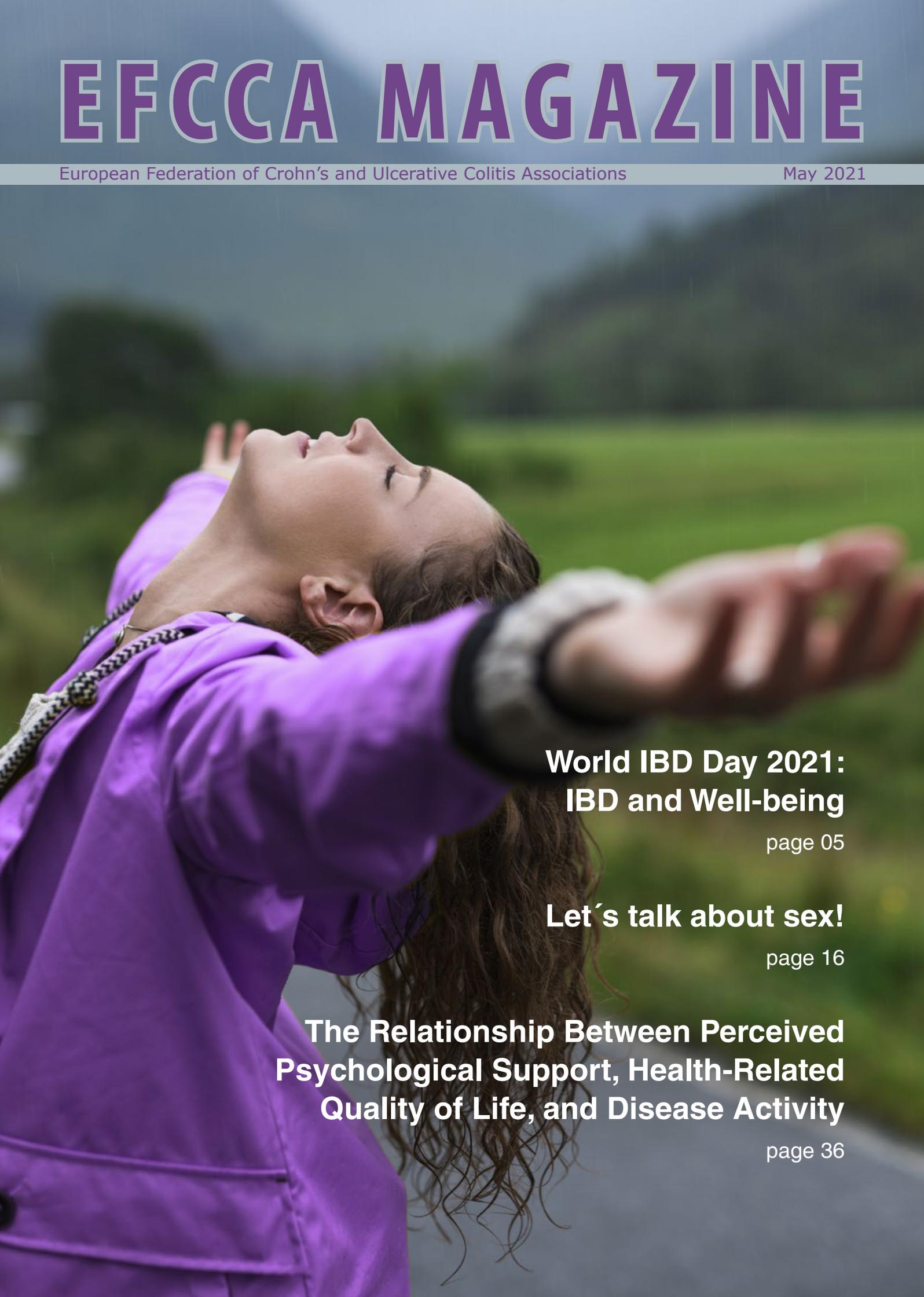


EFCCA MAGAZINE

European Federation of Crohn's and Ulcerative Colitis Associations

May 2021



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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.mccbe.hu

Iceland - CCU
www.ccu.is

Ireland - ISCC
www.iscc.ie

Israel - CCFI
www.ccfi.co.il

Italy - AMICI
www.amiciitalia.org

Latvia - LKKSB
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 - CCUVN
www.crohn-colitis.nl

Norway - LMF
www.lmf norge.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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Break the Silence

It is now the second time that we are going to celebrate World IBD Day during the current health crisis. COVID-19 has turned our lives upside down and it has been a challenging time for everyone but especially the IBD patient community that is experiencing the double burden of isolation. The isolation that the nature of the disease can inflict on people and the isolation imposed due to the social distancing measures that many countries have adopted due to COVID-19.

We might be prevented from gathering but it doesn't stop us to raise our voice! In this issue you can read about our #breakthesilence social awareness campaign for World IBD Day. That's exactly what we are aiming to do: to give people with IBD a voice and to make their struggles visible, to talk about what it is really like to live with the disease. I am very excited, and I look forward to hearing what our community has to say on that day! We will listen very carefully, and our aim is to take your message and the outcome of this dialogue to Health Care Providers and other decision makers in order to see how we can address the issues identified and help in a meaningful way.

With the emergence of various COVID-19 vaccinations, many of our members have requested more information as concerns the new vaccines in relation to IBD. EFCCA has responded by organising a specific EFCCA Patient Talk on this topic. It has been a great honour to have the President of the United European Gastroenterology, Axel Dignass and András Süle, President – Elect of the European Association of Hospital Pharmacists (EAHP) as guest speakers. It puts into evidence our important collaboration with medical societies and organisations that are united in their efforts to improve patient care.



“We might be prevented from gathering but it doesn't stop us to raise our voice! That's exactly what we are aiming to do: to give people with IBD a voice”

You will also find many examples in this issue of how our Members have courageously responded to the health crisis, showing their strength and persistence despite the many challenges to our daily lives. Throughout the months they have continued to provide essential support and be there for their community.

I would also like to mention and congratulate the group of patients that have dedicated their time and efforts to participate in our latest EFCCA Academy training on Clinical Trials which you can read about in the EFCCA news section. Thanks to the newly acquired skills and competences they can play a more significant and proactive role in supporting the design and implementation of clinical studies! Furthermore, they will be able to share their knowledge with their local IBD community.

Our priority theme for 2021, IBD and Well-being, is all about taking control of our quality of life. We do not have to accept a poor quality and it is not “part” of the disease. We need to strive for a good quality of care and a holistic approach to our disease treatment that looks at all aspects including psychological and general well-being so that we finally will be able to have a fulfilling life on all levels.

United We Stand,
Salvo Leone
EFCCA Chairperson

World IBD Day

How does IBD impact on you psychologically? What are the masks that you are wearing on a daily basis? How do you really feel? Are there things you would like to talk to your doctor about but feel there is not enough time, or it does not seem important?

People with Inflammatory Bowel Disease (IBD) might be reluctant to say how they feel deep inside and how the disease is affecting their psychological well-being. They might live with pain and think it's "just" part of the disease. They might feel bad about their self-image but do not talk about it. They might have a good medical score related to their disease, but their quality of life is still poor.

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.

This is why EFCCA has decided for World IBD Day 2021 to focus its efforts on the issue of IBD and Well-being. We want to start a dialogue and discussions on how IBD affects people not only physically but also psychologically and to shed a light on the various aspects of the disease.

Through a social media awareness raising campaign leading up to 19 May we want to show the hidden facts about what it is like to live with IBD. Under the hashtag #breakthesilence we want to invite the IBD patient community to talk about things they feel are not usually talked about as concerns their disease management.



IBD and Well-being

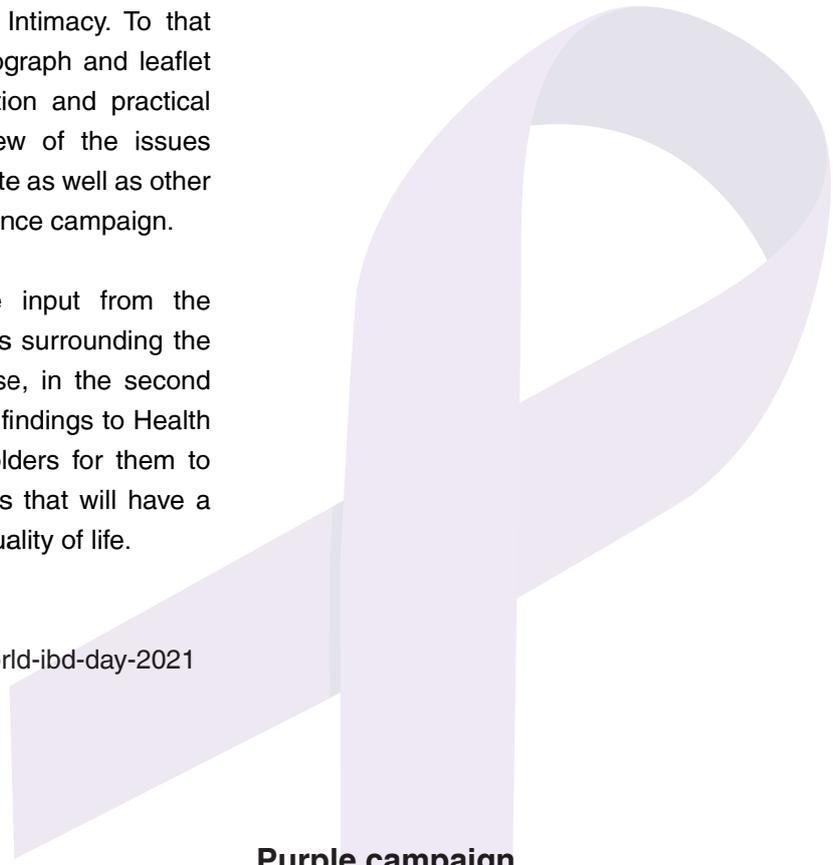


In particular, we want to initiate discussions around taboo subjects such as IBD and Intimacy. To that purpose we have prepared an infographic and leaflet with relevant background information and practical advice that gives a good overview of the issues involved. It is available on our website as well as other information about our #breakthesilence campaign.

Furthermore, once we have the input from the patient community about the issues surrounding the psychological impact of the disease, in the second half of 2021 we want 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



Purple campaign

Since 2012 EFCCA has been coordinating World IBD Day which is led by patient organisations representing over 50 countries on five continents. Over the years many other IBD organisations, IBD activists and stakeholders have joined our fight against IBD. More recently, countries have joined IBD awareness raising by illuminating famous landmarks in the colour of purple alongside the organisation of local events on either the 19th of May (the official date of World IBD Day) or around that date.

The EFCCA office is also distributing purple ribbons worldwide to be handed out at awareness raising events, doctor/patient meetings and other events aimed at promoting World IBD Day (of course permitting local safety requirements on COVID-19). The purple ribbon is the universal symbol of awareness and support for people living with IBD.

