

# EFCCA MAGAZINE



EUROPEAN FEDERATION OF CROHN'S AND ULCERATIVE COLITIS ASSOCIATIONS

MAY 2024

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OMCCV - [www.oemccv.at](http://www.oemccv.at)

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## Croatia

HUCUK - [www.hucuk.hr](http://www.hucuk.hr)

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CYCCA - [www.cycca.org](http://www.cycca.org)

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EPSS - [www.ibd.ee](http://www.ibd.ee)

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## Malta

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## Montenegro

CUKUK - [www.mensa.me](http://www.mensa.me)

## Netherlands

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[www.crohn-colitis.nl](http://www.crohn-colitis.nl)

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## Norway

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ACCU - [www.accuesp.com](http://www.accuesp.com)

## Sweden

MOT - [www.magotarm.se](http://www.magotarm.se)

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Crohn Colite Suisse  
[www.crohn-colitis.ch](http://www.crohn-colitis.ch)

## Turkey

IBHDYD - [www.ibhayd.org.tr](http://www.ibhayd.org.tr)

## UK

Crohn's and Colitis  
[www.crohnsandcolitis.org.uk](http://www.crohnsandcolitis.org.uk)

## Ukraine

Fulfilling life  
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### Brazil

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[www.facebook.com/diibrasil](http://www.facebook.com/diibrasil)

### Lebanon

I Battle Disease  
[www.ibattledisease.org](http://www.ibattledisease.org)

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FPVZK - [www.vzk.kz](http://www.vzk.kz)

### Mexico

Vivir con Crohn y CUCI A.C.  
[www.crohncuci.org.mx](http://www.crohncuci.org.mx)

### Singapore

Crohn's and Colitis Society of Singapore  
[www.ibd.org.sg/english](http://www.ibd.org.sg/english)

### Trinidad and Tobago

NACCTT  
[www.crohnsandcolitistt.org](http://www.crohnsandcolitistt.org)

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# Foreword



Dear members and stakeholders,

Welcome to the latest edition of the EFCCA Magazine, a testament to our community's dedication and achievements.

Our main milestone in recent weeks has been our presence at the ECCO Congress which was a resounding success. Hosting a conference during ECCO's prestigious scientific programme was an amazing achievement for our network, showcasing EFCCA's growing influence and engagement within the global IBD community.

Looking ahead, we are excited about our upcoming round table discussion in Mexico for World IBD Day. This event marks a significant shift as we actively collaborate with major sister IBD patient organisations to address the challenges of the IBD patient community and to strive towards improvements in IBD care and quality of life on a global scale.

In this issue, you'll discover many more examples of our impactful work. From our involvement in Horizon Europe projects investigating innovative IBD treatment options, to groundbreaking surveys and the implementation of EFCCA Academy's training programs, each activity reflects our commitment to empowering and advocating for individuals with IBD.

We thank our members, partners, and supporters for their continued dedication. Together, we are forging new paths and making a positive difference in the lives of those affected by IBD.

*Salvo Leone,  
EFCCA Chairperson*

# Editorial



I am delighted to introduce the May issue of the EFCCA Magazine, where you can find the latest updates on our activities as well as inspiring examples of initiatives and actions that our members and other IBD stakeholders are undertaking in order to raise IBD awareness and to advocate for a better quality of care and life for people living with IBD.

Within these pages, you will discover interesting articles and stories that give evidence of EFCCA's commitment to amplifying patient voices and fostering collaboration. You can explore how EFCCA and its members are making a difference locally and globally, from raising awareness through impactful campaigns to advocating for improved healthcare policies.

Learn more about the exciting new partnerships we are forging, including our collaboration with the European Association of Hospital Pharmacists (EAHP) and our involvement in the EU Cross Border Clinical Trials Initiative (EU-X-CT Initiative).

These engagements exemplify EFCCA's proactive approach to driving positive change within the healthcare landscape and advocating for enhanced healthcare practices and policies.

As we navigate these unprecedented times, EFCCA remains dedicated to providing resources, support and a platform for shared experiences. Together, let's celebrate our achievements and inspire each other to continue making a difference.

Enjoy reading and stay connected!

*Isabella Haaf,  
Editor-in-Chief*

# Breaking New Ground: EFCCA Joins Scientific Agenda of ECCO Congress

This year, EFCCA's presence at ECCO has been quite exceptional! The presentation of the preliminary results of our survey **on people with IBD aged +60** during the ECCO Scientific Programme has been one of our highlights showing EFCCA's strength in research and advocacy. It underlined our ability to contribute valuable insights to one of the most important medical congresses in the field of IBD.

Standing before a diverse audience of over 100 clinicians, researchers, patient representatives and industry leaders, I felt a sense of pride in EFCCA's accomplishments. The survey not only investigated the experiences of individuals aged 60 and over living with IBD but also underscored the importance of patient-led research in shaping healthcare policies and practices.

Shedding light on the experiences of older individuals living with IBD is paramount, yet often overlooked. This demographic represents an underrepresented group within the broader discourse on IBD, yet their challenges and needs call for comprehensive consideration and attention. By prioritising their needs, we are not only ensuring equal access to care for this demographic but we are also laying the groundwork for a more inclusive and optimal quality of care as well as quality of life for all IBD patients.



*Left to right Salvo Leone, EFCCA Chairperson, Britta Sigmund, ECCO President, Alessandro Armuzzi, ECCO Board*



Together with Anne Fons from Leiden University Medical College, we had the opportunity to not only present the preliminary results of the survey during our conference “IBD Dialogues: Building Generations” but to generate a lively panel discussion moderated by EFCCA Vice President, Ciara Drohan, followed by a rich exchange of ideas with members of the audience. Our panellists included representatives from healthcare providers such as Professor Armuzzi, ECCO Board member, Anne Fons, Leiden University Medical Center as well as patient representatives such as Daniel Sundstein and Raffaele Campanella providing different perspectives and viewpoints.



Additionally, the preliminary results were also shared at the poster presentation during the ECCO Congress, providing a representation of our efforts to an even wider audience.

This survey and its presentation at the ECCO Congress serve as a powerful advocacy tool, aligning perfectly with EFCCA's mission to empower all individuals with IBD. It reinforces our position at the forefront of research and advocacy and illustrates our commitment to driving positive change in the global IBD landscape.

*Isabella Haaf*  
EFCCA Secretariat

If you would like to see recordings of the conference and/or presentations please visit: [www.efcca.org](http://www.efcca.org)

# EFCCA Poster presentations at ECCO Congress

EFCCA's commitment to advancing research and innovation took center stage as two studies, in which EFCCA played an important role, were presented during the ECCO Congress Poster Presentation sessions on 23 February 2024.

## **IBD Has No Age: Preliminary results of an international survey among older patients with IBD**

This research was carried out in partnership with the [Leiden University Medical Center](http://www.leidenuniv.nl) and aims to get a better understanding of the epidemiology of Inflammatory Bowel Disease in the older population ( $\geq 60$  years) and its impact on patients' quality of life, from both a physical and mental point of view.



