EFCCA MAGAZINE

European Federation of Crohn's and Ulcerative Colitis Associations | October 2015

Purple team joins 20 km marathon to raise awareness about IBD

page 7

Anaemia from a patient perspective in IBD: results from the EFCCA survey

page 42

Symposium on Patient Safety

page 9

EFCCA Members

Austria – OMCCV
www.oemccv.at

Belgium
CCV: www.ccv.be
Crohn-RCUH: www.mici.be

Bulgaria - BCUCA
www.babkuk.org

Croatia – HUCUK
www.hucuk.hr

Cyprus – CYCCA
www.cycca.org

Czech Republic – OSPs IBD
www.crohn.cz

Denmark – CCF
www.ccf.dk

Finland – CCAFIN
www.crohnjacolitis.fi

France – AFA
www.afa.asso.fr

Germany – DCCV.e.V.
www.dccv.de

Greece - HELLESCC
www.crohnhellas.gr

Hungary –MCCBE
www.mccbe.hu

Iceland – ICCA
www.ccu.is

Ireland – ISCC
www.iscc.ie

Italy – AMICI
www.amiciitalia.org

Luxembourg – ALMC
www.afa.asso.fr/luxembourg

Malta – MACC
www.macc.org.mt

Norway – LMF
www.lmfnorge.no

Poland – J-Elita
www.j-elita.org.pl/

Portugal – APDI
www.apdi.org.pt

Romania - ASPIIR
www.aspiir.ro/

Serbia – UKUKS
www.ukuks.org

Slovakia – SCC
www.crohnclub.sk

Slovenia – SAIBD
www.kvcb.si

Spain – ACCU
www.accuesp.com

Sweden – MOT
www.magotarm.se

Switzerland – SMCCV
www.smccv.ch
www.asmcc.ch

UK - Crohn's and Colitis
www.nacc.org.uk

Associate Members:

Argentina - Mas Vida
www.masvida.org.ar/

Israel - CCFI
www.ccfi.co.il/

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

Contents

EDITOR’S EYE

Growing together

A few months ago we celebrated EFCCA´s 25th anniversary reminiscing about the beginnings of our association and marveling at what it has become 25 years later. We welcomed two new associations from Greece and Romania bringing our total membership up to 32 IBD patient associations. 3 of these members are outside Europe and several other associations reaching from Japan to Latin America have approached us saying that they would like to join our organization.

This shows that even in our current difficult climate of the economic crisis, Inflammatory Bowel Disease (IBD) patient support groups all over the world and in Europe, clearly see the benefit of joining EFCCA to ensure that their voices are heard, to better advocate for their interests and to also exchange knowledge and ideas on how to improve the quality of life of people with IBD.

You will find a detailed account of our last General Assembly (GA) in this issue. It was a particular memorable event as this year we linked our GA also to our World IBD Day activity. We gathered over 40 people to run at the 20 km Brussels half marathon under the purple colours of World IBD Day in order to raise awareness of IBD. Many of the runners were from our member associations and were joined by friends, family members, doctors, researchers etc.. And many of those who couldn’t run joined us at the information booth to inform the public about IBD and to cheer our runners.

As you know in the recent months we have dedicated a lot of our work around the issue of patient safety in particular as concerns the entering of biosimilar medicines in some European countries and beyond. Our efforts have centered around information sharing and ensuring that our members are aware of the issues involved around Biologics and Biosimilars. To that end we have launched not only the BAB survey (as reported in our previous issues) but we have also organized a series of events to provide more information concerning these two treatment options.

We are pleased to present you in this issue you the report of The Symposium on Patient Safety that we organized in Brussels on 30 May 2015. It was a highly successful event and gathered a wide range of stakeholders including patients, doctors, payers and licensing authorities. This has also resulted in EFCCA being invited by the European Commission to co-organise together with the European Patient Forum (EPF) the patient panel of the European Commission’s Workshop on Access to and Uptake of Biosimilars, on 6 October 2015.

Editorial and Publication coordination:
Isabella Haaf

Graphic Design:
Isabella Haaf

Contributions:
Sarah Birch, Brian, Silvio Danese, Leanne Downie, Thomas Hough, Jessica from Uncover Ostomy,

EFCCA Contact details:

Rue des Chartreux 33-35
B -1000 Brussels
Belgium
Tel/Fax: + 32 2 540 8434

Chairman Marco Greco
Tel: + 39 346 800 9433
marco.greco@efcca.org

CEO Luisa Avedano
Tel: + 32 483371194
luisa.avedano@efcca.org

Secretary Ciara Drohan
ciara.drohan@efcca.org

Treasurer, Martin Kojinkov
martin.kojinkov@efcca.org

Communications
Isabella Haaf
Tel: +34 606 849 937
bella.haaf@efcca.org

Registration:
1096/97
revised 22/2/2006
No. 459814543

The workshop is being organised by the European Commission's Directorate-General Internal Market, Industry, Entrepreneurship and SMEs and we are proud to say that together with EPF we will ensure that the patients view is considered in this important stakeholder meeting.

I am also very pleased to see that our new EFCCA Youth Group (EYG) is continuing the good work of previous years particular as concerns awareness raising about IBD amongst young people. In this issue the EYG is looking at the subject of IBD and work/education and you will find two interesting interviews related to this topic.

I would also like to take this opportunity to welcome the newly elected EYG group to the EFCCA family and to thank the previous EFCCA Youth Group leader, Daniel Sundstein, for his excellent and committed work. Daniel, who is now too old for the youth group..:) is replaced by Fergal Troy from the Irish Crohn's and Colitis Society. We have high hopes and look forward to seeing our youngsters working together for a better quality of life of young people with IBD!!

UNITED WE STAND

Marco Greco, EFCCA Chairman

25 years of transnational work

Over 70 EFCCA delegates met on 29 and 30 May 2015 in Brussels for the 25th General Assembly, where the yearly activities of EFCCA, the budget and the future work programme were presented and approved. It was an excellent opportunity to meet face to face with EFCCA members, exchange ideas and projects and discuss new common initiatives and interests.

EFCCA Delegates at the 25th General Assembly, 29-30 May 2015, Brussels

Following the presentation and approval of the EFCCA activities, elections to the new EFCCA Board took place with the following composition: Marco Greco, Chairman (Italy), Salvo Leone, Vice-President (Italy), Ciara Drohan, General Secretary (Ireland), Martin Kojinko, Treasurer (Bulgaria), Eva Björnsdottir (Norway) and Natassa Theodosiou (Cyprus). The new board meets physically 3 times a year and once per month via conference call in order to discuss the strategic development of the organisation.

EFCCA chairman. Marco Greco thanked the previous board members Betty Vandevelde (Belgium), Bruno Raffa (Switzerland), Iva Savanovic (Croatia) and Arne Schatten (Norway) for their hard work and commitment to the board and EFCCA.

This year EFCCA welcomed two new members to the EFCCA community. The Greek IBD association HELLESCC represented by Alexandra Gliati and Georgios Zisis and the Romanian IBD association, ASPIIR, represented by Isabella Grosu and Madalina Bombarascu. This brings our total membership to 32 national patients' associations including 28 European countries and 3 associate members from outside Europe.

Delegates also listened to two interesting case studies made by Isabella Grosu (ASPIIR) from Romania on how her organisation successfully applied and implemented several EU projects under the Erasmus+ programme involving youngsters with IBD. Natalhie Moreau from the Belgian IBD association, RCUH, shared her experience in involving people with IBD through social media such as Facebook.

EFCCA had also been approached by the Turkish IBD association, Inflamatuvar Bagırsak Hastaları Dayanısma Yardımlasma Dernegi, as they interested in our activities and keen to explore opportunities for collaboration. Ms Filiz Tetic Dinc attended the General Assembly as observer and presented her association and the current situation as concerns the over 60 000 people living with IBD in Turkey.

Last but not least, EFCCA was very pleased to welcome as external guest, Dr Julián Panés, Elected President of the European Crohn's and Colitis Organisation (ECCO). In his speech Dr Panés stressed the importance and the need for joining forces with EFCCA as both communities share common interests and parts of their core mission such as improving care for people with IBD and raising public awareness around IBD.

EFCCA is pleased that the work it has carried out in recent years to strengthen its role with ECCO is now bearing fruits. This closer cooperation will ensure that the focus lies on the patient and his/her treatment and that the patients´ view is included in various transnational projects that are being implemented.

More detailed information concerning the presentations, reports and elections is available for EFCCA Members on the EFCCA website.

The General Assembly finished with a Gala Dinner where delegates had a chance to relax after an intensive one and half days of work. A huge 25th birthday cake had been prepared and a DJ ensured that delegates worked off their calorie intake afterwards.

New EFCCA Executive Board (from left to right): Martin Kojinkov, Ciara Drohan, Marco Greco, Eva Björnsdottir, Salvo Leone, Natassa Theodosiou, Luisa Avedano (CEO)

New EFCCA Members (from left to right): Isabella Grosu (Romania), Marco Greco (EFCCA Chairman), Alexandra Gliati and George Ziszis (Greece)

Some relaxing moments during the GA

Purple team joins 20km marathon to raise awareness for IBD

On 31 May 2015 over 40 runners from 13 different countries run under the purple colours of World IBD Day at the Brussels 20 km marathon in order to raise awareness about IBD.

What had started as a smaller event in 2014 where EFCCA gathered 15 runners to participate on behalf of the international IBD community at the annual 20km Brussels race, this year saw a much bigger group of runners including physicians, researchers, family members, friends and representatives from the pharmaceutical industries. They all joined together for a common cause: to show their solidarity for people living with IBD, to raise awareness with the public and to have a good time together!

From 9 o-clock onwards runners gathered at the EFCCA booth near the starting point of the race. Amongst laughter and nervous expectations participants put on their purple t-shirts, attached their registrations numbers, made their final preparations and advanced to the starting point.

