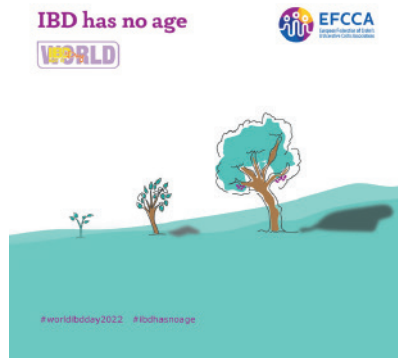


EFCCA ANNUAL REPORT

March 2022 - March 2023

2022 2023



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 to support, learn and share with each other.

3. Integrity: We have strong principles of ethics, honesty, 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 make a valuable contribution to the well-being of people affected by IBD by fostering engagement, involvement, activism and to ultimately find a cure for IBD.

Our 4 strategic areas in which current activities are structured are:

Networking

Awareness Raising

Advocacy

Empowerment

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Foreword

Dear members,

It is our pleasure to present this year's annual report, which provides an overview of our organisation's activities and achievements over the past year. Despite the ongoing challenges brought about by the COVID-19 pandemic, EFCCA has continued to work hard in order to fulfil its mission to improve the lives of people with inflammatory bowel disease (IBD). Over the past year, we have made significant progress in our four strategic areas: networking, awareness raising, advocacy and empowerment.

One of our most significant milestones was the development of our new working methodology, DIVA. We are very excited about this as the data-driven approach of DIVA will revolutionise the way EFCCA advocates for IBD patients and will help to understand the real needs of patients and healthcare systems, advocating for evidence-based and patient-centered policies and treatments.

Another milestone is our involvement in 5 new, major EU research projects (under Horizon Europe), which will enable us to continue our important work in advancing research, promoting patient-centred healthcare, and advocating for the rights of people with IBD. These projects will allow us to collaborate with other organisations and stakeholders to develop innovative solutions and strategies for improving the quality of life for those affected by IBD.

Being involved in multiple research projects increases our visibility and strengthens our reputation as a leading advocate for patients with chronic digestive diseases. It demonstrates that EFCCA is a valued partner for academic researchers, industry partners, and policymakers who recognize the importance of incorporating the patient perspective into their work.

Our bottom-up approach, which involved our members in the development of a new strategy plan for EFCCA, has been another significant achievement. By working collaboratively, we have been able to develop a comprehensive plan that reflects the needs, priorities and aspirations of our community. This plan to be endorsed during our General Assembly in 2023 will guide our work over the next four years and ensure that we remain focused on achieving our mission.

Since the beginning of the war in Ukraine, EFCCA has shown solidarity with its Ukrainian member, Fulfilling Life, and has been working hard to support the association and its IBD patient community. This report showcases the efforts and accomplishments of EFCCA and its members and confirms the strength of our network as we stand united!

We would like to thank all our members, partners, volunteers and supporters for their continued dedication and commitment to our cause. We look forward to working together to continue making a positive difference in the lives of people living with IBD across Europe and beyond!

Sincerely,



Salvo Leone
EFCCA Chairman



Luisa Avedano
EFCCA CEO

The year in figures

- 5** Horizon Europe projects looking at innovative IBD treatment options
- 45** delegates attended our hybrid General Assembly (online and Barcelona)
- 5** online events organised by EFCCA involving over 200 participants
- 8** Patient Advisory Boards and Working Groups
- 3** EFCCA Executive Board meetings held in 2022/23
- 1** new patient association joined EFCCA bringing our total membership to 46 associations
- 6** publications in scientific journals
- 3** publications of the EFCCA Magazine

Digital Impact



7.377

Facebook followers



775

Twitter followers



1.000

LinkedIn followers



29.732 visit

EFCCA website

Networking

Networking is an important pillar of EFCCA's strategy plan. As EFCCA represents a relatively small disease group it is crucial that we develop and strengthen synergies and partnerships that benefit everyone involved. Collaboration, exchange of information, knowledge and practices, as well as the promotion of international activities are all key components of our networking efforts. We recognize the importance of working with different stakeholders and building strong relationships in order to establish a robust IBD community.

Through our networking initiatives, we strive to connect with other organisations, healthcare professionals, policymakers, and industry representatives to create

a collaborative and supportive environment for people with IBD. Below are the main networking activities that took place in 2022 and till March 2023.

Congress

UEG WEEK 2022

UEG WEEK 2022 (8 - 11 October 2022, Vienna, Austria) was an important event for EFCCA, as it provided a much-needed opportunity to reconnect with the scientific community, industries, and stakeholders after a long period of virtual meetings due to the pandemic. This was the first in-person congress since the start of the pandemic and EFCCA board members and staff travelled to Vienna with great enthusiasm to make the most of this event.

One of the main objectives of the UEG Week is to promote knowledge sharing and collaborative learning among experts in the field of gastroenterology. With over 10,000 participants from more than 110 countries, the event was the perfect platform for EFCCA to engage in interactive discussions and proactive debates with IBD specialists and key stakeholders.

EFCCA had the opportunity to share its mission, values and activities and to network and connect with professionals from the scientific community.



The EFCCA team also attended several sessions and symposiums of the scientific programme, gaining insights and knowledge from various perspectives in the field of gastroenterology.

ECCO Congress

The **2022 ECCO Congress** was still held online between 16 and 19 February 2022 due to travel restrictions mainly for countries outside the European region and participants had the possibility to attend the scientific sessions remotely.

More info: www.ecco-ibd.eu/ecco22

For the **2023 ECCO Congress** participants met face to face from 1-4 March 2023 in Copenhagen, Denmark. It brought together top health care professionals, researchers, patient advocates and other stakeholders to exchange the latest knowledge in science about IBD.

EFCCA set up an information booth and EFCCA staff were involved in numerous stakeholder meetings and presented at the ECCO 8th National Study Group Meeting.

Congress of the European Association of Hospital Pharmacists (EAHP)

EFCCA attended the 26th Annual Congress of the European Association of Hospital Pharmacists which took place in Vienna, Austria from 23-25 March 2022. We are pleased to see that our partnership, which began a couple of years ago, has continued to bear fruit and create new opportunities for the benefit of IBD patients. The EAHP Congress offered an excellent opportunity for our CEO and Deputy Director to meet with the EAHP leadership to discuss and explore potential projects of collaboration related to IBD patients in the hospital setting.

As EFCCA's mission is to promote the best possible care for patients with IBD, we recognise that hospital pharmacists play a critical role in counselling patients on medication options, education, and assisting with medication access. They also monitor the efficacy of current treatment and provide valuable input on drug design and treatment success. Therefore, collaborating with the EAHP will be beneficial to the IBD patient community. Projects in the pipeline include educational activities as well as participating in the



The results of the qualitative patient preference study in which EFCCA is involved in, was promoted during the Congress POSTER presentations.



programme of the next congress in Lisbon (2023) in order to provide the patient perspective on the theme of “From drug design to treatment success – what really matters to patients?”

