

EFCCA MAGAZINE

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



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EDITOR'S EYE

Time to turn ideas into reality



Many of you already know that at the end of May, the “EFCCA family” gathered once again for its Annual General Assembly. This time our Polish friends from J-elita were kind enough to welcome us and make us feel-at-home in their capital – Warsaw. Warsaw is particularly beautiful in springtime – the season that is typically associated with rebirths, rejuvenations and regrowth.

And so in parallel, our AGM, also gave birth to several new beginnings:

The 2017 Work plan and budget have been approved by delegates which contain various projects and initiatives, that are probably bigger in scope and number, compared to previous years.

Secondly, the EFCCA family has once again expanded with a new member – the Estonian association, EESTI, has been unanimously approved as full-fledged member. With all the enthusiasm and commitment that our Estonian representative has demonstrated so far, I am sure this new member will enrich and further strengthen EFCCA.

On the more internal side, the EFCCA Board has been renewed following the expiry of the mandates of three of the Board members and the Internal Regulation – our “House rules” have been refurbished, in line with the new Constitution. I am convinced that the new Board members will bring continuity, experience and some fresh ideas, whereas the new Internal regulation will provide a firm basis for EFCCA’s everyday operations in the years to come.

But the General Assembly is a forum which is traditionally not only used for adoption of formal decisions, but it is also an opportunity for networking and bringing to life new ideas: within the meeting, three workshops took place – one dealing with nutrition, one on Summer camps for youngsters with IBD and the last one – on easing some of the daily challenges people with IBD face (the Toilet locator project).

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revised 22/2/2006
No. 459814543

In this edition of the EFCCA magazine, you can learn more about the outcomes of the workshops as well as some other interesting brainstorming events and initiatives that are currently under development throughout Europe. One such example is the Biologics and Biosimilars Policy workshop that took place in Warsaw. Another one – the EFCCA Academy, a pioneering project that aims to train certified patients to raise awareness on IBD.

Usually, the beginning of all such initiatives is accompanied with a lot of enthusiasm, but often the momentum is along the way. This is even more true for voluntary-driven organizations and you may have already experienced it yourself.

Now, in the beginning of autumn, it is probably about time that we start “harvesting” some of the seeds we have planted earlier during the year. To convert the brainstorming sessions and the workshops into more tangible, concrete outputs and results. For the benefit of all people living with IBD!

It is now time to turn our ideas into reality!

United We Stand

Martin Kojinkov, EFCCA chairman



EFCCA ACADEMY: Turning Patient Survey Outcomes to Actions

In 2014, EFCCA published the results of the IMPACT study, previously a large international patient survey had been published in 2013. Then in 2016, the Boston Consulting Group research company connected the IMPACT results with the outcomes of their own patient survey from Italy, Sweden and the UK, in a White Paper. All results showed similar findings, underlining main themes within the unmet needs of the IBD community.

EFCCA's project "From IMPACT to Impactful" aimed at acting on these findings by having patients and doctors brainstorm about potential future activities. The project received an unrestricted educational grant from Takeda and was structured into two workshops that took place in Berlin in March and April 2017.

A group of delegates from EFCCA member associations and physicians met to analyze and discuss the findings of the White Paper and the Impact study. During the first meeting, the patient focus group identified the key issues in the publications and brainstormed about viable solutions. The group listed the following topics to be addressed in future activities:

- The importance of early diagnosis > educating medical students, GPs, nurses
- Patient education > importance of compliance
- Overall (direct / indirect) costs - medicines are just a small part of the IBD costs; costs should be analyzed more holistically
- Low awareness about IBD (general public and GPs / nurses; discrimination, work and school), provocative campaign for raising awareness, break the taboo
- Patient empowerment
- Young people seem to suffer the most (can't perform fully in studies, more sick days, more likely to seek access to nurse or psychologist)
- Collecting and sharing data

Furthermore, the group brainstormed about different solutions to above mentioned issues. Among others, the brainstorming resulted in the following ideas:

- Lectures could be given at universities by

"certified" expert patients. These patients would be educated to educate General Practitioners (GPs) / medical students/ GPs would get education credits for attending training.

- More opportunities should be developed for home monitoring (e-health).
- Regular health check-ups could be organized as a screening measure, e.g. through high schools.
- find a (clean) toilet apps
- Using humor in campaigns, making them fresh, provocative; competitions, awards, etc.
- pan-European campaign for youth / adults / seniors, concentrating on the issue in that age group (work, studies, labor rights)

For the second meeting, the EFCCA delegates met with physicians to further discuss the topics and plan potential further actions based on the brainstorming of the first meeting and three main topics that will be further developed: 1) Awareness raising actions 2) Training "certified" patients and 3) Data collection and ownership by patients

The brainstorming resulted in the idea to develop a pioneer project to create an EFCCA Academy that will train Certified Patients to raise awareness on IBD. Certified Patients would be trained in public speaking, communication skills and in strategic topics, such as life management with IBD, patient rights, work discrimination and labor rights, and to effectively use their own patient experiences and the outcomes of EFCCA surveys.

The EFCCA Academy would train Certified Patients in the pilot phase, and later people who are qualified to train Certified Patients in their own

communities. Certified Patients could work on raising awareness in multiple ways by speaking/teaching on different topics in various events and settings.

The EFCCA Academy will aim to develop partnerships within the IBD HCP community e.g. ECCO, UEG, ESPGHAN, EMA, etc. Cooperation could include developing topics covering guidelines – basics, nutrition, medications, communication with patients (adult/pediatric), how to deal with the health care system, how to deliver patient community's message to pharma companies and how to handle pharma representatives, how to convey the message that IBD is an invisible illness etc.

EFCCA is now ready to launch the pilot phase of the Academy that will be based on a “Certified Patient Course Curriculum”. The Certified Patient training will include a weekend face-to-face workshop, after which the studies would continue via EFCCA's online learning platform. The pilot phase will be carried out in English and there will be a final face-to-face exam. The project will be then taken to local level with local language so Certified Patient Trainers would be training new Certified Patients locally.

The following potential workshops came up in brainstorming and will be carried out either face-to-face or online:

- Aims of the program (Common presentation of main aims of the certified patient program and main messages etc.)
- Public speaking/ Media training
- Communication skills
- Advocacy – how is it done, what is the patient association's role
- Work discrimination and labor rights
- Patient rights
- Crash course on medical/scientific language
- Early diagnosis – Why it is important and how to promote it?
- Main messages of EFCCA surveys – How to interpret and use the data? How to present it?
- How does the health system work? (To be done at the local level, but there could be a general workshop where e.g. EFCCA mapping survey outcomes can be used)

- Life management for IBD patients – how to take ownership of your disease, diet's role
- How to develop fruitful collaboration with stakeholders

The training will be divided into “educational blocks” or “work packages”. In this way, patients could be trained in several areas and then sort of at the end they specialize in some targeted areas, such as: General public, Schools, kindergartens, student unions, Public authorities as well as the IBD community including nurses, doctors (general practitioners, emergency room), dieticians, psychologists, conferences, pharma industries.

After the first group graduates, a register of EFCCA Certified Patients will be created and graduates will commit themselves to be actively involved in Certified Patient responsibilities (raising awareness about IBD etc. tbc) .

Be ready for the next steps

An outline of the curriculum, EFCCA Academy selection criteria and requirements for Certified Patients after completing the training are ready to be delivered to implement the pilot phase.

The project has been already successfully presented at the EFCCA Youth Group end of July in Paris and we are now ready to get in touch with potential teachers (who will be expected to give their real commitment, not for money), choose participants from applicants and outline and organize the first pilot training, which is planned to take place in the end of 2017.

A new adventure is starting: EFCCA is ready to offer a new set of services that are based on the concrete outputs of our members: Austria, Serbia, Spain, Estonia, Sweden, Italy, Poland joined their forces and, coordinated by Sanna Lönnfors, our scientific advisor, co-designed the Academy project. It is now time to turn our ideas into reality.

United we stand,

Luisa Avedano, EFCCA CEO

Exchange of ideas and good practice

Over 50 EFCCA delegates participated in the EFCCA Annual General Meeting (AGM) which took place in Warsaw, Poland from 26-28 May 2017 to discuss common projects and exchange experiences and ideas.

