



*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.*

## Our first New Zealand Camp for young people

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It has been an amazing start to 2015. The first New Zealand based camp for children and teenagers with IBD was held from January 25th to January 30th at Camp Adair, situated in the beautiful Hunua ranges, just south of Auckland. This was a meaningful, fun and transformational experience, not only for the 44 young people who attended the Camp, but also for many of us involved as adult volunteers as well getting to know a rich variety of personalities. There was a great programme of activities, of which the mudslide, confidence course, high swing, flying fox, crate challenge, laser tag and the campfire skits, were some of the highlights! You can see our video of the camp on our website <http://crohnsandcolitis.org.nz/>

The aim of the Camp was to help young people to connect with others of their own age who have IBD, and to build confidence, independence, self-esteem, resilience and empowerment. As part of the Camp, Christchurch clinicians conducted a study of quality of life QOL (IMPACT-III) and disease-specific knowledge (IBD-KID) before and after. Preliminary results show that the vast majority of respondents agreed or strongly agreed that the camp improved their confidence in dealing with IBD, their acceptance of having IBD and their overall quality of life. Most reported that, their fellow campers meeting was the most beneficial experience to come from the camp, with the vast majority reporting that this was their first time being around other children with IBD and that they



made new friends with the same condition at the camp. All would recommend the camp experience to others.

We also held a programme for parents and caregivers on the first two days of the camp, which was also very well received and proved to be a great compliment to the programme offered to the young people.

We have been deeply touched by the fantastic support provided throughout the whole process of organising

*Continued on Page 2*



### From the Chair

Dear Patients, Families and Supporters

It gives me pleasure to send you this Autumn/Winter 2015 letter, to update you with the news since the last edition of our newsletter "Moving On. Here's hoping that this finds you well, since our health is so critical to being able to live to the full!

This update aims to keep you informed about things that might help make life more liveable for people connected with inflammatory bowel disease, and to reduce the isolation that some patients can feel.

So this update is packed with information on the ways that we provide support and with tips that might help your health or give you more options to discuss with your doctor.

Brian Poole, QSM  
Chairman

Crohn's & Colitis NZ Charitable Trust

and holding the Camp. There was a magnificent show of support by the IBD clinical fraternity and from many of those associated with CCNZ, either as patients or relatives themselves, or through their professional connections, for which we are immensely grateful. Many of them were prepared to give the activities a go as well – Richard Stein and Andrew McCombie looked a sight covered in mud at the confidence course, our own Charlotte Perkins from CCNZ head



office conquered the climb up the telegraph pole and the leap off down the flying fox – and you will recognise many others in the photos we took. Our Patron, Lady Janine Mataparae also visited the camp on the final morning to present certificates of achievement to all those involved – see the write up and photos on the Government House facebook site. The financial viability of the camp was of course also greatly assisted by the generosity of corporate sponsors such as Jetstar, Auckland Round the Bays, Fairfax, AbbVie, Janssens, Baxters and Pharmaco.

We recently held a debrief with a representative section of those involved in organising and helping at the camp on May 3rd and from this came a number of recommendations to the CCNZ board about the future of such a camp and a possible format going forward. We can reflect on a very successful first venture and the promise of much for the future with possibly even more able to be added in terms of value to the programme.

A huge congratulations to all those involved! You are all truly CCNZ stars.

## Camping and Quality of Life

Now I know I'm not alone. Participating in a disease specific summer camp improves the quality of life of young people with Inflammatory Bowel Disease.



