The main benefit of participating in this study is ensuring that your side of the story is properly portrayed in this history of the Bermuda Principles, which have become a model for open and collaborative research in genomics and other fields.

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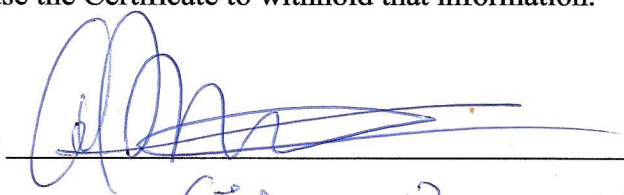
Signature 

Printed Name Gerjan B van Ommen

Date 28/1/2012

If you have read this form in its entirety and agree to the interview and its terms, please sign and date above.

Contact information:

Rachel Ankeny, Ph.D. (University of Adelaide)
rachel.ankeny@adelaide.edu.au
+61-8-8303-5570
Kathryn Maxson, B.S. (Duke University)
kat.maxson@duke.edu
(919) 668-0791
Robert Cook-Deegan, MD (Duke University)
bob.cd@duke.edu
(919) 668-0790

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Interviewee Information. *Please list an address where we can contact you.*

Full name: Gert Jan van Ommen Date of interview: 02 Feb 2012

Current institutional affiliation: Leiden University Med Ctr

Street Address: Einthovenweg 20 2333 ZC Leiden NL

Phone: _____ Email address: _____

Interviewer Information.

Full name(s): Robert Cook-Deegan, MD; Kathryn Maxson, BS

Affiliations(s): Duke University; Duke University

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BCD: We're interviewing a lot of the people that either participated in the meetings or had something else to do with either the lead-in or the follow-on to the Bermuda meetings in '96, '97 and '98. And we're going to be writing a history of the events just because it's attributed such significance as a landmark in open and collaborative science, and the Bermuda Principles in particular have been attracting a lot of press. So we thought it would be worth doing a careful history. So we're going back and we're interviewing everybody. And the way this will work is we'll do this interview and the audio will go onto a computer into a hard drive that is private. But we will send you a transcript. We'll send it off to a transcriber and we'll send you a transcript and ask you to go through it and take anything out that you don't want in it. And there'll be a check sheet with that goes everywhere from, don't let anybody ever see it other than you, all the way to, make it publicly available as soon as you wish, and a whole bunch of options in between. And then we will treat the transcript as that working document, and the audio file will just stay on the drive until it gets deleted some day.

GJvO: Okay.

BCD: So that'll be the process. So after this interview you'll get a transcript in two, three weeks from [KM]. So, [KM], you want to lead us off?

KM: Sure. So we have from numerous sources cobbled together a list of at least the folks who were invited to the different meetings in Bermuda, which to refresh your memory were from 1996 to 1998. And we have on record that you were there in 1997 only. Does that coincide with your memory?

GJvO: Correct.

KM: Okay. So I was wondering if maybe you could just start out a little bit more free form. I sent you the rough interview script but it's best if we just talk about why you believe you were there, why you were invited and what you felt the meeting that you attended was going to be about before you went.

GJvO: Okay. I was invited because at the time, '97, let me think, I'd been president of HUGO in '98 started and until 2000. And then after that I was senior vice president. But before that time, I think from '95 to '97 I was president of HUGO Europe. And HUGO at the time had different substations as it were. They had one in Asia (Australia), they had one in Europe and they had one in the Americas. And then there was the overall president. I think the overall president just before me was either Caskey or Grant Sutherland, but you probably can take out from other records. But it was not unusual that one of the presidents for one of the regions was taken as the next overall president. So basically I was involved in HUGO. I was involved in the meetings of HUGO Europe, which had quite a presence in the whole thing and was closely connected, actually was living in a place that was owned by the Wellcome Trust. And I spoke to Michael Morgan

because I was in the Wellcome Trusts Genetic Interest Group when they established the Sanger Centre. And so one of the things that was reasonably clear from the outset was that it was worthwhile to ask HUGO to be in this. So I think I was there in the capacity of being either president of HUGO Europe and vice president for HUGO, or incoming president for the whole of HUGO. Those are the two things I can imagine.

