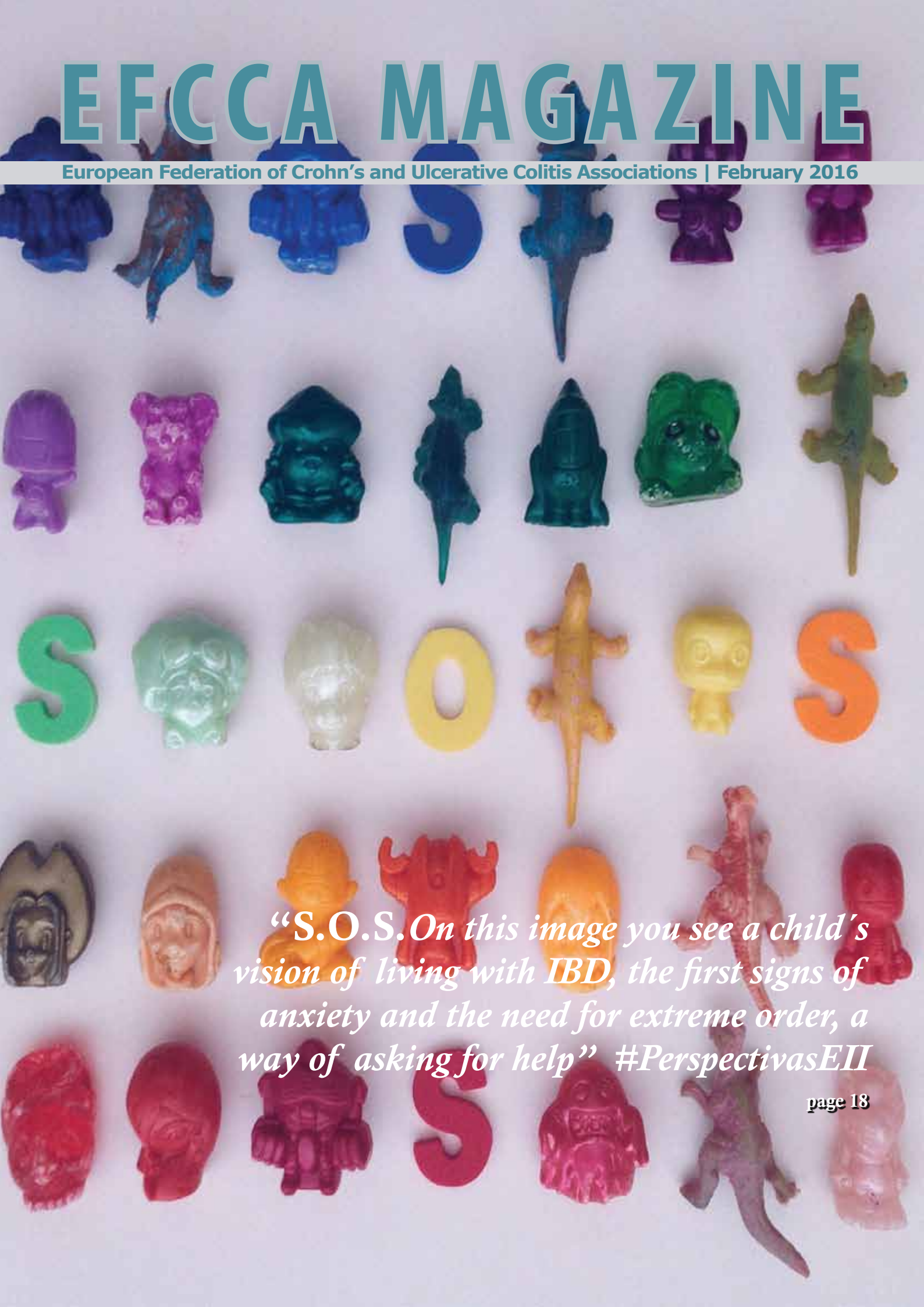


# EFCCA MAGAZINE

European Federation of Crohn's and Ulcerative Colitis Associations | February 2016



*“S.O.S. On this image you see a child's vision of living with IBD, the first signs of anxiety and the need for extreme order, a way of asking for help” #PerspectivasEII*

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# EDITOR'S EYE

## Learning from each other: the added value of international networking



2015 has been the year of the Biologics and Biosimilars survey – BAB.

Its main purpose was to “open a door towards a better knowledge” by getting a picture of the current situation as concerns innovative medicines (biologic and biosimilar) in our IBD community and beyond.

In fact, another umbrella organisation has been involved in the survey – AGORA the southern European Platform representing people with rheumatic and musculoskeletal diseases. This is the first important result of our collaboration with sister organisations that started few years ago and that is now getting stronger and more effective.

EFCCA has been always convinced of the importance of establishing partnerships and developing networking with the multifaceted galaxy of patient organisations dealing with immuno-modulated diseases. We hence believe that the exchange of information and skills can enrich and foster our mutual learning in our common fight of getting more visible and raising awareness about a community of patients that is growing worldwide but that is too rarely taken into account within national and international health policies.

With this same spirit EFCCA has agreed to work in partnership with Gafpa – the Global Alliance for Patient Access - in the organisation of a 2 day training on advocacy for Patient Safety beginning of February this year .

You will read more detailed information of the training and its content in the section EFCCA news of this magazine, however I want here to stress the paramount importance of this unique experience that is leading EFCCA to be a reference point for other international organisations of patients that will be working together in Barcelona.

Besides the huge participation of our members (28 countries and the whole EFCCA Board and staff) many other organisations have applied to our invitation, a further sign of how our international reputation is growing, as well as the proof that the exchange of good practices and mutual learning are important aspects of our international work and commitment.

EFCCA is taking this challenge with pride and sense of responsibility and in Barcelona we will be delighted to welcome friends and colleagues representing other disease areas such as rheumatic and musculoskeletal

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illnesses, psoriasis, ankylosing spondylitis, pemfigo, hidradenitis suppurative and people in need of home artificial nutrition.

We will be all there to share our willingness to improve quality of life of people with chronic diseases like ours whose causes are mostly unknown, whose voices have to be heard more, whose potential is growing.

I am confident that we will be all working together to become better equipped in dealing with new treatments and new health policies in our countries.

Mutual learning and sense of belonging: two important ingredients for the “healthy” growth of our communities.

Luisa Avedano  
EFCCA CEO

UNITED WE STAND





# Advocacy workshop on patient safety

**From 4-6 February 2016 EFCCA is co-organising an advocacy workshop on patient safety together with GAfPA, the International Network of Physicians & Advocates for Patient Access, to take place in Barcelona.**

The overall goal of the workshop is to create greater awareness amongst patient communities regarding the issues impacting access to biologic and biosimilar treatments. The objectives of the workshop therefore are as follows:

- To provide or improve basic understanding of the science and issues associated with biological medicines and biosimilars
- To provide training on how to employ effective advocacy and communication strategies with the goal of raising awareness and understanding amongst key policy makers.
- To allow patient advocacy groups from different geographies to network and share best practices

The programme co-designed by EFCCA and GafPA includes an exciting mix of lectures and interactive sessions as well as a presentation of the results of the BAB survey (Biologics and Biosimilars – an open door towards a better knowledge). BAB has been carried out by EFCCA and involved also patients affected by Rheumatoid Arthritis with the aim to assess patients' knowledge about biosimilars and biologics and to find out to what extent patients are aware of the issues involved around these innovative treatment options.

Participants are made up by patient representatives responsible for lobbying and/or communication activities from the EFCCA membership base as well as patient representatives from other immune modulate disease groups such as AGORA (a platform of associations of people with rheumatic and musculoskeletal diseases in Southern Europe), IFPA (International Federation of Psoriasis Associations), ASIF (Ankylosing Spondylitis International Federation), EULAR (European League against rheumatism), and IAPO (International Alliance of Patients' Organisations). The event forms part of EFCCA's work programme and priority issue of patient safety. The workshop has received an educational grant from AbbVie.

