

Coriell president sits down with WHYY Radio to discuss Personalized Medicine

On May 5, 2008, President and CEO of Coriell Institute for Medical Research, Michael Christman, Ph.D., joined Marty Moss-Coane, host of WHYY's "Radio Times," on air to discuss the Coriell Personalized Medicine Collaborative.

Marty Moss-Coane, Anchor: This is "Radio Times" here on WHYY in Philadelphia. I'm Marty Moss-Coane. We're talking about genetic testing and research with medical investigative journalist, Jeannie Lenzer. Joining us now is Michael Christman, President and CEO of the Coriell Institute for Medical Research located in Camden, New Jersey. Before joining Coriell, he was a professor and founding chair of the Department of Genetics and Genomics for Boston University's School of Medicine, and he joins us to talk about the Delaware Valley Personalized Medicine Project. Michael Christman, nice to have you with us on "Radio Times." Good morning.

Michael Christman, Coriell Institute: Thank you, Marty. My pleasure.

Moss-Coane: Nice to have you here. Tell us a bit about this Delaware Valley Personalized Medicine Project.



Michael Christman, Ph.D.,
President & CEO of Coriell
Institute for Medical Research

Christman: Well, the goal of the project really is to seek to guide the ethical, legal and responsible implementation of personalized medicine. This is coming down the road, personalized medicine, use of personal genome information; it's really going to change medical practice. And we're a non-profit. We simply are seeking to determine best practices in the implementation of personalized medicine. The way the project works is we form partnerships with several of the hospitals in the region. To keep the roll-out of personalized medicine within a medical context, we are offering enrollment initially to employees of the hospitals. These are the medical professionals who are really at the front lines of medical care, and they need to come up to speed on what genomics is and how this can be used in medicine, and then eventually patients of those hospitals also [will be included].

So, we're doing personal genome profiling, similar to some of the for-profit companies, but we're not charging individual participants at all in our study, and we're being very transparent about the way we're doing things. We'll only return genetic information that we deem medically actionable, and we have an outside board of volunteers, experts in the field, who will meet and determine what is medically actionable, so we as scientists running the study will not actually make those decisions ourselves.

Moss-Coane: And I want to pick up on that. If I were to sign up for this study, what would I do, and what would I give you?

Christman: You would donate a couple of milliliters, just a very small amount of saliva, and you would go online and fill out a medical history questionnaire, telling us something about your family history of diseases, and that's basically it. Then you would also grant consent to have your medical records become part of the study, as well, if you want, but again it's up to you. New Jersey has the best genetic privacy laws in the country at the moment, and a participant in the study controls access to all their genetic information.

Moss-Coane: And you said, you know, focusing on medically actionable results. I was reading a bit about the study; the focus is really on cancer and heart disease primarily?



Marty Moss-Coane, host of WHYY's "Radio Times," a regional public affairs program

Christman: Well, those are just the number one and two killers in the United States, and there are complex disease genes that influence those traits. But really we have two arms to the study which, by the way, we now call the Coriell Personalized Medicine Collaborative, because we've already kind of grown out of the Delaware Valley. We're getting so much interest and many different partners involved. But there are two arms to the study; one is the so-called wellness arm, which just means anyone who does not have breast or prostate cancer, and then there's the cancer arm.

Moss-Coane: And then there's the cancer arm, as well. Is this information eventually going to be sold, such as Jeannie Lenzer was telling us, talking about some of these private companies?

Christman: Right.

Moss-Coane: What will you do with the information, beyond sharing it with the particular person who signed up for the study?

Christman: We will not sell it. We're a non-profit, and in our consent form, it clearly indicates that the information in an anonymized form will be made available to other scientists and medical researchers, if you give consent for that. It will be made available to either other non-profits or to for-profit companies at no cost, if you elect to have that done on your consent form. So you can choose whether you want to do that or not. We find that most people do want the information made available to others if it's not being sold, because that's what the drug companies do that's good for us. They might be able to use that information to make better drugs. But we will not charge anything for this.

Moss-Coane: Let me check back to Jeannie Lenzer. Based on what Michael Christman just described, does this sound like, you know, progress on this issue?

Jeannie Lenzer, medical investigative journalist: Well, I still have a problem. I mean, this claim that there is personalized medicine involved here, that you're giving people something actionable, again, I'd ask Dr. Christman to provide the evidence that we know that there's an improvement in outcome by offering this information, particularly around cancer. One of the things these companies do is raise the alarm bell about cancer, and I'll give you an example.

Moss-Coane: Okay.

