

# EFCCA MAGAZINE

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



Tennis player



Belgian



Chocolate fan



Wife



Nature lover



Crohn's patient



Sister



Photographer



Dreamer



Salsa dancer



Teacher



Mother

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Crohn-RCUH: www.mici.be

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Denmark – CCF  
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Italy – AMICI  
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Malta – MACC  
www.macc.org.mt

Norway – LMF  
www.lmf norge.no

Poland – J-Elita  
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UK - Crohn's and Colitis  
www.nacc.org.uk

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www.masvida.org.ar/

Israel - CCFI  
www.ccfi.co.il/

New Zealand- Crohn's and Colitis  
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EDITOR’S EYE

The patients’ perspective



Crohn’s disease and ulcerative colitis are diseases that have a huge impact on our lives. They do not only affect our health but they also influence many other aspects of our existence. They put hurdles in our way and often frustrate us when all we want to do is get on with our lives. They might affect us in accomplishing an education or a career. Or they make it more difficult to participate in social activities or establish friendships and more intimate relationships.

This is one of the main message that we, as EFCCA, want to transmit to the medical community, to health policy makers and to other stakeholders involved in our fight against IBD . We are not “just” patients, we are workers, students, friends, parents, brothers, colleagues. We are people with dreams, ambitions and fears, searching for happiness just like any other person.

The cover title of this magazine nicely illustrates this message. It is also the same message that we are bringing to the debate on the quality of care in IBD for example during the press conference on “Perspectives on IBD Quality of Care” which was organised by ECCO prior to its ECCO Congress. The discussions at the press conference aimed to enhance the general understanding of the physical and socio-economic burdens of the disease and to accelerate the dissemination of new standards of care of IBD among health institutions and health authorities. There again we stressed the importance of involving patients directly in any elaboration of better standards of care in IBD if we want to ensure any real change. We are the main stakeholder in this fight and we believe that our contributions to any debate and attempt to improve standards of IBD care are crucial for succeeding in this venture. We are looking forward to close co-operation and are willing to contribute our experiences and suggestions for future guidelines on IBD care.

Another key mission of EFCCA is to “give a louder voice and a higher visibility to people with IBD in Europe”. We have done tremendous efforts in the past few years to fulfil this mission. I am thinking of the World IBD Day events that we have organised in the European Parliament for two consecutive years or the awareness raising event organised outside the European Commission building in Brussels three years ago. I feel now we are starting to bear the fruits of our labours.

During our 24th Annual General Assembly (GA), which took place in Graz, Austria, we had for the first time in our EFCCA history a recorded opening speech by the European Commissioner for Health Tonino Borg. In his speech to the GA he acknowledged and applauded the work of EFCCA and showed his support to the efforts that the national associations and EFCCA were undertaking to improve the lives of people with IBD. Having

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the Commissioner on Health addressing our General Assembly is an incredible milestone in our efforts to gain more visibility and to create more noise amongst EU policy makers and institutions and we feel confident that in the coming months our voices will be heard especially in view to including IBD in future strategy papers and research programmes launched under Horizon2020.

These efforts have also led to EFCCA being invited to the first European Summit on Chronic Disease organised by the European Commission. Our Chief Executive Officer, Luisa Avedano, represented EFCCA at the summit and you can find an article including her report and reflections on the summit in this issue.

The EFCCA Annual General Meeting in Graz has also reconfirmed me as chairman of EFCCA. I am very proud and grateful to our delegates that they have shown their trust again in me and I will do my best to lead EFCCA ahead in the coming two years and to work towards implementing our strategy as approved during the GA.

I am also very pleased to see the growing role of our EFCCA Youth Group and their continued commitment towards improving life of youngsters with IBD. As a result of discussions amongst EFCCA Youth Group members we have now included in this issue an interesting feature including two interviews about IBD and parenthood. The subject rings a particular note for me: at the start of February 2014 I welcomed my first child, Mario, to this world. Being a father is an incredible experience which I can hardly express in words, so I know very well the concerns and worries of Hanne and Allan expressed in their interviews and I definitely share their experiences with them. I applaud them for speaking so freely about their thoughts and concerns, may they be an encouragement for others in similar situations. I also wish them all the best for themselves and their little offsprings.

You will find further examples in this magazine of how people with IBD face the odds and take control of their lives. EFCCA is there to support them because we believe that UNITED WE STAND!

Marco Greco, EFCCA chairman



## General Assembly re-elects Marco Greco as EFCCA chairman

**From 3-6 April 2014 EFCCA national member associations gathered in the beautiful town of Graz, Austria, for its 24th General Assembly (GA). In total 67 delegates representing 28 countries participated in this yearly meeting allowing for a lively debate and exchange of opinions on priorities and visions for the future work of EFCCA. This year was also election time for three positions to the EFCCA board including the position of EFCCA chairman and EFCCA secretary.**

The meeting was opened by Marc Greco, EFCCA chairman and followed by a pre-recorded welcome speech by Commissioner Borg from the European Commission's Directorate for Health and Consumers. In his speech Commissioner Borg acknowledged and applauded the work of EFCCA and showed his support to the efforts that the national associations and EFCCA were undertaking to improve the lives of people with IBD. Having Commissioner Borg addressing our GA is an incredible milestone in our efforts to gain more visibility and to create more noise amongst EU policy makers and institutions.

The GA also welcomed two IBD associations that were invited as observers to the meeting and that are in the process of joining EFCCA at the next year's GA. The two candidate associations are from Romania and Greece and were represented by Isabella Grosu (Romanian IBD patient association) and Alexandra Gliati (Attica's Society of Crohn's and Ulcerative Colitis Patients). Both gave excellent presentations about their organisations and activities and both transmitted an enthusiasm of being part of a wider network of IBD sister associations seeing it as a valuable asset to their daily work and a good opportunity to share their specific experiences with others.

#### Core meeting

The main discussions focused on the strategy plan for the coming years and its inherent work plan 2014 and proposed budget.

Special attention was given to discussions around the growing role of EFCCA on the international scene and possible scenarios of dealing with an increased

interest in widening its membership base. There was a clear commitment from delegates that EFCCA's future lies in becoming more global. However several national member associations felt that the current structure of EFCCA needed to be reinforced before moving on to a more global scenario. Discussions around this issue will continue in the coming months between EFCCA and its members with a possible vote next year on how to reflect the growing role within the EFCCA statutes.



Marco Greco (left) and Bjorn Gulbrandsen, LMF

Another challenge of this year's GA was to discuss and get a clear mandate from members on the future financial structure of EFCCA. Currently funding of EFCCA is mainly industry based and some funds are gained through membership fees. Several members in the past have shown interest to open EFCCA up to EU funding opportunities. The EFCCA board was asked to prepare a feasibility plan on possible economic structures for EFCCA to be approved by the following GA.



Former EFCCA secretary, Chayim Bell, (left) talking to Josef Busuttil (Malta) and Baubre Murray (New Zealand).

### Elections to the board

The election of three available seats took place on the second day of the GA. Marco Greco (Italy), Iva Savanovic (Croatia) and Chayim Bell (the Netherlands) had been nominated as candidates for the elections. Chayim Bell made an announcement during the GA that he was stepping down from his role as EFCCA secretary as the association he was presenting was no longer a member of EFCCA. A last minute nomination was then submitted proposing Martin Kojinkov (Bulgaria) as EFCCA Board member.

All three candidates were voted to the EFCCA Board. Re-elected EFCCA chairman Marco Greco thanked the delegates for their continued support and



GA delegates taking a break

expressed his commitment to achieving EFCCA's mission to improve life for people with IBD.

### Social programme

Of course it was not all hard work and long meetings. The organisation of the GA allowed for some leisure time so that delegates could pick up on old friendships and/or to make new ones. Saturday afternoon included a sightseeing programme of the city of Graz which was a good occasion for people to mix in a more relaxed way and to get to know the host city. The gala dinner in the castle Gamlitz was a grand way to complete such a long and intensive meeting. Thanks to our colleagues from Austria for having welcomed us in such a friendly way!



New EFCCA Executive Board (from left back row): Martin Kojinkov, Betty Vandevelde, Marco Greco, Arne Schatten, Chayim Bell, Bruno Raffa. Front row: Andrea Broggi (EFCCA staff), Ciara Drohan, Salvo Leone, Luisa Avedano (CEO).

## EFCCA at European Summit on Chronic Diseases

Four years of lobbying and advocacy activities led to EFCCA's first official invitation to the first ever "European Summit on Chronic Disease", a two day conference that Commissioner Borg strongly supported in this last semester of his mandate in the General Directorate on Health and Consumers' Protection (DG SANCO).

The focus was to address the medical, social and economic burden of chronic disease in the European Union bringing together key policy makers, stakeholders and interest groups, including pharmaceutical companies and other health related industries, to explore ways to tackle chronic diseases effectively and to develop recommendations.

It has to be said that the majority of the interventions were focused on the so called major non communicable diseases: cancer, cardio-vascular and respiratory diseases and diabetes, being the first cause of death (so called silent killer) in Europe. Nevertheless same space was also left to other diseases, in particular the mental ones and the vast galaxy of "minor" ones whose impact, in terms of people suffering from them, is still considered less urgent and visible.

However many messages and interventions from speakers and from the floor can be considered an excellent starting point for tuning our lobbying activities and for better placing IBD in the European Commission agenda in the current programming period 2014-2020.

All speakers agreed that chronic diseases have a significant economic impact, however Ricardo Baptista Leite, Member of the Portuguese Parliament highlighted that it was essential to shift away from the vision of health as being a spending and instead to think about health in terms of an investment.

The necessity of involving and empowering patients in the healthcare process was highlighted many times, emphasizing that patients should not be seen as part of the problem but part of the solution as well. For

Luisa Avedano  
CEO EFCCA



proper patients' empowerment, however, proper resources should be made available by the means of patients' based policies that should be established and implemented in all Member States.

