

Spring/Summer 2022

**gUTS
UK!**



25ft is a lot of guts to understand...

But that's exactly what Guts UK exists to do!

For his 8th birthday, Alexander asked family and friends to donate to Guts UK instead of buying him birthday cards or presents. Alexander supports Guts UK in memory of his grandad, Michael, who passed away from pancreatitis. He had recently read about Guts UK's work, and was inspired to help other families, just like his. Alexander's kindness raised an incredible £370 for Guts UK.

Thank you for taking us one step closer to getting to grips with guts!

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Your kindness and generosity moves mountains



Even through the uncertainty of the pandemic, you, stepped up to support Guts UK. You, our gut army, allowed us to fund life-changing research even through the most turbulent of times.

£582,680

In the last 6 months, Guts UK has committed to funding £582,680 of research into the digestive system.

With your support, we can reach more people, help more people and continue life-changing research. Thank you.

Don't be a stranger!

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



@GutsCharityUK



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2021 was the year of the patient voice at Guts UK

Your voice will continue to be heard

In 2021, Guts UK welcomed a new member aboard our team, Helen West. Helen has a number of digestive diseases herself. When she discovered that her consultant's research was being funded by Guts UK, she became a dedicated fundraiser. Helen has been as far as the Saharan desert to fundraise for Guts UK!

Helen was brought onto team Guts UK to ensure that the patient voice, your voice, was heard in every decision we made.



Experts by Experience

Before Guts UK funds any research, we comb through the many applications we receive from researchers. Guts UK funds only the most robust of research projects, with the greatest impact upon patient care.

Last year, we developed an 'Experts by Experience' panel. This panel is a group of patients or carers, affected by a wide variety of digestive diseases. We're proud to say that this panel now assists in deciding which research Guts UK funds, alongside UK medical experts.

In addition, Guts UK is beginning new projects, 'Priority Setting Partnerships'. This is where we ask you what research you want to see into certain conditions. Turn to page 16 for more.

Guts UK will never make a decision that affects you, without you.

When you donate to Guts UK, together, we turn a scientist's determination into life-changing discovery. Your kindness allows us to fund research leading to earlier diagnoses, kinder treatments and ultimately, a cure.

Our guts have been underfunded, undervalued and misunderstood for decades. People are still suffering and dying, due to a lack of knowledge about our guts. With you by our side, we will get to grips with guts. Please donate £3 a month to Guts UK today.



Is my poo normal?

There's a real taboo surrounding poo. When discussing toilet habits, we tend to make the subject humorous, to make the conversation more comfortable and less serious. But your poo is an indication of your health in many ways. It's important to look at your poo, know what is your 'normal', and talk to your doctor about anything unusual for you.








Consistency

Stools that look like a sausage, either smooth and soft, or cracked on the surface are normal.

Many of us have seen the Bristol Stool Chart above, the widely used tool to tell you more about your poo. This tool is a good way to know whether your stools are normal, whether you're currently constipated or have diarrhoea.

- Type 1 and 2
These are classed as constipation
- Type 3 and 4
These are normal
- Type 5, 6 and 7
These are classed as diarrhoea

Bristol Stool Chart

Type 1		Separate hard lumps, like nuts
Type 2		Sausage shaped but lumpy
Type 3		Like a sausage but with cracks on the surface
Type 4		Like a sausage or snake, smooth and soft
Type 5		Soft blobs with clear-cut edges
Type 6		Fluffy pieces with ragged edges, a mushy stool
Type 7		Watery, no solid pieces

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Frequency

Emptying your bowels 2-3 times a day, to 2-3 times a week is normal.

Constipation is:

- Having a poo less than 3 times a week
- Straining or being in pain when you have a poo
- When poo is often hard or lumpy, large and dry, or pellet-like

Guts UK has a free of charge, detailed information leaflet that you can request on constipation. If making changes like drinking more fluids, and eating more fibre do not help your constipation, then you should talk to your GP.

Diarrhoea is:

- Having a poo more than 2-3 times a day
- There might be an urgency to empty your bowels
- These stools become loose, mushy or watery

Guts UK has a free of charge, detailed information leaflet that you can request on diarrhoea. If diarrhoea continues for longer than four weeks, this is referred to as 'chronic' diarrhoea and should be investigated by a GP.

