

It's time the UK  
got to grips with guts!

gUTS  
UK!

Leanne

This is my  
#GutSelfie  
2022 UK!

Ross

Ian

Rachel

Jonald

Autumn/  
Winter  
2024

# Contents

- 3 •• Hello from our new CEO!
- 4 •• Sophie's diverticular disease story
- 5 •• Our Priority Setting Partnerships
- 6 •• Ian's IBS, GORD and BAD story
- 7 •• Order your FREE 'This Can't Wait' card
- 8 •• World Barrett's Oesophagus Day
- 9 •• The research YOU make possible

- 10 •• What does Guts UK mean to you?
- 12 •• Fundraising: Remembering Nicola
- 13 •• Fantastic fundraisers
- 14 •• Diane's Bile Acid Diarrhoea (BAD) story
- 15 •• The "What's Up With My Gut?" website
- 16 •• What is Kranky Panky?
- 18 •• David and Steve's pancreatitis story

YOU  
ASKED

## Do I need to take vitamins or supplements?

### A healthy diet, providing a balance of vitamins and minerals, is key.

If you are healthy, most supplements are not found to have any value for your digestive system. **Vitamin D is an exception for UK residents, especially in the autumn and winter months.** This is because the sun isn't strong enough for your skin to produce enough of it.



The NHS recommends that adults take a vitamin D supplement daily, containing **10 micrograms/400 IU (international units)**. Others who may need more vitamin D include:

- People who cover up their skin.
- People that live in care homes or shared accommodation.
- People who are of African, African Caribbean, or South Asian descent.
- People who have been told by a doctor or dietitian to take it.

**Please note, this advice may not apply to people with a digestive condition. If this applies to you, it's important to discuss your supplement needs with your doctor or dietitian.**



## Don't be a stranger!

We love hearing from you, it's the best part of our day!



@GutsCharityUK



0207 486 0341



info@gutscharity.org.uk

Guts UK, 2 St Andrews Place, London, NW1 4LB  
Registered Charity Number: 1137029

[www.gutscharity.org.uk](http://www.gutscharity.org.uk)

# Hello from our new CEO



**Our new CEO, Suzanne Hudson, reflects on her first few months at Guts UK and shares what's next for our charity.**

“ I joined Guts UK in September and already have seen and heard in volumes the unwavering dedication of our whole community, who come together to fight digestive diseases that affect millions across the UK.

I have had the opportunity to meet a number of patients, families, healthcare professionals, researchers, volunteers, and supporters of our charity and one thing is clear: there is a true sense of connection amongst all involved with our work.

We're a small national charity but our expertise and unwavering commitment is big. We've achieved so much already. From the life-changing research projects we invest in across the whole digestive system (page 9), to the impact our expert information and public awareness-raising activities have on people living with and affected by digestive conditions and symptoms (pages 10-11).

However, the demand for our support and work continues to rise sharply and significantly exceeds our size and capacity. We need and want to do more. We will continue to develop and share our knowledge about the digestive system, so that everyone affected by a digestive condition in the UK gets the information and support they need, when they need it.

As a charity, we need to develop and grow; focusing on your priority needs and ensuring your voice is heard. Funding more research that seeks to answer the right questions. Supporting more individuals, loved ones, and professionals with expert information and help. Raising public awareness and influencing for positive change. We cannot and will not do this alone. We will continue to collaborate and partner with valued healthcare and charity partners, with whom we're proud to work alongside for your benefit.

As you may be aware, we're working on a new strategy to take us to 2030. Thank you to everyone who responded to our survey. Our Board of Trustees will make final decisions in December, and we'll update and share our initial priorities with you next year. The strategy will provide the framework for everything we do in the next five years. However, we cannot develop and grow without your support - in helping us to raise awareness of digestive conditions and Guts UK, working with us including partnerships and collaborations, volunteering including our Experts by Experience and supporting us with sponsored challenges, community fundraising and donations - ensures that together, we will make a difference and help change lives.

It is an immense privilege to lead Guts UK and I look forward to working with and for you in the years ahead. Together, we can create a brighter future for everyone affected by digestive conditions.

