EFCCA MAGAZINE

European Federation of Crohn's and Ulcerative Colitis Associations | September 2012

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EDITOR'S EYE

Watershed

Autumn is here, and this leads us to reflect on the successes obtained during last spring and summer. After the Join The Fight conference in Barcelona in mid-February, I think we can all agree that EFCCA is not the same anymore. The sense of unity that was created in Catalonia during the IBD awareness raising event has offered us a new perspective and new energies.

But also, EFCCA is not the same anymore, after Porto and the Annual General Assembly we held there in April. The IBD associations from Argentina and Israel are now welcomed as part of our family. This gives a complete new sense to our work and to our European view.

And now, in a few days, EFCCA won't be the same and will change again. The World Symposium on research financed by patients organization is the new and promising watershed in our EFCCA history. This event is the first stone, and will be a milestone in the everyday fight that associations from all over the world are running everyday against IBD.

Crohn's disease and Ulcerative Colitis seem not to have preferences and don't follow any boundaries and so will we. Our cooperation will become stronger. Our research support will be more informed and rational. On the 18th of October we will stand up again, making another step towards a better future, because we do not know how far a cure is, but I know we will get nearer, and nearer and nearer.

What is even more important and encouraging, and this can be easily noticed by reading this issue of the magazine, is that EFCCA is for sure growing, but at the same time our members are growing as well. The amount and the quality of the projects and activities that are organised and led by our members is impressive and represents, in many cases, the actual golden standard. Increasing the possibility for all our members to exchange these practices is, and always will be, an important priority for us.

In a similar way, also the EFCCA Youth Group is changing and has developed over the recent months several ambitious programs. We are looking forward to seeing all the new ideas on the launchpad, and to celebrate other successes coming from the group now led by Daniel Sundstein. Having been at his place many years ago, I know how challenging it is, but I'm sure the new team will be capable to leave us without words. I would like to take this opportunity to thank the previous EFCCA Youth Group leader, Chayim Bell, for his long committment and dedication.

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In a new way, we will prepare ourselves for another watershed. Because I can tell you that there will be something else that will change the EFCCA we know. Stay tuned !

An example ? Look at the cover of this magazine. There is nothing to hide. There is only one thing to say: we are proud. We will not hide ourselves. We will not run away from our diseases. The first step for winning this battle, is to be proud of our scars.

It is an hard battle, that requires the capacity of finding new solutions, but also the courage of re-inventing yourself, and the necessity to be resilient. EFCCA is all these things. It is achieving things that were considered impossible not so long ago.

This is not possible without PEOPLE. Not only people with IBD or volunteers.

The transition towards a professionalized EFCCA started some years ago, and somehow it is still work-in-progress. But I am fully convinced that the results achieved during the last few years would not have been possible without our professional team. And I get this chance to thank all of them, not only for their work, but for what they show everyday: the committment to our cause.

It is once again with a message of unity that I want to invite you to start this adventure. Is it an adventure to read a magazine ? Yes, it is. It is the adventure of our fight, in all its declinations. It is a tale of courage, pride and stubborn optimism, and if you want, you can become central in it: you can participate.

UNITED WE STAND

Marco Greco, EFCCA Chairman

Spotlight: World IBD Day

Including IBD in EU policies

EFCCA chairperson Marco Greco with MEP Sergio Cofferati at the European Parliament

On the occasion of this year's World IBD Day, EFCCA organised a meeting in the European Parliament aimed to raise awareness of IBD within EU institutions and amongst European policy makers. The meeting was co-hosted by MEP, Sergio Cofferati, who will support the launch of a Parliamentary Question into the rights of people living with IBD and which will be presented to the European Commission.

Parliamentary questions are questions addressed by Members of the European Parliament to other European Union Institutions and bodies and are usually a first step to initiate debate and possible legislation around a given subject.

The proposed Parliamentary question will ask the European Commission what actions it is going to undertake in order to ensure the "independence, social and occupational integration and participation in the life of the community" of IBD patients and to avoid their discrimination. It will also ask the European Commission to consider the possibility of developing a Europe-wide strategy for protecting the rights of IBD people in the EU and to officially recognize their rights as disabled people all across Europe. Furthermore it will suggest to promote pan-European research aimed at finding the cause and the cure to this disease and to develop awareness-raising campaigns at national and European level to contribute to the social inclusion of IBD patients.

These questions have been elaborated on the basis of the findings of the IMPACT study which has revealed striking health inequalities within the EU as concerns access to care, length of diagnosis, availability of specialist care, treatment regimes etc.

Speaking at the European Parliament Marco Greco, EFCCA chairperson, stressed that : "even if there is still not a great deal of awareness of IBD amongst general society we will not renounce our rights and today we want to make sure our voices are heard and to say to politicians and society that we are here and that our needs must be reflected in EU policies".

Other speakers at the European Parliament event included MEP Sergio Cofferati who expressed his support to the cause of people living with IBD and medical writer and EFCCA member Sanna Lönnfors who gave a presentation on a European comparison of the IMPACT study. Finally a patient testimonial from Michael Sere was read to participants as he unfortunately could not be present at the meeting.

For more information please visit our website where you can also see a video made during the event.

Other MEPs that are supporting EFCCA's efforts in putting IBD on the EU agenda include MEP Romana Jordan Cizelj (Slovenia), MEP Liam Aykword (Ireland), Vesna Loncaric from the Mission of the Republic of Croatia to the EU.

EFCCA is an active supporter of World IBD Day, which this year was marked in 36 countries and on four continents. EFCCA hopes that its local efforts of lobbying the European Institutions will also have a positive effect for patient associations within a wider, global movement and support them in their fight to improve the rights and well-being of people living with IBD..

Delegates at the European Parliament World IBD Day event

World IBD DAY across the globe

Australia: Can't Wait

Crohn's and Colitis Australia (CCA) organised a whole month of Crohn's and Colitis awareness in May. This year its program carried the 'Can't Wait' theme, conveying the key message that the IBD community can't wait, and not just in regards to toilet facilities.

It can't wait for shorter gaps between first consultation and final, correct diagnosis of IBD; for better access to specialist treatment and care; for the government to highlight IBD as a priority in its health programs; for employers and schools to acknowledge IBD as a valid medical condition and to properly accommodate those who are living with it; and for the general public to be more aware of IBD so that people living with IBD can talk about it without feeling embarrassed or stigmatised. As part of the campaign CCA is issuing the Can't Wait Card to members of CCA who have been formally diagnosed with Crohn's or colitis (IBD), to help them gain access to a toilet in times of urgency.

If you would like to find more about this campaign or about CCA please visit their website at. http://www.cantwait.net.au/

Paticipants at the VII Walk for Crohn's and Colitis in São Paulo

Brazil: We made the difference!

As part of the World IBD Day celebrations, the Brazilian Association for Colitis and Crohn Disease (ABCD) promoted the VII Walking for Crohn and Colitis on the 13th of May at Ibirapuera Park, in São Paulo city. Sponsored by Abbot, the event aimed to create public awareness about the importance of an early diagnosis and the correct treatment of the IBD.

"Together we can achieve better results in every aspect – political, scientific development and awareness. When we talk about awareness, I believe it is fundamental to clarify that the Walking for Crohn and Colitis is not targeting only those with IBD but also their relatives willing to give their support. In fact, we want to reach as many people as possible, since in Brazil very few ever heard about it", explained Dr. Flavio Steinwurz, ABCD president and member of the International Organization for the study of Inflammatory Bowel Disease (IOIBD).

"ABCD has the great pleasure to be one of the six world entities that first started promoting the World IBD Day – this number has multiplied and nowadays many others have joined us. ABCD has also contributed with the World IBD Day site development."

Support and Information

The sisters Marli Vicentim and Marisa Lima were the first to arrive at the ABCD stand at the Planetarium. Having a brother diagnosed with colitis, they know very well how difficult it is to have very little information: "Brazilian healthcare is in a very critic situation, public service is very poor. Our brother received a late diagnosis and because of that we looked for ABCD support, both physiological and informative. The family needs to be fully aware." says Marli.

Marco Palmerio, father of little Livia and Laura and 16 years with Crohn Disease, took not only his wife, but also his daughters, brothers, parents and parents in law to the walk. "Since few people know the disease, I think it's very important to inform the public. Media coverage and ABCD's work has changed this scenario a lot but there's still a lot to be done, that's why we are here", he said. His wife, Fabiana, pointed out the importance of sharing experiences with other patients and their families: "It's fundamental. Knowing we are not alone helps us to cope with the disease."

About ABCD

The Brazilian Association for Colitis and Crohn Disease (ABCD) celebrates its 13th anniversary in 2012. As a non-profit entity, founded in 1999, ABCD purpose is to offer easy and effective access to information about the IBD through educational material and programs, providing meetings with self-help groups and interchange with international entities, which allows representativeness and sector updating.

For more information: http://www.abcd.org.br/

Ireland: Raising awareness

Ireland celebrated its first World IBD Day this year and as a first celebration it was a great success. The Irish Society for Crohn's and Colitis (ISCC) Youth Group organised the distribution of the purple World IBD Day ribbons to a number of Government Ministers and medical teams around Ireland. ISCC published a "Top Tips" sheet for IBD patients and a new Travel Booklet was also published – both are available on the following website: www.iscc.ie .

On 19th May in Dublin city centre ISCC also held a Land and Aqua zorbing event where participants took part in either land or aqua zorbing and some even managed both! It was a great success and definitely something to celebrate World IBD Day. ISCC will continue to build on this and is already planning World IBD day 2013.

Members of ISCC during World IBD Day

UK: Sport and Fitness

Using the public interest in the London Olympic Games , Crohn's and Colitis UK highlighted how IBD affects fitness and participation in sport. The charity surveyed almost 1,000 people living with Crohn's or Colitis, 80% of whom had given up or reduced their participation in sport either temporarily or permanently, as a result of their IBD symptoms – in other words, around 192,000 people across the UK find it difficult to be as active as they once were, and all this in a year when, thanks to the Olympics, sport and fitness are high on the national agenda. National and Olympic hero, the oarsman Sir Steve Redgrave, lent his support to the campaign, saying "There were times when it seemed that Ulcerative Colitis would prevent me from reaching that fifth gold medal, but with the right medical treatment I've been able to keep the illness under control and continue with my life …".

