

# EFCCA MAGAZINE

European Federation of Crohn's and Ulcerative Colitis Associations | February 2012

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# EDITOR'S EYE

## *Once upon a time*



I love Olympics Games. I simply cannot help it. I've grown up reading stories of the Games. While other kids were seeking for football news, I was hunting for Olympic Stories. So it came natural, during this Olympic year, to think not only about a program which could have connected "Sport & IBD" but to go beyond.

And what is better than a real Olympic Stadium and an official Olympic Museum? All this in a city which has connected most of its image with an Olympic Edition: Barcelona. And while the Games of the XXXth Olympiad are a matter of weeks, please allow me to tell you a story.

Once upon a time, a French gentleman had the idea of restarting an ancient Greek tradition: the Games of Olympia. Pierre De Coubertin is now famous, he is considered the father of the modern Games, and of the "five circles" flag. What most people do not know is that De Coubertin was an educator.. The idea of the Games came to his mind in

order to promote an active life-style for the youngsters, in order to teach them the importance of being active through their entire life. Today, our society is paying more and more attention to the necessity of being "active": no matter the age. You would be surprised to know how many modern programs for the ageing population still owe to De Coubertin's ideas. Also EFCCA will announce soon a support program for the ageing population with IBD throughout the next year.

But what makes the Games "Olympics" is not a medal, or a record. It is the Olympic "soul", l'esprit Olympique. And I firmly believe that our every day job, as volunteers, as patients' representatives, is permeated of this "esprit". In a society that is every day more competitive, and tries to shut us up when we claim our rights, we state that we want to be an active part of it, to "participate". Because participation is not only an attempt to be made, but a right to be protected. Democracy has no sense without participation: our role is to make this right to participate evident.

IMPACT has shown many different things. We may disagree on the concept, on the statical set up of the research, or we may not like the result. But it is clear that part of our people feel that there are still too many obstacles around us. But IMPACT has also shown what EFCCA has become: an organization capable to collect 6.000 questionnaires in Europe, and so far capable to handle one of the biggest survey ever made on quality of life in a specific disease cohort.

This calls us to a big responsibility: to use the data in the right way, to maximize this moment of participation, to change the status quo. It is not simply to give a "positive image" of IBD, but it is to demonstrate to society that burdens connected to Crohn's and Colitis are unfair. I strongly believe that people with IBD, with the right medical and social support, can be not only active part of citizenship, but a real winner in this society.

And "Sport", for this year, is the way in which we do affirm this. Ever heard of Károli Takács? He was member of the Hungarian Pistol shooting world champion team when in 1938 he lost his right hand, his pistol hand. In 1948 he came back to the Olympics in London and won using his left hand. And what about Oscar Pistorius? Even legs are not any more necessary for running with "normal" athletes: because with the right attitude and



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support, there is no barrier towards a dream of freedom and hope.

You know what I always liked most about Olympic stories ? Underdogs. People that nobody would have bet on, who believed, trained, hoped, against all odds. People who succeeded. Olympic annuaries are full of these stories of how a small Italian baker conquered the heart of the Londoners during the Marathon in 1908, or a shy Finnish guy has become the greatest runner in the world, or a shoeless Ethiopian winning in Rome by running against technology only listening to his heartbeat. I like these stories because they reflect one of the basic principle on which EFCCA has been built and shaped in the last year: the fact that we refuse to be “underdogs” in this society. We refuse to be underestimated. We refuse any kind of discrimination.

Yes, life teaches that sometimes this is not enough. That is why, in the darkest moment, our people have to know that we are here. That there is a strong organization, which is growing every day, and that is ready to “walk with them”, to support them, not to leave them alone.

So far, the choice of an event inside the Olympic Museum should be clear: that is the place in which these values are celebrated. And why also the stadium then ? The answer is: Barcelona, 1992, Derek Anthony Redmond. A British 400 meters sprinter, who during the Olympic semi-final tore his hamstring. Doctors immediately understood the severity of the injury. He did as well. But he stood up. And went on to finish.

I do not think I need to explain how not only inspirational, but also metaphoric this is. I believe it explains everything about our work. We are here for supporting you in finishing your race. And when society shouts at you that you have to “stop”, we shout back that nobody has the right to stop your dreams.

For doing this we need to believe in our capability of changing the status quo and of delivering dreams. We need to build our capacities using the UNITED WE STAND “credo” as a basement. And we need to involve.

Because our role is changing. I do think that we are not only a support, but together we can boost our dreams. That is why in the video announcement for the Barcelona event, we wanted an athlete that is passing the really baton. Because if everybody runs his split, there is no wall that we cannot break.

Going through the next pages, you will find enthusiasm, passion and hope. Because this is the way in which we stand up, we clean away the dust and we challenge IBD. Everyday. Until we find a cure. UNITED WE STAND.



Marco Greco, EFCCA Chairman



# First EFCCA training workshop takes place



Training participants from left to right: Veronika Hanzilova, Stefan Dakovic, Tiphaine Chapeau, Salvo Leone, Ulla Sunvato, Tineke Markus-de-Kwaadsteniet, Magda Staniewska, Arne Schatten

**The first EFCCA training workshop took place in Brussels from 22-23 November 2011 focusing on team building exercises, practical media training and EU affairs.**

As previously reported EFCCA is embarking on an exciting, new initiative aimed at supporting its national associations by offering a series of targeted training courses including executive coaching, leadership skills development and other specific training. This initiative forms part of the six development priorities endorsed by EFCCA's General Assembly in Helsinki in 2010 and reflects EFCCA's new approach to boost a stronger link with national associations and to achieve its goals in a more effective way.

During the first workshop Chief Executive Officers (CEOs) and representatives from eight national member associations (Czech Republic, Finland, France, Holland, Italy, Norway, Poland and Serbia) spent two days in a learning environment, getting to know to

each other, engaging in practical exercises and meeting EU institution representatives.

EU official Christoph Hofbeck from the European Commission's Directorate General Health and Consumer (DG SANCO) gave a presentation on the European Health strategy allowing participants to better understand how health policy at European level is dealt with and how it relates to their national health policy developments. Mr Hofbeck's presentation was followed by a question and answer session and a more general discussion on possible common projects.

This was followed by a team building exercise organized by City Challenge a team development company which uses cities as virtual classrooms to demonstrate leadership, teambuilding and communication skills. The exercise was designed to get people moving and thinking within the busy, real-time, real-life environment of a big city and working within teams against the clock to solve a series of history-themed

challenges. Participants were assisted by Jane Read of City Challenge who ensured that training objectives were fulfilled and also provided feedback and support throughout the exercise.

The final training module was carried out by PR company Hill and Knowlton and provided specific media training on how to conduct interviews and how to get one's message across in an attractive and precise way. Participants took part in a mock one-to-one interview with former journalist Catherine Smith (BBC) whilst the remaining participants observed the interview through a video link. Each interview was analysed and practical tips were given on how to improve the interview techniques. A similar exercise was carried out concerning interviews for audiovisual media.

On the last day of the training participants visited the European Parliament where they had the opportunity to learn in detail about the role of the European Parliament and its decision making processes.

All in all the feedback of the participants was very positive with some preferring the team building exercise whilst others found the media training more useful even though they had undertaken previous trainings. The training also gave participants the opportunity to learn more about EFCCA and the day to day running of the EFCCA office.



**During the city challenge on Grand Place, Brussels**

In 2012 EFCCA will organize two further training workshops for its members, the first being scheduled for June which is mainly aimed at associations that are made up of volunteers. The modules will include project management and “people raising” which will look at the issue of how to avoid a big turnover of volunteers within associations. The second workshop will be similar to the one we just organized but will be aimed at managers of associations that work on a voluntary basis.

For more information please contact: [luisa.avedano@efcca.org](mailto:luisa.avedano@efcca.org)



**Participants preparing the team building exercise at the EFCCA office**



# Members of European Parliament to support EFCCA cause

A small EFCCA delegation composed of Marco Greco, EFCCA President, Luisa Avedano, Chief Executive Officer, Delia Giorgianni, Policy Officer and Isabella Haaf, Communication Manager met with Member of the European Parliament Sergio Gaetano Cofferati (Group of the Progressive Alliance of Socialist Democrats) on 22 November 2011. During the meeting Marco Greco presented the results of the recent IMPACT survey and highlighted the main challenges that needed to be tackled on a European policy level.

The meeting was set up as part of the IBD awareness raising campaign that EFCCA has started this year during IBD World Day focusing on EU institutions and policy makers. The aim is to pave the way for greater cooperation with EU institutions and to make EFCCA more visible on the European arena.

As a direct outcome of the meeting, MEP Sergio Gaetano Cofferati will support an action, on behalf of EFCCA, aimed to gather attention on the difficulties that IBD patients have to face and, in particular on the lack of harmonized recognition, across the 27 European Member States, of the rights and needs of people living with IBD.



**EFCCA chairman Marco Greco meets with Sergio Gaetano Cofferati, Member of the European Parliament**

This support might consist in a Written Declaration directed at the European Institutions or in an Oral Plenary Question.

The Written Declaration is one of the “tools” that can be employed in order to catch the attention of MEPs on a neglected matter, it has to be presented by a maximum of 5 MEPs and after its presentation the promoters have no more than 3 months to obtain the signatures of at least half of the members of the Parliament, when this happens the Written Declaration is presented to the Institution mentioned in it such as the Council of Ministers and European Commission (but also other organization such as the WHO).

The Plenary Question is a query addressed to the European Commission and Council by MEPs. It may be followed by a debate and it consists in a direct form of parliamentary supervision of the state of the art of



Commission and Council actions in a particular field. The Oral questions, in particular, are able to raise the awareness on the EFCCA mission because they are asked in plenary sitting and included in the day's debates.

The support we are receiving from the members of the European Parliament is not only a symbolic action but also a clear statement in favor of IBD people and patients in general and it might be the first step of a legislative process able to fill the lack of harmonization and to eradicate the discriminations on IBD.

Another positive result of EFCCA's closer coopera-

tion with the EU institutions is the support from MEP Glenis Willmott (UK) that EFCCA will receive in relation to our activities planned around IBD World Day. Ms Willmott, who is also member of the European Parliament Group "Environment, Public Health and Food Safety", will host our next IBD World Day event to take place at the European Parliament.

