



GREAT
ORMOND
STREET
HOSPITAL
CHARITY

HIGHLIGHTS REPORT 19/20

HOW YOUR SUPPORT IN 2019-2020 HELPED
CHANGE THE LIVES OF SERIOUSLY ILL CHILDREN

Idris, now two was
born prematurely and
treated on Bear Ward.

WELCOME TO OUR HIGHLIGHTS REPORT

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. Your support is giving seriously ill children the best possible chance of a brighter future.

You can skip to any of the sections below by clicking on the page titles on this contents page. There is a 'return to contents' button on each page of the report so you can come back here at any time.

04.

A MESSAGE FROM OUR CEO

05.

MANAGEMENT OF COVID-19

- Funding Highlights

07.

YOUR SUPPORT IN NUMBERS

08.

FINANCES

09.

OUR IMPACT 2019 – 2020

- **Redevelopment**
The Zayed Centre for Research Into Rare Disease in Children
Sight and Sound Centre supported by Premier Inn
- **Research**
National Cell
LifeArc
- **Investment in staff**
Gosh Learning Academy
- **Support services**
The Play team
Collaborations

16.

THE DIGITAL EVOLUTION

- Young people shaping healthcare
- Advancing research through the digital world

A HUGE THANK YOU!

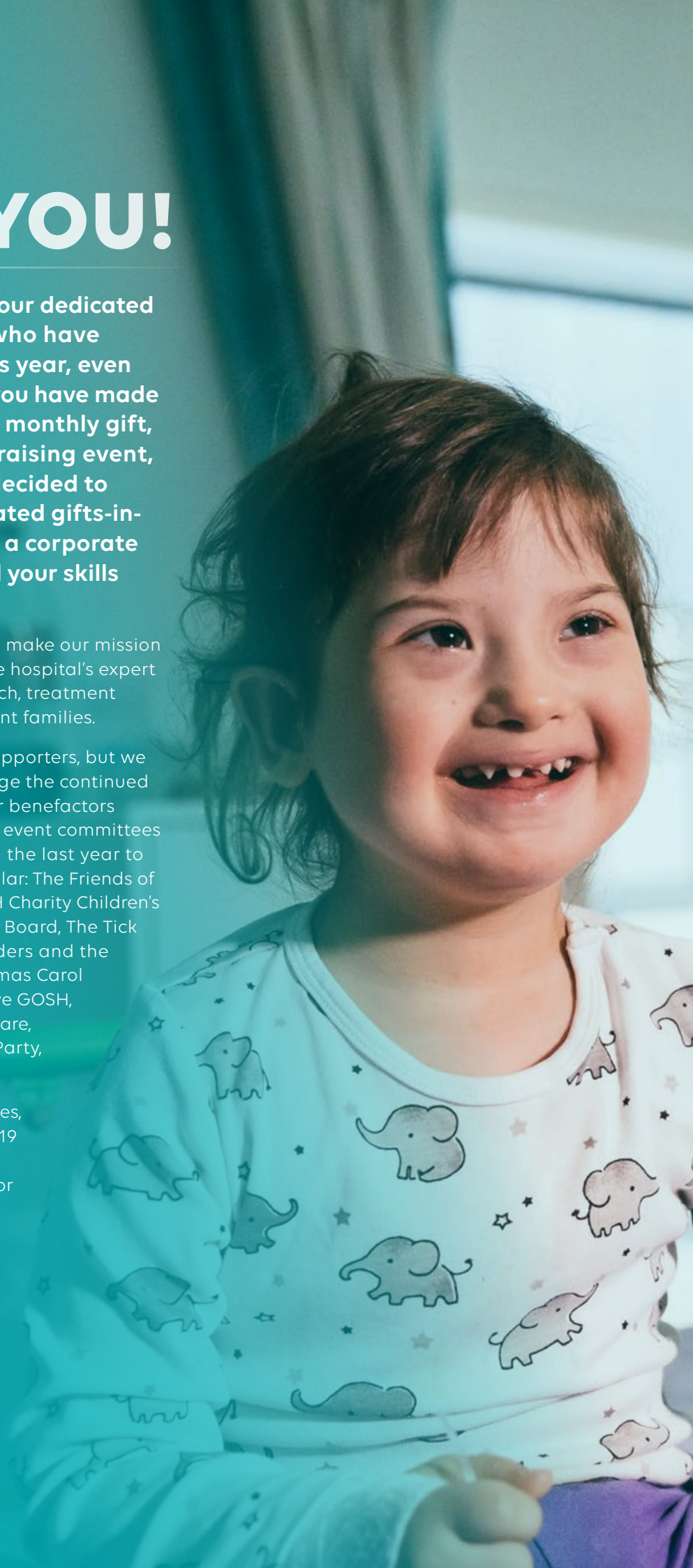
A heartfelt thank you to all our dedicated and generous supporters who have continued to support us this year, even in difficult times. Whether you have made a single donation, a regular monthly gift, hosted or attended a fundraising event, taken part in a challenge, decided to include us in your Will, donated gifts-in-kind, supported us through a corporate partnership, or volunteered your skills or time, thank you.

