

I took a risk having children, but it was definitely worth it

When Colin Tyrie discovered he wasn't 'clumsy' – but instead had a rare genetic disorder – he also learnt he had a 50-50 chance of passing it on. But, he tells **Alice McKeegan**, he is determined to make sure his beautiful daughter Stevie has the best life possible

FOR years Colin Tyrie was labelled clumsy. Teased by his classmates and written off by teachers as troublesome, it was no surprise he left school with no qualifications.

Feeling consigned to the scrapheap at just 16, Colin always suspected there was something medically not quite right with him and he was determined to get to the bottom of it.

But it wasn't until the age of 39 that he found the answers. After dozens of trips to his GP and hospitals, he was finally diagnosed with Charcot Marie Tooth – a rare neurological condition.

The disorder, which affects mobility, is debilitating and results in loss of feeling in the limbs. It is incurable and suffer-

ers can end up in a wheelchair. Around 23,000 people in Britain are thought to have the condition, many of them without knowing.

Although Colin, now 48, from West Didsbury, was relieved to have a diagnosis, it also gave him the toughest dilemma of his life.

He and wife Cath, 40, wanted to start a family but knew there was a 50 per cent chance of passing on the condition.

The couple had to go through weeks of genetic counselling to prepare them mentally and emotionally for the possibility.

But despite some difficult soul-searching they eventually decided to try for a baby and

were thrilled when daughter Billie, now seven, was given the all-clear.

But they longed to give her a brother or sister so had to go through the same ordeal again.

This time, their second daughter – Stevie – did inherit the condition. And, in a double blow to the family, she was also diagnosed with cerebral palsy.

But Colin's fighting spirit kicked in and he was determined to give her all the support he never had during childhood. Stevie, now five, is doing well at the Lancasterian School in Didsbury and is receiving extra help with her learning.

Colin said: "I was considered a clumsy child, regularly falling over and not walking until I was

two. The symptoms weren't really understood and I was seen by various doctors who were baffled by it.

"I couldn't hold a pen for longer than around 20 minutes because my fingers would freeze up so it was impossible for me to complete any exam. It was really tough and I really struggled at school. When I got the diagnosis I was relieved more than anything."

One of five children, Colin was the only person in his family to have the disorder. Neither of his parents had the condition and doctors suspect it was caused by a rogue gene mutation, making it even rarer.

"I guess you could say I'm unfortunate but it's just one of those things," Colin added. "When we realised there was a

'I do feel guilty at times... but those feelings pass'

» **DADDY'S GIRL**
Colin Tyrie and his daughter Stevie
Photograph Howard Walker



50 per cent chance of passing it on to our children it was obviously on our minds. They told us the risks but we decided to take that chance – our desire to have a family was stronger.

"I do feel guilty at times because I think was it fair to pass

it on to our daughter just to satisfy our need of being parents?

"But those feelings pass and then I think it's possible to lead a good life even with the disorder. Having a disability doesn't stop you doing what you want to do. It might just make it a bit more

