Autumn/Winter 2022

GUTS UK!

With you by our side, we will get to grips with guts.

From sterile scrubs to muddy mayhem:

Steph, Karen and Marie work as endoscopy nurses. Day in and day out, they guide and comfort patients through the procedure of having a camera placed inside their body. They play a crucial and often overlooked role in looking after our guts. But this alone wasn't quite enough for this special endoscopy team. They wanted to go one step further, so they took on the Tough Mudder to fundraise for Guts UK, raising over £980!

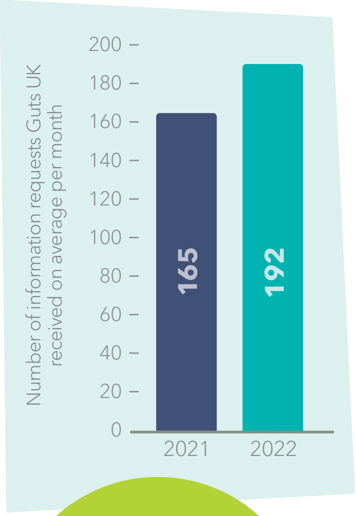
Contents

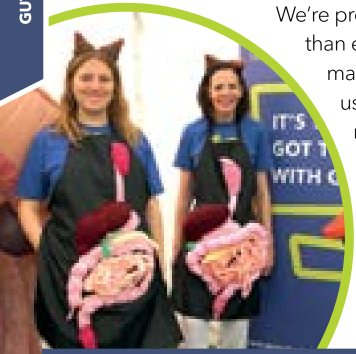
GUTS AT A GLANCE

Reaching those who need us most

As well as funding life-changing research and raising awareness, Guts UK provides expert information for those with digestive conditions or symptoms. We believe that information is power. When armed with information, you can take control of your health and make informed decisions.

We're proud to have reached more people than ever before in 2022. Your support makes it possible. Please donate today using the form on the back of this magazine, thank you.





Esther and Melanie, our Support Hub Administrators love hearing from you.

Don't be a stranger!

We **love** to hear from you; it's the best part of our job.

@GutsCharityUK

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☎ **0207 486 0341**

info@gutscharity.org.uk

www.gutscharity.org.uk

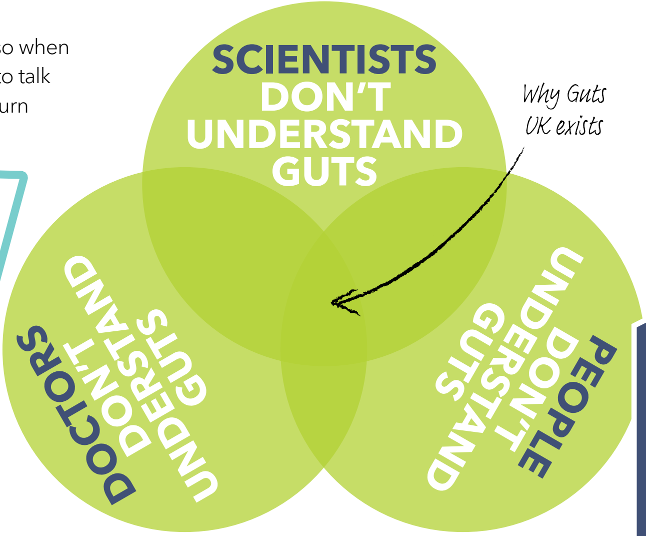
Guts UK, 3 St Andrews Place, London, NW1 4LB

Registered Charity Number: 1137029

Our guts have been underfunded and misunderstood for too long

Guts UK exists because people are in pain, people are suffering and people are dying, all because of a lack of knowledge about our guts.

We all have guts, around 25ft of them. **But we don't understand our guts**, so when something goes wrong, we don't like to talk about it and we don't know where to turn to get help.



Sadly, we're not alone. **Doctors don't understand guts, either**. The lack of understanding about these vital organs can lead to missed diagnoses, more pain and more suffering.

And why don't doctors understand guts? **Because scientists don't understand guts**. They want to, but research into our digestive systems is underfunded and undervalued.

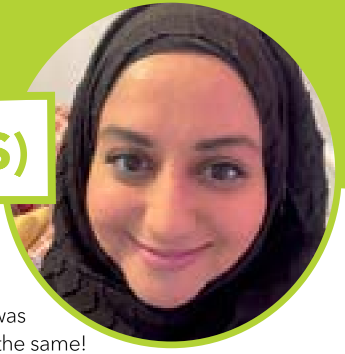
We're reaching and helping more people than ever before. But we must go and learn faster to stop the pain, stop the suffering and save more lives.

With your support, we can reach and help more people, and fund more life-changing research. With you by our side, we will get to grips with guts.

Please donate today. Thank you.

Sofia's Story

Irritable Bowel Syndrome (IBS)



Tell us a little about yourself:

I'm Sofia, I'm a mum of two little girls and I'm trained as a teacher. I had the fantastic opportunity to teach in Dubai for a couple of years too. But when I was out there, I really missed UK chocolate, the Dubai chocolate just didn't taste the same!

When did your symptoms begin?

