

# The charity for the digestive system

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## **Guts UK Facts and Figures**

Guts UK's vision is a world where digestive disorders are better understood, better treated and everyone who lives with one, gets the support they need.

Guts UK's mission is to provide expert information, raise awareness of digestive health and transform the landscape for research into disease of the gut, liver and pancreas.



Full accounts for Guts UK 2017 can be found on our website and filed at the Charity Commission website.

#### Charitable expenditure: research grants in 2018 Because of your continuing support, Guts UK has been able to increase our grants programme and in 2018 will be committing nearly £1m to more vital research into or digestive system.

**Expenditure** £147,420 f.34.3.525 Costs of income generation (7%) Governance costs Investment management costs Support costs Expenditure on charitable activities



You are making this possible. Thank YOU.

#### Raise the banner for digestive health

Our recent name change from Core to Guts UK came out of research with a wide group of stakeholders that included some 787 patients and carers of people affected by digestive disorders. They were brave, bold and honest in sharing with us the impact these conditions have on their lives

We were inspired to adopt these same values in renaming the charity to bring more visibility, clarity and focus to our mission. We listened to people's stories and wanted to bring that energy, attitude, personality and impact to the new brand to get us noticed.

We've all got guts and we don't want anybody suffering in silence through fear of shame or embarrassment. It's not true that people don't want to talk about their guts - ask any health care professional. If you are affected, you need to talk, people are desperate for information to help them understand their condition and take control.

So loud and proud, as part of our mission, we have started to take Guts UK out there to a very warm reception.

## MEET COLIN THE INFLATABLE COLON

#### he's a conversation starter if ever there was one:

I am thrilled and delighted at the recent news that the age for bowel cancer screening will be brought down from 60 to 50 in England and Wales. Great news, more lives will be saved. But my job isn't yet done. We still need to ensure that everyone who gets an invitation uses this opportunity!

said Colin of the announcement made in August.



A cool place to hang out at a hot summer carnival! (those are perdunculating polyps, by the way)



The table holds our expert information booklets and the loo is full of facts and funnies about our digestive system.

Can you ever be too early with a bowel cancer prevention message?



#### Coping with Chronic Intestinal Pseudo-obstruction (CIP) in particular Mesenteric Plexitis.

On reflection it all began in 1969 when Diane presented to her GP on more than one occasion with repeated episodes of colicky abdominal pain. A barium study revealed no abnormalities. Despite repeated episodes, one GP suggested that Diane may benefit from a psychiatric referral!

1974 Diane was admitted to Fazakerly Hospital, Liverpool and underwent two laparotomies, the second of which concluded that Diane had acute Crohn's disease. After a lengthy spell (3 months) in hospital, Diane was finally discharged and her subsequent recovery took several months. As result of her operations and illness it was found that Diane had problems with absorption and monthly vitamin B12 injections were prescribed.

For the next 30 years Diane experienced very good health, rarely suffering from a cold even. Diane enjoyed a full life, she returned to her nursing career which she so loved and enjoyed several holidays abroad with her husband Terry.

2003 Diane was diagnosed with type 2 diabetes which initially was treated with metformin but was subsequently managed successfully by diet alone. However it was also the year that saw Diane collapse and be admitted to hospital with severe abdominal pain, which she recognised as the same pain she had experienced all those years ago. An abdominal x-ray revealed small bowel obstruction. After 24/48hours of conservative treatment the symptoms had subsided and Diane was gradually allowed to start eating and drinking again.

Sadly this marked the long process of reaching a diagnosis of CIP. Over the next 15 years Diane suffered repeated attacks and admissions into hospital, these were made all the more stressful by the dismissive attitudes of some members of the medical profession. A further two laparotomies followed one of

which being a hemicolectomy. The attacks began to increase in severity and frequency. Early on in the disease process, Diane would be able to recognise the start of an attack and get to the emergency department in due course. As the condition progressed the attacks would present very quickly and there was no alternative but to call for an ambulance. On admission Diane would require oxygen, IV fluids and pain relief; however her episodes became so severe that her condition would deteriorate rapidly causing her to have a vasovagal attack and lose consciousness. She also experienced severe gastric loss due to simultaneous episodes of vomiting and diarrhoea. Again abdominal x-rays and CT scans would show nothing more than small bowel obstruction which would resolve after a few days of conservative management.

By now this was having a massive impact on Diane and her family. She and her husband were no longer able to enjoy a carefree existence The attacks were unpredictable; Diane and Terry no longer had the confidence to travel and be more than 30 minutes away from their local hospital and from clinicians who knew of her.

