

EFCCA MAGAZINE

EUROPEAN FEDERATION OF CROHN'S AND ULCERATIVE COLITIS ASSOCIATIONS

MAY 2022



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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
Crohn's and Colitis Ireland
www.iscc.ie

Israel - CCFI
www.ccfi.co.il

Italy - AMICI
www.amiciitalia.org

Latvia - LKKSBB
www.lkksb.lv

Lithuania - CCLA
www.draugija.info

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

Malta - MACC
www.macc.org.mt

Montenegro - CUKUK
www.cukuk.me

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

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

Norway - LMF
www.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.ibhportal.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 - FVPZK
www.vzk.kz

Mexico - CUCI
www.crohnucui.org.mx

Russia - Trust
www.vzk-life.ru

Singapore
Crohn's and Colitis Singapore
www.ibd.org.sg/english

Trinidad and Tobago - NACCTT
www.crohnsandcolitistt.org

Ukraine - Fulfilling life
www.gofulllife.com.ua

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Solidarity

It is a pleasure to introduce this new issue of the magazine, which, as always, is full of information for the community of people affected by Crohn's Disease and Ulcerative Colitis and the scientific community.

We have been faced with an unprecedented two years in which the concept of normality in our lives has been distorted more than we could have imagined, and we have found ourselves facing an emergency caused by a war that is bringing destruction and pain to many people.

EFCCA is an organization for the protection and assistance of patients, so I will not venture into a political discourse that is not within our competence. We were spectators of what was happening, and we accepted the request for help from our Ukrainian association. Since patients there were running out of IBD-specific medications, we launched a support campaign and we received positive feedback.

The EFCCA Staff worked to figure out how to deliver what we collected. We also created a solidarity fund to buy the medications, and I am proud to say that we were able to offer suitable solutions. Yes, we were able to provide to a regional hospital in Lviv, and our association and IBD specialists are working on distributing them to patients in need.

We would like to give a special thanks to Dr. Falk Pharma, Apotheke Helfen e.V., Navis e.V. and to all those colleagues who have helped our efforts to respond to this emergency situation and in particular would like to thank colleagues from our members in Estonia (EPSS), Greece (HELLESC), Hungary (MCCBE), Italy (AMICI) the Netherlands (Crohn and Colitis NL) and of course J-elita from Poland who has been in the forefront and is putting also a lot of efforts in supporting IBD patients who are arriving as refugees in Poland.



“Our General Assembly will be an important moment to reconnect with each other and to understand the basic value of our organisation that is founded on solidarity.”

In this issue you will see that despite this emergency situation we have managed to continue our planned work activities and I am in particular pleased with our new collaboration with the European Association of Hospital Pharmacists and look forward to our active participation in next year's EAHP congress.

And of course, this month is an important time for us when we will rally behind many IBD associations and activists to raise awareness around Crohn's disease and Ulcerative Colitis for World IBD Day. This year EFCCA would like to raise awareness about IBD's impact on older people. We will use the slogan, IBD has no age in order to focus on older people (60 plus) as this group has been consistently underrepresented even though the incidence and prevalence of IBD in older patients is rising. You will find in the magazine more detail regarding the IBD has no age campaign.

This month we will also meet with all our delegates at the EFCCA General Assembly. We have split our GA into two parts: an on-line meeting to fulfil our legal obligation as an association followed by a face to face meeting to finally, after two years, meet with each other again to exchange information and brainstorm on our future activities. I look very much forward to it!

It will be an important moment to reconnect with each other and to understand the basic value of our organisation that is founded on solidarity. Solidarity is about care, affection, closeness and love. We know that some of our colleagues will not be able to join us and we will dearly miss them. A big hug to all patients who are suffering from wars all over the world. Nobody excluded.

United We Stand,
Salvo Leone, EFCCA Chairman

Supporting people with IBD in Ukraine

Since the beginning of the war in Ukraine EFCCA has been standing in solidarity with its Ukrainian member Fulfilling Life and is working hard to support the association and its IBD patient community.

Our first concern was to find solutions to the shortage of basic IBD medicines experienced by our colleagues. We have managed to mobilise many of our stakeholders and as a first step with the help of the NGO APOTHEKER HELFEN e.V. and NAVIS e.V as well as the kind donation of Dr Falk Pharma GmbH we have managed to send a shipment of IBD specific medications to a regional hospital in Lviv (a city in the West of Ukraine and close to the Polish border) at the beginning of April.

Furthermore, we are pleased to say that several of our members have managed to deliver direct support to our colleagues in Ukraine namely our member EPSS in Estonia, HELLESCC in Greece and of course J-elita in Poland that has been involved since the beginning of the war to find solutions and support not only our colleagues in Ukraine but also to refugees with IBD who have and still are arriving in Poland in great numbers.

Our Dutch member Crohn and Colitis NL has organized a fund raiser with funds being destined to purchasing more IBD medicines and we are in discussions with several other members to see how to best provide support. We have set up an emergency fund and have already secured some funding. We hope to use the emergency fund in the future for other ad-hoc support.

At the institutional level, upon advice, our colleagues in Ukraine have submitted a formal letter to the



Volunteers unloading the donated medicines from Dr Falk Pharma delivered to the regional hospital in Lviv

Ukrainian Ministry of Health which has been sent to the Ministry of Health in Poland - that is on the forefront of medicines distribution to Ukraine - to also include medicines for the treatment in IBD in their humanitarian shipping.

These weeks have been busy and challenging - and for sure more will be ahead - but we will work relentlessly to achieve our core mission to improve the life of people with IBD whatever the circumstances are. The solidarity and support shown by our members confirms the strength of our network!

Our thoughts are with all people of Ukraine.
United We Stand!

Isabella Haaf,
Deputy Director

Towards a new EFCCA strategy plan (2023 -2027)

Another year passed without us being able to see each other in person. The pandemic with its ups and downs has continued to influence our lives, our choices, and consequently also our association's life.

EFCCA has invested resources and a bit of creativity to keep alive and vibrant the relationships with its members: the EFCCA Talks, the Happy Hours, and most of all the exchange of ideas and possible joint projects have made this year a little less lonely and we are finally looking forward to meeting again and spending some time together.

At the beginning of this year, the EFCCA Board was confronted with important decisions regarding the General Assembly and its institutional activities in accordance with Belgian law.

Some mandatory tasks need to be fulfilled within May, such as the vote on reports, provisional workplan and budget, elections of board members and this year also the chairperson. In January 2022 the situation still was not clear enough to make a decision on whether to convene the General Assembly in person on the last weekend in May, as we used to do "before COVID", or to hold it online again.

We therefore decided to propose a hybrid solution to our members and delegates:

- To organise the institutional part of the General Assembly online in order to present, discuss and vote the documents of the past year (activity report, financial report, provisional budget, workplan) that are necessary to ensure the proper functioning of our association and to choose the board members and chairperson. This option is giving ALL delegates the chance to participate and be fully informed about the functioning of the Federation.
- To give every delegate the opportunity to attend an event to be held in person in June in the hope that the restrictions due to the pandemic will be finally cleared in most of our member countries. This second event will take place in Barcelona from 10-12 June. The event is particularly important for us: the whole Saturday will be focused on our new Strategic Plan. We will have first an assessment on the previous one and present and debate about the weaknesses and strengths of the activities we have run in the past four years. An evaluation report will be presented, and we will welcome contributions from the delegates.

The second part of the day will be devoted to designing the skeleton and the main strategic areas EFCCA wants to concentrate on from 2023 to 2027. This piece of work is meant to be interactive and creative. The Board aims to involve all delegates in the brainstorming. The final purpose of this group work will be to build the structure of the strategy plan and to fix a calendar of online consultations that will take place between September 2022 and February 2023 after which the new plan will be presented and voted on during the next GA in 2023.

This is a very ambitious goal that will require the active participation and contribution of all delegates. We hope that delegates will keep up the momentum and ensure their continued participation in the coming months ahead. External facilitators, experts in the field of health, advocacy and engagement will be involved throughout the creative process.

We look forward to meeting you all in Barcelona, finally in person.

Luisa Avedano, CEO

World IBD Day 2022

IBD has no age

This year for World IBD Day 2022, EFCCA is raising awareness about IBD in the elderly. Our campaign "*IBD has no age*" will highlight how living with Crohn's disease and Ulcerative Colitis (collectively known as Inflammatory Bowel Disease) is impacting on the quality of life and care of the elderly (60+).

Why focus on the elderly?