## Public awareness of IBD

There has also been a lot of publicity surrounding the Camp that has raised awareness of IBD in the public mind. Our thanks go to the young people who have appeared in magazines and been interviewed for radio interviews. For example, if you would like to catch it, the 20th February Radio New Zealand documentary on Living with IBD was recorded on

<http://www.radionz.co.nz/national/programmes/nz-society/20150220>



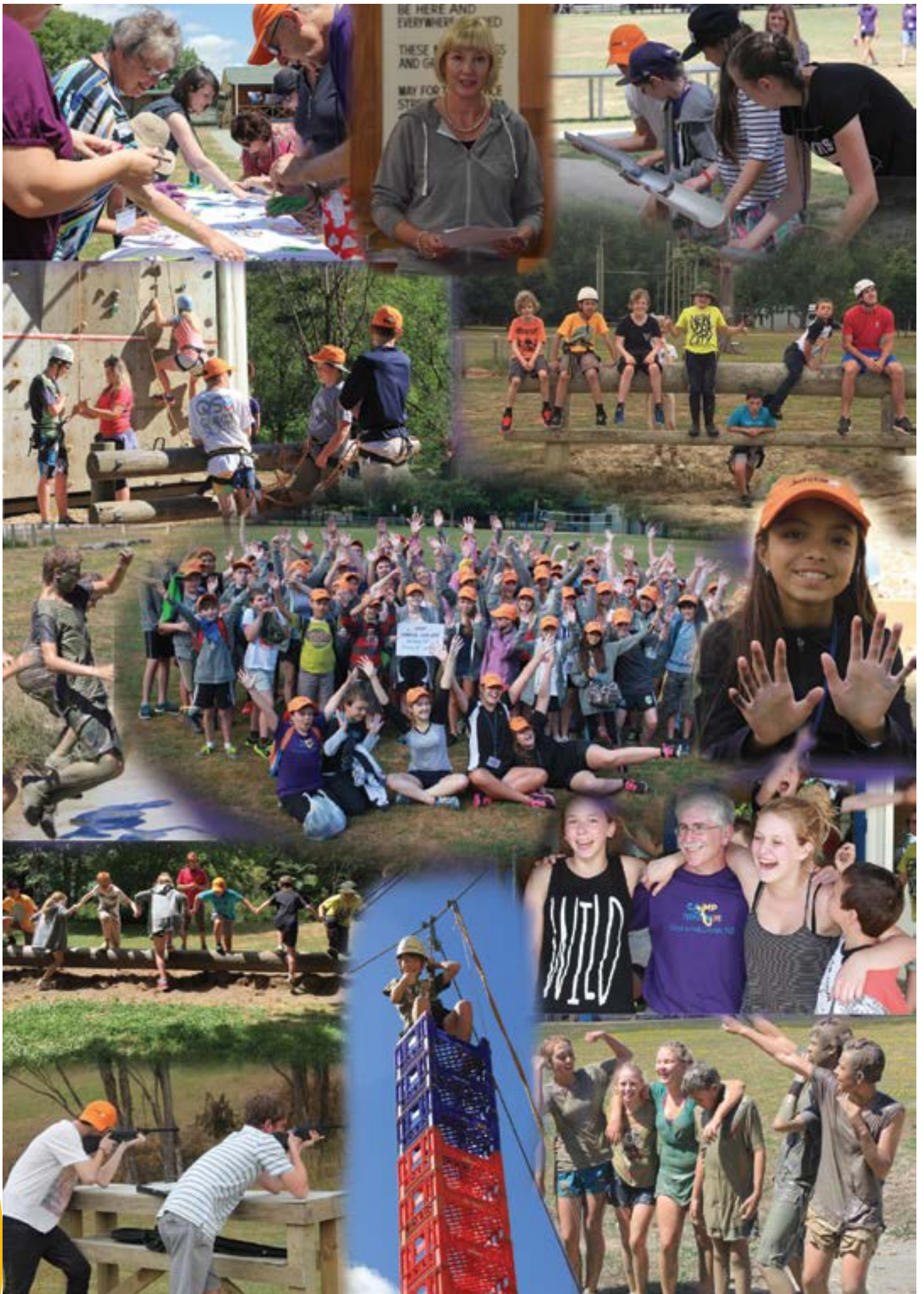
### Background

As you know, Crohn's and Colitis New Zealand's first ever summer camp for children (aged 10-18) with inflammatory bowel disease (IBD) was held in January, 2015. Whilst such camps have been commonplace in Europe and North America for a number of years, there is very little data measuring the impact camps have had on children who attended them. For example, does it improve the children's quality of life (QoL), knowledge about IBD, confidence in dealing with IBD, and the acceptance of actually having IBD? Professor Andrew Day and I joined forces to answer these questions and also to determine how future camps can be improved.