Volunteers and the EFCCA staff remained at the booth handing out purple ribbons symbolising World IBD Day to passer-bys and informing them about Crohn´s disease and Ulcerative Colitis. The area around the booth was highly visited and we had plenty of people coming by curious to find out more about our work and mission. There were other booths representing various causes and disease groups and interaction was very fruitful.

After over an hour the EFCCA crew moved towards the finish line of the race to cheer our runners and to get the first impressions of the race. We are proud to say that all our runners managed to finish the race and the comments and feedback we got was one of exhilaration of having completed this challenging task and of being able to raise awareness on behalf of all the IBD community.

Our group consisted of a wide range of runners, some of them such as Cristian Garrido from Barcelona , Salvo Leone (EFCCA Vice-president) and Martin Kojinkov (EFCCA treasurer) had already participated at last year´s race and are keen sportsmen throughout the year. Others such as Ciara Drohan (EFCCA secretary) and Isabella Grosu from Romania, had never run a half marathon before and were very pleased and somewhat surprised to have made it all the way. IBD gastroenterologists, IBD researchers and representatives were also pleased to have run the race as part of the EFCCA purple team and thus show their support and to contribute to our cause.

EFCCA would like to thank the runners, the volunteers, the sponsors and all our supporter for making the event such a memorable and successful one. Whilst we know that for some people with IBD it´s very difficult and even unthinkable to participate in a marathon we hope that they find our event inspirational and helpful. We hope to see everyone again next year : online or in Brussels.

You can see more pictures and some of the interviews that were taken after the race on the EFCCA website at: www.efcca.org

Getting ready near the starting line

Some of the runners and supporters outside the ECCA booth

Symposium on Patient Safety

On 30 May 2015 EFCCA organized the Symposium on Patient Safety, which took place in Brussels and gathered for the first time representatives from the medical and patient community as well as representatives from the pharmaceutical industries and other stakeholders in order to discuss the issue of biological medicines and biosimilars.

The Symposium aimed to provide clear and accurate information on the current state of art as concerns biological medicines and the new biosimilars that have recently entered European markets. Professor Maurizio Vecchi, Associate Professor of Gastroenterology from the University of Milan, and Director of Gastroenterology and Gastrointestinal Endoscopy Unit at IRCCS Policlinico San Donato Milan and Professor Matthieu Allez, Head of Service at the Department of Gastroenterology, Saint-Louis Hospital, Paris gave detailed presentations highlighting the latest scientific development of biological medicines and biosimilars.

Other invited speakers such as Pr. Jean Michel Dogné and Pr. Richard Vesely from the European Medicines Agency (EMA) gave the regulators point of view and talked about safety issues around biosimilars.

Ms Hilda Juhasz, policy officer representing the European Commission, DG GROW, talked about the Commission´s work around the issue of biosimilars, and presented the publication "What you Need to Know about Biosimilar Medicinal Products". This publication was prepared in order to provide the different target groups with adequate information on biosimilar medicinal products.

Pr. Richard Vesely, from the European Medicines Agency (EMA), speaking at the Symposium on Patient Safety

From left to right: Professor Matthieu Allez, Professor Maurizio Vecchi

Finally, Sanna Lönnfors, EFCCA medical writer, together with Professor Laurent Peyrin-Biroulet - from the Department of Hepato-Gastroenterology CHU in Nancy, France presented the first preliminary results of the BAB survey which EFCCA launched last year. BAB which stands for Biologics and Biosimilars aims to assess patients knowledge about biosimilars and to find out to what extent patients are aware of the issues involved around biosimilar medicines.

The meeting was moderated by Professor Julian Panes, the ECCO Elected President.

The Symposium is the first public event this year of a wider work programme around patient safety and information sharing. EFCCA is planning further events and targeted training sessions addressed to its members in order to enhance knowledge and skills for people with IBD. For more info contact the EFCCA office.

Workshop on Access to and Uptake of Biosimilars, European Commission, 6 October

It is essential that physicians and patients share a thorough understanding of biological medicines, including biosimilar medicines, and express confidence in using either type of therapy. This can be achieved by maintaining a robust regulatory framework and effective risk management, transparency with regard to biological medicinal products, and continued education on biological medicines, including biosimilar medicines. Additionally, factual information on the state of play of the uptake of biosimilar medicinal products in the EU Member States are of interest for the stakeholders as well not only due to commercial reasons but above all as an instrument to make high-quality biologics available to a wider range of patients.

With a global biosimilar market expected to reach $35 billion by 2020 and a significant number of patents and/or data protection of originator's biologics expiring, biosimilars are considered an expanding market. In the EU, the most advanced market for biosimilars world-wide based on the number of authorised products (19) since 2006, the next wave just started in 2014 with the authorisation of the first biosimilar monoclonal antibody, a complex biological product. Since then, the biosimilar market offers even greater challenges for manufacturers but also greater market opportunities and, even more important, improved benefits for patients.

The European Commission is therefore organizing this workshop as a follow-up to the biosimilars-related activities under the Process on Corporate Responsibility / Access to Medicines in Europe (2010-2013), notably the Working Group on Market Access to and Uptake of Biosimilars. The work on biosimilars (co-ordinated by the then Directorate-General Enterprise and Industry of the European Commission (today DG Internal Market, Industry, Entrepreneurship and SMEs) has attracted wide-spread recognition and its concrete deliverables have been endorsed by a broad range of stakeholders.

The European Commission decided to follow-up these activities by:

- publishing a yearly report on the market penetration and uptake of biosimilars in the EU prepared by IMS Health in close co-operation with the stakeholders
- To organise a multi-stakeholder workshop on biosimilars on a yearly basis.

Objectives of the event:

- To provide a regular opportunity for gathering all relevant interested parties in order to facilitate a multi-stakeholder exchange of information, experiences and reflection on the state of play, explanations for differences in market uptake amongst the EU Member States and possible future trends of the market uptake of biosimilars

- In particular, to give a floor for patients, doctors and payers to express their views on biosimilar related developments at European but also at national level

- To present a regular update about market evolution and clinical experience of biosimilars (in terms of both, volumes and prices)

- To stimulate an open discussion and explore needs for action and in particular with regard to further political activities and initiatives at European level

EFCCA in collaboration with the European Patient Forum has been involved in the co-organisation of this event in order to ensure that the patients views and concerns are becoming an integral part of this stakeholders event.


HUMANCARE

EFCCA Youth Group Annual Meeting, July, Tampere

On July 31, young delegates from 16 national associations travelled to Tampere in Finland for the annual EFCCA Youth Group meeting which was hosted by the Finnish Association - Crohn ja Colitis ry.

Thomas Hough was one of the delegates and talks us through the weekend of learning, networking and fun!

¨ It was a real privilege to represent my national association of Crohn's and Colitis UK along side Leanne Downie who like me has volunteered for the charity for several years.¨

Other countries that attended were Belgium, Czech Republic, Cyprus, Denmark, Finland, France, Germany, Iceland, Ireland, Norway, Poland, Slovakia, Slovenia, Sweden and Switzerland.

To encourage the sharing of ideas each country gave a presentation on what their national association has done in the last year for young members. Discussion workshops also took place with this year's topics being "The transition period from paediatric to adult care" and "What should a national association do to attract young members?"

Presentations

Listening to the presentations it was great to see how much action is already being taken for young people with IBD. The common activity was running national camps or local social events like bowling or

EFCCA Youth Group in action!!!

New EYG board from left to right: Katleen Franc, Thomas Hough, Maksim Besic, Daniel Sundstein, Marine Gros, Fergal Troy, Noah Thayalan, Hanna Nymann, Leanne Downie, Teija Aalto

visiting a restaurant. These events allow members to learn more about their conditions, improve their confidence and gain support through making friends whilst also taking part in fun activities.

To support young members further some countries provide age specific booklets and magazines for their members allowing them to learn in a more accessible and fun way.

Awareness Campaigns

At a national level it was great to see unique and engaging initiatives to raise awareness of IBD and give support. These included: Getting the general public to take a "Toilet Selfie" to reduce the taboo of IBD and raise awareness of the need for toilet access in Cyprus. Czech Republic has a "You can still see the world" photo contest – asking people to send in pictures of them travelling to reduce the worries of others. The "Toilet Selfie" was also used in Denmark to highlight the lack of public toilets and being denied access to private toilets in shops.

Workshop 1 - The transition period from paediatric to adult care

The aim of this workshop was to start the process of drafting an international questionnaire to look at the current experience patients go through when either transitioning from paediatric to adult care or just between hospitals. A common theme was that people wanted to be treated as an individual with a proper structure in place that was set against a Pan-European or national standard. They also didn't want there to be any drop or dramatic change in care due to the process.

Workshop 2 - What should a national association do to attract young members?

This was a fascinating discussion topic especially as lots of national associations are currently struggling in this area. It was really interesting to hear why people volunteered for their national association and what problems they found in recruiting members and running events. We also discussed what could be done to get more people volunteering. Some of the suggestions were to be more flexible in terms of volunteer opportunities, set up projects for young people to take ownership of and projects they are interested in.

Social Ice Breakers

The networking and sharing of ideas didn't all take place in conference rooms though. There was time for more discussions to take place in less formal settings whilst playing Mölkky, swimming and relaxing by the lake or just exploring Tampere in smaller groups. These moments were a great addition to the weekend as they allowed for more open discussions and for delegates to learn more about personal experiences that someone brought up in a workshop or presentation. Chatting one on one also creates a stronger and more collaborative youth group for the year ahead when everyone goes back to their associations to put plans into action.

Elections!

Another major aspect of the weekend is to elect a leader, board members and substitute members who run the European Youth Group in-between the annual meeting and who volunteer to work on Pan-European projects throughout the year.

Once all the nominations were received and votes counted the new EYG was formed.

The new leader is Fergal Troy from Ireland. EYG board members are: Maksim Besic (SLO), Hanna Nymann (SWE), Noah Thayalan (NOR) and Thomas Hough (UK). EYG substitues are: Katleen Franc (BEL), Daniel Sundstein (DEN), Marine Gros (FRA), Teija Aalto (FIN) and Leanne Downie (UK)."

