News from the front line of bowel disease research
Welcome

Welcome to the latest edition of our newsletter – bringing you all the news and spectacular happenings here at the Bowel Disease Research Foundation.

We are a small charity that has big ambitions – there is a huge amount of work to be done in the battle against bowel disease. BDRF is the only organisation in the UK that is backed by the leading professional body representing medical professionals working in the field of Bowel Disease – the Association of Coloproctology of Great Britain and Ireland (ACPGBI).

What this means is that BDRF is the charity you want in your corner if you or somebody you know is suffering with a problem with their bowels.

BDRF lead the way in funding ground-breaking and lifesaving research and cover all conditions that affect the bowel from functional disorders through to Crohn’s, Colitis and Bowel Cancer.

Nobody does it better

But we need you to help us to be able to continue play our part in the fight against these often brutally painful and life limiting conditions.

Right now we have research projects that have been approved through our independent peer review process that need funding TODAY so that we can give bowel disease patients a better tomorrow.

I do hope you enjoy reading about some of our latest projects. You can keep right up to date by following our work on Twitter, Facebook and Linked In or by signing up for our free e mail newsletter from our website.

If you like what you read then please do join us in our quest to fight bowel disease and support our cause with a donation.

You can donate online by visiting our website www.bdrf.org.uk or by sending a cheque. Details on the back page.

Thank you.

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Small bowel obstruction (SBO) currently accounts for as many as 49% of emergency surgeries.

Designed and led by trainee collaborators from across the UK, the NASBO audit aims to set gold standard care for small bowel obstruction (SBO).

SBO is a painful and distressing condition which needs vast improvements in treatment. It currently accounts for as many as 49% of emergency surgeries. Little is known about the best care strategies and costs to the NHS are enormous. Many people, in particular the elderly, endure serious complications and even death. Specialists around the country are urgently looking at the problem.

NASBO has begun to identify what most affects both good and bad patient outcomes. By identifying links between care and recovery we will be able to develop an optimum patient pathway and dramatically improve care.

The audit has been hugely successful, with 122 of the UK’s hospitals submitting data on over 2,500 cases of SBO. Incredibly, 83% of Consultants who took part told us their hospital had no guidelines in place for management of SBO. Preliminary results have already been presented to the Royal Society of Medicine and Association of Surgeons in Training. The ACPGBI Conference in Bournemouth will also see results presented.

There is much work still to do, but we are hugely excited about the potential to see NHS clinical practice transformed through BDRF research. We really can put an end to the unnecessary pain and suffering of patients with SBO and their families.

Effective research is impossible without patient input. A study would be next to worthless unless heavily influenced by the views of people with lived experience of bowel disease and its treatment. That’s why involvement of patients and their families is the first step in designing so many of our projects.

ENIGMA PROJECT

We invited people with experience of perianal Crohn’s fistula to join us at the Royal College of Surgeons and build new research. The ENIGMA project will develop a reliable way of measuring people’s quality of life after treatment for a perianal fistula. As anyone affected can tell you, fistula have a devastating impact on physical and mental health. But treatment options are limited and many people feel like they are trapped in a nightmare with no end in sight.

Our team is at the forefront of the battle to improve this. At our event, patients were consulted on a range of subjects and asked for their views on how important each one was to their quality of life. The result is a set of goals for researchers to work towards, and a massive step in the right direction for improving practice.

ROMANTIC PROJECT

Our embryonic study of whether surgery or drug treatments are the best option in ileal Crohn’s benefited from the views of 20 people from around the country, all with direct experience of ileal Crohn’s and its treatment.

The work looks to settle the question of whether drug treatments or surgery are the best front line treatment in this form of Crohn’s, and which patients benefit most from them.

A vibrant day of discussion between specialist gastroenterologists and colorectal surgeons laid the foundations for future work.

Professor Steve Brown, who heads the project, commented during the day that:

“The great thing about being involved in research trials is that you get to focus on the level of care being provided - often by default this can lead to improvements in patient care”

BDRF’s Chief Executive Peter Rowbottom said;

“Bowel Disease, in any of its many forms is pretty nasty and often very painful. Research into improving treatments that lead to better outcomes for patients is what we as a charity are all about.

It was superb to see collaboration across the gastroenterological and the colorectal spectrum along with patients at the very heart of the discussions”.

To the people who came from far and wide across the U.K – a huge thank you for attending – without your efforts, none of this would have been possible.
DREAMS Trial

In 2010 BDRF funded the internal feasibility stage of the DREAMS trial to find out if the steroid Dexamethasone has a beneficial effect in patients undergoing elective bowel surgery. We awarded £131k to the initial work in 2010, which led on to a larger NIHR Research for Patient Benefit grant. The findings have been extremely significant, and are now published in the British Medical Journal.

