Opportunity not exploitation: valuing the Icelandic genome

The Icelandic people are a small population with a uniquely homogeneous gene pool. Research into the Icelandic genome may ultimately lead to new therapies for the treatment of human diseases. In New York, I recently caught up with Kari Stefansson, a native Icelander and the founder and CEO of deCode Genetics, a new, but rapidly growing company based in Reykjavik that targets this valuable resource. He offered some insights regarding the development of deCode and its acceptance by the Icelandic people.

Kari, deCode Genetics sounds like a most interesting enterprise. Tell me about your professional background and why you decided to establish the company.

I'm a physician. I went to school in Iceland, and when I finished medical school, I went to the United States to train in neurology and neuropathology at the University of Chicago, where I joined the faculty and remained until 1993. Then I went to Harvard as a professor at the Medical School until I resigned in April 1997.

I founded the company in 1996. As an academic, I was interested in the genetics of multiple sclerosis, and several genomics and pharmaceutical companies had begun to approach me, so there was obviously a need. I realized the qualities of the Icelandic population that make it an ideal subject for genetic research: the genetic homogeneity; the vast amount of information on genealogy; the high-quality medical care – a national health care system since 1915 with universal access and very good record keeping – and the willingness of the population to participate in genetic studies. I concluded that the scarce item in studying human genetics is not the technology but the population. So, I went ahead and established the company.

Although the Icelandic government did not provide the funding for deCode, from day one they have been very supportive. The people of Iceland have also been thoroughly behind the company. People have perceived it as the beginning of biotech in Iceland.

Why is there so much information on the genealogy of the Icelandic population?

Iceland was settled some 1100 years ago, and for the first few hundred years it was a true democracy. If someone stole your sheep or peed in your water supply, which were serious crimes punishable by death, you had to carry out the sentence. To do so, you called upon your blood relatives. It was important to know to whom you were related. Your genealogy had a direct relationship to social justice. Iceland became Christian in the year 1000 and part of the responsibility of the ministry was to record births, deaths and marriages.

Reykjavik, home of deCode Genetics. The total population of Iceland is only about 270,000, of which 60% reside in Reykjavik. The unique genetic homogeneity of Icelanders represents an excellent opportunity for deCode to be at the forefront of genomic research. Photograph reproduced with permission from the Icelandic Tourist Board.

Fascination with genealogy

The nation has continued to maintain a strong interest in genealogy. There is a professorship at the University in Genealogy, there are many genealogy societies, every year several books of genealogy are published that sell in large numbers, and a daily newspaper has a one or two page column on genealogy every day.

When we founded the company, we had access to the genealogy of the entire nation. Add to that the fact that

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Icelanders have a very strong sense of community; it's a highly educated nation, and we achieve 99% participation rates in our studies. Moreover, we have in one location all the tissue blocks from all biopsies and autopsies performed in Iceland since the second world war. It's clear we have a unique opportunity to do good genetics.

How large is the company now, and what are the major focal areas?

Currently, we have 200 employees. I think that this will grow to about 600 people, which is a very large company for a small country like Iceland. All employees are university trained. It's going to be an extraordinarily large concentration of educated people.

We are working on 25 diseases, including hypertension, cardiovascular disease, Alzheimer's disease, anxiety – most of the common diseases. We have already made important discoveries in the multiple sclerosis, psoriasis and schizophrenia areas, and collaborating Icelandic physicians have collected lots of blood from these patients. We are clearly advanced with the clinical research, but remember, we are only a year and a half-old company.

How are the DNA samples collected?

All of our studies are done in collaboration with community physicians. It is extraordinarily important that the company never approaches the patient directly because of protection of privacy. All of the information that goes into our company is labeled with an encrypted identification number, and our genealogy database is labeled with the same code. So when we get the sample and the disease information, the code does not prevent us from determining who is related to whom and how. I think this system is the best in the world for protecting privacy.

