

The background image shows a group of people on a boat, likely at a social event. In the foreground, a man in a grey blazer sits on a metal chair, looking towards the camera. A woman in a grey coat stands next to him, smiling. A man in a purple poncho stands with his back to the camera. Other people are seated or standing around, some wearing purple items. In the background, a city skyline is visible across a body of water, with a large domed building prominent on the left. The sky is a pale blue.

# **A FOCUS ON QUALITY OF CARE: EFCCA'S FIRST STRATEGIC STEP TO TACKLE DISCRIMINATION**

## **EFCCA Activity Report**

(March 2019 - March 2020)



## EFCCA's Vision

**Our vision is to find a cure for IBD.**

As no cure has yet been found, the members strongly believe that our vision remains to find the 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).**

The word "well-being" is replacing the word "life" used in the previous mission, as it better reflects EFCCA's work. Both Crohn's disease and Colitis are placed in the mission sentence. "Ulcerative" is left out to make sure the mission also covers other forms of colitis, e.g. undefined colitis. Instead of "people with IBD" the members decided to refer to "people affected by IBD" as this covers also e.g. patients' families, friends.

## 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 well-being of people with IBD and we believe that together we work better towards our mission and 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:

1. **Networking**
2. **Awareness Raising**
3. **Advocacy**
4. **Empowerment**

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# Foreword

## A new direction

*One of our major milestones in 2019 has been the elaboration and approval by the General Assembly 2019 of our four-year strategy plan. The Strategy Plan has been drafted by the EFCCA Executive Board and Secretariat and aims to address identified needs and priorities of EFCCA members and the IBD patient community as a whole.*

*It will nourish the 4 strategic areas in which EFCCA's past and current activities have been structured such as Networking, Awareness Raising, Advocacy and Empowerment, and it is the framework in which the annual work plans will be developed setting out objectives, activities and outputs to be achieved each year. The cross-cutting goal of the strategy is to tackle discrimination, since discrimination, in its various forms (and widely understood as impeded or limited exercise of rights and access to services), emerged to be one of the most significant burden on IBD patients.*

*The strategy identifies yearly priority areas with the purpose of better tailoring EFCCA activities.*

*For 2019 the priority area has been identified as **IBD & Quality of care** which builds on our previous work such as equal access to care (EU Mapping project), our involvement with the ECCO Crohn's Treatment guidelines and many activities aimed at improving quality of care for patients with IBD.*

*In 2019 we had a group of 6 patients involved in an ECCO project on the new Ulcerative Colitis (UC) Treatment Guidelines. The participation of these patients in the project will ensure that the patient perspective is included in these new guidelines which are foreseen to be published in early 2022.*

*Another major event for EFCCA this year has been the organisation of the symposium Digital Health and Data collections (14 February 2020, Vienna). It is the*



Salvo Leone EFCCA Chairman

*first time that we are holding a symposium during the ECCO Congress and shows that our relationship with ECCO has reached a new stage and that physicians are recognising the important role that patients can take arounds the issues of personalised care and other important aspects that the digital revolution in health care will bring along.*

*You will find more evidence in this report of how we have been successfully working to advocate and raise awareness on the issue of quality of care and stressing the importance of putting the patient at the center and the need for multidisciplinary teams. Some of these activities will be continued into 2020 and will overlap or be complimentary to our 2020 priority theme of Work and IBD.*

*We feel confident that working in this new structured way will give us the tools and actions needed to improve the quality of care but also quality of life of people living with IBD whilst putting EFCCA at the center of the international IBD community and being on the forefront in the fight against IBD.*

*I hope you enjoy reading about our activities described in this report. The report has been put together under very difficult circumstances due to the COVID-19 crisis which has also led us to cancel our General Assembly in Estonia this May but we are putting all our efforts together to continue with our work in the best possible way.*

A handwritten signature in black ink, which appears to read 'Salvo Leone'. The signature is stylized and fluid, with a large, sweeping 'S' at the beginning and a long, horizontal stroke at the end.

# Networking

Representing a relatively small disease group, it is vital that EFCCA develops and strengthens synergies and partnerships that are beneficial for all. We encourage and facilitate collaboration, exchange of information, knowledge and practices, and the promotion of international activities. We strive to collaborate with different stakeholders to establish and strengthen relationships in order to build a stronger IBD community.

## Medical congresses

EFCCA's participation in medical congresses and meetings is an important occasion to reinforce this work and allows us to network with physicians, healthcare providers and stakeholders in order to discuss common objectives and ideas for collaboration in particular as concerns quality of care.

In 2019/20 we participated in the follow medical events:

### UEGWEEK 2019

The congress took place in Barcelona from 19 – 23 October 2019.

It was attended by over 13 000 delegates (online and onsite). UEG Week together with the ECCO Congress are the major GI meetings in Europe bringing together world class scientific researchers, physicians, nurses and other key stakeholders in the GI field.

EFCCA was represented by our Chairman, CEO and Deputy Director. We had an information booth near the educational and scientific programmes area of the Congress which allowed us to be in close contact with many of the delegates to explain EFCCA's mission and main areas of work.

### ESPGHAN 2019

For the second time EFCCA has been invited and participated in the Annual Meeting of the European Society for Pediatric Gastroenterology Hepatology and Nutrition (ESPGHAN) which took place on 5 – 8 June 2019 in Glasgow, United Kingdom.



*Our CEO and Deputy Director meeting physicians from the United Arab Emirates*

We also participated in a networking meeting between the Public Affairs Committee of ESPGHAN and representatives from various European patient associations where it was decided to create a more formal network between patients and the Public Affairs Committee to better align our efforts and work on projects of common interest.

Our strengthened collaboration with ESPGHAN also resulted in a joint campaign around World IBD Day (see page 9).



# ECCO Congress

EFCCA was present at the Congress which took place on March 6-9 2019 (Copenhagen, Denmark) and 12-15 February 2020 (Vienna, Austria).

In Copenhagen EFCCA organized a networking dinner with several of our members who also had attended the ECCO Congress, giving us a great opportunity to exchange information and discuss future projects.

At the Vienna Congress event most of the EFCCA delegates were present for the EFCCA Symposium (see page 15) and had the chance to network and catch up with colleagues during the 30th anniversary EFCCA dinner.