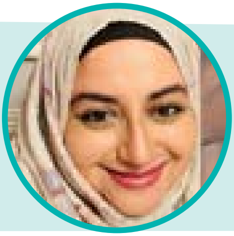
I first noticed symptoms in my mid to late 20s. Every now and again I'd have to run to the toilet quite urgently.

Throughout my life I'd have various tests and I was told it is 'just' IBS. Last year my symptoms became really bad after going out for dinner with my daughter. I became extremely bloated and then started with diarrhoea. I ended up in A&E because of the amount of pain I was in. I actually went to A&E about three times in one week, and one trip I was in there for 18 hours! Unfortunately, I was just discharged and told to take over the counter abdominal pain medication.

After another trip to A&E later and the doctor told me I had food poisoning and gave me antibiotics. Unfortunately, this still didn't help. In the end I decided to seek private advice. There, the doctor told me I had developed post-infectious IBS after a bout of gastroenteritis. I was disappointed to hear that these symptoms can last for up to six months. The private hospital decided they did want me to have another colonoscopy to rule out Inflammatory Bowel Disease (my dad has Crohn's disease). The test results came back negative and I was sent on my way.

How does IBS affect you?

I spent my 40th birthday, Christmas and anniversaries all at home. My biggest anxiety is the thought of having an accident in public. Before I leave the house, my anxiety always kicks in which just sets off my IBS too. People tell me not to stress and to relax, that it's '**just tummy ache**'. But this just makes me feel so unheard.



Why are you sharing your story?

I'm at a place now where I want to raise awareness. I don't have a broken leg to show why I can't come to the party. I can't prove to them that I've been to the toilet five times that day and how exhausting it is. In my community, the response to IBS is 'oh it's just tummy ache'. But it's not. It can be debilitating.

I really appreciate Guts UK being there, sharing stories like mine. Sometimes you just need to know there are real people representing you, and others experiencing the same thing. It gives you comfort and hope. It's relatable, real and raw.

You make it possible, Lena:

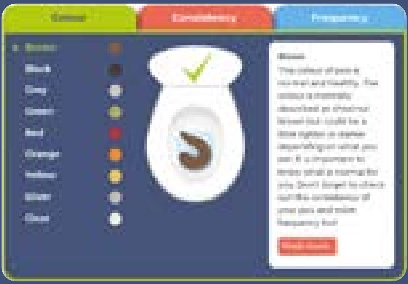
Lena joined our **#GUTSelfie Campaign** (more on page 18). She shared her journey with IBS, joining hundreds of others to raise awareness of invisible illnesses. She asked her followers to support Guts UK Charity, and managed to raise almost £40 with just one **#GUTSelfie**.

Thank you for helping the UK get to grips with guts!

Poo-Torial What is your poo telling you?

Your poo is an indication of your health. It's important to check your poo, and talk to your doctor about anything unusual.

Checking your poo includes being aware of the colour and consistency of your poo, but also how frequently you empty your bowels. Guts UK's **online tool** tells you what the colour, consistency and frequency of your poo could mean.



To use our online tool, scan the QR code above or visit:

www.gutscharity.org.uk/poo-torial

IT'S TIME THE UK GOT TO GRIPS WITH GUTS

www.gutscharity.org.uk

NEW: Oesophageal cancer research

The oesophagus is often referred to as the food pipe, as it is the tube that carries food from your mouth to your stomach. It lies behind your windpipe (trachea) and in front of your spine.

Why does Guts UK fund oesophageal cancer research?

Oesophageal cancer is one of the deadliest digestive cancers, and Guts UK prioritises research into the most underfunded and neglected digestive conditions.

NHS data from 2021 shows that over 20% of oesophageal cancer cases were diagnosed at emergency (like A&E), while just 2.7% of breast and 7.8% of prostate cancer cases were. At this point, the cancer tends to be more advanced and harder to treat.

Only around 15% of those diagnosed with oesophageal cancer will live for five years or more. It is crucial that oesophageal cancer is diagnosed earlier, whilst most treatable, to give people a fighting chance.

What do Dr Katja Christodoulou and team hope to learn?

"We are further developing a breath test to pick up oesophageal cancer in the early stages, when it is more likely to be cured. These tests look for volatile organic compounds (VOCs), which are small gas molecules. Our research so far, including previous Guts UK funded research by Dr Sara Jamel, has shown promising results.

The breath test is a simple, cost-effective procedure that is easy for patients. We hope to pick up those who are at high risk of developing early oesophageal cancer, so we can prioritise these people for an endoscopy."

What do we already know about oesophageal cancer?

Oesophageal cancer in the early stages often has vague symptoms, which can be similar to non-cancerous conditions. This means that under NHS guidelines, people are not always able to have a camera examination of the oesophagus (endoscopy). Unfortunately, many are therefore diagnosed with oesophageal cancer when it is at a late stage.

How will you complete your study?

"We will aim to recruit 228 participants, who will already be approaching our hospital sites for their endoscopy. We will ask them to perform a breath test, which simply involves breathing into a bag. The breath will then be collected into tubes.

