



Our mission

We raise money so that Great Ormond Street Hospital can 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: nine-year-old Shayla is on Squirrel Ward, recovering from bladder augmentation and Mitrofanoff surgery.

Left: One-year-old Eshan, is an outpatient on Kingfisher Ward and is keeping a close eye on everything going on!





A letter from our Chief Executive

The hospital is in the middle of the largest redevelopment of its estate in its 160-year history. It is needed because more and more children are being treated at the hospital each year and the forecast is for this growth to continue as the NHS concentrates more care into fewer, larger specialist centres. At the same time, some of the existing clinical facilities badly need upgrading to provide better space, comfort and privacy for children, families and staff.

Last year, the hospital opened the first part of the major upgrade to its acute inpatient facilities, the Morgan Stanley Clinical Building. This first building in the Mittal Children's Medical Centre is now well into its second year of operation and it is rewarding for all of us to see how well it has been received by families, who are valuing the improved facilities it offers. This is understandably most marked among those families who had previously experienced the older, cramped wards and are now accommodated in the new building.

Work is now underway to prepare for the construction of the second part of the Mittal Children's Medical Centre. We still need to raise £30 million to complete this next building but we are hopeful that with the continued generosity of supporters such as you, we will be able to open the final part of the centre in 2017. I'd like to thank Whitbread Hotels and Restaurants who have pledged £7.5m towards the second building, which will be known as the Premier Inn Clinical Building.

The charity remains committed to its investment in paediatric research. Every week we learn of new and better ways in which the hospital and its research partner, the UCL Institute of Child Health, can potentially help the children and young people treated at the hospital and we want that ethos to continue. We are particularly focused on supporting the kind of research that can be translated into patient benefit quickly. With this in mind, the charity has launched a funding stream called Clinical

Research Starter Grants to support research active clinicians who need some help to get their projects underway.

Working in partnership with other medical research charities is an important part of our strategy. We want more research into paediatric health and they want more research on the specific condition they support. By pooling resources, we can increase the impact we make. This year we have collaborated with both Arthritis Research UK and CHILDREN with CANCER UK and this is a trend we hope to continue.

Some of the money the charity raises goes towards buying equipment for the hospital. This ranges from small items such as pain relief pumps to significant purchases of highly specialised pieces of equipment, such as MRI machines. The items the charity purchases have been prioritised for funding by the hospital to assure the money is spent where there is greatest need.

The hospital recently won the Health Service Journal Patient Safety in Paediatrics Award. This was in recognition of some of the improvement work undertaken by the hospital's Transformation and Improvement team. Charity funding has supported some of this work and is a sign of our commitment to help the hospital do all it can to provide high quality and safe care to its patients.

This impact report gives you an overview of just some of the ways in which donors, fundraisers and volunteers have enabled the charity to help the hospital in the past year. I'd like to thank you all for your support - it makes such a difference to the work the hospital is able to achieve for the children, young people and families it cares for.

Tim Johnson Chief Executive

Nine-year-old Mary Jo is a kidney transplant patient on Eagle Ward, waiting to find out about her angiogram. Mary Jo loves animals, especially dogs, and is a keen swimmer.

What we raised

What we raised

In 2012/13, the charity's total income increased to £70.1 million. This was the third year in a row where the previous year's record performance has been exceeded. As a result of this consistent high level of performance, we remain well-placed to continue supporting the hospital in the future.

Financial review

Yet again, the overall growth in our income was driven by an increase in our voluntary income, which increased by 4.7 per cent to £59.7 million. The continued generosity of our supporters has seen voluntary income increase by 11.9 per cent over the past two years.

The number of people who are supporting the charity through regular gifts continues to increase, reaching 127,000 in 2012/13. This provides us with a regular income that greatly assists us in planning future activities. Our corporate partners, major donors, trusts and foundations continued to make significant contributions, and income from legacies reached record levels. All of these vital contributions drive our ability to fund the redevelopment of the hospital and other charitable activities.

The charity committed £50.8 million on charitable activities during the year (£26.3 million in 2011/12). The largest item of expenditure was a grant of £27.5 million made to the hospital for the enabling works for phase 2B of the redevelopment programme, the second phase of the Mittal Children's Medical Centre.

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 principal funding sources of the charity are shown below, compared to the previous year:

Income sources 2012/13

	2012/13 £ million	2011/12 £ million
	~	
Donations	47.7	45.5
Legacies	12.1	11.5
Trading	2.4	2.4
Other*	2.8	2.0
Fundraising income	65.0	61.4
Investments	3.6	3.4
Property	1.5	1.5
Total	70.1	66.3

^{*}Other includes grants, auctions, tickets and sponsorship

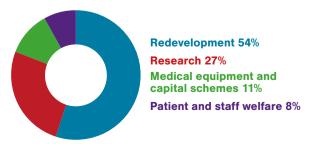


Income for the year totalled £70.1 million (£66.3 million in 2011/12), with £50.8 million committed as follows:

Grants awarded* 2012/13

	2012/13 £ million	2011/12 £ million
Redevelopment	27.5	0.0
Research	14.1	11.8
Medical equipment and capital schemes	5.5	10.2
Patient and staff welfare	3.7	4.3
Total	50.8	26.3

^{*}Grants awarded during the year before adjustments







Objective 1 Redevelopment

One year on in the Morgan Stanley Clinical Building – the first part of the Mittal Children's Medical Centre.

Thanks to the thousands of supporters who generously donated towards phase 2A of our redevelopment programme, we were able to open the Morgan Stanley Clinical Building, the first part of the Mittal Children's Medical Centre, in June 2012.

