

# EFCCA MAGAZINE

European Federation of Crohn's and Ulcerative Colitis Associations | May 2013

## To baby or not to baby? IBD and pregnancy

page 12

Join the Fight Against  
IBD 2013  
page 5

Patients and IBD surgery: rightful  
fears and preconceptions  
page 38



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Contents

EFCCA News	5
Feature: Join the Fight Against IBD 2013.....	5
European Youth Group	10
Member News	16
Living with IBD	25
IBD Planet: Journey through Middle Earth.....	26
Mici pour la vie - IBD for Life.....	28
News from partner organisations	32
Medical Review corner	38
Patients and IBD surgery: rightful fears and preconceptions.....	38

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# EDITOR'S EYE

## United We Stand

### Towards a 2014-2018 EFCCA strategy plan



As everybody knows one of the objectives of our General Assembly in Slovenia was to start drafting members' priorities for our future Strategy Plan.

Thanks to the intense work developed in the working groups that took place on 15 and 16 March I'm pleased to open this editorial by informing you all that a first bunch of important options have been clearly depicted and may become the backbone of the EFCCA's vision for the next 5 years.

Over the past 4 weeks the EFCCA office and the Board have been working on the General Assembly results and, at a first glance, they clearly show an evident and encouraging confirmation that the EFCCA new deal, which started with my document "Blueprint of a dream" - Leading the change towards a new EFCCA, is now fully operative and activities and decisions descending from it and the subsequent Strategy Plan 2009-2013, are now part of our associations' "cultural" heritage.

Looking at the first 5 priorities – according on what it is usually done after this kind of participatory exercises we can see that two out of five activities are already under development: the World IBD Day campaign and related actions organized worldwide. Three out of five activities can be developed and become part of the EFCCA strategy plan 2014-2018, namely increase children and youth programs, Health Technology Assessment and improved circulation of information on the EFCCA Board activities.

Connected to these above mentioned priorities some others can be connected, mainly under the label of a stronger and more interactive information flow between the EFCCA officers and staff and its members, as well as among the members themselves.

Some other project proposals mirror a country based view as they can be easily developed at a country/local level and EFCCA could play a role of facilitator there putting together inspiring practices and working on models that can be adapted accordingly to national legislations. This is the case for awareness raising campaigns in schools, fundraising activities and effective actions to put into practice EU Directives into national laws in the field of antidiscrimination, equal access to health care and equal treatment in education and in the labour market. Nevertheless I think it is important to underline that EFCCA is a so called second level organization whose juridical character cannot intervene into national/regional or local legislation.

EFCCA will focus part of 2013 in involving members to transform these ideas into projects either



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funded by stakeholders or by European funds and work on the transnational added value to be put at disposal of every member.

On the other hand our members put under the spotlight the important but perfectible advocacy and lobbying activity EFCCA has been developing in the past three years. And EFCCA is aware that it is essential to boost those policies and activities in order to make changes possible at country level.

EFCCA's power, force and influence is based on its capability of representing diverse countries (and now nearly continents) that – together – can drive changes from a unique, although, different position. Unity in goals and common engagement on shared objectives are its only negotiation power. Empowering members by the means of a jointly fight against IBD are the basic ingredients of its identity.

This scenario clearly highlights that, in order to achieve better and more effective results, national members need to deeply understand EFCCA inner nature: which are its boundaries and limits, but also strengths that make EFCCA an increasingly stronger interlocutor for EU policy makers and physicians such as IBD experts (ECCO) and gastroenterologists (UEG).

The lobbying activities as well as EFCCA's positioning in Europe and in other continents can be mainly expressed by addressing policy and position papers whose main objective is to attract the attention of supranational bodies that at their turn may then call for attention at national level.

The first test bench and challenge is the World IBD DAY that, according to the priorities issued from the focus groups in Slovenia, aims to become stronger and even more effective.

On 16 May the WORLD IBD DAY campaign kicks off at the European Parliament: I hope everybody will be able to follow it on streaming and contribute in giving shape and content to the huge final conference next October which I am sure will be inclusive with EU policy makers and institutions, working together with IBD people and doctors to make our voice louder and effective not only in Europe but worldwide. In conclusion I think the main and most powerful outcome of the EFCCA General Assembly was and is the tangible, concrete and positive message towards globalization. United with stand... with no borders around us!



Marco Greco, EFCCA Chairman

# Join the Fight 2013

EFCCA and ECCO join forces again in the fight against IBD



Panel discussion (left to right): R. Stockbrügger (UEGF), M. Greco (EFCCA), K. Kadenbach (MEP) and S. Trevis (ECCO)

*In its second year the Join the Fight Against IBD campaign continues to mobilize support from a wide range of stakeholders in order to raise awareness of Crohn's disease and Ulcerative Colitis and to accelerate the dissemination of new standards of care among health institutions, healthcare providers and health authorities.*

This year's press conference took place on 13 February in Vienna and was co-organised by the European Crohn's and Colitis Organisation (ECCO) and the European Federation of Crohn's and Colitis Associations. It focused on the topic: "Chronic Disease in young people. What does it mean to a teenager for daily life to fight with Crohn's Disease or Ulcerative Colitis?"

Daniel Sundstein, leader of the EFCCA Youth Group gave an inspiring presentation of his own personal experience of having been diagnosed as a youngster with Ulcerative Colitis and allowed the audience to get a better understanding of the psychological effects and medical concerns that such a diagnosis brings along.

EFCCA chairman, Marco Greco, gave a more global view on the importance of collaboration between not only the medical and patient community but also other stakeholders such as policy makers, health service providers and even the public at large. "Recognizing the fact that IBD is a challenge for all of us - in that it has a considerable impact on medical, economic, social and human aspects - is the first step for finding a common ground in the fight against IBD" stated Marco Greco at the conference.

ECCO President-Elect, Professor Séverine Vermeire, when opening the press conference, also stressed the importance of collaboration amongst the medical and patient community. Moreover she highlighted the need to manage the disease well in order to ensure and improve the quality of life of people living with IBD.

In his presentation, Prof. Walter Reinisch, ECCO member, pointed at alarming figures, which show that there is a new epidemic of chronic inflammatory disease especially amongst young

children. This was also taken up in Dr. Tine Jess' speech who presented the results of the ECCO-Epicom study on "the Burden of Inflammatory Bowel Disease in Europe" which showed that since IBD affect mainly young individuals in their early adulthood and impact all aspects of the affected individual's life they account for substantial direct and indirect costs to both health care system and society. She argues that further Pan-European epidemiological and follow-up studies as well as strategic disease modifying trials are needed to investigate the role of tight control and early patient profile stratification in the disease management hopefully leading to superior long-term outcomes, improved quality of life, decreased disability rates and ultimately normal life.

The general press conference was followed by country specific press conferences where journalists had a chance to find out more about the situation in their own country speaking to both healthcare professionals and people living with IBD as well as members of the panel from the global press conference.

On the following day, prior to the official



Marco Greco speaking to an Italian journalist

opening of the 8th ECCO Congress, a panel discussion on "Crohn's and Colitis in Europe: The burden of disease in young people" took place including as speakers Marco Greco (EFCCA Chairman), Simon Travis (ECCO President), Karin Kadenbach (Member of the European Parliament) and Reinhold Stockbrugger (Chairman of the UEGF Public Affairs Committee) which concluded with a confirmed commitment to the Join the Fight initiative and future collaboration of all stakeholders involved.

## ECCO Congress

*EFCCA participated in the 8th ECCO Congress which was held from 14-16 February 2013 at the Austria Center in Vienna. The Congress saw a record attendance of 4,515 participants and was a great opportunity to gain access to the latest scientific information and education in gastroenterology with its major focus on IBD.*

Many new contacts were made during the congress, and the EFCCA stand was visited by a wide range of participants allowing our staff and delegates to explain about EFCCA and the activities we are undertaking. For the second year running EFCCA also participated in the scientific poster exhibition. Sanna Lönnfors, on behalf of EFCCA, gave an interesting presentation of the EFCCA poster entitled "Ulcerative colitis versus Crohn's disease:



Differences observed in the IMPACT survey". For more information please contact the EFCCA office.



## Annual General Meeting, Slovenia 14-17 March 2013



During the working group sessions AGM delegates were asked to discuss their vision for the future of EFCCA.

*Unity and cooperation were some of the buzzwords that came out of the intensive working group discussions that were organised during the Annual General Meeting of EFCCA, which took place from 15-17 March in Brdo (Kranji), Slovenia. It was an important meeting in that delegates discussed the 2014-2019 strategy plan and prepared the grounds for a revision of the EFCCA statutes and by-laws to be finalised at next year's AGM.*

Two trainers were invited to facilitate these discussions and to ensure a truly participative approach involving all members and giving them the space to express their views and visions for the future of the organisation. The training went through three stages: the first working group consisted of working in pairs, ideally with another less known person, in order to learn from each others experience about EFCCA and personal expectations. This discovery phase was followed by larger working groups of around 6-8 people engaging in a “dream phase” discussion such as possible scenarios for the future of EFCCA. And finally during the last “design” stage the working groups elaborated concrete proposals for an EFCCA work plan and strategy and laying down recommendations for the revision of the statutes and by-laws.

The strategy plan together with the revision of the statutes and by-laws will be elaborated through a participative process allowing all members to contribute. For this purpose the documents will be made available on a Wiki platform. EFCCA delegates will be given a password to enter this platform, which allows them to make amendments and modifications to the original statutes and by-laws. Comments and modifications will be visible to all. This process will be opened for a few months and by October this year, the EFCCA office will consolidate a final draft, which will be sent to all EFCCA members to be approved at next year's AGM.



