

# EFCCA MAGAZINE

European Federation of Crohn's and Ulcerative Colitis Associations

October 2019



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# We are the sum of everything

I am pleased to present you our latest issue of the EFCCA Magazine.

It's been an exciting few months for EFCCA with the highlights being World IBD Day on 19 May followed by our General Assembly which took place in Prague, Czech Republic on 24-26 May 2019.

During the Assembly I spoke of honour, responsibility and pride. Today I speak of true hope. At our annual members meeting we approved the EFCCA's 2019-2022 strategy plan. The dynamic plan will require teamwork and dedication. The path is long, but we are confident that the best is yet to come.

Over the years, I have heard the stories of so many delegates and patients and learned a lot from their battles and sometimes daily struggles. They have made me a better volunteer, a better leader, and definitely a better man.

I am more inspired and determined than ever to work as a team toward our common goal. I consider the fact that the EFCCA family keeps on growing - within the last ten years we have nearly doubled our membership - a clear sign that EFCCA and our work is a reference point worldwide.

Of course, it is also a sign that the incidence of IBD is unfortunately increasing in particular amongst young people which makes our work even more urgent and important. For this reason, we believe that - within the framework of the EFCCA networking strategy - our strengthened cooperation with the European Society for Paediatric Gastroenterology Hepatology and Nutrition (ESPGHAN) will be beneficial for achieving our goals set out in the strategic plan, and of course we continue our cooperation with other medical societies such as ECCO and UEG.



The recent addition to this networking, i.e. ESPGHAN will give us some valuable insights and direct access to the latest scientific knowledge as concerns IBD in paediatrics. In this edition you will find information about our recent participation in the Public Affairs Committee of ESPGHAN and our efforts to jointly develop activities and initiatives.

A first outcome of this fairly recent collaboration has been our joint work on World IBD Day 2019.

**“If you are willing to fight for what we do, it does not matter if you are an experienced volunteer or a new one, a big organization or a small group of patients, you can be successful”**

This leads me to World IBD Day. Once again, it has been an important and emotional event for us. The kind of solidarity and sense of belonging that this day brings out in people never ceases to amaze me. Hundreds of cities, thousands of volunteers, friends, supporters, healthcare professionals and representatives from the industries coming together to show people with Crohn's and Ulcerative Colitis that they are not alone.

In terms of our advocacy and empowerment work we are currently running two exciting new surveys, one on the perceived impact of smoking on the symptoms and progression of Crohn's disease and Ulcerative Colitis and the second one on the quality of life of people with perianal fistulae in Crohn's disease. We expect the findings of these surveys to give us a better understanding and evidence for relevant actions and advocacy work. You will find more information in this magazine.

These are very promising times for us and I have never been so hopeful about the future. I ask you to support us and remember that together we can make a difference. I believe we can keep the promises we have made to those we represent and to those who created EFCCA.

If you are willing to fight for what we do, it does not matter if you are an experienced volunteer or a new one, a big organization or a small group of patients, you can be successful.

We are the sum of everything we want to do for our patients and for all the people we represent.

Because we all are and forever will be EFCCA.  
United We Stand!

Salvo Leone  
EFCCA Chairman



# Networking at its best

Nearly 60 delegates representing 39 IBD patient associations from Europe and beyond met at our Annual General Assembly which took place in Prague from 24-26 May 2019. The event was hosted by our colleagues from Pacienti IBD (Czech Republic) and provided an excellent moment to exchange ideas and have lively and constructive discussions on EFCCA's future actions and strategies.

Our General Assembly (GA) is a great occasion to gather our members, welcome new members and to hear from other associations that present their activities with view to joining our network. This year we were pleased to welcome as new associate members DII Brasil and FPVZK from Kazakhstan as well as CUKUK (Montenegro) as full member bringing our total membership to 39 members. Additionally, Crohn's and Colitis New Zealand who joined EFCCA in 2013 as an associate member has been accepted as a full member. This year, we focused on our new strategy plan covering the period 2019 to 2022. The Strategy Plan has been drafted by the EFCCA Executive Board and Secretariat taking into consideration previous work, needs and priorities of its members and the IBD patient community as a whole.

The Strategy Plan will nourish the 4 strategic areas in which EFCCA's past and current activities have been structured: Networking, Awareness Raising, Advocacy and Empowerment. It is the framework in which the annual work plans will be developed setting out objectives, activities and outputs to be achieved each year. The cross-cutting goal of the new EFCCA strategy is to tackle discrimination, since discrimination, in its various forms, including impeded or limited exercise of rights and access to services, emerged to be one of the most significant burden on IBD patients. As usual we also held elections to the three available positions on the EFCCA Executive Board. We are pleased to announce that our board members Ciara Drohan, Magdalena Sajak and Natasa Theodosiou have been re-elected. The composition of the new board is as follows: Salvo Leone (EFCCA Chairman), Ciara Drohan (Vice President and



Honorary Secretary), Marko Perovic (Treasurer), Magdalena Sajak, Natasa Theodosiou and the leader of the EFCCA Youth Group. On the second day of the GA we had two presentations from invited guests. We heard from Dr Martin Bortlík from the ISCARE Clinical Centre in Prague who gave us a detailed overview of the situation of IBD patients in the Czech Republic and presented some projects that his organization together with the patient association IBD Pacienti were undertaking together in order to improve the quality of life of people with IBD.

Another fascinating speech was presented by Dr Yoram Inspector from the St. Mark's Hospital in London, UK. Dr Inspector, a psychiatrist and psychotherapist supporting people with various gastrointestinal diseases, explained the relationship between the gut and the brain and how mental well-being of people with IBD is affected by their disease.



*EFCCA chairman Salvo Leone (middle) with our new members from left to right: Thiago Del Grande (DII Brasil), Viv Guerry (Crohn's and Colitis New Zealand, full members), Zdravko Vukasanovic (CUKUK, Montenegro), Salvo Leone, Yerbol Armizhanov, Ardak Dusmanbetov (FPVZK, Kazakhstan)*

## Social Programme

Our colleagues from Prague had organized an inspiring social event for the Gala Diner on the second night of the GA. EFCCA delegates joined delegates of IBD Pacienti on a boat trip along the Vltava River passing several buildings highlighted in purple to honour World IBD Day. We were also given some purple scarfs and blankets which we proudly wore to show our solidarity and unity with people worldwide on this special occasion.

During the boat trip we had a small ceremony to hand out certificates to a small group of delegates that had participated and successfully completed the pilot project of the EFCCA Academy. As you might remember from previous issues of the EFCCA magazine, the Academy is a pioneer project with the aim to provide specialized training helping certified patients to raise awareness on IBD.

All in all, our General Assembly was a huge success which allowed us to connect with our members, make new friends and to reinforce our sense of community and common objectives.



*Presentation of the EFCCA Academy certificates*



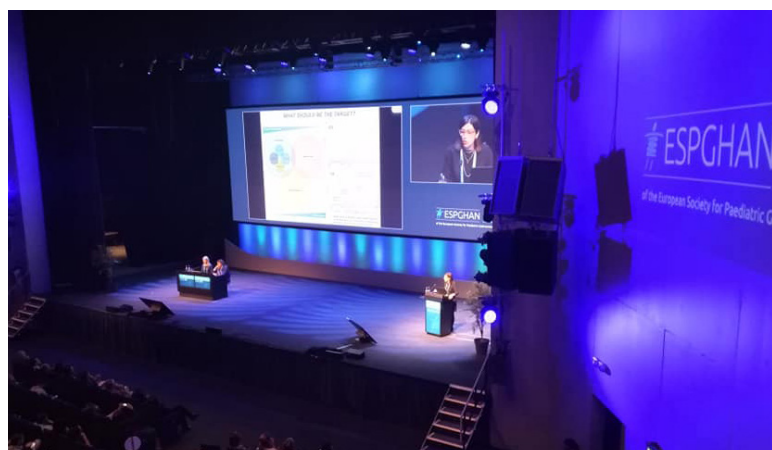


# Strengthening cooperation with ESPGHAN

For the second time EFCCA has been invited and participated in the Annual Meeting of the European Society for Paediatric Gastroenterology Hepatology and Nutrition (ESPGHAN) which took place in Glasgow, United Kingdom from the 5th to the 8th June, 2019.

The Annual Meeting is ESPGHAN's largest event and a great place to hear about the new and upcoming scientific research, learn information from the exhibitors and network with peers. This year, the congress has attracted 4.548 delegates from 97 countries, 47 exhibitors & sponsors and offered more than 1.000 abstract presenters a stage to present their latest research results.

EFCCA had an information booth at the congress venue and also participated in a patients and parents association meeting with members of the Public Affairs Committee of ESPGHAN in order to discuss activities, initiatives and joint-working opportunities with leading members of the Society. We have also been collaborating with ESPGHAN this year within the framework of World IBD Day by promoting a Europe wide study to reveal the invisible costs of IBD to society. The Indirect Costs of IBD study will analyze data from over 3500 people with IBD from 27 countries in Europe and beyond in order to map and compare the invisible costs related to IBD.



Results of the study will allow stakeholders and policymakers to better prioritize effective IBD treatment and support measures aimed at improving the situation for people with IBD in the work place and labor market. The study is conducted by the Institute of Public Health, Jagiellonian University-Medical College, and the International Institute of Molecular and Cell Biology in Warsaw under the direct patronage of Polish Association Supporting People with IBD “J-elita” on behalf of EFCCA.

