At times, the doctor may consider ordering other tests. An electrocardiogram (ECG) can be done on the same day. Other tests such as an electromyelogram (EMG), magnetic resonance imaging (MRI), nerve conduction studies or a muscle biopsy may be ordered for a later date.

Your first appointment at the Neurogenetic Unit may be to discuss an illness that is in your family but for which you show no symptoms. After discussion with the doctor it may be appropriate for you to be referred for pre-symptomatic counselling to discuss the implications of genetic testing and to determine if you are prepared for the results.

What happens next?

At the end of your first appointment you will be told if further tests have been ordered and of referrals to other services. A follow up appointment will take place when your results are available or at another predetermined time. A follow up visit is required to receive the results of any genetic testing. Genetic test results will not be given over the phone.If you have any queries resulting from your first appointment, please contact the Clinical Nurse on 9224 3353.

What is involved in DNA testing?

DNA testing is performed to detect a specific condition. The Neurogenetic Unit does not carry out a general screen to advise people of any genetic mutations they may have.

If the doctor orders DNA testing you will be required to complete a consent form for DNA (Genetic) Testing and Storing. A blood test is then required. When the sample is received in the Diagnostic Genomics Laboratory at Pathwest, your DNA will be extracted from the white blood cells in your blood.

Genetic testing involves complex procedures performed by the medical scientists in the Lab. It can take up to 6-8 weeks for a result to be available. Sometimes test results may take even longer but if this is the case you will be advised at the time you see the doctor.

Royal Perth Hospital
Neurogenetic Unit

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South Metropolitan Health Service

Royal Perth Hospital

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What is the Neurogenetic Unit?

The Department of Neurology at Royal Perth Hospital established the Neurogenetic Unit in February 2000 to provide a service to those whose neurological or neuromuscular condition has an identifiable genetic basis. The Unit is staffed by Dr. Phillipa Lamont, Consultant Neurologist trained in adult and child neurology and neurogenetics, a clinical nurse, a specialised physiotherapist, and secretarial staff. The Unit has strong links with the Diagnostic Genomics Laboratory at Pathwest that carries out an extensive range of genetic tests.

Why have you been referred?

Your doctor has referred you to the Unit to determine if your neurological or neuromuscular condition has an identifiable genetic basis.

Who will you see?

You will have an appointment with the Consultant Neurologist in the clinic. The Clinical Nurse will also be in attendance. At times, the Unit has visiting doctors who may participate in the consultation if you agree.

What can the neurogenetic unit offer you?

- Clinical examination and investigation of a diagnosis of your condition
- Genetic testing where appropriate
- Ongoing management of your condition
- Discussion of the implications of your diagnosis for other members of your family
- Education and information about your diagnosis
- Referral to therapy services in RPH
- Referral to community agencies
- Assistance with funding applications and benefit claims
- Referral for pre-symptomatic counselling if you have a family history of a genetic condition but do not show the symptoms yourself.

What to bring with you to your appointment

- Another family member or support person
- Any test results, eg MRI films
- Names and dosages of any medications you are taking

What will happen at the first appointment?

The doctor will take your medical history and ask you about the symptoms that you are experiencing.

You will also be asked about other family members, parents, brothers, sisters, aunts and uncles. This information creates your family tree. Knowledge of other family members who have similar symptoms allows those people who are affected to be identified in your family tree. The Unit does not contact these people. The information is only used to determine a pattern of inheritance that has implications for you.

The doctor will perform a neurological exam that involves watching you walk, the movement of your eyes and testing your muscle strength and reflexes. It is not an invasive exam and is not painful.

Where appropriate, genetic testing will be organised. You will have a small vial of blood taken at Central Specimen Collection at RPH.