This year, in Slovenia, we had one of our highest attendances with 25 EFCCA members, two incoming IBD association and three guest speakers. The two incoming members were Crohn's and Colitis New Zealand and the Bulgarian Crohn's and Ulcerative Colitis Association who were both approved by the Assembly, with the Bulgarian association as a full member and the New Zealand association as an associate member.

Brian Poole from Crohn's and Colitis New Zealand expressed his pleasure in being part of EFCCA and stressed that even though New Zealand was geographically very far from Europe, the challenges and issues faced by New Zealanders living with IBD were very similar and cooperating on these issues was beneficial to all of us.

Martin Kojinov from the Bulgarian association was also pleased to be accepted as new member and explained that the Bulgarian association was a relatively new one and would highly welcome to exchange information sharing on issues such as access to new medication, innovative treatments etc.

For the first time also the Annual General Meeting was streamed on-line and could be watched by



Marco Greco, EFCCA chairman, during the AGM speaking about his vision for EFCCA.

those delegates unable to attend on the EFCCA channel. All the AGM documentation and presentations made are available for EFCCA members on our website.

## Election to the EFCCA Executive Board

*The AGM also saw the elections to the EFCCA Executive Board. Each potential board member was given the opportunity to present him or herself and to share their vision about their role in the EFCCA Executive Board. The following board members were re-elected: Chayim Bell (the Netherlands), Iva Savanovic (Croatia), Betty Vandeveld (Belgium) and Salvo Leone (Italy).*





There were also two new members: from Ireland, Ciara Drohan and from Norway, Arne Schatten.

As former EFCCA Vice President, Marika Armilo (Finland) decided not to re-stand for election due to other work commitments, the new Executive Board appointed Iva Savanovic to replace her as EFCCA Vice-President.

Following the General Assembly there were also 3 guest speakers including Eyal Bressler from Israel presenting a IBD related Cancer & Mortality Registration Research, Wouter Miedema providing

an update on the work of the IBD Research Foundation and Dr Matic Meglic presenting the epSOS European E-health project.

The host of the AGM, the Slovenian IBD association KVCB, arranged for a wonderful social programme in the evening including a dynamic musical trio, which animated delegates to dance and also relax after two days of intense working. A special and huge thanks to our colleagues from Slovenia!!!

## World IBD Day

### Stakeholders' meeting



*World IBD DAY is an important event for EFCCA to raise awareness of IBD and to unite with our sister organisations worldwide in the fight against IBD and a better quality of life for people living with IBD. World IBD Day is in its third year running and includes the involvement of IBD patient associations from 34 countries.*

EFCCA is committed to taking a driving role in this initiative. Here, at the European level, EFCCA is lobbying and networking with policy makers on more effective governance to ensure that social, economic and health aspects of people living with IBD are considered in all policies in order to break down barriers, prejudices and discrimination.

Continuing with the relationship established last year in the European Parliament, EFCCA on the occasion of World IBD Day will open a consultation process which will build on the findings of the IMPACT survey and elaborate a set of recommendations that will allow us to more effectively target policy makers and to create more visibility in the EU decision making policy process as well as worldwide.

A round table discussion involving EU policy makers (Members of the European Parliament, European Commission officials), representatives from IBD patient organisations, health care professionals such as the European Crohn's and Colitis Organisation (ECCO), the United Euro-

pean Gastroenterologist Federatiwon (UEGF) and N-ECCO (IBD nurses) as well as representatives from the WHO (World Health Organisation) will start this participative process.

A Wiki platform will then enable all stakeholders to feed into the consultation process which will be presented at a global awareness raising conference taking place in October this year.

For more information please contact the EFCCA office. If you would like to learn about activities taking place worldwide please visit the World IBD Day website at: [www.worldibdday.org](http://www.worldibdday.org)

## Marco Greco, EFCCA Chairman, appointed to PRAC

(EMA Pharmacovigilance Risk Assessment Committee)

On 28 February, the European Commission, after a long and challenging selection process, appointed Marco Greco as representative of patients associations to the Pharmacovigilance Risk Assessment Committee (PRAC) of the European Medicines Agency (EMA).

This is a very sensitive and important position mainly focused on assessing and monitoring safety issues for human medicines and Marco Greco together with a second patients' representative, Albert van der Zeijden, member of IAPO will serve on the Committee for a period of three years which is renewable once.

The Pharmacovigilance Risk Assessment Committee (PRAC) was established on July 2012 according to the new European legislation on pharmacovigilance. It is responsible for assessing all aspects of the risk management of medicines for human use. This includes the detection, assess-

ment, minimisation and communication relating to the risk of adverse reactions, while taking the therapeutic effect of the medicine into account. It also has responsibility for the design and evaluation of post-authorisation safety studies and pharmacovigilance audit.

The main responsibility of the PRAC is to prepare recommendations on any questions relating to pharmacovigilance activities related to a medicine for human use and on risk-management systems, including the monitoring of the effectiveness of those risk-management systems.

The PRAC generally provides these recommendations to the Committee for Medicinal Products for Human Use (CHMP), the Co-ordination Group for Mutual Recognition and Decentralised Procedures – Human (CMDh), the European Medicines Agency secretariat, Management Board and European Commission, as applicable.

# Work Plan for the EFCCA Youth Group 2013-15

*By Daniel Sundstein, EYG Leader*

*The EFCCA Youth Group (EYG) has developed a new work plan and communication strategy to be presented at the EFCCA Youth Meeting (EYM) 2013 in Stuttgart, Germany. The main goal of the work plan is to interact with young people suffering from IBD across Europe in close cooperation with the national patient organizations.*

Through three phases of communication and constant continuous cooperation between the EYG and three main partners such as the European Federation of Colitis and Crohn's Associations (EFCCA), the European Patients Forum for the Youth (EPF Youth) and the national (youth) committees, we aim to raise awareness about IBD and help and support patients all across Europe and the world.

The first phase of the work plan is called "Getting out there" and is mainly focused on the use of social media. Already now the EYG has established four different channels to communicate with members, associations and IBD patients: Facebook, Twitter, Instagram and YouTube. If you would like to see the work that has already been done, please look up the "EFCCA Youth Group" on Facebook and @EFCCAYouthGroup on Twitter! We are posting articles and events almost every week!

The second phase is called "Maintaining con-

tact and transparency". It is our plan to create an online calendar where the national associations can connect to and publish events, so that every patient in Europe can join or know what is happening around Europe for raising awareness about IBD or helping patients. This can also be useful for patients with IBD who are travelling, since they can establish contact with the national associations if need be.



Daniel Sundstein speaking at the Join the Fight Against IBD 2013 press conference, Vienna, Austria

The third and last phase of the plan is called "Going beyond borders". The EYG wants to create video projects in this last phase of the work plan. The main goal of this is to create videos to use in European and national events about raising awareness about IBD. Besides that the EYG wishes to create podcast events to advise and consult IBD patients on the internet, but also to create lesser taboo about the life of IBD patients.

Altogether this Work Plan focuses on how the EYG can be the best sparring partner for the national (youth) committees or associations. Hopefully this will show that we are united about the tasks that needs to be done to raise awareness about IBD, take away the taboo of IBD and create better lives and opportunities for especially young people with IBD.



# To baby or not to baby?

## IBD and pregnancy

During our last EFCCA Youth Meeting we had a lot of very important discussions amongst them was the issue of IBD and children.

**What will happen to my IBD if I get pregnant?**

**What will happen to the child?**

**How about adoption?**

These were some of the questions that came up. Since we are lucky to have two members in our Youth Group who have children we have asked them to tell us about their personal experiences.

We have also compiled some basic information about IBD and pregnancy but please remember to always discuss your plans with your healthcare provider.

## Going for a C-section *By Ciara Drohan*



From left to right: Ruby born October 2012 and Grace born January 2011

I have had Crohn's since I was 18 so children were not on my mind at that stage. At the age of 30 we decided to start our family. Overall my pregnancy was really good I was blessed I had no morning sickness and my Crohn's behaved. I remained on all my medication. My obstetrician was fantastic as he had a number of patients who had IBD and his focus was to keep me healthy.

I have perianal Crohns so have fistulas and a seton in place. When I was nearly 5 months pregnant I had to go into hospital for an examination under anaesthetic as I had a suspected ab-

scess, while in theatre my surgeon explained to me that he would not be happy with me giving birth naturally as he felt the risk of damage to me was too high.

I had thought I might need a Cesarean section so was fine with the idea. I was booked in and arrived on the day actually already in labour so was moved quickly down to the theatre. My beautiful daughter arrived safe and sound in January 2011.

Personally I found the C-section fine and was out of my bed the next day. The nurses commented on that maybe with my previous resection and IBD pain my body already knew pain so this was no different.

The 6 week recovery was not too bad either it was worse after my resection. Like many Crohn's patients I flared at about the 6 week stage but an increase and change in my medication sorted that.

My scar caused me no problems and overall my recovery was great. My overall personal experience was great and so my second daughter arrived in October 2012 by Cesarean section.

# My worries were replaced by joy

*By Victoria Cleary*

When my boyfriend asked me to marry him in 2010 I was thrilled. We planned to marry in August 2011. The first question I had for my consultant was “Do I need to come off my Humira six months before the wedding”? as we wanted to start a family straight away. All the advice with the medication is not to become pregnant on the drug and not to breast feed. Obviously this was a major concern for me.