Of course, every now and again, it's not unusual to experience a little constipation or diarrhoea. Constipation for example could be caused by not drinking enough fluids or not eating enough fibre, and diarrhoea could be caused by food poisoning.

Colour

Brown is the normal, healthy colour of poo. From time to time, it can be a little lighter or darker depending on what you eat. Seeing pieces of food in poo is normal too.

If your stool is a different colour, it is worth continuing to look at your poo and be cautious, as the colour of your stool can also be another indication of your health.

For example, black poo can be caused by iron tablets, bismuth-based medication or eating lots of liquorice! Whilst other black poo should

be reported to your doctor, black, tarry poo can indicate bleeding higher up in the digestive system and is a medical emergency.

Another example is orange poo. Orange poo can happen if someone has had a lot of food containing 'beta-carotene', found in foods like carrots, or vitamins and mineral supplements. But orange poo can also indicate a condition called Bile Acid Diarrhoea (also known as Bile Acid Malabsorption).

In addition, yellow stools might be caused by a medication prescribed for weight loss (orlistat). But it can also indicate that the fat you're eating is not being absorbed well, or it can be caused by an infection, coeliac disease, or pancreatic exocrine insufficiency.

In all the above instances, it's important that you don't stop taking any medication that might be causing your stool colour to change without discussing this with your doctor.



Did you find this information useful? Guts UK can only continue producing expert patient information with your kindness and support. Together, we can reach more people who need us, but don't yet know we exist. Thank you.

Franz' Story

Diverticulitis

'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, 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 a little about yourself, Franz:

I'm Franz, I'm 78 years old and I have two dogs at the moment as I'm looking after my granddaughter's dog, which encourages me to do lots of walking every day. When I can, I'll go back to see my friends and family in Germany, plus relatives in Spain.

I want to share my story today to help inform others. It's important to pay attention to your symptoms, listen to your body and seek help if you don't feel right.

Talk us through the time you first experienced diverticulitis symptoms:

When I first started experiencing symptoms of diverticulitis, I'd just had my left hip replaced. I was in hospital and I began feeling unwell. I had a fever, and I woke up one morning in the hospital bed shivering. I expected to feel unwell after such a big operation for some time, but the hospital didn't seem too worried. They did an ultrasound on my stomach, but didn't seem worried, so after five days I was sent home.

Did you feel better after you were sent home?

My symptoms continued, so I called my GP, who prescribed me with antibiotics for a suspected urine infection. I didn't feel any better. I still had awful abdominal pains and an overwhelming fever.

Throughout, I'd been speaking with an endocrinologist that I knew. He called back a couple of times to check up on me. He said that since I still feel and sound so terrible, to ask my daughter to take me to A&E.



What happened at hospital?

In A&E, they did the relevant tests and found out that I had a perforation in my bowel (a tear) that had been caused by diverticulitis. I didn't even know I had these pouches (diverticulosis) in my bowel, so this came as a huge shock.

The hospital told me I needed an operation, and this ended up taking five hours. They had to give me an ostomy bag. This is where waste from the bowel is redirected into a bag that sits on the stomach.

Though this all came as a huge shock, and I was still recovering from my hip replacement, I found getting used to the ostomy bag quite easy. The hospital do think they could reverse this if I wish, but at the moment I'm happy living with it. 'Don't try and fix something that isn't broken' comes to mind.

How do you feel now?

I've gone on to develop trouble with hernias following the creation of the stoma, which I'm currently speaking to my medical team about.

When Guts UK told me that there were over three times more people admitted to hospital with diverticulitis than appendicitis, I was shocked. So few people have heard of diverticulitis, but so many know about appendicitis.

This is one of the reasons I support Guts UK. Last year, I signed up to give Guts UK a monthly donation which I just see as my small contribution towards their great work. I find their magazine really helpful in understanding how digestive diseases have affected others too.

Guts UK can only continue helping and reaching people like Franz with your support. Please sign up to a monthly gift of £3 today. Together, we will get to grips with guts!

With your support

we can be there for others when they need us most



We all have guts, 25ft of them in fact. Every now and again they rumble, and when they are full, we give them a pat.

