



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.

Ports of Auckland Round the Bays Fun Run - Sunday 9th March 2014

Sunday 9th March 2014 saw a team from Crohn's & Colitis New Zealand participate in the Ports of Auckland Round the Bays Fun Run for the first time. The day dawned fine and luckily overcast early on for the start of the race with Helen Millar from the Auckland Crohn's Colitis Support Group and helpers on site at Madill's Farm, bright and early setting up a shady gazebo decked out with IBD balloons and complete with purple beanbags.

We welcomed some of our runners and supporters with cold drinks, sandwiches, muffins, doughnuts and fruit, people coming in steadily through the morning into the lunch hour

– the site is still some walking distance from the finish line so not everybody understandably made it over after their efforts in covering the 8.6km from the start.

Belinda Brown and her friends arrived dressed in purple tutus and T shirts emblazoned with a suitably descriptive slogan, having completed the run determined to cross the finish line whatever the challenges along the way. Her parents Des and Lynette were there to support her and understandably proud of their daughter's efforts.

The Banana man aka the CEO from Produce Delivered came



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CCNZ Children's/Teen Camp

The first NZ camp for children and teenagers with Inflammatory Bowel Disease will be held in early 2015, thanks to money granted and donated as a result of the 2014 Ports of Auckland Fun Run held in March.

Internationally these camps have been held extremely successfully on a regular basis by our sibling organisations in the IBD World. We are fortunate to have been joined recently on the CCNZ Board by Dr Richard Stein, a gastroenterologist at Hutt Valley hospital who was involved in the USA with these camps. In the Seattle area where Richard was based, the camps were run for children from age 7 to 18 years of age, over a 6 day period. Medical staff, camp counsellors and support volunteers were involved in the running of the camps, for groups of up to 100.

A sub-committee of the Board has been set up to organise the running of our first camp and offers are already coming in to assist with this, from both those who can help on a medical and voluntary support basis. The venue will be Camp Adair in Papakura, Auckland which is situated on a large site

with native bush by the Wairoa River and near the Hunua Ranges. The main lodge has been booked for the camp from the 25th to the 30th January 2015. Camp Adair offers a large range of on-site activities including such things as raft and bridge building, a confidence and ropes courses, abseiling,



Round the Bays Fun Run Continued from Page 1

by to have his photo taken, ten year old Charlotte ran the course with her mother, former Auckland President Sue Steed arrived, Bronwyn Stark dropped in for a chat, the North Shore Hospital Gastro staff entered a team, the Rama and Ranchod families entered as a team to support Karishma, and we spoke with many others who called by to say they had donated money to our cause as part of their run.

All in all over 150 people ran on our behalf and/or donated money with in excess of \$3400 raised for CCNZ (a staggering \$1625 of that by Belinda Brown and her accompanying tutu wearing friends) in



addition to the \$25,000 we will receive as a benefiting charity, from the race.

Thanks to the efforts of all these people and others including those who helped with race bib collection at Sky City on the Saturday, a camp for children and teenagers with inflammatory bowel disease is now a reality. On behalf of the CCNZ Board and Support Groups across the country I would like to say how humbled we have been by the courage, commitment and support shown to this cause, through this event.

Such generosity of spirit will ensure that young people with IBD in New Zealand will be given the opportunity to build confidence, independence, self-esteem and resilience and develop mutual support networks with their peers from around the country, in the first NZ camp of this type to be held from the 25th to 30th January at Camp Adair in Auckland. Thanks must also go to the staff at PR Partners, to the Auckland Crohn's Colitis Support Group headed by Helen Millar, to Chanelle and our Facebook supporters, to Charlotte, Brian and Julie in "head" office at CCNZ, who worked hard to make our participation in this event possible and to achieve such a successful result.

Teen Camp Continued from Page 1

a flying fox and high swing, archery, kayaking, air rifles, orienteering and a mudslide. Fully qualified instructors provide an experiential learning experience involving team and personal development and an experience of the outdoors through challenge by choice.