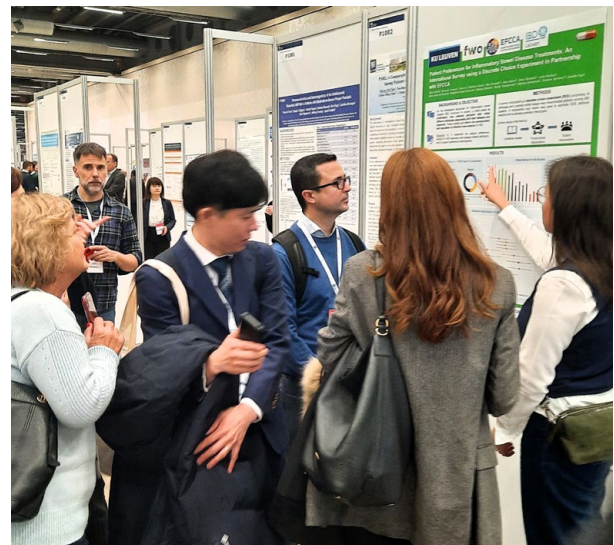
The survey was available in 21 languages and was open for around 6 months. Over 2000 responses were received with the top three country responses from the Netherlands, Italy and Norway. Following the presentation of the preliminary results during

ECCO, EFCCA together with Leiden University Medical Center are now working on the global results of the study to be submitted for publication by the end of this year. Go to [Poster Presentation](#).

## Patient Preference for IBD treatments

This study was carried out in partnership with the University of KU Leuven (Belgium) and aims to find out which aspects, factors and characteristics are important for patients when choosing a treatment for IBD.

There is a growing consensus on the value of patient preference studies, as recognised by the European Medicines Agency and the European Network for Health Technology Assessment. Patient Preference studies provide evidence-based information on treatment characteristics that patients consider important and on the trade-offs patients are willing to accept. Therefore the main goal of the study is to quantitatively evaluate which characteristics are most important to IBD patients so that the results can inform the medicinal product life cycle. Go to [Poster Presentation](#).



# Engaging with IBD Stakeholders

As in previous years, EFCCA actively participated in the ECCO Congress which this year took place in Stockholm on 21-24 February 2024. The congress has become the leading world event for scientific knowledge and driving innovation in gastroenterology related to IBD.

Our EFCCA booth was strategically placed on the way to the Poster Presentations and Industry Exhibition Hall. It provided an ideal space for networking with healthcare professionals (HCPs) and researchers and to communicate our mission and initiatives, with a special emphasis on advocating for the patient community.

Salvo Leone, EFCCA Chairperson, emphasised the booth's role in connecting with attendees: "Our presence at ECCO Congress was instrumental in fostering dialogue and understanding among stakeholders. We highlighted EFCCA's commitment to representing and supporting patients with IBD."

EFCCA's participation at ECCO Congress reinforces the organisation's dedication to empowering patients and advancing IBD care globally. By bridging the gap between patients and healthcare professionals, EFCCA continues to drive change within the IBD community.

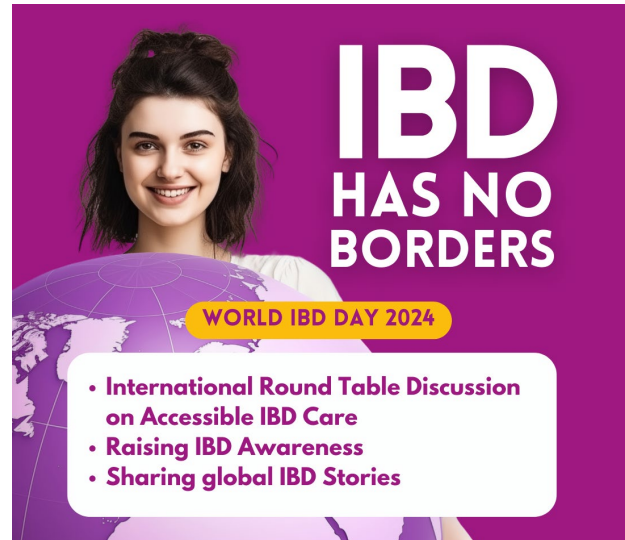


# World IBD Day: EFCCA Hosts Roundtable Discussion on Access to IBD care

In recognition of World IBD Day, EFCCA is taking proactive steps to advance awareness and advocacy for those 10 million people worldwide living with IBD. One of the focal points of this year's campaign **IBD Has No Borders** is a special Roundtable Discussion entitled **Uniting for Access to IBD care** scheduled for 17 Ma, in Mexico City.

The event will bring together founding members of World IBD Day, such as ABCD (Brazil), Crohn's & Colitis Australia, Crohn's & Colitis Canada, the Crohn's & Colitis Foundation (USA) and EFCCA in order to discuss the challenges but also opportunities for good quality access to IBD care globally.

This discussion will also involve expert speakers such as Prof. Claudio Focchi (Cleveland Clinic, US) and Prof. Britta Sigmund (virtual) (ECCO President) sharing insights on the latest advancements in IBD research and current issues around access



to IBD care. Participants will have the opportunity to exchange experiences, discuss challenges and collaborate on strategies to address unmet needs in IBD care.



Moreover, the roundtable will bring together patient associations from the region for a networking event focused on exploring regional challenges and fostering collaboration among patients.

This exciting event underscores EFCCA's ongoing commitment to promoting global partnerships and driving positive change for individuals living with Crohn's Disease and Ulcerative Colitis. By convening diverse stakeholders, EFCCA aims to amplify patient

voices, promote understanding, raise awareness and advocate for improving access to care and the quality of life for the IBD community worldwide.

Stay tuned for updates and insights from this event as EFCCA remains dedicated to making a difference on World IBD Day and beyond!

For more information and to read about our social media campaign that goes hand in hand with this event please visit:

[www.efcca.org/news/world-ibd-day-2024](http://www.efcca.org/news/world-ibd-day-2024)

# EFCCA Academy update

## Leaders of Tomorrow – EFCCA Youth Academy closing ceremony and final work assignments

By the close of 2021, we inaugurated our Youth Academy with the objective of amplifying youth representation, nurturing a unified group of upcoming leaders and empowering young delegates. Tailored for individuals with IBD between the ages of 18 and 30, this educational initiative witnessed 14 students successfully completing their curriculum, proceeding to undertake final assignments from the selection provided below:

- Implementing a youth engagement project
- Assisting the national association in implementing an awareness campaign
- Contributing to EFCCA's upcoming Youth event

The Gala Dinner organised in February 2024 in Stockholm for all the delegates, coinciding with the ECCO Congress, was the perfect occasion to honour the students who successfully completed the Youth Academy training programme. Six out of the eight students who had submitted their final assignment received a diploma commemorating the completion of their studies, in a ceremony that marked the culmination of their two years of learning and effort.



As they themselves recounted, we are convinced that what they learned during their time in the Youth Academy will serve them well in their journey as active members of their respective associations. From EFCCA, we congratulate them on their efforts and hope to continue seeing them in future courses as well as in new events.

As you may all know, we have featured the completed assignments in the previous issues of the magazine. In this new issue, we want to share two more contributions, one from Aleksii Hautamäki from the Finnish Association **IBD ja muut suolistosairaudet ry** and the other from Delphine Khuu, from the Belgian French-speaking Association **Crohn-RCUH**.



In his work assignment, Alekski discusses the activities of the Finnish IBD youth group, which operates under the umbrella of the Finnish Association. Supported by their association, the youth group has been active for approximately twenty years and has recently expanded its membership to accommodate increased activities, including an annual weekend meeting featuring peer support and the recent launch of a youth Discord server (chat group) for peer support and communication. The group, now renamed "Nuosu", plans future events such as pub crawls to engage young members. Alekski also offers advice on engaging new youths, emphasising the importance of effective communication and association support.