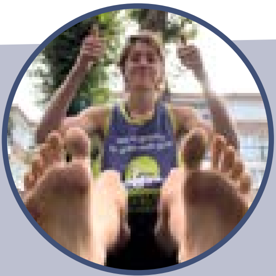
Back at the lab, we will check if we can use these samples of breath to determine if they have cancer or not. We can compare this with their endoscopy test results."

What is the potential future impact for your project?

"A breath test could allow us to pick up oesophageal cancer at an earlier stage, which would increase the chances of curing the cancer and potentially save lives. If we can successfully develop this test, we can avoid unnecessary endoscopies on patients, and prove more cost-effective for the NHS."

This test could save lives by diagnosing oesophageal cancer earlier, when it's easier to treat. Help us give people a fighting chance by donating to Guts UK today.

You make it possible, Olly:



Ever thought of running 13 miles barefoot? No? Well Olly has! He conquered this challenge in memory of his Nan, Margaret, who passed away from oesophageal cancer, raising over £450! We cannot thank Olly enough for his bravery and dedication to changing the future for other families.

Lisa's Story

Diverticular disease

Diverticulosis is when pouches are formed along the bowel wall. Most of the time, these pouches are completely harmless. Sometimes, they can cause symptoms for people like Lisa, which is referred to as diverticular disease. This affects 1 in 3 to 1 in 2 people in the UK in their lifetime. When these pouches become infected or inflamed, they are referred to as diverticulitis.

Tell us about yourself Lisa:

I've worked in many places over the years and volunteered for charities too, but my most recent and best job has been in a school. I've not worked for a while due to heart conditions, so I've recently taken up an allotment. I adore gardening but could never find the time previously - four children and a full-time job kept me busy enough!

I love to crochet, knit and read. I run a number of Facebook groups too, one for people with diverticular disease.

How did you find out you had diverticular disease?

I remember my Grandma struggling with bouts of diverticulitis when I was a child. Back then, she was told to avoid nuts and seeds, so she'd avoid tomatoes like the plague!

I had my first colonoscopy (camera up the bottom) in my 20s, as my constipation was severe. They discovered I had slow transit and a kink in my bowel, so they struggled to get a camera through.

In my 30s, I had another colonoscopy as a doctor feared I might have a bowel tumour (but it turned out to just be poo!) This showed diverticulosis in my bowel. I do have diverticular disease, as I experience symptoms like pain on my right-hand side. When diagnosed, I was told to eat cheese?!

Of course, years on, we now know the evidence says that I don't need to avoid eating anything, or should eat anything in particular. I'm able to eat a normal diet, food and drink doesn't give me symptoms.

My constipation has been severe my whole life. Without laxatives, I have been four weeks in the past without a bowel movement.

I've had episodes of mild diverticulitis (infection) too. My symptoms begin with abdominal pain that grows more intense, I develop a fever, chills and my temperature rises. Antibiotics always fight off the infections for me. It's important to know what's normal for you, that way you can notice new symptoms better.

Did finding Guts UK help?

All I want is for people to have the right information when they need it, and that's exactly what Guts UK does. I love that they do the whole digestive system from top to tail – I despair at the lack of information in this area of health.

Since discovering Guts UK, I'm better able to support people in our Facebook group with information on this condition and their other symptoms. It's comforting and personable to read. Everything they do is person-centred.

Knowledge is power. There's so much nonsense out there, and people profiting off it. There are unqualified people giving incorrect advice. Having Guts UK as an evidence-based support resource is invaluable. Now we can all go to our appointments armed with information. We can make our own choices, and be our own advocate.

You make it possible, Linda:

Linda has diverticular disease too, and has taken on two marathons and one 100 mile cycle for Guts UK. She has raised over £400, there's simply no stopping her! We're so grateful for your dedication to supporting our work.

"From our family, to yours

This edition, we want to remember three members of our community that recently passed away. We wanted to acknowledge their remarkable contributions to our work. Their legacy lives on every single day in the work that they make possible for future families.

Brad Peacock

Brad shared his pancreatitis journey in 2020 with help from Amy, his partner, for Kranky Panky Awareness Month. By bravely telling their experience, whilst Brad was still in and out of hospital, the family helped us reach thousands, raising awareness of the symptoms of pancreatitis.

In 2021 Amy took on The Yorkshire Three Peaks challenge for Brad, alongside her brother Tom and friends Emma, Chris and Rachel. Although Brad wasn't well enough to take on Three Peaks, he met the determined walkers at different points of the journey. He cheered them on and was there to meet them with food and drink along the 12 hour walk. Their loved ones were ecstatic to see them complete the challenge for a cause that meant so much to everyone.

On the 2nd February 2022, Brad passed away aged 38. He leaves behind his children, Lenny (6), Alysha (14) and Harley (13).

Since they found us in 2020, the family have raised almost £1,300.

In Brad's name, you help us put crucial information in the hands of those who need it most, when they need it most. Thank you.

Paul Narramore

Kirsteen, Paul and Ian contacted us after their dad Brian passed away from pancreatitis. In 2019, they came together with mum Janette to share Brian's story – helping to build a community affected by this devastating disease.