The 2012 theme of IBD: Sport and Fitness proved popular with the media and as a result last year's media coverage has already been surpassed. The media outlets ranged from Sky Sports News to BBC Radio 2, with the interviews reaching a staggering 154 stations and an audience of over 51,000,000 people. With the disease affecting 1 person in 250 Crohn's and Colitis UK hope that this will have had a life changing affect on hundreds of thousands of people.

More info on: www.ibd-sportandfitness.co.uk

Footballer Russel Martin and ambassador for Crohn's and Colitis UK

Norway: Good Morning Norway on TV2

The patient association, LMF, was responsible for the Norwegian part of the World IBD day. The arrangement was set up in collaboration with professional expertise from Abbott Norge AS, MSD Norge AS and local branches of LMF.

Camilla Lyngen, a 17 years old, local LMF member from Trondheim succeeded with her initiative to get TV 2 to shed light on inflammatory bowel diseases during their morning show. The show is one of the most popular programs in Norway and is seen by a large number of viewers. Gastroenterologist Oistein Hovde and Bent Hoeie, member of the Norwegian Parliament and chair of the Standing Parliamentary Committee on Health and Care Services took part along with Camilla. The interaction between the patient, Camilla, with high disease activity, the politician and the medical expert gave very useful information on IBD. The website address of our association appeared on the screen and remained there throughout the show. Dr. Hovde took part in an online debate after the show and answered more than 30 questions in a clear and informative way.

World IBD Day staff at the information stand at Oslo Central Station

Other World IBD Day activities in Norway included an information stand at Oslo's Central station, the launch of the new LMF website, the launch of an interactive smartphone application called "the Porcelain Guide" allowing users to register and find the nearest toilet available and an interactive IBD seminar which was broadcasted online. Two doctors lectured on the issue of IBD and life quality followed by a question and answer session. Over 230 people participated in the webinar and LMF considers it a great success and has had lots of positive feedback from people who are either too ill or live too far away to attend seminars like this.

LMF, Abbott Norge AS and MSD Norge AS consider the World IBD Day in Norway a success and would like to thank everybody who took part in making the event a success. All the activities were filmed and will be published as soon as they are ready with subtitles in English.

Greece: "Crohn's Disease and Ulcerative Colitis are not a TABOO!"

That was the message with which the "Attica's Society of Crohn's Disease and Ulcerative Colitis Patients" (ASCC), celebrated World IBD Day, in a public awareness event on Saturday May 19, 2012.

The event took place in downtown Athens on Korai Square and was organized with the support of the Municipality of Athens and under the auspices of the Ministry of Health and Welfare. Members of the ASCC informed the public about the daily difficulties that the patients are facing, the importance of early diagnosis as well as the new available therapies. During the event "Motus Terrae", a street theater group, participated with a specially designed theatrical performance, presenting in an original way the practical and psychological problems faced by patients in their daily life.

To see the performance visit the following link: http://www.hellasnews.tv/site/index.php?option=com_seyret&Itemid=90

New Zealand: Purple Ribbon

Crohn's and Colitis New Zealand organized a media-rich campaign for World IBD Day commencing with a 'purple ribbon' event in the grounds of the NZ Parliament. Over 100 local members and family, wearing purple t-shirts joined together to form a purple ribbon and then reformed to spell IBD.

Local experts joined the throng, together with 18 year old Michael Robinson - one of the local heroes. Michael has recently had a purple ribbon tattoo on his arm, in recognition of his little brother, who at nine years old is struggling with Crohn's disease. The parliamentary host and Member of Parliament, Dr Jackie Blue, presented the IMPACT report. Four other local heroes represented Crohn's and Colitis New Zealand around the country, all were being interviewed by their regional media. National media had also being targeted with the results of the IMPACT report.

Local support groups got out and about in their communities, with display and information stands. Wearing purple t-shirts, they handed out pamphlets, gave out purple ribbons and increased public knowledge of these devastating diseases.

Poland: “WC out – coming out from the toilet”

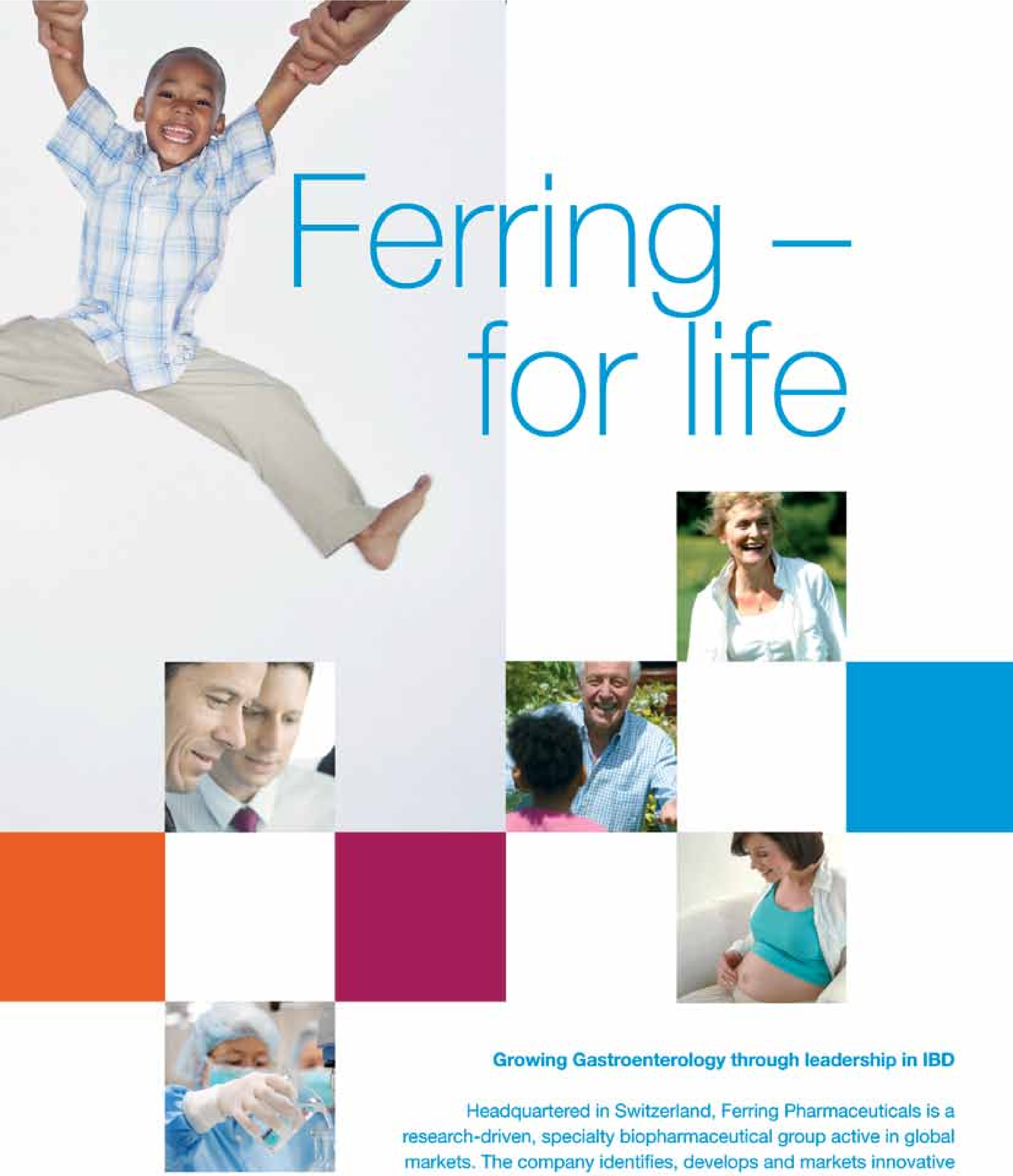
Photograph: Radoslaw Ptak
Model: Emilia Brochocka

World IBD Day celebrations started on 17 May in Warsaw with a press conference “Out of therapy”. Its theme were the draconian conditions which Polish patients must fulfill to get biological treatment. Even if they finally get it, therapy lasts maximum one year. The conference has been a success and the story was shared on TV, printed press and the internet. J-elita (the Polish IBD association) hopes that this will be the beginning of much needed media attention.

On 19 May members from Warsaw, Wroclaw and Katowice organised a variety of lectures about IBD while children learned how to dance salsa and were asked to design toilet paper “clothes”. One of the volunteers spent several weeks preparing her “toilet dress” – the effect was breathtaking. The highlight of the day was a toilet paper battle which attracted many people who learnt about IBD and patients problems.

They could also see pictures taken during a photo session entitled “WC out – coming out from the toilet”.

“By creating this project we wanted not only to encourage people to speak openly about IBD, but also show what IBD is. Let people know that despite IBD we can lead a normal life. Show that we are in happy relationships, we have children, we study, work, plan our future, enjoy sports and do many other “normal” things. Although Crohn or Colitis are our companions for life, we aren't “locked in the toilet”. So do not be shy and do your WC OUT!” said the originator of the session Emily Brochocka who also suffers from IBD.
All images can be viewed at:
http://j-elita.zeno.pl/WCout.pdf .


Ferring –
for life

EFCCA Youth Group meeting

Copenhagen, 12-15 July 2012

Improving collaboration between the EYG and national associations

by Daniel Sundstein

I went to the EFCCA Youth Meeting (EYM) in Copenhagen with many hopes for the days to come and for the future of the EFCCA Youth Group (EYG). On the one hand I was the organizer of the meeting and was very excited to see what delegates would think of the meeting and the city of Copenhagen. On the other hand I was standing as a candidate for the position of group leader. A lot of work was in front of me, but I was prepared and felt ready for both jobs.

