

FRED FRIENDLY SEMINARS, INC.
OUR GENES/OUR CHOICES
PROGRAM 1: WHO GETS TO KNOW?
TRT 56:46
MODERATOR: ARTHUR MILLER

INTRO TO PANEL

01:01:04;15

ROBERT KRULWICH

I'm Robert Krulwich of ABC News. This is Eric Lander, professor at MIT and at the Whitehead Institute. Let's open with this question: I'm running a study and I think I want some of your DNA. Now, what-- what is the minimalist way that I can get a piece of -- your DNA? What do I have to have?

01:01:21;15

ERIC LANDER:

Oh, I can take a little toothbrush, scrub the inside of my cheek and give it to you. And there'll be enough cells there for you to get DNA to work with.

01:01:27;08

ROBERT KRULWICH:

OK. So I get these cells and I take the DNA-- I put them on-- what is this thing here?

01:01:32:01

ERIC LANDER:

This is a DNA chip.....that has detectors there to read out information about your genetic code.

01:01:37;04

ROBERT KRULWICH:

So I can put the DNA on this chip and it will tell me what?

01:01:40;15

ERIC LANDER:

You might be able to read out the sequence or particular gene involved in my risk of colon cancer, for example.

01:01:49;20

ROBERT KRULWICH:

So a few diseases?

01:01:47;28

ERIC LANDER:

A-- a few tests you can do today.

01:01:49;20

ROBERT KRULWICH:

So let me make it interesting. Suppose I took the DNA from you and I put it in a refrigerator for 25 years.

01:01:57:05

ERIC LANDER

It keeps just fine.

01:01:59;19

ROBERT KRULWICH:

Okay.....But meanwhile these chips just get better and better and better at doing whatever they do.

ERIC LANDER:

And surely they will.

01:02:04;18

ROBERT KRULWICH: (animation in/new voice over)

So let me imagine this...That means when you gave me that cheekcell back

in 2003...Back in 2003 you knew that if I checked your DNA...all I could find was a teeny bit of information about you...one disease, maybe two that you might get one day. But not much.

01:02:24;17

ERIC LANDER:

Well, I might have thought that I had given you the contents of one fortune cookie...

01:02:29;15

ROBERT KRULWICH:

About you...

01:02:30;02

ERIC LANDER:

About me. What I've really given you actually is the whole encyclopedia of all my genetic information.

01:02:36;18

ROBERT KRULWICH:

The book of you?

(new voice over)

(Cont.): 'Cause every time scientists discover a new gene...and a new test...they can find out more about you. And more, and more...All from that one cheek cell that's still in the refrigerator.(animation out)

01:02:52;10

ERIC LANDER

...because the information is there. Those little cells are the complete encyclopedia. Every cell has all the information to any of the genetic questions that we're ever gonna be able to ask.

01:03:02;20

ROBERT KRULWICH:

So this technology, then, leaves us open to huge inspection, doesn't it? I mean, once we give a little piece of ourselves everything about us can one day be learned by somebody?

01:03:12;20

ERIC LANDER:

Only if we give permission. And that's the heart of the matter.

01:03:16;15

ROBERT KRULWICH:

Knowing that, you are ready to consider some of the more surprising and fascinating problems that may arise in this issue of privacy. Which means we're ready for Professor Arthur Miller of the Harvard Law School and his Fred Friendly Seminar panelists._ 01:03:29;07

PANEL START

[LOWER THIRD: Videotaped February 23, 2002]

01:03:34;17

ARTHUR MILLER:

Hi. I'm Artie. I'm in my late 30s-- (LAUGHTER) I'm a freelancer, programmer, that sort of stuff, making a mint. But-- Just a little while ago I lost my older sister. She was 43-Colon cancer, secondary ovarian cancer.

01:04:05;18

[LOWER THIRD: Arthur Miller/Harvard Law School]

And ever since she passed I've been sad, I've been distressed, I've been anxious. Can't sleep. It got so bad about a month ago-- that I went to my doctor, Dr. Rodgers. And-- did a colonoscopy.

01:04:24;20 I figured, okay, results came back clean as a whistle. I thought I'd sleep, but I don't sleep. So I'm back, doc. I figure I'm gonna get cancer. Look-- you know, we talked about this last time. My older sister dies at 43. My dad died a few years ago, he was 55, brain cancer. And since-- since I saw you last my first cousin was operated on for colon cancer. And so I'm just anxious all the time Anything we can do?

01:05:04;00 **DR. DENISE RODGERS:**
Well, I think based on the family history that you're describing-- it's reasonable for you to be anxious, that there may be something genetic that's causing-- **[LOWER THIRD: Denise V. Rodgers/Robert Wood Johnson Medical School]**

01:05:17;20 **ARTHUR MILLER:**
What-- what does that mean?

01:05:18;27 **DR. DENISE RODGERS:**
Well, it-- it means that it's possible that there is an abnormal gene, I guess, if you will, that could be passing from generation to generation in your family.

01:05:34;20 The truth is it's very rare that there's a genetic cause, if you will, for cancer. But when you see families like yours where there appear to be an unusually high number of cancers in relatively young people it suggests to us that perhaps-- —perhaps this is what's going on.

01:05:54;20 **ARTHUR MILLER:**
So what do we do?

01:05:56;00 **DR. DENISE RODGERS:**
The first thing that I would suggest that we do is to send you to a genetic counselor.

01:06:03;00 **ARTHUR MILLER:**
Does this cost a lot? Would my insurance cover it?

01:06:05;18 **DR. DENISE RODGERS:**
It depends on your plan, I'll be honest with you. I mean, I think we're gonna have to call your insurance company and find out whether they'll cover it, because not all of them do.

01:06:14;20 **ARTHUR MILLER: (pick up here)**
Hmm, boy, this is-- this is a biggie. What do you think, genetic counselor?

01:06:20;17 **NANCY WEXLER:**
Well, I think that before you and I have a conversation-- you oughtta think about whether you even wanna tell your insurance company that you and I are gonna talk. Because if your insurance company knows that this could be in your family there potentially could be consequences for your insurance. **[LOWER THIRD: Nancy Wexler/Prof of Neuropsychology/ Columbia University]**

01:06:38;20 **ARTHUR MILLER:**
Do I have to tell 'em that you and I are gonna talk?

01:06:40;20 **NANCY WEXLER:**
You don't have to tell 'em. But,
If you wanna pay out-of-pocket we can also have a conversation that would
be potentially life saving for you.

01:06:54;00 **ARTHUR MILLER:**
Potentially life saving?

01:06:55;27 **NANCY WEXLER:**
Yeah, absolutely.

01:06:57;02 **ARTHUR MILLER:**
How so?

01:06:58;20 **NANCY WEXLER:**
If we really look at who in your family is dying early of cancer, we can find
out what risks there are in your family.

01:07:15;23 –01:07:26;07 **Web Marker: PBS.org > Genetic counseling links**

Then we would have a long conversation about the pluses and minuses of
your finding out in you, in particular, if you have these risk factors. For
colon cancer, in particular, if you do-- an early diagnostic test called a
colonoscopy, you can actually take any kind of little polyp out very early so
cancer never ever develops. So, literally it really can save your life.

01:07:44;29 **ARTHUR MILLER:**
Would it be all right to talk to my other sister and brother about this?

01:07:48;16 **NANCY WEXLER:**
Oh, it'd be terrific. They should come right in.

01:07:50;14 **ARTHUR MILLER:**
Congresswoman Slaughter, you're my younger sister. What do you think?

01:07:57;21 **LOUISE SLAUGHTER:**
I would recommend against it. I would not want you to do it because Congress
has failed to act to pass the legislation that would protect you--

01:08:07;21 **ARTHUR MILLER:**
Because Congress has failed to act I die?