As well as raising funds for Guts UK at his funeral, the family took on a New Years Eve 10km walk/run in Brian's name. A beautiful way for the family to remember and celebrate Brian's life, whilst working towards changing the future for others affected by pancreatitis.

In 2021, the family found themselves reaching out for Guts UK's information again. Kirsteen and Ian's brother, Paul, was diagnosed with bowel cancer and secondary liver cancer.

The unstoppable Narramores moved straight onto their next challenge for Guts UK, a 26.2 mile coastal walk, of which Paul also managed to complete. Guts UK has even been a chosen charity for Crawford's Vintage Tractor Display and Dyno Day, as Paul's son-in-law, Ben, put our cause forward.

On the 22nd June 2022, Paul passed away at home, surrounded by loved ones including his wife Gemma, son Will and daughter Georgia.

The family are on track to raise almost £10,000 for Guts UK.

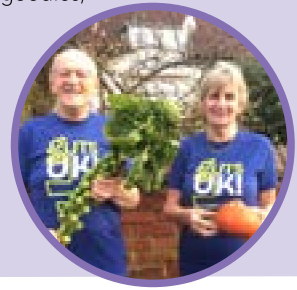
In Paul and Brian's name, you help us turn a scientists' determination into life-changing discovery. Thank you.

John Elliot

During lockdown, Pam and John Elliott had spent their days tending to their vegetable allotment. They had an abundance of vegetables, so much so that the pair alone wouldn't get through them all!

John had been diagnosed with oesophageal cancer during lockdown, and his treatment had been very successful. The pair decided they would set up a vegetable stall outside their house, selling fresh vegetables to the passers-by to raise funds for Guts UK.

From that moment on, the whole community rallied together to do what they could for Guts UK's work into oesophageal cancer. Their local Parish Council further donated and the community decided to host an afternoon tea, spending hours baking goodies, making sandwiches and decorating the village hall.



On the 31st March 2022, John passed away, a month after his oesophageal cancer had been re-diagnosed. He leaves behind three children and three step-children, and is loved and missed by all.

The family and community have raised over £2,000 for Guts UK.

In John's name, you help us raise awareness of digestive conditions, leading people to an earlier diagnosis and ensuring no one feels lost or alone. Thank you.

Your support means the world to thousands of other families just like yours. Your love and kindness helps us lead people to earlier diagnoses, develop effective treatments, and put information in the hands of those who need it.

From our family, to yours. Thank you for giving the gift of hope to the families of tomorrow.

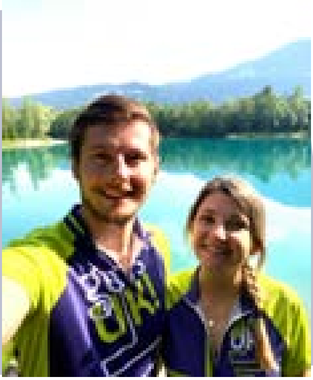
To support Guts UK in-memory of your loved one, contact us today or visit: gutscharity.org.uk/giving-in-memory

Millie

Millie's support to Guts UK in memory of her dad, Daniel, never ceases to amaze us. From a swimming challenge with relatives Lola and Henry, to nominating us as her class's charity of the year, Millie is a superstar fundraiser. Millie and her family have now raised over £5,000 in Daniel's memory.

Milly & Christian

Milly and Christian not only cycled 2,500km from their home to Penne, Italy but they also raised over £15,000 for Guts UK! They took on this almighty challenge in memory of Milly's dad, Graham, who they lost to stomach, pancreatic and liver cancer. An incredible challenge in memory of an incredible man.



Annabel & Alex

Annabel's story of her struggles to get the right diagnosis whilst suffering with gastro symptoms is one we hear far too often. With the support of her boyfriend, Alex, they walked ten miles to support others, just like Annabel.

Rob & Craig

Rob has acute pancreatitis and is always looking for ways to support Guts UK. Rob and his friend Craig held a DJ night in their local pub. This dynamic duo spread the word about Guts UK and raised over £300. Thank you!

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your fundraising ideas:
o@gutscharity.org.uk

James

James cycled 100 miles around the Peak District for Guts UK, to help families affected by achalasia, like himself. Achalasia affect the wave-like movement in James' oesophagus (food pipe). He raised an incredible £1,665 for our small but mighty charity!

> **"Riding a bike is easy for me, I just needed to do something to help other people."**

Elise & Snowy the leopard

Elise wanted to share her birthday this year with Guts UK, in memory of her grandad Michael. She raised an amazing £355 with the support of family and friends. We wanted to say a huge thank you to Elise and her furry pal, Snowy the leopard, for their generosity and kindness.

Charlotte

Charlotte has a condition called Biliary Sphincter Disorder. The Sphincter of Oddi is a muscle that opens and closes allowing digestive juices and more to flow properly through the ducts from the liver and pancreas into the small intestine. When this muscle isn't working properly, it can lead to a backup of digestive juices that can cause severe pain in the abdomen. Whilst managing this life-changing condition, Charlotte also sells her beautiful artwork with 50% of proceeds being donated to Guts UK. Charlotte's creativity and support of our mission warms our hearts.

