

# EFCCA MAGAZINE

EUROPEAN FEDERATION OF CROHN'S AND ULCERATIVE COLITIS ASSOCIATIONS

OCTOBER 2022

Claire,  
Morbus Crohn

# #MAKEITVISIBLE



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**On the cover  
World IBD Day 2022 in Austria**

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photo credit @ Barbara Wirl

www.efcca.eu

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Crohn-RCUH: www.mici.be

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Czech Republic - Pacienti IBD  
www.crohn.cz

Denmark - CCF  
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Estonia - EPSS  
www.ibd.ee

Finland - CCAFIN  
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France - AFA  
www.afa.asso.fr

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Greece - HELLESCC  
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Hungary - MCCBE  
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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

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www.draugija.info

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www.j-elita.org.pl

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www.apdi.org.pt

Romania - ASPIIR  
www.aspiir.ro

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Slovakia - SCC  
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Slovenia - SAIBD  
www.kvcb.si

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www.accuesp.com

Sweden - MOT  
www.magotarm.se

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

Turkey - IBHDYD  
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www.crohnsandcolitis.org.uk

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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  
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Ukraine - Fulfilling life  
www.gofulllife.com.ua

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# Leaping forward

We are proud to share with you our latest issue of the EFCCA Magazine which addresses many of our activities and achievements over the last few months.

Undoubtedly one of our major highlights was the General Assembly which took place in Barcelona last June. It allowed us to finally meet again in person with our dear members, friends, colleagues, and new faces.

For two long years, we had 'only' been able to meet online. I think we all agree that such virtual meetings can have a useful function, however, they cannot replace the richness, benefits and need of personal meetings, where we can interact more humanly and feel the warmth of our colleagues. Such meetings give real meaning to our work and feed our determination and work to advocate for a better quality of life for people living with IBD. Barcelona gave us this new impetus.

There, we were pleased to welcome a new member from Lebanon to our EFCCA family, bringing our total membership to 46 national patient associations.

Our meeting was not only important on a human level, but it also laid the foundations for our new strategy to come. We had an intensive day of discussions, brainstorming and exchanging ideas about how EFCCA should move forward in the coming years. You will find a detailed report in this issue and a description of our consultation process which will run until March 2023.

Another highlight for EFCCA is our continued cooperation with medical societies such as the European Crohn's and Colitis Organisation (ECCO) which this year translates into a new project on the revision of the ECCO Crohn's Disease Treatment Guidelines. ECCO has approached us to nominate a group of patient representatives to be part of the ECCO Working Group on updating these guidelines.



We have selected eight patient representatives including two patient representatives from outside the European region who will be participating on behalf of EFCCA in this project for the coming 18 months.

Engaging EFCCA in the revision of the ECCO guidelines clearly shows that the medical community acknowledges the need of involving patients' associations in decision-making and defining relevant outcomes in a patient-oriented way.

We believe that our inclusion is essential for making the ECCO Guidelines relevant not just for clinicians but also for us patients.

In addition to our project with ECCO, we are also very pleased to inform you that four projects, in which EFCCA is a consortium partner, have been selected under the new Horizon Europe programme.

This is really a big step forward for EFCCA as it will allow us to be involved in cutting-edge research aimed at improving treatment options and the quality of life for people with Crohn's Disease or Ulcerative Colitis: from developing predictive biomarkers enabling more personalised medicines, investigating mechanisms that will allow us to understand better the health-to-chronic inflammation transition occurring in patients for improved disease prevention and prediction, to transforming the treatment of ileal Crohn's disease (CD) by developing a first-in-class oral RNA-based therapy.

Our participation in these four new projects as well as our current two on-going projects IDEA-FAST and ImmUniverse, shows that EFCCA has become the reference point for the research community as a viable partner representing the needs and interests of the IBD patient community.

There are many other inspiring stories in this issue from our members, IBD volunteers, and some of our stakeholders. They all have in common a relentless drive to advocate and fight for a better quality of life for people with IBD.

