

EFCCA MAGAZINE

European Federation of Crohn's and Ulcerative Colitis Associations | October 2014

Cruise around the island of Elba

Unusual summer camp for youngsters with IBD

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Being a parent of a child with IBD

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MRI and computed tomography in the assessment of IBD

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EDITOR'S EYE

The patient first



I am sure the cover photo has taken you right back to this summer, a time, which hopefully for most of our readers has been a moment to take a break and to relax from work commitment. A time when we can be amongst family and friends or seeing new places and making new experiences that allow us at least for a couple of days or weeks to forget about our daily routine and concerns. This is exactly what the summer camps have meant for more than 500 youngsters with IBD across Europe: a place to relax, forget about your worries and making new experiences.

The EFCCA labelled summer camp is a venture that I personally supported since its beginnings, and I am proud to see how the spirit that lies behind the camp is becoming more and more popular giving an ever increasing number of youngsters the opportunity to meet in a safe environment and realising that they are not alone. I would like to highlight one particular EFCCA labelled summer camp - not because it was carried out in my home country - but because it really showed an innovative approach to learning and facing challenging moments whilst

having fun. Four girls participated in a sailing cruise around the island of Elba being guided by a professional crew to take charge of “their” sailing boat. They were accompanied by another boat with doctors and support staff. Both crews had to take the responsibilities that come with sailing a boat and an added, unforeseen value of this constellation was that it allowed our four girls to see their doctors and health care professional undergoing the same “treatment” and doing the same mundane activities as everyone else. You can read more about this and other summer camps in our EFCCA News section.

You will also find information about our World IBD Day activity that has taken place this year in Brussels. Due to the elections to the European Parliament which took place in May and co-inciding with World IBD Day, we focused our activity on awareness raising in general rather than on lobbying Members of the European Parliament. A very motivated EFCCA team participated in the Brussels “half marathon” and the event was a huge success in bringing together our associations and creating a spirit of solidarity. We will definitely continue along this way in the coming years whilst of course also retaking our efforts with the newly elected Members of the European Parliament.

Another important matter that we are dealing with at the moment is the issue around biosimilars. Licensing rights of biological medicines used in the treatment not only of IBD but also other autoimmune modulated diseases are coming to an end and “biosimilar” medicines are being developed to compete with original biological treatment options. Of course we understand the market forces that are in place right now and

Editorial and Publication
coordination:
Isabella Haaf

Graphic Design:
Isabella Haaf

Contributions:
Áslaug Eva Björnsdóttir,
Thorunn Arnadóttir,
Crohn's and Colitis UK
(interview with Beth
Townsend), EFCCA
members, Lynn Ovens

EFCCA Contact details:

Rue des Chartreux 33-35
B -1000 Brussels
Belgium
Tel/Fax: + 32 2 540 8434

Chairman Marco Greco
Tel: + 39 346 800 9433
marco.greco@efcca.org

CEO Luisa Avedano
Tel: + 39 349 4161 157
efcca.ceo@gmail.com

Secretary Ciara Drohan
ciara.drohan@efcca.org

Treasurer, Martin Kojinkov
martin.kojinkov@efcca.org

Communications
Isabella Haaf
Tel: +34 606 849 937
bella.haaf@efcca.org

Registration:
1096/97
revised 22/2/2006
No. 459814543

we welcome the idea and necessity of affordable treatment options to be developed, but we believe that under no circumstances should the safety of patients be compromised. For us, patient safety lies at the core of our work. We need to ensure that treatment options, that are available for IBD, are in the best interest of the patient and not a factor to be considered from an economic point of view.

As member of the Pharmacovigilance Risk Assessment Committee (PRAC) at the European Medicines Agency I know too well the discussions that are taking place at European and international level as concerns biosimilars. We believe it is important for our members to be aware of the implications and issues around biosimilar. We are doing this in various ways, we have already involved several members in highly specialised training session at the National Institute for Bioprocessing Research and Training in Dublin. We are also conducting a survey amongst our members on their understanding of biosimilars. The aim is, at this stage, to take stock of the knowledge that is already (or not) available amongst the patient community. This survey will then allow us to work on a more specific approach and empower us to be a main stakeholder in the discussions and legislations that are taking place in many countries. We are also in contact with the World Health Organisation (WHO) and have just submitted our comments to a WHO public consultation, making sure that they listen to our voice.

You will find plenty of other stories in the magazine showing you the kind of efforts and spirit that we can find amongst the IBD patient community to make our voices heard and to constantly fight for a better quality of life of people living with IBD. UNITED WE STAND!

Marco Greco, EFCCA Chairman



World IBD Day

In its 6th year of existence World IBD Day, which is officially marked on 19 May, is increasingly becoming a truly global event that brings together IBD patient associations to raise awareness about the harsh realities of living with IBD and at the same time to show to the world that you can still have an active life and that there are plenty of options to improve the quality of life of people with IBD.



Some of the runners at the finishing line (from left to right): Peter (Belgium), Christian Garrido (Spain), Vítor (Portugal), Martin Kojinkov (Bulgaria), Salvo Leone (Italy) and Sanna Lonnfors (Finland).

The range of activities and awareness raising campaigns to achieve these aims have been amazing this year with World IBD Day events taking place in all corners of the world from Latin America, Oceania, to North America, Europe and Asia.

Here in Europe, EFCCA together with some of its 27 European member associations took the challenge to participate in the Brussels half marathon as a way to raise awareness about IBD and to show that even with IBD such a demanding event can be done. A group of runners from Slovenia, Belgium, Spain, Italy, Portugal, Finland, Romania, Ireland and

Bulgaria started the race together on an unusually sunny morning on 18 May at the Parc Cinquantaire next to the EU institutions. The first runners to pass through the finish lines were from Spain and Ireland, shortly followed by Portugal, Bulgaria and Slovakia.

Of course we were proud of each and one of the runners, whether they came first or last. The important thing was to gather the courage to run such an enduring race and to test your own limits whilst showing to the wider community that it can be done. A particular bravo goes to our runner, Cristian from Romania. The Romanian IBD patient association,

ASPIIR, has joined EFCCA only this year but has already shown a great commitment to be part of a wider IBD family. Cristian hasn't been doing any serious sports for the last 7 years but on the occasion of the race he was very committed to bringing back a medal to Romania which he achieved! *"It has inspired him to get back into sports and take more control of his physical well-being."* he said straight after the race while catching his breath and admiring the well deserved medal. Salvo Leone, a runner from Italy, said "we want to show everybody that even with IBD you can fully participate in an active life and enjoy the challenge that the race brings".

These are just two of the many personal stories and motivations for doing the race. If you want to know more about the event please also check out the World IBD Day website (www.worldibdday.org). From the positive feedback we have received EFCCA is keen to repeat the event next year and to involve an even bigger group of runners as well as organise an information stand and activities parallel to the half marathon. So get your running shoes on and train for next year!!!

Isabelle, from Belgium, our youngest runner.



Cristian from Romania, taking a well deserved rest and admiring his newly gained medal.

Ivor, from Ireland, brought along the youth group mascot.



New generation of drugs

At the beginning of June, a small EFCCA delegation including Luisa Avedano, EFCCA CEO, Isabella Haaf, EFCCA communications manager, and Sanna Lönnfors, medical writer, participated in a training session at the National Institute for Bioprocessing Research and Training (NIBRT) located in Dublin, Ireland.

The training course was aimed at gaining a better understanding of the processes involved in the production of biological medicines and the implications these have around the issue of biosimilars. It focused both on the production process of biological medicines as well as the regulatory framework and procedures involved for the approval of new medicines by the European Medicines Agency.

As we reported in our previous EFCCA Magazine (“Naming, transparency and traceability for biosimilars: does Europe need to act” page 10, May 2014) there are many considerations to be taken into account on the subject of biosimilars and there is a clear need for patients, patient associations as well as other healthcare stakeholders, to get a better understanding of the complexities around biosimilars. EFCCA is currently preparing a survey amongst its members and other auto immune modulated diseases to assess the level of knowledge around biosimilars which will then be used for further elaboration. The aim is to establish a position on biosimilars aimed at ensuring patient safety and best possible treatment options.

Participants at the September training session in Dublin



Second training session

At the same time, EFCCA organized another training session at the NIBRT center in Dublin which took place on 13 September and included 15 participants of which 6 participants were members of EFCCA (including 1 representative from the EFCCA Youth Group). The other participants were members of the other auto immune modulated diseases associations, namely AGORA (Rheumatic and Musculoskeletal disease in southern countries of Europe), ASIF (Ankylosing spondylitis) and IFPA (Psoriasis).

