

# EFCCA Annual Report

March 2023 – March 2024

2023  
2024



 **IBD HAS NO AGE**  
WORLD IBD DAY 2023  
19 May



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

**EFCCA’s Vision**

Our vision is to find a cure for IBD.

**EFCCA’s Mission**

Our mission is to improve the overall well-being of people affected by Crohn’s Disease and Colitis, collectively referred to as Inflammatory Bowel Disease (IBD).

**EFCCA’s Values**

**United We Stand**

**1. People:** We believe that people are the focus of our efforts. We believe people make EFCCA and people are our greatest resource.

**2. Unity:** We are a community aiming at improving the well-being of people with IBD and we believe that together we work better towards our mission and to support, learn and share.

**3. Integrity:** We have strong principles of ethics, honesty and transparency and expect high ethical standards also from our partners. We will always follow through on our commitments and demonstrate the highest standards of personal and organisational behaviour.

**4. Commitment:** We are dedicated to making a valuable contribution to the well-being of people affected by IBD by fostering engagement, involvement and activism and to ultimately find a cure for IBD.

Our 5 strategic areas in which current activities are structured can be symbolically assimilated into three pillars of a building: **Awareness Raising, Empowerment, Research & Development**; where the foundations are represented by **Networking** activities and the roof is represented by the **Advocacy** work.

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# Foreword

*As we turn the pages of the past year, we proudly reflect on the achievements that have marked a significant chapter in the journey of the European Federation of Crohn's & Ulcerative Colitis Associations (EFCCA). Our annual report offers not just a recount of our activities but showcases the transformative initiatives that have been at the forefront of our mission to enhance the lives of those affected by Inflammatory Bowel Disease (IBD) across Europe and beyond.*

*Among these pioneering activities, four milestone initiatives stand out, highlighting our dedication, innovation and collaborative spirit. The first of these, the DIVA methodology, sets a new benchmark for digital health innovation in the IBD community, leveraging technology to promote better disease understanding and better tools for IBD advocacy. It is important to understand that DIVA is a living organism that is and will be nourished with different sources of data. We started with the publicly available information on clinical trials and then moved to publications and surveys.*

*Following closely, our involvement in two groundbreaking surveys initiated by EFCCA bring invaluable insights into the patient experience and the evolving landscape of IBD care, contributing significantly to our advocacy and support strategies.*

*Furthermore, the launch of new training programmes of the EFCCA Academy marked a leap forward in our commitment to education and empowerment. This initiative has been instrumental in promoting a well-informed community of patients.*

*Another important step towards a stronger and continued partnership with the most prominent IBD medical societies is the participation of 13 EFCCA representatives in two different consultations launched by ECCO. Our representatives will be actively*

*involved in the Multi-society Guidelines on Diagnostics and Monitoring of IBD Patients and in the Consensus on Diet and Nutrition in IBD 2023-2025. This shows the rise of EFCCA's reputation and the growing patient-centric approach that ECCO (and UEG) are adopting.*

*Each of these initiatives reflects our unwavering commitment to the IBD community, driven by the vision to improve the quality of life, access to care and overall well-being of individuals living with these conditions. As we present these milestones in our annual report together with some other equally important activities and initiatives that we have carried out through the reporting year, we extend our heartfelt gratitude to our members, partners and the broader IBD community for their invaluable support and collaboration.*

*Together, we have not only achieved remarkable progress over the past year but have also laid a solid foundation for the promising ventures and opportunities that lie ahead.*



Salvo Leone  
EFCCA Chairperson



Luisa Avedano  
EFCCA CEO

# The year in figures

**7** European Research Projects looking at innovative IBD treatment options

**38** Member countries attended our hybrid General Assembly (online/Bratislava)

**16** Participation/presentations in Conferences, Congresses and Patient Advisory Boards

**3** EFCCA Patient Talks

**7** EFCCA Executive Board meetings held in 2023/24

**2** Publications in scientific journals

**3** Publications of the EFCCA Magazine

**1** Publication of Guidebook for Patients to Review Clinical Trial Protocols

**34%** Increase in social media followers

**29,732** Website visitors

# EFCCA Milestone Initiatives

## DIVA

Data Insights for added therapeutic **VA**lue

Empowerment   
Advocacy

EFCCA's new working methodology aims to identify and address the real needs of patients with Crohn's Disease and Ulcerative Colitis. The working methodology is based on the concept of analysing and interpreting scientific data to improve therapeutic outcomes.

DIVA will make use of publicly available data as well as internal EFCCA data to analyse and interpret the IBD patient communities' unmet needs and to provide harmonised opinions and recommendations to stakeholders such as regulators, policymakers, pharmaceutical industries and healthcare professionals.

On 19 April 2023 we publicly launched the first version of DIVA, which included the following features:

- A multimedia library with instructions for use, ensuring accessibility for all users.
- A European search engine for clinical trials, enabling exploration of:
  - The evolution of new clinical trials by period and conditions.
  - The current status of clinical trials in Crohn's Disease and Ulcerative Colitis.
  - The location of clinical trials and their temporal and geographical evolution.
- A search engine for IBD drugs in the EU, with filters to explore:
  - By conditions and regulatory status.
  - Availability by country.
- A patient status finder by topics of interest, allowing browsing of:
  - Different datasets (we have initially added the fistulas dataset).



Additionally, we have been collaborating with EFCCA member associations to gather feedback and identify potential new features, such as incorporating other territories and surveys conducted by our members in their respective countries.

In the subsequent months and up to March 2024 (closing of the annual reporting period) we have added many more exciting features such as:

### 1. Internal Library

We have created an internal library to nourish DIVA with knowledge. We have added public publications and materials for patients produced by EFCCA and national associations. We have also incorporated open scientific articles that offer the patients' perspective.

### 2. Advanced Virtual Assistant - ChatIBD

We have created a virtual assistant to facilitate the exploration and interpretation of data, thanks to its ability to extract information from this new library. Currently, the assistant can help us understand the patients' opinions regarding epidemiology, patient profile, symptoms and disease impact, needs and

Following the launch of DIVA, we organised an EFCCA Patient Talk on **19 April 2023** to present DIVA and our new working methodology for addressing the real needs of IBD patients. During the Talk we discussed the potential of DIVA, how it works, and its impact on the IBD patient community followed by a first round of feedback from members and discussions.

Additionally, as part of this new working methodology we then elaborated a Guidebook for Patients to Review Clinical Trial Protocols (see Advocacy section) that was presented during two further EFCCA Patient Talks.

priorities of patients, similarities and differences in health systems, trends in pharmaceutical R&D and characteristics of clinical trials (past and present).

### 3. Support Manual

We have created a detailed support manual to ensure the virtual assistant functions at its maximum capacity. This document has been used to train the assistant.

### 4. Access to CTIS trials

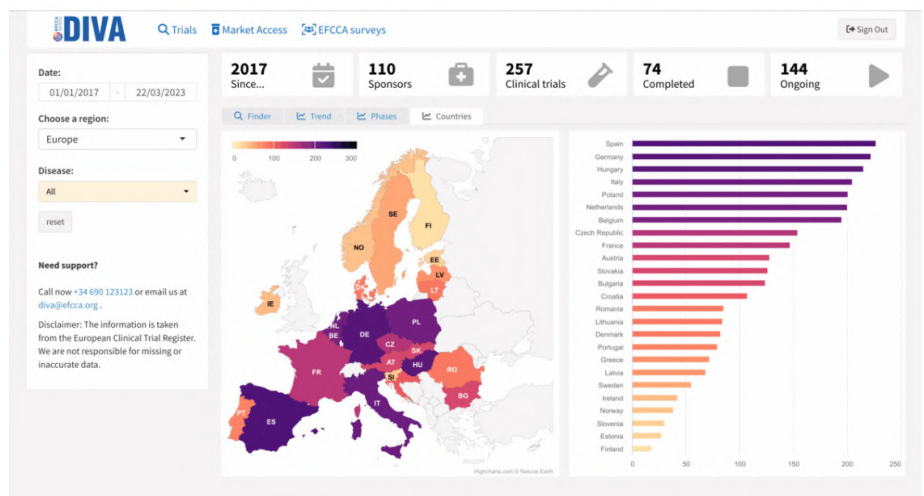
Before this update, DIVA only had access to trials from the old European clinical trial registry. Now, with the inclusion of clinical trials from the CTIS, we have a broader and more detailed view of ongoing research in Europe.

