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*Moving On is Crohn's and Colitis NZ's regular newsletter for people affected by Crohn's and colitis, and their families and supporters. Our aim is to keep you informed on events happening around the country, so you feel part of our IBD community.*

## FROM THE CHAIR

**D**ear Patients, Families and Supporters. We often talk about IBD (Inflammatory Bowel Disease) as being a young persons' disease but I came across someone recently who at the age of 93 had just been diagnosed with Crohn's disease. Then we read about the recent Canterbury study with the data showing that almost twice as many people were diagnosed in 2014 than 10 years earlier. Having the highest rate of IBD in the world is concerning. I am pleased to note that Professor Michael Schultz from Otago University has begun a project to determine whether care and quality of life of New Zealand IBD patients meets international standards. This project has the full support of CCNZ.

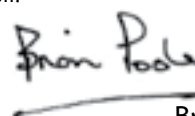
This has been busy year with our second Camp Purple Live being held in Canterbury and the next one in Wellington in January 2017 being planned. We are so grateful for the support of sponsors, health professionals, volunteers, parents and the children for making these camps so rewarding and beneficial. Our 0800 ASKIBD line is well used and we often work with people "lost" in the health system. We are looking forward to the roll out of the website for adolescents with IBD transitioning to

adulthood and all the challenges they face. We are confident this tool will help make the process easier.

Our organisation survives through the skill and dedication of many people, but funding is crucial if we are to sustain our work. There are many ways you and your family and friends can help – fundraisers, regular donations, give-a-little, PayPal and even legacies. We rely on core funders but these are never guaranteed from year to year and to have an alternative funding stream is crucial. Large or small, your gift makes a difference! (As a Charitable Trust all donations are tax deductible).

Finally, we are asking everyone to turn New Zealand purple this month on May 19th to help celebrate World IBD Day and to raise awareness for CCNZ and all the critical support services we offer.

Go Well!



Brian Poole, QSM  
Chairman  
Crohn's & Colitis Charitable Trust



## 2016 Camp Purple Live

**It was a gray morning, but luckily, not raining, as a bus and two vans filled with 48 children and teens arrived at the boat launch on the Waimakariri River outside Christchurch. A few minutes later the owner of Jet Thrills and Karen Clarke, an avid jet boater and nurse from Southern Endoscopy in Christchurch, were powering down the river at high speed with the children, providing a high point to the final day of Camp Purple Live.**

Camp Purple Live, the CCNZ camp for children with Crohn's disease and

ulcerative colitis, ran for its second year at Living Springs outside Christchurch. Forty eight children and over 25 volunteers, including four gastroenterologists and five nurses, spent five days in the sun (and a bit of rain), enjoying each other's company. Aside from the daily routine of receiving medications, occasional nighttime tube feedings, and dealing with an occasional flare of their disease, it was a normal camp experience for these kids. Activities included go carts, swimming and archery, as well as the day of jet boating. Some of the children had never

been to camp before and, for many, it was the first time they were in the company of other kids with the same diagnosis. It was an opportunity for them to test their limits. Among the volunteers were a police detective, a former All White, and a swimmer who will be trying out for the next Olympic Team, all of whom have IBD themselves. One of the physicians noted that "It was so gratifying to see how quickly the children bonded with one another". Not surprising, given the tacit understanding among all the children of the challenges of living with IBD at such a young age.

The camp was funded entirely from donations and all costs to attend were covered, including airfares from all corners of New Zealand. A team of committed volunteers, almost all of whom have IBD themselves spent countless hours over several months in the planning and administration of the camp. A two day seminar for parents and caregivers was held concurrently, with when adults shared experiences and challenges of having children with the disease and were able to network with one another. One offshoot of the camp is an active Facebook page, "The IBD NZ Parent Support Group" which was created by the parents who attended. The group already has over forty members.

Next year's camp will be held in the Wellington region from 13-17 January on the Kapiti Coast. The location by the ocean will provide new experiences as well as an incredible planned excursion to the Adrenaline Forest.

This letter from the parents of one of the campers sums up what the camp was all about:

*"As a family we just wanted to express our heartfelt thanks to all of you involved with the camp. To have exposure to the great doctors, nurses, volunteers and of course the organisers and families -who all have so much information to share- is immense for us, invaluable actually. We think you guys are awesome and are doing amazing things for our children-and for parents like us that is everything. Judy and I loved the opportunity to lap up the knowledge offered freely by the doctors, nurses, families and sufferers themselves. I know that our daughter will be having a great time, building lifelong friendships and coming to the realisation that there is life after her diagnosis. It is a gift to know that it will not hinder her life and most importantly that she is not alone in this predicament.*

We will never be able to repay everyone involved in the camp for the amazing work done - but we are immensely grateful for all you have done for our daughter and our family. Please pass on our thanks to the doctors, nurses, and especially the freely giving volunteers also. In the hasty departure on Monday we did not have the opportunity to thank them all.

