

# Impact Report 2011/12

The child first and always





# Our mission

We raise money to enable Great Ormond Street Hospital to provide world-class care for its young patients and their families, and to pioneer new treatments and cures for childhood illnesses.

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Cover: Kyrio is six years old and has a condition called osteogenesis imperfecta. He visits Great Ormond Street Hospital every three months and stays on Kingfisher Ward. He was feeling very cheeky today and would only have his picture taken if his mum agreed to buy him some toys!

Left: Sydney is seven years old and was born with her bladder outside of her body. She was transferred to Great Ormond Street Hospital and had her first operation at just one day old. Sydney is now thriving – she is in year three at school, loves arts and crafts, and has just returned from Brownie camp!



## A letter from our Chief Executive

2011/12 was always going to be a very important year for us as we celebrated the hospital's 160th birthday and opened the new Morgan Stanley Clinical Building. This building has been made possible thanks to the generosity of so many supporters and we are extremely grateful to all of you.

Many of you will know that this building has been years in the planning, and it was wonderful to see it transform from designs on a page into a fully operational clinical building, where patients are able to receive world-class clinical care in modern and comfortable facilities. The new wards are bright and welcoming and are making a huge difference to the families who use them.

This is the first building within the Mittal Children's Medical Centre and we are now turning our attention to the second building which is planned for completion at the end of 2016. The next part of the centre will see the top floors of the existing Cardiac Wing of the hospital come down and be completely rebuilt to provide additional much-needed inpatient wards and operating theatres. The wards and theatres will be on the same level as the Morgan Stanley Clinical Building to enable teams to work more effectively together.

As well as providing much better facilities for patients, families and staff, the completed Mittal Children's Medical Centre will enable the hospital to treat up to 20 per cent more children.

This was always one of the most important aims of the project as there is increasing demand for the hospital's services with the move within the NHS to concentrate specialist healthcare into fewer, larger centres.

In this report, you'll also find out how the generosity of our supporters has enabled us to fund some important new paediatric

medical research. The hospital works in partnership with the UCL Institute of Child Health to form the largest children's research centre outside North America. This partnership is incredibly important because it means that the work undertaken in university laboratories can be translated faster into clinical trials at the hospital. Many of the doctors who work at the hospital also hold honorary positions at the Institute and vice versa.

While the majority of the charity's research funding goes to the Institute and the hospital, we have also started to fund projects elsewhere in the UK, where the research being undertaken will benefit patients at Great Ormond Street Hospital and more widely.

The charity also funds a wide range of medical equipment that would not be affordable under the NHS. It allows the hospital teams to keep up with the latest advances in medical technology and also means that outdated equipment can be replaced. We have included a few examples in this report.

Welfare is the fourth major funding requirement that the charity is able to support. This includes family accommodation close to the hospital, but also extends to other projects which support patients and particularly mums and dads, who have to be strong during very difficult times.

We are incredibly grateful to all of you who have supported the charity this year. Your gifts have allowed us to celebrate the opening of our new building and enabled the hospital to continue its world-class work.

**Tim Johnson**  
Chief Executive

George is 10 years old and was admitted to Great Ormond Street Hospital after suffering a stroke and losing movement in the left-hand side of his body. After further investigation, tumours were found on his heart and lungs. He started a high-dose course of chemotherapy soon after admission, and is currently awaiting the results of an MRI scan.





# What we raised

### What we raised

In 2011/12, the charity’s total income reached £66.3 million, 3.8 per cent ahead of the previous year’s record performance. As a result of this, we remain well-placed to continue supporting the hospital in its plans for the future.

### Financial review

The overall growth in our income was driven by an increase in our voluntary income, which grew by 6.8 per cent to £57 million. This achievement is due to the generosity of everyone who made a gift to the charity last year and reflects strong performances across all of our fundraising teams.

During the year, the number of people who make regular gifts to the charity increased, enabling us to plan for the future with greater certainty of income. We were also grateful for the number of corporate partners who generously supported us, together with the outstanding support of major donors, trusts and foundations. Such gifts have enabled us to launch a national research call for children’s cancer, and establish Europe’s first Centre for Birth Defects Research.

The charity spent £18.9 million on charitable activities during the year (2010/11: £39 million). This reported spend figure follows a write-back of £10 million on the grant of £110 million originally awarded to fund Phase 2A of the hospital redevelopment, due to the successful management of this project.

Iona, age six, has hip dysplasia. She has been at Great Ormond Street Hospital for one week, but is awaiting a transfer to her local hospital.

The tables on this page show where our funding came from in the past year, and how we used it to benefit the patients at the hospital. The funds raised but not spent during the year are critical to our committed expenditure on the hospital’s redevelopment programme.

The principal funding sources of the charity are shown below, with comparison to the previous year:

Income sources 2011/12		
	2011/12 £ million	2010/11 £ million
Donations	45.5	42.6
Legacies	11.5	10.8
Trading	2.4	2.6
Other*	2.0	2.6
<b>Fundraising income</b>	<b>61.4</b>	<b>58.6</b>
Investments	3.4	3.7
Property	1.5	1.6
<b>Total</b>	<b>66.3</b>	<b>63.9</b>

\*Other includes grants, auctions, tickets and sponsorship

Expenditure for the year totalled £35.1 million (2011/12: £54.7 million), with £18.9 million being spent on charitable activities as follows:

Charitable expenditure 2011/12		
	2011/12 £ million	2010/11 £ million
Redevelopment	(9.6)	3.8
Research	12.3	18.2
Medical equipment and capital schemes	10.2	11.2
Patient and staff welfare	4.9	3.9
Accommodation and other	1.1	1.9
<b>Total</b>	<b>18.9</b>	<b>39.0</b>



# Objective 1 – redevelopment

In order to maintain and advance our position as a world-class centre for paediatric care and research, we desperately need to upgrade our oldest buildings and create additional space to enable more children to be treated.

Our four-phase redevelopment programme aims to rebuild two-thirds of the hospital site over a 20-year period. The first phase was completed in 2006, and we are now working on the second. This is the largest and most ambitious phase, and it will transform clinical inpatient facilities for many of the children we look after.

How the Mittal Children’s Medical Centre will look on completion in 2016.