## ECCO networking event

ECCO organized the 1st Council of National Representatives Meeting which took place in Barcelona 19 October 2019.

The meeting was attended by representatives from the ECCO leadership as well as patient representatives from the EFCCA network including the EFCCA Chairman and CEO.

The meeting was a great occasion to exchange information and for ECCO to present the ECCO strategy and activities.

A specific focus was dedicated to the role of patient

associations and EFCCA.

ECCO agreed in becoming more involved in World IBD Day, in encouraging physicians to refer to patient associations and EFCCA when talking with their patients, in including patient representatives in some educational activities, and to continue to involve EFCCA representatives in activities such as the guidelines revision.



# EFCCA Members

## Meeting with colleagues from Association François Aupetit - AFA Crohn RCH France

On 22 February 2019 the EFCCA Chairman and CEO met the AFA team in Paris. A fruitful meeting including the French association's President, Vice President, Director and Vice Director presenting some of their many projects.

EFCCA came back with good ideas to share with our members and, above all, a warm welcome and a growing understanding of the importance of learning from each other, creating further alliance and sharing common objectives.

The afternoon of the trip was devoted to visit the exposition on Microbiota at Cité des Sciences et de l'Industrie, another impressive achievement of our French colleagues.



## CCUVN, 40th anniversary

Our CEO participated in a meeting organised by the Dutch IBD patient association CCUVN to celebrate their 40th anniversary which took place on 12 April in Bussum, the Netherlands. The celebration started with the official opening of an artwork exhibition of various artists, all related to the community of Dutch IBD patients.

The CCUVN Director presented some of the patients involved and invitees had then the chance to visit the exhibition. EFCCA was pleased to participate at this important event and to see the amazing work and efforts CCUVN has done in the last 40 years for patients in the Netherlands.



# Terrasini Meeting

Our CEO attended upon the invitation by AMICI Italia a conference in Palermo Ospedali Riuniti “Villa Sofia Cervello” on 8 July 2019 with the aim to present to IBD patients numerous aspects of the disease, discuss with them and better understand their needs and priorities. Around 70 people attended the meeting that involved also national IBD specialists.

The day was closed by a charity event called TEN - Terrasini Event Night Meeting where 10 starred chefs (9 women and one man) prepared an excellent dinner that promoted the food and wine products of Sicily. Over 300 people attended the event and the proceeds were donated to AMICI.

The event was an interesting learning occasion on how our Italian member is developing its network of friends and supporters whilst raising awareness about the disease and putting the IBD community at the center.



## Partner Organisations

### European Patient Forum

#### EPF General Assembly

Our CEO participated in the EPF General Assembly which took place in Brussels on 13-14 April 2019. It was an interesting event where the main projects and activities were presented and discussed. Young

patients and the launch of the EPF Congress in November have been the core topics and offered the occasion to better understand EPF's approach and priorities. Marco Greco, our former Chairman was confirmed as EPF President for the next 2 years.



### EPF CONGRESS on Patient Involvement

EFCCA attended the Congress on patient involvement organized by the EPF and driven by the patient community. Over 300 delegates, including patient advocates, healthcare professionals, health NGOs, academics, industry representatives and national institutions participated in this interesting event.

A rich programme where speakers and debaters from the audience contributed in a discussion around opportunities and barriers for meaningful patient, drawing upon many examples of inspiring practice.



## ATLAS Project Steering Committee

Our CEO is part of a steering committee made by physicians and patient representatives that are jointly working on chronic intestinal failure and how to improve standard of care, equal access to treatment as well as quality of life for patients affected by this condition.

A meeting took place in Brussels on 26-27 April with the objective to define a roadmap of activities for 2019. The ATLAS group was started by Shire in 2016 and it is now supported by Takeda.



# Awareness raising

This is a strategic area for EFCCA since there is still little public understanding of the pain and chronic suffering with which IBD patients courageously cope with every day of their lives. Through various initiatives, education and tackling taboos and stigmas around IBD, we want to have IBD accepted and recognized, taking into consideration the needs of all those who are affected.

## World IBD Day Making the invisible visible

World IBD Day remains EFCCA's most powerful tool to raise awareness around IBD. In 2019, EFCCA united 50 countries from 5 continents to participate in World IBD Day.

The theme "Making the invisible visible" was about shining a light on various aspects of the two invisible conditions of Crohn's disease and Ulcerative Colitis. Efforts were centered around two campaigns:

### Coordination of global "purple" campaign

As in previous years many of our members and other IBD patient organisations were using the "purple" campaign of lightening famous landmarks as a steppingstone to gain higher media visibility and to gather momentum around specific activities of their yearly efforts to improve life of people with IBD in their respective countries.



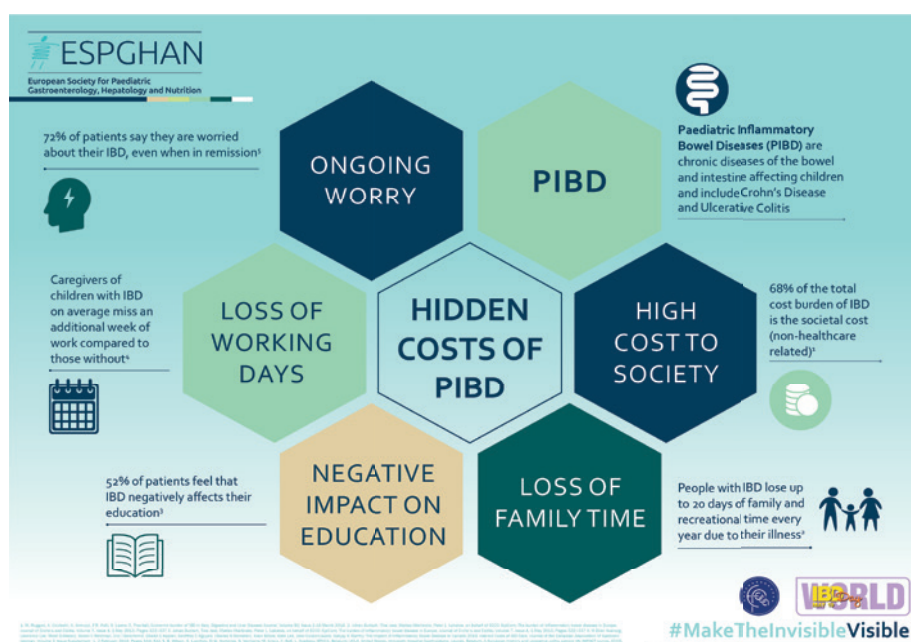
## Indirect Costs of IBD survey

The second activity within the framework of World IBD Day 2019 and which is more focused on Europe was to promote the survey on Indirect Costs of IBD which was carried out by the Polish Association Supporting People with IBD “J-elita” in cooperation with the Institute of Public Health, Jagiellonian University Collegium Medicum and IIMCB under the joint patronage of EFCCA.