The camp was made possible through generous donations from Janssen, Abbvie, Pharmaco, Baxter, Boston-Scientific, TG Macarthy Trust, Nikau Foundation, Pelorus Trust, EFCCA, Jetstar, and countless individual donors.

If you have a child or know of someone who would like to attend the next camp (or parents' seminar) in January, contact Nicola Sweeney at: [campenquiries@crohnsandcolitis.org.nz](mailto:campenquiries@crohnsandcolitis.org.nz).

We desperately need funds for our third annual camp which will be held on the Kapiti Coast from 13-17 January 2017. Contribution can be made through our givealittle page:

<https://givealittle.co.nz/org/camppurple>

Counties Manukau police officer Detective Constable Becs Parker, who last year became an ambassador for Crohn's and Colitis New Zealand, this year attended Camp Purple Live, a holiday programme in Christchurch for children aged nine to 16 who have Crohn's and colitis. She met 11-year-old Aaron Lammas who told her he had always wanted to be a police officer, but believed that because of his Crohn's he would never be able to achieve that goal. He's was diagnosed at the age of seven and has already had several operations, including having two drains inserted in his gut. Becs, who was diagnosed with the disease while she was at Police College, managed to change his mind and at the end of the five-day camp, she said, he had decided not to give up on his dream of joining Police after all.



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# CAMP PURPLE





# Appointment of our first Ambassador

In October 2015, our patron Her Excellency Lady Janine Materparae graciously hosted a function at Government House for CCNZ and announced the appointment of our first ambassador, Detective Becs Parker.

There is a saying “we don’t know how strong we are until strong is the only choice we have”.

Five years ago we began our journey - a fledgling organisation determined to make difference in patient education, assist with patient advocacy, demystify and normalise the disease and make life more liveable.

We had little information to work with and had limited funding but with the extraordinary enthusiasm of our Trustees and commitment and support from our medical advisers and health professionals we started to move from strength to strength.

We still have much to do but with achievements such as our various publications; 12 support groups around NZ; a data base in excess of 1000; Facebook over 1500; being nominated for the Minister of Health award; running two children’s camps; becoming a member of EFCCA also and providing volunteers for numerous clinical trials and research projects

including the Impact study we have indeed become stronger.

At this point I must acknowledge the significant contribution from our sponsors who have believed in us and supported us in so many ways. It is not something we take for granted or lightly. It does however remind us that financial contributions by members are both appreciated and essential. It does in fact send a good message that we are also committed to the cause.

Yes, we are getting stronger but we need to be for a disease that is increasing at a concerning rate. Whilst management of the disease has improved enormously over the years there are still many who do not know what it is like to be well. May they know they are not alone.




Our best wishes to Becs Parker our first ambassador as she begins her duties.



Detective Becs Parker, named as Ambassador for Crohn's and Colitis New Zealand, with guest Nicole Thornton.

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## We're turning New Zealand Purple

**W**orld IBD Day is fast approaching! The theme for this year is "Improving quality of life for people with IBD". As part of this global campaign we are aiming to illuminate famous landmarks (such as city halls, historic monuments etc.) in purple (the colour for World IBD Day) on 19 May 2016.

Images of these highlighted landmarks/buildings will be shared on international and national social media channels aimed to create greater awareness around inflammatory bowel disease. **Niagra** Falls for example will be turned purple! Additionally, local support groups will be hosting events providing information about IBD and issues addressing the quality of

life for people with IBD. Check with your local support group or our website for further information on what might be happening in your area.

We are excited to be part of this global campaign and are pleased to announce the following buildings around NZ will be turning purple on May 19th:

The Michael Fowler Centre, Wellington. The Carter Fountain, Oriental Bay Wellington. The Hikitia Crane, Wellington. The Cable Car, Wellington. The Clock Tower, New Plymouth. The Clock Tower, Palmerston North. The Town Hall, Dunedin. Toitu Otago Settlers Museum. The Dunedin Club.



## A Look at our new website

**H**ave you visited our website lately? Along with a fresh, new look, it's now easier to find your way around!

With more and more of us accessing the world of information through smart phones and tablets, we have redesigned this website to make it mobile device responsive - making it easier for you to access important information everywhere.

We've worked hard to bring you a more modern design and make every section of this site easier for you to read so you can quickly find the information you want when you want it.

We are aware that some things may not yet be perfect and we will continue to improve and fine tune the site over the coming months.

Please look around and tell us what you think. We hope you enjoy it!