01:08:10;07 **LOUISE SLAUGHTER:**
You-- (LAUGHTER) it seem--

01:08:11;09 **ARTHUR MILLER:**
I don't understand this.

01:08:11;28 **LOUISE SLAUGHTER:**
And it seems to me so simple and so important to do.

01:08:14;00 **ARTHUR MILLER:**
Remember what she said to me?

LOUISE SLAUGHTER:

01:08:15;27 Yes.

01:08:16;10 **ARTHUR MILLER:**
She said, you may be at risk too.

01:08:18;09 **LOUISE SLAUGHTER:**
Oh, I understand. And I-- I'm just telling you that from my point of view I can't risk it. I-- I have family to take care of. I'm the sole provider for the health insurance in my family. There isn't any way I would risk losing that health insurance or my job. **[LOWER THIRD: Louise M Slaughter/US Representative (D-NY)]**

01:08:32;17 Because you know in the United States once you lose health insurance you're not ever gonna have it again for anything. So you're finished. You're-- that doesn't happen in most countries as we both know.

01:08:41;11 **ARTHUR MILLER:**
Let me talk to our brother. Justice Breyer you're my brother. (LAUGHTER) You're my brother. What do you think, Steve?

01:08:47;07 **STEPHEN BREYER:**
Well, I-- I think that if you take the test and it turns out positive that means you have a greater risk of getting cancer. **[LOWER THIRD: Stephen Breyer/Justice, U.S. Supreme Court]**

01:08:54;06 **ARTHUR MILLER:**
Maybe I get clear!

01:08:55;22 **STEPHEN BREYER:**
Yes, that's a very good reason to do it, if you feel that way. Apparently what you're gonna learn from this is that maybe you don't have to have so many check-ups. If that's what you wanna know then go do it.

01:09:08;08 **ARTHUR MILLER:**
Cynthia McFadden, we've known each other since we were young. You know, you remember I was sweet on you. But-- (LAUGHTER)

01:09:16;28 **CYNTHIA MCFADDEN:**
It was mutual. (LAUGHTER)

01:09:19;15 **ARTHUR MILLER:**
Well-- you sure didn't show it. —and, look, I'm talking to you on the basis of our friendship, confidence, just-- just the two of us. What do you think?

01:09:31;19 **CYNTHIA MCFADDEN:**
Well, I'm adopted. I know nothing about my genetic past, Arthur, as you know. And I kind of like it that way.
[LOWER THIRD: Cynthia McFadden/Senior Legal Correspondent/ABC News]

01:09:31;19 **ARTHUR MILLER:**
Hmm, spirit of adventure?

01:09:45;08 **CYNTHIA MCFADDEN:**
I'm sleeping better at night than you are. (LAUGHTER)

01:09:48;21 **ARTHUR MILLER:**
So, I gather you're subtly telling me "forget about it?"

01:09:52;01 **CYNTHIA MCFADDEN:**
Well, look I think your health is important, but I'm not persuaded that your genes are the only reason you might or might not get cancer. And, you know, I'm just worried about you. I think you need a psychiatrist, not a geneticist. (LAUGHTER)

That's why our relationship never went anywhere-- (LAUGHTER)

01:10:10;12 **ARTHUR MILLER:**
My last piece of advice, from Justice Durham. What do you think?

01:10:17;08 **CHRISTINE DURHAM:**
I think it depends a lot, as your other best friend just told you, on what you need psychologically. If you've got to have the information in order to be able to sleep at night then get the information. But, I agree with your sister, pay for it yourself because you are at risk both with respect to your health insurance and possibly even future employment if not your present employment.
[LOWER THIRD: Christine Durham/Justice/Utah Supreme Court]

01:10:41;11 **ARTHUR MILLER:**
Hmm, so pluses and minuses and in the end it's my own decision?

01:10:45;28 **CHRISTINE DURHAM:**
I think it should be, although you've done the right thing in talking to your family about it. They've got their own decisions to make. And should you ever find the right person and decide to have a family you'll have to think about your own off-spring if you have them.

01:10:59;19 **ARTHUR MILLER:**
All right, I-- I decide to have the test. You're sitting there, results in hand. it shows an abnormality, HNPCC. What does that mean?

01:11:16;06 **DR. DENISE RODGERS:**
Well, I'm gonna give you the bad news and the good news, quite frankly. The bad news I'm gonna give you is that your test came back positive and so you are at higher risk for developing cancer. The good news is particularly related to colon cancer. This is a cancer that we know how both to detect early, to treat effectively. And so with careful monitoring there's a very good possibility that we will be able to keep you alive.

01:11:45;28 **ARTHUR MILLER:**
What I hear you saying is my worst nightmare, that I'm gonna die of cancer.

01:11:50;16 **DR. DENISE RODGERS:**
That's probably what you're initially gonna hear me say, which is why I'm gonna keep saying to you over and over again "We're going to be able to monitor you. And we're going to be able to do-- make lifestyle changes." So I am gonna tell you to eat a high fiber diet and low fat and all of that. And I am gonna tell you to get yearly colonoscopies so that we can follow you. So that when your polyp is first detected, we can treat it aggressively.

ARTHUR MILLER:

01:12:15;10 Hmmm. Do we know the probabilities here?

01:12:19;35 **NANCY FISHER:**
Well, the probability, I believe, at-- at your age, you said you were 35, is you have about a 20 percent chance, you know, of getting colon cancer.

But, more importantly, your family and your other members are at risk not only for colon cancer. You have a sister, she may be at risk for ovarian cancer. You're at risk for brain cancer.

[LOWER THIRD: Nancy L. Fisher, MD/Regence BlueShield (Washington)]

01:12:39;04 **ARTHUR MILLER:**
let me get this straight. If I've got-this- what do we call this, a marker or abnormality--

FEMALE VOICE:
H--

01:12:45;02 **ARTHUR MILLER:**
--or something. If I've got it then there's a pretty good chance that my siblings have it.

01:12:49;01 **DENISE RODGERS:**
About 50/50.

01:12:50;20 **ARTHUR MILLER:**
About 50/50?

DENISE RODGERS:
Uh-huh.

01:12:52;06-01:13:19;03 **Web Marker: PBS.org > More on genetic risks**

01:12:52;01 **ARTHUR MILLER:**
25 percent chance of colon cancer Now, let's get real hypothetical. Suppose I make it to 50 or 60, what are my odds then?

01:13:09;19 **NANCY FISHER:**
A risk-- is going up, I believe it's around 80 percent.

01:13:12;15 **ARTHUR MILLER:**
That's maybe why my dad died at 55. Hmm. And you'd try to tell me there's good news here?

01:13:21;12 **NANCY FISHER:**
the good news is that looking at the way technology's going and the advancement of medicine at such a rapid pace. You're 35. By the time you're 55 there may be a cure for that. You just don't know.

01:13:34;10 **ARTHUR MILLER:**
What is she gonna learn from you?
01:13:36;26 Does having this gene mean I'm going to get cancer?

WILLIAM HASELTINE:

01:13:40;04 I-- I think it's extremely likely.

01:13:42;10 **ARTHUR MILLER:**
Extremely?

01:13:43;01 **WILLIAM HASELTINE:**
Extremely likely. The probabilities as the decades pass approach 90 percent, which is virtual certainty. This is one of the types of genes that really do make a big difference to cancer. **[LOWER THIRD: William Haseltine/Chairman and CEO/Human Genome Sciences]**

01:13:57;26 **ARTHUR MILLER:**
I spoke about this very generally before I took the test to my brother and my sister. They were violently opposed. Less so my brother than my sister. Do I tell them now the results of this test?