Every single act of support helps to make our mission a reality, enabling us to support the hospital's expert staff to deliver the very best research, treatment and life-changing care to our patient families.

We are hugely grateful to all our supporters, but we would like to especially acknowledge the continued support of our long-standing major benefactors and dedicated appeal boards and event committees who have helped us enormously in the last year to raise substantial support. In particular: The Friends of Adeona, Fundraising Patrons, GOSH Charity Children's Champions, Corporate Partnerships Board, The Tick Tock Club, Brighter Future fundholders and the following event committees: Christmas Carol Concert, GOSH Charity Golf Day, Love GOSH, GOSH Matchplay Cup, Shop Wear Care, Sight and Sound Gala, Valentine's Party, Velodrome Challenge.

Thank you also to our Charity Trustees, Research Assessment Panel, COVID-19 Rapid Response committee and the Research Strategy Advisory Board for their dedication and service.

Isabela was treated on Panther ward at GOSH. She's always smiling and loves watching sing-along shows on the TV.



A MESSAGE FROM OUR CEO



Louise Parkes, CEO

This is an extraordinary time, with the COVID-19 pandemic creating unforeseen circumstances, leading to new challenges for both GOSH and GOSH Charity. But we have much to be proud of and we are delighted to share with you some of the highlights from 2019-2020 and our response to COVID-19.

A stand-out highlight was the opening of the Zayed Centre for Research into Rare Disease in Children – a groundbreaking new centre that brings together pioneering research and world-leading clinical care to drive new tests, treatments and cures for children with rare and complex diseases, from lab bench to bedside. Throughout the COVID-19 pandemic, this building has been an indispensable hub for patient, family and staff testing, as well as helping to contribute to the national research efforts in the management of COVID-19. We have also seen much progress in the exciting creation of a new Sight and Sound Centre, supported by Premier Inn. Due to open in 2021, this will be the UK's first dedicated medical facility for children with sight and hearing loss.

More than 10,000 people took part in RBC Race for the Kids 2019, raising over £1 million. This year, the event went virtual for the first time ever, with participants from across the UK and the globe!

We know the benefits of working collaboratively and this year has seen many successes' which have been built upon partnerships. GOSH Charity, along with the children's medical research charity, Sparks, launched a successful National Call dedicated to supporting child health research.

Supporting staff, patients and families at the hospital has been a continuing focus for the charity. In September 2019, we helped launch the GOSH Learning Academy (GLA), a platform for multi-professional paediatric healthcare education, training and development. We know supporting patients is key to improving the experience for every child that comes to GOSH. This year, we have put a spotlight on our amazing Play team - their phenomenal response to the COVID-19 crisis has helped ensure children at GOSH keep smiling through these challenging times.

Digital technologies have progressed at an unfathomable rate and we are seeing the impact of our investment into the tremendous Digital Research, Informatics and Virtual Environments team and electronic patient record system. They have increased the research capacity at GOSH and better utilised healthcare data with the hope to improve outcomes for seriously ill children.

This year has highlighted some great achievements and milestones. But none of this would be possible without the generous donations from our wonderful supporters that have come together to support the hospital during these recent testing times.

We are confident that working closely together, and with your ongoing support, we will be able to overcome any adversity in the ever-changing landscape of healthcare and we look forward to the future with a sense of hope and optimism.

Thank you so much.

