

Helping Hands



**Making a
difference
for every
child, every
day**

Maryam, age 7



royal manchester
children's hospital **charity**

supporting excellence in treatment, research and care
Registered charity number 1049274



Miles, age 1

Investing in the future of children's health – caring for the whole family

Welcome to Helping Hands

Our Charity exists to support excellence in the treatment, research and care that we provide to our young patients, today, and every day.

We could not do this without the incredible generosity of our supporters – people like you.

Our young patients come to Royal Manchester Children's Hospital not only from the North West but also nationally and internationally. We are the largest single site children's hospital in the UK, offering specialist services including bone marrow transplantation and paediatric intensive care.

Thanks to your support, we continue to help the hospital to offer our patients the best possible care by developing and delivering world-class treatment, research and care.

We have a current campaign for a helipad on the hospital site which will allow us to save even more young lives for those admitted under emergency circumstances.

We have funded ground-breaking research, into a great many childhood diseases, working with a talented group of scientists and clinical researchers. These efforts are advancing medicine and offer the promise of new treatments for patients.

This report will show you what an extraordinary difference your donations have made in the past 12 months, highlighting just some of the major projects which you have helped to fund, not only for the children whose stories you will read in these pages, but for the many thousands of young patients, whose lives will be touched by your generosity.

I hope you will enjoy reading this report and that you will continue to support Royal Manchester Children's Hospital over the coming year, helping us to continue to make a difference for every child, every day.

Thank you for making a difference.

Maurice Watkins, CBE

Chairman – Charitable Fundraising Board





Charleslyn, age 11

Our Mission

Our mission is simple: to enhance the experience of the 240,000 children cared for by Royal Manchester Children's Hospital each and every year.

We are committed to making a real difference to the lives of children and young people in our care by ensuring they continue to receive the highest quality treatment in the very best surroundings.

To do this, we focus our fundraising efforts on three key areas - treatment, research and care.

We purchase specialist equipment to diagnose and provide treatment of our young patients more quickly and easily, fund pioneering medical research to increase our understanding

of children's illnesses and the best ways to treat them, and create a child-friendly environment allowing children to feel welcome and at ease.

Over the past year we have fundraised for a number of projects across each of these areas and, thanks to your support, and many others like you, those projects are already benefitting children and their families, making a difference for every child, every day.

Treatment



Samuel, age 1

Standards for clinical care continue to grow as advances are made in both technology and medicine, allowing for swifter and more accurate diagnoses and improved treatment. Your support enables us to provide our hospital with the very latest state-of-the-art equipment so that we can continue to provide our patients with the very highest standards of care.

Argon Plasma Coagulation (APC) Machine

One of the many side effects that cancer patients suffer as a result of chemotherapy can be painful bleeding ulcers inside the body. The removal of these ulcers currently involves endoscopic surgery, a painful procedure which cuts away the damaged tissue. This procedure can sometimes result in significant blood loss, which can be particularly dangerous in very small children.

An alternative to invasive surgery is treatment using an APC Machine. By electrifying a stream of ionised argon gas APC accurately destroys the damaged tissue whilst simultaneously minimising blood loss, making the procedure safer and reducing the risk of possible complications.

Thanks to your help and support we have been able to purchase an APC Machine. This treatment can now be used across a wide range of procedures throughout the hospital, greatly reducing the amount of pain the child experiences, speeding up recovery and allowing them to leave hospital sooner.

£29,000
raised



**Elijah,
age 1**

Sonosite Ultrasound System

£42,000
raised

With over 9,500 surgical procedures carried out in our hospital each year, the need to ensure safe and effective treatment with minimal complications and swift recovery times is vital. Ultrasound is a hugely effective tool in achieving this, providing anaesthetists and surgeons with very clear images without the need for X-ray and therefore allowing for highly accurate placement of pain blocks during a wide range of surgical procedures. This, in turn, reduces a child's post-operative pain, allowing them to become mobile more quickly and ultimately enabling them to leave hospital sooner. A Sonosite Ultrasound System makes the most accurate placement of pain blocks possible, ultimately meaning we can help more children to go home sooner.

