Two Of A KIND

Ruth's girls suffer from an ultra-rare disorder

Ruth Higginson, 45, St Ives, Cambridgeshire

Phoebe and Amelia are real characters!

Triplets!

'I can't believe we're having triplets!' I beamed.

My husband Mark, then 48, and I had just left the hospital with massive grins.

It was amazing news. We couldn't wait to tell everyone.

Of course, having three babies at once made us nervous. And we already had our daughter Josie, 1. But we couldn't wait for our big family.

Jamie, Amelia and Phoebe arrived in September 2007.

We were so happy, but I couldn't help feeling the two girls, who were identical, were different to Jamie.

When he woke up crying, we'd eventually settle him, like any other baby.

But the girls would scream all night.

As Jamie met his milestones, the girls struggled to keep up.

> 'As Jamie hit his milestones, the girls struggled to keep up'

They weren't feeding or gaining weight properly. They'd also look straight through me, while Jamie would stare back and smile.

Hospital tests were inconclusive, but doctors could see they were disabled.

At 6 months, they were floppy and weak, couldn't lift their heads. Doctors weren't sure why.

'They'll need 24/7 care for the rest of their lives,' they said.

We were devastated.

Now 8, the girls can't walk or talk. They're fed through a tube and suffer from curvature of the spine.

But support's been great. The NHS provided physios, dieticians and carers, and the local council adapted our home to be wheelchair-friendly.

And in March last year, Amelia and Phoebe were finally diagnosed – they were born with an ultra-rare mutation of the gene Grin2b.

Just a handful of people have this disorder worldwide.

Jamie and Josie are a huge help, caring for their beloved sisters. We're a happy family.

The girls love it when we go on weekend trips to parks and fetes – they're little characters!

It's not an easy normal, but it's *our* normal. I wouldn't have it any other way.

FACT FILE

Grin2b gene disorders are so rare that very little is known about them. They're mostly associated with loss-of-function mutations and some cases have been linked to epilepsy and autism. Symptoms vary from case to case but often involve developmental delays, acid reflux, explosive vomiting, and problems with eating and drinking. Sufferers' disabilities are severe and need long-term care.