



WE ARE ALL EFCCA

EFCCA Activity Report 2018

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The European Federation of Crohn's & Ulcerative Colitis Associations (EFCCA) is an umbrella organisation representing 36 national Crohn's and Ulcerative Colitis (collectively known as IBD) patient associations.

We are an organisation of people united in our commitment to improve the life of over 10 million people living with IBD worldwide (3.4 million in Europe alone), to give them a louder voice and more visibility.

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Foreword

The first year of my mandate has come to an end. Since last May in Budapest I had the great honour to represent EFCCA as Chairman and I'm realizing how rich and challenging it has been.

Looking back at the past 12 months I'm so pleased to share that I saw a strong and vital association growing and getting more and more visible worldwide.

Our reputation is increasing while our international networking is clearly demonstrating our capacity in being a trustworthy interlocutor with all our stakeholders, health care providers and medical societies included.

The EFCCA Board and Secretariat have been of paramount importance in developing our activities while the Strategic Plan that will be presented in Prague will show the value of working in a team and sharing common objectives.

Our brainstorming sessions, as well as the meetings we organized with some of our members are reinforcing our assumption that united we can really make the difference for the IBD community.

We discussed, shared ideas and inspiring practices and I'm sure that our attitude of learning from each other will give new impetus to our future plans. In this activity report you will see how our activities have been implemented and we decided to present them in a structure that offers you an easier reading of connections between our work packages.

Awareness raising, networking, advocacy and empowerment will also be the backbone of our Strategy Plan and I'm sure we will become more familiar with them as we implement our Strategy Plan in the coming years.

Among the many projects we developed I'd like to highlight a couple of them since I believe that they represent true milestones on the road to our future.



Salvo Leone EFCCA Chairman

The Symposium on Research funded/supported by Patient Organisations was a great success and we are planning a similar event in 2020 that I hope we will be able to share very soon.

The pilot session of the EFCCA Academy, the involvement of our patient experts, the high level of the speakers substantiated our belief that ad hoc education and training for IBD patient is crucial to empower our people and make them able to claim for rights both at national and international level.

Last but not least I was proud to welcome four observer members at our last General Assembly in Bucharest: listening to their presentations, talking to them and sharing some good time together gave me even more energy and a deeper confidence that we are moving in the right direction. For EFCCA 2018 has been an important year in speaking out for our community and for being at the frontline in defending IBD patients' rights and unmet needs.

A year full of successes and challenges, a further step towards a stronger EFCCA where everyone is taken care of and everyone has its own leading, equal role. We are all EFCCA and we, together, will make the changes that are necessary to bring about a better future for people with IBD.

I hope you enjoy reading the report and look forward to welcoming you all in Prague.

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

IBD Day. The purple ribbon is the universal symbol of awareness and support for people living with IBD.

World IBD Day for EFCCA and our patient associations is an excellent tool to gain visibility and to engage our supporters, be it volunteers, family members and friends or more institutional such as health care providers, pharmaceutical industries and policy makers.

Many of our member associations have been able to reach out to the public and become more visible through media (television, radio, printed press), social media and public acts. Through the illumination campaign, associations have also come in contact with municipal and regional authorities opening up

ways for institutional visibility and potential for further collaboration.

World IBD Day also allows us to reach out to countries where there is no formal representation for patients with IBD. One of EFCCA's missions is to assist in establishing new associations in countries where they do not yet exist. Since we have started to celebrate World IBD Day we have been able to get in contact with groups of patients, physicians and other stakeholders from countries where there are no formal representations of patient associations and to support them in their efforts to improve the lives of people with IBD in their respective countries.

International Symposium on Research funded or promoted by IBD patient associations

EFCCA organized its second research Symposium on IBD Research in Bucharest, Romania on May 28. It brought together over 80 patient group representatives from five continents, gastroenterologists and other healthcare providers and relevant stakeholders providing an excellent platform for patient associations to raise awareness of patients' needs, priorities and roles as concerns IBD research.

The Symposium generated good discussions between patient associations and the scientific community. It laid the grounds for an information model that lets each patient association, individual and researcher know what topics are being investigated and to develop co-operations and better research strategies.

