

World Inflammatory Bowel Disease Day, May 19th

Thursday 19th May is designated World Inflammatory Bowel Disease Day.

Across the globe 5 million people live with Crohn's disease and Ulcerative Colitis, conditions known as inflammatory bowel diseases (IBD). IBD leads to inflammation of the intestine, and is characterised by periods when the disease is active, and other times when it is inactive and patients may feel perfectly well. Between 30% and 50% of patients will require surgery because of their IBD during their lifetime. Extensive or uncontrolled disease can predispose to colon cancer.

Based on data from studies undertaken in Canterbury in 2004-5, and more recently in Nelson-Marlborough and Otago, New Zealand tops the league table for IBD worldwide, with an estimated 15,000 adults and children with these chronic bowel diseases.

These diseases are most commonly diagnosed in the second and third decades (13-30), just when people are approaching their most productive years and contemplating starting families. IBD causes significant direct and indirect costs and is an enormous economic and social burden on the country as well as on those individuals with the illness.

A recent survey of the effects of IBD on patients' lives undertaken in Europe and replicated in New Zealand (the IMPACT study) found that the majority of patients felt tired, weak or worn out even when their disease was thought to be inactive. Over half felt unable to reach their full potential in education and a quarter took more than 25 days off work in the previous year due to their IBD. Additional complaints pertinent to New Zealand were limited access to specialist care and the long delay to a concrete diagnosis.

In New Zealand until 2009 there was patchy and limited access to modern drug treatments but, with the cooperation of the New Zealand Society of Gastroenterology, the patient advocacy group Crohn's and Colitis New Zealand and the government medicines agency PHARMAC, treatment options for those with severe disease have improved rapidly in the last 5 years. There is no cure for Crohn's Disease, however, and we remain behind most Western health care systems including Australia with a limited choice of medications. The NZSG continue to lobby for access to the latest in therapeutic options.

Caring for IBD patients is a multi-disciplinary task and a vital role in the IBD team is that of the Nurse Specialist. These dedicated nurses are a relatively new phenomenon in New Zealand, and there are as yet too few of them. Across the 20 District Health Boards there are only 12 IBD nurse specialists, whereas, according to the British Society of Gastroenterology recommendations, there should be at least 25. So patient access to their support remains patchy.

Yet all is not doom and gloom. Camp Purple 'Live' has now been going for 2 years. At these camps 50 young IBD patients aged 11-16 from all over New Zealand meet for a fun but also information-filled week. These kids and their caregivers come away from this week realizing they are not alone. The camps are organised by volunteers supported by Crohn's and Colitis New Zealand (<http://crohnsandcolitis.org.nz/>).

Issued by the Executive of the New Zealand Society of Gastroenterology. <http://www.nzsg.org.nz/>

Useful contacts:

World IBD Day: www.worldibdday.org

Crohn's and Colitis New Zealand; <http://www.crohnsandcolitis.org.nz/home>

Pharmaceutical Management Agency (PHARMAC); <http://www.pharmac.health.nz/>