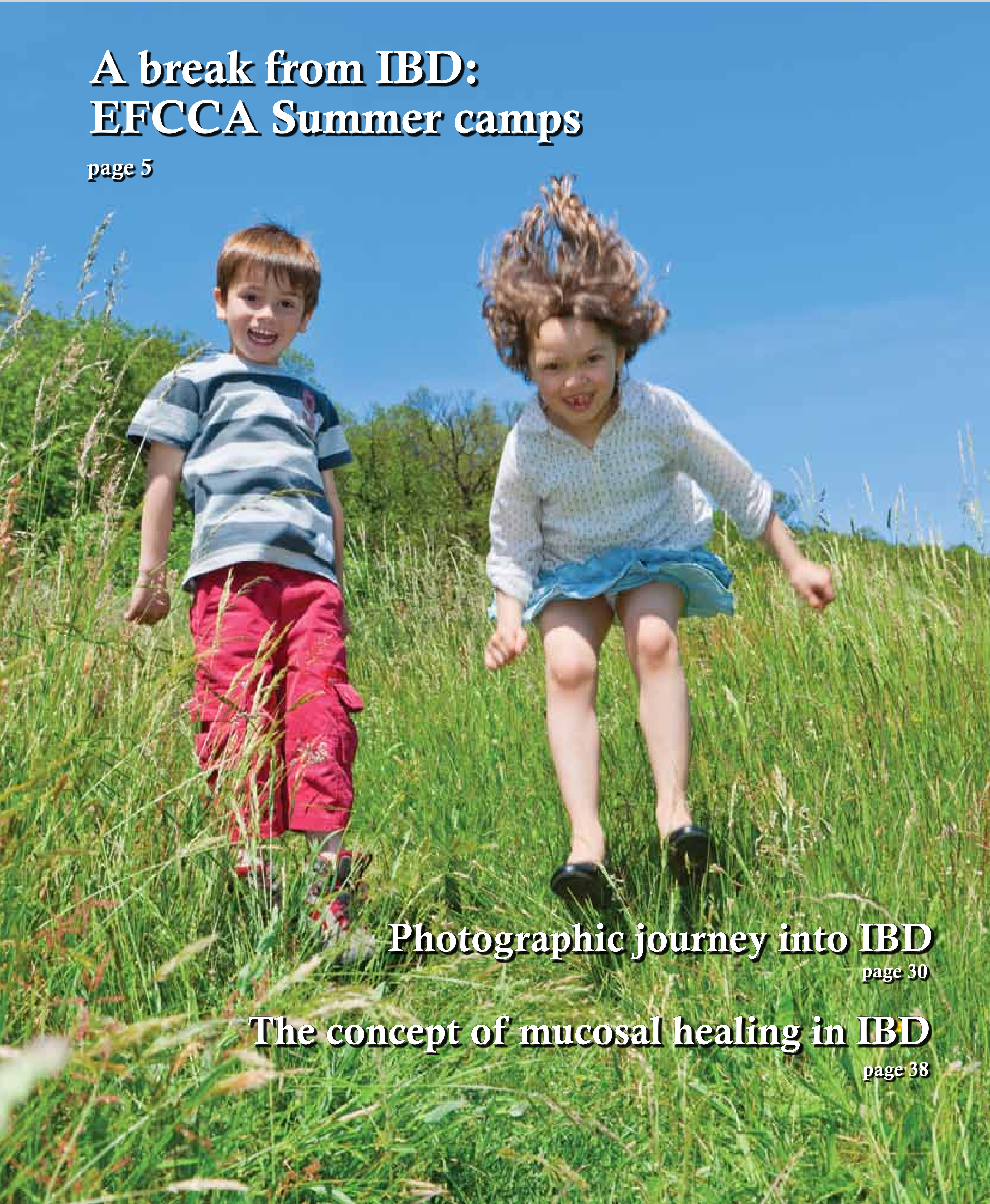
EFCCA MAGAZINE

European Federation of Crohn's and Ulcerative Colitis Associations | October 2013



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New Zealand- Crohn's and Colitis
www. crohnsandcolitis.org.nz/

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EDITOR'S EYE

Investing in the future

When I look back at our initial discussions about organising activities for youngster with IBD in a fun and safe environment I can tell that only a few delegates believed in the possibility that only a few years later we would be involved in the organisation of several summer camps not only across Europe but extending beyond, giving more than 120 youngster the opportunity to meet, relax, learn and have fun. But EFCCA has realized it.

"A break from IBD" is the perfect title for describing what our EFCCA summer camps can offer to youngsters and I am happy to say that the hard work we have invested into organising this and the commitment our national members have shown in sharing best practises and learning from each other to bring the idea of the summer camps a step forward, has allowed many youngsters to better deal with their disease and to for once put a smile on their face.

Reading the accounts from some of the summer camps I can feel the joy and inspiration they are able to give to people. I myself have participated in several of these camps in the previous years and know only too well the kind of friendships that can grow from these meetings and the hope they can provide. Even if the summer camps take place only for a couple of days, the value and benefit they can offer to our youngsters is priceless and will last forever!

This year our youngsters had another reason to celebrate: on 18 July the EFCCA Youth Group Meeting gathered over 30 participants from 19 different European counties to celebrate its tenth anniversary since its official founding but also to look at common goals for the future.

We have come a long way from the early days. From the first proposal made at the EFCCA Youth Meeting in Amsterdam in 1999, through the work done in London 2000 and Stockholm 2001, a small group of people kept on believing in the importance of formalising the creation of a EFCCA Youth Group. We had to wait till the EFCCA GA 2003 in Berlin for the approval of the first "Joint Committee", in a few months re-named "EYG – EFCCA YOUTH GROUP", where for the first time working on how the priorities of youngsters could be better represented within EFCCA. It is not a mystery that I have played a major role in the establishment of the EFCCA Youth Group and I have to say it has been an exciting and rewarding process.

In particular, I'd like to underline that in 2003 within the EFCCA group there was some resistance to the idea of such a big change. We asked then to believe in this vision, and now we can say it was a winning one. Similarly today we are asking to believe in another vision of the future, with the same faith in the possibility of succeeding.

I am very happy to see that the new leaders of the EFCCA Youth Group are taking forward the ideals and enthusiasm of the “founding fathers” in their work and that they are doing their best to give young patients a voice in Europe.

I strongly believe that in investing in our young people is the best way to ensure that our common goals and work will continue to improve the life and give hope to people living with IBD. An organization that invests as we do in its future is a strong one.

But it is not only our youngsters that have reason to celebrate this year. Our efforts with the European Institutions to advocate for better rights for people living with IBD are bearing fruits. We had an interesting exchange with policy makers and representatives of the medical community at the panel discussion organised at the European Parliament on the occasion of the World IBD Day.

This discussion together with a public consultation that we have carried out amongst our members, representatives of health care professionals and other interested stakeholders will feed into the conference “From Citizen to IBDizen: a to do list for achieving full citizenship worldwide” that will take place in the European Parliament this month on 17 October 2013.

This conference will be a major step for recognising the equal rights of people living with IBD in all aspects of their lives, be it at work, at school, at university or in policy discussions. Through this activity we will continue our commitment to put the voice of people living with IBD on the political agenda of EU policy makers.

I am pleased to say that this conference has also brought us closer with our partners the European Crohn’s and Colitis Organisation (ECCO), the United European Gastroenterology Federation (UEGF) and the NECCO (IBD nurses). This fact together with an increased support from policy makers such as for example the Vice President of the European Parliament who will open the meeting, show us that we are going in the right direction.

Finally I would like to thank our members for their active involvement in our World IBD Day campaign. When we started getting involved with the organisation of World IBD Day three years ago I never imagined how far we would take off in such a short time.

Reading about the amazing range of activities that our members have organised around the globe on the occasion of World IBD Day, leaves me very inspired indeed. From organising a giant serpent made out of toilet roles in the Czech Republic to symbolize the suffering of people with IBD to the participation in a high profile gastronomy event on IBD and nutrition in Argentina once again confirms the philosophy of EFCCA…UNITED WE STAND!

Marco Greco, EFCCA chairman

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A break from IBD

EFCCA Summer Camps

Interview with Chayim Bell, co-organiser of the EFCCA summer camps

How was the idea for the EFCCA summer camp born?

Back in 2008 during our EFCCA Youth Group meeting the question on “ How to have fun for a couple of days and forget about your IBD? “ was being discussed and finally led us to the idea of organizing summer camps that would provide youngsters who have IBD with an opportunity to have a fun experience in a supportive, friendly and safe environment allowing them thus to have a “break from IBD”.

> *“The summer camps are different from ordinary holidays because they allow youngster to meet new people and participate in sports and leisure events without worrying about their IBD. They know that if they have a problem or if they can’t participate in any particular activity they don’t need to explain to the others why and no-one will think that they are acting strangely”*

Myself and Marco Greco, who was then also member of the EFCCA Youth Group, discussed these ideas with the EFCCA Board and in 2008 we went on a fact finding mission to the US where the Crohn’s and Colitis Foundation of America (CCFA) had been organizing successful camps for children with IBD for several years. There we had the chance to talk in detail to volunteers, organisers, participants and camp directors as well as participate in one of these events. We came back to Europe with a bag of ideas and finally managed to get some sponsorship from several pharmaceutical companies and developed a three year plan for organising the first European summer camps for youngsters with IBD.

When did the first EFCCA summer camp take place?

The first EFCCA summer camp took place in August 2010 in Appledorn, the Netherlands and was organized by a committee of eight EFCCA Youth Group members. Over 25 youngster from all over Europe came to this camp, where they spend a relaxing four days with other people, participating in activities, having fun but also following more targeted workshops on IBD and a “question and answer “ session with doctors allowing them to talk in a relaxed way about their IBD and concerns they were carrying around with them.

