

# EFCCA MAGAZINE

European Federation of Crohn's and Ulcerative Colitis Associations

October 2020



## EFCCA Patient Talks webinar series

page 8

## Campaigning against additives which might cause IBD

page 22

## OPTIMISE study

page 42

# 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.crohnjacolitis.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 - LKKSBB  
www.lkksb.lv

Lithuania - CCLA  
www.draugija.info

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

Malta - MACC  
www.macc.org.mt

Montenegro - CUKUK  
www.cukuk.me

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

Netherlands - 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

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Brazil - DII Brasil  
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Kazakhstan - FPVZK  
www.vzk.kz

Trinidad and Tobago - NACCTT  
www.crohnsandcolitistt.org

# Content

COVID-19 Special 4

EFCCA News 12

European Youth Group 18

Members News 22

News from Partners 40

Medical Review Corner 42

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# Embracing change

2020 is a year we will never forget and that has required a change for the patient community we represent. It is a change that we had to accept quickly, to prevent health systems and the economy from collapsing, and multiplying the damage of the epidemic.

The COVID-19 emergency has created great uncertainty and represents, also for the next few months, a reason for greater attention to avoid the risk of contagion. EFCCA had to change quickly to respond to patient requests and to provide reliable and verified information about the pandemic and in particular related to Crohn's disease and UC as reported in our special section on IBD and the COVID-19 pandemic that you will find in this issue.

We also had to take into account the risks involved in carrying out the networking activities that usually form an important part of our action. The change sometimes involves waivers and for us the safety of our delegates is a priority: therefore, we were forced to cancel the General Assembly scheduled in Tallinn (Estonia), transforming it into an online event.

It was difficult to organize it, but thanks to the work of the staff and the IT group we were able to involve all the delegates in a meeting with more than 80 connected people.

Although the situation required to limit and suspend activities, EFCCA is responding to the needs of people with IBD and of member organizations, proving to be able to transform quickly, adapt and be innovative. Innovation has meaning when dissemination is the end point. If innovation does not reach the hands of those who have the problems it was created to solve, the entire effort is pointless.



For this reason, our Academy represents one of the most important tools to bring knowledge and empowerment to the IBD community. EFCCA offers a new specialized training for patients in this new edition of the EFCCA Academy which will provide a better understanding of the entire clinical research process and of the patient's role in supporting the design and implementation of successful clinical studies.

2020 is also an important year of growth and projects that have contributed to significantly improve the quality of care, care and life for all the IBD patients.

We are all ready to continue our commitment determined to achieve the primary goal of finding a cure for IBD, without stopping research and continuing to voice our rights as citizens with chronic diseases.

*United We Stand,  
Salvo Leone, EFCCA Chairman*

# IBD and the COVID-19 pandemic

Since February this year the world has been going through some unprecedented changes due to the COVID-19 pandemic which has created a new reality of life that many of us are still trying to assimilate to or even accept.

Social distancing rules, travel restrictions, changed access to healthcare and economic uncertainties are some of the many effects that we are all faced with. And now imagine the IBD patient community! Prior to the COVID-19 pandemic many people with IBD had already to accept a new reality.

Social distancing already happened for many who had to cancel social events, family gatherings or meeting up with friends because of a flare up or other uncertainties about their health. Travelling, especially long distance, required special preparations and could be a source of anxiety. Having good and continuous access to healthcare is vital for IBD patients as it is for any chronic patient. And as concerns economic uncertainties this is for sure something that many IBD patients are familiar with.

So, in a strange way, the IBD patient community has been much better prepared to adapt to this new reality that we are all facing but of course patients - being in a higher risk group - have also lived a double burden of this crisis.

We, as EFCCA, have rapidly moved to adjust to the situation and to respond as much as possible to the many challenges that our members are facing on a daily basis. A first instance was to provide reliable and verified information about the pandemic and in particular related to Crohn's disease and UC.

At the beginning of the pandemic we were approached by a team of gastroenterologists from the Mount Sinai Hospital (NYC) and the University of North Carolina to

help disseminate information about a live registry the team had set up in order to record cases of COVID-19 infection in IBD patients.

The risk factors associated with more severe COVID-19 disease are progressively being identified, but there are still huge gaps in understanding, especially regarding patients with inflammatory bowel disease (IBD) and their immunosuppressive/biological treatments. The **IBD SECURE** project, which has been widely endorsed by various scientific societies including the European Crohn and Colitis Organization (ECCO) aims to help better understand the impact of COVID-19 on IBD patients (for more information please see page 9).

Another measure we took was to collect data to better understand how the current situation has impacted on the lives of the people we support.

The survey **COVID-19 IBD patients' perception** has been codesigned with Prof. Silvio Danese (Milan University Hospital) in order to investigate the concerns, fears, and behaviours of patients with IBD during the early phase of the COVID-19 pandemic. The questionnaire focused on the most frequent questions asked by patients to physicians during the COVID-19 pandemic.

Originally, the survey was thought for the Italian IBD patients' community, given the serious situation people were facing there at the early stage of the pandemic, but due to the rapid spread of the COVID-19 pandemic worldwide, EFCCA considered it important to extend the survey to all our national associations.



The data have been collected during the period March 30th to April 16th 2020 and the survey has been translated into 11 different languages. We received responses from 3815 people from over 51 countries, the top seven countries including Italy, Netherlands, Brazil, Greece, Portugal, Norway and Spain.

Most respondents feared contracting COVID-19 (85%) or infecting other people (87%). Just under a third of patients believed that IBD predisposed them to an increased risk of COVID-19 (30%), and nearly two-thirds of respondents stated that immunosuppressive drugs were associated with a higher risk of infection (64%).

What is interesting is that respondents to the survey felt that patient associations were a significant factor in 'reducing their fears and worries about COVID-19' (42%). In fact, it was the highest score in this category being ahead of relatives (27%) and recommendations from national and international authorities (14%).

This is very inspiring news for patient associations that are working to improve the quality of life of people with IBD and it shows that forming part of a community can have a valuable impact on patients' lives.

It also encourages associations to do their best in providing services to their members and the IBD community worldwide.

This result also demonstrates that there is an urgent need to improve communication between all the stakeholders involved in the IBD patient management, in order to give the patients aligned, coherent and reassuring recommendations, especially during an emergency period that causes even more concerns and disruption to people living with chronic diseases.

In view of the results of the survey EFCCA has decided to organise a series of webinars in order to address some of the main concerns identified. The survey is a minefield of information and will be guiding our work in the coming months. Below you will learn more about the numerous activities we have undertaken in order to respond to the current situation.

## EFCCA Patient Talks - webinar series

Following the results of our survey **COVID-19 IBD patients' perception** we have decided to run a series of webinars inviting representatives from the IBD patient community and relevant experts to discuss

and exchange information on several issues identified in our survey and which have shown to have a huge impact on the quality of life of IBD patients.

### COVID-19 and medicines supply: “Are we running out of medicines?”

*“Will I be able to access my biologics/biosimilars treatment?”, “Will my other IBD medicines be affected by COVID-19?”, “Are costs of my medicines likely to rise?”.*

These and other similar questions reflect some of the concerns and fears expressed by IBD patients.

A few weeks within the COVID-19 pandemic patients of Lupus, rheumatoid arthritis and several other

immune modulated disease groups struggled to access their medication, hydroxychloroquine, which is being used in several countries to treat severe cases of COVID-19.

This situation has increased concerns of the availability of drugs for chronic patients that rely on a regular supply for their treatment as well as the supply of medicines used at Intensive Care Units.

In order to address this topic EFCCA invited Monica Dias representing the European Medicines Agency as well as Piera Polidori, representing the European Association of Hospital Pharmacists (EAHP) in order to gain a better understanding of the current situation and further outlook as well as to learn about measures that have been taken to guarantee a steady supply of medicines in the EU.

The webinar was structured as an interview style, took place on 25 June 2020 and was attended by EFCCA delegates who had a chance to interact and pose questions to the invited guest speakers. The webinar can be viewed on our website.

EFCCA Patient Talks



## COVID-19 and medicines supply: "Are we running out of medicines?"

Free Webinar

Join our discussions with representatives from the European Medicines Agency and the European Association of Hospital Pharmacists.

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

To register send an email to: [veronica.pisco@efcca.org](mailto:veronica.pisco@efcca.org)

Thurs. 25 June 2020 4PM - 4.45 PM

## COVID-19 psycho-social impact of lockdown in patients with IBD

Following the results of the survey COVID-19 IBD patients' perception we decided to organize a webinar that aimed to highlight and answer some of the psycho-social impact the lockdown had on IBD patients.

We heard from several IBD patients' first-hand experience of how the lockdown had affected their mental wellbeing and what it really meant for an IBD patient to self-isolate.

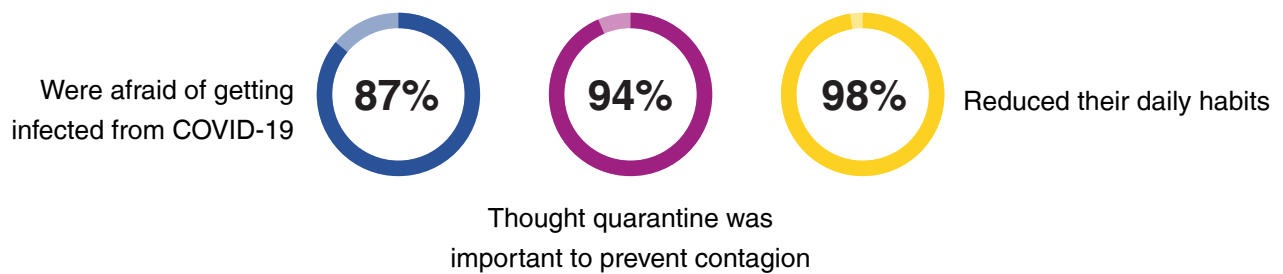
IBD patients Vasiliki - Rafaela Vakouftsi, General Secretary of HELLESCC and Sanna Lonnfors, EFCCA Research and Project Coordinator discussed their experiences with Dr Yoram Inspector M.D. Consultant Psychiatrist (St Mark's Hospital).