EFCCA together with ESPGHAN are calling on policy makers to recognise the invisible cost of Inflammatory Bowel Diseases (IBD) and pledge to take steps to reduce the burden of the diseases on society and improve the lives of patients and their families. For more information please visit:

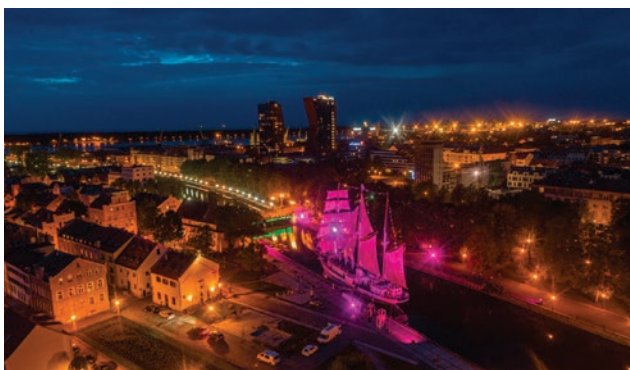
[www.efcca.org/en/press-release](http://www.efcca.org/en/press-release)

EFCCA is very enthusiastic about our recent collaboration with ESPGHAN in particular as IBD unfortunately affects increasingly young people. We believe special attention needs to be given to this age group and are keen to develop common projects and initiatives that are aimed at improving the life of youngsters with IBD.



# World IBD Day 2019

On 19 May the European Federation of Crohn's and Ulcerative Colitis Associations (EFCCA) together with its 36 national patient associations and other IBD sister organisations have joined efforts to raise awareness of the 10 million people living with IBD worldwide.



*World IBD Day 2019, Mexico*



*World IBD Day 2019, China*



*World IBD Day 2019, Italy*

This year's theme "Making the invisible visible" was about shining a light on various aspects of the two invisible conditions of Crohn's disease and Ulcerative Colitis (known as Inflammatory Bowel Diseases or IBD).

As part of the campaign famous landmarks all over the world have been lit in purple (the colour for World IBD Day) as a stepping stone to gain higher media visibility and to gain momentum around specific activities that patient associations are organizing to improve life of people with IBD in their countries.

EFCCA's second activity within the framework of World IBD Day is to promote the survey on Indirect Costs of IBD, which aims to assess the impact of IBD on the patients' productivity at work and other relevant costs for society.

The findings will be presented at a European policy meeting in the second half of this year (see also previous article).

If you want to see what has happened in each country that participated please visit the following website: [www.worldibdday.org](http://www.worldibdday.org)





World IBD Day 2019, France

# Improving quality of life for people with IBD

A new project under the EU call *Innovative Medicine Initiatives (IMI)* will identify digital endpoints that provide reliable, objective and sensitive evaluation of activities of daily living and Health-related quality of life (HRQoL) in Immune-Mediated Inflammatory Diseases such as IBD as well as others such as Rheumatoid Arthritis and Lupus.

We are pleased to announce that the project application under the IMI Call of the European Commission's Horizon 2020 programme has been successful. The project is being led by the Newcastle University, UK and involves over 34 partners including EFCCA.

The proposal aims to identify reliable digital correlates of fatigue and sleep disturbances that are sensitive to change and can therefore potentially be used to objectively evaluate efficacy of therapeutic interventions, building on the university's current programme of research which include a longitudinal study of "digital" profiling of fatigued and non fatigued Sjogren's syndrome patients using different digital devices.



**The Innovative Medicines Initiative (IMI) is a partnership between the European Union and the European pharmaceutical industry. IMI facilitates open collaboration in research to advance the development of, and accelerate patient access to, personalised medicines for the health and wellbeing of all, especially in areas of unmet medical need.**

Digital endpoints or biomarkers are consumer-generated physiological and behavioural measures collected through connected digital tools such as wearable sensors allowing researchers to longitudinally capture objective data throughout a subject's daily life, instead of subjectively assessing a subject's progress at intermittent appointments at the clinical trial center.

There is strong evidence to support the fact that chronic disabling fatigue is not only highly prevalent but a key factor that predicts loss of work productivity in Immune-Mediated Inflammatory Diseases (IMID) including Crohn's disease and Ulcerative Colitis. Sleep disturbance is another common complaint suffered by patients with IMIDs which significantly affects their daily lives.

EFCCA will be involved mainly in the Work Package that looks into "Clinical Knowledge and Insight" in order to provide the patient perspective, needs and priorities. A task force will be created together with representatives from other disease groups in order to provide ongoing advice and input throughout the 5 yearlong project.

This is an exciting new venture and we hope that the results of the project will have a positive impact on the quality of life of people with IBD. We will keep you posted throughout the duration of the project.

## Perianal fistulae and quality of life in Crohn's disease

EFCCA is currently running a survey in cooperation with Takeda to find out the impact of complex perianal fistulae on quality of life from Crohn's disease patients' perspective. The questionnaire, developed in cooperation with both medical experts and patient representatives, looks into topics such as sexual function, work and social impact as well as life activities. The aim is to provide valuable insights into the life of a patient with perianal fistulae.

Fistulae, i.e. abnormal connections between organs and other structures in the body, develop when an organ in the body becomes inflamed.

They are a relatively common complication of IBD, especially in Crohn's disease; around 35% of people with Crohn's disease have at least one fistula. Fistulae are called perianal when located around the anus.

They can cause symptoms such as leaking from the anus, rectal pain and swelling, and pain with bowel movements, and can significantly affect a patient's quality of life.

The survey is currently running and is offered in multiple languages on the EFCCA website at [www.efcca.org](http://www.efcca.org).

Both Crohn's disease patients with fistulae and those without are invited to participate in the study. The first results are expected by the end of 2019.

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

# How does smoking affect Inflammatory Bowel Disease?

There is little patient-centered research that assesses patients' perceived impact of smoking or using nicotine-containing products on Inflammatory Bowel Disease (IBD). EFCCA is therefore supporting a survey on the perceived impact of smoking and the use of nicotine-containing products on the symptoms and progression of Crohn's disease and Ulcerative Colitis.

The cause of both Crohn's disease and Ulcerative Colitis remains unknown. However, certain environmental factors, such as drug use, stress, diet and smoking, can affect the onset and development of IBD<sup>1</sup>.

Smoking is known to be harmful in many ways: it increases the risk of cancer and cardiovascular and pulmonary diseases. In IBD, studies have shown an interesting difference. In Crohn's disease patients, smoking is associated with more severe disease, increased need for anti-inflammatory medication, and early post-operative recurrence<sup>2</sup>. In patients with Ulcerative Colitis, however, smoking seems to be inversely correlated with the risk of developing Ulcerative Colitis and the progression of the disease<sup>3</sup>.

As very few studies have assessed the perceived impact of smoking or nicotine use on IBD symptoms using a patient-centered approach, EFCCA is supporting an online patient survey on the perceived effects of smoking. Sponsored by Philip Morris Products SA, the survey focuses on the perceived effect of smoking/nicotine use on UC/CD symptoms



and disease progression by patients who are current adult smokers and/or nicotine-containing products users, and shall not be, in any circumstance, construed as suggesting cigarettes and/or nicotine-containing products as treatment methods.

The survey will open shortly on the EFCCA website at [www.efcca.org](http://www.efcca.org), and patients with both Crohn's disease and Ulcerative Colitis are invited to participate.

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

## References

<sup>1</sup> Danese, S., M. Sans, and C. Fiocchi, *Inflammatory bowel disease: the role of environmental factors. Autoimmunity reviews*, 2004. 3(5): p. 394-400.

<sup>2</sup> To, N., D.J. Gracie, and A.C. Ford, *Systematic review with meta-analysis: the adverse effects of tobacco smoking on the natural history of Crohn's disease. Aliment Pharmacol Ther*, 2016. 43(5): p. 549-61.

<sup>3</sup> Berkowitz, L., et al., *Impact of Cigarette Smoking on the Gastrointestinal Tract Inflammation: Opposing Effects in Crohn's Disease and Ulcerative Colitis. Front Immunol*, 2018. 9: p. 74.



# European Youth Meeting

This year the EFCCA Youth Group (EYG) gathered for the European Youth Meeting (EYM) in the capital of chocolate, beer, and fries: Brussels, Belgium! On the 19th and 20th of July, 21 young delegates from 14 countries across Europe attended the 2-day meeting hosted by the Belgian Association Crohn-RCUH.

The annual meeting is the perfect occasion for every delegate to share their experience and learn the best practices from one another. As we aim to raise more awareness in each of the member countries and represent the interest of the population aged from 18 to 30 years old, around Europe and beyond, the EYM makes it possible to exchange ideas and collect information between the youth groups of different countries.

After a warm welcome and a quick introduction by Katleen, organizer of the meeting, and Martin, then substitute Leader of the EYG, the floor was given to Ciara Drohan, EFCCA Vice-President, and Marko Perovic, EFCCA Treasurer, to explain the added value of having a group of representatives dedicated to the young population being part of EFCCA.

It is with that purpose that the very first workshop of the meeting was entitled “shaping the mentality of young leaders”.

The group, split into three teams, was asked to define prime notions to have in mind as patient advocate, such as the main stakeholders having interest in our actions, or key words to go straight to our point, as in the exercise of the “elevator pitch” (i.e. a short

description of an idea or organisation that explains the concept in a way such that any listener can understand it in a short period of time).



