

Summer 2015

lifeline



Great
Ormond
Street
Hospital
Charity

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Helping Herb and his family to fight infection

Hope for
children with
rare diseases,
thanks to you

How the care
continues when
our patients
grow up

Meet our guest editor...



Photograph by David Harrison

Hi! I'm Ezara-Mai and I'm 10.

I come to Great Ormond Street Hospital (GOSH) every four weeks for transfusions because I have a rare condition called juvenile dermatomyositis (JDM), which affects my muscles and skin. I know most of the staff in the Lagoon restaurant at the hospital. I love the food there!

I get very tired, especially around the time of my transfusions, but then I have three good weeks that I make the most of. I spend lots of time with my pet chihuahua Ezra, and I also like acting and dancing.

In this issue of *Lifeline* I interview the head of the lab that has extracted my DNA so that it can be examined and stored in a national database. The lab needs a DNA sequencer machine to do this, which GOSH is raising money for.

Because my condition is so rare, I was diagnosed quite late. Thanks to DNA sequencing, perhaps other children with JDM will get faster diagnosis and treatment in the future.

Ezara-Mai

Read Ezara-Mai's interview on p14

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 **Great Ormond Street Hospital**
Charity



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Lifeline online
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Thank you to Ezara-Mai for doing a great job as Guest Editor.

The children's drawings in the magazine were created by patients at the hospital.

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Thank you regular givers!

Regular gifts allow us to plan for the future because we know that we will have a steady income stream day in, day out. These gifts help us support four key fundraising areas:



1. Redevelopment projects in the past year include a new hospital reception. The

local council has also approved plans for the new Centre for Research into Rare Disease in Children, a brand new building in which scientists and doctors can work side-by-side, giving them space and equipment to learn more about rare diseases and discover new ways to diagnose, treat and potentially cure children (see page seven).



2. Fantastic research successes include gene therapy for immune diseases, safer pre-natal testing to avoid the risk of miscarriage, and avoiding antibiotic-associated deafness.



3. New equipment includes an ultrasound machine, modern X-ray equipment and advanced technology to create tailor-made nutrition formulae for sick babies and children.



4. Patient and family support ranges from financial advice and spiritual counselling to accommodation for parents.

Thanks again to all our donors who support us with a regular gift.

Want to set up a regular gift?

If you don't already make a regular monthly donation, find out how to set one up by visiting gosh.org/donate or call 020 7239 3131



News

Pet project brings wagging tails to wards

»» Canine companions are cheering up ever more patients and their families as the Pets As Therapy (PAT) scheme continues to grow. PAT dogs and their owners are crucial members of the volunteer team at Great Ormond Street Hospital (GOSH). The hospital first teamed up with PAT over two years ago.

Therapy dogs are trained to provide comfort and companionship to people in hospitals as well as hospices, retirement homes, nursing homes and special needs schools. Jamie Wilcox, Head of Volunteer Services at GOSH, said: “They play a significant part in the treatment of children who are physically, socially, emotionally or cognitively challenged, providing a welcome distraction from hospital life.”

Volunteer Judy and her dog Woof (pictured) have been coming to the hospital every week for over two years. Judy said: “You can see that Woof does an enormous amount of good – the psychological impact on the children is so great. When you see patients who have severe brain damage and they suddenly respond to an animal, that’s the most rewarding thing of all.”



PAT animals provide a welcome distraction from hospital life



Hospital open days hit the road

»»» Open day afternoon events will take place at the hospital on 7 September and 12 October for supporters who are leaving or considering a gift in their Will. However, if you can't make the trip to the hospital, our Legacy Development Manager, Judy Anderson (above), can bring the hospital to you through the talks she gives to community groups around the country.

Judy would be delighted to visit your group and talk about the history of the hospital, medical breakthroughs, future plans and our young patients' stories.

To register your interest in one of the hospital open days or to book a visit from Judy, call 020 7239 3205 or email legacy@gosh.org



“The best thing about summer is... catching crabs that bite Daddy’s finger!”
Finley, three





GOSH nurses help with Cravings

»»» Devices used for feeding children with severe gut problems are part of a new exhibition at the Science Museum in London.

The exhibition, called Cravings, explores how food affects our body, brain and eating habits. Around 40 children at any one time at Great Ormond Street Hospital are fed by 'total parental nutrition' (TPN), a formula that delivers nutrients straight to the bloodstream. Equipment used to deliver the formula features in the new gallery to help tell the story of a girl who was fed by TPN until she was 16 because most of her intestines were missing.

Lead Nurse Barbara Childs and Practice Educator

Clare Paley helped to prepare the equipment for public display. Clare said: "It's great that something that is used every day in the hospital and not many people know about is being shown to lots of people."