Thank you so much for your continued support of our charity. ”

**Suzanne**





# Sophie's story

## Diverticular Disease



“ I'm Sophie, I'm 22 years old. I live in Scotland with my partner and our daughter, who was born earlier this year. ”

### When did your symptoms first begin and what were they?

“ In summer 2019 I was 17 years old, and I noticed blood when I went to the toilet. Alongside that, I'd also been having stomach pains; an intense stitch-like, uncomfortable pain around my bowels. I knew the blood was something that needed to be looked into, but I was really embarrassed, so I didn't say anything to anyone for months. ”

### Talk us through your diagnosis

“ I was diagnosed with diverticular disease and diverticulitis following tests in hospital. I was given an information leaflet and said, "I'm quite young for this, am I not?" The nurse replied, "Yes, you are." I knew about diverticular disease because my dad has it. I knew that it mostly affected people over 40, so being in my early twenties, I found it quite alarming. The diagnosis was passed onto my doctor and I was put in touch with a dietitian. ”

### How are you now?

“ Most days, I get discomfort and pain in my abdomen and see blood in my bowel movements often. Diverticular disease impacts me socially and mentally, especially during a flare up (when symptoms increase). Whilst pregnant, my symptoms did become much better. I thought, "Maybe my body is too busy building a baby!" It was the best I'd felt in a long time. ”

### How did Guts UK help you?

“ When I found your diverticular disease information online, I felt heard. I trusted it and it was good to read other stories from people with diverticular disease. It felt like they were my voice, especially as I'd felt so disheartened and brushed off for so long. I want to get rid of the stigma surrounding this condition. It took me so long to accept that it's okay to need help. I hope someone with diverticular disease reads this and feels less alone. ”



**Between 1 in 10 and a 1 in 25 people with diverticular disease symptoms develop a complication called diverticulitis. This is where inflammation and/or infection of diverticula (pockets that are around 1cm in size) within the large bowel occurs.**

**If you have symptoms, including worsening abdominal pain, high temperature and nausea (feeling sick) or vomiting (being sick), it's important to seek medical help.**



# Our Priority Setting Partnerships



Since 2021, we have launched four Priority Setting Partnerships (PSPs) to better understand what areas of research we should be funding, and to identify and prioritise the questions that you want answers to.

## What is a Priority Setting Partnership?

A Priority Setting Partnership (PSP) brings together patients, carers, family members, doctors, nurses, researchers and scientists with lived experience and expertise about a specific condition, procedure or area of health, **all with an equal voice**. Together, they decide the top ten research priorities. We work in partnership with relevant expert organisations and charities on our PSPs, which are facilitated by the James Lind Alliance (JLA).

## How does it work?

1

We identify a small steering group, made up of the above people.

2

The steering group defines what the PSP will explore e.g. causes, diagnosis, treatment and care.

The first survey is launched, to give anyone with experience of the condition or procedure an opportunity to ask their questions.

3

4

We review the survey results and summarise them into around 60 themed questions. They're then evidence checked and we remove any that have already been answered by research.

We share these questions with patients, carers and healthcare professionals and ask them to choose their top research priorities.

5

6

Around 25 questions are taken into a final workshop. Here patients, carers, family members and healthcare professionals come together to agree the top ten research priorities for the condition or procedure.

We share the results of the top ten research priorities. These priorities inform the research that we fund.

7

## Find out about our past PSPs

We have funded two PSPs: Pancreatitis and Irritable Bowel Syndrome (IBS).



**A donation to Guts UK today, could help fund the life-changing research of tomorrow.**

## Find out what's next...

The PSPs we are working on currently are for Diverticular Disease and one for Endoscopies.

Information about these PSPs, including ways to get involved, is available on our website at [gutscharity.org.uk/research](https://gutscharity.org.uk/research).

# Ian's Story

Irritable bowel syndrome (IBS),  
gastro oesophageal reflux disease (GORD)  
and bile acid diarrhoea (BAD).



IBS and BAD affect the lower gastrointestinal tract (small intestine to the anus), whereas GORD affects the upper gastrointestinal tract (the mouth to the first part of the small bowel).

“My name is Ian and I’m 44 years old. I live in Liverpool with my wife, Victoria, and our children. I spend most of my time with my family.

- 2004** I was diagnosed with IBS. My symptoms were stomach cramps and increased urgency to empty my bowels.
- 2009** I was diagnosed with GORD. My symptoms were heartburn and severe acid reflux. I had surgery to treat this, which worked for several years. I then experienced more symptoms, including belching, trapped wind, a constant bad taste, and a dry mouth.
- 2014** I was diagnosed with BAD after suffering with chronic diarrhoea and unbearable stomach cramps. My stomach felt like it was on fire and my stool was often bright yellow liquid and left me so sore. I wouldn't wish it on anyone.
- 2022** Heartburn and stomach pains were like nothing I've experienced before. After a few trips to A&E and more symptoms like violet shivering, I was told I had sepsis and was treated with antibiotics. My gallbladder burst and six months later, it was removed. Unfortunately, this made my BAD worse, which can happen after surgery.

Most days, I'm physically and mentally exhausted and constantly sore. I don't go out much in case I have an accident. It's my family that get me through. They're amazing.