The Symposium was opened by EFCCA's former Chairman Martin Kojinkov and Professor Mircea Diculescu, a founder member of Romanian Crohn's and Colitis Club and member of ECCO's strategic

board, who emphasized the role of teams in medicine. After the opening speeches, Professor Claudio Fiocchi from the Cleveland Clinic Foundation - Lerner Research Institute gave an interesting keynote speech.

He highlighted the importance of patient participation in IBD research and pointed out that no matter how hard the medical community works to try to understand the disease as much as possible, patients bring a whole different perspective as they see things



The floor was then given to patient associations to present their research projects. The presentations were divided into three clusters that each focused on a specific topic around IBD.

The clusters were moderated by internationally renowned experts - Professor Ron Shaoul from Israel representing the European Society for Paediatric Gastroenterology, Hepatology and Nutrition (ESPGHAN), Professor Adrian Saftoiu from Romania representing the United European Gastroenterology (UEG), and Professor Gerhard Rogler from Switzerland representing the European Crohn's and Colitis Organisation (ECCO) - and included also time for discussion and questions from the audience.

The first cluster titled "New challenges beyond originators and biosimilars" focused on biologics and biosimilars, a hot topic within the IBD field for several years already, and included topics such as costs of biologics and biosimilars, patients' quality of life and vaccinations for persons treated with immunomodulators.

The second cluster, "Patients' priorities and unmet needs in research" focused on the research priorities of people living with IBD which may not be the same as those of physicians and scientists and touched on issues such as post-traumatic stress, IBD



epidemiology, patient education program efficacy and dietary factors. The third cluster, “Patient-centered research and clinical trials: what do patients need?” highlighted the fact that the patient needs to be at the focus of research, and research needs to be relevant to the patient; it included topics such as the impact of IBD on quality of life and employment, hospital audits and self-managing symptoms via an online program.

The Symposium was closed by Dr. Joana Torres from the Gastroenterology Department at Hospital Beatriz Ângelo in Loures, Portugal, who spoke about paving the way for future scenarios by explaining ideas of prediction and prevention of IBD, IBD in early life, and

finally, presenting a survey on the phenotypic features of IBD in couples with IBD and their offspring. Dr. Torres stressed the importance of understanding the pre-clinical stages of IBD; this might help to predict and prevent IBD development.

The most important take-home message for the Symposium participants, brought up in almost every speech, was the importance of patient involvement in research.

Team work is needed to find the answers in IBD research, and patients must be a part of the team, as they see things from a perspective that the scientific community might not always think about.

IBD and parenthood

Video animation series

Since 2016 EFCCA is involved in an exciting project aimed at helping people to “live well” with IBD. We are developing a series of animation videos that will equip people with practical advice and relevant information and hopefully will bring about positive changes to the way they cope with their disease.

In 2018 we have focused on raising awareness around the subject of IBD and parenthood as well as IBD and fatigue. As part of this process, we have organized a Focus Group meeting which took place on 4 October

at the EFCCA office in Brussels. Participants included four “IBD mums” as well as a specialist IBD nurse, health care professionals and representatives from a video animation company.

We had an excellent discussion with useful insights addressing all relevant issues related to parenthood and IBD as well as IBD and fatigue. The animation company is now developing the storyboard and visuals for the animation, and the final video will be available in the second half of 2019.



Survey on “The phenotypic features of couples with IBD and their offspring”

Given the fact that IBD increasingly affects young people especially during the child bearing years EFCCA strongly supports 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.

There is only scarce literature about the risk of children whose parents both have IBD in developing the disease. Small studies carried out in 2001 have suggested that children of couples where both parents are affected by IBD represent the first-degree relatives with the highest risk of developing IBD. However, these estimates were based on small studies conducted in high risk populations for developing IBD.

This new survey aims to better characterize the subgroup 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.

UC Narrative - a global survey on adults living with ulcerative colitis (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.

Key findings were released around World IBD Day 2018. In the words of our CEO, “The UC Narrative survey gives us important new perspectives that build on previous research about the quality of life impacts of UC. One of these is the fact that it shows people living with UC that they are not alone. There are thousands of others having the same experiences, looking for resources and support. People living with UC must be empowered to speak up and encouraged to find help and hope.”