Aim

To open a new clinical building that would allow the hospital to:

- · increase its capacity in line with growing demand
- provide inpatient facilities that offer more space, privacy and comfort, where a parent or carer can stay overnight by a child's bedside in comfort
- improve facilities for our cardiac services, including intensive care, neurosciences and renal centres
- · provide additional operating theatres
- · provide a new and larger hospital restaurant
- · offer a positive experience for all who use it
- · minimise impact on the environment
- improve models of care for patients by co-locating teams
- · improve the working environment for staff

Achievement

The Morgan Stanley Clinical Building was officially opened by Lord Sebastian Coe KBE accompanied by Baroness Tanni Grey-Thompson in June 2012. The building was completed on time and within budget. It includes the Wolfson Heart and Lung Centre, the British Kidney Patient Association Children's Kidney Centre, The JN and Phyllis Somers Neurosciences 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.

Since opening, staff have been busy adapting to the new wards, working to develop new, efficient ways of working to make best use of the increased space.

The new building has provided vastly improved facilities for patients and parents and has become a home away from home for many families who visit us.

Impact

The world-class facilities in the new building are having a significant impact on patients, families and staff already. Three of the hospital's largest specialties – cardiac, renal and neurosciences – have moved into the new building and have experienced a huge difference with larger ward space and facilities and leading-edge equipment available. There is now an additional operating theatre in use, meaning the hospital has been able to increase the number of operations it carries out. There are more vital cardiac intensive care beds and the space vacated by our previous Cardiac Intensive Care Unit has now been used to create additional intensive care facilities in other parts of the hospital. The new Cupcake Telemetry Unit on Koala Ward has also helped Great Ormond Street Hospital play a leading role as a national service provider for epilepsy surgery.

The new inpatient wards have made a huge difference to patients, staff and families. They have provided more space, including room for a parent or carer to sleep at their child's bedside, access to private en suite bathrooms, more privacy and comfort and additional play spaces with separate playrooms for younger children and adolescents.

State-of-the-art equipment is helping the hospital maintain and advance its position as a world-class centre for paediatric care and research, while continuing to give patients access to the very best treatments and diagnostic tests.

While the increased space has taken some getting used to for staff, there is widespread recognition that the building brings major benefits for patients and families. There are also many positive comments about the improved staff rooms and availability of much-needed meeting rooms.

The demand for the hospital's services continues to increase and this second phase of our redevelopment programme – the Mittal Children's Medical Centre – is an important step to enable the hospital to treat up to 20 per cent more patients.

Great Ormond Street Hospital is extremely grateful to all the supporters who have contributed to the Morgan Stanley Clinical Building, the first part of the Mittal Children's Medical Centre, who have helped make a vast difference to so many people's lives. Without the generous support of these donors this building would not have been possible.

Objective 1 Redevelopment

Carlos de Sousa, Consultant Neurologist, Koala Ward

"As a consultant in neurosciences at Great Ormond Street Hospital for a number of years, I have seen the transformation that the new ward has made over the past year. Before we moved to the new building, our patients were placed in different wards. Children with neurological and craniofacial conditions were on one ward and those having neurosurgery were on another. Some children had to be moved from one ward to another for different treatments. On Koala Ward, we have brought the expertise of the whole Neurosciences team (specialist nurses, neurologists, neurosurgeons and craniofacial surgeons) to every single patient in an integrated way. We are already seeing the difference this has made to our patients after just one year on our new ward, and I am certain it will improve even more in the future.

"As well as enabling patients to benefit from the combined work of the teams, the new physical environment on Koala Ward is a huge improvement for the children we treat and for their families. The Neurosciences team were consulted at the design stage, but it was still a revelation when I stepped onto the ward for the first time. There is much more space and every piece of equipment is state-of-the-art. This includes very sophisticated new measuring and monitoring equipment (video telemetry) for children with

epilepsy, which is supported by technologists working in a control centre embedded on the ward. Other facilities have also made a huge difference to the team who work here. The staff room is ideal and helps colleagues to rest properly while on their breaks. Overall the facilities are much better to work in.

"For the children and families there has been a real step change in the level of privacy and comfort now offered. Sofa beds for parents to sleep comfortably next to their child are a great improvement on the previous arrangements. The increase in the number of single bedrooms offers a greater degree of privacy for families, which I know is very much appreciated. And having en suite facilities in every single bedroom is vital for families who often spend long periods of time on the ward.

"I would like to thank all the donors for their outstanding contribution to making the new ward possible. It is a fantastic environment and we've had so much positive feedback from patients and families."

Koala Ward is part of the The JN and Phyllis Somers Neurosciences Centre.

"It was a revelation when I stepped onto the ward for the first time."





Indy's story by her parents Paul and Philippa

"Almost immediately after Indy was born, we were told she needed to come to Great Ormond Street Hospital as the levels of oxygen in her blood were too low. While we felt reassured that we were coming to the best place possible, we also took it as a sign that something was seriously wrong. Upon arrival they diagnosed the problem with Indy straight away and she underwent open heart surgery shortly after. Following the operation we then spent a month on the old intensive care unit while she recovered. The staff were fantastic but the space was quite cramped, so when the doctors were there you felt you were getting in the way. Also, lack of space meant privacy was limited and you could often hear the conversations that staff and other families were having on the ward.

"When the new Flamingo Ward opened, Indy was one of the first patients to be transferred. Even though the new ward is much

bigger in comparison, the intimate feel with the one-to-one care still exists, and the extra privacy afforded by the space really does make a difference. When your child is in intensive care, having your own space becomes really important as it means you can discuss things properly with the staff and as a family. Also, when Indy moved from intensive care into the new cardiac unit, Bear Ward, there was a similarly big improvement with en suite facilities and a sofa bed so we could stay close to her at night.

"We are so thankful to all the supporters who made the new facilities possible. Great Ormond Street Hospital has always had the best doctors in the world but it now has the environment to match.

Flamingo Ward and Bear Ward are part of The Wolfson Heart and Lung Centre.

"The intimate feel with the one-to-one care still exists."



