



Highlights from the year



The Disney Reef opens

We celebrate the opening of the very special Disney Reef. This colourful, underwaterthemed outdoor play area is in the heart of the hospital where children can relax and enjoy themselves with their families.



UK's first spinal surgery before birth

GOSH and University College London Hospitals (UCLH) surgeons perform the UK's first surgery to repair spina bifida before the child is born. The fetal surgery, brought to the UK thanks to funding from GOSH Charity, UCLH Charity and UCL, could help children avoid lifelong disabilities associated with the condition. See pg 24.



Paul O'Grady meets some little heroes

A six-part TV series, Paul O'Grady's Little Heroes, premieres on ITV. In this heart-warming programme, Paul visits GOSH patients and families from all over the UK, providing a unique insight into their experiences at one of the world's leading children's hospitals.



A bright future for GOSH patients

We host our first-ever GOSH
Teens Careers Festival, inviting
current and ex-patients to
take part in CV workshops,
interview training and creative
team-building challenges. It's
a wonderful opportunity for
some of our amazing corporate
partners to share their
expertise and engage with
young people.



A new space for reflection

GOSH unveils a new multifaith room for prayer and reflection, following a generous donation from a leading UK Muslim charity, the Al-Khair Foundation. The room will be open to families and staff at GOSH, as well as ambulance drivers and paramedics from across the capital who drop off or collect patients.



Believing in the power of research

A major new public fundraising campaign launches to support our ongoing investment in vital child health research. The 'We believe' Research Fund will raise money to help find new treatments and cures for children with rare and complex diseases.



Incredible progress in labgrown organs

A pioneering team, supported by GOSH Charity, unveils the world's first functioning oesophagus grown in the laboratory and successfully transplanted into mice. In the future, this technique could change the lives of children born with severe gut problems, offering hope of personalised, rejection-free transplants.



Building a centre for the senses

Construction work begins to create the UK's first dedicated facility tailored to children with sight and hearing loss: the GOSH Sight and Sound Centre supported by Premier Inn. The centre will be entirely funded by GOSH Charity, with an incredible pledge of £10 million from Premier Inn getting us off to a fantastic start towards our £25 million target. See pg 46.



GOSH leading the UK in genetics and cancer progress

GOSH is announced as one of seven new UK genomic laboratory hubs, selected as part of NHS England's initiative to improve understanding, diagnosis and treatment of genetic diseases. With ongoing GOSH Charity funding underpinning the hospital's world-leading cancer service, GOSH is also announced as the first hospital in the UK to offer NHS patients a groundbreaking new 'CAR-T' therapy, harnessing the power of the immune system to treat a type of leukaemia.



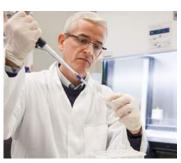
Funding pioneering ideas from bench to bedside

In partnership with LifeArc, a leading UK medical research charity, we launch a new scheme to fund high-quality research projects that are at the brink of being taken from the laboratory into new tests and treatments that can be trialled in children for the first time.



Research to improve epilepsy surgery

Brain-surgeon-in-training Aswin Chari begins his role as our second GOSH Charity Surgical Scientist Fellow. The Lewis Spitz Paediatric Surgical Scientist Programme supports surgeons to take time out of their intense training programme to carry out vital research. Aswin hopes to use the latest electrode technology to find quicker, safer and kinder ways to diagnose childhood epilepsy.



Funding child health research around the UK

We announce a £2.1 million investment in 12 incredible child health research projects through the joint GOSH Charity and Sparks annual national call. This year, funding included two projects in partnership with other medical research charities: Krabbe UK and Dravet Syndrome UK. See pg 18.



A year of families, firsts and fond farewells

Medicine, science and technology continue to move at an unfathomable rate. In the last year at GOSH, we've watched revolutionary researchers developing world-first treatments of tomorrow, invested in state-of-the-art technology, seen flexible, future-proofed clinical spaces taking shape, and supported services designed to support the whole family now and in the future.

We know that we can't achieve everything alone and, this year, key partnerships have underpinned our research successes. Since children's medical research charity Sparks joined the GOSH Charity family in 2017, we've run two incredibly successful funding calls dedicated to supporting child health research across the nation. This year, the call – the largest of its kind in the UK – funded 12 projects through a joint £2.1 million investment. Projects include pioneering gene therapy for children with difficult-to-treat epilepsy, creating superpowered immune cells to treat childhood tumours, and projects funded in partnership with charities Dravet Syndrome UK and Krabbe UK.

Building work has progressed on several exciting rebuilding and refurbishment projects that will help GOSH realise its vision for the future of child health. We've watched the Zayed Centre for Research into Rare Disease in Children coming to life, in advance of its official opening from

summer 2019. An outpatient area and more than 500 researchers will move into this state-of-the-art building designed to bring together scientists and clinicians to more accurately diagnose, treat and cure serious childhood conditions. Construction also began on the Sight and Sound Centre supported by Premier Inn, due to open in 2020. This will be the UK's first dedicated outpatient facility tailored to the needs of children with sight and hearing loss.

It's not all about looking to the future. This year, it has been a pleasure to watch children, families and staff reaping the benefits of your previous support in the world-class Mittal Children's Medical Centre, home to the recently opened Premier Inn Clinical Building and the Morgan Stanley Clinical Building, which opened in 2012.

It's been a huge team effort across the hospital this year to prepare for the launch of a new electronic patient record system. Funded by GOSH Charity, it will replace hundreds of separate systems and transform every aspect of patient care and experience at GOSH. We've also seen researchers beginning to harness the power of an incredible data analytics platform, helping to gain new understanding that will improve the lives of seriously ill children.

We've supported some major upgrades and innovations in imaging technology this year, from funding vital MRI software updates to opening a new suite that allows doctors to see what's happening inside the body at a cellular level. We've also watched two major projects progress that are due to complete next year: the Khoo Teck Puat intraoperative MRI (iMRI) Suite, which will transform brain surgery at GOSH, and the Cardiac Catheter Laboratory, which will provide world-class facilities to treat children with serious heart conditions in a less invasive way.

Each year, we're astonished by the incredible lengths our supporters go to in raising money for seriously ill children and this year has been no different. Whether you're baking, climbing, racing, putting aside a little cash each month or making a one-off donation, your efforts are vital in helping us support seriously ill children from across the UK.

We are, as ever, grateful to all of our dedicated and passionate charity staff. This year we were delighted to receive an 'Outstanding' rating from The Sunday Times Best Not-for-Profit Companies List, as well as a two-star accreditation and 17th place in the Top 100 list.

The year comes to an exciting but bittersweet end for two of us, as we plan to step down from our respective posts at the charity. Tim bids a fond farewell after 17 years, having helped to significantly increase funds raised to support the hospital and amplified its support for vital child health research. John will step down from his role as Chairman, after four years in the post and a wonderful longstanding relationship with the charity. One of John's final contributions as Chairman was overseeing the appointment of the new GOSH Charity Chief Executive. We're thrilled to announce that this is Louise Parkes, who brings more than 20 years of voluntary sector experience to the charity. Louise held leading fundraising roles at major charities including the British Heart Foundation, Shelter and Barnardo's, and begins in her new role at GOSH Charity in May 2019.

Together and with your ongoing support, we can look forward to the coming year with excitement and optimism.



John Connolly Chairman of Trustees GOSH Charity



Tim Johnson Chief Executive GOSH Charity (until March 2019)



Louise Parkes Chief Executive GOSH Charity (from May 2019)

Your support in numbers

None of our lifesaving work with children would be possible without your incredible generosity. Thank you.

381

guests attended Daniel Galvin Bracken's A Night at the Museum gala dinner, raising more than £1 million for a new intra-operative MRI suite that will transform the way brain surgery is performed at GOSH.



1,133

volunteers generously donated their time to support GOSH Charity and Sparks – from the committees organising our events to supporters acting as the face of GOSH in their local community. 9

year-old GOSH patient Rowan completed RBC Race for the Kids for the fourth time, despite undergoing treatment for leukaemia. More than 2,000 Royal Bank of Canada team members also took part.



100

year-old Syd jumped out of a plane on his birthday to raise money for GOSH Charity.



8,955

people responded to our annual supporter survey – thank you! We're using this valuable feedback to shape what and how we communicate with you, and how often. 539

silent auction items donated by our generous supporters were sold at fundraising events, from a £50 signed football shirt to a £10,000 holiday in Miami.



61,295

diners added £1 to their bill at Gordon Ramsay Restaurants in support of GOSH Charity.



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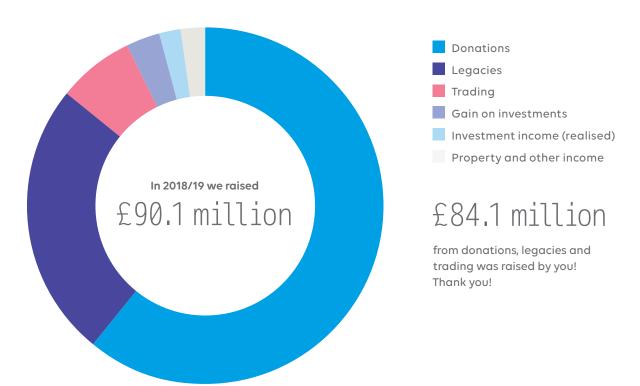
episodes of *Paul O'Grady's Little Heroes* aired on ITV, reaching
an average of 3.5 million people
across the nation each week.