The feedback and responses to the camp have been overwhelming. Great friendships were born, good contacts were made and three years later participants are still regularly in touch with each other.

Who can participate in these camps?

The summer camps are open to youngster with IBD who need to be registered through the national associations. There is a small participation fee and flight costs need to be covered either by the individual or in most cases this is done through the association.

The camp language is usually English, this has not been a problem so far and participants are keen to help each other out.

What are the difficulties you have encountered so far?

The most difficult part in organizing the summer camps has been about the legal issues involved when working with under age people as many special precautions have to be taken care of in terms of legal insurances etc.. This is a lengthy and bureaucratic process, for this reason our first camps were aimed at youngster aged 18-30. However we are now looking at the options of also organizing camps for under age people and in some of the countries this has already taken place, such as for example in Israel and Poland.

What are the plans for the future?

In 2012 EFCCA decided to go a step forward and increase the numbers of youngsters participating in such summer camps. EFCCA linked up with some national associations that organize similar camps and by uniting our efforts we had over 120 youngsters in Europe participating in four summer camps in Poland, France, Portugal and Spain.

We also organized a training workshop in Brussels last year inviting interested national associations to join and learn how to effectively organise a summer camp in their own country. Delegates to the workshop talked about difficulties that might arise and discussed new ideas for camp activities including educational talks, leisure programmes etc. Previous camp organisers also participated in the workshop to share their experiences and provide solutions to some of the common problems that have been encountered during such camps.

This year, in 2013, we have extended activities to the UK, Israel and Poland. For next year we are thinking of providing an "EFCCA" specific session for the camps such as perhaps inviting a doctor or politician to talk about ""European topics" i.e. answering questions on studying abroad, working abroad etc. as this has come up in previous camps. Another idea that is going around is to provide cooking courses for IBD friendly food.

If you would like to organise your own summer camp, get involved as a volunteer or sponsor please get in contact with Chayim Bell at: secretariat@efcca.org

Participants of the first EFCCA summer camp in the Netherlands 2012

Spending the summer with “J-elita”

by Michal Pukowiec

Every year the Polish Association Supporting People with Inflammatory Bowel Disease “J-elita” organizes two summer camps for its members. They are always unforgettable, amazing and very special events. Let me take you on this beautiful journey.

The summer camp for children in the village of Stegna was an unexpected but most welcome success. It was the first time that J-elita chose the Baltic Resort for its camp and it was a surprise for most of our members. The well-prepared resort is located in a pine forest, near the Baltic Sea and the fresh air, the hum of sea waves and the rustle of trees really soothed our minds. However the playground, the volleyball field, the tennis court and the wonderful pool with heated water were all full of rumble and noises during free time.

The children were always in the limelight. Michal and Magda, our counselors, kept them busy and happy all the time. Physical activities, like playing tag or “water volley” ball in the swimming pool, enabled children to release excess energy with good competition and laughter.

We saw that children’s imagination have no limits and great art works were created from salt dough, beach sand or bubble foil. The resemblance of sea animals from the project “underwater world” was also impressive. Clarity of vision and a deepness of realism could be easily found in the children’s creations. To cope with emotional problems the young ones listened to fairy tales with a method called “fairy tale therapy”, which provides them with an imaginary ground to test real life problems. Many of them showed amazing empathy and intelligence.

For trip lovers there was also the possibility to visit the Teutonic Castle in Malbork and the Old Town in Gdansk. In the afternoon all members partied and drank an alcohol free drink called Mojito.

Sunbathing on the beach, activities full of laughter and mutual friendliness contributed to the great atmosphere in the camp and nobody wanted it to end.

Another wonderful place where our second summer camp took place is the charming village of Kluszkowce. A hotel, situated in the Gorce and Pieniny Mountains has a magnificent view of the Czorsztyn Reservoir. Such beautiful natural surroundings was an ideal spot for a holiday including parents and children.

During the first day participants gathered by a campfire, where they find out about organizational issues and could meet medical staff. The following days were full of activities that usually started after breakfast. Excursions included hikes to the Wdzar and Trzy Korony (Three Crowns) peaks, tours to Niedzica Castle and Bukowina Thermal Swimming Pools. Every possible event or point of interest was checked out by our mobile and eager members, like for example the Harvest Home in the village and even neighboring Slovakia was explored by bike by some participants and of course we didn't forget about the famous Dunajec Rafting. Our medical staff was also busy providing information and advice and a doctor gave a lecture on rare methods for managing IBD.

Our psychologist, Dorota, conducted daily activities for children and youth and was available for everyone to help with her skills and experience.

To properly end that great camp, a party with the Highlander Folk Band was organised and laughter was heard from dusk to dawn. Everybody was happy to be there and asked when would by the next camp.

A place where children can just be kids

by Dorit Shomron

Since 2011, CCFI, the Israel Foundation for Crohn's and Colitis has been arranging for 60 children with IBD to attend a week of summer camp at the Jordan River Village.

This August, when children with IBD were at the village we had the pleasure of hosting Chayim Bell, EFCCA's secretary, at the association's office in Tel Aviv and at Jordan River Village (JRV) which is located high above the Sea of Galilee within sight of mount Tabor.

Jordan River Village is part of the SeriousFun Children's Network founded by Paul Newman, the great American actor. The goal and vision is to create

opportunities for children to reach beyond serious illness and discover joy, confidence and new world possibilities, always free of charge. Today, 16 villages operate around the world; among them Jordan RiverVillage that opened its doors in 2011.

Located in the beautiful scenery of the Galilee in the Northern part of Israel, the village is situated on 68 acres which are permanently leased from the State. JRV's mission statement is to be the place in the region where seriously ill children- can just be kids.

The aim is to enrich the lives of children from Jewish, Muslim and Christian backgrounds (aged 9-18) suffering from serious and life-threatening conditions and provide a free, fun-filled and medically safe camping experience. Usually a child stays at the village for 4-7 days. In Israel, each patient association is asked to contribute 25% to support 'its' children's summer experience.The associations are required not to raise funds from parents.

In August the village inaugurated a new spacious and beautiful swimming pool especially suited for the disabled and a specialized in-door gymnasium for basketball, games and sports. These facilities are additions to the existing computer and reading retreat center, the petting zoo, the arts and crafts center, the adventure park, (with a zip-line accessible to wheel chairs) the archery center and the camping grounds.

The medical center is located at the heart of the village. The center is fully equipped to handle any medical emergency. In addition to the permanent medical staff, there are medical professionals who specialize in the particular condition that the campers suffer from. During IBD week for example, if a camper is with Stoma, there will be a volunteer Stoma Nurse on premise the entire time the child is at the village. In the spirit of JRV, even the medical center is a pleasant and fun place to be at.

In addition to hosting children, the village also hosts families in separate occasions. Mr.Hagai Rosenbaum, the CEO, is quoted to say: "It is my wish that JRV will become a central fun place for children from all over the Middle East where they can regain some of their childhood back and celebrate life".

Mr. Chayim Bell summoned his impression of the visit by saying: "Jordan River Village is one of the most advance and impressive camps I have seen. The state-of-the art facilities, the clean and tidy up-keeping, the work procedures, especially from medical and safety perspectives are highly professional. The village is inclusiveness embracing children with every medical challenge and from any ethnic background"

By working together, CCFI and JRV celebrate Paul Newman's conviction in the power of taking fun seriously despite one's physical consequence. The smiling and joyful children we have met confirm that serious health setbacks should not ever be an obstacle for a child to celebrate life.

More info:
CCFI – www.ccfi.org.il
JRV- http://www.jrv.org.il/eng_index.htm

Organising the first summer camp in Switzerland

by Isabelle Prynn

All started during a discussion between Bruno, Bianca and some other SMCCV (Swiss IBD association) members in autumn 2012. Back then we only had a rough idea about the organization of the first Swiss weekend for young people with IBD. Having the idea was easy, but the organisation was much more time demanding than we initially thought. We contacted several business hotels in order to find the right place and thought about an adequate program that would most help people with IBD.

Fortunately we found the National Sport Centre in Magglingen and they were really happy to welcome us. Next step was to find guest speakers, then we sent out invitations and by the end of August we had 16 registrations for the camp.

The first day of the camp, on Friday evening we had dinner together and got to know each other with some funny ice breaker games. After the official part was over we organised some group games and first conversations were made.

On Saturday morning we played a sport called: „Frisbee-golf". That was a lot of fun and laughing. Right after sports we had the pleasure of welcoming Dr. Biedermann from University Hospital Zürich who gave us a very interesting presentation about IBD in general and latest news in research. After lunch we formed discussion groups on two topics: "family and family foundation" and "school / studies / work with IBD". In the afternoon we had a guided tour of the bilingual city of Biel. On the last day of the camp, on Sunday morning, we had a session with a therapist specialized in mental training and hypnosis, learning how to cope with stress and pain and how to control it. At lunch time we had the honour of having Bruno Raffa over, the president of the SMCCV, who gave us the latest information about the association.

The aim of this camp was to enable young people with IBD to get together for more than just one day and to have the opportunity of discussing about different issues that young people with IBD have to cope with in their everyday life and learn from each other. Everybody really enjoyed the weekend and we had lot of fun together. To sum up we can say in one word – the weekend was just „fantastic".

Me and IBD: Facing the Future

by Elliot James

As some of you may be aware Crohn's and Colitis UK's theme for 2013 is focusing on youngster under the campaign: Me and IBD: Facing the Future – School and Beyond. As a result a series of pilot weekends were created and are being held during 2013 across the UK.

For 14 to 17 year olds we held a Summer Camp in an Activity Centre in Northamptonshire. Thanks to a bursary given to us by the pharmaceutical Sanofi we have also developed a number of conference styled residential weekends aimed at 18 to 25 year olds.