Oliver's story by his mum Cherie

"Oliver and I have been coming to Great Ormond Street Hospital ever since he was three weeks old, which is over 12 years ago now. He was born with blood clots on the brain that caused hydrocephalus or 'water on the brain'. To treat his condition he had a shunt fitted and has had numerous other operations over the vears.

"For many years we visited Parrot Ward, which became a home from home and was really cosy. While its size made it feel very warm and comfortable, it did create a few issues. When Oliver became older he outgrew the size of the small cubicle rooms and we sometimes had to share a bathroom.

"We've spent a lot of time on the new Koala Ward over the past year as Oliver has had five brain operations. When I first came onto the ward the size of it just blew me away. There are so many beds, whereas on Parrot Ward the staff were always trying to find you a bed and sometimes we had to use a bed on another ward. We've always been easily accommodated here on Koala Ward.

"As a parent, one of the things I love about Koala Ward is the sofa bed with privacy curtain that I get to sleep on. I know Oliver does find it reassuring when I stay next to him at night, although being a young boy he won't admit it! Not only are the beds comfortable but it's nice that the curtain gives you your own space, for example if you want to read when your child is sleeping.

"I also really appreciate being able to make a cup of tea and relax in a space away from the ward. It makes all the difference being able to have a proper break.

"Oliver loves Koala Ward as well. Having an adolescent chill-out room separate to the young children's playroom is his favourite bit. He finds it upsetting being around younger children who can sometimes be much more unwell than him. I know he really enjoys having that extra space to enjoy himself when he's not in



100%

of patients and families on the cardiac and neurosciences wards now feel the wards are spacious compared to 38 per cent and 68 per cent respectively on the old wards. 94%

of patients and families on the new neurosciences ward feel there is enough privacy compared to 60 per cent on the old ward. "The staff room is nice and bright and is a good place off the ward."

Great Ormond Street Hospital staff member



"The atmosphere is much better, and the accommodation and facilities for children and their families is a vast improvement"

Yvette, Mum of Charlie



"I moved over to the new Koala Ward, which is so much better than the old ward. The problems with the bathroom and parent sleeping situation have been solved."

Susanna, patient on Koala Ward

"Not only are the beds comfortable but it's nice that the curtain gives you your own space, for example if you want to read when your child is sleeping."

Cherie, Mum of Oliver

91%

of patients and families on the Cardiac Intensive Care Unit feel the ward is nice and quiet at night compared to 56 per cent on the old ward.

100%

of patients and families on the renal ward feel the beds are now suitable and have enough space to accommodate all of the equipment needed compared to 30 per cent feeling this was the case on the old ward.

"It's very user friendly, the theatres themselves are larger which is important given the amount of kit needed for operations and the video facilities for teaching are excellent."

Mr Dominic Thompson, Paediatric Neurosurgeon



2000+

stays on both Bear and Koala wards since opening.

"More space and better facilities can only have a positive impact on patient care."

Great Ormond Street Hospital staff member

18

heart transplants have been performed in the new Morgan Stanley Clinical Building theatres since its opening.



89%

of parents surveyed think the Lung Function Unit feels spacious, previously this was just nine per cent on the old unit. "Lovely. Finally theatre staff can see the outside world."

Member of the Great Ormond Street Hospital Theatre team

Objective 1 Redevelopment

Phase 2B and enabling works

The next goal in our redevelopment programme is to deliver phase 2B, which will be called the Premier Inn Clinical Building. Together with the Morgan Stanley Clinical Building, this will complete the Mittal Children's Medical Centre.

Δim

To complete the enabling works and prepare the site for construction of the Premier Inn Clinical Building to begin.

Enabling works are the preparations needed prior to construction, and include site preparation and preliminary building works to create access routes. The result is a prepared site, ready and equipped for the main body of works to begin. For Great Ormond Street Hospital, enabling works also include vacating buildings and relocating wards to suitable alternative areas across the hospital campus. This can often be a complex process.

Before building work can commence on the old Cardiac Wing, we need to move wards, teams and office-based staff out of this building in order for it to be dismantled and rebuilt to create the Premier Inn Clinical Building, and enable us to celebrate the completion of the Mittal Children's Medical Centre in 2017.

Achievement

The Phase 2B enabling works are highly complex but are underway. They have included identifying the new locations needed for wards and offices that were based in the old Cardiac Wing. Subsequent careful planning for ward moves and departments has taken place so the transition to new locations has been seamless both for patients and staff. A range of ground works have also begun, such as laying foundations and installing essential drainage systems. Other important developments as part of the enabling works include reinforcing the structure at Level 3 of the Variety Club Building to allow the new state-of-the-art paediatric angiography suite to be

constructed. The paediatric angiography suite will be used for interventional radiology, which involves diagnostic and treatment procedures guided by ultrasound or X-ray images.

As a result of the reinforcement works taking place on Level 3 of the hospital, an exciting and much needed opportunity arose to refurbish the main hospital reception. This is now well underway and we aim to open a greatly improved reception in spring 2014 that among other things will help families better navigate their way around the hospital and aims to improve their overall experience.

We have also made significant progress with the design of the Premier Inn Clinical Building, and will continue to engage with clinical staff and families to ensure the new facilities meet both the needs of staff and those of our patients and families.

Impact

The enabling works have been progressing well and as a result will allow us to commence construction work on the old Cardiac Wing in summer 2014.

A number of the location moves for the 2B enabling works will provide improved facilities. For example, when we open the new paediatric angiography suite, together with the refurbished main hospital reception, these facilities will make a significant difference to patient care and how patients and their families experience the hospital.

The phase 2B enabling works have kindly been funded by a number of generous donors including the Thompson Family Charitable Trust.





Objective 1 Redevelopment

Our aims for Phase 2B and 3A

Phase 2B

Our ambitious four-phase redevelopment programme aims to rebuild two-thirds of the hospital site over a 20-year period. We are now focused on raising the outstanding £30 million in order to finish phase 2. Looking ahead, we aim to open the Premier Inn Clinical Building, which will complete the Mittal Children's Medical Centre in 2017. This will see the hospital's vision to provide modern facilities for all our acute inpatients become a reality, where a parent or carer can stay comfortably by their bedside.

