Where to Begin?

A Guide for Parents Whose Child Was Recently Diagnosed with Friedreich's Ataxia

A diagnosis of Friedreich's ataxia (FA) ushers in a wide array of emotions and life changes that impact each individual and family in unique ways. This guide can help you navigate through this complex time by providing a starting point for learning about FA. Through this guide you can also find ways to connect with the vibrant and engaged FA community which includes individuals and families affected by FA, physicians, researchers, and others who are working together to find treatments for FA.

Although FA is a rare disease, there are about 15,000 people with FA in the world, with 5,000 people living in the United States. Many parents have stood exactly where you stand now, facing your child's new diagnosis and the ocean of information and emotions that accompany it. We hope you will be able to lean on the strong network of support and friendship you can find in the FA community as your family begins your journey with FA.

This guide does not represent an exhaustive source of information on FA. If you have specific questions, want to learn more, or wish to connect with other parents of children diagnosed with FA, visit curefa.org or reach out to the Friedreich's Ataxia Research Alliance (FARA) at info@curefa.org or 484-879-6160.

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Symptoms of FA

Neurological Symptoms

Early symptoms of FA include **trouble walking** and **frequent tripping**. People may also have **difficulty writing** and **reaching for or grasping objects.**

These symptoms stem from changes in the nervous system including:

- **Ataxia** – loss of coordinated movement of the limbs
- **Reflex and sensory loss** – difficulty sensing vibrations and position of the limbs

FA is a progressive disease, which means symptoms change or worsen over time. As time passes, someone with FA will likely transition through different phases of mobility such as:

- Using walls, furniture, or loved ones as support while walking
- Using a cane or a walker
- Using a wheelchair for longer distances
- Using a wheelchair full time

Most children with FA experience ataxia as their first symptom. Ataxia is the loss of coordinated movement of the limbs. Although it seems simple, voluntary movement, such as taking a step or reaching out to grasp a cup, relies on several types of information that the brain must properly piece together. When reaching for a cup, for example, the reaching arm and the brain communicate to figure out where the arm is in space compared to the cup, the brain tells the arm to move, and the arm confirms its movement with the brain.

Ataxia is caused when certain areas of the nervous system are not functioning well. This prevents the brain from properly sending messages back and forth to the limbs. In FA, specific regions of the nervous system involved in communicating these messages, the cerebellum (in the brain) and the dorsal root ganglia (near the spinal cord), are especially affected by the genetic mutation that causes