The event is scheduled for 15 May 2012 when the European Parliament is in plenary session in Strasbourg. More information will be made available closer to the date.

## EFCCA Youth Group (EYG) Board Meeting in Brussels

*by Arron Gill – EYG Board Member*

After a very successful meeting in Krakow, a number of Skype calls and emails, the new EYG board finally had its first meeting in Brussels on 21 November 2011. The group had a number of projects to discuss which were raised in previous Skype meetings but being face to face meant we could get much more done (and it was also nice to see everyone).

High on the agenda was the EFCCA Youth Group Meeting (EYM) in Copenhagen 2012 as well as the meeting in Germany 2013 (it will be our 10th birthday after all!!). We also spoke about the new youth meetings specially for exchanging knowledge among the youth groups in Europe and the already running activities as the website, EYGZine etc. The group discussed some very interesting ways in which to involve the delegates in assisting the EYG not just during the annual meeting but also throughout the year.

Another subject was our cooperation with the Coe-



### **EYG Team:**

**From left to right, top: Victoria Power, Arron Gill, Daniel Sundstein, Marek Lichota**  
**Bottom: Tiphaine Chapeau, Chayim Bell, Stefanie Weber**

liac Youth of Europe (CYE) group who visited us in Norway. EYG Board member, Tiphaine Chapeau, visited the CYE in Malta in order to further discuss future collaboration between the two organizations. Concerning the EYG website, board member Marek Lichota proposed his ideas and the group came up with some very interesting ways of communication events between youth groups in Europe.

The agenda contained too much to list in such a short

article, however overall the meeting was very successful and gave the group the opportunity to work and discuss ways on taking the EYG forward. A number of very interesting ideas and discussions arose and I'm really looking forward to seeing everyone again soon.

For more information about the EFCCA Youth Group please contact: [eyg@efcca.org](mailto:eyg@efcca.org)

## EYG Announcement: Registration open for next annual meeting for young people with IBD

The Danish Crohn's and Colitis Association (CCF), in collaboration with the EFCCA Youth Group (EYG) and EFCCA are pleased to announce that the annual meeting for young people with ulcerative colitis or Crohn's disease in Europe will take place in Copenhagen, Denmark from 12 to 15 July 2012!

As always, the meeting is designed to be educational, interactive and also fun. You can expect:

- Interactive workshops
- Learning sessions about the different associations in Europe
- A sporting event!
- A gala dinner, on our last night
- Visits to the local area, after the meetings of the day
- News about EYG projects, and ideas of how you can contribute

We aim to have fun whilst learning, working together and sharing ideas as a friendly and understanding community.

The official language for the event will be English.

If you are interested to join, please contact your national association to get more information or sent us an email at [eyg@efcca.org](mailto:eyg@efcca.org).

At the end of February we will send more information on how to apply to the associations.

## New projects

The EYG team is working hard to develop new projects, we are working on a new website, the next issue of our 'Zine (newsletter), translating the IBD game which we have developed, updating information on how to travelling with IBD etc. . This is something we cannot do alone, therefore we ask anyone who is interested to contact us to learn what you can do to help us. Contact us by emailing to [eyg@efcca.org](mailto:eyg@efcca.org).

# Patient perspective at IBD conference

EFCCA President, Marco Greco, was invited to speak at the conference “Leading Change in IBD” organised by pharmaceutical company Abbott, which took place from 20-21 January 2012 in Prague, Czech Republic.

During the session “What changes are needed in Crohn’s disease management” Marco Greco spoke about the impact of Crohn’s disease on the quality of life of patients using the findings from the recent IMPACT survey that EFCCA carried out last year. Other speakers included representatives from the medical profession amongst others Daan Hommes, ECCO, who gave a healthcare professional’s perspective on this subject.

# EFCCA presents poster during UEGW

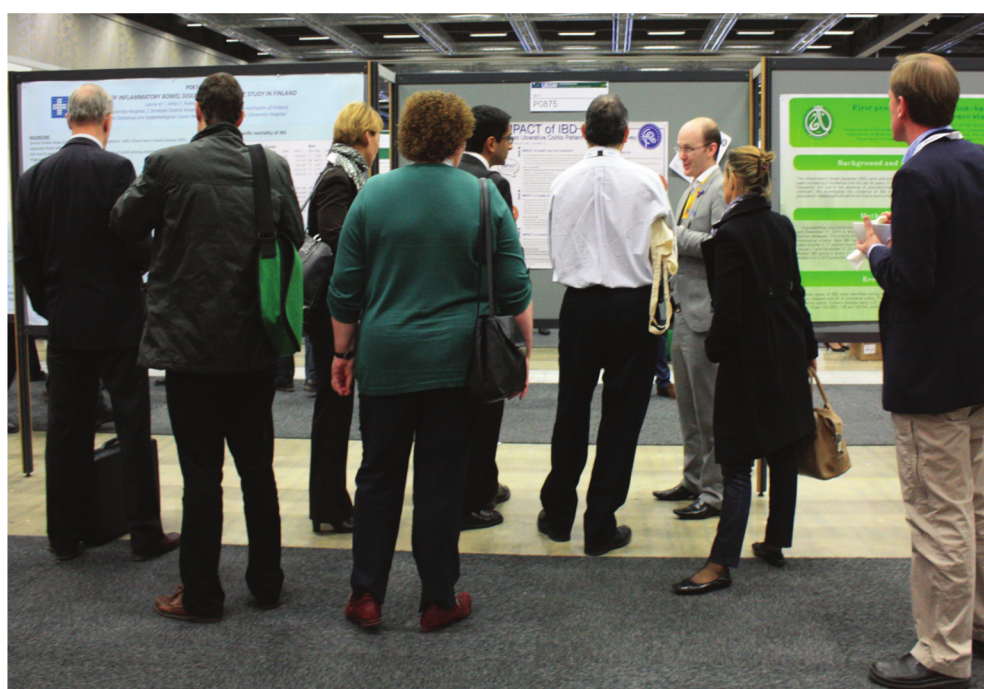
The 19th United European Gastroenterology Week was held in Stockholm from 22 to 26 October 2011 and hosted over 12 000 participants coming from more than 20 different countries.

The UEGW is one of the most important event for specialists and researchers in the field of gastroenterology, it is also a big opportunity for EFCCA to meet those specialists and to raise awareness on our activities and mission; amongst many people we met were also several experts in gastroenterology from Asia and North Africa who were interested in receiving information on our activities and on how to create patients’ organizations in their own countries.

EFCCA was represented at the congress by Board Member Chayim Bell and Ben Wilson as well as new EFCCA Officer Delia Giorgianni. This year’s UEGW was also a very important and special event for EFCCA as for the first time we were allocated a poster space where we released and explained the first results of the IMPACT survey to a very interested public. It is a major achievement for EFCCA - not only to be seen as a credible provider of valuable scientific research but also to have the voice of a patient organization heard in a purely scientific context. EFCCA will continue to participate in the 20th UEGW, which will take place in Amsterdam from the 20th to 24th October this year.

EFCCA also organised a sponsors’ day where Marco Greco presented EFCCA, its work and opportunities for collaboration to representatives from over 10 pharmaceutical companies.

Congress delegates during the EFCCA poster presentation





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





# Join the fight against IBD: IMPACT results to be launched

As reported previously EFCCA undertook a pan European IMPACT patient survey assessing the perspectives of IBD patients about their disease and its impact on their lives, relationships and careers. Over 6000 IBD patients participated in the survey answering 52 questions around A) IBD experience B) Health care C) Personal impact of IBD D) Impact on work and E) Overall Life IMPACT and the role of patient organizations.

During a high profile press conference that will take place in Barcelona on the 15 February the results of the IMPACT survey will be made public to international media and other interested parties. The press conference is co-organised by EFCCA and ECCO under the heading "Join the fight against IBD".

"The main findings of the survey show that the impact of IBD on patients' life is still at an unacceptable level and that efforts needed to be made to address these issues at a policy level" says Marco Greco, EFCCA President who will present these results at the press conference.

For example, even though access to specialist care is usually good and most IBD patients receive a timely final diagnosis there are still around 18 % of patients who wait for their diagnosis for a long time (over 5 years). This can be a period of uncertainty, significant life impact, morbidity, and distress and could create a clinical risk as 64 % may

need emergency care BEFORE the diagnosis.

EFCCA recommends to investigate and find methods to prevent presentation to emergency care, ex-

## The true IMPACT of A European Crohn's and Ulcerative Colitis

Wilson BS, Lönnfors S, Vermeire S, Greco M, Hommes DW, Bell C, Avedano, L.  
EFCCA, Brussels, Belgium. ECCO, Vienna, Austria.

- Survey developed by EFCCA in 10 languages.
- November 2010 – August 2011.
- Self-selection online survey, optional participation – the wider population of people with IBD may be different.
- 4,990 responses.
- Full results available online – [www.efcca.org](http://www.efcca.org)
- Project support by a grant from Abbott.



### IMPACT of diagnosis

- Access to specialist care is good – 70% saw a specialist within the first year of their illness.
- A majority receive a timely final diagnosis, however, 18% wait over 5 years.
- An alarming majority, 64%, require emergency care *before* their diagnosis – a significant clinical risk.

#### EFCCA recommends:

- **Maintain good access** to IBD specialists, especially in the face of financial cuts to health services.
- **Review diagnostic protocols** for those who wait over a year for diagnosis, to reduce this divergence with otherwise good standards.
- **Investigate and find methods to prevent** presentation to emergency care, experienced by a majority, *before* diagnosis.
- **Work with emergency care** colleagues to raise awareness that the majority of people with IBD are treated in this department.

