

Surgeons rebuilt our baby's skull

Little Finley comes up smiling after five major operations

By Jill Foster

Finley Amey is just two years old, yet he has already undergone major surgery five times. He was born with Apert's syndrome, a rare genetic condition that makes the plates in the skull fuse prematurely, and his head shape, as well as his hands and feet, were once severely deformed.

One operation, carried out when he was a month shy of his first birthday, involved dismantling his skull before piecing the bones back together to construct a new forehead – and give his brain room to grow. Taking a total of four-and-a-half hours and the skills of 16 surgical staff, it is an incredibly risky procedure, yet without it he may have been left blind or brain-damaged.

Finley is just one of 600 children who are treated each year at the craniofacial unit at the John Radcliffe Hospital in Oxford, the focus of a forthcoming BBC2 series. The fascinating three-part documentary, filmed over two years, follows the work of the highly skilled team as they perform intricate, pioneering surgery on babies and children.

The unit is one of only four centres in the UK licensed to carry out these complex operations on the skull and facial areas. Families wrestle with the decision to let their child undergo such dangerous procedures.

'The head is extremely delicate and there is always a chance a child won't make it through surgery, could be brain-damaged, or suffer a stroke,' explains consultant craniofacial surgeon David Johnson.

'But everything we do in life is built on weighing up risks and benefits. What you want to hear as a parent is a 100 per cent guarantee but I can't give that. It's normal for parents to be scared. But the risk of doing nothing is often greater than the risk of a procedure.'

Apert's is extremely rare, affecting just one in 65,000 live births, and only about ten children are born with it each year in the UK. Yet Finley is without doubt a jolly baby – and the cosmetic results of his operations are astonishing, considering the challenges his surgeons faced. He has also had metal stents implanted in his nose to assist his breathing – Apert's can affect the nasal passages – and an operation to form new fingers, which were fused together.

Today, playing contentedly at a playground near his home in



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Andover, Hampshire, he seems oblivious to everything he has been through. And his parents, Diane, 31, and Lee, 32, a Royal Engineer in the Army, now hope their son will have the chance to grow up much like his sister Lucy, seven, without fear of ill-health – or the stigma of facial disfigurement.

Diane, a part-time childcare lecturer at a local college, said: 'Of course it was a bit of a shock when Finley was born – Lee said it was as if the wind had been knocked out of him – but that soon wore off. After all, he's just our cute little boy with his big blue eyes and we are totally in love with him. Today, if I had a choice and someone said to me, "Finn will look like this for the rest of his life but he'll have no prob-

lems," then I wouldn't go ahead just for cosmetic reasons. I would not take that risk – although he might not have thanked me later.

'But his health was at stake. He could have ended up with brain damage – that's why we went ahead.'

Although the surgeons take pride in giving these children the best possible cosmetic results, there are limits. 'We tell parents, "Your child is going to look different from everyone else, full stop,"' says paediatric surgeon Jay Jayamohan.

'If we operate, they're going to look different because they'll have a scar and if we don't operate they'll look different because of the condition. Some kids will look very different, regardless of what we can do.'

Within weeks of the skull surgery,



'OUR NORMAL, LOVELY BOY':

Finley with mum Diane, dad Lee and sister Lucy. Above: Finley as a baby

Finley's bones had meshed – babies' bones are quick to heal – and although it's likely he'll need operations in the future, his life chances have been dramatically improved.

'He's just a normal, lovely little boy,' says Diane. 'Before the operation he couldn't sleep with his eyes shut because the Apert's stopped him from closing them. He still slept but with his eyes open, which was a little bit odd but we got used to it. And now he's developing like any toddler.'

Another child featured in the programme is Ollie, 13, who was born with Pfeiffer syndrome, which meant the parts of his skull were fused together so tightly that his skull had a 'clover-leaf' appearance. It has affected his hearing and speech but as he grows, the biggest danger is of fluid building up inside the brain.

In previous generations, the condition would have killed, but Ollie's brain is protected by a shunt, a small valve that drains the fluid into his stomach. He has spent most of his childhood in and out of hospital and arrives back at the unit when his mother Jules notices he's suffering from headaches and may require a further operation – his 30th to date.

His latest operation was another success. But not everyone is as lucky. 'We lost a patient about three years ago and it's about the worst thing that has ever happened to me,' says Mr Jayamohan.

'But we still go on doing the operations – because at the end of the day, I believe the benefits that you're giving to that patient outweigh those risks.'

● *Children's Craniofacial Surgery starts on May 4 on BBC2 at 9pm.*

How to beat cuts to physio services

NHS cutbacks mean that budgets for physiotherapy are in jeopardy, and patients with conditions such as cystic fibrosis, multiple sclerosis and severe asthma are facing six-month waits to be seen. While physiotherapy is an essential service – helping to manage chronic diseases as well as aid recovery after surgery – as DR ELLIE CANNON explains, there are options if you can't get an appointment.

Q What do physiotherapists actually do?

A Physiotherapists help patients to regain physical function after injury or illness. This is done through exercise, massage and manipulation. Hydrotherapy is a type of physiotherapy in water, where the resistance provided by water acts as an aid. Physiotherapy is not just for sports injuries but for a wide variety of conditions, including stroke, arthritis and even incontinence.

Q How is physiotherapy used for asthma?

A Asthmatics benefit from physiotherapy through the breathing exercises, physical exercises and posture habits that they teach. It tends to be used in those with moderately severe asthma as well as those with smoking-related lung disease. It is proven to help by teaching sufferers slow, relaxed breathing that help overcome breathlessness.

Q Is it easy to get an appointment with a physiotherapist?

A Physiotherapists work either in hospitals treating inpatients or within the community seeing patients referred by GPs. In some areas community physiotherapy is already rationed and you can no longer see a physiotherapist for certain conditions. With some sports injuries, patients are offered advice and exercises in a telephone consultation.

Q I have lower back pain and my GP has not referred me to physiotherapy. Where can I get help?

A If you are looking for a physiotherapist privately, you can find one through the Chartered Society of Physiotherapy or via your private health insurance. If this is not an option, your GP should be able to recommend exercise information from an online resource or advise you which exercises may help. The website www.backcare.org.uk offers a range of exercises.

Q What is occupational therapy?

A Occupational therapists help people to live and function independently and overcome effects of illness to participate in daily life. Occupational therapy is another area under threat from the cutbacks.