

EFCCA MAGAZINE

EUROPEAN FEDERATION OF CROHN'S AND ULCERATIVE COLITIS ASSOCIATIONS

FEBRUARY 2023

**EFCCA's new roadmap advocating
for the IBD patient community**

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EFCCA Members

Austria - OMCCV
www.oemccv.at

Belgium
CCV: www.ccv.be
Crohn-RCUH: www.mici.be

Bulgaria - BCUCA
www.babkuk.org

Croatia - HUCUK
www.hucuk.hr

Cyprus - CYCCA
www.cycca.org

Czech Republic - Pacienti IBD
www.crohn.cz

Denmark - CCF
www.ccf.dk

Estonia - EPSS
www.ibd.ee

Finland - CCAFIN
www.ibd.fi

France - AFA
www.afa.asso.fr

Germany - DCCV.e.V.
www.dccv.de

Greece - HELLESCC
www.crohnhellas.gr

Hungary - MCCBE
www.mccbe.hu

Iceland - CCU
www.ccu.is

Ireland
Crohn's and Colitis Ireland
www.iscc.ie

Israel - CCFI
www.ccfi.co.il

Italy - AMICI
www.amiciitalia.org

Latvia - LKKSBB
www.lkksb.lv

Lithuania - CCLA
www.draugija.info

Luxembourg - ALMC
www.afa.asso.fr/luxembourg

Malta - MACC
www.macc.org.mt

Montenegro - CUKUK
www.cukuk.me

New Zealand
Crohn's and Colitis
www.crohnsandcolitis.org.nz

Netherlands
Crohn & Colitis NL
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Norway - LMF
www.lmf norge.no

Poland - J-elita
www.j-elita.org.pl

Portugal - APDI
www.apdi.org.pt

Romania - ASPIIR
www.aspiir.ro

Serbia - UKUKS
www.ukuks.org

Slovakia - SCC
www.crohncub.sk

Slovenia - SAIBD
www.kvcb.si

Spain - ACCU
www.accuesp.com

Sweden - MOT
www.magotarm.se

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

Turkey - IBHDYD
www.ibhportali.com

UK - Crohn's and Colitis
www.crohnsandcolitis.org.uk

Associate Members:

Argentina - Mas Vida
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Brazil - DII Brasil
www.facebook.com/diibrasil

Lebanon - I Battle Disease
www.ibattledisease.org

Kazakhstan - FPVZK
www.vzk.kz

Mexico - CUCI
www.crohncuci.org.mx

Russia - Trust
www.vzk-life.ru

Singapore
Crohn's and Colitis Singapore
www.ibd.org.sg/english

Trinidad and Tobago -
NACCTT
www.crohnsandcolitistt.org

Ukraine - Fulfilling life
www.gofulllife.com.ua

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EFCCA's opinion matters

I am excited to share our latest magazine with you. It features updates on EFCCA's activities and events, as well as news from our members providing valuable insight into the experiences of people living with Crohn's disease and ulcerative colitis, and highlighting the importance of patient-centered care.

Other more personal stories, such as in the section "Living with IBD", are honest, inspiring and hopefully provide support for others affected by these conditions.

One major news we are sharing with you is about DIVA, our new working methodology that we have presented in recent weeks to our members during the HAPPY Hours and to our key stakeholders during UEG WEEK.

DIVA, which stands for **D**ata **I**nsights for **A**dded therapeutic **V**alue is a comprehensive approach to understanding and managing Crohn's disease and ulcerative colitis. The methodology includes the collection and analysis of publicly available data from patients, healthcare providers, and other stakeholders, with the goal of identifying and addressing patients' unmet needs.

One of the key advantages of DIVA is that it allows us to gather a wide range of information from different sources, including patient-reported outcomes, clinical data, and healthcare utilization data. This enables us to gain a more complete understanding of the disease and its impact on patients' lives, as well as identify areas of improvement.

With DIVA, we aim to achieve a more equitable and efficient healthcare system for all patients with Crohn's disease and ulcerative colitis. We believe that this new methodology will help us to better understand and address the needs of patients, and ultimately, improve the quality of life for those living with these chronic conditions.



We encourage all of our members and stakeholders to get involved in this initiative and contribute to the success of DIVA. Together, we can make a real difference in the lives of people with Crohn's disease and ulcerative colitis.

United We Stand

Salvo Leone,
EFCCA Chairman

From unmet needs to solutions - EFCCA's new roadmap advocating for the IBD patient community

Within the context of the new Pharmaceutical Strategy for Europe [Pharmaceutical Strategy for Europe](#) as well as the European Medicines Agency's Engagement Framework [Engagement Framework](#), EFCCA has been developing a working methodology in order to respond to the objectives outlined in the strategy and to support its implementation by means of an innovative patient-centred approach.

This new working methodology will identify and address the real needs of patients and healthcare systems. We will promote the generation, collection and use of evidence-based patient experience data for benefit-risk decision-making and to give **evidence-based** answers to stakeholders such as regulators, policy makers, pharmaceutical industries and healthcare professionals.

DIVA, which stands for **Data** Insights for added therapeutic **Value** will use publicly available data as well as EFCCA data to provide opinions and interpretations and to explore patient unmet needs based on scientific data. **DIVA** includes a pilot working platform to support IBD patient advocates in their daily activities.

“EFCCA hopes this new platform will be a useful and valuable tool for patient representatives, providing a one-stop shop for information and resources on Inflammatory Bowel Disease.”

The platform will be available from 23 March 2023 and will gradually include rigorous information on these diseases. In particular, about the general condition of patients and the frequency and impact of symptoms. It will also include information on the various initiatives underway to improve our knowledge of these diseases and their treatment.

The screenshot displays the EFCCA DIVA platform interface. At the top, there are navigation links for Clinical trials, Trends, DIVA, and Guidelines. Below this, a summary bar shows statistics: 105 Sponsors, 238 Clinical trials, 65 Completed, and 137 Ongoing. A search bar on the left allows filtering by Date (01/01/2017 to 06/10/2022) and Disease (All). A table of clinical trials is shown with columns for Date, Country, Disease, Title, Sponsor, Phase, Placebo, Status, and Info. The table lists four trials: a Crohn's trial in Spain (2022-07-27), an Ulcerative colitis trial in Germany and Spain (2022-07-21), a Crohn's trial in Czech Republic, Hungary, and Spain (2022-06-21), and an Ulcerative colitis trial in Spain (2022-05-17).

Date	Country	Disease	Title	Sponsor	Phase	Placebo	Status	Info
2022-07-27	Spain	Crohn	Clinical trial to evaluate if the laparoscopic administration of cells derived from the fatty tissue can improve the inflammatory stenosis in patient with crohns disease.	fundacion jimenez diaz health research institute	II	✗	Ongoing	Read more
2022-07-21	Germany Spain	Ulcerative colitis	A phase 2/3, multicenter, randomized, double-blind study to evaluate the efficacy, safety, pharmacokinetics and pharmacodynamics of oral ozanimod rpc1063 in pediatric subjects with moderately to severely active ulcerative colitis with an inadequate response to conventional therapy.	Celgene	II/III	✗	Ongoing	Read more
2022-06-21	Czech Republic Hungary Spain	Crohn	Fuzion - efficacy and safety of guselkumab in participants with fistulizing, perianal crohns disease	Janssen	III	✓	Ongoing	Read more
2022-05-17	Spain	Ulcerative colitis	A phase 3 placebo-controlled efficacy and safety study with ritetitinib pf-06651600 in adults with moderately to severely active uc	Pfizer	III	✓	Ongoing	Read more

It also incorporates an intelligent assistant which helps to explore and interpret data from 1) internal sources, like those published in our trials, journals, and congresses, and 2) external sources, like medical guides and government databases.

This initiative will therefore help us to look at important data such as

- The IBD patient profile
- The patient's journey
- Symptoms and impact of the disease
- Patient needs and priorities
- Similarities and differences in healthcare systems
- Trends in pharmaceutical R&D
- Characteristics of clinical trials (past and present)

This means that we will have a complete picture of the situation of patients, which will allow us to understand better what we should focus on to improve their lives. In particular, patient advocacy organisations such as EFCCA will use this information to improve the quality of the support they provide to researchers, clinicians, pharmaceutical companies and public authorities who need feedback to make better decisions for IBD patients.

