EFCCA MAGAZINE

European Federation of Crohn's and Ulcerative Colitis Associations | April 2011

> "Inside she is in pain but she keeps silent. Crohn's and IBD are taboo diseases, talking about them is the first step of the fight"

Image from awareness raising campaign organised by Afa, France, page 14

Promoting Patients' Rights at European level

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précision: CRÉDIT PHOTO : © Rui Vale-de Sousa

EFCCA Members

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www.oemccv.at

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www.ccv-vzw.be

Belgium – RCUH
www.mici.be

Croatia – HUCUK
www.hucuk.hr

Cyprus – CYCCA

Denmark – CCF
www.ccf.dk

Finland – CCAFIN
www.crohnjacolitis.fi

France – AFA
www.afa.asso.fr

Germany – DCCV.e.V.
www.dccv.de

Hungary –MCCBE
www.mccbe.hu

Iceland – ICCA
www.ccu.is

Ireland – ISCC
www.iscc.ie

Italy – AMICI
www.amiciitalia.org

Luxembourg – ALMC
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Netherlands – CCUVN
www.crohn-colitis.nl

Malta – MACC
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Portugal – APDI
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Spain – ACCU
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Sweden – RMT
www.magotarm.se

Switzerland - SMCCV
www.smccv.ch
www.asmcc.ch

United Kingdom – NACC
www.nacc.org.uk

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EDITOR'S EYE

Six steps into the future

The magazine you have in your hands now is a milestone. Only a few months after having announced our intention to transform the EFCCA newsletter into a magazine, we are here presenting the first transitional product - the first draft of what will be an amazing final product.

I am not only talking about the number of pages, but also about the content: more space given to EFCCA's 25 national IBD associations. Because we need to communicate with each association, to learn from them, but also to offer a real forum in which to exchange experience and to better know each other. The first responses to the new publication suggest that we are going in the right direction.

We have devoted much space to our projects. As we know, EFCCA is completing an ambitious renovation that will pass through a so-called "six steps" - the six priorities or frameworks that constitute our strategic view of the future, our vision, and in concrete, our answer to the most felt unmet need: beating IBD.

Beating IBD does not mean only to find a cure, but to limit the effect of the disease, to erase the terrible social impact and to restore hope. Realizing this project, at first sight, could appear to be even more than a dream, maybe a utopia. It is not. This does not mean that we underestimate how difficult it will be. On the contrary, we are perfectly aware of how hard this programme will be to make a reality. But we are not scared. Step by step, we will succeed, as we have done over the past 20 years.

It is important to understand that our work requires activities in a number of forums and arenas: we must be present where decisions about people with IBD are taken. A common strap-line amongst patients' umbrella organizations is "nothing about us without us". It is a great starting point, but to make it a reality, you "have to be there". You have to be present where the decisions are taken, and moreover you have to be able to make your voice clearly understandable and listened to.

Sadly, there is not a great deal of awareness of IBD amongst general society. Obviously we will not renounce our rights for this reason. And so we are finding other ways: SIX new ways, to make our voice louder, our battle better known, and our place in the world re-affirmed.

We are learning, we are improving, we are joining other organizations, we are developing our network, and we are developing our team and our staff. We are working hard. But our growth shall not make us lose contact with our members and the people we represent. Communicating our battle is important, but it is even more important to communicate with whom we represent. And so, here is a new, powerful instrument that over the coming months will continue growing.

This magazine is for YOU. And YOU are invited to use it, to make it, to transform it. This is a first step, and many more will follow: a new communication strategy, new printed materials and the new EFCCA website. But for the moment, please allow me to celebrate this new "number 1". In few months, thanks to the commitment of our new staff member, Isabella Haaf, the magazine has been shaped, moving from our "ideas"

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to paper (and e-format) and I think your expectations will be surpassed.

We made a deliberate choice, for this first issue, to limit the medical content to only one article. In the future, this part will grow. But for this first new issue, we wanted something more focused on our member associations and on our projects. Because this is the starting point.

Here, we also start a clear and direct link with other key organizations, not only IBD-related, because networking is becoming more and more strategic for us.

I want to thank all the persons that have contributed to this issue. I want to thank them because they believed in our possibility of creating such a product in few months: if we have won this bet, they've won with us. Finally, please allow me to thank AFA, the French national IBD association for allowing us to use a key image from their recent communication campaign for our first cover. We have never had a "cover" in the previous newsletters, certainly not an image, and even less a provocative one.

At first, I was not sure that it would be a good choice to use an image coming from a campaign from a specific one of our national associations, but the image from the AFA campaign speaks volumes, and was perfect to convey the true feeling of many people with IBD - our voice is not heard. And sometimes we would like to shout, to stand up and say: "we are here", to politicians, to society and – maybe less than in the past – also to the medical community. With this project we reaffirm our humanity, the fact that we are people, before we are patients. And this image from AFA expresses this, and much more. So, to our friends at AFA, we offer our thanks. And I hope that, in the future, other associations will be happy to share their projects and campaigns with us: as we've said, we're fighting the same battle, and this space is yours. So, as a competition and a challenge, Isabella and I will be waiting for your ideas for the next issue, and the next cover.

If I can express a wish here, I'd like to see this newsletter growing, with even more ambition and with the freedom and independence that has always been the trademark of our organization. I firmly believe in the potential of this project. I trust that the readers will not only appreciate it, but also, through comments, remarks, constructive criticism and contributions, will take the lead, and will use it.

At EFCCA, we are happy, but we will not stop. Other goals are in front of us. And our journey will be successful if UNITED WE STAND.

Marco Greco, EFCCA Chairman

Learning from each other

Training opportunities for EFCCA national member associations
by Luisa Avedano, EFCCA Chief Executive Officer

> **"The idea is to provide an "exchange" arena of mutual learning putting at disposal the network experience and the existing "inspiring" practices which have already been implemented among our members."**

EFCCA is embarking on an exciting, new initiative aimed at supporting national chief executive officers (CEOs) with the management of their national association. We will be offering a series of targeted training courses including executive coaching, leadership skills development and other specific training, which will provide CEOs with additional tools to effectively carry out their work at national level.

This initiative forms part of the six development priorities[1] endorsed by EFCCA's General Assembly in Helsinki last year and reflects our new approach to boost a stronger link with national associations and to achieve our goals in a more effective way.

A provisional period for the first training course has been set for September/October this year and will take place in Brussels. The programme will include an information session on the EU policy context with regard to the EU Health Strategy followed by an exchange of information amongst national member associations. The idea is to provide an "exchange" arena of mutual learning putting at disposal the network experience and the existing "inspiring" practices which have already been implemented among our members.

The final stage will see the drafting and co-design of a training package, which will be then available to all the professionals who are already working locally.

One of the main possible themes for the autumn training will be on developing insurance schemes for IBD (inflammatory bowel disease) patients. In this case, colleagues from the German national association will share their experience on how they have developed their own national insurance scheme for IBD patients. Participants will then discuss and explore possibilities for developing an insurance scheme in their respective countries as well as at a European level.

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[1] Development priority "ATHENS": developing the concept of the 'EFCCA academy', connecting and training Europe's national IBD association directors and staff. Sharing knowledge and best- practice.

Other themes that have been suggested by national members and which will be the subject of further training courses include:

- providing better services for children and their families
- how to increase and keep membership
- how to involve volunteers and keep them motivated
- fundraising and project management
- developing a strategic management plan for an association
- communication and team building.

The wide range of themes suggested by the members clearly shows the need for targeted executive leadership services as many professionals are acting in small and/or medium size associations with very "light" infrastructures that require the executive director to have high skills and output in many fields.

EFCCA hopes that the focus on executive directors will lead to a more meaningful definition of leadership in the context of the patients' organisations we represent. The CEOs' training represents the first step toward a more comprehensive set of training offers that EFCCA is willing to put at disposal to all members with some specific focus on volunteers' involvement and empowerment.

For more information please contact me at efcca.ceo@gmail.com

EFCCA consolidates cooperation with ECCO

by Marco Greco, EFCCA chairman

During the recent European Crohn's and Colitis Organisation (ECCO) congress, EFCCA met with ECCO chairman, Professor Daniel Hommes, in order to discuss cooperation between the two organisations in particular as concerns the IMPACT survey launched by EFCCA late last year (see page 10). As an initial step it was agreed to hold regular bi-annual meetings starting during the next UEGW meeting in Stockholm (from 22nd until 26th October 2011) and a further meeting between me and the ECCO chairman was set up to finalise details of our cooperation.

We are keen to work together with ECCO, the European organisation for healthcare professionals specialised in IBD (inflammatory bowel disease), as we would like to share top level information of these outstanding clinicians and scientists to a wider number of patients, and at the same time provide the latest news on scientific or clinical developments.

Cooperating with ECCO remains a strategic priority for EFCCA in the scientific and medical field and the project represents a new important step towards strengthening this cooperation and continuous interaction.

The ECCO congress, which took place in Dublin from 24-26 February 2011, was attended by over 3000 delegates and provided access to the latest scientific information and education in gastroenterology with its major focus on IBD.

The programme was structured in basic science and clinical sections. In addition, educational activities such as the 9th IBD Intensive Advanced Course for Junior Gastroenterologists with the integrated YECCO Workshop, the ECCO Nurses Network Meeting, which EFCCA was proud to support with educational bursaries (see page 30) and the second NECCO School took place prior to the actual start of the congress.

For a detailed scientific overview of the presentations made during the ECCO congress please read our article in the Medical Review Corner on page 34 prepared by Dr. Silvio Danese, ECCO member, and Dr Hajnalka Szabo.

EFCCA Youth Group will meet in Cracow, Poland

The EFCCA Youth Group (EYG) together with the Polish IBD organisation "PASPIBD" are organising the next annual EYG meeting, which will take place in Cracow, Poland from 30th June 2011 until 3rd July 2011.

EYG meetings are designed to be fun and interactive and delegates are invited to participate in experts' lectures on IBD related topics, workshops and interactive sessions. Delegates also learn about the European Youth Group projects and how they can get involved and contribute to the community of young people with IBD on a European level. During this meeting, for the first time, representatives are invited to present their national associations' youth activities in a 5 to 10 minute presentation.

"The idea of these meetings is to have fun whilst learning, working together and sharing ideas as a friendly and understanding community" says Chayim Bell, Chairman of the EFCCA Youth Group.

This year the European Youth Group meeting will take place in Cracow, which is the second largest and one of the oldest cities in Poland.

The Polish partner "PASPIBD" will be organising a city game for the delegates, which will combine a sporting event with a unique way of sightseeing the city of Cracow. Other social activities will include a welcome dinner at a well-known restaurant with views over Wawel Castle and a gala party on the last night.

Two delegates from each EFCCA national member associations can attend this event.

For more information please contact the EFCCA Youth Group at: eyg@efcca.org or go to:
www.eym2011.krakow.pl/en

Annual General Assembly

This year's General Assembly will take place in Copenhagen from 14-16 April 2011 and will allow our 25 member associations to meet face to face, to exchange the latest information and best practise and to refresh old friendships.

