

My little brother was born to save my life



By ANTONIA HOYLE

EXCLUSIVE: CHARLIE, 6, GETS

YOUNG Charlie Whitaker is showing his little brother Jamie how to go camping.

They've carried their bed sheets into the garden and propped them up with umbrellas. A trench has been dug round the outside with toy diggers and shovels.

Charlie, six, thinks the world of two-year-old Jamie. Because apart from being his baby brother and playmate, he has also saved his life.

Charlie was born with diamond blackfan anaemia (DBA), a rare blood disorder that was expected to kill him before he reached 30.

His only hope of a cure was a transplant of stem cells from a brother or sister who was a near-perfect match.

Which is why Charlie's parents, Jayson, 35, and Michelle, 33, conceived Jamie through a pioneering genetic screening process.

By selecting an embryo with a perfect tissue match, they ensured Jamie would be a suitable donor - and Britain's first "designer baby".

The transplant was carried out a year ago. It was successful - and Charlie has just been given the all-clear.

"Finally, after years of heart-break, we can look forward to our family's future," says Michelle, from Palterton, Derbyshire.

This time last year, Charlie was bald and weak after chemotherapy. Today he's never been healthier. He eats everything in-sight and has even

won a blue belt in taekwondo. "He knows this is because of his baby brother and tells everyone that Jamie saved his life," says Michelle.

It's a story of joy and relief - yet when he was born Jamie was the most talked-about baby in Britain.

Embryonic screening was surrounded with such controversy that it was banned by the Human Fertilisation and Embryology Authority in Britain. So Jayson and Michelle travelled to Chicago, where it was legal. Jamie was the result.

The HFEA lifted its ban in July last year, and now several other British couples have had "saviour siblings" - most recently Jodie Fletcher, conceived to save the life of her three-year-old brother Joshua.

"We're friends with the Fletchers and have supported them all the way," says Jayson, a business manager. "We're thrilled that our fight to save our son has paved the way for other couples."

Michelle first realised something was wrong with Charlie six weeks after he was born. "He was pale

and listless. He didn't cry and wouldn't eat," she recalls. At 12 weeks he was diagnosed with DBA, which stops his body from producing enough red blood cells. His vital organs could fail - and he also ran a higher risk of developing cancer in

adulthood. "We were devastated," says Jayson. "It was supposed to be genetic, but there was no history of the illness in our family."

Charlie needed blood transfusions at Sheffield Children's Hospital every three weeks. Five nights a week, he had to have a blood infusion injected into his stomach for 12 hours.

"It was awful," says Michelle. "Charlie would hide under the table and curl himself into a ball to try and avoid having the injections. He'd have nightmares about needles. We tried to make it less scary by calling the infusions 'Billy blood' or 'jungle juice', but he was still terrified.

"It broke my heart that Charlie got tired so easily and had to suffer so much pain.

We had to carry around his needles and medicine wherever we went."