Stakeholder organisations

EFPIA THINK TANK

EFCCA participated in the EFPIA THINK TANK that took place on the 28 and 29 September 2022 in Brussels involving around 40 participants from pharma and patient representatives. Discussions focused on “Regulation on Health Technology Assessment: what does it mean for patients” and “Understanding unmet medical needs from a patient perspective”.

The EFPIA Think Tank is a collaborative platform created by the European Federation of Pharmaceutical Industries and Associations (EFPIA) to foster discussion and knowledge-sharing among stakeholders in the pharmaceutical industry. The Think Tank brings together experts from industry, academia, patient organisations, healthcare providers, and policymakers to explore and address key challenges facing the healthcare sector.

ICHOM Conference (International Consortium for Health Outcomes Measurement)

Ciara Drohan, EFCCA’s Vice-President and Honorary Secretary, participated (virtually) in the 2022 ICHOM conference event (1-3 November 2022) on “The New Era of Healthcare” as a panellist on the crucial role of patient organisations in driving better patient outcomes.

With over 500 delegates from 40 countries, the event provided a valuable networking opportunity for EFCCA to discuss patient reported outcomes, achieve equitable and inclusive patient care, and address hurdles in implementing value-based healthcare.



EUROPEAN MEDICINES AGENCY
SCIENCE MEDICINES HEALTH

European Medicines Agency

On 18 October 2022 EFCCA attended the “Launch of a public consultation on the EU Data Quality Framework for medicines regulation and multi-stakeholder” which was organised by the European Medicines Agency.

The European Medicines Regulatory Network has released for public consultation the first version of this framework. The launch meeting was a great occasion to collect initial feedback from the audience.



Alliance For Safe Biologic Medicines and Generics and Biosimilars Initiative

On 20 July 2022 EFCCA participated in the online event hosted by the Alliance For Safe Biologic Medicines and Generics and Biosimilars Initiative entitled “Non-medical switching of biologicals/biosimilars: Canada, Europe and the US”.

The meeting dealt with the issue of biosimilar switching for non-medical and strictly economic reasons and included academic clinicians with specialties in oncology and ophthalmology, patient advocates, policymakers and regulatory experts.

Medicines for Europe

EFCCA participated in a meeting organised by Medicines for Europe entitled: “Biosimilar Medicines: Changing patient care pathways, changing outcomes”. Medicines for Europe discussed European initiatives offering an opportunity to effectively deliver better care & outcomes, notably the revision of the **EU pharmaceutical legislation** and the development of the **European Healthier Together Initiative**.

EFCCA’s stakeholder meeting

During UEG WEEK 2022 (9 October) EFCCA organised a meeting with its stakeholders including representatives from the scientific and medical community as well as industry representatives in order to present our new working methodology within the framework of DIVA (see page 19).



Presentations of concrete examples and experiences having delivered more value for health thanks to biosimilar medicines will allow for a debate on key features and enablers to be considered in advancing public health and biosimilar policies.

ONLINE LIVE SESSION

Biosimilar medicines: Changing Patient Care Pathways, Changing Outcomes

#BIOS22 28 April 2022

11:00 - 12:30 CEST



a  medicines for europe sector group



Patient organisations

European Patient Forum

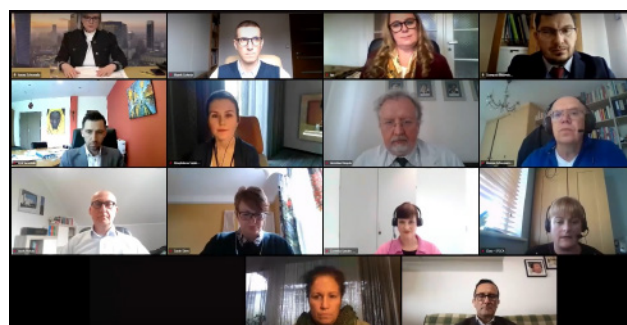
Our CEO attended the online General Assembly of the European Patient Forum (EPF) which took place on 23 April 2022. It was a great opportunity to share our experiences and views and reflect on EPF's development.

Delegates had the chance to meet the new Executive Director and to participate in the election of four board members. EFCCA is a long standing member of EPF.

European Forum of Patients with Inflammatory Bowel Diseases

The meeting that took place on March 31, 2022, organised by the Polish Association Supporting People with IBD "J-elita," together with the Editorial Office MedExpress.pl, and in cooperation with EFCCA, was a significant event in terms of networking. The meeting provided a platform to present different perspectives and experiences from various European countries, including Poland, regarding the personalization of treatment of people with IBD, as well as the experiences of patients during the pandemic.

The crises have demonstrated the importance of personalised treatment, tailored to the patient's expectations, readiness to undertake a specific type of treatment, and the form of administration.



Amongst the attendees were government officials, representatives from the medical societies and EFCCA members from the following countries: Austria, Czech Republic, Germany, Ireland, Italy, the Netherlands, Poland and UK.

EFCCA HAPPY HOUR

In 2022, EFCCA continued the Happy Hour online meeting as a way to maintain connections with its members as introduced during the COVID-19 pandemic. These informal gatherings provided a platform for members to exchange ideas, discuss common projects, and network with one another.

PATIENT OPINIONS MATTER (13 and 14 December 2022). We introduced our roadmap for a new working methodology that entails a significant change in the patient's role, with the aim of recognizing and tackling the actual requirements of our IBD community.



The feedback and discussions were encouraging, and we'll keep you updated on our ongoing efforts.

Patient Advisory Board meetings and Working Groups

EFCCA has participated in the following Patient Advisory Boards and Working Groups that were organised by different pharmaceutical companies as well as European institutions. We believe that collaboration in such meetings can yield beneficial outcomes for the IBD patient community. Through these meetings, we are able to provide the collective patient perspective on various activities, including clinical research and the exchange of information on the patient pathway. As a group, we can more effectively ensure that the patient's voice is heard and taken into consideration in these discussions.



Global IDB Council

On 9 October 2022, the EFCCA secretariat and a number of EFCCA members attended the Global IBD Council meeting in Vienna, which was organised by Pfizer (ARENA). The meeting focused on two main topics: the psychosocial effects of IBD and minimising potential obstacles to accessing treatment. By participating in this council, EFCCA aimed to contribute to the discussions on these important topics, providing valuable insights from the patient's perspective.