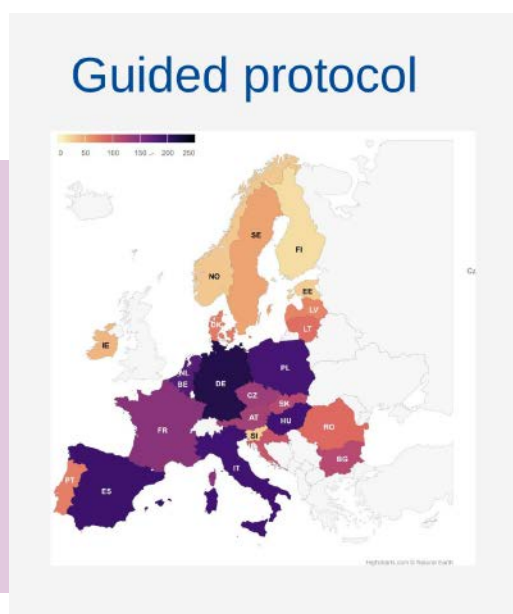
This input will be valuable in finding concrete solutions to patients' real needs, preferences, and priorities. Above all, because it will allow us to work on the details of each of the subgroups of these pathologies depending on the characteristics of the patients, such as age, gender, and disease severity.

Nevertheless, we will also use this knowledge to improve our educational resources, training, and media campaigns to increase awareness of IBD, its impact on patients, and the need for more research and better treatments.

The pilot phase currently has qualitative and quantitative information on the disease and updated information on the status of clinical trials and the regulatory status of different molecules. All with links to the source to allow patients, health professionals, and researchers to verify the information provided and also enable users to access additional information, which helps to better understand the data presented.

EFCCA hopes this new platform will be a useful and valuable tool for patient representatives, providing a one-stop shop for information and resources on Inflammatory Bowel Disease.

Roberto Saldaña,
EFCCA Coordinator of Innovation and
Patient engagement



Question: Spain is usually one of the countries with the highest number of clinical trials for IBD. However, it closed 2021 in seventh position. Why? Explore it for yourself.



HAPPY HOUR 2022

EFCCA hosted the annual HAPPY HOUR, this year entitled “PATIENT OPINIONS MATTER”, on the 13 and 14 of December. We had 26 participants including staff, several EFCCA board members as well as patient association representatives from 18 countries of the EFCCA network. We presented our

road map towards our new working methodology that involves a clear shift in the role of the patient aiming at identifying and addressing the real needs of our IBD community. We were pleased with the positive discussions and feedback. We will be keeping you informed on our work in progress. Stay tuned!



UEG WEEK 2022

First in person congress after 2 years

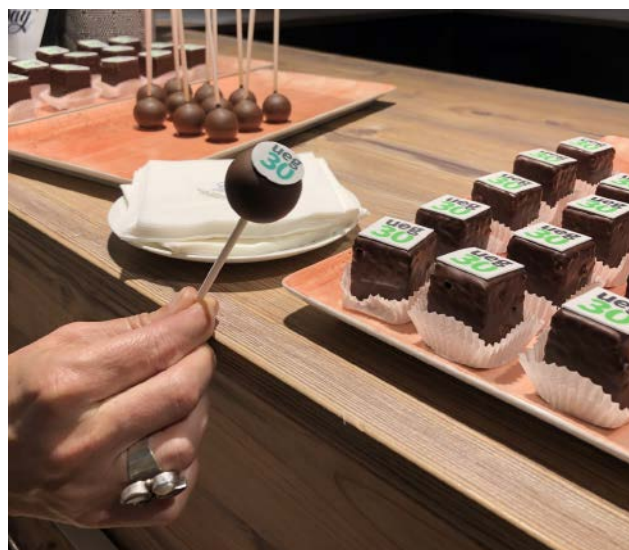
EFCCA board members and staff travelled to Vienna to meet once again in person at the UEG Week in order to connect with the scientific community, industries and stakeholders and to engage in interactive discussions and proactive debates to learn and share opinions and experiences with the aim to benefit patient care.

UEG United European Gastroenterology Week 2022 was the very first hybrid congress held in Austria Center Vienna on 8 to 11 October 2022 bringing together IBD specialists and key stakeholders.



The event gathered over 10.000 participants, 90 exhibitors and 19 industry symposiums from more than 110 countries.

EFCCA was honoured to unite and exchange ideas with various stakeholders at the congress. Firstly we had an exhibition booth which allowed us to network and share relevant information and activities such as our magazine and annual report with professionals from the scientific community.



EFCCA Stakeholders Meetings

Next we organised the EFCCA stakeholders meeting including representatives from the scientific and medical community as well as industry representatives. We convened this meeting in order to present EFCCA's new working approach and sponsorship opportunities for the coming year. Presentations were made by board and staff members as well as external collaborators working on specific actions such as the Patient Preference project.



In addition to our collective EFCCA stakeholders meeting we participated and networked in the following meetings:

- **Global IDB Council**

The EFCCA secretariat and several EFCCA members participated in the Global IDB Council meeting held on 9 October 2022 in Vienna which was organised by PFIZER (ARENA). The Council focused on 2 topics: the psychosocial impact of IBD and reducing potential barriers to accessing treatment.

- **Consortium meeting of the Methylomic project (Horizon Europe)**

EFCCA is a member of this new Horizon Europe project which aims to improve treatment options and the quality of life for people with Crohn's Disease or Ulcerative Colitis by developing predictive biomarkers enabling more personalised medicines. A preparatory meeting to talk about the individual work packages and organisational issues was organised on 9 October 2022 (see also page 15).

- **CONFIDE meeting**

This event was organised by the Lilly company on 7 October 2022 and involved a huge number of Key Opinion Leaders as well as patient representatives. The objective was to present the first outcome of a survey Lilly had organised.



Launch of transitional care forum

During UEG WEEK, EFCCA also participated in the inaugural meeting of a new 'transitional care forum' of patient organisations initiated by the European Society for Paediatric Gastroenterology, Hepatology and Nutrition (ESPGHAN) and the United European Gastroenterology (UEG).

This forum aims to investigate and discuss the key transitional care issues facing paediatric patients with digestive and liver conditions and to develop a consensus on a joint call to action for change to be shared with policymakers and healthcare providers across Europe over the next two years.

Transitioning through paediatric and into adult care is a critical time for patients and, if not carried out effectively and appropriately, can impact on education, mental health and patient outcomes. It has become clear that this is a major issue for patients, their carers and clinicians and that the transition process within and across Europe urgently needs reform.

The inaugural Patient Organisation Workshop on Transitional Care took place on the second day of the UEG Week on 9 October. EFCCA was represented by its board member Magdalena Sajak Szczerba who



gave an in-depth overview of the situation concerning young IBD patients. She also highlighted the important role patient organisations could take when working on recommendations and insights on this topic.



IBD HAS NO AGE

World IBD Day 2023

IBD HAS NO AGE is an EFCCA campaign started in 2022 in to raise awareness of how Inflammatory Bowel Disease (IBD) is impacting on the life of people aged 60 years and over. This year, for World IBD Day 2023 (19 May), we will be launching a survey on people with IBD aged 60 years and over to investigate more on this topic with questions related to both quality of care and quality of life.

Why people with IBD aged 60 years and over?

While IBD commonly peaks in young adulthood, a significant 10% to 15% of newly diagnosed people with IBD are 60 years or older. Moreover, it is estimated that in the next decade, 1/3 of all patients with IBD will be older adults (60 and above).

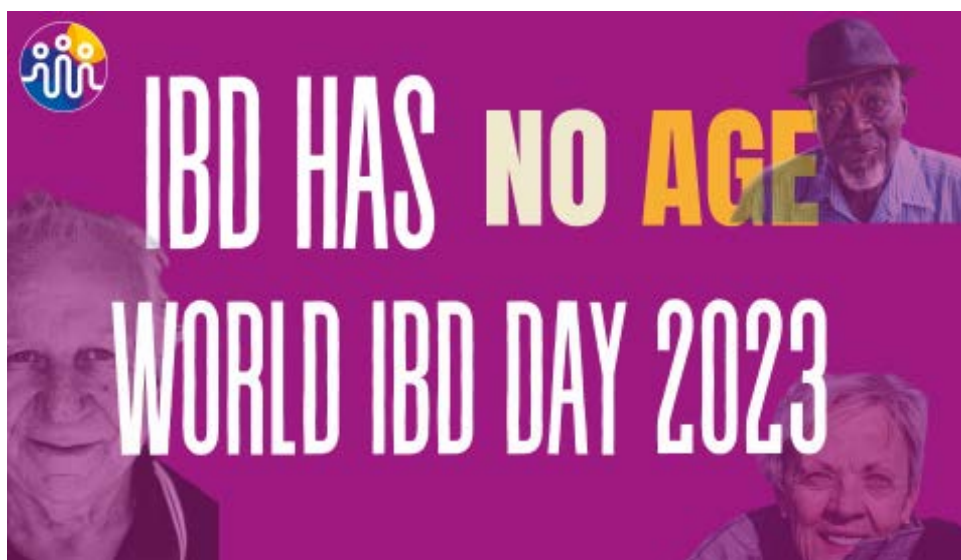
Our Key message are:

Equal access to best treatment options.

