

# EFCCA MAGAZINE



European Federation of Crohn's and Ulcerative Colitis Associations

October 2021

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Summer camp for IBD children**

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# EFCCA Members

Austria - OMCCV  
www.oemccv.at

Belgium  
CCV: www.ccv.be  
Crohn-RCUH: www.mici.be

Bulgaria - BCUCA  
www.babkuk.org

Croatia - HUCUK  
www.hucuk.hr

Cyprus - CYCCA  
www.cycca.org

Czech Republic - Pacienti IBD  
www.crohn.cz

Denmark - CCF  
www.ccf.dk

Estonia - EPSS  
www.ibd.ee

Finland - CCAFIN  
www.ibd.fi

France - AFA  
www.afa.asso.fr

Germany - DCCV.e.V.  
www.dccv.de

Greece - HELLESCC  
www.crohnhellas.gr

Hungary - MCCBE  
www.mccb.e.hu

Iceland - CCU  
www.ccu.is

Ireland - ISCC  
www.iscc.ie

Israel - CCFI  
www.ccfi.co.il

Italy - AMICI  
www.amiciitalia.org

Latvia - LKKSBB  
www.lkksb.lv

Lithuania - CCLA  
www.draugija.info

Luxembourg - ALMC  
www.afa.asso.fr/luxembourg

Malta - MACC  
www.macc.org.mt

Montenegro - CUKUK  
www.cukuk.me

New Zealand  
Crohn's and Colitis  
www.crohnsandcolitis.org.nz

Netherlands  
Crohn & Colitis NL  
www.crohn-colitis.nl

Norway - LMF  
www.lmfno.no

Poland - J-elita  
www.j-elita.org.pl

Portugal - APDI  
www.apdi.org.pt

Romania - ASPIIR  
www.aspiir.ro

Serbia - UKUKS  
www.ukuks.org

Slovakia - SCC  
www.crohnclub.sk

Slovenia - SAIBD  
www.kvcb.si

Spain - ACCU  
www.accuesp.com

Sweden - MOT  
www.magotarm.se

Switzerland - SMCCV  
www.smccv.ch  
www.asmcc.ch

Turkey - IBHDYD  
www.ibhportali.com

UK - Crohn's and Colitis  
www.crohnsandcolitis.org.uk

## Associate Members:

Argentina - Mas Vida  
www.masvida.org.ar

Brazil - DII Brasil  
www.facebook.com/diibrasil

Kazakhstan - FPVZK  
www.vzk.kz

Trinidad and Tobago - NACCTT  
www.crohnsandcolitistt.org

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# Persistence

It is the second year running that we have held our General Assembly on-line. It has been a challenging time and we would have preferred to meet with our colleagues and friends in person, in order to see each other again, better exchange information and develop new ideas for our common cause. However, the situation caused by the pandemic has not allowed us to organise such a meeting.

Instead we held our second online General Assembly. Over 95 % of our members participated in this event and we welcomed four new patient associations to our EFCCA network. This clearly shows that the work we do as a patient organisation is acknowledged worldwide and very much needed.

The incidence of IBD is growing and people living with IBD are looking towards organisations that can help them improve not only their quality of care but also their quality of life.

For World IBD Day 2021 we have brought home this message of how IBD can impact on a person's general well-being and mental health. You will find out more in this issue of how we have initiated a dialogue on the various psychological manifestations of the disease which are not usually talked about.

We are also pleased that our cooperation with representatives from the medical societies has continued throughout the pandemic and even though we have not had the chance to meet our colleagues in person we have been closely working together sharing as much information as possible with our members through the EFCCA Patient Talks and other communication channels.



**“We welcomed four new patient associations to our EFCCA network. This clearly shows that the work we do as a patient organisation is acknowledged worldwide and very much needed.”**

The project “(IBD) Families First” presented at the EFCCA Patient Talk and led by colleagues from ECCO is an interesting opportunity to learn more about the preferences and fears for potential prediction & prevention interventions. We are really excited to follow this project and will keep our members updated on the progress.

Another exciting work that we are currently undertaking is the EFCCA Academy. We have completed a training module on Clinical Trials that highlights the important role that patients and patient associations can and should take starting from the very beginning of the Clinical Trials development phase. Students are now finalising their end of course assignments and you will already find examples of some of the work that students have carried out in order to bring their knowledge to their national patient associations and IBD community. A second round on the same topic is ready to start and this clearly shows that our proposal meets the interest of our members.

We are also using the EFCCA Academy to provide a training programme directed towards young representatives of our members. The idea is to empower, strengthen and expand our youth group and provide them with tools and skills allowing them to increase their representativeness. You will find more information in this issue.

Finally, I would also like to thank our members for their involvement in our cause, be it through World IBD Day or other initiatives that we have organised. Also, reading about the amazing range of activities that our members have organised around the globe despite the current restrictions and difficulties. leaves me very inspired indeed.

It once again confirms the philosophy of EFCCA...  
**UNITED WE STAND!**

Salvo Leone,  
EFCCA Chairman



# Four new members join the EFCCA family

During our latest EFCCA General Assembly delegates voted in favour of four new patient associations from Mexico, Singapore, Russia and the Ukraine joining the EFCCA network bringing our total membership to 45 associations in 44 countries.

The EFCCA General Assembly which brings together representatives from Crohn's and Colitis patient associations was held -due to the current pandemic - for the second time running on-line on 29 May 2021.

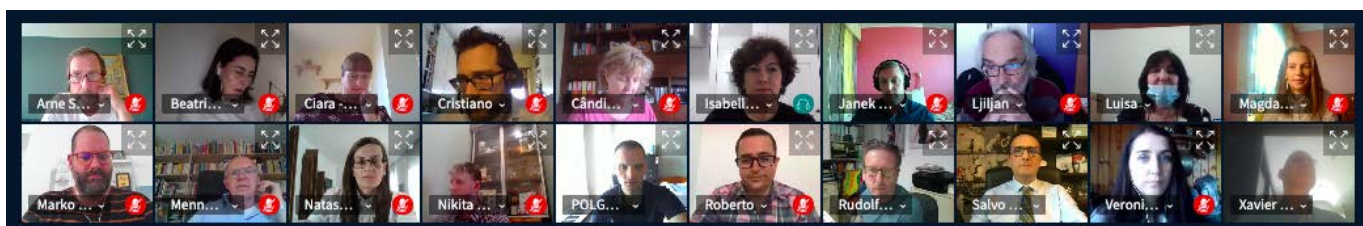
During this annual meeting delegates approve the EFCCA Annual and Financial Reports as well as our yearly work plan. In addition, elections to the EFCCA membership and the EFCCA board are held.

*"It is with great pleasure that I welcome our new members from Mexico, Singapore, Russia and Ukraine. I believe that together we are stronger. Especially, in these difficult moments we need to stay committed to our common cause and support people with IBD worldwide. Let's not forget that IBD*

*has no borders"* said Salvo Leone, EFCCA chairman following the acceptance of the four new members to the General Assembly.

Traditionally, the main focus and membership of our work is based in Europe. In recent years and with IBD increasingly becoming a global challenge, EFCCA has been in contact with many patient representatives from across the world and several associations have applied to become associate members. Associate members can participate in all EFCCA activities but do not have the right to vote during our annual assembly.

Any associate member has the possibility to become full member during a General Assembly, if they fulfil certain conditions.



**Online GENERAL ASSEMBLY**  
**29 MAY 2021**

Elections to the EFCCA Executive Board are also held annually. This year we have welcomed Menne Scherpenzeel as new board member. Menne is the CEO of the Dutch patient association Crohns and Colitis NL. Our long-standing board member Natasa Theodosiou from the Cyprus association CYCCA is no longer member of the board.

Salvo Leone took the opportunity to thank her for all her work and commitment during those years and we hope that Natasa remains an active delegate to our assembly.

Other institutional matters were presented and discussed. All documents can be consulted by EFCCA members in the private area of the EFCCA website.

## EFCCA Patient Talk

### (IBD) Families First

How willing are you to get a colonoscopy as a prediction tool? Would you accept to start a biologic when you do not have IBD? If your risk for having IBD could be predicted by blood and stool tests, would you rather not know? Would you agree to start your child on a special diet for preventive reasons?

This EFCCA Patient Talk gave participants the opportunity to learn more about an exciting new study that investigates first degree relatives of IBD patients on their preferences and fears for prediction & prevention interventions.

The EFCCA Patient Talk which took place on-line on 30 June 2021 was moderated by our Vice-President Ciara Drohan and included speakers Catarina Fidalgo (MD), Bárbara Morão (MD) and Joana Torres (PhD) from the Hospital Beatriz Angelo (Portugal) who are the leading team of the study.

First degree relatives of IBD patients are the population at higher risk of developing Inflammatory Bowel Disease (IBD). Such risk can be further assessed by using prediction models (blood, stool, endoscopic, imaging tests). As global IBD prevalence is rising we need to improve treatment and search for a cure while improving PREDICTION and PREVENTION of new cases.

#### EFCCA Patient Talks

### (IBD) Families First study

#### Free Webinar

Join our discussions and presentation on a global survey aimed at 1st degree relatives of IBD patients on preferences and fears for prediction & prevention interventions

Speakers include:

Joana Torres, PhD and Catarina Fidalgo, MD  
Hospital Beatriz Angelo (Portugal)

More info: [www.efcca.org](http://www.efcca.org)

Watch on: <https://fb.me/e/Apajnw2>

30 June 2021, 5 - 6 PM (CET)

The identification of biomarkers for IBD suggests that it may be possible to identify people at high risk for developing disease. Thus, PREDICTION opens the possibility of treating the disease in its pre-clinical phase, preventing its occurrence.

As concerns PREVENTION this is an ambitious idea, but it is being sought in other areas such as for example in Type I diabetes.

Before designing the study and interventions, the study team, including the 3 presenters of the Patient Talk would like to bring a focus group together with first degree relatives (siblings and children of IBD patients or parents of children at risk) to assess preferences and fears towards prediction tools and preventive strategies.



If you want to find out more please contact the EFCCA office.

## World IBD Day

For this year's World IBD Day on 19 May 2021 EFCCA started a dialogue and discussions on how IBD affects people not only physically but also psychologically with the aim to shed a light on the various aspects of the disease.

Within the framework of our strategy plan, our focus for this year's World IBD Day was and is on the issue of IBD and Well-being. It is important to understand that IBD can take a toll on many aspects of day to day life including general well-being and mental health. Living with a chronic disease might lead to depression, anxiety and a negative self-image affecting not only the person with IBD but also his/her family and friends.

We carried out a social media campaign leading up to 19 May in order to raise awareness about the hidden facts of what it is like to live with IBD. Under the hashtag #breakthesilence we invited the IBD patient community to talk about things they feel are not usually talked about.



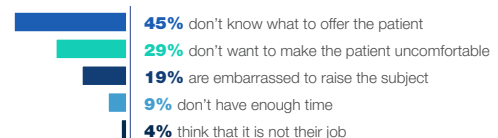
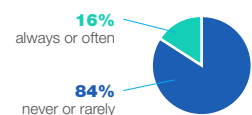
### IT TAKES GUTS TO TALK

Breaking the Silence on IBD and Intimacy

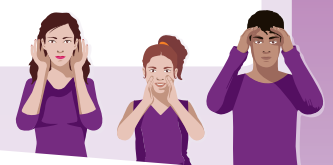
Discussing how IBD affects your personal life can be difficult, and as a result issues surrounding intimacy and relationships tend to be an

overlooked and ignored area. This leaflet provides some tips that you might find useful as you navigate your way around coping with IBD.

The majority of gastroenterologists **never or rarely discuss sexuality** with their IBD patients



Riviere P, et al. Quality of sex life in patients with inflammatory bowel disease: the gastroenterologists' perspective. *Inflamm Bowel Dis*. 2017;23:E51-E52



#worldibdday2021

#breakthesilence

In particular, we initiated discussions around taboo subjects such as for example IBD and Intimacy.

