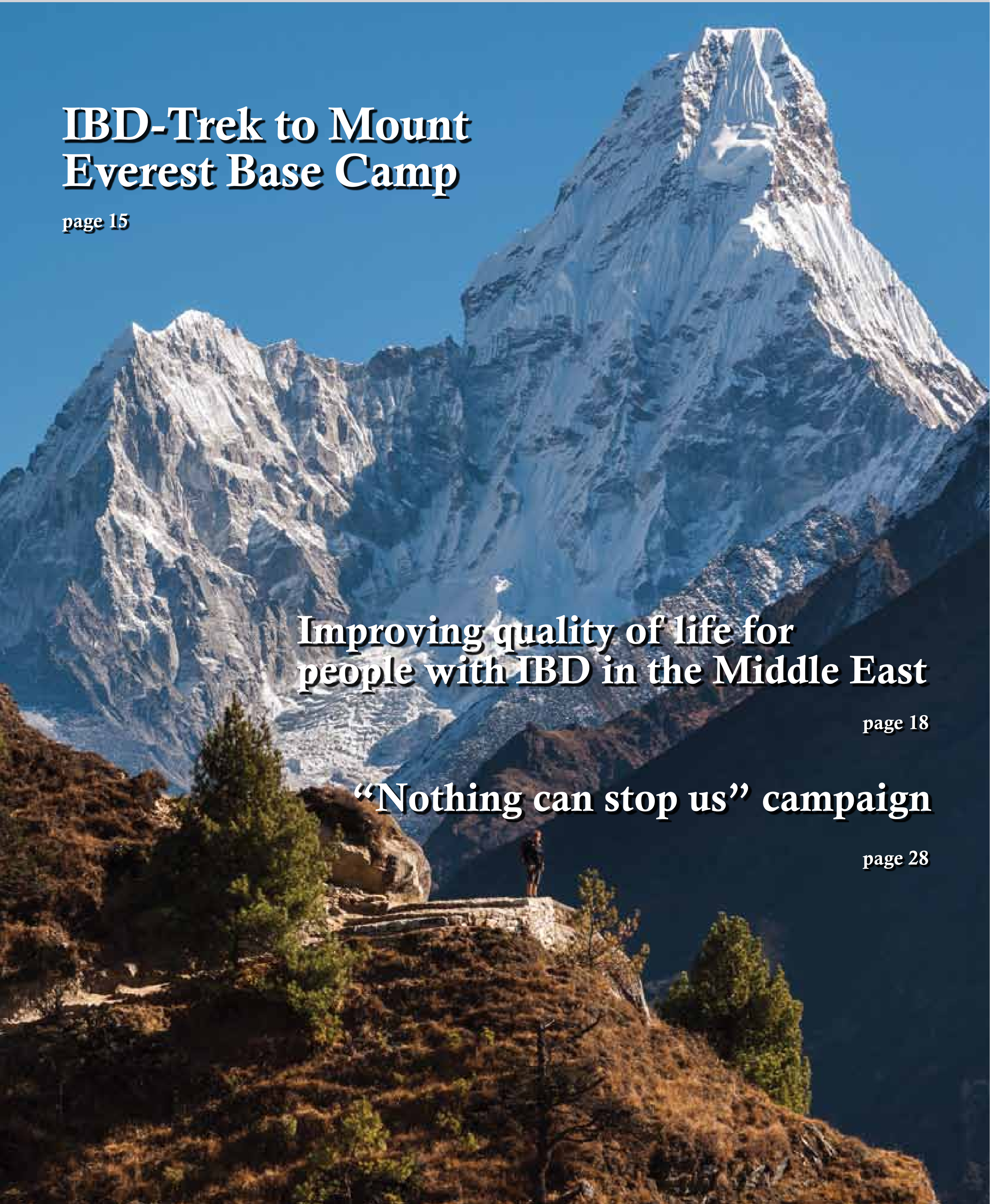
EFCCA MAGAZINE

European Federation of Crohn's and Ulcerative Colitis Associations | February 2015



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New Zealand- Crohn's and Colitis
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EDITOR'S EYE

Grown up

I am pleased to present you with the first issue of the EFCCA Magazine in 2015. This year will be an important one for EFCCA as we are celebrating our 25th year of existence. We have come a very long way from the initial, small gathering in Freiburg, Germany in 1990 when the founding members of EFCCA met with the idea of creating a European Federation aimed at supporting people living with IBD in Europe and beyond.

Over the years we have seen the growth of EFCCA into what it has become now: an active federation including 28 members in 27 European countries as well as 3 associate members from New Zealand, Argentina and Israel, active participation and cooperation with the EU institutions and the World Health Organisation (WHO) in order to raise awareness of IBD and to improve the quality of life of people with IBD in Europe and beyond and active cooperation with other networks such as the European Crohn´s and Colitis Organisation (ECCO), the United European Gastroenterologists (UEG- Public Affairs Committee), the European Patient Forum (EPF), the European Medicine Agency (EMA) etc.

The growing important role of EFCCA is reflected by the fact that we are generating more and more interest also from outside Europe and we had contact in recent years from many IBD groups outside Europe including Japan, Northern Africa and many countries in Latin America that are keen to share information. Our motto "United We Stand" is the same language spoken by these groups. They also believe that if we put together our voices it becomes even stronger and more valuable in particular with the scientific community and health policy makers.

This leads me to an exciting pilot project that EFCCA is currently carrying out and which involved a training workshop in Dubai for groups of patients but also nurses and physicians on how to establish patient support groups in countries where they do not yet exist. This pilot project has been an amazing experience. The region we chose was difficult and we were uncertain whether our training module would be applicable to countries with such different cultural backgrounds.

The results though proved that our doubts were wrong. After the first brain storming session on the needs of people living with IBD in the Middle East we realised that IBD has no borders. The needs were more or less the same as the needs of people in any European country: precise and accurate information, psychological support, nutritional information, support on questions dealing with daily lives…rings a bell? Yes, they are the same needs that each member association of us is dealing with on a daily basis.

The experience in Dubai has shown us that we are going the right way. We hope that this project will be further developed in the coming months and that we will be able to extend our much needed support.

In recent months we have also focused on networking with other European institutions and organisation and we are pleased that recent discussions held with the new president of the European Crohn´s and Colitis Organisation (ECCO), Severine Vermeire, have given us a new impetus to work closer together with our

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colleagues in raising awareness about IBD amongst EU officials and Members of the European Parliament and in particular on the ECCO IBD guidelines ensuring that the patients' view and experience is integrated. On the occasion of our General Assembly, which will take place in Brussels this year from 29-30 May we will also warmly welcome a representative from ECCO underlying our close relationship.

We believe that it is important to intensify our work with youngsters and EFCCA is now organising a training module for our EFCCA Youth Group to be better prepared for reaching out to youngsters with IBD in Europe and to coordinate the valuable experiences gained during the summer camps.

Another very important subject for EFCCA this year is patient safety. Patient safety is a serious concern for many EU Member States and patient safety has becomes a key priority on the European health agenda, both at EU level and in individual Member States. There are concrete mechanisms and practical programmes of activity established at the EU level to take forward patient safety issues (see page 34). Activity at the European level also aims to build upon the programme established by the World Health Organization through the World Alliance for Patient Safety and the work of other key partners.

As a member of the Pharmacovigilance Risk Assessment Committee (PRAC) at European Medicines Agency I and a colleague from the International Alliance Patients´ Organisation (IAPO) have been able to ensure that the patients view is considered when assessing and monitoring safety issues for human medicines.

Within the framework of patient safety EFCCA has also launched the BAB – Biologics and Biosimilars survey last year to assess patients knowledge about biosimilars and to find out to what extent patients are aware of the issues involved around biosimilars medicines.

I want to stress the importance of this activity. As most of you know the exclusive rights for some biological medicines are expiring and similar biological medicines, or "biosimilars", are being developed, with some already available on European markets. For example in 2013 the EU Medical Agency (EMA) authorised two biosimilars for treating patients of Crohn´s and Ulcerative Colitis. Through the survey we want to get a better picture of the already existing knowledge and positions (or lack of it) amongst our members and use this information to effectively advocate for better patients rights with the medicine licensing authorities and relevant governments institutions and/or for a wider information campaign on the issues involved. I would kindly ask our members to support us with this survey.

I look forward to an exciting new year where WE once again STAND UNITED.

Marco Greco, EFCCA Chairman

Planting seeds

From 28th to 29th November last year, a group of people living with IBD, IBD doctors and IBD nurses from 6 countries in the Middle East including Oman, Saudi Arabia, Dubai, Qatar and Kuwait met for the first time in Dubai to exchange ideas and experiences on how to improve the quality of life of people with IBD in the Middle East.

Andrea Broggi (left) and Luisa Avedano summarizing one of the break out session durin ghe Dubai workshop.

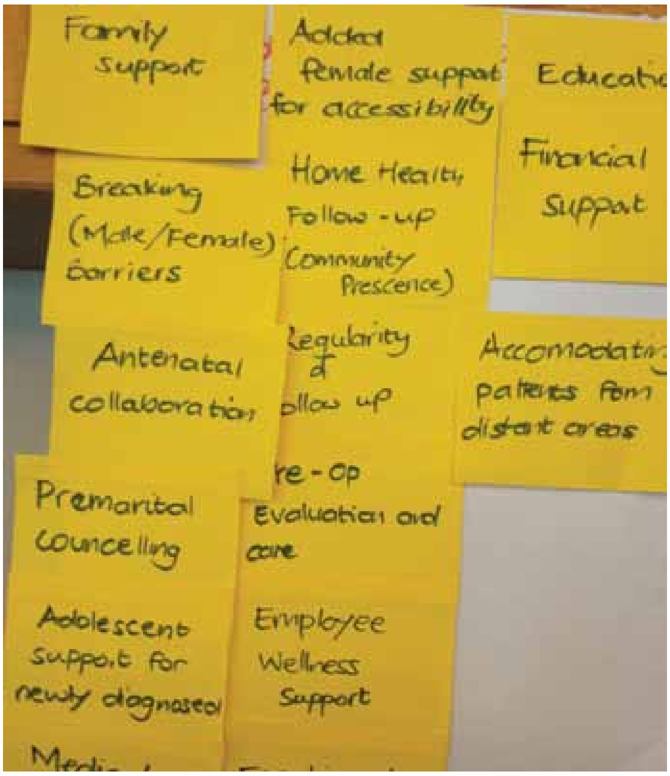
This event forms part of a pilot project launched by EFCCA with the aim to encourage and facilitate the exchange of information as well as to promote the establishment of patient support groups in countries where they do not exist. This activity reflects therefore some of EFCCA´s core values and we are excited with the first positive experience and feedback we had.

