

Endoscopic Ultrasound for the South Island

– our most ambitious and successful project ever

2012 marked the end of the most successful fundraising project that the Bowel and Liver Trust has ever embarked on. The launch of an endoscopic ultrasound (EUS) service for the South Island took place on the 15th of June, 2012 and marked the end of a tremendous effort from the Bowel and Liver Trust Trustees, Trust supporters and the wider community.

Endoscopic ultrasound (EUS) is a test where a thin flexible tube with an ultrasound probe is inserted through the mouth into the stomach. This test provides one of the best ways of visualising abnormalities in the stomach, oesophagus, pancreas and lung. It is especially useful at obtaining biopsies (tissue samples) from difficult to access places, leading to less invasive surgery. This means that patients can have a simple procedure as a day case rather than requiring lengthy stays in hospital due to invasive surgery.

Dr Gary Lim, a Christchurch local, underwent sub-specialty training in interventional endoscopy including EUS in Australia before returning



From left: Bob Paton, Projects Director Hornby Rotary Club, Derrick Abbott, Chair of the Bowel and Liver Trust, Dr Richard Gearry, Gastroenterologist and Trustee of the Bowel and Liver Trust and Dr Gary Lim, Gastroenterologist.

to take up a role as an Interventional Endoscopist and Consultant Gastroenterologist at Christchurch Hospital in 2010. "This equipment enables us to provide South Island patients with the very best EUS service in New Zealand. We are now able to ensure that patients get the very best care, particularly those with cancer."

The EUS service was introduced to Christchurch Hospital on 25 June 2012. So far, almost 400 procedures have been performed with more and more patients benefiting every week. "In addition to providing state-of-the-art imaging and biopsy capability, EUS has played a major role in improving the quality of life of patients. For example, using EUS we can inject nerves in the abdomen to block pain," says Dr Lim.

After the Canterbury District Health Board agreed to fund the basic equipment needed to perform these tests. The Trust was able to raise an additional \$400,000 to provide additional equipment, a research database and staff training. The fund-raising was driven by Trust past Chairman Mr Ron Smith and current Chairman Mr Derrick Abbott.

"This was the largest single project we have ever raised funds for," says Smith. "For the project to be successful, we needed to get our message out to the community and show the benefits of having this equipment in Christchurch. It didn't seem right that this group of patients had to travel to Auckland when we could do the tests here in Christchurch."

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"While we are grateful to the many contributors to the fundraising effort, I would like to individually thank three organisations for their generosity," says Abbott. "The Rotary Club of Hornby came on board early and raised significant funds through a range of endeavours including Golf Tournaments and the "House of Hope" which was built and sold with all profits going to the EUS project. The House-build represented an enormous effort by the Rotary Club of Hornby in collaboration with Today Homes and many other businesses that gave time, product and money."

"The Warner and Patsy Mauger Charitable Foundation were also extremely generous in their support of the EUS project. Both Warner and Patsy were genuinely interested in the benefits that the equipment would bring to the community. We are also very pleased to be able to recognise their support of the Trust with the establishment of a yearly studentship to support young researchers in Canterbury" (see page 8 for more details)

Finally, the Canterbury Community Trust must be thanked for their support of the Trust. The Community Trust has been a long term supporter of a variety of Trust projects and we are grateful for their ongoing support."

Canterbury District Health Board Chief Executive David Meates described the acquisition of the new machine as "a wonderful milestone and example of how community organisations can work with the District Health Board to improve the care of our patients". The EUS project takes the total amount of funds raised by the Trust for equipment, research and patient support over \$1,000,000.

The EUS project has allowed the Bowel and Liver Trust to look forward with confidence as it works with community organisations to ensure the best digestive and gastrointestinal health to Cantabrians and other South Islanders who can now be referred to Christchurch Hospital Gastroenterology Department for EUS. The Trust is proud of this achievement, and grateful to the many people who have made this vision a reality.

The Bowel and Liver Trust – *the early years*



The late Tom George

The Christchurch Liver and Digestive Diseases Trust was formed in November 1993. It was the brainchild of the late Mr Thomas P George. Tom, as he was widely known, had undergone a successful liver transplant in March 1991. He was one of the first New Zealanders to have a liver transplant, which at the time, was only performed in Australia. Tom was a legend amongst Canterbury sports people, having served in high level administration for club rugby (Christchurch Rugby Club) and cricket (Old Collegians Cricket Club) for many years. When he required a liver transplant, the people of Canterbury got behind Tom to raise the large amount of money required to get him to Sydney.