But with less than 2% of medical research funding going into our digestive systems, we don't understand our guts. So when something goes wrong, we don't like to talk about it. We don't know where to turn to get help.

This is where Guts UK comes in.

You have given me a way forward and incentive. I feel empowered and positive, and a little overwhelmed. Thank you again.

Thank you so much for your supportive and helpful letter. It was such a relief to have someone actually take me seriously.

Thank you for being a real person on the end of the phone.

I cannot thank Guts UK enough for your literature and online support at what has been a very scary time for myself and my family.

Thank you for sharing uplifting stories, and for all the important work your charity does.

I felt wrapped in cotton wool after speaking to you.

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

By offering people evidence-based information and advice, we can guide people to an earlier diagnosis. By being on the other end of the phone, an email or a letter, we can make sure people don't feel isolated or alone.

For those feeling confused or isolated with their symptoms or digestive disease, Guts UK offers a safe space. But there is still a long way to go. We need your help to reach more people who don't know we exist yet.

Please support Guts UK by donating £3 a month. With you, our gut army marching alongside us, we can reach more people together. We can be there to help when we're needed most.



Fiona's Story

Stomach Cancer

Tell us a little about yourself

I'm a music teacher! Music has always been a huge part of my life. I have played in orchestras, sung in choirs, and organised classical concerts too.

I'm an active person and love the outdoors. Until 2016, I was healthy and never really had any health scares.

What were your first symptoms of stomach cancer?

In 2016 I went to the doctor with what I thought was gallbladder pain. I was given antibiotics, but then had stomach ulcer symptoms. The doctor did a helicobacter pylori test (a bacteria that can cause stomach ulcers and stomach cancer), but it came back negative. It may have shown a negative result because unfortunately I'd just had antibiotics. My symptoms settled and I felt fine until 2019.

What happened in 2019?

I went back to work after the school holidays, and I generally just felt unwell with severe indigestion. Over the counter medication wouldn't touch the indigestion, and neither would prescription omeprazole. I was breathless walking up the stairs.

I made a doctor's appointment and ended up crying on the doctor, which isn't like me. They were concerned as the medication wasn't helping my indigestion. They booked me in for an endoscopy in a few weeks' time.

I was watching the screen when I had the endoscopy (camera down my oesophagus). When they reached the stomach, they could see a small red patch of inflammation that looked like a mouth ulcer. They took biopsies of my stomach and the endoscopist said it looked like gastritis. It was so small, less than 1cm big.

What happened next?

The biopsy came back positive for Hereditary Diffuse Gastric Cancer (signet ring cell stomach cancer). It was a huge shock. I was 48 years old at the time. I broke down into tears, thinking of my husband, Pete, and my daughter, Alex, who was only 16 years old at the time, just about to take on her GCSEs.



The team were incredible. After numerous scans and a laparoscopy, they explained the cancer was caught early and that I would not require the planned course of chemotherapy.

How did you find treatment?

Surgery was tough. I wasn't used to being in hospital at all, but I trusted the team whose care I was under. I had a total gastrectomy (my whole stomach removed).

Getting used to life without a stomach was hard. I felt sick and lived off pureed food for a long time. My mum was amazing, she came to nurse me and feed me chicken soup for weeks! The weight did just drop off - I ended up losing 2.5st. It was strange, I'd spent my whole life being careful to keep the weight off, and suddenly I was trying to keep it on!

How are you now?

Thankfully, my cancer was caught early enough to be treatable and hadn't travelled. It hasn't limited my life, but it has altered it. It has been an odd two years, but I am well and most importantly, cancer-free.

My family feel it's incredibly important to support awareness, information and research into this neglected cancer for other families. My brother Rob is running the Edinburgh marathon for Guts UK and I am so proud of him for taking on such a huge challenge - I'll be eternally grateful.

← Fiona & Rob



Guts UK doesn't stop at digestive diseases.

We're proud to work within the most underfunded and deadliest digestive cancers too.

Guts UK is a founding charity member of the Less Survivable Cancers Taskforce (LSCT). The LSCT was set up by a group of charities, to double survival rates for the six less survivable cancers by 2029. Four of these six cancers are digestive; stomach, oesophageal, pancreatic and liver cancer. These cancers have been neglected and underfunded for decades.