120

children attended the opening of the Disney Reef, a colourful, underwater-themed outdoor play area where families can take some time away from the ward environment.



What we raised together



Your £1 this year

71p Goes directly to charitable activity

29p

Helps us raise the next pound*
*Based on 2018/19

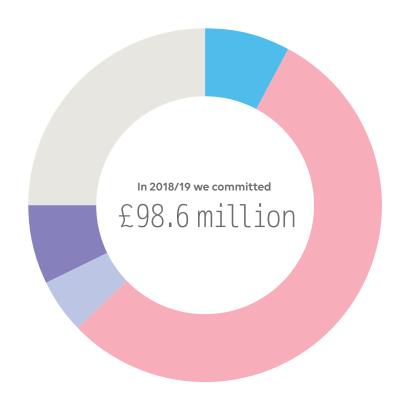
Every pound counts

Whether it's supporting our four key funding areas, helping us save for major upcoming projects or allowing us to raise more money for the hospital's future, every penny we receive is helping to give seriously ill children the chance of a better future.

Some of our biggest projects, such as new hospital buildings, require large upfront funding. That means the way we spend money each year varies. To reflect this, in addition to the annual figure (see left), we also look

at the long-term relationship between the donations you give us and the cost of raising money. On average over the last five years, we've committed 71p out of every pound directly to charitable activities.

Where your money went



£7.4 million*

Pioneering research
Supporting world-leading
scientists to find the diagnoses,
treatments and cures
of tomorrow.

£54.1 million*

Rebuilding and refurbishment Creating flexible, future-proofed facilities designed around children and young people.

£5.1 million*

Child, family and staff support Investing in services to raise children's spirits, ease the burden on families and support the amazing staff who care for them.

£24.9 million

Running costs and raising funds Running the charity effectively and efficiently, and raising more money for the future.

£7.1 million*

Advanced medical equipment and systems Funding cutting-edge kit to address the hospital's most urgent technology needs. *These figures include an allocated support cost to cover essential administration of the grants.

Looking to the future



"I am thrilled to be joining GOSH Charity at such an exciting time. Building on the charity's excellent foundations, I'll be shaping our priorities for the next few years and beyond. This will include transformative building projects to improve the care and experience of patients and their families, as well as the next vital phase of our investment in child health research. I'm also very excited about introducing and embedding innovation within the charity. It will help us to be bolder and to take advantage of new technology and ideas, while ensuring we're making the best possible use of charitable funds."

Louise Parkes, GOSH Charity Chief Executive from May 2019.

Achieved	⊗ Not achieved	Congoing
· / terricaca	O NOC GCITIC VCG	Congoing

2018/19 Aim		Achieved?
Start work on the new Sight and Sound Centre Centre supported by Premier Inn, due to open in 2020.	\bigcirc	Yes, in July 2018 we announced plans for the Sight and Sound Centre, with news of an incredible £10 million pledge from Premier Inn. Construction began in October 2018.
Launch our refreshed privacy policy in May 2018.	\bigcirc	Yes, we fully implemented the amendments required to be General Data Protection Regulations (GDPR) compliant. These practices are now embedded across the organisation and compliance is continuously monitored.
Complete implementation and commence optimisation of our supporter database system.	\bigcirc	Yes, implementation is complete with all GOSH Charity data transferred across to the new system and Sparks data in progress. We are now focusing on resolving any issues and simplifying processes.

2018/19 Aim		Achieved?	2019/20 Aim
Ensure that our working environment and organisational structure enables our employees to perform to their best in order to meet our business goal of helping children at GOSH and across the UK.	\bigcirc	Yes, with excellent progress made in five key focus areas: organisational design, collaboration between teams, working smarter, learning for greater enablement, and business, project and activity planning, governance and learning.	Continue to monitor and improve internal collaboration across the charity by gathering feedback from staff, identifying barriers to collaboration and tracking the tangible benefits of collaborative projects.
Aim to raise at least £91 million from fundraising and £100 million in total income.	\otimes	No, we raised £84.1 million from fundraising and £90.1 million in total.	Aim to raise at least £82.8 million from fundraising and £85.9 million total income. This figure reflects a reduced number of major fundraising campaigns in 2018/19 as we prepare for the next major stage of the hospital's redevelopment programme.
Ensure we make the most of every pound year-on-year and complete a cost-review project.	\mathbb{C}	Ongoing with increased scope, after initial analysis identified several areas where we could improve the effectiveness of our fundraising activities.	Continue work on a cost- review project to maximise our contribution to charitable activities.
Continue to gain traction on fundraising for research.	\mathbb{C}	Ongoing, after the successful launch of our public fundraising appeal and the continuation of our high-value research fundraising appeal.	Develop a research fundraising and communications strategy for GOSH and Sparks, to maximise our research contribution through our high-value appeal, public fundraising and a new multi-year Sparks campaign.
Completion of the Zayed Centre for Research in late 2018, becoming fully operational in 2019.		Ongoing, after some delays to construction. The building will be fully operational from late 2019, after a celebratory event in July.	Celebrate completion of the Zayed Centre for Research.
Confirm key hospital projects and continue to ensure that our funding streams meet the most urgent needs of the hospital.	\mathbb{C}^{2}	Ongoing, with approval for the next stage of the hospital's redevelopment programme expected later in 2019. A joint Hospital and Charity team has been established to help prioritise projects for the charity to support and ensure charity funds are used to drive the largest impact.	Shape our priorities for charitable funding, fundraising plans and financial targets for the next three to five years, informed by a decision on the next phase of the hospital's redevelopment.

In 2019/20 we'll also launch and enable our new innovation team, who will identify opportunities and embed innovation in our ways of working.



Pioneering research
Impact Report 2018/19

Research at a glance

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surgeries to repair spina bifida performed while the child was still in the womb. Thanks to you, we were able to help bring this incredible service to the UK for the first time. 12

research projects funded across the nation through this year's £2.1 million joint national call with Sparks,, from pioneering gene therapy for children with difficultto-treat epilepsy to creating superpowered immune cells to treat childhood tumours. £552,000

invested in early stage research at GOSH, supporting world-class scientists to turn their ideas into life-changing treatments.



"Having laboratory research linked so closely with clinical care on one site is exceptional. It's an opportunity to rapidly translate ideas into results that will benefit children. I always had a real ambition to work here one day. GOSH is a global centre of research and clinical activity for seriously ill children. And the atmosphere is extraordinary. There is particular attention given to the wellbeing of young patients that goes beyond just medical care. I'm so pleased to be here."

Dr Giovanni Baranello, GOSH Charity Senior Clinical Lecturer in Neurosciences, who took up his post in January 2019. Dr Baranello, whose role is part-funded by Muscular Dystrophy UK, will support groundbreaking research and clinical trials into muscle-wasting conditions like Duchenne muscular dystrophy.

In October 2018 Professor Paolo De Coppi's team unveiled the world's first functioning oesophagus grown in the laboratory and successfully transplanted into mice. The research, supported by GOSH Charity, has the potential to change the lives of children with oesophageal atresia, a condition that leaves the oesophagus disconnected from the stomach.

"For Hudson," says mum
Nicola, "an entirely
new, functioning food
pipe would be a game
changer. It would give
him a sense of normality,
so that he can enjoy
his life as fully and
independently as any
other child. We're excited
and hopeful to see where
this research goes."



Hudson, age two, with his brother, Hank

What's next?

- We'll work closely with global experts in childhood heart conditions to identify areas where our funding will make the most difference to children with serious heart problems.
- Together with Sparks and in partnership with research charities, we'll make up to £2 million available for pioneering child health research projects across the UK.
- We plan to recruit an early-career researcher with the potential to become a world-leading childhood cancer researcher, finding the treatments and cures of tomorrow.

Pioneering research
Impact Report 2018/19

Pushing forward new treatments for life-threatening cell disorders

Research takes time. It all starts in the laboratory, where researchers gather vital evidence to show a new test or treatment could work. You help us to invest in this crucial stage, ensuring the most promising ideas get off the ground. This includes research into lysosomal storage disorders (LSDs), conditions that leave the body unable to break down certain molecules, leading to a toxic build-up. There are currently no cures for LSDs and, tragically, many children lose their lives at an early age. Your support is helping to push promising new treatments through the essential stages of development from lab bench to bedside, ensuring they reach children as quickly and safely as possible.





Clinical trials: Sanfilippo syndrome Funded in 2014/15

Sanfilippo syndrome is a rare childhood LSD, caused by an error in DNA — the body's built-in instruction manual. This error leaves the child's body unable to break down a compound, which builds up in cells and causes damage to the brain. It causes progressive dementia, followed by the loss of the ability to walk and swallow. Children with Sanfilippo syndrome sadly don't live past their mid-twenties and there are currently no effective treatments. The condition affects around 100 children in the UK. and over 1,000 worldwide.

In 2014, we awarded funding to leading Sanfilippo sydrome researcher Professor Brian Bigger at the University of Manchester, through the GOSH Charity national call. His team aimed to develop a new, curative treatment for children with Sanfilippo syndrome. The approach – known as stem cell gene therapy - would involve taking blood stem cells from the child, modifying the cells in a laboratory to correct the genetic mistake, then reintroducing the cells back into the patient. Our funding allowed the team to develop a modified virus that could deliver the corrected cells back to the patient and show the technique was safe through laboratory testing.