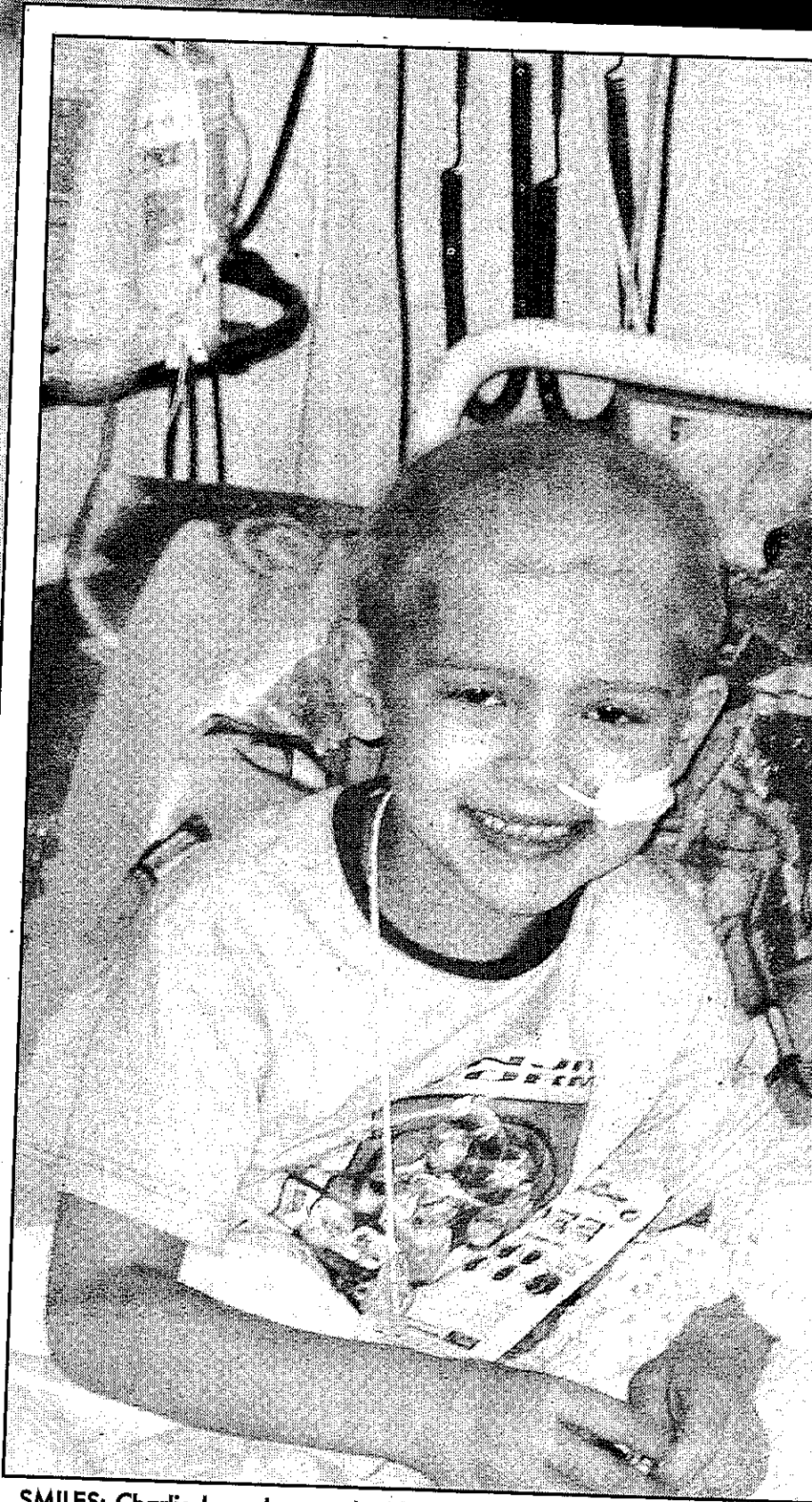
The only realistic chance he had of living beyond 30 was a transplant of umbilical blood cells from a brother or sister. The



JOY: Jayson and Michelle with their healthy trio

BLOOD BROTHERS: Jamie, left, and Charlie

Pictures: GLEN MINIKIN



SMILES: Charlie bravely coped with chemotherapy before the cell transp

HEALTH ALL-CLEAR IN MEDICAL 'FIRST'

Whitakers' second child, Emily, now four, was only a 50 per cent match, but shortly after she was born they heard of medical advances in the US that allowed couples to select an embryo to provide a perfect match for a critically ill sibling. "After two years of frantic worrying, we finally allowed ourselves to hope," says Jayson.

But in August 2002 the fertility specialist they saw said the procedure was banned by the HFEA, who

What's wrong with having a third child to help the first?

deemed it "unlawful" and "unethical" to genetically determine the life of an unborn child.

"We were furious," says Jayson. "We'd always wanted to have four children anyway. What was so wrong with wanting to make sure our third could help the first?"

They contacted the Reproductive Genetics Institute in Chicago, where the world's first "designer baby" was created in 2000. The institute agreed to help, and in October 2002 Michelle started IVF treatment

in the UK to produce eggs for fertility specialists to screen. "As we got on the plane at the end of the month I was nervous and excited," she says. "The treatment cost £20,000, which we got through fundraising.

"Emily and Charlie came with us. There was a wishing well at the hotel. Charlie threw in five cents and wished that his Mummy would have a baby so he could get better." Doctors took 14 eggs from Michelle. "Every time an egg was retrieved I rang a little bell," says Jayson. "Each one symbolised hope for Charlie."