CONFIDE European Advisory Board

On October 7, 2022, the global biopharmaceutical company Lilly organised an important event in which Key Opinion Leaders and patient representatives participated. The aim of the event was to review and analyse the results of the "Communicating Needs and Features of IBD Experiences (CONFIDE) Survey: Impact of ulcerative colitis symptoms on health professionals' treatment decisions". The survey aimed to provide a comprehensive understanding of the challenges and unmet needs of people living with IBD, and to identify potential areas for improvement in their care.

Act4Biosimilars

EFCCA has been involved in the global initiative aimed to help address health inequity and inequality worldwide. Founded and sponsored by Sandoz, Act4Biosimilars aims to increase patient access to advanced medicines by facilitating greater approvability, accessibility, acceptability and affordability (the 4A's) of biosimilars. An Action Plan will be launched in 2023.

JAK inhibitors expert meeting (European Medicines Agency)

In September 2022 EFCCA participated in this EMA expert meeting to review the safety of JAKs. The discussion revolved around the results published in the oral surveillance trial, risk factors, and the suspicion that the adverse reactions detected may be a class effect that regulators should extrapolate to other products in the same category.

Phase 4 Study review in Ulcerative Colitis

In June 2022 EFCCA reviewed for Galapagos the protocol of a post-authorization non-interventional clinical trial. In our feedback, we shared our views on the rationale of the clinical trial, the primary and secondary endpoints, and the safety and efficacy issues that patients are most concerned about, among other topics.

Patient Advisory Group (PAG) and Clinical trial playbook

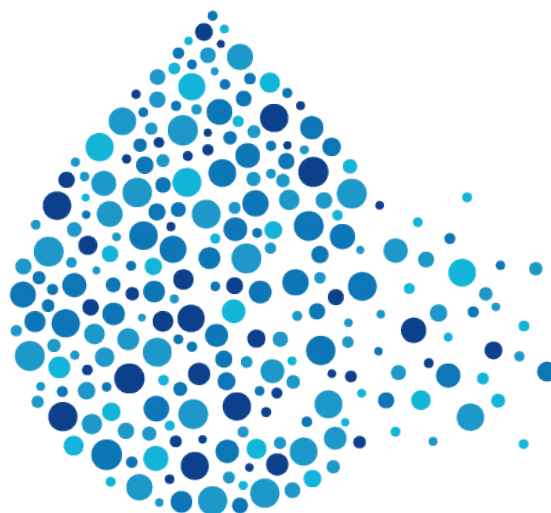
EFCCA participated in several meetings organised by Roche to review a final document which summarises the conclusions of all consultations to the Patient Council for “Integrating individuals living with inflammatory bowel disease into IBD clinical trial development.”

It included: 1) understanding the patients: an overview of the individuals and their experiences living with IBD (the patient journey) and 2) considerations when designing the clinical trial: pre-enrolment, post-enrolment and after-trial completion and 3) Collecting insights with the IBD community: Generating patient insights.

Working groups

Patients’ perception of using telehealth for consultation: insights from the COVID-19 pandemic and development of a tool to predict acceptance of remote consultation. The TELECOVID international study

EFCCA participated in this study to evaluate the patient acceptance of telemedicine as an alternative to face-to-face consultations during the COVID-19 pandemic and identify factors that predict higher satisfaction. Telemedicine is feasible, effective, and satisfactory for physicians and patients. However, patients older than 60 are less likely to agree with telemedicine.



H₂O | HEALTH OUTCOMES
OBSERVATORY

H₂O Health Outcome Observatories

In collaboration with other stakeholders, EFCCA is participating in this European project to build a real-life evidence-generation observatory. The project aims to identify patients’ status and understand the causes of therapeutic success and failure.

Awareness raising

In recent years, progress has been made in the diagnosis, treatment, and management of IBD. However, despite this progress, there remains a significant lack of public understanding and awareness of the disease and the challenges faced by those who live with it. This lack of awareness can lead to social stigma, misconceptions, and isolation for individuals with IBD, preventing them from accessing the care and support they need.

This is why raising awareness of IBD is a strategic area for EFCCA as we recognise the need to tackle taboos and stigmas around IBD and to increase public knowledge of the disease's impact on individuals and society. Furthermore, greater awareness of IBD can help to increase funding for research and treatment development. By raising the profile of the disease and highlighting its impact on individuals and society, EFCCA can help to secure greater investment in research and development, leading to improved treatments and ultimately, a cure.

World IBD Day

World IBD Day is an excellent tool for raising awareness of IBD as it provides an international platform to promote education, encourage action, and draw attention to the challenges faced by individuals with IBD.

IBD HAS NO AGE Campaign

In 2022 and continuing into 2023 EFCCA has been using World IBD Day to raise awareness about people with IBD aged 60 years and over. Our campaign **IBD has no age** aims to highlight how living with Crohn's disease and Ulcerative Colitis is impacting on the quality of life and care of people with IBD aged 60 years and over.

This group has been consistently underrepresented even though the incidence and prevalence of IBD in older patients is rising. Yet, there is little scientific evidence to understand how IBD impacts on adverse

In 2022/3 EFCCA has engaged in a range of activities to provide a better understanding of the physical, emotional, and social impact of IBD, helping to reduce stigmatisation and increase support for those affected by the disease. We have also worked with healthcare professionals, policymakers, and other stakeholders to promote policies and practices that prioritise the needs of those affected by IBD.



health outcomes or quality of life in older people with IBD. To address these issues EFCCA in 2022 organised the following:

Focus group meeting with eight patient representatives to gain a better understanding of IBD in people aged 60 and over and to discuss their experiences and unmet needs. The findings from the discussions were incorporated into our awareness-raising campaign.

A social media campaign that included several patient testimonials to raise awareness about IBD in people aged 60 and over and to highlight 3 key messages: lack of scientific data, need for patient-centric care and the issues around IBD and comorbidities.

Purple EFCCA Talk We organised a webinar on World IBD Day 2022 on the issue of IBD in people aged 60 and over. The key message was the need for more comprehensive scientific evidence. Our invitees included representatives from the scientific community to discuss the challenges and unmet needs of people aged 60 and over and to discuss collaboration on a joint survey on this topic.

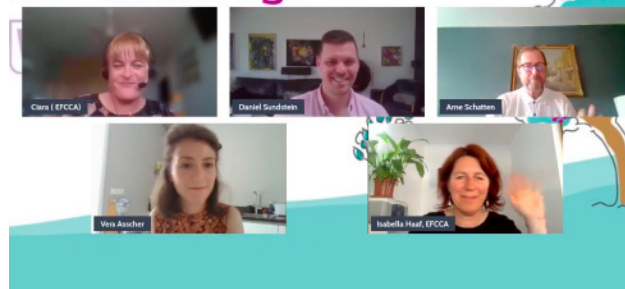
Purple Lightning campaign

EFCCA has been coordinating the global World IBD Day campaign for several years and has been gathering and disseminating information about activities taking place worldwide. Numerous countries participate in the campaign by organising local events and some continue illuminating famous landmarks in purple, the colour representing IBD awareness, around May 19th, the official date of World IBD Day.

