EFCCA MAGAZINE

European Federation of Crohn's and Ulcerative Colitis Associations | October 2011

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EDITOR’S EYE

A Rhapsody of Smiles

Many months of hard work, of preparations, of looking after details, of taking into account any possible adverse event. Everything for maintaining a promise: changing the status quo.

Six months ago, on these pages, we announced the change, another “gear shift” in EFCCA’s history, the one that should take us into a new working dimension. That is what we have achieved over the last months.

We not only want to add a mouth to the face of the picture we used for our cover page in the previous issue, using the impressive French communication campaign, but we want also to see a smile on that face.

A smile is exactly what we have been pursuing with all the projects completed in these last six months.

Starting with IBD World DAY. Celebrated on the 19th of May, as in the past year, the event has been interpreted in a completely new way by our team. The idea of choosing a “street campaign” based on a “toilet man” has paid back more than we could ever have expected. You should have seen what Roundabout Schuman looked like that morning, with delegates from twenty countries distributing toilet paper rolls to people in the majority of the cases completely unaware about IBD. Even though I personally disagree in considering IBD just a “couple of bowel diseases”, I firmly believe that this idea went directly to the point, focusing on the shame, and beating it with the power of laughter and of a smile.

The same smile that, the same day, eleven floors upstairs I saw on the face of the Chief of the Cabinet of DG SANCO when I showed her our team from the window. Yes, it is true: for the first time we have been admitted to a face to face meeting, and I want to thank Mrs. Darmanin not only for her time, but for the concrete commitment shown during a meeting that exceeded the planned thirty minutes.

A similar smile could be seen on the faces of our delegates that were present that day, who helped us in making it real and who then celebrated with the EFCCA team in our office the result of our “premier event”.

And it was only a couple of weeks later that EFCCA, thanks to the success of other initiatives has been able to change its “home”: a new office, bigger and with more facilities was necessary and it has been set up in a few days. Simply. Amazing.

And how to forget our faces when we saw the final figures of IMPAC, that is going to be the most impressive patient lead survey ever done on IBD. The results of IMPACT are important, and not only for the high level of participation, but for the content. We will have to come back on this, and to deeply analyse the data, accepting the fact that probably some of our strategies should be reviewed. Because it is clear, already from the rough data, that the IMPACT of IBD in our lives is sometimes still at an unacceptable level.

Moreover, how could I forget the smile of the participants in the second “Catch your dream Summer Camp”.

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It has been another incredible experience that clearly showed how good the basis of this project is and that it is probably the right time to move forward, extending it to other countries and lowering the participants' age limit.

While the Summer Camp is a leisure event designed for mainly offering fun and joy to youngsters, the EFCCA Youth Group Meeting is probably more serious but not inferior in results. The event in Poland has been perfectly organized by the local association, and I want to thank all our Polish friends for the very warm welcome.

The EFCCA Youth Group is at a moment where new horizons are taking shape. I firmly believe that the leaders for tomorrow have the right environment to grow and looking back at my personal story I can only hope that other volunteers will follow the track.

The smile is also the one that the members of the renewed Czech Association showed me during their annual event: it has been years since I was able to see such an enthusiastic participation.

We wanted a smile, and what we got was a number of smiles, that all together make a rhapsody of musical perfection that gives a sense to our everyday job.

It's not enough. Because, deeply in our hearts, we want "that smile": the smile that can come from finding a cure.

For this reason we will go on, with more enthusiasm then ever. And for this reason, as I think it is finally the right moment, I want to launch here another difficult challenge.

I want to call IBD Associations from all over the world to meet up for the first time and to discuss each others research support projects. This could give us important data for better understanding, on a global level, where we are going and how we can best support research with the money collected from our members. I know, it has never been done before, and it is difficult. But we need this, probably more than we could imagine now.

EFCCA is ready to promote such a unique event, a first World Symposium on IBD Research funded by patients' money. Because it is time to deliver a message. A message of hope. A message of courage. A message of unity. Crohn's and Colitis are going to be beaten. Together we can achieve this.

Marco Greco, EFCCA Chairman

IBD World Day:

EFCCA makes spectacular entrance into Brussels’ scene

On a cloudy, grey morning, the 19th of May to be exact, EU officials going to their offices at the Schuman Roundabout where met with an unsual sight: an English gentlemen, dressed all in white wearing a top hat could be seen sitting on a toilet with his pants down. He was facing the European Commission building on one side and the European Council of Ministers on the other. Many people stopped to stare, not only the EU officials (who were more discreet in their staring) but also taxi drivers, shop owners, tourists, street cleaners, policemen.. well the public at large.

This street performance formed part of a worldwide initiative that is marked each year on May 19th in order to raise awareness of Crohn’s disease and ulcerative colitis also known as inflammatory bowel disease (IBD). Patient associations in over 28 countries including 24 European countries (through EFCCA) as well as the United States, Canada, Australia, and Brazil united their efforts in order to improve the lives of the five million people worldwide who are currently living with IBD.

In Brussels, EFCCA focused on targeting EU institutions and policy makers with the aim to pave the way for greater contact with Members of the European Parliament and to make EFCCA in general more visible on the European arena. To this end a small EFCCA delegation met with Mrs Darmanin, head of Cabinet for Commissioner Dali (DG Health and Consumers’ protection) prior to our

EFCCA chairman Marco Greco meets with Mrs Darmanin, head of Cabinet for Commissioner Dali (DG SANCO)

street event. It was the first time that EFCCA had the chance to directly present its mission and goals to the European Commission. During the one hour meeting agreements were made for stronger collaboration and to participate at our first CEO training programme scheduled in Brussels this autumn. The street performance aimed to get the attention of EU officials and the public and so it did! Not only Greg, the street artist, but also a big toilet wall made of 1000 toilet rolls caused for curiosity amongst people and provided a great opportunity for EFCCA volunteers to inform onlookers and journalists about IBD and what it means to live with this disease. There was a great atmosphere and show of solidarity, a concrete result for people with IBD all over Europe… and of course the rest of the world. Thanks for all those who made it happen.

Of course Brussels is not the only place where activities took place. Many of our EFCCA member associations organised their own "local" IBD World Day events and we would like to share some of these. More information will be available on the IBD World Day website at: www.worldibdday.org

Flashmob in Poland

This was the first time that we, the Polish Association, celebrated World IBD Day. We had agreed on organising a flash mob event in the form of a toilet paper battle. The battle took place in two cities – Katowice and Warsaw and gathered around 500 people. We had received 700 toilet rolls from the sponsors, which served as perfect ammunition. Moreover, some participants brought their own, colourful toilet rolls. One of our representatives, armed with a megaphone, informed passers-by the reasons for the street battle i.e to raise awareness on IBD and at the same time to show that the disease does not exclude people from social life. Among the participants were adults, students and children. The police and municipal officers watched over our safety and an ambulance to help "wounded" was also available. The rolls fluttering in the air encouraged more people to join us. Especially

one tipsy man showed a strong interest in our action by criticizing the government for the shortage of public toilets. Warsaw representatives took example from EFCCA and prepared their own Toilet Man! After the event we jointly cleaned everything up. The following day several local newspapers wrote about the event. Furthermore, in Katowice, two of our members recorded movies which are available on youtube: http://youtu.be/lXCGzc0gfKs and http://youtu.be/x5kalbY_G7g . We believe that the battles were successful events, therefore, enriched with much experience, we will come back next year!

UK launches report on “Crohn’s and Colitis and Employment”

Crohn’s and Colitis UK marked World IBD Day 2011 by launching a report on “Crohn’s and Colitis and Employment: From career aspirations to reality in the UK Parliament. New research has found that 68% of people with inflammatory bowel disease (IBD) feel that they have little or no control over their working conditions and a third receive minimal or no support from their employer. Crohn’s and Colitis UK is calling for greater understanding and action by policy makers, patients, employers and the UK Health Service to improve health and employment support for people living and working with IBD. The findings of the report show serious shortfalls in employer awareness and patchy provision of reasonable adjustment, such as access to a toilet when required.

Austrian members organize toilet race

In Austria IBD is still a taboo subject and only about 5 % of the population has ever heard of it. This eventually leads to isolation of IBD patients as there is little awareness or understanding of their conditions. In order to address this issue the Austrian association ÖMCCV decided to organise a high profile event in form of a toilet slalom race in one of Vienna’s main square. Participants in the race consisted of IBD patients as well as eight well-known public figures which competed with each other using re-modelled toilets as race cars. A maximum speed of 12 km per hour was reached by one of the participants! The event attracted a great deal of interest and attention from the public and press. Reports of the event appeared in several main television stations as well as in national newspapers.

First IBD World Day observed in Malta

In Malta we are relatively new on the scene. The Malta Association of Crohn’s and Colitis (MACC) was only founded in January 2010 but since then we have been very busy with activities aimed at supporting IBD patients in Malta. On the occasion of IBD World Day we arranged a three day long poster display on IBD at the foyer of the Mater Dei Hospital. The main aim of the display was to increase awareness about these two conditions and to provide help and support to sufferers of IBD. Information leaflets on IBD and our local patient association were made available at the stand.

Organising the EFCCA Youth Meeting in Cracow

by Marek Lichota, Polish Association Supporting People with IBD (PASPIBD)

My first experience with the EFCCA Youth Group was at the 13th EFCCA Youth Meeting, which was held in Sommaroy in 2010. I was really impressed with the perfect organization and warm welcome given by the Norwegians. It inspired me to organize a similar meeting in my home city – Cracow.

Together with my friends we decided to organize the 14th International Meeting for Young People with IBD, which finally took place in Cracow, Poland from 30th of June till 3rd of July. The conference was co-organized by the Polish Association Supporting People with IBD (PASPIBD) with the support of the EFCCA Youth Group (EYG). During the meeting we had the pleasure to host 25 young delegates from Belgium, Denmark, England, Finland, France, Germany, Ireland, Italy, Netherlands, Poland and Slovakia.

Throughout the preparations I was wondering how to make our meeting more attractive, so that Cracow and the proverbial Polish hospitality would remain in our guests' memory. Although we are aware of the shortcomings and imperfections in the development of our country, it seemed appropriate to show our achievements, rich history and culture. And Cracow was the best place for this purpose!

Undoubtedly, one of the elements of this approach was the guests' welcome at the airport. Wanting to give it a unique and more joyful character, I dressed myself up as the 'Dragon of the Wawel Hill'. The dragon is the symbol of Cracow and was also used as a logo for our meeting. Although after awhile I felt that I would evaporate from the heat inside the dragon's skin, the positive surprise and warm reception from people gave me the motivation to remain disguised and welcome the rest of the group.

Despite the fact that during the whole meeting the weather had played various tricks, and we certainly could not call it favourable, it was kind enough to enable the guests to admire the beauty of the Wawel Hill during the welcome dinner on the charming terrace of the Kossak hotel.

Participants received a warm welcome at the airport

The next two mornings were spent in the atmosphere of learning and gaining new experiences during the workshops organized by members of the EYG Board. We also had the opportunity to listen to presentations on the activities and achievements from each of the participating associations. I hope that time spent in this way will stimulate the development of new activities within the national associations and that the participants will benefit from the ideas already developed in other countries. It is the youth that should be the engine of the further development and hence it is extremely important to instil in the young a desire for further action.