Cravings will run until
January 2016. Visit
sciencemuseum.org.uk
to find out more

Tell us what you think

»»» Did you notice the readers' survey that came with this issue of *Lifeline*? We want to ensure we are providing you with all the information you need about the hospital and the charity, as your views are really important to us.

By returning a completed survey you will be entered into the prize draw to win a one-night stay at The Marylebone Hotel London for two people*.

*Terms and conditions apply



Please spare a few minutes
of your time to complete
the survey. Thank you!

Talking to...



Talking to... Clare Paley, Flamingo Ward

“On Flamingo Ward, the hospital's Cardiac Intensive Care Unit, we have a number of children on total parental nutrition (TPN). Gut problems are common in children with heart defects.

“In these instances, you don't get the movement of nutrients needed and the gut starts to die off. That's a particular problem for newborns. TPN is delivered

intravenously and provides carbohydrates, glucose and electrolytes such as potassium and magnesium, which are important for cardiac function. The formula is tweaked every day by the TPN pharmacist.

“Many children are unlikely to need TPN for as long as the patient mentioned in the Science Museum, but it is interesting to see what the equipment is capable of.”

An honest account

Dollan Cannell, Series Producer and Co-Director of the third series of *Great Ormond Street*, airing on BBC Two this summer, explains the secrets behind making a great documentary

“The previous two series had an incredibly grown-up, mature attitude to what medical care in difficult circumstances involves. For the third series we wanted to preserve the raw honesty of the previous series but add a different dimension by bringing in more of the child’s voice. Doctors are seen wrestling with their own decision-making but you also see teenage patients who are old enough to be part of that process.

“As a producer, you look for children and families who are comfortable being filmed. Of course we film a lot more stories than we could ever use but we make this very clear to all the families that take part. Our priority was to capture the staff and families in a way that wasn’t sensationalist or exploitative.

“When you’re filming you get extremely close to the families and so you care hugely about what happens to their children. It’s really important that the programme is a true reflection of everything they’ve gone through. It has been an incredible privilege to witness such high-stake situations. You just hope you can do their stories justice.”

Read about six-year-old Herb, who features in the documentary, on page eight



Producer Dollan Cannell: “It’s really important that the programme is a true reflection of everything the families have gone through”

New expertise



Two new experienced and accomplished clinical leaders have just joined the executive team at Great Ormond Street Hospital.



Juliette Greenwood, from Bradford Teaching Hospitals NHS Foundation Trust, has joined as Chief Nurse. Dr Vin Diwakar, Medical Director

of Birmingham Children’s Hospital, has been appointed as Medical Director.

Dr Peter Steer, the hospital’s Chief Executive, said: “Juliette and Vin bring an enormous breadth of clinical and educational experience to the hospital. They join us at a critical time when there are both huge opportunities and huge challenges across the NHS.”

Roll up for the raffle!



Thank you to everyone who took part in this year’s Spring Raffle.

Since the raffle programme launched in March 2011, you have helped us raise more than £1.75 million!

We have two draws a year and tickets for the next raffle will be available from 7 September until 19 November 2015. There are more than 20 prizes to be won, with a top prize of £5,000!

If you would rather opt out of a chance to receive our raffle appeal, please contact us (details below).

To find out more, please call Supporter Services on 020 7239 3131 or visit www.raffleentry.org.uk/gosh

Rare disease centre one step closer to reality

The partnership between Great Ormond Street Hospital (GOSH) and University College London (UCL) will bring hope to children and families affected by rare and complex diseases

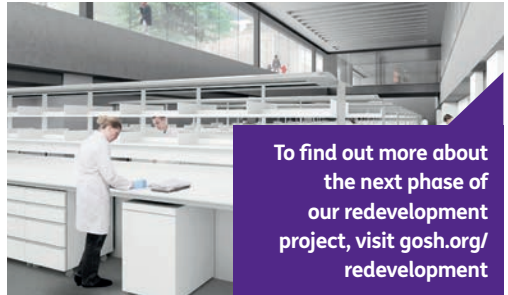
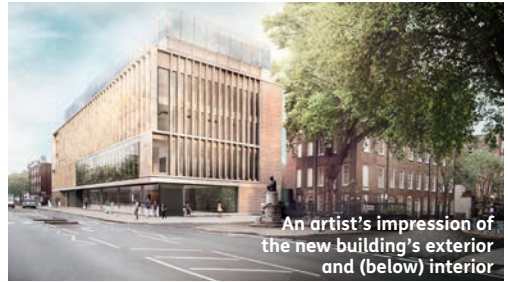
The next phase of Great Ormond Street Hospital's redevelopment project has been given the green light.

Councillors approved plans for the Centre for Research into Rare Disease in Children earlier this year. The new centre will enable clinicians and researchers to advance our understanding of rare diseases, identifying new and better treatments.

"Thirty per cent of children with rare diseases die before their fifth birthday"

There are at least 6,000 rare diseases, and three quarters of these affect children. Thirty per cent of children with rare diseases die before their fifth birthday, so the new centre is vital to saving lives.