In her article, "The Impact of IBD on Young Professionals and the Idea of the Escape Game," Delphine shares the conclusions of the informal meeting held in Brussels with members of the Belgian youth group. She and her colleagues discussed how their health conditions influenced their career choices: Delphine reports her personal experience, which involved initially studying biology but shifting to biotech engineering after being diagnosed with UC, fostering a patient-centric approach in her professional role. Delphine expanded on the challenges of managing treatment and the complexities of healthcare approaches between France and Belgium. Furthermore, she proposes innovative activities for the Belgian youth group,



such as developing an escape game to simulate the daily struggles of individuals living with IBD, aiming to promote empathy and awareness among participants.

Read both articles and the other end-of-course assignments from the EFCCA Youth Academy on our website: [www.efcca.org/news/efcca-youth-academy](http://www.efcca.org/news/efcca-youth-academy)

*Maria Stella De Rocchis*  
EFCCA European Project Officer

## DIVA Empowerment Academy & the upcoming new DIVA Academy

In early January 2024, we launched an online training initiative entitled "**EFCCA Empowerment Academy - Everything you need to know about EFCCA**". This programme is specifically designed for new EFCCA national associations, new delegates, new board members and staff members.

**Clinical Trials Training Programme**

1. Clinical Trials: The basic information you should know
2. Clinical Research overview
3. Patient engagement in research
4. Using Patient-reported outcomes measures and Real-world evidence in Clinical Trials
5. Facts and myths about Clinical Trials - A Clinical Trial from a patient's perspective
6. The industry perspective: Roche

The main objective of this training course is to provide newcomers with an in-depth and insightful orientation on the EFCCA and its many activities. By offering this comprehensive overview, we aim to equip our new members with the knowledge and understanding they need to effectively engage with EFCCA's mission and objectives from the very beginning. We are pleased to announce that 12 participants have registered so far and are actively pursuing the programme.

Last February we asked all our members to help us shape another training course we have in the pipeline, which will focus on our cutting-edge methodology: DIVA (Data Insights for added therapeutic Value).

The DIVA Academy will be a comprehensive programme designed to train EFCCA delegates with the skills and knowledge they need to make full use

of DIVA's potential. We believe this innovative tool is set to revolutionise the way we access and analyse data, enabling us to make evidence-based decisions for the benefit of our IBD community.

The main objective of this course will be to provide our delegates with a comprehensive understanding of the vast potential of DIVA and, more importantly, to collaboratively define priority areas of use in line with your needs and expectations.

The programme is currently being finalised and we will soon inform you about how to participate. For more information write to me at [mariastella.derocchis@efcca.org](mailto:mariastella.derocchis@efcca.org)

*Maria Stella De Rocchis*  
EFCCA European Project Officer

## LILLY FOR BETTER

The human race has always been curious, hopeful and resilient. Discovery is our purpose on this planet. It's our calling and the spirit that's defined Lilly since day one. After more than a century and nearly 100 medicines and countless innovations, we're still searching for the next great discovery that will make life better for people around the world.

*Lilly*

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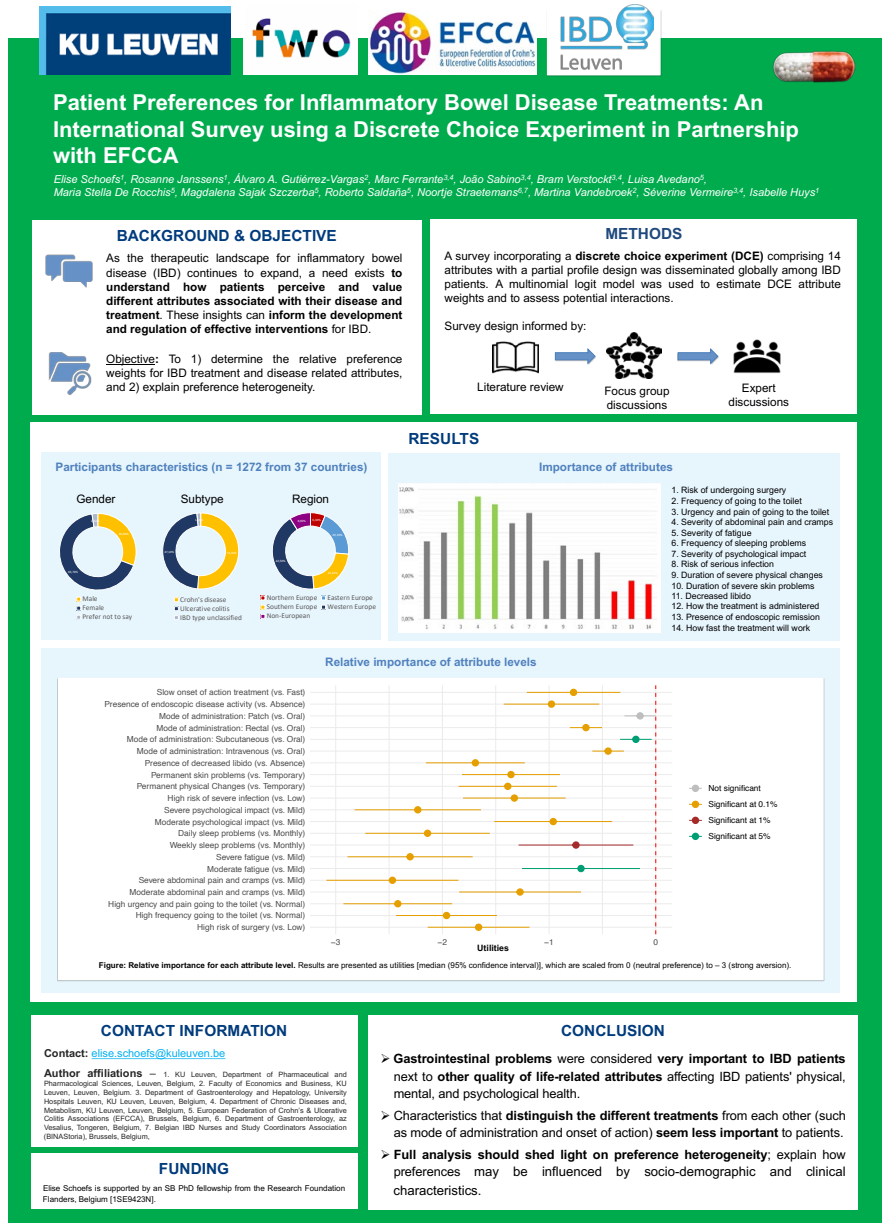
# Patient Preference Survey

Last July 2023, in cooperation with KU Leuven, we launched the Patient Preference Survey. “Which quality of life effects are important to you?”, “Which side-effects do you want to avoid?”, “Which characteristics should future drugs have according to you?”. These are a few questions we aimed to answer with this survey.

We are proud that our efforts have been recognised and we have been honoured to present the poster featuring the preliminary results at the ECCO'24 Congress. These results show that we have received 1272 completed responses from 37 countries, with an average participant age of 42 and 67% being women. Western Europe represented 42.5% of participants, with 6.3% from Northern Europe and 8.3% from outside Europe. Patients rate the severity of pain and abdominal cramps as the most important factors to consider when choosing treatment, followed by the urgency and pain of having to go to the toilet and the severity of fatigue. The lowest importance was assigned to the treatment mode of administration, onset of action and endoscopic disease activity.

Currently, the University of Leuven has decided to keep the survey open for a few more weeks to reach the 1500-response goal. You will find more detailed information about the survey and its objectives on our website, or, if you have not already done so, you can participate in the survey [here](#).

If you have any questions, please contact our European Project Officer, Maria Stella De Rocchis, at [mariastella.derocchis@efcca.org](mailto:mariastella.derocchis@efcca.org)



# Highlights from the 28th EAHP Annual Congress 2024

In a stride towards fostering collaboration with the European Association of Hospital Pharmacists and enhancing patient care, our Chairperson Salvatore Leone participated in the 28th EAHP Annual Congress 2024, held in Bordeaux, France, from 20 to 22 March 2024.