*EYM board members together with Ciara Drohan and Marko Perovic*

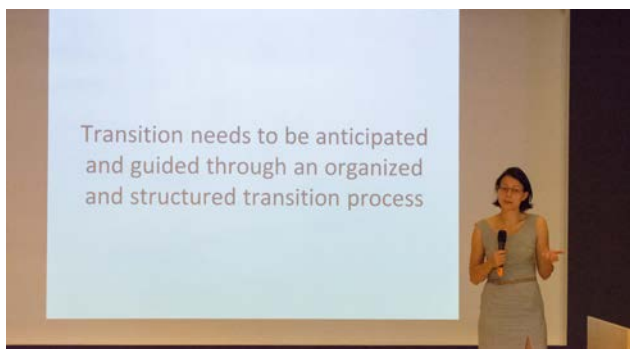
## Shaping young leaders

The main focus this year was put on our flagship project: assessing the challenges of a transition process from paediatric to adult care. In that aim, we welcomed Dr Isabelle Scheers to give a lecture about her point of view as a gastro-paediatrician.

Dr Scheers believes that the most valuable tool to help teenagers make it through the transition period

is an accurate communication between the patient, the paediatrician and the parents. In order to fully understand the situation, the teenager needs a proper introduction of medical terms, and a complete explanation of the illness.

Our role as patient associations is to encourage the doctors, medical staff, and parents to empower the teenagers and encourage them to make their own medical decisions, once they have accepted their condition. After the lecture, delegates took a time for reflexion through a collective workshop where



*Dr Scheers presenting her insights on the transition process from paediatric to adult care*

## A new team for new horizons

In order to revitalise the Youth Group after a very complicated year, a new constitution has been adopted by the delegates.

The newly organized EYG Board will no longer host 5 full-members and 5 substitutes as it used to, but rather 7 members, elected for two years.

## A networking event in the capital city of Europe

To close this very rich and intense couple of days, the Youth Group enjoyed some fresh air and took a walk through the city from the hotel to the European district. After a quick stop by the Manneken Pis and the Grande Place, it was time for the main cultural event of the weekend: the visit of the Parlamentarium. Inside this interactive museum dedicated to the European Parliament, the delegates could have a better understanding of how the European Union works from the inside, and better understand their role as patient advocate for a pan European organisation such as EFCCA. Last but not least, the gala dinner was held in one of the most amazing place in Brussels, in the Atomium top-floor restaurant!

they could share their own ideas of actions to help the IBD community define a softer way to approach the transition period as a teenager, a parent or a healthcare provider. Every team came up with many propositions that will be very useful for the rest of our project. The next step is to create concrete documents to share best practices with people facing transition. Transforming relevant information into a valuable tool will be our challenge for the year to come. Stay tuned with the Youth Group to be aware of our achievements!

After attending the EYM, each delegate will then be asked to participate in the activities of the Youth Group and will be offered specific tasks to complete along the year, until the next EYM.

This year's elections welcomed Selina Huber (Germany), Olga Golebiewska (Poland), Olga Mitrovic (Serbia) and Natalia Mandakova (Slovakia) to join Katleen Franc (Belgium), Simo Natunen (Finland) and Martin Mastrotto (France) on the Board of the EFCCA Youth Group. French delegate Martin Mastrotto has been elected Leader of the Group for the next two years.

Fancy dresses, stunning view and delicious food put a final point to this 2019 edition. Time to congratulate Barbara Korosec from Slovenia, winner of the Loekie Award for best national presentation, and to thank every delegate for their attendance and their active participation all along the meeting.

I am proud to have had such an enjoyable moment. By putting all our forces together we proved ourselves resourceful and I am very much looking forward to achieving great work with a new team of young advocates. I'd like to thank everybody who gave their time and energy to make this edition happen. Particularly Katleen, who did a great job with the organisation; Ciara and Marko, who lead us all along the way. As a group we aim to continue to break down taboos for young people and their conditions.

We will keep sharing articles about our achievements and work towards the vision of United We Stand.

Thank you for reading  
Martin Mastrotto, EFCCA Youth Group Leader

# Kazakhstan

## Supporting people with IBD

During our last General Assembly in Prague, EFCCA welcomed a new member to the network: FPVZK from Kazakhstan. In this interview, Yerbol Amirzhanov explains about the situation in Kazakhstan.

### **Are there any estimates of how many people in Kazakhstan have IBD?**

According to unofficial data there are about 6000 people in Kazakhstan with either Ulcerative Colitis or Crohn's disease.

### **What are the main challenges for people with IBD in Kazakhstan?**

There are several problems people with IBD are facing such as the issue of early diagnosis. Very often, the right diagnosis is made long after the onset of the acute course of the disease. There is also no awareness among patients, and sometimes doctors, that IBD basic therapy can be obtained for free. Our Foundation is constantly working to ensure that patients receive basic therapy drugs in a timely and full manner. As far as biological therapy concerns the procedure for obtaining such medication is very complicated. People on biological therapy must strictly adhere to the injection schedule. Every 2, 6 or 8 weeks, depending on the drug. In order to receive a biological drug patients must go to the hospital. Try and imagine the procedure involved for this: collecting the exams, booking an appointment in the hospital and then hospitalization. And this every 2, 6 or 8 weeks!

We have been contacting the Ministry of Health of Kazakhstan with a request to transfer people in remission to outpatient drugs. Last year, the Ministry of Health of Kazakhstan adopted a law that allowed the transfer of the biological drugs to outpatient use, but for some reason the drugs for people with Crohn's disease have to remain at the hospital. This means that a person with Crohn's disease who takes the drug every 2 weeks does not actually leave the hospital.



*Yerbol Amirzhanov, co-founder of the IBD Foundation Kazakhstan (FPVZK)*

Another challenge is related to new drugs that are being developed. If a certain drug ceases to work for a particular patient this patient has to use another drug, but this drug is not within the state's free treatment protocol so he or she has to buy the new drug. Usually patients are prescribed one type of Mesalazine, the one that is in the free state protocol, however the drug acts on one patient and not on another. In such cases we call on local authorities to provide targeted assistance and provide the patient with the necessary drugs for free. We are simultaneously working on these issues with the Ministry of Health of Kazakhstan to include new drugs in the treatment protocol.



This takes a lot of time, and people have to wait from six months to even a year, until the drug is approved and added to the protocol.

Our state tender procurement system for the drugs is very challenging. Every year, at the beginning of the year patients have problems accessing free drugs because the tender purchases have not yet passed, and at the end of the year very often the drugs are not available anymore and you need to wait a couple of months. Of course, the disease does not wait for the tender procedure to run its course. It is difficult for specialists and local doctors to calculate the correct amount of drugs for their own patients. We are still trying to work out where the shortcoming is in order to develop better practice of pharmaceutical procurements.

#### **When and why was FPVZK founded?**

Our Foundation was created in 2016 upon the initiative of a group of IBD patients. We got officially registered as a foundation in January 2017. The founders are the same patients with IBD who have teamed up to improve the quality of life of people with IBD in Kazakhstan.

#### **What is the main work you do?**

The IBD Foundation represents the interests of people

who have been diagnosed with ulcerative colitis and Crohn's disease in Kazakhstan. We do our best to increase awareness of IBD amongst our population as still little is known of IBD in Kazakhstan. As mentioned before, we are advocating for an expansion of the list of free drugs available for IBD patients.

In special cases we support and try to find solutions to the untimely provision of drugs as part of a free state program.

We are increasing the general awareness of world standards for the treatment of IBD through various events, the media and social networks.

We are also striving to strengthen our dialogue with state officials. We would like to have a good dialogue with officials from the Ministry of Health of Kazakhstan in order to make it easier to bring our problems to the authorized body and solve them faster.

#### **How did you find out about EFCCA and why did you decide to join?**

We learned about EFCCA from our doctor. She returned once from an international medical congress and brought along the EFCCA magazine and other information material. We then searched on the internet and realized that EFCCA is an organization that is able to unite many countries and provide valuable experiences and insight on how to achieve our common goal, to find ways to cure IBD. This was why we decided to join EFCCA.



# Italy

## “Not Waiting for Godot”

AMICI Onlus, in collaboration with Takeda Italy and IG-IBD (Italian Group for the Study of Inflammatory Bowel Disease), promoted a storytelling workshop. Twenty IBD patients met for twelve meetings from April 2018 to June 2019.

Michele Palazzetti, director of IPSE (Istituto Psicologico Europeo), from Viterbo, Italy, coordinated this project. The event took place at AMICI onlus headquarters in Milan. In each session, Dr Palazzetti introduced a topic and the participants were free to talk about their feeling, hopes, fears and thoughts.

The goal of this project was to create an awareness campaign for IBD. The final output was the creation of a theatrical act enacting the life of an IBD patient. The tour touched several Italian cities such as Milan, Rome, Bologna, Naples and Palermo.”

We are happy to share an extract of one of the stories:

“Very often the only obstacle to understand yourself is you. I borrow this phrase from a companion of adventure of our Storytelling Laboratory (Lab) because it “hits the target”.

Thinking back to each member of the group, I think that everyone basically safeguards this hope of being understood even if our way to communicate is often incomprehensible, or silent.

I arrive, I am shy, I am very shy as always, I wish I were not there but I am.

Even if I am “among us”, I would like to be invisible; I’m so worried about what other people can think about me that I prefer to focus less on my feelings.

The laboratory (lab) is ready to begin, we are in a circle, so everyone can be seen by the others and at the same time everyone observes each other.

A laboratory, that is a “lab-ork”, (Laboratory + work) ... but I don’t want to work.



Working on what?

I realize how some guys, more or less peers, have been diagnosed recently and they find themselves in a time of uncertainty between the fulfilment of the incident and the internalisation. Still so many questions and hopes.

