

# EFCCA MAGAZINE

European Federation of Crohn's and Ulcerative Colitis Associations

May 2019

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# People are our biggest strength

I have to confess that the May issue of the magazine is my favourite one. You know why? I am sure by now you do...because the 19th of May is World IBD Day!!!

It's the month when many of our members and other supporters are active in raising awareness around IBD and I am always amazed at the inspiring and creative activities so many of our members and other IBD "fighters" are undertaking in order to shine a light on these invisible diseases and to improve the quality of life of so many people. You will find evidence of this in the many articles and stories of this issue.

The beginning of this year has been a very busy time for EFCCA and in the last few months we have been very much engaged in our networking activities such as our participation at the ECCO Congress, the satellite symposium "The IBD pathway - from a patient perspective" and the Medicine for Europe Conference in Amsterdam to name a few. These events provide an excellent opportunity to promote our cause and to give people with IBD a louder voice and more visibility.

I am pleased that our working cooperation with ECCO has become very solid, one side-effect being that several of our representatives have been involved in the elaboration of the ECCO Quality Standards of Care for people with IBD. We believe this is another important step in improving the overall quality of life of people with IBD.

You will also find information in this issue about two exciting studies that we are working on currently, a survey aimed at assessing the impact of perianal fistulae on a Crohn's disease patient's quality of life and a follow up to the BAB survey on Biologics and Biosimilars with the results ready to be published. Both studies will provide us with valuable insights in order to develop and advocate for better services for IBD patients.



**“I was very happy to read the latest activities from our members and to see how committed and engaged they are in supporting people with IBD”**

Another subject we are exploring now is how we can improve the information flow and patient involvement as concerns clinical studies in IBD and we are working to achieve a higher position of patients in the whole cycle of trials from the design to more friendly information related to the enrolment phase, the follow up and, more importantly, the final outcomes. You will find an article setting the context for this subject as well as a practical example by our French member who are embarking on a new project concerning clinical trials in their country.

I was very happy to read the latest activities from our members and to see how committed and engaged they are in supporting people with IBD. The story and feedback from “Camp Purple” that was organised by our colleagues from Crohn’s and Colitis New Zealand involving over 150 kids with IBD, their families and volunteers has been very rewarding as it gives a real example of the sense and purpose of our work. We have decided to use one of the images from the camp for our cover as it transmits the sheer joy and happiness of the participating youngsters.

I hope you enjoy reading this issue as much as I have! And even though IBD is sadly increasing at an alarming rate you can see that this goes in parallel with an increase in the commitment and work of our members, the Board and the Secretariat of EFCCA.

We are all joined in our efforts to support people with IBD and we believe that people are our greatest resource. I look forward to meeting our members at our General Assembly at the end of this month in Prague, Czech Republic when we will be able to share some interesting news about our future plans and activities.

United We Stand,  
Salvo Leone  
EFCCA Chairman

# World IBD Day 2019

Making the invisible visible, our theme for World IBD Day 2019, is about shining a light on various aspects of the two invisible conditions, Crohn's disease and Ulcerative Colitis, collectively known as Inflammatory Bowel Disease (IBD). There is still little understanding of the daily struggle that over 10 million people worldwide are facing. For EFCCA and its members World IBD Day is an excellent occasion to raise more awareness around IBD.

This year our efforts are centered around two campaigns:

## Coordination of global "purple" campaign

As in previous years many of our members and other IBD patient organisations are using the campaign of lightening up famous landmarks in purple as a stepping stone to gain higher media visibility and to gather momentum around specific activities of their yearly efforts to improve the life of people with IBD in their respective countries.

The May issue of our magazine is always a time where we have so many exciting stories to share, not only from our members but also from other IBD patient groups around the globe but there is just not enough space to list all of the activities that are taking place. If you would like to know what is going to happen on 19 May, all you need to do is open your browser and type: [www.worldibdday.org](http://www.worldibdday.org)

There you can find out which countries are joining our global World IBD Day campaign this year and what activities our members and other IBD activists are organising. The information is in progress and we are daily updating it with incoming information about activities being organised.

"It is heart-warming to see so many people joining these efforts and we very much look forward to the 19 of May and already congratulate all participants for their commitment and support!" says Salvo Leone, EFCCA chairman.

## Indirect Costs of IBD survey

EFCCA's second activity within the framework of World IBD Day 2019, more focused on Europe is to promote the survey on Indirect Costs of IBD which is being carried by the Polish Association Supporting People with IBD "J-elita" in cooperation with IIMCB and the Institute of Public Health, Jagiellonian University

**WORLD IBD DAY**  
19 May

#makingtheinvisiblevisible  
#worldibdday2019

**WORLD IBD** [www.worldibdday.org](http://www.worldibdday.org)

Collegium Medicum, under the joint patronage of EFCCA. The survey aims to assess the impact of IBD on the patients' productivity at work and other relevant costs for society.

The preliminary findings already show interesting results that we believe will be of interest to both national and European policy makers, and will allow EFCCA and our members to work more effectively with relevant policy makers.

Once we have the final and official results, we are aiming to organize a high-level European policy meeting to present these. We hope that the findings will provide us with evidence-based material to develop specific activities in relation to IBD and work-related matters.

## ECCO Congress

The 14<sup>th</sup> Congress of the European Crohn's and Colitis Organisation (ECCO) took place in Copenhagen, Denmark from March 6-9, 2019 and gathered over 8000 delegates including nurses, surgeons, gastroenterologists, physicians, patient representatives, representatives from the pharmaceutical industries as well as many other stakeholders.



*Brainstorming and exchanging information with IBD specialists from the Gulf region, ECCO 2019*

The ECCO congress has become one of the major IBD meetings not only for Europe but worldwide, offering possibilities for participants in the area of IBD to exchange knowledge and participate in a growing spectrum of educational courses and masterclasses.

It's great to see that ECCO reaches out to young clinicians and scientists and offers an international platform across and beyond Europe to achieve an improvement in the care of patients with IBD in all its aspects.

The main theme of this year's congress was "research drives clinical care" as the IBD community is witnessing major breakthroughs of innovation due to new drugs hitting the clinic for patients and many new personalized approaches for individual patient treatments.

The congress sessions were focused on the present best practice for adult IBD patients, included pediatric and surgical lectures, and highlighted the trends for patient management.

EFCCA was pleased to be invited again to the Congress and to be offered an information stand that allowed us to network with colleagues from the scientific community and to give patients more visibility at this important event.

Several of our members from Austria, the Netherlands, UK, France, Denmark, Romania and Spain were also participating at the Congress and we were delighted to host a networking dinner to catch up on our latest activities and present new projects in the pipeline.

If you would like to know more about the ECCO Congress and have a look at some of the highlights that were presented at the Congress please visit their website at:

[www.ecco-ibd.eu/ecco19.html](http://www.ecco-ibd.eu/ecco19.html)



*EFCCA staff and EFCCA members at the information stand during ECCO 2019*

# Developing Quality Standards of Care

EFCCA representatives Ciara Drohan, Evelyn Groß, Sanna Lönnfors and Marko Perovic participated in the ECCO Quality Standards of Care meeting and the 1<sup>st</sup> Guideline Methodology and GRADE Workshop organized by ECCO at the ECCO Congress in Copenhagen on 6 March 2019.

No clear definitions for a global “standard of care” in IBD are currently available. ECCO therefore performed a systematic review on available literature and summarized the results into a basis for developing general recommendations for standards of quality of care in IBD. The aim of the Quality Standards of Care meeting during the ECCO Congress in March was to discuss the list of criteria developed earlier by the project coordinators based on the systematic review, and to modify and finally accept or reject the criteria through a voting. The expert panel, consisting of a multidisciplinary group of professionals and included nurses, dieticians, surgeons, histopathologists, pediatricians, endoscopy experts, pharmacists and, of course, patients, aimed at reaching a consensus to develop the final criteria for the Standards of Quality of Care in IBD.

In the 1<sup>st</sup> Guideline Methodology and GRADE Workshop, the pros and cons of the GRADE guideline development methodology and the previously often used Oxford methodology were introduced and the process of a scientifically sound literature search was explained. The four EFCCA patient delegates presented patient perspectives regarding clinical practice guidelines and explained what patients expect from guidelines and why patients should be involved, not only in the development of guidelines but also in the review and update process. After the panel discussion, the other participants had the opportunity to ask questions. Discussion was lively, even so that time ran out when the other workshop participants still would have had more questions to ask.



*From left to right: Evelyn Groß, Marko Perovic, Ciara Drohan and Sanna Lönnfors*

We are pleased that cooperation with ECCO regarding guidelines and ECCO's involvement of patients in guideline development continues as the four patient representatives have also been invited to a Consensus Meeting in Vienna in September 2019.



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# The IBD pathway - from a patient perspective. Satellite Symposium, ECCO 2019

EFCCA CEO, Luisa Avedano, participated as speaker at a satellite symposium as part of the 14 th ECCO Congress organized by Biogen, Samsung Bioepis that aimed to look at the patient perspectives, such as their expectations and concerns as they experience a switch in treatment of biologics and biosimilar medicines.

With the emergence of biosimilars in recent years, there have been expectations of costs savings for biologic treatment of Inflammatory Bowel Disease (IBD). However, various studies have shown that patients have concerns about the switching process, the reason for the switch or the biosimilar itself, and it is essential that physicians and other healthcare professionals (HCPs) take these concerns into account to allow an informed, shared treatment decision.

The aim of this symposium was to understand treatment of IBD from the patient's perspective, especially when switching treatment to a biosimilar product. It started by reviewing the current and future treatment situation and the implications of the increased availability of biosimilars. The role of HCPs in communicating information about the switch was explored by the multidisciplinary faculty who also compared switching practices at their own treatment centres as well as shared best practices.

EFCCA CEO Luisa Avedano gave the patient perspective and highlighted the importance of involving patients in treatment decisions by providing them with educational materials appropriate to their understanding. She also stressed the need of having a well-functioning multi-disciplinary teams (MDT), including specialist IBD nurses.