Summer camp

On Friday 26th until Sunday the 28th July eight young people from around the UK came to an Adventure Centre in Northamptonshire to join us for a full and fun packed weekend. They were supported by staff from the Member Involvement and Volunteer Team along with three very kind volunteers, two of whom sit on our youth panel and one consultant gastroenterologist from Alder Hay Children's hospital. The aim was simple, to provide young people between 14 and 17 with IBD, the opportunity to meet each other, to share experiences and to have as much fun as possible in the process.

Both the young people and even some of the adult volunteers risked life and limb abseiling, kayaking, mountain biking, and going over assault courses. There was also some time just to socialise with the odd kick about with a football and some volleyball, and even an impromptu hill rolling session.

Some of the more structured activities included team work and problem solving games. In the evenings there was a film night complete with popcorn and a camp fire that included games, a piñata, chocolate bananas and a sudden down pour of rain.

On Sunday we said goodbye and with numbers and emails exchanged, the young people returned home but not without the opportunity for some feedback, so here is some of what they had to say about the weekend: 'I was relaxed and had fun', 'I will see you next year', 'Everyone was friendly and made the weekend fun and relaxed' and even when asked what they would like to change about the event the response was encouraging with one attendee saying: 'An extra day maybe?'

Me & IBD Strategies for Living

The aim behind these initial weekends was to be able to provide a group of 18 to 25 year olds the opportunity to meet each other over a weekend and to share their experiences and views about IBD. We wanted to be able to empower and inform as well as support the attendees, so that they were able to put themselves before their condition and help them to find ways to take control, hence the title Me & IBD.

Youngsters at the Adventure Center

The first of these weekends was held in Liverpool in a venue in the historic Albert Docks, with 12 delegates attending, supported by Crohn's and Colitis UK staff and Volunteers. As well as a number of presentations given by the team from Crohn's and Colitis UK the attendees also took part in a group work project. The initial feedback from this event was very positive with statements such as: 'It was great to meet people in the same situation' , 'It's been a very informative weekend & it was good to meet others with IBD'.

And one participant expressed the feeling that they would like to see these being held more regularly saying: 'Great weekend - need them more often please!'

All of which is very useful in understanding that we are meeting the initial aims of the weekends. Other weekends were held in Edinburgh on the 31st of August followed by Chelmsford on the 28th of September, with both Cardiff and Derry being rescheduled for early in the New Year.

After a review and evaluation period we will aim to make both events regular Crohn's and Colitis UK activity, with plenty of scope to build on this year's experience and further develop this work.

Cycling for charity

From left to right: Daniel Sundstein, Andrea Broggi, Franco Marvulli, Salvo Leone and Daniel Laeremans

On 22 June 2013 the EFCCA Executive Board undertook an unusual board activity. From as early as 6.30 am, on a rather rainy Saturday morning, members of the board got ready to mount bikes and to participate in a charity race co-organised by the Swiss IBD association (SMCCV) and with the financial support of Abbvie.

The majority of the EFCCA Board members cycled 37, 5 km around the lake of Zug and some of our more courageous board members such as Salvo Leone, Daniel Sundstein and Andrea Broggi (EFCCA office) even braved the 67 km race, which started with a high climb up the Swiss Alps.

The PACE Race cycling event was staged for the seventh time. Tradition has it that on this charitable-sporting benefit tour people affected by various chronic illnesses, representatives of patients' organizations, doctors as well as employees of the two companies AbbVie and Abbott AG join together in riding different routes in Switzerland. The proceeds raised from the kilometers ridden all go to benefit the participating organizations. This year's entrants included the triathlete Karin Thürig, sports presenter Regula Späni and professional cyclist Franco Marvulli. A jovial Urs Hürlimann, health director, delivered the welcoming message from the Zug Governing Council and also wants to take part as a cyclist himself next year.

Around 500 patients from a total of 17 different Swiss patient organizations as well as 100 employees of AbbVie and Abbott AG took part in this year's benefit tour. Four routes starting from Baden, Lausanne, Rapperswil and Zug (a circuit around Lake Zug) ended in the town of Cham. People suffering from rheumatic diseases such as ankylosing spondylitis and rheumatoid arthritis, obesity, Parkinson's, kidney, Crohn's disease & ulcerative colitis as well as psoriasis also participated in the PACE Race.

Innovation that revolves around patients

Shire's mission

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

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

History and growth

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

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

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

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

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

To be as brave as the people we help.

Urs Hürlimann, welcomed the participants on behalf of the Zug Governing Council and Regula Späni, the former sports presenter on Swiss television, moderated the official part of the evening as slickly as ever. Appearing for the first time on the Baden circuit was the triathlete Karin Thürig: "I am very impressed by the stamina and motivation of the participants who have traveled to be here."

Professional cyclist Franco Marvulli, who joined the group on the longest and most demanding route from Rapperswil, said: "Congratulations to all participants! I once again have great respect for the effort that the patients show here in their spare time." Patrick Horber, general manager of AbbVie AG in Baar, was able to conclude proceedings by announcing the sum of money raised: in total more than 28,000 km were cycled, equating to a sum of 56,000 Swiss Francs. Horber said: "The event has become very popular in recent years. In order to be able to continue to guarantee personal exchanges between our employees and the patients, this year we deliberately introduced a quota on the number of participants."

EFCCA Executive Board Meeting

EFCCA Board members made use of the sponsored PACE Race event (see article on the left) to organise its second EFCCA Executive Board meeting in 2013. It took place a day before the race on Friday 21 June.

Amongst other things Board members discussed the organisation of the upcoming summer camps and the EFCCA Youth Group meeting in July in Germany. Other items on the agenda were the World IBD Day campaign and the related meeting planned for October at the European Parliament as well as the revision of the EFCCA statutes, which has been made available to EFCCA members through a wikipage. More information can be obtained by EFCCA members through the Members Only section of the EFCCA website.

EFCCA Executive Board and racing cyclist Franco Marvulli at the Pace Race finishing line

World IBD Campaign

From Citizen to IBDizen: a to do list for achieving full citizenship worldwide

Round table discussion a the European Parliament, 16 May 2013, from left to right:
MEP M. Panayotova, Prof. R. Stockbrugger (United European Gastroenterologists Federation) M. Greco, EFCCA chairman, MEP S. Cofferati and Prof. M. Vecchi (San Donato Policlinico Milano)

The first outcomes of the working groups held during our last EFCCA General Assembly clearly show that World IBD DAY is one of the most important and welcomed activity for our members.

Nearly 75% of participants highlighted the necessity of a stronger and more effective public awareness campaign, having a worldwide impact and offering the opportunity of meeting sister organisations and members in a powerful event able to show EFCCA's lobbying, networking, and global approach towards a more and more effective governance on how to fight IBD and overcome barriers and policy makers' silence on prejudice and discrimination against people with IBD.

As a response to this and following up on previous actions in the European Parliament in 2012, a roundtable discussion between policy makers and representatives from the medical and the patient community was organized in the European Parliament on 16 May this year. This discussion was the launch to a wider conference at the European Parliament on 17 October 2013 under the umbrella of the 2013 European Year of Citizens.

The October conference on ”From Citizen to IBDizen: a to do list for achieving full citizenship worldwide” has a strong focus on health care, employment and education and research and is the result of the bottom up consultations which EFCCA has conducted in recent months.

From July onwards an interactive tool has been made available for all stakeholders (EFCCA members, Health Care Professionals and European policy makers and institutions) with the purpose of further elaborating the above mentioned themes for people with IBD.

The Conference is hosted by MEP Cofferati (S&D) in the European Parliament and will be opened by the Vice President of the European Parliament. The event itself has been co-organised with the active involvement of physicians and health care practitioners from ECCO and UEGF and is also gathering increased support from EU policy makers.

Celebrating ten years of EFCCA Youth Group

by Daniel Sundstein, EYG leader


Arriving in Rome for the youth group meeting 2004

In 1998 the German Crohn's and Ulcerative Colitis Association (DCCV) invited active youngsters from a variety of countries for a meeting in the city of Erlangen. The first "International Youth Meeting" was held. During the discussions, the group exchanged ideas and experiences of activities and services for youngsters. Everyone was eager to speak and – perhaps even better – eager to learn! During "free time" discussions continued but on a more personal level.

The Dutch delegates were in a wonderful mood after the meeting and agreed to host the second International Youth Meeting in Amsterdam in 1999. In Amsterdam 'best practice' was again exchanged and during this meeting Marco Greco, a delegate from the Italian IBD association, came up with the idea of developing a European youngsters group. During the following youth group meetings these ideas became more and more concrete and the challenge was then to convince EFCCA that a "separate" youngsters group would fit perfectly well within the EFCCA structure.

It took a lot of discussions, meetings, bureaucracy and hard work before the actual EFCCA Youth Group (EYG) became a reality but in 2003 it finally happened! Definitely an important milestone for young people with IBD throughout Europe. Thanks

First youth group meeting in Berlin, 2003

Youth group delegates in Budapest,2006

to Marco for his commitment!

Among our achievements can be mentioned the Loekie Game, the Summer Camps and the exchange of activities and experiences across the national associations.

The Loekie Game was developed by the EFCCA Youth Group and is now translated into many European languages to help children get a better understanding of IBD. The Summer Camps also have been a positive development for youngsters (you can read more about them in this issue of the EFCCA Magazine). Most important of all the EFCCA Youth Group and the EFCCA Youth Meetings contribute to the development of national youth groups and national youth activities all over Europe.

The EYG has been an active part of EFCCA and in the past 10 years both EFCCA and EYG have changed. New delegates and countries have joined, there has been a change of leaders and a change of board members. But even so the eagerness and the passion of the volunteers and their belief in a better future for people with IBD has and will never change. I am proud to be part of this and want to thank all those people who have made the EYG such a huge success.


