EFCCA MAGAZINE

European Federation of Crohn's and Ulcerative Colitis Associations | February 2014

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EDITOR’S EYE

New Horizons

Looking back at our achievements in the last year I am very proud to say that we have succeeded in giving a much louder voice and higher visibility to people with IBD within the EU institutions. The conference “From EU Citizenship to IBD-zenship” that we organised together with our partners from ECCO and the UEG-Public Affairs Committee in the European Parliament clearly shows that our cause is being taken up by policy makers and the support to our Fight against IBD is growing not only with Members of the European Parliament but also other officials from the European Commission, the European Agencies and stakeholders. This commitment is reflected in the interviews we held with MEP Cofferati and MEP Panayotova which you can read in this issue.

The conference last October has also established stronger links with ECCO, N-ECCO and the UEG Public Affairs Committee with the purpose of creating a more robust critical mass in term of advocacy and lobbying at the European level. Our activities last year brought under the spot light some burning topics that, after being highlighted in the IMPACT survey, are now potential themes for developing concrete actions: employment, antidiscrimination and inclusion policy in the labour market and in education are at the top of our agenda and EFCCAs’ efforts in 2014 will be devoted in seeking for resources to transform ideas and inspiring practices into actions and projects able to involve all members.

This year the European Parliament will hold elections between 22 and 25 May and this will be an important time for us to advocate with the newly elected Members to the Parliament and to consolidate our work with re-elected ones that are already supporting our efforts. And as this issue of the EFCCA Magazine goes to print our efforts with the General Directorate on Health and Consumers’ Protection (DG SANCO) are bearing fruits, one concrete outcome being a meeting with the Commissioner Borg and his closest staff.

Further good news is on the horizon. We have now also established links with the WHO (World Health Organisations) which will open up new doors to an international recognition and understanding of the difficulties and challenges faced by people living with IBD worldwide.

Talking about widening horizons we are also very excited about the European Commissions new Horizon 2020 programme that is being launched with a budget of over €15 billion over the first two years.

Horizon 2020 is the biggest EU Research and Innovation programme ever and promises more breakthroughs, discoveries and world-firsts by taking great ideas from the lab to the market. Under the section "Health, Demographic Change and Wellbeing" Horizon aims to tackle challenges faced to ensure every citizens right for a good quality of life. European research and innovation in health will be an important step to tackle these challenges. It is an investment in our health and, on a larger scale, an investment in a healthy workforce, a healthy economy and lower public health bills. You will find more details information about Horizon in this issue.

But also within EFCCA our horizons are widening up. Following discussions during last year's Annual General Meeting EFCCA will be in an exciting position to consolidate a consensual aspiration to enlarge EFCCA's activities beyond the European borders (such as the World IBD DAY) and a common understanding of the importance of strengthening links and relationships with sister organisations all over the world.

In line with the European Commission programming period EFCCA is now ready to launch its next Strategic Plan: a unique occasion for defining our next 4 year projects within the framework of EU funding and grants opportunities.

EFCCA´s international perspective will be a further part of our efforts: having a global vision when dealing with IBD related issues is becoming more and more crucial: targeted actions addressed to WHO (World Health Organisation) have been tuned and we hope to be able to strengthen our relationships with overseas sister organisations thanks to the strong interest that the IMPACT survey had and already has among IBD Patients organisations worldwide. Japan is already on board and outcomes are expected by the 19 May while Brazil and Gulf Levant countries are ready to start.

New challenges are around the corner, the financial crisis is still affecting our countries and organisations, the coming year(s) will require lot of resources and energy. We know we can count on our members and we are confident to be able to offer diverse and fruitful occasions to you all for working together and improving the quality of life for people with IBD. UNITED WE STAND!

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1096/97
revised 22/2/2006
No. 459814543

Equal Rights for Citizens with IBD

“From EU Citizenship to IBD-zenship”
European Parliament, Brussels

From left to right: MEP Cofferati, Prof. Stockbrügger, Marco Greco, Simon Travis and Eduard Louis

“Equal Rights for Citizens with IBD” was the main message emerging from the conference organized by EFCCA in cooperation with the European Crohn’s and Colitis Organisation (ECCO) and the United European Gastroenterologists Public Affairs Committee (UEG-PAC) which took place in the European Parliament on 17 October 2013.

The conference saw a huge participation of over 70 delegates including representatives from the EFCCA national IBD associations, representatives from other European networks dealing with patients’ concerns (such as the European Patient Forum, AGORA, etc), EU officials and representatives from the medical professions.

The host of the event, MEP Cofferati as well as Vice President of the European Parliament, MEP Miguel Angel Martinez and MEP Panayotova together with a considerable number of other MEPs showed their strong support for better integrating the rights of people living with IBD. The message of solidarity and cooperation was also echoed by the three partners organising the event who called for actions to ensure equal access not only to better treatment option and health care services but also to education and the labour market.

The conference was divided into three panel discussions. The first panel dealt with the issue of IBD, employment and the labour market and saw an interesting presentation from Álvaro Oliveira, DG Justice and some first hand experiences of joining the labour market with a chronic disease from Auslaug Eva Bjornsdottir, EFCCA Youth Group member and Chayim Bell, EFCCA Board member.

The second panel discussion focused on IBD, health care and research where Prof S. Travis, ECCO, Marco Greco, EFCCA Chairman and Professor Stockbrügger, UEG-PAC, debated on the current issues around IBD and visions and possible solutions for the future.

The final panel discussion was on the subject of Youth and Education. Ms. Mary Kyriazopoulou from the European Agency for Development in Special Needs Education (EADSNE) gave an inspiring presentation of EADSNE´s work to develop provisions for learners with special educational needs. Prof. Maurizio Vecchi from the University of Milan stressed the increase of IBD amongst the young and Marian O´Connor from N-ECCO looked at the implication of IBD on young people as concerns education. Daniel Sundstein, EFCCA Youth Group leader gave an account of his personal experience of going through the education system having IBD.

Some of these presentations and more information can be downloaded from the EFCCA website.

Ms. Kyriazopoulou speaking during the panel on youth and education

The event at the heart of the European Institutions was the final part of EFCCA's World IBD Day campaign in 2013 aimed to raise awareness of IBD, especially within the EU institutions and amongst EU policy makers. EFCCA strives to ensure that the concerns of people with IBD are taking into consideration in all EU policies. It will continue its efforts in the coming year and work with EU policy makers towards better legislations that will improve the quality of life of people with IBD.

Taking action at European level

Interview with MEP Sergo Cofferati and MEP Monika Panayotova

The above mentioned conference "From EU Citizenship to IBD-zenship" that recently took place at the European Parliament clearly shows that we, at EFCCA, have managed to give people with IBD a louder voice and make our fight against IBD more visible amongst the EU institutions and policy makers. We have succeeded in gaining the support from an increasing amount of Members of the European Parliament. In this interview we are talking to two MEPs who have supported our efforts in the past years to find out what their personal motivations in joining our fight against IBD are and what thoughts and recommendations they have for the future.

When did you first hear about IBD?

Panayotova: It was about 3 years ago when I went to visit a friend of mine in hospital who was just diagnosed with Crohn's disease. Unfortunately, the information about these diseases is not that wide-spread among the general public and usually it is only after someone you know is diagnosed with IBD that you understand such diseases actually exist.

Cofferati: I know some people in Italy who are affected by these diseases, in particular by the Crohn Syndrome. Therefore I have known from several years of the existence of IBD and of the difficulties and the challenges that IBD patients face every day.

Why did you decide to join our fight against IBD?

Cofferati: It was when I met your representatives from EFCCA, including Mr Greco and Mrs Avedano, here in the European Parliament when they explained to me the kind of work you do at the association, the fight that you are bringing forward, your targets and your views. I then decided to join your efforts and try to help, with the means and the possibilities at my disposal.

