

# EFCCA MAGAZINE

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



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**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 - HELLJESCC  
www.crohnhellas.gr

Hungary –MCCBE  
www.mccbe.hu

Iceland – ICCA  
www.ccu.is

Ireland – ISCC  
www.iscc.ie

Israel - CCFI  
www.ccfi.co.il/  
Italy – AMICI  
www.amiciitalia.org

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

Malta – MACC  
www.macc.org.mt

Norway – LMF  
www.lmf norge.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

Turkey - IBHDYD  
www.ibhportali.com/

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

Associate Members:

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

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

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# EDITOR'S EYE

## Making the invisible visible



The month of May is one of our busiest but also most exciting months of the year. It's when we commemorate World IBD Day on 19 May showing to the world what it means to live with IBD. It's a day about sharing our daily struggles, challenges and fears but also about talking about our hopes, aspirations and dreams.

This year we have decided to continue with last year's highly successful campaign of lightening famous landmarks in purple, the colour for IBD, in order to raise awareness of the 5 million people that are living with IBD worldwide including 3 million in Europe! It's about shining light and making the invisible visible!

It's also an exciting moment as we reach out from our mainly European constituency to other parts of the world, and we are working closely with our partner sister organisations such as the Crohn's and Colitis Foundation (US), Crohn's and Colitis Canada, Crohn's and Colitis Australia and ABCD in Brazil. Moreover IBD associations and individual IBD activists are getting in touch with us to show their support and willingness to join our struggle. From Trinidad and Tobago, to Mexico, India and Russia, just to name a few. This clearly shows us that over the years we have become the main reference point for the global IBD community.

Another interesting development within EFCCA is our potential participation in two Horizon2020 European funded projects. We have been trying for several years to participate in EU funded project and we are pleased that one of the project, in which EFCCA is a partner, has been shortlisted while the other project has been resubmitted.

These projects allow us to establish new networks and links with hospitals and research centers specializing in IBD. You will find more information about these project proposals in the EFCCA news section of this magazine.

Another important subject for us is patient safety and we have been working on this since 2014 with the launch of the BAB survey and the subsequent presentation of its finding at a conference last November in the European Parliament. This work has given us a prominent and distinctive voice in the political and social debate on biologic and biosimilar treatments.

We are continuing with our efforts to promote patient safety and patient empowerment and are organizing, together with the Global Alliance for Patient Access (GAPPA), a further advocacy training to several members and other immune-mediate disease patient organisations taking place in Munich, Germany from 4-5 May

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2017(more details in this issue). With such activities we want to stress the crucial role of patients in all decision making processes and keeping patient at the center.

Finally, to end our long list of activities during the month of May, we will meet with all our members at the General Assembly in Warsaw, Poland from 26-28 May 2017, which is being hosted by J-elita, our Polish member.

In this issue you will find inspiring examples of how EFCCA, the EFCCA Youth Group, our members and partner organisations as well as individuals are challenging IBD. It is our common fight in which we stand together until one day we will find a cure!

United We Stand

Martin Kojinkov, EFCCA chairman



# World IBD Day - Together we are stronger

Following last year's successful World IBD Day campaign, which saw over 140 landmarks worldwide being lit up in purple in order to raise awareness about inflammatory bowel disease (IBD), this year we will continue our efforts to raise public awareness about the over 5 million people that are living with IBD.

The European Federation of Crohn's and Colitis Associations (EFCCA) together with its 33 patient association members and IBD sister associations from Australia, Canada, US, Brazil (and numbers are growing) aim to involve even more cities and countries to join our campaign.

Many cities have already agreed to light up their emblematic buildings and landmarks in purple on 19 May in order to shine a light on the invisible difficulties and challenges that people with IBD face in their daily lives. At the closing date of this publication we had confirmations from over 70 cities/region eager to participate in World IBD Day and to support our cause and many more are expected to join. The

majority of our member associations are using the campaign to advocate at their local and national level for better patient rights, better quality of life and a better recognition and consideration of their members needs and priorities.

EFCCA will also participate in a live video chat on 19 May that is being organized by the Crohn's & Colitis Foundation (US) in order to discuss the differences in IBD diagnosis and treatment globally and many other stakeholders such as physicians, nurses, representatives from the pharmaceutical companies are supporting our cause and are organizing internal events to commemorate World IBD Day.

## World IBD Day 19 MAY

#worldibdday2017  
#unitedwestand2017





The World IBD Day website has been recently refurbished and is our virtual platform to share all the information of activities that are taking place around the world.

World IBD Day has become a very important day for the whole IBD patient community as it provides us with a highly visible opportunity to reach out to people to inform, to educate, to mobilize and to advocate for a better quality of life.

It is also the moment to show solidarity with people in countries where there is only limited or no access to adequate treatment options as well as with those people who feel isolated from their communities because of their disease. On World IBD Day we want to give support, raise our voice and unite in our common fight against IBD because together we are stronger!

For more information about our campaign please visit: [www.worldibdday.org](http://www.worldibdday.org)

## Patient Access and Advocacy Workshop

**EFCCA together with the Global Alliance for Patient Access (GAfPA) is organising a Patient Access and Advocacy workshop, which takes place in Munich, Germany on 4-5 May and brings together a group of around 10-15 participants from IBD patient associations and related immune modulated disease groups.**

EFCCA together with the Global Alliance for Patient Access (GAfPA) is organising a Patient Access and Advocacy workshop, which takes place in Munich, Germany on 4-5 May.

The workshop builds on the joint work that EFCCA and GAfPA have undertaken in 2016 within the framework of patient safety and thus providing or improving basic understanding of the science and issues associated with biological medicines and biosimilars. During the Munich workshop, participants will be discussing issues that impact on the access to biologic and biosimilar treatments and they will be identifying priorities to be brought to policymakers in Europe.

Two of our EFCCA members, Austria and Serbia, will be moderating a Round Table discussion and presenting their national state of the art as far as biologics and biosimilars are concerned. This will offer participants some concrete and inspiring information on what is really going on in our IBD patient community.

For more information please contact the office.



*Last year's publication summarizes the main messages and patient concerns with regard to Biologics and Biosimilars*

# Mapping the access to innovative treatments in EFCCA countries

**National health systems and access to various treatments tend to be unequal in EFCCA member countries, particularly in regards to new, innovative treatments and devices. To help reduce health inequalities in Europe, EFCCA designed a project to thoroughly map the access to and availability of innovative treatments in EFCCA member countries.**

An EFCCA working group designed an online survey, and seven national IBD associations (Finland, France, New Zealand, Poland, Serbia, Slovenia and Spain) participated in the pilot phase in October-December 2016 to test the online survey. In most participating countries, the survey was filled by someone from the patient association in cooperation with gastroenterologists. The pilot phase showed some technical and content issues that were fixed before launching the next phase.

## Pilot phase outcomes

The availability and source of a precise number of IBD patients varied greatly in the pilot countries. In Finland, for example, a number (45 000) is provided by the Social Insurance Institute based on the amount of patients receiving coverage for medication based on IBD diagnosis, whereas Serbia, for example, has a register of patients, but the data is incomplete and the number of patients (7000-8000) is estimated by gastroenterologists. All pilot countries had a universal state insurance / public health service with a possible additional private insurance.

In most pilot countries health insurance is financed by employers, employees and/or the state together, with small variations in who pays what at what point and how the reimbursement process works. In Finland, Poland, Serbia, Slovenia and Spain the patient can choose their GP / specialist / point of care freely, whereas in New Zealand the GP / specialist / point of care is defined by the system based on e.g. where the patient lives.

In France the access to a specialist is granted only if the patient first went to his GP, who then gives his



green light to consultation with specialists. Access to IBD medication requires an official recognition of diagnosis in Finland (a marking on the health insurance card) and Poland (needs to be confirmed by a specialist).