The afternoons were filled with sightseeing– entertaining programs and introducing the tourist attractions of our region. We managed to discover the secret of the philosopher's stone during the city games held within the old city sights, as well as to go 300m underground to admire the charm of the Wieliczka Salt Mine. The idea was to spend that time on getting to know each other better. I believe that there wasn't anybody who missed that opportunity and the bonds of friendships will remain a visible dimension of the benefits of organizing meetings for young people suffering from IBD.

We concluded the meeting during a Gala Dinner in the Restaurant "Amadeus" located near the Market Square. After that we invited our youth to the "Saturday night fever " party in the "Prominent Club" where we summarized the meeting and handed out diplomas and gifts. The party lasted late into the night and I hope that it gave everyone an extra dose of fun and helped us again to form very strong friendships.

During the meeting we were also accompanied by a professional film crew. We are looking forward to the results of its work, as for sure it will be a great keepsake of our meeting.

To sum up, I hope that the 14th EFFCA Youth Meeting was a successful event. From my perspective, I could only regret that due to the organizational issues I could not spend enough time with our dear guests. However I strongly believe, that I will make it up during the realization of other ideas and events related to the work of the EYG Board, which I joined at this year's meeting.

Last but not least, I would like to thank all the sponsors, local authorities and people of good will, whom I had the opportunity to meet during the preparation and organization of EYM and without whom this project could not be held. They strengthened my conviction that the world is not bad, you just should give it a chance!

> **"I hope that time spent in this way will stimulate the development of new activities within the national associations and that participants will benefit from the ideas already developed in other countries.**

EFCCA Youth Group Meeting, Cracow, Poland

“My first time”
Notes from the EFCCA Youth Meeting in Cracow

by Ciara Drohan, Irish delegate

My national association invited me to attend the EFCCA Youth Meeting early in 2011, it was a great honour to be asked. In the weeks before hand we worked on our poster and youth presentation. I had never attended any EFCCA meeting or met anyone outside of Ireland with IBD and I was really looking forward to it, especially as the time got closer and more and more information was being sent about the meeting. Victoria, the other Irish participant and I met at the airport; we were both nervous and excited. On our way through to the departure gates we decided to buy an Irish leprechaun mascot “Paddy” to bring with us to Poland.

> **“It was really great to see what other countries are doing in their national associations and that everyone has some trials and tribulations.”**

We were met at Krakow airport by the Krakow dinosaur also known as Marek. Marek, Pawel and Magda had warned us in on the meeting’s facebook page that one of them would not look like they normally do. We got our bus with other participants and got to know each other on the way to the hotel, the great conversation of guess each other’s ages definitely broke the ice.

Through that first day we got to know all the participants especially when we went on our shopping run and to visit a local monastery. That evening there was a welcome dinner and we received our welcome packs from the Polish delegation and we also had a beautiful birthday cake for Chayim.
Over the weekend we took part in workshops and also a group treasure hunt around Krakow. The workshops were of particular interest as they covered both the importance of exercise and how it benefits IBD and various aspects of the Internet. It was interesting to see how much the Internet can assist patients of IBD and also how important exercise is and how everyone is different with what they can do depending on the stage of their illness. On Saturday morning there was also a very early breakfast Zumba class, which involves dance and aerobic elements. I had only heard about Zumba but with Daniel from Denmark leading us all it definitely woke us all up in preparation for the workshops ahead. The Krakow treasure hunt brought us all around the city in our lovely rain ponchos as the Polish weather was very similar to Ireland.

We also had a beautiful meal overlooking Krakow at night which was truly spectacular. The final night dinner included the presentation of our certificates and the winner of the poster competition that had been voted on by the participants earlier in the day, a deserving Polish delegation won the competition. We were all presented with a souvenir of a wooden toilet and an EFCCA certificate of attendance. I still look at my wooden toilet and remember the great time I had. On our final morning Marek presented everyone with a memory card of photographs of the weekend.

Ciara, third person from right, with other EFCCA Youth group participants.

Ciara was diagnosed with Crohn's disease when she was 18 years of age. She is now 30 and mother of one daughter. She has been involved with the Irish Society of Crohn's and Colitis for over two years and is the director of the associations as well as a representative of the Irish Youth Group which has been set up this year.

It was really great to see what other countries are doing in their national associations and that everyone has some trials and tribulations. There were a lot of discussions both about our illness but also learning from each other and listening to projects that different countries have done. It was a great learning experience as some of the youth associations are very much established and some our new like ourselves. There was also EFCCA Youth Group committee work completed and the election of the new committee which now has a representative from Ireland.

Overall I met many new lifelong friends and I sincerely hope I will get the opportunity to represent Ireland again and attend Copenhagen in 2012. The meeting was one of the best experiences I have had and I learnt a lot from the other participants that I can hopefully use in our national youth group.

Meeting the people behind the associations

EFCCA Annual General Assembly

by Isabella Haaf, EFCCA communication manager

This years Annual General Assembly (AGA), which took place in Copenhagen from 14-16 April was my first AGA with EFCCA. I had been in contact with most members via email but in Copenhagen I finally had the opportunity to meet people face to face and to really get to know them. It was a great turn out with over 40 delegates from 22 of the 27 member associations. It was also a moment for welcoming three new members from Poland, Serbia and Czech Republic to EFCCA.

During the meeting elections to the Executive Board (two year term) were held. The current Board consists of the following representatives: Marco Greco,

Chair Marco Greco (right) congratulating Dusan Baraga for his work as Executive Board member

chairman (Italy), MarikaArmilo, vice president (Finland), Chayim Bell, secretary (the Netherlands), Ben Wilson, treasurer (UK), Bruno Raffa (Switzerland), Salvo Leone (Italy), Iva Savanovic (Croatia) and Betty Vandevelde (Belgium)

It was also a moment to say goodbye to Dusan Baraga from Slovenia who had served as Board member but due to workload was unable to continue work on the EFCCA board. I fully agree with the rest of the EFCCA team that he will be dearly missed and we hope to see him at future events.

This years AGA not only saw the reporting from the Board members on activities such as the Directors Report, the CEO report and reports of other activities such as the IMPACT project, the European Library etc. but also provided a space for members to meet in smaller groups and brainstorm on possible subjects and issues for training sessions to be organized in the coming months.

Two external guest speakers were invited to give the link to a wider European context. Marco Santangelo, thematic expert of the Building Healthy Communities project (see page 21) gave an extensive overview of the EU Health Programme and Anders Olauson, President of the European Patient Forum, highlighted his organisation's activities aimed at ensuring patient's involvement in EU health related policy-making, programmes and projects.

Finally Rod Mitchell and Wouter Miedema presented an update of the IBD Research Foundations activities and initiated discussions for closer cooperation with the various national member associations as concerns research activities.

EFCCA would like to give a special thanks to the Danish Association for the smooth organisation of this event and the warm welcome we received. We would also like to thank Executive Board member, Marika Armilo who supervised the AGA organisation and of course all the delegates for their active participation and for making the meeting such a success.

Marco Greco and Luisa Avedano welcoming new EFCCA members from Czech Republic (left), Serbia (middle) and Poland (right and front)

Making new friends at the EFCCA Summer camp

by Harriet Morgan-Taylor, UK delegate

This June I was invited to participate in the EFCCA summer camp which took place from the 25th-28th August near Amsterdam. Initially, I jumped at the chance but as the date got closer, I started to question my decision. I didn't like the idea of flying to a country I had never been too, with people I had never met. I was put me in contact with Arron a fellow suffer of IBD, someone who I would be meeting in the airport and flying with. We spoke on facebook but I still felt nervous about doing all this new stuff.

The journey

First hurdle done and dusted, managed to find Arron at the airport. Arrived in Amsterdam to rain, my ideas of a nice few sunny days away were soon ruined as I realized Amsterdam is like home from home, lots of rain! Finding the welcoming group at the airport was like a treasure hunt, we were told to head toward the 'meeting point'. There we found Ben and Marinel, they were very welcoming, muffins and coffee! We were given our tickets for the train, and even managed to find the correct platform and train. Four fellow participants accompanied Arron and myself on the short 40 min journey to Amersfoort.

We arrived at the train station I was still feeling a little anxious however I had now met 2 other campers from England. Daniella (camp counsellor) met us at the train station and dropped us off at the hotel, following 'check in', we collected our t-shirts and programmes. The camp counsellors appeared nice and friendly. I was sharing a room with Rachael from England, really glad as we'd already met at the airport, and she seemed nervous like me. So at least we could be nervous together!

Getting to know each other

There were 30 campers in total, from 13 different countries in Europe. But don't worry the main language was English. Found it very interesting to meet people with IBD from Croatia, Slovenia or Norway to name just a few.

Thursday - had lunch, went for swim, had dinner and then sat round chatting in the bowling alley till late, making new friends. Deciding who was going on the 'optional' (but not so optional run, so Sanna and Chayim said) at 7am in the morning.

Harriet (right) during the singing class

Friday 6.45am - dragged myself out of bed for optional run, although I didn't really run, more like jog/walk/crawl/die. Got back had a shower then headed down for breakfast. Following breakfast we headed into Amersfoort for a little treasure hunt, we were split into groups and then sent off with a map. The questions were very difficult e.g. what colour are the windowsills of the art museum? very difficult question for our group, totally stumped us, we walked straight past it a couple of times. Having completed this extremely difficult quiz we managed to sneak in some retail therapy, very nice, very dangerous! Cars can apparently be driven on the pavement to avoid certain things i.e. the dustbin lorry.

Learning in a relaxed environment

After lunch we went off and did an IBD discussion group, this was one of the selected activities I had chosen for the day. We sat around for an hour talking about our experiences of living with IBD, including diagnosis and treatments. It definitely helps me to talk about stuff, because I feel that someone does understand, someone generally has been there before. I can't say I've ever felt that accepted into a group of friends like I did whilst in Voorthuizen. Everyone made me feel at home, and no excuses had to be made when needing the toilet or going to bed early!

> **"Some of the talks became really personal, and as a result of one chat with another girl I have come to realize that if I needed a stoma at any point in my life it wouldn't be the end of the world. This girl is an inspiration to me. She's proof that life does go on past a stoma."**

Next - relaxation session and yet another different group of campers. We all sat around while Sanna one of the counsellors talked us through why we should all know how to distress when dealing with IBD. We all sat there, closed eyes, scrunching up different parts of our body for so many seconds then releasing. Well I'm glad we weren't laid on the floor because I would have been asleep and snoring. It was so relaxing!! I've never done a relaxation session before but I'd be definitely up for another one. On the proviso that we can lay on the floor?!

We seemed to have a good balance between 'free time' where we could relax, chat and do what we wanted (the hotel had a swimming pool and bowling alley on site which was used regularly) and activities. After dinner there was a singing workshop. I don't sing ... well only in the shower! So the thought of singing in a group was like a nightmare. Anyway I went along as all good campers should, there was a very enthusiastic singing teacher and a keyboard. Throughout the whole singing workshop I don't think there was a break of 5 minutes where someone wasn't laughing. Singing isn't my strong point but I had such a good laugh. Making the best of the night, everyone by the end of it was singing to their hearts content.