**Phase 2**  
The second phase of the redevelopment will see the construction of the Mittal Children’s Medical Centre, which will contain two important new clinical buildings and enable the hospital to treat up to 20 per cent more children. Situated at the heart of the hospital site, it will become the pivotal clinical centre. Our aim is to create a dynamic environment that enables us to adapt to the increasingly complex healthcare needs of children with rare disorders, and speed up on-site translational research, bringing real benefits for patients. The new centre will deliver a positive experience for all who use it, while having a minimal impact on the environment.

In June 2012, we opened the Morgan Stanley Clinical Building, the first part of the Mittal Children’s Medical Centre. It includes the British Kidney Patient Association Children’s Kidney Centre, the JN and Phyllis Somers Neurosciences Centre and the Wolfson Heart and Lung Centre, as well as state-of-the-art operating theatres and a new family and staff restaurant, with a 3D cinema and Disney interactive play area.

We now need to redevelop and refurbish the Cardiac Wing, which will become the new clinical building, though we hope to find a donor to name it. Due to be completed at the end of 2016, it will fulfil the hospital’s vision of providing modern facilities for all our inpatients, where a parent or carer can stay comfortably by their child’s bedside.



Photo: Llewelyn Davies Yeang



# Objective 1 – redevelopment

## The Morgan Stanley Clinical Building Part of the Mittal Children’s Medical Centre

### Aims

To complete the construction of the Morgan Stanley Clinical Building, due to open in summer 2012. This included:

- the purchase of equipment to fit out the building
- the installation of signage and artwork to help children and families find their way around the hospital
- the installation of interactive artwork that will help to distract and engage children who are being taken to theatres for operations.

In addition, we will work with the hospital to develop the fundraising strategy for the next part of the Mittal Children’s Medical Centre, which is the redevelopment of the current Cardiac Wing. We will also work with the hospital and the UCL Institute of Child Health (ICH) to develop a strategy for the new site we have acquired on 20 Guilford Street which will become Phase 3A.

### Achievement

Construction of the Morgan Stanley Clinical Building was completed in December 2011 on time and within budget. From early January 2012, the building was a hive of activity, as the hospital transformed the empty building into a working hospital. Equipment was delivered, installed and tested, and staff underwent training in the new

wards. Signage and artwork was added to help families find their way around and provide a welcoming environment. Plaques were added to recognise the generous contribution of the many donors who made the building possible.

When the new hospital restaurant, The Lagoon, opened at the end of March, children were keen to test the new Disney interactive play area and sample the expanded menu. Koala Ward (which treats neurosciences and neurosurgery patients) was the first to move in. By May, all the wards and operating theatres were in use. Staff had spent months planning the move to ensure that patients received seamless care throughout.

Before the patients moved in, supporters who had taken part in campaigns had an opportunity to visit the wards and see the modern and spacious facilities that will be a home away from home for so many families.

In June, the building was officially opened by Lord Sebastian Coe KBE, Chairman of the London Organising Committee of the Olympic and Paralympic Games, and fellow gold medallist and Paralympian, Baroness Tanni Grey-Thompson. They traded sporting tips with Great Ormond Street Hospital patients who have enjoyed

their own sporting success at the British or World Transplant Games. Dr Jane Collins (then Chief Executive of Great Ormond Street Hospital) thanked the thousands of supporters whose generosity made the building possible.

We are now focused on raising the £45 million needed to complete the Mittal Children’s Medical Centre. First the hospital needs to carry out the Phase 2B enabling works programme, which will involve refurbishing areas across the hospital campus, to house teams who are currently based in the Cardiac Wing. The hospital will then redevelop the Cardiac Wing to create a state-of-the-art new clinical building. This is due to be completed at the end of 2016.

Planning for Phase 3A of our redevelopment programme has gained momentum over the past year. It was confirmed that the land acquired at 20 Guilford Street will house a new Centre for Children’s Rare Disease Research, which we hope to complete in 2018. This will enable doctors from the hospital and scientists from the ICH to find new and better ways to help children with rare conditions, using some of the new advances in medicine such as gene therapy and stem cell technologies. Phase 3 will also include a new Ambulatory Care Centre.

The Morgan Stanley Clinical Building, the first part of the Mittal Children’s Medical Centre.

