



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.

Putting IBD on the Agenda

Government policy makers have a duty to ensure nationally equitable access to a high quality service for people affected by IBD. To that end, Crohn's and Colitis New Zealand has a number of objectives when working to improve the health of people affected by IBD, ensuring our lobbying activities remain focused on the vitally important health priorities identified by you – people with IBD.

1. Timely diagnosis

- We made a submission to Ministry of Health regarding the new priority system for colonoscopies
- We raised concerns about MRI waiting times for small bowel investigations, writing to Auckland DHB for small bowel investigations.

2. Equitable access to medications

- We have made two submissions to PHARMAC as it prepares to take over hospital medications in July 2013

3. Improved health services

- We have written to Health Work Force NZ about the shortage of gastroenterology personnel, the need for more IBD nurses and the need to make gastroenterology a priority area in 2012/13 planning, especially

as the bowel cancer screening pilot will squeeze workforce issues further

- We are a member of a working group trying to advance a service improvement plan for paediatric gastroenterology patients
- We have written to Drs Judith Collett and Paddy O'Connor of Southern DHB to support the appointment for an IBD nurse at Kew Hospital, Invercargill.

4. Empowered patients – via our website

- We selected the European ECCO Guidelines as being most relevant as they are closest to New Zealand practice
- The New Zealand Formulary is also on our website and enables you to see how IBD medications are used to treat the disease.

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On the website - Treatments



This site provides information on the regulation of medicines and medical devices in New Zealand on the safe use of medicines.

One of the most important parts of the website is devoted to providing information for patients. This is the Consumer Medicine Information (CMI) section.

CMI provides useful information about your medicine and is written especially for you. It contains advice such as what the medicine is used for, how it should be taken, what side effects can occur, whether you can drive or drink alcohol while taking the medicine, and what to do if you miss a dose. However, CMI do not contain all the available information about the medicine. Ask your doctor or pharmacist if you have any questions or concerns about taking the medicine.

Pharmaceutical companies are responsible for producing CMI. However, in New Zealand there is no legal requirement for them to do so. The CMI information posted on the Medsafe website has been written by pharmaceutical companies, using guidelines set by Medsafe. Medsafe does not evaluate or approve CMIs; therefore Medsafe is not responsible for the information contained in a CMI.



The New Zealand Formulary is an independent resource providing healthcare professionals with clinically validated medicines information and guidance on best practice, enabling healthcare professionals to select safe and effective medicines for individual patients.

Chairman represents CCNZ at EFCCA International Symposium on Research

Brussels 18th October 2012

I was invited to speak as New Zealand's representative at the first International Symposium on Research funded by or involving patient organisations. At first glance this appeared to be a daunting prospect, for a lay person to talk about the research by Crohn's and Colitis New Zealand, given that we are barely two years old. Yes, it was daunting speaking to an audience of over 50 people, which included physicians from all over Europe, Canada, USA, Israel and South America, but it was important to share our progress and get our message across.

New Zealand definitely has a story to tell, as indicated by the key points of my presentation:

- Andrew McCombie, president of the Canterbury Support Group, and PhD student, is researching IBD. He aims to establish whether Cognitive Behaviour Therapy is easier to access and more effective using a computer, or face-to-face therapy.

Andrew is also studying IBD patients with depression and anxiety, prior to diagnosis, and its effect on recovery.

- Dr John Wyeth is a trustee of Crohn's and Colitis New Zealand and a gastroenterologist at Capital Coast Health DHB. He recently studied how IBD affects the child and the family. His findings recommend psycho-social support and interaction with other children.
- Professor Anita Nolan from AUT University is studying Crohn's Disease and diseases of the mouth. This will involve developing surveys to look at the prevalence of oral lesions and whether these are early predictors of Crohn's disease. Anita also wants to study:
 - o 1st degree relatives and how many develop Crohn's disease
 - o environmental factors and their triggers for IBD



- o dental habits of IBD sufferers. It is important to maintain good oral health when your immune system is compromised. We are hoping that Crohn's and Colitis New Zealand will be involved in assisting with this research.

- Nutrigenomics New Zealand (part of the University of Auckland) has been working with IBD patients for many years, to establish which foods to avoid, develop new foods and studying genetic variants relating to IBD.

- Massey University is about to commence a study to establish the role of vitamin D in IBD patients.

- Finally, our own IMPACT study using the European survey has yielded a good response from our members. An analysis of the survey is under way.

During the meeting, I became very aware that - while we are a young organisation - our members are looked after as well as most other countries. Our 'Living with IBD' handbook was viewed enviously with a number of copies being sought by attendees.