Currently, clinical data to inform treatment options practices are based on observational data or indirect evidence because people with IBD aged 60 years and over are underrepresented in clinical studies. Therefore there is a risk of IBD patients in this age group not benefitting from best treatment options.

We need a better understanding of the disease epidemiology among the older population and specific knowledge for the management and treatment of IBD in advanced age. There needs to be more research on specific issues related to co/morbidities, polypharmacy, drug effectiveness and interactions. Visit our World IBD Day page to find out more:

www.efcca.org/projects/world-ibd-day-2023



ICHOM Driving Positive Change: The New Era of Healthcare

The 2022 ICHOM conference event took place on 1-3 November 2022 at Boston Plaza, Boston, USA and welcomed over 500 delegates across patient groups, healthcare providers, regulatory bodies, governments, charities, industries and insurance from over 40 countries.

EFCCA was represented virtually by Ciara Drohan, our Vice-President and Honorary Secretary, who was part of the panel on “Why Patient Organisations roles are crucial in driving better patient outcomes”. Each organisation had the opportunity to speak about how important patient reported outcomes are to the patient and how we can achieve a more equitable and inclusive patient care and lessons learnt from the experience of implementing value-based healthcare.

We also had the chance to discuss our biggest hurdles and our aspirations for patients to be included and play a proactive role when it comes to identifying priorities (unmet needs), solutions or the assessment of new drugs and clinical trial implementation.



Euronews DEBATES: How can Europe shape the future of biosimilar medicines?

Euronews gathered a panel of experts to discuss how Europe can capitalise on - and shape the future of - biosimilar medicines. The debate took place on 15 November, 2022 at the European Parliament in Brussels.

The panel consisted of Adrian van den Hoven, Director General, Medicines for Europe, Tomislav Sokol, MEP, Group of the European People's Party & Member of the EU's Special Committee on the COVID-19 Pandemic: lessons learned and

recommendations for the future and EU40 Board Member, Ian Henshaw, Global Head of Biosimilars, Biogen and Luisa Avedano, Chief Executive Officer, European Federation of Crohn's & Ulcerative Colitis Association.

The discussion was around how biosimilar medicines can shape the future of Europe and why biosimilars are not currently uniformly used throughout the European Union. Our CEO, Luisa Avedano, pointed out that only 20 to 25 percent of the patients in our associations have access to biosimilars. *“We are dealing with a community which is fully aware of the importance of biosimilars, but we are not yet experiencing the big changes that were supposed to happen,”* she said.

Furthermore, she argued that it was important to create “the kind of critical mass that, based on the evidence, can show it’s possible to make changes”. She suggested to the panel that it could be done by ensuring policy makers, industry, medical societies, and associations all join forces.

She added that one issue was that the safety and efficacy of the medicines was not given enough prominence - *“in terms of raising awareness it’s important to stress the point that we are talking about something that’s fully transparent, safe and can give more patients the opportunity to be treated.”*

All in all she called for *“less inequality in access to drugs”* and equal treatment for patients across the EU. *“There are still lots of differences between countries, but I hope with biosimilars this big issue will be finally solved,”* she said.



LIVE FROM BRUSSELS

euronews. DEBATES

Tuesday 15 November - 15:30 CET

			
TOMISLAV SOKOL MEMBER OF THE EUROPEAN PARLIAMENT & EU40 BOARD MEMBER	ADRIAN VAN DEN HOVEN DIRECTOR GENERAL MEDICINES FOR EUROPE	IAN HENSHAW GLOBAL HEAD OF BIOSIMILARS BIOGEN	LUISA AVEDANO CEO EUROPEAN FEDERATION OF CROHN'S & ULCERATIVE COLITIS ASSOCIATIONS

EFCCA Publications

We are pleased to share 3 recent scientific publications to which EFCCA has contributed. The research studies have been published in the Journal of Crohn's and Colitis and in the European Journal of Health Economics respectively.

What are the unmet needs and most relevant treatment outcomes according to patients with inflammatory bowel disease?

This qualitative study forms part of our Patient Preference Project which aims to understand patient preferences among IBD patients, and their most important treatment outcomes and unmet needs.

As more therapeutic options with their own characteristics become available for inflammatory bowel disease (IBD), drug development and individual treatment decision-making needs to be tailored towards patients' preferences and needs.

EFCCA representatives and KU Leuven researchers brainstormed and worked on a shared understanding



and definition of attributes and structure of the study. Then the pilot phase started (September 2022). It consists of interviewing English native speaker patients to get honest and direct feedback on attributes for the survey.

Elise Schoefs, PhD Researcher–KU Leuven also presented our joint survey on IBD patient preferences at the ISPOR Europe conference in November, 2022. [Read study](#) (published in September, 2022)

Paediatric Inflammatory Bowel Disease: A Multi-Stakeholder Perspective to Improve Development of Drugs for Children and Adolescents

The study published in September 2022, aims to find potential advanced treatment options for children with inflammatory bowel disease. A 2-day virtual meeting was held on April 14-15, 2021, for multi-stakeholders (clinical academics, patient community, pharmaceutical companies, and regulators) to discuss their perspectives on paediatric drug development for inflammatory bowel disease.

[Read study](#)

Out-of-pocket expenses of patients with inflammatory bowel disease

There is a high variability of out-of-pocket patient costs of inflammatory bowel disease (IBD), but the issue is not widely recognised. Therefore, this study published in October 2022 compared patient costs of IBD between 12 European countries.

[Read study](#)



European Research Projects

EFCCA is currently involved in 7 European research projects under the previous Horizon 2020 programme and the new Horizon Europe programme. All projects address in innovative ways the needs and interests of the IBD patient community and, if successful, will ultimately improve the quality of life of IBD patients. You can find detailed information about these projects on the project specific websites as well as on the EFCCA website: www.efcca.org

GENEGUT project First General Assembly

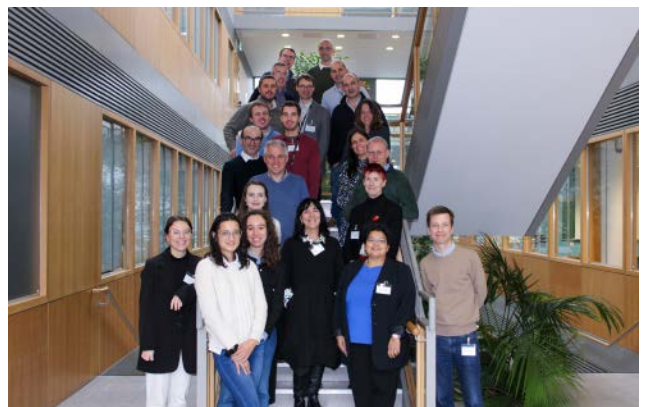
The First General Assembly of the GENEGUT project took place in Cork, Ireland on 10 January 2023 bringing together 30 consortium members of 9 partners from 8 European countries including patient representatives, renowned researchers, expert clinical scientists, SMEs and large pharma companies.

The project, which is coordinated by the School of Pharmacy of the University College Cork, aims to develop a noninvasive, safe, effective, and targeted treatment for ileal Crohn's disease that will be realised in the form of a first-in-class, orally administered RNA-based therapy.

This breakthrough RNA therapy will be developed using complementary technologies that selectively target immunomodulatory pathways within inflamed intestinal cells that reside in specific regions of the small intestine.

"It was great meeting this very inclusive group made up of first class scientists and technicians. We had an open discussion on the strengths and challenges of the project giving every partner the chance to express their opinion and ideas. EFCCA particularly welcomes the patient-centred approach of this project ensuring that our voice and perspectives are included in the debate" said CEO Luisa Avedano representing the

GENEGUT



European Federation of Crohn's and Ulcerative Colitis Associations during the event. *"We are very excited to be part of this project as we believe it can potentially change the treatment paradigm for patients with Crohn's Disease allowing for a better quality of life".*

For more information please visit: <https://genegut.eu>

METHYLOMIC project

Biomarkers as predictor of response to biological therapy in Crohn's Disease

The METHYLOMIC project will build on multiple previous cohort studies that confirmed epigenetic biomarkers (specifically DNA methylation) as the most stringent predictor of response to biological therapy as concerns Crohn's disease (CD). DNA methylation profiles in peripheral blood as biomarkers of response/deep remission for three approved biologics in CD have been specifically discovered and validated. Through machine learning algorithms, treatment response could be predicted with up to 93% accuracy for each biologics for CD.

