OUR SUPER BEN

After losing her precious son, Sarah Crowther, 52, keeps his memory alive

He was always smiling


Beautiful Ben


Our family

Expelliarmus!' squealed my youngest, Ben, zapping me with his wand.

With three sons there was never a dull moment – but I loved our boisterous household. It was always football, superhero games, pranks – and poo jokes!

Obsessed with Harry Potter, Ben and his older brothers, James and Harry, had 'magic battles' all over the house. Ben was fearless and determined to do all his big brothers did.

If he took a tumble, he jumped back up and smiled. If they were teasing him, he gave as good back.

Loving comics, his idol was the mischievous Dennis – so we nicknamed him Bennis the Menace.

In 2018, when Ben was six, he complained of pains in his legs and felt wheezy after running. Though being Bennis the Menace, nothing slowed him down.

It was put it down to growing pains, and Ben was given an inhaler for suspected asthma or hay fever.

But after a particularly wheezy morning that June, where Ben struggled to catch his breath, my husband Scott took him back to the doctor.

'I think there's something else going on,' the GP said, instructing Scott to take Ben to hospital.

Little did we know our boy wouldn't come home for eight weeks – and by then our world would be forever changed.

Ben was given tests and X-rays. The number of medics involved grew, and we heard the word 'oncology.'

It didn't feel real.

Sitting on Ben's hospital bed, I massaged his legs and found a lump in his calf muscle. That was biopsied, then X-rays showed shadows on Ben's lungs.

He was given a lumbar puncture and MRI scan. After 10 days in hospital we had our diagnosis – rhabdomyosarcoma (RMS) and Ben had the worst type. It's a rare and aggressive cancer of the muscles and soft tissue, and Ben was stage 4, with tumours in places including his legs, lungs and chest.

As he began high-dose chemotherapy, Scott and I had to be strong for him. We had to have hope.

After that first long stint in hospital, he had to go back every three weeks for a few nights to have chemo.

It was brutal, but Ben got on with it and kept smiling.

When a nasal feeding tube was fitted he called it his 'energy tube' – because all superheroes need a special energy source.

He loved pranking staff, hiding whoopie cushions on the chairs at the nurses' station and leaving plastic fake poos on the floor.

In early 2019, Scott heard about a charity called The Superhero Project via a dads' support group for fathers of kids with RMS.

The Superhero Project links young people with serious illnesses or disabilities with volunteer artists who create the child's superhero character.

Scott nominated Ben, and the charity's founder Lisa Kollins, from the US, chatted with Ben and his brothers over Zoom.


Ben aged four as Harry Potter


Ben after chemo

Lisa then matched Ben with animation artist Connie Chang. In March 2019, a digital poster created by Connie arrived. She'd turned our boys into superheroes – James was The Happiness Ninja and Harry was Hazza123.

In the centre, brandishing a catapult and wearing a Bennis the Menace striped top was Super Ben, complete with his nasal energy tube. Ben's face lit up with joy as he opened it. It was perfect.

He was so happy and surrounded by love

Ben finished chemo and his hair started to grow back, but tests showed the treatment hadn't worked.

So we concentrated on enjoying every single day, and kept hoping something positive would happen. Scott investigated clinical trials but Ben wasn't eligible.

On March 27, we celebrated his seventh birthday with a house disco for family. Everyone dressed up and played silly games.

Then Ben went downhill suddenly and a couple of months later he went to bed and didn't get up.

A great palliative care team made sure our boy was comfortable.

Family gathered around to support us. Every bed, sofa and floor space had someone sleeping on it.

On June 30, 2019, Ben died in the home where he was so happy, with his family at his side and surrounded by love.

In the wake of his death we founded a charitable fund called Pass the Smile, in recognition of how Ben was always smiling.

We've raised over $620k for children's cancer charities to date.

Ben's memory is very much alive – our friends and family send us poo-related gifts every March to mark his birthday.

I've kept his bedroom just the way he left it.

Still like a tip, I smile.

James and Harry, who were 13 and 10 when Ben died, sit in there at times to feel close to him.

Meanwhile his Super Ben poster hangs overlooking our dining room table.

I always set a plate of food for Ben. James, now 19, and Harry, 16, still squabble good-naturedly over Ben's 'leftovers' – we call them the 'Benny bonus'.

Being turned into a superhero gave Ben a sense of his special and unique identity during the toughest time.

We're forever grateful to The Superhero Project.

A friend sent us a drawing of Ben wearing a cape and flying towards the heavens.

And I like to think our Super Ben is watching over us now.

Visit @thesuperherokid or superheroprojectkids.org

My superhero boys

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