



**16<sup>th</sup> May 2022**

**IMMEDIATE RELEASE**

**MEDIA ADVISORY**

## **WORLD IBD DAY 2022**

There are over 5 million people worldwide who are challenged daily by the symptoms of Crohn's disease and ulcerative colitis (also known as Inflammatory Bowel Disease or "IBD"). 20,000 of them live in our small country, which has the third highest rates of these diseases in the world.

Every year, World IBD Day is observed in fifty countries. It commemorates people of all ages who are affected by these diseases, from the very young to the very elderly. New Zealand's World IBD Day will take place in the Grand Hall of Parliament on 17 May.

This year's IBD event will feature the unveiling of a professional video in which patients across the age spectrum speak very candidly about what it is like to live with IBD. While their symptoms are the same, their challenges at different stages of their lives are very different. Throughout the Grand Hall there will also be an exhibit of over 100 personal stories that New Zealanders with Crohn's and colitis have shared to convey the enormous impact these diseases have on their lives.

The event is being hosted by Brooke Van Velden, MP, who, along with several other MP's, has worked very hard to support the IBD community.

Dr. Richard Stein, gastroenterologist and Chairman of Crohn's and Colitis New Zealand Charitable Trust explains that "These are silent diseases for which there is no cure. They cause symptoms that most people would have difficulty imagining: chronic bloody diarrhoea, severe abdominal pain, and intractable fatigue. While symptoms can often be controlled with potent immunosuppressive medications, this is not always the case. Frequent hospitalisations and surgeries to remove affected portions of the bowel are too often the result. The emotional, social, and financial impact on patients and their whanau is huge. We are patiently waiting for newer medications to be funded here."

### **FOR MORE INFORMATION, CONTACT:**

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## About Crohn's disease and ulcerative colitis<sup>1</sup>:

- Crohn's and ulcerative colitis are chronic, incurable, inflammatory diseases collectively known as Inflammatory Bowel Disease (IBD).
- Over 20,000 New Zealanders have IBD.
- New Zealand has the third highest IBD rate in the world.
- Most people are diagnosed in childhood, their teens or early adulthood, and suffer with these illnesses their entire lives. Children in particular are impacted in their most formative years.
- Symptoms are severe, urgent, bloody diarrhoea, bowel blockages, abdominal pain, perforated intestines, and abscesses and inflammation in the anal area.
- 'Flares' of the disease are common and frequently involve emergency hospitalisation, and repeated irreversible surgeries to remove sections of the bowel.
- Many patients are forced to live with a permanent ostomy (bag).
- IBD has an array of other symptoms including arthritis, diseases of the spine, the liver, diseases of the eyes, skin lesions, and an increased risk of bowel cancer.
- NZ has one of the highest per capita rates of IBD in the world, and it is growing at over 5% per year.
- IBD has profound physical, social and psychological impacts on those living with it, affecting their education, social relationships, work lives, and their ability to have a family.
- IBD costs NZ an estimated \$245 million in healthcare costs and lost productivity.
- There are two effective, but currently unfunded treatments for people with severe Crohn's and Colitis who have failed to respond to medications currently available in NZ :
  - o ustekinumab, which was approved by Medsafe in early 2018, has been given high priority by Pharmac's gastroenterology sub committee, but has not been funded by Pharmac; and
  - o vedolizumab, which is currently awaiting Medsafe registration.

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<sup>1</sup> Snively, S (2017) Reducing the Growing Burden of Inflammatory Bowel Disease in New Zealand.  
<https://www.burdenofibd.org.nz/research>