The under-diagnosed bowel condition

Microscopic colitis

What is microscopic colitis?

Microscopic colitis is an Inflammatory Bowel Disease (IBD). This group also includes Crohn's disease and ulcerative colitis. IBD can be diagnosed by an endoscopy (a small camera that looks at your digestive system). Often, the inflammation can be seen on camera.

Why is microscopic colitis under-diagnosed?

Microscopic colitis, unlike other IBDs, isn't visible on camera. To see the inflammation, a sample of tissue (a biopsy) has to be taken from the bowel, and looked at under a microscope. Unfortunately this step isn't always completed, and many go undiagnosed.

Claire's story

“I put my symptoms down to irritable bowel syndrome (IBS) at first. But eventually I was constantly rushing to the toilet to empty my bowel 15 times a day, even during the night. It was exhausting.

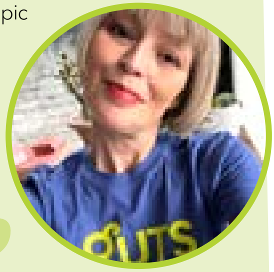
At my worst, I couldn't go to work. I didn't want to leave the house from fear of having an accident on the tube. I spent my life indoors, relying on home-delivery services.

A month in, I contacted my GP who asked me to bring in poo samples. My samples came back normal and I felt really disheartened. I needed an answer for my symptoms. I needed help.

I returned to my GP, who put me on the cancer pathway for a colonoscopy (camera up the back passage). Before my colonoscopy, I did research and found Guts UK's information on microscopic colitis, so I asked if they'd take a biopsy during the colonoscopy. They told me they would be doing this anyway.

I was finally diagnosed with microscopic colitis six months after my symptoms began. I know it takes others years, or even decades to be diagnosed. Treatment has worked for me and relieved my symptoms massively.

It was reading Guts UK's information, and reaching out to the team that gave me the confidence to seek help. I hope people reading my story, thinking 'this sounds like me', can find the confidence to go to their GP and say 'I want a colonoscopy and a biopsy'.”



How many people are thought to have microscopic colitis?

There are 17,000 new cases of microscopic colitis diagnosed each year, but the real number is thought to be much higher. Symptoms of microscopic colitis are similar to those of irritable bowel syndrome (IBS). In fact, one study showed that **1 in 3 patients with microscopic colitis were incorrectly diagnosed with IBS initially.**

Symptoms include:
- Waking in the night to empty the bowel
- Persistent, frequent and watery diarrhoea
- Stomach pain
- Fatigue
- Urgency to empty the bowel

Who does microscopic colitis affect?

Almost 90% of those diagnosed with microscopic colitis are female. Most of those diagnosed are between 50-70 years old. Although microscopic colitis is under-diagnosed, once it is diagnosed, there is a treatment available that works effectively for most people. Do not suffer in silence or alone. Seek help from your GP, or contact Guts UK for further information.

Your support allows us reach and help more people. Please donate today. With you by our side, we can reach those suffering in silence and alone. Thank you.

Bile Acid Malabsorption (BAM)

Like microscopic colitis, BAM may be misdiagnosed as Irritable Bowel Syndrome (IBS) due to some of the symptoms being similar. We want to highlight this condition, to encourage those struggling with symptoms to seek help.

What is bile acid?

Bile acids are made in the liver, stored in the gallbladder and released into the small bowel. From there, almost all of the bile acids are then re-absorbed and returned to the liver, to be re-used.

What is Bile Acid Malabsorption?

BAM, also known as Bile Acid Diarrhoea (BAD), is where this normal cycle is disturbed, which can result in symptoms. BAM affects up to 1 in 100 people in the UK.

What are the usual symptoms of BAM?

Diarrhoea is the main symptom of BAM. This is usually frequent in the day and sometimes at night. Your poo may be pale, greasy and hard to flush away, or unusually coloured (green or orange).

Stomach problems like bloating, cramping, abdominal pain and excessive wind can also occur. Unfortunately, many symptoms of BAM mimic those of IBS, and some people with IBS may actually have undiagnosed BAM.

What causes BAM and who does BAM affect?

BAM can affect those who have had their gallbladder removed, have had radiotherapy to the abdominal area, or have had inflammation or removal of the ileum. It can also result from other diseases like coeliac disease or chronic pancreatitis, but sometimes there is no cause found.

How is BAM diagnosed?

The main investigation for a definitive diagnosis is a 'nuclear medicine test' called the SeHCAT scan. Here, an artificial bile acid is swallowed via a capsule or drink, then two scans are carried out a week apart. The result shows how much bile acid is lost from the body, or whether it was reabsorbed correctly.

Sam's story

Hi, my name is Sam, I'm 30 years old and I have BAM.

My BAM story begins with my diagnosis of Crohn's disease when I was in my early 20s. I had a pretty rough ride with it and ended up having a part of my small bowel removed around 4/5 years ago. Luckily this seems, at the moment, to have stopped the problems I was having due to my Crohn's disease. But that is when BAM struck! I started experiencing bowel urgency and diarrhoea not long after recovering from my operation. It made having a social life very tricky and even just leaving the house could be really anxiety provoking. This became worse due to covid, as I had to shield and became comfortable in not going out. Since we have come out of lockdown, I have been battling with my BAM and also the anxiety that comes with it.