The session was moderated by EFCCA Board member Marko Perovic who also referred back to the survey on IBD patients' perception.



The webinar took place on 16 July and can be viewed on our website at [www.efcca.org](http://www.efcca.org)

### Concerns from the IBD patient community



# EU4HEALTH 2021-2027

## The European Commission's vision of a healthier European Union

EU4Health is the EU's response to COVID-19, which has had a major impact on medical and healthcare staff, patients and health systems across Europe. It was conceived to boost the EU's preparedness for future cross-border health threats and to reinforce national health systems in the long-term.

Originally it intended to invest € 9.4 billion and it was supposed to become the largest health programme able to provide funding to member states, health organisations and non for-profit organisations. Unfortunately, the EU Council's recent decision cut the announced budget down to 1.8 billion.

Nevertheless, the programme is focusing on several important topics and I think it is worth to share a brief introduction in this article.



## EU4Health: areas of action

- Boost EU's preparedness for major cross border health threats by creating:
  - reserves of medical supplies for crisis
  - a reserve of healthcare staff and experts that can be mobilised to respond to crises across the EU
  - increased surveillance of health threats
- Strengthen health systems so that they can face epidemics as well as long-term challenges by stimulating:
  - disease prevention and health promotion in an ageing population
  - digital transformation of health systems
  - access to health care for vulnerable groups
- Make medicines and medical devices available and affordable, advocate the prudent and efficient use of antimicrobials as well as promote medical and pharmaceutical innovation and greener manufacturing.

## European Commission's health priorities

The most urgent health priorities are: the fight against cancer, reducing the number of antimicrobial-resistant infections and improving vaccination rates. As far as rare diseases are concerned, the EU aims to expand successful initiatives like the European Reference Networks for rare diseases and continue to pursue international cooperation on global health threats and challenges.

Some of these priorities and areas of action can be of interest to our community, in particular:

1. e\_health digital health and care
2. making medicines and medical devices available and affordable

According to the European Commission most recent statements "...digital health and care refer to tools and services that use information and communication technologies to improve prevention, diagnosis, treatment, monitoring and management of health and lifestyle.

Digital health and care have the potential to innovate and improve access to care, quality of care, and to increase the overall efficiency of the health sector"

The EFCCA Symposium on "Health and Data: IBD patients' view and perspectives" held in Vienna last 14 February is just one of the most recent proofs of our approach on Digital Health and the role patients can play in defining needs and priorities in this domain.

On the wave of this unquestionable success and thanks to its innovative multi-stakeholder approach, EFCCA is establishing a wide network of potential players and is deciding to invest more resources in this field.

We are currently involved in two Innovative Medicine Initiatives projects (IDEAFast and IMMUNIVERSE - under the Horizon 2020 programme) and are exploring funding opportunities within the European Institute of Innovation and Technology (EIT\_health) (<https://eithealth.eu/>).

Two other EU projects have been submitted and our recent survey on the impact of COVID-19 in our community will nourish further initiatives in collaboration with other European and International interlocutors.

EFCCA is already engaged in international campaigns and awareness raising activities concerning the shortage of drugs and the importance of a more efficient and patient centred cross-border access to care. These topics are getting even more important under the COVID-19 pandemic.

We all know that all EU citizens have the right to access healthcare in any EU country and to be reimbursed for care abroad by their home country. There is the Directive 2011/24/EU on patients' rights in cross-border healthcare that defines the conditions under which a patient may travel to another EU country to receive medical care and reimbursement, however the huge crisis that national health system had to face over the past months clearly shows the need to be vigilant, to facilitate the exchange of information and to support our people putting at their disposal all possible tools to facilitate their access to drugs.



Shortage of medicine is the other side of the coin: we have been supporting some international activities on the issue and we believe that there is a strong need of creating stronger synergies by involving different disease areas and emphasising patients' perspectives all over the globe. As mentioned above, on June 25th we launched the first EFCCA Talk to talk to representatives from EMA and EAHP to have an exchange of information and gain a better understanding of the current situation on potential risk of medicine shortage.

We are aware that not every country is facing the same condition: we are and will be monitoring the situation and will be ready to support our members in case of need since we know that IBD patients are worried about access to medications in the event of a supply shortage.

Finally, EFCCA and many other health organisations are concerned with the huge cut the European Council decided to apply to the EU4Health programme.

The programme's declared aim was to strongly support the European Union in overcoming cross-border health crisis and reinforcing national health system: it was supposed to become the EU united reaction to COVID-19 pandemic putting people's health and wellbeing as of the core priorities of the next 5 years. The cut seems to show that EU is going in the opposite direction.

There is still some time to try to reinvert the route: the fact-sheet [Digital Health and Care](#) still show the past resource allocation.

We want to see it as a sign that there is still room for negotiation.

Luisa Avedano,  
CEO

## SECURE IBD

The Coronavirus disease of 2019 (COVID-19) pandemic has affected millions of persons over the world and continues to cause significant mortality and morbidity. Patients with comorbidities are disproportionately affected by COVID-19, and inflammatory bowel disease (IBD) is a significant chronic health condition that affects millions globally.

Additionally, treatment with immune suppressive medications, such as those used for IBD, can be associated with worse infectious outcomes. Therefore, it is important to determine the short- and long-term impact of COVID-19 on patients with IBD.

In order to monitor outcomes of COVID-19 occurring in IBD patients, we established the **Surveillance Epidemiology of Coronavirus Under Research Exclusion (SECURE-IBD)** registry in March 2020 in collaboration with global IBD experts.



SECURE-IBD is an international, paediatric and adult database to which healthcare providers worldwide are strongly encouraged to report cases of confirmed COVID-19 in their IBD patients.

The web-based survey is available through our website [www.covidibd.org](http://www.covidibd.org) and takes approximately 5 minutes to complete. The survey is currently available in English and in Spanish, and we are working expeditiously to translate it into other languages and make it more accessible to providers worldwide.

Our overarching goal is to identify COVID-19 outcomes in IBD patients and evaluate the safety of IBD medications globally in a collaborative, ethical, transparent, and timely manner.

We provide regularly updated summary information about reported cases, including numbers of cases by country, by treatment, and by other factors and have created an interactive timeline and map to depict cases reported from different regions (Figures 1 and 2).



Figure 1: An interactive map of reported COVID-19 cases and outcomes in IBD patients in the SECURE-IBD registry

The database is stored on secure, encrypted servers at the University of North Carolina, United States of America and contains only de-identified data, in accordance with [HIPAA Safe Harbor De-Identification standards](#). Since March 2020, SECURE-IBD has received overwhelming support from the IBD community with over 2,000 cases from more than 50 countries reported to the registry. Using these data, we have made some very interesting and clinically relevant observations.

We identified that older IBD patients and those with other medical conditions are more likely to experience a more severe course of COVID-19, similar to what is observed in the general population.

Outcomes in IBD patients on biologic medications such as tumor necrosis factor- $\alpha$  inhibitors (TNFi) do not appear to be worse than patients not on biologics. Conversely, baseline corticosteroid therapy was associated with worse COVID-19 outcomes.

We continue to delve into the reasons behind these findings and study the impact of other medication classes as our registry grows. Additionally, we are in the process of reporting on prescription patterns of healthcare providers, and factors that impact them, as well as global and regional disparities in COVID-19 outcomes.

We are collaborating with other registries to understand the impact of immune-modifying medications on COVID-19.

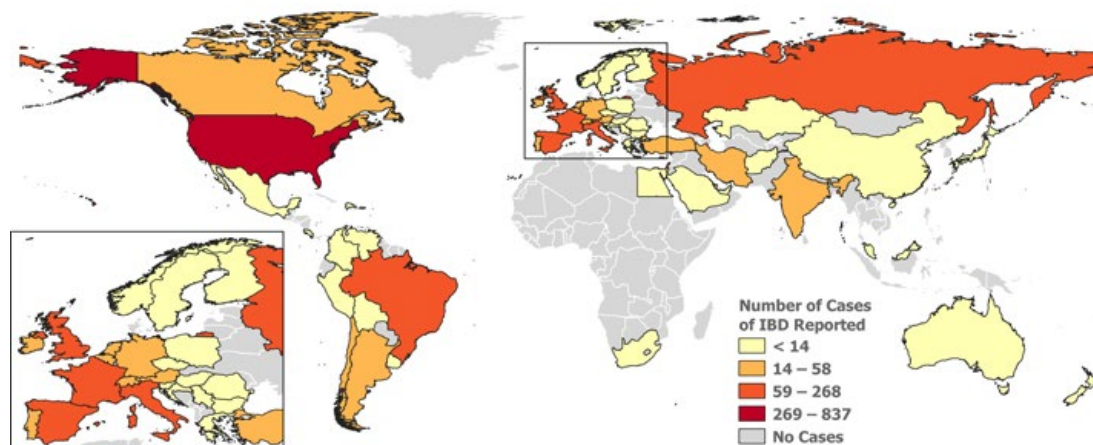


Figure 2: A graph depicting cumulative Crohn's disease (CD) and ulcerative colitis (UC) cases reported to SECURE-IBD since March 2020

We have come this far due to the tremendous support of our community of IBD physicians, other healthcare providers, IBD foundations, patient-advocacy organizations, and most importantly you, our patients. As we learn more about COVID-19 progression and its long-term impact, we plan to adapt and expand our registry to answer critical questions and strive to maximize our research efforts for the benefit of our IBD community.

