JOHN MCLAUGHLIN'S "ONE ON ONE"

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GUESTS: DR. FRANCIS COLLINS, DIRECTOR, NATIONAL HUMAN GENOME RESEARCH INSTITUTE; AND DR. ERIC LANDER, DIRECTOR, MIT CENTER FOR GENOME RESEARCH

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SUBJECT: HUMAN GENOME

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Body

MR. MCLAUGHLIN: The new millennium's greatest advance in medicine. Barely 50 years ago, in 1953, scientists James Watson and Francis Crick published their landmark study on the structure of life's basic ingredient -- deoxyribonucleic acid -- better known as DNA. Watson and Crick gave us the key to DNA crime-solving, genetically engineered farm crops, genetic medicine, cloning, and now the unlocking of the secrets of the human genome.

What's ahead? Will cloned organs replace a human donor's organs for transplants? Will inherited disease be eradicated through genetic engineering? Who decides when genetic manipulation is okay and when it should be outlawed? We'll ask Dr. Francis Collins, director of the National Human Genome Research Institute, and Dr. ***Eric Lander***, director of the Whitehead Massachusetts Institute of Technology Center for Genome Research.

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MR. MCLAUGHLIN: Dr. Francis Collins, will you explain for our viewers what the human genome project is and why it is important?

DR. COLLINS: Well, it is an audacious effort to read our own instruction book. It is a project which aims to determine the complete sequence of all of the human DNA -- the hereditary material -- and also to compare that to the DNA of other organisms in order to help us understand what it all means.

MR. MCLAUGHLIN: What does "genome" mean?

DR. COLLINS: Genome is just all of the DNA, all of the instructions. I have a genome. Yours and mine are very similar. The mouse has a genome that's about 70 percent the same as yours and mine. Each organism has its own genome.

MR. MCLAUGHLIN: What's your budget?

DR. COLLINS: Current budget for the NIH -- the National Institutes of Health -- effort on the human genome project is about $300 million a year.

MR. MCLAUGHLIN: I see $3 billion on my research here. Is that for the whole cooperative venture?

DR. COLLINS: That was the projected cost of this project over a 15-year period. It actually seems that we're going to get to our goals at somewhat less cost than that. This is a project which, I'm happy to say, is not only ahead of schedule but somewhat under budget.

MR. MCLAUGHLIN: Who sponsors it?

DR. COLLINS: Sponsored internationally. The U.S. has taken the lead on this effort. In the U.S., the National Institutes of Health is the lead agency, but the Department of Energy is also a sponsor. But we have important collaborators in Britain, in Japan, in France, in Germany.

MR. MCLAUGHLIN: Dr. Lander, what is your role in genetic research?

DR. LANDER: I'm one of the directors of the Human Genome Centers that are participating as part of this international consortium to get the sequence of the human and other genomes.

MR. MCLAUGHLIN: When this project is completed, what will we have a better knowledge of?

DR. LANDER: We'll have a knowledge of all the building blocks that make up a human being. There are about 100,000 genes, and there are the parts that you use to make your hair, your eyes, your heart, your muscles. And in a sense, it's been amazing we could do medicine at all without knowing the basic parts list was.

MR. MCLAUGHLIN: Inherited physical traits? Hair?

DR. LANDER: Inherited physical traits from predispositions to heart disease, to cancer, to asthma, to many other rarer genetic diseases, all of which tell us about how the body really works.

MR. MCLAUGHLIN: What about intelligence, personality and even character? Will you be able to discover things about that?

DR. LANDER: It's an open question. I think most of the focus in human genetics today is on much more disease-oriented research that can benefit people more directly.

MR. MCLAUGHLIN: Will we have the basic knowledge to modify this genetic structure?

DR. COLLINS: I think the intention from a medical perspective -- and I'm a physician, so I'll advocate for the purpose of this being that -- we should be able to understand the hereditary contributions to virtually every disease, and that will give us an opportunity to develop therapies for diseases that are much more effective than what we currently have.

