

LET'S MAKE IBD WORK!!

EFCCA Annual Report

(March 2020 - March 2021)



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



Salvo Leone EFCCA Chairman

Exactly one year has passed since the world was overwhelmed by COVID-19. The pandemic has put a strain on the world, hitting the most vulnerable sections of the population harder and generating uncertainty that persists.

2020 has undoubtedly changed our programs which envisaged attention as a strategic area “IBD and Work”, but they have not interrupted them.

IBD has a high impact on the health system, in terms of hospitalizations and drug treatments, and on society, resulting in absenteeism from work and loss of productivity. The economic and social impact determined by IBD and associated treatment is burdensome for both the patient and society. The correlation between the severity of the disease and the effects on the subjects’ working capacity is evident.

By highlighting discrimination in the workplace for patients with IBD we aimed to advocate for appropriate rights and legislation for the protection of patients with IBD and to address patients’ difficulties and existing policies to support employees and managers.

We support a patient-friendly work environment by the exchange of information on good practices between associations and member countries to ensure that patients’ needs are met.

Our activities have been catalyzed by the Pandemic and the need to offer the people we represent clear and timely information relating to COVID-19 and its aspects associated with IBD.

For this reason, the “Survey on COVID-19 IBD patients’ perception” gave us the elements to understand which were the areas in which we had to concentrate and then organize the EFCCA Patient Talks.

These online events have allowed patients to understand various aspects such as psychosocial aspects, the importance of seasonal vaccines, and other information to better manage IBD.

The pandemic did not allow the organization of our General Assembly in Estonia. Our GA represents an excellent opportunity, a great meeting point for the EFCCA members, to exchange information and best practices. But the priority was the safety of our people.

We have continued to improve the quality of care and quality of life of people living with IBD despite the global crisis.

Since the genetic sequence of the SARS-CoV-2 virus was published on January 11, 2020, scientists, industries and other organizations around the world have worked together to develop safe and effective vaccines against COVID-19, as soon as possible.

Today more than ever, scientific research gives us hope that we will come back soon to continue with our work as we have always done.

Enjoy the reading

Salvo Leone
EFCCA Chairman

A handwritten signature in black ink, appearing to read 'Salvo Leone', written in a cursive style.

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

UEGWEEK 2019

This year UEG WEEK was organised online and took place from 10-13 October 2020.

The scientific programme was held on the UEG virtual congress platform including access to virtual lecture halls as well as the UEG TV Studio. Each location hosted scientific highlights in extremely interactive ways and delegates had the opportunity to interact live via Q&A tools.

Some of the highlights and of interest to the IBD community were:

1. An abstract presented by Ryan C. Ungaro on the impact of COVID-19 on patients with inflammatory bowel disease (IBD): data from an international registry. This data created to monitor outcomes of IBD patients with confirmed COVID-19, called SECURE-IBD found that increasing age, comorbidities, and corticosteroids are associated with severe COVID-19 among IBD patients.

ECCO Congress

Due to COVID-19 the organisers of the ECCO Congress decided to postpone the congress planned for February 2021 to July 2021. Our attendance at



On the other hand, TNF antagonists (biologic therapies) do not appear to be associated with severe COVID-19.

More info: bit.ly/risk-factors-for-severe-covid-19

2. A Danish population-based cohort study looking at Risk of a post-colonoscopy colorectal cancer diagnosis in patients with inflammatory bowel disease. (Troelsen FS, abstract OP027). It concluded that post-colonoscopy colorectal cancers accounted for a substantial proportion of all IBD-related colorectal cancers. However, IBD patients had a low absolute risk of post-colonoscopy colorectal cancers. More info: bit.ly/post-colonoscopy-colorectal-cancers

ECCO 2020 (12-15 February 2020, Vienna, Austria) has been reported in our previous Annual Report.

European Health Forum Gastein

The European Health Forum Gastein (EHFG) 2020 took place online from 30 September - 2 October 2020. The Forum is an independent organisation founded in 1998 with the aim to provide a neutral and inclusive platform for the discussion and advancement of health policy in the EU and beyond. Its founding principle is the equal representation of all stakeholders in health. It is the first time that EFCCA has participated in this important event which run under the theme “Dancing with elephants - New partnerships for health, democracy, business”.

The main focus of the programme was around the unequal access to medicines and the increasing burden of chronic diseases and aimed to inspire solution-orientated discussions on the future of healthcare, societies and economies in Europe in the context of



**EUROPEAN
HEALTH FORUM
GASTEIN**

the COVID-19 that has highlighted the weaknesses of our current health systems and political decision-making and underlined the urgent need for greater collaboration. In fact, the importance of including patients since the early stages of the implementation of healthcare programs has been particularly stressed in establishing alternative settings for the future. For more information: www.ehfg.org

Patient Organisations

International Alliance of Patients' Organisations (IAPO)

IAPO is a unique global alliance representing patients of all nations across all disease areas. It works to promote patient-centered healthcare around the world. With over 300-member organisations from 71 countries it represents 50 disease areas. Its vision is to see patients placed at the center of healthcare.

