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Moving On

Newsletter – Autumn 2017

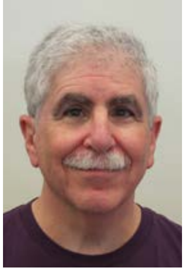
IN THIS ISSUE

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

FROM THE CHAIR

Dear Patients, Families, and Supporters. 2017 marks the beginning of our most exciting year to date. With the successful conclusion of our parents' seminar and Camp Purple Live in mid-January in which 57 children with IBD spent five days together in Wellington, we have several new projects in the works.

We all know and experience the burden of IBD on our daily lives. But despite the fact that the incidence of IBD in NZ is among the highest in the world, there have been no studies on its impact on our small country. Late last year we began our Burden of IBD study which will be completed in May. Made possible with a $40,000 unrestricted grant from Janssen, it is looking at the social, medical, and economic impact of having 20,000 people with Crohn's disease and ulcerative colitis in NZ. It will, hopefully, be a stepping stone for future advocacy projects. All our readers are encouraged to complete our online survey and to share their stories.



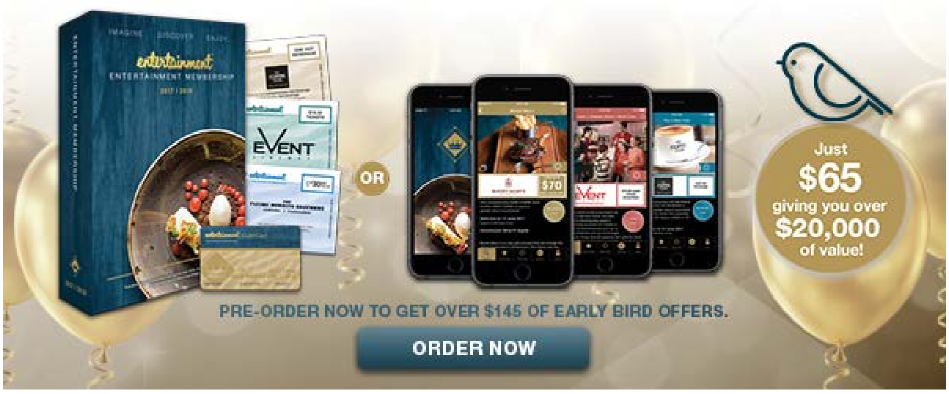
The last month has also seen raised awareness of IBD on television, radio, and in print as a petition written by the children at Camp Purple Live to grant urgent access for people with IBD to employee restrooms was presented to Parliament. The petition is now being formally considered in the Committee on Health. We will do everything that we can as an organisation to see that a Bill comes to the floor of Parliament this year.

We are reorganizing our Board over the next few months and hope to make CCNZ even more responsive to the needs of everyone with IBD, as well as their families and friends, and Support groups. This year we particularly want to expand our support to parents of children who are too young to attend Camp Purple and explore providing more social opportunities for young adults with IBD.

Please feel free to contact our Administrator Charlotte Perkins, Brian Poole, or me directly if there is anything you think we can do better. Brian and I will be serving as co-Chairs for the next six months during this period of reorganization.

It is only by working together as a group that we can all effect change to improve the lives of everyone affected by IBD.

Dr Richard Stein
Co-Chairman
Crohn's & Colitis Charitable Trust
info@crohnsandcolitis.org.nz



Camp Purple Live 2017

On January 13th, 57 children and teens, over thirty volunteers, and 33 parents arrived at El Rancho Camp on the Kapiti Coast. It marked the beginning of Camp Purple Live, now in its third year.

The purpose of the camp is twofold. Firstly, it is just a camp, a place for children and teens to have fun and test their limits. Activities this year included go carting, river tubing, a trip to Wellington, and a day at Adrenaline Forest secondly and more importantly, Camp Purple is a place where our youngest people with Crohn's disease and ulcerative colitis can be surrounded by those who understand the challenges of living with these diseases and make new friends.

Planning each camp is a long process and done by a committee of only seven. Once a venue is selected, work begins immediately on raising funds for the camp, about $70,000 each year. The camp has to be publicised throughout NZ through social media and to medical personnel through various medical societies. Applications need to be sent out to potential campers and every camper's medical form needs to be reviewed by a three person medical team. Volunteers, almost all of whom have IBD themselves, have to be recruited, as well as a medical team which staffs the camp 24/7. Every volunteer needs to be vetted with police checks. A five day schedule of activities, including those offsite, has to be meticulously planned. Over 100 flights need to be arranged. Campwear needs to be designed and ordered. We have to make sure all children are accompanied on those flights and safely collected at the airport. Ground transportation to and from the airport and to off-site activities has to be arranged . We also need to be available to answer innumerable inquiries from parents and make last minute travel arrangements. We have one person whose main job is just to manage meals and dietary restrictions of the campers.

This year's camp was the most ambitious to date as the number of campers (as well as parents participating in the parents' seminar) continues to grow each year. Highlights of the camp included a trip to Wellington where we toured Parliament, visited Te Papa, and took the cable car up to a show at the Planetarium. The following day was spent at Adrenaline Forest. The campers were amazing and fearless as many of them braved challenges over 30 metres above the ground.

We are indebted to all our sponsors and especially those individual donors (too many to mention individually) and volunteers who make the camp possible. Among our corporate sponsors are Abbvie, Janssen, Jetstar, Baxter, Pharmaco, ANZ Staff Foundation, TG Macarthy Trust, Boston Scientific Foundation, Rotary Clubs of Orewa/Wangaparoa and Greenmeadows, Sunshine Rotary, Freemasons NZ Pacific Lodge, Johnsonville Club, Mico Plumbing, Pelorus Trust, EFCCA, Pearl Jam, and Olympus Corporation.

CAMP PURPLE

Camp Purple Toilet Map Initiative

NZ has one of the highest rates of Crohn's disease and ulcerative Colitis in the world and they are diseases that often strike in childhood, causing symptoms that no one likes to talk about: abdominal pain, diarrhoea and bleeding. Imagine being on a school trip and having to stop five times to have an urgent bowel motion. Imagine pleading to use the employee restroom in a shop and having to explain why. Imagine being told that you will need to search for a public rest room somewhere else. Imagine being 12 years old and having an accident in the middle of the city.