During the two day training workshop in Dubai participants had the opportunity to discuss amongst each other the needs and priorities for people living with IBD in the region and to learn from good practice examples provided by EFCCA.

The methodology of the training workshop applied a bottom up approach, allowing all participants to brainstorm on the actual needs of patients in the countries represented.

During the discussions it emerged that - even though in several of the countries the quality and access of healthcare services is very high - people with IBD still felt very much isolated from the rest of society and that there is little support and awareness about the disease. Participants identified a strong need for additional support services both for people with IBD and also their carers and/or family members. There was an overall need for psychological support

One of the participants of the Dubai workshop reporting back from the brainstorming session.



Most of the needs identified for patient support were very similar to the needs met by many patient support groups in Europe.

but also for fighting the stigma of IBD. In particular women who were diagnosed with IBD felt that there was little acceptance in society and that it negatively affected their prospects of getting married.

Participants also talked a lot about the fact that there was little accurate information available in Arabic and that there was a need for measures, other than medical ones, to improve the quality of life of people with IBD.

EFCCA Treasurer Member, Martin Kojinkov from the Bulgarian IBD Association BCUCA, shared his experiences of how he set up the Bulgarian IBD association just over two years ago. "The most important thing, even before finding the money to do some activities, is to find a group of highly motivated and committed people willing to work together - against all odds - to achieve a better quality of life for people with IBD. It´s not easy and there will be many hurdles in the way but you have to persist and keep your common goal in mind" explained Martin during the workshop.

Following the brainstorming session on the needs and actual support available, participants looked at how they could move forward in very practical steps to organize more support for patients in the individual countries. As a preliminary action it was agreed to find and keep involving a group of 3-5 motivated patient volunteers in each country. Their first ¨task¨ would be to define a common objective of such a support group and also to find out information on how to legally establish and structure an entity able to offer information and other support to the whole IBD community.

The first feedback from the pilot workshop has been very positive in that it really encouraged an active participation of all delegates, including IBD patients, IBD nurses and IBD physicians showing their willingness to collaborate together in order to create a more holistic support for people living with IBD. Not surprisingly most of the needs identified during the workshop are very similar to needs for patients from other parts of the world given a few minor cultural variations.

And just few days ago we got the news that a twitter account IBD_gulf has been created and has, at the moment 183 followers, a very promising starting for people with IBD in that region.

From EFCCA´s long experience of working with patient associations, EFCCA is aware that the process of setting up a real support service for patients run by patients requires a considerable amount of time and a lot of effort and motivation from the people involved. We are happy to have grown the first seeds amongst our colleagues in the Middle East during the pilot workshop and we will be available for further assistance as the seeds are starting to grow.

We kindly ask thatour long established member associations support our efforts in any possible way and in finding creative solutions for supporting people with IBD in countries that have no formal patient associations.

This initiative has received financial support from the pharmaceutical company Janssen.

For more information please contact Isabella Haaf:

bella.haaf@efcca.org

IBD: A Rising Threat to the Health of Young Europeans

The event 'Inflammatory Bowel Disease: A Rising Threat to the Health of Young Europeans' which took place on 2 December 2014 in the European Parliament brought together policy-makers, medical professionals and patients' representatives to discuss the latest evidence in IBD research and identify strategies how European health policies could better reduce patient suffering and improve the quality of treatments and their daily life.

The event was hosted by Member of the European Parliament Rebecca Harms, Co-Chair of the Greens/European Free Alliance political group, and was organized by UEG in cooperation with the European Crohn's and Colitis Organisation (ECCO), the European Society for Paediatric Gastroenterology, Hepatology and Nutrition (ESPGHAN), and the European Federation of Crohn's and Ulcerative Colitis Associations (EFCCA).

The event aimed to raise awareness of the special needs of children, adolescents and youngsters with IBD, who make up 30% of patients. IBD prevents many of them from attending school and university, depriving them of social opportunities and barring them from the labour market.

The debate was opened by Thierry Ponchon, Chair of the UEG Public Affairs Committee and moderated by Rebecca Harms (Greens). Severine Vermeire, ECCO President and Geneviève Veereman (ESPGHAN) presented the state of gastrointestinal research in Europe and the discussions focused on identifying policy measures to alleviate the personal and socioeconomic burden of this rising disease.

From EFCCA´s side, Luisa Avedano, Andrea Broggi and Daniel Sundstein, EFCCA Youth Group Leader, participated in the round table discussions and Daniel gave a very inspiring and personal account of what it is like to be living as a young person with IBD. Discussion focused also on the development of a potential project on creating a registry for children and adolescents with IBD that could be funded by the European Commission´s Horizon2020 programme.

For more information please contact Luisa Avedano at:
luisa.avedano@efcca.org

“Now I know I’m not alone”

A recent study carried out by EFCCA medical writer Sanna Lönnfors and Andrew McCombie, University of Otago, Medicine, Christchurch, New Zealand and member of Crohn´s and Colitis New Zealand revealed that participating in a disease-specific summer camp improves the quality of life of young people with inflammatory bowel disease (IBD).

IBD patients are often diagnosed at a young age. Recent British and European surveys have shown that IBD can affect confidence, self-esteem, educational achievement, and career development. Camps may provide a means of overcoming these problems caused by IBD: two previous studies of IDB-specific summer camps for children and adolescents in the USA showed beneficial effects on psychosocial adjustment and health-related quality of life.

EFCCA has been organising EFCCA labelled summer camps since August 2010 giving youngsters in Europe and beyond an opportunity to meet, relax, learn and have fun in a safe environment. What started as an individual summer camp in Appeldorn in Holland over four years ago resulted in 2014 alone the organization of 7 EFCCA labelled summer camps not only in Europe but also Israel and a summer camp in New Zealand about to start in January 2015.

We thought that it was a good moment therefore to use the experiences gained and to get some feedback from participants in order to conduct a survey aimed to find out the effects of summer camps for European young people with IBD.

We asked European summer camp participants from previous years to complete an online survey about whether the camp improved their confidence in dealing with IBD. We also wanted to know whether

Kids having fun during some climbing exercise at the at the summer camp in Isrrael 2013.

In Poland the summer camps attract huge numbers of participants including also family members of kids with IBD

they found it easier accepting their IBD following the participation in the summer camps and whether it has an effect on their overall quality of life. Furthermore we invited them to answer open-ended questions about the camps they enjoyed most. Participation in the survey was completely anonymous and accessible from May to October 2014.

We got answers from 55 people who attended camps between 2010 and 2014 and completed the survey.

The preliminary findings of the survey show that for many participants, meeting other IBD patients was the most enjoyable experience of the summer camp: with comments such as "Interacting with other IBD patients who had a complete understanding of what each other was going through", "Possibility of talking shameless about my problems" and "The knowledge that I'm not the only one with IBD" showing the positive impact.

A detailed analysis of the survey is in the pipeline and we hope to share the results in our next issue. So far though the results show that meeting peers had concrete beneficial effects: "The contact with all other campers inspired me to start new things in my life, things like going back to school, which I was afraid and hesitant to do before. Before the camp I was without job or school, sitting ill at home whole day. People who were more ill than I was and who still did a lot served as a great example of all the things I could still do!"

Attending a summer camp and meeting other IBD patients was beneficial to most young people who completed the brief survey. Most respondents (98.2%) would recommend camps to other people with IBD.

We are also proud to announce that the preliminary results of the camp survey will be included in the poster presentations during the ECCO Congress in Barcelona on Friday, February 2015.

Let´s celebrate

25th General Assembly of EFCCA

2015 is an important year for the whole EFCCA family: it is our 25th anniversary and we are all looking forward to the next General Assembly to celebrate this occasion. This year the Annual General Meeting will take place from 29 to 30 May in Brussels, a location that will allow us to have the valuable support of our 2 Belgium members.

The preparations are on its way and in the coming weeks all the preparatory documents, as well as the practical information will be made available to all our members.

However we are pleased to already inform you that immediately following the General Assembly, EFCCA will participate at the Brussels Half Marathon on Sunday 31 May in order to raise awareness on IBD as part of our yearly World IBD Day activity.

As you may remember last year 15 athletes run under the purple colours of World IBD Day and this year we are planning to involve more runners and supporters and we count on your support to spread the voice and indicate to us participants from your country. See you in Brussels very soon!!

Luisa Avedano, CEO EFCCA

EFCCA and ECCO: paving the way for closer collaboration

On 12-13 December 2014 the European Crohn's and Colitis Organisation (ECCO) invited EFCCA and several patients' organisations of ECCO country members to a meeting in Vienna. Our members from France, Germany, Ireland, Croatia, UK, Belgium, Austria, Serbia, Czech Republic and Finland formed part of the patients' representation.

The purpose of the meeting was to boost networking among peers and identify common burning topics for further collaboration between IBD physicians, nurses and patients' organisations.

EFCCA was represented by Martin Kojinkov (who was also there in his capacity as President of the Bulgarian IBD association) and Luisa Avedano, EFCCA CEO.

After general presentations 3 working groups were formed each of them representing: patients, physicians and nurses. In the brainstorming group of patients, facilitated by Severine Vermeire, the ECCO President, needs and interests of patients were discussed. Among the topics the following priorities were outlined: easier access to medical news, a more friendly version of the ECCO guidelines on IBD and the need to keep on working together in order to raise awareness on IBD.

A second follow up meeting with the nurses, patient representatives, EFCCA and ECCO will take place in Barcelona the day before the official opening of the ECCO congress. ECCO chose to invite a few patient representatives and EFCCA to discuss how to make the ECCO CD and UC guidelines more user-friendly for patients, starting from an English version in lay language. The idea is to then enlarge the brainstorming to all the other organisations and define further translations in different languages.

Group photo of the ECCO patient meeting on 12-13 December 2014 in Vienna, Austria

As a direct result of the above described meeting, Marco Greco and Martin Kojinkov recently had a conference call with Severine Vermeire, the ECCO President. The purpose of the talk was to define commonly agreed actions that our two organisations can develop together.