We prepared and published a comprehensive leaflet with relevant background information and practical advice that gives a good overview of the issues involved. We were pleased that several of our EFCCA members have used this leaflet to provide better services to their members and to stimulate discussions in their own country on this taboo subject.

To download the leaflet please follow this link:

[www.efcca.org/sites/default/files/IBDandIntimacy.pdf](http://www.efcca.org/sites/default/files/IBDandIntimacy.pdf)

Thanks also to Ana Sofia Correia who volunteered and translated the leaflet into Portuguese:

<https://bit.ly/breakthesilence-leaflet-portuguese>

Our next step is to summarize the main issues emerging from these discussions and to take these findings to Health Care Providers and other stakeholders for them to listen and to find together solutions that will have a meaningful impact on a person's quality of life.

For more information please go to:

[www.efcca.org/en/break-silence-world-ibd-day-2021](http://www.efcca.org/en/break-silence-world-ibd-day-2021)

# Patient's perspective on the impact of perianal fistula in Crohn's disease on quality of life

The results of the survey conducted in 2019 in partnership with Takeda have been presented at the latest ECCO Congress in July 2021 and are now finally ready to be published.

People living with Crohn's Disease (CD) may experience perianal fistulas, which can cause intense pain, swelling, infection, and anal discharge. In adult patients with CD, the cumulative incidence of perianal fistulas is estimated to be 15%, 21-23% and 26-28% over five, 10 and 20 years, respectively.

Perianal fistulas in CD are abnormal tracts with an internal opening in the anal canal or rectum and an external opening in the skin near the anus. They may develop from inflamed or infected anal glands and/or penetration of fissures or ulcers in the rectum or anal canal.

Despite this, there have been few studies assessing the patient perspective of living with this condition and therefore, in 2019 EFCCA has launched an

anonymous survey to understand the overall real-world impact of perianal fistula (and complex perianal fistula) in Crohn's disease on quality-of-life taking into account several different areas: overall quality of life, relationship with family and friends, relationship with partner, social life and work life.

The survey was developed with the support of patient representatives and medical experts and was available on the EFCCA website from July 15th until December 31st, 2019. CD patients with and without perianal fistulas were invited to participate. The survey was offered in English, French, German, Greek, Hebrew, Italian, Polish, Portuguese, Romanian, Spanish and Slovenian and collected 820 responses across 33 countries.



In conclusion, the survey found that CD patients living with perianal fistulas reported a more significant impact on their overall quality of life and an increase in certain symptoms, such as anal pain and perianal leaking, when compared to CD patients without perianal fistulas.

CD patients living with perianal fistulas also reported feeling more unhygienic, uncomfortable and guilty about their condition toward family and friends than CD patients without perianal fistulas.

The findings show that as well as impacting work and social life, perianal fistulas had a greater negative impact on CD patients' ability to do sports, work and employment, dating and sexual life.

Significantly important are also the differences in symptoms experienced by men and women and the different impact of living with perianal fistula in the different life areas.

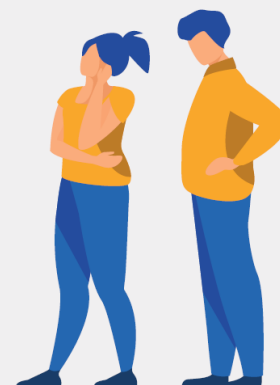
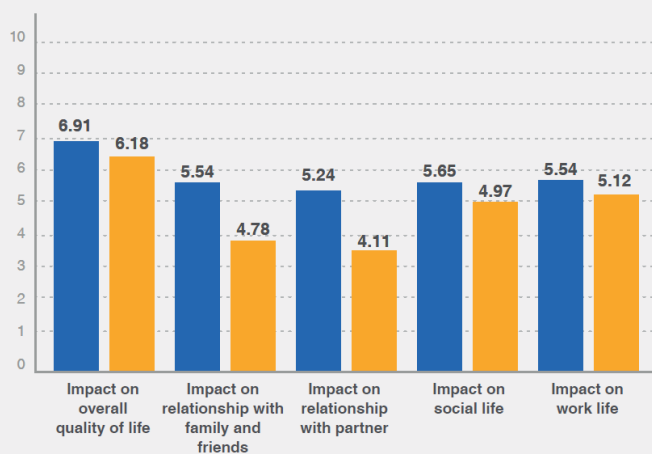
These results are important to consider when tailoring treatment strategy and patient services in a multidisciplinary approach to address individual patient needs. Once initiated a dialogue among its members, EFCCA would like to discuss the outcomes of this survey with healthcare providers and other stakeholders to find together solutions that can have a meaningful impact on the quality of life of patients with PAF/complex PAF.

To read the full results/infograph please follow this link: [www.efcca.org/sites/default/files/fistula\\_infograph.pdf](http://www.efcca.org/sites/default/files/fistula_infograph.pdf)

If you have any questions, please send an email to [mariastella.derocchis@efcca.org](mailto:mariastella.derocchis@efcca.org)

## Impact of PAF/complex PAF among patients with CD on quality of life, relationships, social life and work life

*On a 0 to 10 scale, patients with PAF/complex PAF rated a greater impact of their condition on all life areas than those with CD only*



■ Patients with PAF/complex PAF (532)  
■ Patients with CD only (288)

# EFCCA Patient Talk

## Results of Fistula survey

During our latest webinar, which is part of our EFCCA Patient Talks series, we have shared the main findings of the survey on patient's perspective on the impact of perianal fistula in Crohn's disease on quality of life, reaching 820 participants in 33 countries. (see previous article).

Our guest speaker and lead author of the study, Prof. Antonino Spinelli, Director of the Division of Colon and Rectal Surgery at Humanitas and Professor of Surgery at Humanitas University in Rozzano in Milan (Italy), introduced the subject speaking about the burden of perianal fistulas in Crohn's disease and stressing the importance of gathering patients' feelings and perspectives in clinical practice.

Our colleague Maria Stella De Rocchis presented the overall outcomes of the survey and those of Italy, Spain and Portugal representing the 3 countries from which we have received the highest number of responses. The results clearly showed that from the patient perspective, perianal fistulas severely impact the overall quality of life, relationships with family and friends, intimacy and social and work life in addition to the existing impact of Crohn's disease. The survey also brought to light differences in symptoms experienced by those with Crohn's disease with and without perianal fistulas, but also differences in symptoms experienced by men and women.

The meeting was moderated by Ciara Drohan, EFCCA Vice President and Member of the Irish Crohn's and Colitis Society and it ended with a patient's story, the testimony of Candida Cruz, Vice President of APDI.

For more information and to watch the webinar please go to: <https://bit.ly/fistula-survey-webinar>

### EFCCA Patient Talks

Free Webinar

## Results of Fistula survey

Join our presentation on the results of "the impact of perianal fistula in Crohn's disease on quality of life" survey.

Speakers include:

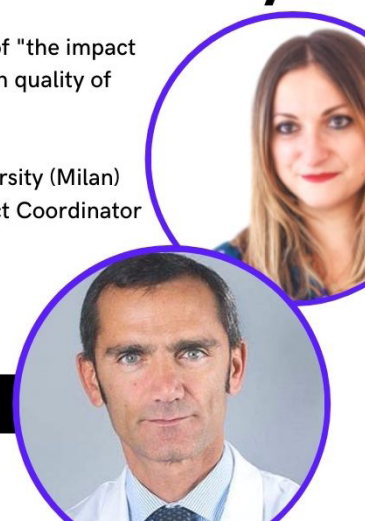
Professor A. Spinelli, Humanitas University (Milan)

Maria Stella de Rocchis, EFCCA Project Coordinator

Candida Cruz, APDI (tbc)

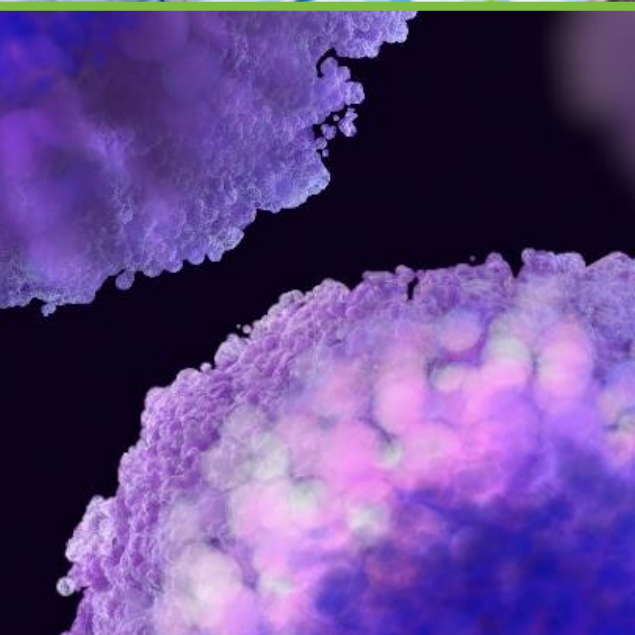
Register: [info@efcca.org](mailto:info@efcca.org)

9 September, 2021 6-7 PM (CET)



### Findet gerade statt





## Learning from the experts.

No one understands the patient journey quite like the patients themselves. That is why we are working closely with the patient community to deliver oral medicines to address patients' needs and help transform the treatment of inflammatory bowel disease.

Come and meet us at <https://www.arenapharm.com>

**ARENA**  
PHARMACEUTICALS  
*Care More. Act Differently.*



# EFCCA Academy: towards the Certified Patient Award on Clinical Trials

## Education should be accessible to all - including IBD patients

Last November 2020 a group of motivated students joined the EFCCA Academy on Clinical Trials with the aim to have a better understanding of the complete clinical research process, and of the patient's role in supporting the design and implementation of clinical studies. We are pleased to present you now with the first four projects accomplished by the students that participated in the training.



A big thanks to students Vasiliki, Anastasia, Nidhi, Beatriz and Bastien on behalf of EFCCA for their great commitment in sharing their knowledge about clinical trials within their IBD communities. Great job!

We are looking forward to telling you more about other successful stories from the rest of the students.  
Stay tuned!

- 
- Students: Vasiliki - Rafaela Vakouftsi & Anastasia Ntanou
  - EFCCA Association: Greece - HELLESCC - Hellenic Society of Crohn's Disease and Ulcerative Colitis Patients
  - Type of activity: Webinar

Their talk was joined by Ioannis Koutroumpakis, Professor of Gastroenterology, Head of Department of Gastroenterology University Hospital of Heraklion and Mrs. Kalliopi Fotinogiannopoulou, Gastroenterologist Department of Gastroenterology University Hospital of Heraklion.

On April 17 HELLESCC organised a webinar sharing the knowledge acquired during the EFCCA Academy. Vasiliki - Rafaela Vakouftsi, General Secretary of HELLESCC and Anastasia Ntanou, Board Member of HELLESCC gave an overview on the subject of clinical trials and explained how important the active role of patients in this practice is.

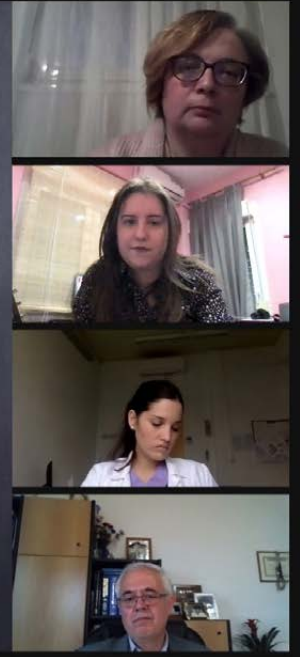
The sections of the webinar were:

- 1) Clinical trials: the active role of patients
- 2) Clinical trials for IBD in Greece

The presentations have been followed by an open discussion with all participants.