A steering group meeting of the above mentioned auto immune modulated diseases associations and EFCCA took place after the training session. The aim of the Steering Group meeting was to finalise the survey on biosimilars and agree on common strategies to collaborate on the issue of biosimilars. Luisa Avedano also shared information about a recent public consultation launched by the World Health Organisation (WHO) (see next article).

The training activities have been supported through an educational grant from the pharmaceutical

WHO public consultation on Biological Qualifier proposal

The World Health Organisation (WHO) has launched a public consultation on its Biological Qualifier INN proposal inviting comments and suggestions, which will then be considered by the Expert Group of the Programme on International Nonproprietary Names (INN).

company AbbVie.

Background

Following requests from some drug regulatory authorities, the INN Expert Group recommended that WHO develop a system for assignment of Biological Qualifiers to similar biotherapeutic products (SBPs). After discussions among interested parties and approval by the INN Expert Group, a voluntary scheme is proposed by which an application can be made to the INN Secretariat for a Biological Qualifier (BQ).

A BQ is an alphabetic code assigned at random to a biological active substance manufactured at a specified site. The scheme is applicable to all biological active substances to which INNs are assigned and is applicable retrospectively. The BQ code will not be part of the INN, whose selection by the usual procedure will remain unchanged.

Where use of a BQ is considered by an authority to be desirable, availability of a single global scheme will avoid proliferation of separate and distinct national qualifier systems. The scheme will be overseen by the WHO INN Expert Group and administered by the WHO INN Secretariat. It will be self-funding through payment of a single fee for each application. Administrative details of the scheme will be explained in due course.

EFCCA's comments

EFCCA has taken the opportunity to share its comments with the relevant authorities of the WHO. EFCCA acknowledges the WHO's effort

for its attention reserved to patient safety, especially since patient safety has been an ongoing priority for EFCCA ever since it was set up. EFCCA stresses the need for patient safety to be a joint effort where every stakeholder has to do its best to reduce the risk of error during treatment and care. For this reason patients and patient organizations have a role to play in offering their direct knowledge and competencies.

EFCCA believes that this proposal is the first step to establishing global pharmacovigilance. Despite the fact that the proposal is based on voluntary action, EFCCA hopes that the important role of WHO will encourage the relevant agencies for the evaluation of medicinal products - in Europe and worldwide - to embed it in their regulations.

EFCCA suggests that the role of patients has to be reinforced. Promoting involvement and action by the patient, and not just passive understanding of health care matters, is a key aspect for any effective policy. Safety is a primary concern for patients.

EFCCA welcomes online consultations and looks forward to further constructive ways to allow patients to express their concerns and suggestions. A platform of all the patient organizations dealing with auto immune-modulated diseases would dramatically benefit from WHO endorsement.

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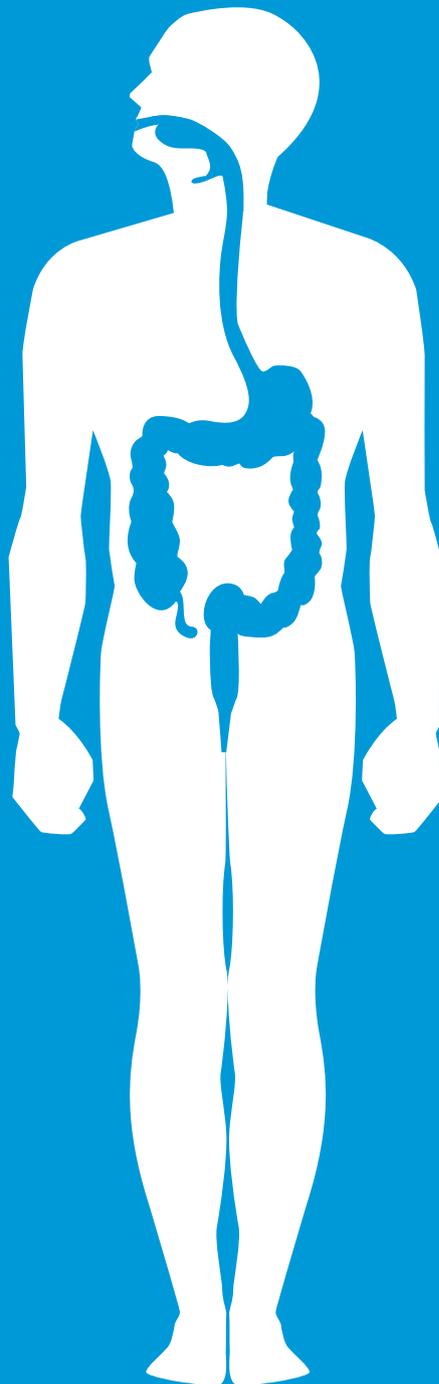
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EFCCA Summer camps

Summer camps for young people with IBD are an excellent opportunity for youngsters to relax and meet other people in similar situations. Being in a supportive environment and surrounded by people who understand their disease allows those youngsters to open up to each other and to speak more freely about their fears and concerns. Most camps provide interesting educational activities with the help of gastroenterologists, psychologists, nutritionists and volunteers to help youngsters to learn more about their disease and ways of managing it. EFCCA has been working over the years to support our members in the organisation of such activities and we are proud to say that this summer there were EFCCA labelled summer camps in 7 European Countries.

Italy

Cruise around the island of Elba

The unusual 2014 Italian Summer Camp “Sailing with AMICI” came to an end on Saturday, 12th July. Four junior girl athletes affected by inflammatory bowel disease and two instructors took part.

The initiative – sponsored by Regione Toscana, Provincia di Livorno and Ente Parco Arcipelago Toscano – was organized by the Italian IBD association AMICI and the Aquarianaturaclub Association in Livorno, with the support of IG – IBD (Italian Group for the Study of Inflammatory Bowel Diseases , http://www.ig_ibd.com) and EFCCA.

The project was presented during a press conference at the Provincia of Livorno, by director of «AMICI», Salvatore Leone, and by the president of the Aquarianaturaclub, Furio Viapiano in the presence of the president of the Provincia, Fausto Bonsignori. “This is an extraordinary initiative” said Mr Bonsignori “which contributes to the awareness of a disease that – in different ways – affects a large number of people with, at times, invalidating physical consequences. That’s the reason why it’s important to work on people’s self-esteem, helping them to get over difficulties they have to face in everyday life. Sailing is an uncommon experience that will represent a hard trial for these girls”.

AMICI has always been engaged in insuring all necessary care for people with IBD and involving its members in new activities. “The Summer Camp”



Members of the crew with our youngsters

explained Andrea Coccioli, AMICI president, “shows how members and patients are able to share socializing and formative experiences. AMICI provides them with experiences that go beyond their everyday social life. The participants will have the possibility to face other patients, to face themselves and even to face their own disease. Certainly we will repeat this experience as it has generated great enthusiasms among members and their families”.

“First of all, communicating means listening. This should be a doctor’s main aim, especially when the patient is young with his/her whole life ahead. We should not restrict our aim to the close examination of symptoms, to the efficacy of medicines or to difficulties of surgery. A doctor has to listen and face a patient’s fears, explaining the uncertainties inherent to this illnesses and the operational therapeutic project to treat them. The journey that a specialist undertakes side by side his patient was well experienced at the 2014 Summer Camp. This is the project that the ITALIAN GROUP FOR INFLAMMATORY BOWEL DISEASES has been pursuing since its foundation: applied research, fieldwork, partnership with Ministerial and Regional groups and AMICI and with INTERNATIONAL SCIENTIFIC SOCIETIES” concluded acclaimed Fernando Rizzello, IG-IBD secretary.

The sailing boat that hosted the girls was paralled by a medical care boat (housing skippers and doctors) and met all the most important ports on the island of



Learning basic sailing skills

Elba in a week’s time. Besides learning the basics of sailing and life on the sea, our four girls visited seaside resorts and villages.

The EFCCA labelled AMICI Summer Camp was a successful pilot experience as it achieved at least two important objectives:



1. Team building activities that strongly contributed in overcoming potential barriers among the different groups of people involved (young people with IBD, sailing team and physicians)

2. A concrete, real life example of EFCCA's desire to youngsters activities like summer camps was and is a milestone in feeding a powerful and skilled

future generation of advocates fighting IBD in all domains.

EFCCA is already working to design a similar camp in 2015 where youngsters coming from different national associations will be able to enjoy a similar experience. Resources and ideas are on their way.

Poland

Two weeks of pure fun

In Poland this year, the summer camp started quite early: during the first two weeks of July around 100 people including 65 kids ranging from age 3 to 18 participated in the camp at the Baltic Resort village Stegna, which was organized by the Polish IBD association “J-elita” and supported by EFCCA.