The Sanfilippo syndrome trial will be one of the first clinical trials to use stateof-the-art gene and cell therapy manufacturing facilities in the new Zayed Centre for Research, funded by GOSH Charity. The project was successful, putting the team in an ideal position to apply for grants from larger funders. Together with Professor Rob Wynn and Dr Simon Jones from the Manchester University Hospitals NHS Foundation Trust, they were able to licence the therapy and win an additional £2.6 million grant from Orchard Therapeutics to cover all remaining lab work needed to take the treatment to clinical trial. As we write this, the team is preparing to launch a world-first clinical trial, working closely with Professor Adrian Thrasher and colleagues at the ICH and GOSH.

"GOSH Charity's funding helped us, at an early stage in the project, to prove that the idea had legs. It was undoubtedly pivotal in getting us to where we are today — seeing children with Sanfilippo syndrome get access to what could be a life-saving treatment. It's fantastic to witness, and the families are so excited to have some hope."

Professor Bigger

Pioneering research



Lab research: Krabbe disease Funded in 2018/19

Krabbe disease is a rare LSD that causes most affected children to lose their lives within two years. This year, you helped us fund an innovative project in partnership with Krabbe UK, to improve treatments for children with this devastating disease.

"Krabbe disease affects many parts of the body," says lead researcher Dr Sara Benedetti, based at the ICH. "In particular, the toxic build-up causes brain cells to degenerate, so children experience seizures, lose their sight and hearing, and progressively and relentlessly lose all of their faculties.

"We know that special cells in the blood – known as blood stem cells – can reach the brain and turn into another type of cell known as a microglial cell. Those cells are great at clearing up the toxic build-up, so they could prevent the devastating brain degeneration we see in these patients.

"The idea of my project is to get as many of these blood stem cells into the brain as possible. But because our brain is so precious, it is protected by a 'gateway' known as the blood-brain barrier (BBB). The BBB determines which cells or molecules are allowed in or out of the brain. My aim is to modify that barrier to temporarily 'open

the gates', so we can flood the brain with extra blood stem cells. Once in the brain, those cells will become microglial cells and clear up as much of the toxic build-up as possible. We'll do this in the lab and in mice, to ensure it's safe before it's tested in patients.

"Krabbe disease is our focus, because these children desperately need an effective treatment. But the principle could be applied to any LSD that causes brain damage and possibly, in the future, to neurodegenerative diseases like Alzheimer's or Parkinson's."

Tom's story

Tom's Dad, Andrew, says: "Tom was born at Hull Royal Infirmary on the 28th of July, 2012. He was a very happy, very healthy little boy. Then when he got to about six or seven months old, he started crying more. He started going into spasms and his whole body would go stiff.

"We took him to the doctor and he said he was admitting him to the hospital. Three weeks later, we got the news that he had a type of leukodystrophy – a group of genetic disorders that affect the central nervous system – called Krabbe disease.

"This meant that from that point, we had a maximum of two years with our son. I just felt numb.



Tom, pictured aged one.

To be told there was no medicine, and no way you could fight the disease; I think that was one of the most frustrating things.

"One of the most shocking things for me was that, as the disease progressed, Tom couldn't do anything for himself. Week by week he lost the ability to do something. I actually have a picture of Tom's last smile. I remember it because the next day he couldn't do it.

"That Saturday, his tummy stopped working so the doctor took us aside and told us he probably had two or three days left. But Tom liked to prove doctors wrong. He survived for another ten days and died on 9 December 2013, aged 17 months.

"The research that Sparks and GOSH Charity are funding for Krabbe disease is incredibly important. We know the enzyme that is missing in children that causes the disease, but we don't yet know how to do anything about it."



Supporting child health research across the UK

Each year, GOSH Charity and Sparks aim to make around £2 million available for researchers across the UK who are working to improve child health. At this very moment, the nation's brightest minds are working hard to turn their ideas into the treatments and tests of tomorrow. This map shows all the active national call projects that you're helping us to fund.

This year, as part of our £6.9 million investment in child health research, we committed an incredible £2.1 million to fund projects across the UK. This included two grants awarded in partnership with smaller medical research charities: Krabbe UK and Dravet Syndrome UK. Thanks to your support, the national call is the largest funding opportunity in the UK dedicated to child health research.



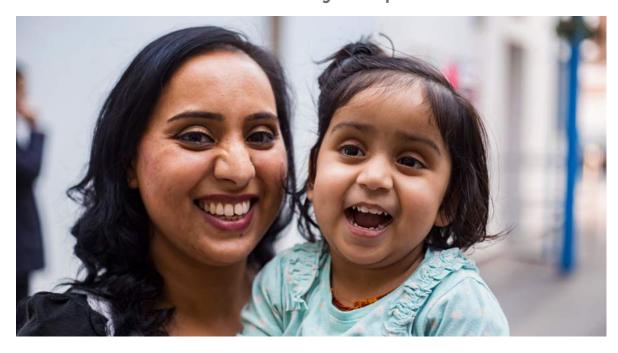
"GOSH Charity, Sparks and other charities like Krabbe UK partnering together is absolutely fundamental to researchers like me getting funding. It means there is a pot of money for clinicians and scientists across the UK to access and use to push forward new treatments. I can't stress how vital that is to the future of child health."

Dr Sara Benedetti, funded through the 2018/19 GOSH Charity and Sparks national call, with partner funding from Krabbe UK.



Pioneering research

From lab to clinic: the story of spina bifida



Tulsi, age two, and her mother Laxmi

Every year, around 700 pregnancies in the UK are affected by neural tube defects like spina bifida. Ongoing research supported by GOSH Charity and Sparks is helping to develop innovative new approaches that could one day save these children from a lifetime of complications.

In the earliest weeks of pregnancy, a layer of cells on the back of the embryo curls up like a sheet of paper and closes to form the neural tube. That tube will ultimately mature into the baby's brain and spinal cord, programming the baby's every thought and movement. But sometimes, this process can malfunction, causing a neural tube defect.

The most common neural tube defect is spina bifida, where the nerves and membranes of the spine are left exposed as the baby develops in the womb. It can cause paralysis of the lower body, leading to urinary and bowel control problems, as well as fluid build-up on the brain. Surgery after birth to repair the defect cannot always alleviate these symptoms.

Andrew Copp is Professor of Developmental Neurobiology and Head of the Newlife Birth Defects Research Centre at the ICH. He has made it his life's work to understand why children are born with neural tube defects like spina bifida, and what could be done to prevent them.



Professor Andrew Copp

From the beginning

More than a decade ago,
Professor Andrew Copp – then a
medical student at Guy's Hospital
– began working on a laboratory
model of spina bifida. "We knew
that folic acid supported a baby's
healthy growth," he says, "but
some individuals didn't seem
to respond and still went on to
develop neural tube defects. We
wanted to see whether another

vitamin – inositol, also known as Vitamin B8 – might help. It had a bigger positive effect than we'd expected."

It took the best part of ten years to plan and conduct a pilot study to test their finding in women.

Over that period, Professor

Copp's team studied 99 women who had experienced a previous pregnancy affected by a neural tube defect.

Of the 99 women, 57 went on to have pregnancies during the study period. Three were affected by neural tube defects, all in women who took folic acid alone. No pregnancies in the group who took folic acid and inositol were affected by a neural tube defect and no adverse effects were reported in any of the women or their babies.

Professor Copp says: "It suggests that women who have had one pregnancy affected by a neural tube defect may be best advised to take both folic acid and inositol when planning their next pregnancy. This should of course be done under supervision of their GP or obstetrician."

The next step for the team is to conduct a full clinical trial to confirm the beneficial effects of inositol. "It's nice to see something that you've done for years and years go into clinical practice," says Professor Copp. "I'm very pleased with the outcome after this long period of research."

Treating spina bifida in the wombProfessor Copp's team has also

been involved in one of the hospital's most incredible clinical advances this year – completing the UK's first pioneeringsurgery in the womb for spina bifida. The procedure involves closing exposed spinal tissue without delivering the baby, and has been proven to help improve the lives of children born with spina bifida. This groundbreaking surgery was made possible thanks to an experienced 30-strong multidisciplinary team and a pan-European collaboration.

Since the team's first UK procedure in summer 2018, several more have been performed and, excitingly, NHS England has recently decided to commission the surgery for spina bifida as an NHS service.

Your support allowed us to fund fetal surgery expert, Professor Jan Deprest, who came to GOSH from Leuven, Belgium, to train the GOSH team. We helped to fund the first 10 surgeries, allowing the team to show that the procedure is possible in the UK. Our funding also ensured free-of-charge, nearby accommodation was provided for mothers undergoing the surgery.

Meet Tulsi, age 2

During her pregnancy, Tulsi's mum Laxmi was told that her baby girl might be paralysed, need a tube on her brain to relieve pressure, or worse, not survive.

Tulsi's best chance at life was to have delicate spinal surgery at GOSH within hours of being born.

Chiari II: A life-threatening symptom of spina bifida

Around 90 per cent of children with the most severe form of spina bifida have a lifethreatening brain defect known as Chiari II. It causes damage to nerves that control breathing, leaving children at risk of severe disability or even death. Supported by GOSH Charity and Sparks funding, Professor Copp's team is investigating why Chiari II is so commonly associated with spina bifida and whether it could be prevented.

Laxmi says: "It was a difficult five weeks, but there were fantastic nurses that took really good care of us both. We've been home for 18 months now and Tulsi is doing really great. She's crawling and standing up, and she loves going to play group.

"We know she'll face challenges, but we're not focusing on the negatives. Tulsi will need to be monitored for the rest of her life so we come back to GOSH for regular appointments for physio and to check her brain, bladder and legs. We take comfort in the fact that she's in the very best hands at GOSH.

