

EFCCA MAGAZINE

European Federation of Crohn's and Ulcerative Colitis Associations | May 2012

“Join the fight against IBD”

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EDITOR'S EYE

Run, Dorando, run !



“Keep your dreams alive.

Understand to achieve anything requires faith and belief in yourself, vision, hard work, determination, and dedication. Remember all things are possible for those who believe.”

(Gail Devers, 3 times Olympic Champion in Track & Field)

I start from the motto which was part of the presentation I made at Porto, on the occasion of our General Assembly. “All things are possible for those who believe”...and in my role of Chairman, re-elected in Porto I'm proud to announce that the year we have just closed has been EFCCA's best year ever in its more than twenty-year history.

It is not time for reviews, but EFCCA, up to today, has increased its membership, multiplied its staff, changed office to a bigger one, triplicated the number of events and enlarged its area of influence. How it has been possible ?

Passion, commitment and a foolish willingness to change the world.

New and ambitious challenges are just around the corner: a lot of work to do, with few people and with resources that are always scarce.

I'm thinking of our World IBD DAY event taking place in Brussels and hosted for the first time in the European Parliament thanks to the involvement of European policy makers. I'm thinking of the Symposium of research funded by patients' organizations from all over the world and I'm also looking at the dramatic growth that EFCCA is experiencing: from Israel to Argentina who are our new associated members, from Bulgaria to Greece who are now in the process of joining our family, fighting together for a better quality of life for people with IBD all over the world. “Guts have no borders, nationality or “colour”- as one of our new members said during our General Assembly, and EFCCA is advocating for people with IBD every day, every second, because there is still a long way to go, many people to reach, many projects to be developed. And the opportunities are becoming more and more numerous.

As said, we have closed 2011 by introducing the subject of “sport and IBD”, as a potential mechanism for raising awareness. What we have already seen in Barcelona, showed us that we were right.

In few months from now, London will celebrate - for the third time in its history - the Olympic Games. This reminds me of a story, which seems a tale, that my “grandpa” told me when I was a kid. The story of a small Italian baker's boy, who appeared even physically ridiculous in comparison with the other athletes and who took part in the London Marathon during the Games of 1908. His name was Dorando Pietri. He ran the most famous marathon in modern Olympics history: surprisingly leading the race from km 39, he entered the stadium alone. That's when he collapsed but he stood up again. Run some more meters, collapsed again, and again he

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stood up. The hot weather, the humidity, the fatigue of the race, made him falling down again. And again. And again. And every time he stood up. Stubborn and guided only by his dream. And he finally cut the finish line. First. But disqualified, because a line judge touched him while he was falling again. His courage, his efforts, his passion conquered people, and Queen Alexandra offered him a gilded silver cup as compensation for the missing medal.

This story reminds me a lot, also about IBD.

How many persons would have bet on us for IMPACT survey which we completed last year? or...how many times in our “life with IBD” have we fallen down? How many times did we have to stand up, again, and again, surrounded by people looking forward to “disqualify” us, as citizens, as worker, as persons ? Many times. Still too many.

Well, that is all about our everyday job. We are there for sustaining people with IBD. For showing you that you can stand up another time. And we will be there fighting for your, for our rights. Because we are not “second level” citizens. We are persons. We are fighters. And like the small runner, we see a winner in you, even when nobody else does. Because we know how hard it is to give life another chance, to cancel the tears, and to face a hard moment with a smile.

And every time you stand up again, we stand up with you. And any time we stand up as an organization after every mistake, we are one step nearer to a future without any IMPACT determined by IBD. Till we will have the courage to stand up, and run, again and again, nothing will stop us..

My last words are back to Porto, to our general Assembly. Only few national associations could not be present. I saw new faces and “old” friends. We welcomed two new members and had the chance of sharing goals and future projects. APDI welcomed us in a warm, professional and friendly way. And APDI is made by people, people with IBD, fighting for rights and a better quality of life, in Portugal and everywhere. João, Laurinda, Amelia, Ana, Candida, Nuño, Vera... these are some of the friends who made possible our fruitful and great stay in Porto, and I want to thank them on behalf of all our people.

Next year we will meet all in Slovenia: looking forward to welcoming all delegates there with a heavy baggage of commonly shared projects, ideas, and a even bigger EFCCA family.

UNITED WE STAND



Marco Greco, EFCCA Chairman

Join the Fight against IBD

Feedback from the Barcelona press conference 15 February 2012

by Tiphaine Chapeau, EFCCA Youth Group Deputy Leader & AFA delegate to EFCCA

On 15 February 2012 under Barcelona's sun, the "Joint The Fight Against IBD" conference organized by both EFCCA and ECCO has been a historical event for people living with Crohn's disease and ulcerative colitis (collectively known as inflammatory bowel diseases or IBD). Europeans have taken a leading role in the fight for international awareness-raising about IBD and its impact on the quality of life for the estimated 5 million citizens suffering from IBD worldwide.

Representatives from most European patient organizations, but also from non-European countries such as Brazil, Japan, Australia, Argentina, or Canada participated in this event. I had the feeling that the whole world was meeting in Barcelona's Olympic Stadium in order to show that we all have one united position and voice advocating for the wide recognition of IBD as more and more frequent chronic disabling disease in all spheres of society (political, economic, social, educational, medical), for the improvement of scientific knowledge, diagnosis, treatments and surgeries, and for the search for a cure.

Marco Greco, EFCCA Chairman, made a very impressive and brilliant speech in front of the 70 journalists that had come from 40 countries to listen to him.

"Can you imagine what it means not to be well, not to be believed by society with nobody understanding you for 5 years, and everybody thinking that maybe you're pretending?! Is this acceptable?! Can you imagine the costs involved for the healthcare system to treat a patient in the emergency room with a situation that is more complicated because of a delay in diagnosis?!"

These words are written in my mind and ex-



press exactly what so many of us would like to say to the society and to the medical community. I would have liked very much for my young European friends who I represent to share this moment with us since it was an amazing message of hope!

Moreover, we discovered that an IBD Disability Index is being developed at an international level and Daniel Hommes, ECCO Chairman, in exemplary fashion, gave us the impression of a united medical scientific community that is very concerned by IBD as an essential global health issue which should be addressed urgently, and a community that is willing to cooperate with patient representatives as real partners and to consider IBD in their entirety with all impacts on health and life they involve. .

Industrial companies were also present and support-

ed this awareness-raising event.

Thanks to EFCCA and ECCO, a part of our common dream is coming true step by step. Therefore we can be very happy and proud to be part of this wonderful European and more and more international story that goes on with the development of international networking, cooperation and partnerships, further advocacy, lobbying and awareness-raising actions, and forthcoming achievements such as the next World IBD Day. Every step forward brings us closer to the improvement of life for people living with IBD and closer to our final objective that is to find a cure.

Hope is there, united we stand and as long as we believe in it and summon up our strengths, we will make it!

Media focus on IBD

The “Join the Fight” press conference has been a great success in making media more aware of IBD and what it means to live with this disease on a daily basis. The media coverage following the event has been enormous and in many country articles have appeared in mainstream national papers such as for example the Irish Times, la Repubblica (IT), Le Soir (Belgium), Sonntagszeitung (Switzerland) etc. but also reaching more global media outlets in the US, Canada, Algeria, Japan etc.

The press conference has also had a positive impact on EFCCA members' patient associations. It has increased their profile in their own country and following the Barcelona event many of our member associations have been invited by their local media to speak on television or radio about IBD and about the work their associations do.

As a consequence of increased visibility in the media, some members have informed EFCCA that there have been more visits to their websites and in some cases also an increase in their membership.



Timeline: Barcelona conference

13.30 -14.30 Olympic Museum – Press conference

Participation at the press conference is much higher than anticipated. Some delegates have to see live transmission of the press conference in a separate room.

Marco Greco, EFCCA chairman, presents results of the large, patient-driven IMPACT¹ survey. This survey is considered to be one of the largest IBD patient surveys done in Europe: 4,670 patients from 22 countries have participated in the patient survey coordinated by EFCCA and which was available in 10 languages.

Daan Hommes, ECCO chairman, presents finding from the IMPACT¹ survey from the medical viewpoint and calls for a need of new standards in care for people living with IBD.

Melissa Selb, who works for the ICF Research Branch in cooperation with the WHO, presents work being carried out in order to elaborate the IBD Disability Index.



14.30-15.30: Visit to Olympic stadium

Delegates visit the Olympic stadium where a giant bowel has been laid out on the stadium's field. EFCCA members use the opportunity to speak to journalists, doctors and other colleagues present at the event. Photo shoots take place and luckily some snacks are served...

16.00-17.30 IBD Clinic tours

Journalists visit Hospital Clinic where they get first hand experience of IBD treatments and patient care. They have face -to -face meetings with IBD doctors and specialized nurses.



20.15-21.00 country specific press conferences

EFCCA members and representatives from the medical profession meet with their respective journalists to present country specific results from the IMPACT¹ survey and to raise awareness about IBD.

21.00 Sponsored gala dinner in Hilton Hotel

EFCCA members, representatives from the medical profession, journalists as well as commercial sponsors dine in the Hilton Hotel, providing a final opportunity to exchange information, build relationships and have some well-deserved fun after a long day!!



