this time, it will be the next time hopefully.

**ADRIENNE ASCH:**  
01:10:39;15 Well, no, your goal-- it sounds--

**LEE SILVER:**  
And don't you think we'll be good parents?

**ADRIENNE ASCH:**  
-- as though your goal is to have a particular kind of child.

**LEE SILVER:**  
01:10:44; We're not trying to have a particular kind of child.

**MEREDITH VIERA:**  
Well, you sort of are.

**LEE SILVER:**  
No, I'm just trying to--

**ADRIENNE ASCH:**  
01:10:48 I think you are. Yeah, I-- I think that you have to be--

**MEREDITH VIERA:**  
You're sort of harassing me to do the test.

**ADRIENNE ASCH:**  
I think you have to be honest and say that you are. You wanna avoid certain kinds of children that you think will have bad lives.

**LEE SILVER:**  
01:10:58; There's no way I can predict what the child will become, except that if we have a test and we can avoid certain medical problems, then that's great.

**PAUL MILLER:**  
01:11:05;15 But my living a healthier life, does that mean to you living a better life?

**FAYE WATTLETON:**

01:11:10; Yes, it's better than going to the hospital and not being able to breath. Th--  
And-- And being free of that is better.

**ADRIENNE ASCH:**

It's different..but I don't know that t is better.

**FAYE WATTLETON:**

01:1:17; Do any of us as prospective parents want to s-- bring a child into the world  
and see that child-- Life i-- brings with it its own set of sufferings without  
our getting involved in that. But d-- do we knowingly want to participate in  
that? Wouldn't we like to have, yes, a healthy child?

**PAUL MILLER:**

01:11:36;28 If society in general continually excludes people with certain disabilities or  
people with certain genetic anomalies, and then you end up a generation  
later and do have that genetic anomaly and weren't eliminated, Society, and  
that's a big "S," Society will look at you and say, "Why didn't you do your job  
and fix this kid? And what were you thinking by having this kid?" and  
Society will look at this kid and say, "Well, why are you here? You're a  
broken child. You could have been fixed."

**JOHN HOCKENBERRY:**

01:12:22;20 That's gonna be a pretty lonely position to be in. Certainly, the the science  
has allowed people to have options that they wouldn't have otherwise had.  
What's the down side?

**FRANCIS COLLINS:**

01:12:34; Well, we say that knowledge is power, but knowledge also carries with it  
tough decisions and responsibilities for making those decisions, which I  
think frankly many people find quite discomforting and-- and  
understandably so. Right now one can test for a small number of things, in  
the future, that list will grow. And so the challenge to educate people who are  
contemplating the test will also grow. And the difficulty in making the  
decisions will also grow. And if we're having trouble now, hold onto your hat.  
It's going to be much more challenging for couples like this. **[LOWER  
THIRD: Francis S Collins/Director/Nat'l Human Genome Research Inst]**

01:13:07;10 Let me hasten to say that what we're considering here is a small part of the  
consequences of understanding genetics. We're considering probably the  
most wrenchingly difficult part, the part that plays out in the pre-natal  
decision-making arena.

But the real pay-off of genetics is not there, I'm sorry. It's not there. I-- The  
p-- The pay-off is in understanding diseases and so if faced with the  
possibility of having a child with cystic fibrosis, in ten or 20 years, it will not  
be a big deal, because we'll know what to do for it. That's where we're  
headed.

**JOHN HOCKENBERRY:**

01:13:38;05 All right, so Meredith and Lee had a lot of trouble with this discussion. They  
need to go seek some professional help. Miss Biesecker, you are such a  
person as a genetic counselor. When people come to you—

**BARBARA BIESECKER:**

Yeah.

**JOHN HOCKENBERRY:**

You know you-- you tell 'em about these tests. What's your recommendation?

**BARBARA BIESECKER:**

01:13:56; I help them figure out what they wanna do.

**JOHN HOCKENBERRY:**

So, you don't recommend what they should do.

**BARBARA BIESECKER:**

01:14:02; I might actually use the words: It sounds like you're thinking you want to do such and such based on what you've told me. (LAUGHTER) [**LOWER THIRD: Barbara Biesecker/Director, Genetic Counseling/Nat'l Human Genome Research Inst**]

**JOHN HOCKENBERRY:**

01:14:13;20 You're sure you're not a lawyer. (LAUGHTER) What sort of emotional state are people in when they get presented with these options?

**BARBARA BIESECKER:**

01:14:22; It varies tremendously. There are some people f-- for whom this is not a very difficult decision. And there are other people, like Meredith, who is conflicted about the decision to have the test and others who know nothing about the test when they walk in the door, far too many of them, who really need a lot of help to arrive at a decision.

**JOHN HOCKENBERRY:**

01:14:41;20 So, the way you deliver the message of these options and these tests varies considerably based on their educational background, socio-economic background.

**BARBARA BIESECKER:**

01:14:49;15 It has to. And usually, they think they're coming to have a test.

01:14:54;01-01:15:02;01 **Web Marker: [PBS.org](http://PBS.org) Genetic counseling links**

So, it's actually a little awkward at the beginning of genetic counseling because you sort of have to undo some of the presumptions that people have when they come in the door. They might say, "Well, my doctor told me to have the test. I mean I'm-- I'm 37, and that-- that seemed to be what he thought I should do." And--

**JOHN HOCKENBERRY:**

01:15:09;00 So that's a recommendation. It sounds like that's--

**BARBARA BIESECKER:**

01:15:09;20 That's a recommendation.

**JOHN HOCKENBERRY:**

-- that's a direct order.

**BARBARA BIESECKER:**

Yeah.

**JOHN HOCKENBERRY:**

01:15:13; Alright. Well, let's-- move ahead. You took the test. And there is, actually, some information to report. You are about to tell this couple about the-- the possibility that within the genetic make-up of their fetus is the propensity for something called Turner Syndrome. And we'll hear about that in a moment. What is the emotional state of parents who hear that kind of information, first of all?

**BARBARA BIESECKER:**

01:15:35;15 I think when parents hear that anything is different about their developing baby, there's a-- a real crisis that ensues. Because it's not what most people expect. And usually the counseling informs them that it's not the most likely thing to have happened.

**JOHN HOCKENBERRY:**

01:15:48;20 Tell this couple what we've just learned from this test.

**BARBARA BIESECKER:**

01:15:52; Okay. Something's been found on the amniocentesis. The baby actually is missing a chromosome. And the chromosome that's missing is-- one of what we'll call the-- the sex chromosomes. And so the baby, instead of having two Xs-- as most females do, has one X.

**MEREDITH VIERA:**

01:16:10;00 What does that mean?

**BARBARA BIESECKER:**

01:16:10;20 It's complex what it means. It means you're carrying a girl. And this little girl-- (LAUGHTER) will have something that's called Turner Syndrome. And Turner Syndrome is a description of being short and probably the most difficult aspect for any woman who's affected with Turner Syndrome is that she will be infertile, most likely unable to have her own biological children.

