



#wecantwait



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Contents

Introduction	1
the heros	3
Harita Gandhi	4
Kellsey Wallace	6
Tim Doherty	8
Danielle Barber	9
James Lowe	10
Lauren Tosh	11
Erin Blair	12
Aaron	14
Tess Rodgers	15
Emma Taylor	18
Mikayla Scott	19
Erin Marsh	20
Jasmika Dadi	21
Courtney Leonard-Wheeler	22
Jennifer Gay	23
Kate Montgomery	24
Danicia Nixon	25
Tamsyn Cornwall	27
Stan Nikitopoulos	28
Shahn	30
Owen	32
Maddy Hayward	34
Becky Rose	35
Sharna Milner	37
Birte	38
Belinda Brown	40
Henry Whitaker	41
Mathew Taylor	42
Emilia Dalton	44
Tama Arthur	46

Joanne Sharpe	47
Shane Barr	49
Emily Morgan	50
Korrin Barrett	51
Rachel	53
Rhys Rigione-Pisone	54
Anonymous letter from a parent	56
Sean Herbert	58
Jessica Port	60
Tabitha Jelichich	61
Nic Burkin	63
Carla Shaw	64
Sam	65
Lee Tymkin	67
Amber	68
Katie Costello	70
Christy	71
Charlotte	72
Anonymous Hero	73
Brigitte Robson	75
Hayley Greer	76
Becs Shaw	77
Hollie Asprey	78
Brooklyn	79
Kirsty Kelly	80
medical team	83
Richard Stein	84
Malcolm Arnold	85
Richard Gearry	86
Jacqui Stone	87
Marian O'Connor	88
James Fulforth	89

Introduction

Dear Reader,

Crohn's disease and ulcerative colitis are "silent diseases". They are diseases which, due to their symptoms, people do not typically discuss with their loved ones and friends. New Zealand has among the highest rates of these diseases in the world. Over 20,000 people are affected. The diseases are chronic, there is no cure, and they usually present in childhood and young adulthood.

It is therefore surprising that New Zealand lags behind the rest of the world in funding medications to bring these diseases into remission, allowing people to enjoy a normal life, rather than facing long hospitalisations and repeated surgeries.

On 2 December 2020, a petition with over 30,000 signatures will be presented to Parliament, asking for New Zealand to fund medication that is funded in over 35 other countries across the globe. The petition is supported by over 100 medical professionals... almost every doctor and nurse who treats these diseases throughout our country.

The following are stories from over sixty patients who decided that staying silent is no longer an option.

Richard Stein, MD, FACG, FRACP

Chairman, Crohn's and Colitis New Zealand Charitable Trust

the heros



Harita Gandhi

Wellington

I was diagnosed with severe ulcerative colitis in 2007 when I was 18 and in my second year of university. Until that point, I had no health conditions and I am the first in my family to have any type of bowel condition. The symptoms were so similar to food poisoning that my GP told me not to worry and it would come right after a week. But of course, the symptoms got worse and I couldn't even eat 3 bites of food without running to the toilet. I had an emergency colonoscopy soon after, where the specialist was able to diagnose me on the spot. I still remember looking at the photos of my intestine compared to a normal intestine and I was shocked at how different mine looked with all the ulcers and blood. This is not how I expected being 18 to pan out!

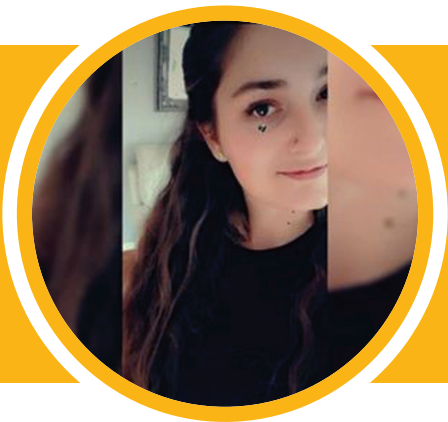
“I still remember looking at the photos of my intestine compared to a normal intestine and I was shocked at how different mine looked with all the ulcers and blood. This is not how I expected being 18 to pan out!”

I took 15 tablets a day for the first year. I had moon face, my hair got thinner, my teeth constantly hurt, and I was always fatigued and in need of the bathroom. I had to go down to part time university studies for 2 years. Instead of enjoying my university years, I was constantly at the doctor's office and in fear of everything I ate.

Since then, I have managed to finish my degree, work full time since 2012, work and live overseas since 2014, and get married. Luckily,

I haven't had any major flare ups with blood since 2012. But I use the toilet a lot more than the "normal" person (5 times a day is my average!) and require routine colonoscopies every 2-3 years.

I know I'm one of the "lucky ones" because I still manage to have a relatively normal life most of the time and I can eat most types of food. But I get tired very quickly, I get the common cold easily, my body is always sore and I have put on a lot of weight over the years due to medications. Simple things like stress, weather change, not enough sleep or eating the wrong food give me a mild flare up. I have been in "remission" since 2013 and returned to New Zealand where I have the help and support of my family. As this is a non-curable disease, I worry that it will continue to get worse as I get older and may affect my chances to have children and cause other health problems.



Kellsey Wallace

Wellington

Before I was diagnosed, I knew nothing about IBD. After I was diagnosed, I still didn't know and struggled to find information. Currently 20,000 NZ'ers suffer terribly from this disease, which is chronic, life long and has no cure only nasty medication or surgery.

After numerous trips to my GP explaining to them that going toilet 30-40x a day with so much blood and pain isn't normal. They gave me medication to stop me going to the bathroom, which never helped and never was going to. My pain was insane. It got to the point I was calling in sick from work, I couldn't sleep, I was having hot flushes all night and sweating up a storm. I became unable to control my bowels and if there wasn't a toilet around, I was in trouble. I literally had 5 seconds to get a toilet or else. Lucky I always made sure there was one nearby. It made daily life so uncomfortable. I was too tired or sore to play with my daughter who was nearly 2 at the time. Seeing my daughter upset and not understanding why I had to be away from her and have all these lines in my arms, bruises, and so sick broke my heart.

“My teeth are horrible, my joints are killing me, I’m tired all the time, I can’t eat a lot of my favourite foods”

In September 2017 I was admitted to hospital, had IV steroids, and an iron transfusion. I was discharged 6 days later and put onto Humira and azathioprine. Since then I've had multiple hospital admissions, changes to my meds, drug trials, and more changes to my meds. I'm now currently on my last attempt at a funded medication (infliximab) before surgery becomes my only option. My teeth are horrible, my joints are killing me, I'm tired all the time, I can't eat a lot of my favourite foods like broccoli, spinach and all

my favourite green veges, and I frequent the bathroom up to 30 times a day. I am now mid flare again as I believe the infliximab isn't working as it should. I've just had two infusions in the space of a week to try and get my flare under control. One of the meds I'm on is azathioprine. It causes sore muscles, sore joints, pancreatitis, organ damage, fatigue, nausea & vomiting & hair loss. Its job is to lower my immune system right down so that it will stop attacking my diseased insides. This means I could catch everything going!

I desperately wish I could just get better now so I could live my best life with my darling daughter. It kills us both when I'm in hospital. She doesn't understand why her mummy is so sick all the time, and why I always have to go away to get better. She is my biggest motivation in trying to get more medication funded so people in the same situation have a chance at living life like we deserve.



Tim Doherty

I was diagnosed in 2010 after six long months of almost continuous diarrhoea and many visits to my GP ruling out all the common and simple things till, I was referred to the gastro department. I was diagnosed with ulcerative colitis and told my entire colon was affected. I was prescribed a series of medicines and spent the next few years with good and bad patches.

During some bad times, something as simple as having a shower was not straight forward. I would go to the toilet before, and after feeling fine and emptied, mid shower have to stop the water and rush to the toilet. Then clean up, finish the shower and have more urgency to go again! It was a very isolating experience to go through as I didn't want to be away from a toilet. I had other symptoms including a lot of pain and nausea.

I managed to stay employed the whole time, but my number of sick days skyrocketed compared to before.

During my medication rollercoaster I was on most of the options around, I suffered some side effects from weight fluctuations, liver problems and damage from certain drugs and even a case of pneumonia which landed me in hospital! I was put on infliximab which is one of the biologic drugs and while it was great for my symptoms, it tanked my immune system and I was told I wouldn't have it anymore. With no other options I was told it would be drug trials or surgery. I tried a drug trial and after a bunch of paperwork and time I was not admitted as I wasn't bleeding enough for them.

If other drugs were available, who knows what may have happened, in the end I chose surgery and to have my entire colon permanently removed with 3 surgeries. It is also important that people do not stigmatise those who need or seek this type of surgery. My life is much better now, but I am forever changed and can't go back to how I was before.



Danielle Barber

Christchurch

“I would like to live without the burden of this disease”

I was diagnosed with Crohn’s disease in December 2016 after two months of symptoms. I was hospitalised many times as my condition worsened and required a subtotal colectomy in August 2017, resulting in a colostomy. The disease was again unable to be managed with medication following this and I had a total colectomy on Christmas day 2017, resulting in a permanent ileostomy. During this time I was being fed through either a nasogastric tube or a PICC line, in constant pain, unable to move without vomiting, developed large ulcers in my mouth and oesophagus and countless other symptoms. The ileostomy developed a significant prolapse and this was surgically repaired March 2019. Since then, Crohn’s has manifested outside of the digestive tract in pyoderma gangrenosum, erythema nodosum and abscesses that have required minor surgery to drain. Even with surgical intervention, the current medications have not been able to fully control the symptoms of this disease. I worry that my future includes a very poor quality of life if these medications continue to remain unavailable in New Zealand. I would like to live without the burden of this disease, but I don’t believe that is possible while relying on the current medications.



James Lowe

Christchurch

I was diagnosed with Inflammatory Bowel Disease (UC) at age 25. I have just made it past my two-year mark and I have to say thank you to my best friend infliximab or more commonly known as Remicade, which has ultimately saved the normality in my life.

This rollercoaster ride has definitely had its ups and many downs. I have had 14 hospital admissions in my first year diagnosed, which meant I spent almost 1 week per month in the gastroenterology ward in Christchurch hospital. I was given intravenous fluids and steroidal medications through IV to help get my disease under control and had to undergo multiple colonoscopies and sigmoidoscopies. These surgical procedures highlighted that my entire large bowel was damaged by my immune system and it was deteriorating rapidly. I was suffering constant PR bleeding and I almost forgot what it was like to go to the toilet normally. I then fell ill to another condition brought on by non-stop PR bleeding, Pulmonary Embolism (PE). This was caused by the internal blood clots formed in my large bowel which then travelled to my lungs.

I had to go through multiple medications since being diagnosed, most failed me. I am currently in remission thanks to my special authority to have infliximab 4 weekly as it wouldn't work for me 8 weekly, along with a newish drug called thioguanine which I take daily in pill form. The scary thing is, what next? I don't have a plan B. If I somehow lose my special authority or my immune system creates antibodies for my current treatment, I will have no other options apart from surgery. Ustekinumab or alternatively known as Stelara is that plan B, my other option if all else fails. #wecantwait



Lauren Tosh

Gore

You might be looking at this photo and thinking, “Oh, Lauren looks like she’s having a great time enjoying beautiful weather”.

Can you tell an hour before this photo was taken; hubby struggled to get me to leave our home? Can you tell I had been curled up in bed crying? Can you tell it was next to impossible for me to get myself ready and out of bed that afternoon? NOPE.