## Wanted new CCNZ Board Members: Call for expressions of interest

**C**CNZ was launched as a charitable trust in February 2010, followed by a formal function later that year at Parliament. The Trust Deed allows for the appointment of a minimum of three and a maximum of ten trustees to the Board with a further three positions available to advisory members.

The recent retirements of longstanding Board members has left the Trust lower in numbers. The Board has therefore resolved to seek expressions of interest from interested parties for appointment as Board members.

We would particularly welcome interest from those who reside outside of Wellington, and from those who would represent the younger age group (who are so prevalent in our diagnostic profile). The Trust Deed allows, if desired, that Board members hold office for three years. If required they may retire by rotation with the order and time to be determined by the board.

Board meetings are generally held bi-monthly via teleconference with a Wellington based Executive assisted by our administrator Charlotte Perkins.

Our current projects include an annual Camp for children with IBD; the review of the IBD Handbook; and IBD Teenage Transition Project; World IBD Day celebrations; Advocacy and Outreach; IBD Standards and Guidelines; Toilet Map upgrade,, Research Partnerships; Investigation of ongoing funding streams; partnership possibilities, and ways to increase our profile and membership.

Please email Charlotte at [info@crohnsandcolitis.org.nz](mailto:info@crohnsandcolitis.org.nz) if you would like to know more about becoming a Board member. Our organisation requires regular new infusions of ideas and energy if it is to continue to take the steps required to grow the organisation as the face of IBD in New Zealand.

**My name is Hilary. I'm 35 years old, I work full time, I have two very energetic young boys, and I have Crohn's disease.**

## 2005

I was diagnosed with Crohn's disease when I was 23, living a busy life in London. After nine months of weight loss, anaemia, stomach cramps, diarrhoea, vomiting, nausea, and fatigue I was referred to hospital for a colonoscopy revealing that Crohn's disease. I was told this in a post procedure daze, given a prescription for Pentasa (Mesalazine), a handful of brochures and sent on my way. IBD is debilitating. Life revolves around a constant need for a handy lavatory and the extreme fatigue which is a symptom of Crohn's disease. I was trying to live a normal life, but the fatigue was extreme.

I was my skinniest ever, my stomach was in pieces, it was winter and I'd had enough. I had MRIs, barium meal tests and examinations, then moved on to the immuno suppressant drug azathioprine, but nothing seemed to help. Tests found that I had an anal fistula. I was disgusted. After Christmas and New Year I finally realised I was too sick to party.

## 2006

In January I had surgery for the fistula and a month off work and started Infliximab (for chronic inflammatory disease) intravenously and the difference was unbelievable.

## 2007

Another peri-anal infection and more surgery. Later that year, after discussion with my specialist, I took myself off all medication in order to start a family. There were a lot of unknowns, but it was a risk I was willing to take and it was worth it. Pregnant, I felt amazing - beautiful skin, thick shiny hair, a gorgeous baby bump and more energy. Perfect Conor's birth led to near-perfect health for three years.

## 2010

Crohn's returned. A round of steroids and a very strict diet kept me off all other medication and I was pregnant again in August 2011. Dylan was born in April 2012 and once again I was in great health.

## 2013

Crohn's flared up again when I stopped feeding Dylan. I was forced to start on the immuno- suppressant drug, Humira. I hated injecting myself every fortnight. I moved onto a paleo diet and that really worked for me and seemed to stabilise my energy levels. I did my first duathlon, ran a few 10km runs and the Lake Taupo cycle race.

## 2015

I started having terrible stomach pains, doubling me over for hours,

or vomiting. MRI results identified deep ulceration of the terminal ileum which blocked the passage, causing the pain. Laparoscopic excision and anastomosis of the terminal ileum and small bowel was the only option. By the end of day two I was feeling nauseous and vomiting. By day three I had developed fevers, chills and raised CRP - a substance produced by the liver that increases due to the presence of inflammation in the body. A CT scan showed inflammatory changes of the colon with peritonitis and a large amount of fluid in the abdomen causing swelling.

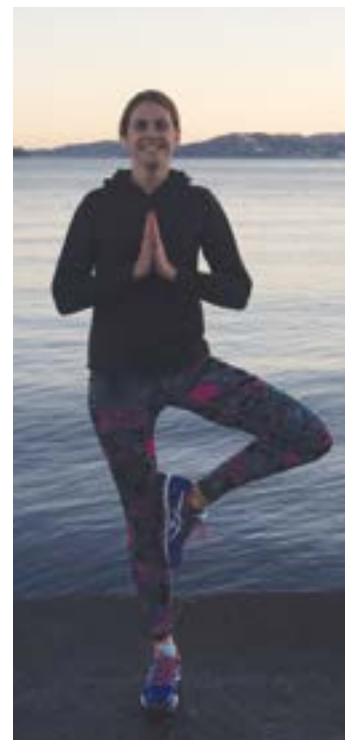
My bowel had perforated. I needed further surgery - urgently. I was scared, really, scared.

