

# EFCCA MAGAZINE

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

## Global Fight against IBD

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# EDITOR'S EYE

## *Wanna sit on the bench, or wanna play?*



It is new Years' eve while I'm writing these lines, and I simply cannot help myself to turn back for a moment, and to have a look at where 2012 has taken us.

We started in a rush, a real Olympic sprint, that has let us to organise in just a few weeks in February the stunning Barcelona event: Join the Fight. What happened at the Olympic Museum and Stadium up Montjuic or later on at the Gala event is something that has never happened before: the scientific community and the patients' one, together, have unveiled the infinite possibilities of a mutual cooperation. Indeed, people from all over the world met up, for giving a new sense in the fight against IBD. Together.

Only a few weeks later and it was time for the General Assembly in Porto: a milestone. Despite the many difficulties, the European IBD Patients' community has given a powerful message to the world: we want to be stronger, we want to grow, we want to be a point of reference for all IBD patients, no matter their nationality, origin, gender, race or social condition. The opening to the associated membership of Israel and Argentina is probably more than a milestone: and there's no rhetoric in saying that from this we will be able to build much more.

And then, in May, not a step but a giant leap has been made in our "saga": for the first time EFCCA had the chance to speak at the European Parliament. I do not think there is much to add to what MEP Sergio Cofferati said about us during his introduction. For the first time we felt that not only our cause was finding an audience, but also that our everyday fight has been understood. And please allow me to say that what Cofferati said about the dignity and seriousness that are evident in our work, made me proud of this organization.

With summer came hope. Catch Your Dream is not only a registered trademark for our summer camps. It is a mission statement. Moving from one camp up to five, in a few years, is nothing else than the result of the highest commitment and the new strategy, based on supporting the local associations in having their own camps, is paying back with a definitive benefit for our kids. Applying for the EFCCA Label is an opportunity for every association, even those that have a locally well established program. Because, once again, extending the boundaries of the local program, and giving it an "international perspective" is in the benefit of the real recipients of any projects: our patients.

18 October 2012 is a day I will never forget in my life. One of the most difficult I have ever lived, honestly. But altogether, one of those days that can give a sense to years of sacrifices by many people and volunteers all over the world. When I firstly spoke about a World Symposium on Patient's funded research into IBD, the initial reactions were rather skeptical. Few months later, delegates from all over the world were there, establishing connections, trying to find together new strategies, dialoguing in an open and honest way with the scientific community. What a day! To see all these persons with a common purpose, working with such a goodwill and delivering what is more than a message of hope: delivering a project that justifies hope !

Giving hope is integral part of our work. Because it is in the darkest moment that a patients organizations should be there. Support means not only to show that there is a light in what appears to be darkness, but means also that we need to work for creating that light of hope.

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During the Symposium someone said “well, now EFCCA has the resources for organizing something like this”. Allow me to respond: “this is the wrong attitude!!” What we need is ideas like this and the courage to transform them into something concrete. Resources will come. Am I optimistic? On the contrary. I simply believe in the value of our projects, and with me our partners think the same, as a result despite the global economic crisis EFCCA managed to improve its overall budget.

And finally, the first meeting of the International Organizations of patients working on immunomodulated diseases. EFCCA is proud to have hosted IFPA (Psoriasis), AGORA (Rheumatic and Musculoskeletal diseases in southern countries) and ASIF (ankylosing spondylitis) to discuss a common information project. And be sure, this is the first draft of what could become a masterpiece. Stay tuned, because these associations, together, have much to say to a world that too often considers the diseases we’re fighting as something different from a priority.

All these results do not make us perfect. Of course we are not. And as a matter of fact there is and there will always be somebody ready to underline our mistakes. Every criticism, by the way, is welcome if it helps us to grow up as an organization.

EFCCA has grown beyond expectations in the last years. We have changed our views, our approach, and somehow even our role. This can be scary, but it is through the acceptance of this challenge, that was the one I was asked to undertake as leader of this organization five years ago, that we can make a difference against IBD.

The battle is hard, and very often not fair, simply because IBD is not fair, and plays according to a different sets of rules. But winning against IBD is a necessity. We have got to get it done. It’s not something that’s going to solve itself or that somebody else is going to solve for us.

So, yes: we are trying to make history. We are moving the challenge to another level: we are trying to work globally. While maintaining our European political reference, we offer ourselves as a global point of reference to catalyze a global alliance against IBD. An alliance involving all other IBD patients organizations as well as considering other patients’ organization in the “immunomodulated disease” environment.

Somebody (can you believe this ?) considers us maybe to be too committed. My answer is that we are not committed enough. IBD is ready to use every weak point we may offer. So far, during 2013 I will go on motivating my team, telling to everybody a sentence that they do perfectly know: “Is this the best way you can play this?”

Because at this point, being able to find the energies for another step forward, can be the difference between winning or losing. “So, what about you ? Wanna sit on the bench, or wanna play in the World Series ?”



UNITED WE STAND

Marco Greco, EFCCA Chairman

# Creating stronger alliances for global fight against IBD

*by Claudio Fiocchi, M.D. Professor of Medicine, Cleveland Clinic Lerner College of Medicine, USA*



**Delegates of the World Symposium on IBD Research, Brussels 18 October 2012**

On October 18th 2012, a very special meeting took place at the historic Hotel Metropole in the heart of Brussels. A group of 70 people from 30 countries representing Europe, North and South America and Oceania gathered in one of the auditoria. They were not economists worried with current financial crises, nor were they politicians aiming at resolving international conflicts, or scientists discussing the latest development in crystallography, biology or astrophysics. So, what could possibly bring together such a diverse collection of people? What did they have in common?

The answer is simple: they all shared a keen interest in inflammatory bowel disease (IBD), a name used to describe two increasingly common and devastating types of chronic intestinal inflammation: Crohn's disease and ulcerative colitis. Why were these diverse individuals coming together among themselves rather than attending a meeting on the latest breakthroughs in IBD, establishing social support groups, or learning about the latest pharmaceutical drug developments? No, the reason is altogether different: these people came together to learn about each other, to learn how different patient associations in different parts of the world deal with IBD at the human

level, to hear how each group and each person in each group can contribute to advance knowledge of the disease by supporting research and raising funds for more and more studies. These noble and laudable objectives became a reality thanks to EFCCA, an all-inclusive lay organization whose main goal is to bring together whoever has a medical, personal, familial or social interest in finding a cure for IBD.

**Marco Greco:** "Research is the main pathway that leads to a better future for people with IBD. Through it we will be able to determine the causes of IBD and hopefully a cure. In a word, research means "HOPE" to us. I hope this Symposium will become the first step towards a stronger global alliance against IBD."

The atmosphere at this very first international EFCCA meeting was openly friendly, but also full of excitement, energy, curiosity, and expectations. These feelings were almost palpable in the



**Prof. Beaugerie and Prof. Fiocchi during the panel discussions**

auditorium as, one-by-one, individual representatives of different patient organizations took the podium to present what research their groups sponsored in his/her country, how they assembled resources to support their efforts, and what success or difficulties they encountered. Differences among patient organizations in various countries were obvious.

This was so because of multiple and disparate reasons: the structure and strength of individual associations, the financial situation of the association or the country they belonged to, the number of IBD patients in each country, and how long IBD has been publicly recognized in their area. Despite these glaring differences the spirit and the goal of all participants was uniform: “we need to do more” to cure IBD.

**Prof. Fiocchi:** “The cure of IBD requires joint efforts by multiple groups such as researchers and patients organisations as well as a great amount of financial resources. Patient’s organisations should play a leading role to address these resources in the best possible way”

To reinforce this goal and putting it in the right perspective four internationally recognized IBD experts, in the basic and clinical sciences, were also present namely Professor Gerhard Rogler from the University of Zurich, Professor Laurent Beaugerie from the

Saint-Antoine University, Prof. Silvio Danese from the Sacro Cuore University, Rome, and myself. We offered personal but complementary views on where IBD stands now, how research is improving, what direction science should take, and what the best possible avenues should be for IBD associations to help.

Many lively discussions took place, all of them translating enthusiasm, commitment and hope for a world free of Crohn’s disease and ulcerative colitis. At the same time, all present were acutely aware that the challenges ahead are enormous: challenges due to the biological intricacies of the disease, its protean and relentless clinical manifestations, and the always limited financial resources to study more and understand better.

**Prof. Rogler:** “Research funds should go to the best researcher, not to “your local researcher”

At the conclusion of the meeting Dr. Marco Greco, the Chairman of EFCCA, put all of these challenges in perspective and outlined a realistic pathway in simple but decisive terms: first of all, he reaffirmed that “United we stand”, the logo of EFCCA; then, he highlighted the need for continuous integration and cooperation, stressed the importance to make all possible efforts to raise funds, and to be honest and insightful enough to choose the most meaningful projects. Strength is in the numbers, especially when strength is accompanied by good intentions and smart choices, and EFCCA is there to help patient organizations worldwide to use this unified strength to win the war against IBD.



# EFCCA Summer Camp Training

France, Portugal, Spain, Poland, Finland, Switzerland and United Kingdom: you are not reading the seven finalist countries of Euro 2013 but the countries (well! their delegates) that participated to the first 2013 EFCCA Summer Camp Training. If you are wondering about the next step about the EFCCA summer camp, you have to read the following lines.

From the 9-11 November 2012 Laurinda, Vera, T i p h a i n e , Magda, Pawel, Livia, Kathy, Sergi and Harri, leaders of the 2012 summer camps and leaders of 2013 camps met in Brussels to share their experiences, ideas and - above all - their enthusiasm and curiosity.



**Participants at the summer camp training at the EFCCA offices**

EFCCA Summer Camp organiser, Chayim Bell, was there to facilitate the discussion and put his long term experience at participants' disposal.

The meeting was kicked off by Mr Marco Greco, EFCCA Chair. For this occasion, the EFCCA office in Brussels was transformed into a "learning room" where delegates shared their views on how the next EFCCA summer camps should be run. New activities and problems were discussed giving everyone the opportunity to present their experience and raise questions. This intense brainstorming day helped to identify several new activities such as: Hot-Tub (Finnish style), Risotherapy (the "Laughing therapy"), Do-in

(a self-massage technique), Karaoke, Flash Mob, etc. But also different workshops were proposed such as therapeutic education, "Sex, love and IBD", "Self-confidence", "Impact Result", "Resilience Factors" and "Fatigue and Anaemia".

Part of the training dealt with problems and risks you may face organizing a summer camp. From a list of common problems (as experienced during previous

camps or risks to be prevented) the delegates shared strategies and solutions to solve them. It was an intense day of training that paved the way for some exciting camps to be held in 2013.

In 2013 EFCCA will support around 8 summer camps. To obtain

the EFCCA label, which implies receiving some economic support, applicants have to respect some criteria such as: implementing at least one activity presenting EFCCA and be open to other neighbour country participants (a full description of the criteria can be consulted writing to the EFCCA Office in Brussels).

The next round of summer camps promise to be amazing so if you have not yet asked for information, you should start planning to do so soon!!!

Andrea Broggi,  
EFCCA Policy Officer

# Cross-diseases co-operation taking shape

## Meeting between immune-modulated diseases patients associations: EFCCA, AGORA, ASIF and IFPA

On 17 November 2012 EFCCA was pleased to welcome AGORA, ASIF and IFPA, three international organisations representing, respectively, people with Rheumatic and Musculoskeletal diseases in southern countries, ankylosing spondylitis and psoriasis.

For the first time a fruitful discussion about potential cross-disease co-operation and the possibility of developing a common strategy on how to gain positive results and achieve higher visibility and stronger lobbying capacity at a European and International level started.

