



Empowering people



EFCCA Annual Activity Report 2017

World IBD Day celebrations, Croatia

The European Federation of Crohn's & Ulcerative Colitis Associations (EFCCA) is an umbrella organisation representing 34 national patient associations. EFCCA strives to improve life for people with IBD and give them a louder voice and higher visibility across Europe.

EFCCA's main objective is to improve the well-being of people of all ages, diagnosed with Inflammatory Bowel Disease (IBD) by:

Networking

We encourage and facilitate the exchange of information and the promotion of international activities. We collaborate with other umbrella associations such as the European Crohn's and Colitis Organisation (ECCO) representing the IBD medical profession, the United European Gastroenterologists Federation (UEGF), the European Society for Paediatric Gastroenterology Hepatology and Nutrition (ESPGHAN), the European Patients' Forum (EPF), and many other networks and organisations working in the health related field.

Awareness raising

Through World IBD Day and other initiatives we want to raise awareness about IBD as there is still little public understanding of the pain and chronic suffering with which IBD patients courageously cope every day of their lives.

Advocacy

We carry 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.

Empowerment

Through the exchange of best practice and capacity building activities such as educational seminars, thematic workshops and policy initiatives we support our members in their work and mission at national level.

Solidarity

We assist in the establishment of new associations in countries where they do not yet exist offering our support and advice. Through World IBD Day and other activities and events we bring the IBD community together in our common fight against IBD.

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Foreword

2017 has been another busy and important year for EFCCA. We have developed and implemented a wide range of activities and far-reaching projects that have allowed us to be closer to our membership base and to strengthen our cooperation with other stakeholders.

One example is the project “Mapping of innovative medicines and devices in EFCCA Member Countries”. The aim of this project was to highlight existing health inequalities in Europe in terms of access to and availability of latest IBD medicines and devices and to support our EFCCA mission on IBD Advocacy. This important piece of work couldn't have been done without the active involvement of our 32 patient associations who provided the necessary information cross checking it with their relevant national authorities and HCPs.

The results of the project will add to our exchange of knowledge and give us a better understanding of European healthcare systems. The fact sheets for each country are a handy resource for someone considering working or studying in another country.

But, most importantly, the project will allow us to more efficiently advocate at national and European level and to facilitate and accelerate equal access to treatment in all countries thus improving not only the quality of care but also the quality of life for people living with IBD.

In parallel to the Mapping project we have been developing another interesting pioneer project called the EFCCA Academy that falls within our work related to patient empowerment. The idea for the EFCCA Academy was born following brainstorming sessions between patients and doctors that looked at potential future activities to address unmet needs of the IBD community as identified in several surveys i.e. the EFCCA IMAPCT study, etc..

The EFCCA Academy will train Certified Patients to raise awareness on IBD and to better advocate at national level, in particular when dealing with policy makers and public authorities. Certified Patients will be trained in public speaking, communication skills and in specific strategic topics.

We are excited to see this pilot phase kick off in June 2018 and we hope to then, in the second phase, train people who are qualified to train Certified Patients in their own communities.

World IBD Day, on 19 May, is of course, one of our most memorable activity in the year. It's the day when we show our solidarity with the 10 million people worldwide that are living with IBD.

We have been amazed at the enthusiasm and efforts our members have undertaken to mark this day, and we are pleased to have seen so many new organisations, people with IBD, families and other supporters joining our global campaign. It has shown us that we are a reference point for the IBD community worldwide and that we can make our voice even stronger.

In terms of networking we have decided to reinforce our role of facilitators in the exchange of information and projects among our members. We have been involved in “regional” meetings where we gathered a small group of EFCCA members to exchange ideas and share best practice.

We believe that amongst our group we have a huge potential of inspiring practices, powerful human capital and specialized knowledge. We want to promote such exchanges and transform our potentials into concrete actions and shared projects.

So looking back at the year 2017, we have seen when EFCCA is at its best....!
When we work closely together with our members. When we talk to each other, brainstorm, gather ideas for common projects, that's when we see our strength. We all share a commitment to serve people living with IBD and to do our best to improve their quality of life. That's what brings us together and makes us who we are.

United We Stand



Martin Kojinkov, EFCCA Chairman



Luisa Avedano, EFCCA CEO

Calendar of activities - 2017

JANUARY

EFCCA Executive Board meeting, 18 January and 11 January, online

Publication of the article “Patient Perspectives on Biosimilars: A Survey by the European Federation of Crohn’s and Ulcerative Colitis Associations in the Journal of Crohn’s and Colitis Vol 11

Voice to Patients meeting, 24-25 January, Amsterdam (the Netherlands)

Advisory Board on Intestine Failure and Short Bowel Syndrome Atlas programme - 28 January, Zurich

FEBRUARY

Biogen Biosimilars Advisory Board, Zurich 21 Feb 17

Launch of the 29 translations of ECCO-EFCCA Guidelines, Barcelona, February 16

ECCO Congress, 15-18 February, Barcelona (Spain)

Publication of EFCCA Magazine – issue 1

Patient Advisory Board on Biosimilars, Rome 7 February (Pfizer)

EFCCA participation in ACCU Executive Board meeting, 4 February, Madrid (Spain)

MARCH

Focus Group meeting - EFCCA Academy, 27 March, Berlin (Germany)

Meeting with new leadership of AMICI, 25 March, Milan (Italy)

Biosimilars Patient Advocacy Group Consultation Multistakeholders Meeting, 13 March, Brussels (Belgium)

Youth Group Meeting, 11-12 March, Brussels (Belgium)

Biosimilars Roundtable – Brussels, 8 March c/o FIPRA
Publication of Interim Report Mapping project

MEP’s Interest group «European Patients’ Rights and Cross-Border Healthcare», 1 March, European Parliament

Publication of Interim Report Mapping project

Launch of new World IBD Day website

APRIL

Focus Group meeting – EFCCA Academy, 27 April, Berlin (Germany)

UC University project meeting, 25 April, Amsterdam (the Netherlands)

European Patient Forum, General Assembly, 10-11 April, Brussels (Belgium)

EFCCA Executive Board meeting, 5 April, online

MAY

EFCCA AGM, 26-28 May, Warsaw (Poland)

EFCCA Board meeting 25 May, Warsaw, (Poland)

Stronger Together Against RA Patient Advocacy Summit, 24 May, Rome (Italy)

World IBD Day, 19 May, EFCCA Chairman in Prague, EFCCA CEO in Bologna

Biologics and Biosimilars: Regional Patient Advocacy Workshop, 4-5 May, Munich (Germany)

‘The Future of Sustainable Healthcare’ event, 2 May, European Parliament, Brussels (Belgium)

Publication of EFCCA Magazine – issue 2

JUNE

EFCCA Board Meeting, 30 June – 1 July, Brussels (Belgium)

Conference on medical nutrition and prevention, EPF and EGAN, 29 June, Brussels (Belgium)

ChangeMakers Steering Committee on patient involvement on clinical trials, 26-27 June, Geneva (Switzerland)

International Alliance of Patients’ Organizations (IAPO) 7 SCA workshop on incontinence, 22 June, Brussels (Belgium)