For more information and to read what is happening in the various countries please visit the official World IBD Day website at: www.worldibdday.org

EFCCA Patient Talk

COVID-19 vaccination and IBD

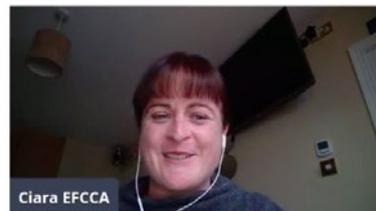
Our latest EFCCA Patient Talk looked at pressing questions around the new COVID-19 vaccinations in relation to IBD as well as its administration efforts across Europe. The webinar forms part of our EFCCA Patient Talk series which EFCCA initiated in response to the current pandemic and with the aim to provide useful and accurate information and to support our members.

In early 2021 the worldwide rollout of coronavirus vaccination has begun and so did many questions of our IBD community around this theme. “Are the coronavirus vaccines safe? How will the vaccines impact Crohn’s disease and Ulcerative Colitis? When will the vaccines be available for IBD patients?” these are just some of the questions that we had been receiving prior to the event which took place on 5 February 2021.

Our guest speakers included Prof. Axel Dignass, President of the United European Gastroenterology (UEG) discussing the potential concerns and implications around the COVID-19 vaccination with relation to Inflammatory Bowel Disease.

Our second speaker Dr. András Süle, President – Elect of the European Association of Hospital Pharmacists (EAHP), talked about COVID-19 vaccine programmes and the challenges that their implementation and administration will present when more vaccines will become available.

Our colleague Maria Stella De Rocchis presented the outcomes of the EFCCA survey on <http://bit.ly/COVID-19-vaccination-protocols> which EFCCA carried out amongst its members in mid-January 2021 in order to have a better picture of the situation in each of the members countries as concerned the availability of COVID-19 vaccines, the administration protocols and whether IBD patients were considered part of the risk groups within national priority vaccination programmes.



EFCCA Patient Talks

COVID-19 vaccination and IBD

Free Webinar

Join our discussions on COVID-19 vaccinations and IBD!

Guest speakers include:

Prof. Axel Dignass, President United European Gastroenterology (UEG),

Dr András Süle, President-Elect European Association of Hospital Pharmacists (EAHP)

More info: www.efcca.org

5 February 2021, 4 .30PM - 5.30PM (CET)

For more information and to watch the webinar please go to:

www.efcca.org/en/events/efcca-patient-talk-no-4

EFCCA Academy: Insights into Clinical Trials

The EFCCA training is almost coming to an end: 14 students from 12 countries who have enrolled in the Academy 2020 edition on Clinical Trials will soon receive their well-deserved Certified Patients Award.

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.

Patient engagement is increasingly recognized as essential to integrating the patient voice in the design and development of research on medicines. Various studies show a lack of knowledge and understanding of clinical studies amongst the public in general, amongst patients and even amongst some patients that are already participating in a clinical trial. That's why EFCCA thought that a training on clinical studies was necessary for our IBD community and we have worked hard to provide a comprehensive course.

Here is a summary of the 3 training modules:

1. Clinical trials: basics

Professors Séverine Vermeire and Marc Ferrante from the Department of Gastroenterology and Hepatology, University Hospitals Leuven / KU Leuven in Belgium opened the training explaining the different phases in the development of medicines, the revolution in IBD treatment over the years, the efficacy of clinical trials and the safety also in the real-world after drug approval.

2. Diving deeper into clinical trials

The second module gave students insights into all the players involved in clinical studies including aspects such as patient education and patients' role within these trials. Speakers included Annick de Bruin from the Center for

Information and Study on Clinical Research Participation (CISCRP), Rob Camp from EURORDIS, Rare Disease Europe and Ana Sofia Correia, Life Sciences & Medical Translator.

3. Breaking the myths around clinical trials

A lecture by Prof. Ariel Liebert from the Department of Gastroenterology and Nutrition Disorders, Nicolaus Copernicus University in Toruń (Poland) dealt with Clinical trials guidelines, benefits and risks related to participation, medical care in progress, participant's insurance, and what to ask before making a decision to join a trial. and what to ask before making a decision to join a trial.

The three modules were followed by an interactive discussion on how industry is collaborating with different stakeholders as part of the drug development process. For this purpose, representatives from Roche provided an insight of the different roles and functions of industries in these trials.

At the end of these modules, an exciting element of our training course will be a real-life simulation of a clinical trial allowing participants to bring the IBD patients' voice into the design of a clinical trial in order to make sure that patient's and caregiver's needs and expectations are covered.

Participants will be part of a patient committee organized by the pharmaceutical company Boehringer Ingelheim that will be established to advise on the conduct of each step of a clinical trial mock simulation and the interpretation of the outcomes.

We believe this training will provide an interesting opportunity to raise patient satisfaction with clinical trials, enhance IBD awareness and patient information and to support patient access to care and healthcare services.

“Thanks to the acquired skills and competences patients can play a significant and proactive role in their local IBD community when it comes to sharing knowledge on clinical trials”

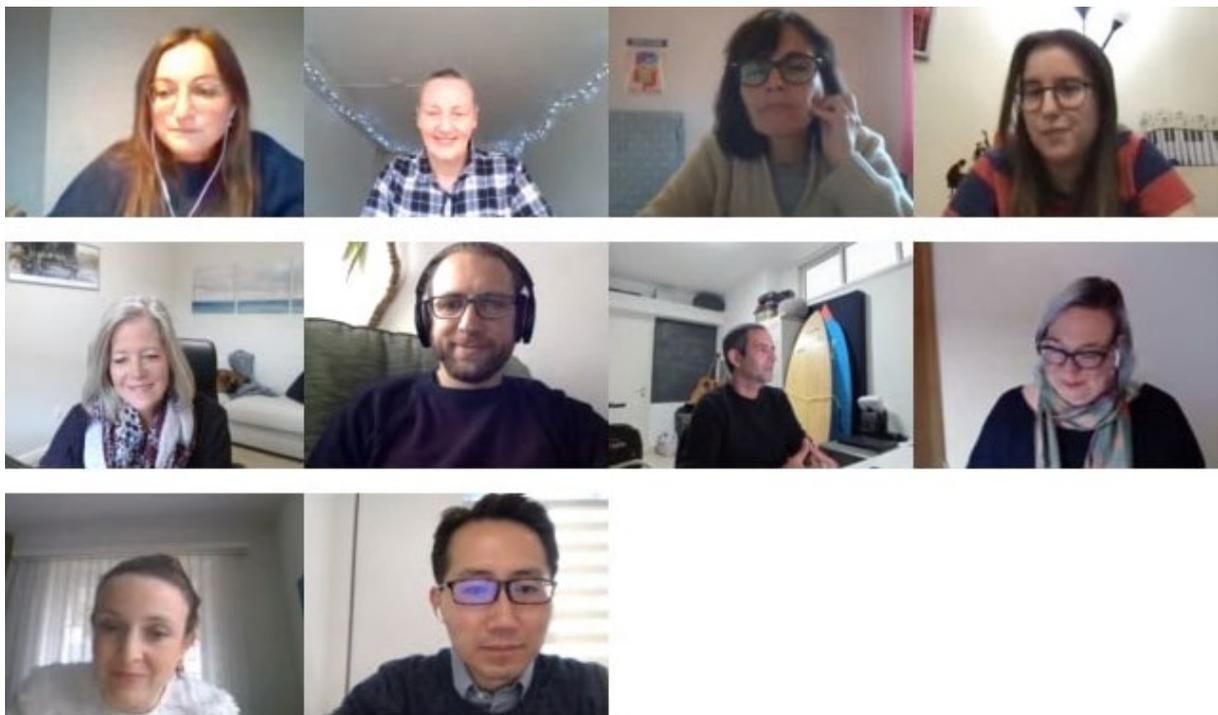
Thanks to the acquired skills and competences patients can play a significant and proactive role in their local IBD community when it comes to sharing knowledge on clinical trials. Therefore, in order to complete their training and validate themselves as Certified Patient in Clinical Trials, the students will now proceed to work on a final assignment.

We expect the Certified Patients to:

- share their knowledge among IBD communities in their country;
- teach member association representatives on the subject;
- play an active role with regards to cooperation with pharmaceutical companies at national level.

We will keep track of the students' projects publishing them in the following EFCCA Magazines. Some interesting and valuable ideas are already being implemented!

Maria Stella De Rocchis,
EFCCA European Project Officer



Student discussions with representatives from the pharmaceutical industry on how pharma is interacting with different stakeholders

New video animation on “Work and IBD”

As part of last year’s EFCCA priority theme on [Work and IBD](#) we have been developing a video animation which provides support and practical advice on a variety of issues related to employment and IBD.

The video forms part of the My IBD Journey animation series which is aimed at helping people to “live well” with IBD. These videos will equip people with practical advice and relevant information and hopefully will bring about positive changes to the way they cope with their disease.

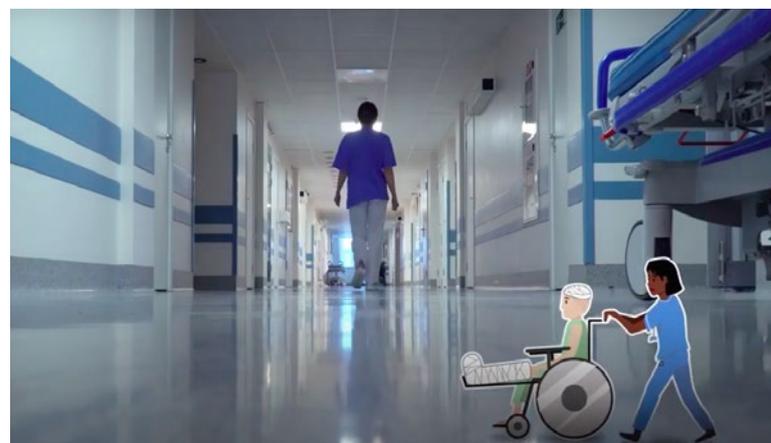
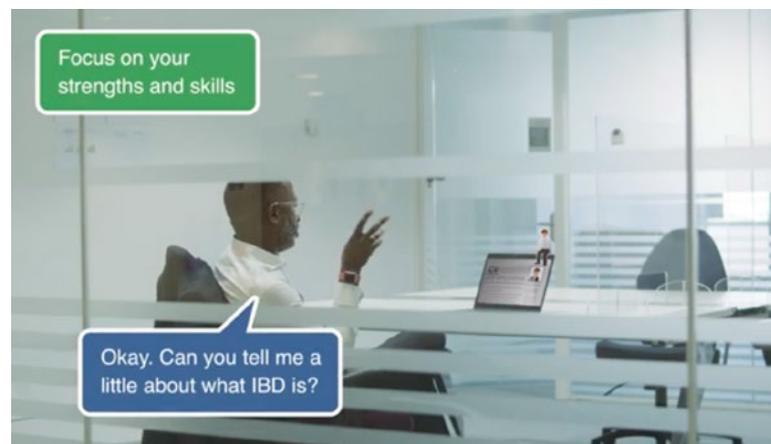
The content of the videos reflects the views and perspectives of real people with IBD in real life scenarios and the stories are positive and upbeat aimed at giving people confidence that they can live well with IBD. The videos target a diverse a diverse patient population and have been elaborated by a group of IBD patients, animation experts, EFCCA and Janssen who is supporting this project.