We managed to get in the pool late on Friday night, fellow campers and counsellors. We had several great ideas, one such idea was 'how many people can you get on 1 raft'? (Ok not original but we thought it was a good idea for a Friday evening). Obviously hadn't thought through the idea with regard to how many times we would fall or get pushed off. After getting dried off a group of us went to Arron's room to watch telly and chat into the early hours of the morning. Some of the talks became

Participants looking for a ball at the farmer's golf (left) and enjoying the bowling alley (right)

really personal, and as a result of one chat with another girl I have come to realize that if I needed a stoma at any point in my life it wouldn't be the end of the world. This girl is an inspiration to me. She's proof that life does go on past a stoma.

The next day: "Counsellors of tomorrow" - fab idea. It was very exciting thinking about how we could plan a camp ourselves and the sort of activities we would do. And then a further choice of activities, a group session with a gastroenterologist, he was amazing listening to everyone. Asking questions about the disease were personalized. We then talked within the group about our experiences.

Following lunch - bike/minibus ride to farmer's golf. Decided to bike it there as the weather was nice. Not for long - it rained!! Poncho on, time to play farmers golf. It was fun(not) walking through fields ankle deep in grass with a golf club, but instead of a club there was a clog. The group I was in won, added bonus. After dinner we had a drum workshop. The teacher was amazing; he made us sing and drum.

The Party – Themed Night, Your Fav Film or TV Character.
I went as snow white; there was music, dancing and a very fun night. We boogied till about 12ish, then had to move from the meeting room due to the bar wanting to close. So we all headed back to one of the girls room to carry the party on. We stayed up talking dancing and generally having a good time till 4am.

Thoroughly enjoyable 4 days, defiantly would go again! Never laughed so much in all my life!! If anyone reading this is wondering whether or not it's worth it. It definitely is!! Never felt so at place and so at home with a group of people. I've made friends for life. And in October of this year I'm flying to Ireland to meet up with a couple of the girls I met in Amsterdam. Thanking Chayim and all the team plus fellow campers for the most amazing experience ever. Love to you all and hopefully see you lot next year .

A collective voice for European patient groups

During this year's Annual General Meeting of the European Federation of Patients (EPF) Marco Greco, EFCCA chairman, was newly elected to the EPF Executive Board on a two year term. EPF is the umbrella organisation of pan-European patient organisations active in the field of European public health and health advocacy. "*Being part of the EPF Executive Board will consolidate and strengthen cooperation with EFCCA with the ultimate aim to unite patients' voices at EU level, manifesting the solidarity, power and unity of the EU patients' movement*" says Marco Greco. EPF currently represent 44 patients organisations – which are chronic disease specific patient organisations operating at EU level and national coalitions of patients organisations. EPF's vision is high quality, patient-centred, equitable healthcare for all patients throughout the European Union.

EFCCA moves offices

Last but not least we are delighted to announce that EFCCA moved into a brand new, independent and bigger office! It is another concrete step towards the establishment of the EFCCA Academy: a big meeting room is now available for our future training courses and meetings and we are sure members will be able to enjoy it very soon. Our new address:

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Rue Chartreux 33-35,
1000 Brussels, Belgium
Tel/Fax: +32 2 540 84 34


HUMANCARE

EFCCA and European Projects

by Luisa Avedano, EFCCA CEO

EFCCA has been experiencing a dramatic change over the past years. As many should know the EFCCA structure lead by a dynamic and creative Board has started a long but concrete journey towards a better position within the European arena in order to give a louder voice to people with IBD in our countries.

Our event around World IBD DAY (see page 5) was the first important sign of this new deal. Many delegates had the chance of actively contributing to it and our Chair, Marco Greco was the first EFCCA Chair who attended a meeting with top level representatives of DG SANCO (the European Directorate General dealing with Health issues within the European Commission).

Other important steps are in the pipeline: from the EFCCA Academy and its first training course to the co-ordination of a bigger worldwide set of events around the World IBD DAY 2012. And many other activities are in the process of definition thanks, in particular, to national associations' support and suggestions.

As far as EFCCA's participation in European projects is concerned, I'm pleased to say that some positive steps have already been undertaken. In fact EFCCA has been involved in two European projects: one on research on IBD and the other one on well-being and quality of life of citizens.

IPODD whose results are presented on the EFCCA website and in this magazine (page 19), marked an initial but crucial involvement of a good number of national associations which translated the document on the IPODD results into various languages, making it available on our website and facilitating thus its understanding for many people with IBD all over Europe.

BUILDING HEALTHY COMMUNITIES represents another concrete example. EFCCA's role is to disseminate its results and to facilitate its communication strategy vis à vis the European Commission and the most relevant European organisations dealing with health and quality of life.

These two examples show how EFCCA and its members can become part of a wider network of players gaining visibility and fostering its role in Europe. Both participations gave EFCCA also a small, but significant, financial acknowledgement, which represents another concrete sign of its growing role in the EU.

I believe that these two projects represent a kind of training ground which allows us to become more familiar with European funds as well as with a working methodology that we enable us to have an even more pro-active role in other European projects in the near future.

My professional background is also based on European project management and I'm particularly pleased that EFCCA is developing this capacity, which is particularly important as far as our role in lobbying and making pressure on the European institutions is concerned. Another brick in the wall for building a stronger EU-wide Federation whose role and message are becoming more and more important for people with IBD and their daily struggle for a better life in every European member states. In the following months we will seek for further potential collaborations and keep you updated in order to involve as many players as possible.

As a final remark, I would like to remind you all that EFCCA is also willing to create a kind of "drawer of ideas" in which all your project ideas or requests can be included in order to be as much equipped as possible when a concrete possibility of being involved in further European projects appears.

Targeting the demolition squad

The EU project IPODD takes a pragmatic approach to IBDs by focusing on the final stages of gut damage

Sergio Pistoi, IPODD Public Information Officer

If criminals were behind inflammatory bowel diseases (IBDs), it would be a band of terrorists, not lonely felons. Dozens of predisposing genes, the immune system and maybe tens of other unknown factors conspire to determine IBDs. There is no puppeteer pulling the strings in these diseases but, rather, an articulate network of causes that ultimately leads to chronic inflammation and damage.

When fighting terrorists- real or biological - investigators follow two strategies. On one side, they look for the big picture, gathering intelligence about their hierarchy and organization. At the same time, they also need to control damage, catching suspects before they do harm.

The EU-funded project IPODD definitively follows the latter approach. Instead of unravelling the causes of IBDs, the project focuses on the last steps of inflammation, which are the ones leading more directly to gastrointestinal damage. The idea behind IPODD is pragmatic: blocking these steps may not avoid the onset of IBDs but, hopefully, will prevent their worse consequences for patients.

About IPODD

IPODD (an acronym for "Intestinal Proteases: Opportunity for Drug Discovery") was launched in 2008 with €3 million funding from the EU seventh framework program (FP7) and will expire in July 2011. The project has put together the expertise of 13 research teams across seven countries.

IPODD's work focused on matrix metalloproteases (MMPs), a family of enzymes that lie at the end of the inflammation cascade. These molecules may not trigger inflammation themselves, but are involved in its final steps leading to intestinal damage.

Because of their ability to breakup proteins (proteases is a general term to indicate "protein-breaking enzymes"), MMPs are a sort of "demolition squads" in the vanguard of inflammation. They dissolve proteins in the matrix (the space surrounding cells), clearing the way for inflammatory white blood cells, and they activate other molecules involved in IBDs, such as cytokines, that also promote inflammation. MMPs may also attack the structural proteins that hold the mucosal lining together, resulting in destruction of the intestinal tissue. About two dozens MMPs are known in humans.

Chasing proteases in IBDs

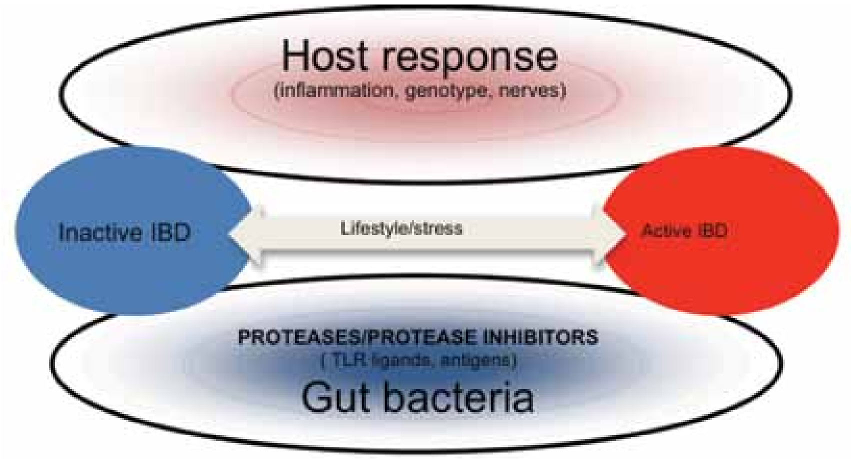
A significant part of IPODD's work was to find which MMPs are active in IBDs and to study their specific role in the disease. Researchers compared the distribution of different MMPs in normal guts and in those affected by IBDs, and looked at the activity of their respective genes in patients.

All these studies led to identification of several MMPs involved in IBDs. They also provided a better picture of how these proteases interact with other components of inflammation, such as cytokines and growth factors, improving knowledge about the last steps of IBDs.

New targets for drugs

Besides looking at the role of proteases, IPODD researchers investigated strategies to block their activity in the human intestinal tract.

Most of today's drugs for IBDs work by suppressing or modulating the immune system's function. Unfortunately, these treatments have significant side effects and are ineffective in some patients. Targeting proteases may help design more effective drugs, because the activation of MMPs is an event that takes place in virtually all patients.



IPODD focused on a family of molecules called TIMPs (Tissue Inhibitors of MetalloProteases), which are known to be natural inhibitors of MMPs. Preliminary results showed that TIMPs can counteract the action of MMPs, and reduce inflammation in laboratory models of IBDs.

Starting from these findings, researchers are now looking for compounds that may increase the gastrointestinal production of TIMPs. Such compounds, or the TIMPs themselves, may become candidates for drugs potentially useful in IBDs.

The importance of microbes

A core aim of IPODD was to investigate another source of proteases: the trillions of bacteria living in the human intestine. One can hardly overstate the importance of these microorganisms: from fending off infections to digesting foods, there is probably no gastrointestinal function that is not influenced by intestinal bacteria.

IPODD's scientists have discovered that many MMPs found in the human gut are indeed produced by bacteria, and not by our organism. Researchers also found evidence that these bacterial-made proteases may contribute to the development of IBDs.

These results show how gut bacteria can be a source of proteases in IBDs, and have prompted researchers to mine these microorganisms for natural inhibitors of MMPs that may be useful as drugs. As expected, they found a number of bacterial-produced inhibitors in the human gut.

One perspective now is to select or engineer gut bacteria that produce these inhibitors of MMPs. Such strains may be used one day as a probiotic therapy to help patients, instead of drugs.

Proteases and flares

As many patients know, relapses ("flares") in IBDs often follow stressful events. Several studies have confirmed the link between nerves, the brain and the immune system in the risk of relapse from gut chronic inflammation.

Are proteases involved in stress-mediated relapses? To address this question, IPODD included groups with expertise in the study of nerves-gut interactions (a discipline called neurogastroenterology), and their answer is: yes.

Indeed, IPODD researchers found evidence that MMPs are involved in stress-reactivated colitis, a study model for flares. These results suggest that inhibiting proteases might also help to dampen the effect of stress on IDB patients and increase the time in remission between flares.