Ice breaker games at EYM Graz, Austria, 2007

Tenth EFCCA Youth Meeting Stuttgart, 2013

By Kata Daru

I was really looking forward to my second EFCCA Youth Meeting (EYM) in Stuttgart. Over the past year, I had learned so much from the other delegates and by working with the Youth Group, and of course, had made so many friends that I was sure this year was going to be as fruitful and as great as the previous meeting in Copenhagen. And what can I say? I was not disappointed at all – special thanks to DCCV for letting it happen.

The atmosphere was great right from the beginning: Steffi and Thomas made our arrivals easy and happy. I loved the sign on the car which said: “EYM Shuttle”. It was like reading a “Welcome Home” sign. And in a way, we were home. We were about to meet a bunch of other young people from 19 different countries with whom we have at least two things in common: IBD and the desire to fight for a better life despite the difficulties of the disease.

The first day was spent with arrivals, catching up with old friends, meeting newcomers, and for some of the delegates, it was the perfect time to finish their presentations or posters for the meeting. The evening began with Daniel’s and Steffi’s unofficial openings, continued with a great dinner, and of course, a lot of talking and fun. It was great to see all the known and new faces together, with sparkle and excitement in their eyes.

The next day started with the official opening of the EYM by Daniel Sundstein, the group leader, who gave a brief summary of the EYM and the EYG, then Chayim Bell, the former group leader talked about EFCCA and the Summer camps for the newcomers, and the hosts prepared some ice-breakers which were successful, since after that I could tell that even the new delegates found their places in the group. Then the hard work began. Some people might think that the youth meetings are just about fun and laughter, but trust me, they are not. At least, not all the time.

The main focus of this year's meeting was on "Sharing our goals" and "Social media". The workshop, entitled "Sharing our goals" was led by Victoria Cleary and Chayim Bell. They have done an amazing job and I am sure that all of us have gained new ideas and learned a lot from the discussions we had about our goals, what we are proud of in our national youth groups, the achievements and the difficulties the youth groups face in each country.

The other workshop, called "Social media", led by Claire Hunt and Margriet Gritter was also extremely helpful. We have discussed the advantages and disadvantages of social media, and also talked about what we have to be careful about regarding what to share and how to share on these platforms.

This year was the first time in EYM history that an enormous number of delegates wanted to become group members or participate in the work of the EYG as substitutes. It is a great feedback for the EYG that the work that has been done by them over the years is getting better and better and more and more people would like to take an active part in this great mission. The new - partly old EYG is: Daniel Sundstein (group leader), Sara Byrne, Claire Hunt, Margriet Gritter and Áslaug Eva Björnsdóttir. The substitutes are: Fergal Troy, Stefan Djakovic, Steffi Weber, Maksim Besic, Sofie Marton and Kata Daru.

The gala dinner was very special for many reasons. First of all, it was the 10th EYM. I think many years ago, the founders of the group might not have thought that soon there would be 31 delegates from 19 different countries, all united for the same cause. Thank you, "Founding fathers" for starting it. We promise not to disappoint you! Second of all, we had two wonderful guests, who got the orange ribbons this year: Hajnalka Szabó and Evelyn Schauer. Thank you for all your commitment, ladies! And of course, the fun, laughter and dancing, which

could not have happened without Thomas Leyhe, the greatest DJ of all times. Thank you, Thomas!

All in all: many people means many great ideas, a lot of experiences, and needless to say, many new friendships. I think I am far from being wrong if I say that all of us can only talk about this Youth Meeting in superlatives. I can't wait to see you all next year!

Workshop on social media

By Claire Hunt and and Margriet Gritter

At the EYM in Stuttgart we organized a workshop on social media. Our idea behind this was that social media is becoming more and more important in the life of youngsters, and very often when they search for information or contacts, they usually do this through using social media. We also thought that it was an easy and cheap way to spread your own information about Meet&Greets, new blogs on your websites and medical news.

The workshop started with some basic information about the different forms of social media and Claire talked about safety issues and the do's and don'ts of social media. Such as for example on how to use multimedia to enhance your work, how to network and grow, and how to provide helpful and entertaining information. The advice given was not to post too many items a day, but at the same time not abandoning the account/social network for long periods of time and of course to make sure not to sell products and never to provide personal information.

Our audience was quite a mixed group, some of the youngster had only a personal Facebook page so the basic information we provided was interesting for them. On the other hand we also had some youngsters who used Facebook for their youngsters group. To give those youngsters more specific information we did a special session with them on day two, showing them some tips and tricks such as using hootsuite.com for planning their tweets, letting them know that they can claim their url when they have a Facebook page (that can be done if you have more than 25 likes), advising them to comment on reactions (that is good for ranking, the higher the ranking the more messages followers see on their time line) and to use photos which are very liked in Facebookland.

The last part of our workshop was a discussion. Our intention was to split the group with basic information for the newbie's and the other group could discuss about how to improve their pages. However the first group didn't work that well and we decided to split them into smaller groups with specific discussion topics (How do you get new followers? Page or group? How to improve? What do you post? What to do with friends/family?) . This worked well and the reactions were great. There was also one group that had no experience with social media at all so we gave them a "crash course".

The feedback after our workshop was great, everybody learned something and participants liked that the workshop was practical. They also felt inspired and full of new ideas to start a Facebook group/page. The workshop worked both ways, we also got new ideas and will use the EYG Facebook to post more about the youngsters group, to share more initiatives so that people can get inspired. So find us on facebook!!

Serbia

Interview with Stefan Djakovic, UKUKS

When was your association founded?

UKUKS (the Serbian association for Crohn's and ulcerative colitis) was founded in 2009 in order to help connect people living with IBD and to improve patients quality of everyday life.

Your association is a relatively new one. How do you manage to attract new members and how do you make yourself more visible?

Our association works hard to attract new members all the time. UKUKS is active through social media and through our website (www.ukuks.org). Most contact with our members is through the online forum, where our members interact daily on a wide range of topics regarding their life with IBD. Moreover we have very good support from our local traditional media, who reports on our activities and several articles and interviews with some of our members have appeared in the press. Our social media pages (facebook etc) are still developing and don't have nearly as much visits as our popular on-line forum.

But of course all is not virtual. We also have very good contacts with our local IBD medical experts who promote our association by giving patients our information materials and directing them to our online pages, so they can register and get involved in our association's work. Doctors have started making a patients register containing information about patients, of course this information is private but we can get an idea of the total number of patients and other statistical data.

What are the main needs of members in Serbia?

Patients in Serbia have significant trouble to get the treatment that they need. Lack of medication, and expensive treatment are significant problems for all IBD patients in Serbia, and that is where our

Participants of a cycling event around a lake in Belgrade

association puts a lot of effort - into advocacy with the government.

Apart from that we provide support for all the members who ask questions about anything related to IBD, whether they need information or advice. We also try to socialize with our members through social and information events that we organize. Our information events are usually covered by the media, which helps the general public to recognize at least some of the problems that people with IBD face daily.

Stefan Djakovic (right hand) at the EFCCA Youth Meeting in Stuttgart

We also organize lectures for our members. Recently we organized a lecture about nutrition and IBD, which was done in the three biggest cities of Serbia (Belgrade, Nis and Novi Sad) and it proved to be a big success. Along with that, we are planning to organize lectures on psychology in IBD.

In September, we organized a cycling event around a lake in Belgrade. Members of our association enjoyed riding bicycles in UKUKS t-shirts thus giving high visibility to our association. This event was also covered by the media, and was considered as a great success and fun.

At the beginning of September our association was invited to become an observing member of the Commission for the Approval of Biological Treatments. For us, this is an important development as it shows that the government recognizes us as part of the system, and at the same time is willing to cooperate.

What are the main challenges that you are facing for the future?

Our main challenge, which is also the main goal of our association, is to improve the quality of life of people living with IBD in Serbia. That means being available for our members at all times, but also advocating for the best possible medication, and the availability of medication for our patients. We are constantly attracting new members, but of course the challenge here is also to attract active members, so far we have a good number of active members and this helps our association a lot

Why did you decide to join a European umbrella organisation?

UKUKS joined EFCCA at the General Assembly in Copenhagen in 2011. We consider this to have been a changing event for our association. Not only did we get many more interested members after we were “certified” at a European level, but we also gained a lot of influence with the stakeholders that we have been lobbying. Joining EFCCA has also helped us to keep up to date with information regarding IBD and to exchange best practices with other IBD associations.

World IBD Day

This year participation in World IBD Day has even further increased. Here you will find some inspiring examples of the many activities that took place in over 34 countries and on 4 continents.

Croatia

The Croatian IBD association organised a PR campaign to raise awareness about IBD and to advocate for urgent and necessary changes in healthcare, education and social protection for people with IBD. At the same time the campaign also aimed to raise awareness of what it's really like to live with these excruciating and debilitating diseases which affect all spheres of patient's life.

The campaign was organised on two levels, firstly the Croatian IBD Association coordinated the campaign and raised awareness with the public and the media, it also organised a street event at one of the main squares in the capital city of Zagreb and made a poster with important statements for necessary changes. Secondly IBD patients and members were ACTIVE participants in lobbying for their rights

any longer!

How do you feel when you have severe abdominal pain and diarrhoea? You don't get out of the house that day?
We have to live with that every day.

And not just with that. **Inflammatory Bowel Disease – Crohn's Disease and Ulcerative Colitis are non-infectious, chronic and severe diseases with no known cure that affect the immune system and can be life-threatening.** The cause is still unknown, and the course and severity of disease are not the same for every person with IBD. These diseases affect children and young people. Many of them in their most productive years can't reach their full potential. We are often forced to leave the education system and labour market due to disease complications.

Sharp pain, long hospitalizations, emergency room, painful examinations, numerous surgical procedures, hard treatment, extraintestinal manifestations...
That's life with IBD!

There are 5000 people suffering from IBD in Croatia, and about 2 million in Europe.

What do we want?

