

Breast Screening for women with NF1



Why is Breast Screening Important?

Women with Neurofibromatosis type 1 (NF1) have a higher risk of getting breast cancer at a younger age, than someone without NF1. In Australia, breast cancer is the most common cancer affecting women, with 1 in 7 women in NSW at risk of developing breast cancer in their lifetime.

Finding a breast cancer early increases treatment options and improves outcomes. For that reason, national standards recommend that women with NF1 take part in yearly breast screening from the age of 30¹.

After age 50, the risk of breast cancer in women with NF1 is not that much different compared to women in the general population. A mammogram every 2 years is recommended. Your doctor may also make suggestions that are specific to you.

What does breast screening involve?

Screening tests might include: an MRI, a mammogram, and an ultrasound.



Breast MRI



Mammogram

If any lumps are found, further tests may be needed. Having further testing ***does NOT mean you have cancer.*** Your doctor can let you know what to expect.

Why are there Multiple Tests?

Women 30-39 years of age may have quite ***dense breasts***. This can make it harder to look at breasts using a mammogram. An MRI is better for picking up breast

lumps in these women as it takes a much sharper picture than a mammogram.

NF1 is a genetic condition which can cause lumps in the body called neurofibromas. These lumps are not cancerous.

Each test gives doctors information about the inside of the breast. By having more than one test, you and your doctor can make the best decision about your breast health.

What Happens After Screening?

Results are given at a follow up Breast Clinic appointment. If no other tests are required, you will be asked to come back the following year to complete screening again.

Where to go for Breast Screening?

The Clinical Genetics team at the Royal North Shore Hospital (RNSH) is currently running a clinical research study looking at breast screening for women with NF1 aged 30 – 50 years.

This program is currently available to patients who attend the RNSH NF1 Clinic. Women with NF1 from outside the area may be eligible, but enrolment is currently limited.

You can also speak to your GP, Breast Specialist or local familial cancer service about where you can access breast screening in your local area.

Please keep in mind that a referral from a non-GP specialist is required to be eligible for an MRI through Medicare. Other services may also be offered through Medicare but best to check with your doctor.

How to Contact Us:

If you would like further information, please contact the Clinical Genetics Team at RNSH on (02) 9463 1727. For more information on breast screening please see our website

<https://www.nslhd.health.nsw.gov.au/Services/ClinicalGenetics/BCS>

¹ <https://www.eviq.org.au/cancer-genetics/adult/risk-management/752-nf1-neurofibromatosis-type-1-risk-manageme#lifetime-risk-of-cancer>