After Tom's successful transplant he returned to Christchurch determined to help those who had helped to save his life. He had been impressed by the work of health professionals working in the area of Gastroenterology and recognised that by supporting their endeavours the people of Canterbury would continue to be well served in the future.

Tom gathered a group of Trustees around him including successful sportsmen, sports administrators and business people. Forming the Christchurch Liver and Digestive Diseases Trust. The aim of the Trust was and remains "to promote research and education into Liver and digestive diseases." In 2012 the Trust was renamed the Bowel and Liver Trust to recognise that the impact of the Trust's work extends well beyond Christchurch.

Since its inception, the Bowel and Liver Trust has raised over one million dollars for research into bowel and liver disease including funding large research programs, cutting edge equipment and grass roots patient support groups. With the ongoing support of the community, the Trust is looking to promote gut health across New Zealand.

visit our website for more information: www.bowelandliver.org.nz

Gut Research Activities – *past, present and future*

A few years ago Dr Richard Gearry identified the Canterbury region in New Zealand as having one of the highest rates of new cases of Crohn's disease (CD) reported anywhere in the world. CD is a disease that can strike anyone at any age, but Richard's study highlighted how susceptible young people in our community are to acquiring this disease. That this disease currently has no cure reflects just how little we know about the different risk factors that underlie susceptibility to CD.

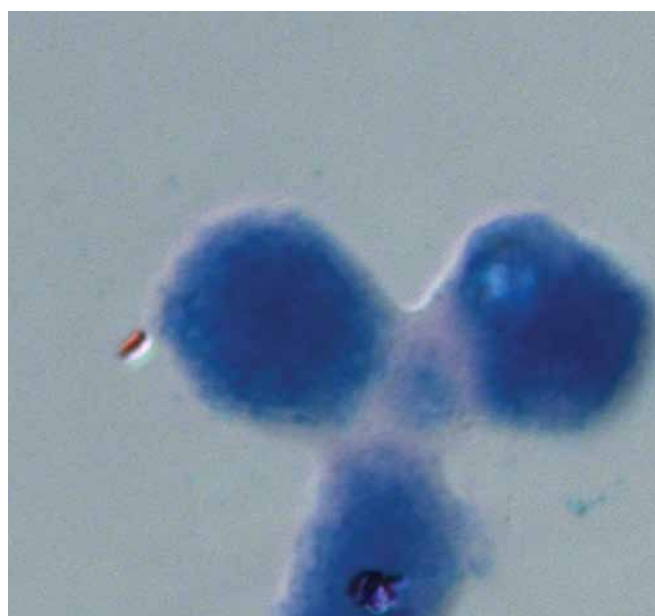
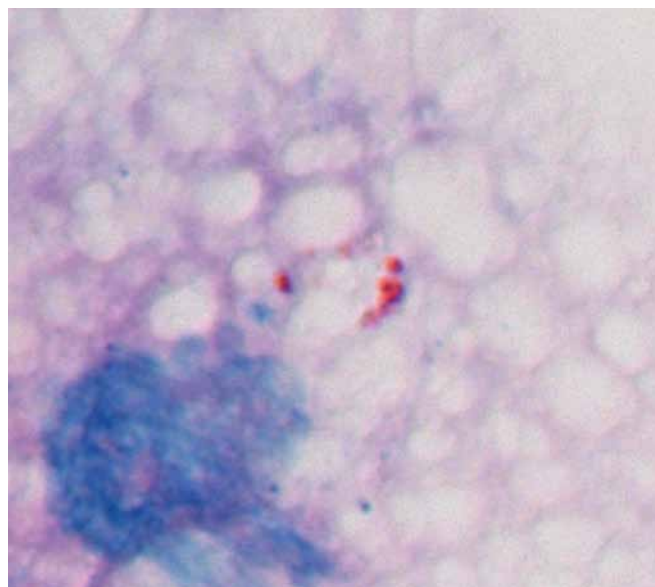
One risk factor that has been identified is the genetic makeup of the host and samples collected from the CD patients in Canterbury have confirmed this, with genetic variability identified more often in CD patients than in healthy controls. Interestingly, most of the genetic variants identified in CD patients have a role in controlling the interactions between the gut lining and bacteria. This is of real interest to us as it strongly suggests that another contributing factor to increased risk of CD is likely to be the gut bacteria.