This group has been consistently underrepresented even though the incidence and prevalence of IBD in older patients is rising. There are estimates that in the next decade, older patients with IBD will represent more than one-third of all patients with IBD. Yet, there is little scientific evidence to understand how IBD impacts on adverse health outcomes or quality of life in older people with IBD.

EFCCA wants to raise awareness around the importance of this issue and launch a survey this year in order to better understand what the current unmet needs of the older IBD patient community are.

Through our social media campaign that includes several patient testimonials we want to be the voice of elderly people with IBD as we believe that focusing on the older population is not only community care, but also selfcare.

More info:

www.efcca.org/en/ibd-has-no-age-world-ibd-day-2022

EFCCA Purple Talk

On 19 May, World IBD Day, we will host an EFCCA Purple Talk with representatives from the scientific and IBD patient community to discuss the need for more research and investigation on the issue of IBD and the elderly.


We strongly believe that such scientific evidence is necessary in order to make decisions on the most appropriate therapeutic management of this age group. Join our discussions to find out more!

Link: www.facebook.com/events/3074406296144950

EFCCA PURPLE TALK:

"IBD HAS NO AGE"

19 MAY, 5 PM (CET)



Join our Purple Talk for World IBD Day 2022 discussing about IBD in the elderly, why it matters and what we are going to do about it

More info: bella.haaf@efcca.org

Focus group meeting

Within the framework of World IBD Day 2022 under the slogan “IBD has no age” we organized an on-line focus group meeting involving eight patient representatives, which took place on 23 February 2022. The aim was to get a better insight into the subject of IBD in the elderly and to discuss and exchange experiences to be fed into our campaign for World IBD Day.

There were lively discussions around the unmet needs of elderly IBD patients and it emerged that many of the unmet needs are similar to the ones of any age group of people living with IBD including a reduced quality of life despite “successful” medical treatment.

What also became evident was the complexity of the disease and that there is no “typical” older IBD person. There is a variety of ways that IBD can affect a patient and some 60-year-olds will have the same physical and capacities similar to many 20-year-olds IBD patients. Other people experience declines in physical



and other capacities at much younger ages.

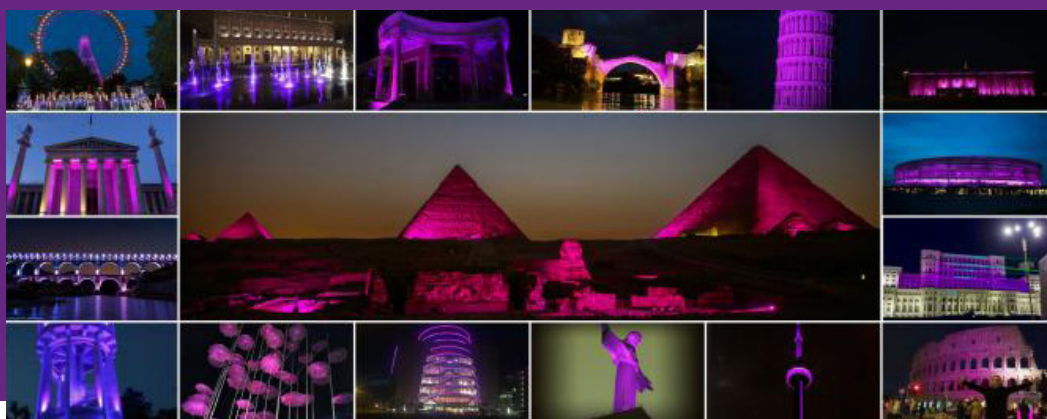
We would like to thank the participants of this Focus group for their time, input and lively participation in the discussion. They have been very useful for our planning of the awareness raising campaign and the development of a survey on this topic.

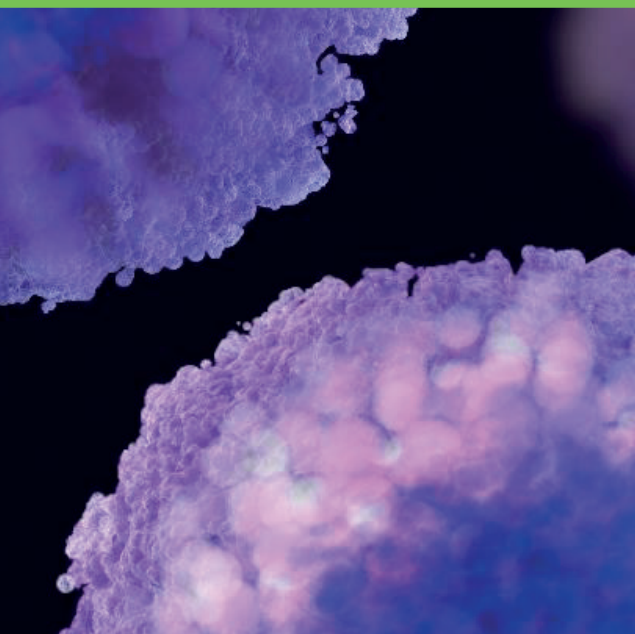
Purple Lightening campaign

EFCCA has been coordinating the global campaign aimed at raising IBD awareness 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.

In some countries the whole month of May will be dedicated to raising IBD awareness.

Check out the www.worldibdday.org website to see what is happening globally!





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
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Care More. Act Differently.

Strengthening our collaboration with Hospital Pharmacists – EAHP Congress

Our EFCCA CEO and Deputy Director attended the 26th Annual Congress of the European Association of Hospital Pharmacists (EAHP) which took place in Vienna, Austria from 23-25 March 2022. The theme of the congress was “hospital pharmacists - changing roles in a changing world”.

As our world is evolving quickly this translates into new needs and expectations from society. The congress aimed to determine and to explore the changing roles of hospital pharmacists in this evolving scene.

We were therefore pleased to have been invited for a meeting with the EAHP leadership during the Congress to discuss common objectives and potential projects of collaboration related to IBD patients in the hospital setting.

Considering that hospital pharmacists play an important role in counselling patients on medication options and medication education as well as assisting with medication access and monitoring the efficacy of current treatment we believe that EFCCA's collaboration with EAHP will be beneficial to the IBD patient community.

Projects in the pipeline include educational activities as well as participating in the programme of next year's congress in Lisbon in order to provide the patient perspective on the theme of “From drug design to treatment success – what really matters to patients?”

Stay tuned!

About EAHP

EAHP represents and develops the hospital pharmacy profession within Europe in order to ensure the continuous improvement of care and outcomes for patients in the hospital setting. This is achieved through science, research, education, practice, as well as sharing best-practice and responsibility with other healthcare professionals.



European Forum of Patients with Inflammatory Bowel Diseases

The meeting was organized on March 31 by the Polish Association Supporting People with IBD “J-elita” together with the Editorial Office MedExpress.pl and in cooperation with EFCCA.

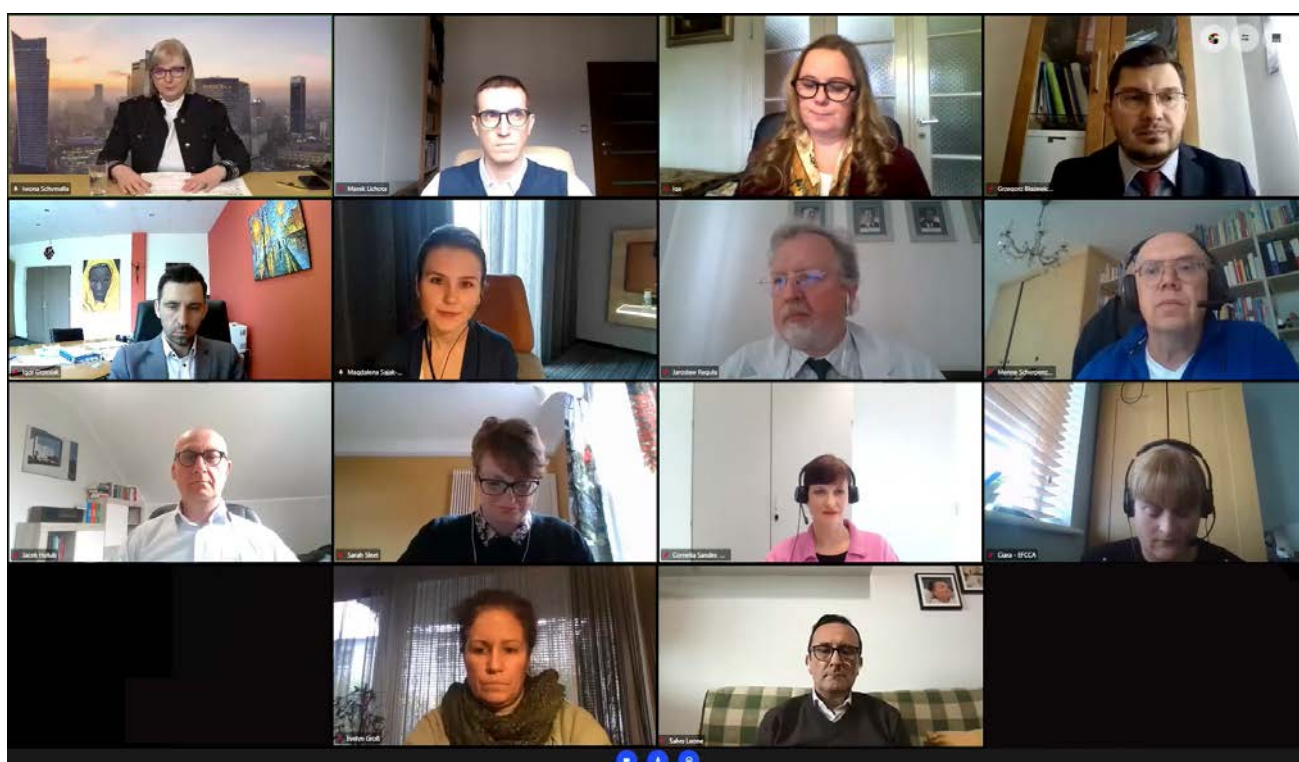
The aim of the meeting was to present different perspectives, experiences from different European countries and Poland regarding the personalization of treatment of people with IBD as well as the experiences of patients during the pandemic. Crises show how important it is to personalize treatment, treatment tailored to the patient's expectations, his/her readiness to undertake a given type of treatment and the form of administration.

