Welcome to your Autumn newsletter!

Happy September from the Viking Genes team!

“Two or three times a year, we publish our Viking Genes newsletter. It is sent by email to almost 9,000 of our 10,000 volunteers. It is a key communication tool for us to inform our volunteers of the latest study updates. However, we thought other researchers, public health stakeholders, and science communicators might be interested in reading it.

As Autumn approaches, we think about the change of season, and here at Viking Genes we also reflect on our changes. Our focus is no longer recruitment and chasing samples back to the lab; we are now busy validating gene variants and implementing the long process of returning actionable genetic results to our volunteers.”

Professor Jim Flett Wilson, Viking Genes, Chief Investigator, University of Edinburgh

In this edition, we have an important study update regarding new funding, a long-awaited announcement, an update on what we've been doing in the lab, and an exciting interview with a researcher using your data. We also have a reminder to ORCADES and Viking Health Study - Shetland volunteers regarding their return of results (RoR) consent form. Finally, we have news of a Viking Genes social media post that reached three quarters of million Facebook users.

Read on to find out more.

Study Update: New funding awarded!

We are delighted to announce the year-long award from the Wellcome Trust Institutional Translational Partnership Award (iTPA) Impact Fund to support genomic medicine in the Northern and Western Isles of Scotland.

Thank you to Jeff Wright and his team for their favourable assessment of our application. This will help us to continue our important work until at least July 2024. The iTPA award also includes invaluable support to the Viking Genes team and pathway identification to develop the project further.

Viking Genes samples shipped to Regeneron

The good news continues. Viking II and Viking III study volunteers will also be delighted to hear that we have shipped their DNA samples to the Regeneron Genetics Centre for exome sequencing.

The image of the Regeneron plates of DNA ready to go is a wonderful sight for the Viking Genes team. There are 66 in total and this represents an important milestone for the study.

The exome is the part of our DNA (genome) that codes for proteins, the workhorses of the cell. This is about 2% of all the DNA sequence we have, but it’s the most important part. Exomes are the most studied and understood part of the genome, where many genetic variants influencing a person’s chance of getting a condition are found. Whole exome sequencing tells researchers which variants are found within each person’s exome.

Understanding exomes is very useful for the research we do in VIKING Genes. It makes it possible for us to study a wide variety of variants. This includes rare variants that only a few people carry, some of which will never have been seen before. We'll use the information to develop our understanding of common complex diseases, such as cancer, heart disease, stroke and eye disease. Rare variants found in exomes also play an important role in some rare genetic conditions. We hope also to analyse some of these, using

the data and samples you have provided. You can learn more about Regeneron and exome sequencing by clicking on the link here.

Return of Results - Actionable variant validation

During our research, we sometimes find genes with rare changes or variants that aren't normally found in healthy individuals. These variants may cause an increased risk of certain genetic diseases, such as inherited high cholesterol or inherited heart conditions. When they are discovered, and are agreed with the NHS as being preventable or improved by NHS treatment, we call this an 'actionable' genetic finding.

Pictured above right is our lab scientist, Camilla Drake, during the process of validating actionable variants.

We want to be as careful as we can when identifying these actionable findings in volunteers and so we apply a 'belt and braces' approach. You have already read about exome sequencing, which is how these actionable variants are discovered, but we then go on to validate them using a different technology.

This is called Sanger sequencing and is the original method of reading DNA invented by Fred Sanger in 1977, for which he won the Nobel Prize. It is still the gold standard for certain tests. The actionable variants that are seen in exome sequencing and confirmed by Sanger sequencing are returned to the volunteers who consented to return of results.

ORCADES and Viking I RoR reminder

In the last newsletter, we reminded you that we received approval for an important amendment to our ethics permissions. This meant we could now ask our Orkney Complex Disease Study (ORCADES) and Viking Health Study – Shetland (Viking I) volunteers for consent to receive 'actionable' genetic results, if they are discovered. This gives all our volunteers in the family of Viking Genes studies the same opportunity to chose to opt-in or opt-out of receiving 'actionable' genetic results.

Earlier in the year, we were busy sending out emails and letters, asking for the Return of Results (RoR) consent. The emails and letters included a short form to complete.

If you follow us on our social media channels, you will have seen that we would still like to receive all the forms back, whether or not you decide to consent to the return of results. Most importantly, if you still have questions, such as the question below, we are here to talk to you.

'I've already reached a good age. Is it worth me consenting to having 'actionable' genetic results returned to me?'

It certainly is worth consenting. The result could still be of benefit to your family. Some gene 'effects' can "skip a generation".

So please everyone take the time to complete the form.