After the associations presentations it was clear that EFCCA, AGORA, ASIF and IFPA are already sharing numerous common objectives and strategic points such as exchanging information, raising public awareness on the diseases, unifying global voice that supports their members towards unmet needs, encouraging scientific, social and other research into the causes, diagnosis and treatment. Besides diversity in terms of structure, organisation and agenda the opportunity of developing something together was then discussed. Our Chairman, Marco Greco proposed a concrete project which can become a real milestone for our four associations.

In the past year EFCCA has worked for seeking funds and expertise for developing the content of a double book presenting biological treatments to patients and to general practitioners. Biological therapy is nowadays the new frontier in the treatment of immune-modulate diseases.

In its daily work with members and people with IBD EFCCA has noticed that there is still a lack of understandable information and some misunderstanding about it either from the patients' and GP's side.

The four associations had the chance to discuss EFCCA's core idea to produce a "modular" book in which, besides the general presentation of biological treatments, specific groups of patients may have a dedicated chapter. In the same way doctors may have general scientific information and more specific knowledge according to different diseases. In order to reach the widest audience and the highest dissemination printed and electronic versions would be published. AGORA, ASIF and IFPA agreed on the importance of such a tool and we really hope that in the coming months the books on biologics will take shape.

Elaborating a double book addressed to patients and GPs may then be a useful step towards better knowledge and a more proactive role of patients in their daily fight against their disease. The collaboration of the four sister organisations will be a powerful tool to develop an immune-modulated patients' organisations alliance able to rise higher the item on the WHO agenda in the coming years.

Luisa Avedano, EFCCA Chief Executive Officer

**Left to right: Seoirse Smith ASIF, Suzi Makri Agora, Lars Ettarp and Kathleen Gallant IFPA**





# Meet the European Youth Group

Following the EFCCA Youth Meeting in Copenhagen, the EYG saw a lot of new faces join both as full group members and as substitutes and also a new leader after being in the safe hands of Chayim Bell for several years. So now, we introduce to you, the new EYG who are ready and willing to work on behalf of youngsters with Ulcerative Colitis and Crohn's all across Europe!

## Daniel Sundstein, Leader



I'm Daniel Sundstein and I was born in Holbaek, Denmark in 1985. At the moment I'm living in Copenhagen with my girlfriend and working as a physiotherapist at a private clinic. I have had UC since May 2007 and attended my first EFCCA Youth Meeting in Paris in 2008. Later on I joined the EFCCA Youth Group as a substitute in Amsterdam 2009 and was elected as a full group member in Norway 2010. I was the organizer of the EYM 2012 in Copenhagen and was re-elected for the EYG in 2012 as well. I was also elected EYG Leader at the meeting in 2012 in Copenhagen.

## Claire Hunt, Group Member



I was diagnosed with Crohn's disease at 15 and had a Ileo-caecal resection and partial hemi-colectomy at 17. I became a member of Crohn's and Colitis UK in 2009 and began fundraising for the charity. I then joined the CCUK Patient Panel and managed the Birmingham children's hospital IBD youth Club. I joined Twitter and Facebook in 2011 and created IBD support groups to meet other sufferers and learn more about IBD. I have since developed a large support group with over 1000 members.

I was asked to join the CCUK youth committee and was sent to Copenhagen for the EYG meeting to represent the UK where I put myself forward as an EYG board member and was elected in 2012. I am currently studying children's nursing at Kings college London where I hope to train as a specialist IBD nurse.

With the help of the EYG I hope to develop many new projects including: an IBD summer camp in the UK, leaflets and talks that

target schools and education, an IBD youth club aimed at teenagers, more hospital patient panels, IBD days out for young people, the use of social network sites and you-tube to help spread awareness and develop support systems, counselling available for young people and access to dieticians and dietary advice for teens.

## Tiphaine Chapeau, Group Member



My name is Tiphaine Chapeau, I'm 24, French and I will soon receive my master's degrees in International Affairs, Governance and Security from Sciences Po Paris and the University of St. Gallen. I have been diagnosed with UC in 2006 when I was 18 and just starting my studies in political science. In my case, all treatments failed during the first year with UC and I survived in very challenging and traumatising conditions. Since that moment I have been living with a pouch which significantly improved my quality of life.

Two years ago, I decided to dedicate myself to action within our common fight against IBD. Now I am a board member of the

French IBD association, AFA, as well as delegate to EFCCA and European affairs, and leader of the AFA Youth Group. In 2011 I was elected as EFCCA Youth Group member. For two years I have been intensely involved in organising educational programs for young people in France and exchanges of best practices in Europe, as well as in lobbying and raising awareness about IBD, their impacts and the necessity for patients to be listened, believed and supported. My purpose and conviction: the empowerment of patients as the key players and decision-makers of their lives and caring processes, and their equal right to reconstruction, rehabilitation and resilience despite IBD.

**Sara Byrne, Group Member**



My name is Sara Byrne, I'm 22 and I'm from Ireland. I am currently training to be a chartered accountant and tax consultant. I was diagnosed with Crohn's Disease when I was 15 years old and had an ileocolic resection when I was 17. I have enjoyed relatively good health since then (besides a few "minor" hiccups) which has enabled me to become more proactive with the Irish Society of Colitis and Crohn's Disease Youth Group and now, also the EYG.

My first experience of EFCCA came in 2010 when I attended the inaugural Catch Your Dream Summer Camp in Apeldoorn, the Netherlands. I made lifelong friends at that event and it encouraged me to become more involved with other European wide events. My aim in joining the EYG is developing more communication between all European Youth Groups to come together and fight our cause for more rights across the continent. I'm also interested in learning of other IBD patients' experiences within their health system and what difficulties we all face in college and beginning our working life.

**Arron Gill, Group Member**



My name is Arron; I'm 24 from Leeds in the UK. I'm currently a member of the EYG Board and have been since 2011 attending my first EYM in Norway 2010. I'm also the EYG representative on the European Patients Forum (EPF) Youth Group and EPF Strategic Planning Working Group youth representative. I was diagnosed with UC in 2006 and during the subsequent year underwent three operations to create an ileo-anal pouch. As a result of my experiences I also work within colorectal

surgery as an operating department practitioner. During my spare time I enjoy playing football, skiing and riding my motorbike.

**Chayim Bell, Substitute and Former EYG Leader**



My name is Chayim Bell and I am 29 years old. I am currently living in Alphen aan den Rijn, the Netherlands. I got diagnosed with Ulcerative Colitis in 2001 and got a pouch in 2002. I have been active within the EYG for 9 years, first as a delegate and then later as group leader. In 2008, I also became a board member of EFCCA and in 2009, I was elected as secretary. In my daily life, I work as a teacher's assistant and IT consultant for primary schools (pupils between 4 and 13 years).

**Kata Daru, Substitute**



My name is Kata Daru from Pécs, Hungary. I am 28 years old and I have had Crohn's disease since 2009. I am extremely lucky, be-

cause I haven't had very serious problems with it so far and my family and friends have always been really supportive. I consider my father the best "coach", who has stood by me from the beginning and made me understand that I am no different from the others and deserve the best, just like anyone else.

In the year of my diagnosis I joined MCCBE, where I worked as a volunteer for 2 years. By now, I am a board member and responsible for international relations and youth. I am sorry to say, we do not have a youth group yet, but we have made steps to establish it in the near future. I feel extremely happy to be part of the EYG team, because as a substitute I can help the board members and learn a lot. I am currently co-working on the Youth World IBD Day. I believe that we can make a change in the life of people with IBD, especially the youth, because all of us deserve a chance for a happy and quality life, and a hope for a better future.

#### **Steffi Weber, Substitute**



My name is Steffi and since 2011 I'm an EYG substitute. I have had ulcerative colitis for 16 years now. Since the first moment, I was supported by the German association

DCCV e.V. and its youngsters. It helped me a lot and that's the reason why I want to give back a piece with my volunteer work. It is a pleasure to work in the EYG-Team. Next year we will celebrate the 10th birthday of the EYG in Stuttgart. I'm very looking forward to organizing this meeting.

#### **Margriet Gritter, Substitute**



My name is Margriet and I'm a member of the Dutch association CCUVN Jong and a substitute of the EYG. In 2010 I was diagnosed with Crohn's disease, luckily my GA quickly sent me to the hospital and it was discovered very fast. After a year, and a couple of medicines later, I started with a treatment which has made my life more normal although I see my bed more often than a normal 25-year-old person.

I work at a publicity department of a book publisher, my focus lies on children's books and Young Adult titles. But as a junior you do a lot of stuff, also the boring things like sending books to the press and printing manuscripts. But being surrounded by books makes up for all that ;) For my association I do also a lot of different things; I'm editing blogs, think up contests and take care of the

social media. I like to be so busy with the associations, it is my way of dealing with Crohn's. Not to give up, but look at the bright side of it. And meeting new people, helping them and see them change during the time really makes me happy.

#### **Victoria Cleary, Substitute**



My name is Victoria Cleary - I was first introduced to the EFFCA EYG when I was sent from the Irish society "ISCC" to be a delegate in Poland in 2011.

I was so excited during my time in Poland as I learnt so much and I was very happy to bring everyone's ideas back to Ireland. I put my name forward to be a substitute to learn what was involved in being on the team, I am so glad I did as we had great success in Denmark 2012. I decided to stay as a substitute as my husband and I are expecting our first child in February 2013 and I knew I would not be able to travel to meetings. I was diagnosed with Crohns Disease when I was seventeen years old in 2001. I run a successful holistic centre in Dublin. I try to combine mind, body and soul in all my treatments.

# EPF Youth Meeting provides EYG with key Role in EMPATHY Project

by Arron Gill, EFCCA Youth Group Board Member

Cooperation amongst youth groups throughout Europe has now become a customary item on the agenda of European Youth Group meetings in recent years. Our hunger to collaborate and exchange best practice led us to try cooperating with the Coeliac Youth of Europe (CYE) when we invited them to attend our EFCCA Youth Meeting in Norway 2010.

Although this relationship never prospered we have once again come back into contact with the CYE however as a member of the European Patients Forum (EPF) youth group. The EPF Umbrella provides a much stronger foundation along with eight other youth associations for us to work with and has already delivered some promising results for the EYG.

The second EPF Youth Meeting was held in Malta earlier this year and focused on two main areas, strategic planning and a new project developed by the EPF Youth Group called Empathy. Empathy stands for 'Europe Meets young patients' and will be a seminar involving approximately 30 young patient leaders including members of the EPF Youth Group, 15 Stakeholder representatives, including senior patient representatives and 10 Policy Makers. (For more information please see previous issue of this magazine).

The seminar is aimed at promoting a more holistic approach to young patients need at EU level. Furthermore it will provide a better understanding of how young patient leaders can approach these subjects.

The meeting in Malta was aimed at generating

ideas, many of which had been raised during last year's EYM in Copenhagen. The ideas were based on four activities which will take place during the seminar. One activity in particular was 'a day in the life', (which the EYG representative is currently collaborating with another youth group representative to organise) aimed at placing a policy maker in a patient's position over the course of the seminar. This enabled the airing of two IBD related videos, one from the Norwegian association LMF and a documentary made during the EYM in Poland (2010).

More significantly the potential to use these videos within the seminar was suggested and when we consider the potential representatives at the Empathy meeting this is an excellent opportunity for the EYG to place IBD related issues at the centre of some of the activities during the seminar.

The final day focused on strategic planning again allowing issues amongst young people to be aired and considered when planning during the future.

Furthermore I was fortunate to be elected to the role of EPF Strategic Planning Working Group youth representative and therefore will be able to represent young people with IBD and the EYG at a higher level.

