Great Ormond Street Hospital Charity

Breakthroughs in children's medicine

Heart and lung

Welcome

From when it first opened as a 10-bed ward on 14 February 1852, Great Ormond Street Hospital has always been a very special and crucial place. Over the years, breakthroughs both big and small have offered a chance of life to some very sick children.

This guide takes you through some of the dramatic milestones – from the very first heart and lung bypass machine for open-heart surgery in children, to pioneering research into how new stem cell treatments might be a lifeline for those with heart failure.

Ours is a story of world-class doctors, surgeons, nurses and researchers, whose vision for the sick children in our care has helped us to treat the untreatable. The passion we feel drives us to go the extra mile for the children in our care and through research we aspire to help children we will never ourselves meet. Both help to explain why we are one of the foremost children's hospitals and research facilities worldwide.

But we would be nothing without our patients and their families. Their bravery is truly inspirational and is the 'fuel' that energises our staff. There's always more we can do to help them. It's why we keep striving to give the children in our care the best possible chance to lead happy, healthy lives.

Professor Martin Elliott
Paediatric Cardiothoracic Surgeon
Great Ormond Street Hospital

Left: Professor Martin Elliott

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Cover image: Elliot, age two, was diagnosed with heart disease at just two weeks old. He was fitted with a Berlin Heart at Great Ormond Street Hospital while he waited for a heart transplant. Elliot has since received a new heart and has been able to return home.


Yesterday

How it all began

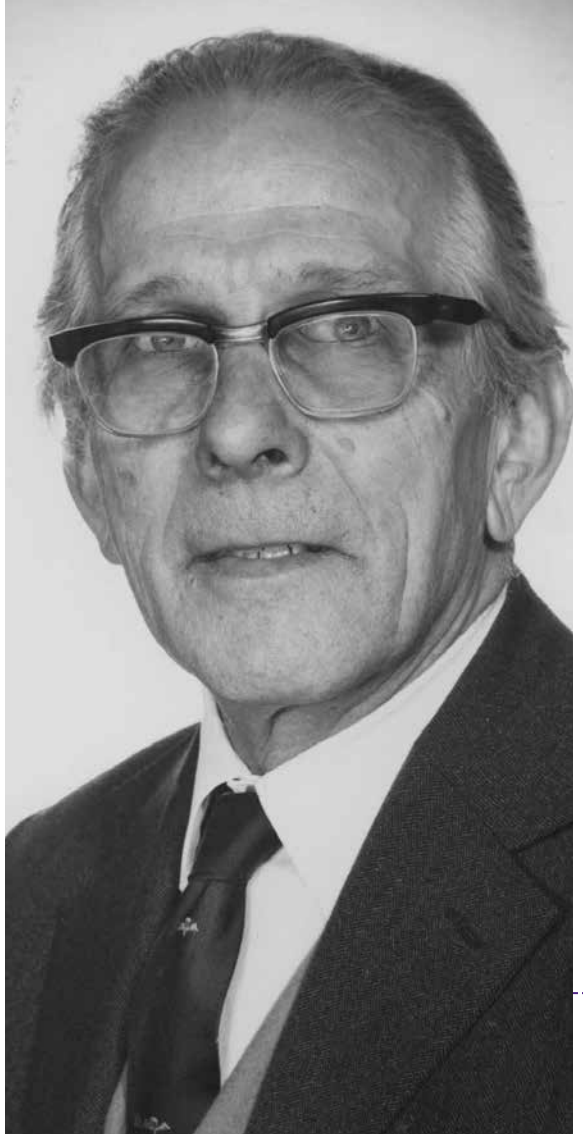
On Valentine's Day in 1852, Britain's first children's hospital opened on Great Ormond Street. One of the first inpatients was three-year-old Eliza Armstrong, who had consumption (pulmonary tuberculosis).

Medicine was very different back then. Cures were in short supply, with doctors treating patients as best they could given the limited resources. As a result, little Eliza would have been given rest and a diet that included milk, beef tea and even wine. It must have worked, as after three weeks she was sent home to attend the hospital as an outpatient. Records show her condition had been 'relieved'.

Other children with severe heart and lung conditions weren't so lucky – life was grim and often short. Medical knowledge hadn't progressed to the point where doctors specialised, and there was a lack of reliable surgical techniques. In fact, for the first 100 years of Great Ormond Street Hospital's existence, little could be done for children with a serious heart and lung condition. The doctors did what they could to lessen the effects of their conditions, but, tragically, the vast majority of their patients died very young.

