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MEDIA RELEASE

For immediate release

MPs to Visit Camp for Children and Teens with Crohn's and Colitis

On 4 January over seventy five children and teens with Crohn's disease and ulcerative colitis from all over New Zealand will be arriving at Camp Carey in Waitakere, Auckland. They will be attending the seventh annual six day camp for children with these diseases.

Crohn's disease and ulcerative colitis have received extensive coverage recently in the media. On 2 December close to a hundred people marched from Civic Square to Parliament, where David Seymour received a petition with over 30,000 signatures asking for funding for desperately needed medication to treat these diseases, medication funded in Australia and 37 other countries, but not in New Zealand. 15% of those affected by these chronic diseases are children and there is no cure.

On the first day of camp four MPs— David Seymour, Brooke Van Velden, Chris Bishop and Chris Penck—will be visiting to learn more about the challenges faced by these children. These diseases affect the intestinal tract and, when symptoms cannot be controlled with those medications funded in New Zealand, repeated hospitals and surgeries often follow.

Camp Purple Live is run by Crohn's and Colitis New Zealand Charitable Trust. The camp, including transportation from all corners of New Zealand, is free for those attending. It gives the children the opportunity to understand more about their illness, challenge themselves, have fun, and, most importantly, learn that they are not alone.

Professor Michael Schultz, Head of the Department of Medicine, Dunedin School of Medicine and one of six doctors who volunteers at the camp, says "The camp gives the children a chance to see their doctors and nurses as people with whom they can talk openly. Nothing can compare to the bond that's formed between these young people and their medical team than successfully dunking them on Carnival Day".

Colleen Flemmer, mum of a camper who has attended camp for the past five years, said "Camp Purple has been life-changing, not only for children, but for their families. The camp has created an extensive support network for the parents and caregivers and has been a life saver for many of us".

Prof Andrew Day, Chair of the Camp Committee and CCNZ Board member, is "especially grateful to the extraordinary young volunteers, almost all of whom have these diseases themselves. They selflessly donate a week of their annual leave to be group leaders and, what's more important, they serve as role models to the children and teens.

Camp Purple is funded solely through charitable grants and personal donations.

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About Crohn's disease and ulcerative colitis:

- Crohn's and ulcerative colitis are chronic, incurable, autoimmune 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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