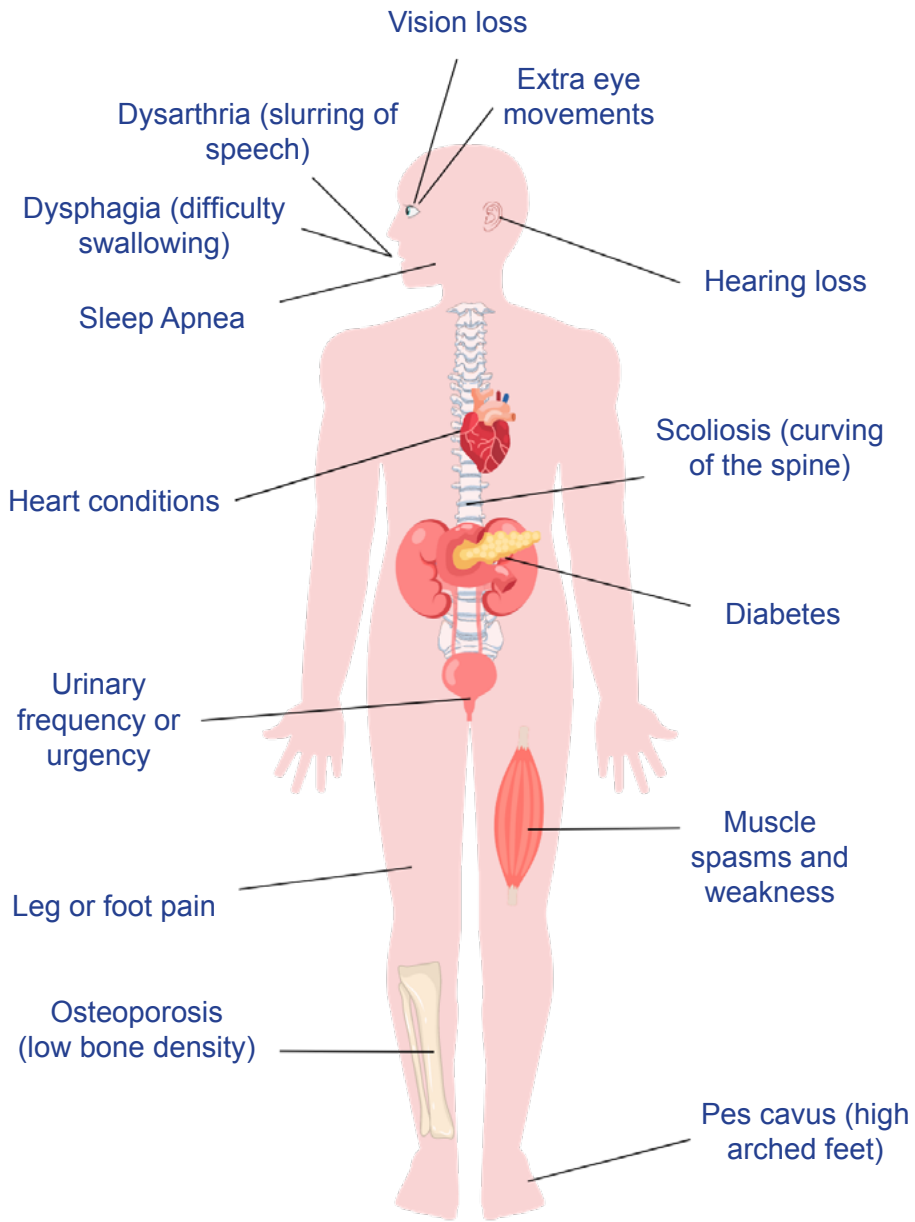
FA (see the Genetics of FA section). This disrupted communication between the brain and the limbs leads to symptoms of poor coordination and balance.

Children with ataxia rely on their vision and touch senses to figure out where their body is in space and to compensate for the jumbled communication between the brain and limbs. You might notice your child touching or grasping furniture, walls, or loved ones to support themselves when walking. This is not because their muscles are weak, but because they are using these objects as a reference point to help their brain figure out where their body is in space. Similarly, you may notice that your child is clumsier in low light or when they close their eyes. This is because they are relying on visual cues to help their brain figure out where they are. Using nightlights or flashlights in the dark or having your child try to keep their eyes open when they're in the shower or bath might help to prevent falls.

FA is a progressive condition which means that the symptoms change or worsen over time. Each person living with FA has their own unique experience of the disease, and not all individuals will experience every symptom or the same rate of progression. On average, the neurological symptoms of FA progress to the point of needing a wheelchair for mobility within ten years of diagnosis.

Other Symptoms of FA

FA is a multi-system condition which means that it can affect multiple organs. This leads to different types of symptoms occurring over time. The diagram to the right *(fig. 1)* shows different symptoms of FA. It's important to remember that not every person with FA will experience every symptom. Symptoms may appear over time, not necessarily all at once. There is no predetermined course of symptom development or progression.



Children with FA may also experience fatigue, low body mass index (BMI), and depression and anxiety.

Fig. 1

Learn more about the different symptoms of FA:

Dysphagia, or difficulty swallowing, may present as choking while drinking liquids.

Heart conditions that can impact people with FA include cardiomyopathy and cardiac arrhythmias.

- Cardiomyopathy is the thickening of heart muscle. Cardiomyopathy can make it difficult for the heart to pump blood efficiently.
- Cardiac arrhythmias are irregularities in heart rhythm.
- Most people with FA will have abnormal findings on an electrocardiogram (EKG), a test that measures the heart's electrical activity. These findings do not always correlate to a diagnosis of cardiomyopathy or cardiac arrhythmia.
- For some children with FA, cardiomyopathy or arrhythmias may be picked up on cardiac tests (described below in Management and Treatment of FA), but otherwise the child will have no noticeable symptoms of heart disease. Other children may feel symptoms including chest pain, difficulty breathing, or heart palpitations (the heart "fluttering" or "skipping a beat").

