

al life

We'll make every second count with our precious girl

When Nikki Marshall, 40, fretted over her poorly baby, nothing could have prepared her for the bombshell to come...

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areassing the soft, tiny head of my newborn daughter, I could barely believe that my dream had come true. I always imagined having three girls and now, in February 2021, there was our third daughter to join her big sisters, Connie, three, and two-year-old Freya. Our little Ruby was so small, with wisps of blonde curly hair. 'She's perfect,' I whispered to my husband, John. Life with three children under the age of four was anything but calm, and I loved every moment. But in the first few months,

Ruby was sickly and I blamed colic. By September, though, when we were on holiday in Cleethorpes, I noticed that she was pale and tired. Back home, the GP suspected a water infection and prescribed antibiotics, but she failed to improve. And I became alarmed weeks later when she turned yellow, her veins pulsing weakly beneath her fragile skin. The GP sent us straight to hospital. Ruby underwent blood tests and when the results came back, my world stopped... Her haemoglobin level was 29 when it

should have been nearer 100 to 140. Her red blood cells, her body's lifeblood, were dangerously depleted.

Within hours, we were blue-lighted to a leukaemia ward. Frightening machines beeped around us as nurses prepared blood transfusions for our tiny daughter. I held John's hand as we tried to understand what was happening to our perfect baby. Desperately, I held on to hope and said, 'It'll be okay.' But John's face was grim when he replied, 'It's not looking good, though, is it?' The tests revealed an infection in Ruby's bone marrow. We prepared ourselves for the diagnosis – a condition which would mean blood transfusions for life.

But the final diagnosis, delivered in January 2022, shattered everything. Ruby had Pearson's syndrome, a devastating mitochondrial disorder so rare that only three other children in the UK suffered from it. The doctors gently explained what the syndrome was, but the words felt like weapons. There was no cure, there would be progressive organ

damage and a shortened lifespan for our beautiful girl.

Mitochondria are the powerhouses of our cells. Ruby's were broken. Her bone marrow couldn't produce enough red blood cells, leaving her weak and vulnerable. Years ahead promised worsening damage – her kidneys, liver, eyes – all would suffer. She'd lose her ability to walk, lose energy, face diabetes, kidney failure. She

could have dialysis and transplants, but it would be relentless. And precious time would slip away.

We were determined to cherish every moment with her. Ruby spent so much time in hospital that she took her first steps there



Ruby loved meeting giraffes at Chester Zoo

I cried when I saw the strength and pride shining in her eyes. To give her some joy, we got Bobby, a goldendoodle, who became her shadow. He was endlessly patient with a little girl who needed him more than most children need their pets. Ruby had blood transfusions every three weeks. The line stayed in her little arm, tethering her to the hospital.

Then came a miracle we barely dared hope for. After two years of transfusions, Ruby's bone marrow began to regenerate itself. The tests improved, and one day the doctor said the words we'd stopped believing in, 'She doesn't need transfusions any more.' Without the line, we were finally free. We could take her out to places. We could plan. We could breathe. John and I sat down with Ruby just after her third birthday. She was in her 'honeymoon phase', as the doctors called it. It was the calm before the storms which would come at some point in the future, and we wanted to make the most of it. 'Now you're feeling better,

let's think of some lovely things you'd like to do,' I said. Immediately, she shouted back, 'Swimming!' And so Ruby's bucket list was born. Simple, bright adventures we could have together.

Next on her list was a magical day at Chester Zoo, where she gazed in wonder, wide-eyed, at the hippos and giraffes. And this determined little girl longed to fly – on a real plane. As her health steadied, we jetted off to Spain, while Ruby grinned from ear to ear, soaring above the clouds. Hiking up a mountain was her next big dream – her dad carried her most of the way, but she took a few proud steps on her own. Glamping, ballet dancing, rollercoasters at Alton Towers, a sleepover with her sisters, riding donkeys at Blackpool, and meeting her favourite book character, Maisy Mouse – each moment was lovingly ticked off the list.

It's thanks to the kindness of strangers and friends that many of her dreams have come true,

giving us moments sparkling with laughter and life, each one a thread in the fabric of our memories. The Lily Foundation keeps us connected to other families facing similar journeys, ending isolation when the world feels unbearably alone. The Rainbow Trust offers a lifeline of support and precious respite.

Her bucket list has grown. She wants a kitten, to start gymnastics, and to meet singers George Ezra and Taylor Swift. I'd love to fulfil her dreams. Ruby is small, fragile, with low energy and a delicate appetite. She catches bugs more easily than other children do and each hospital visit is a jolt. But we cheered loudly for her fourth birthday, grateful for every breath, every smile.

The day she started school was a day I thought we'd never see. Excitedly, she followed her big sisters into the building. She adores playing with friends and being outdoors and she's in a

wonderful, caring environment. Her teacher helps her to eat at lunchtime, and she can see her sisters. Ruby may have setbacks, but she's got a cheeky, feisty personality. 'I'm not coming out,' she declared stubbornly, when it was time to climb out of our neighbour's hot tub.

We are hopeful. The best-case scenario is that her condition advances slowly and gives us time. We cling to that hope like air. Every morning, I wake whispering, 'This is a good day.' Our hearts carry fear, but also fierce love and gratitude. I want to tell Ruby's story to raise awareness of Pearson's syndrome and to encourage people to give blood. That magical gift of blood donations is what has kept Ruby alive and thriving.

We live day to day, moment by moment, stitched together by love, courage, and the fierce will to make every second count with our perfect little girl.

● For more information, visit thelilyfoundation.org.uk, rainbowtrust.org.uk

Proud day when she started school with her big sisters



Ruby needed blood transfusions



The family love trips out to fulfil Ruby's bucket list



'We live day to day'