This year EFCCA has strengthened its relationship with IAPO which is a global alliance promoting patient-centered healthcare worldwide and committed to ensuring that patients play an active role in decision-making processes.

Our affiliation is longstanding, and we recently had the opportunity to meet their CEO, Kawaldip Sehmi, and involve him in one of our EFCCA Patient Talks (see page 14). As we know the incidence of IBD is growing dramatically around the world EFCCA believes that



**International Alliance of
Patients' Organizations**

A global voice for patients

strengthening links with sister associations that share our overall vision can help build a network of solidarity and visibility at a global level and contribute in creating a louder and effective critical mass of patients and communities.

European Patient Platform (EPF)

EPF is an independent non-profit, non-governmental umbrella organisation of patient organisations across Europe and across disease-areas. Its 75 members include disease-specific patient groups active at EU level as well as national coalitions of patients.

As member of the European Patient Platform, EFCCA participates in its constitutional events. In 2020 our CEO attended the EPF General Assembly which took place on 25-26 April 2020 online.

The first day was focused on the previous year results on the discussion towards EPF Strategic Plan (2021-2026). The second day - named Leadership Meeting was focused on the topic of digital health and on how to work to better identify patients' needs.



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.

In 2020 we have been involved in the following Patient Advisory Meetings:

- Boehringer Ingelheim**
 We have been involved in the organization of the Global Patient Summit which took place from 26-27 February 2021. We provided our input and patient perspective during the elaboration of the proposed workshops and general event programme. Our CEO presented some interesting case studies concerning digital health and in particular on Big Data and data collection referring to our Digital Health Symposium organized at the previous ECCO Congress (February 2020, see previous activity report)
- Roche: Global Patient Council**
 EFCCA is involved in a patient council promoted by Roche which was initiated last February (2020) in Vienna during the ECCO congress. Several themes and related activities have been discussed and developed during the year; clinical design and patient input, empowering patients and co-defining mindful solutions are the main topics of the year. Other meetings took place online due to the pandemic: education on clinical trials and the development of a lexicon are ready to be available for the whole IBD community.

SECURE IBD

SECURE-IBD is an international, paediatric and adult database to which healthcare providers worldwide are strongly encouraged to report cases of confirmed COVID-19 in their IBD patients. The overarching goal is to identify COVID-19 outcomes in IBD patients and evaluate the safety of IBD medications globally in a collaborative, ethical, transparent, and timely manner.



EFCCA has been contacted by the SECURE-IBD team which includes renowned physicians such as Michael D. Kappelman, Erica J. Brenner, Jean-Frederic Colombel, Ryan Ungaro, Manasi Agrawal and included in their International Advisory Committee for Europe are Walter Reinisch and Dr. Jean-Francois Rahier.

Since March 2020, SECURE-IBD has received overwhelming support from the IBD community with over 2,000 cases from more than 50 countries reported to the registry. Using these data, has allowed the SECURE-IBD team to make some very interesting and clinically relevant observations.

The web-based survey is available through our website www.covidibd.org and takes approximately 5 minutes to complete. On their website you will also find all the latest news and developments.

ATLAS project

EFCCA is involved in the ATLAS programme that was formed in 2016 as a response to a lack of awareness of Intestinal Failure (IF) and poor harmonisation of standards of care across Europe.

The Steering Committee includes expert clinicians, patient advocates, patient organisation leaders and has initiated and funded by Takeda.

Our CEO attended the online Atlas Steering Committee meeting in July 2020. The meeting provided an update on the project and focused on discussions to ensure alignment on the project objectives for the 2020 roadmap taking into account the COVID-19 pandemic.

For more information visit: www.atlasif.eu



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

World IBD Day takes place on 19 May each year and unites people worldwide in their fight against Crohn's disease and ulcerative colitis, known as inflammatory bowel diseases

In 2020 EFCCA's theme for World IBD Day was on Work and IBD. With IBD on the rise and mainly affecting young people our campaign Make IBD Work aimed to raise awareness of the impact IBD has on a person's professional life. Given the health situation worldwide the awareness raising campaign run mainly through our social media channels. We disseminated useful information material on key issues concerning Work and IBD referring also to good practise case studies of many of our member associations. For more information please visit: www.efcca.org/en/projects/world-ibd-day-2020

An infographic highlighted the key challenges and messages back up by inspiring patient stories on their reconciliation of IBD and work life.

Curiously the pandemic shed a light on the need for more flexible working conditions such as for example working from home (teleworking) as a means to put less strain on the health systems. It has shown that if there is sufficient motive such measures are relatively easy to put in place for many professions.

WORLD IBD DAY
19 MAY

MAKE IBD WORK

19 MAY WORLD IBD DAY

THE CHALLENGE

3.4 million people in Europe live with Crohn's Disease or Ulcerative Colitis (also known as Inflammatory Bowel Disease - IBD)

With IBD on the rise and mainly affecting young people of working age the impact the disease has on a person's professional life is of great concern to society and in particular to policy makers and employers.