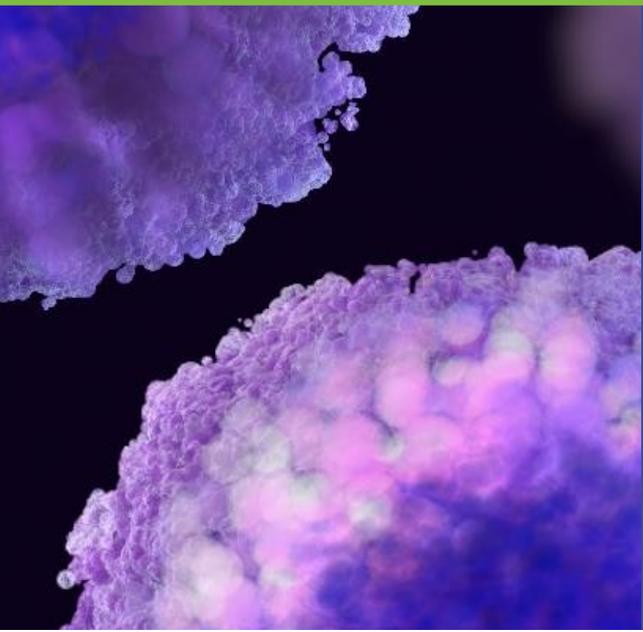
Considering that IBD is on the rise and mainly affecting young people of working age EFCCA decided that Work and IBD to be a priority theme in 2020. Our efforts were aimed to raise awareness of the impact IBD has on a person’s professional life and we showed that with some comprehensive strategies at the workplace (i.e. flexible working hours, teleworking etc.), a better understanding of the disease and a supportive work environment we can indeed make IBD work!

Specifically, the video highlights areas such as job hunting, having a rewarding work experience, how best to talk about your condition with colleagues and other practical advice about managing IBD at work.

To watch the video and more information please follow the link:

www.efcca.org/en/my-ibd-journey-ibd-workplace





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.

European Youth Group

Education should be accessible to all – including IBD patients

Many IBD patients have been diagnosed at a young age. During the ages 15 to 35 many find their first job and go through multiple education degrees. With a chronic disease, managing life can be really challenging! Bathrooms can be unavailable during exams and leaving your house to go to a lesson may prove to be a real challenge.

And even though some educational institutions might offer a wide range of support, your problems with IBD can be difficult to share with the staff of the education centre. Very often students are also not aware of what kind of support they are entitled to.

That's why we, the EFCCA Youth Group, decided to focus on this theme. We want to highlight challenges that students face, but also map different types of support that universities and education centres offer across Europe.

We decided to start mapping from the sources and asked young IBD patients what they thought their major problems in relation to education and IBD were. We created a survey for 15-35-year-old students with questions such as “what kind of support their education institution offers”, “whether they are eligible for receiving support” etc., just to mention a few.

The survey was launched in autumn 2020, and we have received answers from all levels of education from first-degree education to PhD. The education survey was translated into multiple languages, including Serbian, Spanish, English, German, Finnish, Greek, French and Slovenian. By translating the survey, we sought greater reach and significance. And it paid off. In total, over 500 respondents answered our education survey. That's more than we ever expected.



Image by [StockSnap](https://www.pixabay.com) from www.pixabay.com

We have made a preliminary screening of the results. According to the answers, young IBD patients face a wide range of problems when combining education and IBD. The disease makes them miss lessons and exams, face a lack of confidence and motivation, and even totally interrupt their studies. It seems that these issues have had a strong or medium impact on respondents' final grades. The answers suggest that respondents need flexibility in their studies, more support, and a better understanding of their conditions. A more detailed and extensive analysis of the survey data will show us what aspects we will be focusing on in our education project. Our main goal is to share our information with education centres and universities so that they can take better into account the need of IBD patients.

Our next step is to analyse the data with thorough care, to find correlation between the state of health and the impact on the studies and on social life, etc... Once this is done, we will start the final part of our project: improving the situation of IBD patients in education by providing material and good practices to all the actors of our education systems. More information will come on the survey results along the year.

The EFCCA Youth Group



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

Netherlands

All you need to know about IBD medicines

Crohn & Colitis NL recently launched a new infographic about IBD medication. The infographic shows the different steps in medication treatment. No long pieces of text, but illustrations and short explanations with the most important information.

IBD medicines are used in two phases: induction treatment with the aim of calming the disease, maintenance treatment with the aim of keeping the disease at bay.

Which medicine you receive depends on various factors such as:

- Previous experience with medication
- Severity and location of inflammation
- Complaints other than the gut such as skin abnormalities
- Planning to have children
- Complications such as fistulas or strictures

Medicines are usually prescribed in a specific order.

1. In a step-up approach, milder drugs are given first, such as mesalazines.
2. In a top-down approach, the most powerful drugs are given first, i.e. biologics.

Biologics: most powerful medicines

Immunosuppressants: powerful medicines for severe complaints

Corticosteroids: work throughout the body

Mesalazines: act locally on the inflammation

The severity and location of the disease determines which approach works best for you.

Your role in the decision

Together with your doctor, you decide which treatment and medication is best for you.

- Discuss your expectations
- You play an important role in this decision

Medicatie

Ziekte van Crohn, colitis ulcerosa (IBD)

Medicijnen voor IBD worden in **twee fases** ingezet:
Inductiebehandeling met als doel de ziekte **rustig te krijgen**.
Onderhoudsbehandeling met als doel de ziekte **rustig te houden**.

inductiebehandeling
rustig krijgen

onderhoudsbehandeling
rustig houden

Welk medicijn je krijgt is afhankelijk van verschillende factoren.

Eerdere **ervaring** met medicatie

Ernst en locatie van ontsteking

Klachten **buiten de darm** zoals huidafwijkingen

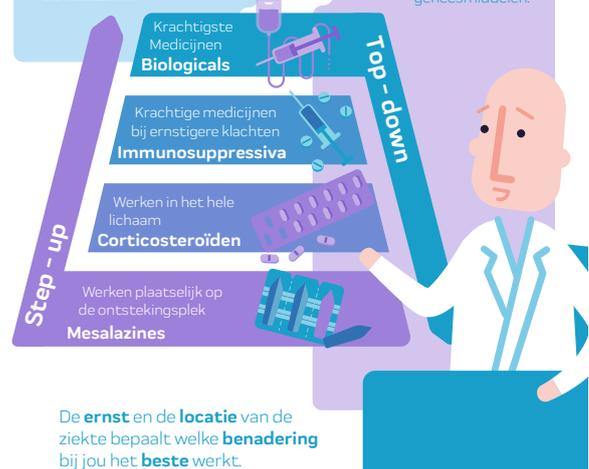
Kindervens

Complicaties zoals fistels of vernauwingen

Medicijnen worden meestal in een bepaalde volgorde voorgeschreven.

Bij een **step-up** benadering worden eerst **mildere medicijnen** gegeven, zoals mesalazines.

Bij een **top-down** benadering worden eerst de **krachtigste medicijnen** gegeven, de biologische geneesmiddelen.



Jouw rol in de beslissing

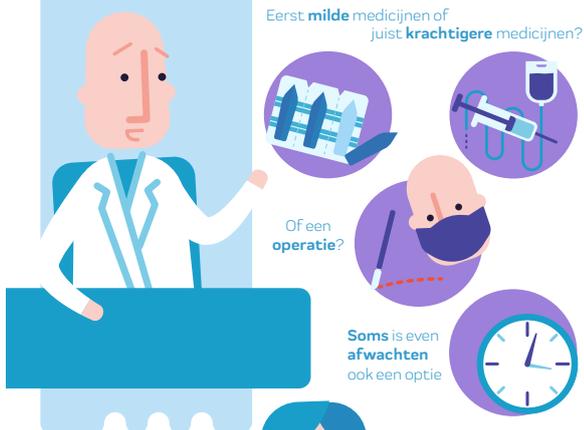
Samen met je arts maak je de afweging welke **behandeling** en **medicatie** het beste **bij jou** past.

Bespreek je **verwachtingen**.

In deze **beslissing** speel **jij** een belangrijke rol.

Drie goede vragen om te stellen:

Wat zijn mijn mogelijkheden?



Wat zijn de voor- en nadelen?



Wat betekent dat voor mijn situatie?



Bespreek ook andere onderwerpen met je arts.



Three good questions to ask:

1. What are the possibilities?
Mild medicines first or more powerful medicines?
Or an operation? Sometimes waiting is also an option.
2. What are the pros and cons?
3. What does that mean for my situation?
Sports and travel, home situation, professional life and wishes

Also discuss other topics with your doctor such as:

- Experience with medicines
- Travel and vaccinations
- Dietary Supplements
- Other complaints

Discuss the details of your treatment with your doctor and take medication appropriately.

- Regularly at fixed times
- The right dose
- Don't just skip or stop

Contact your doctor if you are unsure or concerned about possible side effects.

You will find the most important information about this in the package leaflet or leaflet of the medicines and also how often they occur. Side effects are annoying, but there is always a chance of side effects from all your medications.

More information: www.crohn-colitis.nl
Do you have any questions? info@crohn-colitis.nl

Poland

Let's talk about sex

The Polish Association Supporting People with IBD "J-elita" was the first in Poland to speak out loud about IBD and sex.

Poles with IBD have no place to learn about their disease and sexuality. There are no educational materials or guidelines on this subject, patients are ashamed to ask doctors about sex, and doctors do not have time and are not prepared to talk with patients about such topics. That is why "J-elita", as the largest organization supporting people with IBD in Poland, in cooperation with Takeda company, decided to break the taboo.

At the beginning, two programs were created as part of the IBD Podcast project. The first program, with a psychologist working with patients in the gastroenterology ward of a hospital in Gdańsk, was dealing with the subject of emotions. We talked about patients' fears and anxieties about intimacy, the feeling of shame about their appearance changed by disease, drugs and surgery, and about accepting

our bodies. We also talked about relationships with partners and how a person with IBD could talk to them about intimate matters. We asked what we could do to feel comfortable during intercourse and enjoy sex, both in straight and non-heterosexual relationship.

In the second episode, we talked to a gastroenterologist working in the most famous gastroenterology ward of a hospital in Warsaw, the capital of Poland. The audience heard answers to questions about contraception that is safe for patients with IBD and how to relieve pain during intercourse. Our expert talked about sex related to patients with fistulas and stoma, anal sex and intercourse after bowel surgery. Both episodes were conducted by the spokesperson of "J-elita". Podcasts can be listened to on the most popular podcast platforms as well as on YouTube and Spotify.



