



NF1 WOMEN

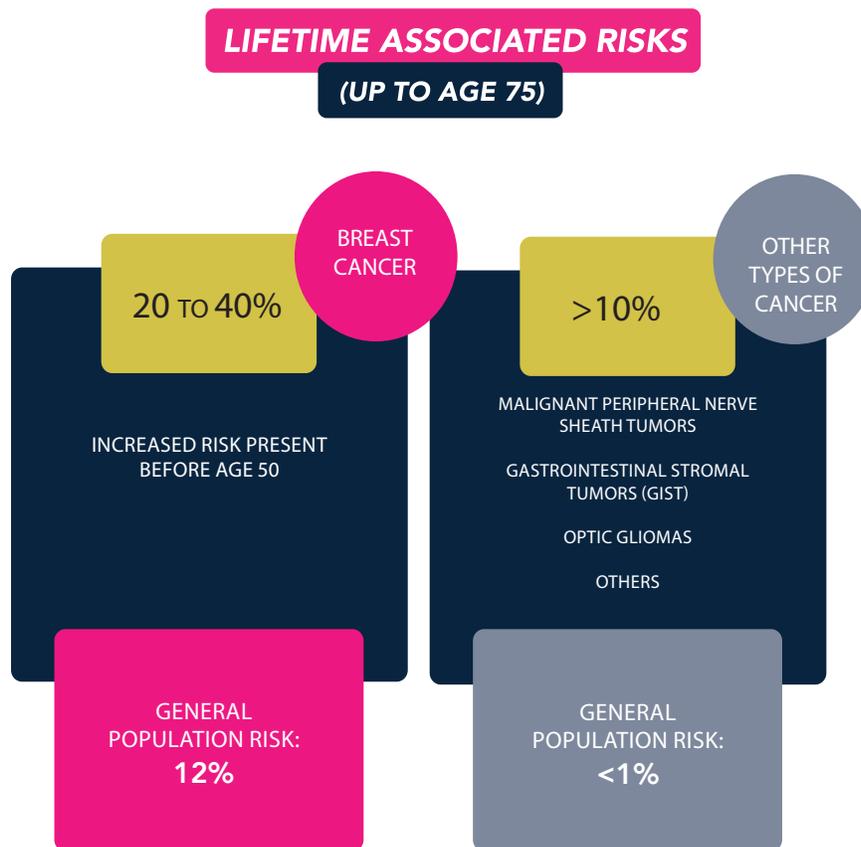


The medical management guidelines from the National Comprehensive Cancer Network (NCCN) for patients with an NF1 pathogenic / likely pathogenic variant are listed in this document.

This overview is for informational purposes and does not constitute a personalised recommendation. **Recommended options may vary based on your personal and family history. Access to some options may also vary from one medical center to another.** The specific references should be consulted for more details before developing a treatment plan.

In addition, the information available on hereditary cancer susceptibility genes is constantly evolving and **it is recommended to check this information annually as the management guidelines may change in the future.**

Neurofibromatosis type 1 (NF1) affects about 1 in 3000 individuals. An individual who is a carrier of a NF1 pathogenic / likely pathogenic variant has an elevated risk of developing benign tumors (called neurofibromas) as well as certain cancers during their lifetime.



References:

Daly M et coll. NCCN Clinical Practice Guidelines in Oncology: Genetic/Familial High-Risk Assessment: Breast, Ovarian and Pancreatic. Version 3.2025-March 6, 2025. <http://www.nccn.org>

Friedman JM. Neurofibromatosis 1. 1998 Oct 2 [Updated 2022 Apr 21]. In: Adam MP, Everman DB, Mirzaa GM, et al., editors. GeneReviews® [Internet]. Seattle (WA): University of Washington, Seattle; 1993-2022. <https://www.ncbi.nlm.nih.gov/books/NBK1109/>



NF1 WOMEN



BECAUSE THE MANAGEMENT OF INDIVIDUALS WITH NEUROFIBROMATOSIS TYPE 1 IS COMPLEX, IT IS PREFERRED THAT THEY BE FOLLOWED AT A CENTRE WITH EXPERTISE WITH THIS CONDITION.

BREAST CANCER

SCREENING

STARTING AT AGE 30

- MAMMOGRAM EVERY 12 MONTHS.
- CONSIDER BREAST MAGNETIC RESONANCE IMAGING (MRI) WITH AND WITHOUT CONTRAST EVERY 12 MONTHS FROM 30 TO 50 YEARS OLD.
 - NOTE: CONSIDER THE POSSIBILITY OF FALSE-POSITIVE MRI RESULTS DUE TO PRESENCE OF BREAST NEUROFIBROMAS.

30

50

STARTING AT AGE 50

- MANAGEMENT SHOULD BE DETERMINED ON AN INDIVIDUAL BASIS

BREAST CANCER

RISK REDUCTION

SURGERY

REGARDING THE NF1 GENE, THERE IS CURRENTLY INSUFFICIENT EVIDENCE TO RECOMMEND A PROPHYLACTIC BILATERAL MASTECTOMY (REMOVAL OF THE BREASTS BEFORE CANCER DEVELOPS).

THIS OPTION MAY BE CONSIDERED BASED ON THE FAMILY HISTORY OF BREAST CANCER.