2015 saw a dramatic increase in frequency and severity of episodes Finally a diagnosis of Pan-enteric Visceral Neuropathy (Mesenteric Plexitis) was reached.



Temu & Diane

Diane was given an admissions letter and alert system detailing her condition and the treatment required for when she presented to the emergency department by her doctor. This "fast-pass" letter became crucial in negotiating her passage through a busy emergency department. A steroid drug regime and dietary advice successfully brought the plexitis under control. For the next eighteen months Diane enjoyed a good quality of life; she and her husband along with their daughters celebrated their golden wedding anniversary, she took up art classes and enjoyed meeting the "girls" for lunch. Everyone began to relax a little.

Spring 2017 brought an unfortunate turn of events and the next six months saw a variety of complications. The impact on Diane and her family was devastating and although we all tried to remain positive, events took their toll and sadly Diane passed away peacefully on 23rd December 2017.

The one thing that Diane and, her family were absolutely determined about was that more research should be done into the nature and cause of this life limiting condition. That information should be "out there" for GP's. surgical teams, junior doctors and all health

care professionals. Sadly a lot of the stresses that Diane and her family experienced were in part due to the attitudes of some members of the medical profession and their reluctance to consider a diagnosis unknown to them or to seek help from another source.

'We fully accept that at the moment this is a condition that cannot be cured. But, it can be managed successfully and patients can enjoy a better quality of life. It needs attitudes to change and early referral to an appropriate nutrition team. Unfortunately there are many patients with complex chronic conditions who will no doubt require repeated admissions into hospital over the course of their lives. A "fastpass" letter and alert system as instigated by Diane's doctor should be considered for this category of patients.'

As told by Terence, Diane's husband and daughters. The Stidston family and fiends have supported Guts UK's research programme with donations inspired by Diane. They also helped review the latest medical update of our information into Chronic Intestinal Pseudo-obstruction which can be found on Guts UK's website or call **0207 486 0341** to be sent a copy in the post.

### Gifts to Guts UK inspired by loved ones

Thank you to the family and friends who have donated to Guts UK's research programme in memory or in honour of the following people

**Catherine Dos Santos** 

**Rosie Willis Seath** 

**Diane Stidston** 

Michael Bentham

**Paul Levick Coulthurst** 

Jill Fox

Wilfred Hatton

Michael Gregg

**Jeffrey Hibbit** 

Maria Hill

Jill Howland

**Morris Lawton** 

Julia New

**Donald Peers** 

**Arnie Price** 

**Roy Reeves** 

**Andrew Tymkewycz** 

**Shirley Spinks** 

**Raymond Russon** 

**Daphne Susan Jarvis** 

Sandra Bald's mum

Ray Butler's father

Peter Claydon's mum

**Edna Mead** 



Guts UK Donation & Gift Aid envelopes are available from the charity for use at any occasion. Order yours by email info@gutscharity.org.uk by calling **0207 486 0341.** 

# **Microscopic Colitis**

#### What is it and could you have it?

#### Are you suffering from bouts of watery diarrhoea? Read on.

Microscopic colitis is an inflammatory disease of the bowel. It is characterised by watery diarrhoea, usually accompanied by urgency and problems with bowel control. People affected often need to identify where toilets are when they leave the house, to avoid accidents. The condition can also cause abdominal pain, tiredness, dehydration and weight loss. Symptoms can be bad and lead to a substantial loss of quality of life.

Microscopic colitis can develop at any time but it is more common in middle-age, with those affected often diagnosed between the ages of 50 and 60. It also occurs more frequently in women.

The condition is thought to be under-diagnosed, which means people with these symptoms might actually have microscopic colitis that has been mistakenly identified for another condition (most often mis-diagnosed as IBS or diverticular disease). This is partly due to low awareness among some health professionals but also partly because of how the condition appears. Unlike other inflammatory bowel diseases, like Crohn's disease or ulcerative colitis, the lining of the bowel appears normal when investigated with a colonoscope (a flexible tube with a camera at the end used to examine the inside of the bowel). It is only if a biopsy (a small tissue sample) of the bowel is taken and examined under the microscope that the inflammation can be seen.

Guts UK are keen to ensure those affected become aware of the condition, so they can discuss it with the health professionals looking after them. This is true both for those who have not been diagnosed and also for those not fully settled on their current treatment. Diagnosis can be easier if more symptoms and signs are considered, in addition to the presence of watery diarrhoea. People who have microscopic colitis sometimes have other diseases that affect the immune system such as some thyroid problems,

coeliac disease, rheumatoid arthritis, psoriasis and diabetes. Even if they are not directly affected by an autoimmune disease, a close blood relative might be affected. Anaemia is also sometimes present in people with microscopic colitis and can also provide clues that can aid a quicker diagnosis.

