

*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.*



## 'Join the Fight against IBD' exhibition

**S**ome opportunities only come once in a lifetime and our evening at Parliament launching the New Zealand IMPACT survey results together with our 'Join the Fight Against IBD' exhibition was one of those rare occasions.

We had the most wonderful evening at Parliament in early July hosted by Scott Simpson, the MP for Coromandel. We also announced that Her Excellency Lady Mateparae had agreed to become Patron for Crohn's and Colitis New Zealand, an honour made particularly gratifying due for her very active interest in health and nutrition.

The Hon Todd McClay, Assoc. Minister of Health, acknowledged those affected by IBD in

his speech, saying "...it is crucial that we understand the impact of IBD – it is only 3 small letters but we cannot underestimate the significance of a disease for which there is no cure or no known cause.

Unfortunately, very few members of the public understand the pain and suffering associated with IBD or the courage needed to fight the disease every single day of their lives."

Following a presentation by Professor Richard Geary of his recent research from Nelson, our guests were able to view Sam Sword's photographic exhibition, which graphically depicts both the personal effects of the disease and illustrates the IMPACT results.

### IMPACT survey results

The IMPACT survey asked New Zealanders living with IBD about the burden of the condition across a range of topics, including relationships and daily life, as well as access to healthcare and services.

The New Zealand results reveal the need to improve standards of care with the findings indicating people are experiencing a delay to diagnosis and high emergency care requirements.

### Of people surveyed:

- 64% presented to emergency care more than once prior to diagnosis
- 57% have been hospitalised in the last 5 years due to IBD symptoms
- 51% are not in remission

The full results, in infograph form, are on page 5.

### In this issue

- ▶ CCNZ joins EFCCA: Page 2
- ▶ What is going on In my gut? Page 3
- ▶ Help needed for research: Page 3
- ▶ Impact results: Page 5
- ▶ Food for flares: Page 6
- ▶ Paediatric Gastro. Clinical Network Page 7



*Sam Sword's photos displayed at Parliament House*



*Scott Simpson MP, Julia Gallagher, Sam Sword, Lady Mateparae and Brian Poole*



## Well-deserved recognition

**B**rian Poole, our chairman, has been recognised in the Queen's Birthday honours list for services to health and the community.

Brian has a life-long commitment to service, through his church and Rotary. However, it is his endeavours to improve awareness and recognition of Crohn's and colitis (IBD) for which we are so grateful.

Brian was diagnosed with IBD as a young man approximately 40 years ago, so has seen many changes in the diagnosis, treatment, and management of IBD. He has always passionately believed that the disease has long lasting effects on people, quite apart from the day-

to-day aspects of physically coping with a chronic illness. Brian set up the Crohn's and Colitis Wellington support group approximately six years ago, and more recently the national organisation, Crohn's and Colitis New Zealand.

As the founding chair of Crohn's and Colitis New Zealand, Brian has established relationships with other Crohn's and colitis organisations internationally and represents our interests at government level.

He has overseen significant improvements in access to a range of medications in the three years since our inception, improved communications with medical professionals, and of course directed the development of a network of support groups throughout the country, to reduce isolation and improve awareness of these devastating diseases.

We thank Brian for his vision and commitment and congratulate him on his Queen's Service Medal, which is so well deserved.



## Crohn's and Colitis New Zealand joins EFCCA

(by Brian Poole, Chairman)

March 2013

I had the opportunity to attend the EFCCA General Assembly in Ljubljana, Slovenia earlier in the year, on the occasion of Crohn's Colitis New Zealand officially becoming an associate member of EFCCA; we join Argentina and Israel in that capacity. There are now well over 30 countries, predominantly from Europe, involved with EFCCA.

This association will keep us updated on international progress in the diagnosis, treatment and management of IBD. It will provide insights into patient support and access to professionally developed evidence-based tools. We also look forward to utilising promotional material that EFCCA develops each year for World IBD Day.