"It's incredible what doctors can do now, like the new spina bifida surgery at GOSH that repairs the baby's spine while it's still in the womb. It's just fantastic. It gives families another treatment choice, which is so important. When you're receiving so much bad news, it's really encouraging to hear that, with surgery, your baby has a better chance of smiling and even walking."



Rebuilding and refurbishment

Impact Report 2018/19

Rebuilding and refurbishment at a glance

In October 2018 we kicked off construction of the GOSH Sight and Sound Centre, supported by Premier Inn. This specialist outpatient facility is due to open in 2020 and will include quiet waiting spaces, a sensory garden and interior design tailored to the needs of children with sight and hearing loss.



"I have a cochlear implant and, when I go to the hospital, I find it hard to understand what people are saying because it's usually really loud. It can make me feel a bit annoyed or upset. But having my family and friends with me really helps. My favourite sound is probably birds in the morning, so I'm really looking forward to seeing the garden in the new Sight and Sound Centre!"

Paris, age 13.

9

children with sight and/or hearing loss, along with their families, gave their insight on patient-friendly design, helping to shape plans for the new specialist centre at GOSH.

£415,000

of work completed to improve the mortuary space at GOSH, giving families as much comfort, privacy and dignity as possible at the most difficult time of their lives.

120

children attended the opening of the Disney Reef, a colourful, underwater-themed outdoor play area where families can take some time away from the ward environment.

This year we marked one year since the completion of the Mittal Children's Medical Centre, with the opening of the Premier Inn Clinical Building. Ward Manager Philomena Cosgrove's team on Nightingale Unit sees the benefits of the new facilities every day as they care for patients undergoing procedures under anaesthetic. They held a special party to celebrate.



"We've gone from having eight beds to having 18. Being able to admit more patients really takes the pressure off inpatient wards, who were having to use their own beds when we didn't have space. Families tell us it's lovely to come back to the same ward after their procedure and be looked after by the same nurse throughout the day. The staff are much happier here too. It's a lovely environment to work in."

What's next?

- We'll celebrate completion of the Zayed Centre for Research, an incredible new facility open from late 2019 that will bring patients and researchers together under one roof.
- In early 2020 we plan to celebrate the opening of the new Khoo Teck Puat iMRI suite. The facility will allow surgeons at GOSH to capture images of a child's brain mid-operation, helping to reduce the need for repeat surgery.
- We will progress plans for a transformative rebuilding project designed to improve the hospital environment and imaging facilities for children with cancer.



Rebuilding and refurbishment



Katie, age 14

Scientists based at the Zayed Centre for Research will focus on three key areas of cuttingedge science:

DNA and data

Deep in the centre of our cells, our genes are written in the form of DNA — the instruction manual for life. Molecules within our cells are constantly 'reading' this rulebook to keep our bodies functioning.

Within the Zayed Centre for Research, scientists will investigate how certain genes in the manual are miswritten or misread, causing rare childhood diseases. The centre's cuttingedge genomics facility will house incredible technology with the potential to 'read' every gene in the body: the entire rulebook. This will not only help researchers

to develop a stronger understanding of diseasecausing genes but also to create transformative new therapies.

Meet Katie, age 14

Katie has a rare movement disorder called dystonia, which causes uncontrollable muscle spasms that force her body into twisting, repetitive movements. It has a huge impact on her daily life and can be very painful. Katie's mum Sarah remembers her difficult early years: "The type of dystonia that Katie was diagnosed with meant that she was declining. She used to be able to ride a bike, skip and hop but she lost the ability to do all these things over the years."

Katie's problems began at the age of two, but it wasn't until she was referred to GOSH at the age of seven that she finally got a diagnosis. Her family met Professor Manju Kurian, Paediatric Neurologist and UCL clinician scientist at GOSH.

For the past seven years,
Professor Kurian has been
working to understand what
causes different types of
dystonia. Her team took DNA
from patients and, where
possible, from their parents
and siblings. "We found an
overlapping region of DNA,"
explains Professor Kurian. "It
became clear that the faulty
gene causing the condition must
be in that region."

Unfortunately, there's currently no cure for most forms of dystonia but, thanks to this new information about the genetic cause, Professor Kurian was able to identify a pioneering technique that could help some patients. Known as deep brain stimulation, the technique uses small wires to stimulate the movement centre of the brain.

Katie is one of a small group of children to have received deep brain stimulation through Professor Kurian's work.
Encouragingly, all 10 have shown considerable benefit, with some regaining or significantly improving their independent walking and hand and arm movement.

Cell and gene therapy

The Zayed Centre for Research will be home to the largest dedicated clean room facility of its kind in Europe. In these labs, researchers will modify cells taken from patients to create therapeutic materials, which can then be given back to patients. This incredible capability could lead to the rapid development of innovative new treatments, from correcting the genetic mistakes responsible for muscle-wasting diseases, to modifying immune cells to target cancer.

Gene therapy involves modifying faulty genes so that they can work correctly. This targeted approach not only has the potential to cure a disease, but could also mean fewer side effects than other, more invasive treatment options.

In 2001, GOSH patient Rhys became the first child in the



Professor Bobby Gaspar

The future of medicine

You're helping us fund a worldclass team of gene therapy researchers. They're working hard to translate the success of gene therapy in treating children with immune system conditions to other disease areas. UK to be treated with gene therapy for severe combined immunodeficiency (SCID). The treatment was delivered as part of a groundbreaking research trial led by world-leading researchers Professors Bobby Gaspar and Adrian Thrasher. Since then, more than 70 children have been treated with gene therapy for immune system disorders at GOSH.

Regenerative medicine

Regenerative medicine is defined as any treatment that restores normal function to tissues or organs, with an emphasis on harnessing the body's natural ability to repair itself.

Cell regeneration is a rapidly growing area of medicine and new stem cell technology is revolutionising the way we approach medicine. Scientists at the Zayed Centre for Research will use a new state-of-the-art facility to transform cells from a patient's own hair or skin into stem cells, which have the unique ability to turn into almost any other kind of cell, such as liver or nerve cells. As these cells hold the same genetic information as the person they came from, they can be studied to understand that patient's illness, or to test which treatments might work for them.

In the future, researchers hope to use these cells to grow new tissues or organs tailored to each individual. This could have huge implications for patients at GOSH, from saving a child's sight to treating children with complex nerve disorders.

What else will be in the Zayed Centre for Research?

- Around 500 academic and clinical staff from GOSH and the ICH, with more than 160 laboratory spaces.
- A cardiac research suite
 where researchers can
 produce 3D models of
 the heart an invaluable
 resource for investigating
 new treatments and devices.
- A dedicated suite for flow cytometry: a method of rapidly identifying and sorting different types of cells. This technique has multiple uses, including diagnosing and monitoring children with blood conditions such as immune system disorders and leukaemia.
- The centre will have an outpatient facility with 21 consultation rooms and eight clinical investigation rooms.

Supporting GOSH's incredible staff

All hours of the day and night, hospital staff are hard at work, delivering the best possible care for children and families at GOSH. They are passionate, diligent, talented and resilient. Many of them are parents themselves. You're supporting these extraordinary people by helping us to provide nearby accommodation, specialist training and a new staff nursery, just around the corner from the hospital. The nursery is providing affordable, reliable and trusted childcare that lets hospital staff focus on the other special children in their lives: GOSH patients.

Mariesa Taylor-Allkins, Ultrasonographer and mum to Axel

"I wouldn't be able to work if it wasn't for the GOSH staff nursery. There are no nurseries available near where I live and my working hours mean it needs to be so flexible. Axel is my first child, and I

was quite anxious about bringing him to nursery. But the staff are brilliant with him and the setup is fantastic.

"I saw the old building and this is worlds apart. The space flows and is designed so well for the children's needs. The fact the Axe is practically on site means I can drop him off just before I start work and pick him up straight away when I need to. I think I'd worry about him if I worked further away. Knowing he's in a safe, structured environment so close by is reassuring and really helps me focus on my work at the hospital."

"Since he started nursery, Axel's development has really come on. His talking, eating, everything. He loves it. Some days he doesn't want to come home with me! They do messy play activities that would be difficult at home and take him out every day in the little garden."



Mariesa and Avel



Did you know?
You help us
to subsidise
nursery fees for
hospital staff or
lower incomes,
letting them
focus on their
vital work at
GOSH supporting
seriously
ill children.



Rebuilding and refurbishment



Caroline

Caroline Brown, GOSH Occupational Development Manager

"When I speak to hospital staff dropping their kids off, I can see clearly how much they appreciate the nursery. One side of it is just having a nursery attached to their place of work. We're very aware how lucky we are to have that, especially in central London. It's only affordable for NHS staff on lower incomes because prices are subsidised, thanks to GOSH Charity. The other side is, now we have the new nursery, staff are incredibly grateful that they can leave their child in such a lovely place. The day we opened, we asked parents to write one word on a flipchart to describe what they thought. It was a such a lovely thing, we didn't get any negative comments at all.

"Parents tell me the nursery has made such a difference to them being able to come back to work, and to their work-life balance. GOSH is a minute's walk down the road, so they feel comfortable knowing they can be here at a moment's notice if their child needs them. It also means

they can spend a bit more time together during their commute. That's important.

"Because staff feel more relaxed, they're less distracted in their role. We hear that first hand, but there's also a lot of research about staff engagement and the difference it makes to patient care. The hospital can be a very difficult and stressful place to work, so it's important we do what we can to support our people.