It is not yet clear what causes microscopic colitis. It is possible that the inflammation might be caused by the body's immune system overreacting to bacteria that live normally in the bowel, or responding to an infection from toxic bacteria or some viruses. Other risk factors, such as bile acid malabsorption and some medications, are currently being considered. Examples of medications that have been linked to microscopic colitis include non-steroidal anti-inflammatory drugs (such as ibuprofen and aspirin); protein pump inhibitors (such as lansoprazole and omeprazole); some diabetic medications (acarbose); some antidepressants (sertraline); and some anticoagulant medications (ticlopidine).

Microscopic colitis can be treated with small changes to the diet, a course of steroids or with symptom-relieving medicines. This strengthens the case for better diagnosis of this condition, which Guts UK hopes will happen through raising awareness among the public and health professionals.

"The really good news is that microscopic colitis can be treated. The correct diagnosis and treatment can make a huge and dramatic difference to a person's quality of life. We don't want anyone suffering in silence so Guts UK wants to raise awareness of this easily overlooked condition and put the patient in control"

The more we know, the better we can look after insides. Please support Guts UK's important work today.

# **Expert Patient Information at Guts UK**

Guts UK charity's mission is to reach all who need information and support with evidence based information from medical experts. Knowledge empowers us as individuals to ask the right questions of our doctors and nurses, to help us get a timely diagnosis, get the right treatment. Knowing more about what triggers our condition, learning about lifestyle factors, diet and nutrition can help us to manage our symptoms better and be in control.

With the help of some of our brilliant specialist gastroenterology nurses and consultants we've recently updated all Guts UK information and been able to get input and feedback from our lay readers too, people affected by these conditions. A huge thank you goes out to everyone who has helped with our update.

You can find all our information online at www.gutscharity.org.uk in an easy to print version.

A super interesting area brought to light is a new approach to a condition previously called "Sphincter of Oddi" and now referred to as Biliary Sphincter Disorders - if that affects you, check out the update.



## Prudential Ride London brings oesophageal cancer

#### survivor and doctor together after 6 years

Twenty brave cycling supporters from different parts of the country entered as our first ever Team Guts UK in the epic Ride London on July 29th. The challenge is no mean feat at 100 miles (or 46 miles) routes plus the added element that we got the soggiest day of the whole glorious summer of 2018!

Steve Metcalfe had signed up to the event to fundraise in memory of his mum who had died of liver and lung cancer. But a conversation with Steve revealed he himself had been diagnosed with stage four oesophageal cancer. Steve called to find out if any other members of the Guts UK Ride London Team were in in the Oxford area, he might train with. Serendipitously Dr Tony Ellis, gastroenterologist and Chair of the Oxford Gut Club was also signed up for doing Ride London - and is the very same doctor who diagnosed Steve's cancer back in 2012.

Steve went to the doctor with symptoms of a general uncomfortable stomach, lots of gas, wind and bloating. The doctor suggested referring Steve for a colonoscopy (a scope to look up the tail end). It was the chance remark that Steve said at the end of the consultation "And sometimes I have trouble swallowing a sandwich," that made the GP also ask for a gastroscopy (a scope looking via the top end).



Alan, Steve & Tonu

The gastroenterologist found oesophageal cancer that had already spread, with secondary cancer in the liver. A gruelling course of chemotherapy took its toll for the year after.

"I was physically thrashed. I couldn't walk 100 yards. My friend Alan English, also part of Team Guts UK, supported me with regular cycling to get back some fitness and has been part of my physical recovery. Meeting up with my consultant again may be a coincidence, who knows, but what a celebration," says Steve who is keen to share his story so that others may be more aware of digestive cancers.

Both doctor and patient completed the 100 mile cycle course to raise money for more research. Shining - if soggy! - examples of hope and belief that research saves lives.

The brilliant Team Guts UK at Ride London 2018 has raised almost £10,000 to date: Thank you to the cyclists and everyone who supported their efforts.



# Less Survivable Cancers Taskforce

Guts UK charity is a member of the Less Survivable Cancers Taskforce. a radical new partnership of six charities targeting six overlooked and underfunded cancers with the lowest survival rates: lung, brain, liver. stomach, pancreatic and oesophageal. Four of these six cancers are digestive cancers.