The truth is photos on social media and the Internet, in general, can be so deceiving. What you see here is a woman with Crohn’s and 37520572 other ailments, smiling because that’s what you do in a photo. You smile.

Hi, I am Lauren, 33 years old and living with Crohn’s & a colostomy plus multiple perianal drains. My struggle with Crohn’s derailed my career, my prospects for further education, many of my friendships, my sense of self, and my personality in my early 30s when my life was supposed to just be beginning. I had over 30 surgeries in three years along with hundreds of procedures and imaging studies since my diagnosis. I’ve dealt with Crohn’s, several fistulas, horseshoe tracts, abscesses, pyoderma over the years in addition to multiple perianal setons & tubes.

To those struggling perianal fistulising Crohn’s disease, my heart goes out to you. Please know you aren’t alone in this battle and together we will face every high and every low.

Please sign the petition to help us get more medication funded in NZ for patients like myself, I have been on 2 infusions and both, I had allergic reactions to and I’m now on weekly Humira injections which is now not working for me.



Erin Blair

Dunedin

When I was about 26, I started to get stomach cramps and a little PR bleeding and was told it was Irritable Bowel Syndrome and due to having my gallbladder out at 18. OK cool I can handle that.

In 2013 I got very sick and spent many months in hospital before being diagnosed with UC, I had been suffering from it for years they reckon not IBS. After having Remicade/infliximab for treatment, I went into remission.

Late 2017, I started to have more pain, PR bleeding and generally unwell. Late December I started talking with the specialists about what the plan would be, another infusion of Remicade/infliximab.

“He told me they were going to take out my bowel. I remember saying to him that I wanted I keep it. The nurse said that if I didn’t get it taken out, I’d be dead in 6 hours. I told him I didn’t want it anymore.”

January 16th, 2018, I had my infusion. 6 days later, I suffered a severe allergic reaction. Rushed back into hospital where the doctors tried everything to save my bowel. After a couple of days of me getting sicker and sicker, the surgeon was called in. He told me they were going to take out my bowel. I remember saying to him that I wanted to keep it. The nurse said that if I didn’t get it taken out, I’d be dead in 6 hours. I told him I didn’t want it anymore.

So out it came and I was left with an ileostomy bag. Not only that but I was still very ill, in HDU for a week then on the ward for another 6 weeks. It took 16 days for my bag to work, so I had a nasal gastric tube in my nose and I couldn't eat. Had 3 pumps, a pic line feeding me liquid food, plus, on top of all that, I had to get to grips with having a bag.

When I was recovering, I found out that I had not only had the reaction but also was suffering from a rare condition called Sweet Syndrome, which as we found sped up the disintegration of my large bowel.

A friend of mine, who had had an ileostomy bag due to bowel cancer, gave me some great advice on how to care for my stoma, etc. She also told me I should name my stoma to help me connect with it. But I really didn't want to name it because at that point, I hated it!

Fast forward to today, I'm still bowel-less but pretty healthy considering everything. My stoma has a name, Phil.



Aaron

My Crohn's journey started 21 years ago, at the age of 10, after a 1-year diagnosis period in which I nearly died. I spent most of my adolescence on steroids resulting in stunted growth, thin bones, and various other side effects while growing up.

At 24 my disease had become so bad I had surgery to remove 30cm of bowel. I was put on Humira and got 5 years of remission. In 2018 my symptoms began slowly returning. I eventually went onto double dose Humira (adalimumab), and now in 2020 onto Remicade (infliximab).

Unfortunately, this too is proving ineffective at regular dosing intervals and I have just been approved, on compassionate grounds, to move onto 4 weekly infusions (effectively double dosing). I also take Methotrexate via injection as my body doesn't tolerate azathioprine/6MP/6TG which are other common treatments. This is to supplement the Remicade and also help prevent my body from generating antibodies against the Remicade.

The effects of Crohn's I have experienced/still experience are numerous including bleeding, diarrhoea, weight loss and gain, anxiety, depression, pain, nausea and insomnia to name just a few. Then of course there are the numerous social issues that come with such a disease.

Should Remicade fail me, my only remaining options are surgery or drug trials. As it stands Pharmac only fund two biologics in NZ (Humira and Remicade) for the treatment of Crohn's. There are many others in a similar situation to me, running out of drug options, this is why #wecantwait

Photo taken during remission 3 years ago.



Tess Rodgers

Christchurch

Crohn's disease - My constant companion

When I was in my late teens, I was diagnosed with Inflammatory Bowel Disease. IBD is an umbrella term used to describe conditions like ulcerative colitis and Crohn's disease. At first, I was classified as having ulcerative colitis. My body was attacking itself, the front-line attack stationed in my large bowel.

Hospitals, drugs, failed drugs, hospitals, blood transfusions, new drugs, hospitals... You get the picture. As my colon was slowly overcome, surgery became my only option.

Ulcerative colitis and Crohn's disease are similar conditions. But they are also different. Crohn's disease can exist anywhere in your gastrointestinal tract, from mouth to rectum. But ulcerative colitis only exists in the large bowel. For me, this was the silver lining. An absolute blessing. With surgery to remove my colon, my disease would be removed and as a patient with UC, that would be that!

Some time after surgery I was given the devastating news that perhaps they were wrong... Maybe it was Crohn's disease after-all. They couldn't really be sure. My symptoms and samples were blurred and conflicting. I was given two possibilities.

1. If it was in fact ulcerative colitis, I would remain symptom free.
2. If I became unwell again, then they would know for sure. It would be Crohn's.

If it was Crohn's, it would likely raise its ugly head again... but nobody could predict when, where or how.

I was perfectly well for 8 whole years. Living with a stoma obviously has its challenges. But daily living became a whole lot easier! I learned to love my stoma. It was a whole lot kinder to me than the bowel I was born with. And as time went on, I slowly started to relax. Then I developed a fistula. A gift only Crohn's can give. Crohn's is sly. It burrows. It likes to create little tracts from one part of the body to another. Fistulas. These can be painful, complicated and often require surgery.

And so there it was. Just like that. 13 years after initial diagnosis, my condition was reclassified. It was undoubtedly Crohn's disease.

More drugs. New drugs. Biologics this time. Injectable immunosuppressants. I injected myself every two weeks and things settled down. But the payoff was I was slammed by every single cold and flu bug that even came close to me. Stopping and starting the drug. Antibiotics after antibiotics. Weeks and weeks and weeks.

The worst part of living with an illness is uncertainty. There is no certain endpoint. Sometimes when you sense the finish line in the distance and you start to relax, the finish line moves away again and another challenge jumps into your path.

1 failed biologic. 1 new one. This time an infusion. Nonetheless another immunosuppressant. And so here I am. Crohn's disease - My constant companion. My teacher of lessons.

This year has been challenging. A realisation I will never really be free of this. But with this new knowledge also comes a greater desire to advocate, educate and share.

We need to normalise this thing. We need to talk about it.

Approximately 20,000 people in NZ suffer from IBD. And this number is rising rapidly. IBD isn't a glamorous disease. It's hard to talk about, it's private and embarrassing. It doesn't get much screen time in the public eye. In NZ there are limited treatments available and we really need to change this!

So please talk about IBD and sign the petition for better funding and access to medications!

***“We need to
normalise
this thing.
We need to
talk about it.”***

Tess Rodgers

#wecantwait

Crohn's disease



Emma Taylor

Wellington

I am from Wellington and was diagnosed in 2015 with ulcerative colitis. Doctor's tried numerous medications and procedures, however after a year they soon decided surgery was the only option to relieve my IBD.

I have had three major surgeries. The first surgery was to remove my large bowel and give me a temporary loop ileostomy and a mucous fistula. The second surgery was to create the j-pouch and move the fistula to where the ileostomy was located. My third surgery was to join my loop ileostomy and mucous fistula back up and allow my j-pouch to function. I now live with a j-pouch but still suffer some mild symptoms of IBD.

“A future without medication choices would be awful.”

A future without medication choices would be awful. Even though I have had surgery, I still go to the bathroom at least three times a day, however without medication I can often go at least six times a day. If I am having a flare it can be anywhere up to ten times a day. Medication certainly helps this, so I would suffer without it. I would be a lot more confident going out in public knowing I do not have to look for every single toilet for that 'just in-case moment'.



Mikayla Scott

Dunedin

I am 21 years old and at the start of this year, I was diagnosed with ulcerative colitis. Since I was diagnosed with UC, I have been on three different medications and none of them have worked.

One of the medications made my white blood cells drop very low. This causes me to get very sick and so I had to come off it. I have been on and off steroids all year and now I am still on them.

I was meant to be going on trial medications but before my birthday I found out that they cancelled the trial. I was then told that there was another trial coming up, but we did not know how long it was going to take, due to COVID nothing has come up yet.

“My life this year has been put on hold and I have missed out on so much.”

Because of this disease, I have had to leave one of my jobs and also have had to cut my hours back to only 7 hours a week at my other job. My life this year has been put on hold and I have missed out on so much. I should be as people say, enjoying life, going out with friends, or going away for the weekends. Now it has come to the point where I have to get my colon removed and live with an ileostomy.

To be told at 21 years old that you will have to have a major surgery done is a lot to take in especially when it is life changing. Now if these drugs were funded it could have saved me from losing my colon for the time being, it could have delayed it for at least a few years.



Erin Marsh

Hawkes Bay

I was diagnosed with Crohn's disease in 2013 but had major bowel issues for years prior. Only this year have I finally gone into remission after many tests' operations and drugs. I had a resection of my terminal ileum at the start of my journey because of a stricture that they tried to stretch but failed so had to be removed, they removed all my diseased part of my bowel so I thought yay this is great... within 6 months it was back.

I keep having stricture issues in the same area , now due to having the surgery I now have lesions that are causing me a bit of pain. I had such bad ulcerations couldn't eat for weeks and for a few days I couldn't even drink water as they were in my oesophagus and it was so painful. I remember having a colonoscopy and saying to the doc I have chicken pox on the inside because that's what it looked like.

I have had many hospital admissions and nasal gastro tube to feed me as I couldn't even eat food. I have had bad reactions to some available drugs for Crohn's, one being anaphylaxis to infliximab on my 6th dose . I'm currently on the very last drugs available, Humira with methotrexate, that I self inject weekly. They are holding me in remission now but if they fail, I have no other options. The next option would be surgery again.

**“The drugs we are petitioning
for are essential.”**

The drugs we are petitioning for are essential to me to avoid inevitably another operation on my bowel.



Jasmika Dadi

Auckland

May of 2019 is when my journey first started. I was in my final year of University and started becoming unwell during the semester. My focus was always on uni, so it took a month of severe bleeding multiple times a day before I decided to tell someone. In late June I had a Colonoscopy which confirmed that I had ulcerative colitis.

I started on pentasa which originally helped, until I had a severe reaction called Pancreatitis. It was the worst pain and hardest thing I had ever experienced - especially while trying to continue working and studying.

After being hospitalised twice, I decided to try Prednisone which was terrible. I gained weight, never slept & definitely became a lot moodier + it didn't help to settle my flare ups at all. I was constantly tired and hated how lazy I felt. My iron levels dropped to almost nothing which went unnoticed for months until I started seeing a Naturopath. I was given an iron infusion which I later had a mild anaphylaxis reaction to.

After trying a handful of different medications & minimising the stress in my life, I am now on mercaptopurine. I try to maintain a healthy diet but still have flare ups occasionally. It is so tough trying to maintain some normality in life while constantly switching medications. I think that it is only fair for myself and others in the same situation to have all our options easily available. You really never know what medication is going to work for you.