**LEE SILVER:**

01:16:37; What are the other health-- consequences?

**BARBARA BIESECKER:**

01:16:41; Turner Syndrome in general can be fairly compatible with good health. But these girls as they get older do have increased risk for diabetes and some other health problems. And they need to be monitored-- throughout their lifetime. Occasionally they can also have heart defects, and that's something that we can look for, actually. Maybe even still while you're pregnant.

**MEREDITH VIERA:**

01:17:01;15 Well, go-- go back to the short for a second. What does short mean? What do you mean? Like two feet? Four feet?

01:17:08;20 **BARBARA BIESECKER:**  
Um..we can't make that prediction for her, or unlikely can make predictions about any developing baby.

01:17:14;20 **MEREDITH VIERA:**  
Do any of those girls ever counsel prospective parents to--

**BARBARA BIESECKER:**  
Yes, they do. They often offer to talk to parents. How do you feel about that?

**MEREDITH VIERA:**  
I'd want to talk to her.

**BIESECKER:**  
Would you? Well, how do you feel about that?

01:17:25;00 **LEE SILVER:**  
I think it's a-- an extremely difficult situation--

**FEMALE VOICE:**  
Uh-huh (AFFIRM).

**LEE SILVER:**  
--of course, because there's this natural sense that I'd like to have my children have children someday. And the idea that my child wouldn't be able to have a child is of concern.

01:17:38;15 **MEREDITH VIERA:**  
I don't think it's the worst thing that could happen to her. This doesn't seem like that big a deal.

01:17:44;00 **LEE SILVER:**  
I think that's right.

01:17:46; **JOHN HOCKENBERRY:**  
Do you feel as though this is a completely neutral message that they're giving you?

01:17:49;10 **MEREDITH VIERA:**  
I don't think you're saying to me "Keep it under any-- under any circumstances." I seem-- I think you're telling me that genetically the child is predisposed to be short and infertile, and that's about it.

**FAYE WATTLETON:**  
Well, I-- I'm--

**NANCY FISHER:**  
No.

01:17:57; **FAYE WATTLETON**  
--just very interested that you guys only heard 'short' and 'infertile', and she also said heart--

**FEMALE VOICE:**  
Uh-huh (AFFIRM).

**FAYE WATTLETON:**  
--heart anomalies and diabetes as a-- one of the problems that-- so it's sort of interesting to me that that sort of got--

01:18:09; **MEREDITH VIERA:**  
I guess I didn't think of--

**FAYE WATTLETON:**  
--wiped away.

**MEREDITH VIERA:**  
--those as serious. I thought, "Oh, those-- that's manageable."

**FEMALE VOICE:**  
Uh-huh (AFFIRM).

**FEMALE VOICE:**  
So I--

**FEMALE VOICE:**  
Yeah, and I guess when you ask me--

01:18:15;15 **PAUL MILLER:**  
But short is more serious than heart disease?

**MALE VOICE:**  
Yeah. Yeah--

(OVERTALK)

01:18:20; **MEREDITH VIERA:**  
No, I swear. Short is what I heard first.

(OVERTALK)

**MEREDITH VIERA:**  
I remembered it. (LAUGHTER)

01:18:24;50 **JOHN HOCKENBERRY:**  
Alta Charo, are they getting information that they can act on?

01:18:28; **ALTA CHARO:**  
Well, I think that in the absence of information, you have the luxury of ignorance. But with information and a forced decision to do or not to do-- but either one is a decision-- you become responsible for the outcome. And it's an important decision for you to make about whether you're obligated to get rid of every possible area of suffering or inconvenience for that child. Because even though suffering certainly offers opportunities to build character, the world will almost certainly offer up some suffering

somewhere down the line for you. And you might as well just wait until it happens. [**LOWER THIRD: Alta Charo/Prof of Law & Medical Ethics/University of Wisconsin**]

**JOHN HOCKENBERRY:**

01:19:04;15

Let's change the facts again. It turns out that Turner Syndrome is not what was discovered in the past — there's an inversion-- in-- one of the chromosomes that potentially affects a gene. If you parents had this same inversion when we tested you-- and that's a part of what we do-- then it would be no problem.

But in this particular case it's new. The fetus has it; the parents don't have it. Which means, according to the information that we have now, is that there's a 95 percent chance it's no big deal. But there's a five percent chance that it's a really, really big deal. First of all, convey this information to this couple. And let's hear their reaction.

**BARBARA BIESECKER:**

01:19:49;15

So when you got my message-- I left information for you that we did find something. We found a change in the genetic material in the developing baby. What we know is that there's an overwhelming likelihood, a huge likelihood that everything is fine with the baby. But there is an increased chance that there is a problem.

**LEE SILVER:**

01:20:13;

Will the problem cause suffering in the child?

**BARBARA BIESECKER:**

01:20:16;

Well, figuring out exactly what this is gonna mean for the baby is a very difficult job for us. Because we actually don't have sufficient information or data to know what this is gonna mean for the baby. There is a chance that some information, got disrupted as a result of that change. And if that happened in a way that was potentially damaging, it could mean that the baby will have mental retardation. There's also a chance for some structural or physical changes, and that's one thing we can maybe offer-- a window into by offering some tests to look for those things. But we will never be able to know--

**MEREDITH VIERA:**

About the retardation?

**BARBARA BIESECKER:**

About the retardation.

**JOHN HOCKENBERRY:**

01:20:55;15

Consult your friend Kathleen.

**KATHLEEN MCAULIFFE:**

01:20:57;00

Well, I faced almost-- the identical predicament, although I was told the risk that the child might have a-- a serious-- disability or deformity might be as high as ten or even 12 percent. And when I asked to see the studies on which this prediction was based-- it really made me nervous. Because-- it was based on a very small-- sample size-- and the study lumped together children

with all kinds of different genetic aberrations. [**LOWER THIRD: Kathleen McAuliffe/Science and Medical Writer**]

**MEREDITH VIERA:**

01:21:28; So they weren't even sure about the percentage?

**KATHLEEN MCAULIFFE:**

01:21:31; No. No. I thought, "Wow, you know, nobody told me that it was based on this shaky data." It made me very nervous. And I cannot presume to tell you what you should do

**MEREDITH VIERA:**

01:21:42;15 Well, how did you make your decision then?

**KATHLEEN MCAULIFFE:**

01:21:45; Wow, it was agonizing. It was a-- a worst-- time in my life. My husband and I initially disagreed. My husband was-- very optimistic. He said, "Wow. With odds like that? Let's, you know, go for it." I initially felt the same way. I also felt that even though the genetic counselor was very non-directional, they didn't ever say to me, "Wow, that is a difficult choice." So it made me feel like "Are you insane to be contemplating this-- to abort the pregnancy?" And then-- you know, I started looking more closely at the data. but all I can tell you is I looked at-- the children that had adverse outcomes (COUGHING), and, you know, it made my hair stand up on my head. I mean, there were children with mushroom heads and there were children with missing limbs and children with, you know, perforated kidneys and malformed hearts. There were some other kids that were only mildly retarded and seemed to do quite well. Other kids with very severe neurological impairment.