Delegates will elect new Executive Board members and discuss the admission of three new national members from Serbia, Poland and Czech Republic to join EFCCA. Discussion will also center on several topics that are of major interest to national members and have been communicated previously to the Executive Board. Following our new working approach, the programme of the GA has been designed in a way that allows the assembly to be more open for discussion, to be more democratic and to offer more time to talk to each other. There will be two discussion groups, which will provide a great opportunity for the exchange of ideas and experiences to feed into the strategic policies for EFCCA and its work programme.

This year EFCCA has also invited external guests such as the ECCO Chairman and the Director of the European Patients' Forum.

World IBD DAY

For some time the IBD global community of Crohn's and ulcerative colitis patient organisations and foundations have been considering the wish to launch a World IBD Patients Day to bring to international attention the needs of people living with IBD, articulated with a unified worldwide voice. As a result of discussions in early June 2009 among patient organization representatives during Digestive Diseases Week in Chicago and subsequently in a teleconference it was decided to hold World IBD DAY on 19th May of each year.

Following last year's first successful celebration patient groups from 24 European countries through EFCCA, the United States, Canada, Australia, New Zealand, Uruguay and Brazil continue working together to draw awareness to Crohn's disease and ulcerative colitis and to convey a sense of global solidarity for IBD patients.

There are more than 5 million people in the world living with IBD, there is no cure, no known cause, and little public understanding of the chronic pain and suffering with which IBD patients cope with every day of their lives.

Here in Europe, EFCCA will be organising an IBD awareness raising campaign in Brussels on 19 of May targeting EU institutions and policy makers with the aim to pave the way for greater contact with Members of the European Parliament and to make EFCCA more visible in the European arena.

OBITUARY

Mrs Els de Graaf, former EFCCA Secretary, has passed away on 7 March 2011. Els has been an important figure within the EFCCA team: she strongly contributed in the growth of our organization since its early years. Kind, devoted and passionate about the EFCCA mission, Els has been an example of great commitment. Many youngsters will remember her for the key role she played in the organization of the International Youth IBD Meeting in Amsterdam 1999. We all remember Els for her professional style and capacity and, paying her our last respect, we thank her once again for sharing with us IBD people the challenge for a better life.

Dusan Braga, KVCB Slovenia, outside the UEGW conference center, Barcelona 2010

EFCCA attends United European Gastroenterology Week

EFCCA Board members participated in the 18th United European Gastroenterology congress which took place in Barcelona from 23rd-27th October 2010 and was attended by over 14 000 delegates making it one of the top class gastroenterology meetings not only in Europe but worldwide.

EFCCA was also represented at the exhibition hall by Solveig Johansson Grip (RMT, Sweden) and Dusan Braga (KVCB, Slovenia) which provided an excellent opportunity for EFCCA to communicate its activities to a wide audience consisting of phycisians and researchers in the fields of gastroenterology, hepatology, endoscopy and gastrointestinal surgery as well as other healthcare professionals and European organisations working on health issues.

Visitors showed particular interest in the recently launched IMPACT project (see p. 10) as well as the "Life and IBD" project (http://www.lifeandibd.org/), which has been concluded. Many delegates were already familiar with EFCCA and/or their national member association, and useful contacts for future cooperation were set up.

EFCCA will also participate in this year's UEGW Congress to take place in Stockholm from 22-26 October 2011.

First results of the IMPACT survey

In December last year EFCCA launched the IMPACT survey which provides a unique and exciting opportunity to discover the true IMPACT of IBD (inflammatory bowel disease) not only on quality of life, but also on the social, educational, employment, and holistic aspects of IBD, on a European level.

The survey, which is still open, is available online in 9 European languages including English, French, German, Spanish, Italian, Portuguese, Dutch, Swedish and Slovenian.

Download resource website:
http://www.efcca-solutions.net/impact/

The specific aims of the survey are to discover:

- The effects of IBD on a wide range of aspects of people's lifestyles
- Whether these aspects are included in consultations with healthcare professionals
- The extent of access that people with IBD have to healthcare and support facilities in various countries from the perspective and perceptions of the patient
- Understanding perceptions of the quality of Health Care provided
- Generally understanding the differences that exist between countries, age groups, genders and different types of IBD
- To provide EFCCA and national patient associations important new evidence to gain attention on the needs of IBD patients and to drive for better resource commitments from official policy bodies, including WHO.

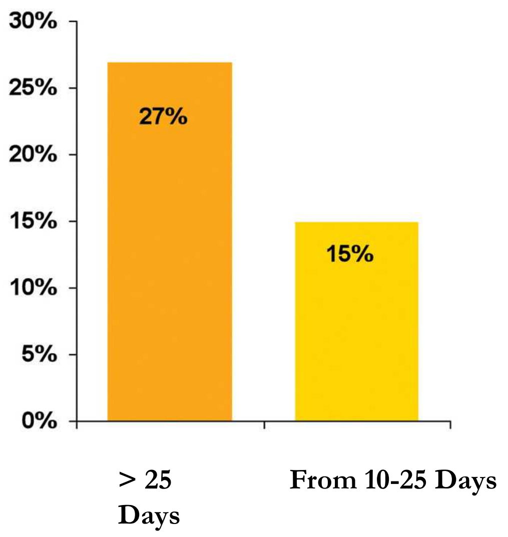
At the closing date of printing this magazine a total of over 1750 responses have been collected and the initial results of the IMPACT survey have been presented during the ECCO congress, which took place in Dublin from 23-26 February 2011.

Most noteworthy so far have been responses to the question of the amount of lost working days due to IBD. 27% of people with IBD have taken more than 25 days' sick leave in the past year and over 66 % felt that their IBD has had a negative affect on their career, opportunities for advancement, or earning/income potential while 48% claimed to have lost a job, or had to quit a job because of their IBD.

On the subject of "the effect of IBD on Intimate Relationships", 1 in 3 respondents, claim that their IBD has prevented them pursuing intimate relationships and 22% claim it has been the cause for ending an intimate relationship.

The following chart summarizes the main initial findings of the survey.

Past Year Lost Working Days



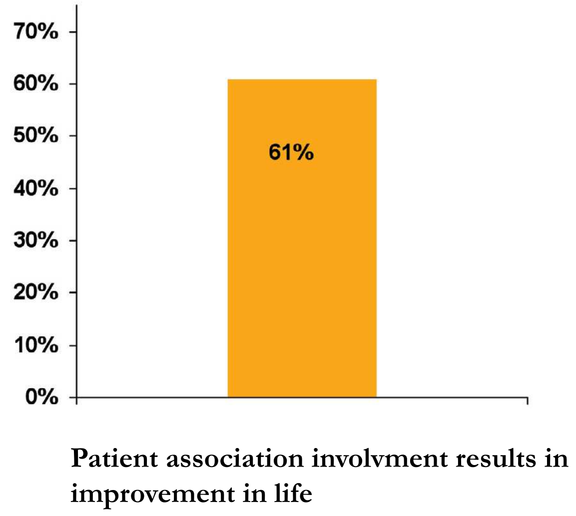
The survey is still open and we encourage everyone to participate in collecting valuable data to help the community of people with IBD across Europe. The survey is completely anonymous.

You can complete the survey at:
www.surveysolutions.co.uk/ibd-survey

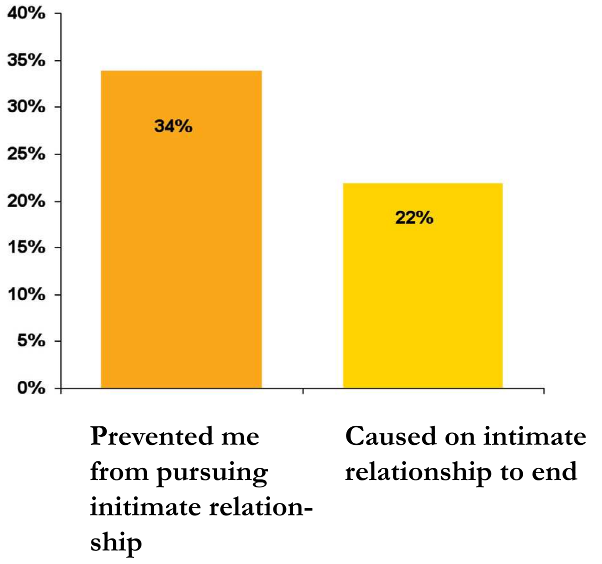
EFCCA would like to thank those who have already participated in the survey and appreciates your commitment to help raise the understanding of IBD across society, and to effect positive change in the care of people with IBD.

The IMPACT project has been supported by an educational grant from Abbott.

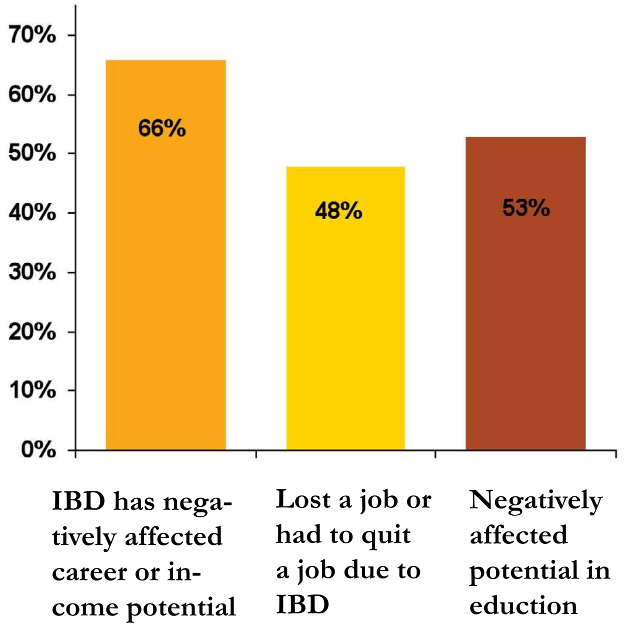
Positive impact on life related to patient association involvement



Impact of IBD on Intimate Relationships



Impact of IBD on Education & Career



The European IBD Library - all the information on IBD you need, in one place

by Ben Wilson, EFCCA treasurer

> **“Knowledge is like water - it must be pumped with energy to make sure it reaches those who need it most.**
>
> **There’s no point leaving it in a reservoir, hoping people will make their own way there with buckets.”**
>
> **Sir Muir Gray**

EFCCA’s 25 national IBD associations are expert at producing high-quality, patient centric information for people with IBD. As the knowledge of people with IBD increases, their fear and anxieties about the disease often decrease, and their empowerment and choice often increase. Those who have access to this high quality information can benefit from it, but often, the existence of this high quality information is not known between the 25 associations, or by individual association members.

EFCCA aims to tackle this problem, by gathering all the best information for patients on IBD from across Europe, and providing one central website resource where this information can be found. The website will include all the details of the information, together with a link to the information in its original location (EFCCA will not copy the information itself but will provide a link to association sources).

EFCCA will establish an ‘editorial steering group’, who will make sure that the information included in the library is of a high-quality, up-to-date, trustable, available for free, and available online. These are the basic criteria for including entries in the library - quality and availability.

EFCCA will host the library at www.efcca.org. It will be available free of charge and information will be presented in a stylish and easy-to-use web portal.