The centre is a partnership between GOSH and UCL. It will cost £90 million, which has been met principally by a gift of £60 million from Her Highness Sheikha Fatima bint Mubarak, the wife of the late Sheikh Zayed bin Sultan Al Nahyan, founder of the United Arab Emirates. A further £20 million will come from the charity and £10 million from the Higher Education Funding Council for England's



Research Partnership Investment Fund.

Paediatric Consultant Immunologist Professor Bobby Gaspar, the centre's Director Designate, said: "This is a significant milestone towards our vision to create a facility that will offer a beacon of hope to children and families affected by rare disease. Together Great Ormond Street Hospital and the UCL Institute of Child Health see one of the largest patient cohorts for rare disease in the world. Our combination of specialist expertise and a diverse patient population puts us in a unique position to harness new discoveries and ensure that patients start benefiting from them as quickly as possible."

“The best thing about summer is... going on trips and playing in the park”
Solyse, 10



Finding NEMO

Getting a definitive diagnosis for Herb's rare disease wasn't easy – and later brought unexpected news for sister Lily...



“We’d had no major issues with our first three children – twins Lily and Kitty, and Rufus,” says mum Emily. “Then in 2010, at 13 months old, our fourth child Herbie contracted meningitis. Almost a year later, he had what we thought was a chesty cold, but it was actually a collapsed lung. We were stunned.”

Due to the severity of the infections, Herb’s local hospital, The John Radcliffe in Oxford, started investigating whether there was an underlying immune deficiency. They called on the expertise of Great Ormond Street Hospital’s Dr Alison Jones, who was running a joint clinic at the hospital.

In December 2012, Herb was diagnosed with NEMO, a rare genetic disease that can cause infections and affect skin, teeth and hair. “There were question marks along the way so the diagnosis took two years. He had a gene mutation never cited before,” says Emily. In the future, delays like this could be reduced thanks to the new Centre for Research into Rare Disease in Children (see page seven) and equipment such as DNA sequencing machines (see pages 12-15), which can identify and categorise gene mutations like Herb’s for doctors’ future reference.

Herb had immunoglobulin replacement

therapy – a blood infusion which provides antibodies needed to fight infection – and for a while “things were ticking along nicely”, says Emily. Then in 2013, sister Lily, then ten years old, became very ill: “Lily is a twin and had been the bigger of the two, but she became skinny and wouldn’t eat. At first the doctor thought she had asthma and gave her an inhaler. Lily said it was making her better but we found out later that, because of Herbie, she

“Because of Herbie, Lily didn’t want to burden us”

didn’t want to burden us. She was secretly being sick as she couldn’t get enough air in her lungs.”

In May 2013, a chest X-ray at the local hospital showed Lily had severe lung disease. After various tests, like Herb, she was diagnosed with NEMO, almost unheard of in girls. Emily says: “Lily spent a week at GOSH on Robin Ward. They put her on immunoglobulin therapy like Herbie and she started to improve. She was transferred back to local care but we were told it was likely she would need a bone marrow transplant soon to replace her faulty immune cells.”

Siblings Rufus, six, and Lily’s twin sister Kitty were tested and it transpired that Rufus was a match for Herb – but not for Lily. →



Herb at GOSH with sister Lily



Robin Ward

Immunology & infectious diseases

90

transplant procedures carried out by GOSH each year



Rufus (left) pressed the button to start Herbie's transfusion

Emily says: "At that point Herbie didn't need a transplant. It was Lily who was ill."

After several months of treatment, Lily finally started to get better and in autumn 2013, Herb started school. Then in November, Lily got a pneumothorax (air trapped next to her lung) and was rushed into hospital. "The same day, Herbie was having uncontrollable temperatures. Lily recovered but tests showed that Herbie had the start of a type of tuberculosis."

By January 2014 it became clear that Herb, then five, needed a bone marrow transplant as soon as possible. Emily says: "Knowing that Rufus was a match was a bittersweet moment – he was only six. We told him that to make Herbie better we needed a superhero – and he said, 'I can do it!'. He was nervous but Professor Paul Veys from the Bone Marrow Transplant Unit made it seem very child friendly and much less scary even for us!"

The transplant took place in May 2014 and Herb spent 10 weeks on Robin Ward. Emily says: "The staff are so caring and friendly. Herbie was first and foremost in their minds but they would always ask about the other

"We can see the Herbie we knew"

children and make sure I was OK too."

The family agreed to take part in the BBC's *Great Ormond Street* documentary series (see page six). "They filmed us for 10 weeks. We thought it was important that the ups and the downs were shown. Anything that raises awareness of immune problems and the work of the hospital is worth being involved in."