Now I think during the remainder…I should probably make something quite clear, and that is the outside world and the press and publicity typically would call this genome project the HUGO project. And I think that ultimately irritated Francis and Michael Morgan and a few other people to no end. I've always done my utter best to make clear that HUGO was nowhere near the actual driving forward of the genome project as such, and the financing of the Sanger Centre and Wash U and getting the people on the rails to engage in what became a competition in '98.

And this was actually before the competition. It was before Craig got out of the, let's say the consortium and said, "Okay, guys, I'm doing it all by myself. It takes too long over there. I'll see you at the finish." Because I think that was something like June '98 or so. In the time we're speaking about, '97, the relationship between the genome project and the people from HUGO was pretty fair but I remember having discussions with Craig actually in Bermuda at the time where he said that he was, I think literally said that he was very underwhelmed by HUGO. But of course it's very difficult for an organization that had no formal way of income other than a few subsidies that were targeted, so say the ethics committee and IP committee had big subsidies from Merck, around $100,000 or more. But other than that there was not really a substantial amount of funds in HUGO's coffers. So what the genome project had in millions is what we had in thousands. So it wasn't at all easy to play a major role.

And what HUGO has always claimed to be, and I think that that actually was acknowledged, was that it was much more the mortar between the bricks than actually a big building block. And so we just took care of the ethics stuff and we took care of the things we've been quite involved, and you probably know that also from the other interviews, with the establishment of people's views on intellectual property of DNA. The IP committee of HUGO, where the president was member of QQ, at the time was chaired by Joseph Straus, an IP lawyer professor from Munich. And I think that Joseph has been very instrumental to actually translate these Bermuda rules or maybe even prepare translating these Bermuda rules, in a broader view on what was and what wasn't sensible for patenting DNA. Because of course in the lead up to this discussion on what, how you could keep the DNA sequence in the public domain, you probably are just as well aware as I do that quite early on when Craig was still working for NIH he patented something like 2,000 ESTs, I think that's what it was called at the time.

And that created quite an uproar. And part of it caused Craig or made Craig to move into Human Genome Sequences together with Bill Haseltine.

And then, if I'm not mistaken, in fall of '94 there was this very densely visited and heavily guarded meeting in a hotel in Washington during the ASHG then where Merck announced this EST sequencing consortium to try to defeat the patenting activities of Human Genome Sciences and shooting for something like 100,000 or 200,000 ESTs to put them in the public domain. So there was something going on before this "let's get the sequence in the public domain every 24 hours," that kicked off this whole movement, towards that these things shouldn't be tied up. And so from those days on I've been party to several of those meetings in various HUGO capacities and related capacities that I can now no longer remember. So at the time of the '97 Bermuda meeting it was fairly logical to ask me over. I'm not entirely sure whether HUGO as an organization was formally invited in the '98 meeting. You will probably know that from your invited people roster.

KM: We just have individuals.

BCD: Yeah, we only have lists of individuals who actually wouldn't know why they would have been invited since we don't have that information.

GJvO: I think of all the meetings, at least for me as a person, the most interesting meeting was actually this meeting. The first meeting was really very much driven by John Sulston and Bob Waterston's opinion on keeping things public. I think that was the birth date of the Bermuda rules. And this meeting went in fact much more about whatever the hell they were doing and should do with all this sequence. And what quality controls were needed. I can remember really serious sessions between the informaticians and the biologists on should you have 10,000 base pairs without an error and what to do with the gaps and how big were the gaps and what it meant when you had less gaps or more gaps and whatnot. I think that that was a much bigger part of the discussion because they actually were getting their hands dirty in doing sequence, much more so than the first year.

KM: So you said you weren't there physically in the first year, right?

GJvO: No.

KM: So I'm interested, as someone who was kind of joining up and was at this party in the second year, what in the previous year had been the types of discussions, and were there any discussions (outside or after the meeting) about the data sharing rules that were conceived in 1996? How was that floating around in the air between 1996 and '97?