I was able to give a presentation on New Zealand (including a map of just where we are in the world) and what we hope to achieve from this new relationship to other member societies.

It was very clear from discussions that although we have a long way to go, we achieved much on our own in improving the lives of IBD patients, but it is also good to know we can embrace in a real way the EFCCA motto "United we stand."

## Vice-regal recognition

We are privileged to announce that Her Excellency Lady Janine Mateparae has offered her support of IBD and our cause, through her vice-regal patronage.

Lady Mateparae has a strong interest in health and nutrition, and is therefore particularly pleased to be involved with CCNZ.

Her support was announced at the "Join the Fight Against IBD" exhibition at Parliament, at which the results of the New Zealand IMPACT survey were launched, together with Sam Sword's photographs.



## Putting IBD on the agenda

**G**overnment 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. Equitable access to medications:

- We support a proposal relating to the establishment of a nationally-consistent list of pharmaceuticals to be funded within DHB hospitals, ensuring equitable access throughout the country.
- Improved access for Humira – fistulising Crohn's disease.

- We have provided feedback to a submission from Pharmac for mesalazine granules to be funded, under Special Authority restrictions, for patients who are under the age of 16 and unable to swallow tablets.
- We are currently preparing a submission in support of the paediatric gastroenterologists request to Pharmac to reconsider the subsidy for special foods, which they reduced in 2011.

### 2. Improved health services:

- Follow-up from a meeting with Health Workforce New Zealand indicates that currently no DHB is able to undertake a pilot study to evaluate the effectiveness of introducing IBD nurse specialists.

# New Zealand research in Crohn's and colitis - What is going on in my gut?

By Dr Liz Forbes-Blom, PhD, Malaghan Institute

**M**alaghan Institute gastrointestinal allergy and inflammation specialist Dr Elizabeth Forbes-Blom believes that management of the gut immune response is key to a healthy gut. She is using experimental models of gut inflammation to address the emerging hypothesis that immune dysfunction in the gut leads to altered microbiota, inflammatory bowel disease, food allergy and metabolic syndrome.

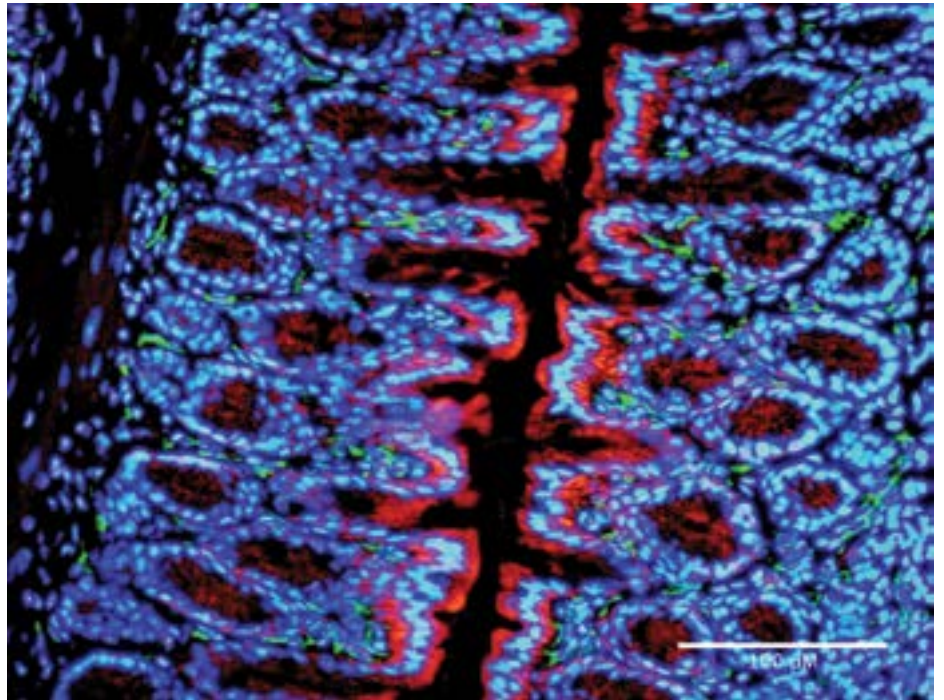
Taken together these findings will provide therapeutic targets for the prevention and treatment of gut allergy and inflammation.

