

Breakthroughs in children's medicine





Welcome to our breakthroughs in children's medicine guide, focusing on surgery. Great Ormond Street Hospital has been at the forefront of the great leaps in surgical treatment since the late 19th century, when the benefits of surgery began to gain recognition.

Today, more than one in three of the patients that visit the hospital undergo a surgical procedure. As the demand for our surgical services increases, we are constantly evolving to develop our care and make surgery more effective for children and young people. Training is something that is close to my heart, and it's the hospital's legacy of mentoring others that has helped us to get to where we are today. We continue to teach and collaborate so that we can pioneer new techniques for patients now and in the future.

Cover image: Twelve-year-old Edward was treated for osteomyelitis and meningitis. Left: Mr Joseph Curry. The wellbeing of our surgical patients relies not only on the skill and expertise of the surgeons, but also the large number of people from across the hospital's multidisciplinary teams – from nurses and play specialists to anaesthetists and psychologists. Thanks to them, thousands of children have benefited from advances in surgical treatment since the hospital opened more than 160 years ago.

I hope you enjoy reading about some of Great Ormond Street Hospital's surgical achievements, and that you continue to support our crucial work. Thank you.

un

Mr Joseph Curry Consultant Neonatal and Paediatric Surgeon Great Ormond Street Hospital

Contents

🌍 Yesterday

The state of surgery	page 8
Safeguarding surgical practice	page 11
The father of paediatric surgery	page 12
Plastic surgery – making an impact	page 15

🌍 Today

Specialising surgery	page 19
Leading the way in separating conjoined twins	page 21
Conjoined twins – the challenges of surgery	page 23
Fiona's story	page 25
Constructing confidence through surgery	page 27
Meet the team	page 28
The new surgery centre	page 31

S Tomorrow

Constant progress to create tomorrow's breakthroughs	page 34
Advancing surgery through research	page 37
Developing treatments for unborn babies	page 39
Regenerative medicine	page 40



Yesterday 🌍

The state of surgery

The first half of the 19th century was tough for children who required surgical treatment. There was little recognition for the benefits of surgery, and for the few operations that did take place the patient experience was grim and incredibly painful.

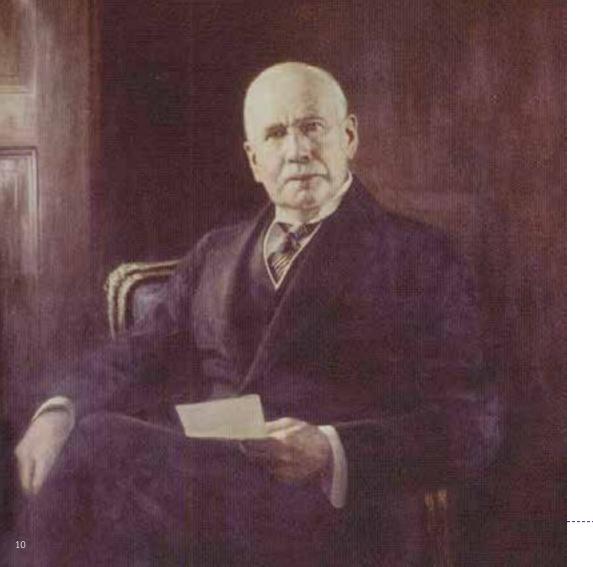
Surgery took place in ill-suited environments with unsanitary conditions, and there was little knowledge about the spread of infection. Anaesthesia had not yet been introduced, which meant that surgeons had to face the harrowing prospect of inflicting severe pain on their young patients. It also meant that speed was the priority – surgeons considered that the faster the procedure was carried out, the more successful the outcome would be.

Right: Operating theatre from the early 1930s.

It was the sick and underprivileged children who endured the worst. In 1843, only 26 of the 2,400 patients in London's hospitals were children under the age of 10, and many families simply could not afford the care provided by the general infirmaries. The opening of the Hospital for Sick Children – now Great Ormond Street Hospital – in 1852 by Dr Charles West was part of a charitable movement to offer dedicated paediatric care to the needy and disadvantaged.