Louise Parkes

OUR RESPONSE TO COVID-19

GOSH has played an important role in the national response to the COVID-19 crisis by treating children from other hospitals across London as those hospitals freed up space to treat adults with COVID-19. The charity is responding by providing support to ensure the needs of GOSH continue to be met throughout the pandemic and beyond.

Like other charities, we have faced disruption to our fundraising activities with many cancelled or postponed due to the ongoing crisis. However, we have been overwhelmed by the generosity of our supporters who responded who have supported with donations and gifts-in-kind. In addition to our wide community of supporters, we would like to say a huge thank you to XTX Markets for their incredible £1m donation to our COVID-19 appeal. This amazing sum of money will help the hospital as it continues its life-saving work throughout the Coronavirus crisis and beyond.



SOME OF OUR FUNDING HIGHLIGHTS INCLUDE:

PROVIDING NEW EQUIPMENT AND RESEARCH FUNDING

We launched a new rapid response funding call for GOSH and ICH researchers for projects that will help benefit GOSH or GOSH staff and the community of patients and families it serves, as well as making valuable contributions to the current management of COVID-19. These projects have ranged from investigating transmission of the virus to understanding how the mental health and wellbeing of children have been affected during the crisis.

We funded new COVID-19 testing equipment to help support the testing capacity at GOSH to help keep patients, families and staff safe. We purchased Giraffe Incubators to protect the most vulnerable newborns in the early stages of life, lung function testing kits and genetic analysers.

SUPPORTING CHILDREN IN ISOLATION

The Play team's phenomenal response to the COVID-19 crisis has ensured that the children here at GOSH can keep smiling through these challenging times. With playrooms closed in line with national guidance, the Play team has used its skills to create activity packs for the children.

These packs include a whole selection of materials for different age groups and interests, such as sensory toys, puzzle books and arts and crafts materials, and are available across the hospital. The team has also designed play sessions electronically over Zoom, meaning children can still enjoy their time with the Play team, while reducing the use of precious Personal Protective Equipment.

SUPPORTING MENTAL HEALTH PRE, DURING AND BEYOND THE PANDEMIC

The Lucy Booth, a drop-in centre at the hospital providing accessible and early intervention services for patients and families concerned about their mental health, has recently been awarded additional funding from GOSH Charity to look at the impact of COVID-19 on the mental health of patients and families at GOSH. This research will evaluate the provision of mental health and wellbeing services during the COVID-19 pandemic compared with existing data collected as part of an ongoing GOSH Charity funded project. Information collected will allow for a sustainable, effective mental health and wellbeing provision for the duration of the COVID-19 pandemic and recovery period.

HELPING PATIENTS AND FAMILIES STAY TOGETHER DURING THE COVID-19 CRISIS

Our family accommodation provides a 'home away from home' for our patients and their families, with kitchens and facilities where families can eat together. Being able to stay close to patients the night before an appointment minimises the disruption to a child's routine and reduces stress for the whole family.

This has been vital during the COVID-19 crisis as hotels and B&Bs were closed across London. The Family accommodation stayed at high capacity, allowing families to be near their loved ones while they were receiving vital treatment at GOSH.

Over **72,000** meals have been provided for hospital staff. These are from organisations set up to feed frontline workers, our corporate partners and local restaurants.

216,000 shopping items were donated for frontline staff members.



SUPPORTING GOSH STAFF AND HELPING THEM TO...

...COME TO WORK

For those staff who have childcare responsibilities, we have supported the staff nursery, which has allowed many staff to continue their essential work at the hospital and provided laptops for staff to work from home.

...STAY ENERGISED

We installed the GOSH pop-up shop – a free shop where staff could pick up household essentials and funded an onsite coffee cart. Hot meals were delivered for frontline workers, thanks to the generosity of our corporate partners, local companies and food chains.

...STAY HEALTHY AND WELL

We have contributed by supporting the health and wellbeing programme at GOSH, helping to ensure there is rapid access to qualified professionals for counselling, support and advice. Staff have access to stress and resilience training as well as extra support to cope with trauma and other stresses that may occur.

In addition, the programme helps staff access appointments to physio and massage therapy when needed, so they can return to work sooner, reduce sickness days, resulting in a robust workforce.