### Questionnaires used

We used questionnaires to ask the camp attendees about their knowledge of IBD and QoL before the camp, one month after the camp, and will six months after the camp; this is to see whether these outcomes improve and are maintained long after the camp is finished. At the conclusion of the camp, we also asked the campers via another questionnaire about whether they felt it improved their acceptance, confidence, and QoL, and also gave them the opportunity to write freely about what they liked and disliked





most about the camp and how they think it could be improved in the future. We also asked the parents who attended the two day workshop at the beginning of the camp to provide feedback about the workshop. This article focuses on the feedback questionnaires given to the parents and the children immediately after the camp. No results are available as yet pertaining to changes in IBD knowledge or QoL scores among the children.

### Responses from participants

In terms of the children, the response rate was very high, with 36/44 (81.8%) completing the questionnaire. The vast majority of respondents agreed or strongly agreed that the camp improved their confidence in dealing with IBD (86.1%), their acceptance of having IBD (83.3%), and their overall QoL (75.0%). Most reported that their fellow campers meeting was the most beneficial experience to come from the camp (77.8%). The vast majority reported this was their first time being around other children with IBD (75.0%), that they made new friends with the same condition at the camp (97.2%), and would attend the same camp again in a year or two (86.1%). All would recommend the camp experience to others. Similar answers were found for the open-ended questions. For example, one response was *"I really enjoyed knowing that the people I met go through exactly what I do, even worse! It made me thankful and not too lonely. It also made me realize you can still live a great life even when dealing with this condition. I also enjoyed the group activities."*

Most parent attendees responded, with 13/18 (72.2%) responding. Among the 13 respondents, all strongly agreed that attending the parents section of the camp was worth it and would recommend it to other parents of children with IBD. In addition, all strongly agreed or agreed that they enjoyed this experience. The favourite module among parents was about the emotional needs of the child with IBD given by Mrs Maria Berrett (a clinical psychologist from Massey University). One comment sums up the general vibes from the respondents: *"Very well organised. I felt really reassured coming here and meeting the staff that have volunteered their time. Loved meeting the families. Really helpful. Thank you so much :)"*

### Our conclusions so far

Overall, Crohn's and Colitis New Zealand put in a huge amount of effort to making the first camp a success. Based on these responses from children and their parents, we can be confident it was worth all the time, money, and effort. We also have some constructive suggestions from the children and parents for making the next camp even better. Most importantly, 86.1% would attend a camp in a year or two, which means we need to start planning for the next one!

### About the author

Dr. Andrew McCombie graduated with a PhD from the University of Otago in December 2014 and serves as a Board member for Crohn's and Colitis New Zealand. His thesis was entitled *"The psychological aspects of inflammatory bowel disease."*



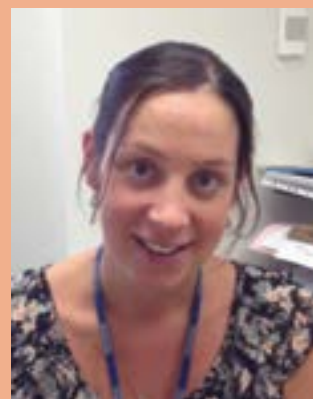
## IBD Nursing!

**W**as thinking of doing an article for the newsletter on most frequent questions asked in my clinic. There are of course common questions but patients have their own journey with their disease and have questions that apply to their disease in which can be personal to them. Throughout my own journey as an IBD nurse our clinics are important and accessible to the patients when they need us.