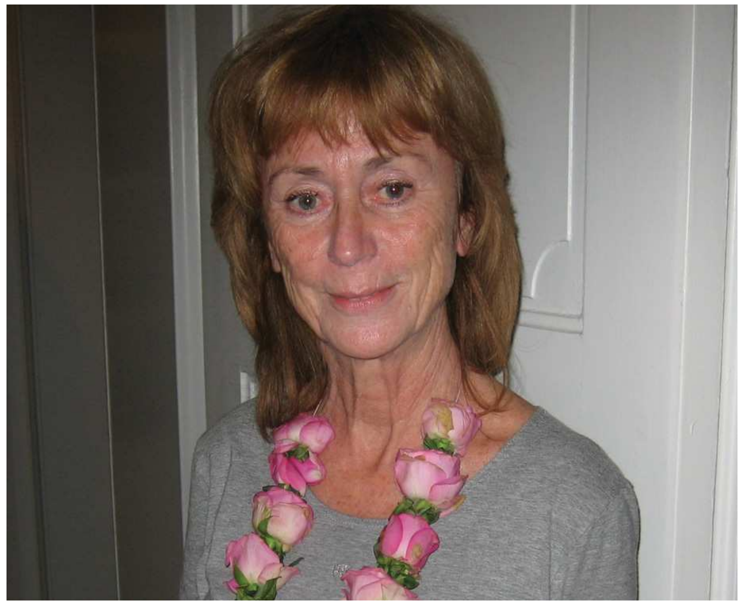
Furthermore, in phase two of the project, EFCCA will include key information for healthcare professionals, from what is known as the ‘top of the clinical knowledge hierarchy’ - key clinical guidelines and systematic reviews related to IBD.

The aim of this is to provide more detailed information for ‘expert patients’, highly skilled information professionals working for IBD associations, IBD association directors and staff, and even healthcare professionals themselves.

The same criteria for quality and availability of information apply. Not everyone with IBD has the same information need - newly diagnosed patients would often like simple, clear, and definitive summaries, whilst people who have lived with IBD for many years might be interested in detailed summaries of new treatments, or clinical guidelines or standards. EFCCA aims to cater for this variety.

To summarize, EFCCA realizes the power of the internet in making information accessible. EFCCA wishes to make the best patient information on IBD in Europe, which is from its associations, highly visible so that people with IBD can benefit from it. EFCCA understands requirements for quality and availability of information.

Join us to define EU policy development!



Within the framework of EFCCA’s new working approach a new project has been created under the call to action “IGNIS”[1] . IGNIS is one of the six priorities areas for development identified by EFCCA.

IGNIS will make EU lobbying a new priority and strengthen EFCCA’s connections with MEPs (Members of the European Parliament), EU institutions, EPF (European Patients’ Forum), EDF (European Disability Forum) and EMEA (European Medicines Agency). EFCCA hopes that Calls to Action make it easier for national IBD associations to become more involved in shaping EFCCA’s work and help access skills and expertise through EFCCA’s large network of volunteers.

The first IGNIS project team meeting took place in Dublin on 27 February 2011. The objective over the coming months will be to develop policy papers on a wide range of subjects such as for example IBD and access to the healthcare, equal opportunities in education and work, good conditions when travelling, etc. taking into account the “Top Five Issues” put forward previously by EFCCA members (see box below).

Policy papers are aimed at raising awareness, people understanding and communicating to European Institutions on IBD issues, needs and priorities. Since these policy papers should be prepared following a wide consultation with national member associations, taking into account cultural, environmental and social differences, we are eager to involve people from many countries.

You are all invited to become involved in this important project. We are aware that most of you are working on limited resources but we hope that you can still contribute – even if only on a small scale - to better shape European position papers. If you are a member of an EFCCA member association and are interested in contributing please contact your own association or the project coordinator.

Solveig Johansson Grip,
IGNIS project coordinator,
solgrip@telia.com

Top Five Issues:

Accessibility-Equal opportunities

Employment policies

Equal treatment in insurances

Communication campaign

Strengthen the involvement in the ”decision making process”

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[1] Latin for “fire”

Raising awareness on IBD in France

Interview with Cédric Diat, Development Officer for the French Association "François Aupetit" and EFCCA contact person

The Association "François Aupetit" (AFA) is the French member of EFCCA, promoting research on IBD (inflammatory bowel disease) and providing support to IBD patients and their families.

What are the services you provide for your members?

When Afa was created nearly 20 years ago there was hardly any research being carried out in the field of IBD and the main purpose of the association then was to support research into IBD. Since then our association has grown widely and we have developed many other services for patients of IBD.

Research still remains one of our priorities. Last year, we gave over 830, 000 € for research (which included an exceptional grant of 500,000 € for two projects dealing with ulcerative colitis' physiopathology). So this is a major area of activity for our association. Apart from that, we also provide information services through leaflets, round tables, conferences etc. trying to reach IBD patients throughout France. We organise supporting activities for patients and their families and we have set up a special assistance fund for members in financial difficulties.

> **"Unfortunately there are still plenty of people around who do not know that they have the disease. It's a permanent challenge to reach them and free them from their loneliness.**

Afa offers many services for youngsters and their parents. We organise each year a summer camp to provide youngsters with information and support they are looking for and to offer a safe environment for holidays at the same time. Each day, a health care professional or a social worker develops an activity to raise youngsters' understanding of their disease. This year it will take place in Mende (South of France) during the first week of August. We also organise a meeting for parents each year and host a yearly week-end for young adults consisting of round table discussions and activities linked to their life with IBD (finding a job or studying with IBD, moving with IBD, how to handle a relationship with IBD etc).

We also offer a special social service to our members: once a week a social worker is available in our office to answers telephone calls or emails from our members helping them with any concerns or worries they might have. We have extended this service with a nutritionist who also works once a week to answers questions concerning dietary issues. And of course members can arrange a direct meeting with the social worker or nutritionist at the "house of IBD" where our offices are located. I believe this kind of permanent service is unique amongst our European colleagues.

What are you priorities for 2011?

For 2011 our priority is to continue with the IBD communication campaign which we started last year and which aims to raise awareness about IBD to the public at large. This is something that our members strongly expect from us, as people with IBD are still too unknown in our country. So far we have had some positive results and we will continue with this work by, for example, publicising information about IBD in public transport and major national newspapers.

Poster used by Afa for its awareness raising campaign

We also want to strengthen services that we offer to our members. Finally, we are organising a "tour de France" with a movie called "Un Mont Blanc pour y croire". We will broadcast the movie in 20 cities thanks to our strong volunteers network and we hope to raise awareness (and funds!) on/for people with IBD.

What are the main challenges that you are facing in your work?

A major challenge for us is to find a good way of building up strong alliances between physicians, nurses and the patients. We need to get the message to healthcare professionals that it's essential to cooperate with patients. Nowadays, for most practitioners it's unusual to work with patients' associations because they think they already have all the solutions for the patient.

Another challenging task is to implement new ideas of how to better support people suffering from IBD. For example we would like to offer an insurance scheme close to the model used by the German patients' association (DCCV). What it would mean in practise is that insurance holders would be able to get help from our association in case they get dismissed from their job or if they need to deal with legal issues.

And of course a constant challenge is to support patients everywhere in France. Unfortunately there are still plenty of people around who do not know that they have the disease. It's a permanent challenge to reach them and free them from their loneliness.

Are you currently working on any new projects?

We are leading a therapeutic education program. Its aim is to offer patients the opportunity to talk to someone who also suffers IBD. This "expert in experience" has been specially trained for animating a specific educational program for IBD patients called EDU-MICI. Ten of our volunteers are currently following a university degree in order to work in collaboration with nurses and gastroenterologists. Once graduated, they become members of the medical staff and lead therapeutic education consultations with a nurse. During these consultations they will deal with all topics that are concerns for the patients. For some of them, it can be side effects of treatments or surgery fear. For others it can be how to handle their job or their sexual life with the disease.

This program already takes place in hospitals in Nice and Lille as well as in our IBD House.

For more information please visit our website:
www.afa.asso.fr

What are the advantages for working at the European level?

We think there are many advantages for working at the European level. First of all it gives us the opportunity to exchange information and to learn from each other. When we receive information about what other European colleagues are doing we very often get good ideas for our own work, so this exchange helps us to better support our own members and not to re-invent the wheel all the time.

What we think could be more effectively done at the European level is to lobby European Institutions such as the European Parliament and the European Commission in order to raise awareness amongst EU officials about the issues surrounding IBD. This would help us at the national level in particular as concerns access to EU public funding for research projects or other activities related to IBD. We think it's important for EFCCA to bring this message to the European level.

Cédric Diat, Development Officer, Afa

Croatia

Celebrating 10 years of HUCUK

Delegates of the patient-doctor symposium

HUCUK, the Croatian Crohn's and Ulcerative Colitis Association, is based entirely on volunteer work and was founded by IBD patients just over 10 years ago. The main objectives of HUCUK are to inform and support people with IBD and to lobby public institutions with the aim to improve IBD patients' status in society.

The number of people with IBD in Croatia has increased significantly over recent years and with it maintenance of the disease has improved and new therapies have been introduced. However the problems which people with IBD face in everyday life such as at school, work and family life have remained the same.

To this end, HUCUK organises patient-doctor seminars and publishes information brochures on different areas of IBD. It also has set up an IBD help line and organises group meetings, and fieldtrips. We collaborate with similar organizations from other countries and work with public institutions, the pharmaceutical industry and the media in raising public awareness. Last year we celebrated our 10th anniversary where we organised a patient-doctor symposium in collaboration with the Croatian Referral Centre for IBD, Zagreb Hospital – Clinical Hospital Centre Rebro.

Iva Savanovic, HUCUK and EFCCA Executive Board member
http://www.hucuk.hr/

Belgium

RCUH: Marking Belgian IBD Day

On 22 October 2010, the new Belgian IBD-Day, three Belgian patients' associations ("Darmereld", "CCV" and "Association Crohn-RCUH") erected a toilet-paper-roll wall (total weight: one ton!) at Brussels Central Station in order to combat taboos relating to IBD' and to improve information to the general public and employers.

The initiative was intended to attract the attention of thousands of travellers on Belgium's new IBD day. We also distributed around 5000 flyers to employers in order to be displayed in the toilets of their workplaces. Thanks to these events, we got a lot of media coverage on IBD about the daily problems faced by IBD patients. You can watch the initiative on youtube at:

http://www.youtube.com/watch?v=RxfTVJN2zh4

I would like to congratulate all my colleagues for their work in organising this event.

Xavier, Association Crohn-RCUH,
http://www.mici.be/

CCV: New EFCCA delegates announced

The Belgian-Flemish Crohn- en Colitis ucerosa Vereniging vzw (CCV vzw) would like to introduce two new EFCCA delegates.

Betty Vandevelde has been a member since the beginning and worked for many years as a medical secretary in one of the largest hospitals in Belgium. Within the own national association and the provincial department Vlaams-Brabant she continues her work as secretary.

Frieda Wieme is our new Public Relations manager. She is perfectly bilingual (Dutch-French) which is a great advantage in Belgium. She has worked in a public institution for pensions and has always been socially committed.