Looking to the future

The IPODD project has opened new perspectives in IBDs. As is typical of cutting-edge research, it also brings a number of new unanswered questions.

What is the exact role of proteases in IBDs? Can we design drugs that inhibit MMPs without unacceptable side effects? Will we be able to harness gut bacteria to inhibit inflammation?

Future studies will hopefully address these and many other issues starting from IPODD's findings. IPODD researchers, however, prompt for caution when thinking about future applications for patients.

"IPODD was a basic research project and only further studies will tell whether it will ultimately lead to clinical applications," says David Grundy, a Professor of Biomedical Science at the University of Sheffield who coordinates the IPODD project. "But the knowledge we accumulated has moved the field further, pointing to new and interesting avenues."

A list of scientific publications arising from IPODD's work is available at http://www.ipodd.eu/ipodd/research/publications

Healthy Urban futures

by Marco Santangelo – BHC Lead Expert

In the past thirty months ten European cities, members of the "Building Healthy Communities" (BHC) URBACT II European network, have tried to design local action plans in which health and quality of life could be considered as keywords and goals . The economic and financial crisis has hit hard European economies in the meanwhile, thus changing dramatically the scenario for locally designed policies. The crisis is reflected in choices and activities designed by BHC partners: many actions were foreseen but their implementation is linked to the diminishing availability of funds; interventions tend to prepare sound programmes for the future rather than scheduling for the next months; attention has been paid to the city's increasing capacity to assess for the right decision to be made and to monitor the implementation process of current activities.

Notwithstanding, ideas and activities reflect the work of the member of the local support groups, their ability in adapting to a changing scenario, and their will to propose a local way to introduce health and quality of life in all urban policies, as promoted by the European Directorate General responsible for health, DG SANCO.

Each local action plan represents a specific situation, local conditions and peculiarities, the city interpretation of the process of building a healthy community. It is, then, possible to see ten very different city approaches reflecting different political and civic cultures, contexts and needs. And yet this diversity has proved to be the real richness of BHC, because the learning process that is usually expected in EU projects even exceeded the first expectations: the project started with three thematic workshop, scheduled to provide partner cities with knowledge on how to assess and monitor health in cities, on different models of healthy lifestyles (and thus policies) and on the available opportunities for funds in the current EU programming period (especially as regards Structural Funds).

But that was not enough: partner cities wanted to know more on how to concretely assess health in urban policies, and a training session on health impact assessment (HIA) was organized in Belfast; the need to improve the effectiveness of local policies since their definition led to another meeting, in Barnsley, in which the use of social marketing techniques for designing health policies has been analysed; finally, the need to understand how to reshape regeneration policies and interventions in order to take into account health and quality of life conditions of the citizens led to two meetings, in Madrid and Lecce, in which the local experiences were at the centre of the attention.

As a result of the difficulties that partner cities were experiencing, there has been a shared strategy of broadening the focus from health considered in a more traditional way to include the general wellbeing of citizens, so to design local action plans that could holistically link different interventions (often already planned or ongoing). From a certain point of view cities were practicing the "health in all policies" principle because it was too difficult to design or promote regular health policies. Furthermore, it became clear that it is at the local level that there is an urgent need to promote integrated interventions to improve the quality of life of citizens, to intervene to prevent certain phenomena to become problems.

As a matter of fact, BHC partner cities have thus focused on a series of activities that could be useful to promote healthier lifestyles, while maximising the integration of different interventions and programmes so to develop positive gains for health. Some cities, for instance, have worked on the links between different initiatives to have a greater impact of their results, with a special attention to physical activities as a way to generate wellbeing and sense of belonging to the wider community.

Many partners have shared this approach, but of course also the need to involve citizens or target groups as young people in a participative decision-making has been considered as very important. On the other hand, where public or EU funds were available, cities have tried to have a more effective and health-oriented use of the money by stressing the links between initiatives and the general wellbeing of the population.

BHC can be seen as a positive experience of cities willing to deal with health and quality of life of their citizens, adopting a proactive attitude towards new ideas, cooperation and exchange of practices. But experiences and knowledge that have been produced are to be shared and debated within a much broader network of cities, organisations, and institutions. BHC as a project has come to an end, but information is available on the URBACT website (http://urbact.eu/en/projects/quality-sustainable-living/building-healthy-communities-bhc/homepage/) and partner cities can be directly contacted to know more about their approaches, activities and practices to continue working on improving health and quality of life conditions of all European citizens.

Kids at the opening ceremony of the office for regeneration in the barriera di milano district (Torino) had just been served a "healthy" meal by BHC organisers

IMPACT: going beyond expectations

The IMPACT survey, which was launched by EFCCA last December (see report on in our last issue April 2011), has now been closed. In total we received 4,670 responses. An important original aim of the project was to achieve at least 100 responses from each of at least 10 countries in order to obtain an international perspective of the impact of IBD on patients' lives. In the final event, this was achieved in 15 countries.

The secondary objective included obtaining a better understanding of the quality of care offered and access to health care and support facilities in various countries, and to better understand the differences between countries, age groups, and different groups of IBD.

Here are some of the main findings resulting from the IMPACT survey:

DIAGNOSIS:
Access to specialist care is usually good and most IBD patients receive a timely final diagnosis. Still, there's a significant remainder who waits for the diagnosis for a long time. This can be a period of uncertainty, significant life impact, morbidity, and distress - and could create a clinical risk as many patients may need emergency care BEFORE the diagnosis.

COMPLICATIONS:
Many IBD patients experience co-morbidities or complications (49% have joint involvement associated with IBD, 34% experience skin involvement associated with IBD, 28.5% regularly use pain pills to relieve their IBD symptoms, 15% have complications of surgery such as adhesions, wound infections or pain)

SATISFACTION:
Most IBD patients are 'somewhat or very satisfied' with their treatment plan, and their surgical outcome (if applicable). However, hospital admission in IBD patients is extremely high, representing significant morbidity, and demand on health services. Access to biological therapy is becoming more established, although a minority of patients takes this treatment. Worryingly, the majority of patients have used corticosteroids, a high proportion experienced side-effects, and almost all were concerned about long-term effects.

ACCESS TO CARE:
Although specialist healthcare professionals are present, a quarter of people with IBD feel they do not have adequate access to them. Access to care needs to be improved, as does the quality of communication in consultations (some patients feel they do not get to ask the questions they want to.)

DAILY LIFE:
Half of people with IBD are fighting active disease today. Most IBD patients experience significant symptoms, regardless of whether they are in remission or not. Fatigue, as an example, is often experienced also when in remission.

WORK AND EDUCATION:
Most IBD patients have taken time off work in the last year due to IBD – most startling, over a quarter of respondents had been absent from work for over 25 days in the last year. Disease severity and ability to work seem to correlate. The majority feels stressed or pressured about taking time off. A significant proportion have received complaints or unfair comments at work, or suffered discrimination. Most patients are fully employed, but some are under- or unemployed because of IBD.

RELATIONSHIPS:
IBD has significant negative social effects, and in particular is responsible for preventing, or causing the end of intimate relationships for an alarming proportion of people. However, meeting others with a similar condition, or becoming part in patients' organizations creates optimism. Membership of a patients' organization has a beneficial impact on life as a whole for a clear majority of people.

CONCLUSION:
Even with the availability of immunosuppressive and biological therapies for more than a decade and adequate access to care, the impact of IBD on patients' lives is immense. This European survey offers new angles on how to further reduce the burden of disease, and important recommendations for treatment and care.

New EFCCA project in pipeline – the European Toilet Locator!

The success of projects within several EFCCA national associations, and requests for a co-ordinated European model, led to a new project from EFCCA, which begin in 2010.

The key objective was to create a European website in which users could quickly locate their nearest public toilet, to add new entries themselves, and to provide feedback or ratings on the entries in the database.

The first part of the project reviewed the great examples of similar websites from our national associations in Denmark, Belgium, and other worldwide locations such as New Zealand. Each of these countries has implemented their own version, with similarities and differences between each. EFCCA has learned from all this experience, particularly when faced with important technical choices, relating to security, database management, and ensuring quality of data.

EFCCA has been working with partner DAMAN-IT, a Danish company with lots of experience with similar projects, most notably the www.flush-it.dk website, which was the first example of an IBD-related toilet locator in Europe.

EFCCA's European-level version, which has the preliminary name 'Find-Toilet.net', aims to help people with IBD in three situations:

Firstly, to provide a source of information for people with IBD on available toilets before they leave home, so people with IBD can plan their day and their route if they need.

Secondly, to provide information on toilet locations on the move – through mobile devices like the iPhone, Android, or Blackberry. We recognize that in many cases, our need for toilets is sudden, and urgent. There may not be time to access and use a website in this situation, but we've developed the possibility as a natural extension to the website, following requests from individuals, and following the best practice of those countries who have similar models.

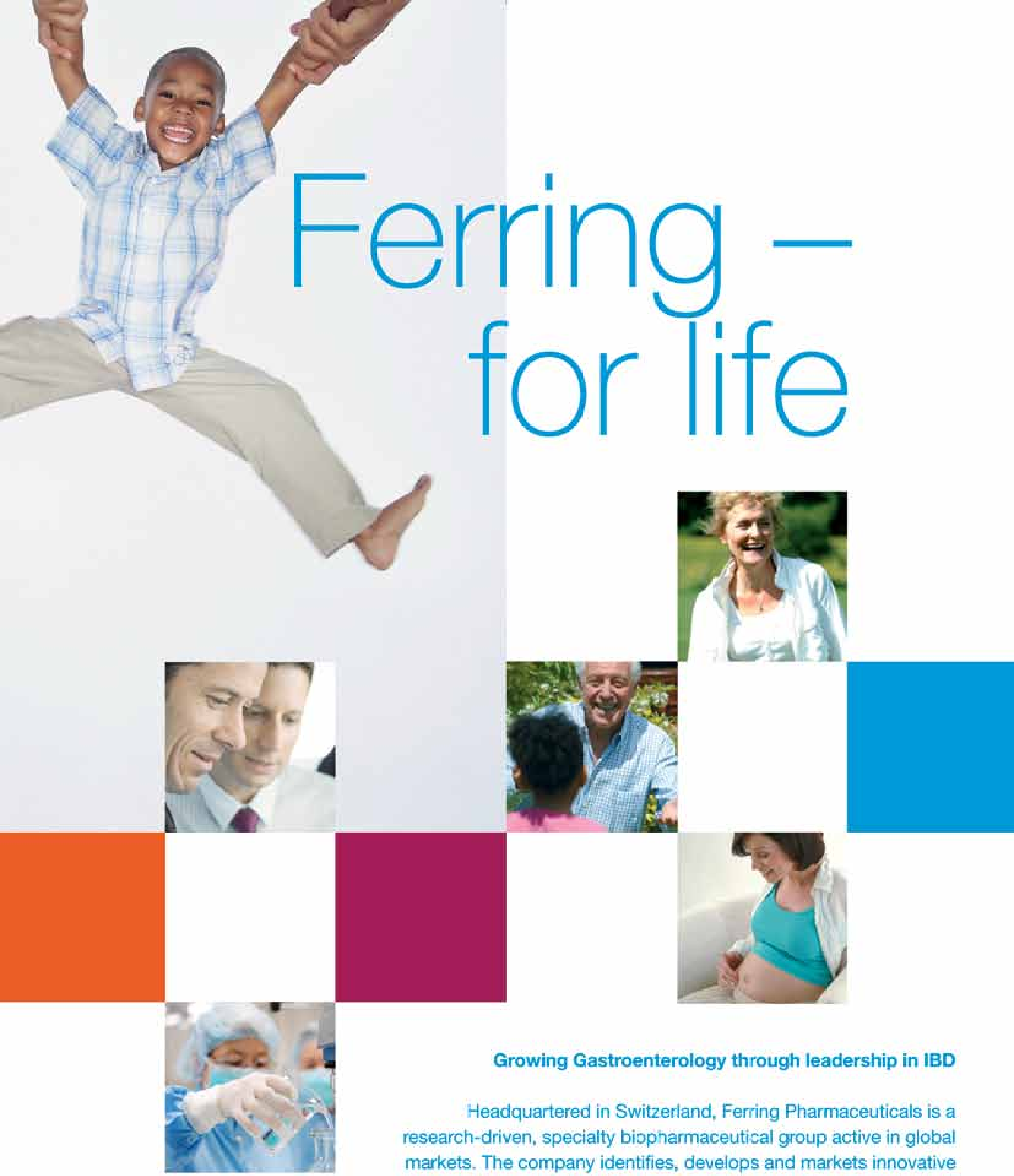
Finally, the entire project is a great opportunity to raise awareness, provide a collaborative resource, and to encourage individuals to contribute to the database, as a fun and quirky activity, which can help, bind us together as a community.

