

Protocol 1277 Informed consent statement for Oral History Interviews

(This form can be sent in advance and signed or read into the tape at the beginning of the interview.)

The interview will be recorded, and I will use the audio file to make a transcript. The transcript will be shared with you, with an opportunity to correct it. The attached form indicates options for making the final edited transcript available.

My name is _____ and I am a student at Duke University. I am in a course on the history of genomics that includes oral history. One goal is to produce a written transcript of interviews with important figures in genomics. Some of the interviews may be archived or made public through a website. The conditions for making the transcripts public (the audio tapes will not be public) are indicated in the accompanying form, and you can choose any of those options, or write in your own conditions.

I selected you as the person I would like to interview. The interview should last 30-45 minutes. Your participation in this interview is strictly voluntary, and you may withdraw at any time. You do not have to answer every question asked. The information that you choose to share publicly will be “on the record” and may be attributed to you, unless use is restricted the conditions you specify on the form.

This interview is being recorded and I may take notes during the interview. The interviews that are posted publicly will be archived as a history resource. If you prefer that the interview be used only for the course and not made public, please indicate this on the form.

One risk of this study is that you may disclose information that later could be requested for legal proceedings. Or you may say something that embarrasses you or offends someone else when they read it on a public website. The benefit of participating in this study is ensuring that your side of the story is properly portrayed in the history of genomics.

Signed: Chris Hansen Date: OCT. 25 2012

Person interviewed: CHRIS HANSEN Student Interviewer Kaushik Patange
(Print clearly) (Print clearly)

Use of archived final transcript

Members of the Duke University community, students, faculty and staff at other institutions, or members of the general public may access the digital archives. Typical research uses of interview materials include scholarly or other publications, presentations, exhibits, class projects, or websites. However there may be other uses made as well, since the materials will be available to the general public. Investigative reporters and lawyers engaged in or contemplating litigation have, for example, used the Human Genome Archive.

Your permission to post the edited, written transcript of your interview, and any related documents, to a digital archive is completely voluntary. Unless you consent to their wider use, all materials from your interview will be available only to members of the research team affiliated with this project.

The form below provides you with different options for how, when, and with whom your interview materials will be shared.

(A) I place **no restrictions** on my interview materials.

OR

(B) My interview materials may be reviewed, used, and quoted by students and researchers affiliated with Duke University; *and in addition* (check all that apply):

Researchers unaffiliated with the Center for Public Genomics may **read** the interview transcript and any related documents only after obtaining my permission.

Researchers unaffiliated with the Center for Public Genomics may **quote** from the interview only after obtaining my permission.

Researchers unaffiliated with the Center for Public Genomics **DO NOT HAVE** my permission to **read or quote** from the interview.

Posting interview materials to public digital archives: In spite of any restrictions listed above, I give permission for my interview materials to be made publicly available on the Internet by deposit in an institutionally affiliated archive:

1 year from the date of this form

5 years from the date of this form

10 years from the date of this form

25 years from the date of this form

After my death

Other: _____ (please specify a date or condition)

Signature:

Chris Hansen

Date:

Oct 25, 2012

[Chris Hansen Interview]

Speaker 1- Kaushik Patange

Speaker 2- Chris Hansen

Speaker 1: Hi Mr. Hansen this is Kaushik.

Speaker 2: Hi. Let me first apologize profusely for, uh...standing you up on Tuesday. I just...I just forgot...it's just as simple as that, I really am very sorry about that.

Speaker 1: It's okay...it's totally fine. It's nice getting a break here, so I had a lot of time to do everything...so yeah.

Speaker 2: Well if it's dragging out much longer than you want it to because the first time I had to cancel on you, I can't take it...that wasn't my fault. That was the hurricane's fault.

Speaker 1: Yeah...yeah, that was Hurricane Sandy...yeah.

Speaker 2: But this one was my fault, and I'm sorry.

Speaker 1: That's okay. And so, you signed the IRB consent form?

Speaker 2: Yeah.

