## THEN, NOW, ALWAYS: OUR MISSION NEVER CHANGES













### OUR MISSION

Our mission at Great Ormond Street Hospital Children's Charity (GOSH Charity) is to enhance Great Ormond Street Hospital's (GOSH) ability to transform the health and wellbeing of children and young people, giving them the best chance to fulfil their potential.

On behalf of the hospital's young patients, their families and the staff at the hospital and charity, thank you. We will always be grateful for your support.

## THEN, NOW, ALWAYS

GOSH wouldn't be the place it is without the millions of people who have supported it. From the day we opened to today, your incredible fundraising efforts have improved the lives of seriously ill children. They will always need us. And we will always need you.



1855

we received our first legacy gift. Legacies continue to be a vital part of our income today.

10

the number of beds when GOSH opened. Today, there are 455.





1929

JM Barrie donated the copyright of Peter Pan to GOSH. The magical story continues to raise vital funds for the hospital, but we promised JM Barrie we'd always keep the amount private.



raised through the incredible
Wishing Well Appeal. People
from all over the country came
together to help us open the
Variety Club Building in 1994 to
replace buildings that were no
longer able to meet the needs
of GOSH's patients.



£99.4m

raised by you – our best fundraising year ever!

31,759

raffle players took a chance to win, raising £588,799 in the process.

2,000

patients and their families enjoyed festive frolics at our Snow Ball.



13,000+

Bernard Bears sold at Premier Inns across the country in 2017, raising an impressive £80,000. Go Bernard!

11,694

people ran, pedalled, addled and perspired in sporting events for GOSH this year. +008

tireless event volunteers generously gave their time and energy to whoop, cheer and help events run smoothly, raising vital

152

volunteer community
ambassadors delivered
45 outreach talks in local
communities this year, helping



member of the Royal Family paid us a visit to celebrate the completion of the Mitta Children's Medical Centre by opening the new Premier In Clinical Building



£136,000

aised by Smyths Toys and ur friend 'Snot – the toy no e wanted', during their 2017 Christmas campaign.





## SHEILA

Sheila started volunteering for GOSH Charity 30 years ago, supporting our Wishing Well Appeal.

Since then, she's helped at many events and spent countless hours volunteering in the charity offices.

### A MEMORABLE YEAR

Since its doors first opened in 1852, GOSH has relied on the tremendous generosity of people like you. And while every year brings new challenges, your unwavering support means GOSH Charity can continue to support the hospital in a wide variety of ways, allowing its groundbreaking work to continue day in, day out.

It's 30 years since the launch of the Wishing Well Appeal – a very successful fundraising campaign that laid the foundations for the charity we are today. This year is also the third year of our ambitious five-year strategy, Raising Our Sights: A 2020 Vision. With those things in mind, we are absolutely delighted that, thanks to your ongoing dedication, we have had our best fundraising year ever. The £99.4 million you have helped to raise will go towards changing the lives of seriously ill children both now and in the future. Thank you so much.

It would be impossible to reflect on the last year without mentioning an incredibly special day – the completion of the Mittal Children's Medical Centre, with the opening of the Premier Inn Clinical Building. We were delighted that Her Royal Highness (HRH) The Duchess of Cambridge was able to lead the formal opening ceremony in January. What makes this building so special is not just the incredible benefits it brings for patients, families and hospital staff, but the fact that the majority of funding came from people like you. Without your support, the new centre would never have been built. We know that the children, families and staff at GOSH are grateful for the difference the new facilities are making now, and the benefits they will bring for many years to come.

It's also been a great year for state-of-the art technology and research. We have committed to providing new facilities that will mean less invasive heart surgery is an option for more children, and a new scanner that will tell doctors more about what's going on inside the cells of the body – helping to diagnose diseases and monitor whether treatments are working. And that's not all. We also invested in an advanced intraoperative MRI (iMRI) suite that will allow the hospital to scan children during brain surgery – reducing the need for repeat operations. And we funded the appointment of two world-leading professors in brain tumour and stem cell biology. These are just a few of the highlights of what we've achieved, thanks to you.

When it comes to fundraising, the creativity and enthusiasm behind your efforts always amazes us, and this year they have been more diverse, determined and dynamic than ever! Scores of you have taken part in sporting events, bake sales, skydives and tower climbs, and increasing numbers of you are giving what you can monthly. We've continued to benefit from exciting corporate partnerships and received some transformational gifts from individuals.

This was also our first year of partnership with the children's medical research charity Sparks, which is now part of the GOSH Charity family.

Testament to the power of partnership, we had great success with our first joint national call for research, receiving more applications from medical researchers than ever before. An incredible £2.1 million was invested into 14 pioneering paediatric research projects from across the nation.

Sparks' fundraising also went from strength to strength with record years for the Rugby Legends' Dinner and Clay Pigeon Shoots, and more people than ever applying to run the Virgin Money London Marathon. It has all contributed to a fantastic fundraising year and we are incredibly grateful to everyone involved.

The coming year promises to be just as exciting. Thanks to GOSH Charity funding, work will start on a new medical centre tailored around the needs of children with sight and hearing loss. We are also looking forward to the completion of the Zayed Centre for Research into Rare Disease in Children, and together, GOSH Charity and Sparks will launch our second national call for research projects. We will also continue to ensure we maintain the highest standards of governance, to protect you, our supporters.

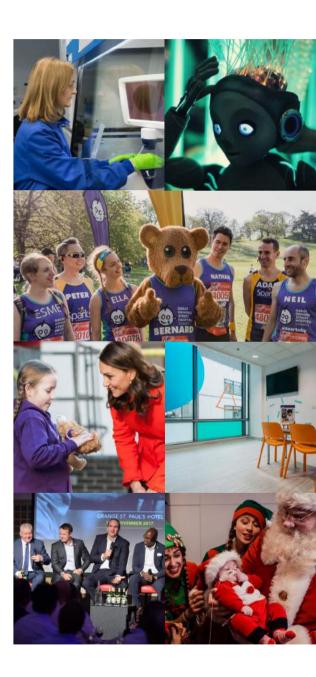
With your help, the year ahead promises to be just as impactful and we look forward to sharing more with you over the coming months.



John Connolly Chairman of Trustees GOSH Charity



Tim Johnson Chief Executive GOSH Charity



#### HIGHLIGHTS FROM THE YEAR



#### Immune systems restored

GOSH clinicians demonstrate that a little-known gland of the immune system can be transplanted into children like Aidan (left) with life-threatening DiGeorge syndrome, restoring their ability to fight off infections.



#### Spooktacular weekend

Children from GOSH attend a special Halloween party to celebrate our partnership with Premier Inn & Restaurants reaching a phenomenal £10 million milestone.



#### Running for GOSH

Children, families, hospital staff and Royal Bank of Canada (RBC) employees join over 4,000 people in Hyde Park, London at RBC Race for the Kids, a 5k fun run to raise vital funds.



#### Funding boost for arthritis research

The Centre for Adolescent Rheumatology receives £2 million. This unique centre is funded by Arthritis Research UK in partnership with GOSH Charity.



support much-needed surgical research, we appoint Sebastian Toescu as our first surgical scientist.



#### New stem cell facility

A state-of-the-art stem cell research facility opens at the UCL Great Ormond Street Institute of Child Health (ICH). Researchers are developing ways of using a child's own cells to treat conditions affecting the muscles, liver, brain and sight.



#### A new roof for research

We celebrate the topping out of the Zayed Centre for Research, the point when construction reaches its highest point. The building was made possible by a transformational gift from Her Highness Sheikha Fatima bint Mubarak, the wife of the late Sheikh Zayed bin Sultan Al Nahyan.



#### Four-legged festivities

ITV presenter Paul O'Grady pays a Christmas visit to GOSH with some of his furry friends from Battersea Dogs & Cats Home.



#### Genetic eye screening test launched nationally

Developed by GOSH and ICH researchers, Oculome looks for mistakes in more than 400 genes known to lead to eye disease. The test is now available across the NHS.



#### A very special visitor

HRH The Duchess of Cambridge visits patients, families and staff for the official opening of the Mittal Children's Medical Centre, home to the new Premier Inn Clinical Building. p48



#### Funding child health research around the UK

GOSH Charity and Sparks announce an investment of £2.1 million in 14 child health research projects across the UK. p24



#### Two new research leaders

We announce two new GOSH Charity Professors: stem cell biology expert Rick Livesey (left) and leading cancer researcher Darren Hargrave. They will drive forward research in these areas to develop new treatments for seriously ill children.



#### **Back to the eighties**We go retro with

1980s-themed campaign 'Then. Now. Always', celebrating 30 years since the Wishing Well Appeal.



#### Arthritis collaboration grows

Researchers from the ICH and GOSH are awarded £5 million to lead a national study to find better treatments for children like Joe (left) with juvenile idiopathic arthritis and the associated eye inflammation condition, uveitis. The project is funded by the Medical Research Council, in partnership with Arthritis Research UK and with additional funding from GOSH Charity.