The gut is a remarkable immunological organ. It learns to tolerate food antigens and commensal microbes that aid in digestion, metabolism and immunity, while retaining the ability to neutralise invading pathogens. Sometimes the immune system in the gut gets this balance wrong, and diseases like food allergy or inflammatory bowel disease (IBD) can occur.

At the Malaghan Institute, the focus of our research is to understand how these complex interactions between the host (that's you) and the commensal microbes can result in health or the development of disease.

Previous research we've done has demonstrated that production of the cytokine interleukin (IL)-25 is reduced in the inflamed gut of patients with IBD. More importantly, following successful treatment, IL-25 production was enhanced in IBD tissue. This suggests that IL-25 may play an important role in limiting inflammation in the gut.

We have recently discovered that IL-25 is critical for the control of appropriate immune education in the gut. The absence of IL-25 in mice results in significant immune deficiencies that are central to



the complex interaction between the intestinal immune system and the commensal microbes. These immune deficiencies result in a disturbance in the balance of commensal microbes, predisposing these mice to increased susceptibility to gut inflammation.

Our latest findings fit with the current thinking that IBD results from the interaction of several different factors. We now have a unique pre-clinical model of the convergence of these factors, which will allow us to test new approaches for the treatment and prevention of IBD. This is the first step in a very long road of medical research. My team is excited to be a part of this fight, in which we hope we can improve the outcome for people affected by IBD.

## Help needed - take part in a research survey

**W**e are delighted to assist Professor Anita Nolan conduct research into the oral health of New Zealanders with IBD.

Professor Nolan is head of the Oral Health Department at Auckland University of Technology.

We are inviting you to take part in this survey, we need 300 people. You must be living in New Zealand and have IBD.

There is increasing evidence that mouth problems, for example, mouth ulcers or cracks at the corner of the mouth, may be associated with IBD. Additionally, some people with IBD report dental issues. This



anonymous survey will help us to gain a greater understanding of the extent of oral health issues in people with IBD in New Zealand. Go to [www.crohnsandcolitis.org.nz](http://www.crohnsandcolitis.org.nz) to take part.

We want to hear from you irrespective of your oral health status, you don't need to have had problems. If you want one of our amazing purple 'join the fight against IBD' t-shirts we have three available to give away to the 100th, 200th and 300th respondents! You have the opportunity to leave your contact details at the end of the survey.

## World IBD Day - May 2013

*Pictures on page 4*

Raffles, cake stalls, eminent speakers and display stands – World IBD Day 2013 was busy, awareness raising and fun.

Local groups made great use of this year's 'toys' – balloons and more t-shirts. Another great poster made everyone's efforts stand out and attract people wanting to know more. It was very gratifying to have so many hospitals supporting us by having displays in their departments and many hospital staff got involved in raising awareness too. These links between support groups and their local hospital are important in providing a seamless continuum of care to support your recovery.



JOIN  
THE  
FIGHT  
AGAINST  
IBD



# JOIN THE FIGHT AGAINST IBD

## A LITTLE BIT ABOUT THIS SURVEY

IMPACT is a nationwide survey undertaken from May 2012 to April 2013, to reveal the impact of living with the chronic auto-immune disease IBD.

IMPACT was first conducted in Europe by the European Federation of Crohn's and Colitis Associations (EFFCA) in 2010 and was replicated in New Zealand using the exact same methodology and survey. The self-selection survey was paper-based and online and participation was voluntary.

The IMPACT survey is an initiative of Crohn's and Colitis New Zealand (CCNZ) and was supported by a grant from AbbVie.