However, the enormous potential that surgical treatment could offer to childhood illnesses was not understood in those early years. But surgery at the hospital was about to embark on a journey of extraordinary improvement.





Safeguarding surgical practice

The introduction of chloroform as an anaesthetic in 1847 opened up new opportunities in surgery. It removed some of the desperate need for speed, and though surgery remained dangerous and complicated, it became a more deliberate practice.

In 1883, Sir William Arbuthnot Lane joined Great Ormond Street Hospital as a consultant and introduced aseptic (sterile) surgery. He established the 'no touch' technique, where only sterilised instruments were allowed to enter the wound with fingers at least four inches away, thereby reducing the risk of infection. Sir William helped to realise the full potential of surgical treatment for children, developing new techniques for cleft-lip surgery, and inventing surgical instruments.

Left: Sir William Arbuthnot Lane.

Despite the growing popularity of anaesthesia, children undergoing surgery still faced a terrifying ordeal: they were taken into theatre and often held down while pain relief was administered. In 1908, the hospital employed its first Honorary Consultant Anaesthetist, Dr Harold Sington, who devoted his career to the research and practice of anaesthesia in children. He reasoned that patients should be sedated before surgery, an idea he called 'pre-medication'.

Yesterday 🥪

This concept of sensitive pre-operative care, which reduced stress for patients and made their experience less upsetting, started at Great Ormond Street Hospital and influenced other hospitals.

Yesterday 🥪

The father of paediatric surgery

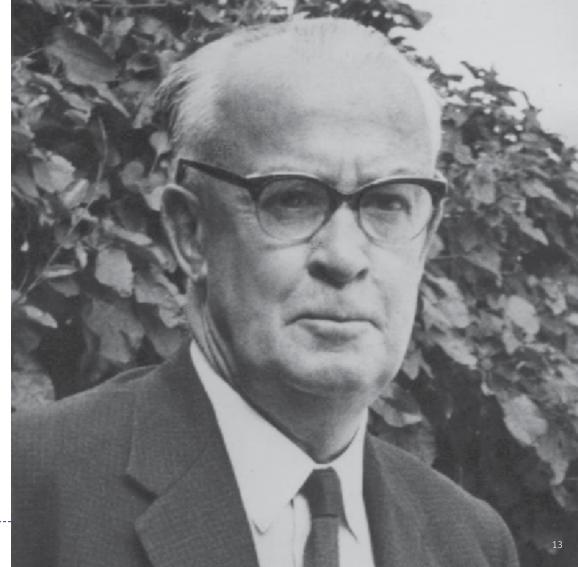
In 1922, Sir Denis Browne joined Great Ormond Street Hospital and within six years became the UK's first full-time children's surgeon, focusing his work on the development of children's surgery.

Sir Denis had many devoted admirers and showed enormous compassion towards children. Through his long-term clinical observations he recognised that specialist skills were required to nurse and operate on such young patients, and based his work on their needs.

Sir Denis placed great emphasis on technical skill and his work revolutionised the approach to paediatric surgery across a range of diverse fields, including talipes (club foot) and cleft-lip. He designed a number of surgical instruments for use on babies and young children, and an extensive range of orthopaedic splints that allowed controlled movement.

Recognising the potentially fatal effects of using poor anaesthesia on a child with a fragile nervous system, Sir Denis invented a more comfortable and child-friendly alternative for its administration. Dubbed the 'top hat', this cylinder-shaped inhaler allowed surgeons to deliver accurate doses of anaesthetic to children without having to cover panicked patients' eyes.

Sir Denis' commitment to the needs of his patients lay the foundation for the paediatric surgery that Great Ormond Street Hospital is famous for today.



Right: Sir Denis Browne.



Plastic surgery – making an impact

By the 1940s, Great Ormond Street Hospital had made great strides in reconstructive surgery thanks to pioneers such as Sir William Arbuthnot Lane and Sir Denis Browne. In 1947, they employed the first Consultant Plastic Surgeon, Dr David Matthews, who had learned his craft treating injured and burned aircrew during World War II.