On the second day of camp the children visited Parliament in downtown Wellington. Many had to stop along the way to use the restroom.

On their tour they asked the tour guide how to go about getting the House of Representatives to enact a law similar to one known as "Ally's Law" in the United States. Ally's Law is named after Ally Bain, a 14 year old girl with Crohn's disease. Ally was denied access to the employee toilet by a store manager in Chicago, resulting in an embarrassing public accident. Ally fought for a law in the State of Illinois and was successful. Ally's law guarantees access to employee toilets to people whose conditions such as Crohn's disease, pregnancy or an ostomy bag require the urgent use of a toilet. There are now similar laws in 15 other States.

Coincidentally, the Parliament tour guide had Crohn's disease himself. He explained the legislative process to the children. Immediately on her return to camp, with the help of one of the volunteers, Nicole Thornton, a 12 year old girl with Crohn's disease, wrote a petition. It requests that the House of Representatives enact a law similar to Ally's Law in NZ. It was signed by all 57 campers, along with 30 of the camp volunteers, including three doctors and four nurses. In addition we received an overwhelming response to the online petition with well over 3,000 signatures within a week of its launch.

The Petition is being sponsored by the Hon Trevor Mallard, MP and was presented to him on the steps of Parliament House, Wellington at 11:00am on Tuesday January 31st.

We urge you to join our cause and help MAKE IT LAW for retail establishments that have toilet facilities for their employees to also allow people who suffer from an inflammatory bowel disease or other medical condition to use the facilities.

You can help by signing and sharing this on-line petition:

https://our.actionstation.org.nz/petitions/camp-purple-toilet-access-initiative?source=facebook-share-button&time=1485294106

Show your support and visit the 'I can't wait NZ' Facebook Page.

Your support will help make our initiative a reality and together, we can build a better and brighter future by making life more liveable.

Microscopic colitis...

by Professor Michael Schultz

Microscopic colitis (MC), as the name suggests is an inflammatory condition affecting the large intestine. However, the inflammation usually cannot be seen with the naked eye or through the colonoscope so biopsies (tissue samples) have to be obtained to confirm a diagnosis. MC is moderately common and studies have shown that up to 16% of patients undergoing colonoscopy to investigate watery diarrhoea have this diagnosis. Data from New Zealand is not readily available. The underlying cause for MC is unknown and several theories including an autoimmune cause or infections are being discussed in the literature. A genetic disposition is unlikely.

A number of clinical characteristics point to the potential diagnosis of MC and help to select patients for colonoscopic evaluation. In terms of clinical presentation, MC mimics other gastrointestinal diseases such as Irritable Bowel Disease (IBS), coeliac disease or in severe form even Inflammatory Bowel Diseases (IBD). Despite some similarities, MC traditionally is not part of the Inflammatory Bowel Diseases. It is usually in older adults, predominantly women with an average age at diagnosis of 50-70 years of age. Symptoms, albeit unspecific, include watery, urgent diarrhoea, night or day that can be severe enough to cause dehydration. In those severe cases weight loss can become apparent but is usually not seen. More often patients present with accompanying joint and abdominal pain. Interestingly, an association with some drugs has been reported with some studies implicating the use of non-steroidal medications (NSAIDs such as Ibuprufen, Diclofenac) but also proton-pump-inhibitors (e.g. Omeprazole) as the cause of MC but these reports are controversial.

A firm diagnosis can usually only be reached endoscopically. Biomarkers such as faecal calprotectin and c-reactive protein are unspecific and not reliably abnormal. However, before colonoscopy is arranged, other causes of diarrhoea should be excluded such as infection (stool cultures), coeliac disease (anti-TTG antibodies) or hyperthyroidism (TSH, FT4) as well as laxative abuse. A thorough review of concomitant medications is recommended and also a dietary history should be taken to reveal increased use of artificial sweeteners or dairy intolerance. The colon in most cases appears normal through the colonoscope but in some cases a blurring of the inner lining indicating oedema has been reported. Biopsies should be taken from the left and right colon and assessed histologically.
The disease can be patchy and therefore a full colonoscopy with segmental serial biopsies is advised. Histologically, the disease typically has two forms – collagenous or lymphocytic colitis, depending on the presence of a thick subepithelial collagenous band visible microscopically. Both disease forms are characterised by the presence of lymphocytes invading the bowel wall. The histological differentiation is, however, clinically not relevant.

Treatment is usually with Budesonide which is fully funded in New Zealand for biopsy-proven microscopic colitis. Budesonide is given at 6-9mg per day until patients achieve remission then tapering should be initiated. Due to the lower side effect rate compared to Prednisone, courses over several months are possible. Although there is a high rate of remission (according to the literature >80%), relapses are very frequent leading to intermittent courses which increases the risk of steroid dependency. In those patients, or in patients with steroid-refractory disease immunomodulators such as azathioprine have been used. Mesalazine and bismuth has also been used with varying success. In day-to-day life low dose budesonide treatment (3mg/d or every other day) is often used to maintain remission. In these cases, regular assessment for steroid-related complications such as hypertension, hyperglycemia, and osteoporosis need to be organised.
For mild cases loperamide is justified. No increased risk of colon cancer has been reported and therefore no specific colonoscopic surveillance is indicated.

In summary, microscopic colitis is a moderately common cause in women with watery diarrhoea in the 5th to 7th decade. The diagnosis can be made histologically from biopsies obtained from the large intestine. Treatment is straight forward with Budesonide, but prolonged treatment is sometimes necessary, leading in some cases to steroid dependency.

Unrestricted Study Grant for Burden of Disease Report(BODR)

By Brian Poole, QSM
CCNZ Trustee

To gain a better understanding of the economic cost of IBD in New Zealand we successfully obtained an unrestricted funding from Janssen-Cilag to prepare a BODR. This has enabled us to commission the well-known economist Suzanne Snively ONZM to carry out this work with a report due later this year.