As to changing the basic structure of the human genome in a way that would be affecting future generations, I think none of us are very enthusiastic about that. We don't understand the risks that would be involved. There are intense philosophical debates about whether that would be a good idea or not.

MR. MCLAUGHLIN: We might enter a few of those as this program proceeds. But at this point, let me ask you this. There is a convergence going on, is there not, there's a convergence going on between genetics and cybernetics?

You have something in your program called -- or working with you in the program called the GenBank; is that correct?

DR. LANDER: That's right.

MR. MCLAUGHLIN: What is the GenBank?

DR. LANDER: The GenBank is a database that collects all the information about the sequences of the genomes of many different organisms. And you can do remarkable studies with it. You find that when you compare different organisms, humans and mice have basically the same sets of genes. Not just that; humans and yeast use the same sets of genes to run their cells.

MR. MCLAUGHLIN: Well, who runs the GenBank?

DR. LANDER: It's a project of the National Institutes of Health through its National Center for Biotechnology Information.

MR. MCLAUGHLIN: What does it link together?

DR. LANDER: It links together research going on in thousands of laboratories in the world, to deposit their data every day into it, and tens of thousands of scientists around the world who reach into it to pull out information for their own studies.

MR. MCLAUGHLIN: Using computers?

DR. LANDER: All using computers --

MR. MCLAUGHLIN: What kind of computers?

DR. LANDER: Oh, everything from little PCs to large supercomputers.

MR. MCLAUGHLIN: To the Cray Supercomputer, correct?

DR. LANDER: Every type of computer is running on genetic data, trying to make inferences about it.

MR. MCLAUGHLIN: What are they going to catalogue and store, Dr. Collins?

DR. COLLINS: In this database? Well, everything we can learn about genes, their sequence, and their function. So not only are we interested in getting the letters of the code put into this database, where anybody with an Internet connection can have access to it; we want to understand how it works.

MR. MCLAUGHLIN: Do they already engage in warehousing of DNA- based pair sequences? I'm referring to food.

DR. COLLINS: There are certainly genome sequences from plants in the database --

MR. MCLAUGHLIN: And animals?

DR. COLLINS: And animals and people and yeast.

DR. LANDER: Bacterias, everything.

MR. MCLAUGHLIN: So I show here 18,000 -- already -- plant and animals species.

DR. COLLINS: That's right.

MR. MCLAUGHLIN: Their pair sequences are already now codified and warehoused in that center.

DR. LANDER: Well, pieces of the sequence --

DR. COLLINS: Yeah.

DR. LANDER: -- many thousands of organisms. The number of organisms for which we have the total, complete genetic code is still on the order of dozens.

MR. MCLAUGHLIN: Now you two are mapping the human genetic code, correct?

DR. LANDER: That's right.

MR. MCLAUGHLIN: But is it not true that species at all levels are being mapped in the GenBank?

DR. COLLINS: That data is being deposited there, or the work is being done in laboratories all over the world. But GenBank is sort of the common place where everybody puts their results, in order to make the most out of them.

MR. MCLAUGHLIN: So we can say that there is this convergence of cybernetics and genetics that's making it possible for the advances that we have seen -- you have seen this year, because you mapped one chromosome, did you not?

DR. COLLINS: That's right. The first human chromosome -- happens to be Chromosome 22 -- was published, its complete sequence, just two weeks ago. And that is a milestone of, I think, a very significant sort. We've never seen a whole human chromosome. We've never even seen a whole mammalian chromosome at one time. And there it is, all laid out in front of us -- rather exciting.

MR. MCLAUGHLIN: How many chromosomes are there?

DR. COLLINS: The human has 24. So this is one of a set, and it's one of the smaller ones.

But you know, in another two and a half years, we will have all of those chromosomes completed. And just six months from now we'll have all of that information in draft form, covering about 90 percent of the human sequence.

MR. MCLAUGHLIN: I think we have that on the screen, available for us. You tell me whether these figures are correct.