Courtney Leonard-Wheeler

Hawkes Bay

I got diagnosed at 21 years old. I picked up the Gastro bug it never seems to go away. My symptoms got worse I was at work one day running a holiday program and it felt like my leg were filled with concrete. I ended in ED at some insane hour with my mum and me trying to convince the doctors that something was wrong. Sure enough after what felt like a million test and a couple of surgeries that told me I had Crohn's disease. It didn't stop there by the time Halloween came round of that same year I ended up with my new friend Sally (that's my ileostomy name). Fast forward to today I have had countless surgeries, been in hospital more than I would like to admit and have tried all but one medication. The reason why I can't wait is if I get into a flare that one medication is all I have. What if it doesn't work like some of the other haven't. What if I have anaphylaxis again. I now have my family and my young son to think about. I don't want them to see me suffer and I don't want to suffer more than I need too.



Jennifer Gay

Kaitia

“I am almost certain I will face surgery,”

I was diagnosed with ulcerative colitis in 2010. My symptoms began with me passing a little blood every time I went to the toilet. I have tried all sorts of things to manage my disease including almost every diet you have ever read about. I gagged on medications and even went into anaphylaxis shock after taking one medication. I would get sick, manage my symptoms by taking steroids, get well again and then the next month the cycle would begin all over again. I lived in the toilet and struggled to get out of bed. Earlier in 2020, I got sick and this time I did not get better. My Doctor went to perform a colonoscopy, my disease was so severe that they could not even insert the scope. By this stage I was suffering from a loss of appetite and had lost fourteen kilograms in weight. I have tried lots of different medications and experienced side effects from almost all of them. I am currently having infusions and they are working, for the time being. However I am nervous about what my future holds. If for some reason my current medication stops being effective, I am almost certain I will face surgery for the removal of my bowel. This will not stop the symptoms of ulcerative colitis. I really don't want to go back to living within my four walls between my bed and toilet, with the fear of leaving my house in case I have an accident in public.



Kate Montgomery

Auckland

I was diagnosed with Crohn's disease in 2005. I underwent four bowel surgeries due to my Crohn's disease, including a partial, then full colectomy. I had a temporary ileostomy for 9 months in 2010 and a permanent one since 2015. Between 2011 and 2015 my Crohn's disease was so severe, I was bedridden, and spent an average of 3 months in hospital each year. While I've already had my surgery to have an ileostomy, I still have a lot of other symptoms that effect my quality of life, these symptoms have not been helped by the medications currently available, and could be helped by medications that aren't currently available in New Zealand.



Dancia Nixon

Christchurch

I got symptoms of Crohn's in 1995. From then, I spent 3 agonising years being misdiagnosed for a myriad of conditions and was even hospitalised for being anorexic. What was worse was that people commented on how wonderfully thin I was, yet I was dying on the inside. I spent those 3 years in and out of ambulances. I was young and living away from family in my second year of university, I had to give that up just before graduating and return home. In late 1998 at a mere 37kg a locum stood in and my world changed. He talked to me about Crohn's and sent me for further tests. To have a name for what I was experiencing was a relief.

It was caught just in the 'nick of time' as it was about to rupture through my bowel. They say if it had of ruptured, I might not have been here. Crohn's had taken over such a large part of my insides that I was rushed through emergency surgery to remove significant dead chunks inside my body.

It's been almost 20 years for me, and I haven't had any significant flare ups with Crohn's. However, with any auto-immune disease they do not disappear completely and present in other ways. Year on year it seems that if it's not Crohn's then it's just another name for something that feels the same in different parts of my body. I've endured Crohn's, Endometriosis, Graves, gallbladder removal and

"I feel for each and every person around the world who suffers in silence. The pain of this disease is debilitating and has you always living in fear."

infertility, which could potentially be from 'trialled' drugs. My body is a myriad of scars and holes.

I feel for each and every person around the world who suffers in silence. The pain of this disease is debilitating and has you always living in fear. I am not the only one affected by Crohn's in my family. My brother had his first flare up just two years after my operation. Luckily for him they were able to diagnose him really quickly.

Whilst I am one of the lucky ones in remission, I still wonder what will be next for me! I continually have my fingers crossed that in between different conditions I stay fit and healthy, but I watch my brother battle every day with medication and the pain of Crohn's. There must be more out there for people to manage these conditions, the suffering is silent, relentless and endless. It's time for NZ to come up to speed with the research, technology and medicated options available to rest of the world.



Tamsyn Cornwall

Auckland

I was diagnosed with Crohn's disease in 1998 when I was only eight years old. I have had many hospitalisations over the years from my symptoms, too many to count. I haven't had any surgeries yet, but this could be a very real option in my future. I am currently on medication that is not working any more and my body has created antibodies to that medication. I am incredibly anxious about what this means for my future options in life.

"I definitely consider myself an IBD warrior, with a sunshine state of mind, however, to say I haven't struggled would be a lie."

I definitely consider myself an IBD warrior, with a sunshine state of mind, however, to say I haven't struggled would be a lie. Crohn's disease has impacted my life in a huge way: some days I can't even get out of bed and simple tasks like having a shower or making myself food are physically exhausting. I am extremely hopeful that more medication options will be made available soon.



**Stan
Nikitopoulos**
Wellington

I was diagnosed with ulcerative colitis in 2007, being 93 kilos, now down to 58 kilos. I have been living in constant pain throughout this whole time.

I have been on Prednisone off and on throughout this time. I have had many flare-ups, hospitalisation periods, was diagnosed with organ failure on my last hospital admission, constant stomach cramps and soreness and I am always fatigued. I have up to 20 bowel motions, mainly blood only, in a 24-hour period and I go at least 3-4 times during the night. I have had numerous iron infusions due to the loss of blood and regular blood tests. I cannot eat normal food. I have mainly soups, as I find it very hard to swallow any type of food. I have had endoscopies, ultrasounds, CT scans, barium X-rays, with no answers to the problem.

In a twelve-month period from 2018 to 2019, I had 8 colonoscopies. My last colonoscopy had to be abandoned due to so much inflammation that the thinnest available scope was unable to be inserted. I have been on Humira injections, infliximab infusions and Infusion Clinical trials at Wellington Hospital with no success, as I have developed antibodies to all the medications available at present.

I have been advised by one surgeon, to have a total bowel removal surgery. This would result in an ileostomy full time. I did seek a second opinion from another surgeon due to my illness and was advised I may be able to have a J- pouch surgery. If successful, this would require a 3-stage operation. I have rejected both surgeries to date and will continue to battle, hoping that the new medications that are available overseas, will become funded in New Zealand.

“To give those that suffer from severe Crohn’s and colitis an option and not have to have surgery as their only option.”

I am hoping that the new medications that are not funded in New Zealand to become funded for 20,000 suffering Crohn’s and colitis patients throughout New Zealand. To give those that suffer from severe Crohn’s and colitis an option and not have to have surgery as their only option.

The above is only a brief description of my journey with ulcerative colitis.



Shahn

Papamoa Beach

Kia Ora I'm Shahn 31, from Papamoa Beach.

I was diagnosed with Crohn's disease in 2015.

Due to the severity I was placed on infliximab immediately after being diagnosed. I was also on Prednisone for nearly 6 months which saw me gain 15kgs. Alongside many other medications. At one point I was taking about 25 pills a day.

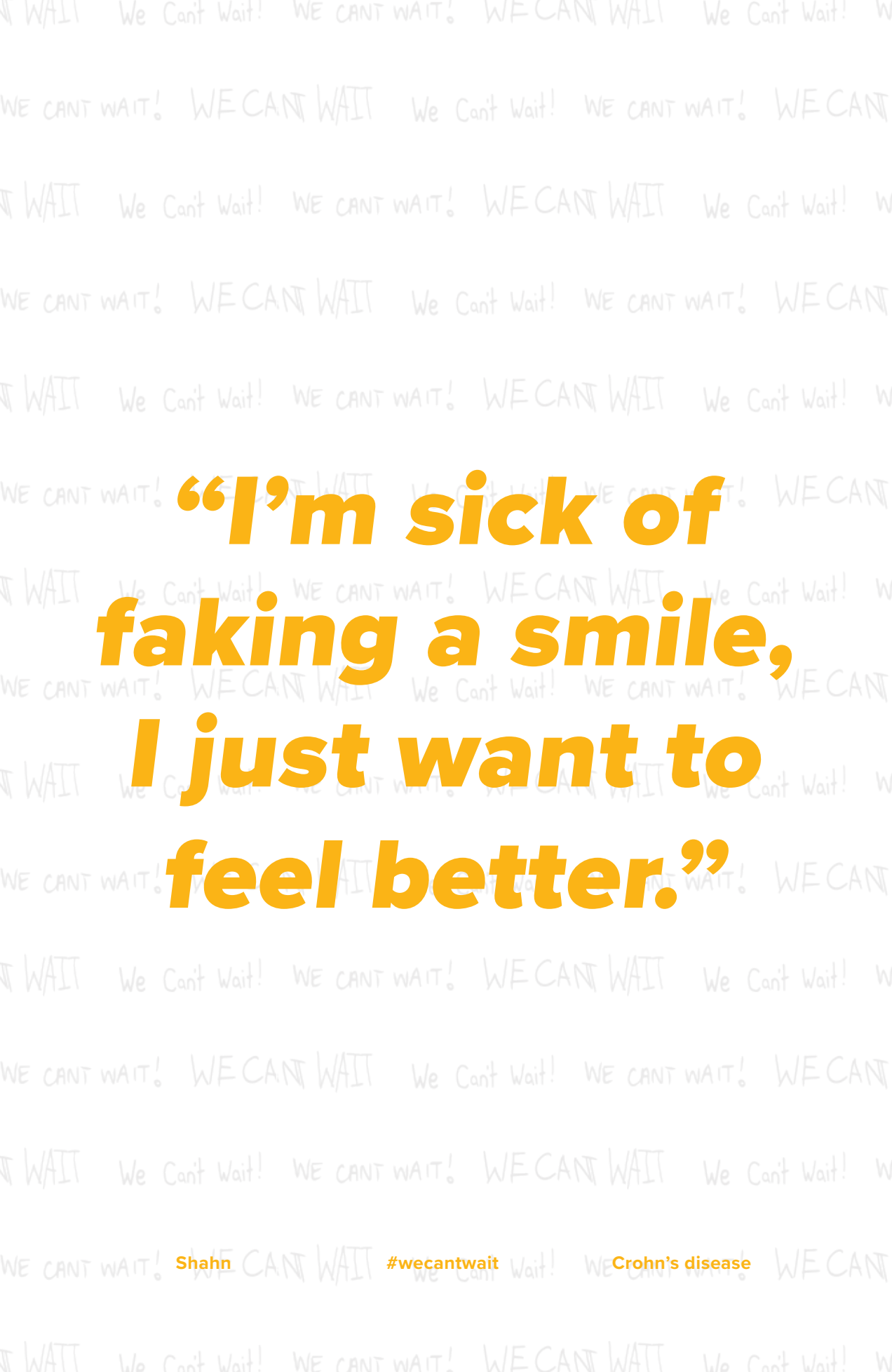
Infliximab was great for a few years but earlier this year after being in a flare for approx. 6 months it was evident my body had developed antibodies against infliximab. I have now been switched to Humira which is a lot more convenient being able to inject myself once a fortnight at home. However my flare still hasn't come right. Being in a flare has caused me to lose 17kgs so I'm constantly being told how great I look; little do they know that it's actually weight loss from being sick. It's hard work living with an invisible illness.

