Individual submissions forwarded via Crohn's and Colitis UK

Ref: 001

I was diagnosed 12 years ago, aged 28 with Crohns. Following 3 months on various steroids (prednisolone, betamethasone) various ASA's including Pentasa, I was rushed to hospital to have a right sided hemicolectomy due to complete breakdown of my bowel.

On leaving hospital I was prescribed Azathioprine, which made me sick daily for 4 years and lot several teeth. On stopping this and not being given further medication I then developed a fistula which has resulted in 12 operations and multiple scans over the last 8 years.

I was then given Humira - adalimumab, which worked for approx. 1 year and then my CRP increased to 70 so I was transferred onto Infliximab for approximately 5 rounds of infusions, which were difficult to fit into my working week as I have luckily forced myself into work throughout, despite feeling truly horrendous at times. It was then discovered this had caused infliximab-induced hepatitis with my enzymes reading 1025 instead of 25. I had to have a liver biopsy to confirm this - another procedure and an MRI and ultrasound. Six months of prednisolone to reduce the inflammation and strangely also resulted in the loss of 2 stone in weight.

I am now on methotrexate initially tablets which I could not tolerate so now IM, which is also not really controlling my Crohn's and results in extreme fatigue for 2 days after taking it, and I am now having investigations for Crohns induced arthritis and oral abcesses - 2 further consultations booked and an radio scan to see if I am absorbing bile salts which may require Questran

….so if there is another option

I have continued to work throughout and the sole earner in my household which is added pressure, so any drug which could induce remission would be welcomed as I do not have many other options left open to me.

Individual submissions forwarded via Crohn's and Colitis UK

Ref: 002

I would like to let you know of my concerns if Vedolizumab is not available for me.

I've had Crohn's since 2007 I've failed every drug so far.
My Crohn's symptoms are inflammation of the Eyes Joints Skin extreme tiredness lots of bowel motions weight loss and a zero quality of life.

6 Mercaptopurin Flu symptoms
Methotrexate Hepatitus
Infliximab Rash
Adalimumab Rash and return of Crohns symptoms Thalidomide Rash extreme tiredness and return of Crohns

I was so ill Nov 2013 that my only option to survive was to have an ileostomy, which I had done Feb 2014.

I'm doing ok, as you know Crohn's cannot be cured and the thought of there not being a drug as a means of getting me well enough to have more surgery or even better to avoid surgery is very, very scary.

To live with active Crohn's really is no life.

For me when I have a flare is:

Liquid Formula Diet for months not days
Not going out to socialise in fear of needing the loo, or having embarrassing accidents No fun in a restaurant drinking formula Unable to walk far as joints so painful Going to bed early. Too tired to work. Rashes so bad I can't wear skirts or shorts. Zero quality of life.

Individual submissions forwarded via Crohn's and Colitis UK

Ref: 003

I want to urge NICE to approve this new drug. I am the mother of one Crohn's patient and the aunt of another and I know what this disease does to young people, and what the amazing new drugs can achieve. Both of my family members have been on infliximab and on adalimumab: one is on infliximab now. The one on infliximab has changed from someone who was in constant pain and exhausted to someone who is doing brilliantly at Oxford University. There is no way that she could study at Oxford without that drug. However, she developed a reaction to adalimumab after a couple of years on that: adalimumab had also helped her a great deal but as it began to fail, she too began to slow down and ended up in hospital. In hospital they could do nothing but as soon as she started her infliximab, she began to fly again. She was energised and without pain most of the time. She follows a careful diet and takes great care of herself, but it is the drug which keeps her going.

If she develops an intolerance of infliximab - which I understand is likely to happen - what will happen? Will she have to drop out of Oxford? Without being able to turn to Vedolizumab, this will be inevitable. Without a degree, her future will be bleak. Without this drug, her future would be bleak. With the degree and the drug, she will be employed and look after herself and contribute to society.

There is no alternative for a patient with moderate to severe Crohn's.

My other relative is now unable to take either of the two drugs I have mentioned as he is intolerant of them. But when he could take them, he was able to enjoy his life and contribute to society. Without them, he is in constant pain and mainly confined to bed.

I truly believe that if he would be given the new drug, vedolizumab, he will once again be able to enjoy his life and be the vibrant and happy person we know he can be.

There is no alternative for this patient NOW. His doctors are not able to offer him anything else.

It must be cost effective when it enables young people with their whole lives ahead of them to get up and out and lead their lives rather than to have to rely on the state to look after them and to be in and out, mainly in, hospital.

Please will NICE fund this new drug. There is no alternative for some people with this dreadful and lifelong disease.

Individual submissions forwarded via Crohn's and Colitis UK

Ref: 004

I am extremely concerned to hear that NICE is currently not recommending Vedolizumab as a treatment for the management of moderate to severely active Crohn's Disease, since my consultant gastroenterologist judges that the drug could be of considerable benefit to me. If we cannot try it, we will never know.

Crohn's Disease is an incurable and relapsing condition, which blights my life. I am an experienced professional teacher and a trustee of a local charity but my ability to contribute to my community, to wider society, and to pay my taxes, is limited by the impact of the disease. It forces me to work part-time when I would otherwise work full-time and I have regular episodes of sick-leave, roughly every 12 - 18 months. The latest period of sick-leave will last six weeks, which is a burden on my employers. The impact on my family and social life is huge. I haven't been able to travel abroad for over two years.