Main findings of the IMPACT study:

Diagnosis

Even though access to specialist care is usually good and most IBD patients receive a timely final diagnosis there are still around 18 % of patients who wait for their diagnosis for a long time (over 5 years).

This can be a period of uncertainty, significant life impact, morbidity, and distress and could create a clinical risk as 64 % may need emergency care BEFORE the diagnosis.

EFCCA recommends to investigate and find methods to prevent presentation to emergency care, experienced by a majority, before diagnosis and to work with emergency care colleagues to raise awareness that the majority of people with IBD are treated in this department.

There should also be a review of diagnostic protocols for those who wait over a year for diagnosis, to reduce this divergence with otherwise good standards.

Finally EFCCA urges policy makers to maintain good access to IBD specialists, especially in the face of financial cuts to health services.

Health care and treatment

As concerns patient's satisfaction with treatment 70 % of patients are satisfied with their treatment plan. However, hospital admission in IBD patients is extremely high at 85 %, representing significant morbidity, and demand on health services. Access to biological therapy is becoming more established, although a minority of patients takes this treatment.

Worryingly, the majority of patients have used corticosteroids, a high proportion experienced side-effects, and almost all were concerned about long-term effects.

“The high hospital admission represents a poor pa-

tient experience, an urgent opportunity for improvement, and significant morbidity. Reducing this burden may somewhat counterbalance the cost of new IBD treatments” states Marco Greco during the Barcelona press conference.

EFCCA recommends that the use of corticosteroids is in line with ECCO guidelines, and that the full range of treatment options are considered, according to comparative risk-benefit profiles.

Access to care

On the subject of access to care a quarter of people with IBD feel they do not have adequate access to them even though specialist healthcare professionals are present.

EFCCA recommends that access to care is improved, there is also a need for an improvement in the quality of communication in consultations (some patients feel they do not get to ask the questions they want to.)

Daily life

In their daily life half of people with IBD are fighting active disease today. Most IBD patients (83%) experience significant symptoms, regardless of whether they are in remission or not. Fatigue, as an example, is often experienced also when in remission.

EFCCA recommends that management plans should include assessment and management of key three symptoms: fatigue, urgency and pain as well as an assessment of the wider symptomatic impact of IBD on everyday life, as well as the clinical context.

Work

In the area of work and education 74% of IBD patients have taken time off work in the last year due to IBD – most startling, over a quarter of respondents had been absent from work for over 25 days in the last

year. Disease severity and ability to work seem to correlate. The majority feels stressed or pressured about taking time off. 25 % of IBD patients have received complaints or unfair comments at work, or suffered discrimination. Most patients are fully employed, but some are under- or unemployed because of IBD.

Flexible, supportive and non-discriminatory work practises are required. Those who face discrimination must be supported in challenging this.

Relationships

With regard to the issue of relationships IBD has significant negative social effects, and in particular is responsible for preventing, or causing the end of intimate relationships for an alarming 40 % of people.

However, meeting others with a similar condition, or becoming part in patients' organizations creates optimism. 63 % of respondents felt that membership of a patients' organization has a beneficial impact on life as a whole.

EFCCA recommends that the impact of IBD on relationships should be considered by healthcare professionals. Healthcare professional should actively signpost patients to national IBD associations.

@ ECCO Congress

EFCCA Board member, Iva Savanovic, and EFCCA Communications Manager, Isabella Haaf, participated in ECCO's Strategic Council Meeting, which took place on 16 February 2012 during the annual ECCO Congress in Barcelona. EFCCA's participation in those meetings is another step towards a closer cooperation with the medical community and shows the increased role that EFCCA is taking in the

European arena.

During the ECCO Congress, EFCCA also exhibited a poster showing the findings of the IMPACT survey, which was awarded a 'poster of distinction' ribbon. EFCCA Board Member Ben Wilson (UK) presented a plenary session of the congress entitled "The True IMPACT of IBD", to the 4200 delegates.

Balkan conference on Rare Diseases

EFCCA CEO, Luisa Avedano, and EFCCA Communications Manager, Isabella Haaf, participated in the Balkan Conference on Rare Diseases, which took place on 24 March in Sofia, Bulgaria. Other European organisations invited were EURORDIS (Rare Diseases Europe) and representatives from research institutes. During the visit EFCCA had the chance to meet representatives of the Bulgarian Crohn's Facebook Group and to participate in their first meeting where members of the group met with three IBD medical specialists in order to discuss the formal establishment of a Bulgarian patient association for Crohn's disease and ulcerative colitis (see page 34).

Ben Wilson at the ECCO Congress posters exhibition



Recognising World IBD Day

Since 2010 EFCCA has been an active supporter of World IBD Day, which is marked on 19 May worldwide when 34 patient associations on four continents are joining efforts to raise awareness on IBD and to improve life of the over five million people worldwide (2.2 million in Europe alone) living with IBD today.

In Europe, EFCCA on behalf of its 27 patients' associations is collaborating with the European Parliament to gain recognition of difficulties faced by people living with IBD and is hosting an awareness raising event in the European Parliament (Brussels) supported by several Members of the European Parliament (MEPs). The support that EFCCA is receiving from the Members of the European Parliament is not only a symbolic action but also a clear statement in favor of people with IBD and patients in general, and it might be the first step of a legislative process able to fill the lack of harmonization and to eradicate the discriminations on IBD in the territory of the European Union.

Many of the 27 EFCCA members are in parallel organizing exciting events in their countries to mark World IBD Day. In the UK for example an awareness

raising campaign organized by Crohn's and Colitis UK focuses on the theme of IBD, Sports and Fitness, using the public interest in the London Olympics to highlight how IBD affects fitness and participation in Sport. Through a special website Crohn's and Colitis UK conducted a survey of nearly 1,000 members and have found that about one third do not take part in any exercise or sporting activities and a quarter said their fitness was low. 80% had had to give up a sport at some time either temporarily or permanently.

64% of the survey respondents have agreed to set themselves a challenge for May to do some form of exercise or sport. Hundreds of people will be walking for Crohn's and Colitis UK in York (May 13) and London (May 26).

Moreover, five sporting champions who have IBD have spoken about their life with Crohn's or Colitis to help the UK media campaign. You can see their stories on the campaign website (www.ibdsportsand-fitness.co.uk)

In Slovenia the IBD patient association is organizing a major set of communication activities. The Commu-



nication campaign is running under the slogan “Currently indisposed - thanks for understanding” and is intended to improve understanding and knowledge of symptoms, because early detection and diagnosis can prevent later complications. It also intends to improve understanding of people with IBD and their specific needs, because this disease affects quality of life in all aspect and requires a lot of adjustment of lifestyle.



Slovenian campaign posters being displayed in public places and events

With this campaign the IBD patient association wants also to reach out to the professionals, particularly general practitioners and urge them towards early detection, faster diagnosis and comprehensive treatment of people with IBD.

The special feature of this communication campaign are a series of short street theater performances that will try to present the problems of IBD to passers-by in an interesting manner.

Among the most important communication activities are the setting up of the human size silhouettes in heavily frequented events and places. These silhouettes represent a variety of roles, occupations of people (eg. physicians) who are currently indisposed due to the departure to the toilet. This is also explained by the sign placed on the silhouettes.

Of course World IBD Day is not only marked in Europe alone, patients' associations worldwide such as in Argentina, Australia, Brazil, Canada, Israel, Japan, New Zealand and the United States are undertaking

important activities to raise awareness of IBD.

In New Zealand for example Crohn's and Colitis (New Zealand) has been planning a media-rich campaign for World IBD Day earlier on 16th May (due to 19 May falling on a Saturday this year), commencing with a 'purple ribbon' event in the grounds of Parliament. Over 100 local members and family, wearing purple t-shirts join together to form a purple ribbon and then reform to spell IBD.

In Argentina the IBD patient association is organizing a press conference on IBD in a horse riding school. Journalists are invited to see for themselves how it feels to cope with a new situation by taking a horse riding lesson. The aim is to draw an unusual parallel of the challenges faced of people living with IBD in having to take control of a difficult situation.

There are many other exciting examples of activities being celebrated on World IBD Day. For more information please check out the World IBD Day website at: www.worldibdday.org

EFCCA Youth Meeting 2012

The next EFCCA Youth Meeting will take place in Copenhagen on July 12-15th. With regards to financial and organisational challenges faced by the host association, EFCCA has decided to support the national association and give them financial support.

We would like to stress how important it is that every national association sends one or two young delegates (18-30 years old) to represent their country at the EYM next July. All EFCCA national member associations should enjoy their equal rights and opportunities to express their voice! As well big countries as small-sized associations, give your youngsters a chance to represent you and to share information with us! This year, the two proposed workshops will deal with:

- How to build and manage a youth group and its projects in your country within your association's framework?
- The specific needs and challenges faced by young adults living with IBD: A contribution to the future EFCCA policy and position papers

In addition, this year, a new EYG leader will be elected. Every association bears one vote, and your vote is important!

You do not know who to send as a delegate? Which profiles would fit best?

Each EFCCA member association can send 2 delegates. They both must be in the age range of 18 to 30 years, living with Crohn's disease or Ulcerative Colitis, and have sufficient

English knowledge allowing them to understand, express themselves and to talk with us.