The growth and success of this registry will depend upon ongoing robust participation and collaboration. Please encourage your healthcare provider to report all cases of COVID-19 in IBD patients to the SECURE-IBD registry.

Please visit our website [www.covidibd.org](http://www.covidibd.org) and follow us on Twitter @SECUREibd to stay updated about our progress. Please feel free to write to us with any questions or comments at [covid.ibd@unc.edu](mailto:covid.ibd@unc.edu). Together, we will help each other get through these tough times.

Stay safe, and stay well

#### The SECURE-IBD team:

*Michael D. Kappelman, MD, MPH  
(Pediatric Gastroenterologist,  
University of North Carolina at  
Chapel Hill)*

*Erica J. Brenner, MD (Pediatric  
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*Industry:  
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(Pfizer)*

*IOIBD:  
Marishka Konings (Secretariat  
IOIBD)*

# Staying connected!

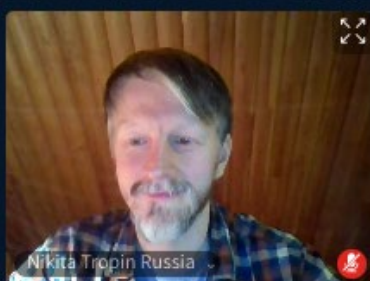
## EFCCA AGM 2020

This year's Annual General Meeting of EFCCA took place on-line and gathered over 60 participants from our members. Despite our social distance the AGM succeeded in bringing together our members and to transmit a strong feeling of solidarity and community.

Due to the COVID-19 lock down measures in most countries of the EFCCA membership the EFCCA board decided to hold our Annual General Meeting on-line.

The meeting took place on 30 May 2020 and the programme included the institutional parts of our organization such as the presentation and approvals of our Financial and Activity reports, last year's minutes, the report from our EFCCA Youth Group (EYG) as well as the work plan for the coming year.

We also held elections to the board and are pleased to announce that the new board is composed of the following representatives: Salvo Leone (Italy, President), Ciara Drohan (Ireland, Vice President), Marko Perovic (Serbia, Treasurer), Martin Mastrotto (France, EYG leader), Magdalena Sajak-Szczerba (Poland), Natasa Theodosiou (Cyprus) and Roberto Saldaña (Spain) who joins the board this year for the first time.





EFCCA members then voted in favour of the incoming members of the IBD patient association from Latvia and Trinidad & Tobago increasing our network to 41 members worldwide.

Finally, we heard presentations from four new observer countries, namely Mexico, Russia, Singapore and the Ukraine, who are keen to join EFCCA next year. All material and presentations can be viewed and downloaded from the private member section of our website.

We had very positive feedback about the meeting and even though delegates could not see each other face to face the chat function that was available on our online platform allowed for live comments and questions from our member.

Surprisingly enough, the meeting gave us a feeling of connectedness and engagement despite the difficult situation caused by the current pandemic.

**“We had very positive feedback and even though delegates could not see each other face to face the meeting gave us a feeling of connectedness and engagement”**



**EFCCA**  
European Federation of Crohn's  
& Ulcerative Colitis Associations

**Brief introduction:**

**MEXICO  
RUSSIA  
UKRAINE**

# World IBD Day


Our theme for this year's World IBD Day is around the issue of Work and IBD. With IBD on the rise and mainly affecting young people our campaign **Make IBD Work** aims to raise awareness of the impact IBD has on a person's professional life.

Many people with IBD want to and are able to successfully work. We believe 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 make IBD work!

The world has seen a dramatic change in our work practices. With the experience of worldwide lockdowns many employees have been working remotely and had the chance to continue their professional life by teleworking and/or incorporating a more flexible approach to working hours.

These are measures the IBD patient community has been advocating for in order to facilitate a better integration of chronic patients into our workforce.

Of course, there are certain jobs where teleworking is not an easy option, however there are many more measures that can be applied that will ultimately benefit both employers and employees.



The graphic is a promotional poster for World IBD Day 2020. At the top left, there is a logo for 'WORLD IBD Day' with 'MAY 19' below it. To its right, the text 'WORLD IBD DAY 19 MAY' is displayed. The central focus is the large, bold text 'Make IBD Work!' in a purple serif font. To the right of this text is a purple rectangular box containing the white letters 'IBD'. On the right side of the graphic, a large group of stylized human figures in various purple business and work attire are arranged in a circular formation. At the bottom left is the EFCCA logo, which includes the text 'EFCCA' and 'European Federation of Crohn's & Ulcerative Colitis Associations'. At the bottom right, the hashtags '#makeIBDwork' and '#worldibdday2020' are listed.

## Our key messages for this year's World IBD Day are:

Comprehensive policies and strategies at the workplace that take into account the situations of people with chronic conditions such as IBD have an overall positive impact not only on the patient but society at large

Direct and indirect costs of IBD can be reduced by better prioritizing effective IBD treatment.

There is a direct link between employment and its positive effects on the general well being of a person.

We have put at the disposal of our members and other organisations interested in this topic resource material providing both the institutional framework as well as interesting best practices carried out by various members of the EFCCA network.

For more information please visit:  
[www.efcca.org/en/projects/world-ibd-day-2020](https://www.efcca.org/en/projects/world-ibd-day-2020)

We were happy to receive an abundance of stories that showed the determination and hope with which people made their career aspirations come true and find a good balance in their professional life.

If you would like to be inspired, please go to:  
<https://www.efcca.org/en/stories>

On 19 May we also run a social media awareness raising campaign around the issue of Work and IBD. We invited IBD patients from across Europe and worldwide to share their stories and let people know how IBD had affected their professional life.

## Make IBD work - personal stories



### Cyprus, Natasa

When I was first diagnosed with Crohn's Disease, I was at my... [Read more](#)



### Spain, Javier

I am a teacher. When I was first diagnosed with Ulcerative Colitis, I was off sick from work for about 6 months. It... [Read more](#)



### Sweden, Nina

My name is Nina Tappegård from Sweden. I was 25 years old when I was diagnosed with Ulcerative colitis 2003. The first two years were tough as I... [Read more](#)

# Fistula survey: complex perianal fistulas have a significant impact on the quality of life in Crohn's disease

EFCCA carried out a patient survey in 2019 in cooperation with the pharmaceutical company Takeda to find out the impact of perianal fistulas on the quality of life on Crohn's disease patients.

At the closing of the survey, over 800 respondents with Crohn's disease had completed the questionnaire. More than half of the respondents had perianal fistulas.

A poster introducing the concept of the survey was presented at the ECCO Congress in Vienna on February 14, 2020. During the summer, the EFCCA team has been working on analyzing the data in preparation for publishing the full results. However, as several medical congresses and meetings have been rescheduled due to the COVID-19 pandemic, the communication plan for the full results of the survey will also need to be rescheduled accordingly.

The survey revealed, perhaps unsurprisingly, differences in symptoms experienced by those with Crohn's disease with and without fistulas, but also differences in symptoms experienced by men and women.

The significant impact of perianal fistulas on a Crohn's disease patient's quality of life was seen clearly on all life areas - social life, working life, relationships with family and friends as well as intimate relationships. EFCCA hopes to be able to publish a more detailed report of the results shortly.

Sanna Lönnfors,  
Research and Project Coordinator

## EFCCA Academy: Clinical trials training

EFCCA offers a new specialized training for patients in this new edition of the EFCCA Academy which will provide a better understanding of the entire clinical research process, and of the patient's role in supporting the design and implementation of successful clinical studies.

Back in 2018, the EFCCA Academy was born following the results of several major surveys that highlighted what were and what are the main issues within the unmet needs of the IBD community.

The pilot project was aimed at providing specialized training addressing these issues and appointing Certified Patients to raise awareness on IBD.



During the years EFCCA has worked on shaping and improving the Academy based on its first participants' feedback and experiences in order to constantly satisfy the participants' needs and to be sure that all important topics are handled in the most effective way.

Thanks to the huge interest achieved by the Academy all over the world in 2018, EFCCA this year proposes to offer another valuable training to interested and motivated IBD patients.

This year, the Certified Patients will be trained on Clinical Trials. The choice of this topic is based on the assumption that patient engagement is increasingly recognized as essential to integrating the patient voice in the design and development of research on medicines.

The aim is to provide to participant patients a better understanding of the entire clinical research process, and of their role in supporting the design and implementation of successful clinical studies.

The original plan was to launch the training during the EFCCA General Assembly last May 2020, but due to the current COVID-19 pandemic online sessions will be organized, which will also allow to expand this educational opportunity to as many patients as possible.

The training will be divided in the 3 following modules:

1. Clinical trials: basics;
2. Breaking the myths around clinical trials;
3. Diving deeper into clinical trials

After each presentation the participant must be able to respond to a set of 4-5 test questions to move on the next session and complete each module. Although the Academy will take place online, after each module we want students to have anyway the opportunity to discuss in depth the topics covered with the speakers and to find answers to their questions. Thus, live sessions will be organized to give students the chance to review the topics with the speakers.