## About GAfPA

The Global Alliance for Patient Access (GAfPA) is a network of physicians and patient advocates with the shared mission of promoting health policy that ensures patient access to appropriate clinical care and approved therapies. GAfPA accomplishes this mission through educating physicians and patients on health policy issues and developing education material and advocacy initiatives to promote informed policymaking.

## Case study: New Zealand

*Crohn's and Colitis New Zealand organised an advocacy campaign for World IBD Day in the grounds of the New Zealand Parliament where over 100 members and volunteers wearing purple t-shirts joined together to form a purple ribbon. On this occasion Member of Parliament, Dr Jackie Blue, was presented with the IMPACT report, which highlighted the needs of people with IBD and advocated for measures to improve their lives.*



# Improving quality of life for people with IBD

## #unitedwestand2016



**Worldwide, five million people live with Crohn's disease and ulcerative colitis, conditions known as inflammatory bowel diseases (IBD). World IBD Day is marked on 19 May each year and is led by patient organisation representing 35 countries on four continents from Argentina, Australia, Brazil, Canada, 28 European nations through the umbrella organisation EFCCA, Israel, Japan, New Zealand to the United States of America.**

To mark World IBD Day 2016 EFCCA together with its 31 member associations and other IBD sister organisations from around the world are uniting their efforts around the campaign "Improving quality of life for people with IBD" in order to create greater awareness about inflammatory bowel disease and to pave the way for improvements in the quality of life of people with IBD.

As part of the campaign we will be asking local, municipal and regional authorities worldwide to light up famous landmarks in purple (the colour for World IBD Day) in support of our campaign. Images of these highlighted landmarks/buildings will be shared on international and national social media channels and many associations around the world will engage in supporting event providing detailed information about IBD and issues addressing the quality of life of people with IBD.

### How to get involved in this campaign?

#### Highlighting buildings/landmarks

Please get in touch with your asking local, municipal and regional authorities as soon as possible in order to present them with the campaign and ask them for their support. In terms of technicalities, lightening up buildings/landmarks in purple involves adding a simple purple filter to the usual lightening equipment of that building/landmark. If you need any help in contacting your relevant authorities please

let us know. If need be EFCCA can provide you with a letter of support.

#### Social Media

Please share information of this campaign on your social media, your national association's website and the World IBD Day website. Whenever you post/share something about the campaign please make sure to use the following hashtag(s) #unitedwestand2016 #worldibdday2016. Please get in touch with EFCCA for sharing information on the World IBD Day website.

#### Involving volunteers

World IBD Day is a good occasion to involve your volunteers, friends and supporters. Many of the EFCCA associations are asking volunteers to gather on World IBD Day at the buildings/landmarks to hand out information material on IBD and to speak directly with people letting them know how IBD affects peoples quality of life and how it could be improved.

#### Media

Please get in touch with your media contacts and share information about the campaign. If you are organising a physical event (see above) please make sure to invite your media contacts. Let us know if you need any support with this.

For more information contact the EFCCA office.

# Survey on iron deficiency in IBD

**EFCCA has been co-operating with physicians from the European Crohn's and Colitis Organisation (ECCO) and the pharmaceutical company VIFOR in the development of a survey on iron deficiency in IBD.**

The survey aims to find out about the impact of IBD and the associated iron deficiency on patient's lives in order to raise awareness about the issue of iron deficiency in IBD and to increase early detection and appropriate treatment.

Although anemia is the most common systemic manifestation of inflammatory bowel disease (IBD), among the broad spectrum of extraintestinal disease complications encountered in IBD, including arthritis and osteopathy, it has generally received little consideration. However, not only in terms of frequency, but also with regard to its potential effect on hospitalization rates and on the quality of life

and work, anemia is indeed a significant and costly complication of IBD.

A planning meeting with all the stakeholders was organised at the Humanitas hospital in Milan on 26 November 2015. EFCCA was represented by Luisa Avedano and Isabella Haaf. Marco Greco participated as an observer in the meeting.

It is foreseen to launch the survey in the coming months and we hope that it will contribute to a better understanding of the issues around iron deficiency and support efforts aimed at improving the quality of life of people with IBD.

## EFCCA at the UEG WEEK 2015

EFCCA has been present for the last few years at UEG Week with a small information booth using the occasion to connect with physicians and representatives of the pharmaceutical industries and other stakeholders. As in previous years the EFCCA staff was present throughout the event as well as EFCCA Board member Salvo Leone who facilitated several meetings with potential sponsors.

UEG Week is the largest and most prestigious meeting of its kind in Europe, and many consider it to be the best digestive diseases meeting in the world. It has been running since 1992 and now attracts more than 14,000 people from across the world. It features the latest advances in clinical management, the best research in GI and liver disease and includes several different kinds of symposia and fora, where cutting edge gastroenterology and hepatology is being discussed.



*The EFCCA staff at the UEG WEEK booth (from left to right): Anna Striscinglio, Luisa Avedano, Isabella Haaf and Salvatore Leone (EFCCA Board Member)*

# Striving for better continence care

**On 1 July 2015, EFCCA and a number of representatives of pan-European patient and civil society groups came together to discuss the issue of incontinence and the provision of better continence care in Europe at home and in the community.**

The roundtable was hosted by AGE Platform Europe, Eurocarers and SCA. A 'hidden' or 'invisible' disease today, the roundtable aimed to contribute to a better understanding of incontinence and encourage relevant policy and stakeholder action to improve continence care. In particular, the roundtable aimed to discuss and agree on a set of key policy recommendations to improve the management of care for people with incontinence and their carers at home and in the community.

The Roundtable discussed the burden of incontinence in people's daily lives and the barriers and solutions to better continence care that will enable people with incontinence and carers to live active, independent and dignified lives at home and in the community.

Participants in working groups identified areas of policy and stakeholder action that will help people with incontinence and their carers better manage

their care at home and in the community, support their independence, well-being and dignity, and increase their active participation in society.

## Areas of action:

1. Increase awareness, recognition and understanding of incontinence
2. Recognize continence care as a human right to live independent and dignified lives
3. Improve information and communication about incontinence
4. Enable choice, involvement and empowerment of people affected by incontinence
5. Develop continence-friendly urban/community and home environments
6. Support and prioritize a research agenda on incontinence

The common work led then to a joint position statement. For more info contact the EFCCA office.

# EFCCA Annual General Meeting 2016

**This year the Annual General Meeting (AGM) of EFCCA will take place from 27th to 28th May 2016 in Brussels, Belgium.**

The meeting is an excellent occasion for all members to meet, discuss and exchange ideas as well as to review the work of EFCCA and its governing board. This year elections for the post of the EFCCA president as well as several other board positions will take place. We will also continue our tradition and organize an EFCCA purple team to run on 29 May at the 20 km Brussels marathon in order to raise awareness for World IBD Day. EFCCA invites each member to identify a suitable runner for this day and to bring that person also to the AGM. We believe this is a good way to involve more people from your association in the wider network of EFCCA.



*EFCCA delegates voting during last year's AGM.*



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



# Relationships and IBD

**We all want to be loved and share our life with those important people who naturally surround us. Whether it is our mother, father, brother, sister, boyfriend, wife or our children but when circumstances change and our lives get turned upside down we often overlook how it impacts those around us.**

When we are faced with these changes many questions go through your mind – Do I talk to my brother? Do I share my symptoms with my partner? Do I tell my peers? Will my treatment impact my relationships?

During EFCCA Youth Group (EYG) meetings we discuss various topics as seen in previous EFCCA Magazines and we try to “Break down taboos” which come with daily life and IBD. Will I be loved less because of my IBD? Will they be able to cope with my symptoms and treatments? Will I be able to have intimate relationships?

Many people with IBD not only face issues such

as having to deal with medication side effects and surgery but guilt and negative thoughts when it comes to trying to keep relationships alive and making time for others when you have to give so much time to yourself.