This marked EFCCA's inaugural involvement in their programme, which convenes hospital pharmacists from Europe and beyond to exchange insights, innovations and the best possible treatment of patients at all levels of healthcare systems.

The Opening Ceremony, conducted by András Süle, President of the European Association of Hospital Pharmacists (EAHP), underscored the important role of hospital pharmacists in fortifying the resilience and sustainability of healthcare systems. Süle provided a clear explanation of their perspective on healthcare challenges, emphasising the significance of engaging policymakers, patients and society at large.

A highlight of Salvatore Leone's participation was his presentation on "Mapping EFCCA Associations' Relationships with National Hospital Pharmacists". Leone described the findings of an online survey conducted to assess the current status quo between EFCCA member associations and their respective national hospital pharmacist organisations. This mapping, which ran from November to the end of December 2023, gathered insights from EFCCA members to better understand existing interactions with hospital pharmacists and to point out areas where collaboration between these associations can be strengthened for the benefit of people living with IBD.

Cooperation between EFCCA and EAHP is vital for optimising care for patients with IBD by integrating patient insights into medication management and advocating for improved treatment access and policy changes. This collaboration will lead to pharmacists' better understanding of IBD care, leading potentially to more personalised and effective approaches that prioritise patient well-being and treatment outcomes.



*Left to right: András Süle (President of EAHP), Dr. Joanne O'Brien Kelly (Beaumont Hospital, Dublin), Salvo Leone (EFCCA Chairperson)*



# Facilitating Cross-Border Clinical Trials with EU-X-CT Initiative

Acknowledging the significant challenge patients in Europe face in accessing clinical trials across borders, EFCCA joined a partnership with the EU-X-CT consortium in 2023. This collaboration recognises the hurdles patients encounter in navigating complex regulatory frameworks and a lack of legal guidance, hampering their participation in cross-border clinical research.

EU-X-CT is a pioneering initiative that aims to revolutionise cross-border clinical trial access in Europe by aggregating comprehensive data from across the continent. This includes insights into legal, regulatory, financial and practical barriers. The ultimate goal is to formulate and disseminate recommendations that streamline cross-border access, facilitating patient engagement in clinical trials. With a volunteer-led approach encompassing diverse stakeholders such as patient organisations, academia, research networks and industry players, EU-X-CT is jointly spearheaded by EFGCP and EFPIA.

For patients fighting with life-threatening or rare diseases, access to investigational medicinal products via clinical trials represents a beacon of hope. However, the absence of a unified legal framework within the EU compounds the challenge, underscoring the necessity for reliable and accessible information.

In an interview with EFCCA Magazine, Ingrid Klingmann articulated the pressing need for patients to access trials in other countries, emphasising the formidable barriers hindering such endeavours. One of some practical solutions includes the creation of a freely accessible database website housing crucial information on legal landscapes, financial options and reimbursement policies across European countries.

To ensure the sustainability of the EU-X-CT Initiative, EFCCA calls upon the IBD community [to actively](#)



*EU-X-CT consortium meeting*

[participate in several mapping exercise surveys](#) aimed at gathering insights and experiences. These contributions are important in shaping the evolution and expansion of the initiative's database website, ensuring its efficacy and relevance over time.

EFCCA produced a video for social media platforms, highlighting the significance of its partnership with EU-X-CT and urging community members to engage in the mapping exercise surveys. Each of these surveys takes around 5-10 minutes to complete

1. The First survey aims to map all the regulatory frameworks or legal guidance about cross-border access to clinical trials that already exist in Europe: [Fill out the Survey](#)
2. The Second survey aims to map all the different paying schemes for cross-border access to clinical trials that already exist in Europe: [Fill out the Survey](#)
3. The Third survey aims to gather information from Investigators and Sponsors/Clinical Operations Experts who have already participated or engaged in cross-border trials: [Fill out the Survey](#)

Together, let us pave the way for enhanced cross-border access to clinical trials, empowering patients and advancing medical research.

## PROJECT NEWS

Over recent months, EFCCA's Horizon Europe projects have seen significant progress towards enhancing IBD treatment. This brief overview provides insight into the latest developments of the projects. For more comprehensive updates on EFCCA's participation in these Horizon Europe and Horizon 2020 initiatives, you can follow our EFCCA PROJECTS DIGEST, which offers regular and fresh information about the projects: [www.efcca.org/projects/efcca-projects-digest-newsletter](http://www.efcca.org/projects/efcca-projects-digest-newsletter)

# FIBROTARGET Consortium Gathers in Athens to Advance IBD Fibrosis Research

The FIBROTARGET project recently convened its General Assembly in Athens, Greece, on 21-22 March 2024, bringing together a consortium of 10 partners dedicated to addressing intestinal fibrosis and fibrostenosis, debilitating complications of Inflammatory Bowel Disease (IBD) lacking effective treatments.

The meeting commenced with a welcome introduction from project coordinators and KU Leuven professors, Séverine Vermeire and Gianluca Matteoli, setting an energetic tone for the two-day event. To foster collaboration and engagement, an icebreaker "Speed Meeting" activity was conducted, allowing consortium members to connect and prepare for in-depth discussions ahead.

Isabella Haaf represented EFCCA at the GA and shared valuable insights on patient preferences for IBD treatment. Her presentation emphasised the importance of integrating patient perspectives

into the project's objectives, advocating the need for patient-centric approaches across research, pharmaceuticals and clinical practices.





Throughout the assembly, the consortium engaged in focused workshops, categorised into three key areas: pre-clinical research, diagnostic/prognostic development and clinical trials. These workshops aimed to enhance collaboration across different workgroups, identifying main risks, critical needs and setting concrete milestones for future progress. Discussions also encompassed strategies for effective communication, dissemination of findings and engagement with stakeholders.

The next six months are anticipated to be a period of intense activity, as the FIBROTARGET project remains steadfast in its mission to transform the landscape of IBD care.

For more information go to: [www.fibrotarget.eu](http://www.fibrotarget.eu)



 **Funded by the European Union**

*This project has received funding from the European Union's Horizon Europe programme under grant agreement No. 101080523.*

# IMPROVING PATIENTS LIVES THROUGH INNOVATION

At Agomab, we are determined to enhance the lives of patients by developing cutting-edge medicines that promise hope and healing. Join us on this transformative journey as we create a brighter and healthier future for patients living with fibrotic diseases.



Learn more about our approach:



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THERAPEUTICS

# GENEGUT online GA

GENEGUT celebrated its 4th General Assembly, held online, marking significant strides in the project's advancement. Led by Prof. Caitriona O'Driscoll from Cork University and with the presence of EFCCA European Project Officer Maria Stella De Rocchis, discussions centred on enhancing project management and collaboration across various work packages (WPs).



Presentations from WP leaders highlighted progress in areas such as RNA-based nanoparticle synthesis, cellular specificity, formulation development, efficacy testing and regulatory readiness. The session fostered synergies among project disciplines, crucial for pioneering a safe RNA-based therapy for ileal Crohn's Disease.

Next meeting will be in person in June 2024 in Porto, Portugal, hosted by partner i3S. For further details, visit the [GENEGUT.eu](https://www.genegut.eu) website.