- **More IBD specialists**
- **Increase the number of IBD specialized day hospitals and policlinics**
- **Availability of biological treatment to all those who need it**
- **Defining the criteria for disability and working ability to achieve our social rights and benefits**
- **There is still no official patient registry**

We can't wait any longer!
We ask relevant institutions to make the necessary changes!
And our fellow citizens please – click 'like' to support us!

www.facebook.com/udrugahucuk
www.hucuk.hr

especially those who were at that moment in hospital.

IBD patients were asked to share one message about living with IBD which best describes what it's like for them to live with IBD and then send it to the IBD association in order to make a promotional video which then again was shared on most relevant Facebook pages like the official Facebook page of the Government of Croatia, the Ministry of Health, Education etc..Patients were asked to be synchronised with other IBD patients and keep reposting the promotional video all day, even if they were in the hospital.

Students with IBD were asked to send the promotional video to their university and other academic institutions.

As a result of the joint efforts of the association and the IBD patients/members, we were invited to a TV show together with an IBD specialist to present the statements of the campaign for necessary changes. More reporters than expected visited the association's booth at one of the main squares in the capital of Croatia, Zagreb and the campaign was covered on primetime TV.

The Mayor of the City of Zagreb visited the booth and promised to "allocate" a municipal apartment to the association for patients who are coming to the capital city for treatment and don't have the financial possibilities to pay for accommodation during their treatment.

The association also went to the Croatian Parliament to present the problem to the working bodies regarding the recognition of IBD as a disability.

The Faculty of Law in Zagreb is the first university in Croatia which will create a model for students with IBD to enable them to have equal rights and which could serve as a model for other universities.

Our campaign was the first ever IBD campaign in Croatia which involved people most affected by IBD. Until now these people thought that due to the severity of their condition they could only be silent in their homes or hospital beds unable to raise their voice as active lobbyist for a better future. But luckily they were proven wrong. All that was required was to simply click and repost the video on relevant Facebook pages or to send a personal message for the video.

An English translation of the promotional video can be found on the following link:

http://www.youtube.com/watch?v=nuhOEaH4n3g&feature=youtu.be

Argentina

This was the second year that the IBD foundation Más Vida took part in the World IBD Day activities celebrated around the globe. This year we carried out a series of activities aimed at raising awareness about IBD and highlighting the life of people living with IBD in Argentina.

The first activity that took place was entitled "our common space" in which people with IBD and their family members participated in a creative workshop. They were invited to artistically express what it means to live with IBD. As a result we spend a wonderful afternoon with colours, fun and expressing our feelings. The workshop was coordinated by plastic artist, Valeria Nerpiti, who helped us with her enthusiasm and talent to create our own piece of artwork named "apron" amongst other paintings and an explosion of creativity.

The "apron" was shown at the art exhibition in the city of Puerto Madryn Chubut as part of a gastronomic event called "Madryn eats" organised by the City's Tourist Department and in which the Foundation Mas Vida participated successfully together with well known cook Santiago Giorgini and nutritionist Marisa Canicoba.

This was followed by a highly popular event on 20 of June when Santiago Giorgini got together again with nutritionist Marica Canicoba to give a maser class on “cooking for health: nutrition and IBD”.

With the participation of over 300 people we managed to show the importance of knowing tools that allow us to reinforce basic concepts of nutrition for people with IBD. There was great participation from the audience and we are proud to say that through this event we managed to gain wide media coverage and much needed visibility of people living with IBD in Argentina.

Luciana Escati
Más Vida

Luciana Escati with the “apron” artwork elaborated during the “our common space” workshop

Norway

In Norway, around 25 000 people are affected by chronic bowel diseases such as Ulcerative Colitis and Crohn’s disease. The Norwegian National Association against digestive disorders (LMF) has conducted a patient survey about their life with IBD, the results of which were launched in May 2013.

The main objective of the survey was to use the results of the patient survey to identify the specific problems and complications for people diagnosed with IBD and to raise public awareness of the diagnosis. It is hoped that the results can be used as a contribution to improve IBD patients’ quality of life in the long run.

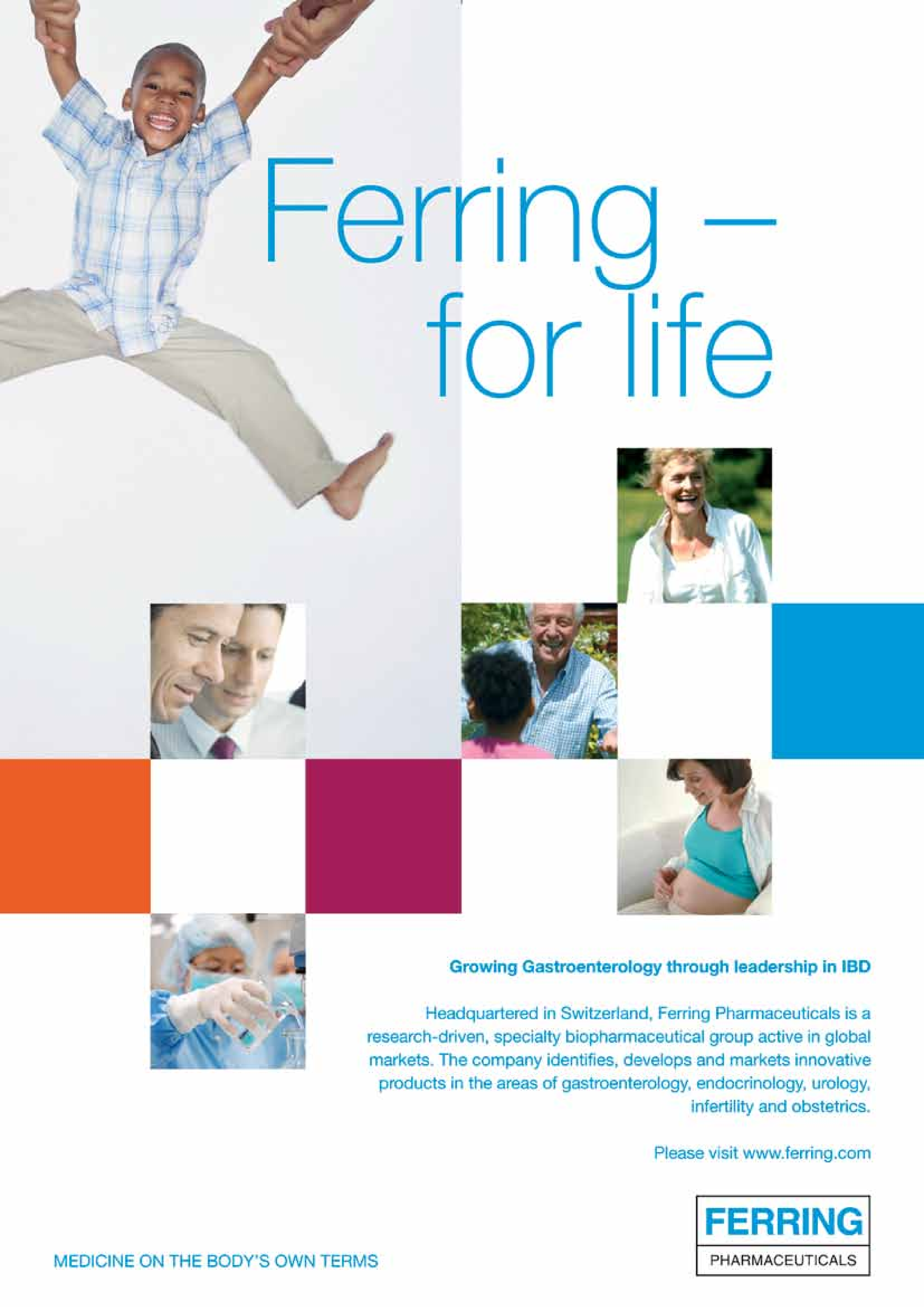
The survey was led by LMF and was conducted among its members. An independent consultant, Geelmuyden.Kiese, was engaged to organize the survey and analyze the results. The survey received support from AbbVie. All in all 424 people responded to the survey within 3 weeks, with a very high participation from women (333 respondents).

The data from the patient survey showed that IBD patients’ quality of life has been reduced due to diagnosis. The survey revealed the serious effect IBD was having on the respondents: a majority of the respondents answered that they felt unusually tired and exhausted, isolated and unable to travel due to their illness.

It showed that increased knowledge about the disease and the importance of earlier diagnosis are key for patients to get the right kind of treatment. LMF is using the results of the survey for a strong media and PR campaign in order to improve awareness within the medical and political communities and among the general public.

So far the media coverage has been very successful. One of the largest national newspapers in Norway referred to the survey on its front page and the largest commercial television station in Norway interviewed a patient in their studio on their morning show. LMF also published articles on their website. For more information please visit: http://www.lmfnorge.no/

Arne Schatte, General Secretary LMF



Ferring –
for life

Czech Republic

On 25th May 2013 members and supporters of the Czech IBD Patients Association met in Prague's Ladronka park to launch for the first time World IBD Day in the Czech Republic. The main goal of the event was to create a giant serpent made out of toilet paper rolls to symbolize the daily difficulties of IBD patients and the increasing amount of people diagnosed with IBD. The event was held under the patronage of the mayor of Prague.

Even though the weather was not too friendly more than 130 members and supporters participated. 19.706 rolls were collected and together we made a toilet paper roll serpent measuring 1.8 km. The sun shone shortly during threading the rolls into the snake as a sort of confirmation to our efforts. The rolls had been collected by IBD patients since September last year. Not only by those who came to the meeting but by many other patients who brought the rolls to gastroenterologists clinics (collecting points) or who sent them to our association's office. Many doctors and nurses in IBD clinics across the country expressed their support for this event and helped us collect the rolls. Some of the rolls had been adorned with paintings made by children.