Monika Panayotova is a member of the European Parliament from the group of the European people's party (Christian Democrats). She is a member of the Committee on culture and education. Before becoming a MEP Monika Panayotova was a member of the Bulgarian Parliament.

Panayotova: First of all, because IBD affects mostly young people in their late teens and early 20s - an age when they are supposed to enjoy life. Instead, they are forced to struggle with the disease, which unfortunately often affects negatively their decisions on future educational and career paths.

The figures show that the number of people affected by IBD is constantly increasing in the EU and in Eastern Europe, in particular. From a rare disease Crohn's disease is getting more and more common. Nobody is insured that he or she won't be the next to be diagnosed with a similar disease. So, I believe that the least we could do as politicians is to raise the awareness about IBD, especially among youngsters.

Do you know anyone yourself who has IBD?

Panayotova: As already mentioned I have a very close friend diagnosed with Crohn's disease. Through him I learnt a lot about the disease and the challenges one has to face in his everyday life. He also made me personally aware of other people living with IBD in Bulgaria. I am very proud of my friend who instead of falling into despair co-founded the Bulgarian Crohn's and Colitis patient organisation which provides Bulgarian patients with information, assistance and courage.

Cofferati: Yes, I know a couple of people in Italy who are affected by these diseases and I am aware of their daily difficulties, pains and challenges, in a lot of different aspects of their life.

What do you think could be done on a European level to improve the life of people with IBD?

Panayotova: In the EU there are differences among member states with regards to access to treatment – both in terms of the quality of healthcare services and medications. To certain extent these issues are within the competences of the member states, but with increased mobility of people within the EU certain common standards have also to be applied. Also, I think, some EU funding, within for example the Horizon 2020 programme (see page 27) could be allocated for fundamental and applied research for healthcare and IBD associated topics, in particular.

Cofferati: I think that there are several actions that should be undertaken at European level. First of all there should be a clear recognition of the invalidating nature of IBD, with all the consequences that would follow this decision.

Secondly there should be an effort with regard to the scientific research on these diseases, also in the framework of Horizon2020. More attention and resources should be devoted to this topic.

Furthermore attention should be given at the working condition for people affected by these diseases. Social partners at European level should develop best practices and guidelines and raise the awareness of their organisations at national level on the needs of IBD patients, which should be taken into consideration and appropriately addressed in the collective agreements and contracts. For example workers with IBD need more flexible working time arrangements and may need periods without working for health reasons. These conditions have to be taken into consideration by the social partners when agreeing the collective contracts that define the working rules and conditions.

These are just some aspect of the fight against IBD that should be dealt and addressed at European level.

What do you think our IBD patient associations could do on a national level to make sure that their cause is taken up at the European level?

Panayotova: Alone, any national patient organisation will find it very difficult to defend its cause on EU level or to influence EU politics. Therefore the establishment of federations that represent the interests of all such national organisations or the so called 'umbrella' organisations is important. In my view, national organisations could define the problems their members confront and if they appear to be similar for most of them and could not be addressed on national level, than actions on EU level would be necessary. In this aspect, I think, communication between national associations is vital. Exchange of opinions, sharing of best practises, specific country problems or challenges can be not only a good starting point for the actions that should be taken at EU level, but also an excellent generator for working solutions that just need to be put into practise.

Sergio Cofferati is an Italian politician who, after serving as mayor of Bologna from 2004 to 2009, is Member of the European Parliament since 2009 belonging to the Group of the Progressive Alliance of Socialists and Democrats. He has a strong background on labour market policies and was leader of CGIL, one of the biggest trade union in Italy, for years.

If you – as patients, already know what you want to achieve, an effective approach would be to raise awareness of your national MPs or MEPs. Let them know about your problems, draw their attention to challenges you face, so that these topics are brought faster to the current political agenda. If I could give you a single piece of advice, it would be 'Be active!' – sometimes problems keep existing for years not because there is no political will for their solution, but simply because politicians are not aware of them.

Cofferati: They have a very important role as well, in my opinion, not only in fighting against IBD at national level, but also in helping their cause at European level. National organisations should cooperate with EFCCA in raising the awareness of this fight between their national Member of the European Parliament and between their governments and their national member of the European Commission.

Only a very coordinated approach that involves the European and the national organisations can produce the political pressure that we need in order to have results at European level.

Need for stronger patient's involvement in designing care services

Reflections from the IBD 2020 Forum, by Luisa Avedano, EFCCA CEO

EFCCA, represented by EFCCA Chairman, Marco Greco, and myself participated in the IBD 2020 Forum, held in Oxford last September 2013. The conference was organised by Prof Travis, President of ECCO and gathered clinicians, academia and patients representatives in a debate on how to improve the quality of care for IBD patients worldwide.

Before the summer break EFCCA was contacted by Richard Driscoll, former CEO of Crohn´s and Colitis UK and gave its support to the involvement of some of its members, namely: France, Italy, Spain, Sweden and the UK national associations that accepted to participate in a survey with the aim to highlight insufficiencies and disparities on quality care on IBD. The survey was promoted by ECCO and its starting point was to analyse how big inconsistencies in care are, as huge contradictions either between or within countries are still a big issue.

The Forum was mainly focused on slide shows of good practices presented by internationally renowned physicians while patients had some say during the working groups steered by physicians and organised per countries. At a first glance, comparing the ECCO survey with the IMPACT survey EFCCA conducted and is still conducting in further countries, it appears that health care professionals rarely discuss with patients main goals or priorities in caring for their conditions and 72% of respondents said that no health care professionals helped to make a plan that could be carried out in their daily life.

The IBD2020 survey showed that care is therapy-oriented and the overall impact of IBD on patient's life is often forgotten. The IMPACT results on the other hand have clearly put into evidence the overall impact IBD has on social life, relationships, work, education, and symptoms also in remission.

The Forum, in our view, showed that quality of care often concentrates on quality of services, therapy, desired health outcomes, effectiveness and timeliness of care while patients' quality of life, can sometimes be forgotten. A patient-focused approach could be a more effective answer when designing care services for people with IBD as patients are more than their illness and they must be more aware of their role, particularly when "first hand" information are needed.

The meeting was very formative and the differences in results of the IMPACT and IBD2020 surveys have led EFCCA to stress again the importance of a stronger patient's involvement in designing services addressed to them.

Decisions have to be made in cooperation with patient and health care professionals and patients should come back to the centre of a common work for achieving a better quality of life for people with IBD. This approach could lead to a better allocation of the actual limited resources but it can work only in the context of an open, transparent and mutual cooperation.

IBD11 - unleash your knowledge

Marco Greco, EFCCA chairman, spoke at the IBD 11 meeting that took place in Prague (14-16 November 2013) presenting EFCCA's work of EFCCA and the patient perspective. The meeting was organised by the pharmaceutical company Ferring and was attended by over 850 physicians from over 50 countries. The meeting was an excellent opportunity for EFCCA to exchange information, to learn about the latest developments in IBD and to make new contacts and refresh existing links. For more information please contact the EFCCA office.

IBD and education

“ Imagine sitting in a hospital during one of the most exciting and challenging times of your life – early twenties or late teens. For a while now, you haven’t been able to fully participate in any social events or all the lectures of your education, and now you are given a diagnosis: Crohn’s disease or ulcerative colitis. Inflammatory Bowel Disease. IBD. A chronic but invisible disease that not many people know of – or want to know of. Probably you don’t even know it yourself. “

Daniel Sundstein, EFCCA Youth Group Leader speaking at a conference in Brussels about his experience of IBD and education.