The second EPF youth meeting in Malta allowed the EYG to establish a solid foundation within the youth group and take leadership of a number of tasks both during the up and coming EMPATHY seminar as well as during future projects. The influence provided by this relationship has already shown promising signs and the EMPATHY Project should help develop these into more solid foundations in future.



## 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.



# Strength in numbers

## Interview with Richard Driscoll, CEO, Crohn's and Colitis UK

Richard Driscoll, chief executive for Crohn's and Colitis UK has seen the charity grow from 14 000 members to its current 30 000 members and from 40 local groups to up to 70 local groups and a much wider range of activities. In recent weeks, after 21 years of working as chief executive, Richard has decided to leave the association in order to get a better work-life balance and spend more time with his family. We have taken the opportunity to talk to him about Crohn's and Colitis UK and to share his long standing experience of working with a patient association.

**Crohn's and Colitis UK is a huge association in comparison to other European IBD associations. How do you achieve such a large membership?**

It's quite a large membership even by UK charity standards and I think we are successful both in recruiting and keeping people as members. I believe that one of the key things is that from the very beginning we have established the health professionals who care for patients as partners in the organisation. Having been included from the early days in the development of our association, they feel that we are trustworthy and that they can refer their patients to us without any reservation because of the value of our information, the publications and the support that we provide. Healthcare professionals are also aware that patients can campaign very effectively. We have been involved in campaigns which have resulted in extra resources in the national health service, for example we now have around 300 nurses specialised in IBD in the country whereas maybe 10 years ago there were only 30 or 40 IBD nurses.

Another aspect is that we have always tried to be very close to people with IBD. We describe ourselves as a member-led association and we have over 1000 active volunteers who are very important to us. So even though we have grown quite large as an association we have managed to maintain quite a strong "family feel"

and that makes people feel at home and loyal.

We also keep our subscription quite low which means there isn't a financial barrier to people joining and if they then want to add a donation they can do so.

Our membership stays around 30 000 because we have the same number of new patients joining each year as leaving. We have asked people why they leave and often it is actually for a positive reason and not anything that is wrong with the association. It is as if they wish to take off the "IBD badge" when they are feeling better and are in remission. We are very happy to have people come and go as they need to. We are always there when they need us.

**What are currently the main areas of activities of Crohn's and Colitis UK?**

Our activities can be placed into four main areas: information, support, influence and research.

**Information** covers our information service for anyone affected by IBD. We get over 5000 calls or enquiries for information each year and we have a team of 4 staff members who respond to those enquiries. Additionally, we provide over 50 publications and have an accreditation from the UK government which means that all our literature can be used freely in the National Health Service by the hospitals. A quarter of a million publications are downloaded from our website each year.

We are not only informing individuals but also organisations for example providing universities and employers with leaflets that help them understand the needs of people with IBD. Finally, we go even broader and raise awareness of IBD with the public at large. About four years ago we did a survey which showed that the awareness of Crohn's and Ulcerative Colitis was lower than other conditions which were

not as prevalent such as Multiple Sclerosis or Parkinson disease. We also found that Crohn's disease was better known than Ulcerative Colitis. When we looked at younger people we found that the knowledge and awareness was even lower than amongst older people. This is something very important for us to correct as half of the people diagnosed with IBD are people in their teenage or 20s.

**Support** includes our helpline with volunteers who are available on the telephone to talk to people. Very often it is not necessarily the patient that might ring up, it may be someone in the family or a friend who is struggling to understand how best to help somebody or it may be patients who feel that they got all the information they need but want to talk through the problems they are having in living with this condition.

We have a special line for parents who want to talk to other parents and we also have some trained volunteers who can help people in applying for their disability benefits which is often a very difficult thing for people to do. In their daily life they may actually more or less cope with their illness but when it comes to applying for the disability benefits they have to really think about all the ways the illness makes life difficult for them or even impossible. The volunteer helps them to talk through how to explain this. It's quite an emotional thing to do and they need to express their illness in the right way for the assessors of the disability benefits to understand the real impact of the condition. Support also includes our 70 volunteer Groups all around the country that provide local support through meetings and other opportunities to get together, to raise awareness, to do fundraising, or just social activities.



Another main area of activity goes under the heading **“Influence”** where we try and influence public and private organisations to understand IBD better. I mentioned universities and employers earlier: they are really important for us and we have done a major piece of work on the impact of IBD on peoples' employment over the last two years. We are really trying to find opportunities to talk to employers and their occupational health staff and recently we had the opportunity to talk to the occupational nurses for TESCO,

one of the biggest companies in the UK. It was really helpful because they have many employees with Crohn's disease or ulcerative colitis and the company nurses didn't really understand inflammatory bowel disease very well.

Influence is also about raising the profile with government, making sure that they take account of IBD in all the activities

that they do. At the moment there is a real issue in terms of the cuts to welfare benefits that are being proposed making the criteria for people to get social security benefits much harder. We are working with a group of other charities with the government department to try and improve the eligibility criteria so that they take account of continence issues in an appropriate way and things like fatigue but it's quite hard to get that message across to officials. Just as important is lobbying to get health services improved. Crohn's and Colitis UK is part of a consortium with health professionals to run a government funded audit of IBD care and a quality improvement programme.

The fourth main area of activities is **research**. We fund research in two different programmes, one is

medical/scientific research looking at the causes of IBD and whether/how treatments can be improved. The other research programme looks at the impact of IBD on people's lives and how people can live best

undertake fundraising. It has been difficult over the last couple of years but we find that we are getting more and more friends and colleagues of people with IBD beginning to understand the impact of the illness

and these people are helping to raise funds through running marathons, doing challenges, skydiving, etc and raising sponsorship money for those activities. It has been a really important growth area: in 2012 we had our best year ever with Great North Run in Newcastle. We also organise some very big national walks when we invite our members to raise awareness and funds.

We get some support from pharmaceutical companies but we don't allow that to be more than 10 % of our overall income so that we maintain our independence as an association.

Legacies and in- memory

donations are an important source of income as well. For the research side we sometimes manage to raise external funds, so we have a project on IBD and fatigue where we applied for and got a half a million pound grant from the national lottery but that's an exceptional achievement. Our day to day money is from people who have the condition and their friends and families.

### **What's your feedback to the research symposium that EFCCA organised last month?**

I thought the chance to share our research programmes and learn about the research programmes from all the other IBD associations was really valuable. I think it showed that we have some areas of common issues in terms of raising money and deciding how best to spend the money but there were also example of how people do things quite differently



**Richard Driscoll during a Croun's and Colitis UK fundraising event**

with the illness. For example we have just had the report in from a project that looked at incontinence: how people actually cope with incontinence in their daily life with IBD and how we can help health professionals to provide more support for the patients. It's very practical research that often uses the experience of our members as the starting point to try and develop and share good ideas. It also influences the services we try to provide: the knowledge from the research informs the responses that our information officers give on the information line.

### **You have a yearly research budget of around 500,000 pounds, how do you manage to raise these funds?**

We do not get any government grants and are relying entirely on members, their friends and families or work colleagues to either donate generously or to



and it was good to understand those and have some new thoughts for our own strategy.

I think one of the questions has been a worry that the money spent was duplicating research across the different countries. It's hard for patients and families to raise money and they need to know that it is being well spent. I was reassured because, although we have some similar research programmes, I think that we are funding different sorts of projects across the different associations. What we are not doing very well is sharing the reports and outcomes of our research and I think this meeting will mark a change. I hope it will happen maybe every two years allowing us to build networks so that we share our research results more.

### **What's in store for 2013?**

Besides our usual activities as described above, we have an exciting challenge in 2013 which is our campaign "Facing the Future: IBD, School and Beyond". What we are looking at are the difficulties faced by teenagers and young people when they are at college or starting work as well as people into their twenties when they are starting new relationships. We have a number of plans to try and identify what their needs are and find out how to help with those. For more detailed information please consult our website at: [www.meanibd.org](http://www.meanibd.org)

On a more personal note, I have recently announced that I have decided to leave the association after 21 years. It has been a difficult decision as I feel the staff, members and health professionals are in a way like an extended family to me and I will miss working with them. However it's time to get a better work-life balance and I hope to continue working part time with patients and patient organisations, but in a freelance role which will mean I have more time to spend with my family and my new grandson. It's really a lifestyle choice but I hope to maintain my links with the association and the many friendships that I have built up. We have appointed a new chief executive, David Barker. He has been working for some years in some other health organisations and brings good experience to the role. I wish him every success taking over as chief executive.

## **Italy**

### **IBD CONNECT PROJECT**

The IBD Connect project (Communication To Guide Patients Towards Disease Control), intends to: improve physician–patient relations, improve understanding of the disease, harmonize mutual expectations, improve understanding of risk/benefit ratio, increase acceptance of therapeutic plans, improve and support results obtained, and to finally improve compliance.

Motivational Interviewing have in recent years been used in the healthcare field internationally with a view to fostering a more effective doctor/patient relationship, for better treatment compliance and to facilitate modification of unhealthy lifestyles.

Scientific evidence confirming the efficacy of motivational Interviewing in this field is very encouraging; the validity of this approach has been demonstrated by several systematic reviews of health care studies and surveys.

The "IBD CONNECT" project, which may very well be the most important one to have been organized by AMICI in 2012, and possible thanks to the support provided by the company Abbott, is the very first Italian experience in providing specific training for gastroenterologists devoted to treatment of Crohn's disease.

Why is it necessary to improve physician–patient communication when dealing with chronic IBDs?

Two surveys have recently explored the impact of Chronic Inflammatory Bowel Diseases on the quality of life of patients. Both the IMPACT survey conducted by EFCCA in 26 countries (6,000 questionnaires collected, 1,000 out of which in Italy) and the DIOGENE survey carried out by AMICI in Sicily (324 questionnaires) have underscored the need felt by patients interviewed for more and better quality communication

with their physicians. More specifically, and in Italy in particular, 81% of people interviewed reports having adequate access to their specialist but that often (in 53% of cases – IMPACT survey) they experience distress at having forgotten something important they meant to tell their physician during the visit.

Building upon this finding, therefore, the project intends to improve several elements which characterize the relationship between physicians and patients by means of a 2-phase approach: training events for clinicians and a series of events held at several reference facilities to promote communication between patients and clinicians. The nationwide training event was held in May in Milano and was attended by a group of young gastroenterologists affiliated to reference centers, and conducted by two national IBD experts (Marco Daperno and Michele Comberlato) and by a Motivational Interviewing expert (Valerio Quercia).

Thereafter, in collaboration with several participating reference IBD centers and with a view to translating into practice the skills acquired during the national course, the association organized a first series of nine meetings in 2012. The objective of the training seminar was to provide attendees with useful suggestions to improve their relationship with their patients by putting into practice several Motivational Interviewing skills.

The enthusiastic response of attendees at the Milano seminar goes to prove that physicians are fully aware of the importance of improving the way they relate to their patients, especially when addressing issues such as the need for lifestyle changes and therapy compliance during visits. On the other hand, international research exploring patient perceptions have confirmed that patients deeply feel the need for being welcomed and attentively listened to by their physicians.

It was pointed out, also during the seminar held in Milano, that it is important also for the nursing staff, that very often works in close contact with patients, to adopt these skills. The approach used for the Milano seminar was the

same used during motivational Interviewing training, and underpinned by the awareness that taking part in the training called for a change in relationship modalities. During the training event, the main principles and techniques taught were to be adopted to teach modalities group leading skills, focusing on the needs and viewpoints of physicians without however neglecting needs of patients.