This invaluable tool also ensures successful first-time insertion of central venous lines, very accurate injection of Botox into the joints of children with very limited movement due to muscle spasticity, and assists in procedures from a wide range of specialties, including orthopaedics, burns and rheumatology. With your help we have now been able to purchase a Sonosite Ultrasound System which allows us to do so much more, reducing complications and ensuring safe treatment for our young patients.

Flexible Ureteroscope

Children with kidney stones often have to undergo invasive and often risky surgery to have them removed, resulting in a painful healing process and permanent damage to the muscle and skin.

Thanks to your support we have been able to supply our clinicians with a Flexible Ureteroscope to remove the stones without the need for surgery, greatly reducing the discomfort of rehabilitation, cutting recovery time in hospital by up to 50% and dramatically reducing the risk of infection and complications.

FUJIFILM FDR Go Flex DR Imaging System

£43,000
raised

Mobile X-ray units can be used at a patient's bedside when they are considered clinically too unwell to be taken to the X-ray department. For these babies and children it is essential that once the X-ray is taken the information it provides is available for the doctors to interpret as soon as possible. Currently the traditional methods employed still rely on the radiographers having to leave the patient's bedside to process the X-ray, often causing delays.

A Go Flex DR Imaging system allows the current mobile equipment to be adapted so that images are instantly available to the medical teams whilst still at the bedside.

Thanks to donors like you we now have this new imaging system which provides countless benefits for the patient. These include quicker assessment, diagnosis and commencement of treatment, minimal disruption if repeat X-rays are required and reduced handling of patients, lowering the risk of both infection and the possibility of disturbing lines and tubes.

£20,000
raised

Research

Congenital Hyperinsulinism of Infancy

£23,500
raised

Building
a healthier
future for our
children

Congenital Hyperinsulinism (CHI) is a rare condition which causes blood sugar levels to fall extremely low because the body produces too much insulin. The current treatment for CHI is diazoxide which has a number of side effects such as cardiovascular complications and excessive hair growth on the body. With your generous support, our researchers have discovered that the use of fish oil not only reduces these complications but also lessens the hypoglycaemic dips associated with brain injury, thus improving long-term outcomes for patients.

Thanks to your donations, the team are now recognised as one of only two highly specialised centres for CHI in the UK, securing a National Institute of Health Research (NIHR) Rare Diseases Translational Research Collaboration and working on a project to provide the pre-clinical development of a new drug for a type of CHI with no current medication. The condition is typically treated by near-total removal of the infant's pancreas and researchers believe this new research will have a major impact on future treatment and reduce the need for surgical intervention.

Meet Lennie

Four-year old Lennie suffers from side effects from the medication he takes for a rare and potentially fatal condition, Congenital Hyperinsulinism.

Diazoxide stabilises his blood sugar levels but comes with a horrible side effect – excessive hair growth. Thick hair started to quickly grow on his arms and lower back, it was really stressful, not just for Lennie but for the rest of the family too, who were worried about how unusual the hair looked on such a young boy and what it would be like if more hair grew over time.

Thankfully, Lennie's doctors were running a study into fish oil extracts and started to give him the fish oil supplement alongside his

medication and the results have been great. Not only has his hair growth lessened, but Lennie's diazoxide dosage has been reduced as the fish oils are maintaining his sugar levels so well.

"No parents want to see their child on lots of medication so we're thrilled with the outcome. Research like this is so important to the NHS and to improving people's quality of life. Not only does it lead to the development of better treatments and medicine, it also helps raise awareness of rare disorders like congenital hyperinsulinism."
Laura, Lennie's mum

Lennie, age 4



Defining the Development of Severe Kidney Failure in Children

Kidney failure is a serious condition in which the kidneys fail to adequately filter waste products from the blood. Thanks to your support, researchers in our Paediatric Nephrology Department are conducting a review of 100 children and young adults with severe kidney failure, many with an uncertain primary cause.

This review provides detailed interviews about patient and family histories, allowing the team to correlate the interviews with patient notes and any genetic tests performed. This crucial information will give researchers a comprehensive set of data to help define the development of this disease for future generations.

