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SUPPLEMENT OF THE YEAR

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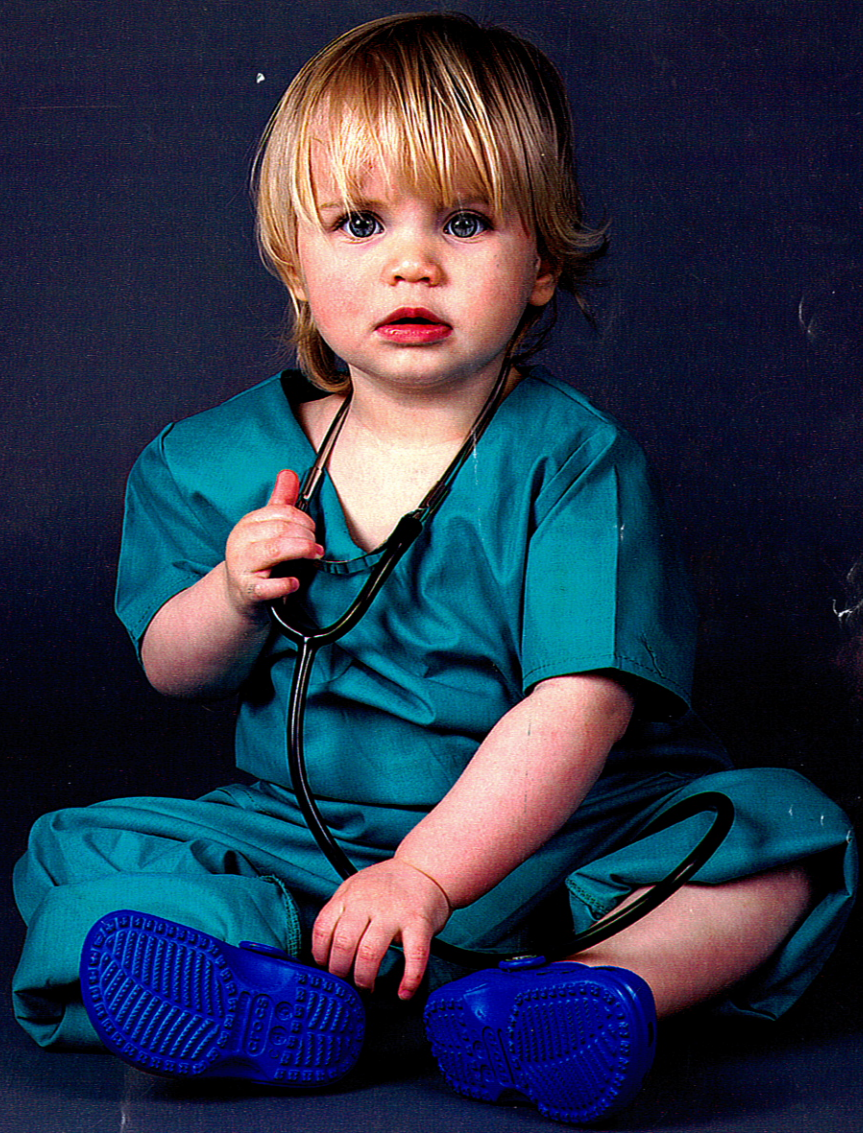
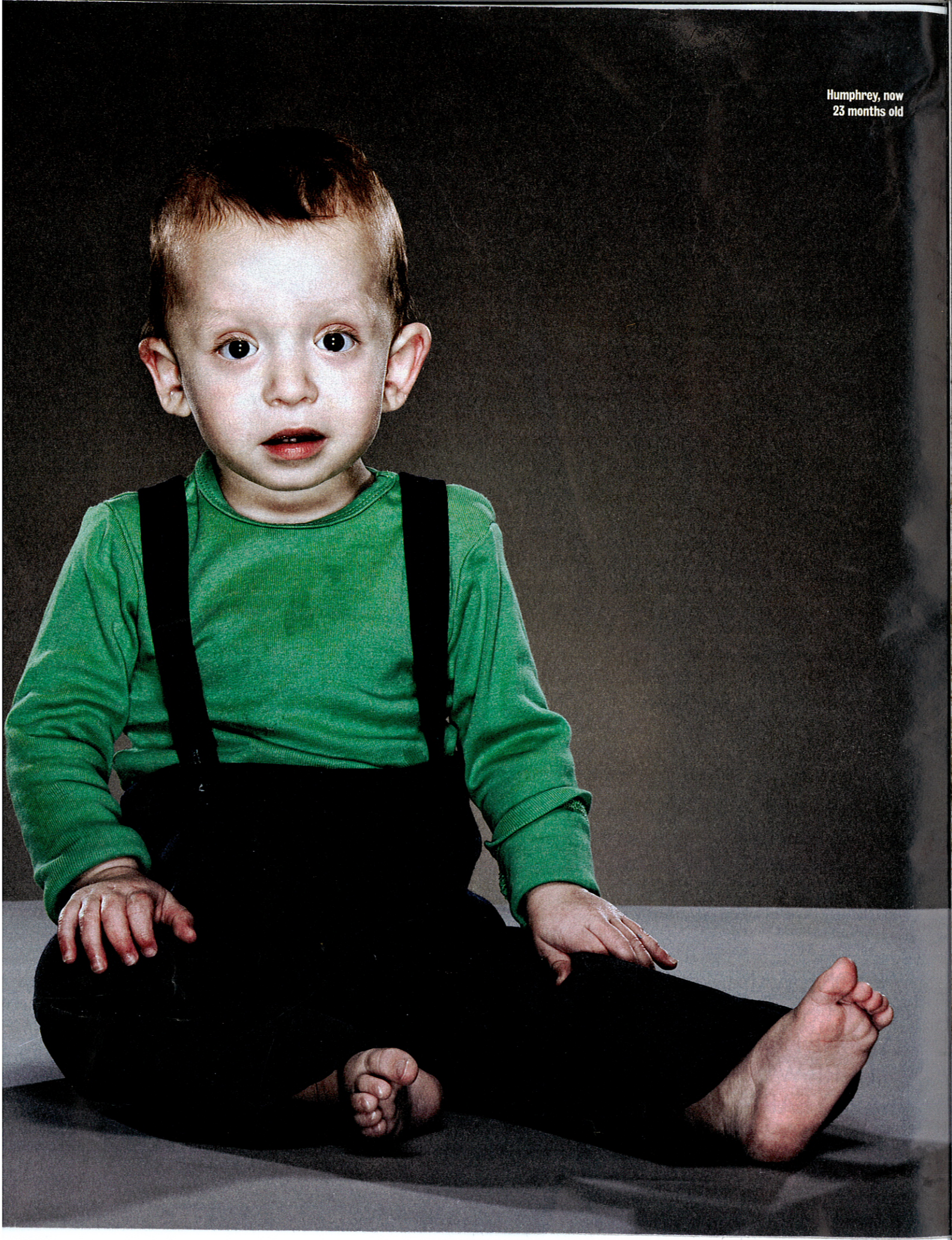