Our kids had an amazing time playing with each other, sunbathing on the beach, swimming in the hotel's swimming pool and visiting wonderful places like Gdansk, Gdynia and Sopot. On our trip to Gdansk the kids visited a museum of old yachts: “Dar Pomorza” and “Dar Młodzieży” as well as one

of the biggest aquariums in Poland. Throughout the duration of the camp a group of psychologists, gastroenterologists, nurses and counselors were available 24h/day and provided support and individual talks whenever needed.

Each day our counselors planned and carried out interesting activities for the kids and every other day kids participated in workshops organized by our psychologists. In addition, we also organized two workshops with psychologists aimed directly at the parents of kids with IBD helping them to better understand the disease from different perspectives and sharing tools of how to behave when their kids didn't feel well.

From the feedback we received from the parents it became clear that these workshops were very useful and that there was an urgent need for such information.

Participants had a chance to learn more about IBD during two lectures presented by Dr P. Albrecht who talked about "articular complications of IBD" and Dr K. Bochenek talked about exacerbation in IBD.

Of course we also had plenty of time for fun and many entertaining competitions took place during our stay. Amongst the most challenging and emotional one was the contest for the best sand sculpture. The winner was a complex piece of art entitled "IBD patient during colonoscopy".

Kids as well as parents also had a lot of fun playing football and volley ball during the day and the evenings dancing at the disco or enjoying our barbecues. As was the case last year, our alcohol-free Mojito was the smash hit!

The sun shined on us for two weeks making it a truly relaxing experience for everyone and the kids can't wait for next year's summer camp! Thank you EFCCA for your support!

Agnieszka Golebiewska, J-elita



France

A summer camp to remember!

This year, 17 young people with IBD participated in afa's (Association François Aupetit) third annual summer camp, which took place in Dinard in Brittany from 2-10 August and was hosted by the Solarcroup Herbert Foundation.

The youngsters together with their siblings between the ages of 20 and 30, spent a whole week together. Two gastroenterologists and a nutritionist visited during the camp allowing the youngsters to learn more about IBD and how to manage everyday life. Several workshops on “how to talk about IBD”, “how to manage fatigue” etc... were presented by our “shock team” of volunteers.

Of course it was not only about working and learning: indeed most of the participants were looking for someone to talk to and to have the chance to meet other young people with IBD. A wide range of fun activities including parties and sports games gave them the opportunity to get to know each other better. And to tell the truth, it was really a fun week. We really enjoyed playing ice breaking games at the beach, bowling competitions, board games, enjoying the ocean... For sure, it was a great agenda with work and fun organized by an amazing team of volunteers.

It was an event to be remembered and everybody was sad to leave. At the end of the week, debriefing with these young adults was very emotional – new friends and great experiences had been shared with so many things learnt. “We will remember this week for a long time” or “it was great, I’m going back home with my heart a bit lighter” were some of the comments we heard. We also had many thanks addressed to the organisation team and to afa. We saw what a great opportunity the summer camps are for young people with IBD and we are so lucky to have an amazing location, thanks to the Solarcroup Herbert Foundation. Thanks also to the other partners for letting our youngsters live such an amazing week: EFCCA and the Association Ensemble pour Pierre-Yves. The team from the youth group did a great job preparing the camp. Let’s hope that more and more young people are eager to go to the afa Summer Camp in the future.

Alix Vié, afa Youth Group Coordinator

Slovenia

Quality time

In Slovenia, the summer camp weekend took place during the first weekend in July (6-7 July 2014) in the beautiful mountain range of Pohorje near Maribor.

We got 10 young people with IBD together between the ages of 18-29 to spend some good quality time with each other and to talk about their difficulties and good ways on how to manage their disease. Two members from the Slovenian IBD patient association, KVCB, who live in Maribor also joined participants. One of them, Jure, organised some fun sessions on basic origami – the Japanese art of folding paper – showing everyone how to make a swan out of paper.

More physical energy was required during the sports activities, which included a visit to a laser tag center.

We also organised an educational workshop on “Food and sports with IBD” which was very much appreciated by the participants. We have had very positive feedback and the fact that five of the participants had already participated in last years summer camp shows us that we are going the right way!

Mateja Saje, KVCB



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- 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.



European Youth Meeting, Dublin 2014

Every year the EFCCA Youth Group (EYG) has a European Youth Meeting (EYM) with member countries taking turns to host the meeting. For 2014, it was Ireland's turn! In July of this year, 37 delegates from 19 countries across Europe descended on Dublin for what promised to be an educational and inspirational weekend.

The concept behind the weekend is to enable these youth associations to share and swap ideas to better manage their groups and provide improved services to their members. In order to facilitate this, each country gave presentations on their successes during the year and their plans for the future. Furthermore, the EYG organised and facilitated workshops with the focus this year on fundraising and raising awareness at both local and European levels.

The timetable for the meeting was jam packed with workshops and presentations taking place in the morning and afternoon. The delegates were

treated to a trip to the Irish houses of parliament, Leinster House, where they were greeted by Minister Ged Nash, and Irish member of parliament who suffers from IBD.

After a tour of the parliament building a treasure hunt around the city was organized followed by a guided bus tour and the highlight, I'm sure everyone will agree, a tour of Guinness Storehouse.

As part of the meeting, the new EFCCA Youth Group was elected! The new group consists of Daniel Sundstein (who was also re-elected to leader

Participants of the EFCCA Youth Group meeting, Dublin 2014



- Denmark), Sara Byrne (Ireland), Maksim Besic (Slovenia), Áslaug Eva Bjornsdottir (Norway) and Fergal Troy (Ireland), alongside EYG substitutes, Katleen Franc (Belgium), Sofie Marton (Sweden), Stefan Djakovic (Serbia), Claire Hunt (UK) and Leanne Downie (UK)

Again thank you to all our sponsors and delegates who made this the most successful European Youth Meeting to date.



In front of the Irish Parliament building

Sara Byrne, EFCCA Youth group

My first EFCCA Youth Group Meeting

As the new coordinator for the Youth Group at the French Association François Aupetit – afa - I took part in the 17th EFCCA Youth Meeting, this year held in Dublin and hosted by the Irish Society for Colitis and Crohn's Disease - 17th to 20th July 2014.

As I had just started my new job at afa, to be part of the meeting was very important to me. Being there gave me a better understanding of IBD and especially of the Young People with IBD. It was a very enriching moment as I had a chance to exchange with people my age from all over Europe.

It's very interesting to talk about our different modes of communication, different ways of raising funds and public awareness. Our cultural differences are vast and as we tend to forget how rich Europe is with so many different cultures, this meeting was a good reminder. Some of us are more humorous, ironic or serious in our ways which are reflected in the fund raising and communication styles leading to public IBD awareness.

I think that this type of meeting is essential for our national associations to raise awareness about IBD.

And of course, it's also very important to create a youth network as we all need information, help ... for and from each other.

I'm sure the meeting is helping the national associations' youth groups to learn how to improve and help them develop their actions in these two fields. There is still a lot of work to do to help them to be more efficient and I am willing and eager to be part of it. For sure, I'm glad I was part of the 17th annual meeting and really looking forward to next year's meeting.

Alix Vié, Youth Group coordinator at Association François Aupetit – afa

Being a parent of a child with IBD

What does it feel like?

I have thought of that quite a lot, especially after a long term hospital admission where my mum stayed by the hospital bed all day long while my dad was at home taking care of my younger brothers. I know that they worried, they worried a lot and for a reason, nobody knew if I was gonna make it this time, not even the doctors. But how much did they really worry? I was an adult, or 21 years old for my first long term hospital admission, I was not really a child any more, but I am always going to be their child.

When I and the others in EFCCA Youth Group started to discuss topics for our communication strategy and the EFCCA magazine this topic came up. All of us have thought about how our parents really feel.

There isn't much focus on the relatives of people with IBD. Most effort goes into taking care of the patient which is understandable. But they, "the parents", are our heroes. We want to put our heroes, our parents, into focus and get their side of our IBD.

I think most parents will at some point worry sick about their children, literally sick. How is their life going to be with IBD? Are they going to make it through school? Will they make it through next hospital admission? Are they ever going to be able to live a normal life?

Our parents are our heroes fighting through IBD and without having it, and never able to take the pain away or the tiredness or bloody diarrhoea! The only thing they can do is be there for us, always supporting, giving good advice and trying to make our days better in any possible way. Even though it is for them often just the ONLY thing they can do, they want to do more, I know that.

This Only thing for us is indescribable support,



it's the support that holds us together and gives us energy to just try again and keep on fighting our IBD, doing the best to get out of our difficult situation.

Our parents are our fighters, fighting IBD with us every single day, even when we don't know about it.

Aslaug Eva Björnsdóttir
EYG communication manager

You have got to be strong!

Interview with Thorunn Arnadottir

Thorunn Arnadottir, a mother of three, speaks about her experiences of bringing up a child with IBD. Her daughter Eva was diagnosed with IBD 12 years ago at the age of 17. Eva is now - amongst others - an active member of the EFCCA Youth Group and very committed to helping other youngsters and familiar members in similar situations.