### 5. Stability Improvements

In addition to significant inclusions, minor corrections have been made to the platform, ensuring that DIVA is more stable and reliable for its users.

The future of DIVA is promising and these updates are just the beginning. If you want to explore the virtual assistant and everything DIVA offers, visit [diva.efcca.org](http://diva.efcca.org)

## EFCCA Patient Talk - Presenting DIVA



# Survey on people with IBD aged 60 and over

Awareness raising

Research & Development

Advocacy

The EFCCA survey on people with IBD aged 60 and over stands as a powerful testament to the organisation's commitment to advocacy, empowerment and raising awareness within the IBD community. Launched on World IBD Day 2023, this survey initiative represents a step towards addressing the unique challenges faced by older adults living with Crohn's Disease and Ulcerative Colitis. It underscores EFCCA's dedication not only to highlighting the experiences of this demographic but also to leveraging research as a fundamental tool for advocacy and policy change.

This survey, an extension of the **"IBD has no age"** campaign, was conceived in response to the growing prevalence of IBD among the older population—a demographic that, until now, has been underrepresented in research efforts. The lack of comprehensive data on older adults with IBD has been a significant barrier to understanding the full impact of the disease on their well-being and quality

of life. By focusing on areas such as comorbidities, polypharmacy and quality of life issues, EFCCA aims to fill this knowledge gap and inform future initiatives and research tailored to meet the specific needs of this age group.

The strategic launch of the survey, its broad reach through translation into 20 languages and the collaborative efforts with patient associations and research teams highlight EFCCA's innovative approach to community engagement and research. The inclusion of diverse platforms for survey distribution, including traditional mail to address digital barriers for older participants, exemplifies EFCCA's commitment to inclusivity and accessibility.

The remarkable milestone of garnering over 2000 participants by November 2023, shows the collective effort and dedication within the EFCCA community.

## "IBD Dialogues: Building Generations" at ECCO'24 Congress (Stockholm)

The preliminary results of the above mentioned survey, presented at the ECCO Congress 2024 as part of the ECCO Scientific Programme, further demonstrate EFCCA's strength in research and advocacy. It shows EFCCA's ability to contribute valuable insights at a leading medical congress. This achievement not only elevates EFCCA's standing in the scientific community but also emphasises the importance of patient-led research in shaping healthcare policies and practices for IBD care.



Left to right: Salvo Leone EFCCA Chairman, Britta Sigmund ECCO President, Alessandro Armuzzi ECCO Board

In summary, the survey on people aged 60 and over with IBD is an important advocacy tool that supports EFCCA's mission to empower all individuals affected by IBD and it reinforces our role at the forefront of research and advocacy in the global IBD landscape.

[Read the presentation of the Preliminary results of this survey](#), presented on 22 February 2024 by Isabella Haaf and Anne Fons during our conference **"IBD Dialogues: Building Generations"**.

A poster presentation by Anne Fons of the preliminary results took place on 23 February 2024 during the ECCO Congress.



## Patient Preference Survey

In 2021, EFCCA collaborated with KU Leuven University in Belgium, embarking on a project to better understand the preferences and needs of patients living with IBD when it comes to their treatments. The primary objectives of this ambitious project were to determine the relative preference weights for IBD treatment and disease related attributes and to explore preference heterogeneity by investigating how preferences may be influenced by socio-demographic characteristics, clinical characteristics and contextual factors.

The survey design was informed by a prior literature review and focus group discussions held with patients. Together with EFCCA, patients, researchers and healthcare providers, the survey was then iteratively adapted. The methodology used in this

[study](#) was subsequently showcased by researcher Elise Schoefs, PhD Researcher–KU Leuven, during the poster presentations at the ECCO Congress held from 1 to 4 March 2023 and also presented at the [ISPOR Europe conference, ECCO Congress and DIA Europe in 2023](#).

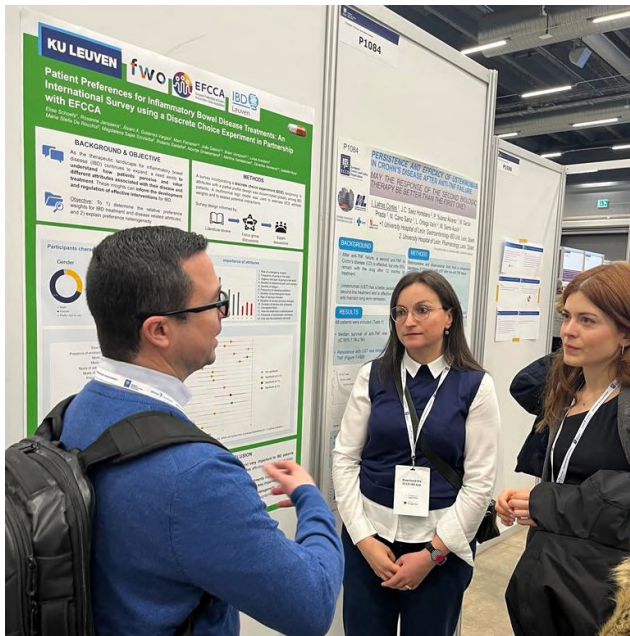
Read the full presentation [here](#)

The collaborative effort with our members saw the translation of the survey into multiple languages, ensuring accessibility to a wider pool of participants across diverse linguistic backgrounds, including English, Arabic, Croatian, French, Dutch, Portuguese, Finnish, Danish, Greek, German, Hungarian, Italian, Spanish, Polish and Romanian.



The survey was first piloted in English on July 24, 2023. EFCCA officially launched and globally disseminated it and this was made possible by the invaluable support of our dedicated members.

In November 2023, over 1200 patients from 37 countries completed the survey. On 14 November 2023, our Project Officer, Maria Stella De Rocchis, was invited by the Research Team of KU Leuven to participate virtually in a panel discussion titled "How to Assess Patient Preferences for Use in Decision-Making Along the Medical Product Life Cycle? Learnings from Patient Preference Studies across Diverse Disease Domains."



The panel was part of the ISPOR Conference in Copenhagen. The discussion explored the valuable insights obtained from Patient Preference Studies and their role in informing decisions throughout the medical product life cycle. Emphasising the engagement of patients and patient organisations as active research partners, the session aimed to improve best practices and suggest potential enhancements for the design and implementation of future Patient Preference Studies.

The culmination of these efforts saw the [presentation of the preliminary results](#) on 22 February 2024 at the ECCO'24 Congress.

These first findings highlighted that gastrointestinal problems were considered very important to IBD patients next to other quality-of-life-related attributes affecting IBD patients' physical, mental and psychological health such as fatigue, sleeping problems and risk of surgery. The differences observed highlight how crucial it is to take those preferences into account when choosing treatments. The final outcomes of this study will serve as valuable insights that could inform decision-making processes within the pharmaceutical industry, regulatory bodies and healthcare payers. More information on what IBD patients prefer is also needed to be included in the development, approval and reimbursement of drugs to improve the quality of care and quality of life.

## EFCCA Academy

The EFCCA Academy saw two key training programmes last year: the Empowerment Academy and the Youth Academy. It represents a significant advancement in our mission to empower and educate within the IBD community. Launched to improve understanding among our members, these initiatives reflect our commitment to building a strong foundation for advocacy and support.



The Empowerment Academy targets new EFCCA members, including national associations, delegates, board members and staff. This training is designed to provide a comprehensive overview of EFCCA's operations, mission and strategic priorities, ensuring that all members are well-equipped to contribute to our goals effectively.

The Youth Academy, aimed at young representatives, focuses on fostering leadership skills and enhancing advocacy capabilities, preparing the next generation to lead with confidence and insight. This programme culminates in the recognition of participants' achievements, highlighting the importance of youth empowerment in our collective efforts.

The strategic implementation of these training programmes within the EFCCA Academy framework shows our proactive approach to community engagement and development. By investing in the education and empowerment of our members, we are not just enhancing individual capabilities but are also strengthening the collective capacity of our community to effect change. Through the Academies, EFCCA is setting a new standard for member engagement and empowerment, ensuring that our community remains at the forefront of advocacy and support for individuals living with IBD across Europe and beyond.

To read in more detail about these two training programmes please go to the Empowerment section of this report (page 17).