BRITAIN'S TOP CHILDREN'S DOCTORS

WHO SAVED HUMPHREY?

What's it like to find out that your baby will die unless he's operated on in the womb in radical surgery that's performed only a few times a year? Olivia Gordon found out – when she was 29 weeks pregnant

PHOTOGRAPHS Mark Harrison



Humphrey, now
23 months old

Throughout the 29 weeks of my second pregnancy, I had been excessively cautious. I hadn't painted my nails, stood near a smoker, eaten forbidden foods... Not once. My first pregnancy had ended in miscarriage, making me ultra-anxious, and it was only as I entered the third trimester, after the 20-week scan was "all fine", that I started to relax.

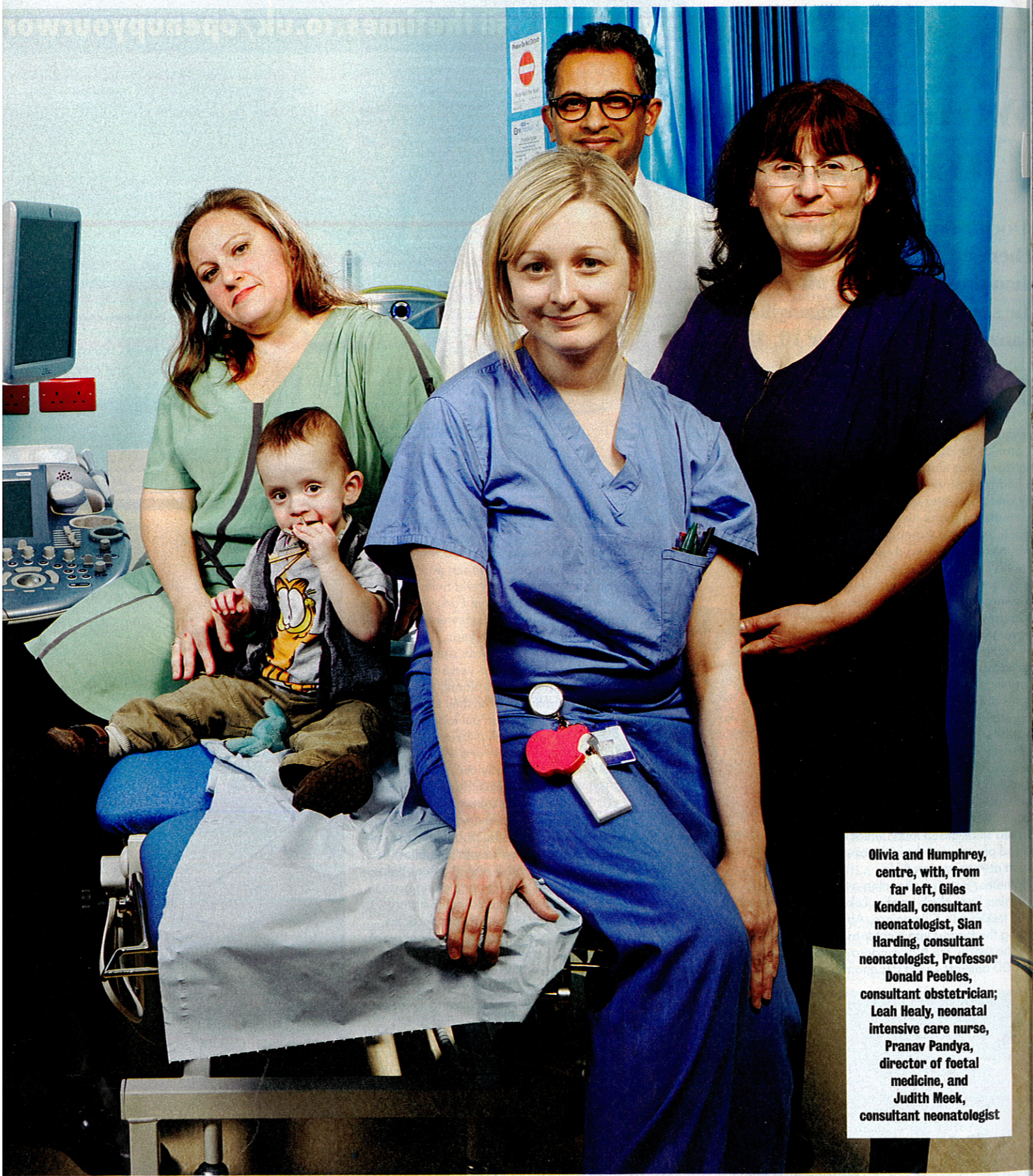
The only thing that bothered me was that I couldn't feel much from the baby. The nurse didn't seem worried, and when we had a scan I was relieved to see the baby moving. I was so engrossed in watching him that I had a delayed reaction to the sonographer's silence. Finally, I asked: "Is something wrong?"