When Eva was diagnosed with IBD, had you heard of IBD before?

Yes and no. My sister has IBD but I didn't really know much about it and it was all new for us.

What was your first reaction?

Eva had been very sick and the doctors just couldn't find out what was wrong with her, so when we finally got the diagnosis to be honest we were quite relieved.

Do you think the health services were supportive when they gave you the diagnosis?

I don't think they were very helpful. I was very scared because Eva was so sick and her doctor at that time was not very good. We tried around 3 to 4 doctors before we found one we were really satisfied with.

How did you cope taking care of Eva?

In 2006 Eva was so sick that she had to be hospitalised. The problem was that the nearest hospital was in Oslo which is about 4 hours away from our hometown. It was a very difficult time as my husband and I were both working. Eva was in hospital for about 3 months and since I couldn't drive to Oslo every day I decided to move to Oslo to be with Eva in hospital. My husband had to stay home as my sons were young and afraid for their sister. Eva got sick again in 2010, when she stayed another 7 weeks in hospital. I stayed by her bed again the whole 7 weeks helping her.

How did you feel at that time?

I knew that I had to be strong, really strong because Eva was so sick, I had to be strong for her. I was off course afraid, she was so sick but I couldn't tell her how afraid I was, obviously. When she got sick in 2010 it was terrible, she was always running to the toilet, up to forty times a day, and we didn't sleep in those seven weeks, it was just five minutes here, five minutes there.. I was really tired. I didn't know that you could be awake for such a long time. But you can.

I also felt very angry. I really wanted to take the pain from her but I couldn't. I didn't know how I could help. Of course I didn't tell her.

And Eva was so strong. It was she who told the doctor to operate. "I am so sick so you cant do much more, you know what you have to do!" she said to him. Afterwards when she woke up from the operation, staying at the post-operative, she needed me to stay with her, she was in a lot of pain. She asked me to help her to see the ostomy on her stomach. I thought it was a little bit soon but I agreed to help her. When she saw her stomach she said "hello my friend, you and I are going to be good friends!" This was amazing she was not angry at all, she just accepted it as the only way to get better.

How about your other children? How did you explain to them about Eva's disease?

I have two more sons, Eva being the oldest. They saw from the beginning how IBD affected Eva and how sick she was before she was even diagnosed.

When Eva was hospitalized and the doctors had a hard time controlling her IBD, her brothers started to really worry. They both had a very different approach to Eva's sickness, especially when she was in the hospital. The younger one was worried for her life and wanted to visit her in hospital. The older one on the other hand, did not want to visit her at all and also didn't want to talk about it even though we know that he was really worried about Eva. He needed to get some help once we got back from hospital so that he could talk it out. As you can see, it was very hard on them, it was hard for the whole family while Eva was so sick.

What would you say to another parent who has just found out their child has IBD?

That's a difficult one. I would say you have to be positive from day one. It is much easier to survive if you can see that. You can cry and be angry but not in the moment when your child is sick.



Thorunn Arnadottir (left) with her son and daughter watching TV together at the hospital

Get support!

Interview with Lynn Ovens

Lynn has two little girls aged ten and thirteen. The younger one, Amy, was diagnosed two years ago with Crohn's disease.



Have you heard of IBD before?

Yes, as I have Crohn's disease myself, and my brother has ulcerative colitis, so we knew about it and I think that's why Amy was diagnosed quite quickly.

What was your first reaction when you found out?

I was devastated. It's terrible enough to have Crohn's disease as an adult and to deal with it. So it's hard to see your child having to go through the same. To be honest it's just awful.

Did you find that the health care services were helpful when your daughter was diagnosed?

Yes, very much so. The paediatric team has been absolutely fantastic, actually much better than the adult services. The way our health care system works means that if a child is diagnosed with a chronic illness you do get access to psychological services to also support the family. I think if it wouldn't have

been for the IBD team we would have really struggled. Obviously having the disease myself is a daily struggle and here you are also dealing with a child which is even harder. So the team that Amy has at the hospital is very supportive and just fabulous.

Do you have any other children?

I have an older daughter, called Rachael, she is thirteen and she is fine health wise. In the past, Amy had to go into children's hospital for long stays and Rachael remained at home. Her dad looked after her but the family has been separated at times and that has been difficult.

How is Rachael taking it?

We have always been very open with Rachael and she fully understands what is happening to her sister. They have a good relationship and we try to make sure she is included as much as possible when we are dealing with Amy's disease. I think for anyone with a chronically ill child it's very difficult and one has to make sure that the other sibling around does not feel left out.

How do you manage to take care of Amy?

Being sick myself has been very difficult and I actually lost my job taking care of myself and Amy. I worked as a nurse and I had to take so much time off work to look after Amy and then I got sick myself so I ended up losing my job. This was after having worked for 20 years, so that was a tough one. Anyway Amy is having a good spell at the moment and we are doing a lot better now.

How is Amy taking it?

Amy has been so resilient. I think children in general are very resilient, obviously we had times when she was very bad going through lots of colonoscopies and other exams but she keeps on playing when she can, she is even raising money for a local charity which is for Crohn's and childhood research. I think that helps her to stay focused and she is so strong about it she is actually putting me to shame.

What would you say to another parent who has a child with IBD?

I would say that it is very important to talk to the consultant and the IBD team. If you can get involved in psychological therapies I would recommend it. We have a fantastic psychologist who really supported and helped us to better understand what is going on. As I have Crohn's myself I understood the pain that Amy was going through. But if you are not sick it is very hard to understand what the person is going through. So I think it is important to get as much information from the people who treat your child.

You know you can go online and google about IBD but I think it is important to have a good relationship with consultants, IBD nurses and the team who is treating your child. Talking it out is very important, it makes you realize that you are not all alone. There is nothing worse than thinking it's only you who is going through that, but if you start talking to other people that can be great support.

Amy raising awareness on IBD



France

The 2nd IBD States General, 24th May 2014, Paris

It was most appropriate that the second IBD States General take place around the World IBD Day (19 May) and the day before the European elections (25 May). The location was symbolic: le Conseil Economique, Social et Environnemental – the third most important legislative body in France meets in this building at the Trocadaro.

The first States General had taken place in 2009 and it was time for an up-date. Chantal Dufresne, President of afa, reminded everyone present of the importance of each citizen to be committed to building the future, especially for people with IBD, and for health in general.

After one year of reflection and work around a panel of citizens from all walks of life and not necessarily concerned with the problems of IBD, Jacques Bernard, the President of the organizing committee, opened the meeting. In the presence of representatives of the Ministry of Health, the President of the French National Society of Gastro-enterology, a lawyer, a company head, a philosopherand many patient members of afa, the presentations and discussions went directly to the heart of the objective: where are we today with regard to the day to day life of IBD patients – their treatments, their daily care, the emergence of “new patients”, better informed becoming the main actors in their health problems, the increase in pediatric cases etc..

Following this most inspiring three hour encounter, the testimonies were unanimous: the quality of the presentations, the high degree of expertise, the enriching debates, all monitored by a professional television journalist - even the doctors, most of whom were gastro-enterologists, were quite impressed. At the end of the day, a strategic appeal of 20 pleas in 8 different themes are carved in stone as the backbone of the fight against IBD throughout Horizon 2020, in France and to be shared with the Europeans and the rest of the world.

The prerequisite to these 20 appeals which will be our guide is to support Research and Communication as, in all evidence, IBD must be more visible by the reserachers in order to find the causes and to better understand the patients and their disease. The 20 strategic appeals can be found in French on our website: egmm2014.fr.

2nd IBD States General, Paris 2014



20 strategic appeals to build a better horizon 2020

200 000 French patients and their families and friends stand up. Our aim is to HEAL. We want the children, the young patients, of which there are more and more, to be cured. We want therapeutic advances, but we would also like to understand the causes of IBD if we want to permanently treat them some day. We then fight for better information, public awareness and lobbying on IBD, to leap from the shadows and make IBD a priority.

TO BETTER KNOW YOURSELF

In claiming his or her identity, there is a dire need to support an IBD patient's real life.

1. Make epidemiology official and open to everyone: how many patients, age, location, development, health expenditures, sick leave, etc..

2. Produce knowledge in Human and Social Science (desocialisation and taboos, behavioural disorders prevention, disease perception, fatigue impact, etc.).

TO BE ABLE TO IDENTIFY WITH

Despite the 2005 law supporting the handicapped, this word is often linked to the stigma on very specific pathologies. There is nothing in the French lexical field on handicap where an IBD patient can be recognized, especially when in remission. The term "invisible handicap" has come about to describe the indescribable.