I've followed Guts UK Charity for a while now and can relate to many stories that have been shared. I hope my story will help other people. ”

- Up to 1 in 10 people are diagnosed with IBS in the UK.
- Heartburn, a symptom of GORD, affects up to 1 in 4 of UK adults.
- BAD affects up to 1 in 100 people in the UK.



You can trust our evidence-based information on over 40 digestive symptoms and conditions. Scan the QR code to view our online information today.





Not every illness is visible. We designed our 'This Can't Wait' cards, with help from our community, for anyone with a digestive condition who needs to use a toilet urgently.

The 'This Can't Wait' cards are wallet-sized so can be taken with you whenever you leave home. You can show them to people in public spaces to let them know you need urgent access to toilet facilities.

**Imogen, age 4, has coeliac disease**

“We were so excited when we received Imogen's 'This Can't Wait' card. For me as her mummy, it has helped my confidence, and I feel more prepared. We haven't had to use it yet but the card is always with us when we are out. I know if ever we are caught short or are unable to find a toilet, we can present the card for access to toilet facilities.”

**Ant, age 34, has ulcerative colitis and a stoma**

“The 'This Can't Wait' cards are a fantastic idea and a great campaign. Even with my stoma, there are times where my bag might leak or I need to get to a toilet to change, so I seriously can't wait. This will help so many people and raise awareness for so many digestive conditions.”



**Shawn, age 52, has achalasia**

“When I first saw the 'This Can't Wait' card, I knew instantly that it was something that I needed to get hold of. With my condition, I have various symptoms, but I can have random bouts of sickness episodes, and if I'm out in public, being able to use a toilet for this will be a huge relief. It's a great idea by Guts UK to produce these cards. Well done!”



**Ben, age 39, has Crohn's disease and a stoma**

“The 'This Can't Wait' cards are a fantastic tool for improving your self-confidence. When you have IBD or a stoma, you can sometimes get caught short. Having the card to show in a shop or restaurant means that you have a better chance of getting the access you need without having to face talking everything through.”



**Sophie, age 28, has gastrointestinal dysmotility and intestinal failure**

“The 'This Can't Wait' card is a brilliant idea, and it was such a privilege to have been part of the focus group during the making of it! Input came from real-life people living with very real gut conditions, who need access to a toilet urgently. To have this card has made many of us feel a lot less anxious when out and about, feeling freer to go out, and it's very important we can raise awareness of it!”





# Guts UK supports World Barrett's Oesophagus Day on 16th May each year

Barrett's oesophagus is the term used for a potentially pre-cancerous condition where the normal cells lining the oesophagus (the food pipe) have been replaced with abnormal cells.



## Let's look at the facts and figures:

- Around 1 in 10 people who have persistent reflux will be affected by Barrett's oesophagus.
- The abnormal cells that develop start from where the oesophagus meets the stomach and spread upwards into the oesophagus.
- A small number of people with Barrett's oesophagus may develop oesophageal cancer, though the majority will not.

## What are the symptoms?

The main symptom is heartburn. Other symptoms include:

- Regurgitation.
- Nausea.
- A metallic taste in your mouth or a chronic sore throat, especially in the mornings.
- Reflux symptoms that wake you up in the night.
- Upper abdominal pain.

Monitoring Barrett's oesophagus is a lifelong part of treatment.



## Geoff and Barrett's oesophagus

“ I am booked in for endoscopies every few months to check for any cell changes that might suggest oesophageal cancer. When I was diagnosed around a year ago, I was told to watch my diet but given little to no direction or support. This is when I found Guts UK. ”

## Can we diagnose Barrett's oesophagus quicker?

**Dr Sara Jamel** is exploring the use of breathtesting for pre-cancerous cell changes in patients with Barrett's oesophagus.



Early diagnosis is a key strategy in cancer research, and using non-endoscopic, less invasive methods to find Barrett's oesophagus is vital to be kinder to people at a time that is often already overwhelming. These methods include saliva biomarkers, breath testing (research carried out by **Dr Sara Jamel** and **Dr Katja Christodoulou**), and the newly introduced Cytosponge® created by **Professor Rebecca Fitzgerald** and her team at the University of Cambridge. Blood markers for identifying Barrett's oesophagus are also being considered, but much more research and trials are needed before these can be used.



Dr Sara Jamel

**Guts UK has helped to fund this vital research, thanks to your support.**

# Making the future brighter through research



Since we were founded in 1971, we've invested **more than £16million** into research. We've backed **over 450 research projects** so far and we won't stop there. We'll continue to fund life-changing, life-saving digestive research to ensure earlier diagnosis, kinder treatments and ultimately, a cure.

## Liver

The liver is the largest solid organ in the human body. From processing the body's waste products to producing bile that helps us digest certain foods and minerals, the liver has an important job.