I ended by saying, 'New Zealand is a small country with finite resources, with patients and researchers widely dispersed. Unless we manage our efforts in a

constructive and collaborative way we will not get the critical mass to achieve the momentum required to be effective.'

The Symposium will be held again in three years with members being asked to keep in focus the key research being done. My hope is that the Symposium is the beginning of a global journey, whereby we all collaborate to deal with IBD so that our children and our children's children will be spared the pain of this insidious disease.

Full details of all presentations can be found at www.efcca.org.

Awareness and fun go hand in hand

Crohn's and Colitis New Zealand is constantly astounded by the generosity and inventiveness of our members. People (and their families) affected by IBD are always coming up with new ideas to increase awareness. Sophie Forsdyke and her dad Murray, together with a great group of friends had real fun promoting our cause, and raised \$1,500 doing so.

Murray is a member of the Horowhenua Chapter of the Sunday Social Riders Motorcycle Club. Every year they run a charity Poker run and this year the club asked Murray if Crohn's and Colitis New Zealand would like to be the benefactor, because Murray's daughter Sophie has been affected by Crohn's disease for a long time.

As a parent and supporter of Sophie, Murray's goal is to raise awareness of Crohn's. Ninety seven bikes and five hot rods turned out for the charity run. Here is a picture of them presenting us with the cheque!



Your Health - Fatigue

(This article appeared in the Spring Issue of NACC News (Crohn's and Colitis UK). Fatigue is a leading concern for people with IBD, but currently it is poorly understood.

Although many research articles describe the physical impact of IBD, they do not report on people's experience of living with it, and how symptoms affect their lives. There is little evidence to support interventions that result in IBD-fatigue being poorly managed. There is also a need for greater awareness of the issue among healthcare professionals.

Researchers Wladzia Czuber-Dochan, Prof Christine Norton and Prof Emma Ream, who work on the Big Lottery Fund Project, have recently looked at previous research conducted on fatigue and IBD.

They wanted to explore the prevalence, causes and severity of IBD-fatigue and assess the fatigue management methods used by patients and healthcare professionals. Twenty-one papers were included, but none of these reported exclusively on fatigue experienced by people diagnosed with IBD. Nor were there any studies that researched peoples' needs or expectations in terms of managing IBD-fatigue by healthcare professionals.

Fatigue prevalence was 36-41% for patients in remission and 86% for patients with active disease. Numerous physical (e.g. gender, disease activity, disease duration, number of relapses, sleep disturbance, anaemia), psychological (e.g. anxiety, depression, social functioning) and situational (e.g. ability to work, achieving full potential, social support) factors associated with fatigue were identified. One study reported on stress management and self-directed stress

management programmes. The self-directed stress-management group showed a small but significant reduction of fatigue after treatment and was maintained after one year.

The researchers concluded that IBD-fatigue has a negative impact on individuals' physical and cognitive performance, resulting in a reduced quality of life. Inconsistent use of terminology and definitions of IBD-fatigue indicate the future research should explore experience of IBD-fatigue from the individual's perspective. The long-term consequences of IBD-fatigue and its prevention and management have not been studied.

Their research will be submitted for publication in an academic journal where further detailed information on the findings will be included. The overall projects will run until July 2014, and the next stage of the project involves developing an IBD-fatigue questionnaire.



Clinical trials

Study – Drug Trial	Participation criteria	Where
Osiris Study	Have severe Crohn's disease not responding to or intolerant of adalimumab or infliximab.	Christchurch Waikato
Andante Study	Have severe Crohn's disease not responding to or intolerant of adalimumab or infliximab.	Christchurch Waikato Wellington
Octave Study (oral medicine)	Have moderate to severe Ulcerative Colitis. (Commences Jan – Feb 2013)	Christchurch Wellington Waikato Auckland
Uniti Study	Have moderate-to-severe Crohn's Disease (CDAI 220+). Uniti1: Must have failed or are intolerant to TNF Antagonist Therapy, i.e. did not respond initially (primary); responded initially but then lost response (secondary) or were intolerant to the medication (significant infusion or injection site reaction or delayed reaction). Uniti2: Must have failed conventional therapy, i.e. are currently receiving corticosteroids and/or immuno-modulators, i.e. AZA, MTX, or 6-MP at adequate therapeutic doses; has a history of failure to respond or tolerate the above drugs and/or a history of corticosteroid dependence and has not previously demonstrated intolerance to anti-TNF's (i.e. due to injection or infusion reactions but inadequate response due to headaches, development of PSA and neurologic reactions OK).	Dunedin Christchurch Wellington Auckland
CCX – anti CCR9 antibody therapy	Have moderate-to-severe Crohn's Disease (CDAI 220+). Must be non-responsive, intolerant, etc. to standard medical treatments (corticosteroids and immunosuppressants). Must have had exposure to Infliximab and Humira.	Dunedin
Shield Study	Must be 18 years of age or older and have been diagnosed with Crohn's disease for at least 4 months. Have not responded to, are intolerant of, or stopped using corticosteroids or immunosuppressants. Cannot have coeliac disease or ulcerative colitis.	Dunedin Hutt Valley Health Auckland
Millennium Study	Enrolling complete.	Dunedin Christchurch Wellington