01:14:11;05 **WILLIAM HASELTINE:**
Yes, I think it could save their life. And if you loved your brother and your sister, which-- you do, I would tell 'em.

01:14:19;14 **LOUISE SLAUGHTER: (check lower third)**
Brother, I want to know. As your sister I really need to know that. I'm afraid to know, not because I'm afraid of finding out the information. I'm scared of what's gonna happen to that information. And I just-- I think we're unprotected here. And that-- that's what bothers me because I really feel that this is the greatest science. And the potential is so marvelous and so wonderful. And I'm willing to face it under my-- you know, we-- we lost our father, lost our sister. I-- I'm willing to face it. I'm just afraid of the consequences.

01:14:49;25 **ARTHUR MILLER:**
—Let me ask another question, Doc, I've been seeing this woman for some time. I was even thinking in one of those moments of madness of proposing. Should I tell her?

01:15:04;26 **WILLIAM HASELTINE:**
Before you get married, if you're going to have children, you should.

01:15:11;19 **ARTHUR MILLER:**
What do you think? Should I tell her?

01:15:14;04 **NANCY WEXLER:**
If you want her not to be furious when you get cancer it's probably a good idea to tell her before you get married. if you don't tell her and you're going for colonoscopies every six months or a year she's gonna say, "Hey, what's up?" Or having brain MRIs—**[LOWER THIRD: Nancy Wexler/Prof. Of Neuropsychology/Columbia University]**

01:15:26;00 **ARTHUR MILLER:**
Oh, I'm on a business trip-- (LAUGHTER)

01:15:28;25 **NANCY WEXLER:**
--you're on a big business trip, all right.

01:15:29;27 **ARTHUR MILLER:**
Use the old business trip shtick.

01:15:31;20 **NANCY WEXLER:**
Then-- then she'll think you're having an affair.(laughter)

01:15:34;26 **ARTHUR MILLER:**
Professor Rothstein, am I under an ethical obligation to talk to my brother,
my sister and my beloved?

01:15:42;17 **MARK ROTHSTEIN:**
what I think you need to do is talk to your at-risk relatives before you're tested and find
out whether they wanna know the results after you're tested. Tell them that
you're gonna undergo testing.

 Obviously, after you've been tested is not the time to approach them and ask
them. With regard to your possible, future spouse, I would agree with your
genetic counselor that-- I-- I think you oughtta do that. **[LOWER THIRD:
Mark Rothstein/Inst for Bioethics, Health Policy & Law/University of
Louisville]**

01:16:10;00 **ARTHUR MILLER:**
I'll tell you what. I-- I'm so upset about all this, particularly-- Sis Louise,
what-- what-- what you're saying. Doc, I want all those records destroyed.
take care of that for me?

01:16:22;20 **DENISE RODGERS:**
I'm sorry, Artie, but I can't.

01:16:25;00 **ARTHUR MILLER:**
Why not?

01:16:26;20 **DENISE RODGERS:**
I'm not willing to go to jail for you.

01:16:29;00 **ARTHUR MILLER:**
Jail?

01:16:30;11 **DENISE RODGERS:**
It's illegal for me to destroy your records.

01:16:32;10 **ARTHUR MILLER:**
Why?

01:16:33;21 **DENISE RODGERS**
Well, they're legal documents.

01:16:35;19 **ARTHUR MILLER:**
Legal?

01:16:36;26 **DENISE RODGERS**
In the sense that-- once I write your medical record, I can't then go back
and-- destroy what I've written.

01:16:44;11 **ARTHUR MILLER:**
let's get this straight.

01:16:46;12 **DENISE RODGERS:**
Yeah.

01:16:46;25 **ARTHUR MILLER:**
I paid for those tests.

01:16:48;24 **DENISE RODGERS:**
You did.

01:16:49;15 **ARTHUR MILLER:**
Remember, we all agreed--

01:16:50;24 **DENISE RODGERS:**
That's right.

ARTHUR MILLER:
-- keep the insurance. And I paid.

01:16:53;10 **DENISE RODGERS:**
Right.

01:16:53;28 **ARTHUR MILLER:**
I understand that those are my records.

01:16:57;11 **DENISE RODGERS:**
They are.

01:16:57;23 **ARTHUR MILLER:**
So if I say to you, Doc--

01:16:59;20 **DENISE RODGERS:**
Right.

01:16:59;26 **ARTHUR MILLER:**
-- "Don't destroy them, give 'em to me."

01:17:02;20 **DENISE RODGERS:**
Right. Then what I'm gonna do is give you a-- copy of them.

01:17:08;22 **ARTHUR MILLER:**
Now why would you do that? (LAUGHTER)

01:17:12;00 **DENISE RODGERS:**
Well, cuz it's my understanding, actually, that I can't destroy your records.
But, since you're very rich and very persistent, I'm gonna (LAUGHTER)
call my lawyer. (LAUGHTER) Because-- (LAUGHTER) I don't wanna get
in trouble in-- either way.

01:17:24;01 **ARTHUR MILLER:**
Now-- if it-- if it weren't illegal--

DENISE RODGERS:
Yes.

01:17:28;04 **ARTHUR MILLER:**
-- if you wouldn't go to jail--

DENISE RODGERS :
Yes.

01:17:30;00 **ARTHUR MILLER:**
01:17:43;01 -- and I say to you-- "Please, Doc, just destroy them all?" (PAUSE)
We could be having--

01:17:43;17 **DENISE RODGERS:**
I don't--

ARTHUR MILLER:
-- a little bonfire while you're thinking about it.

01:17:44;20 **DENISE RODGERS:**
I-- I-- (LAUGHTER) well, I know. On the other hand, you don't want me
making this rash-- giving you this rash answer. I mean I-- I guess for me
there-- there are two considerations here. On the one hand-- I
fundamentally believe that you do have a right to privacy. And quite frankly,
I guess if I'd thought of it ahead of time-- we may have decided for me-- not
to write the information down. But we have to remember-- that this has
much greater implications than-- than just you, Artie.
Pick up here

01:18:16;10 **ARTHUR MILLER:**
But you're my doctor.

01:18:17;11 **DENISE RODGERS:**
I am your doctor.

01:18:18;27 **ARTHUR MILLER:**
Your-- responsibility is to me.

DENISE RODGERS
It is.

01:18:22;09 **ARTHUR MILLER:**
This so-called privilege between us is my privilege.

01:18:25;14 **DENISE RODGERS:**
That's right.

01:18:25;21 **ARTHUR MILLER:**
Those are my records.

01:18:27;21 **DENISE RODGERS:**
That's absolutely right.

01:18:30;00 **ARTHUR MILLER:**
Okay. I've gotten all this advice. Nadine?

01:18:34:00 **NADINE STROSSEN:**
Yeah, Artie? (LAUGHTER)

01:18:37;16 **ARTHUR MILLER:**
We've been seeing each other a long time. (LAUGHTER)

01:18:41;05 **ARTHUR MILLER:**
Simply put, I wanna spend the rest of my life with you.

01:18:45;03 **NADINE STROSSEN:**
How long is the rest of your life? (LAUGHTER)

01:18:51;07 **ARTHUR MILLER:**
Funny you should ask. (LAUGHTER) A-- actually, this proposal-- comes with a couple a footnotes. (LAUGHTER) I had this genetic test. And-- there's this thing called a marker, some gene-- HNPCC abnormality. You know, it's all that jargon. And apparently I have an increased risk for colon cancer.
And-- they say there may be an increased risk for-- brain (COUGH) cancer.

01:19:20;06 **NADINE STROSSEN:**
I really appreciate your telling me this. I--

01:19:22;06 **ARTHUR MILLER:**
Does it make any difference?