Both have had Crohn's disease since the late 70's and therefore are best placed to represent our association. They are also both very motivated and enthusiastic workers who will certainly give value to our presence in EFCCA. Internationally they already participated in projects of IMID and C2Connect.

We are most grateful to Marleen Reynders and Tom Luycks who represented us during a long time but due to their illness are for the moment no longer able to participate in the EFCCA meetings.

Poland

"J-elita" to join EFCCA

"J-elita" was launched in 2005 and gathers about 600 members with several branches across Poland. Our main goal is to help people with IBD by organising meetings with doctors, psychologists, nutritionists etc. but also between our members. For instance every summer we organize a two-week summer camp for children and their parents and a separate summer camp for teenagers/adults. Shorter, occasional meetings take place throughout the year.

Another very important aspect of our activities is to raise awareness of IBD. We accomplish this through our website and various publications such as a three-monthly magazine, guidelines for patients (nutrition and IBD, pregnancy with IBD etc.), general IBD information and healthcare issues, children's comic book and by means of mass media. An important means of communication - not only between our members but also between other people suffering from IBD - is our online discussion forum with 4500 registered users and about 7500 topics. With the aim of mobilizing our members we organize many contests such as literary/art contests for children or competitions for the best BA/MA/PhD thesis about IBD. Finally, we are also in regular contact with the Polish Public Healthcare System.

We are keen to further develop our association and this year in Copenhagen, during the EFCCA General Assembly, we will officially join EFCCA in the hope of a mutual, fruitful cooperation. Furthermore, we are proud to invite the representatives of EFCCA to the 14th EFCCA Youth Meeting, which will take place in Cracow from 30.06.11 to 03.07.11.

Magdalena Staniewska, J-elita Board Member, http://j-elita.org.pl/

'Celebrity ambassadors and supporters 'Step Up' to be counted'

United Kingdom

Step Up and Be Counted

In March 2010, at the home of the Chancellor of the Exchequer in Downing Street, London, we launched a campaign calling for a national UK register for all IBD patients, called: 'Step Up and Be Counted'.

Supported by our celebrity ambassadors, Carrie and David Grant, Jeff Hordley and Rick Parfitt Jnr – together with speeches from a range of our supporters including the former Deputy Prime Minister John Prescott and his daughter in law Roz, we launched a special interactive website to collect signatures and comments from those wishing to support our call to 'step up and be counted'.

By the end October 2010 an amazing 7,412 people registered their support - indicating the interest in the call for a National UK IBD Register.

Over 1,250 people asked about membership of our charity as a result of visiting the special site, and many went on to browse our website to get information about the conditions themselves, and about our events during the year – all of this activity has raised awareness of the work we do, and our need for more people to join and add their voices to ours, to add to our lobbying strength.

The responses on the website are being compiled into a report which will be used to support the progress towards a national register. The first steps towards this register have already been taken. The IBD Registry Board has been formed with representation from the relevant professional and patient organizations and our Chief Executive Richard Driscoll is Vice-Chairman of the Board.

But perhaps the last word should come from just a few of those thousands of people who shared their thoughts on the Step Up site

> *"IBD needs support and exposure. Why should those of us that have IBD be the poor relatives of the health world?"*
>
> *"Very helpful information pack and regular updates from your charity help living with IBD more bearable."*
>
> *"Very close to my heart as I have had Crohn's disease for 16 years, it nearly killed me at University but I fought back and now I have 2 gorgeous children - Wishing everyone with IBD all the best!"*

Germany

New projects for advice and patient information

The most important task for DCCV (Deutsche Morbus Crohn / Colitis ulcerosa Vereinigung) is to help the more than 320,000 people with IBD in Germany to cope with their illness. The advisory services of the DCCV play an important role in this task.

Alongside advice offered by telephone, email and at information events, DCCV has established in 2009 an on-line anonymous advisory service targeted at children and young people with IBD (with the financial support of a TV station: http://www.dccv.de/nicht-allein-mit-ced/kids-teens/kids-teens/).
This service allows users to chat with a qualified psychologist in a protected, closed, virtual area as well as to send questions by email. So far discussions have focused on problems such as accepting the disease and dealing with it. Main topics include: school problems connected to the disease (fear of being different and standing out; exams have to be re-taken because of illness); the feeling of not being taken seriously and not being understood (teachers complain about the frequent absence due to illness) as well as problems with parents. The aim of the on-line service is to help young people with IBD not to restrict their lives due to their illness, and feedback shows that young people feel relieved and happy to be able to talk to someone else about their disease.

We have also recently started a research project, led by a psychologist, on patient education funded by the German Ministry for Education and Research. The aim is to develop, implement and evaluate both out- and in-patient education for those affected by IBD. We will be collaborating with the University of Würzburg, a rehabilitation clinic and medical experts. The educational programme will include six training modules by a gastroenterologist on information regarding medical topics such as the structure of the gastro-intestinal tract and symptoms, diagnostics and treatment of Crohn's disease and ulcerative colitis. A further three modules will be provided by a psychologist discussing aspects such as accepting the illness, self-help and dealing with stressful feelings and situations. Project duration is initially for 3 years and hopefully we will be able to give you further information following the evaluation stage.

Tobias Hillmer, DCCV,
http://www.dccv.de/

Malta

New website launched

This past year has been a very busy one for the Malta Association of Crohn's disease and Ulcerative Colitis (MACC). Following its affiliation in EFCCA in April, MACC embarked on a campaign aimed at raising public awareness about IBD. During the week ending on the 19th May 2010, a poster exhibition was set up by MACC and inaugurated by the Minister for Health at the foyer of Mater Dei General Hospital. This activity was very well received by visitors to the hospital who had the opportunity of learning about IBD and its occurrence, as well as about MACC and EFCCA.

Apart from this activity, MACC also held 2 lectures for its members and the public. A member of the committee and a member of the scientific committee also participated in a phone-in radio programme about IBD.

MACC is also proud to announce that its web site is now on line at http://www.macc.org.mt/. As a result of the signing of an "End user licence agreement" with EFCCA, MACC has included the content of Life and IBD in its website, thereby making extremely useful information available on-line for our members and the public. Our next aim is to address a few accessibility issues relating to the web site and also to eventually translate the content into Maltese in order to ensure that the information is available to our Maltese speaking members.

The web site was set up and produced voluntarily by one of MACC's committee members who dedicated endless hours of work to the task of compiling all the available information. MACC is open to all suggestions related to the web site and greatly appreciates any relative feed back from other associations. In the near future, MACC intends to organise more informative seminars on IBD issues for its members and the Maltese public.

Mary Grech Pace , Chairperson MACC,
http://www.macc.org.mt/

Slovakia

New publication for children

Crohn Club, in cooperation with Doctor Cierna from the children's hospital in Kramare, has recently published a booklet for children entitled "Crohn's Disease, Ulcerative Colitis and Children". The booklet provides basic information about IBD and useful advice and guidelines for teachers and parents. The main part of the publication covers personal stories from children with IBD as well as information about our Crohn Club's activities.

Crohn's Disease, Ulcerative Colitis and Children

We have also successfully lobbied the Slovakian Ministry of Health to provide medical services for IBD patients in the towns of Martin and Trencin and to heavily reduce costs for certain medications (Anti-TNF pen device and 5 ASA sachet).

Ivana Charvatova, Crohn's Club
http://www.crohnclub.sk/

Switzerland

Donating to IBD Research

This year, on 2 April 2011, the Swiss Crohn’s and Colitis Association (SMCCV) celebrates its 25th birthday and on this occasion will donate CHF 25.000 to the IBD Research Foundation.

What is the greatest wish of a sick person?

Above all, a sick person wishes to heal and to be able to live a normal life again, without the challenges of the sickness. Unfortunately, this is not possible – yet. There are drugs that can help us lead a more “normal” life and ease the pain. The causes of autoimmune diseases such as Crohn’s disease or ulcerative colitis are unknown. Thus, there is no ideal treatment strategy or real cure.

In Switzerland there are numerous people suffering from one of the over 60 known autoimmune diseases. There is a need for urgent action, in order to better understand the immune systems’ processes. The study of the causes of Crohn’s disease and ulcerative colitis can be an important contribution to this aim. Whatever helps patients with inflammatory bowel diseases is often also beneficial for patients with other autoimmune diseases.

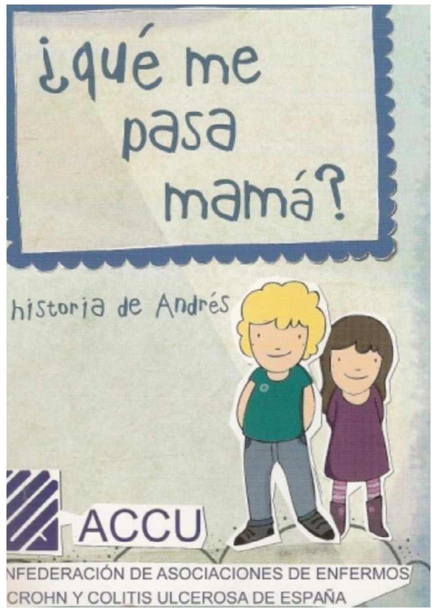
For this very reason the SMCCV has decided to donate CHF 25.000 to the IBD Research Foundation. Thus the money goes to a foundation run by patients for patients: the European IBD Research Foundation (www.ibdresearch.org). Each year, the foundation awards three grants to promising research projects. In 2010 there was even a project from Switzerland.

The SMCCV

The SMCCV was founded on 5 April 1986 as a non-profit association by 20 affected patients. The association takes a neutral stance with respect to politics and religion and is a member of EFCCA, the European Federation with 25 national Crohn’s and ulcerative colitis associations. The SMCCV endeavours to make the two diseases known by increasing their public information efforts. It encourages a better understanding and tolerance of the people affected and is convinced that these measures can draw them out of their isolation.

Spain

Sincrohnízate”



Publication from awareness raising project aimed at school children

ACCU (Confederación de Asociaciones de Crohn y Colitis Ulcerosa de España) has carried out a nation wide survey amongst its members studying the emotional affects of Crohn’s disease. The results were fed into the “Sincrohnízate” awareness raising campaign including a patients’ manifesto, which highlights the needs and problems of Crohn’s patients and which was forwarded to the Ministry of Health.

For this work ACCU together with GETECCU (the Crohn’s and Ulcerative Colitis Working Group) received an award for best initiative on patient service organised by the Farmaindustria Foundation. w

In another study amongst 857 ACCU members on medical treatment for IBD it emerged that patients mainly use immune suppressants. A significant increase in the use of biological treatments was also noted and 85% of patients stated that the final decision for taking a certain medication depended solely on the doctor.

Finally, we have also started a project aimed at awareness raising amongst school children, parents and teachers allowing children to grow up in a supportive environment. Within this project we have published a fairy tale called “What’s happening mum? – stories from Andrés.”