Speakers concluded that the patient's perspective is paramount in the IBD treatment pathway, especially when considering switching to a biosimilar from a reference product. From the initial consultation in which the patient is introduced to biosimilars to all interactions following a switch, communication is regarded as key.

Easily contactable specialist nurses in the MDT are valued greatly by patients, and patient associations are campaigning for increased access to MDT members, along with more consistency in messages and practices regarding biosimilars to inspire confidence in their uptake.

Other speakers included physicians Raja Atreya, Nürnberg, Germany, Yoram Bouhnik, Paris, France and Geert D'Haens, Amsterdam, The Netherlands, as well as IBD nurse Maria de Jong, Amsterdam, The Netherlands.

# Patients as an essential partner in clinical studies

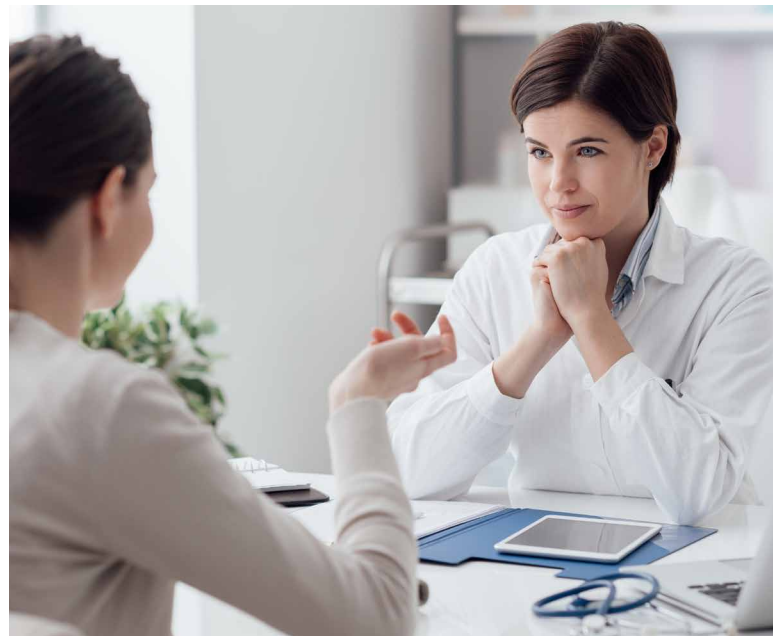
Clinical studies provide unique opportunities and are an important step towards discovering new treatments as well as new ways to detect and diagnose a given disease. For people with a chronic condition such as IBD and where there is no cure available yet, clinical studies provide in a way a light at the end of the tunnel. So how come that patient participation to these studies is persistently low? What can be done to more actively involve patients?

In recent years the trend towards a more patient-centered approach to medicine has opened many opportunities for patients to have a say in their own medical treatment plan. However, as far as clinical studies are concerned, we still see very little evidence of patients being actively involved in the design of them.

Various studies that have been carried out in the past to assess public awareness, perceptions, and attitudes toward clinical trials or studies show clearly a lack of knowledge and understanding of them amongst the public in general, amongst patients and even amongst some patients that are already participating in a clinical trial. There is still a perception of being a “guinea pig” to research and scientists are seen on the one side of the spectrum whereas the patient - the matter of research - is on the other very end.

From practical experience we know that information about clinical studies/trials is at times confusing, too technical and beyond the understanding of a layman. Finding reliable and verified information about clinical studies is another story.

Further obstacles for participating have been cited, such as difficult access to trial sites (in countries where study sites are available only in the capital city, not allowing patients from rural areas to participate) as well as concerns about safety and about being placed in a placebo trial group.



Another issue is the fact that patients often feel left out of the information loop. Once they have completed a trial/study, they rarely receive follow-up information about the progress or results. This leaves patients demotivated and with an additional negative perception.

EFCCA has been taking these concerns on board, and we believe this is an important area of work where we can - together with our members - improve the situation. We are aware that there are various, differing regulations in our member countries as

concerns access to and procedures of clinical trials/studies, but we know there are also many common factors of patient needs that should be addressed.

We are very pleased that our French member, Afa RCH Crohn is embarking on the MY TOTEM App project that aims to better inform patients about the available IBD clinical trials in France and to give their members equal opportunities to take part in the innovation (see page 23). We are looking forward to sharing information about this project and to exploring how we cooperate on a transnational project.

We have also been in discussion with several pharmaceutical industries who are keen to involve patients in their clinical studies process. For example, on 27 March I have been invited to attend a meeting in Zurich, Switzerland, organised by AMGEN. They invited several representatives from patient advocacy groups to discuss, amongst others, on how to engage patients in research and how to make sure to get the patient perspective during various clinical trial phases.

Referring to our International Symposium on IBD Research that we held last year in Bucharest, I stressed the need for close cooperation between the scientific and patient community as we believe that patients are an essential part in the clinical studies. They should be involved as full partners as they are able to provide a perspective that is perhaps not that obvious to scientists.

Recent developments have shown us that things are moving in the right way but we believe that there is still a lot of work to be done to set research priorities that address patients' unmet needs, to look at ways of better designing clinical trials/studies with the active involvement of patients, to improve the access to trials, to improve information with patients and the public in general and finally to also consider mechanisms of post study evaluations and to make results of studies freely accessible.

Isabella Haaf  
EFCCA Deputy Director

## The impact of perianal fistulae on a Crohn's disease patient's quality of life

EFCCA is embarking on exciting new research project together with the pharmaceutical company Takeda to find out the impact complex perianal fistulae have on the quality of life from Crohn's disease patients' perspective.

Fistulae are abnormal connections between organs and other structures in the body. They develop when an organ in the body becomes inflamed and can be a

relatively common complication of IBD, especially in Crohn's disease; it has been estimated that around 35% of people with Crohn's disease have at least one fistula. A fistula is called perianal when it is located around the anus. These fistulae can cause symptoms such as leaking from the anus, rectal pain and swelling, and pain with bowel movements, which can significantly affect a patient's quality of life. Both Crohn's disease patients with fistulae and

those without will be invited to participate in the study. Crohn's disease patients without fistulae will function as the control group when the data is analyzed.

The survey will look into topics such as sexual function, work and social impact.

The questionnaire has been developed in cooperation with both medical experts and patient representatives. It includes questions about diagnosis, symptoms experienced, and the impact of the condition on quality of life in different areas - personal relationships (spouse, family and friends), work, and social life.

The aim is to provide valuable insights into the life of a patient with perianal fistulae.

The survey will be offered in multiple languages within the EFCCA network starting in the early summer. The first results are expected by the end of 2019.

For more information, please contact Sanna Lönnfors at [sanna.lonnfors@efcca.org](mailto:sanna.lonnfors@efcca.org).

# Medicine for Europe Conference, Amsterdam 28-29 March 2019

Our CEO attended the “Biosimilar Medicines Conference” organised by Medicines for Europe that took place in Amsterdam on 28 and 29 March 2019. Regulatory bodies, payers, public administrations representatives, industries and patient organisations were invited to discuss the state of the art on biosimilar drugs in Europe and beyond.





Several sessions and panel discussions contributed to highlighting the weaknesses and the strengths of this new generation of treatments. Although the declared and ultimate objective of the biosimilar uptake is to increase the access to care to more patients, there are currently not sufficient elements to prove that. However, the discussion and the topics presented have been interesting and the conference has been a fruitful occasion to meet other patient representatives and learn more about their positions and concerns.

On 27 March afternoon, before the official opening of the Conference, patient representatives were involved in a workshop whose objective was to share our association's perspectives and offer to the involved stakeholders a better understanding of the issues that patient communities face. The workshop could be a first step to better collaborate and increase patient access to medicines and possibly reduce health inequalities.

## A change of perception on biosimilars?

EFCCA, in collaboration with Prof. Laurent Peyrin-Biroulet and his team (Department of Hepato-Gastroenterology CHU in Nancy) has carried out a follow-up survey called BAB 2 which ran from July to December 2018. Its aim is to find out whether patients' perceptions on biosimilars have changed since our previous survey on the same subject.

The original Biologics and Biosimilars (BAB) survey that ran from 2014 to 2015 showed that IBD patients'

awareness on biosimilars was insufficient and that many of the respondents were doubtful and unsure around the issue concerning biosimilars. Only 25% of the respondents had no specific concerns regarding biosimilars. A follow-up survey, the BAB2, which included the original questionnaire as well as a couple of new questions, was carried out in order to see if there are any significant changes in patients' perceptions 3 years after the initial survey.

Participation was more active than in the first round: over 1600 IBD patients completed the survey. Slightly more respondents, in comparison to the original survey, were currently being treated with anti-TNF medications, and significantly more respondents compared to the previous survey had heard of biosimilars. Although IBD patients were more aware of biosimilars, some of the worries concerning biosimilars that were seen in the previous survey remained.

The most common concerns around biosimilars were still their safety and efficacy. Furthermore, the new questions added in the BAB2 questionnaire showed that IBD patients are not always fully satisfied with the quality and sufficiency of information and communication regarding biosimilars. The research team has written a manuscript based on the results, and it is currently being reviewed for publication. More specific results will be available once the article is published.

## 40<sup>th</sup> anniversary of the Dutch association, CCUVN

I was very pleased to be invited by our Dutch member, CCUVN, to join their 40th anniversary which took place on 12 April in Bussum, the Netherlands.

The celebration started with the official opening of an exhibition artwork of different artists, all related to the community of Dutch IBD patients. I was able to admire paintings, sculptures, photographs and a varied mix of art and emotions in a friendly and committed atmosphere. Tineke Markus, CCUVN Director, presented some of the patients involved and invitees had then the chance to visit the exhibition. All the beautiful art crafts were on sale with the objective of supporting the association, and many guests joined the auction.

I was particularly moved by the event since when I joined EFCCA for the first time it was during the General Assembly in Amsterdam, then hosted by CCUVN while celebrating its 30th anniversary. 10 years have passed since then and I had the feeling that a kind of virtual circle was closed. Ten years in which I have had the privilege to learn a lot and see EFCCA members and friends growing together and joining forces to fight against IBD.