## WHAT WE RAISED, TOGETHER

A breakdown of where our income came from in 2017/18

65%

Donations

 $26^{\circ}/_{\circ}$ 

Legacies

 $5^{\circ}/_{\circ}$ 

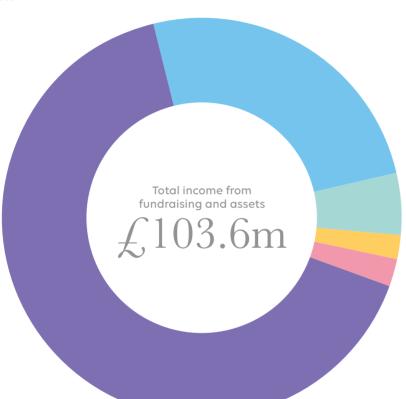
Trading

 $2^{0}/_{0}$ 

Investment income (realised)

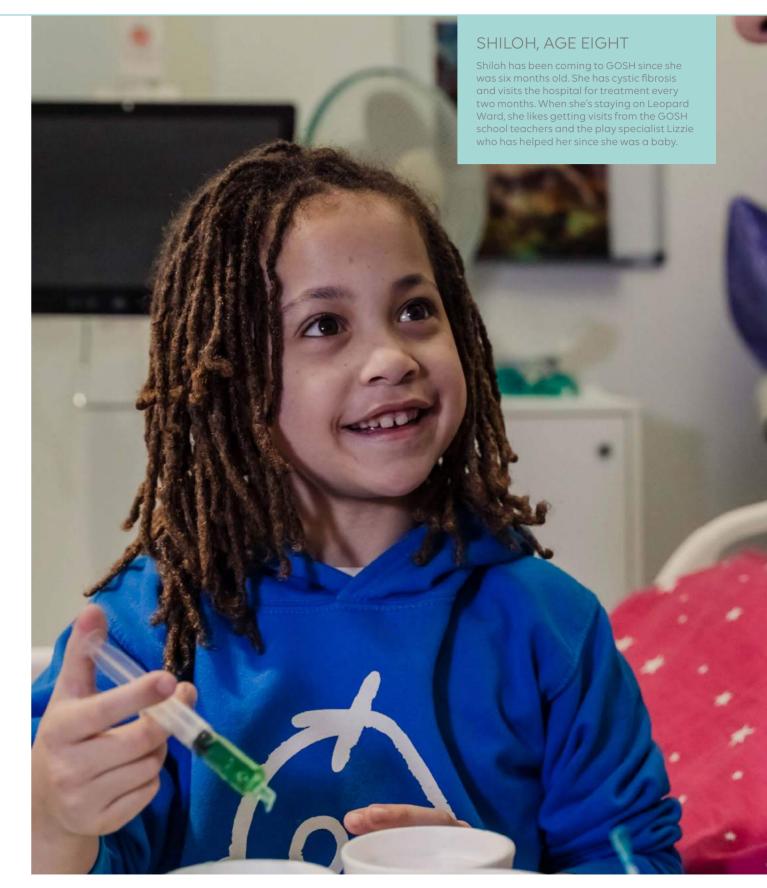
 $2^{0}/_{0}$ 

Property and other income

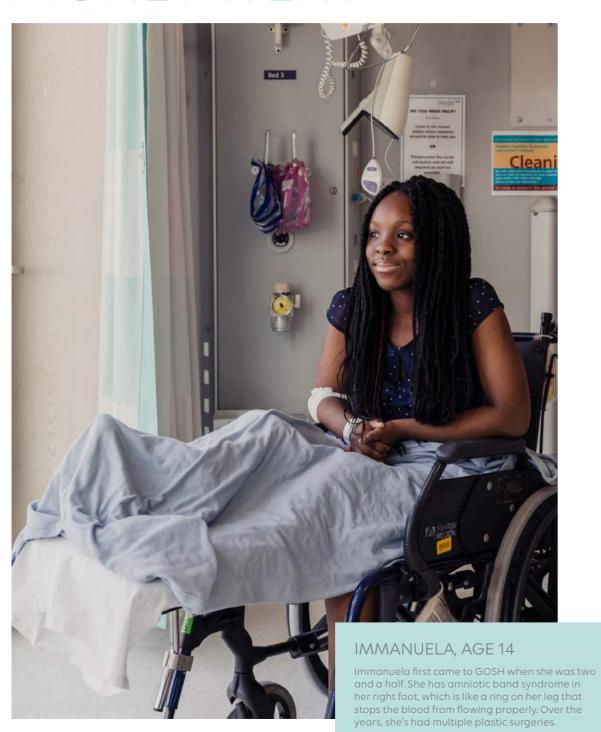


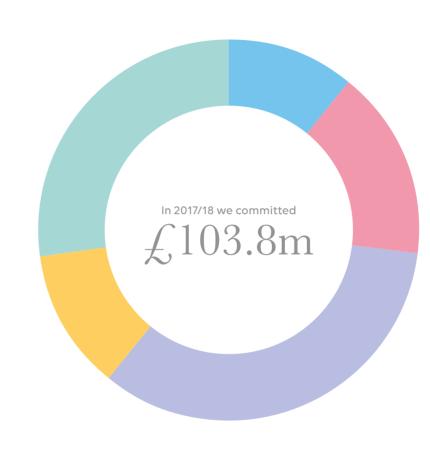
£99.4m

raised by you – our best fundraising year ever!



## WHERE YOUR MONEY WENT





#### **Every pound counts**

Whether it's going towards one of our four funding areas, helping us save for large upcoming projects or allowing us to raise more money for the future, every penny we receive makes a difference to the lives of seriously ill children.

The way we spend money can vary year on year, especially if a big project like a new building requires a large upfront sum. Because of this, we look at the long-term relationship between the cost of raising money and the donations you give us over a five-year period.



£71.5p
Goes directly to charitable activity

28.5p

Helps us raise future income\* \*Average over the last five years

#### £11.5 million

#### Pioneering research

To find ways to diagnose, treat and cure the most complex childhood illnesses. p20-31

#### £16.7 million

#### Advanced medical equipment and systems

To help treat the toughest and rarest conditions, from state-of-the-art scans during surgery, to machines that can do the job of the heart and lungs. p32-43

## £34.9 million Rebuilding and refurbishing

To create facilities designed around children and young people that let the hospital treat more patients in the best possible surroundings.

## £12.1 million Child and family support

Services that can ease the burden on families, raise spirits, and support children and young people through their treatment. p58-71

## £28.6 million Running costs and raising funds

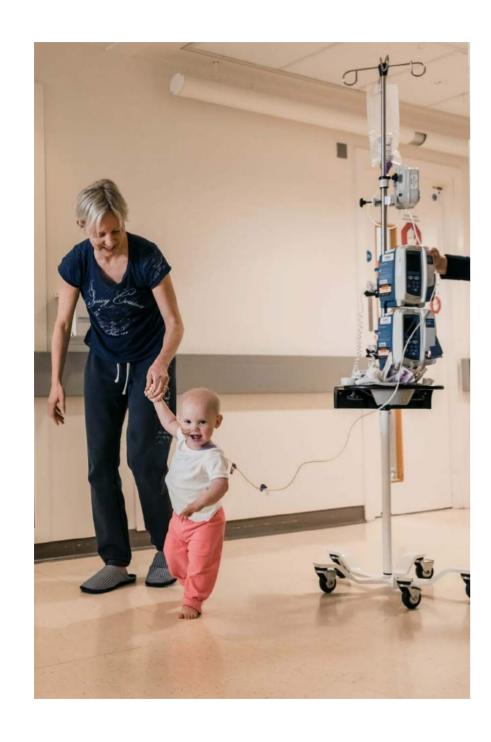
Helping us to run the charity effectively and efficiently, and raise more money for the future.

## AIMING FOR A BRIGHTER FUTURE



Aim	Achieved?	Status	Future
Growing			
Raise at least £98 million from fundraising and our assets.	Yes, our total income was £103.6 million.	/	Aim for £100 million total income.
Ensure we make the most of every pound year-on-year and aim to ensure that, on average, at least 70p from every £1 goes to charitable activity.	Yes, we achieved this. On average, over the last five years, 71.5p went to charitable activity.	<b>/</b>	Ensure we make the most of every pound year-on-year and complete a cost review project.
Fundraising			
Raise £96 million from fundraising.	Yes, our fundraising income was £99.4 million.	~	Aim to raise at least £91 million from fundraising.
Continue to grow support for research, including launching a public appeal to raise £5 million.	Ongoing, we have grown our support for research. Our public appeal will launch later in 2018.	•••	Continue to gain traction on fundraising for research.
Investing			
Celebrate completion of the Mittal Children's Medical Centre by opening the Premier Inn Clinical Building.	Yes, the Premier Inn Clinical Building officially opened in January 2018. p48	~	Start work on a new Sight and Sound Centre in 2018, which is due to open in 2020.
Continue construction of the Zayed Centre for Research.	Construction of the Zayed Centre for Research is ongoing. Topping out occurred in December.	•••	zayed Centre for Research due for completion in late 2018 and becoming fully operational in 2019.
Continue to ensure that our funding streams meet the most urgent needs of the hospital.	Yes. See more detail on pages 20-71.	~	Confirm key hospital projects and continue to ensure that our funding streams meet the most urgent needs of the hospital.
Improving			
Review and update all policies and practices in line with the revised data protection legislation, new guidance and regulations.	Yes, a full review of all data protection practices, policies and procedures has been carried out.	~	Launch our refreshed privacy policy in May 2018.
			Complete implementation and commence optimisation of our supporter database system.
Embed our new people strategy to meet our objective of engaged, enabled and effective staff and volunteers.	Yes, our employee opinion survey scores increased. Some of the areas where we are performing above the norm are: development opportunities, respect and recognition, and confidence in leaders.	V	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.

In addition, 2018/19 will see a key focus on publicising the national impact of GOSH, our international fundraising and innovation to keep the charity growing and relevant.



## ALICE

The hospital's dedicated research partner, the ICH, was founded in 1946 by Professor Alan Moncrieff.

Today, ICH researchers are still working hard to develop new and kinder treatments for children like Alice, who recently underwent chemotherapy.

## PIONEERING RESEARCH

Research is integral to helping GOSH provide world-class care for children and young people.

With your help, in 2017/18 we funded 93 vital child health research projects to help pioneer tomorrow's treatments, investing a total of £11.5 million.

### RESEARCH AT A GLANCE

£11.5m

invested in research to find better ways to diagnose and treat complex childhood diseases.

14

research projects funded across the UK through our £2.1m National Call. p24

£1.2m

invested to support the running of cancer clinical trials at GOSH.



"If GOSH doesn't do research to develop new treatments, things won't get better for families like mine in the future."

Rachel, GOSH mun



"It is a great honour for me to be appointed as GOSH Charity Professor of Neuro-oncology. I passionately believe that increasing our knowledge of brain tumours will allow us to find better and kinder treatments for these children."

Professor Darren Hargrave, who took up his new charity-funded post in 2017. As part of our ongoing commitment to drive pioneering discoveries from lab bench to patient bedside, we also announced leading expert Rick Livesey as the new GOSH Charity Professor of Stem Cell Biology.

#### OUR FUTURE >>

With your continued support, we can fund more research in 2018/19 that could save the lives of seriously ill children. This will include:

In 2018, GOSH surgeons, working alongside
University College Hospital, hope to improve the quality of life of babies with spina bifida by operating while they're still in the womb.
This will be the first time the surgery has happened in the UK.

three research stars of tomorrow. These talented individuals will work to change the face of research into childhood cancers, muscle-wasting conditions, and conditions that affect the body's hormones or chemical reactions.

Together with Sparks and in partnership with smaller organisations and disease-specific charities, we'll fund even more pioneering research projects across the UK.

