

A patient innovates

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IBDrelief



In April 2008 I was given the news I have ulcerative colitis. I was told I wouldn't be able to exercise as much again and it would impact on every part of my life. As a previously healthy and active 21-year-old this was devastating to hear.

After the initial shock of my diagnosis I just started to get on with things. The days turned into weeks and then gradually over the years I reintroduced exercise. I learnt there were things that would trigger my condition - certain foods, stress, lack of sleep - and would work to avoid these. But, it was the 2012 Olympics that really sparked a positive change in the way I dealt with my UC. It made me want to take up athletics again (something I had done in my childhood) and when I started training I realised I was better than I remembered. I started to dream that I might be able to compete at a national level, but I would need to get off my steroid medication first.

I spent hours researching, reading, asking questions on forums - I was like a sponge, soaking up any information about IBD I could find. After making lots of little changes to my lifestyle I managed to come off the steroids. During my research I had started speaking with other sufferers, some who were doing similar things to me, others who wanted to try but didn't know where to start. So, I started offering them support - and at the same time received support from others who were doing better than me. But, gathering information and connecting with other sufferers was a hard process. The resources available had limitations. There wasn't one place which provided the level of information I was looking for and that also provided supportive tools and a place to connect. This sparked an idea. The idea started out just as a blog where I would provide all the information I had learnt about IBD, alongside recipes, exercise and stress management tips. But I realised very quickly this wouldn't be enough, that there was a need for something so much more. And, at about the same time my wife was going into labour with our first child in January 2015, IBDrelief was born.

IBDrelief has become a support and information platform for people with IBD - and the people around them - who want to find ways to improve their quality of life. When fully launched in early 2016 it will connect them, give them an opportunity to share their experiences and help them learn other ways to manage their condition, alongside any medication or surgical procedures they have had or may need.

I hope IBDrelief will help improve the symptoms and quality of life for those living with IBD, and in turn reduce the IBD-related bill for health services (which cost around £1bn just in the UK) around the globe.

Over the past 10 months we've (IBDrelief is run by myself and my wife, Emily) had to learn very quickly. We are lucky that between us we have a lot of the skills needed to create a project like this. I'm a web developer with my own web design and marketing company and Emily has a background in media, marketing and writing. But, even when you have the skills available at your fingertips there are still incredible challenges in trying to get a project like this off the ground. The main one for us has been financial. As an individual with an idea and very limited personal funds it's difficult to get something like this off the ground. We've put a lot of time and all the money we have into the project. It's been a huge strain on us. But, we recently ran a successful crowdfunding campaign which will enable us to build the first phase of our website. After this we hope to make IBDrelief self-sufficient and secure some grant funding to develop the further phases we have planned. Alongside the financial challenge there have been other challenges too. We aren't medical people and we don't know many people who are. This means we have had to work very hard to get HCPs to be aware of what we are doing, let alone take us seriously. We are starting to make some inroads now - I'm on the NHS People's Panel and have spoken at a few medical conferences recently giving me access to some of the right people. But, it's a slow process that is going to take a lot more time. We've also come up against some people who disagree with what we are doing - both medical and sufferers. People who don't believe a platform like this - empowering patients to take control of their condition - can help. No matter what you do in life there will always be people who disagree with you. There have been many more people excited by IBDrelief than against it so we have learnt to cling onto their positivity to keep us going. IBDrelief is also a huge risk for us - both personally and professionally. A project like this is all-consuming. We are putting literally everything into it. We are working all-hours, juggling childcare and other work commitments. We believe in what we are doing so strongly that we aren't going to let anything get in our way.

My advice to anyone starting their own medical innovation - listen, learn and respond to deliver what people need; you will need to do things outside of your comfort zone, but you just have to get on and do them; get the right team with the right skills to deliver your project on board early; don't be afraid to stick your head above the parapet and take a risk - if you don't you might regret it.