Brothers with big ambitions and determination to beat condition

Highlighting Jeans for Genes Day, meet the family fighting not to let genetic condition derail dreams

TWO young brothers are refusing to let a debilitating genetic disorder stop them achieving their dreams, as they this week raise awareness of what they and others like them experience ahead of a special national fundraising day.

Alex Foy, 17, and his 12-year-old brother William, from Broadstairs, have a condition which severely hampers their mobility, leaving them both confined to a wheelchair and in regular pain.

But they are determined to overcome the challenges in their way, and will be joining thousands around the country next month for Jeans for Genes Day – a charitable event that encourages everyone to wear jeans to work or school in return for a donation.

And all monies raised will go to the charity, which specialises in helping children who suffer from genetic disorders.

The Foy brothers were both born with Charcot Marie Tooth (CMT), an inherited condition that causes muscle weakness in the feet, ankles, legs and hands.

It affects one in 2,500 people in the UK, and is one of the most commonly inherited neurological disorders.

The brothers have a 50/50 chance of passing it on to any children they have.

Both inherited it from their father Jonathan, who also has the condition.

Their mother, accountant Rebecca, has given up work to care for the family.

The mother-of-four boys told us: "Each night Alex and William are in pain. My other boys James, 15 and Edward who is 10 do not have CMT.

"We do the best we can. There are all sorts of reasons some people are not able to do particular things in their lives.

"But Alex is starting his career in accounting and he loves it. William want to be a maths professor at Oxford or Cambridge."

Both boys have refused to let their condition stop them performing well academically.

Before he was three, William had taught himself to read in under a week with the use of two alphabet charts. Alex completed grade five violin by the age of 10.

They both use a wheelchair to make everyday life a lot less painful.

Mrs Foy said over the years Alex has broken at least 20 bones, mainly in his feet, ankles and legs.

She said: "For Alex, grammar school was hell. He kept falling over and breaking bones, but he couldn't use a wheelchair because they couldn't adjust their timetables for him. We moved him in Year 10 to a better school and he had a social life again.

"With William, he has a very clear ambition in his mind that he has had for so long. He wants to be a professor of mathematics at Cambridge. He was reading Stephen Hawkins when he was eight. When he talks to me about it, I have to slow him down and explain it to me. He know what he wants.

"I am terrible proud of what they have managed to do against all the odds.

"They are fighters and are determined not to let this condition get them down."

Alex said: "I suppose I'm used to it now. My feet hurt every day, as do my knees and hips and back. I used to take painkillers but I needed so many to reduce the pain that I couldn't think straight, so I stopped using them.

"I don't like people seeing my feet as I have lots of scars from the operations I had two years ago. I may need more operations in the future when I stop growing. I can't tell the difference between hot and cold so I'm not allowed to cook as I may burn myself. It's frustrating having to ask other people to help you all the time especially as you want to be an adult."

And William added: "I always keep a walking stick with me as it helps me when I feel like I'm going to fall over. During the week at school or if I'm travelling long distances I use a wheelchair or mobility scooter as I feel much safer sitting down. Alex has broken his feet a lot of times and I don't want that to happen to me. I know that if I do lots of walking or exercise that I will be tired and in pain and I won't sleep well, so I have to chose what I need to do and what I want to do."

This year the money raised by Jeans for Genes Day will fund 70 places at CMT UK's annual family conference, where there are fun sessions for children and workshops for parents.

The organisation said it is also a chance for people living with CMT to share their experience and get to know people in the same situation.

■ Jeans for Genes Day takes place on September 18. For details of how you can get involved or donate, visit www.jeansforgenesday.org.

> **"My feet, knees and hips and back hurt everyday. I used to take painkillers but needed so many I couldn't think straight, so I stopped using them"**
>
> **Alex Foy,** on day-to-day issues of CMT

VOW: Alex and William Foy sometimes struggle with rare condition, but are throwing their support behind a charity day designed to help fund research

JUST WHAT IS CHARCOT MARIE TOOTH?

CHARCOT Marie Tooth disease is more than one condition and can sometimes be called hereditary motor and sensory neuropathy.

Combined, these conditions attack the peripheral nerves outside the main central nervous system of the brain and spinal cord.

These look after muscle control and send information back to the brain – things like what it feels like to touch.

CMT traditionally creates muscle weakness in the feet, ankles, legs and hands and creates difficulty in walking.

The first signs appear at the age of about five and up to 15, but on rare occasions won't manifest until middle age.

The NHS said it is a progressive condition, making tasks increasingly difficult day to day.

The conditions are caused by an inherited fault in one of the genes responsible for the development of the peripheral nerves.

Because there are so many types, the chance of passing it from parents to child depends on the specific genetic faults.

A GP can refer anyone worried to a neurologist who specialises in the nervous system.

Anyone suspecting it to be in their family should see a doctor if they are considering having children.

There is currently no cure for CMT, according to the NHS.

But treatments can relieve symptoms, aid mobility and increase the independence and quality of life for people with the condition, it said.

Things to try are physiotherapy, exercise, occupational therapy and walking aids. Surgery can sometimes also help.

It is not life-threatening but makes everyday activities very difficult. Living with a long-term, progressive condition can also have a significant emotional impact, the NHS says.