Wick woman speaks out in effort to raise awareness

Claire: My battle with incurable neuro disease

HER struggle coping with a rare neurological disease has caused Wick woman Claire Fraser to speak out in a bid to highlight the condition.

The 31-year-old has inherited Charcot-Marie-Tooth (CMT) which can cause uncontrollable pain, chronic fatigue, twisted ankles, balance problems and falls.

Claire believes her son may have it too, although he is too young to have an official diagnosis.

She revealed some of the challenges of living with the disorder as part of CMT awareness month.

It started with pains and fatigue when she was about 10 and was diagnosed with CMT type 5 when she was almost 12.

Claire said: "Other members of my mum's side of the family also have CMT, including my mum, and they never knew for sure what it was until I was diagnosed. My granny was told as a youngster that she must have polio.

"I have had the usual teasing and funny looks and questions about what's wrong with my teeth because of the name Charcot-Marie-Tooth.

"I was given the name 'gimpy' through high school, which hurt. I left classes five minutes early to get to the next class and couldn't take part in PE.

"I have found it a struggle over the years keeping up with others and now having my own son, who also shows signs of the condition, it can be hard work on my own too.

Claire Fraser believes her son may be afflicted too.

"I have orthosis (a device which helps with posture), which helps a little, but as I live in the north I don't really see any doctors about my disease now as they don't know much about it up here."

Charity CMT UK is aware of 3000 people with the condition but experts believe there are around 23,000 UK-wide sufferers. The charity is keen find the others so it can offer advice on how to manage the condition as well as support with benefits, jobs and family issues.

The disease is named after the three scientists who discovered it. Currently incurable and steadily progressive, it causes muscle weakness in the lower legs and hands, leading to problems such as hammer toes and restricted mobility. However, people with CMT have a reasonable quality of life, with normal life expectancy.

CMT UK's chief operating officer, Karen Butcher, said: "We want to reach out to people who may not be members of CMT UK and urge them to get in touch.

"We know what they're going through and the challenges they face, so we can answer their questions, put them in touch with other people and families with CMT and tell them where they can get help and advice.

"For CMT UK, reaching even a fraction of the missing 20,000 would open the possibility of increased membership and fundraising to support our services.

"As CMT is extremely complex, with around 80 genes causing the condition, some people could even help with valuable research as there is still so much to learn about this rare condition."

■ To find out more visit www.cmt.org.uk or contact 0800 652 6316.