

EFCCA MAGAZIN

European Federation of Crohn's and Ulcerative Colitis Associations | October 2018



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EDITOR'S EYE

Wind of change



It's with great pleasure that I present you this issue of the EFCCA magazine where you will find evidence of our growing importance as reference point for the European and international IBD community.

EFCCA has seen an enormous growth since its foundation in 1989, and I would say that the visions of our previous leaders, in particular that of Marco Greco, have made EFCCA what it is now: a network of 36 patient associations united in their efforts and commitment to improve the life of people with IBD.

Having served as an active EFCCA board member for over 8 years, as well as being very dedicated to our European cause it is a big honour for me to have been elected new EFCCA chairman by our General Assembly in Bucharest this May.

I am eager to continue the great work that has already been done and I was very pleased with the positive results of the International Symposium on IBD Research that we organized

in Bucharest on 27 May 2018 following our GA.

It clearly shows our strength in bringing together representatives from the patient community, the scientific community and other stakeholders that all share a common interest in our fight against IBD. The Symposium provided a unique forum for our members to share their experiences - but also needs in research - with eminent scientists and researchers and to open a dialogue for developing cooperation and better research strategies. I would like to take this opportunity to thank all our speakers that made the symposium such a success.

The Symposium is not just a one-off event; we are keen to keep up the momentum and to continue our dialogue with the scientific community. We are now working on the development of a new strategy for EFCCA, which will include this important link to the scientific, medical and healthcare community because we believe that such alliances will make us more visible and will provide us with mutual benefits.

We hope to develop a mechanism by which we will have a "real time" update of treatments allowing its user to track news and changes in every country as we believe this is a very important ingredient for ensuring optimal quality of care in IBD.

Our new strategy will of course also take into consideration our increased role in the international sphere. In recent years we have become the reference point for many patient groups and associations outside Europe. In 2012 Más Vida from Argentina and the Crohn's and Colitis Foundation of Israel joined the EFCCA family. The following year we welcomed Crohn's and Colitis New Zealand and this year in Bucharest we had as observers AMDII from Brazil, the IBD Fund from Kazakhstan, Crohn's and Colitis Canada and the Montenegro IBD association, with view to joining the EFCCA network next year. This clearly shows us that

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revised 22/2/2006
No. 459814543

we have become an international rather than a “merely” European network. Even though our main focus of work remains on Europe the reality is that IBD has no borders and unfortunately the disease is increasing worldwide calling for alliances that can work on common projects and strategies to ensure a better quality of life and care for people with IBD everywhere.

It gives a new sense to our work and to our European view and we want to make sure our strategy reflects this.

Another great area of work that we have seen in recent months is the capacity building program with regard to advocacy that EFCCA has embarked on. The EFCCA Academy was launched in June this year and I had the pleasure to participate both as an observer and active participants. The Academy is a unique training tool for IBD patients intend on becoming patient advocates and to be better prepared to speak on behalf of the IBD patient community. I completely agree with the feedback of one of our Academy participant in saying that “this is the first school of its kind because it deals specifically with IBD while providing practical skills aimed at advocacy. I can’t wait to implement the things I learned this weekend back home”.

Another exciting project that EFCCA has recently started together with 3 members associations (from Spain, Italy and Sweden) as well as Crohn’s and Colitis Canada is the Patient Voice project. Patient Voice aims to improve patient-doctor dialogue through symptom tracking while giving patient associations full ownership and complete access to their health data. We are still in the preparation phase but once this project kicks off we believe it will be a real value for IBD patients and a step towards better patient and healthcare system outcomes as it will enable patients to be equal partners and take greater control over their healthcare. The Patient Voice Tool will become a powerful resource not only for patients but also physicians and researchers.

During our next Executive board meeting taking place in November we will start shaping our new strategy taking into account all our on-going activities as well as new objectives and visions for the future. There are exciting times ahead, which will bring new opportunities for growth and consolidation of our network, and I look very much forward to leading this process.

United We Stand,
Salvo Leone, EFCCA Chairman



New EFCCA leadership

During our Annual General Meeting (AGM) which took place in Bucharest, Romania from 25-26 May 2018, Salvo Leone was elected new EFCCA chairman. He had already been serving four terms as EFCCA board member and in his acceptance speech he stressed his commitment and enthusiasm in making "EFCCA grow even stronger and inclusive of our growing IBD community".



Outgoing EFCCA chairperson, Martin Kojinkov (left) congratulates Salvo Leone as new EFCCA chairperson.

The 29th AGM was hosted by ASPIIR, 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.

It's worth mentioning that other organisations such as the Crohn's and Colitis Foundation of Canada and Crohn's and Colitis Australia have also expressed an interest in being part of the EFCCA network, thus

confirming our belief that together we can do more to improve the lives of people with IBD.

The Crohn's and Colitis Association of Lithuania (CCAL) was welcomed as new member to the EFCCA network bringing our total membership to 34 patient associations.

The AGM programme included the usual statutory reports and activity updates and elections to the EFCCA board. The composition of the new board is as follows: Ciara Drohan, Vice President



Participants at the EFCCA General Assembly, 25-26 May 2018, Bucharest, Romania.

and Honorary Secretary (Ireland), Salvo Leone, Chairperson (Italy), Marko Perovic, Treasurer (Serbia), Magda Sajak (Poland), Natassa Theodosiou (Cyprus) and Bastien Corsat (leader of EFCCA Youth Group, see page 14).

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. We also heard a brief presentation of the BAB2 survey which has been planned as a follow up to the BAB survey (Biologics and Biosimilars 2014) in order to see the evolution of patients' perspectives on biosimilars now that they are widely used everywhere.

It was a memorable meeting with many new faces providing for interesting discussions and useful exchange of experiences and practices 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 following day on 27 May 2018.

All presentations and other relevant documents can be found in the Members Only section of our website.

From left to right: Martin Kojinkov, Isabella Grosu, director of the Romanian IBD association ASPIIR that hosted the GA and Salvo Leone.



Symposium on IBD Research

EFCCA organized its second symposium on IBD research funded or promoted by IBD patient associations on May 27 in Bucharest, Romania. The second Symposium brought together over 80 patient group representatives from five continents, gastroenterologists and other healthcare providers and relevant stakeholders.

EFCCA wants to encourage patient associations to take a more active lead and reinforce patients' role and voice in IBD research, the aim of the Symposium was therefore to offer patient associations and the scientific community the chance to exchange know-how and discuss and lay 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 chairperson Martin Kojinkov and Professor Mircea Diculescu, a founder member of the 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, patients bring a whole different perspective as they see things that the medical community does not.

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)



Professor Claudio Fiocchi during his opening keynote speech

– 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



Anne Buisson, AFA Crohn RCH France, presenting the research project “Mikinautes - dietary factors for relapse in pediatric IBD patients”

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.

Sanna Lönnfors

Dr Joana Torres (middle) during the question and answer session following a research project presentation



Launching the 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 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 participated in the pilot training that will serve as a base for future classes of the EFCCA Academy.



For three intensive days the EFCCA Academy pilot 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 one's own strengths for 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 and useful 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 feedback for the training has been mostly positive, and moreover, the first EFCCA Academy training has already brought on lots of positive outcomes as the participants of the pilot group have been very proactive within their own associations. In Norway, for example, the Academy participant has been involved in preparing guidelines for patient advocates, and will speak about the role of patient advocates in a youth meeting later this fall. The Austrian EFCCA Academy participant has written articles for the association's national magazine as well as press releases, talked about life with IBD in an awareness campaign film and spoken to newly diagnosed people. For an already experienced patient advocate these tasks were nothing new, but they were easier to handle with the EFCCA Academy lessons freshly in mind.

In Finland, the Academy participant has started organizing a peer support weekend together with the national rheumatoid arthritis youth group and acted

as a support person for newly diagnosed patients; and in Romania, in order to empower IBD patients with more information, a patient forum with the possibility for questions and answers is being planned, and the association will also organize so-called "IBD corners" with plenty of IBD information available in waiting rooms of gastroenterologists.

The EFCCA Academy project has raised a lot of interest all over the world, and EFCCA hopes to be able to offer similar patient education weekends for interested and motivated IBD patients on a regular basis in the future. As the next step, however, the EFCCA team will work on shaping and improving the curriculum of the EFCCA Academy based on the participants' feedback and experiences to make sure that the Academy meets the participants' needs and that all important topics are handled in the most effective possible way.