The discussion revolved then around the need to share best practices across Member States, but also across sectors. In particular European policies would make an impact for citizens supporting joint actions, such as "Health in All policies" (HIAP) considered an important approach that integrates this vision and cooperation between the Member States as well as international and national strategies to control the burden of chronic diseases.

In conclusion Health Commissioner Tonio Borg summarized in his final remarks that a strong political leadership was necessary to prevent increasing rates of chronic diseases in the European Union and he re-affirmed that removing the burden of chronic disease is a Commission priority.

Two intense days of debates that led to a set of policy recommendations under the heading of “Inaction is not an option”. Among them:

**A.** Strengthen political leadership to address chronic diseases - including consistent and coordinated approaches and integration of the health in all policies approach, broad involvement of civil society, prevention by strengthening effective action on the key major risk factors such as tobacco, alcohol, nutrition and physical activity

**B.** Target key societal challenges - ageing societies, addressing the health, social and equity dimension of chronic diseases

**C.** More efficient use of available resources - prevention, behaviour and lifestyle change, effective funding, integration of health objectives into other policies and fully exploit e-health, m-health and other IT solutions.

**D.** Strengthen the role and the involvement and the empowerment of citizens, patients and the health and social sector in policy development and implementation, help and support patients, promote the participation of patients, the role of health and social professions, taking into account equity issues, as well as the social and gender dimension.

**E.** Strengthen evidence and information as well as efforts into research and development.

The full text of the final recommendations is available at :

[http://ec.europa.eu/health/major\\_chronic\\_diseases/docs/ev\\_20140403\\_mi\\_en.pdf](http://ec.europa.eu/health/major_chronic_diseases/docs/ev_20140403_mi_en.pdf)

Finally, this has been EFCCA'S intervention during one of the parallel workshops organised on April 3th. We hope that this small seed will grow: some fruitful contacts have been made during the networking sessions with the purpose of raising IBD at the top of the European Institutions and the World Health Organisation's agenda in the coming years.

Intervention of Luisa Avedano, CEO EFCCA during the European Summit on Chronic Diseases, Brussels, 5 April 2014:

*“I'd like to point out that there is a big set of chronic diseases whose causes/cures are unknown and where prevention is not possible by definition. I'm thinking, for instance of Inflammatory Bowel Diseases that are affecting about 3 million of European citizens and that is dramatically growing among youngsters and children, in particular. IBD have a huge impact in terms of the quality of life, of discrimination against in the labour market and education and I urge the European Commission to take also these chronic diseases into consideration, including them in its strategy and in the research programmes recently launched under Horizon2020.”*

## ECCO Congress

As in previous years EFCCA participated in the 9th Congress of ECCO (Copenhagen, February 20-22, 2014). The congress saw a record attendance of 5,175 participants from 78 countries and included a diverse programme providing delegates access to the latest scientific information and education in gastroenterology, hepatology, endoscopy, gastrointestinal surgery with its major focus on IBD.

EFCCA was present during the Congress with a small stand in the main exhibition hall amongst representatives from the pharma industries and healthcare providers. Being present at the ECCO Congress is a great opportunity for EFCCA to create more visibility of our activities, to create networks and to meet potential sponsors and stakeholders face to face.

## Perspectives on IBD Quality of Care

**On 19 February 2014 the European Crohn's and Colitis Organisation (ECCO) organised a press conference and public awareness raising campaign entitled “Perspectives on IBD Quality of Care” which took place in Copenhagen during the 9th Congress of ECCO. Its aim was to enhance the general understanding of the physical and socio-economic burdens of the disease and to accelerate the dissemination of new standards of care of inflammatory bowel diseases (IBD) among health institutions, healthcare providers and health authorities.**

The press conference was organised within the framework of the IBD2020 initiative which sets out to improve global quality of care in IBD. In September 2013, a multi-professional group of over 50 delegates from 18 countries representing clinical and academic healthcare and patient organisations met in Oxford, UK for an inaugural summit meeting: a programme of presentations, discussions and workshops. The purpose was to share aspirations, describe different initiatives, learn from each other and seek common ground. (see previous issue of the EFCCA Magazine). Some of the results of the IBD2020 survey were presented at the press conference in Copenhagen which included eight speakers with different perspectives discussing the current context of IBD care as well as aspirations for better quality of care.

The press conference was opened by Séverine Vermeire, ECCO President (University Hospital Gasthuisberg, Leuven, Belgium) followed by Daniel Hommes, (UCLA, Los Angeles, United States) who spoke about the current situation and unmet needs. The patient perspective was represented by Gerald Nash, TD, from Drogheda (current government member), Ireland as well as by EFCCA represented by Arne Schatten, EFCCA Executive Board member and General Secretary of the Norwegian IBD association LMF. Arne Schatten stressed the paramount importance of including the patient perspective in any present or future discussions on the subject of IBD Quality of Care.

Richard Driscoll, former General Secretary of Crohn's and Colitis UK, gave an inspiring presentation on the “aspirations for better quality of care” referring to some of the outcomes of the IBD2020 survey carried out by ECCO and involving IBD patient associations



Arne Schatten, LMF, speaking on behalf of EFCCA

from Canada, France, Italy, Spain, Sweden and the UK. Other presentations included information on the latest research on IBD at ECCO presented by Michael Kamm, Melbourne, Australia and Brian Feagan, Ontario, Canada. In his closing remarks, former ECCO President, Simon Travis looked at the challenges ahead and at next steps to be undertaken.

The global press conference was followed by national country press conferences with representatives from patient and medical associations. Afterwards, the opening ceremony of the art gallery "Perspectives – Art, Inflammation and Me" took place in the ECCO conference center and delegates were invited to enjoy this art experience.

From left to right: Daniel Hommes, Gerald Nash, Arne Schatten, Richard Driscoll, Michael Kamm, Brian Feagan and Simon Travis



## Naming, transparency and traceability for biosimilars: Does Europe need to act?

On March 18th I participated as speaker in the roundtable discussion on “Naming, transparency and traceability for biosimilars: Does Europe need to act?” hosted by EuropaBio with the contribution of the Alliance for Safe Biologic Medicines’ (ASBM). Representatives from physicians, industry and regulatory bodies took also part in the debate.

by **Luisa Avedano**  
EFCCA Chief Executive Officer

The meeting was opened by the Alliance for Safe Biologic Medicines (ASBM) with the disclosure of the results of a survey of 470 European physicians. The survey was conducted across five EU countries (France, Germany, Italy, Spain, and the UK) with the aim of highlighting physicians’ prescribing habits and knowledge of biosimilar medicines.

One of the main findings of the survey relates to European physicians’ insufficient knowledge of biosimilars. Only 22% consider themselves as very familiar with this new category of medicines. Whilst a majority (54%) have a basic understanding of biosimilars, 24% of participants cannot define or have not heard about biosimilars before.

Furthermore, the findings stress that using the same International Non-Proprietary Name (INN) for two medicines (innovator biologic and biosimilar) can be misleading.

In fact this may lead to false attribution of adverse event if reporters only refer to the Non-Proprietary Name, but also it may give the wrong impression that these medicines are structurally identical (54% of those surveyed thought that the same INN meant the products were structurally identical).

It seemed thus clear that the use of distinguishable INN for all biologics, including biosimilars, is critical to further strengthen and facilitate patient safety through effective pharmacovigilance.

EFCCA’s presentation was mainly focused on the patients’ perspective, in particular as far as concerns safety and therapeutic continuity. Biosimilar cannot be considered the “generic” of biological treatments as the use of cellular system for producing them does NOT originate an identical “copy” of a molecule and Biosimilars do not follow the usual procedures for the approval of new drugs. They must show their therapeutic equivalence in respect of labelled drugs they are supposed to replace.

These were the questions/issues that, from the patients’ perspective, were brought into the debate:

*Does my doctor know enough about the drug (biologics vs. biosimilars) and enough about my history? "*

*What are the benefits of biosimilars as opposed to biologics?*

*Is the potentially lower price worth the possible risks of the biosimilar?*

These very interesting interventions from participants reinforced our position. The findings of the survey among physicians showed there is still some confusion about these new drugs.

We believe that it is the right moment to launch our own “EFCCA2 survey on biosimilars among our members associations and work together for a better and shared understanding of this burning topic whilst having at the top of our vision patients’ safety and full awareness.

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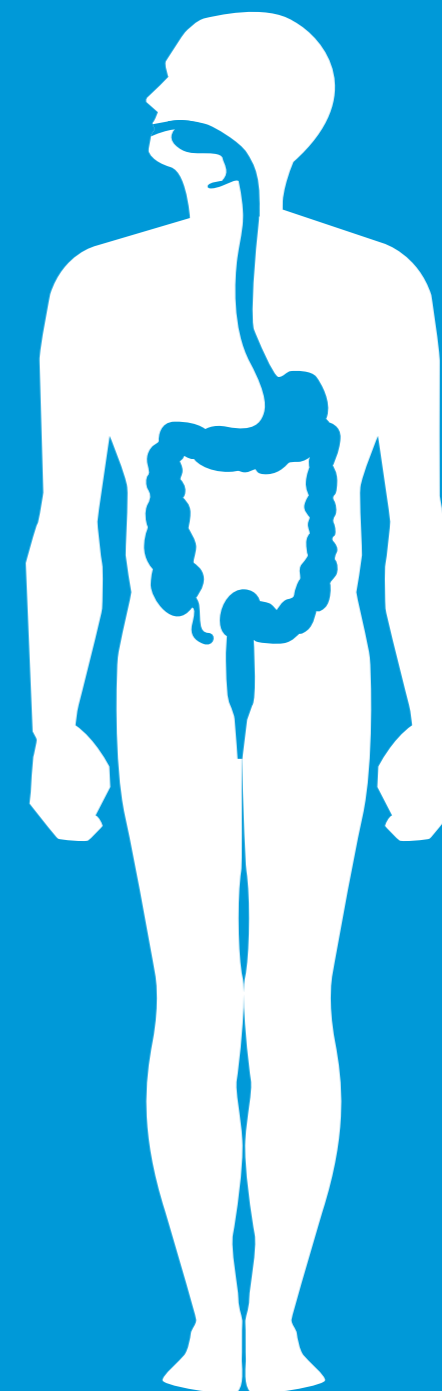
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## IBD and parenthood

**The EFCCA Youth Group consists of people in their twenties. Some of them are in established relationships some are not, but all in all they are all dreaming of a future. A constantly blurry dream about how the future might turn out.**

By Daniel Sundstein (Denmark), leader of the EFCCA Youth Group  
Áslaug Eva Björnsdóttir (Iceland), member of the EFCCA Youth Group



What can we expect? How will our girlfriend or boyfriend react to our next flare up? What about children? Have the medicine or operation affected my body in a way that might complicate having children?