Mapping the human genome, finished sequence, 15 percent; draft sequence, 25.3 percent, due in spring 2000. Is that correct?

DR. COLLINS: That is correct.

DR. LANDER: All right.

MR. MCLAUGHLIN: Let's tie this down a little bit more. What have you found out in mapping the chromosome that you have successfully done?

DR. COLLINS: Oh, a host of interesting details that you could not have guessed at without having the whole chromosome in front of you. So where are the genes? Are they located in certain places? Are they randomly distributed? Where are the repetitive sequences, that is, the part of the genome that happens many times over? How does that relate to the tendency of this chromosome to rearrange and cause birth defects? All of those things came out of this study that you couldn't have guessed at by just looking a piece at a time.

MR. MCLAUGHLIN: Let's talk about the practical applications of what is now being done and the exhilarating prospect of what lies ahead. You're going to have designer medicines developed from this genetic research, are you not, where we use our knowledge of genetics to create a drug therapy designed to work efficiently with a particular individual for a specific illness, correct?

DR. COLLINS: That's right. That's right.

MR. MCLAUGHLIN: That's called somatic medicine.

DR. COLLINS: Well, not ---

MR. MCLAUGHLIN: Somatic genetic medicine, I guess.

DR. LANDER: Well, there are many kinds of medicine that can come out of an understanding of human genetics. Once we know the basis of a disease, sometimes you can treat by changing a diet. Sometimes you may treat by making a small-molecule pharmaceutical in a bottle. And then there are others ideas for treating that might involve a gene therapy.

I think the common thread that knits it all together is that in the past we've tried to solve many diseases without actually knowing what's wrong. But now we can say, for example, some people with heart disease have that heart disease for a very specific reason. Some molecule that's supposed to soak up a lipoprotein, a fat particle, doesn't do its job very well, there's not enough of it. And so you try to make a drug that'll increase that.

Or some people get Alzheimer's disease because of a particular sticky protein that gloms onto something else, and you try to make a drug that interferes with it.

MR. MCLAUGHLIN: Your knowledge of the genetic structure permits a pharmaceutical company of researchers to put together a drug that will meet the deficiencies in that gene as you have examined it, correct?

DR. LANDER: Give or take.

MR. MCLAUGHLIN: Okay. No argument about that. There are -- there's no dispute about that.

DR. LANDER: I think that's right.

MR. MCLAUGHLIN: I mean, designer drugs, and we're talking about biopharmaceuticals, are okay, and everybody accepts that.

DR. COLLINS: Right, and every pharmaceutical company has a genomics division trying to make this happen as fast as they can. This is their future. This is our future.

MR. MCLAUGHLIN: If you can find way for a biopharmaceutical manufacturer to develop a drug to, say, inhibit or to correct Alzheimer's disease, no one's going to fight that.

DR. LANDER: I can't imagine it.

MR. MCLAUGHLIN: Or Tay Sachs or Cystic Fibrosis.

DR. COLLINS: More power to them.

MR. MCLAUGHLIN: Okay. What are the other practical applications? What I show here is cloning of organs from individuals' own genes to replace failing organs. Can you speak to that?

DR. COLLINS: So I think you're talking more about a stem cell kind of approach where you try to replace a liver, for instance, that's no longer doing what's it's supposed to or perhaps the bone marrow has failed or developed a cancer and you want to replace that with normal bone marrow. There are people working on trying to reprogram some of your cells into becoming other types of cells to compensate in that way.

MR. MCLAUGHLIN: Can you clone ahead and bank in the event that you need it, if you're an individual?

DR. COLLINS: "Clone ahead" as in the future, not cloning your head? Okay. (Laughter.)

MR. MCLAUGHLIN: Oh -- oh.

DR. COLLINS: There are certainly people suggesting that that could be a real possibility, that you might want to bank some of your bone marrow against the time where you might need it because you develop leukemia or some other form of disease where having that ready to be used is --

MR. MCLAUGHLIN: Are there other cloning options that you could do in advance of any disease taking over -- or you may know from your research what you are prone to -- can you clone in advance to stay ahead of it and correct it when it occurs?

