

Neurofibromatosis Clinic

The Clinical Genetics Team at Royal North Shore Hospital provides a range of services including clinical diagnosis, genetic testing and genetic counselling services by a team of specialist healthcare professionals. Our team members work together and use their skills and experience to make sure patients receive the very best care.

The Neurofibromatosis Clinic

Neurofibromatosis (NF) is a genetic condition which causes tumours to grow on nerves in the body and on the skin. NF1, NF2 and Schwannomatosis can affect both males and females and is diagnosed in people from all ethnicities and backgrounds.

Local Care, Specialist Advice

The NF clinic uses a consultative approach, providing diagnostic and management advice to people with NF and their doctors. Consultations may be offered by phone, video conference or face to face. Wherever possible, we support local care with your GP or Specialists. This may include a one-off consultation in our clinic or a series of consultations where needed.

People who may benefit from a consultation at the RNSH NF clinic could include:

- Where the diagnosis is unclear despite a consultation with a relevant specialist e.g. local Genetics service or Neurologist/Neurosurgeon
- Where advice is needed on the best approach to manage a specific complication related to NF
- Where there are complex issues that cannot be managed locally

An NF1 skin clinic is also available for treatment of neurofibromas on the skin, as is an MRI breast screening clinic for young women aged 35-50 with NF1.

Our Neurofibromatosis Clinic is led by A/ Professor Yemima Berman. The clinic staff includes doctors (clinical geneticists, neurologists, dermatologists) with experience in treating diseases and conditions of the nervous system and the skin, all working together with genetic counsellors and clinical nurse specialists.

How to Make an Appointment

To make an appointment at the Neurofibromatosis Clinic, you will need a referral from your GP or Specialist. All services provided are bulk billed.

Your Referral

Referrals should be made out to Associate Professor Yemima Berman. Referrals can be faxed to (02) 9463 1057 or emailed to NSLHD-ClinicalGenetics@health.nsw.gov.au

If your Doctor wishes to discuss whether a referral to our clinic is appropriate, they may contact the department on (02) 9463 1727 and speak to a genetic counsellor.

What Will Happen at Your Appointment

You will be seen by a specialist and/or genetic counsellor in person or via telehealth. You may also be contact by a clinical nurse specialist. This appointment will take around one hour.

Depending on the reason for your referral, a doctor may want to perform a physical examination. If genetic testing is recommended, it is usually collected by a blood test and you will be contacted to discuss your results.

After your appointment both you and your doctor will receive a written report about what was discussed, including any recommendations made.

How to Contact Us

Telephone: (02) 9463 1727

Email: NSLHD-

ClinicalGenetics@health.nsw.gov.au