There are many things I struggle with on a daily basis, but my biggest issue is urgency, it's a subject that many don't like to discuss and don't want to know about. But it's my daily reality, if a toilet isn't near then quite often, I won't make it in time. This causes me great distress and gives me great anxiety anytime I leave the house.

My small and large bowels are both greatly diseased and unfortunately it goes right to my colon, I also have scar tissue which sometimes causes a blockage. Due to these I am too severe to have surgery or get a Stoma bag that is reversible. And a permanent bag is not ideal for someone of my age unless it is an absolute last resort.

So as you can see, having access to these drugs could be life changing for me.

I'm sick of faking a smile, I just want to feel better #wecantwait



***“I’m sick of
faking a smile,
I just want to
feel better.”***

Shahn

#wecantwait

Crohn’s disease



Owen

Auckland

I'm normally a very private person and have kept my ulcerative colitis battle to myself and my family, even to the extent of not liking public forums like this one. Recently, I have started to make my illness less secret after inspiration from a brave young colleague who confided in me of her diagnosis and upon hearing about this campaign through my mother-in-law. I realised the importance of this campaign because I am fortunate to receive ustekinumab through my participation of the now complete UNIFI trial. I can safely say ustekinumab has changed my life. I want my story to be a part of this campaign to ensure long-term access for me and to benefit others who may have their lives changes like mine.

My IBD journey starts in 2011, when I suddenly experience cramps and fresh blood in my bowel motions. As a young male nurse, my thoughts first directed to the fear of bowel cancer and I engaged with a Gastroenterologist in private. I didn't have to wait long before my diagnosis post colonoscopy of ulcerative colitis. I met my diagnosis with relief that it wasn't cancer to confusion of what on earth is an IBD??!! I must admit, I just commenced taking the prescribed asacol and didn't learn about my disease.

My next colonoscopy was in 2013 which showed the inflammation had extended and my symptoms were worsening. I was started on azathioprine with cyclosporine as a bridge medication. While my bowel symptoms improved with these medications, the side effects of the drugs were tough to endure. Being a fair skinned Brit immigrant, taking azathioprine while living in NZ was a constant summer battle trying to avoid sunburn. My sun sensitivity was off the scale, and my quality of life was impacted with becoming a sunny day hermit and trying to dampen down my anxiety dealing with skin cancer fears of long-term use.

2014/5 were tough years. I was very symptomatic for most of the time. Aching joints, gross fatigue, terrible toileting, lack of appetite, weight loss etc. Trying to work fulltime as a nurse in a high stress ICU unit, trying to be a father to a 3 yr. old boy and a new-born, there were times I would come home and just collapse with exhaustion into bed, leaving my wife a solo Mum. I was enrolled on a trial called OCTAVE using Tofacitinib. I failed spectacularly!! This shows we in NZ need a choice of medications, not all meds work for all patients.

In 2016, in between courses of high dose steroid to control my flares, I was enrolled into the UNIFI trial using ustekinumab. It was a blinded trial, which means, at first, you don't know which of the three possible doses you are receiving: placebo, low dose or higher dose. At first there were no improvement in my symptoms and I was allowed to keep taking my azathioprine and asacol. I remember not being worried this time, no thoughts I was about to fail another trial, I just believed I was taking the placebo. Then the second part of the trial started. Non blinded, I was to receive the drug. I was very excited; I had read good things in my research of the drug. The change was immediate and fantastic. My toileting improved within a week, not to normal, I'll never be normal with my scarring, but so close!!

Since then I haven't looked back. Whilst I still have off days, with fatigue, aching joints, left flank pain etc, on the whole, I have my life back. This drug is not a cure but is very effective in bringing remission. I don't need to take azathioprine and asacol anymore, I'm just taking the 2 monthly sub-cut injection. I am very grateful for my research team in applying for compassionate supply as a thankyou for being a guinea pig, and I thank Janssen for continuing to supply it for me. My fear is Pharmac, if they do not fund this drug, I worry that Janssen will withdraw and stop my compassionate supply. We need Pharmac to hear us and follow its own expert advice and fund these new drugs. Ustekinumab allows me to be a functional member of society and through my work as a nurse, help others battle their own health issues.



Maddy Hayward

Auckland

| ***“Missing out on life is no fun.”***

I was diagnosed with Crohn's in 2012 when I was 14. I was really unwell in the months leading up to my diagnosis, experiencing fatigue, anaemia, diarrhoea and lots of pain. I felt exhausted and really low. Since my diagnosis I have been really lucky and mainly stayed in remission, but I have experienced these symptoms again when my disease flares up and I have had 5 minor surgeries so far. Unfortunately, the nature of IBD means I don't know what's coming down the track, particularly if I exhaust medication options. Right now I take Humira (with special permission to take twice the typical dose), mercaptopurine, and had my first course of steroids this year. The physical aspects of IBD can be absolutely debilitating but the mental aspects can be just as bad. I am a super optimistic and happy person on the whole, but sometimes it is really hard not to feel down and hopeless about being sick for the rest of my life. I think knowing that there are lots of medication options is so important to give IBD patients hope for the future. Experiencing pain and missing out on life is no fun so I hope that we can get more medication options to help people avoid this, including people who are diagnosed in childhood and have IBD to grapple with along with the usual stresses and joys of growing up. #wecantwait for these options.



Becky Rose

Auckland

In August 2019, Becky was diagnosed with Crohn's disease. While it doesn't define her, it causes her significant pain and she has had many, many hospitalisations and surgery because of it. When the clock ticked over to her 10th birthday, she was in the Starship emergency department, crying in pain. While the disease is now largely under control, Becky is left without a large part of her small intestine, and in fear of a recurrence.

Becky has endured many, many different courses of treatment for her Crohn's - from complete food replacement for over 2 months, to ongoing tablets, injections and infusions of multiple drugs including adalimumab and infliximab. Unfortunately, like many other patients, Becky has developed antibodies to both infliximab and adalimumab, rendering them useless in her fight against Crohn's.

There are drugs, including ustekinumab and vedolizumab, that could help Becky to alleviate her pain, decrease the risks of requiring further surgery to remove affected bowel (with the ultimate risk of having insufficient intestine to maintain her health), and provide a chance to live a normal life. However, in New Zealand these drugs are completely unfunded.

“We are faced with an impossible choice: pay \$6,000 every 8 weeks for the rest of Becky's life, or condemn her to a future of pain and suffering.”

If we lived in Australia, the US or the UK, this would not be the case and Becky could start treatment immediately. However, as we live in New Zealand, we are faced with an impossible choice: pay \$6,000

every 8 weeks for the rest of Becky's life, or condemn her to a future of pain and suffering. We are truly heartbroken by this as would be any parent.

We call on Pharmac to include these drugs in the list of funded medicines, and with urgency.

This isn't an abstract business case discussion. It's about stopping our kid from crying in pain or losing her intestine.

Written by parents Tali and Ben Rose



Sharna Milner

Dunedin

I was diagnosed with Crohn's disease at the age of 21. I was a size 10, weighing in about 45kgs and losing weight more each day. My first colonoscopy revealed signs of Crohn's disease. I went on pentasa for years but every doctor's visit they would ask are you taking your pills? The blood tests measuring my levels were always inconsistent. When I had my next colonoscopy, I was told it's more likely I had ulcerative colitis, but as I had the first diagnosis of Crohn's, it couldn't be ruled out.

I work 30 hours per week to keep me active. Never have any sick leave or annual, as I'd use it all up with this disease. I'd be in the hospital every year for sometimes two weeks at a time with a flare. Even got on a first name basis with some nurses. I've tried every drug possible except for one and now I'm doing drug trials. Why am I doing trials you may ask?

I'm almost at the end of my medication journey. I've built up antibodies or had allergic reactions to the current funded medications. So I take trials in hope that these new medications may get funding in NZ, or this might help someone else and hopefully myself one day.

I've been faking it, to make it nearly my whole life. I've never really let people see I'm in pain, mentally or physically but I tell myself there is heaps of people worse off than me. I've since learnt "it's ok, not to be ok" and take more time for myself.

This picture is of myself and my daughter when I had my last flare.... she is the whole reason I get out of my bed every day!



Birte

My IBD journey started in my mid twenties and it took a while to be diagnosed as the GP's thought I was suffering from haemorrhoids.

Only thanks to health insurance was I finally referred to see a specialist after about 4 months of worsening symptoms (Inability to even go out for short walks due to urgency / diarrhoea / bleeding / accidents etc.)

The consultation was uncomfortable as the specialist “had to have a look” to find out what was wrong... The bad news, it was not haemorrhoids but ulcerative colitis.

At that stage I had never heard of IBD (Crohn's disease or ulcerative colitis) and I went home with the IBD booklet in hand not really understanding what was happening.

Things weren't too bad overall once the shock had worn off and the first flare was under control. Accepting the fact you have to take medications for the rest of your life was not easy and it took many years to come to terms with.

Things probably never fully settled, but you are getting so used to having issues that one can easily forget what “normal” is and keep living with symptoms without realizing it may be time to seek further advice.

The start of an IBD journey can be extremely lonely, often you have very few people to talk about it.

Various dosages of pentasa did keep things well enough until we decided to extend our family. Being young and wanting the best for an unborn baby we decided to reduce the amount of drugs

going into me... much did we know that uncontrolled / active inflammation can be more harmful than the medication itself ! We learnt this the hard way with symptoms flaring and a miscarriage at 12 weeks. Was this related or bad luck? We will never know but it is hard to stop wondering.

After a total of about 8 years on pentasa the medication stopped working and I was put on Prednisone and Immunosuppressants (6-MP) which did help bring the disease under control but also had negative side effects resulting in multiple ED visits and hospitalization.

No more 6-MP and after another try the Prednisone treatment too had to be abandoned due to side effects.

The next step was infliximab for which I am very grateful, however the journey to get approved for this treatment was long and painful and there are already issues with this treatment due to reactions.

How long will I be able to continue on this medication?

How long will it stay effective?

What will be next?

The uncertainty of what the future holds is often as hard as the disease itself. You think things are finally on the up / finally controlled and then the next curveball is thrown your way.

Knowing people in New Zealand had other medical options available would make a massive difference!

We can't wait! It is hard seeing so many people suffer and having to have life altering surgeries just because Pharmac does not want to do their homework! If they would, New Zealanders would have the same access to proven medications already used in 38+ other countries incl. all of Europe and Australia!



Belinda Brown

OPERATIONS MANAGER, CROHN'S & COLITIS
NEW ZEALAND CHARITABLE TRUST

Auckland

I was diagnosed with Crohn's disease in 2002 at the age of 26. After six years of enduring symptoms and many hospital visits, I was told my only option was to have a bowel resection because my disease was so severe. Eight years later, after a pregnancy and two miscarriages, I underwent another bowel resection to remove more of my diseased bowel and adhesions from my first surgery.

As a result of my surgeries and the adhesions from them, I can no longer conceive naturally and had to accept that I was never going to have the siblings, that I had dreamed of, for my daughter. I have suffered bouts of depression and endured many humiliating and degrading side effects of Crohn's disease. It is a real struggle to get myself out of bed some mornings.

“I am desperately trying to prevent further surgeries through medications”

To date I have had sixty centimetres of my small bowel removed and I am desperately trying to prevent further surgeries through medications. I have failed several medications already and am currently experiencing symptoms again. I have one other medication I can try before surgery is once again my only option. I am hopeful more options will be available for people like myself.