My consultant reassured me he had lots of patients that had stayed on their medication throughout the pregnancy and baby and mother were doing well. I was so concerned about my growing babies development and formation as I know some Crohn’s drugs can cause cleft palate in the developing baby.

At my 14 week check they advised me to have a C-Section as they said most Crohn’s patients need to have them. I informed him that my consultant had advised me they would suggest a C-section and that it was not necessary in my case as I have not had any major surgery with the Crohn’s hence no scare tissue.

I had to fight my corner but I was glad I did as I really wanted a natural delivery. Luckily I had a very smooth pregnancy and I was able to have my natural birth. I felt fantastic during my pregnancy and thankfully I had a beautiful baby girl on 19th February 2013 weighing 8lbs 5oz. Jamie Faith Cleary is fit and healthy and thriving.

I did however suffer a slight flare after having her and I informed my consultant, we decided to increase my medication to every week instead of every second week. Jamie Faith is now six weeks old, we are both doing very well. I’m breast feeding while on my medication. I’ve been advised it won’t pass into my milk.

I was very anxious about becoming pregnant and during the pregnancy! Worried that something would go wrong because of my condition.

My pregnancy was fantastic and I hope yours will be too.

# How might IBD affect my fertility?

*By Claire Hunt*

Inflammatory bowel disease (IBD) is the name for conditions that cause inflammation of the digestive tract, including Crohn’s disease and Ulcerative Colitis (UC). Many women worry about how the changes of pregnancy will affect their inflammatory bowel disease and if IBD treatments will harm their baby.

With appropriate therapy, most women can

have a normal pregnancy and deliver a healthy baby. IBD therapy during pregnancy is most successful when a woman receives regular medical care and follows her treatment plan closely. Before becoming pregnant, women with IBD should discuss plans for their care with a healthcare provider. Women who discover that they are pregnant should continue their IBD medications until speaking to a healthcare provider.

## Is it better to conceive while my IBD is under control?

The severity and extent of a woman's disease when she becomes pregnant appears to influence the course of her disease during pregnancy. About two-thirds of women in remission will stay in remission, and women with active disease are likely to have continued active disease during pregnancy. Thus, doctors usually recommend that women try to conceive while their disease is in remission.

## How can I increase the likelihood of having a healthy baby?

For women with IBD it is worth keeping in mind that if your disease is under control while you are pregnant then the baby is more likely to be healthy. It is important to follow your treatment plan and to ensure that you are as fit as possible before and during your pregnancy. Talk to your doctor or IBD team if you have any worries about how to manage your IBD while pregnant.

For any pregnant woman, a balanced and varied diet with sufficient calories, vitamins and minerals is important for the growth of their baby. The World Health Organisation has a range of information on how to stay healthy while pregnant, including information on diets. Having IBD, the increased nutritional needs of pregnancy may mean you need to supplement your diet, especially if you are underweight or have active disease.

All pregnant women are now recommended to take a folic acid supplement for the first 12 weeks of pregnancy to help reduce the risk of the baby having problems such as spina bifida. The usual recommendation is 400 micrograms a day. This can be particularly important for women with Crohn's of the small intestine, as this condition can make it more difficult to absorb folic acid.

*With appropriate therapy, most women can have a normal pregnancy and deliver a healthy baby.*

## What sort of delivery should I have?

During pregnancy, care of women with IBD may be shared between a gastroenterologist and an obstetrical provider. Visits with the gastroenterologist are scheduled based upon the severity of disease during pregnancy. Most women are seen by their obstetrical provider every two to four weeks until 28 weeks of pregnancy. Between 28 and 36 weeks, most women are seen every two weeks.

Women are usually seen once per week between 36 weeks and delivery. Pregnant women with inflammatory bowel disease (IBD) should discuss

their labour and delivery plans with their healthcare provider. In women with Crohn's disease, the type of delivery (vaginal versus Caesarean) depends upon the health of the tissues around the vagina and anus, the patient and physician's preference, and the woman and

baby's progress during labour. If Crohn's disease affects the areas around the vagina or if a woman has an ileoanal pouch, a Caesarean delivery may be preferred to reduce the risk of developing fistulas.

## What are the chances of my child having IBD?

Parents with IBD are slightly more likely to have a child who develops IBD. If one parent has IBD, the risk of a child developing IBD is about 2% for Ulcerative Colitis and 5% for Crohn's Disease, although it may be higher in some population groups. That is, for every 100 people with UC, about 2 of their children might be expected to develop IBD at some time in their lives. For every 100 people with Crohn's, about 5 of their children might be expected to develop IBD. If both parents have IBD, the risk can rise to 35%. However, we still cannot predict exactly how IBD is passed on. Even with genetic predisposition, other additional factors are needed to trigger IBD.





## Shire's mission

Shire is a dynamic and specialist pharmaceutical company inspired to succeed by enabling the patients, and societies, it serves to lead better lives.

Shire's vision is to continue to identify, develop and supply specialist life-changing products that support physicians in helping their patients to a better quality of life. 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 medical needs that are left unmet, coupled with substantial 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. Finding 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, chronic constipation and gastro-oesophageal reflux disease.
- 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.



## CROATIA “Not another NGO!”

Interview with Iva Savanovic, Former President (2000-2005) and current Vice President of the Croatian Crohn's and Ulcerative Colitis Association, HUCUK



Iva Savanovic relaxing by the seaside

### Tell us about the history of HUCUK?

HUCUK was formed in 2000 as an NGO. At that time in Croatia there wasn't any association of that kind, not even any support group in hospitals. I was diagnosed in 1998 after seven long years of struggling to find out what was wrong with my health. Spending lots of time in hospital I met lots of people with IBD and had long conversations at night with people who were unable to sleep under steroids like me.

So I thought that IBD people in Croatia really needed an association. I was a social worker student at my third year of university when I was diagnosed, but before that I was already working a lot in the NGO sector, as a student, for other diseases and conditions. So the idea of establishing an IBD association was something I deeply felt I needed to do, to help IBD people in Croatia by creating a place where we can meet, support each other and to make changes in society.

It was very difficult to start an association at that time. War in Croatia ended in 1995 and with a ruined economy and lots of NGOs dealing with the situation in Croatia, I was told “Not another NGO! ”.

It was easy to find volunteers but not the necessary funds to start an association. My late

grandmother believed in my idea and gave her pension as starting funds and as proof to the national authorities in charge of registering NGOs that this association was economically viable to start working. And that is how HUCUK's journey began.

### How many members do you have?

Today we have between 500 up to 700 members, it varies every year. The population of Croatia is around 4.500 000 inhabitants out of which 4000 people have IBD. At one stage we had around 1500-1700 members because HUCUK was the referent point to people with IBD in Slovenia, Serbia, Bosnia and Herzegovina because at that time those countries did not have their own national association. This has changed and there are now national associations in Serbia and Slovenia.

### What kind of activities do you do?

Our activities are - what I like to call CEC orientated – Cooperation- Education-Change.

Our main activities are cooperation with all relevant authorities and organizations in Croatia like for example the Ministry of Health, the Croatian National Institute for Public Health, the Croatian Gastroenterology Society, hospitals, the Croatian Coalition of Associations in Health, the Croatian ILCO Alliance and other but also cooperation with organizations outside of Croatia like EFCCA.

Cooperation is always orientated toward lobbying for necessary changes to improve life of IBD people. HUCUK's main task at this very moment is to change regulations regarding defining criteria of work ability and criteria of defining disability for IBD. People with IBD go through long and hard processes of assessment by two types of commissions that are not entirely acquainted with these diseases. There are no guidelines to define work ability of people with IBD. It

is done based on medical documentation by the commission usually consisting of the GP's opinion who are not necessarily entirely familiar with the severity of IBD and many complications that come with IBD.

The EFCCA World IBD day in the EU Parliament in 2012 and the Join The Fight Against IBD initiative have a huge impact on our work and we hope that mandatory changes will be accomplished both on our national level and at EU level. We have now a Croatian version of the IM-PACT study and we will use data for our fight of changing regulations about disability in Croatia and raise more awareness. HUCUK is starting a new campaign in May 2013 to May 2014 as one of big steps towards the above mentioned problem. We'd be happy to share more information about this in the upcoming future.

**Education** is also a priority in HUCUK including group meetings, SOS line, Facebook group of support, Patient-doctor meetings (every year in major cities), brochures and sport groups.

But education is also orientated toward General practitioners in better understanding of IBD and that is also one of HUCUK's priority in our campaign for 2014.

It is not my personal observation, but the fact. Since 2000 when HUCUK started working changes for IBD people happened in Croatia. IBD patients are more educated about IBD and that helps them in better understanding the disease and in everyday communication with doctors.

The public is more familiar with IBD. IBD people and their families are not alone; they have everyday support in HUCUK. The status of some medications has changed (now on prescription) together with stoma bags (people used to pay for stoma bags because they received insufficient numbers on prescription). HUCUK is recognised in the medical community and has a strong voice.

Many students received support letters from HUCUK for their universities to better understand problems in studying and absence from universities, the same goes for school children and employed people who got support letters for

their work place.

Still there is a long way to go and many changes need to be done. Croatia as a country was in process of transition and it was not easy to work in a society in transition but we are proud on our accomplishments so far.