*Funded by the European Union (GA 101057491) and supported by the UK's innovation agency, Innovate UK. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union or the European Health and Digital Executive Agency (HADEA). Neither the European Union nor the granting authority can be held responsible for them.*

# IDEA-FAST 5th General Assembly

On 12-13 March 2024, the Horizon 2020 project IDEA-FAST held its 5th General Assembly in Desenzano del Garda, Italy.

The meeting mainly focused on the progress and upcoming challenges related to the ongoing Clinical Observation Study of the project.





Additionally, there was a patient Question & Answer session and breakout meetings for further discussion on clinical significance. Detailed discussions were also held on specific topics such as the European Health Data Space (EHDS) regulations, the sustainability of the DMP & datasets, use case scenarios and the PIE group. Poster sessions were also conducted, during which participants were encouraged to vote for the best one. EFCCA was represented by its CEO, Luisa Avedano, who ensured that the patient's perspective was considered.

The IDEA-FAST project, a five-year Innovative Medicines Initiative started in November 2019, aims to identify digital endpoints that provide reliable, objective and sensitive evaluation of activities of

daily life, disability and health-related quality of life for neurodegenerative diseases, including IBD. It is runned by a consortium of 46 partners across 15 countries in Europe.

Visit the project's website [IDEA-FAST.eu](http://IDEA-FAST.eu) for more information about the project.



*This project has received funding from the Innovative Medicines Initiative 2 Joint Undertaking (JU) under grant agreement No 853981. The JU receives support from the European Union's Horizon 2020 research and innovation programme and EFPIA and PARKINSON'S DISEASE SOCIETY OF THE UNITED KINGDOM LBG.*

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Image: Boehringer Ingelheim



# France

## Fecal Calprotectin: Finally Reimbursed!

Faecal calprotectin is a sensitive and reliable marker of intestinal inflammation, whose value in the monitoring of patients with IBD is now well established. It is a simple and non-invasive tool which has become essential in many situations during the management of IBD.

However, this examination was not reimbursed outside the hospital setting, even though it was covered in hospitals, creating unequal access to this test, with the average price ranging between 40 and 60 euros at the patient's expense.

Afa contributed to its evaluation by the High Authority of Health four years ago and has regularly requested updates from the Ministry of Health. In October 2022, a letter co-signed by the AFA and learned societies put "good pressure" on the director of the Health

Insurance and the General Directorate of Health, who quickly responded by proposing to form a working group consisting of Professor Laurent Peyrin Biroulet (University Hospital of Nancy), Professor David Laharie (University Hospital of Bordeaux), François Blanchardon (Vice-President of AFA) and Anne Buisson (Director of AFA) to make progress and close this discussion.

Finally, in February 2024, AFA Crohn RCH France obtained the reimbursement for faecal calprotectin. This advancement is the result of collective work and a beautiful recognition of our determination to provide patients with equal access to this simple and effective examination!

*Bastien Corsat  
Afa Crohn RCH France*

# Netherlands

## Online consultations for IBD patients

During our campaign week on Work & IBD in October 2023, we launched a new product: online consultation hours. These are one-hour consultations via Teams (Zoom is also possible), on a specific topic which can be accessed by people with IBD from home. After announcing the consultation hours in our newsletter, registrations poured in. Apparently, there was a real need for this.



We organised three online consultation hours on Work & IBD during the campaign week, with the following topics: "Balancing (voluntary) work and private life with IBD", "Reintegrating with IBD" and "What do I tell my (future) boss and occupational health physician/occupational physician about my IBD?"

## Questions for experts

What does an online consultation hour look like? An expert participates in each consultation hour to answer questions that participants have about the relevant topic. When registering for the consultation hour, people can submit their questions to the expert. A week before the consultation, the expert receives the list of questions in order to prepare and get an idea of what other questions might come up during the consultation. Participants also have the opportunity to ask questions via chat during the consultation hour. Therefore, someone from Crohn & Colitis NL always takes part, to introduce the expert, explain how the consultation hour works and present to the expert the questions submitted in advance and asked in the chat.

## Current topics

Since the successful introduction of the three online consultation hours in October last year, we started a monthly online consultation hour in 2024, on the first Monday of the month, from 7.30–8.30 pm. We choose topics on which we receive a lot of questions. It has to be a defined topic, for a relatively small target group. Often these are topics we also write about in our quarterly magazine Crohniek. We then place an invitation with a sign-up link for the online consultation hour, in the article. For example, we wrote in Crohniek about microscopic colitis and announced the online consultation hour. This consultation hour was also very well attended. We also had two other successful consultation hours on Pregnancy & Childhood and IBD & Sexuality.

So definitely worth a try also for other patient associations!

*Barbara Davidson  
Crohn & Colitis NL*



**We innovate in gastroenterology  
so patients can live in the moment**



# Hungary

## MCCBE launches a new mobile application

MCCBE, the Hungarian IBD patient association, is pleased to offer from 9 February a new service to IBD patients: the **Nem tudok várni** (“I can’t wait”) mobile application.

As part of their Corporate Social Responsibility activity, Adroit Group, a Hungarian IT development company, selects every year a project to provide free of charge IT support. In 2023, MCCBE applied for the project and finally (from amongst 100 applications) the “I can’t wait” project was selected.

After the kick-off meeting in June last year, we started working hard to prepare all the necessary documents and finally, the application was released for iOS and Android.

This is the landing page [www.nemtudokvarni.hu](http://www.nemtudokvarni.hu), where companies can join the programme and all information is available.

Patients can download the application and after registration, basic features (like toilets on the map including opening hours) are available. The next step is to upload information about the user’s disease, which will generate the “I can’t wait” card. Once the user has the card, all features on the app can be consulted.

To do this work, we first collected information about all the available public toilets (next to the highways, in the capital city of Budapest etc.). The association also received a lot of support from the Hungarian Government who provided information about approximately 2500 available toilets. In the meantime, we also worked on communication activities about the project and encouraged



companies to join the programme and allow patients to use their public/private toilets for free. Additionally, leaflets were printed and the plan is to send them to all hospitals in Hungary.

Finally, this project - in addition to the support by the Hungarian Government - has also received support from three big pharmaceutical companies (Janssen, BMS and Takeda).

Rita Rácz  
MCCBE



# Italy

AMICI, the Italian IBD patient association, is actively engaging its members with the latest advancements in innovative treatment options for IBD. In a recent report prepared by Professor Lopetuso from Foundation Policlinic Gemelli IRCCS Rome, AMICI explores the efficacy of a new technique, providing critical insights for patients with Ulcerative Colitis. The article below highlights AMICI's commitment to delivering groundbreaking research updates to its community.

## **Fecal microbiota transplant: a new therapy for Ulcerative Colitis?**

Dysbiosis is commonly understood as the alteration of the composition of the human microbiota, or gut microbiota, compared to that found in healthy subjects and has been linked to countless pathological conditions that affect the intestine or even other organs.

Fecal microbiota transplantation (FMT) represents the most powerful weapon to obtain the re-establishment of intestinal homeostasis and microbial diversity. FMT involves the infusion of feces from healthy donors into the intestine of a recipient in order to treat a pathological condition associated with an alteration of the gut microbiota. This can commonly occur via colonoscopy or enema.

## **Promising results especially in Ulcerative Colitis**

Interest in this therapeutic strategy has grown dramatically, especially for Ulcerative Colitis, over the last few years. Several cohort studies and randomised controlled trials have been published and the results have been pooled in many systematic reviews and meta-analyses, which have shown that FMT is significantly more effective than placebo in inducing clinical and endoscopic remission.

## **Long-term risks?**

Repeated molecular screening of the donor's feces, its tracking and the use of appropriate registers represent a fundamental aspect to guarantee the safety of FMT.