Sanna Lönnfors

Daniel Sundstein during his talk "IBD seen from an Osteopathic and Physiotherapeutic point of view".



World IBD Day 2018

In its eighth year of running, World IBD Day is becoming an important global event which brings together patient associations, patient advocates, healthcare professionals, family, friends and other stakeholders to show their solidarity with the 10 million people that are living with IBD worldwide.

EFCCA has been coordinating the global campaign aimed at raising IBD awareness by illuminating famous landmarks in the colour of purple alongside the organisation of local events on either 19th of May (the official date of World IBD Day) or around that date. In some countries the whole month of May has been used to raise IBD awareness.

This year has seen another successful campaign with a high degree of participation from our members and new countries joining the global campaign. Out of EFCCA's 36 member associations, 31 members participated in World IBD Day activities and in Europe alone there were over 250 famous landmarks lit in purple involving over 140 cities and regions.

The World IBD Day website has been an important tool in providing a unique platform for sharing activities that have taken place worldwide and for being a reference point to the international IBD community and those interested in the events. It has allowed us to promote the campaign through our

social media channels and traditional media.

We have seen an amazing range of activities and events that show the creativity, eagerness and commitment of patient associations to make sure that we are visible and that we are heard! Please visit www.worldibdday.org to view country specific activities. For a full report please contact the EFCCA office or go to our website.

We have also been sharing the results of the UC Narrative, a global survey, gathering data from 10 countries including 2,100 adults living with primarily moderate-to-severe ulcerative colitis. The survey, which EFCCA helped develop along with other patient organizations and healthcare providers from around the world, and supported by Pfizer, explored several aspects of living with UC ranging from physical symptoms to patient-physician communication to emotional health and intimacy. to learn more about the UC Narrative initiative and survey findings. <https://www.pfizer.com/news/press-kits/uc-narrative>



We have distributed over 5000 purple ribbons worldwide which have been handed out free of charge at awareness raising events, doctor/patient meetings and other events aimed at promoting World IBD Day. The purple ribbon is the universal symbol of awareness and support for people living with IBD.

Project update: Patient Voice

The Patient Voice Tool, which is an innovative software developed thanks to the support of Microsoft and Softjam, is the result of a consultation process amongst four patient groups and EFCCA that identified the most important information and data to be included in this exciting new project.

On 4-5 July 2018 patient organisations from Italy, Spain, Sweden and Canada as well as EFCCA in its role as coordinator met in Genoa (Italy) to work together on the implementation of the Patient Voice Tool project.

The aim of this tool is to give patients (gathered by country) the opportunity to be involved individually in collecting and monitoring their diseases and to get a comprehensive overview of their health conditions.

The Tool collects 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.

All data of the Patient Voice Tool will be owned by patient organisations whilst EFCCA will play a co-ordination role when it comes to a more general analysis of the information and data breakdown.

An important component for us 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.

The four patient associations that agreed to be part of the pilot phase have been working during the summer to structure a Memorandum of

Understanding that defines roles, responsibilities and further development steps. After a consolidation phase the partnership will be open to further stakeholders and a scientific committee is foreseen to validate the data.

Launched by Takeda at the end of 2016 the project is now fully owned by EFCCA, the pilot partner members and Crohn's and Colitis Canada and will be ready for its pilot launch before the end of this year. A communication campaign as well as interim reports of its implementation will be made available.

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.

From left to right: Roberto Saldaña (ACCU España), Luisa Avedano, EFCCA CEO, Salvo Leone (AMICI and EFCCA), Mina Mawani, Crohn's & Colitis Canada and Jonas Eriksson (Magotarm) following the Patient Voice meeting, Genova, Italy.



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European Youth Meeting 2018

This year the annual European Youth Meeting (EYM) of the EFCCA Youth Group (EYG) took place in Reykjavik, Iceland. We had 18 countries from across Europe join us for an actioned-packed weekend which was filled with learning, collaboration and exploring.



Participants at the European Youth Meeting of the EFCCA Youth Group in Reykjavik, 28-29 July 2018.

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, we want to raise more awareness in the delegates' respective countries, so it was a good opportunity to learn best practices.

The leader of the European Youth Group, Lucie Laštíková, from the Czech Republic, welcomed us warmly on Thursday night during the dinner and gave

us a short introduction of what to expect from the trip.

After a balanced breakfast our group started the day with 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, we had a workshop with the Icelandic psychologist Eygló Guðmundsdóttir and, where we

talked about how to raise awareness about mental wellness and received 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. This was the more active and sporty part of our evening. We were split into several groups to collect pictures of the most known places in Reykjavik. One of the tasks was to film ourselves pronouncing the difficult name of the volcano, Eyjafjallajökull, which erupted in 2010. We thought this was a great and funny way to get to know each other and the city. At the end of the game we met in front of the famous Hallgrímskirkja church to take a group picture.

The next morning, we had the other half of the delegates' presentations. With the aim to strengthen our EFCCA Youth Group, we had several workshops on how we can get delegates more involved, in addition to carrying out a SWOT analysis of our 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 our work session we had the yearly votes for the new Youth Group members. 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) will now be representing the new EFCCA Youth Group, with Bastien Corsat from France as our new leader.

The highlight of the day was the surprise event where we went to the Blue Lagoon, one of the most famous hot springs worldwide. Water temperatures

of around 38°C and stunning nature made the perfect place to relax. We were thankful and happy to have made so many beautiful memories. As another highlight, we had the gala dinner in a traditional local restaurant in Reykjavik. The food was delicious

partnered with good company which made the evening a memorable one.

Thank you to Lucie for leading the Youth Group and Good Luck to Bastien on being the new leader.

As a group we aim to continue to break down taboos for young people and their conditions. We will be sharing articles on these topics in future magazines including a top tips section on mental wellness taking the learnings from the workshop in Iceland.

A special thanks to Angela Müller & Julia Stirnimann for writing this article and to Nathalie Schwarz and Leanne Downie for translating into English.



This is our word cloud of the countries that took part and key words of what the European Youth Group means to us all.

New Zealand

Viv Gurrey takes the helm at Crohn's & Colitis NZ

In February this year, Viv Gurrey was appointed as the new Chief Executive Officer by the board of the Crohn's & Colitis New Zealand Charitable Trust. In this interview EFCCA talks to the new CEO to find out about her vision and tasks for the organisation.

"I am very honored that I have been appointed CEO of Crohn's & Colitis NZ and hope that my unique set of skills gained during my previous senior leadership roles for more than 15 years and most recently with one of the largest volunteer organizations in New Zealand will allow me to bring an already successful organization such as Crohn's & Colitis NZ to the next level", says Viv Gurrey.

"Crohn's & Colitis NZ has been in existence for about 7 years and the role of our organization is very much about building awareness of the disease. We have approximately 20 000 patients with inflammatory bowel disease and it's estimated that for every one patient there are probably another 10 that are affected."

IBD has a limited voice in New Zealand. The emotional, physiological and psychological impact on those who have this disease is immense and completely unimaginable to the wider population, most of whom have never heard of, or experienced life with the consequences of this disease.

"My appointment is the first step in raising a very necessary awareness of the burden of the disease, not only to the individuals and their families who are directly affected, but also to our society as a whole."

"Our objective is to build a robust, insightful and deeply caring support mechanism for those with the disease, one in five of whom are children. I want to

lead an organisation that shapes a health system and society that enables those with this diagnosis to lead productive, happy and contributing lives. "

My team includes our amazing board of trustees, 6 in total, which includes Dr Richard Stein and Brian Poole QSM as Co-Chairs of the organization. We have an operations manager who works alongside me to operationalize our strategy and we support volunteers across 13 regions in New Zealand.

What was one of the first tasks you worked on?

As we didn't have a strategic plan up till now, part of my role has been to develop a strategic planning process in order to build a strong strategy and vision for CCNZ. We have just completed that: we have identified our vision, we have identified our mission and we have re-examined our core values. The result is a strategy based on six strategic themes, which have been grouped into both internal and external themes.