No one's cancer diagnosis should be at an emergency setting, like A&E.

NHS data from 2021 shows that these six cancers are far more likely to be diagnosed in emergency settings, such as A&E. At this point, the cancer is often at a later, more advanced stage, and harder to treat. Diagnosing these cancers as early as possible is crucial for increasing survival rates.

While 2.7% of breast cancer cases and 7.8% of prostate cancer cases were diagnosed in an emergency setting, the figures were much higher for the less survivable cancers. 30.2% of stomach cancer cases, 44.9% of liver cancer cases and 20.5% of oesophageal cancer cases were diagnosed as an emergency. This rises even higher to 52.7% for pancreatic cancer.

What is Guts UK and the LSCT doing to change these facts?



Awareness: The symptoms of the less survivable cancers don't always mirror symptoms that you might typically associate with cancer, like a lump or a change in moles. The symptoms tend to be more ambiguous, like ongoing indigestion or abdominal pain. Therefore, there is a dangerous lack in public awareness of the symptoms of the less survivable cancers.

The LSCT has pushed these symptoms onto national news multiple times, raising awareness of the lesser-known cancer symptoms. The more people who are aware of these early symptoms, the earlier we can get people to diagnosis, and the greater their chance of survival.

Information: With expert information, patients can take control of their health and make informed decisions. Guts UK has detailed information on digestive cancers, such as oesophageal, liver, stomach and bowel cancer. We believe information is power, and our information is only growing.

Research: Guts UK has made research into these neglected cancers a priority. Guts UK is currently funding:

- **Dr Salvatore Papa's liver cancer research.** This aims to better understand the ways our livers gain energy in order to cheat cell death. Damaged liver cells can eventually generate tumours, becoming cancerous. If we can stop the liver changing the way it gains energy, we might be able to prevent cancerous cells from developing.
- **Dr Sara Jamel's oesophageal cancer research.** This looks at the possibility of a 'breath-test' to diagnose oesophageal cancer, rather than an endoscopy (a camera looking at the oesophagus). If successful, this test could save lives by diagnosing oesophageal cancer earlier, when it is easier to treat.

- **Dr Marnix Jansen's stomach cancer research.** This work is exploring an alternative, more targeted way of taking biopsies (small tissue samples) from the stomach. This project will also aim to understand more about the DNA changes that occur. The more we can understand about stomach cancer, the closer we come to finding a cure.

Guts UK's work has the capacity to save lives, diagnosing digestive cancers earlier and giving people a fighting chance. Your donations and kindness make this possible. Help the UK get to grips with guts by donating to Guts UK today.





Since losing their sister Joy to diverticulitis, Joy's siblings have gone above and beyond to fundraise in her memory. From walking the Cotswold way to holding a quiz, they are helping other families in Joy's honour. Sheila, Joy's sister, most recently fundraised for us at a craft fayre. This is just one of the many ways the family have celebrated Joy's life.

Thank you for helping

get to work with

Every bake sale, run, or walk to be there for those who need it. Every walk, sky-dive or step closer to getting it. Whatever you decide.

Feeling inspired?

Contact us today about fundraising at 0207 486 0341 or info@gutsuk.org

Sue was diagnosed with oesophageal cancer in early 2021. She is now recovering and Catrina, her daughter, was motivated to fundraise for other families going through something similar. Sue chose Guts UK. Catrina took on the mighty challenge of 3,000 burpees throughout the month of November. Not only did she smash this challenge but she also raised just shy of £400! Thank you Catrina and Sue.



Dean took on the London to Brighton bike ride for Guts UK in memory of his mum, after losing her to stomach cancer. Dean raised over £1,000 for our small but mighty charity, to help other families just like his.