The spread of stool banks that guarantee robust and validated screening techniques in this scenario will be able to ensure greater security in the future.

## **The limitations of the studies conducted**

However, doubts remain that prevent us from considering FMT in clinical practice for the treatment of UC. Indeed, although published studies have highlighted satisfactory remission rates when compared with those of biological therapies, the available trials were conducted on few patients and with heterogeneous methodologies, differing in timing, number and routes of administration and in the characteristics of the donors. Therefore, we cannot draw definitive conclusions.

*Cristiano Consorte,  
AMICI*



# UK

## World IBD Day 2024: Myth-busting – the truth is out there!

World IBD Day is one of the most important days in the calendar for those of us working to raise awareness of Crohn’s and Colitis. It can be tricky, though, when tasked with planning a World IBD Day campaign, to work out how best to really shine a light on these hidden and complex conditions in a way that serves everyone in our community.

We know that two of the main things people come to Crohn’s & Colitis UK for are the chance to share their stories of living with Inflammatory Bowel Disease and to access the expert, trustworthy information resources we have on our website. This year, we decided to really play to our strengths with a myth-busting campaign, looking at some of the most popular misconceptions people have about IBD and the truth behind them.

We asked a range of people living with Crohn’s or Colitis to list the main misunderstandings they encounter from those who do not know much about the conditions and we noticed the same “myths” coming up repeatedly. Diet, confusion over symptoms and the realities of living with fatigue and pain were some of the most notable examples. So, in conjunction with the experts in our Knowledge & Information team, we embarked on some “myth-busting” to set the record straight.

**DID YOU KNOW?** **Myths about Crohn's and Colitis**

- ✗ Myth**  
If you ate differently, then you'd be cured!
- ✓ Fact**  
Crohn's and Colitis are lifelong conditions for which there is no cure. There is a range of treatments including medicines and surgery that can help you feel better.

**CROHN'S & COLITIS UK** **MYTHS VS FACTS**



“Myth-busting” is a bit of a current trend on social media, so this approach has worked well with our digital audiences. With the help of some influencers and the case studies and ambassadors, we have the privilege of working with every day here at Crohn’s & Colitis UK, we have been able to put a different spin on some of the old clichés people with IBD are used to hearing all the time. The main thing, of course, is that it is a great platform from which to educate the public about Crohn’s and Colitis, which is what World IBD Day is all about!

*Geraldine Cooper*  
Senior Media Lead at Crohn’s & Colitis UK



# Czech Republic

## World IBD Day 2024: IBD Has No Borders

Every year on 19 May, the world marks World IBD Day. This day serves as a reminder of the diseases that afflict more than 10 million people worldwide. In the Czech Republic alone, nearly 60,000 individuals live with Crohn's Disease and Ulcerative Colitis. That's why, in May, we don the colour purple (symbolising our condition), educate the public about idiopathic Inflammatory Bowel Diseases, come together for communal events and even create snakes out of toilet paper rolls. In fact, in 2015, we even made it into the Czech Book of Records with the longest snake measuring 2.4 kilometres.



### MIMOSTŘEVNÍ PROJEVY

a komplikace IBD



Pacienti IBD z.s.

Martin Bortík

In 2024, the theme of our campaign is "IBD Has No Borders." To emphasise this, we're launching a website featuring a world map showcasing the numbers of those affected with these diseases globally, especially in Europe. Because Crohn's Disease and Ulcerative Colitis know no boundaries, we're producing educational videos featuring patients and doctors, as well as an illustrated atlas of the human body, illustrating where their manifestations can occur throughout the body.

In line with this theme, we've also released a special publication titled "Extraintestinal Manifestations of IBD," which we distribute for free among patients. As part of World IBD Day, patients can also explore an educational trail set up in several regions of the Czech Republic at publicly accessible locations.

IBD knows no boundaries, be they regional or anatomical.

*Lucie Laštková  
Pacienti IBD (Crohn, kolitida)*





# New Zealand

## Breaking Barriers to Access to IBD Care

As we approach World IBD Day, the Crohn's & Colitis New Zealand Charitable Trust is preparing to commemorate it under the theme "IBD Has No Borders." This year, we're embarking on a global journey, acknowledging the diverse experiences of individuals living with IBD across the world.

Throughout the month of May, we invite our IBD community to join us in amplifying the voices. We'll be featuring quotes from individuals who have traversed the highs and lows of life with IBD. From triumphs to challenges, every story is significant.

One such anecdote comes from a fellow: "Embarking on my first overseas journey with my injections was nerve-racking. I carefully placed my chiller bag on the security travelator to be x-rayed, ready to explain its contents. Surprisingly, they were more focused on my shoes being removed so they could scan them, than on the medication in my bag."

Crohn's & Colitis New NZ is encouraging people with IBD to share their experiences, particularly those related to accessing medications and treatment abroad.

Furthermore, we will organise a commemoration event for World IBD Day, to be held at Parliament where we will raise awareness, foster understanding and advocate for a world where IBD knows no borders.

*Belinda Brown,  
Crohn's & Colitis New Zealand*



# UEG Talks Podcast

The UEG Talks Podcast is an engaging audio series produced by the United European Gastroenterology (UEG), dedicated to promoting digestive health. This podcast features discussions with experts, clinicians, researchers, and leaders in the field of gastroenterology and digestive health.

The podcast covers a wide range of topics related to gastroenterology, including but not limited to:

1. Medical Insights: Discussions on the latest research, treatment approaches, and innovations in digestive health.
2. Professional Development: Tips and advice for medical professionals on career growth, leadership, and personal development.
3. Patient Perspectives: Exploring patient experiences, advocacy, and the impact of gastrointestinal disorders on individuals and families.
4. Industry Updates: Updates on policy changes, healthcare trends, and initiatives affecting gastroenterology practice in Europe and beyond.



Each episode typically features a guest speaker—often a renowned expert or a key figure in the field—sharing their expertise, insights, and experiences. Listeners can expect to gain valuable knowledge, practical tips, and inspiration from these conversations.

Follow UEG's social media to watch these podcasts: <https://ueg.eu/week>

# European Shortages Monitoring Platform

The European Medicines Agency (EMA) is setting up the European Shortages Monitoring Platform (ESMP) to gather information about medicine supply and demand in order to prevent, detect, and manage human medicine shortages in the European Union (EU) and European Economic Area (EEA).

EMA will collect data via the platform from the national competent authorities (NCAs) and marketing authorisation holders (MAH). EMA is setting up the platform as part of its extended mandate, in line with [Regulation \(EU\) 2022/123](#). The first version of the platform will be available by February 2025.

## Why such a platform?

The European Shortages Monitoring Platform will enable EMA to monitor the supply, demand and availability of critical medicines needed during crisis situations, which can be public health emergencies or major events.

EMA publishes the list of critical medicines it monitors for each crisis situation.

Outside crises, EMA will use the platform in two ways:

- to monitor supply and availability of medicines when asked by [EMA's Executive Steering Group on Shortages and Safety of Medicinal Products](#);
- for preparedness activities to prevent and manage shortages which might lead to a public health emergency or major event, including enabling marketing authorisation holders to routinely report shortages of centrally authorised products.



EUROPEAN MEDICINES AGENCY  
SCIENCE MEDICINES HEALTH

For more information on EMA's role in addressing medicine shortages, see: [Crisis preparedness and management](#).

Following an Agile approach means that the platform will start with basic features and EMA will gradually add more over time.

EMA will keep stakeholders up-to-date on the platform's development with informative sessions, technical guidance and public demonstrations.