## 14 RESEARCHERS

3 UCL Great Ormond Street

4 University of Plymouth

5 Keele University

6 Birmingham Children's Hospital

8 University College London

10 University of Southampton

In February, GOSH **Charity and Sparks** announced a joint investment of £2.1 million to fund national research projects, with the mission of improving treatments for serious

childhood illnesses.

As the largest charitable call dedicated to child health research in the UK, it funded 14 high-quality research projects focusing on areas such as hard-to-treat cancers. nerve-wasting diseases and severe birth defects. Here, we share just four of these projects that could transform children's lives across the UK and around the world.



2 Liverpool John Moores University

Institute of Child Health

7 Oxford University

9 King's College London



Dr Sylwia Ammoun, University of Plymouth

#### Tackling three types of tumour with one treatment

Neurofibromatosis 2 (NF2) is a rare. inherited disease that causes three types of tumour to grow in the brain, nerves and skin. The most severely affected children have large numbers of tumours - and significant associated health problems – by the time they reach their teenage years.

Dr Sylwia Ammoun and her team have previously identified a molecule that's key to the growth and survival of some of the tumours. Thanks to your support, they now hope to understand whether the same molecule is involved in the

other two types of tumour. If the team show that this is the case, they hope to test existing drugs that target the molecule, which would offer new hope for children with NF2.

Dr Ammoun says: "I am delighted to have received this funding, which will enable our team to further investigate NF2. It's fantastic to know that GOSH Charity and Sparks are making such a large amount of funding available for child health researchers across the UK. We made large strides in last year's study, and we're looking forward to making more as a result of this funding."

Neurofibromatosis type 2 affects around one in 33,000 children in the UK.



Dr Thomas O'Brien. Liverpool John **Moores University** 

#### Imaging and algorithms: finding the best treatment for children with cerebral palsy

Cerebral palsy is caused by damage to the areas of the brain that control movement, balance and posture. In the developed world, it is the most common cause of physical disability in children.

Cerebral palsy can affect a child's sight, hearing, swallowing and speech. It also causes muscle stiffness which can severely affect their movement. This stiffness may be due to problems with the muscles themselves, or the nerves that tell them to move. Each type requires a different treatment, but current diagnostic tests can't always predict the best approach for each child. The child may also need a general anaesthetic and an injection into the spine, so treatments come with a certain amount of risk.

Dr Thomas O'Brien and his team want to see whether a combination of ultrasound scanning and complex maths could replace current diagnostic tests. They hope this will lead to a new tool to find the best treatment for each child with cerebral palsy, and avoid the need for invasive and unpleasant diagnostic procedures.

Cerebral palsy affects 1,800 babies and children in the UK each year.



Dr Karin Straathof, UCL Great Ormond Street Institute of Child Health

## Superpowered immune cells take on devastating brain tumours

Could T-cells – key cells in our immune system – be altered, 'engineered' and used to hunt down and destroy rare, aggressive and hard-to-treat brain tumours? Dr Karin Straathof thinks so.

She says: "New treatments for diffuse intrinsic pontine glioma are desperately needed. Surgery, which is usually a major step in treatment for cancer, just isn't an option because the tumour grows around vital brain tissue. This makes it almost impossible to treat, and means the average survival time

after diagnosis is just 9–15 months. We want to modify T-cells so they recognise a specific part of the cancer cell, hunt it down and destroy it."

This approach has already seen hugely promising results in children with blood cancers like leukaemia. "We know this type of treatment works well with children," says Dr Straathof, "as it targets the cancer cell but doesn't affect the child's healthy tissue. We want to cure children without causing other long-term side effects, and this has the potential to do that. This funding will help us to get closer to potential new treatments and cures for the children who need them most."

## Diffuse intrinsic pontine glioma affects around 40 children each year in the UK.



Professor Giulio Cossu, University of Manchester

## Special cells offer hope for young patients with muscle-wasting conditions

Children with Duchenne muscular dystrophy (DMD) have a mistake in their DNA – our in-built instruction manual – that means their bodies struggle to build and maintain muscles.

Although these children often learn to crawl and walk as normal, as they enter their toddler years, symptoms suddenly start to appear. They may find it hard to stand, climb or run, and eventually the condition causes most to need a wheelchair by the time they hit their teens. Devastatingly, most

children with DMD do not reach their thirtieth birthday.

Research could hold the key to a revolutionary new treatment. Professor Cossu's research involves using special cells in a child's body that can grow into muscle cells. His team hopes to use these cells to correct the genetic mistake that causes DMD, and then reintroduce the cells back to the child, where they can create healthy muscle.

Thanks to your support, this project will provide the crucial next step in gathering the information needed for the treatment to be trialled in children with DMD.

Duchenne muscular dystrophy affects one in 3,500 boys in the UK. It's the most common and lethal form of muscle-wasting disease.



## FROM PEA PLANTS TO CURES: THE JOURNEY OF GENETICS



As far back as 2,000 years ago, it was believed that a biological unit of inheritance was passed down from parents to children – tiny slivers of information that made each of us unique. Since then, the journey of genetics has been a long and complex voyage of discovery involving monks, pea plants, intense rivalry and outstanding scientific endeavour. But with our ever-increasing technological know-how, we are entering an incredible era of modern genetics – without which medicine would look very different.



#### A 'book' like no other

DNA is complex. A twisting molecule that holds the blueprint to making a human, causing disease and finding cures. If DNA were a book, then chromosomes would be the chapters, and genes would be the single pages. A spelling mistake on one page might have no effect on the story. Or it could change the meaning of the entire chapter or even the whole book. That's why, for some children, a seemingly small genetic mistake can lead to a major fault in their blueprint, leading to life-threatening or life-changing conditions. But what if you could simply correct the 'typo'?

#### Masking the mistake

Professors Bobby Gaspar and Adrian Thrasher first met in 1992. Little did they know that this encounter would go on to shape both of their careers. After almost a decade of working together and dedicating their lives to becoming one of the leading gene therapy teams in the world, they took the bold step of trying to correct genetic mistakes in children for the first time. Their patients were children who had been born without a functioning immune system, due to a rare condition called severe combined immunodeficiency (SCID). These children,

sometimes referred to as 'bubble babies', were so vulnerable to infections that even a cold could be life-threatening.

At the time, the only treatment available to these children was a bone marrow transplant, but that was an incredibly difficult procedure to go through. So in 2001, with the unwavering support of 10 brave families who agreed to take part, the team took a bold step and started the second ever trial of gene therapy for any disease, anywhere in the world.

Every cell of our immune system starts life in our bone marrow. So that's where the team began. They took a sample of each child's bone marrow and introduced a working copy of the faulty gene. The corrected cells were then given back to the child, where they could get to work rebuilding a healthy immune system. And it worked. All the children quickly recovered with fewer side effects than a bone marrow transplant.

But it wasn't all perfect. One of the potential sideeffects, although exceptionally rare, was leukaemia. The problem was that when they gave the cells the corrected gene, it could take up residence anywhere in the DNA or affect other genes. This meant, if it

settled in the wrong place, it could cause cancer. The professors knew they had to improve the technique before it could be used again.

The answer came several years later, when they found a new method of getting the healthy gene into the DNA. And in 2001, the first child in the world to receive this new treatment was a little boy at GOSH.

Since then, more than 50 children have been treated and the results have been life-changing. But the team remain determined to keep improving the technique for even better results.

Our modern understanding of genetics can be traced back to the work of Gregor Mendel, a 19th century Austrian monk. After eight long years carefully crossbreeding pea plants, Mendel came up with the fundamental laws of inheritance, including the observation that traits are inherited as distinct units, one from each parent.

"When I first heard about gene editing back in 2008, the efficiency was so low that everybody thought it would be a huge challenge to get it to work in patients. Me included. But in the past few years, there has been some extraordinary progress. I'm really excited to see what the future holds."

Dr Claire Booth, Lecturer in Gene Therapy

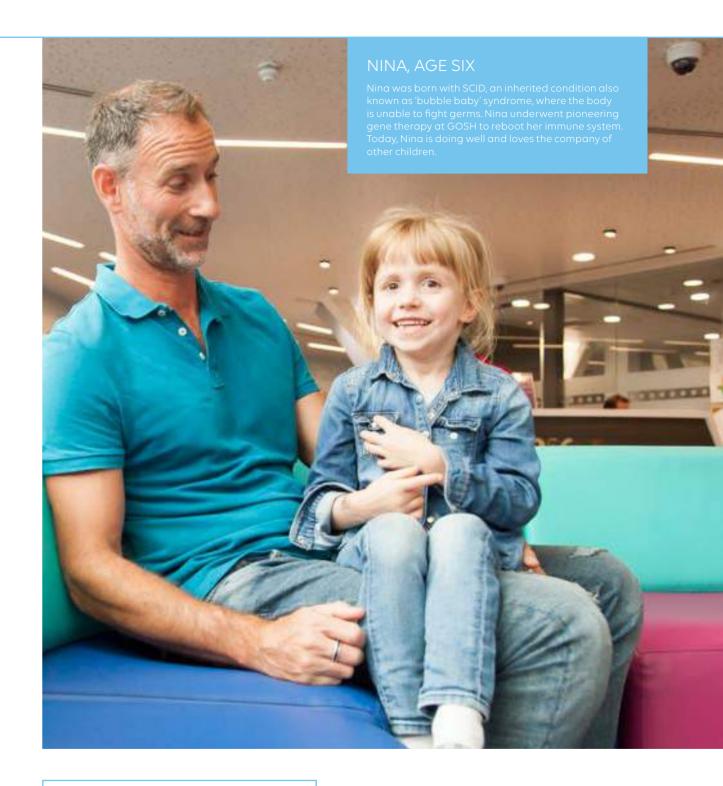
#### **Correcting the mistake**

With charity support, the Gene Therapy team at GOSH continue to strive for more accurate ways to correct genes. They're making use of the latest technological advances, including a wave of new techniques that incorporate the use of 'molecular scissors'. These scissors are chemicals that 'snip' DNA in precise locations so that the correct version of the gene tucks itself into exactly the right place. If this works, it should completely remove the risk of side-effects.

GOSH researchers are exploring this technique for SCID and other conditions, and hope to see the benefits in the years to come.