**“Engaging EFCCA in the revision of the ECCO guidelines clearly shows that the medical community acknowledges the need of involving patients' associations in decision-making and defining relevant outcomes in a patient-oriented way. We believe that our inclusion is essential for making the ECCO Guidelines relevant not just for clinicians but also for us patients.”**

It is working closely with our members, partners, and stakeholders, that makes our work possible and successful. But we need to continue our work and bring issues that matter to patients to the attention of our stakeholders, policymakers and decision-makers. For that, we rely on our members' engagement as together we have a much stronger voice.  
United We Stand!

Salvo Leone,  
EFCCA Chairperson

# EFCCA General Assembly

After two long years of travel restrictions due to the COVID-19 pandemic, EFCCA delegates, board members, and staff met again face to face during the EFCCA General Assembly, which took place in Barcelona from 10-12 June 2022.

With the health situation improving in many parts of the world and travel restrictions being partially lifted, the EFCCA board decided to hold a hybrid General Assembly in 2022. The first part of the General Assembly took place online on 28 May 2022 and dealt mainly with institutional matters of our organisation.

Delegates approved the GA minutes (2021), the Financial Report and the Annual Activity Report. Then elections to the EFCCA Executive Board were held. Salvo Leone was re-elected as EFCCA chairperson, and Marko Perovic was re-confirmed as Treasurer. The newly elected board consists of the following members:

Salvo Leone, Chairperson  
 Ciara Drohan, Vice President  
 Marko Perovic, Treasurer  
 Magda Sajak, board member  
 Menne Scherpenzeel, board member

Delegates then voted on the admission of a new member to EFCCA, bringing our total membership to 46 associations. The new member organisation “I Battle Disease” is from Lebanon and was represented by its president Nathalie Jbeily. You will find an interview with Nathalie in the Member Section of this magazine on page 26. All other documents of the meeting can be found in the private member area of our website.



The second part of our General Assembly took place in Barcelona from 10-12 June 2022. It brought together 32 member associations, the board and staff members. It was an excellent opportunity to catch up with old colleagues and new faces, to exchange ideas, connect with each other and lay the foundations for new, common projects and activities. The article below will go into more detail about the main focus of the meeting in Barcelona.



## A new strategy plan for EFCCA - 2023-2027

On 10 June 2022, our EFCCA Chair and Board kicked off work on developing EFCCA's next Strategy Plan for the coming four years. EFCCA delegates from 32 countries met in Barcelona to lay the foundations of the new EFCCA 2023 – 2027 Strategy Plan. After reviewing the previous 2019 – 2022 Strategy Plan and the external evaluation of the achievements

so far, the entire day was devoted to brainstorming, building on the past success, new needs identified and on what EFCCA should aim at in the next few years. Antonella Cardone, as the external facilitator, led the lively discussions and many ideas were generated and will feed the work in progress on developing the next Strategy Plan.



Following the General Assembly, the board and secretariat shared some preparative documents to feed into the online consultation process. As a first step, members were asked to participate in a survey and give their feedback on our organisation's current vision, mission and objectives. An online consultation meeting with our members planned for October this year will then work on the first draft of the strategy opening the second round of consultation (in November/December). The second draft will be finalised during a second consultation meeting with members (planned for February 2023).

In March/April 2023, there will be final discussions and consultations online before the strategic plan will



be presented during the General Assembly in May 2023, ready for approval by the delegates.

# Updating ECCO Guidelines on Crohn's Disease

On 14 September 2022, the European Crohn's and Colitis Organisation (ECCO) organised the kick-off meeting for the Working Group on updating the Crohn's disease (CD) treatment guidelines. About 50 participants worldwide came to Vienna to discuss this, including six patient representatives from our EFCCA network.

ECCO produces and regularly updates several guidelines to provide evidence-based guidance on critical aspects of IBD care to all health care professionals who manage patients with IBD.

Since the initiation of the first project in 2006, the ECCO Guidelines have become standard references for IBD management in Europe and around the world. ECCO is updating the Guidelines on a regular basis using the [GRADE Methodology](#). The current guidelines on Crohn's Disease treatment are revised into four working groups: induction and remission, maintenance of remission/de-escalation, perianal disease and surgery in abdominal CD. The whole process of the revision will take about 18 months and the guidelines are scheduled to be concluded by 2024.