Concerning the debate on IBD guidelines EFCCA is ready to start a set of exchanges among members on how to achieve a more patient-focused approach. In fact we believe that care should not only be evidence-based but also patient-based. We need to "think outside the bowel"...the patient is more than just his/her illness. Therefore we advocate that patients are the ones to refer to when you need "first-hand" information. A patient with a long history of IBD has a lot of experience and knowledge; book knowledge is not the equivalent of a patient's subjective feelings and long experience with IBD.

After consultation with our members EFCCA and ECCO will work together on organising a press conference during the ECCO Congress in 2016 in Amsterdam to present the outcomes. The event will also be a further occasion to raise awareness on IBD among media and journalists.

ECCO has also shown great interest in cooperating with EFCCA during our World IBD Day event, which will involve participation in the Brussels Half Marathon on 31 May. Ms Vermeire will promote our event amongst IBD specialists encouraging them to join the EFCCA runners during the half marathon.

ECCO has also agreed to put its network of IBD specialist at our disposal for support during the summer camps and EFCCA member associations that are planning to organise a summer camp and that are looking for IBD physicians for support should get in touch with the EFCCA office.

Last but not least we are pleased that ECCO has accepted our invitation to our next General Assembly that will take place in Brussels on 29 to 30 May 2015.

For more information please contact Luisa Avedano: luisa.avedano@efcca.org

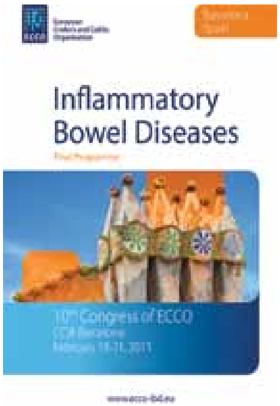
ECCO Congress

This year will mark the 10th ECCO Congress and will take place from 18-21 February in Barcelona. The Congress will offer a broad and exciting scientific programme, covering all aspects of adult and pediatric care, of medical and surgical advances, aspects related to costs and quality of care, and the increasing knowledge about the role of the environment in IBD.

The aims remain to advance the understanding of the causes of Crohn's disease and ulcerative colitis, to share and discuss top-line results of therapeutic agents and algorithms, to stimulate and promote the implementation of guidelines, to ultimately further improve patient care. By promoting research, integrating basic science and clinical practice, fostering international collaboration and friendship, IBD experts strive to bring hope and comfort to the many people who suffer from IBD.

EFCCA is proud to announce that once again a poster presentation presented by EFCCA's medical writer, Sanna Lönnfors and Andrew McCombie (Crohn´s and Colitis New Zealand), has been accepted and will be shown during the Congress. The presentation shows the preliminary results of a survey carried out to find out the effects of summer camps for European young people with IBD. For more information about this survey please read the article "now I know I'm not alone" on page 8.

The ECCO Congress will also host the 6th N-ECCO school which will take place on 18 February and which is targeted at IBD nurses that are new to the specialty. N-ECCO is a subcommittee of ECCO representing IBD nurses. The aim of NECCO is to improve access to nurse education in IBD throughout Europe, to provide a link with the national nursing networking organisations and to essentially improve patient understanding of IBD. As in previous years EFCCA is supporting ECCO with a grant aimed to offer a travel bursary to those participants who are unable to raise funding for travel and accommodation (as in some countries, industry sponsorship for nurses is prohibited). The EFCCA grant will be divided among those participants without industry sponsorship in the form of reimbursements for accommodation and travel expenses.



New EFCCA Communication Strategy

EFCCA is currently preparing a new communication strategy which will see the refurbishing of our website into a dynamic portal for the IBD patient community and people interested in our cause.

The aim is to make our website more user-friendly for any one wishing to find out about Crohn´s disease/ Ulcerative Colitis and about our activities carried out not only at European but also at the international level. At the same time the new website will have a much stronger connection to our members at the local level. It will allow for multi-lingual newsfeed of interested member associations creating a unique space for sharing and exchanging good practices and campaigns or events at a European and also national level giving thus more visibility to individual members.

We are discussing technical details with a team of dedicated IT people who will support us in translating our ideas into an innovative and inviting tool available for our members and the wider public. We are aiming to present an initial draft to our General Assembly in May this year in order to gain some feedback and possibilities for adjusting the interface.

Another pillar of our new communication strategy will be the more active involvement of our youngsters within our overall strategy. We have developed – with the support of the pharmaceutical company MSD – a social media training programme for our youngsters with the aim to enable our EFCCA Youth Group to effectively raise awareness about IBD and the difficulties that young people with IBD face in their daily lives.

The social media training programme is designed to explain social media technologies and functions in simple and easy to understand language. It will explain to trainees how to encourage on-going engagement among young people in their own medium and show them how best to engage with users via sharing comments, pictures / videos and using #hashtags.

The training programme will also explain how to use audience insight from members to help determine the most appropriate platform and how to effectively plan an editorial calendar aimed at generating continued interest.

We are now waiting for the feedback from the EFCCA Youth Group concerning our preliminary training module. The training, which will be in form of webinars, is foreseen to take place between February and April.

For more information please contact Isabella Haaf at bella.haaf@efcca.org

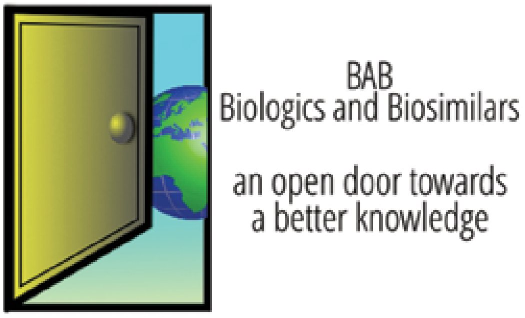
BAB - Biologics & Biosimilars Survey

In late October last year EFCCA launched a short online survey on patient´s knowledge about biosimilars. The purpose of the survey is to assess patients´ knowledge about biosimilars and to find out to what extent patients are aware of the issues involved around biosimilars medicines.

The results of the survey will allow us to elaborate a common EFCCA position to effectively advocate for better patients rights with the medicine licensing authorities and relevant government institutions. The questionnaire consists of 14 questions and will require approximately 10 minutes to complete. So far the questionnaire is available in English, French, German, Italian and Spanish. Russian and Arabic versions will be made available shortly.

It has been designed in collaboration with Prof. Laurent Peyrin-Biroulet and his team at the department of Hepatitis-Gastroenterology CHU in Nancy. The translations, technical tools and dissemination materials are under a unrestricted grant from the pharmaceutical company Abbvie. The survey can be accessed from the EFCCA website.

We are pleased that some of our members are actively engaged in promoting this survey and so far we have had over 500 respondents but we would like to increase this number. We believe that the issue around biosimilars is a very important one for the IBD patient community. This is also reflected in the activities undertaken by several of our members on this subject (for example the articles from France (page18) and Israel (page 19)).



We kindly ask our members to disseminate actively information about the survey amongst contacts and members. It can be helpful if a direct link to the survey is hosted from your own website and/or social media.

For more information please get in touch with Isabella Haaf at bella.haaf@efcca.org

European Parliament Interest Group on Access to Healthcare

To raise awareness around the issue of access within the European Parliament and the EU Institutions, an Interest Group on Access to Healthcare is being set up in the European Parliament.

The objective of this Interest Group is to gather political voices around the “equal access” agenda of Europe. It is a first step in converting the proposals suggested by stakeholders into transparent and effective policy solutions. This Interest Group was launched on 27 January 2015 in the European Parliament in the presence of the Commissioner for Health and Food Safety Mr Vytenis Andriukaitis. EFCCA Chairman Marco Greco representing the patients, attended the launch of this initiative. The challenge lies now in finding as many Members of the European Parliament as possible in order to join and support the group.

IBD and Sports

IBD and sports is a subject of particular interest to the EFCCA youth group. Many of the youth group members lead an active life style despite having IBD and quite a few of us have participated in physically challenging events such as for example participating in marathons, triathlons etc. Some people seem surprised that we can be so active even though we have a chronic disease.

It stands in contrast to the image they have of someone “sick”. Of course there are times when it is just not possible to get out of the house, but that does not define our whole person. When we are better, we are strong enough and motivated to lead an active life and to challenge our mind and body pushing it at times to a limit but once overcome feeling so much better for it.

We discussed with our members that raising awareness of the positive side effects of doing sports was an important mission of our group. When we looked at a study on the topic of sports and IBD which the patient association Crohn´s and Colitis UK carried out in 2012 on the occasion of the Olympic Games being hosted in London, we were alarmed to find out how life-limiting it can be for a young, previously-fit person to be face with IBD.

The study gathered around 1000 answers from the association´s members out of which a shocking 80% of respondents stated that they had given-up or reduced their participation in sport either temporarily or permanently, as a result of their symptoms of uncontrollable diarrhoea, fatigue, joint problems and severe pain.

If this figure accurately reflects the disease limitations faced by all 240,000 people in the UK living with IBD, Crohn´s and Colitis UK estimates that that at some point as many as 192,000 individuals are finding it challenging to be as active as they once were.

Interestingly though the majority (72%) agreed that exercise makes them feel better. On the downside around 23% felt sports made their IBD worse.

Of those who felt that sports made them feel better 46% said that sport and fitness activities made them feel better about themselves and improved their general well being and confidence; 12% said it boosted their energy levels, 9% felt fitter/healthier and 12% stated that exercise helped improve their IBD symptoms, helped their weight control (steroids for IBD treatment can cause serious weight gain) and improved their sleep. Interestingly, 4% said that sport/fitness gave them a focus other than their condition and another 4% said that they felt ‘normal’ when taking part in sport.

So this is a paradox we want to address. We believe that in particular youngsters need to be better supported and encouraged to return to sport once they feel better. We want to break down the barriers they might have about getting into sports and we hope that through our social media and through stories like the one from our EFCCA Youth Group leader, Daniel Sundstein who recently came back from a hiking trip in the Himalayas, we can be an inspiration and example for other young people with IBD.