Through these stories we hope to raise awareness and make people understand the difficulties and challenges we face and go through. We want to change and we want the world to find a cure. So if we can be a part of that - why stop? This is why I encourage you all to read these stories, remember them and tell them to your friends, relatives, doctors and whoever is willing to hear your story.

## The importance of opening up to people close to you

I was attending high school when I started to notice the first signs of the disease. It all started as frequent cramps in my stomach. At first I didn't pay much attention to these pains until I became scared when bloody stool symptoms started. I was diagnosed after 2 months. As you can imagine it was a shock to realise that I have a chronic disease. I was just a normal girl, facing all the normal situations like all teenagers but now I was suddenly a chronic patient.

My initial treatment was high doses of methylprednisolone. At first my acceptance of the condition was positive and people commented on how well I had accepted the diagnosis but after I experienced side effects from my treatment, negative feelings started to sink in. My perfect skin suddenly

became covered in small red acne and between them there were the big ones, the gross ones. My appetite was highly increased, I felt disgusted knowing I ate way too much than I actually needed. My body totally changed, but the swelling was most obvious in the belly and the face.

At this point the rumors were going on at school that I was pregnant and that wasn't even a possibility. All in all, my outer appearance was different, but I soon realised it was not going to be permanent. During this period I didn't have any serious relationships and I talked seriously about my disease to just a few people. I guess for others it was enough to just say some “stomach thing” and that was it. If it weren't for the medications I think most of them wouldn't even



**Maksim (left) from Slovenia has been living with IBD – ulcerative colitis – for more than ten years now. She was diagnosed in her most vulnerable years.**

considered me being ill. I managed to keep my good grades and finished high school. That summer I met my current boyfriend.

It wasn't love at first sight, we were getting there slowly, but one thing was sure – I trusted him from the moment we first met. After couple of meetings I told him about my illness and I was surprised by how well he accepted the fact. He was asking me all sorts of questions around IBD, treatment and diets.

At that time I was in remission, so maybe that helped me in being honest with him from the beginning.

Since the diagnosis, I have been on

methyprednisolone three times, which always helps my symptoms, but it affects my appearance every

time. My self-esteem was not lowered for the last two times, which I give my boyfriend much credit for. He is always there for me, driving me to all the examinations and check-ups, he is very supportive and a good listener. We have been together for 8 years now.

Another important relationship, which has been impacted by IBD,

is my family. I know it was hard for them to accept me as a chronic patient, but they didn't show me the difficulties they were facing. My relationship with my

*“I consider myself a very lucky person as I have so many great people around me, who do not let my life revolve around IBD but are very supportive when I really need them to be.”*

parents and siblings has not changed, I do not feel they pity me and IBD is definitely not our main topic for conversations. I sometimes get a feeling that my mom is much more concerned about my state than I am, but in general she is a very protective person. I know some parents feel guilty, thinking they 'gave' their children IBD as one of the causes of it can be genetic, but I had that conversation with my mom and we cleared things out.

I have mild to moderate disease but quite active nearly all the time. It affects my life daily in general, but I believe for those who have severe forms of IBD it is much harder to maintain relationships. Of course,

I feel that depends also on the character of the person. I consider myself a very lucky person as I have so many great people around me, who do not let my life revolve around IBD but are very supportive when I really need them to be.

I want to share a quote from my beloved book – The Little Prince: *“It is the time you have wasted for your rose that makes your rose so important.”*

## Being there for one another

My name is Ali, I am 23 years old and work as a Modern Languages teacher in a high performing secondary school. My best friend is the Assistant Operations Manager for the NEC and airport and is, quite frankly, the best human being I know.

I have known her now for over 13 years and I always say she is my better half. What I haven't mentioned is that my best friend has both Crohn's and Colitis. She was my best friend before her diagnosis and remained my best friend after. She was diagnosed while we were in our last 2 years of secondary school – a difficult time in any teenager's life. This affected our relationship not a single bit. If anything, I would say that our relationship was made stronger because of her diagnosis.

As a teacher of 11-18 year olds I have witnessed first hand how teenagers relate to each other these days. Everything is online; “Yeah, I'll Whatsapp you.” “Facebook me later.” “I'll send you a Snapchat.” My

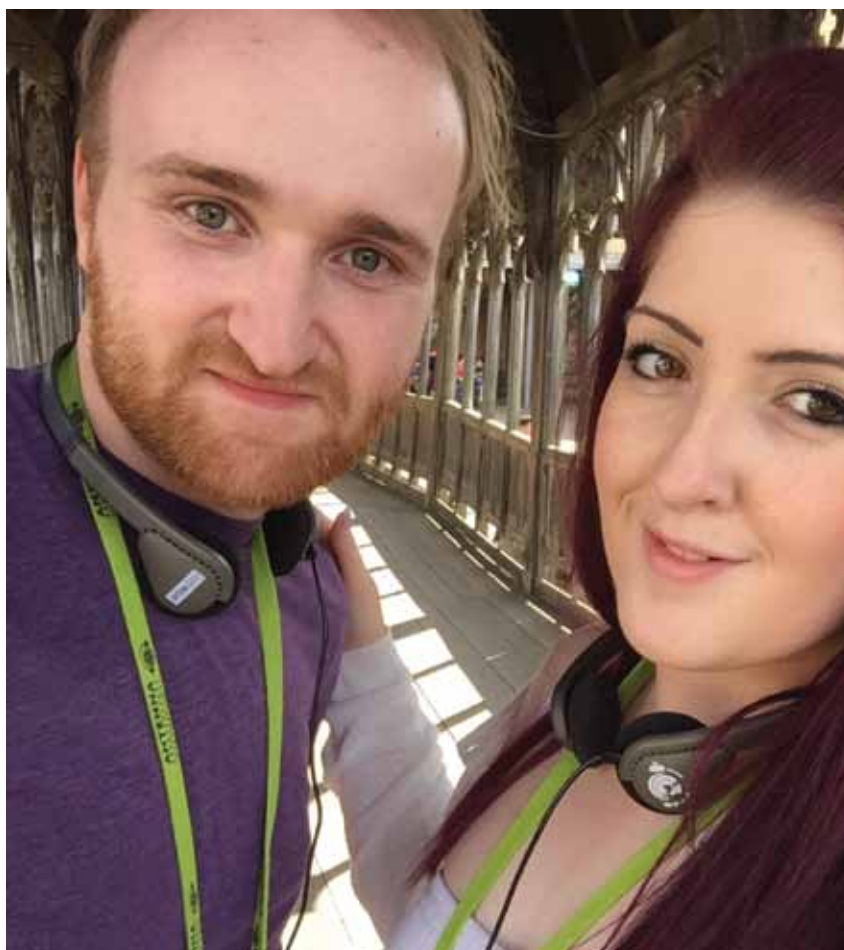
best friend and I weren't afforded that luxury. I spent time with her in hospital, discussing everything and anything. I looked back at that time of her diagnosis as some of the best quality time we have ever spent together.

It goes to show the strength of the bond you have with your very best friends and how little they will care about a diagnosis of any IBD. Don't get me wrong; it wasn't all sunshine and rainbows. I would be dropped off at the hospital every day after school and walk down the ever-familiar corridors to visit her wishing that today was the day she turned the corner and could come home. Thinking of how I felt at that time, I can recall feeling sadness.

***“I would be dropped off at the hospital every day after school and walk down the ever-familiar corridors to visit my friend wishing that today was the day she turned the corner and could come home.”***

Sadness that my best friend had to live with a little understood and discussed condition. It wasn't pity. It was genuine sadness that people weren't and aren't educated about a relatively common illness. But I also felt happiness. Happiness that she would





**Best friends for ever. Ali (left) was there since the beginning when his friend, Leanne, was diagnosed both with Crohn's and Colitis**

be able to live a normal life. Happiness that she would be around for a long time. Happiness that I got to have in depth, meaningful conversations that I just wasn't having with my other friends at the time. It made me reevaluate my life. At 15 what was important to me? Was it going home and sitting on messengers pretending that it was my "friend" that sent a message to my crush? Or was it sitting with my best friend who had just been given news about her health?