Herb is now doing well, Emily says. "There's still a lot of care but we can see the Herbie we knew prior to him becoming ill. The bone marrow transplant is still on hold for Lily, but both she and Herb are seen regularly at GOSH. To have a whole centre dedicated to rare disease research (see page seven) will be fantastic for our children and our children's children."

Donate now!

To make a donation to the summer appeal to help fund a DNA sequencer machine call **020 7239 3131** or visit **gosh.org/donate**



"They made it seem child friendly and much less scary"



Superhero brother Rufus to the rescue: "I can do it!"



Celebrate and Donate

**“Great Ormond Street Hospital
changed my life forever”**

– Chris, 72, former patient

Your big day can make a massive difference.

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**Celebrate and Donate,
it's a piece of cake.**

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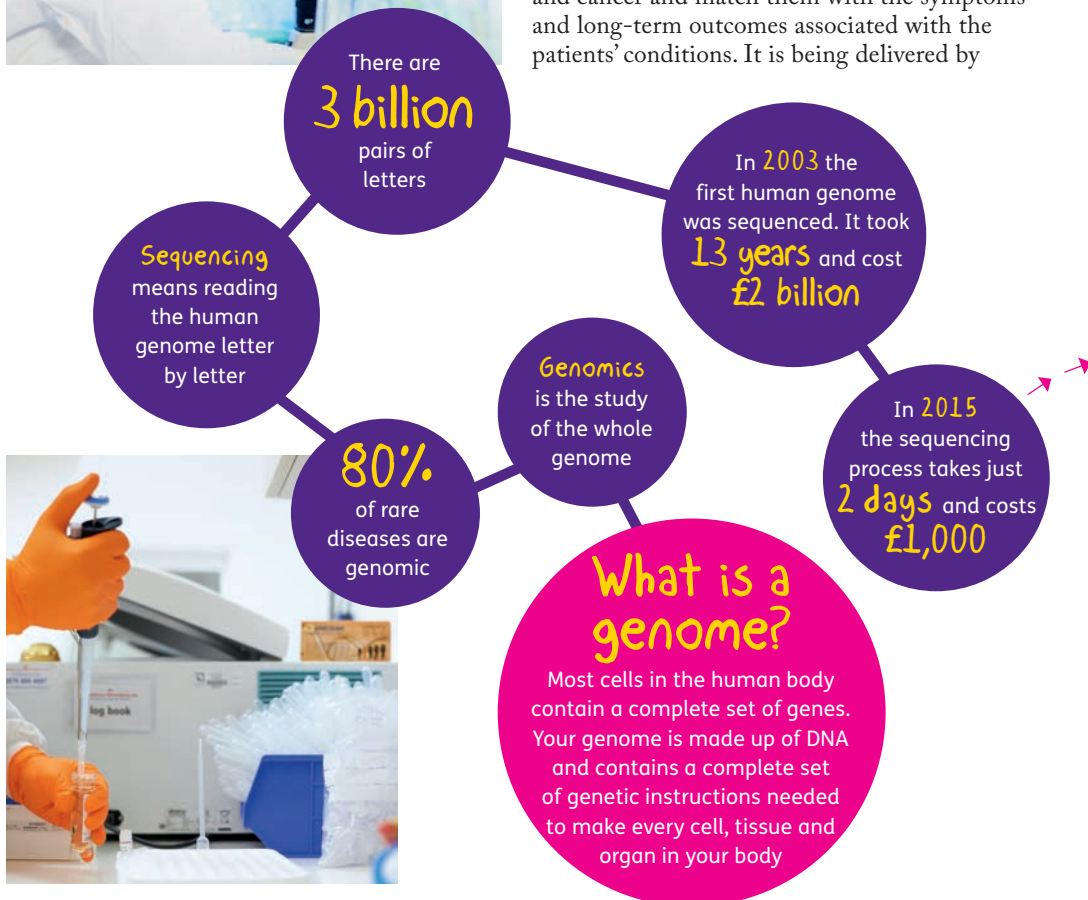
Genomics at forefront of

Great Ormond Street Hospital named as key centre in 100,000 Genomes Project



Great Ormond Street Hospital (GOSH) is set to play a lead role in co-ordinating a network of hospitals involved in sequencing 100,000 whole genomes from NHS patients by 2017.

The ultimate aim of the 100,000 Genomes Project – the first of its kind in the world – is to help researchers and clinicians better understand, and ultimately treat, rare and inherited diseases and cancers. The project will collect and analyse genetic samples from patients with rare diseases and cancer and match them with the symptoms and long-term outcomes associated with the patients' conditions. It is being delivered by



rare disease research

Genomics England, a company wholly owned and funded by the Department of Health.

GOSH is the centre responsible for co-ordinating the recruitment of patients on to the project through the newly formed North Thames Genomic Medicine Centre.