**115 research projects**  
**£1.98m in funding**

## Oesophagus

## Liver

## Stomach

## Pancreas

## Pancreas

Research into the pancreas has been underfunded for decades. We're proud to fund research that helps better understand underfunded conditions and diseases that affect the pancreas, so that people can get the care and support they need.

**41 research projects**  
**£1.63m in funding**

## Gut

With 25ft of guts to get to grips with, you won't be surprised to know that our guts have been misunderstood, undervalued and underfunded for years. We exist to change that.

**132 research projects**  
**£4.25m in funding**

## Large bowel

## Small bowel

## Rectum

## Anus

## Digestive cancers

This covers the stomach, bowel, liver and oesophagus. Many digestive cancers are considered less survivable, so it's vital that we back research that targets earlier diagnosis and improved treatments.

**56 research projects**  
**£4.1m in funding**

## Nutrition

We also fund research into nutrition, to help better understand the impact our diet has on digestive symptoms and conditions.

**28 research projects**  
**£630k in funding**

## IBD

The two main types of Inflammatory Bowel Disease (IBD) are Crohn's disease and ulcerative colitis. Both cause long-term (chronic) inflammation of the digestive tract. The cause is still unknown so it's crucial that we better understand this.

**104 research projects**  
**£3.44m in funding**



You can change and save lives. Donate to Guts UK today to support vital research.

# What does Guts UK mean to you?



We've had another incredible year at Guts UK, working towards a future where talking about digestive conditions and symptoms is not something we need to normalise. It should be part of everyday conversation.

With your support, we can reach people who are suffering in silence and don't yet know we exist. We can reach people who are yet to discover our empowering expert information and our incredible community.

## 1 Providing expert, evidence-based information

At Guts UK, we provide information to people affected by digestive systems or conditions, including families and loved ones, through ways such as email, over the telephone and on our website.

We know how important it is to have the right information. It can help people to better understand the digestive conditions that affect them and help to make informed decisions when it comes to their (or their loved one's) health. It can also help people to take back control and feel less alone.

### Your feedback means everything to us

“Thanks so much for sending such detailed and helpful information. It means the world to me that you have taken the time to explain.”

“The information on your website has helped me make so much sense whilst going through this rollercoaster ride!”

“Great quick answers from your team to specific questions I had. Your website was also very helpful and easy to navigate.”

## 2 Raising public awareness

It's vital that we take our gut health seriously. **58% of people** told us they are **embarrassed to talk about** their digestive symptoms or conditions and 51% told us that they **delay seeking medical advice** for their digestive symptoms for **over six months**.

From your real-life stories to public education events and awareness campaigns, we can't and won't stop talking about our guts.

We're here to break the taboo surrounding our poo, so that more people feel comfortable talking about their gut health and seek the help and support they need, when they need it. From attending our events, like the Science of Digestion in Hull...

“Very well put together with a good range of expert speakers and content. I enjoyed the Q&A.”

... to personal stories and experiences with our community...

“The gutsy family is the best family to be in! Thank you for all of your continued support. You've done my story such justice and helped me to have a voice and reach more people.”



Julie Thompson  
Information Manager



## Our guts have been misunderstood, undervalued and underfunded for decades. It's time to change that.

We're the only UK charity funding research into the whole digestive system, for kinder treatments and earlier diagnoses for people affected by digestive conditions.

Our community is at the heart of all we do. Patients, families and carers are central to our decision making around research. What's important to them is important to us. Together, we set future research priorities for digestive conditions.

We're proud to fund the bright, enquiring minds of tomorrow. We offer Early Career Researcher grants to researchers like Alice:



“As an early career researcher, it is difficult to obtain funding as a principal investigator, as you are not fully established in your career yet. This grant is vital, as it gives researchers early in their careers the opportunity to build their esteem within the field. Abdominal adhesions (scar tissue) is a hugely under-researched disorder and cause significant issues for patients that are affected. The project I carried out using the Early Career Research Grant has meant that we might be a step closer to identifying treatments for adhesions. The data generated from the project is now being used as pilot data for a larger Research Council grant where I aim to study how variability affects tissue thickening and scarring, and how we can use this to identify new, preventative therapies.”



**Dr Alice Laphthorn**  
Senior research fellow,  
who received an  
Early Career Research  
Grant from Guts UK

We want the research we fund to answer the questions you ask, which is why we work alongside patients living with gut conditions, like Rachel:

“It's integral that people who suffer from a condition have a voice and positively influence research. This has been the case with my involvement in the IBS Priority Setting Partnership. From the start, there was a clear and equitable power-share, where I did not feel like an outsider amongst the group. I felt valuable in the whole process and that my skills and expertise were given full and equal consideration. I expect that my participation will generate impactful research that will integrate my lived experience perspectives.”