The election went well for me as I was elected new group leader for the EFCCA Youth Group. A position I would never have never seen myself in just few years ago when I participated in my very first EYM in Paris 2008. Since then I've been at four other meetings in Amsterdam, Norway, Poland and now Copenhagen. Besides that I've participated in the EFCCA General Assembly in Copenhagen and Porto as an EYG observer. This has given me a very good insight into how EFCCA works and how decisions are made.

One thing was to say yes to run for the position - an other thing was to be elected. Therefore I want to thank all of the delegates who voted for me. I was speechless when I was elected and I still don't know how to thank you all enough.

I have a lot of goals I want to fulfil in my time as leader for the EYG, to start with I want the newly elected youth group to have closer contact with national delegates and the national associations. We want to use the information we have got from the EYM 2012 to constantly improve our work in the time between the Youth Meetings.

In line with having a closer contact to the national (youth) organizations I and the group will work for an online platform to share information, activities etc.

I have a personal matter of great importance: Sport and IBD. I know it is a subject that is important for EFCCA in 2012, too, taking advantage of the interest generated by the Olympic Games in London. Since so many of the newly diagnosed are young people in the age group between 15-30 years old, I want the EYG to share the newest information and research of Sport and IBD so that the newly diagnosed patients can get this very valuable information and hopefully use it in their new lives.

Another main focuses will be the EYM in Germany in 2013. It will coincide with the 10th anniversary of the EFCCA Youth Group. We have to celebrate this with the greatest EYM ever. So I hope that we can talk and cooperate with the organizers from the past EFCCA Youth Meetings to make EYM 2013 a memorable meeting.

An alternative World IBD Day for the youth. My thoughts about the World IBD Day are, that many youth organizations in Europe can have another main focus than the "adults" and my hope is that a lot of young people with IBD can get in contact with local and/or national media to tell their story and thereby raise awareness of IBD.

We also must have closer contact with our most important collaborators: the EFCCA board and the European Patient Forum Youth Group.

Last but not least I want to create a youth group with a common cause. Separately we can do a lot, but I'm sure that this group will take the youth group in to something new.

This brings me to the last aim I will have as EYG Leader: to help find a cure. Hopefully in 50 or 100 years there will be no EFCCA. Because then we will have a cure for IBD. I'm grateful for the opportunity I have been given. The opportunity to have met all these wonderful people with IBD. I Hope to see and meet many of you in the year to come. United we stand - together for life!

Saying goodbye...

by Chayim Bell

People are calling it a new chapter, giving other people a chance. I just call it getting old, but it has been a life changing experience. Over 5 years I have been the leader of the EFCCA Youth Group, but now it is getting time to say goodbye. I have worked with and for the youngsters for 9 years, 5 years as leader of the youth group. It is a long time, but time went by so quickly. The experiences I have got, the people I had the opportunity to work with, it was all worth it. When I first came to the meeting in Berlin 9 years ago, I met Marco Greco who was then the EFCCA Youth Group leader. The work he was doing was huge, I never thought I could do the same. Honestly, with my English at that time it would have been very difficult., but I have grown into the job, I learned so much, after 9 years I can really say I made a difference for young adults with IBD.

Chayim Bell during the last EYM in Copenhagen

One of the biggest successes is of course the EFCCA Summer Camp. It took a lot of time, we have worked years on it, but we can now say that the project is a success. There are so many different camps throughout Europe supported by EFCCA, and so many to come in the next years. This project inspired people.

One of our other successes is of course the Game, you can download it from our website. Some organizations even made it into a real board game. I've also enjoyed working with the Coeliac Youth of Europe. Over the years we have worked very closely together to establish different activities and at the moment we are also working together with the European Patients Forum Youth Group.

The EFCCA Youth Meetings were another highlight. It's amazing, the time and effort that goes into the organisation of such meetings but in the end the results always gave me such joy. Seeing 30-40 youngsters coming together, most of them who have never met each other and then within a couple of days they become like a family where you can share anything. For sure it will be an experience I will miss. Next year it will be a special year for the EFCCA Youth Group as it will be 10 years of age. It's a huge accomplishment, so much done but still so much to do.

Another accomplishment is that this year we had so many volunteers that we had to expand the team to 10 members …but one thing stays the same: every member of the team gives themselves 200% to the work. Without all those friends we could have never made it such a success. I'm saying goodbye with pain in my heart, but I won't leave, I will stay active within EFCCA as secretary and I will keep on supporting the youngsters in my own way. The last thing I want to ask you to do is to keep on dreaming, no dream is too big. I had huge dreams for the youngsters, all my dreams came true. As long as you work for it, your dreams will become reality! Till then....

Feedback from a newcomer

by Kata Daru, Hungary

This year was the first - and hopefully not last - time that I participated in the EYM in Copenhagen and I can honestly say that it was one of the most memorable experiences of my life. It was so great to see all those youngsters from Europe who wish to make a change in their fellows' lives who also suffer from IBD. The meeting was very useful and we could learn a lot from each other, as well as develop some new ideas together, in the meantime, it also felt like a big family.


Kata Daru participating in some outdoor activities of the EYM Copenhagen

Currently, we do not have a youth group in Hungary, but after this meeting I came back with millions of ideas for establishing one. I know that we have a long road ahead of us in our association, but I am also sure that we can always count on the support of the other associations' youth groups in Europe. I have already started to develop some of the ideas and hopefully we can start to work on them this fall. On the other hand, I am really grateful for EFCCA, because they immediately offered me to use the explorer pass and paid for the trip. As they said, money cannot be an obstacle in such a case and I had to be there this year. Since our association is very small, it was a great help.

It might sound a bit silly, but in today's world, when everything is about personal success and money, it is extremely nice to be part of a group - or better to say, a family - like this. I am looking forward to working with the EYG this year and I firmly believe that together we can reach anything in this world. Together for life.

EFCCA Network of Summer Camps

Following a 3 year strategy plan of our Catch Your Dream camps, EFCCA proudly co-worked this summer with 3 camps throughout Europe for people with IBD. These camps were co-organized by the local IBD associations in the country and EFCCA including a summer camp in Montargil, Portugal (6-8 July) which was attended by over 70 people (see page 28), a camp in Niechorze, Poland (12-26 July) organized by J-Elita and attended by over 90 children and their families (see page 23) as well as a camp in Dinard, France (4 -12th) August for over 40 young adults organized by Afa.

EFCCA had the opportunity to visit the camps in Poland and France and it was amazing to see the energy among the youngsters keen to learn from each other.

Participants made strong connections and hopefully formed long lasting friendships in an environment where they could share they deepest fears about IBD, but at the same time also learn from each other of how to cope with their daily challenges. The French summer camp also included participants from other French speaking countries such as Belgium and Switzerland.

For EFCCA these camps have been a great success allowing us through this program to support over 200 children and young adults with IBD. In November we will be organizing a special feedback session for the three associations and take the opportunity to evaluate this new way of working in order to decide how to proceed in the upcoming years. We will also be inviting other associations who are interested in creating their own summer camp next year.

If you are interested in learning more about the European Network of Camps please sent an email to me at chayim.bell@efcca.org

Chayim Bell
EFCCA secretary

From left: sand castle building competition (Poland)- out door activities at the French summer camp

World Symposium on patient led IBD Research

EFCCA is launching an exciting new initiative on research in IBD. On 18 October 2012 it will organize the first World Symposium on research funded or promoted by IBD patients' organisations.

It is estimated that there are over 5 million people worldwide who have ulcerative colitis or Crohn's disease (together called inflammatory bowel disease, or IBD), in Europe. There is no known cause or cure for IBD, and the debilitating symptoms can greatly affect a person's quality of life.

Even though there are important researches carried out by pharmaceutical companies and other organisations, which so far have yielded many positive results for people living with IBD, our final objective "to find a cure for IBD" has unfortunately still not been met.

In parallel to pharmaceutical funded research on IBD there are also many patients' associations across the globe that directly or indirectly fund research on IBD. We believe the moment has come to connect with these organisations and to exchange important information on existing and/or planned research projects with the aim to ensure better optimization of research funds earmarked for IBD.

The World Symposium will gather worldwide patient associations that are involved in substantial research programmes on IBD. The Symposium will collect on-going or planned research projects which will be published in a "White Book on Research funded by patients' organizations". This book will be distributed during the Symposium including a special chapter on priorities and needs which will also highlight needs by patients' organisations that do not directly fund research.

Speakers during the Symposium will include representatives from IBD associations presenting their research projects as well as well-known medical experts such as Professor Claudio Fiocchi, Professor Laurent Beaugerie, Professor Gerhard Rogler and Professor Silvio Danese who will set the context.

For more information please check out our EFCCA website.

EFCCA at Digestive Disease Week

The annual Digestive Disease Week (DDW) took place in San Diego from 19 to 22 May.

DDW is considered to be one of the largest platforms for medical practitioners as well as equipmentand service providers in the fields of gastroenterology and other related sectors.

Being held for quite some time now, DDW hosted this year about 250 exhibitors displaying their technologies, products, equipments and healthcare services to visitors including prospective customers, researchers and the like. Comprising of forums, abstract presentations and satellite symposiums, it welcomed more than 15,000 visitors, mainly the medical professionals involved in research and practice in the wider field of gastroenterology, a large number of academicians, clinicians, researchers, students, trainees, GI practice managers and administrators.

EFCCA stall at DDW

EFCCA was present with a booth and three delegates. The core objective was fully achieved: our booth was publicizing the WORLD IBD DAY: purple balloons, ribbons and leaflets attracted the attention of many visitors.

The opening day was also the occasion for officially launching the video shot during our World IBD event in the European Parliament and a number of contacts interested in our future activities on WIBD passed by and left their coordinates.

The EFCCA magazine was distributed to physicians and industries while some of our stakeholders confirmed their interest in our projects and action for 2012 and the coming year.