Speaker 1: So, did you agree with all...do you agree that you don't place any restrictions on the interviewed materials?

Speaker 2: Correct.

Speaker 1: Okay good. So, would you like to get started at all?

Speaker 2: Sure, whenever you're ready.

Speaker 1: So, I noticed you attended University of Chicago's Law School?

Speaker 2: Correct.

Speaker 1: Uh...what lead you to be interested in law?

Speaker 2: I can't ever recall being interested in anything else. I...I knew when I was six or seven years old, I was going to be a lawyer.

Speaker 1: Really...interesting.

Speaker 2: I don't know why.

Speaker 1: What did you do in undergraduate, uh...in Carleton College?

Speaker 2: Uh...I was a science major, uh...but, it was really basically just a broad overlarge education, and I knew I was headed off to law school, and so I was just, you know sort of getting through college in order to get off to law school.

Speaker 1: Okay interesting. So, after that did you...what did...did you join the American Civil Liberties Union?

Speaker 2: The very first year after law school I spent as a public defender in Brooklyn. Uh...the...the Brooklyn Legal Aid Society, the New York Legal Aid Society came and interviewed at the...at Chicago, and I thought it would be a fun thing to live in New York for a year, uh...when I was...while I was young, and so I interviewed and got the job offer, and came to New York to work as a public defender, and I worked there for about a year before I applied for, and got the job at the, uh...at New York Civil Appreciation.

Speaker 1: Okay interesting. So...so, why American Civil Liberties Union, why not another organization? Do you like agree with their beliefs or anything like that, or...?

Speaker 2: Well, yeah...I mean since I worked there forty years, you can assume I was pretty consistently comfortable with the views. You know I was very happy as a public defender. I liked the job as a public defender, um...and while I was a public defender, I read a book, um...called "Prisoners of Psychiatry," by a lawyer named Bruce Ennis, who was a New York Civil Reunion lawyer.

Speaker 1: Okay.

Speaker 2: And it was about representing people who were mentally ill, or mentally retarded, and I thought it was a really, really interesting book, and I...I knew Bruce's wife, and so I told her how interesting the book was, and how much I enjoyed the book, and the...she came to me about a month later and said, "There's a job opening at the NY Civil Union, and were you interested." And I said, "yes"...I jumped at the idea.

Speaker 1: Awesome. So, what would you say is the court case that like...beside ACLU, ...what would you say...which court case would have the most...like have the most profound impact on you, or like challenge you...is it the "Willowbrook" case, Reno Vs. ACLU, or which one would you say?

Speaker 2: Yeah, I mean if...if I were you know to look back over the whole thing that there are sort of four or five cases that stand out in my mind, uh...one is Willowbrook...the first is Willowbrook because that was the first sort of big case I ever participated in. Um...the second was Brown v. Board of Education, and that was mostly just because it was Brown, and it was a very cool thing to be able to work on Brown.

Speaker 1: Yeah.

Speaker 2: Um...the third was...was Reno v. ACLU, and...and Ashcroft v. ACLU, which were all basically the same case...they were all...

Speaker 1: True.

Speaker 2: They were both cases trying to, uh...challenge federal laws that...limited speech on the internet.

Speaker 1: Um huh.

Speaker 2: And then, Gary is...is the one that has been the most fun for the last few years.

Speaker 1: Yeah...so, what are your views or stance on like the BRCA battle lawsuit? I know you're, um...against patenting genes, but were you just like...I just want your opinion on it.

Speaker 2: On what?

Speaker 1: On the Myriad Genetics v. ACLU case?

Speaker 2: Oh yeah, well it's...since it's my case...I clearly believe that...that...I think the law is correct, that you should not be able to pass product of nature, or laws of nature, and the notion that the patent office allows the patenting on human genes strikes me as totally bizarre.

Speaker 1: Um huh.

Speaker 2: Uh...and it...even before I knew anything about genetics, or anything about patent law, it seemed obvious to me that, that was wrong, and when I learned more about both genetics, and patent law, it simply reinforced my views that it was simply wrong.