Ideally they might be communicative, dynamic and enthusiastic about meeting other Europeans suffering from IBD. They might know your association quite well and be able to explain how it is organised and what the existing and forthcoming projects you organise for young adults are.

Young volunteers who want to be more active and to achieve projects in your association might be encouraged. It would be an asset for them to be able to explain briefly and in very easy words how the health-care system in your country works, if IBD are recognised as disabling diseases, if there exists compensation measures for the disability due to IBD, and how young adults deal with the challenges they face in their daily life with IBD. Important is that they can provide us with a general overview of the youth situation in your country.

Our goal is to build stable, regular and constructive relations among the different youth groups in Europe and to develop a lively network with more exchanges and more common projects.

You have not yet registered any delegate for the EYM 2012? Contact the EYG at: eyg@efcca.org

Participants at last year's summer camp (the Netherlands)



Developing Innovative Projects for Young Adults Living with IBD

By Tiphaine Chapeau, EYG member

Since our November board meeting in Brussels, the EFCCA Youth Group (EYG) board has been working hard on the next three-year working plan (2013-2016) which might be adopted by our delegates at the next Youth Meeting in July and which is connected with the budget time-frame used by EFCCA.

The EYG 'raison d'être' and essential purposes are to make possible the exchange of information, knowledge, experiences, and "good practices" among European national associations' youth groups, to enable joined-up working on common causes and interests by building links and bridges between youth groups, to stimulate the development of national youth groups and/or youth projects, and to contribute to EFCCA networking and advocacy actions aiming at raising awareness on IBD and improving the quality of life for European young citizens living with IBD.

Therefore, the EYG working plan will be divided into three chapters: Education, Awareness-raising and Cooperation. The educational section includes the Youth Meetings (EYM), EFCCA summer and winter camps, the creation of Youth Weekends, and the EYG educational games. The EFCCA Youth Weekends would consist of 3-day weekends organized by the EYG team (content and organizational matters) and by the EFCCA national member associations (logistic and some organisational matters) in a European city with an ideal frequency of two or three times a year.

These weekends would give young adults (especially those who usually do not participate in the EYM) opportunities to meet other European youngsters with IBD and to exchange about their own stories and experience, to share and compare information and best practices about their youth groups and the healthcare systems in their countries, and to attend thematic con-

ferences, workshops and discussion groups tailored to their needs. The EYG Explorer Pass could be used in this framework in order to finance the participation of youngsters in financial difficulties and from some countries whose budget would not allow them to support the costs of these weekends.

Concerning awareness, the EYG team plans to develop its communication tools, i.e. its newsletter, the EYGzine, its online presence (website, Facebook page, Youtube Channel with EYG movies and videos), and useful brochures such as a mobility booklet for travellers, exchange students, interns and jobholders who have got IBD and have to expatriate for professional reasons. The creation of a new website is a key and priority issue for our visibility and credibility.

Furthermore, the EYG team is widening and deepening its cooperation with the youth groups of other European patients' umbrella organisations, such as the Coeliac Youth of Europe (CYE), the European Patients Forum (EPF) Youth Group, and the European Disability Forum (EDF) Youth Committee. Indeed, European and international networking can help us to learn from others' experience and to improve the quality of our projects and actions in favour of youngsters from national youth groups.

The EYG team has a wide range of innovative ideas and projects for the forthcoming months and years. We are all ready to devote our energy, free time and skills to them. There are only two things we need: support from EFCCA and national associations to get more youngsters involved, and financing!

For more information about the EFCCA Youth Group, please contact us: eyg@efcca.org

EFCCA General Assembly 2012



Participation in this year's AGM has been a huge success with 25 of the 27 member associations participating in the event. In total 56 delegates traveled to Porto in order to approve the work carried out in the year 2011, to approve the budget and to discuss and vote on the upcoming work plan for 2012. This was followed by elections to the EFCCA Board for the position of EFCCA Chairperson and two board members. Delegates reelected the chairperson, Marco Greco, for a third term. Chayim Bell and Iva Savanovic were also reelected as board members.

Following this more formal part of the assembly, representatives of the EFCCA Youth Group were invited to present their work programme for the coming three years and shared with delegates some very inspiring ideas and innovative plans for the months to come (for more information see page 13).

Other speakers to the assembly included Wouter Miedema from the IBD Research Foundation who presented current and future activities. The General Assembly also voted in favour for the admission of two new members, namely Fundación Mas Vida de Crohn & Colitis Ulcerosa (Argentina) and the Israel

Foundation for Crohn's and Colitis (IFCC). According to the EFCCA constitution it is possible for members outside Europe to join EFCCA as associate members. This allows the new members to participate in most of the activities but does not give them a right to vote. The fact that we have had two associations outside Europe interested in joining EFCCA reflects the increased role that EFCCA is taking worldwide and the support it can give across borders to people living with IBD.

The General Assembly was followed by an amazing social programme organised by the Portuguese Association (APDI) including a sightseeing tour of Porto, a visit to a monastery, a port winery, a trip on a cable car and a boat trip along the river Douro. At the gala dinner participants had the opportunity to sample fine local food and to listen to a traditional Fado singer and musicians. Once again EFCCA would like to thank the Portuguese association APDI and dear colleagues for the wonderful job they did and the warm welcome delegates received!

New associate EFCCA Members, from left to right: Luciana Escati (Argentina), Luisa Avedano, Eyal Tsur (Israel), Marco Greco, Dorit Shomron (Israel) and Nora Penaloza (Argentina)





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Participation in EU projects

By Luisa Avedano, EFCCA Chief Executive Officer

Following the two priorities, as part of EFCCA wider strategy namely **CARBON** (focused on establishing and strengthening collaboration and partnership in Europe and worldwide) and **IGNIS** (based on a more effective advocacy role for positioning EFCCA on the EU arena) the past months offered also the occasion of participating in some projects proposals.

Two of them under the Seventh Framework Programme on research and Innovation:

1) MetaPAS is coordinated by Stanislav Dusko Ehrlich (Département Microbiologie et chaîne alimentaire INRA Jouy-en-Josas, France). It focuses on developing methods and tools for patient stratification based on the composition of gut microbiota.

The aim of this project is to support research and development and/or proof of principle of technologies for application in the area of personalised medicine, i.e. tailored medical interventions which are more effective and have fewer undesirable adverse effects in specifically defined patient groups.

These technologies should be of use for research, screening, diagnostics and/or guidance of therapeutic interventions. Its most valuable expected impact is the development of new and improved tools and technologies to enable the uptake of personalised medicine into clinical practice and support the competitiveness of Europe in this area.

2) INSPIRE is a consortium coordinated by the Business School, University of Hertfordshire, which will be led by Professor Ursula Huws and include Dr Hans Schlappa, Dr Hulya Dagdeviren and Professor Jane Hardy. It focuses on Social Innovation and Public Services.

In both cases, EFCCA will play a role in a variegated stakeholders platform whose main activity will be to read and check the process and the outcomes from a patients' perspective.

One project under the Health Programme 2008-2013 Priority area "Promote health – Measure Increasing healthy life years and promoting healthy ageing – support to the European Innovation Partnership on active and healthy ageing:

ENCOMIUM led by EPPOSI with the main objective to provide European society with a clear systematic modus operandi on how to prepare and execute changes in current delivery of care.

The project has the ambitious objective of delivering indicators and standards for evaluation and monitoring of chronic conditions management as well as to provide the support tools needed to achieve the accompanying attitudinal and behavioral change. Benchmarks and indicators are needed to ensure the execution and sustainability of patient-centric chronic conditions management using a continuum of care approach within different European countries

The last project is under the **Youth for Action - measure 5.1**, co-ordinated by the European Patients Forum. Its main goal is promote a more holistic approach to addressing young patients' needs in EU decision making processes by the means of transnational seminars. EFCCA policy officer Delia Giorgianni is supporting the EFCCA Youth Group who will be involved in its implementation.

These projects are still in their approval phase and we will know if they have been granted in the second half of the year.

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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We believe our responsibility includes making sure that our products reach people who need them, regardless of where they live or their ability to pay. So we've created many far-reaching programs and partnerships to accomplish this. You can learn more about them at msd.com.

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.



Beyond language barriers

Interview with Daniel De Bast (Crohn-RCUH), Xavier Donnet (Crohn-RCUH) and Betty Vandevelde (CCV – vzw)

Why do you have two IBD patient associations in Belgium?

“Belgium is a bi-lingual country and that’s why we also have two patient associations, namely the association Crohn-RCUH- and the Crohn en Colitis ulcerosa Vereniging (CCV)” explains Betty Vandevelde from the CCV. “So the fact that we have two associations in Belgium is purely for linguistic reasons. The association Crohn-RCUH represents French speaking IBD patients and the CCV represents Flemish speaking IBD patients.

The CCV was founded over 30 years ago by a mother of a Crohn’s patient. The mother had called into a Belgium radio programme asking people with Crohn’s disease for some advice. The response was overwhelming, with more than 100 people calling into the station. As a result a group of patients organised a meeting for all these people. I was also present on that day, the place got very crowded and we saw that there was a real need to establish an organisation for patients. It was decided then to found the CCV providing IBD patients with information services and supporting them to cope with their disease.”