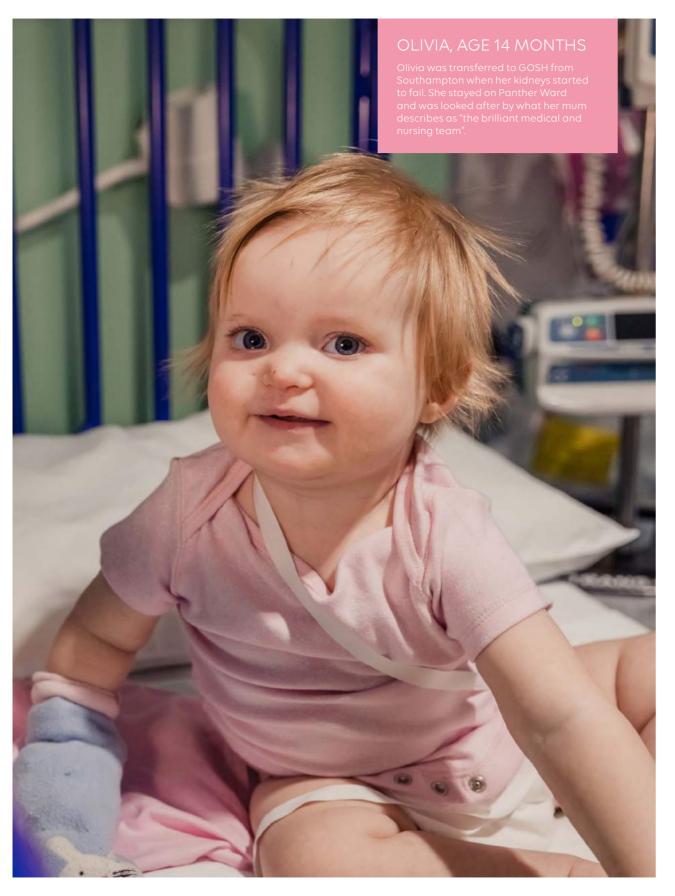
#### **Broadening horizons**

Unsurprisingly, other teams across GOSH are eager to use the team's expertise in a bid to help children with other rare conditions. Researchers studying muscle-wasting conditions, metabolic diseases and sight loss are now working on applying gene therapy to these areas. With your help, we can continue to support groundbreaking work like this, moving us closer to the day when more conditions can be cured with just a single injection.



#### 2001

GOSH patient Rhys Evans becomes the first child in the UK, and one of the first people in the world, to be treated with revolutionary gene therapy.



## ADVANCED MEDICAL EQUIPMENT AND SYSTEMS

Advanced medical equipment has and always will play a crucial role in helping to treat the toughest and rarest childhood conditions.

With your help, in 2017/18 we invested £16.7 million to give children at GOSH access to state-of-the-art medical equipment and systems.

## EQUIPMENT AT A GLANCE

£13m

invested in the Khoo Teck Puat iMRI suite, which allows children to be scanned during brain surgery.

10

vital ECMO machines funded to support children who need life-saving heart or lung surgery.

£900,000

invested in a brand-new SPECT CT scanner that allows doctors to diagnose conditions and even target treatment to specific tissues.



"That little square box, no bigger than a box of A4 paper, saved our daughter's life."

Ava's mum on the importance of ECMO machines, which perform the job of the heart and lungs



"The benefits of having a new SPECT CT scanner are huge. It will support expansion of our service and the audiovisual features mean children feel much more relaxed and comfortable during their scan."

Pippa Mashford, Nuclear Medicine Radiographer

#### OUR FUTURE >>

We need your help to ensure GOSH always has the tools it needs to give children the best chance of a better future.

our hard-working fleet of MRI scanners with the latest software, ensuring patients have access to the very best in diagnostic imaging.

We'll help GOSH specialists treat more children with heart conditions through a tiny 2mm incision rather than open surgery, by giving our **Cardiac Catheter Lab** a much-needed upgrade.

GOSH's **digital revolution** will begin with the launch of new systems across the hospital, transforming the hospital experience for everyone. p40



## DANIEL

In 1977, with help from Billy
Butlin, GOSH acquired the UK's
first paediatric CT scanner,
allowing researchers to capture
detailed images of the living
brain and other tissues.

Today, advanced imaging helps children like Daniel by providing detailed images to guide complex brain surgery.

## STATE-OF-THE-ART SCANS DURING SURGERY

"I started to notice some slight, but noticeable changes in Daniel just before his second birthday," says mum Louise. "Normally enthusiastic and engaging, he became lethargic, began to struggle with his balance and developed a slight tremor. His reflexes were slower, and he often told me that his head hurt.



"We don't take a single day for granted."

Louise, Daniel's mum

"Tests confirmed my worst fears. Nothing could have prepared me for the moment I was told that Daniel had an extremely large brain tumour and required major surgery to remove it. We were referred to the renowned Neurosurgery team at GOSH and placed under the wonderful care of Mr Kristian Aquilina, who performed the five-hour operation.

"It was only after the surgery that we found out the tumour wasn't cancerous. While this was a relief, the size and location of the tumour meant that although the operation was mostly successful in alleviating some of Daniel's distressing symptoms, Mr Aquilina was unable to remove all of it.

"The surgery took its toll on Daniel and he had to learn to do the most basic of tasks again – sit, stand, walk. Even now, we still have a diary full of occupational therapy and physiotherapy appointments to help him regain his strength and fine motor skills

'Daniel is doing very well now – we feel blessed that he is able to lead a stable and happy life. However, because some of the tumour was left behind after the surgery, we return to GOSH every three months for a check-up and MRI scan to ensure it hasn't grown or altered.

"While I am thankful every day for the recovery Daniel has made, as each check-up appointment approaches, so too do the sleepless nights and the worry that the tumour will have returned. We don't take a single day for granted."

#### Taking brain imaging to the next level

Buried within our brain tissue, 100 billion nerve cells transport vital information to control every important function, from seeing and blinking, to thoughts and emotions. To avoid damaging these delicate networks, brain surgeons like Mr Aquilina seek guidance from the most advanced imaging and mapping technologies available, helping them prepare before an operation and evaluate its success afterwards.

Thanks to your support, we're investing in a new iMRI suite that will allow surgeons at GOSH to seamlessly re-image the brain during surgery. This will dramatically reduce the risk of damaging healthy tissue or leaving tumour tissue behind, giving parents and clinicians the answers they need more quickly, and reducing the need for children to have multiple operations.

Children with epilepsy will also benefit. For some patients, removing areas of the brain can reduce the severity of their epileptic seizures. But accuracy is vital and the highly specialised iMRI scanner will ensure children have the best chance of a successful recovery, with minimal side effects.

Mr Aquilina explains: "The new iMRI suite will have two rooms separated by a moving wall, with an operating theatre on one side and an MRI scanner on the other. This means we can operate in the theatre for as long as we need to, and just before we are ready to finish, or if at any point we have any concerns, we can stop surgery, open the sliding door and seamlessly transfer the patient onto the MRI scanner. Once the scan is complete, we can reevaluate where we are, and clearly see if any tumour is left behind and the effect on any other areas of the brain.



An MRI scanner at GOSH.

"If we had the iMRI scanner in Daniel's case, we would have scanned him at the end of the operation and seen the little bit of tumour that was left – it was very small. We would have understood better its relationship with surrounding structures in the brain and exactly where it was. This could potentially have allowed us to completely remove it. We would now be less concerned that it would grow back, and his parents would be less anxious every time he has a scan.

"The new iMRI suite will allow myself and my fellow surgeons to say to parents with complete certainty at the end of surgery, that we have done all we can to improve the life of their child. That will make a world of difference."



"If we had the iMRI scanner in Daniel's case, we would have scanned him at the end of the operation and seen the little bit of tumour that was left – it was very small. We would have understood better its relationship with surrounding structures in the brain and exactly where it was and whether we could have removed it."

Mr Kristian Aquilina, GOSH Neurosurgeon

## LET'S GET DIGITAL

From ink on paper to today's intelligent machines, data has transformed before our eyes. Grabbing this opportunity with both robotic hands, GOSH Charity has invested £37 million in systems that will harness the power of data and revolutionise diagnosis and treatment, propelling GOSH into a new era of medicine.

"Our young patients have grown up with technology at their fingertips," says Dr Shankar Sridharan, Lead Cardiac Specialist and GOSH data champion. "They're booking tickets online, they have instant access to information and everything is stored on the cloud. But when families come to GOSH, they're still carrying pieces of paper.

"Our systems are outdated. We don't have the capacity or technology to capture or analyse data to its full potential. It's making the lives of doctors and patients harder and slowing down progress that could change lives."

Dr Sridharan is campaigning for a digital revolution at GOSH, and he isn't the only one. Professor Neil Sebire is an internationally renowned child health researcher, and decidedly modest pathologist.

"I've been looking down a microscope to diagnose childhood conditions for more than 25 years," he

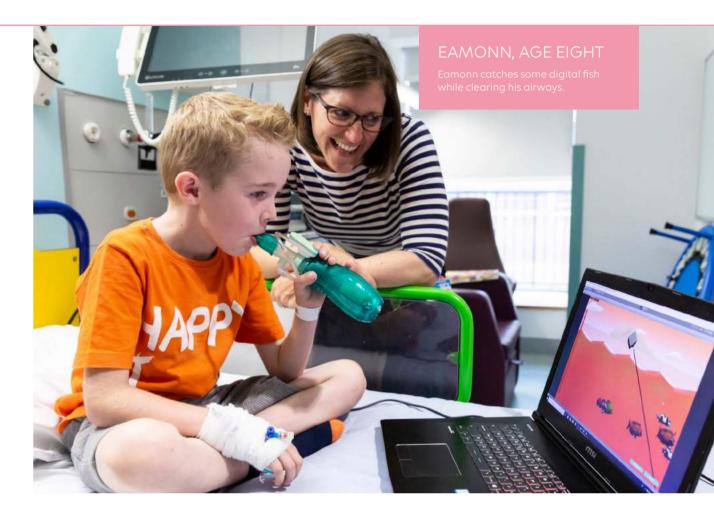
says. "Can I do it better than a computer will be able to do it in future? Absolutely no chance. We're now in a position to really capitalise on advances in computing, data storage and analytics, to make even faster, bigger strides in medicine."

"We're introducing a single, comprehensive patient record system to the hospital," says Dr Sridharan, Chief Clinical Information Officer for the project. "This will replace, if you can believe it, more than 200 separate systems currently being used at GOSH. It's going to bring simple yet transformative changes like giving clinicians and families easier access to information. It will also allow us to tap into incredibly exciting areas like wearable technology, robotics, avatars and telemedicine."

As Chief Research Information Officer, Professor Sebire has his sights set firmly on the research potential of the new system.

