

# 'The disease would have killed me were it not for Viking Genes study'

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"It would have spread and ended up killing me. I have no doubt of that," said Mr Poleson from his home in Whalsay, surrounded by portraits of his family and fishing boats over the years.

"Would have taken years probably, but that's what would have happened if I'd not seen about it and gotten the tests done."

Instead, Mr Poleson went for an MRI shortly after receiving his results letter. Scans, biopsies and the full removal of his prostate later, he has returned to his normal life fishing aboard the *Antarctic* and tending a croft with his wife, Melanie.

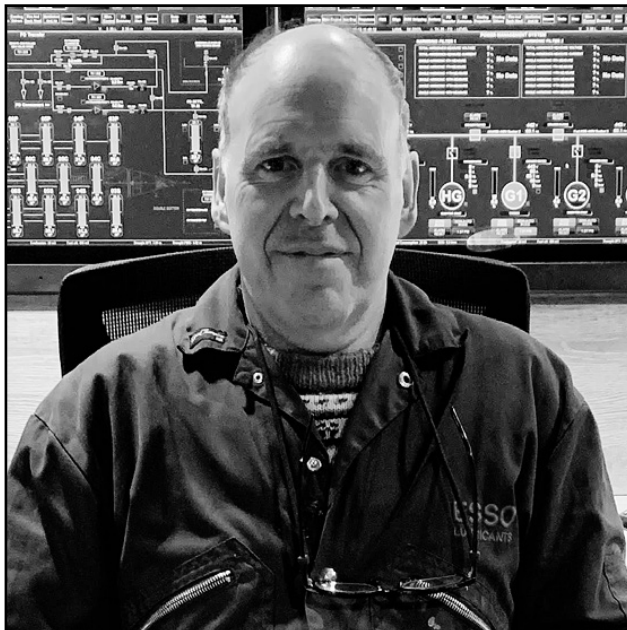
When the Viking Genes project, run out of Edinburgh University, first started soliciting volunteers to build a genetic database in 2013, it was bound by ethical guardrails and boilerplate consent forms to keep the results anonymised.

That research has already found that Shetlanders are more predisposed to carry genetic variants which put them at risk of contracting various cancers, and their children of being born with fatal disorders like Batten disease.

Then two years ago, following a pioneering US model for the ethical return of results, researchers began asking the original cohort of Viking volunteers if they wanted to know what their samples found.

"It was a moral imperative," said Jim Wilson, a professor of human genetics and the project's chief investigator.

"We always believe that the work that we do will be meaningful, but I honestly did not



John Arthur Poleson says the study saved his life.

expect to be able to have such an impact directly on our volunteers when I started out."

Mr Poleson was not the only volunteer whose results have already helped them catch a life-threatening disease before it was too late.

Jacqueline Leask, 33, was working part-time for NorthLink and the Viking Genes project when she volunteered for a test.

She was grateful enough after a couple of years when that role helped her land a full-time job at an eye clinic.

"Then one day I'd just come home from work and checking through the post I saw the letterhead," she said. "It was completely out of the blue."

Mrs Leask learnt she carries a variation in her TTN gene, which increases your chances of a disease which thins and weakens the muscles of your heart until it fails.

Like Mr Poleson, Mrs Leask went for follow-up checks, which caught her condition, dilated cardiomyopathy, while it was still only moderate. Since then she has taken pills to protect her heart and will have an MRI scan today to determine her future treatment.

"I wouldn't have picked up on it until something happened," she said. "I didn't feel ill or anything. There was nothing to make me think I needed to see a doctor."

"You do kind of wonder sometimes," she added. "It could have been very different."



Jacqueline Leask with her daughter Olla.

**I wouldn't have picked up on it until something happened. I didn't feel ill or anything.**

Jacqueline Leask

Mrs Leask's three year-old daughter, Olla, will also have tests when she is old enough.

"She'll have an even greater head start than I had," Mrs Leask said. "I am so thankful to the study."