"If your child is settled, you're settled. The nursery is helping GOSH keep extraordinary people who are the very best at what they do.

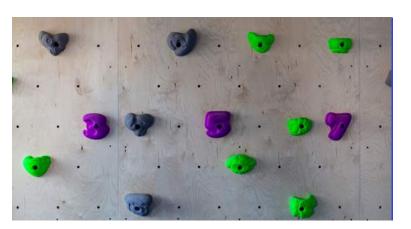
"Occasionally there are special situations where we can step in and help GOSH families too. Last year we looked after a patient who had been in the hospital since birth. She hadn't had the same experience as other children of socialising in a nursery environment, so when she turned five, she started coming here once a week. Hopefully it means

when she goes to a nursery back home in Sheffield, she'll find it easier to settle in.

"Another child whose brother was having treatment for cancer came to us for about three months. I think it was a relief for the parents, because it's such a difficult thing for them to be by their child's sick bed while their other young child needs attention too."

Sima Patel, Nursery Manager

"We have a lot more space now, compared to the old nursery. It means we can have several different activities in one room. That empowers the kids to make choices about what they do and lets them socialise in bigger groups. It's all vital for child development – learning how to interact with others, how to weigh up options and try new things. Having more space also means we can add activities that support physical development, like motor skills. In the baby room, for example, we have a massive canvas on the floor where six little ones can do body painting. We've also got a climbing wall!"







Child, family and staff support

Child, family and staff support at a glance

375

children were supported by the Play Team to overcome anxieties associated with medical procedures, helping them get the vital treatment they need. The Play team interact with many more patients and families on wards across the hospital every day.

2,000

families stay in our accommodation each year. This year we committed to refurbish some of our older facilities, to ensure families have access to comfortable and welcoming facilities just minutes from their child's bedside.

12

GOSH kidney transplant recipients took part in the 2018 British
Transplant Games, an annual sporting event that brings transplant patients together, supports their return to fitness and promotes organ donation. GOSH renal competitors are supported by funding from GOSH Charity.



"The Play team at
GOSH turns negatives
into positives and add
some giggles when
there are difficult
things like blood tests.
They always help by
distracting you with
fun things and make
being at hospital not
so bad."

Emily, age eight.

"Our support can help children 'see the bigger picture'. That can really help to reframe their understanding of what's happening, making them feel calmer and more at peace with the situation. We also speak to GOSH staff, who can deal with upsetting situations every day. We help them understand cultural factors or family dynamics that might allow them to support GOSH families more effectively."

Rev Jim Linthicum leads the hospital's Chaplaincy Service, a support team funded by GOSH Charity and hugely valued by both families and staff.



Rev Jim Linthicum, second from left, with the Chaplaincy service

What's next?

- By funding the refurbishment and running of parent accommodation, we'll ensure families at GOSH can stay in comfortable surroundings just minutes from their child's bedside.
- We'll continue to fund vital services that support children and their families through difficult times. These include the Play team, GOSH Arts, meal vouchers, children's parties and the Patient Advice and Liaison Service.
- We're exploring the possibility of funding a new 'Learning Academy' at GOSH, to support staff with the specialist training required to care for children with the rarest and most complex conditions.



Gabriel is eight years old and has been coming to GOSH every week since he was diagnosed with acute lymphoblastic leukaemia – a rare type of childhood cancer. He loves singing and tickles from his mum.

Beyond the medical

The families who come to GOSH are incredibly resilient, but we believe a little support can go a long way. You help us fund services that ease some of the stress on families while their children are in hospital.

There's increasing evidence that a holistic approach to care – offering support beyond medical care – can help children recover more quickly, avoid traumatic experiences, and reduce the risk of associated mental health problems now and in the future.

Spiritual care

Behind the hospital's main reception is a small oasis of calm, once described by Oscar Wilde as the 'most delightful private chapel in London'. With only eight child-sized pews, the ornate Victorian GOSH chapel is a place of reflection, grief, hope, and comfort.

While the chapel is a Christian place of worship, the hospital's Chaplaincy service – funded by GOSH Charity – caters to everyone, no matter their beliefs.

This year, we funded and unveiled a new multi-faith room for prayer and reflection. The room is open to families and staff at GOSH, as well as ambulance drivers and paramedics from across the capital who drop off or collect patients.

Family accommodation

Imagine suddenly feeling like you might be burdened with the cost of staying in a central London hotel for months. No parent should have to worry about where they're going to



The Chaplaincy team has around

3,800

interactions with patients and families each year.

1,172
children and their families
were supported by the Social
Work service in 2018/19.

7,236
meal vouchers were provided to 412
breastfeeding mothers in 2018/19.

sleep when their child is seriously ill. The hospital's newest clinical buildings, funded by GOSH Charity, have space for a parent or carer to sleep by their child's bedside. But for families with children in intensive care, where they can't stay, we also offer nearby accommodation, allowing parents to be at their child's bedside in minutes. You help us to fund this family accommodation just a short walk from the hospital.

Family relationships

Having a seriously ill child in hospital is incredibly stressful.

Families can experience problems ranging from emotional and mental health issues, to a total family breakdown, as well as significant financial consequences. Without support, some families at GOSH would not be able to cope.

You help us to fund a dedicated Social Work team at GOSH. The team provides support for issues including the mental health and emotional wellbeing of parents and children. The team also provides practical and emotional help before, during, and after the death of a child.

Addressing inequality

There is now overwhelming evidence linking poverty with poorer health. We are committed to supporting disadvantaged families, because all children deserve the same hope for a better future.

Your support helps us to fund a specialist welfare rights service at GOSH, delivered by Camden Citizens Advice Bureau in partnership with the hospital. The team gives advice on a range of issues, from applying for benefits and managing debts, to homelessness and immigration.

Meal vouchers

When a child is ill, families often need to reduce their working hours, or stop working altogether. They face increased costs such as travelling to and from hospital and regularly eating away from home.

We provide vouchers to families who need financial support and mothers who are breastfeeding.

Children's parties

We can't cure every child at GOSH, but we can try to brighten their day. You help us fund children's parties throughout the year, from our Easter eggsstravaganza complete with a chocolate fountain and fluffy rabbits, to our spectacular Christmas party with presents, performances, activities and Santa himself.

These parties are extremely important to families at GOSH, giving them something to look forward to and a semblance of normality during the most difficult times in their lives.

Play

Play isn't just fun, it's a vital part of a child's development. At GOSH, it's even more than that. The GOSH Charity-funded Play team uses play to ease a child's anxieties about being in hospital, to distract them from scary or uncomfortable procedures, and help them recover more quickly by reducing stress. The team develops activities to help children feel in control, from practising procedures on a teddy to choosing a flavour of lip balm to personalise the smell of their anaesthetic mask.

Child, family and staff support





Felicity, age seven, with mum Louise and baby Florence

Meet Louise

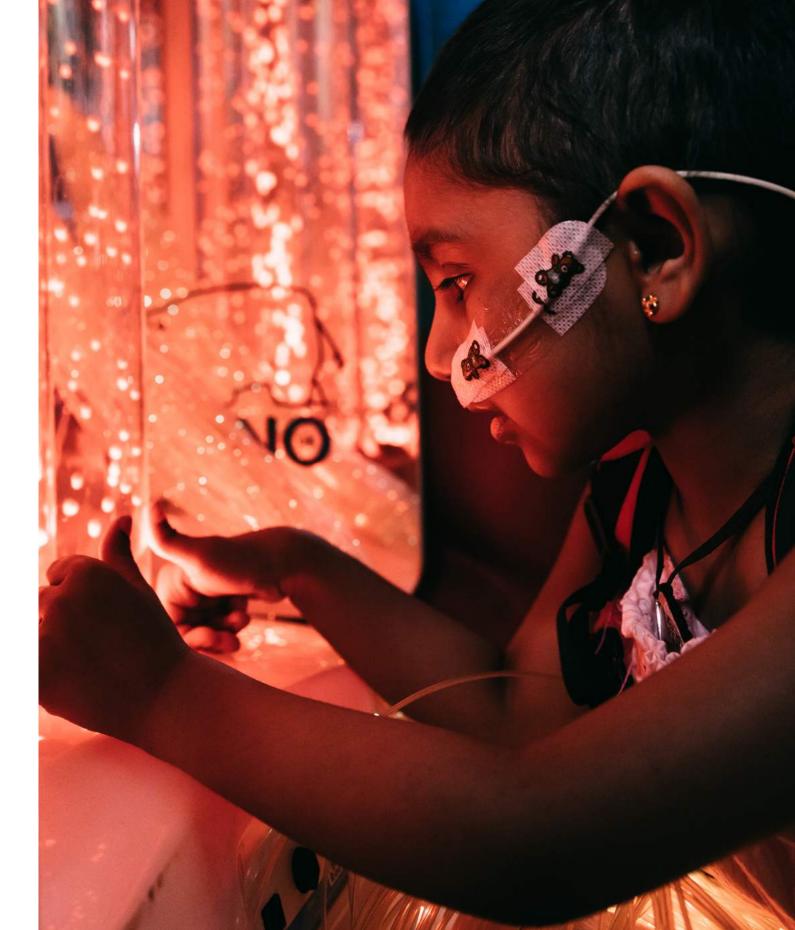
When Louise went to her routine 20-week pregnancy scan, she was told that her unborn baby girl's heart wasn't pumping enough blood. Felicity, now seven years old, had coarctation of the aorta, meaning the main artery pumping blood from her heart was too narrow.