**64%**  
Need emergency care before diagnosis.

**63%**  
Feel IBD associations have beneficial life IMPACT.

### IMPACT of health care and

- 70% are satisfied with their treatment plan, a
- Hospital admission is extremely high – 85% a
- Access to biological therapy is becoming mor
- corticosteroids, experienced side-effects, and

#### EFCCA recommends:

- **Maintain and develop good IBD health servi** guidelines – [www.ibdstandards.org.uk](http://www.ibdstandards.org.uk)
- High hospital admission represents a poor pa
- improvement, and significant morbidity. Redu
- somewhat counterbalance the cost of new IB
- **pay to treat with innovative therapies.**
- Ensure that use of corticosteroids is in line w
- and that the full range of treatment options s
- according to comparative risk-benefit profiles

### IMPACT of health services

- Although 88% of patients have access to a sp
- and 45% have access to a specialist nurse, 24
- have adequate access to specialists.
- The quality of communication in consultation
- they were not able to tell the specialist somet
- wish they were asked more probing question

#### EFCCA recommends:

- **Improve access, as well as provision, of spec**
- **Increase the duration and frequency of spec**
- **Improve consultation techniques** (for both p
- coverage of issues, so that no important infor

### IMPACT on relationships

- 40% feel IBD prevented an intimate relationsl
- However, 39% felt that meeting others with I
- those who joined a patients' association felt i

#### EFCCA recommends:

- **The impact of IBD on relationships** should be
- **Healthcare professionals should actively sig**

Visit us at stand A06:01B

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# ed at Barcelona press conference

perienced by a majority, before diagnosis and to work with emergency care colleagues to raise awareness that the majority of people with IBD are treated in this department. There should also be a review of di-

agnostic protocols for those who wait over a year for diagnosis, to reduce this divergence with otherwise good standards. Finally EFCCA urges policy makers to maintain good access to IBD specialists, especially in the face of financial cuts to health services.

## IBD Colitis Patient Life IMPACT Survey



### and treatment

plan, and 73% with their surgical outcome. 85% admission within the last 5 years. ing more established, but a majority has used ts, and are concerned about long-term effects.

h service standards, in line with published

oor patient experience, an urgent opportunity for y. Reducing this burden may new IBD treatments – it may

line with ECCO guidelines, tions are considered, profiles.

### ces

to a specialist consultant, se, 24% still feel they do not

itations needs to be vastly improved – 53% feel that something that was important, and 65% say they estions.

of specialist IBD healthcare professionals.

of specialist consultations.

both parties), to ensure depth and nt information is omitted.

### os

ationship, 34% feel IBD caused one to end. with IBD made them more optimistic, and 63% of n felt it had a beneficial impact on their life.

ould be considered by healthcare professionals.

ely sign-post patients to national IBD associations.



### IMPACT on daily life

- Half of people with IBD are fighting active disease today – they are not in remission.
- 96% feel tired, weak, and worn out in daily life during a flare-up, only reducing to 83% during remission.

#### EFCCA recommends:

- **Management plans should include** assessment and management of the key three symptoms: **fatigue, urgency, and pain.**
- **Success criteria should focus on** effective management of *symptoms*, as well as IBD as the *root cause*.
- **Management plans should include** assessment of the wider symptomatic impact of IBD on everyday life, as well as the clinical context.

**85%**

Hospital admission within the last 5 years.

**83%**

Still feel fatigue even in remission.



### IMPACT on work and education

- 74% have taken time off work in the last year due to IBD – 26% for over 25 days.
- Disease severity and ability to work seem to correlate.
- 61% feel stressed about taking time off, 25% have received complaints or unfair comments, and 21% have suffered discrimination.

- **Good management of IBD supports employment.** The cost of new innovative treatments for IBD may be counterbalanced by improved employment and reduced social costs.

- **Effective medical consultations** should address the patient's full life context – including work.
- **A patient's employment and educational aspirations** should be regarded as goals and success criteria.

- **Flexible, supportive, and non-discriminatory** work practices are required. Those who face discrimination must be supported in challenging this.

[www.efcca.org](http://www.efcca.org)



As concerns patients' satisfaction with treatment 70 % of patients are satisfied with their treatment plan. However, hospital admission in IBD patients is extremely high at 85 %, representing significant morbidity, and demand on health services. Access to biological therapy is becoming more established, although a minority of patients takes this treatment. Worryingly, the majority of patients have used corticosteroids, a high proportion experienced side-effects, and almost all were concerned about long-term effects.

“The high hospital admission represents a poor patient experience, an urgent opportunity for improvement, and significant morbidity. Reducing this burden may somewhat counterbalance the cost of new IBD treatments” states Marco Greco. EFCCA recommends that the use of corticosteroids is in line with ECCO guidelines, and that the full range of treatment options are considered, according to comparative risk-benefit profiles.



On the subject of access to care a quarter of people with IBD feel they do not have adequate access to them even though specialist healthcare professionals are present. Access to care needs to be improved, as does the quality of communication in consultations (some patients feel they do not get to ask the questions they want to.)

In their daily life half of people with IBD are fighting active disease today. Most IBD patients (83%) experience significant symptoms, regardless of whether they are in remission or not. Fatigue, as an example, is often experienced also when in remission.

In the area of work and education 74% of IBD patients have taken time off work in the last year due to IBD – most startling, over a quarter

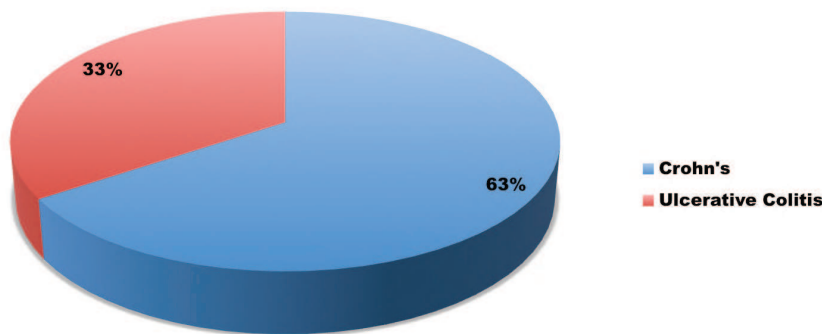
of respondents had been absent from work for over 25 days in the last year. Disease severity and ability to work seem to correlate. The majority feels stressed or pressured about taking time off. 25 % of IBD patients have received complaints or unfair comments at work, or suffered discrimination. Most patients are fully employed, but some are under- or unemployed because of IBD.

With regard to the issue of relationships IBD has significant negative social effects, and in particular is responsible for preventing, or causing the end of intimate relationships for an alarming 40 % of people. However, meeting others with a similar condition, or becoming part in patients’ organizations creates optimism. 63 % of respondents felt that membership of a patients’ organization has a beneficial impact on life as a whole.

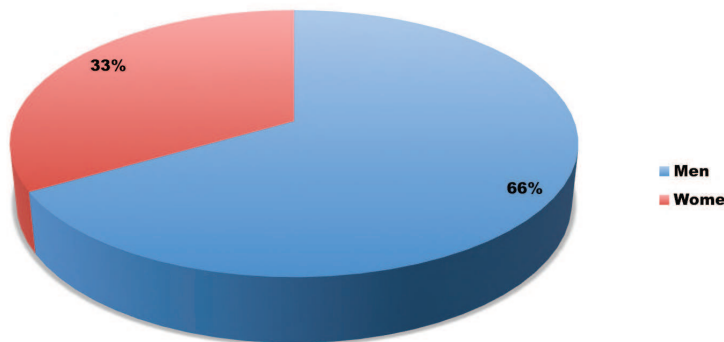
“Even with the availability of immunosuppressive and biological therapies for more than a decade and adequate access to care, the impact of IBD on patients’ lives is immense. This European survey offers new angles on how to further reduce the burden of disease, and important recommendations for treatment and care.” concludes Marco Greco.

A summary version of the IMPACT result will be made available to journalists and can be consulted on the EFCCA website.

IMPACT survey responses: Type of IBD

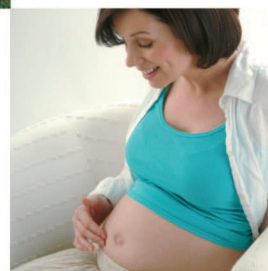


IMPACT survey responses: Gender





# Ferring – for life



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# Uniting our efforts

## ***Interview with Ildefonso Pérez Míguez, President of the Spanish Association of Crohn's and Ulcerative Colitis (ACCU)***

**Spain is the second biggest country in the EU. How is your association organized to ensure that everyone's voice is properly heard?**

In Spain we have over 34 local IBD patient associations that represent the interests of their members. Each group acts independently, has its own financial income and organizes its own activities, meetings and information services. However at the same time these 34 groups are united through our confederation, ACCU España, at national level. The idea to unite patients into one voice was born by the Malaga IBD group over 20 years ago.

Our aim is to provide moral and physical help to persons who are affected by Crohn's disease or Ulcerative Colitis and to ensure that all 34 groups are working towards the same direction and goals. At ACCU España we also coordinate official presentation vis-à-vis institutions and other networks working to improve life of patients. Moreover we carry out activities that have more of a national character rather than a local one but we do this in close cooperation with our local groups and once a year we meet with all group representatives at the General Assembly.

We also publish information leaflets for IBD patients and a magazine called "Crónica" where you can find information on the latest medical advances in the field of IBD as well as information about activities of our 34 groups.

### **What's your involvement at the European level?**

I personally think it's very important to participate and work at a European level. Similar to what we are doing within our confederation, there is also a need to get together at a European level in order to have



a stronger voice and make a better case for common interests we have. Our IBD group in Malaga has been one of the founding members of EFCCA and we are regularly participating in the EFCCA annual meetings and other activities.

However many of our individual members are not able to directly get involved with European work due to communication problems. Unfortunately in Spain - for historic reasons - language education has not been very strong and many of our members - particularly from the older generation - have difficulties in understanding and speaking English. I hope that in the future this will change and allow more members to benefit better from working with our European friends.



**Are you satisfied with the access to health care of IBD patients in Spain?**

We have been fighting for many years to ensure that patients showing IBD symptoms are quickly referred to specialists in order to guarantee personalized and efficient treatment. We have come a long way and over the years more and more special units have been set up in many of our hospitals. As a result we can say that diagnosis of IBD is fairly quick in our country.

But of course we cannot stop here and were are continuing our fight to improve diagnosis and an increase in IBD specialized staff. We want to avoid situations where IBD patients have to go through the emergency department first and we are campaigning for patients to have a direct line of communication with their medi-

cal specialists by telephone, email or other means.