## Access to biologics

Humira (adalimumab) and Remicade (infliximab) are approved to IBD patients in all pilot countries. Only Poland and Serbia had data on how many patients are receiving these treatments. In Finland, Remicade is no longer used in adult patients, and in Poland, Serbia and Slovenia, certain preconditions need to be met for the patient to have access to the drug. Simponi (golimumab) is approved to IBD patients in Finland, Serbia, Slovenia and Spain, but in Spain it is available for ulcerative colitis patients only. In Serbia, the therapy is in the procurement process.

Cimzia (certolizumab) is approved to IBD patients in Finland and Spain (but has no trading license). Entyvio (vedolizumab) is approved to IBD patients

in Finland, France, Slovenia (available for ulcerative colitis but not Crohn's disease patients) and Spain (available for Crohn's disease but not ulcerative colitis patients). No country had data about the number of patients receiving golimumab, certolizumab or vedolizumab.

### Access to biosimilars and devices / techniques

Inflectra (infliximab) is approved to IBD patients in Finland, France, Poland, Serbia (in procurement process), Slovenia and Spain (not available in every hospital). Remsima (infliximab) is approved to IBD patients in Finland (more common than Inflectra), France, Poland, Slovenia, Spain (not available in every hospital). Only Poland had an estimate of how many patients are receiving the treatment; other countries had no data.

Otsuka Adacolumn is available for IBD patients in Finland (unusual, lack of good experiences), France (few gastroenterologists administer it due to its medical complexity) and Spain (unusual due to costs). No country had data about the number of patients receiving the treatment.

### Analyzing the pilot phase outcomes

The pilot phase showed that lots of data, e.g. total number of IBD patients, number of patients receiving a certain drug etc., is simply not available, and that there are variations in policies and access to medicines between the countries or even within one country.

The second phase, where all EFCCA members are expected to participate, is in process and will bring a more clear insight on the situation in Europe. The second phase will close in the summer 2017, the outcomes will be analyzed by the end of 2017, and the final report will be published in the beginning of 2018.

The outcomes of the project will support the exchange of knowledge and experience among EFCCA members, promote a better understanding of European healthcare systems, improve the mobility of people with IBD in European countries and facilitate the access to treatment in other countries; they can also be used in lobbying for the innovative treatments in EFCCA countries.

Sanna Lönnfors, EFCCA Scientific Adviser

## Horizon2020 project proposals

**After several years of attempts to participate in EU funded projects EFCCA is glad to inform that one of the several Horizon2020 projects, where we agreed in partnering, has been shortlisted while a second project proposal has been re-submitted.**

CER4IBD - Comparative Effectiveness Research for Inflammatory Bowel Diseases will involve the following partners: GETAID (Groupe d'étude thérapeutique des affections inflammatoires digestives) in France; the CHE (Centre Hospitalier Universitaire in Nancy - France), the Region Hovedstaden in Denmark, the University of Liverpool, the CHU (Centre Hospitalier Universitaire Vaudois – Switzerland) and EFCCA.

The CER4IBD project is focused on a programme comparing the effectiveness of most frequently used treatment strategies for adults used alone or in combination with other treatments in order to measure their real impact for patients, caregivers and healthcare systems. EFCCA will be in charge of the package related to communication and dissemination of the results and will be also involved in the design of some concrete tools as well as general project



Not just healthcare.



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management. We expect the results of the selection to be announced by October 2017 and hopefully, if successful, we will be able to kick off this EU funded project before the end of 2017.

The APPROACH project is the other Horizon2020 project that has been resubmitted. The lead partner is the Inflammatory Bowel Disease Centre Academic Medical Centre of Amsterdam, coordinated by Professor Geert D'Haens and the aim of the project is to develop a predictive model for treatment response by means of patient stratification and identifying biomarkers that will enable personalised medical treatment of CD patients. EFCCA has signed a letter of support and we will be waiting for more news in autumn.

Finally, a third important opportunity has become a concrete activity: the project "UC University: shared knowledge powered by patients and professionals" with the following partnership: the department of Gastroenterology and Hepatology of the Erasmus

MC (EMC) Rotterdam (the Netherlands), EFCCA, the European Crohn's and Colitis Organisation (ECCO) and the United European Gastroenterology Federation (UEGF). The overall goal of this project is to develop and perform effective education on ulcerative colitis both for professionals and patients that will enhance shared decision in the management of the disease. To implement an effective shared decision model in UC management both patients and professionals will be the target of training modules whose design and implementation will be commonly agreed. The first meeting of the project took place on 24 April in Amsterdam.

These three projects presented above will not be funded through industry grants and represent a concrete sign of our growing visibility and professional reputation in the IBD community.

Luisa Avedano  
EFCCA CEO

## From IMPACT to IMPACTFUL

**This project is based on the IMPACT survey that is still one of the most powerful resources in assessing the perspectives of IBD patients about their disease and its impact on their lives, relationships and careers. The main findings of the survey show that the impact of IBD on patients' life still needs to be improved and further efforts need to be made to address these issues at a policy level.**

A couple of years later another survey – IBD 2020 - involving 6 countries was developed in order to assess the quality of care and define further paths to improve it, identifying, among others, the need of quality measures and improving data quality. Finally, Boston Consulting Group recently published a White Paper with the aim to gather patient-reported outcomes based on the recently released ICHOM standard set, in three European countries (the UK, Sweden, and Italy) in order to measure the impact of IBD on patients' quality of life.

Given the similarities and outcomes of the above-mentioned surveys, EFCCA has started a new project aiming to work on this information and analyze the

main messages / findings of these documents on the basis of our patient community's perspectives and unmet needs.

The main objective is thus to brainstorm and identify further actions and initiatives starting from the most interesting outcomes issued from these surveys. EFCCA is aware that shared knowledge and data collection are of paramount importance for a better tuning of care and quality of life in IBD so we believe that such an exercise could give us further nourishment for our future activities.

The basic assumption that gave shape to this project is that IBD patients' expertise, commitment



*Participants at the Berlin preparatory phase meeting, 27 March 2017*

and competences can contribute to a deeper and more effective understanding of the burden of the disease and improve patients' daily life.

The first part of the project took place last 27 March in Berlin: a preparatory phase with methodology based on a Patient Focus Group that involved EFCCA representatives from Austria, Croatia, Estonia, Italy, Poland, Serbia, Spain and Sweden and which was coordinated by Sanna Lonnfors, EFCCA scientific adviser.

The second part took place on 27 April, in Berlin in order to identify priorities and potential further initiatives issued during the Patient Focus Group, in order to transform them into concrete actions. This phase also benefited from physicians contributions.

The project has received an unrestricted educational grant by Takeda.

## Regional volunteers meeting

**Enrica Previtali, AMICI President, Salvo Leone, AMICI Director, and over 40 regional volunteers met to exchange information, activities and initiatives taking place in the whole Italian territory.**

Luisa Avedano represented EFCCA and talked about main projects and activities, furthermore the meeting provided an excellent opportunity to get to know the concrete work that IBD patients are developing as volunteers in Italy. Some of the projects presented by the volunteers were very inspirational and we hope to have the chance in the near future to co-design similar activities with AMICI and other members.

A friendly environment where a professional approach and engagement made the perfect ingredient of a special sunny day in Milan!



# Travel and IBD

**It might not be the first thing you think of when being diagnosed with a condition or starting to live life with a condition but travelling can become an anxious topic for people living with IBD. Simply from being scared of leaving the house in case of the urgency of needing to go to the toilet or from going on holiday and feeling anxious about travelling with medication or feeling unsure on whether your diet requirements will be met etc it can cause more stress than enjoyment.**

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 leave the house? Can I use public transport? Can I get travel insurance?

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.

## I want to see the world and IBD can't stop me...

My story started when I was diagnosed as a teenager which is exactly the age you want to experience the world, enjoy parties, friends and first love. The first years of my diagnosis were harsh I was constantly in pain, regularly in hospitals and almost all the time near the restrooms. During my studies at university I realised I don't want to just survive but I wanted to really live my life to the max so I got the best medication for my condition that suited me and started my life again, doing the things I had taken for granted previously.

