UNDERSTANDING THE RISK OF BREAST CANCER IN NF1

Tumour Foundation of BC

INTRODUCTION

Women with NF1 have an increased risk of developing breast cancer. Early and regular screening is critical to ensure any potential cancer is detected at a manageable stage.

WHAT IS NF1?

Neurofibromatosis Type 1 (NF1) is a genetic condition that occurs in about 1 in every 2,500 births. Often diagnosed in childhood, it typically presents with hallmark signs like café-au-lait spots on the skin and benign nerve tumours called neurofibromas.

While these symptoms can vary widely, NF1 isn't just a childhood condition—it's a lifelong journey. As individuals with NF1 grow older, they face additional health risks, including an increased likelihood of certain cancers. For women with NF1, this includes a significantly higher risk of breast cancer compared to the general population.

BREAST CANCER

HOW HIGH IS THE RISK?

Women with NF1 have a 5 times higher chance of developing breast cancer before turning 50. The overall risk for women with NF1 of developing breast cancer after the age of 50 remains significantly elevated at 3.5 times higher than women without NF1.

WHAT MAKES NF1-RELATED BREAST CANCER DIFFERENT?

Breast cancers in women with NF1 often have a less favorable prognosis. This is partly because these cancers are more likely to be hormone receptor-negative, meaning they don't respond to hormonal therapies that could otherwise be effective.

SCREENING TIMELINE OVERVIEW

It is recommended that women with NF1 have mammograms and breast cancer screenings by the age of 30 – **ten years earlier than the general population**. Including breast MRIs in routine screening can help detect cancers that mammograms may miss—particularly in younger women with dense breast tissue. If a family member had breast cancer before age 40, women with NF1 should consider starting mammograms 10 years before the youngest age of diagnosis in the family.

Age Range	Recommended Screening	Frequency
Under 30	Self Examinations	Monthly
Under 30	Clinical breast exams	Annually
30-50	Mammogram + Breast MRI	Annually
Over 50	Mammogram	Annually or Bi-yearly

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DETECTING EARLY SYMPTOMS

Early detection can save lives, so understanding the warning signs of breast cancer is crucial. Have your healthcare provider demonstrate proper technique for a self-exam. Pay attention to any changes, no matter how small, and seek medical advice when something seems unusual.

If you notice any of the symptoms below or feel uncertain about something during your self-exam, don't hesitate to consult your healthcare provider.

- Lumps or Thickened Areas in the Breast
- Changes in Breast Shape or Size
- Skin Changes: dimpling, puckering, scaling, or rash/redness.
- Nipple Changes: inversion (pulling inward) or discharge from the nipple
- Persistent Pain or Discomfort
- Swelling or Lump in the Armpit

If your family has a history of breast cancer, genetic testing for mutations such as BRCA1 and BRCA2 may provide additional insight into your risk.

ADVOCATING FOR EARLY SCREENING

Some healthcare professionals may not be aware of the increased risk of breast cancer for women with NF1. Here are some tips to advocate for proper care:

- **Share your NF1 diagnosis:** explain how NF1 increases your risk of breast cancer to help providers understand why early screening is necessary.
- **Leverage NF1 clinical guidelines:** bring research (like this brochure) to doctors' appointments to highlight your increased risk for breast cancer.
- **Request a referral to a High-Risk Clinic:** these clinics can provide specialized care, including regular screenings and genetic counselling.

As a woman with NF1, it's important to proactively manage your risk of breast cancer. Early detection and prevention, healthy lifestyle choices, and having a supportive medical team are key to maintaining your health. The increased risk of breast cancer can feel overwhelming, but you don't need to tackle it alone. Seek support from friends, family, or a counselor when needed.

ADDITIONAL SUPPORT

HEREDITARY BREAST CANCER PROGRAM IN BRITISH COLUMBIA – HIGH RISK CLINIC

Phone: 604-877-6000 ext. 673240

Toll free: 1-800-663-3333

HCPHRC@bccancer.bc.ca

A person with breasts between ages 30 to 50 with Neurofibromatosis Type 1 is eligible for the Hereditary Breast Cancer Program which offers genetic counselling in addition to general support. You can refer yourself to the Hereditary Cancer Program.

High Risk Clinic

High Risk Clinic

BREAST SCREENING BC

Toll free: 1-800-663-9203

Information on screening locations and booking mammograms

BC Cancer

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