Shetland Community Screening Project 2025-2029

Presenting the genetic risks to Shetlanders started with VIKING I in 2023, with VIKING II returns ongoing. Following publicity in 2024, impetus has grown to carry out population-wide screening in Shetland. This can protect the whole community and try to make everyone aware of their own health risks. We are raising funds to screen 5,000 Shetlanders for about 50 important disease-causing variants covering all major heritable conditions prevalent in Shetland.

With the endorsement of Prof Wilson, a committee of local volunteers will support the project and help raise the £1 Million required. Already, a number of privately organised local fund-raisers have set Viking Genes Fund off to a great start with many individuals also donating.

We are currently working to secure enough funds to enable project delivery staff to be appointed for the expected 3-year term that will safe-guard the overall delivery of the project.

We are very grateful for any contribution or support you can provide.

How we plan to deliver the project

- Secure enough initial funds for full-scale project delivery
- Launch the screening, using postal saliva collection of DNA and informed consent
- Samples undergo analysis in expert genetics laboratories
- Starting within three months of returning their saliva sample, volunteers log into their private “genetics health dashboard” to learn about any health risks they have and what steps they can take to reduce these
- Co-ordinate provision of NHS treatments for those who have concerning genetic variants

All work will be carried out with approval from the NHS Research Ethics Committee

What this will deliver for Shetland

The project aims to save lives in Shetland: it enables the identification of people who are at risk of life-threatening diseases. For some, the subsequent follow-up health checks may reveal they have already developed cancer or a heart condition. The screening will allow early interventions, which hopefully will lead to long productive lives in the community.

We will need your help to make this screening a reality. We’ll make Shetland the best example of preventative healthcare anywhere in the UK.

Viking Genes Shetland committee:
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VIKING GENES

Shetland Community Screening Project

Working with the Shetland community to improve health and wellbeing and make future generations safer from genetic health risks

THE UNIVERSITY of EDINBURGH

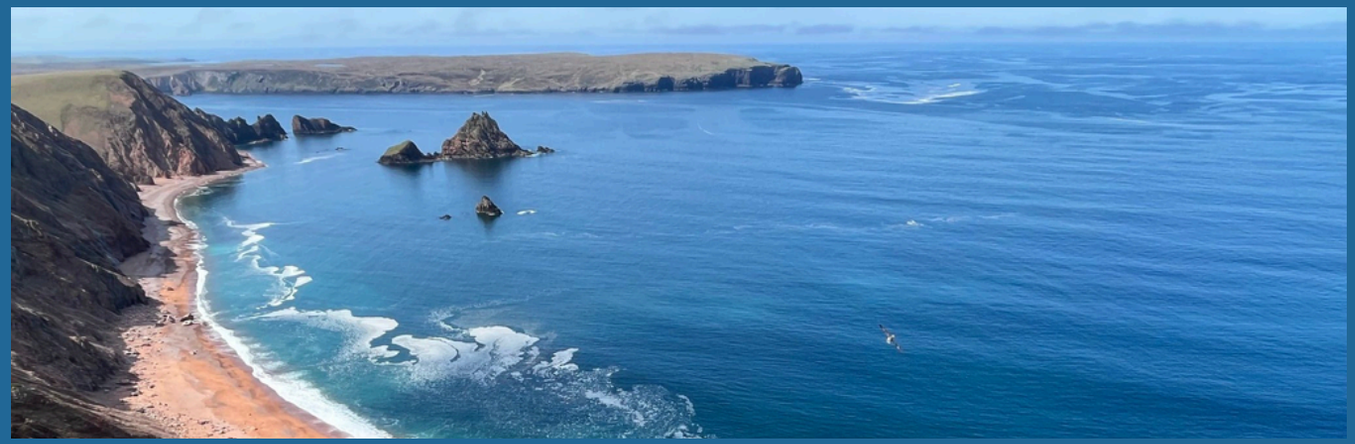
Our health findings

The Viking Genes project revealed that Shetlanders have a much higher chance of carrying a number of potentially deadly disease-causing genetic variants than the general UK mainland population, sometimes hundreds of times higher for Shetlanders. This includes BRCA2 causing breast, ovarian and prostate cancer and KCNH2 causing fatal heart rhythms.

From our Viking Genes data, we can estimate that half of the affected Shetlanders DO NOT currently know that they carry this risk, and without this information they cannot access treatments that can potentially keep them well and save them from suffering from the effects of disease.

We have already returned information to volunteers with disease-causing variants among the 3000+ Shetlanders screened to date, allowing them to take action to protect their health. Offering more screening will benefit more people.

"Our findings have convinced me that population-wide genetic screening in Shetland for all the disease-causing variants can save lives and directly impact the health of hundreds of people who currently don't know of the health risk they carry" -
Professor Jim Flett Wilson



How a population-wide screen will improve the health of Shetland

A population-wide screen will provide a unique opportunity to advance the health and wellbeing of today's island population, while helping protect future generations.

It will move Shetland to the forefront of preventative medicine within the UK. This will result in improved community health, save individual lives across Shetland, avoid or prevent debilitating later stage conditions, and increase the quality of life and health for many Shetlanders.

This can be achieved by a simple saliva-based sample analysis that will identify individuals and their specific genetic risks, allowing preventative healthcare thereafter to keep people well.

For the future, we aim to be able to move on to the devastating inherited diseases such as Cohen syndrome, Batten disease, cystic fibrosis, Wilson disease and others, many of which are incurable. Within two years we hope to start returning information to carriers of these genetic variants.

By screening adults of all ages, including young Shetlanders who have not yet had children, we will identify individuals who have the greatest risk of passing a potentially fatal condition onto their future children, and to take steps to reduce that likelihood through improved health support and medical interventions.

Support Viking Genes