01:22:40;20-01:22:49;15 **Web Marker: PBS.org More personal stories**

01:22:40;20 There were kids with-- certain deformities that it sounded like could be corrected with, you know, one or two operations after birth. They really ran the gamut. I did choose to abort the baby, and I was-- almost age 38. So I had no idea-- whether I'd ever have a child again. And-- it was-- a horrendous-- decision. At the time I aborted the baby, I assumed that the child-- was probably healthy.

**JOHN HOCKENBERRY:**

01:23:13; What led you to that decision?

**KATHLEEN MCAULIFFE:**

01:23:15;15 At the end of the day, I realized I was so scared. I didn't want-- the care of the child to become my entire life.

**MEREDITH VIERA:**

01:23:23; What happened with your husband? Because remember you said he wanted the baby.

**KATHLEEN MCAULIFFE:**

01:23:26;15

It was very, very hard for him initially. And eventually, he did come 'round to my point of view completely independent of myself. But-- to his credit, he-- he looked at me at one point-- and this is when he really wanted to proceed with the pregnancy-- and he said, "You know what? You're the one that's carrying this baby. You're the one that's gonna have to go through the agony of a late-term abortion if you decide to abort it. And you're the one that's gonna have to go through the pain of childbirth." And probably the burden of raising this child-- although I will do everything to help you-- probably the burden of raising this child is gonna fall on you. And as far as I'm concerned, if we disagree, the choice is yours. And I will agree with that."

01:24:05;15

**LEE SILVER:**

The problem with this--

**MALE VOICE:**

Wow.

**LEE SILVER:**

--information, it's very, very vague information which is almost

**MEREDITH VIERA:**

Yeah.

**LEE SILVER:**

--worse than having no information at all

01:24:11;

**JOHN HOCKENBERRY:**

But Kathleen, you asked for this test.

**KATHLEEN MCAULIFFE:**

Yes.

**JOHN HOCKENBERRY:**

Right? You asked to get this test--

01:24:17;20

**KATHLEEN MCAULIFFE:**

Well, not this specific test. I mean, the irony is that here I am, a health reporter. I've written about genetic science on many occasions. And-- I guess my only criticism of the genetic counseling that I heard you guys get was that at no point did the genetic counselor say to you "You know, we're not just looking for Down's Syndrome or other trisomies (PH). We can see a whole range of other kinds of microscopic deletions and rearrangements. In fact, when you get an abnormal result, they occur one in six times. And you know what? We don't really know what they mean. So we can come back to you with really fuzzy odds that you might not have a clue what to make of."

**JOHN HOCKENBERRY:**

So-- so the mes--

01:24:54;15

**KATHLEEN MCAULIFFE:**

And so I would like to see women who go for genetic counseling to be told that. Because the information itself is so stressful. I mean, part of what influenced my decision also was the stress that I was under. I was really

shocked by the degree to which, you know, it just felt like somebody had socked me in the stomach. So people need to think very long and hard what are they gonna do with this information. Are they gonna act on it?

01:25:18;15 **JOHN HOCKENBERRY:**  
Dr. Collins, is the quality of that information too low to be given to a-- a parent?

01:25:23; **FRANCIS COLLINS:**  
I think for somebody who's facing this circumstance, they're hungry for information. If the information is of poor quality, that may still be better than no information at all.

01:25:32; **ALTA CHARO:**  
I'm sorry, but-- but-- but what didn't completely get into the discussion was "What kind of person are you when it comes to information?" 'Cause people are really different. They hear a statistic of 60/40 or 70/30 and they-- some people will interpret that as meaning whatever was the 70 percent chance, that's what's gonna happen. I do think that there's a role for professional judgment about the point at which some information is so difficult to use and so anxiety-provoking that the assumption is that it's not ready for prime-time. But you can, nonetheless, probe with a particular client and you can let this be the one idiosyncratic case where somebody says, "I demand the information," even though as a general matter it's really not usable by the public at this point.

01:26:14;15 **FEMALE VOICE:**  
But why do you need--

**MEREDITH VIERA**  
See, I don't get that. I don't get if it's fuzzy.

**FEMALE VOICE:**  
--we should get that information.

**MEREDITH VIERA:**  
If one in six is fuzzy, why I need to know fuzzy information that no one can interpret, no professional can interpret it. I'm a lay person who's pregnant and pretty emotional to begin with. I can't interpret it, so I'm not gonna act as an informed parent. I'm gonna be acting as God.

01:26:32; **JOHN HOCKENBERRY:**  
Hang on. What's being spent on counseling? What's being—spent on the counseling for the people like Meredith? Because—

01:26:38; **DR.FRANCIS COLLINS:**  
--remember, the billions of dollars are not being spent to try to encourage this sort of setting, which we all recognize is incredibly difficult and wrenching. The billions of dollars are being spent to try and understand diseases so that we can treat and cure them. **[LOWER THIRD: Francis S Collins/Director/Nat'l Human Genome Research Inst]**

**JOHN HOCKENBERRY:**

So where's the money to help parents understand what's going on?

**NANCY WEXLER;**

That isn't available.

**FAYE WATTLETON:**

01:26:56;

But in the meantime--people have to live their lives on a day to day basis, and they don't live them in a laboratory. And it seems to me that these people are drowning in information, and they come to you, pastor--

**REVEREND ANDERSON:**

Yeah.

**FAYE WATTLETON:**

--for an answer. And you give them more information. Where are they gonna go to somebody (LAUGHTER) to finally tell them "This is what I think you ought to do?"

Do you ever do that?

**REVEREND ANDERSON:**

01:27:14;

No. Yes. I-- I was gonna say the-- the best information is going to come from a parent couple that have just gone through the same experience. This is part of the community of life, and, you know, suffering comes to everybody. Everybody has to have. [LOWER THIRD: Rev Michael D Anderson/Westminster Presbyterian Church/Oklahoma City]

**FAYE WATTLETON:**

01:27:27;

Sometimes in life we need someone to tell us what to do.

**KEVIN FITZGERALDGERALD:**

01:27:30;

No. Or-- or something else. This is the thing.

Why is it that in our society at the moment we are being caught so unawares by this information, which is developing very rapidly? And is actually perhaps in some ways turning out to be much more of a challenge to us than we at first thought? [LOWER THIRD: Kevin T FitzGerald,SJ/Georgetown Univ Medical Center]

**JOHN HOCKENBERRY:**

01:27:48;

Because we're being hit by a tidal wave of information. Are we prepared for this?

**NANCY WEXLER:**

01:27:51;

We are definitely not prepared for this.

**JOHN HOCKENBERRY:**

No.

**NANCY WEXLER:**

In any way, shape or form.