3. Create a civil and civic formulation adapted to chronic patients which contains the notions of chronicity, daily problems, long term assistance, and acknowledgement of the family's and friends' position.

TO BE AN ACTOR ACCEPTED AS SUCH

This means that professional care providers must accept the patient – and even her or his family and friends – as full-fledged actors in the health path and respect the patient's knowledge and experience living with IBD. The objective of having the right treatment at the right time, of being well oriented, and being assured of care efficiency can only happen with this collaboration and by properly controlling the care

"system".

4. Make health care work by building the premises with the patient from the very beginning of the diagnosis and by positioning long term care. The better the comprehension of a somewhat complex system, the more efficient will be its follow up.

5. Place the patient in a position to be able to take part in her or his care by her or his knowledge and know how - "therapeutic education" - with simplified access to her or his medical records and by making her or him decide for herself or himself at any time on any changes in the initial strategies (treatments, examinations etc.).

6. Explain that managing the cost of health care doesn't mean discounted care but that each one's responsibility is at stake. That also implies explaining and controlling the possible patient's "out of pocket" payments, especially for patients in precarious financial situations.

TO BUILD PERSONAL LIFE GOALS

Managing the treatment of a disease must go a lot further than just healing the symptoms "recognized" with only "chemistry". The impact on the quality of life implies comprehensive care with the search into and the acceptance of other "therapeutic" means.

7. Make supportive care available as recognized in following up the care given to cancer patients but unheard of in other chronic diseases.

8. Understand "complementary" medicine and all "non-conventional" means which are not recognized, but are generally sought after by patients

in “self-medication” ... and use them sensibly.

TO LIVE IN AN ADAPTABLE SOCIETY

A “lifetime” chronic disease supposes that the patient will be accompanied from a very early age to learn how to manage the discrimination resulting from her or his differences while awaiting changes in education within our societies.

9. Build public awareness by acting from a very early age in educating our children and whenever possible in training at all stages of life. The way people look at the differences must change and teachers at every level must be mobilised.

10. Teach children or adolescents to mobilise their own resources –especially through paediatric therapeutic education – and to manage their disease as best they can to adapt to the world around them.

11. Adapt their training and the professional environment to build her or his self-reliance making the chronic illness a resource. The skills acquired in enduring their condition daily can also be a way to build ones self-image. These people are often fighters who want to show they can succeed.

12. Accompany the elderly who experience the disease late in life as well as those who have accumulated years of treatment of other pathologies.

TO AVOID BEING ALONE

The life of a patient isn't only limited to consultations and hospitals! The patients, their entourage and the health professionals must be aware and recognise the associations' actors, like afa, using them as a resource.

13. Patient associations are reminding the patient – and her or his entourage – that she or he isn't alone faced with the disease, faced with the unknown future, faced with the lack of understanding or the taboo.

14. Identify and selectively accompany the more complicated cases, leading them to better personalized care. Promote volunteers as a “link” recognised by

health professionals, who, once officially trained, can accompany recently diagnosed patients in their health path.

15. Give the association the means to expose and develop the supporting activities, the information and services to improve the “life with” for patients and their close ones.

TO OPEN UP TO THE WORLD AROUND YOU

Having a disease doesn't mean cutting yourself off and giving up, but just adapting your surroundings... or adapting to them! Europe is already one and the same territory.

16. Give access to the needed care (and to its financing) available everywhere, whether in training or on vacation or while working abroad.

17. Offer repatriation insurance which includes telemedicine, existing health professional networks and international experts –certainly to be improved –who can locally insure care in emergency situations in the majority of the cases.

18. Set up a network of geo-localized European toilets which will allow everyone to freely move about anywhere.

TO DEVELOP INNOVATION & RESEARCH

Patients can become actors in research & innovation and offer the youngest generation the prospect of a permanent cure of IBD. We must be collectively mobilised to insure more research, more researchers who can work in synergy, in France as well as in allow Europe, more money for Research and access to new treatments!

19. Fight for Open Data on health information as everyone's input must serve everyone alike.

20. Promote the objective production of knowledge based on the patient as the actor and subject of research.

Denmark

Social Media summer craze

We started to put the photos from our anniversary calendar out on Facebook, and suddenly a craze all over the world, more or less simultaneously, began. If you are on Facebook... you saw it.

All of our models got their share of attention, but Lene (on the right) from a small town in Jutland made it all explode.

Facebook informs us that close to 800.000 Danes saw her picture and read her story and that is quite a lot if you compare it to the total Danish population (5.5 million).

After Lene's appearance, we have been for many months supplying the Danish media with members willing to participate in television, radio, newspapers, magazines etc. And now there is a wave of students from all over the country approaching us, wanting to write about us and IBD.



Best summer ever !

Another great thing in Denmark was that our Ambassador Martin Hoegsted (on the left) won an award of comedy. As part of the duo Danish Dynamite, Martin won the title of "Comedian of the year 2014". One of Martin's characters suffers from Ulcerative Colitis (as Martin himself does) and in a funny way, we all get to know what the consequences can be.

And speaking of potentially funny things, the Danish IBD association made an agreement with a major supermarket chain, allowing us, our members, to use their bathrooms/toilets (1200+ stores). This is an exclusive agreement, even though many supermarkets do not have toilets for their customers to use. Nevertheless, we are the exception, and we are very pleased to be so. 2014 has been a positive year so far, and we hope it will continue in this way.

Michael Koehler, CCF

Spain

World IBD Day

ACCU España y GETECCU held a Press Conference on 19 May where they warned about the increase in numbers of patients with IBD. Due to this fact, they made a public request for more IBD focused units at hospitals as well as a public request in improving the quality of life of patients with IBD.

XXIV ACCU España National Meeting in Burgos

The XXIV ACCU España National meeting was hosted in Burgos last June. Around 200 people suffering from IBD participated in the meeting as well as health care professionals giving several talks related to disability and nutrition of IBD patients. We also handed out awards for the “IV CrohnInCol” competition for best short novels related to IBD.

Handbook for patients “All about IBD”

36 specialists and physicians prepared a handbook for patients with IBD containing important information related to IBD and on how to manage and live day by day with the disease. The information is dealt with from different points of view and has

also a section aimed at helping patients to improve their lives in terms of access to the labour market and finding reliable information on the internet. The guide has been developed in collaboration with GETECCU, and ACCU ESPAÑA and has been sponsored by ABBVie. The handbook will be available free of cost through our association.

Autoimmunity Exhibit: Towards comprehension of autoimmune inflammatory disease

An exhibit named “Towards comprehension of autoimmune inflammatory diseases” is being held by ACCU España together with the Spanish national Arthritis, Psoriasis and Spondilitis Associations. The exhibition is sponsored by ABBVie.

The main objective of this project is to raise awareness about autoimmune pathologies as well as to recognize the role of patients associations as a positive way to support patients to handle their diseases improving thus patients and families quality of life.

Romania

Participating in EU projects

The Romanian Association of people with IBD (ASPIIR) was founded in 2010 and starting from 2012 we began to show interest in running projects through the European Commission programme. The first programme that we approached was the “Youth in Action” programme, focusing on young people. ASPIIR submitted two applications and both have been approved, the first project gained the highest score.

Thus we initiated and implemented in Romania in 2013 two European projects funded by the EU, for young people with Inflammatory Bowel Diseases or disabilities caused by IBD (stomas). One entitled “Developing Our Lifelong Learning Skills” –

D.O.L.L.S./ Calarasi and the other one “Informal Medieval Festival” / Sighisoara. Both projects tried to have youngsters meet each other, young disabled people and non-disabled from Europe who came from very different environments with different living

conditions and different medical systems. Through these projects and their follow-up, we tried to raise awareness about the condition of young people with IBD or disabled and about their needs, no matter where they live. Another aim was to make participants realize that they are all the same no matter what kind of health problem they have or from which part of Europe they come from.

The first project took place in Calarasi, a small town on the Danube. The focus of the project was to use art /creation (building giant puppets) as a good way to bring together young people with IBD and stomas allowing them to overcome their inhibitions and complexes and to get them involved in a social life and at the same time meet other non-disabled youngsters fostering mutual understanding, tolerance and social inclusion.

The target group consisted mainly of youngsters between 18 - 25 years old, 4 participants from each country plus one leader, 20 participants and 4 leaders in total, from Italy, Serbia, Denmark, and Bosnia and Herzegovina. We organized workshops for building giant puppets and also games and other informal activities. The main theme was building two giant puppets: one puppet standing and another one sitting in a wheelchair through which we tried to suggest the idea of tolerance and understanding between disabled and non-disabled people.

The participants also visited Bucharest and the Parliament House, they met actors of the “Masca” Theater and had the opportunity to taste a Romanian traditional lunch, to learn traditional dances and to discover Romanian landmarks.

