



11th October 2022

MEDIA RELEASE

EMBARGOED UNTIL 6.00PM TUESDAY 11 OCTOBER

INFLAMMATORY BOWEL DISEASE (IBD) PATIENTS CELEBRATE PHARMAC DECISION

On 2 December 2020, braving the wind and rain, Crohn's and Colitis NZ Charitable Trust led a march of patients and medical professionals to the steps of Parliament. The purpose was to present a petition with over thirty thousand signatures pleading for funding of ustekinumab, an urgently needed medication to treat people with severe Crohn's disease and ulcerative colitis. The medication, also known by its brand name Stelara, is funded in over 35 other OECD countries.

Today, Pharmac announced it has initiated their consultation process to fund the medication, anticipating it being made available to patients with IBD who have failed to respond to other medications in February, 2023.

Dr. Richard Stein, Chair of CCNZ said. "without newer medications, many patients with IBD, primarily children, teens, and young adults, face a life of debilitating symptoms, including pain and bloody diarrhoea, often resulting in repeated surgeries and hospitalisations. The impact on these patients, their whanau, and, ultimately, the entire country is immeasurable. Many patients have been putting important life events on hold, trying to postpone surgeries in the hopes this medication would be become funded soon".

Belinda Brown, CEO of CCNZ, notes that "there are over 20,000 people with IBD in New Zealand, which has one of the highest rates of IBD in the world and the incidence of these diseases is increasing. I want to thank the entire IBD community who worked so very, very hard to voice their need for newer, state-of-the-art medications".

This announcement comes on the heels of the recent announcement that another medication, vedolizumab (Entyvio) is also undergoing the consultation process for the treatment of severe IBD.

CCNZ applauds these recent Pharmac decisions. The ability to fund these medications underscores the impact of better funding of the agency.

The deadline for this consultation process is **4pm on Wednesday, 26 October 2022**. Please email consult@pharmac.govt.nz with your feedback.

CCNZ would like to thank the patients, their family and friends, and the medical specialists who have supported the #wecantwait campaign.

ENDS

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FOR MORE INFORMATION, CONTACT:

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About Crohn's disease and ulcerative colitis¹:

- 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, has just undergone the Pharmac consultation process and should be available for patients in February 2023.

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