In terms of our internal strategy the first strategic theme is around developing an effective organizational structure followed by a theme that focuses on "Financial strength and sustainability" whereas the third theme deals with visibility, marketing and brand development with the long-term aim of building, protecting and leveraging our brand to increase awareness of IBD and to support the growth of CCNZ.



Left to right: Viv Gurrey; Dr Richard Stein – Co-Chair CCNZ; Brian Poole QSM, Co- Chair CCNZ and Deputy Chair of the National IBD Care Working Group; Nicole Thornton - Youth Ambassador CCNZ; Hon. Trevor Mallard, Member of Parliament and Speaker of the House at the Select Committee Hearing in the New Zealand Parliament (CCNZ Toilet Access Petition hearing).

Our external themes work to support those who live daily with the disease. We do this through a number of areas and our flagship Camp Purple is an annual event where we bring together kids from 9 through to 17 and organize fun activities in a supportive, caring and inclusive environment. The aim is to support the IBD community to move from isolation to connection by normalizing the disease, creating and building enduring friendships and providing a collegial and collaborative community network.

We are now looking at creating a similar event for young people aged between 19-30 years. We are very excited about this activity which we are going to call #retreatpurpleNZ

Then we have our support strategy which focuses on “Collaboration, Engagement, Digital and Education” in order to build a comprehensive and effective support network for everyone living with

IBD with a focus given to key targeted populations.

Our final strategic theme is around representative leadership and research with a very clear objective: to be the leading organization of influence in the IBD sector optimizing the well-being of patients and their families and an active participant in the drive to find a cure. This is a very important strategy that is very much about our advocacy and lobbying work and any sort of political understanding around the disease in New Zealand. We simply want to have a credible seat around every table that matters in respect to IBD.

What do you see as the main needs of patients in New Zealand?

We commissioned a report last year entitled “Reducing the Growing Burden of Inflammatory Bowel Disease in New Zealand” as a first step towards an informed national discussion about the growing problem of IBD in New Zealand. One of

the main issues identified in the report is around the inequity of care available. The report establishes a set of recommendations to address the identified shortcoming in diagnosis, treatment accessibility and standards of care.

We have formed a National Care Working Group that will work on the recommendations that come out of the report in order to ensure the implementation of appropriate and accessible care nationwide. We are very proud to have created this working group which includes all relevant stakeholders such as representation from gastroenterologists, nurses, dieticians, GPs etc.

We have a variety of other initiatives that fall under the advocacy banner and one of these is access to toilets. Along with every other country in the world people with IBD often require immediate access to restrooms. We provide a toilet map on our website but the problem for many is that we don't really have a good network of public toilets. We are petitioning our government right now for what we are calling the toilet access legislation. We are making exceptionally good progress and the petition is now under its second reading by our parliamentary health select committee. We have been told that the committee is very close to a solution, which we believe will be positive. So we are looking forward to some beneficial changes in this area.

Participants of Camp Purple 2018.



Another area identified in the report is around research and we are in the process of submitting an expression of interest to the Health Research Council in New Zealand for research funding, we have partnered with some of the best researchers in the country and one of our major universities..

How do you feel about being part of EFCCA?

I feel very strongly about EFCCA and the value it offers to the wider community. Following the EFCCA General Assembly in Bucharest this year Dr Stein and I submitted a resolution to our board to apply for full EFCCA membership which has subsequently been approved.

I see a major mutual benefit in being part of the EFCCA network, an international alliance where we can share and learn from each other, in particular our experience participating as a small country. I mention this because of our size we tend to be highly innovative in everything we do. We also have easy access to our government, so it's relatively easy to have a real say in the legislative process and bring about positive change. I believe that the continued work we are embarking on with the NZ IBD National Care Working Group and of course the petition could easily have some major benefits that can be fed into the wider network of EFCCA. We are looking forward to growing this relationship and collaboration considerably.

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Lithuania

Support for people with IBD in Lithuania

During the General Assembly in May 2018, EFCCA was happy to welcome the Crohn's and Colitis Association of Lithuania (CCLA) as new member. In this interview Gediminas Smailys, founder and director of CCAL, tells us about his organisation and the situation of people living with IBD in Lithuania.

Why did you decide to create an association for people with IBD?

Since my childhood, when I was diagnosed with ulcerative colitis, I had a lot of contacts with doctors. I guess that's partly why I decided to study medicine and while I was a medical student, I was asked by Professor G. Kiudelis from the Kaunas hospital to establish an association aimed at taking care of people with IBD in Lithuania. At that time little was known about inflammatory bowel disease and it was not that common. Since 2001 only 3000 cases of Crohn's disease and ulcerative colitis have been identified. So there was a huge lack of information about IBD and an urgent need to bring together people with IBD and to ensure an adequate exchange of information. That's how back in 2002 the Crohn's and Colitis association of Lithuania (CCAL) was established.

What's the situation now in Lithuania as concerns IBD?

IBD is still a relatively uncommon disease unlike diabetes, asthma or cardiovascular disorders. I guess that's why it is still not well known. However, improved skills in diagnostics by our gastroenterologists makes it much easier to diagnose IBD and nowadays people can easily find information about IBD on local websites. Apart from that our association has also published several specific booklets on IBD.



Gediminas Smailys (right) and Janek Kapper (Estonia) during the summer camp meeting.

What are the needs of the IBD patient community in Lithuania?

Since the creation of CCLA we have been negotiating with government institutions in order to increase financial support for IBD diagnostics and treatment. Unfortunately there have been shortcomings which created a vicious circle: government institutions were keeping compensation rates for general IBD medicines at low level in order to save money which led to IBD patients using insufficient medicines attempting to save their own money. Of course this only resulted in more costs as uncontrolled and complicated cases of IBD had to be dealt with.

But...we had some great news. In July 2018 our association was informed that quotas (i.e. limiting numbers) for biological treatments were being removed and that all general medicines for IBD will

be compensated 100 percent. So from now on, each IBD patient can get adequate treatment despite his or her income.

What are your main areas of work?

CCLA organizes several times per year meetings in different Lithuanian cities inviting people with IBD and IBD professionals, such as gastroenterologists, psychologist, dieticians or surgeons. These meetings are a great opportunity to get expert advice, exchange information, meet other people with IBD and IBD “experts” and discuss issues that are of interest to the participants. This is really important as there is a lot of ‘unsafe’ data circulating among patients, Facebook and other social media.

Our association is also introducing our members to some additional (not alternatives) kinds of treatments for IBD, which help to reduce anxiety, depression and social isolation such as for example art therapy, equine therapy (working with horse), mindfulness, breathing lessons etc.

We are also trying to create more awareness about IBD and have organized summer camps with some fun activities such as kayaking, visiting museums,

including also family members of people with IBD in our general discussions and activities.

What are the main challenges you face?

We have just reached a milestone with the news that there is now proper funding for IBD available. Now our challenge is to make sure that it remains like this! In case of a new financial crisis our government might once again think about reducing funding for IBD treatment. Other areas that we think need also special attentions are rehabilitation after surgery, adequate stoma care, creating a general registry for IBD patients, free and available access to toilets (and mapping them), updating our website ...a long list!!

Why did you decide to join EFCCA?

Our main objective in joining the European family was to get more additional information and ideas of how to develop our association further. We believe it's important to exchange experiences among members and also to make new links and even friends. Last spring we were happy to participate in the World IBD Day 2018 campaign coordinated by EFCCA. We organized an awareness raising event and had several buildings lit in purple. I think it was a successful start and a good impulse for more collaboration!

Summer camp participants visiting a Winnetou theme park.



Portugal

IBD summer camp

The Portuguese IBD Association, APDI, organised the "DIIICamp2018" meeting, which was held from June 15 to 17, 2018 in Ferreira do Zêzere, a charming and peaceful village in the district of Santarém of the Ribatejo province. The purpose of this initiative was to promote socializing, the sharing of experiences, "empowering" people and to clarify all kinds of doubts people with IBD might have.

We had 20 participants between the ages of 20 and 60 years, 75% had Crohn's disease and 25% ulcerative colitis. We left Oporto on Friday towards our destination and since the beginning it became obvious that participants were willing and keen to be involved in the various proposed activities. Once we arrived at the hotel and had dinner to replenish everyone's energies, we organised a group dynamic activity, with the goal of getting to know each other.