"I'm afraid this is not good news," she eventually said, looking shocked. "You see all this dark space in and around the baby? It shows bilateral pleural effusions: fluid around the lungs – they're squashed. There's some fluid under the scalp, too. And you have polyhydramnios – far too much amniotic fluid."

We had come into the hospital as ordinary nervous prospective parents, assuming we'd be sent home by lunchtime; little did we know we'd be spending the next half a year in hospital, truly terrified. It wasn't just that our baby wasn't well; no one could even tell us if there was a chance he would survive. And the more that senior consultants looked pityingly at us, saying how sorry they were and how very brave we were, the more we realised just how serious this situation was.

Our baby, the doctors explained, had a condition called hydrops fetalis, described when I googled it as "often fatal" and affecting around 1 in 3,000 pregnancies. What happens is that the body's lymphatic, or drainage, system fails. Our baby was breathing in amniotic fluid but not processing it; it was building up within both of us, crushing his organs and restricting his growth. And, frustratingly, no one could tell us why. Hydrops often happens for no known reason, and the only potential treatment, we were ➡

NO ONE WANTED TO GIVE US FALSE HOPE. AS ONE DOCTOR SAID: 'THERE WAS A CASE LAST YEAR WHERE THE BABY WAS FINE'



Olivia and Humphrey, centre, with, from far left, Giles Kendall, consultant neonatologist, Sian Harding, consultant neonatologist, Professor Donald Peebles, consultant obstetrician; Leah Healy, neonatal intensive care nurse, Pranav Pandya, director of foetal medicine, and Judith Meek, consultant neonatologist

told, was still experimental emergency foetal surgery – draining the excess fluid from the baby and womb, and inserting one or more plastic "shunts", or tubes, halfway into the baby's chest wall, to drain more fluid from his thorax into my womb.

Foetal surgery, I soon learnt, is a pioneering field of medicine. Although amniodrainage – draining the womb – was performed in the 1800s, and intrauterine blood transfusions in the Sixties, it was only when ultrasound came into reliable use in the late Eighties that foetal surgery took off.

Most foetal surgeons aim to be as minimally invasive as possible, and undertake procedures very rarely. University College London Hospital (UCLH), one of the few foetal surgery centres in the world, does between 25 and 50 such procedures a year – almost all by its two foetal surgeons, Pranav Pandya and Professor Donald Peebles. It was here, our local hospital told us, that we would have to go. If we didn't, our baby was likely to die. If we did go, the procedure might induce premature labour, heart failure for the baby and infection. But he might live.

The first scan was on a Tuesday evening and, thanks to the NHS, at noon on Friday we were at the foetal medicine unit at UCLH, seeing Professor Peebles, the head of research in maternal and foetal medicine. He was reassuring, but matter of fact. Doctors working with ill babies can't appear sentimental. Their job is to give the patient the facts, even if they are hard to accept. The facts we needed to know were: the shunt treatment was our only resort; it was very rarely done (at UCLH, about five times a year); the longer we left it, the less chance our baby had.

In a daze, we signed the consent form for the operation. I was to have the procedure right away. I asked to go to the ladies, where I steeled myself. Then, five minutes later, I lay on the couch on my back with my belly and baby exposed and vulnerable. Being pregnant, general anaesthetic was out of the question; they could only swab local anaesthetic onto my stomach.

At this point, I turned my head to the right so I couldn't see any more. My husband, Phil, sat on my left holding my hand. The professor was going to watch the operation on the ultrasound screen, so he could see more clearly what he was doing. Phil could see the screen. I couldn't bear to look, but didn't want to close my eyes. I just stared at the edge of the room.

First, the professor inserted a needle into one side of my belly and drained – I later saw – several litres of amniotic fluid. This immediately relieved the pressure in my stomach. Then he moved on to "shunting": stabbing a fine tube very quickly into my belly, into my womb and into our son's chest, just next to his lungs. I felt the visceral, deep force of this plunge and cried out, not so much in pain as in surprise. It felt wrong; the antithesis of protecting my baby.