Right: Doctors did what they could with limited knowledge and resources.

1852 The Hospital for Sick Children opens on Great Ormond Street, but few children with heart and lung conditions survive infancy.



A pioneering partnership

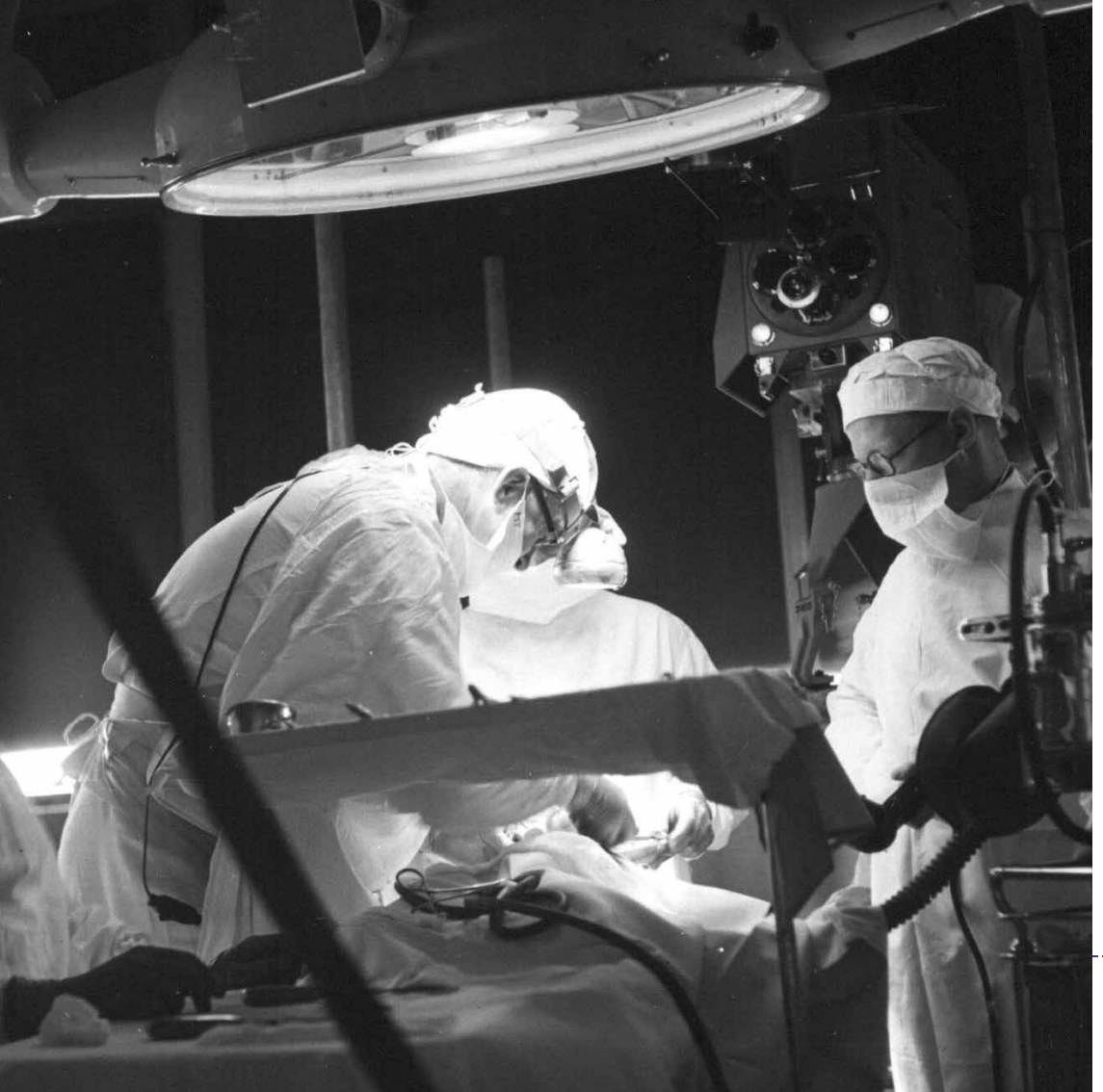
It wasn't until 1947 that the first glimmers of hope came for children suffering with heart and lung conditions, thanks to the efforts of two pioneering individuals. Mr David Waterson was one of the hospital's leading paediatric surgeons, who saw that children with heart and lung problems were in beds all over the hospital. Shouldn't they be together, receiving specialist care and attention? Perhaps then a vision of the future might emerge.