Group visit to the Croatian Academy of Fine Arts with Nevenka Arbanas, Croatian painter

**You are a member of the EFCCA board, in fact you are also the vice president, how do you combine these two roles?**

For HUCUK it is important to be a member of EFCCA, it is one more strong voice in the IBD European movement. I joined the EFCCA Board in 2008 and by today I am still a EFCCA Board member, now in a role of EFCCA Vice-chair. It is not a privilege to me, but a responsibility towards all EFCCA member associations and the IBD community. EFCCA is progressive, dynamic, and powerful because of each member association and because it is United.

I am happy to being part of the EFCCA Board as it allows me to actively contribute to the IBD European movement and to feed back directly to my association of what is being done at the European level and how it can be implemented on our national level. No matter the role I have, delegate, Director of the Board or Vice-chair I will always be committed to work for benefit of people with IBD. Because working with people for people is a responsibility above all.



## FRANCE

### Original summer camp for young adults with IBD

2012 was an extraordinary year for young adults with IBD in France. The AFA youth group called "MICI Jeunes" – with 350 members between 18 and 30 years old – has significantly developed its activities, while the number of young people affected by IBD is still dramatically increasing in the country (20 new cases diagnosed each day). The MICI Jeunes Team, which I lead, has grown with 7 regional and 3 organizational committed youth delegates, supported by 6 volunteers. In 2012, this "dream team" organized 14 local events: 6 meetings in Paris, 4 in Bordeaux, 2 in Lyon, 1 in Rennes and 1 in Toulouse. The team also set up two national meetings: the traditional "Youth Weekend" has taken place in Paris every first weekend of July since 2007 and a new and original event took place, inspired by the EFCCA summer camps, the "Summer Week", which will take place again in August 2013 in Dinard, Brittany. Consequently, AFA has multiplied the youth group budget by three.



This very special "Summer Week" gathered together 26 young adults with IBD who came with a girlfriend, three boyfriends, a sister and a best friend. Some of the participants had never met other people with IBD. They came from all over France, but also from Belgium and Switzerland as this camp was supported by the EFCCA "Catch Your Dream" label. In the Solacroup Institute, a peaceful, very pleasant oceanfront and green do-

main, the young adults were offered a therapeutic educational program tailored to their age, their disease and the specific issues they face. A lecture on the multiple factors involved in IBD and a Q&A session was given by Pr. Philippe Seksik, a Parisian gastroenterologist committed in research on IBD and microbiota. Other workshop dealt with a range of issues such as treatments and motivations, nutrition and cooking with a dietician, self-esteem, self-confidence, relationships with physicians, social life and friendship... The most awaited and successful discussion group was the one on "love relationships, sex and IBD".

The busy days included activities such as relaxation, do-in, sophrology and art-therapy proposed by well-being specialists, as well as free time to enjoy the beach, play football, miniature golf, badminton and other sports, paint, watch the movie of the Mont Blanc climb by people with IBD, visit the city of Saint-Malo, the Mont Saint-Michel, play cards and board games or go dancing at night. The group also adopted a little teddy bear: Malo is now the youth group mascot and a VIP as he travels a lot and meets many people, even the French President of the Republic François Hollande last December!

Most participants were relieved to express strong feelings and find answers to their questions. They exchanged a lot together, sharing their personal experience. Tears were sometimes necessarily released, but the group also shared complicity, laughs, fun and a good sense of humour, making fun of themselves... unforgettable moments! The goal of AFA and the MICI Jeunes Team has been reached: everybody went back home smiling and with more hope, resources and energy to go on fighting against IBD, with the strong belief inside that they are not alone, that nothing is impossible, life goes on and they can make projects and dreams come true despite their disease.

A short movie of the week and filmed testimonials of participants on life with IBD are available

on the AFA web TV youth channel: <http://vimeo.com/channels/428066>.

Young members of EFCCA national member associations are invited to join the 2nd Summer Week on August 3-11th, 2013 if they have a suf-

ficiently fluent level of French. Feel free to contact the organizing team at [micijeunes@afa.asso.fr](mailto:micijeunes@afa.asso.fr)!

*Tiphaine Chapeau, AFA board member and EFCCA delegate*

## POLAND

### Support Group for people with IBD

Three months ago J-elita launched “a support group” for people with IBD. A psychologist leads the discussion on different topics relevant to the participants. The aim of the group is to help people to better deal with their disease and various connected problems, especially emotional ones, for example the last meeting looked at how to cope with stress and the next will be about self-esteem. So far meetings only take place in Katowice but we are planning to also launch them in other cities as soon as we find appropriate psychologists. Usually there are around ten people at the meetings and new people can join at any time. The only restriction is that it's only people above age 18 and a promise to keep confidential of what is being said during the meeting.

Another activity we are involved in are the distribution of “toilet cards” which we have been using for years and now we decided to show them to the world. The card includes (both in Polish and English) the patient's name, address and the place



of treatment as well as the phrase: “I can't wait. Due to medical condition I have to use the toilet urgently. Thank you for your understanding”. The cards are usually respected in public toilets both by the people responsible for them as well as by others waiting in the queue. Moreover patients often have the chance to use the toilets for disabled, thus having a faster access to the facility which is normally closed.

The last things we would like to announce are sort of last-minute news. After our General Assembly, which took place in April, the new President of the Board is Magdalena Sajak (some of you had the chance to meet her during JTF event in Barcelona). Pawel Staniewski who was the President for the last two years is now a Treasurer and Magdalena Staniewska did not stand for elections this because she is expecting a baby due in August.

*Marcin Ruta, J-elita*

## SPAIN

### Support Group for people with IBD

In Spain we are currently involved in several interesting activities:

#### **IMAGE campaign**

On 27 February the IMAGE Campaign was launched in Madrid. The campaign aims to inform

patients, healthcare professionals and the general public about generic and brand drugs. ACCU España is participating in this campaign together with 14 other national associations representing over 2000 associations in total.

### First national day for Ulcerative Colitis

The first national day for Ulcerative Colitis was marked on 27 February in Valencia and was organized by ACCU Spain and ACCU Valencia as well as GETECCU (the medical IBD association). This initiative - aimed at families and health care professionals - wants to inform and raise awareness of the challenges faced by people with Ulcerative Colitis and to help them reduce the barriers against which they struggle in their daily lives.

### 23rd Convention of ACCU Spain in Orense

In May we are going to celebrate our 23 Annual Convention of ACCU Spain, which will be attended by around 200 participants. We have invited various medical IBD specialists who will provide seminars on a range of subject amongst one of which will be the issue of disability in relation to Crohn's and Ulcerative Colitis.



**ACCU Spain to be appear on the ONCE lottery ticket** ONCE is a non-profit organization, which aims to improve the life of the blind and visually impaired. It raises funds through daily lottery tickets. On 14 May ACCU Spain and IBD will appear on the popular ONCE lottery tickets during one week. This will be a great contribution for our social work.

*Yolanda Modino, ACCU España*

## IRELAND

### Chronic Disease Self-Management Programme, Beaumont Hospital Dublin



As part of their Living Optimally with IBD programme, Beaumont Hospital in Dublin are now offering Stanford University's Chronic Disease Self-Management Programme to IBD patients (see EFCCA Magazine January 2013). Three of those involved share their experience.

#### **Dr Jennifer Wilson O'Raghallaigh (Senior Clinical Psychologist, programme leader)**

I was delighted to be part of an Abbvie Ireland-funded pilot programme at Beaumont Hospital

which included training in delivering Stanford University's Chronic Disease Self Management Programme – a six-week course delivered to patients by one health care provider and one patient volunteer. I found it very rewarding to work with a patient volunteer. It reinforced the positive impact of information being delivered between people who share similar experiences.

Having a patient colleague helped give an insight into the patient experience at Beaumont, particularly how the hospital holds many memories and associations for the patients with chronic illnesses who pass through at different stages in their lives. I often meet patients who are at a difficult point in their journey with treatment or illness. They doubt their ability to cope with the changes in their lives and the impact of their illness on themselves and their families.

It was very inspiring to see how patients on the programme came together to discuss and learn strategies for change. All I had to do was help de-



liver the programme and stay out of their way!

**Ciarán Davis (ISCC, programme leader)**

Having had Crohn's for over twenty years I know how isolating it can feel. Any time we can bring IBD patients together at ISCC events I know something very special is happening. But one time is never enough and that frustrates me. With this programme however, not only do people meet others with IBD, they spend a lot of time with them over six sessions and form close bonds that they are encouraged to strengthen through participation in a support group when the programme has finished. There has been huge satisfaction for me in seeing this happen. Feedback has been amazing and I hope to be delivering this programme for many more years to come.

**Sharon Crofton (participant)**

I was diagnosed with UC eight years ago and have felt quite isolated at times. I was a little apprehensive about the self-management programme at

Beaumont but was warmly welcomed by Ciarán and Jenny and immediately felt a sense of belonging with the group. It just felt like I had found the missing piece of the jigsaw! The opportunity to meet people with the same experience was priceless. Problem solving, positive thinking, depression management and all the other topics we covered were very useful in teaching me new coping skills and to become a better self manager. I feel less isolated and better able to communicate with my healthcare providers. I would wholeheartedly recommend this programme for any chronic disease, not just IBD.

Information on this programme can be found at: <http://patienteducation.stanford.edu/programs/cdsmp.html>

*Ciarán Davis (ISCC) and Dr Jennifer Wilson O'Raghallaigh (Senior Clinical Psychologist, Beaumont Hospital Dublin)*

## NORWAY

### LMF winter youth gathering 2013

The 2013 winter gathering started on Thursday 10th of January. 23 new and old faces got together in the large mountain lodge at Hafjell. Hafjell is where the alpine ski competitions took place in the 1994 winter Olympics in Lillehammer and is one of the largest skiing areas in Norway. This is a large lodge with a very good atmosphere, space for all of us and last, but not least – enough toilets! On the program on the first evening was pizza, "get together" games and lots of talking with old and new friends.