We have been collaborating with ESPGHAN to promote this study which is looking at data from over

3500 people with IBD from 27 countries in Europe and beyond in order to map and compare the invisible costs related to IBD. Results of the study will allow stakeholders and policymakers to better prioritize effective IBD treatment and support measures aimed at improving the situation for people with IBD in the workplace and labour market.

Our partners are still working on the results of this survey and the content will be presented in 2020 and be fed into any planned advocacy work.



## “The IBD pathway - from a patient perspective” Satellite Symposium

Our CEO participated as speaker at a satellite symposium as part of the 14 th ECCO Congress (6-9 March 2019) organized by Biogen, Samsung Bioepis that aimed to look at the patient perspectives, such as their expectations and concerns as they experience a switch in treatment of biologics and biosimilar medicines. The aim of this symposium was to understand treatment of IBD from the patient's

perspective. Beginning with a review of the current and future treatment landscapes, the implications of the increasing availability of biosimilars were discussed. The role of HCPs in communicating information about the switch was explored by the multidisciplinary faculty who also compared switching practices at their own treatment centres and shared best practices.



Alongside videos of interviews with patients who had undergone a switch to a biosimilar, the patient advocacy perspective was provided by our CEO who highlighted the importance of involving the patient in treatment decisions by providing them with educational materials appropriate to their understanding.

She also tried to raise awareness of the importance of having a well-functioning multi-disciplinary team (MDT) including specialist IBD nurses. Other speakers included physicians Raja Atreya, Nürnberg, Germany, Yoram Bouhnik, Paris, France and Geert D'Haens, Amsterdam, The Netherlands, as well as IBD nurse Maria de Jong, Amsterdam, The Netherlands.



## UC Narrative: A Global Effort to Create New Resources for People Living with UC

EFCCA has been collaborating in the UC Narrative, a global survey, which gathered data from 10 countries and included 2,100 adults living with primarily moderate-to-severe ulcerative colitis (UC).

The survey was developed with patient advocacy organizations, patients and healthcare providers from around the world and explored a range of topics that may influence quality of life for adults living with UC, including day-to-day disease impact, disease management, goal setting, and communication.

In 2019 the UC Narrative data was presented during the Crohn's & Colitis Congress (Las Vegas, US). New data on the social and emotional wellbeing impacts of UC was shared during the Congress in hopes of fueling more productive engagement between people living with UC, healthcare professionals and patient organizations.



It was also presented at the 2019 ECCO Congress in Copenhagen and during Canadian Digestive Diseases Week (CDDW) in Banff, Alberta.

During CDDW, Advisory Panel members Mina Mawani (Crohn's & Colitis Canada) and Remo Panaccione, MD (University of Calgary), presented data comparing patient and physician perspectives on communication and management of UC.

The members of the UC Narrative Global Advisory Panel convened in Copenhagen, Denmark on March 9-10, 2019 to explore ideas for potential actions, resources, and initiatives to address the barriers to care identified by the first phase of the global survey.

Additionally, the Advisory Panel shared and discussed global and local activities, milestones, and data dissemination accomplished in the past year.

At the end of November, the members of the UC Narrative Global Advisory Panel convened for a series of virtual meetings to review next steps for the global patient awareness campaign and creative concepts. The Panel also discussed recent global and local milestones of the initiative and plans for 2020.

## The phenotypic features of couples with IBD and their offspring survey

There is still no known cause of IBD though it is linked to a combination of hereditary, genetic, and/or environmental factors. A positive family history of IBD remains the strongest risk factor for developing IBD. For someone with IBD who is thinking about having a child the hereditary factor is an important factor to consider.

EFCCA therefore believes that more studies and research into this matter are essential and beneficial to the wider IBD community.

Given the fact that IBD increasingly affects young people especially during the child bearing years EFCCA strongly supported the survey "The phenotypic features of couples with IBD and their offspring" which is being carried out by Dr Joana Torres from the Gastroenterology Department at Hospital Beatriz Ângelo (Portugal) with the support of the European Crohn and Colitis Organization.

The survey aims to better characterize the sub-group couples with IBD and their children and to describe the frequency of couples with IBD and the frequency of the disease in their offspring.



It hopes to provide more accurate risk estimates to couples and prospective parents living with IBD and to improve pre-conception counselling.



Furthermore, identifying individuals from families at high risk for developing IBD could offer the possibility to create a “high-risk” cohort for future studies, which could have important contributions to our understanding about disease pathogenesis.

The survey was available on-line in English, French, Spanish and Portuguese and has been closed in December 2019.

We are excited to read the outcomes of this important survey which will give us much needed information to ensure a better understanding for prospective parents and the medical community and potentially provide better quality of care.

## Other events and meetings

### **Masterclass on Ulcerative Colitis**

Our CEO was invited to present the IBD patient's perspective in a Masterclass addressed to IBD gastroenterologists from all European countries and organized by Pfizer. The meeting took place in Brussels on 15 November 2019 and was attended by more than 80 physicians.

The lecture given by our CEO was part of the module that highlighted the importance of a multidisciplinary team of health care professional treating an IBD patient.

### **Building Bridges in IBD, Falk Symposium**

The event which took place on 13-14 September in Brussels involved a huge number of representatives from medical societies who debated around the topic of Building Bridges in IBD. Our CEO presented the EFCCA Strategy Plan and showed how our networking

and advocacy activities can contribute to reinforcing collaboration with clinicians and industries with a particular emphasis in a better and more friendly way to communicate and thus to improve quality of care.

