



10th May 2022

MEDIA ADVISORY

PARENTS RESORT TO PETITIONING STARSHIP FOR BETTER CARE OF THEIR CHILDREN.

Concerned parents are sending a petition with a strong message to Starship Hospital: they are tired of waiting for basic, standard-of-care treatment of their children with Crohn's disease and ulcerative colitis (Inflammatory Bowel Disease or "IBD"). Specifically, they are tired of waiting for the hospital to hire a paediatric IBD Clinical Specialist Nurse, whose role would significantly decrease the chances of their children ending up in the hospital and under the surgeon's knife.

Even though administrators at Auckland DHB readily acknowledge that employing a paediatric IBD Clinical Specialist Nurse would vastly improve the lives of children with Inflammatory Bowel Disease, for years they have refused to take action, placing budgetary concerns over the welfare of the very children they are charged to treat.

After years of pleading with hospital administrators to fill this position, a committee of frustrated parents, doctors, and nurses decided to petition the DHB to bring this issue into the public arena. Within five days the petition has already garnered over 1000 signatures.

Dr. Richard Stein, a gastroenterologist and Chair of Crohn's and Colitis NZ Charitable Trust, explains that "several clinical studies have unequivocally shown that having an IBD Clinical Nurse Specialist on staff results in better patient outcomes, reduces ED visits and hospitalisations. When you add in the fact that we are talking about children here, it is nothing short of neglect".

"This should be a no-brainer, especially when the position will save taxpayers tens of thousands of healthcare dollars. And this is without even mentioning the devastating impact on the children and their whanau".

Stein points out that "almost every DHB in New Zealand funds this position for adults. But Starship, which manages all the children with Inflammatory Bowel Disease in the North Island, will not prioritise this position for children. It is a question of equity and basic clinical sense."

Why is a clinical IBD Clinical Specialist Nurse so important? The nurse provides direct, immediate medical access and assessment to children when their disease suddenly flares. In these situations, it is prompt treatment which prevents lengthy hospitalisations and life-altering surgery. Under the current system, parents must try to navigate through a maze of bureaucracy, often unable to access urgent specialty care. In many instances they finally end up in the ED when their child is in dire straits. IBD nurses are also the primary educators of both patients and caregivers, they manage immunosuppressive medications, ensure that preventative measures such as vaccinations and screening procedures are up to date, provide advice on diet, manage side effects of medications, and ensure compliance with treatment regimens. Not only does the work of the IBD nurse improve patient outcomes, but it significantly frees up time for their physician colleagues to perform other tasks.

Unfortunately, many parents of children with IBD managed at Starship remain totally in the dark about how an IBD nurse can improve their children's lives. It isn't until their children are older and transition into adult care that they begin to appreciate the difference this could have made during their children's most vulnerable years.

Parent Jean Moor has lived through this: “I am a nurse and thought I knew about IBD. I was very wrong. Trying to negotiate the health system was difficult without an IBD nurse to point us in the right direction, and I work in it! My son suffered with chronic pain for years. I firmly believe if we had had an IBD nurse specialist our journey would have been so, so much better! The difference having an IBD nurse for my son as an adult has been amazing and life changing! PLEASE, PLEASE, don't let other children and their families suffer!

Kirsty Koboski, a mum underscores this point. “Our daughter was diagnosed at 17 and we were so fortunate to be on the adult service of amazing IBD nurse, Marian, in Taranaki. I don't know how we would have coped without her expert guidance. I can't imagine what it's like to be at Starship without a pediatric IBD nurse.... how sad”.

ENDS

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Visit the petition at https://our.actionstation.org.nz/petitions/our-children-with-ibd-deserve-the-same-care-as-adults-starship-needs-an-ibd-specialist-nurse-now?fbclid=IwAR1hNtRzzzIQcapuK6r4psGdN0x4dJvxtGEtOMg_Aoxv2ZEADfAIAILzTEQ

About Crohn's disease and ulcerative colitis¹:

- Crohn's disease 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 rate of IBD in the world.
- Most people are diagnosed in childhood, their teens or early adulthood, and suffer with these illnesses

¹ Snively, S (2017) Reducing the Growing Burden of Inflammatory Bowel Disease in New Zealand.

<https://www.burdenofibd.org.nz/research>

their entire lives. Children in particular are impacted in their most formative years.

- The 2021 Auckland DHB budget included an allocation for 139 new registered and senior nurses (information obtained from Auckland DHB through the Official Information Act).
- 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.