"We'll recruit some brilliant minds in data science to use the analytics software – which sits alongside the main record system – to mine our vast patient data pool. This kind of research has huge potential. The system could learn to predict catastrophic medical events, instantly identify children eligible for clinical trials and recommend major changes in clinical practice. We've already begun using parts of the system, and I can see truly incredible things happening across the hospital."

Professor Neil Sebire, pathologist and Chief Research Information Officer.



#### Fishing for data

Combining clinical expertise with cutting-edge computing, Professor Eleanor Main's team are using the hospital's new analytics system to transform physiotherapy for children with cystic fibrosis.

"The most life-threatening thing for these children is thick mucus building up in their lungs," says Professor Main. "A big part of managing that is trying to get rid of the mucus every day, through a combination of regular physical activity and airway clearance techniques. The daily burden of having cystic fibrosis is tough. We are always trying to find ways of reducing this burden while making treatments better.

"Every airway clearance technique is incredibly boring. And each child has their own preference, so it's difficult to research which ones are most effective, or how often they need to be used.

"The solution to all of this came through working with three immensely clever people at Microsoft Research: Haiyan Zhang, Lee Stott and Greg Saul. "They helped us to put wireless, chipped sensors inside airway clearance devices that would register every breath passing through and turn it into an electronic signal. These signals can be recorded remotely and transmitted to the team.

"The signals can also be linked to computer games, so a child breathing through the device with good technique could drive a car, or catch a fish, or ski down a mountainside. The hope is that gaming will make airway clearance more fun and easier to do every day.

"This has been a dream of ours for a long time – years. But we didn't have the systems to handle data in a way that made it possible. Now we do."

Professor Eleanor Main, Physiotherapy Researcher

"Our Microsoft partners held special hackathons to kickstart the design of different games. They put some computer science students from UCL and other universities in a room for 48 hours with a load of pizza and crisps, and gave them a task: design the best game you can. They came up with some brilliant ideas."

From summer 2018, about 160 children with cystic fibrosis from GOSH and two other London hospitals will receive a chipped airway clearance device and a special Fitbit. Together, these devices will track daily activities for each child over 16 months, from which airway device they're using to how long they run around the playground.

What's your vision of the future?

"We'll invent better tests and technology to monitor kids with lung problems when they're at home. Maybe they'll blow into a device plugged into their smartphone and the hospital will instantly get the results. Then they'll need to come into hospital less often, only when the system spots a red flag."

Emma Raywood, Fizzyo PhD Student and Respiratory Physiologist

"There should be a giant slide on top of GOSH that when the doctors call your name, you slide down and it takes you directly to your appointment."

GOSH patient Fred, age eight

"The next bit, the crucial bit, is linking that data up with the clinical outcomes for each child," says Professor Main. "How does physical activity and airway clearance relate to changes in their health?

"To do this before now would've been a nightmare because the clinical data sits on so many different systems at GOSH. Imagine our joy when we realised the new system would change all that. We'll be able to port in data from the chipped devices and compare it directly with clinical data from GOSH. It is spectacular.

"Code nowadays isn't just a set of instructions – it's intelligent and it can learn. It can spot trends and patterns in data, that we can't reliably see ourselves. Maybe one day we'll be able to say to a child with cystic fibrosis, 'you know what, it's okay if you don't do all your physio, but actually doing 50% of it is absolutely crucial and will make a huge difference to how you feel'. We just haven't had the evidence to say things like that before now.

"The other thing the system will look for are predictors – red flags in the data that tell us a child is at risk of developing something nasty in the near future. It could help us intervene sooner and head it off before they even get ill.

"The potential for this in the future is huge. The more data we get, the more powerful our findings will be. If this works, we'll look at collecting data across the UK, too. Give us 10 years, and it'll start changing the way we think about treating these kids across the world."





Patient case notes from 1897.

"From the moment the doors opened, GOSH founder Dr Charles West kept meticulous notes on all of his patients."

Nick Baldwin, GOSH Archivist

#### Paper trail

As charity-funded GOSH Archivist, it's Nick Baldwin's job to look after every historical document, patient record, letter, memo and photograph kept since the hospital opened in 1852.

"From the moment the doors opened, GOSH founder Dr Charles West kept meticulous notes on all of his patients. They used to bind hospital case notes into one annual or biannual volume for each senior doctor, with patients listed alphabetically within them. That had to stop after World War II, partly because the volumes were getting ridiculously large. Technology was advancing, new tests were being introduced and even more paper was being generated.

"Today, things are very different. The new electronic patient record (EPR) system will completely revolutionise the way we collect, store and use data, and it'll certainly change my job."



## REBUILDING AND REFURBISHMENT

The hospital's wards and facilities will always need updating to ensure that GOSH can treat more patients in surroundings that are not only functional, but help children recover more quickly.

With your help, in 2017/18 we committed £34.9 million to create child-centred spaces equipped to deliver the world-class care GOSH is so well known for.

£,34.9m

invested in creating patient-centred spaces equipped to deliver the world-class care GOSH is so well known for.

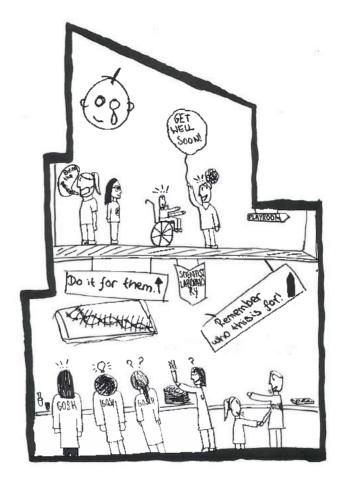
Royal visitor opens the Mittal Children's Medical Centre, home to the brand new Premier Inn Clinical Building.

3,500+

patients treated in the new building during its first six months.



"I could explode! The bigger than the last one!"



Work continued on the construction of the Zayed Centre for Research, a new facility that will bring patients and researchers together under one roof. Children got involved by sharing their vision for the centre.

The picture on the left, drawn by a GOSH patient, sums up the ethos of the centre - turning discoveries in the lab into new treatments for seriously ill children, all under one roof.

#### OUR FUTURE >>

As patient numbers increase and medicine transforms before our eyes, we need your support to ensure children and families are cared for in the very best environment, helping them to recover more quickly.

and Sound Centre, a new outpatient facility that will transform the hospital of our ambitious rebuilding and with sight and hearing loss. p54

refurbishment programme.



## A RIGHT ROYAL SUCCESS

It's 17th January 2018 on Great Ormond Street. There's a buzz in the air. Every ward and corridor brims with anticipation, awaiting the arrival of a very special visitor. A panther waits patiently on Level 6. Down on Level 2, a kangaroo keeps an eye on the door. Around them, six floors of brand-new, gleaming medical facilities are filled with children, families and staff, ready to celebrate the completion of the Mittal Children's Medical Centre and the official opening of the new Premier Inn Clinical Building.

A truly landmark moment for GOSH, the opening was made particularly special by the presence of HRH The Duchess of Cambridge. HRH spent time with children awaiting heart transplants and joined patients with rare and complex medical conditions to take part in an art activity.

Now staff have settled in, ward animals are at home in their new habitats, and more than 3,500 young patients have passed through the doors of the new building. Are the new facilities making a difference? We padded over to one of the eight brand-new wards, Leopard, to find out.

#### Lizzie Penn, Play Specialist on Leopard Ward

"I met a family recently who said that the hospital is beautiful. It was amazing to hear someone use that word to describe a hospital! Their little girl's room overlooked leopards on the walls of the corridor, so we made believe that they come out at night and that there was a little mouse keeping an eye on her when I wasn't there. Her imagination was incredible.

"There are some lovely touches. We have beautiful artwork, and poetry and facts about leopards.

We have a play room, gym and a lovely parents' room for mum and dad to hang out in.

"The whole ward just feels so airy and spacious."

Lizzie Penn, Play Specialist

In the old ward it was so cramped and confined. The virtual window is amazing. In the morning it's like sunrise, then it goes all the way through to sunset.

"The whole ward just feels so airy and spacious. The new patient bedrooms are much bigger, and children and parents get a lot more privacy. That's so important – everybody needs alone time. There's a teenage boy who comes in quite regularly. In what other situation would he be sharing a room with his mum? We had them in a room where the parent bed is round the corner and you can pull a curtain round to separate it. He thought it was great and said he'd sometimes forget his mum was there!





The new Disney Reef play area.

"I think sometimes people underestimate the impact of surroundings on the children and families here. There's a huge amount of research that shows your environment and being able to exercise your creativity can have a significant impact on your recovery. Every day I see the difference it makes when children can socialise, be creative and play. They can do all of that more easily now. I've been at GOSH almost 20 years and this is one of the most amazing transformations I've seen.

"We'll only be one minute away from the new Disney Reef outdoor play area, which is so exciting! Because children like Scarlett with cystic fibrosis are at risk of cross-infection, they can't all be in one place at the same time. Others are on ventilators and can't leave the ward for long periods of time. That can mean they miss out on things, through no fault of their own. Now, if they've got 10 minutes spare, we'll be able to whizz outside to an amazing Disney Reef. They'll love that!"

SCARLETT, AGE SIX

Scarlett has cystic fibrosis, a lung condition that also affects her ability to digest food. She and her family have been coming to GOSH for nearly six years – since Scarlett was just five weeks old. Scarlett's nan, Kerry, says: "I thought the old ward was fine, we were grateful for it. But walking into this was amazing. It's a massive difference. It's more comfortable, there's the storage space, the little private space for parents, the size of the room, and the play room. I thought it would be nice, but not as nice as this! It'll make a massive difference to patients like Scarlett. It's just amazing."

"I thought the old ward was fine, we were grateful for it. But walking into this was amazing. It's a massive difference."

Scarlett's nan Kerry

What do GOSH families think?

 $78^{\circ}/_{\circ}$ 

of children and young people said 'I felt like I had a lot of space on the new ward'. That's a significant 47% more than on the old wards.\*

 $94^{0}/_{0}$ 

of families agreed strongly that the look and feel of the ward was suitable for their child, compared to 52% on the old wards. Maybe that's thanks to the welcoming animal mascots, carefully selected for each ward by patients and staff.\*

\*Based on a survey of 26 children and young people and 66 family members in April/May 2018 on wards in the Premier Inn Clinical Building. Old ward data based on responses from 20 children and young people, and 44 families on wards in the Southwood Building and Variety Club Building.