GJvO: That was one of the other things I was going to say to you that you would probably not have a lot of that information coming from me. I've never been actually very closely involved in high throughput heavy duty sequencing, certainly not at that time. And basically the people who weren't closely involved and in Sanger Centre and Wash U or in editorships of journals at the time would not have a major role in the opinion formation. What you did do is when people invited you in local or in national meetings and when there were newspaper interviews and journalists would ask you what do you think about patenting DNA, then well, basically you would reiterate what the views on that were.

And then on one hand what interested people probably a lot more than, at least in those days, whether or not all this raw sequence was put on the internet every 24 hours, was how this DNA patenting would affect discovery, development of drugs, therapies and so on. So I had much more, say, intricate involvement in discussions with the HUGO part, trying to generate some *communis opinio* on that you had a pipeline from plain discovery to invention. Discovery being snippets of DNA with unknown function. And then from that trying to cobble together genes of which you didn't know what they were doing. And then with further studies and family studies and disease studies finding out that the diseases that might be caused by these mutations, or actually the other way around, study diseases and then finding out what genes were involved and finding mutations. And that would be useful for diagnostics. Then ultimately, knowing mechanisms that might be a more rational inroad to develop therapies.

And so in this whole of the pipeline, and that I think was part of the public discussion, at least when you would speak to journalists or audiences and so on, and I still have slides from that time that say this, that in the course of this pipeline people had their own intelligence and inventiveness and novelty. And so the snippets of DNA with unknown function were just sort of mirror discoveries and the ultimate thing where patenting would be important to actually move therapies ahead, would be the therapy development and the battlefield to actually fight out whether or not to patent DNA would be fought around the diagnostics. There was the Myriad situation with *BRCA1*, and so that was much more on the front of, say, the public view on … well, they perceived every patenting as bad. So I just more often then not had to explain that it's important to protect your stuff once you get into therapies that take a long time to develop and a lot of money. So that was in the eye of the public and the questions that we got as people somewhat between the front line of the Sanger Centre and Wash U and the actual public where we had much more interest and questions.

And then only later, I think by the time that the DNA sequence was almost complete, you could make the point to the public that this was a spectacular way of, say, democratizing research. And then it was the total DNA sequence, because earlier on people had to have friends in high places with sequencing machines to actually get their questions answered. And so that meant that the actual front line

disease gene discovery was in a way restricted to a limited amount of well-endowed laboratories that were politically well connected. And I think that the major thing that happened by these Bermuda rules and getting the sequencing to the public domain is that in one fell swoop it would be possible for somebody in, well, Korea, Taiwan or Singapore or wherever, to just go to the sequence and compare it with the sequence of the specific gene in their disease cohort and make a discovery. So that was only later that I think that people understood what the contribution to discovery for clinical purposes would be.

BCD: So as you're describing the data sharing rules and discussions that were going on, it sounds like there were a whole bunch of reasons that are more or less pointing in the same direction, in the direction of sharing, that is. One is a way of finding out who's doing what so you can allocate which pieces of chromosomes are going to be done by whom and at what level of quality. So that's partly task management and coordination.

GJvO: Yeah.

BCD: Another reason is sharing so that other people can see it and then the politics of all these resources going into a few centers. And others wanting to have access to it and kind of the political alliance of the big centers needing support from the cottage industry to support the sequencing effort so that it didn't become a rivalry.

GJvO: Uh-huh.

BCD: And then a patent overlay of concern about a gold rush from Human Genome Sciences and InCyte and wanting to make sure that that didn't happen, at least to the degree that that could be prevented by the public domain.

GJvO: Yeah.

BCD: And in the wake of *BRCA*, which had just happened in '94 and '95. What's your sense of which of those things were the most important? Or is it that they were just all pointing in the same direction so it wasn't a hard choice?