Patient representatives had the opportunity to provide the patient’s perspective at the start of the meeting. As EFCCA, we welcome that ECCO recognises the need for and importance of involving patients’ associations in decision-making and defining relevant outcomes in a patient-oriented way. The involvement of patients is critical to making the guidelines relevant not just for clinicians but also for patients. We will be updating you on the process of these working groups.



## Changing the treatment paradigm for patients with Crohn’s Disease

The new EU-funded project GENEGUT is set out to develop a first-of-its-kind oral RNA-based therapy for ileal Crohn’s Disease. EFCCA is one of the nine project partners.

Within the last two years, the global COVID-19 vaccination rollout emphatically proved the effectiveness of RNA therapeutics. Now, the GENEGUT project aims to apply RNA therapy to treat ileal Crohn’s disease – a potential game-changer.

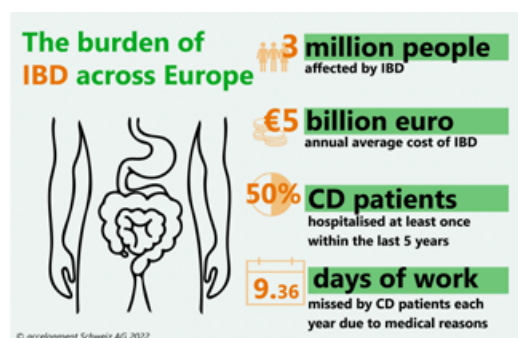
GENEGUT has one major ambition: accommodating the major medical need for new, safe, and effective therapies for Crohn’s Disease patients.

Despite advances in new immune modulators and biological treatment, up to 30% of patients become non-responders. Besides, intestinal fibrosis is a significant challenge in Crohn’s Disease with limited efficacy of current drugs. And lastly, despite all the advances in diagnosis, there has been no significant decrease in mortality in patients with Crohn’s Disease over the last several decades.

This highlights how urgently new therapies are needed as an alternative to surgical interventions and to avoid the associated complications of ileal resection.

The GENEGUT consortium is determined to push beyond the state of the art in RNA-based therapies:

*“Crohn’s Disease, as a highly prevalent disease with an unmet need for targeted treatment, is an ideal candidate for which to develop a safe, effective, targeted treatment exploring non-invasive routes of administration, such as oral delivery.”*



Funded with 5.4 million euros, and over the course of four years, GENEGUT aims to develop a non-invasive, safe, effective, and targeted treatment 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.



The delivery of RNA will be enabled by a combination approach where novel biomaterials, designed to overcome the barriers in the gastrointestinal tract, are synthesised into nanoparticles (NP) which encapsulate the RNA. Using an industry partner's emergent capsule platform technology, the RNA is orally administered and locally tackles the inflammation in the intestinal tissue, avoiding systemic side effects.

As a pre-clinical study, GENEGUT will be the first, potentially revolutionary step toward delivering an advanced form of treatment that more than three million patients in Europe alone could benefit from. This would be the first option for these patients to finally manage the chronic disease and lead a life of improved quality.

The project starting in October of 2022, is coordinated by the School of Pharmacy of the University College Cork and, through a patient-centred approach, brings together the European Federation of Crohn's and Ulcerative Colitis Associations with renowned researchers, expert clinical scientists, SMEs and large pharma companies.

# GENEGUT

*"The multidisciplinary team in GENEGUT will pioneer the development of the next generation of therapeutics for the treatment of Crohn's Disease by producing a patient-friendly orally administered RNA medicine. The project will span the preclinical to clinical space, thus accelerating the clinical translation of orally available RNA therapeutics and ensuring early access to life-altering medicines for the patient."* – Professor Caitriona O'Driscoll, GENEGUT Project Coordinator.

Follow the progress of GENEGUT at [www.genegut.eu](http://www.genegut.eu) and [Twitter](#) and [LinkedIn](#) @GENEGUT\_EU to learn about the project's steps towards a better cure for Crohn's Disease.

Contact: [info@genegut.eu](mailto:info@genegut.eu)



# Consolidating our role as a research partner

We are pleased to announce that four European research projects, in which EFCCA has been included as a project partner, have been selected under the new European Commission framework programme Horizon Europe.