Informed consent

Once we decide to work on a particular disease, we contact a group of physicians who are taking care of such patients. Together, deCode and the physician apply to the Data Protection Commission, a government body, and an ethics committee. We send them a protocol for the study. They must approve it, and also make sure we protect privacy and abide by the protocol. The physician sends us an encrypted listing of patients. Our statistician looks at the family trees in our genealogy database and indicates which families we need.

The physician then sends these patients a letter to ascertain whether they are willing to participate in a study. He explains the study to them and they sign an informed-consent form. He then draws the blood and sends it to us with the encrypted code.

One of the remarkable things I find is the high percentage of the Icelandic people who are willing to participate. This has certainly not been the reaction of a lot of indigenous peoples to the proposed Human Genome Diversity Project.

The problem with the *Human Genome Diversity Project* is that people are coming in from the outside. Arriving in helicopters to extract a pint of blood from indigenous populations and then disappearing. We are an Icelandic company; we were founded by Icelanders for Icelanders. The company is creating employment and opportunities, so the population perceives us as being beneficial and a good prize.

If we succeed as a company in Iceland, it can be argued that the primary beneficiary will be the population, because of the way in which we the company generate value and employment. As the world shrinks, it has become easier for well-educated Icelanders to get jobs abroad. There has been a substantial brain-drain from Iceland. We are reversing the brain-drain by bringing back large numbers of highly educated Icelanders, and highly educated foreigners as well. The community appreciates that – it is terribly important.

Hoffman-La Roche deal

We have an agreement with Hoffman-La Roche which has written into it that if drugs are developed on the basis of discoveries made from the population, Roche will provide those drugs to the entire Icelandic population at no cost. It is not an exclusive agreement; it addresses only twelve diseases, but we will sign many such agreements in the near future.

This is the first such acknowledgment from any company in the entire pharmaceutical industry to the contribution of participants in studies like this. It is a very important issue; it provides a symbolic gesture towards the population, and it shows that Hoffman-La Roche is working in good faith. We will strive to include it in all our agreements; I think it is good business.

Frank Dukepoo, a geneticist at Northern Arizona University (Flagstaff, AZ, USA) has written regarding this agreement between deCode and Hoffman-La Roche, 'If American Indians were to venture into such an agreement with the pharmaceutical companies, they would insist that free drugs be given not only to members of the tribe, but to the world population as a whole' [Mol. Med. Today (1998) 6, 242–243]. How do you react to that statement?

As a middle-aged man who grew up in the 1960s, I used to share such views. However, having been forced to face what most people call 'reality', I also see this as a statement of a man who is really not particularly interested in understanding the world he is living in today. The fact of the matter is that trade is the only mechanism we have for distributing goods around the world.

When a population anywhere in the world agrees that researchers can collect biological samples, there are two kinds of good that can come out of it. One is knowledge for the sake of knowledge, which is important, and the other is new insight into diseases. The ultimate value for people is better methods to treat diseases. But this will not be done without commercialization. Today, it costs about $500 million to turn a biological discovery into a medication. There is no way that the money can be raised except through commercialization, which requires patenting and the involvement of the pharmaceutical industry.

So this proud member of an Indian tribe should do the same thing that I have done. My company is not only doing the best genetics in the world, it also prevents other companies and universities abroad from exploiting the Icelandic people. What I have done is the antithesis of exploitation of the genetic heritage of a proud people. We are building up employment and extracting value from our genetic heritage.

