

FAQs about breast and ovarian cancer and the Westray BRCA1 Gene

- What does the latest study mean for people with Westray ancestry?

A study has found that 1 in 100 people (1%) who have grandparents from Orkney have an alteration in a gene which gives women a higher chance of developing breast and ovarian cancer. Most of these people have one or more grandparents who come from Westray.

Over many years, the Genetics clinic team identified the same specific single variant in the BRCA1 gene repeatedly in women from Orkney with breast and/or ovarian cancer. Prof Zosia Miedzybrodzka from the NHS Orkney Genetic clinic worked with Prof Jim Wilson's ORCADES and VIKING studies to see how common the gene is and where it came from. They found that almost all of the people with the gene alteration share historic Westray ancestors.

- How does BRCA1 link to cancer?

Most breast and ovarian cancers are caused by chance damage in a cell of the breast or ovary. However, some women inherit an alteration in a gene. This increases the chances that breast and ovarian cancer will develop. One of the commonest of these cancer genes is BRCA1. Around one in 1000 women across the UK have an alteration in a BRCA1 gene that gives them a high chance of developing breast cancer and ovarian cancer in their lifetime.

- How are people with BRCA1 looked after?

Around half of the women with the Westray alteration in the BRCA1 gene will develop breast and/or ovarian cancer at some time in their lives. Surgery can reduce the risk of breast and ovarian cancer developing. Annual breast screening using MRI from age 30 can help breast cancer to be caught early when it may be more treatable. These options, along with lifestyle advice, can all improve the health of women with the gene alteration.

Men with the BRCA1 gene alteration do not have a significantly higher chance of getting cancer, but they can pass the gene alteration onto their children.

If someone has an alteration in the BRCA1 gene, the chance of it being passed to each of their children is 50:50 or 1 in 2. It can be passed on from men and from women.

- Who can be tested for the gene right now?

This test is currently available (1) to people with Westray born grandparents who live on Westray, (2) to those who know that someone directly related to them has the gene alteration and (3) to those who have a close and significant history of ovarian or breast cancer in their family.

- Why isn't everyone being offered a test at this stage?

Further work is being done with the Westray community to explore the latest findings. NHS Scotland is looking into whether to make the test available more widely.

- I took part in the ORCADES and want to know if the study found I have the BRCA1 gene alteration. How can I find out?

You can get in touch with Viking Genes at viking@ed.ac.uk for more information.

- I live in Westray and have a Westray born grandparent, how do I get a test?

There are saliva test kits available to collect from the Westray GP practice and the Westray Development Trust office. Read the enclosed information carefully, and more help and advice is available if you need it to be sure you want the test. You may find the videos we have made about what to think about and how to do the test useful. Completed test kits should be dropped off at the GP practice who will send them onto the Aberdeen lab.

- Who can I contact if I have any concerns or would like more information?

The NHS Grampian Genetic clinic is running a helpline for queries about the BRCA1 gene in Westray. Please telephone 01224 553940 or email gram.orkBRCAgene@nhs.scot with your questions. Please do not phone your GP practice about this.

More information on BRCA1 and breast and ovarian cancer in families is available at <https://www.nhs.uk/conditions/predictive-genetic-tests-cancer/> and <https://www.macmillan.org.uk/cancer-information-and-support/worried-about-cancer/causes-and-risk-factors/brca1-and-cancer-risks-for-women>

Cancer support and advice is available from CLAN:
<https://www.clancancersupport.org/locations/northern-isles/orkney/>

Information about cancer symptoms and how to reduce your chances of getting cancer is available from the NHS Inform website. People worried that they might have cancer should read the advice on NHS Inform and consult their GP.