Mr Waterson formed a partnership with Dr Richard Bonham-Carter, a brilliant but unassuming cardiologist. They set up the heart and lung unit, the first dedicated place in the UK where surgeons and doctors could collaborate to diagnose and treat children with heart and lung diseases. Their type of work was often referred to as 'fixing the plumbing', so the new team approach meant that it wasn't long before they were affectionately known around the hospital as 'the plumber and his mate'.

It may have started as just a 10-bed ward, but the heart and lung unit was proof of the two men's unique vision: that by combining disciplines and skills, treatment could be much more effective. The model was far ahead of its time, and set the precedent for how we still work today.

Left: Mr David Waterson (L) and Dr Richard Bonham-Carter (R)

1947 The hospital's heart and lung unit is launched, the first of its kind in the UK.
1954 Catheters allow more precise diagnoses of heart and lung conditions. The first non-invasive heart procedure takes place soon after.



Early surgery and an early breakthrough

When the unit first opened, heart and lung problems were usually diagnosed using a stethoscope. If that was inconclusive, the alternative was for patients to have their chests opened in surgery to determine a diagnosis. Unfortunately, the reality was that three out of every four children admitted to the hospital's new heart and lung unit didn't survive.

A big leap forward arrived in 1954, when Dr Gerald Graham – another heart specialist – came to work with Dr Richard Bonham-Carter to launch a cardiac catheter laboratory. By feeding thin catheter-like tubes through blood vessels in the leg, doctors could measure blood vessels in the heart's chambers.

Now they could better diagnose problems without opening the chest, and even perform non-invasive surgery on some heart conditions, using the catheter as a tiny tool.

These new procedures helped many infants live into childhood. But helping them to survive for more than a few years was a tougher proposition. To repair more complex heart and lung conditions, surgeons would need something that could keep young patients alive while they carried out challenging operations. A device that would keep the body working while the 'plumber' did his surgical work inside the heart.

Left: Heart and lung surgery was very different in the 1960s.