01:19:23;14 **NADINE STROSSEN:**
it makes no difference in my love for you, and it makes no difference in my optimism that we can, should I decide to accept your offer-- (LAUGHTER) we could-- **[LOWER THIRD: Nadine Strossen/President/American Civil Liberties Union]**

01:19:34;16 **ARTHUR MILLER:**
There seemed to be a clause in here. (LAUGHTER)

01:19:37;28 **NADINE STROSSEN:**
Well, whether married or not, we can enjoy many happy years together.

01:19:42;18 **ARTHUR MILLER:**
can I go on to the next footnote?
I-- I just don't think emotionally I wanna be a biological father.

01:19:48;23 **NADINE STROSSEN:**
I want you to know that-- I would accept the risk of-- genetic transmission of this gene

01:19:57;00 **NADINE STROSSEN:**
But I also think that, you know, you're going through a very stressful time right now.
things may change. You may decide that you do, after all, want to have children. So-- but I would marry you for you and not for your offspring

01:20:09;26 **ARTHUR MILLER:**
I've got one more footnote. I worry about you. I guess maybe I've gotten too close to this genetic stuff. maybe neither one of us should be biological parents, and we should adopt.

NADINE STROSSEN:

01:20:26;22 Oh, you're saying you want me to have a test? Or are you saying you-- to allay your anxieties about me?

ARTHUR MILLER:
01:20:31;17 Well, Nadine, we have teased back and forth and had some serious conversations about some of your relatives who-- (LAUGHTER) come on-- I don't know whether you'd call it dementia, or-- (LAUGHTER) Alzheimers.

ARTHUR MILLER:
01:20:46;21 (LAUGHTER) let's face it. Genetically you may be hanging out with those relatives. (LAUGHTER) So--

NADINE STROSSEN:
01:20:56;00 Artie, all I-- you know, I've listened to these doctors, too. And we can never eliminate any risk of-- I mean we should lead our lives-- and based on our greatest fears of what might happen.

ARTHUR MILLER:
01:21:08;19 I have a feeling that, basically, you're resisting the notion that you have a genetic screening.

NADINE STROSSEN:
01:21:14;18 Yes. Because I think that's-- we infer-- the information wouldn't be useful to me.

NADINE STROSSEN:
01:21:20;15 If you feel so strongly that-- with all of the years that we have spent together, and everything we know about each other, and all of the values and commitments we share, that you still think that you need to have some, you know, biological test done to determine whether I can be an adequate wife or mother, I actually find that quite shocking.

ARTHUR MILLER:
01:21:42;11 Mmmm. Mark, was it-- wrong of me-- to ask her about-- having the test?

MARK ROTHSTEIN:
01:21:48;19 it would be wrong for you to coerce her into testing. And it's a very personal decision. You wanted the information.
And-- certainly in her case, there's even less reason to find it, because she doesn't have any-- known risk factors for genetic disorders-- at least of earlier onset.
—and-- I think you're gonna lose her, Artie, if-- if you insist.

ARTHUR MILLER:
Hmmm.

ARTHUR MILLER:
01:22:14;19 We get married. And we decide to adopt a child. we go to an agency. It's Janice Goldwater's agency.

NADINE STROSSEN:
Hi, Janice.

JANICE GOLDWATER:
01:22:26;00 Hi. Nice to meet you. (LAUGHTER)

01:22:28;14 **ARTHUR MILLER:**
We really, really-- wanna have a child.
We don't care what the sex of the child is. We don't care what the age of the child is. We don't care what the religion or the race of the child.

01:22:40;22 We've actually been here before. (COUGH) We haven't spoken to you. And I think we both sort of fell head over heels for Alex. Seven year old that you-- you've got here. We understand-- that he's had some-- some difficulties. And-- his mother's-- rights have been legally terminated. Indeed, when she was last seen she was in a-- a mental institution. But-- we'd like-- we'd really like to take a shot at Alex.

01:23:11;11 **JANICE GOLDWATER:**
Well, that's wonderful. Lemme tell you a little bit about how things work. The first thing that we would like you to do is to join in our training class. Where we'll really take an in depth look at what kinds of special challenges that you will deal with. **[LOWER THIRD: Janice Goldwater/Executive Director/Adoptions Together**

01:23:25;20 **ARTHUR MILLER:**
There is one thing you-- you have to do for us, I think.

01:23:28;26 **JANICE GOLDWATER:**
Yeah, what's that?

01:23:31:00 **ARTHUR MILLER:**
We know nothing about his medical history. Don't even know his father. We would really like to have him genetically screened.

01:23:42:12 **JANICE GOLDWATER:**
Genetic screening is not something that we do at this organization.

01:23:46;15 **ARTHUR MILLER:**
Why not? Wouldn't you like to know as much as you can about Alex?

01:23:53;17 **JANICE GOLDWATER:**
Absolutely. And I think we can learn a lot about Alex by the psychological evaluation that he's had, by his school reports, by the information that's reported by his care givers. And-- it-- I'm-- I'm not sure what you would be looking for in a genetic screening. Maybe you could help me out a little bit by telling me what are-- what concerns would you hope to allay by having genetic screening done?

01:24:17;06 **ARTHUR MILLER:**
We know nothing about Alex. To me, as a rational person, the genetic screen will tell us what the future risks might be. We-- we can be better parents.

01:24:28;20 **JANICE GOLDWATER:**
I'm a little confused, because I'm not sure specifically what you would be looking for in a genetic screen.

01:24:34;10 **ARTHUR MILLER:**
I mean no disrespect.

JANICE GOLDWATER:

Certainly.

ARTHUR MILLER:

But what's your hangup? (LAUGHTER)

JANICE GOLDWATER:

01:24:38;10

What's my hangup?

ARTHUR MILLER:

10:18:09;28

I mean – yeah.

JANICE GOLDWATER:

01:24:40;21

To be honest, you're the first parents that have ever come in looking to adopt a child, a seven year old, and asked for genetic testing.

NADINE STROSSEN:

01:24:47;23

So you – don't specifically have a policy against it, you just haven't thought of it before. Is that fair to say?

JANICE GOLDWATER:

01:24:52;23

That's fair to say, yes.

NADINE STROSSEN:

01:24:55;03

So you don't have any-- specific reason why you think it would be a bad thing to do.

JANICE GOLDWATER:

01:24:59;20

but what I'm talking about is giving you full medical, social, educational information. Every single piece of information we have about him is yours. But I'm saying, though, that the line we don't wanna cross is to-- study him genetically.

ARTHUR MILLER:

01:25:12;25

I-- I-- I-- and I guess Nadine are asking why not? It's another piece of information.

PAUL MILLER:

01:25:20;18

What I think is really important about this whole notion of genetic testing is that we not empower genetic information more than it really is. A genetic test is really only going to tell you a probability. Everybody's got a genetic misspelling for something. **[LOWER THIRD: Paul Steven Miller/Commissioner/Equal Employment Opportunity Commission]**

NADINE STROSSEN:

01:25:50;23

whether it's a good idea or not, we should have the right to the information, shouldn't we?

MALE VOICE:

Not s--

NADINE STROSSEN:

I mean--

PAUL MILLER

01:25:50;23

Not particularly. Because I think the boy also has some rights here as an independent being. And sometimes people don't wanna know information

about themselves. Just because information is knowable-- doesn't mean you wanna know it. Information can be power. But information can also be very limiting, too.

ARTHUR MILLER:

01:26:23;15 It just hit me. It just hit me. Why don't you genetically screen us?

