

INSIGHTS



Family reflections: Our Crohn's disease research journey

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Pediatric Research (2023) 93:734–735; <https://doi.org/10.1038/s41390-022-02330-2>**BACKGROUND**

Our son was diagnosed with Crohn's disease at the age of three. He had a few gut issues in his first year of life with some severe food and preservative intolerances that produced endless vomiting, weight loss, and sludgy diarrhoea of various colours depending on the intolerance of the moment. But, he shook those off through a process of restriction/re-introduction and had been doing pretty well—he caught up on his growth and had a busy life as a hilarious toddler.

We moved from the UK to New Zealand in 2014 when he was 18 months. At the time he was diagnosed at age 3 he had been poorly for about 8 months, but with nothing too specific: fatigue, facial rash, and pain when he pooped. We had a great primary care doctor who pushed to get him seen in hospital when he got worse and worse, and warned us of what his diagnosis may be. When he was assessed by our amazing pediatric gastroenterologist, the news of a diagnosis of inflammatory bowel disease was no surprise, but still a huge emotional blow. Initially it wasn't clear whether he had Crohn's or ulcerative colitis but within about a year his disease had got worse and he was diagnosed with Crohn's disease. Our son had a very rocky first few years with his Crohn's. He was almost constantly in a disease flare, and reacted badly to some crucial drugs that are part of the armoury for children with IBD in New Zealand. This included one of the two biologic drugs currently available, which limits our options going forwards, especially in New Zealand, where access to IBD drugs is very limited compared to other developed countries.

IMPORTANCE OF RESEARCH

Our son has done quite a few research studies since he was diagnosed. I have a research background myself so will happily provide my consent for studies as long as he also gives his permission to take part. He hasn't turned one down yet! As yet there is no cure for Crohn's disease and the focus of the studies he has done has been about improving outcomes for children with IBD while we wait for a cure to be found. IBD is a lifelong illness and it is so important to address factors that affect children's long-term life with the condition, not just fixating on what can make them better in the here and now. Studies that involve having extra tests or blood samples taken, or require input from other members of the family, stand just as good a chance at being done by him/us as those just requiring us to fill in a survey. My kids understand how important it is, and we all have a 'suck it up buttercup' approach to any temporary inconvenience or discomfort any of us may endure for progressing research.

RESEARCH STUDIES

My son participated in a study that is so important for children with IBD that looked at finding non-invasive ways to measure disease activity. Basically, finding ways to see how inflamed their gut is without having to have an endoscopy under general anaesthetic, or having blood tests taken at frequent intervals. Our son provided poop, urine and saliva samples that could be used to compare markers of inflammation against those in his blood. Generally, the blood was taken at the same time he was having them anyway for clinical monitoring, and hey... what's another poop sample? There's plenty of that happening anyway.

My son and his sister, who is 2 years older than him, also took part in a study to look at the levels of nutrients in their blood to see how kids with IBD compared to their siblings. This study also looked to see whether there was any difference between them in terms of food-related quality of life. This research involved repeated blood samples for both kids, to keep diet diaries for them both, and to complete a few long surveys on their feelings about food, eating, and nutrition. Getting children with IBD to eat anything sometimes is a struggle when they feel unwell, in pain, nauseous, and are pooping it straight out, so seeing people research this is so important. As a parent it helps you feel validated and recognised for the battle you go through.

We have also been involved in a number of studies looking at non-medical outcomes, to see whether factors beyond his level of active disease may have a positive effect on the course of his IBD. These mostly focused on something called 'self-management', which we soon realised is a crucial, multi-faceted skill for kids with IBD to learn. As our son gets older he will need to take more and more responsibility for his medical management, and this requires him to know quite a few things! My son took part in two fun studies to help develop a cartoon-based survey for children with IBD to help them report their pain, tiredness and what their poop looked like. As a family we also did an international study to test a survey for measuring how much we all knew about IBD, which certainly made us think. Our son also entered a study where researchers were developing a survey to measure which self-management skills children with IBD were able to do. If the survey shows that children can't manage certain IBD self-management skills then their medical team can teach them or help them find ways to learn, which as a parent is wonderful to see.

RESEARCH WE BENEFITED FROM MOST

When our son was diagnosed with Crohn's disease the main aim was to reduce his active disease and get him in remission

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so that he could put on weight, and get well. This used to be done using steroids, but we were told that research showed that a course of what's called 'exclusive enteral nutrition', or EEN, is as successful at getting them into remission as steroids. EEN had the bonus of helping my son gain some weight back, and didn't have the awful side effects of steroids. Basically, EEN involved an 8-week period where all my son could consume were medically prescribed drinks. No food at all for 8 weeks, at the age of 3, with his fourth birthday halfway through. But, he did it... we did it. It involved lots of rewards, and a birthday cake made with a train mould that we used to freeze his EEN drinks, but he did 8 weeks and we saw so much benefit. We got our smiley, bright-eyed, bouncy boy back for a short while, until his next flare.

RESEARCH WE WOULD LIKE

As any parent does we want to see our child well, able to stay that way, and enjoy life. However, the cocktail of drugs our son is on at times can be overwhelming and research into non-drug-related therapies such as dietary modification has our full attention. Some of the long-term drugs used for IBD can cause an increased risk of health consequences later in life so reducing this risk is so important to us.



Picture 1: Our son in 2016 at the time of his diagnosis

SUMMARY

We found a drug cocktail that suited him and helped hugely, albeit a combination found by trial, error, and serendipity. He still has flares, and is still closely monitored, but we have room to breathe now and our son can enjoy being a rambunctious, quirky

9-year-old who feels less and less defined by how sick he is.



Picture 2: Our son in 2019, 3 years after diagnosis



Picture 3: Our son now in 2022, 6 years after diagnosis

ADDITIONAL INFORMATION

Correspondence and requests for materials should be addressed to Angharad Vernon-Roberts.

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