DR. LANDER: Well, if you know in advance you might be predisposed to heart disease --

MR. MCLAUGHLIN: Yes.

DR. LANDER: -- there are a whole lot of other things you probably ought to be doing first.

DR. COLLINS: (Laughs.)

DR. LANDER: You probably ought to be changing diet, you probably ought to be developing drugs that slow down those degenerative problems --

MR. MCLAUGHLIN: I know, but I'm going to you as a geneticist and I say I want to clone something that's going to correct this disorder that is approaching.

DR. COLLINS: Well, you may want to clone it, but it's not clear that that is a good solution for it today. We don't know how to clone something that would fix up your heart or fix --

MR. MCLAUGHLIN: All right. Now we enter the area where there is real sensitivity, and that is altering genes to prevent inherited diseases from being passed along to one's children.

DR. LANDER: Yeah.

MR. MCLAUGHLIN: This is deep genetic manipulation.

DR. COLLINS: Germ line.

MR. MCLAUGHLIN: Germ line.

DR. COLLINS: Right.

MR. MCLAUGHLIN: Now tell me about that, and what do you see ahead?

DR. COLLINS: Well, the big ethical dilemma is whether that is a pathway we should go down.

MR. MCLAUGHLIN: No, I don't want to hear about that now. What I want to hear about is what do you foresee coming within the immediate future, that is the next 10 or 15 years.

DR. COLLINS: Well, I think these are connected, because I think the ethical dilemmas are so strong that we won't do this in the next 10 or 15 years; we will not interfere with the human sequence that's going to be passed to a future generation because we don't know what we're doing.

DR. LANDER: We certainly better not do that. If you today want to deal with the transmission of a genetic trait to an offspring, there is a choice of in vitro fertilization and selecting which embryo to reimplant. That's a procedure that's already used.

MR. MCLAUGHLIN: Well you're talking about a physical characteristic. I'm not talking about that.

DR. LANDER: No, I'm talking about genetic disease. Suppose you have a genetic disease and you're going to transmit it to half your offspring. What some people do today is they can fertilize in vitro -- out of the body -- do a genetic test before they decide which embryo to reimplant, and then select to reimplant the embryo that didn't pick up that genetic defect. And I think that's a much less ethically troubling way to approach the question.

MR. MCLAUGHLIN: Than to do what?

DR. LANDER: Well, then to actually get in there and try to change the sequence of the human genome, because once you get in there and start manipulating the genes, I think there's not going to be limits to it. People will say, "We'll just fix up some genetic defect. Let's go try to make improvements." And I'm deeply, deeply opposed to the idea of our trying to modify the human genome.

MR. MCLAUGHLIN: You know, they said the same thing when electricity arrived on the scene: "This is going to cause all manner of problems. We are unleashing a Pandora's box." You're echoing that type of alarmist thinking.

DR. LANDER: No, I think changing human heredity is a very different thing.

MR. MCLAUGHLIN: But you're at the primitive stage of development; you're at the earliest possible stage and you're already saying that.

DR. LANDER: Yeah, but if electricity were a bad idea, we could always turn it off. But once you introduce genes into the human germ line, they're going to be transmitted for all generations. There's no product recall here. It's a different ethical question.

DR. COLLINS: I have to agree, this is not a technology, this is ourselves, this is humanity. Are we going to take the chance of altering our entire character as a race for all time in the future? You can't just go back and change it later on. I think that is the strongest possible argument that this is different than any other kind of technology that's been contemplated, we ought not to go down that path.

MR. MCLAUGHLIN: If you can genetically change once, why can't you genetically change twice on the same patient?

DR. LANDER: Oh! You say do a recall.

MR. MCLAUGHLIN: Do a recall.

DR. LANDER: Take everybody who inherited that gene, and whether they want to or not, demand that they come and have their genome changed? I'm not willing to have a society that could do that to people. Once it's out there, it's out there. We'd better think really carefully.