JANICE GOLDWATER:

01:26:26;24 Because I'm sending you to the doctor, and I'm asking your family doctor to tell me that you have a normal life expectancy, and that you're in-- in good health. And that you have--

FEMALE VOICE:

Uh-oh. (LAUGHTER)

JANICE GOLDWATER:

-- the ability to--

FEMALE VOICE:

01:26:38;00 Make trouble. (LAUGHTER)

JANICE GOLDWATER:

-- to raise this child to adulthood.

ARTHUR MILLER:

01:26:44;03 I guess we just changed our family doctor, huh?

FEMALE VOICE:

Uh-oh. (LAUGHTER)

(OVERTALK)

DENISE RODGERS:

01:26:49;12 Not a good idea, Artie.

NADINE STROSSEN:

01:26:50;00 But if you're gonna be consistent, you would not go beyond that. And even if one of us had had a genetic screen, you would not want that information about us, would you? Even if it--

JANICE GOLDWATER:

01:27:00;28 No, only if it-- if it was relevant to your ability to--

NADINE STROSSEN:

01:27:02;25 Oh!

JANICE GOLDWATER:

-- parent the children.

NADINE STROSSEN:

01:27:04;11 Well, I hear a double standard here.

JANICE GOLDWATER:

01:27:06;17 Wait. Your-- I'm confused how--

NADINE STROSSEN:

01:27:08;09 Well, you're s-- because you're saying it might be relevant-- whether we're gonna be good parents. But you're-- saying it's not relevant to us to decide whether this is an appropriate child for us to adopt.

JANICE GOLDWATER:
01:27:18;07 No, I'm not asking for you to be genetically screened.

ARTHUR MILLER:
01:27:20;09 What do you think, Doc? Gonna tell her about my screen?

DENISE RODGERS:
01:27:22;00 I'm not gonna tell her that you were genetically screened, no. I'm-- contemplating whether or not I'm going to tell her that you may be at higher risk for cancers. In-- in part because there's something on her form that-- some line that says, you know, "I certify that this is the truth"-- when I sign it. (LAUGHTER) And that's the part that's sort of-- holding me up a little bit. [LOWER THIRD: Denise Rodgers, MD/Robert Wood Johnson Medical School]

ARTHUR MILLER:
01:27:48;05 What do you think? Do you think we're irrational, wanting to know as much as possible about Alex?

NANCY FISHER:
01:27:55;13 What is the best thing for Alex? I mean as a geneticist, we don't screen children for disorders unless there's some intervention.

HAROLD COXSON:
01:28:04;03 I don't think you can take this in a vacuum.
...And it could be that, in the near future, there will be something you can do for Alex, if, in fact, Alex has a genetic predisposition to a particular illness.

And so it-- I think it would be in Alex's interest. And frankly, it would be in the parents' interest, to know this information. [LOWER THIRD: Harold P. Coxson, Jr./Labor Attorney]

CYNTHIA MCFADDEN:
01:28:20;28 But lemme say this. What makes me really squirmy here is...
...I don't think you're being honest with the adoption agency. Because the fact of the matter is, if you just wanted to worry about how to raise the child the best, and we can argue later about whether genetic testing is good, you wouldn't be worried about having her do the test. What you really wanna know is you wanna sort and paste based upon the information you get from that test, whether you adopt this child. Otherwise, you adopt the child and then go do whatever you want. And that is really troubling. Because
-[CYNTHIA MCFADDEN/Chief Legal Correspondent/ABC News]

ARTHUR MILLER:
01:28:50;06 Okay. Okay. Here's what we're gonna do. We'll take Alex. We'll do our own screen. That's what we do.

ARTHUR MILLER:
Justice Durham ? Do you think this is a somebody that should be subjected to laws or just left to the courts?

01:29:05;24 **CHRISTINE DURHAM:**
It's going to have to be subjected to laws, I think, because of the scope of the policy questions at issue. I mean, the-- the basic question, for example, of whether genetic screening is appropriate for potentially adoptable children and then should be disclosed to potential adoptive parents, it-- it's certainly not one that I as a judge would want to have to decide on a policy basis.

01:29:30;00 It-- it's much more suited to the kind of open discussion input from broad interests across the community than it is to the legal process. [**LOWER THIRD: Chirstine M. Durham/Justice/Utah Supreme Court**]

01:29:41;10 **ARTHUR MILLER:**
Brother, leaving law to one side, what do you say to me?

01:29:45;05 **STEPHEN BREYER:**
From what I've heard so far, I don't see the difference between the genetic test for the child and all the other tests that they perform. Well, from what I've heard so far, the only thing this genetic test does is it tells you if there's a higher risk of getting a certain small number of diseases.

Well, all those other tests do the same. [**LOWER THIRD: Stephen Breyer/Associate Justice/U.S. Supreme Court**]

01:30:04;21 **PAUL MILLER:**
No, there's--

STEPHEN BREYER:
So--

PAUL MILLER:
--a big difference--

01:30:06;06 **STEPHEN BREYER:**
Well, that's what I didn't hear--

01:30:07;19 **PAUL MILLER:**
--between-- I think there's a big difference--

MALE VOICE:
What?

01:30:08;20 **PAUL MILLER:**
--between a genetic test and all the other medical tests. Because the medical tests examine and describe the current state of health of that child as it is today.

A genetic test is-- and this is why people are so concerned with genetics-- is an attempt to look into some fuzzy crystal ball and to make a guess about what that future may be.

01:30:22;27 **STEPHEN BREYER:**
is it true that when you go to the doctor today or you look into the family history of the particular child, you only learn how the child is today?

DENISE RODGERS:

01:30:45;17 Well, the answer is-- is that most of the tests are about the child today.

STEPHEN BREYER
01:30:50;27 Well, I want to know if--there are a lot or some--

FEMALE VOICE:
The-- the--

STEPHEN BREYER:
--or a significant number about what will happen.

DENISE RODGERS:
01:30:54;28 Well, I think the piece that you hit on, though, is the family history. I think that given the mother's history of schizophrenia that we can say to these adoptive parents that there's little question that your child is probably at higher risk of developing schizophrenia over time.

STEPHEN BREYER:
01:31:11;28 Alright. Well, if that's the case and if we want to find that out, then what's the difference whether we find it out through this kind of test or some other test?

FEMALE VOICE:
But I--

STEPHEN BREYER:
01:31:20;23 I mean, I-- that's what-- I had the same reaction you had. (COUGH) Is this mysticism? Is it that somebody uses the word, "Oh-- it's a genetic test," and people start to flap? Or is there something-- that's there in the reality that-- that somehow it's a different kind of test—

01:31:37;00 –01:31:42;23 **Web Marker: PBS.org > More on genetic testing**

NANCY WEXLER:
01:31:37;07 I think a lot of it depends on-- on what the test is. I mean, you know, there are different diseases... And if you're looking at family history, clearly for breast cancer, colon cancer, schizophrenia, depression, there are big risk factors. What a genetic test can do is give you a better handle on those risk factors. But again, it is a question of probability.
[LOWER THIRD: Nancy Wexler/Prof. Of Neuropsychology/Columbia University]

STEPHEN BREYER:
01:32:00;26 But when somebody's asking me as a judge or a lawyer or a legislator-- to pass a law that's going to stop someone from getting information, my first question is going to be 'Why?'

ARTHUR MILLER:
01:32:10;28 Alright. Time passes. Dr. Rodgers, you have a patient coming in very soon. It's my brother, Steve. (LAUGHTER)

DENISE RODGERS:
01:32:24;29 Hi, Steve.

01:32:26;15 **ARTHUR MILLER**
Now (LAUGHTER), ju-- just to remind you, I'm also your patient.

01:32:33;09 **DENISE RODGERS:**
That's right.

01:32:34;19 **ARTHUR MILLER:**
And I did that screen and it came up with the-- HNPCC (PH). You know that.