In 2019, the UC Narrative initiative will expand to even more countries, adding to the wealth of existing local and global data about the impact of UC.

The UC Narrative Global Advisory Panel will continue to work together to turn insights from the UC Narrative survey into relevant solutions or programs that can help make a difference in the lives of people living with UC.

The UC Narrative has been supported by the pharmaceutical company Pfizer.



Congresses and events

The EFCCA Secretariat and Board have participated in several Congresses, events and round table discussions in order to raise awareness about IBD:

Gastroenterologist European Expert Masterclass

This two-day meeting took place in Berlin (23-24 November 2018) and gathered over 120 European gastroenterologists to discuss Ulcerative Colitis management and new treatments. The meeting was chaired by representatives from the European Crohn's and Colitis Organisation (ECCO) namely Julian Panes, Alessandro Armuzzi and Silvio Danese. EFCCA CEO, Luisa Avedano, participated in panel discussion facilitated by Prof. Ailsa Hart (London

North West University Healthcare NHS Trust) in order to present the patient perspective.

Symposium "Working together to improve the quality of patient care in IBD"

This satellite Symposium during UEG Week 2018 offered insights into IBD management and treatment options. Our CEO Luisa Avedano together with another patient representative from Canada presented the patient perspective of the findings of the UC Narrative survey that looked at several aspects of living with



UC, including day-to-day disease impact, disease management, goal setting, and communication (see above).

Symposium on “Delivering precision medicine and patient-centred care through a multidisciplinary approach”

Our CEO Luisa Avedano was invited to present the patient perspective at a satellite Symposium organized in parallel to the ECCO Congress 2018 (14-17 February 2018, Vienna). The round table discussions included ECCO physicians such as Claudio Fiocchi, Antonino Spinelli, Krisztina Gecse and Frank Behrens. Presenters agreed on the importance of the approach of a multi-disciplinary team to provide optimal IBD care.

Internal Takeda meeting

EFCCA Vice President and Honorary Secretary, Ciara Drohan, participated in a Takeda Internal meeting that took place before the ECCO Congress alongside an Austrian patient. The purpose of the meeting was to educate employees on a patient's perspective of living with perianal Crohn's disease and how patients' quality of life and life in general is affected. It was a great opportunity for a patient to explain what life is like and also for an EFCCA board member to explain how similar and yet different life can be for patients across Europe.



Networking

One of the main objectives of EFCCA is to encourage and facilitate collaboration with a wide range of stakeholders and to exchange information, knowledge and good practices through the promotion of international activities. In 2018, we have continued to strengthen strategic synergies and develop existing and new partnerships that are beneficial for all.

Medical congresses

EFCCA's participation in medical congresses and meetings is an important opportunity to network, connect with stakeholders and share knowledge with physicians and other healthcare providers as well as to learn about the latest developments, research and state-of-the art clinical practice.

The Congresses allow us to strengthen our relationships and to develop common projects with the physicians and other interested stakeholders. They also give us a chance to meet up with potential sponsors and discuss collaboration on common objectives. The EFCCA staff attended the following congresses in 2018:

- **UEG WEEK**, 21-24 October 2018, Vienna, Austria. On that occasion we also organised a networking dinner with representatives from the Slovenian and French IBD associations.
- **ESPGHAN Congress**, 9-12 May 2018, Geneva, Switzerland. This is the first time that EFCCA was represented by our Deputy Director, Isabella Haaf at the ESPGHAN Congress. The European Society for Paediatric Gastroenterology Hepatology and Nutrition (ESPGHAN) is a multi-professional organisation whose aim is to promote the health of children with special attention to the gastrointestinal tract, liver and



nutritional status. There are a lot of common grounds for our collaboration with ESPGHAN in particular as concerns the exchange of knowledge, dissemination of science-based information and the promotion of best practices in paediatric gastroenterology involving the patient perspective.

- **ECCO Congress**, 14-17 February, 2018, Vienna, Austria. For the second year EFCCA organised a networking dinner with EFCCA members who also attended the congress including representatives from France, UK, the Netherlands, Slovenia, Israel, Poland, Austria and Italy.