MR. MCLAUGHLIN: We'll be right back.

(Announcements.)

MR. MCLAUGHLIN: Let us put aside the ethical and the moral and the religious considerations connected with deep gene manipulation for purposes of arresting and correcting disease/germ transmission lines, okay? Do I have that right?

DR. COLLINS: (Nods.)

MR. MCLAUGHLIN: Okay. What is the burden on you, what is the amount of work involved, what is the challenge to you, were you to actually set that as your goal? How -- what is the volume, what is the number, what can you communicate to our audience to describe -- what is it, billions or trillions of possible variants for various diseases? You've got 300 -- you know how many strains there are of variants producing, for example, cystic fibrosis?

DR. COLLINS: So take a simple disease, like cystic fibrosis -- we already have counted up about 850 ways for that one single gene to be misspelled and cause this disease. And that's one gene out of maybe 80,000 genes across the genome, each one of which probably has some possible role in disease. So the combinatorial possibilities, as far as flaws in the genome, are substantial.

And you and I all have them. There are no perfect specimens.

MR. MCLAUGHLIN: So one problem with any kind of deep gene manipulation -- germ line -- we're talking about germ line control or modulation -- would be just assembling all the data, which is in itself extremely formidable, right? There are millions of variants that have to be discovered as our knowledge improves, and that has to be stored, and it has to be identified, one strain from another, to determine what is producing the malfunctioning, correct?

DR. LANDER: And that's only the start of the problem, because once you know what misspelling there is in a gene, you've still got to figure out --

DR. COLLINS: Misspelling?

DR. LANDER: A misspelling. A gene has DNA letters, and if one of them's wrong, it can make a misspelling of the gene. It produces the wrong product.

But the problem is, it may be a product that's very disadvantageous under some circumstances, but in a different environment, or in combination with other genes, it might be a good thing. What we really don't understand is how all those genes work together, how the 100,000 parts work together. And so before you actually go in and manipulate a gene, just scientifically you'd need to know about the whole complex, how it works together.

MR. MCLAUGHLIN: You know who Arthur Caplan is?

DR. COLLINS: Oh, yes.

MR. MCLAUGHLIN: Who is he?

DR. COLLINS: He's an ethicist at the University of Pennsylvania.

MR. MCLAUGHLIN: Do you hold him in high regard?

DR. COLLINS: He's a very well-known and respected bio-ethicist.

MR. MCLAUGHLIN: By you, too?

DR. COLLINS: Yeah.

MR. MCLAUGHLIN: All right.

DR. COLLINS: He's a bit of a gadfly, but he's a good guy.

MR. MCLAUGHLIN: He what?

DR. COLLINS: He's a bit of a gadfly. He covers a lot of territory, but he's a good guy.

MR. MCLAUGHLIN: All right. I will see that he gets a copy of this tape -- (laughter) -- and he'll communicate directly with you.

DR. COLLINS: And he won't disagree with respect -- with my characterization.

MR. MCLAUGHLIN: All right. This is what Caplan says: "Some genetic diseases are so miserable and awful that at least some genetic intervention with the germ line seems obligatory."

He's talking here about cancer, presumably; he's talking about Alzheimer's. If people know that they can inhibit the transmission of Alzheimer's, don't you think he is correct in saying that there is a demand, a natural demand, an irresistible demand for that action to be taken?

DR. LANDER: There's an irresistible demand to work on and cure Alzheimer's, but the particular solution he's recommending, I think, is the wrong one.

MR. MCLAUGHLIN: Why?

DR. LANDER: Because you are going in, making a modification you can't control, you don't know the effects of it, you'll never be able to take it back from the human population, when in fact, there are other approaches. Understanding the pathology of the disease and giving medicine. Selecting what embryo to reimplant. All of these things don't have permanent consequences. And I think Caplan is flat- out wrong to suggest that we should take that extreme case, especially at our very early stages in --

MR. MCLAUGHLIN: Isn't it possible that no bio-pharmaceutical could be developed to arrest a disease, but that gene therapy at the level that we're talking about, interventionist gene therapy, germ line therapy, could do it? Would you not then reconsider it?