## NETWORKING

# Strengthening the Foundation of EFCCA

A cornerstone of EFCCA is networking, which serves as the foundation upon which our organisation succeeds. It is the means through which our work pillars—Research & Development, Awareness Raising and Empowerment—find sustenance, enabling us to advance our advocacy efforts with greater efficacy. Recognising the important role of networking, EFCCA has historically invested significant resources in building and strengthening internal networks among its members. In recent years we have extended our reach beyond, first with our stakeholders in the European sphere and more recently we have increased our networking efforts with global stakeholders.

Externally, EFCCA recognises the importance of both European and international partnerships, while continuing our significant engagement within Europe through important stakeholders like ECCO, UEG and EU institutions such as EMA. Aligned with the evolving landscape of organisations like ECCO, which are increasingly embracing an international outlook, EFCCA's approach to external engagement reflects this global shift.

In 2023/24, we have carried out the following networking activities:

# Congresses

## ECCO Congress 2024

EFCCA participated actively in the ECCO Congress 2024, held in Stockholm from 21 to 24 February 2024. A significant highlight of our participation was the organisation of the conference titled "IBD Dialogues: Building Generations" on 22 February attracted over 100 representatives from the patient community, healthcare providers, scientists and industries.

EFCCA was also involved in 2 poster presentations that took place on 23 February at the ECCO Congress allowing us to show our work to a large and diverse audience. This year (2024) ECCO was attended by 7200 delegates including physicians, IBD nurses, researchers, clinicians, industries, IBD students and patient representatives.

Our booth at the ECCO Congress served as an excellent hub for networking with healthcare professionals (HCPs) and researchers. Through engaging conversations and interactive presentations, we were



able to effectively communicate our mission and work, particularly highlighting our commitment to representing the patient community.



## UEG WEEK 2023

EFCCA actively participated in **United European Gastroenterology Week 2023** (14 - 17 October 2023, Copenhagen, Denmark). This important event, attended by over 11,200 individuals from across 120 countries, provided an invaluable platform for EFCCA to advocate for the needs of the IBD community and explore collaborative initiatives to enhance patient care. At our EFCCA booth, we engaged in dynamic discussions with members, healthcare professionals and industry representatives and shared insights into the challenges faced by individuals living with Crohn's Disease and Ulcerative Colitis. Additionally, we highlighted our involvement in innovative IBD treatment projects under Horizon Europe, showcasing our commitment to advancing digestive health research.

## 27th Congress of the European Association for Hospital Pharmacists (EAHP)

EFCCA attended the 27th Congress of the European Association for Hospital Pharmacists (EAHP) in Lisbon from 22 to 24 March 2023. At the congress, EFCCA engaged with EAHP President, Andras Sule and colleagues to explore joint initiatives aimed at enhancing awareness and collaboration with hospital pharmacists. Plans included conducting a member survey to assess current involvement and understanding of hospital pharmacists' roles and potential areas for additional support and education. EFCCA also discussed the possibility of presenting perspectives from the IBD patient community at future EAHP congresses, recognising the critical role hospital pharmacists play in ensuring safe and effective medication management for chronic conditions like IBD. Collaborative efforts between EFCCA and hospital pharmacists aim to improve care and support for individuals with IBD.



## ECCO Congress 2023

EFCCA actively participated in the 18th ECCO Congress in Copenhagen, Denmark, from 1 to 4 March 2023. With over 6,946 attendees from 93 countries, including healthcare professionals, researchers and industry representatives, the congress focused on the latest advancements in Inflammatory Bowel Disease (IBD) research and clinical practice.

EFCCA engaged with its community through a dedicated booth, with CEO Luisa Avedano and Deputy Director Isabella Haaf participating in key meetings. Roberto Saldaña, EFCCA's Innovation and Patient Engagement Coordinator, presented EFCCA's role in supporting independent researchers. Elise Schoefs highlighted key findings from the Patient Preference study during a poster presentation. Fernando Magro was elected as the new President-Elect of ECCO during the General Assembly.

# Conferences

## EpiCom workshop (ECCO)

During the 19 Congress of ECCO, that took place in Stockholm during 21–24 February 2024, our chairman Salvo Leone participated in the EpiCom workshop sharing patient perspectives. In his tandem talk titled “Revolution in patient monitoring”, he stressed the importance of having patients actively involved in discussions about monitoring their own health.



## Satellite Symposium (Galapagos Health)

Our chairman Salvo Leone participated in the Satellite Symposium sponsored by Galapagos Health (on 22 February 2024 at ECCO), which explored patient and physician perspectives on current treatment goals in Ulcerative Colitis (UC) and discussed how recent data can help us manage patients in clinical practice to meet these goals.

## ECONOMIST IMPACT Roundtable

On 28 November 2023, EFCCA participated in the roundtable, “Soothing Systemic Challenges: Innovative Transformation for IBD Care Pathways,” organised by Economist Impact in Brussels, a think tank belonging to The Economist Group. The session addressed the escalating challenges faced by healthcare leaders in Europe, such as constrained budgets, workforce shortages and delayed elective care. It also served to discuss the urgent need for timely diagnosis and treatment, particularly for chronic diseases like IBD. One of the objectives was to position IBD care within the EU’s health priorities, placing patients at the centre of the care journey and to underscore the importance of recognising the link between IBD and broader health policy concerns.

## European Health Summit

On 7 December 2023, EFCCA participated in the European Health Summit in Brussels which focused on the future of healthcare in Europe (Agenda 2024-2029). The summit emphasised digital health, competitiveness, innovation and sustainable healthcare systems. Discussions highlighted the importance of creating a strong European Health Union, with a focus on innovation, access and the integration of digital health. A key discussion on “Revitalising Europe’s pharmaceutical legislation: prioritising patient access and innovation” emphasised strategies such as making Europe more attractive for clinical trials, promoting global regulatory cooperation and ensuring timely drug availability worldwide. Considerations included swift digitization, a robust regulatory framework for future pandemics and addressing mental health concerns.

## Digestive Health Roundtable

During UEG WEEK we participated in the **Digestive Health Roundtable** on 15 October 2023. This groundbreaking initiative, co-chaired by representatives from UEG's Public Affairs Group, Patrizia Burra and Ana Dugic, MD, brought together leading experts and patient advocates to discuss collaborative approaches to improving digestive health outcomes. EFCCA played a pivotal role in launching this initiative, emphasising the importance of learning from patient advocates about their experiences with digestive diseases.

During the roundtable discussions, our chairman, Salvo Leone, actively contributed to the Quality of Life discussion group addressing critical issues such as stigma, lack of understanding leading to feelings of guilt and the impact of strained healthcare systems on both medical professionals and family members. **The Digestive Health Roundtable at UEG Week 2023** facilitated significant discussions and also laid the foundation for ongoing collaborative

efforts to improve digestive health across Europe. The commitment of participants, from patient advocates to leading experts, signifies a united front in addressing challenges and championing positive change in the field of digestive health.



## 19 Biosimilar Medicines Conference

EFCCA was invited, alongside other European patient organisations, to the 19 Biosimilar Medicines Conference, which was held in Amsterdam on 25 and 26 May 2023. Valuable input was gathered regarding the development of patient-friendly materials.

Participants emphasised the importance of providing independent and clear information that enables shared decision making. It was also pointed out that it must be clear for patients that any savings using biosimilars can lead to improvements in care, such as early access for more patients.

## “The Impact of COVID-19 on immunocompromised patients”

On 3 May 2023, EFCCA participated in “The impact of COVID-19 on immunocompromised patients and the lessons learned” webinar. This marked the inaugural event in a series of online discussions centred on immunocompromised patients, as part of EFCCA’s ongoing advocacy endeavours and its newfound collaborations with Members of the European Parliament (MEPs). The event shed light on the challenges faced by immunocompromised patients during the COVID-19 outbreak, including limited healthcare access and increased mental health concerns. Speakers emphasised the importance of EU cooperation, funding and guidance, as well as cross-border collaboration and learning from best practices. Digital tools, teleconsultations and home therapies were identified as crucial for ensuring the safety and well-being of immunocompromised patients.

## European Commission’s Directorate-General for Health and Consumers

On 22 November 2023, Roberto Saldana, EFCCA’s Innovation and Patient Engagement Coordinator, participated in a panel discussion at a stakeholder event focused on implementing the European Union’s Health Technology Assessment (HTA) Regulation. Organised by the European Commission’s Directorate-General for Health and Consumers, the event brought together key stakeholders from Spain, Italy, Malta and Portugal. Participants included national HTA administrators, representatives from patient associations, health professionals, scientific societies, industry representatives, national decision-makers and regional health authorities.