FIPRA (Foresight International Policy and Regulatory Advisers)/Mircrosoft EMEA meeting, 16 June, Brussels, (Belgium)

Advisory Board on Intestine Failure and Short Bowel Syndrome, ATLAS programme, 9-10 June, Zurich (Switzerland)

UC Narrative Focus Group meeting, 7-8 June, Paris (France)

Conference on health data, EFPIA (European Federation of Pharmaceutical Industries and Associations), 7 June, Brussels (Belgium)

JULY

European Youth Meeting, 27 to 30 July, Paris (France)

Patient Leader Advisory Council meeting, 6 July, Brussels (Belgium)

AUGUST

Office closed

SEPTEMBER

European Society for Medical Oncology Conference, 9/10 September, Madrid (Spain)

Biologics and Biosimilars: Regional Patient Advocacy Workshop, September 15-16, Warsaw, (Poland)

OCTOBER

UEGWEEK, 28 October – 1 November, Barcelona (Spain)

ESPGHAN Patient and Parents Day, meeting, 26 October, Barcelona (Spain)

EFPIA-Patient Think Tank meeting, 27 October, Brussels (Belgium)

European Patient Forum: PRO-STEP Final conference, 23-24 October, Brussels (Belgium)

Celgene ChangeMakers Goals on Clinical Trials, 19-20 October, Boudry (Switzerland)

Economics versus Health: EU Proportionality Test for Health Professions, 18 of October, European Parliament, Brussels (Belgium)

EULAR conference, “The future of health research and innovation after Horizon 2020. Do we need a novel approach?”, 17 October, Brussels (Belgium)

Interest Group on Rheumatic and Musculoskeletal Diseases, 11 October, European Parliament, Brussels (Belgium)

Publication of EFCCA Magazine issue 3

NOVEMBER

“Patient – Doctor Relations” APDI Congress, 25 November, Oporto (Portugal)

Biologics and Biosimilars: Regional Patient Advocacy Workshop, 10-11 November, Rome (Italy)

“More Trust, More Data, Better Health, How does Europe grasp the innovation opportunity?”, 7 November, European Parliament, Brussels (Belgium)

European Parliament Interest Group on innovation in health and social care, 27 November, European Parliament, Brussels (Belgium)

DECEMBER

EFPO Meeting, 11-12 December, Paris (France)

Patient Voice project, Steering Group meeting 6-7 December, Brussels (Belgium)

EPF Access Campaign Meeting in European Parliament, 6 December, Brussels (Belgium)

Joint Patient - Cross Healthcare Industry Meeting, 5 December, Brussels (Belgium)

EPF Cross-Border Healthcare Roundtable, 4 December, Brussels (Belgium)

EFCCA Executive Board meeting, 1-2 December, Brussels (Belgium)

ADVOCACY

Patient Safety: Advocacy workshops

Within the framework of our patient safety campaign that EFCCA started in 2014 with the launch of the BAB survey followed by the European Parliament Patient Safety conference in 2016, we have come a long way from participating in the crucial political and social debate on biologic and biosimilar treatments.

As a follow up to the European Parliament conference it was decided to gather patients within a regional context to consider local policy questions around the use of biologic and biosimilar medicines and to ensure that the patient voice informs policy decisions.

As a result in 2017 we organized together with the Global Alliance for Patient Access (GAfPA) a set of three regional Patient Advocacy Workshops which took place in Munich from 5-6 May 2017, Warsaw 15-16 September 2017 and Rome 10-11 November 2017 in order to share experiences and local best practices.

The regional workshops gathered over 50 patients from within the EFCCA network but also representatives from other immune modulated disease groups from 25 countries. Participants discussed issues that impact on the access to biologic and biosimilar treatments and identified priorities

Group photo following the Patient Advocacy Workshop in Rome (Italy), 10-11 November 2017





Round table discussions during the Patient Advocacy Workshop in Warsaw (Poland), 15-16 September 2017

to be brought to policymakers in Europe and at national level.

The workshop reports are available on our website at: www.efcca.org

From the discussions it became clear that overall access to biologics still varies widely across Europe with very poor access in some countries. Patients agreed the importance of working together, along with physicians and health care professionals to increase their share of voice when talking to policy makers. It also emerged that protecting the physician-patient relationship was crucial, to ensure that patients are confident their physicians are making decisions based on medical and not financial reasons.

The workshops provided participants with useful insights and offered concrete and inspiring information on how to influence policy making to reflect the concerns of the IBD patient community. One clear message was that, while equal patient access to medicines across Europe is a priority, patient safety is an equal political and societal priority.

Mapping access to new medicines in EFCCA member countries

Project objective

National health systems and access to various treatments tend to be unequal in different European and non-European countries with representation in EFCCA, in particular when dealing with new/innovative IBD treatments and devices. In some of these countries, there are no national registries of IBD patients available that would assist in obtaining information about IBD patients.

This project aimed to reduce health inequalities in Europe by carrying out a thorough mapping of all innovative treatments and devices (biologics, biosimilars, apheresis) available in EFCCA member countries.

Methodology

A working group was formed from EFCCA members and consisted of Sanna Lönnfors, EFCCA's Research and Project Coordinator, as well as Marc Derieppe from Afa (France), Alejandro Samhan Arias ACCU España (Spain), and Marko Perovic, UKUKS (Serbia).

The working group designed the online questionnaire and it was tested by seven national IBD associations (Finland, France, New Zealand, Poland, Serbia, Slovenia and Spain) that participated in the pilot phase from October to December in 2016.

After the pilot phase, the questionnaire was optimized based on the feedback given, and it was followed by a second phase in 2017 in which data was collected from all other member associations of EFCCA. All in all, thirty-two national associations participated in the survey.