“The French speaking association Crohn-RCUH” explains Xavier Donnet “was founded in 1985 by patient, Nicole Moens. It was initially run on an informal basis but soon turned into a professional association providing information to patients that have been diagnosed with IBD.

Within the association we also have some medical staff that works on scientific subjects and our Board includes 4 patients and 2 doctors. But I would like to stress that the focus of our work lies on support “from patients to patients”. For example people who

call in to our information hotline are more at ease talking to patients rather than doctors. We also provide other information services such as for example on reimbursement of medical costs etc. and activities aimed to support patients and their families.”

Do the two associations collaborate on some of the activities?

“Yes, of course!” confirms Betty Vandevelde. “In particular as concerns collaboration on the national level, for example last year we decided to establish a national IBD day in order to raise more awareness about the disease. On this occasion we worked very well together. We divided the work among the French- and Dutch-speaking members of our respective committees to get appointments with 6 members of the parliament (from different political parties).

As a result of our lobbying activities the parliament finally voted in favour of our petition and we now officially mark IBD Day in Belgium on 22 October each year. This work has been a huge success!

Another interesting project we are working together on is the Ventoux challenge under the title of “Do you have the GUTS to bike?” (note from the editor: see page 25). On September 22-23 people living with IBD from all over Belgium, together with their doctors, will cycle the Ventoux mountain. The idea is to raise awareness about IBD and, at the same time, prove that, given the right guidance, treatment and follow-up, people with IBD too can create new boundaries.”

Why is a national IBD Day important for you?

“To have official recognition from the state in form of a national IBD Day has been a very important step for

us” responds Daniel De Bast, President of the Crohn-RCUH. “First of all it has given us a clear commitment from the parliament to defend the rights of people living with IBD and secondly it has increased our visibility amongst the general public.



Unfortunately there is still too little knowledge about IBD but with our new initiative in place I believe our visibility is growing more and more in the coming years. Having a national IBD day is an excellent way of disseminating information about IBD.

Of course we have to be careful what kind of information we release! We do not want to give too much of a negative picture as this might jeopardize those in the labour market: potential employers might be scared off if we portray the disease as too severe. The challenge is to find a good, honest balance in reporting about IBD.”

“The more visibility we get the better for us” agrees Betty Vandeveld. “For example the CCV has been invited to a talk to over 300 doctors on the occasion of their 10th anniversary. In the past only doctors have been invited to such events but now we have been asked to give a patients’ perspective on future treatment for IBD patients. I think doctors are more aware that there are patient associations and that we are doing a lot of good and reliable work.”

From left to right:

Daniel De Bast, Crohn-RCUH, Betty Vandeveld, CCV-vzw), Xavier Donnet, Crohn-RCUH, Frieda Wieme (CCV-vzw)

Why are you involved with a patient association?

“I joined Crohn-RCUH in 1996 when I was diagnosed with IBD,” explains Xavier Donnet. “At that time my work colleague Daniel De Bast, an active member of Crohn-RCUH, was the only person who could understand what I was going through. Being part of the association has helped me a lot to deal with my disease. I realized that the disease, in a strange sense, also has some positive effect in that I can help others who are going through similar situations. The feeling to be able to help others makes me feel good in return! I am now working as treasurer for Crohn-RCUH and together with Daniel we are also the associations’ EFCCA delegates.”

“I have been with the CCV since its beginnings,” responds Betty Vandeveld. “As I mentioned previously when I entered the overcrowded room of our first meeting I realised there was some real need for formally representing people living with IBD. I have been on and off an active member of our association and last year I was asked to become also an EFCCA Board member.

France



In three words, we would like to share some very intense moments which took place at the afa Annual Meeting last 18th March commemorating the 30th anniversary of our association.



Chantal Dufresne
awards grant

Proud to have been able to give research grants totaling 220 000 € this year and to hear Professor Colombel talk about the advances in these last ten years. The number of scientific publications edited thanks to afa is impressive ! **Proud** also to relive 30 years of activity and service to patients and for the recognition we received from our two Ministries , Health and

Research.

Emotion from the standing ovation of 200 participants for Janine Aupetit, a tribute paid to her as well as to the afa builders. Everyone was there : members, delegates, volunteers, partners, to experience sharing

afa fouders Janine Aupetit, Prs Le Quintrec and Gendre



this moment. **Emotion** from the testimonies and the photos retracing so many memories, so many battles.

Hope to continue even more to mobilize together, to convey together this belief in a better future for young people. This day gave us special energy to pursue our activities and to finally be cured !

afa, Chantal Dufresne



Janine Aupetit and our youngsters

Finland

The central aim of the Crohn and Colitis Association Finland is to offer peer support and medical information about IBD to its members and to look after the special interests of IBD patients and people nearest to them.

Our association emphasizes peer support activities for young people between the ages of 18 and 30 years. This age group, called CroCo Team, has both national and regional meetings and organises activities which are recreational and informative. They also have special group-get-together discussions on Facebook and a joint weekend meetings with patients of the same age group from the national association for stoma patients. We are also introducing experimental meetings for teenagers in Helsinki. They are the group of patients who need a lot of peer support but are rather difficult to reach.

In terms of awareness raising the association closely monitors information about IBD in national media

and reports it to its members through the patient magazine, association web site and social media. The patient magazine Crohn&Colitis is distributed largely around Finland to all central hospitals, other medical units and interest groups. Our web site is an important channel for association information and peer support. Last year it was visited 463 368 times.

Tiina Silvast, CCAFIN

Serbia

Working on visibility and real life problems that people with IBD face every day, the Serbian Association for Crohn's and Colitis (UKUKS) went through some really big steps.

First of all, the "Join the Fight against IBD" event in Barcelona was a huge success for our Serbian association in terms of visibility. Following the press conference two journalists (one from a major newspaper, and the other from the second largest national television) provided the public of Serbia with a lot of information regarding IBD and problems that IBD patients meet in everyday life.

Locally, this resulted in several press conferences and TV appearances in which UKUKS participated. The press conferences focused mainly on healthcare issues as none of the treatment centers in the whole of Serbia have any biological medication for existing patients and authorities have not planned involving new patients into any biological treatment programme..

UKUKS, along with other patients associations for HIV/AIDS, Hepatitis C and rheumatoid arthritis, organized a press conference, aimed at authorities asking them to speed up the process of importing medication. This conference was a success and patients received their treatment in record time. TV appearances of UKUKS representatives resulted in an increase of our membership and more people getting involved in UKUKS online forums and exchange of knowledge and experiences.

UKUKS organized a second national meeting, which had more visitors than the first one. During the meeting patients had the opportunity to receive information and advice from a psychologist.

Following the Barcelona event we had over 60 publications regarding IBD in Serbian newspapers. We see this as a huge success, and hope for further interest from the media.

Stefan Djakovic, Serbia

Norway

We have recently produced two videos: a film entitled "IBD-by remote control" which features the leader of the "Committee of public health" of the Norwegian Parliament. In the film he acts as an IBD patient for one day and gets instructions from the LMF youth representatives by SMS. The idea is to show what it really means to live with IBD. The film has been subtitled into English and has been shown in several countries in Europe and South America.

The other film is much longer lasting 33 minutes. It tells the story of four patients from our youth group, it also features a gastroenterologists and provides information about our association. The film is directed at people with IBD, their families and friends, schools, employers and hospitals. This film has been financed by the Norwegian lottery fund.

Both films can be viewed on Youtube and/or on our website: www.lmf norge.no.

Other activities we have undertaken include a new web-site for www.lmf norge.no and www.lmf ungdom.no (youth website), an application for finding the nearest toilet available, patient seminars, and participation in meetings with gastroenterologists and nurses.

Arne Schatten, LMF

United Kingdom

New Crohn's and Colitis UK Survey shows 200,000 individuals forced to give up Sports

Top sportsmen and women offer inspiration

The first survey of its kind by the charity Crohn's and Colitis UK suggests that the majority of people living with these challenging inflammatory bowel diseases (IBD) have been forced to stop taking part in sport or fitness activities, as a result of their illness at some point.

Of the nearly 1,000 respondents surveyed, 80% stated that they had given-up or reduced their participation in sport either temporally or permanently. If this figure accurately reflects the disease limitations faced by all 240,000 people in the UK with Crohn's and Colitis, the charity estimates that at some point as many as 192,000 individuals are finding it challenging to be as active as they once were.

For the 10,000 (mostly young people) diagnosed annually with these incurable, fluctuating conditions, these findings are particularly poignant when placed in the context of the current Olympic year.

Overall, 88% of survey responders stated that IBD had reduced their fitness levels, although the majority (72%) agreed that exercise makes them feel better. However, 23% of those surveyed stated that exercise worsens their IBD symptoms.

Set against an average survey age of 40, with most having been diagnosed in 2003; the survey findings make worrying reading for the charity and its 30,000 members.

As a result, Crohn's and Colitis UK has recruited the support of sportsmen and women with IBD to offer their tips on how they maintain and return to fitness after a flare-up of their IBD.