Speaker 1: Okay. So, do you know...do you know Mark Skolnick?

Speaker 2: Yes.

Speaker 1: Do...what do you...how would you describe him? Do you know anything...I just want to see your opinions on Mark Skolnick.

Speaker 2: Well, I don't...I don't know him personally...I know who he is.

Speaker 1: Yeah.

Speaker 2: I've never met him. Uh...you know he's...he's trying to make a lot of money, and do some good in the world. I don't have any objection to that.

Speaker 1: Um huh.

Speaker 2: I mean there was...when we originally filed the case, the patent office, it was not, um...uh...a case against just against just [Indiscernible 0:05:23] Genetics, it was also against the Patent Office...at some level the mistake was made by the Patent Office...you can't entirely blame Skolnick for, um...seeking the patent, and once he got it, you can't entirely blame him for enforcing it.

Speaker 1: Um huh.

Speaker 2: Uh...I think he's wrong. I think what he's done has been for science, and bad for women, um...but I...I understand why he did it.

Speaker 1: Yeah...yeah, I think I agree with you, but I...I'm probably on your side, personally. Um...do you know about Mary-Claire King because she founded...

Speaker 2: Yes.

Speaker 1: What do you...do you know like their, um...like antagonism between Skolnick and Mary-Clair King? What do you think of their...they're like both opponents, you know they would have like these huge fights between them...what do you think of that?

Speaker 2: Yeah, I mean I...I think King is almost always right, and Skolnick is almost always wrong. Um...you know I...she's...she's a...I find her a very heroic figure. Um...and I think what she has done is extraordinary over the years, and I understand why they fight about the issues, and I...I'm on her side of that dispute.

Speaker 1: Um huh.

Speaker 2: I don't think that dispute is personal, but I think it's professional and important, and I think she's right, and he's wrong.

Speaker 1: Yeah, do you think it was okay for Mark Skolnick to like retire...like a couple years ago he just retired. You know, um...resigned...you know.

Speaker 2: Yeah. I don't have a problem with that, I mean, uh...yeah, sure that's fine.

Speaker 1: Would you have done it, if you were in his position?

Speaker 2: I...who knows, I...it's impossible to know. I mean it depends on what my financial situation was, and what my family situation was...

Speaker 1: Yeah.

Speaker 2: And what my professional situation was. I can't put myself in that situation.

Speaker 1: Okay. So, do you...so, in this case, do you think congress should be engaged in this debate, or just have the Supreme Court deal with it? Because it is a patent lawsuit, and so do you think congress should be involved in it?

Speaker 2: Well, you know that's a...you're asking a much longer question...essentially it's a complicated question.

Speaker 1: Sure...yeah.

Speaker 2: Which is, to what extent the [Indiscernible 0:07:31] justice is [indiscernible 0:07:33] through the court system, and to what extent...to what extent is justice to be rendered through the legislative system. You know I...the law is...I think the law is very clear that, um...you can't patent products of nature, or laws of nature, and therefore I really don't think there's

anything congress needs to do to change the law, if you will. I think the only problem is that the federal sector refuses to apply the law. Uh...on the other hand, if congress had passed a statute saying, you can't patent human genes, that would have resolved this entire problem. So, I'm...I'm in many ways less interested in the method by which social change is achieved, in that I am in achieving social change.

Speaker 1: Okay. So, what would...what would you think...what would be your solution to this case...like I want to know, what's your solution? To have everything resolved...what would that solution be?

Speaker 2: Yeah, I think the courts should find that human genes are not patentable, and...and I don't...I...you know I don't...I'm...I would be...I have that absolute position, I guess. I think...

Speaker 1: What do you...?

Speaker 2: I think human genes are not patentable.

Speaker 1: Okay, what do you think like the disadvantages would be, of that, or the advantages? Like pros and cons?

