What is it?
FA mainly affects the nerves. The nerves carry signals. They pass from the brain to muscles so we can move. They also allow us to feel things. People with FA have problems with moving. This slowly becomes worse over many years. At first any movement is a bit wobbly. Children are clumsy. They may fall a lot. Then they become weaker. It is due to a defect in a gene (you say gene like jean). We do not know why the defect happens. You are born with it. You do not catch it like the flu. It doesn’t go away. There isn’t a cure. But things can be done to help. About 1 in 50,000 children born in the UK has FA.

What can happen?
Slowly children become weaker. This takes many years. It will become too hard to walk. In most cases this is in adult life. Weakness can cause stiff joints. FA can cause other problems later on. It can cause a curve in the back. In the heart and chest it can make you tired or short of breath. At times the heart can beat too fast or slow. There can be more chest infections. It can become hard to speak and swallow. Choking can occur with drinks or food. Diabetes can occur. This is a problem with sugar levels in the blood. It can be hard for children to do what they want. This can make them feel angry or sad. Help can be given for each problem. FA will affect how long you live. But people with FA can live over 60 years.

How is it passed on?
Our genes make us what we are. Like the colour of our eyes or hair. We have lots of genes. For almost every gene, we get one from our mother and one from our father. So there are two genes for every job. To have FA a child must have a FA gene from both parents. Each parent has one FA gene and one normal one. The parents do not have any problems. But their child has two FA genes. They do not have a normal one, so they have FA. There is a 25% chance (1 in 4) of having another child with FA. The risk stays the same no matter how many children they have. The risk of a person with FA passing it on to their child is very low. This is because the FA gene is so rare. We may be able to test a mother’s baby before birth.

What needs to be done?
Often tests of the nerves and muscles suggest FA. These are called NCV and EMG tests. In many cases a blood test will confirm it. Later, tests will be needed for the back, heart and chest. Like x-rays, ECG and heart scans. The heart scan is like the one a mother has to see baby before birth. Your doctor will see you. The urine is tested for sugar to check for diabetes. There is no treatment for the weakness. Children can do as much as they want. It may be best not to push them too hard. Therapists can help cope with weakness and stiffness. Surgery may be needed for joint or back problems or choking. Help and treatment can be given for other problems. It is best to have all the jabs and two extra ones (pneumococcal and flu). A doctor who knows a lot about gene defects and how they are passed on can see your family. Others may need to be tested. Ask about claiming benefit.
Where can I find more help and information?

**Contact a Family**, 209-211 City Road, London EC1V 1JN, 0808 808 3555, e-mail info@cafamily.org.uk, www.cafamily.org.uk.


**Friedreich’s Ataxia Parents Group**, www.fortnet.org/fapg.

**APTCOO** (a place to call our own), Unit 15, Botany Park, Botany Avenue, Mansfield, Notts NG18 5NF, 01623 629902.

**King's Mill Hospital**
Patient Advice and liaison Services (PALS) on 01623 672222

**Newark Hospital**
Patient Advice and Liaison Services (PALS) on 01636 685692