The meeting was attended by Minister Grzegorz Błażewicz, Deputy Ombudsman for Patients' Rights, as well as Prof. dr hab. n. med. Jarosław Reguła National Consultant in the field of Gastroenterology.

From the part of the IBD community, the meeting was attended by representatives from Austria ÖMCCV - Österreichische Morbus Crohn / Colitis Ulcerosa Vereinigung; Czech Pacienti IBD, Germany - DCCV.e.V. - Deutsche Morbus Crohn / Colitis Ulcerosa Vereinigung, Ireland - Crohn's and Colitis Ireland, Italy - AMICI - Associazione per le malattie infiammatorie croniche dell' intestine, the Netherlands - Crohn & Colitis NL and United Kingdom - Crohn's and Colitis UK. Information on the situation in France was also prepared by the French AFA Crohn RCH France.

In addition, the meeting was attended by representatives from the coalition of Patients with IBD in Poland: the Appetite for Life Association and the EuropaColon Polska Foundation.

The meeting was organized under the patronage of the Institute of Patient Rights and Health Education.



EFCCA Academy

Empowering young IBD representatives

EFCCA has launched the Youth Academy with the aim to increase the representativeness of the youth group, create a cohesive group of leaders of tomorrow and to empower young representatives. The training programme addressed to young IBD patients (aged between 18 and 30) just came to an end.

Last 29 November 2021 we launched the first module of a new training programme for young IBD patients via the EFCCA online learning platform. After this introduction that was mainly focused on the history of EFCCA and its functions, the group of 30 students from 20 different EFCCA IBD associations met (virtually) Marco Greco, founder of the EFCCA Youth Group and its leader from 2003 till 2007 as well as Daniel Sundstein, EFCCA Youth Leader from 2012 to 2015.

In about 50 rapid-fire questions they told students about their first approach with IBD and their first steps in their local IBD associations, then their journey as EFCCA youth leaders to finally provide students with precious advice on how to be an effective leader and the importance of maintaining the youth group active and cohesive as youth represent the future of EFCCA as well as the future of research in IBD.

In the third module Clara Drammeh discussed *“The foundations for the democratic and harmonious development of second-level associations”*, teaching subjects like good governance, youth empowerment and strategic thinking and planning. Clara is a dedicated scout and youth advocate; she is experienced with facilitation in civil society contexts and non-formal education. She is also part of the pool of experts of the European Youth Forum, which is the platform of youth organisations in Europe representing over 100 youth organisations, which bring together tens of millions of young people from all over Europe.



In the final training module called *“Team building and leadership shaping: the basics”* that has been recently released, Clara again talked about *“Community Building and Leadership, Advocacy and Lobbying and Project Management”*, Isabella Haaf, our Deputy Director gave an overview on the role of communication and to conclude, Andrea Broggi, EFCCA Legal consultant, taught students why and how a patient organisation should be accountable and transparent to stakeholders.

The students still have some time to finish the training and we hope that they have been given the right tools to understand the role of a second level association such as EFCCA and what being a good youth advocate means.

Youth Workshop Series

It's not only about education but also good practices! At the end of the training modules of the Youth Academy, EFCCA has organized three different online workshops for its students. The first one focused on Advocacy campaigns, the second on Youth event organization and the latest one, just released last April 6, on Youth Engagement.

EFCCA collaborated with Cora Stalph from European Youth Forum - an intercultural trainer focused on empowering young people and sensitizing them to current developments in society - holding 3 different online interactive workshops with students.

In 9 hours, she brought 14 students from Italy, Ireland, Mexico, Finland, Norway, Slovakia, United Kingdom, Greece, Serbia, Belgium, Portugal, the Netherlands, Latvia and New Zealand into a practical discussion on the following themes: "Starting an Advocacy Campaign", "Basics of (youth) event planning" and "How to engage youths".

Each workshop started with sharing students' expectations regarding the topic. Then Cora continued with giving them an overview on the topic followed by different moments in which students worked in groups. Each workshop concluded with a moment of outlook and feedback.

During the workshop "Starting an Advocacy Campaign", the group of motivated youngsters first learnt how to structure it, then they were asked to work in a group and think of the different EFCCA contexts in which it would be useful to initiate a campaign and how.

The second day focused on "Basics of (youth) event planning". It has been a while that EFCCA has not organized a Youth Summer Camp, and we thought it was now a good moment to take up this activity again. During the workshop students had fun imagining what the next summer camp could look like, structuring it from different points of view but also analysing possible obstacles. They brainstormed on useful topics they could discuss during the summer camp and which can be a good starting point for EFCCA to understand the concerns of young people with IBD today.

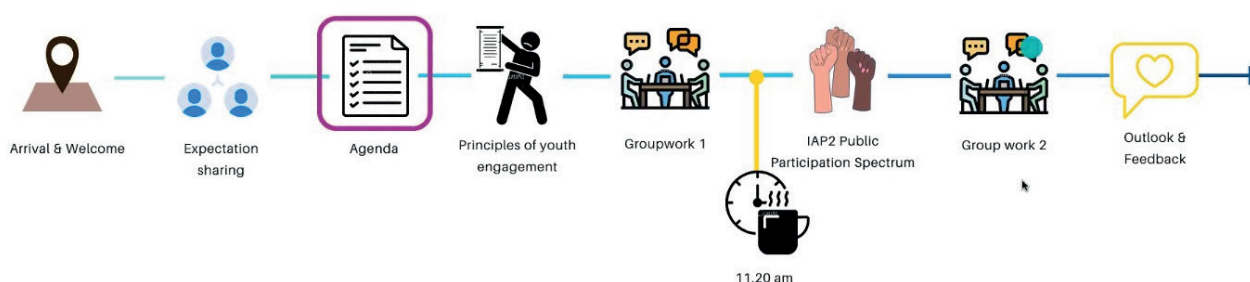
The final workshop "How to engage youths" analysed from a broader perspective the process of involvement of young people in associations and the different ways to make it effective as EFCCA wishes to be able, together with the support of the youth group, to welcome new youngsters who want to become leaders of the future.

More information: Maria Stella De Rocchis, European Project Office, mariastella.derocchis@efcca.org



TODAY'S AGENDA

3rd EFCCA Workshop: How to engage youth?



Ukraine

Without words

I never thought that our “member news” from Ukraine would be so tragic. Since Russia’s invasion of Ukraine our lives have been completely turned upside down. At 4 a.m. on February 24, 2022 we woke up to explosions and saw the message “The Russians are bombing Kyiv, the war has begun!”. That was more than a month ago, but it seems like we’ve been living in this nightmare for ages.

As founder of the Ukrainian IBD patient association Fulfilling Life which joined EFCCA during last year’s General Assembly, I was of course very concerned about how the war would affect our people living with IBD. We reached out to EFCCA and its members and have been working closely ever since to bring some hope and light to this difficult situation.