01:27:55; **JOHN HOCKENBERRY:**  
Right. Well, given the complexity of this information, and the availability of this information, let's ask a parity question. Dr. Collins, how many researchers would you say, are working on the basic research level of genetics-- in the United States?

01:28:08; **FRANCIS COLLINS:**  
Tens of thousands.

01:28:10; **JOHN HOCKENBERRY:**  
Tens of thousands. Barbara, how many genetic counselors are there in the United States?

**BIESECKER:**  
1500.

**JOHN HOCKENBERRY:**  
1500?

**BIESECKER:**  
1500.

**JOHN HOCKENBERRY:**  
And I guess we can presume there are millions of prospective parents in the United States?

01:28:22; **FAYE WATTLETON:**  
There are a lot of people who seem to know what to do. And those are politicians (LAUGHTER) who are willing-- who are jump-- who are ready to jump right ahead and pass laws to put rules on this. On these issues.

01:28:31; **JOHN HOCKENBERRY:**  
Well-- well Congressman, what are some of the stresses (LAUGHTER) on this-- on this-- on this tidal wave? That's a-- a perfect bank shot right there. (LAUGHTER) What are the stresses? What are the pressures on this tidal wave of information? There are people who are going to make use of it.

01:28:47; **RICK LAZIO:**  
Well, a lot of us have been very focused over the last 5 or 6 years on making sure that there has been a significant increase in federal dollars going into biomedical research. And so, let's not forget that it was a big increase in a-- in public dollars that helped make this information possible. Is there another need to try and translate this information? Yes. But is that the only purpose for federal dollars-- in research? No, it's not. **[LOWER THIRD: Rick Lazio/Fmr US Representative (R-NY)]**

01:29:16; **ADRIENNE ASCH:**  
Well, there's thing we're not doing-- talking about so far. Which is that the parents, who have to make these decisions have to make them in the context of a society. And we haven't really talked much about making this society more accommodating for all people with disabilities, so that parents-- can feel safer in making a decision to have a child with a disability as well as not to have one. **[LOWER THIRD: Adrienne Asch/Prof of Bioethics/Wellesley**

College]

**JOHN HOCKENBERRY:**

01:29:41; Dr. Fisher is the priority for creating the level of services that parents are-- are going to need, it's-- is-- is-- that happening, likely to happen?

**NANCY FISHER:**

01:29:15;15 That's a difficult question to answer. I mean, Barbara said there are 1500 genetic counselors. There are about 1,000 clinical geneticists in this country. And so, when you look at that we have, what, 270 million people in this country, the question is what is the right ratio? [**LOWER THIRD: Nancy I Fisher, MD/Prof of Pediatrics/University of Washington**]

I think you have to think about the education of-- pediatricians, family practice people, to have some basic information so that the people that have-- I should say, the really difficult-- questions have time to get their-- get themselves the-- the time to get their questions answered.

**JOHN HOCKENBERRY:**

Paul?

**PAUL MILLER:**

01:30:26; I think the parent is really-- without much of a tool belt to try to figure this stuff out. What we are ultimately talking about generally, are two able-bodied parents, and the perspective of having a disabled child. [**LOWER THIRD: Paul Steven Miller/Commissioner/Equal Employment Opportunity Comm**]

01:30:45; And not knowing anything really g-- about what the life of that child might end up being. And therefore, thinking the worst. And so, I think back to my own situation. And there wasn't genetic testing when I was born. But at some point shortly after my birth, the doctors came into my Mom and Dad, and said, "Your kid's gonna be a dwarf." And my parents thought of circus. They thought of freaks. They thought of institutions. They thought of what they saw in-- movies and fairy tales. And it was really important to sit down and put that information, which falls out of the air, mental retardation, Down's syndrome, Turner's, dwarfism, into some real life context, with real life people.

01:31:33 And that's gotta be somehow folded into the mix. Cause otherwise, a parent can't make a decisions-- in-- in a vacuum.

**JOHN HOCKENBERRY:**

01:31:54;15 I venture to say that if tomorrow a set of parents like Meredith and Lee were told that their fetus was likely to have dwarfism, that the parents would not first think of well, he's gonna grow up and be the head of a federal agency, like you. (LAUGHTER)

**PAUL MILLER:**

But I know-- but

**JOHN HOCKENBERRY:**

01:32:10; They might still think circus. They might still think-- they might-- they might--  
-

**PAUL MILLER:**

01:32:12; They might think, "Oh, my God, my kid's gonna be a lawyer."  
(LAUGHTER) They might.

**JOHN HOCKENBERRY:**

01:32:18; Which of course, is always a safe laugh line (LAUGHTER) in this town.  
Let's-- let's move on. Lee and Meredith, actually there's a-- a completely  
happy outcome. They gave birth to a lovely child, Sophia. They are raising  
their child now at a time of-- of extraordinary developments in-- genetic  
sciences. What is likely to change in the next decade, regarding what we're  
gonna be able to know about children, genetically.

**FRANCIS COLLINS:**

01:32:46; Well, in the next decade, I think we'll uncover what the genetic connections  
are-- with most of the common illnesses, as well as the rare ones that we've  
gotten pretty far along with already. But-- **[LOWER THIRD: Francis S  
Collins/Director/Nat'l Human Genome Research Inst]**

**JOHN HOCKENBERRY:**

01:32:57 What about reproductive technology?

**FRANCIS COLLINS:**

01:32:59; Reproductive technology moves at a pace that is absolutely dizzying. And I  
can't imagine that that pace of new developments of ways to have children is  
gonna suddenly stop-- because of-- people deciding that's enough already.

**JOHN HOCKENBERRY:**

01:33:13; As someone who works in fertility, I'm coming to you, personally, doc.

**ZEV ROSENWAKS:**

Uh-huh.

**JOHN HOCKENBERRY:**

Because-- I know two things about your clinic. You can help me to have a  
whole bunch of embryos.

**ZEV ROSENWAKS:**

Yes. **[LOWER THIRD: Zev Rosenwaks, MD/Ctr for Reproductive Med &  
Infertility/Weill Cornell Medical Center]**

**JOHN HOCKENBERRY:**

Right? And then we can take a look at those embryos, right?

**ZEV ROSENWAKS:**

01:33:30; We can, if there's an indication for it. We would not do it ad hoc for  
anything. I mean, if there is a clear indication.

**JOHN HOCKENBERRY:**

01:33:37; Wait a minute. Wait a minute. I've been on-- I've been on the internet. I've  
been-- I've been checking this out. (LAUGHTER) I know what I'm talking.

And I-- I have learned-- [LOWER THIRD: John Hockenberry/NBC News]

**ZEV ROSENWAKS:**

Yes.

**JOHN HOCKENBERRY:**

--that you can take a cell--

**ZEV ROSENWAKS:**

Yes.

**JOHN HOCKENBERRY:**

--from each one of the embryos of my wife and I--

**MALE VOICE:**

Yes.

**JOHN HOCKENBERRY:**

--and-- and look at a whole range of potential characteristics, right? Not just the abnormalities, true?