The main aspect is communication which is a two way process. 'Nurses need to develop an empathetic and active listening role, and be able to provide essential IBD-related information and holistic support (O'Connor, M, et al, 2013). Building a rapport with patients and developing trust is a key part to the role of the IBD nurse. Patients expressing their issues and challenges are important as with IBD it affects many aspects of an individual life. It affects one's family, relationship and at many times body image and how individuals feel about themselves i.e effects of Prednisone.

As the IBD nurse we can help with these issues by listening and supporting the patients and by helping put mechanisms in place to help through this rough part in their journey. The one common emphasis is that patients need to know 'they are not alone in their battle with this disease' and have support out there. Positive affirmations can help along their journey.

As an IBD nurse we can at times be more accessible than our very busy consultants. So if/when a patient has a flare we can use our skills to gather relevant information and make a plan with the consultant to get control of the patients flare as soon as possible. As part of the role we also assist with ward rounds and seeing patients on the ward. A familiar face in the hospital setting can be very helpful in the road to recovery.



Lisa Griffiths, Clinical Nurse Specialist, IBD Capital & Coast DHB

Since the role has been created in NZ there is a lot of work going on behind the scenes with IBD nurses who are all passionate about their role. As IBD nurses we are making a difference in the role to both consultants and the patients with IBD. Over time this role will continue to grow.

Find your nearest IBD Nurse (for public hospital patients) by visiting the Support page of our website and look up your nearest support group;

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

# Your health

## Travelling with IBD

### IBD Passport online travel advice

It is acknowledged that Inflammatory bowel disease (IBD) and foreign travel is associated with an increased risk of travel-related morbidity caused through exacerbations of IBD, acquisition of infectious diseases endemic to the destination and availability of healthcare and medicines whilst abroad.<sup>1</sup> Detailed pre-travel consultations and vaccinations are advised prior to travel to ensure travellers are armed with the appropriate education and resources to stay healthy during their journey but low rates of pre-travel preparation and deficiencies in the advice provided by healthcare professionals have been highlighted in previous research.<sup>2-5</sup> Kay Greveson, Inflammatory Bowel Disease nurse at the Royal Free Hospital, London, UK has developed an online resource to address this issue to provide support for patients planning travel with IBD and a resource for healthcare professionals who advise them.

IBD Passport ([www.IBDPassport.com](http://www.IBDPassport.com)) is a non-profit, IBD-specific travel resource with the primary aim of developing patient-centred information to support living with inflammatory bowel disease and improve education and pre-travel preparation by providing evidence-based information on all aspects of travel and IBD. The website draws together information from National and International IBD guidelines, patient organisations, reputable travel health websites and government literature into one resource. The website includes three key pages; travelling with IBD, IBD network and MyIBD. Travelling with IBD includes practical information on issues such as obtaining healthcare overseas, managing travellers' diarrhoea, travel following surgery and details regarding travel insurance and vaccination advice specific to the immunocompromised patient. The IBD Network page contains an interactive map of country-specific vaccination advice and a 'search and refer' directory of IBD centres to enable IBD healthcare professionals to



refer to other IBD centres globally. Population of the directory of IBD centres on the interactive map depends on centres registering with the site. The MyIBD page provides downloadable content for patients and future plan are to include link to a smartphone app that will enable individuals to carry secure details of their health records wherever they travel. Most sections of the site can be viewed without registering but you are encouraged to complete the short, free registration to gain access to the full content and functionality of the IBD network, whilst also making yourself and your service visible to other IBD teams throughout the world. Register for free with the site at [www.IBDpassport.com](http://www.IBDpassport.com)

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## Health Schools

It can be a worrying time when your child is forced to miss school due to serious illness. Regional Health schools provide teachers to teach children in hospital or at home if they're unable to go to school because they're sick. There are three health schools based in Auckland, Wellington and Christchurch providing community, in-home and hospital based teaching to children from years 0 to 13.