EFCCA also participated in the breakfast meeting organized by CCFA (Crohn's and Colitis Foundation America) and immediately after the traditional meeting with world-wide sister organizations took place. It was the occasion for sharing the first outcomes of 2012 World IBD DAY and to draft a mid-term strategy on it.

CCFA agreed in circulating a document on a 3 year plan. EFCCA will be in charge to co-ordinate the website and to enlarge wherever possible the number of participant in it. ABCD Brazil will be sharing its interesting experience of an online service animated by patients and physicians.


HUMANCARE

EMPATHY Project: Europe meets Young Patients

A new adventure for EFCCA and EFCCA Youth Group

by Luisa Avedano, EFCCA CEO

EFCCA Youth Group is partner in a European Project named EMPATHY – Europe meets Young Patients, funded within the Youth in Action Programme 2007-2013 – Support the European Co-operation in the youth field (start: 1 August 2012, end: 31 October 2013). The European Patients Forum is the lead partner while the whole partnership is composed of young representatives of EPF members coming from Poland, Estonia, Lithuania, Malta, and, after the first Steering Committee meeting, which will take place at the end of August in Malta, we will be able to give more detailed information on tasks and responsibilities of each participant.

The purpose of this project is to organise a 4-day seminar where young chronic patients will establish an active dialogue with EU-level policy makers, stakeholder groups and patient organisations. It will promote a more holistic approach to addressing young patients' needs in EU decision-making processes. The seminar will consist of a balanced mix of young patients, policy-makers and stakeholders, involving young patients, some more experienced patient leaders from EU-level patient organisations, and a number of EU decision makers and senior-level representatives of stakeholder organisations from the health, education, social and youth policy areas.

Through activities like "a day in a young patient's shoes", stakeholders, policy makers, and senior patients will be able to improve their understanding of young patients' needs and challenges that they face in their daily lives. Likewise, through a set of policy discussions and "policy-making role-plays" young patients will be able to understand the dynamics of decision-making processes having consequences on their life, and they will be able to influence decisions to be taken in the future through commonly agreed recommendations. The seminar will be held in Brussels, in March 2013 and a 6-month preparation period is envisaged, during which a youth steering group made of young participants and an advisory body of representatives of policy-makers, stakeholder organisations and senior patients will be set up to ensure that the event is as aligned as possible to young patients' expectations and centred around key policy issues in the four domains identified for this project.

"A day in a young patient's shoes"is one of the activities foreseen of the EMPATHY project

The expected outputs of EMPATHY are:

- a final report and accompanied by
- 3 sets of recommendations: one for policy makers, one for stakeholder groups, and one for patient organisations on how to integrate young patient perspectives into their work
- a toolkit for young patients on how to make their voice heard in EU policy making.

The EMPATHY resources (infosheet, report, recommendations, toolkit) will be translated into the languages of the partners' countries. It is foreseen for these resources to be distributed at various European and national events.

This is the first time EFCCA and its Youth Group are fully involved in a European project and, as already reported, EFCCA is still waiting for the European Commission's reply on other submitted applications.

Another important step towards a wider involvement in European actions and policies has been made and EFCCA's position in the European arena is becoming more and more structured.

OPTIMISING OUR TOOLS

EFCCA IT PLATFORM IN PIPELINE

by Luisa Avedano, EFCCA CEO, Andrea Broggi, EFCCA Officer

In the past three years EFCCA has been involved in an increasing number of IT projects. The IMPACT survey is the best known and more visible one but from Life and IBD, the toilet locator pilot project to the several clinical trials we have published online it has become more and more evident that our organisation needs to be able to handle diverse IT tools keeping, as usual, data protection and privacy rules at the top.

The increasing number of potential activities we may develop through internet, apps and dedicated programmes made EFCCA design a new long term project whose fundamental instrument will be an IT platform.

In simple words a platform is an underlying computer system on which application programs can run. Moreover a platform is a crucial element in software development. A platform might be simply defined as a place to launch software. We have hardware platforms, software platforms and cross platform. Let's make some examples, Linux and Microsoft Windows are platforms, the web browser you open to see the EFCCA website is also a platform. Facebook became a platform when it decided to allowed third-party applications to be built on top and launch from it.

Indeed one characteristic of an IT platform is allowing others to build on top of it. What can we do with an IT platform managed by us?

Create. We can build applications and tools that allow you to write about your experience, keep records of symptoms and describe your diet.

Share. You can also choose to share part of these records with other people. Moreover your doctor can have access to your profile.

Follow. You can follow people with the same experience, listening and making suggestions.

Welcome. We can develop tools as the toilet locator pilot project allowing anyone to gather distributed data via SMS, email or web and visualize it on a map or timeline.

Analysis. The IT platform can give us the opportunity to launch new online questionnaires and make the IMPACT survey available to other patients' associations that are willing to join it and give the opportunity to doctors, researchers and people who simply want to know more (and in a qualified way) to access data. Moreover we can have an E-library to publish research working papers in order to receive feedback.

Stay safe. We want to develop apps and tools respecting our values. Data have to be stocked in a safe server and be available only from our IT platform.

Denmark

Monday is a Crappy day – a three step model

The rules in Denmark, today, make it very difficult for our youth to finish a secondary education. Nevertheless, the Danish Government proclaims that in the year 2015, 95 percent of all youth beginning a secondary education, will also finish it.

This will be interesting, as they haven't considered that a lot of young people, especially the ones with Ulcerative Colitis or Crohn's disease, may need extra time to complete their education.

Everybody wins when a person gets an education – it's a smart societal investment. To make this happen, the Danish Colitis-Crohn's Association (CCF) has developed a plan in three parts – and the execution is already taking place.

The campaign is called Monday is a Crappy day (Mandag er en lortedag), because yet another week begins on a Monday, and Crap does have a special familiar meaning for us.

Part 1 – the seed is planted
At the Peoples meeting (Bornholm, June 2012), CCF had the chance to meet most of the Danish politicians, a lot of them from the ruling government. Many of them attended a short hearing on the beach, arranged by CCF. Now, they know that not all of our members will be able to fulfil the 95% demand.

Part 2 – pulling the Celebrity card
The best way to show what many of our members have to deal with everyday is to get it on tape - with a famous person experiencing it.

Our ambassadors and famous actors, Paw Henriksen and Mia Jexen, both have Colitis, so they know what it is like, but their famous colleague, Therese Glahn, had no idea. So she was chosen to live like a patient for a day. Our ambassadors used a mobile phone to send text messages to Therese, all day long. Find a toilet now, change your clothes, take your medicine, you are in pain, rest etc. etc.

In September the whole Parliament, and selected journalists, will receive a pair of clean underwear, and a written request to help our members being able to finish their educations.

A group of politicians and doctors will also be living the life of a Colitis/Crohn's patient for a day. To reach the public a special website with videos, pictures, competitions etc. will be launched. By then the whole country should have heard about the problem.

Part three – now we want action
While it is still hot, we want binding declarations from the politicians. In October 2012, CCF will hold a conference in Christiansborg (where the Danish Parliament resides) and conclude the Monday is a Crappy day agenda – with results.

Since a lot of youth is affected, not only CCF-members, we have invited the Danish Patient Association (CCF is also a member) and many handicap and student associations to help us form the content of the conference. Most importantly, we will also meet and talk to some of the ruling Government parties and prominent members of the opposition.

When the conference ends, we will have a finished solution/bill, and a promise that the participating politicians will help us change the present legislation.

Bente Buus Nielsen, CCF

France

Raising funds

In France, National IBD Day is on 6th October this year, and in addition, we have celebrated the World IBD Day on 19th May. afa's objective is double – inform the public about IBD and also raise funds for our different activities. The 30 odd delegates and 200 volunteers in France are mobilised to organise challenges of all sorts – sports, cultural and other creative activities! – Bicycle races, choral concerts, all types of competitions and even belly dancing…

We have focused our attention on that extraordinary tool, the web, to innovate by nationally collecting funds on web pages, set up by anyone who wants to help, whether young or old, via the ALVARUM website, which secures the amount sent directly to afa.

In Paris, we're using the website for a large-scale sports event called Roll'Solidaire, translated Roll'Solidarity, to be held on 29th Septembre in the Bois de Boulogne Park, in Paris.

Over 8 km through the park, led by Taïg Khris, the acrobat rollerblade champion, participants can walk, roll away on their blades or scoot on an unmotorised scooter for those kids from 7 to 97 years old who dare. Each participant in this Roll'Solidarity, prior to the date, has committed to collecting a minimum of € 200 on behalf of afa by opening an account on www.rollsolidaire.fr. The organisation of this event has already been financed by the afa partners, each donation going directly to our research and patient support missions.

This Anglo-saxon sponsoring principle based on running for a cause is still in vogue in France. No doubt our compatriots still expect too much from the State which will less and less be able to finance the great causes like our own. So, we are anticipating!

Chantal Dufresne-afa

Austria

Compass through the fire

The ÖMCCV participated in an interesting meeting entitled "compass through the fire" The meeting united five different disease groups whose patients experience inflammation or "burning pain" (hence the title) on a regular basis. The idea was to promote networking amongst self -help groups that deal with chronically inflamed diseases and to learn from each other. To bring this idea forward an information day was organised bringing together five different self help groups, namely the ÖVMB (the Austrian Association for Ankylosing spondylitis), PSO-Austria (Self help group for Psoriasis), ÖRL (Austrian Rheumatic Association), Rheumalis (Self help group for parents with rheumatic infants, children and and young adults) and the ÖMCCV (Austrian Crohn's and Colitis Association).

Many ideas and proposals were put forward which were shared during a press conference. Participants included patients, family members, doctors, therapists and other healthcare workers who took the opportunity to share information, network and to learn. There were also workshops and presentations with a main focus on medication, therapy and wellness as well patients and communication. Other activities included a dance workshop, yoga, drumming, Quigon and laughter!!! It has been a successful event. Very often one feels alone with ones chronically inflamed disease, one feels misunderstood and one feels that special needs are not recognised and our restrictions in daily life are not taken seriously. I hope all the people present at this event came out understanding that they are indeed not alone!