On Friday we had invited Stine Hellebergshaugen, therapist with lots of passion for her work. She teaches yoga, relaxation techniques and pain relief. We were instructed to lie down on the floor and were taught breathing techniques and went through different exercises

on how to handle pain. For most of us these were new techniques that will help us through painful examinations and help us handle the day to day pain that we all suffer from time to time. Some of us got so relaxed that we fell asleep on the floor!



After lunch there were group projects on the agenda and we were divided into four groups. Two groups were told to make a performance each with the help of hands and socks. This turned into two great sock theater performances with lots of fun. The other two groups made informative presentations on how to listen to your body! These were useful experiences for all of us.

The rest of the evening was filled with activities like board games, Idol on the television, sauna with snow diving and several games of pool. And of course lots of talking, giggles and

laughter until the early morning!

Saturday was the skiing day. It was a beautiful day with lots of sunshine, but rather cold. We were a group of 8 who braved the minus 15 degrees and spent the day in the slopes on skis and snowboards. Those left behind spent the day in front of the fireplace with more chatting and laughing. The skiers stopped for a short lunch break and went back out for more adventures in the slopes. The evening was filled with similar activities as the pre-

vious evenings and with just as much fun.

As leaders we would like to thank this year's participants of the winter gathering for a wonderful trip and for a real good job with the group activities as well as the cooking, the cleaning and the cohesion throughout the weekend. We hope you share these good experiences with us and we look forward to seeing you all on another trip.

*Eva, Thomas and Morten, LMF*

## UK

*Crohn's and Colitis UK are involved with many diverse areas of work this year. Here are just a few that may be of interest to you.*

### **David Barker – new CEO**

I join Crohn's and Colitis UK from Breakthrough Breast Cancer having spent a good number of years in a variety of leadership and management positions in the voluntary sector. I began my career in the commercial world specializing and training in Marketing and Communications and since moving to the voluntary sector have found the work to be most enriching, rewarding and at times heartbreaking. I have been inspired by the courage, strength and determination of so many people whose suffering, triumphs or commitment to an issue or a particular charity has further fuelled my own passion for the sector.

I'm joining the charity during a year when we're placing a strong focus on supporting young people. I was stunned to hear that around 10,000 of the 18,000 people in the UK diagnosed each year will be in their late teens or twenties. This year the charity is focusing on the following:

**The Me and IBD: Facing the Future – School and Beyond Campaign** is already making a significant push into exciting areas such as social media.

Our new micro-site [www.meandibd.org](http://www.meandibd.org) is a key platform for the campaign which is set to reach teachers, schools, universities and young people's healthcare professionals.

**Our First Summer Camp** – will be held in July. It is open to members who are 14-17 years of age. We will be attending an outdoor adventure centre and young people will have the opportunity to take part in activities such as: canoeing, climbing and camp fire.

**Me and IBD – Strategies for Living** – Crohn's and Colitis UK is offering the opportunity to people aged between 18 and 25 to join us for a weekend where we will explore what it means to live with IBD. There will be workshop sessions and time to share experience and coping strategies with others of a similar age as well as have the opportunity for some social time!

**The Family Network** – you may have heard of Smilie's Network. Over the last 20 years this area of work has grown and we are now changing the name of Smilie's Network to 'The Family Network'.

We will be setting up a Group in each of the 4 UK countries. The England Family Network Group already exists. The Scotland Family Network Group is to be launched on 28th April.



David Barker, new CEO

A Family Network Group will be set up in Northern Ireland and Wales in the next 3 years. These Groups will support parents, children with IBD

and their siblings.

If you would like to know more about our activities please contact: [heatherb@crohnsandcolitis.org.uk](mailto:heatherb@crohnsandcolitis.org.uk)

## THE NETHERLANDS

*We'd like to share an article that we published in our Dutch magazine Crohniek. It is part of a series called "dilemmas" as people with IBD are often confronted with conflicts such as: yes or no to a stoma, yes or no to a certain medicine, yes or no to an operation. This is the first article of the series.*

### Dilemma: life with(out) a stoma?

Introduction:

You have Crohn's Disease (CD) and have had to deal with fistulas for years, to such an extent that your quality of life has dropped below zero. Something has to happen. Sandra van Erve (39) and Babs Saris (42) talked with each other about the solution for their dilemma. One chose for a stoma, the other consciously didn't.

**Sandra:** 'My fistulas were so painful, I just couldn't sit down normally anymore. I also had terrible stomach aches and suffered from severe fatigue.'

**Babs:** 'Going to the toilet was a painful experience because of my fistulas. The strange thing is, you somehow get used to that ever present stomach ache. When my doctor stopped working and a new doctor ordered an endoscopy for the first time in nine years, he discovered that my entire colon was infected. He had only one solution: a temporary stoma.' Sandra's doctor advised her to consider a temporary stoma.

**Sandra:** 'It was everything or nothing. I had always taken a stoma into account. I cried for ten minutes, not for fear of the stoma, but the idea of a temporary stoma didn't appeal to me. I didn't want two operations, and told my doctor I wanted a permanent stoma.'



### Shock

Whilst Sandra consciously chose for a stoma, Babs felt like her doctor had given her no choice in the matter. 'I expected that a stoma would be inevitable someday because of all the stenosis in my colon. However, this was an enormous shock.'

**Sandra:** 'I understand that you must have been shocked by the unexpectedness. You should never force a stoma on anybody.' 'My doctor assured me there were no other options', says Babs. 'Luckily the surgeon saw that the timing wasn't right and advised me to seek the advice of another doctor. In the one-hour talk that followed, we decided I would first try medicine clysters.'

### Life saver

**Sandra:** 'I am so happy with my stoma. I can breath and sit without pain. I have my life back again. Eight weeks after the operation I started with sports again and I now have zumba lessons three times per week. My stoma has saved my life.'

**Babs:** 'I still don't like the idea of a stoma. I am not mentally up for it yet and first want to try other options.'

**Sandra:** 'I don't care how I go to the toilet, from behind or in front. But you have to be mentally ready for it, and you aren't.' Luckily the medicine clysters are doing their job. Babs' infections have disappeared and she has loads more energy. She has accepted the fact she needs to use incontinence material. 'It has become part of my life. I even prefer using it, if it means I can postpone a stoma. A stoma feels as an imperfection.'

**Sandra:** 'I hated being incontinent, a stoma was the solution for my problem. I want to enjoy life.'

Barbara Warnar, CCUVN



## DENMARK

### Think positive!

*Inspired by Daniel Sundstein's presentation in Vienna during the Join the fight against IBD event, we decided to create a new group on Facebook called: Positive stories about IBD - and everything else.*

Our daily day lives can sometimes be so hard, that we just want to laugh or hear a success story. Get a break in life, and don't we deserve it. A lot of our members agreed. The group is now sharing a third place with another popular group: IBD and Diet. They both have 263 members... and counting.

There is still a long way to reach our largest discussion group's number (1200+ members) but it is a very new group and it definitely looks "positive".

#### **World record attempt in Australia**

48 days and 23 hours - that is how long it takes to drive all the way round Australia, on a bicycle. At least, that was what Ronny Andreassen from Denmark wanted to show us all.



On Wednesday the 13th Ronny flew down under to Perth, Australia, and prepared himself for the 14.913 km on his bike - all alone and without any help. Does it sound crazy, the idea that Ronny from Crazycycling got? Maybe but then again, it had more than one good purpose.

Ronny was not just doing it to prove something to himself, he was doing it to honor his mother. A mother with IBD. And the best way he could do this, he thought, was by supporting an association that supports her - The Danish Colitis and Crohn's Association.

On his way around Australia, Ronny is at the same time raising money and creating awareness about a disease, he had seen his mother suffer from IBD for too many years.

Many thanks to Ronny and all the best to his mother.

*Bente Nielsen, CCF*

## SWEDEN

### "Do you have IBD? We do too!"

Together with the Swedish national association for ostomy and reservoirs operated, ILCO, the Swedish Stomach and Bowel Association (Mag- och tarmförbundet) have recently finished the project 'Teenagers with IBD'. It lasted three years during which meetings for teenagers with IBD were arranged several times. Now at the end of the project we have made a film with, by and for teenagers with IBD, about how it is to be a teenager and live with this diagnosis.

The film is called "Har du IBD? Det har vi med!", which means "Do you have IBD? We do too!" We hope this film does not only help teenagers with IBD or chronic gastrointestinal illnesses, but also healthcare professional who may have

contact with those teenagers in various ways. The film consists of several parts, such as a teenager's meeting with the doctor when getting a diagnosis, an elite triathlete who talks about having IBD and reaching your goals and dreams, and a part where the teenagers in the film talk about their thoughts and experiences from having IBD at a young age. The aim is to make teenagers feel that they are not alone and that there is hope for the future.

To see the film one can either order the DVD (for free) from either one of the associations, or watch it for free on Internet through our websites.

Another ongoing project is IBD till låns ("IBD by remote control"). The idea comes from Norway and it partly include a series of short films of dif-



ferent kind, like letting a celebrity “borrow” IBD for one day. For more information please read our article in the previous EFCCA Magazine (issue 1 January 2013). In the latest film we’ve released, the young Swedish blogger Daniel Paris tried out life with IBD for a day. So far the film has been viewed by 7,239 visitors and is available through both the project website <http://magotarm.se/ibd>

and Youtube. We hope it will be a successful way to let people know about these diseases and that also young people can fall ill. And it doesn’t always show on the outside.