On the one hand these questions seem to me vain, I stopped asking myself “why me?”.

I do not say that I am indifferent towards the disease, but I realize how I perceive it, not as a monster but just as a medical issue: routine examinations, visits, therapy, phases acute and forward like this.

I feel strong but at the same time weak.

What makes me think of not having to face an emergency that takes me straight to the emergency room suddenly?

Now the idea of invisibility is stronger, I pretend to be invisible even to myself, I know that “it” is there, but I hope it will be under control.

I feel strangely, I only confess to myself now that I had a moment of arrogance, the idea of having not yet lived an operation makes me living in a sort of indifference to other members' stories, only the silent authorization to listen to them. This feeling does not last long, and I am a bit ashamed. The point is that this is one of my greatest fears.

I want to remain invisible; I want the disease stays invisible, inside me, without leaving visible marks, scars, cuts, signs.

Why? They are just excuses, I realize how I have put aside my worst fears in my invisible part, pretending that they do not exist at all.

My thoughts bounce all around here and there while Michele calls us to begin a new meeting of the narrative laboratory.

Here I want to express my gratitude and respect to all those who speak about their fears and frustrations, with no filters and no shame, freely during the meetings.

I want to thank Michele for the courage spread to us during the laboratory and for my companions that help me in taking my mask off. They show me their affinity and all their comprehension. I realize that I was the only obstacle to understand myself. And also, my adventure companion who patiently urged me to get out of my invisibility, which I often tend to hide in, and to make myself visible, to participate.



I would not, but I know that my voice trembles and I can only speak with a whisper, I relax when they ask me to do something different, to smile in a camera, and ... I realized that also me is waiting for something, "I'm not waiting" for something, I'm not waiting for a therapy that I see so far away, I'm waiting to feel good again, even if sometimes I pretend, I'm not waiting for anything.

Gisella Pompilio  
Cristiano Consorte

## Norway

### Update on LMF activities

Since the beginning of 2019, LMF has worked continuously on influencing our states use of bureaucratic methods when approving new treatments for IBD patients. Due to strict regulations governed by the *Norwegian National System for Managed Introduction of New Health Technologies*, the use of Stelara ustekinumab for Crohn's disease has been put on hold until January 1st, 2020. Professor in gastroenterology Bjørn Moum, at Oslo University Hospital, reports this decision has critical medical

consequences for those patients with a high severity of Crohn's disease.

Alongside EFCCA and the other 35 sister organisations, LMF marked the World IBD day on May 19. This year, LMF decided to highlight how we can impact upon the ongoing delays and significantly long waiting time IBD patients have to endure during the process of getting a diagnosis and receiving medical treatment. In addition, we wanted to focus on patients' opportunities to impact upon their medical treatment



plan. We set up a discussion panel in which politicians, a gastroenterologist and our members participated. LMF plans to use the thoughts and inputs arising from the discussion panel - in our organisation's ongoing IBD-advocacy work.

After holding the position as general secretary for 10 years, Arne Schatten steps down and continues to work for LMF as senior advisor. Mads Johansson was appointed new general secretary in June.

LMF regularly arranges meet ups and activities on a local and national level. Our national youth group is arranging a workshop-based seminar for members between the age of 12-17 in November. The teens will

get to impact upon our organisation's advocacy work, expressing their thoughts through fun social activities like music, dancing, drawing and writing.

LMF is working on encouraging doctors to actively talk to their patients about both their mental health and diet and offering treatment by psychologists and clinical nutrition physiologists. We plan to invite health care professionals to participate in a survey on the topic, as well as inviting a range of medical associations to a meeting. In addition, LMF encourages health professionals to inform their patients about the importance of our organisation.

LMF

## Spain

### #LaHistorialInvisible (TheHiddenStory)

For the occasion of World IBD Day ACCU España launched a campaign that aimed to raise awareness about the non-visible difficulties suffered by people with IBD when combining work and daily life with the circumstances arising from their illness.

The awareness campaign has been broadcast via social media under hashtag #LaHistorialInvisible #TheHiddenStory.

The campaign talks about the story of Amelia Mora, who has just returned to Spain after working abroad. This story is not told in the first person, but by professional colleagues and friends such as writer David Generoso and journalist Adolfo Rodríguez. Amelia, and by extension all people with inflammatory bowel disease, has enjoyed the support in social media of José Mota, Rosa Montero, Mago More, Quique Peinado, Antonio Fraguas, Desiree Vázquez, Pablo A. Iglesias, Irene Ferrer, Inma Morandeira and Emilio Linder, all of great Spanish journalists and communicators who talk about her and the relationship they have established. Amelia Mora's character was altruistically interpreted by Carmen Santamaría.

Additionally, the #LaHistorialInvisible (TheHiddenStory) campaign has benefited greatly from the collaboration of GETECCU, MSD, AbbVie, Pfizer, Takeda, Dr. Falk Pharma and Ferring. Learn more about #LaHistorialInvisible (TheHiddenStory) at [www.accuesp.com/lahistorialinvisible](http://www.accuesp.com/lahistorialinvisible)



# An app proposal of the Hospital Niño Jesús wins “Innovando Juntos” (Innovating Together) project competition

The Madrid University Hospital Niño Jesús de Madrid won the “IBD Challenge” competition of the MSD project “Innovating Together”. The proposal presented by the hospital aims to develop an application for smartphones that aim to improve the control of the pathology in children and adolescents with paediatric Inflammatory Bowel Disease.

The objective of the “IBD Challenge” was to seek technological proposals that would improve the lives of patients with Crohn’s disease and ulcerative colitis. Specifically, it looked for possibilities of improvement for the welfare of patients and control of the pathology that may result from innovative initiatives based on new technologies.

In response to this challenge, the Niño Jesús University Hospital proposed a project whose main author is Dr. Rosa Ana Muñoz Codoce, from the Hospital’s Paediatric Service.

She highlights in the project proposal that “a very increasing percentage of cases of IBD are diagnosed at paediatric age”, and “the use of new technologies to better control chronic diseases offers great possibilities to the patient”.

Therefore, the objective of the proposed solution is to develop an application for smartphones reviewed by professionals, easy to understand and intuitive operation, which serves as a tool for the adolescent patient or parents of younger children, “to reduce hospital visits, avoid admissions and anticipate the outbreak to ultimately achieve better management of their disease.



*Winners of the “IBD Challenge”*

The application could include a symptom diary, reminders for taking medication, hospital appointments and an incident function in which, through simple questions, the application detects whether the patient should contact their hospital. It would also contain advice on nutrition, physical activity and medication.

Together with MSD, the Fundación Parque Científico de Madrid, the Spanish Working Group on Crohn’s Disease and Ulcerative Colitis (GETECCU), the Confederation of Associations of Crohn’s Disease and Ulcerative Colitis of Spain (ACCU España), the Nursing Working Group on Inflammatory Bowel Disease (GETEII), the Spanish Society of Hospital Pharmacy (SEFH) and the University of Alcalá have participated in the challenge.

ACCU España

# New Zealand

## Ally Bain Coming to New Zealand

In the United States, “Ally’s Law” is a household word. It refers to a law guaranteeing access to employee restrooms for people with ostomies, Crohn’s disease, and ulcerative colitis. It is named after a 14 year old girl in the U.S. with Crohn’s Disease, Allyson Bain.

Ally was in a large store in a mall in Chicago, doubled over in pain, urgently needing a toilet. She was refused access, despite pleading with the manager. Ally had an accident in the store and vowed that this should never happen to anyone else. Ally went to see her representative in the legislature, Kathleen Ryg, and together they were successful in getting the first “Ally’s Law” passed in the state of Illinois. Sixteen other states have since followed suit, all passing their own “Ally’s Laws”.

Unfortunately, what happened to Ally happens all the time. What was different in her case was her courage to speak publicly about her experience and advocating tirelessly for change. In the process she has made a difference in the lives of countless thousands of people. In New Zealand there is another courageous fourteen-year-old, Nicole Thornton. Nicole’s petition for an Ally’s Law in New Zealand is still under consideration in Parliament but has met

opposition from business owners and organisations. Nevertheless, as a direct result of her petition, the Ministry of Health is considering measures to expand access to toilets and raise awareness about the needs of ostomates and those with IBD. Last year Nicole and Kate Montgomery (one of Camp Purple’s volunteers) spoke passionately and convincingly about the need for change at a public hearing of the Health Select Committee.

Allyson Bain is now a lawyer working for the American Civil Liberties Union in Chicago. She is still advocating for people’s rights and has been in contact with Nicole, supporting her efforts for change.

In November, in partnership with CCNZ, Ally will be coming to New Zealand. With Nicole, she will be addressing the Annual Scientific Meeting of the NZ Society of Gastroenterology on patient advocacy. Her address will likely be a highlight of the meeting. A second speaking engagement is currently being arranged in Australia.



*Nicole Thornton speaking at a public hearing of the Health Select Committee*



*Richard Stein from Crohn's and Colitis New Zealand with Ally Bain*



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# United Kingdom

## It's good to talk

On World IBD Day, the 19th of May, Crohn's & Colitis UK launched a major campaign, **It Takes Guts**, to encourage people to start conversations about living with Crohn's and Colitis.

If you are looking for help initiating discussions with people in your life, the It Takes Guts website ([ittakesguts.org.uk](http://ittakesguts.org.uk)) offers a range of useful tools, including a poster maker, videos and a unique conversation generator, which will ask questions about your condition and then provide personalised suggestions that you can use to start your own conversations today.