Summary

In summary the whole weekend was a massive success and an incredible experience to be surrounded by so many passionate young people who are making a real difference to the IBD community. All the delegates are really looking forward to the year ahead where we take the ideas and knowledge back to our national associations to help them develop the services they offer young members. The EYG will also go from strength to strength growing an even stronger voice for young suffers in Europe.

Reconciling IBD, work and education

Many people with IBD want to succeed and be successful in what they do. But sometimes managing IBD at work or during education can be quite a challenge! Many questions go through your mind – Do I tell my employer/education provider? Do I tell my peers? Will my treatment hold me back?

During EFCCA Youth Group (EYG) meetings we discussed varies topics as seen in previous EFCCA Magazines and we try to "Break down taboos" which come with daily life and IBD. Will I be less likely to be employed if they know I have IBD? Will they think I can't cope with workloads? Will I be able to me commit to deadlines?

Many people with IBD not only face issues such as having to deal with medication side effects and surgery but when it comes to trying to hold down a job or gain qualifications symptoms like fatigue can impact greatly and knock our confidence.

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.

Thomas Hough, EYG Board member

Teaching and IBD: a difficult but rewarding challenge

Interview with Brian, a 25 year old teacher working in Dublin and originally from Cork. On this photo he just completed a charity colour run.

I was diagnosed towards the end of January 2011 having just begun my final semester of college. After my initial meeting with my consultant I was told that I had IBD; there was still a question mark over whether it was Ulcerative Colitis (UC) or Crohn's but I was informed it was probably UC. Like most people, I had never heard of UC nor did I have any idea what it meant. I was given various leaflets relating to IBD and UC – which I found difficult to get my head around.

I was extremely naïve about the reality that was facing me and being honest I probably didn't research my disease properly.

As the year progressed my condition worsened, I suffered very prolonged flare-ups and was prescribed near constant rounds of steroids. These would bring only a very temporary improvement while I was taking a high dose but my symptoms would worsen as I began to reduce the dose. Beginning my teaching career was a huge distraction and also a huge stressor in my life. I was completing a probationary period and was due to be observed and inspected during this time.

Although my boss was aware of my condition I never openly discussed it with her until I had to ask her if I could take sick leave to be admitted to hospital for IV steroids. I became quite the actor during that first term at work; I had not disclosed any information about my diagnosis or my disease with anyone. It took me a long time to feel comfortable and confident enough to tell people about my condition. It can still be quite challenging, even though my colleagues and friends are aware of my condition many still don't fully understand the day to day symptoms I experience.

> *“I became quite the actor during that first term at work; I had not disclosed any information about my diagnosis or my disease with anyone. It took me a long time to feel comfortable and confident enough to tell people about my condition.”*

Teaching is a very demanding job and there are days when you're already exhausted from simply getting out of bed. Having to find the energy to do your job well is stressful as I feel this intrinsic pressure to ensure that my being sick doesn't interfere with my teaching. This isn't always possible, as I have learnt throughout the course of career so far.

Last Christmas I was admitted to hospital for IV steroids and my consultant informed me that my condition had deteriorated to such a degree that I no longer had an option but to begin taking an immunosuppressant; however it was something I was quite against, particularly given that I work in quite a ‘germ heavy' environment! A little over a week after starting my new medication I experienced a septic episode; which was a rather unpleasant way in which to discover a drug intolerance!

I returned to work after a few weeks and was eager to bury that experience deep in my mind. I completed my inspection and everything seemed to be going well until Easter when I suffered another flare up. Following a consultation with my consultant I was informed that I had several treatment options and I finally managed to find something that worked and experienced only a couple of flare ups which were managed with steroids.

In November 2014 I experienced my worst flare up to date and was told that my condition had deteriorated to such a degree that my condition could no longer be managed medically. I was told that surgery was my best option. I was told that I could not return to work until further notice.

I had already missed a month at the beginning of the school year due to complications following a procedure to remove a kidney stone in late August. After seeking a second opinion and beginning new medical treatment I eventually returned to work shortly after Christmas. I had missed over 2 months of work and I felt a strong sense of guilt as if I was letting the children in my class down. It was challenging returning to work as I was still recovering from my flare up and I was still experiencing some symptoms.

Fatigue is a huge challenge in my line of work. Working with children can be very tiring but when you are already exhausted it can be even more challenging. I strive to ensure that I do my job to the very best of my ability but unfortunately this can often take a huge toll on my energy levels. It can be hard to find the energy to keep going after you finish teaching.

When you are teaching you cannot simply leave a class to go to the bathroom so that can be a constant worry when you are experiencing a flare up. I have been forced to hide my symptoms while I am working. Children are not a very patient audience and, through no fault of their own, they simply cannot understand why you are unable to move around the room or why you are using a stress ball to help you manage the very painful cramps you're experiencing. Children are wonderful and can make a really bad day seem a little big brighter but they are also a source of germs and infection. Unfortunately I am very susceptible to picking up infection; most recently I contracted a bad case of gastroenteritis which resulted in hospitalisation. Teaching is an extremely rewarding career but it is certainly a very challenging job when your body isn't always on your side!

Struggling through university with Crohn´s disease

Interview with Sarah Birch, 23 years old, who successfully completed her university degree in history and is now working in Human Resource management in Stafford (UK).

I was diagnosed with Crohn's disease in September 2013, although I had experienced mild symptoms for many years beforehand. It was upsetting but also a huge relief to know that there was a physical cause to symptoms that, although it currently cannot be cured, can be controlled. I was optimistic that as soon as I was on the right medication I would feel much better. However, it did take time for me to accept that this is a life-long condition. I felt very apprehensive about what course my illness could take. Having a family member with Crohn's, I was more than aware that the illness can make you very poorly to the point major surgery is the one of the only options to try and improve symptoms.

My symptoms got worse in February 2014. I was in my final year of university and I was feeling the stress due to dissertation projects and looming final exams. I struggled and often didn't really want to eat due to the pain. I completely stopped going out with friends as I was constantly tired and I lost weight. I also started to miss lectures, although I would often force myself to go as I was so concerned about the effect it might have on my final exams.

My final exams came around and at 3 hours long each, they were a struggle and although I tried my best, I sometimes wonder if I could have done better if I had not been ill, mainly due to the hours I spent worrying if I'd even be okay to sit the exam.

> *"..having an illness like Crohn's disease has made me far more determined to succeed and not let it rule my life, as it can so easily do."*

I was lucky as the work did pay off and I graduated with a 2:1 in History. I also feel lucky in that my symptoms came to a head towards the end of my time at University. If I had experienced this in my first or second year, I think it would have affected my ability to complete my degree much more and also my experience at University as a whole.

I was officially diagnosed as I was searching for a new job as a graduate. On the whole, I would say my diagnosis has not affected my life in the workplace greatly. I have been fortunate in that I have largely been in remission since I have been working. In fact, the diagnosis made me even more determined to be successful.

The medication I was put on made me feel very ill but as I was in training for a new job I would make myself go to work. I knew it would wear off and I would feel better as the day progressed. I changed my medication a week before I started a new job which made me apprehensive, but I have now been successfully for a year and a half.

I have now been working in Human Resources since February 2014 and I really enjoy it. I told my Manager about my Crohn's shortly after I joined, and she was great about it, telling me to take any time off that I needed. The role itself is very flexible and if needed I can work from home so it's great for attending the many medical appointments.

It makes such a difference to have an understanding employer. With the full support of my employer, I completed my Certificate in HR Practice in May of this year and will be starting my Postgraduate Diploma in Human Resource Management in September. As I mentioned previously, having an illness like Crohn's disease has made me far more determined to succeed and not let it rule my life, as it can so easily do. I also feel very fortunate to have experienced generally good health, with the help of my medication, for at least a year and a half now, which has enabled me to be successful in my current role and progress my career further.

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.

Shire

To be as brave as the people we help.

INTSP/IN/MEZ/14/0035   Date Of Preparation: April 2014

Cyprus

Special Training of Nurses for IBD

With the initiative of the Cyprus Crohn's & Colitis Association (CYCCA) and after a discussion with the Cyprus Society of Gastroenterology, an effort started in the spring of this year with the objective to organise in 2015 a specialised training course for nurses - engaged or willing to engage into the care of patients with IBD.

The idea was communicated to the European Federation of Crohn's and Colitis Associations (EFCCA) and the European Crohn's and Colitis Organisation (ECCO) who were eager to participate in the project with the intention of making the Cyprus experience a model for similar training programmes for nurses across Europe. After a few months of contacts and discussions with all stakeholders, a preliminary agreement on the outline of the project has been reached, which comprises of the following:

- The Education Sector of the Nursing Services of the Cyprus Ministry of Health will undertake the responsibility of the whole organisation of the course and the participants will be selected among the nurses employed by government hospitals across Cyprus.

- The University of Nicosia (UNIC), which has a specialised department in nursing studies, will undertake, at no charge, the implementation (in cooperation with the Ministry of Health) of the

At our recent meeting about the IBD Nurse project (from left to right): Andreas Xenofontos, Director of Nursing Services, Ministry of Health, Georgios Efstathiou, Nursing Officer, Coordinator of the Education Sector of the Nursing Services, Ministry of Health, Cyprus, Savoula Ghobrial, Leader of the BSc Nursing Programme, University of Nicosia, Cyprus, Dr Nicos Peristianis, President of the Council, University of Nicosia, Yiangos Yiangou, President of the Cyprus Crohn's and Colitis Association of Cyprus.

programme, which will be mutually agreed.

- EFCCA and ECCO, with their valuable experience, will contribute to the preparation of the course material and the provision of doctors/instructors and experienced nurses from Europe who will teach parts of the programme, while the rest of the instructors will be sourced from the Cyprus Gastroenterological Company, Hospital Staff and University Professors.