Many people with IBD want to and are able to successfully work. Studies have shown that good quality work has a positive influence on overall wellbeing. With some comprehensive strategies at the workplace, a better understanding of the disease and a supportive environment we can make IBD work!

Major symptoms of IBD such as fatigue and cramps can lead to reduced productivity and absence from work, which then leads to feelings of guilt, pressure and more stress

With the right measures in place we can achieve a state of improved general wellbeing which leads to more productivity and reduced direct and indirect costs

MAKING IBD WORK

THE SOLUTIONS

HOW CAN WE MAKE IBD WORK?

- AWARENESS RAISING**
 - Awareness raising with the general public through World IBD Day and national activities
 - Specific awareness raising and educational programmes for employers and colleagues
 - Ensure appropriate training of employers on the issue of chronic diseases and working conditions
- COMPREHENSIVE POLICIES**
 - Work time management (teleworking) and working conditions
 - Ensure equal access to work
 - Incentives to support the employment of people with chronic diseases
 - Flexible, supportive and non-discriminatory work practices
- OPTIMAL TREATMENT CARE**

Beside the €700 billion healthcare costs, chronic diseases cause indirect costs for workers, employers and society

The cost of new innovative IBD treatments may be counterbalanced by improved employment and reduced social costs

Effective medical consultations should address the patients' full life context including work

Patients' employment aspirations should be regarded as goals and success criteria

EFCCA WANTS TO CALL ON EUROPEAN POLICY MAKERS TO:

- Recognize the direct and indirect costs of IBD on society and thus to better prioritize effective IBD treatment which will result in reduced healthcare and non-healthcare costs
- Recognize the need for more comprehensive policies and strategies at the workplace that take into account the situations of people with chronic conditions such as IBD
- Recognize the link between employment and its positive effects on the general wellbeing of a person

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WWW.EFCCA.ORG
WWW.WORLDIBDDAY.ORG

The IBD patient community has been advocating for such measure previously in order to facilitate a better integration of chronic patients into our workforce. Of course, there are certain jobs where teleworking is not an option, however there are many more measures that can be applied that will ultimately benefit employers and employees alike.

Our key messages for World IBD Day 2020 were:

- Comprehensive policies and strategies at the workplace that take into account the situations of people with chronic conditions such as IBD have an overall positive impact not only on the patient but society at large.
- Direct and indirect costs of IBD can be reduced by better prioritizing effective IBD treatment.
- There is a direct link between employment and its positive effects on the general well-being of a person.

On 19 May we also run a social media awareness raising campaign around the issue of Work and IBD. We invited IBD patients from across Europe and worldwide to share their stories and let people know how IBD had affected their professional life. We were happy to receive an abundance of stories that showed the determination and hope with which people made their career aspirations come true and find a good balance in their professional life. If you would like to be inspired, please go to: www.efcca.org/en/stories

Purple landmarks

We continued to collect and share information about patient association's efforts to raise IBD awareness by highlighting famous buildings and landmarks in purple. More info: <https://worldibdday.org/>

My IBD Journey: IBD and work

We have been collaborating with Janssen on the elaboration of a series of animation videos that help people to 'live well' with the disease. The videos aim to equip people with practical advice and relevant information and hopefully will bring about positive changes to the way they cope with their IBD.

The 5th animation series is looking at the issue of Work and IBD in line with our priority theme for 2020. The animation is highlighting common challenges

and looks at practical measures on how to manage your IBD at work. The content of the video reflects the views and perspectives of real people with IBD in real life scenarios and the stories are positive and upbeat aimed at giving people confidence that they can live well with IBD.

For more information please visit: www.efcca.org/en/projects/my-ibd-journey-animation-series



Fatigue and IBD

In line with our priority theme of well-being for 2021 we have started to work on some educational material that is looking into “secondary effects” of the disease, namely fatigue. People with Crohn’s disease or ulcerative colitis are at risk for experiencing fatigue which can have a huge impact on their daily life. The symptoms of fatigue are often overlooked or mistaken as an effect of the disease itself.

We are planning to prepare educational material that will explore the issues around fatigue and the impact it has on the quality of life of IBD patients. In collaboration with patient representatives and IBD specialists EFCCA will prepare a set of information material that will provide professional guidance and knowledge.

The material will allow us to raise awareness on the identified issues and is targeted for the IBD patient community in general and in particular those that are experiencing symptoms of fatigue.

Patients’ perceived impact of smoking or nicotine use on their Inflammatory Bowel Disease (IBD)

There is little patient-centered research that assesses patients’ perceived impact of smoking or using nicotine-containing products on Inflammatory Bowel Disease (IBD).

In the beginning of 2020 EFCCA supported a survey on the perceived impact of smoking. It focused 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 was not, in any circumstance, construed as suggesting cigarettes and/or nicotine-containing products as treatment methods.

As results of this call, most of the responding countries reported that Salazopyrin (500mg tablet) from Pfizer Company was not available. Other countries reported the lack of Questran 4gr powder and Prednisolon tablet as well. However, some countries such as Finland and Poland did not have any problem with drug shortage.