**What is ACCU planning in the year ahead?**

**“We have come a long way and over the years more and more special units have been set up in many of our hospitals(...)But we cannot stop here and were are continuing our fight to improve diagnosis and an increase in IBD specialized staff .”**

I would say one of the main events that are going to take place this year is the ECCO Congress on the 16-18 February in Barcelona. First of all it will be an important occasion for us to find out about the latest scientific advancements and education in IBD. More important though it will give us the opportunity to meet with representatives of the medical profession and thus allow us to keep up the dialogue between our self-help groups and health care

professionals.

ACCU España will be represented by myself and

**Delegates at ACCU Convention**



several Executive Board members. The press conference organized by EFCCA and ECCO which will take place prior to the ECCO Congress will also be a great event for us to share our key messages with not only the local media but also with an international media. This year we will also carry on with our usual activities and will be organizing several events around the 25th anniversary of ACCU España. For more details please visit our website at: <http://www.accuesp.com/es/>

### **What are the challenges you are facing right now at ACCU España?**

Reflecting the challenges being faced by the whole of our country the economic crisis is also having a serious negative effect on the activities of ACCU. Many of our groups that have previously received some kind of financial support through local governments are now facing financial problems as these funds are being systematically cut.

Another problem that we have to deal with is the lack of involvement of IBD patients with our association or groups. We have plenty of people visiting our website a few times and requesting and receiving information on IBD but then they stop getting involved with us. The challenge that lies ahead of us is to convince those people to continue supporting our groups and thus to increase our membership base and to become an even stronger voice speaking out for our rights and interests.

## France

### **2012: A new start for the 30 year old French association**

After closing a challenging 2011 with some increase of membership and a good number of positive actions, AFA is now starting 2012 with many news and I'm pleased to give you a short picture of the coming months.

AFA's strong support to research on IBD is still at the top of its agenda and a second communication campaign addressed to the general public has been launched.

A new idea for IBD National Day is also in the pipeline: it is more focused on targeting regional events developed around the theme "Let's show what is in our belly" and supported by Täig Khris, three times world champion of acrobatic roller skating.

This year a new "Maison des MICI(2)" will be opened in Paris in a different, less expensive neighbourhood, with a more effective office management in order to save money but keeping the same level of services and activities for members. However the new premises do not allow bigger meetings such as the annual youth group meeting, which will now take place elsewhere.

In 2012 AFA will also be launching a smart-phone application and the creation of a web portal ([infomici.fr](http://infomici.fr)), which will provide information to IBD patients, family members as well as health care professional. This will allow us to deepen our collaboration and presence with doctors and other health care workers.

For the third year, we will maintain an awareness campaign, this time with the institutional support of a Laboratoire and not financed by private donations, as previously was the case.

Last but not least, this year we will be celebrating 30 years of fighting against IBD: on March 17th, on the eve of our General Assembly, the "AFA family" will celebrate together with its founders Jeanine Aupetit and Pr Le Quintrec the great steps that we have achieved but most important we will be planning for the future as the fight against IBD goes on!

Chantal Dufresne  
AFA President



## Patients' Therapeutic Education: A Comprehensive and Integrated Caring Process for People with IBD

A new and innovative service is being offered by AFA and patient-experts: patients' therapeutic education (PTE). PTE is part of the patient's care pathway and aims at helping people affected by a chronic disease to understand their illness and treatment and to manage better their daily life. PTE aims at re-motivating the patients, re-mobilising them and allowing their autonomy by giving them tips on how to be in charge of their condition.

PTE is led by a multidisciplinary team that was especially educated for PTE (medical staff, nurses, dieticians, psychologists, patients-experts etc.) and several medical networks and organisations are associated to the programme. Since 2008, AFA has already provided individual health and wellness coaching and collective workshops at the IBD House, as well as in hospitals with a member of the medical staff and a patient-expert. AFA also developed since 2007 an educational programme EDU-IBD with 51 thematic pedagogic tools and especially adapted meetings since 2009.

Patient-experts are people with certain hindsight towards their illness and story, the ability to speak in front of a group, the will to work with other patient-experts and members of the medical staff, and the ability to keep for themselves their personal opinions and story when accompanying someone in a PTE process. Patient-experts have been educated thanks to

university degrees in PTE or a special 40-hour training organised by AFA. At present, 13 AFA patients-experts have graduated or validated their training. These people are not paid in return for the expertise and time they offer.

The PTE programme at AFA is supervised by a special AFA committee and coordinated by Christelle Durance. It is financed partially by the national health insurance as the quality of life has a price!

Tiphaine Chapeau, AFA

### Patient-experts meeting



## Slovenia

### Our Children with IBD in 2011

Most of us would probably agree that the most painstaking aspect of having IBD is learning to live with the restrictions it demands. And this is not even considering the complexity of IBD itself, which makes life additionally difficult, depending on the version of the illness we each have.

Knowing how hard it is for an adult to come to terms with having a chronic illness, we can only imagine what children must go through when their lives turn upside down after being diagnosed with IBD. As this is a rare illness and since symptoms in children usually differ to a large extent from those in



adults with IBD, it usually takes a relatively long time for a diagnosis to be firmly established. Initially the IBD association in Slovenia (now called Društvo za KVCB) was founded for children's sake: to teach them and their parents about IBD, help them overcome any obstacles they come across in learning to live with it, and represent their interests. Eventually the association started also accepting adults with IBD as members and began operating on the national level.



The Slovene version of the Loekie game

Društvo za KVCB tries hard to offer its children members the possibility to spend time and do fun things together. In July 2011 we sent nine boys and girls to a summer camp to Debeli rtič on the Slovene coast for a week. The summer camp is a traditional annual event for children with IBD, where they play, stage creative workshops, go on trips, do sports and listen to lectures. What is most important is that they become friends during that week and that they feel accepted by others of "their kind". Three adult anima-

tors stayed with the children and helped them overcome homesickness as well as encouraged them to eat healthy food and stay active all week long.

In December 2011 we organised a get together for all our children members and their parents in a bowling alley in Ljubljana. While children tried their hands at bowling, parents sat for two lectures: one was given by a paediatrician who spoke about the characteristics of IBD, and another one was by a psychologist who discussed with the parents the problems faced by their children in struggling with IBD. Since it was close to St. Nicholas Day (called Miklavž in Slovene), which is traditionally a gift-giving day for children, we had prepared special gifts for them: the Loekie game which was design by EYG - EFCCA group. We had started working on it just two weeks prior to the event and had managed to adapt the game for our children beautifully. We translated the text and asked a psychologist and paediatrician to check it for suitability, then hired a designer and had 200 copies of the game printed. We called the game Levcek Kroncek or Little Lion Kroncek. Kroncek is what we call our youngest members in Slovenia: it is a pet name for a person with IBD. The game was a big success. Thanks EYG and all the Slovenian group.

Dušan Baraga, Biljana Bozinovski

## Holland

**"I'm so lucky"**

### CCUVN organises sailing competition

23-years old Nadine is on her way to Brest (France) to make it to the finishing line. She is participating in a sailing competition, organized by the CCUVN (Crohn's and Ulcerative Colitis association of the Netherlands) and the foundation 'Live your dreams'.



**Nadine and crew members on the “live your dream” sailing boat**

Nadine was diagnosed with Crohn’s disease in 2003. Back then it was almost impossible for her to imagine that she could ever participate in a sailing competition. She was suffering from severe symptoms. However, people made her believe that she was dramatizing. “During that time I have lost a lot of friends” she tells us. When Nadine looks back on her childhood, she feels sad that she cannot think of any joyful moments because of her severe illness. However, her situation changed positively.

Nadine received an invitation from the CCUVN to compete in a sailing competition, in which she had to travel from Scheveningen (Netherlands) to Brest (France). She accepted the invitation. On the 5th of July last year she and the crew of the ship left the harbor of Lelystad and sailed from IJmuiden to Scheveningen.

When Nadine was sailing the sea, she suddenly started to think back to all the moments when she was feeling ill. She felt tired and anxious. Anxious that she may not make it to the finishing line. Fortunately, the crew on the ship really supported her, also when she had to visit the toilet very often.

On the open waters, Nadine felt free. Free of sorrow and also free of her illness. She started to get to know herself better than before. Nadine also discovered that she was able to achieve more than she thought she was capable of.

Nadine is very happy that the CCUVN gave her the opportunity to participate in this sailing competition. She was able to push her limits and therefore started to live with Crohn’s disease.

## Germany

### Germany’s Federal Joint Committee

#### DCCV and Patient Participation:

In many European countries there are opportunities for patient participation in health care. In Germany the highest decision-making body of the joint self-government of physicians, dentists, hospitals and health insurance funds is called the “Gemeinsamer Bundesausschuss” (Federal Joint Committee).

This Committee issues directives and thus determines the benefit package of the statutory health insurance covering about 70 million people. It specifies which services in medical care are reimbursed by the statutory health insurance. Several organizations of the chronically ill and handicapped in Germany can name patient representatives that have the right of participation in consultations and the right to make applications.

DCCV stands in for patient rights here in several working groups and subcommittees: for example in the subcommittees for Quality Assurance, Pharmaceuticals, Intersectoral Healthcare and Method Evaluation. Thus we were able to prevent the complete cut of reimbursements for drugs against diarrhoea or to fight for new highly specialised outpatient care



in hospitals. Not least because of these possibilities of co-determination self-help has become an integral and government supported part of the health system in Germany. For DCCV the opportunities have been steadily increasing but also the requirements and responsibilities.

Sources: [www.g-ba.de](http://www.g-ba.de)

## Poland

### Annual IBD conferences and the best BA/MA/PhD thesis

Every year since 2008, in December-January, in order to raise awareness of IBD, J-elita organizes scientific conferences for the patients. This time they took place in five cities: Warszawa, Krakow, Zamosc, Wroclaw, Gdansk. Altogether about 600 IBD patients participated in those lectures. Leading IBD specialists working in Poland held the series of lectures. We did not only invite gastroenterologists but also surgeons, dieticians, psychologists and even lawyers (to talk about the case law on disability procedures). They were asked to present their knowledge in an accessible and understandable manner for all participants. And they did it perfectly! The patients were very satisfied with the variety of speeches.

The other important event for our association happened on 6 December. It was the awards ceremony for the best BA/MA/PhD thesis about IBD. The event took place during the meeting of the National Registry of Patients with Crohn's, in the presence of the best gastroenterologists from across Poland. It was a great distinction for our association, the competition's organizer and founder of prizes, as among the five winners were two of our members – two girls with IBD. Furthermore, J-elita is the only patients' association in Poland that grants scientific awards.