For more information:

[bit.ly/european-shortages-monitoring-platform](https://bit.ly/european-shortages-monitoring-platform)



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[GalapagosGlobal](#)



[Galapagos](#)



# Crohn's & Colitis Foundation's IBD Ventures Invests in Developing Novel Therapies to Address Unmet Needs of IBD Patients

The Crohn's & Colitis Foundation has announced its investment in three companies during the 2023 funding cycle of the IBD Ventures program. IBD Ventures focuses on expediting the development of new products by directly investing in research and development aimed at improving remission rates and quality of life for patients with Inflammatory Bowel Disease (IBD), such as Crohn's disease and ulcerative colitis, which collectively affect 1 in 100 Americans.

Only 5% of applying companies are selected, reflecting the Foundation's dedication to investing in the most promising and innovative approaches that address critical **unmet patient needs**, particularly novel therapeutics for IBD.

According to Dr. Andrés Hurtado-Lorenzo, Senior Vice President of Translational Research and IBD Ventures at the Crohn's & Colitis Foundation, "IBD Ventures is thrilled to support these three companies, each pioneering transformative therapies that target crucial unmet needs of IBD patients. These therapeutic innovations cover a range of modalities, including two groundbreaking ventures in the microbiome field and one innovative small molecule pill for gut regeneration. Together, these advancements hold significant promise for improving the lives of patients with IBD."

Since 2017, IBD Ventures has invested in 30 companies and academic institutions to advance new product opportunities. The Crohn's & Colitis Foundation launched IBD Ventures to accelerate the discovery

and development of research-based products with the potential to address the unmet needs of IBD patients.

As a venture philanthropy program, IBD Ventures aims to advance products through the developmental pathway toward patient care by investing in novel early-stage products.

The program funds, advises, and provides resources to for-profit companies worldwide, academic institutions, and other organisations seeking to develop products that can improve remission rates and quality of life for patients with IBD.

To find out more please visit the press release: [bit.ly/crohns-colitis-foundations-ibd-ventures](https://bit.ly/crohns-colitis-foundations-ibd-ventures)



*Designed by Freepik*

# Sandoz takes part in panel discussion at OECD Conference on Medical Supply Chains

Secure medical supply chains are a cornerstone of resilient health systems and shortage of medicines have a direct impact on many people's lives. Medical supply chains are complex and internationalised and OECD's report offers insights into the risks and vulnerabilities of the supply chains of medicines and medical devices. Policy options to anticipate and mitigate risks of shortages of medicines and medical devices, both routinely and in the context of severe crises, are analysed. The report shows that strengthening the long-term resilience of medical supply chains requires collaborative approaches.

On 25 March, Switzerland organised the 2nd OECD Conference on Medical Supply Chains and Arnaud Mahéas, Public Affairs Head Europe at Sandoz who participated in a panel discussion shared his views on challenges in shortage reporting and proposed solutions.

He said "We need a single reporting system coupled with the use of European Medicines Verification System (EMVS) data. Currently, multiple, diverging

national shortage notification systems coexist. The European Commission has proposed extended notification obligations. However, we face three main difficulties in implementing these changes:

**1. Volume and complexity of data:**

With approximately 10 billion prescription packs dispensed annually across the EU and regulated by multiple agencies, the sheer volume and complexity of data pose significant challenges for the off-patent medicines industry.

**2. Lack of harmonisation and interoperability:**

Without a unified reporting system, we risk having multiple reporting/IT platforms across the EU, each with different data requirements and criteria.

**3. Underutilisation of EMVS Data:**

The reluctance to utilise the wealth of data collected through the European Medicines Verification System (EMVS).



To overcome these challenges and ensure a feasible and comprehensive reporting system, the following must be done:

- **Full digitalisation and automation:**

The shortage reporting system should be fully digitilised and automated, providing a one-stop reporting platform for companies and agencies.

- **Harmonised reporting standards:**

Implementing a two-way communication system with standardised requirements, notification criteria, definitions, templates and vocabulary will enable EMA and national competent authorities to access the platform.

- **Leveraging data from EMVS:**

By harnessing the full potential of data from the EMVS, we can achieve a harmonised approach and gain a complete understanding of shortage risks.

In conclusion, it is crucial to build on what we have and avoid unnecessary duplication and bureaucracy. Our supply chains don't need an extra layer of complexity to become more resilient. We must focus on regulatory convergence and simplification to improve the availability of medicines.”

Securing medical supply chains is important for all patients, if you'd like to know more, read OECD's report here: Securing Medical Supply Chains in a Post-Pandemic World | OECD iLibrary ([oecd-ilibrary.org](https://oecd-ilibrary.org))

At Sandoz, our Purpose is to pioneer access for patients. It shines through in our rich heritage, as in our plans for the future. The Sandoz brand, established in Switzerland in 1886, can look back on many scientific breakthroughs, from the world's first oral penicillin to the first biosimilar medicine.



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We'd love to tell you more, at [sandoz.com](https://sandoz.com)



# Access to IBD Care - a global perspective

As we approach World IBD Day 2024, EFCCA is dedicated to shedding light on the global landscape of IBD care. As part of our ongoing campaign, "IBD HAS NO BORDERS," we are committed to understanding the diverse challenges faced by patients worldwide.

Here, we present a selection of insightful studies examining barriers and associated issues pertaining to access to IBD care. Please note that this compilation represents only a portion of available research and is not exhaustive. For access to the complete publications referenced in each geographical section, please follow the provided links.

## Africa

### **Inflammatory Bowel Disease in Africa: what is the current state of knowledge?**

Inflammatory Bowel Diseases (IBD) were traditionally considered ailments primarily affecting Western populations. However, in recent years, these conditions have evolved into a significant global public health concern. Mounting case reports and series from Africa indicate a rising incidence of IBD on this continent. Yet, data on the prevalence of IBD beyond North African nations and South Africa remain limited.

We would like to share the study **"Inflammatory Bowel Disease in Africa: what is the current state of knowledge?"** that conducted a comprehensive literature search to identify all studies related to Ulcerative Colitis (UC), Crohn's Disease, or Inflammatory Bowel Disease (IBD) in Africa. The initial phase of our review involved screening the abstracts and titles of these search results. Subsequently, 150 articles reporting on various aspects such as epidemiology, pathophysiology, diagnostic techniques, or treatment were selected for a full-text review.

It revealed that for several years, the bulk of publications on Inflammatory Bowel Disease (IBD) originated from South Africa. Some efforts were made to compare the incidence of IBD across different ethnic groups. However, it's important to note that there was a significant disparity in healthcare access between black and white South Africans during this period. A report published in 1980 from Baragwanath Hospital in Johannesburg indicated that while Ulcerative Colitis (UC) remained uncommon among black populations, there were indications that its incidence (or at least its diagnostic recognition) was on the rise.

In conclusion, the available evidence indicates a rising incidence of IBD in Africa. If this trend mirrors that seen in Western and Asian regions, it could pose a substantial public health challenge in the coming years. To address this, larger epidemiological studies and the establishment of local and regional registries are essential. These efforts will necessitate significantly improved access to endoscopy and histology services.

The primary research priority is to gather data on the prevalence of IBD. Furthermore, enhanced services are needed to assist in diagnosing IBD and distinguishing it from other conditions like intestinal tuberculosis (ITB), as well as to evaluate treatment response. This epidemiological shift may also provide valuable insights into environmental risk factors influencing the pathophysiology of IBD.

Read the study at:

[academic.oup.com/inthealth/article/12/3/222/5781161](https://academic.oup.com/inthealth/article/12/3/222/5781161)

# Americas

## Canada

### Impact of Inflammatory Bowel Disease in Canada, 2023

Crohn's and Colitis Canada has published a report that offers a comprehensive analysis of the burden, trends and challenges associated with IBD across the nation.