On Saturday, and after a good night's sleep, the day began with a pleasant conversation with Dr. Francisco Portela, Gastroenterologist at the Hospital of Coimbra, who addressed a number of doubts and questions regarding biologics versus biosimilars, future diagnostic exams such as ultrasonography of the intestines, as well as the analysis of fecal calprotectin as an indicator of disease activity.

After these lectures we had the highlight of the weekend. As the weather was excellent we organised some fun water activities in the Albufeira of Castelo de Bode. Throughout the day, participants had the opportunity to try out canoeing or boat riding and for those who preferred to stay on land there was target shooting and pipe blowing. The good mood and cheerful atmosphere stayed on well into the night.

On Sunday, it was time to say goodbye and after each one received their certificate of participation, everybody expressed their wish to repeat the experience next year.

We would like to thank all those who contributed to the success of this initiative, from associates to guest physician and sponsors.



Norway

Report from the Nordic Meeting in Oslo

The Nordic Meeting took place in Oslo, at the Thon Hotel Opera, from 14 - 16 September 2018. All Nordic countries were represented, as well as our contact person and Vice President of EFCCA, Ciara Drohan.

The weekend was filled with group discussions about how we can collaborate on an international level and what challenges we are facing as patient associations. Moreover, we discussed how to retain and recruit members and volunteers, membership benefits, advertisement in our channels, the increased focus on IBS and shared decision making. We also talked about organisational structures and differences across the Nordic Countries. It is fair to say that there are some big differences even between the Nordic countries, which also involves the relationship and collaboration with medical companies, as we have different experiences with that.

Camilla Rødsrud presented a project she has been leading in Norway, which is related to raising awareness about the toilet card (Can't wait card). They ran a pilot in Arendal in August and are planning to roll out the project on a national level in the coming months. They also informed the group about the "Not every disability is visible" campaign which has been undertaken by the UK. In Norway they are looking to do a similar campaign, and after some discussion we decided that we shall look at developing a European standard for the toilet card as well as working on this campaign project on an international level. Ciara will bring thoughts back to the EFCCA Board. We are aware of the similar toilet card project taking place in Spain, and would be happy to welcome any international cooperation.

Bjørn Gulbrandsen informed us about the NOR-Switch study, as well as some other studies he is currently working on related to biosimilars, treatment abortion and consequences, as well as the possible connection between IBD and cancer. It was very



Representatives from the Nordic IBD patient associations, 16 September 2018, Oslo, Norway.

informative, and he will continue to update us as they progress. The NOR-Switch study is completed and has been published in the well known and highly prestigious journal, The Lancet, and concluded that Remicade was not inferior to its biosimilar Remsima.

We also had a visit from CalPro. They informed us about E-health and home monitoring of Calprotectin for IBD. They are working with health departments, patients and doctors in Europe to make this accessible and free of charge to patients.

As a social activity we went on a tour inside the Oslo Opera House. It was very interesting to learn more about this 10 year old building, its history and

its people, as well as being shown the back stage area, workshops and costume rooms. It was a very nice weekend and we all got to know each other better. We

want to work closer together despite our structural differences and have found a common ground. We look forward to next years' meeting in Helsinki.

Raising awareness and creating engagement

LMF is currently working to increase awareness around IBD and other invisible diseases related to the colon. As an organisation we have an important mission to broaden the view of the wider public in what it means to have a chronic disease and an invisible physical handicap. We are also increasing our efforts to include contributions from our members and to actively promote volunteering

Gaining international insight and enhancing international cooperation

Two of our delegates took part in the EFCCA Youth Group meeting in Iceland at the end of July and came back with new knowledge that can further enhance our national contribution in our fight against invisible and chronic diseases. We really believe in the benefits of international cooperation and held a Nordic Meeting in September, including IBD associations from Sweden, Finland, Denmark and Iceland (see article above). We focused on the importance of knowledge and best practice sharing across countries and created an understanding of how our organisations can work together to ensure a broader impact.

Raising awareness

We are currently focusing on two main initiatives related to raising awareness:

We have run a pilot project to test the impact of the Toilet Emergency Card. We tested the Toilet Emergency Card at a convention in Arendal in August to see whether or not the person got access to a toilet where there were no public toilets available. At this convention there are about 70,000 participants, making it a perfect scene to test access to non-public toilets.

The results showed that the card is useful for store personnel to understand the urgent need, but

unfortunately not all employee toilets are accessible to the public. This test was part of a bigger national project which in these days is being carefully planned and is due to be launched sometime during this autumn.

Secondly, we are planning a campaign project to emphasize the need for handicap toilets to be "acceptably used" by other people than those with visible handicaps. We are inspired by the "Not every disability is visible" campaign, which has been successfully implemented in the UK. Therefore, we have already been in touch with Crohn's and Colitis UK and we thank them for their exchange of information and experience with this campaign. We are looking to partner with other organisations working for members with other invisible disabilities, and hope that together we can increase the knowledge and acceptance amongst the wider population. The project is still at a planning stage.

Increasing youth engagement

We are arranging a two weekend seminar for our youth members who want to learn more about volunteering and how to contribute even though one has a physical disability. Days will be filled with workshops, presentations and fun activities, and we hope this will increase our youth members' engagement.

On behalf of LMF, Camilla Rødsrud



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Switzerland

Meanwhile in Switzerland...

The 19th of May became the day for purple fighters when over 1000 people visited the Swiss World IBD Day exhibition and the largest intestinal model in Europe. "We have rarely spoken so openly and experienced so much heart and soul!" - This was just one of the many positive feedbacks from participants as well as exhibitors who provided a lot of variety with their exciting information stands.



The new president of Crohn's and Colitis Switzerland, Bruno Giardina (third from right) displaying the association's new look

The information meeting in the afternoon was filled to the last seat and it's not surprising given the list of renowned speakers: Professor Dr. med. Stephan Vavricka gave a lecture on "Intestinal flora: importance and possible therapies" followed by a lecture of PD Dr. med. Kaspar Truninger which dealt with the topic "Why do IBD patients have an increased risk of colon cancer? What preventive measures are available?".

Nutritionist Diana Studerus, who is also an IBD patient, showed how nutrition impacted on IBD and how she dealt with the five most common questions during her practice. Psychologist Dr. Georg Fraberger, who joined us especially from Vienna (Austria), made a lasting impression with his motivating lecture "Quality of life despite illness" - not least because he himself was born without arms and legs. Susanne

Augustin, a musician from Munich (Germany) with Crohn's disease and founder of the "chronisch cool" association, accompanied the event with musical interludes that moved many to tears.

During the event, our association also held its Annual General meeting. In addition to the usual items on the agenda, we presented our new website. Its new colour scheme reflects what our patient organization represents: Crohns and Colitis Switzerland in purple and a new logo that symbolizes our unity.

But...it was also a sad moment as our former president Bruno Raffa decided to step down after 22 years on the board. We officially thanked him for his work and appointed him as an honorary member. At the same time we were happy to welcome our new president, Bruno Giardina, who was presented during the GA and unanimously elected.

The day was a complete success and remains unforgettable!



SMCCV Vice President, Michael Harnisch with outgoing President Bruno Raffa (right).

Argentina

This is my dragon

The Mas Vida Crohn's & Ulcerative Colitis Foundation proudly presents "This is my dragon: how to live with Inflammatory Bowel Disease", a free distribution book especially aimed at children with IBD. The book has been published in Argentina thanks to an associative agreement between the Mas Vida Crohn's & Colitis Foundation and its Chilean counterpart, the Crohn's & Colitis Foundation "Carlos Quintana".

The author of the book, Sebastian Castro, is an IBD patient himself who learned "to tame his own dragon". He transmits with a great sense of reality what life is like for children and adults who live with the disease. "Having a dragon in the belly" is the sensation that every person diagnosed with Crohn's disease or ulcerative colitis can go through due to the anguish and fear generated by their symptoms. "The chatty and joyful stories of Sebastian Castro and

Rodrigo Avilés explain to children and their families the implications of the disease and the sensations experienced. The aim is to help them accept their diagnosis and achieve greater control of the disease through adequate, specialized medical supervision and long-term treatment," says Luciana Escati Peñaloza, founder and president of the Mas Vida Crohn's & Colitis Foundation.