I should also not forget about the Santa Claus who visited our youngest members in Katowice and Gdansk. Thanks to our volunteers the meetings were full of big laughs and great surprises.

Magdalena Staniewska



The laureates of the best BA/MA/PhD thesis together with the members of the competition's committee



# Serbia

The Serbian association continues to increase its membership and is becoming more visible to both IBD patients and the media. As research of our application forms showed that a great number of patients lives outside Belgrade, Ljiljan Djakovic, UKUKS chairman, visited big cities in Serbia such as Nis and Novi Sad to present the association to the patients and local doctors.

Our meeting in Nis was a great success and was supported by clinic authorities alongside with Prof. Dr Aleksandar Nagorni and nurse Zaklina Pajevic. It attracted a great number of patients who proposed a sub - association on a local level working under UKUKS. After lessons held by Mr Nagorni and Ms Pajevic there was a long discussion between patients and doctors, regarding patients' quality of life. Our meeting in Novi Sad was supported by prof. Ljiljana Hadnadjev and her team and it turned out to be a great experience as the patients present were very interested in working together and sharing each others knowledge. Patients in Novi Sad also proposed forming a sub – association in order to be able to have local meetings and share experiences.

In addition to these local meeting UKUKS held its first National Association Meeting, which took place in Belgrade. Ljiljan Djakovic, UKUKS chairman, presented the association and Dr Zoran Milenkovic provided a medical overview regarding Crohn's and Ulcerative Colitis. Following those presentations patients

## Participants at the patient-doctor meeting



started a discussion, which lead to the idea of making themed meetings with doctors, with a goal of improving patients' quality of life. UKUKS is also translating and printing material on IBD to keep patients and their families informed about the illness.

Stefan Dakovic, UKUKS

# UK

## Study into fatigue in IBD

Crohn's and Colitis UK have been awarded a grant of just over £480,000 by the Big Lottery Fund to conduct a study into fatigue in IBD. The 4 year research project (July 2010 – July 2014) is being carried out with our research partners at King's College London, University College London, Buckinghamshire New University and Addenbrook's NHS Trust.

The programme of studies will examine experience of IBD fatigue and its impact on daily life of people diagnosed with IBD. It will also develop and pilot a fatigue assessment tool and two interventions will be tested to improve the management of fatigue in IBD. To date the qualitative part of the study has been completed, on the bases of which an IBD fatigue assessment tool has been developed. The tool is currently being tested for psychometric properties.

To understand the level of awareness and IBD fatigue information needs among healthcare professionals, we have conducted a baseline survey with gastroenterologists and IBD

nurses. The survey results (which can be accessed at [www.fatigueinibd.co.uk](http://www.fatigueinibd.co.uk)) indicate that healthcare professionals, as well as patients, would welcome more information to help them to gain greater understanding of fatigue.

A review of literature was carried out and identified only one paper that reported qualitative data on patients' experiences of IBD. The review identified no studies reporting exclusively on experience of fatigue as experienced by people diagnosed with IBD. Additionally there were no studies identified that researched peoples' needs or expectations in terms of managing IBD-fatigue by healthcare professionals.

The review concluded that IBD fatigue has a negative impact on individuals' physical and cognitive performance, resulting in a reduced quality of life. There is a need to study long-term consequences of IBD fatigue, as well as fatigue prevention and management. The full literature review will be submitted for publication and detailed information on the findings will be presented.

Work is currently underway to design a clinical screening checklist, which will be used to select appropriate patients for two clinical interventions over the next two years.

The study will be completed by July 2014 and will contribute significantly to the development of knowledge and understanding of IBD fatigue.

If you have any queries regarding the project please email: [fatigueproject@crohnsandcolitis.org.uk](mailto:fatigueproject@crohnsandcolitis.org.uk)

Also a microsite dedicated to the project is available at [www.fatigueinibd.co.uk](http://www.fatigueinibd.co.uk)

# Czech Republic

## Annual Conference

The Czech IBD Patients' Association held its 6th Annual Conference of Patients with Crohn's Disease and Ulcerative Colitis on 17 September 2011 in Prague. The conference was attended by over 120 patients from Czech Republic and Slovakia. Participants met with a wide range of experts such as gastroenterologists, pediatricians, surgeons and specialists in nutri-



### Delegates at the annual conference

tion and the program included interesting lectures on new treatment methods in IBD, laboratory tests in IBD, surgical interventions in IBD and vaccination. Each lecture was followed by a fruitful discussion.

The parallel program, situated in the lobby of the conference centre, allowed patients to find sponsors' stands with information materials and to buy books on IBD with significant discounts. Also the possibility for patients to consult their problems directly with the experts (gynecologist, pediatrician, nutrition specialist, surgeon, stoma Club, Czech Coalition Against Tobacco) face to face was an appreciated innovation of this year's conference.

Participants also received information leaflets and a book on Crohn's Disease and Ulcerative Colitis which has been written by the Czech IBD Working Group of Doctors headed by Prof. MD Milan Lukas, who cooperates with our association on educational matters.





EFCCA president, Marco Greco, also came to greet our patients and give them encouragement in their uneasy life with an incurable disease.

During 2012 we will continue in educational seminars for IBD patients in Prague and Brno. The next annual conference is planned for September 22, 2012. For more information about our activities please visit our website at: [www.crohn.cz](http://www.crohn.cz).



IBD is often described as a silent disease due to the fact that there are very few external symptoms. Stigma associated with the condition means that people are less inclined to discuss their condition, particularly within the workplace. We will be using this research to highlight both the impact of the condition but to also to help inform those who run services in this area on the supports required for people living with the condition in Ireland.

## Ireland

### Launch of IMPACT

The Irish Society for Colitis and Crohn's (ISCC) together with Abbott launched the EFCCA IMPACT SURVEY on 28th November 2011. The research is vitally important to highlight the impact of Crohn's disease and ulcerative colitis on people living with the condition day-to-day.

**From left to right: Geraldine Murphy(Chairman ISCC),Victoria Cleary (ISCC),Dr Dawn Harper and Ciara Drohan(ISCC)**



The launch featured prominently on national TV and newspapers providing a great opportunity to raise awareness on IBD. Victoria Cleary of the ISCC was interviewed on Morning TV along with Dr Dawn Harper, a Celebrity GP, who appears on the UK TV programme "Embarrassing Bodies".

Geraldine Murphy  
Chairman  
- Irish Society  
for Colitis and  
Crohn's Disease



# IBD Planet: Morocco

## Living your dreams and working in rural Morocco

*by Jonathan De Brandt*



*Jonathan is a twenty-five years old Belgian. Despite having Ulcerative Colitis, he left his country, family and friends last November to live his old dream: working as a development co-operation agent. His new home town: Boumalne-Dadès, Souss-Massa-Draâ, Morocco.*

Life is a journey between two extremes: dreams and fears. Whenever you make an important decision, you are attracted by one side or the other, depending on your emotional background at that time. You must find the right balance. But fears can easily take the lead...

I've been diagnosed with Ulcerative Colitis when I

was 22. At that time, I was a student and it wasn't too serious. After the first flare-up, I could easily handle remission with oral medication and there was no consequence in my everyday life at all. The balance remained stable.

A few months later, I had my second flare-up while I was newly employed in a multinational. That time, it was serious and it lasted for weeks. I will always remember the pain I felt in my whole body and those awful pictures of blood. Besides, I got fired. The balance was then disrupted.

Retrospectively, I still think those weeks of sickness were the worst time of my life. But, guess what? I'm now sitting on my Moroccan coach, listening to good music and knowing that I'll go to the mountains tomorrow to talk about irrigation systems with local farmers. And that's great. Some people won't like this, and I'm sorry for those who are in pain, but I think my second flare-up was a real opportunity because I would maybe not be sitting here otherwise.

Of course it wasn't that easy. I was emotionally very negative for months. I spent days in my room watching movies because I didn't want anybody to see my skinny face. I sent CV's hoping nobody would ever follow up on them. My life was rather not hectic and I barely saw my friends. I'll spare you the details, but I once decided it was time for me to look ahead and stop wallowing in misery and fear. Hopefully, my treatment made it possible for me to live a pretty normal life in Belgium. So basically, I went to see two gastroenterologists and two specialists in tropical medicine. They said "Ok for Morocco". And here I am.



**Boumalne-Dadès**

### **Dadès Valley**

Boumalne-Dadès is located in the Dadès Valley between the High Atlas mountains and the Saghro mountains. Rain is scarce and sun is generous, which leads to a semi-arid type of climate. Winter is rather cold (0 °C at night and 20°C during the day) and summer considered as fresh by locals (“only” 40°C under the shadow).

People are very hospitable and friendly. When you meet somebody, a long exchange of greetings starts. “Salam Alikoum ! Labas ? Bikhir ? Tanna ?...”. It never seems to end.

The region is poor. The main economic activities are agriculture and tourism. Both contribute to each other. Tourists come to admire the landscapes of the Dadès Valley, the Todghra gorges and the magnificent oasis which are maintained by agriculture. In return, tourism contributes to local economic development.

The Dadès valley is also known as the “Valley of a thousand Kasbahs”. Those ancient fortresses made of earth give a very romantic touch to the landscapes.

So, don’t come here alone!

### **Living in the Dadès Valley**

When I got selected for the job, you can easily imagine how I felt. On the one hand, I was happy. On the other hand, many questions started to shake my mind. Is it possible to live there where you are immunodepressed? Are water and food safe? Will I find good doctors and hospitals? How can I get treated?

Basically, there are two answers:

- Morocco is awesome;
- Insurance companies suck.

About immunity, it’s alright to live here because there are not many diseases, unlike sub-Saharan Africa (e.g., there is no malaria) and because you can easily have access to drinking water.

In 2004, 60 % of Moroccan people had access to drinking water at home (tap water). Besides, you’ll find bottled water even in the smallest villages. One month after my arrival, I even started to drink tap water and I haven’t had any problem.



The annoying thing with Remicade is getting “living” vaccines (like yellow fever). You must stop the treatment for a while before getting vaccinated. But there is no yellow fever in Morocco!