Nine were fertilised with Jayson's sperm in test tubes and grown into embryos. Two proved a perfect match for Charlie and were implanted in Michelle.

"Waiting to find out if I was pregnant was agonising," she says. Six weeks later she got the news. "Jayson rushed home from work and we clung to each other with joy," she recalls. "As the months

passed and my bump grew, Charlie would pat it in wonder. He was longing to get better. But I was terrified Jamie, too, would have DBA. No one knew what the chances were."

He was born by Caesarean on June 16 2003. Jayson says: "It was my 33rd birthday, and as I counted his tiny fingers and toes I felt like the happiest man in the

world." Jamie's umbilical cord was cut and blood extracted from it and frozen until he got the all-clear from DBA. That would take a year.

"Unlike Charlie, Jamie was a loud, bubbly, thriving baby," says Jayson. "But it was still a horrible time. Now, we weren't just worrying about Charlie - we were worrying about Jamie, too."

"Charlie doted over his little brother. He played with his favourite Thomas the Tank Engine toy with him, and even helped Michelle feed him."

A year later, Jamie got the all-clear. "We were overcome with relief," says Jayson. "But we knew there were tough times ahead."

Charlie went into hospital for his blood transplant in July last year.

First, he was given chemotherapy so his body could accept the transplanted cells. "Watching his hair fall out was horrific," says Michelle. "It confused and frightened him." Blood from Jamie's umbil-

ical cord was then transfused into his body to kick-start producing healthy blood cells.

After the two-hour operation, Charlie spent a month in isolation hospital before being discharged.

After that, he had twice weekly blood checks on his red blood cell counts, which was steadily rising. It had to take an anti-rejection drug.

Last October Charlie started school for the first time since his transplant. But if any of his classmates had so much as a cold, Charlie would have to come home - his immune system was too low to risk catching an infection.

This week Jayson and Michelle finally received Charlie's all-clear. The only medication he takes now is penicillin, to lower his risk of pneumonia. He has blood check-ups every two months and his life expectancy is normal.

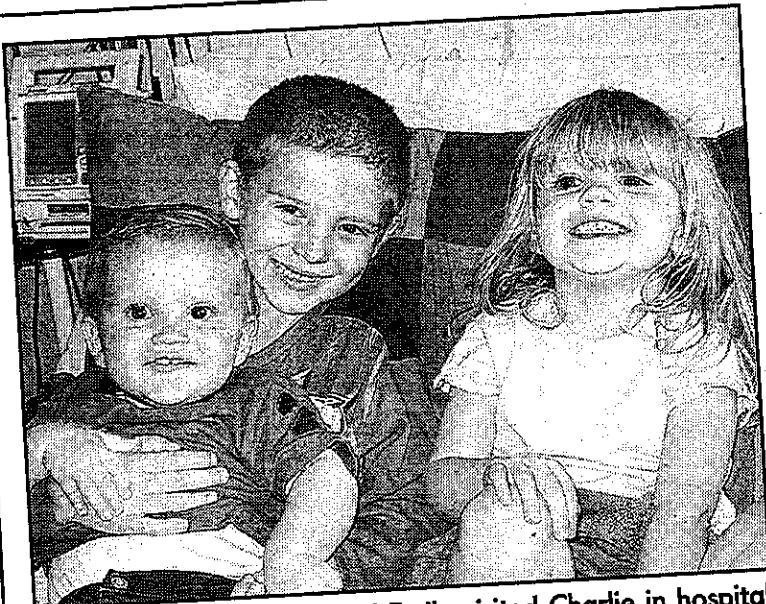
"We went to a play park to celebrate," says Jayson. "Seeing Charlie on the slides together was the best gift I could ever have."

"Jamie's a typical toddler. When he's old enough we'll tell him how Charlie saved his big brother's life."

Charlie's nightmares have subsided. "His hair's grown back," adds Jayson. "He loves it so he won't let us cut it."

Having a "designer baby" has been without risks - but Jayson has no regrets. "At last we're a healthy family," he says. "All because of Jamie."

antonia.woyle@mirr



ON THE MEND: Jamie and Emily visited Charlie in hospital