DR. COLLINS: I think, John, the problem is that that germ line gene therapy would not be shown effective until you had already gone too far down a path that you couldn't reverse. After all, it would take generations to know whether this works. And if the answer was, oh, we cured Alzheimer's disease, but everybody is dying of something else at age 35 because of a change we made without realizing the consequences, what have we done?

MR. MCLAUGHLIN: We're practically at the end of our time, but I want to ask you this. What do you see as the most impressive development on line in the upcoming millennium? We're thinking only in terms of years and decades. What about thinking in terms of centuries and millenniums? Where do you think it's going to end?

MR. LANDER: Oh, I don't think it's going to end. I think --

MR. MCLAUGHLIN: It's not going to end.

DR. LANDER: So far we see no evidence of it ending. The challenge ahead right now is we've spent this first millennium just understanding the parts. The next millennium is about figuring out how they work together. We don't know how the body does all its complex tasks. And we don't know how to understand it as a circuit. When we understand that, we'll be able to understand how to design medicines in really exquisite ways. That's the work of the next century, and I'm pretty optimistic about it.

DR. COLLINS: I agree. I think we'll understand human biology at a level that has previously completely eluded us. It will take decades to do that. Let's not imagine, however, that we'll understand all of what it means to be human. I rebel against the notion that we're going to end up with a purely deterministic view of ourselves. It ain't that way. There's a lot more to humanity than DNA sequencing.

MR. MCLAUGHLIN: We'll be right back.

(Announcements.)

MR. MCLAUGHLIN: Who will decide how best to manipulate genes? Will it be UNESCO? We'll answer that question in a moment, but first, here are the profiles of our distinguished guests.

Born, Staunton, Virginia; 49 years of age; wife, Diane (sp); two daughters. University of Virginia, B.S. summa cum laude. Yale University, Ph.D., physical chemistry. University of North Carolina, Chapel Hill, Doctor of Medicine. North Carolina Memorial Hospital, Chapel Hill, internship and residency, four years. Yale University of School of Medicine, fellow in human genetics and pediatrics, three years. University of Michigan, professor of internal medicine and human genetics, 15 years, currently on leave. Co-discoverer in 1989 of the gene for cystic fibrosis.

U.S. National Academy of Sciences and U.S. Institute of Medicine, member. National Institutes of Health, the National Human Genome Research Institute, director, six years and currently. Hobbies: playing the guitar, riding motorcycles.

Francis Sellars (sp) Collins.

Born, Brooklyn; 42 years of age; wife, Laurie (sp); three children. Princeton University B.A., Phi Beta Kappa. Oxford University, Ph.D., mathematics; Rhodes Scholar. Harvard Business School, professor of mathematics and economics, nine years. Millennium Pharmaceuticals, a public biopharmaceutical company, co-founder and board member, six years and currently. Massachusetts Institute of Technology -- MIT -- director of the Whitehead/MIT Center for Genome Research and professor of biology, 10 years and currently. U.S. National Academy of Sciences and U.S. Institute of Medicine, member.

Winner, the MacArthur Prize Fellowship, the so-called "genius grant." Hobbies: hiking, woodworking, blueberry picking and golden retrievers.

Eric Stephen (sp) Lander.

MR. MCLAUGHLIN: Is it blueberry picking?

DR. LANDER: Love blueberry picking in New Hampshire. Great blueberries. The best.

MR. MCLAUGHLIN: There are a lot of other things going on in New Hampshire these days, though, isn't there?

DR. LANDER: (Chuckles.) Indeed.

MR. MCLAUGHLIN: A branch of the U.N. -- UNESCO -- proposes to declare the human genome public property and to make any alterations to that genome the equivalent of defacing public property, to whit a crime. UNSECO has a draft proposal urging member states to adopt this position.

Should the U.S. sign-on to the UNESCO draft? I ask you, Dr. ***Eric Lander***.