One of Morocco’s weakest points is health care. There are many hospitals and clinics in the whole country. But, the quality often lags behind. Nevertheless, there are many well-furnished pharmacies in the whole country and you will find very good doctors in big cities like Marrakech. For example, the “Centre Hospitalier Universitaire” of Marrakech can treat IBD. The problem is you need to advance money unless you have a good insurance. So I have. But the company doesn’t want to pay anything because of my “pre-existing condition”, a term they invented to maximize their profit even more at the expense of those who are socially weak. That’s why I travel back to Belgium every three (not two!) months to get my treatment, fully-covered by the Belgian health care system. Luckily, there are 15 airports in Morocco and I can fly low cost to Belgium. (The decision to get treated every three months instead of two was made by my gastroenterologist after making me running some tests.)

Let us not forget though that we, as Europeans, are often privileged compared to others. The price of Remicade in Morocco is about the same as in Europe, but the difference is there is no public health insurance system. Just a minority can afford a private insurance.

Last thing about health: you will easily find toilets in public places (it’s compulsory by law in restaurants). If you travel by bus, be aware that journeys can be long and stops are rare (6h30 between Agadir and Ouarzazate, but only two stops).

### Final words

I hope this article will help bring into focus that IBD can cause as many damage to the body as to the mind. The latter though can heal better. You must just find your own way.

And if you want to visit Morocco, just contact me...

### On the road between Ouarzazate and Boumalne-Dadès





# Running a marathon to overcome IBD

*by Daniel Sundstein*

It was in the middle of May 2007 when I was put to bed with what I first thought was a food poisoning, a salmonella infection or something similar to that. I was at the end of the first year of my training as a physiotherapist and the exams were coming up.

Two weeks later I had lost a lot of weight and had anaemia. I was admitted urgently to hospital and the doctors could begin their investigation of what was wrong with me. One week later I was diagnosed with ulcerative colitis and was on a heavy intravenous treatment with cortisone. Although it helped my condition, I was still very ill and the doctors had only Remicade left before they would remove my colon. I had lost about 15-16 kg and was as pale as a ghost because of the anaemia. So they tried Remicade, I got a lot better very quickly and one week later I was released from hospital and could go home with my life changed in a way I had never imagined.

While I was in hospital I began to think about the future. What could I do with my life in the best possible way? What goals did I want to achieve? Basically: Who should I be? Big questions, but when your health and life is put to extremes, you should start wondering about what you can do to help yourself in the best possible way – and my mind was set on exercising! As Edward Stanley once said: “Those who think they have no time for bodily exercise will sooner or later have to find time for illness”.

Back then I did not know what impact having IBD would have on my life. I had my own thoughts, I had the doctors telling me what I could expect and I could read on the internet how other people with IBD were living their lives. I very quickly stopped reading what others wrote on the internet – it was not good for me to read about all these lives. I focused on the negative stories and it de-motivated me and I began to feel



sorry for myself. I then took a decision: having IBD is like having a flu once in a while – just more often. Sometimes I will get sick and be put into bed by this. But most of the time I will be just like everybody else – healthy and happy.

Therefore, I began already in the last week of my hospitalization the training towards my new personal goal: to run a marathon. I also had another aim: to complete my education as planned in January 2010 and my plan was still to have a full-time job afterwards.

Running a marathon was the first thing I wanted to do after getting IBD. It was in my mind the best thing I could do to myself, if I wanted to prove that IBD wouldn't influence on my dreams and goals – in short: I wanted to retake the control of my own life and by

this prove to my family, my friends and myself that everything you want to do is possible.

My first training was walking the stairs in the hospital. At first it was 2x4 steps and then back to bed. Then it was walking the stairs from the ground floor to the first floor. Later, after I got back home it was walking around my mother's house. 1 time, 2 times, 4 times and so on. One week after I got out of the hospital I walked 3 km and 4 weeks later I ran 3 km. The pace wasn't very fast, but I did it and slept many hours afterwards. I was taking all things step by step so to say.

Two months after I was discharged from the hospital, I took the exams that had been postponed and I was then ready to start with my fellow students at the third semester of my education as a physiotherapist. While continuing my education I kept on running. After the exams in August 2007 I was up running 5 km per training and I tried to increase the pace every time I went out. I was on the way to find the "new me" and every day I discovered new things. This could for example be which foods were good for me and which ones were not. In September 2007, just around my 22-year birthday, I had my first flare-up after the acute debut a couple of months earlier. Back then I was still both on Remicade and prednisone, and suddenly had to get a higher dose of prednisone. I then learned a new lesson: contact my specialist as soon as I feel any symptoms of IBD!

The months went by and I continued my training and my education. I was also really aware of keeping in touch with my social life. Without my family and friends I had never been able to manage my new life. Therefore I kept on focusing on three things: training, education and social life.

In the summer of 2009 I reached one of the milestones towards running a marathon. I completed a half-marathon in Denmark and my motivation for the marathon was increasing. In January 2010 I completed my education as a physiotherapist and had already got a full-time job. I could check off one of my goals. I have always told myself that if one goal were accomplished I would have to set a new one. The second goal was the marathon. I searched the internet and found a marathon in Amsterdam in October 2010.

It was an easy decision to sign up and now I just had to run as much as possible.

**“It was the hardest self-selected physical exam of my life until then. But I completed and proved to myself that anything is possible if you really want to.”**

May 2010. Three years after I got my life-changing message I got another flare-up. The day I got the symptoms, I contacted my specialist and was immediately started on treatment with additional medication. It meant I had to train a little less, but I kept

on doing what I was able to and one month later I was “back on track”.

17 October 2010 - the day of the Amsterdam Marathon 2010. It was the hardest self-selected physical exam of my life until then. But I completed and proved to myself that anything is possible if you really want to.

Currently I'm planning on running my second marathon. Hopefully Copenhagen 2012, but this has been delayed a bit because of another flare-up, which I'm just recovering from. Therefore, I'm also considering Amsterdam 2012. Besides that I've set myself a new goal in taking a Masters Degree in Osteopathy. This is a part-time study besides my full-time job.

So my advice to all others with IBD “If you really want to do something, you will find a way. If you don't, you will find an excuse.” (quote by an unknown author)



# Protecting persons with disabilities

## *Interview with Yannis Vardakastanis, President of the European Disability Forum*

The European Disability Forum (EDF) is an independent NGO that represents the interests of 80 million Europeans with disabilities. It was created in 1996 by its member organisations to make sure decisions concerning disabled people are taken with and by disabled people. EDF fights for the inclusion of disabled people in society as a right and refuses the out-of-date charitable approach to disability.

### **What is the European Disability Forum trying to achieve at European level?**

The EDF is first and foremost a human rights representation. We represent the 80 million Europeans with disabilities at European level and in collaboration with our members throughout the Member States of the European Union plus Norway, Iceland and the Western Balkan states.

The European Union has ratified the UN Convention of Human Rights of Persons with Disability and our organisation tries to make sure that all European legislations and policies, be it new legislations or the review of older legislations, take into consideration disability related issues from a human rights perspective.

### **What are the main issues you are working on at the moment?**

Besides our activities around the implementation of the UN Convention at the European level, we are also monitoring the implementation of the European Disability Strategy and we are carrying out a campaign to include disability issues in Cohesion Policy and the new regulations on the Structural Funds.



Moreover, we are engaged in the Freedom of Movement Campaign and have published a “Freedom Guide” which is to increase the freedom of movement of people with disabilities within and among the Member States in the European Union.

We are also working on two very important legislative initiatives that the European Commission is supposed to make public this year: the European Accessibility Act and the Web Accessibility legislation.

Of course we are also working at the UN level, the Council of Europe and the OECD.

### What affect has the economic crisis on your work?

Last December we had a very important meeting in Brussels with the European Commission President José Manuel Barroso, Jerzy Buzek, President of the European Parliament and Herman Van Rompuy President of the European Council. During our meeting we discussed how to improve the lives of Europeans with disabilities and told the EU officials very clearly that they cannot be believed and trusted by Europeans with disabilities to implement the UN Convention of Human Rights of Persons with Disability if they do not protect these people from the austerity policies at Member State level. This gap needs to be filled.

For us it's very clear the European Institutions need to take a very firm step, they have not done yet, regarding saving people with disabilities from the cuts. The cuts are affecting disabled people directly or indirectly in almost every Member State of the European Union and the implementation of national austerity measures without consulting the organisations of persons with disabilities is having dramatic effects.

We are not only talking about those countries that are more hit by the economic crisis, even in other Member States people with disabilities are affected. For example in Sweden discussions are being held to cut down the personal assistance budget for people with disabilities. The general trend is to consider the source of protection as an unproductive part of the economy and to cut down there in order to increase the "productivity rate". If you think of the amount

of public money given to the markets in the last years in the European Union then you would think that the real purpose here is not to protect the people from the crisis but to protect the market.

In the face of the current situation, we have set up the "EDF Observatory of the economic crisis" to make more visible of what is happening in each of the Member States. It is the role of the disability movement to be really active, to fight and demand that the rights of people are respected, that policies are put in

**"We need to be present and visible because decisions are being taken everywhere and every day that are affecting people with disabilities (...) In this year of crisis we need to emphasize in our work those people of disabilities that are in need of support, the most excluded amongst the excluded "**

place and that there are no cuts. Horizontal cuts should not affect people with disabilities. As you know there have been plenty of demonstrations in many European countries protesting against these austerity measures because the general repercussions are less income, less employment opportunities, bad public services and bad services for people who are in institutions.

The meeting in December and the commitment we got from it has created a momentum for the coming months. We need to continue lobbying the European Institutions but our work needs to happen everywhere, also in the capitals of the Member States.

We need to be present and visible everywhere because decisions are being taken everywhere and every day that are affecting people with disabilities. In this year of crisis we need to think most of those people of disabilities that are in need of support, migrants with disabilities, women with disabilities, people that are poor, we really need to emphasize in our work the most excluded amongst the excluded!



# Can't wait awareness raising campaign

## *Good practice from the Australia IBD association*

During National Crohn's and Colitis Awareness Month (May), Crohn's and Colitis Australia (CCA) launched a number of activities to help raise awareness and understanding of IBD in the community. These included newspaper articles, radio interviews, a large-scale postcard campaign and a community service announcement that has been aired on prime-time TV. The shift from an awareness week to an awareness month has paid dividends and generated a great deal of media coverage creating more awareness of IBD among thousands of Australians.