The Crohn's and Colitis UK Sport and Fitness Cham-

pions include, five-times Olympic gold medal winning rower Sir Steve Redgrave; former England Captain and most capped England Flanker Lewis Moody; Norwich City FC footballer Russell Martin; Para-Olympic weight lifter Ali Jawad;

World Champion power-lifter Henry Tosh; racing-driver Rick Parfitt Junior and dancer Della Thielamay. Each one has battled with Crohn's or Colitis and achieved success despite their fluctuating symptoms, surgeries and medications. They all want to offer hope and inspiration to their many fellow IBD sufferers who may be struggling to get back to fitness.

Lewis Moody was diagnosed with ulcerative colitis in 2005. To add to his many physical injuries, Lewis is now throwing himself into the fight to help others living with IBD.

"It's a pain in the arse," Lewis admits, "because if it strikes when you're young and fit, you're too embarrassed to talk about it; you just don't know what's hit you. Sportsmen are used to coping with all sorts of injuries, but the pain, feeling knackered all the time, and the humiliation of not always being able to control your bowels is terrible. Until it hit me, I'd have probably been one of the guys making toilet jokes about it ... but it's no joke."

"I'd urge anyone to tell someone and get help, if they think they've got it. My life was so much easier when



Sir Steve Redgrave

I finally told my mates on and off the team – I only wish I'd done it earlier. Get to know the enemy, get information, talk about it – and then take control – it's your body, and your life."

For the Sport and Fitness Champions' tips, log on to www.ibd-sportandfitness.co.uk for their videos and posters or access them from the main charity website www.crohnsandcolitis.org.uk. The Crohn's and Colitis UK Champions are also taking part in awareness raising activities around the UK during Crohn's and Colitis Month in May.

Nearly one thousand Crohn's and Colitis UK members responded to the survey of how their sport or fitness activities compared before and after having received their diagnosis of these life-limiting diseases.

Deborah Simmonds of Margate, Kent who was diagnosed with Colitis in 2004 comments, "My personal fitness has to be managed in a different way now, as I am unable to continue competitive games but I swim regularly and practice yoga. I also walk and ski where rest stops can be taken as necessary."

Deborah's comments are typical of the survey findings with many people adjusting their sport or fitness activities to better suit their state of health with walking, jogging or running, attending a gym, swimming, cycling or taking part in zumba and yoga the most popular activities.

Richard Driscoll, CEO of Crohn's and Colitis UK, is hoping that with the emphasis on sport and fitness in the Olympic year that the Champions' support will make a difference. Richard explains, "The survey findings indicate that there are many reasons why



Sometimes the goal is to get through the day

I'm 26 years of age, and a professional footballer for Norwich City. I'm supporting Crohn's and Colitis UK in their campaign to encourage people living with inflammatory bowel disease (IBD), to improve their levels of overall fitness by participating in a sport of their choice, or setting themselves an individual challenge, during the Olympic year - and maybe beyond.

I know what it's like to live with Ulcerative Colitis - so I'm joining the ranks of sports men and women, like Darren Fletcher, my fellow Scottish international - who are prepared to speak up about these little-known conditions.

Colitis and Crohn's are both forms of inflammatory bowel disease (IBD) and yet very few people know much about the symptoms, or how living with these conditions can affect lives. In particular, young people aged between 16 and 29 are more likely to be affected - sometimes their lives are put on hold, waiting for a diagnosis, and not knowing who to talk to. As their Champion, I'm fronting a film to go on the charity's website, and I hope that by telling my story, I'll inspire others to tell their own, to break the silence and contact the charity for support.

Russell Martin

Russell Martin – proud Ambassador for Crohn's and Colitis UK

Colitis and Crohn's are inflammatory bowel diseases that can have a devastating impact on education, work, social and family life. They can strike at any age but young people are most at risk and there is no known cure. Crohn's and Colitis UK offers much-needed information and support to the 250,000 sufferers in the UK, and also funds vital research. Further information can be obtained at www.crohnsandcolitis.org.uk

Charity Registered in England and Wales 1117148 Scotland SC098632 Information Line 0845 1302233 General enquiries 01727 8300

some patients will struggle to ever regain former fitness levels – sometimes it is fear of not being able to find an accessible toilet in time. Loss of weight and failure to retain strength may also be an issue in some sports activities. Sometimes it is the fear of having to “pay the price” of extreme fatigue afterwards. With conditions that come and go, some people may limit their activities so as not to “trigger” their IBD symptoms – without realizing just how much they have gradually restricted their lifestyle and that of their families as well.”

Sweden

We have launched a new website for young kids up to 13 years. Tarmalarm.se is a brand new website where children with IBD can learn about their diseases. The site was launched on April the 1st, it's not a April fool's day trick though. In Sweden we try to provide different services for children with IBD and we can see that social media, like Facebook and a website are really good channels to reach out and find the children. We have a youth editor for our Magazine Kanalen, Ebba Persson, who is really encouraging and supportive to kids who are willing to write and tell others about their diseases.

We are very happy with this new website which has received support from the company Otsuka. Please visit our website at www.tarmalarm.se

Wictoria Hånell, Executive Director

Spain

First of all we would like to report that this year we will be celebrating our 25th anniversary. It was 25 years ago when on 27 October 1987 Leon Pecasse and other IBD patients founded a small IBD group in Malaga that eventually formed the basis of the confederation of ACCU Spain (Associations of Crohn's and Ulcerative Colitis).

As concerns other activities ACCU together with GETECCU (the Spanish Crohn's and Colitis Medical Organisation) have recently launched two research grants aimed at patients with IBD.

The grants of 15 000 € each are destined for research projects that show how IBD effects patients on a daily basis, especially as concerns issues around disability as well as work life. Once the research projects have been completed the results will be presented to the relevant Ministries together with a petition to recognise IBD as a disability, which can have a negative impact on work life and personal life for a great number of patients.

In order to make the petition stronger and also to have the support of IBD patients ACCU has started a campaign to collect signatures for this petition. The campaign has been publicised in our Crónica magazine, our website www.accuesp.com and social networks.

Finally in May we will hold our 12th ACCU convention to take place in Benidorm. There will be around 200 participants including representatives from the patient groups, distinguished medical specialists who will carry out workshop on subjects such as disability and IBD amongst others.

Yolanda Modino, ACCU Spain

Slovakia



The Slovak Crohn Club is committed to support IBD patients and their families and to help them overcome the disease burden. Amongst many other activities that are aimed at our members we have recently published a book on “Yoga for IBD patients” written by Milan Polas-

ek and under the patronage of Dr. Ondrasova.

The book presents techniques for all those who would like to find help in practicing yoga. The goal of yoga, or of the person practicing yoga, is to attain a state of perfect spiritual insight and tranquility. The strongest power of yoga is endurance. The aim of the book is to learn how to calm down in every day life situations, especially when one is in

discomfort and/or in a stressful situation. We hope that the book can provide some help for a better quality of life with IBD.

The book has received financial support from the pharmaceutical company Abbott.

Ivana Charvatova, SCC

Belgium

Ventoux-event 2012

“Do you have the GUTS to bike?”

This is the motto of the challenge that the Belgian people with Crohns and ulcerative colitis want to accept, together with their doctors, during the weekend of September 22-23 on the slopes of the Mont Ventoux.

The event is organized by the CCV-vzw (Belgium) together with their French speaking counterparts from the association Crohn-RCUH. After all, people with IBD all speak the same language.

The goal of the event is to raise awareness about IBD and, at the same time, prove that, given the right guidance, treatment and follow-up, people with IBD too can create new boundaries.

At the same time a scientific study is connected to the project that investigates the impact of sports and training on IBD. The competitors undergo a series of cycling-tests before, during and after training. The results of these tests will later be compared to the results of a control group.

While you are reading this, the first training ride in group will be over.

On May 15 we will hold a press conference together

with Sven Nijs and Tia Hellebout (Belgian top-athletes) who have accepted godfathership of this challenge. We can also count on the support of lots of athletes and politicians who want to root for our cause. Ventoux ... here we come!

Hungary

Our association is trying to help IBD patients in every possible way and we have several activities throughout the year that are available for our members. For example we have a club meeting on every last Monday of the month in Heim Pál Hospital in Budapest, where different people (experts, doctors, dieticians, etc.) give lectures about topics related to IBD, such as new treatments, medications, medical aids, natural medicine treatments connected to IBD and nutrition. Furthermore, on these occasions, patients and members are also informed about patient rights and health care issues.

Since February 2000 we also provide nutritional counselling. This takes place before every club meeting with the help of our association's dieticians. Furthermore, brochures and recipes are provided for our members, patients and their relatives.

On World IBD Day in May we will organise lectures and presentations related to IBD, as well as personal guidance, cultural programs, different products and nutritional counselling made available in a relaxed atmosphere. This day is also perfect for the members to exchange their ideas and experiences. It's estimated that around 120 people will attend this activity.

We are also organising a “Psychological group” for IBD patients, where psychologists help patients to cope with their disease and the related problems.

Another important aspect of our association is the protection of patients' rights. Patients, even individuals are represented in official, legal and other platforms via our association. Bills and regulations are commented by our patient law experts.

Finally we also organise regular outdoor activities

such as excursions, theatre nights, and other cultural programs, in order to help the patients and their relatives to be part of a group where they have similar problems, where it is not a taboo to talk about their disease, where they can share their ideas and support each other. In August, we will go on a relaxing weekend with our members (last year we went to Eger), which also provides a great opportunity to rest a little from every days' routine.