Diabetes is caused when the body does not regulate blood sugar levels properly. In FA, diabetes can present in childhood or adulthood and can be managed with standard treatment approaches.

Fatigue impacts many children and adults with FA. More than just general tiredness, fatigue is a type of exhaustion that can prevent someone from carrying out everyday activities. The cause of fatigue in FA is not fully understood but is likely due to a combination of factors. This includes both the large amount of work the body must invest to compensate for balance issues, as well as the fact that the genetic mutation that causes FA directly impacts cellular energy production (see Genetics of FA).

Low BMI, or body mass index, can be a risk for children with FA. FA impacts the body's metabolic processes that turn food into cellular energy, which can cause some children to be underweight or have difficulty putting on weight.

Depression and anxiety are not uncommon for children with FA. It is unclear if mental health issues are a primary symptom of FA caused by the impact of the genetic mutation, or if they are a secondary symptom stemming from the difficulties of living with a complex, rare disease.

"This is not an easy journey, but the path we are on we know that we do not travel alone."

–Beth
Parent of Individual with FA

Example Individuals With FA

FA affects everybody differently. Not every child will develop every symptom, and not every child will experience the same pattern of progression. For example, these three individuals with FA are all affected differently by the disease:

Grace was diagnosed with FA at age 5. She is now a 21-year-old college student who loves to read. FA has had a significant impact on her physically. She has had surgery for scoliosis, uses a wheelchair for mobility, and needs assistance with daily activities.

Kyle was diagnosed with FA at age 17 and is now 40 years old. He is an avid cyclist, using a recumbent bike. He does not have scoliosis, diabetes, or cardiomyopathy. He uses a wheelchair for mobility and lives and works independently.

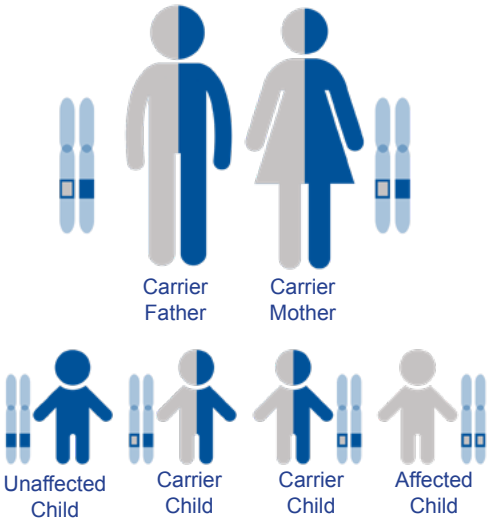
Byron, Keith and Stuart Andrus;
photo courtesy of Raychel Bartek

Keith was diagnosed with FA at age 11. He loved music, collecting sneakers and getting tattoos. He experienced all the symptoms of FA: scoliosis, diabetes, and vision and hearing loss. He passed away at 24 due to complications from cardiomyopathy.

Genetics of FA

FA is a genetic, neurological disorder caused by changes in the FXN gene, which makes a protein called frataxin. Frataxin is used by mitochondria, the energy generating components of cells. FA is caused by a specific type of genetic change known as a GAA repeat expansion and is inherited in an autosomal recessive pattern. Continue reading below to learn about GAA repeat expansions, autosomal recessive inheritance, and how mitochondria use frataxin to provide cells with energy.