ARTHUR MILLER
What's going through your head?

01:32:54;24 **DENISE RODGERS**
I'm thinking, 'Gosh, I hope he knows.' (LAUGHTER) But I'm also thinking I can't tell him.

DENISE RODGERS
So I have seen that you have several close relatives who have died from cancer at a relatively young age. And I'm going to suggest to you as well that you go and talk to a genetic counselor and consider being tested for yourself. Because I think—

01:33:09;19 **ARTHUR MILLER:**
Are you using information you got from me--

01:33:13;02 **DENISE RODGERS**
No. I'm not.

ARTHUR MILLER
--to advise another patient?

01:33:13;18 I'm not. Because I-- when I saw him--

01:33:18;15 **ARTHUR MILLER:**
Don't get defensive.

01:33:19;14 **DENISE RODGERS:**
I'm not getting defensive. (LAUGHTER) I'm not getting defensive. But I want to be clear. I did that same family history on him that I did on you. Now, based on what I know from you, I certainly am going to probably put that issue of going to see a genetic counselor and thinking about getting tested yourself on the table maybe more readily than I did with you.

01:33:41;17 **ARTHUR MILLER:**
let me put some texture on that. Just before you came over to see Dr. Rodgers you had a consultation-- with a couple of people at the White House. you're on the short list for the next, almost immediate vacancy on the United States Supreme Court.

01:34:03;00 **STEPHEN BREYER**
I hope I know what I'm getting into. (LAUGHTER)

01:34:09;03 **ARTHUR MILLER:**
You know that should you get to the very top of that list there may be questions about your health and the hope that you'll be able to serve for

many years to come. Resume the conversation.

STEPHEN BREYER

01:34:24; 09 You mean, whether I want to find out? Well, I-- I know it's a risk, is that right. I know there's a risk. I know it's serious. I know I have to disclose it. And there we are.

LOUISE SLAUGHTER

01:34:35;21 I know that if anybody got a hint that he'd been to a psychiatrist ...or he had genetic defect, even though every human being on Earth has genetic defects, nobody without it, that he will never make the court.
[LOWER THIRD: Louise M Slaughter/U.S. Representative (D-NY)]

ARTHUR MILLER:

01:34:49;02 Look, you get nominated for the court, with your background you're gonna get confirmed very easily. Have the test in six months, don't have it now.

STEPHEN BREYER:

01:34:59;21 Well, I-- I'm-- I'm prepared to compromise on the fringes (LAUGHTER)--

ARTHUR MILLER:

01:35:05;17 Cynthia, you're the journalist. You're now having lunch with Steve. Interview him. You also have heard these rumors, possible nominee to the court

CYNTHIA MCFADDEN:

01:35:20;16 Well, Steve. I have a couple of sources at the White House who suggest that you're the first person on the list.

STEPHEN BREYER:

01:35:27;22 Good. (LAUGHTER)

CYNTHIA MCFADDEN:

01:35:32;14 "You know I knew your parents. I-- I knew that you-- you've had a family medical problem. You know, do you think that's gonna be a problem in the confirmation?"

STEPHEN BREYER:

01:35:41;09 I wouldn't think so. I've even been thinking of-- of getting some genetic testing. The--

CYNTHIA MCFADDEN:

01:35:46;27 Have you had it?

STEPHEN BREYER:

01:35:47;13 No, I haven't, but I'm thinking of it.

CYNTHIA MCFADDEN:

Does it--

STEPHEN BREYER:

--And I'll tell you, I-- I-- if I wanna--

ARTHUR MILLER:

01:35:50;27 Now, why are you being so open?

STEPHEN BREYER:

--know-- you to know in advance--

CYNTHIA MCFADDEN:

It's off the record.

01:35:54;00

CYNTHIA MCFADDEN:

Let me just say, this is the best conversation I've ever had with a Supreme Court Justice. (LAUGHTER)

01:36:00;22

STEPHEN BREYER

Well, I want you to know something, that there are a lot of tests that people can have to discover if they're at higher risk of cancer. And I think it's an excellent thing that they have those tests.

01:36:12;01

Because if you have the test then people can live with the situation and doctors can deal with it. So, if it comes up that I have a higher risk, so be it. I'd like to know. And I think other people should know.

01:36:25;00

CYNTHIA MCFADDEN:

Like the President?

01:36:26;26

STEPHEN BREYER:

Fine, absolutely. And of course, you know, everyone is going to die. Everyone has risks that he carries within them of certain kinds of death. I can live with that.

01:36:39;12

ARTHUR MILLER:

Cynthia, what are you gonna do with this burst of-- (LAUGHTER) honesty?

01:36:43;23

CYNTHIA MCFADDEN:

Unexpected Candor! (LAUGHTER) Yeah. No, well-- I mean, I'm calling my city editor right away. And-- I'm gonna say-- (CLEARS THROAT) break open page one.

01:36:56;06

ARTHUR MILLER:

Yeah. What will the headline be?

01:36:57;15

CYNTHIA MCFADDEN:

Well, I mean, it's a little tricky here. Because in our-- in our-- in our world right now, Steve is not yet on the court. He's in the nomination process. He hasn't had the genetic test himself. I'm the holder of-- secret, confidential information that you have had the test.

01:37:17;12

ARTHUR MILLER:

And, that I have the marker.

01:37:21;23

CYNTHIA MCFADDEN:

Yeah. It's a toughie.

01:37:23;23

ARTHUR MILLER:

Hmm.

CYNTHIA MCFADDEN:

Because-- I mean, I'm in possession of information which I'm not-- (CLEARS THROAT) I know more-- I know more than I want to know right

now. In some ways.

ARTHUR MILLER:

01:37:36;24 And the minute he's nominated?

CYNTHIA MCFADDEN:

01:37:40;18 You know, there's a difference between what you have a right to do, and the right thing to do. [LOWER THIRD: Cynthia McFadden/Chief Legal Correspondent/ ABC News]

ARTHUR MILLER:

Uh-huh (AFFIRM).

CYNTHIA MCFADDEN:

01:37:46;01 I have the right now, to open up page one, and say everything I know. No one's going to pass a law, at least as far as I know, that says I can't do it.

01:37:53;24

I think what I'd do at this point is go to page one and say, "He's considering having genetic testing. He has told the President, or is about to tell the President that-- you know-- there's a family history here." But-- you know, frankly-- as a citizen? I don't care. As a journalist, I know it's a big story. And I know that the confirmation process will think it's a big story.

01:38:14;08

The luncheon is ending. You're getting up and leaving the restaurant. He's been coughing like crazy. He's got a head cold. His napkin is sitting right there. (LAUGHTER)

01:38:36;10

Well, I'd think about it. (LAUGHTER) I didn't see that coming. I'm gonna take it. Now, I don't have to do anything with it. But I'm gonna take it. oh. (LAUGHTER) I can't believe I'm gonna tak-- but I'm gonna take it, yeah. (LAUGHTER)

01:38:58;04

ARTHUR MILLER:

We-- we will-- we will let that one recede. I've been doing great. My-- my business is flourishing. You want to go into a joint venture with me. Want to open up a business. But you keep telling me, we've got to control costs. are you worried about medical costs, and things like that, for the few people we've got working?

01:39:18;25

HAROLD COXSON

Yes. Probably not as much now. But I would be in the future, because we hope to grow.

01:39:24;00

ARTHUR MILLER:

that means-- young and healthy. Not people who are going to be such high cost individual from a health perspective, that are-- premium's gonna go up. Now, our-- our first need-- biggest need, is Director of R&D. And-- I've been looking through the applications, and-- Paul, I-- I think you're a terrific candidate.