If you have lost or not received the email or letter we sent to you, get in touch and we can resend the link or post a copy to your current address. We can also provide more information if you have any questions. Just send us an email at viking@ed.ac.uk or call us on **0131 651 8557.**

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

One other thing, if you have recently changed address or have a new email, this applies to Viking II and Viking III volunteers too, simply update us by clicking on the link below and completing our web form here. You can also send us your updated details by email at viking@ed.ac.uk or call us on 0131 651 8557.

Researcher Spotlight - Linda Repetto

What's your research focus?

My current research focus is on maternal health and breastfeeding. My previous research centered on psychiatric and neurological disorders, as well as mental health and behaviour.

This involved studying various mental health conditions and neurological disorders to gain valuable insights. These experiences now inform my work in maternal health and breastfeeding, allowing me to contribute to this essential field with a well-rounded perspective.

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

My curiosity about the human body and its functions led me to pursue a career in health research. Throughout my academic journey, I have focused on deepening my knowledge of human physiology and health. I am passionate about exploring medical conditions and finding ways to enhance healthcare practices, such as investigating the effectiveness and precision of prescription medications through the study of genetics and proteins. By combining my curiosity, dedication, and passion, I hope to positively impact people's lives and contribute to advancements in the field of healthcare.

How has Viking Genes volunteer data supported your research?

Viking Genes volunteer data has been crucial for my research. The enthusiastic participation of the Scottish islands population provided the opportunity to build a unique and extensive dataset. By utilizing both physical and genetic information, I was able to investigate different aspects of neurological health and identify potential genetic links to mental health conditions, all while utilizing data from blood samples The support of the participants has been invaluable in advancing our understanding of human genetics and health.

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

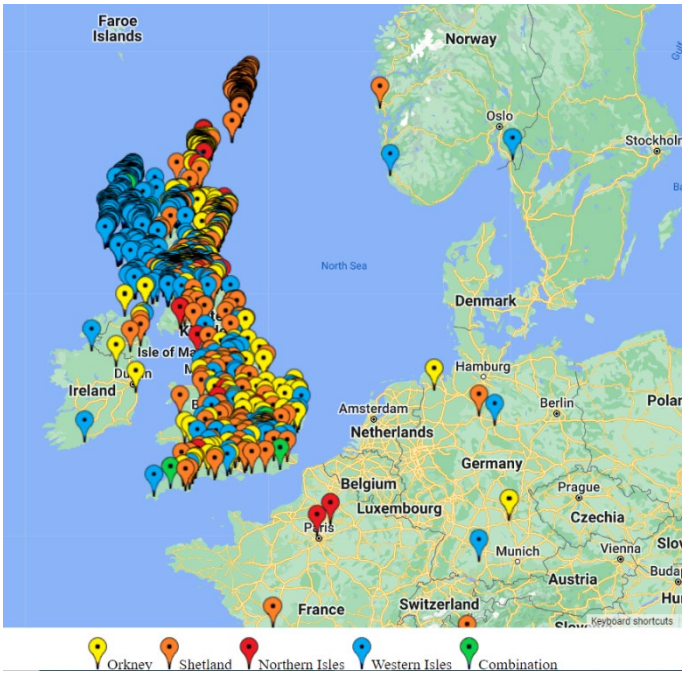
One of the most interesting research projects I worked on within the scope of Viking Genes was one that focussed on the proteomic profiles of mental health outcomes and behaviours. The main goal of this study was to investigate how specific proteins in the blood influence both mental well-being and overall health. Interestingly, we discovered that certain blood proteins appear to have a positive effect in protecting both our mental and physical health. By comprehending the impact of these proteins on human biology, we can potentially develop more effective approaches to enhance well-being and prevent particular health conditions.

Social Media: Viking Genes goes viral!

Our social media channels have played a crucial role in the way we communicate with our volunteers and deliver science for the people. It was also a vital tool in the recruitment of 6,000 online volunteers.

Facebook has always been our most popular social media channel and we are very proud to have such loyal followers. However, we are still keen to tell the rest of the world we exist. In August, we did exactly that!

Our Viking Genes diaspora map, which plots where our volunteers live across the continent of Europe v where their grandparents where born, reached a staggering 0.75 million Facebook accounts. Post engagement exceeded our expectations with over 35,000 people engaged and led to wonderful discussions about Norse DNA.



Follow us on our social media channels:

Facebook
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Future News: MS and Following the Fletts

Jim will be back in Orkney this month to give a talk on genetic genealogy at the Orkney International Science Festival. A full report will follow in the next edition of the Viking Genes newsletter. We also see the return of our 'How You're Helping Research' item and this time we highlight research into the positive and negative role of proteins in autoimmune diseases such as Multiple Sclerosis (MS).

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 or call us on **0131 651 8557**

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.ed.ac.uk/viking/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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