"Once I gave birth, Felicity was transported to GOSH and within two days she was having openheart surgery. Naturally, I felt overwhelmed.

"I was very concerned about how I was going to afford staying in London, but the hospital arranged for us to stay across the street from the main entrance. We didn't have to pay anything, which took away a lot of stress. I could focus on being calm and visit Felicity whenever I wanted.

"I was also offered meal vouchers, which were a great help. Things aren't cheap in London, especially being from Norwich. The vouchers meant we didn't have to worry about the cost of going out for food.

"Felicity is doing very well at school now. She's enthusiastic and sporty, and dreams of becoming an Olympic gymnast. I believe she can do anything she wants." Opposite: Suveeksha is five years old and has been coming to GOSH regularly over the past year. She loves crafting and dancing and really enjoys learning at school. She is interacting with the lights in one of the hospital's sensory rooms.





Child, family and staff support



The children created shapes during the workshop led by artist Lubna Chowdhary

Do not touch

"Many visitors to the building will have some level of sight loss. We want to create an artwork that is tactile, to ensure everyone can enjoy it. The shapes are bold in their outline, creating a colour contrast with the background. And they'll be installed at a height where children can access them easily.

"I hope children will enjoy touching the objects, following their lines, trying to work out what the shapes are. They might also become useful for wayfinding, particularly with regular visitors, as people notice which pieces are in each space."

"I think it's really important to create interactive and playful spaces, particularly in a children's hospital. I have memories of places I went to as a child, and they're intimately linked to my sensory experience."

"It's vital to make this experience a positive one for children, so they can carry it with away with them."

Asking the experts

"Engaging GOSH children and families in the design process was always going to be vital – they're the ones who will hopefully enjoy the final piece! We held a workshop in July 2018, in the hospital's current outpatient waiting area. We asked the children to imagine Ortelli was here today. What sorts of objects might he be making now, or in the future? And what kind of objects might we find around the building in the future?

"We gave out card shapes that the children could combine and stick together in any way they liked. Eight of the objects they created will appear in the final artwork. It will be lovely to see those children recognise their designs when the building opens!"

Lubna will work on finalising her designs over the coming months. In the meantime, we're thrilled to share some of Lubna's early designs that give an idea of the vibrant, playful feel the artwork will bring to the new centre.



The Living Room

The main waiting area will be furnished like a living room, creating a homely environment that helps to put children at ease. This will include a fireplace complete with mantelpiece, laden with Lubna's colourful ceramic shapes. The shapes will also feature in the building's other waiting areas, which include quiet spaces and areas designed for older children.

The Sensory Garden

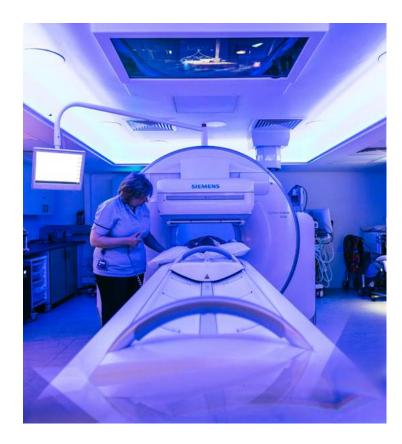
Outside, Lubna's colourful pieces will relate to familiar gardening activities, such as planting, watering and digging. There might even be the outline of a garden shed or greenhouse.

The centre's large garden will include plants chosen specially for children and their families to see, smell, touch and perhaps even hear. It will also feature quiet green spaces and places to engage with nature, including bird feeding stations and insect houses.



Advanced equipment and systems

Equipment at a glance



"MRI is a fantastic window into the heart.
With the latest software, we'll be able to
continue improving cardiac MRI scans,
making them faster and more accurate for
children and babies at GOSH and elsewhere."

Vivek Muthurangu, Professor of Cardiovascular Imaging.

£2.9 million

awarded to give the hospital's cardiac catheter lab an urgent upgrade, helping GOSH specialists treat more children with heart conditions through a tiny 2mm incision rather than open surgery.

Z

MRI scanners to be equipped with vital new software that will mean shorter scans and more accurate diagnoses.

385

unlinked computer systems at GOSH will become one when the hospital's incredible new centralised electronic patient record system is switched on. The system, funded thanks to your support, will transform every aspect of patient experience and care at GOSH.

This year we celebrated the launch of DRIVE – the Digital Research, Informatics and Virtual Environments programme. Supported by GOSH Charity funding, DRIVE's mission is to transform care by harnessing the latest technologies. By consulting young people, the team hope to ensure their visionary products are tailored to the needs of patients and families. GOSH Young Persons Advisory Group member Maryam, age 14, said:

"My favourite project was the virtual reality. It could have lots of different uses, like helping junior doctors during their training. I thought it was the technology that was the closest to being ready for use."





Above: YPAG member Maryam Below: Virtual reality workshop

What's next?

- We'll continue working closely with the hospital to identify equipment most urgently needed and where our support could make the most difference.
- We'll continue to support the incredible DRIVE programme, helping to ensure technology at GOSH stands the test of time in an age of rapid digital change.
- As the largest centre for child heart surgery in the UK, GOSH needs the latest cardiac technology to care for its patients.
 We'll fund vital pieces of equipment designed to help heal the smallest hearts.

Pictures worth a thousand words

Everywhere we look technology is moving at an incredible pace. From folding smartphones, to 5G, the way we see the world is changing. This is also having a huge impact on medicine. New techniques allow us to not only see the shape, position and shadows of organs, but to see chemical reactions and what's going on inside cells, with more detail and clarity than ever before. Over the last few years, we have been helping GOSH take its imaging equipment to the next level.

Deep 'see' images —
Turtle Imaging Suite
Back in 2013, we committed to
fund a new imaging suite with
a state-of-the-art MRI and CT
scanner. Since the suite opened in

2016, it's had a huge impact on children with a range of conditions, from cancer to heart and brain conditions.

GOSH clinicians have seen dramatically improved image quality, leading to faster and more accurate diagnoses. And because they can now image the heart more quickly – in some cases a single heartbeat – less children need anaesthetics to keep still during scans.

Waiting times have reduced significantly, so more children can be seen. And, importantly, when it comes to CT, the suite has helped clinicians reduce the levels of radiation children are exposed to by up to 50%, making vital scans much safer.



Advanced equipment and systems

When medicine goes nuclear

Nuclear medicine shows the processes going on inside cells. It provides vital information about a patient's condition and in some cases can even deliver the treatment itself.

Children are given small amounts of radioactive material that 'label' the processes doctors are interested in. The radiation travels around the body and its journey can be detected by a special camera, producing an image that reveals what is going on inside the cells. These multidimensional scans are mainly used for children with cancer, but are increasingly useful in spinal surgery, conditions of the kidneys and bladder, and other areas of medicine.

In 2017, we funded a brandnew SPECT-CT scanner that can produce better images, more quickly. Installed in 2018, the scanner is supporting vital research to improve the diagnosis

"This new scanner is making a huge difference to research. We're using it in lots of studies, including improving treatment for children with painful joint conditions and targeted treatment for life-threatening leukaemia."

Leanne Price, Medical Physicist.

and treatment of a range of conditions, including difficult-to-treat cancers.

Newer, better, faster, smarter

GOSH currently has five MRI scanners. But keeping up with the pace of modern technology is a challenge. Three of the scanners are already beginning to date. Software updates are desperately needed to ensure they remain state-of-the-art for as long as possible. This year we committed to fund MRI upgrades that will improve image quality while reducing the average scan time to as little as 10 minutes. Quicker scans should reduce waiting times and are much more suitable for younger children, helping to reduce the need for anaesthetic.

Transforming brain surgery

This year, we've watched a groundbreaking new imaging suite taking shape at GOSH. The Khoo Teck Puat iMRI suite, funded by GOSH Charity, will allow surgeons to carry out detailed MRI scans while performing delicate brain surgery to treat brain tumours or epilepsy.

Currently, surgeons rely on images of the brain taken before surgery to guide them through the operation, but structures in the brain can move during surgery, meaning preoperative scans can quickly lose their accuracy. The current facilities at GOSH mean it can be several days after an operation before another brain scan is done. During this time,

patients and families face a difficult and anxious wait until surgeons are able to confirm if all the affected area has been successfully removed.

The new iMRI facility will make imaging the brain during operations a seamless procedure, giving more children the best chance of a positive result.

Kristian Aquilina, Consultant Paediatric Neurosurgeon, says: "To say to parents with even more certainty, at the end of surgery, that we have done all we can to improve the life of their child, will make a world of difference."

Heart surgery with a twomillimetre incision

Thanks to advances in imaging, clinicians can now diagnose and treat some heart conditions without the need for open-heart surgery. That means less pain, a quicker recovery, and less time in hospital. Guided by ultrasound and other imaging, radiologists feed narrow tubes and wires through a patient's blood vessels to find the cause of their symptoms, or even to treat the condition. All that's needed is a tiny two-millimetre incision.

GOSH's current facilities are outdated, limiting the number and types of procedures they can do. The hospital desperately needs updated facilities to give more children the chance to benefit from this type of surgery. That's why this year we supported the construction of a brand new cardiac catheter suite, set to open later in 2019.



Advanced equipment and systems

Meet Connie, age five

After years of health problems, Connie at age three was scheduled for a heart scan at her local hospital. This led to an urgent referral to GOSH, where doctors used state-of-the-art MRI scanners to diagnose her with pulmonary hypertension (PH).