As part of the It Takes Guts campaign, we have launched an app called "In My Shoes" which allows people who haven't experienced Crohn's or Colitis to spend 24 hours living 'in the shoes' of somebody with Crohn's or Colitis. Users are prompted when they need to find a toilet urgently, when they need to take medication and when they are fatigued and need to rest - so they can see first-hand how the conditions can affect every aspect of life.

"I really love the fact people can actually now begin to have an idea of how we live with Crohn's or Colitis and



how it is a task just to cope day-to-day," says Natalie-Amber Freegard, whose mum Rachel spent 24 hours using the app.

Rachel says: "I found it very immersive and it took up a large part of my day. It did give me an insight into how much the condition takes over the lives of someone with Crohn's or Colitis. I underestimated how much pre-planning is required, like knowing where the toilets are, making sure I can buy food easily which isn't high in fibre, and remembering to take my medication."

## New IBD Standards launched

We've launched new IBD Standards to show what good quality care for Crohn's and Colitis patients looks like.

The Standards were developed by IBD UK, a partnership of 17 patient and professional organisations chaired by Crohn's & Colitis UK.

The Standards show what high-quality care looks like for people living with Crohn's or Colitis, whether they're newly diagnosed or managing their condition long-term, and how a hospital should be managed to deliver this.

Chair of IBD UK and Crohn's & Colitis UK's Director of Health Service Development Rukshana Kapasi said: "The launch of the IBD Standards is testimony to the dedication of all the organisations involved to reach a consensus about what good IBD care should look like.

"Patients and carers are the only people who experience the condition from the first symptoms to ongoing care, and their perspective on where improvements can be made provides a powerful insight. Together, we can push up the quality of IBD services."

The Standards have been published in the journal Frontline Gastroenterology and are available on the IBD UK website, which also features a range of practical resources to support healthcare professionals. And, for the first time, hospitals will be assessed against the Standards, through both our patient survey and via an IBD Benchmarking Tool.

So far more than 130 IBD services have registered for the tool, which go live on 1 October and will be open until 15 January. Visit [ibduk.org](http://ibduk.org) for more information.



# Romania

## IBD DAY 2019 CLUJ NAPOCA / 9 May 2019

A few days in advance of World IBD Day (19 May), ASPIIR raised in Cluj Napoca the voices of patients with IBD in a single message “Making the Invisible Visible” - the slogan of World IBD Day 2019.

The event took place in the foyer of the beautiful casino building in the Central Park of Cluj Napoca, with invited gastroenterologists Professor Dr M. Tantau, Conf. Dr A.Tantau, Dr R.Zaharie and with IBD patients and ostomates from Cluj Napoca and other cities in the area. We talked about the experience with IBD and/or having a stoma, we shared our stories - young patients or even an 80 year old; we learned about the support of specialists to help an active community of patients with IBD and we made a retrospective of

the ASPIIR campaigns in recent years, dedicated to IBD Day; we discussed plans for the future forums of patients and doctors in IRGH Cluj Napoca and even for the next IBD Day in May 2020.

In the evening, the casino building was lit in purple, thus enrolling the city of Cluj Napoca, in the international campaign of fighting against inflammatory bowel diseases, along with locations on all continents. The project has been supported by our partners Abbvie, Takeda and Vifor.





## “Making the Invisible Visible” - Dubova, June 28-30, 2019 - IBD Day 2019, Timișoara

Although with a little delay, we celebrated IBD Day 2019 along with Timisoara patients and specialists from 28 to 30 June 2019 with a very different kind of approach. We organised a trip and workshop with a group of adult patients, children, gastroenterologist Dr Adrian Goldis, nurses, and some mothers who were accompanying the very young patients.

On June 28, we boarded the minibus and headed for Dubova, our place for the workshops and project activities over the weekend. The participants came from Timisoara, Arad, Nadlac, the neighbouring rural area: Covasant and Covaci villages, as well as from Bucharest.

A stoma therapist Georgeta P s rin from the Surgery Department of the Fundeni Clinical Institute also joined us. We shared experiences of fighting with IBD, we learned from Dr. Goldis updated information about the treatment in IBD, about ongoing studies abroad (i.e. Prof Colombel - a study comparing the US Army medical files (youngsters enrolled in the past) with the current medical analyses to identify the causes that could leads to the appearance of IBD, the meconium study, etc.).

Parents had the opportunity to ask questions about the evolution of IBD in children; the ostomates were interested in issues related to the situation of

reversal surgery or optimal stoma care; furthermore, we discussed the role of the IBD Day campaign and made plans for 2020.

The workshop was a great opportunity for participants to become more aware of the role of the doctor-patient relationship, of overcoming the psychological barriers, and this activity increased the reciprocal level of communication and trust. That weekend was the Feast of Saints Peter and Paul and some children celebrating their name day were surprised by Dr Goldis who had ordered cake. This was followed by a relaxing boat ride on the Danube river.

Since exercises and sport in generally have a beneficial role on patients with both IBD and surgery, we put it into practice this advise: on Saturday we went on a walk near Dubova village heading on the Ciucaru Mare route to the first belvedere place over the Cazanele Mari. Finally, the dinner sessions were an opportunity to discuss diet in IBD or food health, for sharing experiences and making plans for other project - patients and doctors. All in all, a very satisfying weekend.

ASPIIR



# Poland

## Summer Camps - We're lovin' them!

Summer camps organized by the Polish Association Supporting People with IBD “J-elita” are our 11 years old tradition and with every new camp organized, we are realising how important they are for us and our members.

Every year there are two camps organized by “J-elita” during summer. The first camp is a two-weeks rehabilitation camp for kids at the seaside the second camp is a one-week camp for adults along with their families in the mountains. This year the total number of camp participants was over 250 people! Each camp has its peculiarity, but the overall goal is the same for all camps: to unite the IBD community, enable those affected by IBD to exchange knowledge and experience, to create lifelong friendships, but above all to enable everyone to forget about their disease, pain and everything in between for at least one or two weeks.

For the kids' camp we organized lots of sport and art activities, competitions on the beach, sightseeing of different cities, bonfire evenings, but according to our young participants feedback, the best of the best was a location-based game. The goal of the game was to find in Darłówek (the city where the camp was organized) treasures gathered by Danish king Erick during corsair raids centuries ago. A real challenge and a test of physical strength, equilibrium and ability to handle difficult conditions was also the kayaking trip on the Wieprza river.

The summer camp for adults was organized in the beautiful Tatra Mountains, therefore main activities were hiking, walking in the mountains and cycling. Participants visited the treetop walk Bachledka in Slovakia, did a bike tour of over 40 km from Chochołów to Nowy Targ and back, enjoyed some relaxing time at the thermal pools and of course they hiked - reaching lots of different Tatra summits and an adventurous group of around 20 and with the help of a guide reached even Rysy summit (2499 m) the highest summit in Poland!



Natural beauty, rich highlander folklore, delicious regional cuisine and friendly hosts made the camp a real unforgettable event.

The time that camp participants of both camps spent together gave them new energies and power, built their self-confidence and fostered new friendships, but most of all it proved that even affected by serious disease, such as IBD, people can really reach summits and by fighting together there is nothing to be scared of. Summer Camps - We're lovin' them!

“J-elita” Association

# The Netherlands

## Transfer to adult healthcare

The transition and transfer to adult healthcare isn't always a smooth ride for young people. Reason enough in 2017 for the Dutch Crohn's and Ulcerative Colitis Organisation (CCUVN) and doctors to ask youngsters aged 16 to 23 years which bottlenecks they encountered. The CCUVN gave suggestions for improvement based on the study results.

Transition is the period in which children between 14 and 18 years are prepared for the transfer to adult healthcare. The study showed however, that not all youngsters recognize the transfer period as such. That is why the CCUVN recommended that every step in the transfer should be explicitly named, thus ensuring the youngsters' involvement. It helps to make a time path and talk this through with the parents and their child.

### Differences

Paediatric and adult healthcare differ a lot. Paediatricians give children and parents a lot more attention. Parents accompany their child when visiting the paediatrician, and they actively participate in the conversation. An 18 year old can bring parents, but the doctor expects the youngster to talk and also that he/she acts independently with regard to the disease i.e going to the pharmacy, asking for a new batch of medication on time, contacting the doctor if health problems occur. Although youngsters take on this role when they go to the adult healthcare, CCUVN advises doctors to pay extra attention to this aspect after the actual transfer.

### Support helps

Youngsters that were actively supported during the transition, were positive about this extra attention. Once they go to the adult doctor, they are well prepared and do a lot on their own, such as talking with the doctor. They did, however, say that doctors shouldn't use difficult words and should regularly ask if they understand everything. Also important is that the doctor asks about the impact the disease has on their daily life.

And they appreciate doctors offering psychological help and deciding with them if this is a good option (see Figure 1).

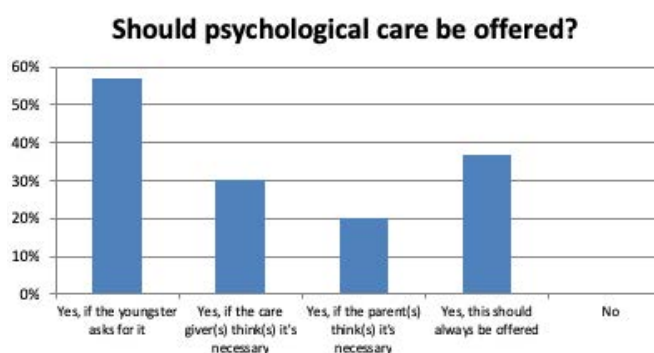


Figure 1: Should psychological care be offered to youngsters? Number of respondents 69, more answers were possible.