Every day, we're helping more people across the UK to get to grips with their guts. With millions across the country affected by digestive symptoms and conditions, there is so much more we want, and need, to do.

**We couldn't do it without the support of our incredible community. Thank you.**

# Fundraising: Remembering Nicola



“ My amazing and beautiful wife of nearly 40 years, Nicola, recently passed away. She had suffered from Crohn's disease since her early twenties but despite this and all the many medical complications that were thrown her way, she loved life and made the most of her good times. Nicola would've wanted me to do one last fundraising for a little charity, and obviously one which supported Crohn's sufferers. After reading about the great job Guts UK do, I thought they were the perfect match. ”

Brian, Nicola's husband

## Ride London



Brian got a place with us in Ride London 2024 and called on family and friends to donate what they could. Brian received incredible support, raising a wonderful **£10,639**.

While Brian was ultimately unable to compete, his and Nicola's friend Ross did take part, and Brian was there to cheer him on.



Brian and his family celebrating the ride in the sunshine.

## Kiltwalk

Nicola's friend Caitlin, decided to take on the Glasgow Kiltwalk in April to honour Nicola's memory. Taking on the 23-mile walk for Guts UK, Caitlin raised a brilliant total of **£1,645**.



“ Fundraising for Guts UK is a very worthwhile cause as I think we are all familiar with someone suffering from a digestive disease . I felt a huge sense of achievement crossing the finishing line and when the last few miles felt tough, I could sense Nicola cheering me on. ”

## Pub fundraiser

In August, Brian's community pub held a Charity Music Day. They sold wristbands and badges for the event as well as tasty cakes, and received kind donations of loose change.



Brian and his friends enjoying the live music in the sunshine, representing Guts UK in their t-shirts.

# Fantastic Fundraisers



## Damien brings in the dough

Damien hosted a pizza party for family and friends, raising funds towards sponsorship for the Brighton Marathon.

“Hospitalised from a ruptured bowel and being diagnosed with diverticular disease, I found lots of helpful information through Guts UK.”

Damien raised over a remarkable **£1,000!**



## #KrankyPanky: Todd makes great strides

Diagnosed with chronic pancreatitis in 2022, Todd took on the Fleet Half Marathon to stride closer to a cure for this horrible condition.

“The invaluable work that Guts UK does is of personal significance to me and has opened my eyes to the pain, suffering and depression that others are going through.”

He raised an amazing total of over **£760!**



## Muddy mayhem for Guts UK!

Dan, Curtis, Ollie, Laura, Sara, Inderjit and Dennis got stuck in and overcame obstacles, all for those affected by digestive symptoms and conditions. All whilst dealing with their own.

“This event was very close to my heart and a very proud, emotional moment for me. It was about taking my community of strong individuals who battle a chronic illness every day and showing their true grit, determination, and belief to be able to overcome obstacles.” - Dan

Their dedication raised over an amazing **£1,250!**



## Luned takes a leap

Luned, who has gastroparesis, irritable bowel syndrome (IBS) and a dysfunctional gut, conquered a skydive for those like herself. Those who need a better future for their guts.

“I was told I was going to die in 2022. Raising money for Guts UK which is something I've always wanted to do. This will help those suffering like myself and help others get answers and support they need.”

Luned, you raised a phenomenal **£1,700!**



If our fantastic fundraisers have inspired you to support our charity, please get in touch at [events@gutscharity.org.uk](mailto:events@gutscharity.org.uk) or **020 7486 0341**. Our Fundraising team would be delighted to support you!





# Diane's story

## Bile Acid Diarrhoea (BAD)



**Bile acid diarrhoea (BAD) affects up to 1 in 100 people in the UK... but what is it?**

Bile acids are made in the liver, stored in the gallbladder, and released into the small intestine (gut) when food is eaten. 97% of the bile acids are then re-absorbed in the final section of the small intestine (ileum) and returned to the liver in a repetitive cycle. When this is disturbed, it is known as bile acid diarrhoea (BAD). Other names for this include bile acid malabsorption or bile salt malabsorption.

**“I’m Diane and I’m 58 years old. My biggest passion is gardening.**

I can track my symptoms back to around 12 years ago. I’d get bouts of sickness, diarrhoea and a lot of heartburn. I put it down to stress, but then it got really bad. I suddenly experienced intense abdominal pain and my stomach was so hard and bloated. If you touched me, I screamed. I was vomiting and had diarrhoea. Eventually, tests revealed gallstones and I needed gallbladder surgery.

