Welcome to your summer newsletter!

Happy summer from the Viking Genes team!

As we welcome the long days of summer, here at Viking Genes we also look back at everything we have achieved together and take pride in delivering impactful research to return 'actionable' results to our volunteers. This includes one of our most important discoveries to date and is our breaking story!

In this edition, Jim highlights an inspiring initiative, the launch of a new fund-raising drive, a study update, and news of a royal cousin.

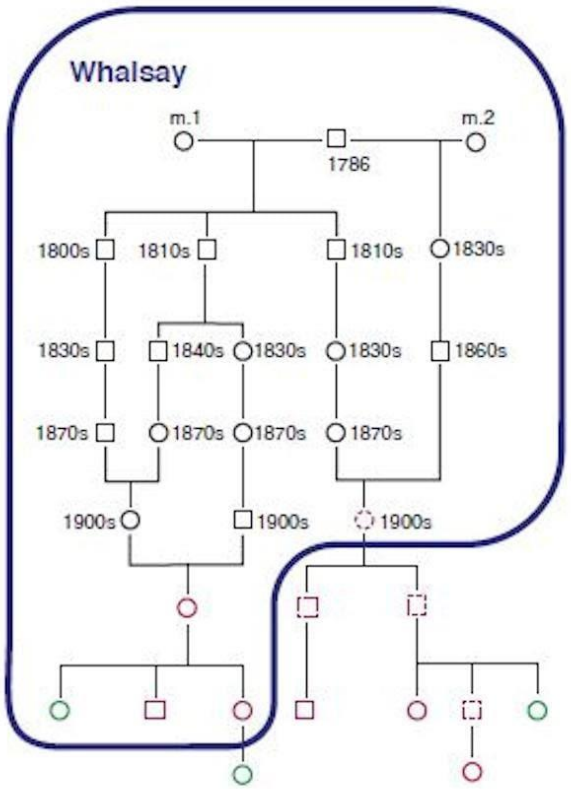
Read on to find out more.

Breaking: Cancer risk gene variant discovered in Shetland

Viking Health Study - Shetland (VIKING I) volunteer data has linked a harmful variant in the gene *BRCA2* to a historic origin in Whalsay, Shetland

Just over a year ago the story broke that ORCADES volunteers data (part of Viking Genes) had helped to identify a founder gene variant that causes a high lifetime risk of developing breast and ovarian cancer in some women from Orkney. Now we highlight our Shetland volunteer research and a harmful variant that can affect women and men.

Historic origin linked to Whalsay, Shetland



We examined the genetic data from over 2,000 volunteers, men and women with three or more Shetlandic grandparents, and found the harmful *BRCA2* "*c.517-2A>G*" variant present in the DNA of nine volunteers. This frequency is 130 times higher than in the UK Biobank.

The variant has been seen by NHS Clinical Genetics in breast and ovarian cancer families from Shetland.

Records of birth, marriage and death indicate genealogical linkage to a founder from Whalsay, one of the isles of Shetland, similar to our observations for the *BRCA1* founder variant from Westray, one of the isles of Orkney.

This variant in *BRCA2* causes a high lifetime risk of developing breast, ovarian and also, **male breast and prostate cancer.** Jim travelled to Whalsay on June 6th to give a talk to the community there about this finding.

Volunteer story

Christine has lived her whole life in Shetland. She is a volunteer in VIKING I.

As part of the Viking Genes return of results programme, Christine found out in 2023 that she was a carrier of the Whalsay BRCA2 variant, which can cause breast and ovarian cancer.

Christine told us:

"In October I went for a mammogram where they found out that I have breast cancer. I am so grateful you told me I have BRCA2, as my next mammogram would have been in another 2 years!!!! It might have been a different story!!!!"

To read more of Christine's powerful story, click on the link below.

Christine's story

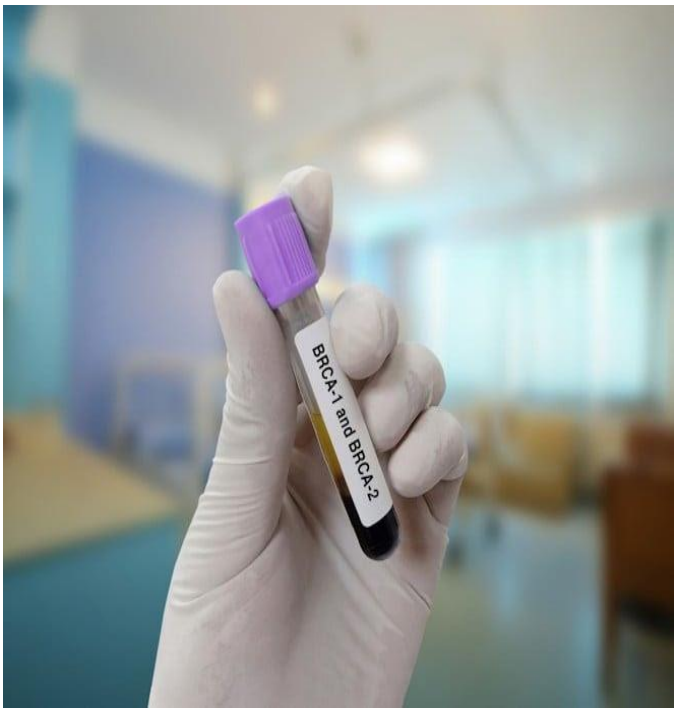
To enquire about eligibility for NHS testing, click on the link below.

The BRCA2 gene, Shetland and Whalsay - Frequently Asked Questions

We can also provide more information if you email **viking@ed.ac.uk**.