To read the full report published by Crohn´s and Colitis UK please visit their website at:

http://www.crohnsandcolitis.org.uk/Resources/CrohnsAndColitisUK/Documents/IBD%20Sport%20and%20Fitness%20Survey%20Results.pdf

IBD-trek to Mt. Everest Base Camp

by Daniel Sundstein, EFCCA Youth Group Leader

Daniel Sundstein (right) on the summit of the Everest Base Camp at 5364 m

For many years I've been thinking about doing a trek in the Himalayas, especially the trek to Mt. Everest Base Camp. The year of 2014 should be the year to do it! I'd never been to Asia before so I had to take my precautions, since we've all heard stories about people getting sick because of the food there. I took the following three precautions before leaving Denmark:

1. Making sure I didn't have a flare up before I left the country by taking some blood
2. I took a drinking vaccine against E. Coli bac teria
3. I bought a glass of probiotics to take the weeks before leaving

Besides these precautions, I of course trained a lot, primarily by running. My running program was most of the time inside, on a treadmill, since we don't have a lot of hills in Denmark – the land is as flat as a pancake as we say. Since there are absolutely no running tracks going uphill in Denmark, I had to use the treadmill in the gym and put it on elevation, so that I could do my running in different elevations. These were the obstacles I had, but it was not a problem to do the preparations.

The main concern before leaving for Nepal was actually not the fear of getting diarrhoea or a flare up, but my main concern was about the heights. I'd never been trekking above 2000m before, so going to almost 5400m was really a mental challenge to me. When you tell people that you are going to the Himalayas you always hear stories about people getting high altitude sickness and are forced to quit the trek to go back down to lower heights. The other concern was flying from Kathmandu to Lukla - the most dangerous airport in the world. The airport is situated about 2800m above sea level, is about 450m long and 20m wide. Besides all this the runway has an incline of 12%. It was terrifying to get into the little airplane that had to take us from Kathmandu to Lukla - seven rows with two seats on each row, one at each side of the plane. The flight only took about half an hour and the landing was the most memorable thing I have seen.

After arriving in Lukla we quickly started our trek towards Everest Base Camp the goal was to get there in about 9-10 days. When you think about it, 9-10 days isn't that much - most of the time in our everyday life 9-10 days just fly by. But when you have to walk 6-11 hours every day from 2800m to 5400m - then you have a challenge.

Depending on weather conditions we got beautiful views of Mount Everest

We started very optimistically - the sun was shining from a blue sky and we couldn't stop looking up at the beautiful view of the Himalaya mountains range. Every morning when you wake up and go along on the trek you see the most fantastic landscapes - it's like walking around in one of the most stunning paintings you've ever seen. On the second day of the trek we passed 3000 meters and here we started getting a bit short of breath and we could feel that we had to be careful with our walking pace. At the end of the day we reached Namche Bazaar (around 3400m).

The EFCCA Youth Group mascot, Paddy, was also enjoying the views and fresh air

Unfortunately we were staying on the 2nd floor in the hotel meaning we had to walk up two staircases to our room - this was like walking from ground to 10th floor back home!

On day three we had our "day of rest" meaning we had to walk for 4 hours going from Namche Bazaar at 3400m to Everest hotel at 3800m and back again. This was the first time we saw the top of Mt. Everest and we were lucky as it was very clear weather allowing us a breath taking view to the top of the world.

You get very tired very early because of the heights. Therefore we usually went to bed just after having eaten dinner at around 8 in the evening. At around ten o´clock on my rest day the worst thing that could happen happened: My stomach started to turn itself around resulting in about 10-15 visits to the toilet that night. The following day should have been an easy start for about approximately 2-3 hours before a very steep climb at the end lasting about two hours. The first part took my group almost 6 hours, since I had to go "off road" every 20 minutes. Can you imagine the guilt you feel in that situation? I felt like a burden to the rest of the group, which I also was and at the same time I felt so afraid that this could be a flare up.

I kept telling myself, that I know what a flare up is and this is not a flare. But I couldn't be sure (you never can) and I felt more and more insecure. When we arrived at the final steep climb I was terrified. I looked up and it was the steepest and longest uphill climb we'd ever face on the trek so far. I was sure this was the end for me - not even half way to Everest. Beaten by the diarrhoea. But the miracle happened: We found a horse! So the last climb I did on horseback - a pure lifesaver for me at that specific time.


A well deserved break to catch some breath

This wasn't the end of the stomach problems. Of course it continued throughout the night and when our guide came into the bedroom the next morning and told me that he wanted to call a rescue helicopter I was forced to do some reflection and reconsideration.

I tried to listen to my gut and I felt no better at all - but it wasn't worse either. So I decided to continue and luckily it went better and better the next couple of days. The diarrhoea continued though, but it was "only" 8-10 times a day and I felt like I could control it. The worst thing was the lack of appetite and the sleepiness the sickness gave me. I was waking up every 2-3 hours and the only things I could eat was a boiled egg in the morning, half a snickers during the day and a little soup in the evening. Therefore I lost 12kg in just 13 days!

I once ran a marathon and trained for that marathon. I've run half marathons and trained for that. I've trained for the Everest Base Camp, but I've never been so much under pressure, so frustrated and so in doubt about my own body strength. I've never felt so physical exhausted and so under pressure in my whole life and I've promised myself that I will never do it again. I've learned tons from it, I now know my body way much better than before - and I thought I knew it pretty well before I left for Nepal.

One thing is training for or running a marathon or a half marathon. It "only" lasts for 1-4 hours. But trekking in the Himalayas, with all different kind of challenging factors, lasting for several weeks. That is something you cannot prepare for neither mentally nor physically. Despite all that ..what a feeling when I reached Mt. Everest Base Camp - for a moment you forget everything!!!

You forget how much weight you lost. You forget you are feeling bad. You forget you are gasping for your breath. You forget everything and the only thing you can think of is that you are standing very close to the top of the world.

I will assure you: when you are getting back to Lukla you feel relieved. After getting to the Base Camp there are 3 days of 9-10 hours of walking down which is very hard. When you leave Lukla and think back of the 13 days you just have been through you feel amazing! And here, a couple of months later you actually miss walking around in the fantastic settings you were in - just you and the wild nature. It was one of the absolutely greatest adventures that I've ever been in - and the absolutely hardest. I will never forget waking up and see the sun hit the world's highest mountains, this will always be on my mind for the rest of my days.

France

Biotherapy….the patients have something to say

Self-management of IBD has been revolutionized by biotherapy. However, many factors seem to still limit the prescription of anti-TNFs: their cost, an unknown treatment period, and most of all the potential side effects which not only the patients dread, but sometimes their gastro-enterologists too, despite the fact that these treatments have been around for more than 15 years.

AFA has made a 49 minute film of testimonies, on behalf of patients and their gastro-enterologist, whose questions and explanations expose the benefits and risks of biotherapy treatment in a preventive informative way. In 2013, 14 patients with Crohn's disease and ulcerative colitis were trained by the association "Tous Chercheurs" and biotherapy expert doctors. The hopes behind this film are to better inform all those concerned by XXIst century treatments.

The film is divided into 4 chapters and each part can be shown all alone, depending on the public.

WHAT THE PATIENTS HAVE TO SAY

The patients deliver their experience with biotherapy, their hopes, their fears, along with their misconceptions about the treatments. Each and every one of them has been faced with a different situation, some having refused the treatments, some who have been on these treatments for a long time and others who still have some apprehension about them.

THEY HAVE FOLLOWED ME

The consultation announcing the new biotherapy treatment is an essential meeting between the doctor and his patient in order to ask the right questions on « living with » as well as on the side effects to be expected.

EXPLAINING BIOTHERAPY

The keys to comprehension for the patients trained by the association « Tous Chercheurs » at INSERM (National Medical Research Institute). What is an anti-TNF, why does it work, what are the risks. Specialists answer these questions.

TODAY...AND TOMORROW ?

What have the patients retained from their training? How do they feel about it? What did they learn? Have they changed their minds or not? How can the training course be more efficient? An expert talks about the future of biotherapy in IBD.

This film is supported by the French National Medication Security Agency (Agence Nationale de Sécurité du Médicament) and was achieved under the impulse of Eric Balez, Vice-President of AFA.

Where can you see this film?

Throughout France between 2014 and 2015 there have been showings followed by debates with IBD experts in biotherapy. If anyone would like a copy subtitled in English, please notify Madeleine Duboé at Afa.

Madeleine Duboé, Afa

Israel

CCFI position on biosimilars for IBD

Throughout the second half of 2014, CCFI has led a campaign aimed to ensure that biosimilars in treatment of IBD patients are not approved in Israel without having significant clinical testing data on IBD patients.

CCFI's position is that extrapolation of efficacy from other diseases, cannot be grounds for approval of biosimilars in treatment of Crohn's or Colitis. This position was formed after numerous consultations with IBD experts in Israel and abroad.

Our advocacy work combined meetings, position papers and media. On May 2014, our board chairman Mr. Eyal Tzur, and the Executive Director, Ms. Silvi Omer met the Health Minister, Ms. Yael German, in order to present and discuss our position.

They also met with the ministry's General Director, Prof. Arnon Afek and with the Head of the Drug Technologies Administration. CCFI has also presented a position paper to the Ministry of Health-Drug Approval Committee.

The approval of biosimilars in Israel has been postponed until sufficient international and local relevant clinical data indicates efficacy and safety in treating IBD with biosimilars. CCFI's stand was published in print and on-line as well as in publications intended for medical staff.

Vadolizumab:

Another drug approval related activity throughout 2014, was aimed to include the biological drug Vadolizumab, in the list of medications that are covered by the National Health Insurance. As the year unfolded, we were notified that this goal has been successful. This decision adds approximately six million Euros annually, to the fight against IBD and an additional advanced treatment choice.

From left to right: Mr. Eyal Tzur, Ms. Yael German the former Health Minister and Ms. Silvi Omer

Prevalence study:

An extensive prevalence study has been conducted by the IBD center at the Shaare-Zedek hospital in Jerusalem. The survey's results have recently confirmed that 473 out of 10,000 people in Israel are diagnosed with IBD. This number is higher than previously estimated, bringing the total number of people living with IBD in the country, to nearly 40,000. This regrettable yet important estimation is a driving force for us at CCFI, to work even harder at achieving results in improving the lives of IBD patients in Israel.

Wishing EFFCA's board, staff and the national associations a healthy, peaceful and successful 2015.

Dorit Shomron, Eyal Tzur and CCFI's management and staff.

Belgium

From IBD Day towards IBD-Week

Since 22 October 2011 we have organised the National IBD-Day event on an annual basis. Last year both the French-speaking and Dutch-speaking IBD patient associations, with the support of the pharmaceutical company AbbVie, have collaborated towards the common goal of erecting a 1500 toilet-paper-roll wall in the entrance hall of several hospitals across Belgium within 3 days.