# Patient Meetings

## 3rd ECCO Council Meeting of National Representatives

EFCCA together with many of its members participated in the 3rd ECCO Council of National Representatives meeting which took place in Copenhagen during UEG WEEK on 14 October 2023. This event which brought

together representatives from ECCO, N-ECCO and EFCCA was a great opportunity to align our visions and discuss collaborative projects that will pave the way for better care and quality of life for people living with IBD.



It also confirmed our long-standing partnership with ECCO and N-ECCO which we have developed over the years and which has resulted in many collaborative projects that have the potential to reshape the

landscape of IBD treatment and support. By fostering such events aimed at collaboration and cooperation, we are setting the stage for a more unified community, where the patient's voice is not just heard but valued.

## Patient Advisory Councils

### Patient Partnership Day

EFCCA participated in a Patient Partnership Day hosted by Galapagos on 15 November 2023. It was an interesting event that reinforced commitment to patient partnership and engagement in healthcare. The day was filled with collaborative discussions, insightful presentations and interactive sessions including Patient Organisation representatives, Key Opinion Leaders, Healthcare Personnel and Galapagos' team.

It provided invaluable networking opportunities, allowing participants to connect with like-minded individuals and organisations and ensuring that patient voices are heard in every stage of healthcare.



### CONFIDE Study

On 21 June 2023, our CEO, Salvo Leone and our Innovation and Patient Engagement Officer, Roberto Saldaña, participated in a working group together with clinicians specialised in IBD from various different countries. The meeting was organised by the pharmaceutical company Lilly and took place in Frankfurt. Participants had the opportunity to review the results of the CONFIDE study and to exchange opinions on the current situation of UC patients, as well as the most frequent symptoms and impact they have on a patients' daily life.

### Global Patient Council meeting

On 27 April 2023, EFCCA as well as several EFCCA members (the Netherlands, Slovakia and Romania) participated in an online Global Patient Council meeting organised by Pfizer. The main topics of discussions included best practices on how to share information with patients followed by insights around patient preferences.



## EMPOWERMENT

Empowerment plays a vital role in driving positive change, both for individuals and communities with IBD. Empowerment isn't just about support—it's about giving individuals the tools and confidence to navigate

the complexities of their conditions but also to enable them to actively engage in shaping the policies, practices and perceptions that impact their lives.

# EFCCA Empowerment Academy

## Launch of the EFCCA Empowerment Academy

On 19 January 2024, we launched the “EFCCA Empowerment Academy: Everything You Need To Know About EFCCA,” a tailor-made training programme specifically designed for those who recently joined EFCCA. The class includes 12 participants among new national associations, delegates, board members and staff.

Led by EFCCA staff and subject matter experts, the programme aims at providing profound insights into the core operations of our organisation, offering participants a comprehensive understanding of EFCCA's structure, mission and strategic priorities.

This training offers a learning journey spanning five modules. In Module 1, “Understanding how EFCCA works under Belgian law: An easy guide,” led by corporate law expert Giulia Mauri, participants gain clarity on AISBL regulations and the roles of key stakeholders within EFCCA. Led by CEO Luisa Avedano and Head of Communications Isabella Haaf, Module 2, “The history of EFCCA: mission, values and strategic priorities,” on its part, delves into EFCCA's historical evolution and its pivotal role in advocating for IBD patients, allowing attendees to gain profound insights into EFCCA's mission, values and decision-making processes. Lastly, Modules 3 to 5 explore aspects such as ethics, transparency, in-depth insights into the practical



implementation of the strategic areas and best practices for patient associations. Led by seasoned experts Andrea Broggi, Isabella Haaf, Maria Stella De Rocchis and Roberto Saldaña, these modules equip participants with the tools needed to better know EFCCA's working methodology and drive impactful change within their respective associations. Each module concludes with an assessment to test participants' comprehension.

The training programme is accessible online through the EFCCA e-learning platform and it will take approximately 5 hours to complete. The video lectures are pre-recorded, offering participants the flexibility to watch them at their convenience, from any

location. Participants are requested to complete the programme within 2 months from their initial login to the platform.

More information: Maria Stella De Rocchis, European Project Officer [mariastella.derocchis@efcca.org](mailto:mariastella.derocchis@efcca.org)

## Empowering Tomorrow: Youth Academy Students Complete Programme

In February 2024, during the Gala Dinner hosted by EFCCA for all of the delegates attending ECCO'24, we awarded diplomas to 6 of the 8 students who successfully completed the training programme of the Youth Academy. This marks the culmination of an initiative established in 2021 aimed at empowering young representatives within the IBD community.

The Youth Academy was created with the objective of enhancing the representativeness of the youth group, fostering cohesive leadership among future leaders and empowering young representatives. From its inception, the initiative has sought to strengthen and expand the youth group's impact within the IBD community. The programme included four teaching modules led by EFCCA's staff (CEO Luisa Avedano and Head of Communication Isabella Haaf), former Youth Group leaders Marco Greco and Daniel Sundstein and Clara Drammeh from the European Youth Forum. It covered EFCCA's history, values and strategic priorities, with a final three-day workshop on youth engagement and advocacy campaigns for local IBD associations.

Throughout 2023, we received four of the fourteen assignments from the previous issue. The submissions were from Jasneel Deo from CCNZ - Crohn's and Colitis New Zealand, Vasiliki-Rafaela Vakouftsi from HELLESCC, Francesca Russo from Crohn's & Colitis UK and Sāra Zdanovska from LKKSB - Latvijas Krona un kolīta slimnieku biedrība.

In his assignment, Jasneel reflects about his volunteer experience at a camp for children with Crohn's and Colitis in New Zealand and uses it to inform and contribute ideas to the EFCCA Youth Summer Camp. Vasiliki-Rafaela shares updates about the newly formed youth group at HELLESCC, aiming to support and involve young members in shaping the future of Greek IBD patients. Francesca's task advocates for hybrid experiences in EFCCA Youth events, drawing on lessons from Crohn's & Colitis UK's model and the pandemic. Finally, Sāra outlines a detailed proposal for the EFCCA Summer Camp, envisioning a week-long event centred on fostering a supportive community and facilitating personal growth.

All the final assignments are available on the EFCCA website: [efcca.org/news/efcca-youth-academy](https://efcca.org/news/efcca-youth-academy).

The other remaining assignments will be shared soon.



# ECCO Guidelines and Consensus Paper

During the second half of 2023 EFCCA has proposed a group of 8 patient representatives to be involved in the Working Group on the **Multi-society Guidelines on Diagnostics and Monitoring of IBD Patients** and 5 patient representatives for the **Working Group Consensus on Diet and Nutrition in IBD**.

Our collaboration on this recognises the need and importance of involving patients' associations in decision making and in defining relevant outcomes in a patient-oriented approach, since in the end they will be the ones mostly affected from the recommendations developed.

A series of online meetings will be held and a final in person event will close the collaboration.

## AWARENESS RAISING

### World IBD Day 2023

World IBD Day 2023 was an important opportunity for raising awareness about IBD. The occasion showcased a diverse range of initiatives, all aimed at promoting global awareness through impactful activities. The [worldibdday.org](https://worldibdday.org) website and social media initiatives played a vital role in aggregating and presenting these activities. Serving as a central hub, the website facilitated global information dissemination, with over 40 national associations actively contributing by sharing their events within the dedicated 2023 section.

While 19 May, the official World IBD Day, stood out as a significant date, numerous associations sustained their involvement throughout the week and extended participation across the month. Activities ranged from city walks to creative flash mobs and enlightening exhibitions. These collective efforts helped uniting members in their determination to raise awareness about Crohn's Disease and Ulcerative Colitis. Globally, landmarks illuminated in purple spotlighted the challenges of IBD, while local events engaged citizens in Brazil, India, Italy, South Korea and beyond.



For the first time our members from Latvia, Lithuania and Estonia organised a Baltic States regional meeting in Vilnius on 20 May 2023. The event featured lectures, interviews and public performances, underscoring the collaborative spirit of World IBD Day. Our board member Magdalena Sajak-Szczerba represented EFCCA during this event.

Pharmaceutical companies and stakeholders also played a vital role, endorsing our “IBD Has No Age” theme and participating in awareness campaigns. Horizon Europe research projects significantly contributed to advancing World IBD Day, alongside our survey targeting individuals aged 60 and above with IBD.

All in all, the success of World IBD Day 2023 owes much to the dedication of EFCCA members and the many volunteers who participated in diverse campaigns.

