

# YOU CAN CHANGE FAMILIES' LIVES

MANOMETRY SYSTEM

The  
Children's  
Hospital  
Charity<sub>x</sub>

# YOU CAN BRING AN INNOVATIVE PAEDIATRIC PROCEDURE, UNABLE TO BE DELIVERED BY THE NHS OUTSIDE OF LONDON, TO SHEFFIELD CHILDREN'S HOSPITAL.

This procedure is only currently offered at Great Ormond Street Hospital. You can change the lives of children who need a diagnosis.



**We need your help to develop our Gastrointestinal (GI) Manometry Diagnostic Service by funding a Manometry System.**

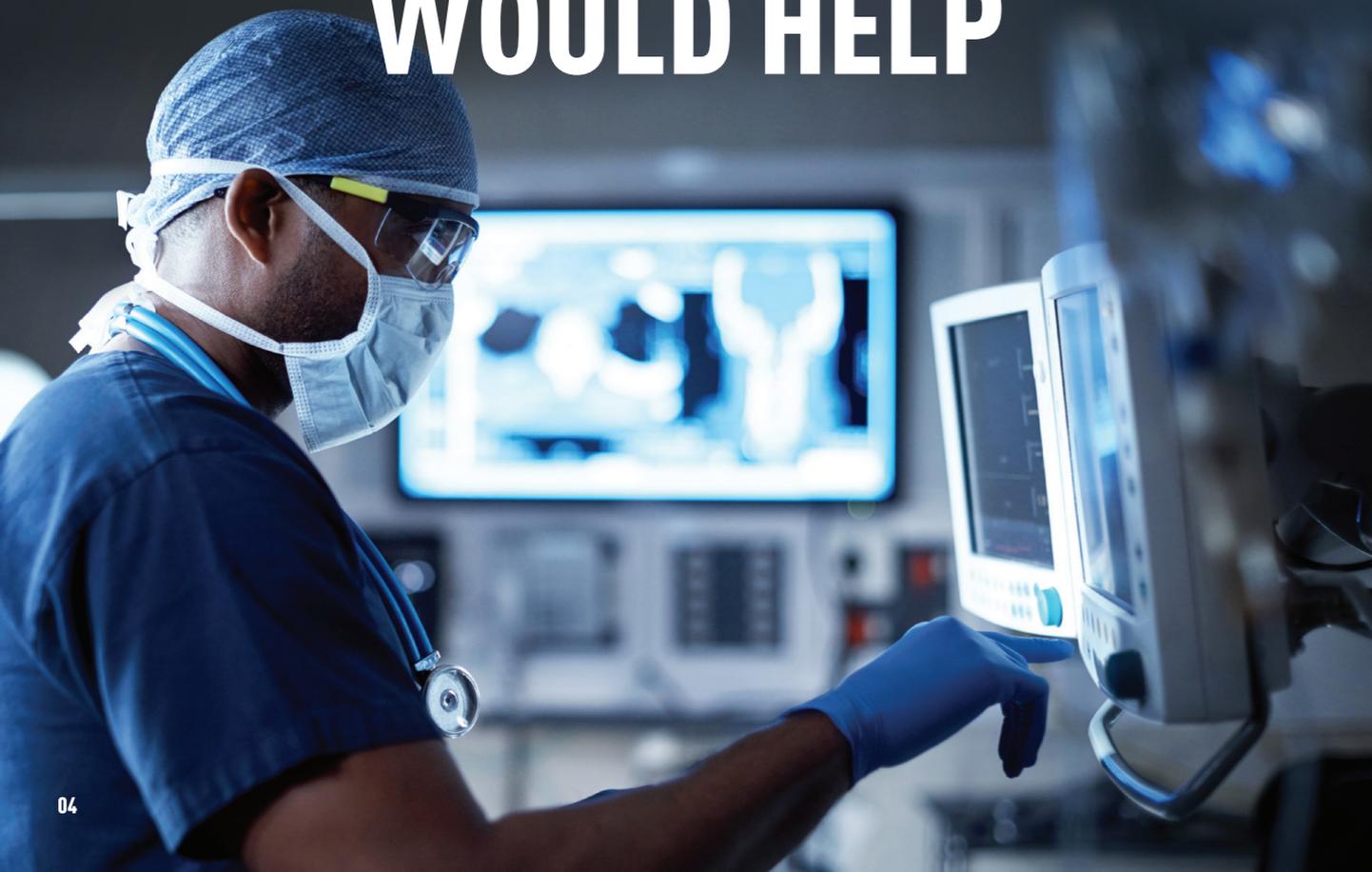
Sheffield Children's Hospital is unable to offer a comprehensive gastrointestinal physiology service for patients. Manometry tests identify problems with the movement and pressure in the oesophagus, which is a food pipe connecting the throat with the stomach. Manometry measures the strength and muscle coordination of your oesophagus when you swallow.