NZJ
PATIENT
EMPOWERMENT
ACADEMY

Chcę
wiedzieć

J-elita

Stowarzyszenie
APETYT
na życie

EuropaColon
Polska

ŁÓDZCY ZAPALEŃCY

Zapraszamy na pierwszy webinar z cyklu
"NZJ - Chcę wiedzieć. Patient
Empowerment Academy"

Seksualność w NZJ

PIĄTEK, 19 LUTEGO
GODZ. 19.00

DOŁĄCZ

Eksperti

lek. med. Magdalena Kaniewska
prof. Zbigniew Lew-Starowicz

Gość specjalny

Agata Młynarska

The third part of the discussion was a webinar with the participation of a well renowned sexologist and psychologist in Poland, a gastroenterologist and a special guest - a popular TV journalist with Crohn's disease, who talked about her relationship, acceptance of her body and life with the disease.

The sexologist told, amongst other things, which sexual positions may be most comfortable for people afraid of abdominal pain, the doctor discussed the influence of medication and the disease on potency and how to prevent embarrassing mishaps, e.g. related to fecal incontinence.

The audience was welcomed by the president of the "J-elita", Agnieszka Gołębiewska, and the talks were moderated by our spokesperson and our representative in the EFCCA Youth Group Olga Gołębiewska.



The lectures and discussion took place as a part of the project "IBD - I want to know. Patient Empowerment Academy". Its co-organizer and patron was Takeda, and partners were three other organizations supporting patients with intestinal diseases.

Podcasts and a webinar are available on the "J-elita" website and they are very popular. The webinar video has almost 11,000 views.

Jacek Hołub
"J-elita" Association

Brazil

What does IBD have to do with your liver?

The Brazilian National Association of Patients with Inflammatory Bowel Disease (DII BRASIL) and the Brazilian Liver Institute (IBRAFIG) have launched a campaign on Instagram to provide information about liver and biliary manifestations in IBD.

Hepatobiliary diseases are underdiagnosed in IBD patients, and their presence may impair prognosis and quality of life. Approximately 1/3 of the patients with IBD have abnormal liver enzymes at least once in their lifetime, mostly due to transient hepatotoxicity. This is one of the reason why the Brazilian Liver Institute (IBRAFIG) and the Brazilian National Association of Patients with Inflammatory Bowel Disease (DII BRASIL) cooperated together to provide information through an Instagram campaign ("@tudosobrefigado" and "@diibrasil") in order to raise awareness about liver and biliary manifestations in IBD.

An Instagram® live took place on 9 April 2021, allowing followers to engage with specialist physicians by open questions. The meeting was well attended and a huge success.

About liver and IBD¹

Non-alcoholic fatty liver disease is the most common liver disease in IBD, while primary sclerosing cholangitis (PSC) is the most specific. In this regard, 60% of the Brazilian patients with PSC have IBD and 4% of those with IBD have PSC. PSC can cause serious complications, increase the risk of colorectal cancer and may lead to cirrhosis. Occasionally, some patients may develop drug-induced liver injury, since many medications used in IBD are hepatotoxic. Methotrexate, azathioprine and anti-TNF-alpha carry the higher risk for hepatotoxicity, and, in many cases, a simple dose adjustment may normalize the liver biochemical tests. Reactivation of hepatitis B virus with immunomodulators or biologics is also a major concern, and adequate screening and vaccination, should be warranted prior to treatment. Furthermore, the relationship between IBD and gallbladder stones has been well recognized, especially in Crohn's disease, with a prevalence of approximately 35%. In order to minimize liver-related diseases, people living with IBD should be counseled to adopt a healthy lifestyle.

1. *Guilherme Grossi Lopes Cançado*
(Gastroenterologist and Hepatologist, member of Scientific Council DII BRASIL and IBRAFIG - Hospital das Clínicas, Universidade Federal de Minas Gerais; Hospital da Polícia Militar de Minas Gerais, Belo Horizonte, Brazil)

Patrícia Mendes (President of DII Brasil - Belo Horizonte, Brazil)

Paulo Lisboa Bittencourt - on behalf of DII Brasil and IBRAFIG (Hepatologist and President of IBRAFIG - Hospital Português da Bahia, Salvador - Brazil)

Some tips are listed below:

- Maintain adequate body weight;
- Eat a balanced diet (avoid highly processed foods, which are rich in refined carbohydrates, saturated fats and fructose; avoid added sugar and salt);
- Practice regular physical activity - at least 250 minutes per week;
- Avoid alcohol ingestion (no more than one alcoholic drink per day for women and two drinks per day for men);
- Drink coffee and eat dark chocolate regularly - some studies have shown benefits for the liver;
- Avoid over-the-counter medications including herbal and dietary supplements;
- Adhere to routine clinical and laboratory visits scheduled by your doctor.

Campaigns to raise awareness within the IBD community about the relationship of IBD and liver are important that's why we want to further work on this during Purple May 2021 ("Maio Roxo").

Remember that, in general, what is good for your gut is good for your liver!

Cyprus

“Walking by the sea for IBD”

The Cyprus Crohn's and Ulcerative Colitis Association (CYCCA) organized a Hiking Day on Sunday, April 4, 2021 in the town of Limassol. The purpose of this activity was to promote the slogans of EFCCA “Break the Silence” and “Make the invisible visible”, in an effort to help our patients get out of their shell and to

talk about their illness and their relative feelings.

We also aimed to make society aware of Crohn's and Colitis and to make people more sensitive about these chronic illnesses. At the same time, we tried to raise funds for CYCCA and to claim the rights of our patients.

The Hike took place under the auspices of the Director of Volunteerism of Cyprus. The route was along the seaside front, from the Eastern part of Limassol up to the Old Port of the town. The distance covered was 12 km and participation was excellent, easy on a pleasant and sunny day.

This initiative started from Mr Alexis Sofocleous, a philanthropist and candidate for the European Citizen Award for this year, who was leading the hiking team. It's worth noting that Alexis, under the slogan "Cyprus step by step", has walked around Cyprus, covering more than 1000 km so far.

Present at the activity were also the Director of Volunteerism of Cyprus, 2 Mayors, 6 Members of Parliament, the President of the Federation of Patients' Associations of Cyprus, a representative of the European University of Cyprus, journalists, TV and radio representatives and professional photographers. Overall, it was a successful and heart-warming event which demonstrated once again what can be achieved despite the difficult circumstances we are all facing due to the pandemic.



Italy

Creation of a Parliamentary Intergroup for the protection of IBD patients

On 31 March 2021, at the Italian Senate, a Parliamentary Intergroup for the protection of IBD patients was established with the aim to ensure the constitutional right to health and to improve the quality of life of the over 250.000 people affected by these diseases in Italy.

This Parliamentary Intergroup is of high institutional value and provides an effective way for the national IBD patient association AMICI Onlus, together with the scientific societies, to have a better influence in the decision making process on healthcare putting IBD patients' need on the political agenda.

The Parliamentary Intergroup includes all Italian Chamber and Senate political parties and seeks to work together to identify legislative actions in order to help people with IBD and their caregivers both physically, morally and psychologically.

“Thanks to this Intergroup” said Senator Maria Rizzotti “we will be stronger, and we will make a good team, there are no ideological or political exclusions because health is for all.”

Deputy Minister Pierpaolo Sileri declared: “Research, prevention, education and investments are fundamental to help and cure IBD. I am sure that the Parliamentary Intergroup will be crucial both with specific amendments and with pressuring the government in order to implement protective measures for the sake of IBD patients”.

The former President of the AMICI Onlus, Enrica Previtali was pleased with the foundation of the Intergroup saying that it “underlines the importance for patients to have the Institutions at their side so as to not feel alone”. The Parliamentary Intergroup was presented during an awareness event organized by AMICI Onlus aimed to raise awareness on Healthcare Associated Infections.



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United Kingdom

Crohn's and Colitis Care in the UK: The Hidden Cost and a Vision for Change

On 27th April, the [IBD UK](#) alliance, chaired by Crohn's & Colitis UK, released a report about the quality of care for people with IBD across the UK. "[Crohn's and Colitis in the UK: The Hidden Cost and a Vision for Change](#)" presents the findings from a unique assessment of care against the IBD Standards 2019, from the perspective of over 10,000 people with IBD and more than 70% of IBD services.

IBD UK is a partnership of 17 professional bodies, royal colleges and patient organisations working together to improve treatment and care for people with IBD. Its aim is to ensure that everyone with IBD receives safe, consistent, high-quality, personalised care, whatever their age and wherever they live in the UK.

Since its formation in 2017, IBD UK has developed the third iteration of the [IBD Standards](#), which defined high-quality care, and the IBD Benchmarking Tool, which enables care to be assessed by both patients and clinicians. Based on the IBD Patient Survey and Service Self-Assessment, carried out between July 2019 and January 2020, reports for local IBD services were published in March 2020 and are available from www.ibduk.org.

The national report reveals a concerning picture of IBD care, with delays to diagnosis, investigations and surgery and a lack of holistic multidisciplinary care. This is leading to high levels of costly emergency care. The impact of the COVID-19 pandemic has worsened these serious problems, despite the positive work of staff and services throughout.

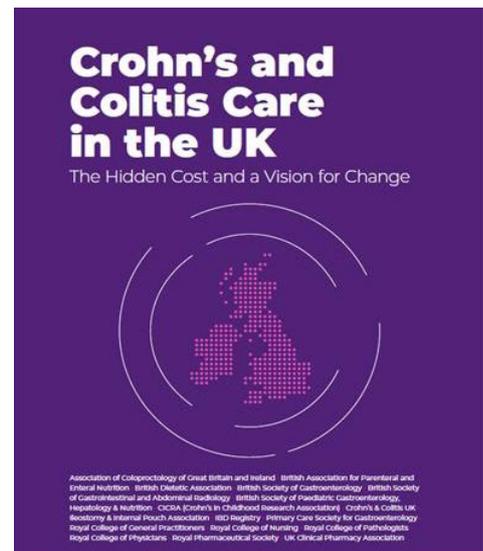
The report highlights some examples of excellent practice and calls for a different approach to the delivery of services. The recommendations call for action from political decision makers across the four UK nations, as well as NHS managers, IBD services, health professional associations and patient organisations.

The vision set out has the potential to transform IBD care for the estimated 500,000 people living with IBD across the UK, offering greater value for the NHS and vastly improved experiences and outcomes for people with Crohn's and Colitis.



IBD UK launched the report at a virtual launch event alongside an action for supporters to email their local politician and will be working to promote change over the coming months.

For more information, visit www.ibduk.org and Improving care & services Crohn's & Colitis UK (crohnsandcolitis.org.uk)



Austria

Our latest Initiatives

#makeitvisible

In 2020 our association the “Österreichische Crohn Colitis-Vereinigung (ÖMCCV)” launched the campaign #makeitvisible involving a photo shoot showing the “bare facts” of unveiled bodies.