Henry Whitaker

Waikato

In August 2019 I was diagnosed with ulcerative colitis. I was admitted into hospital in late October 2019 and spent nine days there with a flare. My flare has been ongoing since then. I have been put on medication but have seen no real improvement. Because I have not responded to the medication, I only see one place I am heading to and that is surgery. Thankfully, I have not had to head down this path yet.

I am back at work but would love to get back to my happy, healthy self. I have had to limit my physical exercise which, as a firefighter has meant I can no longer compete in combat challenges or any other fire service related experiences. I would really hope that more medications were funded within New Zealand for IBD patients like myself, who have had no luck receiving the right medication to help manage their health issues.



Mathew Taylor

Invercargill

At aged 21 I started to pass bloody stools and have stomach cramps. A year later and no improvement I had another colonoscopy and was diagnosed with Crohn's. Started on pentasa and steroids which kept things in check for around 10 years mostly but slowly needing stronger doses.

“A bad day was pretty much 20 odd visits to the loo before 10 am.”

At about this time I caught a cold which developed into a full-blown chest infection which took six weeks of antibiotics to get to clear up which really upset the apple cart. I was then classed as having UC as everything was in my lower bowel and all in one area. My symptoms were pretty random but a bad day was pretty much 20 odd visits to the loo before 10 am and having nothing to pass except blood by the end, which would right my day off and be home in bed to recover. This could start at any time of the day without warning which when working on site was disastrous.

I had just started a family and was unable to go far in fear of an accident, even driving to work was too far away from a toilet some days.

Just over a year ago I became ill again but this was different and put it down to flu. After a 5-day stint in hospital I was told I had caught campylobacter. I also requested a stoma bag at the time, but I wasn't sick enough to warrant one as an emergency procedure and not well enough to have one electively. I started on infliximab and was referred for elective surgery.

Went 5 weeks without having at least one accident a day as I had lost all control of the bowel. This continued after the infliximab did its thing so right up until 24 days ago accidents were still a common event. I am now 24 days post total proctocolectomy (ken bum with ileostomy bag). And have absolutely no regrets.

Surgery had its ups and downs and had a couple of extra days in hospital but already feel a different person and can feel other aspects of my health improving.

My journey would not suit everyone but to me it was only a matter of time before this outcome was inevitable and better to do it while I was healthy and get my quality of life back now. If I knew what I know now and it was possible I would have done the surgery at diagnosis, but at the time it would have been scary without having travelled my journey.



Emilia Dalton

Auckland

I was diagnosed in Feb 2010 with severe ulcerative colitis. In total I have 4 autoimmune diseases/disorders! Over the years I've had numerous hospital visits, many surgeries and countless visits to my GP.

For the last 6 months I've been in a full flare. My body is no longer responding to my usual cocktail of medication and my faulty immune system viciously continues to attack my body!

I'm often told "Oh You don't look sick" but if you'd turn my insides out.... it will tell a completely different story... yes, it is truly an invisible illness to the outside world!

What is it like living with an incurable disease? Well the best way I can describe it is that it's a soul sucking, incredibly debilitating, energy stealing, very painful, physically exhausting, emotionally and mentally draining disease!

Even the simplest of daily tasks become a struggle! Whilst battling with this disease, I am still mum, I still have a full-time job and run a small business! Life doesn't stand still when you're sick!

Through all my struggles, I've learnt that I am a fighter, I'm a proud IBD warrior and my will to survive is stronger than my disease, I fight hard, even though it's got the upper hand at the moment... it will never crush my spirit nor my determination!

By signing our #wecantwait petition you can make a difference by giving us the opportunity to try different medications so that it can enable us to hopefully live a relatively normal life.

***“My will to
survive is
stronger than
my disease.”***

Emilia Dalton

#wecantwait

ulcerative colitis



Tama Arthur

Invercargill

“I don’t want to feel sick again.”

I was diagnosed with Crohn’s disease in 2017, I was 11. I have spent lots of time in hospital and had heaps of surgeries. I did 8 weeks of not eating food and only having special milkshakes to try and make all the ulcers and inflammation inside my body better, it was yuck. My first year at high school I spent most of it at hospital and home and being taught by a health school teacher because I was too sick. I take medicine everyday I need this for the rest of my life. I go to the hospital for one day every 8 weeks to have another medicine called infliximab I have this through an IV line over the day. I am on double doses of this because it wasn’t working properly. Having Crohn’s disease isn’t fun, I feel better now on double doses I don’t want to feel sick again if double doses doesn’t work. I don’t know what other medicine I can have if this stop working, I think it will be good to have other medicines out there.



Joanne Sharpe

Wellington

In April 2019 I had such severe stomach cramps that I ended up in ED. Over the next 6 months I would experience cramps almost daily. No other symptoms came up and as a woman who is used to menstrual cramps I grinned and bared it and got on with life.

In November I went tramping with friends, and at the end of our walk we stripped off to jump in the river. They looked at me strangely and so I looked down and realised I was skeletal. It was the first time I had noticed this dramatic change in my body.

I went to the doctors. A faecal sample showed high calprotectin levels I was referred to a gastroenterologist. I was fortunate to have private health insurance so had a colonoscopy within 2 weeks of referral. This showed severe inflammation in my colon and I was diagnosed that day with Crohn's colitis.

The symptoms then got worse, bowel movements 15 times a day, terrible fatigue and more cramping. I was put on Prednisone and quickly got my appetite back and the weight followed. As I came off the Prednisone it felt like getting sick all over again. I am now on pentasa and azathioprine. The fatigue is hardest symptom to deal with. I can't easily explain it to those around me. I feel constant guilt about not being efficient enough at work and having to take time off when I can't get out to bed.

“There is no silver bullet for this condition and the more options that are available the better the results for Crohn's and colitis sufferers.”

When I read others stories about the length of time it took for them to be diagnosed, I consider myself lucky. I have supportive Doctor's. My gastro specialist calls me after every blood test to let me know how everything looks and always makes himself available by phone, even when on holiday. He cares about his patients and will do everything he can to support them, including lobbying for ustekinumab to be available for free in NZ.

11 months on from diagnosis, I have a long way to go to work out how to manage my condition. I have just started eating fresh food again which feels like a wonderful step forward. Should the azathioprine stop working, Biologics would be the next step for me. It would be great to have more options available including ustekinumab. There is no silver bullet for this condition and the more options that are available the better the results for Crohn's and colitis sufferers.



Shane Barr

Tauranga

I was very ill on and off for 10 years and was diagnosed with Crohn's at the end of 2010.

Cameras up the rear and down the throat were just the start... acid sensor up the nose and down the throat not a fun event.

Had my first surgery Jan 2011. After 4hrs of surgery I was stitched up and ready to mend...or so I thought. My health deteriorated and after a day or 2, scans were done and an infection due to a leak at one of the joins was detected. Back in for more surgery. I now weighed 56kg and had a temporary ileostomy. After 27 days in hospital I was sent home.

After a couple of months my Crohn's symptoms returned with a vengeance. Scans etc revealed a narrowing at one of the joins. Thankfully, this was able to be reached and stretched with a little balloon during a colonoscopy. Obviously, the Crohn's wasn't staying away, I started taking another round of medications.

I then applied for and was accepted for the ustekinumab trial. I felt better within days. Years later when the study was unblinded I was found to have been on the drug rather than the placebo.

I still have Crohn's and have recently had surgery to remove 2 strictures and I have 6 other strictures that may need attending to at some point. These strictures probably started forming after the first operation and have slowly progressed. I can't help but wonder if I'd gone onto the ustekinumab trial earlier, would it have stopped the strictures sooner?

After the risks and challenges that people like myself have faced, I feel it's morally reprehensible that Pharmac does not fund Stelara. #wecantwait.



Emily Morgan

Blenheim

I was diagnosed with Crohn's disease when I was 16 years old. My older sister, brother and Auntie also have Crohn's disease, so we picked it up faster with me. I was very sick throughout college and suffered with anxiety and depression. I thought being in pain everyday was normal. Leaving home was really hard, I was too fatigued to socialise and never had enough energy to do anything. I've had my fair share of countless doctor appointments, hospital trips, changing medications and just trying to balance everything. I was experiencing excruciating pain every single day, diarrhoea, nausea, blood loss, weight gain, constipation, joint pains, bloating and the list goes on.

“People who live with IBD don't want an extraordinary life. We just want a normal life.”

Crohn's disease is a constant battle but if we had more access to medication, hundreds of New Zealanders wouldn't have to live in pain every single day. People who live with IBD don't want an extraordinary life. We just want a normal life. Because we can't wait.



Korrin Barrett

6 years ago (September 16th) I had reversal surgery on my ileostomy and it has absolutely changed my life! I do know just how much getting a bag can improve so many lives but for me it was absolute hell...here's why! This is my story.

In March 2012, while I was living in Australia, I lost my 52 year old mother to bowel cancer so when I started experiencing horrendous pain and blood in my stools in the July of that year I feared the worst and went to see my GP. I had a colonoscopy in August and was told I had very severe ulcerative colitis, I was put on anti-inflammatories and a steroid and told 'you'll be right'...2 weeks later I'm in hospital with fevers, extreme pain and feeling like I might die...7.5 months later I got out of hospital!

Turns out I had a perforated bowel and the hospital had dosed me up on morphine for 7 days instead of finding the cause. I was rushed in for emergency surgery, had 90% of my large bowel removed and was given an ileostomy bag...I was 33 years old and thought my life was over just because of a small bag attached to my stomach, little did I know that was the going to be the least of my problems!

Sepsis meant my body started shutting down, I was rushed in for another surgery and my lungs failed. I was placed on life support and given a 5% chance of survival. I survived but as a result of the sepsis I had to have all 4 limbs amputated, hence the next 2 years with a bag and no hands was absolute hell! I had numerous blockages and surgeries to untwist my bowel and then in 2014, my reversal surgery which means I have a j-pouch and have to be on life long antibiotics and an immunosuppressant but I have quality of life and independence.

“I can only pray that the medication and treatment we’re all entitled to is available if that happens... #wecantwait!”

I’m healthy, living life to the absolute full and for now the medication is working but I know there’s always the chance that might stop one day and I can only pray that the medication and treatment we’re all entitled to is available if that happens...#wecantwait!



Rachel

Otago

I was diagnosed with Crohn's disease 11 years ago at 23 years old. 4 years ago I had to reduce the drug I was on because it was damaging my liver. I spent the next 2 years flared up. I tried the funded drugs, but they didn't work for me. I was losing so much blood I needed blood transfusions, iron infusions and could barely walk 10 seconds without getting dizzy and needing to sit down.

I was so lucky that there was a drug on a clinical trial that I qualified for and it has worked for me. I've NEVER felt this good!! I am aware that most drugs don't finish these clinical trials in NZ and if they do, they're likely not to get funded. They can also take up to 8 years to complete the trial process. I try not to think about how long this drug is available to me and how long I have my good health for.

You're not allowed to get pregnant on clinical trial drugs. At 34, my husband and I now face the decision if we want to get pregnant, I need to give up this drug and my health. I would be facing first time pregnancy and motherhood with a high risk of flaring up again. I'll have no pregnancy friendly drug options to keep my Crohn's in remission. I can't imagine trying to grow and care for a baby when I couldn't care for myself whilst flared up. I would not be allowed back on the trial drug if I come off it. I also can't freeze my eggs whilst on this trial drug.

There's so much uncertainty with this disease. Having more funded drug options would be such a relief for so many people suffering needlessly. I accept every limitation I need to with this disease but it's very hard to accept that there are options available, we just don't have the support and understanding that so many other countries have.



Rhys Rigione-Pisone

Napier

My battle with Crohn's started in 2011, at the age of 15.