Outcomes

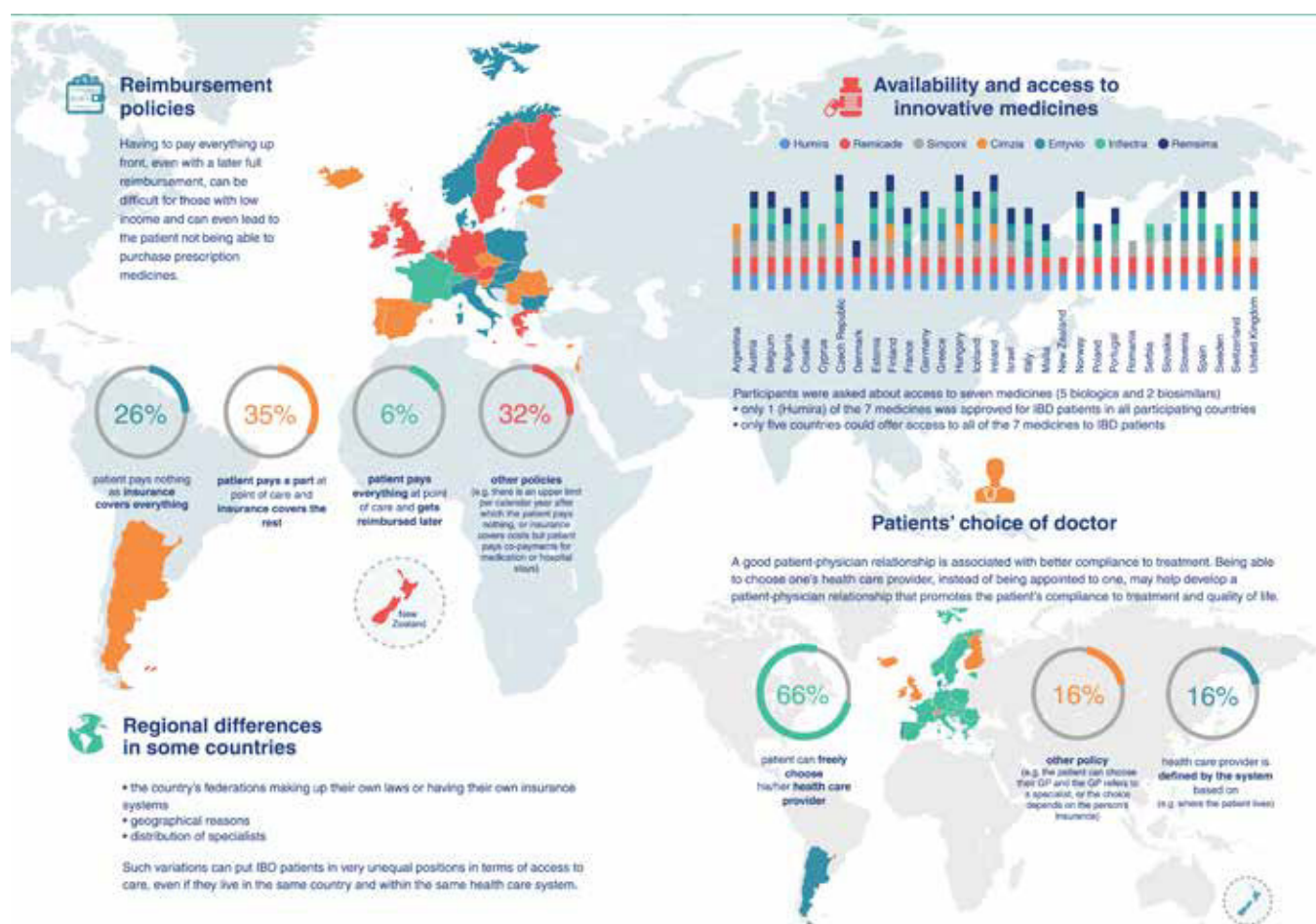
The availability and source of a precise number of IBD patients or prevalence of IBD varied greatly in the participating countries, as did access to biologic and biosimilar medicines.

IBD patient registries are available in very few EFCCA member countries, and several national associations also reported regional differences in their country. The final outcomes of the project give a detailed, general overview of the situation in EFCCA member countries, including the level of involvement of different payers and the

role of national health authorities.

The findings clearly show discrepancies across Europe in terms of access to and availability of innovative treatments and devices.





The final report as well as a summary leaflet of the project “Mapping of innovative medicines and devices in EFCCA member countries” is available for download from the EFCCA website.

EFCCA and its national member associations will use this data to work with national and European policy makers to stress the importance of equal access to treatment as well as the need of accelerated access to new innovative therapies.

Through the project we have achieved an excellent exchange of knowledge and experience among EFCCA countries which will lead to a better understanding of European healthcare systems and improve the mobility of people with IBD in European countries and facilitate the access to treatment in other countries.

To tackle the issues in the member countries brought up in the survey, EFCCA recommends that national associations use the outcomes of the survey in their work to advocate for faster access to innovative

therapies. Telemedicine and online services should be developed in rural areas and regions where distances are long, and the development of IBD patient registries on national or European level should be encouraged.

To find out the details of the mapping please consult the Final Report that is available on the EFCCA website.

Next steps

While working on the data collection for the project we realised that the issue of innovative medicines is a constantly changing environment EFCCA plans to create an observatory of innovative medicines and devices aimed at keeping information updated and accurate.



EMPOWERMENT

EFCCA Academy

EFCCA's project "From IMPACT to Impactful" aimed at acting on the findings listed in recently published papers, EFCCA's own IMPACT study (2014) and a White Paper by the Boston Consulting Group (2016). Results showed similar findings, underlining the main themes within the unmet needs of the IBD community.

EFCCA reacted to these unmet needs by having patients and doctors brainstorm about potential future activities. The project received an unrestricted educational grant from Takeda and was structured into two workshops that took place in Berlin in March and April 2017.

In the first meeting, a focus group consisting of a group of delegates from EFCCA member associations met to analyze and discuss the findings of the said publications. Key issues were identified, and the group brainstormed about viable solutions.

The idea of training Certified Patients who would be trained in patient advocacy and awareness raising was conceived, and in the second meeting, where the group consisted of both patients and physicians, it was discussed and developed further. By the end of the second meeting, a pioneer project to create an EFCCA Academy that will train Certified Patients to raise awareness on IBD was born.

Certified Patients will be trained in public speaking, communication skills and in strategic topics, such as life management with IBD, patient rights, work discrimination and labor rights, and to effectively

use their own patient experiences and the outcomes of EFCCA surveys.

The EFCCA Academy will train Certified Patients first in the pilot phase in June 2018, and later people who are qualified to train Certified Patients in their own communities.

The EFCCA Academy will aim to develop partnerships within the IBD caregiver community, for example ECCO, UEG, ESPGHAN, EMA, etc. Cooperation could include developing topics covering guidelines – basics, nutrition, medications, communication with patients (adult/pediatric), how to deal with the health care system, how to deliver patient community's message to pharma companies and how to handle pharma representatives, how to convey the message that IBD is an invisible illness etc.

The pilot course will aim at offering participants the following workshops, among others:

- Public speaking, communication skills and media training
- Work discrimination and labour rights
- Patient rights
- Crash course on medical language
- Main messages of EFCCA surveys
- Life management for IBD patients

In the pilot phase, the Certified Patient training will consist of a weekend face-to-face workshop, after which a final project will be presented by the



Focus Group meeting in Berlin, Germany, which lay the foundations for the EFCCA Academy

students either via EFCCA's online learning platform or potentially in another face-to-face meeting. The pilot phase will be carried out in English. After the training, the pilot students will be asked to give their

feedback in order to improve the curriculum and the execution of the course before the next round, to which members of EFCCA members associations will be eligible to apply.

Patient Voice project

EFCCA has been involved in the first designs of a potentially innovative project named Patient Voice. Some EFCCA members, namely ACCU Spain, AMICI Italy, Mag-och tarm förbundet Sweden and Crohn's and Colitis Canada participated in a first brainstorming session last December 2016.

Patient Voice is a digital tool which aims to proactively involve patient organisations from across the EU and beyond and support them to digitally collect their members' patient reported outcomes in order to engage in evidence-based advocacy.

The tool is based on the ICHOM standard (recently endorsed by OECD) for measuring IBD outcomes which allows individual patients to track their symptoms on a simple website or app on a bi-weekly basis. The website/app generate dashboards that then allow the patients to show graphically the

progression of their symptoms to their healthcare professionals and improve the quality of the doctor-patient conversations.