GJvO: Well I think that this thing of patenting breast cancer has been really a landmark event. So in a way it was good that it happened because at least it got everybody sitting on the tips of theirs chair and thinking about it. And in fact, we were, and I mean we as the Dutch say, diagnostic DNA, diagnostic clinical geneticist community, was actually somewhat of a main player in taking this on, together with the Belgians and the French in Europe. And because, well if you have public health care that is insured through public means then it's going to be very expensive to have to shell out, what is it, $2,500 for any test to be licensed to Myriad. Then in addition … but that was … that later on had come back to, well, basically not bite me, but at least generate questions now and then, is we, and

that's my laboratory, actually made the discovery of *BRCA1*. At the time the mutations in *BRCA1* was 35 percent of all the chromosome 17 segregating breast cancer. So people knew that they were missing a big contingency of mutations but they had no clue what they were missing. And that was because they were doing this analysis by PCR. A PCR doesn't see big deletions.

And it turned out that the laboratories who were now maybe slightly behind or slightly more tranquil and had more time, they still were doing Southern blotting, including our laboratory, and by the Southern blotting we found that actually in addition to the 35 percent that you could detect by PCR we found 30 percent more of mutations in the *BRCA* gene. So increasing the diagnostic take from 35 percent to 65 percent, so that was really sizable, by big deletions. So we decided at the time to patent this finding. And only I think two months ago we have relinquished this patent, and it was never meant for making money out of it. It was plainly meant to, when Myriad would have taken action, to be able to defend ourselves by explaining to them that they were breaching our patent. And so basically we, together with the other clinical genetics labs in the Netherlands, we made clear that we would actually act jointly there. And this has actually been brought forward by the guy who opposed our opposition, defended this patent in Europe. They had this top-level patent lawyer, I think he's called Jaenicke. And he seems to be quite a legal shark, at least that's his reputation and from what I know from more people this is pretty spot on. And he actually took and he explained that while we were so shook up by Myriad patenting this, look what happens. They are doing the same thing. But of course we never tried to enforce this or made money out of it.

So I was basically already around this time also in another sense a party in how to deal with patenting when the rubber would hit the road. And that's in the time of the diagnostics and of the therapies. And I think for diagnostics it's really going to increase the cost far too much to have these patents and it may be that ultimately they find ways to make patent thickets for microarray or sequencing or whatever. But if you look at where things are going now, where people are thinking about just plain out sequencing the whole genome of people with, say, clinical complaints that might have a genetic basis, I can't see that anyone will be able to enforce a patent on a gene. Because you are not asking a question to a gene, you will just sequence the whole genome. You just run into a *BRCA* mutation. So ultimately it's being made, I think this whole patenting of genes for, say, diagnostic purposes is indefensible. And that was being realized in the beginning. I think that Myriad was really a case, landmark case, to just ignite this discussion. And I think that a lot of the other stuff of trying to put sequences behind bars came up to the same thing. People would call it human heritage and it's common property and you can't say…but the plus, of course, you know as well as I do, is that we're sort of continuous reaction tubes and we generate mutations all the time. So that in a way it's sort of undefined, all this stuff with mutations and how you can patent it. And that's different in therapeutic sense.

BCD: And do you know if this was discussed over beers and dinners there in Bermuda, the patent situation? And the sharing norms, do you think that was part of the drive? Part of the reason for the open sharing agreement?

GJvO: I think, yes. I mean the situation with Myriad and also the situation with other companies taking totally different policies were certainly part of the discussions at the table, yes, for sure. Because those were the examples where people would say, well look what happens.

KM: So now you mentioned you were in Bermuda as a representative of HUGO, and I'm curious as to whether your lab specifically was involved in any of the sequencing or mapping projects for the public human genome project? And if not, what was your relationship with any other scientists from the Netherlands who were involved? And I'm curious particularly about this in the context of the government in your country and whether it was problematic, the idea of releasing sequence data into the public domain for everyone to see? Because we've talked to some other folks whose scientific contributions to the human genome project were problematic with their governments' policies in terms of data release.

GJvO: Well …

KM: There was like six questions in one.

GJvO: Yeah, where shall I start? Well, my department was originally headed by somebody called Peter Pearson. I think [BCD] will know him. And he actually then later went on to be the head of the genome database at Baltimore, at Johns Hopkins. He left around like 1990 or '89 or around about. And so that was when I succeeded him. Before that time we were, but then we go very much back in the past, before that time I think the Pearson lab was one of the first and foremost labs of generating what was then called RFLP probes, restriction fragment length polymorphisms. And there was a time … and so our laboratory was in fact in the Netherlands the principal laboratory for this pre-genomics type of science.