“During motivational Interviewing – explained Dr. Valerio Quercia, the motivational Interviewing expert conducting the physician training event – the communication style adopted by physicians aims at creating a collaborative relationship with the patient. Such a relationship on the one hand upholds the physician’s clinical knowledge but on the other allows the patient to state his/her point of view regarding the change in habits and lifestyle: all this occurs in an empathic and nonjudgmental atmosphere”

“We must admit we initially were somewhat skeptical about this program – said Dr. Michele Comberlato (tutor for the national training course together with Dr. Marco Daperno) but as time went by and we “trained” to improve our communication skills, we realized it would allow us to meet patient needs that we hadn’t even been aware existed”. “We believe that the intervention of the IBD-CONNECT project – explained Dr. Marco Daperno - might have a major favorable impact on the day-to-day management of the physician-patient relationship. The process of changing entirely our communication modalities and listening more to our patients is neither easy (our time constraints are getting more and more demanding), nor quick, but one small step after another, we have been experiencing new ways to interact. We will try to use them more and more during our clinical practice”.

Thanks to meetings organized throughout Italy, patients will be able to enjoy a new relationship with their physicians when discussing the best strategies to manage their disease. For more information and for event calendar, visit the AMICI Onlus website [www.amiciitalia.net](http://www.amiciitalia.net)

# Finland

## VESSAPASSI – Passport to Open Doors?

CCAFIN released a membership card in the beginning of 2012 with a passport to toilets on the reverse side of it. VESSAPASSI, as it is called in Finnish, comes from the words vessa, an everyday word for a toilet, and passi meaning a passport. This is a nice bonus of our Finnish language, the word rhymes nicely and rolls cozily in the speaker's tongue making it easy to remember.



The concept of VESSAPASSI is not new. Many countries have their own toilet passports for IBD pa-

tients. Our aim is to open all toilet doors in Finland for IBD patients - a huge task since many doors still stay tightly shut. It will require years of hard work, but at the end of the day we want every shopkeeper and every man in the street to know what the word VESSAPASSI, not only means, but what is behind it.

Our simple tactic has been to appeal to shopkeepers by reminding them that people with IBD are, like any handicap group, the group which needs attention. It is common to have invalid parking spots close to exit doors and ramps for wheelchairs and buggies, so there is really no excuse to treat IBD patients differently. Opening the toilet door, even if it is a toilet only for staff, is a free and easy way to help. Doing so, shopkeepers will not only improve the lives of IBD patients, but also gain new customers.

So far VESSAPASSI has turned out to be a success story. Never before in Finland has IBD had media

coverage as widely as it has during the past eight or nine months. Once news about VESSAPASSI and information of IBD got on national TV it started to spread like wildfire. After TV followed nationwide newspapers and magazines, then radio and local papers and finally national news bulletins.

We started VESSAPASSI as an experiment, but it has proved its value and is here to stay.

## Twisted Bowel – a New Book for Children

In collaboration with Otsuka Pharmaceutical CCAFIN has published a book about IBD called “Mutkikas suoli”, Twisted Bowel. It is a book about children with IBD for children with IBD. It also works nicely as a guidebook about IBD for children who don't have IBD. The book is meant to be distributed to hospitals, schools, libraries, homes and where-ever knowledge about IBD is needed to be presented to children.

The book tells about Anna and Elias, two kids with IBD, their friendship and lives with IBD at school, home and hospital. The book is written and illustrated by Eeva-Kaisa Suhonen.

## New President at CCAFIN

Marika Armilo was elected as new president of the Board of Directors of CCAFIN for the year 2013. Marika has been board member in 1998-2003 and then since 2008. In 2011 and 2012 she was elected as a vice president of the Board. She has also represented Finland in EFCCA for several years and at the moment is acting as vice president of EFCCA as well as member of Board of Directors of the IBD Research Foundation.



**Marika Armilo,**  
new CCAFIN President

Tiina Silvast, CCA Finland

# Sweden



Scene from one of the short films about IBD

## IBD by remote control

1.5 million Swedes are living with a gastrointestinal disease and still it's not widely known that you can get one. This has to change. And the project "IBD by remote control" is one way to try to do so.

The project consists of a website with information about IBD and the project, as well as short films about IBD that link to the website. The short films are either films that show different situations that may occur when you have a gastrointestinal disease or films where a celebrity, such as an artist, comedian and/or politician, "borrow" IBD from a person who has it. The celebrity then gets text messages in their mobile phone during the day with instructions on what to do. For instance that they have to run to a toilet really quickly, regardless of what they are doing at that very moment.

The idea of the project is to make people watch and share the films, visit the website and tell their friends about it, in order to spread knowledge and awareness about gastrointestinal diseases and IBD. We use the social media to disseminate the films and the project website gives people the opportunity to ask questions to a doctor.

"Help us share this project on Facebook and other social medias sites. Make your surroundings aware about what IBD really is. We have to dare to talk about these diseases. We believe that short films can be one way to do it" says Wictoria Hånell, administrative director at Mag- och tarmförbundet – the gastrointestinal association in Sweden.

The first films were launched at a seminar during The Almedalen week,

which is a week where politicians, organizations and others meet to discuss political matters.

"The initial idea of the project idea comes from Norway and we got the permission to pursue their campaign", says Wictoria Hånell. The project will run until December 2013 and will hopefully be a fun yet serious way to let the public, politicians and others know about IBD. The address of the website is <http://magotarm.se/ibd>.

Ebba Persson, for Mag- och tarmförbundet

# France

## afa web TV

The afa web TV was developed thanks to afa volunteers, and amongst them our afa Secretary General, Provence Côte d'Azur Delegate, Eric Balez.

Eric is creative and full of energy; he's a pioneer in therapeutic education, the man in the IBD Mont Blanc adventure, the film which is still showing from town to town, from prize to prize !

With Web TV, patients aren't alone, they can compare their day to day lives, question health professionals who know the answers, undertake procedures involved in their daily lives and legal problems.

There are now 4 channels :

1)patient testimonies on their daily life

- 2) medical testimonies from doctors and other medical professionals
- 3) researchers testimonies
- 4) finally, those from association consultants and partners.

Along the same line, ANSM (our medicinal agency), have given us a prize of € 25 000 to make a film destined to inform patients on biotherapy: “Explain biotherapy to me... patients want to know”. This film can be shared in education therapy for all chronic disease patients interested in biotherapy.

In future, two other channels will be available. One will be dedicated to patients’ rights. The other will be directed towards young patients who are the biggest population concerned by IBD and really “into” this model! Watch us on [afa.asso.fr](http://afa.asso.fr)

Chantal Dufresne, afa Chairperson

## The challenge of finding toilets!!!

There are times IBD patients need immediate access to a restroom facility. However, these facilities are not always accessible, especially in retail establishments that limit use of restrooms to employees only.

Since the 3rd French National IBD Day, afa has written up a Book of Proposals called the “Livre-Propositions” which has been sent to political decision makers all through France. Its contents are a constructive summary of the 1st States General on Intestinal Bowel Diseases, in March 2009. Article 7 of this book talks about the need to make available to IBD patients public and private toilets in urban areas all over France.

Of course, this issue concerns not only IBD patients but anyone and everyone in need of toilets while outside of their homes or workplace. However, many IBD patients no longer dare to leave their home not knowing where they can easily access clean toilets in an emergency and free of charge or any explanation.

Several cities (Agen, Rostrenen, Pau) have now signed convention between afa and the municipal officers along with restaurants, cafés, hotel union and merchant associations to make public toilets available in good condition when needed for the holders of the official European card delivered free of charge by afa to its members.

In the city of Pau, I have conducted a survey throughout the first 6 months of this year and

met about 30 different merchants ranging from restaurants, cafés, boutiques, pharmacies, hairdressers and paramedical offices, medical centers, etc.. The majority was very willing to learn about IBD and welcomed afa member card holders as well as other people needing quick access to toilets.

Pau is the city with over 50 000 inhabitants to have the most free public toilets with 23 new installations all to be finished by 2013. Now my task is to round up some volunteers to go to each store and eating place or café offering to install their address in the new smartphone application, *afa mici*, and asking them to put the new toilet access sticker in their window. I have also been invited by some merchant associations and the union to present afa and the new toilet accessibility convention in the coming months.

Madeleine Duboé, EFCCA French Delegate

### Municipal toilet in the city of Pau



# Spain

## Summer Camp 2012 in Cadiz

On a farm school in Arcos de la Frontera, where everything was uncertain to me, there I was, it wasn't far, but it felt like a long journey to me, I had high expectations. Once I got there I had the pleasure to meet all the 55 youngsters. Everybody was friendly, at the beginning we talked about our disease and how we were dealing with, but only at the beginning. The first night, we did very entertaining activities, laughs came easily, it began by presenting some people with a microphone as an ice breaker, after that we did many activities in order to start knowing each other. It was a well spent, funny night, I fell into bed exhausted and satisfied.

The next day we had outdoor activities related to a farm, like milking a goat or feeding animals. We rowed canoes (a lot of fun and exciting!), and rode horses (only if you could make the horse move), we also had beekeeping for the brave ones, zip-lining, and some even learned to make bread. All this on the same day. Before lunch the great Dr. Leon Peces gave us a talk about sexuality relating it to our illness.

At night there were again animation activities, this time we played a game in the darkness. We split into teams and chased and stalked each other with flashlights to steal points. A red man and his minions in black were all around scaring everyone and a woman with candelabra helped the needed. After the game we danced and partied.

The next day we went to visit Cadiz with a tour guide, I had no words to describe the wonders I saw. We ate at a nice restaurant, the food was good and we never got anywhere without drinking. After that, some of us went shopping and some went to the beach of La Caleta. Before heading to the farm, my President proposed me as youth coordinator of Malaga, and I accepted delighted for such an honor. We were back at the farm at dinner time, during the night a group of poets and singers charmed us with their performance.

There were also some interesting workshops. The first one taught by Dr. Francisco J. Correro about nutrition, the second one by Don Juan Manuel Picardo was on stress and relaxation. After lunch, we had a lecture about social relationships and a risotherapy workshop given by Doña Consuelo Lopez. The last workshop was on quality of life of the partner and patient by Dr Sixto Ruiz.

That night a magician amazed us with his tricks. Later, the new ones had to make a speech with the microphone expressing how they felt during these days, me and the organizer of the summer camp (Pablo Bella, what a wonderful guy) included.

Next morning we had to say goodbye . Everything good has to end. I hugged everyone because I wouldn't see them for a long time. I left with very good impressions, I felt at all times accompanied, understood, and well ... many wonderful things that I cannot describe. I was smiling all the time, actually I am still smiling right now as I write this and it feels like my disease is getting better. Thank you all for making this possible, many came to that special event, I hope next time we are even more!

Adrián Madueño Casado,  
ACCU Málaga youth coordinator.

## Everything about Crohn's – new booklet on IBD

A new booklet for Crohn's patients has been prepared by 36 IBD specialists. The booklet provides important information on Crohn's disease and how to live with it on a daily basis. It deals with a wide range of subjects such as for example general symptoms, impact of IBD on personal/sexual life, IBD and the work environment or searching the internet for further information on IBD. The main aim of the booklet is to support the patients and to improve their quality of life.

This work has been made possible by GETECCU (the Spanish Working Group on Crohn's and Ulcera-

tive Colitis) in collaboration with ACCU España (the Confederation of Crohn's and Ulcerative Colitis Associations) and under the patronage of Abbott laboratory.

The booklet is available for free from the ACCU's local associations.

Yolanda Modino, ACCU España

## Denmark

### The Danish Toilet book 2013 – now included with the Danish CCF

In Denmark, a good friend of toilets, is the annual "Lokumsbogen" or "toiletbook". If you like reading when using a toilet (and some of us do...) this is the book for you – especially this year. Five full pages of the book contains information about the Danish Colitis and Crohn's Association, and a lot of information regarding Crohn's disease, Ulcerative Colitis etc. And not to mention a section regarding EFCCA.