“The diagnosis of a chronic disease is not easy for any person, even less so when it comes to a little known disease, as is the case of IBD in Argentina and the rest of the Latin American region. The understanding of ‘why my child?’ or ‘why me?’ is often fraught with uncertainty, especially since specialized professionals and available information are scarce in our country.

Therefore, when our Chilean colleagues shared the book with the rest of the Spanish-speaking patient organizations, many of us wanted to promote this wonderful effort by publishing it locally and free for distribution,” says Escati Peñaloza, who regrets not having had similar material available in 2008, when her daughter Juana was diagnosed with indeterminate Colitis. “Being able to count on this type of tool helps us parents to talk with our children, to understand their illness and the best way to live with them”, she reflects.

“This is my dragon” aims to make children with IBD better understand their disease, their symptoms, the importance of visiting a specialist and the importance of adherence to treatment. It aims to teach about adjustments in daily life, diet and changes in a cheerful way. The book explains that “all patients with Crohn’s and ulcerative colitis have a dragon that lives inside”, and through a tour of the myths and



Book cover of the Spanish version of “This is my dragon”.

truths of this disease provides greater understanding and gives tools to “tame the dragon” and to become a “Master of dragons”.

The book is distributed free of charge in IBD reference centers and can also be downloaded on the Mas Vida Foundation’s website: http://masvida.org.ar/wp-content/uploads/This-is-my-dragon-C3%B3n-web_v-ARG.pdf

Those who are interested can also contact the Crohn’s & Colitis Foundation “Carlos Quintana” who owns the book which has also been translated into English and Portuguese (info@crohncolitisulcerosa.cl).

UK

David Barker steps down after five and a half years at the helm

Crohn’s & Colitis UK has expressed its sadness and gratitude at the departure of chief executive David Barker, who stepped down in September. After five and half years, he has left the charity to set up his own consultancy business, advising and supporting charities and not-for-profit organisations.

Sue Cherrie, chairman of Crohn’s & Colitis UK, says: “David led the organisation through a significant period of transformation, modernisation and growth.

Under his leadership, the charity doubled in size and income, and we are now reaching and supporting record numbers of people, as well as funding a growing

portfolio of research and delivering campaigns and partnerships to drive lasting change.

“As our chief executive, David always put the needs of people affected by Crohn’s and Colitis at the heart of our work. and he has been a great champion for the organisation and a tremendous advocate for the cause. He is very highly regarded by all our stakeholders and, thanks to his work, the charity is well placed to ensure that it continues to thrive and deliver the greatest possible impact for everyone affected by Crohn’s and Colitis across the UK. “The board of trustees and I are enormously grateful for all that he has done for the charity and he will leave us with our heartfelt thanks and best wishes for his next endeavour.”

David says: “It has been a tremendously fulfilling and enjoyable five and a half years with the charity, and I am very proud of what we have achieved



Outgoing Crohn's & Colitis UK CEO David Barker

together. It has been an honour to work alongside so many talented, inspiring and determined individuals and I wish you all my best wishes and every success for the future.”

Potential for change

A recent Quality of Life survey by Crohn's & Colitis UK notes the impact of Crohn's and Ulcerative Colitis (UC) on careers, education and more.

Around 8,000 people living with IBD participated in the Crohn's & Colitis UK's 2018 Quality of Life survey, which explored the ways IBD affects them on a daily basis. “We wanted to understand the actual impact on your day to day; how you feel about yourself and your life, and the things that you do,” says Dr Georgina Rowse, clinical psychologist at the University of Sheffield, who helped to shape the questions for the survey and analyse the results.

“When you're trying to understand how people are living with their IBD, it isn't as clear cut as how many times you are going to the loo a day,” she says. “One person who goes to the loo 10 times a day could be absolutely fine and they manage it. “For another person who goes 10 times a day it could be really difficult and it could upset your social networks, your work and education.”

With this in mind, the survey was shaped around how people felt their Crohn's or Colitis affected the quality of their lives. Nearly half (48%) of respondents said that their Crohn's or Colitis stopped them from doing what they wanted to do – with 44% stating that their condition hindered them reaching their potential at work.

Additionally, nearly a third of people with Crohn's agreed it had prevented them fulfilling their potential in education, and around a fifth of those with UC felt that way. The majority of respondents felt that their IBD impacted on their ability to do various activities such as exercise, chores and socialising at least some of the time. Around 10% reported experiencing stigma or unfair treatment regularly or most of the time because of their condition. In terms of maintaining their wellbeing, only 3% of respondents reported never

finding it hard to cope with IBD, while the majority (51%) found it occasionally hard to cope with their condition – and the rest finding it frequently so.

Dr Rowse says: “We can use these findings to make a difference so we can limit the impact Crohn’s and Colitis are having on people’s lives. We can create information leaflets, look at service provision and, ultimately, maybe develop psychological interventions.”

Amber Davies, a 20-year-old supporter with Colitis, said: “The past years have been extremely difficult and draining both physically and mentally as a result of my Colitis. I spent more time in hospital than in school, with my symptoms worsening with age. Due to my illness, I didn’t achieve what was once hoped for on paper. Perhaps in a world with better or more effective treatments this could happen. However, I am still immensely proud of what I’ve managed to do while battling Ulcerative Colitis at the same time.”

Serbia

Support for people with IBD

The Serbian Association for Crohn’s disease and Ulcerative Colitis (UKUKS) was founded in 2009 with the main purpose to educate, raise awareness and improve the quality of life for people with IBD in Serbia.

As of 2012 we are member of the EFCCA network and we are honored to attend meetings, exchange ideas, meet new people and follow the latest trends in the field of IBD.

With less nervousness than last year in Paris, our Serbian delegates Svetlana Nikolic and Olga Mitrovic presented the activities of UKUKS at the EFCCA Youth Group meeting in Reykjavik, Iceland and showed how much progress has been made in the IBD field in Serbia. Recently UKUKS has collaboration with the Belgrade Public Speaking and Rhetoric center so in the past year our members had the opportunity to attend free courses and improve their public speaking skills.

Moreover, UKUKS organizes free individual psychological counseling. Individual sessions with psychotherapist are available to all of our members in our office in Belgrade but also via skype.

We are specially proud about the project “In their shoes“, which has been realized to mark World IBD Day. We created an animated movie which in an interesting way presents all life segments of people



Olga Mitrovic (left) and Svetlana Nikolic at the EFCCA Youth Group meeting, July 2018, Iceland

affected by IBD. The movie is translated in English with subtitles.

Finally, this year UKUKS published brochures which contain information about pregnancy and IBD. And one of our UKUKS members started a blog where the author shares her experiences with IBD in an interesting way.

France

Reimbursement of Vedolizumab (Entyvio®): a fine victory for patients with Crohn's disease in France

After multiple steps and a relentless fight from afa Crohn RCH France, which managed to make healthcare professionals join the cause, Vedolizumab (Entyvio®) is now funded by the health insurance in France for Crohn's disease patients, with failure to treatment or with intolerance to anti-TNF therapies!

Review of the facts

Vedolizumab (Entyvio®) was available in France following an afa Crohn RCH France request for temporary use, pending the regulatory approvals. In December 2015, the reimbursement of Entyvio® was refused in Crohn's disease whereas the treatment is reimbursed in Ulcerative Colitis - because Entyvio® is evaluated less effective in Crohn's disease than in Ulcerative Colitis.

From one day to the next, most of the Crohn's disease patients treated with Entyvio® - approximately 1,000 patients - were called by their hospital center in order to cancel the next appointment for the medicine injection, because of the reimbursement interruption. We know many patients that had found an efficient treatment with Entyvio® that suddenly were without a therapeutic solution!

Following that decision, afa Crohn RCH France created an action group in January 2016 with partners that are IBD experts: Getaid (gastroenterologists from major university hospital centers), ANGH (general hospitals), Cregg (gastroenterologists), Synmad (syndicate of gastroenterologists) and SNFGE (French National Society of Gastroenterology).

The negotiations had begun with the Ministry of Health, in order to allow Crohn's disease patients treated with Entyvio® - at least - to remain on the

treatment. An overview of the situation was assessed by physicians that committed themselves to review the treatment prescription when possible. The Ministry provided a significant funding envelope to maintain the treatment, although more than 700 patients remained without any therapeutic solution. And a reimbursement halt was still a possibility once the envelope had been spent! Moreover, the question of equal access to treatment for all patients arose. Therefore, afa Crohn RCH France encouraged the pharmaceutical company to submit again an assessment file with further data including data of "real life" reported by Crohn's disease patients through a questionnaire.