## Φάση III

- Πρέπει ΥΠΟΧΡΕΩΤΙΚΑ να εξαχθούν συμπεράσματα για την αποτελεσματικότητα και ασφάλεια του φαρμάκου. Απαραίτητα για την αδειοδότηση από τον FDA και τον EMA
- Μπορούν επίσης να εξαχθούν παράλληλα συμπεράσματα για την ποιότητα ζωής των ασθενών, τις προτιμήσεις τους, την αντίδραση του φαρμάκου με τον οργανισμό του ασθενούς κλπ



- Student: Nidhi Swarup
- EFCCA Association: Crohn's & Colitis Society of Singapore
- Type of activity: Webinar

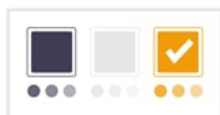
On the occasion of the ninth annual Crohn's & Colitis Patient Education Seminar which took place last May 18, Nidhi Swarup, President of Crohn's & Colitis Society of Singapore, had the opportunity to raise awareness around the theme of Clinical trials which,

according to her, are limited in numbers in this part of the world, especially in IBD.

She shared some information regarding the training she has received from EFCCA and encouraged attendees to be open to learn about such an important subject.

The conversation was joined by three other IBD specialists from leading hospitals in Singapore who have been supporting patients diagnosed with Crohn's Disease or Ulcerative Colitis for many years.

## IBD IN ASIANS: SAME OR DIFFERENT?



- "IBD Medication is for life" FACT or FALLACY?
- Call for National and Asian Research
- New Drugs and Singapore Clinical Trials
- IBD Patient's Role: Participate in Design, Planning and Implementation
- EFCCA Online Training Modules on Clinical Trials



- Student: Beatriz Capdevielle
- EFCCA Association: Vivir con Crohn y CUCI A.C. Mexico
- Type of activity: Webinar

On 26 June, Beatriz Capdevielle, President of Vivir con Crohn y CUCI A.C., with the support of our EFCCA Board member, Roberto Saldaña, presented a webinar on clinical trials for the Mexican association. In his presentation Roberto covered areas such as: health systems and standard of care, innovation cycle, introduction to clinical trials, ethics in clinical trials and informed consent and usual doubts that patient associations recommend to clarify before accepting participation in any clinical trial.

About 28 people participated in the webinar, and it became evident that there was an important lack of patients' knowledge on this subject. EFCCA is looking into expanding the training to ensure that also other patients have the opportunity to learn about this important topic.

Vivir con  
CROHN & CUCI A.C.  
FUNDACIÓN

TE INVITA A LA PLÁTICA POR ZOOM

# ENSAYOS CLÍNICOS, ¿UNA OPCIÓN PARA MÍ?

PONENTE:  
ROBERTO SALDAÑA  
EUROPEAN FEDERATION OF  
CROHN'S & ULCERATIVE COLITIS  
ASSOCIATIONS (EFCCA)  
SÁBADO 26 DE JUNIO  
11:00 AM HORA CDMX

REGISTRO NECESARIO PARA OBTENER LINK DE ACCESO  
[HTTPS://FORMS.GLE/1EXRMF61GU21QYBY6](https://forms.gle/1EXRMF61GU21QYBY6)

## FAQ ÉTUDES CLINIQUES

**Ce document répond aux principales questions relatives aux études cliniques. Il se veut le plus exhaustif possible mais il est probable que nous ayons oublié certaines questions. Si après la lecture de ce document vous avez encore des questions sans réponse, n'hésitez pas à contacter l'afa et nous nous ferons un plaisir de vous aider.**

### QUI PEUT PARTICIPER À UNE ÉTUDE CLINIQUE ?

Il est impossible de donner une réponse générale car chaque étude clinique a ses propres règles. Avant de commencer les essais à proprement parler, un protocole de recherche est rédigé. C'est dans ce document que sont définis, entre autres, les critères d'inclusion et d'exclusion des patients. Autrement dit, à chaque étude clinique correspond un ou plusieurs profil(s) de patient(s).

**Les critères d'inclusion/exclusion sont variés et peuvent par exemple porter sur (liste non exhaustive) :**

- l'âge,
- le sexe,
- le poids,
- le type de traitement actuellement suivi,
- le type et le stade de la maladie,
- le mode de vie,
- les résultats d'analyses médicales.

Il faut donc regarder étude par étude si vous correspondez au profil recherché.

- Student: Bastien Corsat
- EFCCA Association: afa Crohn RCH France
- Type of activity: Document informative

Bastien Corsat, volunteer and board member of afa Crohn RCH France, together with the board of the French association identified what would be the most useful tool for the IBD community to be acknowledged on clinical trials. And so, the idea of creating a Frequently Asked Questions (FAQ) document containing information about the following questions:

- Who can participate in a clinical study?
- How to find a clinical study?
- Which are the benefits and potentials risks in doing a clinical trial?
- What questions to ask before making a decision?
- 6 myths about clinical trial

The document also contains useful links for the French IBD community.

You can download the document clicking on "FAQ ÉTUDES CLINIQUES" just below the video:

<https://bit.ly/afa-essais-cliniques>

PDF: <https://bit.ly/faq-etudes-cliniques-pdf>



# Pioneering for patients

We don't think it is good enough that countless people affected by fibrotic and inflammatory conditions are still living with debilitating symptoms. That is why we are determined to change this. We are relentlessly searching for medicines to tackle the progression of the disease itself. We are driven by thinking about the positive impact this could have, not only in changing the lives of those affected, but also on their families, friends and societies in general.

**Discover more at [glpg.com](https://www.glp.com)**

**Galápagos**  
Pioneering for patients

# Leaders for tomorrow: EFCCA Youth Academy

EFCCA is launching a long-term training programme addressed to young IBD patients (aged between 18 and 30). The pre-registrations are still open for EFCCA members who have not already sent their request and want to take part in this exciting educational offer.

As presented during the EFCCA Happy Hours and discussed during our last General Assembly, EFCCA is launching a tailor-made module of the EFCCA Academy addressed to young representatives with the following main objectives:

- to increase the representativeness of the youth group;
- to create a cohesive group of leaders of tomorrow;
- to empower young representatives;
- to strengthen and expand the youth group.

The training programme will be released online as part of the EFCCA Academy and it will be launched soon.

Teaching subjects will include:

- the history of EFCCA, its mission, values and strategic priorities;
- the journey that led to the creation of the youth group;
- the foundations for the democratic and harmonious development of second level associations;
- team building and leadership shaping: the basics;
- testimonials and inspiring practices from the IBD community.

We need your help to make EFCCA stronger and ready for the future, including and involving the new generation of the leaders of tomorrow.

For more information and to pre-register please send an email to: [mariastella.derocchis@efcca.org](mailto:mariastella.derocchis@efcca.org)







## LILLY FOR BETTER

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*Lilly*



# New Zealand

## Unmasking IBD

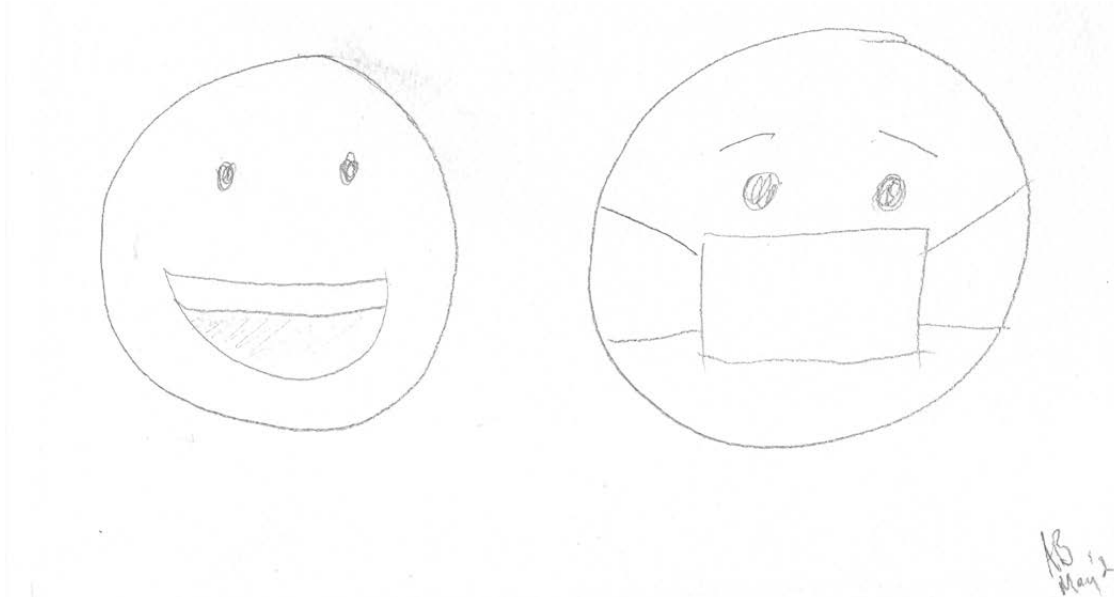
This year, Crohn's and Colitis New Zealand's World IBD Day event took place in Parliament, where the organisation has been very active, having recently presented a petition with 30,000 signatures for funding new medications and where our youth Ambassador, Nicole Thornton, testified in front of the Health Select Committee at the age of 13, for better toilet access for the disabled.

In the Grand Hall of Parliament, a striking installation was unveiled, titled "Unmasking IBD". The installation was the creation of well-known, local artist, Katie Gracie Marshall. Using donated mannequins, Katie's talents transformed these "happy figures" into "real people", dealing with real-life diseases, each holding a mask, behind which they could hide their pain.

The artist, who donated weeks of her time on the project, said *"I have ulcerative colitis, so the project was hugely personal for me. I wanted to reveal the state that many people are in, when they are in the privacy of their own homes-heartache, depression, and pain to name a few. Another piece I created was a purple ribbon, the international symbol of IBD, out of origami butterflies to represent hope. I used 200 butterflies, each to honour 100 people who suffer from these diseases in New Zealand"*.



Some of the doodles presented at the exhibition





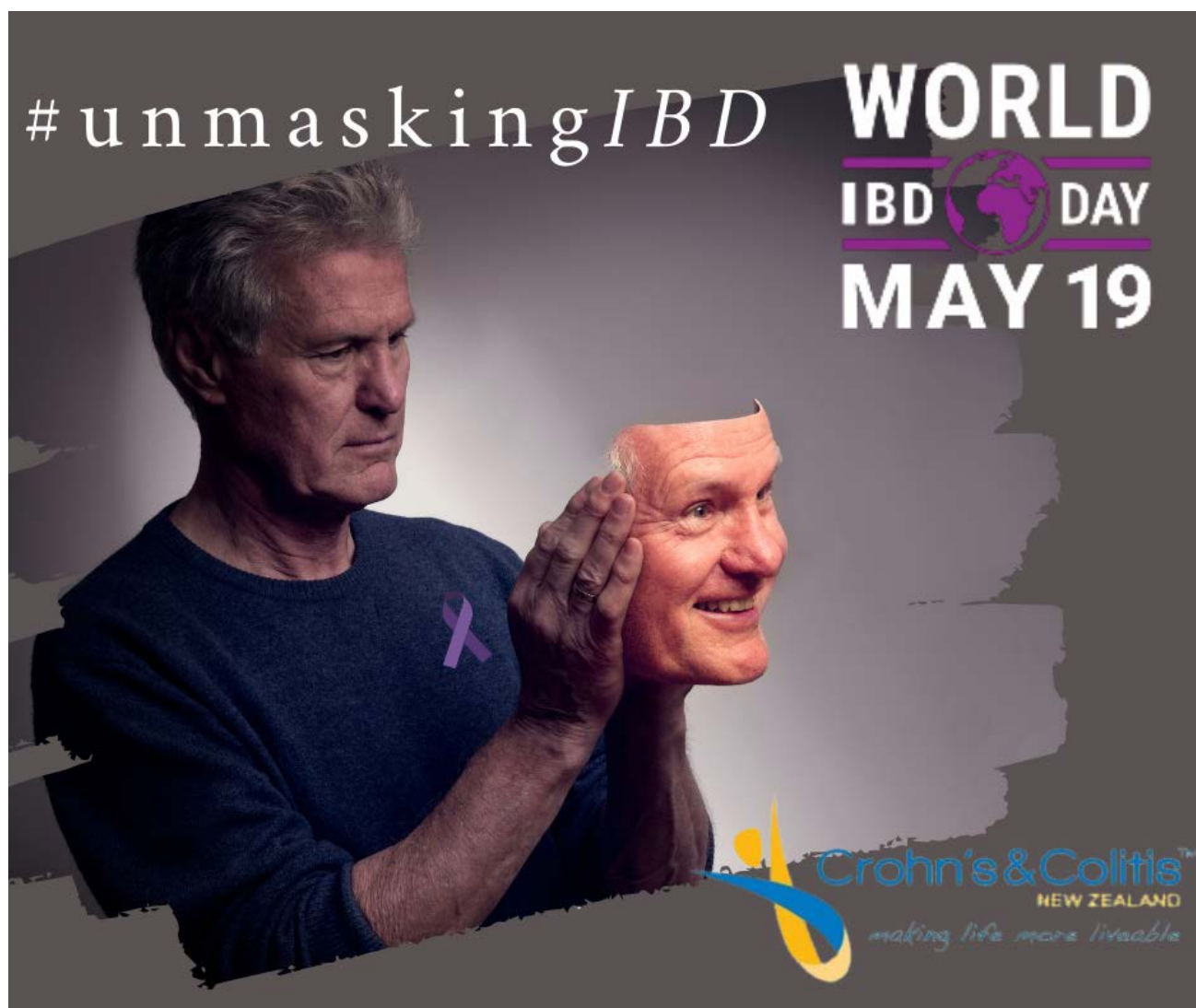
Katie adds, "Accompanying the installation, we asked prominent people in the community as well as members of the general public, to draw doodles, also along the theme, unmasking IBD'. We exhibited over fifty of these. We had so many entries, from notables like Ashley Bloomfield, our Director-General of Health, the leaders of the National, Green, and ACT parties, even an entry from singer Kimbra."