The event was attended by the President of the Slovac Crohn Club Mrs Viola Števurkova and Dr. Martin Bortlík, representing the Czech IBD doctors working group. The programme continued in the spirit of competitions and games, where the main property was toilet paper. One of the patients – Mrs. Irena Kousalova -who is a singer prepared a small performance of her own songs. The event was finished by an award for the best IBD nurse voted by Czech IBD patients.

A gift to our members was the launch of our new website (www.crohn.cz) where patients can add comments, discuss and inform us about their needs.

All in all, the first celebration of World IBD Day was really successful and was preceded by a press conference giving us more visibility in the Czech media. We hope to continue this tradition in the next coming years.

Veronika Hanzlikova, Martina Pfeiferova

...and other member news

UK

Me and IBD – Facing the Future, School and Beyond

We have been busy with our PR and youth work. The 2013 PR campaign key outcomes will support teenagers and young people with IBD to enable them to:

- cope better with their IBD from the point of diagnosis by pointing them to the support available and engaging them in dialogue with each other and their professionals
- feel better understood and supported
- communicate easily with each other via shared experiences
- inform the relevant people in their lives

The 2013 PR campaign needed to be supported by a strong online present for today's savvy teens and twentysomethings. It was therefore decided to continue with the dedicated campaign microsite that had proven successful in the past two campaigns and add specific campaigns on Facebook page, Twitter account and Blog.

Young people were also enjoyed through a new Blog entitled "The Blog Roll" – on the site. The blog was launched April 2013, to allow for more information that simply could not be housed on the microsite.

It featured the full text from Crohn's and Colitis UK Information Sheets broken down into article series, published one a day to drip feed information and retain interest. We actively sought out young IBD bloggers to write guest posts for us. An added bonus to the information and support that the guest posts brought to the blog was friendships formed through it. For example, guest writers Gabi and Steph, who are now firm friends and speaking to their own readers about each other and the campaign.

Enthusiasts signing up for our annual charity walks

Our media coverage, drawing on case studies volunteered by young people living with IBD, has been excellent so far. Coverage has included:

- 21 regional case-study led feature articles
- 1 full page Women's magazine article
- A Daily Mail online article, reaching over 100 million readers
- 15 Online social media articles from bloggers and others
- 5 Education publication feature articles
- 4 Medical articles
- 4 TV spots

In September, we rolled out a new sub-report, entitled "Inflammatory Bowel Dises in Young People, The Impact on Education and Employment" this, together with other resources, can be downloaded from our main site www.crohnsandcolitis.org.uk or from our dedicated site for young people www.meandIBD.org

In September we will use our Clinical Communities website to share the findings from our survey of healthcare professionals, looking at best practice in dealing with younger patients.

In October we intend to release the final part of 2013 survey findings "Me and IBD – the crushing impact on young lives" looking at the psychological and social impact of living with IBD for young people.

We will round up the communications for this year with "Break the Silence" – a new survey summary/manifesto to assist young IBD patients steer their future communications.

This year we have also piloted our first Summer Camp for young people and our first residential youth weekends entitled "Strategies for Living." We had record numbers of people of all ages signing up for our annual Walks in London, Rutland and York .

Our theme for next year is Fatigue, and we will be reporting on the findings of our three year Lottery-funded project during Crohn's and Colitis month in May 2014. The Fatigue work includes a ground-breaking measuring tool for assessing levels of fatigue, as well as possible interventions to help patients cope with this devastating symptom of IBD.

Suzi Clark, Crohn's and Colitis UK

Sweden

First of all we're pleased to announce that this summer we managed to send two young Swedish members to the EFCCA Youth Group meeting. They have reported back saying that the meeting was not only fun but also very educational and interesting. We're thankful for this opportunity and hope the work within the EYG will inspire more young ones to engage in trying to make life better for those who have IBD.

We have recently arranged a Family Weekend nearby Stockholm. It's a weekend where families with children with gastrointestinal diseases can meet, learn about different conditions and have fun. While the kids danced, played and made bracelets with the words "Fight IBD/IBS", their parents received information on important issues related to IBD and also connected with each other. All in all it was a weekend full of activities for everyone and hopefully it was well appreciated by all the participants.

Our groups for Unga Magar in social medias (Facebook) are growing and so do the activities in our county and local associations around the country. It's a very positive development and we are confident for the future. That, if nothing else, is very encouraging and inspiring. Not the least for children and young ones, who need hope for the future. Let's keep on fighting IBD/IBS!

Ebba Persson, youth editor, Mag- och tarmförbundet (The Swedish Bowel and Stomach Association) and its children and youth section Unga Magar ("Young Stomachs")

New Zealand

Crohn's and Colitis New Zealand is delighted to spread our good news – Brian has been awarded a Queen's Service Medal for services to health and the community.

Brian has a life-long commitment to service, through his church and Rotary. However, it is his endeavours to improve awareness and recognition of Crohn's and colitis (IBD) for which we are so grateful.

Brian was diagnosed with IBD as a young man approximately 40 years ago, so has seen many changes in the diagnosis, treatment, and management of IBD. He has always passionately believed that the disease has long lasting effects on people, quite apart from the day-to-day aspects of physically coping with a chronic illness. It is the isolation that these diseases cause and the effects on education and people's ability to work that have always inspired Brian's efforts to gain recognition. It is these things that initially motivated

Brian to set up the Crohn's and Colitis Wellington support group approximately six years ago, and more recently the national organisation, Crohn's and Colitis New Zealand.

As the founding chair of Crohn's and Colitis New Zealand, Brian has established relationships with other Crohn's and colitis organisations internationally, represented our interests at government level by meeting with cabinet ministers and Ministry of Health officials. He has overseen significant improvements in access to a range of medications in the three years since our inception, improved communications with medical professionals from gastroenterologists to dieticians and psychologists, and of course directed the development of a network of support groups throughout the country, to reduce isolation and improve awareness of these devastating diseases.

We thank Brian for his vision and commitment and congratulate him on his Queen's Service Medal, which is so well deserved.

Julia Gallagher

Here Brian is photographed with His Excellency, Lt Gen The Right Hon Sir Jerry Mateparae, GNZM, QSO, the Governor-General of New Zealand.

Slovakia

The Slovak Crohn Club has celebrated its twentieth anniversary in 2013. On this occasion we organized a press conference for a group of medical journalists to inform them about IBD, available treatment options, the work of our association and a new web application (www.wckompas.sk) which allows users to find available toilets in several towns in Slovakia. We also represented the new book "Zivot s Crohnovou chorobou a ulceróznou kolitídou."

In the evening we organized a gala conference in Casta-Papiernicka near Modra which included the participation of the general secretary of the Ministry of Health., the president of the Slovak Gastroenterology Society and several doctors that had been collaborating with the Slovak Crohn's Club since it was established.

Prof. MU Dr. Milan Lukáš, CSc. from the Clinical and Science centre for IBD illnesses ISCARE Lighthouse (Prague) gave a presentation on "New possibilities for IBD treatments" which was followed by a lecture on "IBD and pregnancy: yes or no" by doc. MUDr. Zuzana Zelinková, PhD.

Our foreign guests included EFCCA members from Austria, Croatia, Czech Republic and Slovenia who enjoyed with the rest of the participants the social programme in the evening with music and dancing and a trip to Cerveny castle for wine tasting.

Zusana Bertuskova

Travel and IBD

If you have IBD you may find the thought of travelling daunting. A change of climate, water, or food can upset anyone's bowels. Yet many people with IBD travel widely. They may go for a short break or a long holiday lasting several weeks or months. With careful planning ahead it should be possible for you to travel to most places.

EFCCA member Crohn's and Colitis UK has prepared an excellent information sheet with information answering questions that you may have when thinking about going on holiday or on a business trip. It also includes suggestions for people who have a stoma.

Insurance

If you need medical treatment when abroad, there are many countries where you would have to pay for it, so it is usually a good idea to arrange travel insurance to cover healthcare costs.

For travel to most parts of Europe you can get a free European Health Insurance Card (EHIC). This card entitles you to reduced cost or free treatment in most European countries. However, you may not wish to rely on this alone, because it does not help you get home, or cover your family's expenses.

It may not occur to you to mention your IBD to the insurance company when you are arranging your insurance. However, if you do not, you may find that your insurance is invalid or that you have problems should you need to make a claim.

If you do become ill during your travels and you wish to claim on your insurance, you will need to keep receipts for every thing, such as taxi fares to hospital.

Vaccination

Try to find out several months in advance whether vaccinations are needed or recommended for your destination. Some vaccinations need to be taken two or three months before travel. You could check with your travel agent or doctor.

Malaria

If you are travelling to an area with malarial mosquitoes, you are advised to take an anti-malaria medication. Most tablets have to be started a week before travel and continued for four weeks after return. Like any medication, there may be side-effects when taking anti-malarials, and these may affect your IBD. There can also be adverse interactions between some anti-malarials and some immunosuppressant drugs for IBD. You may wish to discuss with your specialist which preparation is suitable for you.

Preventing mosquito bites is just as important as taking the medication. Mosquitoes bite particularly between dusk and dawn. You can help to protect yourself by wearing light coloured, loose clothing to cover your arms and legs, and using an effective insect repellent, such as one containing DEET (diethyltoluamide).

Packing medicines

If possible, try to take enough medication for your whole trip, as well as extra in case of delays, to ensure you do not run out. If your medication has to be kept refrigerated, you could store it in a small cool bag. As well as taking a full list of your medications you could also check with the relevant pharmaceutical company whether your medications are likely to be easily available in the countries you plan to visit. If your medication cannot be obtained where you are going, then you could ask your doctor for a private prescription, and purchase extra supplies.

Taking medicines abroad

If you are travelling abroad, the government advises you to keep your drugs in their original packaging to show at customs. You may also need to show them your letter from your GP or consultant. Storing your medication in your hand luggage when flying will help if your baggage is lost. Hand luggage restrictions mean that if you have more than 100ml of medicine in your hand luggage you will need to show a letter from your doctor stating your medical need.