It was remarkable to see how people deal with their fate by courage and self-confidence. And it is unbelievably impressive how twelve men and women showed their bodies with all their scars from operations or carrying a stoma.

Throughout their life many of them had to face setbacks and difficult challenges, but even so, it seems that the disease has made them even stronger. The photos of these twelve people and their personal stories were published via Instagram @cedkompass. But we want to do much more with these life-pictures, we want to produce a magazine and an exhibition gallery this year.



Credits: Barbara Wirl

“Brain Work and Bowel Feeling” - Survey and Conclusion

“How a person feels living with IBD” was the theme behind a survey with which we wanted to start a discussion amongst our society and representative from the healthcare system.

We identified as an unmet need the fact that despite better therapy within the last years, people with IBD still cannot lead an unrestricted life.

The analysis of the findings of the survey resulted in a detailed report. Data shows a deficit in the quality of life of IBD patients not only physically, but also mentally,

financially and at the workplace. 18 % of respondents were affected most severely. The outcome of this project “Brain work and Bowel Feeling” was presented at three different round tables with IBD-experts and representatives of healthcare care, political and social departments offering the chance to pave the way for structural and social reform.

Such reforms are urgently needed in order to improve IBD patients’ well-being as well as reduce the economic burden. We keep you posted!

Apps for IBD-Coaching

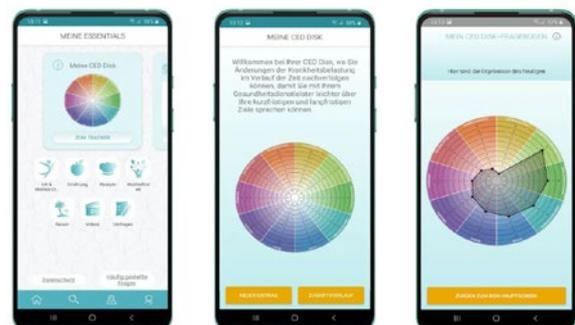
In order to work on the theme of “IBD and well-being” which is also EFCCA’s priority theme for World IBD Day 2021 we have designed an app aimed to reach specifically youngsters.

This app called “Sidekick” was developed as a personal 16-week coaching program guiding users into sports and mindfulness exercises with many tips around “living with IBD”.

Another helpful app “For You, With You“ gives advice on personal well-being and nutrition and functions as well as a reminder for injection’s date, medical appointments or for monitoring your disease.

Nutrition Booklet

Together with a gastroenterologist for IBD and a dietician the ÖMCCV released a nutrition booklet explaining “clinical nutrition” which is aimed at the phase during an acute flare-up when our body needs essential nutrients. It also gives a general overview around food and essential nutritional ingredients. To make it an enjoyable experience the booklet provides practical recipes, most of which are considered “favourites” amongst our big IBD-Community.



Christine Gmeinder
ÖMCCV - Editorial Office
Austrian Crohn's Colitis Association www.oemccv.at

Finland

Our association is now called “IBD and other intestinal diseases” (IBD ja muut suolistosairaudet ry)

We have changed our name. Our target group has now expanded from Inflammatory Bowel Diseases to other intestinal diseases which is now also reflected in the name of our association.

Changing our name was made possible through a change in our constitution. The meeting in which the constitution change was discussed was supposed to be held in the spring last year but because of the COVID-19 pandemic it was moved to the next Annual General Meeting which took place in autumn. In this meeting, Finland’s Crohn ja Colitis ry entered a new chapter in its history, as the name of the association is now IBD and other intestinal diseases. The new name was chosen from suggestions collected from our membership in late 2019.

“The name of the association must describe the association and especially the membership now and the membership in the future. Thus, the change was necessary”, summarizes Jarkko Lignell, the Chairman of the Board.

The association for Crohn’s patients was originally founded as a sub-group of Finnico, an association for patients who had stoma surgery. Later the association separated from Finnico as Crohn ja Colitis ry. More patients with ulcerative colitis and other intestinal diseases started joining the association.

“The name Crohn ja Colitis ry served us well, but lots of things have changed in the past years. We have received wishes for widening the target group and access to information, peer support and lobbying from both patients and health care personnel. The need for peer support and correct information will continue to grow”, says Executive Director Ulla Suvanto.

The current target group is wide: currently, the target includes, apart from Inflammatory Bowel Disease (Crohn’s disease and ulcerative colitis), microscopic colitis, short bowel syndrome, Irritable Bowel Syndrome, congenital chloride diarrhea, diverticulosis and bile acid diarrhea.

Something new, something old, something purple

Despite the name change, the website of the association remains www.ibd.fi. The graphic representation also stays the same, apart from the logo.



Information regarding each illness is offered on the website and in printed patient guides. The information provided in the member magazine and social media will be kept diverse and comprehensive. Live lectures on various illnesses, given by experts, will be regularly offered on our Facebook page giving patients the opportunity to discuss with those experts.

“Although the intestinal diseases are different, many things that patients face in their everyday life are similar regardless of the illness”, adds Suvanto.

In peer support, all intestinal diseases will be taken into consideration. Peer support will be offered face-to-face as well as online.

“Local peer meetings, for example, are open to everyone with an intestinal disease, and the peer groups on Facebook will function in a more targeted way as previously” says Peer support coordinator Leena Tuutijärvi. “Our wish is that more and more patients with an illness other than IBD will join as volunteers, for example as peer support persons. The volunteers trained by the association are in a key position to enable peer support.”

Renja Nikula

EU4Health programme enters into force

Following the European Council adoption on 17 March and the vote on the programme by the European Parliament on 9 March the EU4Health programme finally came into force on 26 March 2021 with €5.1 billion being made available to strengthen the resilience of health systems and promote innovation in the health sector in the European Union.

EU4Health will make a significant contribution to the post-COVID-19 recovery by making the EU population healthier, supporting the fight against cross-border health threats and boosting the EU's preparedness and capability to respond effectively to future health crisis, as part of a future strong European Health Union.

Stella Kyriakides, Commissioner for Health and Food Safety said: "As of today, we start charting a new course for EU health policy. The entry into force of our EU4Health Programme will give us the tools at hand to make long-standing changes in public health. This unprecedented budget of €5.1 billion will enable us to make targeted investments to enhance our crisis preparedness and build stronger, more resilient and more accessible health systems. This is what our citizens rightfully expect from a European Health Union."



The EU4Health Programme is an ambitious and dedicated funding programme for 2021-2027 to ensure a high level of human health protection in all Union policies and activities in keeping with the One Health approach. The Programme, proposed by the Commission on 28 May 2020, is the EU's response to COVID-19, which has had a major impact on medical and healthcare staff, patients and health systems in the EU. EU4Health is the largest EU health programme ever in monetary terms and will provide funding to EU countries, health organisations and NGOs.

EU4Health aims to:

- Improve and foster health in the Union;
- Protect people in the Union from serious cross-border threats to health;
- Enhance the availability, accessibility and affordability of medicinal products, medical devices and crisis-relevant products;
- Strengthen health systems, their resilience and resource efficiency.

Next steps

The programme entered into force on 26 March, when it was published in the EU's Official Journal. The first work programme for 2021 will be adopted and rolled out by the Commission following consultation with Member States in the EU4Health Steering Group as set out in the EU4Health Regulation. The programme will be implemented by a new executive agency, the Health and Digital Executive Agency, that started on 1 April 2021.

For more information:

https://ec.europa.eu/health/funding/eu4health_en



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IAPO supports the #TeamVaccines campaign

The International Alliance of Patient Organisations has joined the #TeamVaccines, a global digital campaign designed to build confidence in COVID-19 vaccines launched by the International Federation of Pharmaceutical Manufacturers & associations (IFPMA).

The campaign tells the human stories of real people involved in the making of COVID-19 vaccines; people from around the world who work within the biopharmaceutical industry and who have been affected by the global pandemic in many of the same ways everyone has - balancing work and home schooling, supporting family members and friends, dealing with illness and loss - all the while working to help advance science and urgently bring new COVID-19 vaccines to the world.

The biopharmaceutical industry, academia, governments and regulators have come together to rise to the challenge of our age. We have accelerated R&D and delivered vaccines in record time and are making vaccines in huge numbers that have not been seen before. But we are doing it in the way we always do - to the highest of scientific and regulatory standards. The #TeamVaccines campaign shows how the biopharmaceutical industry embraces rigorous independent scientific evaluation and robust independent approval processes.

Not just scientifically, but also in the way the COVID-19 vaccines are being produced, distributed and monitored.

#TeamVaccines is all of us united by a shared goal: end the suffering, protect the ones we love, and help the world get back to normal. We invite to view the content and share widely among your networks.

More info:

www.iapo.org.uk/news/2021/mar/8/iapo-joins-teamvaccines-campaign



Crohn's and Colitis Canada launches new PACE Project in partnership with the University of Manitoba

Crohn's and Colitis Canada is pleased to announce Dr. Charles Bernstein and Dr. Lesley Graff at the University of Manitoba will join the Promoting Access and Care Through Centres of Excellence (PACE) network with their research project: Integrating psychological and nutritional interventions for patients with IBD.

Launched in 2016, the Crohn's and Colitis Canada PACE network is the first national network of IBD Centres of Excellence, with each centre housing a multidisciplinary team that specializes in the treatment and management of Inflammatory Bowel Disease (IBD). The teams at five leading IBD Centres – Sinai Health System, McGill University Health Centre, McMaster University Medical Centre, University of Calgary, and the University of Alberta – work to advance best practices for healthcare professionals and elevate the standard of care received by Canadians living with IBD.

Dr. Bernstein, Director of the Inflammatory Bowel Disease Clinical and Research Centre at the University of Manitoba, and Dr. Graff, Professor and Head of the Clinical Health Psychology Department at the University of Manitoba, are joining the PACE network to find a way to make essential, personalized mental health, diet, and nutritional care accessible to Canadians living with IBD.

"In Canada, the mental health, diet, and nutritional needs of individuals living with Crohn's or colitis are not included in a typical care plan. The best way to provide care is with a qualified team that is able to address an individual's unique needs through a holistic and personalized approach based on evidence," says Susan Cowan, CEO of Crohn's and Colitis Canada. "We are proud to expand the PACE network to include the important research work of Dr. Bernstein and Dr. Graff to increase the accessibility of mental health, diet and nutritional care."

Dr. Bernstein and Dr. Graff will develop an online screening tool that enables an individual to communicate

their personal needs, in regard to mental health, diet and nutrition. The healthcare provider will use this information to deliver clinical education and interventions tailored to the disease-related needs identified by the individual. Clinical education materials, and mental health and nutritional approaches most commonly used during the pilot will be distributed to IBD clinics across the country to improve the overall approach to integrated patient care.

"Though people living with IBD and their healthcare providers increasingly recognize the importance of the connection between the disease and mental health, too often these needs are not integrated as part of the IBD care, and there continues to be gaps in fully assessing and addressing them," says Dr. Graff.