The aim of these attention-seeking events was to fight the taboos relating to IBD and to share information with people passing through the hospital, whether as a patient for a consultation or as a visitor.

The purple ribbon – also a symbol of World IBD Day – was built into the toilet-paper wall, and near the wall a plastic toilet with a chain gave the chance to passers-by to symbolically flush the common preconceptions about bowel diseases down the drains.

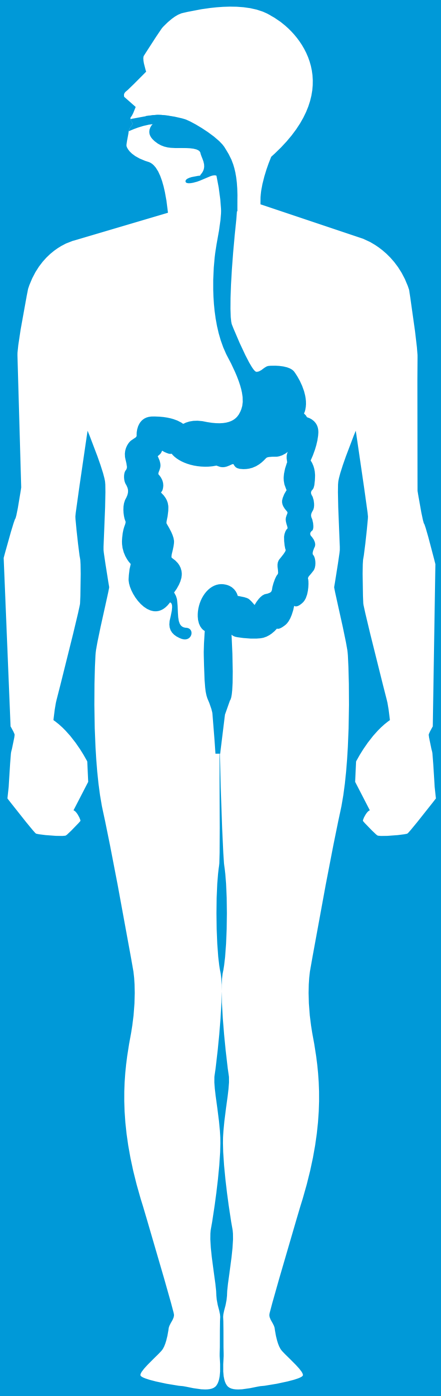
Within these 3 days, hundreds of flyers have been distributed to visitors and we noticed that most people know at least one IBD patient in their close circle…actually this seems logical as we know that 1 out of 400 people suffers from IBD, and 400 is the average number of friends a person has on Facebook !

Thanks to the 2014 IBD-Half-a-Week, radios and papers have covered the subject of IBD in their programmes and explained to its audience what it means to live with IBD. Last but not least, let's hope that our politicians have listened to the programmes and will be now more aware of our problems…. United we stand !

Xavier Donnet on behalf of the RCUH and CCV

PEOPLE COME FIRST AT FERRING

Making a difference to people's health and quality of life, today and tomorrow.



TODAY

FERRING ENJOYS A STRONG REPUTATION WITHIN THE INTERNATIONAL GASTROENTEROLOGY COMMUNITY.

Our research activities have resulted in the development of many effective products that help improve patients' lives.

FERRING BELIEVES IN THE VALUE OF SHARING KNOWLEGDE AND WORKS TOGETHER WITH PATIENTS TO RAISE THEIR VOICE.

TOMORROW

OUR COMMITMENT TO RESEARCH:
LIVER DISEASE,
INFLAMMATORY BOWEL DISEASE, FUNCTIONAL BOWEL DISORDER.

FERRING is a research driven company that invests heavily in its research infrastructure both in terms of people and technology.

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Romania

IBD Art-Perspectives

Our association, ASPIIR, has organised an exciting new initiative called "IBD Art Perspectives" which gave a new dimension to the current understanding of inflammatory bowel diseases and their impact on patients and society.

We organized an exhibition with fifteen artworks: fifteen stories of patients who face IBD in their life and fifteen artists who listened to these patients and created their interpretation of those stories. The exhibition took place at the Crowne Plaza Bucharest, on 25 to 27 September 2014 and coincided with the National Symposium of Gastroenterology of the Romanian Club for Crohn's disease and ulcerative colitis.

The fifteen artists, after hearing stories from patients, were inspired to translate these into paintings, engravings, photographs and other art works that came together in the "IBD Art – Perspectives exhibition". The works showed a new side to these diseases and the daily challenges associated with them. In addition to professional artists, the program included students from the Bucharest University of Art.

We are proud to have achieved many of our objectives through this exhibition, in particular we have managed – through artistic expression – to show how society and others around us, perceive a person with an autoimmune disorder. The artists actually gave us a vision of how an outsider understands a person's life with a chronic illness. What's more, we have encouraged patients to be more open and talk about their disease. At the same time we managed to spread the message of the importance of a more healthy and balanced lifestyle and the need to go to the doctor when digestive symptoms persist.

Last but not least another of our goals was to raise awareness amongst the medical staff to understand that their patient does not only represent a medical record, but a person - often young - with hopes, dreams and a rich personal, professional and social life.For us the exhibition was a great success!

Isabella Grosu, President of A.S.P.I.I.R. Association

Some of the art work being exhibited during the event

Spain

National meeting of IBD psychology specialists

ACCU España and the regional association of patients from Guipúzcoa (ACCU Guipúzcoa) organized the first national meeting of IBD psychology specialists with a focus on "Practical Therapy on IBD patients". The Meeting was hosted in San Sebastian on 14-15 November 2014.

The aim of this initiative is to develop a working group to serve as a platform for discussion about collaborative work, sharing information and the development of project proposals in order to enhance research and specialized formation in these pathologies. With this measure ACCU España is encouraging the development and formation of professionals specialized on IBD, still an undeveloped multidisciplinary area that needs to be potentiated to effectively increase the quality of life of patients with IBD. Lately, the number of patients in Spain, suffering IBD under the age of 25 years has increased three fold. The appearance of these pathologies produces a strong physical and emotional impact that needs to be improved on all levels including social, familiar, work and educative levels.

Alejandro K. Samhan Arias, ACCU España

Denmark

Each day in December – a new Patient story

What many people forget during the holidays is that it is difficult to "forget" a chronic disease – especially if you have one…. which many of us do. But a little understanding from the people around us, makes a very big difference.

One of the ways to achieve a little understanding, is by letting everyone know what is going on. Call it information, awareness, openness etc. as long as the message gets out. We can't expect everyone to read our minds and feel our pain. If we keep it a secret, it will remain a secret… and that is not helping anyone.

So, to help our members and ourselves, each day in December we posted a new story on Facebook. A candid story about a person's life with IBD, with full name and picture. A story that not only should be read and "liked", but also shared. We did have some attention from the Media (TV, Newspapers), even though the stories could be a little too close for comfort. The real success story was, besides getting many new members, we helped a lot of people telling their individual story – to others.

Some even did this for the first time ever (!), expressing their relief at the same time. Family, friends and colleagues read about "it" for the very first time. We received so many positive responses from fellow patients as well as everyone else.

Nothing beats the feeling of knowing you're not alone and getting a lot of your worries of your chest. Well, maybe a cure would be a lot better, but getting recognized and understood, is essential for having a good life. Not only during the holidays, but all year round.

2015 looks very promising, and we hope it will be the best IBD-year ever – for all of us.

Martin Koehler, CCF, Denmark

Norway

Norwegian inflammation network – NORIN

NORIN is a Norwegian foundation established In March 2014 by representatives from hospitals, the medical industries, institutions and patient associations. The aim is to create a better environment for research and room for cooperation for professionals working within inflammatory diseases, including IBD, with interdisciplinary expertise inside the diagnosis of give inflammatory diseases.

Arne Schatten (left) with colleagues from NORIN

Several patient associations are among the participants and Arne Schatten, general secretary of LMF, is representing the patients associations as a member of the board of NORIN.

NORIN arranges four assemblies per year and in 2015 a big meeting with information for patients suffering from the different inflammatory diseases is planned. The information will include for instance about new treatment, new medication, common symptoms and treatment of these common symptoms. This patient meeting follows a very successful IMID seminar in March 2014 arranged by the patients associations participating in the Norwegian IMID group.

LMF appreciates the importance of cooperation within the different organisations and the sharing of expertise. It is vital that shared challenges and solutions to these considering inflammatory diseases are promoted in a proper and justifiable way so they can benefit all member in the best way possible.

Arne Schatten, LMF

Poland

Active life against an active disease

"Active life against an active disease" is the project led by the Polish Association Supporting People with IBD "J-elita" in 2014 as a part of a grant contest "Simply Active". The main goal of the project was to make people with IBD and their families active on the labour market.

It targetted the unemployed as well as high school students facing the problem of selecting a career path. In the second case, it is extremely important for those with IBD to make the right choice and gain qualifications that will ensure employment adequate to his/her health condition.

The project consisted of two weekend meetings, organized in June and October with around 90 participants. Each meeting included a two day seminar aimed to increase confidence of people with IBD to enter the labour market. A career officer trained participants on how to prepare their applications including CV and cover letter. Through some questionnaires each person´s strengths, weaknesses and professional skills were determined which is crucial for choosing a right walk of life. During the training given by sociologists and psychologists the position of the disabled person on the labour market was also explained. The situation was described from the perspectives of advantages for the employer as well as from the viewpoint of the employee. One very important issue the trainers wanted to transmit was that the disease should not be a reason for feeling helpless or to withdraw from society. Each person has the same rights and it also applies to the labour market. A specialized lawyer gave additional information about labour rights for people with a disease and measures how to enforce them. He explained that the Polish law does not foresee any special rights for people with a disease unless they have a disability degree certificate. A further subject dealt with the issue of mobbing at the workplace. Finally a session was also dedicated to stress management classes driven by a psychologist and a motivation trainer.

The interest in the project of our members as well as the large number of attendees confirmed to us, that the subject of activeness of people with a disease on the labour market is a very burning issue and needs more activities of this kind.

Agnieszka Kowalczyk, Katarzyna Bartczak, Magdalena Sajak, J-elita

Cyprus

Press Conference to inform public about IBD

After a year of hard work and a number of successful activities, we decided that we had to focus on raising awareness of the young people of Cyprus, as they constitute the future of our society.