We have worked closely with the hospital to develop an effective fundraising strategy for phase 2 of the redevelopment programme and are continuing to implement this in order to reach the phase 2 income target of £321 million.

Over the coming years we have many exciting challenges ahead. In the next year we aim to achieve significant progress in constructing the Premier Inn Clinical Building. The key milestones we are currently working towards include:

- · going out to tender for a contractor
- · appointing a contractor
- demolishing the old Cardiac Wing, which is due to commence in summer 2014
- completing construction of the Premier Inn Clinical Building by the beginning of 2017
- opening the completed Mittal Children's Medical Centre in autumn 2017

Phase 3A

In addition to fundraising for the completion of phase 2B, we are also concentrating our fundraising efforts on raising funds for phase 3A of the redevelopment programme, the Centre for Children's Rare Disease Research at Great Ormond Street Hospital. This £85 million translational research facility will be a world-class multi-disciplinary centre of excellence that will bring together clinicians from Great Ormond Street Hospital and researchers from the UCL Institutes of Child Health and Cardiovascular Sciences.

Using cutting-edge technologies, the centre will focus on better understanding certain types of rare diseases and rapidly translating these findings into treatments for our patients. Having already purchased the land for this project, most recently we have taken a significant step forward with this project in appointing architects Stanton Williams. We are now looking forward to working with them to create a design that will maximise the space available and facilitate cross-team and cross-discipline working. When funding is secured, the existing building will be demolished and a new purpose-built research centre will be created, housing laboratories, manufacturing facilities and clinical and research offices.

The development will also provide much-needed outpatient clinical space, completing the translational research circle from pure research to practical patient treatment.

Objective 2 Research

Great Ormond Street Hospital has always been at the forefront of ground-breaking research into childhood illnesses. Research is crucial for new and better treatments, while maintaining our position as a world-class centre for paediatric research.

Last year you helped us invest £14.1 million into research, making us the largest dedicated funder of paediatric research in the UK. One of our key areas of focus last year was cancer, and we committed £3.8 million towards cancer projects that will have most impact for children at the hospital. By better understanding the disease and discovering newer therapies, our projects are committed to improving survival rates for children with cancer.



National research funding

Aim

To make up to £2 million available for clinically-driven translational research across the UK that seeks new and better paediatric cancer treatments.

Achievement

Last year, in partnership with CHILDREN with CANCER UK we completed a national funding call for translational paediatric cancer research. We encouraged applications that aim to rapidly translate research findings to direct benefits for children with cancer at Great Ormond Street Hospital and beyond. Applicants were asked to address one of three areas:

- · developing novel therapies
- · improving clinical outcomes
- understanding and improving the social impact of therapy

Impact

We chose eight leading projects to support over three years, representing vital research that has the potential to tangibly benefit children with cancer. The work will take place at the Institute of Cancer Research, Glasgow University, UCL Institute of Child Health, UCL Cancer Institute and the University of Cambridge. Three of these projects are explained in more detail below.

We are grateful to Merrill, Amelia and Tatiana Fitzgibbons for their support towards these projects.

University of Cambridge

Professor Nicholas Coleman and Dr Matthew Murray's research could lead to developing a blood test that measures a child's response to childhood cancer treatment.

The research will look at whether short pieces of genetic code, called microRNAs, found at high levels in tumours, are also present at high levels in the bloodstream of cancer patients. If they are, the work could lead to developing a blood test that measures levels of microRNAs in the blood. Their theory is that if treatment is effective, the levels of microRNAs in the blood would drop.

UCL Cancer Institute

Professor Tariq Enver and Dr Nicholas Goulden at GOSH are collaborating with children's units at Oxford and Bristol universities to understand why cancer returns in some children and not others.

One of the challenges associated with the treatment of acute lymphoblastic leukaemia (ALL) is the cancer returning. The team think it may be caused by a small number of cancer cells that are able to persist after treatment. These resistant cells, referred to as minimal residual disease (MRD), predict whether the cancer is likely to come back. However, the cells responsible for MRD remain largely unknown and this study aims to better define these cells.

"Identifying the cells responsible for MRD will allow us to know how much leukaemia is still present in a child's blood and bone marrow at various stages of treatment. It will allow the monitoring of patient remission and could aid in tailoring treatment that best meets the need of the child." – Professor Tariq Enver.

University of Glasgow

Professor Robert Mairs and Dr Mark Gaze are working together to develop new treatment options for neuroblastoma.

Neuroblastoma is responsible for about 15 per cent of all childhood cancer deaths, yet the treatment options for children with this aggressive form of cancer remain poor. This study aims to find new treatment combinations for neuroblastoma that have a lower toxicity than current standard treatment and mean that children are likely to experience fewer side effects, such as gut toxicity and hair loss.

"Our investigations will optimise the design of new therapies for neuroblastoma while minimising side effects. Although a rare disease, our research will lead to improved clinical outcomes for patients." – Professor Robert Mairs.

"There is a need for the development of new and improved ways to diagnose and follow-up childhood cancers. This work is likely to benefit patients by significantly reducing the need for radiation exposure caused by repeated scans, or the need for further surgery for tumour samples".

Professor Nicholas Coleman





Objective 2 Research

Drug redeployment for childhood leukaemia

Aim

To identify whether existing drugs that have been clinically approved for other diseases can be used as new treatment options for childhood leukaemia.

Achievement

Childhood leukaemia is the most common form of paediatric cancer, with about 600 children diagnosed every year in the UK. While survival rates have dramatically improved, children still need to undergo quite long and intensive treatments, often with unwanted side effects, and in a percentage of children the treatment can still fail. There is an urgent need to find new therapies for these patients.