You might have heard about IBD having a genetic component, so you might be wondering whether your kid could get IBD from you. Can you then live with yourself maybe having given your child IBD? Or if the child gets IBD maybe you could be the best parent in the world for your child since you know what they are going through?

All these thoughts are thoughts from young people living with IBD. Young people in an important stage of their life where they are trying to establish families, careers and create a life for themselves – just like any other man or woman at this age. However at the same time they have to struggle with a chronic disease: Inflammatory bowel disease (IBD).

These thoughts and questions were raised during the EFCCA Youth Group meeting that was held in January 2014. We were planning our Work Plan 2014-

16 and suddenly the discussion narrowed into this topic among others. We decided that the Work Plan had to deal with the taboos that exist about IBD in society in general. As a natural result of the great articles we published last year about pregnancy and IBD, we thought the follow up to this should be IBD and parenthood.

IBD parents can have many more thoughts that seem unthinkable to others or to relatives. Unanswerable questions that many people haven't ever really thought that people with IBD could think. Questions of how I should take care of a child when I risk being admitted to hospital. One parent in hospital and one parent working and taking care of the child - or the children - are not just hard for the child and for the family, but also for the parent in the hospital. The feeling of guilt, the feeling of not being there. The thoughts about how the child will react seeing a parent lying in a bed in hospital, maybe having intravenous medicine at the same time.

We don't know the answers and we often raise a lot more questions for ourselves along the way. Questions that we didn't know we would have and questions that can never be answered. All we can do in the EFCCA Youth Group is try to put as much focus as possible on these taboos starting with this one about "Parenthood and IBD". More topics are to come but for now let's focus on this one. We hope you will enjoy it and we hope you'll take this notice into consideration when reading the brave stories of Allan and Hanne.

## Being a father



**Allan Matthews is a lively 30 year old father from Ireland who has Crohn's disease for the last 9 years. Three years ago he and his partner got married and just over a year later they decided to have a child together. Their son Feilimí was born 20 months ago.**

**Allan, can you tell us what your main concerns were when you decided to have a child?**

Well my concern at first was that I hated the thought of having a child who might also get IBD and that it would be my fault if he did. But in the end we never know what will happen down the line and at the moment everything is fine. I was also worried about myself, I was wondering what would happen if I were sick and I need to take care of him...luckily I have been pretty well for the last number of years and particular the last two years I have been very good.

**Can you tell us what your most challenging moments as a dad have been and how you managed to cope with them?**

Having children is not something you can be prepared for, but luckily we have a very good child, he sleeps and eats very well and he does everything he is supposed to do. He very rarely cries so he has been easy to manage and it's a very stress free environment. I suppose it would be different if he was sick or if there was something wrong with him. Then it might not be so relaxed to be around or to be a parent.

In general there are no problems with him, perhaps sometimes there is some trouble with my IBD. If I have to mind him for example and I need to go to

the toilet urgently that's the only thing I can think of that has been a bit challenging. But we have a fairly big bathroom so I have no problem taking him with me and if my wife is around then obviously this is not even an issue.

I do take care of my son a lot during the day as my work is flexible and I can work from home whereas my wife, who is a teacher, is away. Being at home makes it easier dealing with situations related to my IBD.

**What would you say to people who are in a similar situation?**

I would tell them to have a child. There is no point worrying about the what ifs? or what it is going to be like? The joy you get out of a child is much greater than any worries you might have or the stress about not knowing what is going to happen. So I would tell them to have the child, well obviously if they are ready for it. I think it's important that you are ready for having a child such as being in a stable relationship and being financially secure, etc..

Being a parent makes you a happier person and in a way I think it can help with the disease because it takes away some of the stress in your life which can

trigger your IBD conditions. It definitely helped me, I feel an awful lot better in the last two years.

### What have been the reactions from your family and friends?

My family is in love with my child, it's my parents first grandson so they are very, very happy. In relation to my friends I still manage to see them, I still go out sometimes to play football and do other stuff, perhaps not as much as before but I think being a parent should not affect your life in a bad way, the contrary it improves and enhances your life.

### Are you thinking of having another child?

Yes I do! I definitely would like to have more children although perhaps not at the moment. It's quite a lot of work having a child and sometimes when I see people with two kids I wonder how they manage...I guess when our boy is a little bit older we will try again.

## Being a mother

**Hanne Jacobsen, from Norway, is a 29 year old mother who was diagnosed with ulcerative colitis in 2009. Currently she has a eight months old daughter, Ella Albertine and works as a carer for children with special needs.**

### Hanne, what went through your head when you thought about having a child?

Well, it was my boyfriend and I, we both wanted to have a child and we had a long discussion about it. I was quite sick in 2012 and I had to try a lot of different medicines. I told my health care professionals that I was planning to have a child and that I wanted to get better as soon as possible. They advised me to wait a bit before having children because of my poor health at that moment. Then towards the end of 2012 I got a little bit better so we gave it a try and I got pregnant straight away. It was amazing, I just got better overnight. I was so lucky during pregnancy and I can't remember having been in such good shape for a long time.

Normally, I have a lot pain in my joints, I have migraines, I am very very tired, well, all the usual

### Have you thought of how you will explain to him about your disease?

I have thought about it once or twice but the fact that he will probably see me being sick as he grows up means it will not seem strange to him. I think it

***“The joy you get out of a child is much greater than any worries you might have or the stress about not knowing what is going to happen”***

would be different for someone who is a ten year old kid and then suddenly one of their parent falls ill. In my case I don't think it's an issue, I just hope that he won't have to go through what I have to go through.

stuff you get with IBD but everything was fine when I got pregnant. I didn't even feel sick one day. For me it was really positive being pregnant, I guess I was really lucky!

Of course I worried about my daughter getting IBD and I hope she will not. Maybe it's a selfish choice to have a child. We have IBD in my family, so I know that there is a possibility, but we also thought that you never know what will happen. We wanted to have a child more than worry about what could happen. Who knows, perhaps in the future, in another 20-30 years there will be better medicines around. We know a lot about IBD, we will deal with it if it should happen.

### Were you worried about being physically up for it?

Yes I thought a lot about that, too. I have been always



working out a lot and I feel that has helped me a lot during pregnancy but also at other times when I have been sick. The hospital and my doctor took very good care of me during my pregnancy even though I was in good shape. Towards the end of my pregnancy I saw my doctor once a week. I had a normal, natural birth and everything went fine. So far my health condition has been good, even my boyfriend mentioned that he nearly forgot that I had the disease because I have been in such good shape in the last year and a half. Having said that, recently I am starting to not feel so well.

### What have been your most challenging moments and how do you cope with them?

I guess the most challenging moment is that I simply don't get enough sleep. In general I get really tired when I do not get enough sleep and of course it's very different when you have a baby. As she is not sleeping through the night, I have to get up very often and that's very tiring. For me that's the biggest challenge. My boyfriend takes care of her quite a lot, sometimes he takes her out of our apartment so that

I have a couple of hours of being alone to relax or to sleep, but to be honest up to now it hasn't been a big issue. It could be something to do with the fact that until now I have breastfed her. Now, as she is starting to eat more solid food and I breastfeed her less, I feel that my IBD symptoms are slowly coming back.

I think my partner probably will have to take more care of the child than perhaps other daddies do. We also have a lot of family and friends around us. They all know about my IBD and they tell me all the time

that they will always come and help me. We are very grateful for that.

### What would you say to people who are in a similar situation like you?

It's a difficult decision because you never know how your body will respond to getting pregnant but it is so fantastic to have and raise a child. I think it is important to have a lengthy discussion with your doctor and to ask for special care during and after birth. It's also important to take your medicine, maybe a lot of girls might be afraid to do that as they might worry about

possible side effects on their baby, but I trust my doctor on that who said that it was fine.

I think it's also a decision which needs to be thoroughly discussed with your partner. But if you are ready for it you should do it. Personally I feel we are able to take care of our child like any other couple. Anyway you never know what can happen to you. People who do not have IBD also don't know what their future holds in for them.

### Will you have another child?

Yes of course, I hope I will have the chance to have another child. Maybe not right now but in the future I would do it again. I don't know if I will be that lucky again during my pregnancy. I might get sick, you never know, I prefer to stay positive. We will deal with the issues that may or may not come when they actually happen.

## Next EFCCA Youth Group Meeting to take place in Dublin, Ireland

**The next EFCCA Youth Group Meeting (EYM) will take place in Dublin, Ireland from 17 to 20 July 2014. The meeting is organised by the Irish Society for Crohn's and Colitis (ISCC) in collaboration with the EFCCA Youth Group (EYG) and EFCCA.**

The EYM are a great opportunity for youngster with IBD from all over Europe to meet for a couple of days in order to have fun whilst learning from each other and working towards common goals aimed at improving life for youngsters with IBD. The EYM include workshops, learning sessions, news about EFCCA and EYG and its on going EYG projects. Of course it's not all hard work, there will also be time to explore the city of Dublin, there will be some sporting events and activities full of fun and laughter. See the Irish article in the Members News section on what you need to do if you are interested in participating in the meeting (see page 29).

Once you have been selected you should prepare together with the other delegate a presentation about your national association youth activities or activities where youth is present. The best presentation will receive the Loekie award! Please also prepare a poster about one specific youth activity in your country or association and you will be asked together with your colleague to present the poster during the presentation. Each national association will be given ten minutes to make their presentation.

