Viking Genes Newsletter Winter 2025

Welcome to your winter newsletter!

Happy New Year from the Viking Genes team!

As we say goodbye to 2024, here at Viking Genes we look back at a year packed with impactful research, but the launch of our fundraising drive has set our eyes firmly on what we want to achieve in 2025.

In November, our incredible volunteers and supporters in Shetland raised over £20,000 for Viking Genes. The Leith lasses raised a magnificent £4,112.50 at the Lerwick Legion Halloween fundraiser. Co-organiser Christine Glaser featured heavily in our *BRCA2* coverage last summer. Then the Viking Genes Fundraising Auction - Shetland raised an incredible £15,787 during their online auction. You can learn more about the inspiration behind the auction in our powerful volunteer story later in the newsletter. The 2nd fundraising gig by the Shetland band the 'Paves' at the Lerwick Masonic Club raised a superb £259.48. They have now raised over £700 for the Viking Genes Fund and will be back at the Masonic Club on 15th February for another charity gig in aid of Viking Genes.

Professor Jim Flett Wilson said: *"It shows an extraordinary level of engagement with the community's own health and future health in Shetland."*

In December, Orkney Tweedy Bears raised a terrific £435 (rounded-up to £500) in their raffle to win Magnus the Bear and Thor the Viking.

The new year kicked-off in style as Sharon Deyell's annual swapshop in Aith (Shetland) raised an incredible £6,500 to be split between Viking Genes and Clan Cancer Support. Raffle prizes included a sparkly jacket donated by ITV's Lorraine Kelly, and Gibbie o' Taft bear donated by Burra Bears.

These vital funds will help support the work of PhD student Ben Fletcher who features in this edition's Researcher Spotlight. We can't thank all our fundraisers enough!

In this edition, we also have news of an important research project, a summary of our latest research paper, news of Jim at Westminster, and a brilliant podcast featuring Prince William’s motherline DNA!

Viking Genes Study Update: Haemochromatosis UK funding!

We are delighted to announce that the charity Haemochromatosis UK has awarded a “Furneau” Medical grant to Prof Jim Wilson. This small but important grant will allow Dr Shona Kerr to work with colleagues in Edinburgh and Dublin on a research project to investigate the frequency of genetic haemochromatosis within the Scottish island populations, using Viking Genes data, and also data from research volunteers across the rest of Britain and Ireland.

Genetic haemochromatosis (GH) is a recessive disorder, which means that the risk of iron overload is high if both copies of the gene contain a risk variant. This genetic predisposition accounts for 90% of those diagnosed with haemochromatosis. Someone with only one copy of a variant rather than two is a carrier. If only one copy is faulty, an individual will usually be unaffected. A carrier is able to pass on his or her copy of the gene to a son or daughter and when two carriers have children together, there is a one in four chance that each child will have two copies of the variant and thus be at heightened risk of haemochromatosis.

Haemochromatosis is sometimes described as the ***Celtic Curse,*** because many people with GH can identify Celtic family roots. The condition can affect people of all ethnicities, but it is a lot more prevalent in people from Scotland, Northern Ireland, the North-West of England and the Republic of Ireland.

The new project aims to provide scientific evidence of the priority target areas in which to begin implementation of the offer of population screening for the actionable risk genotype. There is considerable benefit in identifying the genetic risk for haemochromatosis, since the symptoms evolve over decades, and

the opportunity to intervene and prevent disease is both simple and effective, primarily through regular blood donation.

All volunteers in Viking Genes with an actionable genotype in the haemochromatosis gene have been sent their return of results letters.

In December, Professor Jim Flett Wilson was a guest speaker for Haemochromatosis UK's webinar entitled 'Developing a Genetic Haemochromatosis Atlas'. **You can watch Jim discuss his team's work, followed by a Q&A with Haemochromatosis UK members here**.

Learn more about Genetic Haemochomatosis by visiting the H-UK website here.

Jim at Westminster

November was a busy month for Professor Jim Flett Wilson. First, he headed to the USA to the American Society of Human Genetics (ASHG) conference in Denver, Colorado where he was a guest speaker. He explained to the audience how Viking Genes identified 'actionable' genetic variants in volunteers and implemented return of results. Jim then met with Neil McClements of Haemochromatosis UK and MPs Alistair Carmichael and Torcuil Crichton, respectively, at Parliament in Westminster to talk about his work and make the case for population screening.

Jim appeared on BBC Radio Shetland's 'Heartbeat' programme where he told Ross Cowper-Fraser about our research and what's next for Viking Genes. It also featured a powerful interview with Viking Genes volunteer, Christine Glaser. Just click on link below. This will take you to the University of Edinburgh's Media Hopper page for Viking Genes.

Shetland's Heartbeat - BBC Radio Shetland - Viking Genes - 30th Oct, 2024

November also saw the release of a terrific podcast. Jim spoke to Patrick Short of Sano Genetics about his work with the Scottish island communities, sequencing Prince William's motherline DNA! And his IFTA-winning work with the Irish Traveller community. It's a great listen!

Listen via Spotify here.

Watch via YouTube here.