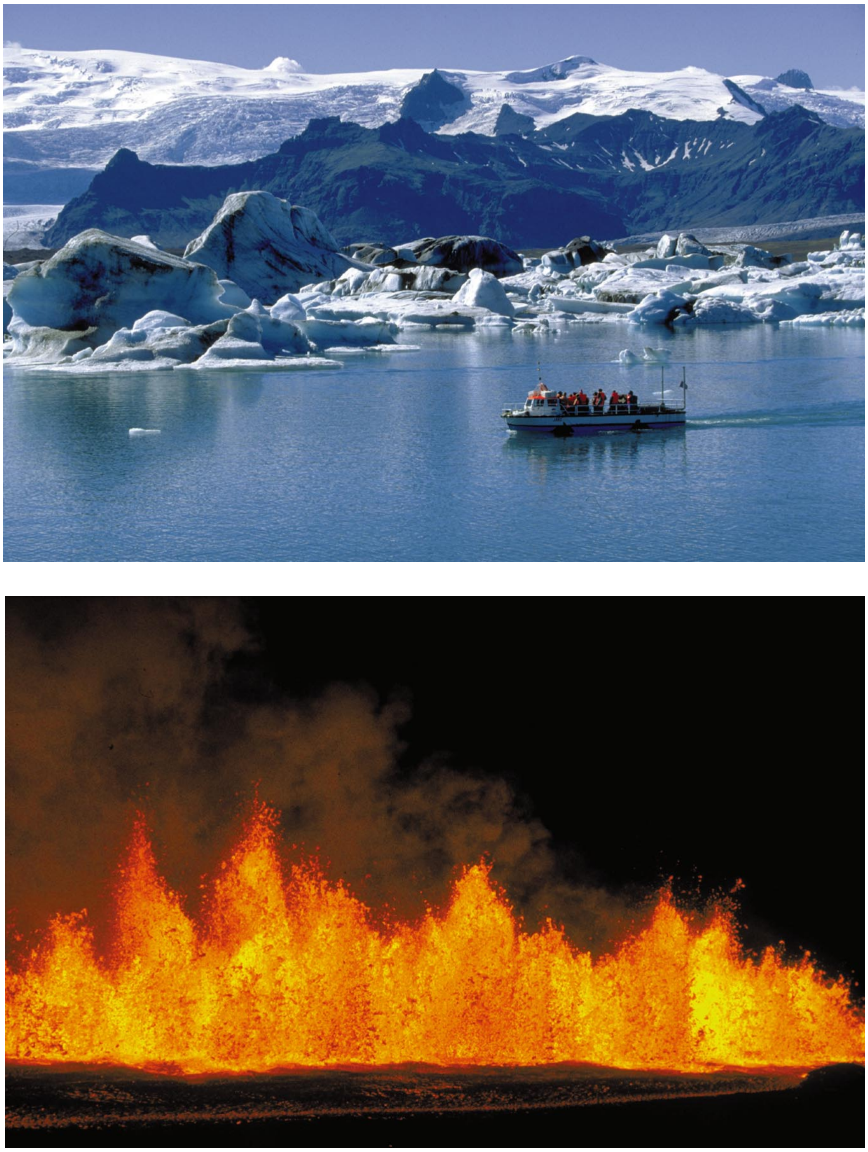
Poetic justice

Another spin is that most of our genetic homogeneity is because we lived in isolation, which contributed to the enormous poverty of the country, and that there were two population crashes in Iceland. The first was the bubonic plaque, which hit in the early 1400s and reduced the nation by 60%. The second was the volcanic eruption in the 1700s that covered the entire country with ash, and again reduced the population by 50%. Today, we are seeking poetic justice for the misery caused by the very same things that have made Iceland into a unique place for genetic studies.

Were such disasters useful because they were selective pressures?

No, I'm not suggesting this from the point of view of selection. The bubonic plague affected a particular part of the country more than others as did the volcanic eruption. There was an uneven weeding out of the population, which makes the effective genetic base of the population narrower. It reduced the size of the effective founding population.

Let me give you an example. Let's say there were five original founders who brought a disease into the population, all of whom had descendants. However, due to the weeding-out effect of the catastrophes, we may, today, only have the descendants of one of the founders in the population. So these events clearly diminished the effective genetic diversity, and that helps us in our work.


Land of ice and fire. Iceland's isolation and natural disasters, such as the volcanic eruption in the 1700s, have created the genetic homogeneity of its population. It has meant that the Icelandic genome is an ideal target for research. Photographs reproduced with permission from the Icelandic Tourist Board.

If you stop looking at genetics as a collection of molecular tricks, and take it for what it is, you find that it is bioinformatics. It is information that in most cases remains constant from generation to generation. Special creationists say, 'In the beginning was the word' – they just forget to mention that the word is written in the nucleotides of DNA.

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