Speaking at the event were the artist, Katie Gracie Marshall, CCNZ Youth Ambassador Nicole Thornton, Member of Parliament Chris Bishop, CCNZ Chair Dr. Richard Stein, Board member Hettie Arends, and CCNZ Operations Manager Belinda Brown.

Crohn's and Colitis New Zealand Charitable Trust (CCNZ) plans an event every year to commemorate the day .

Of the ten million people with these diseases, 20,000 live in our small country which has the third highest rate of IBD in the world. CCNZ runs an internationally recognised, free week-long camp for over 75 children with IBD each year, an annual retreat for young adults, a yearly networking educational seminar for parents and caregivers, and actively advocates for people with IBD in Parliament.

The turnout for the event was huge and was hosted by Chris Bishop, MP. It was supported by an unrestricted grant from Janssen Pharmaceuticals. The installation and the doodles will be exhibited throughout the country over the next several months.



# Romania

## 100 Companies for IBD

On the occasion of World IBD Day, the Romanian IBD patient association ASPIIR launched a campaign entitled “100 Companies for IBD” in order to raise awareness about the impact of Inflammatory Bowel Disease at the workplace.

In Romania, approximately 15,000 patients are diagnosed with IBD. Most people with IBD are of active age when diagnosed. This means that they are likely concerned about their job and their employment prospects. Fortunately, many people with Crohn's disease or ulcerative colitis can lead a normal life, can work successfully to their full potential, especially when they have proper disease management.

Within this framework, ASPIIR in partnership with the Romanian Society of Gastroenterology and Hepatology (SRGH) and the Romanian Crohn's Disease and Ulcerative Colitis Club (RCCC) have launched a campaign that aims to publicly discuss the impact of IBD at the workplace and invite as many employers as possible to provide appropriate measures and strategies for patients with chronic diseases in general and specifically for people with IBD. At the same time ASPIIR carried out a survey amongst its patient community to investigate which measures needed to be put in place to improve the situation at the workplace.

A manifesto-guide provides employers with ten practical tips of how to easily and better integrate people with IBD into the workplace covering topics such as flexible working hours, accessible toilets, awareness raising with employers/colleagues etc.

*“Through this campaign, we wanted to understand directly from patients those measure sthey need to be able to stay active at work and perform well. We hope to convince as many companies as possible to sign this document so that we can change together for a better working life for chronic patients in general and specifically for people with IBD”* said Isabella Grosu, ASPIIR president.



For more information about this campaign please visit our website:

<https://aspiir.ro/100-de-companii-pentru-bii/>

The campaign was supported by Takeda; Pfizer, Janssen, Sandoz, Vifor and consulting partner BPI Group Romania.

Isabella Grosu,  
ASPIIR President

# Brazil

## Brazil might have a National Policy for Awareness and Guidance on IBD

Bill 5307/2019, authored by Federal Deputy Domingos Sávio, from the state of Minas Gerais, Brazil, is in the Chamber of Deputies of Brazil, establishing the “National Policy for Awareness and Guidance on Inflammatory Bowel Diseases - Crohn’s Disease and Rectocolitis Ulcerative - and assistance to patients”. With the proposal, a series of precautions is listed, such as educational campaigns to be developed with society, in addition to regulating the procedures that will be adopted by health professionals and by public entities responsible for offering social care to patients. Through the Bill and in partnership with the Brazilian Association of Inflammatory Bowel Diseases - DII Brasil, the deputy wants advances in the public health sector to alleviate the suffering of those who have the disease. *“From the approval of the Bill 5.307/2019, I hope that we have a diagnosis in Brazil being made earlier and more efficiently in all health units. Therefore, the suffering of these patients will be minimized and the chances of recovery will be increased with the correct treatment”,* reveals Domingos Sávio.

He also proposes the integration between the Union, states and municipalities to set a maximum period of 30 days for carrying out laboratory tests and images in suspected cases, from the date of the initial consultation. The proposal foresees the carrying out of joint effort colonoscopies in public hospitals, prioritizing cases considered suspicious, in addition to establishing partnerships and agreements between public agencies, civil society entities and private companies, in order to produce joint works on IBD and authorize patients in prison, serving their sentence in separate cells during the crisis.

According to the proposal, the dissemination campaigns should be intensified, every May, through the introduction of Maio Roxo (Purple May), as it already happens with Outubro Rosa (Pink October, breast cancer) and Novembro Azul (Blue November, prostate cancer).



## Purple May 2021

This year, through DII Brasil (IBD Brazil), the National Congress of Brazil was illuminated in purple between the 12th and 17th of May to expand the mobilization and promote visibility to Crohn's Disease and Ulcerative Colitis.

*"The lights reinforced the need to institute a national calendar of awareness and preventive actions. It was one more way to sensitize society and parliamentarians to mobilize for the approval of Bill 5.307/19. With the measure, the cause that was limited to part of society*

*and to people with the disease, now also belongs to the Brazilian Legislative", explained Patrícia Mendes, president of DII Brazil.*

Today, it is estimated that around 100,000 people in Brazil live with an Inflammatory Bowel Disease.

Article written by journalist Ana Guimarães.

Translated by Thiago Carvalho.

Both are volunteer members of the Communication Committee of DII Brasil.

## Spain

### Doctors and patients sign a joint agreement to improve clinical practice, research and innovation and to raise awareness of IBD

- Coinciding with the commemoration of World IBD Day in May
- Among other aspects, the agreement seeks to promote the participation of patients in the care processes together with the different socio-health professions

GETECCU (the Spanish Working Group on Crohn's Disease and Ulcerative Colitis) and ACCU Spain (the Confederation of Associations of Crohn's and Ulcerative Colitis Patients of Spain), the two leading organisations for IBD at national level, have renewed their collaboration agreement in order to continue promoting the improvement of patient care and raise the profile of this disease.

Thanks to this agreement, which renews the one already signed by both societies in 2018, the collaboration activities will continue, through the promotion of cooperation activities in different areas such as the improvement of clinical practice, social and healthcare assistance, research and therapeutic innovation, as well as training for people diagnosed with Crohn's disease and ulcerative colitis and raising awareness of these diseases.

Both organisations will carry out various actions to ensure compliance with evidence-based medicine, as well as the participation of patients in the care processes together with the different socio-health professions, something that both organisations describe as "absolutely necessary".

Likewise, the collaboration agreement will enable the defence of patients' rights and their participation in procedures that require their representation before public or private institutions.

To put the commitment into practice, GETECCU and ACCU will maintain permanent, transparent and fluid bilateral communication.



# France

## Cross Views

CROSS VIEWS (Regards croisés sur les MICI) is a national study carried out by the afa CROHN RCH France, the French IBD association. The aim was to raise awareness, improving the knowledge and recognition of IBD repercussions on daily life for French patients in 2020. Three different perspectives were studied: that of patients, of their families and of gastroenterologists.

Among the respondents, there were 2582 patients suffering from IBD (58% with Crohn's disease, 40% with ulcerative colitis, and 2% with an undetermined IBD). 853 patient relatives (mostly spouses and parents) and 118 gastroenterologists (among which a third have their practice in the Paris region and half of them in the private sector).

In line with the first study carried out in 2006 on the same topic, there is some instability of patients living with their disease. Indeed, the majority of them reported intense fatigue during the flare ups and remission periods. In addition, abdominal and/or joint pain was noted in 38 to 65% of cases and mild depression is observed in 33% of patients. So much pain and complications that are often poorly perceived by doctors and patient relatives, sometimes leading to patients abandoning the idea of having a relationship

with a spouse or leaving behind their plans to have a child. Regarding patient relatives, the most impacted by the IBD symptoms are patients' spouses who are the most solicited. However, even if most patients say they have a good support network, they all agree that they feel lonely and sometimes misunderstood.

However, clearly improved in this survey is the advancement of digital technology in the IBD sector, which allows for better communication and an easier search for information. This is a very good point, knowing that for half of the patients, the questions of nutrition, fatigue and side effects are very important in the diagnosis scale. However, for 74% of doctors they are less crucial. This is why only 2% of patients had access to a therapeutic education program during the long process (around two to five years) of their diagnosis.





Regarding treatments, a majority of patients feel they are effective, but 4 out of 10 patients consider them to be constraining, mainly in the way they are administered (infusion/enema) and due to the fact that most of them cannot be administered at home and imply being hospitalized. Hence, the best treatments in the patient's view are those with no side effects.

Afa CROHN RCH France is an association whose services should be better known and should be

more "prescribed" by gastroenterologists, since all respondents agree the association is useful and improves patient care. However, 80% of patients also said they did not receive this information.

Therefore, in the future, a systematic information campaign should be directed toward the medical profession about the existence of afa and all of its services.

## Sweden

### News from MagTarmförbundet

The Swedish association has finally joined our friends in EFCCA and embraced the purple ribbon as a symbol for the fight against IBD! As a Christmas gift to our members, we sent out two purple ribbons with each number of our member magazine: one ribbon to wear yourself, and one to give away to a friend. By doing so, about 11.000 ribbons were put into circulation all at once.

The pandemic hit our association quite hard. Sweden may not have had a "hard closedown" compared to other countries, but rules and recommendations on social distancing caused important project plans to be put to an abrupt halt. Add to this the concern that nobody really knew if persons with severe diseases such as IBD risked being especially severely affected by the corona virus.

If there is any positive outcome from Covid-19, it would be that we quickly had to adapt and start using digital solutions to a greater extent than before. With 17 regional chapters spread out over Sweden, digital meetings are an economic way to meet that we surely will continue to use after the pandemic has passed.

In April 2021 we held a postponed General Assembly over Zoom. A new board was elected where almost half of the members were replaced. This is the largest change in a decade. On the one hand it means that

we have lost a lot of experience and knowledge, but on the other hand we gained new energy, enthusiasm and opened up for changes and development. Jonas Eriksson, the Swedish EFCCA-delegate for the last six years, was elected as new chairman.