The second project, “Informal Medieval Festival” took place in the medieval Transylvanian town of legendary Dracula – Sighisoara and gathered 25 youngsters from Spain, Croatia, Czech Republic, Romania and Italy. Our activities here focused on the legend of Dracula and the participants created masks on this theme. We organized an intercultural evening, visited the Sighisoara Museum and the City Hall, the Bran Caste and Cheile Gradistei mountain resort. The participants presented their organizations, shared experiences and made plans for the next projects.



The project integrated other NGO's and schools and we cooperated with the Cultural and Scientific Foundation “Gaudeamus”, the “M.Eliade” College and the “Veritas” Foundation. The project ended with an informal medieval parade organized by the participants and their characters in the Old Citadel of Sighisoara.

ASPIIR will continue working on new EU applications for the next year and we would be glad if other organizations and members of EFCCA would join us.

We would also like to mention that ASPIIR celebrated its first World IBD Day this year, by organizing an education and information campaign: “Choose to be the winner!” – a campaign that lasted for 3 days, between 19- 21 of May, in Unirea Park , Bucharest . The aim of this event was to inform about IBD and their implications in the social, professional and family life of the people affected by these diseases; the necessity of going to the doctor as soon as digestive symptoms appear and persist longer; the importance of having nutrition as healthy as possible and a healthy lifestyle. A Giant Colon was placed in

Unirea Park, Bucharest, and people have been invited to visit it in order to find out relevant information about the factors that affect the normal functioning of this part of the body. The volunteers enlivened the space by distributing leaflets, encouraging people to inform themselves and to adopt a positive attitude towards the doctor – patient relationship and to understand the necessity of the regular medical check-ups. Students, dressed in medical uniforms, delivered a positive message regarding the relation between a doctor and the patient with inflammatory bowel diseases. They invited passersby to visit the colon, our association's stand and to inform them about these chronic diseases.

Every day there were different cultural events that attracted people.

Isabella Grosu

President of Romanian Association of People with IBD



New Zealand

First summer camp

Children and Teenagers with Inflammatory Bowel Disease (IBD) face the challenges of living with an unpredictable and embarrassing disease. For many of these children, as you well know, living with Crohn's disease and Ulcerative Colitis can be very isolating. That is why the Crohn's & Colitis New Zealand Charitable Trust (CCNZ) is proudly establishing the first NZ based camp for Children & Teenagers with IBD.

The CCNZ Children's & Teen's camp at Camp Adair, Auckland, is a one-week, overnight, summer camp experience for youth (ages 10-19) with Crohn's disease and Ulcerative Colitis. Most of these children have never been to camp due to their disease. Most have never met another child with the same disease. Providing extraordinary kids a unique opportunity for growth through challenging, fun, enriching, and magical experiences. Whilst an important part of the camp experience for these kids is the interaction with compassionate and fun volunteers, the camp will allow these children to be campers, enjoy the outdoors

and have fun instead of being "IBD patients". It will give children and teenagers a chance to experience fundamental elements of childhood – the ability to play outdoors, challenge themselves and to be proud of their accomplishments, to learn independence and nourish self-esteem.

For the summer of 2015, CCNZ will provide about 50 young people from all over New Zealand a once in a lifetime opportunity to attend overnight camp with their peers. Running from January 25th to January 30th, 2015, the camp will take place at the

well-established YMCA Camp Adair, nestled amongst 100 acres of property, overlooking the spectacular Hunua Ranges.

The camp would not be possible without our team of 30 plus dedicated volunteer staff and professional staff— many of whom are adults also living with IBD. These volunteers, which include two gastroenterologists, three IBD nurses, and a paediatric psychologist are giving up their holidays and paying their own expenses to provide a safe environment for the children.

Running concurrently with the camp, there will be a two day programme for parents and care-givers, focusing on education of these diseases and coping mechanisms in dealing with the challenges of raising children with chronic medical illnesses. The group will be led by our medical staff and should establish a long-term support network for the participants.

Every child deserves to feel like just that – a child – and we want to ensure that at the core of every child’s experience is positivity, optimism and shared triumphs.

Our vision is to provide these children with avenues for fellowship, to help build self-confidence, to help them cope with their disease, to prepare them for life, and at no cost to their families.

It is with a heart full of thanks to the generous support of our corporate partners and funds raised and donated that we have seen our vision become a reality. We look forward to sharing the next instalment of news with you following the camp in January.

Charlotte Costain, The Crohn’s & Colitis New Zealand Charitable Trust.

Germany

Four countries meeting

In August the CEOs of four Crohn’s and Colitis Associations met for a general discussion in Berlin at the office of the German DCCV. David Barker (Crohn’s & Colitis UK), Tineke Markus (CCUVN, Netherlands), Alain Olympie (AFA, France) and Board member Madeleine Duboé (AFA, France) met with Ella Wassink and Stefan Zipter (both DCCV, Germany).

The afternoon was spent almost completely on sharing news and information on what each single organization is up to. As usual in these kinds of meeting all sides were profiting from getting new ideas, learning new things about differences in the health system of the concerned countries and sharing thoughts on topics that are relevant to all Crohn’s and Colitis patients. It was the fourth meeting of these western countries of which three are members of EFCCA.

Ella Wassink, DCCV

Finland

30th anniversary

“Crohn ja Colitis ry (CCAFIN) from Finland is celebrating its 30th anniversary at Tampere on 11 October this year. With almost 7000 members we have reached a solid position as a trustworthy partner for the patients, the health care professionals and other patient organisations as well.

At the moment we are working on a makeover for our website. At the same time we are finding new ways to operate in the social media. We believe that presence in the social media is important but also in the traditional media outlets. That’s why we have arranged for several articles about IBD in the Finnish newspapers and magazines this autumn.

Heli Parjanen, CCAFIN

UK

Fatigue in IBD

Crohn's and Colitis UK are nearing the end of a 4 year Lottery Funded research project on fatigue in IBD. The study, which was a collaborative one with research partners at King's College, University College London and Addenbrookes' NHS Trust, was the first of its kind undertaken by the charity.

Crohn's and Colitis UK has worked as a research partner with the academic researchers, helping to shape the research and ensure that the patient voice has been central to the success of the project. The charity has learnt a lot about hands on research which has expanded our understanding of the research process and we will apply that knowledge to the research grants that we manage in the future. We have also made many valuable contacts and have been able to highlight the under-researched area of fatigue in leading academic journals and international medical conferences.

Commenting on the collaboration Professor Christine Norton from the Florence Nightingale School of Nursing and Midwifery at King's College London said that "The experience of working so closely with a patient organisation on a topic that members feel passionately about has been hugely enjoyable, but more importantly has enabled us to keep the focus of the project on what is most important to patients. I believe that as a result of this close working we have developed findings that really reflect the patient voice, and our tools, such as the fatigue assessment scale, which will be valuable to both people with IBD and their clinicians.

Our lead researchers at King's College London and University College London have delivered several key outcomes from the study in partnership with Crohn's and Colitis UK, including:

» In-depth interviews with patients to understand the nature and experience of living with IBD fatigue

- » A literature review of fatigue in IBD
- » The development and psychometric testing of the first ever IBD fatigue rating scale
 - » Interviews with healthcare professionals to understand the current level of understanding and awareness of IBD Fatigue.
 - » The development of a clinical checklist that can be used to treat reversible causes of fatigue in IBD, this will be released as an 'app' in Autumn 2014-09-10
 - » A patient information sheet on fatigue in IBD
 - » Awareness raising videos on fatigue in IBD
 - » A small scale RCT testing a dietary and lifestyle intervention with IBD patients, which is due to conclude in November 2014.

Further information can be found at our website www.fatigueinibd.co.uk the fatigue rating scale can be found on this website and is also available on the following open access journal [http://www.ecco-jccjournal.org/article/S1873-9946\(14\)00158-5/fulltext](http://www.ecco-jccjournal.org/article/S1873-9946(14)00158-5/fulltext).



LOTTERY FUNDED

Switzerland

Fear and IBD, Workshop in Emmetten

On 10 May, workshop participants met early in the morning on the sunny terrace of hotel Seeblick, Emmetten, for coffee and cake. After a brief introduction of all participants we moved on to the subject of the workshop: fear.

Imagine that you are sitting with other participants in a room. You close your eyes. Two people are moving around the room and touch individual participants who then have to go into the middle of the room and carry out specific tasks in front of the others. What do you feel when these people come closer? Does your heartbeat increase? Do you have an oppressive feeling in your chest? Do you feel ill? These are exactly those kind of feelings that were dealt with in the 2 day workshop.

We divided the groups and talked about our fear of living with IBD. Soon I realized that I am not alone with those fears. All of us have similar fears: We are scared of our disease, we are scared of hospitals, medical exams (endoscopies etc) and operations. We are scared of the side effects of our medication. We are scared not to find a toilet. We are scared not to be able to have a normal life. We are scared to lose our partners. We are scared of the future.