I returned home the day after surgery and had diarrhoea for a few weeks. However, it didn’t improve. I was going to the toilet eight to ten times per day, and sometimes more. My poo was often yellow, and it would leave me sore.

I am part of an online support group for diverticular disease (pockets in my bowel) and I saw someone talking about Gut’s UK’s patient information on BAD. I read through the information and thought, “this all sounds familiar!”

After a few visits to my GP, I was prescribed bile acid sequestrants (the treatment for BAD). The idea was that if the medication worked, then I most likely have BAD. I was referred to a community dietitian and after I initially had doubts, she read up on Guts UK’s information and helped me to avoid too much fat in my diet with my BAD. I am doing so much better now I’m on prescribed BAD medication.

I’m so pleased I found Guts UK. They listen, and it’s so often that we don’t feel heard. It is very lonely when you first get that diagnosis. If you’re lucky, someone might hand you a leaflet. Knowing there was a support network out there, from people who care and listen, meant the world. I couldn’t have done it on my own. ”

**If you suspect you might have bile acid diarrhoea, ask your GP for a referral to a gastroenterologist for a diagnosis.**

# 'What's Up With My Gut?'

Earlier this year, we were involved in the launch of a brand new website, designed to support people trying to get a diagnosis for gut problems.

## Why was the website set up?

If you've experienced digestive symptoms of any kind, you might have asked yourself 'what's up with my gut?' With so much taboo surrounding our poo, it can feel confusing and isolating to experience digestive symptoms.

Getting the right support is so important when it comes to our guts. But we know that getting the right diagnosis isn't always easy. This website aims to tackle this problem from all sides - providing information to healthcare professionals, people experiencing digestive symptoms, and parents of young people with symptoms.

## How does it help?

The website makes the pathway to diagnosis clearer. Every day, people across the UK contact their GP to find out why they have gut problems and symptoms. Whether it's coeliac disease, irritable bowel syndrome (IBS), Crohn's disease, ulcerative colitis or another digestive condition, getting a diagnosis can be complicated and overwhelming.

### The website:

- Provides support to GPs and other healthcare professionals with the decisions they make.
- Makes the process of diagnosis easier to understand and less overwhelming for those with symptoms.

For people trying to get a diagnosis for themselves, and for parents of children with symptoms, the website provides step-by-step guides to support and empower them to understand the actions their GP will take.

The website was developed in partnership with other charities, people diagnosed with gut problems, and healthcare professionals.

# WHAT'S UP WITH MY Gut?



Find out more at  
[whatsupwithmygut.org.uk](https://whatsupwithmygut.org.uk)



# Kranky Panky Pancreatitis Awareness Campaign

## What is the pancreas?

The pancreas is a gland that lies in the upper half of the abdomen, behind the stomach and in front of the spine. It is roughly 25cm (nine inches) long and salmon pink in colour.



## What does the pancreas do?

**The pancreas helps us to properly digest food in two ways:**

- It makes juices that contain digestive enzymes and substances that balance the acid in the stomach.
- It makes hormones (chemicals) including insulin. Insulin helps sugars enter body cells from the blood, to use for energy and increase overall energy stores in the body.

## What is acute pancreatitis?

Acute pancreatitis occurs when the pancreas is damaged, resulting in the release of digestive enzymes into the pancreas. It occurs in 34 per 100,000 people every year.

## What is chronic pancreatitis?

Chronic pancreatitis is a long-standing inflammation of the pancreas. Although the condition is rare, between 6,000 and 12,000 people in the UK are given a new diagnosis every year.

## What are the usual symptoms of pancreatitis?

### Acute pancreatitis:

- A sudden onset of abdominal pain, usually starting in the upper abdomen. It develops over minutes to hours.
- Pain that can also travel through to the back.
- Feeling sick (nausea) and being sick (vomiting).
- A fever and a high heart rate, particularly in severe disease.

### Chronic pancreatitis:

- Pain
- Nausea
- Vomiting
- Diarrhoea
- Weight loss
- Fatigue

Some people with chronic pancreatitis have only one or two of these symptoms.

**For more detailed information, please visit our patient information at [gutscharity.org.uk/advice-and-information/conditions](https://gutscharity.org.uk/advice-and-information/conditions).**



Back in 2016, the pancreatitis community came knocking on our door. The community was underrepresented and there was little information about the condition.

We knew we needed to raise vital awareness of the condition and provide, evidence-based information that was easy to understand and accessible to all. People affected by pancreatitis had a huge unmet need and we knew then we had to do something about it.

In 2018, we got together with two pancreatitis patients - Kirsty and Amy - and the Kranky Panky Pancreatitis Awareness Campaign was born. The name itself was given by the community, who used the term to describe their disgruntled guts!