- Sponsors will be required in order to cover the necessary expenses of this first programme.

- Among the things that will be further discussed and decided, is the possibility of running part of the programme to a large degree online, in order to avoid inconvenience of the participants in Cyprus and to reduce the travelling expenses relating to vising instructors from Europe. The UNIC is willing to cover this aspect which, in fact, was their own suggestion. This idea would also facilitate the future participation of European nurses in such programmes.

All the above form a framework that will make the whole programme feasible. What remains to be done is the detailed discussion on practical issues and the setting of a starting date. The language of instruction will be Greek but the selected candidates will have a good knowledge of English so that they can follow lectures by guest speakers from Europe and to be able to read through possible written material that will be handed to them.

The successful implementation of the programme will constitute an important step in the direction of offering better and specialised care to patients with IBD in Cyprus and across Europe.

UK

£430,000 awarded to universities investigating IBD

Crohn's and Colitis UK has backed innovative medical research into treatments for inflammatory bowel disease (IBD) by granting almost half a million pounds to UK universities. The charity's Medical Research Awards for 2015 has granted £430,000 in funding to six projects that will investigate possible causes of Crohn's Disease and Ulcerative Colitis (UC). The university-runprojects aim to develop new treatments, including cell therapy and a protective probiotic to control inflammation.

Helen Terry, the director of policy, research and public affairs at Crohn's and Colitis UK, said: "The cause for Crohn's and colitis is unknown, so these investments into research are critical if we want to improve lives now and ultimately find a cure.

"We are delighted we have been able to fund so many innovative projects we hope will prove groundbreaking in learning more about possible causes, and finding new treatments for over 300,000 people in the UK who have IBD."

Crohn's and Colitis UK has been at the forefront of research on IBD for more than 30 years. Its 2015 awards were made in partnership with the charity forCrohn's, which fully funded two of the projects with £70,615 and a donation from the Rick Parfitt Junior Foundation.

THE WINNING RESEARCH PROJECTS

THE ROLE OF BACTERIA IN IBD. A team at the University of East Anglia has been awarded

£119,018. Led by Dr Lindsay Hall, it aims to develop a protective probiotic to help control inflammation. Dr Hall said: "At the end of this project we shall be in a position to generate a 'super-protective' strain of bifidobacteria and prepare it for test in patients with IBD." This project was founded by a donation from the Rick Parfitt Junior Foundation.

CLASSIFYING IBD-RELATED BOWEL CANCER: The University of Oxford will be granted £115,500 to find a new way of classifying bowel cancer. The project should help doctors choose the best treatment for IBD patients with bowel cancer. Project leader Dr Leedham said: "Too little is known about the molecular pathways driving cancer formation in IBD."

EXPLORING A SPECIAL TYPE OF WHITE BLOOD CELL: King's College London has been awarded £114,689 to explore white blood cells called Tregs. The aim is to create a new form of cell therapy treatment for IBD. Dr Nick Powell of King's College said: "Cell therapy is an exciting and novel therapy for inflammatory bowel diseases."

ANALYSING THE LINK BETWEEN BACTERIA AND FUNGI IN THE GUT: A team at the University of Liverpool has been awarded £60,615 to discover whether fungi play a role in causing IBD. Possible new treatments could suppress the fungi. Professor Chris Probert, who is leading the project at the university, explained: "The results of this programme of work will be a greater understanding of the role of fungi in the cause of Crohn's disease." The project is funded by forCrohn's.

HOW THE GUT HANDLES BACTERIA : The University of Oxford has been granted £10,000 to investigate whether an abnormal way of tackling bacteria causes Crohn's. Dr Holm Uhlig said:"The aim is to develop therapies for IBD patients that do not necessarily function as immunosuppressives, but target bacteria-handling defects." The project is funded by forCrohn's.

INVESTIGATING GENE RPS6KA2: The University of Edinburgh has been awarded £9,926 to research the role of the gene RPS6KA2 in the causes of IBD. "Identification of the genes involved should allow us to design new therapeutic targets to better control IBD," said research fellow Dr Elaine Nimmo.

Dr Elaine Nimmo is investigating the gene RPS6KA2

Switzerland

General Assembly in royal surroundings

On 9 May 2015, the 29th General Assembly of SMCCV was held in Brig and gathered over 60 SMCCV members.

Participants were welcomed with coffee and croissants in the stunning courtyard of the Stockalper castle. The meeting was held in the elegant Knight´s hall with views to the beautiful castle garden and the slightly snowy mountains.

After Bruno Raffa, SMCCV president, opened the Assembly with the SMCCV bell, Esther Waeber-Kalbermatten, Councillor for the Department of Health, Social Affairs and Culture, addressed a few words to the Assembly, expressing her joy that the event took place in sunny Valais. She also showed her support for people with IBD and thanked the SMCCV for their important work.

The mandatory items on the GA´s agenda as well as the amendments to the statutes were dealt with fairly quickly. Furthermore, the Board thanked the outgoing board member Bernhard Laim for a job well done. Unfortunately Bernard was unable to attend the meeting in person as he had other commitments on that date. A new member, Yasemin Töremis, aged 24, was elected to the board.

At the end of the meeting Rudolf Breitenberger, President of the Austrian Association (ÖMCCV), shared his cordial greetings from the neighbouring country, praised the good relationship between the two associations and gave a gift to the Siwss board: a transparent "medicine" bottle.

It was a successful meeting and was followed by a joint lunch in the castle restaurant and lively discussions took place thanks to the large round tables.

Traditionally, we also always organise a cultural part after our GA . Eleven of our members took the small Dotto train through Brig and then on to Naters, where they visited the Swiss Guards Museum . The tour of the museum and the story of its former, proud Guardsmen Martin Karlen, was extremely exciting, instructive and amusing. The tour guide´s fascination with the Swiss Guard infected also our participants and they would have listen to even more information even though it was only 15 C degrees inside the fortress.

Our other members opted for a guided tour of the Stockalper castle. Arthur Huber, the Castle Keeper, led one of the two groups. The castle served as a residence for Kaspar Stockalper von Thurm. Mr Huber told the life story of the Stockalpers in such a lively and exciting way that one might have thought he had been there himself. He also led the participants through the old walls and showed them the beautiful gardens.

After the day had begun a little chilly, members were able to commence their backward journey in bright sunshine . The Board would like to take this opportunity to thank sincerely the two organizers Stephanie Johann and Andrea Zbären for this successful event.

Original text Caroline Mülhaupt, SMCCV

Poland

The 10th Anniversary of J-elita

It has been ten years since the foundation of "J-elita", the Polish Association Supporting People with Inflammatory Bowel Disease. In May 2005, a group of people united by a common problem, determined to help others like them, decided to start a patient association supporting people with IBD.

During its first meeting a Board, consisting of 7 members, was appointed and a statute approved. In July 2005 "J-elita" was officially registered and received its ID numbers.

The idiom "time flies" is a truism for everyone, but for "J-elita" time really does fly. During the first year of its existence, the association set up a website and developed a forum. Volunteers were giving consultations to patients via internet and telephone. "J-elita" began to be present in the public media. What's more, initial cooperation with other IBD patients organizations began, as well as with healthcare providers and doctors. That same year, the first rehabilitation camp for IBD patients took place. The participants consisted of 9 families, and camp activities included meetings with doctors and a psychologist.

In 2006, the first companion for IBD patients was published. In 2007, "J-elita" received a Public Benefit Organization status and the first issue of the "J-elita"

Members and supporters of J-elita during World IBD Day celebrations, photographer: Luke Kalata

Quarterly Magazine was released. In 2011, "J-elita" joined EFCCA and became international! Every year the number of its members grows rapidly.

On 22-24 May 2015, in Popowo near Warsaw, a meeting celebrating the 10th Anniversary of "J-elita" took place. During this time, over 100 people reminisced about all that had been done. The difficulties at the beginning, the immeasurable efforts, made by hundreds of volunteers so "J-elita" could be what it is today. We are the biggest IBD association in Poland. We have 12 regional branches, over 1400 members. We have published 8 companions for IBD patients and 29 issues of the "J-elita" Quarterly Magazine. Every year, we organize two rehabilitation camps (one for kids and one for adults) with a total number of almost 200 participants, educational congresses for IBD patients attended by over 1000 people, happenings, and meetings with doctors and psychologists. We also run the project "Together we can do more!", which helps people, facing financial difficulties, buy medication, as well as organize contests for the best BA/MA/PhD thesis in the field of IBD. We give donations to hospitals, attend Polish and international congresses, write letters concerning IBD issues to the Ministry of Health and other political institutions, and so on and so forth…

The enormous effort of hundreds of people allowed "J-elita" to be, where we are today. But every child's smiling face and every patient, who's not alone in dealing with their disease reassures us, that we're on a good path, and that we're do something extremely important. United we stand in our fight against IBD!

Magdalena Sajak

Spain

Training programme for IBD patient

ACCU España has signed an agreement with Stanford University (California, USA) relating to a training module inside the University´s "Chronic Disease Self-Management Programme".

This programme will be initiated in September with a special focus on patients. It is an online open programme that will be available to all IBD patients.

The programme is focused on the following subjects: 1) techniques to deal with problems such as frustration, fatigue, pain and isolation 2) self monitoring 3) appropriate use of medications 4) appropriate exercise for maintaining and improving strength, flexibility, and endurance 5) communicating effectively with family, friends, and health professionals 6) nutrition 7) decision making, and 8) how to evaluate new treatments.

What do we expect from this course? We expect that this course will improve the quality of life of IBD patients.

STANFORD
PATIENT EDUCATION
RESEARCH CENTER

Several studies have shown that people who took the programme, comparing to those who did not take it, demonstrated significant improvements in exercise, cognitive symptom management, communication with physicians, self-reported general health, health distress, fatigue, disability, and social/role activities limitations. They also spent fewer days in hospital and outpatients visits. Many of these results have been observed for more than three years.