For someone with Inflammatory Bowel Disease (IBD), their first experience of the disease tends to come between the ages of 15 and 25, a time when they are gaining their education and skills, and forming their career aspirations. A diagnosis of an incurable disease and the traumatic symptoms it causes can create a huge obstacle for young people who are trying to acquire qualifications and start their working life.

In many EU Member States, it is against the law for a school or other education provider to treat disabled students unfavourably. This includes ‘direct discrimination’ - e.g. refusing admission to a student because of disability. An education provider has a duty to make ‘reasonable adjustments’ to make sure disabled students are not discriminated against. All universities and higher education colleges should have a person in charge of disability issues that a student can talk to about the support they offer. A person suffering with IBD has the right to be treated the same as any other student.

The disability issue

Hopefully, young people with IBD don’t feel “disabled,” but for the purpose of accommodations and other academic considerations, the student´s IBD will probably qualify as a “disability,” because IBD is a chronic medical condition that lasts over time and can be episodic, as opposed to a medical condition with a specific start and end point.

Studying Abroad

European student exchange programmes, such as for example the ERASMUS programme , offer students the possibility of studying or working abroad in another European country for a period of at least 3 months and maximum 12 months. They are highly popular and allow students to get to experience with another culture and a new way of looking at your subject.

Having IBD doesn’t necessarily mean that one should not take advantage of such programmes. That’s a decision based on many factors, including how the person with IBD is doing at the time. With planning, there are many students who still pursue this exciting college opportunity.

EFCCA represents patients’ associations from 27 European countries. Students who consider studying abroad are highly encourage to get in touch with one of these associations in their country of destination and in particular with their youth group if available. They might be able to help with getting names and numbers of local doctors who are familiar with IBD, or a local medical center, if a student needs care while you're abroad.

The situation in the UK

By Claire Hunt

A recent report conducted by Crohn's and Colitis UK titled "Inflammatory Bowel Disease in Young People - The impact on education and employment" demonstrated that 69% of respondents stated that their condition has prevented them from reaching their full educational potential (Report available http://www.crohnsandcolitis.org.uk).

As a higher education student living in England, you can apply for a Disabled Students' Allowance (DSA); this can help with additional costs that might occur because of IBD such as specialist equipment.

All Higher education establishments must have a disability advisory service which is available for all students to access for additional support during their education. Each student's needs are assessed on an individual basis. If you suffer with IBD you are able to discuss extra support and allowances you might need while you study, for example extra exam time and allowances to use the toilet in the exam. The disability service can also help with accommodation if you need an en-suite room etc. Whilst the UK has a strong support system for people with disabilities during their education there is always room for improvements. Educators need to be alert to what is a sensitive condition and ensure that people with IBD do not face unnecessary obstacles that could set their careers back or limit their quality of life.

Claire Hunt during her nurse training

Crohn's and Colitis UK are currently campaigning to improve employment and educational services for young people with IBD. Their aim is to ensure all elements of the system NHS, welfare, careers advisers, and employers interact coherently and in a holistic manner to improve outcomes for people with IBD in their working lives, particularly with regard to young people and those with lower levels of education.

My own experience at University with IBD

"My London University have been extremely helpful and supportive during my studies. I was seen by the disability support service and they made sure I was able to get extra time to sit exams in case I needed the toilet. They also provided me with extra money for things like a taxis in case I was too ill to travel by public transport. I have a close link with my personal tutor who checks in to see how I am doing and makes extra allowances if I can't attend lectures. It has been extremely hard studying whilst my Crohn's disease is flaring, but having the support from the university has made a huge difference".

The Nordic experience

Interview with Arne Schatten, General Secretary LMF

Arne Schatten has been General Secretary of the Norwegian IBD patient association, LMF, for 5 years now , previously he was chairman of the LMF Executive Board. He finds his work very rewarding and meaningful because of the positive change that he and his colleagues are making for people with IBD. "Many people contact us because they don't know a lot about their own IBD, they don't know what to ask their doctors, or they might be scared…and we try and help them as best as we can. Sometimes they call back again and say thank you very much! I think this gives meaning to your life."

When was the LMF established?

The Norwegian IBD association, LMF, was founded together with a group of gastroenterologists way back in 1987 and since 1991 LMF has been "taken over" by patients only although of course we are continuing our close cooperation with the gastroenterologists as well as with health care systems, hospitals, the pharmaceutical industry and other stakeholders. We have grown over the years and currently we represent around 3300 members.

How high is the prevalence of IBD in Norway?

Norway has a significant amount of people with IBD. Statistics show that there are over 25 000 people with IBD with a total population of just over 5 million.

There has been an interesting study looking into the incidence of IBD across Europe. The EC funded study showed that IBD was significantly higher in the Nordic countries.

As for the reasons other than the differences in climate and tobacco consumption there is no conclusive explanation for this however.

So is awareness raising of IBD still an important part of your work in Norway?

Yes, of course, it is still important for us to inform about Crohn´s Disease and Ulcerative Colitis. First of all we want to make sure to give reliable information to patients, their families, friends and colleagues and secondly, on a more general level, we want to increase the awareness around IBD with the general population.

Last year we have run a huge awareness raising campaign under the title "IBD by remote control". Our association challenged the politician Bent Hoie (Minister of Health in the Norwegian government) to experience how life with IBD manifests itself. It was an experience far more challenging than he had imagined in advance. He was put on "remote control" by two young members of our association. They sent messages (SMS) to his mobile phone and totally controlled the politician. The film has been a huge success last year, however sadly due to new legalislation concerning politicians we can no longer show this movie.

So this year we have made another very interesting 32 minutes films about IBD. In the film, actors who have IBD, talk about themselves and how they manage their life in a positive way. I also appear in the film and talk about the work we do at the LMF and what it can do for patients, finally a gastroenterologists talks about IBD, colonoscopy and how to make it less dangerous. The film has become very popular and has been shown in hospitals and can be watched on our website for free.

What other activities do you organise through the LMF?

A lot of our work centers around assemblies for young people and families. We believe that it is very important for young people with IBD to be connected with other youngsters and the assemblies are a good forum for that. We are very successful in what we are doing and many of the young people are in contact with each other between the assemblies and we want to be of help to all of those who don't know of us so that they are no alone when they are diagnosed.

This year we have also managed to secure some funding through the Norwegian national lottery to support our work with young people. In October we will organise a camp for youngsters aged between 15 and 18 years old where they can get a chance to relax with other kids in the same situation and at the same time learn more about their condition and ways of coping with it.

Another project we are embarking on is the organisation of an interactive webinar on "fatigue and chronic diseases", which we are organising together with the Psoriasis and Rheumatic patient associations in March. During the webinar a professor will talk about his survey on chronic diseases and fatigue, another presentation will look at a survey on how to live with a chronic disease or a disease that you cant see but has a huge impact on your life. Finally there will be some patient testimonials and information concerning nutrition. We will also allow time for some questions and answers.

For us such webinars are the future especially since there are quite cost effective. We already organised a hugely successful webinar last year where more than 1000 IBD patient participated. We received a lot of positive feedback from people saying that they would have never participated in the event if it hadn't been online as they were too ill to participate or couldn't travel so far.

What are the main challenges for your association?

Having more people working for us as volunteers is always a challenge which we are trying to meet. Currently we have around 170 volunteers including our local associations. We also have a small office in Oslo with 3 people working part time on an honorary fee.

Another big challenge, which I guess is similar to most of our colleagues, is the financial situation. We would like to do more than what we are actually doing. We would like to have more and bigger family assemblies but of course these are very costly….

How is your cooperation with other stakeholders?

We do have close cooperation with the Norwegian Gastroenterological Association and they are helping us with all the medical information we are putting in our booklets concerning patient information. Many times doctors also refer their patients to us once they have been newly diagnosed and/or patients can find information about us in the waiting rooms in the hospitals.