Only in last two years with my supportive boyfriend have I started to travel more, visiting more than twenty places around the world. We have enjoyed visiting exciting places which include the North Pole, Norway to see the Northern Lights, Chernobyl where we spent some time in a radioactive area as well as being fortunate enough to also explore Italy, Slovenia, Germany, and Austria.

This April 2017 we drove around California, Nevada, Arizona and Utah. It was a three week adventure filled with beautiful nature, animals and interesting places. Plus America has toilets everywhere, even in a desert. So why not to go?!

Over the years travelling with IBD has allowed me to develop several techniques which I use while preparing to travel.

My traveling tips:

### **Travel in remission (if possible)**

It is always best to travel when in remission as when you are in a flare up it can cause mental or physical stress which can take the enjoyment away from the holiday. Remember if you do have to try while in a flare to explore all options to make your trip more comfortable, seats close to toilets on the plane,





*“I’m Lucie Lastikova, a young passionate traveller as well as a patient with Ulcerative Colitis. I have been involved with the EFCCA Youth Group and wanted to share my story to help support others to ensure they know they aren’t alone.”*

special underwear to combat accidents etc.

### **Have a good health insurance**

Always ensure you get the right travel insurance for the trip you are taking, it is not worth taking the risk when you have a chronic condition.

### **Take extra medication**

Always take a few extras days’ worth of medication – just in case you get stuck at an airport or destination.

### **Have a list of your medication in English – just in case**

Some medication might not be commonly known in countries you are visiting so it is always handy to have a full list of medication you are taking in English just in case you need to share with medical professionals or even airport security.

Some countries have strict drug policies so it’s

always good to check embassy website or even the World Health Organisation website (WHO).

### **Vaccination**

Choose wisely where you travel. If you are on immunosuppressants you probably can’t be vaccinated for some diseases and it is safer to choose another country. Due to Malaria or Typhus I am choosing not to travel deeper into Asia, at least not yet.

### **Water and Food**

Everyone should consider this point while travelling, but especially if you have IBD. It is advised to drink bottled water and eat in establishments that have good hygiene ratings, for example, it may be best to avoid street food and ice cream.

### **Hot weather**

My body struggles in the heat this is why I tend



to choose places with cooler climate but even exotic places are great to visit in cooler seasons. Travel when it suits you and if it is hot ensure you keep drinking plenty of water and keep in the shade.

### **Do not be stressed**

Make the people who you are travelling with aware of your condition to ensure you don't worry or stress about needing extra toilet stops.

### **Try to relax and enjoy your trip**

IBD can cause a lot of anxiety especially when travelling so ensure you relax and enjoy rather than over thinking the "what ifs" in your head which could ruin the trip.

I don't know where my next adventure will take me but I know they will continue and IBD will not stop me.



*Lucie in Chernobyl (above) and some fun sports activities (below)*



# Tom's Top Travelling Tips...

Keep your routine - Mornings are the worse for my symptoms so I always tend to need to wake up an hour earlier than others and I stick to this even when away, making sure I also have at least something for breakfast. Snacking during the day helps me too so I

sometimes bring some snacks with me from home on shorter trips.

Stay hydrated - on holiday I'm on the move a lot exploring cities and it's hard to remember to drink enough so I typically carry a water bottle (where the





tap water is safe to drink) or purchase bottled water in the morning and carry it with me.

Toilet access - hotel toilets are great as don't really need to ask for permission to use them or potentially learning the name or phrase for using the toilet in the local language. Carrying tissues and hand sanitiser is also a good idea as you're never sure on the standard of toilet until it's too late!

Choose the aisle seat - More for long haul flights or days when you're not feeling great as I never like to disturb passengers sitting next to me too much by potential repeated visits to the toilet. Sometimes I've swapped seats telling them I have a dodgy stomach if they ask why.

Medication and insurance - remember to bring enough with you and always get your IBD covered

under your travel insurance. Medication also includes pain relief as you never know where you'll be when you'll need it most.

We hope you have found these real life examples and tips useful and that it helps to reassure you are not alone when it comes to learning about your travel needs with IBD.

*Tom Hough is member of the EFCCA Youth Group and travels a lot for holidays as well as running marathons, sharing them all on his blog called 'The Chronic Adventurer'. For this issue he has shared his tips that help reduce the impact his Crohn's Disease has on his adventures.*

## About the EFCCA Youth Group

The EFCCA European youth group have been continuing to help support young sufferers with IBD as well as breaking taboos which come with the conditions.

We are a group of young people who all suffer with IBD and know what it is like living with conditions associated with IBD.

Just like the previous youth group who published articles about taboos and IBD to try and break barriers and crush stigma that might be associated with the conditions, we are continuing with this essential work by writing first hand 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.





## 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.



## UK

# Toilet sign campaign gains momentum

**An email campaign launched by Crohn's and Colitis UK in 2016 has persuaded the UK's supermarket giants to install new signs on their accessible toilets to acknowledge that not every disability is visible.**

Nearly 19,000 emails have been sent to CEOs of leading supermarkets in the UK, with Asda, Morrisons and Tesco all now on board.

Access to toilets when away from home was the number-one issue raised by Crohn's and Colitis UK members in a survey that asked what would have an impact on their lives, with 86% saying improved access was needed.

According to a Colostomy Association survey on the quality of life of ostomates living in the UK, 30% had been challenged for using an accessible toilet. The Crohn's and Colitis UK campaign seeks to raise awareness of IBD as a hidden disability.

Dan McLean, director of marketing, communications and membership at Crohn's and Colitis UK, said: "This is a great step towards reducing stigma and raising awareness that not every disability is visible and everyone is grateful to the supermarkets for making these changes so swiftly. People living with IBD can be very disadvantaged by the impact of their condition. The experience or fear of unpredictable incontinence is undermining to a person's confidence and self-esteem, and can lead in some cases to the person affected becoming too anxious to leave their home."

Sam Cleasby, 35, from Sheffield, has a permanent ostomy bag and wrote a blog post in 2015 that went





viral after facing criticism from a fellow shopper for using an accessible toilet. Sam who is a community champion for Crohn's and Colitis UK, said: "There are times when going to the supermarket feels more like climbing Mount Everest. I have Ulcerative Colitis and a permanent ostomy bag, which I sometimes have to change while out and about. Yet to look at me, you wouldn't be able to tell that I had any extra needs.

"When I called out the people who tutted, laughed and judged me for using an accessible toilet on my blog, So Bad Ass, I never expected the enormous response I received from people who had faced the same issues: my story was read two million times and was shared all over the world. It was heartbreaking

to read so many similar stories from people with all manner of 'invisible disabilities', such as dementia, cancer, Tourette's, and those with ostomy bags or other toilet needs whose lives were being made more difficult by the judgment and ignorance of others.

"To know that supermarkets are making a positive change in signage to alert the public that not all disabilities are visible simply means the world. It means the next time I am facing my Mount Everest moment, those around me might just have learned enough to stop judging and know that sometimes there is more than meets the eye."

## Streets ahead

**More than 3,250 people helped raise £308,000 for Crohn's and Colitis UK in 2016...by walking. This year's event will be bigger and better, taking place in eight cities during June and July.**

Sarah Jane Lamond, 31, from North Ayrshire participated in the Edinburgh 5k WALK IT event last year. Sarah Jane was diagnosed with Crohn's Disease in July 2015. Her mother also had the condition, and sadly passed away aged 40 due to complications that resulted in a pelvic abscess in 2000.

Along with her husband Chris and daughter Isla Mae, four, Sarah Jane was accompanied on the walk by her sister-in-law Shauna Lamond, and friends Andrew and Claire McKay and their daughters, Holly, six, and Erin, three.