The camp's broad objectives would be to enable young people to build confidence, independence, self-esteem, resilience and empowerment in a safe, supportive, patient specific, therapeutic peer group environment, resulting in an enhanced knowledge of IBD, self and peers, and the development of mutual support networks.

An application process to attend the camp will shortly be developed. CCNZ will work with Support Groups and medical staff throughout the

country to publicise the camp. Further details about the process will be available in due course through the website, newsletters, and Facebook. In the meantime if you are interested in coming to, or helping with the camp, please contact Charlotte at CCNZ at info@Crohnsandcolitis.org.nz and she will pass your details onto the sub-committee.



A Great Conference!

On March 1st and 2nd we proudly hosted our third annual Support Group Conference here in Wellington, a unique opportunity to bring together our support group community from around New Zealand.

Our Patron, Her Excellency Lady Janine Mateparae, was unable to attend the conference but sent her apologies and best wishes and is looking forward to knowing how it all went.

Every year we are very fortunate to have a number of experts in their respective fields participate in our conference, and this year was no exception. Gastroenterologists, Nurses and other healthcare professionals shared with us their expertise and topic knowledge. Their invaluable contribution and willingness to share their insights resulted in our very successful presentations and weekend.

The wide range of topics covered issues, relating to the physical, social and psychological side effects of Inflammatory Bowel Disease, highlighting the latest concepts in the diagnosis and treatment of IBD.

Conference Highlights

- Complementary and Alternative Medicine - proved to be a hot topic at this year's conference!

Complementary and Alternative Medicine (CAM) encompasses many different therapies such as Herbal remedies, Probiotics, Fish Oil, Aloe Vera, Acupuncture, Hypnosis, Yoga and Meditation.

Their use among patients with inflammatory bowel disease is becoming increasingly more common, in fact many people with Crohn's disease, have used some form of alternative or complimentary therapy. Doctors are embracing CAM therapies, too, often combining them with mainstream medical therapies – spawning the new term “integrative therapy”.



A key component of this topic was 'Probiotics', its place in the treatment of IBD and how the use of this natural bacterium could potentially help mitigate the symptoms of Crohn's. Chris Budgen offers over 30 years' experience in Pharmaceuticals and gave us an insight into the beneficial health effects of this “good bacteria” that can boost your immune system, improve your digestion and much more.

Probiotics are live microorganisms that are believed to play very important roles in regulating proper intestinal function and digestion – by balancing intestinal microflora.

Élie Metchnikoff first suggested the possibility of colonizing the gut with beneficial flora in the early 20th century.

Andre Prassinis who is the co-founder of BioBrew, a Rotorua company that specialises in making microbial products for the agricultural sector has been working on creating a probiotic product for human health. Andre and Chris share a common passion; that probiotics will play a positive role in the treatment and management of Crohn's disease.

Side effects and ineffectiveness of conventional therapies are often primary reasons for seeking alternative care. For many people CAM therapies offer a safe, natural approach to treatment. Studies from a decade ago reported that up to 50 percent of patients with IBD have used alternative therapy.

Hypnotherapy has long been used to help people cope with stress. No matter what the source of stress is, hypnosis is a relaxation technique that calms the body and mind into a deeper state of relaxation. Dr. Patrick McCarthy; an internationally recognised and medically trained hypnotherapist gave a fascinating discussion on how these relaxation techniques can be very helpful in reducing the symptoms of Crohn's disease by decreasing stress, increasing relaxation, and easing the feelings of anxiety.

- Vitamin D

Following on from the previous discussion about CAM therapies – PhD Student (Massey University) Hannah Morton is conducting a study that looks at the link between inflammatory bowel disease and Vitamin D. “Higher levels of vitamin D are not only good for your bones, but they also help boost your immune system and are believed to reduce disease, reduce disease activity, decrease the risk of Crohn's disease and reduce levels of inflammatory markers. Vitamin D promotes good health and overall well-being.