To find out more about this unique integrated service you can visit the website at;

<http://www.minedu.govt.nz/> under regional health schools.

## A new Patient Guide to the Colitis Activity Index

(used to determine how sick you are)

A reminder that the Patient Guide for patients with ulcerative colitis is on the CCNZ website at [www.crohnsandcolitis.org.nz](http://www.crohnsandcolitis.org.nz) It enables you to record the details of your health on the same points-system as your medical team is likely to use.

The Guide is called "How to complete your own Simple Clinical Colitis Activity Index". The idea is that, before appointments, you can fill it in with the details about your symptoms that the medical team are likely to ask about. Or, if you think that your colitis is flaring up, you could fill it in at home to verify this and then, if you need to seek medical help, you have got the information that the medical team will need to be able to take care of you. Our thanks go to Dr Russell Walmsley of North Shore Hospital for his work on this.

# Tame Your Gut

## Psychological Therapy Program for People Living with Inflammatory Bowel Disease

Many IBD patients are confronted with fatigue, pain, embarrassment and physical disablement that have negative effects on social and work life. Consequently, individuals with IBD have been found to report poorer quality of life and more anxiety and depressive symptoms. Poor quality of life in turn, has a negative impact on relapse and disease activity.

Cognitive behaviour therapy (CBT) is a type of short-term treatment that can be highly effective for many disorders. This 10-week on-line program of cognitive-behavioural therapy (CBT) is conducted under the auspices of Dr Antonina Mikocka-Walus, Psychologist and Drs Jane Andrews and Peter Bampton, Gastroenterologists. The program has been tested with IBD patients in South Australia and has been found to improve quality of life in people who experience problems with their IBD management. The program is focused on improving coping with



All you wanted to know about living with IBD

IBD but also overall wellbeing. Each week there is a set of activities to complete, but they do not have to be done on one day and can be spread throughout the week. You may also like to practise activities from previous weeks while learning new skills.

<http://www.tameyourgut.com/>

## Shared Stories

### There's always something new to experience with Crohn's and colitis.

When I went into hospital in December, I wondered whether I had an obstruction. A new kind of pain – something very troubling indeed. It's one thing to experience the same gut twists again and again, on and off. But it's quite another to have a new sort of abdominal agony begin to build, and build and build.

I've had IBD symptoms for about eight or nine years. I was diagnosed with UC fairly promptly after I finally dragged my sorry self to the doctor. I was re-diagnosed with Crohn's when I had my first surgery at 23 – a Hartmann's procedure that left me with 15cm less of my colon, and a colostomy to boot. I'd know my fair share of IBD-related pain.

In the past, the constant grumble had been by my side for years on end, occasionally interposed with impossible stabbing sensations that would eventually go away after a few hours of middle-of-the-night stomach-clutching and moaning. My various GIs have commented that it blew them away that I hadn't ever checked into ED, with the severity of my symptoms. But as much as they were terrible, they were familiar, and I knew that, as a rule, they would

settle back into a place that I could 'handle' them. As much as you can ever handle that kind of pain, that kind of social/dietary/timing inconvenience.

But this was new. And ten days of increasingly bad, unidentifiable gut pain later, I finally took myself into the emergency department at Wellington Hospital. A few days under observation and a script for prednisone and buscopan later, I went home, feeling poorly but not utterly defeated. December passed, I survived the Christmas season in retail, and I finished the course of prednisone. And promptly found myself experiencing that horrible new pain again.

This time, I was sent for a CAT scan. Lo and behold, it wasn't an obstruction – it was a perforation. Which, if you haven't experienced it, is pretty much as fun as it sounds. The result was emergency surgery, a couple of weeks in hospital and over a month off work.