These actions, from local to global, have fostered empathy and support for those living with IBD, shining a light on the challenges faced and uniting communities in a common cause.

We invite you to learn more about all the events in our annual World IBD Day Report, available on our website.



## “IBD HAS NO AGE”: Awareness raising campaign

For World IBD Day 2023, EFCCA launched a survey focusing on people with IBD aged 60 and over. This initiative aims to get a better understanding of the epidemiology of IBD in the older population ( $\geq 60$  years) and its impact on patients' quality of life (QoL).

The increasing prevalence of IBD among people aged 60 and over is met with insufficient research representation and limited data, hindering a comprehensive understanding of its implications on the well-being and quality of life for that age group. The campaign, titled “**IBD HAS NO AGE**”, initiated by EFCCA in 2022, sought to highlight the challenges faced by older adults grappling with IBD and to advocate for their needs.

Central to the “IBD HAS NO AGE” campaign were key messages advocating for equitable access to optimal treatment options. Concerns arose from the



underrepresentation of older adults in clinical studies, leading to a reliance on observational data and indirect evidence for treatment decisions. This disparity raised the risk of older IBD patients not receiving the most effective treatments tailored to their needs. During World IBD Day, patient associations proactively engaged, leveraging social media and diverse platforms to promote the survey on people with IBD aged 60 and over.

We closed the survey by the end of November 2023 by which date we had received over 2000 responses. The preliminary results were presented during the ECCO congress, which attracted over 7,000 attendees. For more information about our presentation at ECCO see the page 7.

This strategic dissemination not only raised awareness but also fostered discussions and collaborations among researchers, healthcare professionals and policymakers, further advancing efforts to improve care and support for older individuals living with IBD.

## EU-X-CT Initiative

Last year, in 2023, EFCCA partnered with the EU-X-CT consortium, acknowledging the significant challenge patients in Europe face in accessing clinical trials across borders. The absence of a unified legal framework exacerbates this issue, hindering cross-border participation in clinical research.

EU-X-CT seeks to revolutionise cross-border clinical trial access in Europe. By collating information from all European countries, including legal, regulatory, financial and practical barriers, the initiative aims to develop and publish recommendations to facilitate cross-border access. Led by volunteers from diverse stakeholder groups, including patient organisations, academia, research networks and industry, EU-X-CT is co-led by EFGCP and EFPIA.

Participating in clinical trials is particularly crucial for patients with life-threatening or rare diseases, where investigational medicinal products offer potentially life-saving treatment options. However, without a legal EU framework defining conditions for cross-border access, reliable and accessible information is essential.

You can read more about [EU-X-CT Initiative here](#).

For the October 2023 issue of our EFCCA Magazine, we published an interview with Ingrid Klingmann.



Through this interview, EFCCA Magazine aimed to foster a deeper understanding of the challenges encountered by patients seeking to participate in cross-border clinical trials and the imperative of initiatives like EU-X-CT in addressing these obstacles.

[Read the complete interview here](#)



*Chairperson of the European Forum for Good Clinical Practice (EFGCP) and co-founder of the EU-X-CT Initiative*

We also [produced a video](#) for their social media channels elucidating the primary reasons for this partnership with EU-X-CT and urging the community to engage in surveys to continue gathering information to support patients.

## RESEARCH & DEVELOPMENT

# European Research Projects

Over the past year, EFCCA has been actively involved in five Horizon Europe projects. EFCCA's participation in these five large-scale research projects represents a significant accomplishment, highlighting our dedication to advancing the understanding and treatment of IBD.

By engaging in these innovative and important initiatives, EFCCA aims to facilitate collaboration with academic researchers, industry partners and policymakers and to actively ensure the integration of the patient's perspective into the research framework, guaranteeing that research efforts address the genuine needs and priorities of patients.

### miGut-Health

This four-year project aims to create a personalised blueprint for intestinal health to predict and prevent IBD. The miGut-Health consortium includes a dozen partners in addition to EFCCA from various universities and research centres.

The kick-off meeting took place in Kiel, Germany on 23–24 May 2023 and was attended by EFCCA's CEO, Luisa Avedano and EFCCA European Project Officer, Maria Stella De Rocchis. The subsequent meeting, held virtually on 21 September 2023, focused on preventive measures in IBD.

During its first year, the project identified patient groups, collected omics data, studied socio-psychological factors in IBD and tested a prolonged dietary intervention in a clinical trial. In December

These Horizon Europe projects have held various general meetings and assemblies, both in-person and virtually. EFCCA has ensured its participation in all of them to provide the patient's perspective and to share with our members the main content discussed. In line with this, in August 2023 we began publishing our newsletter, "EFCCA Projects Digest" (see below), created to inform about any other aspects of interest related to these projects.

Following, we provide a summary, one by one, of the main advances made by the projects over the past year. At the end of each, you'll find a link to their websites, where you can expand and update the information provided.



2023, as it approached the end of its first year, the consortium published a leaflet summarising its work and objectives.

More info at: <https://migut-health.eu/>



Funded by  
the European Union

*This project has received funding from the European Union and is supported by the Swiss State Secretariat for Education, Research and Innovation (SERI).*

## GlycanTrigger

The GlycanTrigger project is a consortium involving nine participants, led by Instituto de Investigação e Inovação em Saúde da Universidade do Porto (i3S). This six year project investigates how alterations in the makeup of sugar chains (glycans) on the surface of the gut lining trigger disruptions in local and body-wide processes. The aim is to understand how these alterations can initiate a chain reaction leading to intestinal inflammation.

After its kick-off meeting in Porto on 13–14 March 2023, the project has already yielded its first results with two scientific studies offering detailed insights into glycans' role in immune regulation. In September 2023, the consortium held a virtual semi-annual Steering Committee meeting, attended by our European Project Officer Maria Stella de Rocchis, where the project partners convened with representatives from the External Advisory Board.



Furthermore, the project has sought to promote initiatives from its inception to showcase its progress. The most notable are its newsletter and a podcast series aimed at providing a framework for engaging discussions between experts on the subject, with our CEO Luisa Avedano as a guest speaker for its first episode, released in January 2024.

More info at: <https://glycantrigger.eu>



*This project is funded by the European Union under the Grant Agreement No. 101093997.*

## METHYLOMIC project

Involving participants from 9 countries, the METHYLOMIC project aims to enhance medication effectiveness in chronic immune-mediated diseases like Crohn's Disease by developing a rapid epigenetic biomarker that predicts response to existing biologicals, thus bringing personalised treatment selection to clinical practice.

Following its official kick-off in January 2023, with EFCCA's participation, the project has progressed in its research over the past year. Its first advancements were shared in a webinar on 5 July 2023 and particularly at the General Assembly held in Amsterdam on 13 December 2023.

During this later meeting, in which EFCCA CEO Luisa Avedano and European Project Officer Maria Stella de Rocchis participated, leaders of the Work Packages provided updates on their current activities, highlighted their communication achievements and outlined upcoming plans for the online first Stakeholder Workshop next autumn.



As part of its dissemination efforts, METHYLOMIC initiated in November 2023 a monthly 3-questions interview series. The second instalment featured our CEO, Luisa Avedano, who outlined the primary objectives of EFCCA's participation in the project and identified the main challenges of its goal to enhance patients' quality of life.

More info at: <https://methylomic.eu>



*This project has received funding from the European Union's Horizon Europe programme under grant agreement No. 101095449.*

## GENEGUT Project

GENEGUT is a four-year research project coordinated by the School of Pharmacy at University College Cork and involving nine partners from eight European countries. Through a patient-centred approach, the project aims to develop an oral RNA-based therapy for targeted delivery to the affected area.

Over the past year, the project has made strides in its goal to revolutionise the treatment of Crohn's Disease developing an oral RNA-based therapy that targets inflammation locally in the intestinal tissue. Its advancements were reflected in its 2nd General Assembly, held online on 22 May 2023, which featured participation from our CEO, Luisa Avedano and Head of Communications, Isabella Haaf, who offered attendees insights and knowledge on communicating the research objectives of the project in a more patient-friendly language.

EFCCA was also present at GENEGUT's General Assembly held in Budapest, Hungary, on 12-13 September 2023, where consortium members, including patient representatives, researchers, expert clinical scientists and commercial organisations, shared updates on their contributions, fostering synergies among them. The 4th GA, held online on 17 January 2024, focused on reviewing progress, emphasising cross-disciplinary collaboration and planning for the project's second year.



