

journey

core
FIGHTING DIGESTIVE DISEASES

Fighting digestive diseases

Our past, our future, and why we want you to join us on our journey

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Our
journey
so far...

Our TRANSPLANT story



Ellie (in blue) with sister, Grace, and brother, Monty, at the back



Ellie Bleiker, 13, was diagnosed with Biliary Atresia as a baby and six months ago a liver transplant saved her life. Almost 50 years since the world's first ever liver transplant, her mother Anna shares their family's story to highlight the importance of research into digestive diseases.

“ Ellie was our first child, and things were absolutely fine to begin with. But when she was four weeks old, a visiting nurse noticed Ellie's urine was yellow, which led to major tests including a liver biopsy and eventually a diagnosis of Biliary Atresia (BA) – something neither I nor my husband D'Arcy had heard of. **Ellie's Kasai operation, to create a new bile duct, was relatively successful but it was the start of a slow journey.**

We always kept Ellie as well informed as her age would allow. We were unsure for many years how long her liver would hold out for – the doctors predicted that she would probably need a new liver around the age of eight. The problem was that Ellie's Kasai really had taken a bit of time to kick-in and her liver was scarring until it did. Irreversible damage was done, and although it would work well enough for the time being, it would almost certainly not last a lifetime. **As Ellie got older, the word 'transplant' was mentioned more frequently and we were listed for transplant in October 2016.**

On the day we found out a liver had become available, we got the call at midnight and the ambulance arrived within seven minutes. We were on the ward by 5am, waiting expectantly, but Ellie didn't go to theatre until 12 hours later. We subsequently found out that our donor was on life support, and they were going to turn it off once everyone was ready and in place for the incredible multiple transplants that had been arranged following the family's consent to do so.

This was a terrifying day and night and nothing prepared us for how Ellie looked afterwards. She was utterly dwarfed by the technical equipment around her. **She had so many tubes connected to her that we could barely see her amongst it all.**

Amazingly, we were home just 12 days after the operation – testament to our brilliantly strong little girl and to the incredible work done by the NHS.

It has been six months since the transplant now, and things are remarkably different. **We saw the whites of Ellie's eyes for the first**

time after just 24 hours - which in itself was a special moment.

The itchiness that has plagued her stopped immediately, her appetite changed and she actually became nicer! The sleep deprivation had taken a huge toll on her well-being, her daily moods and her capacity to think. She had been sleep-deprived her whole life.

We are all very aware of the debt we owe to an incredible young woman who tragically lost her life, but was able to save our daughter and others. We continually thank the NHS for their incredible care and support. We owe them our family. ”

£190,000 Research Grant, Dr Neil Henderson explains:

“Biliary Atresia is a devastating condition which causes inflammation and destruction of children's bile ducts and can lead to scarring of the liver, liver failure and death. In 2014, Core provided a three-year research grant with the Children's Liver Disease Foundation to me and my team at the University of Edinburgh to help investigate new treatments. When biliary fibrosis becomes severe, the liver begins to fail and currently our only available treatment for end-stage liver scarring is transplantation. However, a shortage of donor organs means many patients die on the waiting list, and patients undergoing liver transplantation have to take immune system suppressing drugs for the rest of their life. Therefore, effective new treatments for biliary atresia and fibrosis are urgently required.”

Four decades of fighting digestive disorders

1969

Gastroenterology recognised as a speciality with Royal College of Physicians

Looking back on



With running, knitting, cycling, teaching, networking, story-sharing and lots of other fabulous events, 2017 has been a busy time for our supporters, staff and trustees.

Superstar supporters

Runners took part in the London Marathon, London 10k, Edinburgh Half Marathon, Leeds 10k and Robin Hood Marathon, and an intrepid team from Sanderson Weatherall in Knutsford cycled coast to coast (pictured below).

Two amazing supporters, individually inspired by loved ones, took on a series of challenges throughout the year to raise sponsorship for Core - thanks Ali and Chase!

Ormskirk School held their 'Shine Around the World' Fashion Show in aid of Core, a dazzling night packed full of talent and directed by the inspirational Mrs Hayley Coggins. It was even featured in Lancashire Life!

A special shout-out has to go to the **Marsh Women's Institute 'Cupcakes and Cocktails' group**, who knitted the whole digestive system using the 'knit one purl one' technique. Core's CEO Julie Harrington and Kevin Whelan, Professor of Dietetics at Kings College London, are pictured with the finished product.