“I want to do this to help this charity with cases like [mine] so it may not end the same way for another person.”

you for
the UK

grips
guts!

head shave enables us
with digestive diseases.
or climb takes us one
g to grips with guts.
le to do, thank you.

inspired?
your fundraising ideas:
@gutscharity.org.uk

“ Finding Guts UK has shown me that there are so many people out there trying to raise awareness and doing amazing research into these issues. The support I've received through my own journey has been heart-warming - knowing that I'm not alone has been a massive help. ”

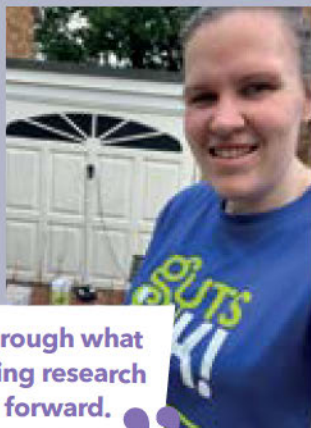
Dawn has achalasia, a condition affecting the oesophagus and the ability to swallow. For the past 2 years she has donated her birthday to Guts UK. Each year she is blown away by her family and friend's support. Together, they have raised over £500 for Guts UK.



“ I wouldn't have had the courage to tell my story if it hadn't had been for this charity, as it made me feel so comforted and proud. ”

Courtney found Guts UK through social media. She was inspired by our bold, brave and honest take on digestive health, so much so, she decided to fundraise for us. Courtney walked 100 miles for us last August. Thank you Courtney!

Rebecca spent the best part of 2020 in hospital suffering from acute pancreatitis. In 2021, she was determined to fundraise and raise as much awareness as she could. One of her fundraising efforts was to sell her gorgeous handmade cards with all the proceeds coming to Guts UK. Rebecca has raised over £1,600 for our charity. A true inspiration.



“ I truly wouldn't want anyone else to go through what I did, so I want to support Guts UK in funding research into this condition to help others going forward. ”

Guts UK

Research Update

Investing in future researchers

Guts UK is passionate about investing into the researchers of the future. We recognise the importance of those bringing new insight into our misunderstood area of health. To encourage and maintain the supply of bright, inquiring minds, Guts UK and Dr Falk reward the research work of clinicians, nurses, students and dietitians. Meet some of our recent award winners:

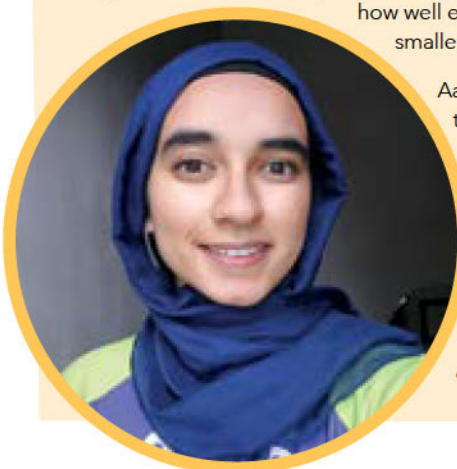
Alcohol-related Liver Disease Aaminah Mohammed iBSc

Aaminah was awarded the Medical Student Bursary Prize for her work into the differences between men and women with alcohol-related liver disease. Liver cirrhosis is the scarring of the liver, caused by long-term liver damage such as drinking alcohol. Alcohol-related cirrhosis used to affect more men than it did women, but now the numbers of males to females have evened.

Studies have shown that women are at greater risk of developing cirrhosis (scarring) than men, when consuming the same levels of alcohol. Variations in alcohol-related liver disease between men and women are ill-understood. But studies in the USA have shown that women are less likely to be selected for a liver transplant than men. This might be due to women having the same test ranges for kidney function as men, despite having different function. The kidney function test is used to score how well enough a person is for a transplant. Women also need smaller livers for transplant, which are not as available.

Aaminah's work also found that at in current clinical practice, there is no difference in the management of alcohol-related cirrhosis by sex. This means that despite women reacting differently to treatment than men, women receive the same treatment plan as men.

With future researchers like Aaminah studying healthcare inequalities, we can look towards a future with more inclusive and individual treatment plans. Thank you Aaminah for your dedication towards improving equality and diversity within access to healthcare.



Irritable Bowel Syndrome (IBS)

Helen Dumpleton

Helen is a gastroenterology dietitian who wanted to do an investigation into the effectiveness of dietary advice for IBS patients within the NHS trust she works for.

First, Helen carried out a review of the notes of almost 400 patients with IBS who had some form of input from a dietitian. She checked these notes against 'key markers', such as whether the patient had been tested for coeliac disease first.