**ZEV ROSENWAKS:**

01:33:58; No. We have specific abnormalities that we look for.

**JOHN HOCKENBERRY:**

01:34:00; But what you can look for, right? You could look for a lot of stuff.

**ZEV ROSENWAKS:**

01:34:04; I'm not sure where you're coming from. So, you have to (LAUGHTER) kind of (UNINTEL).

**JOHN HOCKENBERRY:**

01:34:07; Well, you know-- you know where I'm coming from. Because you know--

**ZEV ROSENWAKS:**

Yes.

**JOHN HOCKENBERRY:**

--that my father is one of the most legendary, famous violinist that ever walked the face of the earth.

According to my research, and again, you're the doctor here, (LAUGHTER) but it is possible to identify the chromosome, the allele for perfect pitch. My Dad had perfect pitch.

**ZEV ROSENWAKS:**

Yeah.

**JOHN HOCKENBERRY:**

I don't know if that relates to the fact that he was a great violinist. But you can do that, right?

**ZEV ROSENWAKS:**

01:34:37; To my knowledge, you can't. Unless Dr. Collins has discovered the-- (LAUGHTER) gene for perfect pitch.

**JOHN HOCKENBERRY:**  
01:34:42; Can he identify the allele for perfect pitch?

**FRANCIS COLLINS:**  
01:34:35; People are searching for that. And probably in a matter of a few years, it won't be an allele. It'll be a mixture of probably several genes that contribute to that. But it's clearly a strongly genetic trait.

**JOHN HOCKENBERRY:**  
01:34:56 Would you do it?

**ZEV ROSENWAKS:**  
No.

**JOHN HOCKENBERRY:**  
What?

**ZEV ROSENWAKS:**  
I would not do it.

**JOHN HOCKENBERRY:**  
Why?

**ZEV ROSENWAKS:**  
1:35:02; Because we have limited our use of pre-implantation genetic diagnosis-- to looking for devastating illness, debilitating ill-- illnesses. We will not subject anyone to a risk, just to look for a particular characteristic.

**JOHN HOCKENBERRY:**  
01:35:17; These-- these are my wife and my embryos here. We want you to select for these positive characteristics.

**ZEV ROSENWAKS:**  
01:35:24; Yeah. Well, I think perhaps a caveat here would be that we really don't look for anything or do a test unless it's been reviewed by institutional review board, as far as doing something. And-- when necessary even the ethics committee of our university, and in fact, we do not (LAUGHTER) perhaps I could call it acquiesce to the requests of a patient. Nothing we do in medicine is without a potential risk, including an embryo biopsy to avoid a major problem. On the other hand, if you were to do in vitro fertilization and-- just to look for a particular characteristic that you wish to have, we might consider this to be a frivolous request.

**JOHN HOCKENBERRY:**  
01:36:07; Yeah, but we're already in the IVF--

**ZEV ROSENWAKS:**  
And we would not do it because--

**JOHN HOCKENBERRY:**  
--we're already in the IVF tank.

01:36:09;29-01:36:21;23 **Web Marker: PBS.org More on prenatal testing**

**MALE VOICE:**  
--of risk.

**JOHN HOCKENBERRY:**  
We already have the evidence--

01:36:10;15 **ZEV ROSENWAKS:**  
Nevertheless, as I mentioned even an embryo biopsy could destroy an embryo. And we respect every embryo. Because that embryo is a potential life--

**JOHN HOCKENBERRY:**  
Unless it has--

**ZEV ROSENWAKS:**  
--and we would like that—

01:36:20; **JOHN HOCKENBERRY:**  
--Down's. Unless it has these-- various sort of--

01:36:24; **ZEV ROSENWAKS:**  
Well, no. No, I don't think anyone has ever said that. I think even from the discussion as-- as I hear it here, there's a tremendous respect for human life by all members of the-- panel here.

01:36:34; **JOHN HOCKENBERRY:**  
Right. And in my respect for human life, I want another violinist like my Dad. Lee Silver--

**MALE VOICE:**  
Well, I--

**JOHN HOCKENBERRY:**  
--is somebody gonna be able to find the services that my wife and I are looking for here?

01:36:43; **LEE SILVER:**  
First of all, I don't think we all agree on the-- on the value of a-- of a group of human cells at the earliest stage. I-- I take cells off my body every night when I take a shower. Those cells-- **[LOWER THIRD: Lee M Silver/Prof of Biology & Public Affairs/Princeton University]**

01:36:53; **JOHN HOCKENBERRY:**  
You know, don't go into that if you-- (LAUGHTER) if you-- just--

**MALE VOICE:**

So, there's--

**LEE SILVER:**

01:36:57;

--there-- I don't think there's agreement on that. But I would say-- I would say that I may not want to do it myself. But I think that, in-- in this country certainly there are a lot of fertility clinics out there who are basically for profit. And I think that a couple like yourself and your wife, might be able to find a doctor 10 years from now, who might be willing to do this for you. And I would say, it's up to them to decide if they want to take that risk.

**FRANCIS COLLINS:**

01:37:17;

But wait a minute--

**FEMALE VOICE:**

Yeah.

**FRANCIS COLLINS:**

--let's be sure we get a science right here. While I agreed that there is a hereditary contribution to perfect pitch, it is certainly not the sort of thing that you dial in by doing the appropriate test on the right embryo, and putting it back in there. John, you may end up then with a son, whose particularly appreciative of the heavy metal music that he listens to in his room while he smokes pot. (LAUGHTER) He may be completely disinterested in playing the violin. In fact, he may be insulted that you tried to track him into that. And this whole notion that simply by picking this gene or that gene, you can improve your chances of having what your vision is of the child you want, is scientifically severely flawed. What happened to learning and the environment?

**JOHN HOCKENBERRY:**

01:37:53;

Right. But-- but I listen to Metallica. I'll take that risk. (LAUGHTER) The question is--

**MALE VOICE:**

Well--

**JOHN HOCKENBERRY:**

--do I have the freedom?

**FRANCIS COLLINS:**

01:38:00;15

Here is the classic dilemma. Does the right of a couple to make choices about the characteristics of their offspring, which is generally a-- a right that we consider pretty important, does that trump society's need to put limits upon the applications of technologies, so that we don't begin to devalue human life?

**JOHN HOCKENBERRY:**

Congressman?

**RICK LAZIO:**

01:38:21

No, absolutely not. I mean, it-- it-- there is a fair balance. But there is not an unfettered ability for parents to-- to engineer a child. [LOWER THIRD: Rick Lazio/Fmr US Representative (R-NY)]

01:38:31; **PAUL MILLER:**  
Somewhere along the line, you as representative of a Congressional body, society says that's not okay--

**FEMALE VOICE:**  
Right.

**PAUL MILLER:**  
--for parents to make choices about that. But somehow it is okay for parents to make choices and abort fetuses with Down's Syndrome, with Cystic Fibrosis, with Turner's Syndrome--

01:38:56;15 **JOHN HOCKENBERRY:**  
Faye, go ahead. Is there a contradiction between reproductive rights and the potential options for parents, based on all of this...