I still remember one of the first lectures when Eric Lander, then still a mathematician, was taken by Botstein to the Helsinki human gene mapping meeting in 1985 and delivered a lecture there on what you could do with all these new technologies. And at the time I think our laboratory was already very well known. There was one other laboratory in the Netherlands which was more or less on a par, and that was the Nijmegen laboratory with Hans-Jörg Rheinberger as the head. But the other laboratories weren't there yet. I think in or around '94-95 the Leiden probes for polymorphisms were representing 55 percent of all the probes in the world. Mind you, that was 250 probes. So we're making different…we've had some progress since then. But three of those probes actually knocked around the X chromosome and one of them was the most informative probe for doing diagnostics with Duchenne muscular dystrophy.

So basically we came from studying diseases, DMD mainly in the beginning, Huntington's disease also, polycystic kidney disease, Migraine, FSHD, and in all we have actually played major parts in the gene discovery and subsequent studies. So it didn't come out of the blue sky that I got to be involved, first through Peter, with the genomics crowd. There were Cold Spring Harbor meetings, people met each other yearly at the human gene mapping meetings. I think at some time they were actually two yearly. My first one was 1983 in Los Angeles and then '85 Helsinki, '87 Paris. And well then in '89 there were already noises that Peter would leave, and that was when I was coming into his succession and being approached for, say, HUGO activities because HUGO was busy being set up around that time and Peter was one of the people involved in setting it up.

So my history in the HUGO/HGM community was already there for quite some time. I'd been in many of those committees. In the early days they had committees for groups of chromosomes, 17 -19, 20 - 22, while 1, 2, 3 and 4 were big chromosomes so these were single committees. I was the chromosome 4 committee together with Jeff Murray. And then ultimately every chromosome had its own committee. And we got together with very early stage computing capacities in Cambridge and Yale and in London and wherever, and generated what was then called the human gene map. That was not sequence based.

And I think that one of the big, say, disconnects in this field, and I'm still not sure if this has been, well, useful or detrimental, was that in the early times of the real sequencing, the sequencing in earnest, that community basically gave up on human gene mapping because the maps were not precise, people were quibbling all the time, there were whole segments of chromosomes that were inverted. The beginning of physical maps arrived, to replace the genetic maps, e.g. by YACs. Around I think '92 Daniel Cohen came with his first yeast artificial chromosome map. And so that was a time that a lot of things happened but people were very clear that you could never get the mapping order by just taking it apart in blocks and do only, say, genetic mapping, which was the name of the game in the polymorphism time. And that in principle was the root of that when the sequencing started people basically left the whole of the body of knowledge of the human gene mapping community, essentially aside for quite some time. They just went for the sequence and then had this attitude of, "we'll cross that bridge when we get to it." I still remember that the Duchenne gene had been on chromosome 3 for a year and a half because one of the DMD YACs that was sequenced was mismapped to chromosome 3 and all these young Americans with ponytails out of their caps sitting behind screens, well, you couldn't explain to them that this was just impossible, and it took a long time for them to come around to just sticking it back on the X chromosome.

And the same actually happened with PKD: for quite a while the polycystic kidney disease gene on chromosome 16 had vanished from the map altogether because that was sequence that they couldn't sequence because of the

repetitiveness. And so basically it wasn't there. And so there were quite a few things, I mean, this is over now with all what can be done nowadays. But really, to mix in the genetics and the biology with the high throughput sequencing was, I think, the grand rapids. It took a while to coalesce again.

BCD: So to go back to … I'm just reviewing our questions to make sure that we've gotten through some of the stuff.

GJvO: The next question was how this was seen by the government.

KM: By the government, right.