Affectionately named 'two-hand Matthews' for his ambidextrous skill, Dr Matthews remained at the hospital for almost 30 years, becoming an expert adviser in plastic surgery and advancing the field internationally. His appointment transformed plastic surgery from a discipline that focused strictly on the physical problems to one that provided patients with a tremendous psychological boost. The positive results

Left: Ellen as a child. Right: Dr David Matthews. of plastic surgery provided withdrawn and dispirited patients with a newfound confidence, nurturing their emotional wellbeing and transforming their lives.

Yesterday 🥪

Ellen had plastic surgery at the hospital for cleft-lip in the 1950s: "I was treated by Dr Matthews – without the plastic surgery and care, my life would have been very different. I wouldn't have been able to go to school, meet friends or just live my life.

"Everyone at the hospital was kind -I used to cry about going home! It has meant everything to have had the care and opportunities as a result of the work and expertise of

all the wonderful people that I met at the hospital."



1937 The first blood bank opens, helping to make more surgery possible by replacing blood during procedures.





Specialising surgery

Building on the work of Sir William Arbuthnot Lane and Dr Harold Sington, surgeons at Great Ormond Street Hospital have continued to advance their field. Following World War II, attitudes towards childhood medicine shifted, recognising the need for experts in surgical subspecialties to tackle the multitude of conditions that children can face. At the hospital, the surgery department expanded to include neurosurgery, orthopaedics, urology and cardiac surgery.

The combination of specialist teams and technological advances has allowed the hospital to provide the very highest standards of care for our patients. Advances in laparoscopic (keyhole) surgery have made the biggest difference to patient recovery in the last 20 years. Taking what surgeons had learned by implementing laparoscopic techniques on adults, equipment became miniaturised in order to apply similar surgical techniques to smaller patients.

Today 🌍

As a result, operations have become less invasive, less painful, and allow patients to recover more quickly. In addition, by using smaller incisions, the risk of infection decreases considerably. Procedures of this kind allow surgeons to use their time more effectively, providing them with more capacity to meet the growing demand of those patients who desperately need their specialist help.

Left: Chantelle has come a long way since her operation using keyhole surgery.

1999 Tom Lobe and Steve Rothenberg conduct first keyhole surgery for children whose wind and foodpipes are tangled.



Leading the way in separating conjoined twins

Great Ormond Street Hospital is the leading centre in Europe for the care of conjoined twins. The procedure to separate is highly complex and involves a number of multidisciplinary teams from across the hospital working together to provide the full range of expertise and resources needed.

During his 20-year career at the hospital, Professor of Paediatric Surgery Lewis 'the Prof' Spitz became world-renowned for leading surgical teams in the separation and treatment of conjoined twins. Not only does surgery of this nature require great skill and experience, it demands a compassionate character to deliberate the ethical consequences and offer support to patients and parents experiencing such a distressing situation. The culmination of Professor Spitz's work was televised in a BBC documentary, where eight surviving twins separated by Professor Spitz over two decades came together from the UK and USA to honour him. "Putting so much emotional energy into the patients' care, one becomes really attached," says Professor Spitz. "Watching them grow up and achieve – that's something which is greatly satisfying for me."

Today 🌍

But Professor Spitz's legacy at the hospital extends elsewhere. He was pivotal in the development of multidisciplinary collaboration, a move vital to the success of the diverse teams working here then and now, as well as the effective and safe care of conjoined twins.

Left: Professor Lewis Spitz.



Conjoined twins – the challenges of surgery

The surgery required to separate conjoined twins is fraught with danger. In 2003, conjoined twins Jannat and Zainab weighed just 6lb and shared a liver when they were separated by Professor Spitz and his frequent collaborator, Surgeon Edward Kiely. Joined from the chest to the abdomen, the twins lay facing each other and sucking each other's thumbs.

Separating the twins was extremely difficult: the join was less than a centimetre from their hearts and dissecting the liver was a very delicate procedure. The surgical team used an ultrasound dissector, which vibrated at an extraordinarily high rate and shook the liver cells to pieces. Those pieces were then extracted so that the blood vessels could be sealed and divided.

