

# My Year with IBDoc®

Lee Stanley, long term Crohn's sufferer shares his experience of managing his disease with the help of calprotectin self-testing.

*I am a 48 year old male living in the Manchester metropolis. I have two beautiful children, an incredible wife and a loving, close family. I have had the misfortune of having Crohn's disease for the last 27 years; I have had two resections, the first resection in 1992, and the second in 2001. I was in remission for 9 years until a severe flare in September 2010. Since then I have been battling this disease, physically, mentally and emotionally.*

*I have tried steroids, helminths, azathioprine, 6mp, biologicals, anti-map, LDN ... you name it ... but the side effects have most often outweighed the results.*

*The most successful tool which I keep returning to is control by diet, this takes incredible will power to stick to and monitor.*

## Calprotectin Monitoring

*On the quest to control my Crohn's disease through diet, I have used calprotectin tests to effectively monitor my Crohn's symptoms over the years. I was fortunate to work with Professor Hunter for three years who first introduced me to the calprotectin test via a clinic in London.*

*I learnt some fundamental pointers about my disease activity:*

- *I was well (ish) if I could keep my calprotectin to 50µg/g – 250 µg/g*
- *If I introduced a food over a week that created inflammation in my gut the calprotectin result would shoot up to over 1000 µg/g*
- *If I stuck to my diet rigidly it would drop back down to 70 µg/g and if I kept 'cheating' here and there I would receive results around 800 µg/g*



*For me this kind of data is invaluable and reduces the anxiety of not knowing if you are making your condition worse, which can be a significant part of having IBD.*

*Every month or so I would send a sample to the labs and a week later I would have a result that I could act on. The actual clinic could turn the results around in forty-eight hours but posting it to London added an extra day. The real time delay of process though, was the administration; the results going to the professor, then to my GP and eventually to me.*

*Now, when I do a calprotectin test (currently managing via diet and vedolizumab), assuming I can get the Calprotectin to as low as 50 µg/g I know I am not increasing the length of inflammation in the bowel.*

*It is through this deep understanding of my individual Calprotectin results I am confident that the Crohn's remains contained to a specific length of bowel and hasn't increased now for over five years. So I need to stick with the diet but I do need to introduce more foods.*

*I have been on a very basic LOFFLEX diet of rice, chicken and carrots; every time I introduced a food I would have to report back to the dietician every six weeks but it was just too long to achieve sensible conclusions.*

## IBDoc® Calprotectin Home Testing

*So a while back I wrote an impassioned article for Alpha Laboratories, publication 'Perspective', with the headline 'IBDoc® will change people's lives but only, if patients can monitor instant results'.*

*I had been prompted to write the article on hearing about IBDoc, the inflammatory detection system using calprotectin, developed as a home testing kit. Unfortunately I was instantly disillusioned on hearing that my clinic could not give me access to it.*



*However, I'm sure you've heard the old adage, "you create your own luck". As with many fellow IBD sufferers I have a determination and resolve to break through the admin barriers to get results and that article led to the amazing opportunity for me to test IBDoc as a Crohn's sufferer.*

*“The reassurances the [calprotectin] result provides for me is priceless.*

*For the first time I can actually have a small understanding and control of what's going on in my bowel without visits to the MRI scanner or the dreaded colonoscopy.*



*I am delighted to report I have been using IBDoc roughly once a month for over a year and it's now time to share my findings.*

*I have been eating rice, chicken and carrots for so long my body seems to react to anything new I put in it. The obvious route now is a full re-introduction of food groups back into my diet. But are they causing inflammation or have I developed intolerances?*

*It's the great unknown but with IBDoc at least I can understand what's going on.*

## Peace of Mind

*The number one thing for me since beginning the IBDoc trial is that I have found that my anxiety levels have dramatically decreased.*

*I haven't felt the need to call the IBD helpline or prompt my GI secretary to try to move my next appointment up. Of course the reason being in no small part due to the IBDoc.*

*It has reduced the "waiting time" for results down to hours instead of days or weeks. This means I'm not constantly second guessing or monitoring how I feel, which I find mentally exhausting.*