Luisa Avedano  
EFCCA CEO



# IBD and taboos: employment

The EFCCA youth group would like to take the opportunity to talk about topics which we have experienced as young people living with IBD. A lot of these experiences are taboos and rarely spoken of, we want to talk about them, we want to crush the stigma that might be associated with the conditions.

We hope you find support in the articles we write and are able to share them in order to support and reassure people with IBD, their families and friends letting them know they are not alone and as well possibly provide answers to questions they might not have been able to ask anyone before.

The majority of people with Crohn's Disease and Ulcerative Colitis are of working age when they are diagnosed or at least thinking about their future careers. This means that there can be concerns about their current job and their employment opportunities. However, many people with Crohn's Disease or Ulcerative Colitis want to and are able to work successfully and fulfil their potential.

Typically, people living with IBD prioritise maintaining their attendance and performance at work. Also, one of the difficulties with having IBD is that most people who have it can look healthy, which leads to people commenting that "you look well" and might not appreciate the support you may need.

Keeping your condition away from your boss or colleagues could cause you stress as you are trying to hide the symptoms you might have, as well as putting extra pressure on yourself trying to "prove" you are capable of working.

You might also already work within a stressful environment at work or your job might go through changes which can cause stress, so it is essential to find ways to help manage this, so you don't become overwhelmed, which can lead to a flare.

**“My employers have always been understandable about my situation and they often have an IBD patient within their own circles of friends and family.”**

As a youth group we have put together a short list of ways we manage stress:

- Listen to music
- Keep a journal
- Talk to friends or family
- Yoga
- Exercise

Please also refer to the last EFCCA youth group article for more information about stress & IBD.



We hear many stories of people living with the conditions and their own experiences of working which can be good and bad. We hope this article helps give

people with IBD hope that they can still have positive experiences with work. But also, ways to manage the situations if it isn't as positive.

My name is Simo and I have usually been upfront about my IBD to my employer, because that way I don't have to make up excuses about my urgent visits to the toilet and sick leave.

I work in the restaurant industry, so breaks depend pretty much of existing situations and there isn't always time to run to the toilet. Of course, if you have to go, then you just go. My employers have always been understandable about my situation and they often they have an IBD patient within their own circles of friends and family.

Even though my health is not the employer's business, I believe that being upfront about my employers have always been understandable about my situation and they often have an IBD patient within their own circles of friends and family.

Even when I had to take two months sick leave after surgery, I felt they were supportive and understood. I'm open about my IBD, so that I can focus on my work and show that despite the condition I can achieve great things.

Unfortunately, not every employer is as understandable as mine but that might be because they are unaware of the conditions.



National associations can support with useful information to support you talking to your employer, but it is worth being clear from the start on the below areas which may be an employer's concern, they may have never heard of the conditions like Simo said.

We have included some quick highlights you can share with employers to start to help them understand.

## What is IBD?

Crohn's Disease and Ulcerative Colitis are similar illnesses and are often referred to together as Inflammatory Bowel Disease (IBD). They cause inflammation, swelling and ulceration in the digestive system.

These conditions are life-long and may flare up unpredictably. However, many people with IBD will have long periods when they have few or no symptoms at all.

## What are the symptoms of IBD?

- Diarrhoea
- Blood in the stools
- Urgent and/or frequent need to go to the bathroom
- Tiredness
- Lack of appetite and weight loss, also sickness

Some people with IBD may also suffer from painful joints, eye problems, mouth ulcers, and skin rashes.

## Common questions could also be:

Is the condition contagious? - No

Is IBD the same as Irritable Bowel Syndrome (IBS) - No

As a youth group we have put together a short list of reasonable inexpensive adjustments employers can make to support you with your condition to ensure you feel comfortable within the work place:

- Allowing time off for medical appointments or treatment
- Unlimited toilet breaks
- Moving your work station close to a toilet
- Offering a car parking space close to the front entrance

Until you speak with your employer you might not be aware of the support, they can give you.

Remember it is your decision to disclose this information and it shouldn't be forced from you. However, you might be surprised in how much your employer can support you. You might ask yourself why you didn't talk about it sooner.

Remember you will have employment rights, which are typically additional to your contract.

These vary in different countries but remember to check these out or reach out to your national association who may be able to advise on how you can manage employment and your condition.

The whole point of these articles and sharing our stories is to make more people aware of the different areas that having the condition effect people.

We hope it allows for more people to feel less alone and isolated by them but also to empower and equip people with facts.

We are always looking for new topics to talk about to ensure we stay relevant to what subjects are wanted to be discussed.

If you have any ideas of what you want to see in our next article, please email:

efccayg@gmail.com

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# Spain

## Comprehensive care for people with IBD

About 2000 people from different parts of the country have benefited during 2018 from the “Comprehensive care service for people with Inflammatory Bowel Disease (IBD)” implemented by the Confederation of Associations of Crohn’s Disease and Ulcerative Colitis of Spain, ACCU España, which has improved the quality of life of people affected by the disease and their families.

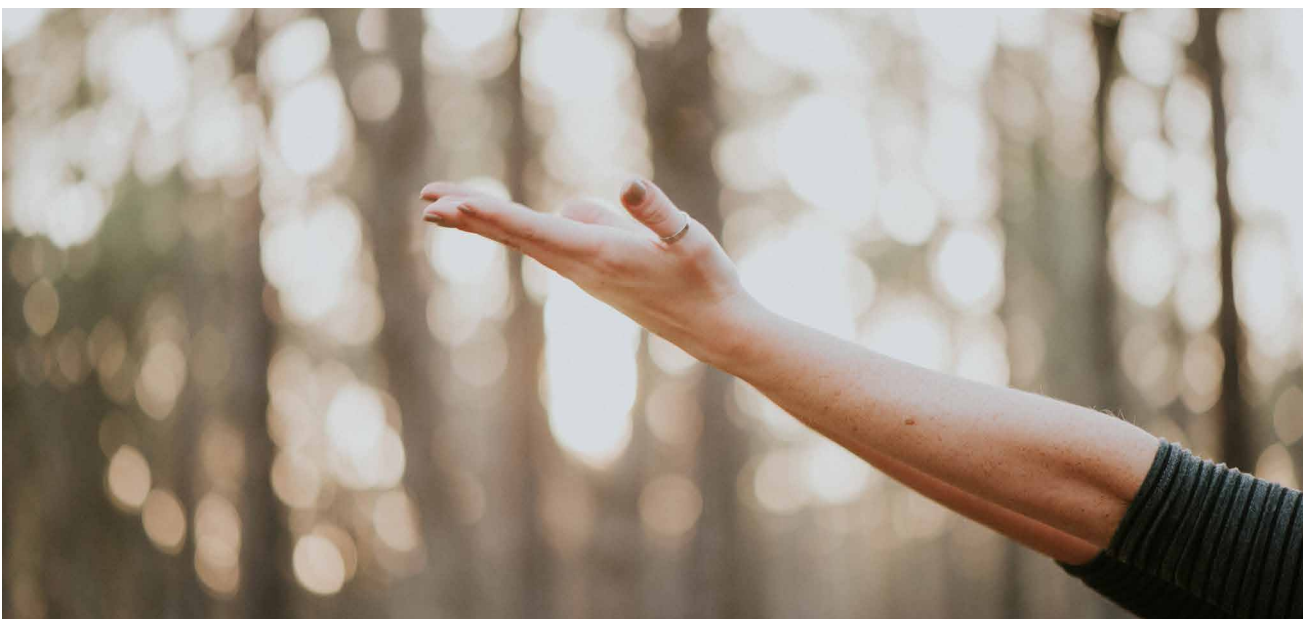
This project was developed thanks to a subsidy from the Ministry of Health, Consumer Affairs and Social Wellbeing and managed by the Spanish Confederation of People with Physical and Organic Disabilities (COCEMFE). With the development of this project, information and guidance on IBD has been provided, as well as advice on their rights as patients including disability, social benefits and resources to deal with the emotional impact of these chronic diseases.

According to Julio Roldán, president of ACCU España, “the impact of the disease not only manifests itself physically but also at work, in education and in social life. Generally speaking, the consultation with the IBD specialist does not involve discussions on

psychosocial problems encountered by IBD patients, which in many cases significantly affects their quality of life, which is why it is of vital importance “to offer services adapted to the needs of patients who inform and orient them in a specific way so that they can face their situation and overcome the limitations that the conditions generates in their day-to-day life”.

“This information and guidance service responds to a real demand of people affected by IBD and we see the number of people requesting service increasing year after year,” adds Roldán.

Currently, ACCU España is the only national entity in Spain that provides comprehensive care services to people affected by Crohn’s disease and ulcerative colitis, their families and their immediate environment.



# UK

## Searching for relief from pain New strategy focuses on quality of life and pain management

Crohn's & Colitis UK is taking an exciting new approach to combating pain, which is a debilitating symptom for many people with Crohn's and Colitis, even during remission. The aim is to improve both how pain is managed and the quality of life for people living with the conditions.

We are seeking research projects specifically focused on pain and will invest £220,000 towards these in 2019.

Additionally, we have created a Pain Collaborative Network - consisting of top clinicians and researchers within the field of pain research - to promote new ideas and research on pain in IBD, which has been identified as an area of unmet need by researchers, clinicians and, most importantly, people living with Crohn's and Colitis. Our target is to create opportunities for collaborative research across disciplines and stimulate the discussion about pain in IBD.

The Pain Collaborative Steering Group, which will help shape the network and recommend research projects, met for the first time in spring. The group is made up of leading researchers and healthcare professionals - spanning several areas including gastroenterology, psychology and nursing - and patients who have become experts through experience.

Nikul Bakshi, research programme lead at Crohn's & Colitis UK, said: "We know that pain rates highly as one of the worst symptoms for people with Crohn's and Colitis, and we want to take steps to improve this.

"The first meeting of the Pain Collaborative Steering Group was a huge success. It was incredible to have so many experts in the same room, and their knowledge will be vital in making sure our pain project delivers the best outcomes for people living with Crohn's and Colitis."



*Pain Collaborative Steering Group*

# Risk of surgery for Crohn's decreases by almost 50%

A British database study funded by Crohn's & Colitis UK has shown a significant decrease in surgeries for Crohn's Disease between 1994 and 2013.