Which all sounds fairly horrific. But, there are unexpected perks. In the operation, they reversed my ostomy – something that was always planned, but not on the cards for quite some time. Being that sick meant that a lot of attention was given, and a lot of thought went into my case over those couple of weeks. I'm now on twice the usual dose of a biologic drug (weekly injections – not fun, but more fun than the alternative!) and a daily pill regime. But I have medical and surgical teams who really listened to me, who paid attention to my case – and as a result, I'm feeling better now than I have done in years.

Sometimes it takes something extreme to get back into life full-force.

Briar Lawry

## Your area

The contact details of our local support groups are on our website at <http://crohnsandcolitis.org.nz/Get+Involved>

New and existing members welcome. Some of the groups hold informal get-togethers where you can share experiences with other people with IBD. Sometimes the groups have a speaker. Recent talks this year have included "Surgery Options for IBD" in March in Manawatu and "Gut Instincts – gastrointestinal tract in health and disease" in Christchurch in February as part of the Public Health Lecture series.

**Find support and be part of a caring community.**

## Our future

### 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>

# How do we identify the bad guys driving inflammatory bowel disease?

As late as the 19th century we still believed in miasma – that infectious diseases travelled on ‘foul air’. The word malaria literally translates as bad air. Robert Koch and Louis Pasteur then defined the germ theory, that specific microbes cause specific diseases; revolutionising the treatment of infectious disease. Antibiotics together with vaccination and increased hygienic practices have resulted in a marked reduction in the morbidity and mortality of infectious diseases; and to date remain one of the only measures that can eradicate established disease. Concomitantly however, there has been a rapid rise in allergy, cancer, obesity, diabetes and inflammatory bowel disease (IBD), now known as ‘the secret killers’ of the modern world. These diseases have reached epidemic proportions and, for the first time, they are reversing the increase in life expectancy that has been achieved over the last century.

Until recently, we have neglected beneficial gut microbiota and their interactions with the immune system in our quest to understand and treat these new immune mediated diseases. For too long we have considered gut microbiota simply as co-living organisms residing in the gut lumen. Our gut is an ecosystem housing trillions of microbes, with ten times the number of cells and over 100 times the number of genes when compared to the human body. Through recent cutting edge discoveries we now recognise the gut microbiota co-evolves in a mutualistic relationship with its host, a crucial event that impacts the function of the host’s immune system. Indeed, the absence of gut microbial colonisation results in a poorly developed immune system and high susceptibility to infectious pathogens.

While the gut microbiota provides many benefits to the host, it requires strict immune control to maintain intestinal health. Imbalances of gut microbiota are associated with a number of disease states including allergic responses, adiposity, the formation of tumours, and intestinal inflammation such as IBD. A number of immune defence mechanisms contribute to control the location and composition of the gut microbiota and regulate immune responses

in the intestine. Of these, immunoglobulin A (IgA) is an antibody that plays a critical role in the intestine. The main function of IgA is immune exclusion, preventing bacteria from reaching the epithelial cells. It also has an important role in both neutralising pathogenic bacterial antigens and toxins, and to nourish gut microbiota to maintain health. IgA deficiencies have been linked to microbial dysbiosis and increased intestinal inflammation. A new study now suggests the potential of identifying specific gut microbiota that promote an inflammatory state by assessing the degree to which IgA coats these bacteria<sup>1</sup>.

These authors hypothesised that specific gut microbiota responsible for promoting intestinal inflammation in IBD could be identified by the degree to which they are coated with IgA. Stool samples from 27 patients with Crohn’s disease (CD) and 8 patients with ulcerative colitis (UC) were compared to 20 healthy controls. These investigations identified that the percentage of IgA-coated gut microbiota in the CD and UC patients was significantly increased relative to healthy controls. Thirty-five gut microbiota species were highly coated with IgA in IBD patients. While some of these species were also present in the stool from healthy controls, they were not coated with IgA.