This report will be a high level (evidence based but without collecting new data) replication of the Australian PWC 2013 study details of which can be found at:

https://www.crohnsandcolitis.com.au/site/wp-content/uploads/PwC-report-2013.pdf

It assumes open sharing of the framework with two workshops of key stakeholders in the health sector including GPs, IBD specialists, patients, and their families. Ideally based on this, a hypothesis would be framed about how the New Zealand pathway to care could lead to better health outcomes while reducing long term economic and other costs.

How is Inflammatory Bowel Disease disabling?

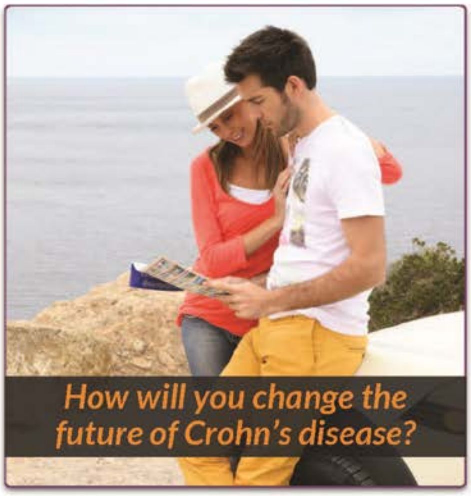
The nature of IBD, associated stigma, and varying degrees of knowledge among health professionals often means that those affected do not have ready access to information and advice about the range of debilitating impacts IBD has on their lives. Public knowledge of the diseases to this day remains very low. The IMPACT study, a worldwide study on the effects of IBD, presented some stark figures demonstrating the debilitative nature of Crohn's disease and ulcerative colitis. It showed that:

- 85% of those affected have been admitted to hospital in the last five years as a direct result of their disease, 40% have had surgery, 75% have missed time from school or work due to their illness and 61% of young people have had their schooling significantly affected. These extended periods of time (often many months) away from school owing to IBD results in poorer educational outcomes and employment issues associated with high sick leave needs.
- Close to 70% of those affected are worried about the availability of toilets when they are away from home. This leads to embarrassment and social isolation for patients.
- 40% have felt that their disease prevented them from having an intimate relationship owing to associated complications from the diseases.
- 25% of patients noted that they have had people jest about their symptoms, which was felt to be more due to a lack of understanding than insensitivity. This further isolates patients.

While diagnosis can provide relief, it means that patients must come to terms with a potentially life-long chronic condition. Many people with IBD require hospital care, and multiple life-changing surgeries. Medication is necessary to treat and manage symptoms of IBD, and the high use of medications such as corticosteroids can lead to a range of side effects on top of symptoms. Complications from IBD can be life threatening.

IBD is more prevalent than Type 1 Diabetes yet despite this, IBD remains an invisible illness, shrouded in silence. There is no cure, no known cause, and little public understanding of the pain and suffering with which IBD patients courageously cope every day of their lives.

We thank Janssen-Cilag for their generous and timely grant and we are hopeful that the Burden of Disease report will put IBD in a better light.



To pouch or not to pouch

By Dr Andrew McCombie

Unfortunately, many ulcerative colitis patients find little joy in medical and dietary management of their disease. Fortunately, ulcerative colitis patients do have the option of surgically removing their colon (called a "colectomy"), thus "curing" them of their disease. However, due the radical nature and inherent risks of colectomy, this is usually seen as a last resort for patients who have failed all other treatment (80% of ulcerative colitis colectomies) or are in need of an emergency surgery due to an acute medical situation (20%), such as a perforating bowel.

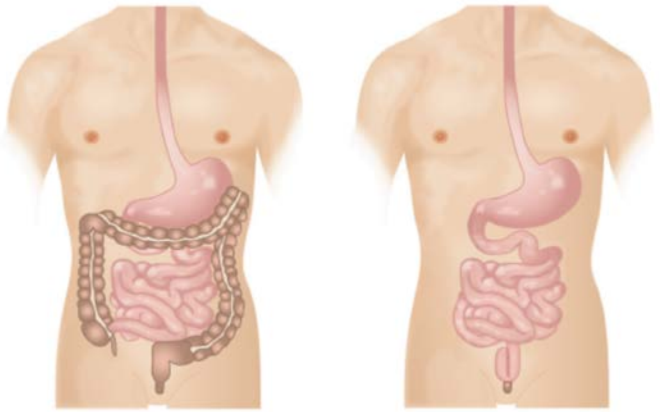
After colectomy is decided on or imposed upon the patient, they will then have a choice about whether to stay with a "stoma" (requiring the patient to wear a bag on their stomach to collect their waste) or having an "ileal pouch" sculpted out of their small intestine (eliminating the need to wear a bag on their stomach).

Overall, there are two fundamental questions for ulcerative colitis patients considering surgery:

1. "Should I have a colectomy?" If the patient is being managed well medically the answer is clearly no but in other cases the answer is yes.
2. If the first answer is yes, then the next question becomes "Should I stick with an ileostomy or advance to an ileal pouch?" Whilst it may seem clearcut to some that advancing to an ileal pouch is more desirable, it needs to be considered that this requires more surgery and carries the risk of a failed ileal pouch.

What is an ileal pouch?

An ileal pouch is a surgically constructed internal (i.e. inside the body) reservoir for stool that is made out of the last part of the small intestine. The commonest type of ileal pouch is the J-pouch, which is called this because it is shaped like a J (as shown in the picture below). See in the picture below that the colon has been removed on the right. In effect, the ileal pouch's job is to do what the colon used to (i.e. store stool).



A booklet recently made in a joint effort between myself (patient with an ileal pouch), Associate Professor Tim Eglinton (Colorectal Surgeon), and Professor Richard Gearry (Gastroenterologist) is designed to help ulcerative colitis patients better understand and answer these questions for themselves. It explains the nuts and bolts as well as the risks (of complications) of these procedures. Accordingly, it is called "Considering whether to have ileal pouch surgery."