## **MIGut - Personalised blueprint intestinal health**

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 solutions for health promotion and disease prevention that would enable active patient engagement in health and self-care management.

## **METHYLOMIC - DNA methylation markers to predict treatment success of biologics in Crohn's disease**

Currently we cannot predict which biologics will be effective in an individual patient, with only <40% of patients showing primary response to any given treatment. Treatment failure is associated with disease complications, and increased health care costs. This project aims to develop predictive biomarkers to guide personalised medicine.

## **GlycanTrigger - glycans as master triggers of health to intestinal inflammation transition**

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. This project proposes a thorough and innovative approach to better understand the health-to-chronic inflammation transition occurring in patients with CD that will be translated into improved disease prediction and prevention.

## **GENEGUT - Oral delivery of encapsulated RNA nanotherapeutics for targeted treatment of ileal Crohn's disease**

GENEGUT will transform treatment of ileal Crohn's disease (CD) by developing a first-in-class oral RNA-based therapy, tackling inflammation locally in the intestinal tissue, while avoiding systemic side effects.



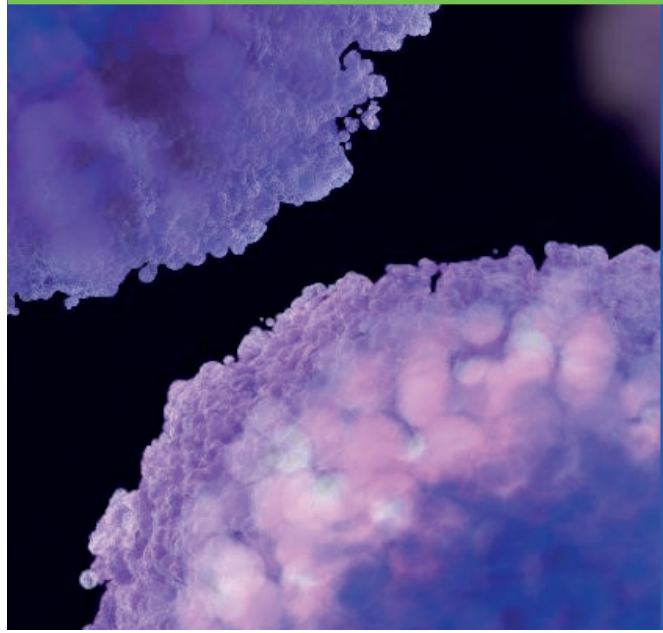
The article above gives you a more detailed description of the project.

The first three projects have been approved by the European Commission on 5 August 2022 and we are now working with the Consortium partner to define the first steps and the official kick off. As soon as we have more information available we will share with our IBD community. The GENEGUT project has been approved previously with the planned kick off for January 2023.

We are also already involved in two other research projects, namely IDEA-FAST and ImmUniverse under previous calls. Even though our role in these projects is small, and mainly focused on communication and dissemination of the results, it still represents an excellent opportunity to increase the expertise of patients and patient associations and to gain visibility within the international IBD community.

Finally, two further projects in which we are partners, have passed the first phase of the selection process and we have now entered into the second phase with a communication from the European Commission about the results to be expected in several months.

Our involvement in the eighth research project (two under development) clearly shows that EFCCA has become the reference point for the research community as a viable partner representing the needs and interests of the IBD patient community.



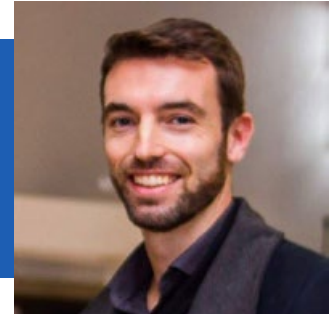
## Learning from the experts.

No one understands the patient journey quite like the patients themselves. That is why we are working closely with the patient community to deliver oral medicines to address patients' needs and help transform the treatment of inflammatory bowel disease.

Come and meet us at <https://www.arenapharm.com>

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We are pleased to share an article written by **Jorge Ascensão**, Clinical and Health Psychologist of the Portuguese IBD patient association, APDI. In this article he deals with the issue of IBD and the elderly which is a priority theme for EFCCA in 2022/3.