We have also a very good cooperation with the IBD nurses and we are regularly invited to their Annual General Meetings. Actually in the sense of patient outreach our cooperation with the nurses is very important. We find that doctors have a very short time to talk with their patients and referring them to us might not be priority, however nurses spend much more time with the patient and can point their patients in the right direction.

Why is it important for you to be part of a European network?

I think it is very important for LMF to be part of EFCCA and to know that we belong together. I believe we have similar problems, perhaps the solutions differ from country to country but it is very interesting for us to know what is happening elsewhere. The meetings that are organised within EFCCA are a good way to talk to representatives from other patient associations and see how they are dealing with subjects like "biological treatments" for example. We believe in information sharing so as not to create the same information twice!

We also meet with other Nordic countries usually once a year. We talk about common Nordic issues such as for example the hospitals or social security because our countries are quite similar and we share more or less the same problems.

UK

Crohn's and Colitis UK Launch Updated IBD Standards with Key Partner Organisations

On 30th October 2013, Crohn's and Colitis UK launched the updated Standards for the Healthcare of People who have Inflammatory Bowel Disease (IBD) in the UK Houses of Parliament, on behalf of the multi-stakeholder IBD Standards Group. The event was very well-attended by politicians, clinicians, healthcare specialists and people with Crohn's Disease and Ulcerative Colitis. It was an important opportunity to bring together a wide range of people who have a role in making the IBD Standards a reality.

The original IBD Standards were produced in 2009 following the first UK-wide audit of IBD service and care, which took place in 2006. The audit revealed substantial local variation in the provision, organisation and clinical quality of IBD services and significant aspects of care which did not meet existing clinical guidelines. As a result, organisations representing patients and professionals collaborated to define for the first time what was required in terms of staffing, support services, organisation, patient education and audit to provide integrated, safe, effective, patient-centred, high quality IBD services.

The UK IBD Audit, currently collecting data for its fourth round, now measures IBD services directly against these Standards. The findings show that there have been significant improvements in provision and care since 2006. However, they also demonstrate that there are still some key challenges ahead.

For example, the percentage of services with a dedicated gastrointestinal ward has increased from 67% to 90% between 2006 and 2010, while those with IBD Nursing provision has increased from 56% to 78%. Telephone access to an IBD specialist has gone up from 78% to 96%. For those experiencing a relapse, 89% of services can now provide specialist review within 7 days, compared with 69% in 2006.

This is all very encouraging. Yet the number of IBD Nurses is still too low for most services to ensure cover at all times and access to dietetic services and psychological support needs to be improved. At the last audit round, half of services did not have an electronic database of their IBD patients, which is essential for integrated care. Overall, coordination between primary and secondary care is still poor and there is a strong need for better patient information on discharge from hospital and where care is shared between GPs and specialists. This is especially important as we move towards care which is provided closer to home, with access to specialists where needed. Patient involvement in service planning is also still at very low levels (21%).

The IBD Standards have been updated to reflect changes in the health policy landscape in all four countries of the UK, new guidelines and developments in IBD and the most recent UK IBD Audit findings. The update also comes ahead of the development of a quality standard for inflammatory bowel disease by NICE, the National Institute for Health and Care Excellence.

Crohn's and Colitis UK will continue to work with other patient and professional organisations, including those representing gastroenterologists, GPs, nurses, surgeons, dietitians and pharmacists, to ensure that care quality is further improved for all those affected by IBD and that patients are at the heart of all developments.

IBD Standards Group Chair and Crohn's and Colitis UK Chief Executive David Barker said today: "Thanks to really effective partnership and collaborative working I'm delighted that we have seen services for patients with IBD improve. Increasingly, services across the UK are recognising the importance of the IBD Standards and are raising their ambitions to meet them. However, there is clearly no room for complacency and the message is very clear - great work to date, but a significant journey is still ahead of us."

For more information on the IBD Standards, including the updated document, please visit www.crohnsandcolitis.uk/ibdstandards and/or the dedicated website www.ibdstandards.org.uk.

Jackie Glatter, Health Service Development Adviser, Crohn's and Colitis UK
E-mail: jackie.glatter@crohnsandcolitis.org.uk.

Crohn's and Colitis UK has just published "Suffering in silence - the psycho-social impact of IBD on young lives"

Based on the findings of the Me and IBD Survey of nearly 1,100 adolescents (16 – 29 – being the most likely age of diagnosis) at the beginning of 2013 , the new Report reveals that a third of young people living with IBD feel isolated and have concerns about their future as a result of having to cope with their overwhelming symptoms.

Crohn's and Colitis UK CEO David Barker explains, "Too many young people in the UK are suffering in silence. These findings remind us all that a diagnosis of IBD brings with it not just a medical impact but a very significant psychological and social impact. 32% of the young people responding to our survey report living isolated lives as a result of their acutely embarrassing and sometimes life-threatening symptoms. Greater awareness, understanding and acceptance of these devastating conditions amongst teachers, education professionals and within the general public is what we need if we are to begin to reduce some of the challenges they face."

The findings from the survey show:

» One third of young people felt that their IBD affected their ability to attract a girlfriend or boyfriend and that the illness had negatively affected a long-term relationship with a partner.

» Many young people with IBD can suffer with particularly aggressive disease, involving multiple surgeries which can negatively impact on their relationships and their futures.

» 20% stated that their symptoms of extreme tiredness made it hard to have a social life.

» 11% of the young people stated their

future fertility was their main concern, often as a side effect of multiple abdominal surgeries.

» With the added challenge of reduced access to fewer public toilets, more than 1 in 10 were fearful of being incontinent while out.

» One in ten was unable to tolerate alcohol, adding further pressure and awkwardness to social situations at college/work.

» The wide-ranging, negative impact on a young person's life is summed up by one survey correspondent who wrote "I don't just need medication - I need some help to cope with being ill. It is destroying me psychologically."

The new Report, the third from the Survey, is available to download from the Me and IBD website www.MeandIBD.org.uk or from the charity's main website www.crohnsandcolitis.org.uk along with the other two reports which identify the concerns of young people with regards to their communications with their education and healthcare professionals.

Suzi Clark, Crohn´s and Colitis UK

Poland

The more the merrier

On 8 November 2013 at the Musical Theatre of Lodz a very special charity concert entitled "The power lies in a group - The more the merrier" organized by the Lodz Affiliate of the J-elita IBD patient association took place.

The event was unique because of its noble aim to support IBD patients in need. That's why the tricky advertising slogan was chosen "the more the merrier" meaning that the strength, the power of actions and new challenges lies always in a strong, friendly group of open-minded and open-hearted people, who want to act together for a better tomorrow of IBD patients. All proceeds of the concert went to J-elita to support IBD patients.

The Concert was divided into two parts. During the first part the choir The Gospel Time appeared on the stage singing both gospel and popular songs and playing instruments. At the beginning the artists performed dressed in classic black and white dresses and suits and as the music and atmosphere livened up, they changed into more colourful clothes. The choir charmed the audience with its great voices and the music simply caught our hearts and souls.

The second part of the concert was consisted

of a completely different type of music played by the Soundbusters group of beat-boxers. A combination of enthusiastic gospel music with talented beat-boxers gave us all a shot of positive energy and made for an unforgettable impression. During the breaks the artists in a spontaneous manner created a great relation with the audience and everyone joined in clapping hands to the rhythm of the music.