YOUR SUPPORT IN NUMBERS

More than
10,000

people took part in
RBC Race for the Kids
(the biggest ever!) and
raised over £1M!

345

guests attended
the Sight and Sound
Gala, raising more
than £630,000

1,560

miles walked by the
Workspace group who
took part in the Winter
Walk as one team

5,406

guests attended
special events
throughout the year

£13.6MILLION

raised for a new Khoo Teck Puat intraoperative
MRI Suite by the Tick Tock Club

1,497

guests attended the
Valentine's Party over
the last three years

700

members of the public
visited The Zayed
Centre for Research
into Rare Disease in
Children for the
Together Festival,
inspired by Mark
Titchner's artwork for
the building, 'Together
we can do so much.'

More than
1,541

miles trekked by
Premier Inn and
Restaurants employees
& suppliers on the
3 Peaks

£9MILLION

spent on advancements
in medical equipment
and systems

85

Young people
attended the fourth
GOSH Teens Careers
Festival in Feb 2020

More than
145

committee members
made our Special
Events and
Galas possible

£30,000

the highest amount
spent on a single
auction item this year

FINANCES

EVERY POUND COUNTS

Whether it's supporting our research to develop personalised medicine for children with rare and complex conditions, save for new major upcoming projects or helping us to raise more money for the hospitals' most urgent needs, every penny we receive is helping to give seriously ill children the chance of a better future.

Some of our major projects and redevelopments require large upfront funding. That means that the way we spend and allocate money each year varies. In addition to the annual figure [see below stat], we also look at relationship between the donations we receive and the cost of raising money. On average, over the last 6 years, we've committed 71p out of every pound directly to charitable activities.

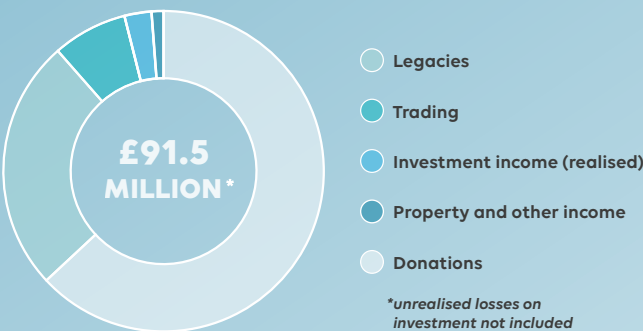
YOUR £1 THIS YEAR

71p Goes directly to charitable activity

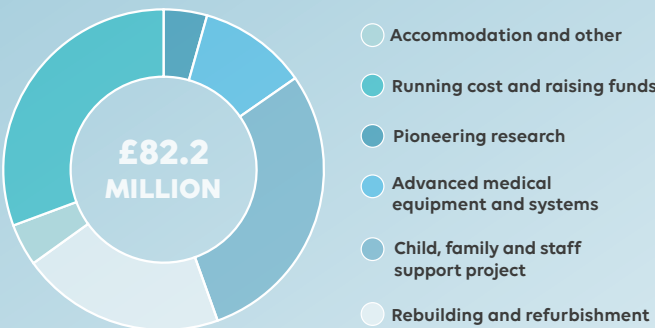
29p Helps us raise the next pound

****** Based on 2019/2020

WHAT WE'VE RAISED



WHAT WE'VE SPENT



£3.6MILLION*

PIONEERING RESEARCH

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

£24MILLION*

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

£25.2MILLION*

RUNNING COSTS AND RAISING FUNDS

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

£16.9MILLION*

REBUILDING AND REFURBISHMENT

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

£9MILLION*

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.

REDEVELOPMENT

GOSH Charity enables the creation of patient-centred spaces, designed to deliver world-class care for some of the UK's most seriously ill children.

In 2019/20 we were delighted to complete several major redevelopment and refurbishment projects. This included the Khoo Teck Puat iMRI suite, which was made possible thanks to our amazing Tick Tock Club members, and the new cardiac catheter lab which was supported by the asset management network CASCAID.



The Zayed Centre for Research was created from a partnership between GOSH, UCL and GOSH Charity. It was made possible thanks to a transformative gift of £60 million pledged by Her Highness Sheikha Fatima bint Mubarak, the wife of the late Sheikh Zayed bin Sultan Al Nahyan, Founding father of the United Arab Emirates.