Raising awareness on transitioning from paediatric to adult care

During UEG WEEK, EFCCA participated in the launch of a transitional care forum, led by the European Society for Paediatric Gastroenterology, Hepatology and Nutrition (ESPGHAN) and United European Gastroenterology (UEG), to raise awareness of major issues faced by paediatric patients with digestive and

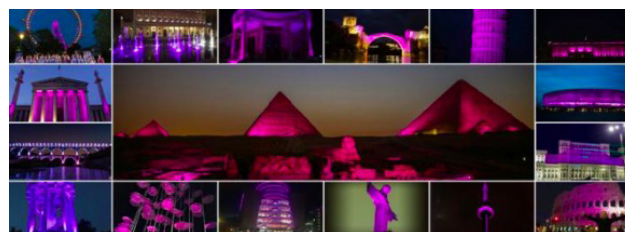
IBD has no age



Launch of survey (planned for World IBD Day 2023). As a continuation of our 2022 campaign we are planning to launch a survey on people with IBD aged 60 years and over to investigate more on this topic with questions related to both quality of care and quality of life.

More info:

www.efcca.org/projects/world-ibd-day-2022



Check out the www.worldibdday.org website to see what has happened globally in 2022.

liver conditions during the transition to adult care.

The forum aims to develop a joint call to action for change by bringing together key stakeholders, including patient organisations, to share with policymakers and healthcare providers across Europe in the next two years.

At the inaugural Patient Organisation Workshop on Transitional Care, EFCCA's board member, Magdalena Sajak Szczerba, highlighted the critical role of patient organisations in providing recommendations and insights to ensure a seamless transition process for young IBD patients. EFCCA's involvement in this forum is a significant step in raising awareness of the needs of patients and ensuring their voices are heard in shaping the future of transitional care.



Euronews DEBATES: How can Europe shape the future of biosimilar medicines?

On November 15, 2022, Euronews hosted a panel of experts to discuss the potential impact of biosimilar medicines on the future of Europe. The debate, which took place at the European Parliament in Brussels, aimed to explore how Europe could shape the future of biosimilar medicines. The panel was composed of Adrian van den Hoven, Director General of Medicines for Europe, Tomislav Sokol, MEP and Member of the EU's Special Committee on the COVID-19 Pandemic, Ian Henshaw, Global Head of Biosimilars at Biogen, and Luisa Avedano, CEO of EFCCA.

She suggested that a “critical mass” could be created by bringing together policy makers, industry, medical societies, and associations to demonstrate that it is possible to make changes based on evidence.

One issue that was identified during the discussion was that the safety and efficacy of biosimilar medicines are not given enough prominence. Avedano emphasised the importance of raising awareness of the transparency, safety, and effectiveness of these medicines to give more patients the opportunity to be treated.



For EFCCA it has been an excellent score to be part of this debate which provided a platform for raising awareness and promoting critical thinking about the future of biosimilar medicines in Europe.

The panel discussed why biosimilars are not currently being uniformly used throughout the European Union and how this issue could be resolved. Luisa Avedano pointed out that although the importance of biosimilars is well-known among patients in their associations, only 20 to 25 percent have access to these medicines.

IBD and Fatigue

EFCCA has prepared informative material to raise awareness about the impact of fatigue on patients with IBD. Fatigue is a commonly reported concern among IBD patients, affecting almost 50% of those in clinical remission and 80% of those with active disease. It can significantly decrease their quality of life and impair work productivity and functioning.

Our efforts focused on providing information about the issue and possible solutions for fatigue in IBD patients. The knowledge can help patients and healthcare providers work together to improve patient outcomes and quality of life. It is crucial to recognize and address the impact of fatigue in IBD patients to ensure they receive appropriate care and support.



For more info:

<https://efcca.org/projects/ibd-and-fatigue>

EFCCA Magazine

The EFCCA magazine is an excellent tool for raising awareness about IBD and related issues. With three issues published during the reporting period, it provided valuable insights into the latest research, treatment options, and patient experiences.

By featuring stories and interviews from patients, our members and healthcare professionals, the magazine gives voice to those affected by IBD and sheds light on the challenges they face. It also provides a platform

for organisations and individuals working to improve the lives of people with IBD to share their insights and initiatives.

The EFCCA magazine is an essential resource for anyone interested in IBD and related issues. It helps to raise awareness, promote understanding, and facilitate collaboration among patients, healthcare providers, and stakeholder organisations whilst highlighting EFCCA's commitment to providing valuable resources for the IBD community.



Advocacy

EFCCA is committed to advocating for the needs and priorities of people living with IBD. One of the key aspects of EFCCA's advocacy work is engaging with our stakeholders to promote a more patient/person-focused approach to IBD care.

Traditionally, IBD care has been centred around therapy-focused approaches that solely prioritise medical interventions. However, EFCCA recognises that people living with IBD have diverse and unique needs that go beyond just medical treatment. Therefore, it is essential to move towards a more patient/person-focused approach that takes into account the broader needs of individuals living with IBD.

To achieve this goal, EFCCA collaborates with various stakeholders to ensure that the voices and concerns of people living with IBD are included in the decision-making process for policies and other related health initiatives. This advocacy work involves promoting policies that prioritise the needs of people living with IBD ensuring that policies and health initiatives are developed with the patient in mind, resulting in better outcomes and improved quality of life for people living with IBD.

Updating ECCO Guidelines on Crohn's Disease

The European Crohn's and Colitis Organisation (ECCO) launched the new Working Group on updating the Crohn's disease (CD) treatment guidelines (14 September 2022). This meeting brought together 50 participants from around the world, including six patient representatives from our EFCCA network.

ECCO produces and regularly updates several guidelines to provide guidance on critical aspects of IBD care to all healthcare professionals. Since the initiation of the first project in 2006, the ECCO Guidelines have become standard references for IBD management worldwide. ECCO is updating the Guidelines using the GRADE Methodology, and the current guidelines on Crohn's Disease treatment are being revised into four working groups.

The involvement of our patient representatives in the meeting highlights the importance of their perspective in decision-making and defining relevant outcomes in a patient-oriented way. As advocacy is an important strategic objective for EFCCA we welcome this recognition of the need for patients' associations'



involvement in the process. It is critical to make the guidelines relevant not just for clinicians but also for patients, and the involvement of patients ensures their needs are considered.

The revision of the guidelines is an 18-month process, scheduled to be concluded by 2024. EFCCA will keep the IBD community updated on the progress of these working groups. This initiative by ECCO demonstrates the importance of advocacy in the IBD community, ensuring that the voices of patients are heard and their needs are addressed.