The General Meeting was hosted by J-elita, the Polish IBD association, who did a wonderful job to make delegates feel welcome and helped the EFCCA secretariat with organizational matters and logistics as well as preparing an exciting social programme for our delegates.

This year we had two guests from the Baltic States. Janek Kapper from the Estonian IBD association EESTI, who formally joined EFCCA during the AGM. Gediminas Smailys from the Lithuanian IBD association presented his association to the delegates with the aim of joining EFCCA in 2018. With the new addition from Estonia our total membership is now up to 34 IBD patient associations with several new

associations, such as the Lithuanian association and associations from Russia and Montenegro, showing their interest in joining EFCCA in the near future.

The AGM programme included the usual statutory reports and activity updates and elections to the EFCCA board. We are happy to welcome Magdalena Sajak from J-elita as new EFCCA board member and congratulate Salvo Leone and Ciara Drohan for being re-elected to the board.

The composition of the new EFCCA Board is as follows: Ciara Drohan, EFCCA Secretary (Ireland), Martin Kojinkov, EFCCA President (Bulgaria), Salvo Leone, EFCCA Vice-President (Italy), Marko Perovic,

Delegates during the Opening Session of the EFCCA Annual General Meeting, Warsaw, 26 May 2017



EFCCA Treasurer (Serbia), Magda Sajak (Poland), Natassa Theodosiou (Cyprus) and Fergal Troy (EFCCA Youth Group).



From left to right: Gediminas Smailys (Lithuanian IBD patient association, Martin Kojinkov, EFCCA President and Janek Kapper, Estonian IBD association).

This year we also allocated some time towards working groups in order to share ideas and develop future EFCCA projects amongst all the delegates that attended the meeting. In total three workshops were organised and delegates signed up to these

workshops prior to attending the GA. The subjects of the workshops were: EFCCA summer camps, a pan-European Toilet Locator project and a workshop on nutrition. The workshops presented an excellent opportunity for our members to share information and to brainstorm on ideas for concrete projects. For more details please see the summary reports of the workshops following this article.

On the second day of the GA agenda we invited Professor Pawel Kawalec as guest speaker to present an interesting on-going study “A burden of IBD in Europe” which aims to assess the burden of IBD for patients, families, and societies in selected countries of Europe and to check differences between countries.

The study looks into work-related outcomes among patients with IBD as well as work-related outcomes among informal carers of patients with IBD and finally work-related outcomes in relation to disease activity (remission vs active). More information can be found on the following website: www.ibdcosts.eu

All presentations and other relevant documents that were presented at the EFCCA Annual General Meeting in Poland can be found in the Members Only section of our website.



The new EFCCA Board (from left to right):

Luisa Avedano (EFCCA CEO), Magdalena Sajak, Marko Perovic, Treasurer (behind), Natassa Theodosiou, Martin Kojinkov, President (behind), Ciara Drohan, Secretary, Salvo Leone, Vice-President, and Fergal Troy (EFCCA Youth Group)

Workshop reports

Summer camp for youngsters with IBD

Since 2011 the EFCCA Youth Group and EFCCA have been investing resources and energy to organise and launch the Catch Your Dream Summer Camp to offer some leisure and capacity training addressed to young adults coming from our national members.

In the subsequent years, the EFCCA labelled Summer Camps network became the instrument of gathering youth through camps organised in several countries. It was an occasion to empower young patients and give them a chance to meet.

EFCCA and its Youth Group organized the Summer camps workshop to join forces to design a more innovative and effective instrument able to give value to all national initiatives addressed to youngsters where EFCCA could offer its competences and skills with the shared objective of investing in the leaders of tomorrow.

The working group consisted of representatives from 8 national associations as well as members of the EFCCA Youth Group with discussions being led

by Sanna Lönnfors. The main objectives and plan of action for the new summer camp are as follows:

The new camp will be for relaxing, having fun and meeting other youngsters with IBD, but also for learning and offering young people encouragement, motivation and leadership training. The age range would be kept at 18-30 and activities could be arranged so that people can choose different things according to their interests if one activity does not “fit” everyone.

Since the camp is not “just for having fun” but also has the aim to educate young people to become leaders of tomorrow and organize camps in their own countries, participants need to go through a certain application process in which they can show



their motivation (more details are in the complete workshop report).

As previous feedback has shown that young people would like to have enough time to rest and more free time to get to know each other, this will be ensured for the new camp. Some free time / rest time will be planned so that it also functions as an activity, such as watching a movie, having a barbecue etc. where participants can mingle, chat etc. In general, team activities will be preferred, as well as things that familiarize the participants with the local culture.

On the educational side, workshops will not be medical/scientific but instead practical, interactive, hands-on and more tangible such as for example lifestyle management of IBD, step-by-step guide on how to set up a camp etc. The educational activities of

the international camp will be built around a “theme of the year” which the participants will then overtake at their own national camp the following year.

As concerns national camps of EFCCA members, EFCCA will develop a set of criteria to obtain an “EFCCA label”, financial support and use of the material from international camps. The camp steering group was formed and includes: Eva Bjornsdottir, Thomas Hough, Sanna Lönnfors, Magdalena Sajak and Fergal Troy. Dana Smith from New Zealand, active in the Camp Purple organizing group, expressed interest in joining the group. The next steps will include thinking about the “Theme of the year” for the 2018 international camp as well as a suitable venue, and creating an application form. If you would like to read the full report please contact the EFCCA secretariat.

Toilet Locator project

People with IBD are often obliged to share personal and intimate details to obtain quick access to a toilet. Despite numerous awareness campaigns it is evident that the number of public toilets is not sufficient and that toilets are usually at the disposal of customers and / or employees only.

In response to this issue, many EFCCA members have developed in their respective countries certain tools and cards to facilitate access to toilets for people with IBD. We all know from experience that these types of tools genuinely improve the quality of life of people with IBD.

ACCU España, our Spanish member, got in touch with the EFCCA secretariat to propose a joint action with the aim to create a network of already existing information and good practices and thus offer an integrated service to all EFCCA members by the means of a common platform which would show private and public institutions/entities that open the doors of their toilets to people with IBD as well as the creation of a European Card facilitating access to toilets in Europe.



Madeleine Dubois (from the French IBD association Afa) shares her experience as concerns access to public toilets in France

15 national associations joined the Toilet Locator workshop to share their national experiences and discuss the development of a European wide Toilet

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Locator Card. Participants agreed that the best possible solution would be to have a double faced card, one side containing national information and the other side containing a uniform, international logo and relevant information.

Certain information on the international side such as the use of an expiry date, ID and photo would depend on the national side (i.e. where this was national practice it would also become international

practice).

The next step following the workshop will be to establish a small working group for defining and developing the European side of the card as well as to create an information sheet on the card to issue to national associations and potential awareness raising actions.

For more information please contact the EFCCA office.

Effect of environmental factors on health

Patients' awareness on importance of healthy food choices may play an important part in managing IBD since consuming certain foods may represent a more sustainable way of handling the disease while including some other foods in the diet can negatively influence quality of life.

According to the results of an EFCCA pilot - questionnaire on food, majority of respondents do not inform themselves on questions of pesticides, herbicides, fertilizers and / or additives in food. Therefore, the purpose of this workshop was to pass on the information and open a discussion on the effect of environmental factors on health.

IBD-friendly food, may-cause-inflammation substances, nutrition as therapy and environmental interactions in childhood are some of the main topics that were addressed in this food - related workshop.

In the course of the workshop the participants discussed about: processed foods, additives, organic food, fat and sugar, gut bacteria and their link to inflammatory bowel diseases.

Participants from 11 EFCCA national associations were divided into three working groups for the whole duration of the workshop which was moderated by Martina Jovic, EFCCA Policy Officer. The workshop consisted of:

A) two educational videos on: gut microbiota, processed foods, fat, sugar, and nutrition labels (given by lecturers from Stanford University and University of Aberdeen + TED video)

B) article on Georgia State University study on additives in food and their link to inflammation

C.1.) two group exercises with groups presenting their recommendations at the end of each exercise

C.2.) one group exercise on nutrition labels where no recommendations were asked of participants (the goal was opening the discussion on nutrition labels and practice reading them)

The working group generated good and interesting discussions amongst participants. Several representatives pointed out that their members consider diet/environment to be the culprit for the disease but also the cure.

