NATIONAL **FRAGILE X**
FOUNDATION

Your In-Person Visit to a Fragile X Clinic

The Fragile X Clinical & Research Consortium (FXCRC)

The Fragile X Clinical and Research Consortium (FXCRC) was created by the National Fragile X Foundation in response to the growing needs of families whose members have one of the Fragile X-associated conditions. The FXCRC is composed of over 30 clinics, each of which has expertise in Fragile X.

Though all clinics serve individuals with FXS, many also serve those or have referrals for those with FXTAS, FXPOI, and other Fragile X premutation-associated health needs.

Though each clinic operates independently, they often collaborate with one another, sharing resources, participating in research projects, and attending meetings of the FXCRC. New clinics are being added regularly across the U.S., and around the world.

FIND A FRAGILE X CLINIC

Where to Begin

We encourage families to visit the clinic closest to them, but, in some cases, visiting a different clinic might be advisable based on the expertise of a specific healthcare provider.

Once you locate a clinic (review the list here), contact the clinic coordinator to discuss your concerns about your child or family member and what you hope to get out of the visit. Ask about the following:

- **What has to be done before the visit?** Paperwork, etc. See "Information Needed" below.
- **What does a typical visit entail?** Some clinics conduct evaluations over two days, which requires an overnight visit. Others may require only several hours.

- **In addition to seeing the clinic director, what evaluations are offered and by whom?** Examples might include speech, occupational, physical, and behavioral therapies, and genetic counseling.
- **What other specialists are available?** For example: psychologists, audiologists, neurologists, cardiologists, ophthalmologists, etc.
- **Are referrals made to local providers in your area?**
- **After the evaluation, will the clinic director be available to review and discuss the results?** Will each specialist be available, or will the clinic director review the findings of each specialist with you?
- **When will a written evaluation be available?** Will it consist of separate reports by each clinic specialist or one report? Can you request that the report be sent to your providers, teachers, therapists, etc.?
- **Who will be available to interact with your local providers?** To make sure treatment recommendations are clarified, discussed, and implemented?
- **Do they have a visual schedule of the visit you can access?**

Also Ask About

- **What written or online materials will be available?** A list of state and local resources? Handouts or articles on Fragile X for you to take back to school personnel, doctors, and other providers?
- **What kind of insurance does the clinic accept?** If you do not have insurance, ask if there are alternative payment plans and/or opportunities to participate in research trials.
- **Will there be a possibility to participate in research?**
- **Do they have recommendations for lodging facilities?** To meet your needs regarding price, proximity to the clinic, dining opportunities, etc.? Do any of them offer discounts for those making hospital visits?
- **What restaurants, grocery stores and other attractions are in the area?** (You may want to make a mini vacation of the visit.)

- **Is there an NFXF Community Support Network group or local family you could talk to?** About the area and about your visit to the clinic? (The Community Support Network (CSN) is volunteer-led groups/people providing local support.)
- **A special consideration for those with FXTAS?** Make sure to inquire about hotel and transportation/wheelchair issues.
- **The Fly with Me Fund?** If you need financial assistance to travel to this clinic, ask about this fund.

Information Needed

You may be asked to provide or share the following records at or in advance of the visit. Many healthcare records are now electronic; therefore, the clinician may have access already.

Each clinic has an intake form, and you may be asked questions about you or the individual with Fragile X's history, including:

- **Information about your immediate and extended family, including:**
  - Diagnoses of any individuals — living or deceased — with developmental delays, behavioral disorders, neurological disorders (including late onset conditions), fertility issues.
  - Any genetic testing that has been done, especially for the individual being seen.
- **If your visit is for FXS—**
  - Medical and other records, like psychological, speech, and occupational therapy evaluations and/or records from school therapists and teachers.
  - Information about developmental milestones, past and current illnesses, medications (including any reactions), and/or therapeutic interventions.
- **If your visit is for FXTAS—**
  - Records like any MRI reports, neurological and/or psychiatric records.
  - Any journal of symptoms and their progression.
- **If your visit is for FXPOI—**
  - Records of medications, medical, menstrual/pregnancy history.

    - Questions related to medical management or reproductive issues/options.
- **If your visit is for other health concerns related to the Fragile X premutation—**
    - Information from other doctors that may be appropriate.

Preparing your questions

As you prepare for your visit, begin to write down basic questions for the clinic staff that may not have been covered in your initial discussion with the clinic coordinator. Please know — and continue to remind yourself — that no question is silly or strange or unwelcome.

If you are wondering about something, it's likely that the very same question has occurred to many other people — and Fragile X professionals have probably heard it.

Clinic staff are well-informed, trained, and compassionate, ready to answer (or find out the answer to) any question you may have. So please do ask!

Typical questions include:

- Why does my child/family member do _________?
- What can or should I do in these situations?
- What can I expect from this type of therapy or medication?
- Is it wrong to _________?
- What if I have follow up questions after receiving the report(s)?
- Will the doctor answer questions/converse by phone or email following the visit, even months later?
- How often should I expect to make an in-person visit?
- Will the doctor do telehealth visits?

Don't Forget To . . .

- Bring things to keep you and your loved one(s) busy—think electronics (and their chargers!), books, favorite toys, puzzles, blankets, foods, and other comfort items. Headphones in waiting rooms can come in very handy.

- Ask for special accommodations if you feel they would help. It is even better if you can ask in advance. For example, if staying in the waiting room is difficult for your child, perhaps the staff can call you on your cell phone when they are ready to see you.
- Build in some downtime during what can be a highly scheduled visit. If possible, find some time to visit a park, zoo, museum, attend a sporting event, go swimming, or anything else your family likes to do.
- Treat your clinic visit as but one step in your family's long-term education about Fragile X.

Many NFXF Fragile X Clinical & Research Consortium clinics offer telehealth visits in addition to in-person. Note there are specific parameters to these visits, and they vary from clinic to clinic and state to state. We have gathered information to help you make the most of your online telehealth visit to a Fragile X clinic.

LEARN MORE

Telehealth Visits: Suggestions for Parents on How to Prepare | NFXF