These six cancers account for 51% of all annual cancer deaths.

Currently around 90,000 people are diagnosed with one of these less survivable cancers every year. Yet the current five-year survival rate of these less survivable cancers grouped together stands at just 14%. This compares to 64% for the more survivable cancers. That's a huge difference and we want to do something about it so there is a fairer chance for everyone fighting cancer.

> We want to see the five year survival rate doubled to 28% by 2028. That would save thousands of lives in the UK each year.

#### The five core objectives of the taskforce are to:

- · raise awareness of symptoms
- speed up paths to treatment
- remove barriers to treatment trials
- increase investments in research.
- set government backed survival targets for each cancer











The government's 70th birthday present to the NHS of an extra £20bn a year by 2023 means more can now be done to improve treatment and care, and could help drive an improvement in the outlook for every patient diagnosed with a less survivable cancer.

This autumn, the taskforce will take action to try and get the target of doubling of these cancer survival rates included in the Cancer Strategy for England.

#### No one should be written off. Every cancer patient should be given the best chance possible.

We believe that this target is achievable if we all work together. If you or someone you love has been affected by a digestive cancer, please share your story and add your voice to our campaign at info@gutscharity.org.uk.

#### The taskforce is made up of the following charities:











## **The Guts and The Glory:**

## YOU make it all possible

Up and down the UK folks are doing fabulous fundraising for Guts UK research. Beard shaves, bake sales and BBQs, curry and guiz nights, mountain walks, marathons and Tough Mudders - you are all quite brilliant. On behalf of all those who benefit from the research you have funded, we thank you.





On August 19th before most of us mere mortals had even woken to our Sundays, Jenn Flaherty from Huddersfield had dived into a lake in Copenhagen to begin her Ironman challenge. She swam 2.4 miles, cycled 112 miles then ran a 26.2 mile marathon, in that order without a break all within 11 hours. Jenn was cheered on in Copenhagen by 23 members of her family who must have been busting with pride to see her get her Ironman medal. What drives an Ironwoman? Jenn's inspiration is her Auntie Helen "whose determination and humour" through her diagnosis and gruelling treatment for pancreatitis has been her focus all the way through months of training and the event.



#### Will you fundraise for Guts UK?

Help us start that conversation about our digestive system.

Whatever you can do, please do it for Guts UK

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Turn your birthday or special occasion into gifts to Guts UK research. Our Facebook Donate button is active and a super effective way to get friends and family to make a donation to Guts UK.

If you need that extra incentive and want a challenge to work to, why not take up one of our Guts UK Team places?

#### Cycling

We have 40 Guts UK places for Ride London 100 on Sunday August 4th 2019

#### Running

Up for a half marathon? We have 15 places in the Vitality Half-Marathon in London on March 10th 2019 so please contact us to reserve your place, we would love to have you on board.

We are looking to develop our challenge event programme but if you have secured your own place in a local event, contact us we will be thrilled to let you have a Guts UK technical top and support your fundraising.

Call 0207 486 0341 or email info@gutscharity.org.uk





# **Guts UK Collecting Tins available**

Creative uses abound for these small but powerful icons of support. For example, start a collection in the workplace; what about a "Potty Mouth" swear box? And if you are in a choir, you can ask for a donation for every "Bum Note"? Order yours today



## **Help Guts UK**

# Raising Awareness about Pancreatitis

Pancreatitis is a serious and complex condition. It causes immense suffering, can have a severe effect on quality of life and may result in reduced life expectancy. In the past, there has been lack of knowledge on how to manage pancreatitis and this has resulted in clinicians avoiding those with the disease and conflicting advice being offered. With this guideline it is hoped that sound advice will be provided to enable people with pancreatitis to receive appropriate care to improve the outcomes from this difficult condition.

NICE guidelines Pancreatitis, Diagnosis and Management (Draft March 2018)

The new NICE guidelines on pancreatitis will be published on September 5th 2018 and the quote above is the final paragraph from the introduction.

The guidelines have been two years in the making as they bring an array of specialists on pancreatitis together. The lay members of the committee for this work must be praised for the excellent job they have done in representing the patient and carers views. You can really hear the patient voice (and hard earned expertise) in the guidelines which are stonger for this. Our congratulations to Amy Lucas, Louise Carr and Stuart Wood for their important input to these guidelines. Here's what they have to say about the new guidelines and the process of getting there:

Many patients suffer because their pancreas problems are misdiagnosed or undiagnosed. I am hoping that the new Pancreatitis Guidelines will give us the opportunity to raise the profile of a poorly understood disease within the general medical profession and also to the wider public.