Researcher spotlight: Introducing Ben

In the Autumn edition of the newsletter, we told you that we were delighted to have received £10,000 from the SHOARD charity shop on the isle of Whalsay, Shetland, and that this generous donation will help to part pay for the first year of Ben Fletcher's PhD.

The subsequent fundraising by our volunteers and supporters has been staggering, so we are now very pleased that we can finally introduce you to Ben.

What's your research focus?

My research is focused on identifying gene variants that can cause disease in isolated populations. Currently, I am continuing a project that was started before I joined the Wilson Group, where we are cataloguing all of the gene variants in the Viking Genes cohort that have previously been reported to cause

disease in a public database called ClinVar. Once this is finished, I will need to expand the analysis in several ways, such as by using bioinformatics to identify variants that seem to cause disease even though they haven't yet been reported anywhere else. The ultimate goal of this work is to provide evidence for genetic screening panels tailored to people with ancestry from Shetland, Orkney, or the Hebrides, which will focus on the gene variants most likely to cause disease in each of those populations. This is important because, while most disease-causing variants are rare, some will be significantly more common in specific populations.

What made you interested in pursuing a career in health research?

Before moving to Edinburgh, I spent some time in research groups that studied different forms of cancer—some of them heritable. My research there primarily involved developing cell models to understand if a gene variant seen in a patient might be causing their cancer, and, if it was, whether this particular variant could tell us anything about which treatments might be most effective for them. I really enjoyed this work because it allowed me to shed light on the biology of cancer cells while also being directly connected to patient outcomes. For my PhD (and as my career progresses afterward), I knew I wanted to continue doing work that was both biologically fascinating and directly impactful for members of the public who may be at risk of disease. Working with Viking Genes has made this possible!

How has Viking Genes volunteer data supported your research?

None of my current work would be possible without Viking Genes volunteer data. This is such a useful and unique resource—because of the high levels of participation, we will be able to get a detailed picture of the landscape of disease-causing variants affecting these populations in a way that would be hard to achieve anywhere else.

I've also been incredibly impressed by, and grateful for, the enthusiasm and involvement of Viking Genes volunteers. In addition to working with Viking Genes volunteer data, the stipend that enables me to do this work for the next 3+ years is largely funded by donations from the Northern and Western Isles. I'd especially like to thank the Shoard Charity Shop, as well as everyone who contributed to a recent Facebook fundraising auction—each of these efforts raised over £10,000, enabling us to continue the work we do.

Tell us about the most interesting Viking Genes research you've worked on.

What I'm working on right now is really interesting! In addition, this past summer, as part of an MSc programme I was completing, I did another small project with Professor Wilson for Viking Genes. This involved trying to find the gene variant causing a heritable muscle condition called neuromyotonia affecting a family from Orkney.

Whereas my current work is population-focused, this project took a family-based approach. Groups of two, three, or even ten close family members share some segments of their genome exactly in common with one another because they have all inherited that part from the same recent ancestor. As you add more family members, fewer and shorter segments of the overall genome will be shared by all of them together. For this project, I essentially compared the genomes of all the family members who appeared to have inherited the condition, as the genetic cause would have to be in one of the few genes shared by all of them.

I was able to identify one gene that might be responsible, and follow-up work by another collaborating group at the University of Edinburgh is currently underway. If that doesn't provide a clear answer, there are additional analyses we can perform to hopefully solve the mystery. This work was only possible because of the incredibly detailed information provided by the family and their determination to recruit family members to Viking Genes.

Volunteer story

My name is Laura Wishart. I am 36 years old and I am from Aith. I have Wilson's disease which is a genetic disorder that prevents the body removing excess copper which causes a build-up of copper in several organs like the brain, liver and eyes.

I began showing symptoms in 2015 but as Wilson's disease is known to be very rare this wasn't tested for until 4 years later. My symptoms included a severe tremor in all my limbs and neck, dystonia (muscle rigidity and spasms) in wrists, ankles, shoulder and tongue, and psychosis. I was born with the condition, as my parents, unbeknown to them, were both carriers of Wilson's Disease.

Through the Viking Genes health study that was in the news recently, it has been found that Shetland has a higher proportion of Wilson Disease carriers than the general population. This being the case, I want to raise awareness of this condition, which is fatal if not treated.

Dr Jim Wilson, who conducted the Viking Genes health study, believes that the Shetland population should be screened for the 10 rare conditions that has been found to be more prevalent in Shetland, one of which

is Wilson's disease. To do this, a screening roll out across Shetland would be required, which needs considerable funding. Myself along with others began this fundraising effort by running an online auction on Facebook in November that raised £15,787 for Viking Genes. We were bowled over. We were aiming for 100 lots but the donations kept coming in. The community just rallied together. They know the impact this has on themselves and future generations.

To read more of Laura's powerful story, click on the link here.

Viking Genes continues to grow on social media.

We now have over 3.9k followers on Facebook. Thank you!

To find us on Facebook, click on the button here.

You can also follow us on:

X

Instagram

Contact Us

Our research team is based at the University of Edinburgh, in 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 www.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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