The study, led by Venkat Subramanian and his team at the University of Leeds, discovered the risk of Crohn's patients having surgery within 10 years of diagnoses reduced from 44% in patients diagnosed in 1994 to 21% in patients diagnosed in 2003, a decrease of almost a quarter ( $P < 0.05$ ).

There was also a significant reduction for those needing a second resection within 10 years after the initial surgery, from 40% in 1994 to 17% in 2003, another decrease of almost a quarter ( $P < 0.05$ ).

Using the U.K.'s national ResearchOne primary-care database, the researchers studied Crohn's patients diagnosed from 1994 through 2013.

The BSG guidelines, which are currently being updated states, "The lifetime risk for surgery may be as high as 70-80% for Crohn's disease".<sup>1</sup>

Subramanian's research has revealed that approximately 1 in 5 people (21%) with Crohn's will have surgery within 5 years of disease and Helen Terry, Director of Research at Crohn's & Colitis UK said:

*"This study is highly important and could dramatically change how people with Crohn's look at their prognosis. Surgery is a positive life-changing event for many, but we also acknowledge that many patients can find the prospect scary. Being able to tell patients that their chance of surgery is now 1 in 4 or 1 in 5, as opposed to 4 in 5, could make a real difference."*

Duration of disease, younger age at diagnosis, smoking, and immunomodulator use were positively associated with first surgeries. Not surprisingly, disease duration was significantly associated with the risk of a second resection.

The use of immunomodulators was likely to be associated with a more severe disease phenotype increasing the need for surgical management, according to the researchers. They suggested the general decline in smoking rates may have accounted for some of the overall reduction in surgeries.

Chief Investigator for the study, Dr Venkat Subramanian of University of Leeds said:

*"Whether this reduction is due to improved, co-ordinated clinical care, patient education, reduction in smoking, or alternative factors is uncertain, but the disease course appears to have changed, with newly diagnosed individuals being less likely to need surgery than those in the past. It is important for clinicians and patients to be aware of the risks of surgery to help inform discussions about long-term management and patient expectations."*

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<sup>1</sup> 1 in 4 (26%) within 10 years. This information is extremely significant for both clinical care and patient mindset.

# France

## Clinical Research Development via the MY TOTEM App

For many years now in France there is a relatively bad image as concerns clinical research. Many investigators have trouble recruiting patients, leading to always asking the same patients to undergo the clinical trials.

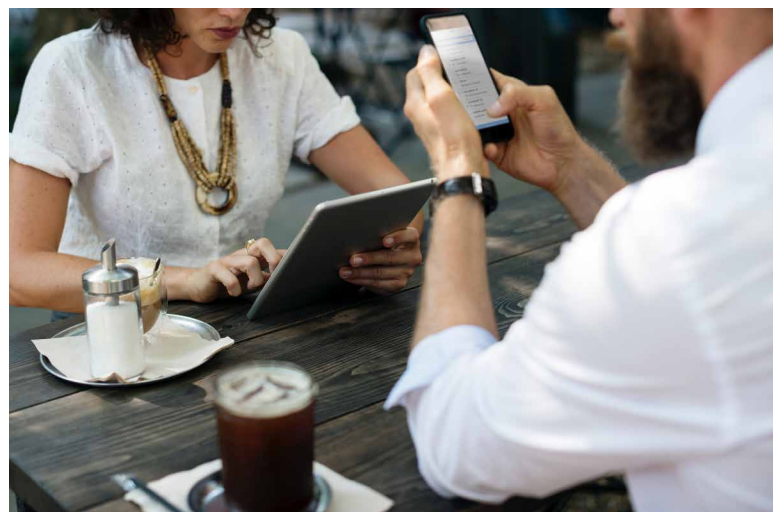
From the patient viewpoint, many are unaware of clinical trials and those who are aware do not have the specific information on the clinical trials taking place around their disease, whereas many patients concerned would be happy to be involved.

What AFA would like is:

- To be able to inform patients about the available IBD clinical trials in France to give them equal opportunities to take part in the innovation. Today, there is no area where extensive information showing the availability and global vision of existing clinical trials can be found
- To hold an affirmed position in their role as mediator, especially concerning the information on the post clinical trial results as well as at every other level of the trials.
- To optimise the patient education by organising “training” which would erase the idea of being a “guinea pig”.

The GETAID, (Intestinal Digestive Disease Therapeutic Experimentation Group) is the learned society in IBD uniting all of the IBD academic clinical research in France. Prof. Yoram Bouhnik and others from this group have developed an application for the doctors to allow them to match a patient with an ongoing clinical trial.

AFA decided to work with the GETAID to develop the patient interface, enabling the patient, him or herself, to find a clinical trial nearby which matches his/her health situation through this application.



This innovative project is a first, called MY TOTEM (MY TOMorrow TrEatMent). It is in the course of development and will allow French IBD patients to more readily and rapidly access a corresponding clinical trial. Geolocation modules and a phone call with the study coordinator will complete the program. My Totem will be accessible on the AFA website where there will be an information campaign on this new application. Of course, the objective is to present all of the Phase 3 clinical trials while building partnerships with the promoters. The patients will also have quick access to the results of the studies.

This application will complete the information which AFA has made available for a long time concerning clinical research: films about clinical trials as well as videos on the WebTV viewed directly from the IBD congresses relating the study results found.

by AFA Crohn RCH France

# Cyprus

## My life with Crohn's and an Ostomy bag

The Cyprus Crohn's and Colitis Association (CYCCA) would like to share the story of a dear friend and colleague who recently completed a marathon in order to raise awareness around IBD and to raise some funds to support our work in Cyprus.

About 3 years ago, after 10 years of struggling with Crohn's disease, I saw myself at a crossroad where I was faced with a life altering decision. During the 10-year period, I had tried most of the usual medication a Crohn's patient is prescribed; from steroids and immunosuppressants to biological factors, but, none of them succeeded in placing me under full remission.

The disease progressed to a stage where even everyday tasks seemed like impossible missions. The decision I had to take was simple. The implications though to my social life seemed to be complicated, *or so I thought!*

I had to decide, or accept if you will, to undergo a medical operation and live the rest of my life with an ostomy bag or probably keep delaying the inevitable. Obviously, I had all the typical questions anyone would have; how will it look, will it hurt, am I going to be able to hide it? Fast forward and three years later I can assure you that it does not hurt, it looks OK I guess and no, I do not need to hide it.

Most importantly, I got my life back and in three years I somehow managed to squeeze in most of the things I was putting off during my 10-year struggle. The ostomy bag did not stop me from doing anything; on the contrary, it allowed me to have a normal life.

The latest item I managed to tick off my list was to run a full marathon with the donations going to fund the work of Cyprus Crohn's and Colitis Association (CYCCA). Beyond the financial support, the message I wanted to get across is a simple one: you can achieve anything if you truly believe it and work for it.

An ostomy bag did not stop me and should not stop you or anyone else. After all, 42km is nothing compared to the fights a Crohn's or Colitis patient gives and wins every day.

Chrysanthos Kanari







Chrysanthos during the marathon (No. 453)

# Argentina

## If in doubt, find out!

From 8 to 10 February 2019, the Mas Vida Foundation for Crohn's & Ulcerative Colitis carried out a summer campaign on the beaches of Mar del Plata, Argentina, in order to raise awareness about Crohn's Disease, Ulcerative Colitis and Indeterminate Colitis, collectively known as Inflammatory Bowel Disease (IBD).

The action, which has been supported by the pharmaceutical company Takeda, sought to promote the early detection of Crohn's Disease (CD), Ulcerative Colitis (UC) and Indeterminate Colitis (IC). These diseases are of low prevalence in Argentina and are therefore difficult to diagnose as symptoms and signs are similar to other, more frequent digestive diseases more frequent, such as irritable bowel syndrome or celiac disease, among others.

The campaign included free access to portable toilets on the beaches as well as free access to an on-line symptom checker for those people who reported persistent digestive symptoms and signs related to IBD, such as: increased frequency or evacuation urgency, persistent diarrhea for more than 4 weeks,



abdominal pain, mucus and/or bleeding in the stool, perianal lesions, fever and/or vomiting, among other digestive symptoms.

People who participated through the IBD Symptom Checker received general information material prepared by the Mas Vida de Crohn & Ulcerative Colitis Foundation, and those whose check indicated a potential IBD diagnosis received data on how to reach a medical specialists at the national level both from public and private institutions so that they could perform a consultation.

The IBD Symptom Checker is a tool developed by the Mas Vida Foundation and helps to guide diagnosis for these diseases. It is available at [http://masvida.org.ar/?page\\_id=2872](http://masvida.org.ar/?page_id=2872) and consists of 10 questions related to the digestive symptoms.

Results of the campaign:

- Installation of 5 portable toilets free of access
- More than 1000 people benefited from its use
- Around 25,000 stickers and information flyers were handed out
- 587 people performed the symptom checker within 3 days
- 230 reported having digestive problems
- 16.53% had symptoms of suspected IBD



## Brazil

### Strengthening Patients with IBD

The National Association of Patients with Inflammatory Bowel Disease - IBD Brazil (DII Brasil) - was born out of the need to encourage the formation of an association for patients in all states and federal districts of Brazil. The statutes of DII Brasil, a non-profit NGO, has as its objective that associations in each state will receive adequate support so that they can grow and be strengthened.

As Brazil is a very big country it is important to grow the capacity of each of the federated associations and provide them with the best possible assistance in their respective territories.

Currently, we have 19 IBD associations for people with IBD affiliated to DII Brasil. They are present in the following states: Bahia, Goiás, Mato Grosso, Piauí, Minas Gerais, Paraná, Santa Catarina, Rio de Janeiro, Rio Grande do Sul, Ceará, Espírito Santo, Maranhão, Pará, Paraíba, Pernambuco, Rondônia, Rondônia, São Paulo and Tocantins, in addition to the Federal District - ADIIDF.

“We serve our state associations so that they can serve their patients as we believe that together we are much stronger” explains Patricia Mendes - President of DII Brasil.