Genes & Autosomal Recessive Inheritance



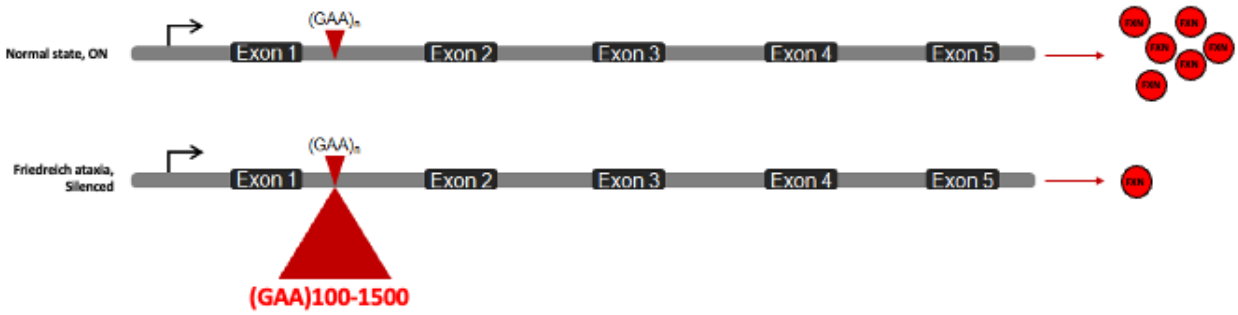
Our DNA, or genetic code, is organized into units called genes. Genes contain the instructions for making protein, the building block of cells and tissues. Humans have two copies of every gene. One is passed down from the mother, and the other from the father. FA is an autosomal recessive condition, which means it occurs when non-functioning copies of the FXN gene are passed down from both parents. A person with FA has two non-functioning copies of the FXN gene.

Parents of a person with FA are called carriers: they each have one working copy and one non-functional copy of the FXN gene. In the United States, it is estimated that 1 in every 100 people, or 1% of people, are carriers of FA. When both parents are carriers, each of their children has a 1 in 4, or 25%, chance of having FA.

Because FA is an inherited disease, there may be other people in your family who should consider genetic testing, including your child's siblings. Genetic testing is a personal choice that requires careful consideration and discussion. Visiting with a genetic counselor may help you and your family make these important decisions.

GAA Repeat Expansion

All genes are composed of a genetic alphabet containing 4 letters: C, G, A, and T. The spelling of the FXN gene includes a repetition of the three letters "GAA." People unaffected by FA usually



have between 7 and 30 GAA repeats in the FXN gene. FA is caused when this stretch of GAA's is expanded. Symptoms of FA become noticeable in individuals with 100 or more GAA repetitions on both copies of the FXN gene. Higher numbers of repetitions have been linked to earlier age of onset and increased symptoms of FA.

Most people with FA have two FXN genes with over 100 repeats. But FA can also be caused by other types of changes in the FXN gene. In these cases, the correct letter of the DNA sequence is replaced by a different letter or letters are deleted from the gene. Five percent of people with FA have one FXN gene with over 100 repeats and one FXN gene with another type of mutation.

Frataxin & the Mitochondria

The FXN gene encodes the instructions to make a protein called frataxin, which supports the function of a part of the cell called the mitochondria. The mitochondria create energy for the cell to use in the form of a molecule called ATP. In the mitochondria, frataxin helps to transport iron molecules and form iron-sulfur clusters. These iron-sulfur clusters play a vital role in energy production within the mitochondria. When this system is working well, enough ATP energy is made to keep cells functioning normally.

The genetic mutations that cause FA lead to a deficiency of frataxin, which prevents the mitochondria from producing enough ATP to keep the cell functioning well. Low levels of frataxin also lead to a buildup of excess iron within the cell. Too much iron can trigger the formation of reactive oxygen species, toxic molecules which damage the cell and lead to cell death. Because of its relationship to energy production and cell health, low levels of frataxin especially impact high energy organs such as the nervous system and the heart. In FA, cells in the brain, spinal cord, and heart muscle do not have enough energy and are damaged by reactive oxygen species. Over time, this damage and lack of cellular energy causes the symptoms of FA.

Management and Treatment of FA

FA Care Team

Most children with FA receive care from a variety of specialists to manage and monitor their symptoms. After a new diagnosis, the list of specialists to see can be overwhelming and learning how to best manage all of these visits can take time and patience.

Here are the specialists to see after a new diagnosis:

- Neurologists are typically the primary providers for children with FA because they are able to track symptoms related to ataxia and reflex and sensory loss. Upon diagnosis, your child's neurologist should perform a neurological assessment to understand their current symptoms and functional level. As your child's main FA care provider, their neurologists will likely be the doctor referring them to the other specialists who will be part of the team. Neurologists with FA experience can be found through the FA Global Clinical Consortium https://www.curefa.org/research/clinical-network-trials.

