

Receiving a diagnosis of Ataxia may make you feel as though you are losing control of your life. One way to feel more in control is to take an active role in your health care and becoming informed is an important way to achieve that goal. Choosing your medical professionals to supervise your overall health care is essential. It is worth the time and effort it takes for you and your physicians to build a relationship of openness, caring and mutual respect. Such a relationship can be a powerful factor in your own physical and emotional well-being.

You will want to be seen by a neurologist who will provide the expertise needed for the disease of Ataxia. This fact sheet is to assist you in having productive appointments with your neurologist so that you can feel and function better with Ataxia. This fact sheet will also provide information about Ataxia clinics and the value of being seen at an Ataxia clinic at least once after your diagnosis.

Your role during your medical appointment with your neurologist is to provide information about your health, health history, medications, and honest and concise symptoms. Neurologists who see patients with Ataxia suggest the following to make your appointment a beneficial experience:

### **Prior to the appointment:**

- Send the following to your neurologist's office several weeks prior to your appointment
  - List of your general health examinations including vaccinations and other health maintenance

- A record of all your medical test results including actual images of any MRIs and/ CT scans of the brain and spine on a CD or provide electronically a bookmarked PDF with all imaging and other tests.

- Reports from any genetic testing you have had. This prevents the necessity and expense of having tests repeated and allows your physician to confirm any findings from your previous evaluations

- Ask family members (grandparents, parents, aunts uncles, siblings, and cousins) about medical conditions that exist in your biological family. Ataxia is often a hereditary disease and this information is helpful for the physician. If there are other diseases or conditions that run in the family (neurological or otherwise), include those as well.

### **Bring the following with you to your appointment:**

- Bring a complete list of all the current, recent and past medications with the dosages as well as any vitamins or supplements that you are currently taking.
- Bring an accurate and complete family medical history with specific walking or coordination problems that family members may have had or currently have. Draw out a family pedigree.
- Write down 3-5 of your most important questions that you would like answered at the appointment or select the top 3 symptoms or problems that are the most severe that you want to discuss during the appointment. You may use the back of this fact sheet to write your questions.

### **At the start of the appointment:**

- Provide the name and contact information of the physician who should receive a copy of the medical report following your visit, i.e., your primary care physician.

- Talk about any illegal drugs you may be taking. It is understandable you may be reluctant to talk about this, but it is important to tell your physician.

### During the appointment:

- Be prepared to answer the following questions as specifically as possible.
  - How and when did you first see symptoms of Ataxia?
  - How have the symptoms changed?
  - What activities are you finding difficult?
  - What makes the symptoms better?
  - What makes the symptoms worse?
- Ask the 3-5 important questions you wrote down prior to the appointment. Your neurologist may ask specific questions about those symptoms. Stay focused, listen closely and carefully so you can answer his/her questions accurately and to receive the answers that you need.
- Describe other medical conditions that you may have and any allergies or adverse reactions that you have had to medications.
- Be sure you understand what the neurologist has discussed with you. Ask for any clarification – do not leave the physician's office confused. If necessary, bring a relative or friend with you who can write the information down or ask the physician to write down the key points.
- Be sure you know how to contact the physician or his/her office if you have questions that come up after you get home.

### Following the appointment:

- Make follow-up appointments immediately for any tests, therapy or other instructions. In some cases, physician's orders can expire within a certain time frame which makes it important to make these follow-up appointments immediately.
- Confirm that your primary care physician received the report from your neurologist.
- Fill prescriptions immediately and begin taking them as prescribed. Report any troublesome side effects immediately.
- Call the physician's office if you have forgotten or are confused about anything that was discussed or prescribed. Do not wait until the next appointment.
- Consider joining an Ataxia support group which can offer companionship and information for coping with hereditary or sporadic types of Ataxia and the challenges that accompany those disorders. National Ataxia Foundation has a listing of known Ataxia support groups at [www.ataxia.org](http://www.ataxia.org).

Ataxia research has moved into the clinical phase, and pharmaceutical companies have begun recruiting participants for clinical trials. Individuals with Ataxia or who are at-risk for Ataxia are encouraged to enroll in the CoRDS Ataxia Patient Registry. To access the Registry, go to NAF's website [www.ataxia.org](http://www.ataxia.org) and click on the "Enroll in the Patient Registry" tab and follow the directions on the CoRDS website.