This first meeting was an opportunity for EFCCA to become more visible, thanks to the collaboration with MEP Rivasi and the Greens and a way of lobbying the EU health agenda. We will continue to focus our efforts on this important issue and to bring these matters to the responsible policy makers.

Fistula survey: improving quality of life in Crohn's disease

Perianal fistulas have a huge impact on the quality of life of Crohn's patients. Even so, there is little published data on how the condition affects a patient. For these reasons EFCCA has carried out a survey in 2019 in cooperation with the pharmaceutical company Takeda in order to find out more about this debilitating condition.

At the closing of the survey, over 800 respondents with Crohn's disease had completed the questionnaire. More than half of the respondents had perianal fistulas. A poster introducing the concept of the survey was presented at the ECCO Congress in Vienna on February 14, 2020. During the summer, the EFCCA team has been working on analyzing the data in preparation for publishing the full results. However, as several medical congresses and meetings have been rescheduled due to the COVID-19 pandemic, the communication plan for the full results of the survey will also need to be rescheduled accordingly.

The survey revealed, perhaps unsurprisingly, differences in symptoms experienced by those with Crohn's disease with and without fistulas, but also differences in symptoms experienced by men and women.

The significant impact of perianal fistulas on a Crohn's disease patient's quality of life was seen clearly in all life areas - social life, working life, relationships with family and friends as well as intimate relationships. Once the results have been made public, we will use these to find possible solutions on how to improve the quality of life of affected patients.

More info:

www.efcca.org/en/news/impact-perianal-fistulae-crohn's-disease-patient's-quality-life

Survey on COVID-19 IBD patients' perception

As the result of the COVID-19 pandemic we decided to raise awareness and provide information on how the IBD community was affected by this health crisis. The survey aimed to better understand the concerns and fears of patients with Inflammatory Bowel Disease (IBD) within this context.



The survey has been co-designed with Prof. Silvio Danese Head of the IBD Center at Humanitas University Hospital in Milan and was originally thought for the Italian IBD patient community, given the particularly serious situation in Italy. After a quick consultation with the EFCCA Board it was decided to involve all its members and publish the English version immediately. Thanks to the prompt reaction of many associations and volunteers, 11 translations of the survey were made and published.

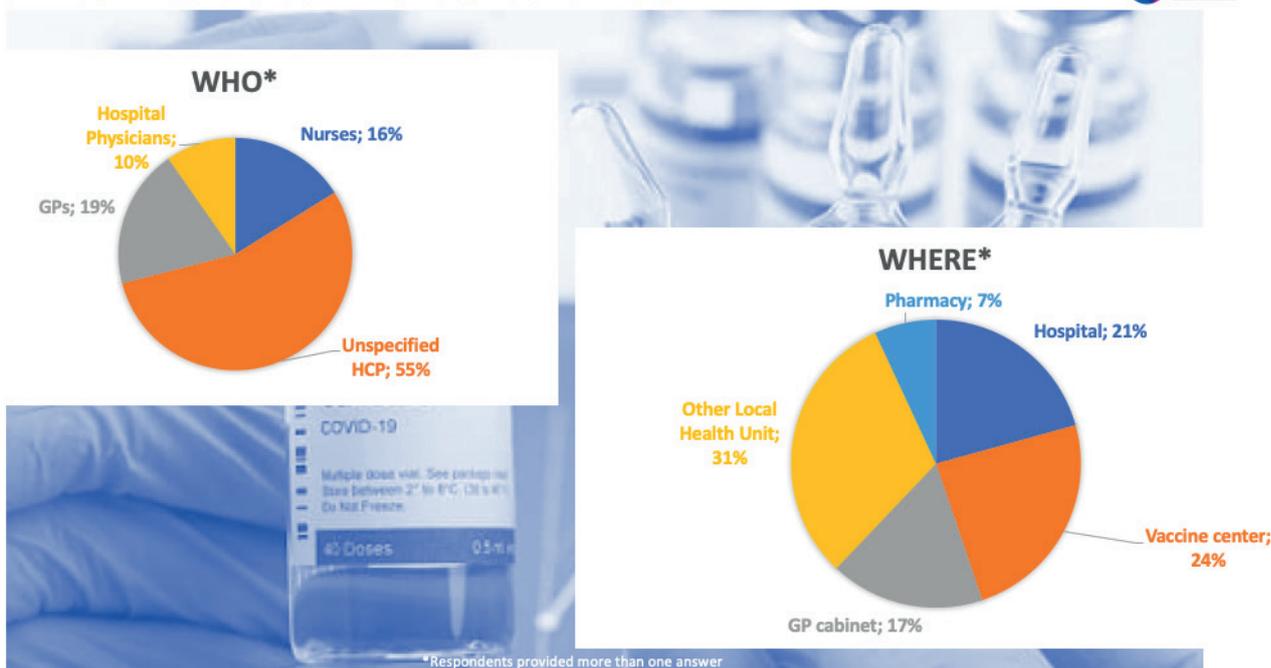
The data was collected during the period from 30 March to 16 April 2020 and saw a huge participation amongst our members with over 3800 respondents. You can see a summary report on our website at: www.efcca.org/en/results-COVID-19-ibd-patients-perception

COVID-19 Vaccination protocols

In response to the current health crisis EFCCA ran a poll amongst its EFCCA members in mid-January 2021 in order to have a better picture of the situations in each of the members countries as concerned the availability of COVID-19 vaccines, the administration protocols and whether IBD patients were considered as part of the risk groups within national vaccination programmes.