"Everyone was in very high spirits, with participants of all ages taking part in the walk and raising awareness for the charity. The kids had a bouncy castle and face painting, which was great fun in the lead-up to the walk," says Sarah Jane. "Walking through the city itself was electrifying, and the number of people who looked at the T-shirts and spoke with us on our way



meant there was a great amount of support for all the walkers."

Sarah Jane says even the three young girls managed to complete the walk without too much stalling “but an ice cream along the way helped!”

As a team, the families managed to raise £500 for Crohn's and Colitis UK. “It was considerably more than we expected,” says Sarah Jane. “We were all exceedingly grateful for the generosity of friends and family.”

Sarah Jane explains her reasons for doing the walk: “I wanted to raise awareness of both of the conditions, and support the charity and others who may not have been able to participate.”

She was also celebrating her own better health. “In July 2015 I could barely walk due to a mass on my right side,” she says. “I was admitted to hospital for a week. I had a CT scan, steroids, antibiotics and a blood transfusion. The results showed septicaemia and Crohn's Disease.

“I came home and tried to just get on with the day-to-day business of looking after my daughter, aged three, and working as a self-employed mobile massage therapist while on 25 pills a day. However, deep down, I knew I was nowhere near being well.”

Sarah Jane says that, after much deliberation, she took her consultant's advice to have a right hemicolectomy on 14 October 2015.

“I was lucky I did make that choice, as it saved my life. I had a major blockage, had perforated my bowel and my bowel had also attached itself to my abdomen wall,” she says.

“Well, to say it was a scary time is an understatement, but it was the best decision I have ever made. After 12 weeks off work I returned and I'm busier than ever. I have a much better quality of life, even managing a holiday to Spain in Easter last year. From 25 pills a



day last July I'm now on just one immunosuppressant a day.

"I know the real effects this disease can have on an individual and a family." For others considering joining a WALK IT event in 2017, Sarah Jane says: "Please come along and show your support. It's

a great day out for all the family. Take your friends and family along to support you and the great charity. "Having my friends' and family's support since my diagnosis has got me through my journey. They've not only supported me physically after my operation and on the WALK IT event, but mentally too."

## Belgium

### VENI, VIDI, VICI...IBD !

**A bit more than two thousand years ago (50 BC), when conquering Gaul, emperor Julius Caesar made his historical remark: « veni, vidi, vici » which translates into "I came, I saw, I conquered".**



As Belgians belonging to ancient Gaul, we decided to use this famous quotation in our war against IBD, especially as the acronym IBD translates as MICI in French, which nicely rhymes with the 3 previous, latin words.

So..we printed "VENI, VIDI, VICI...MICI !" on one thousand purple wristbands which sell like hot cakes for the modest sum of €2. Given its pronunciation, IBD also rhymes with those words, so why not making those purple wristbands on an international level ...? When we win the war against the IBD, we also will say : veni, vidi, vici... ibd !





# Israel

## CCFI on Advancing Patients' Rights

**Advancing patient's rights is one of CCFI's fundamental goals and has been at the forefront of the association's activities in the past years. CCFI's strategy is to promote initiatives and take an active role in driving change.**

This year, following a two year initiative, the Ministry of Health has finally issued a regulation, replacing CT's and making MRI as the preferred medical examination, for patients who are exposed to repeated radiation. This is a case where the association identified an urgent problem that cannot wait for the system to correct from within. Although it took the time it did, the result is tremendously important.

Another initiative we took this year was to provide the necessary tools for every patient to fully receive social benefits granted by law. Materializing lawful rights is a challenge for patients as the information is scattered over multiple resources. We have compiled the material and issued a booklet summarizing the benefits and rights of the chronically ill in general, and of patients with IBD in particular.

Another booklet in this series, is dedicated to children's rights in schools. Although there is a regulation issued by the Ministry of Education regarding children with IBD, parents face multiple challenges in providing a broader perspective on the everyday challenges that a child with IBD faces at school. This booklet which is a result of cooperation between CCFI and the Ministry of Education, is aimed to bridge gaps and provide children with the best chance for success in their academic studies and social life.

In the pipeline is another booklet that specifies rights granted by CCFI which are not covered by social benefits, such as our financial aid fund, psychological support, dietary advice and advice on social security benefits. Legal assistance in processing social security benefits and other health related legal rights, is also provided with the help of the Legal Clinic.



*CCFI chairman Eyal Tzur at the High-tech conference, Tel Aviv, September 2016*

This pro-active approach has led to another significant initiative, which is the need to connect between science, technology and the funding necessary to advance and materialize scientific and new technology breakthroughs.

This necessity steered CCFI to initiate and produce a first conference of its kind in Israel. The target was to create a platform that connects the medical and science community with relevant investment sources such as pharma companies, investment firms, angel investors and others that see the great potential in investments in medical knowhow and new technologies in the field of autoimmune diseases with focus on IBD.

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The First Interdisciplinary Global Hi-tech & Investment Gabfest IBD, was held in Bar-Ilan University, near Tel Aviv, On September 7th, 2016. CCFI was honored that Marko Perovic attended the event with other international guests, among them Dr. Marco Greco. The conference is also presented in

CCFI's Bright Idea poster.

We hope that the active path we take in promoting patients' rights and aiding the advancement of scientific and medical technologies makes a difference in patients' lives today and tomorrow.

## France

# Let's talk about Complementary Therapies!

**Increasingly, patients suffering from IBD are questioning complementary medicine and its effects. Now it appears that most of those patients who try these therapies and talk about them on the forum, don't say anything to their doctors fearing they will be "judged". Furthermore, the euphoria at the start when « it works » - ends up sometimes disappointing and no one expresses this end!**

So, it seemed important for Afa to set down an inventory of practices and therapies, said to be complementary; first by trying to identify those most commonly used in order to better inform the patients, and then to find out what really is used and how by the IBD patients themselves. The impact on quality of life was truly expressed in the results of the SUMMAC study (on the use of Medicine called Complementary used by IBD patients) carried out by the ANGH and Afa in 2012. These results may be consulted on the IBD Observatory (Observatoire des MICI) website: [www.observatoire-Crohn-RCH.fr](http://www.observatoire-Crohn-RCH.fr)

### What is a complementary therapy?

Alternative or complementary, soft, parallel, traditional, non-conventional... these words abound to designate the therapeutic practice other than so called allopathic medicine at the root of our health system. Two essential characteristics group together these methods and distinguish them from western medicine founded on scientific validation through clinical trials and/or a consensus from the professional community. First of all, the patient doesn't necessarily consult a medical graduate practitioner and secondly, the care doesn't rely on prescribed medicine, but on physical manipulations, "non-medicinal products"



taken orally or applied to the body (needles, mineral or herbal substances, light...). The World Health

Organization (WHO) has accounted for 400 of these complimentary medicines, whether they are methods based on natural products (herbal medicine, aromatherapy,...), techniques focused on physical manipulation (osteopathic, chiropractic...), on body and mind therapies (meditation, hypnosis...) or on global methods based on theory (acupuncture, homeopathy...). It's impossible to consider all of these as a whole!

From here, Afa decided to dig further into the subject by developing four axes:

- Inform people affected by Crohn's disease and ulcerative colitis on the various therapies providing fact sheets which can be found on the Afa website. It's a long and drawn out task and we're starting with those most commonly used. In the facts can be found not only the rationale behind the therapy, the qualifications needed by the practioners and the average cost. Afa's Scientific Committee could possibly give advice about each fact sheet.

- Evaluate the interest of each therapy and the way each patient uses them by questioning on their day to day use. Who, better than the user can give a true point of view and feeling about these therapies?
- Establish a dialogue between health

professionals, in particular with the gastroenterologists, on the internet on the advantages of such therapies in addition to the classic treatments.

- Develop efficient tools for patients to better manage their daily lives and improve the quality of life. Recently, a podcast and some videos were made by Afa and put on the Afa website: «How to relax in 1, 2 or 5 minutes », «Simple gestures you can do at home using Shiatsu » ...

