

Referral Criteria for RNSH NF Clinic

The Neurofibromatosis Clinic at the Royal North Shore Hospital provides diagnostic services for adults and children with Neurofibromatosis type 1 and 2 (NF1 and NF2) and schwannomatosis. The team provides support to local care providers, including GPs and offers advice on the management and follow up care of complex issues. An NF1 skin clinic is also available for treatment of neurofibromas on the skin.

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.

Referral Criteria for RNSH NF clinic

1. For patients who do not have a confirmed diagnosis of NF1, NF2 or schwannomatosis, review in an NF specialist clinic is indicated if the diagnosis is uncertain despite consultation with an appropriate local specialist (eg Clinical Geneticist, Neurologist or Neurosurgeon) and specialist review is requested
2. For patients with a confirmed diagnosis of NF1, review in an NF specialist clinic may be indicated for patients with complex manifestations of NF1 such as:
 - a. Growing or painful plexiform neurofibromas
 - b. Optic pathway glioma in children
 - c. CNS or spinal cord tumour
 - d. Epilepsy
 - e. Pseudoarthrosis
 - f. Receiving investigational drugs
3. For patients with a confirmed diagnosis of NF2 or schwannomatosis, review in an NF specialist clinic is indicated for:
 - a. Concerning growth of schwannomas or meningiomas
 - b. New symptoms to indicate growth of space occupying lesions
 - c. Receiving chemotherapy
 - d. Heavy disease load
 - e. Complex social issues
4. If your patient does not fulfil these criteria, but you believe they would benefit from a consultation with our service, please contact us on 94631727 to discuss this with our NF team. Review in a specialist NF clinic is available to support management of NF-related issues for patients with uncomplicated NF1, NF2 or schwannomatosis on an as needed basis with ongoing management provided by a local health care provider.

Referral criteria for RNSH NF Skin Clinic

1. Link to criteria

Referral criteria for local genetics service

1. Residing within local health district
2. To confirm a suspected clinical diagnosis of NF1 or initial review after new diagnosis of NF1
3. Family history of NF1
4. Uncomplicated NF1 as defined above
5. Genetic testing
6. Pregnancy planning

Other resources

- We recommend annual clinical review for all individuals with NF1, NF2 and schwannomatosis
- Individuals with uncomplicated NF1 or schwannomatosis should be referred to their local primary care physician for annual review, an NF1 clinical review checklist is available to guide reviews
- Individuals with complicated NF1 and NF2 can be referred to either the RNSH NF clinic or their local NF specialist (e.g. general physician, paediatrician, neurologist, etc.) for regular review.
- The RNSH NF Nurse is available to provide support for local health care providers with regards to NF related issues
- NF MDT and radiology meetings are held regularly at RNSH to discuss complex cases and can be joined by non NF specialists to review cases following discussion with the NF service