Stuart Wood

Louise Carr

The NICE guidelines will have an enormous impact on standardising the level of care in both acute and chronic pancreatitis across England and Wales. The NICE guidance will also empower patients to take more control of their own care pathway, this is a positive step forward for all patients.

Amy Lucas

There is so much confusion with Pancreatitis with diagnosis, treatment and so on. I feel that these guidelines will help guide the medical professionals, and then lead to the appropriate action being done quicker to help reduce the patient suffering. The guidelines are going to empower patients to take control of their health and be there to support them when speaking to medical professionals. I as a lay member feel empowered from my experience and I hope others feel the same also.

NICE guidelines are recommendations for the care of individuals with specific clinical conditions or in specific circumstances within the NHS – from prevention and self-care through primary and secondary care to more specialised services.

The reality is that an attack of pancreatitis can come out of nowhere and is painful and frightening. It is difficult to diagnose and we hear many stories of the swift damage an attack can do. But these guidelines go a long way to showing patients what should happen with regards to diagnosis and treatment and are a step in the right direction.



Find the guidelines on www.nice.org.uk.

## **Kranky Panky Weekend**



#### November 23<sup>rd</sup> - 25<sup>th</sup> 2018

November has become the purple coloured month because of the campaign to light windows and buildings across Europe in purple to show support for pancreatic cancer charities. As a digestive cancer, we have funded research into pancreatic cancer and actively campaign for better survival rates as part of the Less Survivable Cancers Taskforce (see page 9). This year we will also have a focus on pancreatitis within November so that this non-cancerous pancreatic disease keeps apace with the demand for higher levels of investment into research.

We are going to use our website and social media, Facebook and Twitter to share

30 stories for 30 days

30 facts for 30 days

Have you or your loved one been affected by pancreatitis? Please share your story. Real stories have a powerful way of giving real insight that others can understand and learn from. We hear from our supporters that they are always interested in hearing how a condition or symptoms affects others, how they cope. A story that prompts someone to go to the doctor may just save a life.

## Otherways you can support Kranky Panky Weekend for Guts UK:

- Donate your birthday or special occasion gifts to Guts UK via Facebook Donate button
- Hold a fundraising dinner party (with a pancreatitis friendly menu?)
- Organise a quiz event with fascinating digestive facts
- Run a raffle
- Set up a Guts UK information table and take a collecting tin to work
- Order Guts UK christmas cards (handmade by Lois)
- · Commit to a sponsored run, ride, walk, swim challenge event



It is probably safe to say most of the general public haven't got a clue they have a pancreas, nor any idea what it does. Least of all that it can backfire with tragic consequences. Only families that have been affected by pancreatitis really understand the devastation it causes.

Let's raise the profile of the pancreas this November with our Kranky Panky Weekend and support Guts UK to fund the only fellowship into pancreatitis in the UK, £180,000 every 3 years.

Call us at Guts UK for your fundraising resources for Kranky Panky weekend.



Charities like Guts UK are desperately important in the fight to understand chronic pancreatitis, but also, perhaps more vitally, in reducing the stigma and raising the awareness of the condition and its effects on so many people and the people around them. It could mean that people like my husband would be able to access the treatment they need.

Ruth and Craig Potts



More will be on our website

## Dr Conor McCann

#### Achalasia and gastroparesis

Think about the last time you ate a sandwich. You chewed it, savoured it and then swallowed it: job done. We tend to forget about the food we eat as soon as we swallow it but for some people the journey of the food down the gullet, into the stomach, and onwards into the small intestine can be more challenging.

When we swallow, the gullet contracts at regular intervals, creating a wave-like movement that pushes the food forward. This process is called peristalsis. Once the food enters the stomach, the walls of the stomach contract to churn the food, mixing it with the gastric juices that help to break the food down. Once churned into a smooth liquid, the food enters the small intestine slowly, where it gets broken down further and absorbed into the blood stream.

Unfortunately in some people these contractions do not work well. Achalasia and gastroparesis are two conditions that cause the progress of the food through the gut to slow down or stop.

Achalasia is characterised by faulty peristalsis, the wave-like movement in the gullet, leading to food getting stuck there. People affected can experience difficulty swallowing, heartburn, pain and vomiting. In gastroparesis the walls of the stomach do not contract properly, which means that food stays in the stomach for longer, leading to a feeling of fullness, nausea, vomiting, bloating, acid reflux, and pain.