Finally, in January 2018, the French Health Authority has reassessed the therapeutic value of Entyvio®, going from moderate to significant. This decision has created a positive perspective for the medicine reimbursement access. After this crucial step, some price negotiations were needed between the Ministry and the pharmaceutical laboratory which led to a final price being set early August 2018! All Crohn's disease patients - with anti-TNF treatments intolerance or failure - have finally access to Entyvio®.

The struggle for access to Entyvio® is another example, if ever needed, of the value of patients' associations such as afa Crohn RCH France, that defend the rights of patients, in particular in relation to innovative treatments access.

Spain

"Haz de tripas corazón": a project to facilitate patient - doctor communication

Haz de tripas corazón (to bite the bullet) is an ACCU España project that aims to improve doctor-patient communication and to raise awareness about the importance of sharing with the medical team those aspects related to quality of life that are affected by IBD.

The pilot phase was launched last year in Zamora and the Canary Islands and consisted of an online survey of 14 questions on the symptoms and impact of the disease on the patient's quality of life, an issue that is often overlooked during consultation but which is important for the specialist so that he/she can make a complete assessment. Participants had the option to send the answers to their medical team via a platform.

By the end of 2017, more than 700 people had participated and their responses provided interesting data such as:

- 48% percent of patients are always or very frequently tired
- 40% feel "always or very often" depressed or discouraged.
- 95% of the patients who participated had extraintestinal symptoms such as joint pain, skin conditions, back pain, eye pain or vision loss.
- More than 30% also have a second immune-

mediated disease diagnosed, such as rheumatoid arthritis (15.4%), psoriasis (6%) or ankylosing spondylitis (6%).

- 30% say they feel the need to go to the toilet urgently "always or very often".

- 25% said they are not adhering to their treatment or not taking it.

- 41% say that it affects their work (this might be due overexertion they make to perform their duties or to adapt to their schedules in spite of the symptoms and the pains).

- 47% percent have seen their sleep affected.

- 51% have emotional problems.

It is hoped that the findings of the project will lead to better dialogue and understanding between patients and doctors. The project has received financial support from AbbVie.

More info: www.hazdetripascorazon.com



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Cyprus

Raising awareness

On the occasion of World IBD Day, the Cyprus IBD association CYCCA participated actively and supported local events in Cyprus in an effort to raise awareness by lobbying and providing information to patients and society in general.

Our ultimate goal of our activities is to unite people in the fight against IBD. On May 5, 2018 we participated in a conference in cooperation with the Cyprus League Against Rheumatism titled *“Rheumatic disease and IBD. Can they appear together?”* Apart from the introductory speeches, the topic was presented and analysed by two distinguished doctors, one rheumatologist and one gastroenterologist. Also three patients talked about their personal experiences with the two diseases, giving a valuable and different perspective. The conference was concluded with an extensive ‘Questions and Answers’ session. The result was inspiring and satisfied all those present.

On May 19, 2018 a conference with the title *‘Kids and IBD’* was organised in Nicosia and the Pediatric Medical Centre for Liver, Gastroenterology and Nutrition of the Makarios III Hospital, which operates in collaboration with Kings College Hospital



From left to right: Chryso Yiasoumi, Andri Phoka, Natasa Theodosiou (CYCCA) and Souzi Makri, 5 May 2018

(London), was presented. At the same time, the newly recruited first Pediatric Gastroenterologist in Cyprus addressed the audience and an interesting and fruitful discussion followed, with the active participation of the audience.

“Rheumatic disease and IBD. Can they appear together?” conference, On May 5, 2018



Estonia

Team “Bowels 100”

Since 25th April this year members of the Estonian IBD association (EPSS) have been participating in the annual LHV Bank's Running & Walking Series. The five-member team named “Sooled 100” (The Bowels 100) is running at weekly events held at different locations in Tallinn until the end of September.

The recreational events take place at different urban and suburban health tracks, but also at the Tallinn Botanic Garden, the Tallinn Zoological Gardens, the Estonian Open Air Museum and in Tallinn's Old Town.

The team Bowels 100 has been participating in the Running & Walking Series' wide variety of locations with great excitement.

EPSS board member and EFCCA delegate Janek Kapper hopes for a wider participation among fellow members of EPSS for next year. *“Meeting up on a weekly basis strengthens the bond between the members of EPSS and encourages team spirit. For the individual member the participation as a team is motivational for keeping active and, therefore, could also improve their overall life quality in the long run”*, he said.

Team “Bowels 100” at the finishing line.



EPSS Board member Janek Kapper during one of the runs.

Every active participant of the LHV Bank's Running & Walking Series can make a gift of at least 100 healthy kilometres, hence the name of the EPSS's team, covered during the 21 events of the Series to themselves and their home country while celebrating the 100th anniversary of the Republic of Estonia.



IBD nurses: a key to quality care

EFCCA is proud to have supported several nurses to participate in the 9th N-ECCO School, which took place in Vienna, Austria on 14 February 2018. In total 62 nurses and dietitians from 24 countries participated in the School with the aim to promote quality of care for patients with IBD.



Participants of the 9th NECCO School, 14 February, 2018, Vienna, Austria

@ecco

The N-ECCO School (Nurses of the ECCO network) was created to provide educational opportunities for IBD nurses throughout Europe, to increase networking opportunities and to meet and share best practice. The 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).

This year's programme included a general introduction on diagnosis and assessment, surgery in IBD and medical treatment as well as specific workshops on multidisciplinary management in IBD, nursing roles in IBD management, psychosocial implications of living with IBD and nutritional

assessment in IBD in addition to specific case studies providing practical examples.

Participants were highly satisfied with the selection of the speakers, who all presented topics relevant to the nurses' clinical practice. This year ECCO provided the learning objectives to participants online and all PowerPoint presentations (subject to speaker authorisation) have been uploaded to the e-CCO Learning platform, which is accessible for all ECCO Members. Participants have also been invited to join the N-ECCO Network Meeting or the N-ECCO Research Forum for their further education in the coming year. We believe that this cooperation between EFCCA and ECCO is providing practical value at a local and national level. It supports the nurses' roles in caring for patients with IBD and will lead to the overall welfare of people with IBD. A big thanks to the organisers and participants!!

The Value of Health: Improving Outcomes

The initiative “Value of Health: Improving Outcomes” has just published its final report which provides a multi-stakeholder perspective on value in health systems and the use of health outcome measures to enhance value.

The Value of Health multi-stakeholder initiative began in 2014 with the aim of providing a European level, health community response to debates on health system performance and reform. Confronted by the need to control public spending in the immediate aftermath of the economic crisis, governments across Europe were faced with the challenge of containing health expenditure growth whilst continuing to improve the quality and effectiveness of services provided.

At European level, these objectives were reflected in the EU’s economic governance process (the European Semester), which each year publishes structural reform recommendations – including on improving the cost effectiveness of health spending.

Among health stakeholders, there was concern that the policy response focused too much on cost containment, with too little attention given to the overall performance of the health system – in particular with respect to quality of care and health outcomes. Over time the European Semester has adopted a more balanced approach: a less prescriptive approach to cost savings, and a broader view of health system performance that recognises the importance of health outcomes, access to care, and quality of care. However, further improvements are still possible (see recommendations).

This final report is based on the discussions and findings of the Value of Health initiative over the past four years, including seven multi-stakeholder roundtables, and working groups on patient-centred outcomes, public health outcomes, and the analysis of health outcomes variation. While many of the case studies in the report are taken from projects and

initiatives in West European countries, the findings and perspectives provided by the report are relevant to health systems in all EU Member States. The report is divided into two main chapters: The first aims to provide a multi-stakeholder perspective on the concept of value at the level of the health system and argues that health outcomes must be at the centre of any value definition; after all, improving the health of patients and the population is the fundamental purpose of all health spending.

At the same time, the report highlights an array of other objectives, and potential benefits, which underpin and drive public health expenditure, and which must be included in a comprehensive analysis of value for money. These include: access to care, patient-centredness, health equity, health workforce sustainability, outcomes for carers, and the economic and social benefits of good population health.