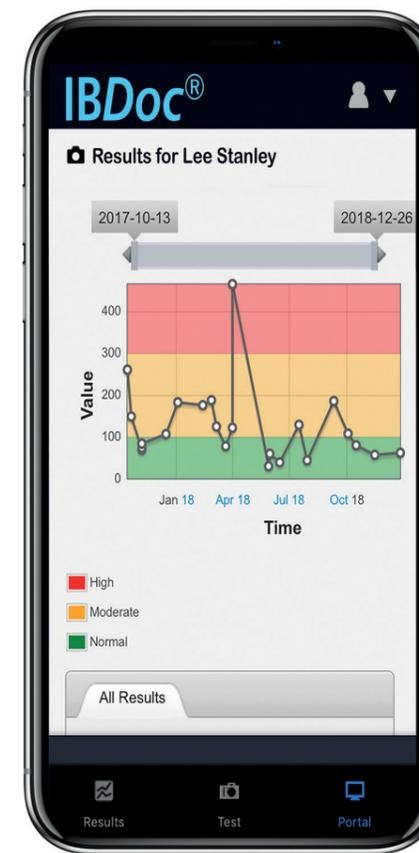
*I'm also very mindful that my fantastic GI team don't have the resources to be on hand 24/7. So that pain I had felt last night or that extra trip to the loo now doesn't result in me calling my IBD nurse for reassurances she can't give me. On reflection I haven't called my IBD nurse once since I began the IBDoc trial.*

*I believe what IBDoc has allowed me to do over the course of the last year is fundamentally educate myself in understanding my disease state.*

*I now have just over a years worth of hard data to discuss with my GI. [Figure 1]*

*Looking at my data for the year, we can clearly see that I've managed, with medication and diet to remain roughly between "Normal" and "moderate". The average result over the course of the year was, 138µg/g; I consider this to be satisfactory (apart from the huge spike which was due to an Easter meal), as my GI is comfortable with results below 200µg/g.*

*Crohn's disease is a physical condition, we know that of course, however one cannot underestimate the mental pressures this disease presents. So I may have an upset stomach or my bowel movements may have increased or I may feel nauseous, but I know after a year of using IBDoc I'm not going to end up in A&E with a stricture or spend weeks on a ward waiting for invasive procedures to tell me I have little or no inflammation. The symptoms are caused by things other than the Crohn's, so there is no need to panic that things are moving out of control.*



**Figure 1**  
**Monitoring calprotectin levels over a year using home testing.**  
**Screen shot from the IBDoc App**

## A Powerful Tool

*Having Crohn's disease for twenty-seven years has taught me many things; fundamentally that patients need to self manage and IBDoc is one powerful tool in my self-managing tool kit. I wasn't expecting IBDoc to provide me with the answers to everything; using IBDoc I haven't suddenly found a miraculous cure, I'm still searching for the "perfect" diet and optimised plan. However, I believe IBDoc has contributed significantly to both the physical and mental aspects for the management of my disease.*

*Follow my continuing journey, on my blog: <https://ibdocandme1.blogspot.com/2017/11/Crohn's-disease-me-and-ibdoc.html>*

## IBDoc® Patient Self Tests:

- Quantitative rapid test
- Excellent correlation with laboratory based tests
- All components contained within each kit
- CE marked

## See what IBDoc can do for your patients

To find out more please visit [www.calprotectin.co.uk/ibdoc](http://www.calprotectin.co.uk/ibdoc)

If you are interested in evaluation of IBDoc in your clinic please email [digestivedx@alphalabs.co.uk](mailto:digestivedx@alphalabs.co.uk)

# Stay Ahead of the Game with IBDoc® Remote Management for IBD Patients

## Improve Monitoring

- Monitor mucosal health
- Predict flares
- Optimise treatment selection
- Prioritise clinic visits

## Reliable Results

- Quantitative rapid test
- Excellent correlation with laboratory based tests
- Simple sample preparation minimises pre-analytical errors
- All components contained within each kit
- CE marked

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Please visit [www.calprotectin.co.uk/ibdoc](http://www.calprotectin.co.uk/ibdoc) to find out more. If you are interested in evaluation of IBDoc in your clinic please email [digestivedx@alphalabs.co.uk](mailto:digestivedx@alphalabs.co.uk)