Yolanda Modino, ACCU Spain,
http://www.accuesp.com

Slovenia

Summer camp

KVCB organized a summer camp for young people with IBD near a beautiful place in Osilnica next to the Kolpa river. The first day was dedicated to getting to know each other and talking about personal experiences of living with IBD. On the second day we organized a workshop on stress and how to deal with it, run by a professional psychologist. The following 3 days were filled with sports activities such as rafting, paint balling and “zorbing”. Zorbing consists of entering into a huge rubber ball and rolling downhill in it. You can imagine that the camp was a huge success and even the bad weather – there was rain and floods across the whole country – did not spoil our spirits. We returned home full of adrenaline, a bag full of wet clothes and mission and plans for organizing a new camp.

Youngsters of the summer camp enjoying a rafting expedition on Kolpa river, Slovenia

Best Public Toilet competition

We also organised the “Best Public Toilet competitions” project coinciding with World Toilet Day on 19 November 2010. Our competition is meant to increase public awareness in Slovenia of the importance of public toilets as well as tell our members (and non-members) where in the selected towns and cities they can count on public toilets to be available. Last year’s competition included estimating public toilets across 10 municipalities that we had examined in 2009 as well as 15 randomly selected additional municipalities. The project was completed in November, when we invited representatives of all municipalities to the closing ceremony in Maribor. The municipalities that failed to comply with the criteria of orderly and well accessible public toilets were awarded a toilet brush. The toilet brush is a symbol of the efforts that the municipality still has to invest in order to eliminate the obstacles facing its people with IBD. To symbolically encourage the municipalities that currently have no public restrooms yet, we awarded those a brick.

Dusan Braga, KVCB,
www.kvcb.si

The Netherlands

Crohn's at work

Having a chronic illness doesn't automatically mean you are chronically absent from work. This is the motto of the project Crohn op je werk (Crohn at work) that was held for the second time in 2010, after a very successful start in 2009.

Crohn op je werk is an initiative of the CCUVN, Abbott and the Care Group. Crohn op je werk was introduced to show people that despite having Crohn's disease or colitis, you can still have a job and enjoy working. It isn't all doom and gloom.

Winnaar
Crohn op je werk verhalenwedstrijd
Selma Boerrigter

"Op onderdelen heb ik hem wel zijn zin gegeven. In elke relatie moet je concessies doen, ook in die met je Crohn. Ik geef hem nog steeds dagelijks zijn dosis lekkers."

In je mand!

Een tijdlang volgde ik de Crohn. Ik kon niet anders dan doen wat hij verlangde. Dan kon ik het huis niet uit, omdat de Crohn wilde thuisblijven. Wilde ik naar school, liet hij me mijn bed niet uitkomen. Als ik boodschappen wilde doen, moest ik eerst wachten tot die Crohn eens wat rustiger werd. Maar ach, waar heb je boodschappen voor nodig, als je Crohn je je maaltijd niet gunt? Het was als een onhandelbare hond die voortdurend aan zijn riem trok, ging blaffen als je weg ging en beet zodra je thuis was.

Nu volgt de Crohn mij. Ik heb hem getemd, met een flinke dosis pillen en overheerlijk astronautenvoedsel (jum!) als beloning voor goed gedrag. Nu wandelt hij braaf achter mij aan en volgt me waar ik maar wil gaan. Soms heeft ie een ochtendhumeur, maar dat tolereer ik dan maar. Ik weet dat dat meestal over is tegen het middaguur. Meestal ligt ie gewoon in zijn mand te snurken.

Op onderdelen heb ik hem wel zijn zin gegeven. In elke relatie moet je concessies doen, ook in die met je Crohn. Ik geef hem nog steeds dagelijks zijn dosis lekkers. De paardenmiddelen zijn vervangen door andere medicijnen, maar dat lijkt hem niet zo te deren. In plaats van astronautenvoedsel krijgt ie tegenwoordig ook wel eer chocola of pizza. De laatste tijd vindt ie bijna alles wel best. Af en toe krijgt ie een aai over de buik, dat vindt ie lekker. En zo vaak ga ik niet meer weg van huis. Ik wee eigenlijk niet of mijn Crohn het zo gewild heeft of ikzelf, maar feit bli dat ik, sinds ik van de universiteit ben, altijd vanuit huis heb gewerk Dat vindt hij wel fijn, kan ie gewo thuis in zijn mand blijven liggen. I vind het zelf ook lekker makkelijk: werken wanneer je wilt, uitslapen als je daar zin in hebt en je staat nooit in de file. En als de Crohn mijn aandacht wil, kan ik hem dat makkelijk geven. Ik hoef ook geer dag vrij te nemen als ik met hem naar het ziekenhuis moet, dat pla ik gewoon in. Had ik eerst nog een dienstverband, sinds januari ben ik ZZP'er: zelfstandige zonde personeel. Dat geeft me de vrijhei om te doen en laten wat ik wil. Ik zit alleen nog aan die Crohn vast. Woef!

Sorry…

Mijn verhaal gaat over de tijd dat ik nog niet wist dat ik de ziekte van Crohn had. Toen ik een paar maanden na de geboorte van mijn dochter elke keer van die rare stekende pijn had, en daarbij zo misselijk werd dat alles er weer uit moest, is er niet aan de ziekte van Crohn gedacht.

Ondertussen werkte ik bij een evenementenhal. Daar was ik de vliegende keep. Achter de balie, vlooienmarkten organiseren, geldverkeer tijdens evenementen regelen et cetera… Juist op dat soort momenten frustreerde het me mateloos als ik weer van die vreselijke krampen had of zo misselijk was. Zo is het meerdere keren voorgekomen dat terwijl ik de klanten aan de receptie te woord stond, ik 'sorry' mompelde en naar het toilet rende om over te geven, snel een beetje water in mijn gezicht plensde, een kauwgompje in mijn mond deed, en weer terug rende. Of je hebt zo"n kramp dat je echt MOET! En tja, 'sorry, mensen ik ben zo terug!' riep. Op zich verwonderlijk dat de klanten zoveel geduld en respect voor je hebben. Toch ervaar je het zelf niet altijd als prettig hoor.

Voor je gevoel houdt iedereen bij hoelang je op het toilet zit. En op dagen dat je niet zo lekker in je vel zit, kan dit best vervelend zijn. Na drie jaren van pijn en misselijkheid werd toch de knoop doorgehakt. Ze wilden opereren om te kijken wat er aan de hand was. Ze dachten aan een verstopping. Toen ik bijkwam van de narcose stond de chirurg naast me, en het eerste wat hij tegen mij zei was: Sorry! Sorry, omdat ze niet eerder wilden opereren… mijn darmen waren zo slecht dat ze een stuk hebben verwijderd. Een deel daarvan ging op de kweek, en eindelijk, na drie jaar onzekerheid, kwam de uitslag! Ik heb ook de ziekte van Crohn! Al drie jaar gaat het met behulp van medicatie eigenlijk heel erg goed. De evenementenhal waar ik destijds werkte, werd verkocht, dat betekende solliciteren. Met mijn positieve instelling, ben ik in de tijd van de recessie, tijdens het eerste sollicitatiegesprek aangenomen. Nu werk ik als trainee Teamleider Secretariaat, en ben tevens meewerkend op het planbureau van Dimence, een GGZ-instelling. En heb ik een keer een mindere dag, en moet ik op het werk wel eens wat vaker naar het toilet, dan zeg ik: 'Sorry!'

Simone Horstman-Hietbrink

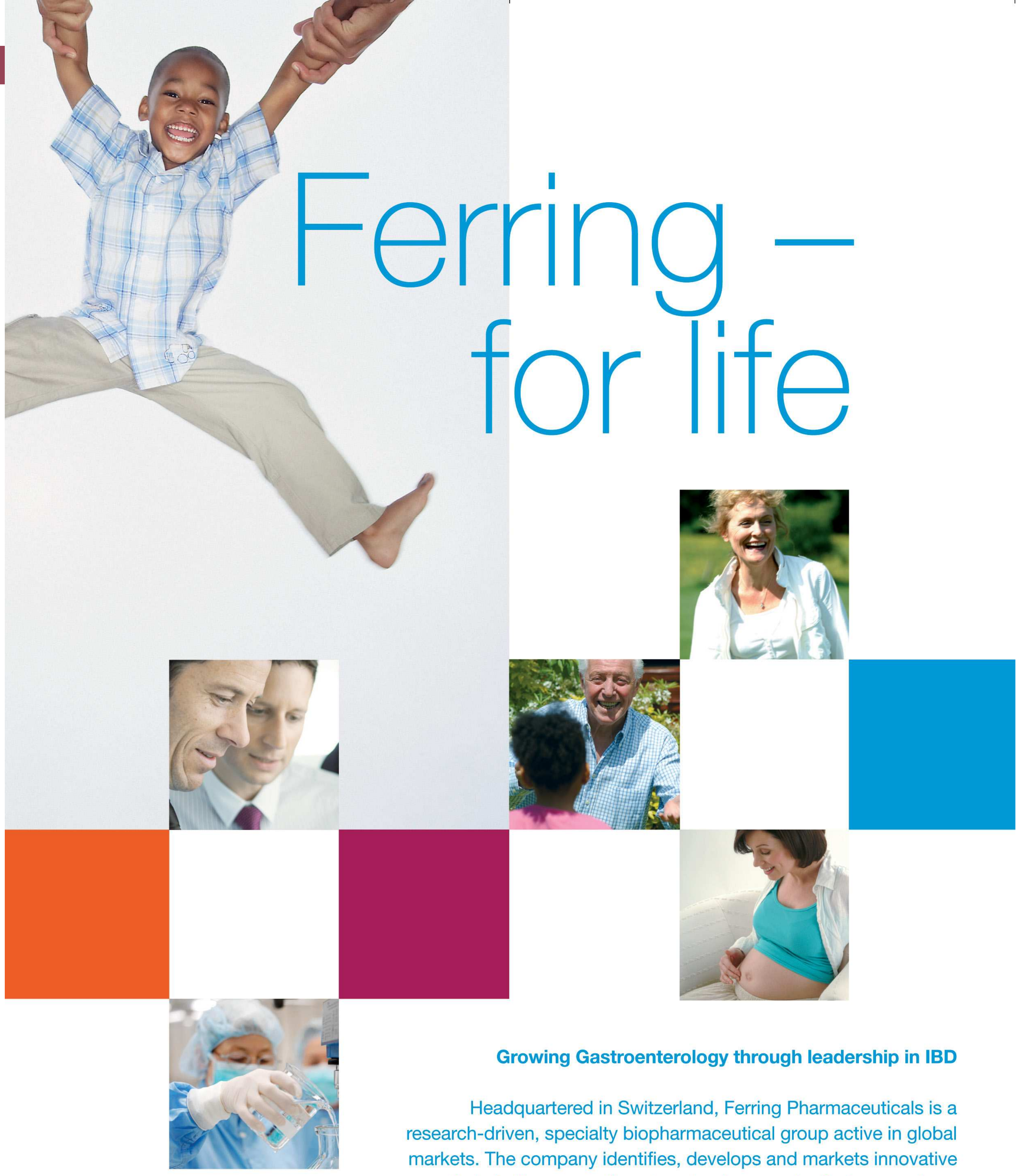
"Met mijn positieve instelling, ben ik in de tijd van de recessie, tijdens het eerste sollicitatiegesprek aangenomen."