The slow tempo caused by the pandemic also gave us the opportunity to do a survey to collect more information regarding our members experiences with the Swedish healthcare, their quality of life and socio-economic status. An important activity in order to build a platform for change and influence in the future.

Peter Eneroth,  
MagTarmförbundet





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# The Netherlands

## Goodbye paediatrician, hello gastroenterologist

When children turn eighteen, they no longer go to the paediatric gastroenterologist, but to the regular gastroenterologist. If all goes well, children and their parents have already been prepared for this in the previous years. That's called transition. Paediatric gastroenterologist Hankje Escher of the Sophia Children's Hospital and Tim Santcroos (20), who has Crohn's disease, tell us more about this.

*"...despite the fact that children have usually been prepared for the transition during the previous few years, it turns out that a large group (70-80 percent) realizes what this actually means when they sit opposite the gastroenterologist for the first time",* says Escher. This group of young adults therefore needs extra help and guidance from the gastroenterologist or nurse. And that extra help unfortunately differs per hospital, according to Escher.

That is why a thorough preparation is very important. Also for parents, because they can no longer call the doctor with their questions once their child turns eighteen. Their child is now expected to arrange everything him or herself.

### Independence

The Ready Steady Go programme (see below) is a great way to prepare children for the switch. *"It is a talking document with questionnaires, for in the doctor's office, which children start with from the age of twelve",* explains Escher. *"On the basis of completed answers, care providers can see how far a child is in independence and self-reliance".*

The Hello questionnaire (from 18 years old) helps to check how far a young person is with self-management after the switch.

*"Unfortunately, a lack of time among gastroenterologists often turns out to be the reason that the 18-year-old does not always receive the guidance that is needed after the switch. Fortunately, there is increasing awareness among doctors that a good transition is essential, and that gastroenterologists need to listen better to their young patients. We hope that health insurers are prepared to pay for a better transition by appointing an extra nurse."*



Paediatric gastroenterologist Hankje Escher, Sophia Children's Hospital

## Ready Steady Go

In 2020, a panel of seven young people, paediatricians and gastroenterologists, from the Rotterdam University of Applied Sciences and Crohn & Colitis NL, worked together to improve the existing transition process.

This happened with the (originally British) Ready Steady Go program that supports, challenges and strengthens young people in developing independence and self-direction. For more information about Ready Steady Go and the transition research visit:

[www.readysteadygo.net/rsg.html](http://www.readysteadygo.net/rsg.html)

<https://bit.ly/transition-research>

Tim Sancroos (20) literally switched to the gastroenterologist on his eighteenth birthday, because he was in hospital at the time. *“I experienced that transfer as warm, because my new gastroenterologist and the paediatrician came to see me together.”* Tim was one of the participants of the youth panel (see above). The young people suggested introducing such a warm transfer as standard. *“During our discussions in the panel, it became especially clear that every young person is different and needs their own guidance. It is important that doctors and nurses are aware of this. The Ready Steady Go (and Hello!) questionnaires can help with this.”*



Tim Sancroos, Crohn's patient

## Poland

### Let's go to the seaside! With the Polish Association Supporting People with IBD “J-elita”

The decision to spend two weeks in Stegna at the camp organized by the “J-elita” Association was the best decision I have made since my son's diagnosis. Together, we were 120 strong - a great turnout.

Last year my 9-year-old son Jack was diagnosed with Crohn's disease. I was in shock. Countless hospital visits, blood works, colonoscopy, gastroscopy... I was terrified, totally lost and angry at the whole world and at myself, looking out to blame someone. If I hadn't met “J-elita”, and the families with IBD kids, I would

still be in this dark place. The “J-elita” Camp was our first holiday after the diagnosis. What are we going to eat? Are the toilets close? And what if Jack has a flare? He's on immunosuppressive drugs! I was overwhelmed with questions and worries. Today, I know, they were completely unfounded.

My biggest fear - food! - turned out to be groundless. We had a chance to speak to the chef to discuss our diets; we were more than happy with the outcome. We were in really good hands; the volunteers from “J-elita” took great care of us all. At first, we worried a lot! What are we going to talk about with others? Well, IBD is a good topic for any first conversation! We spend the first few days doing just that; talking and getting to know each other. The community of “J-elita” is like one big family. It’s no exaggeration to say that friendliness, openness and solidarity are the three traits that bound us all. As if we have known each other for years!

Our main goal was for Jack to meet other IBD kids. And an independence lesson for our 5-year old non-IBD son. All my worries yet again turned out to be unfounded!

Kids become friends at the speed of light! Those two weeks gave my sons more than the whole year of remote education under the pandemic restrictions! They both learned how to be independent, how to resolve a conflict, how to plan. And to be confident. What did I learn? That our kids really know all of this already! All they needed was a little bit of trust.

Every day during the camp, we had plenty to do at our own leisure. However, “J-elita” organized a lot of events as well. The two big parties were the highlight of the fun time; the Hollywood dress up party and a scavenger hunt organized by the IBD teenagers. Nonetheless, it wasn’t all fun and games. Every day, we could sign up for an appointment with the gastroenterologist, rehabilitation classes, meetings with a psychologist and daily yoga.

I went to the camp for my son Jack, convinced that he needs to meet other IBD kids to get help to accept his diagnosis. But actually, it was me who needed help. To meet other IBD families and understand that all doubts and limitations were all in my head. The worries were not my son’s, they were all mine from the start.

Dagmara Corrigan





## Photo exhibition

“J-elita” recently organised a photographic exhibition specially prepared by Professor Rafał Filip and Dr Krzysztof Pisarek. The exhibition was titled “...be Napoleon” and took place on 10 September in the Galeria Nierzeczywista (Illusion Gallery) in Rzeszów.

The photographs presented were the result of the remarkable concept and cooperation between Prof. Filip (Head of the Gastroenterology clinic in Rzeszów hospital) and the photographic artist Dr Pisarek (from the Fine Art Institute of the University of Rzeszów). Patients with Ulcerative Colitis and Crohn's Disease were photographed over a period of 3 years.

Each patient was photographed twice: A black and white portrait showed the difficult emotions and experiences connected to living with a chronic illness, and a colourful full-length photograph captured the more joyful side of life.

Prof. Filip had collected some of the patients' personal quotations and these were displayed alongside the photographs.

“I am not only a disease”. This is something that can be sensed from the images of the participants: A serious, sad face on a smaller black and white photograph sits next to an expressive, colourful action photograph of the participants enjoying either their work, hobby or pastime. Between the feelings conjured in the photos there is a kaleidoscope of normal days - sometimes in pastel, sometimes in gloomy grey. These colours mirror the real life contrasts between the warmth of the work and home routine (pastel) and the worry of another attack of the illness and how long it will last (gloomy grey). The exhibition is about all of us. We are not defined by our problems all of the time. There is always hope.

As Prof. Filip states, the action photo shows that despite the physical and mental pain, patients' lives are not only restricted to the cycle of attacks of illness and subsequent recoveries. These people are still able to do practically anything and everything.

They can work with others, Thai boxing, yoga, walk the dog in the woods and admire the beauty of nature - to name but a few things.

In the photos the participants are seen to be telling us: “no matter what has happened to us we keep our heads up and carry on”. Hence the title of the exhibition is “...be Napoleon”. It is part of a quotation from Marek Edelman's book “God is sleeping” which reads: “If you do something with the best intentions you should continue. If you are unsuccessful it means that the situation makes it impossible to happen. Of course you are not Napoleon, but be Napoleon as much as you can”.

We are certain that this exhibition is going to capture the attention of a wider audience and spread its message to many people who constantly fight the physical, psychological and social consequences of chronic illnesses. We also hope that the exhibition will make people more sensitive to the problems of sufferers with many kinds of disabilities.

Link to the event:

[www.facebook.com/events/6215043035235143](https://www.facebook.com/events/6215043035235143)

Jacek Hołub,  
“J-elita” Association



# Report Exposes Burden of 7-year Global Delay in axSpA Diagnosis

In the summer of 2020, Axial Spondyloarthritis International Federation (ASIF) launched its landmark Delay to Diagnosis campaign. At the heart of the campaign is the ambition to deepen understanding at a global level of the factors that contribute to the current seven-year average delay in axial spondyloarthritis (axSpA) diagnosis; and highlight the considerable burden that the delay places on individuals.

This burden can be even worse for people suffering with additional disease manifestations. The International Map of Axial Spondyloarthritis reported from its European survey findings that 22.4% of axSpA patients suffer with Uveitis, 8.4% with Ulcerative Colitis and 7.5% with Crohn's Disease.

The Delay to Diagnosis campaign was launched in the recognition that this seven-year delay is, quite simply unacceptable, particularly as there has been little improvement in this figure in recent decades. For many individuals, the delay can be even longer. This is especially the case for women, who on average wait a further two years to receive a diagnosis compared to men, due to outdated perceptions that axSpA is a “male” disease.

To help inform the project, ASIF convened two virtual Global Forum events in Autumn 2020, bringing together a wide range of patients and Patient Organisations, researchers, rheumatologists and other healthcare professionals involved in the management and championing of axSpA care from around the globe. Almost 50 delegates attended each event, representing 23 countries, across 5 continents.

Outputs from these discussions played a key role in shaping the findings of ASIF's recently published report, which also draws on a review of latest available academic literature and expert contributions from leading global axSpA clinical and patient voices.



Alongside shining a spotlight on the physical, psychological, and broader societal impacts of the axSpA diagnostic delay, the report also outlines the key barriers that contribute towards this delay. Six distinct barriers were identified: a limited awareness of axSpA amongst those with symptoms; a lack of axSpA understanding amongst the general population; incorrect/misdiagnosis at first point of healthcare system contact; pathway and referral challenges; difficulties in accessing specialist care; and challenges within rheumatology itself.

It is hoped that, through setting out these barriers, which are described in detail in the report, we will be able to support improved understanding of patients' typical diagnosis journeys. The report also highlights several areas of best practice in reducing the delay, detailing a range of innovative and encouraging examples from the United Kingdom, Argentina, the Netherlands and Russia.

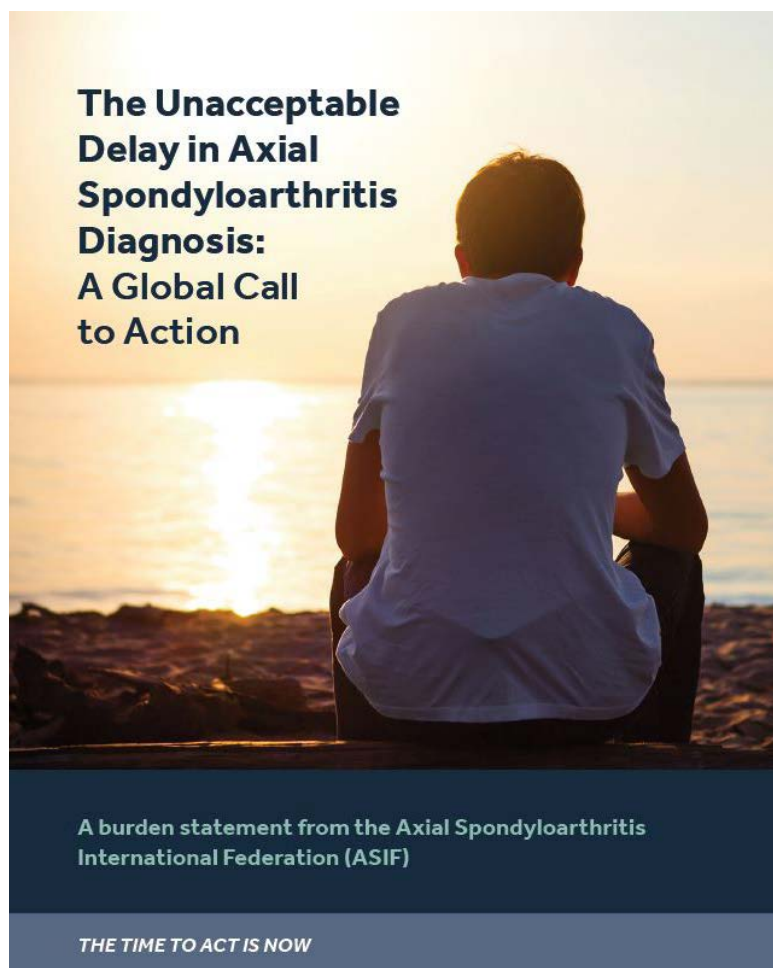
ASIF was delighted to launch the report at two virtual events on 7 July 2021.