"Similar to mental health, people with IBD would benefit from expert guidance to address their nutritional health in the context of IBD. The project will determine the extent to which routinely identifying and responding to mental health and nutrition needs in the IBD clinic using a tailored approach can improve outcomes and quality of life", says Dr. Bernstein.

Every project incorporated into the PACE network is selected after undergoing a competitive peer-review process, and aligns with Crohn's and Colitis Canada's promise to discover cures and improve quality of life for everyone affected by IBD. Crohn's and Colitis Canada thanks all of the exceptional researchers in the IBD community for submitting their applications. To learn more about the PACE network, please visit crohnsandcolitis.ca/PACENetwork.

ECCO Congress and UEG WEEK to be held online in 2021

Due to the ongoing COVID-19 pandemic the two major congresses related to IBD – UEG WEEK and the ECCO Congress - have decided to organize their events virtually in 2021.

The ECCO Congress which has been held annually in February since 2006, with over 7,000 delegates hosted in 2020 will now take place virtually on July 2-3 & 8/10, 2021. It will provide a unique opportunity to gain access to the latest and best scientific information and education in gastroenterology, hepatology, endoscopy, and gastrointestinal surgery with its major focus on IBD.

More info: <https://www.ecco-ibd.eu/>

UEG, or United European Gastroenterology, is a professional non-profit organisation combining all the leading European medical specialist and national societies focusing on digestive health.

More info: <https://ueg.eu/week>

UEG Week Virtual 2021 will be held on October 3 – 5, 2021, with its programme featuring across many virtual lecture halls and its Vienna-based TV Studio. Each location hosts scientific highlights in interactive ways and in almost every session, delegates can interact in real-time via Q&A tool. On October 22 – 23 PGT Virtual 2021 returns to its 3-year curriculum and will follow the curriculum for year 1.



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“My IBD won't stop me!”

By Andrea Cabassi

Mandalay (Myanmar), March 2020 - I watch the sunset from the terrace of the Iceland Hotel. Not the name I would have expected for a hotel in former Burma, but there you go. This morning the alarm clock went off at 5am. I wanted to enjoy the sunrise dotted with hot air balloons flying over the temples of Bagan. Wonderful, but also very touristy.

Perhaps the view would have been more impressive if I had chosen to board one of those balloons, but frankly spending 300 dollars seemed to me a greater effort than the taste I would have gotten from it. After a rich and unhealthy breakfast, I reached Mandalay by bus. Five hours of jumping up and down...it seems they don't really understand here what it means to level asphalt. This early morning wake-up makes me feel tired but also a lot of peace. Sitting at a rather kitschy beige table, I sip a brown water-flavoured instant coffee with the satisfied expression of someone who knows he has made his dream come true.

When I was not yet of school age, I dreamed that one day I would set out to discover the world. Instead, I grew up following the script: school, bachelor degree, permanent job. Although there were pit stops along the way. At the age of 23, I was diagnosed with Ulcerative Colitis. You can't see it, but it's there. Fortunately, I have so far avoided surgery. I get by with pills, suppositories, colonoscopies, occasional relapses, and trips to the bathroom with varying frequency. A real pain in the arse. But the show must go on.

When I turned 40, something led me to leave everything behind and move to Dubai, together with my IBD, thanks to a job offer from a well-known Swedish multinational. A huge upheaval at an age when the world expected me to start a family. I wrote about it in my book 'Let Me Insist - I Changed My Life At 40'. A bet I won. Once I got over that huge hurdle, I got a taste for it. A terrible accident involving my brother-in-law reminded me that there is only one life, really. On that intensive care bed, in a coma, it



could have been me. So, at the age of 43, I decided to quit my job, my beautiful (but stressful) life, my tax-free salary, my managerial career, take off my formal clothes, fill a backpack and become a writer-traveller indefinitely, leaving with a one-way ticket, shouting “my IBD won't stop me!”

In less than a month I will be 45 years old. I have an unkempt beard, long grey hair, no dress code to observe and I am the master of my time. Apart from a couple of 'technical' returns - to have my colon serviced - over the last two years I have travelled solo for over 630 days through 18 countries. It has been extremely difficult and exciting. Pure life!

I chose travelling because, as Gio Evan (Italian songwriter, Ed.) says, I find it a great school of life, which strengthens thoughts. I chose the trip because I wanted to discover the world for myself, tired of believing television and those who invent enemies that perfectly fit our nightmares. I chose the journey to learn to be “beyond”. Beyond frontiers, beyond borders, beyond traditions and beyond cultures. I chose travelling because, of course, travelling is beautiful. I chose the “do-it-yourself” trip to have problems to solve, unforeseen events to manage, to mingle with the locals, because for me staying in a resort is the same as eating chips without licking my fingers. I chose to go solo because this is my dream. Mine and no one else. And also, because going solo does not mean traveling alone, but with the rest of the world.

Now I have a shipload of colourful stories to tell my grandchildren. Of sea lions, endless beaches and carnival floats. Of Argentine tango and glaciers that, if they did not exist, I would not know how to imagine. Of reefs so brave to face the Pacific Ocean’s breakers. Of fin del mundo, (‘the end of the world’ in Southern Argentina) unmovable icebergs and grumbling volcanoes. Of valleys that seem painted (autumn on canvas). Of magical islands and “what-a-pity-not-to-be-gay” surfers. Of those big moai heads on Easter Island. Of wines that listen to Gregorian chants, of shooting stars that cannot stand upright, of geysers and deserts so dry that a honeycomb feels wet in comparison. Of witches, giant condors, ancient civilisations, penguins, whales, piranhas, dolphins and parrots all dressed up. Of rainbow-coloured mountains, red-nosed clowns and festive, filthy, happy children. Of blue butterflies as big as hands, of shamanic rituals and old-fashioned markets.

Of iguanas teleported from the Mesozoic era, of wimpy sharks and waterfalls so beautiful that if you get killed, it’s OK. Of giant swings and the smell of coffee. Of Gabriel Garcia Marquez, the Caribbean Sea and kite-surfing. Of graffiti that seem animated, of skyscrapers that pierce the clouds and fluorescent plankton that illuminates the night. Of Vucciria, Capo and Ballarò (Palermo’s popular markets). Of nasi goreng, muezzins and the island of Gods. Of coloured fish chasing each other among the corals. Of a world without internet, of streets without asphalt and houses without roofs. Of ancient temples, crazy shopping centres and unsustainable 7-star hotels.

Of 5 rhythms, of meditation and holistic festivals. Of sailboats, ghostly lakes and a sea so blue that it seems backlit. But above all, of extraordinary people at every latitude, without money but ready to lend a hand or offer you a plate of soup, perhaps the only one available. Who watch little news, don’t rob supermarkets in COVID-19 times and even less sell hand sanitizer for 100 Euros. If anything, they give it to you as a present.

But on the same ship I also have matters of Ulcerative Colitis, tablets, suppositories and relapses. Like the time when that bitch that they call ‘toilet paper’ threw the reality in my face again: there were traces of live blood. I had no other symptoms. It was April 10, 2018. After a long bus transfer, I had just arrived in Puyuhuapi, a charming little village in the Chilean Patagonia. I had been travelling for a month and a half and my body was probably feeling the effects. After a few days, things seemed to have settled down spontaneously, until I arrived in Dalcahue, on the island of Chiloé, where I had to resign myself to the evidence: the blood was clearly present and, indeed, increasing. There were no other symptoms, but I could not go on peacefully in that condition, as I expected to continue travelling for several more months.



The next stop was Bariloche, Argentina. A big city in a civilised country, I was sure to find a gastroenterologist who was up to the job. I left immediately by bus. A two-day journey via Puerto Montt. I got a recommendation for a private clinic from my local contacts, looked for a hostel nearby and went in search of a gastroenterologist. An hour later I found myself in the office of Dr. Coconi, an Argentinean with obvious Italian, or rather Emilian, or rather Parmesan origins like me, that I am from Parma. My paternal great-grandmother was a Cocconi. We would later incredibly discover that we were distant relatives! The missing 'c' in his surname is a transcription error at the time of migration. Let's get to the point: from the symptoms, 99% were haemorrhoids, which I had never suffered from. However, to confirm the diagnosis, the specialist suggested a rectoscopy to be performed the next morning. I shrugged my shoulders and accepted: I had to find the necessary serenity to enjoy the journey. I left his surgery with the purgative in my pocket: I had to do the odious intestinal preparation. Tip: dissolved in apple juice - as is the local custom - it doesn't taste so bad. So it was that I found myself in Patagonia, Argentina, in a hostel, purging myself. This was not exactly how I had imagined the trip, but there was no point in getting depressed. The examination went flawlessly and confirmed the diagnosis of the previous day. I spent about 300 euros, which my travel insurance later reimbursed. I "only" had to get rid of my haemorrhoids, the lesser evil. I hitchhiked back to San Martín de los Andes, more enthusiastic than before.

Or I could write about the time I found myself in a slum, among gangsters, in Bogota, the capital of Colombia. Amazing country. Thanks to a government rehabilitation programme, some gangsters have laid down their guns to become tourist guides in their neighbourhoods.

“...thanks to this experience as a wanderer, I am acquiring a more modern vision of life, in line with my new, distorted priorities and focused on the true wealth of the third millennium: my time. Ulcerative Colitis permitting”

They waited for me in the crowded central square of La Candelaria, among acrobats and storytellers. “You will recognise us, don't worry.” The two ugliest faces I remember seeing were smiling at me, toothless. It had to be them. The only participant in that day's Invisible Borders tour, I plucked up courage and followed them. As we entered the Egypto neighbourhood, life seemed to have disappeared. The streets were deserted, but I was watched on sight by eyes peeking out from behind peepholes and doors that opened ajar as we passed. All that was missing was a rolling bush and a saloon. They told me to wait on a bench, the boss was coming. I had with me

the clothes I was wearing, the money to pay for their service, some change for tips, an outdated mobile phone. But also, my body, including my colon. “You are under our protection, nothing will happen to you,” the boss reassured me, proudly showing me the four bullet scars he had around his body. “This one and this one were put on me by those hijos de puta cops. This was the time I went out to avenge an insult to my son”. And so on. They told me, in tears, that they had lost brothers and cousins, killed while crossing the road. Yes, because ‘invisible borders’ means the borders

between their block and the enemy gang's block. Those who crossed them without authorisation were mowed down by gunfire. In 2015, not the Middle Ages. I had lost my words. They escorted my unsteady step into the favela of the neighbourhood. None of my friends or family knew I was there. “If they lock me in a room, take away my heart, kidneys, eyes and feed me to the dogs, no one will know.” I thought. The unexpected sight of a brand-new football pitch with artificial turf contrasting with ramshackle hovels and rivulets of foul-smelling filth somehow calmed me down. We started joking, I told them the sequence of choices that had brought me with them that day.