Therefore, the idea of organizing a Pancyprian Student Competition was formed and materialized between January-March 2014. The competition title was paraphrasing an old Greek saying which quotes that "Cleanliness is half of our wealth" to a slogan quoting that "Cleanliness in public toilets is half of our health". Our target group was young students who could express their ideas by creating a related poster or a video or even by taking a photograph.

Eventually, on December 4, 2014, a Press Conference was held by the Cyprus Crohn's and Ulcerative Colitis Association at Strovolos Municipality premises, to inform the state about Inflammatory Bowel Diseases. It was an opportunity to promote the work of Raphaella Hadziioannou from Emba High School in Paphos who excelled in the Pancyprian Student Competition. The project was turned into a poster that invites everyone to keep public toilets clean, with a very short and concise slogan "At least think of the next user...".

The Association aims at making the public recognize the importance of keeping the toilets clean, as a simple ethos and respect to the patients with chronic diseases, who are taking immunosuppressive medicines and are vulnerable to contagious diseases.

The winning poster was sent to all schools of Cyprus, Hospitals, Medical Centers, Ministries, Municipalities, Universities etc in a number of copies, enough to cover public toilets and other visible spots of their premises.

Natasa - Revekka Theodosiou, CYCCA

Participants of the press conference on 4 December 2014 in Strovolos

Our mission is to help patients live a better life

Shire's mission

Shire is one of the world's leading specialty biopharmaceutical companies - but, more importantly, we make a difference to people with life-altering conditions, enabling them to lead better lives.

Shire's vision is to continue to identify, develop and supply life-changing products that support physicians in transforming the lives of patients with specialist conditions. 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 unmet medical needs, coupled with 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. 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 and chronic constipation.
- 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.

INTSP/IN/MEZ/14/0035   Date Of Preparation: April 2014

To be as brave as the people we help.

#NadaNosPara
(Nothing can stop us)

“Nothing can stop us” is an exciting campaign launched by Cristian Garrido in order to raise funds for research into Crohn´s disease and Ulcerative Colitis. It encourages people to do sports and donate their kilometres for this cause, which are then converted into money. Within only a few days the campaign, which has been promoted mainly on social media, has gained enormous interest and so far around 1800 “donators” have signed up for it. Cristian, a 26 years old sports fanatic from Barcelona tells us how and why he has dedicated himself to such an initiative.

What´s the story behind this campaign?

Well, it goes back a long time. When I was 13, I was diagnosed with Ulcerative Colitis (UC). I took some medication and at first I had only a few mild symptoms. I preferred not to tell anyone at school about my UC as I didn’t want to be the odd one out. Even though I was absent quite a lot for medical check-ups or feeling unwell I pretended nothing was wrong with me. The older I got however the worse I started to feel but didn’t want to admit it to myself. It was only after I had a motorbike accident and had to spend a day in hospital that I really got much worse and finally went to see my doctor. I was immediately hospitalized, this was around Christmas time and new year and - to make things worse - followed by my 18th birthday which I also celebrated in hospital.

Cristian Garrido during the triathlon race

I hit my low point then. Remember, I hadn’t told my friends about my UC so they didn’t know about me being in hospital. After a few months I recovered but since that moment I started getting various flare ups per year. In 2012 I had enough and decided to do something about it.

How did you get into sports?

It´s strange but when I decided to do sports I started to feel better. I never had felt so good before. I got addicted, it wasn’t only about feeling good physically, but I also felt more positive about myself and my life in general. “That´s it, this is my way to do something about my UC.” I thought. I got into it so much that I decided to sign up for a Triathlon race.

I had 11 months to prepare for it. I was working very hard to get fit and imagine how I felt as I got a

Campaign photo of the DeportistasEII group (IBD Sportsmen)

flare up just before the race. Not just a simple flare up, no, no a flare up with complications. This time I had gone to the doctor immediately but nothing seemed to work.

On the day of the triathlon I decided to participate anyway even though I had spent the whole night before in the bathroom. I was so angry about my UC. "You will not get the better of me! Nothing will stop me" that´s what went through my head. Actually this is how the name of our campaign "nothing can stop us" came about.

As I was standing with the other 500 participants about to jump into the sea I felt like going to the bathroom but there was no way…so I jumped and as I was in the water I had to concentrate so much on keeping afloat with everyone else splashing around in the water that I completely forgot about my urges. When I finally got out of the water to continue on the bike I was exhausted and felt dizzy. I took some rest, drank some water and after awhile I jumped onto the bike and felt better.

After that the only thing left was the running part. I did it but in the end it wasn't about "doing" the triathlon, it was something much more personal. It was about overcoming my UC. I would not allow my UC to take control of me!!! Something changed in me during the race. I realized that I had to do something bigger. I had to fight UC and I had just won an important battle.

How have you become so popular in social media?

Well, after the Triathlon race I prepared for a marathon. It was during the race that I met a very popular "youtuber" called Valenti Sanjuan, who was interested in my story. While we were running he asked me to talk about my disease and how I use sports to overcome it. He wanted to use the material to upload it onto his videoblog.

I was a bit apprehensive. On the one hand it would be a good way to give visibility to the disease but on the other hand everyone would know about me. This guy had about 2 million followers and was quite famous. For years I had kept my disease secret and by this stage only a few close friends knew about it. If he posted something on his videoblog everyone would know about my UC.

Again I jumped into unknown waters and did the video clip with him. The response was amazing. I didn't expect to get so many positive reactions from people in similar situations and from friends and family members of people with IBD.

This led me to set up a closed Facebook page called DeportistasEII (IBD sportsmen), with the help of ACCU Catalunya (the local IBD association) and initially with 5 people. We designed and handed out T-shirts with the motto "Nothing stops us" and we used social media as much as possible to gain visibility.

> ***"when I decided to do sports I started to feel better. I got addicted,greate it wasn't only about feeling good physically, but I also felt more positive about myself and my life in general."***

For example members who had just done 10 km of walking, cycling or hiking took pictures of themselves and posted them on their social media accounts. We have now over 230 members including people from Argentina and Uruguay as well as some IBD physicians providing some medical insights. Even though the number of the closed group is not that high the visibility we get for our cause through their public contacts is huge.

And the campaign?

The Facebook page was very satisfying especially since it got more and more people into sports. One member told us that the group was her motor to get going in life, but I didn't want to stop just there, I decided that all the enthusiasm and interest in our Facebook group could be used to do something bigger.

As you can imagine my main interest is to find a cure for UC. I am young and I want to see a cure during my lifetime, so I want to do something about it. I want to raise money to go to research into IBD.

I found out about a new start-up company called IWOPI. The objective of IWOPI is to animate people to be active in sports and donate their kilometres to a cause. Through a simple process the kilometres accumulated during a sports activity - be it walking, cycling, running etc. - are being transferred from a mobile phone application directly to IWOPI. Sponsors will then convert these kilometres into money supporting the chosen cause.

I got in touch with IWOPI and they were interested in my cause. IWOPI will provide us a space on their platform during 3 months in order to raise 200 000 km. We are now looking for a sponsor who will join our cause. Once we find a company/sponsor we will look at a new challenge. For example if our "donors" reach 15 000 km in 30 days, the company/sponsor will donate 5000 Euros to our cause.

The money that we are planning to raise through this campaign goes to IBD research carried out at the hospital Germans Trias I Pujol (Can Rubí) that has an important track record on IBD investigation.

We now need the help of everyone, including you dear reader, to inform about our cause and to help us find a company/sponsor interested in supporting us.

We are very much committed to this campaign because it lies in our interest to find a cure for this disease. It is a lot of work but it has changed our lives, we are more positive, we see our future in a better way. We all win with this campaign.

To contact Cristian please write to cgarrido89@gmail.com

European Patient Platform:
Position Paper on Discrimination in healthcare

The Europa Patient Forum (EPF) recently published its Position Paper on discrimination in healthcare. In EPF's vision, the fundamental goal of healthcare is to support every citizen in achieving the best possible health outcome and quality of life and to enable them to take their rightful place in society. Patients have a fundamental right to health.

Yet there is important evidence both from research and from feedback of patient organisations that patients face various forms of discrimination in the European Union, because of their health status and/or other grounds. Furthermore, patients are not always protected by non-discrimination legislation within the European Union, depending on the grounds on which they are discriminated and on the Member States where the act of discrimination occurs, and of their disease.

Promoting the development of EU and national policies that tackle discrimination faced by patients in health and social care as well as in domains like education and employment is one of EPF's strategic goals.

This position paper was adopted after two member consultations, as well as input from the Policy Advisory Group and the Working Group on Access.

The aim of this position paper, in line with EPF's Strategic Goal 6, is to promote the development of EU and national policies that tackle discrimination faced by patients.

The position paper presents various forms of discrimination patients encounter in healthcare, and makes recommendations on the implementation of 5 key rights to tackle discrimination:

- Right of access and equal treatment in healthcare for all;
- Right to be protected from discrimination on health status;
- Right to respect and to dignity in healthcare facilities;
- Right to information and support;
- Right for vulnerable groups to participate in anti-discrimination policies.

The European Patients' Forum is strongly committed to realise its vision that all patients with chronic and/or lifelong conditions in the EU have access to high quality, patient-centred equitable health and social care. This implies that healthcare should be free of discrimination, and that it should be respectful of and responsive to the diversity of patients in the European Union. We encourage more engagement from the EU on this theme.

EPF will circulate the paper to decision makers and to other organisation active in the field of discrimination in healthcare. Members are also encouraged to disseminate this paper within their network. In 2015 EPF will consult members on a position on discrimination in education and the workplace.

Please do not hesitate to share this position paper with your members and contacts.

The complete version can be downloaded from the EPF website at: http://www.eu-patient.eu/).

If you have comments or reactions, please send them to EPF Policy Officer Laurène Souchet (laurene.souchet@eu-patient.eu).

Health inequalities require EU-wide response

" Increasing cooperation between EU institutions and member states in health policy is the only way to tackle obstacles to healthcare access" writes Andrey Kovatchev.

Concerning the issue of discrimination in healthcare we are reprinting an interesting article written by Andrey Kovatchev, vicepresident of the Union of European Federalists and which was published in the Parliament Magazine last year.

The newly elected European parliament is about to begin its work with healthcare issues high on its political agenda. The ground was set during the previous legislature when the problem of access to quality healthcare across Europe was addressed by a number of MEPs' initiatives.