The hospital, alongside NHS hospitals and foundation trust partners from across London, will provide blood samples ready for genetic analysis. Specific groups of patients and families at GOSH will be eligible to take part in the project and will be identified and approached for consent by clinicians before they attend appointments. Information will

then be sent to families and the project will be discussed in more detail when attending clinics.

Our summer appeal has been launched to fund a new DNA sequencing machine and contribute to the vital role of genomic medicine in developing better diagnosis and treatment. Visit gosh.org/donate to make a donation.

Find out more about genomes in the infographic below – and turn the page to see how this research could help children who, like our Guest Editor Ezara-Mai, have rare conditions

The 100,000 Genomes Project

There is now an opportunity to turn these scientific discoveries into a potentially life-saving reality for NHS patients

Patients

with rare diseases and cancer are identified and approached and their consent sought

Information

including sequenced DNA and details of illness is gathered and analysed

Results

of the analysis are sent to the patient's doctor and to a secure genome reading library

Leading to...

quicker diagnoses and better medicine

Genomic data from patients

is analysed to identify common trends and help make diagnoses

Why DNA really matters

“Hi, I’m Ezara-Mai, Guest Editor of this issue of *Lifeline*. I’m asking Lucy Jenkins, Head of Service for Molecular Genetics, about rare disease and why the hospital needs a new DNA sequencing machine to help with its research”

Q What do you do in the lab where you work?

I’m the director of this lab and here we test people’s DNA to see what genetic changes they might have that caused their disease.

Q Why is Great Ormond Street Hospital (GOSH) such an extraordinary place?

GOSH is special because we care for children who have some very rare conditions. So in a lab like this where we specialise in testing for rare diseases, we get to see if we can help them by looking at their DNA.

Q My DNA has been processed at your lab. What is going to happen to it?

Yes, we’ve extracted the DNA from a blood sample you gave us. Your DNA will be stored here safely, but we’re going to send part of it away to a facility where it will be sequenced as part of the 100,000 Genomes Project (see page 12).

Q Why do you need a new DNA sequencing machine?

In every cell in your body there are three billion bases of DNA and we need to be able to look at all of those to find out genetic differences.



We need a machine of immense power to be able to sequence all these bases.

Q How much will this cost and where will the money come from?

The machine itself costs £471,000, so it’s quite expensive. We’re very lucky that the hospital has the charity, which raises a lot of money, so when a piece of equipment like this is needed, they can help us buy it so we can provide the tests we do.

Q How rare is my condition, JDM?

I understand that of a million children born, only three would have juvenile dermatomyositis (JDM). It’s very, very rare.

Q How many different rare and genetic conditions do you know about?

We’re developing a new test for 5,000 genes, so that will be 5,000 different genetic conditions we can look at in one go.



Watch it online

gosh.org/lifeline



Q What do you like about your job?

I like my job because it's always changing. Genetic technology and the research that goes on means that there are always new things to learn, new things to test for and new ways to help people – this year we're developing the new test for 5,000 genes and we're also helping out with the 100,000 Genomes Project. Next year there'll be something new again. It's a very fast-paced field.

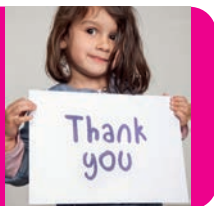
“We want to know the genetic cause of every child's condition”

Q What's your greatest hope for the future?

It would be nice if every child that came to GOSH could have their DNA taken and stored in a lab like this, and sequenced so that we know the genetic cause of everybody's condition.

Donate now

To make a donation to the summer appeal to help fund the DNA sequencer machine call **020 7239 3131** or visit **gosh.org/donate**



Talking to...

Lorna, Ezara-Mai's mum

“ Ezara-Mai developed a rash on her hands, ankles and knees when she was four years old. She had just begun horse riding so I thought she was allergic to horses, but the rash spread to her face and her hair became limp and fine. She was clingy and tired and wanted me to carry her everywhere.

“She was referred to a dermatologist and was initially diagnosed with psoriasis. But within another year she was almost immobile. We went back to the dermatologist, who investigated Ezara-Mai's continuing symptoms and told us that she may have a condition called juvenile dermatomyositis (JDM). The condition is so rare he had never seen it before – that's when I knew how serious it was. We were referred to GOSH and it was such a relief because they knew all about the condition and had experience treating it.

“Once Ezara-Mai started infusions we saw an improvement within days. In the early days I couldn't even pronounce the condition properly, although Ezara-Mai could. It's so rare that no one has heard of it and it can be frustrating having to explain it all the time. But Ezara-Mai is very positive and her school has been amazing. She went on a school trip to France recently and the teachers really looked after her. She really enjoyed it and I was very proud of her to do that.”

Find out more about our new Centre for Research into Rare Disease in Children on page seven



Teenager Mark recently returned to Bear Ward for his regular check-up. His family told us why he has needed the care of Great Ormond Street Hospital for the past nine years

Growing up with GOSH



Bear Ward

Cardiac low & high dependency unit

550

open heart operations are performed at GOSH every year

"My husband Bryn had a stroke on Christmas Day 2006," says Mark's mum, Michelle. "Then three months later, Mark, who was eight, was showing similar symptoms."