“We’ve realised the bad life we used to have, now we’ve settled down. The scars, on the body and in the soul, unfortunately remained, but we want to redeem ourselves.” They took me back, safe and sound, to my starting point, showing me, with a touch of pride, the police station that they themselves, ten years earlier, had forced to close down with machine gun fire. And I used to feel cool at school with my Bic peashooter. Relieved, I greeted them with sincere emotion and a hug, pledging to talk about them whenever I had the chance. I am not crazy. I had been influenced by the situation, Colombia and the stories in the newspapers. But I never really felt in danger. What’s more, that tour had been recommended to me by a German girl, a friend who had done it solo a few weeks earlier, telling me to take it easy. I keep it in my album of amazing memories.

I would like to conclude by stressing that, thanks to this experience as a wanderer, I am acquiring a more modern vision of life, in line with my new, distorted priorities and focused on the true wealth of the third millennium: my time. Ulcerative Colitis permitting.

I could go on for hours telling anecdotes but, rest assured, we will have other opportunities. I am compiling it all into a new book, which will see the light of day sooner or later. In the meantime, if you wish, you can find “Let Me Insist - I Changed My Life At 40” on Amazon (<https://amzn.to/2nmeole>) or you can download the first 52 pages for free from www.andreacabassi.com.

If you want, you can also follow my adventures on social media:

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Have a nice trip!
Andrea Cabassi



Newly Diagnosed Patients with Inflammatory Bowel Disease: The Relationship Between Perceived Psychological Support, Health-Related Quality of Life, and Disease Activity

Kristy Engel, Maher Homsy, Rie Suzuki, Karla Helvie, Jeremy Adler, Caitlyn Plonka and Ellen Zimmermann

Introduction

Patients with newly diagnosed Inflammatory Bowel Disease (IBD; Crohn's disease [CD] and ulcerative colitis [UC]) have questions and are looking for answers. Similar to most patients with other chronic illnesses, they access a variety of health-related sources; however, the most relevant personalized health information should come from their primary care physician, their gastroenterologist, and other medical professionals with whom they interact. It is not uncommon for patients with IBD to experience significant psychological and social stress associated with their chronic disease diagnosis thereby contributing to a reduction in their health-related quality of life (HRQoL).^{1–3} Interestingly, lowered HRQoL and persistent psychological distress can exist despite experiencing clinical remission; therefore, it is likely other variables separate from disease activity influence a patient's HRQoL.^{4–8} We investigated the possibility that the doctor–patient relationship and access to educational and psychological support affect patients' HRQoL.

Patients adjusting to their IBD diagnosis will benefit from resources provided by medical professionals. The early months after diagnosis are particularly challenging for patients with IBD because of the complexity of the medical information, testing, medication adjustments,

and therapeutic strategies being discussed and implemented. It has been shown that patients with greater knowledge about their disease tend to have more adaptive coping strategies.⁹

Furthermore, patients with a better knowledge base tend to have better adherence to medical regimens leading to better patient outcomes.¹⁰

Psychological support is an important dimension of patient care, particularly early in the disease course. In oncology, cardiology, and rheumatology care, social support has become a standard part of patient treatment protocols as this support improves performance status and adherence to medication plans.¹¹ Resources received by patients with IBD from a medical professional during an educational or psychological support session have the potential to positively impact how a patient copes with the diagnosis.¹² To our knowledge, no studies have focused on patient's satisfaction with available psychological and educational support, disease education, and the relationship with a gastroenterologist early in the disease course. We hypothesized that patients who are satisfied with their educational and psychological support will report a higher HRQoL and demonstrate improved disease activity.

Materials and Methods

Ninety-four patients were recruited from the University of Michigan Health System Inflammatory Bowel Disease Clinic. Patients were eligible if they were > 14 years, if they fulfilled the diagnostic criteria for IBD provided and verified by their treating gastroenterologist, and if they had been diagnosed with IBD within 5 years of the study's commencement. The diagnosis was confirmed by standard diagnostic criteria. Out of the 94 patients who were recruited, one patient withdrew after starting the survey. Two additional surveys were eliminated due to the patients' diagnosis date not being confirmed. Two surveys were only partially completed. Therefore, 89 completed surveys were analyzed.

Excluded from the study were patients with multiple health complications not related to IBD, and patients who had difficulty understanding and/or speaking English. Informed consents were obtained from all patients. Patients not being seen for an office visit during the time of the face-to-face questionnaire distribution were contacted by mail. Participants received an incentive of five dollars for participating in the study. This study was approved by the University of Michigan Institutional Review Board (HUM00047447).

Demographic questions were asked that pertained to age, gender, race, ethnicity, marital status, educational level, and employment status. Questions aimed to categorize patients into IBD categories of UC, CD, or indeterminate colitis in addition to obtaining information on the month and year of IBD diagnosis.

Survey instruments

The questionnaire utilized in the study comprised original and modified questions from the Short-Form Inflammatory Bowel Disease Questionnaire (SIBDQ)¹³ and the Medical Outcomes Study Social Support Survey (MOS).¹⁴ The SIBDQ is a tool that measures HRQoL in patients with IBD. The MOS was modified to include

questions pertaining to the patients' interaction with their gastroenterologists, and is, therefore, noted in the study results as The Modified Medical Outcomes Study Social Support Survey (GI-MOS). Lower GI-MOS scores represent a decrease in satisfaction with gastroenterologist. Disease activity was measured utilizing the Harvey Bradshaw Index (HBI),¹⁵ and the Simple Clinical Colitis Activity Index (SCCAI).¹⁶ Higher scores indicate more disease activity. Finally, patient demographic questions were adapted from the Center for Disease Control and Prevention's Behavioral Risk Surveillance System.

Statistical analysis

Descriptive statistics were used to characterize the population's demographics. The Spearman rank correlation was calculated to investigate the impacts of disease activity (HBI and SCCAI) on HRQoL (SIBDQ) and the impacts of patients' satisfaction with gastroenterologist (GI-MOS) on disease activity (HBI and SCCAI) and HRQoL (SIBDQ). The Spearman rank correlation was used because both the GI-MOS and SIBDQ provide ordinal results and thus require nonparametric statistic.

Table 1. Demographic Data of Study Cohort

	n (%)
Demographic characteristics	89
Age (mean in years)	37.63 (SD=16.87)
Gender (male:female)	46:45 (51:49)
Ethnicity (1=white)	86 (96)
Relationship status	
Married	44 (49)
Divorced	6 (7)
Widowed	2 (2)
Separated	1 (1)
Never married	36 (40)
Disease diagnosis	
UC	53 (60)
CD	36 (40)
Disease duration	
0-3 months	3 (3)
4-6 months	9 (10)
7-9 months	10 (11)
10-12 months	7 (8)
1-2 years	49 (55)
3-5 years	11 (12)

CD, Crohn's disease; SD, standard deviation; UC, ulcerative colitis.

Table 2. Medications Taken by Patients Participating in the Survey

Group	No. of patients, n (%)
Biologics-based therapy	18 (19)
+ no other medications	8
+ immunomodulators	5
+ 5-ASA products + steroids	5
Immunomodulators-based therapy	34 (37)
+ no other medications	12
+ 5-ASA products	8
+ steroids	7
+ 5-ASA products + steroids	4
+ other immunomodulators + steroids	1
+ allopurinol	2
Steroid-based therapy	32 (34)
5-ASA + steroids	31
Corticosteroids alone	1
No medications	7 (8)
Other	2
Double-blind clinical trial (Remicade vs. placebo after surgery)	2

Biologics: anti-TNF therapy and vedolizumab; immunomodulators: azathioprine, mercaptopurine, and tacrolimus; 5-ASA product: any mesalamine containing product; steroids: prednisone, budesonide, or rectal steroids.

The data were sorted and calculated using Microsoft Excel and the Statistical Packages for the Social Sciences (SPSS) software program (version 24; IBM SPSS, Inc.). A p-value ≤ 0.05 was considered statistically significant.

Results

Patient demographics and therapy are shown in Tables 1 and 2. A majority of patients had been diagnosed within the past 1–2 years (55%). Table 3 displays patients' surgery history. Twenty patients had surgery history (15 patients with CD and 5 patients with UC). Most common surgeries were intestinal resection (6) or abscess drainage (6).

Table 3. Surgical History of Patients Participating in the Study

Surgery	CD	UC
Colectomy	2	2
Ileostomy	0	2
Ileoanal pouch anastomosis	0	1
Fistula surgery	1	0
Abscess drainage	6	0
Intestinal resection	6	0
Total	15	5

As expected,¹⁷ the patients' HRQoL correlated with disease activity for both CD (HBI) and UC (SCCAI). IBD patients with active disease have a reduced HRQoL (SIBDQ, $r = 0.69$, $p < 0.0001$, $n = 89$).

We used a modified MOS (GI-MOS) to incorporate questions pertaining to a patient's perception of his or her gastroenterologist (Table 4). Patients with IBD who reported higher level of satisfaction with their gastroenterologist (GI-MOS) also reported a higher HRQoL. When analyzed separately, GI-MOS correlated positively with HRQoL for CD but not for UC (GI-MOS vs. SIBDQ for CD: $r = 0.33$, $p = 0.04$, $n = 36$; GI-MOS vs. SIBDQ for UC: $r = 0.15$, $p = 0.27$, $n = 53$).

CD patients with more active disease had lower satisfaction with their gastroenterologist (GI-MOS). GI-MOS correlated negatively with disease activity in CD but not UC (GI-MOS vs. HBI, $r = 0.53$, $p < 0.001$, $n = 36$; GI-MOS vs. SCCAI, $r = 0.03$, $p = 0.80$, $n = 53$).

Perceived psychological support

Patients were questioned on psychological support in their lives in general and in their IBD treatment plans. Patients reporting rarely and never receiving psychological support had the most active CD ($r = 0.33$, $p = 0.043$, $n = 36$). Forty-nine patients (56%) reported receiving these forms of support on either an intermittent basis to never (Fig. 4A). Only 11% of the patient population reported having educational and psychological support as part of their current treatment plan (Fig. 4B). Eleven patients (80%) of those receiving educational and psychological support in their treatment answered that it was beneficial (Fig. 4C). Forty-nine percent of patients (39) who have not received educational or psychological counseling regarding IBD diagnosis feel that they could have benefited from it (Fig. 4D).