Right now, the website is being finalized, graphic designed, and tested. We're making the final design choices right now, and we'd like to thank all the individuals and countries who have reviewed our work and provided feedback.

Most importantly, the next step is to import the data on the toilets listed so far by several EFCCA associations – bringing this data into the European model means we can launch with hundreds of listings already in the system.

As a further resource for our national associations, we are pleased to offer our experience – technical and organizational – in helping EFCCA countries to set-up similar national models, or contribute more directly to the European model.

Ben Wilson, EFCCA treasurer



The power of volunteers

Interview with Ulla Suvanto, project manager, Crohn's and Colitis Association, Finland

The Finnish Crohn's and Colitis Association was founded in 1984 at the initiative of a group of IBD patients wishing to improve general knowledge on IBD, to form social contacts among IBD-patients by organizing peer support activities and to improve the quality and availability of the treatment of IBD. The association has a membership of over 5700 members.

How is your association organized?

The office of the Crohn's and Colitis association is based in Tampere where we have two employees working fulltime and one part – time employee, however our activities are taking place nearly all over Finland. We do this mainly through our volunteers. We have over 30 volunteers who act as "regional leaders" and who organize regional meetings for people with IBD. A further 20 volunteers provide support to people with IBD through a phone help line or through email contact.

The work of our association is supervised by our Executive Board, which meets on a regular basis to define the association's work programme and strategic development. Once a year we organize a General Assembly which is attended by our members and which elects the Chairman on a one year term and Board on a two year term.

What are the main activities you are working on at the moment?

One of our main activities is the peer support project, which I am currently managing. The project has the following aims:

- to develop peer support activities and start peer support activities in new areas
- to organize peer support and activities for families with an IBD child and for young people
- to develop new models for peer support through the internet
- to develop training and support of regional leaders and peer support volunteers

Since the project started two years ago, we have mobilized a great amount of new volunteers and started youth activities in many cities. Our young volunteers have created a facebook group, which serves as a group discussions forum and we have created a special support e-mail address for young people as well as a support telephone help line which is available each Wednesday between 6 am and 9 am.

Once a year we organize a national youth meeting and a family day meeting. Next year we are planning to organize a weekend away for families where one of the parents has IBD.

As you can see we try to find various ways to organize peer support activities for different target groups.

Of course we also offer to our members information services such as our newsletter which is published four times a year, guides on IBD and information on the peer support meetings that are taking place throughout Finland. We have an extensive website with a discussion area and we have –as mentioned previously- telephone and email help lines.

Most of the people working for your associations are volunteers. How do you motivate your volunteers and ensure that they stay with you?

Yes, volunteers make up a very important part of our association; they are so to speak the pillar of Crohn's and Colitis Finland. Most of our volunteers have a personal interest in the issue, they either have IBD themselves or they have a family member with IBD. Volunteers are the ones who carry out most of our peer support activities. We make sure that we meet with them on a regular basis and organize training courses where they can meet each other, get high quality information and plan together peer support activities. Part of my job is to provide support to our volunteers and I am here to answer their questions, advise them, help them and generally make sure that they understand the importance of their work and how it contributes to the well being of the IBD community.

Volunteering also has a real impact upon volunteers themselves – often serving as a valuable stepping stone into training and paid work, facilitating social mobility and developing mental well-being, making friends and having fun.

Are you involved in any European activities?

Our association has been quite active on a European level. As you know one of our Executive Board member, Marika Armilo, is also the vice president of EFCCA. Through this link we have been in regular touch with other European colleagues. And in 2010 we organized the EFCCA Annual General Meeting in Helsinki where we had the opportunity to welcome and share information with other associations from across Europe.

We are also actively participating in the European Youth Meetings and the summer camps that are being organized each year. Usually we send two delegates to represent our association.

I think that it is very important to co-operate with other European countries, because it gives us such a great potential to learn from each other and exchange information and ideas. One example is an idea that came up when we met our Danish colleagues which was to publish a book for children with IBD. Our children's book is to be published next year.

What are your future plans for the association?

The number of people with IBD in Finland is constantly increasing - to give you an idea - over 2000 people are diagnosed with IBD each year. Having said that IBD is not very well known amongst the general population and we must work even harder to raise awareness about IBD and how it affects peoples' lives.

Next year we are also hoping to receive some funds through the Finland Slot Machine Associations which would allow us to extend our professional team. We will be hopefully able to employ an Executive Manager who would be able to work on a more political level in trying to improve even more the quality and availability of treatment for IBD amongst other things.

Members of the Finnish association enjoying some outdoor games after having spent all day sitting in a conference room

Slovenia

Survey on smoking and IBD

Smoking is one of the evident risk factor in IBD. The mechanism by which cigarette smoking affects Crohn's and ulcerative colitis is not known. Smoking has a negative effect on the course of Crohn's, as concerns ulcerative colitis (UC) some results show that "never smoking" to "formerly smoking" status increases the risk of it. Speculating with this finding the Slovenian association wanted to assess whether IBD patients were aware of concerns about smoking so we run a small informational survey amongst our members. We send out 310 invitations. The questionnaire had 3 parts: a general part, a part about the disease and therapy and a final part about smoking. 111 patients in total answered the questionnaire.

58% of the respondents were females and 42% males out of which 61% were patients with Crohn's and 39% with UC. 55% of respondents never smoked, 31 % of them are former smokers, 14 % smoke on a regular basis or occasionally. Smoking status as regards to disease show that we have more smokers among Crohn's patients than amongst UC patients. Crohn's patients have almost the same percentage of smokers as the general population.

About half of smokers do not know if smoking has any influence on the course of their disease. Most of the regular and occasional smokers (75%) want to quit smoking or are already trying to quit.

Amongst patients with Crohn's who take »strong« therapies (biologic drugs, immunosuppressive, corticosteroids or any combination of this) we have 25% of smokers and amongst those who take «light« therapies (5-ASA or nothing) we have 13% of smokers. So smokers need in greater percentage more potent therapy to control their disease.

In conclusion, the range of smokers among patients who are members of the national IBD association is lower than in the rest of the population. The majority of smokers responded that they would like to quit smoking. This is something our association should address in form of support programs for its members.

Please note that these findings are intended for informational purposes in helping the Slovenian association to define potential projects in supporting its members. They should not be considered of scientific value.

Dusan Baraga, KVCB

Croatia

Patient –doctor seminars to be held in autumn

Every year we organize interactive Patient –Doctor seminars across Croatia where people with IBD have the opportunity to ask questions and debate with doctors. The next meeting will take place in Osijek on 18th October 2011. The main speaker will be Dr. Vladimir Borzan, gastroenterologist, from the Clinical Hospital Osijek. Another such meeting will take place in Split during the first half of November 2011 with Prof. Dr. sc. Ante Tonkic, gastroenterologist, Clinical Hospital Split, as speaker. These seminars are sponsored by the Ministry of Health and Social Welfare –Republic of Croatia, MSD and ABBOT.

Other upcoming projects are related to our Patient-doctor seminars, but we would like to include some new topics, for example, hypertension- hypotension and renal complication in IBD, physiotherapy (how to prepare for surgery and recover after surgery, osteoporosis etc.).

HUCUK also hopes to embark on a successful cooperation project with the "Legal clinic". The "Legal clinic" is an initiative of the Faculty of Law of the University of Zagreb lead by University professors and students who provide free legal advice to citizens on a wide range of subjects such as patient rights, acquiring disability pensions according to the Croatian law etc. HUCUK hopes that this cooperation can help all its members and all people with IBD in Croatia to have adequate legal advice related to law issues for free.

Iva Savanovic, HUCUK

France

Preparations for national IBD Day under way

On 8th of October, as every year, AFA organises numerous events on the occasion of the National IBD Day in France. This year, the campaign "Let's show what we have in our bellies" will take place for the first time: a one-day national mobilisation marked by challenges to surpass ourselves and will give AFA the opportunity to collect more money. The goal is to collect €200,000, which means €1 per person living with IBD in France – ambitious by these times of economic and social crisis but necessary to raise awareness, support research and develop projects in our IBD House and everywhere in France! This unprecedented campaign will be led by our patron, Taïg Khris, world champion of roller and record-holder with his jumps from the Eiffel Tower and the Sacré Coeur. This time, Taïg Khris will realise a big roller show at the Montparnasse station in Paris.

As a preview, Clémentine Célarié, AFA's female patron and famous actress, will give a press conference on October 4th which will be followed by the showing of the documentary film "Mont Blanc: Seeing is believing", a movie about an amazing challenge accomplished by several French "heroes" with IBD who decided to climb the highest European summit. This movie has been shown at the Cannes Festival Short Corner and at the EFCCA Youth Meeting in Krakow. A comic book "The Mont Rose roped party" has also been published recently by Olivier Balez, the brother of Eric Balez, the main movie's character. This comic book describes Eric's story with IBD and the fantastic achievement of the operation "The Mont-Blanc of IBD".

The AFA national meetings continue with a new conference in Bordeaux on September 24th entitled "Promoting tolerance at school" with a special focus on the children and teenagers living with IBD in France. With this new round table, AFA will bring together different key actors so that they share and confront their points of view and generate very concrete ideas on which everybody could work in order to improve the quality of life and the integration at school for these young persons with IBD.

Finally, AFA would like to pay a special tribute to Cédric DIAT who left the association this summer in order to experiment on new adventures. Cédric has been responsible for the development of AFA for four years and was also an AFA delegate to EFCCA, which made sense for a strongly convinced European! His work was very appreciated inside AFA and also by EFCCA: from putting forward constructive criticism to giving very interesting strategic and political advice. Of course, he will stay close to us and we wish him good luck in his new career and new life.