The events welcomed attendees from 25 countries and featured live panel discussions involving a range of patients and axSpA experts from across the world. As well as expert presentations, delegates watched three patients talk about their experience of diagnostic delay. These videos are powerful, compelling and - above all - highlight the turmoil and destructive effect on people's lives as they wait for a diagnosis.

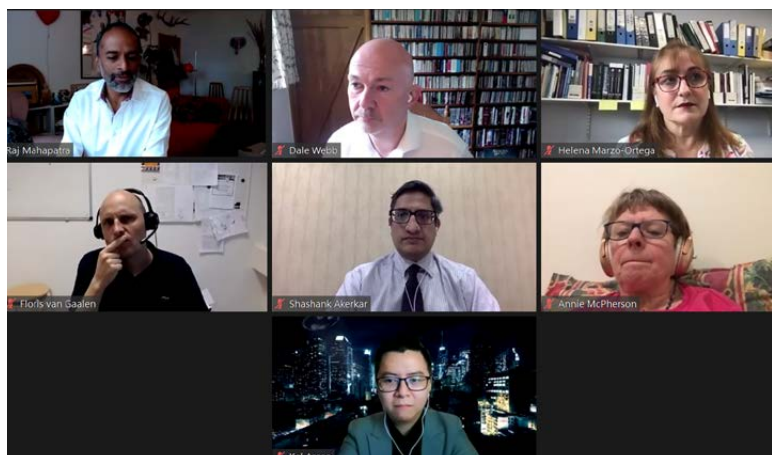
While the launch of this new report represents an important milestone, it is vital that we continue to build on this momentum if we are to be successful in convincing decision-makers that now is the time to get serious about transforming how axSpA is diagnosed.

You can read the report and watch the presentations and videos from our launch event at [asif.info](http://asif.info) or contact [projectmanager@asif.info](mailto:projectmanager@asif.info) to find out more.

Jo Lowe,  
ASIF



JUNE 2021





# European Patient Forum: Congress 2021

## The Digital Transformation of Healthcare

EPF is organising its second European Congress exploring patient involvement in digitalised healthcare driven by leading representatives of the patient community, in a virtual setting to take place from 26-29 October 2021.

This Congress will provide an exceptional opportunity for dialogue and engagement with a wide range of health players who aspire to showcase patient-led innovation. Together, EPF will explore what meaningful patient involvement means in a rapidly changing healthcare environment using new technologies, and why it is critical to successful innovation. EFCCA as a long standing EPF member will participate in the congress and report back to our membership.



*Professor Laurent Peyrin-Biroulet, ECCO President*

## ECCO Congress

This year's ECCO Congress (ECCO'21 Virtual) took place on-line on July 2-3 & 8-10, 2021. It saw the participation of 6,798 participants from 104 countries with 828 accepted abstracts.

The Virtual Congress Platform worked very efficiently, allowing top-quality online scientific sessions with lots of interaction and discussions and the participation of a very high number of ECCO Members from all over the world. The Scientific Programme this year was centered around the topic "IBD Precise", highlighting new advances in pathogenesis, diagnostics and novel therapies that are enabling progress towards customised treatment for IBD patients.

Luckily, the current health situation is allowing the ECCO Office Team to make the necessary preparations to hold the upcoming 17<sup>th</sup> Congress of ECCO on-site in Vienna in February 2022. There, the usual high-quality scientific and educational content will be complemented by a fantastic social and networking programme.



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# Clinical trials: launch of a new Information System

On 31 July 2021 the European Commission published its Decision launching the Clinical Trials Information System (CTIS), a basic IT system tool designed to apply the Clinical Trials Regulation (CTR), as of 31 January 2022.

The application will bring substantial changes to the authorisation and supervision of human research on medicinal products. Stella Kyriakides, Commissioner for Health and Food Safety said:

*"The pandemic has clearly shown the importance of efficient clinical trials that do not compromise on rigorous safety and efficacy standards. With the Clinical Trials Regulation, we will be able to guarantee higher safety protection for participants of clinical trials, support EU-wide clinical trials, and deliver faster access to the most promising safe and effective medical products to citizens, for the COVID-19 crisis and beyond."*

The goal of the Clinical Trials Regulation is to create an environment that stimulates the establishment and undertaking of clinical trials in the EU. At the same time, it aims to guarantee the highest standards of safety for participants of clinical trials as well as increased transparency of clinical trial information.

The Regulation makes the use of the CTIS mandatory for newly applied clinical trials. However, until 31 January

2023, applicants can still choose whether to submit their application to start a clinical trial according to the current system (Clinical Trials Directive) or according to the Clinical Trials Regulation.

From 31 January 2023 onward, submission according to the CTR becomes mandatory and by 31 January 2025, all ongoing trials approved under the current clinical trial directive will need to transition to the new Regulation.

The Clinical Trials Information System will also, together with other EMA IT tools, support the coordinated assessment of safety reporting in the context of clinical trials and therefore contribute to the understanding of the benefits and the risks of medicinal products that are planned to enter or are already on the market of the Union. More information on the Clinical Trials Regulation and on the Clinical Trials Information System can be found here: [ec.europa.eu/health/human-use/clinical-trials](https://ec.europa.eu/health/human-use/clinical-trials)

For more information:

Arianna Podesta - Tel.: +32 229 87024;

Anna Wartberger - Tel.: +32 229 82054





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# Invisible Illness: My Insider's Guide to Health and Happiness with Crohn's Disease

**By Heather Hausenblas, PhD**

On December 6th, 2018, my son was diagnosed with Crohn's disease after months of trying desperately to figure out what was wrong. He was just 16 years old.

This wasn't the news I wanted. But officially naming it gave me information, and information is power. My reactions to his diagnosis were fear, anxiety, shame, and confusion. In short - I was beyond overwhelmed. Was this my fault?

No one could understand what my son was going through. Crohn's disease is personal. Not only is it about the stuff you're taught not to talk about, but it shows up differently in each person. The very nature of Crohn's disease is that your body is too inflamed to heal the way it should. It's an isolating disease. It's an invisible disease.

As a researcher and as a mother with a severely sick son, I began a journey to understand this disease. Why's it on the rise? What roles do our environment, our genes, and our health behaviours play? What's the best treatment? Can I get my son - not just better - but "cured" from an incurable disease? What I found was disjointed information, lack of research on health behaviours, too many diets to humanly comprehend, heroic healthcare workers, narrow-minded healthcare workers, new friends, and, ultimately, peace with myself and my family and a new outlook on what it means to be healthy.

During my journey to regain his health I began to write - the end project after almost a year was a book titled Invisible Illness: An Insider's Guide to Eliminating Overwhelm and Rediscovering the Path to Health and Happiness with an Autoimmune Disease. This book arose from the intensity of my experience. Everything you think you know about yourself as a parent changes when your child gets sick.

**“As a researcher and as a mother with a severely sick son, I began a journey to understand this disease. Why's it on the rise? What roles do our environment, our genes, and our health behaviours play? What's the best treatment? Can I get my son - not just better - but “cured” from an incurable disease?”**





*Heather Hausenblas, PhD, believes we can all have healthy and happy lives - and we can get there through our behaviours.*

*She is a health psychology expert, award winning researcher, and author. When Heather's not walking the family dog, cooking with natural ingredients, watching her sons play sports, and exercising outdoors with friends she's researching wellness.*

*She's a health and science nut - it's her career, hobby, and passion. She resides in Jacksonville, Florida with her husband and three boys.*

As a mother, a researcher, and a health educator, I attempted to bring all these experiences together. While I'm not a medical doctor, I'm a Doctor of Philosophy (PhD), and my expertise is health behaviours. This means I'm a researcher, thinker, and lifelong learner of health habits. I research how our exercise, sleep, diet, mood, and stress affect our health.

I needed to get a handle on my son's diet, his medicine, and his symptoms. So, I created a journal to track his health. I began to track his daily symptoms, energy, mood, and pain levels. I also tracked what he was eating and how he felt after he ate, along with how much he was sleeping and exercising.

Food journals are a great source of accountability because most of us are terrible at estimating how much and what we've eaten. Journaling improves not only our health but our happiness, and I knew this process would not only keep me organized but would help me become aware of my son's eating habits, what triggered his symptoms, and then develop strategies. I quickly found out that many people have an interest in journaling about their health, with almost 70% of American adults tracking at least one health behaviour. The most common behaviours tracked are weight, diet, and exercise routine.



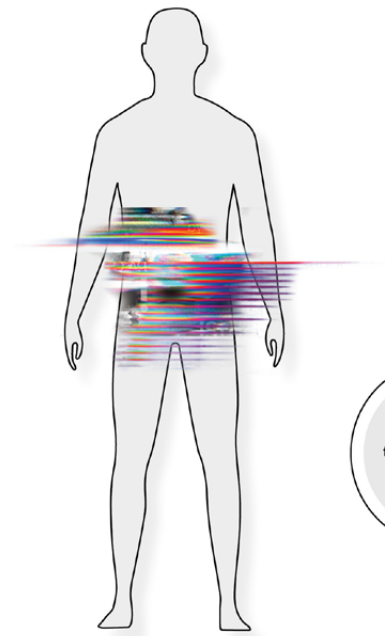
For many, journaling works. Almost half of people find that journaling changed their approach to maintaining either their own health or the health of someone they care for. And many journalers say it led them to either ask their doctor new questions or to get a second opinion. Journaling can also lead to better sleep, a stronger immune system, more self-confidence, and a higher I.Q.

Most IBD patients find that journaling about their food and symptoms is easy and helpful. And it's also one of the cheapest things you can do for your health. All you need is a journal and a pen. Journaling - whether it's about your poop, what you're thankful for, how much you have exercised, your sleep quality, or what you have eaten - is a powerful and simple way to improve your health and wellness. It helped me get my son on the road to recovery. I'm grateful for what this disease has taught me. Now, I look at health and wellness differently. I grow some of our food, make many dishes from scratch, buy only from trusted sources, and slowly (yes this was a very slow process for me) found some joy in cooking.

My prescription for health and wellness is to run barefoot through the grass, swim in the ocean, hike in the hills, unplug from electronics, eat seasonally and locally, bike on the trails, ski in the mountains, fish in the lakes. Eat dirt, wear your shoes in the house, smile at a stranger, fly a kite, grow house plants, breathe deeply, play a board game, have a pet, star gaze, pray before meals, and sit by a fire. Wake up without an alarm, eat real food, hang out with friends and family, enjoy the sounds of silence. Throw out your hand sanitizer and replace it with soap and water. It's that simple and that complex.

My dream is that everyone with Crohn's disease or any chronic illness has the recovery and resources I had. A bigger dream is preventing this disease altogether. And for those who have Crohn's disease a simple cure. A small goal is that this book can help others navigate through the storm of medical and wellness information to figure out the right wellness path for them. You have the power to reclaim and maintain your health or the health of someone you love. Whether you're suffering from a serious health condition or want to have more energy during the day, this book will help you on your wellness journey.