Whilst for many ulcerative colitis patients the decisions about surgery will never be cut-and-dry, this booklet at least outlines the risks and benefits more clearly for the patient to better facilitate joint decision making to be made between physician and patient.

We are excited at this booklet's release which will assist in making "life more liveable" for IBD patients in New Zealand and abroad. It will be available through Crohn's and Colitis New Zealand and will be distributed to IBD Nurses throughout New Zealand.

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www.ibdandme.nz

NEW CCNZ WEBSITE FOR IBD TEENAGERS –

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SHARED MOMENTS

Kallia's Story

My name is Kallia. I am 38 years old and I was diagnosed with Crohn's Disease at the age of 23.

My story starts when I was in the Air Force working overseas, when I had severe stomach pains, no appetite and was passing blood in my stools every time I visited the Portaloo. I was flown back to hospital in Townsville for tests. This felt wrong! I was meant to be helping others, not in bed myself! I was allowed to finish my deployment, but needed to see the medical team as soon I arrived home.

When I got home to New Zealand, things got worse – cramps, faecal blood, always tired. The Air Force made sure I received specialist care and I was given various medications to find the best for me - at one stage18 pills a day – some to counteract the effects of others. Going to work was a struggle and I was often absent.

I was officially diagnosed with Crohn's Disease, which meant I was too high a risk to work overseas and I needed to take a medical discharge. Devastating!

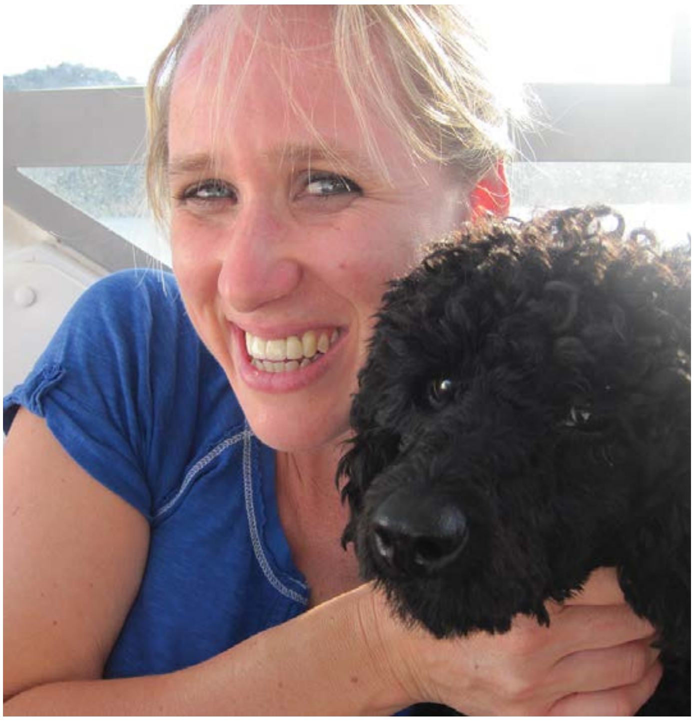
Nine biopsies later I returned home to Palmerston North. At 2am that night I could not stop bleeding and a friend called an ambulance. The surgeon I saw told me I had "4 days to get 400% better or it is surgery", which in fact took place the next morning. They had to take my colon, leaving me with a stoma and an ileostomy. Slowly it sunk in. An ileostomy for life - very hard to accept for a young woman proud of her body! I was grossed out.

I was told I could go home once I started to eat and as I desperately wanted to see my new born niece I managed some potato and gravy. I looked like a skeleton and was on a lot of pain killers, but I got to see my beautiful first niece.

The next surgery I had was to remove my rectum. I had been too ill previously. After a long operation I was told there were three things I wouldn't be able to do – deep sea dive, wear a bikini or be an astronaut.

I could now leave the house without worrying about a toilet, but I didn't want my ileostomy to be public knowledge. I wouldn't and couldn't talk about it and was terrified people would see it. The turning point came when I was desperate one day, sitting on the floor crying and asking "Why me?" I realised now that I needed to have belief in myself if I was going to enjoy my life. I decided to follow a childhood dream and go to university, get a degree and train to be a teacher.

Half way through my degree I moved to Auckland for a new life. I learned some control and to look after myself and share my life with my partner. My health was good, I married my partner and had a job as a teacher. I had an ileostomy, a completed degree, a husband, and a new job and we had bought a house. Sadly, our marriage dissolved after three years.



I still told only couple of close friends about my ileostomy and they were incredible. With their support, I made new friends and met an amazing man who accepted me as I am. With his encouragement I completed my diving certificate, (tested by a diving doctor), travelled and wore a bikini! Did I ever want to be an astronaut? I regained my self belief and lived my life.

Still reticent to mention my ileostomy, I was surprised when my hairdresser mentioned her son had Crohn's and I was able to discuss my journey more and more as we shared our stories. She convinced me to own my disease, and live with it, and encouraged me to offer to help at Camp Purple, which I did and loved it, in spite of my self doubt. Camp was one of the most rewarding and healing experiences for me.

I took another step forward when I used my hospital experience and life changing story (less details) to help my class with writing their life stories. I explained about my time in hospital and what it meant for me. They were great and it did help them to write their stories.

I now know that I can own this disease, it does not own me. With positivity, help and support from family and friends, I know I am strong. I know it is better to talk and share with others who understand. I hope my story will help others.

2017 ECCO conference in Barcelona

By Sarah Cook; IBD CNS

Late last year I was delighted to be given the opportunity to apply for the IBD nurses travel grant through CCNZ. I was thrilled to be told that I had been successful.

The team I work with at Waikato DHB had been planning to attend the ECCO (European Crohn's Colitis Organisation) conference in Barcelona in 2017. The grant meant I was able to join them. The conference is designed for those who specialise in IBD – including gastroenterologists, nurses, surgeons and dieticians. It is a yearly conference and there are sections of the conference allocated to the different specialties as well as the scientific content.

