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## Icelanders Put deCODE Genetics and Roche on Ice

### Corporate Gene Hunters Postponed in Bid for Exclusive Monopoly on Icelanders' DNA

deCODE Genetics, a human genomics company founded in 1996, and Iceland's only biotech company, was the envy of the genomics industry in 1997 when it announced plans to tap into the DNA of the country's 270,000 inhabitants. The plan was called "a biotechnologist's dream" because the company would gain access to an extraordinary degree of homogeneity in Iceland's inhabitants, enabling the company to uncover genetic mutations for complex diseases.<sup>1</sup>

The Icelandic population is descended from a small number of founders who originally settled on the island in the 7<sup>th</sup> century. With little inward migration, the Icelandic population is considered a "fabulous national resource" from which corporate gene hunters can pinpoint and patent human disease genes.<sup>2</sup> deCODE claimed that it would also gain access to genetic information on past generations of Icelandic families because it would gain access to the government's well-documented human tissue bank with autopsies and biopsies dating back to 1915.

Early reports on deCODE's genetic prospecting suggested that the Icelandic people were not only in favor of the deal, but eager to cooperate. According to *BioWorld Today*, "the people of Iceland are highly educated and are prepared to cooperate with scientists."<sup>3</sup> DeCODE's president and CEO, Kari Stefansson, told *Science* that his company was forging partnerships with local government leaders and academics, and that nearly all of them fully support the project.<sup>4</sup>

The deal proved irresistible to pharmaceutical giant Hoffman-La Roche, which announced in February, 1998 that it would pay \$200 million to deCODE Genetics in a partnership to identify disease genes from Icelander's DNA. It was described as the largest human genomics deal on record.

Responding to the \$200 million collaboration to mine Icelandic DNA, the Prime Minister of Iceland, David Oddsson, said he was keen on the deal as a new form of foreign investment for Iceland:

“It is extremely important for us to secure foreign investment in Icelandic companies, and I am delighted to see an investment of this size in a high-tech venture in our country,” told *BioWorld Today*.

### **“Not so fast!” respond Icelandic Scientists**

But many Icelanders are not enchanted with corporate gene hunters nor with the notion of exclusive monopoly patents on Icelandic DNA.

A letter appearing in the June issue of *Nature Biotechnology* from researchers at three Icelandic institutes reports that “the Icelandic government has now been forced to postpone a bill designed to give deCODE Genetics Inc. an exclusive license to collect current and retrospective medical information about all Icelanders into a centralized, comprehensive database” that would have given the company the sole right to commercial exploitation.<sup>5</sup>

In the words of four prominent Icelandic scientists who signed the letter in *Nature Biotechnology*:

“The bill took the Icelandic medical and scientific establishment completely by surprise. The existence of the bill was unknown to everyone here except the government and leading executives of deCODE until its announcement on March 31. No discussion had taken place on the desirability or otherwise of the measures in the proposed bill. It became clear that the government intended to rush the bill through parliament to forestall debate. Following very strong opposition from the medical and scientific community, the bill was postponed to the autumn.

There are three major concerns. First, is the database justifiable on scientific, economic and ethical grounds. Second, should the database be a commercial asset of a private company. And third, is it right to offer a single company legalized monopoly control. If the bill became law, it could be used to restrict the research of Icelandic scientists who work in the medical field and wish to remain independent of deCODE Genetics.

Another cause for concern in the scientific community is the Icelandic tissue bank which holds samples that go back some 40 to 50 years. The access to samples from the bank will be governed by a new law. The contents have not yet been disclosed.

There are advantages to studying genetics in the Icelandic population. What has not been shown is that the commercial exploitation of a nationwide database and tissue bank would further genetic research. Many questions of ethics and confidentiality remain unanswered in the proposed legislation. It is to be hoped that the oldest parliament in Europe does not let democracy slip in order to allow one company the right to order legislation exclusively for its own ends.”

The letter is signed by:

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Action taken by the Icelandic people to defer deCODE and Roche's quest for commercial exploitation of Icelandic DNA is encouraging news for all of the populations now under siege by corporate gene hunters worldwide. The letter written by Icelandic scientists eloquently calls into question the right of private interests who seek exclusive monopoly control over human DNA in the name of advancing medical research. The dilemma faced by the Icelandic people also points to the glaring lack of international regulations to protect human subjects from commercial exploitation, and social and ethical violations related to the collection and patenting of human DNA.

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<sup>1</sup> Williams, Sue, 1997, "A Unique Inheritance," in UNESCO Sources, No. 94, October, 1997.

<sup>2</sup> Williams, Sue, 1997, "A Unique Inheritance," in UNESCO Sources, No. 94, October, 1997.

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<sup>3</sup> Moran, Nuala, "Roche to Pay DeCODE \$200 M for Disease Gene Discovery," BioWorld Today, February 3, 1998.

<sup>4</sup> Marshall, Eliot, "Whose DNA is it, anyway?" Science, No. 5338, Vol. 278, October 24, 1997.

<sup>5</sup> "deCODE deferred," letter to the editor in Nature Biotechnology, Volume 16, June 1998, p. 496.