As different doctors have different opinions on the link between diet and IBD, patients feel that they are



Jonas Eriksson, representing the Swedish IBD patient association Magotarm, sharing his ideas about diet and IBD to the working group

not able to get the full picture and understand what is happening in their gut microbiota and their body in general.

All of the participants stressed that more valid information and research on the link between diet/environment and IBD was necessary. Research on quality of food and its effect on IBD should not be undertaken without active involvement of patients.

Participants also emphasized the need for practical tools such as cookbooks (offering various types of diets), to help them navigate better through daily diet with IBD.

The group recommended some specific actions including awareness raising and advocacy activities.

Advocacy activities should include advocating for decision makers to introduce labeling of food products as IBD friendly and/or marking in red all the additives in food products that are scientifically proven to be (or might be) harmful to people with IBD.

Also, advocacy activities should be directed towards making organic food more affordable and therefore accessible to larger population.

Awareness raising activities should include an international awareness campaign on the link between diet (“good“ and “bad“ food) and IBD (following the collection of substantial quantity of scientific data) .

Data collection in form of surveys in EFCCA member countries on national dietary habits followed by the development of “Dietary guidelines” was also seen as an important activity that could be undertaken in the future.

Furthermore, the working group suggested the establishment of strategic partnerships with other bodies that are working on the questions of diet, additives in food, inflammation etc. for educational, advocacy and raising-awareness purposes.

A full report from the workshop is available from the EFCCA secretariat.



World IBD Day: making the invisible visible

On 19 May, the official date of World IBD Day, over 45 patient associations and other IBD activists from five continents joined forces to raise awareness about the 5 million people that are living with Crohn's disease and ulcerative colitis (collectively known as IBD).

Following last year's successful campaign when over 140 landmarks worldwide were lit in purple to mark World IBD Day the European Federation of Crohn's and Ulcerative Colitis Associations continued its efforts this year to coordinate the global campaign involving even more countries and cities. Alongside illuminated landmarks many associations and activists also organised local awareness raising events aimed at lobbying and providing information about IBD to the public.

"World IBD Day is an important day for us as we reach out to the global IBD community and highlight the daily struggles and impact of the disease on the 5 million living with IBD, including over 3 million people in Europe" said Martin Kojinkov, Chairperson of the European Federation of Crohn's & Ulcerative Colitis Associations (EFCCA).

"It's truly amazing to see the support and participation from so many cities and citizens coming together in our efforts to make the invisible visible."

World IBD Day is an excellent occasion for EFCCA to strengthen its collaboration with its partner organisations such as Crohn's and Colitis Canada, the Crohn's and Colitis Foundation (US), ABCD (Brazil) and Crohn's and Colitis Australia but also connecting with other IBD organisations from Latin America, Africa and Asia.

EFCCA also participated in the first-ever international YouTube Live video chat about IBD care around the globe, which was organized by the Crohn's and Colitis Foundation (US). Ciara Drohan, EFCCA secretary, joined the video chat to present the perspective of people living with IBD in Europe.

You can find more information about local events and a collection of all the images used during the global campaign (hashtags: #unitedwestand2017 and #worldibdday2017) on the World IBD Day website (www.worldibdday.org).



From top clockwise: The Mole (Turin, Italy), The Giant Ferris Wheel, Vienna, Austria, Umbrellas, Thessaloniki, Greece, colleagues in Bangladesh and Zagreb, Croatia



Mapping access to new medicines in EFCCA member countries

The EFCCA's mapping project that kicked off earlier this year aims at reducing health inequalities in Europe by thoroughly mapping all innovative treatments and devices available in the EFCCA member countries.

EFCCA hopes that the outcomes will support knowledge and experience exchange among member associations, promote a better understanding of different healthcare systems, improve the mobility of people with IBD between countries and facilitate access to treatment in other countries.

In October-December 2016, national associations from Finland, France, New Zealand, Poland, Serbia, Slovenia and Spain participated in the pilot phase of the project. Their comments were used to optimize the online survey before the second phase. Already the pilot phase yielded interesting results for example in terms of the availability and source of a precise number of IBD patients:

In Finland, for example, a number (45 000) is provided by the Social Insurance Institute based on the amount of patients receiving coverage for medication based on IBD diagnosis, whereas Serbia, for example, has a register of patients, but the data is

incomplete and the number (7000-8000) is estimated by the gastroenterologists dealing with IBD.

In the beginning of September, most EFCCA member associations had completed the survey online. In the final months of 2017, EFCCA's working group will work on the final results of the survey, and in early 2018 the final outcomes will be ready for presentation. There will be a fact sheet for each country, a handy resource for someone considering working or studying in another country; a comparison sheet for each question to be able to quickly see differences between countries; and a written final report presenting the most important outcomes in a more detailed way.

The final outcomes can be used to display discrepancies to national and European policy makers and to stress the importance of equal access to treatment.

Sanna Lönnfors, Project Coordinator

Incontinence and containment strategies

In June 2017 EFCCA Policy Officer, Martina Jovic, participated in a workshop on incontinence and containment strategies. The initiative for the workshop came from IAPO (International Alliance of Patients' Organizations) and was organized by Essity (formerly a SCA group company) in Brussels.

The aim of the workshop was to identify and discuss views and perspectives on how to best manage incontinence on a daily basis but also to develop key messages for policy makers and payers.

During the half-day discussion, participants identified several key issues and needs, such as:

more information, choice and access to adequate containment products; access to specialist advice and support; Accessible toilets and understanding of specific needs; lack of awareness and understanding of incontinence; persisting misconceptions about incontinence.

Patient and carer representatives emphasized the necessity for decision makers to understand that incontinence impacts patients in many areas of their life including: emotional health, relationships, work life, sex life, mobility, impact on what you drink and eat.

At the same time, it is important for decision makers to understand that it is perfectly possible to live with incontinence, as long as you have the right support in the form of the right care and access to the

right containment products.

However, incontinence is still a taboo topic and it remains hard for people to speak up about it. That is why the next step following this workshop will be the development of an advocacy toolkit on incontinence/continence care for patient advocates, destined to help them in their raising-awareness and advocacy activities.

Martina Jovic, EFCCA Policy Officer

Biologics and Biosimilars

The Global Alliance for Patient Access (GAfPA) in cooperation with EFCCA organised a regional workshop on Biologics and Biosimilars which took place on September 15-16 in Warsaw, Poland

Patients, advocates, physicians and health care professionals from 7 different European countries provided their perspectives on the use of biologic and biosimilar medicines. Delegates also shared experiences from the practice of medicine in their own countries. Despite most participants coming from European Union member states, their accounts presented diverse experiences with biologic and biosimilar medicines. The divergence highlighted an important reality: many questions about medicines are still answered at a national level..

Delegates proceeded to discuss how to influence and advocate policymakers at both a national and an EU level and bring them on board about patient concerns. Patients agreed that their voice can be stronger if they work together, particularly when patient groups join forces with organizations of physicians and health care professionals. Delegates also agreed that patients, alongside their physicians, must be central to any treatment decision. Excluding patients introduces the risk of undermining the trusted relationship between patients and physicians, which is fundamental to quality health care.



European Youth Group Meeting

This year the European Youth Meeting for EFCCA (EYM) took place in the country of cheeses, fashion, love and the Eiffel tower. Yes, this year we were in France and more precisely we were in Paris



EFCCA Youth Meeting delegates, 27-30 July 2017, Paris, France

Around 40 young delegates from 20 European countries met to share their experiences and learn from the other delegates attending. AFA (the French IBD national association) as well as Marine and Bastien, IBD sufferers and delegates from France were proud to host the event.

The focus this year was on therapeutics of IBD. We had two presentations which were given on the subject; what are the different groups of therapeutics and for which disease are they efficient? As well as; what are the strategies created by the doctors in order to treat your individual disease?