We also continue to work for children and young people with gastrointestinal diseases and are using youth-pages in the member’s magazine Kanalen (“The Channel”) to its full potential, as well as the website for Unga Magar (“Young Stomachs”, <http://magotarm.se/unga-magar/>). Another important part is our activities in social medias, such as Facebook. We are full of good ideas and have plans for several other projects: we hope to be able to make them all come true.

*Ebba Persson, Youth Editor, Unga Magar, Mag- och tarmförbundet, Sweden.*

## ISRAEL

### Rock and IBD

2012 was a year full of activities. We organized more meetings, added support groups and webinars, expanded our community outreach services and experienced over 100% growth in new paying members.

One of the year’s highlights was an empowerment Desert Jeep trip for children. The vehicles were driven by volunteer drivers that also have IBD.

Although the on-going activities yield gratifying results, by September we were facing new financial challenges that needed to be fixed by the beginning of 2013.

There was no time for long term fundraising plans. In times of trouble we needed a great idea to turn things around. Sometimes what may seem as an ambitious idea in the boardroom turns out to be the best.

We approached one of Israel’s most popular and critically acclaimed rock star musicians, Mr. Barry Sakharov through his agent, asking to donate a closed fundraising show to our community

(patients, members, doctors and friends).

Mr. Sakharov graciously agreed and we were on our way. One of the best music clubs in Tel Aviv, The Zappa, donated the place. We were busy selling 650 tickets in four group prices via our volunteers, staff and board.



Barry Sakharov (left) and Gidey Shomron

January 7th was a memorable evening for everyone. Mr. Lior Manor, Info-trainer, mind reader and a magician generously donated his time with a delightfully entertaining opening performance. Mr. Sakharov and his talented band followed with a fantastic, sweeping and energetic performance.

For CCFI it was a memorable event that solved an urgent problem. We got more than we could have wished for. We made many people happy, including our accountant... It was a wonderful opportunity for us to show our contribution and appreciation to those who support us. On that evening we were all united in spirit and goals for a better future.

## IBD Planet: Journey through Middle Earth

*by Jennifer Coady*



Jennifer Coady on her travels around New Zealand

Travelling has been something I have always had a passion for in life. To travel to all the wonders of the world, see different cultures and meet amazing people along the way. But in November of 2007 all dreams were held up when I was diagnosed with Ulcerative Colitis. I had been suffering for a year with it before the doctors came across it during a colonoscopy. After that it was a struggle to even travel to the shop without panic creeping in. Wondering how long I would last before begging to use some form of toilet. Fear can be a very powerful thing once you allow it into your mentality and this led to me rarely leaving my home or somewhere I knew I was safe in the knowledge that there was toilets very close by.

As I gradually got worse over the years with the illness and changing different medications I eventually started to lose hope of ever seeing the world through my eyes instead of on the television, trav-

el magazines or through friend's photos. But to my relief I managed to find a way of controlling my illness through diet and exercise that changed my life for the better. Within a couple of months of feeling the best I had ever felt I began saving for my travels. My first stop being the other side of the world. New Zealand. A country I had always wanted to visit especially being a fan of the Lord of the Rings trilogy.

November arrived and I was on my way. Taking a flight from Dublin to Abu Dhabi, Abu Dhabi to Sydney and then Sydney to Auckland. I was extremely worried about how long these flights were and how I would cope on them. I remembered to drink a lot of water and walk around the plane and sleep as much as I could. I didn't have any issues on the flights thankfully and began getting very excited about spending Summer time in New Zea-



land.

I stayed in Auckland for a few days to settle my body clock and see how my bowels would react to the time difference. My excitement seemed to have stopped any jet lag and I got into the swing of things straight away. Trekking up dormant volcanoes, through lava caves and jet boating.

The bus journeys began then as I started travelling around the north island. This being a huge fear as anyone with IBD would know. Most journeys were a minimum of 4 hours. This scared me a little but I need not have worried as the public transport there was amazing. Buses stop for toilet breaks every hour and if you have an issue or were feeling ill the bus drivers take note and will stop for you whenever without the disgruntled attitude you would get from most bus drivers. It never ceased to amaze me how helpful the bus drivers were and I began to look forward to the 7 hour bus journeys rather than dread them.

The big activity on the north island I was looking forward to was the Tongariro Alpine Crossing. I had been practising at home for this as it was a full day 19.4km trek over volcanic terrain on Mount Tongariro and passing by Mt Ngauruhoe. Most of you would know this mountain by its Middle Earth name 'Mount Doom'. It takes about 7 hours to get through it with a good level of fitness. My big fear was the lack of toilets as there was only access to three toilets along the journey. One of them right at the beginning. So of course I made use of that. I was wise about when I was going to eat and made sure to drink plenty of water along the way to keep me hydrated and prevent any bad moments with my illness.

Parts of the journey were very challenging with knee troubles from Colitis walking in loose gravel and terrain, but luckily with the amazing 25 de-

gree weather we could see where we were going as we headed further up into the mountains. I just made sure to take my time and enjoy the views which were absolutely spectacular. Some areas looked closer to terrain on Mars rather than Earth.

There was also a lot of snow and ice in the area so along with a few friends I made along the journey we made the most of it and played in the snow in the dead heat. It was a surreal feeling. As we headed further on it went from dusty sand to alpine grass and then right into a large bush walk. By the time I was finished the trek my legs were weak and I was very tired but I had a huge smile on my face knowing the achievement I had just done.

*“If you have a dream and determination you will get there eventually. It will never be easy, it will be challenging but it will be so, so worth it when it comes true.*

I travelled more of the north island seeing beautiful areas like Napier and Hastings which is known to be wine valley country, Bay of islands where I got to see dolphins out at sea and climbed under waterfalls, Hobbiton in Mata Mata where The Hobbit and Lord of the Rings set is and Rotorua which is famously known for its smell due to it being a thermal wonderland

filled with geysers and hot mud pools. When the travelling was done I settled into working life in Wellington, the capital of New Zealand, where I made plenty of friends and met amazing people. I worked there for five months to save for my journey around the south island to begin more adventures.

When that day arrived I packed my bags and headed for the ferry to Picton. Excited about what was in store as the south island was known for its amazing scenery and extreme activities.

Kaikoura was the first stop which is known for dolphin and whale watching. Unfortunately the weather was pretty bad to take a boat when I was

This is where the real fun began as I made my way south towards glacier country. I hit Franz Josef with a nervous excitement as this was where I was going to do my sky dive over the Southern Alps. I thought it would be the best way to view this stunning landscape and the highest mountain in New Zealand, Mount Cook.

The morning of my dive I did not feel nervous at all. I had this sort of calm although I was having a fear of bowel movements in what I was doing. Even the healthiest of people would, doing what I was about to do. But I was not going to let that stop me. I headed for the loo six times (just in case) before they suited me up and we took off in the little airplane gradually getting higher until we hit 16,000ft. By this stage we needed oxygen masks being so high up.

The scenery was stunning and as I sat in the doorway of the plane I realised there was no going back now. Falling out of the plane is one of the craziest sensations as your whole body tries to fight what is happening to it. The first few seconds were the scariest of my life but once my body adjusted I got to enjoy it and smile for the camera making my way down in one minute free fall before the

parachute was opened. I was on a high for the rest of the day as I ventured on towards Fox Glacier. This time it was the challenge of trekking up a glacier for the day. Not for the unfit or faint hearted.

Again before we headed off we were warned that there were no toilets for the day so I made my way to the toilet before decking myself out in glacier hiking gear and ice clamps. This was an amazing experience as we headed further up into the glacier with our guide hacking steps out of ice with an axe and having us climb up parts with a rope which I admit was extremely scary considering one slip and you could have broken bones or worse fall down one of the crevices to your death. That did not put me off as I looked at the beauty of this glacier and the area surrounding it.

My overall experience was phenomenal considering what I had achieved in a short period of time under the difficulties of having a chronic illness. All I can say is if you have a dream and determination you will get there eventually. It will never be easy, it will be challenging but it will be so, so worth it when it comes true. I am already planning my next adventure.