Regional network - EFCCA members

As previously reported, EFCCA has put its efforts into reinforcing our role of facilitators in the exchange of information and projects among our members, and as a direct outcome, a regional networking meeting was hosted by AMICI Italy on 23-24 February 2018 involving AMICI, ACCU España (Spain) and APDI (Portugal). The meeting served to explore and discuss the management of national organisations where the need to be present in every region requires a long-term strategy and a clear idea of the deliverables.

On 29 September EFCCA Chairman and CEO were invited to attend the three countries seminar on “doctor-patient relationship” hosted by our German member DCCV e.V. with the involvement of our Swiss and

Austrian colleagues (SMCCV and OMCCV). Over 200 participants met in Friedrichshafen (Bodensee, Germany) and contributed to its great success. The meeting was an excellent occasion to meet our colleagues and friends, sharing some ongoing activities and projects.

Our Vice President and Honorary Secretary Ciara Drohan participated in the Nordic Meeting (Norway, Sweden, Finland, Iceland and Denmark) that took place from 14-16 September 2018 in Oslo, Norway. Ciara had the chance to meet the patient representatives of six associations and to exchange ideas and information about activities as well as providing the European perspective.

Home Parenteral Nutrition

Home parenteral nutrition - i.e. intravenous feeding administered outside the hospital, either at home or in a nursing home - may improve patients' quality of life and support their ability to perform daily activities. For instance, home parenteral nutrition may allow patients with chronic or acute diseases to manage their needs for additional nutritional intake outside the hospital. For certain patients, this may mean in practice less pressure to eat in sufficient quantities, ability to perform daily activities, including family life, ability to work, ability to travel and increased independence in daily life.

EFCCA is pleased to be collaborating with the Medical Nutrition International Industry (MNI) by supporting and contributing to the launch of a campaign aimed at informing patients, carers, healthcare professionals, and other stakeholders on the use of home parenteral nutrition.

As part of this collaboration our Board member, Magda Sajak, participated in the Round Table multi

stakeholder meeting on Home Parenteral Nutrition (HPN) organized by MNI, which took place on 22nd October 2018 in Munich, Germany. The aim of the meeting was to share views and experiences on HPN between all stakeholders, to ensure that the initiative will address all questions related to HPN and will be built on real-life situations of patients on home parenteral nutrition. The initiative is designed to be a long-term cooperation and we are looking forward to a mutually beneficial work to improve the lives of people with IBD.

MNI will also soon launch a website dedicated to home parenteral nutrition to unfold more information about it and to share patients' experience on its use, benefits and safety features. Stay tuned!



Advocacy

EFCCA carries out advocacy work with the EU institutions and international organisations such as the WHO to ensure that patients' concerns are included in the decision-making process for policies and other related health initiatives. We do this by generating evidence through surveys and studies allowing us to develop advocacy materials and tools.

The Indirect costs of IBD

This study aims to assess the indirect or *invisible* costs of Crohn's disease and ulcerative colitis, collectively known as Inflammatory Bowel Diseases (IBD). The study has been presented during our previous General Assembly in Warsaw, Poland (2017) and has been launched Europe-wide at the end of 2018. It is conducted by the Polish Association Supporting People with IBD "J-elita" in cooperation with the Institute of Public Health, Jagiellonian University Medical College, and the International Institute of Molecular and Cell Biology in Warsaw under the joint patronage of EFCCA.

We believe the findings of the study will provide patient associations with a powerful tool to discuss

with policy makers on how to improve the situation for people with IBD.

The study will map and compare the level of indirect costs related to IBD and provide evidence to policymakers and stakeholders - using a cost-utitarian approach - to better prioritize effective IBD treatment and support measures aimed at improving the situation for people with IBD in the workplace and labour market.

The report of the survey will be presented at a European Policy event in the second half of 2019, and a detailed analysis will be disseminated by publication in a world-wide research journal.

BAB 2

The BAB2 survey, carried out in the end of 2018, follows up on the original BAB (Biologics and Biosimilars) survey, carried out in 2014-2015 to find out about IBD patients' perspectives regarding biosimilars.