One of the striking revelations of the study is the escalating prevalence of IBD in Canada. From an estimated 270,000 Canadians living with the disease in 2018, the numbers have surged to approximately 322,600 by 2023.

Beyond the economic realm, the study delves into the personal impact of IBD on individuals and caregivers. It highlights the diverse presentations of the disease, associated extra-intestinal manifestations and barriers to accessing care. It highlights that those with low socioeconomic status, who live in rural, remote and Northern communities and Indigenous peoples face additional barriers to care.

Key findings underscore the need for tailored approaches to address the unique challenges faced by different segments of the population. From children and adolescents to seniors, Indigenous peoples, immigrants and members of the LGBTQ2S+

community, understanding the distinct nuances of IBD's impact is paramount to delivering equitable and effective care.

Moving forward, the study advocates for concerted efforts to enhance access to specialised care and allied health professionals. Leveraging innovative eHealth platforms, implementing evidence-based care pathways and addressing systemic barriers are identified as key priorities in advancing IBD care in Canada.

Read the complete report at:

[bit.ly/IBD-report-english-LR](https://bit.ly/IBD-report-english-LR)

# Latin America

## Exploring IBD Barriers in Latin America: A Continent-Specific Analysis

Latin America (LATAM), a vast region comprising 47 countries and territories, presents a unique tapestry of cultural, historical and healthcare complexities. Despite the growing recognition of IBD's impact, there is a lack of high-quality data on its epidemiology and treatment landscape in LATAM.

A recent study titled "IBD barriers across the continents: a continent-specific analysis: Latin America" looks into the intricacies of accessing IBD care throughout the region. The study compiles data from various sources, including epidemiological studies and surveys distributed to physicians across LATAM.

The findings underscore the **fragmentation and inequities** within LATAM's healthcare systems, resulting in differential and often delayed access to quality care for IBD patients. While there have been improvements in IBD care over the decades, challenges persist, particularly concerning **access to advanced therapies** and surgical interventions.

Despite the availability of anti-TNFs in most countries, newer biologics and advanced therapies remain less accessible, posing a significant hurdle to effective disease management. Moreover, the study highlights the need for comprehensive data on surgical rates to better understand their correlation with disease control and treatment outcomes.

Moving forward, collaborative research efforts across LATAM are imperative to elucidate the region-specific challenges in IBD care and inform international strategies for improving patient outcomes. With IBD being a global concern, understanding and addressing the unique barriers faced by patients in LATAM is paramount to advancing patient care on a global scale.

Read the complete article:  
[pubmed.ncbi.nlm.nih.gov/37124371](https://pubmed.ncbi.nlm.nih.gov/37124371)

# Europe

## Crossing barriers: the burden of Inflammatory Bowel Disease across Western Europe

Despite publicly funded healthcare systems in most European countries, there is notable variation in how patients access and pay for biologic medications. We are sharing the study "**Crossing Barriers: the Burden of Inflammatory Bowel Disease across Western Europe**" which aims to provide an overview

and discuss the diverse healthcare systems within Western Europe, **highlighting barriers** that impact the management of a changing IBD landscape. These barriers include differences in hospitalisation and surgical rates, medication access and participation in clinical trials.



The study begins by comparing the various healthcare systems across Western Europe and looks into country specific characteristics and barriers. It then looks into the incidence and prevalence in IBD in those countries as well as surgical and hospitalisation rates with considerable variation between countries with the highest hospitalisation rates in Denmark, Ireland and Portugal with lower rates seen in Norway, Greece and Italy.

As concerns access to drugs, the study finds that although there is consistency in drug registration and professional guidelines established by the British Society of Gastroenterology and the European Crohn's and Colitis Organisation (ECCO), treatment approaches remain notably diverse. One significant contributor to this variability in drug access is the considerable expense of biologics, with annual drug therapy costs exceeding 10,000 euros per

patient with the Eligibility criteria to initiate biological treatment being highly variable and additional requirements such as failure of a non-biological drug (steroids and/or immunosuppressants) is seen in most European countries.

Read the full study at:

[www.ncbi.nlm.nih.gov/pmc/articles/PMC10748558](http://www.ncbi.nlm.nih.gov/pmc/articles/PMC10748558)

## **Barriers in Inflammatory Bowel Disease care in Central and Eastern Europe: a region-specific analysis**

This study focused on assessing the state of IBD care in selected Central and Eastern European countries (Croatia, the Czech Republic, Hungary, Moldova, Poland, Romania and Slovakia), specifically examining the availability and reimbursement of diagnostic and therapeutic options, the role of specialised IBD centers and the status of education and research in IBD.

The findings revealed disparities in the availability of certain cost-saving tools (such as the calprotectin test and therapeutic drug monitoring) across countries, largely due to variations in reimbursement policies. Moreover, most participating countries lack dedicated dietary and psychological counselling services, often relying on recommendations provided by gastroenterologists instead.

However, despite these challenges, most participating countries demonstrated adequate availability of recommended diagnostic methods and therapies for IBD.

Additionally, established IBD centers have been implemented in the region, contributing to improved patient care and management of these complex diseases.

Read full study:

[www.ncbi.nlm.nih.gov/pmc/articles/PMC10272651](http://www.ncbi.nlm.nih.gov/pmc/articles/PMC10272651)

# Asia Pacific

## IBD barriers across the continents – East Asia

Over recent decades, there has been a notable rise in the incidence of IBD in East Asia. However, there remains a considerable gap in the diagnosis and management of IBD in this region. The growing awareness of IBD in East Asia, coupled with a persistent high rate of tuberculosis, presents a significant challenge for effectively diagnosing and managing these conditions.

This review aims to investigate the barriers to diagnosing and managing IBD in East Asia, to provide insights into enhancing the healthcare system for the management of this complex disease.

The study looks at various barriers such as the high prevalence of infectious diseases which mimic IBD. In particular tuberculosis which is widespread in East Asia, representing 43% of global cases. Intestinal tuberculosis, primarily affecting the ileocecal area in 50–70% of cases, poses a significant challenge as it closely mimics Crohn's Disease (CD) in regions where tuberculosis is endemic. Distinguishing between CD and intestinal tuberculosis is particularly difficult, leading to management challenges for Inflammatory Bowel Disease (IBD) in East Asia.

Another barrier is the long waiting time for medical care and diagnostic services in certain regions in East Asia. Diagnosing IBD necessitates a multidisciplinary approach. However, in certain parts of East Asia, particularly rural areas, this comprehensive approach may not be readily available, leading to suboptimal care and diagnostic delays. Additionally, the significant diversity in healthcare quality across different Asian regions, stemming from economic disparities, further complicates the diagnosis and management of IBD.

In its conclusion, the study calls for new collaborative research initiatives focusing on the gut microbiome and environmental factors in disease prevention. Innovative healthcare delivery approaches, such as enhancing multidisciplinary care models and leveraging big data and artificial intelligence, need to be developed in East Asia to enhance the monitoring and treatment of IBD. It will require coordinated efforts from healthcare policymakers, experts, local committees and researchers to overcome the unique challenges associated with diagnosing and managing IBD in East Asia.

Read the full study:

[journals.sagepub.com/doi/10.1177/17562848231212089](https://journals.sagepub.com/doi/10.1177/17562848231212089)



# EFCCA

European Federation of Crohn's  
& Ulcerative Colitis Associations



## EFCCA

European Federation of Crohn's  
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