Patients were invited to share their experience by writing an article. The best stories appeared on the website of Crohn op je werk and in a special magazine. The winner received a cash prize.

In 2010 employees were also able to nominate the best boss. A manager of Eneco Energy won the prize as she had made it possible for her employee with Crohn's disease to have flexible working hours and days and to work at home. She now sees it as her task to be an ambassador and share her experience with other managers. According to her " it is all about open communication, a working relation based on trust and looking at possibilities instead of obstacles."

Also this year, a debate was organised in Nieuwspoort, at the heart of the Dutch government centre. Undersecretary for Work, Paul de Krom was present, and also delegates from political parties, trade unions, patient organisations, employers, and other organisations involved in finding work for people with a chronic illness. At the end of the afternoon, which was attended by nearly 100 people, an inspiration document was presented to the undersecretary, who promised to keep the dialogue open and to advocate the cause of people with a chronic illness to employers.

T. Markus, CCUVN
http://www.crohn-colitis.nl



Promoting Patients' Rights at European level

Interview with Nicola Bedlington, Director of the European Patients' Forum

What were the initial reasons for setting up a Patients' Forum at European level?

When EPF was set up in 2003 by 13 European disease specific organisations, it was felt - through various discussions with the European Commission - that a united voice could be of extreme value on issues that were cross cutting and affected all patient organisations. At that time this was particularly linked to pharmaceutical policy but even then, it was recognised that many other health policies would benefit from a strong united patients' voice.

In a sense, EPF was created as an official and credible interlocutor for the European Commission and other EU institutions on patient issues that affect all groups. The added value of EPF is also to enable disease specific groups to focus on their own disease areas, knowing the general issues are being dealt with appropriately. Our organisation has developed greatly over the years and nowadays we represent almost 50 member organisations that are European specific disease organisations as well as national coalitions of patients' organisations.

What are the main areas you are working on?

Our work plan is quite ambitious and our approach is that we need to intervene on every single EU policy area that will have an impact on patients but obviously the degree to which we do that depends on various factors. I would say our work can be divided into three core areas:

1) Influencing EU/Health policy from the patients' perspective;

2) Being involved and/or designing projects that help us to feed in more effectively to the policy environment by providing very substantial evidence;

3) Providing capacity building to our members so that they can get the most out of EPF and at the same time ensure that we, as EPF secretariat/governance structure enable member organisations to properly transmit their unique experience and expertise thus reflecting a genuine patients agenda.

In terms of priorities, in 2011 EPF will continue to play a pro-active role in promoting a patient-centred philosophy and agenda and continue our work on legislative and non-legislative proposals on Patients' Rights in Cross-Border Healthcare, Patient Safety and Quality of Care, Health Literacy, eHealth, the Pharmaceutical Package (Anti-Counterfeiting, Pharmacovigilance and Information to Patients), Clinical Trials, Medical Devices, Health Technology Assessment, as well as Health Inequalities.

We will extend our activity to new policy strands, notably the challenges of older patients and access to healthcare for other vulnerable groups such as migrants, including undocumented, ethnic minorities, refugees and asylum seekers in order to provide equal rights to patients and provide protection against discrimination due to their health status.

Our policy work on Health Technology Assessment (HTA) will continue through involvement in EUnetHTA launched in 2009 and a new Joint Action to be launched in 2011, the wide dissemination of EPF's resources on Health Technology Assessment, and the series of surveys on patient/patient organisations' involvement in HTA.

It is also important for us to ensure that various legislative instruments that have been adopted at EU level are now carefully and strategically followed up with our members at national level such as for example legislation around Cross Border Health Care.

> **"Our work plan is quite ambitious and our approach is that we need to intervene on every single EU policy area that will have an impact on patients but obviously the degree to which we do that depends on various factors."**

In terms of events, at the beginning of July and coinciding with the Polish EU presidency, we will be organising a conference in Poland on the needs and rights of older patients that will directly link to the European Innovation Partnership on Active and Healthy Ageing. This is a very important initiative and we want to make sure that we inject a strong patients' perspective there.

EPF at the Pharmaceutical Forum

Finally, the other big area we are focusing on this year - and that's where we would like to exchange ideas with EFCCA - is involving young patients in EPF more effectively. We have already developed a youth strategy and would like to embark on that more seriously during our next AGM.

What do you see as a major challenge to your work?

In a broader policy environment we feel there isn't enough collaboration yet between different sectors. We would like to encourage more co-operation between for instance the pharmaceutical sector, the medical device sector or the IT sector and between different stakeholders who advance patient – centred chronic disease management.

Concerning the way governments are organised there needs to be much more collaboration between the health sector and the social sector, particularly as we are moving more and more towards an ageing population with chronic diseases that will have other needs than purely healthcare.

In terms of our future, I feel that EPF has seen many positive changes in the last few years and we have achieved a strong voice in the Brussels arena. The challenge now is to make sure that this also resonates at the national level and that we do everything we can to assist our member organisations and their leaders to take things forward at national level. For this purpose EPF intends to launch a major capacity building programme in 2012, which will build on the outcomes of the Value+ project. For more information see our website: http://www.eu-patient.eu

Are there any events or initiatives that might be of interest to EFCCA members and how could we improve cooperation between EFCCA and EPF?

We will be organising a regional advocacy seminar in Romania in autumn this year, which might be interesting for some of your members from that region. The focus of the seminar will be twofold: a general advocacy exchange that we organise in terms of how Brussels works etc. and a specific exchange on the relationship between patients' organisations and health professional organisations and how that dialogue can be strengthened for the benefit of both.

Regarding more general collaboration, EFCCA is already an active member of EPF and you make sure that your specific disease issues' challenges are integrated into the broader EPF agenda. This helps us to substantiate our policy input with very strong and concrete examples.

There are other ways you could collaborate more actively such as becoming a direct member of our Policy Advisory Group and be involved in our policy development on a regular basis.

Finally, I think it is important to ensure that your own members know the added value of being part of an umbrella body like EPF and the solidarity and impact that it can actually bring about.

European disability movement calls for EU action

Following a recent meeting of leaders of the European disability movement to debate the main issues that European Union institutions will be dealing with in the upcoming months, the European Disability Forum (EDF) issued a press release calling on the European Commission to ensure that the future proposal of a European Accessibility Act can become an effective legislative tool to improve the lives of 80 million persons with disabilities in Europe.

Basic freedoms are enshrined by the European Union Treaties: free movement of persons, goods and services. The EDF Top Campaign for 2011 aims to remove the barriers to active citizenship, to tackle the barriers to the free movement of goods and services, and facilitate the movement of persons with disabilities.

"We need to send a clear message to the EU institutions and the governments of Member States that we will not compromise on the accessibility of persons with disabilities in all aspects of society despite the burden of the financial crisis." Stated EDF President Yannis Vardakastanis.

As a result of the debate on the economic and financial crisis, we want to make sure that it will not put persons with disabilities in situations which put them at risk of social exclusion, poverty and unemployment.

Further to the conclusion by the EU of the UN Convention on the Rights of Persons with Disabilities, the EDF board has adopted a proposal for a coordinating mechanism based on the creation of a European Disability Committee. EDF calls on the European Commission to take concrete actions based on obligations coming from the UNCRPD in areas such as the creation of an independent body, the reporting on the actions taken to ensure compliance with the UNCRPD and the full participation of organizations of people with disabilities in the implementation and monitoring of it.

The European Disability Forum is the European umbrella organisation representing the interests of 80 million persons with disabilities in Europe. The mission of EDF is to ensure disabled people full access to fundamental and human rights through their active involvement in policy development and implementation in Europe. EDF is a member of the Social Platform and works closely to the European institutions, the Council of Europe and the United Nations.

Supporting innovative research into IBD

IBD Research Foundation

As many will be aware the IBD Research Foundation was established in 2008 as a separate legal entity, resulting from an initiative by the members of EFCCA. In its early years the "European patient powered" IBD Research Foundation has primarily been raising funds for novel Crohn's and Colitis research and has welcomed funds from all sources.

Although the economic recession has had a very substantial impact on early fundraising efforts, fortunately money has come in from several EFCCA national member associations. We are extremely grateful to them for supporting the foundation in this way. We are particularly thankful in these early years to the Irish Society ISCC for their substantial donation of 20,000 Euro which enabled the Foundation to award its first Mini Grants. We are delighted also to inform readers that in the past weeks we have heard that the Swiss association SMC-CV is donating CHF 25,000 (approximately 18,000 Euro) to the IBD Research Foundation on the occasion of its 25th anniversary. These donations secure our plans for financing research for the time being, however further donations are very welcome. In fact they are crucial for the continuity of our research initiatives.

We also want to thank all the eminent European Scientific Reviewers for their valuable assistance in assessing the applications for research grants. Also many thanks to the members of the patient review committee, who made the final decision upon choosing research projects to be awarded a grant. The patient committee consisted of representatives from both the EFCCA and the IBD Research Foundation.

Eight applications from across Europe were received and after formal review 3 Mini Grant awards of 5,000 Euro each were made to assist the following innovative projects:

Marika Armilo and Heli Parjanen of the Finnish patient assocation selling "Caps for the cure"

1. Stefania Vetrano Bsc of Clinico Humanitas, Milan, Italy - The protein C pathway: a novel mediator in intestinal homeostasis in IBD

2.Professor Giulio Muccioli PhD of Universite Catholique de Louvain, Belgium: Exploring the potential of N- palmitoylethanolamine in a mouse model of inflammatory bowel diseases

3. Dr Jessica Mwinyi of Universitats Spital Zurich, Switzerland: Analysis of PPAR-y haplotype structure and its influence on disease susceptibility, pathogenesis and activity of inflammatory bowel disease

For further information about these projects please see: www.ibdresearch.org

In the download section see "Breaking news" and research projects selected for grants

The success of our first call for applications has inspired us. As our foundation represents the patients voice in research, we have begun to think further about how we can represent the patient perspective best, for instance by giving the associations and individuals who donate to the foundation a vote in the choice of research projects.

We are also seeking people to help us for instance by promoting the foundation or by organizing fundraising activities. Of course we also need donations to build up our Research Fund and secure our continuity. Please note that any amount is welcome, as many small donations also add up to substantial funding opportunities.

According to the constitution of the foundation two members of the management board have to stand down in 2011: Rod Mitchell (Chairman) and Wouter Miedema (Secretary). They will be candidates for reappointment. One management board member will remain in the board: Hajnalka Szabo. The supervisory board is responsible for appointing the members of the management board. As the management board can consist of five members, four members can be appointed. Anyone who is interested in a position for the management board should contact the chairman of the supervisory board Marco Greco.

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IBD nurses: an essential part of patients' care

Since 2007, the European Crohn's and Colitis Organisation IBD Nurses (N-ECCO) organizes annual network meetings, gathering nurses from across Europe with an interest in IBD to exchange experience and views together with invited medical doctors. The N-ECCO Network Meeting aims to improve professional nurse education, increase networking opportunities for specialist nurses in IBD and improve IBD patient education throughout Europe.