Evelyn Schauer, ÖMCCV

The Netherlands

Colitis Collectie shows life with Ulcerative Colitis

What does your life with Ulcerative Colitis look like? That is what the eight participants of the Colitis Collectie (Colitis Collection) are trying to capture with their video camera. The aim is to show how Colitis influences their lives, how they are sometimes confronted by their own boundaries and how difficult it is that you cannot always participate in events, due to fatigue.

Four years ago the power of image over words already became apparent. Nine people with Crohn's Disease portrayed their lives on video, for the project Crohnjuwelen (Crohn's Jewels). The project was an enormous success. It even won a prestigious healthcare communication prize. Now it's high time to give people with Ulcerative Colitis the chance to capture their life on video.

Recognition

After selecting eight participants that differ in age and background, some with a pouch or stoma, a weekend was organized to get to know each other and to look for the answers to the questions: what does having Ulcerative Colitis mean for me and how am I going to capture this on video? During the weekend, the participants were given instructions on the best way to film themselves.

Director of the Crohn and Colitis Ulcerosa Vereniging in Holland, Tineke Markus, says the following: "There is an incredible need for recognition. We already saw with Crohnjuwelen that video blogs (vlogs) can provide this recognition. Participants will have to show a lot of themselves for the Colitis project. I think it is extremely brave that these people are committing to this film project. They are the heroes of the project." Participant Siety says the following on this: "Before I came here I was afraid the others would be pathetic people. But they are all strong people with their own stories, in which I recognise a lot."

The national premiere of the Colitis Collection will take place on 13 October in Amsterdam.

Tineke Markus, CCV

Poland

Solidarity for people living with IBD

Since 2006 J-elita has been organising summer camps dedicated for children with IBD. In 2012 our camp took place in mid-July. As youngsters were under 18, they were accompanied by their parents or other family members. J-elita invited also professional supervisors (gastroenterologist, psychologists, teachers) who helped organise the time for our young participants. The programme was very dense and covered many exciting activities such as competitions (volleyball, discovering the secrets of pirates, games, building sand castles) and trips to exhibitions (gardens, lighthouse, museums, aquarium).

We organized educational workshops with psychologists and of course also managed to relax in the evening when we had barbecues and bonfires. Other popular activities with the children included horse riding and a trip to an amusement park. Jelita rented the whole resort for our group (ca 90 people with 40 children among them) and a special diet was available in the canteen. Moreover, this year J-elita was awarded the EFCCA Label as a part of Summer Camp Network and we welcomed the visit of Chayim Bell - EFCCA Secretary, to the campsite. We're much grateful for the support!

Recently J-elita has launched a new way of helping individuals who suffer from IBD and who have financial difficulties to buy the necessary medicines. We set up a new cooperation programme between J-elita and one of the foundations from the pharmaceutical sector. The aim of the programme is to give to these people prepaid cards which they can use in one of the Polish pharmacy chains. The funds come both from J-elita and the foundation (50%:50%). The card can only be used to pay your prescribed medicine in the pharmacy, it can not be used to withdraw the cash. The cards are issued for several prescriptions therefore the user does not have to use up total credit in one go. We have advertised the cards in our Magazine to allow people who needed help to apply for them. An easy application form together with the doctor's opinion are required. It helps us to decide who should get the cards first.

Now we are negotiating participation in the programme's next year edition and getting ready for the "adult" summer camp which will take place in the Sudeten Mountains, last week of August.

Pawel Staniewski, J-elita

Switzerland

PACE Race 2012: Bike-a-thon with cycling champion Franco Marvulli

Saturday, June 16th, marked the sixth edition of the PACE Race cycling event. This bike-a-thon brought together patients suffering from different chronic diseases, representatives of patient organizations, doctors and Abbott employees, who cycled different routes throughout Switzerland. The proceeds of the cycled kilometers were distributed to the participating organizations. Franco Marvulli,racing cyclist, Multiple World Cup Winner, European and World champion participated in the race as a guest star. Director of Public Health Urs Hürlimann delivered a moving and inspirational opening speech on behalf of the Government Council of Zug.

More than 600 smiling members of 16 distinct Swiss patient organizations entered the bike-a-thon under this year's slogan "Tour de Suisse". Four different routes were prepared, with starting points in

Burgdorf, Baden, Rapperswil and Zug (Tour of Lake Zug) and ending in Cham. Among the participants in the PACE Race organized by Abbott AG from Baar, were patients suffering from rheumatic diseases such as Morbus Bechterew and rheumatoid arthritis, as well as people affected by adiposity, Morbus Crohn, Ulcerative Colitis and psoriasis patients. For the first time this year, patients suffering from renal and cystic fibrosis as well as Parkinson disease also participated in the race. Urs Hürlimann, Director of Public Health, welcomed the cyclists in the glistening sunshine on behalf of the Government Council of Zug and praised the commitment of the host.

Altogether, the participants cycled almost 30,000 km, which translated to a total donation of CHF 54,000.-. Cycling champion Franco Marvulli, who tackled the route from Rapperswil to Cham, commented, "The participants, many who are patients, have done a tremendous job. I am very impressed by their motivation. This is why I would like to contribute another CHF 1,000.- out of my own pocket."

Patrick Horber, General Manager at Abbott AG in Baar, welcomed the European guests: Marco Greco, President of the EFCCA (European Federation of Crohn's & Ulcerative Colitis Association) and Luisa Avedano, EFCCA-CEO. They expressed, "We are very impressed that it is possible to reunite such a large number of people with very different diseases in one spot for one common cause. Fantastic!"

Photo Kayhan Kayar/Alexander Hanna on behalf of Abbott AG

Ireland

Open Day event

The ISCC held its AGM and Open Day on 21st April in Dublin. There was a large attendance and we had a very packed agenda.Following the AGM there were presentations from ISCC Committee members Colette Cotter and Victoria Cleary.

Tricia Mc Ardle from the ISCC Youth Group then gave a short address outlining events planned by the Youth Group for the coming year.

We then had presentations by a Gastroenterologist and Surgeon from the Mater Hospital Dublin followed by a lengthy Question & Answer Session.

Ireland also celebrated its first World IBD Day this year, for more details please see page 8 and/or our website www.iscc.ie .

Geraldine Murphy and Ciara Drohan
Irish Society for Colitis & Crohns Disease

Argentina

Promoting early diagnosis of IBD

In Argentina in recent years we have seen the development of public health policies and disability legislation that take into account the needs of people suffering from diseases of major prevalence. It is only now that we are starting to face the challenges to develop and implement sustainable and effective strategies that address the issues of Rare Diseases such as IBD.
Fundación Mas Vida de Crohn & Colitis Ulcerosa, in collaboration with socially responsible companies, have elaborated a plan of action, which aims to optimize available resources in order to disseminate and raise awareness about IBD amongst the population and the medical community by providing valuable information.
A concrete action has been the distribution of information material such as posters and flyers to health

centers and specialised gastroenterologists units both for adults and children all over Argentina. With this action we hope to facilitate early detection and diagnosis of IBD.

Another great challenge we have met is to raise funds for two fellowships for research on the epidemiological study of IBD at the national level that is being implemented by two, prestigious, scientific institutions, the Argentina Paediatric Society and the Argentina Society of Gastroenterology.

Argentina, like many other Latin American countries does not have an official record of this pathology and the issues surrounding Rare Diseases remain a great challenge for all stakeholders involved in this process from public authorities, industries, health professionals and NGOs.

Luciana Escati, Fundación Más Vida

United Kingdom

Crohn’s and Colitis UK scoop commendation

Crohn’s and Colitis UK were Highly Commended in the Best Healthcare Partnerships category at the prestigious Communique Awards recently, in acknowledgement of their work with Abbott last year to produce their report “Crohn’s, Colitis and Employment” which, together with their Fact Sheets for Employers and Employees, has had thousands of downloads in the past 12 months. The report, and explanations of what reasonable adjustments employers might take in order to keep employees living with IBD in the workplace, realising their full potential, can be found at: http://www.wix.com/emi653/gooddeskbaddesk

From left: Suzi Clark, Director of Marketing and Fundraising, Helen Terry, Director of Information and Support, Crohn’s and Colitis UK with Danielle Frewin, Senior Communications and Patient Relations Manager, Abbott

Northern Ireland paediatric update

Crohn’s and Colitis UK are working with IBD teams and consultants in Northern Ireland to tackle issues around transition from paediatric to adult gastroenterology services, as currently newly-diagnosed adolescents as young as 13 go straight into adult clinics or wards. The charity has also lobbied for extra IBD specialist nurses for Northern Ireland where, until recently, there was only one part-time post. A factor in the campaign has been the UK-wide IBD audit, in which the charity is a leading partner. Gathering information from over 90% of the UK’s hospitals, the audit has been run every two years since 2006. “We have campaigned for more nurses since we launched the IBD Standards document at the Northern Ireland Assembly in 2009” said Richard Driscoll, CEO of the charity, “and we’ve done well to get this commitment for a full-time and three part-time specialist nurse posts – particularly at a time of such pressure on NHS budgets.”

Prescription Charge Coalition

Crohn’s and Colitis UK has taking over the leadership of the Prescription Charge Coalition from June 2012. The Coalition of 24 influential organisations, including Asthma UK, the British Heart Foundation, Parksinsons UK, MS Society and the Royal Pharmaceutical Society is campaigning for exemption from prescription charges for everyone in England with long-term medical conditions.

Past research has shown clearly that prescription charges can impact detrimentally on peoples' lives, sometimes affecting management of the condition, leading to impossible decisions about whether to spend money on treatment or on other basic necessities.

This is big step for Crohn's and Colitis UK and a great opportunity to stand up for members on this issue, as well as developing our profile among the public, politicians and other charities.

