Viking Genes Newsletter Autumn 2024

Viking Genes

Welcome to your autumn newsletter!

Happy autumn from the Viking Genes team!

As we say goodbye to the long days of summer, here at Viking Genes we also look back at everything we have achieved together, but have eyes firmly on the future.

In this edition, we have an update on our fund-raising drive, research using our volunteer data, a report from a sell-out talk on Shetland, another powerful volunteer story, and a Viking Genes website update.

Read on to find out more.

Viking Genes Study Update: Fundraising

We are delighted to announce that SHOARD, the famous charity shop on the isle of Whalsay, Shetland have donated a magnificent £10,000 to the Viking Genes Fund.

Shoard means "support" in Shetlandic and this generous donation will help to part pay for the first year of Ben Fletcher's PhD, which started in October. We look forward to updating you on Ben's work in the winter edition of newsletter.

Professor Jim Flett Wilson pictured with the Shoard committee in Whalsay in the summer.

The wonderful donations continue. Frank Miller and his band The Paves got in touch to tell us they raised a brilliant £442.17 at a recent gig at the Scalloway Boating Club. Thank you to Frank and his band! And the offers continue to come in. Christine Glaser and Alison Leith are having a fancy-dress Halloween party at the Legion in Lerwick on Friday 1st November to support us. If you are a Facebook user, details can be found here. And look out for an online auction this November that will be raising vital funds for Viking Genes. We will share details on our Facebook page here.

The goodwill shown towards Viking Genes and the support for our research from volunteers and the wider community has taken us aback with its strength. We need your support to continue our work, which plays an important part in the health and wellbeing of the Scottish Island communities through genetic screening and analysis**.** There is so much still to do!

Learn how you can help us by visiting the Viking Genes Support Us page here.

Researchers find 67 genetic variants across the UK that cause disease!

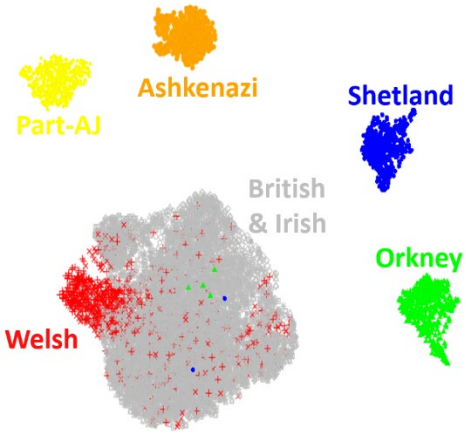
Viking Genes volunteer data has helped to identify harmful genetic variants enriched in different UK regions

ORCADES and Viking Health Study - Shetland volunteer data (part of Viking Genes) has helped researchers to identify 67 regionally enriched genetic variants across the UK that cause disease.

The findings highlight the importance of regional gene pools in the UK and call for thorough assessment of the regional frequencies of all rare disease variants. These findings should feed into strategies for future genetic screening for disease carrier status in these populations.

6 regionally enriched genetic variants found in Shetland

Using data from Viking Genes and the large UK Biobank study, researchers from the University of Edinburgh and the Regeneron Genetics Center analysed 18 geographic regions of the British Isles and Ireland, along with 2 Jewish groups.



Four populations were clearly distinct from all others in their genetic make-up: the part and full Ashkenazi Jews, Orcadians and Shetlanders. The Northern Isles were about as divergent from the other populations as the part Ashkenazi Jews.

Welsh, Irish and mainland Scottish groups were the next most differentiated. The ten regions across England weren't as genetically distinct, which might reflect the relative lack of geographic or cultural barriers to mixing such as sea channels, mountains or language differences between the English regions studied.

The researchers went on to discover 67 disease-causing genetic variants, which were at least five times more common in a particular region. Six of these were enriched in Shetland, including a variant that when two copies are present causes the fatal neurodegenerative condition Batten disease (also called neuronal ceroid lipofuscinosis-1), and a variant which is 138x more common in Shetland than elsewhere, and causes the muscle disorder congenital myotonia when present in both copies of the gene.

To read more on this important research, including a link to the paper, click here.

Jim delivers sell-out talk on Genomic Medicine in the Northern Isles and gives compelling interview on BBC Scotland

In September, Professor Jim Flett Wilson and Dr Shona Kerr delivered impactful talks at this year's Orkney International Science Festival. We've attended the festival almost every year, for more than 10 years, to share our work and interact with those attending. Read more about our long-standing support for this brilliant festival here.

Jim continued on to Shetland to deliver a memorable talk to a capacity audience at the Shetland Museum and Archives in Lerwick. He told the audience that genetic screening of people with Orkney

and Shetland ancestry is needed after his work has led to the discovery of eight further disease-causing variants that are much more common in the islands. These are in addition to those mentioned above that require both parents to be carriers, such as for Batten disease. The BRCA1 variant in Westray, Orkney and the BRCA2 one in Whalsay, Shetland are just the tip of the iceberg!

October saw Jim appear twice on BBC Scotland to promote the findings from our recent research into the 67 regionally enriched genetic variants across the UK that cause disease. You can watch and listen to the television and radio clips via the links below.

Click here to watch Jim's recent interview on BBC Scotland's 'The Seven' programme.

Click here to listen to Jim's recent radio interview on 'Good Evening Shetland'.

Volunteer story: Jasmine

Jasmine is a volunteer in VIKING II.

In 2013 Jasmine had a life-changing event caused by Long QT Syndrome, which is an inherited heart problem that affects how your heart beats. Jasmine later found out she is a carrier of a LQTS variant and is keen to stress that screening will help prevent early death by finding carriers before they become ill.

Jasmine said: *'Long QT is a genetic condition that can be managed. The work being done in this field is saving lives. Professor Wilson and his staff working with Viking Genes are carrying out such exciting and pioneering work, making amazing discoveries that will help prevent early death in families like mine throughout Shetland and further afield.'*

To read more of Jasmine's powerful story, including our LQTS research, click here.

Viking Genes website: News and Media hub

If you have recently visited the Viking Genes website you may have noticed a few changes. In the summer we had a wholesale review of the content and asked an important question: can you find what you are looking for? Well, we couldn't always say yes to this question, so we have updated the website and we hope the new changes are much more user friendly.

We also have a new page within the website that is dedicated to news and media.

Here, you can catch-up on our media coverage, latest news and forthcoming events, as well as see back issues of our newsletters. We have also created a press area that includes a press release archive and image collection. **Visit our News and Media Hub here.**

Viking Genes continues to grow on social media.

We now have over 3.8k followers on Facebook. Thank you!

To find us on Facebook, click here.

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.

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