Lenzer: '23 and Me' warns women there's a one in eight chance of developing breast cancer, and then they offer snips that put you at a higher risk of developing breast cancer. The problem is, what they don't say is it's only once a woman reaches the age of seventy that she has that one in eight risk, and that only three percent of women who die will die of breast cancer. And, if you do the same thing, the exact same numbers can be used for men and prostate cancer. Dr. Gil Welch, who I quoted in this article, said that one of the problems is when you talk about this dramatic increase in your risk, which is what the companies are doing, they'll say, 'Well you have a snip and your risk is now increased by eighty percent.' When you think that men have only a three percent risk of dying of prostate cancer, of course the statistics are presented very differently, much more like the women they say 'one in eight chance of developing it over your lifetime,' not mentioning that most won't develop it until they're in their seventies or eighties, and most of those won't have a clinical problem with it. As they say, most men will die with it, not of it, and they never know they had it.

But what Gil Welch said is instead of saying this alarming number that you have an eighty percent risk of developing it, the truth is their risk, even with this increase, wouldn't increase to even six percent risk of dying of prostate cancer. And then the question is, what are you going to do about it? Recent studies have not found that either early intervention or even late intervention is making a difference. So what we need to do is — I'm not saying it's impossible for these things to be beneficial, I'm just saying the evidence isn't there. But before people start peddling their wares, we should have evidence for benefit, so the studies need to be done.

Moss-Coane: And this notion of risk assessment, as well. Michael Christman, can you speak to that? Then we'll get to our callers.

Christman: Sure. I mean, I think what we're using in our study is an eminent panel of people who will meet several times a year in Philadelphia and attempt to hammer out exactly what is medically actionable, and they will take into account that kind of information. Our panel is chaired by a member of the National Academy of Sciences from Harvard University, Erin O'Shea, and this group's goal, their charge, is to figure out exactly the kinds of issues that were mentioned and whether it is truly beneficial. I think that I agree that in the broader sense, it will take a long time before we know whether most of the kinds of variants that are out there now are indeed useful. We're not charging anybody for this, and I'm very confident that this is such a long process and a complicated issue rippling through many aspects of society that we need to get started

now because it involves medical education. Doctors and nurses need to come up to speed on what this information is.

We need to figure out the information technology infrastructure, to relay information to participants, and our participants are centered around a medical context, which are our hospital partners. They can then choose to give consent to their physician to view the same information. We provide educational material for physicians and for participants.

So I agree that in many cases, it is not clear whether this will be beneficial, and this will take decades to determine. Meanwhile, a flood of information about medical variants that do affect health is coming, and I think the purpose of our project is to, without charging people, try to see it implemented in a responsible way. This panel that needs to decide what is actionable will also make their decisions completely transparent, so we will post publicly which variants are approved as medically actionable and why, and then we'll solicit, through a sort of wiki model, input from the scientific community. Our goal is to be completely transparent about this, but I think it's time to get started.

Moss-Coane: Well, and just very quickly to you Jeannie Lenzer, it sounds like what your concern is what an individual, either patient or consumer, does with the information that they get back, based on this genetic research.

Lenzer: Yeah, and their perception of the information as medically useful information, rather than that they are simply being research subjects. I have no problem with people being research subjects, it just should be clear that that's exactly what they are. They are not getting, at this point, what is known to be actionable or personalized health information. They are getting a class category.

Christman: I agree with that very much. Our study is IRB-approved, that's a human subject's word, approved research study, and we make it clear to people that the Coriell Personalized Medicine Collaborative is a research study.

Moss-Coane: That's Michael Christman, President and CEO of Coriell Institute for Medical Research. Also with us is medical investigative journalist, Jeannie Lenzer. We've got a full bank of calls here. Let's see what some of our listeners have to say. We've got Patricia from Princeton joining us. Hi, Patricia.

Patricia, Caller: Hello?

Moss-Coane: Hi, you're on the air.

Patricia: Hi. I'm living in Princeton now, actually I'm originally from New York, and I'm adopted, and I've got absolutely no ability, legally, to know anything about my biological parents. So I'm wondering if there's any possible benefit to somebody like me who really knows nothing about her biological family or genetic background.

Moss-Coane: Well, let me toss the question back to you though, Patricia. Is this something you're thinking about as you learn more about genetic testing and research?

Patricia: Well, honestly, I've thought it about more because of having children of my own and getting so tired of the questions of 'Do you have this in your family background?', 'Do you have that in your family background?' I mean, now that genetic testing is getting sort of mainstream, I have been thinking about it. I haven't been lying awake at night thinking about it, but I mean I'm hearing you now, and it puts the idea in my head yet again.

Moss-Coane: Fair enough, and I think it's an important call. Let me first get to Jeannie Lenzer to respond. I realize you're not in the advice business, Jeannie, but if someone is adopted, and they want to know information about themselves, what kind of information can you get from genetic testing?