Some patients are forced to migrate to another country to find a suitable therapy when they cannot access proper diagnosis and treatment in their home country. This problem is particularly severe in new member states whose healthcare systems remain insufficiently reformed. Disparities have also been exacerbated by austerity measures which mean that equal access to quality healthcare is far from being a reality.

Legally speaking, the areas of protection and improvement of human health remain largely with the member states. The EU has only a supportive role to play in tackling health inequalities affecting all EU countries. As vicepresident of the Union of European Federalists, I'm advocating for more competences at EU level in public health policy. EU patients are paying the cost of a lack of European policy in healthcare. European problems must be given European solutions. EU citizens recognise more and more that EU collaboration is in their interest.

"EU patients are paying the cost of a lack of European policy in healthcare"

In 2011, MEPs raised health inequalities as an issue that should be afforded an EU response. They voted on a resolution on this issue of major concern for all EU member states and candidate countries. I have been involved from the onset of this initiative, staying idle because a lack of competence in healthcare is a no-go for Europe. The EU should be as close as possible to citizens and help them solve their problems. This also means supporting member states to remove obstacles to quality healthcare services for patients. The European commission is very positive in outlining possible working solutions that should be implemented by the member states.

The commitment from parliament has resulted in the creation of a patient access partnership on equity of access to quality healthcare. Led by patients - the European patients' forum and the national patient organisation of Bulgaria - the partnership will work as a network of partners that brings together the patients' movement, the medical community, the industry, policymakers and politicians.

Partners want to foster more action and cooperation between member states and institutions to tackle roadblocks to access healthcare in the next legislative term. They are also conducting a mapping exercise to have a clear overview of current initiatives in this area to scale up good practice and synergies.

It is important to ensure these proposals are heard by the EU institutions and enter their agendas. That is why I intend to initiate an informal interest group on equal access to quality healthcare once parliament restarts. Bridging the access platform with EU policymaking will be our main goal. Many of my MEP colleagues are committed to working for greater visibility of the issue and the better involvement of stakeholders in policymaking. This informed my decision to work in the parliament's environment, public health and food safety committee.

European Commission: Patient Safety

Patient safety is high on the European Commission´s agenda. A patient safety package that was published last year highlights how the Commission and EU countries are addressing the challenge of patient safety, the progress made since 2012 and barriers to overcome in ordere to improve patient safety as foreseen in a Council Recommendation of 2009.

While significant progress was made in terms of shaping national programmes for patient safety and putting in place systems for patients to report adverse effects, there is still a long way to go in terms of implementing provisions on patient empowerment and in particular on education and training of healthcare workers. The documents published on the DG Sanco´s website will feed into the reflection process currently underway on future EU-level action on patient safety and quality of care.

The Report on the Implementation of the 2009 Council Recommendation on Patient Safety

In 2009 a Council Recommendation on patient safety and healthcare associated infections put forward an overarching strategy at EU level with four areas for action: 1) policies and programmes on patient safety, 2) empowering patients, 3) reporting adverse events, and learning from errors, and 4) education and training of healthcare workers.

Following the 2012 report on the implementation of the Recommendation, which demonstrated progress by Member States and identified areas requiring further efforts, the latest report points to further progress over the last two years, notably in the following areas:

- Development of policies and programmes on patient safety: 26 countries developed or are finalising patient safety strategies or programmes. Patient safety standards are now mandatory in 20 countries (11 in 2012), and 19 countries use patient safety guidelines.

- Reporting and learning systems on adverse events: these now exist in 27 countries (15 in 2012), mostly at national level (21) and healthcare provider level (13). Patients are now more likely to report that they were harmed while receiving healthcare – 46% reporting adverse events in 2013 while only 28% in 2009.

- Patient empowerment: 18 countries inform patients about patient safety standards, safety measures to reduce or prevent errors, the rights to informed consent to treatment, complaint procedures and available redress (only five in 2012)

When it comes to the impact of the Recommendation, 21 out of the 28 reporting countries said that it increased awareness at political level, 20 said that it increased awareness in healthcare settings and 16 said that it triggered concrete action.

However, the report concludes that there is a need for continuous efforts at EU level to increase patient safety and quality of care, and proposes a list of actions including developing guidelines on information to patients, on patient safety standard and a common definition of quality of care.

As regards preventing healthcare associated infections, the report concluded that greater efforts are needed in particular to ensure specialised infection control staff in healthcare settings and isolation capacity for infected patients.

The Eurobarometer survey on patient safety and quality of care, conducted between November and December 2013 in all 28 EU countries, shows that:

- Just over half (53%) of EU citizens think it is likely patients could be harmed by hospital care in their county. However, this percentage varies widely between countries - from 82% in Cyprus to 21% in Austria.

- As in 2009 – the last time such a survey was conducted, just over one quarter (27%) said that they or a family member have experienced an adverse event while receiving healthcare. Those living in northern and western areas of the EU were more likely to say this.

- Of those who experienced an adverse event 46% reported it, as compared with only 28% in 2009, pointing to a marked increase in patient empowerment. The rise was even more significant in specific countries, e.g. France (+61%), Spain (+40%) and Luxembourg (+32%).

- Despite this, in 37% of the cases that the adverse event was reported 'nothing happened'. However, one in five received an apology from the doctor or nurse, while 17% were given an explanation for the error by the healthcare facility.

The Results of the Public Consultation that ran between December 2013 and February 2014 shows that civil society (over 90%) still see patient safety as an issue in the EU. The results showed overwhelming support for all areas of improvement identified by the Commission. According to the respondents, the most effective measures are involving health professionals, binding national laws, involvement of patient organisations and EU cooperation on patient safety.

Moreover, the majority of contributors (72%) consider that enlarging the scope of EU action from patient safety to wider quality of care would bring considerable benefits. Patient safety is seen as result of high quality of care which needs to be safe, effective and respectful of patients' needs and dignity.

Background

It is estimated that 8-12% of patients admitted to hospital in the EU suffer from adverse events whilst receiving healthcare, such as: healthcare-associated infections (approximately 25% of adverse events), medication-related errors, surgical errors, medical device failures, errors in diagnosis and failure to act on the results of tests. An estimated 4.1 million patients per year in the EU acquire a health-care associated infection, and at least 37 000 die as a result.

All documents, and more information on patient safety in the EU, can be found here:http://ec.europa.eu/health/patient_safety/policy/index_en.htm

Commissioner Borg's website: http://ec.europa.eu/commission_2010-2014/borg/index_en.htm

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European Disability Forum: Disability Intergroup elects new bureau

Throughout its years of existence, the Disability Intergroup has been a key ally in advocating for and advancing the rights of persons with disabilities in the European Parliament. It also contributes to enabling participation of persons with disabilities in decisions that concern them. It remains for the moment the only grouping of disability-friendly MEPs

On 15 January 2015 the Disability Intergroup of the European Parliament held its first meeting at the European Parliament in Strasbourg after its re-establishment. During the meeting, the whole Bureau of the Disability Intergroup was elected, and now it consists of 4 co-presidents and 8 vice-presidents. This new structure will allow a broad consensus through which the Disability Intergroup can effectively promote the rights of persons with disabilities inside the European Parliament and in Europe.

The Disability Intergroup of the European Parliament is an informal grouping of Members of the European Parliament (MEPs) from all nationalities and all political groups who are interested in promoting the rights of persons with disabilities at the European Parliament as well as at national level.

The European Disability Forum will continue holding the secretariat of the Disability Intergroup and working in close cooperation with it.

The Disability Intergroup is a very important group for EDF, to ensure that the UN Convention on the Rights of Persons with Disabilities (UN CRPD) is implemented by and within the European Parliament and across Europe.

This year is a critical year for EDF, for the European Parliament and all EU institutions. The UN CRPD Committee will examine the progress that the EU has made since it ratified the UN CRPD. It is the first time that any human rights body examines and makes recommendations to a regional organisation. EDF hopes that the Disability intergroup will actively contribute to all stages of the dialogue between the UN CRPD Committee and the EU including through report and plenary debate.

EDF also looks forward to working closely with the European Parliament on the review of the European Disability Strategy and the Europe 2020, as well as on the adoption of the European Accessibility Act and of the general anti-discrimination directive.

The UN CRPD in its article 4.3 calls on State Parties to actively involve persons with disabilities through their representative organisations. To this end, EDF will continue to work very closely with the Disability Intergroup of the European Parliament.

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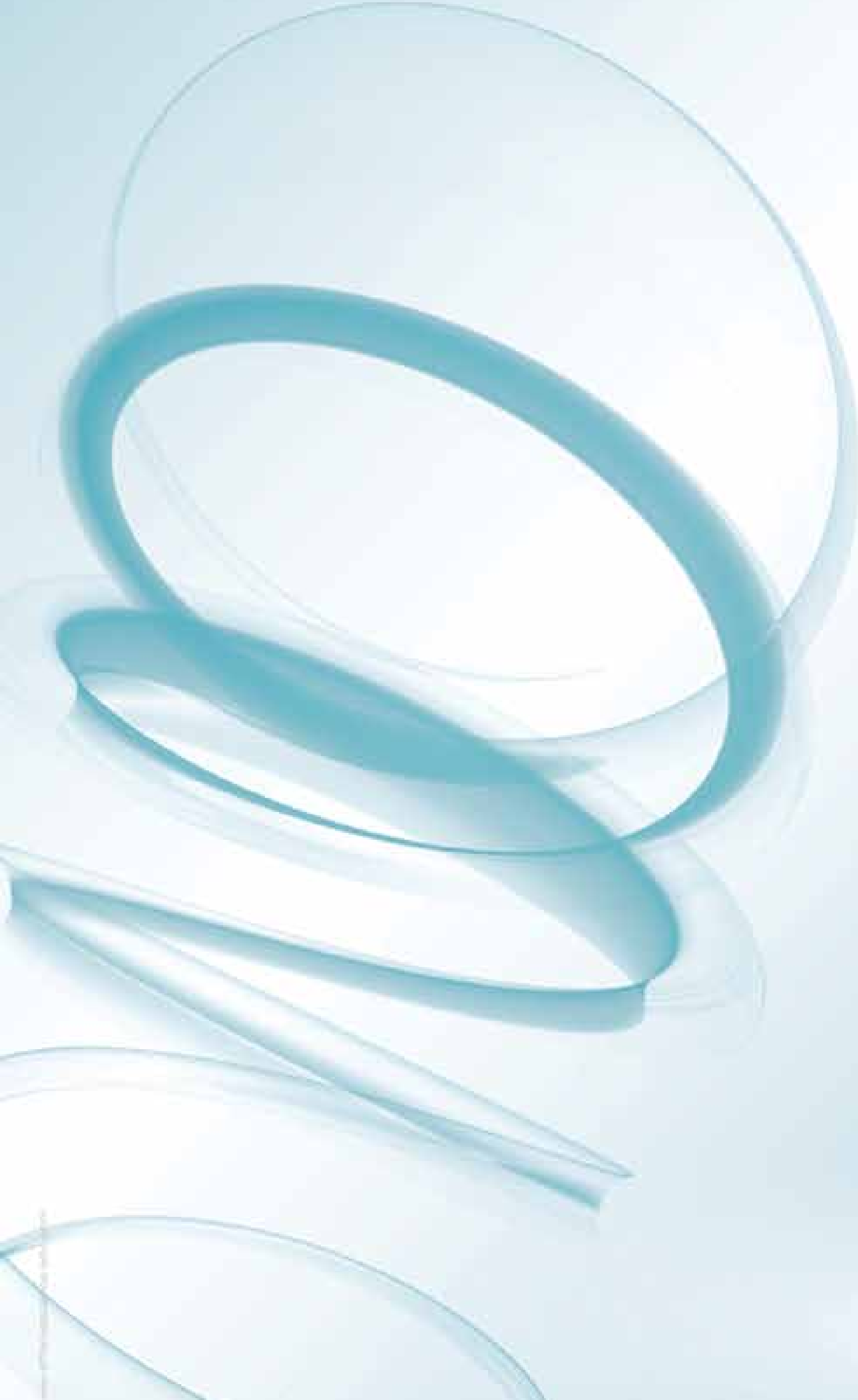