Dr Jasper de Boer's laboratory is testing up to 3,000 existing low toxicity drugs that have been clinically approved for other diseases and may have the potential to be redeployed as new treatments for two particular types of childhood leukaemia. These new treatments are likely to have fewer side effects and will reach children more quickly because they have already been tested in clinical trials to show that they are safe. This process is known as drug redeployment and it has become a major focus of cancer research because it means patients will have access to new treatments faster.

Dr de Boer says: "The cost of discovering new treatments has soared over the last 20 years. Drug redeployment offers an alternative and cost-effective approach to identifying new drugs for leukaemia by using medicines that are known to be safe."

This work has been generously supported by The Alternative Hair Charitable Foundation and Richard Wright.

Impact

This innovative route to discovering effective new treatments will significantly reduce the time and costs associated with taking a new drug from the bench to the bedside, which can often take 10 years or longer. As a result, children can benefit from new treatments as quickly as possible. Great Ormond Street Hospital and its academic partner, the UCL Institute of Child Health, provide an excellent environment for this type of clinically-focused research. State-of-the art facilities such as the Somers Clinical Research Facility provide the support required to test any new drugs that are identified.

Dr de Boer says: "In the last 10 years only one drug has been approved for use in the treatment of childhood leukaemia. Our research is adopting a different strategy to develop new therapies for certain types of leukaemia. Funding for this research is vital as it offers a real opportunity to identify new drugs to overcome the side effects and length of current treatments."

Objective 2 Research

Face Value

Aim

To improve the clinical outcomes for children born with a rare facial condition known as craniosynostosis.

Achievement

Craniosynostosis is a rare birth defect in which different sections of the baby's skull fuse too early during pregnancy, possibly weeks or months before a baby is born. This restricts the baby's head and face from growing and developing normally. The irregular shape of the baby's skull can cause problems including a build-up of pressure, visual impairment, breathing difficulties and can restrict the growth of the brain, so children need surgery soon after they are born to try and correct the shape of the head.

The Craniofacial Surgery team at Great Ormond Street Hospital performs pioneering surgery to treat these children by gradually repositioning the face. The procedure has significantly improved outcomes for children. However, at the moment, the team has no exact way of knowing how successful the operation will be to restore normal shape. Through an ambitious five-year programme of research – the Face Value project – world-leading craniofacial surgeons Mr Owase Jeelani and Mr David Dunaway will explore innovative surgical devices and techniques that will help them to more accurately restore the shape of a baby's head and face. We are grateful to the Beckwith family for helping establish the Face Value appeal.

Earlier in 2012, the Craniofacial team took part in a collaborative project, Me in 3D, at the Science Museum, to define the key features of a normal face. Using high-tech cameras, the group collected 12,000 three-dimensional scans of people's faces. The Face Value team can now use this information for planning a child's surgery, because it gives them a baseline for what is considered 'normal'.

The novel devices that will be used during surgery, known as distraction devices, apply gentle force to shape the bone in a particular direction. The idea behind this is to push apart the bones as they grow and make space within the skull. This builds on the team's earlier work using custom-built springs, but now aims to give more precise control over the level of force applied.

Impact

Face Value's aim is to have a significant impact on the lives of children with craniosynostosis. The distraction devices will allow for the accurate planning and delivery of surgery, making surgery safer, more effective and less invasive.

The information collected on face shapes from the Me in 3D project will help the team to plan operations better for children, moving away from a 'one shape fits all' approach, towards surgery which is tailored to each child's unique face shape. The distraction devices will also precisely control where the bones of the face and skull end up following surgery. The combination of these approaches will facilitate the accurate planning and delivery of surgery.

The opportunity to develop better distractor devices will also circumvent the need for more invasive surgery because they do a lot of the work. The use of these devices will also mean that children may be less likely to need the external frames that are currently fitted to the child's head for many months afterwards, which can be cumbersome for children.

Mr Dunaway is optimistic about the impact this research will have on children with craniosynostosis: "Children with craniosynostosis undergo multiple operations. I think it is only right that as one of the largest institutions in the world conducting craniofacial work we strive to develop better surgical techniques to benefit these children. We hope this will contribute to transforming their lives and allow them to lead a normal and fulfilling life".

The Me in 3D project was a collaborative effort involving Great Ormond Street Hospital, the Science Museum, University College Hospital and the Eastman Dental Hospital and the UCL Eastman Dental Institute.

"I think it is only right that as one of the largest institutions in the world conducting craniofacial work we strive to develop better surgical techniques to benefit these children."

Mr David Dunaway, Consultant Plastic Surgeon



that causes premature fusion of different sections of the skull.

"Oscar was first transferred to Great **Ormond Street Hospital when he was** three months old and at the time we were quite frightened. Since then he has needed seven operations to relieve pressure on his brain and eyes and to help him breathe more easily. Putting

we know they're essential for Oscar. When Oscar is older he'll need another major operation at the hospital to help reshape his skull so that his brain can keep growing. This is why we set up the Face Value appeal to support craniofacial surgery research.

"Owase Jeelani and David Dunaway in the hospital's surgery team have been

to helping Oscar and the many children like him and are constantly working to improve surgery for these children. Having heard how their work is moving the field forward we have total faith in what they are doing. Developing these life-changing techniques will improve the outcome of craniofacial surgery for so many other children like Oscar and help them live normal lives."

Objective 2 Research

Livingstone Skin Research Centre for Children

Aim

To establish the Livingstone Skin Research Centre for Children, the first centre in the world dedicated to skin biology research in children.

Achievement

The Livingstone Skin Research Centre for Children was established as the first children's skin research centre in the world. It brings together leading scientists and clinicians in skin biology from across Great Ormond Street Hospital and its academic partner the UCL Institute of Child Health, to find new treatments for a range of skin diseases. It will build on an already established foundation of skin research thanks to the generous support of lan and Natalie Livingstone.