More info:

<https://efcca.org/projects/ecco-grade-crohn's-disease-cdtreatment-guidelines>

Multi-stakeholder initiative to enable cross-border access to clinical trials in Europe

In November 2022 EFCCA attended the kick-off meeting of the “Multi-stakeholder initiative to enable cross-border access to clinical trials in Europe “EU Cross-Border Trials” or “EU-X-CT” organised by the European Federation of Pharmaceutical Industries and Associations (EFPIA) and the European Forum for Good Clinical PRactice (EFGCP).

The meeting involved industry, academia and patient representatives. Its overall objective is to identify possible solutions to enable cross-border access to clinical trials, therefore 4 Task Forces have been established to deal with specific topics.

Roberto Saldana representing EFCCA will be one of the co-leaders of the 4th Task Force (Role of patient organisations, European Research Networks and other networks to support patients’ cross-border access to trials).

EFCCA’s participation in the “Multi-stakeholder initiative” is an important step in ensuring that patients with IBD have access to groundbreaking treatments through clinical trials.

Patients with IBD often struggle to find effective treatments, and clinical trials can offer new hope for better outcomes. However, access to clinical trials can be limited by a range of factors, including location, language barriers, and regulatory requirements.

The initiative aims to address these barriers and improve access to clinical trials across Europe. By mapping out the logistical and financial requirements for conducting cross-border trials, the initiative can identify solutions to enable patients to participate in trials regardless of their location.

As a co-leader of the Task Force on the Role of patient organisations, EFCCA can bring the patient voice to the table and help shape the development of solutions that are patient-centered. The initiative will end in December 2024.

Patient Preference Study

In 2021 we collected already existing data and reviewed health literature published on the topic. Very little information is available regarding IBD and its community, therefore in 2022 we focused on formulating priorities and needs identified with the involvement of our associations and we started our collaboration with KU Leuven.

Several online meetings took place from the beginning of 2022: focus groups involving EFCCA representatives, KU Leuven researchers and clinicians.

A fruitful partnership that has led to the co-design of a survey where a multidisciplinary advisory board identified 14 attributes related to IBD patients' treatments and/or disease.

The survey is now ready to be translated into at least 10 languages and launched after a pilot phase when the English version of the questionnaire was tested by patients.

In the meantime articles related to the project methodology and the definition of the attributes have been published in IBD specialised Journals and posters presented at medical congresses.



Risk of undergoing SURGERY

This is the risk that you need to undergo surgery because:

- Medical therapy cannot adequately control your intestinal inflammation
- You have recurrent flare-ups
- There is a puncture in the wall of your bowel (perforation), a narrowing in a part of your bowel (stricture), or a pus-filled area in the wall of your bowel (abscess)
- There is a high risk of cancer in the bowel
- There is cancer in the bowel

Surgery may be accompanied by the construction of a (temporary) stoma.



FREQUENCY of having to go to the toilet

This is the frequency that you have to go to the toilet.



URGENCY and PAIN of having to go to the toilet

This is the urgency that you have to go to the toilet and the pain that you experience with it.



Severity of daily ABDOMINAL PAIN and CRAMPS

This is the severity of abdominal pain and cramps you may daily experience.



Severity of FATIGUE

This is the severity of an overwhelming sense of tiredness, lack of energy, or feeling of exhaustion that is not relieved after rest or sleep.

Data Insights for added therapeutic VAlue (DIVA)

During the second half of 2022 EFCCA has been developing a new working methodology in order to respond amongst others to the objectives outlined in the new Pharmaceutical Strategy for Europe as well as the European Medicines Agency's Engagement Framework.

This working methodology will identify and address the real needs of patients and healthcare systems and will promote the generation, collection and use of evidence-based patient experience data for decision-making and to give evidence-based answers to stakeholders such as regulators, policy makers, pharmaceutical industries and healthcare professionals.

DIVA (Data Insights for added therapeutic VAlue) will use publicly available data from government sites or other official, validated sites as well as EFCCA data (from published studies) to provide opinions and interpretations and to explore patient unmet needs based on scientific data. DIVA includes a pilot working platform to support IBD patient advocates in their daily activities.

EFCCA Publications

We are pleased to share that during this reporting period 5 scientific publications to which EFCCA has contributed have been published in the Journal of Crohn's and Colitis and in the European Journal of Health Economics respectively.

Publications in medical journals are an important part of our advocacy efforts because they help to raise awareness and provide evidence-based information about IBD to healthcare professionals, policymakers, and the general public.

Publications in medical journals provide a platform for EFCCA to share the latest research findings and



DIVA is set to revolutionise the way EFCCA advocates for IBD patients and the data-driven approach will help EFCCA to understand the real needs of patients and healthcare systems and advocate for policies and treatments that are evidence-based and patient-centred. The DIVA platform will also be a valuable tool for EFCCA members.

EFCCA's new approach was presented during UEG WEEK 2022 (9 October) at the EFCCA's stakeholders meeting including representatives from the scientific and medical community as well as industry representatives as well as during the Happy Hours (see above) address to EFCCA members.

insights into the care and management of IBD which will ultimately improve the quality of care provided to people living with IBD, as healthcare professionals will have access to the latest information and research.

Furthermore such publications can be used to advocate for policy changes that benefit people living with IBD. By providing evidence-based information and data, EFCCA can make a compelling case for policy changes that promote better access to care, improved quality of life, and increased support services for people living with IBD.

Journal of Crohn’s and Colitis: What are the unmet needs and most relevant treatment outcomes according to patients with inflammatory bowel disease?

EFFCA collaborated with Leuven University in this study to understand the preferences and unmet needs of patients with inflammatory bowel disease (IBD) regarding their treatment outcomes. Our findings suggest that patients with IBD need treatment options that improve their symptoms, prevent surgery, provide long-term clinical remission, enhance their quality of life, and minimise adverse effects. They also need more psychological support and communication with healthcare providers regarding their disease and emotional well-being. Our study highlights the importance of shared decision-making processes in IBD treatment and drug development to address patient preferences and unmet needs.

[Read study](#)



Journal of Crohn’s and Colitis: Paediatric Inflammatory Bowel Disease: A Multi-Stakeholder Perspective to Improve Development of Drugs for Children and Adolescents

The study published in September 2022, aims to find potential advanced treatment options for children with inflammatory bowel disease. A 2-day virtual meeting was held on April 14-15, 2021, for multi-stakeholders (clinical academics, patient community, pharmaceutical companies, and regulators) to discuss their perspectives on paediatric drug development for inflammatory bowel disease.

[Read study](#)

The European Journal of Health Economics: Out-of-pocket expenses of patients with inflammatory bowel disease

There is a high variability of out-of-pocket patient costs of inflammatory bowel disease (IBD), but the issue is not widely recognised. Therefore, this study published in October 2022 compared patient costs of IBD between 12 European countries.