NAF provides accurate information for you, your family, and your physician about Ataxia. Please visit the NAF website at [www.ataxia.org](http://www.ataxia.org) for additional information, including a listing of ataxia support groups, physicians who treat Ataxia, social networks, and more. For questions contact the NAF directly at 763/553-0020 or [naf@ataxia.org](mailto:naf@ataxia.org).

Learn as much as you can about your disease. Find and use only reputable and accurate sources for information. The following websites have reliable information on ataxia:

**The National Ataxia Foundation:**

[www.ataxia.org](http://www.ataxia.org)

**National Organization for Rare Diseases:**

[www.rarediseases.org](http://www.rarediseases.org)

**National Institute of Neurological Disorders and Stroke:**

[www.ninds.nih.gov](http://www.ninds.nih.gov)

**Recommended Reading:**

***You –or Someone You Love – a Devastating Diagnosis***

by Jessie Gruman, PhD.

When faced with a devastating diagnosis people must quickly understand the prognosis and often choose from several treatment options and further testing – all while still in shock. Social psychologist Jessie Gruman offers a practical, ten-stage approach to making clear-headed, informed decisions. Jessie Gruman's website: <http://www.aftershockbook.com/>

***Living With Ataxia: An Information and Resource Guide***

by Martha A. Nance, MD, for the National Ataxia Foundation.

The message of this book is that living a good life is an entirely reasonable aspiration even with Ataxia. The book is packed with practical information for everyday living, and it provides useful resources. Available at [www.ataxia.org](http://www.ataxia.org)

**Making an appointment at an Ataxia Clinic/Center:**

Ataxia Clinics are specialty clinics committed to providing specialized medical care for people diagnosed with cerebellar and other forms of Ataxia. Ataxia Clinics are specialty clinics committed to providing specialized medical care for people diagnosed with cerebellar and other forms of ataxia. Clinics are devoted to the diagnosis, treatment and management of Ataxias as well as prevention and management of complications affecting this group of patients. Patients with the many types of rare ataxias can benefit from multidisciplinary specialists, which often include genetic counselors, speech therapists, physical therapists and other specialists who are devoted to the care and treatment of those with Ataxia.

While each Ataxia clinic is set up a little differently, they all offer similar services. They are staffed by people who understand Ataxia. Evaluations offered at clinics often include: neurological exam, speech, occupational, physical and behavioral therapy, and genetic counseling. Additional specialist services may include referrals to physical therapists, speech and swallowing therapists, cardiologists, ophthalmologists, social workers, and health care professionals as deemed appropriate. After your visit, most clinics will provide you with a written summary of your condition, along with recommendations that you can take back to your local doctor and/or school district and/or workplace. Visiting a clinic does not replace the need for a local physician. It is still very important that you have a family physician and/or neurologist who can handle the everyday ailments of you or your child(ren), but it is crucial that this doctor is willing to work with you on your specific issues regarding Ataxia.

Once you establish a relationship at an Ataxia clinic, the clinic physician becomes a valuable resource for your local physician.

If you have never been to an Ataxia clinic or it has been a while, or if you are having new symptoms of Ataxia, or if you want to get involved in clinical or research trials, it is suggested that you visit one in the near future.

Once you make that initial visit, yearly follow-ups are recommended. Visiting an Ataxia clinic keeps you up-to-date on the status of new treatments and current research in cerebellar Ataxia. Visiting a clinic keeps you in-tune and hands-on with what's going on in the Ataxia world. The specialist will also be able to chart the severity and changes of your Ataxia and other symptoms, which will be helpful to you and your local physicians in understanding the progression of the disease and planning your current and future medical care. Those who take an active role in preparation for the clinic appointment are usually happier with the visit and get more out of it. Prior to your appointment at the ataxia clinic, follow the same guidelines as were described at the beginning of this fact sheet.

A current list of ataxia clinics is located on the National Ataxia Foundation's website at [www.ataxia.org](http://www.ataxia.org).