At the end of the training, the participants will be asked to work on a final project at national level using the knowledge and skills gained during the course. We think that with the right skills, knowledge and competences a patient can play a significant and proactive role in their IBD community.

At the end of the training we expect the Certified Patients will:

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

Before starting with the first module, EFCCA is finishing the interviews with the students who have applied responding to specific selection criteria for participation.

We are proud of having received applications from all over the world and of seeing very high motivation from the students and we are certain the knowledge gained during the course will empower the patients and local communities.

Maria Stella De Rocchis  
EFCCA European Project Officer



# An usual European Youth Meeting

A very particular summer is ending for the Youth Group. The annual European Youth Meeting (EYM), expected to take place in Madrid on August 8, had to be unfortunately postponed due to the current sanitary crisis. Nevertheless, we were not feeling like giving up that easily!

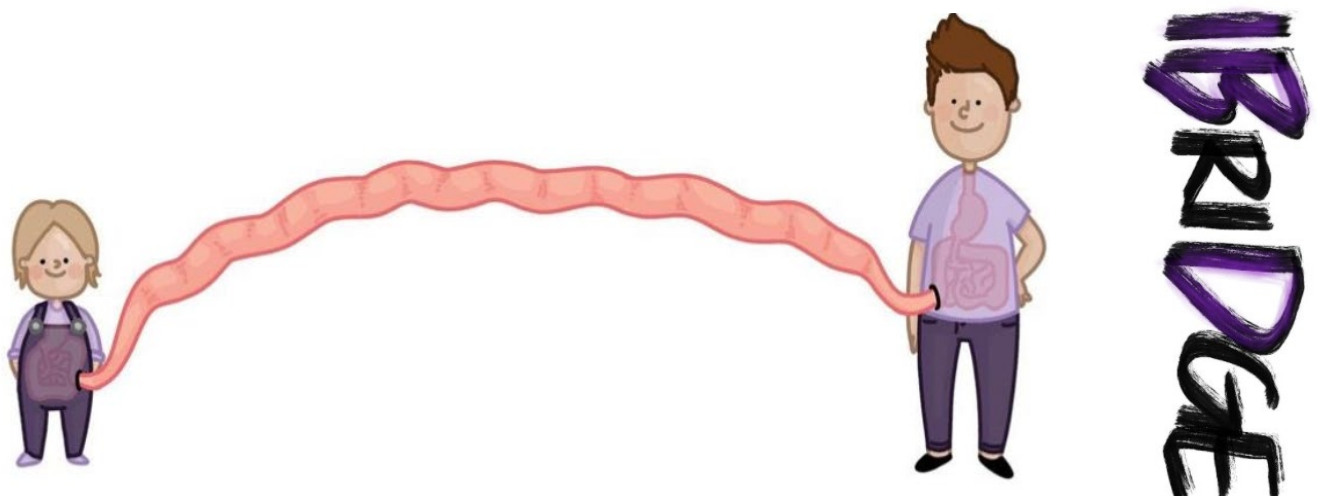
Instead, a shorter event with a completely new format came to life. Inspired by the success of the EFCCA General Assembly, the European Youth Group (EYG) decided to reshape the event and hold the meeting online to allow young delegates to connect, despite the eeriness of the period. An enjoyable moment shared by the 27 attending delegates from 16 European countries, and one newcomer, Brazil, whom we welcomed with open arms.

## One half day to cover all topics

From a two-day agenda to a single-afternoon videoconference, many things had to be left aside, but the key topics have been addressed successfully.

The introductory activity report presented by EYG Leader Martin Mastrotto and EFCCA Treasurer Marko Perovic, followed by the official closing of the Transition project, recently named IBriDge. This project was a big topic for the Youth Group. After three years, it was taken over by the new Board after 2019 EYM, with the ambition of wrapping it up during the next summer meeting.

Over the past 12 months, it was reshaped with a new name and visual identity, the resources were completed by interviewing several national association executives and healthcare professionals, including the results of Dr. Scheers' intervention during the Brussels Youth Meeting and the workshop that followed (see issue from September 2019).



*We proudly presented the new name and visual identity for our transition project*

The information gathered was then used to implement a dedicated website that addresses specifically the issues faced by young people facing transition from paediatric to adult healthcare and how to ease the process. The webpage aims to help all the different individuals involved in this process, from patients to family and also practitioners. It also includes examples and advices to ease the work of national associations.

## **Enough of the past, let's talk about our future!**

As soon as the closing of IBriDge was announced, the Youth Group officially launched the new topic that we aim to target, IBD and Education.

As many of our member have helped with the kick off stage of this project (for which we are extremely grateful), you might have heard about our online questionnaire aiming to target the barriers and

challenges faced by a young adult that undergoes superior education, and the support a student is entitled to access during its course, for each country. In order to have a full overview of the project, a whole hour was spared in the meeting agenda to organize a workshop with all of the 27 delegates attending the online session.

Thanks to the help of the back office, the group could be split in smaller breakout rooms, each of them moderated by a Youth Group member, to ease the conversation and include each and every delegate in the decision-making to decide the outcomes and targets to expect from this project. The session brought some encouraging perspectives from the 17 different represented countries and the outcomes of it will be closely analysed by the Youth Group and merged with the results of an online survey in order to map the exact needs of our young IBD students' community.

## **Our Board**

This year's EYM included an election for the two available positions in the Youth Group and, with no surprise, the election validated Amaranta Cantero (Spain) and Simo Natinen (Finland) as board members for another 2-year.

An excellent news for the Group who will have plenty on their plate for the upcoming term. In order to get you more comfortable with the team, we would like to introduce you the members of the EYM



### **Martin Mastrotto, group leader**

I'm 25 years old and member of the EYG since 2018. I became EFCCA Youth Group leader last year. I am also board member of AFA Crohn RCH France, and active volunteer in my local chapter in Bordeaux, France.



### **Amaranta Cantero, deputy officer**

I'm 28 years old and I come from Spain. I joined the Youth Group last year doing a variety of things and, after this election, I'll be helping Martin as deputy officer and also, if COVID-19 allows us, organise the EYM 2021 in Spain. I'm also actively involved in ACCU, the Spanish association.



**Simo Natunen**, social media management

I'm 27 years old and from Finland. My role in the Youth Group is to take care of our social media channels. I'm also the leader of the youth group of the Finnish association.



**Olga Mitrovic**, education project

I am 25 and from Serbia, my regular job is working as a resident medical doctor. I joined the Youth Group in 2017 so I can share my ideas with you and make great things together. I'm also the vice-president of the Serbian association.



**Selina Hubber**, delegate management

I'm 23 years old and I come from the south of Germany. I've been a member of the Youth Group for two years already and I'm currently taking care of the delegate management. I'm a member of the DCCV in Germany and work in their youth committee.



**Olga Golebiewska**

I'm 23 years old. I live in Warsaw, Poland and have Crohn's Disease. I am a volunteer for J-Elita association, helping with organising summer camps for kids with IBD and I've been a EFCCA Youth Group member since 2018.



**Natalia Mandakova**

I am from Slovakia and I have Crohn's. My first European Youth Meeting was in Paris in 2017. Since 2018 I volunteer for the EYG as a board member. I am also member of our national organization, Slovak Crohn Club.

## How can you help us progress?

Although we expect to have quite a busy year coming ahead, all these activities cannot be possible without your help! If we want to be the most impactful as possible with our projects, we will need implication from all of our member organisations.

If you feel keen to assist us in our development as a youth working group and as young leaders, here are some examples of our next steps where your aid would be more than welcome:



- **The IBriDge website** is now live in English beta version. The young delegates have been solicited to bring their insight on the current version to make it more complete and user-friendly. Comments from the national associations will be also appreciated. As the website has been developed fully internally, we have the possibility to extract the source code and the content to create translated versions. If you are interested in translating the website into your mother tongue, please come forward. We will be happy to collaborate with you.
- **The Education survey** is out since May 2020 and will remain open until the end of the year. Designed in English at first, it was then translated in a dozen languages, and shared locally in multiple countries, thanks to the cooperation of several young delegates and national associations. Work remains to be done to access more languages and include more people through national and regional networks. Your help can be valuable to us in the diffusion and communication of the survey among your youth community.
- While awaiting next year's **EYM**, we are managing a private group chat to keep closely in touch with national young delegates. If you have a national youth group in your country, or active young people from 18 to 30 years old, we are strongly encouraging you to introduce them to the EFCCA Youth Group, by sending us a message or an email. We will then invite your youth representative to join our group chat where he/she will be able to follow all the current activities of the Group, connect with people from other countries and accelerate next EYM registration.
- Last of it all, you are free to add any comment or suggestion to our activities at any point during the year. Your insight and encouragement will always mean a lot to us. Thank you very much for the confidence you showed to the Group this year. We hope to have the chance to collaborate as much as possible with our member organisations and with fellow youth groups over the course of our future projects.

The primary results of the Education projects will be shared on the first semester of 2021 in an official paper and more outcomes are expected for the year 2022. Stay tuned to our communication channels to know more about it and about our activities.

In the meantime, you are welcome to contact us anytime at [eyg@efcca.org](mailto:eyg@efcca.org).

**“If we want to be  
the most impactful  
as possible with  
our projects,  
we will need  
implication from  
all of our member  
organisations”**

# Norway

## Campaigning against additives which might cause IBD

The Norwegian association for people with digestive diseases is currently campaigning against food additives which can potentially cause and maintain Inflammatory Bowel Disease (IBD).