## TRINITY

"They took care of me and GOSH was very nice and clean."

Trinity, age eight, was treated on Pelican Ward in the new Premier Inn Clinical Building, where she says she had the pleasure of being surrounded by lovely staff.

The newest wards are just down the corridor from the oldest part of the hospital. The ornate chapel, constructed as part of the first purpose-built clinical block all the way back in 1875, is still standing today.

## EYES, EARS AND ENTREPRENEURS

Tucked away in the corner of a leafy London square, just a stone's throw from GOSH, a beautiful building with a fascinating history is about to undergo a very special renovation. This makeover will mark the beginning of a new chapter for this listed building, as it becomes home to a unique centre, tailored specifically around the needs of children with sight and hearing loss.





#### A problem solver

In 1884, after witnessing a fellow Italian struggling to be treated in an English-speaking hospital in North London, successful businessman Commendatore Giovanni Battista Ortelli decided to open a hospital for Italian speakers. The entrepreneur, who made his fortune making looking glasses and lenses, found what was then, a relatively rural spot in Queen's Square, Bloomsbury. Being located around the corner from the Hospital for Sick Children on Great Ormond Street, it was the perfect place to make his vision a reality. And so began the story of the Ospedale Italiano – the Italian Hospital.

Ortelli oversaw the redevelopment of the whole site, originally separate houses, and the building as we now know it opened in 1899. The Sisters of the Charity of St Vincent de Paul provided nursing care to Italians, others in need and fee-paying patients. Over the years, the hospital expanded by turning adjacent buildings – including a pub – into new facilities. It ran independently for almost 100 years, but eventually closed in the 1990s before becoming part of GOSH.

#### Going back to its roots

Since then, the building has housed everything from offices and accommodation for parents and patients, to a nursery. But now its new role circles back to Giovanni Ortelli's original job of making eyeglasses. Spanning five floors that will be full to the brim with creative lighting, colour, texture and acoustics, this interactive space will be designed around the needs of the largest outpatient group at GOSH – children who are fully or partially deaf or blind.

"Audiology has come a long way from the so-called auricular training of the past – which made it sound like children were being taught to wiggle their ears! The new Sight and Sound Centre will be a huge help in taking GOSH to the next level."

Fiona Duncan, Lead Audiologis

#### A new lease of life for an old building

As children and young people arrive at GOSH's main entrance, they are greeted with a virtual fish pond, colourful artwork and a ship-themed reception desk. Fun wayfinding signs and animal-themed wards are a welcome and stimulating distraction at what could be a scary time. But for children with sight or hearing loss, that vibrant and bustling environment can quickly overwhelm the senses. This can lead to additional stress for the child, making it more difficult for them to participate in hearing and sight tests.

What's more, these children may have complex conditions that mean seeing more than one clinician at each visit and multiple trips to different rooms in different hospital buildings. So, although these children are already receiving world-class care, their overall hospital experience could be dramatically improved.

For the first time in the hospital's history, the GOSH Sight and Sound Centre supported by Premier Inn & Restaurants will bring together audiology and ophthalmology clinical specialties under one roof. This new centre will have specialist labs and examination, consultation and treatment rooms. There'll even be a new home for the hospital's special opticians, who can help design glasses that meet the specific needs of each GOSH patient.

And because many of these children also have appointments with other specialist services, other teams will be getting in on the act too. The top floor will house rooms dedicated to teams such as Ear, Nose and Throat, and Speech and Language Therapy.

#### Beyond the clinical

From the moment you step through the front door, this one-of-a-kind centre will offer unique sensory experiences for its young visitors in an environment that will be as homely and sensitive to their needs as possible.



Artist's impression of a sensory garden in the new centre.

Specially commissioned artwork will engage and inspire young patients with sounds, sights and textures that remind them of home. And there will be a large garden with plants specially chosen to stimulate all the senses. There will be quiet green spaces, bird-feeding stations and homes for feathered friends and creepy-crawlies – allowing children to get closer to nature.

#### A sound investment

Work on this exciting charity-funded project will begin later this year and the centre is due to open in spring/summer 2020. Thanks to you, we can improve the hospital experience for young patients with sight and/or hearing loss, while bringing a new lease of life to a unique old building.



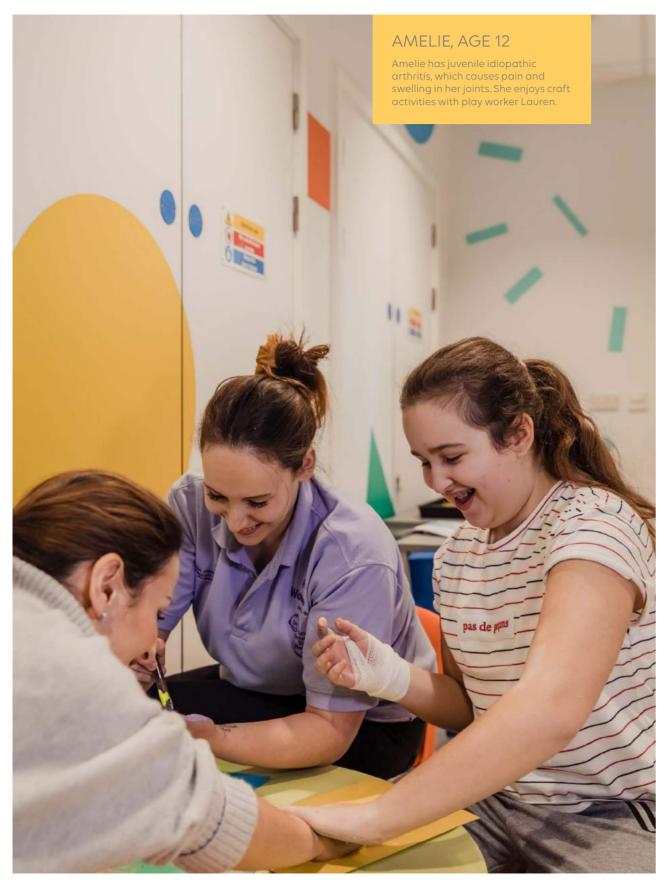
GOSH Dispensing Optician Jess Gowing.



"My role is to design and fit glasses to children at GOSH. In a way, it's similar to any high-street dispenser, but the service here is so important for children whose condition has affected the shape of their face or head. If their glasses don't stay on properly, the child won't wear them, and they'll miss out on the benefits."

Jess Gowing, GOSH Dispensing Optician, whose team will be moving into the new Sight and Sound Centre.

ay, it's



## CHILD AND FAMILY SUPPORT

Child and family support services help to ease the burden on families, raise spirits, and support children and young people through their treatment.

With your help, in 2017/18 we invested £12.1 million to make a difference to children and their families

## CHILD AND FAMILY SUPPORT AT A GLANCE

£12.1m

invested in supporting patients and families.

250

in creative activities at GOSH each week.

8,500+

children, families and staff supported by the Spiritual Care team this year.



"When our son, Sami, was rushed to GOSH, the very last thing we had a chance to think about was where we would stay."

Matt Dawson, Sami's dad, who stayed in GOSH Charity-funded accommodation

#### October 201

New family accommodation opens on Sandwich Street, a short walk from the hospital Morgan Stanley House and GOSH Charity House provide families with a comfortable home-from-home, allowing them to stay close to their child at all times.



GOSH patient Leo, age 17

"The music really cheered my son up loads after a hard week – it's the first thing that made him smile."

GOSH parent, after watching a performance organised by GOSH Arts

This year, GOSH parents nominated one of the hospital's play specialists for a hero award, recognising their incredible work to ease anxieties and help children avoid more invasive procedures.

#### OUR FUTURE >>

We know that treating a child at GOSH is also about looking after the whole family. That's why, with your support, we will continue to provide services that help children and families through some of the most trying times.

work to refurbish some of our existing **family accommodation**, ensuring parents of seriously ill children can stay close to the hospital in comfort.

the **Play team**, who help children at GOSH feel in control, calm and informed about what's happening, owell as providing endless opportunities for fun.

we'll continue to fund other services designed to support patients and their families, from the multi-faith chaplaincy to GOSH Arts.

# DOLCIE. AGE FOUR Dolcie had a high temperature just a week before she came to GOSH, but had never been

thought she had a virus, but within 48 hours her

lungs had filled with fluid and she was brought

to GOSH for treatment.

## A HOME-FROM-HOME FOR PARENTS

Sleek design, spacious rooms,
Hypnos beds and comfortable
communal areas make
Sandwich Street more than
just a place to rest your head.
Their modern facilities offer
true respite for the parents of
critically ill children at GOSH,
who come from all over the UK.

In October 2017, we celebrated the opening of Morgan Stanley House and GOSH Charity House, located on Sandwich Street, just a 10 minute walk from the hospital. Together, these buildings provide 11 private en-suite rooms and two family suites, allowing parents and other family members to stay, free of charge, with the comfort of knowing they are just minutes from their child's bedside. The facilities include a communal kitchen and living area, where parents going through similar experiences can meet and support one another.

#### What accommodation means to parents

Ex-England rugby player Matt Dawson says: "When our son Sami was rushed to GOSH, critically ill from meningitis, our lives were turned upside down. When you don't know whether your child is going to survive an hour or a day, you want to be there for every single second. The very last thing we had the chance to think about was where we would stay.

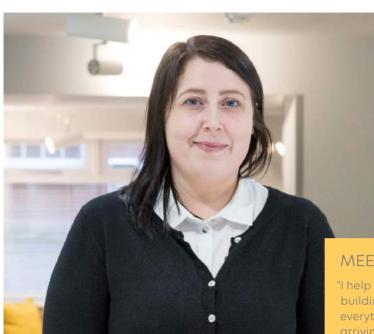
"Thanks to GOSH Charity, we stayed in parent accommodation, just a stone's throw from the hospital, so we never needed to be far from Sami's side. I was delighted to help open Morgan Stanley House because it's giving more parents a place to stay that is close to the hospital and their child."





"I was delighted to help open Morgan Stanley House because it's giving more parents a place to stay that is close to the hospital and their child."

Ex-England rugby player Matt Dawson, Sami's dad



"If their child has been rushed into hospital, their head might be all over the place. I can make sure some of the little things are done, which hopefully makes things a little easier."