A human typically carries ten trillion (that's 1 with 12 zeros after it!) bacteria in their gastrointestinal tract at any one time. These bacteria are usually acquired in early childhood and represent the host "microbiome" throughout life. Moreover, like a person's genes, their microbiome is usually unique to themselves. However, we still don't know whether it is these bacteria that contribute to an increased risk of CD or, instead, bacteria that are acquired as the result of exposure to environmental pathogens.

One bacterium that has been the focus of our research is *Mycobacterium avium* subsp. *paratuberculosis* (or MAP for short). These bacteria have been implicated in the development of Johne's disease in ruminant animals (such as cattle, goats, sheep or deer) worldwide, including farmed animals in New Zealand.

Intriguingly, Johne's disease in animals presents with strikingly similar pathology to CD in humans, which has increased our interest in MAP as a potential bacterial risk factor for CD in our community. Indeed, studies in Christchurch have shown that people presenting with CD are more likely to carry MAP DNA in their blood than healthy controls.

In the laboratory, we are studying how MAP (which are generally considered non-invasive bacteria) might get from the human gut into



MAP bacteria (pink) and human white cells (blue) at one (top) and five (bottom) weeks post infection. (Image from Dayle Keown's MSc Thesis)

the white blood cells, where they take up residence. With funding from the Bowel and Liver Trust, we have been exploring the idea that an acute gut infection might play a role in this process. New Zealand has one of the highest rates of *Campylobacter* infections reported in the world. People infected with this bug get diarrhoea and this is associated with a "leaky" gut. While this leakiness may only last for a few days, it provides the means for bacteria like MAP to cross the gut barrier and hide in white cells (see figure).

Dr Jacqui Keenan

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Hepatitis C: Frequently asked questions

How common is Hepatitis C?

An estimated 50,000 New Zealanders are infected

How do people get Hepatitis C?

Risk factors include injecting drug use, tattooing or body piercing using contaminated equipment, unsafe medical, dental or cosmetic procedures and blood transfusion prior to the introduction of screening in 1992. Sexual transmission and mother-to-infant is uncommon.

Is Hepatitis C a big deal?

Hepatitis C is the most common reason for liver transplantation in New Zealand. It is also one of the most common causes of liver cancer and death due to liver failure.

Is there a vaccine for Hepatitis C?

In contrast to Hepatitis B, there is no vaccine against HCV, and whereas Hepatitis B can be treated but not cured, it is possible to cure HCV with a course of medication.

Who gets which treatment for Hepatitis C?

Factors in the doctor's decision whether to treat are currently

complex. Many HCV patients are being treated in clinical trials both within the Gastroenterology Department and in trials available at the Christchurch Clinical Studies Trust (CCST). Tracy Noonan is responsible for the Gastroenterology Department HCV clinical trials patients. To enrol, the patient must fit the strict requirements of the trial protocol. Standard treatment also exists for Hepatitis C although there are many issues to discuss with patients to ensure that they are ready to embark on a treatment course.

What's new for Hepatitis C treatment?

It is an exciting time to be working in this field, with the development of new medications which will increase the treatment success rates and reduce the duration of treatment for most.

We expect that PHARMAC will approve funding of at least one of the new Protease inhibitor drugs soon. Other drugs which do not have the major side effects of current Interferon-based treatments are in the late stages of clinical trials and are expected to become available in due course.

Linda Erikson

Make a real difference to gut health in New Zealand

If you would like to support the Bowel and Liver Trust in its work then please consider a donation, bequest or becoming a supporter.

You will regularly receive newsletters and information about upcoming events and projects.

You can contact us by email at: info@bowelandliver.org.nz

Or you can make a donation at: <http://www.bowelandliver.org.nz/donate/>

The Role of the Hepatitis Clinical Nurse Specialists

Judith McLaughlin and I share the Hepatitis Clinical Nurse Specialist (CNS) role in the Gastroenterology Department at Christchurch Hospital. The main focus of our position is supporting patients who have been referred by the gastroenterologists for treatment of Hepatitis C (HCV). Tracy Noonan, Gastroenterology Department Research Nurse, coordinates the care of HCV patients who have been enrolled in clinical trials.

Before a patient starts treatment, Judith or I meet them to discuss the likely impact of treatment, which lasts for six to twelve months and has chemotherapy-like side effects. We outline the treatment process and explain the need for close monitoring including four-weekly blood tests and appointments at our nurse-led clinic.