In the beginning of April, we were so happy when some of our efforts finally bore fruit and when we received 2 tons of IBD medicine from the German company Dr.Falk Pharma. Thanks to the sponsor company Dr.Falk Pharma GmbH and the organization NAVIS e.V. - Schnelle Hilfe ohne Grenzen that delivered medicines from Germany also of course to all the people that helped with this and in particular to Dr Kovalchuck who took on the role of coordinator in Lviv.

We were equally happy to receive other donations from EFCCA members in Greece (HELLESC) and Estonia (IBD EESTI) and for the relentless support from our colleagues in Poland at J-elita.

We are pleased to let you know that the first batches of medicines have already gone to over 12 regional hospitals in Kyiv, Kharkiv and Transcarpathia. There is still a lot of work to be done in order to deliver medicine to patients in different corners of Ukraine (some extremely difficult to reach). But this is a very fulfilling job we are happy to do!



I hope that this war is over soon and that I will be able to meet many of you in person as I want to give you all a big hug.

Elena Sotskova, Founder of Fulfilling Life



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

France

“If I were President...”: IBD proposals for tomorrow

For the French presidential election, 10 and 24 April 2022, afa has launched the questionnaire “If I were president...: My measures for the IBD cause”. 575 participants answered and transmitted their ideas to improve daily life for patients and their relatives. These measures will be the object of a letter addressed to the future President of France and will guide afa’s actions in the months and years to come.

Here is an overview of the main ideas:

To improve daily life: unsurprisingly, toilets are a priority, but also insurance and food.

For 74% of the participants, there are not enough toilets in the cities, a plea to politicians that afa has been making for over 10 years. Although some cities like Marseille have made great efforts (they started out with few or no toilets!), there are still too few accessible AND CLEAN toilets in the urban areas. Furthermore, afa would like to see the “toilet priority card” become official for all patients diagnosed with IBD.

The second priority is the suppression of the health questionnaire formerly required to obtain loan insurance, which was approved by 68% of respondents.

Food is a concern for 54% of respondents who want more warning information in their daily lives: the name of additives and preservatives clearly visible on labels, and having more clarity in the choice of their purchases.

In your verbatims to improve daily life: nutritional assistance, better awareness and education on food as of a young age, accessible refrigerators in long-distance transportation (trains, planes) for medicines.

To improve school, university and professional careers: specific recognition of invisible disabilities.

Even if the disability situation is already recognised, the invisibility of the disability is sometimes a problem in school, university or in professional life. 80% of respondents want this specificity to be recognised: fatigue, pain, eminent bowel movements, so many symptoms that cannot be seen! 49% want more opportunities and possibility to rest at work, and 54% more teleworking to be in a safer environment and avoid stressful transport.

Many also want better care from occupational medicine, to adapt working hours, possibly to have access to early retirement, in short, to have better consideration of IBD disability in the professional sector.

To improve the treatment process: more coverage of non-reimbursed, yet essential, procedures or consultations!

42% percent of respondents advocate the reimbursement of psychological support, as well as complementary therapies, dieticians, faecal calprotectin testing, etc.

And 67% want doctors’ training to teach more empathy, but also for general practitioners to be better trained in IBD.

Facilitating follow-up at home: 39% want more treatment at home and 27% want more teleconsultations. The observation is clear: they want to go less and less to the hospital for follow-ups or for treatments, because it is restrictive: additional fatigue, travel, obligation to take leave or time off work, etc.

To change the way Crohn's disease and ulcerative colitis are viewed: use the mainstream media.

70% want more reports on IBD on television and 66% want more communication campaigns. Objectives: eliminate the taboo, recognise the impact of the disease, all this from a very young age, since 63% of them believe that more awareness should be raised at school among pupils and teachers.

To raise awareness and the recognition of IBD, afa is calling for IBD to be recognised as a major national cause. Recently, endometriosis was declared a national cause by France's President Emmanuel Macron, so why not IBD and its 300,000 sufferers!

Measures to help relatives better understand the disease.

The Regards croisés sur les MICI study (Crossed views on IBD - afa 2020) revealed the significant impact of the disease on relatives, parents of young children (but also of older children), spouses, brothers

and sisters, and friends. 71% of respondents would like to ask for specific time off for relatives who need it, and 61% think that they should receive psychological support. Other ideas included a "special family consultation" to explain the disease and its impact. At the very least, raising awareness among doctors of the role played by patients' entourage could enable a shared consultation with a relative.

Another request was to set up more meetings reserved for relatives to encourage sharing and exchange. For example, the family weekend organised by afa for parents of very young patients, accompanied by their brothers and sisters, or the workshop for teenagers who can come with a friend or sibling to better understand their daily life with the disease. These moments of sharing and learning about IBD are good for the whole family, including the young patients. We cannot ignore the fact that the family and the support given to the sick person is essential in getting better, so we must accompany the immediate family as well as the patient! The family member must also be recognised by the medical profession as a full-fledged actor in the care process.



Poland

Polish Association “J-elita” in solidarity with Ukraine

Vladyslav from Kiev is twenty-three years old; he is a fourth-year law student at the University of the Ukrainian capital and suffers from ulcerative colitis. He came to Poland together with his mother, fourteen-year-old sister and father after Russia's invasion of his homeland.

They had to fit all their life's work in two suitcases. In Rzeszów, a Polish city of 200,000 people close to the border with Ukraine, the whole family came under the wings of the regional branch of “J-elita”.

“Father and son got a month's pass from the army. Vladyslav arrived terribly emaciated and exhausted, he is in severe exacerbation. Due to the war, he could not continue biological treatment in Ukraine – says Marlena Szajer from the branch of the “J-elita” Association in the Podkarpackie Voivodeship.

Many friends of “J-elita” - people, institutions and organizations were involved in helping Vladyslav and his family. Thanks to their kindness, the refugees found an apartment, got a living allowance, and Vladyslav receives biological therapy at the Provincial Clinical Hospital No. 2 in Rzeszów.

2.5 million refugees have come to Poland since the beginning of Russia's aggression against Ukraine. Volunteers of “J-elita” help them at the border and in various cities. “J-elita” has created on its website a special tab in Ukrainian for the IBD community.

The tab publishes information among others about free medical assistance and possibilities of obtaining a prescription. Patients from Ukraine who contact the “J-elita” Association, like Vladyslav, can get help in consulting a specialist and continuing treatment. Thanks to help from EFCCA, “J-elita” will soon launch a special helpline in Ukrainian for people with IBD and the possibility of telephone consultation with a

Ukrainian gastroenterologist who works in Poland. Additionally, refugees with IBD who face financial difficulties will receive gift cards for pharmacies that allows them to purchase medicines.

The “J-elita” Association also maintains constant contact with the Ukrainian IBD Patient Organization “Full life”. Thanks to this, “J-elita” mediates in talks with government agencies about the supply of medicines to the east. At the beginning of April, a transport with gifts, among others with adult diapers, catheters, dressings, toys, blankets, sleeping bags and cleaning products set off to Lviv in western Ukraine. We also delivered medications donated to Ukraine by the Hellenic Society of Crohn's Disease and Ulcerative Colitis Patients (HELLESCC). They were taken to Ukraine by volunteer of “J-elita” Daria Szajer.

*“ We are shocked by the war in Ukraine, and we are doing our best to support patients with ulcerative colitis and Crohn's disease, both in Poland and in the country invaded by Russia. We would like to thank EFCCA for supporting us in this effort.”*says Agnieszka Gołębiewska, President of the “J-elita's” Board.

Since there is no end in sight to this war, and the needs of IBD patients and their families are increasing, we appeal for further support for the people of Ukraine.

Jacek Holub
“J-elita” Association



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Italy

The value of collaboration

The Italian patient association AMICI signs two agreements with IG-IBP⁽¹⁾ and SIGENP⁽²⁾, continuing a common path for Italian IBD patients.

AMICI Onlus is committed to improving quality of life and care for people with IBD by raising awareness of IBD with the public ensuring a better integration into all aspects of a patients' life.

The role of AMICI Onlus

In recent years, AMICI Onlus worked together with doctors to demonstrate that early diagnosis and the use of "expensive therapies" can be a strategy to contain costs in the long term. The Diagnostic Therapeutic Assistance Pathway was an example of how patient organizations can propose solutions that are appropriate, sustainable and patient-centric.

Collaboration with scientific societies

AMICI Onlus submitted to the Ministry of Health 34 new services to be provided for IBD patients. Collaborations between patient associations and scientific societies are a new benchmark in healthcare.