The results were positive. Helen found that the trust had screened 100% of the patients for coeliac disease, reducing the possibility of a missed or incorrect diagnosis. It also highlighted that their individualised dietetic service, with 72% of people receiving dietary advice achieving good relief from their symptoms, therefore improving the quality of life for many.

Guts UK and Dr Falk were delighted to award Helen the Dietitian Recognition Award. Helen took on a review of the dietary services her department were offering, to discover whether they were working for patients. With future researchers like Helen getting to grips with guts, we can continue transforming and improving aspects of patient care.



Chronic Intestinal Failure

Dr Maja Kopczynska

Chronic Intestinal Failure (CIF) is the long-lasting reduction of gut function, which can lead to the inability to digest food and nutrients properly. Maja won Guts UK and Dr Falk's Doctor Research Award for her project exploring the psychological impacts of sex and quality of life with CIF.

Maja wants to discover how common psychosexual dysfunction is in those diagnosed with CIF. CIF can negatively affect people's mental health, quality of life and social life. This can include social changes (like being cared for), a sense of loss of control of their life and changes in body image.

One area that is not often considered is how CIF affects people's feelings about the quality of their sex life. Psychosexual dysfunction is a sexual problem that is psychological (arises in the mind), leading to problems being sexually aroused or feeling sexual satisfaction. This is an area that Maja is eager to explore within her project.

This project could lead clinics to better understand patient needs as a whole, and finding ways to deliver more personalised care.



You can help us turn a scientists' determination into life-changing discovery. Please support Guts UK today and help the UK get to grips with guts.

Is my heartburn normal?

Many of us experience heartburn, particularly when we might eat or drink a little more than usual. Like other digestive symptoms, you might not know what's normal, and when you might need to speak with your GP about your symptoms. Guts UK is here to help. You can request our full leaflet on heartburn and reflux by contacting Guts UK.



What is heartburn?

Heartburn is a chest pain that often occurs after eating, lying down or bending over. It is usually described as a 'burning' sensation in the chest. The pain is located at the lowest end of the breastbone in the centre of the chest. The discomfort often rises upwards and outwards.

How common is heartburn?

Heartburn is extremely common, affecting up to 1 in every 4 UK adults.

What causes heartburn?

Lifestyle factors can increase the risk of heartburn, such as smoking, drinking excess alcohol, stooping or bending forwards or being overweight.

Pregnant women can also develop heartburn during the later stages of pregnancy, as the growing baby pushes on the stomach.

If you have a hiatus hernia (where part of the stomach slides upwards into the chest by pushing itself through a hole in the diaphragm muscle), you might be more likely to have reflux symptoms.

How can I reduce my heartburn or reflux?

- Leave three hours between your evening meal and going to bed.
- Include soft drinks in-between alcoholic drinks. This will also reduce your overall alcohol intake, and keep you hydrated.
- Chew your food well and take time over meals – don't rush.
- Allow gravity to help by sitting upright when eating (not slouching).
- If you don't already, eating breakfast can help, as it makes you less likely to 'over-indulge' at lunch.
- Lifting the head end of the bed might help reduce heartburn and acid reflux. Sleeping on your left-hand side might also help, due to the shape of the stomach and its connection between the oesophagus being on your other side.

When should I see my GP about heartburn?

You should contact your GP about your heartburn if you begin experiencing the following:

- If you experience symptoms like food getting stuck in your oesophagus, frequently being sick or unintentional weight loss.
- If lifestyle changes and pharmacy medicines aren't helping your symptoms.
- If you have heartburn most days for three weeks or more.
- If you have difficulty or pain when swallowing food.
- If you have heartburn, indigestion, hiccups or an unpleasant taste in your mouth for three weeks or more.

**We can only continue producing expert information with your support.
Please donate to Guts UK today. Thank you.**

Sharan's Story

Crohn's disease

"No matter what I said, she wouldn't let me use the disabled toilet"



“ I have Crohn's disease. My symptoms can include severe diarrhoea, pain and fatigue. At the time of this story, I'd just had an emergency subtotal colectomy (removal of part of the bowel). I was getting used to using my ileostomy bag (stoma), so it could take me 15-20 minutes to change my bag. I still felt uneasy about leaving the house.