It turns out that it was just being able to be there for her. To let her know that I was always going to be there for her whether we were 15 or 50. Our friendship now is no different to that of my friendship with other friends. Well, I tell a lie; the only difference is that maybe we talk about going to the toilet a bit more than I do with my other friends but I can honestly say that that is the only difference I can think of. We still

do everything we want to do. We try and cram in as much time as possible with our busy schedules. We talk daily. We do everything we can, when we can, not because we have lingering thoughts of "Let's do this in case of a relapse", but rather because, simply she is my best friend and that's what best friends do.

The positive side of my best friend's diagnosis is that I get to meet inspiring people at amazing events. Be it sitting in a park having a picnic and eating ice cream, sitting in a beer garden at a barbeque, or sitting in a pub smashing the heck out of a pub quiz with some of the nicest people I have met; none of it would have taken place were it not for her diagnosis.

# Make the invisible iceberg of young patient visible

**In September last year the European Patients' Forum's (EPF) 5th Annual Youth Group meeting was held in Bucharest. The EPF is an umbrella organisation that works with patients' groups in public health and health advocacy across Europe, of which EFCCA is a member of. Thomas Hough, EFCCA Youth Group board member, represented EFCCA at this meeting and shares his experience with us.**

This was my first year at the event so I didn't really know what to expect and was slightly nervous knowing that most of the members had been part of the group for quite a while and they were all representing different health conditions and associations. I need not to have worried though, because the group is like one big family and they welcomed me in with open arms from the moment I met each member. One of them was even kind enough to meet me in baggage collection in the airport after realising our flights landed at the same time.

All of the delegates having different health conditions wasn't a big divide either, as I quickly learned through the discussions and socialising that due to the invisible nature of our conditions we all suffered from common problems such as a lack of awareness and understanding, stigma and isolation. Problems I was really pleased to see the group were tackling with their campaign and tag line that "Young patients are young people". It was also great to see that the main topic of the weekend was to improve the group's visibility and identity using facilitation tools such as the elevator pitch to develop a concise mission statement and vision for the group. These will then be used to promote the group and to help members and the EPF confidently talk about the group to external associates.

## **Mission of EPF Youth Group**

To make the invisible iceberg of young patient visible to policy makers and the wider public by mobilizing, educating and empowering them to improve the lives of young people with chronic illness.

## **Vision of EPF Youth Group**

Young people with chronic conditions are valued

members of society by being actively engaged, to influence policy changes and public awareness.

Another important part of the meeting was the elections for the board of the EPF Youth Group. After nominees and votes were counted the three elected members of the Board of the EPF Youth Group were Aneela Ahmed (National Voices, UK) as President, Polis Stavrou (International Diabetes Federation Europe, Cyprus) and Cristina Iscu (Coalition of Patients' Organisations with Chronic Diseases, Romania) as Vice Presidents.

With Aneela as President I feel the group is in strong hands with her passion and determination. Her aims for the future of the group are "The hope of better healthcare that is integrated and involves the voice of young patients is one main aim that the Youth group and I will strive to achieve."

Before closing down the meeting for another year plans were sketched out for the Youth Groups work for 2016. One of them was for a roundtable discussion on the transition to adult care, something that I am really keen to see the results of with our own EFCCA Youth Group also currently developing a questionnaire to look into this very issue in 2016.

Overall I was amazed by the amount of work that got covered in only 1 and a half days with even time to experience some of Bucharest with a walk around town and seeing a light show in the evening.

I can't wait to see 2016 unfold now and for the EPF Youth Group to achieve their goals set for the coming year.

Tom Hough, EFCCA Youth Group Board member



## 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.



# Romania

## Mountain of hope

**The Romanian Association of People with Inflammatory Bowel Diseases (ASPIIR) and the Romanian Club for Crohn's Disease & Ulcerative Colitis (RCCC) organized a mountain trek in order to raise awareness about Inflammatory Bowel disease (IBD) and its impact on patients' lives.**



*IBD patients and doctors braving the weather to raise awareness about IBD.*

IBD patients and IBD doctors joined the initiative of ASPIIR at Cheile Gradistei, which took place within the framework of the 7th Annual Symposium of Inflammatory Bowel Diseases organized by the Romanian Club for Crohn's Disease and Ulcerative Colitis, between 24th- 26th September 2015. Given the presence of doctors from many university towns and clinics around the country at the Symposium, ASPIIR used this opportunity to hand out some informational material, to set up an information stand and to distribute some publications meant to highlight

the effects that these diseases have on the life of an IBD patient.

Through the "Mountain of Hope" Project we wanted to support and encourage persons living with IBD and to prove that a correct management of the disease can enable the patient to take control of it and lead a normal life. At the same time, by forming a team made up of doctors and patients who climbed together the mountain ridges we intended to consolidate the doctor-patient relationship and to



emphasize the importance of working as a team, of struggling together not only to conquer the peaks of the mountains, but also to surmount the difficulties and the complications brought about by IBD.

Even though the weather was far from glorious and the 27th of September was a rainy day, with fog covering a large part of the mountain slopes, the team of patients and doctors didn't give up and carried the project through, covering a distance of 13.5 km in about 5 hours, on the following track: Fundata - Moieciu de Sus - Coltul Zilistea - Culmea Lunga - Dealul Cremenii - Satul Cheia - Pârție Biathlon Fundata.

Soaking wet clothes dried during a stopover, slippery muddy footpaths and not even the fog which from time to time split up our group reducing visibility to several meters did not make us abandon our project. On the contrary, these difficulties cemented the feeling of interdependence, making us look after each other. All of these considered, even the sandwiches damped by the rain and eaten on the way had a surprising taste, while the hot soup that was offered to us on our descent by the owners of Cheile Gradistei resort came as a blessing.



*Even the rain didnt manage to dampen our spirits!*

Through the success of this project, our hiking group, made up of patients: Hans Vihta, Octavian Marinescu, Isabella Grosu; doctors: prof. Liana Gheorghe, prof. Mircea Diculescu, dr. Tatiana Arisanu; as well as guides, journalists, friends or organizers, illustrated once more the importance of the doctor-patient relationship in IBD and their working as a team, confirming the message that patients can return to a normal life, including activities like mountain climbing.

Isabella Grosu, ASPIIR

## Slovakia

**The Slovak Crohn Club launched a new, informative book entitled “Children with IBD” which is aimed at children with IBD and family members. The book was presented during an educational seminar on 6 June 2015 coinciding with International Children’s Day.**

The seminar was held under the auspices of the President of the Slovak Gastroenterology Society – Section for Pediatric Gastroenterology, Hepatology and Nutrition as well as the Director of the Children’s University Hospital in Bratislava and took place in the pleasant atmosphere of Bojnice town in the Regia hotel.

The keynote presentation looked at ‘New findings in the IBD children’s and adolescent’s treatment. ‘ followed by discussions where participants could ask

experts questions about treatment options for IBD and other issues concerning IBD. Furthermore, Doctor I. Cierna, PhD, presented a book on “Treatment of IBD in children and adolescents.

The social programme of the seminar included an interesting tour of Bojnice castle tour and a visit to the the local zoo.

Ivana and Viliam, Slovak Crohn Club

# Argentina

## #PerspectivasEII

### A social media, art initiative to raise awareness about IBD

The Foundation Mas Vida Crohn's and Colitis Argentina has launched an innovative social media (instagram) campaign entitled #PerspectivasEII (IBDPerspectives) which aims to raise awareness about the experiences of people living with IBD.

The aim of the campaign is to show through photography what life is like for people with Crohn's and/or Ulcerative Colitis. The Foundation Mas Vida Crohn's and Colitis Argentina has chosen Instagram as a platform because of its popularity amongst social media user and the visual impact it has.