Since then, the campaign has given voice to more than 200 people living with or affected by the condition, who've boldly shared their stories and experiences with us. We regularly update our expert information on acute and chronic pancreatitis, ensuring that people with symptoms or diagnosed with the condition can find the information they need.

### Your voice matters

Throughout November, we share pancreatitis stories on our website, with a few highlighted on our social media pages to help raise vital awareness of the condition.

Kranky Panky is a powerful and heartfelt campaign. It highlights the need for more information, awareness and research. But don't just take our word for it:

“Pancreatitis is so rare in children but can have life-threatening complications. That's why we need research into diagnosis and treatment options for this awful condition.”

Nicola, Jude's Mum

Jude

“I want to give people the strength to live life. There is hope, you can't lose hope, and there are people you can talk to.”

Katen

“Talking to the team at Guts UK has been amazing, knowing I'm not the only one. But I feel this responsibility to raise awareness of pancreatitis to try and save lives, which is why I'm telling you my story today.”

Sammy

“My dad, Martin, was the strongest man I've ever known. He was fit and healthy. Nothing can prepare you for this. I think about him every day and wish there was some way to bring him back. The only real actionable thing I can now do is try to raise awareness and help find a much-needed cure!”

Katie and Martin

Robert

“I set up a monthly donation to Guts UK to show my support. In my eyes, Guts UK has the greatest of tasks in front of them. They will need far greater resources than most charities, but they are also so community-centric and close to their people. I want to help them some way towards getting to grips with guts.”



# David and Steve's story

## Acute Pancreatitis



David has been a supporter of Guts UK since 2020, after receiving support from us when his late husband, Steve, was diagnosed with acute pancreatitis. He tells us why he's leaving a gift to our charity in his Will.

“My husband, Steve, died from acute pancreatitis in March 2020 after three months in intensive care. We were given very little information or support by the hospital, so I searched online and luckily found the Guts UK website. The wealth of information and support available really did mean the world to us both.

The information and support provided by Guts UK explained exactly what pancreatitis is, what might have caused it, the possible outcomes of the illness, and the lifestyle changes these might entail. None of this information was provided by the hospital. Most importantly, it made us feel we were not alone.

Finding out that the challenges we faced in hospital were not unique - and allowing us to connect to others who had gone through the same journey - made a huge difference and gave us hope during a very dark time.

After Steve died, I wanted to learn more and join the fight to find a cure for this terrible disease. I connected with Guts UK and discovered an incredible team dedicated to supporting, raising awareness and funding research into digestive disorders.

My close involvement with the charity has shown me at first hand their amazing work, which is why I'm leaving a charitable gift in my Will. ”

**Guts UK is the only charity in the country supporting research into the whole digestive system from top to tail, including the gut, liver and pancreas.**



Steve and David

**We couldn't do what we do without people like David, whose kind legacy gift will ensure we're here for more people who need us in the future.**

**With your help, we can keep providing expert information and support and can continue to fund life-changing research into digestive conditions from top to tail.**

# Your life, your legacy



Writing your Will is an opportunity to make sure that the people you love are taken care of. It's also a chance to do something incredible for people affected by digestive conditions and make sure your values live on.

## Could you leave a gift to Guts UK in your Will?

As a small but mighty charity, we rely on donations of all kinds, including legacies. A legacy is a gift that someone leaves in their Will.

At Guts UK, legacies help us to continue providing our expert information and fund life-changing research into the gut, liver and pancreas. They also make sure that we can be there for everyone who needs us, now and in the future.



Find out more about writing a Will and if you choose to do so, how you can leave a gift to charity.

**Visit [gutscharity.org.uk/legacy](https://gutscharity.org.uk/legacy)**  
for your free digital legacy pack.

# Patient information leaflets

Guts UK is the charity for the digestive system, top to tail.  
Visit [gutscharity.org.uk](https://gutscharity.org.uk) for all our information leaflets.  
If you'd prefer a hard copy sent by post, email us at  
[info@gutscharity.org.uk](mailto:info@gutscharity.org.uk) or call us on 020 7486 0341.