Suzi Clark, Crohn's and Colitis UK

Sweden

Developing our youth group

The last year has been a good year for the youth section of the Swedish association Mag- och tarmförbundet, called Unga Magar ("Young Stomachs"). From being an association that struggled with trying to reach out to people under 30, we can now look back on a year of which we've grown and built up a foundation that can become even more. It's still in its starting point, but the development so far has been good. In all it looks quite different in different parts of the country, yet the youth section is starting to find it's way in our association.

Unga Magar turns to everyone up to 30 years of age. This means we have a very broad spectrum of ages to try to offer something to. You have different needs if you're 5 years, a late teenager or 28 years old. Still we're trying to offer something to everyone, rather than trying to make everything fit for everybody.

We have our own website and our own permanent pages in the national magazine of the association, Kanalen. We're trying to use the social medias such as Facebook, where we have an official group and also a hidden one – for those who feel they don't want to declare their diagnosis or illness to the world. It can be a sensitive thing, especially when being young.

We also have different projects for young members and non-members, such as the meetings for teenagers with IBD, together with the Swedish association ILCO and another one for families. We have a website for children up to 13 with IBD, called Tarmalarm ("Bowel alarm").

We are also working on a mentorship program for young members, Faddersystemet (idea comes from a young member!). Recently we published the first short movies (and a website) about IBD and gastrointestinal diseases under the project IBD till låns ("IBD by remote control"). It was aimed to raise awareness about gastrointestinal diseases, IBD in particular, and our association. We hope this will be successful, not at least when it comes to spreading information to younger people. We also have a real editorial youth team: one youth columnist and two youth reporters.

Looking back at the year we can see that we've increased the number of members in our Facebook-groups, the number of visitors to our website, contacts from readers of the magazine and contacts from visitors on the website. Some regional associations already have young members on their boards and active youth groups, our interests lies to make it a reality everywhere. We have a long way to go, but together we will make the difference and we've already built up a foundation for the future.
Personally I want to thank everybody, all children, youngsters, young adults, parents, office staff and members of the association and the board who have been very supportive and helping out in trying to make this come true. Without you all, none of this would be possible.

Ebba Persson, Youth Editor, Unga Magar, Mag- och tarmförbundet, Sweden.

Shire GI

Innovation that revolves around patients

Shire's mission

Shire is a dynamic and specialist pharmaceutical company inspired to succeed by enabling the patients, and societies, it serves to lead better lives.

Shire's vision is to continue to identify, develop and supply specialist life-changing products that support physicians in helping their patients to a better quality of life. Fostering innovation and delivering value not only promises a better understanding of diseases but also provides the best hope of treating and eventually eliminating them.

History and growth

Since its foundation in 1986, Shire's endeavour to provide innovative treatments for medical needs that are left unmet, coupled with substantial investment in research and development (R&D), has resulted in considerable growth and diversification.

Shire's focus on improving outcomes for patients with GI diseases

Gastrointestinal diseases affect millions of people, reducing quality of life for both patients and their families. These diseases also add to overall healthcare costs. Finding new medicines will help reduce that burden.

- Shire understands the unmet needs of patients with GI diseases and endeavours to provide innovative treatments to the specialist physician for the benefit of the patient.
- Shire aims to be at the forefront of the development and provision of treatments for GI diseases including ulcerative colitis, chronic constipation and gastro-oesophageal reflux disease.
- Shire is determined to build and maintain relationships with patient advocacy groups, both through providing research funding and education, as well as encouraging a regulatory environment that supports innovation and value.
- Shire is committed to providing new treatment options and working in partnership with physicians that make a real difference in the lives of patients with GI diseases.

Shire

To be as brave as the people we help.

INT/BU/MEZ/12/0027 Date Of Preparation: May 2012

Portugal

APDI summer camp 2012

Last year during the first summer camp organized in Portugal for young people with inflammatory bowel disease (IBD) a promise to repeat the event was made so this year in July 2012, APDI kept its promise and prepared a three day weekend for young people with IBD.

This time we held a relaxing program with some learning moments about the disease and ourselves and some challenging activities for everybody to have fun. Special activities and debates were also organized for youngsters with IBD and for their friends, boyfriends, girlfriends and family members. The meal times were carefully prepared in order to challenge some of the myths associated with food restrictions and IBD and to learn more about this too.

Participants came from all parts of the country to Montargil where the bungalows and the sun were prepared and waiting for them. Some faces were already known and some were completely new. It was really great to see these participants to mix and share.

Doctors and nurses were also invited and kindly accepted the challenge of sharing three days with our young people and their friends. We are grateful for their kindness and really appreciate the natural way they interacted with the youngsters and their openness in answering questions in an accessible language so everybody could understand what was being said. The presence of the doctors was also crucial for the debates and for a better comprehension of the disease, the medication and treatments, for clarification on doubts about nutrition and pregnancy. Yes, we had the participation of a 8 month pregnant young women with IBD, so this subject became "the issue of the day" and many questions and curiosity emerged amongst the youngsters.

Each night ended with a party with some funny games, music and energy till late in the night. Once again, so much to share, and much to learn.
Although we had one more day of camping this year, we tried to extend the goodbye lunch till the very last second, sharing phone numbers, e-mail contacts and promising to be more active in the APDI daily activities. Some offered as volunteers for the association so APDI will get back to them and hopes to see them in the near future!

It is always hard to put to paper the experiences of the summer camp days and even harder to stop writing cause we feel we could keep on telling you so many interesting things that were lived in this event, but as we hope to keep sharing and talking about this event on facebook, everybody who wants to know more about these days can visit us www.facebook.com/apdi.portugal.
Finally we would like to highlight the support of the ABBOT laboratories for the concretization and success of this event, as well as the engagement of the APDI team in the all process.

Joao Machado, APDI

Summer camp participants

IBD Planet: Parental nutrition and trave

By Marek Lichota

I am thirty-one years old and live in Cracow, Poland. Since 2002 I have suffered from Crohn's disease. At the beginning the disease was taking its normal course, but these were only make-believes and in 2005 I had one surgery. I got married, became a father, and worked. Unfortunately, my "normal life" was ruined by a disease flare up in 2008. I was subjected to four operations and after a month-long struggle to stabilize my condition, I was left with approximately 80 cm of small intestine and a stoma.

Daily eighteen-hour parenteral nutrition (nutrition given intravenously) and the need to live with a stoma caused a change in the mode of my life. It took me a long time to accept the situation. Then I started to focus on things that I could do, while trying to forget the obvious limitations resulting from my poor state of health.

Fortunately, the coming months brought a gradual improvement of my health, so after one and a half years of treatment, I could undergo another operation. It's unbelievable, but in six months after this surgery, I managed to put on over 10 kg of weight. This has strengthened not only the need to consume more food taken orally, but has also allowed me to feel the proverbial "appetite for life."

Live your dreams

Since that time I have decided that I will try - to the maximum possible extent - to realize my life plans regardless of parenteral nutrition. One of the first manifestations of this idea was my participation in the EFCCA Youth Meeting in Norway in 2010.

It was my first time to come across the air transport of nutrition bags. Generally, I experienced more kindness and help from the airport service than trouble and unnecessary problems. In the end, I could consider the entire five-day trip very successful. I gained knowledge that has helped me during subsequent visits.

In June 2010, I set out together with my wife and daughter on another trip, to spend a lovely week on the shores of Lake Garda in Italy. This time we traveled by car with a mobile fridge in which we kept nutrition medicaments. During this journey we gained even more experience, as due to some damage we had to leave our car at a service station and look for a rental. I will also not forget another thing that I experienced during this trip: a dip in a pool for the first time after nearly three years.

Undoubtedly, appetite for life wasn't missing during a trip to the Polish mountains with a group of other people suffering from IBD, and the ascent of a 1,300-meter peak, after a nearly three-hour-long approach.

I also couldn't give up my favourite winter discipline, which is skiing. Once I came across the first opportunity, I went to a ski resort located 100 km from my house to deal with snow for the first time after a long time. Although the effort that I made was out of proportion to the result, it gave me a lot of satisfaction.

elling

Shortly after this week, I decided to spend the winter holidays skiing in Slovakia with my family.

These tours, as well as the opportunity to spend my thirtieth birthday with my family, friends, and colleagues, intensified my optimism in life. I try to exploit every second given and I set myself far-reaching goals.

The evidence of this is my trip to Minneapolis in the USA for the "Alive, Well, and Even Better" Oley Foundation Conference for parenteral and enteral nutrition consumers, where I obtained a huge dose of information that will pay off in further treatment. The Oley Conference gave me an extra dose of positive energy and allowed me to get to know many interesting people.

Organisational adjustments

In addition, I can also boast of a British accent. I spent two weeks of my 2011 holidays travelling by camper throughout England, Scotland, and Ireland. To be able to enjoy the natural beauty of the Cumbria Lake District, Highlands, Isle of Skye, and Cliffs of Moher, I agreed with my doctor to have a batch of nutrition bags sent to the airport in Dublin via courier, because the ones I took with me could be stored in the refrigerator for one week only. Although our return luggage looked like a come-back from six months rather than a two-week expedition, the enormity of positive memories and impressions of this trip will long remain in my memory.

PN in Poland

I think it could be interesting for you to know how I deal with my PN at the moment. Every week I get three 1.7 liter nutrition bags from my hospital (PN provider). The bags have to be kept in cooling conditions and they require additional vitamins and a few other medicines before infusion. All this is done by me or by my wife. Our health care staff is responsible for our training and examination, and for providing all necessary medicines and IV accessories.

Usually I get my PN during the night. It takes approximately twelve hours. For two years I've been using a Fresenius Ambix Activ portable pump. It enables me to put my nutrition bag into a rucksack and then I don't have to take my IV stand when I'm going away. That makes my life much easier. Unfortunately, the portable pump is not refundable in Poland, so the patient has to bear the cost of it.

Future Plans

Summing up, the implementation of all plans mentioned above has required from me and my wife a lot of effort and organization. Often it was associated with the pain and discomfort that accompanies Crohn's disease and PN. Never, however, will this be able to outweigh the satisfaction and joy drawn from life on the rightful basis. I think that for all of us it is important to fight with the limitations, and as far as possible to prevent our disease from dominating our lives in any aspect.