£17,500
raised



Lexie, age 6

Developments in the Treatment of Sanfilippo Syndrome – the long lasting difference your support can have

Charitable donations help our state-of-the-art Children's Clinical Research Facility to develop treatments to help children with a great many rare diseases, including Sanfilippo Syndrome, a condition for which there is currently no effective treatment.

Sanfilippo Syndrome is a very rare disease caused by a deficiency in the enzyme needed to break down food, creating a build-up of chemicals, or poisons, in the body. This leads to brain disease causing patients to suffer severe neurological problems including progressive dementia, aggressive behaviour when young, loss of vision, hyperactivity and an inability to sleep for more than a few hours at a time. Sanfilippo Syndrome is most commonly diagnosed in a child's pre-school years and many sufferers do not survive past their mid-twenties.

Previously, support from our donors enabled the development of a gene therapy treatment in which the enzyme in a bone marrow transplant could be increased, correcting brain function and hyperactive behaviour in mice with Sanfilippo.

Now, thanks to the support of our donors, and working alongside a new therapeutics company, our researchers are set to take this gene therapy to human trial.

This new clinical study will aim to explore whether stem cell gene therapy can be used to produce blood cells that express corrected versions of the missing enzyme in humans. If our researchers can show that it is possible to treat single gene brain diseases, such as Sanfilippo, with stem cell gene therapy, this will pave the way for treatment of other inherited metabolic and neurometabolic disorders for future generations of children.

Care

Visiting hospitals and meeting doctors and nurses in an unfamiliar and clinical hospital environment can be extremely intimidating for a child. Projects supported by the Charity help to ease this anxiety by creating a less clinical environment and helping patients and their families feel welcome and comfortable during the most stressful of times.

Enhancement of the Paediatric Emergency Department (PED)

Every year, the Paediatric Emergency Department sees approximately 46,000 children of all ages from across the North West. Every visit is, at best unplanned, and at worst an emergency, often creating high levels of anxiety in both the child and their family. Whilst the PED provides the highest level of clinical care, the facility itself was stark and unwelcoming, lacking any opportunities for play or stimulation.

Studies have shown that diversions such as play and stimulation can greatly help to relax and reassure young patients, reducing stress levels and subsequently making assessment

and treatment easier for our medical teams to complete.

With your generous help, the department is currently undergoing a major refurbishment programme which is due to complete later this year. The programme will introduce facilities for play and entertainment, artwork to stimulate and distract in both corridors and treatment rooms, and a colourful and welcoming introduction to the hospital from the moment a patient and their family arrives.

£185,000
raised

Enhancement of the Bone Marrow Transplant Unit (BMTU)

Children undergoing a bone marrow transplant will be hospitalised for anywhere between several weeks to six months. Throughout this time they are cared for in isolation, unable to leave their cubicle throughout their stay and with only a handful of family or friends allowed to visit.

Thanks to your support we will now be able to make their long stay in hospital as pleasant as it can possibly be by providing much-needed entertainment systems and colourful artwork for each isolation cubicle, providing stimulus for young patients and the opportunity to enjoy activities with their visiting family.

Our donors have also ensured that we have also been able to provide internet access for patients and their families on the ward and more comfortable chairs and beds for parents who choose to remain on the unit with their child.

£105,000
raised



The difference charitable support can make

Meet Josh

Josh was just three years old when his parents were told he had lymphoma, a form of cancer so rare it accounts for only 3% of childhood cases of cancer every year.

Josh's treatment involved aggressive chemotherapy and he became seriously ill within days of completing his first round. The hospital became home for Josh and his family for nearly three months until, thanks to the treatment he received, he was given the all clear.

"I simply do not know how to put into words the level of respect and admiration I have for the incredible staff. No matter what was happening to us, however ill Josh became, however deep our despair at his situation, they always knew exactly what to say, how to make things seem better, somehow." - Ian Cubbin, Josh's Dad



Josh

Innovative Interactive Patient Survey App for Under 7s

Listening to patients' views and collecting their feedback is essential to providing the very best health service to our young patients. However, historically most feedback came from parents, with a significantly low number of responses from children aged under 6 years old.