Now-- could we get some letters of reference, from-- people you've worked for in the past?

01:40:02;09

PAUL MILLER:

Absolutely.

ARTHUR MILLER:

01:40:03;05 Good. Could we get-- let's say, transcripts from college and graduate school?

01:40:09;20 **PAUL MILLER:**
Sure.

01:40:10;20 **ARTHUR MILLER:**
Good. how about those standardized tests that you've taken, for college, and graduate school? Can we get those?

01:40:18;10 **PAUL MILLER:**
If you think that's important. **[LOWER THIRD: Paul Steven Miller/Commissioner/ Equal Employment Opportunity Commission]**

01:40:21;20 **ARTHUR MILLER:**
We'd like to hire you. there are a couple of conditions, First, how's your diet?

01:40:28;17 **PAUL MILLER:**
My diet's okay.

01:40:30;25 **ARTHUR MILLER:**
Not too much red meat? (LAUGHTER)

01:40:33;20 **PAUL MILLER:**
Vegetarian.

01:40:36;21 **ARTHUR MILLER:**
Hmm. Do you smoke?

01:40:38;19 **PAUL MILLER:**
Do I smoke? No. But why do you want to know this information?

01:40:46;21 **ARTHUR MILLER:**
Well, I've been told-- that smoking increases the cost to an employer. Just-- by some staggering amount.

Any family history? Me-- medical history, problems?

01:40:59;14 **PAUL MILLER:**
I just don't see how this is really relevant to my working for you. And I feel-- a bit uncomfortable talking about my health history-- as a--

01:41:12;26 **ARTHUR MILLER:**
This is a young company, Paul. We want young--

PAUL MILLER:
-- as a condition--

ARTHUR MILLER:
-- vigorous, energetic people.

01:41:19;22 **PAUL MILLER:**
And I am all of those things.

01:41:22;15 **ARTHUR MILLER:**
So, it bothers you somehow, to talk about medical history?

01:41:26;06 **PAUL MILLER:**
I don't know if that's really an appropriate conversation for us to have at this particular stage.

01:41:33;16 **ARTHUR MILLER:**
I want you as part of our family. So, what's wrong with knowing something about your family?

01:41:38;22 **PAUL MILLER:**
I want you to hire me based upon my qualifications.

01:41:45;14 - 01:42:03;24 **Web Marker: PBS.org > More on genetics & privacy**

01:41:45;12
And I will give you all of the information that you need to know about whether I can perform-- adequately, and s-- and-- and be a superior, and loyal and dedicated employee to this company.

01:42:03;20 **ARTHUR MILLER:**
Okay. Now, everybody that works here-- we have to do a simple medical test. Okay? Great. So, no problem. Dr. Haseltine. Now. You're-- the company doctor. Or, you've been contracted to do the company doctoring. And-- do a genetic screen on him.

01:42:25;03 **WILLIAM HASELTINE:**
Can't do it.

01:42:25;20 **ARTHUR MILLER:**
Why not?

01:42:26;03 **WILLIAM HASELTINE:**
It's not ethical.

01:42:28;00 **ARTHUR MILLER:**
Not ethical? What isn't ethical--

01:42:30;00 **WILLIAM HASELTINE:**
Not ethical. Get a-- different company doctor. (LAUGHTER) I will do the standard medical tests.

01:42:34;28 **ARTHUR MILLER:**
Nancy, how about you?

01:42:37;25 **NANCY FISHER:**
Would I be the doctor--

ARTHUR MILLER:
Yeah.

(OVERTALK)

NANCY FISHER:
And draw genetic tests on him?

ARTHUR MILLER:

Yeah.

01:42:40;24 **NANCY FISHER:**
Absolutely not.

01:42:41;00 **ARTHUR MILLER:**
Absolutely not?

01:42:42;19 **NANCY FISHER:**
Not without his permission.

01:42:45;00 **ARTHUR MILLER:**
Hmm. Are there doctors who would?

01:42:47;17 **NANCY FISHER:**
I don't know. I can't speak for them.

01:42:50;29 **ARTHUR MILLER:**
So, there may be a company-- or a company doctor.

01:42:54;28 **PAUL MILLER:**
We've run across them. (LAUGHTER)

01:42:58;08 **LOUISE SLAUGHTER:**
Th-- they're known to be out there.

FEMALE VOICE:
Okay.

01:43:00;20 **CYNTHIA MCFADDEN:**
I have to have somewhere to take my napkin. (LAUGHTER)

FEMALE VOICE:
Yes, well. (LAUGHTER)

01:43:10;20 **ARTHUR MILLER:**
What about that, Dr. Rodgers?

01:43:12;00 **ARTHUR MILLER:**
there are doctors who, if requested by their employers-- will do genetic testing without disclosure.

01:43:19;20 **DENISE RODGERS:**
That's right.

01:43:20;23 **ARTHUR MILLER:**
Is that troublesome?

01:43:23;05 **DENISE RODGERS**
Very troublesome to me.

01:43:26;27 **ARTHUR MILLER:**
Suppose Paul is subjected to that. And the result shows a marker. What is the obligation of that company doctor, to Paul, at that point?

01:43:46;01 **DENISE RODGERS:**
Well, the interesting thing-- from my perspective is that my obligation, if I'm that doctor, in drawing the blood in the first place, was clearly to the company. To protect the company. Cuz that's the only way I could justify doing the test in the first place. [LOWER THIRD: Denise V. Rodgers, MD/Robert Wood Johnson Medical School]

ARTHUR MILLER:
Uh-huh.

01:44:01;20 **DENISE RODGERS**
In the worst case scenario, I hang on to that-- obligation to the company. So, I don't care about Paul. I don't care whether he knows about this information or not. If-- if Paul wants to find it out, then he can go out and find it on his own.
But I have no obligation to tell him, that I did a test on him, that-- by the way, he never knew I did. And that, by the way, he may not want the results of.

01:44:21;20 **HAROLD COXSON:**
Artie, I'm getting more and more nervous about our partnership. (LAUGHTER)

01:44:26;25
I-- I don't know why-- we would want this information. It's too remote. Too speculative. To base a present employment decision on whether or not-- down the road, he may or may not contract some illness.

01:44:40;04 **DENISE RODGERS:**
The other thing that we've not talked about in all of this, is actually the psychological consequences of this testing. When you go out and you test Paul here, perhaps giving him this result, can take away your ideal employee. Because he may be psychologically devastated by that.

01:44:54;16 **ARTHUR MILLER:**
You know, that's-- that's an interesting point. Doesn't that support the notion that we don't tell Paul what the results of the test are? Haven't you just validated this brilliant decision I made?

01:45:07;29 **DENISE RODGERS**
Well, what-- what I-- what I believe I've really validated, is the decision of your partner, who's far wiser than you, to not do the test in the first place.

01:45:14;00 **ARTHUR MILLER:**
He just looks wiser. (LAUGHTER)

01:45:17;12 **DENISE RODGERS**
let's assume he has the same marker that you do.
while I would want to say that my-- obligation is solely to the company, because they paid me, and they've clearly paid me a lot to do this test. I am very, very torn about what to do. And I'm-- I actually may risk my professional career. Because it is going to go down the tubes, when I r-- reveal this to Paul. But-- but it may be, indeed, the right thing for me to do.

01:45:42;02 **ARTHUR MILLER:**
When I started talking to Paul, he was willing to give me references. College grades, graduate grades, SAT, GRE's, LSAT's. All of which are simply

predictors. Right? That's not you Paul.

PAUL MILLER

01:46:01;08

No.

ARTHUR MILLER:

01:46:02;00

But as soon as I wanted to do anything physical to him-- which are just another set of predictors-- he gets uptight. You run like a scared rabbit. (LAUGHTER) The doctor finds ethics, suddenly.