## MICI pour la vie – IBD for life

Interview with Jean Michel Hédreux,  
former EFCCA delegate and member of Afa

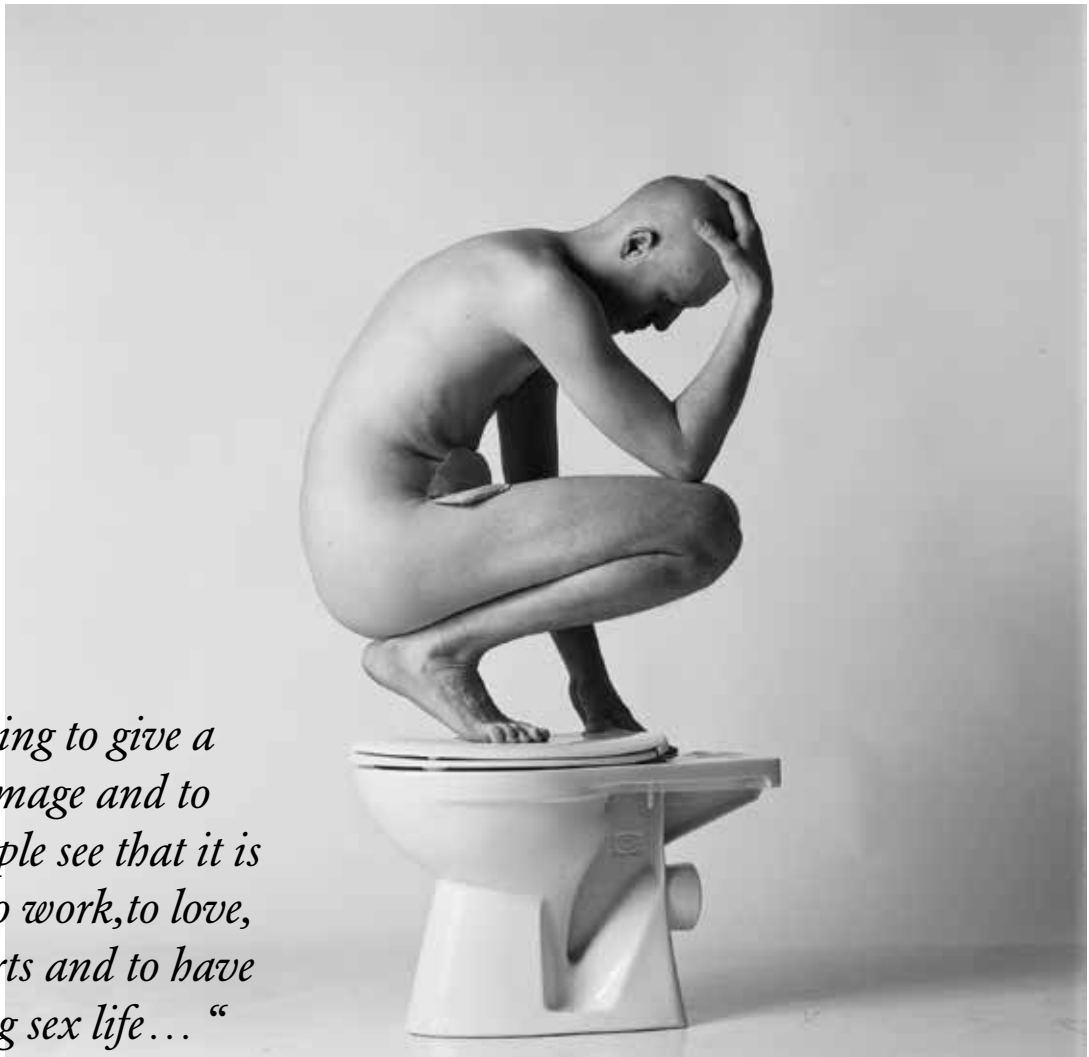
*Jean Michel Hédreux, from Brittany in the west of France, has been diagnosed with IBD 15 years ago and following numerous surgeries he opted to have a permanent stoma. Since then Jean Michel has been determined to live life to the fullest and at the same time help other people like him to do the same. In 2010 he set up an association called “Mici pour la vie” (IBD for life).*

**What were the reasons for creating “MICI pour la vie” ?**

I established “Mici pour la Vie” in 2010 in order to

promote a book I had written about my experience of living with IBD and having a stoma. I wanted to let others know what it really is like and to create a link between people with and without IBD. The book, which is called “Recto la vie c’est nickel Crohn”, contains both a narrative part as well as photos of my body to illustrate in a very uncovered way what exactly I am talking about. I wanted to make sure not to overwhelm readers with hard facts but to show with humour and a lot of good energy the reality we, IBD people, have to face in our daily lives.

*“I am trying to give a positive image and to make people see that it is possible to work, to love, to do sports and to have a fulfilling sex life...”*



I do a lot of sports and I think I have an attractive body, which I want to put to use to show that having a stoma does not mean the end of the life. I am trying to give a positive image and to make people see that it is possible to work, to love, to do sports and to have a fulfilling sex life...

I set up “Mici pour la Vie” as a non-profit association with the idea to use the profits from the sale of the book to start new projects aimed at helping other people.

### **What other projects have you started then?**

Just over two months ago I decided to launch a collection of sensual lingerie for women with a stoma. It's not that such clothing didn't exist before but personally I didn't find those clothes very

appealing. I wanted to create a collection that was highly sensual and attractive at the same time.

This idea came about as I am very often asked by hospitals and doctors to speak to people who are about to undergo surgery to have a stoma or people who just came out of such a surgery. Many people I spoke to - and in particular women - had a very negative view of their bodies. They thought that they could never like their bodies again and feared that men would not find them attractive anymore. As result many resigned themselves to a possibility of living alone forever.

When I hear this I usually say to them: “it's your body, nobody can judge your body because of your stoma. You have a stoma, that's life, you



have to find a way to accept it in order to be happy again.”

My initial dream when I created this collection was for the husband to offer this lingerie to his wife after she comes back from hospital.



Ensemble Noir with pouch cover from the lingerie collection “MICI pour la vie”

### What are the reactions to your launch?

I had very positive feedback so far. Many women have told me that this initiative has helped them to gain back some confidence about themselves, made them feel more attractive and improved their intimate life.

I don't think this collection is such a big deal but some times small things can have a big impact in helping people to feel better about themselves - especially after an operation - or to see their stoma in a different light.

### Do you think women suffer more than men from the image of their body?

Yes, I think in general women suffer more than men. This is also related to the fact that it is much easier for men to conceal their stoma by using adequate underwear.

That's why I think using attractive garments for your stoma will improve your general confidence about your body image.

### What's your next project?

Well I just started this lingerie collection and I am still busy with that but in the next 3-4 months I want to look at designing swimming clothes for men with stoma.

For more information please check out the website: [www.micipourlavie.com](http://www.micipourlavie.com)



Women's accessoires in white from the same collection

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# IBD Research Foundation

## Water and Sunshine

*In January our IBD Research Foundation finalized its 2012 grant program. It took us a little bit longer than expected, due to the record number of applications and because of the comprehensiveness of the applications. Therefore we highly appreciate the efforts of our peer reviewers and our patient reviewers. As usual the patient reviewers decided which projects to award a grant, taking the results of the peer reviewers into consideration.*

The following research projects were awarded a grant:

**Does the intestinal microbiota contribute to disease activity in IBD?**

Dorothea Jonkers

Department of Internal Medicine, Division Gastroenterology-Hepatology

Maastricht University Medical Centre, The Netherlands

**Adenosine pathways and gut wall fibrotic remodelling in the presence of bowel inflammation: a research program on the immune mechanisms by means of molecular and pharmacological approaches**

Luca Antonioli

Interdepartmental research centre of clinical pharmacology and experimental therapy

University of Pisa, Italy

**Observational Study for Outcome and Predictors after Discontinuing TNF blockers in Crohn's Disease**

Jan Preiss

Medizinische Klinik für Gastroenterologie, Infektiologie und Rheumatologie

Charité - Universitätsmedizin Berlin, Germany

During the EFCCA general assembly in March, the IBD research foundation was represented by its secretary. It provided us an excellent opportunity to get in touch with the representatives



Wouter Miedema, IBD Research Research Foudation

of national IBD associations which are member of EFCCA, as well as the representatives of the EFCCA youth group. Among other things, we expressed our appreciation for the associations which supported us with donations last year, which were the Swiss association (SMCCV), the Austrian association (OEMCCV) and the Finnish association (CCAFIN). We even received a donation from the Swiss association twice. Naturally, we also highly appreciate the various private donations we received.

Hopefully we can expect similar support this year, as donations are crucial for our foundation in or-



der to continue our quest for the cure. In fact, each donation makes our foundation stronger in our common fight against IBD.

During the EFCCA GA we also explained that our foundation not only requires donations in order to become stronger, we also simply require help from people. We require for example people with skills in finances, public relations, graphic design, communications, legal matters and of course fund raising. We were very pleased that a few people from the EFCCA youth group volunteered right there during the EFCCA general assembly, to help us review the applications for our next grant program.

We require people who are not only capable of coming up with creative and helpful ideas for our foundation, but who are also prepared to take ownership of those ideas and make them reality.



After all, like flower seeds requires water and sunshine to grow, good ideas need people prepared to realize them. We were very pleased about the positive reactions and look forward to welcome new people in our team, to become our “water and sunshine”.

#### **Donations**

Donations can be made either through the website ([www.ibdresearch.org](http://www.ibdresearch.org)) using a credit card, or through a transfer on our bank account: ABN AMRO Bank the Netherlands Account number: 9746.86.158 IBAN: NL37ABNA0974686158 BIC: ABNANL2A

#### **Contact**

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## **IBD nurses meet at 4th N- ECCO meeting in Austria**

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

N-ECCO currently counts over 310 members and we are happy about constantly increasing interest in N-ECCO and N-ECCO Membership. In 2013 the first N-ECCO Consensus statements will be published in JCC, aiming at providing practical value at a local and national level to develop nurses’ roles in caring for patients with IBD



Group photo of the 28 N-ECCO course participants  
© ECCO

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

The N-ECCO National Representatives are also invited to attend the N-ECCO School to sup-

port the participants from their country, with language and translations in particular as many of the nurses attending do not speak English as their first language.

### **The N-ECCO School PROGRAMME – February 14, 2013**

The programme of the 4th N-ECCO School featured a full overview of IBD history in order to give nurses a basic introduction to the specialty by expert speakers. Our aim was to teach basic knowledge in a clear way for nurses, with the objective of improving nurse education throughout Europe.