At first, doctors thought it was Irritable Bowel Syndrome (IBS) but after a diet change didn't fix my daily symptoms of abdominal cramps, urgent bowel movements, and appetite loss, I had a colonoscopy which showed that I had Inflammatory Bowel Disease (IBD).

The first few months were hard, the abdominal cramps were so painful I couldn't walk which meant I missed a lot of school work. To help reduce the inflammation I was put on pentasa, this reduced the intensity of my symptoms to where I could go back to school. Near the end of the year, I started feeling normal again so I chose to come off pentasa and live a normal teenage life.

Over the next 5 years, I lived with this invisible disease, when I should have been fighting it. There were so many things I didn't know at the time about how I could manage my Crohn's to reduce or avoid symptom triggers. Eventually, my condition worsened but I was too scared to figure out why, I didn't want to be the sick kid again, I just wanted to live a normal life.

During the middle of 2016, it all came crashing down, my Crohn's had caused so much damage in my small intestine that it started bleeding. I passed out at home due to the amount of blood that I had lost. My family rushed me to the ER where nurses told me it was pretty touch-and-go, thankfully I was stabilized and taken into my first major surgery to remove 35cm of my small intestine which was badly diseased.

Since then I've been on azathioprine and most recently adalimumab (Humira), after having my second surgery this year to remove

a stricture in my small intestines, to reduce the chance of future surgeries. But like most treatments, our bodies can grow resistant to them rendering them ineffective. If this happens to me with adalimumab then I have only one option left, infliximab (Remicade).

“IBD isn’t something we live with, it’s something we fight against”

We Can’t Wait because IBD isn’t something we live with, it’s something we fight against. We fight using medication, diet, mindfulness, and resilience. So not funding alternative medications, like ustekinumab (Stelara) which is funded in multiple other countries, is reducing our options, making it harder to fight back and easier to lose.

Help us fight back.



Anonymous letter from a parent

My son has ADHD. Along with this came an abundance of energy. He swam twice a week, played soccer and was often on his bicycle.... Absolutely full of life. My son was 8 years old when it first started. A couple of GP appointments for peri-anal infections, angular cheilitis and masses of mouth ulcers that just wouldn't clear. Then came the trouble with swallowing. It was too painful to eat. We thought that our son was just wanting to skip to dessert. Weight loss came next, to the point where his ribs and vertebrae were protruding. We were 'lucky' with a quick diagnosis though. Our son happened to be under a paediatrician because of his ADHD, and our GP had advised us to mention the perianal abscesses as they were continuous. Our paediatrician saw the angular cheilitis, the abscesses, difficulty swallowing. That's when we first hear it: Crohn's disease. Scoping confirmed there was ulceration throughout his oesophagus (hence the difficulty swallowing), and intermittently throughout his digestive tract. The perianal disease continued to develop, with numerous fistulas and infections. The exhaustion became relentless. Weeks of schooling missed, no activities, no drive. He was barely existing. We tried so many things to get him into remission: fluid diet, Prednisone, azathioprine... no improvement. In fact, his perianal disease was getting worse, as was his mental state.... What was the point of anything anymore? Why him?

We started on infliximab... eventually one dose every 8 weeks. Although we had some improvements, it didn't last long. No antibodies, so began the whole regime again, with the same response. His treatment was varied... now we are on double dose every 4 weeks. That is, every 4 weeks, he sits in a hospital bed and has an IV line inserted. The disease? My son is still not in remission, with the perianal disease still very much active. He is at constant risk of severe infections. So, he is on daily antibiotics. His energy?

We are lucky if we get 3 weeks, often it's 2. The last week before his next infusion is difficult. No energy and school missed once more. We could try Humira to see if he has a better response, but with limited biologics available, if the Humira was unsuccessful, we would have no options left. Although he is not in remission, he has some quality of life, and in the 2 weeks of energy, he gets to be normal.

He is now 12. The thought of having no biologic treatment available absolutely terrifies me. Without it, it is inevitable that his perianal disease will become uncontrollable. We are desperately trying to hold off surgery for as long as we possibly can. Knowing that there are other treatments are withheld because of funding is devastating. My son could be given a chance at a normal life, but all he is guaranteed at the moment at best is a few good bits in-between a lot of uncertainty. We can do better.

The past few months, my son has found increased difficulty swallowing his food and medication. It got to the stage where things became lodged in his throat. This weekend, we had a terrifying incidence where my son choked in front of us, he could not dislodge the item in his throat. He turned purple. Finally, he managed to remove it... but what about next time? will he be as lucky? We are waiting to see if this is Crohn's related or another auto immune disease, Eosinophilic Oesophagitis. For a diagnosis, we need another endoscopy and biopsies. My biggest fear is my son continuing to choke. But my second is the implications this may have on his medications. If Crohn's related, then obviously the infliximab is no longer working. If it is a new auto immune disease, what are the implications for his treatments? Are there any available in NZ for this?? It is so emotionally, mentally and physically draining dealing with a lifelong illness without all the extra, massive worries that we are being dealt in regard to treatment. Health should not be a lottery; kiwi's deserve equality and consistency from the government.



Sean Herbert

Wellington

I don't know where to begin but this is a very brief insight into my journey that I've been fighting for the last 23yrs of my life.

23 years ago I got diagnosed with Crohn's disease. I was weighing a mere 47kgs at the age of 21 and struggling to hold on to life. I finally got my diagnosis with some relief it wasn't the big C, I was told I had Crohn's disease instead.

I have endured multiple surgeries during the past 23 years and lost count at my 20th operation. My body is riddled with scars and if humans had 9 lives, I would be on my 10th life.

10 years ago we moved to Brisbane, Australia and my illness came back to haunt me, lying there in my hospital bed clutching for life because my lungs had collapsed, I was rushed to ICU where I fought for my life for 2 weeks. While fighting the disease the doctors left my stomach open and I was hooked up to a machine that was pumping out the infection from my stomach. I had a machine on me 24/7 for 3 months and spent over two months at one time in Brisbane hospital.

10 years has passed from that ordeal and now I'm in the battle of my life yet again, my insides are eating me from my inside out. I've had my bum sewn up and my stomach removed. I now have a permanent bag and struggle to live a pain free life.

Last year I wasn't allowed to eat or drink for 11 months, I had lines coming out my chest that were going straight to my heart where I was on a feeding machine that fed me through those lines the vital nutrients my body needed.

I'm now having complications from the major surgery I had early last year. I'm unable to work. I have been informed that the risks for operating on me again are far too high.

***“If humans
had 9 lives,
I would be on
my 10th life.”***

Sean Herbert

#wecantwait

Crohn's disease



Jessica Port

Wellington

I am 34 years old and have been living with severe Crohn's disease since (and before) my diagnosis in 2007 at age 21. A month after my diagnosis I underwent a bowel resection. Since then I have had surgeries involving two temporary ileostomies fitted. To be honest I have lost count of the amount of surgeries I have had, but I know it is more than thirty. I now have an ileostomy and am facing the prospect of losing my large bowel if further drug treatment does not work.

I was studying web development when I was diagnosed but the disease interrupted that career and full-time work has eluded me as the Crohn's has progressed. I have a lot of issues with my ileostomy and my skin which is why I do not want it forever if there is another option.



Tabitha Jelichich

Auckland

Hey! My name is Tabitha, I'm currently 18 years old, and living with Crohn's disease.

I was diagnosed on the 17th of November 2017 through a colonoscopy and a gastroscopy. I had symptoms of Crohn's for 10 months prior to receiving my diagnosis. I consulted a GP finally after struggling with fatigue, constant cramps and knowing something wasn't normal. This diagnosis wasn't easy. I had no family history of Inflammatory Bowel Disease so all I thought it could be is Irritable Bowel Syndrome.

My journey with this disease has had its positives and its negatives. I've had the pleasure of meeting some amazing people at Camp Purple over the last couple years and I know they'll be lifelong peers. Camp Purple has made me come to terms living with Crohn's disease and has unlocked a support system that has made me who I am today.

While I haven't had any hospital admissions, I have struggles with fatigue, a fistula, fissures, stomach ulcers, abdominal pain, joint pain, and others on the daily. I've had a few scopes, scans, blood tests and samples here and there, but I find positivity is key and it can help you through almost anything.

Currently I am taking Humira (adalimumab) fortnightly and I have had only a single flare since starting this medication. Having a flare while on Humira definitely stressed me out a lot with the constant fear that it maybe becoming ineffective. With only 1 funded

"I am scared that I may be left with no options."

biomedical medication left to try, I am scared that I may be left with no options. Ustekinumab would be a life changing drug for kiwis suffering in New Zealand. So many bowel resections and removals that could have been prevented because of this drug that seems to be accessed everywhere else. Before trying Humira, I was on azathioprine which left me feeling extremely nauseous 24/7 which was most definitely not the answer. I was put on an 8-week course of Prednisone which left me 10kg heavier and really played with my mental health. Overall I am a very happy, healthy girl as of now and I'm looking forward to the rest of my life and what it has to.



Nic Burkin

Hastings

I was diagnosed with Crohn's disease in 1997 when I was just 12 years old. I woke up to the Paediatrician waiting for me and he apologised as he had gotten it so wrong and that in fact, I was a very sick girl. I have had countless stays in hospital from my teenage years onwards. Some were only a few days, other were weeks and at one point it was two months at a time. I have had all the procedures you can think of repeated over and over, ultrasound, CT, small bowel barium x-rays, pill cameras, gastroscopies, colonoscopies and at times blood tests done weekly. I was in day surgery so often that I knew all the nurses and anaesthetists by name and they knew me. I had never been over 50kgs until I was 21 years old. Constant diarrhoea, bleeding, stomach pain, absolutely no energy, I was exhausted for a good 9 years of my life. I have had a bowel resection and have ended up with a "temporary" ileostomy when I was 21 (14 years ago) and still have it now. I have rheumatoid and Crohn's related arthritis. Daily pain in my back, neck, fingers, ankles, knees, wrists and hips. My life is what happens when you don't have the right medication!

If we had access to decent medication, I may not have had to have my ileostomy. I still live with fatigue every day. Trying to function "normally", looking after my family, working, coaching sports teams, all whilst having "nothing in the tank" from breakfast time.



Carla Shaw

Auckland

I was diagnosed with Crohn's disease in 2010 aged 28, after a dramatic and sudden decline in my health days before I was due to start a new job with NZ Customs. My visit to the GP led to a three month stay in hospital, and sadly after trying failed steroid and infliximab infusions, I was faced with two options to leave hospital, with an Ostomy or in a box.

"I was faced with two options to leave hospital, with an Ostomy or in a box"

While my surgery to create an Ileostomy was life changing for the better, though with enormous lifestyle and physical changes. I couldn't help feeling "Is this really it, is there nothing more we can try first?"

Ten years, 60+ general anaesthetics during a one year stay in North Shore Hospital and a body full of lifelong scars later, I want more for those who are faced with a diagnosis of IBD.

To people looking in, IBD (Inflammatory Bowel Disease) is an invisible illness, you only see what a person living with the disease wants you to see. This is my life, but is it too much to ask for just a little more. I don't want a lavish life, I just want a chance at life, and I want it for everyone else with IBD too.

If there had been a few more choices of medication available, maybe I might be in a different place mentally and physically right now. I might be in a different job, the chance to build a career might have been an option. Maybe the last years of my parents' lives wouldn't have been spent constantly worrying about their daughters' health, the first question they would always ask when we spoke. It would be nice to know that if there are options out there, they might give someone a chance.