The follow-up survey aims to find out whether patients' perspectives on biosimilars have changed now that biosimilar pharmaceutical products have been longer in the market, more IBD patients have come into contact with them and more awareness on biosimilars has been raised.

The outcomes of the BAB2 survey will give an insight into how patients' perspectives, thoughts and worries regarding biosimilars have changed in the past five years. The outcomes will help EFCCA see whether awareness on biosimilars has been effectively raised among IBD patients, which worries still remain, and what needs of IBD patients are still unmet in the biosimilars field. Such insights help give direction to biosimilar-related initiatives and shape EFCCA's activities in the future.

In addition to raising awareness and educating patients on biosimilars, the BAB2 results can be used in advocating for equal and adequate access to health information as well as shared decision-making between patients and health care personnel.

The BAB2 data is analysed in early 2019, and results will be available later in the year. The research group, led by Professor Laurent Peyrin-Biroulet at the Nancy University in France, is looking to publish an article about the results in a peer-reviewed scientific journal.

Biologics and Biosimilars: Guidance to policymakers

With view to the European Commission stakeholder event on Biosimilars which took place on 14 September 2018 in Brussels, GaBi has published a manuscript titled ***“How to realise the potential of off-patent biologics and biosimilars in Europe”*** which has seen the contribution of multi-stakeholders including EFCCA.

This manuscript aims to provide guidance to policymakers with a view to fostering a fair, competitive and sustainable market for off-patent biologics and biosimilars in Europe. It is the result of a series of round table discussions including representatives from patient groups, clinicians, healthcare professional organizations, government bodies, and industry.

Better IBD care: specialized nurses

EFCCA believes that specialist care for people with IBD promotes the overall wellbeing of the patient. Specialist IBD nurses play an important role in supporting patients and their families to better understand the disease and in introducing and educating about a change in behaviour and lifestyle that can better help disease management.

For this purpose, EFCCA is proudly assisting several nurses to participate in the N-ECCO School which run yearly in parallel to the ECCO Congresses.

In 2018, a total of 62 nurses and dietitians from 24 countries participated in the School with the aim to promote quality of care to patients with IBD. The N-ECCO School (Nurses of the ECCO network) was created to provide educational opportunities for IBD nurses throughout Europe and to increase networking opportunities, to meet and share best practice. The



@ecco

School has been running since 2010 and gives nurses who might still be in training and have an interest in IBD the possibility to attend courses with a main focus on IBD. The EFCCA support allows ECCO to offer a travel bursary to those participants who were unable to raise funding for travel and accommodation (as in some countries, industry sponsorship for nurses is prohibited).

Empowerment

Allowing patients to gain greater control over decisions and actions affecting their health is a prerequisite for better quality of care and supports potential long-term cost-efficiencies. EFCCA promotes the exchange of best practice and capacity building activities such as educational seminars, thematic workshops and policy initiatives in order to support our members in their work and mission at national level.

EFCCA Academy

The EFCCA Academy, the pioneer project born as a result of two patient focus group meetings that looked into tackling the unmet needs of the IBD community, was launched on June 14-17 2018 in Brussels. For three days, the EFCCA office was transformed into a school class, and nine enthusiastic students, all IBD patients willing to learn more about patient advocacy and becoming skilled patient experts, volunteered to be a part of the very first group that will serve as a base for the future classes of EFCCA Academy.

The group learned about public speaking skills, patient advocacy, understanding medical language, patient rights and workability, IBD and nutrition, the importance of early diagnosis in IBD, patient empowerment, traveling with IBD, and looking at IBD from an osteopathic perspective.

They were also taught about the results of EFCCA's patient surveys and how these can be used effectively in patient advocacy work, and finally, the course was closed with an interactive workshop that focused on finding your own strengths for your work as a patient advocate.

As the June meeting was a pilot, the participants gave detailed feedback on each part of the training; this feedback will be used to improve and shape the future training rounds to make the training as efficient as possible.





After the face-to-face meeting in Brussels, the participants have been working on their “homework”, a final assignment in which they are asked to plan a project using the knowledge and skills gained during the course.