BRCA2 variant discovered in Shetland

NHS genetic screening in specific populations



Prof Jim Flett Wilson explains: "I would like to draw attention to the recent launch of a pioneering screening service in NHS England for people of Jewish ancestry to see if they carry harmful breast and ovarian cancer (BRCA) variants.

When populations are identified where these disease-causing variants have become relatively common, it makes sense to have a specific screening programme. There are strong parallels, in terms of distinct gene pools, between the Ashkenazi Jewish populations and the Scottish Island populations.

One example is that our recent discovery that just the **two** founder variants described in this newsletter account for over 90% of damaging BRCA variants in Orkney and Shetland. For comparison, **369** variants would need to be tested to account for the same proportion of cancer risk from BRCA variants in the general UK population. Thus any future screening programme for the Northern Isles should be very cost-effective, just as the Jewish screening programme is.

I believe that one of the most important things we can do in Viking Genes is to provide the scientific evidence which underlies opportunities for screening people of Orcadian, Shetlandic and Hebridean origins for each sufficiently common actionable variant that we find in our research. I am therefore very encouraged that the new scheme in the Jewish population is now operational in NHS England and hope similar screening will also be made available for Jewish populations in Scotland, as well as for Orcadians, Shetlanders and Hebrideans. That would bring equity of service delivery, which is missing at present."

This inspiring initiative is explained well in the website: Jewish BRCA

Viking Genes Launches Fundraising Campaign

We are delighted to announce the inaugural community fund-raising event of our new fundraising campaign.

We'd like to say in advance a big thank you to Anita Sparrow, who does amazing work in her community all year round and has been a tremendous help to us arranging our talk and community engagement in Whalsay too. Anita is going to organise a number of events locally to help raise money for the Viking Genes Fund. We are also pleased to be supported by Shoard, the local charity shop in Whalsay.

We've started our fundraising campaign to help continue the work of Viking Genes, which plays an important part in the health and wellbeing of the Scottish Island communities through genetic screening and analysis. Our work has uncovered high levels of several rare genetic variants in the community, and that knowledge directly led to many people coming forward for screening and being treated for cancers that they didn't know they had. We are very proud to have played a part in those individuals being able to continue to lead full lives with their families and loved ones.

We want to continue our work and to identify further groups of people at risk from genetic variants. We are striving to influence policy too, so that high risk groups on the Scottish Islands can get equitable access to potentially life-saving treatments. With your help we will certainly be able to do more and hopefully save more lives.

We will be looking for other partners across Orkney, Shetland and the Hebrides to help raise funds.

To visit the Viking Genes fund-raising page, click on the link below.

Support Us

We have the genetic data for Viking II and Viking III

Some important Viking Genes news!

We have received the genetic data for our Viking II (Orkney and Shetland) and Viking III (Hebrides) studies, started analysis and have just begun the process of sending out letters to Viking II and Viking III volunteers. Only those with 'actionable' genetic findings will hear from us, and it will take over a year to consider all variants and send all letters out.

New research means that findings could continue to be made well into the future. We will try to continue to return results for as long as possible but are reliant on new funding.

Which actionable results will we return?

We start by using a list of genes containing actionable variants that is compiled by the American College of Medical Genetics and Genomics, ACMG. This is updated annually and currently contains 81 genes.

Actionable variants in several of these genes increase the risk of heart diseases. Examples include *KCNH2,* predisposing to heart rhythm problems; *TTN*, increasing the risk of weakening of the heart muscle; and *LDLR*, causing inherited high cholesterol. Our analysis can also identify some hereditary bowel, breast and ovarian cancer predispositions, and rare metabolic disorders.

We do not return results on "carrier" status of gene alterations that can cause conditions such as cystic fibrosis. This is because they have no effect on the individual volunteer who has them, although could affect their children, only if both parents are carriers.

The actionable gene changes will always be agreed with NHS geneticists before we notify any Viking Genes volunteer. The NHS team is led by Prof Zosia Miedzybrodska, who has over 20 years experience in delivery of genetics services to the people of the Northern Isles and Western Isles.

The Viking Genes list differs slightly from the ACMG list, as NHS experts make the final decisions, and in future gene variants more specific to the isles may be identified.

You can learn more about our Return of Results Policy by clicking on the link here.

The new Queen of Denmark has cousins in Viking Genes!

Australian born Queen Mary of Denmark has Orcadian ancestry and 10 cousins in Viking Genes!

Mary (nee Donaldson) of Tasmania married the Crown Prince of Denmark in 2004 and they were crowned King Frederik X and Queen Mary in 2024.

Mary is the daughter of John Donaldson and Henrietta Horne, originally of Port Seton, East Lothian, Scotland. Henrietta's father was Archibald Horne b 1911, and his father was John TT Horne b 1886. John's mother was Mary Tait b 1848 in Orphir in Orkney, daughter of Thomas Tait 1805 and Hannah Leask 1811, both of Orphir.

We were very pleased to see that a social media account (probably) belonging to King Frederik X of Denmark started following us on Facebook!

We now have over 3.5k followers on Facebook. Thank you!

To find us on Facebook, click on the button below:

Follow us on Facebook!

You can also follow us on:
X
Instagram

Contact Us

Our research team is based at the University of Edinburgh, in the MRC Human Genetics Unit and the Usher Institute. If you ever have any questions, you can email us at viking@ed.ac.uk

Your Data Privacy

We want to make sure you're aware of how we protect your data when conducting our research. For more information about how we use your data and keep it safe, please see our Privacy Policy at **viking.ed.ac.uk/privacy-notice**, or let us know if you'd like to have a copy posted to you.

MRC Human Genetics Unit

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