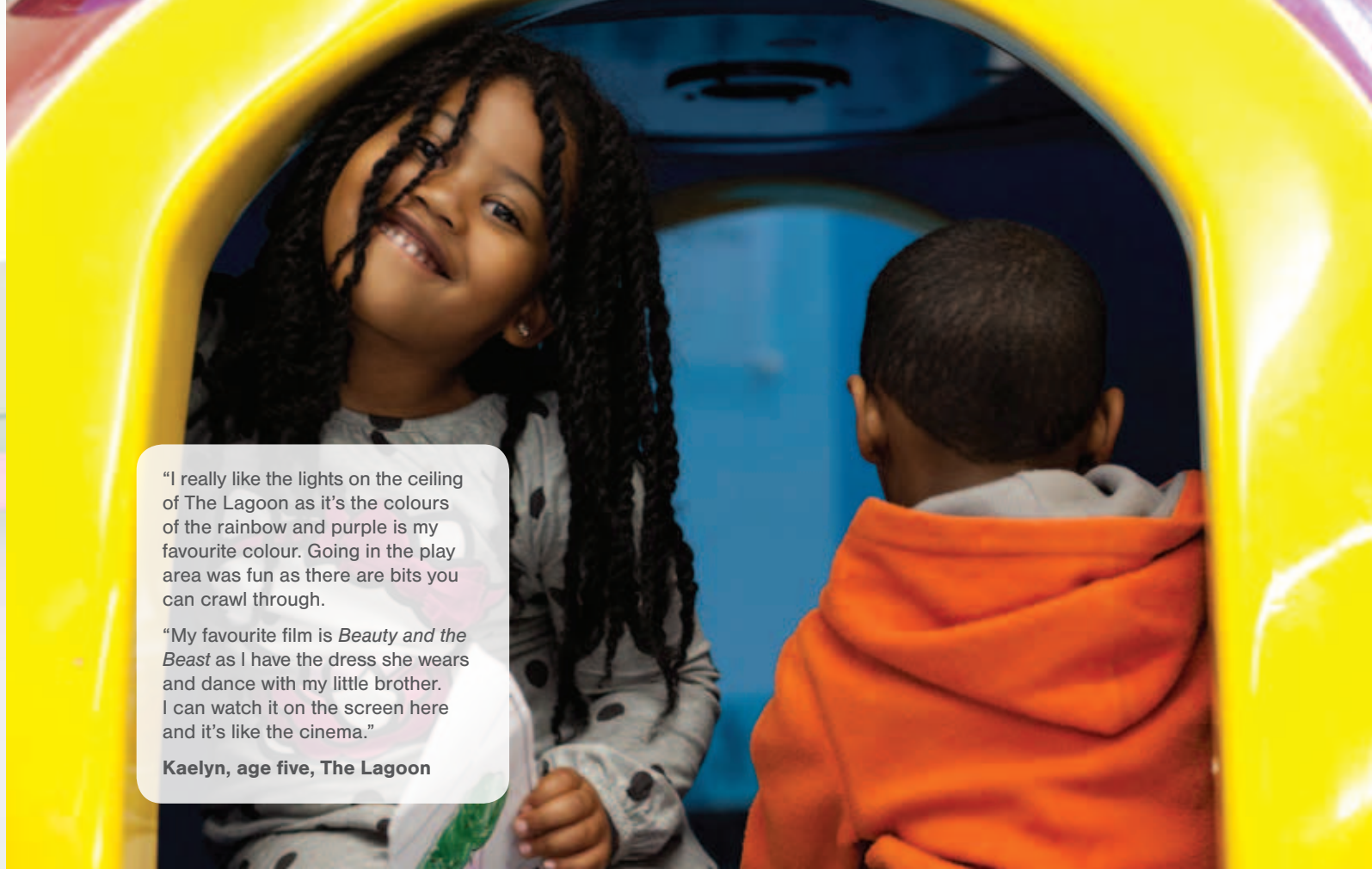


Photo: EAM and Lourdas Photography Ltd



# Objective 1 – redevelopment

The Morgan Stanley Clinical Building offers better facilities for parents and an improved working environment for staff, both of which will contribute to the primary objective of delivering world-class care for children. To truly appreciate the difference it has made, it is best to hear from the people who live and work in it each day.



“I really like the lights on the ceiling of The Lagoon as it’s the colours of the rainbow and purple is my favourite colour. Going in the play area was fun as there are bits you can crawl through.

“My favourite film is *Beauty and the Beast* as I have the dress she wears and dance with my little brother. I can watch it on the screen here and it’s like the cinema.”

**Kaelyn, age five, The Lagoon**







“The facilities on Flamingo Ward are outstanding and a dramatic change from where we were. Before we moved, we had 16 beds which were almost always full. On the new ward, we have 21 beds, thereby increasing the number of children we can care for.

“The size of the bed space has also grown significantly. The extra space makes it easier for clinicians to work and conduct research, but also for the families to spend time with their child with greater privacy and dignity.

“Having visited other international centres of excellence, I’m proud to say that the facilities on Flamingo Ward are easily as good as anything I have seen.”

**Dr Allan Goldman, Interim Clinical Unit Chair for Critical Care Services**

“The new Eagle Ward is spacious, bright, modern and very well thought out. They’ve really thought of parents who need to be on the wards with their children.

“For example, it’s very important for me to sleep next to Samaviya. Previously, we had to use the parent accommodation and it never suited us because with her condition, she can be up every half an hour during the night. Having a sofa bed is brilliant. It’s very compact and comfortable. I’ve got my own privacy but, at the same time, I know she’s here in the same room as me and I can get up and see her when I need to.

“On the old ward, we would share a bathroom with sometimes nine different families. It makes a great difference having an en suite. Samaviya likes playing with water so I can take her in there without having to share with someone else. There’s a lot more privacy.”

**Nazya, mum of Samaviya, Eagle Ward**



### Our next challenge

Building work on the second part of the Mittal Children’s Medical Centre, the new clinical building, will commence shortly. This will be another complex project as we remove the top four floors of the ageing Cardiac Wing and rebuild brand new facilities. When completed, the building will contain more inpatient wards and additional operating theatres. The new clinical building is due to be completed at the end of 2016.

It is vital that we continue to do the very best we can for children, and we can only do that through the generosity of those who support us.



# Objective 2 – research

As the UK’s largest dedicated supporter of paediatric research, we’re investing in projects right around the country. These partnerships are all part of our mission to pioneer new and better treatments for the very sick children and young people we look after.

## National research funding

For the first time last year, we completed a nationwide funding call that would allow leading researchers at other UK institutions to obtain support for their work. All applicants had to demonstrate how their research would advance the diagnosis and treatment of children with neurological conditions at Great Ormond Street Hospital, as well as at other specialist centres around the country.

We chose six projects to support over the next three years, representing a range of vital research into both common and rare neurological diseases. The work will take place at the Universities of Leeds, Manchester and UCL’s Institute of Child Health, and at paediatric hospitals including St Luke’s in Bradford, Oxford John Radcliffe, Leeds General Infirmary, Guy’s and St Thomas’, and Great Ormond Street Hospital in London.

The projects range from genetic studies to identify the precise origins of diseases affecting the brain and nervous system, to ways of diagnosing neurological illness more accurately, and improving existing drug and surgical treatments for epilepsy. These projects are now well underway, with each standing to make a tangible difference to the lives of the very sick patients treated both here at Great Ormond Street Hospital’s JN and Phyllis Somers Neurosciences Centre, and at other institutions across the UK.

### UCL Institute of Child Health

**Professor Peter Clayton and Dr Philippa Mills are helping children who currently face a lifetime of epileptic seizures.**

They are developing tests to refine the therapies on offer to children for whom conventional drug therapies are ineffective. With these tests, they hope to identify which children might respond to a form of vitamin B6, deficient in some patients whose epilepsy does not respond to anticonvulsant drugs.

“Poorly controlled epilepsy causes brain damage, impairs a child’s ability to develop normally and reduces their quality of life. For some, vitamin B6 could reduce the number and severity of their seizures, and give them the first chance of a confident and healthy childhood.”