The project plans for the participants’ final assignments include important topics and interesting and creative ideas, such as educating expert patients in local hospitals, raising awareness on the fact that also people with invisible illnesses use disabled toilets, and designing an e-learning IBD course.

The EFCCA Academy project has raised a lot of interest all over the world, and EFCCA hopes to be able to offer such patient education weekends for interested and motivated IBD patients on a regular basis in the future.



EFCCA
academy

ECCO Quality Standards of Care Project

After participation in the ECCO consensus meeting on Crohn's Disease treatment Guidelines development (2017), EFCCA representatives have been invited again to participate in the **ECCO Quality Standards of Care Project**.

A group of four EFCCA members participated in a face-to-face meeting with European IBD doctors under ECCO auspices to discuss and vote on the list of criteria in relation to CD standards of care.

In addition, EFCCA also participated in **1st Guideline Methodology and GRADE Workshop** during the ECCO Congress 2019.

The discussion in the panel highlighted patient perspectives of GRADE methodology as well as the need and values of patient involvement.

EPIS - Patient Empowerment The Digital Perspective

EFCCA Chairman and CEO participated in the European Patient Innovation Summit 2018 (15 November, Milan). The Summit involved several representatives of diverse disease areas and was organised in connection with other seven hubs in other EU countries that shared the same agenda and objectives. The main goal of the meeting was

to discuss how digital technologies are transforming the life of patients with chronic diseases and listened to the patients' feedback on this. Luisa Avedano presented the EFCCA perspective on the topics and the important role patient organisations can play concerning data ownership and data collection and analysis. The Summit was organised by Novartis.

Artificial intelligence and Big data

In the last two years, EFCCA has embarked on a new block of activities that are dealing with artificial intelligence and the use of data. EFCCA believes that, given the importance of sharing health data, patient associations have to play a central role when it comes to health data collection in order to be able to ensure patient rights and to have an equal say in the identification of priorities and unmet needs as concerns health care and quality of life.

Patients are generally willing to share their information if it can help save lives, but they want to first be made 'owners' of their data. Hence, patients should be able to easily find where their data is being stored and who has access to it. They also need to be better informed about what rights they have. Rules governing data protection need to be transparent and there should be a common agreement between all stakeholders, with clearly defined roles and responsibilities.



Patient Voice meeting from left to right R. Saldaña (ACCU España), L. Avedano EFCCA CEO, S. Leone (AMICI), M. Mawani (Crohn's and Colitis Canada) and J. Eriksson (Magotarm Sweden).

Likewise, systems processing health data need to be transparent and should provide feedback to patients on how and where their data is being used. Finally, sharing success stories of where these goals have already been achieved will be a key step, and can help to further raise awareness around the benefits of digital health.

Within this framework our CEO, Luisa Avedano, has participated in several events dealing with this topic such as the event “More Trust, More Data, Better Health” (Milan, 24 September 2018) and the Health and Artificial Intelligence Summit held in Brussels on 4-5 December 2018 whose main objective was to explore the potential role that clouds and artificial intelligence can play to transform health, improve health outcomes, enable faster diagnosis, empower clinicians and putting patients at the centre of how care pathways are designed.

Furthermore, we have explored a joint initiative, the Patient Voice project, involving EFCCA, our members from Spain, Italy, Sweden and Crohn's and Colitis Canada around the creation of a database on IBD

owned by patients at national level and coordinated by EFCCA at transnational level.

The database would collect two sets of information: the first set is focused on quality of life and the second set on more scientific aspects based on the ICHOM measurement. ICHOM, the International Consortium for Health Outcomes Measurement, is a non-profit organization with the purpose to transform health care systems worldwide by measuring and reporting patient outcomes in a standardized way.

An important component for EFCCA is that patient associations will have the ownership of the data collection allowing them to make use of the data to analyse many aspects of living with IBD, such as the effects of a given treatment or the impact of the disease on the patient's daily life. It is foreseen that the tool will enable associations to play a stronger advocacy role with national policy makers, healthcare providers, professionals and scientists.