In recovery, I was told that I was going to ICU. The next few days were quite a blur. I'd open my eyes to see my mum sitting and staring at me. I didn't understand the severity of the situation, but I kept thinking that this might be it. During the days in ICU I realised that I had an ileostomy bag and quite frankly I didn't want to know about it.

I spent 26 days. In hospital and I began to wonder if I was ever going to go home. I had nightmares; I got pneumonia; I had an abscess the size of a tennis ball next to my bladder that had to be drained through my buttock; I had an allergic reaction to the iron infusion; lost 9kg's; had two drains on either side of my abdomen and a central line in my neck with a nasal gastric tube. And a poo bag!

It was a hard slog and the hardest part of all was dealing with the ileostomy bag. I was very self conscious about it and had some disastrous experiences with the bag becoming unstuck or bursting. By the time I had the reversal operation to remove the bag I had got used to it!

I am now really well and 'normal'. My Crohn's is in remission and I am completely drug free. I know that it will flare up again, but I try not to think about that. I've learnt to grab hold of the good days with two hands - you never know what tomorrow will bring.





# Crohn's and Colitis New Zealand Inflammatory Bowel Disease GEM Project



**T**he GEM Project has arrived in New Zealand! GEM stands for Genetics – Environment – Microbiome and is a multi-national study, initiated by Crohn's Colitis Canada and introduced to CCNZ several years ago. As medical adviser to CCNZ I saw the merit in such research and after considerable negotiation was able to secure the rights to conduct the study in NZ.

The GEM study aims to recruit healthy First Degree Relatives of patients with Crohn's disease and to follow them for 6 years. The aim is to find the difference between those who develop Crohn's disease in this timeframe and those who don't. FDRs are being asked to complete multiple questionnaires and give a blood, stool and urine sample. Following this, it is just a short phone call every six months for six years or until they develop

Crohn's disease. The relatives should be between 6 and 36 years, so we are looking for children and siblings primarily.

So far, 3500 people have been recruited world-wide, whom 40 have developed Crohn's disease. This study is a monumental effort. Every patient counts. Through CCNZ we hope to obtain the required number of patients and FDRs.

If you are interested, please send your name, date of birth and if you have it, your NHI number to us in Dunedin (Aroha Bolton; aroha.bolton@southernhb.govt.nz) or myself; michael.schultz@otago.ac.nz). We will approach you and if you agree talk to your relative. We will then negotiate with your local specialist to be seen there. Please help to give this study a NZ flavour.

## Increasing rates and high rates of IBD in Canterbury

**A** very high incidence of Crohn's disease has previously been shown in Canterbury (16.5 per 100,000 people in 2004).

A more recent study showed that in 2014 (ten years later) 205 patients were diagnosed with IBD in Canterbury. The age-standardized incidence for Crohn disease was 26.4 per 100,000, while the rate for IBD overall was 39.5 per 100,000 people. This new data shows one of the highest rates of Crohn disease in the world, and also shows that almost twice as many

people were diagnosed in 2014 in Canterbury than ten years earlier.

Gearry RB, Richardson A, Frampton CM, et al. High incidence of Crohn's disease in Canterbury, New Zealand: Results of an epidemiologic study. *Inflamm Bowel Dis.* 2006;12:936-943.

Su H, Gupta V, Day AS, Gearry RB. Rising Incidence of Inflammatory Bowel Disease in Canterbury, New Zealand. *Inflamm Bowel Dis*, 2016, In Press.

## Research Position Vacant – Seeking PhD Student

### Quality of Care of Patients with Inflammatory Bowel Disease in New Zealand and Impact on Quality of Life

**Primary Supervisor:** Associate Professor Michael Schultz, Gastroenterologist, Department of Medicine, Dunedin School of Medicine, University of Otago. michael.schultz@otago.ac.nz

**Co-supervisors:** Associate Professor Sarah Derrett, Health Services Researcher, Department of Preventive and Social Medicine, Dunedin School of Medicine, University of Otago. sarah.derrett@otago.ac.nz

Dr Trudy Sullivan, Health Economist, Department of Preventive and Social Medicine and the Dean's Department, Dunedin School of Medicine. trudy.sullivan@otago.ac.nz

**Level:** PhD – this is a project suitable for a PhD student with a background in health research and preferably a good understanding of New Zealand's health care system.