Georgina, Housekeeper at Sandwich Street

#### MEET GEORGINA

"I help with practical things that keep the building running, including making sure everything is prepared for new families arriving. The other side of my role is supporting the families that stay here, in whatever way I can. It might seem silly, but if they want something, like a newspaper, I can pick that up for them on my way in. If they need to do some washing and the machine is busy, sometimes I'll be able to help by putting their washing on while they're out. Especially if their child has been rushed into hospital, their head might be all over the place. I can make sure some of the little things are done, which hopefully makes things a little easier.

"I've been working here at Sandwich Street since it opened. I collect feedback from families, which has been overwhelmingly positive so far. The beds are always the first thing people mention! Apparently, they're really comfortable."



#### **Bringing families together**

Georgina says: "Families seem to really appreciate the communal areas. They have their breakfast in the kitchen before heading out to the hospital. Then they can come back for lunch and make a proper dinner in the evening. It's always being used. Some of the parents who stay for a while really get to know each other and share their stories. No one can understand better than someone who is going through the same situation.

"The first family that came were so thankful for the facilities at Sandwich Street because it meant the whole family could be together. Especially as it was around Christmas time – it was so important to them. And I think being only a ten-minute walk from their child was a comforting thought.

"The accommodation here brings a bit of normality to parents' lives. A lot of them have been rushed in and don't have any of their belongings with them. It's nice for them to be able to have a shower in their own bathroom, make their own breakfast and a cup of tea. Even little things like having a hairdryer and a washing machine helps. Those things are small when you consider that the parents are here because their child is seriously ill. But the way I see it, we can still try to make everything outside of the hospital as simple and comfortable as possible. A little effort can make a huge difference."

"They were so thankful for the facilities at Sandwich Street because it meant the whole family could be together. Especially as it was around Christmas time – it was so important to them. And I think being only a 10 minute walk from their child was a comforting thought."

Georgina, Housekeeper at Sandwich Street

## THE GIFT OF TIME

Volunteering runs through the very core of GOSH. Back in 1852, the Hospital for Sick Children opened its doors as a 'voluntary hospital', and medical staff, including the hospital's founder, Dr Charles West, devoted their time free of charge.



By the late 1800s, women who described themselves as 'lady superintendents' and 'lady visitors' supported the hospital without pay by entertaining or educating patients, and keeping a close eye on the hospital's performance as a charitable institution. During World War II, GOSH had a Ladies' Association, whose volunteers helped with tasks such as padding splints and sewing pyjamas.

Nowadays, GOSH's legion of volunteers remain dedicated to supporting staff and providing positive patient and family experiences. In the last year alone, volunteers donated over 227,300 hours of their time, delivering services worth more than £2 million.

#### MEET COSTA

Costa was born with a condition that affected his immune system's ability to fight off infections. Now 24, Costa volunteers regularly at GOSH and particularly enjoys meeting families



Jamie Wilcox, who joined as Head of Volunteer Services in 2009, explains how the service has grown into what it is now, and the impact they have made.

"When I joined, I worked with senior staff, heads of departments and directors at the hospital, as well as GOSH Charity's Chief Executive, Tim Johnson, to build a strategy and develop the volunteer programme. In just over eight years, we have built the service up from about 60 volunteers to just over 1,100 volunteers. The key to success is a very robust programme of training and preparation, which would not be possible without the charity's support. We now have volunteers working in almost all wards and departments.

"We have the most diverse range of volunteer roles of any other UK hospital and we're doing things that no other hospital is doing. For example, we have volunteers working closely with the family liaison nurses in our three intensive care wards. And we are the only NHS hospital in the country with a baby buddy role. Baby buddies are volunteers trained to hold babies and cradle them when they have lots of tubes coming out and sometimes have quite severe conditions. It's a very rewarding role. Since we launched this, several hospitals have approached us for advice on setting up the programme at their hospital."

"I love this job! I am passionate about how volunteering can support the hospital.
Volunteering is not just a tag on, it's an important part of the GOSH experience and hugely benefits and impacts patients and families."

Jamie Wilcox, Head of Volunteer Services



#### Striving for pawfection

"The other thing that we have pioneered is our therapy dog programme, in partnership with the Pets As Therapy charity, which is rapidly growing. We started the programme about six years ago with one dog and quickly recognised its value and impact. Everyone loves seeing dogs around. We now have 12 that visit GOSH at least once a week, and five more in training and registration. We have a mixture of dogs, from quieter dogs that sit on beds and allow children to cuddle them as they fall asleep, to those that help with therapeutic exercises.

"The dogs (and their owner) have a schedule to visit most wards and departments across the hospital. They support services such as Occupational Therapy and Physiotherapy. For example, if a child has brain damage and is learning how to pick up a cup or hold something, they may find picking up a cup boring and refuse their exercises. So, our volunteers would bring in a therapy dog and ask the child to pick up a hairbrush to brush the dog. The child focuses on brushing the dog instead of doing exercises. This is working extremely well.

"On the Orthopaedics ward there was a child who needed to walk around as part of their treatment, but often refused to unless the therapy dog was around!" "On the Orthopaedics Ward, there was a child who needed to walk around as part of their treatment but refused to unless they walked with the therapy dog. The nursing staff were so excited and overwhelmed by it that they wanted the volunteer to come in every day!"

#### Thanks to you

"In the last year, charity support has allowed us to pilot a weekend club that now includes Sunday activities. Each weekend, we now have 160 volunteers that help run exciting activities in the activity centre or go to the wards to play games, do arts and crafts, read, or sing songs with patients who are unable to move from their beds. We have had fantastic feedback from families and patients about the weekend club.

"Also, we have worked with our partner external organisations and charities to ensure a diverse and broad range of services for patients and families. We currently have 37 organisations registered with GOSH, which we support by making sure their staff and volunteers are vetted, checked and trained."

"I can't thank the charity and its supporters enough. I look at other hospitals and see how they struggle to maintain, develop or grow a volunteer programme simply because of the lack of funds. Thanks to the charity, we have one of the largest volunteer programmes in the country."

Jamie Wilcox, Head of Volunteer Services

12

specially trained and registered therapy dogs (and owners) working across the hospital.

This year, Volunteer
Services increased the
number of volunteer
roles from

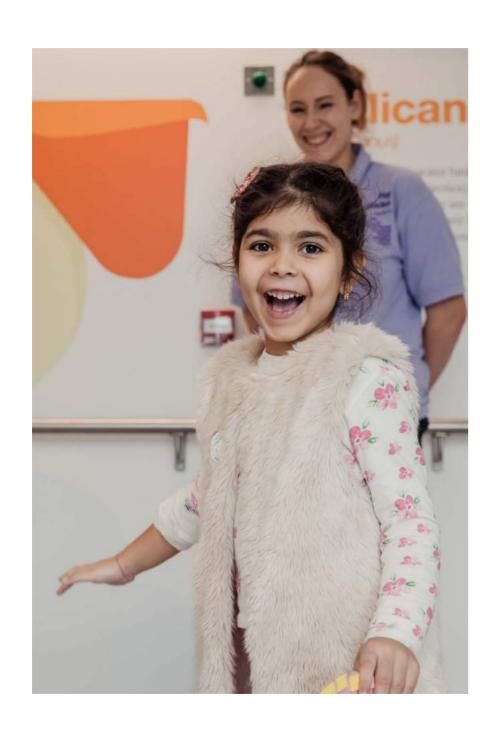
 $109_{\scriptscriptstyle to}127$ 

Many roles were created in partnership with wards and departments at their request.

Volunteer Services help run

3

main events each year, including the Christmas, Summer and Halloween parties.



## ZDZAUKA

In 1946, Mildred Creak became the hospital's first female consultant. She recognised that young patients' emotional and psychological needs are tied into their physical recovery, and pushed for increased visiting hours for parents.

Today there are no restrictions on visiting hours and we fund vital services like the Play team, who interact with more than 58,000 children like Zdzauka each year to help them stay calm, engaged and happy.

## BEHIND THE SCENES: 30 YEARS AT GOSH



Sometimes it takes a moment of reflection to realise how far we've come, together. One of GOSH's longest-serving doctors, Professor Martin Elliott, first came to GOSH in the '80s. Although he has now retired, he continues to work closely with the hospital that has been a major part of his life. Here, he shares his experiences of GOSH, GOSH Charity and how things have changed over the years.

#### Finding my feet

The first time I stepped into GOSH, it was 1984. I couldn't understand anything that was going on with the first four patients I saw – I felt like everybody in the room was a world-leading expert, except me! Every child's case was so complex, and the medical staff were just so incredibly good – they still are. I quickly adapted and from that day it was always an exhilarating challenge – every day I saw something I'd never seen before.

#### Moving with the times

To begin with, the Cardiac team was in a portacabin on top of a 1930s brick building. There was no dedicated area for intensive care, there were no computers, no automated pumps to administer medicine – it was all done manually. From operations to getting test results, everything took such a long time.

Then computers arrived. Initially they were just isolated machines that couldn't talk to each other. It's hard to imagine that now. Imaging and scanning was also primitive. Ultrasound was just starting – it was like looking at a snow storm. Then, much later, MRI came along which was a massive improvement. Now, things are evolving all the time. I've seen every bit of technology improve with increasing pace over the past 30 years – and some of it is unbelievable. We would never have stayed up-to-date if it hadn't been for the charity.

In the 80s, facilities for families were pretty awful compared to now. We had to be creative and find places to chat offsite rather than in the hospital, because there was nowhere to sit with them. We would have to sleep on the floor or chair next to the patient to stay close and that meant the parents had nowhere to go.

Thanks to the charity, that's a thing of the past. The new facilities, buildings and accommodation the charity has helped fund, addressed all those problems and much more. What's amazing is that it's entirely down to the public's generosity and a growing recognition that dignity, space, family, and peace and quiet aren't just nice, but necessary for children to get better.

#### The importance of research

From the moment I arrived at GOSH I have been involved in research. It's so important.

Some of the most obvious examples of progress are the huge advances in the knowledge of genetics and the immune system. When I graduated we knew hardly anything, and then over the years those two things have exploded in almost every part of medicine.

A whole new set of understandings has developed, in part due to people who work here and who have had support from the charity. Those big steps forward have influenced everything we do, from diagnosis to treatment.

Also, computing has changed how we can plan operations and educate families. We use it now without even thinking about it, like using virtual reality to do a fly-through of a child's heart. We can see inside, helping us and them to understand what's wrong and how we might fix it.

"A whole new set of understandings have developed, in part due to people who work here and have had support from the charity. Those big steps forward have influenced everything we do, from diagnosis to treatment."