### Directives

In the meantime the directives for IBD-care for patients up to 18 years have been amended. The above suggestions have been incorporated and the directives refer to the CCUVN study (2017).

The directives advise hospitals to appoint one IBD doctor or nurse who is responsible for the transition of youngsters. The CCUVN has produced a film on transition and transfer. The film has English subtitles. <https://youtu.be/8-2gcaphD6A>



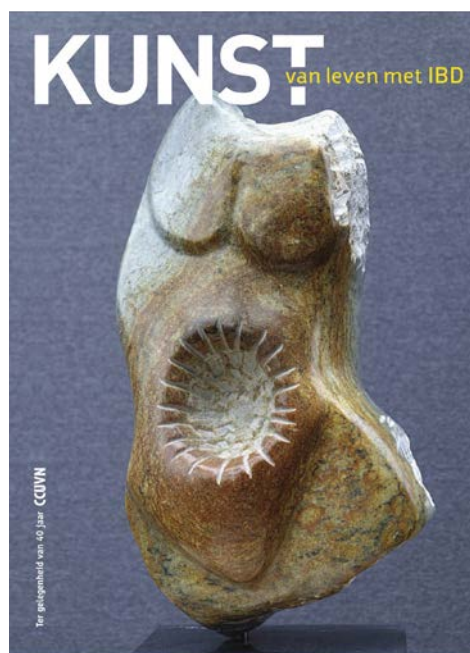
# “Art of living with IBD”

The Dutch Crohn's and Ulcerative Colitis Organisation (CCUVN) exists for 40 years. In these years we have told and shared many beautiful, sad, emotional, gripping and personal stories. The impact of IBD and short bowel syndrome is not always apparent to the outside world. They are invisible diseases that still lack the attention they deserve.

That is why we published a book full of stories and beautiful arts works. The stories in the book 'Art of living with IBD' all show optimism, perseverance and a reluctance to give up. That's an art in itself. And that's why the Art of living with IBD is our jubilee's theme. We asked artists to create an artwork about and with patients. The result can be seen in the book.

There are so many beautiful art works and just as many beautiful stories. The stories in the book are in English and in Dutch. The photos of the arts works, patients and artists speak for themselves.

If you are interested in the book, please send a mail to [info@crohn-colitis.nl](mailto:info@crohn-colitis.nl)



*Art of living with IBD, with the sculpture 'Inner fight' on the cover.*

## France

### A 2019 View of the State of IBD in France

For a better grasp of the effects of IBD on patients' daily life, AFA launched in 2006 a broad survey including 2500 patients: "A View of IBD". Three views of IBD were confronted: the patients' view, the view of their surroundings, and the doctors' view.

The objective is to better understand the patients' life, patient management, the effects of the disease on their personal, family and professional life.

The survey was aimed at learning the patients' expectations and needs and also to identify the discrepancies between the patient's perception and that of their surroundings and of their doctors.

- **The Patient's View:** at the centre of the survey, the patient could express the effects of the disease

through a personal questionnaire, whether UC or Crohn, on private and professional life, along with how you live with the disease, etc.

- **The View of the Surroundings:** a relative or friend of the patient, recommended by the patient, was questioned by phone. This opinion is essential with this type of disease in which the patient doesn't open up very easily.

- **The View of the Doctors:** the doctor designated by the patient was questioned through a questionnaire.

A first phase qualitative investigation took place made up of interviews with patients, relatives/friends and doctors. This investigation was supervised by AFA's Scientific Committee in which a few patients and relatives/friends were included.

In 2019/2020, we propose a remake of this large study on the patients' status today, along with the doctors and relatives/friends view, essential to the study. What has changed? What has improved? What hasn't changed at all and needs to be pushed? To do so, AFA will use the 2006 questionnaire in order to make the comparisons, with only a few extra sections:

digital, the patient's course, the interest of a patient association, the relevance of information, etc., to avoid making the questionnaire burdensome. The study will take place in the framework of AFA's IBD Observatory and in partnership with the health professionals and other French societies.

#### Timing

End of 2019: Beginning of the qualitative investigation phase with the active enlisting of a few patients, a few doctors and a few relatives/friends, with the added data to enrich the questionnaire. This phase is supported by the Ministry of Health. Beginning of 2020: quantitative study launch via social media. Mid 2020: Analysis and public dissemination of the results with a plan of action to follow.

AFA

## Israel

# Patient centric care - Next generation Patient Journey Hackathon May, 2019

## The Israel Foundation for Crohn's Disease and Ulcerative Colitis (CCFI)

During IBD Awareness month & World IBD Day in Israel, we organized the first Patient Journey Hackathon. This was a patient-centric event, led by the Crohn's Disease and Ulcerative Colitis Foundation of Israel (CCFI), and was run and organized by IBD patients in collaboration with IBD physicians. The main aim of this endeavour was to engage and involve patients in identifying unmet needs in IBD care and brainstorming the solutions to these crucial gaps that are currently not under the spotlight of the IBD community. Given the chance, patients know best!

#### Introduction

On 9 May 2019, after spending time with their families and friends on our Independence Day exactly at 21:00, 20 out of 20 registered participants arrived to the first ever Patient Journey Hackathon by CCFI. The event was held in a cutting-edge coworking space equipped with everything they needed, including health care professionals from the Chaim Sheba Medical Center at Tel-Hashomer. The event was guided by two health coaching experts from Toot-Coach.



*Patient Journey Hackathon, opening session, May 9, 2019 21:00*

## Objectives of Hackathon

The goals of Patient Journey Hackathon were:

- Exploring different aspects of coping with IBD.
- Identifying difficulties in each aspect of QOL (Quality of life).
- Create and suggest ideas for service/product that can help IBD patients cope better with the disease and improve their QOL (Quality of life).
- Create a worldwide-shared “Patient Coping Toolbox”.

## Organization (timeline)

Patient Journey Hackathon took place from 21:00 Thursday night until 11:00 Friday morning. Participants assigned into five groups while each group explored different aspect of QOL such as family, relationships, sexuality, work etc.

We divided the event into 3 sessions:

- **Explorative session**  
this session included learning and exploring different aspects of IBD. Each group of patients studied a different aspect of QOL, identified the challenging topics and created a report for a status meeting that took place around 01:00.  
  
Prof. Uri Kopylov & Dr. Tal Engel sat down with each group providing them with research data and a doctor's point of view. By the end of the session participants filled out a report stating what they learned and identified key difficulties coping.
- **Creativity session**  
this session included “Brainstorming” and creating an idea to a service/product. By the end of the session, participants filled out a report describing the idea they had and how to implement it.
- **Summary session** this session took place at the end of the event (10:00 Friday morning) while each group presented their idea.



*Night session with Prof. Uri Kopilov and Dr. Tal Engel, presenting new and innovative ideas by patients*

## Outcome

In the morning, each group presented a set of innovative and surprising ideas, such as:

- Mobile application translating physical measurements into communicative text, helping patients explain their surroundings how they feel.
- Smart sticker (QR) that can be placed at intimate locations helping patients access intimate information such as sexuality and IBD.
- Smart IBD Club connecting employees and IBD patients.

We started processing all ideas created at this event in order to help the participants make them happen for the benefit of the Israeli and global IBD community CCFI will help participants to promote and implement their ideas while share them with other IBD foundations and EFCCA.

Adam Elgressy, Patient experience leader, The Israel Crohn's Disease and Ulcerative Colitis Foundation - CCFI.

Eyal Tzur - Chairman, The Israel Crohn's Disease and Ulcerative Colitis Foundation - CCFI.

Tal Engel, MD, Department of Gastroenterology, Sheba Medical Center, Ramat Gan, Israel.

Uri Kopylov, MD, Head of IBD Service, Department of Gastroenterology, Sheba Medical Center, Ramat Gan, Israel.

Eyal Raffalovitch - Health coaching expert, Toot-Coach.



# Denmark

## CCF participates in Pride Parade

It's the first time that CCF Denmark decided to participate in the Pride Parade in Denmark this year. The first Parade took place in Aarhus, the second largest city in Denmark. CCF Denmark were placed in the last part of the parade alongside the worker union and the society for people with autistic diagnosis. Our chairwoman, the secretary and two other patient ambassadors participated.

A high and cheerful spirit was present amongst the participants which also was heightened by the cycling music stereo system, which blasted music from different areas. By participating in the parade CCF wants to encourage the message of basic human rights for all, and also by presenting CCF as a patient union that is inclusive for all.

Although CCF is a small union, we support our own, but we do also wish to show our support to the diversity and want to support equality of all people with diseases and diagnosis.

Our wish is to break the taboo about certain diseases, and by CCFs Denmark's presence in the Pride Parade we show that all deserve to be respected and heard for how they are, no matter what diseases.

The weather was a bit windy, but this did not discourage the people present, and later we thought the Egyptian sun god Ra showed a bit of support (we are not aware of any Nordic sun god).

The Parade is and will always be a festive march, but it is important to remember that it has not always been so, and this also resembles us that are afflicted by IBD.

It was a cheerful day, with focus on colours, joy, diversity, and where a decorative theme was implemented with balloons, bracelets, purple hairspray, ties, whistles (that also were thoroughly used).

Our black t-shirts with the CCF logo and text, attracted attention, and several people asked what it was. Mostly people knew of IBD, but it is important to continue to increase the knowledge about the disease.

By participating in the Pride Parade, we want to show that this is one step for setting IBD on the agenda in Denmark, while at the same time supporting a good cause.