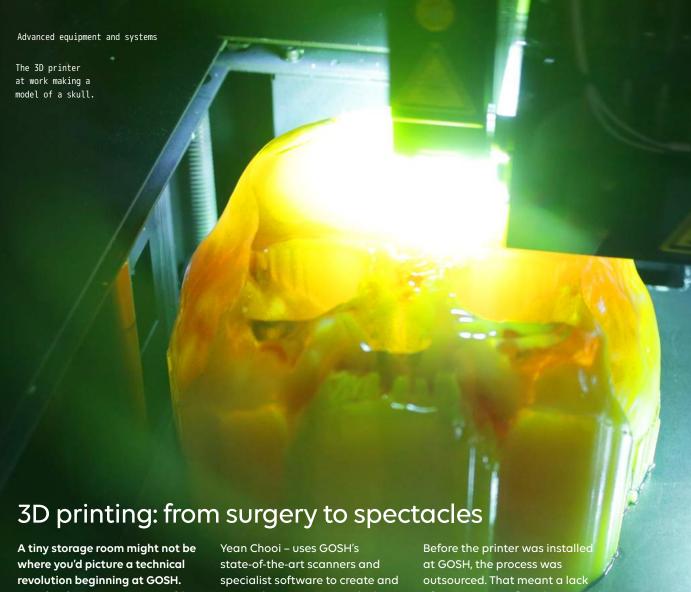
The condition affects the arteries supplying blood to her lungs. High blood pressure in these vessels had put a strain on Connie's heart, causing the right side to enlarge. Doctors quickly gave her life-saving medication. The drugs improved blood flow to her lungs and helped to keep her heart stable, but they didn't reduce its size.

Scans were a crucial part of tracking Connie's progress, and the speed of new MRI scanning technology meant she didn't need general anaesthetic for doctors to get a good picture of her heart.

After discussing options with the team at GOSH, Connie's parents decided to go ahead with a procedure to connect some of the blood vessels surrounding Connie's heart, relieving the pressure. Surgery went well and Connie was back at nursery in just three weeks.

Connie is now five years old and, sadly, there's no cure for her condition, but every stage of her future treatment will be supported by regular scans.





A tiny storage room might not be where you'd picture a technical revolution beginning at GOSH.
But, thanks to your support, this is exactly what happened just before Christmas 2017. In that small room, surgeon Juling Ong set up what he describes as an early Christmas present, and it heralded in a new era for surgery at the hospital.

Mr Ong unwrapped GOSH's first 3D printer, a relatively small machine that now lives right next to the hospital's operating theatres. Its human counterpart – biomedical engineer Dr Kok Yean Chooi – uses GOSH's state-of-the-art scanners and specialist software to create and manipulate 3D images, which can then be printed to inform and improve surgeries, tailor implants and empower patients.

3D printing works by building up objects one layer at a time. The machine deposits tiny droplets onto a surface, in a similar way to a standard printer. But, instead of ink, it uses tiny resin droplets, which are then solidified using a UV lamp. Each layer can be as thin, or thinner, than a human hair.

Before the printer was installed at GOSH, the process was outsourced. That meant a lack of consistency, inflated costs and using companies that specialise mainly in adults. Now the service is in-house, the advantages are clear across the hospital. From improving craniofacial surgery, where children have conditions affecting the shape of the skull, to planning heart surgeries and even helping a large team of surgeons prepare to separate conjoined twins. And there have been other unexpected benefits too.



Personalising surgery

"In the past, if we needed to replace a part of the skull we would use a titanium plate that was pressed into a mould or physically moulded," explains Mr Ong. "Now we can use each child's scans to print an implant that fits perfectly onto their head. It can even have all the screw holes in place and we'll know exactly which length screws we need to use, all before surgery."

3D technology is also helping the team develop and test new surgeries tailored to each child. "There is a very rare condition called lambdoid synostosis, which causes flattening of the back of the head," says Mr Ong. "We didn't have a good solution for correcting the shape of these children's skulls. But with the 3D printer in place, we could print incredibly accurate models and trial several different surgeries, selecting the best to then offer to that specific patient. This was a problem we'd been trying to work out for years and the best part is, the family were delighted with the outcome."

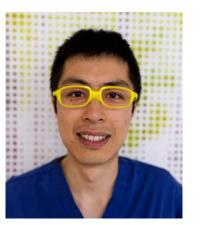
It's also helping to involve children and their families in key decisions. "I was treating a girl whose condition means one side of her face hasn't grown," says Mr Ong. "These facial asymmetries are very difficult to correct. We decided to create some options – 17 in all – and send them to the patient. She

could look through them and say 'actually I like this one'. I shouldn't be making that decision on how they will look, it's very personal for each child and family, so if they can see it on themselves on a screen in 3D or as a printed model, it empowers them to make that decision."



Thinking outside the box

The printer has had some surprising benefits in unexpected places. Buttons on anaesthetic machines kept getting lost during cleaning and, at more than £40, it was a costly inconvenience to replace them. The 3D printing team created a replica and can now print it on request for a fraction of the price. They've also helped GOSH's Play team to recreate stackable toy cups with lids that had gone out of production. These were a great tool in helping assess a child's motor skills and how they learn and play. Now the team can get more whenever they need them.



Dr Chooi in his 3D-printed specs.

A new project could also see the team printing bespoke glasses. If a child has a condition that affects the shape of their skull, or if they are born without ears, getting glasses to fit can be a challenge. If glasses are uncomfortable, children don't want to wear them. Now Dr Chooi is exploring if printing perfectly fitted specs could be the solution. He even trialled the very first pair himself! "They were surprisingly lightweight and, what's great, is that the children can pick the colour they want," he says.



Unlimited potential

"There are many ways 3D printing at GOSH could evolve," says Mr Ong. "As materials are developed, that will open up a whole range of new applications and the field is moving quite quickly. Printing ceramics is going to be interesting because bone is actually a bit like ceramic, and also porous materials, because they are particularly important in the body. There's even the potential to print with biological materials. In the future it could even be possible to print with different materials at the same time and design a whole organ."

For now, the team are focused on the present, as Mr Ong explains: "If we can improve safety, reduce the need for repeat operations, help children spend less time in theatre and improve outcomes for each child, that can only be a very good thing".

What does the future hold for GOSH?



GOSH Chief Executive Matthew Shaw

New technology, changing models of care and incredible innovations hold the promise of a brighter future for seriously ill children. But how does one of the world's leading paediatric hospitals stay ahead of the curve? What could the future hold in 10, 20 or 50 years? As the hospital's new Chief Executive, it's Matthew Shaw's job to navigate GOSH through the ever-changing landscape of children's healthcare.

What do the next few years hold in store for GOSH?

"We're on the cusp of a genetics revolution, which looks set to transform the way we care for children with rare and complex conditions. It's incredibly exciting

to see GOSH already playing a major role, from its recent appointment as one of the UK's seven Genomic Laboratory Hubs, to the opening of new Zayed Centre for Research. This will be one of the only places in the UK where researchers can modify a patient's own immune cells to create cancer-fighting cells that can then be given back to the child. And that's just the beginning. We'll need to continue to adapt our ways of working, and our facilities, to support this, and other paradigm shifts, in children's medicine.

"As we learn more about the complexities of many conditions, we're seeing medicine in the UK move away from trying to treat them in district general hospitals and instead ensuring people receive treatment in specialist centres like GOSH. You need a lot of specialist staff, facilities and expertise to care for seriously ill children and it makes sense to have that focused in one place to provide consistent care. I can definitely see our cardiac and neurology services growing, as well as potentially our orthopaedics and spinal services."

How will GOSH continue to adapt?

"An important part of our future vision is creating flexible spaces that can adapt to rapidly changing technology and models of clinical care. That goes far

beyond addressing capacity issues. We want to create family-friendly environments that can actually support a child's recovery, integrate research throughout the hospital, and link up key services to ensure children are getting holistic, personalised and co-ordinated care.

"An increase in capacity will also

present an incredible opportunity to advance childhood medicine. More patients means we can recruit more children onto research studies, which should help to get promising new treatments and tests approved more quickly. Our ambition is to be a true research hospital, and to give every child in every bed a chance to be part of research that could change the future. We've already taken great strides towards this vision with the completion of the Mittal Children's Medical Centre in 2018. and we're starting to discuss the next exciting phase of our rebuilding programme."

"You never quite know what the future holds and the changes in care that we'll see, so creating a building that allows you to switch facilities from, for example, general surgery to high dependency, is massively important. Our newest buildings were designed with flexibility in mind and it yields lots of advantages."

What role will technology play? "Technology is moving so quickly.

You buy a mobile phone and it's instantly out of date! It's the same for scanners and medical equipment - technology can move on in just a few years. For patients to feel the benefit of these advances, we need to ensure we're investing in flexible kit that can be integrated with other systems. With the support of the charity, we can be as nimble as possible in adopting the most advanced technologies as and when they come on the market. This makes a big difference to the children in our care.

"We've already taken strides to become one of the world's leading digital hospitals – like preparing for the launch of our electronic patient record system this year. It will be truly transformational. Every single patient will have a digital record in one system, replacing hundreds of systems previously used across the hospital. It means staff in any department can access and share patient data so much more easily - it seems incredible it wasn't possible before – and this will mean the experience of patients and families is hugely improved. Vast amounts of patient data will be anonymised and entered into our new research analytics platform, where it can be interrogated by data experts to help us understand childhood disease and find new approaches to treatment. It's a massive opportunity to transform child health in the UK and beyond.