Takeda developed the prototype and agreed to put the tool for free at disposal of those IBD patient associations that meet the following criteria:

- Ability to set up a robust framework in conformity with applicable laws and regulations in their country for the collection and management of the data.
- Establishment of a governance body in charge of reviewing, analysing and interpreting the collected data in accordance with recognized scientific standards; outcomes of this analysis and interpretation should then be in the public domain and available to all interested parties in a non-profit spirit.

►Willingness to work with patient organisations in other countries for the international comparison and analysis of this data. Such cooperation should be carried out in line with applicable international data privacy laws and regulations.

The role of EFCCA is to technically support national associations and act as an intermediate body that analyses and works on national shared aggregate data on a transnational basis.

In this way the data collected by national patient organisations not only allows the organisation to monitor the outcomes of the IBD patients they represent and tune their local advocacy, but, through EFCCA, common findings, unmet needs can be collected so as to be able to lobby at EU level and design shared strategies when it comes to its training offers and knowledge sharing.

In December 2017 our Swedish member and Crohn's and Colitis Canada shared the outcomes of their pilot experience that showed the great potential and interest of the patient community as well as the importance of patient empowerment in improving outcomes.

UC Narrative survey

EFCCA has been involved in the design of the UC Narrative survey, together with some EFCCA members (France, Spain, Italy, Finland), Australia, Canada, USA and Japan.

The survey, focused on adults living with Ulcerative Colitis, UC patients, aims to partner with the whole community and for this reason, a similar survey addressed to physicians working in the targeted countries was conducted in parallel.

The surveys have been then fielded in each country and a market research firm contacted patients and health professionals by phone.

Some of the findings have been presented to the patient and medical community in Vienna the day

There are still some important issues to be tackled, such as a unique server to host data (at least for the European participants, a series of technical adjustments and the full management of the legal framework on privacy such as the European Union General Data Protection Regulation (GDPR) that will come into full effect in May 2018.

During the past year EFCCA had also the chance to meet officers of DG SANCO and DG Connect who expressed their interest in the implementation model that, if successful could be put at disposal of other patient groups suffering from chronic conditions. Patient Voice, in light of ongoing thinking about focusing on eHealth, could be used as a potential 'case study' to illustrate how the healthcare sector can become more digitalised, with patients at the centre of the system.

The Microsoft Directorate for Health Industry - EMEA has showed its interest in the project that was also presented on the occasion of the Conference "More trust, more data, better health hosted" by MEP Sean Kelly in November 2017.

after the closure of the ECCO Congress and a final set of outcomes will be made available in the coming weeks.

Despite the initial effort that EFCCA, its members and sister organisations put in the preparatory phase of the initiative, some concerns were raised on the way the survey was administered, since patients have been enrolled without involving any patient associations.

Nevertheless, some of results showed that patients' symptoms can have a direct impact on their life choices and we hope that we could all work together to transform the outcomes of the survey(s) into a set of activities that help real-world needs and concerns about living with UC.

AWARENESS

My IBD journey animations

Introduction

EFCCA is involved in a multiannual exciting project aimed at helping people to 'live well' with IBD.

We have been developing a series of animation videos that are destined to equip people with IBD with practical advice and relevant information and hopefully are bringing about positive changes to the way they cope with their disease.

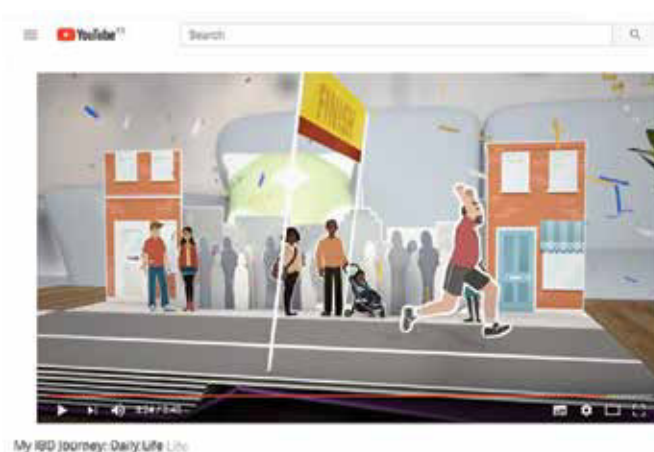
Why did we decide to use animations rather than some other medium? It was because of their accessibility, universality and simplicity of message (language/cultural differences).

The animations are aimed at a diverse population and have been elaborated by a group of IBD patients, animation experts, EFCCA and Janssen.

So far we have launched two animated videos with the third, and last one, being developed at this moment. The content of the two videos 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.

First video animation:

For many people, diagnosis with inflammatory bowel disease (IBD) can be an overwhelming and confusing time - not just for the person with the condition, but also for those who are close to them. Therefore, we wanted to make sure that two



important messages are present in the animation : that being able to move forward following a diagnosis is important, as well as that people need to have the confidence to know that they can live well with their condition.

Consequently, the first animation video “My IBD Journey: life after IBD diagnosis” provides people with some practical advice on steps to take but it also sends a message that people with IBD are not alone.

There are other patients out there going through the same problems and struggles and, support is available, you just need to reach out.

Watch the first video on:

<https://www.youtube.com/watch?v=q7HIwaWWHKU>

Second video animation:

“My IBD Journey: Daily Life” focuses on some of the

common challenges people living with an IBD may face and ways to overcome them. For many people diagnosed with IBD living with the symptoms can have a significant impact on their daily life.

Therefore, in the animation we focused on typical daily activities such as traveling, eating out, socializing and communicating with a new partner or a long-term partner about IBD. The animation also touches upon the topic of work life & education and all of the adjustments that could be made in order to help people with IBD to stay in the workforce or continue their studies and pursue the career that they wish.

One of the objectives of this second animation was also to show how community support can make a world of difference to people living with IBD and can help motivate them to keep pursuing their individual goals, ambitions and aspirations.

The second animated video was presented by Martina Jovic EFCCA Policy Officer, at a satellite event during UEG Week on 28 October, Barcelona.

Watch the video at:

<https://www.youtube.com/watch?v=hyZxuFCbZtU&feature=youtu.be>

Conclusions

The purpose of the animated videos is not only to hopefully help people with IBD with some practical advice, but also to raise awareness amongst the healthcare practitioners and the general public. If this animation helps spread the information, opens



Martina Jovic, EFCCA Policy Officer, presenting the second animation video, 28 October 2017, Barcelona, UEGWEEK

a dialogue and contributes to making life for people with IBD more taboo-free then we will be able to say that we are one step closer to achieving better quality of life of people with IBD.

These videos have been produced by Janssen, in collaboration with the European Federation of Crohn's and Ulcerative Colitis Associations (EFCCA).

Providing the patient perspective

We are very proud that our close cooperation with the United European Gastroenterologists has resulted in some concrete activities, which allowed EFCCA to raise awareness about the perspective and concerns of people living with IBD.