01:39:04; **FAYE WATTLETON:**  
Well, reproductive rights, the centrality of it is that parents have options. And that those choices should be guided by their ethical framework. And by the circumstances of their lives. That's the essence. [**LOWER THIRD: Faye Wattleton/President, Center for Gender Equality**]

As science has advanced and given us more knowledge it has demystified biology. And we know now that we do have the capacity to control more than we did before. And yes, we should be able to take advantage of those options.

01:39:30; **ADRIENNE ASCH:**  
Here is where I think Faye's right. If we're going to have reproductive technologies, people get to make the decisions they want to make. But the-- they need to get to make them in the context of a society that supports all kinds of decisions. And that supports the legitimacy of people with musical gifts and Turner's Syndrome and Cystic Fibrosis, all being legitimate people to be born if people want to bear and raise them. [**LOWER THIRD: Adrienne Asch/Prof of Bioethics/Wellesley College**]

01:39:58; **ALTA CHARO:**  
But I really think the discussion here would be-- would be made much clearer if we were to separate out the concerns people have. [**LOWER THIRD: Alta Charo/Prof of Law & Medical Ethics/University of Wisconsin**]

I think that almost all of us, if we looked at our parents, would say about our Mothers, "Wow, they chose somebody as their husband-- who is-- wonderful in many ways. But probably could be improved upon slightly. (LAUGHTER) Whether it's with regard to the receding hairline, or the paunchy belly. Or the-- you know, the tendency towards high blood pressure." And if your Mother had to use a sperm bank, right, chances are very interesting query would have been presented. Do you want to get somebody who resembles your husband in all respects? Right? Warts and all. Or somebody who is a slightly improved version?

01:40:39; **KEVIN FITZGERALD:**  
You keep talking about options. And you keep talking about society. And you keep talking about we. But there are many people in this society of ours that do not have these options. They do not have access to this technology. And they will not have access to the new technologies. **[LOWER THIRD: Kevin T FitzGerald,SJ/Georgetown Univ Medical Center]**

01:40:54; **JOHN HOCKENBERRY:**  
Reverend Anderson, what sort of society-- what sort of verdict on society is it if we have one group with these options, one group without these options? And how do we resolve it?

01:41:04; **REVEREND ANDERSON:**  
The total environment of the organism we call a human being is very, very complex. And it's far beyond just-- genetic controls.

And I think these-- the-- the society..  
**[LOWER THIRD: Rev Michael D Anderson/Westminster Presbyterian Church/Oklahoma City]**

01:41:14;29-01:41:25;23 **Web Marker: PBS.org More on genetics and ethics**

01:41:10;29  
What is the ultimate view of what does it mean to be human? If we look at the entire history of our-- life as homo sapiens over millions of years, hundreds of thousands of years, we are always adjusting to the environment in which we live, to make the greatest possible life for the whole community. And we are going to have to do this with this new knowledge. And this is where government also comes in. We're gonna have to make all of these new sciences accessible. And at the same time, people are saying, "But I don't even have a doctor. And I want to have access."

01:41:51; **JOHN HOCKENBERRY:**  
What can legislation do to prevent either the society you're talking about or preserve the reproductive rights that-- Faye is talking about?

01:41:59;15 **RICK LAZIO:**  
What you'd hope would be that you'd have a much broader debate than just a debate inside of congress. Or just inside the political sphere. Or just inside the medical community. Or just inside the religious community.

01:42:11; **JOHN HOCKENBERRY:**  
There's a broad debate going on about cloning right now.

**RICK LAZIO:**  
It's-- it's-- it's not broad enough, frankly. I-- I don't think enough people know what's going on. We've got to somehow look at this issue as sufficiently fundamental and profound. And we have the kind of social debate, where we can help shape the-- the direction of science, as opposed to science defining the social outcome. And the moral outcome.

01:42:35; **JOHN HOCKENBERRY:**  
Hmm. Is there anybody on this panel who would, even in their wildest dreams, ask for the service that I described--

**KATHLEEN MCAULIFFE:**  
Never.

**JOHN HOCKENBERRY:**  
--looking for perfect pitch?

**KATHLEEN MCAULIFFE:**  
Never.

**JOHN HOCKENBERRY:**  
Anyone?

**KATHLEEN MCAULIFFE**  
Never.

**JOHN HOCKENBERRY:**  
Anyone?

**KATHLEEN MCAULIFFE**  
I think it's--

**JOHN HOCKENBERRY:**  
No one would do it. No, I--

**KATHLEEN MCAULIFFE**  
I think it's appalling that--

**JOHN HOCKENBERRY:**  
--all I wanted to know is yes or no.

**KATHLEEN MCAULIFFE**  
No, I don't think-- I would--

01:42:49; **NANCY WEXLER:**  
I think--somebody would ask for a disease and say, "As long as you're looking for the disease, why don't you look for the perfect pitch." As long as you're looking for it. Two for the price of one. **[LOWER THIRD: Nancy S Wexler/Prof of Neuropsychology/Columbia University]**

01:42:57 **JOHN HOCKENBERRY:**  
Would you do that?

01:43:02; **NANCY WEXLER:**  
I-- would I do that? Ah-- maybe, how about that? (LAUGHTER)

**JOHN HOCKENBERRY:**

Nice. Nice.

01:43:05; **KATHLEEN MCAULIFFE**  
That's genetic enhancement. That's going down a very frightening path. I think there's a big distinction here. You're talking about trying to improve the human race--[LOWER THIRD: Kathleen McAuliffe/Science and Medical Writer]

**MALE VOICE:**  
Thank you.

**KATHLEEN MCAULIFFE**  
--if you will.

**FRANCIS COLLINS:**  
I mean--

**KATHLEEN MCAULIFFE**  
--versus trying to prevent disease.

**FRANCIS COLLINS:**  
--I'm-- I'm shocked as well.  
Let's try a situation here. (LAUGHTER)

**JOHN HOCKENBERRY:**  
--quick situation. And then we're gonna move on. Cause I've got a situation for--

01:43:22; **FRANCIS COLLINS:**  
Suppose that he had not asked about perfect pitch. But he and hundreds of other people sitting in the waiting room-- right behind him, had said, "You know, I want a boy." Now--

**FAYE WATTLETON:**  
Well, that's all over the world right now.

**FRANCIS COLLINS:**  
--trivial to do. Well, is it a good thing?

01:43:35; **FAYE WATTLETON:**  
It's better than infanticide.

**FRANCIS COLLINS:**  
I think that's not a fair response.

**FAYE WATTLETON:**  
I think it is a fair response. Because that's day to day reality.  
(LAUGHTER)

01:43:41; **FRANCIS COLLINS:**  
You're not engaging on my scenario though.

