EFCCA MAGAZINE

European Federation of Crohn's and Ulcerative Colitis Associations | February 2017

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EDITOR'S EYE

"Things do not change, we change!!"

The beginning of each new year gives us the opportunity to look back and reflect on what has happened in the previous year, what we have achieved and what still needs to be done. When we look back at 2016 we can say it has been a very challenging and yet successful year.

Together, we have raised awareness for IBD around the world and have spoken on behalf of the 5 million people that live with IBD. Some of us engaged in sport activities to inform the public that about these cruel diseases and some of us have used other means to raise awareness. For the first time some of the most iconic landmarks in the world have been lit in purple for the World IBD Day celebrations on 19 May – as a reminder that even though these diseases are no visible for the people walking down the street, they do exist. They exist and affect many of us regardless of age, sex and nationality.

Another topic that was also emblematic for the past year has been the topic of patient safety, relating in particular to innovative treatments – biologics and biosimilars. It has been discussed on numerous forums and events on both national and European level. The conference in November at the premises of the highest institution representing the interests of the European citizens – the European Parliament is but just one of the examples. It brought 70 patient advocates and physicians from across Europe and beyond together and allowed them to discuss topics with substantial impact on the lives of patients with immune-modulated diseases.

In this edition of the EFCCA magazine you can read more about this event and also about a number of other initiatives and projects that took place in the last months of 2016 throughout Europe.

The common theme amongst all of these activities are that they have all the potential to make the life of people living with IBD at least slightly better and easier to manage and that they have become a reality because of you!

I would therefore like to thank all volunteers, researchers, physicians, EFCCA members, EFCCA Board and EFCCA staff for all the efforts, time and energy invested in the fight against IBD, in 2016!

Now, in the very beginning of 2017, we have the opportunity to also think about the future and where we want to go. It is the ideal time to outline priorities and set targets. And quite some of them are already on the EFCCA agenda:

In February the "ECCO-EFCCA patient guidelines" project is expected to be finalized. The guidelines (for each disease group, ie Crohn´s Disease and Ulcerative Colitis) will be translated into 30 languages allowing a population of over 500 million access to latest medical knowledge on the treatment of IBD. This work has been a tremendous efforts for bother representatives of the national patient associations as well as representatives

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from the physicians national associations. We hope that these efforts will become a useful tool at the national level.

On the 19th of May we will repeat our World IBD Day campaign from last year and we would like to invite even more countries and IBD activists to join us on this day. Let´s shine a purple light and highlight the daily challenges that so many of us face.

End of May we will have the EFFCA Annual Assembly in Warsaw where we will invite several new IBD associations and hopefully we will further extend the EFCCA family.

We are also waiting for the first results from the pilot phase of our EU mapping project which aims to get an overview of the availability of innovative medicines and device across Europe in order to promote mobility of people with IBD in European countries and equal access to treatments. Once the results are available we will extend the project o include all EFCCA Members. And of course we will continue our work on patient safety collaborating with a wider alliance of representatives from immune modulated and chronic disease groups.

I would like to conclude this editorial with an inspiring quote from a prominent philosopher: “Things do not change, we change!”

So, let’s keep on working, together, on the change we all want to see!

UNITED WE STAND

Martin Kojinkov, EFCCA chairman

Patient Safety Conference, European Parliament

On 15th November 2016, more than 70 patient advocates and physicians from across the European Union attended the Patient Advocacy and Safety conference at the European Parliament in Brussels, Belgium representing a variety of autoimmune conditions in the fields of gastroenterology, rheumatology, and dermatology.

From left to right: Lorenzo Repetti (MEP assistant), Sergio Cofferati (MEP, Italy), Martin Kojinkov (EFCCA Chairman), Vladimir Urutchev (MEP, Bulgaria), Andrey Kovatchev (MEP, Bulgaria) and Dr Armuzzi (Italy).

The aim of the conference was to explore the topic of biologics and biosimilars and how different policies and practices across Europe impact on patients. Patient advocates raised concerns around non-medical switching, tracking and traceability, and informed patient consent.

The event was opened by three Members of European Parliament (MEPs), who were amongst those who kindly sponsored the room for the event: Vladimir Urutchev (MEP, Bulgaria), Sergio Cofferati (MEP, Italy) and Andrey Kovatchev (MEP, Bulgaria). The three MEPs reinforced the message that, while equal patient access to medicines across Europe is a priority, patient safety is an equal political and societal priority. Further MEPs and their staff also attended the session.

The second half of the conference was an interactive workshop, in which patient advocates were able to learn from each other about effective advocacy. They considered how the patient community could effectively proceed in educating policymakers, physicians and regulators about patient safety issues.

Building on the Barcelona Advocacy Workshop on Biologics and Biosimilars

The EU Parliament event followed the successful advocacy workshop convened by EFCCA and GAfPA in February 2016. The previous meeting was designed to provide patient groups with a greater understanding of the biologics and biosimilars landscape, and educate patient representatives on the potential ways to increase advocate involvement in the policymaking process, with a practical focus.

The first presentation by Dr Alessandro Armuzzi, Head of IBD Unit at Catholic University Hospital of Rome, provided attendees with an overview of the differences between biologic and biosimilar medicines. Delegates heard then a powerful story from Bente Buus Nielsen (former CEO of the Danish IBD patient association), who recounted her personal experiences of non-medical switching in Denmark. She highlighted that patients are generally opposed to non-medical switching, particularly if the decision is made on the basis of cost alone.

Ms Nielsen noted that 25 percent of all incoming adverse event reports to medicines are generated by patients who have been switched from a biologic to a biosimilar. She referred to social media posts and enquiries from patients facing new side effects or conditions reoccurring after a switch.

Sanna Lonnfors, EFCCA's Scientific Adviser presented the results of the EFCCA Biologics and Biosimilars (BAB) survey which had 1,181 respondents from a range of disease areas and aimed to assess patient views on biosimilars.

Luisa Avedano, Chief Executive Officer of EFCCA, and Fergal O'Regan, the EU Ombudsman's Head of Inquiry, helped explain how patients and patient groups can work with regulators to ensure patient safety. Mr O'Regan spoke on protecting personal data for patients and the level of transparency within the EMA.

Ms Avedano led the discussion of the role patient advocacy groups can play at the Pharmacovigilance Risk Assessment Committee (PRAC) at the European Medicines Agency (EMA).

During the **afternoon session**, neurologist David Charles, M D, Chair of GAfPA's National Physicians Biologics Working Group, gave a presentation on the NOR-SWITCH study. Dr Charles highlighted that, while the study showed that the biosimilar was "not inferior" to the originator treatment, the study had some limitations.

These limitations include the fact that the study is applicable only to two specific biologics/biosimilars, that it pools data rather than separating it by individual disease states. It also does not take into account the effects of multiple switches and may not directly apply to disease areas not studied by NOR-SWITCH. Dr. Charles raised the importance of being able to track and trace biosimilar medicines to record any adverse reactions to a particular treatment.

Conference participants outside the European Parliament building, 15 November 2016, Brussels

Pharmacovigilance across the EU

Professor Michael Kaeding, of the University of Duisburg-Essen, Germany, provided delegates with an overview of his research on pharmacovigilance, set for publication in February 2017. Professor Kaeding's research focused on the pharmacovigilance systems of six EU member states, specifically concerning biologic medicines and the reporting of adverse events.

The research included a series of interviews with relevant parties in each country, and sought to capture the challenges around pharmacovigilance and adverse event reporting as well as revealing examples of best practice.

The findings underscored the importance of reporting any side effects which patients may have to their medication and ensuring that these reports provide the correct information to regulators.

Accurate patient reporting will help keep biologics and biosimilars that are available as safe as possible and allow any issues to easily be traced back to the manufacturer.

The day's discussions revealed that patient concerns still remain around certain issues such as:

EDUCATION (patients need to be given more information on biosimilar medicines),

Bente Nielsen, former chairman of the Danish IBD patient association speaking at the European Parliament.

EXTRAPOLATION (some patient advocates still feel uncomfortable about the fact that biosimilar medicines are not always tested in every disease area),

SWITCHING (patients are being switched from medicines, at times without their knowledge or consent),

TRACEABILITY (proper registries need to be created to accurately track and trace the use of biologics and biosimilars in the case of adverse events) and finally

PATIENT CONSENT (meaningful and informed patient consent is crucial when switching a patient who is well established on a treatment to a biosimilar).

EFFCA and GAfPA will continue their collaboration on the issue of biologic and biosimilar medicines in Europe in 2017.

Living well with IBD - animation series

EFCCA is involved in an exciting project aimed at helping people to 'live well' with IBD. We are developing a series of animation videos that will equip people with practical advice and relevant information and hopefully will bring about positive changes to the way they cope with their disease.

The animations are aimed at a diverse patient population and have been elaborated by a group of IBD patients, animation experts, EFCCA and Janssen. We hope that the animations provide a quick and easy medium to cover multiple topics and involve people at different ages and life-stages. Altogether we will be developing three animated videos to provide positive, practical advice to people living with IBD and to help overcome some of the key issues they face.