The participants from CCF Denmark, concluded after the walk, that this was a good initiative that is worth repeating. CCF Denmark once again would like to thank everybody, who have participated in Aarhus, Aalborg and Copenhagen.

Charlotte R. Nielsen, chairman CCF Denmark  
Teitur Vágadal, secretary CCF Denmark



# Portugal

## Sexual dysfunction

We would like to share this important and insightful article about sexual dysfunction and IBD prepared by our psychologist, Jorge Ascensão, who runs regular features for the Portuguese IBD patient association APDI.

When you hear the expression “sexual dysfunction” (SD) what comes to mind?

Men with impotence? Erection problems? Ladies with “headaches”? Unwillingness to have sex?

Yeah! it seems we live in the 21st century, but not for everything. At least, when it comes to sexuality, we seem to be way back there. We do talk about sex more easily than before, but still! Do you know the expression “talk a lot without saying anything”? So, it's more or less like that. We use “sex” as the easy joke, to scare off or to get people's attention, but when the subject gets serious, when your turn comes to deal with it, we develop the “ability” to deflect the issue.

However, when it comes to Inflammatory Bowel Disease (IBD), this issue is unavoidable. You don't think so? You really think you can avoid dealing with a problem that can affect about 8 people out of ten with IBD?

Well, you could be right! Actually, sexual dysfunction isn't really discussed. On average, about 10% of the people with sexual dysfunction and IBD approaches this issue with their doctors. Although about 80% of people with IBD are suffering from SD.

On the other hand, health teams don't seem to be comfortable, or do not have enough time, or self-confidence to discuss the problem with their patients. So, if the patient doesn't talk about it, it's probable that we won't ask. There are a few times that this subject is approached.

However, as the patient isn't comfortable exposing his/her doubts, and/or sexual limitations, the usual

answer will be “I'm fine” and it all stays the same. It's like we feel humiliation, guilt or shame asking for help about our sexual needs. Almost thinking that sex isn't important to our health and quality of life.

“I've lost so much already, sex is just a whim” - we say to ourselves. So, from now on, I suggest that you read the rest of this in “whispering mode”. No joke! Sex is no longer a taboo, but it still is a “secret”, so I think whispering is more suitable to what we will read next.

We can't leave this matter at hands like this. Now we have to clarify all those questions you had back there: “How is it possible that there are so many people with IBD that suffers from sexual dysfunction?” Did you really think it was just you that suffered from SD? That you were just one of the “lucky ones”?

This way, you can start to learn more about this thing called sexual dysfunction.

According to WHO, sexual health is a state of complete physical, emotional and mental well-being associated with sexuality, and not only the absence of disease or impairment.

For example, the physical changes that directly impact our sexual response. The primary sexual dysfunction factors group. Here you can find intestinal dysfunction in general.

The abdominal pain so dominant in some cases of IBD, the flares, the diarrhoea, fistulae, gases, incontinence... You can also include in this group the decreased libido, erectile dysfunction and/or lack of lubrication that impairs and can limit sexual activity.

You can also have other factors (the secondary ones) that, being physical, and IBD related, can impact your sexual health in an indirect way. After all, who hasn't felt fatigue? Yes, I'm talking about that inexplicable tiredness that you don't know where it came from nor do you know when it's gonna be over. You just know that it's there and that it's so hard to explain to others.

Remember that muscle weakness or that localized/generalized pain that bothers you or even makes you forget you have sexual desires? They can fit in this group too. And, what about the psychosocial issues that can negatively alter your sexual function? Self-confidence, the way you see and/or think about yourself, and even the level of dependency that someone has with his/her caregiver.

If they could wear our shoes. Someday, sometimes, maybe, just maybe, they could see that we make sense after all, right? Like a patient was telling me the other day: "within half an hour he wants me to stop feeling dependent, and turn into some kind of sexual goddess?? How can I be good in bed if I feel frustrated about myself most of the time?"

Think to yourself: how well can you imagine a chronic disease patient, having quality and satisfying sex? And now, think about the way you feel about yourself. Our beliefs about sexuality in general and the beliefs you have about your own impairment are always "at risk".

Changes in the family status also matter. When you're on "medical leave" for too long, or when you just don't feel the same way when you're among your relatives, the way we think about, and approach, sexuality in a couple changes too. And remember that depressive mood and/or anxiety can affect anyone that lives with IBD, so it can also have an impact on their sexual life.

This is a delicate subject. Sexuality, and sexual dysfunction in IBD, is very challenging even for the medical staff or the research teams. There aren't many studies, and there's not sufficient funding for research on psychosocial subjects that doesn't involve drugs.

It's important that you know how many people deal with this kind of issue. You're not alone with it! Sexual dysfunction, in all of its variations, doesn't have to be chronic like your IBD.

For most situations it can be managed and treated so that you can have a healthy sex life just like you wanted. For instance, did you know that sometimes, discovering and trying new positions during sex can actually solve some of the issues described before? Did you know that there's a link between smoking and erection or lubrication problems? That sometimes discussing these problems with your doctor can lead to a change in the prescription, and that it could get you rid of your SD?

The first step? Talking about it! With your husband or wife, boyfriend or girlfriend, your doctor or your nurse, your psychologist. You can choose with whom you feel more comfortable with. Trust him/her/them! You'll feel lighter, closer to a solution, closer to having sex like you really deserve! Isn't IBD enough?



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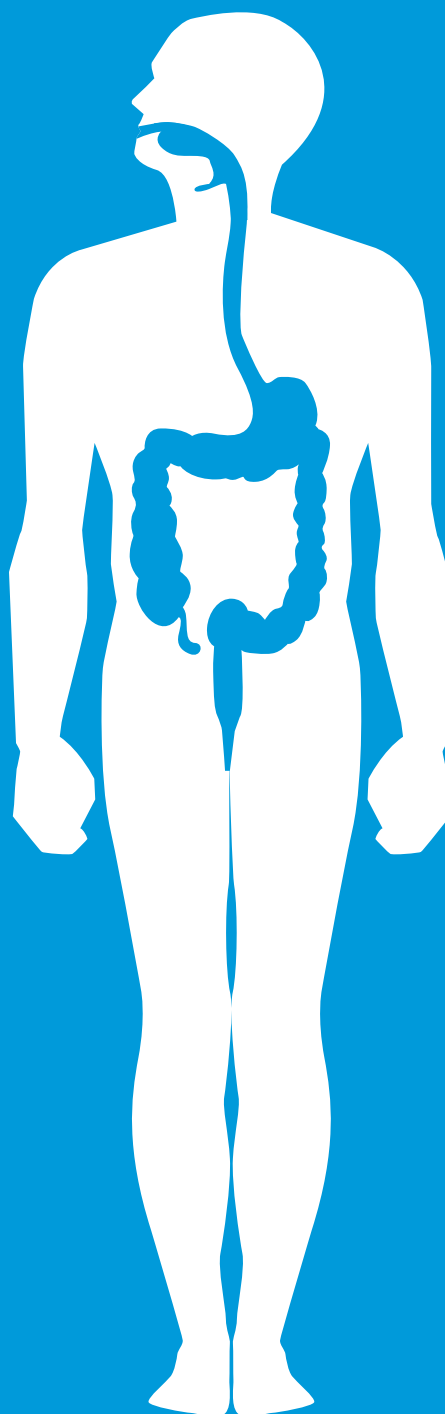
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# Making the Invisible Visible

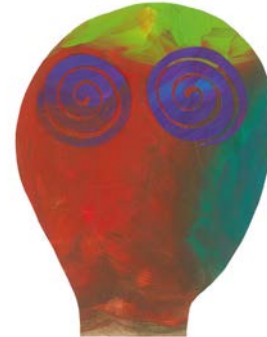
## IBD and Fatigue

Making the Invisible Visible was our recent collaborative project which aimed to explore what fatigue feels like for people with Crohn's and Colitis through the use of the arts. The project was supported by Kings Culture at Kings College London whose remit is to embed culture into its research through brokering relationships between artists and academics.

Dr Wladzia Czuber-Dochan at the Department of Adult Nursing at Kings College London had completed a PhD looking into the impact of fatigue on people with IBD's lives. Crohn's and Colitis UK were research partners in this project. The findings showed that often people felt their fatigue was invisible and they were imprisoned in their unreliable body. Artist Ali Winstanley is a specialist in Arts and Medicine and has a background working on a variety of arts, medicine and wellbeing projects across community and social care settings as well as in clinical institutions like Great Ormond Street Children's Hospital.

Wladzia had long been interested in using the arts to further explore the area of fatigue in IBD so we were both connected by the Kings Culture team as potential collaborators. From our first meeting it was clear there were many ideas we could pursue, and with Ali specialising in illustration we had an 'ideas storm' where we thought about all the potential outputs of a collaboration - from a book, leaflet or posters to an exhibition or workshop.

Through the collaborative process and ongoing discussions, we came to the conclusion that a series of illustrated flashcards, depicting physical and emotional elements of fatigue in IBD, might be the most straight forward, achievable and cost-effective output, as well as being something that could easily be duplicated and rolled out to help people on a wider basis.



**Like a zombie**

The overall aim became producing flashcards that could be used in clinical practice to help patients with IBD properly express their extreme and atypical experiences of fatigue, both to clinicians and also family and loved ones around them. We were keen that this 'invisible' symptom of fatigue could be made visible and tangible for those people experiencing it. The next step was to recruit participants for a patient group to explore their experiences of fatigue.