Tiphaine Chapeau, AFA

Campaign poster to raise awareness about IBD

Sweden

RMT to co-organise Public Health event

Our Swedish association, Riksförbundet för mag- och tarmsjuka (RMT), is co-organising the Public Health event “Save your belly- alcohol and its effect on your stomach “ which will take place on October 22 in Stockholm preceding the United European Gastroenterology Week meeting. Its the third time that members of the public and delegates of UEGW are invited to attend a Public Health Day on occasion of the UEGW. The event is organised by the UEGF Public Affairs Committee in collaboration with the Swedish patient organisation Riksförbundet för Mag- och Tarmsjuka, ILCO Riksförbundet för stomi och reservoaropererade, 1,6 miljoner klubben - hälsa och livskvalitet för alla kvinnor and will be chaired by Mr Benny Haag, famous actor in Sweden. This event will offer the opportunity to hear from world renowned experts and patients’ representatives on the latest medical opinion and research on alcohol-related diseases.

UEGF is also organising a “Don’t drink – RUN” charity run to help people who suffer from digestive diseases! ‘Riksförbundet Mag-och Tarmsjuka, RMT’ will benefit from the proceeds of the Run.

Wictoria Hannel, RMT

Serbia

UKUKS expanding its membership

The Serbian association for Crohn’s and Ulcerative Colitis (UKUKS) was established just over a year ago, with the objective of raising awareness, informing people about IBD and sharing with the public the problems that IBD patients have in everyday life. During this time UKUKS has increased its membership which exceeded one hundred members. The association’s chairman Ljiljan Djakovic was a guest on 3 Serbian TV stations, talking about IBD, about the association and World IBD Day, alongside with some renowned experts. UKUKS is constantly making new contacts with local media, who offer to help in providing information to the public. UKUKS’s members created an internet forum (http://www.ukuks.org/forum) which is also seeing a significant growth in users. We have also written a letter to the Republic Institute of Health Insurance, regarding biological treatment and in the near future UKUKS plans to organize patient meetings, seminars about IBD and to publish printed brochures and leaflets. Finally, the association is planning to take part in our National Gastroenterologist’s Congress.

Stefan Djakovic, UKUKS

Switzerland

“Movies & more“ anniversary event a great success!

When 30 motivated members of the SMCCV grab their cameras, interview and film themselves, and openly talk about their illness, the result can only be a success! The event „Movies & More“ was held in Solothurn on 3/4 September 2011. Swiss director Stefan Haupt (www.fontanafilm.ch) explained what motivated and encouraged participants to grab a camera themselves and to talk about the things most people concerned remain silent about. The resulting films will be published as soon as possible
It is almost unbelievable. Silvia Steiner was awarded this extraordinary prize in the SMCCV contest. Ten other lucky winners also received great prizes. The SMCCV would like to thank all participants and organizers of this event and is looking forward to watching the videos. You will be able to download them on this website: www.ausdembauchheraus.ch. Thank you for your kind support!

Bruno Raffa, SMCCV

Portugal

APDI organises its first summer camp

The Portuguese association for people with IBD (APDI) organized its first summer camp for young people with IBD. It was not an easy job but, after some hard working months, everything was ready to finally receive those young people as well as doctors, nurses and public figures that kindly accepted our invitation to be present in this summer camp. We choose the region of "Alentejo" to be our landscape and to accommodate the participants that came from all over the country. It was a sunny weekend and all of the participants were invited to enjoy the sun, share experiences about their lives with IBD, talk informally with the gastroenterologists and nurses, work as a team to complete the sport activities that were prepared and most of all, to HAVE FUN…

The weekend ended with a "goodbye breakfast", after very little sleep due to the "goodbye party" that had kept us awake till late in the night. In the end, everybody shared the same feeling and we were even more enthusiastic then in the beginning of the camp. It was too little time there still was so much the youngsters wanted to talk about… But the promise of repeating the camp next year stayed in the air and APDI hopes to keep it with the support of all those who have collaborated: members, associates, doctors, nurses and also ABBOTT laboratories whose contribution was crucial for the success of this initiative!!"

João Machado, APDI

Spain

New online application

In recent months the Spanish Confederation of Crohn´s and Ulcerative Colitis Associations (ACCU-España) together with the Spanish working group on Crohn's disease and Ulcerative Colitis (GETECCU) has developed an internet application called "Crohn al día". This application allows the collection of data on a patient' condition to be shared, in real-time, with his/her doctor. It also serves as a multi-platform and can be accessed through a special website (www.crohnaldia.com), Iphone, Android phones and tablets. The project has been sponsored by ABBOTT laboratories.

We have also been busy lobbying with private health insurance and life insurance companies to negotiate terms for people with inflammatory bowel disease. Currently people with chronic diseases are not admitted to life insurances schemes or private health insurances.

Finally, in Malaga we are organising regular walking clubs in order to overcome problems of osteoporosis which is frequent in IBD patients. Even though the majority of our patients are young, growing older, osteoporosis generated before the age of 50, can produce many troubles. Nowadays doctors prescribe Calcium and Vitamin D as well as modern biphosfonate drugs and suggest regular exercises. Our club organises a 2-3 hours walk in the mountains every two weeks including a picnic. Of course, if you have a flare-up it's more difficult but with modern drugs available most patients can walk two or three hours without problems. We find that walking together especially in the mountains, is really the best thing for your bones and as a side effect to also keep your spirits high!

Members of the walking club in the mountains surrounding Malaga

Goodbye IBD!

Interview with Tanit Tubau

This is the story of Tanit Tubau, an inspiring 22 year old girl from Barcelona that has been suffering from Crohn's disease since the age of 9. In February this year she organised a concert in Barcelona in order to raise funds for investigation on IBD. With the help of her family and friends she approached several well-known music bands and journalists to participate in the event. During the concert she also organised an auction with interesting items ranging from sausages of a local food store to a signed T-shirt of world famous Barcelona football player Gerard Piqué. The concert was attended by over 900 people and Tanit managed to raise € 17 500 which were donated for research into new treatments for IBD to the Foundation of the Hospital Clinic of Barcelona.

Following the concert Tanit was invited to several interviews on local radio and television station helping to raise awareness and understanding of IBD. With her enthusiasm Tanit not only managed to raise much needed funds for research but she also inspired many other people living with IBD to take more control of their life.

> **"For me music is one of the best weapons to fight this little "alien" called IBD. My intention was not only to raise money for research but also to make noise: raise awareness of these diseases."**

The concert you organised in Barcelona at the beginning of this year was totally sold out. How did you manage to mobilise so many people?

I have many friends and they helped me to promote the concert through facebook and Youtube. In order to generate interest in the event I had asked people to take photos of themselves showing how they rejected Crohn's disease. These photos were then projected on a giant screen during the concert and people could see themselves. At first a few photos were sent in with people pulling out their tongues and other gestures showing their attitude towards Crohn's. I created a facebook photo album and started tagging people. Once friends of friends saw these photos more and more people got animated to send in their photos, now my facebook page has over 1000 friends.

I also managed to get in contact - through a friend of a friend with Gerard Piqué the famous football player of FC Barcelona. He was keen to support me organising this event and kindly recorded a video clip speaking out for our cause. He also donated a signed T-shirt for the auction. This has also helped a lot to reach a wider group of people to come and join the concert.

What was your motivation for doing the concert?

Last summer I was feeling very bad and had to have an operation. There were some complications and my doctor gave me four options to decide upon. Each of these options was worse than the other: remove my whole intestine, transplantation with very little chances of success, medication with very strong side effects and the final – which I chose – taking a medication which has not been approved by the European authorities for the treatment of Crohn's as it's not considered a condition severe enough for the use of this medication.

I started to reflect on my life. I have had Crohn's since I am 9 years old. It started with a pain in the belly and now I had reached a stage where my options were minimal. It seemed so unfair and I wanted to do something so that no-one would have to be in my situation, I wanted to find a solution. I talked to my mum and decided to organise this concert in order to raise funds for the investigation of new medications for Crohn's.

For me music is one of the best weapons to fight this little "alien" called IBD. My intention was not only to raise money for research but also to make noise: raise awareness of these diseases. For many people it is a taboo subject, for others, it is a tummy ache and for some it is simply unknown. These diseases are chronic, serious and require a lot of research. Still, I want to give hope to all who suffer: you can draw strength from this situation, we must learn to fully enjoy the good times. Having a chronic disease is not the end of the world, it is the beginning of a new life and each one must paint it with the colour they like.

What are your plans for the future?

I would like to organise more concerts and raise yet more money for research. At the moment I am organising a concert in Madrid and next year I want to organise another concert in Barcelona, though I am a bit worried because now that we have already organised such a successful one expectations will be high.

As concerns my personal plans I first need to recover from the many operations I had last year and I am hoping to go to university next year to study Communications.

Tanit on the night of the concert

IBD Planet: Israel

Travelling with IBD

by Sanna Lönnfors

Sanna is originally from Pyhtää, Finland, but has been living in Berlin, Germany since 2005 where she is working as a medical writer. She was diagnosed with Crohn's in 1998 when she was 18. She got involved with EFCCA some time in her early 20s when she became the youth representative of Finland. One of her passions is travelling.


Sanna in the surroundings of Jerusalem

When people hear that I like travelling in particular to Israel, the comments I get are usually along the lines of "but it's all desert" and "it's dangerous there, aren't you afraid?" Well – no, it's not all desert, and no, I'm not afraid. You can find deserts there – it is the Middle East, after all – and of course security is of a higher concern than what we are used to in Europe, but I've never had a reason to be afraid. If anything, the extended security checks and the visibility of armed soldiers make you feel safer.

Although having IBD is in my opinion not a problem in Israel, there are a few key points that you need to consider when travelling in Israel (or anywhere, for that matter). Food, obviously; what to do if you do get sick during your trip; and a couple of Israel-specific issues.

Food
Israeli food is a mixture of the cuisines of the areas that the country's heterogeneous population originated from. It may be a bit different and spicier from what you have in your own fridge (although in international hotels and restaurants you will find very familiar tastes). Depending on what you can handle, I suggest you feast on olives, pita, hummus, falafel, fish and local fruit and vegetables – fruit and vegetables at home will taste like paper after this experience! Generally, Israeli food is rather healthy. The only time I ever got sick from it was around the Passover holiday, not because there was something wrong with the food, but because I simply ate too much – it was too difficult to resist…

As for drinking, tap water is safe to drink. If you're worried about the food being too exotic, bring something "safe" with you. After I was diagnosed, I used to bring emergency snacks that I knew were safe wherever I travelled, but stopped doing it shortly after, when I noticed I never ate it and so it was just waste of suitcase space. However, if you're in for a long bus or car ride and don't trust gas station food, it might be smart to bring a safe snack with you.

Getting Around
Usually the journey from Jerusalem to the Dead Sea takes about 1,5 hours by bus, but my bus got stuck in a traffic jam around Jericho once and it took way over 3 hours. Travelling by bus from Jerusalem or Tel Aviv to Eilat will take you around 5 hours. The long-distance buses have a few stops along the routes but it actually never worried me as I never really think of any worst case scenarios. When there's a will there's way... I was reading an Israeli travel website the other day where it said "Israel is not a shy society" and they suggested to just ask the bus driver to let you out on the side of the road if you need a toilet...