We are also currently thinking about establishing a voluntary help network and hospital help service for the patients; to submit health care related proposals and to take part in IBD-related health care legislation issues by officially commenting on them.

Kata Daru, MCBBE

Austria

Charity Football tournament

„one for all – all for one“

An innovative capacity building programme was launched in district MA6 of the city of Vienna. The programme which included various courses and seminars aimed to increase leadership potential of its citizens. Special attention was given to the elaboration and implementation of a social project: 18 participants in cooperation with the ÖMCCV worked on a delicate subject matter, namely IBD.

That's how it all started and the result was a wonderful project elaborated by „team 18“. Under the project title „Crohn friendly place“ they managed to engage other districts (34 and 44), the Vienna Chamber of Commerce, adult education authorities and other related institutions and au-

thorities. They also created their own Facebook page, managed to ensure that media reported on the subject of IBD including on national television (ORF), supported our activities around IBD Day when we organised a toilet race in Vienna and also presented an application allowing ist users to search for public toilets that are available in Vienna.

But the masterpiece of „team18“ was the organisation of a Football Charity tournament last October.

It was a brilliantly organised tournament full of excitement and high quality sport and even included a raffle allowing participants to win wonderful prizes. Team 18 worked very hard to ensure a high turnout to the event and the involvement of many sponsors. As a result it was able to donate over 13 000 Euros to the ÖMCCV. A huge effort went into this and it is an incredible success!!!

The ÖMCCV doesn't really know how to repay this kind of commitment from Team 18 and we would like to thank them again for their great work and cooperation. We want to ensure them that the donation will be used for the benefit and work of our members.

Rudi Breitenberger, ÖMCCV

Team 18





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.



IBD Planet: Trekking

IBD Adventures takes travel to new heights

By John O'Shaughnessy

Rob Hill, the Canadian climber with Crohn's Disease who climbed the Seven Summits--the highest mountain on each of the seven continents--launched IBD Adventures through his Canadian Charity IDEAS in 2009. IBD Adventures are fundraising treks to some of the world's most famous high places aimed at raising funds for IBD research and awareness of intestinal diseases. There's also another mission:

"When we started the program through the Intestinal Disease Education and Awareness Society," explained Rob. "We wanted to take some people who are dealing with the illnesses directly on these amazing adventures to show them, and to demonstrate to other patients, that they could still do these incredible trips and that they shouldn't let IBD stop them from living the kinds of lives they wanted to."

Rob was scheduled to finish his Seven Summits campaign, aptly named No Guts Know Glory, on the summit of Mount Everest in the spring climbing season of 2010. After sickness prevented his 2008 attempt on the mountain, Rob knew he needed to get back up to a high place in order to help prepare his body for high altitude again. Altitude can cause inflammation of the soft tissues in the body--a symptom that is no stranger to anyone who suffers from intestinal disease. But the effects of altitude aren't always the same



Team on the summit of Kilimanjaro mountain, Tanzania

for everyone so there is nothing to say that someone with IBD will be more likely to suffer altitude sickness than anyone else.

To get high up, Rob decided he would return to Mount Kilimanjaro in Africa: "It's one of my favourite climbs," Rob said. "Because it's accessible and not very technical, I was able to have some friends and family join me the first time I went. When I decided to go back, I put the call out to my network of friends to see if anyone wanted to come with me. Things just grew from there. The next thing I knew, someone suggested we fundraise for the charity, another suggested we find a youth with IBD to join us and do an awareness campaign around their story and

then all of a sudden, we had almost 10 of us training and fundraising, speaking to groups, and then on the mountain. It was incredible! And that's how IBD Adventures was born."

Abbott Laboratories, makers of the drug Humira used to treat IBD and Convatec, a leading manufacturer of ostomy supplies, had both agreed to support Rob's Seven Summits campaign. They quickly agreed to support IBD Adventures too, sponsoring youths to join in the treks.

All members of the Kilimanjaro team reached the summit, including then 16-year-old Clinton Shard from Squamish, British Columbia, a small community just north of Vancouver. Clinton had been fighting the symptoms of Crohn's disease for over 3 years at that time.

"I'd given up a lot as a teenager because of the sickness," Clinton said. "I had to stop playing soccer because I couldn't keep up. There were months when I couldn't go to school, and there were weeks spent

in the hospital because of my disease. I hadn't had a flare-up for six months when Rob asked me if I thought I could go to Africa and climb Kilimanjaro with him. He told me if I could stay healthy through the training, he could bring me along. Standing on top of that mountain was when I knew I had beaten Crohn's."

Since that first trek, IBD Adventures has held three more treks. A team of trekkers, with five members who had had IBD and ostomy surgery, joined Rob on his trek into Everest Base Camp in April 2010. All team members spent two nights in Base Camp getting a rare glimpse of the mountain expedition most trekkers never do. In September 2010, IBD Adventures successfully led another team of eight on the world famous West Coast Trail on the west side of Vancouver Island south of Tofino, British Columbia.

And most recently, Rob and the IBD Adventures program travelled to Peru in March of 2012 to trek the Inca Trail to one of the Seven Wonders of the World, Machu Pichu.

**Clinton Shard
reaching Base
Camp on
Everest**



“All of the IBD Adventures treks have been memory-making,” Rob said. “But Machu Pichu was simply amazing. We had an incredible team; most of us had IBD and those that didn’t were intimately aware of the illnesses because they were close friends or family members of the ones that did. For four days we hiked up and down the steep slopes of the Andes, visiting ancient ruins and seeing a culture that is incredibly rich in history and character. Our local guides were amazing and they made sure we took the less traveled paths and saw the sights that the usual tours don’t get to. The magical reputation of Machu Pichu is well deserved.”

Like the first IBD Adventures trek on Kilimanjaro just two and half years earlier, Machu Pichu served as an awakening for several members of the trekking team when it came to themselves and their experiences with IBD. Ashley Anderson, a young woman from Canada who suffers from Crohn’s Disease said the trek served as a perfect metaphor for her journey with her illness.

“When I was diagnosed, I had so many doubts and fears about being able to handle being chronically ill,” explained Ashley. “Of course I was excited to go to Peru, but mixed in with that excitement was nervousness and fear. Would I be able to stay healthy in a foreign place? How would my body and Crohn’s react to the very high altitude I would be trekking at? What if I get a flare-up will in Peru? I decided to not let the fear prevent me from trying. When I reached Machu Pichu it was amazing. Reflecting back on all

that I’d been through, I’m so glad that I had this opportunity to remind myself that this journey has made me a really strong person.”

Traveling to foreign countries is challenging for anyone. Dietary changes, water quality changes and hygiene issues are common sources of sickness for travellers going to less-developed nations. If you have IBD or an ostomy, your health system is compromised and could present additional challenges. All participants in IBD Adventures treks must go through a medical check-up with their own physician prior to travel. Regardless of past medical history, it’s generally recommended that all people traveling to foreign countries consult medical professionals with knowledge of travel medicine to ensure they are fit to travel and have received proper immunizations for diseases common to the areas they plan to visit.

For more information on IBD Adventures, please visit the program website at www.ibdadventures.com

Team after walking through the Sun Gate over looking The Lost City of Machu Picchu, Peru



Blogging is my therapy

By Michael Seres

Just over 30 years ago as a 12year old boy I was diagnosed with Crohn's disease. Back then it was relatively rare and took about 18 months to diagnose. I remember the doctors at first thinking that I just wanted to skip school, then they thought it was psychological and eventually after a whole series of tests my parents were told it was Crohn's.

Wind the clock forward 30 years and times have changed enormously. New drugs come on the market at a far greater rate than previously and surgical techniques have advanced massively.



I have been unlucky in that prior to my last surgery I had over 20 different operations. My first few were in my late teens/early twenties and then you would lie in bed until the bowel started working again.

In my case that could be 4 weeks. Now they get you up the day after surgery. Wow what a change! Unfortunately after all my surgeries I found myself with very little bowel left and eventually with intestinal failure. My life at 42, married to an amazing lady with 3 wonderful kids, was going to be one on intravenous feeding known as TPN and a relatively restricted daily life.

I know that plenty of people cope well on tpn but for me I wanted to be a normal dad running around with the kids and a husband that did everything he could possibly do. I guess that maybe I'm not that good at compromise.

Michael Seres in hospital showing his "treats"

After a journey to the USA and back my wife and I found ourselves at The Churchill Hospital, Oxford, England sitting in front of their bowel transplant surgeon and transplant coordinator. Amongst everything he said that day there were 5 words that have stayed with me to this day. "I can change your life".

And he has! A bowel transplant was not even something we had contemplated but here I was on my journey from Crohn's Disease to a bowel transplant. I decided that the best way of explaining to friends and family what was happening was to start a daily blog.

I was as computer dummy at the time but I gradually realised that blogging was also my therapy. It was my way of telling everyone how I felt especially in the build up to such massive surgery. After the intense round of tests and evaluations I eventually was listed

and late last year I became the 11th patient to have a bowel transplant in Oxford.

Nothing can prepare you for such surgery and what you do through afterwards. Without doubt it has been the toughest challenge of my life. You need though several things in order to keep going.