Lenzer: You know, I'm not qualified to respond to that. I can only respond as a lay person who also has been following the topic and say that I lost that information myself, and lost access to that information, and decided not to be tested, but that was my personal decision. I just didn't think that the benefits outweighed the potential for misleading conclusions.

Moss-Coane: Well, let me get the response from Michael Christman.

Christman: The answer is that absolutely, it could potentially be very beneficial. Now granted, at this early stage, we don't know what the majority of the genome means in medical terms, but because humans have a shared history that goes back to an African origin, we all share the same gene variants that cause complex diseases, like cancer, heart disease and diabetes. In principal, it is possible to take an individual for which you don't know anything about the family history and then still assess risk of various diseases.

Moss-Coane: But you're saying, where research stands today, it's inconclusive. Not inconclusive, but you can learn certain things, but probably not all the things that you'd want to know about your background.

Christman: That's right. I say that the technology has reached the point where we can scan your pattern of genome variation, your personal pattern, pretty comprehensively, but where we don't know much yet is what that means in medical terms. We know a little bit, and there will be an explosion in the next few years.

Lenzer: I'm just going to jump in, if I could, for a second there. I do also have concerns that physicians are not ready for this. And Dr. Christman may be absolutely right that this is a worthwhile testing to do for our caller, and that's fine. My concern is when it comes to the snips that are being offered. I'll give you an example. Doctors were presented with statistical information about the benefits of statin for lowering cholesterol, and when they were presented the information using relative risks — that's one way of presenting statistical information versus presenting the identical information as an absolute risk — the doctors had very different responses about whether they'd prescribe the medication.

So doctors can be fooled by the way information is presented, which is precisely what I was talking about with the risk of an eighty percent increase in prostate or breast cancer. What do you do with that information? How do you understand it, and are doctors ready to understand what that means?

Moss-Coane: Patricia, thanks for the call. We've got Marcy now from Bensalem joining us. Hi, Marcy. Go ahead, you're on the air.

Marcy, Caller: Hi.

Moss-Coane: Hi there.

Marcy: Can you hear me okay?

Moss-Coane: Yes, yes. Go ahead.

Marcy: Okay, I am someone who has just sent in saliva to '23 and Me,' and I thought it was sort of funny, you were talking about how do these folks advertise. I heard about it on NPR, so that's the first thing I would say...

Moss-Coane: Fair enough.

Marcy: ...is that I listen all the time, and there was a previous show that mentioned it, and I went online based on hearing the name and found them. You also were talking about possible benefits, and the thing that induced me to do it, there were two things. One thing had to do with being able to find out more about ancient heritage; apparently that's something that they give you a picture of, where your family wanderings have been.

Moss-Coane: Right.

Marcy: And the other thing had to do with the opportunity to provide input about my diseases, adverse experiences, whatever, to add to the general store of knowledge. I really liked what the gentleman that was speaking was saying. I think that as much information as possible needs to be collected. Pharmaceutical companies can benefit greatly from knowing which kind of genetic profile is likely to have which kind of adverse experience so that they can also adapt prescribing information, and so that doctors are better educated about who is more likely to have an adverse experience.

Moss-Coane: Fair enough.

Marcy: I want to add my information into the pile, and I'm willing to pay for that.

Moss-Coane: No, I appreciate it. I hear you, and I want to give Michael Christman a chance to respond to your call because we're going to have to say goodbye to you, Michael, in just a couple of minutes.

Christman: Okay.

Moss-Coane: Your thoughts?

Christman: Well, I think that that is potentially beneficial. I mean, ancestry information certainly can be obtained from the genome. In our project, the Coriell Personalized Medicine Collaborative, we are not going to return ancestry information to people, at least until it proves to be medically actionable. Many people have preconceived notions about their ancestry that may prove to be wrong from the genetics point of view. It's kind of a minefield in my view, but some of the for-profit companies do that. And really, I think there are a tremendous number of difficult ethical, legal and social issues surrounding the implementation of personalized medicine, and our project is simply seeking to address all those questions.

If we say that there are too many issues to deal with, we as a society, the logical extension of those arguments is that we simply walk away from using the human genome to improve medical care. And I think we cannot wait until it's perfect. We have all the information and every physician has been educated to this level of medical training, until we begin to do this. What our project is designed to do is try to address all those issues, provide genetic counseling to people at no cost. We'll give the information back to their physicians and try to engage the medical professionals in the project in order for them to come up to speed. It's hard to build a barn, but we have to start.

Moss-Coane: Well, on that note, we have to say goodbye to you. Michael Christman, thanks for joining us at AM Radio Times.

Christman: Okay, Marty. My pleasure.

Moss-Coane: And he's the President and CEO of Coriell Institute for Medical Research. Staying with us for the rest of the hour is Jeannie Lenzer; she's a medical investigative journalist...