I am a massive supporter of Guts UK and for raising awareness for BAM, as when I was first diagnosed, I had no idea what it was or the impact it would have on my daily life. Of course, it's all made easier due to my incredible family and girlfriend, who have helped me endless amounts in dealing with both conditions! For anyone suffering with BAM, I hope you know you're not alone and there is help and advice available!

NEW: Pancreatitis research

The pancreas lies behind your stomach and in front of your spine, and produces digestive enzymes that help us digest fat, carbohydrates and protein. The pancreas also produces hormones, such as insulin.

Pancreatitis is an inflammation of the pancreas. It can be both sudden (acute pancreatitis) or long-standing (chronic pancreatitis).

Why are Guts UK funding pancreatitis research?

In the UK, 30,000 people each year are affected by acute pancreatitis. There is little data for those living with chronic pancreatitis, but we know there are 12,000 hospital admissions each year.

Acute pancreatitis can be fatal. Sadly, of those who become severely unwell with pancreatitis and require intensive care, one in four will die. Others can spend weeks or months recovering from their attack, potentially needing to learn how to walk or speak again.

Chronic pancreatitis is also life-changing for most. Many people live in pain, risk becoming malnourished or losing dangerous amounts of weight. As with any chronic condition, people may suffer symptoms such as depression or relationship problems.

There is no effective cure or treatment for pancreatitis. We are dedicated to changing that.

What do we already know about pancreatitis?

Part of the function of the pancreas is to make powerful digestive enzymes that help to break down the food and drink that we consume. But in pancreatitis, these enzymes attack the pancreas itself, and can cause life-changing and life-threatening damage. This can cause further damage to other organs like the lungs, heart and kidneys in the most severe cases. Those with damage to multiple organs are often those who become most unwell.

What have Dr Kattakayam and the team discovered about pancreatitis?

Previous research by the University of Liverpool has shown that damage to the powerhouse of the pancreas cells (the mitochondria) is a crucial early step that begins pancreatic inflammation.

The team also know that severe acute pancreatitis is a disease that can progress from near-by damage to distant organ damage. However, it has been noted that distant organ damage can occur, without any evidence of near-by damage to the pancreas.

What does Dr Kattakayam's work aim to discover?

"We hope to assess whether protecting the mitochondria (cell powerhouses) outside of the pancreas cells (within other cells and organs), reduces the severity of the condition and prevents worsening damage to the pancreas itself.

We will use the most modern scientific equipment and high-powered microscopes to observe the changes happening within these cells. The better we can understand this process, the better we can determine whether medication that has the role of protecting the mitochondria within the cells would be effective, and potentially life-saving."

There is no effective cure or treatment for pancreatitis. But the more we know about the complex cell changes that occur during pancreatitis, the closer we move towards developing an effective treatment for this devastating disease.

You make it possible, Desi and Mark

Desi and Mark took on the South Coast Challenge for Guts UK in memory of their son-in-law, Kev, raising almost £1,000! "It has been almost a year since Kevin left us all, so unexpectedly and tragically taken away from his friends and family by pancreatitis. A disease not so well known, but dangerous and merciless". Thank you for your dedication to changing the future for others.

With your donations, we can work harder and faster to fund more projects like Dr Kattakayam's that could save and change lives. Please donate today.

The Prison Dietitian

The role of a dietitian within the NHS is crucial, yet often overlooked. Dietitians are the only nutrition professionals regulated by law. They can assess, diagnose and treat dietary and nutritional problems. We sat down with Fran, known online as 'The Prison Dietitian', a registered dietitian who works in the UK's largest prison for men.

Why did you want to become a dietitian?

I'm a huge foodie and always wanted to work in the NHS. I like helping people and stumbled across dietetics. My love grew from there!

For prisoners with digestive conditions, do you find they're able to access the dietary requirements they need?

This is difficult. We have some special diet provisions, like vegan, allergen free and gluten free. The kitchen offers good variety and there are normally at least a few options to meet a patient's needs.

There are limitations though unfortunately. For example if a man has Irritable Bowel Syndrome (IBS) and requires a low FODMAP diet, this can be a logistical nightmare. We do the best we can. I just try to encourage the men to choose one of the menu choices that best suits their needs.

We saw that you work to a budget of £2.02 per day per prisoner. How is this achieved for specific diets?

The kitchen staff and I do have a good level of respect for one another. I understand they need to stick to their budgets, and I treat these men as patients, not prisoners.

When a prisoner goes on a 'special diet' even for a digestive condition, they sign a contract that states if they break their diet, they're immediately taken off this diet. It's viewed as a special privilege, despite it being a medical requirement. I can intervene sometimes, for example if a prisoner has coeliac disease, it's vital that they are on a gluten free diet.

Are there any difficulties you experience being a dietitian in a prison?

You have to remember that anything can be traded in prison, including medication and special dietary foods.