We launched this poll in connection with our 4th EFCCA Patient Talk on COVID-19 vaccination and IBD (see page 15) and are keen to monitor the situation so to be able to detect best practises and learn from experiences gained so far.

Who will administer the COVID-19 vaccine and where?



The survey was conducted starting as from 18th January 2021 as preparation for our "EFCCA Patient Talk COVID-19 vaccination and IBD". 21 members responded.

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.

EFCCA Patient Talk Series

The EFCCA Patient Talks have been a direct response to the COVID-19 pandemic. A survey that we carried out in April 2020 (see page 12 “Survey on COVID-19 IBD patients’ perception”) highlighted several areas of concerns for the IBD patient community. The Patient Talks are aimed to provide information and possible solutions as well as connecting patient representatives with experts and relevant authorities.

During the period of this activity report we have organised 4 EFCCA Patient talks as follows:

- COVID-19 and medicines supply: “Are we running out of medicines?”**
 A few weeks within the COVID-19 pandemic patients from several immune modulated disease groups struggled to access their medications. The issue of drug availability is not a new one, but the pandemic exacerbated the situation. In order to address this topic EFCCA organised its first EFCCA Patient Talk which took place on 25 June 2020. Invitees to the talk included Monica Dias representing the European Medicines Agency and Piera Polidori for the European Association of Hospital Pharmacists (EAHP) exchanging information with patient representatives in order to gain a better understanding of the current situation and further outlook as well as to learn about measures that have been taken to guarantee a steady supply of medicines in the EU. More info: www.efcca.org/en/events/efcca-patient-talk-no1

EFCCA Patient Talks



COVID-19 and medicines supply: “Are we running out of medicines?”

Free Webinar

Join our discussions with representatives from the European Medicines Agency and the European Association of Hospital Pharmacists.

More info: www.efcca.org

To register send an email to: veronica.pisco@efcca.org

Thurs. 25 June 2020 4PM - 4.45 PM

- COVID-19 psycho-social impact of lockdown in patients with IBD**
 During our second webinar which took place on 16 July 2020 we heard from several IBD patients first-hand experience of how the lockdown taking place in many countries around the world had affected their mental wellbeing and what it really meant for an IBD patient to self-isolate. IBD patients Vasiliki - Rafaela Vakouftsi, General Secretary of HELLESCC and Sanna Lonnfors, EFCCA Research and Project Coordinator discussed their experiences with Dr Yoram Inspector M.D. Consultant Psychiatrist (St Mark's Hospital). The session was moderated by EFCCA Board member Marko Perovic who also referred back to the survey on IBD patients’ perception. More info: www.efcca.org/en/events/efcca-patient-talk-no2

- **Seasonal vaccines and IBD**

The hot topic on vaccines, patient safety and medicine availability was discussed amongst patient representatives and invited guest speakers on 27 November 2020. The third webinar took a closer look at the issue of seasonal vaccinations in relation to IBD, patient safety and general awareness around vaccines as well as medicines shortages. The meeting was moderated by Ciara Drohan, EFCCA Vice President and Member of the Irish Crohn's and Colitis Society with the participation of Dr Bogdan Mateescu, Head of Gastroenterology Department at the Colentina Clinical Hospital (Bucharest) and Kawaldip Sehmi, CEO of the International Alliance of Patients' Organisations (IAPO). More info:

www.efcca.org/en/events/efcca-patient-talk-3

- **COVID-19 vaccination and IBD**

The fourth webinar took place on 5 February 2021. As the worldwide rollout of coronavirus vaccination started in the beginning of January 2021 the IBD patient community had many concerns and questions around this theme. EFCCA invited Prof. Axel Dignass, President of the United European Gastroenterology (UEG) to discuss the potential concerns and implications around the COVID-19 vaccination with relation to inflammatory bowel diseases whereas Dr. András Süle, President - Elect at European Association of Hospital Pharmacists (EAHP) talked about the EU COVID-19 vaccine programmes and the challenges that their implementation and administration will follow when more vaccine will become available. More info:

www.efcca.org/en/events/efcca-patient-talk-no-4

EFCCA Academy: Training on Clinical Trials

One of our flagship activities in terms of patient empowerment is the EFCCA Academy. The Academy was launched two years ago to provide specialized training for people with IBD enabling them to raise awareness on specific topics and to become advocates for their IBD patient community. Academy qualified patients will become trainers of trainers within their own local community. Training usually takes place on-line as well as during face to face workshops.