Horizon 2020

EFCCA has been involved in two project applications under the European Commission's Horizon 2020 programme. Horizon 2020 is the biggest EU Research and Innovation programme ever with nearly €80 billions of funding available over 7 years (2014 to 2020) - in addition to the private investment that this money will attract. It promises more breakthroughs, discoveries and world-firsts by taking great ideas from the lab to the market. We will know in the course of 2019 whether our applications have been successful. So far, one of the project proposals has been shortlisted.

EU Innovative Medicine Initiatives call on “Digital Endpoints in Neurodegenerative Diseases and Immune-mediated Diseases”

This proposal is being led by the Newcastle University, UK. The ultimate goal of this grant call is to identify digital endpoints that provide reliable, objective and sensitive evaluation of activities of daily living (ADL)/disability/Health-related quality of life (HRQoL) in Neurodegenerative Diseases (NGD, e.g. Parkinson's disease (PD), Huntington's disease) and Immune-Mediated Inflammatory Diseases (IMID) (e.g. IBD, RA, lupus, etc.).

There is strong evidence to support the idea that chronic disabling fatigue is not only highly prevalent but a key factor that predicts loss of work productivity in both NGD and IMIDs including Crohn's disease and Ulcerative Colitis. Sleep disturbance is another common complaint suffered by patients with NGD and IMIDs and significantly affect their ADL.

The proposal aims to identify reliable digital correlates of fatigue and sleep disturbances that are sensitive to change and therefore potentially be used to objectively evaluate efficacy of therapeutic interventions, building on the university's current programme of research which includes a longitudinal study of “digital” profiling of fatigued and non-fatigued Sjogren's syndrome patients using different digital devices.

UC-Dat EU Fast Track for Innovation project “A Fast and Simple Blood-based IVD test for Disease Monitoring and Relapse Prediction in Ulcerative Colitis”

This project that was submitted to the European Commission in May 2018. After its rejection it was re-submitted in February 2019. The UC-Dat project is about an innovative blood test aiming at monitoring and hopefully predicting relapse in Ulcerative Colitis.

The project is based on the idea that there is an urgent clinical need for a single diagnostic test based on minimally invasive procedures for frequent monitoring of UC disease activity. This need has been confirmed in the European Crohn's and Colitis Organisation (ECCO) consensus statements.

Up to date, in fact, the number of tests required to monitor UC cost time and money and do not always provide conclusive answers, while frequent endoscopy and imaging are a huge burden for patients.

If successful, the ultimate goal of the project is to offer a tool that could replace the set of expensive, time-consuming and uncomfortable clinical examinations that are performed nowadays.

EFCCA Annual General Meeting 2018

The 29th Annual General Meeting (AGM) of EFCCA took place in Bucharest, Romania from 25-26 May 2018. It was hosted by ASPPIR, the Romanian IBD association, and brought together over 60 delegates from 32 patient associations as well as observers from patient associations from Brazil, Kazakhstan and Montenegro showing the increasing importance of a more global perspective and a need for a worldwide representation of the IBD community.



The Crohn's and Colitis Association of Lithuania (CCAL) was welcomed as new member to the EFCCA network bringing our total membership to 36 patient associations.

The AGM programme included the usual statutory reports and activity updates and elections to the EFCCA board. The elections saw Salvo Leone, Director of the IBD association AMICI, as new EFCCA chairman with Ciara Drohan taking the role of Vice President and Honorary Secretary and Marko Perovic the role of Treasurer. More information about the newly elected Executive Board can be found below.

The second day was dedicated to specific project presentations such as the EFCCA Academy including its pilot phase report and overview of the planned next steps, the EU mapping project and the follow-up idea of establishing a permanent observatory of the latest

medicines available in the EFCCA member countries and finally a brief presentation of the BAB2 survey which has been planned a follow up to the BAB survey (Biologics and Biosimilars 2014) to see the evolution of patients perspectives on biosimilars now that they are widely used worldwide.



It was a memorable meeting with many new faces providing for interesting discussions and useful exchange of experiences and practice as well as an opportunity to talk about common objectives and projects.

The GA was followed by the International Symposium on Research which took place the day after, on 27 May 2018 (see page 5).