If you wish to participate in any of these trials, please contact your physician.

Risks and benefits

Worried about being struck by lightning? – Well, don't be because there is only a one in 80,000 chance of it happening. However, there is a one in 261 chance of being killed in a car accident. So how do we decide how much risk is associated with our actions? Just How much risk are we prepared to take?

Risk is defined as the chance or possibility of danger or adverse consequences. Therefore, when we are taking a medication we need to know how big the risk of side effects is compared to the benefit.

People often seek information from the Internet, where there is an emphasis given to the risks, rather than the benefits of medications. In addition the way numbers are presented can be confusing, for example:

“There is 33% chance of gastrointestinal intolerance” is ambiguous and could be interpreted like this - “Patients will have GI intolerance in a third of doses” or this - “Each dose will be partly not tolerated and mostly tolerated” or even this - “A third of all patients will not tolerate all drugs”

What it really means is this - “Out of every three people taking this drug, one person will develop gastrointestinal upset”

The level of risk associated with side effects for a medication is defined by frequency: very common, common, rare or very rare. This chart defines these terms visually and makes it much clearer.

Dr John Wyeth recently gave a presentation at our National Support Groups meeting in Wellington to give a better understanding of the actual level of risk there is associated with some of the medications prescribed for Crohn's and colitis.

He specifically addressed the increase in risk of cancer due to patients receiving combination therapy of an anti-TNF and an immune-modulator, and informed us that this side effect is rare.

Non-Hodgkin's lymphoma is a rare side effect from taking combination therapy for Crohn's. To help clarify have a look at this illustration (L).

This shows that the risk of developing non-Hodgkin's lymphoma from taking combination therapy is 6 in 10,000 people taking the medication (not 6 in every 10,000 people living in New Zealand).

This means that 9,994 out of 10,000 people receiving treatment will not get non-Hodgkin's lymphoma.

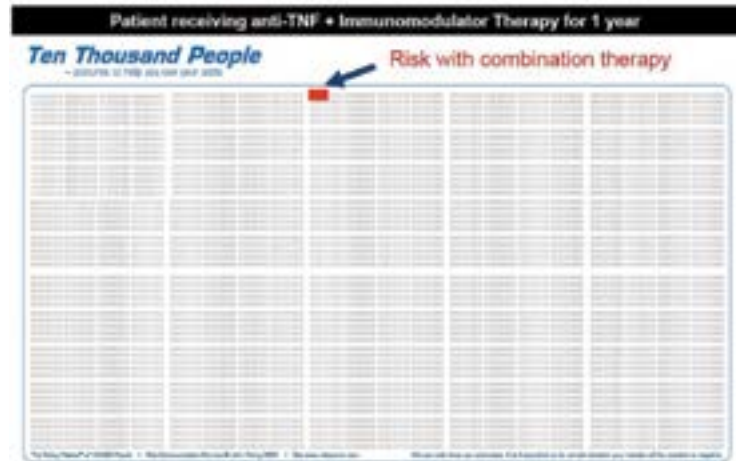
Now there are the risks associated with having uncontrolled IBD. If IBD is not controlled it usually leads to surgery for Crohn's disease

- Within 1 year of diagnosis four in ten people will require surgery
- Within 5 years of diagnosis five in ten people will, and
- Within 20 years of diagnosis eight out of ten will require surgery

The likelihood of surgery (colectomy) for ulcerative colitis within 20 years of diagnosis is 20%.

Therefore, we have to decide for ourselves the risks of treatment, versus the risk of untreated disease.

Risk of Developing non-Hodgkin's Lymphoma



Ngel CA, et al. Clin Gastroenterol Hepatol 2009;7:674-81

Very Common
occurs in more than 1 in 10 people. More than 10% are likely to get this side effect.