The consortium consists of 19 partners including clinical, epigenetic, and DNA diagnostics experts, patient organisations, and companies across nine countries to ensure effective communication and commitment to help ease the challenges faced by patients with Crohn's disease.

EFCCA, as a partner, will play a role in launching multiple communication actions to boost the interest of patients and stimulate preparedness to participate by assessing and discussing research proposals and protocol and patient information form (PIF) from a patient perspective. EFCCA will also promote the research in patients with IBD through patient



Participants during the Kick-off meeting in Amsterdam

organisations in the countries where the research is taking place. The project will run for four years, and the kick-off meeting took place on 18 January 2023 in Amsterdam.

For more information please visit:

www.efcca.org/projects/horizon-europe-methylomic

MIGut, GlycanTrigger and FIBROTARGET projects

The **MIGut** and **GlycanTrigger** projects were approved last summer (2022) and are now ready to be launched. Furthermore at the end of last year (December) we were informed by the European Commission that the application for the **FIBROTARGET** project has also been successful. Below is a brief summary of these three projects that will start in 2023.

- The **MIGut-Health** consortium aims to develop a personalised blueprint of intestinal health to predict and prevent IBD. The overall goal is to deliver interdisciplinary health promotion and disease prevention solutions that would enable active patient engagement in health and self-care management.

- Chronic inflammation underlies several diseases. In Crohn's disease (CD), there is mounting evidence of a preclinical phase characterised by immunological changes that precede symptoms. The **GlycanTrigger** project proposes a thorough and innovative approach to understand better the health-to-chronic inflammation transition occurring in patients with CD that will be translated into improved disease prediction and prevention. The project will run for six years, and the kick-off meeting will commence in Porto (Portugal) from 13 to 14 March 2023.
- **FIBROTARGET** is a new project that aims to validate novel immunotherapeutic targets against fibrosis in inflammatory bowel disease to obtain patients and regulatory approval for implementing these novel noninvasive imaging modalities as diagnostic and prognostic tools for fibrotic IBD. This will allow vital future therapeutic development for intestinal fibrosis by providing better molecular and clinical stratification of IBD patients at risk for fibrosis. If successful, this project aims to pave the way in preventing and treating this invalidating IBD comorbidity.

IDEA-FAST and IMMUNIVERSE projects

EFCCA is a partner of two Horizon 2020 projects that have been on-going for two years

The **IDEA FAST** project aims to identify digital endpoints that provide a reliable, objective and sensitive evaluation of activities of daily living and Health-related quality of life (HRQoL) in Immune-Mediated Inflammatory Diseases, including IBD. The project's first newsletter (called IDEA-FAST COS) was published in November 2022. 13 clinical sites were opened, and patients were successfully recruited to identify digital endpoints to assess fatigue and sleep disturbances better. A total of 136 participants were recruited. So far, a new research paper has been published, and it presents the results of using wearable sensing technology to assess fatigue and

The **ImmUniverse** project aims to improve diagnostic and therapeutic options for patients living with ulcerative colitis and atopic dermatitis. ImmUniverse, has published an interesting position paper in "Frontiers in Immunology" in November, 2022, which highlights the current unmet need for the treatment of immune-mediated inflammatory diseases and emphasises that an advanced methodological approach is needed for improvement. Follow the progress at immuniverse.eu



sleep in patients with chronic diseases. The article provides clinicians with insights on monitoring patients in the natural everyday settings of a patient's daily life. Follow the progress at idea-fast.eu



GUIDANCE TO BETTER LIFE

We are a pioneer in the biopharmaceutical space in pursuit of a better life.

We help people around the world by expanding access to innovative and high-quality biologics.

Celltrion Healthcare is committed to delivering innovative medications to promote patients' access to advanced therapies. Our products include the world's first antibody biosimilar, the world's first subcutaneous formulation of infliximab, the first high-concentration adalimumab biosimilar and a monoclonal antibody treatment for COVID-19. Celltrion Healthcare endeavours to offer high-quality cost-effective solutions through an extensive global network that spans more than 110 different countries. To learn more visit: www.celltrionhealthcare.com

Hungary

IBD centres on MCCBE website

MCCBE (the Hungarian Crohn's and Colitis Ulcerosa patient organisation) is happy to announce that our website has been expanded with additional content including information about Hungarian IBD centres www.mccbe.hu/ibdcentrumok

Alongside basic information about IBD, patients can find IBD centres listed on a map: Such information has previously not been available anywhere, that's why we decided to fill the gap and provide a helpful tool.

Our homepage provides a patient journey description to help shorten the time between diagnosis and treatment recommending that the ideal time window to access treatment is within 1.5 years. We believe that the informed patient is the best advocate of their healing journey; therefore, we identify the practical information provided here as an essential step in our patient education efforts.

We have also added some of the **My IBD Journey animation videos** ("Life after IBD diagnosis" and "Daily Life"), and we are planning to publish some new animation videos about IBD and IBD centres soon.

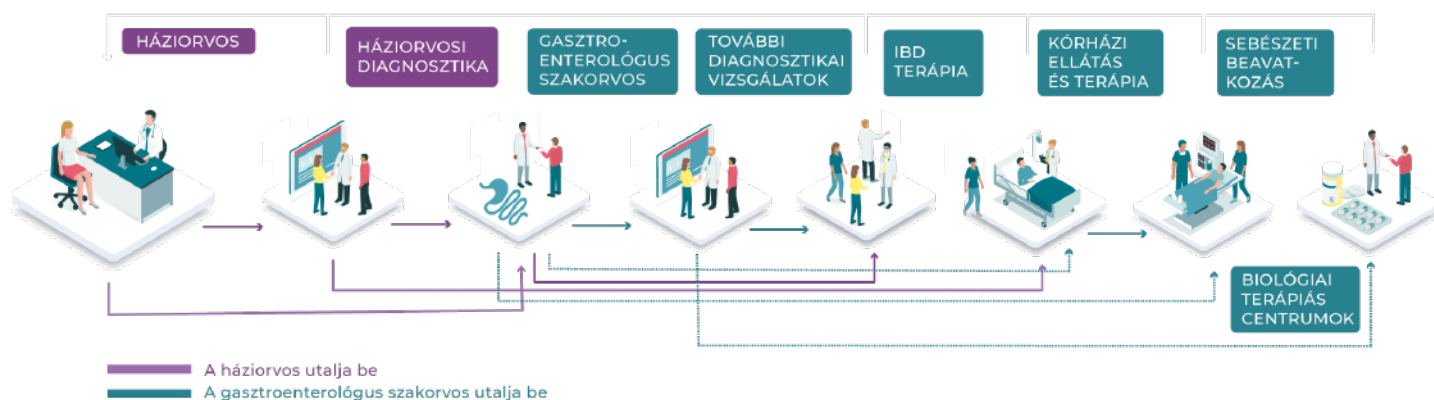
Bemutatjuk az IBD centrumokat!

Tudj meg többet az IBD centrumokról és a centrumokban elérhető kezelési lehetőségekről!



Members of the Colon Section of the Hungarian Society of Gastroenterology provided professional insights on our homepage. We are utmost grateful for their support which underline the importance of cooperation between medical experts and patients outside healthcare institutions.

Janssen supported the project, so we would like to thank them for their hard work on this project.



Netherlands

Earlier detection of emotional symptoms in adolescents

Every year, about 300 adolescents up to age 18 are diagnosed with IBD. A third of these adolescents subsequently experience gloomy feelings, depression, anxiety disorders or other so-called psychosocial complaints. The earlier it becomes clear that a young person is suffering, the faster help can be provided. The new tool, “IBD on my Mind” helps young people with their mental health.

Research shows that about 30 percent of adolescents up to age 18 experience sombre or anxious feelings after being diagnosed with IBD. *“Therefore, it is important that the IBD treatment team not only pays attention to the physical symptoms but also has an eye for the psychological consequences of the disease,”* says Patrick van Rheenen, paediatrician-MDL at UMC Groningen.

Tool content

IBD on my Mind works as follows: based on questions, young people receive information about possible feelings they may be having. Then they are advised on how to deal with them. *“That can vary from discussing it with parents or peers to seeking help from a psychologist or other health care provider,”* says Daniëlle van der Horst of Crohn & Colitis NL. Videos can also be found in the tool. Five youngsters came up with the themes together with the project group. Then the youngsters worked the themes out and filmed them. The themes deal with problems young people may face in everyday life, such as fatigue, lack of understanding, acceptance, body image and the future.