**Dr Shamima Rahman is giving families hope and advancing our understanding of mitochondrial diseases.**

At their severest, these diseases can be both untreatable and fatal, causing brain degeneration, blindness, deafness, and heart, kidney and liver failure. This project will enable more children and families to receive a confirmed diagnosis, removing some of the fear and anxiety associated with these conditions.

“A challenge remains to provide an accurate and prompt diagnosis, and develop effective treatments for children with mitochondrial diseases. I hope to improve genetic diagnosis for affected families, and ultimately translate this genetic knowledge into curative treatments for children with these disorders.”

**Dr Torsten Baldeweg is pioneering new ways to image the brains of children with epilepsy who have had brain surgery, and identify how to ensure their long-term recovery.**

Brain surgery is a successful yet highly delicate procedure for many children with drug-resistant epilepsy. Dr Baldeweg is using imaging that can trace the pathways of the living brain, critical for speech, memory and learning.

“Mapping the essential functions of the brain is crucial to ensure neurosurgeons do not remove regions that are vital for higher cognitive functions. I hope to help surgeons ensure that their operations to prevent seizures are as safe and successful as possible, giving children the best chance of a healthy recovery.”

### University of Manchester and Leeds General Infirmary

**Professor Yanick Crow, Dr John Livingston and Professor Marjo van der Knaap are carrying out a project to improve the likelihood of a precise clinical and genetic diagnosis for children with unclassified neurological diseases that are associated with abnormal build-up of calcium in the brain.**

These children can have very variable symptoms, ranging from tremors, stiffness and mild learning difficulties, to severe physical and mental disability. However, precise diagnosis is often elusive. The aim of the study is to identify unique patterns of calcium which can be recognised on brain scans, and provide a major clue to the true nature of a child’s disease.

“Distinctive patterns of calcium in the brain are a poorly recognised clue to a child’s illness – and we need all the clues we can get. Through this research, we want to offer families more precise diagnoses, and appropriate medical advice and counselling for their child’s condition.”

### University of Leeds and St Luke’s Hospital, Bradford

**Dr Eamonn Sheridan is investigating the genetic causes of inherited neurological diseases among ethnic minority families.**

Though many of these children’s diseases are untreatable, an early and accurate diagnosis is crucial to improve the management of these often complex conditions. Professor Sheridan will use the latest DNA sequencing techniques to identify the genes responsible for a child’s disease, as the first stage to developing new diagnostic tests for children across the UK.

“A significant number of families have had to wait over five years before their child’s condition is finally diagnosed. I hope we can offer more accurate testing and better family planning for couples who want to have a child. It’s important we help to give these communities better choices.”

### Oxford John Radcliffe Hospitals NHS Trust, Guy’s and St Thomas’ Hospital, London, and Leeds General Infirmary

**Dr Michael Pike is looking to improve the care of children with a rare disorder of the nervous system called opsoclonus myoclonus syndrome (OMS).**

Also known as ‘dancing eye syndrome’, OMS causes young infants to develop unsteadiness, jerkiness, irritability and disordered eye movements. No evidence-based standard treatment exists, and children face a risk of behavioural and learning problems. Dr Pike will work with other experts around the UK and across Europe to investigate these children and assess how to improve their treatment.

“It’s really important that we offer children with OMS a package of treatments that have been agreed by other experts and that we have confidence this will improve their lives. Until we understand more about this rare disease, we can’t begin to set up proper trials of new therapies – so I hope we can begin to build an evidence base that’s critically lacking at the moment.”



## Objective 2 – research

### Gene therapy – a new frontier of medicine

#### Aim

To expand our life-saving gene therapy programme for children with immune diseases, cancer and other rare childhood disorders.

#### Achievement

Great Ormond Street Hospital and the UCL Institute of Child Health (ICH) have led global advances in understanding children’s natural immunity to disease and ways to treat conditions arising from a failure of their immune system.

Ten years ago, we became one of the few centres in the world to begin trials of a revolutionary new form of therapy for children with ‘bubble boy’ disease. This complete failure of a child’s immune system is named due to the total isolation that young males with this condition had to undergo, to keep them free from infection.

Professor Adrian Thrasher led a team that engineered a genetic therapy – where patients’ DNA is modified in the laboratory and re-introduced – using a man-made virus to supply a healthy copy of the faulty DNA responsible for causing their disease. Now armed with the vital genetic instructions which they previously missed, these cells can grow into the full spectrum of immune cells crucial for fighting disease.

Last year, international media celebrated the team’s announcement that this technology had cured 14 children – lives that would have almost certainly been lost had they

undergone more conventional therapies. With the support of Scott and Suling Mead, the Elimination of Leukaemia Fund, the Michaelis Charitable Trust, and the Jeffrey Kelson Foundation, the team have now built a highly sterile facility, capable of producing live gene therapy treatments for a range of previously incurable and often fatal conditions.

#### Impact

The lives of 14 children like Jack are testament to this pioneering work.

This year, Professor Thrasher’s team is planning a trial of a new therapy for HIV, which uses a re-engineered version of the HIV virus itself to deliver a hybrid gene. They hope that this gene might protect the body’s disease-fighting cells from the effects of HIV, literally turning the virus on itself to immunise patients who currently face a lifetime of antiretroviral therapy.

Trials are also being planned to deliver gene therapy for severe forms of inherited skin disease, metabolic diseases, and cancer.

Professor Thrasher is optimistic about the potential of this remarkable new treatment. “With support, I believe that a decade further on, gene therapy will be able to improve the life and health of many children with life-threatening diseases, where other treatment methods are either ineffective or non-existent. It’s a very exciting time to be working in this field.”

#### Donations make a difference

Last year, you helped us to invest over £6.5 million in research. This has meant that we’ve been able to launch 44 new projects spanning our four key research priorities, namely finding the causes of disease, diagnosing children accurately, developing new and better treatments, and improving children’s care.

For more information on the exciting range of projects your donations are allowing us to support, you can visit our Bringing Research to Life website at: [www.gosh.org/brtl](http://www.gosh.org/brtl)

### Jack’s story, by his mum, Debra

Jack was diagnosed with X-linked severe combined immunodeficiency (X-SCID), a rare immune disorder otherwise known as ‘bubble boy’ disease.