Both conditions can cause loss of appetite. leading to unintentional weight loss and nutritional problems. They can also make people feel very unwell and decrease their quality of life. At present there are no cures for either condition, with treatment limited to drugs or surgery to alleviate symptoms.

It is not clear what causes either condition but it seems damage to nerve cells in the gullet and the stomach might be involved. These nerve cells are responsible for stimulating the muscles that contract to squeeze the gullet and the stomach.

Damage caused to nerve cells by poorly controlled diabetes can be a cause of gastroparesis (diabetic gastroparesis). Gastroparesis in turn can make controlling diabetes much harder, by slowing down the emptying of the stomach and affecting the levels of sugar (glucose) that reach the blood.

Guts UK are currently funding a three-year Fellowship for £210,000 to Dr Conor McCann at University College London. Dr McCann is investigating whether those damaged nerve cells can be replaced and by doing this, restore appropriate muscle contraction in the gullet or the stomach. If he is successful, we might be able to treat achalasia and diabetic gastroparesis in the future by injecting new nerve cells into the relevant part of the gut, to restore its function.



Conditions such as achalasia and gastroparesis that affect the upper part of the gut (upper gastrointestinal, or upper GI) are a priority for Guts UK. We fund research in this area via our Guts UK Derek Butler Fellowship, which is the award that Dr McCann received. We have also launched a new Fellowship with Olympus exploring how best to use endoscopy to diagnose and manage other upper GI conditions, namely Barrett's Oesophagus and Gastroesophageal Reflux Disease (acid reflux).

If you are interested in supporting our work in upper GI conditions, which is hugely important, please donate to our 'Upper GI Fund'.

## Diverticular disease Dr David Humes

Diverticular disease is extremely common in the UK, with a third to half of people developing the condition as they get older. The condition appears as pouches or pockets sticking out from the wall of the bowel, especially on the left side. Pain, bloating, and diarrhoea or constipation (pellet-like stools) are common symptoms.

If one of the pouches becomes infected or inflamed the condition is referred to as 'diverticulitis'. Diverticulitis is very unpleasant but is usually treated at home with antibiotics and paracetamol. However, in some cases, diverticulitis can develop complications such as bleeding from a pouch, the formation of abscesses, or burst pouches leading to perforations of the bowel. These complications can be very severe and need emergency hospital treatment. It is not clear why some people develop serious complications from diverticulitis, which can make looking after the condition more difficult

Diverticular disease, and diverticulitis, is a priority area for Guts UK, so a couple of years ago we funded a project in collaboration with another small charity, Bowel & Cancer Research, to Dr David Humes from the University of Nottingham.

Dr Humes wanted to find out how frequently do abscesses and perforations happen as complications of diverticulitis, and whether they are more common in men or in women, and in certain age groups. He also wanted to determine how likely people are to die following these complications. Additionally Dr Humes wanted to find out how the different treatments for complicated diverticulitis compare to each other in terms of patients needing to be readmitted to hospital or needing to undergo further surgery. He was particularly interested in finding out how do newer and/or less invasive treatments, such as using laparoscopy to drain the abdomen after perforation or remove an abscesses, compare to more invasive treatments like surgery. Understanding these issues better would help clarify who is more at risk of developing serious complications from diverticulitis.

Dr Humes looked at data from hospitals and GP surgeries in England from 2000 to 2013. He found that both abscesses and perforations had become more frequent, with a 50% increase in abscesses for all age groups, and a similar increase in perforations but only in younger people (those under the age of 55).

However Dr Humes also noted that the increased frequency of both complications seemed to be matched with an increase in the use of CT Scans (a test that creates a detailed image of the inside of the body). Dr Humes suspects that the CT Scans are picking up more cases of abscesses and perforations, which might have been missed before. However it is possible that CT Scans are picking up less severe complications and it is yet unclear what is the best way to teat this particular group of patients. These results are still too preliminary and more work needs to be done to understand the best way to treat the complications of diverticulitis.



For more details on Dr Humes study or information on diverticular disease visit the Guts UK website.

#### Joint Funded by





## Guts UK collaboration

ForCrohns

This year Guts UK and for Crohns collaborated in the award of two exciting and promising research projects on Crohn's disease. for Crohns is a volunteer-run charity with a mission to fund research that helps those with Crohn's disease today and contributes towards finding a cure in the future.

These projects are particularly important because Guts UK and for Crohns asked the researchers to address one of the top ten research priorities identified by patients and their carers as part of the James Lind Alliance Priority Setting Partnership on Inflammatory Bowel Disease. This approach ensures that the projects focused on issues that had been flagged up as important to those who are more likely to benefit from the research: people affected by Crohn's disease and those looking after them.