For example during UEG Week, which took place from 28 October – 1 November 2017 in Barcelona

and which was attended by up to 13 000 participants, our CEO, Luisa Avedano, addressed delegates at the closing session of the Congress about patient empowerment and IBD care. The physician's perspective was presented by Pr Subrata Gosh and the session was moderated by Pr Matthieu Allez. This session generated some interesting insights and discussions and showed the importance of patient

involvement in such events allowing stakeholders a better understanding by providing the patients' priorities and unmet needs.

Another occasion to raise awareness about the patient perspective was during the European Society of Medical Oncology (ESMO) Annual conference which took place in Madrid 9-10 September 2017. Our CEO, Luisa Avedano was invited to talk about

the IBD patient community's perception and view on biosimilar medicines. A presentation reporting the outcomes of the BAB survey and the experience of the advocacy seminars on patient safety offered the opportunity of deeper exchange with other patient groups and showed the importance patients have when it comes to data ownership, collection and analysis.

Telling your story

Another great tool for us to raise awareness about the daily challenges that people living with IBD face is through our EFCCA Magazine that is published 3 times a year and that has a readership of around 5000.

In the 2017 issues we have featured many stories that give first hand experience of the efforts that our members and other IBD activists are making in order to raise awareness about IBD and ultimately improve their quality of life of people with IBD. These stories include the successful collaboration between a nurse and an IBD patient in Belgium to spread a positive message to newly diagnosed patients, a Master degree student who is developing an application to make paediatric IBD patients

better cope with their condition, the preparation of a booklet by patients and physician to help ulcerative colitis patients better understand the issues involved around colectomy or the story of a brave girl that when in remission set herself a year of challenges to raise money for an IBD cure to name a few.

The common denominator of these stories are that they are very honest and show what it really feels like to deal with IBD every day. These stories are written by people sharing their experiences and their personal struggles but also their willingness to inspire other people and empower them to overcome obstacles, no matter what. We can't think of better ambassadors to raise awareness.

From left to right: Lizzie Smith during a competition to raise funds for IBD research, Ingel Vandelanooote (left) with her IBD nurse, Liesbeth Moortgat



NETWORKING

Medical Congresses

EFCCA was present with an information booth in the 12th **ECCO Congress** (15-18 February 2017) and in **UEG Week** (28 October - 1 November 2017). Both Congresses took place in Barcelona, Spain. Additionally CEO, Luisa Avedano attended the **Patient and Paediatricians Day** organised by the European Society for Paediatric Gastroenterology Hepatology and Nutrition (ESPGHAN).

Our presence at these medical congresses and meetings are an excellent opportunity to network, meet stakeholders and inform physicians and other healthcare providers about our activities. They allow us to establish effective relationships and to develop common projects with the physicians and other interested stakeholders. They also provide a good occasion to meet up with potential sponsors and discuss collaboration on common objectives.



EFCCA CEO, Luisa Avedano, addressing delegates during UEGWEEK 2017, Barcelona, Spain

Promoting regional meetings between EFCCA members

2017 has been a year of pilot initiatives and a re-definition of old and more recent relationships. The three workshops that we organised during our last General Assembly in Warsaw clearly showed the

enormous potential that EFCCA and its members have when working together and co-creating initiatives. We decided then to reinforce our role of facilitators in the exchange of information and

projects among our members: we listened to our members and tried to visit them, to participate in their activities. We learnt a lot and we “discovered” a treasure of inspiring practices and a powerful human capital where volunteers and officers join forces for a better life of people with IBD and for constructive and encouraging relationships between patient and health care professionals.

There was a lot of enthusiasm and the willingness to transform dreams into reality. In some cases, we strengthened our alliance in meeting stakeholders, redefining roles and partnerships, in others we facilitated the flow of information and helped sharing projects.

And one of the first concrete results has been a meeting hosted by AMICI Italy in Milan that took place last February 2018.

Our Portuguese and Spanish members and friends explored and discussed with AMICI and EFCCA about the management of complex national organisations where the need to be present in every region requires a long-term strategy and a clear idea of the deliverables.



Representatives from Italy, Spain, Portugal and EFCCA at the AMICI office in Milan, Italy

Our role there was to learn and share our transnational experiences and realise that there are so many common challenges that, together we can meet and overcome.

We hope that 2018 brings new themes and ideas and we will do our best to keep this new and fruitful approach more and more fruitful and effective.

Cooperation with European and international stakeholders

EFCCA has been networking with a wider range of organisations that are dealing with patient rights and concerns, health care issues and health policy making. By exchanging information and attending conferences, Annual General Meetings, European Parliament Interest Group meetings and other events we ensure to maintain and strengthen our relationship with our colleagues such as for example the European Patient Forum, the European Federations of Pharmaceutical Industries and Associations, the International Alliance of Patients' Organisations, the European Parliament Interest

Groups on health etc. You will find a complete list of meetings that took place in 2017 on page 6.

Through such collaboration and networking we are able to expand our knowledge on issues that are of concern to the IBD community and to gather forces in order to better advocate for common objectives. It also enables us to develop new ideas for common projects and initiatives with the aim of improving the quality of life of patients and making our voices heard.

World IBD Day 2017

SOLIDARITY

2017 has seen another successful World IBD Day global campaign with more than over 200 landmarks being lit in purple in order to raise awareness about IBD. Our associations and other interested stakeholders used this highly visible campaign to organize at their local and national level events aimed at improving patient rights, promoting better quality of life and a better recognition and consideration of their members' needs and priorities.

In total 40 countries participated in the global campaign involving 25 countries from the EFCCA membership base. We think it's a good sign of strength that patient representatives and interested stakeholders from 15 countries that are not linked to our network joined our campaign and were keen to become part of our global efforts. It shows us that the international IBD community is looking to us for joint actions and cooperation and we hope that we can further strengthen this role as we believe that World IBD Day is an excellent opportunity to reach out globally, to educate, to mobilise and to show our solidarity with the 10 million people that are living with IBD.

New World IBD Day website

EFCCA has decided to refurbish the World IBD Day website that was first created in 2010 following a meeting between seven IBD sister organisations during Digestive Disease Week (DDW). The new website is our virtual platform to share all the information of activities that are taking place around the world, not only information from our EFCCA members but also from other IBD sister organisations, physicians, IBD activists, nurses and anyone that is supporting our cause. For more information please visit: www.worldibdday.org

Cooperation with IBD sister organisations

On World IBD Day 2017, EFCCA participated in a live video chat that was hosted by the Crohn's & Colitis Foundation (US) in order to discuss the differences in IBD diagnosis. You can watch the video chat at: <https://www.youtube.com/watch?v=o-Rp9V5EEOA>



Transition project

In the IBD community, the term transition is used to describe the process of moving from the paediatric system to mainstream adult care. To get a better understanding of the needs and experiences of younger IBD patients throughout their transition process, the EFCCA Youth Group carried out an online survey in 2017.

Although the survey was small, the results show that more than 1 in 4 young IBD patients was disappointed in how the transition process went, and more than 1 in 4 felt their condition deteriorated as a result. We believe that patient associations could and should play a crucial role in not only providing peer support and guiding young IBD patient through the transition process, but also in educating health care

professionals to make the transition as smooth as possible for young patients.

Therefore this survey created the basis for the development of the Transition project which aims to achieve a greater understanding and awareness of the effect the transition process has on an IBD patient and their families amongst healthcare professionals, national associations, local and national administration and the general public.