The content of the videos reflect the views and perspectives of real people with IBD in real life scenarios and the stories are positive and upbeat aimed at giving people confidence that they can live well with IBD.

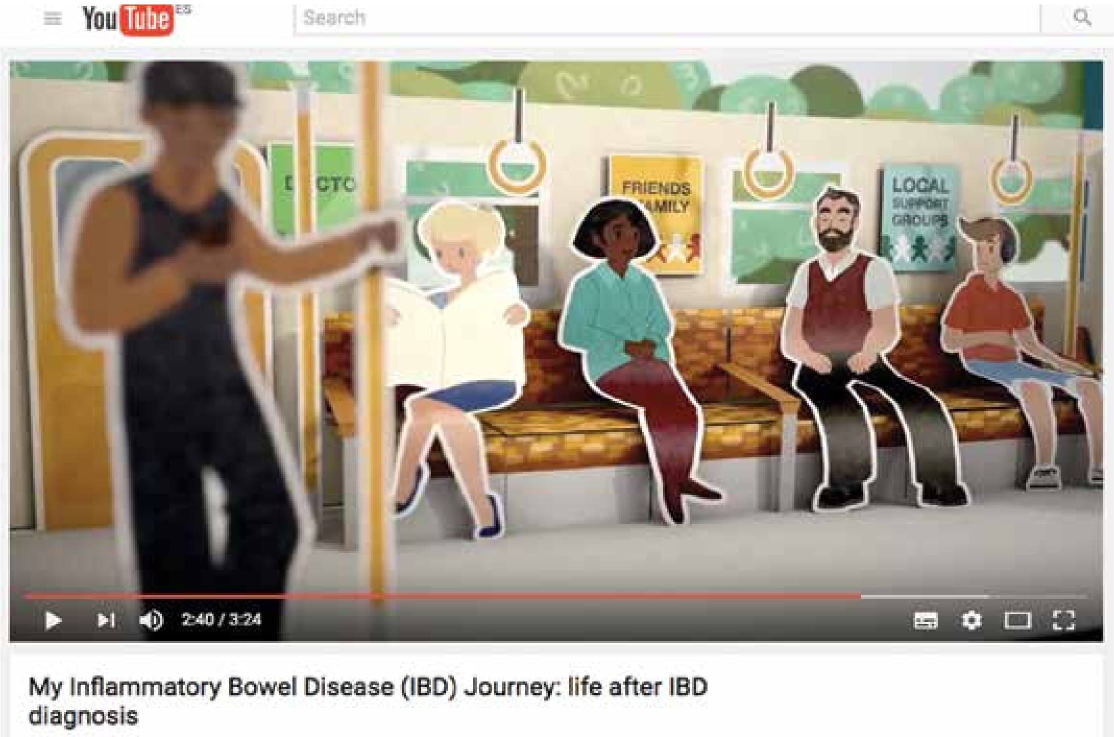
The target audience are people with IBD, friends, family, colleagues and healthcare professionals.

The first animated video was presented by Martina Jovic, EFCCA policy officer, together with Emily Bone, Janssen pharmaceuticals during a satellite event at UEG Week on 17 October 2016, in Vienna.

The animation takes the form of a ‘pop-up’ book to tell the story of three people newly diagnosed with an IBD. Each ‘page’ looks at different aspects of the diagnosis from a practical and emotional perspective. There is one narrator who provides the voice of experience and three characters who have been diagnosed at different stages of their lives and have different concerns regarding relationships, family and employment. The first animation is centred on how to move forward with your life once you have received an IBD diagnosis.

The second and third videos will be developed this year and will look at maintaining a good quality of life and exploring other Quality of Life aspects associated with living with a chronic disease. The videos are available to all EFCCA members with an option to translating them into local languages. For more information please contact the EFCCA office.

Martina Jovic (left), EFCCA policy officer with Emily Bone, Janssen, during UEG WEEK presenting the first animated video



My Inflammatory Bowel Disease (IBD) Journey: life after IBD diagnosis

The first animated video entitled “life after IBD diagnosis” is available on YouTube as well as on the EFCCA website.

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

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MSD
Be well

The importance of transnational work

On 9 December 2016 I was invited by EFPO, the European Federation of Hidradenitis Suppurativa patients' organisations (maladie de Verneuil in French) to its first Board of Directors meeting that took place in Paris after the official establishment of the international association of last June.

EFPO is thus a new-born umbrella organisation made by 6 national patient associations: Italy, France, Spain, Netherland, Belgium and Denmark whose main objective is to raise awareness about HS and support people suffering from the disease in Europe.

HS is a chronic inflammatory disease of the terminal follicular epithelium in the apocrine gland–bearing skin, its cause its unknown and whose incidence in growing fast in many countries.

After a first meeting during the Advocacy Workshop on Patient Safety we held last February in Barcelona, Giusi Pintori, EFPO President asked EFCCA to participate and make a presentation on the challenges of being an international second level organisation and the importance of the transnational approach when supporting national/local organisations in their daily activities. It was a vibrant and interesting discussion where I had the chance to talk and listen to the Board members' experiences and activities. We talked about some basic keywords that are the glue of organisations like ours: multiculturalism, diversity, unity, continuity and … patience.

I learned a lot and I spent a fruitful day with new friends: a powerful group of women that agreed – together – not only to work within their national associations, but also at European level.

I left the meeting with the promise of meeting again and the offer to support them during their first constructive phase where, sharing experiences and lessons learned can make things easier. Good luck EFPO!
Luisa Avedano, EFCCA CEO

Meeting ECCO: a biennial occasion to strengthen mutual cooperation

On 8-9 December 2016 the European Crohn's and Colitis Organisation (ECCO) invited EFCCA and several patients' organisations of ECCO country members to a meeting in Vienna. 31 countries were represented, including ECCO and N-ECCO national representatives.

The meeting is a two-year tradition and it is becoming a useful occasion to exchange views and ideas, boost networking among peers and identify common topics for further collaboration between IBD physicians, nurses, patients' organisations and EFCCA.

EFCCA was represented by Martin Kojinkov, EFCCA Chairman and Luisa Avedano, EFCCA CEO.

After general presentation, that focused, among other topics, on the launch of the ECCO-EFCCA Guidelines in their English version, and their subsequent translation into 29 other languages, 5 projects from patient organisations were presented:

1. A couching programme developed in Israel and presented by Adam Elgressy from our member CCFI (Israel) whose objective is to weekly support people with IBD in their daily life in order to connect them to each other and make them more included in their working activities. A second step will be to train a team of patients to become coaches so to help other patients affected by chronic diseases;

2. The training programme for nurses in Cyprus presented by Yiannis Antoniades from Cycca (see page 15)

3. Kids and teens chat presented by Kathrin Abel from DCCV (Germany), an innovative online project addressed to children and teenagers to facilitate individual communication and exchange of information with the support of a psychologist.

4. My IBDCoach presented by Tineke Marcus from CCUVN (Netherland). This is a e_health tool designed and addressed to patient to facilitate communication and easy monitoring between HCP and patients. Patients have also access to e_learning modules.

5. Education Days presented by Malgorzata Mossakowska, J-Elita (Poland), a national educational programme made by 8 meetings addressed and open to all Polish IBD patients that involved a wide range of experts: physicians, nutritionists but also lawyers and experts on social welfare and patient rights.

Two presentations by ECCO representatives followed: one on the UR-CARE project, by Pr. Baert. UR-CARE is an innovative project developed by ECCO that consists of a huge data base at disposal of any IBD center and hospital to collect data and keep track of patients. The date is at the disposal of physicians and nurses. The second presentation by Dr. Lindsay and Dr. Kemp focused on IBD Nurses' education, IBD Curriculum and the ECCO e-Learning programme.

The second part of the day was devoted to working groups where patients, nurses and physicians had the chance to talk about the methodology, timeline and expected results of the translations of the ECCO-EFCCA Guidelines in 29 languages. Patient representatives and ECCO national representatives agreed in working together and reviewing the translations of the guidelines made by a professional translation company chosen by ECCO. By February 2017 the translated versions of the Guidelines will be available and downloadable on the ECCO and EFCCA website, while a promotional flyer will be distributed at the ECCO Congress.

Useful discussion and interesting brainstorming were the ingredients of the meeting; some ideas for further common projects have already been drafted in the hope that the new year will bring even more energy and collaboration within the wider IBD community.

Luisa Avedano – EFCCA CEO

Photograph by Evelyn Groß

Breaking taboos

The new EFCCA European youth group have been established now since July 2016 and look to continue the amazing work of past groups.

We are a group of young people who all suffer from IBD and want to help, support and make a difference for people living with IBD.

Past youth groups have wrote articles about taboos and IBD to try and break barriers and crush stigma that might be associated with the conditions. We want to continue this essential work by continuing to write articles about taboos and topics sufferers want to read about.

Hopefully by sharing these articles we will help to support and reassure sufferers and their families and friends that they are not alone as well as possibly providing answers to questions they might not have been able to ask anyone before.