### **Internal meeting with Roche**

Prior to UEG WEEK our EFCCA chairman and CEO participated in an internal meeting organised by the pharmaceutical company Roche.

The meeting gathered over 100 Roche affiliates worldwide and the objective of the session was to raise awareness of the patient perspective in particular as concerned unmet needs of patients. Both EFCCA representatives stressed the importance of involving patient organisations in efforts raised to tackle the issue of unmet needs of the IBD patient community.

The EFCCA chairman pointed out that despite on-going discussions for many years about the unmet patient needs there still seemed to be a lack of an effective and coherent strategy to overcome some of the identified obstacles.

# Patient Advisory Board meetings

EFCCA alongside several of our EFCCA members have been invited on various occasions to Patient Advisory Board meetings organized by industries with the aim to share information and raise awareness of the needs and priorities of the IBD patient community.

## **Patient Advisory Board, Mainz (Germany) 15-17 November Boehringer Ingelheim**

Our Deputy Director participated in the Patient Advisory Board meeting organized by Boehringer Ingelheim (BI) which involved EFCCA, 8 EFCCA members as well as representatives from IBD patient organization from the US and Singapore.

As BI is developing new medication in the IBD field they were keen to learn more about IBD, how patient organisations are working and their priorities as well discussion issues around clinical trials and patient treatment preferences.

## **Global Advisory Board, Zurich 9th/10th of October Roche**

Our Chairman participated in the Patient Advisory Board meeting organized by Roche to discuss the following topics: what are the most important burdens associated with living with IBD and key unmet needs; what benefits from IBD medicines are most important for patients; challenges IBD patients face in

communicating their needs to health professionals and potential solutions and how IBD clinical trials can be more patient friendly. Some topics were a continuation of the conversation we started in March with Roche and some were important additional topics as patient friendly studies in IBD.

## **Patient Advocacy Leaders' Summit, Zurich 26-27 March AMGEN**

Our Deputy Director participated in the PALS meeting organised by AMGEN which took place from 26/27 March in Zurich, Switzerland. The meeting was attended by delegates from various European patient organisations and networks representing different disease groups as well as medical/scientific and advocacy staff from AMGEN. Our Deputy Director presented the IBD patient perspective as far as concerns the importance of including Quality of Life data in the design of studies and clinical trials.

Other topics included big data and artificial intelligence to improve patient outcomes, how to involve patients in phase III and IV studies and how to expand patient access to medicines.



# Advocacy

EFCCA carries out advocacy work with EU institutions and international organisations such as WHO to move from a therapy-focused approach to a more patient/person-focused approach, ensuring that concerns, needs and priorities of people living with IBD are included in the decision-making process for policies and other related health initiatives.

## Symposium on Digital Health and Data Collection

EFCCA gathered representatives from the IBD patient community, Health Care Providers and the pharmaceutical industries to initiate discussions on how digital technologies can bring benefits and opportunities for all. The multi stakeholders met at the **Symposium on Digital Health and Data Collection** organised by EFCCA which took place on 14 February 2020 during the ECCO Congress in Vienna.

In the past two years, EFCCA has been in the forefront of the discussion on how digital health and big data can contribute in delivering more personalised care and offering a higher quality of life for patients with IBD.

The digital “revolution” in health care as well as the data collected from patients, can represent an opportunity to achieve a more harmonic combination between the quality of care and quality of life data. Collecting and analysing data can become a powerful and unique way to achieve earlier diagnosis, better care strategies and identify patterns in health outcomes in partnership with medical societies and all relevant stakeholders.

Led by patient organisations the symposium aimed to gather perspectives from all the relevant stakeholders including physicians, Health Care Providers and the pharmaceutical industries.



We are now working on preparing a conference report of the symposium and hope to continue the dialogue involving a wide range stakeholdership.

We strongly believe that patients and patient organisation have an important role in contributing to the opportunities that digital technologies will bring to our overall healthcare.

The Symposium report will be available on the EFCCA website by mid-April 2020.



## ECCO UC Treatment Guidelines

The ECCO Guidelines have become standard references for IBD management in Europe and around the world. The guidelines are freely accessible and available for download on the ECCO Website and on JCC Online.

ECCO is updating the Guidelines on a regular basis, which goes hand in hand with continuous ambition to work according to the highest standards. In this context, with the Guidelines generation 2018-2023, ECCO has started to use GRADE Methodology for its major Guidelines on Therapeutics in CD and in UC.

We are pleased that as a result of our long-established cooperation with ECCO we have been invited to participate in the new project on the new Ulcerative Colitis (UC) Treatment Guidelines.

Our participation is aimed to ensure that the patient perspective is included in these guidelines.

A group of six UC patient representatives will form an integral part in the discussions and will vote on the most relevant questions to be addressed during guideline development. The group will also participate in the discussion and voting around the most important outcomes to be considered in each area.



*Patient representatives during the Kick off meeting in Vienna*

The patient representatives are from our member associations in the UK, Finland, Czech Republic, Poland, Iceland and Romania.

An initial kick-off meeting took place in Vienna on November 22-23, 2019 and the project will run until 2021 when patient representatives will also be invited to attend the final consensus meeting where guideline statements will be discussed and voted on.



# Medicine for Europe Conference

Our CEO attended the “Biosimilar Medicines Conference” organised by Medicines for Europe that took place in Amsterdam on 28 and 29 March 2019. Regulatory bodies, payers, public administrations representatives, industries and patient organisations were invited to discuss the state of the art on biosimilar drugs in Europe and beyond.

Several sessions and panel discussions contributed to highlighting the weaknesses and the strengths of this new generation of treatments. Although the declared and ultimate objective of the biosimilar uptake is to increase the access to care to more patients, there are currently not sufficient elements to prove that.

However, the discussion and the topics presented have been interesting and the conference has been a fruitful occasion to meet other patient representatives and learn more about their positions and concerns.

On 27 March afternoon, before the official opening of the Conference, patient representatives were involved in a workshop whose objective was to share our association's perspectives and offer to the involved stakeholders a better understanding of the issues that patient communities face.