Through attending the conference I found there were aspects that were particularly relevant and interesting to my nursing practice. I was particularly focused on learning more about the nursing prospective and this was offered as part of the conference through a specialised nurses meeting. There were approximately four hundred IBD nurses from around the world who came together for 8 hours to learn about various relevant topics. The main themes of this meeting were quality of care, special considerations and medical management in IBD. I will give you a small snippet of a couple of things that I found of particular interest.

The quality of care aspect looked at the patient being central to all care given and how we as IBD nurses can have a positive influence on the quality of care given. This then proceeded on to looking at ways of how we could best measure these quality outcomes so we can improve on areas that are lacking. Ways of measuring included using PROM (patient reported outcome measure) and regular auditing against the UK IBD standards. Reported by using PROM and audits, it was found to improve clinical effectiveness, patient safety, clinical outcomes and patient experience. To add to this, I am aware that Australia has recently released IBD standards at www.crohnsandcolitis.co.au, which maybe potentially more relevant to the IBD settings we have in NZ.

There was an excellent talk about IBD and pregnancy and the importance of preconception counselling, talking about the importance of remission prior to pregnancy and necessity of drugs to maintain disease remission. (ECCO also has guidelines for treatment of patients with IBD) ECCO statement 3A (see reference below) – states "If conception occurs at a time of quiescent disease, the risk of relapse is the same as in non-pregnant woman, but if conception occurs at a time of active disease this increases the risk of persistent active disease throughout pregnancy". This highlights the importance of remission if possible, prior to pregnancy. I also took from this presentation, the importance of preconception counselling to all women who are of reproductive age.

There was also a talk by Kay Greveson. She is an IBD nurse from the UK who developed the website www.ibdpassport.com. I often refer patients who are travelling abroad, to this website. It has a lot of helpful information and tools for the traveller with IBD. Kay emphasised the importance of IBD covered travel insurance.

I was fortunate to arrive in Barcelona a few days prior to the conference starting and spent time touring by foot around Barcelona. My favourite part of Barcelona and most memorable was the incredible Sagrada Familia – a large Roman Catholic Church designed by Spanish architect Antoni Gaudi. The construction of this building commenced in 1882 and is due to be completed in 2026 -2028. This building is a true masterpiece.

On reflection from my learnings from the conference, I feel New Zealand is doing well looking after IBD patients. I need to acknowledge at this point there is a gap in medications available to IBD patients in New Zealand.

In conclusion, in my initial application for the CCNZ travel grant I wrote I had a real passion for patients with IBD. This has been heightened by this opportunity to attend the European Crohns colitis organisation (ECCO) conference. I would like to thank CCNZ and ABBVIE for allowing me to have this awesome experience and would encourage other IBD nurses to apply for the travel grant allowing them this opportunity.

References

www.ecco-ibd.eu

Teenage Transition Website, 'IBD & Me'

In 2015 Pharmaco approached CCNZ and proposed sponsoring the development of New Zealand's first IBD Transition Website/On-line Forum, 'IBDandMe'. This initiative followed research conducted by Atlantis Healthcare between July and October, 2014. The aim of the research was to understand the process of transition from adolescent to adult services amongst people living with Inflammatory Bowel Disease, both from the patient's perspective and the HCP's perspective.

The transition from paediatric to adult care for young people living with IBD is ideally a staged process where young adults are gradually integrated into adult care. Viewing this transition as only an isolated 'event' can mean that young people reach adult services not possessing the skills required to self-manage their condition, and run the risk of drop-out or health-negating non-adherence.

Practical skills such as booking tests through to lifestyle skills such as managing diet and activity levels are also called upon, as well as navigating health-risky behaviours such as alcohol consumption, smoking and sexual activity (Day, N.D.). This level of self-management is underpinned by the process of adolescence itself, where identities are being formed, cognitive and social skills are developing, and a gradual shift to independence from key caregivers is taking place (Royal Australasian College of Physicians, 2000). Currently there is no official or consistent process through which young adults with IBD in New Zealand transition from paediatric to adult services. It is understood that most clinicians recognise there is a need in the community for a more structured and inclusive process, but what this might look like is not yet bedded down.