Flushing the facts

We were delighted to be invited to **Alder Hey Children's Hospital** as part of their Research Day, and thoroughly enjoyed sharing 'toilet humour' with the kids, as they pulled jokes and facts out of our camping loo.

Sharing stories

We heard some powerful personal accounts from patients at the fourth **Liverpool National Pancreatic Patients Forum** in May. Amy Lucas, 28, (pictured above) said: **"I support Core in order to help others. I have quite a big story to tell. It's so sad that some people don't make it to tell their story."**

Donations inspired by loved ones

Hugh Allard, Deniece Allen, Wendy Anderson, Gillian Arrowsmith, Joyce Bell, Jack Brown, John Caddy, Edith Colville, Briony Daniels, Daphne Fallows, Arthur Gibbons, Ronald H Gilliver, Joan Goode, Alan Greenough, Jackie Grey, Rachel Louise Hawkins, Russell Henderson, Margaret Holmes, Margaret Judson, Mary Kelly, George Large, Steven Marsh, Alun Mon, Jeffrey Overend, John Quinn, Mervyn Ranford, Susan Rutherford, Jessica Samways, Hilary Sheldon, Phyllis Sinclair, Jean Steel, Margaret (Daisy) Stevens, Charles Talbot, Vera Timson, Mary Walsh, John White, Jean Wilson, Cynthia Young, Irene Marie Fletcher.

£ INCOME AT A GLANCE

Total Income at December 2016

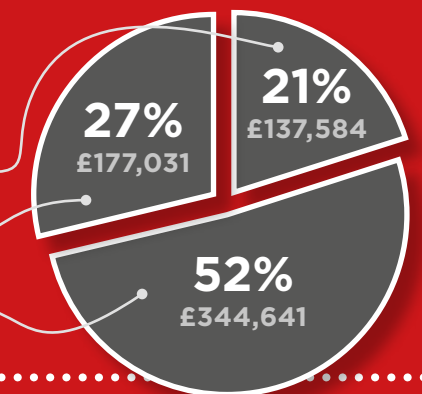
£659,256

(up 19% on 2015)

Income Generation & Governance

Retained for Future Use

Research/Info/Support



1974

Core delivers its first research grant, investigating the possibility that Crohn's disease could be transmissible

1978

Development of "pouch" rectal surgery replaces ileostomy for some ulcerative colitis patients

PAYING IT FORWARD



Money invested in research today saves lives in the future, and legacies are vital to our survival as a charity.

**REMEMBER A CHARITY
IN YOUR WILL**
Help the work live on...

In September, we joined forces with **Remember a Charity**, the largest consortium of its kind in the UK working to promote legacy giving. This year's theme for Remember a Charity Week (11-17 September) was 'Have Your Say' and teamed with a **sixties pirate radio theme** courtesy of Last Pirate FM, it was the perfect fit with Core's 40 years of pioneering research.

Our legacy legends

Professor Chris Hawkey

Our president is not just a legend in gastroenterology circles. An acquaintance of Bill Clinton and founder of the Pink Koala Club (you may well ask) he has recently been immortalised on the airwaves during Remember a Charity Week, as he discussed lifelong charitable giving and his own experiences of pirate radio in the sixties. The song he chose to 'leave behind' was ***We'll Sweep Out the Ashes in the Morning*** by Gram Parsons.

Lois Greenough

This wonderful lady has one simple aim - to find a cure for pancreatitis. She tragically lost her husband, Alan, to acute pancreatitis and has so many questions that are still unanswered. Why wasn't it detected sooner? What can we do to make sure this stops happening to families? We are delighted that Lois got to have her say on the radio during Remember a Charity week, and chose a record and a legacy to leave for the next generation. For several years now, she has created homemade cards to raise funds for Core, and is a fantastic ambassador for us, as well as a great spokesperson for relatives and patients.

Margaret Watkins

Margaret was inspired to leave a gift in her will when she heard about our research prizes for young investigators in the area of liver disease - a subject very close to her heart after her husband, Jack, benefitted from a life-saving liver transplant 20 years ago. Margaret said: *"Jack was able to return to work as a lecturer, saw his children graduate and*

get married and became a doting granddad to two boys. We had many wonderful holidays and lived life to the full. Jack died in 2006 following a heart problem, in no way connected with his liver. I want to leave a legacy to facilitate more research into digestive diseases and broaden public awareness to help more patients like Jack and give them their lives back."



Chris Hawkey below left, Lois Greenough below right, Margaret & Jack Watkins above.



Will you remember us?

As part of our partnership with Remember a Charity, Co-op Legal Services are offering a generous 20% discount on the usual price of their wills to Core supporters. Visit www.co-oplegalservices.co.uk to find out more.