The proposed research focuses on New Zealanders with inflammatory bowel disease (IBD) and is supported by Crohn's and Colitis New Zealand. Australia and UK have standards of care for IBD (e.g. High Quality Clinical Care, Local Delivery of Care, Maintaining a Patient-Centred Service, Patient Education and Support, Data, Information Technology and Audit, Evidence-Based Practice and Research). We seek to:

- determine whether care in New Zealand meets international standards
- understand patients' experiences of health services
- describe patients' quality of life (e.g. health, wellbeing, participation and socioeconomic status) in relation to IBD services
- identify strategies for improving care.

# A better path to IBD patients understanding their illness: The ECCO-EFCCA Patient Guidelines for Crohn's Disease and Ulcerative Colitis

by Dr Andrew McCombie

**I**t is important that a doctor never underestimates the intelligence or overestimates the knowledge of their patient; in other words, it should be assumed that the patient does not know everything that is going on but is capable of understanding everything that is going on if they are told. If patients understand their illness and its treatment better, they will be more likely to have a positive disease journey. However, how can we be sure that medical professionals are telling their patients enough and that the patients even understand what the medical professionals are saying? Moreover, how are the patients themselves supposed to know if their medical professionals are telling them enough and are giving them the correct information?

The answers to these questions lie partly in the recently released translations of the Crohn's disease and ulcerative colitis consensus guidelines which I contributed significantly to. Before explaining the advantages of translating these guidelines, it is important to first understand what consensus guidelines actually are. By definition consensus guideline statements are statements about treatment and diagnostic pathways that have been highly agreed upon by a majority of gastroenterologists. No statement will be considered a consensus statement if most gastroenterologists do not agree with them. This means that if a gastroenterologist is doing something contradicting the consensus guidelines they are doing something that the majority of gastroenterologists would not do. Just some examples of topics covered in consensus guidelines are:

- How IBD should be diagnosed
- How left-sided colitis (i.e. ulcerative colitis of the left side of the colon only) should be treated as compared to pancolitis (i.e. ulcerative colitis of the whole colon)
- When surgery for ulcerative colitis should occur
- How abdominal masses in Crohn's disease should be managed

These consensus guidelines in their original form are written in quite complicated language that is not easily understood by

people who are not medically trained. The primary aim of the patient translations was to make these guidelines more accessible and understandable to a lay audience, including IBD patients who are usually not medically trained and often newly diagnosed! This meant defining technical terms, trying to replace big words with smaller words, and making the average sentence word length smaller.

I wrote the first draft of the translations of these consensus guidelines as well as the glossary; these were then debated upon and finalized by panels of a majority of patients and minority of physicians who adjudged as to whether the statements were more understandable without compromising their meaning in the original statements for physicians. The ultimate primary question asked at the end of the translations was "Will more people understand these guidelines now?" Fortunately, the answer is "Yes."

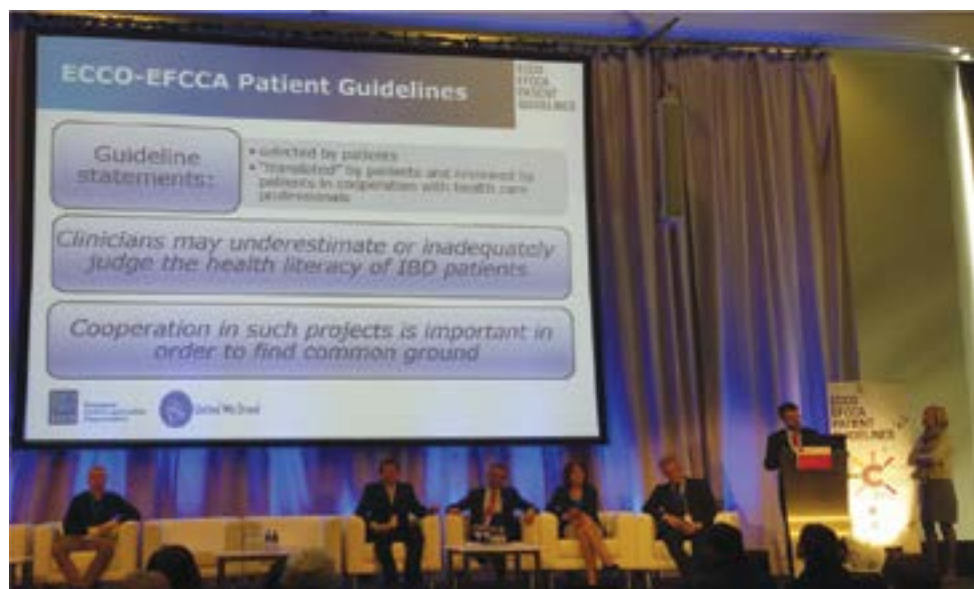
As patients understand what the majority of gastroenterologists think about different aspects of IBD diagnosis and treatment, they will be empowered by this understanding and will better understand the rationale of the thinking of the physicians treating them. As patients become more informed and empowered, their disease journeys will improve through knowing why they are receiving the treatment they are getting and will feel less as though they are merely "blindly following" their doctor's advice.