**FAYE WATTLETON:**  
But-- but-- but-- (LAUGHTER)

01:43:45; **FRANCIS COLLINS:**  
If you are going to live in a world where pre-implantation diagnosis and selection of embryos is to have absolutely no boundaries upon it whatsoever, because the rights of the couple are the only principle that enters that discussion, then you have to live with a world where sex selection becomes available to anybody who asks for it.  
Where deciding that you would like to have a child that's 6 foot 4, instead of 5 foot 8 is perfectly acceptable. And you say right then that society has no interest in trying to establish boundaries. Not to Congress, let's not get hung up on whether the legislature does it....Let's talk about us

**MALE VOICE:**  
That's right.

(Lots of overtalk)

**FEMALE VOICE:**  
So, how do you--

**MALE VOICE:**  
This is all of us.

01:44:23; **JOHN HOCKENBERRY:**  
Well, wait a minute. There's a-- there's a more basic question though. There's a more basic question. Would you want to live in that society, Dr. Collins?

**FRANCIS COLLINS:**  
I would worry greatly about living in that society.

**FAYE WATTLETON:**  
Well, Dr. Collins--

**FRANCIS COLLINS:**  
That's a society that devalues diversity.

01:44:31 **FAYE WATTLETON:**  
--what about-- what about a world that says that you have no business mapping out all the genes that you have mapped out. Because we should not have, as a society, we should not have that knowledge? Everything should be random. And we should let nature, through it's randomness, take care of the survival of the species?  
I mean, if-- if-- if flies in the-- **[LOWER THIRD: Faye Wattleton/President, Center for Gender Equality]**

01:44:38; **FRANCIS COLLINS:**  
If it were the societal consensus, I would take it seriously. It's not.

01:44:51; **FAYE WATTLETON:**  
You would-- you would--

**JOHN HOCKENBERRY:**

Well, we--

**FAYE WATTLETON:**

--think that science should restrain research and-- and the pursuit of knowledge, in such a restrictive fashion--because you find it objectionable?

01:44:57;

**FRANCIS COLLINS:**

Knowledge is one thing. The application of the knowledge is another. That's where the responsibility--

**FAYE WATTLETON:**

But once-- once you have the knowledge--

**FRANCIS COLLINS**

--hangs on all of us.

**JOHN HOCKENBERRY:**

Alright.

**FAYE WATTLETON:**

--you are going to put it back in the bottle.

01:45:03;

**JOHN HOCKENBERRY:**

Which leads us to the next-- which leads us to the next scenario for Lee and Meredith. Within the last few weeks, you've had a terrible car accident. Your first child, who's so important to you, that was such a joy, did not survive the car accident.

**MEREDITH VIERA:**

Sophia is dead now.

**JOHN HOCKENBERRY:**

Sophia is dead. So. (LAUGHTER) And that's about the only place where that would get a laugh. (LAUGHTER)

A doctor comes to you knowing your emotional state. And says, "We've preserved tissue from Sophia."

**FEMALE VOICE:**

Oh.

**JOHN HOCKENBERRY:**

"We are in a position to clone her." What's your response?

01:45:39;

**LEE SILVER:**

I see no reason to do it.

**MEREDITH VIERA:**

01:45:40; I see absolutely no reason to do it. I think it's dangerous. Doesn't that Dolly the sheep now bark like a dog or something, I read recently? (LAUGHTER) Or something's weird with that sheep. (LAUGHTER) I am not gonna go down that path.

**JOHN HOCKENBERRY:**

Hey--

**MEREDITH VIERA:**

And we're not gonna get Sophia back.

**JOHN HOCKENBERRY:**

01:45:53 Hey... Alright, so what-- let's-- let's extend the scenario. You are infertile. And you've lost Sophia. The option of cloning is now your only option--

**LEE SILVER:**

Well--

**JOHN HOCKENBERRY:**

--to have a child.

**LEE SILVER:**

01:46:04 --and there's a presumption-- at-- at-- at the very, very start, the presumption is at some point in the future it actually can be done safely. Before that point, I don't think we would consider that. But now we're talking about being able to have a child. A completely unique, different child. It's not going to be Sophia. Although it will look a lot like her. **[LOWER THIRD: Lee M Silver/Prof of Biology & Public Affairs/Princeton University]**

**MEREDITH VIERA:**

01:46:23; But I don't think that's true. I think that it's emotionally so charged. Because I-- if I gave birth-- to a-- a-- a-- cloned Sophia, to me it would be Sophia. So--

**LEE SILVER:**

01:46:33; But it won't be. The girl will be different as she grows up.

**MEREDITH VIERA:**

Well, then let's adopt a child that is different. Or let's have a surrogate. Why do we need to clone—

**LEE SILVER:**

01:46:41 What—what's wrong with having your own child?

**MEREDITH VIEIRA:**

01:46:43 It will be a clone. That's what it's called, it's cloning. It will be a clone. **[LOWER THIRD: Meredith Vieira/Co-Host, The View/ABC News]**

**LEE SILVER:**

No, it won't-- it won't be a clone.

**MEREDITH VIERA:**

Well I don't know, because we haven't done it yet, but I don't want to go down-- then let me-- can you introduce me to a clone? Somebody here (LAUGHTER)-- somebody from your parish is a clone to talk to me?

**JOHN HOCKENBERRY:**

01:46:58; Doctor-- what-- what is the-- that this option-- would be presented to a couple like Meredith and Lee in the near future?

**ZEV ROSENWAKS:**

01:47:07; I would say zero to zero.

**JOHN HOCKENBERRY:**

Zero to zero. Dr. Collins, would you go along with that?

**FRANCIS COLLINS:**

01:47:14; Absolutely.

**JOHN HOCKENBERRY:**

01:47:16; Really? So this is not a technology that would ever be offered, ever be available?

**FRANCIS COLLINS:**

I hope not.

**JOHN HOCKENBERRY:**

Lee Silver ?

**LEE SILVER:**

01:47:24; Well, clearly it's zero in the near future. But I don't think it's appropriate for a scientist to say this is never going to be possible or that it's not gonna be possible to fix the-- the technical problems. And I think there are probably clones within 100 feet of me right now. They may not call themselves clones, but identical twins-- are clones.

**JOHN HOCKENBERRY:**

01:47:41; Identical twins.

**LEE SILVER:**

Yes.

**JOHN HOCKENBERRY:**

Are clones.

**LEE SILVER:**

That's right.

**MEREDITH VIERA:**

01:47:44; I didn't think of a twin as being a clone.

**LEE SILVER:**

Many people don't.

**MEREDITH VIERA:**

Well that makes me feel a little differently.

**JOHN HOCKENBERRY:**

So you might go for it.

**MEREDITH VIERA:**

I'm still inclined to say no. But I never thought of it as having-- Sophia's twin.

**JOHN HOCKENBERRY:**

01:47:57; Let's check the science on this. Would such a child look-- like Sophia?