“Once we had the diagnosis, we were admitted to Great Ormond Street Hospital. Jack’s health had deteriorated in the transfer from Leicester and, when we arrived, we spent a week on the Paediatric Intensive Care Unit.

“We were told he would need a bone marrow transplant, but a match couldn’t be found. It was then the team discussed the option of gene therapy with us.

“By that point, we didn’t really have a choice, because Jack had run out of available treatment options. In hindsight, we look back and see gene therapy was actually much kinder on Jack, because he didn’t need to have the chemotherapy he would have needed with a bone marrow transplant.

“Jack still takes medication and is on immunoglobulin. We are cautious with him and take each day as it comes, but he is doing really well now, both in school and socially, which is incredible to see given how ill he was as a baby.

“The doctors and the rest of the team at Great Ormond Street Hospital are amazing; we can’t thank them enough for their work and research.

“We hope our experience will give other families hope too. When Jack was diagnosed, we felt like our whole world was ending, and that he would never be able to do ‘normal’ things. Jack is living proof these children can reach their milestones and lead a good quality of life.”





## Objective 2 – research

### The Newlife Birth Defects Research Centre

#### Aim

To create Europe’s first Birth Defects Research Centre at the UCL Institute of Child Health (ICH), addressing the number one cause of infant mortality in the western world.

#### Achievement

Of the 4,000 known birth defects, some are very rare while others, such as heart defects, spina bifida, cleft lip and Down’s syndrome, are more common. This major programme of redevelopment of the second and third floors of the ICH has brought together world-class scientists in state-of-the-art facilities, thanks to the support of the Newlife Foundation for Disabled Children, Sweets for Life Ltd, the Dromintee Trust, and many others.

The Newlife Birth Defects Research Centre houses over 65 world-class researchers in three key specialist units, working together in a multi-disciplinary approach to research.

The Neural Development Unit will look at the very earliest stages of animal development to understand how our nervous and gastrointestinal systems form, and how to treat and prevent diseases that affect the gut, spine, head and face. Work in the Molecular Medicine Unit will investigate how the

chemicals that underpin life – DNA, proteins and other biological molecules – are altered or disrupted in syndromes that result in birth defects. Working in close partnership with these teams, researchers in the Developmental Biology Unit will look at how to modify the way cells grow and behave, as the first stage to developing pioneering new therapies.

The centre also houses crucial facilities and equipment, such as time-lapse cameras, advanced laser microscopes and tissue culture laboratories, which researchers can use to prepare and examine biological materials under investigation.

#### Impact

The Newlife Birth Defects Research Centre is providing a unique setting that encourages researchers to share ideas and discuss challenges. Working alongside Great Ormond Street Hospital’s leading clinicians ensures that children’s needs remain at the very heart of the research and that any laboratory findings can be rapidly translated to the clinic for patient benefit.

One in 33 children in the UK are born with life-threatening or life-limiting birth defects. This vital work will transform

the prospects for treating these conditions, such as inherited retinal diseases, responsible for around 14 per cent of cases of childhood blindness.

Earlier in the year, Jane Sowden, Great Ormond Street Hospital Children’s Charity Professor of Developmental Biology and Genetics, was part of a pan-UCL research team that demonstrated it was possible to restore the sight of night-blinded mice by transplanting light-sensitive cells into the eye. Working in the new centre over the coming years, she hopes it will be possible to develop similar approaches for the treatment of human blindness.

Professor Andrew Copp, Director of the ICH over the last 10 years, remains committed to leading research efforts within the centre. “Sadly, we cannot always do as much as we would like for children with birth defects,” he reflects. “The new centre gives us hope that we will be able to do more – and importantly will give hope to the children and families who turn to us in their hour of need. The charity’s generous supporters are allowing us to capitalise on the scientific strengths we already have, and make a fundamental impact on global child health.”

Sandra, a researcher working in the Neural Development facilities.





## Objective 2 – research

### Life-saving research to re-establish children’s immune systems

#### Aim

To conduct Europe’s first trials of a new therapy for children born with a rare condition, which can put affected patients at risk of severe and potentially fatal infections.

#### Achievement

Working in collaboration with researchers in the UCL Institute of Child Health’s Immunobiology Unit, Dr Graham Davies is offering a lifeline to children born with a condition called DiGeorge syndrome. In its worst form – ‘complete’ DiGeorge syndrome – this rare disease can result in children being born without a functioning thymus, an organ which produces an important group of blood cells known as T cells, which fight infection and regulate other parts of the immune system.

The thymus acts as a T cell factory, producing T cells and teaching them to fight invading germs, yet not attack the body’s own cells. Children without any functioning thymus cannot manufacture these vital T cells, resulting in a profound susceptibility to infection.

Dr Davies has established a programme of research to transplant healthy thymus cells taken from patients undergoing open heart surgery, into children with complete DiGeorge syndrome, to re-establish a functioning immune system.

#### Impact

These transplants are saving patients’ lives. Dr Davies and the research team are excited about the potential of this new approach for children with complete DiGeorge syndrome, which although is still in its earliest stages, is proving promising. They hope that with further research, the technique could be applied to help rebuild children’s immune systems after a bone marrow transplant, or following heavy chemotherapy for cancer.

For patients and families receiving this therapy, the impact of this research is significant – until now, they would have had to travel to the United States to receive the treatment. Having been successful in securing further funding for this vital research, Dr Davies hopes to make thymus transplantation more widely available to other children who may benefit from this pioneering treatment.

“Research to develop this complex therapy continues to reveal new insights into how our immune system works. It is another example of how we’re constantly refining our knowledge of how the body fights disease. I hope thymus transplantation could be used to improve the outcome for a much broader range of severe clinical conditions affecting both children and adults.”



#### Charlie’s story, by his mum Rachel

When Charlie was born he wasn’t breathing properly, and spent the first weeks of his life in intensive care at his local hospital.

When he began to lose his hair and developed a rash all over his body, he was transferred to a hospital in Newcastle. Doctors there confirmed he had a life-threatening immune disorder. They told the family he probably had six to 12 months to live.