This aim will be achieved through training, internal and external advocacy and networking activities and is foreseen that project activities will commence by 2018.

For more info please contact the EFCCA office.

ATLAS project

Our EFCCA CEO, Luisa Avedano, was involved in two preparatory meetings that gathered several renowned European gastroenterologists, the patient organisations Appetite for Life in Poland and Patients on Intravenous & Nasogastric Nutrition Therapy (PINNT) in the UK.

The project aims to identify unmet needs of people with chronic intestinal failure (chronic IF) and to raise awareness amongst stakeholders. In fact, chronic IF does not feature highly on current national and EU policy agendas, and care inequality across and within EU countries needs to be addressed to ensure that patients receive standardised access to treatment.

Among other findings the issue that current home and social care are inadequate to meet the quality of life of patients and their families was highlighted and the importance of patient associations acknowledged.

Alongside some activities mainly focused on the medical side to the issue, a policy paper was developed to provide clinicians, policymakers and patient organisations with direct calls to action for the future management of people with chronic IF and reduce the disparity of care for people with chronic IF across Europe.

The next step will be a meeting in the European Parliament to raise awareness about the condition. Although IF, short bowel syndrome and artificial nutrition are not the core business of our Federation we are convinced that establishing new partnerships and getting in touch with more specific needs is crucial to better support the whole EFCCA community. We are fully aware of the disparities in care that IBD patients face in their countries and we believe in the importance of creating alliances.

The project is supported by an educational grant from Shire.

INSIDE EFCCA

General Assembly

Over 50 EFCCA delegates participated in the EFCCA Annual General Meeting (AGM) in Warsaw, Poland from 26-28 May 2017. The meeting was hosted by J-elita, the Polish IBD association, who did a wonderful job to make delegates feel welcome and helped the EFCCA secretariat with organizational matters as well as preparing an exciting social programme for delegates.

This year we had two guests from the Baltic States. Janek Kapper from the Estonian IBD association EESTI who formally joined EFCCA during the AGM and Gediminas Smailys from the Lithuanian IBD association presenting his association to the delegates with the aim of joining EFCCA in 2018. With this new addition from Estonia our total membership is now up to 34 IBD patient associations with several new associations, such as

the Lithuanian association, showing their interest in joining EFCCA in the near future.

The AGM programme included the usual statutory reports and activity updates and elections to the EFCCA board.

This year we also allocated some time towards working groups in order to share ideas and develop future EFCCA projects. Three workshops on EFCCA summer camps, a pan-European Toilet Locator project and a workshop on nutrition were organized and presented an excellent opportunity for our members to share information and to brainstorm on ideas for concrete projects.

On the second day of the agenda we invited Pr. Pawel Kawalec as guest speaker to present an interesting

EFCCA delegates during the plenary open session, Warsaw 26 May 2017



on-going study “A burden of IBD in Europe” which aims to assess the burden of IBD for patients, families, and societies in selected countries of Europe and to check differences between countries. The study looks into work-related outcomes among patients with IBD as well as work-related outcomes

among informal carers of patients with IBD and finally work-related outcomes in relation to disease activity (remission vs active).

More information can be found on the following website: www.ibdcosts.eu

GA workshops

During the General Assembly we organised three workshops. Here you have a small summary from the workshops. Work is still in progress, and we are aware of the busy schedules our members have, but we hope to have some positive outcomes soon. If you would like to read the full reports please contact the EFCCA secretariat.

European Toilet Card project

15 national associations joined the Toilet Locator workshop to share their national experiences and discuss the development of a pan European Toilet Locator Card. The workshop was coordinated by Roberto Saldaña from ACCU España. Participants agreed that the best possible solution would be to have a double face card, one side containing national information and the other side containing a uniform, international logo and information.

Certain information on the international side such as the use of an expiry date, ID and photo would depend on the national side (ie where this was national practice it would also be international practice).

A small working group has been established for defining and developing the Pan European side of the card as well as create an information sheet on the card to issue to national associations and potential information awareness raising actions.

Nutrition workshop

Patients' awareness on importance of healthy food choices may play a crucial part in managing IBD since consuming certain foods may represent a more sustainable way of handling the disease while including some other foods in the diet can negatively

influence quality of life.

During the GA in Poland 11 EFCCA national associations participated in the nutrition workshop which was coordinated by Martina Jovic, EFCCA Policy officer. The working group generated good and interesting discussions amongst participants. They stressed that more valid information and research on the link between diet/environment and IBD was necessary. The group recommended some specific actions including awareness raising and advocacy activities.

Furthermore, the working group suggested the establishment of strategic partnerships with other bodies that are working on the questions of diet, additives in food, inflammation etc. for educational, advocacy and raising-awareness purposes.

EFCCA Summer camps for youngsters with IBD

The working group consisted of representatives from 8 national associations as well as members of the EFCCA Youth Group with discussions being led by Sanna Lönnfors. Since the camp is not “just for having fun” but also has the aim to educate young people to become leaders of tomorrow and organize camps in their own countries, participants need to go through a certain application process in which they can show their motivation. (more details are in the complete workshop report).

The camp steering group was formed and includes: Eva Bjornsdottir, Thomas Hough, Sanna Lönnfors, Magdalena Sajak and Fergal Troy. The next steps will include thinking about the “Theme of the year” for the 2018 international camp as well as a suitable venue, and creating an application form.

EFCCA Executive Board

The EFCCA Executive Board is elected by the General Assembly for a term of two years. The board meets 3 times a year as well as via conference call in order to discuss the strategic development and work of the organisation. In 2017 we welcomed Magda Sajak from J- elita (the Polish IBD association) as new EFCCA board, whilst the rest of the board were re-elected. The new board is made up by: Ciara Drohan, Secretary (Ireland), Martin Kojinkov, President (Bulgaria), Salvo Leone, Vice-President (Italy), Marko Perovic, Treasurer (Serbia), Magda Sajak (Poland), Natassa Theodosiou (Cyprus) and



Fergal Troy who was replaced in December by Lucie Lastikova (EFCCA Youth Group).



Martin Kojinkov

I have been serving the EFCCA Board for 4 years now. In 2014, I was elected Treasurer and in 2016 chairman of the Board. Being chairman is a great honor and an even bigger responsibility. Some of the more general responsibilities include outlining the priorities areas for EFCCA, liaising more frequently with the staff on operational matters

and ensuring that compromises are reached and decisions are taken at Board level. At the same time, I have been involved in couple of projects, I had the pleasure to represent EFCCA at several forums and I took the lead on the closing of the IBD Research Foundation.

I've joined the EFCCA Board to make a difference as I believe that things do not change by themselves, but rather that we have the power to change them. In the last year, I've learnt that this is even more true when done by a dedicated team of friends. As I will

not apply for a next mandate as chairman, I would like to wish to my friends at the Board and the ones that will be elected at the 2018 GA to have a lot of inspiration for new initiatives, courage for bold decisions and to always stay united. I am sure that the best years for EFCCA are yet to come!