Another special attraction were the video films and pictures shown on beamers made by and taken by IBD patients, who call themselves with the Polish term “CuDaki”. This term combines the two abbreviations for both inflammatory bowel diseases, namely CU for ulcerative colitis and CD for Crohn’s disease. The word “CuDaki” has in Polish also another meaning: “strangers”. The films and pictures were patients testimonies showing how they can cope with the disease, how they can live their lives, fulfill their dreams, realize their plans despite the disease. They formed a unique background to the stage appearing and disappearing while the artist were singing and playing. The testimonies in films and pictures were also a great support for other patients helping them to step out from the shadow, to conquer their everyday fears and anxieties caused by the chronic, disabling disease.

The seats of the concert hall were almost all filled including members of J-elita, their relatives and friends, doctors, nurses and other medical staff, priests and all others who wanted to listen to this energetic and vibrant mixture of music. Closing the concert the presenters thanked all charity donors, organizers, musicians from both groups and all these persons without whom the concert could not have happened.

After the concert a sweet surprise was waiting for all the guests – a huge, delicious cake with J-elita logo and “the more the merrier” written on top.

Joanna Sieczka, Kuyavian-Pomeranian Affilate of J-elita Association

Transaltion: Maria Wisniewska-Jarosinska, Lodz Affiliate of J-elita Association

Bulgaria

New publication

At the end of 2013 Bulgarian Crohn’s and Ulcerative Colitis Association (BCUCA) published a Handbook for people living with IBD. The purpose of the book is to present in an accessible and easy-to-understand manner information on different aspects of the diseases, to answer some of the questions almost each patient with IBD has already come across, as well as to provide some ideas and “little tricks” which could help IBD patients overcome the challenges they face in their everyday life more easily.

The Handbook is the result of the collaboration between BCUCA and Crohn’s and the Crohn’s and Colitis New Zealand Association which has given the copyrights of a similar handbook it has released free of cost.

Working closely with the gastro-clinics, the ambition of BCUCA is to provide a copy of the Handbook to all newly diagnosed IBD patients in Bulgaria.

Martin Kojinkov
Bulgarian Crohn’s and Ulcerative Colitis Association (BCUCA)

Belgium

Crohn-o-Bike

On Sunday, November 17, a sporting event called "Crohn-o-bike" was organized in Mons-Expo. The challenge was to gather hundreds of people supporting IBD by cycling on exercise-bikes to ride 150 virtual kilometers, and every kilometer would be sponsored by different enterprises at the fare of 1 euro for every kilometer ridden on these static bikes.

The idea of this great challenge came from one young patient's father belonging to a business club (Club41 from Saint Ghislain, near Mons). He asked the French and the Dutch speaking IBD associations in Belgium to help him realize this wonderful idea.

The success has been on the cards : from 10 am to 6 pm, one hundred and forty teams (made up by 2-8 people) cycled the 150 km !!!

Among these teams, we were happy to have some gastroenterologists' teams, pharmaceutical representatives' teams and an IBD nurses team. Two nice coaches and swinging beats livened things up.

Various meals (Belgian fries!) and drinks (Belgian beers !) provided this event with a true party taste. We also made sure to organize activities for kids so as to allow parents to cycle and to party.

The atmosphere was so great that a lot of participants have asked us to do it again, and a lot of patients who couldn't attend have asked it too when they saw the pictures...

Xavier Donnet, Association Crohn-RCUH

Germany

Using new media for providing information on IBD

Last year the German Crohn's and Colitis Association (DCCV) has taken steps towards using new media in a more active way: in addition to our website– which will be completely relaunched in 2014 – DCCV has started to use Twitter on the channel @ dccv_Germany and is also much more active on Facebook to inform those who are interested in news concerning IBD and activities of the DCCV.

Moreover, for the first time a live streaming of a lecture of six experts has been broadcasted on the internet. These lectures have been uploaded as separate videos and are now part of the new DCCV-Youtube Channel (https://www.youtube.com/dccvvideo). Our channel has been set up in December 2013 and might be interesting for those of you who speak German. We already offer up to ten videos on different topics. Within the next three months another five videos will be uploaded as we had the opportunity to make more videos on IBD and how to live with it. Thanks to two well-known experts who offered to spend a day in front of the camera for free and to the sponsorship of a Compulsory Health Insurance Company we were able to make these films within two days.

The first two of these videos is dealing with explanations about what Crohn's or Colitis actually are and how to treat it. Other topics will deal with issues such as colonoscopy, pregnancy and IBD, and how family and friends are dealing with the situation of a friend, child or co-worker having IBD. The feedback so far has been very positive: within only ten days the videos were being watched a thousand times and we received many positive and thankful remarks and emails.

With buying a small camera and using that to record lectures of experts during our physician-patients-seminars we hope in future to be able to get even more information on video to offer to IBD patients.

Ella Wassink, DCCV

Sweden

The latest news from our organization is that we've now completed our project IBD by Remote Control (IBD till låns in Swedish). The project consists of a website and short films we've made about what it's like to have IBD. The goal of the project is to raise awareness about gastrointestinal diseases and IBD among the public. In the films famous people of different sorts (like bloggers, politicians, artists and so on) have "borrowed" IBD for a day. During the day they've got text messages on their mobile phone from a young person with IBD. The text messages gave the famous persons instructions that they were obliged to follow, such as "You've got severe stomach ache. You can't eat for the entire day and have to sit 20 minutes on the toilet". The original idea is from Norway.

It's all been successful and through the films we've managed to raise awareness among young people about these conditions. The last film of the project was released 13th of December 2013. It was a film where young people with IBD thanked everyone for watching and learning about IBD. The films are available at youtube.com and the project website http://magotarm.se/ibd .

We've also developed our Iphone-app Toahjälpen ("The Toilet Aid") for the city of Gothenburg together with the company Yomaco. The app was already available for Stockholm and Visby, the capital of the island Gotland. Now you can download the app for Gothenburg too, in order to quickly find a toilet near you at the very moment you need it. The apps for Toahjälpen are available for free through App Store.

Ebba Persson, Youth editor, Unga Magar, Mag- och tarmförbundet/ The Swedish Stomach and Bowel Association

France

Encouraging results for the first WORLD TOILET DAY!

Access to toilets : A public health issue worldwide… and a 100% French problem! Afa launched a big citizenship campaign to challenge the politicians and to register the number of public toilets throughout France.

World Toilet Day is commemorated each year on 19th November and some may find this funny…This day clearly opens the heart of an alarming reality: 2.5 billion people in the world do not have access to toilets and 2 million children die every year due in great part to a lack of good sanitary conditions. The objective of this day is to alert the public on a capital issue at a planetary level. Even the UN is involved!

Last 24th July, the UN General Assembly adopted a resolution instituting the World Toilet Day which will be commemorated on 19th November. « One out of three people (throughout the world) does not have access to decent sanitary conditions", declared Jan Eliasson, Vice-Secretary General at the United Nations.

Nevertheless, this matter of hygiene isn't only a problem in the southern countries. In France, it is equally hard to mobilize public opinion and the politicians on this subject – and yet of general interest to all – not always taken very seriously… Afa wanted to take this issue to the national level through concrete action in the interest of all concerned.

There was a dual objective in this day and we are very proud of what was accomplished ...

1) Alert the political authorities on the availability of toilets in France

Over one thousand mayors received our flyer with an attached letter inviting them to place public toilets on their list of actions in the municipal election campaign and to give us the GPS position of their toilets to be on the "afa Mici » smartphone application, developed by afa, geo-localizing the nearest toilets.

A great number of deputies were also alerted about this problem. Many have communicated their support and one of them took the initiative of being our spokesperson by proposing our recommended legislation to the French government for a public toilet for every 5 to 10 000 inhabitants.

Even more, thanks to the implication of our delegates and other volunteers in the field, new "emergency toilet" conventions are on the way to be signed in 2014 in cities like Nice, Aix en Provence, Montpellier, Chambéry, Aix les bains, Lons le Saunier… (and many more).