CCA wants to thank everyone who participated in the survey that formed the basis for the key messages of the Can't Wait awareness campaign. The survey results showed that people with IBD are still having difficulty accessing retailers' toilets, with 41 per cent of respondents requiring urgent access to a toilet told to go elsewhere, and 61 per cent having difficulty accessing facilities. (Full survey results are available on our website at <http://www.acca.net.au/>)

Unfortunately, the results were similar to the responses to CCA's 2008 survey, indicating that more needs to be done to highlight the needs of people living with IBD. In addition to using the media to create awareness of the issue, CCA has developed stickers that retailers can display in their shop window to indicate that the Can't Wait card is welcomed at their venue. CCA also sent federal and state politicians letters alerting them to World IBD Day on May 19, and asking them to show their support by displaying the Can't Wait stickers in their electorate offices.

Another prominent aspect of the Can't Wait campaign has been the television commercial, appearing on national networks. The advertisement features the face of last year's awareness campaign, Amber Miall, media personality Pete Timbs and surfer Brittani Nicholl. The ad highlights the needs of people living with IBD, and directs viewers to the [www.cantwait.net.au](http://www.cantwait.net.au) website, which provides more details about the campaign, and offers donors the chance to win an Apple iPad2 by nominating what they can't wait for.

CCA also created a viral awareness campaign, developing an online postcard promoting the Can't Wait message and the website. The card was emailed to members, who were asked to forward it.

CCA would like to thank Amber, Pete and Brittani for putting their face to the campaign, which has garnered favourable responses from other members, including one member who has lived with ulcerative colitis for 25 years who wrote: "This is the first campaign that does not make me cringe or want to continue to hide from the world and my illness - a very sincere thank you". It would also like to thank all of the other CCA ambassadors who spoke on CCA's behalf or undertook fundraising events to create more awareness of Crohn's and colitis.

### **About the CCA**

CCA was established in 1985 by people who have IBD or have a family member affected by the illness. It is a not-for-profit organisation with an honorary board of Directors committed to finding a cure for IBD and providing and implementing services to assist members' needs. CCA collaborates with the Gastroenterological Society of Australia, Digestive Diseases Foundation, IBD Australia special interest group and other medical, surgical societies or accredited professional organisations to produce specific IBD publications. These publications are distributed nationally and internationally to patients and medical professionals, and to the global network of IBD patient organisations.

# IBD Research Foundation

Inflammatory bowel disease (IBD) is becoming more common worldwide, according to a study recently published in the journal *Gastroenterology*. The researchers of the university of Calgary Canada, conclude that in time-trend analyses, 75% of Crohn's disease studies, and 60% of ulcerative colitis studies had an increasing incidence of statistical significance.

(Source: [http://www.gastrojournal.org/article/S0016-5085\(11\)01378-3/fulltext](http://www.gastrojournal.org/article/S0016-5085(11)01378-3/fulltext))

These findings provide more reason to intensify and extend research efforts in order to understand more about these diseases, which hopefully lead to clues how to improve treatment.

## Progress of projects awarded a grant in 2010

In 2010 the IBD Research foundation awarded three projects a grant.

The project by researcher Stefania Vetrano titled "The protein C pathway: a novel mediator in intestinal homeostasis in IBD" finished by the end of 2011 and our foundation received the final report. Its results are published in *PNAS*, one of the world's most-cited multidisciplinary scientific serials. Also see: [www.pnas.org/cgi/doi/10.1073/pnas.1107140108](http://www.pnas.org/cgi/doi/10.1073/pnas.1107140108)

The IBD Research Foundation is acknowledged in the full text version as source of funding for the project.

The project by researcher Jessica Mwinyi titled "Analysis of PPAR- $\gamma$  haplotype structure and its influence on disease susceptibility, pathogenesis and activity of inflammatory bowel disease" also finished by the end of 2011 and our foundation received the final report. The final version of this report will be published shortly in the journal *PPAR Research*, with the IBD Research Foundation acknowledged as the funding source

The project by researcher Giulio G. Muccioli, titled "Exploring the potential of N-palmitoylethanolamine in a mouse model of inflammatory bowel diseases" is

still in progress and we have been promised an update in February.

We will provide short summaries of the results of these projects on our website.

## Projects awarded a grant in 2011

In 2011 another three promising IBD related research projects were awarded a grant by our IBD Research Foundation:

- Helen Mohan, University College Dublin Ireland: "NR4A orphan nuclear receptor signaling: a novel pathway in inflammatory Bowel disease"
- Kacper A Wojtal, University Hospital, Zurich, Switzerland: "Development of novel biomarkers for prediction of the outcome of anti-TNF therapy in IBD patients"
- Anja Schirbel, Charité Universitätsmedizin Berlin, Germany: "Modulation of bacterial ligand-induced angiogenesis by probiotics through distinct Toll-like (TLR) and Nod-like (NLR) receptors in IBD"

As the applications were very comprehensive we are very grateful for the help of the members of both the Scientific review committee and the Patient representatives committee. In order to ensure the patient perspective in awarding the grants, it was up to the patient committee to make the final decision. After all, the IBD research foundation is not only managed by patients, it is also funded by patients; either through individual donations or through donations from patient associations. The input from the Scientific Review committee was essential for the Patient representatives committee to make a solid decision.

## Donations

The Austrian patient association (ÖMCCV), donated 1,- euro per member, which added up to the substantial amount of 1230,- euro.



The Swiss patient association (SMCCV) donated 25000 CHF (about 20600 euro), which is the second time we have the privilege to receive such a very substantial donation from the SMCCV.

Of course individual donations are also very welcome, such as the 60,-euro donation we recently received from a mother who's son has IBD and hopes that supporting research might eventually help to improve treatment. This makes us aware again of the essence of our foundation.

### Board

We welcome Salvo Leone and Chayim Bell as new members of the supervisory board.

### 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: 97.46.86.158

IBAN: NL37ABNA0974686158

BIC: ABNANL2A

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## Health First Europe

Health First Europe (HFE) is a non-profit, non-commercial alliance of patients, healthcare workers, academics, healthcare experts and representatives of the medical technology industry. It is based in Brussels and has 20 member organisations as well as 10 individual members. Its mission is to ensure equitable access to modern, innovative and reliable medical technology for all citizens of Europe and to promote a new approach to healthcare, based on the consciousness that it represents a vital investment in the future of Europe.

It is based on the premise that our Health Care Systems have to be rethought in order to face the challenge of our era, and patients' rights, in particular, have to be taken more into consideration and have to be defended with actions capable to assure, in the future, an equitable access to modern, innovative and reliable medical and health services.

This goal cannot be reached without building synergies with actors operating in the health care field, this is one of the reason why EFCCA is proud to be member of other patients' and healthcare workers' organization which share the same vision and values.

On 15 December 2011 EFCCA attended the HFE Annual General Meeting. The HFE Secretariat and members discussed HFE 2011 activities and the 2012 work programme. In addition, HFE welcomed Ms. Nathalie Chaze (Head of Unit, Health Systems, European Commission DG SANCO) for an informal discussion on Health Technology Assessment.

2011 saw HFE actively involved both on the policy activities (e.g. with the launch of a Task Force on Patient Safety, the Joint Action on Patient Safety and Quality of Care, the e-Health Week etc) and two key events hosted at the European Parliament : the launch of the publication "E-Quality in E-Health" on promotion of awareness and use of innovation in health, and, on 29th November, the "Innovation Day".

The HFE programme for 2012 is very dense and will focus on the Patient Safety and Health Technology Assessment (HTA) with a series of actions aimed at, for example, influencing the Commission's report on Member State implementation of the Council Recommendations on patient safety, and follow up of the successful initiatives started in 2011.

For more information please visit the HFE website at: <http://www.healthfirsteurope.org/>

# FAST TRACK & IBD

**by Antonino Spinelli, MD PhD and Piero Bazzi MD**  
**Istituto Clinico Humanitas, IRCCS, Milano Italy**

One of the major innovations that characterized colorectal surgery over the last twenty years is the development of a multimodal enhanced recovery programme (Enhanced Recovery After Surgery, ERAS), also referred as Fast-Track (FT) Surgery.

In the beginning of the 90s, Professor Henrik Kehlet from Copenhagen was the first to propose and to introduce in clinical practice a new model of perioperative care programme combining recent developments

in surgical and anaesthesiological techniques with evidence-based adjustments to the use of nasogastric tubes, drains, urinary catheters, preoperative bowel preparation and fasting, postoperative oral feeding and mobilization. Kehlet analyzed the main perioperative risk factors related to the most common postoperative complications and proposed this new set of protocols, called “multimodal rehabilitation programme”, resulted from the understanding of perioperative physiology to improve surgical outcome.