Van der Horst: *“We want to use the videos to show that it is not strange for a young person to have emotional problems. That’s part of having IBD, and it’s not your fault.”* For example, the fatigue video shows that you don’t have to feel bad because you are tired. Fatigue is part of the disease, don’t fight to have it. The video about lack of understanding zooms in on the lack of understanding



you can experience from loved ones and friends. The film about the future deals with feelings of uncertainty about what the future will bring. And also that young people are sometimes already busy with the question of which study suits their illness. The film about acceptance deals with the fact that you can feel alone or excluded and angry or sad about that at first. Or jealous of others with lots of energy. Only when these feelings have subsided can you look at what you can still do.

In the consultation room

It is essential to pay attention to possible psychosocial problems in young people in the consultation room as soon as possible after the diagnosis. *“The tool helps young people to draw attention to the subject, making it easier for them to ask for help,”* Van Rheenen continues. Topics of the tools and the five videos should also be discussed in the consultation room with the paediatric gastroenterologist, according to Van Rheenen.

Reaching more young people

“Crohn & Colitis NL is pleased with this project and the attention that psychosocial care for young people deserves,” continues Van der Horst. “We hope to reach many young people. And more importantly: young people realise that their complaints are not their fault and that

there is nothing they can do about it. Openness and talking about it helps. The earlier you do this, the better it is for the young person.”

You can find “IBD on my Mind” on [our website](#)

France

Afa CROHN RCH France celebrates its 40th birthday: exciting moments with memorable encounters and a goodbye to our CEO!

A 40-year fight against IBD for Afa! A wonderful odyssey for the only IBD national association, now recognised as one of the top health associations in France in its dynamic activity. The partnership has written its story of committed and active volunteers and core workers.

Afa chose to mark these 40 years in many stages. A 2-day seminar was held in May 2022 bringing together the Afa Board and core workers to audit the association’s development in the past years and forge a plan for the future. A questionnaire was sent to include the volunteers’ ideas and comments. This served as a base for reflection in setting down the priorities for “the beginning of what was to follow”.

Three days in October were dedicated to commemorating the 40 years. Starting Friday 21 October with an all-day seminar organised by AFEMI (Association Française pour l’Education thérapeutique dans les Maladies Inflammatoires Chroniques de l’Intestin), an association co-founded by Afa to develop and coordinate Stress Management programs. On Saturday 22 October, our IBD Congress was held with an outstanding array of activities. Last but not least on Sunday 23 October all our volunteers present over these three days gathered around the Afa projects and perspectives. Three days



marked this anniversary, uniting Afa members and its driving forces, volunteers, and core workers, not to mention many health professionals and stakeholders.

The main event (22 October) saw over 700 participants who had accepted the invitation to our IBD Special 40th Congress (Salon des MICI spécial 40 ans)! A look at some of the highlights at the Cité des Sciences et de l’Industrie (Paris 19e):

Renowned Experts

With a focus on five ambitious themes, leading experts in the field of IBD in France were mobilised: Prof. Laurent Peyrin-Biroulet (well-known at EFCCA) opened the Congress with a conference on “Where are we today with the objective of an IBD cure?” followed by Prof. Yoram Bouhnik “Personalised medicine: Which treatment for which patient?” and Prof. Benoît Chassaing ended the morning session with “Processed foods: What role do they play in IBD?”. The afternoon was more societal with Prof. Grégory Ninot, who resented “*How to improve disease through non-medication therapies*” and finally a round-

table composed of an Afa patient, Ronan Boulesteix, Féreuze Aziza from France Assos Santé (a federation uniting several chronic disease associations) and Elodie Jacquelet (Hôpital Necker – Childrens’ Hospital) on the theme of “*Invisible Handicap: strength or weakness?*”.

These major experts reminded us of Afa CROHN RCH France’s fundamental role, which is to support IBD Research and to promote advocacy. They underlined the urgent need for improved medical care and the recognition of these pathologies.

Precious moments in sharing experiences and friendship

Other significant highlights were the exceptional turnouts for workshops of discussions in small groups: families, close friends and relatives, young people, and people with ostomy. Talking openly about their disease and its daily impact is often challenging, with no taboos, between peers, finding reassurance, and sharing advice. This reflects the objective of our Afa groups which may be found on the Afa CROHN RCH France website!

Moments shared continued with the accounts from three IBD patients: World Fencing Champion Hélène Ngom, a young author Joanna Ebane and our Afa Champion, Eric Balez, who reached the summit of the Mont Blanc for

IBD, among other victories. All three told stories of their inspiring journeys and how they overcame the disease’s obstacles to reach their dreams or find the right path for each one. A book corner was created for the authors to autograph their books and discuss their work with the public.

Of course, visitors could talk and ask questions to the many volunteers and core workers, active listeners and specialists, on the various Afa stands: nutrition, family, legislation & work, etc. and discover all of the tools and services Afa has to offer.



40 Years: History and Advancement

This Congress was also an opportunity to mark this milestone by honouring all of the advances achieved, thanks to our collective mobilisation and commitment of the founders and of all those who have preserved and passed on the flame, not forgetting all of the volunteers in the field.

Finally, the closing of the congress was devoted to starting a new path of priorities for the future. Around fifty volunteers were present to validate the new directions for the coming years, the plan forged by the Board and the core working team. The ambitious objective is to prioritise IBD advocacy in French Public Health. Especially in the personalised treatment of each patient to be given the answers and never be left alone in the health professional networks ensuring that patients are oriented toward Afa Crohn RCH France.

A team of core workers has launched this future managed henceforward by Anne Buisson, Afa's new CEO since 1st January 2023, following my retirement after 17 years of strong commitments, which will not cease as I'll now be an Afa volunteer. The fight against IBD goes on! I will have had the pleasure of sharing too few but precious moments with the EFCCA teams, as health priorities are also European, and that's also a priority for Afa. May I reach out to you all with our best wishes for the New Year and fond memories of the past years since 2004!

Alain Olympie,
Afa CROHN RCH France

Italy

Eating disorders and IBD, an interesting link investigated by the University Hospital of Palermo, Italy

Anorexia, bulimia, food disorders: the correlation with Crohn's disease and ulcerative colitis is complex and little investigated, even if affecting many patients. The most hit are young people, women and subjects with a long history of the pathology.

Doctors **Maria Cappello** and **Francesca Maria Di Giorgio** from the Gastroenterology and Hepatology unit, have investigated more about the complex relationship between IBD and Nutrition.

IBD patients usually tend to avoid foods considered harmful. This implies a risk of nutritional deficiencies or real eating disorders.

Several studies (**2017 Spain**, **2021 JCPP Advances** based on Danish database, **2022 Clinical Gastroenterology and Hepatology Journal**) illustrated

a correlation between IBD and eating disorders. In particular, between anorexia nervosa and Crohn's among women between 10 and 44 years old or the fact that anorexia nervosa in healthy patients could be associated with an increased risk of having a subsequent IBD diagnosis. Finally, more than 60.7% of IBD patients affected by this eating disorder are malnourished.

Factors could be several, but the main one could be the microbiota composition, which is also linked to the adoption of restrictive diets and the altered relationship with food.

IBDs and eating disorders frequently occur in young people, so it is inevitable to focus on body image perception.

A new study this year, published in Inflammatory Bowel Diseases Journal, found that a third of young participants with IBD show body image disturbances while more than 10% live with an eating disorder. This is particularly common in anxious patients and those with a long-standing IBD diagnosis.

Finally, the research group, led by doctors Cappello and Di Giorgio, analysed the prevalence of orthorexia, the pathological obsession with healthy food. This recently recognised eating disorder is also prevalent among young people. According to this study, the risk is that 70% of IBD patients, single and low weighted, can also suffer from orthorexia (according to survey).

From this, it is evident the importance of the nutritionist within the multidisciplinary teams in the centres dedicated to diagnosing and treating IBDs.

The hope is that nutritionists can help patients with IBD with their pathology and avoid mistakes in diets that could become severe eating disorders.

“IBD patients usually tend to avoid foods considered harmful. This implies a risk of nutritional deficiencies or real eating disorders.”



Estonia

The Estonian Inflammatory Bowel Disease Society (EPSS) proudly introduces the new charity children's book “Epsik”

There are nearly 2,500 people in Estonia who have been diagnosed with Inflammatory Bowel Disease or IBD. They also include many children who have to live with the disease all their lives.



Inflammatory Bowel Disease can begin at any age, but is most often diagnosed in teens and early adulthood. The incidence has increased globally among children and adolescents in recent decades. 25% of all cases of IBD begin before the age of 20. A child may also receive a diagnosis during infancy.

For some time now, children who have been diagnosed with IBD will receive a troll doll called Epsik handcrafted by Monika Põder. The troll doll is aimed to support the child both in learning about IBD and as a cuddly toy. The EPSS mascot was born in cooperation between members of the society and artist Pia Hanslep.