ACCU ESPAÑA is very proud to be part of this activity and to have the opportunity to increase the quality of information to be disseminated.

New website

Homepage of our new website

ACCU España has just released a new website, actually a beta version, to project a modern brand image.

What we are trying to achieve is to help patients to find information faster than they have done so far. One of the objectives is to better organise content and to make it more user friendly. Visitors will also be able to quickly find their ¨local association¨ in order to identify services and available activities closest to them. Finally, we also hope that the new look will provide sufficient support and information to the patient without having to contact the office.

The main changes are as follow: A new logo. The official ¨World IBD¨ colour has been used. New content and sections. Filters to search by services, activities, regions and dates. A new space for interaction between patients, professionals and volunteers.

Elections

ACCU España celebrated its Annual National Assembly in Mérida (Badajoz) during last April. Under the bylaws, the board needed to be re-elected this year for the 2015-19 period. The General Assembly enabled Ildefonso Perez to stand for his third mandate and he was elected as a president for our association. For any inquiry concerning our association you can still contact him at: presidente@accuesp.com

Participants at the General Assembly

As part of his new team the following patients joined to the new Executive Board Members:

Consuelo Salcedo, Patricia García, Francisca Cano, and Fernando Jimenez.

Alejandro Khalil Samhan Arias, ACCU España

Norway

What you need to know about biosimilars

Not much has happened in LMF, the Norwegian patient organization during the summer, but board member Marc Dudley has spent some of the summer translating and making a short summary of the ECC document «What you need to know about biosimilars».

"By making it into a more patient friendly document, patients will find it easier to discuss this with their doctors when or if the subject comes up, which is very important," says Marc Dudley.

In Norway many hospitals have decided to switch most or all of their patients from the biological product Remicade to the biosimilar product Remsima. Both LMF and patients around the country are worried about the risks in doing so, as there has been various stories in social media about people having worse side effects after changing their medical treatment product. There is an on-going study in Norway about changing from Remicade to Remsima and the results of the study are set to be published in 2016. However, with some patients being told they have to change to Remsima even if they don't want to LMF are worried about the long term risks and implications this may have.

"We have heard stories of people being forced to change and even being told that the products are identical, with no risk whatsoever. It is important for us that doctors give the right information to patients, which is why I made this document so that all our members/patients know about the products before speaking to their doctor," says Marc Dudley.

LMF have also released two short films, one about living with Crohn's Disease and one about living with ulcerative colitis. With AbbVie and the local hospital in Stavanger, LMF have developed two short films about what it is like to live with the illness. Both films are available on YouTube and will most likely be released in English as well sometime next year.

"We have received a lot of positive feedback from patients, as it explains what a patient with IBD has to deal with on a daily basis,"

Marc Dudley, LMF

Marc Dudley is a British citizen and lives in Norway. He´s member of the Norwegian IBD patient association LMF.

Czech Republic

Czech IBD Patients‘ Association 2015 – World IBD Day

Counting 780 members, the Czech IBD Patients‘ Association is continuing to grow rapidly. It is a nonprofit, volunteer driven organization dedicated to help patients to cope with their disease by supporting them with information and advice, initiating and funding research and acting as their political spokes organization.

On 6th May 2015 we organized a press conference for the media informing them about upcoming World Day IBD 2015, about our general work of the association and our projects: WC compass and WC card. We then started our "Information and Invitation" campaign for World Day with the regional media (radio, newspapers) and on Facebook. The aim of the campaign was to invite the public on 29. 5. 2015 to IBD centers in different regions of the Czech Republic. We wanted to focus on awareness raising and encouraging timely visits to the doctor in order to promote early detection and diagnosis of Crohn's disease and ulcerative colitis. Our main target group was young people, who are increasingly frequent patients.

So on 29th May 2015 the members and the supporters of the Czech IBD Patients Association organized World IBD Day 2015 in collaboration with IBD centers in Prague, Brno, Ostrava, Hradec Kralove and Pilsen. On that day anyone could consult a doctor and was provided with information and promotional materials. In selected cities, there were events organized jointly by the local IBD centers, volunteer associations, and patients. We had many well-attended and successful events.

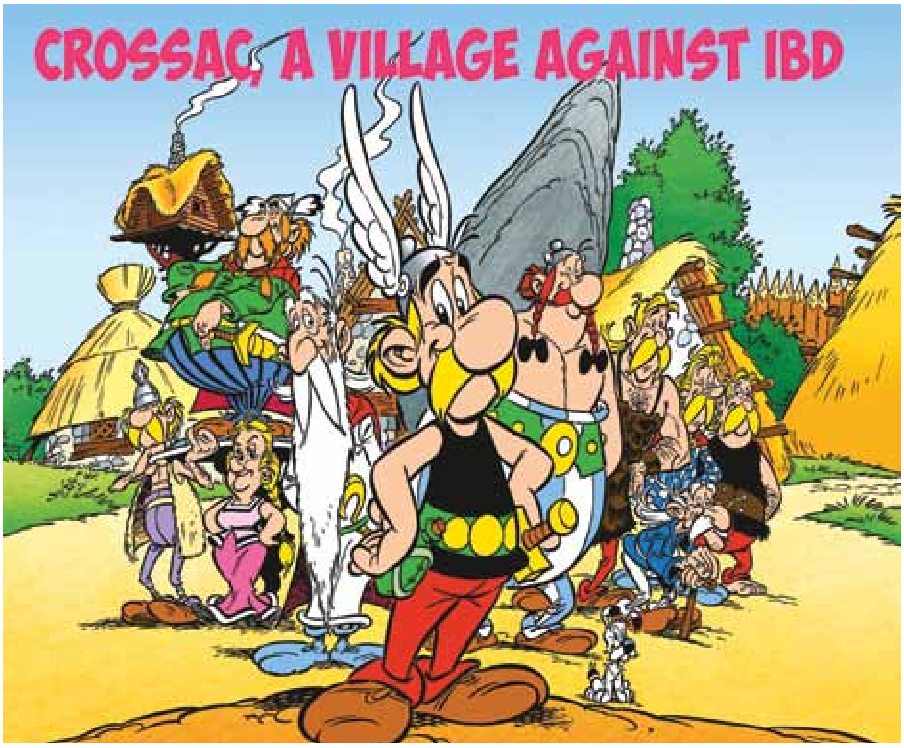
Throughout the year we cooperate with other patients‘ associations such as the Stoma Patients‘ Club, association of Psychosomatics and other stakeholders in the field of healthcare. Furthermore we collaborated with several organizations with regard to the elaboration of new legislation, namely the Czech National Disability Council, Association of Public Benefit Organizations and Czech Coalition for Health. And of course our collaboration with the Czech IBD Working Group of Doctors is very important.

Martina Pfeiferova, Czech IBD Patients' Association

France

Crossac, a village against IBD

A small village near Nantes, like the one in the comic books of Asterix and the Gauls, has been resisting, not against the Romans, but against IBD!



For the last 11 years, more than € 200 000 have been donated to afa for medical research thanks to this extraordinary group of people who, every year, make a point of organizing in September a sporting event and a get together nobody should miss!

This adventure began with an unusual encounter between Jean Cyril Robin and two adorable little girls with Crohn's disease, who had parenteral nutrition in their knapsacks.

This professional cycler decided to create a cycling race to raise money for afa to fight against IBD, allowing Claire, Gaëlle and so many other children to hope for recovery.

The energy deployed in this tiny village is striking: what is the magic potion?

Most likely their generosity, their solidarity and the impulse of personalities like Jean Pierre Eon (Crossac Cycling Club), Pierre Nivard (Crossac Animation) and Laurence Ouvrard, afa delegate...but most of all from the 600 volunteers who have given so much of their time to make this festival the great success that it is with their enthusiasm, their warmth and their creativity...a real unforgettable day!

Chantal Dufresne, (translation: Madeleine Dubois), afa

Finding Love

written by Jessica for the Uncover Ostomy blog. Uncover Ostomy is an awareness campaign sparking a positive conversation about the ostomy. We share positive stories and thought provoking images—dare we say sexy?—to spark this conversation. See more at http://uncoverostomy.org/

Like any young girl with a library of Disney Princess movies, I often dreamed of finding my Prince – someone who would come into my life and sweep me off my feet and we'd ride off into the sunset and live happily ever after.

What? I was like 7.

No matter my age, as I grew from a young girl to a middle-schooler, to a high-schooler, it felt like my dream was drifting away.

It was in middle-school where the girls began to find their "boyfriends" among the boys in our grade. Everywhere, these kids were "coupling" up, and I remained awkwardly on the sidelines. It didn't help that my Crohn's Disease flare left me alone in the hospital, but on my return, I wasn't even considered to be anyone's "crush." I was awkward and overweight, and had been gone almost 2 years. Yes, it was just middle-school, but it still hurt.

High-school was where I hoped things would turn around. I was in a new school with new people and had a fresh start. Unfortunately, the weight I had put on from my inability to move from my hospital bed, as well as the moonface I had from steroids, didn't exactly make me look like the prettiest flower in the bouquet. Instead, I became a target for ridicule by the popular boys in school, and was quickly placed in the "friend zone" by all my male friends, whom decided to date all the other girls in my friend group – I was deemed the third-wheel (well, more like 7th wheel). Fun fact: I was also the girl that brought a guy friend to prom, who did not hesitate to abandon her immediately to go hang out with another group of friends.

University was where things actually turned around. I was no longer that awkward, overweight teenager, and had finally grown into my own. It even turned out that I was "datable"!

It was weird, but for me, I was actually more concerned that guys wouldn't want to date me because of who I was, based on my history, and not because I had an ostomy. My parents, however, had originally worried the exact opposite. It turned out that they had also been concerned with my future love life since the day I had ostomy surgery – wait - before I had ostomy surgery. Apparently, my parents had insisted that I would have an ostomy over their dead bodies because they didn't think that a girl with an ostomy would be able to find her happily-ever-after. It was quickly after surgery that my parents realized that I'd be able to live just fine, but they still questioned whether or not I'd be able to have a normal relationship.