This was in October 2018 and took the format of a group discussion facilitated by Wladzia who gave clinical information about fatigue and IBD and with a peer support element, and a creative session led by Ali where participants were invited to further express and explore their particular sensations of fatigue first through brainstorming words and metaphors they connected to their symptoms and then by using coloured pens, paper and modelling clay to create visual representations of these.

Group members were encouraged to put finished artworks on the wall and a relaxed collaborative atmosphere was created, with no pressure for participants to have artistic skill, just to enjoy expressing themselves creatively and to keep creating as many images as they felt like. Ali also created artworks alongside them in response to some of the words and descriptions generated and to help foster a cohesive feel to the group.

At the end of the session, a discussion around the artworks produced was facilitated, with participants being invited to reflect and feedback on how they found the experience and what emerged for them.

Participants reported many positive effects at the end of the workshop, with the value of being really listened to and having a chance to express visually experiences they had felt were invisible misunderstood being deemed as particularly helpful. The peer support element was also reported as being extremely beneficial.

It was agreed that Ali would create the final flashcards based on ten of the words and phrases gathered from the workshop and Wladzia's previous research and try and incorporate when possible some of the imagery and visual ideas created by participants at the workshop. In January 2019, Ali then used what they had created to design hand painted collages depicting different physical and emotional experiences of fatigue, gaining feedback and approval from the patient group throughout the process.

The artworks were made into flashcards which the team plan to give to IBD clinics and make available to help people living with IBD to talk about fatigue to others.

There was also an exhibition of the original artworks and flashcards at Kings College on The Strand in London in February 2019, with participants from the patient group attending and with positive feedback about the final results.

Since then, we have seen the project being featured online by a variety of international Crohn's and Colitis organisations to tie in with World IBD Day in May 2019 and meant that audiences across the UK, Norway, Poland, New Zealand and Canada encountered the project.

We are now very keen to expand the project further - making the flashcards widely available to anybody who might find them useful in clinical practice, but also to further explore the potential of the arts in expressing the experiences of people with IBD.



*From left to right: Artist Ali Winstanley and Dr Wladzia Czuber-Dochan*

We are also very open to opportunities to share our experiences and findings from the project with international audiences and would love to hear from anybody interested in potential collaborations or in finding out more about the project.

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# Supporting people with Home Artificial Nutrition (HAN)

We are pleased to announce that the alliance of patient organisations from around the world supporting people who live with Chronic Intestinal Failure and Home Artificial Nutrition (PACIFHAN) is registered and ready to begin working for the benefit of Chronic Intestinal Failure and Home Artificial Nutrition (HAN) patients worldwide.



As an international non-profit association, PACIFHAN proudly exists for the benefit of all living with HAN. And by authentically presenting the patient and carer perspective, the Directors look forward to fulfilling PACIFHAN's mission which is "to work together to promote the international sharing of information and resources to improve the quality of life of HAN patients."

PACIFHAN is the International Alliance of Patient Organisations for Chronic Intestinal Failure and Home Artificial Nutrition, and already has members representing 10 countries around the world (Australia & New Zealand, Czech Republic, Denmark, France, Italy, Poland, Sweden, United Kingdom, United States of America), with more countries ready to join.

In the words of PACIFHAN's inaugural Chair, Monika Malickova, "the great value of PACIFHAN is that it brings together national leaders from around the world who either live with HAN themselves, and/or represent patients and carers living with HAN in various countries.

We are the patient voice in our home countries and together we form a trusted international reference on HAN from the patient perspective." In recent times, PACIFHAN Directors had concentrated their efforts on attaining registration in Brussels as an international non-profit organisation.

Now that this has been achieved, they are exploring options and opportunities to increase awareness of the realities of living with HAN and ultimately improving the quality of life of HAN patients.

World HAN Day has already been established as 15th October each year and PACIFHAN's Directors and members have begun planning for 2019 awareness campaign activities.

The Directors also invite ideas from other HAN stakeholders in order to raise visibility and recognition of this special Day.

World HAN Day will not be PACIFHAN's sole activity however. Monika adds, "PACIFHAN invites national HAN patient organisations and international HAN stakeholders to contact us. We envisage exciting opportunities to engage and add value to the international HAN conversation."

For more information, contact PACIFHAN's Chair, Monika Malickova at [info@pacifhan.org](mailto:info@pacifhan.org) or visit [www.pacifhan.org](http://www.pacifhan.org)

PACIFHAN Directors



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# Call for all sponsors to publish clinical trial results in EU database

The European Commission (EC), the European Medicines Agency (EMA) and the Heads of Medicines Agencies (HMA) have co-signed a letter reminding all sponsors of clinical trials conducted in the European Union of their obligation to make summaries of results of concluded trials publicly available in the EU Clinical Trials Database (EudraCT).

Transparency and public access to clinical trial results, whether positive or negative, are fundamental for the protection and promotion of public health. It assures trial subjects that their voluntary participation in clinical trials is useful and that the results have been collated and reported for the benefit of all. In addition, for those medicines which are placed on the market or used in further clinical trials, it allows patients and healthcare professionals, or any other citizen, to find out more information about medicines they might be taking or prescribing. Transparency also enhances scientific knowledge and helps to advance clinical research and support more efficient medicine development programmes.

It is the responsibility of sponsors to ensure that the protocol information and results of all clinical trials is submitted in EudraCT; this information is publicly available through the EU Clinical Trials Register (EU CTR). Since July 2014, sponsors are required to post results within one year after the end of a clinical trial (or six months for a paediatric trial). This information is also shared with the World Health Organization's (WHO) International Clinical Trials Registry Platform (ICTRP) of which EU CTR is a primary registry.

As of April 2019, the EudraCT database included 57,687 clinical trials in total, out of which 27,093 were completed.

Out of these completed trials, 18,432 should have had results posted; sponsors were in compliance with the publication requirements for 68.2% (12,577) of the trials, however results were still lacking for 31.8% of them (5,855).

The reporting compliance of non-commercial sponsors (e.g. academia) was much lower than for commercial sponsors (i.e. companies), with 23.6% of results posted for non-commercial sponsors vs 77.2% for commercial sponsors. Academic sponsors or smaller companies often lack awareness or incentives to post clinical results, therefore EU authorities are taking various steps to ensure sponsors are aware of their obligations and can act on them.

One of these initiatives is the "letter to stakeholders regarding the requirements to provide results for authorised clinical trials in EudraCT", co-signed by Anne Bucher, Director General of the EC's DG Health and Food Safety, Guido Rasi, Executive Director of EMA, and Thomas Senderovitz, Chair of the HMA Management Group. It will be disseminated to various stakeholder groups, with a goal in particular to reach academic sponsors. This should help to spread the word about the importance of making clinical trial results publicly available.

Amongst other initiatives conducted at EU level, EMA has since September 2018 been identifying trials with missing results on a monthly basis and sending reminders to the sponsors of those trials to ensure compliance with the transparency rules and their follow up on their results reporting obligations.





# Consensus report

## Clinical recommendations for the prevention and management of the nocebo effect in biosimilar treated IBD patients

Lieven Pouillon, Silvio Danese, Ailsa Hart, Gionata Fiorino, Marjorie Argollo, Carlo Selmi, Carmelo Carlo Stella, Damien Loeuille, Antonio Costanzo, Anthony Lopez, Elena Vegni, Simona Radice, Daniela Gilardi, Marie Socha, Maria Fazio, Marien González Lorenzo, Stefanos Bonovas, Fernando Magro, Laurent Peyrin Biroulet

This paper has recently been published in *Alimentary Pharmacology and Therapeutics*, Volume 49, Issue 9 (May 2019).

The aim of the report was to develop evidence-based consensus recommendations for the prevention and management of the nocebo effect in biosimilar-treated patients with IBD.

The nocebo effect is a negative effect of a pharmacological or non-pharmacological medical treatment that is induced by patients' expectations, unrelated to the physiological action of the treatment, which can negatively affect treatment outcomes.

In order to develop evidence-based consensus recommendations for the prevention and management of the nocebo effect in biosimilar-treated patients with IBD, a European consensus group aimed to review the literature and develop clinical recommendations.

The "NOCE-BIO Consensus Group" was composed of 19 members from five European countries and included gastroenterologists with expertise in IBD (7), pharmacists (3), oncologists (2), rheumatologists (2), methodologists (2) and one dermatologist, one psychologist and one nurse specialist in IBD.

A literature review on the nocebo effect in biosimilar-treated IBD patients, with specific focus on information about its prevention and management was performed. Based on the literature review, preliminary statements were formulated and voted on during a consensus group meeting held in Milan, Italy in July 2018.

The results of the consensus group meeting showed that the true burden of the nocebo effect in biosimilar-treated IBD patients is hard to estimate, but its prevalence rates in IBD patients switching from biologic originator to a biosimilar were higher than 10 %.

This was similar compared with patients with rheumatic disease and shows that the nocebo effect is still under-recognised.

The nocebo effect may also negatively impact on the cost-savings of biosimilars, since it can lead to unnecessary cessation of biologic treatment, thereby altering IBD patients' outcomes in clinical practice and in clinical trials.

The panel agreed that patient-health-care provider relationship is a key driver of acceptance of biosimilars, which limits the risk of negative bias and the nocebo effect. Lack of knowledge among patients and health-care providers about the effectiveness and safety of biosimilars should be minimized. Education about biosimilars need to be tailored to the individual patient, and positive framing is recommended. Future research should focus on the magnitude, the risk factors, the impact, and the management of the nocebo effect in biosimilars-treated IBD patients.

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