Epsik is not a normal doll, she has her own story and tender soul. Metsavana draws a heart on Epsik's tiny bulging stomach, which occasionally hurts. Metsavana is a doctor in the troll world. But even he can't completely take away Epsik's stomach pains.

Epsik's story was invented by Kristel Lempu, member of the EPSS. Epsik's story has now entered the book. There, Epsik talks about her family, her illness, and the troll world. The doll encourages families to seek help. From 2023, every child receiving a diagnosis of IBD will receive both an Epsik doll and the book with the support of the Estonian Inflammatory Bowel Disease Society.



United Kingdom

Crohn's & Colitis UK launch new campaign for early diagnosis

It's taking too long for people with Crohn's and Colitis to get diagnosed - with more than a quarter waiting over a year. Delays in diagnosis and treatment affect people's ability to continue education and work and narrows their treatment options while increasing their risk of being hospitalised or needing emergency surgery.

On 2 November, Crohn's & Colitis UK launched a national public awareness campaign - Cut the Crap: Check for

Crohn's and Colitis - aimed at 18 to 34-year-olds, helping them to recognise signs of Crohn's and Colitis and encouraging them to contact their GP. The campaign seeks to improve lives through early diagnosis. The earlier people are diagnosed with Crohn's or Colitis, the earlier they can be treated and the better they do. If you ignore the signs of Crohn's and Colitis for too long, treatment becomes more difficult and you are more likely to need stronger medication, hospital admissions or surgery.

A recent survey of 10,000 people across the UK commissioned by Crohn's & Colitis UK revealed that nearly half of people across the UK have not heard about Crohn's and Colitis. As a result, too many people delay contacting a healthcare professional when they have the most common symptoms, especially when they don't have all the symptoms - or not all the time. The survey found 2 in 5 people would delay going to the GP if they had diarrhoea, stomach pain or blood in stools. The research found young adults aged 18-34 were even more likely to ignore the key signs of Crohn's and Colitis, with 4 in 5 experiencing at least one barrier in getting medical advice from healthcare professionals, such as their GP.

The campaign features a symptom checker, developed in partnership with GPs and gastroenterologists. The online tool takes 30 seconds to complete. It advises individuals about whether they should contact their GP, which symptoms they should talk about, and what to expect from their appointments. To date over 30,000 people have completed the symptom checker.

- Crohn's & Colitis UK commissioned a 2022 national survey of 10,000 people, revealing that two fifths of people in the UK would delay going to the GP for more than a month when they had diarrhoea, stomach pain or blood in stool with symptoms.
- In the majority of cases, patients first visit their GP with stomach pain, diarrhoea, or blood in their poo. Yet, one in two adults do not know these symptoms could be signs of Crohn's or Colitis.
- Findings from 2019 revealed that more than a quarter (26%) of people with Crohn's and Colitis wait more than a year to be diagnosed, while nearly half (41%) will end up in A&E at least once before they are diagnosed.



Read more about the early diagnosis campaign and use the symptom checker at www.crohnsandcolitis.org.uk

Research

The survey of 10,000 people which Crohn's & Colitis UK commissioned was carried out independently by Censurwide in August 2022.

IBD UK's survey in 2019 found more than a quarter (26%) of people with Crohn's and Colitis wait more than a year to be diagnosed while nearly half (41%) will end up in A&E at least once before they are diagnosed.

Austria

Let's talk about digestive problems

Most people reading this article will probably know that IBD can lead to a severe reduction in the quality of life. Especially for young people, who want to explore the world, this can be a very depressing and challenging experience. Topics such as friends, school and partying may be discussed, but health issues often get ignored because they are seen as taboo subjects.

We-Marie Probst, Sina Zangerl and Jakob Scherl - want to change that! Since many people in our environment have IBD, we know how challenging it can be. Our mission is to break the taboo and help adolescents discuss their digestive problems. The main aim of our diploma thesis is therefore to inform and educate about this topic in particular. To further support people living with IBD, we have also made a tea that helps with mild symptoms.



This tea was made available during our awareness raising activities for the “Tiroler IBD Day¹” which took place on 15 of November 2022.

1. Tirol is a federal state in Western Austria

Cyprus

In November 2022, the Cyprus Crohn's and Ulcerative Colitis Association (CYCCA) along with the “Children with Liver Diseases Foundation – Giorgos Psaras Round Table” held a dinner in honour of Dr Babu Vadamalayan (Paediatric Gastroenterologist – King's College Hospital, UK). He visited Cyprus once again after the strict restrictions of the Covid-19 Pandemic. Representatives of the Association and the Foundation, respectively, were joined by Dr Panagiota Protopapa (Clinical Lead and Specialist Paediatrician), Dr Elena Savvidou (Paediatric Gastroenterologist) and Mrs Angela Angeli (Senior Nurse), who attended the dinner.

Dr Babu Vadamalayan visits Cyprus at least three times a year. He supports the Pediatric Center for Liver, Gastroenterology and Nutrition at Makarios III Hospital, Nicosia, while his permanent position is at the King's College Hospital, UK. Between 2012 and 2018, the centre was housed at the Health Center of Engomi in



Nicosia. From 2018, when it moved, to this date, this Department has been fully functional at Makarios III Hospital (Nicosia), where it provides daily medical care to children with liver and gastroenterological diseases. Around 2000 children with rare chronic liver and gastroenterological diseases are treated at the centre with the valuable help and support of Dr Panagiota Protopapa and Dr Elena Savvidou.

CYCCA has been supporting the centre and the doctors as much as possible and at every opportunity, for them to keep the technical agreement (signed in 2014) between Makarios III Hospital in Nicosia and King's College Hospital in London. This agreement is vital for the children as they can now be treated and monitored in Cyprus.

In this, we stand united, and with all our supporters' help, we will continue to work towards a better future for our patients.

Romania

Presidential Decree awarding ASPIIR the Order “Merit for the Promotion of Human Rights and Social Commitment” in the rank of Knight

It has been almost 13 years since the Association of People with Inflammatory Bowel Disease was founded in Romania. Although one might think to associate the number 13 with bad luck, it has been the contrary for us. We have received the distinction conferred by the President of Romania, the Order “Merit for Human Rights and Social commitment” in the rank of Knight. This has brought us a crowning to our involvement, passion and efforts made in these years in support of patients with Inflammatory Bowel Diseases and ostomates.

At the end of November 2022, the Official Monitor of Romania published the Presidential Decree granting this distinction in the rank of Knight to ASPIIR - which brought us so much enthusiasm and made us proud.

The distinction granted by the President of Romania - a recognition of the results and social commitments at the national and international level - is particularly honourable for ASPIIR. At the same time, it makes us more responsible and motivates us to continue developing our capacity to support patients with Inflammatory Bowel Disease and stomas. We share this honourable recognition with the medical societies that have been with us and supported us since the

beginning, the Romanian Club for Crohn's Disease and Ulcerative Colitis and the Romanian Society of Gastroenterology and Hepatology.

We were entering an unknown territory without the expertise to approach patients with their needs when we initially set up this association. This situation was similar to gastroenterologists who faced tremendous challenges managing the wave of lesser-known diseases in Romania, like Inflammatory Bowel Disease. However, after 12 years of engaging in many activities and efforts, we are in the position in which the Presidential administration recognises ASPIIR as a factor of social commitment at the national level and awards it the title of Knight for the promotion of human rights, respectively, the rights and support of patients with Inflammatory Intestinal Diseases.

The awarding ceremony is to be announced.

Isabella Grosu
President ASPIIR Romania

Health First Europe - What essential skills does the European health workforce need?

The EU Health Policy Platform Stakeholder Network on “Profiling and Training the Healthcare Workforce of the Future” [Report](#) was launched on 22 September 2022 in the European Parliament. The report tackles the question of what essential skills the European health workforce needs to cope with 21st century challenges such as demographic change, the increasing number of chronic and non-communicable diseases or the digital and green transitions.

The European Parliament’s Interest Group on Innovation in Health and Social Care gave a platform to the EU HPP Stakeholder Network to present its new report on essential skills for the European health workforce. The event was hosted by MEP Istvan Ujhelyi and was honoured to welcome representatives of the European Commission and the Committee of the Regions for a panel discussion.

The European Institutional speakers highlighted the importance of data collection at the Member State and regional levels and quicker data availability, which probably the European Health Data Space (EHDS) could make feasible. Secondary data of the EHDS will be crucial for more effective health workforce planning. Up-to-date and more accurate information is also needed about cross-border collaboration. Evidence and data are crucial for decision-making at all levels.

Skills are essential but infrastructure development is also needed to make sure that citizens have access to equally high-quality care not only in urban areas or in capitals but also in rural and remote areas. Around 50% of rural areas do not have broadband Internet

connection although access to fast Internet would be the basis of digital tools and developing digitalised services.