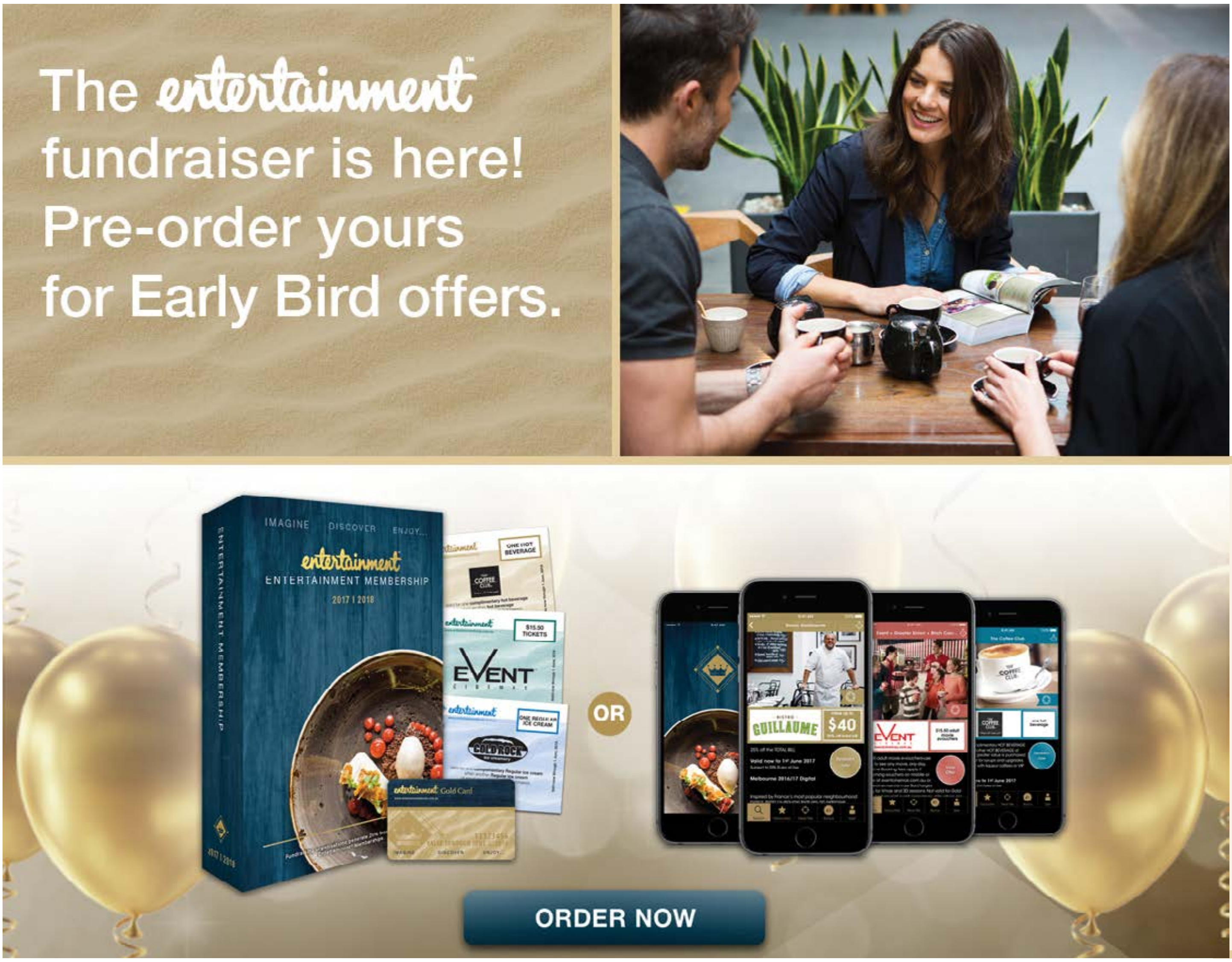
In 2016 CCNZ put together a project team that comprised of a select group of physicians, IBD Nurses and specialists who are actively involved with providing and supporting the care of teenagers through the transition phase from adolescent to adult services, to assist in the development of the new website.

The objective of this site will be to empower teens and parents of young children with IBD to effectively manage their disease. 'IBDandMe' will be a resource portal with tips, videos and information to prepare and assist patients' transition from paediatric care to adult care. CCNZ felt an IBD Transition Website was crucial – with age appropriate information, however, the key to making a difference was creating community and an Online Chat Forum would help create that community.

CCNZ, together with Pharmaco NZ Ltd are proud to bring you New Zealand's first IBD Transition Website, 'IBDandMe'.

We invite you to visit the new website at www.ibdandme.org.nz

The online forum will be completed later in 2017.



Managing the psychological and social Impact of IBD (Inflammatory Bowel Disease)

By Maria Berrett

A diagnosis of IBD brings with it multiple challenges. Many of these are of course related to the physical impact of illness. But along with the physical impact inevitably comes uncertainty and changes which can lead us to feel very much outside our comfort zone.

There are many reactions and emotions which you might experience. Most people understandably feel anxiety about what might happen with their health, and there can be many worries such as: how you will cope in social situations, whether and what to tell others, medical procedures like colonoscopy; what treatment decisions to make, the impact of treatments (e.g. steroids or immunomodulators or anti-TNF agents or surgery); how you look; what impact IBD will have on relationships – the list goes on...

Other psychological consequences can include low mood or depression - especially after a new diagnosis, during a flare, or following surgery. It can be tempting to isolate yourself or withdraw from others and not be bothered about things that you might have cared about or been involved in previously. Fatigue, pain, and poor sleep can exacerbate the tendency to withdraw, increasing isolation.

For some, these responses occur during a period of adjustment and the distress lessens over time – particularly in periods of remission. However, for others, stress, worry, and/or low mood can be ongoing.

Fortunately, just as there are a variety of medical/physical treatments for IBD, there are a variety of options and strategies that can be used to support psychological wellbeing and adjustment. Key amongst these are self-care; managing your stress levels; and support from others.

Self-care is essential especially when you are fatigued or feeling over-whelmed. It's important to listen to what your body is telling you and take time out to relax and do something that you enjoy. This might mean spending time alone, for example, sitting in the sun, or reading a book, or it might mean spending time just relaxing with friends. It might simply mean giving yourself more time to sleep. Good self-care involves maximising your sleep and nutrition within the constraints of IBD and its treatment.

Reducing stress levels where possible is also helpful - especially in relation to worry and anxiety. One technique which can help with this is mindfulness. Mindfulness is a skill in which attention is focussed on the present moment and which is now widely and very effectively used to assist to reduce stress and enhance a sense of calmness and wellbeing. A good website to visit to learn more about mindfulness is http://www.mindful.org/meditation/mindfulness-getting-started/.

Finally, and essentially, the importance of support from others (family members, friends, support group members, and professionals such as IBD Nurses) cannot be overstated. Support can be provided in a variety of ways including practical support, providing a listening ear, and through information and advice. In particular, talking to people you trust about your feelings, your thoughts, your experience, and your hopes for the future will assist those others to better understand the impact of IBD and to know how best to help you thereby enhancing your own wellbeing.

Bio – Maria Berrett

My name is Maria Berrett and I am a Clinical Psychologist based at Massey University in Palmerston North. For the last 9 years, I have been managing Clinical Health Psychology Services in the MidCentral DHB for people who have a range of physical health conditions. Prior to this role, I spent 10 years working in Child and Adolescent Mental Health. I have personal experience of IBD in my family and have IBD myself. I am passionate about the importance of psychosocial care for patients with physical illness and know, through the experience of working in Clinical Health Psychology Services, that psychosocial care and support has a significant contribution to make to the wellbeing of IBD patients and their families.

We're fundraising with Entertainment™

Crohn's & Colitis New Zealand receives no direct Government funding so we rely on our own fundraising efforts. The money we raise each year through selling Entertainment™ Books helps CCNZ to provide ongoing support services, free of charge to the 20,000 people who are affected by IBD.