The workshop could be a first step to better collaborate and increase patient access to medicines and possibly reduce health inequalities.



## Integrating modern approaches into daily practice for IBD treatment - Faculty Talk

Our CEO was invited to talk at one of the UEG WEEK faculty conference on the topic of “integrating modern approaches into daily practice for IBD treatment”. She presented the challenges and opportunities of apps/health data collection defining the needs and priorities and the role that patients can play in this process.

From a patient perspective big data are the future and collection of health data could ultimately lead to better personalized healthcare including the anticipation and prevention of flares, decreasing hospitalization, improving and facilitating communication between patients and health care providers and overall improving patient's quality of life.

An important issue to consider in the discussions around health data and collection is the need for interoperability between quality of care and quality of life data and to be able to combine in a meaningful way clinical data with Patient Reported Outcomes (PROs).

Patient data privacy and data ownership and data analysis are an important aspect in this process. To conclude our CEO also stressed the importance of strong multidisciplinary teams as the best approach to IBD care.



## GRADE Workshop and Guideline Methodology (ECCO 2019)

EFCCA representatives participated in the ECCO Quality Standards of Care meeting and the 1<sup>st</sup> Guideline Methodology and GRADE Workshop organized by ECCO at the ECCO Congress in Copenhagen on 6 March 2019.

No clear definitions for a global “standard of care” in IBD are currently available. ECCO therefore performed a systematic review on available literature and summarized the results into a basis for developing general recommendations for standards of quality of care in IBD. The aim of the Quality Standards of Care meeting during the ECCO Congress in March was to discuss the list of criteria developed earlier by the project coordinators based on the systematic review, and to modify and finally accept or reject the criteria through a voting.

The expert panel, consisting of a multidisciplinary group of professionals and included nurses, dieticians, surgeons, histopathologists, pediatricians, endoscopy experts, pharmacists and, of course, patients, aimed at reaching a consensus to develop the final criteria for the Standards of Quality of Care in IBD.

In the 1<sup>st</sup> Guideline Methodology and GRADE Workshop, the pros and cons of the GRADE guideline development methodology and the previously often used Oxford methodology were introduced and the process of a scientifically sound literature search was explained.

The four EFCCA patient delegates presented patient perspectives regarding clinical practice guidelines and explained what patients expect from guidelines and why patients should be involved, not only in the development of guidelines but also in the review and update process. After the panel discussion, the other participants had the opportunity to ask questions. Discussion was lively, even so that time ran out when the other workshop participants still would have had more questions to ask.

# **BAB 2 (Biologics and Biosimilars)**

## **A change of perception on biosimilars?**

EFCCA in collaboration with Prof. Laurent Peyrin-Biroulet and his team (Department of Hepato-Gastroenterology CHU in Nancy) has carried out a follow up survey called BAB 2 which ran from July to December 2018. Its aim was to find out whether patients' perceptions on biosimilars have changed since our previous survey on the same subject.

Participation was more active than in the first round: over 1600 IBD patients completed the survey. Slightly more respondents, in comparison to the original survey, were currently being treated with anti-TNF medications, and significantly more respondents compared to the previous survey had heard of biosimilars. Although IBD patients were more aware of biosimilars, some of the worries concerning biosimilars that were seen in the previous survey remained.

The most common concerns around biosimilars were still their safety and efficacy. Furthermore, the new questions added in the BAB2 questionnaire showed that IBD patients are not always fully satisfied with the quality and sufficiency of information and communication regarding biosimilars.

The results of BAB2 survey were analyzed in 2019 and have been published in the United European Gastroenterology (UEG) Journal on December 2019. The article with the results of the BAB2 survey can be read in full text for free at:

[www.ncbi.nlm.nih.gov/pmc/articles/PMC6893997/](http://www.ncbi.nlm.nih.gov/pmc/articles/PMC6893997/)

The results will help us in advocating for more information sharing on this subject and to involved patients in the decision making on the management of their disease.

## **Medicines shortage**

EFCCA was involved in a campaign supported by AFA Crohn RCH France and promoted by the European Association of Hospital Pharmacists which focused on the issue of medicine shortage. It is an issue that many countries and our members as well are currently

facing and EFCCA believes it is important to join forces to have a louder voice in the European arena. A first important success is a meeting that DG Santé agreed on organising to hear firsthand information from the involved patient organisations and EAHP.

## **EFPIA Think Tank**

Our CEO attended the European Federation of Pharmaceutical Associations (EFPIA)'s Think Tank regular meetings after the Board's decision to play a more active role in this working group composed by EFPIA, patients and industries representatives. The objective of the meeting was to discuss the strategic vision and goals of the Think Tank and decide how to work on the different topics participants chose in a previous survey.

Among the themes discussed some are of particular relevance for EFCCA, such as clinical trials, EFPIA regulatory strategy and Value Base Health System and in particular the the role of patient-relevant outcomes measurements to inform healthcare decision-making, delivery and resource allocation.



# Empowerment

EFCCA supports its members in their work and mission at national level through the exchange of best practise and capacity building activities such as educational seminars, thematic workshops, policy initiatives. EFCCA wants to invest in creating sustainable resources, training independent, self-confident patients and in increasing the collaboration with members. With Quality and Care being a priority area for 2019 we have been engaged in several activities that will give us a better understanding on ways to improve a patient's quality of care but also quality of life.

