

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

In New Zealand there are approximately 20,000 people living with Crohn's disease or Ulcerative Colitis: almost 1 in 225 people. This group of conditions is called Inflammatory Bowel Disease (IBD). Studies originally from Canterbury and confirmed by other regions have shown that we are in the unfortunate position of having one of the highest prevalence in the world and the rate is continuing to rise.

IBD leads to inflammation of the intestine. When it is active patients may suffer from abdominal pain, fatigue, diarrhoea and intestinal bleeding. At other times when it is inactive patients may feel perfectly well. Between 30 to 50% of patients will require surgery during their lifetime because of their IBD. If left untreated or is badly managed, IBD can lead to colon cancer.

The diseases are most commonly diagnosed in the second and third decades (13-30 years), 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 for 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 (NZSG), the patient advocacy group Crohn's and Colitis New Zealand (CCNZ) and the government medicines agency PHARMAC, treatment options for those with severe disease have improved. However, despite that, we do remain behind most Western health care systems with a more limited choice of the medications needed to control the disease. Having limited access to medications and specialist health care is not without consequences. CCNZ are soon to release a report into the physical, economic and social consequences of living with IBD in the New Zealand context (for further information please contact Brian Poole, chairperson CCNZ brian@crohnsandcolitis.org.nz)

Management of IBD is long term and often complicated. Shortages of specialist doctors and nurses within the DHBs makes the care of this condition less than ideal. There are currently just 12 IBD Specialist Nurses across the country serving a population of 20,000 patients. CCNZ, in collaboration with NZSG, are looking to improve the outlook for people with IBD. There is an annual Activity Camp for children with IBD. The camp, now in its third year allowed 48 children from all over New Zealand, aged 10 to 19 years, to meet together for 5 days of fun.

The World Gastroenterology Organization incidentally has made IBD its primary focus for 2017 with world-wide collaborative events arranged to bolster research and awareness of the condition.

Chances are you know someone personally with IBD. Don't be shy to show them your support, especially on Friday 19th May.

Any media enquiries can be directed to the NZSG President, Michael Schultz 027 610 2395.

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/>