The trial particularly looked at postoperative nausea and vomiting (PONV), which are among the most common problems bowel disease patients face after surgery. PONV can delay recovery and patients’ return to their normal diet and activity. Dexamethasone has previously been shown to have a significant benefit in patients, especially in the reduction and prevention of PONV after surgeries categorized as low and intermediate risk procedures. Its use in bowel surgery patients, however, has not been as thoroughly investigated. This study of dexamethasone specifically examined whether administering patients with doses of the steroid before surgery would have positive effects on their PONV symptoms following bowel and gastrointestinal procedures.

The study was a blind randomised trial, and consisted of two core groups of patients that were recently admitted into outpatient clinics. All groups received the same anaesthesia and treatment before and during surgery, the only difference being whether or not the group received dexamethasone treatment before surgery. The initial results of the DREAMS trial showed that dexamethasone use led to a significant decrease in patients experiencing PONV. Additional benefits included accelerated rates for patients returning to normal diet and a decrease in patients’ need for additional drugs following surgery. Furthermore, these beneficial results were found to be long-lasting.

We now have further information on this specific steroid to work with in order to improve the pre- and postoperative lives of those undergoing bowel surgery. It could mean shorter hospital stays, reduced costs to the NHS and a better experience for patients. Professor Dion Morton, Professor of Surgery at Birmingham University who was part of the DREAMS collaborative group comments:

“We are extremely grateful to BDRF, whose funding got this work off the ground. Their support has enabled us to make a big step forward in improving care for patients who need bowel surgery, which wouldn’t have been possible otherwise. The changes to routine clinical practice resulting from this study are being adopted nationally and have already been taken up into international guidance, enabling more patients to recover in comfort and get home more quickly.”

Reference BMJ 2017;357:j1455

Lower Gastrointestinal Bleeding (LGIB) Audit

“Practical, sensible and potentially lifesaving” – these were the words of former ACPGBI President Professor Bob Steele as he endorsed the recommendations of BDRF’s Lower Gastrointestinal Bleeding (LGIB) Audit.

Lower Gastrointestinal Bleeding (LGIB) Audit.

LGIB is a common but distressing condition associated with all forms of serious bowel disease. It can be the first sign of bowel cancer, or indicate undiagnosed Inflammatory Bowel Disease. Despite this, optimum investigation and treatment options were not known. Researchers in Oxford set out to tackle this, designing a nationwide audit to build gold standard pathways for diagnosis and treatment. 143 of the UK’s hospitals submitted reports on the treatment of over 2,500 patients, making this the largest audit of the condition conducted in the world. Now the findings are making real waves, garnering attention from across the globe.

Results and recommendations have been presented to the scientific community in Edinburgh, Barcelona, Milan, Vienna and Orlando.

Publications in the impactful BMJ and Gut journals have been released, with articles in other influential titles anticipated.

We are well on the way to seeing national guidelines established that will shape NHS best practice for years to come. An immensely proud achievement for our researchers, donors and supporters!

The largest audit of LGIB conducted in the world
The ROMANTIC Trial

Two weeks ago, I was invited to the Royal College of Surgeons in London for discussions of a new trial for ileocecal Crohn’s patients.

This has been the first time I’d been invited – well, I had sought out this day for my own medical geeky-ness – to participate in something so formal and important as a possible trial. Its objective was to gain the perspectives of both patients and doctors in to whether the premise, the thesis of this trial, was valid and if it was, how it was then going to be done and its hopefully outcomes. I was very interested in the prospective trial, was valid and if it was, how it was then going to be done and its hopefully outcomes.

What I came away with was the feeling that I was valid. That my thoughts, feelings and experiences of having ileocecal Crohn’s Disease are important.

It was humbling to be in a room with other people who are part of that exact same process; patients who have tried medication and had surgery. Patients who have just begun life with Crohn’s and on medication. Some who were years into this and on the same, good medication. Those who had just had surgery. The cross-section of patients was great, thanks to The Bowel Disease Research Foundation’s recruitment.

So were the medical professionals involved. Gastroenterologist, colorectal surgeons, radiographers, trainee surgeons; the wealth of knowledge was huge. The potential for knowledge was there. The thirst for answers was definitely palpable. And the fact that these people – doctors in the top of their field, those training to be amazing doctors – had given up their time to be there – like the patients had too – to help gain some insight in to how improve care for these types of patients. It is wonderful to see care and attention being given to IBD – Crohn’s here specifically – and not on finding a cure but on developing strategies to help patients in a variety of cross sections – so those who are perianal, small bowel, terminal ileum, those with fistulation, those with extra manifestations. Care is being taken to improve both medicine and surgery. Care is being taken! That is key.

Purpose of the trial

“ROMaNtIC is aimed at working out the best treatment for patients with Crohn’s disease affecting the junction between the small bowel (ileum) and the large bowel (colon).”

... Both medical treatments and operations on the bowel are currently used, but no-one knows which is better, or which types of patients will benefit from each of these treatments.”

We were asked a simple question:

If given the chance again, would you have liked a surgical option in addition to your medical options upon initial diagnosis?