In January 2017, a work group was created to better develop this axis.

Anne Buisson, Afa France

Afa is also financing studies on complementary therapies for:

1. The study on food additives by a team at Robert Debré Hospital in Paris with Prof. Jean-Pierre Hugot.
2. The study on the impact of hypnosis on Crohn's disease patients with the team in Grenoble with Prof. Bruno Bonaz.
3. The study on the impact of Curcumine in Clermont-Ferrand with the team of Prof. Gilles Bommelaer.

## New Zealand

### Camp Purple Live

**On January 13th 57 children and teens, over thirty volunteers, and 33 parents arrived at El Rancho Camp on the Kapiti Coast of New Zealand. It marked the beginning of Camp Purple Live, now in its third year.**

The purpose of the camp is twofold. Firstly, it is just a camp, a place for children and teens to have fun and test their limits. Activities this year included go carting, river tubing, a trip to Wellington, and a day at Adrenaline Forest. More importantly, Camp Purple is a place where our youngest people with Crohn's and

colitis can be surrounded by those who understand the challenges of living with these diseases and make new friends. Planning each camp is a long process and done by a committee of only seven. Once a venue is selected, work begins immediately on raising funds for the camp, about \$70,000 each year. The camp has

to be publicised throughout NZ through social media and to medical personnel through various medical societies. Applications need to be sent out to potential campers and every camper's medical form needs to be reviewed by a three person medical team. Volunteers, almost all of whom have IBD themselves, have to be recruited, including the medical team which staff the camp 24/7. Every volunteer needs to be vetted with police checks. A five day schedule of activities, including those offsite, has to be meticulously planned. Over 100 flights need to be arranged. Campwear needs to be designed and ordered. We have to make sure all children are accompanied on those flights and safely collected at the airport. Ground transportation to and from the airport and to offsite activities has to be arranged. We also need to be available to answer innumerable inquiries from parents and make last minute travel arrangements. We have one person whose main job is just to manage meals and dietary restrictions of the campers.

This year's camp was the most ambitious to date as the number of campers (as well as parents participating in the parents' seminar) continues to grow each year. Highlights of the camp included a trip to Wellington where we toured Parliament, visited Te Papa, and took the cable car up to a show at the Planetarium. The



following day was spent at Adrenaline Forest. The campers were amazing and fearless as many of them braved challenges over 30 metres above the ground.

We are indebted to all our sponsors and especially those individual donors (too many to individually mention) and volunteers who make the camp possible. Among our corporate sponsors are Abbvie, Janssen, Jetstar, Baxter, Pharmaco, ANZ Staff Foundation, TG Macarthy Trust, Boston Scientific Foundation, Rotary Clubs of Orewa/Wangaparoa and Greenmeadows, Sunshine Rotary, Freemasons NZ Pacific Lodge, Johnsonville Club, Mico Plumbing, Pelorus Trust, EFCCA, Pearl Jam, and Olympus Corporation.





# Cyprus

## National Youth Award

Natasa Revekka Theodosiou, a very active member of the Cyprus Crohn's and Colitis Association (CYCCA) from the post of Deputy President, was awarded "The Young Person of Year 2016" award at the 1st National Youth Awards organized and presented by the Youth Board of Cyprus and the Cooperative Central Bank during an official ceremony on the 15th of February 2017.



*"I dedicate the award to all those who dared to talk about Crohn's Disease and Ulcerative Colitis and those who will do it today" Natasa Theodosiou*

According to the organizers, the Youth Awards aim to present and promote positive role models for the youth, people who are active in multiple areas such as science, culture, innovation, sports, environmental actions, business initiatives and volunteering.

The "Young Person of the Year 2016" award aims to highlight young people who are active citizens and who help their co-citizens by raising awareness of important and vital issues that concern us all. Natasa's award gave her a great opportunity to talk in public about Crohn's and Ulcerative Colitis, diseases which are relatively unknown in Cyprus,

giving a voice to 5000 patients who live in silence with their problem.

CYCCA is proud to have young people like Natasa on its Board of Directors, who never stop fighting for the patients' rights among its members.

"Don't be afraid to talk about Crohn's Disease and Ulcerative Colitis", Natasa says.

Yiannis Antoniadis  
Vice President of CYCCA

# Malta

## Living with IBD is not at all rosy and easy!

**People living with IBD expect their relatives, friends and their peers to know what this condition means and entails. People with IBD would appreciate that others understand how they feel, what they are going through and what their requirements are. .**

IBD patients need continuous treatment and satisfactory health services. Besides, they need constant support and love not only from their relatives and friends but also from their peers suffering from their same IBD condition.

These are some of the reasons that personally triggered me once again to step on my feet and do something for my fellow IBD patients in Malta following a long period of difficulty in the organisation of MACC.

A new MACC Committee has been recently formed, consisting of a group of sincere, loyal, energetic and committed persons, all striving to support IBD people as best as they can. I cannot thank these people more for their dedication, support and love that they are giving to other IBD people, friends and relatives.

A number of initiatives are currently being discussed by the MACC Committee and underway to be achieved locally. Some of these initiatives will soon be completed and attained and some others require more time since they are more challenging and hence, more resources are needed. But this new Committee has one common and clear goal to achieve, that of supporting and helping people with IBD.

Living with IBD in a small country like Malta has both advantages and disadvantages.

A small island community of around 420,000 people is much easy to reach and communicate with, especially by means of social media and modern technology. MACC acknowledges this fact and revamped its informative website ([www.macc.org.mt](http://www.macc.org.mt))

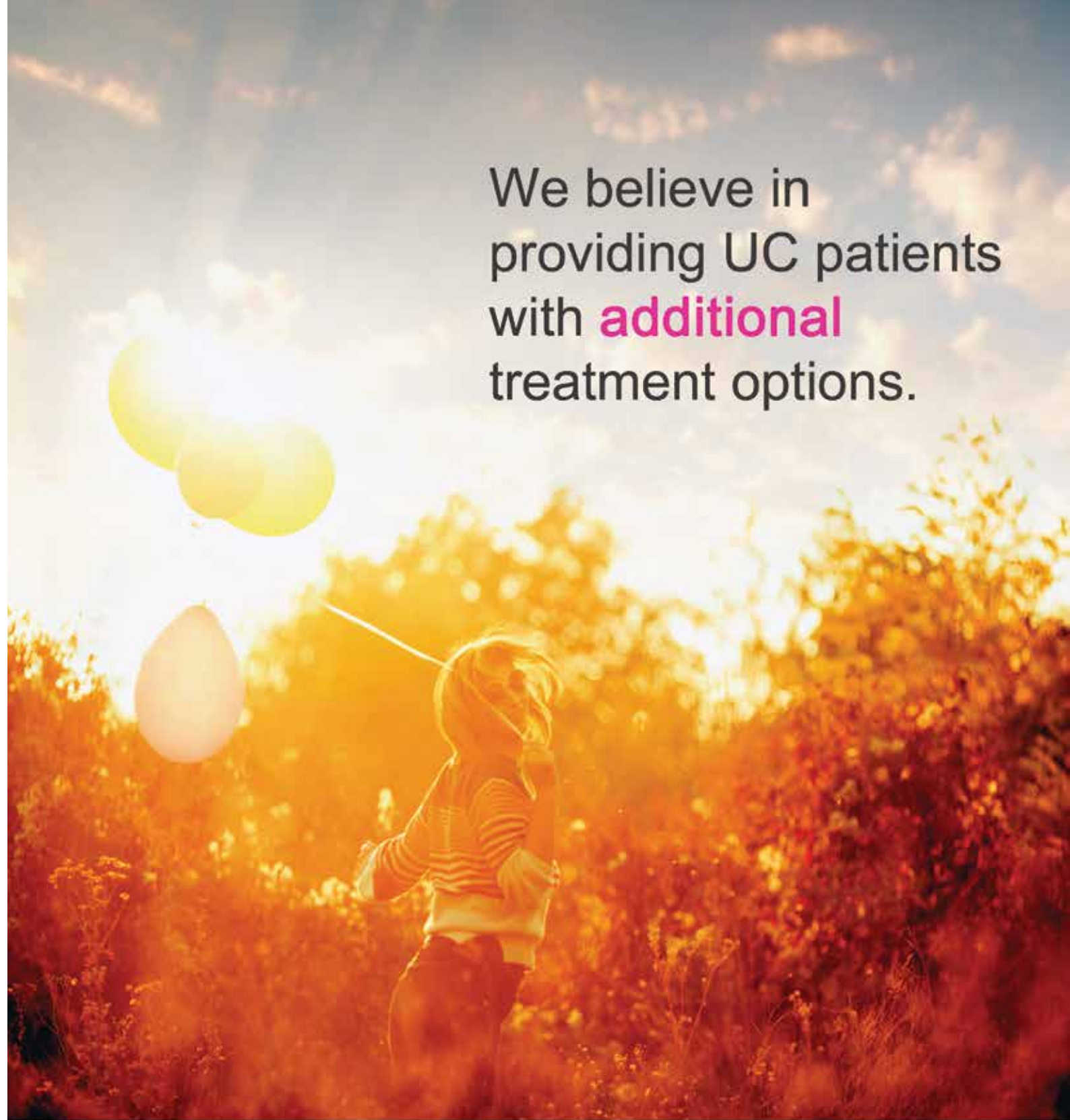
and also maintained its Facebook Page to reach as many people as possible, thus creating the necessary awareness of MACC, its services and IBD as a medical condition itself. MACC has also embarked on an organized awareness campaign. Thanks to a number of local tv and radio programmes, MACC committee members, sometimes also assisted by prominent people from the medical profession, were invited and participated in popular programmes. This helped MACC to reach a wider spectrum of people from various walks of life.