For example, if a man is telling me that onions and spicy foods are triggering symptoms, it's more than likely that this person has IBS. But if he's telling me that cheese and onion crisps cause symptoms, but ready salted crisps are fine, I may have further questions!

I think the most important thing is to treat everyone equally and just be honest with the men about what we can and cannot do, never promising something that can't be achieved.

Why did you decide to share your experience of working in a prison?

I love highlighting that working in a prison is a great place to work if you want to make a change to people's lives. I believe there are only three dietitians working in prisons. It would be great to have a few more of us.

Gilbert's syndrome

What is the liver?

The liver is the largest solid organ in the body. It lies under the lower rib cage on the right-hand side of the body, but stretches across the middle about as far as the left nipple. The liver performs many important functions in the body including processing of many of the body's waste products (or toxins) to render them harmless. It also produces bile, which is not only needed to digest certain foods, but also helps to absorb several important vitamins. It's helpful to think of the liver as a 'factory', manufacturing many important proteins and other chemical substances that the body needs to work normally. The liver helps regulate the energy and fluid stores in the body.

What is Gilbert's syndrome?

It's estimated that 1 in 20 people in the UK have Gilbert's syndrome. Gilbert's syndrome is caused by a defect in the gene that helps make a protein that helps to excrete bilirubin. Bilirubin is a breakdown product of haemoglobin, that occurs in the liver. Haemoglobin is responsible for carrying oxygen in red blood cells. This is a mild defect and results in a small increase in bilirubin in the blood. This does not do any harm and in most people is not even noticeable, although at times of stress for instance after surgery or during an infection such as influenza, the levels may rise to be detectable as a mild yellowing of the eyes and skin (this is called jaundice).

What causes Gilbert's syndrome?

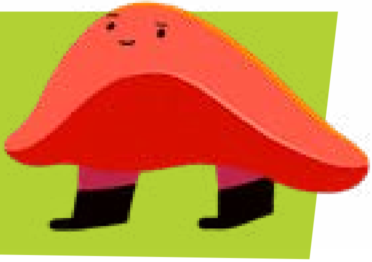
Gilbert's syndrome is hereditary, meaning it is passed down in a gene through families. There are no other known causes or risk factors, and it is not caused by anything you do such as your lifestyle. It is important to note that apart from mild yellowing of the eyes there are no other symptoms attributable to Gilbert's syndrome and if you are experiencing other symptoms another cause should be sought by discussing the symptoms with your GP. The mild jaundice of Gilbert's syndrome may be brought on by fasting, dehydration, illness, a lack of sleep, or activities that are strenuous for your body such as surgery or lots of physical activity.

Gilbert's syndrome doesn't cause any symptoms, apart from mild jaundice.

How is Gilbert's syndrome diagnosed and treated?

Your doctor will be able to diagnose Gilbert's syndrome through a simple blood test. This will measure your bilirubin levels, and make sure there is no other cause of the jaundice, as jaundice can occur when there are other problems with the liver. It can be confirmed by a genetic test to look for the faulty gene. They may also ask you questions regarding how often you have had jaundice, or about your diet and lifestyle.

Gilbert's syndrome is completely harmless, so there is no need to treat it. In fact, there is some evidence that those with Gilbert's syndrome have an increased life expectancy due to the higher levels of bilirubin, which protect against some forms of heart disease.



How you can help the UK get to grips with guts

A big thank you!

The Chocolate Shop in Sevenoaks have raised over £250 for Guts UK in less than six months, by hosting a collection tub in their shop. Adie, Tina and Jacqui support Guts UK as Tina's Great Nephew, Zaki has pancreatitis.

Laura's son, Jake, has pancreatitis. Their family have a local shop, Chapmans Stores in Southminster. The community know and love Jake's family, and wish to show their support to the family. Since 2020, they have raised over £2,500 in their collection tubs for Guts UK!

Do you or a close loved one own a shop? Could you host a collection tub for Guts UK and help the UK get to grips with guts? Contact us today!

Knitted Guts?!

We're looking for enthusiastic knitters to produce life-sized replicas of our insides. These knitted digestive systems are used as part of Guts UK's public awareness project – educating and raising awareness on digestive health across the country.

If you are a talented knitter and fancy taking on a unique project, contact Guts UK today for the pattern.

#GUTSelfie 2022

26th June 2022 marked our second #GUTSelfie campaign.

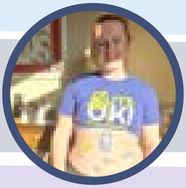
A day where we ask our community to decorate their bodies with temporary tattoos and talk openly about their digestive condition online. Last year we had 60 people join us, this year it was closer to 200! 200 brave and powerful voices uniting with one message; it's time the UK got to grips with guts.

Sharan: “Having spent the first 15 years of my Crohn's diagnosis keeping it entirely to myself, I'm so grateful to Guts UK charity. The stigmas attached to these conditions can make it incredibly difficult for us to open up, but what we need to be doing is normalising these conversations.”

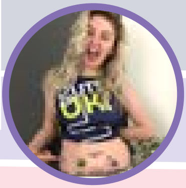
Annie: “For the first time in a long time, I finally feel visible with my invisible illness.”