Transport

You may be travelling on holiday via car, bus, train, ferry or airplane. Whichever way you are travelling, there are issues that you may wish to consider. If you are travelling by car, you may wish to check the location of accessible toilet facilities when planning your route. They can often be found in places such as Tourist Information Centres, supermarkets, and fast food restaurants, as well as service stations.

When travelling by bus, train, or airplane, it may be worth checking whether there is an accessible toilet on board, and, if possible, booking a seat close to it. If you are flying, you can usually pre-arrange your in-flight meals for any particular dietary requirements, such as dairy free or low -fat. If you are going on a long flight you might want to consider taking an anti-diarrhoeal beforehand. Cabin air is often very dry and drinking plenty of water and avoiding alcohol and caffeine should help to prevent dehydration.

Travelling with a stoma

If you have an ileostomy or colostomy you may have particular concerns about travelling.

However, with careful planning, having a stoma should not stop you from going away. It is important to take ample stoma supplies. You are likely to be eating differently and you may have to change your appliance more often than usual, especially in hotter climates. You may need to take more supplies than you think you will use – some people suggest twice as much as normal. You could check whether your supplier delivers abroad, as some companies offer this service. If you are travelling by air, taking your supplies in your hand

luggage ensures that you are not without them should your luggage go missing.

Food and drink

Anyone travelling abroad is at risk of getting a stomach upset, especially in less developed countries. A common problem is traveller's diarrhoea,usually caused by bacteria, parasites or viruses in contaminated food and water. Having IBD means you have to be particularly careful about hygiene and what you eat and drink.

Treating Traveller's Diarrhoea

Traveller's diarrhoea often passes within three to four days. Drinking plenty of

liquids replaces the fluids lost by diarrhoea, and prevents dehydration, but be careful of

ice-cold,alcoholic, caffeinated, or citrus drinks, which can aggravate diarrhoea.

If you do not get better within a couple of days, or you develop a fever or any other symptoms associated with your IBD, see a doctor or go to a hospital. Bloody

diarrhoea could either be down to a flare -up of your IBD,or a bacterial infection

which needs treatment with antibiotics.

Dehydration

In hot weather you will need to take care not to become dehydrated. Symptoms of

dehydration include thirst, a dry mouth, headaches, dark coloured urine and tiredness. It helps to avoid strenuous exercise during the hottest hours and to drink plenty of non-alcoholic liquids (at least 8 -10 average glasses).

Sun exposure

While it is important for everyone to protect themselves from the effects of the sun, you will need to take even more care if you are on immunosuppressive drug treatments for your IBD. These include azathioprine, mercaptopurine and methotrexate , any of which will make your skin more sensitive to sun damage, and may increase the risk of skin cancer. You should use a high skin protection factor sunscreen (SPF 25 or above).

If you would like to consult the full text of the information sheet prepared by Crohn's and Colitis UK please visit their website at: http://www.crohnsandcolitis.org.uk/

Thanks to Crohn and Colitis UK for making this material available!

Photographic journey into IBD

Sam Sword was swallowing up to 26 pills a day to manage his chronic pain after being diagnosed with Crohn's disease. "I was trying to fight a forest fire with a garden hose" he told in a recent interview with The Press. "The pain was always there".

Sword's painful journey began in 2006 when the 32 year old was rushed to hospital with severe abdominal pain. Doctors believed his appendix had burst, but after "dozen of tests", Sword was diagnosed with Crohn's disease. Sword spent the next few years in and out of hospital in agonising pain. He has since undergone 2 surgeries and had 46cm of inflamed bowel removed. Sword now feels like he can finally manage his disease. "I am now in remission. I will still have flare ups but I finally feel like I am getting somewhere".

Sword who is one of 15 000 suffers of IBD in New Zealand has turned his journey into a photographic exhibition for the unveiling of a new survey on IBD in New Zealand. The exhibition was shown at the Crohn's and Colitis NZ's 'Join the Fight Against IBD' function at the Parliament and has been open for public viewing.

His powerful images provided a human backdrop to the results of a year-long survey looking into the impact of IBD on the lives of New Zealanders.

"I felt by communicating to my friends and family and explaining to them what Crohn's disease is and what it does to me allows me to live a semi normal life. I don't what the future holds, I guess it's waiting for a cure in the meantime I plan to enjoy my life as much as possible and I encourage you to do the same."

Where to now? (Keywords – Unknown, Direction,)

The worst thing about having an illness that has no cure yet is the unknown. I don't know what the future is illness wise. So it's just a waiting game for a cure. But in the mean time I plan to enjoy my life as much as possible.

Urgency and Desperation (Keywords – Discomfort, Bowel Motions, Worried)

Part of having Crohns is the worry of when I do go out to places I need to know there is a toilet close by. So when I do go somewhere or walk into a venue or somewhere new the first thing I do is find out where the toilets are.

Understanding and Support (Keywords – Counselling, Family, Friends, Support Groups.)

At the start it was hard to find support as Crohns isn't very well known in today's society. My Specialist suggested talking to other people in a support group might help me release some of my frustrations.

European Commission pulishes report on health ineqaulities

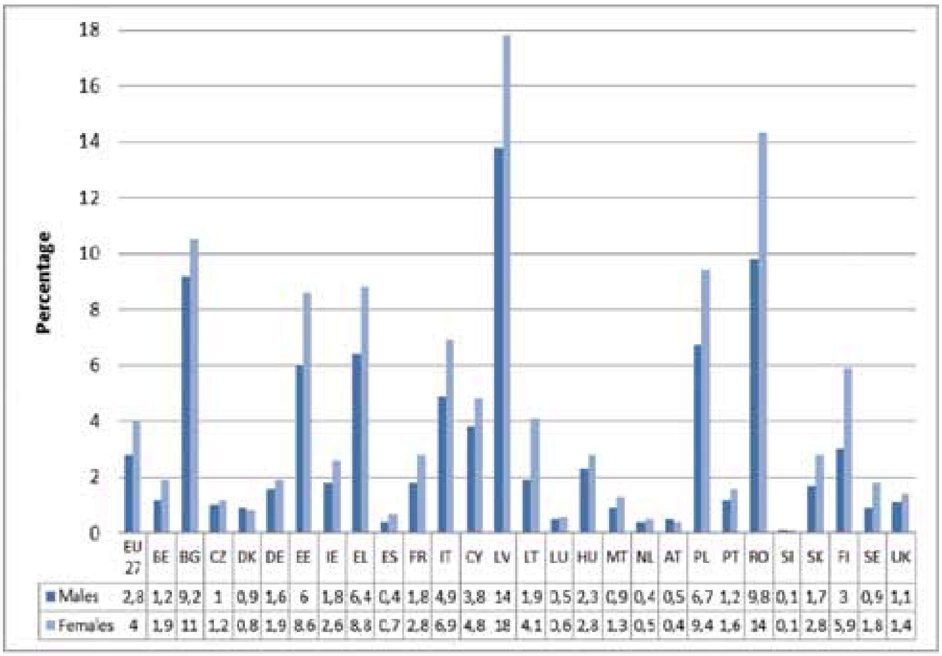
The DG for Health and Consumers (DG SANCO) of the European Commission has published its Report on Health inequalities. The report examines various factors causing health inequalities and finds that social inequalities in health are due to a disparity in the conditions of daily life and drivers such as income, unemployment levels and levels of education. The report points to some positive developments in implementing the EU strategy on health inequalities, 'Solidarity in Health', while concluding that more action is needed at local, national and EU levels.

"Solidarity in Health: Reducing Health Inequalities in the EU" was adopted by the Commission in 2009. The progress report published now looks at how far we have come on the five main challenges laid out in the strategy: 1) an equitable distribution of health as part of overall social and economic development; 2) improving the data and knowledge base; 3) building commitment across society; 4) meeting the needs of vulnerable groups; and 5) developing the contribution of EU policies.

Overall, the Commission's action aims both to support policy development in EU countries and improve the contribution of EU policies to address health inequalities. An ongoing Joint Action, running from 2011 to 2014, is a major vehicle to achieve this.

Achieving the goals of Europe 2020 for inclusive growth is fundamental to addressing health inequalities. In February 2013, the Commission adopted a paper on Investing in Health, as part of the Social Investment package. The paper strengthens the link between EU health policies and national health system reforms and presents the case for: smart investments for sustainable health systems; investing in people's health; and investing in reducing inequalities in health.

Figure 24: Self-reported unmet needs for medical examination for reasons of barriers of access (too expensive, too far to travel or waiting list) by sex, 2011



	EU 27	BE	BG	CZ	DK	DE	EE	IE	EL	ES	FR	IT	CY	LV	LT	LU	HU	MT	NL	AT	PL	PT	RO	SI	SK	FI	SE	UK
■ Males	2,8	1,2	9,2	1	0,9	1,6	6	1,8	6,4	0,4	1,8	4,9	3,8	14	1,9	0,5	2,3	0,9	0,4	0,5	6,7	1,2	9,8	0,1	1,7	3	0,9	1,1
■ Females	4	1,9	11	1,2	0,8	1,9	8,6	2,6	8,8	0,7	2,8	6,9	4,8	18	4,1	0,6	2,8	1,3	0,5	0,4	9,4	1,6	14	0,1	2,8	5,9	1,8	1,4

Source: EU-SILC. Data extracted 6.2.2013.

European Health Commissioner, Tonio Borg, said: "Inequalities in health in terms of life expectancy and in particular in infant mortality have been significantly reduced in the European Union in the past few years. This is encouraging. However, our commitment must be unwavering in order to address the continued gaps in health between social groups and between regions and Member States, as shown in this report. Action to bridge health inequalities across Europe must remain a priority at all levels."