The centre will focus on new treatments for skin barrier diseases, such as eczema and Netherton syndrome, a rare condition causing skin inflammation, itching, severe dehydration and stunted growth. The centre aims to translate discoveries in the laboratory into clinical practice. As lead scientist for the centre, Dr Ryan O'Shaughnessy has shown how this approach has already identified a number of new therapies for an inherited skin disease, which causes a dark reptilian-like appearance over the skin, known as lamellar ichthyosis.

Using his experience in skin research, Dr O'Shaughnessy has been able to successfully grow both normal skin and skin resembling lamellar ichthyosis in the laboratory. By comparing the difference between the two, he has found a number of molecules that are present in greater levels in the lamellar ichthyosis skin.

As a result of this research and by working closely with dermatologists at the hospital, a drug to block one of these molecules, Interleukin-1A, is being explored as a first-in-human clinical trial for treatment of this condition. This is a promising development for children with lamellar ichthyosis who currently rely on managing their disease through either drugs known to cause unpleasant side effects or spending several hours a day moisturising their skin.

Impact

As the largest organ in the body, skin acts as a barrier to protect the body from infections and injury. However, when skin fails to function properly because of disease, it is very visible. Dr O'Shaughnessy's work has shown the benefit of modelling the disease in the laboratory for testing potential new treatments. This approach, which has been successfully used for lamellar ichthyosis, will be used for a variety of other skin conditions to try and identify potential new treatment targets.

Professor John Harper, Director of the centre and Professor of Paediatric Dermatology says: "The Livingstone Skin Research Centre for Children integrates all areas of major skin research at the UCL Institute of Child Health and Great Ormond Street Hospital. Treatments even for common skin diseases such as eczema are limited and only treat the symptoms rather than the disease itself. This new centre will provide the basic scientific foundation for identifying and developing new treatments for children with skin barrier diseases."



Objective 3 Equipment

Last year, our donors helped us to fund new specialist equipment and capital schemes worth nearly £5.5 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.

Automated DNA extractor

Aim

To improve the efficiency and increase the number of DNA diagnostic tests that the hospital can perform through the purchase of a state-of-the-art automated DNA extractor.

Achievement

The Regional Genetics Service Laboratory at Great Ormond Street Hospital provides diagnostic testing for a diverse range of inherited disorders such as Down's syndrome, cystic fibrosis, deafness, cardiac conditions, immune deficiencies and metabolic disease. Using genetic tests to establish a clear diagnosis for the patient is becoming more and more important and as a result, the demand for these tests is increasing year on year.

Purchasing this state-of-the-art piece of equipment in December 2012 has helped the laboratory to run a more efficient service, providing a seamless process of DNA extraction. Processing samples will require less hands-on time, enabling more samples to be tested and greater flexibility as well as improving DNA quality. The service is currently extracting DNA from over 15,000 samples each year and is growing at a rate of 10–20 per cent.

As DNA is now automatically extracted from clinical samples, it has freed up the time of laboratory technicians to analyse these samples. This has allowed the service to expand, with more tests being developed and carried out.

Impact

The previous DNA extractor had been in operation for approximately 10 years and was nearing the end of its life, often breaking down and putting the service at risk of delaying results. The new automated DNA extractor enables tests to be turned around quicker, providing a faster diagnosis for patients and their families. This in turn will mean that patients are able to be counselled, managed and offered the appropriate course of treatment more quickly.

Once in full operation and capacity, the automated DNA extractor will improve efficiency because it allows the processing of 48 samples per batch, instead of the usual 20. It is expected that the Regional Genetics Service Laboratory will therefore be able to meet the increased demand for testing without having to increase its workforce.

As well as extracting DNA from diagnostic samples, the machine is also used for research studies that greatly benefit the wider research community.





Objective 3 Equipment

Exercise machine for heart and lung tests

Aim

To improve and expand the service provided by the Cardiac Physiology department through purchasing an exercise machine for heart and lung tests and investigations.

Achievement

The Cardiac Physiology department provides medical and surgical treatment for children with congenital and acquired heart and respiratory diseases. They use cardiopulmonary (heart and lung) exercise tests as a key assessment tool for identifying conditions in children.

The department purchased a new exercise bike for heart and lung tests in July 2012. This monitors how well a patient's heart responds and can cope when put under stress during exercise. It is used for patients that are being treated for a range of heart and respiratory problems and need investigations and treatments. The machine is used for pre-assessment clinics before vital heart surgery, such as determining whether a patient needs or is suitable for a heart transplant. For children with particular conditions, such as pulmonary hypertension, it is essential for ensuring a child is on the right course of treatment. The equipment is also vital for managing long-term treatment for patients with very complex congenital diseases. The clinic sees up to 500 children a year.

The machine was generously funded by guests at the 2012 GOSH Ball and The Stanley Sanger Foundation.

Impact

The new exercise machine for heart and lung tests is essential for the service provided by the Cardiac Physiology department. Having replaced an ageing machine that was prone to breaking down, the new bike is more reliable, efficient, and user-friendly and produces the most accurate results available. The purchase of this piece of equipment has meant the Cardiac Physiology department has also increased the number of patients it sees.

We are now able to run long-term research projects as the new exercise machine for heart and lung tests provides high quality and consistent results. These involve patients being put onto tailored treatment plans based on the test results acquired from the machine. The clinical team can also carry out follow-up tests to see which treatment plans most benefit different groups of patients.

As a result of the new machine, more appointments are able to run on time and to schedule, so there is no delay getting results back to patients and therefore ensuring patients are placed on the best course of treatment as soon as possible. It has made a real difference for staff and the patients the department sees.

Objective 3 Equipment

Pain control pumps

Aim

To purchase pain control pumps, which are essential for providing children with effective pain management.