But Lokumsbogen is more than that. It is a fun book loaded with facts. You learn while you laugh and do what else you usually do, when visiting a toilet. Lokumsbogen saw its first toilet in 1999, and is in Denmark more or less considered a part of Christmas (the Holiday Season). That's when you receive it, as a present. But some can't wait, and get it themselves first on the 1st of November. The idea behind the toilet book comes from a journalist and an editor, both annoyed of reading declarations from the back of shampoo bottles etc.

Why not make a book with funny, interesting, unique and mind expanding facts and stories? So they did, and we all can sit back and reap the fruits of their doing.

The front page of Lokumsbogen 2013 has "Anbefalet af Colitis-Crohn Foreningen" (Recommended by the Danish Colitis and Crohn's Association) written

on it, and that is exactly what we are doing. Not only do the authors write about us and the diseases we have, they also gave us a substantial discount on the book, so our members would be able to get a very good deal.



Thanks to Lokumsbogen 2013, for letting others know who we are.

### Setting the political agenda

A discussion on the rights of people with chronic diseases for equal terms in the educational system took place late October at Christiansborg (where the Danish Parliament resides) with a full conference day and a concrete political move. This move may have significant meaning for a lot of young people with Ulcerative Colitis or Crohn's Disease.

Young people with a chronic disease find it much more difficult to finish education than their healthy class mates. For example, a young person diagnosed with Crohn's Disease will have more absenteeism, partly because he or she is not feeling well all the time, and partly because of examinations and treatment.

Too much absenteeism can result in a full syllabus, less funding or simply having the student being kicked out of the educational system. Besides the serious problem of high absence, young people with chronic diseases and handicaps often have extra expenses, which means that they e.g. have to pay for their medicine themselves.

These uneven terms became very obvious at the

conference “Monday is a crappy day”, arranged by the Danish Colitis and Crohn’s Association on October 23rd 2012 (see also previous issue of the EFCCA Magazine).

The 18 year old high school student, Kristoffer Brix Larsen, spoke about the difficulties of having Ulcerative Colitis and being at an age where you are in the making of your own identity. And how it feels when all your friends are able to enjoy sports and other leisure activities, and being considered “the strange guy that always has to go to the bathroom”. The latter because you don’t feel like going public with your embarrassing disease, and telling everyone about the balance of having an active disease and staying in the classroom at the same time.

### **Vast expenses on medicine**

Kristoffer Brix Larsen made it very clear, that he was one of the lucky ones. He had parents with enough money to pay for his medicine - every month. If he had to pay for the medicine himself he would have approx. 400 DKK (~ 50 €) left of his educational monetary support.

He is also lucky with his principal, because he knows

what IBD is, and Kristoffer did not receive a warning when he had 10 percent absenteeism. If he did, he would probably face a full syllabus and no financial support from the system.

His classmates did not know about his condition before he had to be admitted to a hospital, but after telling about his disease, it became much easier for Kristoffer to be a part of the class.

### **More Chronics demands a flexible society**

The problem in Kristoffer’s situation, and also for many other Chronics, is more visible now because the current Government has set a goal that 95 percent of all youth must, as a minimum, finish a secondary education. But 13 percent of all youth between 16 – 24 years of age have a handicap or a long term restricting disease, and it will be necessary to ease their conditions in the educational system to achieve the goal of 95 percent.

According to Chairman of the Danish Patients, Lars Engberg, patients with chronic diseases are very often engaged in their own disease and would like to handle it as much as they can. But the society must be supportive and focus on individual needs, better mobilization of the patient’s

### **Uneven conditions of the chronic diseased were on debate at Christiansborgs**





resources, more relevant treatment and better access to it.

### **It pays off**

Health Economist, Jakob Kjellberg from the Danish Institute of Health, made it very clear that the chronic diseased are not a burden to the Health System if you compare it to how little they can contribute to the society, if they don't get the help they need. There is a great potential by influencing the educational system and working relations for the chronic diseased. It is actually incredible cost-effective doing so.

### **Concrete suggestions for improvement**

The chairman of the Danish High School coalition, the Chairman of the Danish Commercial School Association and the Danish Colitis and Crohn's Association, have been working on what exactly was needed done to help the Chronics.

The political initiative consists of two suggestions. The first is a handicap contribution to the existing educational funding. This will help paying the expenses not covered by a Health Insurance or other types of rebates and it will also make it fairer, since a lot of e.g. chronic diseased are unable to have a job after school. The second suggestion points out a lot of changes in how the absence regulation should be maintained at the Secondary Education schools.

For instance it is desired that the absence regulations are the same, and not up to a principal's interpretation. Furthermore the period could be extended as it is allowed in Team Denmark, where an athlete is allowed to finish High School in four years and not three as every one else.

### **And a lively debate**

The debate panel consisted of three politicians, Jane Heitmann (V), Lotte Rod (RV) and Rosa Lund (EL), besides Bente Buus Nielsen (CCF) and the two student representatives Zacharias Polonius and Malene Nyborg Madsen.

Besides praising the suggestions, the one politician coming from a government party (Lotte Rod) made it clear that more money is not an option. Everybody

then agreed that the Danish educational funding system should be the same for all. Meaning that all students should receive the same amount of money when taking a secondary education. But Lotte Rod suggested that they could look into the pool of money the government have, in order to help the handicapped. Either you get the full amount or nothing. Maybe that could be changed in order to help more students.

At the conference Bente Buus Nielsen urged the politicians to think out of the box, and let the ministers cooperate, and Malene Nyborg Madsen referred to one of the earlier presentations stating that helping the chronic diseased now, would be investing in the future.

The Politicians expressed that they would take the suggestion with them and present it at the coming negotiations, regarding the new directions of Government educational funding.

The suggestions regarding the rules of how to manage absence and having a similar solution extending the period as Team Denmark, seemed feasible as they were about rules and not directly concerning the economy.

At the same time the two parties from the opposition (Right and Left parties) declared that they would cooperate on this particular matter.

And every one agreed that the "Chronic Disease" should be written into the notification, and not only as it was today with the words "Handicap or reduced functionality".

All in all, a lot of concrete initiatives to work with for the politicians – especially regarding the coming educational funding reform.

So in many ways it was a huge success that the Danish Colitis and Crohn's Association also managed to bring the attention from "Monday is a crappy day" into Christiansborg.

Bente Buus Nielsen, CCF, Danish Colitis and Crohn's Association

# Poland

## Santa Claus is coming to town...



Lots of ideas, laughter, a group of people acting for a common goal and a pinch of mobilizing stress. Sounds like a mysterious potion? But no! It's all a recipe for a unique event, which takes place every year in the autumn/winter break in Poland.

In 2012 Days of Education about IBD' took place in eight cities which is a new record. Five years ago we started with a small meeting in one city. The final number of participants

exceeded our wildest expectations (so far 180 people in Katowice, 230 in Krakow, 150 in Warszawa, other meetings are still ahead of us).

Generally, "Days of Education about IBD" are a series of lectures presented by professionals and dedicated to the patients. Professionals explain the issues about IBD in a clear and tangible way. The topics concern e.g. ABC of IBD, comparison of the disease between children and adults, IBD treatment, diet and many others (the lectures differ in every city, together we engaged about 20 doctors).

We invited also a psychologist who showed us possibilities of self-help in the fight against IBD. After all, we know that a positive attitude can make a significant contribution to improving the quality of life. Time for Q&A followed the presentations. Moreover, every participant can take any materials we have

about IBD and our Association (magazines, guides, leaflets) and try special, nutritional products for people with IBD.

"Days of Education" are for teenagers/adults but we also have the children in mind! During the lectures and then in the gastroenterology wards (three, big hospitals this year) a Santa Claus was coming to our young patients.

Heads full of precious knowledge, new friends and the smile accompanying the children who get the gifts from Santa (ok, sometimes they are afraid and cry ;) ) and the people leaving the meeting place – priceless.

Magdalena Staniewski, J-elita

# Czech Republic

## Annual IBD Conference

The Czech IBD Patients' Association held its 7th Annual St. Wenceslaus IBD Conference of Patients with Crohn's Disease and Ulcerative Colitis on 22 September 2012 in Prague. The conference was attended by 150 patients from the Czech Republic and has become a popular event amongst our patients. The program included interesting lectures on new treatment methods in IBD. Participants met with a wide range of experts among Czech IBD gastroenterologists, pediatricians, surgeons and nutritionists and could consult their problems directly.

The parallel program allowed patients to buy books on IBD with significant discount. This year we also welcomed representatives from the Slovak and Polish associations who presented their activities.

Participants received an information brochure as a gift. This brochure was contained answers to questions presented by patients during previous seminars and conferences. Its name was chosen by Woody Allen's movie – "Everything you always wanted to know about IBD, but were afraid to ask". This brochure was done in cooperation with doctors from the Czech



### Participants at the annual conference

IBD doctors working group. The next annual conference is planned for September 28, 2013. For more information about all activities of the Czech IBD Patients' Association please visit our website [www.crohn.cz](http://www.crohn.cz).

Martina Pfeiferova

## Iceland

### Let thy food be thy medicine and medicine be thy food" - Hippocrates

The Icelandic CCU Association was founded in October 1995. Presently we have 229 members and have been members within EFCCA since 2002. We are thankful for the EFCCA support and we embrace the sharing of information and the power of the mass to make a difference.

We are always seeking new ways to improve our life. We have been working with the Icelandic Ostomy Association on issues that we share and we also look to our neighbours in the Nordic countries to see what they are doing. To take a step forward we applied last October to become a member of "The Organisation of Disabled in Iceland". We are very pleased to inform that we have been accepted and we think that this is an important step for us to better support our members. We will have better access to information and will be better able to offer assistance in difficult circumstances.

One of the most important work within our association is to provide our members with information on all matters related to the disease as well as the latest news in Research and Development. We have a website ([www.ccu.is](http://www.ccu.is)) and recently we have opened a Facebook page. Within Facebook we offer our members to become part of two closed groups i.e. food related group and group for parents with sick children.

In our educational meetings we have noticed an increased interest on food related issues. This fall we have had two educational meetings with Health Coaches. Attendance was really good (the best we have seen for several years) and members shared their experiences with each other. We found out that despite some difference in diet, most of us avoided the same things. However, doctors are not too eager to say that food matters. Their main argument is that there are no studies or tests that support the theory that food matters.

We have read about people that have changed their lives by practicing new lifestyles, changing their diet etc. We therefore decided to start a group focusing on diet in co-operation with the Ostomy Association. One of the issue that came up was to gather information from a large number of patients, focusing on diet. The group wanted to do this properly so the information could be usable in some way. They contacted Einar Björnsson, the Medical Chief of Gastroenterology at the University hospital in Reykjavík. He was very interested in this project and has formed a group with doctors and nutritionists. They are launching a new Research on diet and nutrition among people with Crohns and Ulcerative Colitis. The team has received some funding to launch the research and we are looking forward to some results.

Even though we cannot cure the diseases yet, we can affect the state of our health from day to day by taking good care of ourselves. If the result means that we feel better, it is well worth it.

Warmest regards from Iceland.