Thanks to your support we launched an Interactive Patient Survey App, the first of its kind at an NHS children's hospital. Working in partnership with leading data capture and analysis specialists, we developed an electronic survey using a storybook concept 'Humphrey Bear Goes to Hospital' to allow children to engage with the story in relation to their hospital experience.

The interactive and accessible storybook is aimed at children aged 3-6 years, incorporates play for participant motivation and has an overriding educational element.

After just one month, results showed a significant improvement in responses from young children, allowing hospital staff to improve services for patients in this age group, based directly on their feedback.

£14,500
raised



Coby, age 5

Securing a healthier future for our children



Leanne, age 7

Now, more than ever, we work hard to continue to provide vital support to the hospital, allowing continued investment in state-of-the-art equipment, pioneering research programmes, therapeutic services and creating a welcoming child-friendly environment. These are just a couple of examples of the projects we hope to support throughout the coming year, but to make this happen we are reliant on the support of our donors, **people like you.**

Miltenyi Prodigy for Therapeutic Stem Cell Laboratory

The hospital's Bone Marrow Transplant Unit is a leading centre regionally, nationally and internationally; treating more than 50 children per year with blood disorders, cancers such as leukaemia, and genetic and metabolic diseases.

For some patients finding a donor match is difficult and the Transplant Team have no other option than to ask a parent to donate their stem cells. The harvested cells are then required to go through a process of manipulation by a Prodigy Machine to ensure the cells are suitable for transplant, before the final blood stem cell product is given to the child. The Prodigy Machine is also able to manipulate cells in different ways including gene therapy techniques which will help the Unit in its future gene therapy protocols.

Currently parents have to travel to London to give their stem cell donation; where the cells are manipulated,

before the final product is returned to Manchester to be given to the child as an infusion, often before the parent has returned.

We want to equip our hospital with a Prodigy Machine of its own, to ensure that families do not need to be separated during an already distressing and anxious time. Having this machine would mean that parents could make their donation at Manchester Royal Infirmary, which is co-located with Royal Manchester Children's Hospital, therefore ensuring that families can stay together and that parents are able to be with their child during their infusion treatment.

**£150,000
needed**

USCOM Non-invasive Cardiac Output Monitor

Every year, the Paediatric Intensive Care Unit receives approximately 800 admissions with a lot of these children needing cardiac support and drugs to improve their blood pressure as well as their heart function monitoring.

Presently the unit uses standard cardiac monitoring tools alongside an invasive system that requires the patient to have monitoring lines and leads inserted into their body. Not only can this cause complications for the child but can be very distressing for parents at an already difficult time.

We would like to help these critically ill children by providing the Unit with a piece of equipment known as an Ultrasonic Cardiac Output Monitor (USCOM). USCOM is a simple, fast and reliable non-invasive monitoring system that is based on ultrasound technology. Not only does the USCOM mean that the critical care team can access important and relevant data quicker, aiding the treatment process, this non-invasive method is also helping to reduce the distress experienced by the parent at the child's bedside.

£22,240
needed

Neonatal Phototherapy Treatment

In 2014, 15% of newborn babies attending our Paediatric Emergency Department required treatment for raised jaundice levels and needed to be admitted to a ward for phototherapy treatment to begin. Currently newborn babies requiring this treatment lie undressed in a neotherm unit wearing goggles to protect their eyes from the UV light. Breaks in treatment need to be taken for feeding.

With your help, we want to provide the ward with a more family-centred piece of equipment known as BiliSoft, which allows babies to be wrapped, fed and held by their parents during the phototherapy sessions.

The BiliSoft system enables a blanket to be placed in the babygrow, helping the baby and parents to interact as normal whilst treatment continues. As the treatment is unbroken, the BiliSoft enables babies to complete their treatment and be discharged more quickly.



£8,150
needed

Your support can make a difference for newborn babies

To make a donation or find out more about the projects we are supporting this year please visit www.rmchcharity.org.uk or contact the Charity Team on 0161 276 4522.



Noah, age 4

**Thank you
for making a
difference for
every child,
every day.**

Find us and follow us:

  **Royal Manchester Children's Hospital Charity**

 **@RMCHcharity**

www.rmchcharity.org.uk

Tel: 0161 276 4522

Email: charity.office@cmft.nhs.uk

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