"We're also looking at things like facial recognition to track patients and staff around the hospital. This will obviously need to be considered carefully, but it would mean we could measure flow and movement, and the cameras could even recognise emotion. Monitoring the mood of children, families and staff, as well as how people use our spaces, could be so valuable in allowing us to support people and create environments that make clinical care easier and more effective."

How will the charity help realise this vision?

"When you walk through the hospital's entrance, the first thing you see is the boat-shaped reception, designed to make children feel more comfortable when they arrive here. You might visit the Lagoon canteen, meet members of our Play team or take part in an activity with GOSH Arts. You might have a procedure in one of our stateof-the-art operating theatres, or stay on an animal-themed ward in the Mittal Children's Medical Centre. In all those areas, and indeed everywhere you go in the hospital, you're seeing the impact of charitable funding. Without GOSH Charity supporters we simply wouldn't have those facilities. That support has been, and always will be, absolutely vital in realising our vision of GOSH as a future hospital."

Thank you

Our sincere thanks go to the individuals and organisations who have so generously supported the charity in 2018/19, including those who chose to give anonymously. Every single donation is helping to create a better future for seriously ill children at GOSH and around the world.

On behalf of the inspiring children, their families and the remarkable staff at the hospital, thank you.



Friends of Adeona

Friends of Adeona recognises our most generous benefactors, without whom GOSH would not be the world-class children's research hospital it is today.

A warm welcome to our new Friends of Adeona, listed in bold below, who became members this year.

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The Al Fayed Charitable Foundation

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Brighter Future Funds 2018-19

A lasting tribute in memory of someone special. All funds raised through our Brighter Future Funds allow GOSH to continue providing care and support for patients and families.

The Shani Berman Brighter Future Fund The Archie Brennan Brighter Future Fund The William Andrew Joshua Crook Brighter Future Fund The Toby Hambrook-Skinner Brighter Future Fund The Veer Jesani Brighter Future Fund The Little Jimmy Brighter Future Fund The Tiana Kishinani Briahter Future Fund

The Anna Lewis Brighter Future Fund The Scarlett Lill Brighter Future Fund The Lexi Mace Brighter Future Fund Cerys' friends, Sharon, Holly and Paul Mason-Hughes The Nadia Miragliotta Brighter

Future Fund

The Maggie-Mae Morgan Brighter Future Fund

The Aniga & Rehaan Syed Brighter Future Fund

Active Appeals and Fundraising Committees 2018/19



Carol Concert 2018

A heart-warming family event of carols and readings from special guests and patients at St Pauls Church, Knightsbridge, and The Jumeriah Carlton Tower Hotel.

Chair

Stephanie Léouzon

Co-Founder

Bridgett Walters

Producer

Jo Broadhead

Suzy Payne

Sukeena Rao

Caroline Shaikh

Jennifer Spink

Murray Stroud

Cydonia Tarrant

Committee Hannah Chambers Emma Chandler Antonia Christie Vanessa Colomar Kelly Curtin Nick Ede Katie Flach Timothy Knatchbull Natasha Leith-Smith Eugène Léouzon Claire Merry Kate Moore Alice Page

Corporate Partnerships Board

A network of industry leaders who help GOSH Charity secure mutually beneficial corporate partnerships.

Chair

Tim Score

Board Members

Michael Abel Marc Allera Tim Burrage Matteo Canonaco Timothy Collier David Craig Simon Ewins Jonathan Grundy Sara Hale Steve Ingham Cyrus Kapadia Audrey Klein John O'Higgins Matthew Ponsonby Simon Smith David Thomas Georgina Vaughan

John Waples

Anight Museum

Daniel Galvin Bracken's 'A Night at the Museum'

A gala dinner held at the Natural History Museum, which raised funds for a new state-of-the-art intra-operative MRI suite that will help improve outcomes for young patients undergoing brain surgery at GOSH.

Chair

Louise Galvin

Committee

Debra Blair Caprice Bourret Pilar Boxford Samantha Cameron Annie Cortazzi Jacqueline Fine Lindsey Hall Sam Hughes Ivona Kirschel Chrissie Rucker Anna Singh Alison Swinburn Plum Sykes Sayoko Teitelbaum

Melanie White



Fine Wine Dinner

A dinner served with exceptional wine at The Honourable Society of Gray's Inn, in support of GOSH Charity and Sparks.

Chair

Gavin Prentice

Committee

Desmond Browne Kate Gallafent Sir Mark Potter Simon Picken David Potts

Frank Slevin



The Friendship Ball

GOSH Charity and The Children's Medical & Research Foundation at Our Lady's Children's Hospital, Crumlin, joined forces to raise money for cardiac research.

Chair

Cyril Delamare

Committee

Linda Boschetto
Ron Boschetto
Bernard Heffernan
Rachel Kavanagh
Nathalie Knauf
Aymeric Lechartier
lain O'Rourke
Valentin Pierburg
Gillian Shubotham
Dermot Smurfit



The GOSH Gala

A Peter Pan-themed gala dinner.

Chair

Ken Costa

Committee

Andrew and Zoë Law Afsi Moshri Zeze Oriaikhi-Sao Nana Sao Ramez Sousou

Tiziana Sousou



The GOSH Matchplay Cup

A unique golf event hosted by GOSH Charity at Buckinghamshire Golf Club to raise money for the hospital's most urgent needs.

Chair

Tim Stansbury

Committee

Ben Crook
Edward James
Marcus Jansa
Tara Kengla
lain Marr
Marc Patrick
Nick Stewart
Jason Stoop

Mark Worrall



Love GOSH x

A Valentine's-themed evening of fundraising, dining and entertainment, raising money for two consultation rooms in the new Sight and Sound Centre, due to open in 2020.

Co-chairs

Tara Falk Tom Cox

Sponsored by

Brit Insurance
Delta Air Lines
Renaissance Re

Natalie Avvoltoio

Committee

Jason Collins
Tom Cox
Lorraine Denny
James Furlonge
Helen Fussell
Alex Goward
Janet Henderson
Peter McLoughlin
Marianne Robson
Tricia Rumola
Andrea Thompson

Bella Von Ribbentrop Jayne Walder Susan Wells

THE SIGHT & SOUND GALA

The Sight and Sound Gala Committee

A gala dinner raising funds for the new Sight and Sound Centre at GOSH, due to open in 2020.

Impact Report 2018/19

Co-Chairs

Nicola Bearman D'Arcy Vigors

Committee

Alice Tanielian

Heather Beckwith
Jessica Beckwith
Amanda Galloway
Charles Hoffman
Tessa Lamb
Lisa Makin
Jennie Miners
Nicole Ronson Allalouf



Tick Tock Club 4

A giving club set up to address the hospital's most urgent needs. The Club is now in its fourth appeal – raising funds for a new state-of-the-art intra-operative MRI suite that will transform the way brain surgery is performed at Great Ormond Street Hospital to improve outcomes for our young patients.

Chair

Dame Rosemary Squire

Patron

Garv Lineker OBE

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Caprice Bourret

Amy Dorfman

Louise Galvin

David Ian

Lady Madeleine Lloyd Webber

Cheryl Potter

Alison Swinburn

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Caprice Bourret Comfort and

Ty Comfort

The Entertainer

Galvin Bracken Foundation

John Grayken and Eilene

Davidson Grayken

David Ian

Oleksandr Yaroslavsky

Khoo Teck Puat UK Foundation

Sir Howard Panter and

Dame Rosemary Squire

Kewal Ramani family

Ian and Carol Sellars

Alison Swinburn

The Thompson Family

Charitable Trust

THE VELODROME CHALLENGE

The Velodrome Challenge

A competitive, high-adrenaline velodrome event held at the historic Lee Valley Velopark in partnership with the Gordon and Tana Ramsay Foundation.

Chair

Tick Tock Club Charity Golf

Day Committee

Alan Bennie

Huw Jenkins

Paul Roy

David Best

Sponsored by

Morgan Stanley Freshfields

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Katie Alexander

James Beresford

Gary Blesson

Dean Downing

James Golding
James Hatchley

Edleen John

Chris Lipscomb

Simon Orton

Rosanna Ruff

Neil Shelton Mark Sinclair

James Smethhurst

Mungo Tennant

Jason Turner

PARTY

Valentine's Party, Big Hearts for Little People

A Valentine's-themed family fundraising event, which raised funds for the new Sight and Sound Centre, due to open in 2020.

Co-Chairs

Samantha Bauer Lisa Reuben

Committee

Maryam Akhavan Natasha Barnaba

Eiesha Bharti Pashricha

Berry Bloomingdale

Patricia Dente Haimes

Zeina Embiricos

Sabrina Friedman

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Elizabeth Hawtin

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020 3841 3841
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Thank you to everyone who gave permission for their picture to be used in this report, as well as the many members of the charity staff who helped during its production.

This Annual Impact Report 2018/19 is available to view at www.gosh.org.

We will always treat our supporters' personal details with the utmost care and will never sell or swap with other organisations for their marketing purposes. We will keep all personal data safe and private, holding the information provided for communication, marketing, analysis and administrative purposes. We will send postal information based on our legitimate interest to communicate with our supporters, but this can be stopped at any time or preferences changed by contacting us on 020 3841 3131, or at supporter.care@gosh.org or by writing to 40 Bernard Street, London, WC1N 1LE. For full details of what information we hold and how we process your data, please visit gosh.org/privacy.