1980

Classification of acute pancreatitis leads to improved diagnosis

1982

Use of endoscopes develops from "looking" to "treating"

1985

Evidence of hereditary bowel cancer leads to life saving screening

1989

The virus that causes hepatitis C (HVC) is discovered

Introducing...

After 13 years as Core, we're planning a rebrand so we can make even more impact, transform the levels of research into gastroenterology and be the leader in information services for people affected by digestive conditions.



Why the change?

Core was adopted as the working name for the Digestive Disorders Foundation charity in 2004, however, this name doesn't state clearly who we are and what we do. We need an easily recognisable name so people can access our services and support our vision.

The charity conducted some market research from November 2016 to April 2017. We surveyed 158 stakeholders and 787 patients and carers to inform the charity's decisions about the new direction of the organisation. The majority of people (73%) had not heard of Core before the survey.

Introducing Guts UK!

LEADING THE FIGHT FOR DIGESTIVE, LIVER AND PANCREATIC HEALTH

We have worked with a brand specialist agency Toucan to develop a new look. Creative partner, Kevin Frost, is a Core supporter following the loss of his brother, Stephen, to pancreatitis. He and his team really understand what we are trying to achieve.

When our survey asked patients and carers how their digestive health affects their lives, their responses were incredibly personal, honest, brave and bold. And Toucan used these values to come up with three different approaches to a new name. We then tested these again, putting patients and our loyal supporters right at the heart of our decision making. The clear winner was a dynamic, bold, 'say-what-it-does-on-the-tin' name, and Guts UK! was born.

What will Guts UK! stand for?

We believe it's time for the guts to get the attention they deserve.

Guts UK! will help people get expert information and enable them to ask the right questions. This will then speed up diagnosis, treatment and effective self management.

Research into our guts is woefully underfunded and has been for decades.

We should rival levels of investment into heart and cancer research.

With our new name and improved outreach, Guts UK! will be the voice for those who feel their digestive condition is not well understood or taken seriously enough.

Guts UK! will raise the banner for all digestive disorders to remove stigma, raise awareness and talk free from fear, shame and embarrassment.

By bringing the urgency of the patient need alongside the expertise of health professionals, together we can understand more and help others.



What do you think?

We're always listening, and we'd love to know what you think about the rebrand. Turn to the back page to find out how to get in touch with your thoughts.

1991

Possible relationship between H pylori infection & stomach cancer is first demonstrated

1993

The Wilson's disease gene (where excess copper in the body can cause organ damage) is discovered

1996

Genetic research localises genes that mark susceptibility to ulcerative colitis and Crohn's disease in families

Our research

Your donations make this happen

By funding research we can increase our understanding of digestive disorders, which helps develop more accurate diagnosis, more effective treatments and better ways to manage the disorders. And we want to make sure that nobody suffers through ignorance or embarrassment so we work to raise public awareness of digestive disorders, their symptoms and impact. We couldn't do any of this without our wonderful supporters.

Core prioritises research into six areas where research is underfunded and where we can make a significant difference.

Pancreatitis

Thanks to the Amelie Waring Foundation Fellowship and donations from our supporters, Core has been able to fund research on the causes and management of acute and chronic pancreatitis. We have made remarkable progress, though there is still much to be done. For example, even though gallstones and alcohol are common causes of pancreatitis, some episodes are caused by other factors. The new Amelie Waring Fellow, Dr Kristof Nemeth (University of Liverpool), will investigate how some medications might trigger acute pancreatitis. Dr Alastair Hayes (University of Edinburgh), the previous Fellow, focused his research on how to contain

the inflammation caused by pancreatitis, so that the damage does not spread to other organs.

Functional abdominal pain and IBS

Core understands the need for more research on the causes and management of IBS and functional abdominal pain. We also think that raising awareness and understanding of the conditions is essential. To help us do this we invited Professor Peter Whorwell and Professor Kevin Whelan to speak at our 'Exploring the Science of Digestion' public event held in Manchester on 19th June 2017. We are also supporting a study from the University of Sheffield that is trying to understand how people with IBS use phone or computer applications (apps) to log details to monitor diet and/or fitness to help them manage their condition.

Heartburn, Barrett's Oesophagus and oesophageal (gullet) cancer

Last year Core supported some really exciting research and projects on disorders of the oesophagus. In collaboration with Action Against Heartburn and the British Society of Gastroenterology, Core brought together patients and healthcare providers to identify their top ten

priorities for research on Barrett's Oesophagus and heartburn.