IBD specialist nurses provide exceptional support to enable informed patient choice and shared decision-making. In the 21st century, patients must be involved in treatment decisions, which affect them, as national and European standards and legislation are beginning to require. The specialist nurse often has greater expertise, understanding, and experience, to ensure that patients can accurately interpret and appraise their options, and arrive at the best and most appropriate decision for them. This control over one's own treatment and condition is often empowering and liberating.

Ils Van de Schoot, study coordinator for clinical trials in IBD

People with IBD universally emphasize the role of the specialist IBD nurse, where present, as an essential part of their care, and that including a specialist nurse in the IBD team is a tangible and pragmatic means of increasing quality of care, and ultimately supporting better patient outcomes or reducing morbidity.

Ultimately, IBD specialist nurses decrease fear and anxiety, increase confidence and choice, and offer both 'treatment' and 'care' - and this is of the most tremendous value to patients.

Despite all this it is often difficult to persuade healthcare commissioners, managers, and government to fund and sustain the essential work of specialist IBD nurses, especially with increasing health service demand and economic pressures. EFCCA is therefore keen to support the activities of N-ECCO. For this purpose it has made available a special travel grant which allowed 20 nurses from a wide range of European countries to attend this year's N-ECCO Network meeting, which took place in Dublin from 24-25 February 2011.

"It was the first time for me to have access to any formal training on IBD and it gave me the opportunity to learn more about the disease itself and about the latest available treatments" says nurse Ils Van de Schoot who has been working for the last three years as study coordinator for clinical trials in IBD at the IMELDA hospital in Bonheiden, Belgium.

"I started my professional career as a midwife which meant that I had to gain all my knowledge related to IBD through practical work experience and home studies. In that sense the N-ECCO meeting in Dublin has been extremely useful to me and allows me to give better and up-to-date information to my patients. It has also been helpful to share experiences with other IBD nurses from across Europe and to learn how they inform and advice patients about their disease.

I think it is important to offer nurses access to specialist courses on IBD, which ultimately will also benefit patients. In Belgium we still don't have such courses but I hope we will soon! "

Participants of the N-ECCO Network meeting, Dublin 24-25 February 2011

Cant' Wait

By Jacqueline Waldorf, Crohn's and Colitis Foundation of Canada's

"I did not apply to medical school."
"I can't work full-time outside the home."
"I stopped work because of the travel."

Those are words from Canadians living with inflammatory bowel disease (IBD) who answered the Crohn's and Colitis Foundation of Canada's (CCFC's) bathroom access survey during the summer of 2010.

The results, based on just under 1,400 IBD sufferers and supporters who completed the survey, indicate that due to the fear of having an accident in public, about three-quarters of people with IBD stay home during a flare-up, don't take vacations and have been embarrassed to ask to use bathroom facilities. Another 44 per cent have had an accident in public due to bathroom inaccessibility.

"I feel quite confident that anyone around the globe living with inflammatory bowel disease would answer these questions the same way," says Dr. Kevin Glasgow, Chief Executive Officer of the Crohn's and Colitis Foundation of Canada.

"We have known for a long time that bathroom access is literally a visceral issue for people living with Crohn's and colitis," he adds. "People living with IBD too often face their conditions in silence, afraid to venture away from home, cutting off the possibility of many great experiences."

To reduce the feeling of isolation experienced by people living with IBD, and to raise awareness about this chronic disease so others will grant access to their bathrooms, CCFC launched an iPhone, Android and web application during Crohn's and Colitis Awareness Month last November to help people find the public bathroom closest to them in a hurry. The Can't Wait mobile application works in two ways: it uses GPS to track the user's location and point to the closest bathroom; and it allows users to add bathrooms. It is available as a free download through iTunes and the Google app store, by searching for Can't Wait.

The web-based version of Can't Wait is online at www.cantwait.ca. It allows users to search for a specific location in Canada and find public bathrooms either en route or close by. Users can also link to both versions through our website www.ccfc.ca. Both the mobile and web applications use Google maps, which means bathrooms can be added anywhere in the world.

Since the app was launched in November, users have added nearly 1,400 bathrooms across Canada. The app has been downloaded nearly 3,000 times so far, and averages 100 new downloads per month. The campaign received significant national and regional media coverage across Canada, making it CCFC's most successful awareness campaign to date – further reducing the sense of isolation felt by those living with IBD.

About CCFC
CCFC was started in 1974 by a group of concerned parents who saw the need to raise funds for research into IBD and to educate patients and their families about these diseases. The mission remains strongly focused on raising money to fund the cure for IBD, but education and awareness is also a critical part of CCFC's mission.

To date, CCFC has invested more than $65 million in major medical research projects and is one of the world's leading sources of non-governmental funding of IBD research.

What's new under the sun?

The latest from the experts' 6th Congress of ECCO, 24-26 February 2011, Dublin

by S. Danese and H. Szabò[1]

The annual congress of the European Crohn's and Colitis Organisation (ECCO) was held at the end of February 2011 in Dublin. Exciting new data were presented in basic science and clinical medicine.

It is well known that in inflammatory bowel disease (IBD) gut bacteria induce an abnormal innate immune response mediated by toll-like receptors (TLRs) and Nod-like receptors (NLRs); and that intestinal fibrosis is caused by excessive extracellular matrix deposition. Riedler and his colleagues investigated the possible connection between these two processes by evaluating the fibrogenetic response by human intestinal myofibroblasts (cells playing a fundamental role in fibrosis) after TLR and NLR activation. The results suggest, for the first time, the existence of a direct link between innate immunity and fibrosis in human IBD. Hopefully the better understanding of the fibrotic process will lead to the development of potential anti-fibrotic treatments.

Several clinical reports have been presented as well. New data were presented regarding the safety and efficacy of adalimumab in paediatric age. Hyams et al. presented a multi-center, randomized, double-blind study to compare the efficacy and safety of two adalimumab dosage regimens for induction and maintenance of clinical remission in pediatric patients with moderate to severe Crohn's disease (CD). The results show that adalimumab is efficacious for inducing and maintaining remission of CD, with a safety profile comparable to that observed in adult patients with CD. Greatest efficacy was observed for patients never treated by biologic drug (infliximab/IFX) receiving high-dose adalimumab, but adalimumab treatment also benefitted IFX-experienced patients.

Several novel drugs have been presented, as well as optimization of treatment with some of the drugs already available in clinical practice.

An interesting idea from Vandepapeliere and colleagues was to stimulate the patients' own immune system for creating anti-TNF α antibodies by vaccination against TNF-α. 21 patients were vaccinated with different dosages of TNF α-Kinoid, an antigen that should induce anti-TNFα antibody production in the organism. Up to 50% of the patients were in clinical remission. The idea is certainly innovative, and showed promising results, but further evaluation is necessary.

There was great expectation for the new monoclonal antibody to block IL17 in Crohn's disease. In a multicenter randomized double blind study, Simon Travis presented the trial, showing lack of efficacy of this new molecule for CD treatment.

Many new studies for ulcerative colitis were presented. In particular, the efficacy of adalimumab in inducing and maintaining remission was presented in a study by Sandborn and colleagues: 494 patients with moderate to severe UC were treated with adalimumab vs. placebo in a randomized, double-blind trial. Patients demonstrating inadequate response could switch to open-label adalimumab therapy at Week 12. Adalimumab was efficacious in inducing and maintaining clinical remission in patients with moderate-to-severe UC who did not adequately respond to conventional therapy with oral corticosteroids/immunosuppresants. The safety profile in UC was consistent with the known safety profile of adalimumab. Hopefully these results will accelerate the approval of ADA offering a further treatment possibility for patients with UC.
In addition, Laharie and colleagues conducted a randomized trial com-

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[1] IRCCS Humanitas – IBD Unit, Rozzano, Italy

paring the efficacy of cyclosporine versus the anti-TNF-α monoclonal antibody, infliximab in i.v. steroid refractory acute severe UC, a condition that is highly associated with colectomy. The authors found that both cyclosporine and infliximab are equivalent in the efficacy and in colectomy rates, suggesting that in this clinical setting either drug could be used.

Another study, UC SUCCESS in moderate and severe UC compared infliximab, azathioprine (AZA) and the combination of both in inducing and maintaining steroid free remission. The study design is similar to the previous SONIC trial in CD. According to the results the combined therapy was superior to AZA monotherapy in inducing steroid-free remission in patients with moderate-severe UC, and all the infliximab arms were superior to azathioprine for inducing response and mucosal healing. This study then suggests once again, similarly to SONIC, that double immunosuppression is more effective than one drug at the time in inducing disease remission.

Finally sessions on cancer were presented. Vetrano and colleagues reported a possible new regulator of colon carcinogenesis, Junctional Adhesion Molecule-A (JAM-A), which is a tight junction protein expressed by epithelial and endothelial cells, and has a crucial role in controlling mucosal homeostasis by regulating the integrity and permeability of the intestinal epithelial barrier function. The results of their investigation demonstrate that the low levels of JAM-A correlate with increased incidence of tumour development and tumor aggressiveness.

Peyrin-Biroulet and colleagues presented the results from a French cohort study about the possible role of thiopurines (azathioprine and 6-mercaptopurine) in promoting skin carcinomas. 19,486 patients with IBD were enrolled, at baseline, 5,867 (30.1%) of patients were receiving, 2,809 (14.4%) had discontinued, and 10,810 had never received thiopurines. During the study thirty-two cases of skin carcinomas were recorded, and present or past exposure to thiopurines significantly increased the risk of skin carcinomas in patients with IBD. This increased risk is already present before the age of 50. This result strongly support sun protection and suggests dermatological screening in these patients.

Overall, the scientific papers were excellent and hopefully most of these scientific breakthroughs will change the way clinician practice and will raise the standards of care.

Antibiotics increase risk of IBD in children

UEGF issued a press release on a recent Danish study which links antibiotic use in childhood with a major increase in the risk of the child developing inflammatory bowel disease (IBD). Researchers have found that only one course of antibiotics could more than treble the risk of Crohn's disease, with penicillin looking particularly culpable.

The Danish study involved a careful examination of the use of all systemic antibiotics in children born in Denmark between 1995 and 2003. The children were followed for up to 10 years for the development of Crohn's disease and/or ulcerative colitis. Almost 600,000 children were followed, and almost 500,000 of these (85%) received at least one course of antibiotics during their follow up. Fifty cases of Crohn's disease and 67 cases of ulcerative colitis were identified.

In antibiotic users, the risk of Crohn's disease was especially high. Children who had taken antibiotics were more than three-times more likely to develop Crohn's disease than children who had not. Again, the risk of developing Crohn's disease was highest in the 3 months following the antibiotics, and highest with penicillin V and extended-spectrum penicillin.

To read the full press release please go to: http://www.uegf.org

Understanding clinical trials

by Ben Wilson

What is 'evidence based medicine'?

Since the 1950s, doctors in Europe have thought that instead of using traditional treatments, or relying on personal experience alone, medicine should be based on scientific evidence and testing. Each patient should be treated as an individual, whilst learning from experience gained in the treatment of others — research.