As well as thinking about starting treatment, we emphasise that being able to cope with treatment and complete the full course is critical to maximise the chance of a cure. We explore what their strengths and supports are, discuss contingency plans if time off work might be needed, and ensure that they understand the requirement to use contraception for the treatment and follow-up period.

Once we have arranged their baseline tests and arranged their prescription, we ask them to come to an appointment for their first injection. We teach them how to self inject the subcutaneous interferon injection and check that they are storing their medication and disposing of their syringes correctly.

We provide advice regarding the quite severe 'flu-like' symptoms following the first injection, and reassurance that the symptoms will reduce after the first two or three weeks.

During the treatment period we monitor blood test results and advise any required medication dose reductions in conjunction with their specialist. We have a wealth of experience in managing side effects, and if necessary we arrange referrals to other specialists. We must act swiftly if there is any question of emerging depression. Irritability and anxiety can affect relationships at work and at home.

Really our role is to listen, encourage, remind, advise and at times be quite firm with people to maximise their chance of completing treatment and follow up. We claim to be rather good at detective work as on occasions we call on our network of contacts with pharmacies,



Hepatitis Clinical Nurse Specialists Linda Erikson and Judith McLaughlin

GPs and caseworkers from other agencies to locate people who may be difficult to contact.

The Clinical Nurse Specialist role is changing and evolving. Judith has developed a series of EXCEL spreadsheets to record treatment referrals and track treatment outcomes, and to identify suitable candidates for clinical trials. She keeps current details of pending clinical trials to ensure that as many patients as possible can be enrolled.

A new task for us is to coordinate and check the required six-monthly ultrasound referrals, blood tests and appointments for 150 or more patients with liver cirrhosis in the care of the Gastroenterology Department. We have developed online progress notes so that they can be accessed in the absence of the clinical notes. We act as an information resource for other health professionals and community groups and are available for teaching sessions.

We work closely with the Christchurch Hepatitis C Community Clinic which plays a major role in diagnosis, assessment and referral of people who are unlikely to engage with a GP. We sincerely hope that funding will be continued for the Community Clinic.

During the next few years our role in hepatitis C treatment might diminish if the goal of effective, short term treatment with minimal side effects is realized. Because there is a large number of people whose HCV has never been diagnosed or treated, we believe that the Hepatitis CNS role will be increasingly involved with an aging population with advanced liver disease.

We are extremely grateful to the Bowel and Liver Trust's support over the years to improve outcomes for patients with Hepatitis.

Linda Erikson

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Coeliac Disease – *focus on local support group*

Few people realize that coeliac disease affects 1/84 Cantabrians. This was one of the major findings of research performed by Dr Bramwell Cook and colleagues that was supported by the Bowel and Liver Trust in the 1990s. While coeliac disease is common, most who have it have not been diagnosed.

The good news is that the diagnosis can be made easily with a blood test and confirmed by a simple procedure called a gastroscopy where a flexible tube is introduced through the stomach and a small piece of the lining of the small bowel or duodenum is biopsied.

Unlike many medical conditions, the treatment of coeliac disease requires patients to strictly adhere to a specific diet – the gluten free diet. While this may sound simple, lifestyle change is often more difficult to achieve than taking a medication.

The Christchurch Coeliac Support Group meets three or four times per year to provide support and information to patients with coeliac disease, dermatitis herpetiformis and those advised by their doctor to follow a gluten-free diet for medical reasons.

Meetings usually take place in a local restaurant or café or a member's home. Cantabrians following a gluten free diet are increasingly well catered for by restaurants, cafes and retailers.

Coeliac New Zealand works with local support groups and provides a national voice for people with coeliac disease. In addition to working with patients, Coeliac New Zealand works with dietitians, doctors and food manufacturers.



Christchurch Coeliac Support

contact persons:

Lyn:

Email: lyn390@gmail.com

Telephone: 385 1881 (after 6pm)

Heather:

Email: heather.abrams@stgeorges.org.nz

Telephone: 021 2146607

Natalie:

Email: john.ston@paradise.net.nz

Telephone: 942 0062

Help line 09 820 5157

Website: www.coeliac.org.nz

In the next issue:

- An update on capsule endoscopy – pill cam in action
- An Introduction to IBD Nursing
- Crohn's and Colitis NZ and the Canterbury support group – an introduction and update
- History of the Bowel and Liver Trust (Part 2): the first ten years
- An update on recent research activities

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A New Approach to Medical Diagnosis – *the SIFT-MS*

Imagine simply breathing into a machine to diagnose a medical condition or disease. This may seem fanciful but this could be the future of medicine according to Associate Professor Richard Gearry, Bowel and Liver Trust Trustee and Gastroenterology researcher.