The first time I'd left the house after my surgery, my bag leaked. I was in a regular toilet cubicle. It was dark and I didn't have water on me. I had to clean up as best I could with hand sanitiser. This experience made me realise the importance of disabled toilets to me.

I was getting on the train to go to a festival. I contacted the festival in advance, who were so accommodating from the beginning. I had a wristband for accessing the disabled toilets, which gave me the confidence I needed to attend.

I went to use the station toilets before boarding the train. The toilet attendant was there. I tried to open the disabled toilet, but it was locked by more than the usual radar key. I asked the attendant if she could open the door. She said "no, I've just cleaned it". I explained that I needed to use it, but she looked at me and said "you don't look disabled to me".

Though hesitant, I explained that I had Crohn's disease. She said she knew someone with it too, that they didn't use disabled toilets and that the normal toilets were spacious enough for me. I felt I had to explain further that I'd just had surgery and if I've leaked, I need access to a sink. She refused again. I was forced to use a regular cubicle.

Sadly, this changed how I approached situations for months. It made me nervous about the festival and put my social life almost to a stop for a while.

My confidence has since grown. To anyone who is new to these experiences or an invisible illness, please use whatever you need to. Don't bend and minimise your own needs just because of how others look at you or treat you. As hard as these experiences are, the stronger and more confident you become with each one.

”



Thank you to Sharan of IBDesis for bravely sharing your story. IBDesis is a group dedicated to uniting and empowering South Asians living with Inflammatory Bowel Disease (like Crohn's disease and ulcerative colitis) around the globe. You can find IBDesis on Facebook: @ibdesis

Illnesses and disabilities take many forms. Some are visible, and some are invisible. But all are valid. Guts UK is dedicated to raising awareness of invisible and visible conditions, so no one ever has to feel dismissed, unheard or embarrassed. You can help us spread this important message further by supporting Guts UK today.

Guts UK's 'new' type of project

Your voice, the patient voice, is central within every decision we make

Guts UK is delighted to be funding our first ever Priority Setting Partnerships (PSPs). These are projects that are designed to identify and prioritise 10 unanswered questions that research has the potential to answer. This is our way of asking you what research you want to see into the condition that affects you.

The process of a PSP brings together patients, carers, doctors and other healthcare professionals – all with an equal voice. Guts UK is proudly funding two PSPs, one for Irritable Bowel Syndrome (IBS) and one for pancreatitis.

What does the PSP process look like?

Guts UK is taking on these PSPs alongside the 'PSP professionals', known as the James Lind Alliance.

1 The first stage of the PSP is pulling together a 'Steering Group'. This is a group of patients, carers, family members and healthcare professionals, all with different experiences of the digestive condition.

2 Next, this group decide upon aims and the direction of the PSP.

Once the intricacies have been decided, the group launch the first survey. This survey is open to patients, carers and families affected by the digestive condition. It is also open to healthcare professionals with experience of treating the digestive condition, such as nurses, doctors or dietitians. The survey anonymously gathers information such as; specifics about your condition, your gender and age. At the end of the survey, you list the questions that you want future research to answer.

4 Once the survey has gathered all the responses, the steering group and information specialists work through these questions. They look at which questions have already been answered by research, and which ones haven't.

5 The questions that haven't been answered by research yet, but could be, go onto a second survey.

6 This second survey is open to the same groups of people again. It usually lists 50-70 questions, that you can choose up to 20 from the list that are a priority for you.

7 After this tried and tested process, a list of 10 research questions are created. These become the top 10 research priorities for the specific digestive condition, and will ignite change in attitudes, and can lead to increased, more specific research funding for the condition.

An exciting announcement for diverticular disease!

Guts UK is delighted to announce that in 2022, we are also aiming to launch a brand new PSP into **diverticular disease**. Like IBS and pancreatitis, there has never been a PSP into diverticular disease. Diverticular disease is an underfunded and misunderstood condition.

Guts UK's research has the capacity to change lives, and your donation make it possible. Help the UK get to grips with guts by donating today. Thank you.



Kranky Panky 2021

Every November, Guts UK shares one pancreatitis story a day for the whole month. Some of these stories are tough to read, but need to be told.