The national association should cover the costs for travel and participation. Please contact them to make sure. There will be a €85 participation fee to be paid to the Irish association. More information will follow with the official invitation. The Irish association will cover any other costs for overnight accommodation, meals and activities during the official program. Any additional costs that you make in your free time needs to be covered by yourself. Please make sure you have a European Health Insurance, and the European Health Insurance card (EHIC). You can get that from your insurance company. Let us know if you have any problems with this. Also don't forget to buy Travel Insurance when you book your trip to Ireland.

When you and your association have agreed on who will come, fill in the application form with them. You will receive the official registration form with this invitation. Information on how to get to the hotel and any other useful data will be sent to you after you apply for attendance. And don't forget to join us at Facebook: "EFCCA Youth Group" and on twitter: @EFCCAYouthGroup.

## Our mission is to help patients live a better life

### Shire's mission

Shire is one of the world's leading specialty biopharmaceutical companies - but, more importantly, we make a difference to people with life-altering conditions, enabling them to lead better lives.

Shire's vision is to continue to identify, develop and supply life-changing products that support physicians in transforming the lives of patients with specialist conditions. 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 unmet medical needs, coupled with 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. 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 and chronic constipation.
- 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.



# Spain

## A life time commitment to serve people with IBD

**At the age of 84 years, Leon Pecasse is probably one of the oldest IBD patients around. In this interview we are finding out about his vast experience of dealing with the disease as well as in his instrumental role of not only setting up the first IBD patient association in Spain but also being a founding member of EFCCA and serving as chairman for several years.**

**Leon, although Spain is your adopted country you are originally from Holland, what is the story behind this?**

That's right, I was born in Maastricht, Holland in 1929 where I worked until 1972 as a chemical researcher in the central laboratories of the Dutch paper mills KNP. I was diagnosed with Crohn's in 1963 after many years of pain, diarrheas and losing weight. Doctors told me it was all "nerves", until one day a doctor admitted me to hospital and made the right diagnosis. I was the second patient diagnosed at that time.

The first 10 years were horrible: the only treatment available was corticoids and later Salazopirine. In 1972 I was unable to go on and I was declared an "invalid" and sent to Spain. Here I got much better, ( but the Crohn did not disappear) and in 1974 I decided to study medicine at the Málaga University ( to cure myself). I got my degree in 1980 and in 1981 was accepted as resident in internal medicine, until 1986, when I was admitted to the university hospital as internist, specialised in IBD. That's how I ended up in Spain.

**How did you get involved with founding the Spanish association for IBD patients?**

It all started whilst I was working in the hospital. Soon all my colleagues sent me their Crohn's patients to be treated and I started a special consulting hour for them. At that time Crohn's disease and ulcerative colitis were practically unknown. I was one of the

few people around who knew about the disease. That's when I decided to found a local association in Malaga for patients with IBD. At first this was a local association but soon enough people from other provinces in Spain started to join the association. Later on we changed our statutes so as to become a national association made up of local groups. I travelled all over Spain, to all the provinces where I helped to set up groups with IBD patients which are federated under ACCU Spain. Now we have around 8000 members.

At the same time Dr. Miguel Angel Gassull in Badalona (Catalunya) started a similar consulting hour for IBD patient as I did in Malaga. He invited me to a meeting with his colleague and friends in Zaragoza in 1989 where we decided to form a research group on IBD. Moreover he promised to help me to establish groups of IBD patient associations all over Spain.

Since then, the doctors in his team which is called now GETECCU, are helping especially IBD patients. In Spain we have now about 30 special IBD consulting hours where patients can go immediately if they have a flare-up and where all patients have "their" doctor with an excellent relationship.

I find this very important for the functioning of the associations and I know that all over Europe there are doctors willing to cooperate and instead of being the almighty God they are a friend and listener of the patient.

**How did you get involved into representing patients at the European level?**

In 1989 I was invited by the Dutch IBD patient association to speak at their tenth anniversary about the doctor-patient relationship. Being a doctor and patient at the same time I really had perfect insight into both sides. This was something very new.

At that meeting I heard from several other national associations that they were thinking of setting up a European Federation of IBD associations. We had several informal meetings with colleagues from the UK, Germany, Luxembourg and Belgium. At the beginning we did not know exactly what to do, what language the association should use, what kind of association we should form etc etc.

It has been a difficult process and we had to deal with different cultural backgrounds, mentalities and various expectations of what we could and should do.



Leon Pecasse in his adopted home city Malaga, Spain

However once the association (ie EFCCA) was established it was very easy to attract new members. I think this is due to the fact that we had several interesting and good projects going.

One project looked at comparing the social security systems in all the different countries. Another project was dealing with the subject of Quality of Life and IBD. People were implicated and we were off on a good start.

**Do you think life has improved for people with IBD over the years and to what extent have patient associations contributed towards this goal?**

Yes a lot. In the past IBD was still considered a rare disease but now more and more people know about it, treatment options are better and the time of diagnosis has been reduced even though in some cases it still takes too long.

Patient associations have taken on an important role in improving the doctor-patient relationship not only for IBD but other immune related diseases. Even though this is still not 100 percent accepted by the doctors. There are still doctors around who think that they have explained everything to the patient and the patient thinks that the only good information they got is from the association and not from the doctor. We are getting there and as I mentioned before things have gotten a lot better.

**You have decided to retire. It's remarkable that you have been committed to the cause for IBD people for so long.**

Unfortunately in the last few years my health is not very good and I couldn't be as active with the association and with EFCCA as I would have liked to. I regret very much not to be able to go on with all the activities I had until now, but I know that many others like you, have the torch now and go on.

## Norway

### Joining forces

**After the IMID summit in Vienna last autumn we decided to start working on a Norwegian Imid project. The Norwegian IBD association, LMF, together with the Rheumatic association and the Psoriasis and Eczema association now form the Norwegian Imid group.**



Arne Schattten (right) with IMID colleagues

We agreed to organise a seminar which was held in the Oslo Congress Center and received the financial support from Abbvie (50% of the total cost.). Due to the strict regulation of sponsorship from the pharmaceutical industry, we had to avoid all medical themes during the seminar. We discussed what health issues the three patients groups had in common and that would be of interest to all of our members which are totalling approx. 40000 members. Finally we came up with the theme of fatigue as the main topic as well as topics related to quality of life.

Prof. dr. med. Omdahl from the university hospital in Stavanger agreed to come to Oslo and give a lecture

on the subject. He has already done extensive research on the topic and gave us a lot of information. He concluded with the fact that there is no doubt about the connection between our diseases and fatigue and that the only thing that has shown to help is condition training – walking, jogging, swimming and so on.

Next on the program was a lecture on how to find balance in your life with a chronic disease. Coach Ann-Christin Hansen gave us some good ideas on the subject and had us all jumping and dancing. Psychologist Elin Fjerstad, who works in one of the hospitals in Oslo talked to us about coping with chronic disease and the mental aspects of having a good life despite disability and pain. She told us to give our disease some room in our life, but also that it was important to concentrate on the good and healthy parts of life that we all have.

Next on the program was Randi Danielsen, a patient with severe ankylosing spondylitis. She showed us fantastic pictures and gave us the story on how she

climbed to the top of Kilimanjaro in spite of her illness. Last on our program was Ann-Christin Hansen, who is also a nutritionist, gave us good advice on what to eat to keep up energy in our bodies. Proteins were the keywords in her talk.

The seminar was also shown on the web so that people around the country could see it and also ask questions. This broadcast will remain on our web pages.

Before we started organizing the event, we talked about being happy with an audience of around 50-60 persons. By the time we closed the registration we had 145 on our lists! All in all, we had a pleasant and informative Saturday afternoon. The feedback from the audience was good, but we learned that next time, when dealing with rheumatics, we will choose a meeting room without steep steps!

Arne Schatten, LMF

## France

### THE AFA IBD OBSERVATORY

### Why OBSERVE Intestinal Bowel Diseases?

**It is quite alarming to see that there are more and more cases of Crohn's disease and ulcerative colitis being diagnosed every day in France and has been considerably on the uprise in the past 20 years. It is therefore legitimate that the French national IBD patient association question WHY?**

It has been established that these complex diseases involve genetic, bacterial and environmental components. What allowed this discovery was more often, first and foremost, observation: for example, the acknowledgement that IBD was more frequent in identical twins opened the gate to genetics; the high number of smokers who have Crohn's disease led the way to the environmental factor of tobacco, etc.

Observing IBD means finding risk factors, on one hand, but based on studies on the general population,

it also allows us to build real hypotheses which are at the origin of the most productive research endeavors. For the last 25 years, this is what Dr. Corinne Gower-Rousseau has been doing. She runs the EPIMAD (EPIdemiologie des Maladies inflammatoires chroniques de l'Appareil Digestif) Registry in the north of France, which today is the largest IBD registry in the world made up of 22 000 IBD patients, observing very methodically all the newly diagnosed cases and their development over time.



**Dr. Corinne Gower-Rousseau**  
EPIMAD

Observing IBD is also looking at the way these diseases influence the patients' daily life and how to evaluate what the economic, social and societal consequences may be. In that way, research in human and social sciences, as well as in the studies called «observational», can expand on the way patients are cared for, how society accepts them, on their financial problems, their school and professional integration, all of which can possibly be improved.

This data is useful, in particular, to pressure the public authorities, but that's not all. To that effect, also in evaluating an association like afa's activities, it can be used to observe the development of living conditions with IBD referring to the services an association can render, can be of great interest in order to allow the patient associations to be better recognized for all the work they do.

Translated by Madeleine Dubo  , AFA Delegate

## Denmark

### Happy Birthday to... us!

**This year we celebrate our 25 years anniversary. It has been a long ride, but as a patient organization, we can now see the light at the end. We are being heard and getting attention from both the media and the politicians. This is a huge step in the right direction, which is getting IBD on everyones agenda and finding a cure very soon.**

Our resources are scarce, so we tried to find sponsors and volunteers to help creating a memorable magazine and poster for our celebration. And we succeeded.