It was so surprising to see how much access to therapeutics varies across European countries. The presentations highlighted how there is still work to do to allow everyone to have the same opportunity to

treat IBD and manage the symptoms.

Another highlight from the weekend was being able to test an “App” which is going to hopefully be available to help support the management of IBD conditions. We were able to do scenarios and role play to test the App and give feedback to the developers... Watch this space!!

The EYM was filled with lots of time for bonding and sightseeing which allows for long lasting relationships to be built and developed and to really build a strong IBD network across Europe.

We don't know what everyone's lasting memory will be but we hope these few days spent together will stay in minds for many years, as a united force towards our common goal. #UnitedWeStand

Newly elected EFCCA Youth Group Executive Board (including substitutes)



Now it's time to put our ideas and new thoughts to practice and build on the success of the EYM 2017.

We have a new team of 5 young individuals as EYG Board members including Fergal Troy, EYG Leader (Ireland), Leanne Downie (UK), Bastien Corsat (France), Nathalie Schwarz (Germany), newly elected, and Rakel Yr Aoalsteinsdottir (Iceland). As well as 5 substitutes including Marine Gros (France), Tom Hough (UK), re-elected, Kathleen Franc

(Belgium), Lucie Lastikova (Czech Republic) and Beatrice Larsson (Sweden), newly elected.

The board members and substitute members carry out main tasks for the European Youth Group throughout the year. These tasks include the magazine, projects and work plans which are all working towards the vision of United We Stand.

Leanne Downie, EFCCA Youth Group

Disabled? How comfortable are people being labeled as disabled?

The United Nations Convention on the rights of persons with disabilities states that “persons with disabilities include those who have long-term physical, mental, intellectual, or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others”.

You're defined by the terminology of being disabled under various acts set by governments and associations across Europe. The definition of how you are measured if you are classed as disabled tend to be - “if you have a physical or mental impairment that has a ‘substantial’ and ‘long-term’ negative effect on your ability to do normal daily activities”.

The inflammation and other side effects associated with IBD requires long-term management. In fact, the condition itself is considered chronic, or lifelong. IBD can vary widely in severity among individuals so are we right to be labelled? Can it be a comfort or is it more of a hindrance?

It is not always easy to deal with the label of being disabled. When I asked about the topic within various different groups of IBD sufferers mainly within the European Youth Group and their countries associations most of the people who suffer with IBD answered that they weren't able to talk about their condition freely and they don't want to be seen as disabled, even if it could help them in daily life e.g. use of specific toilets/car parking spaces.

Some felt ashamed to be called disabled because they think there are worst situations than their own, they may be seen to be "faking it" as they are able to walk for an example.

I feel the mentality we have around the word disability is where we go wrong and as a society we could do more to understand the term and the different types of conditions associated with it. Typically the first thing that comes to mind is a person in a wheelchair, a person living with amputated limbs or maybe someone who is blind or partially sighted, this is the image that has been portrayed for multiple years.

Even though campaigns in many countries have been carried out to try and raise awareness I think due to the taboos and side effects associated with IBD more work still needs to be done. Campaigns are needed to break down these taboos, encourage talking about the invisible symptoms and raising awareness of how the chronic conditions can affect people.

The impact on day to day life from socialising to the work environment can be tough and disclosing you have a disability can still be seen as a negative which can mean you don't disclose this information which then puts added pressure on your life and management of the conditions. This is where you can become isolated, unable to talk to friends, family, co-workers, and your boss.

For us to be comfortable with the terminology of disabled or having a disability we need to continue raising the positive awareness of the conditions and so judgments and barriers start to fade away.

This isn't going to happen overnight but work has already started to be done to set us on the right path for us to feel comfortable in our own skin.

We learn to love ourselves and our condition, people will soon see there isn't an issue when it comes to our conditions and with some reasonable adjustments, more and more people can feel a part of society and not ashamed to talk about their conditions.

The Facts*


- 1 in 4 people of working age (15 to 64) are estimated to live with long standing health problems that restrict their daily activities. The majority of these health problems come directly from chronic diseases.
- Remaining at work with adequate support often results in improved quality of life and minimises the negative financial impact and the risk of social exclusion.
- Lack of adequate rights, or where they exist lack of awareness from both employees and employers can lead to discrimination within the work place.

Together, we need to change the image and the way of thinking. Together we are stronger, united we stand.

We hope you have found this real life topic example useful and helps reassure you are not alone when it comes to learning about living with IBD.

Leanne Downie, EFCCA Youth Group

* *European Patient Forum Factsheet on "Equity at work"*



Our mission is to help patients live a better life

Shire's mission

Shire is one of the world's leading specialty biopharmaceutical companies - but, more importantly, we make a difference to people with life-altering conditions, enabling them to lead better lives.

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

History and growth

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

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

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

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



Romania

Recognition and implementation of criteria for centers dedicated to patients with IBD

Like every year in May, we organize an activity for World IBD Day. Last year, ASPIIR (the Romanian IBD patient association) organized a roundtable discussion with the Health Commission of the Deputies Chamber of the Romanian Parliament and this year we continued this initiative by gathering at the Amphitheater of the Fundeni Clinical Institute important decision-makers, officials, physicians in the field of IBD, patients, students and media.



Among the issues we discussed was developing and updating good practice guides, training and accreditation of IBD pathology, patient-centered care, increasing quality of life, preventing hospitalizations, complications and surgical interventions and overall reducing the burden of IBD.

We were pleased that the event was attended by high level politicians such as the Minister of Health - Florian Bodog; the State Secretary in the Ministry of Health - Corina Pop; the Representative of the Presidential Administration, State Counselor, Department of Public Health, - Diana Loreta Paun; the Vice President of the Senate, Public Health Commission - Renica Diaconescu; and as always, our dedicated medical teams: Prof. Liana Gheorghe - Head of the Clinical Department of Gastroenterology and

Hepatology III; Prof. Mircea Diculescu - Head of Gastroenterology and Hepatology Center Fundeni; and Prof. Cristian Gheorghe - Chief Clinical Department of Gastroenterology I, Fundeni.

As well as guests from clinics throughout the country: Conf.dr. Adrian Goldis - Clinic of Gastroenterology and Hepatology Timisoara, Prof. dr. Cristina Cijevschi-Prelipcean - Institute of Gastroenterology and Hepatology Iasi and Prof. Marcel Tantau from Cluj.

The event had a large impact and we hope it will lead to an improvement in the quality of life of Romanian people living with IBD.

Isabella Grosu, ASPIIR

Switzerland

Charity Golf supporting people affected by Crohn's Disease or Ulcerative Colitis

Many of you know my love of Scotland, the country which is known as the „Home of Golf“. No wonder with 578 golf courses on an area of 77 910 km² – in other words, golf is the Scotland National Sport and my parents fell in love with it.

As my parents are getting older they had to look for something closer and have found the Golf Club Sedrun (Swiss Alps) as a beautiful replacement to the Scottish Golf Club Brora (Northern Highlands). But they wanted to bring something with them, which is well established with the Scots, respectively, in whole Great Britain: Charity Events. They also wanted to bring the game mode Mixed Foursome, where a pair shares/plays one ball, to be the events game mode. So this year already the 6th Fanta's & Russi's Mixed Foursome Open took place in Sedrun, Switzerland with 45 couples.

In order to increase the donation income, golf balls of 20.- Swiss Francs were raffled in the evening at the Hotel La Cruna in Sedrun. As a big bonus, the Chedi Resort in Andermatt donated two nights for two people including a round on their golf course. And so it came that an awesome sum total of 5'316.- Swiss Francs came together.



As members of the SMCCV (Swiss Crohn's and Ulcerative Colitis Association) and as my parents, they are thrilled with what the SMCCV is doing and this without financial support from the Swiss state. So it was clear for them to support the SMCCV! Of course they also raised awareness by carrying out brochures, and as my parents – I have Crohn's for over 21 years now – they had enough knowledge of IBD to enlighten others. Each donor received our purple ribbon as a sign.

I wholeheartedly thank in the name of all Crohn's and Colitis Patients and, of course, in the name of the SMCCV for this great Charity/Action.

Thank you, Mum and Dad!