ZAYED CENTRE FOR RESEARCH INTO RARE DISEASE IN CHILDREN

In 2019, we saw the opening of the Zayed Centre for Research into Rare Disease in Children. It brings together pioneering research and clinical care under one roof, helping to drive forward new treatments and cures for seriously ill children both in the UK and internationally. One of the first patients to be treated at the Zayed Centre for Research is Kai Clark, now aged 10. Kai has hypertrophic cardiomyopathy, a rare cardiac condition, and he experienced multiple cardiac arrests before receiving a donor heart earlier in 2019.

Kai will be receiving continued care in the Zayed Centre for Research outpatient clinic and he also taking in part in a research project led by GOSH clinician Dr Juan Kaski, which is aiming to discover new biological markers of inherited cardiac conditions.

Mat Shaw, Chief Executive at Great Ormond Street Hospital for Children NHS Foundation Trust (GOSH) said:

"I am delighted to see this world-leading facility open its doors and welcome patients for the first time. The opportunities that the Zayed Centre for Research offers for the integration of technology with cutting-edge medical research, and the collaboration we'll see between research and clinical teams working side by side, is incredibly exciting."



Kai Clark

SIGHT AND SOUND CENTRE SUPPORTED BY PREMIER INN

At GOSH we aim to deliver high-quality specialised care to patients every day, that is why we have invested in a new Sight and Sound Centre, opening in 2021. Children with sight or hearing loss make up the largest outpatient group at GOSH, with more than 8,000 patients seen by the Audiology and Ophthalmology teams annually, resulting in around 30,000 appointments each year! Although the Audiology and Ophthalmology clinical team deliver world-class care, they lacked a purpose-built dedicated space designed to the needs of young children.

In October 2018, construction began on the new Sight and Sound Centre supported by Premier Inn - the UK's first dedicated centre for children with sight and hearing loss. Located in the historic Italian Hospital, the new centre is starting to come to life, with much of the construction nearing completion.

PUTTING PATIENTS FIRST

We put patients at the heart of what we do and children with sight and hearing loss were involved in the design of the new centre, helping to create a welcoming, comfortable environment that is fully accessible and easy to navigate. Features include a new welcoming arrival zone, artworks with sensory elements and a garden with plants that children can touch and smell.

The Sight and Sound Centre will hugely improve the patient and family experience, with improved space, shorter waiting times and a more relaxing environment.

Jess Gowing is one of the dispensing opticians at GOSH. Her role involves measuring, making, supplying and fitting glasses for all of the paediatric patients at GOSH, including those with unique head and facial characteristics where a standard pair of glasses is inappropriate.

"I am so excited about the new Sight and Sound Centre, especially our new Opticians room! Having a building dedicated to sight and sound will enable us to provide a service designed around our patient's specific needs. For example, low-level lighting so that it's not too bright for patients after they have had eye drops and a calm environment for children who have sensory issues. I think it will be a really lovely place for all the patients to come for their eye care."

The new centre has been made possible thanks to the extraordinary support of Premier Inn and Restaurants. Staff, guests and suppliers have fundraised across the country to ensure that children with sight and hearing loss are treated in an environment designed specifically for their needs and where they will feel at home.



The **sensory garden plans**, including plants the children can touch and smell



RESEARCH

Our research strategy focuses on the delivery of personalised medicine for children with rare and complex conditions. Along with our partner charity, Sparks, we have a passion and commitment to support paediatric research nationally.

This year, GOSH Charity has partnered with several other research charities and institutions to help strengthen its research offerings and help develop new treatments for children with rare and complex diseases everywhere.



THE NATIONAL CALL

By supporting the GOSH Charity and Sparks National Call – the UK's largest dedicated fund for child health research – you are helping us to develop life-changing treatments that travel from the laboratory bench to the children's bedside as efficiently and as safely as possible.

Of the £2.3 million pledged to support research into some of the most difficult and hard-to-treat childhood diseases, £183,000 has been made available by three condition-specific charities - the Norrie Disease Foundation, Dravet Syndrome UK, and the Myotubular Trust - to help co-fund research into these areas.