Nevertheless, IBD is still considered a taboo by many. Some people living with IBD may not be comfortable to talk about their medical condition with others and may also find it difficult to admit and accept the fact that they suffer from IBD. This may hinder the growth of MACC in Malta being a small community where more people know each other. This reality is the hardest nut to crack for MACC but as chairman, I am delighted to note that the new committee is faithfully working towards tackling this challenge and there are promising plans by which MACC will assist better IBD patients in Malta in the near future, irrespective of their age and how they perceive their medical condition.

Challenging as it may be and thanks to the new committee members once again, MACC is back on its feet to help Maltese IBD people and together with our European counterparts through our EFCCA Membership, the MACC Committee strongly believes that our scope can and will be achieved.

Josef Bisutti  
Chairperson of MACC



A child in a striped shirt and dark pants stands in a field of tall, golden-brown grass. The child is holding a string attached to a large, light-colored balloon. In the background, there are more trees and a bright, hazy sky with a few other balloons floating. The overall scene is warm and sunlit.

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# To pouch or not to pouch

**Unfortunately, many ulcerative colitis patients find little joy in medical and dietary management of their disease. Fortunately, ulcerative colitis patients do have the option of surgically removing their colon (called a “colectomy”), thus “curing” them of their disease.**

However, due to the radical nature and inherent risks of colectomy, this is usually seen as a last resort for patients who have failed all other treatment (80% of ulcerative colitis colectomies) or are in need of an emergency surgery due to an acute medical situation (20%), such as a perforating bowel.

After colectomy is decided on or imposed upon the patient, they will then have a choice about whether to stay with a “stoma” (requiring the patient to wear a bag on their stomach to collect their waste) or having an “ileal pouch” sculpted out of their small intestine (eliminating the need to wear a bag on their stomach).

Overall, there are two fundamental questions for ulcerative colitis patients considering surgery:

1. “Should I have a colectomy?” If the patient is being managed well medically the answer is clearly no but in other cases the answer is yes.
2. If the first answer is yes, then the next question becomes “Should I stick with an ileostomy or advance to an ileal pouch?” Whilst it may seem clearcut to some that advancing to an ileal pouch is more desirable, it needs to be considered that this requires more surgery and carries the risk of a failed ileal pouch.

A booklet recently made in a joint effort between myself (patient with an ileal pouch), Associate Professor Tim Eglinton (Colorectal Surgeon), and Professor Richard Gearry (Gastroenterologist) is designed to help ulcerative colitis patients better understand and answer these questions for themselves.

It explains the nuts and bolts as well as the risks (of complications) of these procedures. Accordingly, it is called “Considering whether to have ileal pouch surgery.”



Whilst for many ulcerative colitis patients the decisions about surgery will never be cut-and-dry, this booklet at least outlines the risks and benefits more clearly for the patient to better facilitate joint decision making to be made between physician and patient.

We are excited at this booklet’s release which will assist in making “life more liveable” for IBD patients worldwide.

It will be available through Crohn’s and Colitis New Zealand and EFCCA and should hopefully be distributed to healthcare professionals worldwide.

Dr Andrew McCombie, Crohn’s and Colitis New Zealand



# Considering whether to have ileal pouch surgery

*A guide for ulcerative colitis patients*



By Dr Andrew McCombie  
(Ulcerative Colitis Researcher and living with an ileal pouch)

Co-authored by Associate Professor Tim Eglinton (Colorectal Surgeon)  
and Professor Richard Geary (Gastroenterologist)

# 18 years of support for people with IBD in Brazil

**The Brazilian Association of Ulcerative Colitis and Crohn's Disease (ABCD), which has associate members in all corners of Brazil, aims to help and support IBD patients and their families to achieve a better quality of life.**

ABCD is a not-for-profit organization and was founded on 4 February 1999 in Brazil to gather patients with inflammatory bowel disease, their families and health professionals dedicated to these diseases including doctors, nurses and nutritionists.

ABCD offers its members the opportunity to exchange experiences, provides accurate information about IBD and also offers legal advice. Our organisation is represented in official bodies of the Brazilian government and receives support from other IBD sister organisation such as the Crohn's and Colitis Foundation (CCF, United States), Crohn's and Colitis Foundation Canada (CCFC) and the European Federation of Crohn's and Ulcerative Colitis Associations (EFCCA, Europe), among others.

Throughout its 18 years of intense work and thanks to the dedication of many professionals, ABCD has achieved many milestones. One of these milestones was the introduction of the healthcare law of the Ministry of Health in November 2002. This law defined that medicines used for Crohn's disease and ulcerative colitis should be included in the list of high-cost exceptional medicines and should be distributed free of charge by the Unified Health System (SUS). This benefits thousands of IBD patients in our country.

"There are still difficulties in diagnosing Crohn's disease and people still do not know exactly where to seek care in Brazil," says gastroenterologist Marta Brenner Machado, president of ABCD, noting that the lack of knowledge about IBD makes a correct diagnosis difficult which in turn leads to a delay in appropriate treatment options and may ultimately lead

to hospitalization and/or surgery.

Due to this lack of knowledge, the dissemination of information about IBD through national campaigns - such as for example "purple May" - is essential in order to mobilize the population to support our cause, to inform about symptoms and to let them know that there are new treatment options with good results.

As Brazil is a huge country we organise several events throughout the year and have also prepared an institutional video explaining who ABCD is, the importance of support groups for a better understanding of the disease, the need for partnerships and how to better cope with IBD. The video also includes a simple and didactic kind of lesson given by a physician so that patients and their families can better understand the disease.

Each associate member throughout the country has access to this virtual support as well as other support material, such as brochures and T-shirt and we aim to promote the greatest possible union of all IBD patients in Brazil. "With a united and strong group we will have the power and the necessary voice to demand adequate treatment options and to advocate for better rights of patients with IBD. United we stand! ", says ABCD president Marta Brenner Machado.

Flavio Steinwurz, gastroenterologist, president emeritus and founder of ABCD, recalls how IBD was nearly unknown in Brazil for many years causing great difficulties for patients as well as doctors. "With the foundation of ABCD in 1999, this panorama has changed and today most people have access to information and health professionals participate





in continuing education and refresher courses” he explains. “However, there is still much to do, the more we know about IBD, the faster we will be able to have an early diagnosis and access to adequate medication.