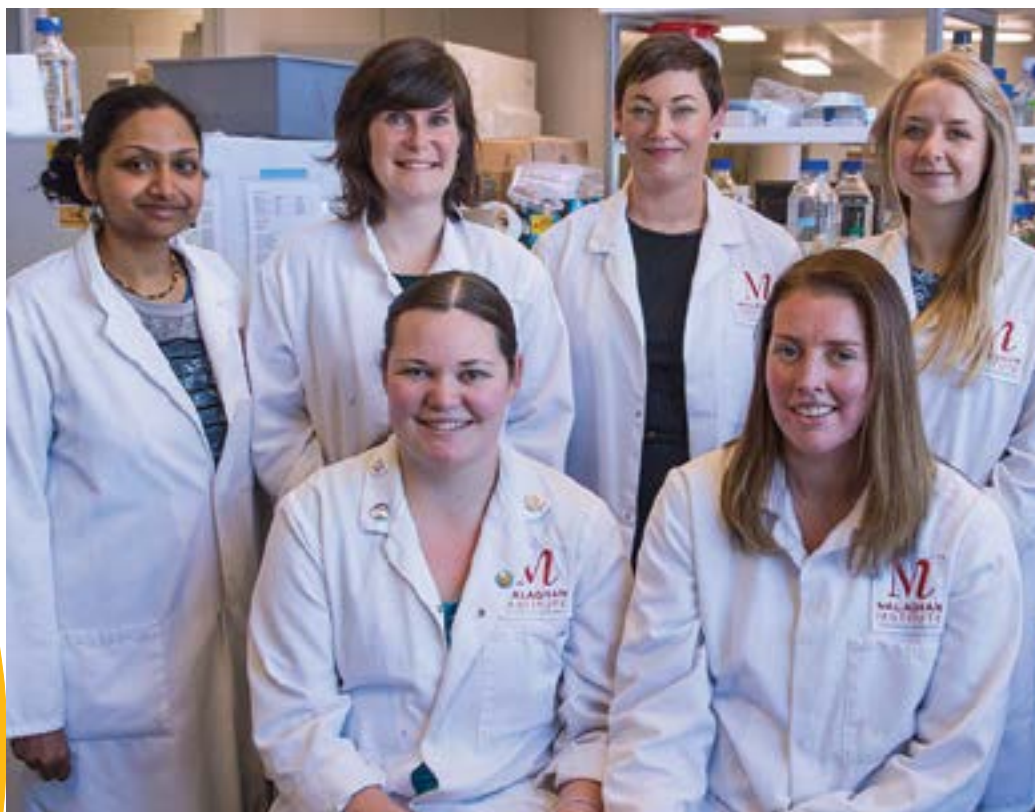
Sophisticated culture techniques were then employed to generate gut microbiota samples from both IgA and non-IgA bound gut microbiota communities from faecal samples of 11 IBD patients. These faecal samples were then transplanted into germ free mice, which are mice that lack any living viruses, bacteria or fungi. When these mice were exposed to intestinal injury, the mice that had been colonized with the IgA coated gut microbiota developed significant intestinal inflammation that resembles ulcerative colitis in patients. Conversely, the mice exposed to the non-IgA coated gut microbiota had markedly less intestinal inflammation.

These findings now suggest that IgA coating could potentially identify inflammation associated gut microbiota in patients with IBD. More

research needs to occur to address the following questions. Are there more than the 35 identified IgA bound gut microbiota species to be found in a larger number of IBD patients? Do patients in clinical remission have less IgA-coated gut microbiota as compared to when they were first diagnosed with disease, or their last disease flare? Most importantly, can we target these IgA coated gut microbiota without affecting the rest of the gut microbiota community needed for health? This represents a major challenge, and it is likely this approach may be applicable to only a subset of IBD patients. Yet such a possibility represents an exciting breakthrough for IBD, and may provide a novel approach to disease treatment.

By Dr Liz Forbes-Blom, PhD,  
Malaghan Institute

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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.**

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[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.

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