



Dear Friend,

I am the mother of 3 boys. One of my sons was diagnosed with Friedreich's ataxia (FA). Below, I have written out my thoughts and observations regarding the adjustments in my family's life that have resulted from that diagnosis.

All families are different, but I hope you and your family find something helpful in my experience. If you would like to talk personally with a parent of a child with Friedreich's ataxia, please call FARA at (484) 879 6160.

Sincerely,

Raychel

Raychel Bartek

Prior to Diagnosis

When my son Keith was in the third grade, he slowly began showing signs of fine-motor skill problems. His handwriting got progressively worse and he would shake his hand because it cramped when he wrote just a few sentences. It took him hours to do his homework. His grades began to fall. The school ruled out emotional or learning disabilities. He would also fall and lose his balance for no reason. Despite early enthusiasm with karate lessons, he grew frustrated with his balance and decided to stop taking the lessons. Following a number of meetings with teachers, counselors and administrators, Keith was placed on a waiting list for an appointment with a pediatric neurologist to check for medical problems. Two years had passed by that time and Keith was completing the 5th grade. Everyone was frustrated — school officials, parents and, most of all, Keith.

Receiving the Diagnosis

At Children's Hospital, Keith was given a series of neurological tests, an MRI and an x-ray of his spine. The neurologist took out the "little hammer" to test reflexes in his knees. There was no response. I felt a chill and shudder come over my body. I knew something was terribly wrong. The doctor then performed a nerve conduction test where Keith's legs and arms were wired to receive electric current to see how his nerves responded. After this painful test, the doctor asked Keith to go play in the waiting room. Sensing that it was bad news, I pleaded for the doctor to tell me what her suspicion was. Her eyes watered as she told me Keith had a neurodegenerative disorder called Friedreich's ataxia.

From the information I would find that night on the Internet, I would learn that Friedreich's Ataxia would slowly rob Keith of his ability to run, walk, write, and speak clearly. He would probably be in a wheelchair by his late teens. He would develop serious scoliosis and possibly diabetes. Worse yet, the heart condition accompanying the disorder, I read online, reduces the average life expectancy to early adulthood.

My first question to the teary-eyed doctor was, "What medication can he take to help him?" I was not prepared for the answer, "There is no treatment and there is no cure." Gathering as much composure as I could muster, I walked out to see Keith. He looked up and asked me why my eyes were red and the only thing that I could think to say was that the alcohol smell in the hospital made my eyes water. As we drove home, I felt like I was in a trance. Several weeks later, the results of a genetic blood test confirmed the diagnosis of Friedreich's ataxia. Once we had an official diagnosis, we had many adjustments to make regarding our family, coping, and the educational and medical needs for our child. You will probably have similar adjustments, questions, and experiences.

Telling Your Child

Is your child old enough to understand? If you have more than one child, how will the others react? Are you able to discuss the diagnosis without becoming overly emotional? Will your child be accepting, angry, scared? When will you want to tell your child?

Keith was 11 years old when he was diagnosed. His brothers were 9 and 13. We waited a few days before we all gathered together. It was important to stay calm and composed — meaning Mom should try not to cry. We told the boys that we finally knew why Keith had been having so much trouble in school and why his muscles were cramping and he fell sometimes. We told him and them that he had Friedreich's ataxia and that it would make it harder for him to walk, run, skateboard, and ride a bike. We found it helpful to keep the explanation simple and general. We think it important not to lie to the kids, but we don't feel you have to go into great detail. After the family meeting, we met with just Keith to answer any other questions he may have had. Over time Keith's questions become more specific and we have always answered his questions honestly.

My Brother has FA

When Keith's older brother, Byron, was in Middle School, he wrote a school report about Keith's diagnosis. Here are his words:

"When we were first told that Keith had Friedreich's ataxia, we were confused because we had no idea at the time what it was. My parents explained it to my younger brother and me and we understood that Keith would soon need our help for certain things. For example, he can barely write at all and I sometimes need to help him with his homework. He cannot do PE in school, so he has to be in adaptive PE, which is probably very boring. His friends sometimes give him help carrying his books and backpack. He has to wear a back brace for most of the day because he has a curve in his spine and the doctors are trying to keep it as straight as possible. One day he'll need an operation to keep it straightened. He also gets tired if he has to walk too much and he sleeps a lot on the weekends, usually twelve or thirteen hours a day."

School - Your Child's Education

A child diagnosed with Friedreich's ataxia is served by the Individuals with Disabilities Education Act (IDEA). This law entitles your child to have an Individual Education Plan (IEP), which provides a blueprint for how the child's education needs must be met. IEP teams, usually consisting of parents, administrators, teachers, and sometimes the student and outside experts, meet to craft each child's IEP.

[The Individual Education Plan \(IEP\)](#)

Telling Classmates

My son Keith was in 6th grade when the school recommended we tell his classmates about his diagnosis. He had been diagnosed at the end of 5th grade. Keith, his dad, and I appeared before the 3 different sections of 6th grade — about 25 kids per section. I prepared remarks — mainly to avoid becoming emotional or rambling. After the prepared remarks, we opened the floor up for student questions and answers.

Coping - Where can I turn?

An excellent resource available for helping you and your family cope with living with FA is a group of parents facing the same diagnosis and challenges. If you are a parent of a child diagnosed with Friedreich's ataxia, the [Friedreich's Ataxia Parents Group \(FAPG\)](#) welcomes you and wants to tell you that you are not alone anymore! From all over the world, parents communicate with each other through this e-mail list. Parents share the joys of raising their children, as well as the heartache of the progressive condition called Friedreich's ataxia.

I have met many helpful and caring parents through FAPG and I'm proud to have developed many lifeline friendships from this group. I can compare educational and medical needs with other parents, as well as advice on coping skills, helpful devices, and helping hands in the community. FAPG parents understand, too, that sometimes you need to discuss the challenges of your day with someone who can relate. In one word: invaluable!

Life After Diagnosis - There is hope!

After receiving this diagnosis, your family life is in an upheaval of change. As time passes, a "new normal" evolves. And yes, on some days you will wonder why you complained about anything prior to Friedreich's ataxia entering your family circle.

There is hope through research. FARA is working every day to promote research seeking a treatment or cure for Friedreich's ataxia. Please consider helping FARA by raising funds to support research. Together, we CAN change the timetable of this disease.

Another way you can help is to consider [participating in a clinical trial](#).