In 2020-2021 we have developed an exciting set of training modules on the issues of clinical trials. Clinical studies provide unique opportunities and are an essential step towards discovering new treatments as well as new ways to detect and diagnose a given disease, yet patient participation in these studies is persistently low. Various studies that have been carried out in the past to assess public awareness, perceptions, and attitudes toward clinical trials or studies show clearly a lack of knowledge and understanding of them amongst the public in general, amongst patients and even amongst some patients that

are already participating in a clinical trial. Information about clinical studies/trials is at times confusing, too technical and beyond the understanding of a layman. Finding reliable and verified information about clinical studies is another issue.

Further obstacles for participating have been cited, such as difficult access to trial sites as well as concerns about safety and about being placed in a placebo trial group.

The Academy training modules dealt with the majority of these issues. The first module "**Clinical trials: basics**" took place online on 18 November 2020. Professors Séverine Vermeire and Marc Ferrante from the Department of Gastroenterology and Hepatology, University Hospitals Leuven / KU Leuven in Belgium provided basic information on the different phases in the development of medicines, the revolution in IBD treatment over the years, the efficacy of clinical trials and the safety also in the real-world after drug approval.

The second module (17 December 2020) “**Diving deeper into clinical trials**” gave students insights into all the players involved in clinical studies including aspects such as patient education and patients’ role within these trials. Speakers included Annick de Bruin from the Center for Information and Study on Clinical Research Participation (CISCRP), Rob Camp from EURORDIS, Rare Disease Europe and Ana Sofia Correia, Life Sciences & Medical Translator.

The last module took place on 21 January under the title “**Breaking the myths around clinical trials**”. A lecturer by Prof. Ariel Liebert from the Department of Gastroenterology and Nutrition Disorders, Nicolaus Copernicus University in Toruń (Poland) dealt with Clinical trials guidelines, benefits and risks related to participation, medical care in progress, participant’s

insurance, and what to ask before making a decision to join a trial. This was followed by an interactive discussion on how industry is interacting with different stakeholders as part of the drug development process. For this purpose, representatives from Roche provided an insight of the different roles and functions of industries in these trials. The training saw the active participation of 15 students from x countries. They will now proceed to work on a thesis in order to complete their training. For more information please contact Maria Stella De Rocchis, EFCCA European Project.



Patient Preference Study

EFCCA has been involved in the IBD Patient Preference Study (P-Power IBD) granted by Abbvie and involving several IBD Key Opinion Leaders (KOL) such as Professor Eduard Louis and Subrata Gosh among the others.

The main objective of the study that was divided into a qualitative part and a quantitative one, was to analyse the preferences IBD patient express when it comes to include not only the clinical impact but also the quality of life.

The study has been recently closed and it is about to be published. For this reason we cannot now share more information, however we believe that some of the outcomes will be very useful to define EFCCA next steps in exploring the topics of Patient Report Outcomes and Patient Preferences, which have been identified as the pillars of our 2021 Strategic theme: IBD and well-being.

EU Projects: Innovative Medicine Initiative

IDEA-FAST Horizon 2020

EFCCA is involved in this exciting project that 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 and which will ultimately have a positive impact on the quality of life of these patients.



We have been participating in the bi-weekly meeting involving all members of the Consortium.

Following the Kick-Off meeting in Newcastle in February 2020, the IDEA-FAST team worked hard to make the vision of the feasibility study come to life. By August 2020 the IDEA-FAST data management platform was launched and ready to receive data collected from the Feasibility Study. In the most recent development IDEA FAST agreed to collaborate with

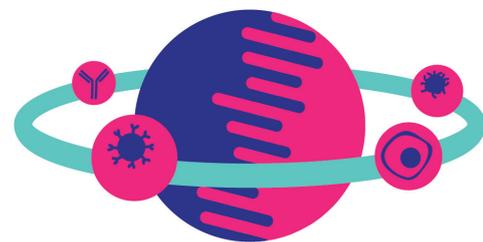
the Mobilise - D project (IMI Project) to bring synergy and increase the impact and benefits of the digital health technologies developed by both projects. The collaboration will exploit common themes and approaches across the projects, to develop digital biomarkers in mobility, sleep and fatigue, including large observational studies involving diverse patient cohorts. More info: <https://idea-fast.eu/>

ImmUniverse Horizon 2020

EFCCA is involved in an exciting EU Research Project under the Innovative Medicines Initiative (IMI 2) (Horizon 2020).

The ImmUniverse project main goal is the improved diagnostic and therapeutic options for patients living with ulcerative colitis and atopic dermatitis. New insights into disease severity and progression will enable personalised therapy for each individual patient.

From May to July 2020 our CEO has been involved in bi-weekly meetings organised by the ImmUniverse communication group with the objectives to create the website of the project and fact sheets to be made available to the wider public regarding the project objectives and deliverable. The website has been launched in September 2020.