Guts UK's Kranky Panky 2021 campaign was our most successful to date, we reached 3x the amount of people we reached in 2020! We are dedicated to finding an effective treatment, a cure for this misunderstood and underfunded condition.



“ I’m an orthopaedic surgeon, so when my organs began failing, I knew exactly what was happening to me. It was terrifying. When I was well enough, I’d research pancreatitis online. I was shocked at the lack of research and data available! ”

Rishi

Rishi spent his 40th birthday in hospital with pancreatitis. He says that pancreatitis taught him to learn to live every day as if it was his last. Rishi plans on hosting a big fundraising event for Guts UK. Thank you, Rishi.

“ I am 30 with chronic pancreatitis caused by heavy drinking in my teens and twenties. After my first attack, I’d wake every morning throwing up. I was skin and bones. I felt like I didn’t have the right to moan, as I’d done this to myself. I don’t want anyone to go through what I did, feeling so alone. That’s why I’m sharing my story. ”

Claire



YOUR STORIES



Zaki

Zaki was just three years old when he was diagnosed with acute pancreatitis. He had woken, vomiting, complaining of extreme tummy pain and unable to walk.

“ We remain so proud of Zaki and his resilience throughout what has been one of the most difficult year of our lives. ”

Claire and Mohamed, Zaki’s parents

July 2nd was like any other day for Nadine and Kev, until Kev went to the bathroom to be sick a few times. He began experiencing severe pain. Just eight weeks later, Kev lost his life to severe acute pancreatitis. He leaves behind his wife Nadine and their three children.

“ Kev was the most amazing husband; he was my best friend and a fantastic daddy to our 3 children. Like many people, we didn’t know much about pancreatitis, so Guts UK were a massive help during his time in hospital. At Kev’s funeral, we raised over £1,300 for Guts UK in his honour. ”

Kev



Disability Awareness Day

2021

Last September, Team Guts UK were thrilled to attend Disability Awareness Day in Warrington. This fantastic day brings awareness to all disabilities and showcases charities and businesses supporting those with disabilities.

Guts UK was there to proudly represent invisible illnesses, hidden disabilities and to abolish the poo taboo!



Colin the Inflatable Colon



We had a wonderful time and the people of Warrington loved meeting Colin the Inflatable Colon. They jumped at the chance to punch a polyp!

When the Guts UK roadshow comes to town, we empower people to seek help.

Why you're

getting to grips with guts

Fifty years ago, our founders got together and decided they wanted to do something to end the pain and suffering that you and I know all too well. A lot has changed since then. We've transformed aspects of patient care and made ground-breaking research discoveries. But the truth is, the UK still has not got to grips with guts.

We know it's a big ambition, but with people like yourself supporting us, we cannot and will not fail.

Here is a small selection of notes left alongside your donations:

My 3-year-old nephew has chronic pancreatitis, and my 3-month-old niece has just been told she has the same genetic mutations. Any research towards a potential cure is a step in the right direction.

Very grateful for the emailed advice Guts UK gave to me.

I have stomach and bowel issues myself and I want to help fund more research into it.

I am donating today because of my girlfriend who suffers from gastroparesis.

I have a stream on a gaming website and dedicate this to my fellow patients who suffer with IBS.

In appreciation of the recently supplied booklets you sent me, very informative and helpful. Thank you.

After reading so many people are struggling with their guts and not enough research is being done to help them, I wanted to try help with your charity seen as though you're the only charity trying to help. Thank you for all you do.

My colleague and friend recommended donating to this charity on World Cancer Day.

Excellent website with sound, up to date advice.



THE CHARITY FOR THE DIGESTIVE SYSTEM

REQUEST YOUR FREE EXPERT PATIENT INFORMATION LEAFLET TODAY

- Achalasia
- Acute Pancreatitis **NEW**
- Adhesions
- Alcohol & The Digestive System
- 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
- Gilbert's Syndrome **NEW**
- 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 **NEW**
- Painkillers causing Constipation and Digestive Symptoms
- Pancreatic Exocrine Insufficiency (Pancreatic Enzyme Replacement Therapy)
- Pelvic Radiation Disease
- Perianal Disease **NEW**
- Polyps in the Bowel
- Primary Sclerosing Cholangitis
- Rumination Syndrome
- Stomach Cancer
- 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.

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