

Fragile X Alliance Clinic

(Incorporation No. A0036906U) (ABN 78965364337)

263 Glen Eira Rd, Nth Caulfield 3161

Tel (03) 9528 1910, Fax (03) 9532 9555

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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 collected via the website, email or paid for on the day)

This is an annual fee (calendar year) of **\$44**

→ *Organise a **medical** consultation with [Jonathan Cohen](#)

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

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

→ *Have you had a recent (within 2 years) **IQ test**?

If not, we can organize one with [Astra King](#)

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

584 Inkerman Rd
Nth Caulfield 3161
Ph: 9525 9570

→ *Organise a Fragile X **Optometry** appointment with [Rashelle Cohen](#)

Cost: **bulk-billed**
(International: \$110)

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

→* Organise a Fragile X **Audiology** appointment with [Peter Altidis](#)

Cost: **\$65**

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

→ Complete the necessary pre-clinic paperwork
(which will be sent to you by Sarah Borrie)

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.