During the workshop, Patrick Widmer explained to us what fear is and how it is developed. Then we moved on to recognize those fears, accept them and break them down. After a delicious lunch, we split into two groups to learn through the means of two methods how to break down our fears. Gabriela spoke about self-hypnosis and Patrick about Logosynthesis.

Logosynthesis helps people to overcome their fears and blockages. Patrick gave an introduction to the subject and then showed us how – through exercises and applying logosynthesis we could deal with our fears and overcome them. It's amazing the effect this can have. After a very interesting and educative afternoon we were tired and hungry. During dinner we admired the amazing view over the "Vierwaldstätter" lakes. We

then enjoyed the last evening sunshine talking late into the night. We went to bed tired but satisfied.

On Sunday, after a rich breakfast, we changed groups. Gabriela gave us an introduction to the subject of self-hypnosis, which can also help to break down fears. Gabriela showed us how to do self-hypnosis and we all had a go at it. In the end we were encouraged to break a piece of wood with our bare hands: some of the brave ones gave it a try and following Gabriela's instructions they achieved this with no problem!!! Congratulations to those who tried and achieved this. It illustrated to us very well what can be achieved with the help of right instructions and will power. And this was also the end of our weekend seminar. After taking a group photo to memorize the good moments, we started our journey back home.

I very much enjoyed this weekend amongst people living with IBD and it has done me a lot of good. I realised that I am not alone with my fears. I also realised that we speak the same language and I felt understood. The two methods that we learned to overcome our fears have been very helpful. Many thanks to Gabriela and Patrick for their introduction and explanations on the subject of self-hypnosis and logosynthesis. They have taken a lot of time and took care of each and everyone of us. Also many thanks to the Swiss IBD association, SMCCV, for organising this weekend. A special big thanks to Adela and Bruno who were with us during the weekend seminar.

Joëlle

Argentina

Good practise

The tsunami of information and the speedy development of new technologies place us in a position where understanding whether information is reliable or not becomes more and more difficult. The main challenge is therefore to change the “culture of roles” that until now has been divided between the governments, health care professionals, NGOs and the industry. Each one of them separately sharing their knowledge as concerns the social and health reality of people living with IBD.

Taking advantage of international knowledge and good practices, we have now made great advances in Argentina to work together with all the stakeholders. The work of cooperation.

Creating a new culture of collaboration the Inter-American Association of Gastroenterology (AIGE), the Inter-American Society of Digestive Endoscopy (SIED) and the Mas Vida – Crohn’s and Ulcerative Colitis Foundation have got together to organize a series of actions to spread information about IBD within the framework of the Pan-American Digestive Disease Week which will take place on 6-9 October 2014 in Buenos Aires, Argentina.

On 6 October we will hold a press conference including national and international IBD specialists next to representatives of the patient organization Mas Vida – Crohn’s and Ulcerative Colitis sharing latest information on scientific advances in IBD, the regional context of IBD and the reality of living with IBD. Alongside the press conference there will be an exhibition of artwork entitled “Perspectives: Art, Inflammation and Me” which was first shown during the 9th ECCO Congress in Copenhagen in February this year.

Moreover we are expecting a huge turnout from patients and their families from all over the country during the Community Day where participants can directly interact with a panel of IBD specialists.

The Mas Vida Foundation is putting a lot of effort into its work to collaborate with health care



Presentation by the Mas Vida – Crohn’s and Ulcerative Colitis during the 5th Gastroenterology, Hepatitis and Paediatric Nutrition Congress, 13-16 August 2014, in Buenos Aires organized by the Argentinian Paediatric Association.

professionals in order to provide projects and services to its community on social assistance as well as legal, psychological, nutritional and information issues.

Luciana Escati, Más Vida



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Holiday snap going viral

Little did Bethany, a makeup artist from Worcester, realise that a photo she simply hoped would inspire confidence in others and raise greater awareness of Inflammatory Bowel Disease (IBD), would have such an enormous impact – on her personal life and the lives of others.

Many of you may have already heard of Bethany Townsend. This summer, with Bethany's permission, Crohn's and Colitis UK posted a holiday snap on their Facebook page of the 23 year old model baring her colostomy bag. What resulted was an unprecedented level of support and international media attention.

Overnight, Bethany became an Internet sensation. 11 million people have viewed her inspiring photo through Facebook, with many following her example and sharing their own photographs on our page. (see article from Denmark in the Member News section).

Bethany told in an interview with Crohn's and Colitis UK that "The public response to my photo has been amazing, I still get comments on my Instagram and Twitter, with everyone thanking me and it is nice. People email me to say they finally have the confidence to 'get their body out' on holiday. It's things like that that make me feel so glad about what I did – knowing that I've helped other people as well.

"The media attention has been absolutely crazy. It's all been positive, which I'm really pleased with. I think when anything goes public, you worry about what people are going to think and if anything bad will come of it, but it didn't and I was pleased that everyone was so supportive."

Bethany has had Crohn's Disease since she was

three, but was fitted with a Stoma in 2010 as part of life saving surgery when her bowel ruptured during her recovery from a previous operation. Bethany woke up from surgery not knowing that she had a colostomy. Yet, with great strength and determination and support from her family and friends, Bethany decided that she wouldn't let her colostomy bags rule her life.

"It takes everybody their own time to get their confidence back. Everybody is different in so many ways and this just makes us a little bit special."

"Having colostomy bags saved my life – I knew that if I didn't have them that I would have died. If it had been part of planned surgery, I might have felt differently about them, but I couldn't really be upset in this instance because having them saved me. I adapted really quickly. I cried once when I came out of hospital and that was it. They're a part of my everyday life, a part of me."

Dan McLean, Director of Communications and Membership at Crohn's and Colitis UK, said: "Thousands of our members with Crohn's Disease or Ulcerative Colitis - and many more supporters - have told us that Bethany's actions have inspired them to shed insecurities of their own.

"What Bethany has also achieved is to shine a light on two of the most common forms of IBD - greater awareness of which can really help us to change the way that people perceive and treat those with the condition."



This is the holiday snap that was posted on Facebook and then went viral with many other people with IBD following the example.

Bethany's future is bright. She has since found the confidence to resume modelling and has been signed up with a modelling agency. She is also continuing to raise the profile and donations for organisations that fund research into Crohn's disease and continues to champion the work of Crohn's and Colitis UK wherever possible.

Bethany said: "I really want to help people and it seems that people are looking to me, so if I can help

in any way then that's what I'd like to do. "It takes everybody their own time to get their confidence back. Everybody is different in so many ways and this just makes us a little bit special. That's what my mum used to say to me!"

Patient Safety

A few days before the summer break the Directorate general Health and Consumers Protection Commission (DG SANCO) launched a public consultation on the “Future EU agenda on quality of health care with a special emphasis on patient safety.”

The opinion, elaborated by the Expert Panel on Effective Ways of Investing in Health, aims to define the core dimensions of health care and patient safety and to propose the future direction of EU level work in this area. The public consultation allows stakeholders to comment on the opinion of the panel - though this opinion is non-binding.

The key recommendations from the Panel with regards to future work focus on:

1. Establishment of a EU Health Care Quality Board (to coordinate all EU initiatives in health care quality)
2. Establishment of a Health System Performance Analysis Framework (to allow for comparisons between EU healthcare systems quality performance)
3. Suggestion to initiate a Council Recommendation on health care quality
4. Further sharing of knowledge on Health Technology Assessment (through the permanent network/ EUnetHTA)
5. Promotion of a Europe-wide health education programme encompassing health literacy, patient safety, and health care addressed towards a patient-centred approach

In terms of specific proposed actions at EU level, the panel suggests :

- » Guideline development and sharing of best practice
 - » Funding research related to quality and safety
 - » Economic issues related to the defined quality dimensions
 - » Education and training in their new roles for

both patients and healthcare professionals

- » Information technology and information systems significant for health quality and safety

- » Quality and safety aspects of the burden of chronic disease and inequalities in health

- » The HTA network, increasing attention for Health System Impact Assessment

»

EFCCA is really pleased that the issue of patient safety is becoming more and more important in the European agenda, in particular with regards to training of healthcare professionals, sharing of best practices, the importance of research, a specific focus on chronic diseases, however we share with Health First Europe that there still are topics that are not taken into consideration in the EU safety agenda. The opinion, in fact, does not touch upon creating minimum standards for safety or developing a European strategy on healthcare associated infection (HAI) as it only looks at the development of a harmonised EU wide surveillance of HAIs. Additionally, there is very little consideration of safety outside of acute settings.