Several animal studies have shown that certain additives can alter the micro biotic composition in the intestines, and in turn cause gut inflammation. The specific additives are carrageenan (E407), Polysorbate 80 (E433), Carboxymethyl cellulose/ Sodium carboxymethyl cellulose (E466) and Ethyl hydroxyethyl cellulose.

These are emulsifiers found in certain types of bread, pastries, tortilla, dairy products, ice cream, cold cuts, bacon, coconut milk, gravies and tooth paste among others.

So far, human studies on these additives are few, but the EU body European Food Safety Authority (EFSA) has requested more investigations to explore it further. In the meantime, the additives are legal and used in both food, nutritional drinks and medicines.

“It is quite upsetting that the authorities let the consumers carry the risk, while they will spend years finding out whether these additives are safe for humans or not. We are expecting them to work preventive and be more cautious on behalf of the consumers,” said Secretary General Mads Johansson of the Norwegian association for people with digestive diseases.

The Norwegian health authorities say they are bound by EFSA's regulations. They claim that Norway as a member of European Economic Community (EEC), cannot make other regulations than the EU.

The Norwegian patient organization has now started a campaign with the aim of collecting at least 10.000 signatures. It will be used to pressure the food and health authorities in Norway, politicians and food producers.

To learn more about the additives, please read the article *The Western Diet-Microbiome-Host interaction and Its Role in Metabolic Disease* by Marit K. Zinöcker and Inge A. Lindseth, which was published in *Nutrients* March 17, 2018. Another recommended article is *The Role of Carrageenan and Carboxymethylcellulose in the Development of Intestinal Inflammation* by John Vincent Martino, Johan Van Limbergen and Leah E. Cahill, which was published in *Frontiers in Pediatrics* May 1, 2017.

“We hope that patients all across Europe will be made aware of these potentially very harmful additives. IBD is mainly a Western problem, so it is not unlikely that the cause of our problems is found in our food,” said the Norwegian Secretary General.

# United Kingdom

## New resource: Your Guide to Appointments

Crohn's & Colitis UK have developed a new resource to help patients navigate their healthcare appointments. This guide to appointments will help people get the most out of their time with health professionals, whether that's face-to-face or a virtual appointment, and focus on what matters to the individual.

Many people with Crohn's or Colitis struggle to make themselves heard during doctors' appointments - people often feel rushed, feel they are being judged, or simply don't know how to articulate what they wish to discuss. Our new Appointments Journal guides patients on how to address questions such as:

- What do you want to get out of the appointment?
- What should you ask?
- How can you make sure you're being listened to?
- How should you prepare beforehand?
- How should you follow up after the appointment?

My Appointments Journal is free to download and print out to help patients take note of how they're feeling in between appointments and plan their appointment time.

Readers will find tips on talking to health professionals, focusing on your goals, and asking questions. Visit [www.crohnsandcolitis.org.uk/appointments](http://www.crohnsandcolitis.org.uk/appointments) to view the resource.



### Coronavirus Information

Crohn's & Colitis UK have been at the forefront of the coronavirus response for people living with IBD in the UK, with the NHS signposting patients directly to us for information. Crohn's & Colitis UK have been at the forefront of the coronavirus response for people living

with IBD in the UK, with the NHS signposting patients directly to us for information. We have developed a variety of resources to help people understand how their condition may affect the precautions they need to take during the pandemic, such as:

- Decision trees for people to quickly and easily assess their risk level - one for adults and one for children
- Detailed information on employment, benefits, and finances
- Letters of support to explain risk levels to employers
- Information to help people decide whether or not to return to work, or send their child to school
- Information about what to do if you have coronavirus symptoms, including stopping medications

One supporter told us: "During this COVID-19 pandemic, I have been quite worried and often confused about what government advice applies to me. Throughout, though, I have been able to rely on the expert knowledge from Crohn's & Colitis UK and that has been a massive help."

We have also supported the British Society of Gastroenterology and the IBD Registry to develop the [COVID-19 UK IBD Tool](#) a 15-minute online survey to help IBD patients see what their risk level is. Patients enter their health information, and the results of the risk assessment will be available to download/save.

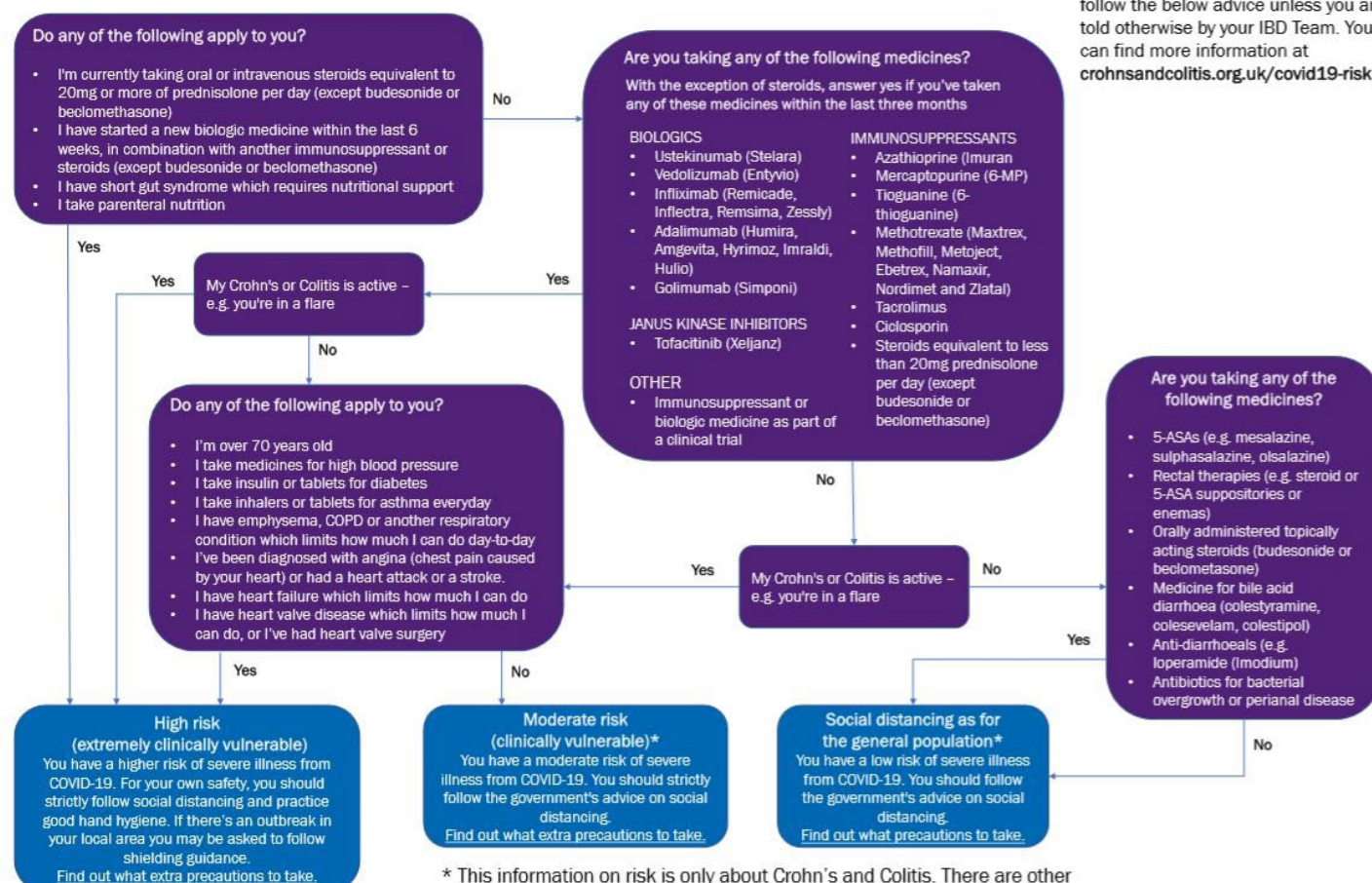
The information about a person's risk will also be sent to their IBD medical team. This will allow IBD teams to support patients better during this difficult time, as they will be able to contact patients directly with relevant advice.

Visit [www.crohnsandcolitis.org.uk/coronavirus](http://www.crohnsandcolitis.org.uk/coronavirus) for the latest guidance.

**CROHN'S & COLITIS UK**

## What's my risk level?

We are working with the British Society of Gastroenterology (BSG), who have put together specific guidance for people with Crohn's and Colitis. Please follow the below advice unless you are told otherwise by your IBD Team. You can find more information at [crohnsandcolitis.org.uk/covid19-risk](http://crohnsandcolitis.org.uk/covid19-risk)



\* This information on risk is only about Crohn's and Colitis. There are other factors which can impact your risk, such as your gender, ethnicity, age and other health conditions. Speak to your GP or healthcare team if you're worried.



# Poland

## “J-elita” Association reaches IBD community on-line

Instead of educational meetings on IBD for patients - webinars and podcasts. Polish Association Supporting People with IBD “J-elita” reaches IBD patients during the COVID-19 pandemic period on-line.

The educational seminars about IBD are one of our flagship projects. We organize around 11 meetings in the biggest Polish cities every year. During each seminar gastroenterologists and specialists from other fields give lectures about IBD and related subjects. Unfortunately, this year the COVID-19 pandemic forced us to cancel all of them. Instead of seminars, this spring we launched a special subpage on our website with information about IBD and the novel coronavirus. We also began providing free of charge psychological consultations for those who face difficulties while in isolation. In autumn we will start our webinars.