Edda Svasvarsdottir, ICCA

# Ireland

## Living Optimally with Inflammatory Bowel Disease

### A new initiative for IBD patients from Beaumont Hospital, Dublin

*By Mary Forry, IBD Nurse Specialist, Beaumont Hospital, Dublin, Ireland (writing for The Irish Society for Colitis & Crohn's Disease)*

A Dublin hospital has developed a support programme for patients with IBD, incorporating what is thought to be the first delivery of Stanford University's Chronic Disease Self Management Programme specifically to patients with IBD. The Living Optimally with Inflammatory Bowel Disease programme is an initiative being run by the Gastroenterology Department, Psychology Department and Liaison Psychiatry Department in Beaumont Hospital. It comprises of:

#### **The Living with IBD Workshop**

During the workshop there are talks from a dietitian, clinical psychologist, and a specialist registrar in gastroenterology. The Health Promotion Department provides a session on well being and stress management. Chaired by the IBD Nurse Specialist, the workshop gives participants a chance to meet and chat with others with IBD.

#### **The Chronic Disease Self Management Programme**

Developed by Stanford University School of Medicine, this programme is delivered over six weekly sessions to groups of between 12 and 18 IBD patients. The course is led by two trained leaders, one of whom is a healthcare professional, the other a patient with IBD. The focus is on understanding and managing common symptoms of a chronic disease. Through a combination of discussion, active problem solving, brainstorming, action planning, goal setting and education, participants are encouraged to take an active role in the management of their IBD. Time is spent on communication skills, exercise methods, nutrition, medication adherence and decision-making in medical care. To date 19 leaders have been trained, six of whom have IBD (including Ciarán Davis and Johanna Giles from the ISCC). The other 13 are made up of nurses, psychologists, doctors and social workers.

While there is much positive research regarding the programme in other chronic illnesses, we have been unable to find any published research regarding its use in IBD. Because of this participants complete questionnaires before and after the course to evaluate the impact that the course has on the lives of people with IBD.



#### **IBD Support Group**

The feedback from the courses has been overwhelmingly positive and there has been a natural evolution to what had been identified as the third element of the initiative. Participants from the Chronic Disease Self Management Programme meet to form an IBD Support Group to build on the relationships and supports received during the six weeks of the programme. This support group is organised and led by people who have taken part in the programme. These meetings take place monthly.

The programme is being co-ordinated by Assistant Psychologist Emma McDonnell under the supervision of Senior Clinical Psychologist Dr Jennifer Wilson O'Raghallaigh and IBD Nurse Specialist, Mary Forry.

The programme is made possible through funding from Abbott.

## Two cross-border patient support groups collaborate in a very special meeting

By Ciarán Davis (*Irish Society for Colitis & Crohn's Disease*)

**The meeting was opened by Gerald Nash TD (Member of the Irish Parliament) who shared his experience of growing up and living with Crohn's Disease**

The Dublin-based Irish Society for Colitis and Crohn's Disease (ISCC) in conjunction with the Northern Ireland Area Group of Crohn's and Colitis UK, held a public meeting on Saturday 22nd September 2012 in Dundalk (on the southern side of the border with Northern Ireland). Although the two groups have met before, this was the first full-scale cross-border meeting that they had organised.

It was a great success with a large attendance from both sides of the border. Mr Gerald Nash TD (member of the Irish parliament), who was diagnosed with Crohn's Disease at the age of 14, opened the meeting. He shared his personal experience of the disease and explained how it has not prevented him from living a full life and being elected to the Dáil (Irish parliament). Michelle O'Brien from the Irish Osteoporosis Society gave a presentation which is very relevant to sufferers of IBD. She encouraged all present to get their bone density checked, because steroids – a common treatment for IBD – can lead to osteoporosis. Cian Mahony, who has Crohn's Disease and is a financial adviser, gave practical advice about making an application for life assurance products for people with IBD.

Dr John Keohane from the Louth-Meath Hospital Group gave a very engaging presentation on IBD,

which ISCC Chairman Geraldine Murphy said 'hit the spot perfectly'. Dr Subhasish Sengupta, also from the Louth-Meath Hospital Group, then outlined how the provision of services to people with IBD is evolving in the north east. He was particularly pleased to announce the appointment of a part-time IBD Nurse Specialist for the region. This will greatly relieve pressure on services as well as enhancing the standard of care delivered to IBD patients.

Geraldine Murphy, Chairman of the ISCC, was delighted with the success of the day. "Some people

who previously didn't know about us attended their first meeting and met others with IBD for the first time. This is an important step for anyone with IBD because it can be a very isolating disease". Geraldine was also very positive about the evolving collaboration and friendship with her Northern Ireland counterparts and

promised more joint meetings were in the pipeline.

Peri Gillespie, Chairman of the Northern Ireland Areas Group of Crohn's and Colitis UK, was equally as enthusiastic and commented on "how much we enjoy keeping the friendship and rapport with the two groups. We often think we have different problems but in reality we are fighting the same problems whether it be in the North or the South of Ireland. We work well together and have picked up lots of tips from the way the two groups hold meetings and advertise. We plan to continue with this bond and meet next year probably in the North, as it's our turn to host the meeting."



**Ciara Drohan (ISCC), Gerald Nash TD, Geraldine Murphy (ISCC)**

## Update from the Irish Youth Group

The Youth Group started 2012 with our first full year of events planned as this was our second year up and running. This update covers our activities since September 2012, when we held our second informal meet up which again was a great success and again gave people the opportunity to meet.

In October we launched our first edition of the ISCC Youth Group ezine "Tummy Times". This has been a great achievement for us and we look forward to launching the second issue early in 2013.

In November our second Youth Day was held, we decided to theme the day around Well-being and Sport and called the event HUDDLE. Grace Walsh opened the event based on her experience of attending last year's day. We then had some ice breakers to ensure everyone was a bit more comfortable with each other. There were three great medical speakers organised for the day. After lunch we had a Coping Skills Workshop. We finished the day with a tour of the stadium including the player's dressing room and the players' lounge. Thank you to Abbott for sponsoring HUDDLE.

So as 2012 is coming to an end the ISCC Youth Group look forward to 2013 and no doubt another busy year for us.

# Cyprus

## Cooperation between UK and Cyprus Hospitals

Dr Babu Vadamalayan, a child specialist in gastro-enterological problems from King's College Hospital, has visited Cyprus from 25 to 28 of November 2012, within the framework of a Memorandum of Cooperation which has been signed earlier this year between the Ministry of Health of Cyprus and King's College Hospital, UK.

Dr Vadamalayan has examined 24 cases of complex gastro-enterological, liver and nutritional problems, which under normal circumstances would have to be referred for treatment abroad, since there are no child specialists in this field in Cyprus. The examinations took place at the new specialized clinic which started its operation in Nicosia, following the implementation of the Memorandum of cooperation, under the management of Dr Panayiota Protopapa.

Furthermore, according to the above mentioned Memorandum, one child specialist will be selected from the Ministry of Health of Cyprus who will attend a special training at the King's College Hospital for specialization in gastroenterology. In the meantime, the specialist from King's College Hospital will be visiting Cyprus 3 times a year in order to attend complex cases which, unfortunately, increase rapidly.

The Pancyprian Association for Ulcerative Colitis and Crohn's Disease, the Pancyprian Association for Children with Liver Diseases and the Cyprus Association of Coeliac Disease, offered a dinner gathering in Nicosia to honor and thank Dr Vadamalayan, in the presence of the Ex-General Manager of Makarion Hospital, Dr Andreas Hadzidemetriou and Dr Panayiota Protopapa.

Yiangos, Yiangou

# The Netherlands

The Dutch Crohn's and Colitis Association, CCUVN, is proud to present the results of an exciting project on labour participation among people with IBD that we have been involved in. For more information please take a closer look at our project poster.

T. Markus, CCUVN



# Labour participation among people with inflammatory bowel disease in the Netherlands

**Aim:** to provide insight in the labour market position of people with inflammatory bowel disease (IBD) in the Netherlands and in the factors that contribute to, or impede, their labour participation.

**METHOD** Nationwide survey (December 2010) among people aged 15 to 64 with IBD (N=1115 responders; response rate 81%). Statistical analyses included descriptive statistics and multinomial logistic regression analysis.

**SAMPLE** Of the total sample, 29% were male and 71% were female. The majority of respondents were younger than 45 years (62%). Only seven percent had a low education level, whereas 46% had finished high vocational education or university. Crohn's disease (53%) appeared to be more prevalent in the sample than ulcerative colitis (42%).

Since women and patients with Crohn's disease were overrepresented in our sample, and consequently men and patients with ulcerative colitis underrepresented, we used a weight factor (based on gender and IBD type) to correct for selection bias.

**RESULTS** Most people with IBD participate in the labour market and evaluate their own functioning, in work and private life, as successful.

Labour participation rates (percentage working  $\geq 12$  hpw) among people with IBD are not lower than among the same gender/age categories in the total Dutch population. However, people with IBD work less often in a fulltime job (see Figure 1).

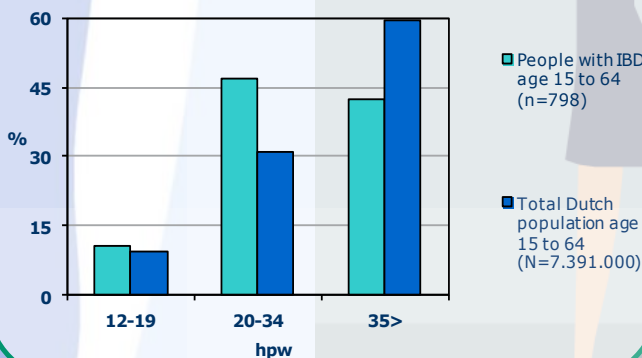
Regarding people with IBD who do not have a paid job:

- 35% would like to have a job.
- Flexible work schedules, work close to home and the possibility to work at home are mentioned as factors that would increase their labour participation chances.

Regarding people with IBD who have a paid job ( $\geq 12$  hpw):

- 11% would like to get more support of their supervisor.
- Fatigue, stress and concentration problems are mentioned as factors that impede the performance of (paid) work.

Figure 1: Hours worked per week among people working  $\geq 12$  hpw



This study was conducted by NIVEL, the Netherlands institute for health services research, in collaboration with the Crohn and Colitis patient association Netherlands, and with financial support from the Dutch Crohn and Colitis research foundation.

Please refer to the information on this poster as: Netjes J. & Rijken M. Labour participation among people with IBD in the Netherlands. Utrecht, the Netherlands: NIVEL, 2011. Phone: +31 30 2729700; E-mail: j.netjes@nivel.nl; m.rijken@nivel.nl.

## Do you see UC?

# “To slay the demon, you must first know its name.”

That was the phrase that went through my head when my doctor told me the name of this particular demon was Ulcerative Colitis. Initially it was a relief. I thought if they knew what it was, they probably knew how to cure it. Unfortunately this demon proved harder to slay than most and ten years later it still creeps out of its cave every once in a while.

In ten years I think I've tried every kind of drug, herbal remedy, food combination, new-age cure and exercise associated with the disease. Nothing worked for me. When I had a flare-up I just had to ride it out, which usually took 3-4 months. It's hardly surprising then that I soon found myself unemployed because of excessive sick days. During really bad flare-ups I just couldn't set foot outside the door, especially in the mornings.

While most of my friends were getting married, I couldn't even leave the house long enough to meet anyone, and even if I did, I had no money to take them anywhere. I did manage a few disastrous dates while the disease was in a comparatively inactive phase, but it isn't the easiest (or sexiest) subject to broach on a first date. Also, thanks to a lengthy period on steroids, my weight had ballooned to extreme proportions, which doesn't have the ladies queuing up either.

Sitting alone in my flat every day, I decided to rekindle an old hobby. I had always loved writing and had dreamt of someday writing a book. Now, with nothing but time on my hands, I started writing the novel that would eventually become *Vampire Dawn*. After I finished it I went straight into writing another book while I searched for a publisher. *Vampire Dawn* was picked up by an American firm and published the next year. Two more books followed; *Mind's Eye* and

*Vampire Twilight*. I think I would have lost my mind if I hadn't discovered a passion for writing. It kept my brain active in a way daytime TV never could.