During a coordination meeting in a relaxing and intimate environment, 4 patients exchanged experiences and stories of living with IBD with 12 artists from the Huntgram company that works on Instagram. The artists then captured on an image the stories they had listened to. Each of the artists used their own personal style, understanding and creativity in order to transmit the stories and thus raise awareness amongst their followers.

You can find the images in Instagram using this hashtag #perspectivasEII. You can follow us on @fundacionmasvida.

This activity has received the financial support from AbbVie S.A.

Luciana Escati, Foundation Mas Vida Crohn's and Colitis Argentina

*Image on the right: Each step on a sinuos and stinging path defines how difficult it is to live with Crohn's disease or Ulcerative Colitis. A path full of emotional symptoms where support becomes the only means to cross it. #PerspectivasEII*





*S.O.S. Crohn's disease and UC affect children as well as adults. This game shows a child's vision of living with IBD, the first signs of anxiety and the need for extreme order, even a way of asking for help #PerspectivasEII*



*You can't see Crohn's disease and Ulcerative Colitis, so it's difficult to imagine the physical and emotional drain they cause. During flare up patients tend to isolate themselves. Chronic diseases whose origins are unknown and no cure exists. They cause a feeling of loneliness and anxiety. When one sees a patient coping with it you only have admiration left. #PerspectivasEII*

# France

## The Bird Study

## The Burden of Inflammatory Bowel Disease

**The impact of IBD (Crohn's disease and ulcerative colitis) on patients' every day social and professional life has never been evaluated until now on a large population. The impacts, in terms of quality of life, of fatigue, of occupational handicap, of eating habits and of moral disposition are very real and most present.**

Starting from this level of awareness, the largest study ever carried out, made up of several questionnaires (28 pages), took place in 2014 and today the preliminary results are most revealing.

The IBD Observatory, founded by AFA, in France, in collaboration with Professor Laurent Peyrin-Biroulet of the University of Nancy, France, conducted this cohort including 1 211 patients throughout France. One-third of the patients represented a population with a mild case of IBD, one-third had a moderate case and one-third was in a severe flare up.

According to Prof. Peyrin-Biroulet\*, world renowned IBD specialist, “for 30 years, the focus was on the subjective notion of quality of life, which varies greatly from one patient to another. The purpose of this study is to measure, for the first time, in a more objective manner, the collateral danger caused by the disease referring to an index built on a scientifically validated occupational handicap”.

The first results known from the study have been revealed by AFA since last Spring, shedding light on the daily problems caused by IBD. The study has revealed the Patient Reported Outcomes Measurement (PROMs) showing that 50% of the patients are depressed and one-third are very anxious. In fact, half of the patients complain about severe fatigue, no matter what degree or stage of the disease they may be in. A third admitted to feeling handicapped in their daily activities and a third expressed difficulties in leading a professional life, which could even be the cause of absenteeism for 10% of them.

Prof. Peyrin-Biroulet admits that “if the family, friends, professional entourage understand, the occupational handicap is greatly reduced”. According to him “the objective now is to act in favor of the patient returning every day to normal life”. In order to achieve this, it is absolutely essential “to increase the disease check-ups, follow up on the stability of the disease and keep in touch regularly with the patient in his home.”

This study is the starting point of the IBD Observatory, which has attracted more and more professionals from different medical sectors interested in IBD. The new IBD Observatory is a partner with EPIMAD, the oldest and largest IBD register in the world, founded in 1988, with 25 000 data files registered to date. This partnership gives the IBD Observatory a solid and broad-scale foundation.

Madeleine Duboé - AFA, France

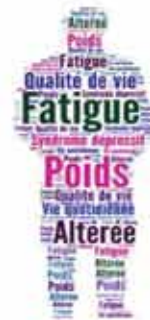
IBD Observatory website :

<http://www.observatoire-crohn-rch.fr/>

\*Interviewed by the magazine Le Quotidien du Médecin – May 2015



# BIRD



## THE BURDEN OF THE INFLAMMATORY BOWEL DISEASE



MARCH 2014 : 6000 questionnaires sent to members of afa



Questionnaires :  
SIBDQ - SF36  
HAD - FACIT  
IBD Disability Index



1 211 patients with different forms of IBD replied  
1/3 with mild case,  
1/3 with moderate case,  
1/3 with severe flare up .

Population well represented.



...and 30% suffer anxiety. These figures corroborate our active listening experience, an alarming fact



50% of patients have symptoms of depression



1 patient out of 2 admitted to severe fatigue.  
We observe it daily :  
fatigue not easily understood by the patient's entourage,  
experienced even by patient with a mild case.



Almost 1/3 of patients feel handicapped with IBD in their daily life



1 out of 3 expressed difficulties in leading a professional career...



...causing absenteeism for 10% of them



# ACTION !

- Better accompany patients on a daily basis
- Be more attentive to the psychological aspects of their lives
- Develop employability and job security programs
- Recognize, understand and treat fatigue

# UK Crohn's and Colitis Awareness Week

We organized Crohn's and Colitis Awareness Week from 1-7 December 2015. Thank you to everyone for joining in and



Our Facebook activity reached over 3 MILLION people and we gained over a 1629 new Page likes during the awareness week



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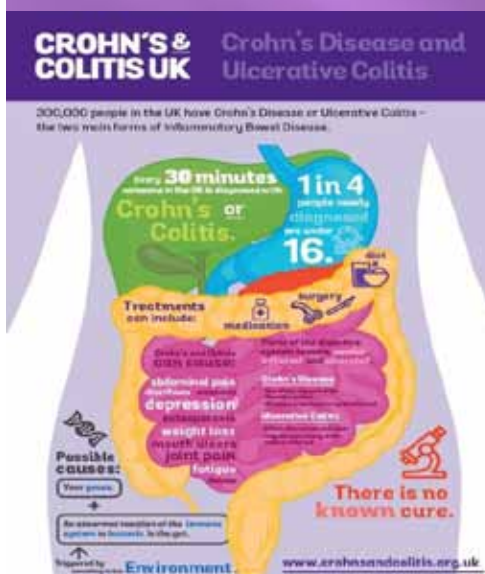
£5000 was raised online and a further £2000 was raised through the text to donate code throughout the week - plus Gift Aid



327 limited edition t-shirts  
327 were sold, raising  
around £1,900.

Early Day Motion  
submitted in  
Westminster as well as a  
debate raised by George  
Freeman MP, The  
Parliamentary Under-  
Secretary of State for  
Business

Our  
infographic  
was broken  
into sections  
throughout  
the week.  
The most  
popular post  
was the first  
section which  
reached  
550.2k



The web  
40,000 v  
the wee  
views an  
Week su  
over 800

A series of blogs featured on  
the website from members of  
the charity - the most  
popular was by Thaila Skye  
with 1900 page views

shouting loudly to support our cause. Here a collage of the exciting events that took place:

...ohn's And

...week achieved over  
...ces of media  
...age including 7  
...al publications  
...as the Huffington  
...and the Metro

Total impressions on twitter over the week were 249.2k

Our celebrity supporters tweeted their support

Our social media Thunderclap - reached 740,567 people on social media.

MP's showed their support and appeared in several regional newspapers

Workplaces across the UK went purple

...site received  
...visits throughout  
...k, 93,000 page  
...d the Awareness  
...bsection received  
...00 views



## Spain

# Patients ask for a Spanish legislation regarding biologics

**On 22 January 2016 ACCU España together with several other associations of chronic patients participated in the conference “Rights of patients on biological treatment” which took place in Madrid in the headquarters of wecare-u.**

One objective of the conference was to explain the differences between biologics and biosimilars and the relevant regulations that are in place in Europe which need to be applied in Spain. Further topics covered the difference between “interchangeability” and “replacement” (automatic replacement can not be done without the authorization of the treating doctor and without the knowledge of the patient). The meeting also aimed to provide details concerning the current legislative issues as well as transparent information in terms of the different types of biological treatments that are presently available on the market.

“Such initiatives, that provide legislative knowledge

and share information about biologics, are very useful” said Ildefonso Pérez, president of the Confederation ACCU España, “patients these days, have a much stronger position: they are listened to and participate in many discussion forums, however even though our voices are nowadays considered, we still have a lot of work ahead of us.”