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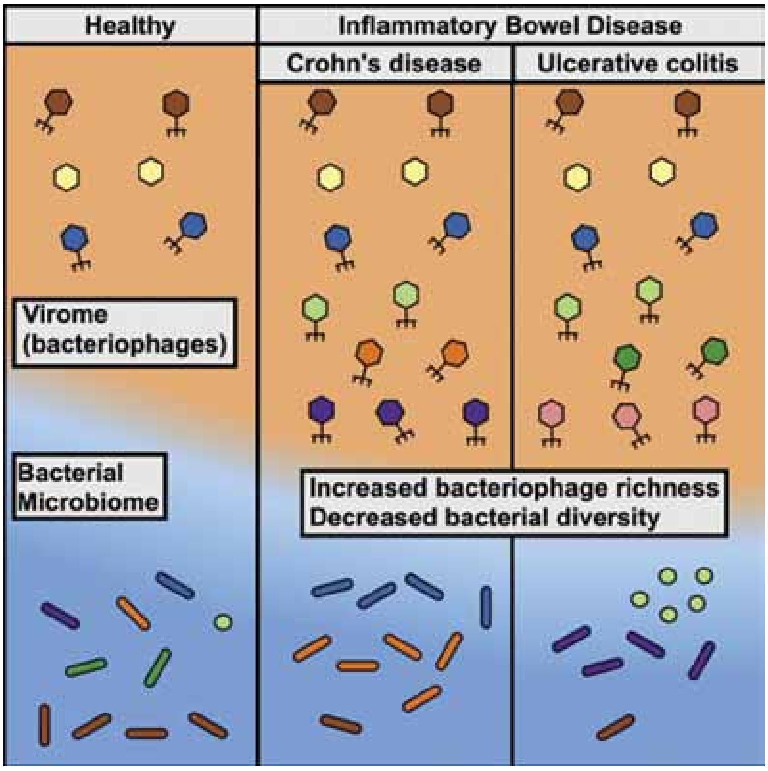
New study on the role of viruses in inflammatory bowel diseases, IBD*

Inflammatory bowel diseases are associated with a decrease in the diversity of bacteria in the gut, but a new study led by researchers at Washington University School of Medicine in St. Louis has linked the same illnesses to an increase in the diversity of viruses.

The scientists found that patients with inflammatory bowel diseases had a greater variety of viruses in their digestive systems than healthy volunteers, suggesting viruses likely play a role in the diseases.

Scientists only recently started recognizing the role of the microbiome -- the bacteria in and on the body, and the bacteria's genes -- in illness. For example, changes in the gut microbiome have been linked to obesity, diabetes, metabolic syndrome and inflammatory bowel diseases.

The new research is the first to associate disease with changes in the virome, or the viruses in the human body and their genes. According to the researchers, the results raise the possibility that viruses may have unrecognized roles in obesity and diabetes and the two most common inflammatory bowel diseases, Crohn's disease and ulcerative colitis.



Graphical abstract of the research

The findings suggest that scientists should be studying the virome as closely as the microbiome, said senior author Herbert W. Virgin IV, MD, PhD.

"This is the tip of the iceberg," he said. "A significant portion of the viral DNA we identified in these patients is unfamiliar to us -- it comes from newly identified viruses we don't know much about. We have a great deal of groundwork to do, including sequencing the genetic material of these viruses and learning how they interact with the gut and gut bacteria, before we can determine if changes in the virome cause these conditions or result from them."

The Centers for Disease Control and Prevention estimates that inflammatory bowel diseases affect about 1 million people in the United States. Crohn's disease and ulcerative colitis are thought to involve misdirected immune attacks on gut tissue and can lead to weight loss, bleeding in the gut and rectum, and loss of appetite.

Surgery to remove part of the bowel is often necessary to treat Crohn's disease.

Virgin and his colleagues studied three groups of patients with Crohn's disease or ulcerative colitis living in Chicago, Boston and the United Kingdom. In each group, they compared viral DNA purified from the feces of participants with viral DNA from the feces of healthy people living in the same areas and, in some cases, the same homes.

"Much of the increased viral diversity in participants with inflammatory bowel diseases was in the form of bacteriophages, which are viruses that infect bacteria and can incorporate themselves into the bacteria's genetic material," said Virgin, the Edward Mallinckrodt Professor of Pathology and head of the Department of Pathology and Immunology.

Changes in the gut that eliminate bacteria in inflammatory bowel diseases may unleash bacteriophages in the dying bacteria, Virgin speculated. Or the introduction of a new bacteriophage to the gut, perhaps through the foods in a person's diet, may trigger a reaction in the digestive system or the microbiome that causes the disorders, he said. It's also possible that a combination of these mechanisms may contribute.

To develop better treatments for inflammatory bowel diseases, scientists need to learn more about how the gut microbiome and the gut virome interact with a patient's genes.

"We know that mutations in human genes affect the risk of inflammatory bowel diseases, and scientists also are exploring how bacterial genes may influence risk," Virgin said. "Our results show that the virome's potential effects on the gut also need to be a part of these investigations."

The researchers are developing an animal model of inflammatory bowel diseases to make it possible to determine whether human, bacterial or viral genes, or some mixture of all three, are driving these illnesses.

The research was funded by the National Institutes of Health (NIH(, the Crohn's and Colitis Foundation, the Broad Medical Foundation, the Agency for Healthcare Research and Quality, the European Union and the Leona M. and Harry B. Helmsley Charitable Trust.

***The research appears online in the medical journal "Cell" and in the journal's print edition Cell, Volume 160, Issue 3, 29 January 2015.**

"Disease-Specific Alterations in the Enteric Virome in Inflammatory Bowel Disease"

Jason M. Norman, Scott A. Handley, Megan T. Baldridge, Lindsay Droit, Catherine Y. Liu, Brian C. Keller, Amal Kambal, Cynthia L. Monaco, Guoyan Zhao, Phillip Fleshner, Thaddeus S. Stappenbeck, Dermot P.B. McGovern, Ali Keshavarzian, Ece A. Mutlu, Jenny Sauk, Dirk Gevers, Ramnik J. Xavier, David Wang, Miles Parkes, Herbert W. Virgin

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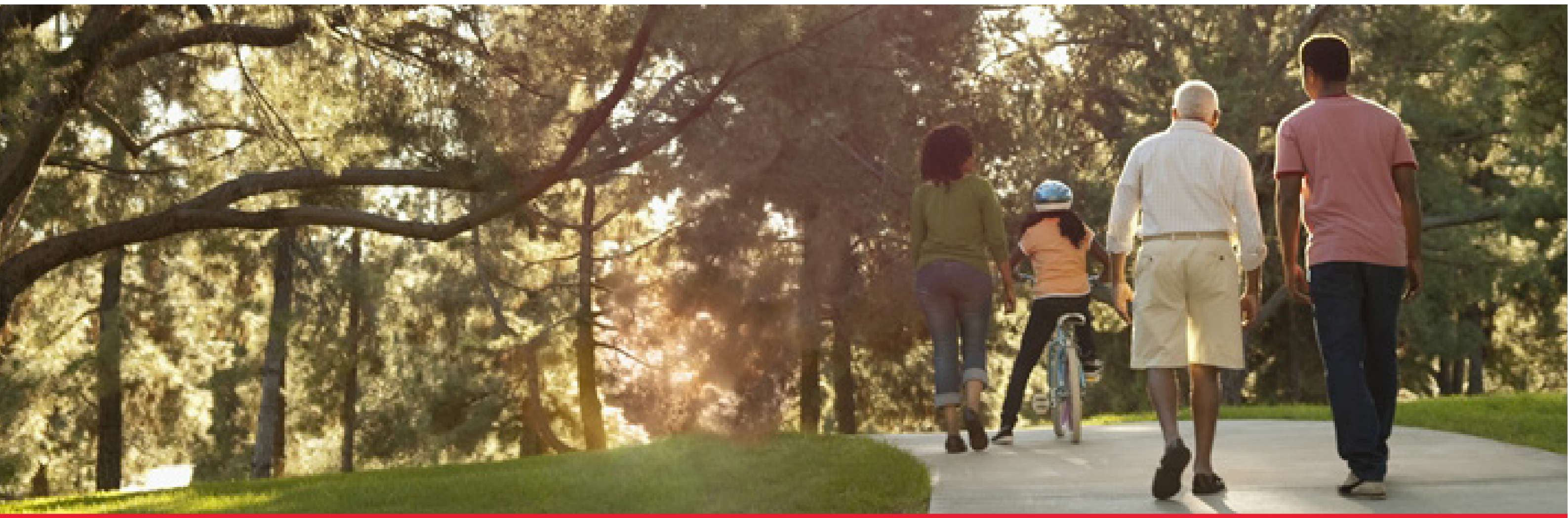

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