# GENEGUT



EFCCA's attendance in all meetings ensures that a patient-centred approach remains central to the project's working methodology. One outcome of this patient-centric approach was GENEGUT's online publication in November 2023 of a "Factsheet for patients," summarising key project information tailored to patients and providing details about the project, RNA therapy, future clinical studies and EFCCA's involvement.

The project leader, Caitriona O'Driscoll, Professor and Chair of Pharmaceutics in the School of Pharmacy, University College Cork (Ireland) was invited by EFCCA to present the Genegut project during our last General Assembly in Bratislava.

More info at: <https://genegut.eu>



Funded by  
the European Union

*This project has received funding from the European Union (GA 101057491) and is supported by the Swiss State Secretariat for Education, Research and Innovation (SERI) under contract No. 22.00119.*



## FIBROTARGET

FIBROTARGET is a five-year Horizon Europe initiative led by the University of Leuven (KU Leuven) aimed at improving the prevention, diagnosis and treatment of intestinal fibrosis and fibrostenosis conditions associated with IBD, for which no treatments are yet available. The consortium consists of 8 partners, including EFCCA, which is tasked with ensuring patients' voices and insights are considered throughout the process.



Aligned with that, EFCCA has been present at various meetings held by the project, starting with the kick-off meeting in Leuven on 28 April 2023. We were also present at the 2nd General Assembly, conducted online, where discussions ranged from introducing new partners to presentations on management strategies and data management plans and progress in key areas was shared indicating promising advancements in tackling intestinal fibrosis.

These were followed by two more virtual GA Meetings, on 9 October 2023 and 8 January 2024, both chaired by KU Leuven Coordinator Prof. Séverine Vermeire. They highlighted significant progress in characterising fibrosis biomarkers, evaluating inhibitors in IBD and initiating a clinical trial for fibrostenotic CD patients. More info at: <https://fibrotarget.eu>



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

## Horizon 2020 Projects

### IDEA-FAST

Led by a consortium of 46 partners across 15 countries, the IDEA-FAST project was initiated in November 2019. It aims to identify digital endpoints for neurodegenerative and immune-mediated inflammatory diseases such as IBD, to provide reliable, objective and sensitive evaluation of activities of daily life and health-related quality of life, addressing the limitations of current subjective evaluation methods.



The project held its 4th General Assembly on 16–17 March 2023 in Barcelona, with EFCCA's participation, marking its first face-to-face meeting of the whole consortium since the kick-off meeting. The meeting aimed to review the project's progress and future requirements and strengthen communication among consortium members; it also featured a poster session. The 5th GA took place on 12 March 2024 and both were attended by EFCCA representatives. In December 2023, the consortium published a brief report on its activities during the year, highlighting the achievement of surpassing 1000 participants and recruiting 194 IBD patients out of a target of 500. Its extensive data collection positions it as a leading project in wearable device research, enhancing understanding of the impact of wearable technology in IBD and neurodegenerative diseases. More info at: <https://idea-fast.eu>

## ImmUniverse

ImmUniverse is a European transdisciplinary consortium established to explore the interaction between tissue microenvironment and immune cells in the progression and treatment response of Ulcerative Colitis and Atopic Dermatitis.

The project's most notable event in 2023 was the successful hosting of its 3rd Annual Progress and General Assembly Meeting in Milan on 15–16 May 2023. The occasion allowed the partners to assess progress made in the previous year and to discuss future project steps. With EFCCA's support, emphasis was placed on actively involving patients to gain their valuable perspective. Additionally, in February 2024 the project released its first Plain Language Summary of Publication to disseminate its work effectively. More info at: <https://www.immuniverse.eu>

## EFCCA led research

As previously mentioned (Milestone Initiative) EFCCA has implemented 2 studies in collaboration with



*This project has received funding from the Innovative Medicines Initiative 2 Joint Undertaking under grant agreement No. 853981.*



*This project has received funding from the Innovative Medicines Initiative 2 Joint Undertaking (JU) under grant agreement No. 853995 with EU Horizon 2020 and EFPIA support.*

renowned research institutes such as KU Leuven (Belgium) and Leiden University Medical Center, LUMC, (the Netherlands).

## ADVOCACY

Advocacy is central to EFCCA's mission of improving the lives of those with IBD in Europe and beyond. It's about speaking up for patients and ensuring their needs are heard and addressed in healthcare and policy decisions. In today's fast-changing healthcare landscape, advocacy is more important than ever.

EFCCA works to break down barriers to quality care, quality of life and support for individuals. By raising awareness and collaborating with stakeholders, we aim to drive meaningful change and create a more supportive environment for those living with these chronic diseases.

# Guidebook for Patients to Review Clinical Trial Protocols

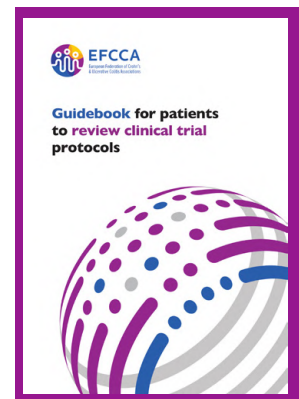
As part of the new DIVA methodology (see milestone initiative), EFCCA worked towards enhancing patient engagement in clinical trials through the elaboration and publication of the **"Guidebook for Patients to Review Clinical Trial Protocols,"** led by Roberto Saldaña, EFCCA's Coordinator for Innovation and Patient Engagement. Presented during two EFCCA Patient Talks held in the latter part of 2023, this guidebook aims to empower patients to actively participate in the evaluation of clinical trial protocols while offering structured feedback to improve their quality.

The guidebook serves as an advocacy tool, equipping patient representatives with the knowledge and resources needed to understand the intricacies of drug research strategies and identify critical aspects to consider when reviewing protocols. EFCCA orchestrated two virtual sessions to introduce the guidebook to its members and industry stakeholders, fostering a collaborative environment for feedback and discussion.

During the EFCCA Patient Talk on 8 November 2023, EFCCA members engaged in lively discussions, demonstrating their enthusiasm for utilising the guidebook to contribute meaningfully to protocol reviews. Specific queries were raised, highlighting the eagerness of patient advocates to integrate this resource into their advocacy efforts.

In a closed meeting on 26 October 2023, industry stakeholders, including representatives from Pfizer, Lilly,

Takeda and Galapagos, delved into the guidebook's development context and methodology. This session provided valuable insights and perspectives, fostering a collaborative environment conducive to patient engagement in clinical trials.



The constructive dialogue during both meetings underscored the initiative's importance in promoting a patient-centric approach to clinical trial development. The positive response from patient advocates and industry stakeholders alike reflects a collective commitment to ensuring that the guidebook aligns with the needs and expectations of all stakeholders involved in the clinical trial process.

This tool will significantly enhance patient representation and collaboration with key stakeholders in the healthcare sector. By providing comprehensive and accessible information, we empower patient representatives to make informed decisions and contribute meaningfully to developing treatments for their conditions. We look forward to the continued growth and improvement of DIVA and the Protocol Review Handbook and we welcome feedback from all users and stakeholders to help us improve these tools.

# Study on the use of Patient Reported Outcomes (PROs) in the development of new biologic drugs for Inflammatory Bowel Disease (IBD)

The research is conducted by patient organisations, including the European Federation of Crohn's & Ulcerative Colitis Associations (EFCCA), the Crohn's & Colitis Young Adults Network (CCYAN) and the Crohn's & Colitis Foundation and in collaboration with the Health Policy Department of the London School of Economics.

The development of new drugs is a complex and lengthy process that involves various stakeholders, including researchers, healthcare professionals and regulatory agencies. In recent years, there has been a growing interest in involving patients in drug development and one way to achieve this is through the use of patient-reported outcomes (PROs). PROs are assessments of health-related quality of life that are completed by patients themselves, providing valuable information on the impact of a disease and its treatment on patients' lives.

This patient-centred research focuses on the use of PROs in the development of new biologic drugs for

Inflammatory Bowel Disease (IBD). It examines the use of PROs at different stages of drug development, from clinical trials to regulatory approval and reimbursement decisions.

At the end of the study, the patient organisations will provide a statement outlining what the international IBD patient community considers to be patient-centric. This statement will guide other stakeholders, such as healthcare professionals, industry, regulatory agencies and health technology assessment (HTA) bodies, on the use of PROs in the development of new biologic drugs for IBD.

In summary, patient-centred research that incorporates PROs is crucial for developing drugs that truly meet the needs of patients with IBD.