In the concluding remarks, María Dolores Cantos, from the Spanish Association of Sjogren Syndrome stressed the need to be strong and united to achieve that the Spanish health system has a high quality and to avoid that the economic crisis has a negative impact on patients.

*Participants at the conference: “Rights of Patients on Biologic Treatment”*







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# Travelling with IBD

## Exploring South America

The cold, long winter months often make us dream about escaping to some warmer destination. Here we would like to share a story as posted on the website of our colleagues from Crohn's and Colitis Australia asking volunteers to share their experiences about travelling with IBD. Please note that this information is not intended to be used as medical advice and you should speak to your health care provider before planning a trip.

### Where did you go?

South America (Brazil, Argentina, Bolivia, Peru, Chile).

### Were there any language barriers?

Very basic Spanish (and even more basic Portuguese in Brazil) was enough to get me through in most situations.

### What tourist attractions did you visit?

I suppose the main ones were Inca Trail/Machu Picchu, the Amazon region, up the coast of Brazil from Iguassu to Rio.

The Inca Trail is the one that would cause the most problems – isolated, absence of toilets, physically demanding, at altitude etc.

### Did your IBD cause you any issues on this trip?

My issues were related to my medication. Being immune-suppressed because of my drugs I was unable to have the yellow fever vaccine (it's a live vaccine) – which is very highly recommended for the Amazon region. We weighed up the risks, and went ahead with that part of the trip – just needed to ensure that I was lathered in repellent and long clothing. Didn't have issues – but it certainly needs to be considered. Some countries will not allow you in without the

vaccine – but I was never checked – until I returned to Australia, at which point I was essentially quarantined to south of Mackay for 2 weeks. This would obviously affect anybody from far north Queensland who was travelling.

### Was there anything out of the ordinary that stressed you out, or could potentially stress out someone with IBD?

Nothing out of the ordinary for me. Passport controls in foreign countries are always have some levels of stress. I'm pretty calm about most things.

### Can you recommend how many days/weeks is a good time to visit this location?

We had six weeks throughout South America – we weren't particularly rushed in any place.

### Can you tell us what the food and cuisine is like?

I loved the food – it's pretty varied across the continent. Obvious Spanish influence, but it's always good to try some local, exotic fare.

### Toilet advice?

There were a couple of long drops on the Inca Trail. I always carried my own paper in a backpack just in case.



*On the Inca Trail, Machu Picchu, Peru*

**On a scale of 1-5 how much does your IBD affect you?** (1 being in remission and 5 being in a flare)

2 – some discomfort, but pretty much symptom free due to my medication. I have travelled while symptomatic before – not on this trip.

**On a scale of 1-5, how difficult was it to manage your IBD while on this trip?** (1 being no issues and 5 being very difficult to manage)

2 – Only issue was related to the vaccines.

**Were there any activities which challenged your IBD management?**

The Inca Trail and Amazon.

**Would you recommend this place for people who have IBD?**

I'd recommend it for anybody!!

**Additional comments?**

I love to travel, I'm at the lower end of Crohn's cases, and I'm pretty stress free generally. With this in mind, the travel never caused me many issues, at least that I didn't think weren't outweighed by the great times I've had. I also don't like "can't" – although I'm sure that for others it will affect them greatly. I recommend learning a bit of the language (particularly as it relates to IBD), do your research, get insured, and be as comfortable as you can that you've crossed every T. And get out there!



# Crohn's and Colitis Canada: Smashing success during Crohn's & Colitis Awareness Month

**Crohn's and Colitis Canada is determined to bring the experiences of living with these diseases out from "Behind Closed Doors" – as our new TV announcement states clearly.**

Crohn's and Colitis Canada is determined to bring the experiences of living with these diseases out from "Behind Closed Doors" – as our new TV announcement states clearly.

By increasing public awareness and understanding about Crohn's and colitis, we will transform people's lives by ending the stigma, decreasing their isolation, and gaining recognition for the many serious issues faced by people living with these diseases.

This November's Crohn's & Colitis Awareness Month was a smashing success - thanks to the dedication of so many GUTSY Canadians. By helping to spread the word and raise funds throughout the month, you have helped to start the conversation about these diseases.

Over 1,600 Canadians 'gutsified' their Facebook and Twitter profiles, and media coverage from coast-to-coast resulted in 54 million media impressions. Crohn's and Colitis Canada is even featured in Maclean's 'The Year In Pictures' - you can view the article [here](#). To see a full list of all our great media attention, visit our [Media page](#).

To close out the month, our Awareness Month Youth Ambassador Julien spoke to Rogers TV about leading the charge to spread the word and raise money in Awareness Month. A big thanks to Julien for his hard work, and to all the volunteers who helped spread the word about Crohn's & Colitis Awareness Month!

## European Patient Forum - Patient Empowerment Campaign

**In 2015 EPF launched a thematic Patient Empowerment Campaign, to build momentum for the real empowerment of patients in Europe. With this campaign EPF aims to promote the development and implementation of policies, strategies and services that empower patients to be involved in the decision-making and management of their condition.**

### Update - What happened in autumn 2015?

In October EPF released the official campaign video during the patient empowerment workshop that we organised at the European Health Forum Gastein. In the video, patients share their views on why patient

empowerment is important, and explain why we need to act now to make patient empowerment a reality.

The campaign leaflet, which explains what patient empowerment is and the purpose of the campaign, was translated in 12 different languages. By the end of



the year it will be available in all EU languages to ensure that the campaign material reaches the widest possible audience in the EU.

As part of the campaign, EPF launched an information collection form to gather information on good practices and activities that are already happening in Europe and aim to promote patient empowerment. We encourage you to complete it and share it with your network.

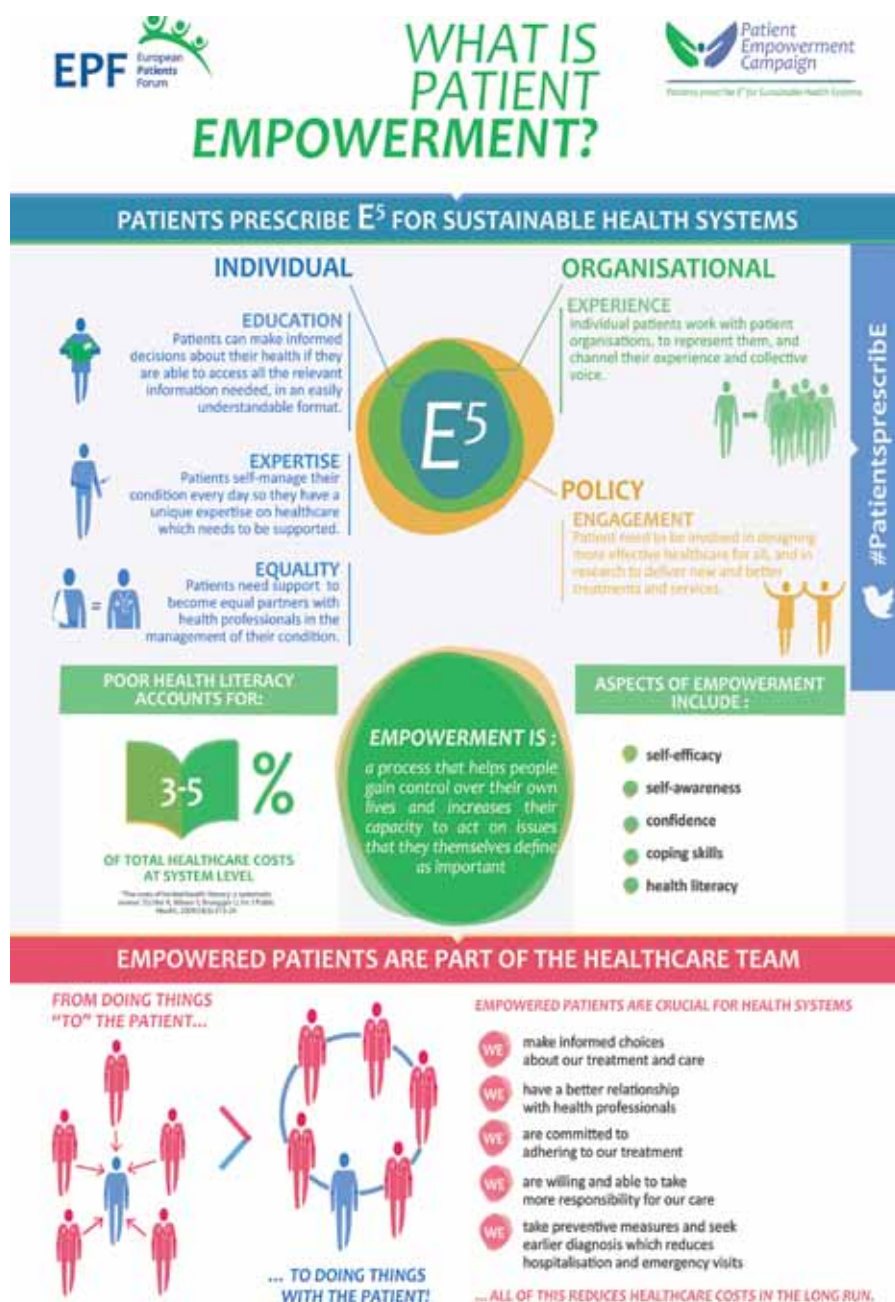
In November, EPF released a significant campaign document for consultation, the “Charter of Patient Empowerment” which is a set of fundamental principles of patient empowerment in ten points, as defined by patients.