Adele Fanta, SMCCV



Finland

World IBD Day 2017

As May evenings in Finland are so bright that lighting up buildings with purple colors doesn't really make sense, Finland's IBD patient association thought of something else for the World IBD Day and organized an awareness event in Helsinki.

Lectures and rock'n'roll

The event took place at the Dubrovnik Restaurant in downtown Helsinki and began with afternoon coffee and giving the participants an opportunity to look at stands of the association's cooperation partners. The magician Joni Pakanen was also there showing his skills.

The more "official" lecture part of the evening began with a presentation by Outi Abrahamsson, a family psychotherapist. She spoke about the illness of a child and parents' resources. It is important for the parents of a child with IBD to take good care of themselves; if the worries of the parents grow so that all revolves around the illness, it could happen that the child only perceives him or herself through the illness.

Especially teenagers need to know that their parents are getting help in regards to their child being ill. Parents in general should concentrate on positive and useful kind of thoughts, such as "I have always survived before" and "I have done my best".

Specialist doctor Pia Oksanen gave a short presentation on IBS and IBD, and the participants also heard a presentation on voluntary work. The lecture part of the evening was closed by Finnish media personality Taru Valkeapää, who spoke about well-being and stress management as well as, for example, the meaning of colors and nature for our well-being. The evening was concluded with a concert by the Finnish rock band Tuohimaa.



24 hours on a bike

Another kind of an awareness raising event had begun already at midnight: the sports club IBD Cycling, led by the professional ice hockey player Teemu Ramstedt, cycled on wattbikes for 24 hours under a tent set up at a very central place in Helsinki, the Narinkkatori square.

A number of well-known people, including the politician and former Prime Minister Alexander Stubb, supported the event by cycling along IBD Cycling for an hour or two. The event received lots of attention; several newspapers and television broadcasters came by and reported about it. According to Teemu Ramstedt, people were very interested in the event, many came to have a chat and a few passers-by even spontaneously jumped on a wattbike to cycle along for a while.

Sanna Lönnfors



Pfizer Inflammation & Immunology

Building on a heritage of more than 60 years, Pfizer I&I is a leader in transforming the lives of people with inflammatory and autoimmune conditions.

The leadership of Pfizer I&I is demonstrated by the development and delivery of medicines to help address the unmet needs of patients living with certain rheumatology, medical dermatology and gastroenterology conditions. Pfizer provides resources to help educate people living with these conditions so they can better understand how to get the most out of their treatment and care. We also provide services to ensure that patients have access to the benefits of our breakthrough scientific advances.

With multiple potential regulatory milestones worldwide, our expansive research program and pipeline will sustain our momentum and strengthen our ability to put more I&I patients first around the world.



Pfizer
Inflammation &
Immunology

New Zealand

“IBD and Me” Teenage Transition Website

The transition from paediatric to adult care for young people living with IBD is ideally a staged process where young adults are gradually integrated into adult care. Viewing this transition as only an isolated ‘event’ can mean that young people reach adult services not possessing the skills required to self-manage their condition, and run the risk of drop-out or health-negating non-adherence.

Practical skills such as booking tests through to lifestyle skills such as managing diet and activity levels are also called upon, as well as navigating health-risky behaviours such as alcohol consumption, smoking and sexual activity. This level of self-management is underpinned by the process of adolescence itself, where identities are being formed, cognitive and social skills are developing, and a gradual shift to independence from key caregivers is taking place. Currently there is no official or consistent process through which young adults with IBD in New Zealand transition from paediatric to adult services. It is understood that most clinicians recognise there is a need in the community for a more structured and inclusive process, but what this might look like is not yet bedded down.

Over the last two years CCNZ and Pharmaco NZ Ltd have worked with Atlantis Healthcare to develop an approach that addresses this major clinical gap. We believe the project uncovered the optimal transition process for young people living with IBD in New Zealand to progress from paediatric to adult care. In 2016 CCNZ put together a project team that comprised of a select group of specialists who are actively involved with providing and supporting the care of teenagers through the transition phase from adolescent to adult services, to assist in the development of a new website.

Interviews were held with key stakeholders – including Gastroenterologists, IBD Nurses specialists, a clinical psychologist, and young people living with IBD who have recently transitioned from paediatric to adult care. A draft “optimal transition”



pathway was generated and used as a blueprint for assisting young people with this transition.

The end result has been the launching of a website, ‘IBDandMe’. The objective of this site is to empower teens and parents of young children with IBD to effectively manage their disease. ‘IBDandMe’ is a resource portal with tips, videos and information to prepare and assist patients’ transition from paediatric to adult care. CCNZ felt an IBD Transition Website was crucial – with age appropriate information, however the key to making a difference was creating a community and soon to follow will be an interactive online chat forum, which will help create that community.

CCNZ, together with Pharmaco NZ Ltd are proud to bring you New Zealand’s first IBD Transition Website, ‘IBDandMe’.

We invite you to visit the new website at www.ibdandme.org.nz

Charlotte Perkins, Crohn’s and Colitis NZ

Cyprus

New Training Seminar for nurses

Further to the Training Program for Nurses which the Cyprus Crohn's and Colitis Association (CYCCA) organised very successfully during October/November 2016, we kept our promise to continue our efforts and activities relating to nurses' training in Cyprus.



Once again, in co-operation with the Ministry of Health and the University of Nicosia, CYCCA organised an all-day seminar on June 29, 2017 which was in fact, the continuation of last year's Nurses' Training, but this time it addressed all nurses both from the public and private sectors.

The attendance was massive and reached 97 people.

The topics covered were: the role of the nurse in cases of Crohn's and Ulcerative Colitis, the transfer from biological to biosimilar medicines, the new medicines for the above diseases, the ECCO-EFCCA Patient Guidelines, the medical and psychological preparation of patients who are about to start treatment with biological medicines and the implications of IBD diseases on patients.

We had the honour of the presence of Dr Gerassimos Mantzaris, Coordinator Consultant of

Evangelismos Hospital in Athens, Greece, who was the main speaker, Mrs Revital Barkan, N-ECCO Member from Israel and Mrs Savoula Ghobrial, Lecturer of the Nurses School at the University of Nicosia.

The seminar was very successful and all parties were very satisfied with the content, the attendance and the benefit that the participants gained. The attendees were awarded a certificate of attendance and merit points allocated by the Ministry of Health.

CYCCA wishes to express their sincere thanks to all the teachers as well as the co-organisers of the seminar and we hope that we will be able to continue similar activities in the future, for the benefit of the nurses and consequently our patients.

Yiannis Antoniadis
Vice President of CYCCA

UK

Nurses drive change in care

At her interview for the post of IBD clinical nurse specialist at Northampton General Hospital NHS Trust, Tracey Shaul was asked what she would do first if she got the job. “I said I would put together a business case for a second nurse,” says Tracey. “They thought I was joking but I had worked at Milton Keynes Hospital for eight or nine years, so I knew exactly what issues we’d face and that we’d need further assistance very quickly.”

True to her word, after arriving in December 2013, Tracey submitted a business proposal every year. “It didn’t get very far until this year,” she says.

“The Crohn’s and Colitis UK ‘More IBD Nurses – Better Care’ campaign came about and I spoke to the Northampton branch and asked if they could highlight it to their members around the area. I also advised patients to email the hospital’s chief executive to help raise the profile of the campaign.” Tracey says that the campaign, a new business manager and her tenacity combined to get the message heard. Again, a business case was put forward for a second IBD nurse and an admin assistant – and this time it was successful, with nurse Alison Saunders starting in June.

Demand for the IBD nurse service has increased since Tracey came into the role. The advice line she set up, which patients can call if they have any concerns or are going through a flare-up, started with about two patient calls a day but is now receiving around 10.

“I like to get back to patients within 24 hours of their call, but with me on my own I’d become a victim of my own success and it could take up to 72 hours to respond.”

With her new team, the advice line can be handled more efficiently. The timely response means patients can quickly access any extra treatment they need. That avoids worsening symptoms – or a visit to A&E.

Tracey also has plans for more effective monitoring of patient treatment. She and Alison will also be able to restructure how they keep in touch with patients so



Tracey Shaul and Alison Saunders supporting the “More Nurses - Better Care” campaign

that “walking well” patients have their consultations over the phone, freeing up clinical slots for consultants to see new patients.