# INVISIBLE ILLNESS



With over  
50 inflammation-  
fighting recipes for  
better health and  
wellness

**An Insider's Guide to Eliminating Overwhelm  
and Rediscovering the Path to Health and  
Happiness with An Autoimmune Disease**

**HEATHER HAUSENBLAS, PhD**

## Simple Health Tips

- **Health journaling.** Use a science-based guided journal to help you eat healthier, track symptoms, sleep better, and move more.
- **Clean kitchen.** Go through all your kitchen cupboards, pantry, and fridge and get rid of processed foods. If you can't pronounce the ingredients - then throw it out. This includes your cleaning products.
- **No sugar.** Stop eating refined sugar.
- **Eat whole foods.** Eat whole foods - real fruits and vegetables.
- **Eat at home.** You will have control over what you're eating.

*Heather with her son Tommy*



For more information on my books, journaling, and health please visit the following sites:

[www.heatherhausenblas.com](http://www.heatherhausenblas.com)  
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# Patients' perceptions of surgery for inflammatory bowel disease

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## INTRODUCTION

Common symptoms of inflammatory bowel disease (IBD) may impact the quality of life (QoL) of patients in both psychological and social domains [1-3]. Surgery has a pivotal role within the multidisciplinary team (MDT) in the treatment of IBD [4,5]. Indeed, surgery is a valid option at various stages, eliminating the target organ of ulcerative colitis (UC) and providing effective remission in Crohn's disease (CD), leading to a significant improvement in long-term QoL [6-10]. Despite the generally positive outcomes, the need for surgery itself represents one of the most common fears among IBD patients [11]. Patients with UC are reluctant to accept surgery, especially when it includes the possibility of a permanent stoma. Indeed, many patients would rather accept a risk of lymphoma or severe infection from medical therapy, regardless of drug efficacy [12]. Similarly, CD patients feel distressed when coping with surgery and often perceive it as a last resort due to failure of medical therapy [13]. This negative perception of surgery may trigger a negative loop that affects patients' willingness to undergo surgery; as a consequence, delayed surgery may lead to increased postoperative complications and impaired postoperative recovery [14,15]. The mismatch between surgical prejudice and reasonable outcomes deserves an in-depth analysis [16-18]. It is crucial to understand patients' subjective experiences and perceptions, of both those who have undergone and those who may undergo surgery, as these may shape their behaviour. This information is important in providing adequate counselling and empowering patients in the decision making process. Despite its high clinical relevance, there is a shortage of studies investigating the experience of IBD patients in relation to surgery. The present study aims to investigate the subjective perception of surgery in IBD patients.

## METHOD

An international online survey (Appendix S1 in the Supporting Information) was created to explore IBD patients' perceptions of surgery. The survey was available in English, Italian, French, German and Dutch. Participants were invited by the European Federation of Crohn's & Ulcerative Colitis Associations (EFFCA) and national IBD patients' associations to complete the survey. The link to the survey website was also distributed through newsletters for patients with IBD, surgeons, gastroenterologists and other caregivers. Patients who had prior surgery and those who had not were all invited to join the study. The survey explored individuals' perceptions of surgery, including information, expectations from surgery (postoperative complications, function and thoughts about a stoma), QoL after surgery, feelings before and after surgery and overall concerns, including psychological and social impacts. The survey was created with the Qualtrics suite (Qualtrics). The estimated time required to complete the survey was 30 min. Only the answers of responders who completed the entire questionnaire were included in the analysis. Participants' informed consent was obtained before accessing the survey questions. The survey was available online from February 2019 to January 2020.

## Statistics

Categorical variables are presented as their frequency occurrence and overall percentage. They were compared using the chi-square test or Fisher's exact test, as appropriate. Continuous variables are presented as mean ( $\pm$  standard deviation) or median (range) according to their distribution. All reported p-values are two-tailed, and p-values of less than 0.05 were considered statistically significant. Statistical analysis was performed using IBM SPSS Statistics for Windows, version 25.0 (IBM Corp.).



## RESULTS

### Demographics of responders

The survey attracted 510 self-registered participants from 39 countries. The questionnaire was completed by 425 of these (83.33%). The most widely used language was English (57%), followed by Italian (25%) and German (13%). The majority of respondents were female (68%), with an average age of  $38 \pm 12$  years. CD was the most frequent diagnosis (61%), followed by UC (36%) and other IBD diagnoses (3%).

### Surgical information

Overall, 300 (71%) patients had previously undergone surgery, while 121 (29%) had had no prior surgery. Respondents who had surgery were significantly older than patients who had not ( $39 \pm 11.75$  years vs.  $33 \pm 11.57$  years,  $p < 0.001$ ), yet there was no difference in age at diagnosis of IBD ( $25 \pm 11.13$  years vs.  $25 \pm 10.88$  years,  $p = 0.97$ ).

The majority of patients who had not undergone surgery (89/121, 67%) were not aware of a surgical option for their disease. Conversely, a minority of patients (25/121, 21%) reported no interest in surgery, despite having received a suggestion from their gastroenterologist to consider surgical intervention. Only 15/121 (12.5%) participants were scheduled to undergo surgery at the time of the survey.

Among the patients who had surgery, the time interval between IBD diagnosis and when surgery was proposed for the first time ranged from 0 to 480 months (mean  $85 \pm 197$  months). Most patients reported that they knew about surgery as a treatment option mainly from a gastroenterologist (63%), sometimes through the Internet (12%) and less frequently from a surgeon (10%). When surgery was specifically offered as a treatment option, it was initially suggested by a gastroenterologist (73%) and less frequently by a surgeon (17%). Patients were informed about the potential risks and benefits of surgery either by a surgeon (62%) or by a gastroenterologist (61%) (Figure 1). Sixteen per cent of respondents obtained their primary information about surgery from the Internet. In most situations, the decision to advise surgery was a shared decision between surgeon and gastroenterologist (76.2%).

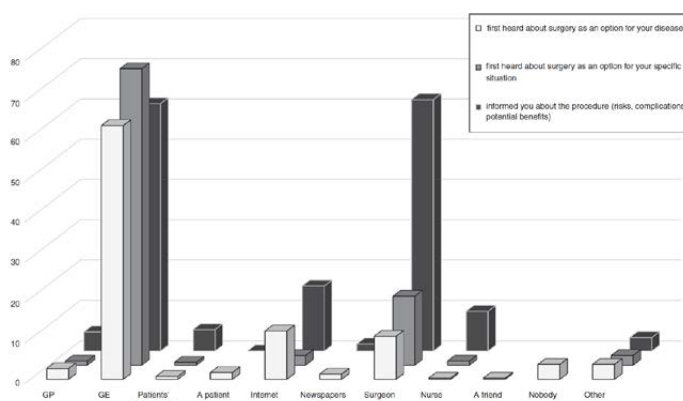


FIGURE 1 Sources of information about surgery

### Additional sources of information on surgery besides healthcare professionals

Approximately two-thirds of the patients (69%) searched for additional information on the Internet (82%). Only a minority of patients obtained information directly from other patients (10%).

### Patients' fears and positive expectations

The majority of patients (80%) perceived surgery as the last option after many medical treatments rather than an alternative therapeutic option (20%). In general, the indication for surgery was perceived as negative: on a scale from 1 (very positive perception), to 7 (very negative perception); the mean score was  $4.51 \pm 1.78$ . The most reported negative fears were surgical complications (73%), incontinence after surgery (51%), the need for a stoma (50%), developing short bowel syndrome (40%) and change in body image (37%) (Table 1). Conversely, the most frequently reported positive expectations were symptom relief (30.8%), prolonged well-being (16%) and reduced pain or complete elimination of pain (15%) (Table 1).

Surgery was a planned procedure in 67% of the patients, while it was an emergency procedure for 33%. Of those operated on, 58% of patients experienced postoperative complications while 58% reported a recurrence of clinical symptoms after an average of  $4 \pm 7$  years (range 0-48 years). Most of the participants (83%) did not require reoperation, and the majority of patients (57%) did not require postoperative medical treatment.

Feelings before and after surgery

Among those who were operated on, the feelings just before surgery were described as “afraid” (57%), “depressed” (23%), “impatient” (14%) and “ambivalent” (8%), but also “hopeful” (41%) (Figure 2). Immediately after surgery, patients reported a decrease in all the negative feelings and a stable increase in positive sentiments, which lasted for 2 months after surgery. The feelings of “relief” (32%), “comfortable” (22%) and “happiness” (26%) had the biggest increase compared with presurgery status. Positive feelings were also highly reported at the time of the survey, when the patients were asked to recall their past surgical experience (Figure 2).

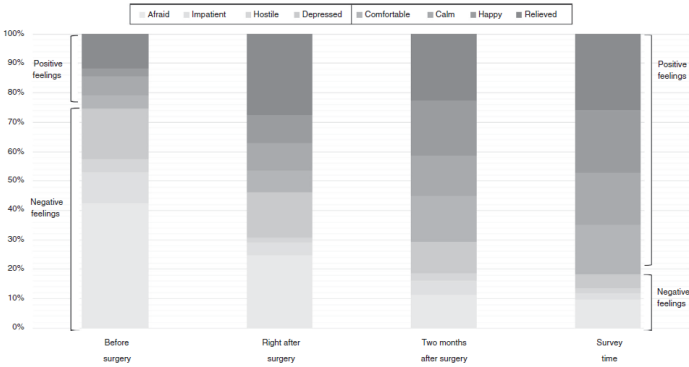


FIGURE 2 Patients' predominant feelings before and after surgery

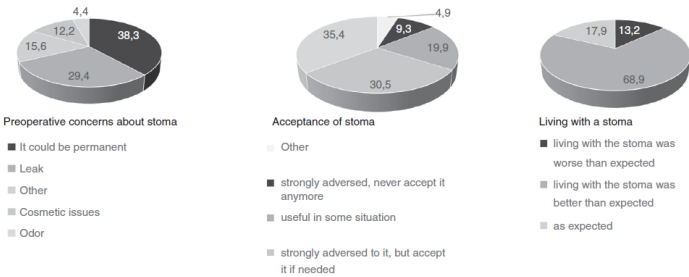


FIGURE 3 Preoperative concerns and postoperative acceptance of stoma

TABLE 1 Specific concerns and positive expectations related to surgery

	Responders, n (%)
Concerns	
Surgical complications	255 (72.6)
Having problem with continence after surgery	178 (50.7)
Stoma	175 (49.9)
Short bowel syndrome	140 (39.9)
Change of body image	131 (37.3)
Death	104 (29.6)
Cosmetic issues after surgery	93 (26.5)
The effect of your medications on the results of the surgery	58 (16.5)
Transfusions	27 (7.7)
Other	20 (5.7)
None	13 (3.7)
Positive expectations	
Symptoms relief	108 (30.8)
Prolonged well-being	55 (15.7)
Reduced or no more pain	51 (14.5)
No more drugs	26 (7.4)
Fewer drugs	19 (5.4)
Social life restoring	19 (5.4)
Greater life expectancy	15 (4.3)
More opportunities for leisure activities	7 (2.0)
Reduced or no more anxiety	7 (2.0)
Reduced or no more depressed mood	5 (1.4)

The need for social and family support

About half of the participants (53%) spoke with someone who had undergone the same intervention. The vast majority of patients (78%) reported the need for social or family support, either for a short (46%) or a long (32%) period. Almost all participants (98%) felt supported by their families and from the social environment (80%).

Perception of the timing of surgery

About a third (35%) of the patients regretted that surgery had not been proposed earlier and 14% had thought of having surgery before receiving the suggestion from their gastroenterologist. Most patients reported that the timing proposed for the intervention was correct (55.4%), while a third declared that it was too late (37%), with only a limited number of patients (8%) responding that it was too early. The duration of the medical treatment was considered too long by 31%.

Experiences with a stoma

Only half of the surveyed patients (52%) received information about the possible creation of a stoma before surgery and 64% believed that they had been properly advised on possible complications. This information was considered accurate by most of the patients (68%), while some thought that potential problems were underestimated (29%) by their physicians, and only a few participants believed that these were overestimated (3%).

