

ENABLING MODERN GENOMICS IN HEALTHCARE



Dr. Pál Weihe, head of FarGen.

Visualizing ‘a new health paradigm for personalized health’ through full genome sequencing, the Faroese healthcare system could become a model for the rest of the world, explains Pál Weihe, the Faroe Islands’ most renowned scientist.

MEEET MEDICAL doctor and researcher Pál Weihe, Chief Physician of the Department of Occupational and Public Health, Professor of Public Health at the Faroese University, and head of the FarGen project. His 120 peer-reviewed articles published in scientific journals, with some 5,000 academic citations, make Dr. Weihe one of the Faroe Islands’ most widely recognized scientists.

His vast body of research, dating back to 1984 and continuing—some 35,000 research hours to date—is primarily steeped in the field of environmental

medicine, focusing largely on the effects of heavy metal marine pollution. Specifically Mr. Weihe has looked into, for example, risks of unborn children suffering mercury poisoning in result of their mothers consuming certain amounts of whale meat.

30 years of scientific research have given Mr. Weihe unique insights into various issues related to public health and the Faroe Islands. At the same time, with his numerous travels and extensive network of fellow researchers across the world, Mr. Weihe has a truly international perspective.

Aside from a host of research projects in environmental medicine, a different project, FarGen, was initiated in the Faroe Islands a few years ago.

The original idea, “to identify the potential for human genetics in the Faroes,” soon turned into something more ambitious.

“From focusing on only a few specific Faroese high frequency diseases,” according to Mr. Weihe, “the FarGen idea evolved into a holistic health care model visualizing a new health paradigm for personalized health.”

One main reason for the leap of purpose was the rapid advances taking place in biotechnology, genetics, and information technology.

“In the last seven years or so we have seen an accelerating development taking place in whole genome sequencing in a research context. So with FarGen, of course this pace of development was taken into account quite early on.”

In other words, FarGen is all about applying modern genomics and how to take the Faroese healthcare system to the next level, and in the process inspire others in the drive to make genomic information usable and standard routine in healthcare.

HOMOGENOUS NATION

“As far as I can see, the future of genomics and healthcare lies in personalized medicine,” Mr. Weihe said. “That implies moving away from the ‘one-size-fits-all’ philosophy, and away from the old deterministic approach—toward embracing the reality of gene-environment interaction which concerns the crucial interplay between a person’s external and internal environments. In all of this, education plays a significant role, not least to build trust and avoid stigmatization and similar potential ills; even more fundamental is addressing the ethical, legal and social implications. In my opinion the Faroe Islands has so far managed this process very successfully.”

In response to growing interest in genetic research, a special law was passed by the Faroese parliament in 2006 to regulate the area, designed to introduce privacy safeguards and establish the Genetic Biobank (Ílegusavnið) under the Ministry of Health. The establishment of the Genetic Biobank that year subsequently provided a natural home for the FarGen project.

As per its own definition, “The Genetic Biobank is a coordinating unit within the Public Health Sector whose mandate is to organize, develop and administer a Tissue Registry, a Diagnosis

Registry and a Genealogy Registry and to process applications for permission to study the information contained in said registries.”

Thus the Genetic Biobank “started its efforts to develop the infrastructure to establish and maintain an active biobank, to utilize such a resource in conjunction with medical and genealogical data to support research projects aimed at discovering the relationship between genetic background, environmental influences and disease onset and progression.”

Hardly surprising, as a genetically homogenous nation the Faroe Islands tends to be of interest for genetic research. Applying genetics at the systemic level in healthcare, however, presents a different set of challenges.

OVERSEAS FUNDING

The fact that the Faroese genome is being made part of the public healthcare system is believed to be important for the prevention of potential abuses.

Said Mr. Weihe: “To achieve success in making the genome an integrated part of the healthcare system, you have to isolate it from negative perspectives and perceived risks. Technically the practical arrangement of the personal data and medical records involved—especially the separation between chemical sequencing and bioinformatics processing—makes the system very difficult to abuse.

“The Faroese healthcare system is advanced in spite of the minuscule size of the population. In effect the Faroese society is reminiscent of a laboratory, which of course makes it interesting in the context of research.”

In 2013, an international FarGen Conference was held in Tórshavn with the participation of scientists from several countries. The event helped generate publicity and brought it to the attention of lawmakers, resulting in a 10 million DKK (1.34M EUR) boost from the Danish Government.

“We are very pleased with this development,” Mr. Weihe noted.

FarGen

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The Faroese Genome Project (FarGen) aims to sequence whole genomes of the Faroese population. Together with existing health and genealogical records, such a comprehensive sequencing project can improve health knowledge, treatment and prevention services in the Faroese health system. The project is owned and managed by the Genetic Biobank (Ílegusavnið).

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The Genetic Biobank is a governmental institution under the Ministry of Health www.hmr.fo, with a mandate to organize, develop and administer a Tissue Registry (biobank), a Diagnosis Registry and a Genealogy Registry and to process applications for permission to access and study the information contained in the said registries. The Genetic Biobank is the official institution authorized to conduct genetic research on human tissue from individuals registered in the Faroes.

“There is a wide range of research topics that are relevant to FarGen and this cash injection will make it possible to launch such projects. Without such extra funding, there is little we can do in the way of research.”

Over the years, by far the majority of Mr. Weihe’s research projects have been financed through funding from overseas, especially from the United States and European Union.