Ciara Drohan

I am currently General Secretary of the board. I decided to join the board to assist other patients and raise awareness of our invisible disease. Often I have felt that there are never enough hours in the day but this year has also taught me that we are making a difference and our voices are heard and will continue to be heard. My main task is

to provide support for the organization of the General Assembly but behind the scenes I actively participate in whatever I can and where I can so that we can ensure continued growth and success of EFCCA to allow our disease and patients to be heard by all.



Salvo Leone

I am Salvo Leone, CEO of the Italian Association and EFCCA Vice President. I am delegate since 2003, board member since 2008 and vice president since 2015. I decided to join EFCCA because I have always been convinced that I had to do something for people with IBD, to give them an opportunity and because I hope, one day, to find a cure.

We had a busy year in 2017 and it has taught me that you can never do enough and that you always have to raise the bar to do better. I have helped as much as I could to team up with board and staff and to support our president when he could not attend an event. For the future I would like to instill in the people who participate as delegates the sense of a team and a membership that should guide us. I would like everyone to see the great opportunity that we have in representing people with IBD and the possibility of changing the lives of many people through our work.



Marko Perovic

I'm from the Serbian IBD patient association and have served the EFCCA board 2016 when I was elected as a board member. My principal responsibility is that of treasurer, responsible for financial reporting and budgeting of the EFCCA funds, including the implementation of transparency principles.

Personal engagement at different levels for me has always been a way of fighting IBD, through patient activism, empowerment and advocacy for change. Coming from a small volunteer patient organization, I believe we need to pool our strengths together

and fight the disease united, with solidarity and collaboration. I also believe that we can improve the quality of life of people living with IBD only if we continuously do research, gather data and generate evidence which helps us design our response to be effective and impactful.

2017 taught me that the patient's role does matter, even though we need to fight for it. Our collective commitment and focus on our right to be heard, consulted and involved in the decisions that matter for us have been visible in our work with the healthcare professionals, researches and academia, as well as with governments at the European level. The year has also taught success can only be achieved if we work together and united in making things we care about happen.

Besides working as a treasurer, last year I was mostly involved in the project on mapping of innovative medicines in Europe and the preparations for the EFCCA Academy this year. I hope the EFCCA Academy will be recognized by the IBD community as a way of strengthening people with IBD becoming advocates of change that matter for the life of IBD community at the European level and beyond. I also look forward to our joint work, and the collaboration between various European IBD associations in giving a stronger voice to people living with IBD and ensuring better quality of their lives.



Natasa Theodosiu

to participate in the EFCCA Board as a member. Of course one of my main aims is to represent my

I am a board member of the Cyprus IBD patient association, CYCCA. My inner need for volunteering and my will to learn more about Crohn's disease and Ulcerative Colitis and also to take a closer look on how an association like EFCCA works were more than enough for me to make the decision

country and at the same time facilitate the flow of information on the news and progress made in Europe concerning the patients' rights and the improvement of the quality of life.

My participation is a great experience for me because I was given the chance to participate in group meetings and events. My contribution to the Board concerns the edition of EFCCA magazine since we make a lot of effort to send articles from Cyprus. In 2016 I have contributed in the organization of the pilot programme of Nurses Education in IBD in Cyprus, my role was to facilitate the cooperation of EFCCA and the Cyprus Association (CYCCA).

Also I have represented EFCCA the same year at the opening ceremony of the programme in Cyprus. Currently we are collaborating with our colleagues from Spain on the design of a logo of our EU Toilet Card. This project has started during our workshop in Poland and we will soon have our card ready.

My participation is very fulfilling; therefore I look forward to a lot of future activities that will give me the opportunity to work as a Board member.



Magda Sajak

I'm a member of the Polish IBD association, J-elita, and I joined the EFCCA Board in 2017 to voluntarily support EFCCA and the Board.

In the past year, besides current board member activities, I have been responsible

for coordinating from the EFCCA side the "Polish

Survey" – survey about indirect costs of IBD. In my first year as board member I learned a lot about EFCCA, its policies, rules, etc. which allowed me to become an active, conscious Board Member.

For the upcoming year, I am very happy to take an active role in working with EFCCA members on common ideas and projects. I believe that EFCCA is as strong as its weakest link and we can be strong only when we are all together in accordance to the idea of "United we Stand". Therefore it is extremely important for EFCCA to strengthen the relation between EFCCA and its membership countries.

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 is in charge of EFCCA's external and internal communication strategies as well as international relations in particular the coordination of global World IBD Day.

Our policy officer, Martina Jovic, has been responsible for office support, networking with European and International institutional organisations in Brussels and developing new project ideas such as work

focused on nutrition.

Sanna Lönnfors, Research and Project Coordinator, has been leading the working group of our project Mapping of innovative medicines and devices in EFCCA member countries as well as on the design of the EFCCA Academy.

EFCCA has been collaborating with the association "Officine Digitali" on IT matters (website, IT tools, software and hardware implementation, etc) and Antonella Montanari has supported Isabella Haaf on communication issues for the global World IBD Day campaign 2017.

EFCCA Youth Group (EYG)

The EFCCA Youth Group had yet another busy and productive year. This is an important year for the Youth Group as they are now fully recognised as part of EFCCA and as a result the Youth Group Leader sits on the main Board of EFCCA. This allows the Youth to have a vote and a larger input in the direction to which EFCCA is moving, cementing the future of the Youth Group as part of EFCCA.

The EFCCA Youth Group had a year full of challenges and changes. Using social media and EFCCA magazine EYG was focusing on taboos around IBD. Members promoted topics such as mental wellness or intimate relationships. At the end of the year the YG leader stepped down and a new one was elected.

Transition Survey

It is always hard to switch a doctor, even more if the patients are moving to different city or transitioning from pediatric to adult care. The EFCCA Youth

Group carried out an online survey in 2017 to get a better understanding of the needs and experiences of younger IBD patients throughout their transition process. The survey contained 16 key questions that covered a range of areas ranging from reason behind the transition through to how the process was managed.

EFCCA Youth Group Annual Meeting

The most important event of the EFCCA Youth Group is the annual International Youth Group Meeting. This year it took place from 27th to 30th July in Paris, France. The meeting was hosted by the French association called Association François Aupetit (AFA). This year's European Youth Meeting had forty delegates from 21 countries. We are very happy that six new countries attended the meeting (Austria, Bulgaria, Denmark, Hungary, Slovakia and Switzerland).

The main aim of the EFCCA Youth Group Meeting

European Youth Meeting delegates, 27-30 July, Paris (France)



is to encourage all delegates to interact and share stories and gain experiences from all over the world. As part of this process and as with every year, each country is invited to give a short presentation on the youth activities of their association. It is an excellent opportunity to listen to what other associations are doing for their youth members and get new ideas to bring back home.

This year's workshop was specialized on patients app. Participants were working on a project called Care4Today, testing and helping to develop an app for daily use of patients with Crohn disease. All delegates had chance to find out how patients are treated in France and what medication is available thanks to a presentation by "Access to therapeutics in Europe". After work delegates enjoyed a cruise on the canal Saint Martin.

EYG Elections

Elections are a big part of every Youth Group Meeting. France was no exception. With all the votes cast and counted the new EYG was formed. The group welcomed one new member and four substitutes who will continue to work throughout the year on new projects and plans.