Salvo Leone (middle) welcoming Gediminas Smailys (right) from the Crohn's and Colitis Association of Lithuania (CCAL) as new EFCCA member

Executive Board Meeting

The Executive Board following elections at the 29th EFCCA Annual General Meeting in Budapest 26 May 2018 consists of the following members: Ciara Drohan, Vice President and Honorary Secretary (Ireland), Salvo Leone, Chairman (Italy), Marko Perovic, Treasurer (Serbia), Magda Sajak (Poland), Natassa Theodosiou (Cyprus) and Lucie Lastikova (provisional leader of EFCCA Youth Group, later replaced by Leanne Dowie).

board started discussions on the elaboration of a new strategy for EFCCA.

- **Face to Face Executive Board meeting - 11/13 January 2019** The Executive board met at the beginning of 2019 at the EFCCA office in Brussels in order to finalize board discussions on the elaboration of a new strategy for EFCCA.

The following meetings took place in 2018-2019:

- **On-line Executive Board meeting - 20 June 2018**
The new EFCCA board held an online board meeting to discuss feedback from the General Assembly, Symposium on Research and the EFCCA Academy. The board also discussed EFCCA's participation in UEG WEEK in October 2018, the agenda and dates for the next face to face board meeting staff matters as well as an update on several projects in pipeline.
- **Face to Face Executive Board meeting - 16/18 November** EFCCA organised a face to face board meeting which took place in the EFCCA office in Brussels. Apart from some operational issues, the



EFCCA Youth GROUP

The Annual Youth Meeting of the EFCCA Youth Group took place in Reykjavik, Iceland from 28-29 July 2018. 18 countries from across Europe joined the meeting for an actioned-packed weekend which was filled with learning, collaboration and exploring.

32 representatives between the ages of 18 and 30 years met with the aim to share and collect ideas to help sufferers deal with their disease. Additionally, the EFCCA youth group wanted to raise more awareness in the delegates' respective countries, so it was a good opportunity to learn best practices.

The interim leader of the European Youth Group at that time Lucie Laštíková (Czech Republic) welcomed participants and gave a short introduction of what to expect from the trip. The next day, this was followed by a welcome and "get-to-know" session. Afterwards, delegates from different countries had the opportunity to present the latest achievements of their home associations regarding their youth work.

In the evening, there was a workshop with the Icelandic psychologist Eygló Guðmundsdóttir, who talked about how to raise awareness about mental wellness and giving some advice on how our own mental health can be improved by using breathing and relaxation techniques. This was followed by a treasure hunt through Reykjavik, to get to know each other and the cultural aspect of Iceland a bit better.

The next morning, youth group presentations from delegates continued. With the aim to strengthen the EFCCA Youth Group, the board arranged several workshops on how to get delegates more involved, in addition to carrying out a SWOT analysis of the current situation. The active group work was especially impactful as it not only gave us an insight into the work of other youth groups but also into the general health systems in different countries.

At the end of that work session there was the yearly voting for the new Youth Group members which resulted as follows:



Henna-Maria Räisänen (Finland), Katleen Franc (Belgium), Leanne Downie (England), Nathalie Schwarz (Germany), Martin Mastrotto (France), Natalia Mandakova (Slovakia), Olga Golebiewska (Poland), Selina Huber (Germany) and Simo Natunen (Finland). Bastien Corsat from France became the new EFCCA Youth Group Leader.

The group decided to continue breaking down taboos for young people and their conditions. They decided to share articles on these topics in future magazines including a top tips section on mental wellness taking the learnings from the workshop in Iceland.

Towards the end of 2018, the EFCCA board was informed that Bastien Corsat, the new Youth Leader could no longer stay in his role as leader for personal reasons. Board member Leanne Downie was then appointed as the new leader. Previous to the EYM Meeting and afterwards the EFCCA board has been in touch regularly with the EYG board to assist with their current challenges due to three changes of the group leader within one year.

List of members as of 2018

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.crohnjacolitis.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

Luxembourg

ALMC

www.afa.asso.fr/luxembourg

Lithuania

CCLA - www.draugija.info

Malta

MACC - www.macc.org.mt

Netherlands

CCUVN - www.crohn-colitis.nl

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.crohnclub.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.ar

New Zealand

Crohn's and Colitis

www.crohnsandcolitis.org.nz

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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