- Cardiologists work with individuals who have FA to monitor the heart for signs of cardiomyopathy (thickening of the heart muscle) or arrhythmias (irregular heartbeats). After diagnosis, a cardiologist should test your child's heart function with an echocardiogram (an ultrasound of the heart) and an EKG (a measurement of the heart's electrical activity).

- Physical and occupational therapists work with children with FA to build strength and learn how to modify different daily tasks that are impacted by symptoms, so it is recommended to be evaluated by these specialists after diagnosis.

- Primary care physicians, such as your family doctor or pediatrician, are important members of your child's care team. It's important to have a local doctor who knows your child well and can help with urgent situations or run-of-the-mill illnesses and injuries.

In addition to the exams done by a neurologist and cardiologist, it is important to have screening for scoliosis and blood glucose assessed after an FA diagnosis. Your child's FA specialist may recommend other procedures that are unique to your child. **After these initial evaluations, neurological assessment, heart function tests, physical and occupational therapy assessments, scoliosis assessment, and blood glucose evaluation should be repeated every year.**

Each person with FA has their own unique set of symptoms. These additional evaluations may be needed from other specialists based on an individual's symptoms and disease progression.

- Speech therapists can do assessments of speech and swallowing if your child is experiencing dysphagia (difficulty swallowing) or dysarthria (slurred speech). They would also help to treat these symptoms.
- Orthopedists can help manage scoliosis (curving of the spine) or pes cavus (high arched feet)
- Endocrinologists can help manage diabetes, growth differences, and low bone density (osteoporosis)
- Mental health professionals like therapists, psychologists, and psychiatrists, can help your child manage mental health issues
- Dietitians can make a care plan to help your child maintain a healthy weight
- Audiologists can assess for hearing loss and suggest adaptations.
- Ophthalmologists can assess for vision loss and suggest adaptations.
- Geneticists and genetic counselors can help you and your family understand how FA is inherited and facilitate genetic testing for other family members.
- Pulmonologists and sleep specialists can help assess for and treat sleep apnea.

Lastly, the most important member of the FA care team is you. As the parent of a child with FA, your input and advocacy are integral to the care team. Some of your new specialists may not be familiar with FA, so it may fall to you to introduce them to different aspects of the condition. Don't be afraid to speak up if you feel like a care plan isn't going in the right direction; you are the expert in the room when it comes to your child's FA symptoms and experiences. As you work to build your child's FA care team, you may need to try different doctors until you find those who are the right fit for your team.

If you are meeting with a new clinician who is unfamiliar with FA, it may be helpful to refer them to resources that explain the condition including this guide and the FA Clinical Care Management Guidelines, which are intended to assist qualified healthcare professionals make informed care plans for individuals with FA https://frdaguidelines.org/.

SKYCLARYS® (Omaveloxolone)

The first treatment for FA, SKYCLARYS, was approved by the Food and Drug Administration (FDA) in early 2023. SKYCLARYS is a once daily oral medication that is currently available to individuals diagnosed with FA in the US who are 16 and older. Clinical trials will be conducted to investigate

safety, dosing, and efficacy of SKYCLARYS in children with FA.

SKYCLARYS improves mitochondrial function through several mechanisms, including increasing production of antioxidants, molecules that protect the mitochondria from reactive oxygen species. This allows mitochondria to function better even with deficient frataxin levels. Clinical trials showed that SKYCLARYS improves neurological function and slows progression of FA symptoms.

Future Treatments: Research, Clinical Trials, and Clinical Studies
SKYCLARYS is not a cure for FA, but an important first step in treatment. Physicians and scientists believe multiple treatments will be needed to address all aspects of FA and stop the progression of the disease.

The Friedreich's Ataxia Research Alliance (FARA) is dedicated to advancing treatments for FA. Currently, there are several possible treatments being researched and pursued. Visit FARA's website to learn more about the research pipeline https://www.curefa.org/research/research-pipeline

Two types of research that people with FA can participate in are clinical trials and clinical studies. Clinical trials involve testing a treatment in patients to collect data about the safety of the treatment and how well it works. Clinical studies do not involve testing a treatment but rather focus on observing a population of patients to collect data about the disease. Our current understanding of FA, the approval of Skyclarys, and the approval of future treatments are owed to all of the people with FA who have participated in clinical studies and trials. Learn more about clinical studies and trials here: https://www.curefa.org/pdf/Clinical-Trials-101-Guide-for-Participants.pdf