The successful projects include unravelling the drivers of aggressive childhood brain tumours; supporting the UK arm of a global clinical trial to test whether the breast cancer drug tamoxifen could help children with a rare and debilitating muscle disorder; exploration of a novel gene therapy to treat the devastating and life-limiting neurological condition Dravet syndrome, and developing an implantable and removable liver 'patch' that could hold the key to reducing toxic chemical levels in the blood of children with rare metabolic conditions.

Kiki Syrad, Director of Grants and Impact at GOSH Charity and Sparks, said:

"Collaboration in the field of rare disease research is of fundamental importance, so I am also delighted that GOSH Charity and Sparks have been able to partner with other rare disease charities through this funding call. We will achieve more together than we could alone and that is crucial if we're going to drive new, urgently needed ways to diagnose, treat and cure rare diseases that affect children."

11 new child health research projects funded

6 institutions across the UK

£2.3 million invested

RESEARCH PARTNERSHIPS

LIFEARC PARTNERSHIP WITH GOSH

GOSH has partnered with LifeArc in a £1 million grant, helping to support researchers to translate their findings into practical benefits for patients by delivering new therapeutics or diagnostics.

This year's funding covers projects from new gene editing techniques for blood disorders to novel treatments for neurodegenerative conditions.

Dr Karin Straathof, clinical scientist at Great Ormond Street Hospital UCL Institute of Child Health, is looking at how super-powered immune cells can help treat aggressive childhood brain tumours. Despite significant advances in cancer treatment, it is still the leading cause of death in children aged 1-14. The most life-threatening types are tumours in the brain and nervous system. These cancers kill around 80 children each year in the UK.

Among the most difficult brain tumours to treat are high grade gliomas (HGG), which grow into healthy tissue and are often impossible to remove surgically without damaging vitally important areas of the brain. One example is diffuse intrinsic pontine glioma (DIPG), a highly aggressive cancer diagnosed in around 30 children each year in the UK. Despite significant research into better treatments, the average survival for a child after diagnosis with DIPG is just 9-15 months.

One promising technique involves editing DNA inside the body's own immune cells, adding genetic instructions to recognise, hunt down and destroy cancer cells. These modified cells, known as CAR T, work by harnessing the natural defensive powers of our immune system. CAR T-therapy could offer long-term protection against cancer, because the immune system 'remembers' the instructions it is given.



Dr Karin Straathof.

Dr Straathof said:

"For some children, we currently have no treatments that can cure the cancer, which is utterly devastating for the child and their family. For others, we need to give them such intensive treatment – surgery, chemo, radiotherapy, antibody therapy – that they're left with significant short- and long-term side effects of treatment. And for some, despite all that treatment, the cancer comes back.

"To address these challenges, we're developing CAR T-therapy. First and foremost, to save more of these young lives. But also, because it's so targeted, we hope it will leave children free of health problems afterwards.

"We're working closely with colleagues treating children with leukaemia to understand how different cancers defend themselves against CAR T-therapy. Some of these challenges are the same, while others are unique to solid cancers, for example finding a way to ensure the CAR T-cells can reach all tumour areas and stick around long enough to clear all cancer cells."

This promising technique is being studied in multiple cancers, providing hope to some when few options are left.

INVESTMENT IN STAFF

We aim to make a real difference to the children that the hospital sees and treats, through investment in the people who care for them.



GOSH LEARNING ACADEMY

Education is the third pillar of GOSH's core mission, alongside research and care. On 1st September 2019, the GOSH Learning Academy (GLA) was launched. The aim is to be the first choice for multi-professional paediatric healthcare education, training and development for the whole workforce, utilising state-of-the-art technology in contemporary learning environments.

It offers 19 clinical modules, including highly specialist areas of care modules with our partnership hospitals, such as Haematopoietic Stem Cell Transplantation with the Royal Marsden Hospital and University College London Hospital, and Spinal and Orthopaedic Care with the Royal National Orthopaedic Hospital. Approximately 500 students have joined the academy to date.

CLINICAL APPRENTICESHIPS

GOSH aims to fund several clinical apprenticeships over the next five-year period, including:

- 20 undergraduate nurses
- 20 Nursing Associates
- 10 Allied Health Professionals
- 5 Advanced Clinical Practitioners

These posts will allow GOSH to keep pace with the national healthcare agenda, trail-blazing in piloting new national workforce models in collaboration with NHS England and NHS Health Education England.