A new world, new health needs

The future world will be hyper-connected: collaborations between organizations will be crucial for success, but this can only be possible using a common language. The strength of scientific societies and associations is understanding and accepting mutual differences. Collaboration is increasingly successful when you create something together and that's why collaboration also helps build trust among everyone involved.

Innovation and care-personalization are the new boundaries that we will have to face in the future to

assist IBD patients. It will be necessary to offer the right solution to each patient at the right time and provide multidisciplinary assistance, focused on the condition of the IBD person. We have come a long way together, but our journey has only just begun.

IBD in paediatric age: common plan is needed

The collaboration between SIGENP and AMICI Onlus has led to a registry, which currently records about 2000 patients from all over Italy and allows us to collect information and data to study IBD in paediatric age.



AMICI Onlus president Giuseppe Coppolino (left) and doctor Flavio Caprioli (President IG-IBD) (right)

Scientific activity

The joint action, with SIGENP and AMICI presented to the Ministry of Health, area clear desire of patients to join forces and take action to improve the condition of paediatric patients in Italy.

“We need to face several challenges in the next years”

Dr Flavio Caprioli, IG-IBD Secretary General, says that the cooperation with AMICI is crucial. Only through collaboration between patient associations and scientific organisations can we make a difference at the regional and national legislative level. Some of the most important issues we are working on are a national program to raise awareness, new clinical studies and a national register dedicated to IBD patient.

-
1. IG-IBD: (Italian Group for Inflammatory Bowel Diseases), Scientific association
 2. SIGENP (Italian Society of Gastroenterology, Hepatology and Paediatric Nutrition), Scientific Association



Paolo Lionetti (President SIGENP) (right) and AMICI Onlus President Giuseppe Coppolino (left)

Cyprus

Disabilities and benefits for IBD patients

The Pancyprrian Association of Ulcerative Colitis and Crohn's disease (CYCCA) is carrying out research that investigates the current status-quo with respect to the rights, disability allowance schemes, and their eligibility criteria, including any other disability-related benefits for IBD patients as experienced elsewhere in the EU.

Why is this important?

The increase in chronic health conditions and an ageing population means that a much higher number of people are experiencing disability. People with disability are faced with various barriers such as stigmatization and discrimination when accessing

health and health-related services and strategies. [Article 25 of the UN Convention on the Rights of Persons with Disabilities \(CRPD\)](#) stipulates the right of persons with disability to attain the highest standard of health, without discrimination.

CYCCA is interested in gaining information from other member countries of the EU with regard to state help for IBD patients, eligibility criteria for disability allowance, disability rights for IBD in terms of public services (transport, parking etc.) as well as other discounts in basic utilities, taxation etc.

For more information, please write to Athina Spanou at: cycca.org@gmail.com

Singapore

Our journey

In June 2011 when Nidhi Swarup was diagnosed with Crohn's disease she realized that there was a service gap and mobilized a few Rotarians to set-up an organization to provide a Patient Support Group.

Ten dedicated volunteers from six Rotary clubs stepped forward to create a support system for persons diagnosed with Inflammatory Bowel Disease (IBD). Founded on 18 May 2012, the Crohn's & Colitis Society of Singapore is a registered charity under the Ministry of Health Singapore.

An estimated 2,000 people in Singapore have an organization to turn to for reliable information, financial assistance, and peer support for lifestyle changes and emotional challenges.

Mission and achievements

To create a seamless patient support system that improves the quality of life of patients diagnosed with Crohn's Disease, Ulcerative Colitis, and related health conditions with a focus on four key areas:

- Patient Support Group
- Public Education & Awareness
- Advocacy
- Promoting Research

Rotary Club of Raffles City has been generous in supporting CCSS since its inception. The most significant contribution was the sponsorship of a training seminar in Chromoendoscopy. In 2018, experts from USA trained about 100 Gastroenterologists from nine countries of the Asia Pacific region.

Annual Public Awareness and Patient Education Seminars are well supported by IBD Specialists from various leading hospitals, nurses, medical social workers, and other stakeholders. A quick Google search about CCSS will pop-up various articles published by different language newspapers and magazines in Singapore. Currently, we are at the tail-end of the first qualitative research project. Over the last 10 years, we have also published a few research papers in various journals.



Key Opinion Leader: Dr. Roy Soetikno

In 2022, we are looking forward to the launch of the Singapore IBD Registry, and IBD Expert Video Series. CCSS has also created an Instagram account, YouTube channel, Website and Facebook page to engage more patients.

These social media resources will help increase our outreach and increase public awareness. We hold the unique distinction of bringing the Asian IBD Patient Journey to the world by hosting a Podcast titled, “Life takes Guts with Nidhi Swarup”.



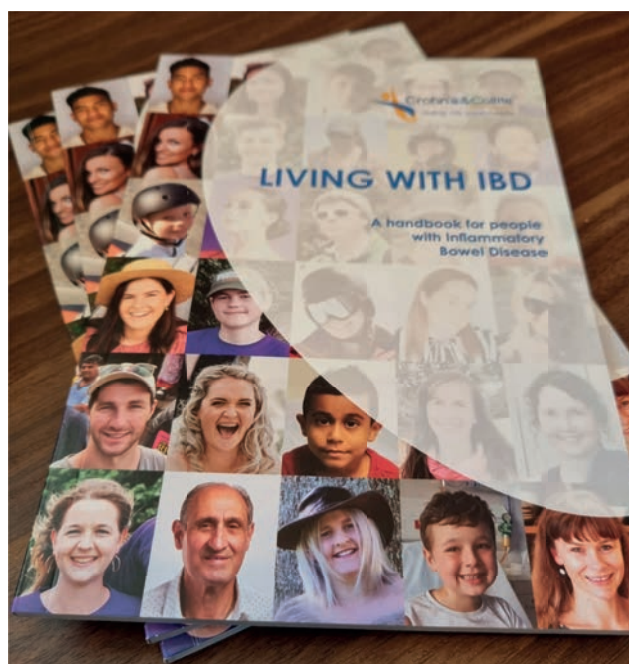
From left to right PP Henry Lim, PP Kaka Singh, Ng Boon Tee, PP Corina Lai, PP Nidhi Swarup, Patrick Lim, Ann Trevina

New Zealand Living with IBD Handbook

Being given a diagnosis of Crohn's disease or ulcerative colitis can be overwhelming. In 2012 Crohn's and Colitis New Zealand Charitable Trust published its first edition of the *Living with IBD* handbook. The purpose of the handbook was to answer many of the questions people have upon being first diagnosed, but also to serve as a reference in the future.

Much has changed in that time and in 2021 CCNZ undertook the huge task of rewriting and updating the *Living with IBD* handbook. With the new edition, we wanted to give the handbook a New Zealand flavour. We wanted patients to pick up the handbook and see familiar, friendly faces of IBD patients and medical professionals across New Zealand. So every picture that you see in this handbook has a connection with IBD in New Zealand.

This updated version is a result of a collaborative effort between New Zealand doctors, nurses, allied health professionals, and, most-importantly, people with IBD. The *Living with IBD* Handbook is a useful resource to enable patients to think positively about their future and identify ways with which they can better manage their condition in partnership with their medical team.



If any EFCCA members would like a copy of this in PDF, please get in touch with us. We are happy to share the contents with our fellow member organisations.

We gratefully acknowledge all the New Zealand patients and medical professionals who submitted photographs that appear throughout this handbook.

UK

New research shows over 1 in 123 people in UK living with Crohn's or Colitis

A new study commissioned by Crohn's & Colitis UK have shown that the number of people living with Crohn's Disease or Ulcerative Colitis (as well as Unclassified IBD) in the UK has been vastly underestimated.

The research is the largest of its kind worldwide and measured the incidence (the diagnosis of new cases) and prevalence (the number of cases in the population in 2020) of Crohn's and Colitis over the last 20 years. It gives the best picture so far of the scale of the problem across the country. The study involved researchers analysing the health care records of 38.3 million people registered with GPs as part of a UK-wide study.

The research raises concerns about the capacity of the health service to provide the required care, as:

- Over 540,000 people in the UK live with the conditions, nearly double the previous estimate.
- 1 in 123 people are living with the conditions, increasing to 1 in 67 for people aged 70 and over.

The research also highlights inequalities in prevalence:

- The lowest rates of IBD are in London compared to the rest of the UK, and the highest rates in Scotland.
- People from deprived areas are less likely to be diagnosed with conditions compared to those from affluent areas.
- People who declared their ethnicity as white are more likely than any other ethnic group to have a diagnosis of IBD.