If health outcomes are at the heart of our value definition, it is essential that they can be measured and that they include measuring the outcomes that matter most to the users of the health system.

Patient-reported outcome measures have a key role to play here – providing the patient perspective on the impact of treatment and care on outcomes such as pain, mobility, psychological well-being, and ability to carry out normal day-to-day activities.

The report also makes three recommendations which should inform the future work of the European Union on health systems.

To read the full report please visit: <http://valueofhealth.eu/>

How to realize the potential of off-patent biologicals and biosimilars in Europe?

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 biologicals and biosimilars in Europe. It is the result of a series of roundtable discussions including representatives from patient groups, clinicians, healthcare professional organizations, government bodies, and industry.

In its conclusion, the authors of the manuscript suggest that policymakers need to introduce a long-term, sustainable and specific policy framework based on a multi-stakeholder approach with a view to fostering a fair, competitive and sustainable market for off-patent biologicals and biosimilars in Europe. Although there exists residual uncertainty regarding the appropriate terms for switching off-patent biologicals and biosimilars, the authors believe that such issues will be clarified and resolved over the coming years with the development of new studies, data and experience with these products. Additionally, the authors advocate that a policy framework for the off-patent biological and biosimilar market needs to be founded on multiple building blocks including the implementation of supply- and demand-side incentives, and the prospective evaluation of gainsharing arrangements.

Competition among off-patent biologicals and biosimilars in Europe benefits patients as it may help to control drug expenditure, expand access to health care, increase treatment choices, and encourage pharmaceutical innovation. However, there remains uncertainty about switching patients from a reference

biological product to a biosimilar; from one biosimilar to another biosimilar; and about switching on multiple occasions. Therefore, the authors believe that the clinical profession, academia and patients need to be involved in developing a policy framework for off-patent biologicals and biosimilars. Due to the complex nature of off-patent biologicals and biosimilars, it is clear that the appropriate use of these products needs to be a clinical decision made by a treating physician for an individual patient on the basis of shared decision-making with that patient.

To read the full manuscript please visit: <http://gabi-journal.net/how-to-realize-the-potential-of-off-patent-biologicals-and-biosimilars-in-europe-guidance-to-policymakers.html?print>

About GaBi

Generics and Biosimilars Initiative (GaBI) was founded in 2008 by Pro Pharma Communications International. The mission of GaBI is to foster the worldwide efficient use of high quality and safe medicines at an affordable price, thus advancing and supporting the idea of accessible, affordable and sustainable health care.

Europe is “failing” to deal with chronic digestive disease burden

Europe is currently failing to manage the increasing burden inflicted by chronic digestive diseases, according to leading digestive health experts

A report, published during the launch of MEP Digestive Health Group (15 May 2018), reveals alarming issues, challenges and inequalities in a range of chronic digestive-related diseases, including digestive cancers, alcohol-related digestive diseases, paediatric digestive diseases and functional gastrointestinal (GI) disorders. Upon reviewing the latest statistics from across the continent and canvassing the opinions of both policymakers and scientific experts, the report reveals that:

- 59% of men and 45% of women in the EU aged 18 and above are overweight
- Digestive cancers represent 28% of all cancer-related deaths in the EU (365,000 deaths)
- One in four deaths from gastrointestinal diseases are directly attributed to alcohol
- Inflammatory bowel disease diagnosis can commonly take up to five years

The five most common digestive cancers – colorectal, gastric, pancreatic, liver and oesophageal cancer – are responsible for over 590,000 cases each year in the EU. If current population trends continue, the number of deaths from these cancers across the EU per year will increase by over 40% by 2035. Approximately half of all cancers are preventable and their significant burden could be reduced by addressing lifestyle factors, such as rising levels of obesity and heavy alcohol consumption.

In addition to the threat posed from digestive cancers and obesity, experts are also warning of the socioeconomic burden inflicted by functional GI disorders, such as irritable bowel syndrome (IBS) and constipation.

Professor Markus Peck, of United European Gastroenterology, which represents over 22,000 digestive health specialists, comments, “The impact

inflicted by digestive diseases continues to increase across Europe. With chronic digestive diseases, our society fails and the burden is only going to become greater. We’re seeing notable increases in the incidence of most gastrointestinal disorders, from digestive cancers to liver disease. The current outlook for young people’s health, for example, is extremely alarming, with childhood obesity rates expected to almost double by 2025.”

Current predictions, trends and attitudes demonstrate that the challenge presented by obesity, heavy alcohol consumption and poor nutritional choices is increasing and urgent action is required to reduce this burden and improve health outcomes in generations to come.

To address this difficult challenge, policymakers and digestive health experts met in the European Parliament to inaugurate the MEP Digestive Health Group. The group’s overarching mission is to ensure that continually improving digestive health becomes and remains an integral part of the EU health agenda, serving as a platform of exchange between the scientific community and policymakers.

“Rising obesity levels, functional GI-disorders and heavy alcohol consumption across Europe have major implications for future healthcare provision and it is essential that these largely preventable issues are tackled through health policy and action” adds Professor Peck. “United European Gastroenterology welcome the MEP Digestive Health Group and look forward to close collaboration in achieving the mission of tackling the burden of chronic digestive diseases across Europe.”

More info: <https://www.ueg.eu/press/>

Patient-reported healthcare expectations in inflammatory bowel diseases

Valérie Pittet, Carla Vaucher, Florian Froehlich, Michel H. Maillard, Pierre Michetti on behalf of the Swiss IBD Cohort Study Group (1)

The objective of this study was to look into expectations of patients with inflammatory bowel disease. Patient-reported experience is an important component of a holistic approach to quality of care. Patients' expectations of treatments and global disease management may indicate their illness representations and their satisfaction and hopes regarding quality of care.

Introduction

Patients' expectations play an important role in their assessment of the quality and delivery of health services. Healthcare expectations may be defined as anticipated beliefs and values, formed through cognitive processes, related to healthcare processes, events, or outcomes. In other words, these expectations may correspond to the difference between expected and experienced healthcare. Assessing healthcare expectations may be a first step in understanding satisfaction with healthcare, although expectation is a much broader concept. Indeed, expectations are multidimensional and complex, they can include passive and active components, and no standard instrument for their evaluation is available. Expectations may be general, related to, for example, access to information, discussions of problems, or psychosocial support, or more specific, related to, for example, requests for specific tests or treatments, coping strategies, and ways to return to "normal" life status, including prevention tips.

Inflammatory bowel disease (IBD) includes Crohn's disease (CD) and ulcerative colitis (UC), 2 related, chronic, intermittent diseases that cause progressive bowel damage and require lifelong management. Little work has been done, however, to measure patient-reported experience in IBD. Several recent studies assessed the satisfaction of

patients who have IBD or their healthcare providers with healthcare services, but no study has assessed healthcare expectations in large groups of patients. Satisfaction was much more often assessed because validated quantitative scales exist, as compared to expectations that mostly require qualitative exploration and study designs. Involvement of patients with IBD in their own care and their request for more active participation in disease management is a serious topic nowadays, but a broad assessment of how and where patients expect to contribute is lacking. We may indeed ask whether patients who express wide-ranging specific expectations and communicate them regularly to their physician, thus taking the role of active participants in their own care, influence both the cost and quality of care. This may be of particular importance in decision-making when the patient has specific requests, considerations, desires, or values that have to be taken into account.

Thus, a constructive partnership for better care at a reasonable cost might be formed between knowledgeable, empowered patients and healthcare professionals. For this reason, there is a need to develop knowledge transfer and activation programs for patients with IBD, and to increase direct collaboration with them, in order to improve follow-up and outcomes. We took the opportunity of two ongoing research projects to address the question of what are current expectations of IBD patients

regarding their care and treatments: 1) the Swiss IBD national cohort (SIBDC) study starting in 2006, and 2) a research project focused on patients and physicians perceptions of appropriateness of care in IBD. In this last project, we used combined methodological study designs to qualitatively explore and quantitatively describe perspectives and possible values of patients regarding risk of benefits of their treatments, and overall care related to their disease. In this purpose, we collect information on concerns and expectations, the last being the focus of the present manuscript.

The aim of this study was, first, to conduct a qualitative study to identify a set of disease and treatment-related expectations of patients with IBD. Second, we performed a cross-sectional study among a large number of IBD patients to quantify the identified expectations and study associated factors.