Jessica was born in Toronto, Ontario, Canada on September 3rd, 1989. At 9 years old, after visiting multiple doctors and going through countless torturous tests, she was diagnosed with Crohn's disease. When Jessica was 13 years old, she was given a choice: have ostomy surgery or die. The choice, to her, was obvious. Since surgery, Jessica has received her B.A (hons) from the University of Western Ontario and her M.A from New York University and specializes in digital media, community management, and marketing and acts on the side.

Well, one day, I quickly set them straight when I told them I had already moved on from the boyfriend who had broken up with me the night before. They never questioned it again.

I had moved passed my "undatable" phase into a world where there were plenty of guys to choose from (university is a wonderful place). Though, I knew that having an ostomy wasn't going to get in the way of dating, I had hoped that it would have some impact in the guys who wanted to date me. I mean, an asshole wouldn't want to date a girl with a bag, right? Of course not.

Sadly, I was wrong.

I went from being "undatable" to being the girl who had no idea how to pick the guy that was right for her. I dated a fair number of assholes, because I have no idea why. I also went through 2 long and arduous relationships that I was sure were "the one", that really, I should have never been in, in the first place. Both relationships were stressful and borderline abusive, and by the end of the last one, I was certain I was done dating.

I mean, having a bunch of cats as children can be great too, right?

I was ready to accept my fate.

Until one day, on a trip to Jamaica for a good friend's wedding, I spotted Jake Gyllenhaal in Toronto Pearson Airport.

Ok, it wasn't Jake Gyllenhaal, but it was Matt, a guy that looked a lot like him.

We ended up on the same plane, the same resort, and it turned out, he lived in the same city that I had gone to school in, only 2 hours away. We spent the entire week of our Jamaica trip hanging out, getting to know one another, and had a great time. He was a great guy – sweet, funny, awkward, and smart. Oh, and you know, looks like Jake Gyllenhaal. Everything I've ever wanted in a guy.

However, being the rational individual that I am (I was by this point!), I decided that I didn't want to do anything long distance. I didn't have a car, and 2 hours can be really far without one. We hung a few times after the vacation, until I told him that it wasn't going to work. I was still ready to accept my fate of being a cat mother, but he had been a nice distraction.

Fortunately, this guy refused to let me adopt a litter of fury felines. He said that it wasn't far and that he had a car to drive to me. Despite my stubborn refusal to maintain a long-distance relationship, he promised he would do a lot of the traveling, and he pretty much did. I somehow found myself a few cars and some train tickets to him, and he even let me crash at his place for weeks on end. After a number of months of traveling back and forth, Matt decided to just move to Toronto to be with me (and better jobs, he says as I write this beside him…ha!)

In the two and a half years that we've been together, I have never been happier.

He not only makes me feel like a princess, but he appreciates my smarts, my drive, my determination, and knows how to handle my stubbornness. We both have the same values and enjoy the same things. We also dislike the same things, and find comfort in disliking them together. Even though he says I'm not as funny as I think I am, he laughs at my jokes, and I think he can be pretty funny too. He lets me be the centre of attention and enjoys sitting and listening to me while I talk about nothing. He knows how to calm me down when I'm upset, and he knows how to make me smile like no other.

Finding love can be hard. It's been hard for me my entire life.

But, somehow, when I wasn't even looking for it, I found it. Even when I tried to get rid of it, I couldn't.

On my 26th birthday, Matt asked me to marry him and I said yes.

I found love, and I'm never letting it go.

—————-

PS – I will of course be posting lots of things wedding related in the coming months, so follow along with: #jessandmattrimony !!

- See more at: http://uncoverostomy.org/blog/#sthash.lYnaBvDH.dpuf

UN examined how EU supports the rights of persons with disabilities

In August, the European Disability Forum (EDF) and its members were in Geneva and took part in the examination of the EU by the UN Expert Committee on the Rights of Persons with Disabilities.

On 27-28 August, the UN Committee held a Constructive Dialogue with the EU delegation on the EU's work on the UN Convention on the Rights of Persons with Disabilities (UN CRPD), the first international human rights treaty ever ratified by the EU. On Thursday 3 September the UN Committee will adopt its recommendations for the EU and set the EU agenda for the next years for the human rights of 80 million persons with disabilities in Europe.

EDF was present with many of its European members in Geneva. The EDF delegation consisted of Autism Europe, Inclusion Europe, European Network of (Ex-)Users and Survivors of Psychiatry, Mental Health Europe, European Network on Independent Living, CBM/IDDC, European Federation of Hard of Hearing People, International Federation for Spina Bifida and Hydrocephalus and the European Union of the Deaf.

EDF and members held a side event on 27 August before the start of the EU Constructive Dialogue. EDF and its members presented the priorities on the implementation of the CRPD in Europe and answered to the many questions of the UN Committee members.

The constructive dialogue started on Thursday 27 August in the afternoon and continued on Friday morning on 28 August. The EU delegation consisted of Michel Servoz, Director-General of the Commission's DG Employment, Social Affairs and Inclusion, and his colleagues of the UN CRPD focal point of the European Commission, the Disability Unit of DG Employment, Social Affairs and Inclusion. 20 representatives out of the 28 Member States of the EU were also present as observers.

WHAT DID THE UN ASK THE EU?

Many UN Committee members questioned the EU delegation on its composition and on the absence of representatives of the other EU institutions, in particular DG Justice, the European Parliament and the Council of the EU. During the dialogue, the Committee posed deep questions on EDF and members' priority issues such as the revision and transformation of the European Disability Strategy into a comprehensive strategy to implement the CRPD across all EU institutions and Member states, the need for a structured dialogue with DPOs in EU decision making, and the need for a CRPD compliant focal point and EU monitoring framework, and the absence of an EU inter-institutional coordination mechanism to implement the CRPD.

The Committee also had many questions and comments on the use of the EU funds, the absence of comprehensive equal treatment legislation and the European Accessibility Act. EDF members brought in the perspective of persons with intellectual and psychosocial disabilities, hard of hearing and deaf persons and expertise on health, international cooperation, and independent living, amongst others.

Visit EDF's website (www.edf-feph.org) and find more information about the constructive dialogue in Geneva!

European Patient Forum - Patient Empowerment Campaign

EPF officially launched a major one-year campaign on Patient Empowerment on 20-21 May 2015. We will work in concert with the health community to promote understanding of what patient empowerment means from the patient perspective among political decision-makers and health stakeholders. As part of the campaign deliverables, we will release a Charter of Patient Empowerment and a multi-stakeholder Roadmap for Action in November 2015.

"Patients with chronic conditions are often referred to as the most under-used resource in the health system while patient-centred care models have demonstrated better quality of care as well as potential long-term cost-efficiencies. Too many patients are still struggling to get the support they need to become equal partners in care. To make real progress, we need to make patient empowerment a priority, starting with the development of an EU-wide strategy and action plan" EPF President, Anders Olauson

What is Patient Empowerment?

Patient empowerment is a process that helps people gain control over their own lives and increases their capacity to act on issues that they themselves define as important."

Aspects of empowerment include:

- self-efficacy
- self-awareness
- confidence
- coping skills
- health literacy

Why a campaign on Patient Empowerment?

"Patients prescribe E5 for sustainable health systems" is the tagline of the EPF campaign to demonstrate that patients are active people who can, if supported and according to their individual capabilities and situation, make a difference for the sustainability of healthcare systems.

The five "E" of Empowerment stand for:

- **Education:** patients can make informed decisions about their health if they are able to access all the relevant information, in an easily understandable format.

- **Expertise:** patients self-manage their condition every day so they have a unique expertise on healthcare which needs to be supported.

- **Equality:** patients need support to become equal partners with health professionals in the management of their condition.

- **Experience:** individual patients work with patient organisations to represent them, and channel their experience and collective voice.

- **Engagement:** patients need to be involved in designing more effective healthcare for all, and in research to deliver new and better treatments and services

For more information please visit the EPF website: http://www.eu-patient.eu/

Crohn´s and Colitis Australia - Great Wall of China Challenge 2016

Walk a mile (and then some) in our shoes
Living with Crohn's and colitis can feel like an uphill battle sometimes, so why not go all the way and make it a trek?

CCA is currently seeking adventurous IBD patients or supporters keen to push their limits and take on the challenge of a lifetime – trekking the Great Wall of China.

The 11-day adventure in October 2016 will take you into the very heart of China's ancient culture. After a few days in Beijing, you will trek between mist-covered mountains, into local villages, across rolling farmlands and through dense forest.

The Great Wall trek, in collaboration with Inspired Adventures, will be CCA's biggest fundraiser, with a fundraising goal of $50,000. We are aiming to bring together a challenge team of 10-20 eager CCA supporters to fundraise as much as they can for what is sure to be an adventure like no other.

As well as exploring the way tradition and modernity meet in China's capital city of Beijing, you will discover the ancient history of the Forbidden City, learn about the history of the Great Wall, and know you have helped CCA with its crucial work for the IBD community.

Every dollar fundraised by participants in the Great Wall challenge will go towards the continual work of CCA, providing research grants, raising awareness, and offering support to the IBD community through support groups, information forums, youth programs and more. CCA does not receive regular government support, and relies on grants and donations from those who understand the impact that IBD can have on a person's quality of life.

Who can join?

Anyone who thinks they are up to the challenge! While no trekking experience is required before you register, this adventure trek is specifically designed for people who are relatively fit and willing to train. Trekking the Great Wall is a physical challenge, and the fitter you are, the more you'll enjoy the experience.

In the months leading up to your trip, it is recommended you increase your physical fitness with aerobic exercise – walking, running, cycling, and stair climbing will all strengthen your legs and improve stamina.

Participants must be at least 18 years old, but CCA would love to have a variety of participants, from the young to the not-so-young. You don't need to have IBD to join the challenge either. It can be the perfect corporate fundraising challenge or a personal goal for someone who has a family member with IBD.