The Bowel and Liver Trust is embarking on a new fundraising project to purchase a SIFT-MS machine, which retails for \$250,000. The machine can measure volatile organic compounds (VOCs) in breath or other gas samples.

The SIFT-MS machine also known as the Voice200 is designed and manufactured in Christchurch. While the primary use of this machine has been for detecting minute amounts of toxic gases in confined workspaces or other environments, medical researchers in Christchurch have identified clinical uses for this technology.

Dr Michael Epton, Respiratory Physician and head of the Canterbury Respiratory Research Group says “We have made major steps in understanding how best to use this technology in medical and other scientific research. With this background we can now move forward with carefully designed projects in many medical and related fields.”

Dr Malina Storer, Research Manager of the Canterbury Respiratory Research Group says, “Several research groups within the CDHB and the University of Otago have been using SIFT-MS as an important tool for their research. The success of these early studies has given us all confidence that use of this technology will continue to benefit research and eventually routine health care.”

“Raising funds for such an important piece of research equipment that crosses so many different areas of health is a new challenge for us but one that was a natural progression from our previous projects” says Derrick Abbott, Chair of the Bowel and Liver Trust.

“After seeing the many applications of this machine in bowel and liver disease, the wider benefits to other areas of medical research will enable us to partner with other organisations on this project.”

At present, local researchers plan to use the equipment to perform ground-breaking research in the following areas:



Dr Malina Storer from the Canterbury Respiratory Research Group shows how easy it is to use the Voice200.

- Bowel cancer
- Inflammatory bowel disease (Crohn's disease and ulcerative colitis)
- Irritable bowel syndrome
- Liver disease
- Environmental and pollution exposure
- Occupational exposure
- Anesthetics
- Intensive Care
- Airway inflammation and infection
- Nutrition (including specific diets and nutraceuticals)

Contact the Bowel and Liver Trust to find out more about this project and support this cause.

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Tom Currie Summer Studentship

I'm Tom Currie a 5th year medical student. This summer I undertook a summer studentship with Mr. Tim Eglinton, a colorectal surgeon at Christchurch Hospital and Senior Lecturer at the University of Otago, Christchurch. The Studentship studied the impact of a modern medication on the treatment of perianal Crohn's Disease.

Crohn's disease is a form of inflammatory bowel disease (IBD) that can affect any part of the gut from the mouth to the anus. It is over represented in Canterbury when compared to international rates. Approximately 1 in 3 of these patients develops problems in and around the anus (bottom) including abscesses and fistulas (abnormal tracts between the anus and the skin). Recently developed medicines known as anti-TNF- α antibodies have been used with some success to treat these complications of IBD.

The aim of my studentship was to determine the outcomes of patients treated with these medicines in Canterbury since their introduction and in particular whether any particular patients were more likely to respond to these medicines than others.

Seventy-five patients qualified for the study and data was collected from patient notes. The main findings were that 73% responded to the anti-TNF- α therapy but only 20% healed completely. We couldn't identify any definite factors predicting a successful outcome with this treatment. However, we did find that the patients that didn't respond to anti TNF- α therapy tended to have more severe disease and despite their drug therapy many of them still required frequent surgery.

Surgery for severe perianal Crohn's disease can be major, debilitating and can require a permanent stoma. For this reason further research into optimising the current therapies in this disease is necessary.



Mr Tim Eglinton (Colorectal surgeon), Mr Tom Currie (Medical student and researcher), Mr Warner Mauger, Mrs Patsy Mauger, Mr Ron Smith (Bowel and Liver Trust Trustee)

This research will need to focus the optimal duration of therapy, its combination with other medical and surgical treatments and whether any blood or genetic markers will help predict response to these potent medicines.

On a personal note it was a great experience to undertake this research and I'm sure what I learned will hold me in good stead for research in the future. It was also highly beneficial to learn about a disease in depth that affects our community on such a significant scale. I would like to thank Warner and Patsy Mauger for their very generous sponsorship through the Bowel and Liver Trust: this would not have been possible without their help.

Tom Currie



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Contact us by mail or email for more information: PO Box 21074 Edgeware Christchurch 8143 or Email: info@bowelandliver.org.nz

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