1962 The hospital pioneers the first heart and lung bypass machine for children to help repair heart problems.

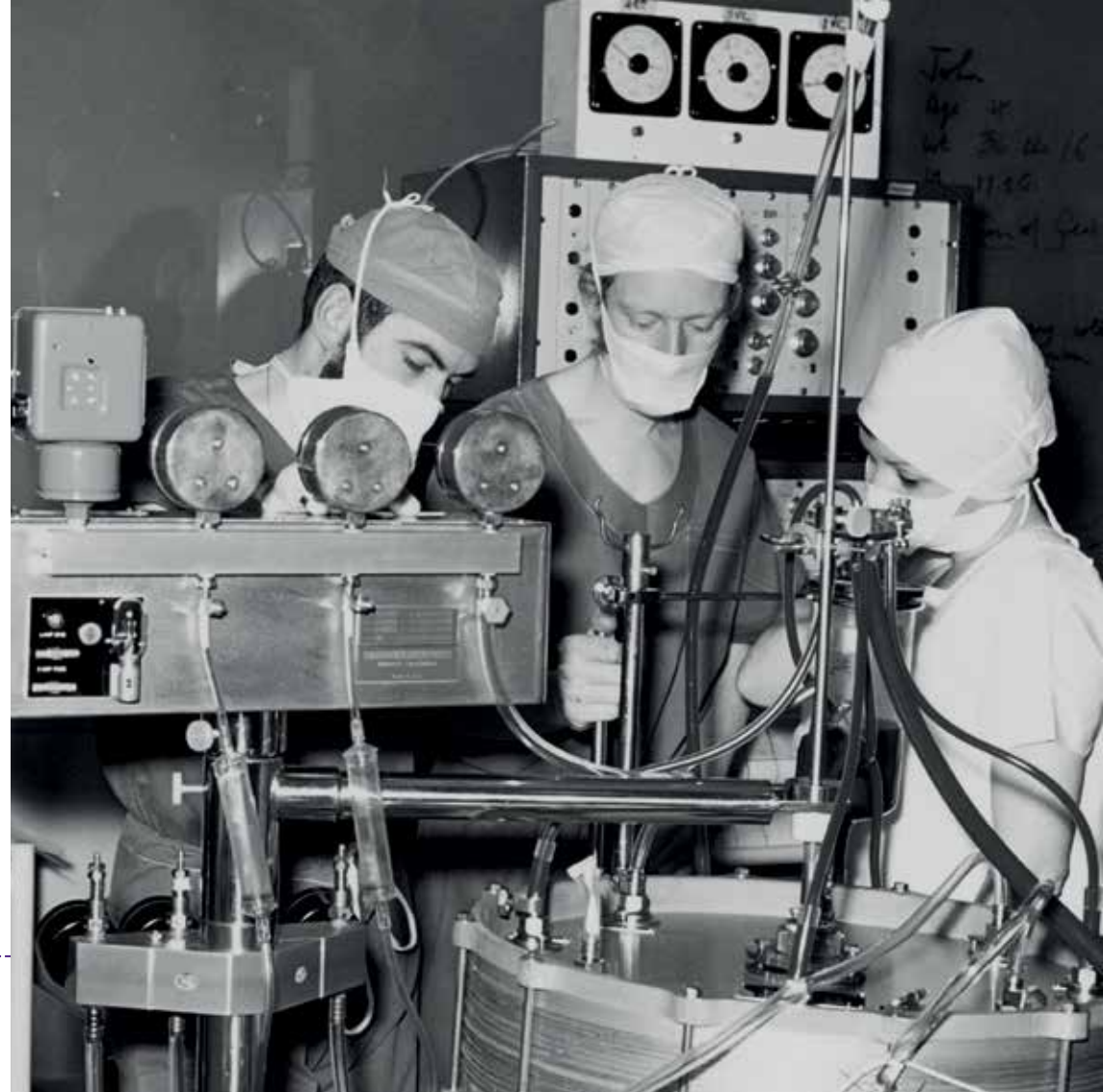
How a little machine had a huge impact

By the mid-1950s, the heart and lung bypass machine had made open-heart surgery possible in adults. By pumping oxygenated blood around the body, it performed the functions of a patient's heart and lungs while surgeons carried out their work on the heart. But adult machines couldn't be used on small children because they removed too much blood from the child as they worked. The risk for these seriously ill patients was too high.

Sadly, for the children on the heart and lung unit, the hospital could only offer basic operations that relieved some of their pain. However, in 1957, Mr David Waterson set up the heart and lung unit's first research programme.

Funded with a charitable donation of £25,000, its aim was to design a bypass machine that could be used in babies and infants to give children born with severe heart and lung conditions the chance of a longer life.

After five years of painstaking design and testing, the first ever paediatric heart and lung bypass machine was ready to use. A year later, five children's lives had been transformed thanks to surgery that tackled their previously untreatable heart conditions. By 1964, more than 50 children a year were benefitting from the bypass machine, and by 1967, 60 per cent of infants with severe heart and lung problems were surviving.



Right: An early heart and lung bypass machine.

1964 One patient a week is admitted for life-saving surgery on the bypass machine.
1967 60 per cent of children admitted to the heart and lung unit now survive.

HEALTH MATTERS

Were you in hospital in 1962?

Richard and Carol make a heart pilgrimage to St Paul's

Heart op kids were pioneering patients

SUN TV

A party of children celebrating the fact that they are still alive

YOUNG LIVES SAVED BY A NEW OPERATION

£250,000 for 'blue

Richard and Carol, the 'blue babies'

Richard and Carol were among the first children to have life-saving open-heart surgery at Great Ormond Street Hospital. They're both now in their fifties; but without improvements led by the surgeons here, things might have been very different.

They were born with transposition of the great arteries, a condition that affects one in 5,000 babies. It means that the two main blood vessels leaving the heart are swapped over, so only blue blood (which hasn't been oxygenated) circulates around the body.

Babies born with this condition have a blue skin tone, but successful surgery means their skin tone changes from blue to pink almost immediately.

Prior to his surgery, Richard's condition meant he couldn't walk, and had spent much of his life stuck in an oxygen tent. But after the operation, he really made up for lost time, playing football and running cross-country.