ImmUniverse

The observational cohort will in total include 270 UC patients at various clinical sites across Europe. In November 2020 with the inclusion of the first two patients, one for UC and one for Atopic Dermatitis (AD) by the work package leader CAU the study has now officially kicked off.

More info: www.immuniverse.eu

PRECISE PROJECT – IMI

Between March and June 2020 EFCCA and AFA have been involved in the design of an IMI (Innovative Medicine Initiative) project named PRECISE IBD and promoted by the Sorbonne University in Paris.

PRECISE stands for Personalized real-world data-based assessment of efficacy and safety of immunosuppressive drugs in IBD. The project objective was to provide physicians with a tool for a personalized individual prediction of efficacy and safety of the current major immunosuppressive strategies for IBD while its core concepts were the following:

- to use and assemble European real-world databases with various sizes and degrees of phenotypic precision;
- to use and confront supervised statistics and artificial intelligence models for yielding personalized prediction;

Despite its high score the project was not granted but we hope to be able to re-submit it in a further round of EU funds.

Annual General Meeting

Due to the COVID-19 lockdown measures in most countries of the EFCCA membership the EFCCA board decided to hold our Annual General Meeting on-line.

The meeting took place on 30 May 2020 and the programme included the institutional parts of our organization such as the presentation and approvals of our Financial and Activity reports, last year's minutes, the report from our EFCCA Youth Group (EYG) as well as the work plan for the coming year.

We also held elections to the board and are pleased to announce that the new board is composed of the following representatives:

- Salvo Leone (Italy, President)
- Ciara Drohan (Ireland, Vice President)
- Marko Perovic (Serbia, Treasurer)
- Martin Mastrotto (France, EYG leader)
- Magdalena Sajak-Szczerba (Poland)
- Natasa Theodosiou (Cyprus)
- Roberto Saldaña (Spain)

EFCCA members then voted in favour of the incoming members of the IBD patient association from Latvia and Trinidad & Tobago increasing our network to 41 members worldwide.

Finally, we heard presentations from four new observer countries, namely Mexico, Russia, Singapore and the Ukraine, who are keen to join EFCCA next year.

All material and presentations can be view and downloaded from the private member section of our website.



Executive Board

Following the elections at the EFCCA General Assembly the new Executive Board has had three online meeting: 6 July 2020, 13 October 2020 and 10 February 2021 during which it discussed the implementation of our work plan and strategy plan.

A dedicated brainstorming session for activities related to World IBD Day 2021 was held on 7 November 2020. Furthermore, the Petit Comité consisting of the President, Vice President, Treasurer, CEO and Deputy Director held several ad-hoc meetings to discuss urgent issues arising.

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.

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.

Our long-standing colleague **Sanna Lönnfors**, Research and Project Coordinator, who has been recently leading the work on two surveys, (Fistula and Smoking Survey) has ceased to work for EFCCA as of December 2020. We wish her all the best for her future careers and hope to involve her in some ad-hoc work representing the IBD community.

One of the areas Sanna has been working on is the EFCCA Academy, which is now being managed by **Maria Stella De Rocchis** European Project officer who joined EFCCA end of 2019

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



European Youth Group

Despite the repetitive lockdown and flight restrictions due to the COVID-19 crisis, the year 2020 have witnessed an important batch of actions that have been carried out by the EFCCA Youth Group.

The last activity report period ended soon after the last physical meeting of the EYG, in Brussels on the 18th of January 2020.

This document is aiming to record the principal activities that have been accomplished by the Youth Group during the period going from March 2020 to February 2021.

European Youth Meeting (EYM)

The EYM 2020 took place during half-a-day on the 8th of August 2020. As for EFCCA General Assembly, and due to the numerous travel restrictions imposed by most of the European governments at that time, the European Youth Meeting originally expected to take place in El Escorial, near Madrid, had to be reorganized and adapted to an online event.

Nonetheless, this lightened version of EYG's annual meeting covered many important topics and had been the occasion to address several evolutions in the EYG roadmap. This enjoyable moment had been shared by 28 attending delegates from 17 countries, including Brazil, that was celebrating its first attendance.

With a shorter agenda than expected, many things had to be left aside, but the key topics have been addressed successfully. The introductory activity report featured EYG Leader Martin MASTROTTO and EFCCA Treasurer Marko PEROVIC. The annual elections for a 2-year term in the EYG Board validated Amaranta CANTERO (Spain) and Simo NATUNEN (Finland) as board members to continue with the Group a little longer.

The entirety of the meeting has been recorded and later shared on our social media channels, as well as with the full list of attendance to guarantee a full transparency and straight communication with all our member associations.

Transition Project

One wager taken by the new EYG Board after the EYM 2019 was to wrap up and close the then ongoing, Transition project. As a reminder the project has been launched in 2017 by our predecessor and was aiming to identify the barriers and challenges faced during the transition from a paediatric hospital to an adult health centre in order to facilitate the process and harmonize some part of the protocol.