Today 🌍

After four-and-a-half hours, the procedure was finished, and each of the twins was given a new belly button. Unfortunately, Jannat had a hole in her heart and underwent further surgery four days later. The twins were in hospital for three months in total.

"They had excellent care – it could not have been better," says mum Nipa. "The staff were so friendly and our questions were always answered. When I could finally take them home, everyone was overjoyed."

Left: Twelve-year-old Jannat and Zainab.



Fiona's story

As quickly as Fiona was passed to mum Emi for her first feed, she was rushed to special care. Her jaw was a lot smaller than normal and caused problems with her breathing. Doctors diagnosed her with Nager syndrome, a rare genetic disorder that affected her face and hands.

At 10 days old, Fiona had an emergency tracheostomy – a hole was made through the front of her neck and into her windpipe for her to breathe. She went home for the first time when she was almost three months old.

When Fiona was 18 months old, she was referred to Consultant Oral and Maxillofacial Surgeon Peter Ayliffe, who recommended distraction surgery to lengthen her jawbone. Doctors cut her jaw in half and fitted bolts and a screw that they turned every day to stretch the jaw out. "It was such a difficult operation," says Fiona's dad, Andrew, "but the hospital was wonderful. They made us feel very relaxed, and Fiona trusts Mr Ayliffe so much. She's never nervous before operations."

Today 🌍

Fiona also had surgery on her thumbs and has a permanent bone-anchored hearing aid, as a bone growing across the inside of her ear blocks sound. She may need further surgery on her jaw, as she can't open it very far, but she has learned to use the sign and symbol language Makaton to communicate.

Andrew said: "Without the expertise of doctors at the hospital and the care of other medical staff, Fiona wouldn't be the little girl she is now."

Left: Six-year-old Fiona after the fifth stage of her complex surgery.



Constructing confidence through surgery

Today, surgeons at Great Ormond Street Hospital perform more ear reconstructions than at any other hospital in the UK. Between 35 and 40 procedures of this kind take place every year, five of which are bilateral reconstructions (both sides). Kieran, who was born with microtia (a small or absent ear), underwent a bilateral reconstruction in 2014.

Consultant Plastic and Reconstructive Surgeon Neil Bulstrode carried out the six-hour operation using ears sculpted from Kieran's rib cartilage. "The operation brings a significant improvement in quality of life," said Mr Bulstrode. "The child's confidence improves exponentially, as does their performance at school. If you can increase a young person's confidence, you can alter their whole trajectory in life." Before his operation, Kieran said: "I've always wanted big ears, and now I'm finally going to have them." As soon as he woke up, Kieran's parents Louise and David helped him to take a 'side selfie' of his new ears, and Kieran responded: "Wow."

Today 🌍

Doctors and scientists at the hospital and its research partner, the UCL Institute of Child Health, hope to improve ear reconstructions in the future by growing new ear frameworks from a child's stem cells. This approach will be far less invasive for the patients, and will ensure that the new structures grow with the patient and won't be rejected.

Left: Nine-year-old Kieran shows off his new ears.

Meet the team

The surgical breakthroughs at Great Ormond Street Hospital would not be possible without collaboration between the hospital's multidisciplinary teams. By sharing ideas and expertise, we are able to offer the very best care to our patients and their families.



Today, an anaesthetist is seen as much more than someone who arrives on the day of surgery, provides an anaesthetic, and ends their relationship with the child and the team when the patient returns to the ward. We are part of the multidisciplinary team involved in the pre-operative preparation, assessment and decision-making when children with complex medical problems are considering surgery, for example children with neuromuscular diseases needing spinal surgery. Anaesthetists also work as part of the Pain Service, managing postoperative pain. The best thing about my job is the opportunity to improve, even if only in a small way, the experience and outcomes for children with severe medical problems undergoing surgery. "

Dr Elizabeth Jackson, Consultant Paediatric Anaesthetist and Divisional Director for Surgery

On a day-to-day basis, me and my team are friendly and welcoming, and create an environment where children feel safe and well cared for. We try to put patients and their families at ease with our expertise, not forgetting that it's a very difficult and daunting time for them.