The patient translations were released collaboratively on the 16th of March, 2016 by the European Crohn's and Colitis Organization (a Medical Professionals Group) and European Federation of Crohn's and Ulcerative Colitis Associations (a

Patient Group of which Crohn's and Colitis New Zealand is an associate member) in Amsterdam at The 11th Annual Conference of the European Crohn's and Colitis Organization. This is a link to the story and the translated guidelines themselves:

<http://www.efcca.org/index.php/multimedia/breaking-news/139-ecco-efcca-patient-guidelines>

*CCNZ wish to have similar guidelines for NZ patients and we are pleased to share the good news that the project for Quality of Life and Standards of Care for IBD patients is getting off the ground. We acknowledge Michael Schultz for leading this.*





# The importance of Blood Testing

## Why do we test your blood?

Several laboratory studies are of value in assisting with the management of inflammatory bowel disease (IBD) and provide supporting information. However, no laboratory test is specific enough to adequately and definitively establish the diagnosis of IBD. Laboratory values may be used as surrogate markers for inflammation and nutritional status and to look for deficiencies of necessary vitamins and minerals. Serologic studies have been proposed to help diagnose IBD and to differentiate Crohn's disease from ulcerative colitis, but such studies are not recommended for routine diagnosis of Crohn's disease or ulcerative colitis.

## Hematologic tests

### Complete blood cell count

The components of the complete blood cell (CBC) count can be useful indicators of disease activity and iron or vitamin deficiency. An elevated white blood cell (WBC) count is common in patients with active inflammatory disease and does not necessarily indicate infection.

Anaemia, (a condition in which there aren't enough red blood cells to carry adequate oxygen to your tissues) is common and may be either an anaemia of chronic disease (usually normal mean corpuscular volume [MCV]) or an iron deficiency anaemia (MCV is often low). Anaemia may result from acute or chronic blood loss malabsorption (iron, folate, and vitamin B12) or may reflect the chronic disease state. Note that the MCV can be elevated in patients taking azathioprine (Imuran) or 6-mercaptopurine (6-MP). Generally, the platelet count is normal, or it may be elevated in the setting of active inflammation.

**Nutritional evaluation: Vitamin B12 evaluation, iron studies, RBC folate, nutritional markers**

Vitamin B12 deficiency can occur in patients with Crohn's disease who have significant terminal ileum disease or in patients who have had terminal ileum resection. The standard replacement dose of vitamin B12 is 1000 mg subcutaneously (SC) every month, because oral replacement is often insufficient.

Iron deficiency occurs in about 60-80% of patients with inflammatory bowel disease ... Anaemia is thus by far the most common extraintestinal complication of IBD. Serum iron studies should be obtained at the time of diagnosis, because active IBD is a source for GI blood loss, making iron deficiency common. A microcytic hypochromic anemia suggests iron deficiency; if confirmed with serum iron/total iron-binding capacity (TIBC), iron can be replaced either enterally or parenterally. For parenteral replacement, intravenous (IV) iron sucrose can be used, with a maximum of 30 mL (1500 mg) at once.

Although folate deficiency is not common in persons with IBD, several concerns have been raised regarding this vitamin.

Sulfasalazine (Azulfidine) is a folate reductase inhibitor and may inhibit normal uptake of folate; thus, many practitioners commonly administer folate supplements in patients taking sulfasalazine. Folate supplements are indicated in all women who are pregnant to help prevent neural tube defects; this is particularly true for patients with IBD, and supplementation with 2 mg/day or more (rather than the usual 1 mg/day) should be considered in those on sulfasalazine.

Nutritional status can be assessed by serum albumin, prealbumin, and transferrin levels. However, note that transferrin is an acute-phase reactant that can be falsely elevated in persons with active IBD. Hypoalbuminemia may reflect malnutrition because of poor oral intake or because of the protein-losing enteropathy that can coexist with active IBD.

### ESR and CRP levels

The erythrocyte sedimentation rate (ESR) and C-reactive protein (CRP) level are often used as serologic markers for inflammation, but they are not specific for IBD. However, measuring such inflammatory markers also aids in monitoring disease activity and response to treatment. A small but significant number of patients with Crohn's disease or ulcerative colitis may not have elevated ESR or CRP levels even in the setting of significant active inflammation. In addition, inflammatory markers may be elevated in the setting of superimposed intestinal or extraintestinal infections.