The two primary diagnostic tests undertaken are oesophageal (Upper GI) and anorectal (Lower GI) manometry.

**Upper Gastrointestinal:** Upper GI tests will support the diagnosis of conditions around swallowing and reflux disorders.

**Lower Gastrointestinal:** Lower LGI will support the diagnosis for pelvic floor and incontinence conditions.

# HOW A MANOMETRY SYSTEM WOULD HELP



**Manometry is the evaluation of pressure. This specialist piece of equipment uses a procedure and probes specifically designed for children to record the functionality of the muscles. This procedure is currently available for adults in the north but not for children or teenagers.**

## **This specialist piece of equipment would:**

- Test how the muscles and nerves work.
- Identify areas of abnormality in the gut as well as structural abnormalities to better help surgeons and clinicians correctly diagnose and treat patients.
- Help identify specific conditions such as Hirschprung's disease, a condition that affects the large intestine and causes problems with passing stools. The condition is present at birth as a result of missing nerve cells in the muscles of the baby's colon.
- Be used in general surgery as a multipurpose diagnostic device.

We need to bring our diagnostic service in line with paediatric hospitals in London, offering this kind of procedure for the first time in the north. Endoscopies are currently done under general anaesthetic for children, but with your help we want to do this procedure under sedation which would be an innovative procedure reducing the risk to our young patients.

## **Why is it needed?**

When these muscles and nerves don't work children can grow up with gastro problems which have both physical and physiological effects and could lead to mental health issues in the future.

- Studies have shown that the gut is the second brain and these are closely linked. Which is why anxiety and stress can link to bowel movement and gastro problems and vice versa.
- Gastrointestinal and liver disease is the third most common cause of death and the most common cause of hospital admissions.
- The only current option for patients to be diagnosed is to travel to Great Ormond Street Hospital.
- There is already a waiting list of children in need of diagnosis and treatment.

# OUR CHILDREN'S CHAMPIONS NEED YOUR HELP TO RAISE £90,000 TO HELP TO DIAGNOSE PATIENTS SUFFERING FROM GI DISORDERS.



**Currently our hospital sees around 60 patients a year suffering from problems relating to their gastrointestinal health. A Manometry System would ensure faster diagnosis for these children**

Unfortunately, this is not something the NHS can provide for paediatric care due to the number being so low. However, for those patients this can be life threatening. Gastrointestinal and liver disease are the third most common cause of death and the most common cause of hospital admissions.

Gastrointestinal problems also impact mental health. Patients who are suffering from these conditions are often also battling with low self-esteem.

We need your help to transform the lives of patients longing for a diagnosis.

# ALEX'S STORY

**Alex from Doncaster was just 14 years old when he began losing weight in April 2015. Three months later, he noticed blood in his faeces for the first time, and a three-year journey to diagnosis and recovery began.**

The immediate reaction was panic. Alex's Mum recalls: "My first thought was 'Oh my gosh- we could be talking about something really horrible here, your mind goes to the worst possible scenarios. I was concerned it could be cancer."

Alex then had a colonoscopy and gastroscopy, which revealed his digestive tracts to be inflamed and ulcerated.

The symptoms were characteristic of Crohn's Disease, a type of inflammatory bowel disease (IBD). Alex began treatment but wasn't getting better. After

an MRI scan, ultrasound and intravenous steroids during a short period in hospital the symptoms seemed to subside, but Alex was still in pain. It caused the teenager to associate eating with the discomfort, which worsened the weight loss.