Erik Clausen, a famous Danish artist (and much more), agreed without hesitation to create and paint a picture. His hands were untied, meaning he had

artistic freedom, and the outcome was perfect. The title of the picture is "Outside", and without knowing it, Erik hit a sore spot.

A few months earlier in some of our Facebook groups, patients began to show their stomachs - Scars and/or Ostomy. It was a relief for many to being able to show themselves without being ashamed or uncomfortable.



**Camilla: I am like everybody**

**Anders: I am back at work full time**

One thing led to another, and we found a professional photographer with IBD, a Hairdresser with IBD and so on, but most importantly, 15 brave and beautiful IBD models. They were all tired of feeling like outsiders; it was now time to show the World that they were quite normal people – with IBD. The way they did it, was by wearing lingerie made by a designer (with IBD), having their photo taken and their story told. The two men could choose to wear their own trunks (and they did). It was a fantastic weekend with both tears and laughter with emphasis on the latter.

Since Erik Clausens painting was showing exactly how the models did not want to be seen, it was chosen as the front page as well as an independent poster. The special magazine tells the whole story about the Danish Ulcerative Colitis and Crohn's Association and much more, but the photos of all the models is what we are all about. Helping our members, and getting rid of all the taboos.

The formal celebration will be in Copenhagen in combination with the World IBD Day. The theme of the day will be Patient Empowerment, and there will be speakers (only 10 minutes per person) and workshops with a total of 80 people (patients, politicians, nurses, physicians etc.) discussing the presentations and hopefully we will end up with tools to be used by, primarily patients and physicians.

Even though it will be hard work for all the involved, we will be able to celebrate. We are having coffe/tea, food and drinks. But you cannot celebrate a birthday without a cake... Luckily we found some sponsors for that as well, so it will not be all hard work. There is a sweet treat in the end.

Michael Koehler, CCF

## UK

## Young people with IBD enter parliament

**Our political internship scheme gives young members of the charity an incredible career experience at the heart of British politics while also teaching politicians about the impact of IBD. Philip Reynolds reports. This year Crohn's and Colitis UK has launched an exciting new programme of paid political internships for young people with IBD in the offices of politicians across the UK.**

The scheme aims to empower young people undertaking the internships and demonstrate to everyone that IBD need not be a barrier to a successful career in any field.

The scheme follows research commissioned by the charity in 2011, which found 40% of survey respondents with Crohn's Disease and a third of those with Ulcerative Colitis agreed that their IBD had prevented them from pursuing their preferred job choice.

So far two young people have been placed with MPs in Westminster for 12 weeks and a third is due to start in the Scottish Parliament later this year.

One young person, placed in the office of a Labour MP, has drafted speeches, undertaken research, watched debates in the House of Commons and even met the Prime Minister.

The second, due to start in the coming weeks, will be supporting a Conservative MP in his work on the influential Health Select Committee.

The third intern will begin working for a Shadow Minister in the Scottish Parliament in August – shortly before the referendum on Scottish independence.

In addition to providing positive, career-enhancing experiences for young people with IBD, the internship scheme is also a valuable opportunity to help politicians from all parties understand what it means to have IBD. Crohn's and Colitis UK is now looking to extend

our internship scheme to someone in Wales aged between 16-25, with a possible placement in the Welsh Assembly later this year, depending on an AM's availability.

Interns will receive payment equal to the national minimum wage for the duration of their internship, and reasonable expenses will also be covered.

If you are interested in participating in the scheme, please contact Policy and Public Affairs Officer Philip Reynolds at [philip.reynolds@crohnsandcolitis.org.uk](mailto:philip.reynolds@crohnsandcolitis.org.uk)



## Getting the message across

**Increasing coverage in the media and large scale fundraising means that 2014 is shaping up to be an amazing year for raising awareness of IBD.**

"You are now at the beginning of a very long and sometimes frustrating journey, but the key is to learn how to own your illness without being defined by it."

These words were written by Crohn's and Colitis UK Ambassador Carrie Grant in an open letter in *Now* magazine to reality television star Sam Faiers, the latest in a string of well known names who have been telling their IBD stories to the media.

Indeed, it's been impossible to miss coverage of Crohn's Disease and Ulcerative Colitis this year. Sam, best known to viewers for her role on *The Only Way Is Essex*, also appeared on ITV's *This Morning* to discuss her diagnosis of Crohn's Disease and to raise awareness of the condition. This was followed by Carrie's letter which received a record number of hits on our Facebook page when we featured it online.

"Stand strong," she wrote. "When you go to see your specialist remember you are not a victim - you are the expert client because no one knows your condition better than yourself. The charity Crohns and Colitis UK are a huge help."

Former England footballer Ray Wilkins announced earlier this year that he has had UC since 1990. At the same time, Darren Fletcher, Manchester United midfielder and captain of the Scottish national team, was throwing his support behind United for Colitis. This charity dinner dance, organised by Jon McLeish who has UC, and his wife Diana, has been a great boost to fundraising and has also hugely increased the profile of IBD in general.

This event is also being backed by former England rugby captain, Lewis Moody, who also has UC (pictured above with Darren Fletcher), other Manchester United players and former manager Sir Alex Ferguson. Darren has now returned to top level



football after surgery and has been keen to talk about his experiences.

"I found it very difficult making up stories and reasons why I wasn't at training, why I was looking ill, why I was rushing off to the bathroom," he told the ranks of national sports reporters at a special news conference. "I found that very difficult, making up stories and basically lying to people's faces."

Of course it is not just the famous names and faces who are making an impact, all those who fundraise, volunteer or talk to the media about IBD are doing an equally marvellous job in ensuring as many people as possible are educated about the conditions.

Fundraising events have been extremely varied, from rowing across the Atlantic (see page 19 for more details) to those closer to home, such as the sellout gig by The Wurzels at Paulton Rovers Social Club which raised more than £3,000 for Crohn's and Colitis UK.

In the last few months, readers around the UK have seen features from Steven Sharp in the *Sunday Post* and Beckie Oakley in the *Harrogate Advertiser*, while Amber Gamble, one of our media volunteers, spoke about life with Ulcerative Colitis on BBC Three Counties Radio.

## Italy

# New App to help patients manage and share the effects of IBD

**AppMICI was unveiled at the CONGRESS HELD BY IG-IBD – The Italian Study Group on Inflammatory Bowel Disease – held in Padua. Instant access to exhaustive information on the conditions, patient diaries and direct contact with personal doctors using a computer, tablet or smart phone.**

The project, conducted jointly by IG-IBD and AMICI, the Italian Association for Chronic Inflammatory Bowel Disease, promoted by EFCCA, the European Federation of Crohn's and Ulcerative Colitis Associations, was made possible by the unconditional support of MSD.

“Access to information that can help manage Crohn's disease and ulcerative colitis in order to cope with it better. Keeping and constantly updating a “diary” concerning one's health, a sort of journal of the condition and main events. Sharing key clinical data and test results with specialists, building a dialogue and establishing direct and on-going communication that does not stop with regular appointments.”

**“All just a click away, using a computer or – even more simply – on a tablet or smart phone.”**

AppMICI helps patients living with Crohn's disease or ulcerative colitis to manage their illness: this support comes from an instrument with a great innovative impact, that was presented in Padua during the congress organised by IG-IBD – the Italian Study Group on Inflammatory Bowel Disease – between the 7th and 9th November.

Unfortunately, in Italy, these conditions have medium–high incidence and prevalence, with a constant increase recorded over the past two decades. According to Dr.

Ambrogio Orlando, Secretary of the IG-IBD, one of the main aims of the congress was undoubtedly “to work towards a greater uniformity of treatment and care on a nationwide level and overcome the potential confusion concerning new diagnostic and therapeutic approaches. The large number of experts present also favoured the first steps towards defining the specific targets of good treatment, as already occurs for glycaemia in diabetic patients or for blood pressure and cholesterol values in patients with arterial hypertension and cardiovascular illnesses”.

The aim of the Congress was to debate the most important and controversial aspects of the management of patients with CIBD. The event was split into six sections – all characterised by the significant space dedicated to the oral presentations chosen from the abstracts submitted to the Congress – which dealt with a range of issues such as “Multidisciplinary management”, “Quality indicators and the appropriateness of diagnostic tests”, “Measuring treatment success and failure”, “Management of chronically active CIBD” and “Treatment objectives in controlled clinical trials and clinical practice”.

Technology played a leading role with AppMICI, the first app developed for patients with Crohn's disease and ulcerative colitis, developed in association with IG-IBD and AMICI, the Italian Association for Chronic Inflammatory Bowel Disease, promoted by EFCCA, European Federation of Crohn's and Ulcerative Colitis Associations, and made possible

by the unconditional support of MSD. The technical and editorial aspects of the AppMICI were managed by Springer-Verlag Italia.

The app, which can be used with smartphones, tablets or PCs, consists of three easy-to-consult sections. The first section, known as “Useful information”, that can be accessed freely even by unregistered users, is a streamlined collection of instructions that can help patients to live with Crohn's disease or ulcerative colitis better and manage their illness. It provides detailed information concerning vaccinations, travel, diet, special cases, the medications available, pregnancy and check-up visit optimisation. Users may also consult a list of Centres partnered with the IG-IBD and a useful glossary of the terms most commonly used in the chronic inflammatory bowel disease field.

“Your diary” is the second section. With this diary, users can record certain aspects of their illness, to build a kind of ‘journal’ of their condition. In the diary, they can record any events experienced and their severity, body weight and appetite on a day-to-day basis, together with personal notes. Users can access this section on completion of a straight forward registration process.

When commenting on this feature, Andrea Coccioli, the Chairman of A.M.I.C.I. Onlus was eager to point out that “by implementing the flow of information patients usually provide to their doctor and focussing on the most important issues, the app helps enhance communication, however, it is not intended to be nor must it become the only point of contact between doctor and patient”.