### **Course Outcome and Conclusion:**

With the 4th N-ECCO School, the cooperation between ECCO and EFCCA facilitated an educa-

tional programme, which will improve the quality of patient care and thus benefit the welfare of patients in IBD.

The support of EURO 5,000 of EFCCA allowed ECCO to offer a travel bursary to those participants who are unable to raise funding for travel and accommodation (as in some countries, industry sponsorship for nurses is prohibited). All participants were asked to disclose whether their participations at the 4th N-ECCO School was sponsored. The EFCCA grant will be divided among those participants without industry sponsorship in the form of reimbursements for accommodation and travel expenses.

All course participants received a printed syllabus with the core slides, educational objectives and summary of each presentation. The nurses

who attend the school are encouraged to use this syllabus when they return to their hospital and use it as a means of informing and educating their nursing colleagues.

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

The evaluation forms provided us with valuable feedback on improvements for the future, and participants were also very satisfied with the selection of the speakers, who all presented topics relevant to the nurses' clinical practice.

A short report on the N-ECCO School in Vienna will be printed in the 1st issue of the ECCO News 2013.

## Giving a voice to people with Ankylosing Spondylitis

*By Seoirse Smith, President of the Ankylosing Spondylitis International Federation*

*The Ankylosing Spondylitis International Federation, (ASIF), was formed in 1989 as a charity with the appointment of a President, an Executive Committee and the ratification of a constitution at the first council meeting in Leukerbad, Switzerland in July of that year.*

The idea for ASIF arose from discussions starting in 1984 and culminated in an inaugural meeting in April, 1998 in Bath, England. Following the first Council Meeting in Switzerland there have been Council Meetings in 1992 in Austria, 1994 in Portugal, 1996 in Norway, 1999 in Germany, 2002 in Slovenia, 2005 in Denmark, 2007 in Czech Republic, 2009 in Austria and 2011 in Turkey.

Our vision is to be the global voice of those living with Ankylosing Spondylitis. We aim to increase awareness of Ankylosing Spondylitis (AS) and disseminate knowledge of the disease around the world to all key stakeholders be they people living with AS, health professionals, researchers,

pharmaceutical organisations, policy makers and the general public.

Therefore our key objectives are;

**To exchange information and experiences among the member societies.**

**To support the development of newly formed societies.**

**To cooperate in international research projects.**

**To encourage the exchange of articles for publication in the journals of member societies.**

**To contact Ankylosing Spondylitis stakeholders, (primarily people living with AS and health professionals involved in managing the condition), in countries where an AS society does not yet exist**

We currently have 35 member organizations in 33 countries, with applications in process from two further countries. In keeping with our vision to be the global voice for those living with Ankylosing Spondylitis, we need to reach out and encourage the formation of patient organizations and membership in more countries, particularly those in northern climates and with populations of people from northern climates among whom the incidence of HLA-B27 and Ankylosing Spondylitis is higher. We have in mind such countries as Finland, Poland, Belarus, Lithuania, the other Baltic States, Iceland, Chile, Argentina and South Africa.

All those living with Ankylosing Spondylitis need to know that they are not alone and deserve representation through patient organizations and membership in a worldwide community.

ASIF would not be a voice for those living with Ankylosing Spondylitis without advocating and lobbying for them. We can most effectively do this in partnership with or being a member of other organizations that bring the scientific, health care and patient communities together and have aims and objectives aligned with ours. Accordingly, as part of this activity we will participate in:

**EULAR**, the European League Against Rheumatism.

**PARE**, the Patient with Arthritis/Rheumatism in Europe, a standing Committee of EULAR.

**ASAS**, the Assessment of Spondyloarthritis International Society

We will seek out other organizations that benefit those living with Ankylosing Spondylitis for partnership and co-operation opportunities. For example, in this regard we will participate in the Fit for Work Europe Coalition and any other opportunity to influence policy makers at national, European or global levels.

We will determine how to actively participate in a professional manner in these organizations to make our voice heard in consort with theirs and seek to dedicate a member of ASIF to that participation on a more fulltime basis.

As part of our advocacy effort we will establish an Ankylosing Spondylitis patients' Bill of Rights incorporating standards of diagnosis and care and best practice models of care for treatment options. To avoid confusion in patients' minds we will be clear about the terminology used by health care professionals and researchers as it relates to Ankylosing Spondylitis and Axial Spondyloarthritis and about our mandate to serve those suffering from Ankylosing Spondylitis.

An important aspect of ASIF's desire to represent people living with AS is appreciating who else might have similar interests, challenges, issues and needs. This is what makes the cooperation with organisations like EFCCA so important.

The needs of all of our members are very similar. By cooperating together we have an opportunity to establish a greater presence as advocates for our conditions collectively. We also have an opportunity to share experiences, knowledge and indeed contacts that would be advantageous to each of our organisations.

The more organisations like ours with common interests that join together the greater our voice will be.

For more information please visit our website at: [www.asif.info](http://www.asif.info)





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# Patients and IBD surgery: rightful fears and preconceptions

Antonino Spinelli, MD PhD, Matteo Sacchi, MD  
Colorectal and IBD Surgery, Istituto Clinico Humanitas,  
Rozzano Milano, University of Milan, Italy



Antonino Spinelli, MD, PhD serves as Head of IBD Surgery at Humanitas Clinical Institute in Rozzano, Milano and as Assist. Professor of Surgery in the University of Milan

Surgery represents a valid and efficient option for treating IBD in presence of a correct indication, resulting in a relevant improvement in quality of life, as reported by patients themselves.

In referral centers surgery greatly improved over the last 20 years, with the introduction of innovations as minimally invasive surgery and enhanced-recovery protocols (described in our

previous article on EFCCA Magazine, February 2012); consequently, complication rates decreased compared to earlier times. Nevertheless, patients' perception of IBD surgery remains generally poor.

Surgery is often perceived as the last resource, the enemy to avoid, even when medical therapies are becoming clearly ineffective and do not allow anymore an acceptable quality of life.

This negative psychological approach, even if understandable, has important consequences not only on psychological attitude towards surgery, but even on surgical possibilities because it leads to a delay of surgery often resulting in suboptimal timing, worse general conditions as well as, in many cases, a more complex disease.

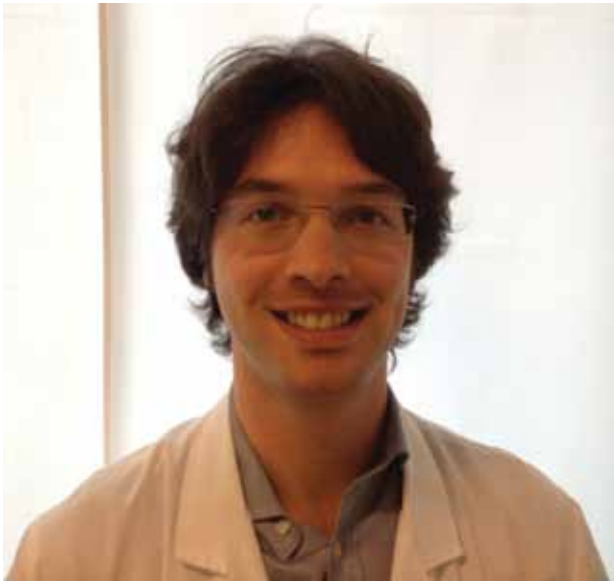
Surgeons, on their side, are sometimes too worried about technical issues, forgetting to answer questions important to their patient and to plan jointly with their patients, whenever possible, the best timing for surgery, considering also patients' requirements regarding studies, work, family needs. These are only some of the many clues of a defective communication between patients and surgeons in IBD.

As surgeons dealing every day with patients' expectations, hopes and worries, we thought that it would have been important to try to understand the reasons of such misperception.

That's why, with the help of EFCCA and the collaboration of many international dedicated surgical centers, we started two

projects on patients-focused communication and information about IBD surgery.

In the first project we aimed to get a clearer idea of patients' perception of surgery. For this purpose, we asked an international task force of IBD experts to formulate questions that will be assembled in a web-based questionnaire for patients in order to understand their main fears about surgery.



Matteo Sacchi MD is currently completing his residency in General Surgery in the University of Milan, working in the IBD Surgery Unit at Humanitas Clinical Institute in Rozzano, Milano

What do patients fear the most? Which are the major negative concepts associated with surgery? Are they justified or related to preconceptions? And later on, are they satisfied after surgery? What is their opinion about the timing of their operation? Too early or too late? What is their self perception after surgery? Studying these aspects we felt it was essential to analyze how patients get information about surgery for their disease.

Most patients in the internet era look on the web for any sort of information: disease, procedure, complication, surgeon, hospital... Besides the many known limitations and problems related to internet-picked up information (generalizations,

lack of adaptability to the single patient's situation...), we aimed to assess the reliability of such information, using a validated and objective score.

Our second study aimed therefore to analyze the scientific quality and the origin of the information available on websites about Surgery for Crohn's Disease and Ulcerative Colitis.

We are asking patients to provide the keywords they would use on this topic and then using them to perform a search on popular search engines like Google and Yahoo.

Our two projects, both supported by EFC-CA, will account on prestigious partnerships involving, beside the University of Milan (Italy), the University of Oxford (UK), University of Leuven (Belgium), University of Amsterdam (Netherlands), University of Paris (France), University of Barcelona (Spain), University of Linköping (Sweden), University of London (UK), University of Cajuá (Brasil).

We are strongly convinced that independent and correct information is essential for a balanced decision-making on IBD therapies and that the importance of a direct and open dialogue between specialized surgeons and single patients has to be rediscovered and implemented.





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