**ZEV ROSENWAKS:**

01:48:03; They would look very similar. However, I would like to say that I don't think anyone has said that cloning is impossible technically. I think there's every reason to believe that cloning is a highly inefficient, but possible procedure to do in any species. [**LOWER THIRD: Zev Rosenwaks, MD/Ctr for Reproductive Med & Infertility/Weill Cornell Medical Center**]

The most compelling biological reason not to do it is that, to me, at least intuitively, cloning seems to be an imperfect reproductive method. We've always thought about genetics and about reproduction as reinvigorating the species with every generation. Resetting the clock, if you will. Cloning doesn't allow you to do that.

**LEE:**

01:48:42; Some of the same things you just said were said about your own field-- in vitro fertilization. And it took ten years of experimentation for the first baby to be born by in vitro fertilization. There were 103 failures before Louise Joy Brown was born in 1978.

**JOHN HOCKENBERRY:**

But-- well--

**LEE SILVER: cont..**

But today, I think, you know, if Congress had these results in front of it, they would have said no more research. We cannot do in vitro fertilization, and then there would have been hundreds of thousands of people out there who would have gone without children.

**JOHN HOCKENBERRY:**

01:49:11; Is that the scenario, though, in this new cloning technology? That in ten years we're gonna be--

**LEE SILVER:**

No, this is clearly--I'm not saying it's-- (UNINTEL) ten years--

**JOHN HOCKENBERRY:**  
(UNINTEL) today.

01:49:18; **LEE SILVER:**  
But I'm just speculating on the possibility that it might be safe.

(OVERTALK)

**JOHN HOCKENBERRY:**  
Would you allow it if it was safe?

**LEE SILVER:**  
In our situation? For this particular situation? Yes.  
Adults with informed consent should be able to reproduce by themselves or with somebody else.

01:49:33; **JOHN HOCKENBERRY:**  
Father Fitzgerald, does the society have a stake in that one?

01:49:38; **KEVIN FITZGERALD:**  
Does society have a stake in that?

**JOHN HOCKENBERRY:**  
Yeah.

**KEVIN FITZGERALD:**  
I'd say yes. Okay. (LAUGHTER) Next question.

**JOHN HOCKENBERRY:**  
(LAUGHTER) I am so shocked...So what would you do about it? Forbid it? Shut the doors on this floodgate of-- technology?

01:49:50; **KEVIN FITZGERALD:**  
I think some of this technology is forcing us, I hope it's forcing us to do, is to stop and ask ourselves very seriously what kind of species do we wanna be? What kind of society do we wanna build? Do we want a society where, in fact, 11,000 children die every day because they can't get clean water. Not cutting edge research, not health care delivery. Clean water. **[LOWER THIRD: Kevin T FitzGerald,SJ/Georgetown Univ Medical Center]**

01:50:16; **JOHN HOCKENBERRY:**  
Is it gonna be moral, the way this is resolved?

01:50:19; **PAUL MILLER:**  
I-- listened to the learned men of religion talk. And-- and that's not the world of Washington. And quite frankly, I don't think that it's really an issue of-- children dying from bad water or-- perfect pitched kids or whatever. The tidal wave is coming so fast, what we in Washington may make as policy today may be irrelevant next year. Or morals may change in such a way that the test tube baby of ten years ago is now a common practice. **[LOWER THIRD: Paul Steven Miller/Commissioner/Equal Employment Opportunity Comm]**

01:50:55; **JOHN HOCKENBERRY:**  
But you advocate the freedom for people to decide to use virtually whatever option is available to them.

01:51:03; **PAUL MILLER:**  
As a parent, I would be very, very angry having somebody from Washington come in and say well, that may be good enough for you and you may wanna make that decision. But society is better off if you make this decision. I don't want society in that room, in that decision making. I want that to be me and my wife. Or ultimately my wife. And ultimately that's the case. And quite frankly--

01:51:31; **JOHN HOCKENBERRY:**  
You've opened-- you've opened a can of worms here. Where-- people like you may very well be extinct.

01:51:38; **PAUL MILLER:**  
But I think it's not so much the problem that I will be extinct. The problem is going to be the individual who is there and who is even-- more unique and more unusual than I am today. What is life gonna be like for that dwarf kid that everybody looks at and says you could have been fixed. You could have been eradicated.  
And I am willing, quite frankly, to take the risk of that child out there and-- family and religion and community will shore that kid up to allow for parents to make the choices that fit their lives. It is absolutely arrogant for me, I think, to say to a parent, I'm a dwarf, you better keep that dwarf kid. Because my life is of value. If they don't have the wherewithal to do it.

**JOHN HOCKENBERRY:**  
Hurts a little though, doesn't it?

**PAUL MILLER:**  
I think-- it hurts a little because-- it would hurt-- because of what-- it says as a culture about what my-- life is today.

01:52:54; **JOHN HOCKENBERRY:**  
Nancy Wexler.

01:52:55; **NANCY WEXLER:**  
I totally agree with Paul. Practically how would we actually create laws and enforce laws that didn't become a Gestapo state. I mean you're gonna have to have-- you're gonna have to have embryo police on every single ward at every single hospital. **[LOWER THIRD: Nancy S Wexler/Prof of Neuropsychology/Columbia University]**

One question is, what kind of actual laws you know, and regulations. The second, what kind of culture and society do we wanna live in? I don't want to live in a society that takes away my civil liberties. I don't want to live in a society that tells me what kind of children I can or can't have. But thirdly, I would prefer to live in a society in a culture that actually does value diversity. That wouldn't say just because you find something different, that's the end of that line.

01:53:37; **JOHN HOCKENBERRY:**  
Dr. Collins, at the very least, we are gonna be living in a society where there is an explosion of options. Of choices. Are you-- confident that people are going to be able to deal with the power of that information?

01:53:52; **FRANCIS COLLINS:**  
We have a huge amount of work ahead of us to prepare for that And that's not just amongst – parents or prospective parents. That's amongst the supposed experts. [**LOWER THIRD: Francis S Collins/Director/Nat'l Human Genome Research Inst**]

The health care providers. Many of whom also find this all rather unfamiliar territory. Everybody will want to do the right thing. But the information will be-- presented in such a confusing way that people won't really be able to make an informed decision. Because they won't understand what the facts were. And maybe they weren't presented in the fashion that anybody could have understood. The principles that underlie genetics, the things that we're talking about are pretty straight forward. This is not rocket science as people say, it's not neuroscience, thank God, it's just DNA and the consequences of DNA.

01:54:36; **JOHN HOCKENBERRY:**  
Yeah..it's just molecular science.

01:54:41; **FRANCIS COLLINS:**  
....it's just molecular science...

**JOHN HOCKENBERRY:**  
Welcome to the 21<sup>st</sup> century...

**FRANCIS COLLINS:**  
...if we could take away all the mystery, which we scientists perhaps, in some ways use, because it makes us feel special, and actually explain things in their rather straightforward terms, we have a fairly good chance of being able to communicate about this in a way that really informs choices.

01:54:57;11 **JOHN HOCKENBERRY:**  
I wanna thank you all very much for a terrific discussion. Thank so much.

(APPLAUSE)