2) Raise awareness and to make an inventory of the toilets throughout all of France on Afa's smartphone application for all of the patients

Afa Patients or their family or friends responded to our call to meet shopkeepers in their neighborhoods to inform them of the afa toilet project and asking them to be referenced in the afaMici application to compensate for missing public toilets.

The new V2 application on the new afa website, launched on the World Toilet Day, also enables people without a smartphone to register toilets on the internet.

Finally, there was good media (press, radio and TV) coverage in the French regions. It was another opportunity to talk about Crohn's disease and ulcerative colitis, about the lack of available toilets (both public and private) and about the strong action afa is taking. And tomorrow ? Why not have a European application with a European inventory!

Madeleine Dubois, AFA

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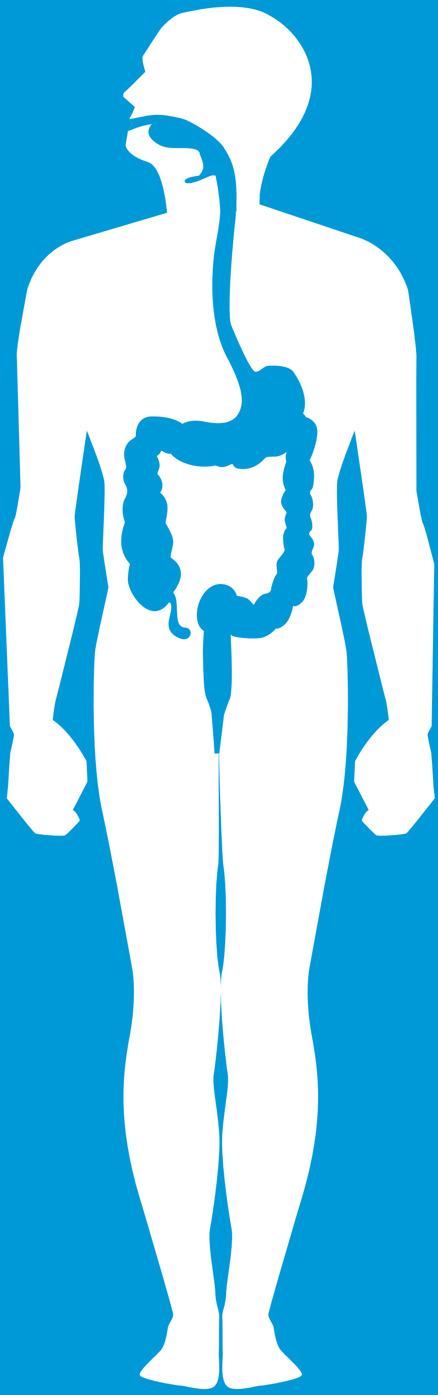

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PA/030/2014/CH3a

Out of sorrow comes hope…

Interview with Alessandra Incerti

Alessandra is an inspiring young woman who decided to turn her grief into something positive. Having lost her Moroccan partner who suffered from Crohn´s disease, Alessandra has decided to put her efforts into supporting and helping other people with IBD in his country.

What is your motivation for setting up a patient association in Morocco?

It´s for a sad reason. My fiancé ,who was from Morocco, fell ill in 2010. At first we didn't know what was wrong with him and it took over two years until he finally was diagnosed with Crohn´s Disease. In Morocco the disease is not very well known and his physician and the general doctors were not really aware of it. I myself had never heard of it.

We were looking for a support group to see how other people coped with the disease. We found such organisations in Italy, France, UK, Belgium etc. but we couldn't find any similar organisation in Morocco. This was really hard for my fiancé because he felt alone and so different from everyone else.

Unfortunately by the time he was diagnosed he had lost so much weight and the doctors couldn't´ save him anymore.

This has been a turning point in my life and I made a promise to myself: to try as long as I can to help other people in Morocco affected by IBD. That's the main reason why I really would like to set up a patient association. For us it would have been so useful at that time to be able to meet and to speak to other people who were going through a similar experience.

What were your fist steps?

As I mentioned we had found a lot of information on the internet and I got in touch with Afa, the French IBD patient association. Sadly it was too late for my fiancé but the contact with Afa helped me a lot. First of all it was good to tell my story to someone who could understand me and secondly it showed me how supportive a patient association can be. I got plenty of ideas about what I want to do.

Through Afa I also got in touch with other IBD patients and went to Morocco to meet them. The people I spoke to also feel that there is a need for a patient association but they found it very difficult to find volunteers and to get people involved and one girl told me "our society is not ready yet for this". It has been a bit frustrating because I feel there are many obstacles but then I say to myself that Rome hasn't been built in a day, has it?

On the other hand I also had meetings with doctors there and spoke to one IBD specialist who was very supportive of the idea. She said that her patients often ask her about organsiations that could help and she would be interested in cooperating.

In your view, what are the main problems people with IBD face in Morocco?

I think the main problem is an economic problem. Once you have been diagnosed with IBD you will have to find a way to pay for your own medications, which are very costly, or for an operation if needed. There is limited health care service but this is available only for people employed by the state or with high income levels. It is also difficult to get a private health insurance if you have a chronic disease.

What are your plans for the future?

I will continue my efforts to try and set up a patient association in Morocco and I am open to hear from people. I believe it is important to actually be in the country to get things moving more quickly, at the moment this is not an option for me for work reasons.

I am in touch with Afa who informed me of an important meeting in Paris with doctors from the French speaking world, the "Journées Francophones d'Hépato-gastroentérologie et d'Oncologie Digestive" from 20-23 March 2014. There will be a group of IBD specialists including doctors from Morocco. Afa has agreed to be in contact with these doctors to see if we can get a committed group together. I am also hoping to be in contact with other associations and organisations that might be able to help.

Do you think you fiancé would be still alive if there had been more help around?

This is difficult to say, for sure if he had received his diagnosis earlier things could have been different. It would have definitely helped us a lot to have the support of a patient association and to be able to talk to other people. It has been a very tough and lonely experience.

If you would like to volunteer, give some strategic advice or have some ways to help please get in touch with Alessandra at:

incerti.alessandra@gmail.com

Investing in education

By Sanna Lönnfors

Having received an educational grant from EFCCA I have had the opportunity to participate in a conference organized by the European Medical Writers Association which took place in November last year.

I attended the workshops on Health-Related Quality of Life, Statistics in Medical Writing, Introduction to Health Economics and Basics of Genetics for Medical Writers.

The workshop on Health-Related Quality of Life (HRQoL) concentrated on learning how to use and understand various instruments for measuring HRQoL for different purposes. In the statistics workshop, basic statistics were introduced; although statistical analyses and the actual calculations are usually done by statisticians, medical writers need to understand the data they work with. The genetics workshop helped participants to understand the basic genetic principles. Medical writers need to have a basic understanding in many different fields of science, and to be able to communicate new genetics-related research or study results.

Working as a freelance medical writer for EFCCA, I have written scientific articles and posters, conference abstracts and study reports. I attended my first EMWA conference in Berlin in 2011 and the second one in Barcelona in 2013, wanting to complete four more workshops towards an EMWA certificate in Medical Writing.

Although there was a lot of new information to adapt in a short time, the experienced workshop leaders managed to make the learning fun, engaging and interesting; instead of listening to lecturing for a full three hours, the workshops usually include at least one exercise in groups or pairs, enabling interaction among the participants.

IBD research foundation

New management board team

At this time our foundation is still in the process of changing its way of working. We aim to select a specific research project first and then raise funds for that particular project. We expect that this way of working will enable us to support a larger project. What's more, we also hope that this way of working makes it more attractive for associations to help us with fund raising. However, the success of this new way of working depends on whether there are enough people willing to help us within the foundation.