### Medication Monitoring

It is important to have regular Renal & Liver testing to check for drug toxicity and for those on biologicals checking for antibodies to the medication (that makes it less or non-effective) These are drugs that have proven efficacy in the treatment of Crohn's disease where others have failed)

The thiopurine drugs azathioprine and 6-mercaptopurine (6-MP) are well-established in the treatment of inflammatory bowel disease (IBD). However, there is a wide inter- and intra-patient variation in the concentrations of active and toxic metabolites due to their complex metabolism and do require metabolite monitoring. So blood count monitoring should remain standard practice.



# What happens if I run out of intestine? Do I die?

**T**hose were my questions to my gastroenterologist in 2003 following my third unplanned small bowel resection for Crohn's disease (CD) and the diagnosis of Short Bowel Syndrome (SBS)! I actually don't remember my gastroenterologist's exact answer, but I do remember being reassured that he had something else up his sleeve should I 'run out of intestine' and life wasn't going to end quite so quickly.

I'd had CD for 13 years at that stage, and it was becoming more aggressive. The start of SBS with this last surgery had its own new challenges, including kidney stones and at the start, diarrhoea like you wouldn't believe – I just had to think about or smell food and I would need to run to the toilet. Dehydration was an issue too, so there were even more dietary issues.

Three years on, with severe malnutrition and anorexia, and rampant CD, I stopped work altogether and discovered the 'something else' my gastroenterologist had up his sleeve – Parenteral Nutrition! I'd recently had a total colectomy (brilliant for dealing with diarrhoea!) and needed another small bowel resection, but without some extra oomph, no-one had much hope of me surviving. So I was put on Parenteral Nutrition in hospital. Parenteral Nutrition (PN) is food in a liquid form which is delivered via a catheter in a vein close to the heart, when there is a problem with the digestive system. The nutrients are in a bag of sterile solution which is infused through the intravenous catheter. All connections and procedures must be aseptic, to minimise infection risk from bacteria entering the bloodstream.

Calories and nutrition!! Exactly what I was needing. I had surgery, however the result was a diagnosis of Intestinal

Failure. I was left with between 20-35cm of small bowel which meant I was never going to be able to absorb sufficient nutrients to live. So, I was then taught how to infuse PN myself, so that I could do it at home (Home Parenteral Nutrition or HPN) overnight, everynight for the rest of my life.

I admit, it was very daunting at first and took a good while to get the hang of it – HPN is a highly complex life support therapy and there are dangers involved, but it means I'm alive! By God's grace, I've been alive for 9 extra years as a result of HPN and I'm celebrating life! Not only do I have sufficient nutrition, but I've also been incredibly blessed that the once increasingly aggressive CD which was close to taking me out, is in remission!

Life on HPN is pretty extreme. It's not well-known or understood. There are only about 215 adults and children of all ages on HPN across New Zealand and Australia on HPN. Short Bowel Syndrome from CD makes up a significant portion of these, but there are also other causes of Intestinal Failure requiring HPN, including Gastroparesis, Chronic Intestinal Pseudo Obstruction, Malrotation Volvulus and many other weird, wonderful and sometimes very rare digestive disorders.

As Crohn's & Colitis New Zealand offers support for those living with CD and Colitis, Parenteral Nutrition Down Under (PNDU) was established 6 years ago to specifically support those living with HPN across New Zealand and Australia. If you'd like to know more about PNDU, HPN or Intestinal Failure, feel free to visit [www.pndu.org](http://www.pndu.org) or email [contactpndu@gmail.com](mailto:contactpndu@gmail.com).

By Karen Winterbourn

## YOUR AREA

**Joining your local support group is a fantastic way to meet people and get involved!**

CCNZ support groups provide the opportunity for anyone affected by IBD (for example patients, their families and friends) to meet other people who understand the challenges of IBD. These local groups hold regular meetings, providing a safe and supportive environment where individuals impacted by IBD can express themselves openly and receive support and understanding from others with similar experiences.

These groups are run by people with IBD for people with IBD, providing information and services for their local community.

View our list to find your nearest support group and contact them for information

<http://crohnsandcolitis.org.nz/Get+Involved>

We are delighted to announce the launch of two new support groups in Taranaki & Rotorua.

**Do you live in Northshore, Auckland – Would you like to get involved?**

We are seeking people who would be interested to help start and run a support group on the North Shore, Auckland. Ideally the support group would be an ongoing occurrence, meeting



once a month for 30 minutes to an hour each support session. It would be great to have four volunteer facilitators just in case of sickness.

The focus of the support group is to bring people together who have IBD

on the North Shore to meet and have relaxed catch-ups, as well as formal meetings with guest speakers and some fun family outings.

If we get enough interest we would look to start the support group in June 2016, giving everyone plenty of time to see if they are available and for the facilitators to organise something exciting.