### What is next for 2016?

In 2016 EPF will release the second major campaign document, the “Multi-stakeholder Roadmap to Patient Empowerment” which will be the basis for concrete actions that European policy-makers and healthcare stakeholders should take.

The two major documents will be officially presented in February at a European Parliament event that EPF will organise, to ask for the continued support of Members of the European Parliament to this campaign. Watch out for the dates – to be circulated in early New Year.

EPF will close the campaign on a high note in June by bringing its outcomes to the heart of



European democracy with an exhibition hosted by an MEP in the hall of the European Parliament. During this event, we will arrange a high level roundtable meeting where EPF will share the outcomes of the campaign as well as follow-up actions.

Contact: EPF Communications Assistant, Valentina Stylianou at [valentina.stylianou@eu-patient.eu](mailto:valentina.stylianou@eu-patient.eu)

# Camp Oasis: Life-Changing Experience for Children with Crohn's & Colitis

**For more than 11 million children and adults, summer camp provides an escape from every day life- a chance to enjoy the outdoors, meet new people, and participate in fun and exciting activities.**

NEW YORK, NY – For 23-year-old Jessica Heitzler, summer camp has provided her with much more than a week away from home- camp saved her life.

Heitzler was diagnosed with Crohn's disease when she was 8-years-old. For years, she lived with constant debilitating pain, doctor's appointments, medications, and emotional issues. It wasn't until she first attended Camp Oasis as a high school junior that she felt like herself.

"Camp saved my life. It was the first time in my life that I didn't have to hide who I truly was," Heitzler said. "Everyone at camp- both campers and volunteers- taught me that Crohn's isn't who I am, but it is a part of me and I should embrace it. Camp Oasis helped me grow into a confident woman who accepts and loves herself for exactly who she is. I am now completely open about having Crohn's disease and I have Camp Oasis to thank for that."

Applications open today for Camp Oasis's 2016 summer sessions. Camp Oasis is the Crohn's & Colitis Foundation of America's (CCFA) summer camp program that enriches the lives of children with Crohn's disease and ulcerative colitis by providing them with a safe and supportive camp community. CCFA runs 12 week-long camp sessions across the country, attracting not only campers but also hundreds of volunteer counselors and medical professionals. CCFA underwrites 65 percent of the cost of camp attendance, and scholarships are available for campers-in-need.

Disney Channel Liv and Maddie actor Benjamin King, a Crohn's disease patient, stresses the importance

of having an outlet like Camp Oasis for children with Crohn's disease and ulcerative colitis to come together.

"Dealing with Crohn's as an adult, I know how difficult it can be to cope with this disease. I can't imagine how hard it must be for children to live with the debilitating pain and uncertainty Crohn's and ulcerative colitis can cause," King said. "As a father, I've seen firsthand the benefits that summer camp has on children. The existence of Camp Oasis to give children with Crohn's and colitis a safe environment to come together and bond over a shared experience is tremendous."

For more information about Camp Oasis: [www.ccfa.org/get-involved/camp-oasis/](http://www.ccfa.org/get-involved/camp-oasis/)

## About CCFA

The Crohn's & Colitis Foundation of America (CCFA) is a non-profit, volunteer-driven organization dedicated to finding the cures for Crohn's Disease and ulcerative colitis. Since its founding over four decades ago, CCFA has remained at the forefront of research in Crohn's disease and ulcerative colitis.

Today, it funds cutting-edge studies at major medical institutions, nurtures investigators at the early stages of their careers, and finances underdeveloped areas of research. In addition, its educational workshops and programs, along with its scientific journal, *Inflammatory Bowel Diseases*, enable medical professionals to keep pace with this rapidly growing field. The National Institutes of Health has commended CCFA for "uniting the research community and strengthening IBD research."



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Learn more at [www.janssen-emea.com](http://www.janssen-emea.com)



The image depicted contains models and is being used for illustrative purposes only.

Janssen Pharmaceutica NV



# International Day of Persons with Disabilities

**On 3rd December 2015, the European Union (EU) celebrated the International Day of Persons with Disabilities in the framework of the European Year for Development. The aim of the one-day conference was to answer the question, if the 2030 Agenda for Sustainable Development is to be fully inclusive of persons with disabilities then what practical steps do we need to take now?**

The conference, which took place in Brussels, was attended by almost one hundred participants representing the EU Institutions, EU Member States, organisations of persons with disabilities (DPOs), and other civil society organisations and networks from Europe and developing countries. The European Disability Forum was one of the organisers of the conference and was actively involved in the programme of the event.

So, what does it take to leave no one behind? Ten practical action points for the EU to implement the 2030 Agenda for Sustainable Development in the framework of the Convention on the Rights of Persons with Disabilities (UN CRPD) were presented during the closing address. One key recommendation, which should be undertaken from now, is the development of a work plan in consultation with development partners including DPOs and other civil society organisations.

This work plan should include: measures to create awareness of the CRPD, advocating for the rights of persons with disabilities in the world, and politically supporting the inclusion of disability in Agenda 2030, in particular the adoption of disability-related indicators.

The EU should build its own organisational capacity, ensuring that there is a behavioral shift towards a rights-based approach, sharing of best practice and knowledge, reinforcing its own human resource capacity, including ensuring disability focal points, and using its programmatic tools and budget to promote the CRPD.

The call to carefully review, apply and monitor the EU's own obligations concerning accessibility was reinforced by the adoption of a proposal for a European Accessibility Act by the European Commission (EC) on December 2nd. All projects funded by the EU must be fully accessible for persons with disabilities.

Working in partnerships and ensuring the participation and empowerment of persons with disabilities in all aspects of Agenda 2030 is crucial.

More info at: <http://www.edf-feph.org/>

## What is UNCRPD?

UNCRPD (United Nations Convention on the Rights of Persons with Disabilities) is the human rights convention concerning persons with disabilities. It is a list of rights guaranteed to persons with disabilities to improve their access to society, education and employment. Persons with disabilities are still covered by other UN rights and convention documents; however, the CRPD specifically spells out rights that pertain to the ability of disabled people to interact within their own communities.

It was written by government representatives from around the world in active consultation with civil society agencies - particularly persons with disabilities and their representative organisations, help to shape the convention.