DR. LANDER: I haven't read the draft exactly, but the spirit, I would sign-on to. If we're ever going to make changes, it better be to repeal the ban that we've had in place for quite some time, so that if we're ever going to make changes, it's for a darn good reason. I would sign on.

MR. MCLAUGHLIN: Don't you think it's premature to place germ line therapy off limits?

DR. LANDER: No, just the contrary. It's premature to think that should allow anybody to go try it today. We should start with a ban on it, I think, and then reverse it only if there's darn good reason.

MR. MCLAUGHLIN: Do we have absolute knowledge that there are negative consequences, any consequences whatsoever, to eradicating mental or physical illness through gene manipulation?

DR. LANDER: Absolutely.

MR. MCLAUGHLIN: Do we have any certain knowledge?

DR. COLLINS: We have not done that in humans, and that's why we don't have certain knowledge that it would be dangerous. But we modify the germ line in mice all the time, and things happen that you don't expect. Things happen in other genes that you didn't intend to target. This is not a technology that's refined so you can go in and change one letter and everything else is left exactly the way it was. We have all sorts of uncertainties in this technology that we haven't got control of yet. And do you want to be the person that we try out our technology when we don't quite know what we're doing? It's too early for that.

MR. MCLAUGHLIN: Well, there was a teenage boy who chose to accept that risk, and people regard that as a noble experiment. He died. Do you know of whom I speak?

DR. LANDER: Jesse Gelsinger.

MR. MCLAUGHLIN: Where?

DR. COLLINS: That was not a germ line gene therapy experiment. That was a sematic gene therapy experiment. This would never have changed the consequences to his offspring, if he had lived to have them. This was an experiment where into his liver a gene was placed.

MR. MCLAUGHLIN: What kind of experiment it was is not important, it was the intention of going forward with it which is correcting disorder, horrendous disorder like cancer or Alzheimer's.

DR. LANDER: Right. But in those experiments there is a pretty high probability of success. When we modify genes in the germ line in mice, 50 percent of the time we have a surprise as to what goes on; it's not what we expected. With those sort of odds, we don't belong in people today.

MR. MCLAUGHLIN: Well don't you think you're being pessimistic in thinking that this cannot be a self-correcting, self-improving process --

DR. LANDER: No, no! Let's do it first -- show we can do it right in mice.

MR. MCLAUGHLIN: You're like Columbus in the Dominican Republic first arriving on the America -- heading towards America.

DR. LANDER: No, no --

DR. COLLINS: John, I don't think either Eric or I are saying that a germ line approach to human illness might some day be manageable and safe, but it sure isn't now.

MR. MCLAUGHLIN: Thanks so much for being my guests, Dr. Francis Collins and Dr. ***Eric Lander***.

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PBS SEGMENT

MR. MCLAUGHLIN: Who should have access to this genome information? Should it be patented? I ask you.

DR. LANDER: Well, everybody in the world should have access to this information. It's the infrastructure for doing science and for doing medicine. And the whole premise of this international project is to make it available to everybody on pretty open terms.

MR. MCLAUGHLIN: In the instance of that young adolescent who died when he got biopharmaceutical medicines derived from gene research, there was a total rejection of the idea that the pharmaceutical manufacturers, I guess, and others should reveal data, because it was proprietary and it had commercial advantage. What do say to that?

DR. COLLINS: Well, actually, they do have to reveal all that to the FDA, but that's kept behind a veil of secrecy because of proprietary considerations.

MR. MCLAUGHLIN: Do you want full disclosure?

DR. COLLINS: I sure want full disclosure of anything that goes wrong. Any adverse effect everybody ought to know about right away.

MR. MCLAUGHLIN: Do you want patenting?

DR. COLLINS: I do not want patenting of the basic genome sequence --

MR. MCLAUGHLIN: Do you want patenting?

DR. LANDER: Of the basic sequence? No. When you make a discovery that's a therapeutic, sure, but only when you've got something you can really bring value to.

END

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