Speaker 2: Well, the obvious...I think there are a lot of advantages. I mean first of all, it...it makes the law consistent with common sense, which I think is actually a...a underrated advantage, um...second, I think it opens up research, it opens up clinical testing, it opens up second opinions, it uh...will break up costs of...of the patent, uh...of the testing. I do not think it will have a negative effect on research. I do not think it will have a negative effect on a commercialization of research, uh...I think there are only sort of positive benefits to happen. I don't actually see a downside to it, myself. So, yeah I...I recognize that there are commercial interests out there who think that, uh...the effect of a decision in our favor would be to undercut, um...further research, or further commercialization of research, I just don't see that as likely to be true, at least in the context of genetics. Now, you know depending upon how broadly the courts were to write an opinion saying that human genes are not, um...patentable, or how narrowly it might or might not have spillover effects that are positive, negative, but...but that...the...the narrow of question, are human genes patentable...I don't think has negative consequences.

Speaker 1: Okay.

Speaker 2: If it just goes the right way.

Speaker 1: Yeah, so why do you...why do you think there's...there would be no inhibition of the research exactly. Like I want just like specific reasons, I'm just curious.

Speaker 2: Yeah. Historical reasons, um...you know when the...when the two genes were actually found, multiple labs were looking for them, and most of the other labs who were looking for them had already announced that, if they were the ones to find them first, they would either not patent them, or they would patent them, and make them available to the world without costs. And so, we know...that's just as a matter of historical fact...we know that if anybody else had

beat Myriad to the punch, the genes would have never have been patent, and it...A. would have been found, and B. would not have been patent.

Speaker 1: Um huh.

Speaker 2: So, then the next question is, if they...even if they had found, and patent, and made available to the world, would anyone have actually developed the test to look for genetic variations that correlate with breast or ovarian cancer, and we know the answer to that as well because...because the testing process itself is, um...totally [indiscernible]...people test for all kinds of diseases through genetic testing for all kinds of diseases all the time, and...and given the [indiscernible] of breast and ovarian cancer, it...it's a certainty that multiple labs would be doing multiple different kinds of genetic testing of the two genes if they had been found, and not patent.

Speaker 1: Yeah.

Speaker 2: You know I think as a matter of historical fact, that in this particular instance there was no need for the incentive of the patent system in order to either, uh...you know either push the research forward, or push the commercialization research forward.

Speaker 1: Okay interesting. So, I think a couple months ago, on September 25th, that you filed a petition for a Writ of Certiorari that basically questions if human genes are patentable substances. So, what do you predict will be the Supreme Court's ruling, what do you predict will be their ruling? Do you think...?

Speaker 2: I...I never try and predict whether or not the Supreme Court is...what the Supreme Court is going to do. I never try to predict what any court's going to do.

Speaker 1: Okay, is that like a...?

Speaker 2: I used to predict what courts were going to do, and I got it wrong too often, so I stopped doing that.

Speaker 1: Oh...okay. All right, um...so, do...?

Speaker 2: You know the first question is whether they'll accept the case. The second question is, if they accept the case what result will they reach? I don't know the answer to either of the questions.

Speaker 1: Yeah...okay. So, you don't...you don't think genes should be patentable...like you believe the methods for discovery, and using the genes should be patentable, and why, or why not?

Speaker 2: Yeah, if it's...if it's a...if it's otherwise meets the requirements of the patent system, so that if it's, you know novel, and...and useful, and um...non-obvious...you know all of the other things that the patent system requires, I don't have a problem. You know you develop a new method of curing cancer, if it's new and novel, and nobody else thought of it before, I don't have a problem with it being patent.

Speaker 1: Okay, so I think that's the end of my questions I have. Do you have anything to ask me, or anything?

Speaker 2: Nope.

Speaker 1: Okay.

Speaker 2: Nope...nope.

Speaker 1: So, that's it.

Speaker 2: I'm happy to do it.

Speaker 1: Thank you so, so much for this for the opportunity.

Speaker 2: Well, I'm sorry it took so long.

Speaker 1: It is totally fine. But, thank you so, so much for this.

Speaker 2: Sure, my pleasure.

Speaker 1: Okay bye.

Speaker 2: Bye.

Total Time: 29:32