



Neurofibromatosis

Neurofibromatosis (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.

Check out these resources! Use your phone to scan the QR codes to open the links!

Books

These books have been recommended by Alberta Children's Hospital staff and community partners. Books can be borrowed from the FCRC Family Library or you can check with your local library to see if they are available.

<https://collections.follettsoftware.com/collection/5f3162a2e272f70012ec4b87>



FCRC Information Prescription

Check out all these resources and more on our website.

<http://fcrc.ahs.ca/rx/nf/>



Kids Health

Kidshealth.org has an article written for parents about neurofibromatosis; it's symptoms, diagnosis, and treatment.

<https://kidshealth.org/en/parents/nf.html>



NF Society of Ontario

The NF Society of Ontario created this website with information on type 1 and 2 neurofibromatosis.

<http://www.nfon.ca/what-is-nf.html>



Children's Tumor Foundation

The Children's Tumor Foundation has a great resource centre with information about NF in multiple languages, a parent guide book, and resources for kids.

<https://www.ctf.org/>



Tumour Foundation of BC

The Tumour Foundation of BC is a charitable organization that has been supporting individuals affected with NF and their families. The resources include a parent guide, information on NF, and an NF Support Line.

<https://www.tumourfoundation.ca/>



Orphanet

Orphanet is an online database containing information on various rare disorders. This website contains information on NF. Search for “Neurofibromatosis Type 1” or “Neurofibromatosis Type 2.”



<https://www.orpha.net/consor/cgi-bin/index.php>



NORD

The National Organization of Rare Diseases (NORD) collects current information on the diagnosis, symptoms and treatment of rare diseases. Search for “Neurofibromatosis.”

<https://rarediseases.org/>

Need more information?

Contact the Family Librarian

 403-955-7745  ChildHealthInfo@ahs.ca  <http://fcrc.albertahealthservices.ca/>

Family & Community Resource Centre

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

This material is designed for information purposes only. It should not be used in place of medical advice, instruction and/or treatment. If you have specific questions, please contact your doctor or appropriate health care professional.

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