IBD and nutrition

Many people with IBD find they can no longer eat certain foods or are needed to follow a strict diet. It can be hard to adjust to something that was previously taken for granted and this can then become a fear and start to isolate the individual in something that happens every day.

Many questions go through your mind – Will I be able to eat out in a restaurant? Will I be able to eat fruits and vegetables? Will people understand if I can't drink alcohol?

During EFCCA Youth Group (EYG) meetings we discuss various topics as seen in previous EFCCA Magazines and we try to "Break down taboos" which come with daily life and IBD.

Through these stories we hope to raise awareness and make people understand the difficulties and challenges we face and go through. We want to make a 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.

Food is essential for everybody and is usually one of life's pleasures. This essential activity can often be taken for granted until you are diagnosed with a condition which impacts the way you eat or the thought process behind having a meal.

Many people find that certain foods affect symptoms and can also cause pain due to it being difficult to digest.

It is important to be seen by a dietician or a consultant which can advise on diet as IBD can affect everyone differently - IBD is a very individual condition and what works for others may not work for you.

For this issue one of our EFCCA members, Veronika Hanzlikova from the Czech Republic, shares her experience with IBD as concerns food.

We hope you have find this real life example useful and that it helps reassure you that you are not alone when it comes to learning about diet and IBD. Remember the relationship with food and IBD is different for everyone, learn your own body and as well it is helpful to keep a food diary to really gain a greater understanding when trying to find a diet that works for you.

We wish everyone a healthy 2017 and we look forward to sharing more articles with you throughout the year.

Leannie Downie, EFCCA Youth Group

Blogging about life with IBD and nutrition

I´m Veronika Hanzlikova, 33 years old and have been diagnosed with Ulcerative Colitis since 2003 during my university studies. I´m a blogger about nutrition and help patients with IBD to find a healthy, nutritional balance

My first signs of Colitis were phlegm and blood in my stools. Fortunately my practitioner recommended me to the gastroenterologist immediately. After fourteen days I knew my diagnosis and received the treatment.

I have started to study many books about IBD and nutrition. However I didn't want to restrict eating fruits and vegetables too much which is usually recommended. Step by step I have started to discover which food I can eat without flatulence and abdominal pains.

Since my diagnosis I have started to work in the office of pharmaceutical quality. I was working there for seven years until my maternity leave. Now I'm at home with my son and I'm working from home. I'm a blogger about nutrition and life with IBD and I actively help Czech IBD patient's organisation.

I don‘t have any specific diets but my diet is inspired by principles of traditional Chinese medicine and nutrition. When it comes to my diet I try to keep gluten and dairy products to a minimum as this has been very essential for my wellbeing. I don't eat the peels of apples and grapes. I don't drink coffee or alcoholic drinks except the occasional glass of wine. To my pleasant surprise I can eat nuts without any problems.

I do try to avoid fast food and fried food when eating out in the restaurants. When I go out to restaurants, I tend to choose: some grilled meat with rice or boiled potatoes, soups, pasta or pizza. I love sushi.

I know that my condition and my nutrition are closely linked. Therefore I try to eat the best for me, my skin and my gastrointestinal tract. Consumption of large quantities of pastry, milk and dairy products is worse for me then eating fibre of fruits and vegetables. I look at quality of fats and oil that I consume. I prefer cooking with extra virgin olive and rapeseed oil, high quality butter and fish oil and cold pressed plant oils.

I will continue to blog about my nutrition and life with IBD as I know it can be a very personal journey for everyone to manage and I find this helps me by helping others.

Cyprus

Employment programme for patients with chronic diseases

On request of a number of patients, the Cyprus Crohn's and Colitis Association (CYCCA) took the initiative to help IBD patients gain employment. At a meeting with the Minister of Welfare, Labour and Social Insurance, the problem of exclusion and the difficulties the patients undergo through lack of employment were discussed and she was very understanding and willing to help.

The discussions led to a special program funded by the Cyprus Government together with the European Social Fund (ESF), which eventually was extended to cover all patients with chronic diseases and was put under the umbrella of the Cyprus Federation of Patients Associations, of which CYCCA is a member represented in the Board of Directors.

The program invites employers to express their interest in hiring chronic patients for any needs they may have and patients who are interested for a job apply by filling in a form describing their qualifications, experience and desired position. The Ministry will then match employers with applicants and interviews will be arranged to finalise a deal. The employment can be on a full time or part time basis.

Employers who accept to hire patients will be subsidised by the program with 75% of the cost of the patient's employment and they are allowed to hire up to 5 people. A minimum salary applies for all employed persons and the program is open until the end of March 2017. Its duration will be 12 months with a prospect of extension.

The ultimate goal and CYCCA's hope is that a good number of IBD patients will be able to acquire full time employment in perpetuity through this program.

CYCCA Board together with the Minister for Labour, Ms Emilianidou (third from the right)

Training programme for IBD nurses

The first training program for IBD nurses in Cyprus took place in Nicosia from October 6th to November 10th, 2016. The program duration was 35 hours and it consisted of 8 modules which covered the whole spectrum of IBD nurse knowledge and care. The content of the program was prepared by ECCO and EFCCA in cooperation with the University of Nicosia, which undertook and sponsored the organisation and execution of the program.

The idea and initiative came from the Cyprus Crohn's and Colitis Association (CYCCA) and it was approved by the Cyprus Ministry of Health which undertook the selection of the 21 participating Nurses from all the public hospitals of Cyprus. The program was also supported by EFCCA, ECCO and the Cyprus Society of Gastroenterology. The instructors, 18 in total, came from ECCO and N-ECCO, the King's College Hospital of London UK, Doctors/members of the Cyprus Society of Gastroenterology and other Health Professionals from Cyprus (surgeon, psychologist, nutritionist, etc).

The program was very successful and all participants passed their final test at the end of which they received a certificate of attendance and merit points from the Ministry of Health. The obvious conclusion regarding the program was that this kind of training is very much needed and it should be repeated. CYCCA intends to continue to promote similar programs and to expand them to include nurses from the private sector as well.

A very important benefit was the acquaintance between the participating nurses and the frank exchange of ideas and experiences. The following quote is from a 'thank you' letter to CYCCA from a nurse just after the completion of the program, which gives an idea of how participants benefited from the program: 'We have met Cypriot Doctors and Health Specialists whom we knew about but we had never met before and have learnt a lot from them. We were also very lucky to meet and learn a lot from foreign speakers, mainly from European countries, who are specialists in their home country hospitals.'

A significant addition to future programs would be the inclusion of visits of a number of nurses to hospitals in other countries which offer different and more diversified nursing.

CYCCA was very pleased to note during the ECCO Representatives Meeting in Vienna in December 2016, that ECCO intends to proceed with training programs for IBD Nurses in Europe in an organised way. There is no doubt that this will contribute considerably to the well-being of the IBD patients.

Cyprus Crohn's and Colitis Association

Germany

PIBD-SETQuality – research project for children with IBD sponsored by the EU

Inflammatory bowel diseases (IBD) can affect people at a very young age. The importance of controlling the disease activity is obvious, the disease should influence the child's/adolescent´s physical and social development, including education, as little as possible. However, the medication available is not necessarily tested in clinical studies with the relevant patient population.

Clinical studies often include only adults and the results are extrapolated to children and adolescents. Some medicines (azathioprine and methotrexate for example) are not approved for the use in children, but are none the less administered to children (off label use). Children, however, are not little adults and the efficacy and adverse effects that are recognized in adults might not correspond one to one to those in children.

The research project PIBD-SETQuality wants to provide a remedy for this dilemma. An international research consortium of pediatric gastroenterologists, basic researchers, health economists, and representatives of patient organizations addresses different questions concerning the medical care of children and adolescents with IBD. This project is scheduled for four years. It has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 668023.

One of the main tasks of the project is the evaluation of therapeutic options within a clinical study. This clinical trial has the goal to evaluate the most suitable medical therapy for a certain subgroup of children with IBD. Medical drugs that are used in pediatric medical care for years are evaluated for the first time in a scientific setting. In this clinical study the active substances methotrexate, azathioprine, and adalimumab are compared directly. Children and adolescents that are newly diagnosed with Crohn's disease (CD) can participate. The innovative concept of this trial is the pre-randomization classification of children with a high risk of severe progression of the disease and those predicted to have a mild disease course. These groups will run in two different subsets of the trial. The participants in the subsets will then be randomized in either an azathioprine-arm or a methotrexate-arm (mild disease course) respectively a methotrexate-arm or an adalimumab-arm (severe disease course). This setting allows the comparison of different risk-based therapy regimes and aims to collect data on how to optimize the treatment for the needs of the individual child with CD.

This study has started at the end of 2016 in centers in different European countries, in Israel and Canada. Two patient organizations are involved in the project: the DCCV (German Crohn's and Colitis Association) as a cooperation partner and the AFA (Association François Aupetit) as part of the advisory board. By involving patient organizations, the project has the chance to integrate real life experience of people who live with the disease, a concept nowadays required by many institutions that fund research. The research facilities involved in this project also come from different countries.