Rachel explains: “The doctors explained that Charlie didn’t have a thymus organ, and so was unable to produce any T cells, which meant he couldn’t fight infection. Although there was a centre in the United States that had carried out some thymus transplants, Charlie was too poorly to fly and the

treatment was horrendously expensive. “It was a really frightening time, Charlie had no real quality of life. He wasn’t well enough to be moved home and so he stayed at our local hospital living in total isolation to stop him picking up infections. His brothers and sister couldn’t go into his room at all.”

“In February 2010, Dr Graham Davies contacted us to let us know that Charlie could be eligible for a thymus transplant at Great Ormond Street Hospital. We were so excited. This was a chance we had to take.

“Charlie had the transplant when he was 19 months old. Small incisions were made into his thighs and slivers of the donor thymus were placed into Charlie’s leg. Everything went as well

as it could – and by August 2010, we were able to return home.

“Although he will always have some symptoms of his condition, like reduced hearing, Charlie has done brilliantly. In January 2011, he started nursery which was a major milestone. I was overwhelmed taking him in as I never thought that day would come.

“Our other kids can have their friends over and, as a family, we can do things together – like go to church and hopefully next year, take a summer holiday.

“We are so grateful to Dr Davies and his team. We think he has given Charlie a chance to live a proper life, for which we are eternally grateful.”



Objective 3 – equipment  
Last year, our donors helped us to fund new specialist equipment worth nearly £2.8 million. This enabled us to replace old and outdated machinery as well as purchasing new state-of-the-art technology, which is essential to the hospital’s work.

X-ray equipment

**Aim**  
To purchase specialist X-ray equipment to plan and assess dental and maxillofacial treatments, procedures and operations.

**Achievement**  
The orthopantomogram and lateral cephalostat equipment was purchased and installed in 2012. It replaces a 15-year-old machine, which developed an unrepairable fault in 2011. When the old equipment stopped working, the hospital had to refer patients to another hospital for imaging. This was inconvenient for families, and costly to the hospital.

The equipment benefits many patients across the hospital, including those undergoing treatment for dental conditions, severe facial abnormalities, cleft palate, craniofacial conditions or rheumatology conditions.

The new equipment provides detailed images of the face, neck, jawbone and teeth, which are vital for planning surgery and assessing a patient’s recovery after an operation. These

images cannot be provided by standard X-ray equipment.

**Impact**  
When planning delicate procedures or operations, surgeons need access to high quality images of the patient’s anatomy. A picture is like a map, revealing how complex the procedure will be, and where facial bones, nerves and roots are located. Images will be stored on the hospital’s picture archiving system and can be displayed on a monitor in the operating theatre.

The equipment shows the roots of the teeth under the gum, so that a dentist or surgeon can see how the teeth are developing, which direction teeth are growing in, or the location of a fracture. It also helps monitor patients after surgery, to see how treatment is progressing.

For the first time, the Radiology department has access to cone beam CT technology for these patients. This can take high quality 3D images, with less radiation than a standard CT scanner.

This equipment helps surgeons map tiny bones and nerves before a delicate procedure or operation.





# Objective 3 – equipment

## Ultrasound machine

**Aim**  
To purchase a new state-of-the-art ultrasound machine to help diagnose muscle disorders in babies and children.

**Achievement**  
The new machine was purchased in May 2012 and is used to assess about 350 new patients each year. It helps clinicians make a faster and more accurate diagnosis of conditions such as muscular dystrophies, myopathies and motor neuron diseases.

**Impact**  
Neuromuscular disorders affect around one in 2,000 babies, children or teenagers. The Dubowitz Neuromuscular Centre at Great Ormond Street Hospital is one of a few centres worldwide to perform muscle ultrasound as a part of diagnostic neuromuscular consultation in an outpatients setting.

Muscle ultrasound is a quick and painless way of identifying whether a muscle is healthy or diseased as a consequence of muscular dystrophy or congenital

myopathy. It can provide information which can rule out the need for more invasive and expensive tests, such as a muscle biopsy or muscle MRI, or pinpoint the exact muscle to biopsy for further investigation. It is a safer way of assessing infants and young children, as it does not require sedation.

This machine replaces an older model. It is more reliable and provides better quality images, which can help identify minor movements of muscle fibres under the skin surface (fasciculation). The machine comes with a facility for storing digital images. Because it is portable, it can also be used to assess patients on the ward.

After diagnosis, patients can begin a management programme, including physiotherapy and respiratory and heart monitoring, to help reduce complications of the condition and improve survival. Treatment can help manage breathing difficulties, musculoskeletal problems or cardiac complications. Staff also counsel parents and work with them to plan their child’s ongoing care.

An ultrasound helps diagnose muscle disorders. Because it is quick and pain-free, this test can be used for small babies and children.





# Objective 3 – equipment

## Nutrition equipment

### Aim

To purchase a new compounder to prepare formulae for patients who are unable to digest normal food.

### Achievement

The compounder was installed in the Total Parenteral Nutrition Unit of the Pharmacy department to produce bespoke parenteral nutrition formulae for around 45 patients per day. This equates to about 16,425 feeds each year. This equipment was generously funded by the City of London School.

### Impact

Food is crucial to a young patient’s growth and development, but some babies, children and young people are unable to digest or obtain vital nutrients from ordinary food or milk. A specialised formula needs to be produced to deliver nutrients such as glucose, amino acids, lipids and added vitamins and minerals, this is called parenteral nutrition. It is delivered via the blood stream, bypassing the normal process of eating and digestion.

Patients who need parenteral nutrition include premature babies, intensive care patients, and those receiving treatment for bowel or gastrointestinal conditions, or cancer. Because they are in a fragile state or receiving strong medications, these patients need a precise recipe, with the right balance of fluids and nutrients.

The new equipment replaces a 13-year-old machine which was becoming unreliable and was no longer supported by the manufacturer. With the newer technology, staff can programme the recipe in and the machine will make the exact formula. It then weighs the mixture, to ensure that the quantity of each ingredient is precise. This automated process is safer for patients. It is also quicker, producing more feeds.