When an association becomes a member of DII Brasil it works with us in partnership. There are no membership fees and the projects of the member associations and DII Brasil are independent, but always have the backing of the national association. We value the autonomy of each member and are looking at the best ways for supporting each other!

For example, recently DII Brazil and its 19 associations have decided to adopt a joint graphic style for T-shirts and other materials to celebrate Purple Month (in Brazil World IBD Day is celebrated the whole month called “Purple May”). We have also been working to raise funds and establish close partnership with companies to support our cause. We are looking into ways how we can financially support the 19 state associations but have not formalized it yet

Ana Guimarães,  
Voluntary Press Advisor DII Brazil

Italo Garcia,  
Translator and Member of The Scientific Council



# Finland

## Project creates new ways to support families with IBD

In Finland, approximately 2,000 people get diagnosed with IBD each year, and over 250 of them are children and teenagers. As the numbers grow, so does the need for support. To help children with IBD and their families, the Finnish association Crohn ja Colitis has started a project called Support for Families.

### Developing new channels for support

The main goal of the project is to increase the wellbeing of children and young people who have IBD, and their families. We want to make sure that families get all the information and support they need in each step of their journey with IBD. The project lasts for three years, from 2018 to 2020, and is financed by The Funding Centre for Social Welfare and Health Organisations (STEA), from the gaming revenue of Veikkaus Oy. The project has one full-time employee as a project manager.

In order to know what families actually need and to innovate new modes of support and materials, we use workshops and surveys. We also gathered a group called the Family Team consisting of parents of IBD kids to help us. Parents are the best experts by their own first-hand experience.

Of course, we also work together with health professionals, teachers, psychologists and other professionals who meet IBD families in their work. The professionals make up the steering group of the project.

### Peer support for families

When a child gets diagnosed, the whole family needs time and support to adjust to the new situation. Often families feel like they are alone, so it is important they get to meet other families in similar situation. We organize peer support-based theme days, weekends



and expert lectures both live and online. Events are held around the country, often in cooperation with other Finnish patient associations and companies.

We aim to support the whole family in different turning points of childhood and teenage; for example when the child goes to day care or starts going to school, in teenage years and when transitioning to adult medical care.

## Providing reliable information

During the project we produce videos, guidebooks and other materials for families both online and as a printed “starter package” to be distributed in hospitals when a child gets the IBD diagnosis. Materials are aimed for children and young people themselves, their parents, sisters, brothers and all those around the family.

An IBD guidebook for families called “When a child gets diagnosed with IBD” (in Finnish) will be published this spring.

## Raising awareness of IBD

Many professionals and also the general public need more information of IBD and how it affects children’s and families’ everyday life. Therefore, we raise awareness among personnel in day care, schools and other surroundings of these families.

During the project we contact professionals around

Finland and provide materials to inform what kind of support might be needed for example in schools. There is much work to be done, but together we can make a great difference!

By Leena Tuutijärvi,  
Support for Families project manager



## Crohn ja Colitis ry

### The Finnish association Crohn ja Colitis ry

- Nationwide association for people with IBD or some other type of bowel disease, and their families
- Main tasks: advocacy and influencing, sharing information and providing peer support
- Has been growing fast and has almost 8,000 members
- Has eight employees
- Is financed by The Funding Centre for Social Welfare and Health Organisations (STEA)
- 50,000 people are living with IBD in Finland
- More info in English: [ibd.fi/in-english](http://ibd.fi/in-english)

# New Zealand Camp Purple 2019

In January of this year over 72 children and teens with Crohn's disease and ulcerative colitis arrived in Christchurch in the South Island of New Zealand to attend Camp Purple Live hosted at the Living Springs complex in Allendale along with approximately 40 volunteers and 38 parents.

Viv Gurrey Chief Executive of Crohn's & Colitis NZ says "This year's Camp Purple was unprecedented in terms of numbers and was an incredible success. To experience first-hand the results that come from such hard work over the course of the year is both extremely rewarding and a privilege to share in this experience. We couldn't achieve this without the financial support of our partners and the incredible involvement of our IBD community in NZ - work is in hand to prepare for Camp 2020 in Wellington and this will be another overwhelming success"

Campers spent an amazing week in the outdoors in fine Christchurch weather playing kickball, swimming at the river and pool, climbing, abseiling, doing archery, and participating in team building activities.

They were so excited to spend the day at the Antarctic Centre in Christchurch with the rescue huskies, travelling on the snow mobile and learning about the penguin colonies and care programme.

Wednesday evening saw us joined by the local Community Police for a Blue Light Fluro Disco and a great night was had by all! Most importantly though, they spent the time talking and just being together, sharing personal experiences and being in the company of others who totally understand their immense challenges.

For many, this is the first time they have been able to do so. It is difficult to convey the impact the camp has on these children. Seeing them hug each other goodbye at the airport on the last day of camp was



particularly moving and said all that was needed to demonstrate the importance of Camp Purple.

Camp Purple is organized and managed by a highly effective Camp Committee chaired by Dr. Andrew Day, Paediatric Gastroenterologist at Canterbury District Health Board. Organizing a camp for children and teens with IBD presents special challenges. Belinda Brown who is a Trustee of Crohn's & Colitis NZ plays a critical part in our Camp. Belinda says "I feel honoured and proud to be part of the amazing team of volunteers who organise Camp Purple Live. Camp Purple 2019 was a huge success and the fact that it was our biggest camp to date, speaks to that success. I can't wait for Camp Purple Live 2020, in Wellington, and to see all those smiling faces on our parents, campers, medical staff and volunteers. Bring on 2020!"

Dr Richard Stein, Gastroenterologist and Chair of Crohn's & Colitis NZ is a major contributor of time, experience and expertise for Camp. Attending for the duration of camp as part of the medical team and also playing a major role in the yearlong work of the Camp committee, he said that "The volunteers and campers are like a large, extended family. The camp embodies everything we strive to do as an organisation: giving of our ourselves and improving the quality of our members' lives".

We always had a highly experienced volunteer medical team of Doctors and Nurses to dispense medications and address all the medical issues that inevitably arise over the course of a week with a team on call. This team is made up of both doctors and IBD nurses and a dietitian who worked tirelessly in the kitchen to assure that all the children on restricted diets could safely attend. Over thirty volunteer leaders, all with IBD themselves, served as role models for the children. The volunteers overwhelmingly felt that they benefitted from the camp as much as the children. One evening was devoted to a group discussion with the nurses where the children shared stories in a safe environment, asked questions about medications, surgery, and other issues such as whether they would be able to have families.



Volunteers contribute so much and achieve so much for their own self-development one volunteer reflects on Camp and says: "My first year as a volunteer for Camp Purple has been amazing! This experience has given me a totally new perspective on life as I live with my disease. Learning from everyone is amazing and inspiring - the list of moments from this incredible Camp experience are endless - I truly hope I am able to come back again next year!"

Camp Purple also supports parents and runs a day and a half parent day to both involve parents and educates, informs and supports.

One parent says "My son has just completed his first Camp Purple after a diagnosis of Crohn's 7 months ago. He has only recently been in remission (thanks to infliximab), and has struggled immensely the past year, feeling isolated and scared. *Camp Purple has turned everything around!* When I asked him, what was his favourite thing about camp, he answered "being around others with Crohn's".

We have been mostly honest and upfront with our son about his IBD. The one thing I couldn't cover was the real possibility of surgery, especially as he has perianal disease... I was too scared and didn't want to overwhelm and scare him. His leader covered all this with him, from openly discussing his own surgery and future, to answering all his questions. He does not feel scared at the prospect of surgery, or the possibility of a colostomy bag... He accepts that if that's an option in the future, then it's to give him a better quality of life. *That alone is priceless to me.* Moreover, having a week of being "normal" was awesome... I truly haven't seen him look so happy, relaxed and content since his diagnosis as he did in the Facebook photos.... *Another priceless gift.* I was humbled by the volunteers with IBD, their stories were inspirational and allowed me to see that our son can have as bright a future as he wants, he just must work at it differently to other non IBD children.

They are true ambassadors, as are the medical staff who selflessly give their time for the children to experience camp."



Camp Purple 2019



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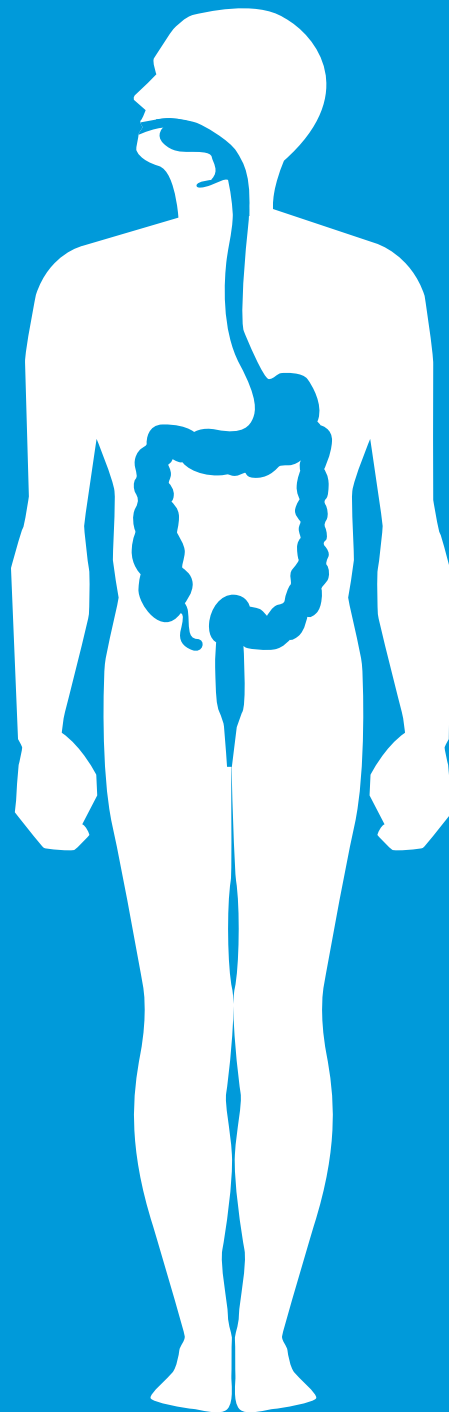
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# Backpacking through Southeast Asia

## Interview with Caroline Greenan

Caroline is originally from Ireland but currently resides in the UK. She has a huge passion for travelling and together with her partner, Steve, she has been backpacking for the last ten months through Southeast Asia. Caroline was diagnosed with Crohn's disease in 2002 following a series of wrong diagnoses such as food poisoning and Irritable Bowel Syndrome. After a long period of remission she had flare ups again and required surgery. Now she is now on infliximab and other medications.