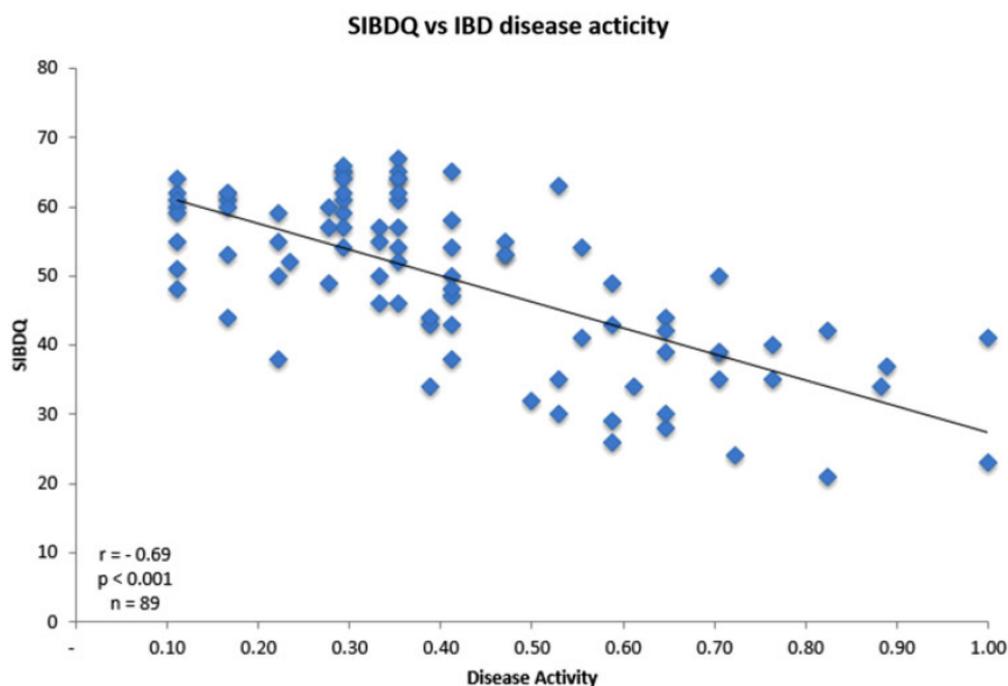


FIG. 1. The relationship between and the SIBDQ and combined disease activity of UC and CD. CD, Crohn's disease; SIBDQ, short-form inflammatory bowel disease questionnaire; UC, ulcerative colitis.

Discussion

A major finding of this study is a correlation between patients' relationship with their gastroenterologist and their overall HRQoL. This finding highlights the need for patients to feel comfortable in their relationship with the treating gastroenterologist.

Table 4. The Modified Medical Outcomes Study Social Support Survey

1. Your gastroenterologist is someone you can count on to listen to you when you need to talk about your IBD diagnosis
2. Your gastroenterologist is someone to give you good advice about your IBD diagnosis
3. Your gastroenterologist is someone to give you information to help you understand your IBD diagnosis
4. Your gastroenterologist is someone to confide in or talk to about yourself or your IBD problems
5. Your gastroenterologist is someone whose advice you really want
6. Your gastroenterologist is someone to share your most private worries and fears about your IBD with
7. Your gastroenterologist is someone to turn to for suggestions about how to deal with your IBD
8. Your gastroenterologist is someone who understands your problems

All questions had the following answers to pick from (none, a little, some, most, or all of the time).
IBD, inflammatory bowel disease.

A good bidirectional relationship is critical for eliciting pertinent historical information, effectively communicating disease-related information, comfortably asking questions and expressing concerns, and cooperating in decision making regarding testing and treatment. Communicating potentially sensitive information regarding mental health, sexuality, or substance use/abuse also relies on a good working relationship. Creating a safe atmosphere where patients are encouraged to be open and forthright about supplemental therapies that the physician may or may not favor is also important. In our study, a shockingly high percentage of recently diagnosed patients (80%) perceived little or no psychological support in their treatment plan. This suggests that IBD patients may have unmet mental health needs, which could hinder overall treatment. In CD, the patients who reported little or no psychological support had the most active CD. Although we cannot determine from our study whether this association is causative or whether patients who are more ill are less likely to acknowledge support or are biased in their assessments, the connection is important and warrants further study.

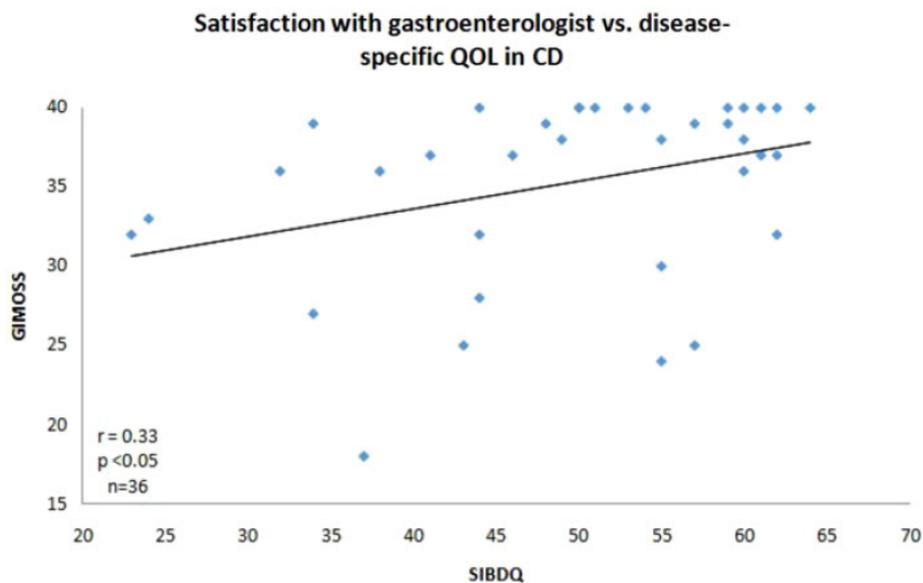


FIG. 2. The relationship between patient’s satisfaction with gastroenterologist and the SIBDQ in patients with CD. GI-MOS, The Modified Medical Outcomes Study Social Support Survey; QOL, quality of life.

In our study, the noted associations with disease activity were observed for CD but not UC. CD symptoms are more likely to include abdominal pain compared with UC that favors diarrhea as a major symptom. It is likely that patients with pain have different exacerbating or alleviating factors that rely on a good relationship with their gastroenterologist and benefit from added psychological support. The associations were also stronger for the disease activity measure than the quality of life measure. This may reflect the characteristics of each measure, especially the nature and number of the measure’s elements.

Our study is consistent with prior studies demonstrating the value of a multidisciplinary approach to IBD care.^{18,19} When surveyed, our study patients expressed the desire for educational and psychological support to be included in their treatment protocol although few acknowledged receiving this support. Furthermore, our study patients emphasized a desire to meet with a nurse, health educator, or counselor to discuss their diagnosis. Oliveira et al.²⁰ and Ballou and Keefer¹⁹ emphasized the importance of addressing not only the physical demands of a chronic disease but also the psychosocial ramifications.

“In our study, a shockingly high percentage of recently diagnosed patients (80%) perceived little or no psychological support in their treatment plan. This suggests that IBD patients may have unmet mental health needs, which could hinder overall treatment”

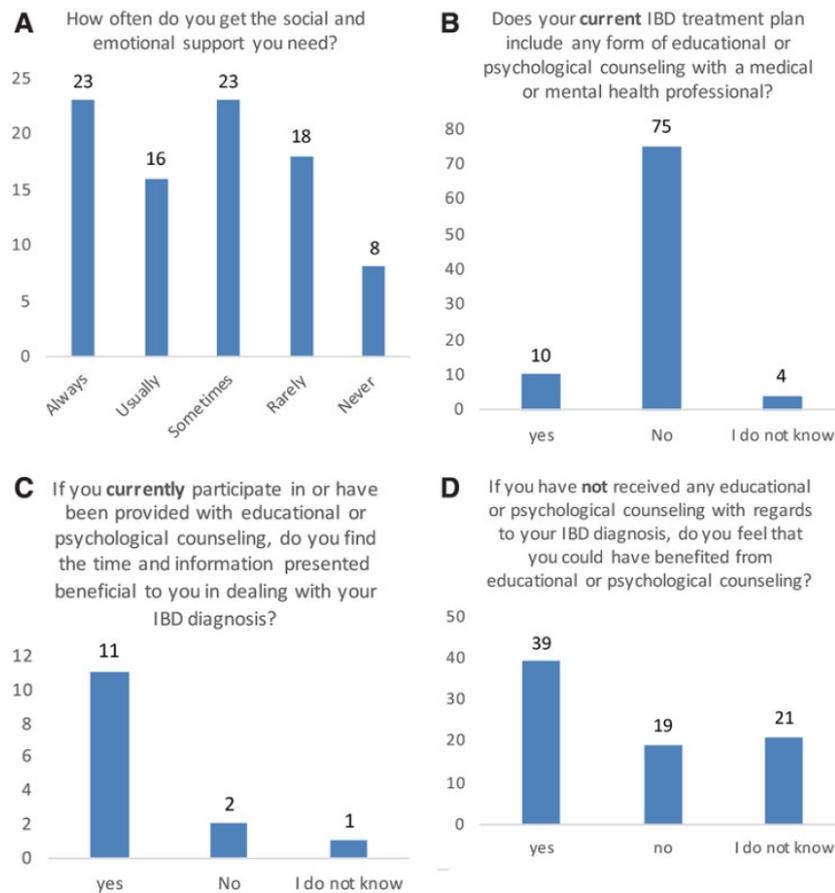


FIG. 4. (A) How often do you get the social and emotional support you need? (B) Does your current IBD treatment plan include any form of educational or psychological counseling with a medical or mental health professional? (C) If you currently participate in or have been provided with educational or psychological counseling, do you find the time and information presented beneficial to you in dealing with your IBD diagnosis? (D) If you have not received any educational or psychological counseling with regard to your IBD diagnosis, do you feel that you could have benefited from educational or psychological counseling? IBD, inflammatory bowel disease.

Having the opportunity to discuss additional concerns regarding their IBD diagnosis with a health care professional would provide the social support for patients that could potentially influence their disease activity.²¹

The new avenues for health care information and psychological support on social media are constantly evolving. Data suggest that patients utilize social media for information, although disease-specific information is most commonly derived from their physicians.

The sources of information and support are age dependent.²² Therefore, newly diagnosed IBD patients in their second or third decade of life are most likely to seek information and support on social media platforms

that provide easily accessible interactions. The value of social media relationships with respect to medical information and psychological support requires ongoing assessment.²²

Our study has several limitations. Currently, there is no validated survey instrument focusing on patient satisfaction pertaining to gastroenterology care. Therefore, to measure this aspect, we modified the previously validated MOS survey. As with any survey modification, original validation becomes nullified; however, this modification proved to be a key piece of the research process and could potentially inform future research.

The survey provided to patients was lengthy, including 61 survey questions plus additional questions associated with diagnosis (HBI, SCCAI). Long survey tools contribute to patient fatigue and hasty responses if interest and time begin to wane. In addition, the research was conducted in a tertiary care center that can influence generalizability.

Finally, the initial visits of a CD patient to the gastroenterologist's office are often lengthy and encompass discussions of gastrointestinal symptoms, test results, treatment options, potential disease or medication-related complications, and health care maintenance issues. The first few visits after the

diagnosis is made are particularly busy leaving little time to address psychological needs. This study highlights the patients' perception of the importance of psychological support. Our findings reinforce the importance of a team approach with interaction between the patient and several caregivers and encourages enlisting professional mental health services in some cases. Further research should be aimed at stratifying psychological needs based on risk assessment and patient's perception.

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