Parenteral nutrition can be adjusted constantly, according to a patient’s fluid balance, blood levels and liver and kidney function. As the patient’s condition stabilises and they approach their optimum weight, other types of feed can be introduced.

Only a few hospitals in the UK are able to provide tailor-made parenteral nutrition formulae.

Delicate patients need a precise mixture of nutrients, vitamins and minerals. This equipment prepares special formula to assist their growth and development.







Maya and her mum Sylwia now have more time together at home due to the home haemodialysis programme.

Objective 4 – accommodation and welfare  
We believe in caring not only for the child but for the whole family. This care comes in many forms, from financial advice and spiritual counselling to the provision of accommodation for parents.

### Home haemodialysis

**Aim**

To establish a pilot programme to enable kidney patients to undergo haemodialysis treatment at home.

**Achievement**

The first patient started treatment at home in 2010. Over the course of the year, four patients were treated at home via the programme.

This programme was generously funded by Arnaud Bamberger, the Charity’s Dickensian Ball, Edward Dwek, Charlotte Holman, Martin Hughes, the family and friends of Frances Mant, Nazenin Moshiri, David Reuben, Guy Weston, as well as many others.

**Impact**

Haemodialysis treatment is a lifesaving treatment but also has a big impact on the lives of patients and their families. Children must come to hospital at least three times a week to be dialysed, some travelling up to two hours each way.

As a result, children and young people regularly miss school. Parents or carers are required to accompany them on their journey to London, and thus need to take time off work and arrange childcare for other siblings where needed. Arranging holidays can be extremely challenging and in truth, rarely achieved. The home haemodialysis programme can bring a huge improvement to a family’s quality of life, as it frees them from this routine.

Eight-year-old Maya has end-stage kidney failure and is awaiting a kidney transplant. Before she joined the programme, Maya and her mum, Sylwia, had been travelling to Great Ormond Street Hospital three days a week for six months. The journey took at least one hour and often coincided with peak hour traffic. Since May, Maya has been undergoing dialysis treatment at home.

“Maya missed so much at school because of the dialysis and hospital

stays. She can go to school five days a week now. The teachers are remarking that she has improved so much,” says Sylwia. “She is catching up in her school work and her friendships as well.”

Within weeks, Sylwia also noticed an improvement in Maya’s health and general wellbeing. “She never felt better on dialysis. She eats more and we’ve stopped the overnight feeding. She needs less medication and her blood pressure is so much better. This form of dialysis is more gentle and it seems to be more effective.”

Sylwia says that her family is also able to go on holiday now: “We can take the machine and go on holidays like everyone else.”

Following the successful pilot project, the NHS has funded the service on an ongoing basis, and it has been expanded to seven patients, including two outside of Great Ormond Street Hospital.



# Objective 4 – accommodation and welfare

## Chaplaincy

**Aim**  
To help provide spiritual and religious support to patients, families and staff at Great Ormond Street Hospital by contributing to the running costs of the chaplaincy service.

**Achievement**  
The multi-faith Chaplaincy team provides around the clock support to patients, families and staff throughout the year, and holds regular events and services to provide spiritual and practical help to families. This project was generously funded by the Liz and Terry Bramall Foundation, as well as many others.

**Impact**  
Great Ormond Street Hospital treats some of the sickest children from across the UK. Sometimes they come to us as a last resort, having exhausted other treatment options. Understandably, this can be a very stressful time for parents and carers. Similarly, staff may need support with the difficult situations that they experience in their day-to-day work treating very ill children.

Some members of our hospital community have a religious affiliation, others do not. The Chaplaincy team is here to provide support to all of them, in accordance with their personal beliefs and in whatever form they need; be it a quiet space to reflect, a listening ear, or prayer.

The multi-faith Chaplaincy team comprises representatives of the Christian (including Greek Orthodox), Jewish and Muslim faiths, and is able to access spiritual care givers from all faiths and philosophies as needed. Amid the busy hospital, St Christopher’s Chapel and the multi-faith room provide a space where visitors can gather their thoughts.

Throughout the year, the team host celebrations, helping families to maintain a sense of normality while in hospital. The popular Christmas Carol Service sees patients of all ages, from tiny babies, to teenagers, fill the chapel with their families. Some are in a bed or attached to a drip. More than 85 family members and staff gathered for Eid festivities last year, to celebrate the end of Ramadan, the Islamic holy month of fasting. Regular coffee mornings enable parents to connect and share their experiences.

The Lead Chaplain, James Linthicum, believes that spiritual support can help people deal with life’s challenges, find hope and meaning, or see how their experiences are part of a bigger picture.

The multi-faith Chaplaincy team helps patients, parents and staff through difficult times, and hosts celebrations to help families maintain a sense of normality while in hospital.







Looking  
forward

Joseph, age 10, is having tests on Kingfisher Ward to find out the cause of his dizziness. Since his arrival at Great Ormond Street Hospital, he has really enjoyed hanging out with his pal, Kyrio.





## Looking forward Our Chairman's report

The most important thing for me to do is to thank everyone who has supported the charity this year. We have had our most successful year ever in terms of fundraised income, which means that we have been able to fund more projects for the hospital.

I hope that some of you have had a chance to see the new Morgan Stanley Clinical Building, either personally or by viewing the film which is on the charity's website. It was wonderful to be able to open it this year and the trustees were delighted that it was ready on time and on budget. It was also good to hear that the detailed planning by the clinical and redevelopment teams in the hospital meant that the moving of wards from their old locations to the new building went smoothly. I'd like to thank everyone at the hospital who worked so hard to make that happen.

We are now focusing on the second part of the Mittal Children's Medical Centre, rebuilding the current Cardiac Wing. We still have £45 million to raise towards this centre, which the hospital is planning to complete in 2016. The new building will have four floors of inpatient wards and additional operating theatres. It is incredibly important to all of us because it will mean that the hospital will be able to treat up to 20 per cent more children, and that inpatients will be accommodated in modern wards suitable for 21st-century healthcare.

The hospital has always been at the forefront of paediatric research and we want to help them continue this proud tradition. The charity is starting to fundraise for a new Centre for Children's Rare Disease Research. This centre will be located close to the hospital and the UCL Institute of Child Health, and will be a building

where doctors from the hospital and scientists from the Institute will work together to translate pioneering research techniques to give hope to children who have rare conditions.