Without further investment into infrastructure development, the digital divide will but grow and together with the digital divide the digital skills divide will also intensify as well. Member States and regions have several funding opportunities to exploit from the Recovery and Resilience Facility, the Regional Development Funds and many others.

In their national Recovery and Resilience plans, all Member States have included developments in the area of health. Some Member States such as Italy, Austria and the Netherlands will specifically target skills development.

As a next step, member organisations of the EU HPP Stakeholder Network under the leadership of EHMA and HFE will explore collaboration opportunities with European, national and regional level policy makers, will map other relevant initiatives to join forces and will seek synergies to support the implementation of the numerous recommendations they have included in the report.

More info: bit.ly/EventSummary2022



European Patient Forum - Health in the European Semester 2022

The European Patient Forum has published a report entitled “Health in the European Semester 2022”



The aim of this report is to provide an overview of the health-related aspects of the Commission’s 2022 European Semester process and explain its major elements, timeline, and relevance to the patient community represented by EPF.

As part of the European Semester process, the Commission issues a series of Country Reports (CRs). The report provides a summary of the CRs for each Member State, with a focus on health and the United Nations (UN) Sustainable Development Goals (SDGs).

Read the report [here](#)

European Disability Forum - Conference on “Disability Rights, Accessibility and Artificial Intelligence”

The European Disability Forum (EDF) and the Swedish Disability Rights Federation (Funktionsrätt Sverige) are hosting a conference on “Disability Rights, Accessibility and Artificial Intelligence” on March 31, 2023.

The conference is co-funded by the Swedish Ministry of Health & Social Affairs and the Swedish Post & Telecom Authority. The event will contain a series of sessions to discuss paramount topics impacting persons with disabilities in the European Union today including ways to implement and respect Disability Rights.

Conference sessions will also cover topics related to the new AccessibleEU Center and ways accessibility regulations impact regional and local communities. The afternoon sessions will explore digitalization and Artificial Intelligence (AI) in the context of disability rights to ensure full, equal, and unrestricted access for persons with disabilities in society.

Venue

The conference will be held at the [Quality Hotel Globe](#) Room “Galaxen” in Stockholm, Sweden and online via Zoom.

Anyone is welcome to participate in the conference online. However, in-person participation is limited, and in-person participation is by invite only. If you would like to attend in-person, please contact Erika Hudson at erika.hudson@funktionsratt.se to express your interest.

Accessibility

We will provide international sign interpretation and real-time captioning in English.

The event is open for online participation (a link will be sent separately by email to those who register for the online event). The online event will include international sign interpretation and real-time captioning in English.

For any questions, please contact Raquel Rianza raquel.riaza@edf-feph.org



Not just a walk to the supermarket

By Simone Hasselriis Haulrich

Interview with Simone Hasselriis Haulrich, a 29 years old pharmacist from the University of Copenhagen who works with quality assurance of vaccines in her daily work.

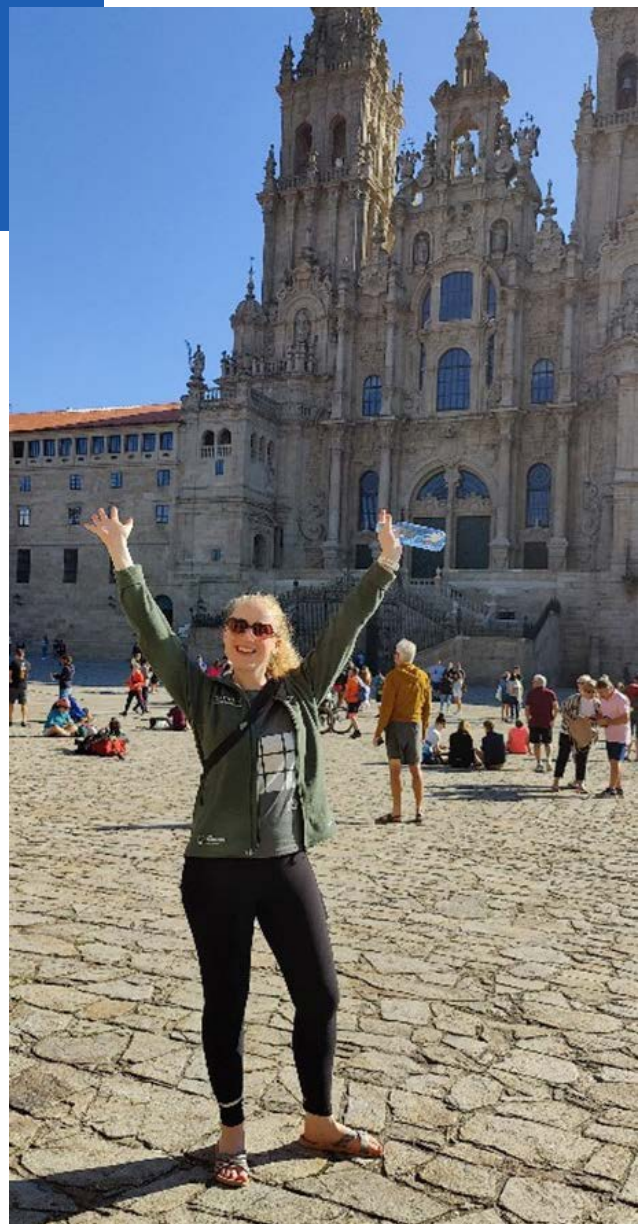
"Whether you think you can or you think you can't, you're right"

Henry Ford

On a cold February day in snowy Copenhagen, I rode my bike to a colon doctor's clinic. Still sweaty and wrapped in my favourite mint green sweater, I found myself on my left side at a doctor's desk. Please take my advice: A woollen sweater is not the right choice for a first colonoscopy. Important lesson learned. Camera up the butt, and here we go. "Yeah... Well, the cleanse has not been too successful", the bald doctor said to the nurse. Based on the video on the screen, which certainly did not show 'Friends', I would agree with him.

Colitis ulcerosa was the verdict back in February 2021. I left the clinic with a strange feeling of flutter in my stomach. Although I was well aware that the diagnosis was chronic, I was mostly relieved to have an explanation for the blood and discomfort I had felt. At the same time, I was excited to investigate what treatments existed and curious about how my body would react to them. The excitement and curiosity were mainly of a professional pharmaceutical interest.

As months went by, the IBD journey was a rollercoaster. Many ups but mainly many downs. In September 2021, I was looking forward to spending a couple of days with my sister at Bornholm, a beautiful Danish island



with stunning nature (worth a visit if you have never been there). Just before I left with the ferry, I had my calprotectin measured and was awaiting the result.

The following day at Bornholm, I woke up feeling well-rested. The bunk bed was surprisingly soft and warm, and the birds in the trees crowning against the blue sky sang outside my window, welcoming the new day. It was all very Disney-like, and I felt like a princess yawning gracefully. That illustration was ruined with one look at my phone. The calprotectin result had ticked in; >1800 x 10⁶. Ouch. What could have been a wonderful day with my sister did not seem so bright anymore. The result knocked me out, and I spent several days muttering and feeling blue.

Attempting and experimenting with different treatments over the next few months, I discovered that I could achieve some control over my disease. And that was a turning point for me. I had felt my body was completely out of control for the past months. At this point, I was reminded that one thing I definitely could control was my mind. Only I can decide my thoughts. Wow.

The new-found belief in myself brought me to start dreaming again. I had dreamed of walking El Camino Frances in Northern Spain for many years. One day, by what seemed like a coincidence (but really it was not if you believe in the Universe as I do), I came across a post on Instagram: Be part of a great project and walk the Camino. Click.

The project was a fundraiser for the Danish Children's Phone. Twenty-four hours every day of the year, volunteers pick up the phone or answer the chat when a child or young person contacts the phone or chat. The Children's Phone offers great support for those who require an independent grown-up to talk to. The primary aim of the fundraising project was to collect money to ensure sufficient resources available to always offer children an ear to listen all the time.

I applied and was accepted to be part of the 100 Danes travelling to Santiago in September 2022. Woohoo!

Besides the primary aim of collecting as much money as possible for the children, the focus was also on preparing for the physical part of the trip, the 'hiking 120 km in five days' part. I already had a solid pair of boots and was in decent physical shape. What I needed to train/practice

were the toilet visits in nature. To find the "guts" (haha) to sit down behind a tree, knowing that the rest of my team was waiting just a few metres away. It was not appealing at all. Especially in the periods when even a short trip to the supermarket seemed impossible as the comfort and safety of my own "porcelain throne" would be too far away. I am sure many IBD fighters know the feeling.