From Europe there are members of the research consortium from France, Germany, Great Britain, the Netherlands, Belgium, Italy, and Spain. Researchers from non-European countries come from Canada and Israel. But those are only the centers that were involved in developing the project and applying for the research grant. The actual research project also includes pediatric gastroenterologists from other countries who are part of the PIBD net (Pediatric Inflammatory Bowel Disease Network).

The second key aspect is the generation of an international, independently financed inception cohort that includes children and adolescents up to 18 years who have either been (freshly) diagnosed with Crohn’s disease or with Ulcerative Colitis. This international cohort allows the collection and comparison of data of a lot of young people with inflammatory bowel diseases (IBD) and might offer the possibility to draw conclusions about the causes of IBD in children and the circumstances under which different disease courses can occur.

The project runs for four years and the support of the patient organizations across Europe and also in the non-European countries can help to gain the acceptance among young people with IBD and their families to participate in this research project. This project is a chance to gain knowledge on the most successful treatment options according to different disease circumstances (personalized medicine). Therefore the public funding of the European Union and thus funding that is not based on economic interests of a company gives great hope for good and valid data that helps to optimize the treatment of children with IBD.

Birgit Kaltz/Cornelia Sander (DCCV e.V.)

UK

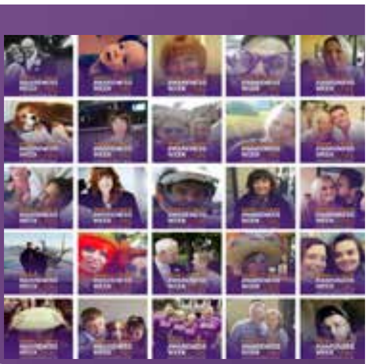
Crohn´s and Colitis Awareness Week

CROHN’S AND COLITIS
AWARENESS
WEEK 1 –7 DEC
crohnsandcolitis.org.uk

4279 completed the Crohn’s, Colitis and Me posters – the target was 1000

We announced that Morrison's were changing their toilet signage following our campaign at the start of the week

18,603 people uploaded the twibbon that was created by one of our supporters



28,000 people viewed the poster gallery

1555 supporters shared their poster on Facebook and 536 shared their poster on Twitter

Siobhan-Marie O’Connor used the twibbon on her social media

There was a 4.5 million reach on Facebook over Awareness Week

Purple Friday Text to donate raised £3500 with over 20 corporates taking part

We received 47 pieces of press coverage including 3 TV appearances, 2 radio features, 10 national pieces and 28 regional articles

Groups held 17 events throughout the week including information events at hospitals and supermarkets as well as social events

A Direct Mail appeal was launched during the week and is currently at £17,000

Finland

Youth Activities: From Ninjas to Crocos

The Finnish ”Crohn ja Colitis ry” association organizes youth activities for IBD patients aged 13 to 17 years. A weekend of peer support, the Ninja Camp, is organized yearly for the so-called IBD Ninjas. In 2017, the weekend combines old and new – a new thing is a third night in addition to the former two, and following the old habit, everyone can bring a friend who does not have IBD to enjoy the weekend!

During the weekend the young people can enjoy activities with the entire group, peer discussions in small groups, outdoor activities, sports, and most of all relax and spend time in a group in which going to the toilet often is nothing weird.

Four young adults, also IBD patients, will act as leaders of the weekend. The peer leaders also tell the young participants their own stories about life with IBD, the so-called Ninja stories. In the previous years, particularly the stories heard from the peer leaders and their support have been very important to many young people.

As the first target group, the Ninjas have also tried a chat. The IBD Ninja Chat was organized four times in December-January. Each chat session had its own theme, for example school and studying, future dreams, free time and hobbies, relationships and managing the everyday life.

The chats were able to reach young people who had previously participated in various activities as well as people who had never spoken with other IBD patients before. The chat offered the participating young patients a chance to write with their peers and share thoughts that give them trouble and joy in their everyday life. IBD Ninjas have earlier been unreachable to the online peer support activities, but we hope that the chat will make headway and offer also teenagers the online peer support they need.

18 to around 30-year-old Crocos

IBD patients between 18 and around 30 years of age are familiarly called Crocos. Crocos have both local and nationwide activities. Local peer meetings often include fun activities, for example bowling, eating or doing sports. Local meetings reach Croco-aged patients well, and they have been very popular and desired. The main national event is the peer support weekend for Crocos in the fall.

photo by Renja Tolvanen

The volunteer weekend of the year 2016 was organized on the first November weekend at a spa hotel. Instead of the traditional meeting lasting for three nights, a one night meeting was tested. The short time was used efficiently in the small group of ten people, and good things were shared. During the weekend, we had time to closely discuss touching topics as well as relax and eat well. This year we managed to get together a group of ten people.

"I participated in the peer support weekend now for the first time as a leader. The year before I had really enjoyed the peer support weekend and now I wanted to offer the same to others. There were lots of old friends among the participants, but I was happy to see also completely new faces" said Oona Karhunen, one of our weekend leaders.

The weekend was started by breaking the ice with laughter yoga. Any tension was quickly gone when we imitated pigs and rolled over each other. The "Naurava kulkuri" song gave a nice rhythm for everyone's laughter. We also got to try different laughing styles and experience how contagious laughter is between people. It was good for the mind and even though this was far from traditional yoga, the body relaxed as well.

The days were also full of discussions. We tried to create close-knit discussions in two small groups. First, we built a treasure map and thought about future dreams. In another session we thought about nutrition and everything that is closely bound to it.

The Purple Party on Saturday evening offered small activities and time together. As the tradition goes, the best costume of the evening was awarded. This year, the award went to the participant with the most purple clothes on.

Judging by the feedback, the participating Crocos enjoyed the meeting and felt that the weekend was rewarding. We got praise especially for having the weekend in a spa environment. Many participants had time to relax at the spa several times.

Renja Tolvanen, Teija Aalto and Oona Karhunen

photo by Oona Karhunen

Slovakia

Taming of Crohn's and soul searcing

At a recent educational meeting of IBD patients in Turčianske Teplice we presented a new book aimed at people with IBD. We are very pleased that this book has been produced in cooperation with psychologist and sexologist Dr Phil. Laura Janacckova, CSc.

In the book entitled "Taming of Crohn's and soul searching" the author talks about taboo topics. It is the first publication dedicated to the psychological surviving and the soul of an ill person and is directly devoted to IBD patients. It accompanies the patient from the beginning of the disease, solves his/her concerns, fears and it does not avoid intimate questions. Not only does it contain a lot of useful advice, psychological methods and tips, but it also offers a lot of advice and recommendations for family and friends who want to be helpful to these patients in their struggle with the disease.

We are very grateful that the author has found time in her busy working life to provide important useful advice not only to strenghen the psychology of IBD patients but also to ease and understand their disease. For us patients the book is a new light inside the sore body. The edition of this book was supported by the pharmaceutical company AbbVie.

Ivana Charvatova, Slovak Crohn Club

Spain

Easy parking for IBD patients in Ourense

A new project, started in Ourense, allows IBD patients with incontinence to park in the loading and unloading zone during 15 minutes if they need to find a toilet while driving.

The requirements to use this service are being member of the "Asociación de Enfermos de Crohn y Colitis Ulcerosa de Ourense (ACCU Ourense)" and getting the incontinence accredited with a medical confirmation.

The local police issues a card that should be visibly displayed in the car when it is parked in the authorized zone. Before picking up the card all users must sign a statement that they will comply to the rules of its use.

Till now there are 26 approved cards and 10 in process. At the same time, others ACCU organizations are promoting this project in their cities.

Fernando José Jiménez, ACCU Ourense (middle) with the mayor of Ourense (right) and Councillor (left)

Challenge is overcome successfully

Barcelona Triathlon is one of the most renowned races wordwide and every year it transforms the Ciudad Condal in a real party for the lovers of this kind of competitions.

During the last edition, 3600 athletes from different countries participated in the race. Among them, and for the third year in a row, a group of IBD patients named "Grupo Deportistas EII ACCU Catalunya" and supported by the "Associació de Malalts de Crohn i Colitis Ulcerosa de Catalunya" (ACCU Catalunya) participated with 27 triathletes from different Spanish regions.

They got excellent results in the three following categories:

SUPER SPRINT: 1st place

SPRINT: 10th place

OLYMPIC: 9th place.

To give the highest awareness to IBD all group members offer the best of themselves according to their possibilities. Also they show everyone that, in spite of the illness, some challenges can be reached and a lot of dreams can come true.

Members of the Group ¨Deportistas EII ACCU Catalunya (IBD sportsmen) during the Barcelona Triathlon

France

IBD & WORK

Thanks to extraordinary therapeutic findings, intestinal bowel disease (IBD), especially in young adults, are better diagnosed and treated. Nevertheless, for the last 5 years, the French association, Association François Aupetit (AFA) active listeners have been called upon more and more concerning professional life and the impact these diseases have on working conditions.