**Table 1**

COMPLICATION	PATHOGENIC FACTORS	INTERVENTIONS
Cardiac	Cardiac stimulation, hypoxaemia, fluid disturbances	Stress reduction (minimally invasive surgery, neural block, pain relief), oxygen administration, avoid heat loss and fluid overloading
Pulmonary	Impaired pulmonary and diaphragmatic function, pain, immobilization, fluid disturbance	Stress reduction (minimally invasive surgery, neural block, pain relief, physiotherapy), avoid supine position and fluid overloading
Thromboembolism	Altered coagulatory/fibrinolytic balance, immobilization	Antithrombotic prophylaxis, stress reduction, mobilization
Cerebral dysfunction	Surgical stress, hypoxaemia, psychoaffective drugs, withdrawal syndromes	Stress reduction, oxygen administration, mobilization, avoid unnecessary opioid, psychoaffective drugs
Infection	Contamination, immunosuppression, hypoxaemia	Avoid contamination, use antibiotic prophylaxis, immunosupportive therapy, nutrition, oxygen administration, mobilization, remove catheters and drains as soon as possible
Nausea and gastrointestinal dysfunction	Afferent stimulation, anaesthetics and opioid analgesics	Stress reduction, avoid unnecessary opioid, use antiemetics
Impaired wound healing	Malnutrition, catabolism, hypoxaemia, infection	Minimally invasive surgery, oxygen administration, mobilization, avoid infection, provide pre and post-operative nutrition
Fatigue, reduced functional capacity and convalescence	Loss of muscle and function, immobilization and impaired cardiovascular adaptation to exercise, malnutrition	Stress reduction, early oral nutrition and mobilization

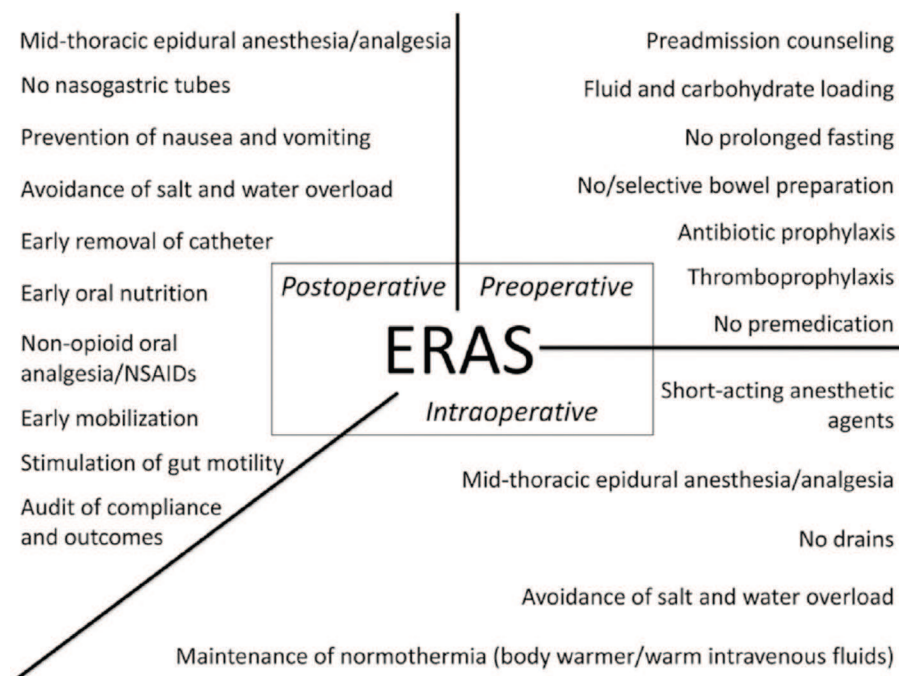
**Table 1. Postoperative complications, pathogenesis and prevention (Kehlet H. Multimodal approach to control postoperative patho-physiology and rehabilitation. Br J Anaesth 1997;78:606–17).**



The aim of these programmes was to minimize surgical-related pain and discomfort by reducing both the physiological and psychological stresses associated with operation, allowing lower rates of organ dysfunction and morbidity and enhancing recovery.

The main topics of FT protocols could be divided into three areas: pre-operative preparation, intraoperative factors and postoperative care

(Figure 1).



**Figure 1. Items of FT protocols (Varadhan KK, Lobo DN, Ljungqvist O. Enhanced recovery after surgery: the future of improving surgical care. Crit Care Clin. 2010 Jul;26(3):527-47, x).**

#### 1) Preoperative preparation

- Preadmission assessment and counseling: it requires participation of the entire multi-disciplinary team (surgeon, anaesthetist, nurse) in order to give complete information, ensure compliance and promote active participation by the patient.
- Fasting protocol and carbohydrate loading: reduction of preoperative fasting to a minimum of 2 hours; administration of carbohydrate drinks appears to increase insulin sensitivity, contrasting the surgery-

related insulin-resistance and catabolism.

- Mechanical bowel preparation: not used, on the basis of data that found out no differences in septic complications between patients prepared versus those who received no bowel preparation; furthermore, these patients report less discomfort, pain and fatigue.

#### 2) Intraoperative factors

- Anaesthetic protocols: improved use of short acting anaesthetic agents, minimizing opioids and fasting recovery from general anaesthesia. Epidural anaesthesia and analgesia is considered the best option for pain control, to contrast ileus and to attenuate the endocrine-mediated stress response to surgery. Avoidance of fluids overload is recommended to limit cardio-pulmonary-renal stress and inhibition of gastrointestinal motility; maintenance of normothermia with warmed forced-air cover or warmed fluids gives advantages in terms of reduction of general complications.

- Surgical techniques: minimally invasive surgery (laparoscopy) thanks to both limited surgical trauma and tissue handling is associated with several benefits respect to traditional approach: reduction of postoperative pain and analgesics use, shorter ileus and better cosmetic result with greater satisfaction for the patient. Its advantages can be improved by combining this surgical technique with a FT care. Routine

use of drains have no role, except in circumstances of high risk for bleeding.

### 3) Postoperative care

- Opioid-sparing analgesia: postoperative pain is managed at best with continuous epidural anaesthesia for a two to three day period; in absence of epidural catheter, non-steroidal anti-inflammatory drugs and paracetamol are regularly used to limit/avoid opioid drugs.
- Early mobilization: patients are encouraged to mobilization since 2 hours after surgery; it's useful to mitigate the muscle loss, to improve pulmonary function and reduce thromboembolic complications. Urinary catheter is generally removed the first day after surgery.
- Early feeding: Nasogastric tube is removed immediately after surgery and patients start oral intake in a few hours with the aim to contrast catabolism and shortening ileus.

The benefits of FT surgery in terms of improved recovery and shortened hospital stay were demonstrated by several clinical trial focused on colorectal resection for cancer; despite this increasing evidence, worldwide surgeons show a very slow change in clinical practice to FT programmes. There are several possible reasons for this slow response: the difficulties in multidisciplinary collaboration, insufficient expertise and staff support, a lack of quality-data in the literature, external barriers and the skepticism to innovations...long-standing tradition is difficult to overcome!

As for laparoscopy, also FT programmes developed slower and have been less applied in patients with inflammatory bowel disease (IBD) than in patients affected by other diseases (cancer, diverticula...). Nowadays, in expert hands, surgical operations for Crohn's disease (CD) or ulcerative colitis (UC) can be performed laparoscopically with the same safety and efficacy than traditionally; in particular, laparoscopic ileocolic resection for primary CD has become the first choice treatment.

Nevertheless, in the current literature there is a lack of experience in managing IBD patients with FT periop-

erative care. This can be explained by several reasons: the different types of presentation and characteristics of the disease lead to a multiple and various type of operations, denying the possibility of standardized procedures; the greater technical difficulty due to high frequency of complications (fistulas, abscesses, multiple sites involved by the disease...); the higher risk of anastomotic fistula due to chronically inflamed tissues; the higher risk of postoperative complications due to prolonged medical treatment with immunosuppressant drugs and the poor general conditions of many patients at surgical time.

Anyway, we believe that benefits related to FT programmes could be especially important for patients with IBD, and should not be negated a priori. FT perioperative care may reduce both surgical and psychological stresses, allowing to a smoother recovery with a potential decrease of postoperative morbidity and overall hospital stay, with faster return to customary activities; this can also lead to a quicker return to work or school, reducing social costs. These advantages should be emphasized in IBD patients because they are generally young, active and often require repeated operations: all valid reasons to maximize the efforts of an enhanced recovery with reduced stress!

In conclusion, FT surgery is a validated combination of multimodal and integrated perioperative care programmes that may reduce surgery-related stresses, resulting in an enhanced recovery with shorter hospital stay. Its application has been experienced predominantly in patients who underwent colorectal resection for cancer, while there is still a lack of data focusing on laparoscopy-treated IBD; nevertheless the few available clinical studies and the experience of centers already using such protocols have shown very good results, demonstrating its safety, feasibility and encouraging a spread development of this innovative model of perioperative management in this subset of patients. Some conditions, however, must be respected to guarantee final success: FT laparoscopic surgery for IBD needs a multidisciplinary team of surgeons, anesthesiologists and dedicated nurses having undergone a specific education and it is essential that patients are strongly motivated to be actively involved in their recovery.

# Anaemia in IBD – an important cause of fatigue

by Ben Wilson

As many of us unfortunately know, fatigue is said to be one of the ‘big three’ symptoms of IBD (pain, fatigue, and urgently needing the toilet). Even though this is common knowledge, the IMPACT survey helped to quantify just how many people consider that their fatigue persists, even when they are relatively well. Remarkably, 83% of the 5000 survey respondents still felt significant fatigue, even when they’re not experiencing a flare-up.

Several important articles note that anaemia may be especially significant in people with IBD. In particular, some people with IBD might not absorb as much iron from their diet as other people, due to dietary problems, due to inflammation in the digestive system, or due to loss of blood through the digestive system. One article stated that amongst associated conditions reported by people with IBD, “anaemia had the fourth most significant negative impact on quality of life behind arthritis, heart disease and age” (Gasche et al., 2004).

This is why EFCCA would like to explore this issue in more detail, and to do this, EFCCA is working with A+A Research, supported by Vifor Pharmaceuticals, on a short, focussed follow-up survey, which aims to find out:

- The effects of anaemia in IBD from the patient’s perspective, and how symptoms of both IBD and anaemia may be related.
- The effect of fatigue on a variety of activities in daily life.
- The level of knowledge of anaemia in IBD within the community of patients, and how healthcare professionals approach and communicate anaemia in IBD.

With the knowledge from this focussed survey, we hope to be able to gain more detail about the precise impact that this symptom has, which could help us better understand the problem, raise awareness, and capture the attention of those in a position to help us with the aspects of daily life that are affected.

Many articles note that anaemia can be effectively treated, and even better, it can sometimes be prevented. Published clinical guidelines offer a suggested framework for healthcare professionals who might encounter it:

- **Confirm** the diagnosis of iron deficiency anaemia.
- **Assess** the person to determine the cause and severity of anaemia.
- **Refer** (from family doctors, or to other departments).
- **Treat** the underlying cause – including IBD.
- **Treat** the anaemia.
- **Monitor** as appropriate.

PRODIGY (2011)

Combining this medical knowledge with the knowledge we could gain from the survey could help us to tackle this symptom in both the medical and real-life context.

The survey will be launched in the next couple of months – check the EFCCA website for more information on how to take part, and how to access the results.

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Serving our patients is the heartbeat of our work. From breakthrough scientific research to innovative projects, our mission is to make a difference in the treatment and care of people all over the world. Just like you.



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