Fortunately quite recently we found Marko Perovic from Serbia willing to help us. As Marko has outstanding qualifications to join our management board team, we were very pleased when the supervisory board appointed him. Please let us introduce our new management board member.

Marko is 36 years old, and he was diagnosed with Crohn's disease at the age of 16. He graduated at the Belgrade university and he is currently finalizing his thesis, which looks into illness as a phenomenon of postmodern individuality, identity and it discusses how illness in our times impacts one's identity and image of oneself, and how one's perception of the other is influenced by the notion of illness.

Furthermore, Marko has been working at an international NGO dealing with socio-economic support to vulnerable migrants and at the United Nations Development Program on various projects targeting vulnerable populations. He also worked on a health project at the Ministry of Health.

In his different functions, Marko gained significant skills in project management and in project development. The research Marko has been involved with, has mostly dealt with social inclusion, i.e. access to rights and services. He also has been involved in drafting questionnaires and assisting in design of research methodology, conducting interviews and surveys, compiling data, co-authoring reports and proofreading. He is skilled in working with vulnerable populations and in working with the civic society. Marko has sound knowledge of social media and he also has experience in fundraising in the local context.

Marko joined UKUKS (Serbian IBD Association) in early 2012, and he has been actively involved in organizing various community/social events, actions aimed at mobilizing the public, promotions etc. He also prepared several project proposals to raise funds for the association's activities and contributed to setting strategic direction of UKUKS as a young association.

Marko's motivation to join our foundation:

"My social science academic background and experience in research and social inclusion is well coupled with my personal interest in contributing to betterment of the position of IBD patients in Europe. I believe that research is vital to fighting IBD: it opens way for new knowledge and gives impetus for further fight towards finding the cure. On the other hand, I believe that strong and effective research can support work of national IBD associations in increasing IBD awareness and promoting patients' rights and perspectives. In return, research needs to be based on actual needs expressed by European IBD patients. This is why I believe it is important to increase the visibility of IBD research, to promote partnerships and to strengthen the position of the foundation among European IBD associations, to enable adequate fundraising and perspective for further research, being the only promise for the cure."

Donations

Donations can be made either through the website (www.ibdresearch.org) using a credit card, or through a transfer on our bank account:

ABN AMRO Bank the Netherlands
Account number: 97.46.86.158
IBAN: NL37ABNA0974686158
BIC: ABNANL2A

Contact

Wouter Miedema – Secretary
Hemmerbuurt 130
1607 CM Hem
The Netherlands
info@ibdresearch.org

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Twitter: @ibdresearch

Health First Europe

Model For Community Care

Aiming to meet the enormous challenges faced by health systems across Europe, Health First Europe has launched its' Model for Community Care which it has elaborated together with other stakeholders including EFCCA.

Meeting with EU Health Commissioner Tonio Borg, on 9 December 2013 Health First Europe members called for the European Commission to prioritise community care on the EU health agenda and bring forward a dedicated policy.

The HFE Community Care Model is a road map identifying six areas of needed reform to facilitate care that puts citizens at the centre of the system. The model focuses on establishing guiding principles to increase patient empowerment, preventive care and innovation to benefit citizens, carers, health systems and society.

Community care is about integrating patient care across the continuum of life. It is the missing gap between acute, treatment-driven demand, and normal, healthy living. In some cases, community care will redefine the relationship between different providers of treatment, and in other cases introduce new stakeholders, but essentially it will provide another channel of "healthcare" based on a more patient centric and patient empowered model using innovation to attain long-term benefits that can contribute significantly to improving the well-being of each of us.

"Health systems continue to rely on a model where patients are cared for on the basis of acute episodes. With the rise of chronic diseases, this system will no longer be able to meet the demands of patients at the level of quality required. Community care can support overall citizen health and well-being in order to prevent the onset of disease, but also to ensure that care is managed in partnership with the citizen, throughout his/her life – not just during episodes of care. " stated Health First Europe Honorary President John Bowis.

Representing healthcare workers, Health First Europe Vice-President Bert van Caelenberg agreed and argued that, "Community care offers many opportunities for healthcare workers. I hope that upcoming European Commission initiatives in 2014 focus on how professionals, patients and innovation can continue to be better connected to provide high quality care throughout the EU."

For more information, please contact:
Amanda Bogg
Director
info@healthfirsteurope.org
+32 (0)2 626 1999

UEG's elects new President

Michael Farthing, University of Sussex, UK is taking over from Colm O'Morain as UEG President for 2014-15. In a video he explains more about key targets such as identifying and promoting young talents in UEG and other strategic plans of the new Executive Team for the upcoming years.

He stresses that UEG is ready to face the challenges ahead such as for example the uncertain the economic situation and rising health care costs. One way of facing these will be to introduce live streaming of the many lectures and symposiums of the UEG Week and to enhance capabilities of online distance learning. Also the UEG journal which has been launched last year will act as an important way of communication outside the large annual meeting.

The video can be seen at https://www.ueg.eu/about-ueg/who-we-are/strategic-plan/?vstart=true

European Commission

New report on health inequalities in the EU

A new EU-funded report "Health Inequalities in the EU", produced by a consortium led by Sir Michael Marmot (University College, London), was published recently.

This report provides an outline of new evidence on health inequalities in the European Union (EU) and the policy response at EU and national level to health inequalities since 2009.

The report confirms significant health inequalities between and within EU Member States. The size of the health inequalities is for the most part similar to that identified in a previous report published in 2006.

The report warns that the current financial, economic and social crisis is threatening to undermine existing policies, and may negatively affect health inequalities. It urges that tackling health inequalities remain a priority and be mainstreamed into the health sector's core policies, and addressed also by other sectors. The report puts forward key recommendations for the Commission, EU Member States and Regions.

To read the full report, please go to:
http://ec.europa.eu/health/cross_border_care/docs/cbhc_leafletet_en.pdf

Horizon 2020

The European Commission has for the first time presented calls for projects under Horizon 2020. Worth more than €15 billion over the first two years, the funding is intended to help boost Europe's knowledge-driven economy, and tackle issues that will make a difference in people's lives.

Horizon 2020 is the biggest EU Research and Innovation programme ever with nearly €80 billion of funding available over 7 years (2014 to 2020) – in addition to the private investment that this money will attract. It promises more breakthroughs, discoveries and world-firsts by taking great ideas from the lab to the market.

Horizon 2020 is the financial instrument implementing the Innovation Union, a Europe 2020 flagship initiative aimed at securing Europe's global competitiveness.

Seen as a means to drive economic growth and create jobs, Horizon 2020 has the political backing of Europe's leaders and the Members of the European Parliament. They agreed that research is an investment in our future and so put it at the heart of the EU's blueprint for smart, sustainable and inclusive growth and jobs.

By coupling research and innovation, Horizon 2020 is helping to achieve this with its emphasis on excellent science, industrial leadership and tackling societal challenges. The goal is to ensure Europe produces world-class science, removes barriers to innovation and makes it easier for the public and private sectors to work together in delivering innovation.

Horizon 2020 is open to everyone, with a simple structure that reduces red tape and time so participants can focus on what is really important. This approach makes sure new projects get off the ground quickly – and achieve results faster.

The EU Framework Programme for Research and Innovation will be complemented by further measures to complete and further develop the European Research Area. These measures will aim at breaking down barriers to create a genuine single market for knowledge, research and innovation.

Health, Demographic Change and Wellbeing

Many challenges need to be met to grant everybody's legitimate wish for a long, happy and healthy life. Chronic and infectious diseases, pandemic threats and antimicrobial resistance are on the rise. Also, the side effects of an ageing population will need to be addressed - the number of people in the EU aged over 65 will have grown by 70% by 2050.