We are funding Professor Laurence Lovat at the University College London Hospital to investigate whether he can develop a simple saliva test to identify people at risk of oesophageal cancer - which will be more convenient and comfortable for patients, and much cheaper for the NHS.

We are also funding Dr Conor McCann, at the UCL Great Ormond Street Institute of Child Health, to do some really exciting research on two digestive disorders, achalasia and gastroparesis.

Diverticular disease

We are currently funding Dr David Humes, at Nottingham University, to investigate whether less invasive surgical techniques, such as keyhole surgery, might be better and safer for diverticulitis.

We are also supporting another study from the University of Sheffield. They are developing a leaflet that contains helpful information about diverticulitis with space for patients to write down any symptoms they may experience. Patients can then give their annotated leaflet to their healthcare provider to help explain their symptoms.

2001

The FDA approves the use of laparoscopic adjustable gastric banding as a weight loss surgery

2004

Digestive Disorders Foundation becomes Core

Core is currently funding over **£1.25m** of research across the country



- ① University of East Anglia
Inflammatory Bowel Disease
- ② University Hospital Southampton
Paediatric Crohn's Disease
- ③ Queen Mary University of London, King's College London and University College London
Barrett's Oesophagus
Children Post-Liver Transplant
Oesophageal Cancer
Oesophageal Achalasia and Diabetic Gastroparesis
- ④ University of Edinburgh
Acute Pancreatitis
Biliary Atresia and Fibrosis
Inflammatory Bowel Disease
- ⑤ University of Nottingham
Diverticulitis
Crohn's Disease
Upper Gastrointestinal Bleeding
- ⑥ University of Oxford
Colon Cancer Metastasis
- ⑦ University Hospitals Coventry and Warwickshire
Colorectal Cancer
- ⑧ University of Liverpool
Drug-induced Pancreatitis
Paediatric Inflammatory Bowel Disease
- ⑨ University of Birmingham
Alcoholic Hepatitis
- ⑩ Plymouth University Peninsula Schools of Medicine and Dentistry
Alcoholic hepatitis



Gut and liver disorders in children

Core has a fruitful collaboration with BSPGHAN, the society representing specialists in childhood gut, liver and nutrition disorders. Together we have funded nine research projects over the years. The latest two have been on Inflammatory Bowel Disease; one at the University Hospital Southampton with Professor Sarah Ennis, and one at the University of Liverpool with Professor Chris Probert. Our relationship with BSPGHAN is very important to us as it allows us to prioritise research on digestive disorders in children, who often have different needs

to adults, and for whom gut, liver and nutrition disorders can have a profound impact on growth and development.

Healthy nutrition encouraging healthy gut bacteria

Our research has always recognised the importance of gut bacteria in digestive diseases and gut health. For some time, we have funded nutrition research as a priority. We want to increase funding into research on diet and gut health and to be able to offer sound advice to people. We also want to tackle the challenging issue of obesity as we think there

are ways we can make an impact on this important area. For instance, exciting new evidence shows that gut bacteria affect the development of obesity, probably affecting appetite and eating behaviour. Core research has shown how appetite is controlled and how fizzy drinks can lead to fatty liver. But we also investigate undernutrition and have a proud record in understanding conditions that affect undernutrition in the third world.

Find out more about our research, and how you can be part of our pioneering journey, by visiting www.corecharity.org.uk

2013
The first successful faecal microbial transplantation for C difficile infection

2017
Core becomes Guts UK! and a new journey begins

Let's continue the journey together



FOR MORE ON
OUR MAKEOVER,
SEE PAGE 3

Core is becoming **Guts UK!**

We would love to hear your feedback as we start this journey to transform the landscape of research into gastroenterology.

What's your gut feeling about our new name?

We're listening.

You can share your thoughts with us in the following ways:

Write to us at **Core, The Media Centre, 7 Northumberland St, Huddersfield, HD1 1RL**

Email us at **info@corecharity.org.uk**

Call us on **01484 483123**

You can also share your views on

Twitter @CoreDDF and on

Facebook @corecharity

Will you come with us on our journey?

We'd love to keep in touch with you as we become **Guts UK!** but we want to do it on your terms. Tell us what you want to hear about, how you want to hear from us, and how often, by filling in the form that came with this pack or by visiting www.corecharity.org.uk



**Share your stories
with Guts UK!**

We've all got guts, and we truly believe they are fascinating. Tell us about yours by emailing info@corecharity.org.uk



www.corecharity.org.uk

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