Given that this opinion also looks at wider quality of care (including community care issues such as patient-centric care, care and treatment, and quality care standards), the panel does not touch upon issues policy related to integration of care/community care, value of innovation or access/reimbursement.

Anyway, it is clear that the role that patient associations may play in this debate is crucial. EFCCA will look at every chance to have a say on such topics as many of the key words mentioned in the opinion are part of our daily lobbying activities.

Health actors urge new European leaders to renew efforts to tackle public health challenges

At the beginning of September, the European Public Health Alliance (EPHA) held its two-day annual conference entitled “Tectonic tensions – wealthy Europe’s fear of commitment”. The event brought together more than 30 speakers from across Europe’s health professions, governments, the European Commission, civil society and an audience of more than 200 people.

The conference addressed the future of public health in Europe just before the start of business of the new European Parliament and Commission as well as the review of the EU’s long-term objectives (Europe 2020). The main topics discussed were:

- The public health consequences of the economic crisis

Protecting and improving the health of everyone living in Europe is a core value of the EU. The economic crisis however forced many EU Member States to make across-the-board budget cuts. It resulted in shrinking health care and social budgets that undermined access to, and the quality of, health care. Overall, the crisis severely worsened health outcomes. The EU’s role in addressing this decline in public health and the limits of the reach of ‘Brussels’ were discussed along the lines of should the EU be doing more or should it be doing what it does better.

“The EU has made, and will continue to make, a meaningful contribution to improved public health in Europe by supporting and facilitating co-operation between EU countries, as well as by supporting the efforts of certain countries in the reform of their health systems. The current consultation on the Europe 2020 review is a window of opportunity for stakeholders committed to health to stress the importance of the health sector to the European economy, and to highlight areas where EU collaboration should be strengthened,” said Mrs Testori Coggi, Director-General for DG Health and Consumers, European Commission.

Speakers in the room agreed that a closer

collaboration between the EU and its Members States is crucial to achieve better health for all.

- The Transatlantic Trade and Investment Partnership (TTIP)

The European public health community is deeply concerned that decades of hard-fought public health gains may be set back if the TTIP is not negotiated in a way that protects social safeguards and health (3). These include concerns over technical barriers to trade, intellectual property rights and drug patenting, challenges to the way that the EU and Member States regulate on food safety, chemicals, alcohol and public services. Yet Mr Ignacio Garcia Bercero, director at DG TRADE and the EU Chief Negotiator on TTIP, believes that the TTIP will be able to both promote economic growth and protect social rights. As he said, “I am convinced that we can achieve an ambitious TTIP agreement that fully respects our legislative framework and protects public health in the EU.”

As Peggy Maguire, EPHA President concluded, “without the involvement of the health community and proper consideration of health impacts, the TTIP risks undermining social and public health safeguards. The TTIP negotiators should uphold the European values of democracy and human rights in their negotiations, including the right to health. This trade pact must not uphold mechanisms that empower firms to sue governments outside of national or European legal structures.”

Contact information

Javier Delgado Rivera EPHA Communications Coordinator Email: javier@epha.org

Magnetic resonance imaging and computed tomography in the assessment of inflammatory bowel disease

by Julián Panés, Gastroenterology Department, Hospital Clínic de Barcelona, Spain and Jordi Rimola, Radiology Department, Hospital Clínic de Barcelona, Spain

Diagnostic investigations are crucial in every stage of inflammatory bowel disease (IBD) management: for evaluation of suspected IBD, assessment of disease extension and activity, evaluation of therapeutic responses, and detection of complications.

Over the past few years the spectrum of diagnostic and therapeutic investigations has considerably widened with recent technical progress such as small bowel capsule endoscopy, double balloon endoscopy, high resolution computed tomography (CT), and magnetic resonance imaging (MRI). Ileocolonoscopy remains the gold standard for evaluation of inflammatory lesions in the colon and terminal ileum. However, ileocolonoscopy cannot always be complete, and there are several drawbacks related to the invasiveness, procedure-related discomfort, risk of bowel perforation, and relatively poor patient acceptance.

CT and MRI allow visualization of the entire small and large intestine enabling evaluation of the type and extent of intestinal inflammatory lesions and extraintestinal complications. MRI has the potential to overcome some of the limitations associated with CT, mainly lower incidence of adverse events related to the intravenous contrast employed compared to CT, and lack of ionizing radiation.

Radiation exposure is an important issue when considering imaging modalities in IBD. The chronicity of the diseases, the fact that symptoms poorly reflect disease activity, and the typically young age at the time of IBD diagnosis often lead to multiple radiologic tests being performed in these patients.

In that regard, it is essential to develop evaluation protocols and management guidelines that minimize or completely avoid diagnostic radiation exposure, as long as a clear threshold for an increased risk of cancer has not been established, and young age increases the risk of malignancy derived from diagnostic radiation.

Clinical applications

1. Evaluation of suspected IBD

Colonoscopy with multiple biopsy specimens is established as the first line procedure for diagnosing colonic inflammatory lesions. Ileoscopy is superior for the diagnosis of Crohn's disease of the terminal ileum when compared

with radiological techniques including MRI and CT especially for mild lesions.

Capsule endoscopy and enteroscopy with biopsy are useful procedures for diagnosis of Crohn's disease in selected patients with suggestive symptoms after failure of conventional radiology. Crohn's disease may affect the ileum out of reach of an ileocolonoscope, or involve more proximal small bowel (10% of patients.) Additionally, at the time of diagnosis 16% of patients have penetrating lesions (fistulas or abscesses). Endoscopy and radiology are complementary techniques to define the site and extent of disease, so that optimal therapy can be planned.

2. Assessment of disease extension, activity, and severity

Colonoscopy predicts the anatomical severity of colonic inflammation in both Crohn's disease and ulcerative colitis with high accuracy. When there is severe, active disease, the value of full colonoscopy is limited by

a higher risk of bowel perforation and diagnostic errors are more frequent. In these circumstances initial flexible sigmoidoscopy is safer, and it has been recommended to postpone ileocolonoscopy until the clinical condition improves.

Given the high sensitivity and specificity of MRI for the detection of severe lesions, and the importance of these findings to guide therapeutic decisions, whenever disease severity leads to contraindicate a full colonoscopy, or a stricturing lesion prevents evaluation of proximal intestinal segments, MRI should be performed to document the existence and nature of inflammatory lesions.

In patients with a well-established diagnosis, MRI could replace ileocolonoscopy in reassessment of disease activity and extension, with the additional advantage of assessing the whole gastrointestinal tract in only one diagnostic procedure

3. Assessment of therapeutic responses

Assessment of responses to a particular therapeutic option should not be only based on clinical symptoms. It is well established that persistence of mucosal lesions, even in the absence of symptoms, is associated with higher risk of relapse and complications requiring hospitalization and surgeries. Whereas the value of treatment intensification based only on persistence of mucosal lesions remains to be demonstrated

with appropriate trials, persistence of mucosal lesions should lead to close monitoring or consideration of other therapeutic alternatives before irreversible intestinal damage leading to loss of function and/or surgery occurs. Since lesions associated with a severe course of disease are ulcerations, documentation of cure of these lesions should be the main objective of assessment of responses to therapy. For that purpose both CT and MR have high diagnostic accuracy and are alternatives to conventional ileocolonoscopy. Furthermore, it has been recently demonstrated that MRI is an accurate technique to monitor the response to therapeutic interventions, and thus avoids the need of endoscopy to assess if healing of lesions is achieved.

4. Detection of complications

CT and MRI provide crucial information for evaluation of stricturing and penetrating complications of Crohn's disease. In stricturing disease CT, and particularly MR can provide information on the predominant nature of the structuring lesion, whether a predominantly inflammatory or fibrotic process is present.

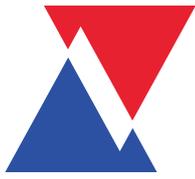
CT and MR provide also invaluable information on anatomical and functional aspects of a stricturing lesion such as length, shape, and proximal dilatation, which should be considered for electing medical treatment, endoscopic dilatation, or surgery.

In the evaluation of fistulizing lesions CT and MRI have a central role. Perianal fistulizing disease is best assessed using MRI (Figure). The high soft tissue contrast provided by MR facilitates the identification of fistulous tracts and abscesses. Intraabdominal fistulas and abscesses can also be assessed using MRI.

Summary

MRI and CT imaging techniques are gaining an increasing role as a reference technique for assessment of IBD activity. The high accuracy on detection for CD activity, identification of stricturing and penetrating complications, together with the lack of radiation, are the main strengths of this technique.

Information provided from pathological specimens and MRI correlation will help to precise the diagnosis, extension and assessment of the severity, and may improve the therapeutic decision-making in patients with CD. Also, the fine mapping the location and nature of the lesions can be of utmost value to guide surgical approaches.



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