It wasn't a total success – the shunt had lodged too far into our baby's thorax – but the overall volume of fluid was much better. "When you came in, your baby's chances of survival were 50-50," Pranav Pandya, the head of the foetal medicine unit, said a week later. "But it's gone up to 80 per cent, and I'd even say now it's at 90 per cent." His breezy manner was oddly reassuring.

A few days later – my fluid levels having gone up again, and having started to bleed – I gave birth, prematurely but naturally, to my 32-week-old son, Humphrey, in a room full of doctors and nurses (including a brilliant young neonatologist called Giles Kendall). Having lain for a second on my tummy, a little hat on his head to keep him warm,

HE WAS ONLY STABLE ENOUGH TO LEAVE THE INCUBATOR AFTER A WEEK FOR 40 MINUTES. I BARELY DARED TOUCH HIM

Humphrey was rushed to intensive care. The next 24 hours were critical; although the UCLH neonatal unit is one of the best in the world, the doctors could count on two hands the cases they had treated of neonates born with hydrops. And although the foetal surgery had allowed his lungs to re-inflate a little, and I'd been given steroids to boost the baby's lung development, his breathing was not good. No one wanted to give us false hope. As one doctor said: "There was a case last year where the baby was fine."

The neonatal unit was a machine-bleeping world of its own, where the only reality was desperately sick babies. Visiting Humphrey for the first time, I longed to hold him, but could only stand and look. He was only stable enough to come out of the incubator for us to hold at the end of the week for 40 minutes, by which time I barely dared touch him, such was his vulnerability. Soon, I couldn't imagine how any baby had ever managed to breathe unaided, or what it was like to pick up a baby. I lived in a world where babies couldn't eat and where they couldn't be touched without thoroughly sanitising your hands. There was no crying audible from the incubators, just eerie silence.

We weren't allowed to stay with Humphrey overnight. Every day, we travelled from North London, carrying bottles of my expressed milk, then left at night. As I walked towards the hospital, I felt a magnetic pull towards my baby; then, when I entered his ward, I was enveloped by a terrible sadness of finding him in this lonely place, being cared for by strangers, and having to leave him there. I had to set my alarm clock through the nights at home to express milk for his tube feeds, while he lay in a plastic box, having never tasted a drop of it.

The nurses were not only gentle and compassionate in their handling of Humphrey, but incredibly kind to our whole family. We'd come in one morning to find an X-ray was looking positive and they were going to try giving Humphrey a millilitre of milk per hour; the next day, he'd be diagnosed with an infection and have a drip agonisingly fitted into his scalp or a tube put down his throat. He came out of intensive care and into high dependency, then suffered heart failure and was rushed back.

But under the extraordinarily intensive care of Kendall and consultants Sian Harding and Judith Meek, the fluid around Humphrey's lungs and under his scalp disappeared. And slowly, overcoming complications and more surgery, he got better. For the first five months of his life he was in three different hospitals, cared for by more than 100 specialist doctors and nurses, most of whom we still reminisce about fondly. To them, we were just another family. To us, they were gods.

Finally, in June last year, we were allowed to take our baby home, and today, 23 months after his birth, the hydrops is just a memory. Humphrey still has some medical problems and will always need monitoring. He has, we have learnt, a rare condition that has left him with heart and gastrointestinal problems, and he has chronic lung disease (although he is capable of very loud screaming). For now, he still has the shunt; the cardiothoracic surgeon at Great Ormond Street says they monitor only one other child with a shunt inside them from foetal surgery, and over time they will decide whether it's best to leave it there or take it out. But right now, he's just our active, happy little boy, living his life to the full.

What remains from that nightmare? Photos of my baby, ill in hospital, which I still can't bear to look at. The memory of us feeling so very different from all the normal, healthy mothers and babies. A resistance to googling illnesses. Two needle marks, faded almost to invisible, on either side of my belly. And, thankfully, "Team Humphrey": the 15 or so health professionals who, remarkably, still track every aspect of my child's health, who have given me an abiding love of the NHS, and without whom we wouldn't have a son at all. ■