If you are interested in having your child participate in clinical trials and studies, you can enroll them in the FA patient registry to be contacted about upcoming studies and trials: https://fapatientregistry.org/ One study that is open to all individuals with FA is UNIFAI, an international natural history study. To join this study, contact one of the coordinators: https://www.curefa.org/research/clinical-network-trials

Exercise, Nutrition, and Supplements

Exercise and Physical Therapy

Exercising regularly is an important part of maintaining health for everyone. Because FA affects balance and coordination, exercises focused on improving mobility, balance, and strength are particularly useful for someone with FA. Exercise that strengthens muscles may help your child compensate for their balance and coordination issues, and exercise may also help improve fatigue and sleep. Exercises that are recommended for people with FA include strength training of the arms,

legs and trunk (core), cardiovascular exercise (such as swimming, walking, or biking), balance exercises, and stretching.

Adaptive exercise equipment, including recumbent trikes and hand cycles, are great options for individuals who use mobility aids. Check out the Ataxian Athlete Initiative, which helps people with ataxia access adaptive cycling equipment. https://www.curefa.org/ride-ataxia/ataxian-athlete-initiative

Physical therapists are integral members of the FA care team who can teach your child exercises and develop an exercise plan tailored to your child's specific needs and goals. Regular physical therapy sessions can help children with FA maintain strength. Physical therapists can also help address any new mobility issues that may arise.

Nutrition

Nutrition is another aspect of health that impacts all people. Eating a balanced diet may help to increase energy levels, aid digestion, and improve mood. Like all other aspects of FA, nutritional needs are unique, and no two children with FA will thrive on the same exact diet. Although balanced diets are usually considered high in protein and fiber and low in simple carbohydrates, it is important to work with your care team to find the diet best for your child.

FA affects the way the body breaks down food to make cellular energy (see Genetics of FA). Children with FA are at risk of having low BMIs, or body mass indices. This means that some children with FA may struggle to maintain or put on weight. Your child's general pediatrician can assess their BMI and refer you to a nutritionist if your child seems to be struggling to put on weight. A nutritionist can create a plan to help ensure your child is getting enough calories and nutrients to support them through development.

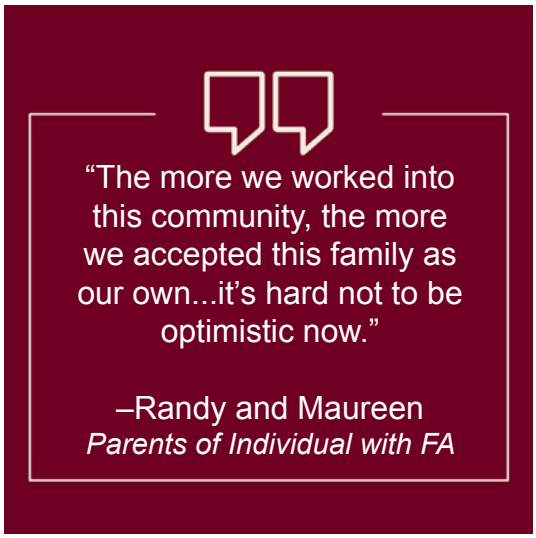
Additionally, people with FA may experience dysphagia, or trouble swallowing. This symptom often presents as choking when drinking water or other thin liquids. Using straws or liquid thickeners may help avoid choking.

Supplements

Supplements are vitamins and minerals that our bodies need to properly function and stay healthy. Most of us get enough of these vitamins and minerals from our regular diets. If someone is not getting

enough of a specific vitamin or mineral from their diet, they may need to add a “supplement” of the lacking nutrient.

Some individuals with FA take the antioxidant supplements idebenone, CoQ10, or vitamin E. Antioxidants are thought to support mitochondrial health by protecting against damaging free radical molecules. Because the root cause of FA is mitochondrial dysfunction, several research studies have investigated the use of these supplements as treatments for FA. Studies in animal and cell models suggested the supplements may benefit people with FA. Clinical trials where these supplements were tested in people with FA showed that the supplements were safe to consume. However, the clinical trials were not able to prove that these supplements slowed the progression of FA symptoms. The clinical trials were small and short in duration. Because of the small number of trial participants and the fact that FA symptoms tend to progress slowly, it is possible that these supplements do have a positive impact that the trials were simply unable to capture.