## Perianal fistulae and quality of life in Crohn's disease

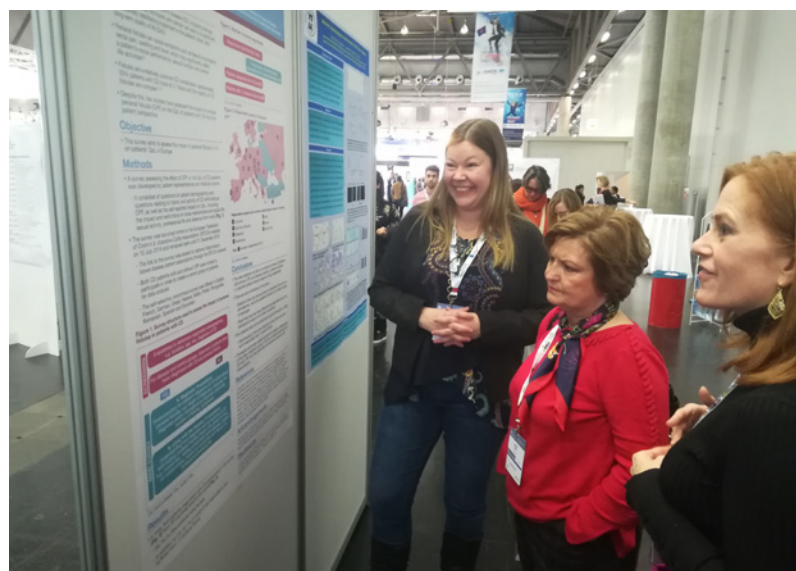
In 2019 we run a survey to find out the impact of complex perianal fistulae on quality of life from Crohn's disease patients' perspective. The questionnaire, developed in cooperation with both medical experts and patient representatives, looks into topics such as sexual function, work and social impact as well as life activities. The aim is to provide valuable insights into the life of a patient with perianal fistulae.

Fistulae, i.e. abnormal connections between organs and other structures in the body, develop when an organ in the body becomes inflamed. They are a relatively common complication of IBD, especially in Crohn's disease; around 35% of people with Crohn's disease have at least one fistula. Fistulae are called perianal when located around the anus.

They can cause symptoms such as leaking from the anus, rectal pain and swelling, and pain with bowel movements, and can significantly affect a patient's quality of life.

The survey was offered in multiple languages and was closed at the end of December 2019. We presented a poster on the concept of EFCCA's fistula survey at ECCO Congress in Vienna

We are now analyzing the results which hopefully will be presented during UEG WEEK 2020 and give us a better understanding of how to improve the quality of life and care of people with fistula.



*Poster presentation at the ECCO Congress 14 February 2020*

# EFCCA Academy

The EFCCA Academy is a pioneer project which aims to provide specialized training addressing the unmet needs of the IBD patient community and to provide skills and knowledge to better develop advocacy strategies both at a national and international level.

After the successful first round of training on communication and the meaning of advocacy in general, that was delivered in 2018-2019, for the Academic Year 2020 EFCCA has been preparing a comprehensive training focused on Clinical Trials.

The choice is based on the assumption that patient engagement is increasingly recognised as essential to integrating the patient voice in the design and development of research on medicines. With skills, knowledge and competences patient can play a proactive role in defining unmet needs and have a greater influence on the choices of decision-makers, such as political, economic and social institutions.

The training will be organized through face to face and online sessions to optimize costs and to be able to expand this educational opportunity to as many patients/students as possible.

It will consist of three modules within a time frame of one year.

The chosen topics/modules are the following:

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

The online modules will be divided into learning sessions of no more than 15 minutes each.

Teachers will follow a specially prepared teaching structure and will present the chosen topics in video clips. At the end of each video the participant will be given a set of 4-5 test questions to see what he/she has learned. After successfully responding to the questions, the participant will be able to move on to the next session.

## Survey on the perceived impact of smoking

There is little patient-centered research that assesses patients' perceived impact of smoking or using nicotine-containing products on Inflammatory Bowel Disease (IBD). EFCCA is therefore supporting a survey on the perceived impact of smoking and the use of nicotine-containing products on the symptoms and progression of Crohn's disease and Ulcerative Colitis.

The cause of both Crohn's disease and Ulcerative Colitis remains unknown. However, certain environmental factors, such as drug use, stress, diet and smoking, can affect the onset and development of IBD [1].

Smoking is known to be harmful in many ways: it increases the risk of cancer and cardiovascular and pulmonary diseases. In IBD, studies have shown an interesting difference. In Crohn's disease patients, smoking is associated with more severe disease, increased need for anti-inflammatory medication, and early post-operative recurrence [2].

In patients with Ulcerative Colitis, however, smoking seems to be inversely correlated with the risk of developing Ulcerative Colitis and the progression of the disease [3].

As very few studies have assessed the perceived impact of smoking or nicotine use on IBD symptoms using a patient-centered approach, EFCCA is supporting an online patient survey on the perceived effects of smoking.

Sponsored by Philip Morris Products SA, the survey focuses on the perceived effect of smoking/nicotine use on UC/CD symptoms and disease progression by patients who are current adult smokers and/or

nicotine-containing products users, and shall not be, in any circumstance, construed as suggesting cigarettes and/or nicotine-containing products as treatment methods.

The survey which was hosted on our website was closed at the end of February 2020 and patients with both Crohn's disease and Ulcerative Colitis were invited to participate.

<sup>1</sup> References 1 S. Danese, M. Sans, and C. Fiocchi, Inflammatory bowel disease: the role of environmental factors. *Autoimmunity reviews*, 2004. 3(5): p. 394-400.

<sup>2</sup> To, N., D.J. Gracie, and A.C. Ford, Systematic review with meta-analysis: the adverse effects of tobacco smoking on the natural history of Crohn's disease. *Aliment Pharmacol Ther*, 2016. 43(5): p. 549-61.

<sup>3</sup> Berkowitz, L., et al., Impact of Cigarette Smoking on the Gastrointestinal Tract Inflammation: Opposing Effects in Crohn's Disease and Ulcerative Colitis. *Front Immunol*, 2018. 9: p. 74.

## IDEA-FAST Horizon 2020 – Innovative Medicine Initiative – IMI Project

Our project application under the IMI Call of the European Commission's Horizon 2020 programme has been successful.

This huge research project led by Newcastle University and involving about 40 partners from academic institutions, researchers, industries and patient representatives will identify digital endpoints that provide reliable, objective and sensitive evaluation of activities of daily living and Health-related quality of life (HRQoL) in Immune-Mediated Inflammatory Diseases such as IBD as well as other such as Rheumatoid Arthritis and Lupus.

Digital endpoints or biomarkers are consumer-generated physiological and behavioural measures collected through connected digital tools such as wearable sensors allowing researchers to longitudinally capture objective data throughout a subject's daily life, instead of subjectively assessing a subject's progress at intermittent appointments at the clinical trial center.





EFCCA will be involved mainly in the Work Package that looks into “Clinical Knowledge and Insight” in order to provide the patient perspective, needs and priorities.