PAUL MILLER:

01:46:19;09

But I think the difference is-- I can-- study hard, and get better grades. I-- somehow, own my future, with respect to-- recommendations, and-- school work, and everything else. With respect to genetics, a genetic test-- there's nothing I can do about that. It-- you are going to-- define me, in a way that I get boxed in. Because I really want this job. and I know that if I stonewall you on this information, regardless of what the law is, you're not gonna hire me.

ARTHUR MILLER:

01:47:01;25

And if you accede to the information request?

PAUL MILLER:

01:47:07;01

I don't know. That's the trouble that I, as a potential employee, as an applicant, face.

ARTHUR MILLER:

01:47:16;00

Mark ,What do you think?

MARK ROTHSTEIN:

01:47:18;06

I think as an employer, you have a right to learn all the information that's relevant to whether he can do the job that you are considering-- hiring him for. And-- the other kinds of information that you may obtain, particularly of a health-related nature, are so intensely personal, that we run a risk of having all sorts of negative consequences occur. I'm very troubled. By-- by this. [LOWER THIRD: Mark A. Rothstein/Inst for Bioethics, Health Policy & Law/University of Louisville]

ARTHUR MILLER:

01:47:49;16

Time passes. Nadine's prediction that I might change my mind about fatherhood— proved correct. And we now have a daughter, Rachel.

01:48:06;14

So, we have Alex and Rachel. Unfortunately, our marriage has fallen apart. (LAUGHTER) And divorce is on the table. Nadine, you're represented by the man who just abandoned me, as my partner. All right? One of the people in the office, looking through the papers, discovers that Artie had this genetic screen. Nadine wants custody of Alex and Rachel. You think-- that information is relevant?

HAROLD COXSON

01:49:00;27

I'm representing Nadine?

ARTHUR MILLER:

Uh-huh.

01:49:03;01 **HAROLD COXSON:**
Certainly.

01:49:07;19 **ARTHUR MILLER:**
Why is it relevant?

01:49:10;23 **HAROLD COXSON:**
I think it's-- it's relevant-- with respect to custody. Whether or not you will be able to take care of-- Rachel and-- and Alex-- in a-- in a fashion-- better than Nadine. I'm representing Nadine. I'm her advocate.

01:49:30;00 **ARTHUR MILLER:**
So, because I'm medically at risk? You are willing to trumpet to the relevant judge--

01:49:37;12 **HAROLD COXSON**
I'm willing to--

ARTHUR MILLER:
-- that she's a better parent than I am?

01:49:39;20 **HAROLD COXSON**
I'm willing to try.

01:49:41;09 **ARTHUR MILLER:**
Justice? You think lawyer's are gonna be doing that in the future?

01:49:45;11 **CHRISTINE DURHAM:**
Oh, I think lawyers-- lawyers probably are doing that as we speak. But the threshold question is going to be relevance. And-- and I haven't heard anything yet, from-- anyone, that suggests that-- probability of a particular disease at some undetermined point in the future, is relevant to-- to a current custody decision. **[LOWER THIRD: Christine Durham/Justice/Utah Supreme Court]**

01:50:06;09 **ARTHUR MILLER:**
Suppose the marker, however, is-- something far more terrible, and more predictable, like Huntington's disease.

01:50:14;07 **CHRISTINE DURHAM:**
And what's the level of probability?

01:50:16;04 **ARTHUR MILLER:**
What's the level of probability, Wexler?

01:50:19;01 **NANCY WEXLER:**
if he has the gene, it is 100 percent certain that he will get sick, if he lives a normal lifespan.

01:50:27;03 **CHRISTINE DURHAM**
But you won't be able to say when.

01:50:29;10 **NANCY WEXLER**
No. Can't exactly say when. But you know usually the onset's 30, 40, 50. That's kind of where he is, a little bit. He's grown up.

01:50:38;05 **CHRISTINE DURHAM**
It's a much closer question on relevance.

01:51:08;18 **CHRISTINE DURHAM**
depending on the age of the children, the-- constellation of the family, the other alternatives, it's probably relevant, at-- at that point. Although-- going out on a limb a little bit there.
Medical information of all kinds operates as a wedge, in-- in litigation. And in this instance, it's hard to see why the-- the genet-- the fact that the information comes from genetic testing as a source, changes-- changes it nature in any fundamental way.

01:51:19;29 **CHRISTINE DURHAM:**
Although that's true of the family history as well, and of other sorts of medical information. Any kind of a psychiatric history, for example-- will have similarly damaging impact.

01:51:29;20 **NADINE STROSSEN:**
I think that's true. But I keep reading about how employers and insurers are putting more weight, mystical weight-- I think unjustified weight-- but they're discriminating against people who have these genetic markers, in a more systematic way than they are against people based on medical histories.

01:51:46;27 **CHRISTINE DURHAM**
But are you suggesting that a court should keep the information out, on-- on an analysis based on those social factors?

01:51:53;12 **NADINE STROSSEN**
Well, they do have to be-- you're-- you know, you're weighing. You're saying, it's a judgment call. And you-- and we talked about the totality of--

01:51:59;08 **CHRISTINE DURHAM**
Well, I said relevance was a j-- judgment call.

01:52:02;02 **NADINE STROSSEN**
Yeah. Well.

01:52:02;02 **NANCY WEXLER**
But, I think one of the-- one of the issues here is-- and I think that it is important, actually, for the judiciary to really be looking at the relevance issue. Because-- you're torn. You have an obligation to the welfare of the children. And to consider what kind of home they're living in.

As well as, to protect the privacy and the confidentiality of the litigants, in this case. And

01:52:24;03 **CHRISTINE DURHAM:**
you know, courts are bad places for some of these questions to be resolved. Because for example, you were commenting about the obligation to protect

parents in a-- the confidentiality of parents, in a custody dispute. There is no such obligation in the courts. That's not part of our job. And when people bring a piece of litigation into the courts for resolution, they are choosing a public forum for the resolution of those disputes. And relevant evidence is gonna be public.

ARTHUR MILLER:

01:52:52;06

Now, Justice Breyer

How do you react to this discussion, and the possibility of where we are today, on-- genetic testing and where we might be next year, or next decade?

STEPHEN BREYER:

01:53:05;15

The reactions that I have, which are not tremendously informed-- is that people break down, including within each individual-- between on the one hand, a concern about privacy, and misuse of information. And on the other hand, an absolutely clear understanding that civilization is what it is today, because of research, and the sharing of information. [**LOWER THIRD: Stephen Breyer/Justice, U.S. Supreme Court**]

01:53:31:22

And so, the problem is, how do we protect both of those interest? Obviously the greatest concern in the employment case, is that you want the information. So that the insurance company can charge a higher rate to the people who have the gene. And we react negatively to that. But insurance companies are in business to assess risks. To tell them they shouldn't, is a little tough for them not to do. Or, you say, "Don't give them the information. Well-- that may be appropriate. And it also may cut off information that's valuable for people-- particularly when they need to take a test, and they don't do it, cuz they're frightened." Or-- which we haven't discussed-- we could socialize the cost. I.e.-- don't make the company pay the cost of a person having a special risk of cancer. Maybe the government should do it, perish the thought. So, we have a complicated system. And we also have an approach. And the approach, I think, is being exhibited. The discussion takes place, among experts. Legislators. Commissioners. Maybe judges. And lots of ordinary citizens. I mean, eventually, we come to odd consensuses. And if you want a definite solution, you're not going to get one from me. (LAUGHTER)

ARTHUR MILLER:

01:54:58;27

Thank you to the panelists. (Applause)

01:55:05;18

End