Common
occurs in up to 1 in 10 people.
8 out of 10 are unlikely to get this side effect.

Uncommon
occurs in up to 1 in 100 people.
99 out of 100 are unlikely to get this side effect.

Rare
occurs in up to 1 in 1,000 people.
999 out of 1,000 are unlikely to get this side effect.

Very Rare
occurs in up to 1 in 10,000 people. 9,999 out of 10,000 are unlikely to get this side effect.

Students find Nelson link on Crohn's disease

Professor Richard Gearry of Otago University's Christchurch campus supervised a summer research project by two medical students from Nelson has discovered that the Nelson region has one of the highest rates of Crohn's disease yet found in the world.

Gabrielle Kemp and Peter Meffan spent 10 weeks analysing data compiled over a decade by Nelson gastroenterologist Darryl Fry and specialist nurse Belinda Heaphy, who oversee the care of nearly 500 inflammatory bowel disease patients in the Nelson region.

Their findings are in line with a similar project in Christchurch and a third in Geelong, Australia over recent years. Read this article on Stuff for further details - <http://www.stuff.co.nz/nelson-mail/news/8218363/Students-find-Nelson-link-on-Crohns-disease>

Annual National Support Group Meeting

We held our second very successful annual national support groups meeting in November in Wellington, which was attended by co-ordinators from around the country. This year the delegates all got home in good time – and were unaffected by the snow which last year meant that Mary from Invercargill took three days to get home.

The meeting was a combination of workshops and presentations. Speakers included Sheridan Bruce from Fresco Design who very generously facilitated a session showing groups how to use the website, and Vicki Beban, ostomy nurse specialist from Hutt Valley Health. Sarah Elliot from Food Savvy took delegates on a supermarket

tour – reading labels and discussing gluten free and FODMAPS diets in a live setting.

It was great to involve many of our delegates, sharing their experiences and talking about highlights of their year and issues affecting small groups.

We were delighted by the tremendous support for the meeting from our partners, with education grants from Abbott and Ferring Pharmaceuticals. Products and samples were generously supplied by Whittaker's Chocolate and Harraway's (delicious little single serve of their porridge). Thank you all for your generous contributions.



Left-Right: Mary Rae - Southland, Henriette Rawlings and Jo O'Leary - Otago

Are you thinking about making a Will?

Your family is always your first priority, but it is possible to both the people you love and Crohn's and Colitis New Zealand. You can help us make a positive difference to people with Crohn's disease and ulcerative colitis, their families, friends and carers, and secure for them a Future Free of IBD.

Your gift will help support our mission to provide information, education and support to people living with IBD and fund the vital services that we provide.

We recommend you seek professional advice from a solicitor to ensure your bequest is clear and legally stated.

If you would like further information - in the strictest confidence - about making or updating your will, please contact us via info@crohnsandcolitis.org.nz or phone Julia Gallagher on 04 972 3149.

Around the regions

It has been a busy year for all our wonderful volunteers around the country who have organised support meetings and events (ten-pin bowling in Auckland earlier this year) for their members. CCNZ relies heavily on the work and goodwill of these people who devote so much of their personal time to promoting our cause and provide much needed support. A big thank you to everyone from Northland to Southland, and all points in between.

We know how valuable these meetings are, as it is so important for people to know there is someone nearby who understands what they are going through, to offer information and support.

Your local support group has access to Crohn's and Colitis New Zealand facilities and resources including feedback from our medical advisors, and links with other IBD organisations around the world. Go to the support section of www.crohnsandcolitis.org.nz for contact and meeting details of your nearest group.

Crohn's and Colitis New Zealand has held four community meetings this year, in Christchurch, Hamilton, Invercargill, and Palmerston North. It was a real pleasure for Brian, our chairman, and I to get out and about. This photo was taken at the inaugural Waikato Support meeting held in July, which was attended by 80 people, including several families, all eager to hear Dr Tony Smith speak.



Dr John Wyeth of Wellington - a long lost Southlander and trustee of Crohn's and Colitis New Zealand - spoke at the Southland meeting in August. As the doctor who attended 'Happy Feet' the penguin at Wellington Zoo, John created a great deal of interest at the meeting.

I had the opportunity to tick off one of the items on my bucket list – a visit to Bluff and here is the photo to prove it!



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
PO Box 22280
Khandallah
Wellington 6441

 info@crohnsandcolitis.org.nz



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

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

Crohn's & Colitis NZ
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 Wellington 6441.

Please do not send cash.

Thank you for your donation

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Donation amount (\$):

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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

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