### SURVEY POPULATION SNAPSHOT :

- Crohn's Disease (63%) was the most commonly reported type of IBD followed by Ulcerative Colitis (34%)
- The majority (65%) of respondents are female
- Young adults aged 25-34 years was the largest (23%) represented age group
- Just half (50%) of respondents are currently employed full-time



## EMPLOYMENT & EDUCATION



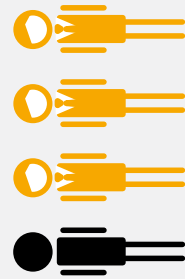
**41%**

agree their IBD has negatively affected their ability to perform to their full potential in an educational setting

*'I believe that IBD has negatively affected my career path, opportunities for advancement, income and/or earning potential'*

**45%**

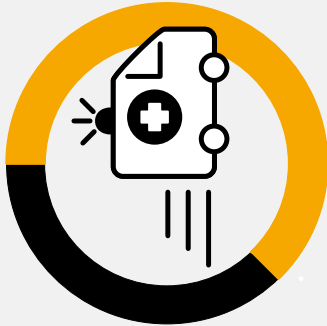
agree with this statement



**ONE IN FOUR**

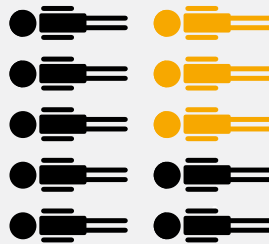
of those living with IBD have lost or quit a job due to IBD

## DIAGNOSIS



**64%**

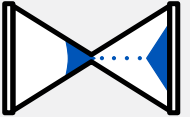
of IBD patients need emergency care before they are diagnosed



**SEVEN out of TEN**

with IBD waited longer than six months to be diagnosed

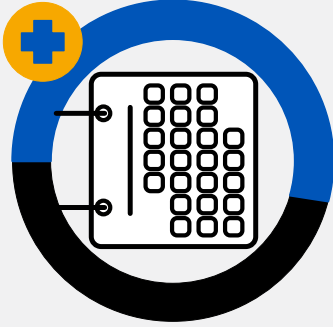
## ACCESS TO HEALTH



**SIX out of TEN**

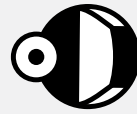
people with IBD waited more than 6 MONTHS to see a specialist after they were diagnosed

## HOSPITALISATIONS



**57%**

of people with IBD report they have been hospitalised in the last 5 years due to IBD symptoms



**49%**

of those with IBD have had surgery due to their IBD

## RELATIONSHIPS



**33%**

report IBD has prevented them from pursuing an intimate relationship

**TWO out of TEN**



people with IBD report their IBD has prevented them from making new and/or keeping friends

## DAILY LIFE



**51%**

of people describe their disease as not in remission



**43%**

of people with IBD report that they wake frequently from sleep due to their IBD



**36%**

with IBD keep a list of clean, accessible toilets



**52%**

of people with IBD say meeting someone with IBD made them more optimistic about the future

PROUDLY SPONSORED BY

abbvie

# Food for flares

(From CCFC booklet "Food for Thought")

If you are experiencing a flare you are probably feeling drained of energy. Fatigue and a general feeling of being unwell can aggravate your symptoms and prevent you from wanting to eat and drink.

Combined with the fact that IBD often reduces your body's ability to digest and absorb nutrients (such as protein, fat, carbohydrates, water, vitamins and minerals), you may be in danger of becoming malnourished or dehydrated.