GJvO: And I should say that at the time I think that our government agency had no specific opinion on genomics or DNA patenting at all. There were some get-togethers by the ministry of economic affairs on DNA patenting and then basically they invited an expert to say these things, and there was an odd number of experts below three that they invited. That was me. So if anything, they usually just got to me. Actually someone else too in the genomics community here but he was much more into *C. elegans* and around 10 years younger, Ron Plasterk, who later became minister of education for a while. And so it was Plasterk and me, who in, let's say, 2003-04-05 were the names on genomics in the Netherlands. In the Netherlands, most of the scientists were still very much into real cell biology on single gene-based and mechanism-based approaches. So there wasn't a lot of interest. In effect, I think somewhere in 1997/8 or so, the Dutch MRC started a program which was HGA, human genome analysis. And the then-director of the Dutch MRC approached me to help set up a committee to guide this call and get grants and so on. So I think that I actually in those days played quite a role in the Netherlands for, say, opinion building, if at all, on DNA sequencing and the patenting and the public versus private. I don't think that it, at the time here it wasn't really top of mind.

KM: So you mentioned that genomics and DNA sequencing weren't top of mind, but what about more generally for data release of government-funded research? So not DNA in particular but just allscientific information, was there any policy dealing with release of data funded by the government?

GJvO: Well it's slowly coming. But there had been the first decade of this century I think that people got to be aware that there was an issue with data release and making data available. I think that was basically even more prompted by private investors … or no, let's say private charities … who were also in part closely connected to patient communities. Say, the Cancer Fund and the Heart Foundation and the Kidney Fund, and those were I think moving on earlier about getting data in the public domain. And so in the beginning the whole attitude was very much on public data should be in the public domain full stop. And then ultimately the ideas came through that actually it would be the task of scientists to protect their

knowledge and protect what would be patentable. But in the Netherlands the patenting of knowledge is something that only the last five years has been moving up in people's attention. Nowadays it's rather typical, there is this whole new scheme now, just now there is this big circus of people running around with the new government for a year, called the Top-sectors and they have to do public-private consortia and scientists should have almost a second societal task to actually protect their knowledge. But that is really, like I say, the last three-four years. And I think it's a good development. And so now finally there is slowly something like a liaison between industry and academia, and that just took a long time going. Not many universities, Leiden and Nijmegen being somewhat of exceptions, have well-advanced TTOs. They all have TTOs and they have a network in the Netherlands. But it's really coming slowly.

KM: So more to the point about the Bermuda Principles in particular, looking back now over the last 10, 15 years since the birth of these sharing norms, how do you describe just the implications for the nature of research, particularly in biology but perhaps elsewhere? For instance, the Bermuda Principles are held up as this gold standard for open science and sharing data. And I wonder philosophically if you saw at the time or if you see now these sharing norms during the human genome project as something that were part of a greater shift in science to a new way of doing things? So more philosophically how might you react to these principles?

GJvO: Let me take a second or so to think. I don't think that it is the end point of the development to make everything openly available, philosophically. Over the last, say, three, four years I am actually also very involved in the national biobanking activities. And much of the research in complex diseases requires an enormous amount of, say, biobanks, live samples, big investments, industry support. So while I would think it would be wonderful to put everything in the public domain, in practice I think there are actually two arenas that make this difficult. One is the privacy arena. It's all nice and well, but DNA information is pretty privacy sensitive. And especially since this paper that you can sort of reconstruct who was in a cohort of thousand people if you know the sequences, although that is contested, means that people haven't been as forthcoming as before to make individual genome sequence connected to a person publicly available. I think that's also a phase in time; ultimately I think in the 21st century, privacy's out the window.

And so you should make better rules on what people are allowed to do with information, rather than try to stop information getting in or getting out, because that's just a lost battle. But it will take a lot of time for people to find the best way of setting these rules for what people are allowed to do and are not allowed to do, especially in the biobanking field, of course.

The second problem is the acknowledgement of effort, important for people's careers. There is a tremendous amount of, say, phenotypic information behind the

biological and genetic data, and this phenotypic information has been taken and gathered by many people in a very, well, painstaking way. So it will take a while before people will be easy in sharing that information because it often has taken them like 30 years to collect it.