The third section, which is, again, for registered users, goes by the name of “Your check-ups” and is intended to favour the sharing of clinical data between the doctor and patient. In this section, users can enter their most recent test results (including haemoglobin, complete blood count, protein and electrolyte values) and other data on their general health that can be sent directly to their doctor, almost in real time, by a simple e-mail.

This is undoubtedly one of the most interesting features of the app and makes it possible to create opportunities for direct doctor-patient communication in addition to their routine check-ups.

“The advantages of this procedure”, explained Dr. Ambrogio Orlando, Secretary of the IG-IBD – speak for themselves, particularly in terms of the optimisation of the time that the doctor dedicates to visiting his/her patients: on the one hand the clinician can download a PDF file of the data before the patient's appointment, allowing him/her to evaluate it thoroughly before the meeting and, on the other, the patient can make better use of the appointment time, for example asking about aspects of particular interest or exploring certain issues related to his/her condition”.

**“This is the first experience of this level in Europe. We hope that Italy will act as a pioneer for other countries thanks to the great potential of this instrument. We expect that it will bring an immediate advantage to those patients who are most at ease with technology and a medium-term advantage to everyone”.** (Marco Greco, EFCCA chairman)

This important project is the fruit of an extensive cooperation. As the Chairman of A.M.I.C.I. Onlus, Andrea Coccioli, pointed out “in all fields of life, sharing experience and using it to full advantage is a good practice that leads to improvement. Cooperation between patients, doctors and pharmaceutical companies can be a winning model if the relationship is founded on a series basis, mutual respect, absolute decision-making autonomy and the absence of conflicts of interest, as our experience shows”.

AppMICI is available from the Apple Store, Google Play and the websites: [www.amiciitalia.net](http://www.amiciitalia.net), [www.ig-ibd.com](http://www.ig-ibd.com) and [www.viverelacoliteulcerosa.it](http://www.viverelacoliteulcerosa.it)

# Israel

## Welcoming World IBD Day in Israel

**World IBD Day (WID) in Israel provides CCFI with an opportunity to strengthen the IBD community and raise awareness for IBD on a national level. In order to gain maximum benefit from the opportunities World IBD Day presents, we extend activities to a month long series of events.**

This year, CCFI has initiated new projects that will run throughout the month of May:

**Discussion with the Minister of Health** - the main event will be an open and widely publicized discussion with the Minister of Health on three topics that concern the IBD community in Israel: First, the issue of regulating Biosimilars: CCFI's stand is that Biosimilars need further clinical trials to prove safety and efficacy in IBD. Second, reducing exposure of CT radiation and transitioning to diagnosis via magnetic imaging, especially with children. Lastly, strengthening IBD centers of excellence and providing the general public and the periphery access to them. Pending results, the discussion may possibly be extended to the Israeli Parliament – the Knesset.

**National IBD Patient Event** at the Eretz Israel Museum in Tel Aviv is an event which aims to gather and strengthen the IBD community and our members' constituency. The new chairman of - Israel Gastroenterology Association (IGA), Prof. Arber will speak. Additional lectures will be about new medical technologies, IBD and sexuality and coaching methods for coping with disease. The coaching session will be led by Israel's 'celebrity' coach.

**Consortium session with IBD specialists** - this project is a first time joint event for WID, organized by CCFI with the IBD society within the Israel Gastroenterology Association.

CCFI aims to provide access for patients with especially complex cases, to an unprecedented ad hoc consortium of the best skilled IBD specialist in the

country, who volunteer their time for this event. We are also aiming at raising awareness for the need for a second opinion and for the importance of receiving treatment from a Gastroenterologist who is an IBD specialist. We hope this event will be the first in a 'tradition' developed especially for World IBD Day.

**Raising awareness media campaign via National TV infomercials** - a one minute infomercial on symptoms will run on Israel's main three TV channels starting on May 18th. The production of the infomercial was donated to CCFI by the Yoram Bar Advertising agency and the Israeli Television Authority has donated the air time. Our goal is to raise awareness on symptoms for people who suffer from warning signs identified with IBD, but have yet to be diagnosed, and for the general public. We hope that year after year, more and more people will become aware of the existence of Inflammatory Bowel Diseases and their symptoms.

**The Children Empowerment Event** will be a unique two day experience at the "Nitzana Educational Community" in the Negev Desert. This is a joint event of the Shaare-Zedek Pediatric Gastroenterology Unit, and CCFI. Nitzana is situated in the Western part of the Negev desert. The educational community is a special place where children's self empowerment, a love for the desert, the importance of sustainability, ecology and conservation are stressed.

Our children will enjoy desert sports challenges and educational experiences on settlement in desert conditions, ecology, water conservation, solar energy

and agriculture. Meanwhile, parents will have an opportunity to discuss issues in open sessions with IBD specialists from the medical center. The event is at no cost to the parents or the children. Every child attending the event will receive a copy of the 'Crohliti' board game which was 'unveiled' in our meeting in Gratz.

An exciting and busy May awaits us. This brings an opportunity to thank our dynamic General

Manger, Ms. Silvi Omer and the many volunteers, donors, supporters, staff and board members that help materialize ambitious plans and services for the benefit of the estimated 30,000 IBD patients in Israel.

We wish our friends in EFCCA associations, a successful 2014 World IBD Day.

United We Stand  
Dorit Shomron

# Ireland

## International Meeting for Young People with IBD

**The ISCC, in collaboration with the EFCCA Youth Group (EYG), and EFCCA are pleased to announce that the 17th annual meeting for young people with ulcerative colitis or Crohn's disease in Europe will take place in Dublin, Ireland from 17 to 20 July 2014!**



We aim to have fun whilst learning, working together and sharing ideas as a friendly and understanding community. The official language for the event will be English.

Youngster who are interested should contact their national association and inform them about the next EFCCA Youth Meeting. They should check with their national association to decide who will be the association's 2 delegates this year. After the deadline in June participants will receive the official paper including an additional registration form, which needs to be filled in together with their national association.

For more information please also check out the European Youth Group section of this newsletter or get in touch directly with the EYG at [daniel@sundstein.dk](mailto:daniel@sundstein.dk)

As always, the meeting is designed to be educational, interactive and also fun. Participants can expect interactive workshops, learning sessions about the different associations in Europe, a sporting event, visits to the local area, after the meetings of the day, news about EYG projects, and ideas of how participants can contribute and of course our famous gala dinner, on our last night.

# Poland

## 6th Educational Days about IBD

**The Polish Association Supporting People with Inflammatory Bowel Disease “J-elita” aims to inform its members, IBD patients, their families and everyone who is interested in IBD, about IBD so that people who have the disease don’t feel lost, lonely and left on their own.**

At the turn 2013 to 2014 another edition of the Polish Educational Days of IBD took place. Our list of host cities was growing enormously! This time lectures were being organized in: Gdynia, Lodz, Katowice, Warsaw, Krakow, Olsztyn, Lublin and for the first time, in Wrocław. The total number of attendants: almost 750 people!

Whilst an increasing number of patients with IBD should not be a source of joy, what is positive, is enlarging knowledge and awareness of people with IBD, sharing knowledge about medicines and modern forms of treatment. Every year the organizers put a lot of effort to meet high increasing expectations of our participants.



Thanks to the support from our medical colleagues, “J-elita” manages to have top physicians and specialists speaking at these events. Attendants could listen to a large variety of lectures, for example on: “IBD – how to choose an optimal treatment?”, “Indications for the surgical treatment”, “Biological treatment – What? Whom? When? Why?”, “What can be seen by endoscopy?”, “Patient’s rights in the age of biosimilars”, “Parents facing IBD in kids”, “IBD and pregnancy”, “Nutrition of people with IBD”. Everyone could find something interesting.



Educational Days of IBD are not only a perfect opportunity to increase one’s knowledge about the disease but among all, it is an unique chance to meet other people with IBD, share experiences, seek for support and develop new friendships that can sometimes turn into something more... Another positive effect: many people who help with the organization of Educational Days and who show great commitment forget about their diseases. It is some kind of therapy and “stepping-stone” from the everyday IBD-life. It gives a motivation to turn get our of home, to do something for others and to do something for one’s self.

Now, World IBD DAY is coming and we are convinced that the events organized by “J-elita” will enjoy the same success as Educational Days and our “J-elita” family will be as always the same, if not bigger, support to the people with IBD.

6th Educational Days were supported by the Operational Programme Civic Initiatives Fund.

Author: Katarzyna Dobrzycka

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# Diary of an Ironman

**IRONMAN is an internationally known triathlon event. During the Scandinavian event (Kalmar, Sweden) contestants swim in the Baltic Sea ( 3.9 km), the bike course is over the 6 km long bridge to the touristic island Öland (totalling 181 km) and the running course (42.2km) goes through central parts of Kalmar with the finish line located on the main square.**

**Jan Hruz a sports fanatic from Slovakia and member of the Slovak Crohn's Club participated in the Ironman Triathlon last year. Here he shares his experiences of the race which he fought despite his IBD proving to himself and the world that it is possible to fulfill one's dreams.**

It's 6:50 in the morning. I stand tightly wrapped into my neoprene suit waist deep in water with about two thousand other racers from around the world. The heart pumps adrenaline into your veins.

7:00. Start. There is a big rush to get ahead of everyone else, legs, arms, hands are being splashed around to pass through a narrow corridor. At first I don't manage to get up to speed but then things calm down a bit and other than having swallowed some salty water I did not come to any harm. After an intensive 1 hour 21 minutes I am getting out of the water at the triathlon depot where I find my blue bag with my stuff. I shed my neoprene skin and put on my cycling gear.

From the town it's a beautiful ride towards the magnificent 8 km long bridge linking the island of Öland Kalmar. On the bridge there is strong cross-winds which makes it very difficult to keep straight. On the island it's getting already better.