Read the full reports and find out more about EU action to address health inequalities:

http://ec.europa.eu/health/social_determinants/policy/index_en.htm

Empathy project

As part of the EMPATHY project in which EFCCA is a stakeholder the EPF Youth Group organized a four-day seminar that took place in Brussels on 8-11 July under the title a meeting entitled "Europe meets Young Patients". Policy discussions focused mainly on two major topics: health issues and discrimination.

A role play launched the policy discussion on health issues, highlighting the major challenges young patients face in their daily lives. The teenagers highlighted the lack of direct communication between them and health professionals. Indeed the intermediary role of parents alters the relationship and young people do not always have the chance to express their concerns directly. Moreover parents' attitude may be overprotective or not supportive which creates another barrier for young people.

This situation is further amplified during the transition from childhood to adult care. This transitional phase can be critical if young patients cannot rely on the emotional and practical support, both of their family and of their healthcare providers.

A good relationship is however possible. It depends on the ability of health professionals to play the role of a 'bridge' between parents and teenagers. They need to adopt an even more human approach to address the young people's concerns.

Young patients, when empowered, can also become self-health advocates, like adults. They can take more responsibilities in the management of their treatment and advocate for their own needs. Patient organisations can provide peer support to young patients and their parents as well. They can also act as a bridge in communicating with health professionals.

The second policy discussion looked at discrimination and stigma. Young representatives identified three sectors where they face discriminatory behaviours: education, access to employment and access to treatments.

- To ensure equal access to education, administrative rules may need to be adapted to their specific needs. Examples are numerous: the need to miss courses because of treatments, difficulty to perform exams because of health condition, etc. Teachers and examiners may sometimes be the involuntary cause of discrimination as 'standard' rules do not fit all.
- Discrimination often appears during job seeking. Young patients soon learn that a selection process may not be based simply on meritocracy and professional skills. Employers sometimes fear that chronic conditions might undermine their employee's performance. Employers need to be trained and learn that a chronic disease does not necessarily affect the quality of work.
- Finally young patients face discrimination in access to treatments. They may experience difficulties in accessing treatment while travelling abroad for studies, for instance.

Young patients had their first opportunity to express their needs towards European policy-makers and stakeholder actors. With the help of EPF, they wrote a press release to call European decision-makers to adapt their policies to their specific needs. For more information please visit the EPF website: www.eu-patient.eu/

IBD Research Foundation

The IBD Research Foundation completed successful grant programs during the past three years. We awarded 9 IBD related research projects grants of 5000,- euro each. Our supervisory board and our management board considered it time for some reflection.

During a joint meeting of these boards, we concluded that our support for IBD research may be more effective when we support one slightly larger project, instead of a series of smaller projects. In order to make it more attractive for associations help us with donations, we concluded that it'd be best to find an interesting research project first and then request support for that particular project.

Therefore we did not start a regular grant program this year. During the past years we'd continuously raise funds and annually select three research projects to support. However when we raised funds we could not tell yet for which kind of project the funds would be used. When we look for an IBD research project first, we are able to tell in advance how the funds will be used. Hopefully that will lead to more significant funding and also to more effective IBD research.

The foundation still requires help in all kinds of areas. Are you interested in helping us? Please send an email to Wouter.miedema@ibdresearch.org

At this time our supervisory board consists of Micke Lindholm (Finland), Chayim Bell (the Netherlands) and Salvo Leone (Italy). Marika Armilo (Finland) left the supervisory board earlier this year. The management board consists of Rod Mitchel (United Kingdom), Hajnalka Szabo (Italy) and Wouter Miedema (the Netherlands).

Donations

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

Wouter Miedema, IBD Research Foundation, Secretary

ABN AMRO Bank the Netherlands
Account number: 97.46.86.158
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HUMANCARE

The concept of mucosal healing in IBD: implications for the patients

by A. Orlando, DI.BI.MIS., Internal Medicine, Villa Sofia-Cervello Hospital, University of Palermo, Palermo, Italy

Inflammatory Bowel Disease (IBD), which includes both Crohn's Disease (CD) and ulcerative colitis (UC), is a chronic idiopathic inflammatory disorder affecting the gastrointestinal tract. CD and UC affect more than 1 million people in the United States, with thousands of new diagnoses annually.

The natural history of CD and UC is characterized by repeated episodes of inflammation and ulceration of the bowel. This results in complications implying a worse quality of life and significant healthcare costs, due to hospitalization, surgery, and an escalation of therapy. The main goal of the therapy in IBD is to achieve and maintain disease remission, with an improved health-related quality of life, less hospitalization, and less surgery. The concept of remission has changed in recent years. The concept of clinical remission, where only the patients' symptoms are in remission, has been replaced by the new concept of deep remission. This implies not only a sustained clinical remission but also a complete mucosal healing (MH), together with the normalization of serological activity indexes (C-reactive protein, CRP). MH is thought to be an important prognostic feature for the efficacy of treatment in IBD. MH is assessed by endoscopy and is a component of intestinal healing, which determined by endoscopic healing, histological healing, transmural healing and fistula healing.

Currently, there is no validated gold standard definition of MH in CD. Historically, endoscopy, rather than histology, has been the focus of mucosal assessment in CD patients for several reasons. Because of the segmental nature of CD, which can lead to sampling error when biopsies are performed, and the predilection of CD forthe ileum, histological scoring is inherently difficult. Also, despite a number of histological activity indices have been developed, none of them has been prospectively validated. In addition, endoscopic assessment of disease activity in CD has been shown to be better correlated with transmural inflammation and therefore to the actual severity of the disease. Finally, there is a paucity of data evaluating the impact of histological healing on clinical outcomes.At the moment, there are 2 validated indices for assessing endoscopic activity in CD: CDEIS and SES-CD. However, both are too complex and cumbersome to be used routinely in clinical practice. Many different definitions of MH have been used over the years and, unfortunately, none of them has been validated or even universally accepted. A recent expert consensus report defined MH in CD as the "restoration of normal mucosal appearance by endoscopy of a previously inflamed region and the complete absence of ulceration and macroscopic and histological signs of inflammation". This rigorous combined endoscopic and histologic definition has not yet been applied to clinical trials, which have primarily used endoscopic indices to define MH.

Similarly to CD, there is no validated goldstandard definition of MH in UC. Numerous endoscopic and histological indices have been developed to measure disease activity in UC. All these indices include overlapping endoscopic mucosal features, such as vascularity, granularity, erythema, friability, bleeding, and ulceration. However, in many of these indices, clinically meaningful cut-off scores for endoscopic remission or improvement have not been defined, and none has been prospectively validated. Similar to CD, there is much heterogeneity in the way MH has been defined in UC, and none of these definitions has been validated or universally accepted. The challenge lies in collectively interpreting the results of studies that use different definitions of MH.

With regards to the clinical implications of MH, the analysis of the significance of MH requires evaluation of the therapeutic results in relation to the drivers of the direct costs of IBD, mainly meaning hospitalization and surgery. Therefore, those factors that may affect the therapeutic results of these patients will have significant impacts in terms of reducing the social cost of this disease. In this context, many observational studies showed that patients obtaining MH presented a lower rate of hospitalizations and surgical interventions.

Among other clinical implications of MH, we should consider the relapse rate of the disease after drug withdrawal. In this regard, Louis et al. recently performed a study to assess the risk of relapse after discontinuation of infliximab in patients on combined maintenance therapy with immunosuppressors. By multivariate analysis complete MH was among the factors strongly associated with a decreased risk of clinical relapse after infliximab withdrawal.

Similarly, another end point that needs to be taken into account is quality-of-life benefit. A sub-study of the EXTEND trial (a randomized, double-blind, placebo-controlled trial that was performed to evaluate adalimumab for induction and maintenance of MH in 135 adults with moderate to severe ileocolonic CD) showed, at multivariate analysis, the significant predictive effects of week 12 endoscopic assessment scores for quality-of-life outcomes at week 52. Interestingly, the EXTEND trial had MH as primary end point of the study.

Finally, particularly for UC, it is important to consider that there is a clear relationship between the grade and chronicity of the inflammation in the colon and the risk of colorectal cancer. Indeed, greater reduction of inflammation, as demonstrated by MH, may be associated with a decreased risk of colorectal cancer. In this regard, in a study of patients with long-standing UC who were undergoing surveillance colonoscopy, in univariate analysis the degree of colonoscopy and histologic inflammation correlated with the risk of developing colorectal neoplasia. By contrast, in multivariate analysis only histological inflammation was an important determinant of risk. In the follow-up study, the multivariate analysis also showed that UC patients who had a macroscopically normal colon had a colorectal cancer risk similar to that of the general population .

A new therapeutic target that is emerging in the scientific community is the concept of deep remission, which has already been defined as the combination of clinical remission (CDAI < 150) in the absence of the residual use of steroids, along with more objective variables, such as negativity of the indexes of biological activity of the disease (CRP), and in association with MH.

While deep remission is an emerging concept in IBD, in rheumatoid arthritis, treatment goals no longer include symptom control alone but also alteration of the biological processes underlying synovial inflammation and progressive structural destruction, thereby preventing structural joint damage and functional decline. Achieving deep remission (clinical remission and MH) might be the only way to alter the course of the disease in IBD patients.

It is becoming clear that treatment for clinical remission alone may not be an adequate approach for IBD in the long term. There is a growing body of evidence that the attainment of MH in IBD is auspicious, as it leads to a number of improved clinical outcomes.

MH, which is a new concept concerning the goal of deep remission, and rarely achieved with traditional drugs, can now be achieved and maintained by means of biological drugs. Current evidence suggests that the achievement of MH might significantly change the course of the natural history of IBD and should represent an objective end point of future therapeutic trials, particularly for colonic diseases. However, until future prospective studies identify and validate a single gold standard MH scoring system (separately for CD and UC) that is relatively easy to use and predictive of clinical outcomes, establishing a critical time point for measuring MH, and demonstrating that treatment to MH can change the natural history of these diseases, MH will remain an admirable secondary goal in the treatment of IBD patients.