AFA, in partnership with Takeda Laboratories, decided to carry out a national survey in order to understand how IBD patients are integrated in the employment market. The survey was carried out online by the IFOP Healthcare Institute, from 8 March to 6 April 2016, with 1126 active participants, 18 years old and up, affected by IBD. The results of this study are quite revealing of the problems encountered by the patients in the workplace, which lead AFA to reinforce its activities on this theme.

PATIENTS WANT TO WORK, BUT…

IBD IMPACTS PROFESSIONAL LIFE

76 % of the participants surveyed are in the work force and satisfied with their working conditions. The figures show that IBD patients strongly aspire to holding a stable job even if it means holding a position for which they are over-skilled or of lesser interest to them. They have more trouble than the average French person with the same educational degree to be promoted and to reach an executive level position.

81 % of the respondents on the work force mention the impact of the disease on their professional life. IBD affects career choices (giving up the type of work desired, choosing or adapting to a job on the basis of the disease constraints) along with personal career development.

39 % of the total sample recognize having to reorient their career path due to their illness.

Optimistic for the most part (59 %) for those working, the patients questioned feel fine in their company environment (89 %) and are particularly motivated (78 %). Yet they are more stressed out in their working environment than the average French worker (68 % vs. 54 %).

FATIGUE IS THE MOST SIGNIFICANT SYMPTOM

Fatigue is recognized as the most significant symptom in professional life according to 41 % of those now working. Even throughout long periods of time in remission, fatigue is diffusely present and has an impact on work performance. Spreading work out over time, working more hours, working in the evening at home, patients look for strategies to counter this drawback to insure completion of the workload to the detriment of their private life. 34 % of them are not satisfied with the proportions between their professional and private life.

The symptom of diarrhea is in second position. With 25 % of the working population who consider this to be the most annoying symptom, this problem makes any sort of travel worrisome and complicated, public transportation being particularly critical.

INSIGHTFUL TYPOLOGY

Each individual has a different perception of his/her illness. Partly correlated to the severity and the development of the disease, this perception varies based on personal, economic and social criteria. The study carried out by IFOP for AFA allowed them to identify 5 groups of patients.

TALK ABOUT IT OR NOT IN THE WORKPLACE

In the case of these digestive diseases, there are only 39 % who have freely spoken to their professional entourage. Although 74 % have informed their immediate superiors, they only talk about it if they have to, in order to manage their work properly or because they cannot accomplish certain tasks. On the other hand, talking to their colleagues is easier (85 % of the patients do). Nevertheless, 18 % of management have reacted negatively.

HOW TO IMPROVE QUALITY OF LIFE IN THE WORKPLACE?

The areas identified at the end of the study are essentially:

-Work time management including: therapeutic part-time (for 60 % of the people in the survey), availability of telework (58 %) and the possibility to be treated and undergo medical examinations on company time (60 %)

-Working conditions (adapted work posts, increased number of toilets and dedicated rest rooms on the workplace).

AFA ACTION

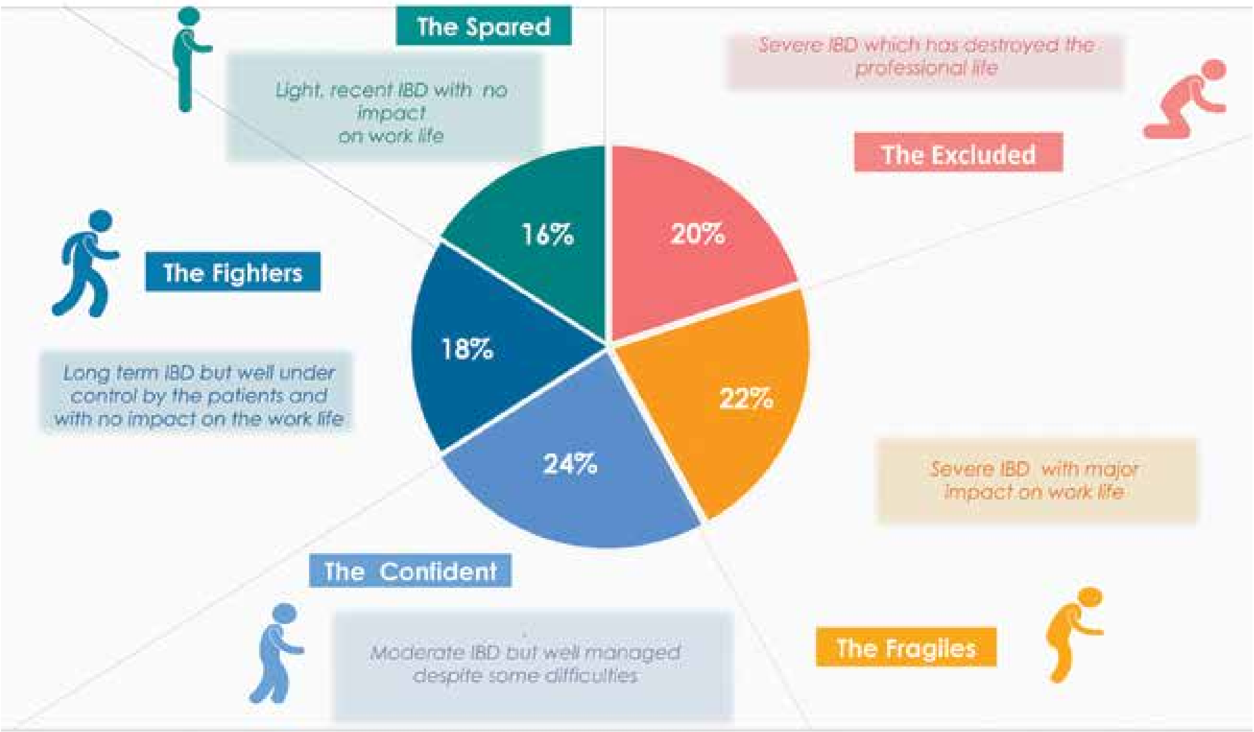
In addition to the existing action, for example the AFA website, dedicated publications on the subject of IBD & Work, responding to calls on the hotline with the support of the AFA social worker and lawyer, AFA has developed a new service: Work Coaches, to help patients to develop their professional project in view of their disease.

These Work Coaches are AFA volunteers, who have been trained in active technical listening enabling them to offer information on available help programs which manage to conciliate illness and work.

Their task is to accompany the patients in a series of interviews, generally over the phone, to help them get through being reinstated in their former position or orientation to find a new job after a long leave of absence due to the illness.

Their Work Coaches help patients to build a network furnishing precious information, but they support the patients by helping them to step back objectively without having to face their situation alone. They help develop their self-esteem in building their future and believing in themselves.

Marie-Hélène Ravel
AFA FRANCE



Romania

8th National Symposium on Inflammatory Bowel Disease

ASPIIR joined gastroenterologists at the National Symposium on Inflammatory Bowel Diseases of the Romanian Crohn's and Colitis Club from 29 – 30 September 2016 at the Crowne Plaza in Bucharest.

The purpose of this event was to show the difficulties that IBD patients face and the constant struggle of both patients and doctors against IBD. Our project "ME & IBD" during the event was directed at three levels: guests, speakers and exhibition.

We were very glad that Luisa Avedano – EFCCA CEO, could join us as special guest, in particular as ASPIIE only became member of EFCCA two years ago. Our event was a good opportunity for EFCCA to meet with Romanian IBD patients and gastroenterologists. Some of the main topics that were brought into discussion were EFCCA's future plans and projects in partnership with other European institutions, such as ECCO and other interested parts as well as the concerns of European IBD patients' needs.

Ingrid Anette was another special guest to the event. Known as the ¨Crohn Princess¨ in Norway, Ingrid shared her impressive story about her life with Crohn's starting from her high school years. After many bad experiences and a series of surgical interventions which left her with a stoma, she managed to regain her balance and lead a normal family life (now being a mother of 3 children) and what is more important, to break down many stereotypes. We were very grateful for her taking part in the event and sharing her story.

Her experience represents an encouragement for IBD patients and for ostomates, as well as a huge opportunity for doctors and other participants in IBD management to learn more about the problems that young IBD patients have to deal with throughout their life.

From left to right: Ingrid Anette, Luisa Avedano (CEO, EFCCA), Isabella Grosu (Director, ASPIIR)

We also held the "ME & IBD" exhibition at the Crown Plaza hotel lounge. The exhibition consisted of 10 artworks created by artists and their challenge was to picture problems that IBD patients face in their life. The aim was to illustrate artistically the traumas of young IBD patients and their relationship with society, family and friends, which sometimes end in isolation.

The exhibition contained also a sculpture made by sculptor Sorina Mihalache. Her model was a young ostomate patient who had been struggling with ulcerative colitis since 14 years old, when she had her first surgery followed by an internal pouch which she kept for 3 years followed by another surgical intervention.

The "ME & IBD" project was realized with the support of our partners: Abbvie, MSD, Takeda, Vifor Pharma , Egis Pharmaceuticals and Medical Express.