Because the trials could not prove that these supplements slow progression of FA symptoms, idebenone, CoQ10, and vitamin E are not recommended or approved treatments for FA. However, because they are safe to consume, linked to mitochondrial health, and can be acquired without a prescription from a doctor (over the counter), some individuals with FA take these supplements.

Even though you usually don’t need a prescription to get these supplements, it is important to speak with your child’s doctor or care team before taking any supplements or vitamins. Your child’s doctor can help determine if these supplements may benefit your child and ensure that the supplements will not interact with any other medications or vitamins your child may be taking.

Talking to Your Child About FA

How do you talk to your child about their new diagnosis? Although the exact answer will look different for each family, it is important to view this as an ongoing discussion that will evolve as your child ages. Involving your child in their doctors' appointments when appropriate, such as encouraging them to speak directly with the doctor about their symptoms or questions, may help facilitate this. These are some ideas and questions that may help you frame the conversation with your child:

Starting the discussion

Meet your child where they are. Maybe you both are ready to learn more about FA and meet other members of the community, or maybe one of you isn't ready to learn more. The FA diagnosis will affect each member of your family differently, and it's okay to allow each other to be at different stages in the journey.

Listen to your child and reflect their language in your conversations. Your child may already understand that they are different from their peers and may have specific words to describe the symptoms they feel. Explain to them that the doctor did some tests and they found out these differences and feelings are because of something called Friedreich's ataxia.

Describing FA

The bodies of kids with FA are different from the bodies of kids who don't have FA. This is something that you are born with, like hair color or eye color or being short or tall.

Discuss symptoms of FA based on what your child experiences. For example, you may say, "FA is the reason why it's hard for you to walk," or "FA is why sometimes you can't balance well."

Answering questions

Be informed and prepared to answer questions when they arise. It's okay to answer a question with "I don't know, but we can find out," and use resources such as your care team or FARA to help find answers.

These days, children are adept at using the internet and may be able to learn about FA on their own without your guidance and support. It's important to be as honest as possible with your child when they ask questions about FA symptoms or their future without overwhelming them. Simple and direct answers are best.

Sources of support

Lean on others for support and advice. If you meet with a clinician who has FA expertise, they may be able to give you suggestions on how to speak to your child about the diagnosis based on other families they've worked with. Reaching out to other parents of kids with FA may also be an avenue to learn about ways to frame the discussion, but what works for others may not work for your family!

Remember that you know your child best. You know their quirks, loves, fears, and habits – the FA diagnosis doesn't change that. If you have talked to your child about difficult or complex issues in the past, relying on those experiences for guidance may help you as you discuss the FA diagnosis.

The FA Community: You Are Not Alone

After a new diagnosis, it is common for parents and their children to feel isolated and struggle to find support. Despite the fact that FA is classified as a rare disease, there is a strong FAmily of other people with FA, their family members and friends, and others ready to support you. It can be overwhelming to jump right into a community you were never expecting to be a part of, but these resources are here for you whenever the time is right.

Contact FARA at info@curefa.org or 484-879-6160 for support.

Connecting With the FA Community

FA Parent's Group: For parents or caregivers of children with FA or other pediatric onset ataxias http://www.faparents.org/fapg/

FARA's FA Ambassador Program: for patients 16 and older who want to volunteer to support FARA's mission to cure FA https://www.curefa.org/ambassador-blog/

FA Hangouts: a safe space to hangout online for adults with any kind of ataxia and their friends, family, or caregivers. Contact dillon.fahangouts@gmail.com for more information.

Teen Hangouts: a safe space to hangout online for teens with FA, moderated by two FARA ambassadors. Contact farateenhangouts@gmail.com for more information.