- Psychological Factors in IBD

Inflammatory bowel disease doesn't just affect you physically – in fact Crohn's disease and Ulcerative Colitis affect virtually every aspect of a person's life so understandably it takes an emotional toll as well. Coping with the physical symptoms of a chronic disease such as inflammatory bowel disease can be very challenging. IBD not only causes pain, but symptoms such as diarrhea and gas that are difficult to deal with in professional and social situations.

PhD Student (Otago University, Christchurch), Andrew McCombie, discussed the day-to-day challenges faced when you live with a chronic disease such as inflammatory bowel disease and the increased risk of mental health conditions like anxiety and depression.

- IBD in America

Dr Matthew Cohen is a visiting Gastroenterologist from America who has been working at Wellington Regional Hospital and Kenepuru Community Hospital since July 2013.

While working as a gastroenterologist in New Haven, Connecticut, Matthew was formally recognized by his peers for providing exceptional care to patients and exceptional teaching to medical trainees.

Over his 15-year career in the States, Matthew directed a hospital-based gastroenterology clinic,



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a community-based private gastroenterology group and a medical research center.

We were very fortunate that Matthew could join us at our conference to share with us his insights into IBD in America, covering all aspects including Diagnosis, Treatment, Surveillance, Research and Resources.



Other topics included...

- IBD Nurse Specialist and Viva Nurse Specialist and their role in managing IBD
- The first New Zealand-based camp for teenagers with IBD
- Insurance options for IBD patients
- The launch of our new 0800ASKIBD number

It was certainly inspiring to hear all about the great work being done and there is nothing more powerful than when this community comes together to share ideas, stories, and hope.

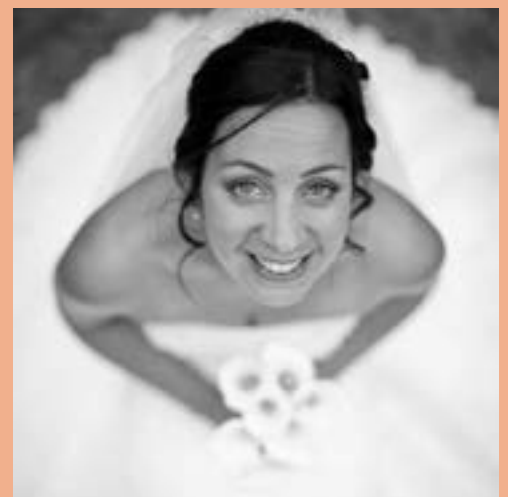
Our support groups, across New Zealand, do a remarkable job and offer fellowship in a community of people who understand what you are going through and share your concerns. Loneliness can be a terrible side-effect of a chronic disease but it doesn't have to be. Don't let IBD isolate you from other people.

These support groups are run by people with IBD for people with IBD. They provide support, information, meetings and services for their local community. For more information, or to find a support group nearest to you please visit our website cohnsandcolitis.org.nz and look under support.

Comings and goings - Welcome to our new Trustees

Welcome to our two new board members, Dr Richard Stein, Gastroenterologist, Hutt Valley DHB and Lisa Griffiths, Clinical nurse specialist, IBD at Wellington Hospital, Capital Coast DHB Health Board. We will welcome their expertise and dedication to IBD patients.

Below left is a picture of Dr Richard Stein and Mike McCready backstage at Auckland's Big Day Out. Mike is the lead guitarist for Pearl Jam and has Crohn's Disease. You can find about him online. Dr Stein talked to Mike about the CCNZ Teen Camp next Summer and he was very excited about it and offered us signed memorabilia to support the camp, so watch this space.



Congratulations to Lisa on her recent wedding. Here she is!

We also said farewell recently to Julia Gallagher, our former CE, at the end of 2013 and thanks go to her and best wishes for her future.

Laboratory tests - Faecal calprotectin

You may have heard about a test that is relatively new called a stool or faecal calprotectin level. It is a test that measures a protein called calprotectin in the stool.

What is calprotectin?

