

# Attending the FXA Clinic

## Things to do to attend an FXA Multidisciplinary Clinic

### BEFORE

- Provide the Fragile X Alliance Inc. with a copy of the **DNA report** confirming Fragile X Syndrome.
- Become a member of the Fragile X Alliance Inc. (application form can be downloaded collected via email or paid for on the day). This is an annual fee (calendar year) of \$44
- \* Organise a **medical consultation with Jonathan Cohen**

Fragile X Alliance Inc.  
263 Glen Eira Road  
North Caulfield  
Ph: 9528 1910

Cost: bulk billed, therefore no out-of-pocket expense (International: \$250)

- \* Have you had a recent (within 2 years) IQ test? If not, we can organise one with Astra King.

361 Nepean Highway  
Frankston 3199  
Ph: 9770 6777

Cost: To be arranged (depending on assessment and administrator) – approximate range \$100-\$300

- \* Organise a Fragile X Optometry appointment with Rashelle Cohen:

Caulfield Family Medical Practice  
263 Glen Eira Road  
Caulfield North  
Ph: 9528 1910

Cost: bulk-billed (International \$110)

- \* Organise a Fragile X Audiology appointment with Peter Altidis (It is important to specify this is for FXS)

2 East Concourse  
Beaumaris (on a Wednesday)  
Ph: 9589 5122

Cost: \$65

- Complete the necessary **pre-clinic paperwork** (which will be sent to you). This will consist of:
  - The parent/guardian or house supervisor/manager must complete:
    - FXS General Information booklet
    - Consent Form
    - Speech Questions
    - ADHD checklist
    - ABC checklist
    - Sensory Profile (short)
  - A teacher or day placement supervisor needs to fill out a separate copy of the following documents as well. It is recommended that they return the paperwork to you, so it can all be returned in one package
    - ADHD checklist
    - ABC checklist
    - Sensory Profile (teachers: teacher companion; other: short)

Once each of the previous steps have been completed, we can organise a clinic date for you. If you have limited availability, we suggest you tell Sarah Borrie or Jonathan Cohen **in advance** to allow us to temporarily reserve a date. If you have not satisfied the above criteria within two weeks of the reserved date, you will not be able to attend at this time.

**\*Please Note:** for those travelling internationally or interstate, we arrange these pre-clinic appointments differently. These appointments are organized by Sarah Borrie, and you will be given the appointment times and dates in advance. The general schedule for travelers is as follows:

Tuesday = arrive in Melbourne

Wednesday = **Medical** with Jonathan

Wednesday = **Optometry** with Rashelle

Wednesday or Thursday = **Audiology** with Peter

Wednesday or Thursday = **IQ** with Astra, (if not already done)

Friday afternoon = **Multidisciplinary Clinic** with post-clinic discussion/**review**.

## **THE CLINIC**

The multidisciplinary clinic is run (generally) on the last Friday of the month. It starts at 1pm and goes until about 4pm.

This clinic consists of:

- Speech Therapy with Felicia Schmaman
- Psychology with Astra King
- Occupational Therapy with Debbie Isaac

Due to the type of assessments undertaken, the clinic cannot be bulk-billed.

**Cost: \$660.**

This can be paid for in a number of ways:

- Some may be claimable by Medicare

- If you have private health insurance with extras, a percentage of the cost can be reimbursed to you following submission of a claim
- If you receive funding from any other source, you are advised to discuss the possibility of gaining funding from this body prior to attending the clinic
- Thanks to the generosity of the Fragile X Association of Australia (FXAA), a small number of our patients are funded by them. To be eligible for this, you must also be a member of the FXAA, which is a small annual fee (financial year) of \$25. It is important for you to notify Sarah that you are a member to ensure Sarah can explore the possibility of receiving funding from FXAA.

If you still have problems obtaining funding, please speak to Sarah Borrie or Jonathan Cohen on (03) 9528 1910

## **AFTER**

Following the multidisciplinary clinic, the team will assemble their reports. These consist of a summary of topics discussed at the clinic, recommendations on where/who to go to from here and any other pointers.

Hopefully within 3 weeks of the clinic, you will receive a copy of:

- Clinic case summary
- OT report
- Speech report
- Psych report
- Audiology report
- Optometry report
- IQ (if done)

It is important you read over these reports and begin implementing the proposed techniques.

If you are not travelling interstate or internationally, you will be due for a **review appointment** with Jonathan Cohen approximately one month following the clinic. Here, Jonathan will go over the reports and discuss any remaining questions you may have about any of the reports.

Depending on the developmental stage/environment and recommendations made by the team, it is suggested you review all of these appointments every 2 years. This will allow the team to continue to provide up-to-date and appropriate care for families with Fragile X Syndrome.