If you are interested in being a facilitator or if you have another special skill that can help the support group, or if you would just like to come along. Please email Courtney Leonard-Wheeler at [cokelw2@hotmail.com](mailto:cokelw2@hotmail.com), with the reference North Shore Support Auckland in the Subject line.

We look forward to hearing from you :)





## You can help make a difference!

Read these amazing stories from our remarkable fundraisers. See some of the different and inspiring ways people like you have raised money to support us.

## Round-the-Bays 2016

### Raising funds for Camp Purple Live!

**C**amp Purple Live is a cause I am extremely passionate about. I participated in the Auckland Round the Bays in 2014 to raise funds for the very first camp and decided it was a good opportunity to raise funds and awareness again this year for the camp.

The first year I did it with two friends in purple tutus. This year I decided to rope in more people and have them wearing as much purple as possible.

The aim was to create awareness for IBD. We were certainly stopped a lot along the way and were asked many questions about IBD. It was great to have Beth turn up as she herself has been to camp twice, as a camper, and it's fantastic to have the kids participating and raising awareness for their own camp.

I am also extremely fortunate to have such wonderfully supportive people in my life who also turned up and walked with me. The plan is to encourage even more people to participate with me in the coming years so we can have a SEA OF PURPLE!

Belinda Brown



## CAMP PURPLE LIVE NEEDS YOUR HELP!

**W**e are trying to organise a country wide sausage sizzle to raise money for Camp Purple Live, the camp for children with IBD. The Mad Butcher is providing sausages at a discounted price and the Camp Committee will offer help, provide posters, hand out information, and can help with seed money to get started. This is a great way to raise awareness about IBD, connect with others in your community, while supporting a very worthwhile cause!

If you are interested, contact your local support group leader (who is aware of this campaign) or email: [campenquiries@crohnsandcolitis.org.nz](mailto:campenquiries@crohnsandcolitis.org.nz).

### Donations

As a non-profit, volunteer driven organisation, Crohn's and Colitis New Zealand relies on donations, grants, sponsors and bequests to maintain our work.

If you would like to donate to CCNZ, our email is [info@crohnsandcolitis.org.nz](mailto:info@crohnsandcolitis.org.nz) and a donation facility is on



the CCNZ website at <http://crohnsandcolitis.org.nz/Donate>  
Legacy Giving! Go well, Yours sincerely

Brian Poole, QSM  
Chairman, Crohns & Colitis New Zealand

The Crohn's and Colitis New Zealand Charitable Trust was established to respond to the needs of significant numbers of New Zealanders affected by Inflammatory Bowel Disease. CCNZ aims to:

- Provide information and support to those affected by Inflammatory Bowel Disease and their families.
- To advocate for greater recognition of Inflammatory Bowel Disease as a critical public health issue.
- To promote public and professional awareness of Inflammatory Bowel Disease diagnosis, mitigation and treatment.

**We want a future free of IBD.**

**Crohn's and Colitis New Zealand**  
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 Wellington 6441

 [info@crohnsandcolitis.org.nz](mailto:info@crohnsandcolitis.org.nz)



[www.crohnsandcolitis.org.nz](http://www.crohnsandcolitis.org.nz)

## Payroll giving is simple

You might like to consider making a regular donation to Crohn's and Colitis New Zealand through payroll giving. Your employer will have information on this, but we can provide you with a form, which can be downloaded from our website, for you to give to your employer. We will acknowledge your first payment, and then send you a receipt at the end of the financial year, for tax purposes.

Go to our website for more information and the downloadable form.

**Your donations are tax deductible.**

## Our Supporters



NZ Agents:  
 Pharmaco (NZ) Ltd  
 PO Box 4079, Auckland 1140



You can make a one-off donation on our website at:

<http://crohnsandcolitis.org.nz/Donate>

For postal donations, please use this form and post to us at:

Crohn's & Colitis NZ  
 Charitable Trust,  
 PO Box 22280, Khandallah,  
 Wellington 6441.

**Please do not send cash.**

**Thank you for your donation**

### YOUR DETAILS

Please send us your details so that we can post you a receipt

Name:

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Donation amount (\$):

**Cheque:** Payable to Crohn's and Colitis Charitable Trust

**Direct debit:** Please use your name as reference for the payment.

Date payment made: \_\_\_\_/\_\_\_\_/\_\_\_\_

Our Bank Account Number: **03 1355 0630209 00**

Bank: SBS Bank, Nelson

**Credit card:** If you would like to make a donation by credit card please make your donation via our website [www.crohnsandcolitis.org.nz](http://www.crohnsandcolitis.org.nz)

CCNZ is a registered charity with the Charities Commission.  
 Registration Number CC43580.