After analysing the results from a workshop held in Brussels during the EYM 2019, and after collecting testimonies from the IBD youth community all along

the year, the EYG decided to create a specific website that would be dedicated to this particular issue. With help from the EFCCA IT team, the EYG succeeded in delivering the said website just a few weeks before the deadline of the EYM 2020.

The project has been renamed IBriDge for the occasion to emphasize its aim to bridge the gap, caused by the lack of understanding, between the youth and the adult world. A specific communication campaign had then been undertaken to announce and present the brand-new website to our community.

Education Project

A second announcement that has been proudly made during the EYM 2020 was the disclosure of the new project of the EFCCA Youth Group.

Indeed, during the last physical meeting of January 2019, the EYG decided to reflect on a new topic of study to be announced during the EYM. After consultation with the EFCCA Youth delegates, the Group selected to issue of "Education and IBD" as the next topic to be developed.

The first step of this project consisted of a workshop held during the EYM with the attending delegates. The purpose of this workshop was to collect insight on the best angle to adopt in order to optimize the impact of the study we were about to begin.

The second step was to design, edit and disseminate a tailored survey intended for the young IBD patient across Europe and beyond, to map the principal breaches in the support provided by the different type of educational centres from different geographical locations, and to identify the impact that IBD can have on one's post-high school education course.

The EYG made good use of their growing delegates community by asking openly for assistance in the translation of the survey from English to local languages, and then of the answers back into English. The demand received an enthusiastic echo and many delegates volunteered to help with the translation.

The survey has been open from August to December 2020 and has been translated in 11 different languages. At closing time, more than 500 respondents participated in the study. In January 2021, the EYG has started the analysis of the results and agreed on the roadmap to conduct regarding the deliverables of this project.

Participation in EFCCA events

All these studies and activities would not have been possible without the confidence and guidance of the EFCCA Board. Furthermore, the EYG had the chance to participate in all EFCCA Board Meetings organised over this period of time, under the representation of the Youth Group elected leader. An EYG activity report has also been presented to the EFCCA members during the General Assembly on 30 May to update our IBD community on, not only the results, but also the needs that the EYG presents in order to continue delivering the best insight of young patient's journey.

Such representation has been a good way to keep shining a light on the close collaboration between EFCCA and the EYG that was in practice all along the year 2020, as we remember the attendance of two EYG representatives during the EFCCA Symposium held at the ECCO event on the 14th of February, and the participation in pharmaceutical consulting during the physical EYG board meeting on the 18th of January.

Communication campaigns

As we know, a strong and impactful way to communicate with our young patient community has always been through social media.

On that side, the year 2020 has seen the launch of a new Instagram channel, fully complementary with our older Facebook channel, that allows us to reach more efficiently our targeted recipient group. In less than 1 year of activity, the Instagram page reached 215 followers and has been implied in all our online communication campaigns.

Many publications have been shared over the last period of time, respecting a precise publication schedule adapted to the type of content and the channel used. We can name two main campaigns that have been undertaken by the EYG this year.

The first one occurred during spring 2020 and aimed to raise awareness on the challenge that can present the transition from one hospital to another for a young adult. This campaign was directly linked to our Transition project and consisted in collecting and publishing stories of transitions experienced by some of our European youth delegates.

The second campaign was launched in December and was built around a series of short videos recorded by the member of the EYG Board to address our good wishes to our community for the New Year.

In addition to a continuous communication on our online channels, the EYG also regularly shares update with EFCCA members thanks to our internal communication tools. In that way, articles have been published for the February, May and September issues of the EFCCA Magazine, as well as in the regular monthly newsletter.

Internal meetings

Last but not least, the internal communication of the EYG has shown its importance more than ever during the period of uncertainty that we all experienced at the beginning of the COVID-19 crisis. A monthly call is organised every first week of the month with the EYG Board to share the latest updates and exchange inputs and ideas to carry on with our current project in the most efficient way as possible. The frequency of these regular check ups has even been upgraded to one every two weeks during the COVID-19 lockdown, from March to July 2020, in order to accelerate our exchanges during this very sensitive period.

Since such regular meetings are often limited in time, the Youth Group board also organised a half-a-day meeting on the 16 January to exchange deeper on the ongoing Education survey and determine the full roadmap of the project.

List of members as of 2020

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

OSPs 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

MACC - www.cukuk.me

Netherlands

CCUVN - www.crohn-colitis.nl

New Zealand

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

Norway

LMF - www.lmf norge.no

Poland

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

Portugal

APDI - www.apdi.org.pt

Romania

ASPIIR - www.aspiir.ro

Serbia

UKUKS - www.ukuks.org

Slovakia

SCC - www.crohclub.sk

Slovenia

SAIBD - www.kvcb.si

Spain

ACCU - www.accuesp.com

Sweden

MOT - www.magotarm.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

Associated members

Argentina

Mas Vida - www.masvida.org

Brazil

DII Brasil
www.facebook.com/diibrasil

Kazakhstan

FPVZK - www.vzk.kz

Trinidad and Tobago

NACTT - www.crohnsandcolitistt.com

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.





EFCCA

European Federation of Crohn's
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