THINKING AHEAD
As you prepare for your visit, begin to write down 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 is virtually certain 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______?

DON’T FORGET…
- To bring favorite toys, puzzles, blankets, foods and other comfort items for your child(ren).
- To ask for special accommodations if you feel they would help. 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.
- To bring books, music, laptop computers, and other enjoyable items for yourself. (Headphones in waiting rooms can come in very handy.)
- To build in some downtime during what can be a highly scheduled visit. If at all possible, find some time to visit a park, zoo, museum, attend a sporting event, go swimming, or anything else your family likes to do.
- To treat your clinic visit as but one step in your family’s long-term education about Fragile X.

ABOUT THE NFXF
The National Fragile X Foundation (NFXF) was founded in 1984 to support individuals with fragile X syndrome (FXS), their families, and the professionals who work with them. Today, it is a comprehensive resource not only for FXS, but also for the more recently discovered conditions of fragile X-associated tremor/ataxia syndrome (FXTAS) and fragile X-associated primary ovarian insufficiency (FXPOI). The organization offers a toll-free phone line and email support; education through an extensive website, quarterly journal and other publications; and awareness activities throughout the country. It also organizes international conferences, funds scientific research, and leads legislative advocacy efforts in Washington, DC.

Special thanks for assistance on this brochure to: Jayne Dixon-Weber, Liane Abrams, MS, CGC, and also to parent leaders of our LINKS groups network for their helpful feedback.

Additional copies available free of charge.

The NFXF helps coordinate a nationwide network of clinics and parent support groups (LINKS) for families impacted by Fragile X. For more information on this and other topics related to Fragile X, email: treatment@fragilex.org or log on to: www.fragilex.org.
**YOUR VISIT TO A FRAGILE X CLINIC**

The Fragile X Clinical and Research Consortium (FXCRC) was created by the National Fragile X Foundation (NFXF) in response to the growing needs of families whose members have one of the three identified Fragile X-associated Disorders (FXD)—fragile X syndrome (FXS), fragile X-associated tremor/ataxia syndrome (FXTAS) and fragile X-associated primary ovarian insufficiency (FXPOI). Each clinic is staffed by knowledgeable specialists experienced in the evaluation and treatment of FXD.

Though each clinic operates independently, they often collaborate with one another, sharing resources, participating in research projects, and attending meetings of the consortium. For a regularly updated map and clinic information, visit: fragilex.org/treatment-intervention/fragile-x-clinics/.

The NFXF maintains a network of parent groups (“LINKS”) to assist families in maximizing their clinic visit experience. Go to: fragilex.org/community/links-support-network/.

**WHERE TO BEGIN…**

In some cases, you begin by calling the main hospital/facility number to make the appointment. Ask to speak to the Fragile X Clinic coordinator. When you talk to the coordinator you can discuss your concerns about your child or family member and what you hope to get out of the visit. Then, ask about the following:

- What does a typical schedule involve? Some clinics conduct evaluations over two days, which requires an overnight visit. Others may require only several hours.
- In addition to seeing a medical doctor, what evaluations are offered and by whom? Examples might include speech, occupational, physical and behavioral therapy, 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 medical doctor be available to review and discuss the results? Will each specialist be available or will the medical doctor review the findings of each specialist with you?
- When will a written evaluation/report 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?

**ALSO ASK ABOUT…**

- What written or online materials will be available? A list of state and local resources? Handouts or articles on FXD for you to take back to school personnel, doctors and other providers?
- Will there be a possibility to participate in research? Ask about participating in the FORWARD Registry and Database that uses information from your clinic visit to answer important research questions.
- 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.)
- 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?
- Ask the clinic coordinator about the “Justin Silver Fly With Me” travel grants that can help with expenses related to your visit.
- What restaurants, grocery stores and other attractions are in the area? (You may want to make a mini-vacation of the visit.)
- Ask about participating in the FORWARD Registry and Database that uses information from your clinic visit to answer important research questions.
- 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, and any genetic testing that has been done. Bring photos of any family members who may have fragile X syndrome.
- Information from baby books, scrapbooks, and journals that would note ages of developmental milestones, illnesses, medication (including any reactions), therapeutic interventions, etc.
- If your visit is for FXS, bring genetic test results, medical or psychiatric records, psychological, speech and occupational therapy evaluations, and any other records from the school and teachers.
- If your visit is for FXTAS, bring MRI reports, neurological and/or psychiatric records, and any other records from the clinic.
- If your visit is for FXPOI, bring records of medications, medical, menstrual/pregnancy history, and any questions related to medical management or reproductive issues/options.

The wait to be seen at a clinic varies, but in some instances can be as long as 3-6 months.

**THE CLINIC PROCESS**

Each clinic has an intake form for which you will most likely need the following:

- 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, and any genetic testing that has been done. Bring photos of any family members who may have fragile X syndrome.
- Information from baby books, scrapbooks, and journals that would note ages of developmental milestones, illnesses, medication (including any reactions), therapeutic interventions, etc.
- If your visit is for FXS, bring genetic test results, medical or psychiatric records, psychological, speech and occupational therapy evaluations, and any other records from the school and teachers.
- If your visit is for FXTAS, bring MRI reports, neurological and/or psychiatric records, and any journal of symptoms and their progression.
- If your visit is for FXPOI, bring records of medications, medical, menstrual/pregnancy history, and any questions related to medical management or reproductive issues/options.

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