Social inclusion project for youngsters

We are pleased to announce that we have received funding for a new Erasmus + project which ASPIIR implemented in collaboration with the Duha Tangram Association from Prague and an organization from Malta.

The project focused on the social inclusion and reunited young people with special needs, chronic diseases or disabilities, student volunteers and young artists who have contributed over time to other artistic projects of ASPIIR (such as “Perspectives” or “Me & IBD”). For 10 days participants from Romania, Malta, Greece and Czech Republic tested their creative abilities, by modeling clay into windows and buildings of the Gothic style discovering Prague’s Gothic architecture by visiting Prague’s City Hall, the National Gallery, St. Agnes Monastery (Prague’s most representative Gothic building), the National Museum, Prague’s Castle and the famous Cathedral, Charles bridge and the old city center.

Set in a very beautiful period of the year, that of winter holidays, the project offered participants the chance to enjoy the specific atmosphere before Christmas, to discover together the customs and traditions of Czech culture related to this celebrations, the Christmas markets, culinary habits and customs preserved and practiced in the evening of Saint Nicholas. All these activities boosted communication among the young participants, favored the social inclusion, and increased the tolerance for youngsters with special needs; the project contributed to a better bonding among the young people from the 4 countries and helped to lay the foundations for further projects.

Italy

AMICI Onlus receives gold medal award for public health merit

We are pleased to announce that our IBD association has received a gold medal for public health merit from the President of the Italian Republic, Professor Sergio Mattarella, on proposal of the Minister of Health Beatrice Lorenzin.

The award ceremony took place in Rome at the Auditorium of the Ministry of Health on October 21st, 2016. In his speech during the award ceremony the Minister thanked the President of the Republic, prof. Sergio Mattarella, for awarding the work carried out in favor of the sick and most vulnerable people and recognizing the courage, simplicity and everyday heroism. *"Today we are rewarding not only doctors but also those who, through their work and through volunteer activities, defend the health of people in Italy and abroad".*

The honor was attributed to AMICI ONLUS for the following reasons:

"The Association AMICI ONLUS, made up of people with Ulcerative Colitis and Crohn's Disease and their families, pursues exclusively charitable purposes by carrying out social welfare activities and social services.

It aims to promote and encourage awareness of Inflammatory Bowel Disease, in order to facilitate the correct diagnosis and effective treatment. In recent years it has actively developed initiatives to improve the protection of patients, ensuring appropriate means of assistance to patients and their families".

The medal and certificate of merit were received by AMICI President, Enrica Previtali and the National Councillor, Luciana Balestrucci.

The award ceremony was concluded with a quote from Sophocles:

From left to right: Enrica Previtali, AMICI President, Sergio Mattarella, President of the Italian Republic, Beatrice Lorenzin, Minister of Health and Luciana Balestrucci, AMICI Councillor

"The most beautiful work of man is to be helpful to the next".

Luciana Balestrucci,AMICI

Raising funds to find cure for IBD

My name is Lizzie Smith, I live in Nottinghamshire in the UK. I am 29 years old and work as a Physiotherapist at my local hospital. Last year I decided to raise money for the profit free organisation Cure Crohn´s Colitis.

I was diagnosed myself with Crohn's Disease at age 14, after several years of worsening symptoms, including abdominal pain and persistent diarrhoea. Initially my symptoms were thought to be puberty, but a colonoscopy confirmed that I had large amounts of inflammation within my bowel.

Throughout my school years and whilst attending University I had several flares of my Crohn's Disease and I tried a variety of treatments, this included medication such as steroids and anti-inflammatory drugs and over 6 months of liquid feeds. I also changed my diet and lifestyle to try and manage the recurrent flares.

The cycle of flare ups and trying different treatments continued for several years, until eventually when I started work, I became very ill with a flare up and had no choice but to have major bowel surgery at age 23. I suffered with complications post-operatively but thanks to a fantastic surgeon I was able to avoid an ileostomy (for the time being). I struggled with the recovery after my surgery and received Cognitive Behavioural Therapy to help me adjust and mange my chronic condition. Since my surgery I struggled with symptoms until I had another large flare, confirming a reoccurrence of Crohn's Disease and a stricture within the bowel. I was keen to avoid any more surgery in my 20's, so my consultant at my local hospital decided to trial a course of Mercaptopurine and 8 Weekly Infliximab Infusions, as a last resort to surgery.

I have been on the infusions for over 2 years now and have avoided any flare ups of my Crohn's Disease. I still suffer with abdominal pain, diarrhoea, fatigue and joint pain but not nearly as severe as it was with a flare up and I also suffer with the side effects of the medication, but I will take that any day compared to flaring again.

I decided at the beginning of 2016, I wanted to make the most of being in remission and set myself a year of challenges to raise money for Cure Crohn's Colitis. A profit free organisation, where 100% of funds raised goes to helping find a cure for this

In 2016 I participated in 7 Muddy Obstacle Courses

awful disease. I joined an online support group called IBDSuperheroes, whose members organise events to fundraise for Cure Crohn's Colitis. The group also provides online support for any individual with Inflammatory Bowel Disease. It is something I wish I had access to as a teenage/young adult with IBD.

> "I want to inspire and empower to show that.... Obstacles, no matter what they are, don't have to stop you... If you run into a wall.. Don't give up.."

So, the challenges I set all had to be superhero related and something different… I set myself a challenge of completing a 10k Superhero themed run every month of the year in 2016. I also took part in over 7 Muddy Obstacle Courses, including a weekend running over 20 Miles with over 200 obstacles. I also applied to take part in Ninja Warrior UK, a TV show with one of the hardest obstacle courses in the World. To raise awareness for IBD, I went to my audition dressed as Wonder Woman with a t-shirt with the poo emoji, to try and break some of the stigma and taboo associated with Inflammatory Bowel Disease. Out of 30,000 applications, I was chosen as one of 220 to take part in the show. This is being aired in Jan 2017 in the UK.

I have completed all these in between receiving my 8 weekly infusions and taking daily medication and trying to manage my Crohn's.

Through my fundraising I have raised over £1,400 for Cure Crohn's Colitis. As a team IBDSuperheroes have raised over £11,000. I have also qualified via my last obstacle course of 2016 to represent the UK as an Elite Woman in the European Obstacle Race Course Championships in the Netherlands in 2017. I am hoping to also qualify in March to represent the UK in Canada at the World Obstacle Course Race Championships. My fundraising will also continue.....

I want to inspire and empower to show that.... Obstacles, no matter what they are, don't have to stop you... If you run into a wall.. Don't give up..Figure out how to climb it, get around it, go through it...or smash it HULK style. As not all SuperHeroes wear capes (well sometimes).

This is what my parents Dawn and Tony Smith have said….

"We're so proud of our loving and caring 29 year old daughter Lizzie who was diagnosed with the often misunderstood chronic disease called Crohn's some 14 years ago.

During this time, we have seen her battle through the relapses, a major operation, liquid diets for up to 6 months, frequent visits to hospital and invasive procedures/infusions/treatments. Initially rejecting the notion that she had a chronic disease she endeavoured to control her condition & the pain/suffering/limits on leading a normal teenage life causing insecurity, uncertainty and a lack of self confidence, even though she achieved first rate A levels, a first class honours degree and her ambition to qualify as a Physiotherapist.

From her early 20's she has developed her resilience and learned to manage and live with her disease with a positive philosophy of taking each day as it comes and making the most of life. We have seen her personality grow, becoming more assertive and confident yet more compassionate and caring.

This "can do attitude with a smile" has led her to combine her passion for keeping as fit as possible with muddy obstacle course racing (OCR), Ninja warrior training and raising funds for IBD. We're delighted that she has qualified for the European OCR in Holland next year and look forward to supporting her. Lizzie is our super hero and we hope that she inspires fellow Crohn's and Colitis sufferers to live with this disease with a positive attitude and readers of your article to donate to this worthy charity with the objective of finding a cure. For more information:

https://www.justgiving.com/fundraising/EG-SMITH1

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

How the world fell out of my bottom…and other tales

Angela Rolle is the author of "How the world fell out of my bottom…and other tales", a short book which describes her experience with Ulcerative Colitis.

I am originally from Bristol, but have been living in London for over 15 years. I have an M.Phil. in Musical Composition from the University of Leeds. Although I have a background in music and the arts, I worked in education for many years.

I currently work in higher education as a Careers Advisor, but I also think of myself as a 'new' writer due to self-publishing my first book in May this year.

My experience with IBD was quite limited. I heard about the disease many years ago and met people whom had Crohn's Disease. I didn't know anything about Ulcerative Colitis, and was unaware of the problems and challenges I would face - uncontrollable bowel movements, weight loss and many foods which I am unable to tolerate - wheat, gluten, dairy, lamb, pork, raw fruit and vegetables, olive oil, sunflower oil, processed foods and spicy foods. I no longer go out to lunch or dinner as my options are limited and I don't know how the food is prepared.