Carol was four when she had surgery, having survived thanks to a hole in her heart that allowed red (oxygenated) and blue blood to mix. Luckily for Carol, this hole occurred naturally. However, without further surgery, the best that Carol's parents could have hoped for was that she lived to her teens. Mr Waterson's operation fully corrected the heart's plumbing and changed her life – her mother still remembers Carol's fingernails being pink for the first time after she returned from the operating theatre.

Left: Richard and Carol's surgeries were big news.

1971 Survival rates for heart and lung conditions increased to 80 per cent.
1974 Echocardiogram technology allows surgeons to capture images of the heart in real-time so they can diagnose heart disease in children without performing surgery.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Hill-Rom
Today

New techniques mean a new era

By the 1980s, specialist techniques and equipment had revolutionised the way we treated heart and lung conditions. Most patients were now surviving surgery in early childhood and many looked set to enter adulthood. Never before had children with congenital heart diseases prepared to face adult life.

The next step for the team was to make sure their operations were helping patients to survive well into their adult lives. Heart surgery at the hospital was led by Professor Jarda Stark and Professor Marc de Leval, who collaborated with specialists across Europe to find better ways to treat children who, like Richard and Carol, had transposition of the great arteries.

In 1986, a revolutionary new surgical technique called the 'switch' was adopted. The transposed arteries were disconnected and literally 'switched' over. The tiny coronary arteries also had to be switched, and the operation performed within a couple of weeks of birth – all of which amounted to a huge technical challenge.

Like the original bypass operations in the 1960s, there was a steep learning curve. But within a couple of years, switch surgery became standard. The result was that transposition in children was no longer considered fatal. Instead, those with the condition could expect to live for an average of 62 years.

In 1988, Professor de Leval set up the transplant unit thanks to a £200,000 fundraising appeal. It was one of the first centres in the UK to carry out life-saving transplants on children with heart failure.

Chances of survival for babies and small children born with cardiomyopathy (disease of the heart muscle) are very poor, so a transplant can be a lifeline. Today, the programme is one of the largest in the world, performing around 20 heart and lung transplants a year.

Left: Professor de Leval at work.

1980s The life expectancy of children born with transposition rises by an average of 46 years.

Meet our patients

Tineke: from patient to expert

“It was the only hope I had of any kind of life. I can still remember being on the cardiac ward and hearing my parents’ cries of anguish coming down a corridor as the doctors told them I had only a few months left.”

Above: Tineke on her wedding day.

Tineke was born with two holes in her heart, a defect that developed as she grew with a rare condition called Eisenmenger syndrome. This eventually caused her lungs to fail and, at 16 she finally became so ill that she was listed for a transplant at Great Ormond Street Hospital.

Following her successful heart and lung transplant, Tineke went on to complete a degree in medical physics and a PhD at Addenbrooke’s Hospital, itself one of the UK’s pioneering transplant hospitals. But disaster struck again, as it was discovered that Tineke had inherited a congenital kidney disease from her father. Thankfully, she received a replacement from her mother, and was able to return to her career. Tineke was only the third person to have a heart and lung transplant at Great Ormond Street Hospital, and is now in her 28th post-transplant year.

Hannah’s extraordinary story

Hannah is a remarkable girl. She had heart failure as a baby, and was only three when a donor heart was grafted onto her diseased heart at Harefield Hospital. It’s a technique called ‘piggybacking’, where the new organ supports the original.

But it wasn’t easy. The medicines Hannah needed to take suppressed her immune system so that her body wouldn’t reject the donor heart. These medicines had a terrible side effect – they caused cancer. Hannah needed chemotherapy and yet more drugs to fight it, while her medication also had to be greatly reduced.

But this reduction meant that Hannah’s body started to reject the donor heart.At one point, she was rushed back to Great Ormond Street Hospital experiencing seizures caused by a cancerous growth pressing on her spinal cord. Thankfully, the cancer was eventually eradicated.

Ten years after the original piggybacking operation, in an incredible – and unique – turn of events, Hannah’s donor heart was removed at Great Ormond Street Hospital because her own heart had recovered sufficiently to work on its own.

“I’ve got a normal life just like all my friends. I’ve just done my GCSEs, and I’ve now got a Saturday job looking after animals, which I couldn’t have done before. I’m really glad that I don’t have to rely on life-saving drugs anymore.”

Above: Hannah, a heart surgery patient.