The ‘More IBD Nurses – Better Care’ campaign has had an impact across the country, too. More than 1,300 emails have been sent to hospital CEOs, urging them to make sure everyone living with IBD has access to a specialist nurse. Four trusts have already secured funding for new posts.

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biopharmaceutical company committed to
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Italy



Summer Camp Junior 2017: a very special week with superheroes!

Amici Onlus has organized a campus for children with IBD during the first week of September. What is your superpower? That was the mission of this week for 16 special children from 7 to 14 years old.

IBD often has social impact starting from daily life (Am I able to go to school today? Am I able to play with my friends?) to their feelings of fear (to be accepted, to be understood).

The Summer Camp wanted to bring these children into a different context outside their family, so we have hosted them in a wonderful Hotel “Fattoria La Principina” near Grosseto in Tuscany. Here they had the possibility with different volunteers, educators, doctors, nutritionist and psychologists to try different sports, do group activities, learn about healthy eating,

sharing joy, fear and thoughts and above all sharing their IBD experience.

Every day was full of activities: Tennis, Football, Volleyball, Archery but also workshops to create and paint their own T-Shirts and to cook and decorate healthy cookies. Every day ended with everyone in the swimming pool and then a relaxing group time with psychologists.

All of us had a wonderful experience: we played together, we sung and danced, we laughed and we

cried together. We showed our courage and overcame our fears in the Go Ape Adventure Park, walking from a tree to another on a rope bridge, flying from 5m (someone also 10m!) up on a pulley or as one participant described “ I just hung there like a sausage!”

We have also spent time at the sea where we tried SUP (Stand Up Paddle), canoeing and enjoying ourselves on the beach. We built sandcastles and for a while we forgot about IBD.

The final party was an explosion of enthusiasm with children and adults dressing up, dancing, eating cookies made by ourselves. A room full of smiling children! The summer camp also showed us children conscious of their conditions, taking responsibility and autonomy for their treatment. Children helped

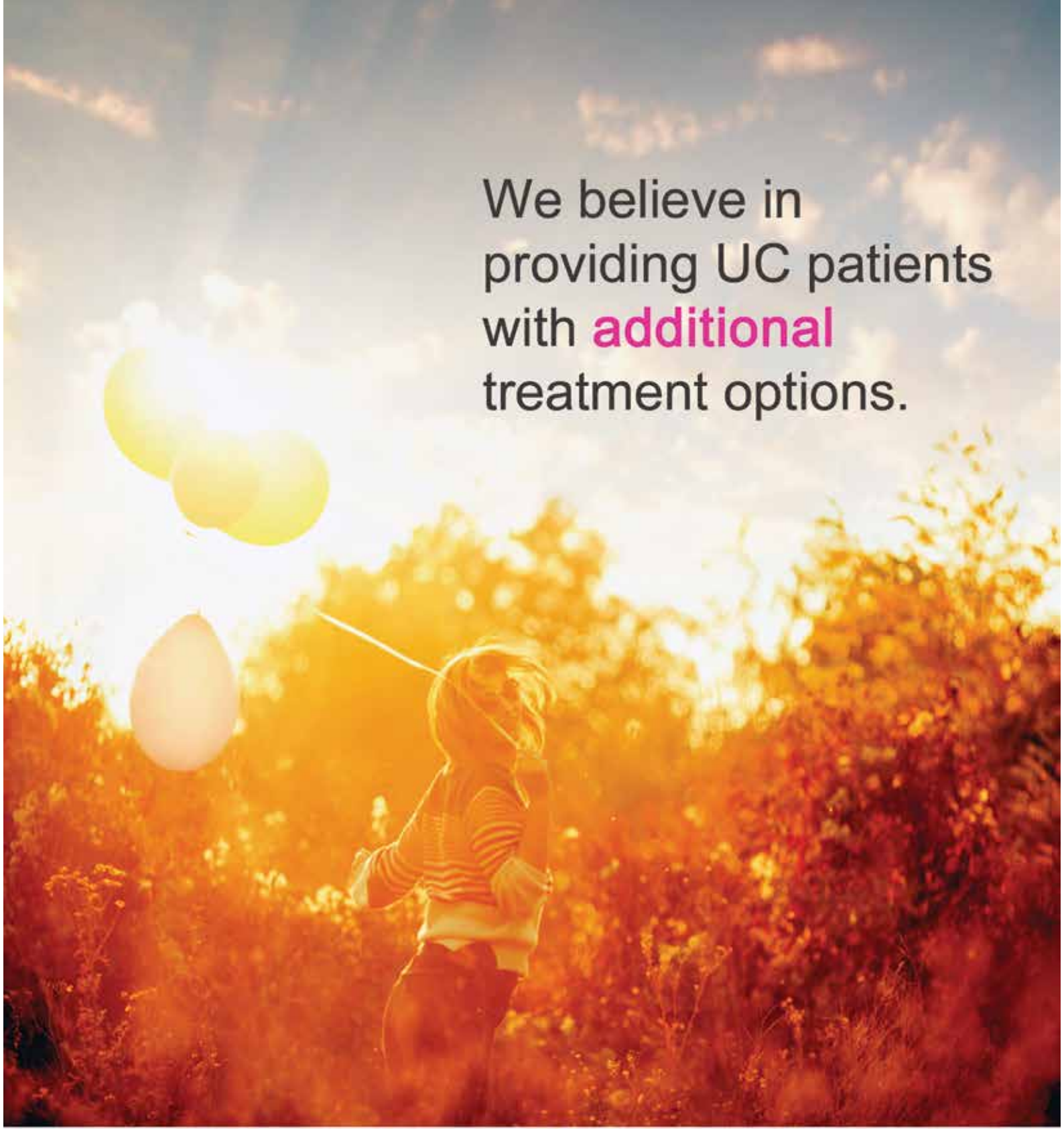
each other preparing their daily medication and encouraging each other.

At the end of the summer camp we could see that the kids were aware that they can live with IBD without giving up on dreams and wishes.

We all started this Summer Camp Junior with our own expectations but we all come back with much more than expected. We thought we had to teach them strength and courage during this week but it was they who gave us a lesson in life with their courage, persistence, simplicity, tears of joy, smiles and hugs.

And so....what is their superpower? Friendship! Sharing experiences is the best therapy to fight their fears and become stronger. They were already superheroes, they are very special children!



A child in a striped shirt and dark pants stands in a field of tall, golden-brown grass. The child is holding a string attached to three balloons: two yellow and one white. The background is a bright, hazy sky with soft clouds, suggesting a sunrise or sunset. The overall mood is warm and hopeful.

We believe in
providing UC patients
with **additional**
treatment options.

Otsuka Pharmaceutical is a global healthcare company with the corporate philosophy: 'Otsuka-people creating new products for better health worldwide.'

The Otsuka Group is comprised of 158 companies and employs approximately 42,150 people in 25 countries and regions worldwide. Otsuka is committed to focusing its research and development on innovative products which address unmet medical needs, particularly in our specialist areas of gastro-intestinal, renal, endocrine, oncology, and central nervous system disorders.

Can healthy diet positively effect quality of life for people with IBD?

Nutrition is one of the factors that can trigger the start of Inflammatory Bowel Disease (IBD). A healthy diet is important, both for people with or without IBD. However, nutrition isn't always taken seriously in the consulting room. And nutrition and lifestyle are not always included in the patient's treatment plan.



A pilot research project into nutrition and IBD by 'Voeding Leeft', together with the LUMC (Leiden University Medical Centre), will probably change this. Members of the Dutch IBD patient association, CCUVN, have been invited to participate in the pilot.

Voeding Leeft

Voeding Leeft is an independent foundation that develops innovative lifestyle programmes for chronic diseases. They seek to use nutrition on a scientific basis as a health intervention. Also they wish to increase the awareness of the impact nutrition has on our life and on our disease. Voeding Leeft already introduced nutritional programmes for diabetes type 2, MS and arthritis.

The research question for this pilot project is: can fresh vegetables, legumes, fruit, real (so not processed) meats, poultry and fish, nuts, full dairy products and natural fats, give your quality of life a boost in case of Crohn's disease or ulcerative colitis?