Achievement

Thanks to many generous donors, we have purchased new pain control pumps that are being used throughout the hospital. Pain control pumps are vital pieces of equipment, providing effective pain management for more than 2,000 children a year. Pain control pumps can be set to administer a constant level of medication, but also allow the child or nurse to safely administer additional doses of pain relief medication as and when it is required. As a result, the child feels in control of their pain and is able to manage it effectively.

Each year, for the last eight years, the Pain Control Service has seen a six per cent increase in demand for pain control pumps, and has been able to meet this demand as a result of purchasing the additional equipment.

The pain control pumps allow the hospital to meet the recommendations for Good Practice in Post-Operative and Procedural Pain Management 2012 set by the Association of Paediatric Anaesthetists.

Impact

More than 2,000 patients a year have benefited from this equipment. As a result of purchasing pain control pumps, Great Ormond Street Hospital has been able to safely care for children with complex conditions, following painful operations or procedures, and while receiving other treatments such as chemotherapy. Having pain control pumps with the ability to administer the dose of medication when needed has also meant many patients can be safely moved from intensive care to a ward.

The Pain Control Service has also been able to collect data on more than 24,000 patients who have experienced using pain control pumps. This information has been used to provide evidence for the effectiveness of this technique in children and young people, which will benefit children throughout the world.





Objective 4 Patient and family support

We believe in caring not only for the child but for the whole family. This care comes in many forms, from spiritual counselling to the provision of accommodation for parents. Last year, our donors helped us to fund £3.7 million worth of projects.

Patient and parent accommodation

Aim

To support the families of children receiving treatment at Great Ormond Street Hospital (GOSH) by providing nearby accommodation including:

- The upkeep of 30 rooms in the Paul O'Gorman Patient Hotel, part of Weston House, which provides overnight accommodation for a child and their parents or carers before their admission to GOSH for an inpatient stay, daycase procedure or after their discharge.
- The upkeep of eight self-contained flats in which families can learn to provide the specialist care their child needs before they return home or to their local hospital.

Achievement

Thanks to a number of generous supporters last year, including Centre Parcs UK Limited, we were able to provide accommodation free of charge in the Paul O'Gorman Patient Hotel, located across the road from the main hospital entrance, for thousands of patients and their families.

Weston House provides a "home away from home" for our patients and their families, with kitchens and facilities where families can eat together. There are phones in each of the

bedrooms that connect directly to the hospital, so parents can be in contact with the wards when needed.

The hospital has also begun to change its model of care through providing both short stay accommodation to facilitate day treatment patients and also long term accommodation for families of children with complex needs who benefit from learning the skills they need in a homely environment before taking their child home.

Impact

Being able to stay at the patient hotel the night before an appointment minimises the disruption to a child's routine and reduces stress for the whole family. It has proved to be particularly beneficial for children with a long distance to travel. For some families with early morning appointments/admissions, travelling into London before 9am can be both costly and unsettling for a child, especially if the child has to fast for 24 hours prior to blood tests and surgeries. Providing this type of accommodation has also freed up beds on wards, enabling us to admit more critically ill children who do need to stay in the hospital overnight. In addition, the eight transitional care flats have provided a supportive home-from-home environment, enabling parents to practise how they will care for their child when they get home, while they are still close enough to the hospital to ask staff for help if they need it.

Robyn's story

For 10-year-old Robyn and her parents, Great Ormond Street Hospital is a very special place. Robyn has achondroplasia, a disorder of bone growth that causes the most common type of dwarfism. Since first coming to Great Ormond Street Hospital, Robyn and her family have made the journey to the hospital from Pembrokeshire in Wales more than 40 times, for pre-op appointments and operations. When she comes to the hospital they stay in the patient

accommodation. Robyn's mum, Jane, said: "I can't say enough how fantastic GOSH is. It's really changed Robyn's life. "Not only has she received fantastic care, she's also grown into a confident young girl. "GOSH is a long way from home as we live in West Wales. So it's fantastic to know that we've got somewhere to stay when we come for appointments and that we can cook healthy meals for the family."





Objective 4 Patient and family support

The Play team

Aim

To provide support and a welcomed distraction for patients and families via play and play therapy.

Achievement

Children in hospital often feel they are missing out on what is happening in the outside world and struggle to cope. The Play team tries hard to counteract this by working closely with patients and families to provide lots of fun activities tailored to the interests of each child. Working with children over a wide age range, from birth to 18, the Play team arranges special celebrations for birthdays, or to mark big events. This helps patients maintain some normality and ensures children don't miss out on being children.

The Play team uses a range of distraction techniques to take a child's mind off the experience of being in hospital. Play specialists provide a vital service in helping to prepare children for procedures to give them the tools they need to cope with what is about to happen to them. It is normal for a child to be afraid in hospital and play specialists help children realise it is ok to be scared. They use a range of distraction techniques to support the child and young person during treatments and procedures. This helps to empower children and show them they can still have choices and some control over what is happening to them.

Play specialists offer support not only to the patient but to the wider family. They work with siblings to help them understand what is happening to their brother or sister. They also look to ease parents' stress and give them the opportunity to have a much-needed break, if only for an hour. The Play team also helps free up nurses' time so they are able to deliver clinical care. The service the Play team provides is invaluable.

Impact

The Play team is a crucial part of the hospital and the patients' treatment, and can mean the difference between a successful or an unsuccessful stay at the hospital for the patient and their family.

They enable children to get better by showing them how to cope with their situation and help children realise that fun things can happen in hospital. If a child is too sick to leave their bed to go and play in a playroom the Play team will go to the child to help them play. Often it is the play specialists (among other staff) who build the strongest relationships with patients, giving the child someone they can talk to and ask the questions they are often afraid to ask.

Many children at Great Ormond Street Hospital are also at key developmental stages and often have to be in hospital long-term. It is important they continue to develop where they can and the Play team plays a vital role in this.

In helping to prepare patients for procedures ranging from blood test to organ transplants, the Play team works together to ensure the smooth running of day-to-day hospital work. If a child has gone through a difficult procedure, the Play team will work with a child to 'play it out' using post procedural play to enable them to come to terms with the experience.