A task force will be created together with representatives from other disease groups in order to provide ongoing advice and input throughout the 5-year project.

Its objective will be to investigate the links between chronic disabling fatigue and sleep disorders are key factors that predict loss of work productivity and lower quality of life in Immune Mediated Inflammatory Diseases including CD and UC.

Our CEO participated in the preparatory meeting which took place from 17-19 November in Kiel (Germany) to define tasks, responsibilities and roles in this EU project with a duration of 60 months.

EFCCA is very excited to be part of this project and we hope that the results of the project will have a positive impact on the quality of life of people with IBD. The official kick off meeting took place in February 2020 in Newcastle.

## ImmUniverse Horizon 2020 IMI project

Another EU Research Project EFCCA is involved in is the ImmUniverse project under the Innovative Medicines Initiative (IMI 2) (Horizon 2020).

Through molecular profiling techniques, the project will identify signatures of biomarkers and mechanistic principles which reveal information on disease severity and progression enabling personalised therapy decisions for each patient at the right time.

Immune-mediated inflammatory diseases (IMIDs) are an increasing medical burden in industrialised countries worldwide. They are characterised by an enormous heterogeneity with regard to disease outcome and response to targeted therapies, which often cannot be adequately tailored to individual patients. Hence, an in-depth understanding of this heterogeneity and the biomarkers which predict disease control and therapy response over time are important prerequisites for future precision medicine strategies in IMIDs.

The pathogenic components (“omics”) responsible for the disease outcome in each individual patient, i.e. environment, genes, gut microbiota or the immune system, are remarkably multifactorial, with thousands of constituents all interacting with and impacting on each other.



**ImmUniverse**

The project team comprises 16 academic partners, led by Humanitas University, five industrial project partners, two small and medium-sized enterprises as well three European patient organisations to ensure efficient dialogue and a continuous focus on the actual needs of patients living with Ulcerative Colitis and Atopic Dermatitis. The project will run for a period of five years.

Patients will be represented by EFCCA, EFA (European Federation of Allergy and Airways Disease) while EPF (European Patient Forum) will support in the dissemination of the project results.

EFCCA and EFA will be involved in the Work Package 1 (WP1) and will join efforts to assure that all the material addressed to patients is translated into a lay language and that publications and outcomes are made easily available for the patient community.

## Study on Patient treatment preferences

Within our priority theme of Quality of Care in 2019 EFCCA got involved in a study that aims to learn about patients' perspectives and treatment preferences for ulcerative colitis and Crohn's disease.

The research will foster further understanding of how well IBD therapies address patient preferences and

may also inform future research to ensure that drug therapies best reflect patient needs. This study also aims to understand patients' perspective to better inform future patient-doctor interactions.

## Observatory to follow up EFCCA's mapping survey

The EFCCA team is in the process of creating an online observatory with up-to-date information and interactive features regarding availability of and access to innovative medicines in the EFCCA member countries. The observatory will build on the result of EFCCA's Mapping survey carried out in 2017, but as this is a dynamic field with lots of changes, new medicines coming in the market etc., it will also provide regular updates from EFCCA's member countries.

The Mapping is still under construction as many new drugs are coming into the market and we want to have a full picture before launching it and sharing it with our members.

# Inside EFFCA

## Annual General Meeting

The annual general meeting took place in Prague from 24 to 26 May 2019. The event was hosted by Pacienti IBD (Czech Republic) and nearly 60 delegates participated to represent 39 IBD patient associations from Europe. It was an excellent moment to exchange ideas and have lively and constructive discussions on EFCCA's future actions and strategies.



In 2019 we were pleased to welcome as new associate members DII Brasil and FPVZK from Kazakhstan as well as CUKUK (Montenegro) as full member, bringing our total membership to 39 members. Additionally, Crohn's and Colitis New Zealand, who joined EFCCA in 2013 as an associate member, has been accepted as a full member.

Following the annual elections, the new board meeting was elected as follow: Salvo Leone (EFCCA Chairman), Ciara Drohan (Vice President and Honorary Secretary), Marko Perovic (Treasurer), Magdalena Sajak, Natasa Theodosiou and Martin Mastrotto, leader of the EFCCA Youth Group.

On the second day of the GA, Dr Martin Bortlík, from the ISCARE Clinical Centre in Prague, gave the GA a detailed overview of the situation of IBD patients in Czech Republic and presented some projects undertaken jointly by ISCARE Clinical Centre and IBD Pacienti, in order to improve the quality of life of people with IBD.

Dr Yoram Inspector, psychiatrist and psychotherapist from the St. Mark's Hospital in London, UK, explained the relationship between the gut and the brain and how mental well-being of people with IBD is affected by their disease.



## Social Programme

IBD Pacienti organized an inspiring social event, the Gala Dinner, on the second night of the GA. The Dinner took place during a boat trip along the Vltava River, passing several buildings highlighted in purple to honour World IBD Day.

We were also given some purple scarfs and blankets, which we proudly wore to show our solidarity and unity with people worldwide on this special occasion.

We also took the occasion to celebrate the small group of delegates who attended and successfully completed the pilot project of the EFCCA Academy. The Academy is our pioneer project, with the aim to provide specialized training, helping certified patients to raise awareness on IBD. All in all, our General Assembly was a huge success, which allowed us to connect with our members, make new friends and to reinforce our sense of community and common objectives.

## EFCCA Executive Board

The EFCCA Executive Board is elected by the General Assembly for a term of two years. The Board meets 3 times a year as well as via conference call in order to discuss the strategic development and work of the organisation.

The following meetings took place in 2019-2020:

### **Face to Face Executive Board meeting 11-13 January 2019**

The meeting took place at the EFCCA office in Brussels. It was the occasion to finalize the Board's discussions about the elaboration of a new strategy for EFCCA. This strategy will be circulated to our members before the General Assembly.

### **Face to Face Executive Board meeting 28-29 September 2019**

The EFCCA Executive Board took place in Brussels. Board members and staff discussed implementation of the EFCCA Strategy Plan, Work Plan 2020 and other pending issues.