"The big difference we've seen over the last five to 10 years in surgery is the move from open procedures to laparoscopic work (minimally invasive surgery), which really benefits patients. Initially, the patients follow the same pathways operatively, but they go home about two days earlier, so there's less pain and anxiety post-surgery, and their recovery time is quicker.

Rachel Pennington, Surgical Sister

My role is about enabling children and their families to cope the best they possibly can with the stress of being in hospital. This involves gaining an understanding of what they think and feel about being unwell and helping them to develop strategies to cope with any difficulties.

"There has been a growing recognition about how patients can benefit from having a psychologist as part of their multidisciplinary team. As the hospital is at the forefront of cutting-edge surgery, psychologists are increasingly being asked to be involved in helping families find ways of coping with uncertainty, decision-making, and a potentially long and complicated journey to recovery.





29

Dr Clare Coakes, Principal Clinical Psychologist for Specialist Neonatal and Paediatric Surgery



The new surgery centre

Between 50 and 60 operations take place at Great Ormond Street Hospital every day. We always aim to provide the very best care to every patient who comes to the hospital for an operation, and to do that we must ensure we have modern facilities.

In order to satisfy the increasing demand for our services, we need to use the space as efficiently as possible. Currently, beds are spread across five wards in four separate buildings, and these impracticalities make for difficult environments in which to nurse children, and there is no room for a patient's family to stay close by.

A new surgery centre, due to open in 2017, will provide areas with more light

Left: Artist's impression of what an operating theatre will look like within the new surgery centre.

and space to house state-of-the-art equipment, which will help a patient's stay to be more comfortable. Each of the new bedrooms is designed for comfort, privacy and dignity, with a bed for parents and en-suite facilities. Play is an important part of a child's recuperation, and new playrooms will offer the hospital's young patients a place to relax and recover.

Today 🌍

We are currently fundraising for the centre, which will bring all of the hospital's surgery units together in one place, a vital step in the process of transferring patients from theatre to the wards. The integrated space will also help teams from different specialties to share ideas and work together to deliver the very best care.

Tomorrow 🤝

Constant progress to create tomorrow's breakthroughs

The gloomy state of surgical practice in the late 1800s is in stark contrast to the cutting-edge care available to patients at Great Ormond Street Hospital today. As surgeons continue to develop techniques and pioneer new approaches, research has become an integral part of the field's future – surgery simply could not progress without it. We are one of very few hospitals from around the world that partners specialist surgery with groundbreaking research, allowing us to provide the very best for our patients.

"Surgeons are continuously driven to improve, to prioritise the needs of the patients, and to ensure that the care they deliver uses the hospital's resources as effectively as possible," says Mr Joseph Curry, Consultant Neonatal and Paediatric Surgeon at Great Ormond Street Hospital.

"Advances in other specialties have enabled us to advance surgical practice. This includes areas such as anaesthesia, which we now consider to be safer than a child crossing the road, and developments in X-rays and other scans that help us diagnose conditions without performing invasive procedures."

Every small improvement we make paves the way for bigger breakthroughs and brighter futures for the children at Great Ormond Street Hospital. It is only through the ongoing generosity of our supporters that we can continue to advance and improve the lives of children that require our help.



Above: Turtle Imaging Suite where patients undergo CT and MRI scans.



Advancing surgery through research

In the UK, developmental dysplasia of the hip (DDH) – a problem with the way the hip joint develops – is the most common musculoskeletal problem present at birth. Also known as 'clicky hips', early and accurate diagnosis of the condition is key: as a child grows, the likelihood for surgery increases. If severe cases are missed, they can result in permanent disability.

However, DDH can be difficult to detect and diagnose, and clinical experts have previously disagreed on how exactly to identify the condition, resulting in 232 different diagnostic criteria.

Dr Andreas Roposch, Consultant Orthopaedic Surgeon and Honorary Reader at the UCL Institute of Child Health, has led pioneering work to reduce those criteria to just seven, thereby radically simplifying diagnosis. This will now allow clinicians across the globe to ensure that the right patients receive the specialist treatment they urgently need.