## Old is the rag

We have a Portuguese saying that goes something like “Old is the Rag”. The general idea is to empower older adults as valuable persons instead of comparing them to a piece of old cloth, like rags. Rags are the torned remains from an old piece of fabrics. At first glance, they seem useless, however they could indeed be used for various purposes. They could be used as a sponge, tourniquet, pan base, you name it.

When we refer to older adults today, it doesn't seem that we're describing or valuing their experience, the path and the elder. But, just like the saying above, we are defining and using what is left of the person.

On the other hand, addressing and treating inflammatory bowel disease (IBD) at an earlier age makes it possible to reduce the progression of the disease throughout life, improve these patients' quality of life, and increase their life expectancy of these same people.

We engage in research and clinical trials, develop treatment adherence strategies, and involve partners, children, family and the community as we want to treat IBD as well as possible! One day, these “children” with properly controlled Crohn's or Colitis will achieve a healthy and advanced age, with an adequate quality of life and well-being.

Why so?

Why should we prolong life, improve health, and increase its quality and well-being, when we know all goes downhill after the age of sixty?

The common scenario is that we are in a constant loop of established routines by complying with “acting our age” or we try to run away from playing the role of the “sick person” our whole life.

We wonder if we should continue to be John, Amber, the teacher, the lawyer, the barber, and get into retirement and be an “old person”? We get nostalgic and homesick when we think back to who we were. It's not surprising then that, in Portugal, we have depression prevalence rates of 18% in the older population and suicide rates above 22% after the age of sixty-five.

The feeling of uselessness most days, there is a decreased interest and pleasure in daily activities, reduced ability in terms of concentration, attention deficit and a much slower processing of information. These are the clinical characteristics of depression and, unfortunately, many times, it correlates to what someone over sixty year old makes of their daily life.

And no. It's not change itself that frightens or upsets the older adult. They've had changes their whole life. They changed for the better, for worse, for the unknown, for the unforeseen and the expected. They survived! They're there! Seventy years or more, reached! Accomplished!

Do we think we know a lot because we've had Crohn's or Colitis for ten or twenty years? They've had it for over forty or fifty years. And without effective treatment at first, with a few surgeries and a crisis on top. It gave them knowledge and heartache, trauma and victories. And plenty of stories to tell.

And now, on top of the many years of experience with the stereotype of being an “ill person”, there’s the stigma of being an “elderly person”. That they are fragile, ineffective, stubborn, with no interest in learning or starting new endeavours, let alone having an intimate and sexual life.

However the vast majority of older adults have good cognitive health as well as lower rates of depression than younger adults. They can maintain good adaptability, functional health, and meaningful interpersonal and sexual relationships.

Plus, (to be true), as expected, they adapt well to changes in life and demonstrate good personal and interpersonal development abilities. They know that more than what one is and what one observes, often, what one looks like or expects or feels about something seems to be worth more. Thus, perception and thinking are distorted by belief, normativity and generalisation.

When we finally get to be older adults, we’re already experts in living and being human. So many miles walked in our shoes, and so much experience gained should be enough for an honorary doctoral degree in this universal mystery of life.

However, it’s sometimes older adults themselves who trip on their prejudice about age. The wrinkled image in the mirror, the pain that starts to settle in, and the possible functional, psychological and social limitations help do just that. Feeling “less than before” and “less than the other”.

Failing to comply with the medication or missing medical appointments can happen at any age. The teenager can have some difficulties understanding why, or the young adult can struggle with his schedule or all the things one has to think about.

As well as the older adult who can ask himself: “what for? What’s the point of caring for a body that doesn’t agree with me?” This body does not reflect the inner self of who I truly am. It’s not me in the mirror anymore. That’s not my strength, nor does it have anything to do with everything I once was or had.

Ageing is a dynamic and challenging process of change and adaptation, but not of conformism to physical or mental limitations. It’s essential to look beyond our discomfort about our age, our relationship with our elders, and the awareness of our limits and mortality. The elderly can indeed experience a variety of losses. Along the way, they changed and sometimes lost people, animals, relationships, belongings, social roles, independence and financial comfort.