By involving patients in the drug development process and considering their perspectives, we can develop more effective and patient-centred treatments.

## Publications in Scientific Journals

Incorporating the publication of articles in scientific journals as a component of advocacy work serves as a strategic avenue to advance the goals and priorities of an organisation. By disseminating research findings, insights and patient perspectives through renowned scientific publications, advocacy efforts gain credibility and visibility within the academic and medical communities.

Moreover, publishing in scientific journals facilitates knowledge dissemination to a broader audience,

including healthcare professionals, policymakers and stakeholders involved in shaping healthcare policies and practices. These publications serve as a platform to highlight critical issues, present evidence-based solutions and contribute to ongoing conversations within the field. Furthermore, leveraging scientific publications as part of advocacy endeavours can influence policy development, drive funding allocations for research initiatives and ultimately improve outcomes for individuals affected by IBD.

## The Impact of Crohn’s Perianal Fistula on Quality of Life

In a concerted effort to shed light on the often-overlooked impact of Crohn’s perianal fistula (CPF) on quality of life, EFCCA collaborated on a significant initiative. CPF, a prevalent yet profoundly debilitating complication of Crohn’s Disease (CD), affects a substantial portion of CD patients, with estimates ranging from 23% to 38%. Alarming, approximately 70% to 80% of CPF cases manifest in a complex form, exacerbating the challenges faced by patients.

Recognising the imperative to comprehend the burden imposed by CPF, EFCCA, in collaboration with medical and patient representatives, commissioned an international, anonymous survey comprising 46 crafted items. This undertaking garnered a robust response,

with 7,820 patients from over 10 countries participating. The survey unveiled plenty of insights, revealing fatigue as the most prevalent symptom among both CD patients and those with CPF, closely followed by joint pain. Disparities between individuals with CPF and those with CD alone, particularly among women, underscored the profound impact of CPF on various facets of patients’ lives.

The culmination of this collaborative effort yielded comprehensive findings, which were disseminated to the wider scientific community through publication in the Journal of the Crohn’s and Colitis Foundation on 23 July 2023.

[Read the complete study here](#)

## What are the Unmet Needs and Most Relevant Treatment Outcomes According to Patients with Inflammatory Bowel Disease? A Qualitative Patient Preference Study

In April 2023, EFCCA collaborated on the publication of a qualitative study in the Journal of Crohn’s and Colitis, that aimed at understanding the unmet needs and treatment outcomes deemed most relevant by patients with Inflammatory Bowel Disease (IBD). Against the backdrop of increasing therapeutic options for IBD, the study sought to tailor drug development and treatment decisions to patients’ preferences and requirements.

The study employed a multi-faceted approach, including a scoping literature review, two focus group discussions (FGDs) involving 11 IBD patients utilising the nominal group technique and two expert panel discussions.

Results from the study revealed a diverse array of unmet needs among IBD patients, spanning symptom management, side effects and psychological and social support. Patients expressed concerns regarding potential surgery, medication effectiveness and onset, long-term

effects and the psychological toll of IBD. Notably, attributes such as preventing surgery, achieving long-term clinical remission, improving quality of life, managing urgency and enhancing labour rates were identified as particularly crucial by participants.

The findings underscored the necessity for IBD drug development and treatment strategies to address symptoms and adverse events that significantly impact patients’ quality of life. Moreover, the study highlighted the importance of involving patients in shared decision-making processes to ensure their treatment preferences and uncertainties are acknowledged and addressed. Through this collaborative effort, EFCCA continues to advocate for patient-centred approaches in IBD research and care, striving to meet the diverse needs of individuals living with the condition.

[Read the complete publication here](#)

## INSIDE EFCCA

# EFCCA's 2023 General Assembly (Bratislava and online)

From 9 to 11 June 2023, EFCCA convened its members in Bratislava, Slovakia, for its **Annual General Assembly (GA)**. This gathering provided a useful platform for participants to network, exchange experiences and lay the groundwork for a future marked by our shared goals. The GA in Bratislava was preceded two weeks prior by the online **institutional General Assembly** when members approved the Annual Report, Financial Report and the Work Plan. **Elections** to the EFCCA Executive Board were held with Menne Scherpenzeel (Netherlands) stepping down as board member and Lucie Laštíková (Czech Republic) being elected as new board member as well as the re-election of board member Ciara Drohan (Ireland) and Magdalena Sajak-Szczerba (Poland). EFCCA Chairperson Salvo Leone thanked Menne for his work and dedication during his term and welcomed the new board members.

The face to face GA in Bratislava allowed for plenty of interactions during breaks, meals and social events, nurturing a sense of camaraderie and shared purpose among attendees. The presence of Professor Cairtriona



O'Driscoll as a guest speaker, presenting the GENEGUT (Horizon Europe) project, further underscored EFCCA's dedication to advancing research and healthcare for the IBD community.

The unveiling of EFCCA's Strategy Plan at the GA represented an important moment in our journey towards enhanced global cooperation. Recognising the interconnectedness of our community, the plan seeks to broaden engagement beyond Europe, embracing diverse voices and perspectives to drive collective progress.

## EFCCA New Strategy Plan 2023–2027

During the General Assembly in Bratislava, EFCCA presented its 2023-2027 Strategy Plan, subsequently endorsed by the Assembly. This milestone marked the culmination of a collaborative journey initiated in Barcelona the previous year, involving extensive

consultations with our members and periodic discussions by the EFCCA Executive Board. The Strategy Plan serves as a framework guiding EFCCA's annual initiatives, projects and actions.

Central to the Plan is the concept of “*Global collaboration based on shared knowledge*” encapsulating EFCCA’s innovative approach and commitment to empowering the global community of IBD individuals. At its core lies DIVA, a pioneering methodology aimed at leveraging shared knowledge to benefit patients worldwide. Through DIVA, we seek to establish an EFCCA data bank—an extensive repository accessible to our members and stakeholders—facilitating evidence-based advocacy and policy formulation.

The Strategy Plan is structured around three pillars: **Awareness raising, Empowerment and Research & Development**. Each pillar delineates specific actions aimed at advancing EFCCA’s mission. Notably, Research and Development emerges as a new focus, underpinned by DIVA’s data collection capabilities, facilitating collaborative research with healthcare institutions and researchers. By participating in transnational projects like the Horizon programme, we aim to promote patient-centric research addressing real-world concerns.

Furthermore, **Networking** forms the basis of our strategy and of our advocacy efforts, fostering relationships with stakeholders and proactive engagement with international institutions. **Advocacy**, positioned as the roof of the EFCCA house, underscores our commitment to evidence-based advocacy and innovative policy promotion to address the unique challenges faced by the IBD community globally.

As we embark on implementing the Strategy Plan, EFCCA remains receptive to community feedback, committed to continuous improvement and steadfast in its mission to amplify the voices of IBD individuals worldwide. With a culture of collaboration and a strategic roadmap in place, we are poised to drive meaningful change and advocate for a stronger, more vocal IBD community across continents.

[Read full document here](#)

## Executive Board

For the reporting period of this Annual Report the Executive Board has met online and in-person on the following dates:

### **Brussels, 21 to 23 April 2023 (previous Executive Board).**

The meeting started with a presentation and discussion of the final steps of the Strategic Plan, which was led by Antonella Cardone. After a lunch break the board members focused on preparing for the Institutional General Assembly and the organisation of the event in Bratislava. They discussed various aspects of the event, such as the agenda, guest speakers and logistical details, to ensure a successful and productive assembly. Other discussions included an invitation from Lithuania to collaborate in their World IBD Day

IBD-related initiative, an invitation from Medicine for Europe and a MEP group on immunocompromised patients and other on-going project updates.

### **Bratislava, 10 June 2023.**

The newly elected board met to assign the positions within the board and to debrief on the GA. The date for the first face to face meeting of the new Executive Board was agreed. The newly elected board consists of the following board members:

Salvo Leone, EFCCA Chairperson  
 Ciara Drohan (Ireland), EFCCA Vice President  
 Marko Perovic (Serbia), EFCCA Treasurer  
 Lucie Laštíková (Czech Republic)  
 Magdalena Sajak-Szczerba (Poland)

### **Brussels, 29 September to 1 October 2023.**

Discussions included activities for the final trimester of 2023. Among the key items on the agenda were the UEGW/ECCO Patient Council event in Copenhagen (October 2023) as well as the organisation of the EFCCA Patient Talk before the end of the year. The

staff provided updates on ongoing projects and financial matters, including the Patient Preference Survey, Elderly Survey and our involvement in the Horizon Europe projects. Plans for EFCCA’s actions for World IBD Day 2024 were presented and approved.