Research is so important to help make progress with the understanding and management of Crohn's disease. In this sense, partnering up with others with the same goal can make such a positive difference and we are delighted to be able to work together with Guts UK on.

Lisa, forCrohns Trustee

The awards went to Dr Nick Powell, at King's College London, for a project looking at ways to optimise and personalise treatments for Crohn's disease, and to Dr Kostas Gerasimidis. at Glasgow University, to develop a solid version of the liquid-only diet that is given to Crohn's disease patients as an initial form of treatment.



Read more about both projects on the Guts UK research section of the website.

# The legacy of Dr

## lan McLean Baird Guts UK Nutrition Fellowship

The fight against obesity has many champions but Guts UK are proud to count Dr Ian McLean Baird among its standard bearers. Dr Ian McLean Baird was born in Glasgow and educated at St Andrews University. He was a lecturer in Pharmacology and Therapeutics before becoming consultant physician at the West Middlesex hospital in 1965. Even then Dr McLean Baird was aware of the impact of obesity on health, as well as of the difficulties in managing the condition. He dedicated his life to coming up with pioneering diets and therapies to tackle obesity.

He was fascinated by the field of nutrition and, in collaboration with scientist t the University of Cambridge, he devised a special 'Very Low Calorie Diet' of 330 calories, which was effective and safe in managing obesity. This became known as the Cambridge Diet, which has been used successfully by millions of people all over the world. The diet is still available now.

Throughout his lifetime Dr McLean Baird donated generously to charities and he set up the Nutrition Research Foundation trust fund. Guts UK (then as Core) was one of the leading recipients of funds and as a result we were able to award a number of research grants to doctors working on obesity and nutrition. After Dr McLean Baird's death, the fund was closed and the remaining funds came to Guts UK for us to continue his pioneering work in the field of nutrition.

Guts UK are very proud to continue supporting the aims and vision of Dr McLean Baird, by continuing to award research grants and Fellowships investigating the role of obesity, nutrition and diet on gastrointestinal and liver conditions. We are also excited to broaden this work to include the key research area of the microbiome (gut bacteria) as this area has been shown to have a major impact on obesity and other conditions, including many gut disorders.

#### Investing in the researchers of the future

#### Young researchers are the bright enquiring minds that will shape our future research.

Guts UK are currently funding projects led by two Gastroenterology Trainee Networks, in collaboration with the **British Society of Gastroenterology.** One based across the East and West Midlands and the other based in the North West. The aim of these trainee-led networks is to deliver powerful studies that can have a positive effect on patient's care. The trainees form a network rotating between hospitals in a particular region, which allows them to undertake large-scale research projects or audits to answer clinically important questions.

#### North West Trainee Network led by Dr Wadiamu Gashau

Inflammatory Bowel Disease increases the risk of developing bowel cancer, which in turn causes the death of up to 15% of people with IBD. People with IBD need to be screened with a colonoscopy (an internal examination of the bowel) every few years, with the aim of

detecting early changes to the bowel that could lead to cancer. There is an optimal procedure that improves the detection of these precancerous changes, but it is not followed by all hospitals. The gastroenterology doctors of the North West Trainee Network are working together to understand these variations in screening across multiple hospitals in their region, and the reasons they vary.



## East and West Midlands Trainee Networks led by Dr Richard Ingram



Internal bleeding from the gut (gastrointestinal bleed, or GIB) is one of the most common medical emergencies. Bleeding from the top part of the gut (upper GIB) can be particularly serious and nearly one in ten people will die. Over the past two decades, certain treatments have been shown to improve outcomes for GIB. These include giving the right amount of fluids or blood into the vein, certain medicines, and control of bleeding using endoscopy. National standards of care recommend all these treatments. However, care does not always meet these standards and could be improved. Gastroenterology doctors are joining forces across the Midlands to better understand and address this problem.

#### Finding out about IBS and FODMAPs

Irritable Bowel Syndrome (IBS) affects more than 1 in 20 people worldwide. People affected experience pain and cramps in their gut, often made worse by eating and improved by visiting the toilet. People can suffer from abnormal bowel movements, with some people experiencing diarrhoea, some people having constipation and a third group enduring both in turns. Bloating and nausea are also common. Symptoms can appear suddenly and many people believe certain foods can trigger a flare up. IBS is immensely frustrating, can be exhausting and decreases quality of life in those affected.