And so for instance in the Netherlands now from the social sciences, the MRC social sciences … well that's a research council, it's not the MRC … has come out pretty outspoken about that all data that are publicly funded should be public. And that has actually caused the whole complex of research councils to be in uproar and at war with each other because many other research councils, including the medical research council, realize that this is just plainly impossible, for instance, in the biobanking field. And it would also not get the public support.

And so these things are very important, science must keep the public on their side. I think that things started moving on DNA patenting when the newspaper writers and so on understood the issue and the public got on the side of the general opinion. And so I doubt that it will be very quick that people will be comfortable with sharing enormous amounts of, say, DNA data, phenotypic data that are in biobanks. Notably for existing biobanks it is going to be very difficult because of all the legal systems in the different countries. And so, well, it's a hard road. And I don't know exactly what my opinion would be on making … say, my own philosophy on making everything available.

I do know, you may have heard of this but also may not have heard of this, when the first high throughput machines came on line I think late 2006 or so, we were one of the first to buy an Illumina machine. Well it was the first one delivered to continental Europe. And so we thought, let's do something of which we are sure that we will not succeed, biting off something that is too big to swallow. So let's, other than our paid-for projects, actually start sequencing an individual. And we had a female clinical geneticist called Marjolein Kriek, and then somebody in the laboratory said, oh that's good, after Watson now we can sequence Kriek. And so that was what we did. And so then it turned out that that was actually the first named female person that was sequenced. Before that you had Watson and Venter and a Yorubian male and an unnamed female cancer patient at Washington University. And so basically we just released a very modest press release. It was, I think, May 26 or so, 2008. And that was picked up absolutely everywhere so that we were written about in the Bali news and the Adelaide news. Actually they have a headline saying, Finally Men Will Be Able To Understand Women. [Laughter].

All in all at the time we had like 130,000 Google hits if you would Google Marjolein Kriek. And so actually Kevin Davies picked up on that for his book *The $1000 Genome* and he interviewed Marjolein and me for the book. And actually in the last American Society of Human Genetics, in Montreal 2011, there was a session of people on stage that had their sequence done. Jim Lupski was there,

Watson, Marjolein was there and a Korean guy. And it was quite something to have like 4,000 people in a room and those on stage just speaking about why they did it and how they did it and how they look back at it now and so on. And it has actually, especially because Marjolein is a clinical geneticist so she sees it from two sides, she also sees patients, … at least informed consent was, if anything, pretty fair. But it really for her was a way to explain to people that it might not be as creepy and dangerous and scary as people would think. So this has helped making the issue of your DNA sequence and what it is and also what it's not, putting it under the public eye.

BCD: So, [GJvO], I'm reviewing our questions and it looks like we've covered most of the stuff that we wanted to get through but there are a few kind of questions that might provoke you to think of some documents or other people that we should talk to. Do you have any documents that would bear either on the Bermuda meetings or on kind of the historical context in which those meetings were taking place that would be relevant that we should take a look at, or that we could make public through an archive or something like that? And so that's one question, documents. The other is, are there some people we might not get by only looking at those who were actually at the meetings who you think we should talk to?

GJvO: Okay. On the documents, the answer is very simple. My lab moved places four or five years ago and everything that was in our older archives has been lost or destroyed or whatever. I don't also think that I would have a lot of documents that you wouldn't be able to derive from other people. What I do know is that Michael Morgan, that you probably will also speak to or have spoken to, has been very active in asking the same question about a year ago, or a half year ago or so. And so I know that he has been trying to get an archive on the genome project together, and also to ultimately make it accessible through Internet. So it probably would be very sensible if you got in touch with him, what he has available, if you haven't already done so.

BCD: Yeah, so we are talking to Michael, and in fact we're hoping … the Wellcome may be, in fact, the place where a lot of this stuff, either Wellcome or Cold Spring Harbor, may be …

GJvO: Yeah, that, I wouldn't be amazed, yeah.

BCD: So we are trying to make sure that anything we do doesn't duplicate what they're doing.

GJvO: And then maybe one of the people that you would want to speak to, but I think most of them were either in one or more of the Bermuda meetings. People like Charlie Cantor and Pieter de Jong. Pieter de Jong was certainly at many of those meetings.

