

Time is running out for my Maddi

Carina Thurgood, 48, is desperate to find a cure for her daughter's rare disease...

Watching as my daughter Maddi walked out of the front door with her backpack on, I smiled. Arm in arm with her best friend, they were deep in conversation – if I had to guess, from the giggles, I'd say they were talking about boys.

'Oh, to be 13 again!' I thought to myself with a grin. Only, as I watched the girls stroll up the road apparently in no hurry to get to school, I noticed something. Maddi was walking oddly, as if dragging her left leg.

I couldn't remember her mentioning anything about it to me or her dad Paul. I made a mental note to ask her about it that evening, and got on with my day, heading to work as a florist.

'Did you fall over in PE?' I asked Maddi that night, as she and her big sister Alex, then 23, set the table for dinner. Maddi just shrugged her shoulders. 'Nope,' she said. 'My leg is just sore.'

I don't know why – after all, kids hurt themselves all the time – but call it mother's instinct, something told me this was more serious. 'Mum, it's fine,' Maddi sulked, as I dragged her to see the GP two days later.

At first, the doctors agreed with Maddi, suggesting it was probably an ache from her ice-skating lessons, or growing pains. But months passed

and the limp was still there. I lost count of how many times I took Maddi to the doctor, but each time I was told the same thing – the limp would disappear on its own. 'I'm sure it's OK,' Paul said, when I expressed my concern. Only the limp didn't disappear. And, a year later, although Maddi was still her bubbly self, the pain was getting worse.

Anxious wait

Soon her leg was aching so much we couldn't go on our usual mum and daughter Saturday shopping trips, and family walks near our home in

Essex were impossible. Sometimes Maddi was in so much pain I had to keep her off school. Finally, in

December 2015, determined to get to the bottom of what was going on, I took Maddi to see a private doctor. I don't know what I was expecting to hear but when the doctor spoke, his words terrified me. 'I think there may be a neurological problem,' he said. They'd need to do more tests.

Paul and I tried to keep positive, for



Maddi has to use a cane to walk – here with her mum Carina



Maddi now spends much of her time in hospital

Maddi and Alex's sakes, saying the tests and scans were all procedure, that there was nothing to worry about. But, waiting for news, I grew more and more anxious.

On 22 April 2016, two days before Maddi's 15th birthday, we left the girls at home, putting up decorations for the party we'd planned and went to the hospital for the results.

There, Paul and I were told Maddi had Krabbe disease, a progressive condition of the nervous system. It would be fatal. I broke down, sobbing hysterically as Paul sat there silent, in utter shock. All I could think was how could I tell my beautiful daughter she was going to die?

We got home just as party guests were starting to arrive. We'd decided we couldn't tell Maddi, not

tonight. It was three days later we finally confessed the truth. 'Maddi, the doctors have given us the results from your test,' I said, visibly shaking, as Paul and I sat down with her in the living room.

Holding back tears, we told her she had a very serious, rare condition but that we would fight it together. Maddi was so scared and confused. 'Why me?' she asked. But I wanted to know that too. Why my girl? Why us?

Then in June 2016, the doctor decided to run more tests to rule out another condition. When he said Maddi had been misdiagnosed, I felt my heart leap – maybe it would be good news. But it wasn't. 'I'm

'Through it all my brave Maddi is still smiling'

shock and Alex broke down in tears. By now, Maddi was regularly falling over and tripping up, she was emotionally and physically exhausted. She started using a cane to walk and had a wheelchair, too. At 15, all she should have been worried about was school and what boys she liked, but most mornings I'd come into her room and her eyes would be bloodshot. 'I couldn't sleep, Mum,' she'd say. 'What's going to happen to me?'

We'd lie on the bed and I'd hold her, desperate to protect her, but feeling so helpless.

'I've got to do something,' I cried to Paul. So we started researching – it was hard, given how rare the disease was

afraid Maddi has the rare and eventually life-limiting disease spastic paraplegia gene 15,' the doctor explained. It could lead to paralysis of the limbs, progressive brain abnormalities and can cause juvenile Parkinson's disease. Maddi was the only person in the UK and one of just 20 in the world to have SPG15. With so few people having the condition, nobody would fund research into it.

When we told Maddi about the new diagnosis, she was in

– but we found some clinics in America, which said they would look at Maddi's case. Using our savings, in October 2016 we visited specialists in Pittsburgh, Washington, Baltimore and Michigan. But nobody had the right treatment.

Disheartened and desperate, we came home, not knowing where to turn. 'There's nothing we can do for Maddi,' doctors said again. But how could I accept that? How could I look my girl in the eye and tell her that?

Just when we thought all was lost, at the end of 2016 a professor at The University of Sheffield offered us a glimmer of hope. 'I want to help,' he told me on the phone. Scientists at the university said they could develop a gene therapy to try to find a treatment or cure for SPG15. But it wouldn't come cheap – we would need at least £224,000, and that was just to kick off the research. But of course, as any mother would, I said yes immediately. 'We'll find the money somehow,' I vowed.

Fundraising

Since then, all our friends and family have been fundraising non-stop, spreading the word, asking for donations. The Save Our Maddi campaign has so far raised £144,000, which is all going into the research. But we're still desperately short. Maddi's body is slowly shutting down. She visits hospital a few times a week, some days she can barely stand. Through it all my brave girl is still smiling, but I can see how scared she is, that one day she'll just disappear.

And the truth is, I am terrified that she's right, that time will run out. No parent should watch their child suffering like this. ●

● To donate, visit themaddifoundation.com



Carina, Alex and Maddi