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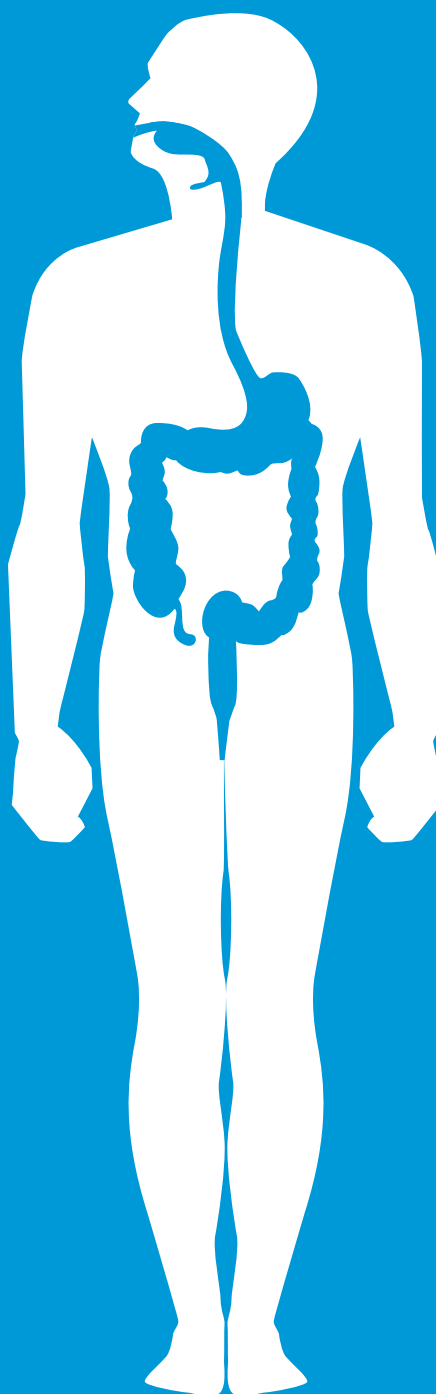
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## TOMORROW

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# NCRC Scientists close to “turning off” inflammatory bowel disease

Dr Pat Walsh and consultant paediatric gastroenterologist Dr Seamus Hussey whose pioneering investigations into Inflammatory Bowel Disease featured in the *The Sunday Times* (page 8, 10/01/16 Irish edition) written by Siobhán Maguire.

Research at the National Children’s Research Centre (NCRC) has identified elevated levels of a specific protein in children diagnosed with Inflammatory Bowel Disease (IBD), opening the way for a drug to be created that can “turn off” production of the protein.

The identification of the “damaged” protein in children means scientists now know the gene responsible for colonic inflammation in chronic disease such as ulcerative colitis (UC) and Crohn’s disease (CD).

The study was led by Pat Walsh, a scientist at the School of Medicine in Trinity College Dublin, and Seamus Hussey, consultant paediatric gastroenterologist at Our Lady’s Children’s Hospital, Crumlin, who found the small protein. Walsh said the next step was to figure out how to “block” the protein and help alleviate symptoms for sufferers.

“We looked at children who have UC and CD and compared them with children who didn’t and the major thing that jumped out was this protein that was much higher in kids with UC versus those that didn’t have the disease or who have CD,” he said. “Because kids with UC had a higher level of the protein and inflammation in the gut, this makes you think the protein is playing a role in this type of disease.”

Scientists have previously made a link between the protein, called IL-36. And psoriasis, a skin disease, but its role in IBD, where the intestine is irritated or inflamed, had not been made.

“The finding is important because very little is known about the early stages of IBD, in children,

before other diseases emerge in adulthood to cloud the causative picture,” said the NRC, which funded the research through charity donations. “It might provide a treatment or a cure for IBD. The researchers have provided the pharmaceutical industry with a massive short-cut in terms of developing a new, powerful drug that can effectively treat IBD.”

There are an estimated 15,000 people in Ireland with IBD, and there has been a 90% increase in childhood IBD over the past 10 years. Our Lady’s Children’s Hospital records more than 100 new cases of the illness in children each year and while the incidence of the disease is on the increase in other countries, Ireland has one of the highest rates of IBD in the world.

The NCRC said: “The cause of IBD remains unknown, but the main culprits include a low-fibre, high sugar modern diet, rising obesity levels, sunlight exposure and vitamin D deficiency. There are host of other factors, which have been suggested as causing IBD including genes, smoking, stress, infection, and the consumption of anti-inflammatory drugs.”

The Irish Society for Colitis and Crohn’s Disease (ISCC), a patient support group for people who are living with IBD, welcomed the findings.

“Any development of possible cure in IBD is a great turn,” said Fergal Troy, a 29-year old surveyor from Dublin who is on the board of the ISCC and suffers from UC. IBD is very heavily dominated by quite invasive medicine for sufferers and I myself am on two medications a day. If a new drug would allow sufferers to limit the amount of medication that is need or give them a more normal type of life, that

would be very beneficial.”

Rachel Kane, chair of Gutsykids Ireland, a support group for families of children and teenagers with IBD, said there are more than 500 children with the disease in the country, including Tadhg, her 15-year old son, who is on medication and required to have blood tests in Crumlin hospital every eight weeks.

“He was diagnosed when he was 10 but it took two years to get to that diagnosis so he had two years of being in and out of the A&E department and sent

home without a red flag system that would say this child has been in here three or four times with the same pain,” she said.

“There is no definitive cause, no cure, this is a lifelong illness which steals the quality of life from a child, some of the treatments are used to treat cancer, the side effects can be just as bad as the disease sometimes. The pain, mental anguish, embarrassment and lack of support for this invisible disease is shocking.”

## Creation of large and innovative research and information exchange platform

**40,000 patients come together with researchers and doctors to create \$40 Million game-changing IBD research initiative. IBD Plexus® is the largest and most innovative research and information exchange platform ever created**

Orlando, FL (December 11, 2015) – For the first time, more than 40,000 IBD patients, researchers, and healthcare providers will be brought together by IBD Plexus® to create the world’s largest registry of IBD patients of all ages which will transform how IBD research is being conducted. IBD Plexus, the Crohn’s & Colitis Foundation of America’s (CCFA) newest research initiative, is the largest and most innovative research knowledge and exchange platform for Crohn’s disease and ulcerative colitis ever created. Patients will come from existing CCFA initiatives, including CCFA Partners and CCFA’s Pediatric RISK research project, as well as a Quality of Care cohort and a newly established prospective adult research cohort (SPARC IBD).

“As the leader in IBD research, CCFA is truly the only organization that can undertake this type of initiative,” said CCFA’s Chief Scientific Officer Caren Heller, MD, MBA. “Rather than having multiple, fragmented research efforts and registries, IBD Plexus is providing access to data across study cohorts from

a single point. IBD Plexus utilizes technology that enables its stakeholders to capture, organize and link large amounts of data on individuals with IBD, and to mine and share this data for insights into the causes of and potential treatments for IBD.”

With seed money provided by The Leona M. and Harry B. Helmsley Charitable Trust, CCFA embarked on a two-year discovery and planning process to conceptualize and design IBD Plexus. Dr. James Lewis, professor of medicine and clinical epidemiology at the University of Pennsylvania, and Chief Scientist for IBD Plexus, led a small group of IBD researchers who developed the plans to create this game-changing resource. At the end of this planning process in early 2015, the Helmsley Charitable Trust awarded CCFA an additional \$17.5 million to support the development and implementation of IBD Plexus. The initiative has already made significant progress.

For more info:

[www.ccfa.org/news/ccfa-ibd-plexus-preview.html](http://www.ccfa.org/news/ccfa-ibd-plexus-preview.html)



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CHRONIC  
HEART  
FAILURE



IBD



COELIAC  
DISEASE



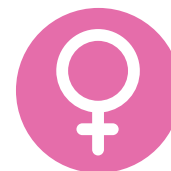
CANCER



KIDNEY  
DISEASE



BARIATRIC  
SURGERY



WOMENS  
HEALTH