A blood test at the local hospital showed Mark had dangerously high cholesterol.

"It was 18.4, which is really high in a child, considering in a healthy adult it should be under five," remembers Michelle.

Mark was transferred to the metabolic unit at Great Ormond Street Hospital (GOSH) as an outpatient and put on medication. The family was later genetically tested, which confirmed they all have the genetic disorder familial hypercholesterolemia.

When the unit first examined Mark, they also discovered he had a heart murmur and referred him to the cardiology unit. A scan revealed a leaky aortic valve. Michelle says: "It wasn't major so GOSH weren't too worried but they scanned his heart every year. Then in 2012, when Mark was 14, the scan showed a narrowing of his aortic chamber – it looked like an hour glass. GOSH hadn't seen this before in a child."

In the following 12 months Mark's health deteriorated very quickly: "He had shortness of breath and chest pain," says Michelle. "But he

has a high pain threshold and doesn't make a big deal of things – so he went on a geography trip to Wales."

"I was too tough for my own good," says Mark. He was due at GOSH soon afterwards and by then his condition had gone from severe

"We had every confidence in GOSH"

to critical. Just walking to school was a problem. Dad Bryn says: "They told us Mark wasn't to do any cardiovascular activity whatsoever – we'd just sent him up Snowdon!"

The family was advised that Mark would need open-heart surgery to widen the narrowing. "They said that without it Mark had a five per cent chance of reaching his 18th birthday," says Michelle. "It was like the rug had been pulled from under my feet. But we had every confidence in GOSH."

Bryn adds: "In the seven years leading up to the operation, we had built up so much trust. We were in the best place in the world."

Mark's operation was on New Year's Eve 2013. It took nearly five hours, which Michelle describes as "the longest five hours of our lives".

But everything went well and an hour later, Mark was recovering on Flamingo Ward, the Cardiac Intensive Care Unit.

"I expected to be a bit shocked seeing Mark in the intensive care unit," says Michelle, "but the Clinical Nurse Specialist Lyndsay-Kay Leaver and all the nurses prepared us so well that it didn't seem that way." Two days later, Mark was transferred to Bear Ward. →

Mark, aged 10, living with his condition.

By 15, open-heart surgery was the only option (below)





What next?

Mark will eventually need treatment for his leaky aortic valve and although he is currently still under the care of Great Ormond Street Hospital (GOSH), next April he turns 18. So what happens then?

"Mark has been coming to GOSH for half his life. It seems strange that it's coming to an end," says dad Bryn. "But he is now transferring to St Bartholomew's Hospital. Over the past year, a doctor from Barts has sat in on our appointments at GOSH to get a feel for Mark. That level of handover between the different hospitals is so reassuring."

Mum Michelle adds: "It's the same surgical team, so you have that continuity. He will always be in the best hands."

To find out more about how patients are prepared for adult health services, visit gosh.nhs.uk/transition

"I had my own room and the food was actually very nice," he says. Michelle slept in the room on a sofa bed and they spent a lot of time playing cards. "I didn't let Mum sleep!" says Mark. "But it hurt to laugh..."

While Mark was on Bear Ward, the nurses from Flamingo came up at the end of their shift to see him. "The level of care was amazing," says Michelle.

Five days after the operation, Mark was able to go home and three weeks after surgery he

"The staff are second to none and we are eternally grateful"

was back at school. "The worst thing was that I wasn't allowed to play football – and I'd just got new boots."

Mark still needs medication for his cholesterol and regular apheresis, a procedure that filters the blood. It needs to be done every two weeks at Harefield Hospital and is expected to continue for the rest of his life.

In spite of everything, Mark passed the GCSEs he needed to go on to college to study IT. "I feel much better now," he says. "I can play football and I'm taking driving lessons."

Bryn jokes: "He's even started doing some washing up at home!"

Mark is now on a six-monthly check-up at GOSH for his heart and Michelle says: "Without Great Ormond Street Hospital, Mark wouldn't be here today. The staff are second to none and we are eternally grateful."

The family organised a charity night in August 2014 and raised nearly £3,000. Bryn says: "We'll continue to fundraise – but we're never going to be able to pay back this place. It's been fantastic."

Donate now!

If you would like to make a donation, please visit gosh.org/donate or call Supporter Services on 020 7239 3131



Fantastic fundraisers

A BIG THANK YOU to everyone who has donated, spread the word, baked a cake, run a race, or done anything in aid of Great Ormond Street Hospital Children's Charity. We can't include all of you, but here are some of the highlights, plus some upcoming fundraising events and ideas...