Professor Martin Elliott





Princess Diana on a tour of the hospital.

"Every single one of us was fighting for that one child. And we made progress for them and thanks to them."

Professor Martin Elliott

#### From portacabins to precision medicine

Looking to the future, I'm sure data and digital technology will have a huge impact on medicine. It's already showing promise by capturing the data behind those squiggly lines you see on bedside monitors. If we analyse all that information, we might be able to predict rapid deterioration in a child before it even happens. We've already started doing this in intensive care alongside hospitals in Boston, Toronto and Birmingham.

I would also hope there will be more precision. Firstly, that will mean faster and more accurate diagnoses based on exactly what's causing a child's disease. Secondly, once you know the root cause, you can target treatment more effectively, reducing the toxicity and side-effects.

Another area where I think there will be huge change is in transplants. Instead of having a whole new kidney, it might be possible to place relevant cells somewhere else in the body and have the same effect. That technique is already looking promising for patients who need pancreatic cells. GOSH researchers supported by the charity are also pioneering techniques to use special cells to grow organs in the lab. And I think over the next 30 years it will completely revolutionise this area of medicine. It could also work for cells, like those in the eye, and I think this will mean we'll see trials that could cure blindness.

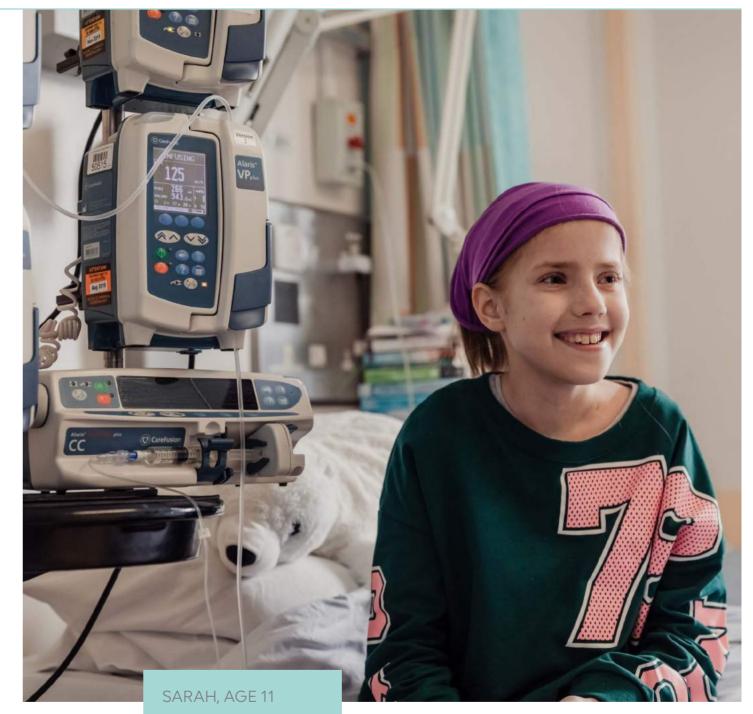
I'm also continually inspired by how well placed GOSH has become to make these types of advances. With the ICH and hospital working together with the surrounding institutes, as well as all our national and international collaborations, it's a hive of activity.

#### Stories that stay with you

I have so many amazing memories from my time at GOSH, stories that will always stay with me.
One was during the Wishing Well Appeal, when we were fundraising for the Variety Club Building. I was lucky enough to show Princess Diana around. I was astonished by what she remembered from her visit. Months later, the children she spoke to would get invited to Kensington Palace, or get Christmas cards or even birthday presents. It was amazing and an immense skill that I think few people have.

Many of the children also stay in touch with me, which is incredible. Recently I got a photograph of someone graduating from medical school and sometimes I get invitations to weddings or graduations. The feeling that gives me is indescribable. I've even had people come up to me after I've given public lectures and say "you operated on me".

I could never pick just one patient to mention out of all the sleepless nights I've had over the years. But what I do remember are the specific, complex cases that really affected me. And I never forget that every innovation we made was triggered by an individual patient. We would phone around the world, read all the latest research, argue about it and try to work out the best thing to do. Every single one of us was fighting for that one child. And we made progress for them and thanks to them."



Sarah had a heart transplant as a very young baby and has been under the care of the Cardiac Transplant team at GOSH ever since. Earlier this year, she developed post-transplant lymphoproliferative disease and is being treated with chemotherapy on Giraffe Ward.



## KERRY

Kerry was born at 26 weeks and weighed just 1lb and 6oz. She had a perforated bowel and had three operations at GOSH, saving her life.

"Now, I have huge scars across my stomach which I am mostly proud of, as they make me who I am." Thirty years after being treated at GOSH, Kerry is back on the wards as a nurse.

### THANKYOU

Our sincere thanks go to all those individuals and organisations who have so generously supported the charity in 2017/18 and those who have chosen to give anonymously. These donations are critical to improving the lives of seriously ill children.

On behalf of the children, their families and the 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 in 2017-18.

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Great Ormond Street Hospital Children's Charity

Impact Report 2017/18

## ACTIVE APPEALS, FUNDS AND FUNDRAISING COMMITTEES 2017/18

#### **ARRT Garden Party**



A family-friendly afternoon of live music by The Arts Club, magicians, a barbecue and much more.

#### Chai

Tom Hodson

#### Committee

Katie Alexander

Isabella Baruzzi Hannah Brown

Alexandra Burston

India Goss

Salvo Gula

Claire Hobbs

Freddie Parker

Alessandro Raspa

Tom Rees

Harriet Ruff

Rosanna Ruff

Giovanni Segato

Rebecca Di Sora

Charlie Steel

#### Brighter Future Funds 2017–18



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

The Ollie Anstey Brighter Future Fund
The Shani Berman Brighter Future Fund
The William Andrew Joshua Crook
Brighter Future Fund
The Toby Hambrook-Skinner Brighter
Future Fund

The Anna Lewis Brighter Future Fund
The Tyler Reader Brighter Future Fund
The James Shaw Brighter Future Fund
The Rory Spinks Brighter Future Fund
The Elliot Martin Stevens Brighter
Future Fund

The Heidi Taylor Brighter Future Fund

#### Christmas Carol Carol Concert 2017 Sponsored by Trailfinders



A heart-warming family event of carols and readings from special guests and patients at St Pauls Church, Knightsbridge. All funds raised went towards Room to Breathe, a three-year appeal to raise £1 million towards the redevelopment of the Respiratory ward.

#### Chair

Stephanie Léouzon

#### Co-Foundar

Bridgett Walters

#### Producei

Jo Broadhead

#### Committee

Anita Bott

Jo Broadhead

Emma Chandler

Antonia Christie

Vanessa Colomar

Kelly Curtin

Nick Ede

Sarah Golding

Matthew Hurlock

Timothy Knatchbull

Natasha Leith-Smith

Eugène Léouzon

Patricia Madara Eileen Mannion

Claire Merry

Kate Moore

Alice Page

Suzy Payne

Luciana Redi

Matthew Saunders

Maritzina Slater

Jennifer Spink

Murray Stroud

Dawn Vernon

Susan Wells

#### Corporate Partnerships Board

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

#### hair

Tim Score

#### **Board Members**

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Matteo Canonaco

David Craig

Simon Ewins

Jonathan Grundy

Steve Ingham

Cyrus Kapadia

Audrey Klein

John O'Higgins

Matthew Ponsonby

Simon Smith

David Thomas

Georgina Vaughan John Waples

#### The Discovery Appeal

#### DISCOVERY APPEAL

An appeal to support vital research into new treatments and cures for rare and complex diseases, helping to transform the lives of seriously ill children at GOSH, across the UK and ground the world

#### Cha

Ruth Kennedy

#### **Board Members**

Alice Bamford

Adam Crozier

Tony Hayward

Sachin Khajuria

Lucie Kitchener

Christian Meissner

Ewan Venters

#### The GOSH Matchplay Cup



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

#### Chair

Tim Stansbury

#### Committe

Edward James

Jason Stoop

Marcus Jansa

Mark Worrall Nick Stewart

#### Leading the Lions

In partnership with the British & Irish



#### **Chief Operating Officer**

Charlie McEwen

#### Love GOSH

Sponsored by BRIT Insurance, Delta Airlines and Renaissance Re



A Valentines-themed evening of fundraising, dining and entertainment that raised money for a four-bed high-dependency bay in the hospital's new surgery centre over the course of a two-year appeal.

#### Chair

Tara Falk

#### ommittee

Natalie Avvoltoio

Tom Cox

James Furlonge Alex Goward

Janet Henderson

Marianne Robson

Tricia Rumola Andrea Thompson

83

Susan Wells

#### **Shop Wear Care**

S W C

An exclusive shopping event where, for one night only, the world's leading fashion designers donated collections for guests to purchase at a discounted retail price with 100% of the sales going directly to the hospital.

#### Chair

Sayoko Teitelbaum

#### Committee

Juliet Angus Samantha Bauer

Pilar Boxford

Georgina Cohen

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Madeleine Macey

Eloise Margoline

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Martine Montgomery

Carmel Scott

Jordan Wallace

Saskia Winbergh

Amie Witton-Wallace

#### Tick Tock Club Intraoperative MRI Suite Appeal



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-ofthe-art intraoperative MRI scanner.

#### **Founding Patron**

Gary Lineker OBE

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#### Tick Tock Club Charity Golf Day

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Andrew White Matthew Wright

#### The Velodrome Pursuit



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

#### Committee

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Mark Sinclair

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Chris White

Bob Willmott

#### Valentine's Party, Big Hearts for Little People



A Valentine's-themed family fundraising event, which is part of a three-year campaign to raise funds for a new Sight and Sound Centre as part of the hospital's rebuilding and refurbishment programme.

#### Co-Chairs

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#### Committe

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Berry Bloomingdale

Lynette Cowen

Patricia Dente

Zeina Embiricos

Shannon Fidyk

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Tami Goven

Elizabeth Hawtin

Arianne Kamyab

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## RAFAEL

Rafael was born with renal failure and was a dialysis patient until he was four years old. He had a kidney transplant from his dad just a week before this photo was taken.

This year, we funded two new haemodialysis machines, helping children like Rafael feel better until transplantation is possible.

Great Ormond Street Hospital Children's Charity 40 Bernard Street London WC1N 1LE 020 3841 3841 www.gosh.org



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Designed and produced by Great Ormond Street Hospital Children's Charity Marketing and Communications.

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 2017/18 is available to view at www.gosh.org.

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