When doctors look at the research before recommending a treatment, they are using evidence-based medicine. An important part of gathering evidence is the clinical trial.

What is a clinical trial?

A clinical trial compares the effectiveness of two treatments, or the effectiveness of a treatment compared to no treatment at all. In the trial, a treatment is given to a real person, and the results of the treatment recorded. Clinical trials can provide good evidence to use in the treatment of others.

What types of trials are there?

Controlled trials

To make sure a trial is fair, information is recorded about the treatment, as well as what happens if no treatment is given. There are two groups of people in the trial, the 'intervention' group, who are given the treatment, and the 'control' group, who are not given any treatment.

Randomized trials

The type of person chosen to take part in a trial is called the population. Individuals from the population are then selected to be in the intervention, or control groups. But, if only certain types of people are chosen to be in these groups, then the results of a trial could depend more on the type of person chosen, than the effectiveness of the treatment.

In good quality trials, the population and randomization is explained in detail.

Single- and double-blinded trials

If the people taking part in a trial know whether they are in the 'intervention' or 'control' groups, then the results could depend more on the person's expectations, than the treatment itself. To solve this problem: in a single-blind trial, the person taking part doesn't know whether they are in the intervention or control group. In a double-blind trial, neither the researchers nor the people taking part know which group they are in.

Placebo controlled trials

In a 'placebo controlled' trial, the control group are given medication which doesn't contain any active drugs, like sugar-pills. This way, the true effectiveness of the real medication can be discovered.

Peer reviewed trials

Good quality clinical trials are 'peer reviewed'. This means other doctors and researchers read the information, find problems, and make sure that good methods have been used. Trials are often published in peer reviewed journals, where editors review each trial in detail. Some journals, like the British Medical Journal (BMJ), or The Lancet are very well known and trusted.

What are 'systematic reviews'?

Sometimes a single randomized controlled trial doesn't really tell us enough about a treatment, or it might disagree with other trials. A better answer can be found by combining the results of many randomized controlled trials into one systematic review, which helps to highlight common findings which are often more reliable.

Further information

BMJ (2007) Best treatments website. (www.besttreatments.co.uk)
Gray, J.A.M. (2002) The resourceful patient. (www.resourcefulpatient.org)
Taylor. P. (2006) From patient data to medical knowledge.

Health Priorities under Hungarian Presidency of the EU

Hungary took over the rotating EU Presidency from Belgium in January 2011. As concerns its health priorities the main focus will be on "Patient and Professional Pathways in Europe" which emphasizes the need to focus policy on both individuals and processes, and in particular on the needs of those communities to which the health system is most important - those who use it, and those who make it possible.

It will give priority to "Action for Prevention" and to "Investing in the Health Care of the Future and Human Resources for Health". During an informal health ministerial meeting, the Hungarian Presidency aims to raise issues on how the necessary knowledge-base, stock of experts, increased co-operation, joint research, exchange of information and best practices could be established to support Member State governments in their efforts to modernise their health care systems.

eHealth is also identified as a key issue for modernising healthcare services and the Hungarian Presidency is keen to promote the role of e-Health in cross-border care, in relieving workforce shortages and in IT support in health policy decision making. With regard to elements of the legislative Pharmaceutical Package that was submitted by the European Commission the Hungarian Presidency's objective is to achieve a political agreement on the draft for information to patients on prescription medicines.

Other key areas are injury prevention and safety promotion, mental health and health security (emphasis on childhood immunization) and the future of the EU Public Health Programme.

More info: http://www.eu2011.hu/

Patients' Rights in Cross-Border Healthcare

Health systems and policies across the EU are becoming more interconnected than ever, due mainly to movement of patients and professionals, increasingly shared expectations of people across Europe and dissemination of new medical technologies and techniques thanks to computerisation.

In July 2008, the Commission proposed a new EU directive on the application of patients' rights in cross-border healthcare to provide legal certainty over patients' rights to seek healthcare in another EU country and reinforce cooperation between those countries. The Directive, which has been adopted on 19 January this year, will benefit patients across Europe by clarifying their rights to access safe and good quality treatment across EU borders, and be reimbursed for it.

Patients travelling to another EU country for medical care will enjoy equal treatment with the citizens of the country in which they are treated. This new law will benefit EU patients in several other ways. It will make it easier for national health authorities to work closer together and exchange information on quality and safety standards of healthcare. It will help patients who need specialised treatment, for example those who are seeking diagnosis or treatment for a rare disease. It supports the development of "European Reference Networks" bringing together, on a voluntary basis, specialised centres of expertise already recognised in Europe. Health experts across Europe will be able to share best practices on healthcare and provide standards of excellence.

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

Rare Disease Day

February 28th 2011 marked the fourth International Rare Disease Day, an annual, awareness-raising event coordinated by EURORDIS and organised with rare disease national alliances in 25 countries. On that day hundreds of patient organisations from more than 40 countries worldwide organised awareness-raising activities converging around the slogan "Rare but Equal".

The main objective of Rare Disease Day was to raise awareness amongst the general public and decision-makers about rare diseases and their impact on patients' lives. More specifically, in 2011, Rare Disease Day sought to draw attention to the gaps in health that exist for rare disease patients between and within countries as well as the gaps in health that exist for rare disease patients compared to others in society.

For more information: http://www.rarediseaseday.org/

European Medicines Agency publishes final 'Road map to 2015'

The European Medicines Agency has published its final 'Road map to 2015', which sets out the Agency's vision in further developing its role as a European public-health agency in the field of medicines. Building on the achievements made by the previous road map initiative between 2005 and 2010, the new road map proposes three priority areas for future actions to strengthen the Agency's role in protecting and promoting human and animal health in the European Union:

- Addressing public-health needs by: stimulating medicines development in areas of unmet medical needs, neglected diseases and rare diseases, and for all types of medicines for veterinary use; facilitating new approaches to medicines development; applying a more proactive approach to public-health threats where medicines are implicated.

- Facilitating access to medicines by: addressing the high attrition rate during the medicines-development process; reinforcing the benefit/risk-balance assessment model; continuing to improve the quality and the regulatory and scientific consistency of the outcome of the scientific review.

- Optimising the safe and rational use of medicines by: strengthening the evidence base in the post-authorisation phase to enable better regulatory decision-making; enhancing patient safety by avoiding unnecessary risks to patients as a result of the use of medicines; becoming a reference point for information on medicines evaluated by the Agency; improving the decision-making process by taking due account of patient experience, thus contributing to the rational use of medicines.

The road map has been drafted in consultation with the Agency's European partners, stakeholders, including patients' and doctors' organisations as well as pharmaceutical industry, and the public, to ensure a broad consensus on the best approach to be taken for the Agency to fulfil its public mandate to protect and promote public health in the European Union over the coming years.

More information: http://www.ema.europa.eu

New website

'Optimising the delivery of health care to European citizens'

Policy-oriented research for public health has been mainstreamed under the Seventh Framework Programme (FP7) for Research 2007-2013. This research includes an activity entitled 'Optimising the delivery of health care to European citizens'.

This activity aims at developing new research methods and generating the necessary scientific basis to underpin informed policy decisions on health systems, and more effective and efficient evidence-based strategies of health promotion, disease prevention, diagnosis and therapy. The strategy of this part of the Health Theme is to put the citizen first where research on healthcare is concerned, aiming at bringing the results of health research to the benefit of European citizens in particular through benchmarking, comparisons and analysis of models, systems and data.

The new web site includes three sub-areas as clinical research into practice, health systems research and health promotion and disease prevention. See: http://ec.europa.eu/research/health/public-health/index_en.html

Fake medicines

European Parliament approves new rules to protect patients better

A new law to prevent fake medicines from entering the legal supply chain was approved by the European Parliament on 16 February 2011. Internet sales will be covered by the law, which also introduces new safety and traceability measures, as well as sanctions against counterfeiters. This law still needs to be formally approved by the Council of Ministers.

"Falsified medicines are silent killers, either because they are devoid of effect or because they contain toxic substances that may harm, or even kill, those who take them. The absence of a legal framework encourages counterfeiting, an organized crime. We have been witnessing a huge growth of this criminal activity, with an increase of 400% in seizures of fake drugs since 2005. Protecting patient safety is the core aim of this directive", said Marisa Matias (GUE/NGL, PT), who led discussions in Parliament. Her report was adopted with 569 votes in favour, 12 against and 7 abstentions.

An estimated that 1% of medicinal products currently sold to the European public through the legal supply chain are falsified and the share is growing. In other parts of the world, up to 30% of the medicines on sale may be fake. In particular, more and more innovative and life-saving drugs are counterfeit.

Read more: http://www.europarl.europa.eu/news/public/default_en.htm

European Year of Volunteering

The EU has designated 2011 as the "European Year of Volunteering".

In the European Union, almost 100 million citizens of all ages invest their time, talents and money to make a positive contribution to their community by volunteering in civil society organisations, youth clubs, hospitals, schools, in sport clubs, etc. For the Commission, volunteering is an active expression of civic participation, which strengthens common European values such as solidarity and social cohesion.

Volunteering also provides important learning opportunities, because involvement in voluntary activities can provide people with new skills and competences that can even improve their employability. This is especially important at this time of economic crisis. Volunteering plays an important role in sectors as varied and diverse as education, youth, culture, sport, environment, health, social care, consumer protection, humanitarian aid, development policy, research, equal opportunities and external relations.

Objectives of the Year:

The EU will use the Year to work towards four main objectives:

- To create an enabling and facilitating environment for volunteering in the EU;
- To empower volunteer organisations and improve the quality of volunteering;
- To reward and recognise volunteering activities; and
- To raise awareness of the value and importance of volunteering.

Each Member State has been asked to designate a National Coordinating Body (NCB) that will be responsible for the planning, coordination and organisation of events and activities in its territory during the European Year. The National Coordinating bodies will also coordinate with Community level activities and the overall planning of the Year.

If you are interested in carrying out an activity in the framework of the European Year, please make sure you inform the National coordinating body for your country. (http://ec.europa.eu/citizenship/annexes-citizenship/doc1069_en.htm)

EU Health Programme: Work Plan 2011

The European Commission has published the Work Plan for 2011 for the implementation of its second programme of Community action in the field of health. It sets the annual priorities for implementation of the EU Health Programme.

The publication of the Work Plan is followed by the calls for proposals for joint actions, operating grants, projects and conferences. The Executive Agency for Health and Consumers (EAHC) publishes calls for proposals for projects, operating grants, conferences and joint actions.

The 2011 Work Plan gives more emphasis and resources to a focused cooperation with the Member States. The amount of 17,040,000 euro will be dedicated to the funding of five joint actions.

In comparison to 2010 the total indicative amount available for operating grants for non-governmental organisations or specialized networks active in the field of Public Health has increased and is 4,000,000 euro.

The indicative amount for the call for proposals for projects is 4,650, 000 euro. This call for proposals is seeking for very specific projects in seven different areas, where only one project per call will be funded; exception will be made for the rare disease networks. Funds will also be made available for grtants for conferences (800,000 euro).

The deadline for submission of proposals is 27 May 2011.

For more info: http://ec.europa.eu/health/programme/policy/index_en.htm