

## Small island nation to sequence genome of entire population

October 6 2011, by Bob Yirka

(Medical Xpress) -- The small island nation of the Faroe Islands is planning to offer free full genome sequencing to all of its 50,000 citizens. Though only partially sponsored as yet (by genome-sequencing company Illumina) the project is expected come to fruition and will eventually cost close to \$50 million and take up to five years to complete. Its main purpose is to provide better medical care for the population, though such a project would undoubtedly provide a great deal of useful information for medical research studies as well. The project was announced at the Cold Spring Harbor Laboratory during a meeting of genome researchers this past week.

The Faroe Islands is a self-governing dependency of Denmark located about halfway between Iceland and Norway in the Norwegian Sea. Its first inhabitants aren't really known, but it is believed that most came from either the Norse countries or parts of Ireland or Scotland. Its citizens speak their own language, Faroese, which is believed to have evolved from Old Norse. The reason this is all relevant is because fully a quarter of the people who live in the country, are carriers of a gene responsible for Carnitine Transporter Deficiency, or CTD, a disorder that plays havoc with metabolism in infants and young children. If not diagnosed, it can lead to heart failure. Thus, it's not difficult to see why the citizens are so open to the project.

The idea grew out of a previous project started in 2009 to identify people carrying the CTD disorder gene, and has blossomed into the more expansive project now called FarGen. An initial venture has already



kicked off that will sequence the genes of just 100 adults as a means to figure out how to build a program that will include all the rest of the people in the country. As it stands now, the plan is to include a link between digital medical records (which are already in place) with the sequenced profiles. Patients would not be given access to the profile unless they specifically ask for it, and doctors would only be given access if they have a legitimate reason. The hope is that such a system will prevent misuse of personal medical data while giving patients access to information that could save the lives of their children.

If successful the project could serve as a test bed for future projects in other countries, providing information not just on specific disorders for individual patients, but ways to conduct such testing without infringing on patients rights to privacy. Also, researchers are of course hoping that a database of such information could offer new insights into genetic diseases and their presence in certain populations.

More information: via GenomeWeb

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