Sam

This is the story of my son's journey with Crohn's disease. I have been meaning to tell his story for some time and currently he is in hospital, so with time on my hands, I have had a chance to write it down.

Sam was diagnosed with Crohn's disease when he was 7 years old, after 2 years of poor appetite, significant weight loss, lethargy and severe stomach pain.

He was referred to Starship hospital straight after his diagnosis and started on exclusive enteral diet (liquid only) for 6 weeks. However after 4 weeks, Sam could not tolerate the diet anymore and his blood work showed that the diet was not working. So Prednisone and azathioprine were started. Unfortunately, this did not help to control his disease either and so his doctor started him on 2 monthly intravenous infusions with infliximab (biological agent).

Although infliximab initially seemed to help eventually Sam was having the infusions every 4 weeks at a double dose with poor control of his Crohn's symptoms. Poor weight gain and appetite continued to be a concern and so a nasogastric tube was inserted so supplementary night feeds and daytime top ups could be given. Eventually after considerable deliberation, it was decided for Sam to have surgery with the hope that infliximab would work better once the burden of his disease was reduced.

Sam underwent his bowel resection surgery in the middle of July to remove the worst affected portion of his small bowel. Since coming home there has been some improvement in his Crohn's symptoms however the nasogastric tube is still required and he now has profuse diarrhoea, which is a result of the bowel resection.

He is in the early stages of trying to get his symptoms under control with infliximab again. He is in hospital the moment because he has developed an infection through his PICC line which was inserted

during his surgery to enable easy intravenous access for ongoing blood tests and infusions.

Sam's journey with Crohn's disease is far from over. What I have written above is just a summary of his treatment and what it's fails to illustrate is the emotional toll and effect on his day to day life.

I would like to finish my story by saying two final comments. One being how exceptional proud we are of Sam for his endless resilience and courage and also how thankful we are to the doctors, nurses, play specialist and dietitian that are all heavily involved in Sam's care.

One of our major concerns with Sam's treatment is that at some stage infliximab may not work to control his disease. With only one other biological agent funded in NZ (adalimumab) and Sam being so young, then we have a chance that we may be left with few options further down his treatment path. We need ustekinumab to be funded in NZ.

Written by Sam's parent



Lee Tymkin

Lower Hutt

“I want to be here - healthy and alive for my kids and husband”

My name is Lee. I'm 39 and I was diagnosed with Crohn's almost 13 years ago. I'm a mum to 2 great kids and I have a wonderful supportive husband.

A few years ago I wasn't responding to any medications available to me other than steroids. I was bleeding every day. Rushing to the loo, had no energy and couldn't be a mum to my kids. I had pain daily. I had to push myself to do simple tasks like having a shower or taking the kids to their sports.

I didn't respond to any medications - either I was allergic to them or they didn't work for me. My only option was to have surgery and have a temporary ileostomy placed to give my large colon a break and the medications a chance to work. I had it for 3 years and thankfully it helped get me into remission. I then developed an allergy to the ostomy bag adhesives so had to have my stoma reversed. I was lucky, I was stable and had the option to reverse.

I have since then developed antibodies to one of the drugs that was helping to keep me in remission.

I'm OK at the moment but I worry about what will happen to me if I start to flare again. What if the bleeding and pain comes back? It's already been proved to me that all drugs available in NZ don't work for me so what next?

I want to be here - healthy and alive for my kids and husband.



Amber

I was diagnosed with Crohn's disease in 2019. After the scope, I was told I probably had ulcerative colitis, however when the biopsies came back, I was told Crohn's.

Prior to that I spent most of my life seeing all sorts of doctors, specialists, going to hospitals, having tests, so many different medications, time off school and nobody could figure out what was wrong with me. In the end, nobody had answers and I fell into exclusion dieting in my teens.

In 2018, after years of issues, cutting out more and more foods from my diet, I found that even the small amount of "safe" foods I had left would make me unwell. I begged my GP to help me, and they wrote a referral to the gastro department.

6 months later I had my first gastroscopy and colonoscopy and was immediately put on medication. Prednisone is no fun, am I right?? Unfortunately, I kept getting worse. I had to stop working, and thankfully had a very understanding boss who let me do what I needed to with no fuss.

After a while I got put on 6MP. Turns out I am a "SHUNTER"! My body was turning the medication into a toxin.

In December of 2019, I started on infliximab. I had a reaction every time I had an infusion.

I would still be sick for a week, then I would see an improvement for a few weeks... I got upped to double dose. I felt a lot better within two days this time! And then about four weeks in I went downhill. Going to the bathroom 20 times a day, I barely ate for a month, at points going weeks without any food and had a lot of trouble even drinking. I also started carrying a spare change of pants just in case.

I had another colonoscopy done, that showed things in my large bowel were not getting better. Following that, at my next infusion I had a serious reaction to the medication. Obviously, the decision was made to take me off it.

I have now tried my last-ditch medication in an attempt to avoid surgery. I'm now off ALL treatment and having to manage symptoms while I await screening and wash out for the drug trial; and last week I met with a surgeon to discuss having my large bowel removed.

“This is not the life I envisioned for myself”

I'm honestly terrified. I've gone through so much in my life. I'm afraid that this is the thing that gets me, tears me down. I feel like I've missed so much. I can't keep up with my friends. I can't do a lot of the things I want to do. Most days it's a struggle just to get out of bed. I'm very worried for my future. This is not the life I envisioned for myself. This is why #wecantwait!



Katie Costello

Christchurch

I was diagnosed with Crohn's disease in 2010 at just 10 years old. It took multiple blood tests, an MRI, Ultrasound, Colonoscopy and terrible flare or Erythema Nodosum before we found out what the heck was going on with me. Once we had an answer we got straight into treatment as my inflammation was very aggressive. To settle things initially I went 8 weeks without eating, only able to drink water and supplement milkshakes, along with taking steroids and other meds.

Since then I've only been hospitalized two or three times. There was a concern during my most recent stay in hospital that my medication was no longer cutting it when it came to keeping my symptoms under control. We switched to a stronger drug, Humira, which was an injection every two weeks. This became quite difficult to handle mentally, so after two or three months, once things had settled, I was able to go back onto my regular meds.

My symptoms are thankfully now back under control, for the most part, with daily medication. I have routine blood tests and visits to the specialist to keep an eye on things too. I am so grateful to be in a good place at the moment, however I would be lying if I said I don't think about the "what if's" when it comes to medication no longer working for me, like it does so many others with this illness.



Christy

“Everyone deserves the same chance”

At 10 I had symptoms of IBD but was not diagnosed till high school. All my life I have had to carefully conserve my energy, it was tough getting through university and then trying to work full time. I would sleep in my car between lectures, or study lying on the floor because I was too nauseous to sit up. When interviewing for jobs my references would say I was a good worker but had health problems and that tough decision between candidates became easy for them. The only drug that had any impact for me was steroids, which damaged my bone density and was a cruel cycle of helping while I was on it, weaning off it, then waiting till I couldn't bear my UC symptoms anymore and going back on it.

A few years ago, I began to flare even while on steroids and I was also diagnosed with Endometriosis. After a year of waiting we reached the top of the IVF waiting list, but they said it wasn't safe to start while my UC was uncontrolled and I was too sick to begin. My specialist advocated for infliximab and that was the drug that worked well enough for me that I was able to undergo IVF and safely carry my child. Not every drug works for everyone and there are no more drug options in New Zealand for me when infliximab stops being effective.

Everyone deserves the same chance I had, to find the drug that allows them to live a full life and right now we don't have the same options as other countries.

Fertility, equality (and an energetic toddler) is not something that can wait.



Charlotte

Christchurch

I've battled with IBD for over 10 years now and recently got diagnosed with Crohn's in February when a massive flare came with full force out of the blue and I ended up in hospital.

It's exhausting living with this disease. I am on Humira and it's not doing much. The severe tiredness, the cramps, the bloody stools, just the unknown. It drains you. I am scared for my future. I have a 2-year-old little girl and battling this chronic illness while juggling motherhood and a career is such a battle some days.

The hardest part is the invisibility of this disease - you look fine on the outside. We need this medication in NZ. Please!



Anonymous Hero

So briefly, my story....started about 30 years ago as it took at least 6 years to be diagnosed. Unfortunately, it was in hospital like so many of your contributors are still saying. What a relief to be diagnosed, it had been horrible feeling like the world's biggest hypochondriac and getting nowhere....Hospital experience was less than ideal, punctured lung (inserting TPN line), septicaemia and massive blood transfusion. I was also 4 months pregnant with our 3rd child and was moved from medical to maternity and back to medical again. After 5 weeks I was allowed to go home. Added to this was the worry for my husband coping with a 3-year-old, 1 year old and trying to work and visit me! After being home for 24 hours, I had to go back, we lost the baby.... I didn't receive a lot of information and was often bumped off a specialist appointment. This went on for some time until I eventually had my bowel removed, a temporary stoma and bag and then re-joining after a few months. Fantastic. Not that simple of course but I had no hope of going back to work and that gave me a shot at a more normal life. I have really put all of that behind me, it was such a terrible time. I have allergies to a few antibiotics and I get pouchitis on occasion but am way better off I feel. I haven't seen a specialist in years and years.

When our son phoned me to tell me he was having a colonoscopy (at only 24) it was hard not to cry on the phone. I told him what was wrong and fortunately his doctor was very switched on and had mentioned IBD to him as a possibility. I am grateful that he

“I wouldn't wish IBD on my worst enemy – let alone my children. I honestly would give my right arm for this not to happen to him.”

was diagnosed early on and has an IBD nurse. But I have many sleepless nights worrying about him. He went to university and is in the NZ Defence Force with a great future ahead. He has always worked very hard and is worried this will jeopardise his career. Recently he had a flare up while overseas with no access to medication, because of Covid it took 3 days to get some steroids and he had been told to stand down from some vital work. I wouldn't wish IBD on my worst enemy – let alone my children. I honestly would give my right arm for this not to happen to him. I fervently hope Pharmac comes through – soon. Beyond that I hope medical science can make advances to at the very least mitigate this awful disease.



Brigitte Robson

South Canterbury

I was diagnosed with Crohn's disease in 2013 in my final year of high school. From there it was a downward spiral as I tried medication after medication to try to get my disease under control. After spending some time on a medication that somewhat helped my symptoms I was diagnosed with drug induced lupus, requiring me to stop the medication I was taking and instead turning to steroids and then corticosteroids to reach remission as the final funded biologic was no longer an option for me.

Should my Crohn's flare again my medication options are very limited which is also the case for thousands of other New Zealanders who can't wait any longer for more funded IBD medications.



Hayley Greer

Wellington

I was diagnosed with ulcerative colitis towards the end of 2013, just before starting university. I suffered throughout my first year of university with the disease, as well as trying to juggle that with making new friends, living in a hall of residence and studying first year. I eventually had a couple of good years in remission before the medications I was on stopped working for me. I tried all medicinal options that were available to me, but nothing worked and I got so many infections due to poor immunity and spent a lot of time in hospital.

I had my entire colon removed in January of this year and now live with a temporary ileostomy, with the option of reversal in the future. It's hard to think of the 'what-if's' if this medication was funded here in NZ. Crohn's & ulcerative colitis are awful diseases affecting every aspect of life, and since the surgery I am still battling problems from this disease. I am hopeful for more funded medications so that others don't have to go through what I have been through.