It wasn't until I was being interviewed for a local magazine after the release of *Vampire Twilight* and the interviewer asked me: “Why are all your books about outsiders, isolated from society in some way?” that I realised how therapeutic writing had become to me. I had unwittingly been writing about myself and my condition all this time. When I tell interviewers the circumstances of how I came to be a writer they are always surprised by how much humour there is in my books. I tell them I've always loved to laugh and I've always tried to see the funny side, I won't let UC change that. No one wants to read a depressing book, and I don't want to write one.

Now fully aware of the subtext in my books, I started writing *Freak*, determined to address the subject more directly than ever. The idea came to me during one of the hottest summers in memory. I was having a really bad flare-up and was housebound. The flat I lived in was just across the road from a park. I used to stand at my window and watch everyone in the park enjoying the sunshine and the summer. I wondered what they would say if they saw my pale face looking out at them. I imagined they would say, “What a freak!”

Though *Freak* is a modern gothic horror story that never even mentions UC, I think anyone with the disease who reads the book will know that I'm not really talking about anything supernatural. Underneath the action and scares I'm describing how it feels to have Ulcerative Colitis. I hope it helps others like me to cope. If nothing else, I hope it lets them



know they're not alone.

Over the last couple of years I've started dabbling in film. It really is amazing what you can do with a HD camcorder and a PC these days. I've made a few short films and I'm working on a screenplay for a full-length film to raise awareness of UC & Crohn's. The trick is to get the balance right; no one wants to watch a depressing film about illness, so I'm trying to get the serious nature of the condition across, but balance it with laughs (all those disastrous dates will be mined for material). That may sound callous to people who are going through a bad time, but it is based on my own experiences, and I've always tried to keep a sense of humour, even during the worst times.

It can be hard to see anything positive about a disease

like this, but I've just published my eighth novel and I don't think any of those books would have been written had I still been in the dead-end job I was fired from. When I was a factory worker I always wished there was some way I could be a writer. In the future, I'll be careful what I wish for.

Philip Henry  
Portstewart, Northern Ireland

Anyone wishing to contact the author should do so through his website: [www.philiphenry.com](http://www.philiphenry.com)

### Philip Henry at the book-signing of his latest book in Waterstones



# Greece: Our welfare state is on the brink

*Interview with Alexandra Gilati, Attica's Society of Crohn's Disease and Ulcerative Colitis Patients, Eleftheris Tampouridis, Northern Greece Society of Crohn's Disease and Ulcerative Colitis Patients*

## **Please tell us about your associations?**

*Alexandra:* “The Attica's Society of Crohn's Disease and Ulcerative Colitis Patients was founded in 2006. It started informally with a group of patients, including me, who decided “to come out” and start talking about IBD. We felt we couldn't get this support from our doctors or even psychologist . So the basic idea was to support each other and to talk openly about the problems we were facing at work, school and in our relationships with doctors and nurses. That was the starting point. Now we are representing around 350 members in the Attica region (Athens and its surrounding) providing information services, free access to group or individual therapy and organising meetings and workshops where patients have the opportunity to meet with doctors and other healthcare professionals but we know that our outreach is much wider than our membership.

## **Can you explain this?**

Well, even though we only have 350 registered members we keep in contact with over 500 people. These people come to seminars and other information activities that we organise. We are also getting many enquiries for information, help and support from people with IBD but when it comes to becoming a member they somehow get stuck in their mind and postpone the decision.

First of all it's a taboo issue: by becoming a member, people have to face up to their disease! But I think

in Greece there are also cultural reasons. In Greek society it is expected to get help from your family and/or friends. To ask for help and help other people you don't know is an alien concept. Many people are still having difficulties to understand that being a member could solve many other problems but instead they prefer to keep their problems “private”.



**Alexandra Gilati during 2012 World IBD Day (in the middle holding toilet roles)**

*Eleftheris:* “The idea to form a Northern Greece Society of Crohn's Disease and Ulcerative Patients emerged in 2005 during an IBD specialist congress where we participated in a roundtable discussion with doctors on relations between doctors and patients. Most of our members are from Thessaloniki but we are also covering other cities in the entire area of Northern Greece. Altogether we represent around 170 members.

In terms of services, we provide an education programme for patients after they have been diagnosed with IBD such as information on nutrition, the latest information on medication and therapies that are available etc. . Besides that, we also cooperate with psychologists who are specialised in chronic diseases to provide support to patients and their family members. Currently we have two support programmes: individual therapies and group therapies, both therapies are designed to assist patients in better coping with their disease.”

## **You are a regional organisation, do you have a national representation in Greece?**

*Alexandra:* “When we set up Attica's Society of

# Bank of collapse

## Ulcerative Colitis Patients and Crohn's Disease Patients

Crohn's Disease and Ulcerative Colitis Patients we received support from the Crete Association of IBD patients helping us with some basic things such as access to their website etc. Given the situation at that moment we decided to set up a regional association, however we are in discussions with our colleagues from the Northern Greece association (since the Cretan association is no longer active) to unite under the umbrella of a national association.

### How is the situation concerning treatment of IBD in Greece?

*Alexandra:* "As you know Greece is suffering severely from the economic crisis. IBD treatment is identical to the treatment you can get in Western Europe, but because of a serious lack of funds in the health system, patients are asked to pay themselves for a lot of the treatment. Since the crisis started a few years ago, patients are not getting the same quality of care as previously. We are afraid that in 2013 we will face major issues in terms of medication and treatment for IBD as many people simply will not be able to afford it.

Due to cost cutting measure hospitals have now become understaffed which means that levels of care have dropped dramatically as well as sanitary standards with a lack of basic equipment such as syringes, disinfectants in many public hospitals and long delays for blood tests, biopsies, endoscopies etc.

Moreover, pharmacies have not been paid by the government and are asking patients to pay the full price of their medication and directly ask the government for reimbursement which takes usually at least up to 6 months. On an average salary of between 600-800 €



**Eleftheris Tampouridis**

gross a month, expensive IBD medication are an enormous burden for patients and this burden will become unbearable and life threatening if the government stops providing drugs such as Humira and Remicade for free.

I am sorry to say this (as it is an insult to so many people who fought over the past century for the acknowledgement of the human and patients rights), but both the welfare system and national health system have started to collapse in 2012 and our gov-

ernment officials only seem to care about numbers and not people. I think Greece is the worst example but I think this situation might be reproduced elsewhere, in Spain, Portugal, Italy for example.

Nowadays in Greece, if you are unlucky enough to have a chronic disease it's bad luck. If you don't have money to pay for a private insurance you have to survive with whatever the public health care can – if you can afford it, that is. I think Greece is the worst example but I think this situation might be reproduced elsewhere, in Spain, Italy for example.

### What are you doing on the level of the association to deal with the situation?

*Eleftheris:* "The constant changes in regulation of the private and public health sector that need to be followed make our work as an association quite difficult. The latest regulation has increased the patients' participation in the cost of medication to 25%. Previously this cost was at 10 % for chronic patients. We are in discussion with some public and private entities on how to find a solution to such financial problems.

Moreover, both of our societies have created a Facebook group amongst our members and we try to help each other as much as we can, for example if someone doesn't have enough money to buy medication we support each other.

We are also cooperating with the Attica Society and

other patient organisations to contact the ministry of Health and explain the seriousness of the situation but it's very difficult to get hold of government officials or to talk to them directly. The problem is that the main aim of the Ministries right now is to cut cost at whatever price. We are trying to explain that this is a short-sighted strategy as the long term costs of people with no treatment or bad treatment is much higher when they eventually end up in hospital. So we are lobbying for earlier diagnosis, specialised IBD centers and more follow up examinations which will result in lower costs in the longterm for both the government and patients.

### Why are you interested in joining EFCCA?

*Alexander:* “EFCCA for us is an extension of the work we do on the ground. We believe we are part of the big family and we need to have the information of how other associations are dealing with common issues. Another reason is that EFCCA hopefully can help us make people aware of the issues we are facing here in Greece. Our government does not provide this kind of information. The measures that are being implemented are having a very negative impact on our lives and we need the rest of Europe to be aware of this.”

## Putting psoriasis on the agenda

More than 125 million people all over the world suffer from psoriasis – a complex and serious disease that can have a large impact on a person's life, family and community. What many people might see as a mere discomfort, or a cosmetic problem, is in fact a serious, inflammatory, immune-mediated disease. Psoriasis can also, due to its very visual nature, be highly stigmatizing, in some cases leading to ostracism, discrimination and severe loss of self-esteem, even thoughts of suicide.

For more than 40 years, the International Federation of Psoriasis Associations (IFPA), has been working towards a better understanding of what psoriasis is, and almost as importantly, what it isn't. In many parts of the world psoriasis is still seen as nothing more than a skin condition, albeit one that in some cases can be severe, disfiguring and even life-threatening. But over the last 10-15 years the research around psoriasis, its epidemiology and pathogenesis has revealed what many people living with it have known for a long time – this is not a skin problem, it is something that involves the whole body.

This has of course changed the entire playing field completely. With the new facts came new treatment regimens, among them the ground-breaking biologic therapies, but the interest in research around psoriasis also grew exponentially. The increase in research conducted within the field of psoriasis also brought with

it a new understanding for what other implications the disease might bring. It is now well-known that having psoriasis puts you at risk for a number of serious co-morbid conditions, such as diabetes, high blood pressure, cardiovascular disease and, most commonly, psoriatic arthritis, which affects up to 42% of people with psoriasis.

This being the situation, IFPA has focused its attention on primarily three areas: awareness, education and recognition.

### Awareness – World Psoriasis Day

One of the main programs of IFPA is World Psoriasis Day – 29 October. World Psoriasis Day is an annual day specially dedicated to people with psoriasis and/or psoriatic arthritis. Formed by a global consortium of patient associations in 2004, World Psoriasis Day aims to raise the profile of a condition which needs to be taken more seriously by national and international authorities. On and around World Psoriasis Day, psoriasis patient associations, medical societies and other stakeholders carry out a large number of different awareness-raising activities. In 2012 the theme for World Psoriasis Day was “Psoriasis – a global health challenge”, with a special international photo campaign which featured the core message “Put psoriasis on the agenda now!”.

The photo campaign was a great success and thousands of people all over the world took an active part

At MSD, we work hard to keep the world well. How? By providing people all around the globe with innovative prescription medicines, vaccines, and consumer care and animal health products. We also provide leading healthcare solutions that make a difference. And we do it by listening to patients, physicians and our other partners — and anticipating their needs.

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The recent merger between MSD and Schering-Plough expands and strengthens our capabilities to help make the world a healthier place. Our goals are clear and our commitment is fierce. We are dedicated to solving problems and pursuing new answers.



in raising awareness for psoriasis.

### **Education – the IFPA World Psoriasis & Psoriatic Arthritis Conferences**

Another main program is the IFPA World Psoriasis & Psoriatic Arthritis Conferences, a series of scientific conferences arranged every three years, based upon a survey of the priorities of all IFPA member associations. These scientific conferences gather the leading experts within psoriasis, psoriatic arthritis and co-morbid conditions such as diabetes, to share the latest research within their respective fields. The latest conference was held in Stockholm in June 2012 and welcomed over 1 200 doctors, nurses, allied health professionals, medical students and patient representatives from 67 countries.