[Read study](#)



Inflammatory Bowel Diseases Journal: Indirect Costs of Inflammatory Bowel Diseases

The study showed a high relevance of the indirect cost of IBD in the context of economic evaluation, as well as a between-country variability of work-related impairment or informal care.

[Read study](#)



Journal of Crohn's and Colitis: Anti-SARS-CoV-2 vaccines in IBD

Anti-SARS-CoV-2 vaccines clinical trials did not include patients with immune-mediated conditions such as inflammatory bowel disease (IBD). The study aimed to describe the implementation of anti-SARS-CoV-2 vaccination among IBD patients, patients' concerns and side-effect profile of the anti-SARS-CoV-2 vaccines using real-world data.

[Read study](#)



Journal of Crohn's and Colitis: A Narrative Systematic Review and Categorisation of Outcomes in Inflammatory Bowel Disease to Inform a Core Outcome Set for Real-World Evidence

EFCCA developed a core outcome set for real-world studies in adult patients with inflammatory bowel disease (IBD). Other indicators include, for example, clinical, endoscopic, and biomarker remission, fatigue, and urgency to go to the toilet.

[Read study](#)

Empowerment

Empowering patients is a vital activity for EFCCA, as it lies at the core of its mission to support its members at the national level. EFCCA achieves this by facilitating the exchange of best practices and building capacity through educational seminars, thematic workshops, and policy initiatives. By increasing collaboration with members, EFCCA seeks to create a more cohesive patient community that can advocate for their needs and shape the policies that affect their lives.

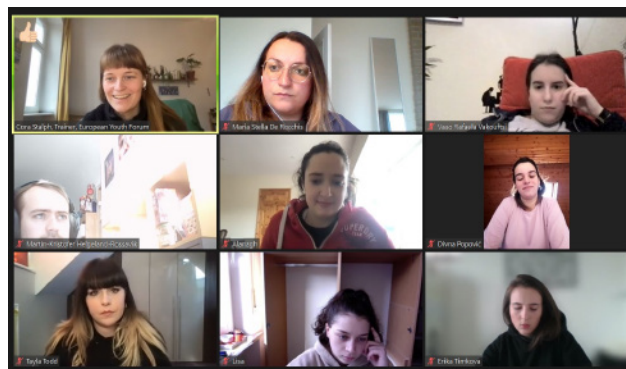
EFCCA's commitment to patient empowerment goes beyond the support it provides to its members at the national level. EFCCA is also actively involved in large-scale European research projects, such as Horizon Europe, which are crucial for advancing the understanding and treatment of chronic digestive diseases.

Through its involvement in Horizon Europe, EFCCA collaborates with a range of stakeholders, including academic researchers, industry partners, and policymakers. By participating in these projects, EFCCA ensures that the patient's perspective is included in the research process, and that the needs and priorities of patients are addressed.

EFCCA Academy - Empowering young IBD representatives

In 2021 the EFCCA board in discussion with the Youth Group has decided to offer an educational program to increase their representativeness, to create a more cohesive group of leaders of tomorrow, to empower them and to strengthen and expand the youth group. In the first semester of 2022, 21 students from 15 associations successfully completed the online training program. The program consisted of four teaching modules, which involved completing questionnaires and homework assignments. This required the active participation and dedication of those involved in the program.

Upon completion of the EFCCA Academy, students were then required to complete a final assignment that serves two purposes. Firstly, it provides an opportunity for the students to demonstrate the skills and knowledge that they have acquired throughout the training program. It can be presented in a variety of different formats. Past examples have



included webinars, presentations, podcasts, comics, informative documents, posters, and more. In this way, the final assignment is an opportunity for students to highlight their abilities and to make a meaningful contribution to the IBD community.

Secondly, the final assignment is designed to benefit the local IBD association. It is aimed at providing the association with valuable insights and information on specific topics related to IBD. By sharing this information with their local IBD association, students can contribute to support their work. Overall, it is a critical component of the EFCCA Academy, allowing students to apply what they have learned while also making a meaningful impact in their communities.

Students are therefore now busy in contributing to various projects and campaigns and have also been actively involving youth local groups whenever possible. EFCCA is committed to sharing the progress and achievements of the students.

More information:

Maria Stella De Rocchis, European Project Officer
maria.stella.derocchis@efcca.org

European Research Projects

EFCCA is currently involved in several European research projects under the previous Horizon 2020 programme (2 projects) and the new Horizon Europe programme (5 projects). All projects address in innovative ways the needs and interests of the IBD patient community and, if successful, will ultimately improve the quality of life of IBD patients.

EFCCA's involvement in these projects provides opportunities for knowledge transfer and capacity building. These projects will run for four years and it is foreseen to develop training modules in relation to these projects through our EFCCA Academy. Through participation in training programs, workshops, and other events our members will be able to develop the skills and expertise necessary to engage effectively with research projects and policy initiatives.

EFCCA's involvement in 7 European research projects is a significant accomplishment that reflects the organisation's commitment to advancing the understanding and treatment of IBD.

Horizon Europe

miGut

Personalised blueprint intestinal health

The miGut-Health project aims to develop a personalised blueprint of intestinal health to predict and prevent IBD. The overall goal is to deliver interdisciplinary solutions for health promotion and disease prevention that would enable active patient engagement in health and self-care management.

The consortium comprises 12 partners coming from 9 countries and University Hospital Schleswig Holstein / affiliated entity Kiel University will be the coordinator

of the project. EFCCA virtually met with the whole consortium for a pre-kick off meeting on the 27 February 2023 which will be also followed by an in-person one in Kiel (Germany) in May 2023.



GlycanTrigger

Glycans as master triggers of health to intestinal inflammation transition

Chronic inflammation underlies several diseases. In Crohn's disease (CD), there is mounting evidence of a preclinical phase characterised by immunological changes that precede symptoms. This project proposes a thorough and innovative approach to better understand the health-to-chronic inflammation transition occurring in patients with CD that will be translated into improved disease prediction and prevention.

The consortium comprises nine organisation participants with Instituto de Investigacao e Inovacao em Saude da Universidade do Porto (i3S) as the lead partner to ensure efficient dialogue and a continuous focus on the actual needs of patients living with Crohn's disease. The project will run for six years, and the kick-off meeting will commence in Porto (Portugal) from 13 to 14 March 2023.



METHYLOMIC

Biomarkers as predictor of response to biological therapy in Crohn's Disease

The METHYLOMIC project will build on multiple previous cohort studies that confirmed epigenetic biomarkers (specifically DNA methylation) as the most stringent predictor of response to biological therapy as concerns Crohn's disease (CD). DNA methylation profiles in peripheral blood as biomarkers of response/deep remission for three approved biologics in CD have been specifically discovered and validated. Through machine learning algorithms, treatment response could be predicted with up to 93% accuracy for each biologics for CD.