According to the Ironman triathlon rules athletes have to keep distances of 10 meters from each other. Overtaking has to take place in 30 seconds with a distance to the other rider of 1.5 meters and once overtaken you have to keep the 10 meters distance. That's the theory. In practise things got far more crowded and I only managed to keep sort of 5 meters space between the other riders....and forget about the 1.5 meters!

I drink energy drink and bananas trying to get 60g of carbohydrates per hour. Once in a while I have a salt pill into order to avoid cramps.

The first 60 km are mainly uphill and against the wind and by the time I return to the bridge I am at a speed of 33km per hour. This is followed by another 60 km on the mainland. I turn left, right, waver a little bit and at 140 km I am faced with disaster! I lose my grip on the paddle and have to reduce speed. In any case, the last 20 km I am slowing down so as to prepare myself for the running part.

I reach the depot. Stop my watch. Excellent time! 5 hours 40 minutes at an average speed of 32.1 km / h and average heart rate at 140.

I pick up my red knapsack containing running stuff. My socks are soaked from the swimming gear but luckily I have another pair in my bag.

After the long bike the body needs to get used to the new movement. You have to pace yourself because you feel that you are running slowly, but there is a danger to burn out which at a marathon distance can have disastrous consequences. Every 2 km there are some refreshments.

I run three laps. The first run is along the waterfront, then through a park. After 6 km we turn and run back a different route to reach the historic part of the city.



**Jan Hruz running through the finishing line**

I know that at home people are watching me on the internet via a live tracker. Whenever I go through the checkpoint and it beeps, I know that the update will be instantly on the web. This gives me support and my energy flows.

The crisis point is usually around 35 km. So far no problems with the stomach, I manage to hold a steady pace, although my legs are getting heavier and heavier and the small climb is getting harder each round. The target is getting closer and closer. In principle, even though I am gently slowing down, I still feel good. It seems I beat crisis point today.

The last lap is taking place and finally I can stretch. I slow down and enjoy my results: 11 hours 24 minutes 31 seconds. I ran the marathon in 4 hours 9 minutes with an average heart rate of 139.

I jump of joy and immediately get a cramp in both legs! I get a medal, pose for a photographer and only



**Cycling across to the island**



**Luckily the weather improved throughout the day**

with difficulties can I control my emotions. I am on the phone to my other half tears in my eyes! I am exhausted but it was all worth it!

This is the Ironman lifestyle. For me Kalmar was a long but fun journey and gives me energy to reach other objectives in life. It took a lot of compromises, sacrifice, sometimes even fear such as "what if the disease will win again?!", but somehow I know that even if some future disease wins the battle, I won the war, and I will enjoy the novelties and dreams fulfilled with my loved ones.

I want to thank all who have encouraged me throughout the year and who have welcomed me and enjoyed together with me this success.

## Rowing the Atlantic for IBD

**James Prior flew out to Grand Canaria in early February in order to break the Atlantic rowing record of 32 days. For a novice rower it has been a stern test, but James has exceeded his target of raising £100,000.**

His nine-year-old son Fergus has Crohn's Disease and during flare-ups eats a special diet through a gastric tube for up to eight weeks.

"Fergus deals with his condition incredibly well," says James, pictured right. "Despite getting frustrated, he takes his pain on and never complains. He's a fighter and I've taken on the Atlantic Challenge to highlight the daily challenges faced by people with IBD. I am going up against the Atlantic elements for one month, Fergus has a lifetime of Crohn's challenges ahead. We want to help by tracking down the elusive cure." Life on the boat is far from plain sailing; the crew row in

the same seat, and sleep in the same part of the boat every day. It is scorching on deck and stuffy and hot in the cabins – they only row for no more than an hour in the heat of the day, and enjoy the night shift row much more. The main danger they have encountered is "flying fish" that fly out of the water and hit the rowers at all times of the day and night.

David Barker, Crohn's and Colitis UK's Chief Executive, said: "We are very grateful to James, his wife Fiona, and their four boys who are determined to boost funding to help find a cure for Crohn's by supporting Crohn's and Colitis UK research projects."

**James Prior arriving at the port in Grand Canaria**



## IBD Nurses Training: 5th N-ECCO School

**The ECCO Nurses Network – N-ECCO – is now an established part of ECCO, the European Crohn's and Colitis Organisation. N-ECCO was created to provide educational opportunities for Inflammatory Bowel Disease (IBD) nurses throughout Europe and to increase networking opportunities for nurses caring for IBD patients to meet and share best practice.**

N-ECCO currently counts over 330 members and we are happy about constantly increasing interest in N-ECCO and N-ECCO Membership. In 2013 the first N-ECCO Consensus statements have been published in JCC, aiming at providing practical value at a local and national level to develop nurses' roles in caring for patients with IBD

In 2010, the N-ECCO Committee successfully introduced a new educational activity for IBD Nurses – the N-ECCO School. The N-ECCO School intends to give nurses who might still be in training and have an interest in IBD, the possibility to attend an IBD focused course. This one-day course consists of lectures and workshops and the participants are invited to join the N-ECCO Network Meeting for their further education in the next year. Participation at the N-ECCO School is based on nominations which are submitted by the N-ECCO National Representatives and access is only granted to ECCO IBD nurse members. Each ECCO member country can nominate 1 nurse for participation (31 places).

The N-ECCO National Representatives are also invited to attend the N-ECCO School to support the participants from their country, with language and translations in particular as many of the nurses attending do not speak English as their first language.

### Course Outcome and Conclusion:

With the 5th N-ECCO School, the cooperation between ECCO and EFCCA facilitated an educational programme which will improve the quality of patient care and thus benefit the welfare of patients in IBD.

he support of EFCCA allowed ECCO to offer a travel bursary to those participants who are unable to raise funding for travel and accommodation (as in some countries, industry sponsorship for nurses is prohibited). The EFCCA grant will be divided among those participants without industry sponsorship in the form of reimbursements for accommodation and travel expenses.

All course participants received a printed syllabus with the core slides, educational objectives and summary of each presentation. The nurses who attend the school are encouraged to use this syllabus when they return to their hospital and use it as a means of informing and educating their nursing colleagues.

Those course participants who have handed in a completed evaluation form were sent a certificate of attendance by email.

A short report on the N-ECCO School in Copenhagen will be printed in the 1st issue of the ECCO News 2014.

### PROGRAMME – February 19, 2014:

The programme of the 5th N-ECCO School featured a full overview of IBD history in order to give nurses a basic introduction to the specialty by expert speakers. Our aim was to teach basic knowledge in a clear way for nurses, with the objective of improving nurse education throughout Europe.

## TRAFFIC project

**The primary objective of the TRAFFIC clinical research studies is to find out if the investigational medicine being studied is effective in reducing the severity of the symptoms to the point of remission in individuals with moderate to severe ulcerative colitis or Crohn's disease when compared to placebo.**

The secondary objective is to evaluate if the investigational medicine being studied is effective in sustaining disease remission. Remission means absence or sustained reduction of symptoms.

### Study participants must be:

- 18 to 65 years of age
- Diagnosed with: a moderate to severe ulcerative colitis for three months or longer or moderate to severe Crohn's disease for six months or longer
- Experienced an unsatisfactory response to medications to treat your condition i.e., your symptoms continued despite treatment or your symptoms came back while still on treatment or you experienced negative side effects

There are other eligibility requirements that the study doctor will review with you if you are interested in participating in this study. Only the study doctor can

determine whether you are eligible to participate in the study or not.

Patients who qualify and wish to get more information could receive an initial study-related consultation, study-related examinations, and active study medication and /or placebo (an inactive substance).

Find out if you may be eligible to participate in an inflammatory bowel disease clinical research study.  
[www.TRAFFICIBDSTUDY.com](http://www.TRAFFICIBDSTUDY.com)

For ulcerative colitis you can also visit:  
<http://www.clinicaltrials.gov/ct2/show/record/NC-T01694485?term=amg+181&rank=4>

For Crohn's disease you can also visit:  
<http://www.clinicaltrials.gov/ct2/show/NCT01696396?term=amg+181+crohns&rank=2>

Thank you for your interest in clinical research. Participants in clinical research play an integral role in developing potentially better ways to treat various medical conditions.

## IBD Research Foundation

**During the first weekend of April our IBD Research Foundation was invited by EFCCA to attend the Annual General Assembly. This gave us once again a terrific opportunity to provide an update about the research projects we fund and about our plans for the future.**

What's more, it provided us with many opportunities to get in touch with the delegates from the associations which are members of EFCCA. Hereby we could not only provide more specific information, but we could also explain why being involved in our foundation is

so rewarding. We were very happy that through this, some people became enthusiastic about helping our foundation.

We also had an opportunity to meet with our

supervisory board and with the EFCCA board. Among other things we discussed was how to shape the collaboration with EFCCA in our future plans. Moreover, we were highly pleased that supervisory board member Chayim Bell was willing and prepared to help our foundation within our management board. Considering Chayim's comprehensive experience within EFCCA and his huge network of people who are involved in the field of IBD, we are convinced he will give a huge boost to our plans for the future.

### Donations

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

Account number: 97.46.86.158  
IBAN: NL37ABNA0974686158  
BIC: ABNANL2A

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## Patient + Participation = Our Vote for a Healthier Europe”.

**The European Patient Forum organised a Patients Campaign at the European Parliament which closed on 20 March 2014 on a positive note.**

EPF was able to bring its campaign to the heart of the European democracy as many Members of the European Parliament (MEP) and/or candidates for the next elections signed its Manifesto “Patient + Participation = Our Vote for a Healthier Europe”. “This campaign is absolutely crucial to make national and EU decision-makers understand that health policy needs to be further developed. Patients are often the weakest part of the chain while they can contribute to make health systems more effective”, said MEP Dagmar Roth-Behrendt who hosted the exhibition.

The exhibition was also organised under the auspices of the Greek Presidency of the Council of the European Union. EPF was very pleased to welcome Greek Health Minister Adonis Georgiadis to the exhibition on Tuesday 18 March 2014. “From 22 to 25 May, we, as European citizens, will decide on the future of Europe. I support this campaign because it is important we also decide for a ‘Healthier Europe’, where patients are part of the policy decisions towards making health systems more effective and accessible to all of our citizens,” he said.