### **Recognition – IFPA’s Advocacy project – Strategy for recognition of psoriasis**

Initiated in 2009, this long-term project aims to come to terms with the lack of recognition for psoriasis as a serious disease within the global health system. With the support of a number of international medical societies, IFPA’s national member associations and even some sovereign states, IFPA seeks to put psoriasis firmly on the global political agenda. Official recognition of psoriasis, and of IFPA projects such as World Psoriasis Day, would be a hugely important step towards people suffering from psoriasis receiving a proper diagnosis, access to treatment and better care, regardless of where in the world they may live.

We are of course aware of the fact that there are many, many disease areas that all deserve attention and resources, and that we still have a long way to go before we can see any kind of equal medical treatment for all people with psoriasis. This is why it is so important to IFPA and to a number of other organizations to unite, to come together and speak for as many people as possible. In IFPA’s case, it is therefore logical to belong to the NCD Alliance Common Interest Group, as psoriasis is a noncommunicable, chronic disease. But it is also important to form collaborations with disease areas that are even closer to ours, such as the immune-mediated inflammatory diseases, or IMIDs.

It was therefore with great pleasure IFPA accepted the

kind invitation from EFCCA this fall, to meet with our sister organizations EFCCA, ASIF and AGORA. United by many common factors, it feels more than natural, and logical, to work together to have an even stronger voice on the global health arena, as we then represent the many hundreds of millions of people who suffer from an IMID. To echo the apt slogan of EFCCA – “United we stand”, and united we can hopefully achieve a better life for people living with chronic, debilitating diseases, all over the world.

### **Facts about IFPA**

Founded: 1971, Members: 48

Regional members: 3 (Europe, Latin America and Asia), African region under development

Headquarters: Stockholm, Sweden

Websites: [www.ifpa-pso.org](http://www.ifpa-pso.org), [www.worldpsoriasisday.com](http://www.worldpsoriasisday.com), [www.underthespotlight.com](http://www.underthespotlight.com)

Twitter: @PsoriasisIFPA

## **IBD Research Foundation**

Last October the EFCCA research symposium took place in Brussels. Representatives from a variety of patients’ organisations which fund IBD research, presented their organisation. Obviously we were very pleased to have the opportunity to present our IBD Research Foundation. What’s more, we were very pleased with this opportunity to learn from the other organisations, particularly since it turned out that our organisation was by far the youngest.

The projects we supported during our first grant program have all been finalized now. Two of these projects resulted in a publication in well known scientific media:

- Project “The protein C pathway: a novel mediator in intestinal homeostasis in IBD”; results published by “PNAS - Proceedings of the National Academy of Sciences of the United States of America”: <http://www.pnas.org/content/108/49/19830.full>

- Project “Analysis of PPAR-  $\gamma$  haplotype structure and its influence on disease susceptibility, pathogenesis and activity of inflammatory bowel Disease”; Results published by: “Hindawi Publishing Corporation – PPAR Research”: <http://www.hindawi.com/journals/ppar/2012/349469/>

The third project we supported requires an additional study before submitting the results for publications (project: “Exploring the potential of N-palmitoylethanolamine in a mouse model of inflammatory bowel diseases”)

The projects we supported during our second grant program are all in progress at this time. As soon as these projects are finalized, we will publish information about the results. At this time we are finalizing our third grant program, which appears to be quite a challenging task as we received a record number of 11 applications. Since each application is very comprehensive, it is a complex task for our patient reviewers and peer reviewers to accomplish the thorough assessment which is required. Therefore we highly appreciate the efforts of our reviewers. Although we are a young organisation, we are eager to learn quickly and we are very determined to move on in the right direction. Our organisation is characterized by our choice to open our grant programs for any research project in Europe which complies to our terms of submission. This opens the opportunity to support IBD research projects which suits the needs of the patients best, regardless where in Europe it is accomplished.

The amounts we have been awarding so far, have been limited to a maximum 5000 euro per grant. Therefore, we have supported either small projects, or slightly larger projects together with a number of other funding organizations. We realize that chances are small that these projects will directly result in improved treatment for IBD. However, we do sincerely feel that the results of these projects are highly valuable, as it increases the knowledge of IBD. It helps to solve a part of the puzzle of the cause of IBD. It adds building blocks to the foundation of what actually may result in improved treatment, or eventually even a cure for IBD.



**Young researchers searching for a cure (photo by: Marika Armilo)**

Therefore we are very inspired to move on and in order to do so, continuous support is crucial from anyone and any organisation which shares our dream: to find a cure for IBD.

**Donations** can be made either through the website ([www.ibdresearch.org](http://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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MEDICINE ON THE BODY'S OWN TERMS





# Ustekinumab – a novel treatment for refractory Crohn’s Disease

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## Introduction

Crohn’s disease (CD) is a chronic transmural inflammatory disease of the gastrointestinal tract that may involve every segment of the intestine. It generally evolves by acute episodes separated by periods of remission. The progression of the disease is associated with appearance of intestinal complications such as perforation, abscess or bowel obstruction. Conventional treatments of CD include mesalamine, corticosteroids (such as prednisone, methylprednisolone or budesonide) and immunomodulators (such as azathioprine, mercaptopurine or methotrexate).

In the last years the use of anti-TNF agents (such as infliximab and adalimumab) has become one of the most important treatment options for CD. Unfortunately one third of patients do not respond to this therapy (primary non-response) and another one third have only a transient response

(secondary non-response). Development of new additional treatment prospects for CD, particularly in those patients not responding to anti-TNF agents, is thus mandatory.

## A new drug: ustekinumab

Ustekinumab is a fully human immunoglobulin G (IgG1K) monoclonal antibody against interleukins 12 and 23 (IL-12 and IL-23), which contribute to the pathophysiology of Crohn’s disease, by activating T-cells, natural killer cells and antigen-presenting cells.

Their inhibition by ustekinumab may thus reduce the inflammatory activation in CD. This has already been shown in murine colitis models, and a previous phase 2a study in humans has already shown efficacy in patients affected by moderate-to-severe CD. Ustekinumab has also been approved for use in other human inflammation-related diseases such as



**Professor Silvio Danese, IBD Center, Istituto Clinico Humanitas, Secretary of the European Crohn’s and Colitis Organisation (ECCO)**

moderate-to-severe plaque psoriasis.

Sandborn et al published recently in the NEJM the results of a 36-week, multicentered, randomized, double-blind, placebo-controlled, phase 2b trial study of ustekinumab (comprised of an 8-week induction and a 28-week mainte-

nance phase).

The patients participating in the trial had moderate-to-severe Crohn's disease, as defined by a score of 220-450 points on the Crohn's Disease Activity Index (CDAI), all of whom were either primary or secondary non responders to anti-TNF agents, or else had unacceptable side-effects of such therapies (it is noteworthy to point out that 50% of these patients had a story of failed treatment regimens with at least two anti-TNF agents).

### The trial

526 patients were randomized first in the induction phase to receive intravenously either ustekinumab at doses of 1, 3 or 6 mg per kg of body weight or placebo in the first week (week 0). At the last visit of this phase (the visit at week 8), final response to the induction therapy was evaluated and transition to the maintenance phase was initiated.

The patients underwent a second randomization in the maintenance phase, based on how they responded to the treatment received on the first 8 weeks (i.e. on the induction phase) and were as a consequence divided in four groups.

In the group of those who had received ustekinumab in the induction phase, responders and nonresponders were separately randomized to receive either subcutaneous injection of 90 mg of ustekinumab at weeks 8 and 16 or placebo. Whereas those who had received placebo were randomized

to receive subcutaneous injection of placebo at weeks 8 and 16 if they were responders to placebo in the induction phase or subcutaneous 270 mg ustekinumab at week 8 and 90 mg at week 16 if they were nonresponders to placebo.

Maintenance endpoints were evaluated at the end of this phase, i.e. at week 22, and then patients were followed-up for an additional 14 weeks (until week 36) for safety analysis.

Overall, 336 patients out of the original 526 (63.9%) completed the full course of treatment and follow-up through week 36.

The primary end-point of the study was clinical response, defined as a decrease in the CDAI score of at least 100 points at week 6 (for patients with a CDAI score of 248 or less instead, a decrease in CDAI score to <150 points was required to define a clinical response).

Secondary end-points were clinical remission (CDAI score <150 points) at week 6, clinical response at week 4 and clinical remission at week 22 of the patients who had achieved the primary end-point.

### Results

In the induction phase, the primary end-point was significantly greater among patients receiving ustekinumab (at a dose of 6 mg per kg of body weight) than those receiving placebo (39.7% vs 23.5%), whereas the other doses of ustekinumab (1 and 3 mg per kg of body weight) did

not perform significantly better than placebo. Ustekinumab performed equally in those patients who had previously received only one anti-TNF agent and in those who had received at least two anti-TNF treatment regimens.

As for the secondary end-points in the induction phase, no statistically significant difference was observed between patients receiving ustekinumab and those receiving placebo. It is noteworthy however to point out that the proportion of patients with a reduction in CDAI of 70 points was greater among patients receiving ustekinumab than those receiving placebo, as was the mean reduction of CDAI score and the mean reduction in C-reactive protein (CRP) levels, an inflammatory marker, even though these did not reach statistical significance. Moreover, in a small subgroup of patients who performed endoscopic evaluation of CD, though the study did not require it, greater number of patients receiving ustekinumab experienced mucosal healing than placebo.

In the maintenance phase, by definition, only the secondary end-point could be evaluated. Ustekinumab (at a dose of 6 mg per kg of body weight) performed significantly better than placebo in inducing clinical response at week 22 (69.4 vs. 42.5%). Among the patients who received ustekinumab at induction phase and reached the primary endpoint, greater proportion of those who continued receiving ustekinumab experienced clinical remission at week 22 than those who were

randomized to placebo (41.7% vs. 27.4%), even though this did not reach statistical significance. This may be due to higher median CDAI score at baseline (333) in this group compared to the other groups, which rendered it more difficult to reach the definition of remission (CDAI <150). In the same group reduction in CDAI score and CRP levels were sustained, which did not happen in those receiving placebo.

Moreover in this group, significantly more patients had a sustained clinical response (i.e., a clinical response at every visit during maintenance phase) than placebo (55.6% vs. 32.9%). Among the patients in remission at week 6, greater proportion of patients who continued ustekinumab maintained remission at week 22 than those randomized at placebo. Generally more patients who received ustekinumab were in glucocorticoid-free remission at week 22 than placebo.

In the group who didn't achieve the primary end-point (i.e., who didn't respond to any of the doses of ustekinumab), no significant difference was discernible between those who continued receiving the drug and those randomized to placebo.

Whereas in the group who didn't respond to placebo in the induction phase and was crossed over to ustekinumab, up to 35.3% had a clinical response at week 16.

### Safety

No significant difference between



Manol Jovani, IBD Center, Istituto Clinico Humaitas

ustekinumab and placebo was observed during the induction phase in terms of safety profile.

Whereas during the maintenance phase, one basal-cell carcinoma was reported in one patient who had received 1 mg/kg of ustekinumab followed by 90 mg at weeks 8 and 16. For the rest, the rate of adverse events was similar between those receiving ustekinumab and those receiving placebo. In particular there were no treatment-related death, major cardiovascular event, tuberculosis or other serious opportunistic infections.

The overall safety profile of ustekinumab appears thus quite satisfactory, even though caution is due in consideration of the relatively short follow-up.

### Conclusion

In conclusion, ustekinumab was shown to be a novel drug with an acceptable safety profile, that may be useful in the future treatment of patients affected by moderate-to-severe CD in whom previous anti-TNF treatment regimens have failed. This study shows that it performs better than placebo in inducing clinical response and in such patients, when administered as maintenance therapy, determines significantly greater response and remission rates.

Whether such results can be extrapolated to the broader reality of Crohn's disease population, needs and deserves to be further investigated.



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