There are more than 6,000 recognised rare diseases, so while individually they may not be known to most people, collectively they affect one in 17 of the population. Advances in techniques such as gene therapy or regenerative medicine have already meant that the hospital has been able to help children with previously untreatable conditions. Improving understanding of rare conditions will also help to increase understanding of more common diseases.

Five to 10 years in the future, the clinical and research teams hope to be able to help many more children. The new centre will be critical to that ambition and we have a fundraising target of £66 million to complete this project.

These plans were established under the leadership of Jane Collins while she was Chief Executive of the hospital and the charity. Jane has now left to take on an important new role, but I would like to thank her for all she did for the hospital and the charity. I know she would also want me to thank you for enabling us to help the patients, families and staff at Great Ormond Street Hospital.

Thank you.

**Alan Hodson**  
Chairman

One-year old Ismat-Hibatullahi has Pompe disease, which is a disorder caused by the build-up of glycogen. She has been staying on Sky Ward and is very excited to be going home tomorrow.





Saoud is 11 years old and lives in Kuwait. He is being treated for childhood leukaemia on Bumblebee Ward. Saoud likes football, swimming, and helping mum in the kitchen. He would like to be a doctor in future to help people.

## Our objectives for 2012/13

Our objectives for 2012/13 continue to focus on what matters most to us – supporting the patients and families who need the hospital today, as well as helping children who may need the hospital in the future.

### Fundraising

To raise at least £50 million.

### Redevelopment

Raising funds for the redevelopment of the hospital continues to be one of the biggest challenges. In this financial year, we aim to provide funding to allow the hospital to:

- refurbish areas of the hospital so that patients and hospital staff can move out of the Cardiac Wing, in preparation for its redevelopment
- confirm detailed floor plans for the new clinical building (Phase 2B)
- appoint a contractor for the new clinical building
- appoint a project manager and develop the business case for the Centre for Children's Rare Disease Research (Phase 3A).

### Research

To help tackle childhood cancer, we will partner with CHILDREN with CANCER UK to fund up to £2 million worth of research projects that seek to improve the lives of children and adolescents with cancer through new and better treatments.

As the UK's leading paediatric research funding charity, we will also support at least £4 million of new projects, senior researchers and PhD students at Great Ormond Street Hospital and the UCL Institute of Child Health.

We will continue to raise awareness and vital funds via our Bringing Research to Life initiative, and launch a research symposium and engaging online materials to demonstrate how research can transform the lives of children at Great Ormond Street Hospital and across the UK.

### Equipment

We aim to fund £1.8 million worth of new medical equipment for the hospital. These items are prioritised by the hospital, according to its most urgent needs, and could range from pain relief pumps (£2,300 each) to high-tech X-ray equipment (£250,000).

### Patient welfare

We aim to fund at least £1.8 million worth of welfare projects which provide additional help and support for patients and their families during very difficult times.





Jade, 13, had a heart transplant at Great Ormond Street Hospital at the start of last year and, shortly afterwards, developed symptoms of diabetes. She is now a member of the Young People's Forum, which has been created to give young people the opportunity to develop and improve the hospital services they use.

## Our funding priorities for 2012/13

### New facilities

We need to replace cramped, outdated wards with new, modern facilities to give our patients and their families a better, more flexible and comfortable service.

Your support could help to:

- fund an operating theatre and anaesthetic room in the new clinical building: **£5 million**
- purchase an angio biplane machine for pioneering keyhole procedures: **£806,000**
- fund a patient bedroom with en suite bathroom in the new surgery centre: **£100,000**
- fund an interview room where parents can speak privately with clinicians in the new clinical building: **£50,000**
- equip a patient bedroom in the new Respiratory Unit: **£8,000**.

### Research essentials

We are committed to finding treatments and cures for some of the most complex and challenging illnesses for the benefit of children at the hospital and worldwide.

Your donations could help us to:

- fund projects nationally to drive advances in diagnosing and monitoring children's diseases: up to **£1 million**
- develop safer tests to detect prenatal illnesses and counsel families at risk of genetic diseases: **£620,000**
- support a leading researcher working on ways to grow rejection-free transplants from a patient's own stem cells: **£175,000**
- ensure children's voices are heard in the care of young people with learning disabilities: **£70,000**
- pay for the cost of sequencing a patient's DNA to determine the origin of a rare disease: **£2,000**.

### Equipment

It is essential that our exceptional doctors and nurses have leading-edge equipment to provide children with world-class care.

We need:

- echocardiogram machines to help diagnose heart conditions: **£250,000**
- surgical instruments to carry out more operations: **£100,000**
- a mini image intensifier to guide surgical procedures, particularly with tiny babies: **£50,000**
- dialysis machines so that children with kidney problems can receive dialysis treatment at home: **£16,000**
- patient beds for our new Surgery Centre: **£2,000 each**.

### Family accommodation

For some families, visiting the hospital can be a traumatic experience and it is vital that we support them during this difficult time. There can be no better care and reassurance for a child than to know that they have a parent at their bedside.

Your support could help to fund:

- a sofa bed for a parent to stay beside their child in the new clinical building: **£1,000**
- The upkeep of a room for a parent or family member to stay overnight near their sick child: **£12**.





THANK YOU

Our sincere thanks go to those individuals and organisations overleaf who have so generously supported the charity this year.

We would also like to thank the general public. Thousands of people give generously to us throughout the year, and these donations are critical to the important work we do for sick children. On behalf of our inspiring patients and remarkable staff, thank you.



# Thank you

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Four-year-old Milan is an oncology  
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#### Bengali

অমৃত্যু কল্যাণ হাসপাতাল শিশুদের হাসপাতাল থেকে এই লেখার  
অনুবাদ, বড় অক্ষর, ব্রেল বা অডিও বিবরণ পাওয়া  
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ਮੰਗ ਕੇ ਲਏ ਜਾ ਸਕਦੇ ਹਨ।

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Turjubaan ayaa cinwaanka kor ku qoran  
laga heli karaa markii la soo codsado.  
Daabacad far waa-wayn, farta indhoolaha  
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