ADVANCEMENTS IN LEARNING

A virtual learning environment is being developed with a dedicated digital education team to deliver cutting-edge e-learning and disseminate this to external healthcare professionals nationally and internationally.

With the aim to expand its current simulation programmes for clinical professionals, the GLA is embedding technologies such as augmented and virtual reality. This delivers a relevant, contemporary learning experience in support of a multi-disciplinary workforce.



Pre-registration or 'pre-reg' simulation is used to enhance and develop students' skills within a supported simulated clinical environment.



Gosh patient Yasir
with a play worker

SUPPORT SERVICES

At GOSH Charity we provide services to ease the burden on families, raise spirits, and support children and young people through life-changing treatment.

Whether it's through brightening up the hospital wards with art and live music from GOSH Arts, providing support and advice through our multi-faith chaplaincy service or ensuring parents can stay close to their child in our dedicated family accommodation, the charity remains committed to supporting the GOSH community.

SPOTLIGHT ON: THE PLAY TEAM

The Play team provides a therapeutic service with a core aim of reducing anxiety and improving co-operation with treatments and interventions. The team has implemented many new procedures within the last year.

The team communicates with the children about their care and treatment in a way that they understand. For example, demonstrations of medical procedures using toys, and tours of clinical areas to help children to prepare for treatment and surgery. Distraction therapies are also used, such as games and puzzles, to help a child cope with painful or difficult procedures.

Laura Walsh, Head of Play Services at GOSH, said:

"It's amazing sometimes to see a child who is quite nervous be transformed into somebody who is high-fiving the anaesthetists on the day – because they fully understand all the elements that are going to be there and happen to them."

48 Play workers and play Specialists

Approximately **500** children benefit each day from the extraordinary skills of the Play team

COLLABORATIONS: PLAYING TOGETHER

The Play team has set up some important partnerships, both within the hospital and with external collaborators for the benefit of children at GOSH.

The Play team works very closely with other service teams at the hospital, like GOSH Arts. One of the highlights of this partnership over the last year is a project that took place in one of the hospital's respiratory wards (Leopard), focused around 'Touch'. The Play team worked with GOSH Arts to facilitate a series of workshops with dance professionals to explore the idea of touch through physicality. As the team is embedded within the wards, it was able to help guide GOSH Arts on where the programme would be best received, and also to ensure contentious issues such as safeguarding and infectious control were addressed. The programme was a huge success.

Laura Walsh, Head of Play Services at GOSH, said

"I got this wave of feedback about how positive it had been. People would spontaneously burst into tears – it was so emotional and powerful"

The Play team also works closely with the learning disability team at The Children's Hospital School at Great Ormond Street, and has supported one Play worker to become Makaton trained to a level that they are now able to support the Trust to improve communication with all children at the hospital.

The Play team uses The Disney Reef with patients all the time and often hear from families how much it means to them that such an amazing resource exists at GOSH.

One of the most notable collaborations the Play team has been a part of is our partnership with Disney. Throughout the partnership Disney and the Play team have worked together to bring the magic of their stories to life in the hospital. Together we've sprinkled Disney's magic on the wards through film showings, fun activity packs and seasonal events. However, off the wards is the biggest show of the incredible collaboration between GOSH Charity, Disney and the NHS Trust - The Disney Reef. This amazing effort to improve the hospital environment for patients was recognised by winning the 'Best Collaborative Approach Gold Award' at the Corporate Engagement Awards 2019.



THE DIGITAL EVOLUTION

A young person at the DRIVE
GenerationR YPAG Health tech event

From filing cabinets to intelligent cloud storage, data storage and technology has evolved before our eyes. Capturing this opportunity, GOSH Charity made £37 million available for upgrading the hospital's technological data systems, helping to revolutionise diagnostic and treatment options and propel GOSH into the next stage of medical advancement.

The new electronic patient record (EPR); Epic - has a child and young person friendly portal- MyGOSH. Epic makes the lives of patients and their families easier by giving them the ability to book appointments online and access relevant information on their health and wellbeing.