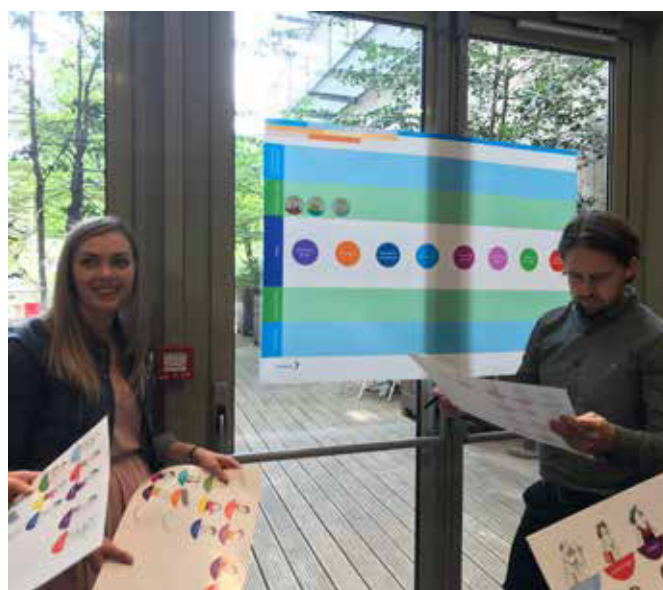
Members:

- Lucie Laštíková (Czech Republic), elected Leader in December 2017 - after Fergal Troy (Ireland) retired
- Rakel Yr Adalsteinsdottir (Iceland), elected in 2016
- Leanne Downie (United Kingdom), elected in 2016
- Bastien Corsat (France) – elected in 2016
- Nathalie Schwarz (Germany) – elected in 2017

Substitutes:

- Thomas Hough (United Kingdom)
- Marine Gros (France)
- Katleen Franc (Belgium)
- Beatrice Larsson (Sweden)

Sharing ideas, experiences and best practices, gaining inspiration and making new friends who



During the EYM workshop session

have the same condition. We are glad to report that these expectations were met and that the European Youth Meeting had a direct positive impact for forty delegates.

Next year the annual European Youth Meeting will take place in Iceland on 26th to 29th July 2018 and will be hosted by the Association CCU - Crohn's og Colitis Ulcerosa samtökin.

EPF Youth Group

Our youth group sends a representative to bi-annual European Patient Forum Youth Group meetings and they work on their youth projects throughout the year. In March Thomas Hough represented us at the meeting in Milan, Italy and in October Nathalie Schwarz attended the meeting in Leuven, Belgium.

EPF Summer Training Course for Young Patient Advocates

In July Lucie Laštíková and Thomas Hough both attended the EPF Summer School in Vienna, Austria to learn more about overcoming discrimination and develop their patient advocacy skills. This was a great opportunity for them to develop but also network and learn from other youth delegates who attended representing other health associations across Europe.

EFCCA Members

As of May 2017 the current EFCCA members are:

Austria: ÖMCCV - Österreichische Morbus Crohn / Colitis Ulcerosa Vereinigung
Website: www.oemccv.at

Belgium:
CCV-vzw - Crohn en Colitis Ulcerosa vereniging vzw
Website: www.ccv-vzw.be/nl/

RCUH - Association Crohn-RCUH
Website: www.mici.be

Bulgaria: BCUCA - Bulgarian Crohn's and Ulcerative Colitis Association
Website: www.babkuk.org

Croatia: HUCUK - Hrvatsko udruzenje za Crohnovu bolest i ulcerozni kolitis
Website: <http://www.hucuk.hr>

Cyprus: CYCCA - Pancyprian Association of Ulcerative Colitis and Crohn's
website: www.cycca.org

Czech Republic: Pacienti IBD z.s
Website: www.crohn.cz

Denmark: CCF - Colitis - crohn foreningen
Website: www.ccf.dk

Estonia: EPSS - Eesti Põletikulise Soolehaiguse Selts
Website: <http://www.ibd.ee/>

Finland: CCAFIN - Crohn ja colitis ry
Website: www.crohnjacolitis.fi

France: AFA - Association française aupalet - AFA
Website: www.afa.asso.fr

Germany: DCCV.e.V. - Deutsche Morbus Crohn / Colitis Ulcerosa Vereinigung
Website: www.dccv.de

Greece: HELLESCC - Hellenic Society of Crohn's Disease and Ulcerative Colitis Patients

Hungary: MCCBE - Magyarországi crohn-colitises betegek egyesülete
Website: www.mccbe.hu

Iceland: CCU-SAMTÖKIN - Crohn's og colitis ulcerosa samtökin
Website: www.ccu.is

Ireland: ISCC - Irish Society for Colitis and Crohn's disease
Website: www.iscc.ie

Israel: The Israel Foundation for Crohn's Disease and Ulcerative Colitis
Website: <http://www.ccfi.org.il/>

Italy: AMICI - Associazione per le malattie infiammatorie croniche dell' intestino
Website: www.amiciitalia.it

Luxembourg: ALMC - Association luxembourgeoise de la maladie de crohn (represented by Afa)
Website: www.afa.asso.fr/

Malta:MACC - Malta Association of Crohn's and Colitis
Website: www.macc.org.mt

Norway: LMF - Landsforeningen mot fordøysessykdommer
Website: www.lmf norge.no

Poland: J-elita - Polskie Towarzystwo Wspierania Osób z Nieswoistymi Zapaleniami Jelita
Website: www.j-elita.org.pl/

Portugal: A.P.D.I. - associação portuguesa da doença inflamatória do intestino
Website: www.apdi.org.pt

Romania: ASPIIR - ASociatia Persoanelor cu boli Iflamatorii din Romania
Website: <http://www.aspiir.ro/>

Serbia: UKUKS - Udruzenje obolelih od Kronove bolesti i ulceroznog kolitisa Srbije
Website: www.ukuks.org

Slovakia: SCC - Slovak Crohn Club
Website: www.crohnclub.sk

Slovenia: KVCB - Društvo za kronično vnetno crevesno bolezen
Website: www.kvcb.si

Spain: ACCU - Asociación de enfermos de Crohn y Colitis Ulcerosa de España
Website: www.accuesp.com

Sweden: Mag- och tarmförbundet
Website: www.magotarm.se

Switzerland: SMCCV - Schweizerische Morbus Crohn / Colitis Ulcerosa
Website: www.smccv.ch
or: www.asmcc.ch/

Turkey: iBHDYD
Website: <http://www.ibhportal.com>

United Kingdom: Crohn's and Colitis UK
Website: www.crohnsandcolitis.org.uk/

ASSOCIATED MEMBERS

Argentina: Fundación Mas Vida de Crohn & Colitis Ulcerosa
Website: <http://www.masvida.org.ar/>

New Zealand: The Crohn's and Colitis New Zealand Charitable Trust
Website: <http://www.crohnsandcolitis.org.nz>

Thanks to our donors

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 of the activities that are mentioned in this report:

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Celgene



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Janssen



Merck -MSD



Pfizer



Sandoz



Shire



Takeda



Tigenix



Vifor Pharma





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