The first webinar with gastroenterologists - prof. Agnieszka Dobrowolska and prof. Piotr Eder from University in Poznań took place in June. The specialists were talking for over one hour about diagnosis and IBD treatment during a pandemic period and also were responding to questions posted by viewers. A video from the webinar is placed on “J-elita” website and Facebook Profile. It was seen by over 3600 people and we have received lots of emails with acknowledgements. Since July and August is a holiday period in Poland we plan to continue our next webinars in autumn and winter.



“J-elita” also provides patronage for IBD podcasts which are created with the support of Takeda. Talks about problems of the IBD community are hosted by a spokesperson of “J-elita”, Mr Jacek Holub, who was diagnosed with Crohn’s Disease over twenty years ago. So far his guests were Magdalena Sajak-Szczerba, Secretary of the Board of “J-elita” Association and EFCCA Board Member, Olga Gołębiewska, Board Member of EFCCA Youth Group and psychologist Agata Rudnik from the University in Gdańsk. Magda was talking about work and IBD, how to reconcile one thing with another, while Olga gave advice on how to travel with IBD.

A discussion with a psychologist was devoted to the acceptance of the disease, its influence on a treatment process and quality of life of IBD patients. There are new podcasts with IBD patients planned. IBD podcasts series created by Takeda are available in all podcast applications.

Let us not give into the pandemic. “J-elita’s” motto is: “We are stronger together”. If we cannot be in person, we will be on-line!

Jacek Holub  
Magdalena Sajak-Szczerba  
“J-elita” Association  
[www.j-elita.org.pl](http://www.j-elita.org.pl)

## Cyprus

### Bringing doctors and patients together!

The year 2020 has undoubtedly been a very difficult one with COVID-19 upsetting people’s lives and raising many questions regarding public health, thereby making people feel more vulnerable.

In May, Cyprus was under a strict lockdown and no people gatherings were allowed. Thus, the Cyprus Crohn’s and Ulcerative Colitis Association (CYCCA) had no opportunity to bring doctors and patients together on World IBD day, as we usually do. On the other hand, we felt it was essential to do something for our patients who were really anxious not only about their disease but also about the possible effects in case an IBD patient were to contract COVID-19.

We finally decided to bring doctors and patients together through the radio. We arranged two live radio programs one in the morning and one in the afternoon of May 19, with nationwide coverage, in which patients could phone in and ask doctors any questions they had related to both diseases.

This effort was very successful and the patients who tuned in were very grateful for the opportunity given to them. They expressed their relief after finding out that at least five IBD patients had been hit by the virus up to that day, without any further complications to their existing condition.

In such times of uncertainty and turmoil, we remain committed to supporting patients using any means available to us. We urge all patients to exercise social distancing and take precautions when they need to go out in public and we encourage them to stay in touch with our organisation should they wish to receive any information or voice any concerns.

CYCCA

# Serbia

## IBD podcasts

UKUKS in collaboration with Stetoskop info has embarked on an exciting new information campaign on IBD. Our interlocutors are well-known Serbian doctors, psychotherapists, psychiatrists, nutritionists as well as members of UKUKS.

We have subtitled all our material and hope that other EFCCA members will make use of our material and get a good insight on how challenges of IBD patients can be solved working together as a team. Our plan is to expand our topics from gastroenterology to surgery, dentistry, ophthalmology, dermatology and so on including all types of treatments available.

We are working on the project in cooperation with the Stetoskop.info platform, a platform dedicated to scheduling examinations in private medical practice. So far, we have covered several topics and we are continuing our work and are constantly searching for adequate interlocutors. We had great support from friends of our association who understood the need to create a project like this.

This is the link to our material in English: [UKUKS Vice President: IBD podcast](#). The Serbian version can be found on our website [www.ukuks.org](http://www.ukuks.org) in our podcast section.

As concerns other activities, unfortunately, COVID prevented us from realizing the planned actions, such as marking the 10th anniversary of UKUKS or marking World IBD Day.

Instead our activities have become more virtual and we started an online IBD counseling center where those interested can talk to gastroenterologists, psychotherapists, psychologists, and in the coming period we will also involve nutritionists.



This September we are publishing two brochures, one on anemia written by Dr. Olga Mitrović, our representative at the EFCCA Youth Group and the second brochure deals with pregnancy and IBD prepared by Dr. Zoran Milenković Gastroenterologist from the Military Medical Academy.

Finally, during the epidemic we made sure that patients receive therapy regularly and safely, so we organized transportation and delivery of drugs to those who could not come to receive therapy on time due to distance or justified reasons.

Of course, we were in constant contact with associations from the region, exchanging experiences in order to provide our members with the best possible quality of life with IBD.

UKUKS  
Ljiljan Djakovic



*Dr. Olga Mitrovi, author of the anemia brochure*





# Czech Republic

## Make IBD Work in Czech Republic

This year, due to Covid pandemic, we had to postpone our celebration of World IBD Day.

Well we had more time to prepare a really great campaign! In August the Czech IBD organization Pacienti IBD raised awareness about inflammatory diseases and explained to the public how difficult it can be to make it work with IBD. We fought the prejudices and showed that even IBD patients can be successful and have fulfilling careers. The week culminated with a special trip in Prague. More than hundred patients met in a historic train ride through Prague. We used mobile toilets and put stories on them.

Showing real people and their work successes.

So be courageous and @MakeIBDWork!



*These mobile toilets carried personal stories of what life with IBD and in particular Work and IBD is like for many people in the Czech Republic*



# New Zealand

## Urgent need for funding of new IBD medications

New Zealanders are mounting a strong campaign to obtain funding for standard medications that are available to people with IBD throughout the world. The country, known for its beautiful scenery and continually ranked as one of most desirable places in the world to live, gets a very low rating by many with IBD for taking care of its citizens with Crohn's disease and ulcerative colitis.

New Zealand has one of the world's highest per capita rates of IBD. Despite this, it has provided no funding for new medications since 2009, when it was one of the last OECD countries to fund infliximab and adalimumab. Unfortunately, the only option open to patients who fail to respond to these medications is surgery.

Doctors and patients are not only frustrated, but angry with Pharmac, the government agency charged with funding ustekinumab (Stelara) and vedolizumab (Entyvio). Pharmac's own Gastroenterology Advisory Committee has repeatedly recommended these medications be funded with the highest priority, only to have their advice ignored for the past two years. In response to this situation, on 24 August, EFCCA member Crohn's and Colitis New Zealand Charitable Trust launched a petition, urging the NZ Parliament to provide funding.

In only four days the petition received over 20,000 signatures, an impressive number for such a small country.

The petition has also raised incredible awareness and interest in IBD throughout New Zealand. It was a feature story on the nation's two largest evening news programs, received extensive coverage on national radio and was covered in two of country's largest newspapers, both in print and online.

The petition has the strong support of the New Zealand Society of Gastroenterology and the IBD Nurses Group of the New Zealand Nurses Association, representing virtually every medical professional in NZ who treats these diseases. With national elections approaching, it has become an election issue.

As a fellow EFCCA member, CCNZ is seeking the support of its international friends and partners to support and sign this petition. New Zealand accepts signers from abroad.

CCNZ has accepted no funds from Pharma for this campaign. It is being funded entirely through individual donations.

People around the world can help by signing the petition on its website: [www.wecantwait.nz](http://www.wecantwait.nz).

Please help.

Richard Stein  
Crohn's and Colitis New Zealand







# A world free from immune and inflammatory diseases. **That's our vision.**

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Through science and collaboration, we look to transform how diseases like rheumatoid arthritis, Crohn's disease, plaque psoriasis and asthma are treated today—and prevented tomorrow.

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But bringing forward new solutions isn't enough. We want to shorten the journey from diagnosis to treatment. And through our education and awareness programmes, we're here to help forge that path.

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The image depicted contains models and is being used for illustrative purposes only.

# Estonia

## Toilet cards for people with IBD

The Estonian Inflammatory Bowel Disease Association (EIBDA) has launched the first stage of the toilet/WC cards project issuing to members of the Estonian Association cards which enable them to use the closest toilet as fast as possible. In Estonian there are approximately 2500 people who need that every day. The card bears the name of the user and is issued to the members of the association for one year.

The Estonian Inflammatory Bowel Disease Association has carried out a questionnaire among its members at the beginning of May to find out how much their life is influenced by their disease. The aim of the questionnaire was to assess on a broader scale how much IBD influences the everyday life of people suffering from the disease. The majority of respondents (87.5%) confirmed that the disease has an impact on their everyday life. It includes unpleasant situations, embarrassing moments and also issues connected with getting and keeping a job. The questionnaire was carried out among the members of the association (EIBDA), including 32 patients within the age group in between 16 to 73 years. The respondents included people who had lived with this disease for 6 years and some even for 45 years! It was actually surprising that the main problem was connected with the complicated access to toilets in public places. The aim of the issued card is to confirm that the owner of the card may urgently need to go to the toilet.

The representative of EIBDA Janek Kapper says that people with IBD often have to use the toilet as quickly as possible because the disease does not let the person wait even for a very short time. "It may seem strange that we have to deal with such issues in the 21st century when people are queuing for toilets at big events and information providers working in different centres are not very prone to consider the concerns of the people suffering from IBD" said Kapper. "Visual observation does not reveal the person's problem and explaining the diagnosis in a loud voice is extremely uncomfortable," added Kapper.



Kapper hopes that now the card with a concrete reference confirms the urgent necessity to use the toilet and within a certain time period it may increase the awareness of the problems.