With this exhibition, EPF encouraged the Members of the European Parliament going for re-election to sign the EPF Manifesto and therefore commit to including a patient perspective in their work for the new parliamentary session. Those not standing are also important allies of the patient's movement and EPF encourages their continuing support too, in their future endeavours.

All MEP supporters of the EPF campaign will be listed on the EPG website and will have the opportunity to be interviewed to appear on the EPF YouTube channel ([www.youtube.com/user/eupatient](http://www.youtube.com/user/eupatient)).

Supporting this campaign means that, when we will cast our votes on 22-25 May 2014, we will be confident to vote for patients' friendly candidates who work towards achieving a healthier Europe, as outlined in our Manifesto “Patients + Participation = Our Vote for a Healthier Europe”.

For more information, please contact EPF Communication Officer, Cynthia Bonsignore, at [Cynthia.bonsignore@eu-patient.eu](mailto:Cynthia.bonsignore@eu-patient.eu)

## A Focus on Biosimilar Medicines\*

**Biotechnology has enabled the discovery of treatments for a variety of serious diseases. Worldwide, over 350 million patients have benefited from approved medicines manufactured through biotechnology. Currently, over 650 new biological medicines and vaccines are being developed to treat more than 100 diseases. As the exclusive rights for these biological medicines expire, similar biological medicines, or “biosimilars”, are being developed, with some already available on European markets.**

Biological medicines are comprised of proteins and other substances that are often naturally produced in the human body. In healthcare, biotechnology is being used in three primary areas: therapeutic medicines, vaccines and diagnostics. When compared to chemical medicines, biological medicines are generally more complex and usually much larger in size than chemical medicines. The complexity is predominantly due to the manufacturing process for biological medicine, as they are developed in living system the exact characteristics and properties are highly dependent on the manufacturing process. Chemical medicines can be approved either by national medicines authorities or by the ‘centralised procedure’ carried out by the European Medicines Agency (EMA), however all biological medicines products must follow the ‘centralised procedure’ for approval.

Due to the composition and large molecule size of biological medicines, they have the inherent potential to induce (unwanted) immune reactions. Therefore, in order to identify unwanted immune reactions, and for post regulatory approval commitments, treating physicians should state the

brand name and batch number, as opposed to the International Non-Proprietary Name (INN) when prescribing. Furthermore, due to the unique nature of biosimilars, there should not be automatic substitution of the reference product, this decision should be left with the treating physician.

Generics and Biosimilars have an important role to play in fostering competition in the market place, and thereby contributing to the sustainability of healthcare budgets. However, as the research and development costs of biosimilars are much higher than generics, suitable pricing and reimbursement environments are needed to foster the development of new products. Furthermore, adequate intellectual property protection is vital to ensure that companies are able to fund research and development of biological medicines, and therefore develop and produce more potential treatments. Upon expiry of such protection, biosimilar products (unlike chemical generics these are not exact copies, as they are made in living systems the exact characteristics are dependent upon the manufacturing process) can enter the market to compete with the original “reference product”.

So far the European Union has approved 7 biosimilars, across 3 product classes. In the United States, the Biologics Price Competition and Innovation Act, signed into law in March 2010, created a statutory framework for the approval of biosimilars by the Food and Drug Administration (FDA). Over the last two years, the biosimilar market shares have steadily increased in most countries. In several European countries, biosimilars now have a higher volume market share than the reference product, and this trend appears to be accelerating.

**\*This information is from the EuropaBio literature “Guide to Biological Medicines”.**

**EuropaBio is the voice of the European biotech industry and represents the interests of the industry towards the European institutions so that legislation encourages and enables biotechnology companies in Europe to innovate and provide for our society’s unmet needs. The European Association for BioIndustries was created in 1996.**

## The potential impact of BIOSIMILARS

### For patients

Patients need and deserve to be fully informed about any medical treatment that they are receiving. If a physician chooses to prescribe a medicine to a patient, the patient should be involved in that decision, meaning that the patient understands why the choice has been made as well as what it will mean for his or her treatment.

Patients may not be completely aware of the complexities of biologicals, including biosimilars, and the implications of using them. This includes the potential of different products to provoke different immunogenic reactions in the patient. It is important that patients are not obliged to “switch” their treatment from one biological to another purely on cost grounds, the specific therapeutic needs of the patient must always be taken into account.

According to a survey by the International Alliance of Patients’ Organizations (IAPO), the key interests of patients with regards to biosimilars are:

- Cost and the potential to increase access to biological treatments;
- Safety and efficacy;
- Patient information and decision-making;
- Regulatory process; and
- Interchangeability.

Therefore, it is very important that the label and other product information relating to the biosimilar reflect the specific

characteristics (such as reference product, potential side effects etc).

### For healthcare professionals

Healthcare professionals need to understand the EMA approval process for biosimilars and be aware of the scientific data underlying their approval (in particular the abridged clinical data requirements, which can allow the extrapolation of indications).

For physicians too, it is very important that the label and other product information relating to the biosimilar reflect the specific characteristics (such as reference product, potential side effects, etc). The summary of product information on biosimilars should also list the available data in order to show which applications were substantiated by studies and

which were derived from the biological medicine of the original manufacturer without separate data via extrapolation.

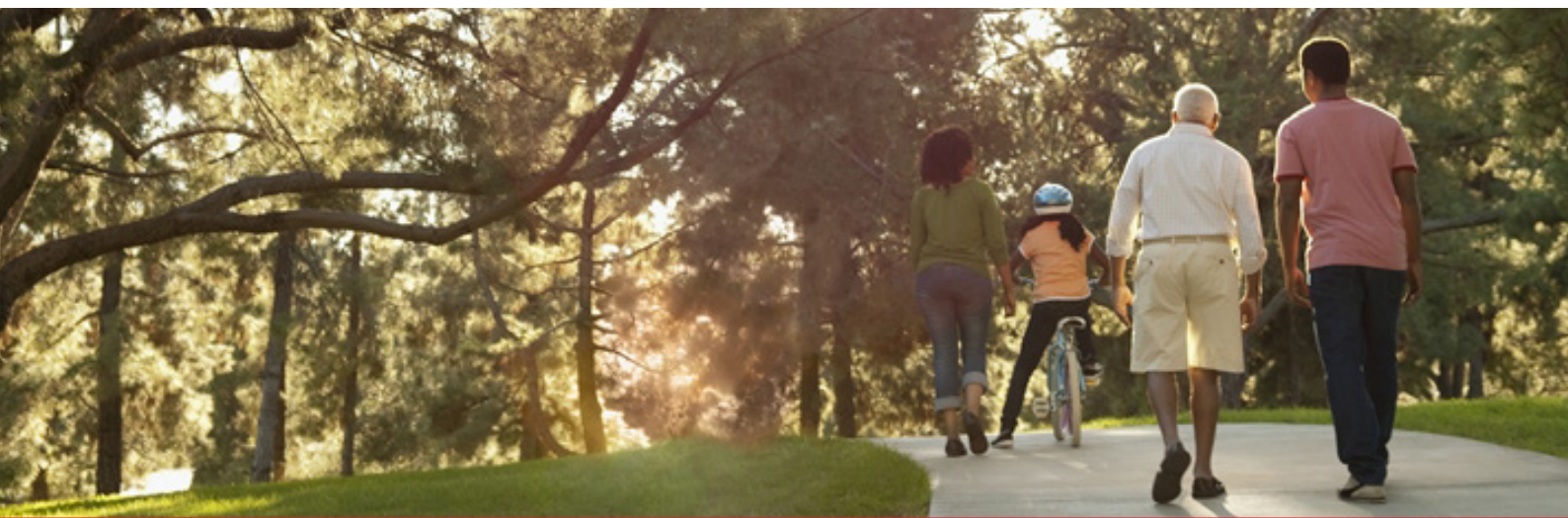
Healthcare professionals must be aware that the interchangeability between the biosimilar and its reference product has not been evaluated by the regulatory authority. Physicians should not be obliged to prescribe a certain medication purely on the grounds of cost, but should be allowed to exercise appropriate clinical judgment.

With regards to patients, it is very important for healthcare professionals that the label and other product information of the biosimilar reflect its specific characteristics (clinical data, reference product, etc.).

**The specific characteristics of biologicals are taken into account by the European legislator and regulator:**

**1. The updated European legislation on pharmacovigilance, due to be implemented mid-2012, establishes that Member States must make sure that “all appropriate measures are taken to identify when biological medicinal products are prescribed, dispensed, or sold in their territory which is the subject of a suspected adverse reaction report, with due regard to the name of medicinal product (...) and the batch number.”**

**2. All biological medicines, originator and biosimilar products, need to have a “Risk Management Plan” in place. This Risk Management Plan defines a set of “pharmacovigilance activities and interventions designed to identify, characterise, prevent or minimise risks relating to medicinal products, and the assessment of the effectiveness of these interventions”. Assessment of the immunogenicity is a key measure in the Risk Management Plan of any biological medicine.**



## YOU MIGHT BE MORE THAN JUST TIRED

- Downloadable fact sheets for patients
- Fatigue survey
- Interactive symptom browser



CHRONIC  
HEART  
FAILURE



IBD



COELIAC  
DISEASE



CANCER



KIDNEY  
DISEASE



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Vifor Pharma, a company of the Galenica Group, is a world leader in the discovery, development, manufacturing and marketing of pharmaceutical products for the treatment of iron deficiency. The company also offers a diversified portfolio of prescription medicines as well as over-the-counter (OTC) products. Vifor Pharma, headquartered in Zurich, Switzerland, has an increasingly global presence and a broad network of affiliates and partners around the world. For more information about Vifor Pharma and its parent company Galenica, please visit [www.viforpharma.com](http://www.viforpharma.com) and [www.galenica.com](http://www.galenica.com) or contact us at [communications@viforpharma.com](mailto:communications@viforpharma.com)

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