That's why this year I set up an association for HPEN consumers in Poland. With the amazing example and experience from the Oley Foundation and PINNT (Patients on Intravenous and Nasogastric Nutrition Therapy, based in the UK), I hope that it will be even easier for me now. Just after three months of functioning we've got more than 50 members and we're growing very quickly.

So I hope that we will build strong community of people who will support each other and share their experience on nutrition field. In last two months I have had a pleasure to join few European physician nutrition courses, to gain new knowledge and represent our association. Again it was a great chance to meet a lot of nutrition authorities from Europe and USA.

Having the opportunity to present my case, I would like to ask you all for help in finding people in your countries who are on parenteral (PN) or enteral nutrition(EN). As a member of EFCCA Youth Group Board I've got a strong will to present positive attitude and share my experience with other PN or EN patients using EFCCA network. We call it "United we stand"

Helping each other

by Claire Hunt, EYG youth group

As a teenager there are many challenges we face, pressure to fit in, to make friends, to look good and keep up with the latest trends and to achieve the grades you want to pursue your desired career. So imagine how tough it was for me when rumours started going round my school that I had anorexia. As if I didn't have enough to cope with being a small, stocky, country girl I had to face people coming up to me every day asking if I starved myself on purpose.

Claire joined Twitter to find other people living with IBD

Within a period of 8 months I began to dramatically lose weight and dropped down to 34kg aged 15 years old. I had no idea what was going on but my friends and family were convinced I had an eating disorder. No matter how hard I tried I could not convince them this was not the case and I just couldn't eat. I was taken to the doctors many times over this 8 month period and my GP claimed I was an attention seeking teenager and just told me to eat more. Many more arguments later I was marched to a different doctor by my dad and she thought I might be depressed. I still remained 34kg and had to resort to wearing clothes for 9 year old girls. My family doctor finally agreed to refer me to a gastroenterologist at my local children's hospital.

In March 2005 Professor Booth saved my life and only had to look at me to diagnose Crohn's Disease. A colonoscopy and barium meals supported his suspicions. My family and I were both relieved but confused; we had never heard of Inflammatory Bowel Disease. Unfortunately all biological treatments were failing and I needed surgery in 2006. I count my blessings every day I spend in remission as the surgery gave me my life back and I was able to function like a normal person after nearly 2 years of suffering.

It was at this point when I decided that I wanted to help other people who suffer with IBD.

I began to train as a children's nurse in 2007 but unfortunately I had to drop out in my second year as my Crohn's decided to rear its ugly head and I could not continue to study. It was a huge setback for me as I felt like I had let myself down and began to question if I could lead a normal life with a chronic illness.

It took 2 years and copious amounts of jobs before I realised that nursing is the only thing I want to do in my life and my Crohn's Disease is not going to stop me from helping others. My consultant put me back on maintenance drugs to get my condition under control and I was able to return to college in 2011 to get the qualifications I had missed out on as a teenager.

It was at this point that I decided to join Twitter to try and find other sufferers as I had realised I had had IBD for 7 years and not met anyone with the same condition as me. Twitter opened my eyes to a whole different kind of support system. I started to talk to lots of people who had the same condition and it felt so good to speak to others who understood how I was feeling. After a while I decided I wanted to meet these people in person so I set up a meeting in Birmingham for anyone who wanted to come for dinner and chat about our experiences with IBD.

It was a fantastic success and everybody had a great time, it was so rewarding to meet people who shared the same disease and we acted like we had known each other for years.

Since I joined twitter I have continued to support sufferer's online and have organised more meetings in different parts of the country. I met members of Crohn's and Colitis UK who asked me to join their youth panel which aimed to support young people with IBD. I jumped at the chance to meet young people with IBD as these were the people I would be caring for as a nurse in the future.

In the past year I have organised more social meetings, I have been actively fundraising for Crohn's and Colitis UK and in September I and a UC sufferer will be jumping 12,000 ft out of a plane for the charity. So far we have raised £2500.

I also created a video for World IBD day and have been in my local papers raising awareness for IBD. I regularly write a blog and video diary in order to help others come to terms with their disease, it can be found here http://www.tumblr.com/blog/crohnieclare89

Claire at the EFCCA Youth Group meeting in Copenhagen with Arron Gill and Chayim Bell

I was honoured to be asked to represent my association at the EFCCA youth meeting in Copenhagen. I learned so much from the other associations and devised so many ideas that I could take back to my association and implement in order to help young people with IBD.

I also put myself forward as board member of the EYG and was amazed to get elected. This will enable me to speak up for my association and get ourselves heard and supported more whilst developing exciting new projects as part of the EYG.

In September I will be moving to King's College in London where I have accepted my place on a Children's Nursing degree. Once I qualify I want to specialise in Gastroenterology and become an IBD specialist nurse for children.

All of this would not have been possible if I had not joined twitter and met so many other people with IBD. I want to continue with my twitter support group as over 500 sufferer's from all over the world have benefitted from it and it's a way of letting people know that they are not alone and there is support and help for people with IBD no matter where you live.

I hope to be able to organise a summer camp for the UK and create a better support system within our association for young people with IBD.

A journey through Crohn’s disease

Interview with Jonathan Mirin, scriptwriter, actor and producer of the theatre show “28 FEET”.

“28 FEET” has toured nationally and international to critical and audience acclaim since its 2010 premiere. It is a comedic, emotional journey about getting sick, getting better, and growing up and is inspired by Jonathan Mirin’s 20 year battle with Crohn’s disease.

Since childhood Jonathan has suffered from health problems but it wasn’t until his first year at university when he was finally diagnosed with Crohn’s disease. After completing university he moved to New York in 1994 where he started his acting career whilst struggling with his disease. Nearly 10 years after his diagnosis Jonathan was hospitalised and had to have surgery. It was around that time when he underwent a professional transition; instead of working for other people as an actor he started to write his own scripts and produced them, often with his wife and production partner Godelième Richard – a Swiss native who directed “28 FEET.”

What has been the motivation for your show?

It grew out of the experience I had when I did my first solo performance “Riding the Wave.com.”. I toured that show a lot and discovered that I loved the one man show form. I began wondering what‘s the next subject that feels the most urgent? It was clear that my experience with Crohn’s disease was on the top of the list. There are various reasons but the main one being that it had been such a difficult time for so long: ten long years which were very physically and emotionally challenging. Being a young actor can be difficult but even more so when you are sick. In those days I didn’t want to know anything about Crohn’s disease and didn’t really look for any help. It wasn’t until I did the show and therefore connected with the Crohn’s community that I realised it was actually helping me to speak to other people with Crohn’s disease. It’s also been gratifying that there’s been a newspaper, radio or TV story about the show in almost every city we’ve played – we’re helping to raise the awareness of the general public.

How did you come up with the title for the show?

It was a very tough title to come up with and several ideas were floating around. 28-29 feet is the average length of the human intestine (of course depending on the size, person and other factors etc), I guess I very much liked the visual image of the 29 being crossed out and the 28 being put over it. It’s like an editorial change that happened when you edit a manuscript for example. The other reason I liked it is because it connotes some kind of journey, the feet you walk with and a distance that you have covered.

It’s a very specific subject, how do you manage to promote your show?

Obviously our main audience have been people with Crohn’s disease or ulcerative colitis and their family members and friends but it is interesting to see that other people with chronic diseases or depression come to see the show. I am happy that I can serve them and they seem to think it's a good use of an hour of their lives.

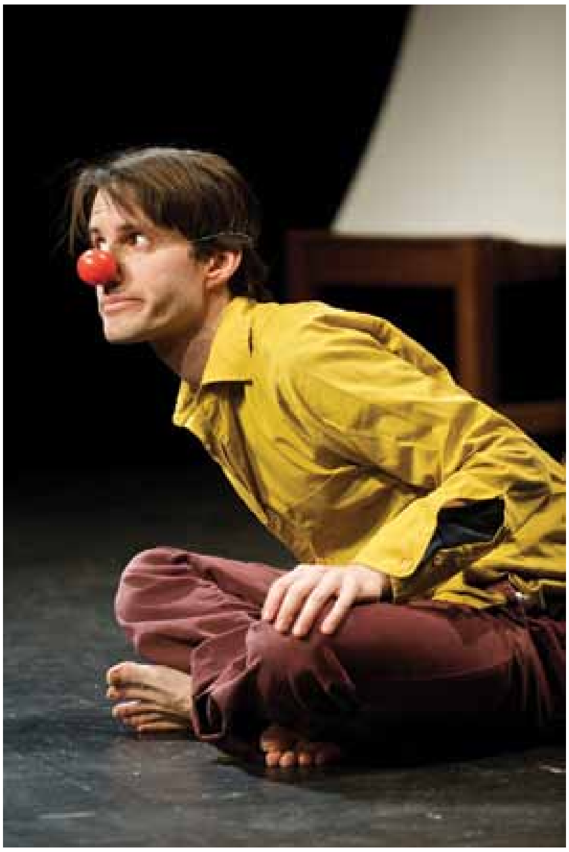
We've also performed for other audiences – for example, the staff at UCB Pharmaceuticals as part of an "Awareness Week" and now a professor at a medical school in the U.S. would like us to perform for physicians-in-training to give them more insight into the emotional lives of their patients.

In general I'm drawn to comedy and we makes this clear in the promotional material about our show. This is not a depressing show on the contrary there is a lot of hope and laughter. It's unlikely that it will ever become mainstream but that has never really been the goal.

What are the reactions from the audience?

Often in theatre there are talkbacks especially on the opening nights when directors and actors talk with the audience afterwards. With 28 FEET we do this after every show so I have had a lot of feedback. The most common feedback is that there was a moment or sections of the show that were very much aligned with the viewers' own personal experience: something about the emotional trajectory of chronic illnesses and Crohn's, that seems to be very similar and that people recognize in the show.