Calprotectin is a protein that is found in white blood cells, the cells that are involved in causing inflammation in the body. Since there is an increased number of white blood cells in the intestines of people who have active IBD, measurement of the stool calprotectin level can be used as a marker of inflammation.

How good a test is it?

Calprotectin is a very good marker of inflammation, but, like any test, there can be false negative and false positive results. In one study in patients with Crohn's disease, however, it correlated much better with the inflammation seen on colonoscopy than some of the tests that we currently use like the CRP and the Crohn's Disease Activity Index (CDAI).

How can the test be used?

Some people propose that it can be used as a screening test in people with symptoms suggestive of IBD (such as diarrhoea and abdominal pain) to determine if they should undergo a colonoscopy (particularly in children in whom we might want to avoid doing the procedure). Others have suggested that it can be used as an objective measure (rather than relying on symptoms alone) to see if people are responding to their medications.

Are there conditions other than IBD that can cause an elevated calprotectin level?

Yes. Calprotectin levels can be raised in ANY condition which causes intestinal inflammation (such as infections).

Is the test accurate?

While the cutoff for a normal test is <50 mcg/g stool, there is a "gray zone" where higher levels may or may not be significant. A very high level (>500) correlates very well with active inflammation.

How you do the test?

It is very simple. You just have to bring in a stool sample (you only need a few grams). Calprotectin is very stable so the specimen does not need to be refrigerated or brought immediately to the lab.

Is it expensive?

It costs about \$150, but price varies from lab to lab. Most DHBs cover the test.

How come I never had the test done?

This is just one test that doctors can use, but it cannot replace a thorough history and physical examination. In most situations, it is not a necessary test to determine the best treatment, but it may have a place in the situations mentioned above. As usual, more studies need to be done to best determine how to use this test.

A new drug on the horizon

By Dr Liz Forbes-Blom, PhD, Malaghan Institute

Immune cell migration into an organ such as the intestine is a tightly regulated process, involving a network of chemical messengers and cell adhesion molecules. The chemical messengers instruct the immune cells to migrate into the intestine and the cell adhesion molecules allow them to get in.

These cellular adhesion molecules do so by interacting with a ligand specific to the intestine. So, the cell adhesion molecule is like a key and its ligand is similar to a lock.

In the intestine, the integrin 'key' is called alpha-4 beta-7 (also known as $\alpha_4\beta_7$) and the ligand or 'lock' is mucosal addressin cell adhesion molecule 1 (or MAdCAM-1 for short).

Just like the key/lock analogy, each integrin is specific for its ligand. Therefore, the ability to interrupt the migration of inflammatory cells by targeting the specific key is highly desirable, as this generates very precise intervention at the site of inflammation.

Vedolizumab is an antibody that targets the intestine specific integrin $\alpha_4\beta_7$, effectively preventing it from being able to 'unlock' intestinal inflammation. Excitingly, the results from the phase III clinical trial of Vedolizumab have shown this antibody to be effective both in the reduction and in the maintenance of remission of ulcerative colitis. Specifically, 47.1% of patients on Vedolizumab compared with 25.5% on placebo showed a clinical response at week 6 of the induction regimen, and 16.9% compared with 5.4% were already exhibiting clinical remission at that time point [1]. Maintenance treatment with 4-weekly

Vedolizumab resulted in 44.8% of patients being in remission at the 52-week time point compared with 15.9% on placebo [1].

The results from the Crohn's disease trial were also very hopeful. The primary endpoint of clinical remission at 6 weeks was not reached, however, there were significantly more patients on Vedolizumab in clinical remission at this time point compared with placebo-treated patients [2]. This included 39% on 8-weekly Vedolizumab, 36.4% on 4-weekly Vedolizumab, as compared to 21.6% on placebo were in clinical remission at week 52 [2].

There are many possible explanations as to why Vedolizumab was so remarkably effective as a therapeutic for the ulcerative colitis trial, yet did not reach clinical remission at 6 weeks during the Crohn's disease trial. These include different kinetics of therapy in Crohn's disease compared with ulcerative colitis, or the possibility $\alpha_4\beta_7$ integrin might be required for immune cells that drive remission of Crohn's disease to also migrate to the intestine.