### **ABCD Activities in 2017**

During the second half of this year, ABCD will launch a “patient journey” survey, to be conducted online amongst IBD patients in Brazil. The main goal of the survey is to understand the obstacles and difficulties faced by people with IBD in Brazil, be they physical, medical, emotional, psychological or financial. It seeks to establish the current scenario of how the patient coexists with his / her illness, including aspects of treatment and how IBD impacts their life. The results may help us to guide our activities and priorities for ABCD but also for other patient-related associations with IBD with view to specific projects, educational materials and other tools. In addition, the results of the survey may serve as an information and orientation tool for public agencies to provide improvements in the treatment of IBD in Brazil.

Our survey is based on the IMPACT survey

carried out between 2010 and 2011 by the EFCCA and which revealed how IBD impacts on the physical and emotional well-being of 5,000 people with inflammatory bowel disease in 27 European countries.

From 2-4 June 2017 we will be co-organising SIMADII, our bi-annual Intestinal Inflammatory Disease event, aimed to update doctors and health professionals. It’s the most traditional Brazilian event since 1999 specifically addressing Crohn’s Disease and Ulcerative Colitis. In 2017, in its ninth edition, it will have a different format, keeping the best speakers from Brazil and the world, along with PANCCO - Pan American Crohn’s and Colitis Organization”

More info: <http://panccosimadii.com.br>

### **World IBD Day**

ABCD has for many years organised various activities to celebrate World IBD Day and to raise awareness about inflammatory bowel diseases. In 2016, ABCD joined the Purple May World IBD Day coordinated by the EFCCA and we had support from numerous public bodies and private companies to

light up in purple buildings, historical monuments, statues and other venues. The huge participation in “purple May” demonstrated that patients, family members and health professionals are closely united in their common goal of disseminating and clarifying doubts about IBD.

Throughout the month of May, joint events were held between ABCD and different patient associations, aimed at improving, in every sense, the quality of life of people with IBD.

Also this year we will continue to organise awareness raising walks, organise IBD lectures in several cities and of course we will join the global campaign and illuminate even more monuments, buildings, bridges and other points of interest throughout Brazil. “We hope that World IBD Day 2017 will be even bigger and can serve a greater number of people, because we believe that by spreading information can we help even more patients with inflammatory bowel disease,” stresses ABCD president, Marta Brenner Machado.

In addition to the actions taken during the commemorative date, physicians and patients will develop joint activities throughout the year that will highlight the negative impact that IBD currently has on the quality of life including social and professional losses. Moreover ABCD will maintain its virtual channels for communicating with patients through social networks, such as:

<https://www.facebook.com/abcd.org.br>;

<https://twitter.com/abcdsp>;

[Instagram@abcd.org.br](https://www.instagram.com/abcd.org.br)

and specific communities of IBD such as Healthunlocked/abcd and Virtual Community Of DII - first in the world created in partnership with BIREME/PAHO (<http://cvdii.bireme.br>).

To learn more about our work, please send an e-mail to [secretaria@abcd.org.br](mailto:secretaria@abcd.org.br) or call (5511) 3064-2992.

[www.abcd.org.br](http://www.abcd.org.br)



# Exploring areas and benefits of cooperation in Cross-Border Healthcare to protect patients' rights\*

**Three years after the deadline for national transposition of the Cross-Border Healthcare Directive in Member States (2013), patient mobility for planned healthcare remains low. Relatively few patients have used the Directive to receive treatment abroad, despite the fact that the last Eurobarometer of the EU Commission (September 2015) showed that they would like to do so.**

Also, serious concerns regarding a proper and satisfactory implementation of the legislation persist: low awareness among EU citizens of patients' rights to cross-border healthcare, complicated systems of prior authorization, little or denied reimbursements, lots of administrative requirements, disparities between National Contact Points in the way they operate and with regard to the information they provide.

This clearly demonstrates that there is a need to enhance the quality of information addressed to patients in order to make them aware about their rights to cross-border healthcare. At the same time, it is essential to work together to realize its full potential and make it a true added value for all citizens and patients living in the EU.

During the last conference on cross-border healthcare held by the EU Commission, Health Commissioner Vytenis Andriukaitis emphasized the importance of this legislation for patients' rights and called for further work to improve patient information and National Contact Points coordination. The Commissioner also underlined the importance of enhanced cooperation with patient organizations, healthcare providers and insurers to overcome the main obstacles to a proper implementation of the Directive 2011/24/EU.

Last but not least, he highlighted how "the Directive provides a framework for a number of areas where cooperation across borders might form part

of the solution to the eternal problem of how to do more with less". Cross-border cooperation will help make better use of resources that exist just across the border.



Indeed, the Directive 2011/24/EU encourages cross-border collaboration in healthcare provision and has set several cross-border initiatives as, for example, the establishment of the European Reference Networks to bring together highly specialized healthcare providers and centers of excellence from different Member States. The European Reference Networks show how cooperation between health systems can help patients suffering from a rare and complex disease by pooling expertise from across different EU countries.

The meeting was an open debate between civic and patient associations from different Member States, experts in the field of civil rights, Institutional representatives from the European Parliament and



the European Commission, National Contact Points and several stakeholders at EU level.

During the meeting the necessity and benefits of fostering cooperation among Institutions, patient organizations, National Contact Points and European Reference Networks to improve patients' awareness and access to care abroad was thoroughly discussed. They also shared case histories, experiences and common challenges related to cross-border healthcare.

For more info please visit:

<http://www.interestgroup.activecitizenship.net/>

\* this is a reprint from the Active Citizenship Network (ACN) website.

Active ACN is a European network, composed by more than 100 civic, patients and users organizations. Established in 2001, it is coordinated by Cittadinanzattiva, the Italian non-profit organization founded in 1978. The main objectives of ACN are the promotion of civic activism and participation in the political arena, and the protection of citizens' rights, which are both the strength and the uniqueness of ACN.

## Equal access to health care

**The European Patient Forum (EPF) has launched a campaign on access to healthcare. Patients across the EU are facing several barriers to access to healthcare. According to the UN Sustainable Goal (SDG) on Health, EU Member States have committed to achieve Universal Health Coverage for all by 2030.**

This campaign is an opportunity to build on the current political momentum and aims at fostering more EU cooperation on access to healthcare, prompting Member States to act on their engagements towards achieving the UN SDGs.

The kick off meeting of the campaign took place on 27 February 2017 in the European Parliament where EPF General Secretary, Nicola Bedlington outlined the five key dimensions needed to ensure equitable access to high quality healthcare from the perspective of patients such as:

1. Availability – Healthcare services and products are available in the healthcare system of a country
2. Affordability – Healthcare does not cause financial hardship to patients
3. Accessibility – No barriers stopping patients from accessing healthcare
4. Adequacy – Quality healthcare and involvement of patients in shared decision-making with healthcare professionals

5. Appropriateness – Healthcare meets the needs of different groups in the population

The overarching goal of the campaign is to contribute to making 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.

For each of the five areas, EPF and the campaign's partners will develop a set of policy recommendations and actions to achieve the objective set out by the campaign. All the recommendations from the different areas will be presented in a policy document at the end of the campaign, setting priorities and measures to be taken in order to reach Universal Health Coverage for All by 2030.

Martina Jovic, EFCCA Policy Officer, represented EFCCA during the meeting. For more information please contact our office.



# Improving quality of care for people with IBD

**The 8th N-ECCO School was held on 15 February 2017 in Barcelona running parallel to the ECCO Congress. The school was attended by 40 nurses and 7 dietitians from 21 different countries as well as 11 N-ECCO National Representatives.**

The aim of the N-ECCO school is to teach basic IBD knowledge in a clear way for nurses, with the objective of improving nurse education throughout Europe.