People with IBS often undergo tests to identify the cause of their problem but no physical evidence of disease is found: the problem lies with the function of the gut, which is why IBS is called a functional disorder. This makes IBS harder to diagnose and treat. It also makes it harder to identify the cause of IBS – or more likely, causes – though gut infection appears to be a common prelude to the development of IBS in some people.

Treatments for IBS do not always work and because people with IBS often blame certain foods for their flare ups, there has been interest in exploring whether diet could be used as a treatment. Researchers and health professionals have developed a diet that can help some people with IBS. It is called the Low FODMAP Diet and it excludes certain foods such as some fruits and vegetables, milk and some cereals.

The Low FODMAP Diet is difficult to follow and needs to be personalised to each patient, so people who follow it need to get advice and support from a dietitian or a health professional with the right expertise. The aim is to identify which foods are triggers and exclude those, and ensure that the patient follows a nutritionally balanced and socially acceptable diet in the long term. Avoiding unnecessary restriction of foods is also important because the Low FODMAP Diet changes gut bacteria in ways that are not fully understood at present.

The Low FODMAP Diet was originally developed by an Australian University and has been adapted to the UK diet and foods by a team from King's College London (a London University) and Guy's and St Thomas' Hospitals (a group of London hospitals). The diet has helped many people affected by IBS and the team at King's College London have trained over 1,000 dietitians to be able to deliver the Low FODMAP Diet to their patients all over the UK. Visit the Guts UK webite for more information on their excellent work and on the Low FODMAP Diet.

Guts UK are delighted that such progress has been made bringing the Low FODMAP Diet to the UK. The team at King's College London and Guy's and St Thomas' Hospitals continue to work on the diet, as well as explore whether it might be useful in other digestive conditions. However, more funding needs to be directed to IBS and other gut diseases.

Iam running the Big Fun Run in aid of Guts UK because this charity is very close to my heart. My aim is to raise awareness for digestive disorders especially IBS. IBS has a reputation for being "incurable" because it is so complex to treat and a cure is yet to be found. The more awareness/money raised in aid of Guts UK will give them a better chance of trying to find cures for digestive diseases such as IBS.

Bobbie Vandal, Guts UK fundraiser and supporter



Visit the Guts UK website for a longer version of this article. Please support our work so we can understand more and find treatments that can help bring relief to more people affected by the daily misery of IBS.

## A gift in your will to Guts UK

Legacies to Guts UK play a crucial role in funding our research programme and we wish to acknowledge the following people for remembering Guts UK with a gift in their will:

#### Joan Breach, Dorothy Wrench, Mavis Ethel Forster, Joyce Alice Shiner

The medical research that benefits people today, was paid for by the gifts of yesterday.

Pay it forward with a gift in your will. Be part of our future.



Help us find the answers to life's biggest questions by leaving a gift in your Will.

Ask the HumanSearchEngine.org/gutscharityUK





Guts UK is a proud member of the Remember a Charity consortium of charities who work together to celebrate how powerful it is to leave a legacy to charity. It can often be the single, largest gift a person can make. None of us ever really know what we need in our lifetime so ensuring you have included something in your will to a cause close to your heart ensures you will be play an important part in the future.

This year we are joining forces with 200 other charities up and down the UK to launch *Human* – the world's first charity-powered search engine. *Human* will enable the public to ask some of life's biggest questions and to hear directly from charities, including Guts UK, what they are doing in response. Have a look at our videos **at www.humansearchengine.org/gutscharityuk** 

The activity is part of Remember A Charity Week, 10-16 September, which sees hundreds of charities come together to encourage people to leave charitable gifts in Wills and, by doing so, pass on something wonderful to the next generation.

# THE MORE WE KNOW ABOUT OUR DIGESTIVE SYSTEM, THE BETTER WE CAN LOOK AFTER IT.

At Guts UK legacies play a vital role in funding our research into diseases of the gut, liver and pancreas. Your kindness today will ensure more research in the future.



Find out what your life-changing gift can do. Visit **gutscharity.org.uk**, call Julie on 020 7486 0341 or email info@gutscharity.org.uk



REMEMBER US IN YOUR WILL Help our work live on...



Charity Registration No. 1137029

#### **STOP PRESS!**

Any natty knitters out there?

This fantastic knitted guts set (donated by Cupcakes and Cocktails Women's Institute group, Huddersfield) is already hard at work educating about the digestive system – but we need more knitted guts please!



Are you or someone you know nifty with a pair of knitting needles? Up for a new craft challenge? Contact us for a pattern on 0207 486 0341 or info@gutscharity.org.uk.