Long-term use of aminosalicylates and immunosuppressants gives me only partial remission: the disease is currently absent from my colon (where it has been in the past) but remains severely active in my terminal ileum and caecum. The symptoms of the active disease are very debilitating: explosive diarrhoea, excruciating abdominal pain, severe nausea, projectile vomiting and extreme fatigue. At crisis points I have been treated with steroids and antibiotics, which calm things down for a while but cannot be used long term. I have been on an exclusive liquid diet for the last two months and I will shortly be having surgery: an ileo-caecal resection. I hope this will give me a few years of respite but Crohn's Disease has a habit of returning to the site of a bowel resection.

If the Crohn's does return after the surgery, my consultant's options are very limited. I am intolerant of Azathioprine and 6-Mercaptopurine. I have been on Methotrexate for four years. If I develop dangerous side effects from the latter, I will be in trouble.

I cannot be given Infliximab or Adalimumab because they both carry significant cancer risks for me. I had breast cancer four years ago and later learned that I carry the BRCA2 genetic mutation. My gastroenterologist therefore concludes that using anti-TNF drugs in my case would be too dangerous. At the moment, Vedolizumab looks like the only other viable option for my further treatment. I am sure that I am not the only patient for whom anti-TNF treatment is not suitable. Please give us the opportunity to access Vedolizumab.

Individual submissions forwarded via Crohn's and Colitis UK

Ref: 005

No amount of surgery can remove Crohn's due to its ability to occur anywhere in the GI tract, in fact surgery tends to make matters worse as sections repeatedly get removed till you end up with lifelong symptoms, and expenses involved in treatment, caused by a shortage of bowel. It's on this basis I believe no drug, especially ones with a relative success rate as this, should be off the table, even if only used in a small number of cases. To do so condemns large numbers of people to a life of unremitting pain, illness and life limiting symptoms. And I say that as someone who is in that situation, and have been for 15 years - had two major surgeries and had every drug available, yet still the illness persists. My outlook at present is to be condemned to never working again, having no social life, depression and having a diet limited to less than ten food items. I know drugs are expensive, but that is not the patients fault and it's unfair to penalise those of us for whom every available drug has failed. And I doubt the cost of treatment of this drug would exceed my current intake of 16,376 tablets and 30 injections every year, which will just roll over year after year after year unless a new drug treatment is successful.

So please reconsider your preliminary decision on this drug's usage for Crohns disease. And thank you for reading.

Individual submissions forwarded via Crohn's and Colitis UK

Ref: 006

I consider my Crohn's to be moderate. Apart from some nasty flare-ups and the intermittent bouts of severe pain that I will summarise below, I am fortunate that I can live a pretty normal life, working full time and participating in sporting activities. The bad times, however, have been tough both physically and mentally. I have, on occasion, felt pretty helpless when there has not been an obvious solution to my symptoms and when I've had to miss out on doing things I enjoy. I have suffered from depression, although it is not clear exactly how big a role my Crohn's has played in that. I would definitely say that it has contributed, maybe subconsciously at times. I have also chosen not to share my illness with my employers over the last few years, mainly out of fear that it would work against me both before and after being recruited (having been out of work for several months in the past, I would rather not take the risk). Living this sort of lie is ok when receiving effective treatment, but it can be stressful when feeling unwell - I've often had to work through flare-ups, rather than highlight that there is a problem and invite awkward questions. Please see below, I will try to keep my treatment history brief and informative!

In 2010, after severe bouts of abdominal pain and vomiting caused by Crohn's and strictures in my gut, I started a course of Infliximab (anti-TNF) treatment. I was already using Azathioprene tablets. I took the Infliximab intravenously every eight weeks and suffered very few problems until Autumn 2013, when I apparently built a tolerance to it. I then tried Mercaptopurine, but it disagreed with me and gave me diarrhoea following a gradual build up of the dose.

Since 2010 I had been prescribed Fortisip nourishment drinks to help maintain my weight, which seemed to fall off without much encouragement. I was the envy of several women, apparently. This is a constant problem for me (the weight loss): I can lose several kilos of weight very quickly by not eating well or by suffering a flare-up, but it takes me weeks or even months of solid calorie intake to put that weight back on. Malabsorption as a result of the Crohn's, I suspect.

After the unsuccessful trial of Mercaptopurine, I did not use any medication for my Crohn's for several months and suffered more intermittent bouts of abdominal pain. Like when I first experienced these problems, eating became very difficult at times. I would tread carefully, eating small portions and being very selective about my diet (tried to keep it low fibre, as I still do, but this did not necessarily equal success). It was usual for me feel to like I was ok, start to vary my diet or eat larger portions, then come crashing down with the severe pains.

I was due to begin Humira in Spring/Summer 2014, but I developed new Crohn's symptoms that stalled this plan, although it took some time to establish that Crohn's was causing them. I had not experienced oral Crohn's since the early days when I was first diagnosed, but I suffered from very sore, bleeding gums on top of the abdominal issues. I was given a course of Prednisolone steroids, as I was not supposed to begin the Humira with an existing mouth problem. I felt comparatively amazing during the next couple of months! Between finishing the Prednisolone and 'adapting' to the Humira, I felt pretty awful. I was concerned that the Humira wasn't working after a few weeks' use, but I suddenly improved and have been mostly well since late November 2014. It was suggested that we may have to go back to Mercaptopurine (a more gradual build-up of the dose) or look at surgery. I am not necessarily against surgery and I'm told it can be more successful option for many, but I tend to think that it's better to avoid surgery unless absolutely necessary. I will then have more options available to me later on in life - I don't want to deploy my back-up plan just yet. If Humira becomes less effective for me as Infliximab did, I am not aware of another treatment that can delay the necessity for surgery.