Statistically, about 40% of Crohn’s patients have an issue in the terminal ileum. It is thought to be the main source of why medications tend to fail and the most likely cause of bowel resection. Currently, both medications and surgery is used to remedy this particular portion of the bowel, but no one can agree on which one works best and which patients benefit most from intervening with surgery sooner. Some patients respond very well to medication, where as some suffer with side effects and problems, ultimately resulting in a resection anyway. This trial would help medical professionals determine the best treatment plan for ileocecal Crohn’s disease patients.

A day in the life - by Louise Hunt

Who was going to be invited?

Ideal candidate for this trial is going to be someone who has been recently diagnosed with Crohn’s disease isolated to the terminal ileum, who is currently taking steroids but needs to be moved off them and onto something else. Here, the trial would be offered; explaining that medications for the condition can work and so can a bowel resection. Both come with risks and side effects; all of which would be explained, with a Gastroenterologist and a colorectal surgeon present so that both sides are given equal validity. It is then up to the patient to decide on if they would like to enter the trial. It is important to stress that the patient does not get to choose medication or surgery that is to be assigned randomly; consent to the trial is being acquired at this stage; of course, with time for the patients to consider what this undertaking would be.

The trial is for twelve months, hopefully gaining 246 patients in total to help gather information about how to best treat ileocecal Crohn’s disease.

Why is this important?

Well, ultimately it is a significant aspect of IBD care and management. It is something that knowledge is needed on, going forward; not just for a couple of years but for future generations too. It ultimately comes down to which out of medical or surgical gives the patient the best Quality of Life after twelve months. The data gathered will analyse that primarily but hopefully provide insight into improvements in other aspects too; possibly into some standardisation of care and into sharing best practices on a larger scale.
My personal views

I have had Crohn’s Disease since 2011 and in that time, I’ve had every IBD medication out there thrown at me. I believe it stands at 11 tried and failed medications, where I ultimately had a Right Hemicolectomy to remove my terminal ileum and some small bowel in May 2016 and then my colon removed and permanent ileostomy performed in August 2016. I consider that a lot to go through, in such a short space of time. I do not regret any of the decisions my IBD medical team made regarding my care, which included second opinions and referrals to other specialists for related issues. What I do have issue with not being able to see a colorectal surgeon sooner. Yes, on the one hand, why tempt fate and ask questions which are completely hypothetical if you are no way near close to needing surgery to fix your bowels. But, why not be allowed the opportunity to ask questions directly to a surgeon? Would this be considered a waste of time? Who knows.

I feel very strongly that I would have liked to have more inclusive team on my case from the very beginning; including a colorectal surgeon. So, I am not pushing for surgery over medication – I believe both have their validity and its down to patient’s choice – but in order to make a choice, you need all the facts. If you know anyone who would be interested in taking part in this trial, do get in contact with the Bowel Disease Research Foundation for more information.

www.youngcrohns.co.uk

BDRF-funded workshops giving medical students the skills to recruit patients into surgical trials have been hailed as a major step toward fostering a generation of research-ready junior doctors. Medical students currently receive no training on how to approach and recruit patients for surgical trials, meaning many don’t feel confident doing this until years after they qualify. Randomised trials are widely seen as the best way of improving treatments, but too many patients miss out on entering one due to this gap in training.

A team of researchers have set out to change this, launching the GRANULE programme of workshops in May last year. These aim to bring consultants together with medical students to equip them with the skills and confidence to start taking a leading role in research from the moment they qualify. In the long run, this will develop a cohort of junior doctors who are ready to start leading research projects from day one, making research recruitment an everyday occurrence in the UK’s hospitals.

Twenty delegates were selected for the inaugural session, and hailed the opportunity to engage with consultants. All delegates were surveyed before and after the session – just 25% said they would feel ‘confident’ about recruiting patients into a research trial going in, but this number rose to 75% at the end of the course. One student commented that “The professional feedback from consultants was incredibly useful. I wouldn’t feel comfortable consenting patients without this course”.

The workshops were designed and delivered by the STARsurg research collaborative, in collaboration with the Birmingham Clinical Trials Unit and the Bristol Medical Research Council ConDuCT-II hub. BDRF provided funding to set up the workshop at the Royal College of Surgeons in London.

Rolling out over the next 5 years, this work will be exceptionally good value for money and make a difference that lasts a generation.

Research is our most potent weapon in the fight against bowel disease. Since the 1980s, twice as many people who get bowel cancer survive it. More and more IBD patients are taking back control of their lives. Stigmas around continence are breaking down, people don’t just have to ‘get by’.

In the words of one our supporters who lost her father to bowel disease:

“If your research stops even one family going through what we did then it will be the best money I’ve ever spent”.

A gift from you today will help us pursue our revolutionary research strategy, which has patients’ needs at its very heart.
Please join us in the fight against bowel disease and make a donation to support our work TODAY

Please visit www.bdrf.org.uk to make your donation online
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