Having found a swathe of dangerous genetic variants which are unusually common in Shetland, Prof Wilson hopes the stories of volunteers like Mr Poleson and Mrs Leask are just the start.

"This paper is a real milestone," he said. "The culmination of over 20 years of work – and at the same time a strong building block of evidence towards the establishment of population-wide screening for the people of Shetland."

Prof Wilson now has a goal – testing 5,000 Shetlanders for 50 genetic variants which are both dangerous and actionable, giving them the knowledge to get tested, or make informed decisions about their children.

This personalised genetic "dashboard" would take three or four years to run, he said, and cost roughly a million pounds.

Nor would it be entirely unique. Jnetics was a platform established in 2010 to screen Jewish communities also at higher risk of certain variants for their genetic makeup. Where the money will come from for Shetland remains unclear, however, after an initial appeal to the community fund set up by Viking Energy appeared to fall on deaf ears last month.

"I very much hope that we will be able to find the support to continue this work to its logical conclusion and translate it into impact for the population of Shetland as a whole," said Prof Wilson.

Meanwhile, for Mr Poleson – back at the fishing after having his prostate out just last month – the only remaining question is whether he is actually descended from Vikings after all.

"I never really found out," he said. "To be honest, I think I'm not too interested in that anymore. There's Viking blood here, some way."

# Union leader says sick day difference is 'vast'

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The former worker added: "So the guys that don't want it to happen, the guys that have concerns about it, are being swallowed up."

The anonymous source said staff have been approaching them with copies of their contracts. And they "can't make head or tail" of what is in them.

Every service in the fleet is working on different contracts now, according to the former ferry crew member.

"Now that tells you something," they said.

Unite the Union representative Isabella Sutherland told this newspaper that extensive work patterns were against what Cosla had been championing.

"The demand is that they actually follow the protocol that Cosla has signed up for," Ms Sutherland said.

Ms Sutherland was shown the figures received by this newspaper, and described the increase in both sick days and mental health sick days as "vast".

This was believed to be down to increase in pressure on the staff, being asked to work so much throughout the week.

"This is all against Cosla regulations," she said.

If all councils across Scotland put in place the 35-hour week, it would promote "transparency" and a healthier "work-life balance".

As the SIC inter-island ferries have been understaffed, with vacancies left to be filled, it has meant staff available at the time were being told to agree to overtime.

Ms Sutherland added: "If they increase hours at sites with ferries, then they're not complying with the Cosla."

SIC environment and transport chairwoman Moraig Lyall was asked to comment on the figures revealed to *The Shetland Times* but she said it could be part of a bigger picture.

"I think probably what you would find is that you'll see that there's a significant rise across large areas of the council, and I'm just saying that as a gut

feeling from figures that we've seen in other reports," Mrs Lyall said.

"But I think, obviously, the amount of illness from mental health issues is a national issue. It's not something that's particularly specific to our internal ferry network."

She added that if one or two people were off on long-term sickness, it would have a "massive impact" on the figures.

The former member of staff called that a "bullshit answer". It sounded like it was "dictated to her by corporate services".

Giving a specific example of what pressure crewmates were under, the former staff member highlighted a story of a mate who was recruited from south.

The person was given three days' training and expected to become a Master of the vessel.

"The ferry they were going to slip away was on the Fetlar route in the middle of winter, when the vacancies were both tight and everything else that happened here, including cement mixers turning over on the ferry, and expecting that after three days of training, he would be able to be the Master," they said.

This also, in turn, had an effect on the people who were asked to sign-off and give their approval.

Masters asked to give the green light for this mate's training and promotion would refuse because the mate would be "incapable of doing the job" with so little experience or training.

SIC executive manager for ferry operations Andrew Inkster said the council takes the health of its staff "seriously".

He said there were policies in place to support staff during and after a period of absence for ill-health.

"It's important to say that people may need to take leave for their mental health for a variety of reasons, not all of which may be work-related," Mr Inkster said.

"Delivery of ferry services is becoming ever more challenging and our crews do a great job, sometimes in the face of significant public scrutiny, and we'll continue to do our best to support them."



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