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EFCCA youth meeting Slovenia 2016

By Dana Smith, Trustee

Last July, our youth representative, Dana, along with 30 delegates from around Europe, had an express summer getaway in Ljubliana, Slovenia, where she had the privilege to represent Crohn's and Colitis New Zealand at the European Youth Meeting held by the EFCCA Youth Group (EYG). The EYG is a sub-committee of EFCCA, the European Federation of Crohn's and Ulcerative Colitis Associations and aims to give young people with IBD a voice. The meeting was an 2-3 day annual event to allow young people who volunteer for their national associations to network, share ideas and experiences and to discuss areas for improvement.

It was a unique and special experience learning how other associations work and what they offer in their country. Most of the groups had regular social gatherings such as dinners and bowling meet-ups to normalise their life and have a catch up. Youth camps were also very popular in a few countries, and Dana was very proud to share the success of Camp Purple Live in New Zealand. She also found it was interesting to share the struggles around raising awareness and learning about the different cultures around Europe, such as in Germany, where they do not like to talk openly about their IBD, as they are worried it will affect their job opportunities.

All associations have a very similar goal to us here in New Zealand, 'to make life more liveable'. It was overwhelming to meet other young people making a real difference in their country for people that have IBD, then come home with numerous ideas for Crohn's and Colitis NZ to think about in the future.

A PR consultant taught a workshop on 'Social media and NGOs', and it was interesting to learn some pointers to bring home and has contributed to the development of our own Facebook page for CCNZ.

We invite you to like us at: www.facebook.com/crohnscolitisnewzealand

Much, much more than just a sore stomach – Inflammatory Bowel Disease

By Briar Lawry,
Hardy's Magazine, Winter 2016

Bathroom behaviour is a delicate topic at the best of times. But if your insides aren't behaving in the way that they are supposed to, things become even more of a minefield. Nearly 20,000 New Zealanders are estimated to live with inflammatory bowel disease (IBD) – one of the highest rates in the world. So what is IBD? And what can you do to keep yourself as healthy as possible if you have it? Learning about IBD can be a bit gruesome, it's true – but with so many Kiwis affected, it's important to get past the toilet humour and find the facts.

IBD vs IBS

The first important thing is to get the rather confusing acronyms straight. IBD isn't the same thing as IBS. IBS, or irritable bowel syndrome, is an unpleasant condition, but is generally less serious. On the other hand, inflammatory bowel disease encompasses several conditions, the most common of which are Crohn's disease and ulcerative colitis.

Where both IBS and IBD can cause pain and either constipation or diarrhoea, IBD goes much further. Like the name suggests, the key component is inflammation. In ulcerative colitis, the inflammation is limited to the large intestine and rectum whereas, in Crohn's disease, anywhere in the digestive tract can be affected – from the mouth right down to the anus. Inflammation can lead to varying degrees of pain, bleeding, malnutrition, nausea, fever, weight loss... the list goes on. Everyone with IBD has their own experience.

Serious business

It's easy to wrinkle your nose or giggle when you think about things like bowel movements – but IBD is no laughing matter. Many patients with Crohn's disease or ulcerative colitis require intensive medicine regimes – and according to research, between 70–90% of Crohn's patients and 23–45% of ulcerative colitis patients will require surgery at some point. It's not just a tummy ache, that's for sure.

Making a meal of it

Unfortunately, there isn't one diet that prevents IBD symptoms either. Just because one person finds they can't eat dairy doesn't mean that everyone with Crohn's or ulcerative colitis has the same problem – the same thing goes for things like gluten and soy. Some people can eat anything – others go through phases of liquid-only diets because solid food causes too many problems.

At the end of the day, the individual person knows their body best so if you, or someone you know is experiencing IBD, don't get too caught up in Aunt Beryl's well-meaning assertions that she cured her Crohn's by cutting out white bread. Unfortunately there is no cure for IBD, only management through periods of flaring and remission. Some people get lucky, and have extended periods of time with no symptoms. However, there are some things that you can do to increase your chances.

Helen Millar, president of the Auckland Crohn's & Colitis Support Group, is very proactive when it comes to supplements. "I believe that in combination with appropriate medications, positive dietary and lifestyle changes, supplements can greatly benefit many people living with IBD. In my personal experience managing Crohn's, I have found a number of different supplements helpful – these include the probiotic S. Boullardii, pure aloe vera juice, flaxseed oil, apple cider vinegar and slippery elm. Everyone's body is unique, though, so it's important to find the right combination that works for you."

Being a probiotics pro

Probiotics are a useful addition to any diet, but there's research showing that they are of particular benefit to people with bowel related issues, like IBS and IBD. Different strains of probiotics have different health applications. For example, Lactobacillus plantarum (299v) can assist with the management of medically diagnosed IBS. Similarly, a study followed IBD patients who took a particular probiotic (S. boulardii) along with twice daily doses of a maintenance IBD drug (mesalazine) and found that these people had a much lower rate of relapsed symptoms than patients who had three doses of mesalazine a day and no probiotic .

There appears to be a change in gut flora in many IBD patients – with research suggesting that there's a relationship between the particular composition of the flora and inflammation triggers. So trying to top up probiotic levels to get things looking more normal and healthy is a safe and easy way to work towards intestinal health. With inflammation being the root cause of most of IBD's most unpleasant and debilitating symptoms, anything that can help to minimise it is worthwhile.

Getting on top of nutrients

While it's important to work with your specialist to find the best treatment plan for you, there are nutritional areas that are a common cause for concern for many IBD patients. Since the intestines aren't usually doing such a good job of absorbing nutrients – hard to blame them, with all the swelling and bleeding and general pain they've got going on – the levels of some vitamins and minerals can become dangerously low.

Iron

Iron deficiency anaemia is a common issue for those experiencing IBD. Between the lack of absorption and the potential for near-constant bleeding, a lack of iron is almost inevitable in some cases. If things are really out of control, gastroenterologists will usually recommend an iron transfusion or even a blood transfusion in some cases. However, taking an iron supplement is a good way to keep things in check and may be all that is needed in more mild cases.