Pilot

In the pilot project participants with Crohn's disease and ulcerative colitis experience how another nutritional diet during three months, effects them, in combination with a healthy/healthier lifestyle. Participants will receive professional coaching.

'Fresh, pure, unprocessed, varied and no sugars, but.....delicious!'

If the pilot results are positive, then the next step is to see, together with gastroenterologists and health insurers how such a nutritional programme can be included in the treatment of IBD.

The pilot starts in January 2018 with workshops (1 day) on nutrition and lifestyle. Participants set their goals and receive a recipe book. They return after one and two months, to exchange experiences. They can also exchange experiences online and experts provide assistance when needed.



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Launch of national association for IBD patients in Brazil

Brazil is a deeply federated country where there are nine local and regional patient associations. "Minas Gerais" is one of the oldest regional associations and is taking the central lead in the foundation of the national IBD patient association which aims to improve the quality of life of people with IBD nationwide.



From left to right: Ana Luiza, Patricia Mendes and Chantal Dufresne , Afa Director, during a recent meeting in Rio de Janeiro, Brazil

Brazil has a population of more than 200 million, it's the 8th world power, with 28 States, some of which are bigger than France, and an « official » number of 70 000 IBD patients, a much under-estimated figure.

During my family visit to Brazil, I was lucky to be able to meet, in Rio de Janeiro, a few of the Brazilian IBD Patient associations' representatives, Patricia Mendes de Belo Horizonte, Ana Luiza Guimaraes and Thiago del Grande. All three very nice and truly invested in their associations will soon announce the great news about the foundation of a national

association, DII Brasil, along with another in the state of Rio, ADIRIO.

At the present time, there is only one national association of doctors, ABCD, well established and known in the medical congress world. Brazil is a deeply federated country where there are nine local and regional patient associations, besides two others being created. The Minas Gerais one is the oldest and takes the central lead of the national structure. Patricia Mendes heads this association and she will become the national president of DII Brasil.

According to Patricia, this new national association is great news and will have a role to play as a patient support group and as a base for new local entities to be established. The challenge is as great as are the inequalities in this giant country, made even greater with the present economic crisis.

« Two major difficulties must be confronted, the lack of medication in some of the States and the refusal by the health authorities to recognize UC . Biotherapies are not available for UC and there is much legal action. »

Patricia Mendes asked me to relay a message :

« We are very happy to announce the official foundation of DII Brasil. We participate in the Latin American Committee of Associations and we have already had a first meeting last April in Buenos Aires.

The European organizations, their achievements, are a source of inspiration to us. We hope to soon be able to become part of, not only South America, but also part of the world context, by uniting our efforts to find solutions for the patients. »

Chantal Dufresne, Afa CEO and Madeleine Duboe

Self-Management In Patients With Chronic Conditions

The European Patient Forum is organising the final conference of the EU-funded PRO-STEP pilot project will take place in Brussels on 23 and 24 October 2017. Around 100 delegates are expected to attend the event where the projects' preliminary outcomes will be presented.

Pro-STEP is a pilot project focusing on self-management in chronic conditions. While this shares some similarities with self-care in minor conditions, such as the importance of health literacy, there are important differences as chronic disease requires a long-term approach with emphasis on patient empowerment and appropriate support services.

The project explored the added-value of self-management in chronic diseases, in a context of promotion of self-care in European health systems.

The general aim of Pro-STEP is “to put in place a framework for action to enhance self-care at EU level and develop strategies to support the broader implementation of effective self-care” building on findings from other work e.g. EMPATHiE (2014) and PiSCE (2014-).

The specific objectives include the identification of good practices, the analysis of added-value in terms

of cost-benefits, proposals for possible methods for promoting self-care, taking into account previous and ongoing work in the field and identification of elements for scaling-up /transferability of good practices

The final conference aims to gather views on the topic of self-management in chronic conditions, how it can be promoted, and how it can contribute to improved quality of life and sustainability of health systems and to discuss steps forward. Invitees from different backgrounds and Member States will contribute to the conference to stimulate fruitful discussions.

The final results of the pilot project will be submitted to the European Commission in early 2018, and will certainly boost discussions on how to better implement and integrate self-management good practices in evolving healthcare systems..

Chronic Illness Bloggers

Why they do it and for whom they do it

When being confronted with a diagnosis of chronic illness, people show different reactions. Whereas some of them might chose to be secretive about it, others are straightforward. Amongst those outspoken ones are a few who go even one step further: they become bloggers.

Why do they blog? And why do others read what they are writing?

I am a chronic illness blogger and I have my reasons why I do it. But I can tell you that there is no one right answer to the first question. The second question is even trickier. I will try to analyze potential motives of bloggers and blog readers.

Let's start with the first question:

Most people blog because they have something to say and they want to be heard. Through their online activities they are able to connect with like-minded communities and exchange valuable experiences, information and ideas. Their main audience are fellow chronic illness warriors.

Others have a more political approach: they want to raise awareness with their stories. They blog to change the world. Those bloggers are aiming to have all sorts of readers; especially stakeholders and decision-makers.

Chronic illness can lead to isolation and loneliness. Blogging is the way out for some people. Comments and feedback to their thoughts, their personal chronic illness story and their daily suffering mean the world to them. Those bloggers see their readers as potential friends.

Being sick is unpleasant, whether it is life-threatening or not. The diagnosis itself is often traumatic and dealing with chronic disease on a daily

basis is pure hell. Writing helps. It is proven that expressing emotions eases stress and trauma. Cathartic blogging is not meant to be an end in itself, but to reach a wider audience. The stories are inspirational for all kinds of people.

Blogging can be a job for people who do not have a standard employment anymore. It requires a lot of discipline to find a new subject to write about, do the necessary research, structure one's thoughts and publish regularly.

A few chronic illness bloggers earn money with their blogs. Most don't - yet they are doing something useful for themselves and for society – however their disease might affect them.

I have already mentioned the kind of audience different categories of bloggers intend to reach. Nevertheless, I have realized that the people who actually read what you are writing are not necessarily those for whom you intended your well-crafted lines.

There are those who are in the same boat, the fellow chronic illness warriors. I have found out that the blog entries I prefer are either psychological ones or those providing information about the healthcare system. I don't like the ones about symptoms and pain too much, when I peep into other blogger's stories.

The feedback I receive when I post a new entry shows that my audience reacts the same way: entries about my fears, coping with the disease and dealing with physicians are the most commented and shared ones.



People who rarely visit chronic illness blogs of patients are professionals. Nurses, therapists, physicians and psychologists are readers who can make a difference, though. I know that some physicians don't like patient bloggers, because they view them as amateurs who are meddling with their professional affairs. Many of us write about medical aspects and some of us criticize the way they are treated in medical practices and hospitals.

I think it is crucial to understand that chronic illness warriors who blog don't claim to be wiser than the professionals, they just want to advocate for their point of view. And that is highly legitimate. One of the highlights of my blogging career was when a nurse told me that she was using some of my posts in her patient groups.

The first ones to read a blog are usually relatives and friends. Through social media and by word-of-mouth, acquaintances and your wider environment

will know about it. As a blogger, I love having my website as a referral point for my circle of friends and acquaintances.

All my answers are there for them to read now and I do not have to go through the annoying process of explaining my disease from A-Z every time. Nonetheless I am confronted with misunderstandings once in a while.

Although I often write about the invisibility of my illness, people tend to be surprised or even disappointed when they meet me in person. I have the feeling that I am boring a few of my readers who were extremely interested in my blog in the beginning. They seemed to expect more drama, suspense and climaxes which I cannot offer. A truly chronic dilemma.

By coincidence, complete strangers are going to find out about a blog. Although chronic illness is something they are not primarily interested in, they

will find a post because of certain keywords or photos or they will be lead to it through the baffling mazes of social media. As raising awareness for invisible illness is one of the reasons I am blogging, I always try to make sure to communicate with those who are new to the world of chronic disease. In a sense, I hope to create advocates in a way by providing useful information, links and explaining “spoonie problems”.