Please do not hesitate to contact Burcu Borysik, Head of Policy and Campaigns at Crohn's & Colitis UK Burcu.Borysik@crohnsandcolitis.org.uk



“This study shows that there are nearly twice as many people living with Crohn's Disease and Ulcerative Colitis in the UK than previously thought, yet outdated figures mean the scale of the issue has been overlooked for too long. Lifetime costs for the NHS for treating these conditions are comparable to heart disease and cancer. They can have a profound impact on a person's life and patients need expert care from doctors, specialist nurses, dietitians, pharmacists and psychologists. It's crucial that the NHS recognises the scale of the growing numbers with Crohn's and Colitis and does more to prevent lives being blighted for decades by these debilitating illnesses.”

Sarah Sleet, CEO of Crohn's & Colitis UK

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Ireland

We have changed our name!

The ISCC was established in Ireland in 1984, as a patient support group for those affected by IBD. 2022 is the new beginning of a new chapter for IBD patients across Ireland. With more events, engagement and community building, this was the perfect opportunity to start off afresh under our new name.

We are very excited to introduce our brand-new name: Crohn's and Colitis Ireland!

Crohn's and Colitis Ireland is a support organisation in Ireland for people who are affected by Inflammatory Bowel Disease (IBD). We work to improve the quality of life and well-being of the IBD community through sensitive support services, including our phone helpline, educational webinars about life with IBD, national advocacy campaigns, provision of information, training and events.

For more information visit us on social media.

Facebook

www.facebook.com/CrohnsAndColitisIreland

LinkedIn

www.linkedin.com/company/crohns-and-colitis-ireland

Twitter - <https://twitter.com/ISCCIRL>



Gutcast

Gutcast, the first podcast for people living with inflammatory bowel disease (IBD) in Ireland, developed by the ISCC and Janssen Sciences Ireland UC, has returned for a third season. Hosted by Amy Kelly, ISCC Director, who lives with Crohn's disease,

Gutcast features a range of guests including healthcare experts and people living with IBD, providing insights and advice on a range of topics. Listen to our latest episodes on our website and leading podcast sites (Spotify & Apple player).



Climb for Crohn's and Colitis

This August, director of Crohn's and Colitis Ireland Amy Kelly, will take on Africa's highest peak, Mount Kilimanjaro. Standing at an incredible 5,896m (19,430ft), Amy will spend 7 days hiking to the mountain peak, all to raise funds for the Crohn's and Colitis Ireland (formally ISCC).

Crohn's and Colitis Ireland will join Amy's training and fundraising efforts over the coming months. On Saturday, May 21, our wonderful team of volunteers will tackle Ireland's highest mountain, Mount Carrauntoohil, Co. Kerry, Ireland.

For more information, to donate or join us on the day, visit our event page:

www.idonate.ie/event/3535_climb-for-crohn-s-and-colitis.html

We will also host additional hikes over the coming months. Follow our social media channels for the latest news and developments from Crohn's and Colitis Ireland.



Tea for Two

Tea for Two is an online fundraiser for Crohn's and Colitis Ireland, more info as described in the flyer.



TEA FOR IBD

MAY 19TH, 2022

What is Tea for IBD?

Tea for IBD is an online fundraiser for Crohn's and colitis Ireland. Grab your friends, family or work colleagues and host your own virtual coffee morning, to raise awareness of IBD across Ireland.

How to get involved

Step 1: Choose a time on World IBD day, Thursday 19th May.

Step 2: Set up your call and invite your friends!

Step 3: Make a donation on the Tea for IBD fundraising Raffle. Visit us on <https://www.idonate.ie/raffle/TeaforIBD2022> for more details.

Step 4: Enjoy your coffee and share our facts about IBD.

Step 5: Share your coffee morning on Social media. Make sure you tag Crohn's and Colitis Ireland. **#TeaForIBD**

Where can I find more Information about IBD?

Visit our website and follow our social media channels to find out more about life with IBD.





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Statement from CPME

The concept of value should not be misused to justify high medicine prices

The European Doctors (CPME) represent national medical associations across Europe. We are committed to contributing the medical profession's point of view to EU and European policy-making through pro-active cooperation on a wide range of health and healthcare related issues.

European doctors strongly oppose any pricing strategy which misuses the concept of value to justify high prices of medicines.

New medicines frequently enter the market at ever-increasing, unaffordable prices, posing a great challenge for the sustainability of health budgets and affecting doctors' and patients' ability to choose the appropriate treatment.

For a long time, the standard explanation given by pharmaceutical companies for high medicine prices was that they were necessary to cover research and development costs and to compensate for the associated risks.

However, as these arguments are increasingly questioned, the industry seems to be changing its rationale, arguing that R&D costs are irrelevant and that medicine prices actually correspond to their "value".

Notably, the industry's assessment of medicine value seems to disregard the multidimensional approach characteristic to value-based pricing models, which often consider medicine efficacy and safety outcomes, improvement in patient quality of life, or quality of evidence, but also economic evaluation that may include a wider societal perspective to assess medicine costs and benefits.

In contrast, the industry appears to place a disproportionate weight on economic aspects, arguing that the value of a medicine equals the costs it saves society. From this perspective, the medicine price relates to the costs that the disease would cause to society if not treated, or if treated with the second-best therapy. Following this logic, such monetary calculation should indicate the final price.



While it is common to incorporate the societal perspective for economic evaluation and to consider all relevant costs and benefits related to disease management in medicine value assessments, the logic that the price of a medicine should equal the costs it saves society should be strongly opposed.

In value-based pricing, social value is typically used to define the boundaries of a fair price (a cost-effectiveness threshold) rather than to set an exact price. Although the industry's approach can be justified from a market perspective, medicines should not be perceived as any other commodity and the actual assessment of their value should take into account all relevant components.

Therefore, instead of following the industry's logic, European doctors advocate that the priorities required in pharmaceutical pricing should first concern patient's rights and ethical provisions, then be applied to solidarity in care determined by need, and finally concern cost efficiency.

Transparency on net medicine prices and R&D costs is indispensable for competition and a balanced market.

Read a broader discussion on the misuse of the concept of value by the pharmaceutical industry on our website here: <https://bit.ly/cpmemedicineprices>

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United European Gastroenterologists (UEG) – New PAC chairman

Prof. Patrizia Burra has been appointed as the new Chair of UEG's Public Affairs Committee (PAC). Public affairs is a core pillar of UEG alongside research and education, amongst others. It is PAC's mission to act as the united voice of European gastroenterology towards European policymakers and the greater public.

At EU level, health has gained considerable spotlight in the recent years. There is no better example in this sense than the current rollout of [Europe's Beating Cancer Plan](#), European Commission's flagship initiative aimed to reduce the impact of cancer on European society.

In 2022, a key policy development within EU's Cancer Plan of great interest for the Public Affairs Committee's work is the revision of the [Council Recommendation on Cancer Screening \(2003\)](#). To ensure that the revision takes into consideration UEG's recommendations on the feasibility and effectiveness of screening programmes for gastric, liver and pancreatic cancer, as well as the latest evidence and best approaches in colorectal cancer screening, UEG has issued a response to the EU consultation and published a position paper.

Read position paper [Digestive Cancer Screening Across Europe](#)

The UEG PAC works to shape EU policies by engaging directly with policymakers to raise awareness for better prevention, improved treatment and greater understanding of the causes of digestive diseases. To that end, UEG is



honored to have the support of the [European Parliament Interest Group on Digestive Health](#) (MEP Digestive Health Group). This year's [meeting](#) of the MEP Digestive Health Group on May 16, will be focused on the prevention of digestive cancers and the current policy opportunities to deliver improved digestive health.

The UEG PAC's advocacy efforts extend beyond presenting scientific evidence to EU decision makers. To enable healthful environments, it strives to also inform patients and the public about disease prevention, risk factors and early signs. Its main public awareness campaign - [Digestive Health Month](#) - takes place annually in May.

To learn more about UEG's public affairs activities, check out [ueg.eu](#)

New proposals from the research-based pharmaceutical industry should reduce inequalities in patient access to medicines across Europe

The new pledge from EFPIA member companies should drastically increase the availability of innovative medicines in EU countries and decrease the time patients must wait for new medicines by several months. From 11 April 2022,

EFPIA member companies commit to file for pricing and reimbursement in all EU countries as soon as possible and no later than 2 years from the central EU market authorisation, provided that local systems allow it.

The commitment is designed to help deliver faster, more equitable access to medicines for patients across Europe.

Data published by EFPIA in March showed that disparities in the time it takes for patients to access new medicines in different EU Member States are increasing. Patients in Germany wait around 133 days to access new medicines compared to patients in Romania that endure a wait of 899 days.