### **What made you decide going on a backpacking trip?**

I really like travelling and I am keen to see other parts of the world. I also really like eating!! Especially food from all over the world. My partner and I have been travelling a lot in the past. We realised one year that we had six different holidays and if we would have saved money we could have gone on a backpacking trip for a year...so that's where the idea came from.

### **Did you have to make any special arrangements because of your Crohn's disease?**

Yes, my disease has been a big factor when planning this trip. At first, we thought we would go backpacking for a shorter period of time and I discussed it with my consultant to see what his thoughts were because I was still on the infliximab infusion which I need to get every 8 weeks. I briefly thought about coming off the drug but then decided against it as I got scared to have a flare up again, which wouldn't be that great, especially in Southeast Asia.

Plan B was to come back to the UK every 8 weeks for the infusion but as I was talking to my nurse while I was having my infusion, she suggested that I look for



a hospital within Southeast Asia where I could get my treatment.

So that's the plan we went with. It involved a lot of discussions with my consultant and my nurses as well and once they were on board there was a lot of logistics about how I could take the medication with me, how I could store it as well as bring my other medication. Obviously getting a good travel insurance was another major factor to sort out as well.

**How did you find out about the hospital in Southeast Asia?**

I searched on the internet. I am a scientist by background, so I am familiar of how hospitals run which helped me a lot. I looked at private hospitals in Singapore because they have the best healthcare system within Southeast Asia. I also looked into hospitals in Bangkok but in the end, I chose a private hospital in Singapore.

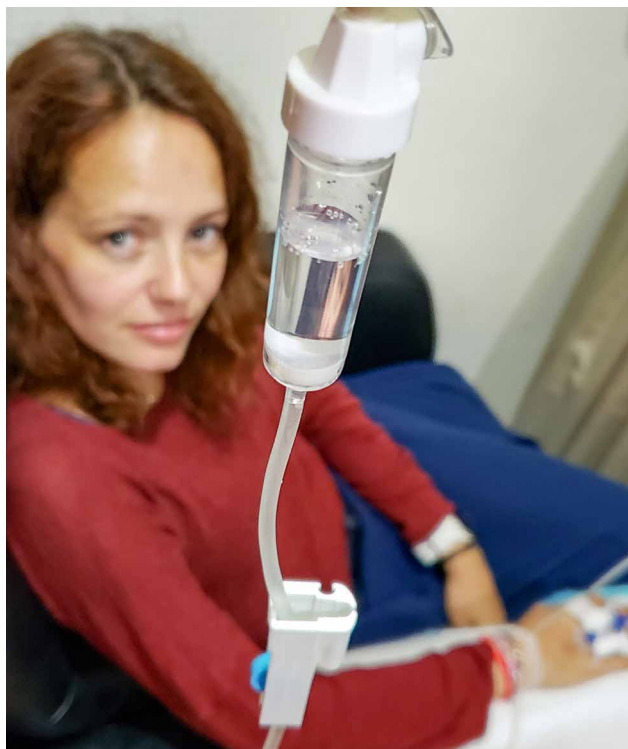
My first idea was to buy the medication in Singapore, but that was going to be very expensive, so I decided to take the drug with me from the UK. My first stop when I left the UK was Singapore in order to drop off the medication so the hospital could store it for me and that's when I met with the consultant.

So every 8 weeks I fly to Singapore, get a blood test done and then, when my results are back, I meet the consultant and get the infusion. So far all has gone to plan and I have been there 3 times for my infusion. After 6 months of travelling I had to go back to the UK to restock on the medicines.

I had no problems carrying the medicines on the plane as I had a letter from my consultant explaining what it was. For Singapore though I needed to apply for an import licence as I was taking more than 3 months' supply of medication into the country.

**What do you find the most challenging part of backpacking in relation to your IBD?**

The fear of having another flare up. Four months into



my travels I got a nasty travel bug and I was very worried that it was the start of a Crohn's flare up because the symptoms were so similar. For about two months my stomach wasn't too well, running to the toilet a lot etc. but I got antibiotics for my stomach and it did clear it up.

That was the challenging part of my trip as well as that, I need to remind myself to take it easy sometimes. I still get fatigued, when you are travelling you are moving all the time, we usually never stay at a place for more than 2-3 nights. At the start we tried to fit a lot in but then I got really tired, so I have learned now that whenever I need a day off, I have to just do it and take it easy. It's all about finding the right balance.

### What would you tell people with IBD who are thinking of doing the same?

I would tell them to definitely do it!!! Discuss it with your medical team and consultant. I was very lucky because my medical team is very supportive. I also travel with my partner which helps a lot and he is very supportive. Obviously, it's good to know that there is someone with me if something goes wrong.

We do have a blog which we update on a regular basis, it's like a sort of country guide of all the countries that we have visited so far. If you go on the blog you will see my experiences also in relation to travelling with Crohn's and if you have any concrete question please contact me. Don't let your IBD hold you back!

Caroline's travel blog:

[https://onewanderatatime.com/travelling\\_with\\_crohns\\_disease](https://onewanderatatime.com/travelling_with_crohns_disease)



## The green journey of IBD (Le voyage vert de MICI)

Two French adventurers: Fanny, 32, and Jerome, 34 years old who met whilst studying in Strasburg. For a very long time, their dream has been to discover the world. The dream is becoming a reality through the project “Le voyage vert de MICI”, in English, “The green journey of IBD”.

Our project includes several goals that reflect our personalities, life experiences and values: - Explore other parts of the world. - Travel in a friendly, environmental way, for example, without airplanes. We will take the time to travel at an easy pace, for example, we will cycle the first 2500 km.

The purpose is to make the journey in association with AFA Crohn RCH France emphasising Inflammatory Bowel Disease (IBD) and environmental preservation. Two themes which we care much about. Why these subjects? In January 2014, Jerome was diagnosed with IBD.

After six months with a stoma, Jerome's digestive system was reconnected but without a colon or rectum. Through our co-partnership with the French IBD associations we would like to promote the following:

- Communication about IBD conditions
- Transmission of a positive message to the people affected by IBD
- Collection of useful information about toilets on the cycle route (location, free of charge or not, clean or not, etc.)

As concerns environmental preservation: we took the "Géographie Environnementale" course (Atlas of Sustainable Developments) and worked for environmental conservation in order to continue in this way during the journey. We are seeking for some missions like waste collection, awareness raising of the population etc. which we will try to apply throughout the whole journey.

The journey is divided into two parts ... just the two of us with backpack. ...

On the first trip, cycling from Strasbourg to Romania through nine countries, around 2500 km in 2½ months from June 2019 and (we hope) finishing in August 2019... "Tous en selles !" (All in the saddle!) ... then in September, we continue by train to join Russia and then aboard the trans-Siberian to the Lake Baikal, then by various modes of slow and less pollutant transport (as much as possible), to travel to Mongolia, China, Vietnam, Laos, Cambodia, Myanmar, and Thailand finishing in New Zealand.

If you want to join us in our adventure, or to welcome us in your village for an IBD meeting, please find our contact details below.

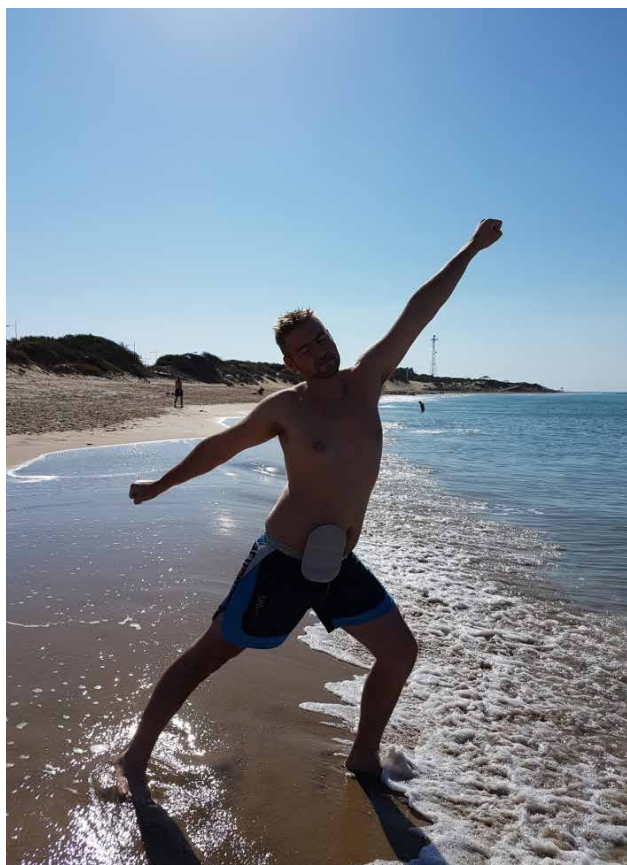
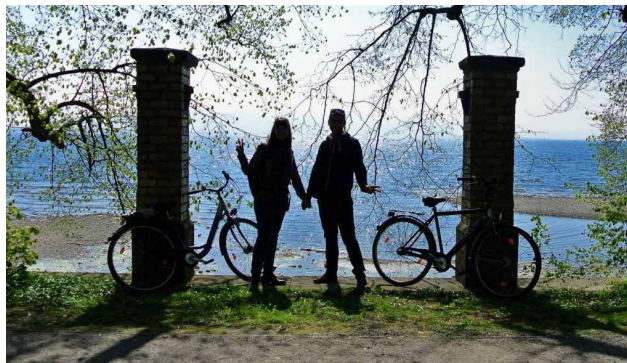
Our contacts:

Fanny ORTLIEB et Jérôme LEHMANN

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<https://www.facebook.com/levoyagevertdemici>



# European Patient Forum - General Assembly

The General Assembly of the European Patient Forum took place from 13 to 14 April 2019 in Brussels, Belgium. Our CEO Luisa Avedano participated on behalf of EFCCA.