Further studies are warranted to fully understand what is going on.

- 1 Feagan, B. G., Rutgeerts, P., Sands, B. E., Hanauer, S., Colombel, J. F., Sandborn, W. J., Van Assche, G., Axler, J., Kim, H. J., Danese, S., Fox, I., Milch, C., Sankoh, S., Wyant, T., Xu, J. and Parikh, A., Vedolizumab as induction and maintenance therapy for ulcerative colitis. The New England journal of medicine 2013. 369: 699-710.
- 2 Sandborn, W. J., Feagan, B. G., Rutgeerts, P., Hanauer, S., Colombel, J. F., Sands, B. E., Lukas, M., Fedorak, R. N., Lee, S., Bressler, B., Fox, I., Rosario, M., Sankoh, S., Xu, J., Stephens, K., Milch, C. and Parikh, A., Vedolizumab as induction and maintenance therapy for Crohn's disease. The New England journal of medicine 2013. 369: 711-721.

0800 ASK IBD

We are here to help!



We have made it easier for you to contact us!

CCNZ is very excited about the recent launch of our new 0800ASKIBD number. We are here to help and support you the best we can and are proud to offer you this service for general Crohn's & Colitis related enquiries. You can still contact us by email, online enquiry form, and post and you can now call us from anywhere in NZ without the worry of how much the call is costing you, including from a mobile phone.

For a general enquiry about Crohn's & Colitis and our services please call 0800ASKIBD. We welcome you to leave us a message and we'll always undertake to respond quickly and efficiently to your question or request.

Should you require medical assistance or attention then we encourage you to contact Healthline, a free 24x7 health advice helpline.



World IBD Day - Diet and wellness

This is the national theme for World IBD Day on May 19th this year. See your local support group for more details about what your local area is proposing to do to mark our national day.

Diet

For those of you interested in pursuing diet ideas, there is more information available now on diet possibilities that may either improve the extent of disease or your symptoms. Diet benefits seem to vary for each person and what works for some doesn't always work for others. But it might be the case that eating a bit more of the foods that are common recommendations of both of the two main diets talked about in the IBD space could help symptoms.

- The CCNZ website has a video of Professor Lyn Fergusson's recent presentation to the Wellington Support Group on foods that can reduce inflammation. See <http://crohnsandcolitis.org.nz/>
- Food choices low in FODMAPS can help some patients especially if they also have irritable bowel syndrome. The foods to eat and foods to avoid in this diet are now on the internet – see

<http://stanfordhospital.org/digestivehealth/nutrition/DH-Low-FODMAP-Diet-Handout.pdf>



Clinical trials

The clinical trials currently recruiting in New Zealand are listed on the website of the Ministry of Health and the Health Research Council of New Zealand - <http://clinicaltrials.health.nz/>

It is very important to talk to your doctor if you might be interested in joining a trial, but those on the Ministry of Health website include the following:

Crohn's disease

- PF-04236921 In Subjects With Crohn's Disease Who Are Anti-TNF Inadequate Responders (ANDANTE) – estimated study completion date February 2015
- Ustekinumab Induction Therapy in Subjects With Moderately to Severely Active Crohn's Disease (UNITI-2) – estimated study completion date June 2014
- PROCHYMAL® (Remestemcel-L) Intravenous Infusion in Subjects Who Have Received Previous Remestemcel-L Induction Treatment for Treatment-refractory Moderate-to-severe Crohn's Disease - estimated study completion date June 2014

- PROCHYMAL[tm] (ex Vivo Cultured Adult Human Mesenchymal Stem Cells) Intravenous Infusion for the Induction of Remission in Subjects Experiencing Treatment-refractory Moderate-to-severe Crohn's Disease – estimated study completion date December 2015

Ulcerative colitis

- Various trials for Oral CP-690,550 (tofacitinib) (OCTAVE)
- Study to Evaluate the Long-term Safety of rhuMAb Beta7 in Patients With Moderate to Severe Ulcerative Colitis
- Efficacy and safety of RPC1063 in Ulcerative Colitis Receptos trial

For more information

- Talk to your doctor
- the <http://clinicaltrials.health.nz> website links through to U.S information
- There is other worldwide information about the trials, and the results and approval status of the drugs so far, on the internet.