GOSH also uses this data in their Digital Research, Informatics and Virtual Environments (DRIVE) Unit, with the aim to accelerate research and utilise cutting-edge technology to benefit patients' families and staff at GOSH.



YOUNG PEOPLE SHAPING HEALTHCARE AND TECHNOLOGY

In April 2019, the DRIVE unit ran a workshop with 25 young people to help digital researchers and industry engage with a diverse group to better understand how their technology and devices could be improved to better meet the needs of children and young adults.

During the day the group took part in interactive workshops of robots, virtual and augmented reality, gamification, mobile devices and apps, with DRIVE industry partners.

The young people attending were all part of Generation R, a network of National Institute for Health Research Young People's Advisory Groups (YPAGs) from different centres across the UK. They get actively involved in the design and delivery of research to ensure it is relevant for children, young people and their families.

The social robots being demoed included SOTA, who can respond to voice commands and be connected to blood pressure meters and other monitoring devices, and Jibo who is able to remember and build relationships with people.

"My favourite was the virtual reality. It could have lots of different uses like helping junior doctors. I thought it was the technology that was the closest to being ready for use," said GOSH YPAG member, 14-year-old Maryam.

ADVANCING RESEARCH THROUGH THE DIGITAL WORLD

The Aridhia Digital Research Environment (DRE) is a research platform supported by the DRIVE team. The DRE enables GOSH to capitalise on its digital developments and harness the power of health data to support and perform research studies.

The DRIVE team continues to build on its activities and has introduced the Aridhia DRE to staff across the trust and, using several other projects, have demonstrated the advantages of using the platform to capitalise on analytics, with the number of projects increasing from 51 in its first year, to 113 in its second year.

In addition, a PhD Fellow has been appointed to help develop a new tool to characterise lung disease severity.

Doctors often rely on a single measure of lung function to decide treatment and intervention for patients with lung disease. However, lung function alone is not the best way to describe how sick patients are. Understanding how different factors affect lung health is even more important now, since modern treatments focus on maintaining lung function in the normal range, yet children are still at risk of poor health.

This project plans to capitalise on the EPR system through GOSH-DRIVE, which provides an opportunity to collect and examine large amounts of data from a large number of children with cystic fibrosis, a type of lung disease, to better understand how multiple factors, in combination, affect their condition. The team will use a simple form of artificial intelligence to group patients with similar characteristics and track each patient over time. Based on these results, the team will use a web-based tool to develop a 'health score' to give to patients and their families, as well as the team of health professionals supporting them. This will provide a better overall measure of health – as opposed to lung function alone.

The implementation of a health score would promote a more personalised and focused approach to care. This kind of approach may also be transferable to other chronic respiratory diseases in children and young people.

The DRIVE team hope to continue to grow and support research across the Trust and capitalise on the healthcare data collected at GOSH through the newly implemented EPR System and improve the outcomes of children cared for at GOSH whilst supporting clinical trials.



GET IN TOUCH

Despite the challenging circumstances we find ourselves in, the charity will be working hard and adapting to the changing environment to keep supporting the incredible work that takes place in the hospital every day, to benefit the children and families who rely on its expert care.

Your support is more important than ever. There are so many ways you can help us continue to make a difference to the inspiring children, their families and the remarkable staff at the hospital. Whether you choose to take part in an event, fundraise for us, make a donation, or leave a gift in your Will – your support, however big or small, is helping to create a better future for seriously ill children at GOSH and around the world.

Do get in touch if you'd like to find out more how you can help further, we'd love to hear from you.

To make a one-off or regular gift, please visit gosh.org/donate or call **020 3841 3131**.

If you would like to discuss making a major gift please email philanthropy@gosh.org or call Rachel Hughes on **020 3841 3083**.

If you are thinking about leaving a gift in your Will please visit gosh.org/legacy or email legacy@gosh.org.

For corporate partnerships, such as employee fundraising and engagement, commercial opportunities or one-off events please contact: Corporate Partnerships companies@gosh.org.

To take part in one of our charity fundraising events, please visit gosh.org/events to find out more.

If you're interested in finding out more about our Special Events and Galas, please contact special.events@gosh.org.

GOSH patient **Tulsi** recieved delicate spinal surgery at Great Ormond Street Hospital within hours of being born.