How do I meet the fundraising target?

Just like with any fundraiser, you can raise the target of $4000 in hundreds of different ways. Once you register, you will receive a detailed registration pack filled to the brim with great fundraising ideas, and a member of the Inspired Adventures team will be available to help you come up with great ways of hitting that target.

With the right commitment and a good fundraising plan, you will have plenty of time before the challenge in October to reach your goal.

If you would like to join us for the CCA Great Wall of China Challenge, you can get in touch with Lauren at the CCA Head Office on 03 9815 1266, or head to http://inspiredadventures.com.au/events/great-wall-china-for-crohns-colitis-australia/ to register your interest. We look forward to you joining us for the adventure of a lifetime!

European
Commission

EUROPEAN PATIENTS' RIGHTS DAY:

10 benefits the EU brings to patients

A high level of health protection; the right to benefit from medical treatment; access to healthcare - preventive, diagnostic and curative treatment regardless of financial means, gender or nationality. These principles are enshrined in the European Union's Treaty and its Charter of Fundamental Rights and the EU institutions are bound to them in their actions. On European Patients' Rights Day, let's take a look at some of the benefits of being a patient in the European Union. As an EU citizen, you can expect:

1 TO RECEIVE HEALTHCARE WHEN VISITING ANOTHER EU COUNTRY

If you fall ill unexpectedly during a trip to another EU country and need to visit a doctor, there's no need to cut short your visit to return home for treatment. Take your European Health Insurance Card with you to a local doctor.

2 TO BE REIMBURSED FOR HEALTHCARE SOUGHT IN ANOTHER EU COUNTRY

Should you decide to receive medical treatment in other EU country you can be reimbursed for it at home, under certain circumstances, and normally up to the amount you would be reimbursed in your home country for the same treatment. In some cases, your home country may require you to seek prior authorisation before travelling for treatment.

3 TO RECEIVE INFORMATION ON SAFETY AND QUALITY STANDARDS IN EU COUNTRIES

A national contact point in each Member State shall provide information to patients on their rights to healthcare across Europe. Access to information on the quality and safety of care will allow you to make informed decisions.
These contact points can also provide information on the European Reference Networks where you can receive highly specialised healthcare in the case of complex, low prevalence or rare conditions.

4 TO BE TREATED BY QUALIFIED HEALTHCARE PROFESSIONALS

Patients have the guarantee that whether receiving medical care in their home country or another EU country, they will be treated by healthcare professionals – be they doctors, dentists, nurses, midwives or pharmacists, who have met EU-wide minimum requirements. Patients will, upon request, receive information from their national contact point about a healthcare provider's right to practice.

5 TO GET A COPY OF YOUR MEDICAL RECORDS

When you are treated, your healthcare provider must make a medical record of the treatment provided. As a patient you have the right to a copy of this medical record in order to secure continuity of care and be treated by a doctor of your choice, also if you continue treatment in another Member State.

6 TO HAVE YOUR PRESCRIPTION RECOGNISED IN ALL EU COUNTRIES

The Commission has set rules on mutual recognition of prescriptions between Member States and on a minimum list of elements to be included in a cross border medical prescription.

As a patient, when travelling to another EU country it is reassuring to know that your prescription can be recognised at your destination. To avoid delays, interruptions in treatment and extra costs, ask your health professional for a cross border prescription before you leave.

7 TO BE TREATED WITH SAFE AND EFFECTIVE MEDICINES

Medicines must be authorised by the Member States or the European Commission before they can be placed on the EU market. This ensures patients are treated with medicines that are in compliance with strict standards on quality, safety and efficacy.

Once a medicinal product has been authorised in the Union and placed on the market, its safety is monitored during its entire lifespan to ensure that, in case of adverse reactions, appropriate action is taken swiftly, including additional warnings, restrictions of use or even withdrawal of the product.

8 TO BE ABLE TO REPORT SUSPECTED SIDE EFFECTS OF MEDICINES

As a patient, you have the right to report any adverse reactions to medicines you are taking directly to your national authorities. You can also do so through your doctor, pharmacist, nurse or other healthcare professional.

Medicines for which additional monitoring is considered necessary have a black inverted triangle in the package leaflet, along with information on how to report suspected adverse events through the national reporting system.

9 TO BE TREATED WITH SAFE MEDICAL DEVICES

EU rules on medical devices, varying from simple bandages to the most sophisticated life-support machines, aim to ensure a high level of patient safety and rapid access to innovative technologies.

10 TO BENEFIT FROM COMMON HIGH STANDARDS OF QUALITY FOR BLOOD, ORGANS, TISSUES AND CELLS

To guarantee quality and patient safety, the EU has developed common rules that apply across the EU to ensure that all donated human material is safe and carefully screened to prevent transmission of disease, for example HIV or hepatitis.

In addition, the EU funds projects and actions that support national authorities and healthcare professionals e.g., in training inspectors or improving vigilance systems as well as with the organisation of and access to national transfusion and transplantation services.

For more information:
http://ec.europa.eu/health/cross_border_care/policy/index_en.htm
http://ec.europa.eu/health/patient_safety/policy/index_en.htm

How to promote Health in the WHO European Region?

Health ministers and high-level representatives of the 53 Member States of the World Health Organisation (WHO) European Region, partner organizations and civil society, took part in the sixty-fifth session of the WHO Regional Committee for Europe which took place in Vilnius, Lithuania from 14-17 September 2015. . Civil Society organisations have issued several statements highlighting the importance of a better and more inclusive healthcare framework for Europe, access to skilled health workers providing essential health services as well as the potential negative health impacts of the Transatlantic Trade and Investment Partnership (TTIP).

Participants of the 65th WHO Europe Regional Committee meeting called for continued involvement and support from WHO to respond adequately to the public health implications of large influxes of people by conducting additional assessments in countries and by providing policy advice on contingency planning, training of health personnel and delivery of supplies. It was decided that a high-level WHO conference would be organized as soon as possible to agree on a common public health approach to large-scale migration in the Region.

Nongovernmental organizations (NGOs) such as the European Public Helath Alliance (EPHA), the International Alliance of Patients Organisations and other stakeholders have issued several statement linked to health related issued discussed by the WHO Europe Regional Committee.

For example the **Statement on Agenda Point 5a) Promoting Intersectoral and Interagency Action for Health and Well-Being in the WHO European Region**

The Health 2020 is essential, as assumed by all European Member States, to improve the health status of European citizens, by recognising the utmost importance of social determinants of health and promoting intersectoral cooperation. Member States need to make the effort of involving the different sectors of society in health decisions and to focus their attention to all the policies taken at the national level, giving meaning to a Health in All Policies approach. Nonetheless, we believe that there is still a long way to go in order to fully take advantage of this collaboration.

Environmental determinants of health, access to food, good habitation Conditions and more efficient and greener cities must be a priority of the Regional Office and Member States. Investment in active advocacy towards a healthier planet, aligned with the post-2015 Sustainable Development Goals, and building health systems with sustainable health workforce that are ready to address the needs that might arise from the climate change consequences are needed. European states must take strong stances in CoP21 defining effective agreements that will improve the stated needs.

Other statements were issued on point 5c of the agenda) Priorities for health systems strengthening in the WHO European Region 2015–2020: walking the talk on people centredness as well as a Statement on the session ‘Promoting intersectoral and interagency action for health and well-being in the WHO European Region, with special focus on social determinants and health, and health literacy: links and coherence between health, education and social policy and health in sustainable development and foreign policy’

The full text and more information are available on this link:
http://www.epha.org/a/6432

FERRING
PHARMACEUTICALS

PEOPLE COME FIRST AT FERRING

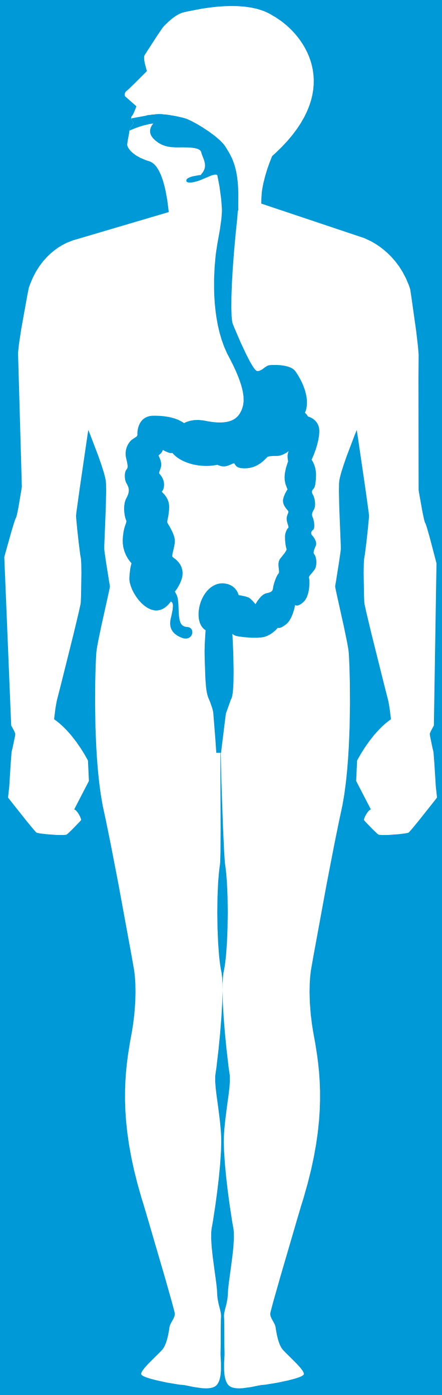
Making a difference to people's health and quality of life, today and tomorrow.

TODAY

FERRING ENJOYS A STRONG REPUTATION WITHIN THE INTERNATIONAL GASTROENTEROLOGY COMMUNITY.

Our research activities have resulted in the development of many effective products that help improve patients' lives.