1983 More than 1,000 children a year are admitted following an assessment by echocardiography.

Image: Felix Clay/Guardian News and Media Ltd 2009

When Anthony met ECMO

Sixteen-year-old Anthony had just returned from a school trip to Disneyland Paris when he collapsed and was rushed to Great Ormond Street Hospital. When he woke, he didn't know where he was. Thankfully, his mother was standing over him – she told him he was in hospital with pneumonia, before he lost consciousness again.

But Anthony had three other infections too, and over the seven weeks he spent in the hospital, his heart stopped a terrifying 12 times.

Fortunately, the hospital had adopted the revolutionary new extra corporeal membrane oxygenation (ECMO) machine. Similar to a bypass machine, ECMO acts as a child's artificial heart and lungs if theirs are failing while they wait for a transplant or further treatment. This new technology kept Anthony alive through his ordeal – his nurses called him 'the big miracle'.

Since 1992, ECMO has kept nearly 1,000 children alive against all odds.

Right: Anthony didn't just meet ECMO but also his hero, musician Pharrell Williams.

1986 The new 'switch' operation is introduced. The hospital estimates that children born with transpositions now have a life expectancy of up to 62 years.

Heart repairs...without surgery?

Since 2001, thanks to a radical technique introduced to the hospital, we've been able to replace defective heart valves without resorting to surgery to open a child's chest.

The new valve is placed inside a 'stent' – an ultra-thin, collapsible, platinum mesh cylinder – and mounted on a tiny, deflated balloon on the end of a catheter. It's then placed in a blood vessel and pushed into place in the heart. As the balloon inflates, the stent and valve expand to the required width. Then the balloon is deflated and the catheter can be withdrawn, leaving the valve in place.

This technique has many more potential uses, but most importantly, it eliminates the need for open-heart surgery. Valves may need to be replaced as patients grow up, but it's hoped that they can undergo this procedure three or four times before they need more invasive surgery.

Patients undergoing this treatment have usually already had open-heart surgery at least once. Each time their chest is opened, operations are trickier and recovery takes longer. By avoiding this type of invasive surgery, children can leave hospital within 24 hours and avoid intensive care. Since the technique was introduced, hundreds of children have been treated at the hospital, with 100 per cent survival at the time of the procedure. We're proud of the breakthrough, but we're even prouder of the statistic.

Left: A pioneering technique uses a 'stent' to put new heart valves in place.

1988 Professor Mark de Leval sets up the transplant unit.

Breathing easy

Imagine trying to run a 100-metre sprint and then breathing through a straw.

It wouldn't be easy, would it? But for children born with very narrow windpipes, every single breath is that difficult. So, in 2000, Professor Martin Elliott launched a tracheal service to save the lives of children born with this condition.

Operating on tracheas is difficult and not always successful. True to the spirit of Mr David Waterson and Dr Richard Bonham-Carter, the approach we took was multi-disciplinary. The team included specialists in ear, nose and throat (ENT), interventional radiology, intensive care, physiotherapy and heart surgery.

They developed a surgical technique in which the trachea is opened in the front and the back. It is then slid up on itself and reconnected to make the trachea shorter, but much wider. Since the launch of the tracheal service, the team has initiated an international training programme for hospitals around the world. In 2010, we pioneered a new treatment to save the life of patient Ciaran who was born with a life-threatening narrowing of his windpipe. It was the world's first trachea transplant in a child, grown from a patient's own stem cells.

Right: Professor Martin Elliott launched the hospital's tracheal service.

2000 The hospital launches its programme to replace heart valves without open-heart surgery.

Harvey's Berlin Heart

As heart transplants have become a more effective way to treat children with serious heart conditions, waiting lists have grown. Sadly, around a third of all children waiting for a suitable donor heart will pass away.

In 2004, a portable new machine was introduced to keep children alive while they wait for a donor. Like an ECMO machine, the Berlin Heart helps pump blood around the body, and its compact size means that patients aren't confined to bed.

Harvey is one of our Berlin Heart record-breakers. At 15 months old, he was brought to Great Ormond Street Hospital as a result of a rare metabolic condition that affected his heart. He was placed on an ECMO machine in the hope that his heart would recover. But two weeks later, his heart was still failing and a transplant seemed his only option. The team decided to trade his ECMO circuit for two Berlin Hearts to pump the blood around his body.

The Berlin Hearts kept Harvey alive for 167 days, after which a donor heart finally became available. His nine-hour surgery was a success, and he was soon running around and playing football again.