Janek Kapper turns to the representatives of shopping malls, administrative agencies, catering facilities, etc. and asks to inform the Estonian Inflammatory Bowel Disease Association whether they are ready to join the appeal and put a sticker saying "Not all disadvantages are visible" on the doors of the toilets.



It would ensure that the employees' awareness of the institution is increased and the patient with a toilet card could use the toilet immediately without any long explanations.

Our association is ready to post the names of the institutions, which have joined the project, on their web page so that also the members of the association know, which institutions are so-to-say IBD-friendly and can be visited without any major concerns.

As many developed countries have implemented analogical cards, the card owners can choose to visit these places while travelling.

Hereby, we invite patient organisations to cooperate more with each other to create an all-European toilet card system. As issuing a toilet card is not enough yet, a lot of information has to be distributed to institutions.



The second stage of the toilet card project is about to start, in which the Baltic States are to create a mobile application of the common toilet card that enables to find the closest toilet in Estonia, Latvia and Lithuania immediately. If you want to join the toilet card project, please contact us and we will do that together! United We Stand!

Janek Kapper. EIBDA

## Brazil

### Virtual event to mark Purple May 2020

A virtual congress held between the 10th and the 31st of May, with dozens of themes related to Inflammatory Bowel Diseases, marked Purple May 2020 in Brazil. Promoted by the National Association of Patients (DII Brasil) in partnership with regional associations, the event featured lectures by professionals from different areas.

Doctors from a wide range of specialties, nutritionists, dentists, psychologists, nurses, stoma therapists, pharmacists, lawyers, physical educators and therapists addressed the issues in videos that remain available to the public on the DII Brasil's Youtube channel.

Due to the COVID-19 pandemic on Purple May 2020 we wanted to provide knowledge and clarifying doubts of patients with Crohn's Disease and Ulcerative Colitis. Our association had to adapt its original plans and to move to a virtual event, but we are proud to say that after our evaluation the results of our virtual actions have been positive. The internet allowed us to reach more people and we could be more effective in this way.



“We managed to reach a significantly greater number of people than we would have managed during face-to-face events” reflects the president of DII Brasil, Patrícia Mendes.

In addition to the Purple May Virtual Congress, the DII Brazil promoted the World IBD Day (May 19) together with the main soccer teams from some Brazilian regions.

Flamengo, Botafogo, Vasco da Gama, Atlético Mineiro and Grêmio posted on their social networks referring to World IBD Day. On Instagram, Flamengo's post reached 29,899 likes. Botafogo, 12,961 totalizing 42,860 likes.

Throughout May in partnership with our regional associations, DII Brasil also carried out a campaign to publicize photos on social networks.

With a standardized layout reinforcing that social distance does not detract from the cause, each patient was highlighted with their names and which IBD they have to deal with in their daily life.

For more info: [www.youtube.com/c/DIIBrasil](https://www.youtube.com/c/DIIBrasil)

By Ana Guimarães  
DII Brasil

## France

### COVID-19 and IBD: AFA on the Digital Front

The COVID-19 crisis and the resulting quarantine have upset our daily lives and have caused unprecedented situations. Discovering this virus day by day, its impacts, the risks involved related to the treatments or to each one's own pathological problem have raised issues with numerous questions and uncertainties.

The impact of this lockdown, the lack of economic perspective, in particular, haven't escaped afa.

Very quickly it became obvious that the role of patient associations wasn't limited to the day to day routine: more than ever, in times of a crisis, patient associations must be even closer to their patients and their family and friends to inform and reassure them, but also (and most importantly) to carry the voice of these patients to the higher levels of the political and health decision makers to insure and provide the proper sanitary security.

In fact, the first thing afa decided to do in early March, even before the quarantine was announced, was to challenge the Ministry of Health and Solidarity

by suggesting the recommendations which were necessary for IBD patients, in accordance with the medical societies, to not suspend their treatments.

#### Support and Reassure

In order to respond to the many patient requests and reassure them, afa regularly published several pages of information on the social network and on the afa website. Afa reinforced the IBD Info Service hotline, open all day, handled by volunteer patients trained in active listening and Therapeutic Expert Patient (ETP) procedures to help patients with their urgent need for information and psychological reassurance. A professional work monitoring unit was also developed every week by e-mail and phone.

The psychological impact due to the lockdown and to the epidemic context made it necessary to develop specific themes to accompany patients: a specific heading on the afa website forum, virtual “MICI Kawas” (patient support groups to exchange feelings and experiences led by the regional volunteers), psychological permanence and a special virtual ETP workshop aimed at releasing the feelings and emotions created by the crisis.

To help live through these unusual times, afa and its volunteers launched “MICI Coach” (IBD Coach): a video programme to provide well-being and moral building: relaxation, well-being, physical exercises and mindfulness, cooking... A highly successful programme which has motivated afa to continue!

## Inform and fight against fake news: a digital role

The internet has become a vital ally providing information in fighting against fake news, especially during the lockdown. It was also a constant lifeline to stay in touch with the medical teams who regularly provided the quality medical and research information shared with the patients.

More than 10.000 people watched live or in replay afa’s programmes and interviews with experts linked to the COVID-19 coronavirus: specific medical questions on IBD and COVID-19, practical social and professional concerns, paediatric issues...

Another successful program over this period of time: “Directs de l’afa” one-hour webinars on specific themes in conference-style with eminent physicians, interviewed by the afa staff and equally produced by afa. Launched in 2018, these interactive web conferences have become extremely popular.

They allow afa to treat a subject in depth with experts who can answer web surfers’ questions directly and immediately.

Three “Directs de l’afa” took place over the two-month quarantine period with thousands of participants.



The themes discussed were:

- COVID-19 and IBD: Ask your questions
- Vaccination at the heart of the crisis
- Quarantine or no quarantine: that is the question

In the coming months more “Directs de l’afa” are scheduled, particularly on the role of nutrition and environment on IBD, living with a stoma...

These may be viewed in replay on afa’s Web TV on YouTube at <https://www.youtube.com/channel/UCTNFBFnbh07oQ3Y8cj9DD4w>

# Spain

## Patients' complaints when using certain adalimumab products are justified

361 IBD patients receiving adalimumab participated in an online survey launched by ACCU España aimed to verify if the change in pain perception during subcutaneous administration correlates with the drug formulation and, if so, the consequences related to this phenomenon.

Among other reasons for running the survey was that it is only through scientific evidence that decisions are made at different levels: administration, management and clinical consultations. And right now we are faced with people who justify the use of painful products, since they consider pain to be a subjective factor and, therefore, related to each patient's perception and not to the product itself.

The results of our study will be presented at two important scientific meetings: the National Congress of the Spanish Society of Hospital Pharmacy (SEFH) and the United European Gastroenterology (UEG) Week 2020. This year, thanks to our study, IBD patients will be given a voice so that both hospital pharmacy professionals and gastroenterologists will be aware of our requirements.

What results will we share at these events?

It is correct to say that pain is, to some extent, subjective: regardless of the product formulation, some patients feel pain when injecting adalimumab, and others do not.

The percentage of people receiving adalimumab with citrate buffer who claim to feel pain is higher than those who use adalimumab without citrate.

The intensity of pain perceived by patients using biosimilars with citrate buffer is 1.5 and 1.8 times higher than the one reported by people receiving the corresponding treatment without citrate or the original drug, respectively.



We are aware that the data presented are preliminary and that there are other factors that may affect a patients' satisfaction with their treatment (e.g., size of the needle, manageability of the device). Even so, previous studies already demonstrated the role of citrate in the perception of pain and here we confirmed patients' ability to recognize between different adalimumab formulations. Thus, we ask that patients' preferences are taken into account when prescribing adalimumab.



# WORK and IBD

On May 19 ACCU España launched a clear message “productivity relates to people and companies, not to the disease” with the campaign #TrabajarconEII (workwithIBD).

With this campaign we joined the initiative promoted by EFCCA which asked its members to talk about IBD and employment.

In Spain, there was a great deal of participation in speaking and commenting good practices that are necessary to reconcile work life and chronic illness and showing ways of implementation. This was narrated in the first person by patients themselves, managers and team leaders and the international company INDRA.

Our regional associations were an essential part of the campaign and showed both through social networks and press releases that people with Crohn's

and ulcerative colitis can develop all their assets and commitments within a company if the right conditions are in place.

1. ACCU Jaén created several videos for World IBD Day with a testimonial by Angela who spoke about her working life as a patient.
2. ACCU Canarias shared a video with the testimony of Noah.
3. Amparo Cuenca, partner and volunteer of ACCU C-LM also talked about the campaign
4. ACCU León joined the campaign with the videos of Estíbaliz and Álvaro explaining the good practices that occur in their workplaces.
5. ACCU Madrid participated with 3 patient videos. Elisa, Isabel and Dani explaining their work experiences: all of them positive but very different from each other.

## Concepto creativo



## ¿Qué supone realmente trabajar con EII?

- ✓ Los retos, dudas, miedos, objetivos son los mismos para una persona con EII que para el resto.
- ✓ Todos, todas, queremos hacer bien nuestro trabajo, sentirnos orgullosos, llegar a objetivos y desarrollar nuestra parte profesional como cualquiera, tenga o no EII. Por eso las personas que tenemos EII no somos menos válidas, ambiciosas, competitivas, responsables o peores trabajadoras.

# EU4Health Civil Society Alliance



70% of Europeans want the EU to do more for health, according to a recent Eurobarometer survey. This is why a pool of European organisations came together to ensure that the European institutions will continue to guarantee health protection and promotion.