I have regular appointments at my local hospital, and see a team of consultants, doctors and specialist nurses. I have had flare-ups that disrupt my day, and I have been hospitalised. Due to IBD, my day-to-day routine of work, relationships and social life has changed dramatically.

After being diagnosed with Inflammatory Bowel Disease – Ulcerative Colitis in June 2015, I kept a diary of coping with the condition on a day-to-day basis, from food shopping, to socialising and travel – everything most people take for granted. I tried to keep a sense of humour about the changes I had to make to my life. There are chapters before and after being diagnosed with IBD.

'How the world fell out of my bottom…and other tales' is a short book and an easy read – under 5000 words. It is written in an accessible style - plain language. It is an e-book and can be read on Kindle, PC, tablet and smartphone.

To quote a reviewer on Amazon - 'I'd recommend this to anyone with any long term condition, not just IBD; and also to those who have friends and family members with IBD. 'The book is wittily written and a humbling window into the lives of those with the condition'.

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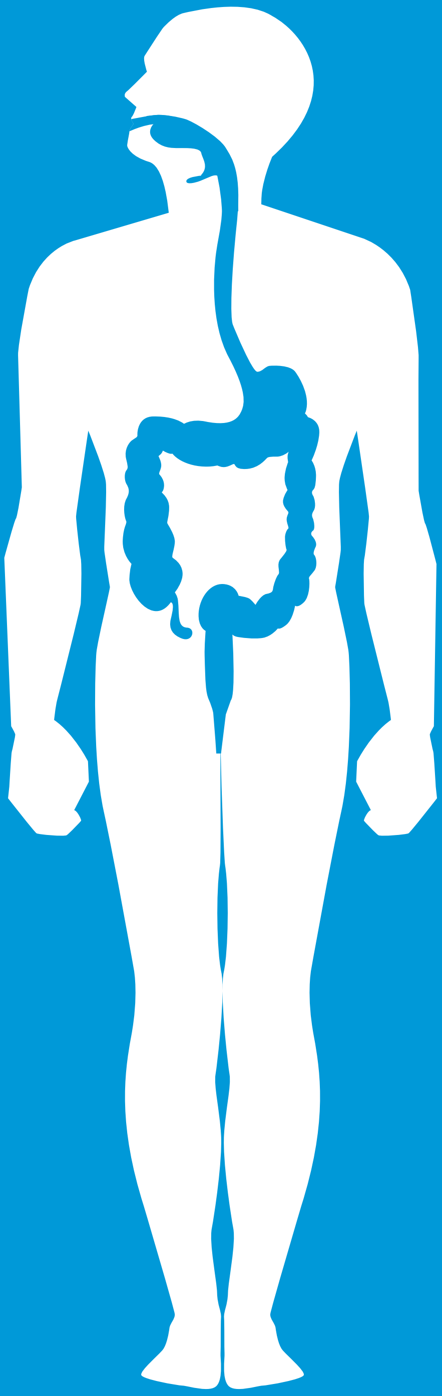

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FERRING ENJOYS A STRONG REPUTATION WITHIN THE INTERNATIONAL GASTROENTEROLOGY COMMUNITY.

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

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PA/030/2014/CH3a

Improving quality of life for people with osteoarthritis

Interview with Dr. Josep Vergés

Josep Verges is the president of the Osteoarthritis Foundation International (OAFI), which was recently established in October 2016. He is also is a medical doctor and vice president of the Spanish League for Rheumatology (LIRE).

What were the reasons for establishing OAFI?

As medical doctor many osteoarthritis patients have approached me asking for help on how to better manage their disease. They were in a lot of pain and felt that their voices and daily concerns were not properly heard.

Following discussions with the Arthritis Foundation (AF) in the US and the Pan-American League of Associations for Rheumatology (PANLAR) we decided to create an international taskforce and our first step was to establish the Osteoarthritis Foundation International which also includes other organizations such for example the Spanish League for Rheumatology (LIRE) and we are in contact with associations in Italy and Belgium.

We are also cooperating with other relevant stakeholders such as medical societies, research and development centers, public administrations and private companies.

The issue of osteoarthritis is increasingly affecting more people of different ages and currently there are over 242 million people that suffer from osteoarthritis, 30 million in Europe alone, which makes up 6 % of the European population.

Osteoarthritis is the first cause of permanent incapacity (lack of mobility) and patients are also at high risk of suffering from other diseases such as cardiovascular diseases, hypertension, anxiety and depression.

Who gets affected by osteoarthritis?

There are three risk groups for osteoarthritis:

The first risk group includes the elderly or let´s say people over 60. This is a huge concern for Europe as we have one of the oldest populations.

The second risk group consists of sportspeople that are involved in high level sport activities such as marathons, triathlons, professional football players etc. And finally, the third risk group includes menopausal women (above 45). Recent studies show that over 80 % of menopausal women suffer from some kind of joint pain.

What´s your main mission?

Our main mission is to improve the quality of life of people with osteoarthritis and my dream is that OAFI becomes a platform that helps people with osteoarthritis, be it older people, sports people or menopausal women, to feel better.

We are trying to do this through awareness raising and prevention of the disease. We believe that educational activities, starting already with children, are essential in preventing the disease and ensuring healthy joints.

Are you working on any concrete projects?

Yes, we have recently signed an agreement with the ¨la Caixa Foundation¨ that will support us in an exciting project involving over 200 osteoarthritis patients. During the initial phase, a smaller group consisting of 12 patients will receive a training programme aimed at complementing their medical treatment plan.

The training programme will address issues such as how to lose weight (a common concern for elderly OA patients), how to improve/build up muscles, what kind of sports to practice, options/methods that provide psychological support etc. Relevant experts including rheumatologists, psychologists, rehabilitation specialists and nurses will provide this training.

The idea is that this group of patients will not only learn how to improve their own quality of life but they will also be trained to help a wider group of patients involving over 200 people.

Through this training programme we hope to improve patients mobility as much as 20 % and if successful this project could be implemented nationally as well as internationally.

We are also currently preparing a project involving 1200 schools where we want to teach children the importance of joints, how they can protect their joints from lesions and overuse, what kind of sports they can do taking into accounts each child´s individual body shape and orthopedic condition etc.

An addition to these two projects we are also carrying out an international survey amongst osteoarthritis patients to assess their perception of the disease and we are keen to get a registry of all OA patients from around the world.

We are also in the process of launching the OAFI website so that we can reach more patients and stakeholders and let them know about our valuable work.

Finally, we are also planning to organize the first international congress of OA patients in Barcelona next year, probably in October 2017.

What are your main challenges?

Our main challenge is to change people´s perception about osteoarthritis. It is commonly seen as an unavoidable “side-effect” of ageing even though the elderly might be otherwise healthy. As a consequence the disease is not properly managed and the patient´s quality of life diminishes.

As mentioned previously the disease does not only affect the elderly but also high performance sports people. It is important to raise awareness about this and to start with early prevention measures.

For more information please visit OAFI´s website www.oafifoundation.com or follow them on social media @OAFIFOUNDATION.

European Patient Forum: Campaign on Access to Healthcare

From January 2017, EPF carries a flagship campaign on Access to Healthcare. This theme is a long standing priority for EPF and its membership, and is at the heart of the vision of the organisation.

Under the tagline 'Universal Health Coverage For All', the campaign is an opportunity to raise awareness about the barriers patients face in accessing healthcare, and to build on current political momentum – including the UN Sustainable Development Goals for health – to foster more EU cooperation on access to healthcare.

The EPF Working Group on Access drafted the following overarching strategic objective for the campaign: "The EPF Access campaign will contribute to make universal access a reality for EU patients by 2030, through defining and promoting concrete actions, in concert with the health community, to which decision makers need to commit, to ensure we achieve the Health SDGs by 2030."

EPF has used its prior work on access to shape the messages of the campaign; in particular looking at the definition of access to healthcare, and the statement on pricing and reimbursement of innovative medicines.

Practical info

The one-year campaign will be officially launched on 27 February at the European Parliament, in Brussels. The event – co-hosted by MEP Katerina Konecná (GUE/NGL, Czech Republic) and MEP Andrey Kovatchev (EPP, Bulgaria) – will be an opportunity to present the campaign and to discuss what actions should be taken to achieve Universal Health Coverage at European level.

Rationale – Why a campaign on access?

Disparities in access to healthcare predate the financial crisis in Europe, but against a background of austerity measures and falling healthcare spending in many Member States since 2009, inequalities have been made worse. Access to care is affected by austerity policies in response to the economic crisis, such as cuts in healthcare budgets and in insurance coverage, increased fees and co-payments, and cuts in social protection measures.

At the same time, healthcare systems are facing increasing demands as a result of demographic change. As the population ages, the number of patients with chronic diseases is growing. Patients who developed a chronic disease at a younger age are also living longer, thanks to modern medical treatments. Patients with chronic diseases develop specific needs which the healthcare systems need to adapt to.