FERRING BELIEVES IN THE VALUE OF SHARING KNOWLEGDE AND WORKS TOGETHER WITH PATIENTS TO RAISE THEIR VOICE.



TOMORROW

OUR COMMITMENT TO RESEARCH:
LIVER DISEASE,
INFLAMMATORY BOWEL DISEASE, FUNCTIONAL BOWEL DISORDER.

FERRING is a research driven company that invests heavily in its research infrastructure both in terms of people and technology.

PLEASE VISIT
WWW. FERRING.COM

PA/030/2014/CH3a

Anaemia from a patient perspective in IBD: results from the EFCCA online survey

by Silvio Danese, IBD Center, Istituto Clinico Humanitas, Milan, Italy

Iron deficiency is the main cause of anaemia. Iron deficiency anaemia occurs when dietary iron intake or absorption of iron is below required levels and consequently production of red blood cells is impaired. Other causes of anaemia include blood loss or malabsorption of iron, both of which can be experienced by patients with inflammatory bowel disease (IBD).

Malabsorption can occur, as the small intestine is the main site of iron absorption and inflammation negatively affects the ability of the intestine to absorb iron as well as other nutrients. Iron deficiency and anaemia are common problems in patients with IBD and are reported to occur in 39–81% and 25–67% of patients, respectively.

Iron is involved in many cellular and organ functions, in addition to its role in transporting oxygen in the blood. Without adequate iron various processes in the human body begin to not function properly, which can lead to symptoms such as fatigue, weakness and shortness of breath. Not long ago members of the European Federation of Crohn's and Ulcerative Colitis Association (EFCCA) were invited by e-mail to participate in a 30 minute online survey. This online questionnaire investigated IBD patient perceptions of iron deficiency anaemia or anaemia and included patients aged over 18 years with suspected or confirmed IBD.

The results were recently published in the European Journal of Gastroenterology and reported an interesting patient perspective, regarding management of iron deficiency anaemia or anaemia.

A total of 655 patients responded (response rate 1.63%), 68% of whom were female, with a mean age of 37 years and most had Crohn's disease. Overall, 41.2% were in remission from IBD, 29.8% had mildly active flares, 16.8% had moderately active flares, and 5.4% had severely active flares. 67% of respondents believed that iron deficiency anaemia or anaemia occurred frequently in IBD, with patients believing such anaemia was associated with blood loss (45%), iron deficiency (31%) or inflammation (18%). Patients believed that weakness and fatigue/tiredness were linked to both IBD and anaemia.

Of the patients responding 83.2% reported currently feeling fatigue/tiredness, with 62.6% reporting weakness. Those with IBD and anaemia, who also reported fatigue, reported a major negative impact on their daily life, including physical activities, productivity and home life. In addition, 53% of patients with IBD and anaemia experienced fatigue nearly every day, primarily during IBD flare-ups. Notably, many patients, including those who had been presented with a diagnosis of anaemia, had not discussed in any depth the relevance and treatment options of anaemia with a healthcare professional.

Of patients receiving treatment for iron deficiency anaemia or anaemia, 42% received oral prescription iron, 27% intravenous iron, 19% nonprescription iron supplements and 10% prescription liquid or syrup iron. The majority of patients taking liquid or syrup iron (77%), oral prescription iron (74%) and non-prescription iron supplements (68%) were dissatisfied, primarily due to poor tolerability, i.e. side effects they had experienced. In contrast, 72% of patients having received intravenous iron treatment were satisfied.

The results of this online questionnaire confirm that iron deficiency anaemia or anaemia is common in patients with IBD. Intravenous iron may be better for patients with IBD, as it can quickly resolve iron deficiency, alleviate fatigue, is better tolerated and it is associated with greater patient satisfaction.

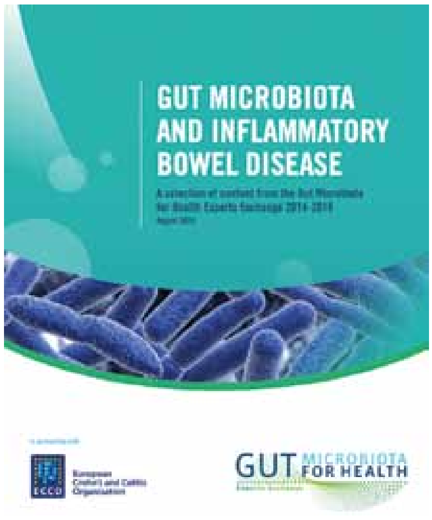
In the near future a follow-up, online patient questionnaire will be launched to assess additional aspects of iron deficiency anaemia or anaemia management. Already now we would like to encourage all IBD patients to participate in the next survey, which will help generate further valuable data, helping to improve patient well-being and quality of life.

The writing of this manuscript was funded by Vifor Pharma

GUT MICROBIOTA AND IBD

A selection of content from the Gut Microbiota for Health Experts Exchange 2014-2015 August 2015

Inflammatory Bowel Disease (IBD) research has made some exciting progress in the past decade, thanks to the myriad studies investigating the role of the gut microbiota. The Gut Microbiota for Health Experts Exchange has covered Crohn's disease and ulcerative colitis more than any other topics and, reflecting the importance of intestinal microbiota in IBD. Moreover, the European Crohn's and Colitis Organisation (ECCO-IBD) who share a common interest in the gut microbiota, has joined the European Society of Neurogastroenterology & Motility (ESNM) Gut Microbiota & Health Section in 2015.



GUT MICROBIOTA AND INFLAMMATORY BOWEL DISEASE

Although patients stand to gain enormously from these advances in understanding, there is so far no consensus on how to take into account the gut microbiota when treating IBD. Research how probiotics dampen inflammation, modulate immunity, and enhance digestive health is promising, but much more human research must be carried out. This "Gut Microbiota and Inflammatory Bowel Disease document can be a starting point for doctors, patients, and associations to begin discussing how to move forward on personalized treatment strategies.

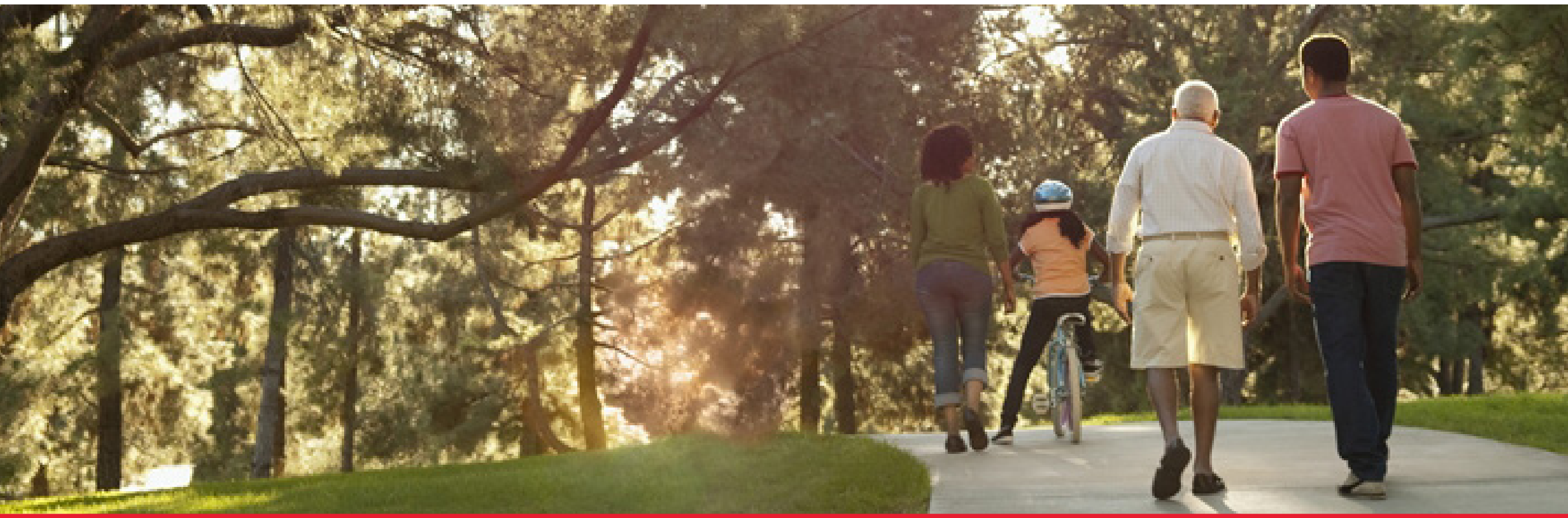
After reading through this document edited by Prof. Philippe Marteau and Harry Sokol, you'll have a picture of how probiotics, genes, the immune system, the intestinal microbiota, and environmental triggers might interact in the onset and course of IBD in both adult and pediatric populations. Below, you can read exclusive interviews with Harvard's Wendy Garrett, University of North Carolina's Balfour Sartor, University of Southern California's Brent Polk, and other leading IBD researchers, as well as the pioneering work on fecal microbiota transplantation to treat IBD.

Finally, we bring you a selection of 10 Twitter accounts to follow if you have a particular interest in IBD related topics. Also don't forget to follow our @GMFHx Twitter account! Check our website for more IBD research or sign up for our newsletter to stay up to date. Enjoy your reading!

The Gut Microbiota for Health Experts Exchange Publishing Team

Link to the document
http://www.gutmicrobiotaforhealth.com/gut-microbiota-inflammatory-bowel-disease-selection-content-gut-microbiota-health-experts-exchange-2014-2015-8567

IronDeficiency.com



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

BARIATRIC SURGERY

WOMENS HEALTH

Vifor Pharma

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 and www.galenica.com or contact us at communications@viforpharma.com

IronDeficiency.com is intended to provide educational information to an international audience, at the exclusion of US residents. All information contained therein is intended for educational purposes only and should not be used to replace a discussion with a healthcare professional. All decisions regarding patient care must be handled by a healthcare professional, and be made based on the unique needs of each patient.