Significant disparities also occurred in terms of availability of innovative medicines since less than 30% of centrally approved products are available in smaller and Eastern European Member States compared with 92% in Germany and 46% on average in the European Union.

Modelling by IQVIA predicts that the commitment to file would increase the availability of medicines from 18% up to 64% in several countries depending on the country's payer resource for assessment of the increased number of applications. Critically, the modelling also estimates that the commitment would reduce the time patients wait for new medicines by 4 to 5 months in several countries such as Bulgaria (-179 days), Poland (-129 days) and Romania (-155 days).

However, the time between getting marketing authorisation and companies filing for pricing and reimbursement in a country is just one part of the story. According to analysis by Charles River Associates, there are 10 inter-related factors that cause barriers and delays in patients getting access to new medicines. These causes are rooted in Member States' access systems and processes and their corresponding impact on commercial decision-making.

This is why the commitment to file is supported by the launch of an online portal where marketing authorisation holders can provide timely information regarding the timing and processing of pricing and reimbursement applications in the EU-27 countries. Bringing greater transparency to the barriers and delays to access will facilitate finding solutions in partnership. Further details of both the commitment to file and the online portal are included in [Addressing patient inequalities in Europe](#), a position paper published by EFPIA last month.

Speaking about the launch of the new commitments, EFPIA Director General Nathalie Moll said. *"By reducing the time it takes to file for pricing and reimbursement in all 27 EU member States, by bringing greater transparency to the barriers and delays to access, by co-creating an equity-based pricing system, by adopting an efficient system of EU assessments of relative efficacy and by sharing information on the implementation of novel pricing mechanisms, we believe that together we can create a step-change in the access landscape for patients across Europe."*

More info: www.efpia.eu



About EFPIA

The European Federation of Pharmaceutical Industries and Associations (EFPIA) represents the biopharmaceutical industry operating in Europe. Through its direct membership of 36 national associations, 39 leading pharmaceutical companies and a growing number of small and medium-sized enterprises (SMEs), EFPIA's mission is to create a collaborative environment that enables our members to innovate, discover, develop and deliver new therapies and vaccines for people across Europe, as well as contribute to the European economy.

Pursuing geographical equity in IBD care

By Glòria Macià Muñoz

Integrated IBD care from diagnosis to old age is essential in supporting a patient's journey towards a healthier and happier life. Equal access to health care or equal health outcomes are among the objectives of every country's health care system and yet - in practice - geography is associated with important variations giving rise to profound ethical concerns. In this article, I would like to use data science to illustrate how my Spanish regional patient association - ACCU Catalunya - is raising its voice against geographical health care disparities.

A brief introduction to Spain and its Health Care System

Spain is a country in its largest part situated on the Iberian Peninsula and consists of 17 autonomous regions with diverse geography and cultures. Spain's single-payer health care system has been ranked year after year top 5 in Europe by several entities like the World Health Organization (WHO). The system offers universal coverage as a constitutional right and (almost) no out-of-pocket expenses for patients. Each autonomous region

is responsible for planning and managing the regional health care system. In my region - Catalonia - the government agency is named CatSalut. The reader may think about it as "the payer". Like the health care system, other stakeholder groups are also organized at a regional level. Examples are the IBD patient association ACCU Catalunya and the gastroenterology society Societat Catalana de Digestologia.

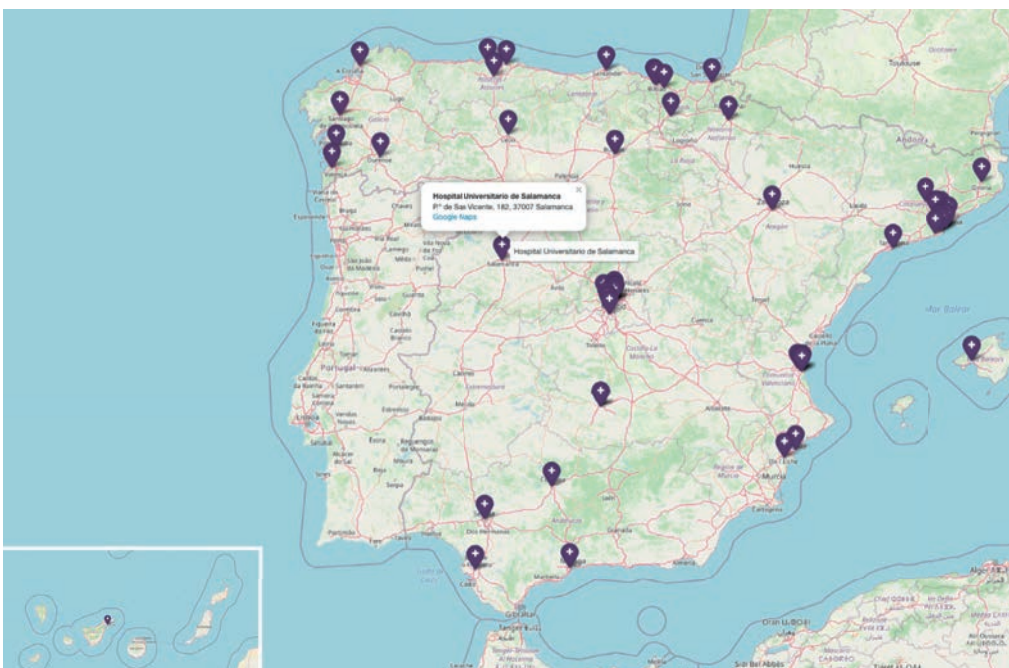


Figure 1. IBD integral care units certified by GETECCU's program - Spain's IBD quality of care certification. The web application can be accessed from <https://scd-pla-estrategic-mii.herokuapp.com/geteccu>

IBD integral care units - A nationwide quality certification program

Increasingly, health care stakeholders from different collectives and regions come together to discuss national health care challenges. A good example is the Spanish Working Group on Crohn's Disease and Ulcerative Colitis (GETECCU) which, in collaboration with patient associations and nurses, developed 53 quality indicators

for IBD care in Spain. To date, 62 health care organizations nationwide have qualified for this certification. To democratize this knowledge among patients, I used my data science skills to build a web application which pins the geographical location of the IBD units in Spain.

Standing for IBD patient's access to health care

Unfortunately, it is not enough for IBD patients to be aware of which hospital holds a certification of excellence in their region or that they are willing (and able) to travel across their region. Patients should also be entitled to receive care in that hospital. In Catalonia, CatSalut ("the

payer") has further divided the region into a series of administrative health zones delimited according to many factors (geographical, socio-economic, demographic, labor, epidemiological, climatic...). IBD patients may only receive care within their assigned zone (Figure 2).

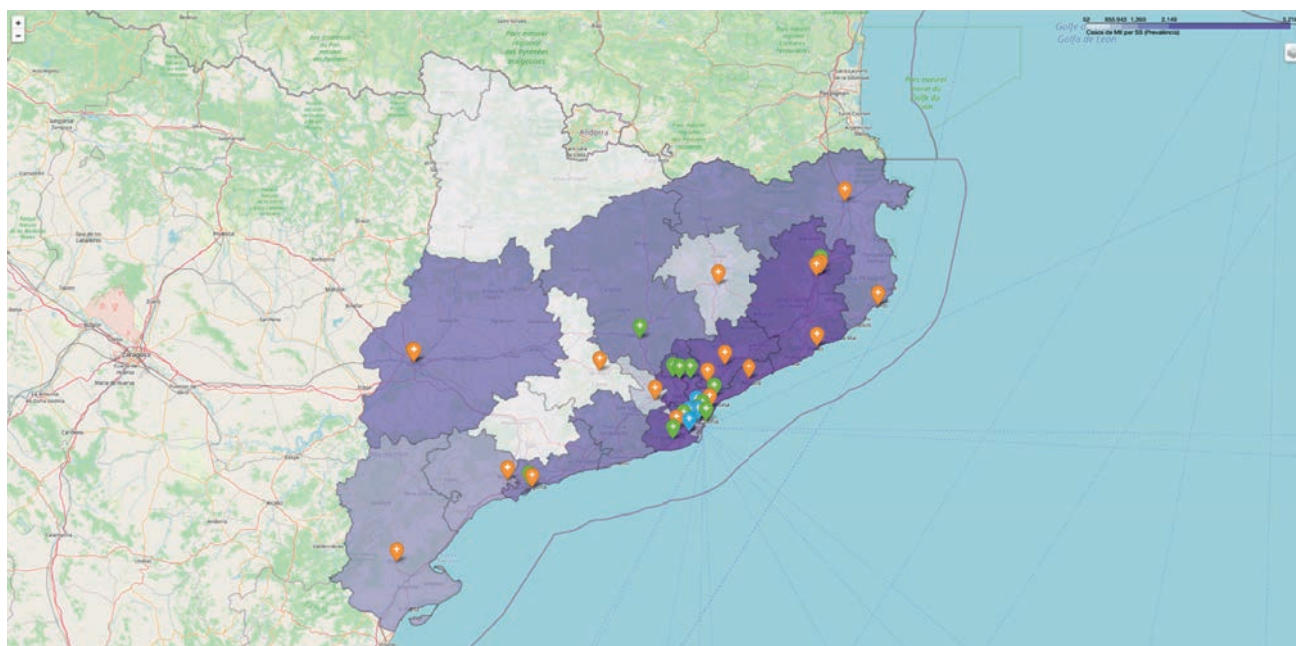


Figure 2.