Becs Shaw

Auckland

Hi, I'm Becs, 30 years old, I'm an ex cop/detective, and now studying a Bachelor of Sport and Recreation. I was diagnosed with Crohn's disease over 10 years ago and I have peri-anal complications which involves a very complex fistula. Biological drugs are the one thing that stand between having my bowel removed or not. I have just started back on the biological drug adalimumab (Humira) after an 11-month break. It is too early to know if it will work for me again. If Humira doesn't work then my options are either, to live with ongoing pain, loss of appetite, frequent toilet trips and extreme fatigue or, ultimately, have my bowel removed and live with a permanent ileostomy bag.

People living with Inflammatory Bowel Disease are at a greater risk of suffering with anxiety and depression. Both of these are things have had an impact on my life. When I was aged 22, I had a temporary ileostomy bag for about 10 months which allowed my fistula to heal, but within weeks of the reversal operation, the fistula returned. Through my struggles with accepting the fact I had IBD, the damage to my self confidence and body image when having a bag, and the many operations and procedures I had to endure, I ended up going through a bout of depression.

Now days I have rebuilt my life, I have two beautiful children and an amazing wife who has supported me every step of this IBD journey. My struggle is not over, and never will be as this disease is incurable. For me I need medications such as ustekinumab and vedolizumab to be funded in order to give me future options. This would prevent the need to have my bowel removed and avoid the risk of suffering with depression again.

Please sign our petition to support people like me who just want to live a 'normal' life as possible.



Hollie Asprey

Wellington

In 2019 I was diagnosed with ulcerative colitis through colonoscopy. Five days after my diagnosis, my symptoms became so severe that I was admitted to hospital. Whilst in hospital I received a range of treatments to try and stabilise my condition. Following discharge from hospital, I continued to experience difficulties and was readmitted for a further period of time, with additional treatments trialled. My condition is currently stable with careful management using a combination of daily medications and eight weekly intravenous infusions. Whilst these medications are currently offering some relief from severe symptoms, I am aware that, over time, these medications may fail. Unless other medications become funded in New Zealand, my only other treatment option may be surgery.



Brooklyn

Christchurch

I was about 3 years old when I started to get sick. My mum noticed I wasn't growing over the course of a year. I was back and forwards to the doctors because I just wasn't well, then mum noticed blood in my poo, but the doctors still couldn't figure out what was going on.

I had lots of tummy pains & I was going to the toilet with bloody stools 14+ times a day. My illness got so bad I couldn't walk so it was off to hospital where I stayed for 5 days while they figured out what was going on. I had a colonoscopy & was diagnosed with Crohn's disease. My Mum cried.

Since then I've only had a couple of flares up & I've had to have steroids both times. I hate taking steroids, they make me mad & my face looks like a balloon. I now have to take 7 pills everyday, have to have bloods every 3 months & hospital appointments. Sometimes I can't go to school cause my tummy hurts or I feel sick.

I start high school next year hopefully my tummy doesn't hurt so I can go to school. My doctors tell me my Crohn's may play up more as my body changes. I don't know what the future holds for me & my diseases, but I'll keep kicking it in the butt when it decides to play up.

Brooklyn is now 12.



Kirsty Kelly

Canterbury

I was diagnosed with Severe Perianal Crohn's disease 4 years ago at the age of 39.

I lost 16kgs over two months, had bleeding and constipation, extreme pain with bowel movements, nausea and loss of appetite. Due to all of this I had no energy and I was a single Mum struggling to cope. My mother came to the rescue and lived with me for 8 months to help care for me and my son while I struggled to try and get some kind of answers and medication to stop my symptoms.

After an MRI, CT scan, colonoscopy and endoscopy it was discovered that I had ulcers all through the rectum and Crohn's disease up to the Colon. I ended up on multiple antibiotics to try and get the symptoms under control. Unfortunately, this was not the end of my journey by a long shot. I developed an abscess and ended up in emergency surgery where fistulas were found. I had drains inserted to stop the fistula tracks from healing over and forming more abscesses. Every time I went in for surgery to get the fistula tracks drained the surgeons seemed to find another one. I ended up with three drains in and no medications seemed to be working.

I tried Humira which I developed antibodies to and azathioprine which gave me pancreatitis. Because of the severity of my disease my options for medications were running out pretty quickly. My last chance to save me from having a permanent ileostomy was infliximab along with Methotrexate to hopefully stop my body building antibodies. I started having infusions every 8 weeks at the hospital and I started to feel a lot better, over time though the medication felt like it started to "wear off" and my symptoms would start to return close to my infusion dates. I started on double doses and this seems to be working for now. I need a special exemption to be able to continue my medications every 4 weeks.

“To date I have had 21 surgeries for my fistulas including colonoscopies, sigmoidoscopies and biopsies and I’m looking at surgery about every three months for the foreseeable future.”

It’s pretty scary that I’m onto my last option for treatment as if this fails, I will have to have a permanent ileostomy. The real kicker for me though is that even with an ileostomy it will probably not heal the fistulas that I have so I will not only have to live life with a bag but will also still be dealing with the complications from my fistulas. To date I have had 21 surgeries for my fistulas including colonoscopies, sigmoidoscopies and biopsies and I’m looking at surgery about every three months for the foreseeable future.

Infliximab has helped me to be able to start to live a normal life again and I live in hope that this continues for me. It’s been a huge journey so far and I would love it if other people had more options in the future for treatments so that they may not have to go through some of the things, a lot of us already have. Please fund these new medications for us all so that we can all live a somewhat normal life. I’m lucky that I have a small person that I have to get out of bed every day for who pushes me to be the best version of myself that I can be. With access to other medication’s this will allow me and others to continue to do this in the future.

medical team



Richard Stein

MD, FRACP, FACG, AGAF

Chair, Crohn's and Colitis New Zealand
Charitable Trust.

Lower Hutt

Richard is a consulting gastroenterologist and Chairman of Crohn's & Colitis New Zealand Charitable Trust. US-born, he is a graduate of Columbia University and the University of Illinois and did his gastroenterology fellowship at Emory University in Atlanta. Before moving to New Zealand in 2007 he practiced for many years in Seattle and was Assistant Clinical Professor of Medicine at the University of Washington Medical School.

Richard currently practices in Lower Hutt, but also works at Northlands and Hawkes Bay DHBs. He is a Clinical Senior Lecturer at University of Otago School of Medicine, Wellington and an elected member of the Hutt Valley District Health Board.

Richard has a strong interest in IBD and a long history of advocating for his patients. In the States, he was Chairman of the Northwest Chapter of the Crohn's & Colitis Foundation of America, and helped organise one of the first camps in the US for children with IBD. He was the recipient of the Ashley O'Connor and Mike McCready Award for his contributions to patients with IBD. His dream was to start an annual camp for children with IBD in New Zealand, which became a reality in 2015.



Malcolm Arnold

MB, ChB, FRCP, FRACP

President, New Zealand Society of
Gastroenterology

Christchurch

Malcolm is a Gastroenterologist in CDHB having moved from Hawkes Bay to Christchurch in March 2020. He graduated from Glasgow University in 1984, trained in Gastroenterology in Portsmouth, Southampton, Manchester and Liverpool and moved to New Zealand in 1994, initially working in Hawera, Taranaki, then moving to Hastings in 2000. He is currently President of the New Zealand Society of Gastroenterology. He has an interest in IBD and also in quality in endoscopy and is the Clinical Lead for the National Endoscopy Quality Improvement Programme in New Zealand. He is a member of the board of CCNZ. He has attended all but the first of the Camp Purples where he is inspired by young people demonstrating so ably their ability to cope with the adversity of IBD, and is a keen advocate for providing the best possible care for IBD and all other patients in his care.



Richard Gearry

MB ChB, PhD, FRACP

Professor of Medicine, University of Otago

Christchurch

Richard is a Gastroenterologist at CDHB and is Head of the Department of Medicine at the University of Otago, Christchurch. He has a clinical and research interest in Inflammatory Bowel Disease and is an executive and only New Zealand member of the International Organisation for the Study of Inflammatory Bowel Diseases, Asia-Pacific IBD guidelines group and the World Gastroenterology Organisation IBD Guidelines Group. Richard collaborates widely and his research interests include IBD epidemiology, clinical outcomes, biomarkers, nutrition and therapeutics. He is IBD section editor for Alimentary Pharmacology and Therapeutics and is proud to have been a Medical Advisor to CCNZ since its inception.



Jacqui Stone

NP, MN

Clinical Nurse Specialist & Chair, NZIBDNG

Auckland

Jacqui Stone NP, MN, was appointed to the role of Nurse Practitioner (Gastroenterology & Hepatology: long term conditions) at Middlemore Hospital (CMDHB) in 2016, following a 20+ year career working as a nurse with a strong focus on gastroenterology, hepatitis, and research. Jacqui's current role sees her running a number of nurse-led and community clinics (inclusive of 2 prisons), treating a variety of gastro and liver conditions. Jacqui is involved in nurse education, including as Chair of NZ IBD Nurses Group. She is a keen advocate, both for her patients and fellow nurses and maintains an active membership in the NZ Nurses Gastroenterology Association, Australasian Hepatology Association and associate member of NZSG. She has a Master of Nursing and Postgraduate Diploma in Health Sciences.



Marian O'Connor

RGN, MSc in Health Studies

Clinical Nurse Specialist and Co-Chair of
the NZ Inflammatory Bowel Disease (IBD)
Nurses Group

Taranaki

Marian works as a Clinical Nurse Specialist (CNS) in Taranaki, providing care to patients with Crohn's and Colitis, following a move from the UK in January 2018.

Prior to living in New Zealand, Marian trained and worked in London, England for 18 years working at internationally renowned St. Mark's Hospital (national and international referral centre for patient with gastrointestinal disorders). Marian led the IBD nursing service there for more than 10 years and built the largest IBD CNS team in the UK with eleven CNS staff, in order to accommodate the cohort of 10,000 patients.

Marian is the past chair of NECCO (Nurses European Colitis & Crohn's Organisation), having been a founding member of NECCO since 2008. Marian also led on publishing the first N-ECCO consensus statements (2014) on the role of nurses in caring for patients with IBD. Marian co-edited the first Inflammatory Bowel Disease Nursing book.

Marian has completed her Masters (MSc) in health studies and at the University of Bedfordshire in November 2014. Marian has also been awarded GI Nurse of the year 2012 and awarded an ECCO Mark Of Merit in 2014 for her work with N-ECCO.

Marian is currently co-chair of the NZ IBD Nurse Group and also board director of GENCA (Gastroenterology Nurses College Australasia).



James Fulforth

MBChB, BSc (Med Sci) Hons, FRACP

Consultant Gastroenterologist,
Waikato DHB

Waikato

James graduated from the University of Edinburgh in 2006 and moved to New Zealand for the first time in 2008. After experiences in Hutt Valley, Wellington, back in Edinburgh and in Melbourne, he returned to New Zealand in 2015 to undertake specialist training in gastroenterology, two years of which were spent in Christchurch under the supervision of Professor Gearry.

James has a clinical and research interest in IBD and in 2018 undertook an advanced fellowship at The Edinburgh IBD Unit. Here he was able to experience first-hand the impact that newer treatments can have for the lives of patients with Crohn's & Colitis.

Since July 2019 James has been working as a consultant gastroenterologist at Waikato DHB, where he continues to pursue his interests in improving outcomes for patients with IBD.

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Special thanks to Belinda Brown, Rhys Rigione-Pisone and Richard Stein for creating a book that makes an invisible disease, visible.

And lastly, thank you to the 30,385 people who lent their signatures to the We Can't Wait petition so the voices of the 20,000 Kiwis with Crohn's and colitis could be heard.

wecantwait

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