The main concerns regarding a stoma were the fear that it could be permanent (38%), followed by the fear of leakage (29%), cosmesis (12.2%) and foul odour (4%). Most patients did not have a stoma (63%); less than a fifth of the patients (19%) had a stoma at the time of the survey and about the same proportion (18%) had undergone a stoma in the past. For most of them, the stoma was temporary (73%). Among those who had a stoma, living with the stoma was better than expected for the majority of the participants (69%), while only a minority reported that living with the stoma was worse than expected (13%). The perception of having a temporary stoma varied among those who experienced it. However, an overall acceptance of a possible stoma was reported by 86% of respondents (Figure 3). Among these patients, 35% reported that they would prefer to avoid it but would accept it if needed, while 31% were strongly averse to it but would accept it if needed and 20% believed that it could be useful in some situations. Only 9% were strongly against a stoma and indicated they would not accept having one. When comparing perceptions of life before and after having a stoma, respondents reported a significant decrease in social ( $p < 0.001$ ) and professional ( $p = 0.002$ ) aspects of their lives, but no differences were found when comparing sexual activity and sports before and after the stoma (Figure 4).

### Quality of life after surgery

Following surgery, respondents reported an improvement in their physical well-being, but also in their psychological well-being and in activities of everyday life (Figure 5). Overall, the average quality of life among responders was ranked good at 6.76 (SD = 1.96) on a scale from 1 (very bad) to 10 (excellent), whereas limited depressive feelings were noted (4.74, SD = 2.57) on a scale from 1 (not depressed at all) to 10 (very depressed), and this was coupled with anxiety (5.47, SD = 2.55), on a scale from 1 (not anxious at all) to 10 (very anxious).

## DISCUSSION

This international survey on the perception of surgery for IBD patients highlighted clinically relevant aspects which have not yet been extensively explored. The survey allowed a better understanding of the fears and concerns related to patients' perceptions of surgery. Additionally, it

addressed the unique perspective of patients who have had surgery compared with those who have not, and their respective outlooks. Most of the time IBD patients had a negative perception of surgery, despite a favourable outcome for the majority of the patients which eventually matched the positive expectations of patients prior to embarking on surgery. In fact, QoL clearly improved after surgery, in line with a recently published randomized study comparing early surgery with intensified medical management [19].

The picture which emerges shows that the surgeon is not often involved in the decision-making process or as an information-provider. To date, few studies have addressed the perception of surgery among IBD patients at institutional or (occasionally) national levels [13,20-23]. The present survey investigated a large international target population and provides a real-world picture beyond referral centres or a specific national health system. In our study, about 30% of patients had not undergone surgery. Surprisingly, 70% of the surveyed patients who were naïve to surgery were not even aware of surgery as a possible option for their disease, while 21% reported a lack of interest despite recommendations from their physician. These findings confirm a well-known general lack of patient knowledge and are consistent with previous studies showing poor disease awareness [18,24,25]. On one hand, limited knowledge may be related to inadequate physician performance when addressing the needs of IBD patients, with a lack of adherence to the guidelines [26-29].

On the other hand, as reported by a recent qualitative survey, some IBD patients claimed they did not need additional medical information as they already felt secure and trusted their physician. Furthermore, some believed that additional information may be frightening and have a detrimental effect on their psychological well-being [24]. As a result, a mismatch in communication may be triggered by both patient and physician.

The majority of patients had already undergone surgery at the time of the survey, and had primarily received general information about surgery and tailored advice for their specific situation from their gastroenterologist. The involvement of the surgeon in an early phase with counselling patients about surgical alternatives was very limited and only occurred when specific information on surgical risks and benefits was requested.



Importantly, indication for surgery was not a shared decision between gastroenterologist and surgeon in one-third of patients. Most guidelines advise that correct practice is to involve the surgeon at an early stage of the decision-making process [19,30-32].

Additionally, according to a previous study on preoperative counselling of IBD patients, patients themselves prefer to have an earlier consultation and discuss a surgical option with a surgeon rather than a gastroenterologist [20]. The percentage of patients collecting primary (up to 16%) and additional (82%) information on surgery from the Internet is compelling. This very common practice eventually carries a high risk of misinformation. In fact, patient-oriented websites on surgery for CD and UC (e.g. the first 100 websites found by the two most popular search engines) have been rated very poor in terms of reliability using the DISCERN criteria (in 88% and 98% of cases, respectively) [33,34].

Overall, the quality of life of those who had surgery was significantly higher than in those who did not have surgery ( $p < 0.001$ ). No significant differences were found in the levels of anxiety or depression. The specific fears of patients associated with surgery were mostly related to surgical complications (70%), which are reasonable preoperative concerns. These concerns are in contrast with the postoperative course reported by the majority of participants (83%), who did not experience major complications or reintervention during the same hospital admission. Although we do not have clinical data for the patients surveyed, the reported patient outcomes were much better than the preoperative concerns, suggesting a possible lack of preoperative counselling and overstated fears. When considering patients' feelings before and after surgery, negative emotions (being afraid, impatient, hostile and depressed) clearly improved, while positive emotions (being comfortable, calm, happy and relieved) increased and remained stably high over time.

Perceptions around the timing of surgery, which were measured postoperatively, revealed dichotomous thoughts related to preoperative fears and concerns that may have actually delayed a balanced decision to undergo surgery. In fact, many patients believed that surgery was delayed for too long and, conversely, that medical treatment was continued for longer than was necessary. A third of patients regretted that surgery was not proposed earlier. These findings are

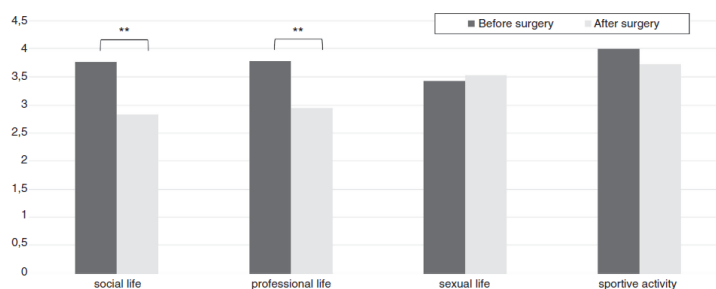


FIGURE 4 Quality of life before and after surgery

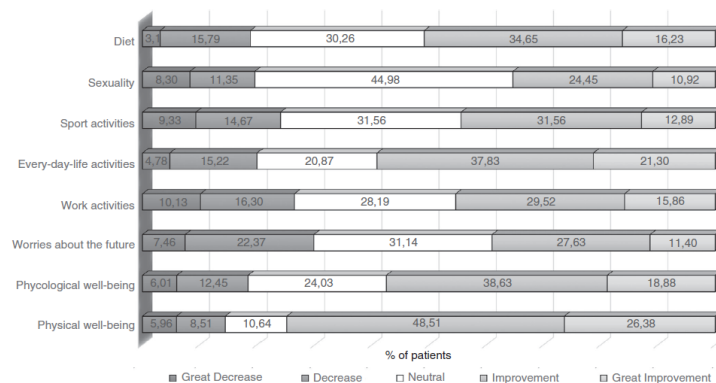


FIGURE 5 Impact of surgery on quality of life

consistent with previous studies on QoL after restorative proctocolectomy (RP). Patients undergoing RP have reported high satisfaction after surgery and regretted not undergoing surgery earlier [35,36]. This concept holds true in CD, as reported in the randomized LIRIC trial comparing surgery with intensified medical treatment, as well as other studies [19,20]. The postoperative opinion of responders regarding stoma construction highlights further misperceptions and a need for more counselling. On the one hand fear of having a stoma was reported by 50% of responders as a specific preoperative concern. Although the stoma was mostly temporary (70%), for those respondents who had one (nearly 40% of the responders) living with the stoma felt better than expected. Additionally, 86% of responders who had a stoma would accept it again if necessary. These results are consistent with the existing literature, as concerns and fears about stomas are common in IBD patients [37,38]. Importantly, a high stoma acceptance rate has been reported in association with patient compliance and good interpersonal relationships [39]. Having a stoma is clearly associated with a decreased QoL, in particular for aspects related to social and personal life.

This is in agreement with a recent meta-analysis that reported a high impact of stoma-related problems on the QoL of the minority of patients who are long-term ostomates with stoma complications [40]. The

most prominent positive expectations reported by the responders were symptom relief, prolonged well-being and reduced pain, which translated into improved postoperative QoL when compared with preoperative status. This study has its limitations. The study's sample consisted of self-selected patients who were willing to participate and were interested in contributing to the study's goals. Moreover, only those who completed the survey in full were included in the analysis. This issue could have biased the results of our study. Additionally, we are not able to tell whether the experience of self-selected patients might represent a reliable sample of the IBD population. Our self-selected cohort retains similarities, in terms of demographics, with the latest epidemiological studies on IBD [41-43]. The similarities include the distribution of gender-specific prevalence, age-specific prevalence and the rate of surgery among the IBD population. Although respondents were evenly distributed throughout the various countries, the healthcare systems and culture may differ. Lastly, IBD patients were addressed as a whole, and the possible differences in perceptions between CD and UC patients were not taken into account. For instance, surgery is essentially curative for UC, and UC patients bear a higher cancer risk than CD patients. Additionally, patients' recall bias with regard to surgical information might be considered as a limitation to this study, along with the fact that no information on actual disease stage (mild or severe form) and type of medication was gathered.

The results of this survey may help to fill a gap in perception between patients' and clinicians' perspectives. In fact, healthcare providers could step up and offer improved interdisciplinary counselling earlier in the course of IBD so as to inform the patient and allow for shared decision-making, not only between gastroenterologists and surgeons but also together with an empowered patient. Ultimately, a well-informed patient will be more likely to follow the advice of an IBD MDT, including surgical options, which in turn could allow for a less stressful disease course. Patient information and education are crucial when managing IBD patients and optimizing patient-reported outcomes. Empowering patients by engaging them with timely and practical information is key to improving coping strategies, treatment outcomes and QoL, and thereby achieving a reduction in healthcare costs [18].

## ACKNOWLEDGEMENTS

The European Federation of Crohn's & Ulcerative Colitis Association (EFFCA) endorsed the survey. The European Crohn's and Colitis Organization (ECCO) and the surgeon of S-ECCO promoted the dissemination of the survey. Carmen Correale revised the manuscript as a native English speaker.

## CONFLICTS OF INTEREST

AS has acted as speaker/consultant for Johnson & Johnson and Takeda. MC has acted as speaker for Pfizer. SD has acted as consultant for AbbVie, Allergan, Amgen, AstraZeneca, Athos Therapeutics, Biogen, Boehringer Ingelheim, Celgene, Celltrion, Ely Lilly, Entera, Ferring Pharmaceuticals Inc., Gilead, Hospira, Inotrem, Janssen, Johnson & Johnson, MSD, Mundipharma, Mylan, Pfizer, Roche, Sandoz, Sublimity Therapeutics, Takeda, TiGenix, UCB Inc. and Vifor, and speaker for Abbvie, Amgen, Ferring Pharmaceuticals Inc., Gilead, Janssen, Mylan, Pfizer and Takeda. LA has acted as speaker/consultant for Abbvie, Amgen, Atlantic Health Care, Celgene, Celltrion, Janssen, Mylan, Pfizer and Takeda. LA has acted as speaker/consultant for Abbvie, Amgen, Atlantic Health Care, Celgene, Celltrion, Ferring Pharmaceutical, Janssen, Merck-MSD, Mundipharma, Otsuka, Pfizer, Shields, Shire, Tigenix, Takeda and Vifor Pharma. MA, HT, WB, LP-B, FP and JW have nothing to disclose.

## AUTHOR CONTRIBUTIONS

AS and FP conceived the study. FP MC and AS analysed and interpreted the data. MC, AS, FP and MA drafted the manuscript. YP, JW, LP-B, SD, HT, WAB, LA, AdH, LL and PGK critically reviewed the manuscript. All authors critically reviewed and approved the final manuscript.

## DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

## ETHICAL STATEMENT

Informed consent was obtained from all individual participants involved in the study.

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## SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section.

<https://doi.org/10.1111/codi.15813>

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