Kindness of strangers

Former GOSH patient Elena, Guest Editor of Lifeline in 2012, is taking part in our seven-day Iceland Trek this July. Elena reached her fundraising target of £3,000 in May. Here she talks about one of the fantastic donations she received

"I was not supposed to be in London on that Tuesday. My best friend had persuaded me to stay. I went about the day, visiting my favourite spots, when I suddenly decided go to Great Ormond Street Hospital to see a couple of the nurses. Luckily one of them was in.

"She introduced me to this lady whose daughter was

undergoing craniofacial surgery like I had eight years ago. I was talking to her about my experiences with the process. I also spoke about the Iceland Trek.

"I only spoke to this lady for about 10 to 15 minutes and gave her my email address. When people say they would like to donate, you are grateful, but whether they live up to what they say is another matter.

"She gave me £200! When the email came through from JustGiving I thought my eyes needed checking. I am overjoyed by this donation and I'm keeping in regular contact

with this lovely lady and her daughter."

"I am overwhelmed with the kindness that people have shown by donating their hard-earned money to the hospital. It gives me great pride in knowing that as an ex-patient this money will benefit children in need of specialist care.

"I plan to do as many challenge events as possible in the future. GOSH drastically benefited my life and anything I can do to help raise money, awareness and the profile of the hospital is an action I'd take without second thought."



Elena at an event she organised, which raised £1,300



“The best thing about summer is... not having to go to school!”
Cathal, 12



For more information on our range of challenge events, visit gosh.org/challenges

If you wish to support Elena taking part in the Iceland Trek visit justgiving.com/Elena-May-Reading

A Brighter Future for Team Jude

David Taylor tells us about keeping his son's memory alive through The Jude Taylor Brighter Future Fund and Team Jude

***“Jude was born in April 2014 with a rare condition called hypoplastic left heart syndrome, meaning he essentially had half a heart. He was rushed to Great Ormond Street Hospital (GOSH) and underwent open heart surgery at just five days old.

“Though Jude’s operation was a success, his condition deteriorated. His heart was just too tired and on 28 April 2014, Jude passed away in my wife’s arms, peaceful and pain free.

“We miss Jude every second of every day, but his courage and bravery are an inspiration. The care Jude and my family received at GOSH was out of this world.

“Opening The Jude Taylor Brighter Future Fund in October 2014 was the perfect way for us to give something back. We wanted his fund to help other children like him. Our aim is to raise £17,000 to buy a new portable X-ray machine for Flamingo Ward, the Cardiac Intensive Care Unit where he was treated.

“The ever-growing Team Jude currently has 28 members, all taking on challenges. I started my fundraising by doing the Cromer Boxing Day five-mile run and North Sea dip! So far, we have raised more than £16,000.

“Fundraising has given me a focus and it feels great that it keeps Jude’s memory alive. Nothing will mend our broken hearts, but by giving, spreading the word and raising as much as we can for this amazing hospital, we will help other children and families like us in his memory.”

To learn more about our Brighter Future Funds visit gosh.org/bff or call the team on 020 7239 3002



David (left) with wife Mary and son Elliot

Every little (sleepsuit) helps!

*** F&F has launched its first ever range of premature baby clothes, in support of Great Ormond Street Hospital. The range has been in selected Tesco stores across the UK since 27 April 2015, and will raise vital funds to support the lifesaving work of the hospital’s Neonatal and Paediatric Intensive Care Units.

The stylish and affordable range includes packs of sleepsuits, bodysuits, cover-up and bottom sets and gift sets in sizes 3lbs, 4lbs and 5lbs, priced £6-£9, with at least 60p from the sale price of each product being donated to the charity.



A willing donor

Ronald leaves a valuable gift

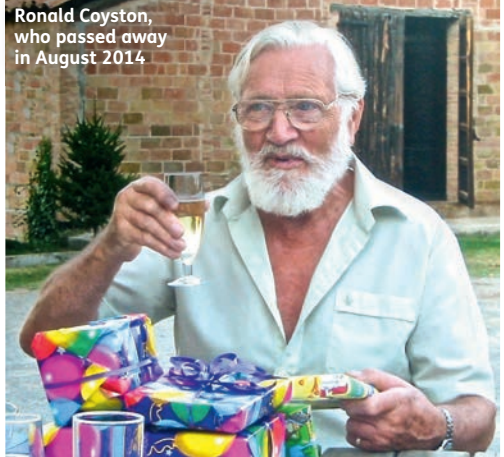
>>>The grandfather of a former Great Ormond Street Hospital (GOSH) patient has left a sizeable legacy that will benefit children at the hospital for years to come. Ronald Coyston, who died last August, was so impressed with the care when his grandson Nicholas was being treated at GOSH in 1997 for non-Hodgkin T-cell lymphoma, he decided to leave a donation in his Will.