IBD prevalence for each administrative health zone in Catalonia, Spain. Orange markers correspond to the location of hospitals with a gastroenterology unit but no IBD integral care unit. Green markers correspond to IBD integral care units. Blue markers are an excellence distinction among IBD integral care units.

The web application can be accessed from: <https://scd-pla-estrategic-mii.herokuapp.com>

This constraint would not be a problem if the distribution of IBD integral care units was homogenous in Catalonia. Ideally, each health zone should have at least one IBD integral care unit. However, as can be observed in Figure 2, reality looks quite different: IBD integral care units

(green or blue markers) are located in urban areas, most of them surrounding the city of Barcelona. Most gravely, some health zones do not even have hospitals with a gastroenterology unit (orange markers). Our health care system is failing those IBD patients who live in rural areas.

While data science is a very useful tool to visualize geographical equity in health care, it can alone not solve such an ethical problem. For this reason, the regional patient organization and gastroenterology society are planning to meet with the regional payer.

Our short-term goal is to convince CatSalut of allowing IBD integral health care units to be reimbursed for services to rural patients from other health zones while a more equitable solution should be envisioned in the mid-term.

“Our health care system is failing those IBD patients who live in rural areas.”

A Spanish IBD patient advocate's perspective

If you find this read interesting, I would like to know your opinion on the topic. Does your country face similar geographical inequalities in IBD care? What role does your patient organization play to resolve them? What would be your advice if the payer does not take action?

You may contact me at:
gloriamaciamunoz@gmail.com.



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There Is a World of Possibilities Beyond Crohn's Disease: Introducing the YELLOWSTONE Clinical Trial Program

The YELLOWSTONE clinical research program is currently accepting new Crohn's disease study participants for a series of clinical trials. This program will help determine whether the investigational medication ozanimod is safe and effective for treating moderately to severely active Crohn's disease.

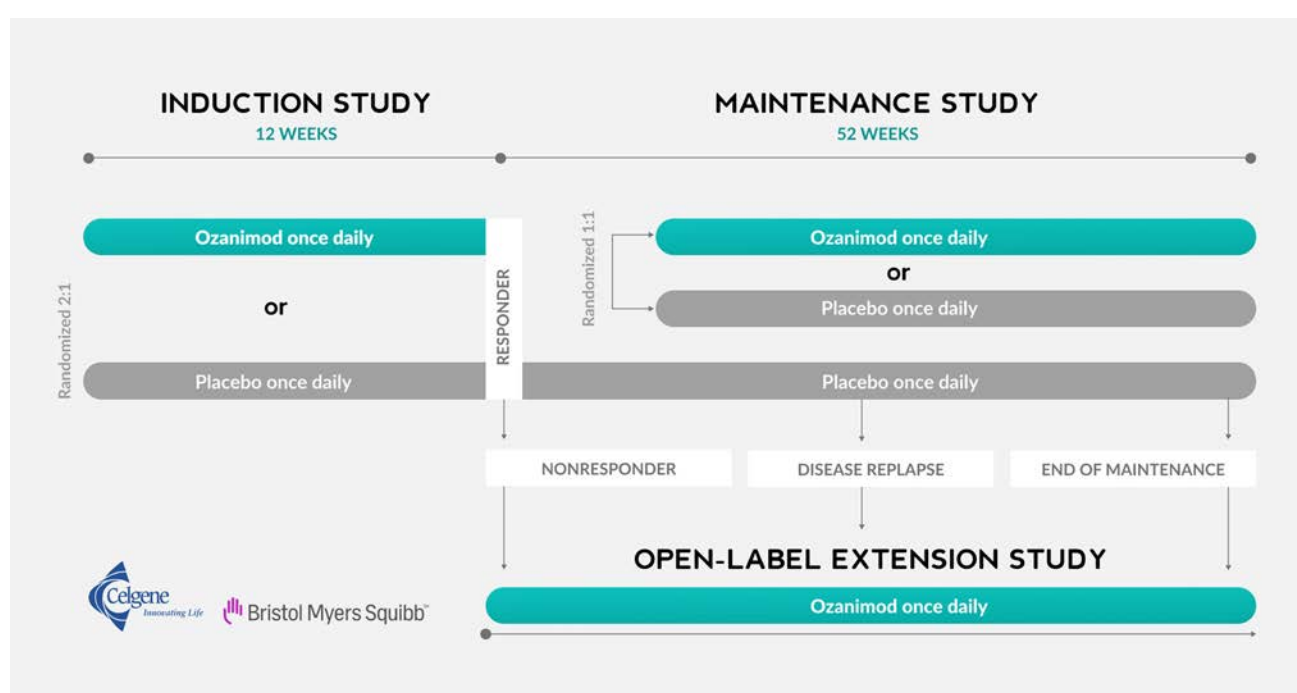
Ozanimod is an oral, selective sphingosine 1-phosphate 1 and 5 receptor (S1PR1/R5) modulator in development for Crohn's disease. It is also being studied for the treatment of ulcerative colitis and multiple sclerosis.

Selective binding with S1PR1/R5 receptors is hypothesized to withhold a specific subset of lymphocytes in lymph nodes, thus reducing their numbers in the circulatory system.

The result is a reduction of pro-inflammatory lymphocytes circulating to sites of inflammation. Importantly, immune surveillance is maintained. Ozanimod is not approved for Crohn's Disease in any country.

About the YELLOWSTONE Program

- YELLOWSTONE is comprised of several clinical trials.
- The Induction 1 and 2 studies are Phase 3 studies and are currently accepting new Crohn's disease study participants.
- The Maintenance study will only accept participants who have completed either the Induction 1 or Induction 2 study.
- Crohn's disease study participants may also have the opportunity to enroll in an open-label study following the Induction or Maintenance studies.
- For each study, patients can expect to have visits with a doctor every one to three (1-3) months. The length of each visit may vary.
- Patients can stop participation in either study at any time.





Key Inclusion Criteria

Patients must satisfy the following criteria* to enroll in the study:

- Diagnosis of moderately to severely active Crohn's disease, defined as CDAI score ≥ 220 and ≤ 450 .
- An average daily stool frequency ≥ 4 points and/or an abdominal pain score of ≥ 2 points.
- Disease duration of ≥ 3 months prior to screening.
- Diagnosis confirmed by clinical and endoscopic evidence and corroborated by a histology report (note: endoscopy and histopathology confirmation may be obtained during screening if no prior report is readily available).
- Total SES-CD ≥ 6 or ileum segmental SES-CD ≥ 4 .
- Failure of or intolerance to at least one of the following: corticosteroids, immunomodulators, or biologics (e.g., ustekinumab, TNF α antagonists, or vedolizumab) for the treatment of Crohn's disease.

**Other eligibility criteria will apply*

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Exclusion Criteria

The presence of any of the following criteria* will exclude a patient from enrollment:

- Diagnosis of ulcerative colitis, indeterminate colitis, ischemic colitis, radiation colitis, or known strictures or stenosis leading to symptoms of obstruction.
- Need for bowel resection within 12 weeks of entry into the study, in physician's judgment.
- Extensive small bowel resection (> 100 cm) or known diagnosis of short bowel syndrome.
- Requirement for total parenteral nutrition.

**Other eligibility criteria will apply*

There are YELLOWSTONE clinical trial sites around the world. For more information on clinical trial sites in your country, visit [ClinicalTrials.gov](https://clinicaltrials.gov) or crohnsstudies.com, websites <https://morbuscrohn-studie.de> (for Germany, Austria, Switzerland), <https://crohns-study.co.uk> (for the UK) and <https://chorobacrohna-badanie.pl> (for Poland), or email clinical.trials@bms.com



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