If you are exhibiting some or all of the following signs, you may be suffering from general malnutrition or a specific deficiency of one or more nutrients because of your disease and your eating habits:

- Weight loss
- Interrupted menstrual cycles
- You bleed or bruise easily
- Skin changes, dull, dry hair and brittle nails
- Weakness and loss of muscle mass
- Changes to your eyesight
- Muscle spasms
- Mood alterations

Dehydration (or fluid loss) is also a very real possibility for people with IBD, due to diarrhoea. In addition to the fluid loss, your electrolytes (such as sodium, potassium, magnesium, calcium and chloride) may also be depleted. Aside from thirst and a dry mouth, symptoms of dehydration include:

- Fatigue
- Light-headedness

- Rapid weight loss over a period of a few days
- Decreased urine output (you wee less than normal)
- Stomach cramps

If you think you are suffering from malnutrition and/or dehydration, contact your physician right away. Ask for a referral to a registered dietitian and get started on the road to healthier eating.

During a flare you may want to modify your diet to avoid aggravating an already sensitive gut. Here are some tips to help you get through an acute episode of IBD:

## 1. Identify and Eliminate Trigger Foods

During this time, avoid the foods that are "triggers" for you. Triggers are food and drink that can cause increased symptoms such as abdominal cramps, bloating and diarrhoea; they are unique to each individual so there is not a specific list that will apply to everyone. We can tell you though, that many people find alcohol, sugar, caffeine, greasy foods and dairy products containing lactose to be fairly common triggers. Spicy foods may be a trigger for you; however some people do not find them to be a problem. Discover your individual triggers by keeping a Food Journal.

## 2. Eat Smaller Meals, More Frequently

During your acute episode, try eating small meals frequently during the day as this will be less taxing on your gut and will be easier for your digestion. Five to six meals a day are ideal. If you can make the midday meal your main meal (rather than the end of day) you may also find that food is better tolerated.

## 3. Safe Foods

"Safe foods", like trigger foods, are also unique to each individual. This group of foods is those that cause the least irritation for you and can help you ride out an acute episode by minimizing your gut's reaction during digestion.

Like trigger foods, you need to identify the foods that you are able to tolerate. In general though, many people find that the following foods are safe for them:

- White bread
- Herbal teas
- White rice
- Bananas
- Applesauce
- Eggs
- Meal supplements
- Chicken, turkey and other white meats



When your gut is really bothering you, some people find that the BRAT diet (bananas, white rice, apple sauce and toast) is a soothing solution.



## Around the regions

Crohn's and Colitis New Zealand assisted the Northland Support Group with their inaugural meeting in April. Dr Mark Lane from Auckland Hospital spoke to a large audience, answering a myriad of questions. It was great to see a number of health professionals attend too, improving their knowledge and supporting their patients.

Our support groups have held over 30 meetings throughout New Zealand in the last twelve months. The groups' leaders have been going to great lengths to involve wonderful speakers, presenting on fascinating topics. They have been attracting increasing numbers of people, but we are very mindful of the fact that younger people tend not to want to engage in this way. This is an issue we want to address and we welcome your input and suggestions on good ways to appeal to younger people with IBD. Either get in touch with your local group, or contact Julia at Crohn's and Colitis New Zealand.

# Paediatric Gastroenterology Clinical Network - report

(from The Paediatric Society Newsletter – July 2013)

**A**s the only paediatric gastroenterologist in the South Island, Professor Andrew Day has a formidable territory to cover, especially given his 0.5 University role. Andrew is tasked with setting up a gastroenterology outreach service to cover the South Island, from Nelson to Invercargill, catering to the complex needs of children with liver disease such as biliary atresia or previous liver transplant, and those with gut problems such as inflammatory bowel disease or coeliac disease. Andrew has also recently taken on a role as chair of the newly formed Paediatric Gastroenterology Clinical Network.

Paediatric gastroenterologists are thinly spread over all of the country, with just the one in the South Island and 4 serving the North Island. Given that the workload has rapidly increased as more and more children are diagnosed with increasingly complex gastroenterology conditions, it is unsurprising that the service was identified as vulnerable in the MoH Paediatric Tertiary Services Review in 2009.