### **Brussels, 28 November 2023.**

Due to several board members not being able to attend this meeting last minute (due to illness) it was decided to use the meeting to brainstorm with the chairperson and the EFCCA staff on upcoming activities.

### **Online Executive Board Meeting, 1 February 2024.**

This extraordinary board meeting was convened in response to allegations raised by board member Lucie Laštíková.

### **Online Executive Board Meeting, 8 December 2023.**

An online board meeting was held to discuss how to approach the changes necessary to the EFCCA Constitution in line with the new Belgian Code of Companies and Associations (BCCA). A limited review is needed to check the compliance of EFCCA Constitution articles and amend them accordingly, if necessary.

### **Online Executive Board Meeting, 27 February 2024.**

Board members met online to discuss the organisation of the EFCCA GA 2024 to take place in Brussels (7/9 June 2024). An update of EFCCA’s plan for World IBD Day 2024 was presented and several other topics (AOB) were discussed.

## **Communication activities**

### **EFCCA Magazine**

The EFCCA Magazine serves as an important instrument for raising awareness about IBD and more generally about patients’ concerns. Throughout the last year, three editions were released, providing valuable perspectives on the latest research, treatments and insights from our members and other IBD stakeholders.

By showcasing narratives and dialogues from patients, our members and healthcare professionals, the magazine amplifies the voices of those affected by IBD and sheds light on the daily challenges of living with these two chronic diseases.



- [Issue February 2024](#)
- [Issue October 2023](#)
- [Issue May 2023](#)



## Digital impact and Social Media

In recent years, we have intensified efforts to expand our digital community across key platforms, indicating a growing reach and engagement with our audience.

On LinkedIn, our presence has flourished, witnessing a surge in followers to 1,950 by March 2024. This represents an impressive increase of over 50% within a year, highlighting the escalating interest and recognition of EFCCA's initiatives within the professional realm.

Likewise, our Facebook community has experienced significant growth, boasting 7,568 followers as of March 2024. This marks a notable rise of 30% over the past year, demonstrating the resonance of our content with a diverse audience. Additionally, our presence on X has steadily gained traction, garnering 900 followers by March 2024.

Moreover, [our website](#) has continued to serve as a hub for information and resources, attracting a significant influx of visitors seeking valuable insights and support. The steady increase in website traffic further underscores the expanding reach and impact of EFCCA's digital presence, reinforcing our commitment to providing accessible and relevant content to our global audience.

As we continue to harness the power of digital platforms to connect, educate and empower individuals affected by chronic illnesses, we remain dedicated to fostering a vibrant and inclusive online community that supports and advocates for the needs of all those impacted by Inflammatory Bowel Disease.



## EFCCA Project Digest

In August 2023, we launched the EFCCA PROJECT DIGEST: a newsletter exclusively dedicated to keeping up to date with the latest developments in Horizon Europe and Horizon 2020 research projects, in which EFCCA participates as a partner. The EFCCA Project Digest will provide regular updates every 2 to 3 months, reflecting the ongoing progress and impact of these projects on our collective efforts within the Horizon Europe framework.

To find out more and read the newsletter, visit [efcca.org/projects/efcca-projects-digest-newsletter](https://efcca.org/projects/efcca-projects-digest-newsletter)



# EFCCA Staff



The EFCCA staff is headed by Chief Executive Officer (CEO) **Luisa Avedano** who is responsible for the overall implementation of the EFCCA work plan and its institutional representation.



**Isabella Haaf** is Head of Communication and Editor-in-Chief of the EFCCA Magazine. She also coordinates World IBD Day and EFCCA's international relations.



**Maria Stella De Rocchis** is our European Project officer responsible for the development of the EFCCA Academy as well as following several EU projects under the Horizon Europe programme.



**Roberto Saldaña**, our Innovation and Patient Engagement Coordinator, is responsible for our new working methodology DIVA. He also represents EFCCA at several Patient Advisory Boards and at the European Medicines Agency.



**Francesc Esparza-Pagès** joined our team in May 2023 to assist EFCCA's communication work. In November he started to provide support to the EFCCA Academy and EU funded projects.



**Laura Cervetto** joined EFCCA in December 2023 to assist with our communication activities with a main focus on social media platforms as well as internal newsletters and information material.



Our finance team is headed by **Tatiana Negurita**, our Finance Project Officer and **Ivan Fomin**, our Financial Assistant.

Michele Pasino, William Ronco and Antonella Montanari from **Officine Digitali** are in charge of our IT support, online training platforms and video recordings.

# Members

## Austria

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

## Belgium

CCV: [www.ccv.be](http://www.ccv.be)  
Crohn-RCUH: [www.mici.be](http://www.mici.be)

## Bulgaria

BCUCA – [www.babkuk.org](http://www.babkuk.org)

## Croatia

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

## Cyprus

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

## Czech Republic

Pacienti IBD – [www.crohn.cz](http://www.crohn.cz)

## Denmark

CCF – [www.ccf.dk](http://www.ccf.dk)

## Estonia

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

## Finland

IBD ja muut – [www.ibd.fi](http://www.ibd.fi)

## France

AFA – [www.afa.asso.fr](http://www.afa.asso.fr)

## Germany

DCCV.e.V. – [www.dccv.de](http://www.dccv.de)

## Greece

HELLESCC  
[www.crohnhellas.gr](http://www.crohnhellas.gr)

## Hungary

MCCBE – [www.mccbe.hu](http://www.mccbe.hu)

## Iceland

CCU – [www.ccu.is](http://www.ccu.is)

## Ireland

ISCC – [www.iscc.ie](http://www.iscc.ie)

## Israel

CCFI – [www.ccfi.co.il](http://www.ccfi.co.il)

## Italy

AMICI – [www.amiciitalia.org](http://www.amiciitalia.org)

## Latvia

LKKSBB – [www.lkksb.lv](http://www.lkksb.lv)

## Lithuania

CCLA – [www.draugija.info](http://www.draugija.info)

## Luxembourg

ALMC  
[www.afa.asso.fr/luxembourg](http://www.afa.asso.fr/luxembourg)

## Malta

MACC – [www.macc.org.mt](http://www.macc.org.mt)

## Montenegro

CUKUK – [www.cukuk.me](http://www.cukuk.me)

## Netherlands

Crohn's & Colitis NL  
[www.crohn-colitis.nl](http://www.crohn-colitis.nl)

## New Zealand

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

## Norway

Magetarm – [www.magetarm.no](http://www.magetarm.no)

## Poland

J-elita – [www.j-elita.org.pl](http://www.j-elita.org.pl)

## Portugal

APDI – [www.apdi.org.pt](http://www.apdi.org.pt)

## Romania

ASPIIR – [www.aspiir.ro](http://www.aspiir.ro)

## Russia

Trust – [www.vzk-life.ru](http://www.vzk-life.ru)

## Serbia

UKUKS – [www.ukuks.org](http://www.ukuks.org)

## Slovakia

SCC – [www.crohncub.sk](http://www.crohncub.sk)

## Slovenia

SAIBD – [www.kvcb.si](http://www.kvcb.si)

## Spain

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

## Sweden

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

## Switzerland

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

## Turkey

IBHDYD – [www.ibhportali.com](http://www.ibhportali.com)

## UK

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

## Ukraine

Fulfilling life – [www.gofulllife.com.ua](http://www.gofulllife.com.ua)

## Associate Members:

### Argentina

Mas Vida – [www.masvida.org.ar](http://www.masvida.org.ar)

### Brazil

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

### Lebanon

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

### Kazakhstan

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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**EFCCA**

European Federation of Crohn's  
& Ulcerative Colitis Associations

## Contact Details

**Rue des Chartreux 33-35  
B-1000 Brussels Belgium  
Tel/Fax: +32 2 540 8434**

Registration: 1096/97  
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No. 459814543

Chairman:  
Salvo Leone  
salvo.leone@efcca.org

Honorary Secretary and  
Vice President: Ciara Drohan  
ciara.drohan@efcca.org

Treasurer:  
Marko Perovic  
marko.perovic@efcca.org

CEO: Luisa Avedano  
Tel: +32 483 371 194  
luisa.avedano@efcca.org

Head of Communication:  
Isabella Haaf  
Tel: +34 606 849 937  
bella.haaf@efcca.org