Some blog visitors are rather unwelcome. Those include vendors, spammers and people who contact you because of other financial, sexual or romantic interests. I have had millions of salespersons wanting to boost my social media reach; multiplying my followers and hits.

Recently, I have received lots of comments by voodoo gurus, who promise to bring my lost love back to me. There are health fanatics as well who assure me that only by relying on their products I will get better again. The latter group can become quite adamant and even offensive if not taken seriously.

I will certainly keep on blogging. I have met a huge number of interesting people, other patients, physicians, nurses, therapists, pharma industry employees and others.

I have heard lots of heartbreaking stories and it seems that some of my posts were relevant to persons suffering tremendous losses or going through a health crisis. I don't care about pageview statistics as long as I can reach some of these persons.

Famous Crohn's Disease bloggers include Krystal Miller who raised awareness by showing off her ileostomy bag in beautiful photos and Sara from “Inflamed and Untamed” who also has a highly commercial blog and lifestyle YouTube video channel.

If you want to start blogging as well, consider becoming part of the Chronic Illness Blogger Network (<http://chronicillnessbloggers.com/>).



Teresita Bauer suffers from CLL, a chronic form of blood cancer which affects the immune system. She started her blog “Life is an Option” to raise awareness for invisible illnesses and to connect with like-minded communities, the so-called “spoonies”.

More info: <http://www.lifeisanooption.com>

MyIBDcoach: more medication adherence and less polyclinic visits

MyIBDcoach (mijnIBDcoach) is an e-programme suitable for all IBD patients, developed in close cooperation with patients, specialists, nurses and the Crohn en Colitis Ulcerosa Vereniging Nederland (CCUVN). Its main objective is to reorganize IBD-healthcare and stimulate self-management by IBD patients.

The regular healthcare for IBD patients is based on planned routine polyclinic visits, where the frequency mainly depends on the given treatment (medicines). Extra visits are planned in case complaints increase.

However, treatment based only on the illness symptoms has in the long run, not led to a considerable improvement (inflammations, use of steroids, hospitalisation, complications and operations).

Recent guidelines therefore suggest better monitoring and an earlier intervention. Furthermore, most gastroenterologists don't systematically monitor relevant health-related aspects such as medication adherence, nutrition, psychological issues, despite the fact that these aspects can positively influence the illness.

Insurance companies, governments and patient organisations, increasingly demand the registration of PROMs (patient reported outcome measures). Current IBD polyclinics lack the resources to register this information.

MyIBDcoach is a personal webpage and monitors illness activity, and also PROMs regarding medication adherence, nutrition, smoking, medication side effects, employment participation, quality of life, fears and depression. Users are invited to answer questions on periodical basis.

The results are summarized in a treatment review. If answers exceed an alarm level, a signal is forwarded to the hospital's back office where the patient is treated.

An immediate treatment advice is given, additional research is done, or an extra polyclinic visit is planned. Users can also send messages via the protected network.

Besides monitoring aspects, myIBDcoach also offers a diverse set of knowledge modules such as self-management, medicines, stop smoking, nutrition, and the importance of medication adherence.

The effects of myIBDcoach were researched in a pilot study in 4 hospitals. 909 patients were included: 465 used myIBDcoach for 1 year and 444 were given their regular care. There was a significant drop (40%) in polyclinic visits to the gastroenterologist and IBD nurse by patients using myIBDcoach.

Also there were 50% less hospitalisations compared to the patients given regular healthcare. There were no difference in the occurrence of inflammations, the use of steroids, the number of ER visits and the number of IBD related operations.

Patients using myIBDcoach were just as satisfied with the quality of care as the other group. Finally, the medication adherence significantly increased amongst myIBDcoach users (30%).

The pilot results lead to widespread publications in the media, and in the Lancet.

T. Markus-de Kwaadsteniet, CCUVN

Environmental factors linked to inflammatory bowel disease

A recent study carried out by the Children's Hospital of Eastern Ontario (CHEO), the University of Ottawa and other Research Institutes based in Canada showed a lower risk of inflammatory bowel disease (IBD) for people living in rural areas as well as those who spent their first 5 years living in a rural household.

IBD has been linked to a Westernized environmental life-style, with its incidence increasing dramatically over the past 50 years in developed countries. The highest prevalence of disease is seen in populations in North America and Northern Europe; however, a slow and steady increase in prevalence is now being described in the developing world as well, making IBD a global disease.

While the exact cause of IBD is not clear, it is thought to involve an inappropriate immune reaction by the body against food and normal bacteria in the digestive tract. People who develop IBD are likely to have a genetic makeup that makes them more susceptible to environmental or microbial factors that can trigger the disease.

Early life exposure to these risk factors may be critical in IBD pathogenesis. Smaller family size and early life exposure to antibiotics are associated with higher risk of IBD, while early life exposure to farm animals is associated with a lower risk of IBD.

Increased urbanization is one hypothesis for the rising incidence of IBD. Urban residence is associated with higher incidence of both Crohn's disease (CD) and ulcerative colitis (UC), as demonstrated by a systematic review and meta-analysis of 40 studies (1).

The Canadian study consisted of two different studies involving over 45,000 IBD patients, with 6,662 in rural households and 38,905 living in urban households over that period.

The first study was a retrospective cohort study aimed to show potential links between IBD incidence

and rural/urban residence at the time of diagnosis excluding people who changed their residence from rural to urban or vice versa in the year prior to diagnosis.

The second study was a birth cohort study which looked at links between length of early life exposure to the rural/urban environment and the subsequent development of IBD. This study included all residents where full administrative data and birth location were available in three participating provinces (Alberta: 1996–2010; Manitoba: 1988–2010; and Ontario: 1991–2010).

The results showed that rural residence at diagnosis and at birth were linked to a lower incidence of IBD compared to urban residence particular as concerns onset of IBD in childhood. The authors pointed to some inconsistencies in the results due to the use of different definitions of rurality. Rurality has been determined in multiple distinct ways by Statistics Canada, based on population size, population density, or the economic and social influence of a city on neighboring regions. For example, when the Metropolitan Area and Census Agglomeration Influenced Zones (MIZ) definition, which included several criteria, was applied there was a trend towards a protective effect in more rural communities compared to the most urban levels.

However, the finding that rural residence was protective for IBD in children was consistent across most definitions and and shows the importance of early life environmental risk factors in the development of IBD. According to the authors this is consistent with other studies demonstrating that



antibiotics and air pollution in early life is associated with increased risk of IBD in late childhood or early adulthood. Therefore, the findings of environmental links with IBD may be more successful in children.

It is uncertain how rural residency protects against IBD but may include dietary and lifestyle factors, and environmental exposures. Similar studies showing the protective effect of rural residence against the development of asthma showed that in a mouse model of asthma, farm dust or low-dose endotoxin reduced epithelial cell cytokines that activate dendritic cells, thereby suppressing type 2 immunity and house dust mite-induced asthma. This suppression results from induction of ubiquitin-modifying enzyme A20.

In the gut, the microbiome may be involved in inducing A20, resulting in suppression of inflammatory reactions to commensal bacteria. This tolerance to a healthy microbiome composition may be missing or inflammation stimulated by the absence of farm dust or another environmental factor in the urban environment, resulting in an increased risk of IBD.

A previous study from Germany reported that early life exposure to farm animals resulted in strong protection against later development of Crohn's Disease. Nevertheless, farming is only one aspect

of rural life. Air quality, water sources, and dietary differences may contribute to differences between urban and rural incidence of IBD especially for children, and these factors vary by province. These effects may be stronger in children because their gut microbiome is in evolution and may be vulnerable to changes in the first two years of life.

The authors of the study hope that results from such investigations can, for example, help researchers to determine the interactions between genetics, environment, and gut microbes that lead to IBD and in particular help researchers to establish the age at which intervention could best prevent the disease.

In addition, the authors expect that researchers will work to understand exactly what environmental differences exist in rural and urban Canadians to explain the altered risk observed. These differences may contribute to alterations in the intestinal microbiome or epigenetic changes.

1 "Rural and Urban Residence During Early Life is Associated with Risk of Inflammatory Bowel Disease: A Population-Based Inception and Birth Cohort Study", The American Journal of Gastroenterology, 2017



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