Totally faith in your transplant team which I have to this day. From the lead surgeon to every member of the nursing staff I cannot fault their kindness or commitment to making me better. My surgery lasted just over 10 hours.

The walk to theatre was the worst moment of my life. I gripped my wife's hand so tightly but was determined not to cry as I didn't want to worry her. I knew she was shaking too. I also knew that the next ten hours were going to be even harder for her than me but we both believed in our team and that this surgery could change our lives.

You also need to have incredible support around you. I couldn't have done this without my wife and kids and without the incredible support of family and friends. Going in to it you feel that you can cope but when you are actually in the thick of things having people around you to help makes life that bit easier.

My wife also took over my blogging whilst I was in hospital. Again it started as a way of keeping everyone updated but also it became a source of therapy and a way of letting off steam.

Slowly but surely the numbers reading the blog began to grow. The final component I feel that you need is mental strength. When you are told that the whole journey might take up to a year with ups and downs on the way you think, yes I can do that.

It is very different when you are in the middle of it and having the mental strength to keep going and to help boost each other is so important. As the weeks went on so the pain starts to subside and you start to improve. By that stage I began to realise that my blog was being viewed around the world.

I made a conscious decision that aside from keeping everyone informed of my progress I wanted it to be a vehicle to help others. To let other Crohnie's out there know that there were people who knew what they were going through and also to explain what a bowel transplant is and the effect it has on you and your family.

I realised that members of my medical team were also reading it to keep up to date with my progress but better still they were telling other medical students to have a read so that they could understand what transplant was really like.

From my blog I have been very privileged to now be involved with a number of crohn's/colitis/ bowel transplant patient forums around the world. I have met some amazing people and am in touch now daily with patients and their families.

I now am on twitter and Facebook and various other social media sites, and if you are squeamish don't read on but I ever pinned a picture of my Stoma on Pinterest which attracted conversations everywhere.

I am writing this article from my hospital bed as I recover from a few infections, just minor blips. I am though determined to use my experiences to help others. Information is key and I really believe that in this current world social media can play an important part in patient recovery.

And all of this from a computer dummy! I know that I have a few more hurdles to get through before I'm over the finishing line. That will put more pressure on my wife and kids but we will get through it and I guess that you just have to keep on smiling.

If you fancy reading my blog then please go to:

<http://beingapatient.blogspot.com>

or follow me on twitter @mjseres

Patient safety and Health First Europe – towards a strong European strategy

By Amanda Bogg, Health First Europe

Following the adoption of the Directive on Patients' Rights in Cross-border Healthcare last year, European policymakers are looking to strengthen regulation on patient safety where significant public health concerns - such as safety, quality of care, education, innovation and cost - exist. In addition, the economic crisis and scandal on PIP breast implants, has increased the awareness of individuals about issues of quality and safety when they enter a healthcare setting in any Member State.

Health First Europe believes that the EU can, and should, play a greater role in protecting patients. By raising awareness with EU policymakers about how health policy can support patients, healthcare staff, hospitals and industry, Health First Europe has been seeking not only to strengthen patient safety standards, but also to encourage the development of EU level strategies to decrease healthcare associated infections (HCAIs).

As part of Health First Europe's continuing work on patient safety, an internal Task Force dedicated to the issue was launched in 2011 under the patronage of MEP Christofer Fjellner (EPP, Sweden). The Task Force produced concrete, targeted recommendations on patient safety to supplement the Council Recommendation of 9 June 2009 on patient safety, including the prevention and control of healthcare associated infections. The European Commission is currently reviewing Member State implementation of these recommendations. HFE Members such as the European Health Telematics Association (EHTEL), Eucomed, the International Alliance of Patients Organisation (IAPO), the International Diabetes Federation – Europe (IDF - Europe) and the European Federation of Crohn's and Ulcerative Colitis Associations (EFFCA) contributed to the Task Force's success which culmi-

nated in a roundtable event in the European Parliament on 24 April.

The high-level roundtable event included the participation of representatives from the European Commission, the European Centre for Disease and Prevention Control, the European Parliament, the German Coalition for Patient Safety, the World Health Organization and the European Patients' Forum in addition to various other HFE members and relevant health stakeholders. Sponsored by MEP Fjellner and chaired by HFE Honorary President, John Bowis, discussions focused on HFE's recommendations on patient safety and urged the European Commission and the European Parliament to adopt measurable improvement targets for Member States on patient safety, create harmonised reporting systems for comparable data on HCAIs and produce a European strategy on HCAI to further protect patients in all healthcare settings. Receiving considerable support for the recommendations of the Task Force, Health First Europe will continue to collaborate with policymakers to ensure that these recommendations are taken up in the Commission's June report and beyond.

As MEP Fjellner declared, "We can do more to protect patients." Health First Europe will continue to ensure that together with the EU institutions, more is being done to ensure safety for all of us in a healthcare setting.

To read more about Health First Europe on our work on patient safety, visit: www.healthfirsteurope.org



Establishing a Crohn's Patients' Association in Bulgaria

Interview with Martin Kojinkov, Bulgaria Crohn's and Ulcerative Colitis Association

What is the situation in Bulgaria as concerns IBD?

In Bulgaria IBD is not a very known disease. Officially there are around 500-1000 cases of Crohn's disease, I am not that familiar with the statistics as concerns ulcerative colitis. We have around 5-6 medical centers that can diagnose and treat Crohn's disease, most of them are based in the capital city, Sofia and there is also a medical center in Varna and another one in Stry Gorod.

So this means that people living with IBD mainly have to travel to the capital city to get a diagnosis/treatment?

In my opinion it's not a problem that we only have a few medical centers for IBD patients. I believe it's more important to have highly qualified doctors in those centers and to make sure that the system works well. That means that GPs (General Practitioners) have to have some kind of knowledge of those diseases so that they can refer the patient to the specialised centers.

What was your own experience? How long did it take you to get diagnosed?

When I started to get sick I had no idea what was wrong with me. I had been living healthily for 25 years so when the first symptoms began I thought they would go away by themselves. By the time I went to see a doctor – a year later – I had serious problems. Luckily I had access to a highly qualified doctor and after examining me she diagnosed me with Crohn's disease.



However I know plenty of other people in Bulgaria who weren't so lucky and for some it took them over a year to get a diagnosis going from one hospital to another.

How did you get involved with the patient association in Bulgaria?

About a year ago I was surfing the internet looking for information on Crohn's disease in Bulgaria when I came across a Facebook page on Crohn's disease. I joined the group and now we are around 30 people in the group. We exchange information about doctors, about medicine, about alternative cures etc.

I think it is essential to have such a group and some structure to represent patients not only because it makes it easier to lobby with public authorities but more importantly – this kind of informal communication helps people to recover fast and also to be diagnosed faster as they have first hand experience and advice available.

What is the feedback from the Facebook group?

Recently I decided to move things forward and invited members of the Facebook Group to meet in order to discuss the formal establishment of a Bulgarian Crohn's and Ulcerative Colitis Association. The meeting took place in Sofia on 23 March 2012 and I was happy that 6 people out of the 30 came to the meeting.

Additionally I had also invited several journalists, two EFCCA representatives and three highly specialized gastroenterologists who gave their full support to this initiative. Indeed at the moment it's the only kind of IBD organization in Bulgaria.

I hope that the other Facebook Group members will be more active in future once they see that we are actually putting our efforts together in order to improve life of people living with Crohn's disease. I strongly believe that as patients and with the support of the doctors we can make things better in Bulgaria.

What are your expectations of being part of a European network such as EFCCA?

To answer this I should first let you know that the motto of our national assembly "joined, we are strong".

This is very similar to EFCCA's motto "United We Stand". If more people share their problems and act together they can change!

Being a member of EFCCA will be a good opportunity for us to find out more about IBD, how to gain access to new medication, about innovative treatments etc. well all things that are very important for us as patients.

Launch of French Rare Disease association

By Chantal Dufresne, Afa

Last month I experienced an emotional moment. I was at the launch of the Rare Disease Foundation, which took place in the magnificent Great Room of the Academy of Science in Paris.

This new foundation enables those who play a significant role in research and care to work together: the AFM Telethon, the Alliance des Maladies Rares, Inserm as well as hospitals and universities. It will be run by Pr. Nicholas Lévy and chaired by Pr. Jean Pierre Grünfeld. The global endowment is 4 million euro, among which three quarters have been donated by the AFM (the French Association against Muscular Dystrophy).

The various speakers' voices were often filled with emotion, such as L. Tiennot Herment's. As the Head of the AFM, she mentioned the role played by the donors of the Telethon, making this creation possible – over a billion euros ever since the origin has allowed the financing of the Genethon. So was Viviane Viollet's, the Head of l'Alliance des Maladies Rares, who recalled the long way up since the beginning, and more particularly the role played by herself and our Vice Chairman, Jacques Bernard, at the start of this federation of 200 groups, amongst them our IBD association "afa". Rare diseases affect 3 million people in France, covering 7 thousand types of diseases. IBD is not regarded as a rare, except for paediatric cases, We share a lot of characteristics though, erratic diagnoses, a strong impact on the quality of the patient's life; but we have differences too, an important one is life expectancy and of course there are treatments.

Thus we are not considered as orphan diseases. Nevertheless we share many of the struggles and we wish this new Foundation all the success it deserves.