The consortium consists of 19 partners of clinical, epigenetic, and DNA diagnostics experts, patient organisations, and companies across nine countries with University Medical Center Amsterdam as the lead partner. The kick off meeting took place on 18 January 2023 in Amsterdam.

For more information please visit:

www.efcca.org/projects/horizon-europe-methylomic



GENEGUT

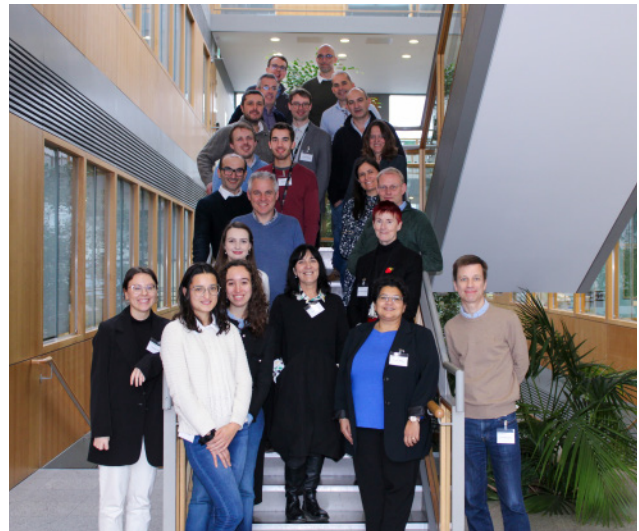
Changing the treatment paradigm for patients with Crohn's Disease - Genegut project

GENEGUT aims to develop a non-invasive, safe, effective, and targeted treatment that will be realised in the form of a first-in-class, orally administered RNA-based therapy. This breakthrough RNA therapy will be developed using complementary technologies that selectively target immunomodulatory pathways within inflamed intestinal cells that reside in specific regions of the small intestine.

The delivery of RNA will be enabled by a combination approach where novel biomaterials, designed to overcome the barriers in the gastrointestinal tract, are synthesised into nanoparticles (NP) which encapsulate the RNA. Using an industry partner's emergent capsule platform technology, the RNA is orally administered and locally tackles the inflammation in the intestinal tissue, avoiding systemic side effects. The project started in October of 2022, and the consortium involves 9 partners from 8 European countries with the School of Pharmacy of the University College Cork as the lead partner. The First General Assembly of the project took place in Cork, Ireland on 10 January 2023.

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

GENEGUT



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.



Innovate
UK



Funded by
the European Union

FIBROTARGET

Novel immunotherapeutic targets against fibrosis

This project aims to validate novel immunotherapeutic targets against fibrosis in inflammatory bowel disease to obtain patients and regulatory approval for implementing these novel noninvasive imaging modalities as diagnostic and prognostic tools for fibrotic IBD. This will allow vital future therapeutic development for intestinal fibrosis by providing better

molecular and clinical stratification of IBD patients at risk for fibrosis. If successful, this project aims to pave the way in preventing and treating this invalidating IBD comorbidity.

The consortium involves 10 partners from 7 countries, with the Katholieke Universiteit Leuven as the lead partner.



Funded by
the European Union

Horizon 2020 Projects

IDEA-FAST

The IDEA FAST project aims to identify digital endpoints that provide a reliable, objective and sensitive evaluation of activities of daily living and Health-related quality of life (HRQoL) in Immune-Mediated Inflammatory Diseases, including IBD. The project's first newsletter (called IDEA-FAST COS) was published in November 2022. 13 clinical sites were opened, and patients were successfully recruited to identify digital endpoints to assess fatigue and sleep disturbances better. A total of 136 participants were recruited. So far, a new research paper has been published, and it presents the results of using wearable sensing technology to assess fatigue and sleep in patients with chronic diseases. The article provides clinicians with insights on monitoring patients in the natural everyday settings of a patient's daily life.

Follow the progress at www.idea-fast.eu



ImmUniverse

The ImmUniverse project aims to improve diagnostic and therapeutic options for patients living with ulcerative colitis and atopic dermatitis. ImmUniverse, has published an interesting position paper in "Frontiers in Immunology" in November, 2022, which highlights the current unmet need for the treatment of immune-mediated inflammatory diseases and emphasises that an advanced methodological approach is needed for improvement.

Follow the progress at www.immuniverse.eu



ImmUniverse

These two projects have received funding from the Innovative Medicines Initiative 2 Joint Undertaking (JU) under grant agreement No. 853995. The JU receives support from the European Union's Horizon 2020 research and innovation programme and EFPIA.



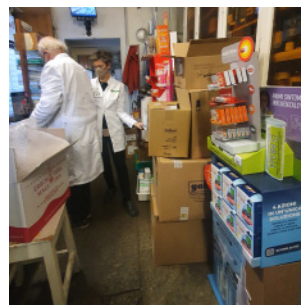
Supporting people with IBD in Ukraine

Since the beginning of the war in Ukraine EFCCA has been standing in solidarity with its Ukrainian member Fulfilling Life and is working hard to support the association and its IBD patient community. Our first concern was to find solutions to the shortage of basic IBD medicines experienced by our colleagues. We have managed to mobilise many of our stakeholders and as a first step with the help of the NGO APOTHEKER HELFEN e.V. and NAVIS e.V. as well as the kind donation of Dr Falk Pharma GmbH we have managed to send a shipment of IBD specific medications to a regional hospital in Lviv (a city in the West of Ukraine and close to the Polish border) at the beginning of April 2022.

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

We set up an emergency fund and hope to use the emergency fund in the future for other ad-hoc support. Apart from receiving funds through our sponsors, our members have also contributed to this fund such as Crohn and Colitis NL (Netherlands), Crohns and Colitis UK, AMICI Italy, LR Krono ir opinio colito ligu draugija (Lithuania) and the Japanese Patient Associations. Donations came also from individual members of AMICI and the IG-IBD (the Italian Physicians Organisation).

This allowed us to organise two follow up shipping of IBD medications with the generosity of our members and friends and the commitment of volunteers,



physicians and some pharmacists who helped us to find the drugs, pack them and ship them. (Shipping took place on 27 April 2022 and 12 November 2022). At the institutional level, upon advice, our colleagues in Ukraine have submitted a formal letter to the Ukrainian Ministry of Health which has been sent to the Ministry of Health in Poland - that is on the forefront of medicines distribution to Ukraine - to also include medicines for the treatment in IBD in their humanitarian shipping.

The solidarity and support shown by our members confirms the strength of our network! Our thoughts are with all people of Ukraine. United We Stand!

EFCCA General Assembly

With the health situation improving in many parts of the world and travel restrictions being partially lifted, the EFCCA board decided to hold a hybrid General Assembly in 2022. The first part of the General Assembly took place online on 28 May 2022 and dealt mainly with institutional matters of our organisation. The second part of the General Assembly took place in Barcelona from 10-12 June 2022.