Now 10 years old, Harvey still comes to GOSH for check-ups every six months, but he never complains about all the medication he needs to take. He loves sports – tennis, badminton, cricket, wrestling and, of course, football. This year, he'll be competing again at the British Transplant Games in Liverpool.

Right: Harvey, age 10, shows off a recent football trophy.

2003 The hospital starts an electrophysiology programme to electrically stimulate the heart and cure children with irregular heartbeats (arrhythmias).

Saving Sarah

Sarah was only six days old when she became lethargic and stopped eating. She had viral meningitis, which later went on to attack her heart.

Sarah was rushed to the cardiac intensive care unit at Great Ormond Street Hospital, but, after a few days in the team's care, they felt she only had up to 48 hours to live. For the first time since Sarah arrived at the hospital, her mum, Jennie, was allowed to pick up and cuddle her daughter.

Miraculously, a donor heart was found the next day, a very rare occurrence for someone so young. At just a few weeks old, Sarah became one of the UK's youngest ever heart transplant patients.

Sarah is nine years old now, and still comes into the hospital for check-ups. She's doing really well and loves activities like ballet, tennis and running around.

Left: Sarah, age three, gives her teddy care too.

2005 The hospital performs its 100th lung and 200th heart transplant.

Meet the team

None of the breakthroughs you've read about would have been possible without the people who work in Great Ormond Street Hospital's heart and lung unit. Their collaborations have helped to change the lives of hundreds of patients and families, and for many more generations to come.

"I'm inspired by the people that work here – there are so many world leaders across the hospital. But the real key is the range, severity and volume of heart disease that's referred here – it's quite unique, both in the UK and internationally. I feel that I am working at the leading edge of paediatric medicine, and that has to be helpful to the children we treat."

Professor Mike Burch
Paediatric Cardiologist and Director of Cardiothoracic Transplantation

2009 Approximately 20 heart and lung transplants are carried out each year.

"It is quite a privilege to be able to do this sort of work. It is a very high-pressured job – mentally, one has to be very strong. There are not that many professions I can ever imagine that would need to deal with life and death within a very short time. We always need to remember that the cardiac unit here offers the last hope for families with very difficult problems. With that in mind, we always try to help."

Professor Victor Tsang
Paediatric Cardiothoracic Surgeon

"It's a huge privilege to see babies and children that I cared for 20–30 years ago return with their own children. It's like being part of one big growing family. We now have excellent survival rates after surgery at Great Ormond Street Hospital, and more children with congenital heart disease are transitioning into adulthood. This means that there are now more adults in the UK with congenital heart disorders than children.

It's been such an honour to have been a part of this for 40 years. As an educator of nurses, it's been rewarding to pass on knowledge and experience to the next generation of nurses."

Di Robertshaw
Practice Educator, Cardio-respiratory Unit


Tomorrow

Giving children a brighter future

These breakthroughs in treatments for heart and lung conditions are the result of years of painstaking research. That desire for progress still fuels the work of Great Ormond Street Hospital every day. Techniques are constantly being developed and refined to improve the care for the seriously ill children that come through the hospital's doors.

Together with their research partner, the UCL Great Ormond Street Institute of Child Health, the hospital is the UK's leading centre of excellence in research into childhood illnesses.

The hospital is dedicated to transforming the health and wellbeing of children and young people. Thanks to the generosity of our supporters, the spirit of innovation envisaged by Mr David Waterson and Dr Richard Bonham-Carter is taking the hospital to an amazing new level of care.

The work that takes place at Great Ormond Street Hospital covers everything from neonatal conditions to the beginning of adulthood. In addition, the hospital's Somers Clinical Research Facility allows children to benefit from research that is fully integrated into their treatment in a way that's designed to minimise stress and make them comfortable.

Most importantly, by sharing its findings with other leading hospitals, the hospital's research benefits children around the world. When you consider that childhood health problems determine adult health too, it's an incredible responsibility.

Left: An artist's impression of the Mittal Children's Medical Centre.

Could 10-pin bowling beat cystic fibrosis?

Cystic fibrosis is the most common genetically inherited disorder in the UK. A steady decline in lung function is just one of the symptoms that causes premature death in affected children. Stopping that decline is vital for helping them to grow up to lead healthy adult lives.