European research and innovation in health helps to tackle these challenges. It is an investment in our health and, on a larger scale, an investment in a healthy workforce, a healthy economy and lower public health bills.

Finally, European research and innovation in health is about working together across borders, sharing each other's knowledge and resources and improving our health and care system together.

Under the Horizon 2020 Sections: Health, Demographic Change and Wellbeing there are currently 3 calls for proposals for the 2014:

Personalising Health and Care
Deadline: Tue, 11 March 2014
Personalising Health and Care
Deadline: Tue, 15 April 2014
Personalising Health and Care
Deadline: Tue, 14 October

For more info: http://ec.europa.eu/programmes/horizon2020/en

Health Commissioner, Tonio Borg, welcomes agreement on the revision of EU rules on Clinical Trials

"Clinical trials are indispensable for developing and improving medicines and ensuring that EU patients can have access to the most innovative and effective treatments, under high safety and ethical standards. The revised rules will ensure that the EU remains an attractive location for clinical research – which is of vital importance for Europe's competitiveness and innovation capacity. I welcome that the new rules will take the form of a Regulation, which is directly applicable throughout the European Union. " stated Commissioner Borg after an agreement was reached on the revision of the EU rules on clinical trials.

Background

Clinical trials are investigations in humans intended to discover or verify the effects of one or more investigational medicinal products ("IMPs").

Requirements for the conduct of clinical trials in the EU are provided for in " Directive 2001/20/EC of the European Parliament and of the Council of 4 April 2001 on the approximation of the laws, regulations and administrative provisions of the Member States relating to the implementation of good clinical practice in the conduct of clinical trials on medicinal products for human use" (" the Clinical Trials Directive ").

Clinical trials performed in the European Union are required to be conducted in accordance with the Clinical Trials Directive. If the clinical trials are conducted outside the EU, but submitted in an application for marketing authorisation in the EU, they have to follow the principles which are equivalent to the provisions of the Clinical Trials Directive.

EudraCT

A European database - EudraCT - contains all ongoing or completed clinical trials falling within the scope of Directive 2001/20/EC, i.e. with at least one investigator site in the EU (incl. the European Economic Area) and commencing after implementation of Directive 2001/20/EC by the Member States. This database gives the competent authorities of the Member States, the EMA and the Commission the necessary information to communicate on clinical trials and to maintain oversight of clinical trials and IMP development. This provides for enhanced protection of clinical trial subjects and patients receiving IMPs.

Revision of the Clinical trials Directive

On 17 July 2012, the Commission has adopted a "Proposal for a Regulation of the European Parliament and of the Council on clinical trials on medicinal products for human use, and repealing Directive 2001/20/EC(767 KB) " (hereinafter "Clinical Trials Regulation").

The proposal has been adopted by the Council on 20 December 2013.More info on: http://ec.europa.eu/dgs/health_consumer/index_en.htm

Shire's mission

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

Shire's vision is to continue to identify, develop and supply specialist life-changing products that support physicians in helping their patients to a better quality of life. Fostering innovation and delivering value not only promises a better understanding of diseases but also provides the best hope of treating and eventually eliminating them.

History and growth

Since its foundation in 1986, Shire's endeavour to provide innovative treatments for medical needs that are left unmet, coupled with substantial investment in research and development (R&D), has resulted in considerable growth and diversification.

Shire's focus on improving outcomes for patients with GI diseases

Gastrointestinal diseases affect millions of people, reducing quality of life for both patients and their families. These diseases also add to overall healthcare costs. Finding new medicines will help reduce that burden.

- Shire understands the unmet needs of patients with GI diseases and endeavours to provide innovative treatments to the specialist physician for the benefit of the patient.
- Shire aims to be at the forefront of the development and provision of treatments for GI diseases including ulcerative colitis, chronic constipation and gastro-oesophageal reflux disease.
- Shire is determined to build and maintain relationships with patient advocacy groups, both through providing research funding and education, as well as encouraging a regulatory environment that supports innovation and value.
- Shire is committed to providing new treatment options and working in partnership with physicians that make a real difference in the lives of patients with GI diseases.

INT/BU/MEZ/12/0027 Date Of Preparation: May 2012

To be as brave as the people we help.

Latest developments in the treatment of

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In the recent years, many clinical trials have been conducted to search for a more effective treatment for Inflammatory Bowel Disease. In particular, a new drug has recently been approved for the treatment of Ulcerative Colitis (UC).

This disease affects 1.1 million people in Europe and 2.5 million in the world, and for these patients golimumab is now available. This drug, an antiTNF-alpha antibody, still approved by the U.S. Food and Drug Administration, has recently been approved also by the European Regulatory Authority, called the Committee for Medicinal Products for Human Use (CHMP).

For this approval, data from two trials, belonging to the same development program, were considered. The *"Program of Ulcerative Colitis Research Studies Utilizing an Investigational Treatment (PURSUIT)"* evaluated golimumab regarding its safety, the definition of the induction and maintenance doses and its efficacy. These trials were the Induction study (PURSUIT-SC) and the Maintenance study (PURSUIT-M), multicenter, randomized, double-blind, placebo-controlled trials conducted between July 2007 and October 2011.

Efficacy

These two studies have demonstrated the efficacy of subcutaneous administration of golimumab, for the treatment of moderate-severe Ulcerative Colitis in adult patients with insufficient response or intolerance to conventional therapy, including corticosteroids, 6-marcaptopurina (6-MP) or azathioprine (AZA).

In PURSUIT-SC study were enrolled 1065 patients. In the golimumab group a significant proportion of patients reached clinical response and clinical remission at week 6, as measured by evaluating the presence of rectal bleeding, the stool frequency and the endoscopic evaluation of bowel mucosa. Even Petients' quality of life, as measured by the specific Inflammatory Bowel Disease Questionnaire (IBDQ), improved in this group, when compared with the patients treated with placebo.

The PURSUIT-M trial enrolled 1228, and golimumab group showed a significant maintenance of clinical response until week 54.

Induction and maintenance doses

During induction, the most effective schedule was represented by a first dose of 200mg, followed by a second dose of 100 mg administered two weeks after. The 200/100 mg scheme was superior, after 6 weeks, to the 400/200 mg ones in terms of clinical remission, mucosal healing, decreasing of the partial Mayo score and of the C-Reactive Protein (CRP), and quality of life improvement.

The maintenance approved dose is based on body weight and can be upgraded in relation to clinical response. For patients with body weight inferior to 80kg, the maintenance dose is of 50 mg every four weeks; while for patients with body equal or superior to 80kg, the maintenance dose is 100mg every four weeks.

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In case of loss of response during the maintenance phase, patients receiving 50mg every 4 weeks, could increase the dose to 100mg every 4 weeks, while patients treated with 100mg every four weeks could upgrade the dose to 200mg every 4 weeks.

Safety

The drug was well tolerated by almost all the patients. During both the induction and the maintenance trials the incidence of adverse events and infections was similar to placebo group.

The most common were infection, arthralgia, abdominal pain, headache and rash. Some differences were noticed as regarding skin reactions and allergic or hypersensitivity events between induction and maintenance study. Injection-site reaction were uncommon, but skin rashes were reported in some cases during the induction trial, with no no allergic or hypersensitivity reactions.

Otherwise no skin reaction and only some allergic or hypersensitivity reaction was noticed during the maintenance trial, even if in a similar proportion of patients both in the golimumab and in the placebo group. Globally no anaphylactic reaction was reported.

Conclusions

This therapy is a new intriguing option for the treatment of ulcerative colitis. It could in fact induce clinical response and remission of the disease and help to improve quality of life of patients with a good safety profile. Moreover the possibility of self administration certainly is a good option for patients, which will not have the need to spent much time in IBD Center for drug administration, but will only reach the hospital for drug dispensation.