### **Face to Face Executive Board meeting 10-12 January 2020**

The Executive Board met in Brussels. The main points of discussions were the forthcoming EFCCA Symposium, World IBD Day 2020, update on EFCCA's involvement in several Horizon2020 projects as well as an update of the European Youth Group activities.

### **Executive Board Meeting - General Assembly 2019**

Following the election during the General Assembly the new board convene to discuss the challenges, work plan and budget for the coming year.

# EFCCA Youth Group

## European Youth Group Meeting

The EYG meets once a year involving many youngsters from the EFCCA membership. In 2019 the European Youth Meeting took place in Brussels from 19th and 20th of July. 21 young delegates from 14 countries across Europe attended the 2-day meeting hosted by the Belgian Association Crohn-RCUH. Ciara Drohan, EFCCA Vice-President, and Marko Perovic, EFCCA Treasurer took also part in the meeting to explain the added value of having a group of representatives dedicated to the young population being part of EFCCA.

The main project of this year was the transition process, from paediatric to adult care. In order to evaluate the challenges of this project, Dr Isabelle Scheers participated to the meeting to give a lecture about her point of view as a gastro-paediatrician.

Dr Scheers believes that communication between the patient, the paediatrician and the parents is key to help teenagers in the transition process. In order to fully understand the situation, the teenager needs a proper introduction of medical terms, and a complete explanation of the illness.



The role of the patient associations is to encourage the doctors, medical staff, and parents to empower the teenagers and encourage them to make their own medical decisions, once they have accepted their condition.

After the lecture the delegates organized a workshop to reflect on which actions could help IBD community defining a softer way to approach the transition period as a teenager, a parent or a healthcare provider.

In line with this project, the Youth Group has surveyed local associations and health care professional about their good practices on the topic and what could be improved at a European level. The full report from their research should be published around May 2020.

For that purpose, the final goal will be to elaborate a website that could guide patients, their families and medical team to a smooth transition.

The Youth group decided also to divide the guide into three main categories based on the targeted population to reach: the patients, the medical team, and the relatives. The goal is to create a guide as complete as possible.

Another important achievement obtained during the meeting was the adoption of a new constitution.

The EYG board has now 7 members elected for two years. This year's elections welcomed Selina Huber (Germany), Olga Golebiewska (Poland), Olga Mitrovic (Serbia) and Natalia Mandakova (Slovakia) to join Katleen Franc (Belgium), Simo Natunen (Finland) and Martin Mastrotto (France) on the Board of the EFCCA Youth Group. French delegate Martin Mastrotto has been elected Leader of the Group for the next two years.

The Executive Board of the EFCCA Youth Group held two face to face meetings as follows:

### **Brussels 5-7 April 2019**

EFCCA Youth Group representatives met at the offices in Brussels to define their activity plan and the latest details for the organisation of their annual meeting (see above).

Our CEO also participated in the meeting and provided some general advice on some of the youth group's projects and plans for future activities.

### **Brussels 17-19 January 2020**

Members of the Youth Group gathered in Brussels to decide the shape and content of the future website dedicated to the transition process project.

This project, known as "IBriDge", aims to bridge the gap between pediatric and adult care. During the same weekend, the EYG also welcomed Chiara Danelli from Janssen' Care4Today development team to provide patient-oriented advices about Janssen's new smartphone app.



# 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.



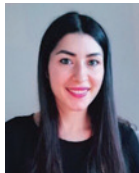
**Isabella Haaf**, Deputy Director is assisting with the overall implementation of the EFCCA work plan with a main focus on communication and international relations in particular the coordination of World IBD Day.



**Sanna Lönnfors**, Research and Project Coordinator, has been leading the work on two surveys, (Fistula and Smoking Survey) as well as working on the EFCCA Academy.



**Maria Stella De Rocchis** - European Project officer started her collaboration at the end of December 2019. Her main tasks are to support the CEO and the Deputy Director in writing the two new IMI – H2020 projects that EFCCA is developing as a full partner in bigger research Consortia.



**Veronica Pisco**, assistant, is based in the EFCCA's headquarter in Brussels, providing administrative support to the whole EFCCA network as well as representing EFCCA in meeting and conferences held within the European institutions.



**Eva Izquierdo Sanchez** has been supporting us with our social media activities (Facebook/ Twitter).



**Antonella Montanari** has been supporting EFCCA around World IBD Day and during the General Assembly.



We would also like to thank our former colleague **Anna Strisciuglio** who has provided her support on a voluntary basis.



EFCCA has been collaborating with the association “**Officine Digitali**” on IT matters (website, IT tools, software and hardware implementation, etc).

# List of members as of 2019

## 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

OSPs 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

CCAFIN - [www.crohnjacolitis.fi](http://www.crohnjacolitis.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)

## Luxembourg

ALMC

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

## Lithuania

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

## Malta

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

## Montenegro

MACC - <http://www.cukuk.me>

## Netherlands

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

## Norway

LMF - [www.lmf norge.no](http://www.lmf norge.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)

## Serbia

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

## Slovakia

SCC - [www.crohnclub.sk](http://www.crohnclub.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

SMCCV - [www.smccv.ch](http://www.smccv.ch)

Crohn Colite Suisse

[www.asmcc.ch](http://www.asmcc.ch)

## Turkey

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

## UK

Crohn's and Colitis

[www.crohnsandcolitis.org.uk](http://www.crohnsandcolitis.org.uk)

## Associated members

### Argentina

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

### New Zealand

Crohn's and Colitis

[www.crohnsandcolitis.org.nz](http://www.crohnsandcolitis.org.nz)

### Brazil

DII Brasil

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

### Kazakhstan

FPVZK - <http://vzk.kz>

# Sponsors

EFCCA is funded by its national members that contribute with an annual fee based on their number of registered volunteers.

EFCCA is also supported by projects that are developed in partnership with donors. EFCCA usually works with a multi-stakeholder partnership for its projects in order to ensure its independence.

EFCCA supports a policy of full transparency regarding its funding sources. The EFCCA transparency rules can be downloaded from the EFCCA website in the “Funding” section.

We would like to thank the following donors who have supported us in several activities that are mentioned in this report.

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# EFCCA

European Federation of Crohn's  
& Ulcerative Colitis Associations

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