



The Friedreich ataxia clinic

Monash Medical Centre - Clayton

The aspirations of our clinic

- We aim to maximise the overall health, function, and quality of life of individuals with Friedreich ataxia (FA) in the community.
- We aim to be a world leader in specialised, contemporary care for people with FA.

Specialist clinicians at the clinic

- **At the clinic** you will have time efficient access to many specialised clinicians who are expert in the specific care to manage different aspects of living with FA. The clinicians that you can routinely see include:
- **Neurologist** - specialised in management of FA.
- **Geneticist** - specialised in management of genetic issues and FA.
- **Occupational therapist** - activities of daily living, upper limb management, wheelchair/seating prescription.
- **Physiotherapist** - mobility and exercise, walking aids, gymnasium.
- **Social Worker** - personal and family counselling, links to community resources eg. support, accommodation, recreation, travel.
- **Speech Pathologist** - communication, swallowing and saliva management issues.

- **Echocardiographer** - ultrasound and electrical monitoring (ECG) of the heart.
- **Associated specialist services** - other services can be accessed if required including cardiology, rehabilitation, ophthalmology, urology, respiratory and orthopaedics.

The service we provide

- **Co-ordinated Care**
The clinic staff will discuss an overall plan of care that will be co-ordinated with services of your choice that are in your community. We provide support and expertise to other health providers to promote care that will be streamlined and sustainable.
- **Focus on key issues**
Your issues will vary according to your age group and stage of FA. When we see you, your immediate concerns are central to the focus of our discussion. We aim to equip you with ways to address issues that may affect your life now and in the future.
- **Measurement and Monitoring**
We measure how FA is affecting you with a range of different scales and tests. This assists us to identify factors that impact on you, to intervene specifically and to monitor the outcome eg. measuring and treating your heart function.

- **Proactive approach**

To ensure that you are continually able to function at your best, we will provide you with strategies to avoid problems that are preventable – there is a lot that can be done eg. exercise to maintain muscle strength and flexibility; safety at home and work; managing FA at school and in the community with counselling and support.

- **Research**

An important role of the clinic is to engage in research as this is the only way to improve treatment. There is the opportunity to participate in research if you wish to do so.

How the clinic operates

- **Booking in**

- Phone or email the clinic co-ordinator for an appointment: phone (03) 8341 6228, email louise.corben@ghsv.org.au
There is a waiting list for new referrals.
- A detailed appointment letter will be sent one month prior to your appointment.

- **Frequency of attendance**

Yearly - unless specific follow-up is needed. Clinics are monthly including four clinics per year that are for people less than 30yrs.

- **What to bring to the appointment**

- Your referral and questions to discuss
- A list of your medications and exercises
- Any walking aids or usual wheelchair
- Orthotics (if worn)
- Glasses (if worn)
- Wear warm comfortable clothes (easy to get on and off for echocardiogram)
- Reading material/ gameboys etc. for waiting times
- Bring a carer for support and to assist with transfers if required – the day is usually very tiring

- **What happens on the day**

The clinic operates from 2 – 5pm. During this time, you will see all specialist clinicians however there are no specific appointment times. Each clinician will call you from the central waiting area.

- **We will arrange for you to attend** Cardiology for an echocardiogram and an ECG.

Appointments are usually on the morning of a clinic day or another day. The test takes about 90 minutes and will require you to remove clothing from the chest and change into a gown.

- **Follow up with local services**

We will communicate with your local health services to ensure you get the ongoing follow-up you require. If necessary, we will help you to find appropriate services in your area.

How the clinic operates

- **Getting results**

- A letter detailing your echocardiogram result will be sent to you and an appointment may be made for you to see the cardiologist.
- All results relevant to your visit will be sent to your referring doctor and relevant health care providers involved in your care.

- **Contact in between visits**

You may contact the clinic staff for advice in between visits or contact the clinic co-ordinator for general questions. Dr Churchyard provides private follow up on a regular basis if required.

Costs

- There is no charge for people with an Australian medicare card (all consultations bulk billed).
- State government funding *may* subsidise the cost of accommodation and travel to the clinic for those from interstate – enquire at booking.
- People from outside of Australia will be billed for the clinic consultation and cardiology. Information about these costs will be given at time of booking.

The clinic structure

- **Governance and affiliations**

The clinic is part of Monash Medical Centre (MMC) at Clayton and is a collaboration between Monash Institute of Neurological Disease (MIND) and Genetic Health Services Victoria (GHSV).

- **Funding**

The clinic is funded by Friedreich Ataxia Research Association (FARA) and charitable donations, Southern Health, MIND and GHSV.

- **Clinic Directors**

Dr Andrew Churchyard, Neurologist
A/Prof Martin Delatycki, Medical Geneticist

- **Clinic Co-ordinator**

Louise Corben, Senior Clinician
(Occupational Therapy)

- **Clinic location and contact details**

Special Medicine Centre
Monash Medical Centre - Clayton
246 Clayton Road, Clayton, Victoria 3168
ph. (03) 8341 6228

- **Public transport**

Closest train station is 'Clayton' – approx. 500 metres away on the Cranbourne or Pakenham line.

- **Travelling by car**

If driving, enter Monash Medical Centre, Clayton from the Clayton Road entrance and turn right at the first roundabout. The clinic is located within the Special Medicine Centre on the right.

- **Map**

Detailed maps will be sent with your appointment letter.

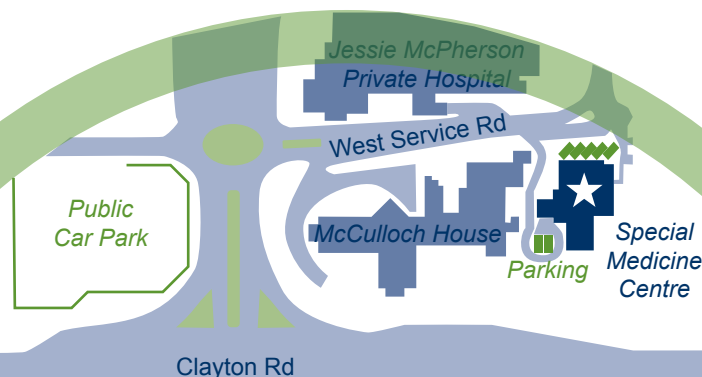
- **Parking**

All day parking is available in the public car park at specified rates. Free parking is available to patients outside the Special Medicine Centre for the afternoon clinic, however, there are limited 2 hour spaces.

See reception to authorise a longer time.

- **Useful links**

Genetic Health Services Victoria -
www.genetichealthvic.net.au/FAclinic.html
Friedreich Ataxia Research Association -
ph. 03 9867 1910 www.fara.org.au/
Murdoch Childrens Research Institute -
www.mcri.edu.au/Friedreich



Southern Health