Over the years, we've led the way in finding ultra-sensitive ways to measure lung function in infants and detect early lung disease before other symptoms become visible. This work has led to a unique programme to monitor and treat children with cystic fibrosis from birth, generously funded by supporters of Great Ormond Street Hospital Children's Charity.

"Until now, it's been hard to get children under six to co-operate with tests to measure their lung volumes" says Dr Colin Wallis, who – in partnership with Professor Jane Stocks – leads the new programme. "But hook up the output of the test to a virtual 10-pin bowling game and it's hard to get them to stop!"

As yet, there is no cure for cystic fibrosis, but Dr Wallis' programme will help doctors intervene in the crucial early years, so these children can enjoy productive adult lives. "We need to begin treating as soon as possible, before the disease takes hold" continues Dr Wallis. "Waiting for these children to become unwell is waiting too long."

Right: Virtual 10-pin bowling helps the hospital measure children's lung volumes.

“I was born in 1955, and my first operation at Great Ormond Street Hospital was when I was just 18 months old. I had another one at the age of nine as my health was deteriorating fast.

I have treasured memories of my time there and, despite being born with heart problems, I have no regrets. I’m glad to be involved in Dr Bull’s study, as I can never repay Great Ormond Street Hospital for what they have done for me.”

Steve, former patient

The right surgery at the right time

Many ‘blue babies’ have a condition called tetralogy of Fallot, a congenital heart condition that reduces the heart’s ability to circulate oxygenated blood. Since the 1960s, the teams at the hospital have operated on more than 1,000 children born with this condition. Today, the great majority of children experience a normal childhood, but the operations they had as babies leave a leaky valve on the right side of their hearts.

At present, it’s very difficult to know the best time to offer any new valve implantations. Too soon, and the child may outgrow the valves. Too late, and the heart muscle may get too tired with years of extra work. Dr Kate Bull led a long-term study examining different patients between the ages of one and 50, determined to find the optimum times to perform the surgery to insert a new valve.

Since Dr Bull’s retirement, Dr Kate Brown has been leading this study, working with experts to look at the short- and long- term effects of major heart surgery.

“We’re looking at whether we can improve the information that we give to families when they go home, so that they are better equipped to recognise and act when their child is becoming unwell. We’re also looking at whether we can improve communications between the specialist centres and the healthcare in the community, so that we can ensure that children get the help they need in a timely way, and grow up to lead fuller lives.”

Left: Dr Kate Bull with Steve, our 14th patient to have surgery to repair tetralogy of Fallot.

Turning virtual hearts into real improvements

The hospital's programme to replace faulty heart valves without the need for open-heart surgery has changed the lives of hundreds of patients. However, everyone's heart is unique, which means that this technique can only be used on 15 per cent of the children who need the hospital's help.

Now, Professor Andrew Taylor and his team are using the latest cardiac imaging and computer modelling to potentially remove the need for open-heart surgery for thousands more patients every year.

"Advances in computer modelling mean that we can design and test implants virtually" says Professor Taylor. By using MRI scans to create 3D models of patients' hearts, his team can build and test bespoke valves before they're implanted. The use of these devices in the future could prevent up to 10,000 patients a year around the world from having open-heart surgery.

Looking ahead, Professor Taylor's team are taking another pioneering step into the unknown, using CT scans to monitor the valves after they've been inserted. "Every patient is different, and we're taking huge steps to make sure that their treatment is tailored precisely to their needs" he says.

Left: Professor Andrew Taylor
Above: One of Professor Andrew Taylor's 3D models of a virtual heart.

Thank you

Thanks to the specialist cardiac surgeons and the transplant team at Great Ormond Street Hospital, more than 400 children with heart failure have been given the chance of life. But for children in need of a transplant, both time and donor hearts are in short supply. What if that need could be removed?

As we've shown earlier in this guide, devices such as Berlin Hearts can keep children alive while they wait for a transplant, but Professor Mike Burch and his team have a longer-term hope: they're exploring how using a patient's own stem cells could help the heart heal itself while a donor is being looked for.

And, one day, they hope to remove the need for transplants altogether.

Everything our specialists are doing for tomorrow is based on the same principles that inspired Mr David Waterson and Dr Richard Bonham-Carter all those years ago. By using our unique skills to work together, we can help more children than ever before. And as technology develops and our knowledge increases, who knows what is possible?

Right: Great Ormond Street Hospital patient Shiloh, who has cystic fibrosis.

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.

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