The key initiative arising from this review was to establish a Service Improvement Program with goals to clearly identify issues affecting gastroenterology services around NZ. The service appeared quite variable around the country, and one of the first steps undertaken by Andrew and colleagues was to survey all DHBs about their management of gastrointestinal problems in children. Although the survey tool was not able to provide all the required details, Andrew notes that it showed big variations in DHB structure, service provision and pathways to tertiary services. The children in some smaller centres don't have the same access to specialist nurses, specialist dieticians and specialist allied health care as children in larger centres do. The survey also gave guidance by identifying a number of gaps in how service management processes are administered and where the inequities lie. The plan is to circulate the survey results back to DHBs shortly so that the providers can see how their service compares.

One result already arising from this has been to develop additional outreach services so that our Paediatric Gastroenterologists can provide support to paediatricians in the regions.

Until recently the Ministry of Health's business unit, the National Health Board was managing this network within their Service Improvement Plan. Since early 2013 the programme has been transitioned to PSNZ to be developed into a national Clinical Network. The key goal for this change is to support the on-going development of paediatric gastroenterology services in NZ. The clinical advisory group for this network includes NZ's five paediatric gastroenterologists, two general paediatricians, paediatric gastroenterology nurses and members of key patient groups. Since the Clinical Network was established in March, a number of work streams have been instituted and initial projects identified. One of these is the formulation of a national guideline for the management of inflammatory bowel disease (IBD) in children and youth. New Zealand is known to have high rates of IBD and around a quarter of patients with IBD are diagnosed as children. Another work stream is looking at guidelines for the management of biliary atresia, of which affects 15-20 infants each year [there are 15 – 20 diagnoses a year] in New Zealand.

The Clinical Network will then set up further initiatives and work streams to ensure that its goals are met and that the children of NZ have equity of access to high quality care and management.



## IBD no barrier to Nick

**N**ick Kennedy is 17 years old and is mad keen on golf. He's been playing since he was 14. A year later he got his first set of golf clubs and spent most weekends at the Otago Gold Club, leading to a significant drop in his handicap.

However, through the winter of 2011 Nick experienced his first symptoms of Crohn's disease and by the end of the year he barely had enough energy to complete a round of golf, and had to pull out of all other sports, basketball, swimming and cross country.

A diagnosis of Crohn's was made in January 2012, and with it came a huge sense of relief as medication improved his health to the point where he could join his school team on a trip to Melbourne for the World Schools Golf Challenge. By this time Nick had dropped his handicap to 18! Nick says that his golf was good, but not great, but the experience was amazing and he met some incredible people.

Nick's golf handicap is now 11 – and he took part in the World Schools Golf Challenge again this year, in Thailand. He says, 'I love golf, it has helped me through some really tough times, by giving me something positive to focus on.'

Crohn's and Colitis New Zealand was delighted to provide a grant to assist Nick with his travel costs.



## Stacey's story

**S**tacey Stewart is at Victoria University, volunteers at the SPCA and works part-time. She's busy, active and has ulcerative colitis. She recently took part in our media campaign, launching the results of the IMPACT survey. Stacey's story confirms the results of the survey.

Stacey says she'd had 'tummy problems' from the age of 13 years, but living in a regional town meant that her symptoms were not diagnosed and partially put down to stress. She wasn't referred to a specialist.

It was five years before she was admitted into hospital, malnourished, delirious and exhausted. In hospital a diagnosis of ulcerative colitis was made quickly, but following her hospital stay she was left to fend for herself and manage her illness alone.

The DHB didn't, and still doesn't, have a specialist gastroenterologist.

Moving to Wellington has made a huge difference to the level of care Stacey receives; specialists, IBD nurses, access to clinical trials and belonging to a support group means that although Stacey's colitis doesn't seem to respond to medications, she is in the care of a knowledgeable team of specialists, has met other people her own age with the disease and she knows she's not alone.

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](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



PHARMACEUTICAL COMPANIES  
 OF *Johnson & Johnson*



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:

Postal Address:

Postcode:

Telephone:

Email:

### DONATION DETAILS

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.