Started as a reaction to the Future of Europe white paper presented in 2017 by European Commission President Jean Claude Juncker, which included, in the 5 outlined scenarios, the option to “do less” on some policy areas, the [EU4health](#) campaign aims to ensure that EU action on health remains strong after 2020.

## How to harvest long-term health benefits of the EU4Health programme?

Despite the concerning European Council’s budget cuts, already commented (see page 7), the [EU4Health](#) programme still represents a unique chance for the EU to improve population health, healthcare access and quality, while preventing diseases, reducing unfair and avoidable health inequalities and bringing innovation to our health systems for the benefit of all people in Europe.

However, its goals will be achieved only through adequate long-term resourcing, and a forward-looking inclusive and co-developed design, implementation and evaluation of the Programme itself. Public interest health civil society will be a partner throughout the process!

The EU4Health Civil Society Alliance carried out an informal, joint analysis of the [EU4Health Commission programme](#), following their previous [statement](#), and issued in reaction to the cuts in the health programme, the following key conclusions.

The programme should:

1. Ensure long-term health improvements by boosting disease prevention, health promotion and public health action;
  2. Ensure access to care by reducing inequalities in Europe;
  3. Strengthen European health systems beyond the COVID-19 crisis.
- The [EU4Health Civil Society Alliance](#) also agreed on some common views and principles that should guide the new EU4Health programme:
1. The EU4Health programme and its budget should address not only the COVID-19 recovery, but a sustainable system able to cope with emergency situations and crises in the future;
  2. Civil society health organisations are an essential resource in shaping health policy at national and European levels;
  3. The role of health promotion, primary prevention and recovery support should be strengthened and prioritised to improve physical and mental health, and the well-being of all people living in Europe;
  4. The EU4Health programme should include actions to support health literacy and digital health literacy improvements for people of all ages living in Europe;
  5. The focus on cancer offers an exciting case study and template for what focused EU health cooperation can achieve;
  6. Special focus should be given to other non-communicable diseases and their risk factors such as nutrition, smoking and alcohol consumption;
  7. Coherence should be ensured with other elements of the EU budget;
  8. Solid governance and dedicated coordination structure for the EU4Health programme;
  9. Better harmonised data systems;
  10. Strengthening of EU agencies, in particular the ECDC and EMA.

More info: <https://eu4health.eu/>



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Modern medicine has changed the world – but billions of patients still lack access to the medicines they need.

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# US Patient groups warn: Administration policy encourages discrimination in health care

In June 29 patient and consumer groups representing millions of people in the US with pre-existing health conditions issued the following statement in response to administration's final rule. The rule attempts to undermine Section 1557 of the Affordable Care Act by removing explicit protections against discrimination of patients by providers and institutions:

"By finalizing these changes, the Administration tries to unwind significant advances that have ensured vulnerable populations, including individuals with pre-existing conditions, are free from discrimination and able to access healthcare. The elimination of these important protections will result in severe consequences for the health and well-being of Americans seeking health care, especially those with serious, acute, chronic or other pre-existing conditions and those in vulnerable and under-served communities.

Many Americans and their dependents will now be less likely to access preventive, diagnostic, and critical health care, or to enforce their rights to obtain such care.

This is especially detrimental to the health and well-being of those living with pre-existing conditions, as well as women, LGBTQI+ individuals, people with disabilities, and those with limited English proficiency. These communities have long faced discrimination, bias, stigma, substandard care, and the denial of care. We are disturbed that the Administration is trying to undermine the equitable application and enforcement of the law and making it more likely that providers and institutions will discriminate against millions of Americans in need of health care.

Particularly as the world confronts a global pandemic, these actions have no place within our system of care and put the public's health at risk. Those that fear discrimination will be less likely to seek care and treatment for COVID-19. This puts the entire population at risk and undermines federal, state, and local efforts to control the virus.

As a result, we express our continued opposition and deep concern over the changes finalized by the administration and urge immediate action to prevent this regulation from taking full effect."

- *Alpha-1 Foundation*
- *American Cancer Society*
- *Cancer Action Network*
- *American Kidney Fund*
- *American Lung Association*
- *Cancer Support Community*
- *Cancercare*
- *Chronic Disease Coalition*
- *COPD Foundation*
- *Crohn's & Colitis Foundation*
- *Epilepsy Foundation*
- *Family Voices*
- *Hemophilia Federation of America*
- *Immune Deficiency Foundation*
- *Leukemia & Lymphoma Society*
- *Mended Hearts & Mended Little Hearts*
- *Muscular Dystrophy Association*
- *National Alliance on Mental Illness*
- *National Health Council*
- *National Hemophilia Foundation*
- *National Multiple Sclerosis Society*
- *National Organization for Rare Disorders*
- *National Patient Advocate Foundation*
- *National Psoriasis Foundation*
- *Pulmonary Hypertension Association*
- *Susan G. Komen*
- *The AIDS Institute*
- *The American Liver Foundation*
- *United Way Worldwide*
- *WomenHeart: The National Coalition for Women with Heart Disease*



# International Self-Care Foundation

## 2020: A new decade of self-care amid the COVID-19 pandemic

The coronavirus (COVID-19) pandemic has illustrated the importance of self-care - in good hygiene practices such as handwashing, covering coughs and sneezes, and the use of facemasks. Self-care is also central to mutual risk reduction through physical distancing, in community spirit and collaboration, and in cultivating mental and physical wellbeing during lockdowns.

This is especially true for elderly people and those with pre-existing chronic conditions including cardiovascular disease, cancer, hypertension, respiratory conditions and diabetes and obesity. The benefits of self-care are particularly significant for people with such chronic diseases.

To further illustrate how the lessons from the COVID-19 experience makes self-care a central component of everyone's health, [a new paper by the Mitchell Institute in Australia](#) has been published in time for International Self-Care Day. July 24th is set aside each year to recognize self-care as an essential foundation for good health for individuals and populations.

The new report, "Self-care and health: by all, for all" Learning from COVID-19, highlights the effectiveness of self-care in improving health and wellbeing for individuals and communities.

Professor of Health Policy in Australia, Rosemary Calder says that "We have had strong national and local leadership throughout the COVID-19 experience that has been focussed on getting each one of us to help keep ourselves safe from infection, and to help others by doing so. We have a once-in-a-lifetime opportunity to apply this lesson to develop our health system to help people to be healthier, rather than waiting for them to be unwell with health problems that are preventable - which is what happens now."



The report recommends that governments focus on enabling the health system to embed self-care support in all health care services and to prioritise prevention and management of both infectious and chronic diseases, particularly in primary health care. "Self-care by all, for all, needs to become usual behaviour and practice in community life, with the same strong leadership from governments and health experts that has been so effective through the pandemic.

This approach will not only help improve the health of individuals, it will build our ability to protect ourselves against infectious diseases like COVID-19."

Covid-related self-care measures (hand hygiene, masks and social distancing) are but a part of the Seven Pillars of Self-Care. When all seven pillars are encouraged and followed, the health benefits to society and the individual self-carer can be enormous.

For more information, please visit: [isfglobal.org](https://isfglobal.org)

# Is there a better way to optimise disease control for patients with ulcerative colitis? A new study aims to find out

Achieving and maintaining effective control of ulcerative colitis is the goal of treatment, but, as all patients know, it can be a challenge. Current management of mild-to-moderate ulcerative colitis is typically guided by symptoms, with therapy increased during a flare and decreased when controlled.

## OPTIMISE

This can be considered quite reactive and may result in patients quickly moving through increasingly strong therapy options, such as steroids and biologics, which can potentially have serious side effects, to combat a disease flare.

The arrival of new, easier ways for patients to accurately measure their disease activity, such as measuring faecal calprotectin levels, has the potential to better guide treatment optimisation and achieve better outcomes.

A new international study called OPTIMISE ([clinicaltrials.gov](https://clinicaltrials.gov/ct2/show/study/NCT043340895) NCT043340895), organized by Ferring, aims to find out if a more proactive approach to management does indeed improve disease control and patients' lives.

The OPTIMISE study has a practical (pragmatic) design and will compare two management approaches in patients with active mild-to-moderate ulcerative colitis who are currently receiving either no treatment regimen or mesalazine (5-aminosalicylates, 5-ASA):

1. Current management - treatment decisions based on symptoms.
2. Proactive management - treatment decisions based on faecal calprotectin levels and symptoms.

The proactive management approach has a number of potential advantages over current management:

- Increased patient involvement in management of their disease
  - > Home monitoring of faecal calprotectin
- Earlier treatment decisions
- Improved use of mesalazine treatment and use of locally acting steroids with few side effects
- Avoid use of (systemic, wide acting) steroids and biologics when not needed
  - > Reduced side effects for patients
  - > Money savings on biologics for the health care system
- Avoid endoscopies/colonoscopies by monitoring faecal calprotectin
- Longer-term disease control (remission) by basing treatment decisions on actual disease activity, rather than just on symptoms
- Help doctors to manage their patients better by providing simple information on when best to increase and decrease treatment

The study duration for each patient will be 1 year and involve around 240 patients from 30-50 hospitals and is recruiting currently in 3 countries (Poland, Czech Republic and Netherlands) and looking to expand to other countries.

If you have active ulcerative colitis and are currently receiving no treatment or mesalazine treatment and live in one of the study countries, please contact your doctor / IBD service about potentially being involved in the OPTIMISE study.

**Increased, proactive involvement by patients in monitoring their disease activity may offer a better way to help optimise treatment for ulcerative colitis**

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