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Screening for the 'Celtic curse' could be game changer, says MP

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The Western Isles could take a major leap forward by using gene-based preventative medicine to help treat people at risk of developing serious diseases such as liver cancer, according to an MP who is backing calls for a pilot screening programme.

Torcuil Crichton said the archipelago could find itself "20 years ahead of the NHS" if plans to screen for an inherited genetic disorder are given the green light. He expressed hope that such a project could be financed by renewables firms for the wider benefit of the community.

The Labour MP for Na h-Eileanan an Iar was diagnosed with haemochromatosis in 2008, a hereditary disease which causes a dangerous build-up of iron in the body and, if left untreated, can lead to liver cancer, cirrhosis, arthritis, and other conditions.

A research project, led by Professor Jim Flett Wilson of the University of Edinburgh, and funded by the charity Haemochromatosis UK, has provided scientific evidence of the priority target areas where the need for population screening is highest.

Outer Hebrideans are among those most at risk of developing haemochromatosis, with one one in 62 people estimated to be carrying the major risk variant, compared to just one in 212 in southern England.

The researchers said mainland Scots, particularly in Glasgow and south-west Scotland, were also at increased risk of the condition, with one in 117 estimated to carry the variant.

The risk is higher in males than females, due at least in part to monthly blood loss in pre-menopausal women. Men with haemochromatosis are eight times more likely to develop liver cancer.

Prof Wilson "strongly believes" there should be community screening for the genetic variants, with the research identifying "priority areas" where such a programme would be of the most benefit.

Now, he and Mr Crichton will be staging a series of information events in Stornoway and rural Lewis later this week to raise awareness of the findings, and the campaign for a pilot screening initiative.

"When I was diagnosed with this condition in 2008, I was a journalist, and I wrote about it – dare I say it, it was probably one of the most effective pieces of journalism I ever produced," Mr Crichton said. "I would be approached by people letting me know their children were being treated as a result.

"Because it's mostly asymptomatic, you don't really know you've got it in later life, so the campaign for a screening problem is key, and the events are a way of letting people know about it."

Mr Crichton, whose brother was also diagnosed in his mid-30s, said that at the time he was tested, he felt arthritic symptoms in his hands, which he attributed to repetitive strain injury as a result of his work a political journalist, but since undergoing treatment via venesection – a regular procedure that removes a specific amount of blood to treat iron overload – the pain "went away".

Even more importantly, he said, being treated mitigated the higher risk he faced of developing even more serious conditions, such as liver disease.

"What we're at risk of is all of these what you would call west of Scotland diseases, such as kidney disease, liver failure, and heart disease," he explained. "But preventing that would put us 20 years ahead of the NHS in terms of what we're moving towards in terms of gene-based preventative medicine. If we were to carry out a pilot we would find out how well it works."

The UK National Screening Committee (NSC), which advises ministers and the NHS does not recommend screening for haemochromatosis.

Based on its most recent review of the condition – a disorder sometimes known as the 'Celtic curse' – the committee said that although a faulty HFE gene is known to cause iron to build up, this does not happen to every person with the faulty gene.

The review in March 2021 also concluded that screening would identify people who may never experience symptoms, with limited evidence on whether treatment is more effective in individuals without symptoms compared with those who have symptoms. It added that there is no evidence that a screening programme is the best way of helping people with the condition.

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However, Mr Crichton said that the evidence compiled by Prof Wilson and his colleagues meant that there was now a case to look at the issue again.

"The NSC is open to new approaches, so with Jim's evidence we're going to ask for a pilot project in the Western Isles," he said. "We're building up scientific evidence, public evidence, and feedback from engagement with the community.

"We haven't costed the screening yet, but Prof Wilson has access to gene data sampling through his own work, and we both agree we shouldn't just be screening for haemochromatosis – we should offer full DNA testing across the islands on a voluntary basis, which could find out if people are carrying rare cancer genes, or are more at risk of heart disease or diabetes."

He added: "We think it would save money, but of course, it would also cost money at the start in what are straitened times. We've spoken informally to people about it, and it's a great opportunity for commercial windfarm operators and the communities who are taking a share in renewable projects; some of that money could be used not just to help them save bills, but to fundamentally change their life chances and those of their children."

Mr Crichton and Prof Wilson be holding information events this Thursday at Urras Oighreachd Ghabhsainn Business Centre in South Galson from 3 pm to 4.30 pm, and in Stornoway Town Hall from 7.30pm to 9pm. An event will also take place between 10am and 11.30am on Friday at Kinloch Historical Society Community Hub in Balallan.