For iron to absorb properly you also need a kick in the vitamin C department – so if your supplement doesn't contain both, it's a good idea to take a vitamin C supplement at the same time. Or you can always wash that iron tablet down with a large glass of freshly squeezed orange juice!

Vitamin D

Vitamin D is another one to watch out for. Studies suggest that there is a relationship between low levels of vitamin D and IBD, – and with vitamin D levels among New Zealanders tending to be low, there are some schools of thought that suggest there might be a correlation between these low vitamin D levels and the high incidence rate of IBD in Aotearoa.

One of the main sources of vitamin D is sunlight – and since we're both quite a way from the equator and particularly wary about sun exposure, it's not a total mystery as to why vitamin D levels can be lacking in our corner of the world. Going and baking yourself in the sun isn't recommended. However a few minutes of sunshine each day – if you can – is a good way to make sure you stay on top of your vitamin D needs. If you think you need an added boost, talk to a Hardy's expert about vitamin D supplementation.

All the rest

Then there's vitamin B12. And folate. And calcium. These can all be negatively affected if you're insides aren't working as well as they should be. A chat to an expert, and potentially blood tests, will help to tell the tale of how your body is coping when it comes to absorbing nutrients, and help you assess what particular vitamins and minerals you should be supplementing your diet with.

Crohn's and Colitis Annual Conference

24-25 September 2016

Board members, Support Group representatives and invited guests came together last year again in Wellington for the Annual CCNZ Conference.

The programme featured presentations from Brian Poole as the CCNZ Chair on the CCNZ journey to date featuring many of our achievements and was followed by a session looking at CCNZ and its Support Groups, setting expectations of each other. Strategically CCNZ recognises that it has a number of key challenges for the future – reaching more patients, continuing to develop information and communication processes, increasing the level of cooperative engagement with medical professionals, growing its membership base, alongside the need to access more funding and personnel resources to maintain progress and build strength, as well as attract future leaders at national and local levels. As part of this it is felt that the respective roles and links between the Board and Support Groups needs review. The question of what we would want from a Support Group as a newly diagnosed patient or family member and what CCNZ needs to do to facilitate and support this, was explored.

Maria Berrett gave a talk on Positive Psychology and Communication Skills, followed by Natalie Richardson from the Waiarapa DHB, who spoke about building relationships with your local DHB. Wellington Support Group Coordinator Anna Scanlen presented ideas for running a successful support group and followed up on the SWOT analysis done at the previous conference. Chris Budgen, the Nelson Support Group Coordinator, then finished the first day with a talk on the use of low dose Naltrexone as a novel anti-inflammatory treatment for chronic pain. A buffet dinner rounded off the day.

The Sunday programme featured Sheridan Bruce and Charlotte Perkins from CCNZ exploring fundraising and use of the CCNZ brand. Andrew McCombie then presented on a study done on Canterbury ileal pouch patients and their long term outcomes and followed this with a talk about IBD Smart and Telemedicine – a new app for IBD patients and clinicians.

Dana Smith and Andrew McCombie gave an overview of their recent attendance at the EFCCA Youth Conference and an update on the European Patient Guidelines. An update on Camp Purple Live 2017 being held at El Rancho in Waikanae from the 13th – 17th January was delivered by Kallia Patching and Helen Legge.

The conference wrapped up with a look at our objectives and goals moving forward and a presentation to former Board Members, Secretary Julie Melville and Treasurer Baubre Murray, who stepped down at the end of 2015 after serving on the Board since CCNZ's inception. Retiring Chair Brian Poole was also thanked for all his work in establishing CCNZ and growing the organisation to that which exists today, often effectively acting in the role as a fulltime unpaid CEO. Brian continues on the Board as a member in the role of immediate past chair.

An open afternoon session was devoted to a presentation from key note speaker Dr Russell Heigh from the Mayo Clinic in the United States. Dr Heigh focused on an overview of the state of play in IBD care examining the differences and similarities in the NZ and USA contexts. A video recording of Dr Heigh's very informative presentation can be found on our website. Simply go to Presentations under the heading 'News' and select 'Disease and Treatments' to access the following link:

IBD TODAY

or go to https://player.vimeo.com/video/189566012

OUR FUTURE

Event for Young Children...

CCNZ wants to know if there is interest in us hosting an event for children under the age of 9 (who are too young for our camp) and their parents. The event would focus on activities for the children in conjunction with an educational and networking program for the parents. In short, it would be an opportunity for the children to meet others their own age with IBD and for parents and caregivers to meet others for support.

Depending on the level of interest, we will move forward with this program in one or more cities, depending on the response. The program would be without charge.

If interested, please email Charlotte at:
info@crohnsandcolitis.org.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.

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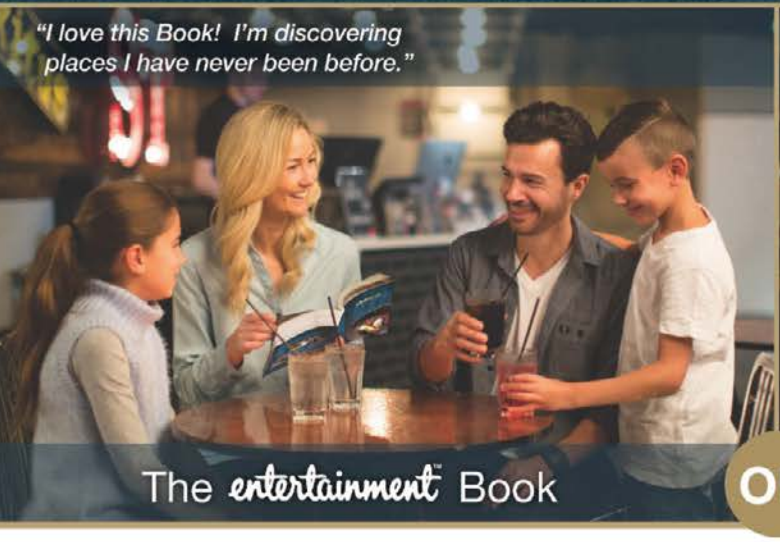

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