This year's programme covered a wide range of topics for novice IBD nurses and dietitians from diagnosis and assessment, to case studies in disease management and multidisciplinary disease management.

Following the ECCO'15 Congress, the Dietitians Working Group of ECCO (D-ECCO) and the Nurses Committee of ECCO (N-ECCO) discussed and agreed on the importance of the involvement of dietitians in the care of IBD patients. Therefore, in 2016 the N-ECCO School was opened for dietitians interested in gaining knowledge about the basic aspects

of IBD and in 2017 we had a total of 7 dietitians participating in the programme.

EFCCA supports the N-ECCO school with a yearly grant which allows ECCO to offer a travel bursary to those participants who were unable to raise funding for travel and accommodation (as in some countries, industry sponsorship for nurses is prohibited).

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

*Course participants at the 8th N-ECCO School, Photo @ECCO*



# Inflammatory protein involved in autoimmune diseases has healing potential

**TNF-alpha, a proinflammatory molecule and protein produced by the body's cells during infection, also promotes the immune system regulatory responses by first inducing immune surveillance cells. This is a finding that could lead to more targeted drug therapies for treating several autoimmune diseases, say researchers.**

A team of researchers in the School of Medicine at the University of California, Riverside has now found that 'TNF-alpha, while promoting inflammatory responses, also promotes the immune system regulatory responses by first inducing immune surveillance cells, called M cells. The finding could lead to more targeted drug therapies for treating Inflammatory Bowel Disease (IBD) as well as other autoimmune diseases -- such as multiple sclerosis and type 1 diabetes -- in which TNF-alpha plays a role.

"The induction of M cells by TNF-alpha suggests that the body may have a built-in system that promotes the inflammation as well as regulates and ultimately suppresses the response," said David Lo, professor of biomedical sciences, who led the research study.

The study, performed on mice, focused on the gut, which the Lo lab has been researching for many years. Study results appear online in *The American Journal of Pathology*.

"If we don't know what triggers the disease then the best we can do is treat the disease by suppressing inflammation," Lo said. "Currently, the main drug therapeutics being used to manage IBD are anti-inflammatory treatments. One of the newest is a series of biologicals -- basically antibodies -- that absorb the inflammatory molecules that promote the inflammatory response. There are half a dozen of these biologicals -- specifically targeting the cytokine TNF-alpha. They don't work in all patients, resulting often in some patients having to try one biological after another to find out what works."

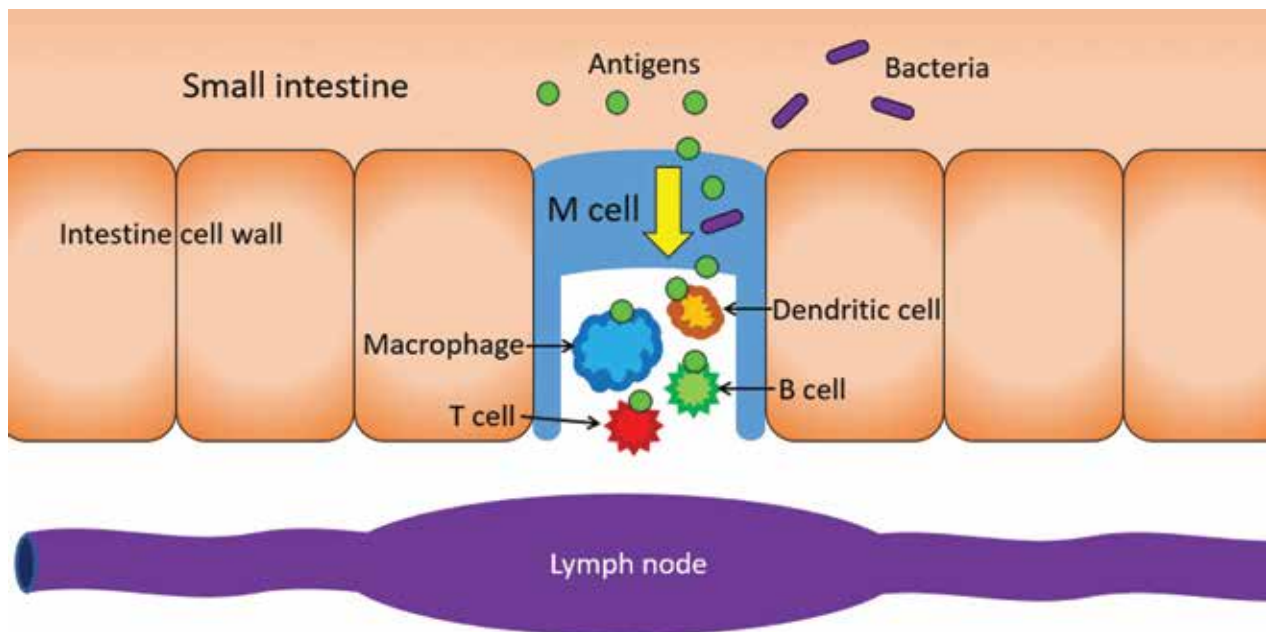
Lo explained that TNF-alpha promotes the

destruction of tissues. But this cytokine also promotes tissue healing. "Cytokines are regulators of host responses to infection and inflammation," he explained. "Some make disease worse because they are proinflammatory. Others reduce inflammation and promote healing because they are anti-inflammatory. TNF-alpha plays a dual role in that it does both. If we had a more focused way of dealing with the undesired inflammatory aspects of TNF-alpha, we could still retain the healing, restorative aspects of this cytokine."

The body's intestinal lining has epithelial cells that form a barrier so that bacteria in the gut do not pass on into the rest of the body. During inflammation -- whether from disease due to a person's genetic predisposition or from an infection -- TNF-alpha is one of the proteins produced. Lo's team found that in the case of IBD infection TNF-alpha triggers an increase in the number of M cells up and down the colon. Further, the M cells act like selective gates.

"They show up in the colon where they didn't exist before, alerting the immune system that something is up," Lo said. "Through the M cells and their selective gatekeeping, the immune system is able to do some sampling of the gut -- both more frequently and along the whole intestine. The colon is not normally a place where you have this sort of sampling going on. To significantly ramp up the sampling process by these M cells this way can help us figure out how the immune response will gear up its ability to either deliver a more powerful immune response or, alternatively, regulate and suppress the inflammation, and thus restore normal homeostasis in the intestine."

For several years now, Lo has studied M cells in



*M cells are specialized epithelial cells of the mucosa-associated lymphoid tissues. A characteristic of M cells is that they transport antigens from the lumen to cells of the immune system, thereby initiating an immune response or tolerance.*

terms of how differentiation decisions get made to produce them.

“In the course of our research, it became evident to us that some of the factors that promote M cell differentiation overlap with the factors that produce disease, inflammation and destruction,” he said. “We knew that diseases like IBD produce some of the same factors. We wondered if IBD also triggered M cell differentiation, and launched an investigation.”

Besides leading to the development of more targeted drug therapies, the new work could help scientists like Lo better understand why people afflicted with IBD have a chronic type of inflammation in the first place.

“Advanced immune surveillance is a clue into how the immune system is attempting to restore balance and calm in the tissues,” Lo said. “If M cell production is a critical part of this restoration process, then it means we can develop more targeted therapies that don’t block this restoration. Many of the biologicals being used today absorb and wipe out TNF-alpha, but in the long run this may be harmful to the patient because removing TNF-alpha altogether also blocks its ability to produce restorative mechanisms.”

Next, Lo’s lab plans to focus on the different receptors in the body that receive signals that then trigger inflammation and tissue restoration.

“We would like to know which receptors are responsible for what,” Lo said. “Which promote the undesired inflammatory effects, which promote the restorative effects? How does this trigger a sequence of events leading to restoration of calm and inflammation removal? The ultimate goal would be to have drug therapies that are more targeted so it’s no longer like throwing a sponge at the infection and hoping something will work.”

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