I did learn, though and was getting more ready for the long walk. The trip to Spain was coming closer, but I was spending more time in bed because of stomach cramps, an extreme lack of energy, and not practising and building up those leg muscles. Bummer.

On the days spent in bed, I studied and played with the power of the mind. Just a year before, those days would have been terrible to my mood, but I had learned to accept them and how to twist my mind and enjoy the days. Instead of focusing on the restrictions, I thought: What is the opportunity of being bound to my bed? Remember: Where attention goes, energy flows. I used the opportunity to imagine the wonderful journey lying ahead. To visualise the steps taken on the gravel paths under the warming Spanish sun and the immense, overwhelming feeling of gratitude I would be filled with once I reached the square in front of the cathedral in Santiago de Compostela at the end of "the Way".



Slowly, the picture became so clear to me that it almost felt like I had already done it. I phrased the mantra, “I am so happy and grateful now that my body is strong and healthy while walking to Santiago”. It kept me focused on the goal of completing the one-week trip on the Camino in the best way possible. And I did.

Just a week before departure, my calprotectin was measured. It was uncomfortably high – even higher than the result at Bornholm –but this time, it did not affect my mood. I looked at the test result and thought, “well, that is a high number”. That was it. I moved on with my day and thought that this seemingly random number did not get to decide how I felt. A completely different take on a result that was way beyond acceptable compared to my reaction to Bornholm. What a difference a year of working mentally with a chronic illness makes.

The team of happy campers was ready for the long walk. A lot of money had been raised, so we were off to enjoy Spain and test our hiking shape. Off we go!

We walked for many hours daily, which was nothing less than amazing. I walked 120 km without a single blister or any other, even minor, injuries. At one point, I asked a teammate: “Would you say that you’re a pilgrim if you had not suffered the least during the pilgrimage?”. The question was in no way meant as flabby as it came out.

However, it was a clear sign of just how GREAT I felt. I was almost high from all the physical movement, and the thought of the fundraising purpose was very uplifting. Multiple times, I was filled up with a feeling of deep gratitude.

All in all, we collected just around 270,000 € for the children and were all extremely pleased with the result. On my way home from Spain, I reflected on how great the experience had been. I was amazed that I could finish a physically demanding walk like the Camino. With a “strong and healthy” body as visualised.

What a vast difference there was from being stressed about going to the supermarket compared to walking 120 km in Galicia. Worlds apart.

It felt like nothing was impossible from the bottom of my heart and the very inner of my soul.

Please feel free to reach out to me. I do not consider myself an expert in handling the impossible IBD life, but I genuinely enjoy learning how to.

Enjoy living the impossible.

Simone Hasselriis Haulrich
Instagram: [@simonehasselriis](https://www.instagram.com/simonehasselriis)



European Medicines Agency (EMA)

EMA confirms measures to minimise risk of serious side effects with Janus kinase inhibitors for chronic inflammatory disorders

EMA's human medicines committee (CHMP) has endorsed the measures recommended by the Pharmacovigilance Risk Assessment Committee (PRAC) to minimise the risk of serious side effects with Janus kinase (JAK) inhibitors used to treat several chronic inflammatory disorders. These side effects include cardiovascular conditions, blood clots, cancer and serious infections.

These medicines should be used in the following patients only if no suitable treatment alternatives are available: those aged 65 years or above, those at increased risk of major cardiovascular problems (such as heart attack or stroke), those who smoke or have done so for a long time in the past and those at increased risk of cancer.

JAK inhibitors should be used with caution in patients with risk factors for blood clots in the lungs and in deep veins (venous thromboembolism, VTE) other than those listed above. Further, the doses should be reduced in patient groups who are at risk of VTE, cancer or major cardiovascular problems, where possible.

The recommendations follow a review of available data, including the final results from a clinical trial of the JAK inhibitor Xeljanz (tofacitinib) and preliminary findings from an observational study involving Olumiant. The review also included advice from an expert group of rheumatologists, dermatologists, gastroenterologists and patient representatives.

The product information for JAK inhibitors used to treat chronic inflammatory disorders will be updated with the new recommendations and warnings. In addition, the educational material for patients and healthcare professionals will be revised accordingly.



EUROPEAN MEDICINES AGENCY
SCIENCE MEDICINES HEALTH

Information for patients

- Janus kinase (JAK) inhibitors used to treat chronic inflammatory disorders have been found to increase the risk of major cardiovascular problems (such as heart attack or stroke), cancer, blood clots in the lungs and in deep veins, serious infections and death when compared with TNF alpha inhibitors.
- These JAK inhibitors (Xeljanz, Cibinqo, Olumiant, Rinvoq and Jyseleca) are used to treat one or more of the following chronic inflammatory disorders: rheumatoid arthritis, psoriatic arthritis, juvenile idiopathic arthritis, axial spondyloarthritis, ulcerative colitis, atopic dermatitis and alopecia areata.
- If you are aged 65 years or above, have an increased risk of major cardiovascular problems or cancer or if you smoke or have done so for a long time in the past, you should only be prescribed these medicines if there are no suitable treatment alternatives for you.
- If you have certain risk factors, your doctor may reduce the dose of your JAK inhibitor or switch treatment depending on your inflammatory disorder and the JAK inhibitor you are taking to treat it.

- If, at any stage during your treatment, you experience chest pain or tightness (which may spread to arms, jaw, neck and back), shortness of breath, cold sweat, lightheadedness, sudden dizziness, weakness in arms and legs or slurred speech, contact your doctor immediately.
- Examine your skin periodically and let your doctor know if you notice any new growths on the skin.
- If you have any questions about your treatment, speak to your doctor.

More info [here](#)

Clinical Trials

We are pleased to be introducing this feature as part of our new working methodology. Within the framework of information sharing we will feature articles from our stakeholders highlighting their latest news and information relevant to our patient community taking into account ethical guidelines and the Code of Practice as established by the European Federation of Pharmaceutical Industries and Associations (EFPIA).

What is the optimal treatment target for patients with active ulcerative colitis? The VERDICT trial aims to answer this question¹

When recommending treatments for patients with ulcerative colitis, physicians may use a number of different markers of disease activity to assess whether the disease is active or responding to treatment.¹

These assessments are typically based on symptoms (e.g. bleeding, stool frequency), endoscopy (i.e. how inflamed the bowel looks on direct visualisation) or histopathology (i.e. whether there is evidence of inflammation under the microscope on tissue biopsies).¹⁻³

Normalisation of symptoms is an important treatment target that allows patients to continue with the daily activities of life. However, some patients who reach this symptomatic treatment target will still have inflammation that increases their risk of disease complications such as flares or hospitalisation.^{4,5}

Patients who reach a more stringent treatment target involving endoscopic mucosal healing (i.e., no signs of inflammation on endoscopy) or histologic remission (i.e., no signs of inflammation on tissue biopsies) may have a lower risk of complications.^{4,6,7}



Nevertheless, the optimal treatment target that would prevent complications for ulcerative colitis remains uncertain^{8,9}.

Identification of the optimal treatment target has the potential to better guide therapeutic approaches for patients with ulcerative colitis in clinical practice and future clinical trials.^{8,9}

In a collaboration between Alimentiv and Takeda, the VERDICT trial aims to determine the optimal treatment target for patients with active ulcerative colitis (Clinicaltrials.gov: NCT042591382)¹⁰.

This international trial in patients with moderately to severely active ulcerative colitis is designed as a randomised controlled study comparing 3 different treatment targets:

1. Symptomatic remission only, without the use of steroids
2. Endoscopic and symptomatic remission, without the use of steroids
3. Histologic, endoscopic, and symptomatic remission, without the use of steroids

The primary objective of this study is to determine if the combined treatment target of histologic, endoscopic, and symptomatic remission leads to a higher reduction in the subsequent occurrence of disease complications, compared to the treatment target of symptomatic remission only. Enrolled patients will receive escalating therapy until they reach their randomly assigned treatment target.

The study findings may translate to advantages for patients with active ulcerative colitis, including reductions in their risk of disease flares, hospitalisations, and other complications upon achievement of the optimal treatment target.

The VERDICT trial began in September 2020 and is currently being conducted at 55 sites across 10 North American and European countries. The study has enrolled more than half of the targeted 660 patients as of late 2022 and is expected to be fully enrolled by late 2023.

Determining and treating the optimal treatment target for ulcerative colitis may help patients reduce their likelihood of having a relapse.^{8,9} Doctors might use this potential treatment target in their clinical practice, and it may improve the design of future clinical trials that will evaluate new therapies.

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2. The VERDICT trial (In active ulcerative colitis, a Randomized Controlled Trial for determination of the optimal treatment target; EudraCT Number: 2019-002485-12)

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