Senior Play Specialist Janet Holmes says: "If you take play away from a child it's totally abnormal. That's what we're here for: to try and put some normality back in an environment that isn't normal to a child. We help children find ways to cope. We show them they can have fun and be in control in hospital."

Having a full-time Play team at Great Ormond Street Hospital has been made possible thanks to a number of generous donors.







Looking forward Our Chairman's report

I must begin by thanking all of you who have supported the charity in the past year. This support has come in a range of forms - from fundraised and sponsored income to legacies and gifts from individuals, foundations or corporate partners. Your generosity in time and money has made a tremendous difference to the vital work of the hospital and we are very grateful to you.

This year, we need to raise more money towards the hospital's redevelopment to enable us to complete the second part of the Mittal Children's Medical Centre, Located in the heart of the hospital, the Premier Inn Clinical Building will be constructed on the space currently occupied by the old Cardiac Wing, which badly needs updating. The new building will be adjacent to the Morgan Stanley Clinical Building and importantly on the same levels, enabling clinical teams to move seamlessly between wards, transforming working methods for many teams.

The new building will contain new surgery and respiratory centres as well as providing much better facilities for patients with skin, rheumatic or immune conditions or those with infectious diseases, all of whom need to be in special isolation rooms. It will also contain new operating theatres and a post-anaesthetic recovery unit.

We will also be focusing on raising funds to build a new Centre for Children's Rare Disease Research. This is an important new development for the hospital, for UCL and for the charity as we work together to ensure that we are able to realise the potential from scientific breakthroughs and new medical techniques such as stem cell technology

and gene therapy. These new techniques offer new hope, particularly to children with rare conditions, some of whom currently have very limited treatment options.

Alongside laboratories and manufacturing facilities, the building will also include a new and much-needed outpatients department for the hospital. This will include clinic space for some of the research active clinicians based in the centre, further reinforcing the organisation's commitment to translate research into clinical care as soon as possible.

This project has been boosted by a grant to UCL of £10m from the UK Research Partnership Investment Fund in recognition of the importance and potential for this type of research. The charity is now working with our senior leadership board chaired by John Connolly, to begin fundraising for this important new initiative. We are waiting for the final plans from the architects but anticipate we will need around £70 million to complete the centre.

Redeveloping the hospital, together with the continued demand for new equipment, research and welfare and enhancement projects mean that we will continue to rely on your generosity and support. Together we can help the dedicated staff at the hospital provide the highest quality care to their young patients and families.

Alan Hodson Chairman

Our objectives for 2013/14

Our objectives for 2013/14 continue to focus on putting the child first and always and supporting our remarkable patients and families who need the hospital today, as well as helping children who may need the hospital in the future.

Fundraising

To raise £65 million.

Redevelopment

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

- continue the phase 2B enabling works to make the site ready for construction
- go out to tender and appoint a contractor for the Premier Inn Clinical Building
- empty the old Cardiac Wing so that demolition can commence in summer 2014
- work with the newly appointed architects to design the new Centre for Children's Rare Disease Research (phase 3A).

Research

We will run two funding calls next year, with a focus on rapidly translating research findings to clinical practice so as to tangibly benefit children treated at the hospital and beyond. Clinical Research Starter Grants will ask investigators to focus their research question on a clinical problem that is faced by the hospital. The theme of our national call for research projects will be the identification and validation of biological markers or 'biomarkers', that could be used for the diagnosis or treatment of particular children's diseases.

As the UK's leading dedicated paediatric research funding charity, we will also support around £2 million of new projects, senior researchers and PhD students at the UCL Institute of Child Health, the hospital's academic partner.

Equipment

We aim to fund around $\mathfrak{L}2$ million worth of new medical equipment for the hospital. These items are prioritised by the hospital, according to its most urgent needs, and range from volumetric IV pumps (£1,800 each) to high-tech automated immunoassay analysers for new-born screening (£200,000).

Patient, family and staff welfare

We aim to fund at least £3 million worth of welfare and enhancement projects, which provide additional help and support for patients, their families and hospital staff during very difficult times.

Our funding priorities for 2013/14

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 a patient isolation bedroom with en suite bathroom in the new rheumatology, dermatology, infectious diseases and immunology ward: £100,000
- fund an interview room where parents can speak privately with clinicians: £50,000
- equip a patient bedroom in the new surgery centre: £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 treating children's diseases: up to £1 million
- fund clinically-focused research projects at the hospital: up to £500,000
- support a clinical researcher working on the evaluation of long-term outcomes for children with specific inherited heart defects: £200,000
- support a clinical researcher who will look to develop and test novel assessment and intervention tools for children with visual impairment: £65,000

Equipment

It is essential that our exceptional doctors and nurses have state-of-the-art equipment to provide children with world-class care.

We need

- equipment for the expansion of the Neonatal Intensive Care Unit and Paediatric Intensive Care Unit so we can treat more children: £353,000
- a piece of equipment called a MALDI-TOF to aid in the rapid identification of the bacteria causing an infection in a patient: £120,000
- mobile X-ray units for safe imaging for post-operative patients who are too unwell to be moved: £36,000
- a phantom (dummy) that simulates children's bodies and is used to check CT radiation exposure: £14,000
- patient beds for our new surgery centre: £2,000 each

Family accommodation

For many families, visiting the hospital can be a stressful experience and it is vital that we can support them during this difficult time. There can be no better care and reassurance for a child than to know 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 daily upkeep of a room for a parent or family member to stay overnight near their sick child: £12



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 the inspiring patients and the remarkable staff at the hospital, thank you.

Thank you

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Thank you

We would like to thank all of the board and committee members who give their time and energy to help the charity in its fundraising.

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Andrew Taee

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

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

This *Impact Report* is available to view at www.gosh.org

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