Patients across the EU are reporting multiple barriers to access to healthcare, whether it's not available, not adapted to needs, or not affordable. EU Member States need to overturn the current trends of short sighted decisions on investment in healthcare, and commit to realising universal access by 2030 by taking concrete steps. EU Member States need to achieve universal health coverage and improve access to healthcare by 2030 according to the UN Sustainable Development Goals.

Contact

If you have questions about the campaign, don't hesitate to contact us!

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Discovery of new organ in the digestive system

Following research at the University of Limerick the team of Prof J Calvin Coffey has identified the mesentery as a single structure and has reclassified it as an organ. The mesentery connects the intestine to the stomach and previously has been considered to be made up of lots of separate parts.

Introduction

The mesentry has been known for centuries by surgeons, medical illustrators and physicians but it is only now that it is regarded as contiguous and as a separate identity. It emerges from the superior mesenteric root region and fans out to span the intestine from duodenum to rectum; however, the continuity can be seen only when the mesentery is exposed in a certain way.

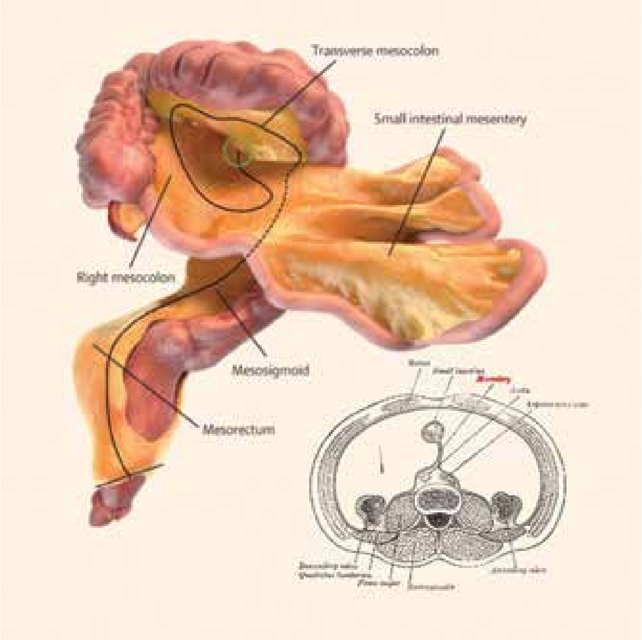
In an observational cohort study, patients undergoing complete mesocolic excision, the authors demonstrated the mesenteric contiguity. This was also confirmed by similar observations made in cadaveric study of the same approach.

Why is this discovery important?

Universal recognition of the mesentry as a separate organ allows for standardisation of the resection process and permitting valid comparisons in clinical trials. This has so far been lacking, and related surgical literature is dominated by trials comparing types of mesenteric-based surgery (total mesorectal excision, complete mesocolic excision) with ill-defined approaches collectively referred to as "conventional" surgery.

It is also highly relevant for educational matters making it possible for the colorectal community to be systematic in performing and reaching intestinomesenteric mobilisation and resection.

However the most important aspect of this discovery is that it now enables a rigorous and scientific study of it. It provides for new, promising investigations into the role of the mesentery in health and disease.



The mesentry is implicated in the pathobiology of diverse abdominal and non-abdominal disorders, including colorectal cancer, inflammatory bowel disease, diverticular disease, cardiovascular disease, diabetes, obesity, and metabolic syndrome.

Clarification of mesenteric anatomy has also substantial benefits for colorectal surgery as it can be more systematized, allowing for educational information and lead to standardisation of the surgical process.

In terms of Inflammatory Bowel Disease such as Crohn´s disease recommendations have been made that the mesentery should be included in resections. This has been previously largely ignored due to the dangers (e.g. extensive haemorrhage) associated with division of the Crohn's mesentery. Reoperation rates remain as high as 40% after resection for Crohn's disease.

Another area that will benefit from these findings is mesenteric pharmacology. So far few data are available on drug pharmacokinetics or pharmacodynamics within the mesentery. Early findings in mouse studies suggest that infliximab can alter the mesenteric cytokine environment. It is foreseen that with the growing recognition of the central functionality of the mesentery, the number of studies is likely to expand.

In summary the research promises benefits to gastroenterology in terms of improved diagnostics and an expansion of therapeutics in general. Benefits to radiological appraisal of the abdomen will be achieved by increased accuracy in the interpretation of abdominal disease. Pathology will benefit from enahnced comprehensive understanding in an array of abdominal and non-abdominal conditions. In surgery, it is expected that surgical technique, standardisation of the craft component of abdominal surgery, and its future scientific investigation will all be improved.

"The mesentery: structure, function, and role in disease", J Calvin Coffey, D Peter O'Leary, Lancet Gastroenterol Hepatol Lancet Gastroenterol Hepatology, 2016.

Stimulation of Vagus nerve to help control inflammation in IBD

A recent study at the Georgia Institute of Technology researched the anti-inflammatory effects of vagus nerve stimulation through a newly developed device that allows the nerve to be electrically stimulated without causing unwanted side effects.

The vagus nerve is the longest of the cranial nerves, extending from the brainstem to the abdomen passing through various organs such as the heart, esophagus, and lungs and interfaces with parasympathetic control of the heart, lungs and digestive tract i.e. keeping the heart rate constant and controlling food digestion.

The study, which was published in the jouranl Scientific Reports, investigated how stimulation of the vagus nerve could control inflammation which is highly relevant for IBD patients that suffer from serious, chronic activation of the inflammatory pathways. It is important though to note that vagus nerve stimulation can also have the opposite effect and lead to inflammation, that´s why engineers from the Georgia Institute of Technology studied how to promote the good effects and how to keep unwanted side effects to a minimum.

"We use an electrode with a kilohertz frequency that blocks unwanted nerve conduction in addition to the electrode that stimulates nerve activity," said principal investigator Robert Butera, a professor involved in the study.

"The original studies in animals on the anti-inflammatory benefits of vagus nerve stimulation resorted to nerve transections to achieve directional stimulation as well as boost effectiveness of nerve stimulation," Yogi Patel, the study's lead author, said in a news release. "But cutting the vagus is not clinically viable — due to the multitude of vital bodily functions it monitors and regulates. Our approach provides the same therapeutic benefit, but is also immediately reversible, controllable, and clinically feasible."

"Kilohertz frequency nerve block enhances anti-inflammatory effects of vagus nerve stimulation", Yogi A. Patel, Tarun Saxena, Ravi V. Bellamkonda & Robert J. Butera, Scientific Reports 7, published online 5 January 2017.

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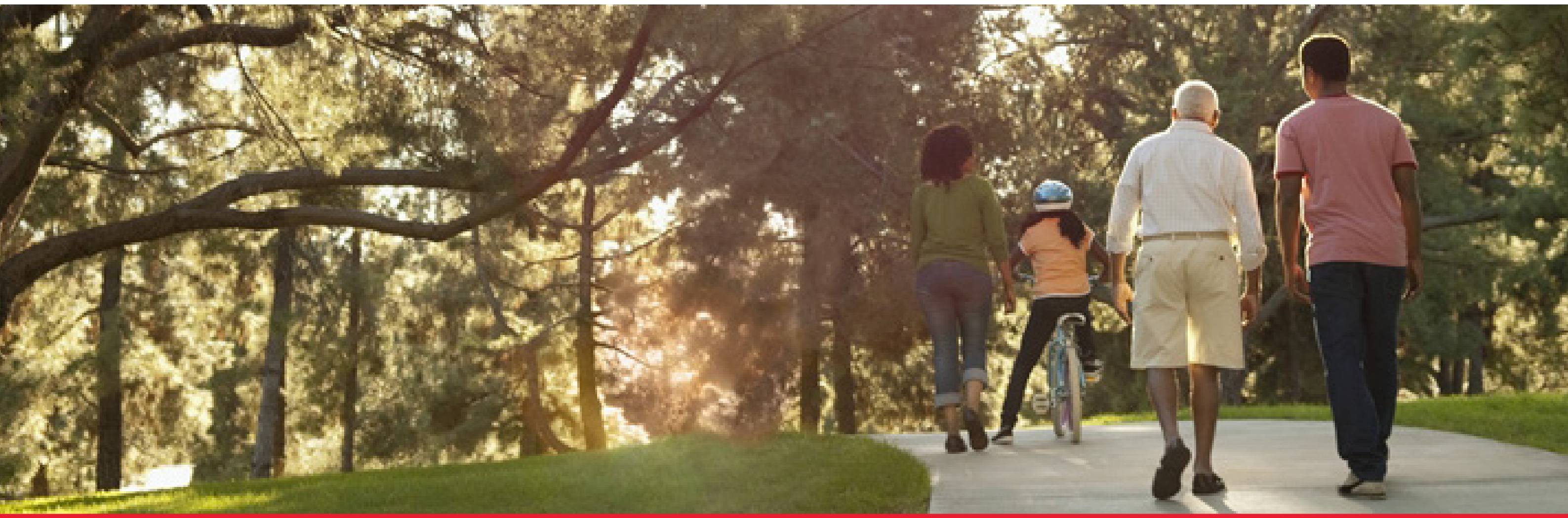

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