Jessamy: “#GUTSelfie helps break the taboo and stigma around having digestive issues, which can quite often be really embarrassing to talk about.”

Jessica: “Guts UK charity has helped me to feel more confident within my scars and accept who I am.”



Laura: “We lost my dad last year to oesophageal cancer and doing #GUTSelfie just means that we're spreading awareness. Hopefully people can get the help that they need sooner, rather than later.”



Alicia: “#GUTSelfie halts the filtered images that we constantly see every day on social media.”

Ella: “The friends I've met via social media are so great, understanding and empathetic.”

Connor: “#GUTSelfie has helped me reach out to new people and make new connections.”

Ziyad: “What I love about the #GUTSelfie campaign is it's a chance to show that not every illness is visible.”

Liam: “It reminds us that we're not alone and that we're all there to support each other, together, as one team.”

Natasha: “I love #GUTSelfie. #GUTSelfie helps stop the stigma around invisible illnesses.”

Each year, #GUTSelfie takes us one giant leap forward in abolishing the crippling taboo surrounding our guts. Donate to Guts UK today, to ensure no one suffers alone or in silence. Thank you.

Grace's Story

Grace could wait a lifetime for a cure.

Grace's parents knew something was wrong with their beautiful baby when they tried to wean her onto finger food. Their usually happy little girl kept choking, coughing, and being sick. Terrified, they took Grace to hospital where she was eventually diagnosed with achalasia.

Grace is now three years old and unless we find a cure she will spend a lifetime struggling with the pain and shame of a condition that prevents her from swallowing food.

But there is hope. Research into achalasia could lead to a clinical trial. A clinical trial could lead to a cure. And by the time Grace may be thinking about starting a family of her own, achalasia could be a condition of the past.

When you support Guts UK, you can fund life-changing research that will end the pain and suffering of children like Grace.

IT'S TIME THE UK GOT TO GRIPS WITH GUTS

Support Guts UK today

GUTS UK!

www.gutscharity.org.uk

THE CHARITY FOR THE DIGESTIVE SYSTEM

REQUEST YOUR FREE EXPERT PATIENT INFORMATION LEAFLET TODAY

- **Achalasia**
- **Acute Pancreatitis**
- **Adhesions**
- **Anal Fistulas**
- **Ascites**
- **Barrett's Oesophagus**
- **Bile Acid Malabsorption**
- **Biliary Sphincter Disorders** (Sphincter of Oddi Dysfunction)
- **Bowel Cancer**
- **Chronic Intestinal Pseudo-Obstruction**
- **Chronic Pancreatitis**
- **Coeliac Disease**
- **Constipation**
- **Crohn's Disease**
- **Diarrhoea**
- **Diverticular Disease**
- **Dumping Syndrome**
- **Eosinophilic Diseases**
- **Faecal Incontinence**
- **Gallstones**
- **Gastroparesis**

NEW & UPDATED!

- **Gilbert's Syndrome**
- **Gut Microbiome (Poo Testing)**
- **Healthy Eating & The Digestive System**
- **Heartburn & Reflux**
- **Helicobacter Pylori**
- **Indigestion**
- **Irritable Bowel Syndrome (IBS)**
- **Liver Cancer**
- **Microscopic Colitis**
- **Non-Ulcer Dyspepsia**
- **Oesophageal Cancer**
- **Painkillers causing Constipation and Digestive Symptoms**
- **Pancreatic Exocrine Insufficiency** (Pancreatic Enzyme Replacement Therapy)
- **Pelvic Radiation Disease**
- **Perianal Disease**
- **Polyps in the Bowel**
- **Rumination Syndrome**
- **Stomach Cancer**
- **The Mediterranean Diet & Gut Health**
- **The Role of Gut Bacteria in Health & Disease**
- **Ulcerative Colitis**
- **Wind, Burping, Flatulence & Bloating**

Much more information on conditions, health and lifestyle tips can all be found at gutscharity.org.uk

You can request your free of charge hardcopy in the post by emailing info@gutscharity.org.uk or calling 0207 486 0341.

Donation Form

I'm getting to grips with guts!

Please return this form to:

Freepost RTJK-YYUL-XXSZ, Guts UK, 3 St Andrews Place, London, NW1 4LB
Or call us on 020 7486 0341

YOUR DETAILS

Name ☐

Address ☐

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☐ Postcode ☐

Tel ☐

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MAKE A ONE-OFF DONATION

☐ I enclose a cheque payable to Guts UK charity

Name ☐

Card no ☐

Expiry ☐ / ☐ Security Code ☐

Address (if different from above) ☐

Please call me on ☐ to take my details ☐

I would like to support Guts UK with a donation of

£5 ☐ £10 ☐ £25 ☐ £50 ☐ £100 ☐ £500 ☐ Other £ ☐

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.

☐ Yes, I would like to be updated by email

☐ Yes, I would like to be updated by phone

☐ Yes, I would like to be updated by text message

☐ 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.

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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 ☐

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Instruction to your Bank or Building Society

Please pay Guts UK Direct Debits from the account detailed in this instruction subject to the safegaurds 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.

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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.

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