Interesting sights
The Dead Sea, the lowest point on Earth, is worth paying a visit to. First of all, the sceneries are beautiful and floating in the highly salted water is fun. But

what's more, some scientists claim that because the area is below sea level and therefore oxygen pressure is increased, spending time there may improve tissue oxygenation. A study has actually been made, where Crohn's disease patients got better after spending 1-3 weeks at the Dead Sea…!

And if – despite the healthy food, amazing weather and spending time at the Dead Sea – you do get sick during your trip, you don't need to worry. Health care in hospitals and clinics is of high standards, and hospital and pharmacy personnel are helpful and usually speak English.

IBD shouldn't stand in the way of travelling, and definitely not in the way of travelling in Israel. Besides, it's hard to even remember that you're chronically ill when you float in the Dead Sea, lay at the beach in Tel Aviv or ride beautiful Arabian horses across the Judean Mountains!

> **“ IBD shouldn't stand in the way of travelling (...) it's hard to even remember that you're chronically ill when you float in the Dead Sea, lay at the beach in Tel Aviv or ride beautiful Arabian horses across the Judean Mountains”**

Olives at a market in Jerusalem

FACTS: ISRAEL WITH IBD

When to go?

If you're in an acute phase of IBD, summer (June to September) might not be the right time to go because of the heat. You will be adding up to the risk of dehydration. My advice: go in the spring when it's not yet scorching hot and the nature is astonishingly beautiful.

Getting there

Many airlines fly to Israel from all over Europe. The flag carrier of Israel, El Al, is known as the world's safest airline, however be aware of security interviews and checks that might take a while. I suggest you use the bathroom before hitting the queue.

Shabbat

Keep in mind that the week runs differently in Israel than in Europe. Shabbat starts at sunset on Friday and lasts until sunset on Saturday. During this time all public offices and especially in religious neighbourhoods most private businesses and restaurants are closed. Public transport doesn't operate like on weekdays and some streets may be closed. Hospitals work in a Shabbat way; the emergency room is open and there's always a specialist doctor working. Also, at least one pharmacy will be open in every city (you'll find the information on the internet or your hotel desk).

Medical Emergencies

For medical emergencies, call 101 from any phone.

Israeli IBD Association

http://www.ccfi.co.il/

The website is in Hebrew, but I'm sure they can help you with your concerns if you write to them in English at info@ccfi.co.il.

Promoting European co-operation on gastroenterology

Interview with Professor Rolf Hultcrantz, President of the United European Gastroenterology Federation

Rolf Hultcrantz is professor of Gastroenterology and Hepatology at the Karolinska Institute, a medical university in Stockholm, Sweden. In 1999 he was elected president of the Swedish Society of Gastroenterology where he first became involved in international affairs but his "European career" truly took off when he started working for the Association of National European and Mediterranean Societies of Gastroenterology,a founding member of the United European Gastroenterology Federation (UEGF), which is the federation organising the United European Gastroenterology Week (UEGW) meetings. Since 2007 he is the president of the UEGF.

What were the main objectives for setting up a United Gastroenterology Federation in Europe?

More than 20 years ago a number of medical associations started to organise scientific meetings across Europe. In order to give these meetings more weight the seven founding members of UEGF thought it would be more useful to organise one major annual meeting (UEGW) instead of each association organising its own event. This arrangement carried on for several years until 2004 when it was decided – in order to be better organised - that UEGF should take the sole responsibility for organising the UEGW. This resulted in the creation of the Scientific Committee amongst others and gave UEGF more influence on cash flow allowing it to use some of the revenues on other activities such as research, education and public affairs.

Throughout the years UEGF has become a major platform for the exchange of knowledge and expertise between medical scientists and clinicians internationally. We organise and support continuing medical education by providing courses for physicians and nurses and we also inform political decision makers as well as the public on current trends and findings within gastroenterology.

UEGF represents the medical profession that is working for the benefit of patients. How do you ensure that patients' voices are heard within your organisation?

We strongly believe in the coordination of activities across Europe in order to treat the various diseases of the digestive tract. Patients benefit greatly from these collaborations, resulting in a steady improvement of diagnosis, therapy and disease management. Patients' organisations are important partners for us and at the European level we seek to join forces with various patients' groups such as EFCCA but also other organisations representing liver patients, cancer patients etc.

Since 2009 the UEGF Public Affairs Committee organises a patient day during the annual UEGW. It works in close cooperation with a local patient organization to develop a programme with the latest news on a particular condition. Coffee breaks and individual seminars make this event the ideal forum for discussion among patients and world-renowned experts. This year's patient day will be on alcohol and gastrointestinal disorders and we will be cooperating with local Swedish patients' associations.

Gastroenterology is a huge field. UEGF represents over 8 disease groups. What place is IBD taking amongst them?

IBD is a very prominent disorder amongst our disease groups. In many countries the prevalence is 0.5 to 1 %. So this is a major patient group and a great part of our research and educational activities are related to IBD. To put it into a day to day context I'd say a general gastroenterologist spends around 30-40 % of his working time on IBD related disorders.

UEGW is one of your core activities. What are you planning for this year's meeting in Stockholm?

UEGW 2011 will feature the latest advances in clinical management, cutting-edge translational and basic science, and the best original research in GI and liver disease.

Our popular clinical symposia will be even more interactive with dedicated key pad voting, debates, tandem talks, case-based management sessions and questioning through text messaging. Particular highlights will include modern personalised medicine, live endoscopy, inflammatory bowel disease, GI and liver oncology, viral hepatitis, GORD, nutrition, obesity, and a Cochrane Collaboration symposium.

The Postgraduate Course will feature a day of IBD management for physicians and surgeons, coeliac disease, functional bowel disease, a cutting edge liver course including management of acute liver problems, controversies in pancreatic disease, a 2-day endoscopy course including live endoscopy, and surgery in IBD, pancreatitis and hepatic metastases. Delegates can move freely between sessions.

We will continue our "Today's science; tomorrow's medicine" initiative, . In Stockholm, the theme will be "The role of gut bacteria in chronic GI diseases". We will also continue our increasingly popular basic science workshops featuring interactive discussion of rapidly advancing fields.

Finally, we will continue to promote and improve facilities for presenting our best new research. We will continue to improve oral free paper sessions with more time for discussion and a "workshop" atmosphere. Posters will have more room, a new format to improve reading and presentation, and increased interactive opportunities with invited Faculty.

How do you promote research and education?

For the time being research is mainly promoted during our annual meeting. We also encourage basic research through our UEGF Teaching Activity on Basic Science, which intents to create a platform for personal and scientific exchange between young investigators and distinguished representatives from established European research institutions.

As concerns our educational activities the UEGF Education Committee has established several successful programme formats of its own, which focus on varying subspecialties from both scientific and clinical perspectives.

Recently we have also started an e-learning tool called OLGa (On-line Learning in Gastroenterology), which delivers up-to-date educational material in the field of gastroenterology created for gastroenterology specialists across Europe and beyond. OLGa allows the learner to browse through the available learning resources and search for interesting material.

For more information please visit our website: www.uegf.org

As a European Federation how do you work on a political level to influence EU policy?

Close contact with politicians and opinion leaders in Brussels is vital in order to put the patients' needs on top of the European policy agenda. To enforce these endeavours, we have entered into active networking with EU decision makers by enlisting a professional public affairs agency in Brussels.

Last year we have been successful in getting through a written declaration to raise the awareness for Colorectal Cancer among EU officials and to fight against this fatal disease in Europe. A majority of Members of the European Parliament adopted this declaration urging the Member States and the European Commission to reinforce primary prevention and screening for colorectal cancer in all EU Member States. The Written Declaration calls on the European Commission and all 27 EU Member States to support lifestyle awareness campaigns, introduce nationwide colorectal cancer screening, and encourage best screening practice.

What do you see as a main challenge in your work?

Besides steadily improving research and education in order to improve patient care, I believe that we still have some organisational details we need to work on in order to get a more unified organisation in Europe. Another challenge lies in communicating better with patients' organisations in order both to support patients but also to reach common goals in health care. We need to improve our methods to get in contact with politicians because gastroenterology is still a rather unknown field despite the fact that the diseases are very common.

Are you free enough?

News from the European disability forum

Right now, the European Disability Forum campaigns about Freedom of movement in Europe. The European Union's Internal Market seeks to guarantee the free movement of persons, goods, services and capital within the EU's 27 Member States. Three of these freedoms are essential parts of the EDF campaign in 2011: free movement of persons, goods and services.

However persons with disabilities cannot yet fully enjoy their Freedom of movement. They do not have the same opportunities as persons without disabilities: they face barriers when studying, trying to take up a job outside their country, travelling abroad, purchasing goods and services or simply accessing information.

This is why the European Disability Forum is campaigning for Freedom of movement.

The first question we are asking to ourselves is about the real impact of those obstacles on the rights of persons with disabilities. Right now, we are assessing what are the real obstacles to the freedoms of movement across Europe and how they are impacting on people's lives on a daily basis. We are meeting experts and exchanging analyses in a soon-to-be-released-publication: The Freedom Guide.

Through this analysis, the European Disability movement wants to bring relevant solution to set up 2 legal tools that the European Commission might propose in the coming years.

1. The Adoption of a strong European Accessibility Act
2. The Adoption of a European Mobility Card

In addition, we are suggesting a series of additional solutions to the barriers to freedom of movement, such as exportability of disability benefits and social security.

Support of the disability movement:
The engagement of our supporters and activists is a very important ingredient of the campaign. Actions, undertaken by them at national level cover essential areas of lobbying and their competent support helps EDF elaborate adequate policy instruments:

Elaboration and adoption of the Position Paper and the Shadow Act of the European Accessibility Act,

Raising awareness of our demands and call for action by meeting the responsible government officials;

Consultation on the examples of barriers and best practices and existing useful documentation for the Freedom Guide;

Lobbing and campaigning to ensure the Mobility Card is adopted.

More info and toolkit available on EDF website. Maria Nyman | +32 2 286 51 84 | maria.nyman@edf-feph.org

IBD Research Foundation

We were very happy to receive a very substantial donation of €8500 recently from the Luxembourg association (ALMC). Earlier this year we received a donation of approximately € 18.000 from the Swiss association (SMCCV) on the occasion of its 25th anniversary. Donations such as these are crucial in order to continue and expand our efforts in stimulating IBD research.

We were very pleased to be invited by EFCCA during its general assembly in Copenhagen. It provided us the opportunity to inform the EFCCA delegates about the achievements of the foundation so far. What's more, it was an excellent opportunity to discuss our plans for the future. There was a general sense of approval for our initiatives, especially from the associations which do not have their own structure for funding research. One suggestion which came from the floor, was to ask the associations to reconfirm their support for the foundation. After all, before the foundation was established, the associations were asked whether they would support a European IBD Research Foundation. Since it has actually been established, this request for support has not yet been reconfirmed. The benefit of such a formal declaration of support, would be that it may result in a stronger sense of commitment to help the foundation raise funds.

Following the EFCCA general assembly, there have been a few changes in the foundation supervisory board. Marco Greco, Dusan Baraga and Iva Savanovic left the supervisory board, while Marika Armilo joined the supervisory board. The management board highly appreciates the work of those who left the supervisory board and welcomes Marika.

At this time we are near the deadline for submitting applications for our 2011 Grant program. When we launched this program, we requested the EFCCA delegates to help advertise our program to researchers in their country. Hopefully this helped to provide researchers in each European country the opportunity to participate in our grant program. Obviously at this time we are very excited to receive the applications and to continue our procedure with the assessment and peer review.