It was an interesting event where the main projects and activities were presented and discussed in a positive and vibrant atmosphere. Young patients and the launch of the EPF Congress in November have been the most interesting topics and offered the occasion to better understand EPF's approach and priorities. Marco Greco, our former Chairman was confirmed as EPF President for the next 2 year.

The EPF community then thanked and greeted the Nicola Bedlington EPF General Secretary who, after 13 years, decided to leave her position but will continue to work with the association on some of its main projects. The new director, Osman Khan was then introduced and we look forward to a fruitful cooperation with our colleagues.



For more information please visit:  
<http://www.eu-patient.eu>

# EU elections lead candidate Weber supports European disability Movement

The President of the European Disability Forum, Mr Yannis Vardakastanis, met with Manfred Weber, the European People's Party lead candidate for the European Parliament Elections.

The EDF delegation, led by Yannis Vardakastanis, presented 5 key demands from the disability movement:

- Legislation and support to assure that persons with disabilities can be employed in an equal basis with others.
- An ambitious European Disability Strategy 2020-2030, that involves persons with disabilities in all its phases and with a significant budget allocated. The strategy should be followed by all EU institutions, bodies and agencies.

- The next EU budget, post 2020 needs to fully comply with the UN Convention on the Rights of Persons with Disabilities.
- An accessible Europe: implementing existing accessibility legislation, assuring all new EU initiatives consider accessibility for persons with disabilities and guarantee that EU Commission makes sure all its web tools and infrastructure is accessible.

**Mr Yannis Vardakastanis**, President of the European Disability Forum stated: “It is estimated that next year there will be over 120 million persons with disabilities living in the European Union. However, much remains to be done. People’s lives are not improving and this is feeding the populist agenda in Europe. We need more social investment, we need innovation, we need forward looking initiatives. We need strong leaders that ensure the rights of persons with disabilities.”

**Mr Manfred Weber**, lead candidate for the European People’s Party said: “In the European Union we make many statements about the fight against discrimination and about democracy. Yet millions of people with disabilities will not be able to vote at the next European elections and decide about the future of our continent. This is unacceptable!



*Mr Manfred Weber, lead candidate of the European People’s Party (on the left) and Mr Yannis Vardakastanis, President of the European Disability Forum*

We need to guarantee that persons with disabilities fully enjoy all the opportunities our societies offer without any discrimination, starting with their basic democratic rights. No one should be left behind.

This is why I fully support the campaign launched by the European Disability Forum. As the EPP candidate for the presidency of the European Commission I will commit to a EU that defends Disability Rights.”

## About the European Disability Forum

The European Disability Forum is an umbrella organisation of persons with disabilities that defends the interests of 80 million Europeans with disabilities.

EDF is a unique platform which brings together representative organisations of persons with disabilities from across Europe. It is run by persons with disabilities and their families. EDF is a strong, united voice of persons with disabilities in Europe.

For more information please visit: <http://edf-feph.org>



# Crohn's and Colitis Australia: My IBD Experience - Research Report

Crohn's & Colitis Australia have released research findings from a national patient experience survey of IBD care. The report demonstrates there is a high burden of Crohn's disease and ulcerative colitis - the two main forms of IBD - in Australia. The patients are commonly young, unwell with active disease and had lived with the condition for more than a decade.

Crohn's disease and ulcerative colitis, collectively referred to as Inflammatory Bowel Diseases (IBD) affect 85 000 Australians. Total hospital and indirect costs related to IBD for 2012 in Australia were estimated to be \$2.7 billion.

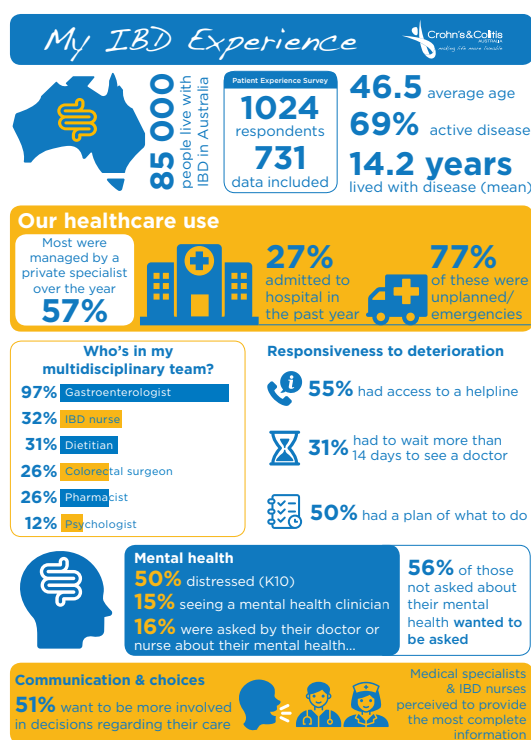
To explore the quality of care for people with IBD Crohn's and Colitis Australia (CCA) undertook an audit of 71 hospitals in 2016. It identified that generally care did not meet the national standards for this chronically unwell group and that mental health issues were prevalent and service access limited.

This study sought to measure the quality of care through the patient experience to provide evidence for co-created improvement in care.

The online survey targeted all people over 16 years of age living with IBD through CCA membership, online forums and through hospital and other medical clinics and settings. The survey focused on the experience of health care for people living with IBD against established standards, their needs, attitudes toward and access to psychological services and the variation in patient experience of health care for people in different service environments.

The response total of 1024 participants makes this the largest patient experience survey of people living with IBD in Australia and complements the scale of the IBD Audit undertaken by CCA 2016.

The majority of participants in this study were currently experiencing illness as a result of their condition, had the condition long-term and were managed by



a private specialist. For many the experience of care did not meet the level described in the Australian IBD Standards 2016, in particular, multidisciplinary care was lacking. Co-morbidity of mental health distress was common and mental health services were not readily accessed despite willingness to engage with them. Standards of care were also not met in various areas including multidisciplinary care, responsiveness, choice in care and clinical communication.

To read the full report please follow the link:  
<https://www.crohnsandcolitis.com.au/ibdqc/2018-patient-experience-research-report>



# Bridging health and social care

## Rare Disease Day 2019

The 12th edition of Rare Disease Day which took place on 28 February 2019 and which is coordinated by EURORDIS, focused on bridging the gaps in the coordination between medical, social and support services in order to tackle the challenges that people living with a rare disease and their families around the world face every day.

For most people living with a rare disease, as well as their family members or carers, the reality of daily life can include any combination of the following: collecting and taking medicines, attending appointments, participating in physical therapy, using specialist equipment and accessing various social and community support services and respite care. Managing these care-related tasks alongside their usual daily activities such as work, school and leisure time can be challenging.

There are over 6,000 rare diseases that affect over 300 million people worldwide. Each disease has an impact on everyday life, including the need for a daily care routine. According to the first ever Europe-wide survey on juggling care and daily life with a rare disease carried out by Rare Barometer, 8 in 10 patients have difficulties completing basic daily tasks. As a result, the majority of care is usually coordinated by people living with a rare disease and their family members who spend a significant amount of time organising care. According to the survey 70% of patients and carers describe it as time consuming.

Organising care can involve researching local services, making phone calls, accessing treatments and rehabilitation, handling administrative procedures and adapting the home or work space.

As a consequence, people living with a rare disease are often off work or school. It becomes a complex and frustrating process, especially when a lack of coordination across services means having to



repeat the same information over and over again. Communication between different services needs to improve so that services are delivered efficiently to meet patients' best interests.

To read more about Rare Disease Day:

<https://www.rarediseaseday.org>

More info about EURORDIS:

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# Barriers to clinical research in children with inflammatory bowel disease: The patients' perspective

Wael El-Matary, Vini Deora, Kanika Grover

## Introduction

Inflammatory bowel disease (IBD) is a group of chronic immune system disorders characterized by remissions and relapses. Inflammatory bowel disease encompasses two related but distinct disorders: Crohn's disease (CD) and ulcerative colitis (UC). CD is a chronic, idiopathic, transmural, patchy, inflammation of one or more segments of the gastrointestinal tract. UC is a chronic, idiopathic, diffuse mucosal inflammation of the colon [1, 2]. For patients with no clear features of either UC or CD, the term IBD-unclassified (IBD-U) could be employed.

The peak incidence of IBD is between the ages of 10 and 30 years. A recent study showed that 8-10% of all patients with IBD usually present in childhood and adolescence [3]. In Manitoba, we have recently shown that the sex- and age-adjusted incidence of pediatric CD has significantly increased from 1.2/100,000 in 1978 to 4.68/100,000 in 2007. For UC, the incidence has increased from 0.47/100,000 in 1978 to

1.64/100,000 in 2007. During the same time period, the prevalence of CD has significantly increased from 3.1 to 18.9/100,000 and from 0.7 to 12.7/100,000 for UC [4].

Scarcity of evidence-based knowledge in many aspects of IBD is a major challenge that could be related to several barriers. Those barriers include research funding difficulties, research-design related factors (such as randomized controlled studies versus observational studies), and physicians and health workers-related factors. For example, patients may have lower threshold to consent for research conducted by their treating physicians versus physicians and health care workers who are not involved in their care [5,6].

In a survey among North American Gastroenterologists examining barriers against clinical research, uncompensated research costs and a lack of specialized support were the most common barriers to research [6].

One major barrier to clinical research is the reduced willingness of patients to participate in clinical

research [5,6]. Data on barriers for recruitment are limited, especially in the pediatric age group. The aim of this study was to determine the proportion of patients' caregivers willing to participate in clinical research and examine possible barriers against clinical research in children with IBD from the perspective of patients and their caregivers.

## Subjects and methods

### Study design and participants

In a cross-sectional analysis, patients (< 18 years) with an established diagnosis of IBD following the Porto diagnostic criteria by the European and North American Society of Pediatric Gastroenterology, Hepatology and Nutrition (ESPGHAN & NASPGHAN) [7] and have been followed by the Section of Pediatric Gastroenterology at the Winnipeg Children's Hospital and their caregivers were invited to answer a survey after obtaining all necessary consents.