## Conditions

- Achalasia
- Acute Pancreatitis
- Adhesions
- Anal Fistulas
- Ascites
- Barrett's Oesophagus
- Belching Disorders
- Bile Acid Malabsorption (BAM)
- **Bile Duct Cancer** ← NEW
- Biliary Sphincter Disorders (Sphincter of Oddi Dysfunction)
- Bowel Cancer
- Chronic Intestinal Pseudo-Obstruction
- Chronic Pancreatitis
- Coeliac Disease
- Crohn's Disease
- Diverticular Disease
- Dumping Syndrome
- Eosinophilic Diseases
- Faecal Incontinence
- Functional Dyspepsia
- Gallstones
- Gastritis
- Gastroparesis
- Gilbert's Syndrome
- Helicobacter Pylori
- Irritable Bowel Syndrome (IBS)
- Liver Cancer
- Microscopic Colitis
- Oesophageal Cancer
- Pancreatic Exocrine Insufficiency (Pancreatic Enzyme Replacement Therapy (PERT))
- Pelvic Radiation Disease
- Perianal Disease
- Polyps in the Bowel
- Primary Sclerosing Cholangitis
- Rumination Syndrome
- Stomach Cancer
- Ulcerative Colitis

## Symptoms

- Bloating & Distension
- Constipation
- **Diarrhoea** ← NEW
- Heartburn & Acid Reflux
- Indigestion
- Painkillers Causing Constipation & Digestive Symptoms
- Wind

## Information

- Alcohol & The Digestive System
- Fibre
- Faecal Microbiota Transplantation
- Food Intolerance Testing
- Gut Microbiome (Poo Testing)
- **Healthy Eating** ← NEW
- Introduction to Gut Bacteria
- Our Personal Plumbing System
- **Surveillance For Gastric Atrophy and Gastric Intestinal Metaplasia** ← NEW

More information on digestive symptoms, conditions, lifestyle and more can be found at [gutscharity.org.uk/information](https://gutscharity.org.uk/information) or by scanning this QR code:

© Charity Registration No. 1137029



# Donation Form I'm getting to grips with guts!

Please return this form to:  
**Freepost GUTS-UK-CHARITY**  
**Or call us on 020 7486 0341**

## YOUR DETAILS

Name	<input type="text"/>		
Address	<input type="text"/>		
	<input type="text"/>		
	<input type="text"/>	Postcode	<input type="text"/>
Tel	<input type="text"/>		
Email	<input type="text"/>		

## MAKE A ONE-OFF DONATION

☐ I enclose a cheque payable to Guts UK charity

Name	<input type="text"/>		
Card no	<input type="text"/>		
Expiry	<input type="text"/> / <input type="text"/>	Security Code	<input type="text"/>
Address (if different from above)	<input type="text"/>		
Please call me on	<input type="text"/>	to take my details	<input type="checkbox"/>

I would like to support Guts UK with a donation of

£5	<input type="checkbox"/>	£10	<input type="checkbox"/>	£25	<input type="checkbox"/>	£50	<input type="checkbox"/>	£100	<input type="checkbox"/>	£500	<input type="checkbox"/>	Other £	<input type="text"/>
----	--------------------------	-----	--------------------------	-----	--------------------------	-----	--------------------------	------	--------------------------	------	--------------------------	---------	----------------------

We would love to be able to send you the latest research updates, fundraising activities and the latest news on the impact your support is having on our work to end the suffering for the millions affected by digestive diseases. Let us know below how you prefer to be contacted.

<input type="checkbox"/> Yes, I would like to be updated by email	<input type="checkbox"/> Yes, I would like to be updated by phone
<input type="checkbox"/> Yes, I would like to be updated by text message	<input type="checkbox"/> No thanks, I do not want to be updated by post

To make any changes to your preferences, email **info@gutscharity.org.uk** or call us on **020 7486 0341**

Please don't forget to turn your £10.00 donation into £12.50 at no extra cost to you. Turn over to add Gift Aid if applicable to you.

*giftaid it*



## SUPPORT BY REGULAR GIVING

Instruct your Bank or Building Society to pay by Direct Debit.  
Please fill in the form in ballpoint pen and return in the envelope provided.



Monthly

☐

Quarterly

☐

Annually

☐

Name(s) of Account Holder(s)

Bank/Building Society Acc No.

Sort code

Name and Address of your Bank or Building Society

Branch Name

Address

Postcode

Contact No

### Instruction to your Bank or Building Society

Please pay Guts UK Direct Debits from the account detailed in this instruction subject to the safeguards assured by the Direct Debit Guarantee.

I understand that this instruction may remain with Guts UK and, if so, details will be passed electronically to my Bank/Building Society.

Signature

Date

Payment Date

☐

1st of the month

☐

15th of the month

Amount

### Please turn every £10 you donate into £12.50 - at no extra cost to you!

I am happy for all gifts of money that I have made to Guts UK charity in the last four years and all future gifts of money that I make to be Gift Aid donations. I am a UK taxpayer and understand that if I pay less Tax & Capital Gains Tax in that tax year than the amount of Gift Aid claimed on all my donations across all charities, it is my responsibility to pay any difference. Guts UK charity claims 25p for every £1 you donate from the tax you pay for the current tax year.

*giftaid it*

If your circumstances, name or address change, please do let us know.

☐

Add Gift Aid

Signature(s)

Date