Shortly we will be investigating additional ways to raise funds, for example by organizing charity events throughout Europe. This could be a sports event or a music event for example. However, this can only be successful as a joint effort with the local patients' association; a perfect example of 'United we stand'.

Donations

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

ABN AMRO Bank the Netherlands
Account number: 97.46.86.158
IBAN: NL37ABNA0974686158
BIC: ABNANL2A

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Mesalazine in the treatment of IBD: in the biological era is it still a therapeutic option?

Ambrogio Orlando, Sara Renna and Mario Cottone
Biomedical Department of Internal Medicine and Specialization (Di.Bi.M.I.S.), A.O. Hospital Riuniti Villa Sofia-Cervello, Palermo, Italy

Introduction

In recent years many new treatments have been introduced for the management of inflammatory bowel disease (IBD) but a role is still played by old drugs such as 5-Aminosalacylicacid (5-ASA), especially in ulcerative colitis (UC). Sulfasalazine (SASP), which consists of 5-ASA and sulphapyridine joined together by a diazo bond, was the first aminosalicylate used for the treatment of IBD.

The efficacy of SASP was clear in the treatment of a mild to moderate active UC, but it resulted to be only marginally superior to placebo for the treatment of Crohn's disease (CD). Until now it has been considered an effective treatment for patients with peripheral rheumatic manifestations. The observation that 5-ASA was the active component of SASP and that sulphapyridine was responsible for more of the side effects of SASP has led to the development of new preparations of 5-ASA without sulphapyridine. In recent years, in order to improve the compliance of 5-ASA treatment, a new system of delivery has been introduce: the Multi Matrix System (MMX) technology, a high dose delayed release formulation of 5-ASA, that allows less frequent dosing compared with current 5-ASA formulations.

5-ASA in the treatment of ulcerative colitis

Induction of remission

In 2009, an analysis of different studies (meta-analysis) confirmed the effectiveness of 5-ASA in the treatment of UC. A dose-related efficacy of 5-ASA was observed. After this meta-analysis new studies were published, looking at the efficacy of different dosages and to the patient's adherence with medication. In a large study it was shown that a formulation of 5-ASA (Asacol) at the dose of 4.8 g daily is effective and safe as compared with the dose of 2.4 g daily. In another study the safety and efficacy of balsalazide was evaluated at the new twice-daily dosing regimen (3.3 g twice daily). At the end of the study a larger proportion of patients achieved clinical improvement in the balsalazide group compared with the placebo group.

In 2005 the first study compared the efficacy of MMX with topical 5-ASA in patients with left sided UC. In both groups a similar rate of clinical remission was achieved. Subsequently another study evaluated the safety and efficacy of three different doses of MMX (1.2 g, 2.4 g and 4.8 g) given once daily and no difference in the remission rate was observed between the three groups of patients. Later, other studies demonstrated the efficacy of MMX compared with placebo.

Maintaining of remission

In a recent meta-analysis the effectiveness of 5-ASA in the maintenance of remission in patients with UC was confirmed. A dose response trend was not observed. A comparison between the efficacy of the different 5-ASA formulations in maintaining remission was not performed.

Historically 5-ASA has been administered in divided doses; recently a study, focusing on patient compliance evaluated the efficacy and safety of once-daily dosing of 5-ASA compared with twice-daily dosing for maintaining clinical remission. After 6 and 12 months of treatment a difference rate of maintained clinical remission was not reported between the two groups.

Both regimens were well tolerate. Also the efficacy and safety of once daily administration of Pentasa was investigated in maintenance of remission, compared with the classic twice daily dosing regimen. At the end of the study a better efficacy of once daily dosing was reported. In addition, the adherence to therapy was significantly greater in the group given the once daily regimen, compared with twice daily groups and the rate of reported adverse events was not different between the 2 groups.

Two studies evaluated the efficacy of MMX in maintaining of remission in UC. In both studies no difference was found among the patients treated with MMX once daily and twice daily and Asacol twice daily.

Efficacy of topical 5-ASA

In UC the inflammatory process usually spreads proximally from the rectum to a variable extent around the colon, so administering the 5-ASA rectally offers the advantage of delivering the treatment directly to the site of maximal inflammation while potentially minimizing the frequency of systemic adverse effects.

The delivery formulations that are currently available for rectal administration include suppositories, foams, gels, and liquid enemas, according to disease extent. Patients with UC limited to the left colon may be particularly suitable for topical therapy but some recent evidence suggests that even those with an extensive disease may benefit from 5-ASA enemas.

Several studies compared the efficacy of rectal 5-ASA and placebo in UC showing superiority of topical 5-ASA to placebo. A meta-analysis demonstrated that although the dose is not important, the duration of treatment does matter with remission rate.
A more recent review on the topic 5-ASA showed that rectal 5-ASA was superior to placebo for inducing symptomatic, endoscopic and histological improvement or remission, and that rectal 5-ASA was superior to rectal corticosteroids for inducing symptomatic improvement and remission.

Rectal 5-ASA resulted to be not superior to oral 5-ASA for symptomatic improvement. No 5-ASA dose response relationship was observed.

A problem related to topical treatment is the patient's compliance. No consistent difference in efficacy was noted among the various rectal 5-ASA formulations, but comparative data are limited.

It was evaluated if combination therapy with oral and rectal 5-ASA was more effective than rectal or oral 5-ASA alone in distal UC. Studies evaluating the efficacy of combination treatment in active UC reported higher values of remission rates, compared with that of patients treated with oral or topical 5-ASA alone. It was also evaluated the efficacy of combination therapy with oral 5-ASA and topical beclomethasone dipropionate (BDP) showing that this combination therapy may be a safe and useful therapeutic approach in the treatment of UC not responsive to oral 5-ASA alone.

Finally it was evaluated the efficacy of combination therapy with topical 5-ASA and topical BDP, that seemed to be superior to single agent therapy.

Maintenance of remission by 5-ASA enemas in left-sided UC was the topic of a meta-analysis.

No difference was shown between oral and topical treatment. Thus, it can be concluded that topical 5-ASA formulations are effective not only for the treatment of acute UC but also for the maintenance of remission, although long term treatment may not be acceptable to many patients.

5-ASA in the treatment of Crohn's disease

Induction of remission

A meta-analysis evaluated the efficacy of 5-ASA in the treatment of CD. After 16 weeks of treatment 5-ASA resulted superior to placebo, but the clinical outcome of efficacy and the studies included in this analysis are debatable.

More than 10 years ago the efficacy of 5-ASA was compared with that of budesonide. After 8 and 16 weeks of treatment, clinical remission was observed more frequently with budesonide than with 5-ASA. Recently, the efficacy of 5-ASA was again compared with budesonide in patients CD.

After 8 weeks of treatment, budesonide resulted not statistically more effective than 5-ASA. However the results of this study are debatable.

In conclusion, a recent meta-analysis showed that there was a trend towards a benefit with SASP over placebo but no definite benefit of 5-ASA over placebo. Thus the role of 5-ASA in inducing remission in active CD remains uncertain.

According to the European Crohn's and Colitis Organization (ECCO) guidelines, the benefit of 5-ASA is considered limited for the treatment of CD, but SASP is considered modestly effective for mildly active colonic disease.

Maintaining of remission

There has been much debate regarding the effectiveness of 5-ASA maintenance therapy in CD. Early studies failed to demonstrate the efficacy of SASP. Subsequently, many studies compared the new 5-ASA formulations with placebo to prevent a clinical and endoscopic recurrence in patients with a surgically or medically induced remission.

In a meta-analysis therapy with 5-ASA significantly reduced the risk of symptomatic relapse, but the risk difference was significant in the postsurgical setting and not in the medical setting. More recently, another meta-analysis concluded that there was no evidence to suggest that 5-ASA preparations are superior to placebo for the maintenance of medically induced remission in patients with CD.

In conclusion, a meta-analysis published this year concluded that neither SASP nor 5-ASA were effective in preventing quiescent CD relapse.

Prevention of post-operative recurrence

The efficacy of 5-ASA in preventing postoperative recurrence in CD is controversial. A meta-analysis showed a modest but significant reduction of recurrence rate in the post-operative setting in patients treated with 5-ASA compared with placebo-treated patients.

In a more recent meta-analysis, 5-ASA was confirmed to be associated with a significantly reduced risk of clinical recurrence and severe endoscopic recurrence when compared with placebo.

Adverse events of 5-ASA

Although SASP and rarely 5-ASA may cause hypersensitivity reactions, ranging from fever and rash to more generalized allergic reactions, the long-term treatment with 5-ASA is generally well tolerated, but some severe side effects were observed and must be considered in maintenance treatment.

A number of cases of 5-ASA induced pancreatitis, serious skin reactions, hepatitis, blood dyscrasias and nephrotoxicity have indeed been reported in patients with IBD. SASP can also cause reversible abnormalities of sperm number and morphology that can be related to impaired male fertility. In rare instances, 5-ASA may also cause worsening of abdominal symptoms.

Safety of patients treated with MMX was evaluate in four published studies. Only two patients had serious adverse events, treatment related (pancreatitis). The most common treatment related adverse events were headache, flatulence and abdominal pain. There was no evidence of a dose relationship with MMX for any tolerability parameters.

Despite the reassuring results of all RCTs on side effects, in recent years attention has been focused on the renal effects of 5-ASA. In 2009, a study concluded that a significant dose and treatment duration dependant decline in renal function exists in patients treated with 5ASA. So, because 5-ASA is widely used for long-term maintenance therapy in patients with IBD, it will be recommended to periodically monitor serum urea and creatinine levels in patients receiving any 5-ASA containing preparation.

Colorectal cancer chemo prevention of 5-ASA

Patients with IBD have long been reported to have an increased risk for colorectal cancer (CRC) but the quantification of the risk in this specific population varies widely in different studies.

Risk factors include extent of disease, age at onset, severity and time course of inflammation, a positive family history. So cancer prevention has become an increasingly important consideration in IBD.

A candidate chemopreventive drug for IBD patients is 5-ASA. Several retrospective studies have suggested that the long term use of 5-ASA in IBD patients may significantly reduce the risk of development of CRC.

In a study the most significant finding was the strong protective effect association of regular 5-ASA therapy, reducing cancer risk by 75 %.
A recent meta-analysis reported a protective association between 5-ASA use and CRC. It has also been shown that the compliance to therapy can influence the risk of CRC.

It is not clear if one 5-ASA therapy is better than another for the prevention of CRC and what is the optimal 5-ASA dose for chemoprevention.

No study evaluates whether a patient receiving another treatment (likewise azathioprine) would benefit from additional 5-ASA in term of chemoprevention.

Conclusions

In the biologic era, 5-ASA is up to now the treatment of choice in the induction and maintenance of remission in mild to moderate UC. SASP, despite similar efficacy, is hampered by more side effects, but in presence of peripheral arthropathies it remains a good treatment choice.

The new delayed release MMX formulation seems to be promising in reducing compliance problems.

Regarding CD treatment, in a mild active ileocecal disease 5-ASA cannot be recommended because of controversial evidence. In a mild colonic disease SASP could be effective. The maintenance of remission in this setting is debatable but SASP seems the better choice.

The possible chemopreventive role of long term treatment with 5-ASA strengthens the indication to the long term use of 5-ASA.