Methods

Two focus groups were conducted with 14 patients to explore their expectations about treatments and disease management. From qualitative content analyses of focus group discussions, we built a 22-item expectations questionnaire that was sent to 1756 patients of the Swiss IBD cohort. Answers were collected on a visual analog scale from 0 to 100, and medians (interquartile range [IQR]) calculated. Factor analysis identified main expectation dimensions, and multivariate analyses were performed to describe associations with patient characteristics.

Results

Of 1094 patients (62%) included in the study, 54% were female, 54% had Crohn's disease, 35% had tertiary education, and 72% were employed. Expectation dimensions comprised realistic, predictive, and ideal expectations and were linked to information, communication, daily care, and disease recognition. Half (11 of 22) of the expectations were ranked as very high (median score > 70), the 2 most important being good coordination between general practitioners and specialists (median score: 89, IQR: 71–96) and information on treatment adverse events (89, IQR: 71–96). Women had overall higher levels

of expectations than did men. Expectations were not associated with psychosocial measures, except those related to disease recognition, and most of them were highly associated with increased concerns on disease constraints and uncertainty.

Discussion

In this study, we aimed to explore, quantify, and describe the expectations of patients with IBD related to their disease and treatments. Expectations were first explored through a qualitative study based on 2 focus group discussions. A set of 22 expectations derived from content analyses of these discussions was used to survey patients with IBD who were included in a nationwide cohort study. We found 4 main expectation dimensions related to network and communication, information, daily care, and disease recognition. Two-thirds of all expectations were given a median score of over 50 and one-quarter a median score of over 87, which was very high. Women had significantly higher expectation levels than did men, regardless of the dimension. Expectations were not associated with psychosocial measures, except those related to disease recognition, and most of them were highly associated with increased concerns on disease constraints and uncertainty.

This is the first study that aimed to identify patient-reported expectations about disease and treatments in a large set of patients with IBD. Therefore, an overall comparison with previous similar studies is not possible. In relation to previous theories and studies on expectations, we could categorize the main dimensions of expectations as follows: healthcare network and communication, as well as information on treatments and follow-up, might both be considered realistic expectations, the first being active behavior or activation of the patient and the second more passive behavior. Daily care expectations are predicted expectations[6] in that they may reflect what the patients expect to be beneficial for improving their outcomes.

Finally, disease recognition expectations are ideal or value expectations, related to hopes and desire for a better life and social integration. As mentioned by

Bowling et al, expectations are complex to describe and understand. We found few independent variables associated with expectations. Symptoms severity or frequency were not associated with expectations, and, globally, expectations did not vary according to diagnosis.

We found that women concerned about disease constraints and uncertainty, i.e. reflecting the chronicity of the disease and its associated treatments and outcomes management, are those with higher information and communication expectations. We assessed expectations levels, not satisfaction with healthcare. Therefore, we could not further explore whether this only reflects a gender perspective (i.e., different levels of information and communication expectations but equal levels of satisfaction), or if there is an actual variation in the IBD healthcare management according to gender leading to increased or unmet expectations.

Some expectations were particular (e.g., “take fewer daily treatments”), others more general (e.g., “Good quality of healthcare”), which reflect the way patients expressed them during focus groups. This might indicate that general expectations like good quality of healthcare, for which the answer is not straightforward, would probably benefit to be further and individually explored to break down all related aspects, depending also on healthcare system where patients may evolve. As an example, one recent publication was performed in Sweden, exactly focused on this question of exploring patients’ perceptions of healthcare, indicating that expectations might be eg. in direction of respectful and trustful relationship, facilitating healthcare staff and patients to work as a team in fulfilling individual needs.

Expectations linked to information were highly expressed by patients, as shown in previous studies. Casellas et al showed that satisfaction with information was scored the lowest of the 6 rated domains and that lack of information was a constant complaint of patients over time, especially for those with mild to moderate conditions who were not mainly followed by gastroenterologists. Some patients’ views of quality improvements in gastrointestinal diseases were

directed at increasing access to patient organizations and groups, having consistency and coordination between GPs and hospital management, improving knowledge of GPs on IBD, and being more involved in defining disease-related concerns and prioritization of outcomes.

We also observed that communication within the healthcare network was not considered optimal. This finding may indicate that knowledge transfer tools need to be developed urgently, not only from physicians to patients, but also within the physicians’ community, especially for primary care physicians, who did not appear to be always up to date with IBD care or treatments.

On the basis of observations made within groups of GPs and the report of their attitudes, their lack of knowledge, and the difficulties they face with the management of IBD care and treatments, healthcare initiatives should probably go towards establishing the use of a chronic care model approach. Such attempts have been questioned and tested recently in Australia and the United States and could be used not only by integrating GPs, but also by integrating psychological advice or follow-up.

Our findings also showed that patients had a number of daily care expectations that may be interpreted as a willingness to participate more actively in the decisions regarding treatments, potential prevention, and anticipation of flares. The desire of patients to be actors in their own follow-up and the willingness of gastroenterologists to take this into account is not new. Attempts have been made to increase shared decision making and to build patient activation programs, but this appears to be still in its early stages and more difficult to develop than expected, at least in Switzerland.

Despite the ongoing longitudinal data collection in cohort studies or registries, integrated solutions offering optimal on-site decision-sharing tools, where doctors and patients can equally contribute and access information, are lacking. Interesting projects in the direction of patient empowerment have recently emerged, in parallel with increasing attention given

to assessing patients' requirements and their need to access electronic health records or personal health records, as well as to the potential contribution to chronic disease management.

Interestingly, daily care expectations were significantly higher among French-speakers as compared to German-speakers, which indicates that cultural sensitivity is an important issue to be considered, at least in Switzerland. French-speakers patients had higher levels of expectations as German-speakers regarding follow-up management (i.e., regular follow-up with gastroenterologist, contact with a nurse, advices on self-management and follow-up through services or professionals outside the medical field). This may also indicate that generalizing expectations at a global population level is difficult, unless they are stratified for specific targeted groups. Based on this observation, we could e.g., argue that groups of patients from all major linguistic regions should be equally involved, when developing patient empowerment tools expected to be used at a country level.

Finally, we observed that disease recognition expectations were given very high scores. This is in line with patients' concerns about these issues, as well as observations from recent studies indicating that stigmatization in gastrointestinal diseases, especially IBD, is still present. Indeed, although patients are perhaps more prone or willing to share their experiences with the disease now than they were in the past, IBD does not seem to be recognized or accepted in all social circles, especially for women and CD patients. Patients with disease recognition expectations had less concerns on the long-term impact of the disease, which might reflect they have more concerns on the short-term, i.e., the current impact of the disease.

The main strength of our study is related to the large sample size of patients with IBD who could be surveyed. We could investigate patients' expectations at a national level, with patients followed in university centers, regional hospitals, or private practices. Our goal was to describe patients' expectations, not to validate a psychometric tool, while acknowledging

that expectations might evolve with time. Moreover, we did not aim to measure satisfaction with healthcare.

One limitation is related to the survey's response rate, which may lead to a nonresponse bias, although the impact on the results, in terms of potentially different distributions of expectation ratings among non-respondents, remains undetermined. Another limitation may be related to our results being more representative of patients with long-standing disease than newly diagnosed. Indeed, the large majority of patients who accepted to participate to focus groups, as well as responders to the questionnaire, had a disease duration of 5 years and over. It thus seem to be more difficult to capture expectations of patients diagnosed for a short time. We could however hypothesize that expectations may be, at that time, more difficult to express for those having only a short experience of their disease, and especially less experience with the chronic aspect of the disease. We consider our work as a first attempt to capture patients' expectations, but a deeper qualitative assessment of expectations is probably needed for groups of newly diagnosed versus patients with long-standing disease to get more insight in the whole spectrum of patients' expectations.

In conclusion, this study showed patients have high expectations for information and communication among caregivers, the levels varying by gender and region. Patients also appear to request more active participation in their disease management, which is an important signal, first because we could benefit from potential newly generated patient data data to improve or validate, eg. patient-reported outcomes, second because it is a step towards the development of a chronic care model where the patient could contribute.

(1) To read the full study and references please visit: <https://journals.plos.org/plosone/article?id=10.1371/journal.pone.0197351>



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