"By diagnosing patients more quickly and accurately, we will see a reduction in the number of babies inappropriately referred to Great Ormond Street Hospital," says Dr Roposch. "This will allow us to focus on those children who need our help the most."

Dr Roposch's work will reach beyond the boundaries of the hospital, impacting on the diagnosis of DDH around the world. It is just one example of the importance of combining surgical practice with specialist research.

Left: Dr Andreas Roposch with 10-month-old Inaaya immediately after her surgery.



Developing treatments for unborn babies

Around one in 100 babies is born with a severe birth defect. Usually, these conditions can be detected using an ultrasound while a foetus is still in the womb. Being able to perform surgery on a foetus can improve the chances of survival and significantly reduce lifetime disability. Pioneered in the 1980s, this work has been effective for treating conditions such as spina bifida, where the spinal cord and surrounding vertebrae haven't formed properly thereby causing a gap in the spine.

Great Ormond Street Hospital surgeons are playing a key role in the development of new imaging techniques to visualise blood circulation before and during surgery. This will allow surgeons to better plan and perform operations on unborn babies. Working with research teams at University College London and University of Leuven in Belgium, our surgeons are also developing new instruments to improve flexibility and precision in surgery.

Tomorrow G

Consultant Paediatric Surgeon Professor Paolo De Coppi is leading on the hospital's involvement in the project. "As the safety of foetal surgery increases, it is possible that many of the operations that we currently perform on newborn babies at the hospital will become foetal procedures. That's very good news for a child's long-term outlook – the earlier we can correct a serious defect in a growing foetus, the better the outcome is likely to be for the child and their future development."

Left: Artist's impression of an unborn baby in the womb.

Tomorrow 🌍

LEICA 7s

Regenerative medicine

Every year, hundreds of the children who come to Great Ormond Street Hospital require an organ transplant. Current transplant techniques carry significant risks and with the availability of donor organs in decline, we are in desperate need of a better option.

Professor Paolo De Coppi is pioneering research to create rejection-free alternatives that will grow with the patients and offer them a healthy future with fewer surgical interventions. He has been working to manufacture and transplant organs grown from a patient's living cells, a technique known as regenerative medicine. Not only does this reduce the risk

of those organs being rejected by the patient's immune system, it could shorten



recovery time and improve the quality of life for patients and their families.

In 2010, Professor De Coppi and his team were able to successfully manufacture and transplant the first stem cell-supported trachea (windpipe) into patient Ciaran. By combining Ciaran's stem cells with a donor trachea, the surgical team provided him with a new organ. Following the surgery, Ciaran has gone on to live a healthy, normal life.

Looking ahead, Professor De Coppi and his team plan to produce a range of organs. In five years, they aim to produce a whole bladder by using the wall of the intestine. In 20 years, Professor De Coppi hopes to engineer more complex organs with multiple functions, such as the liver, kidney and lung.

Left: Ciaran is doing well since the procedure. Right: Professor Paolo De Coppi in the lab.



Thank you

We have come a long way since the Hospital for Sick Children opened in 1852. Our dedicated and passionate staff have pioneered many new and better ways of treating children with some of the most life-threatening conditions. But we are yet to find a cure for all of the patients we see. Throughout the hospital's history, it has been the continued and generous support of our donors that has helped to fund the research that provides new breakthroughs. With your ongoing generosity we seek to give hope to all children that need our specialist help.

Right: Six-month-old Ava was treated for gastroschisis, a condition where she was born with her intestines outside of her body.



🤝 Find out more

Our website has more information about the specialists, patients and treatments you've read about in this guide, as well as the pioneering research Great Ormond Street Hospital carries out.

If you'd like to find out more, or you have your own stories that you'd like to share with us, please visit **gosh.org/breakthroughs**

We need to raise money to continue to support the legacy of breakthroughs

at the hospital. Your donations are used to rebuild and refurbish the hospital, to fund the most up-to-date equipment, to support research for breakthrough treatments and to provide accommodation and other support services for patients and families.

These are just some of the developments that have taken place since the hospital opened in 1852. Amazing things continue to happen at Great Ormond Street Hospital every day.