The National Ataxia Foundation has several support groups for children and adults affected by ataxia as well as family members and caregivers https://www.ataxia.org/support-groups/

Facebook has several FA support groups, including international groups

Patient and Caregiver Stories

Friedreich's Ataxia News: articles written by members of the FA community and forums where people with FA, FA caregivers, and FA clinicians can communicate. https://friedreichsataxianews.com/

Meet the Community on FARA's website: https://www.curefa.org/meet-the-community/

Videos from the FA Community on FARA's YouTube page https://www.youtube.com/playlist?list=PLdr4vvwxGhYfmpEfAcGF2U3kxgKOJ168A

Two Disabled Dudes: podcast hosts Kyle and Sean, who have FA, discuss living life beyond circumstances and have conversations with other members of the disability and rare disease communities. https://twodisableddudes.com/

FA Voices: a podcast and video series focusing on the FA experience produced by Reata Pharmaceuticals. https://www.connectfa.com/fa-voices/

International Ataxia Organizations

Argentina: La Asociación Civil de ATaxias de ARgentina http://www.atar.org.ar/ ; Ataxia Patients and Friends Group https://www.gpatax.org/

Australia: Fara Australia https://www.fara.org.au/

Brazil: Ataxia de Friedreich Brasil http://abahe.org.br/

Canada: Ataxie/Ataxia Canada https://lacaf.org/en/

Czechia: FRIEDA https://frieda.cz/

Denmark: FORENINGEN for ATAKSI HSP

Europe: Euro Ataxia https://www.euroataxia.org/

France: Association Francaise de l'Ataxie de Friedreich https://www.afaf.asso.fr/

Germany: Friedreich Ataxie Fordeverein e.V. https://www.friedreich-ataxie.de/ ; Deutsche Heredo-Ataxie Gesellschaft https://www.ataxie.de/

Greece: Hellenic Friedreich's Ataxia Association https://hefaa.org

India: Ataxia Awareness Society https://www.ataxiaindia.com/

Ireland: FARA Ireland https://faraireland.eu

Italy: Italian Association for the Fight Against Ataxia Syndromes (AISA) https://www.facebook.com/aisatassia.campania

Lebanon: Friedreich's Ataxia Lebanon Association http://falassociation.org/

New Zealand: FARA New Zealand https://www.fara.org.nz/

Portugal: Associacao Portugesa de Ataxias Hereditarias http://www.apahe.pt

Spain: La Federacion de Ataxias de España https://fedaes.org/

Sweden: Bota FA http://www.bota-fa.se/

United Kingdom: Ataxia U.K. https://www.ataxia.org.uk/

FA Events Near You

Check FARA's websites to find any charity or educational events happening near you: https://www.curefa.org/events

Ways to Get Involved

- Join the Patient Registry to be contacted about research studies and clinical trials. https://fapatientregistry.org/
- Get involved in FARA's fundraising efforts by attending a fundraising event or donating online. https://www.curefa.org/events/ https://www.curefa.org/donate/
- Volunteer with FARA at events to spread awareness of FA and promote relationships with key research and industry stakeholders.
- Attend a FARA symposium or FA community event: https://www.curefa.org/events

What is FARA?

The Friedreich's Ataxia Research Alliance (FARA) is a national, public, 501(c)(3), non-profit, tax-exempt organization dedicated to the pursuit of scientific research leading to treatments and a cure for Friedreich's ataxia. The mission is to marshal and focus the resources and relationships needed to cure FA by raising funds for research, promoting public awareness, and aligning scientists, patients, clinicians, government agencies, pharmaceutical companies and other organizations dedicated to curing FA and related diseases.

What You Can Do Next

- Start building your child's FA care team by reaching out to specialists and planning appointments.
- Download the Clinical Care Guidelines to give to doctors that may not be as familiar with FA: https://frdaguidelines.org/.
- Enroll your child in the FA Patient Registry to ensure you are notified about clinical trial and study opportunities by visiting www.fapatientregistry.org.
- Consider joining the UNIFAI natural history study to contribute to our understanding of FA.
- Connect with others in the FA Community through FA Hangouts, the FA Parents Group, or our Meet the Community series.
- Attend a FARA event such as a symposium, rideATAXIA, or other local event. Look through upcoming events on www.curefa.org/events.
- Sign up for FARA's newsletter to stay up to date on current research, trials, and events.

"Connect with FARA and the FA community. They are a wealth of knowledge and support."

–Rolf and Katie
Parents of individual with FA