A hundred and twenty patients with IBD are followed in our IBD clinic. The study was conducted between December 2016 and July 2017.

### Study procedures

The demographic data from the list of pediatric IBD patients who were followed by the Section of Pediatric Gastroenterology were examined. Potential participants were contacted by telephone by the study co-coordinator.

The study was explained over the phone and a verbal consent from patients and caregivers was obtained. Once the consent was obtained, a phone survey with patients (when appropriate, depending on the patients' age) or their caregivers was conducted.

### Study tool

In addition to the main question addressing patient's willingness to participate in research studies, the survey had 25 questions divided among the 3 main domains:

- Research-related factors: such as research design, frequency of visits and nature of required biological samples
- Patient-related factors: such as family income and parents' education
- Disease-related factors: such as subtype and duration of the disease and medications

A 5-point Likert scale (definitely,

probably, neutral, probably not, definitely not) was used to capture the response information for willingness to participate.

The questions were adopted from surveys employed in previous studies [5-7] and piloted before formal recruitment. Ten children and young adolescents representing different age groups were randomly chosen and were asked to complete the survey. We observed them and their caregivers during answering the survey and we asked for their feedback. The questionnaire was then modified in view of the suggestions that were received.

### Data collection

Clinical data on disease subtype, duration, disease distribution, clinical disease activity at the time of the survey and IBD-related surgery and medications were collected from medical records.

The postal codes of the participants' residences were collected as an indicator for their socioeconomic status (SES). The primary outcome was the proportion of caregivers who are willing to participate in clinical research.

Secondary outcomes included factors affecting willingness of patients/caregivers to participate in clinical research including research-related factors such as study design such as randomized controlled studies versus cohort studies (both were explained by

the research assistant) and type of biological samples to be obtained for research.

Other factors included patient and disease-related factors such as demographics and disease status.

### Statistical analysis

Data analysis was performed using Stata 9.1 (TM) (Data Analysis and Statistical Software, College Station, Texas, USA). Univariate summaries (median and interquartile range (IQR)) were obtained for the continuous variables (i.e. age), while frequency distributions were provided for categorical variables (e.g. gender, level of education attained by parents) along with the 95% confidence intervals (CIs) for the means and proportions.

Proportions were compared using the *Chi-square test* or *Fisher's exact test* where appropriate, while a two-sided *Student's t-test* was used to compare continuous variables.

Univariate logistic regression analysis was used to examine the possible effect of variables examined such as educational levels attained by parents and family income.

Model assumptions were assessed using residual diagnostic techniques. A P value of 0.05 was used for defining the level of significance.

### Ethical considerations

The study protocol was approved by the Health Research Ethics Board of The University of Manitoba.

# Results

A total of 118 (98.3%) out of 120 caregivers of children (age < 18 years) with IBD who were approached completed the survey (Median age 14.46, IQR: 12.00-15.75 years, 60 boys, 61 CD). 110 (92%) participants were over the age of 7 years. Patients were followed for a median duration of 1.73 years (IQR 0.4-3.6 years). Patients' demographics are summarized in Table 1. 14 (12%) participants had at least one sibling diagnosed with IBD.

One hundred and four (88.2%) caregivers were "Definitely" or "Probably" willing to participate in clinical research while 14 (11.8%) were "Neutral" or "Probably" unwilling to participate (P<0.001). Responses are summarized in Table 2.

Seventy-four (62.7%) participants previously participated in at least one study and 21 (17.8%) previously declined participation in one or more research studies. The majority of participants [71 (60.2%)] patients thought that a monthly clinic visit would not make any difference in encouraging participation in clinical research.

Ninety participants (76.3%) agreed to participate in studies that include obtaining "two small" blood samples, 88 (74.6%) agreed to give one urine sample, and 71 (60.2%) agreed to give a stool sample. On the other hand, 84 (71.2%) patients would decline participating

Age (years)	
Mean	13.54± 3.23
Median	14.46
Interquartile Range	12.00–15.75
Gender	
Male	60 (51%)
Female	58 (49%)
Mother's Education	
Bachelor's Degree	58 (49%)
No Degree	59 (50%)
Don't know	1 (1%)
Spouse's Education	
Bachelor's Degree	55 (46%)
No Degree	54 (45%)
Don't know	1 (1%)
No spouse	8 (7%)
Family Income	
<\$31,000	4 (3%)
>\$31,000	74 (62%)
Prefer not to answer	40 (35%)
Disease type	
Crohn's Disease	61 (51%)
Ulcerative Colitis	56 (48%)
Inflammatory Bowel Disease-Unclassified	1 (1%)
Currently in Relapse*	11 (9%)
Previous Surgery	7 (6%)
On Biologic (Infliximab or Adalimumab)	54 (45%)
On an Immunosuppressant (Methotrexate or Azathioprine)	74 (62%)

\* As defined by clinical disease activity indices

Table 1

Willingness to participate	No. of patients	%
Definitely	92	78
Probably	12	10.2
Neutral	11	9.3
Probably not	3	2.5
Definitely Not	0	0.0
Total	118	100

Table 2

in studies that include obtaining endoscopy biopsy samples.

Fifty-eight (49.2%) participants thought that money (\$100) would encourage participation in clinical research (P = 0.8). Patients were less likely to participate in clinical

research if they had longer disease duration (P = 0.019), or were in clinical relapse at the time of participation (P = 0.03).

Patients were also less likely to participate if they were asked to provide tissue biopsy samples (P = 0.05).

Other biological samples such as blood samples ( $P = 0.7$ ), urine ( $P = 0.1$ ) or stool ( $P = 0.8$ ) samples did not seem to make any difference on patients' willingness to participate.

Nature of research studies such as randomized controlled studies ( $P = 0.2$ ) or open labelled studies ( $P = 0.3$ ), family history of IBD ( $P = 0.4$ ), parents' education ( $P = 0.8$ ), family income of over \$ 31,000.00 per annum ( $P = 0.5$ ), money incentive ( $P = 0.8$ ), and medications, such as immunosuppressive or biological medications, at the time of the survey did not have any significant effect on willingness to participate.

## Discussion

The variety of barriers against recruitment for clinical research studies in children with inflammatory bowel disease (IBD) needs to be identified and examined in order to work towards resolving these barriers and encourage recruitment. In our study, the majority of children and their caregivers were willing to participate in clinical research, especially if they had shorter disease duration or were in clinical remission at the time of the survey.

Studies examining barriers to recruitment in children with chronic diseases including IBD are scarce. In a cross-sectional study, Hoberman and colleagues surveyed parents previously asked to provide consent for their child's participation in the trial about factors that influenced their decision.

Having graduated from college and private health insurance were associated with lower likelihood of providing consent. Parents who perceived the study as having a low degree of risk, resulting in greater benefit to their child and other children, causing no or minor interference with the standard care or who perceived the researcher as professional were significantly more likely to consent to participate [8].

In our study, parents' education did not seem to have a major association with willingness to participate in clinical research. A major limitation of the study by Hoberman et al was the low participation rate of the survey as only 44% of those who were invited to participate actually answered the survey questions.

In comparison to our study, invasive procedures such as colonoscopies or sigmoidoscopies did not have a positive influence on willingness to participate in research studies for adults with IBD in a study that surveyed 200 patients with IBD [9]. Other factors that interfered with willingness to participate included the need for frequent physician visits and the blinding design. Male gender, compensation, and active disease at the time of survey were associated with higher willingness to participate [9].

A telephone interview with patients with systemic lupus erythematosus who accepted or refused to participate in clinical trials indicated the presence of several factors

that affected the decision-making process of participation. Those factors included health status at the time of participation, study design, physician involvement, altruism, personal benefit and incentives. Good health status, encouragement from one's physician and personal desire to learn and contribute stimulated participation [10].

The gender of participants is another potential factor that may affect willingness to participate in clinical research.

Ding et al. explored this factor in a multi-center study to examine the willingness of patients with cardiovascular disease to participate in clinical trials. Women were less willing to participate as they perceived greater risks of chronic disease-related harm [11].

We did not encounter the same finding in our study as parents' views for their children to participate in clinical research may be different from their willingness for their own participation i.e. Parents may have a lower threshold to participate in clinical research as they feel less anxious compared to their feelings towards their children's participation.

Although ethically controversial, paying participants as a motivator for participation in clinical research was explored among other factors in a study by Halpern et al [12]. Willingness to participate decreased by lower payment level, higher risks of adverse events, and higher risks for being assigned to placebo.

Higher payments did not alter participants' reaction to the examined risk factors such as adverse events, suggesting that higher payments did not alter participants' perception of risks. Interestingly, in this study, wealthier participants were more likely to state that payment was important in their participation decision [12]. In our study, paying money as an incentive for participation did not seem to be associated with a higher willingness to participate.

Our study is unique and novel. This is the first study examining barriers to clinical research among parents and children with IBD. In addition, the study has an excellent response rate to the invitation to complete the survey reaching up to 98.3%. This may reflect a high level of motivation of both patients' caregivers and our research team. On the other hand, our study is limited by using a non-validated survey tool. However, there is no validated tool in this context.

Although the majority of our participants were willing to participate, actual consent for participation in clinical research may vary. Nonetheless, our study highlights some factors and difficulties that should be taken into consideration when researchers plan for studies for children with IBD.

Disease relapse may not be the best time for approaching participants. Researchers should be aware that they may not be able to obtain endoscopy biopsy and stool research samples in up to

70% and 40% of children with IBD respectively.

This could be proven valuable in sample size calculation. On the other hand, patients seem to be willing to donate blood samples over stool samples. This might be explained by the easiness to collect blood over stools and the fact that adolescents seem to feel disgusted by the process of stool collection.

## Conclusions

The majority of caregivers of children with IBD, especially those with Crohn's disease, are willing to participate in clinical research. Patients are less likely to consent for clinical research if they have longer disease duration and were approached at the time of clinical relapse. Future research studies examining strategies to change the attitude of patients' caregivers towards certain barriers such as collection of tissue sample biopsies are warranted.

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