



Info Rx

Neurofibromatosis

Neurofibromatosis (pronounced neuro-fi-bro-ma-to-sis), is a genetic disorder of the nervous system that causes tumors to form on the nerves anywhere in the body at any time.

Borrow these books from the FCRC or check your local library!

Neurofibromatosis: A Handbook for Patients, Families and Healthcare Professionals

Bruce Krof and Allen Rubenstein

This book is packed with clear and practical guidance to help those with neurofibromatosis. It includes information about new genetic and diagnostic advance; the psychosocial impact of NF; and cardiovascular and endocrine abnormalities.

Thriving with Neurofibromatosis

Kristi Hopkins

For some, neurofibromatosis is as clear as the tumors on their face. For others, it hides beneath the surface, creating tumors that destroy hearing, vision, and more. Most people with NF, or any of a thousand other genetic disorders, focus on surviving from day to day. In her book, Kristi Hopkins focuses less on surviving and more on thriving with NF.

Still Emily: Seeing Rainbows in the Silence

Emily Owens

At the age of 16, Emily was diagnosed with neurofibromatosis type 2 (NF2). With gentle humour and heart-breaking honesty, Emily shares her story. Slowly and painfully, she discovers value in new places, seeing the rainbows in the silence.

Bumpy Roads have Soft Shoulders

Nicole Porlier

Nicole Porlier wrote this book about her experience with neurofibromatosis. NF can affect so many different organs within the body, causing such severe complications that it can sometimes be difficult to see life in a positive way. Her goal is to give adults and children affected by this disorder the hope that one can live a happy, fulfilling life despite NF.



Need more information?

Child Health Information Specialist

 403-955-7745  ChildHealthInfo@ahs.ca

 fcr.c.ahs.ca/rx/nf/

Family & Community Resource Centre

2nd Floor, Alberta Children's Hospital
28 Oki Drive NW, Calgary, AB, T3B 6A8

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