Negotiating the health system

Some people find it hard to access the healthcare that they need. Here are some options that might help you to navigate the system:

- You can ask your GP to refer you to a hospital specialist if you are not under specialist care at the moment.
- If you are under specialist care, ask your specialist what is the best way to contact him/her if you are having problems.
- If you have been diagnosed with IBD and your DHB has an IBD nurse, you may be able to contact them for help. See the contact details on the CCNZ website of some of the IBD nurses connected to our support groups
- DHBs and doctors often have different treatment preferences. Last year, PHARMAC set standard nationwide guidelines for access to medicines. Ask your doctor whether your medications are the best ones that are currently funded
- Hearing from other patients might help. The FACEBOOK page linked from the CCNZ website offers a wide range of patient experiences, and something there may give you ideas of what might be worth investigating
- Patients with IBD sometimes underestimate how sick they are. If you are very ill, it might be time to consider going to the Emergency Department of your hospital
- You could ask your doctor for a letter to help you get through Emergency Department quickly if you often get stuck there
- Colonoscopies for IBD assessment should be done within 6 weeks, under 2012 national referral criteria for outpatient colonoscopies. Some DHBs may be struggling to meet these targets, but that is no reason not to pursue a timely colonoscopy if one is needed
- Similarly, there are target times by which DHBs are supposed to provide surveillance colonoscopies for IBD patients with a greater risk of colorectal cancer (eg after 10 years with

ulcerative colitis or Crohn's colitis). Talk to your doctor about surveillance colonoscopies

- There are new processes now for sharing your patient information amongst the various people in the medical team who look after you. Talk to your team if there seems to be difficulties getting everyone on the same page
- Patients being cared for in the private system sometimes get different treatment options than patients in the public system, and not necessarily better treatment, so it is sometimes worth investigating
- You can always ask for a second opinion
- Your hospital also has information on patient rights.
- See the patients' IBD Handbook on the CCNZ website for more advice.

Employment issues

Work issues were rated as one of the highest of member concerns in 2010, as working and having IBD can be difficult for some people.

The Government promised before the 2011 election that any employee will be able to ask for flexible working arrangements, in the same way that caregivers can at present (although the employer will not have to necessarily agree). The Government bill to implement the promise has now emerged from select committee, so watch this space.

Did you know that New Zealand has one of the HIGHEST rates of Inflammatory Bowel Disease (IBD) in the World!



The Institute of Food, Nutrition and Human Health at Massey University is conducting a nationwide study to investigate IBD risk factors specific to New Zealand



WHO CAN TAKE PART?

We are looking to recruit individuals aged 16 years and over with a confirmed diagnosis of Inflammatory Bowel Disease (Crohn's Disease, Ulcerative Colitis, or Indeterminate Colitis); and healthy controls (those who do not have Inflammatory Bowel Disease)

WHAT DOES THE STUDY INVOLVE?

- Completion of a questionnaire (all participants)
- Vitamin D measurement (optional)
- Skin tone measurement (optional)

If you are interested in participating in this study, or would like more information please:

- Register your interest at www.massey.ac.nz/IBD
- Email IBD@massey.ac.nz
- Call 0800MASSEY and ask for extension 83076
- or Text 027 681 7557

THE ENGINE OF THE NEW ZEALAND

COMMITTEE APPROVAL STATEMENT: This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern A, Application 13/06. If you have any concerns about the conduct of this research, please contact Dr Brian Finch, Chair, Massey University Human Ethics Committee: Southern A, telephone 06 350 5759 x 84359, email humane@hicsoutha@massey.ac.nz

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



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



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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

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

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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

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