Another common feedback from people is gratitude for being able to laugh because they maybe never have laughed about what's happened to them. Taken from a certain perspective, if you step outside of the pain of it, there are things that happened - whether it's in hospital or in the doctor's office - that in retrospective become funny. In theatre we say that comedy equals tragedy plus time.



Jonathan Mirin performing in "28 FEET"

We have also had children coming to the show along with their parents. And even though the content is not geared towards children there is enough movement, puppetry and singing that it also works for them at some level. For parents the show has been very positive. Crohn's is a lonely disease and it's not that easy to talk about it outside the family or even within the family. To have a public audience and to see other people with chronic diseases in the audience has been very supportive for many parents.

What are your plans for the future?

Our Piti Theatre Company is currently located in Shelbourne Falls, MA (US) and also in Ponts-des-Martel (Switzerland) where we are producing our first show in French. It's our fourth major production and is entitled in English "to bee or not to bee".

It's an environmentally-themed production for family audiences and primary schools but it's not totally separate from the 28 FEET show. It deals with the disappearance of the honey bee but also connects the challenges bees are facing to human health.

This project has taken up a lot of energy this year and we will be touring the show in French speaking countries (Switzerland, France, etc). I will go on tour again with 28 FEET when we return to the US at the beginning of next year and will be back in Europe in the summer and fall of 2013.

For more information about our work please visit our website at: http://ptco.org/ or contact me via email at: jonathan@ptco.org

How to promote health in times of austerity?

On June 6th 2012 the European Public Health Alliance (EPHA) held a conference entitled ”Restructuring health systems: How to promote health in times of austerity?” The debate, hosted by the European Economic and Social Committee brought together for a first time more than 20 speakers from all across Europe’s health professions, experts and civil society along with several institutional actors and an audience of around 200 people in an exercise aimed at assessing the impact of the current downturn in the continent’s health systems and identifying actions to move forward.

Zsuzsanna Jakab, WHO Regional Director for Europe, captured well the spirit of the conference when she stressed that “European countries must think about the way they pursue the well-being of their people. Health should be a priority for heads of government and not only for ministries of health.”

One of the key cautionary messages in which most speakers agreed to was the humanitarian crisis that Europe is facing. There was a widely-shared feeling in the room that this long-standing economic and financial crisis is exacerbating vast inequalities, with the poor being the first and worst-hit victims.

Several of the speakers emphasized the need to recognise health as a human right and not as a commodity, making public health a fundamental component of mainstream public policy-making.

The speeches delivered along the day shared two common denominators: that Europe is wasting an awful amount of human capital essential for growth; and that well thought-through investments in health will make public care sustainable. The prevailing atmosphere in the room was underpinned by the certainty that good health is a pre-condition for economic growth.

Ms Jakab, WHO Regional Director for Europe at the conference

Monika Kosinska, Secretary General of EPHA, voiced that “we need political solutions for the economic and health dilemmas currently faced by Europe. Governments do have the power to fix the current status quo .”

In his closing speech, Commissioner Dalli encapsulated the spirit of the event when asserting that “the economic crisis should not turn into a health crisis. Financial hardship cannot jeopardize people’s health and access to healthcare. What Europe needs now is to deliver more and better healthcare within sustainable health budgets.”

About EPHA

EPHA is a platform bringing together public health organizations representing health professionals, patient groups, health promotion, disease specific NGOs, academic groupings and other health associations. It’s mission is to protect and promote public health in Europe and help build capacity in civil society participation across Europe in the health field, and work to empower the public health community in ensuring that the health of European citizens is protected and promoted by decision-makers. Its aim is to ensure health is at the heart of European policy and legislation.

IBD Research Foundation - Update

by Wouter Miedema

The IBD research foundation was very pleased to be invited by EFCCA to its general assembly in Porto earlier this year. It gave us the opportunity to explain once again what our foundation is about.

Among other things we emphasized the strong link of the foundation with EFCCA, not just because the majority of foundation supervisory board members are EFCCA representatives, but also because the foundation has its roots in EFCCA.

What's more, we explained that the foundation focuses its fundraising efforts on associations which do not have their own fundraising organization, so there is no element of 'competition' for funds. We make funds available for research which otherwise would not have been available, enabling IBD research projects which otherwise would not have been possible. We look forward to opportunities of collaboration, so we can support larger IBD research or projects together.

We also underlined that our foundation is the only organization which supports IBD research internationally and from a patient perspective. We finished our presentation in Porto by emphasizing the importance of collaboration with EFCCA and by emphasizing that IBD research gives us a chance for a better quality of life.

We were extremely happy with the huge level of support from the associations which attended the EFCCA general assembly. It confirmed that our work has a very solid basis of support within the patient community in Europe. This support was also very inspiring for us personally to continue and extend our efforts for the foundation.

At this time our 2012 grant program is in progress and we highly encourage researchers to participate. We will select three innovative research projects in the field of inflammatory bowel disease to be awarded a grant of 5000,- euro each. These projects may concern basic science or clinical research. More information can be downloaded from our website www.ibdresearch.org.

Wouter Miedema speaking at the EFCCA Annual Meeting

Donations
Donations can be made either through the website (www.ibdresearch.org) using a credit card, or through a transfer on our bank account:
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TOFACITINIB, a novel treatment for act

by Silvio Danese, Manol Jovani

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Istituto Clinico Humanitas, Milan, Italy

Ulcerative colitis (UC) is a chronic inflammatory condition causing continuous mucosal inflammation of the colon of variable extent, characterized by a relapsing and remitting course. Conventional treatments of UC include mesalamine, corticosteroids, azathioprine and anti-TNF agents, such as infliximab and adalimumab.

These treatments may be ineffective in inducing or maintaining disease remission and/or can have important negative side effects which limit their usage. Development of new additional treatment prospects for UC is thus mandatory.

Tofacitinib is an oral inhibitor of the Janus Kinase (JAK) family, with a greater affinity for the JAK1 and JAK3 kinases. It acts as an immunomodulator by blocking or attenuating the intracellular signal-transduction mechanisms responsible for the activation, proper function and proliferation of the inflammatory B and T cells which result from the stimulation by multiple cytokines, such as interleukins 2, 4, 6, 7, 9, 15, 21 and interferon-y, while maintaining intact regulatory T-cell function.

Tofacitinib has already shown efficacy in the treatment of other inflammation-related diseases such as rheumatoid arthritis and psoriasis and in the prevention of organ allograft rejection.

Sandborn et al published recently in the NEJM the results of an 8-week multicenter, randomized, double blind, placebo-controlled, phase 2 trial evaluating the efficacy, safety and appropriate dose of tofacitinib, for the treatment of ulcerative colitis.

The patients participating in the study had moderate-severe UC, defined as Mayo score of 6-12 (see Table 1 below), and for the most part had failed conventional therapies in the previous 12 months.

In all 195 patients were randomized, but 194 received the study medication. They were randomized in five arms to receive twice daily 0.5 mg (31 patients), 3 mg (33 patients), 10 mg (33 patients) or 15 mg (49 patients) of tofacitinib or placebo (48 patients).

Table 1. Mayo score

Mayo index	0	1	2	3
Stool frequency	Normal	1-2/d >normal	3-4/d >normal	5/d >normal
Rectal bleeding	None	Streaks	Obvious	Mostly blood
Mucosa	Normal	Mild friability	Moderate friability	Spontaneous bleeding
Physician's global assessment	Normal	Mild	Moderate	Severe

ive Ulcerative Colitis

The course of treatment was 8 weeks, followed by 4 weeks of follow-up. Most of the patients (80,9%) completed the course of treatment.

The primary end point of the study was clinical response, defined as an absolute reduction in the Mayo score of > 3 points and a relative decrease of the score by 30% or more compared to the baseline score plus the reduction of the rectal bleeding subscore of > 1 point or an absolute bleeding subscore of 0 or 1.

The most important secondary end points were clinical remission (defined as total Mayo score of 0-2, with no subscore >1), endoscopic response (defined as decrease of > 1 point in the endoscopic subscore compared to baseline) and endoscopic remission (endoscopy subscore of zero).

The quality of life was measured using the Inflammatory Bowel Disease Questionnaire, while C-reactive protein (CRP) and fecal calprotectin (FeC) levels were measured at regular intervals.

The results of the study showed that tofacitinib at a dose of 15 mg BID performed significantly better than placebo with respect to both the primary and secondary end-points, whereas at a dose of 10 mg BID it performed significantly better than placebo only with respect to the secondary end-points, but not with respect to the primary end-point.

The other two doses of tofacitinib (0.5 and 3 mg BID) did not achieve significant advantage in the treatment of active ulcerative colitis as compared to placebo.

There was an overall reduction in CRP and FeC levels together with an improvement of the quality of life in the patients receiving tofacitinib.

These results are very encouraging and tofacitinib may herald the beginning of a new class of effective drugs for the treatment of moderate-severe ulcerative colitis, desperately needed in cases where conventional therapy has failed.

There was no life-threatening or severe adverse event during the observation period. The most common adverse events were mild, such as influenza-like symptoms and nasopharyngitis. There were two cases of infection (in the 10 mg BID tofacitinib arm) and three cases of neutrophenia (neutrophilic count of less than 1500/mmc; one in the 10 mg and two in the 15 mg tofacitinib arm) with no case that surpassed the 1000/mmc threshold. Moreover there was a dose-dependent increase in both LDL and HDL cholesterol concentration in patients receiving tofacitinib, which regressed after drug withdrawal.

The safety and tolerability profile of tofacitinib appeared thus to be quite satisfactory, even though we should bear in mind that the observational period was too short to allow for their comprehensive assessment in patients with UC.

In conclusion, treatment with tofacitinib resulted in better clinical response and clinical remission than placebo, with an acceptable safety and tolerability profile, in patients with moderate-severe UC most of which had failed previous treatments with conventional therapies. Tofacitinib is therefore a new promising additional therapy for the future treatment of UC which needs to be further explored.

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