During the on-line/institutional GA delegates approved the GA minutes (2021), the Financial Report and the Annual Activity Report (2021). Then elections to the EFCCA Executive Board were held. Salvo Leone was re-elected as EFCCA chairperson, and Marko Perovic was re-confirmed as Treasurer.

Delegates then voted on the admission of the patient association “I Battle Disease” from Lebanon represented by its then president Nathalie Jbeily as new member to EFCCA. This brings our total membership to 46 associations.

The 2022 Executive board consists of the following members:

- Salvo Leone, Chairperson
- Ciara Drohan, Vice President
- Marko Perovic, Treasurer
- Magda Sajak-Szczerba, board member
- Menne Scherpenzeel, board member

The face2face General Assembly in Barcelona brought together 32 member associations, the board and staff members. It was an excellent opportunity to catch up with old colleagues and new faces, to exchange ideas, connect with each other and lay the foundations for new, common projects and activities. It was also the moment to launch our consultation for the new EFCCA strategy, see next item.



Towards a new EFCCA strategy plan (2023 -2027)

During our General Assembly in Barcelona (10 June 2022) EFCCA kicked off work on developing EFCCA's next Strategy Plan for the coming four years.

After reviewing the previous 2019 – 2022 Strategy Plan and the external evaluation of the achievements so far, the entire day was devoted to brainstorming, building on the past success, new needs identified and on what EFCCA should aim at in the next few years.

Antonella Cardone, as the external facilitator, led the lively discussions and many ideas were generated which have fed the work in progress on developing the next Strategy Plan.

Following the General Assembly, the board and secretariat shared some preparative documents to feed into the online consultation process. As a first step, members were asked to participate in a

survey and give their feedback on our organisation's current vision, mission and objectives. Further online consultation meetings with EFCCA members took place throughout the year resulting in the first draft of the strategy followed by a second round of consultation.

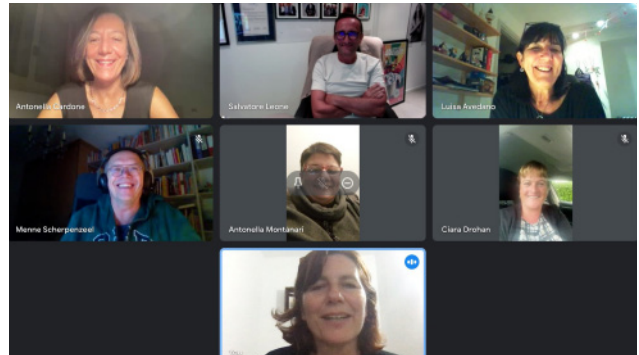
The second draft and final discussions and consultations online are still underway at closing of this report. The finalised strategic plan will be presented during the General Assembly in May 2023, ready for approval by the delegates.



Executive Board

The elected board has met online and in-person on the following occasions:

- **11 July 2022 (online):** discussions focused mainly on the consultation process with our members about the new strategy plan for EFCCA.
- **21 September 2022,** (online) in order to further discuss our work on the new EFCCA strategy, DIVA, World IBD Day 2023 and EFCCA's involvement in 5 new Horizon Europe projects.
- **21 January 2023,** (Brussels) to discuss our upcoming General Assembly, new strategic plan, DIVA, ongoing and new projects and activities, including Horizon Europe, Patient Preferences, UEGW and the upcoming ECCO Congress.



EFCCA Staff

EFCCA has a small staff 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, Deputy Director is assisting with the overall implementation of the EFCCA work plan with a main focus on communication and international relations and the coordination of World IBD Day.

Maria Stella De Rocchis is our European Project officer and has been working on the development of the training programmes of the EFCCA Academy and following several EU projects under the Horizon Europe programme.

Roberto Saldaña, is our Innovation and Patient Engagement Coordinator and has been working on our new roadmap advocating for the IBD community and working methodology called DIVA. He has also represented EFCCA at several Patient Advisory Boards and at the European Medicines Agency.

Priya Raja is our new communications assistant, who joined EFCCA in September 2022. She has been working with the Deputy Director to assist with developing and designing content for the EFCCA website, social media channels, newsletters, Magazine and Annual Report.

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

List of members as of 2022

Austria

OMCCV - www.oemccv.at

Belgium

CCV: www.ccv.be
Crohn-RCUH: www.mici.be

Bulgaria

BCUCA - www.babkuk.org

Croatia

HUCUK - www.hucuk.hr

Cyprus

CYCCA - www.cycca.org

Czech Republic

Pacienti IBD - www.crohn.cz

Denmark

CCF - www.ccf.dk

Estonia

EPSS - www.ibd.ee

Finland

CCAFIN - www.ibd.fi

France

AFA - www.afa.asso.fr

Germany

DCCV.e.V. - www.dccv.de

Greece

HELLESCC
www.crohnhellas.gr

Hungary

MCCBE - www.mccbe.hu

Iceland

CCU - www.ccu.is

Ireland

ISCC - www.iscc.ie

Israel

CCFI - www.ccfi.co.il

Italy

AMICI - www.amiciitalia.org

Latvia

LKKSBB - www.lkksb.lv

Lithuania

CCLA - www.draugija.info

Luxembourg

ALMC - www.afa.asso.fr/luxembourg

Malta

MACC - www.macc.org.mt

Montenegro

CUKUK - www.cukuk.me

New Zealand

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

Netherlands

Crohn & Colitis NL
www.crohn-colitis.nl

Norway

LMF - www.magetarm.no

Poland

J-elita - www.j-elita.org.pl

Portugal

APDI - www.apdi.org.pt

Romania

ASPIIR - www.aspiir.ro

Russia

Trust - www.vzk-life.ru

Serbia

UKUKS - www.ukuks.org

Slovakia

SCC - www.crohnclub.sk

Slovenia

SAIBD - www.kvcb.si

Spain

ACCU - www.accuesp.com

Sweden

MOT - www.magetarm.se

Switzerland

SMCCV - www.smccv.ch
Crohn Colite Suisse - www.asmcc.ch

Turkey

IBHDYD - www.ibhportali.com

UK

Crohn's and Colitis
www.crohnsandcolitis.org.uk

Ukraine

Fulfilling life - www.gofulllife.com.ua

Associate Members:

Argentina

Mas Vida - www.masvida.org.ar

Brazil

DII Brasil
www.facebook.com/diibrasil

Kazakhstan

FPVZK - www.vzk.kz

Lebanon

I Battle Disease
www.ibattledisease.org

Mexico

CUCI - www.crohncuci.org.mx

Singapore

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

Trinidad and Tobago

NACCTT
www.crohnsandcolitistt.org

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