IBD Research Foundation - Update

by Wouter Miedema

Foundation Management Board Chairman Rod Mitchell joined the EFCCA representatives in Barcelona in mid February at the invitation of the EFCCA Board and was able to be present in the Olympic Stadium for the European “Fight against IBD” events which publicized many of the issues and difficulties for patients with Crohn’s and colitis across Europe and beyond.

Keeping abreast of the challenges that patients face and being briefed about the latest research through attending the annual ECCO Congress in the city after the high profile EFCCA awareness raising events remains important to the work of the IBD Research Foundation as is the opportunity to talk with EFCCA and the national IBD patient representatives, health professionals and other related stakeholders. During the Barcelona days in February we were also able to hold a joint meeting on the Saturday of the Foundation Supervisory and Management Boards led by Micke Lindholm and Rod Mitchell and to begin to review our plans for the future.

We continue to be grateful to the EFCCA and the member associations who support us though we realize that for some, with their own annual research initiatives, this is more difficult, especially in the present economic conditions.

We hope though in time that we may be able to collaborate with them in jointly funding a research study.

In the next weeks the Foundation will again be issuing the 2012 Call for IBD research applications and we should be pleased if the readers of the EFCCA Magazine will also inform the health professionals in their own countries and to tell people generally about our work – see: www.ibdresearch.org

Later in the year the Foundation will be making a special appeal for funding and we hope that you will take part and share news about the Foundation. We also seek people to actively help us in our work and if you are interested please do get in touch with our Secretary, Wouter Miedema. For those who may wish to donate funds details of our bank account can be

Hajnalka Szabo (left) and Wouter Miedema(right) receiving a check of 25000 CHF from Bruno Raffa (middle) during the 25th anniversary event of the Swiss patient association (SMCCV) in Fribourg



found with this report, as can the contact address of the Foundation Secretary.

The Foundation would like to thank all those that support us so enabling us to continually contribute to the IBD research programmes, the outcomes of which we all wish to see leading to the still elusive cause and cure. It is pleasing to see the increasing global co-operation among all IBD healthcare partners and that the World IBD Day in May will again provide an excellent opportunity for the patients' voices worldwide to be heard and to remind us all of the real benefits of working together in locating the missing pieces of the IBD jigsaw puzzle!

Donations

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

Account number: 97.46.86.158
IBAN: NL37ABNA0974686158
BIC: ABNANL2A

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European Patient Forum

The European Patient Forum has published recommendations for a patient-centred implementation as concerns amendments to the the EU Pharmacovigilance legislation (Directive 2010/84/EU and REGULATION (EU) No 1235/2010).

These recommendations have been developed by the European Patients' Forum and its member organisations representing the interests of patients with chronic diseases throughout the European Union. They aim to provide the authorities and bodies in EU Member States tasked with the transposition and implementation of Directive 2010/84/EU with a set of recommendations to ensure that this Directive, as intended, will lead to a strong, open and transparent pharmacovigilance system that ensures the confidence of patients, health professionals and regulators alike and represents a step forward for safety, high quality, and patient-centred healthcare.

Patients and their organisations have a wealth of expertise and experience that can contribute to higher patient safety, and quality of medicines in Europe. They are committed to sharing this expertise and contribute both at national and European levels to the successful implementation of the Directive. The pharmacovigilance framework encourages patient involvement at national and European level. This document therefore highlights areas where patient organisations can provide valuable input and support to the national authorities.

The Directive amends the definition of Adverse Drug Reaction included in the community code [Article 1(a).11]. The inclusion of mis-use and medication errors is an important aspect that is now addressed in the new rules. This is a step towards better patient safety and protection of public health, as it will lead to the collection of more information on the real life working of medicines when they are used in different circumstances by different people.

Country comparison of the IMPACT Survey - Conclusions

by Sanna Lönnfors

Discrimination at work: the Amsterdam Treaty and the IMPACT survey

The Amsterdam Treaty (1997) put a great emphasis on e.g. the rights of individuals. One of the changes was the inclusion of a non-discrimination article, included in Article 6a of the Treaty (Article 13 in the renumbered Treaty).

The amended article recognizes the issue of disability discrimination, but merely allows the Community to take action against disability discrimination. Considering that one in five respondents in our survey had experienced discrimination at the workplace, this is a serious issue and actions definitely should be taken, including e.g. raising awareness of rare conditions to securing the position of the disabled by producing new legislations.

42% of respondents had had to make work adjustments (such as working from home or part-time), and as for education, 52% of the participants – and up to a striking 69% in the United Kingdom – felt they were not able to perform to their full potential in an educational setting due to IBD. As most IBD patients are able and willing to work and study, finding flexible solutions and making adjustments in work and educational settings should be supported. Such solutions are not necessarily expensive and will be cost-effective in the long run.

Health inequalities within the EU

Striking differences could be seen in terms of e.g. access to specialist care. For example, 86% of Czech and 82% of Spanish and German respondents felt they had adequate, timely access to their IBD professional, whereas this was reported only by 59% of the Slovenian, 58% of the Greek and 57% of the British respondents, and 54% of the Israeli and 53% of the

Norwegian respondents outside the European Union. The Czech Republic was the only country in the survey where 100% of the respondents reported having access to a gastroenterologist at the clinic that they go to.

30% of the respondents to this survey did not get to see a specialist in the first year after starting to experience IBD symptoms; just over half (54%) of all respondents received a final diagnosis within a year. 67% of the respondents had had to visit an emergency department or clinic at least once before receiving a definitive diagnosis (93% in Spain, 89% in Slovenia, 86% in Austria; but only 47% in Germany and 55% in Israel and the United Kingdom).

The variations could be due to different health care systems and policies of referring patients to specialists; but in order to avoid extensive costs of emergency care and shorten the time of living without a diagnosis and corresponding treatment, early access to specialist care should be facilitated. Access within the first year seemed to be the easiest for respondents from Slovenia and Israel (83%, respectively) and Spain (80%). It may be, however, that many respondents in Spain and Slovenia were only referred to specialist care after visiting emergency department. Such associations in the data should be further looked into in the future to see if there is an actual connection.

Treatment regimes within the EU

In addition to access to care, treatment regimes used for participants from different countries seemed to vary greatly. For example, biological therapies (infliximab, adalimumab) were used by only 13% of Finnish and British respondents, but by 77% of the German respondents. These therapies are known to be rather costly, and according to a Canadian study, low income

may be associated to increased surgery risk in pediatric IBD patients, possibly due to not being able to afford costly therapies. Without looking into different health insurance policies in the European countries and the socio-economic status of the respondents, it is impossible to make such conclusions; nevertheless, it is important to ensure adequate access to all necessary medication to all patients across Europe. Ensuring access to treatment and therapy is also important in order to possibly reduce hospital stays; the majority (85%) of the respondents (90% in Ireland, 88% in The Netherlands) had been hospitalized in the past five years because of IBD, 48% for longer than five days.

Role of patient organizations

The patient organizations across Europe do important work in raising awareness, which may increase the understanding of IBD and help reduce discrimination. Furthermore, according to the results of this survey, engaging in the associations' activities has a beneficial impact on most IBD patients in terms of peer support. Therefore, the work and activities of EFCCA and its member patient associations in individual countries should be supported.

EFCCA RECOMMENDATIONS

For diagnosing IBD:

- Maintain good access to IBD specialists, especially in the face of financial cuts to health services.
- Review diagnostic protocols for those who wait over a year for diagnosis, to reduce this divergence with otherwise good standards.
- Investigate and find methods to prevent presentation to emergency care, experienced by a majority, before diagnosis.
- Work with emergency care colleagues to raise awareness that the majority of people with IBD are treated in this department.

For health care and treatment:

- Maintain and develop good IBD health service standards, in line with published guidelines.
- High hospital admission represents a poor patient experience, an urgent opportunity for improvement, and significant morbidity. Reducing this burden may

somewhat counterbalance the cost of new IBD treatments – it may pay to treat with innovative therapies.

- Ensure that use of corticosteroids is in line with ECCO guidelines, and that the full range of treatment options are considered, according to comparative risk-benefit profiles.

For health services:

- Improve access as well as provision, of specialist IBD healthcare professionals.
- Increase the duration and frequency of specialist consultations.
- Improve consultation techniques (for both parties), to ensure depth and coverage of issues, so that no important information is omitted.

For relationships:

- The impact of IBD on relationships should be considered by healthcare professionals.
- Healthcare professionals should actively sign-post patients to national IBD associations.

For daily life:

- Management plans should include assessment and management of the key three symptoms: fatigue, urgency, and pain.
- Success criteria should focus on effective management of symptoms, as well as IBD as the root cause.
- Management plans should include assessment of the wider symptomatic impact of IBD on everyday life, as well as the clinical context.

For work and education:

- Good management of IBD supports employment. The cost of new innovative treatments for IBD may be counterbalanced by improved employment and reduced social costs.
- Effective medical consultation should address the patient's full life context – including work.
- A patient's employment and educational aspirations should be regarded as goals and success criteria.
- Flexible, supportive, and non-discriminatory work practices are required. Those who face discrimination must be supported in challenging this.

To consult the complete country comparison report please contact the EFCCA office (see page 4)



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