BCD: Yeah, he was certainly there at least one. I can't remember which one. We'll bring him up.

GJvO: And so that was somebody who I now and then spoke with because he had a Dutch background. So at least you could … well you could converse in this remarkable site of the Bermuda hotel. I mean, that alone was just worth the go.

BCD: It turns out Pieter was at all three.

GJvO: Oh, okay, I wouldn't be amazed. Yes, he was in Lawrence Livermore, Berkeley, I think …

BCD: Yeah, that would be …

GJvO: … and he was the one generating the BACs or the YACs or whatever. So, yes. So and then in Cold Spring Harbor you probably will or should speak to Jan Witkowski because he organized most of the Cold Spring Harbor meetings, including the genome meetings. And you might not think of him because he has always been a person in the background of all these activities.

BCD: We actually are in contact with him, but I hadn't thought of interviewing him about this. We're interacting with him a lot about our more general human genome project archive.

GJvO: Yeah, yeah, yeah, okay. No, I'm not sure …

BCD: That's actually a really good idea because he certainly organized the one that happened in May of '98 where all hell broke loose.

GJvO: Yeah, so that would be one person I would think of. And then maybe a few of the people that were involved in Europe that might not have made it to the Bermuda meetings but were in the early phase of the genome project quite important. Somebody like Jean Weissenbach from Paris.

KM: We're talking to him next week, actually, so perfect.

GJvO: Good. And Daniel Cohen. He was the guy who first basically stood up the Americans and had the first physical map of the human genome by YAC mapping. It's a paper in '92.

KM: Right. I have that paper on my desktop.

GJvO: Ah, okay. He's a very outspoken, unusual person, but you would certainly … I don't know where he is now and wouldn't … but you probably would be able to find him through the French channels. Somebody who has been in this human

gene mapping and is still sort of old, but aware is Jean-Claude Kaplan and he actually still works at the hospital in Paris. But he is long beyond retirement. I think that he should be like 75 or so now. But he was close to … you had of course, the person who had this other gene mapping database, the GENATLAS, Jean Frezal, I think he died a few years ago and a younger person who took over his duties, and I'm not entirely sure … he's much more clinical than genomic, is Arnold Munnich, and I'm not entirely sure if he would be very informative for this.

BCD: Well if you do happen to have some other thoughts just flip us an email or …

GJvO: Yeah, I'll put it on the mail. If somebody just pops in my mind on maybe you should want to speak to them … you certainly should speak to the succession of the HUGO presidents, so Caskey, you should definitely speak to. And Grant Sutherland from Australia. And somebody who has also been very close to all this is Lap-Chee Tsui. He now is president of the Hong Kong University, but he's been HUGO president after me and of course he was very much in the race for the…and one of the winners in race for the cystic fibrosis gene. And he was in the human gene mapping community also. So I think that certainly he would be having a lot of additional information on what that time was about.

BCD: Good, well thank you so much, [GJvO], and like I said, we will turn this into a transcript and send it to you with the form saying here's what you should do with it when you get it back. And you should be hearing from us in about two or three weeks or something like that.

GJvO: Oh yes, one person that I can think of, Karen Kennedy. Are you in touch with her?

BCD: No.

GJvO: She was the secretary of many of the committees at the Wellcome Trust where Michael Morgan was also involved. And Karen has after that been working for quite a while in Genome Canada.

KM: Okay.

GJvO: And so you could probably get in touch with her through Genome Canada. And there's a lady in Genome Canada who organized all these people and organized the whole of the Canadian genome project. *[This is Cindy Bell, very much worth talking to.]* If I think of it I'll just put it on the mail.

BCD: Okay. Well thank you, [GJvO]. And so we'll stay in touch, and thank you so much for being so helpful here.

GJvO: I think that I provided a lot of background, but not very specific information on that Bermuda meeting. But well I think gradually a picture emerges.

BCD: That's what we're hoping.

GJvO: Okay.

BCD: Well thank you so much.

GJvO: Well thanks for speaking to me.

KM: Yes, thank you so much.

GJvO: Okay, yeah, a good time. Bye-bye.

END OF RECORDING