**"Every time he was eating, he was suffering, so he stopped. On medical advice, we then opted to tube feed him and then move to juices for four months because it was the only way to bypass the effects on his digestive system. That was really hard, because you don't realise just how much socialising**

**revolves around food," Alex's Mum continued.**

By this time, the 5' 10" teenager weighed just seven and a half stone. An overnight pump ensured that Alex could continue to go to school, although turns in the night frequently caused the lines to dislodge and the alarm to sound, disrupting sleep for everyone at home.

Alex would also drip feed himself during school breaks and he was also stopped doing one of his favourite things, playing sport. Given the nature of the condition, only his teachers and his closest

friends knew anything of what was happening.

"People knew he was unwell, but they didn't know why. He hated to talk about it, and while teenagers tend to get embarrassed about the smallest things in life, my son felt he lost his dignity. He was sticking out for all the wrong reasons."

While it was hoped the time would allow his digestive system to repair, the reintroduction of solid foods once again caused Alex's symptoms to return.

Alex's continuing problems put a huge strain on the family, with his Dad often away with work and a younger brother at home. The wait for a confirmed diagnosis also took its toll.

"When you're told it's something, you can go away and Google. You can learn and as a parent it makes things easier- you can work with the hand that you're dealt with. It was difficult," Alex's Mum explained.

In June 2017, Alex was referred to The Northern General Hospital in Sheffield for a proctogram which finally confirmed the diagnosis

using the anorectal manometry system, shortly before the service was suspended for children.

A procedure known as a Stapled Transanal Resection of the Rectum (STARR) was performed, where a stapling device removes the prolapsing segments of rectum and staples the two non-prolapsing sections together. The operation finally stopped Alex's bleeding.

The surgery was delayed to allow Alex to sit his GCSE exams. It was successfully completed, leaving no long-term issues and he has since been discharged.

"The care was incredible from day one. At every stage, they clearly explained it and we understood what conclusions were made and why. From the nurses to the consultants, they did their best for Alex throughout and that's all you can ask for. In the end, we got there together."

His Mum was also amazed to learn the service which helped finally diagnose Alex had been suspended, with children facing similar conditions referred to London.

**"Even if we could get the most convenient appointment, it still took Alex out of school for half a day at the least. These were his GCSE years, they were crucial. To add the trouble of travelling all that way with an ill child for the testing would have been awful."**

Alex will shortly turn eighteen and is currently completing his A-levels. For the first time in three years, he is enjoying being able to fit in again with his friends and is optimistic about the future ahead of him.

"It's no longer an embarrassment because it's not noticeable. For him, that chapter is closed, and his quality of life has vastly improved. It doesn't stop him doing anything now and he feels he can take on the world again."



Alex and his family wish to remain anonymous due to the sensitivity of Alex's condition.

# THE CHILDREN'S CHAMPIONS ARE CRUCIAL IN HELPING SHEFFIELD CHILDREN'S HOSPITAL REMAIN AT THE FOREFRONT OF PAEDIATRIC CARE.

Our Children's Champions collectively fund life-saving specialist medical equipment which is above and beyond NHS provision. This unique group of individuals, companies, charitable trusts and foundations all share one passion, to help our patients and their families at Sheffield Children's Hospital. These incredible ambassadors make a significant difference to the lives of young children across the region and beyond; writing history and leaving a legacy for years to come. Here are a the champions projects together we have completed so far.



## 2015 INTRAOPERATIVE 3T MRI SCANNER

More than 6,650 scans have taken place without the need for General Anaesthetic and 2,710 scans with General Anaesthetic using the Intraoperative 3T MRI Scanner in the first three years.



## 2016 MULTI-PURPOSE FLUOROSCOPY

The Fluoroscopy Suite was used by over 1,300 patients within the first six months of its opening in June 2017.



## 2017 SPECT CT SCANNER

Opening in 2018, the SPECT CT scanner incorporates nuclear medicine gamma scanning (SPECT) with an inbuilt CT scanning function. This means images can be taken in two planes so radiologists can get the benefit of gamma and CT scanning in one session.

# The Children's Hospital Charity\*

Registered Charity No. 505002

**Find out more about how you can  
become a Children's Champion**

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**ALL OUR CHILDREN'S  
CHAMPIONS ARE  
SUPERHEROES**