“Ronald was so impressed with the care at GOSH, he left a donation in his will”

His desire to leave a legacy to the medical community also extended to his own body, which he donated to a medical school. This, his family says, was typical behaviour for this strong-willed and generous man.

Ronald was 88 when he died, leaving behind an extended, loving family and many friends made during a distinguished career as a pilot.

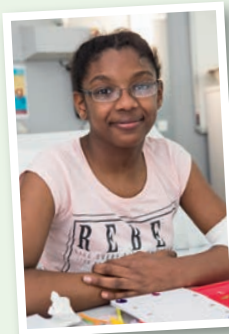
Ronald Coyston, who passed away in August 2014



If you would like to arrange to talk in confidence about leaving a gift of any size in your Will, email legacy@gosh.org or call the Legacy Team on 020 7239 3105. The team is also running open days at the hospital on 7 September and 12 October 2015. See our news story on page four for more information



“ The best thing about summer is... eating ice lollies ”
Theo, six



“ The best thing about summer is... all the fun things we can do outside ”
Iara, 10

The best gift you can make

Former patient Faiza is a volunteer at GOSH and also asked for donations to the charity instead of gifts for her 21st birthday

“When I was one week old, my GP found a problem with my heart and I was transferred to Great Ormond Street Hospital (GOSH),” Faiza said. “I was diagnosed with a complex form of congenital heart disease and had treatment and operations at the hospital throughout my childhood. I wouldn’t be here today without the hospital.

“I celebrated my 21st birthday for GOSH by asking people to make a donation if they could instead of buying me presents. It’s easy and anyone can do it. I asked my friends to have a place in their hearts for GOSH and donate instead of buying me a gift, because this is the best gift you could give.

“The hospital is such an amazing place. I always felt the nurses cared about me. The doctors spoke directly to me – which made such a difference. The staff are world class. You’re



treated like a normal person, not made to feel like that special child that’s got all the problems.

“I want to do anything I can to help raise money for the charity, because they saved my life. You can see where the money goes – the transformation of the hospital over the last few years has been amazing. So I’d encourage everyone who has a birthday or celebration coming up to consider asking for donations to GOSH. It can make an incredible difference for children who are patients at the hospital just like I was.”

To find out more, visit
gosh.org/celebrate
or call
020 7239 3002

Thanks to you!

“We’d like to say a big thank you to our generous supporters who contributed to the success of our fundraising appeals throughout the past year.

Thousands of you responded to the Christmas Stocking Appeal in 2014 with heart-warming festive messages and donations totalling more than £1.2 million!

Speaking of hearts, the

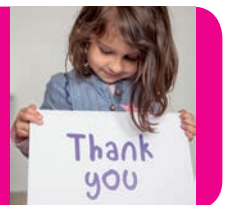


Valentine’s Appeal 2015 was also a huge success, raising over £420,000. The money raised has funded a new state-of-the-art heart and lung bypass machine to help treat hundreds more children who need open heart surgery. Once again, thank you for your continued support.



Donate now!

If you would like to make a donation, please visit
gosh.org/donate or call
Supporter Services on
020 7239 3131



Get involved

If you're ready for a challenge, how about signing up for one of these fundraising events?

Kilimanjaro Trek 11–21 February 2016

Trek to the top of the world's tallest free-standing mountain and take in the sights of the African plains. Visit gosh.org/kilimanjaro

UK Trek Series Various dates

Put your fitness to the test in our 25, 50 or 100km endurance challenges across the beautiful English countryside. Visit gosh.org/uktrek

London to Paris July 2016

Join us for the cycling challenge of a lifetime. Visit gosh.org/london2paris

Skydiving Various dates

Experience the rush of freefalling from 12,000ft at 120mph. Visit gosh.org/skydive

Brighton Half Marathon 28 February 2016

Take in the sea air as you run along the cliffs and past the iconic sights. Visit gosh.org/brightonhalf



Find out about more exciting challenge events online

Visit: gosh.org/challenges
Call: 020 7239 3164
Email: challenges@gosh.org

Have you seen our breakthrough guides?



Our guides give a unique insight into our pioneering research developments through time.

If you would like to request a copy of one of these guides, please contact our Supporter Services team on 020 7239 3131, email supporter.care@gosh.org or write to Supporter Services, Great Ormond Street Hospital Children's Charity, 40 Bernard Street, London WC1N 1LE.





Great
Ormond
Street
Hospital
Charity

Shop at GOSH this summer!

By buying gifts from our online shop, you are helping support thousands of sick children in the hospital's care.



We have hand-picked a fabulous range of gifts ideas for you this Summer. Visit our online shop www.gosh.org/shop to see the fabulous range selection of **excellent quality** and **great value** gifts and GOSH favourites.

100 per cent of the profits from all of your purchases go to the hospital, so by buying items from our online shop, you are helping many of the children cared for at Great Ormond Street Hospital **to get better and get home.**

Happy shopping!