However, continuity, as well as change, have been a part of human life since birth. The development of younger people is shaped by their ability to integrate and grow into adulthood. On the other hand, the development of older people will depend on their ability to deal with the normative transitions of a later stage of life.

We can always philosophise about the meaning of life. About the essence of our existence. Where are we going? Or, what is the purpose of all this? It is true that, at any age, we can remember the past and personal experiences to better understand ourselves in relation and perspective to this “path”. However the advantage of the older ones is uniquely intense in which, with some ease, they can use their past memories to integrate the new experiences in the present. Furthermore, it seems that it’s with our people, in our “tribe”, if you will, that seems to lie the “secret” for everything.

Integrating gains, losses, general change in individuality, and the value of personal relationships with our intimates, friends, family and all others, we keep “conquering”, getting to know, and “winning”, even in this later stage of life.

Suppose it’s time that’s valuable and socialising doesn’t fulfil us. In this case, it could be that we find well-being in close, intimate and significantly emotional relationships. Like roadmaps of stories, places, and smiles wrinkled by experiences, may we finally be more focused on the moment we’re living in than that fear of what will happen.

Jorge Ascensão,  
Clinical and Health Psychologist of the Portuguese  
Patient Association APDI

# France

## 40 years of patient support and fundraising for medical research!!

This year afa Crohn RCH France is 40 years old! The French association of patients and relatives involved in the fight against Crohn's disease and ulcerative colitis will be organising an exceptional national exhibition of Crohn's disease and Ulcerative Colitis to take place in Paris on 22 October 2022.

40 years ago, these diseases were unknown to the public and gastroenterologists: lack of research, few treatments, erratic diagnosis, and inadequate care. It took Janine Aupetit's courageous mobilisation, mother of François Aupetit, who died prematurely from Crohn's disease. Janine and Professor Yves Le Quintrec were the founders of the association in 1982. The other major players in the cause have never ceased to mobilise researchers, encourage the exchange of medical data between gastroenterologists at conferences, and enable the creation of a network of volunteers dedicated to active listening and patient support.

Over 40 years, the progress made for the cause of patients and their families has been immense! Through the financial support of afa to research, afa has contributed to the emergence of innovative treatments, better knowledge of these diseases, and in particular, the understanding of the role of the intestinal microbiota, an immense source of hope. Afa has undertaken to lobby for better recognition of the impact of the disease on the daily life of patients and the so-called invisible disability. It is also for better care and improving the pathway to care for all patients. Many campaigns to break the taboo around these diseases have taken place to help those affected to rebuild their often damaged self-esteem.

But the needs are still immense, and recovery is a hope that must be realised! Today, more than ever,



patients and their families need reliable information, local support and personalised tools (for children, parents, adults, seniors, etc.) to help them live a better life with their disease.

To mark these 40 years of struggle and progress, to draw up tomorrow's major orientations, and of course, to offer the information, support and conviviality that patients and their families need, afa is organising an exceptional national exhibition on Saturday 22 October 2022 at the Cité des Sciences et de l'Industrie (Paris 19e)!

Research conferences led by world-renowned IBD experts (Pr Laurent Peyrin-Biroulet, Pr Benoît Chassaing), testimonies from patients with inspiring backgrounds (fencing champion Hélène NGom, navigator Pierre-Louis Attwell), theme workshops, interaction with specialists in food, work and social issues not forgetting an exceptional concert by Fredo, an IBD patient and singer of the group Les Ogres de Barback are all part of the programme.

This is a very special moment for all patients and their relatives. Especially for the many who feel alone and helpless in the face of the disease!

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# Spain

## I ACCU Congress

On 3 June 2022 ACCU España celebrated its first International People with Crohn's Disease and Ulcerative Colitis Congress, with the support of the Spanish Group of Work in Crohn's disease and ulcerative colitis (GETECCU), the Spanish Nurse Group of Work in Crohn's disease and ulcerative colitis (GETEII) and Farmaindustria. At the opening conference Julio Roldán, president of ACCU España, welcomed more than 600 people that attended both online and in-person, as well as the professionals that joined us.

From the scientific side, Dr Manuel Barreiro, president of GETECCU, Isabel Pineos, director of the department of access of Farmaindustria, and Dr Héctor Guadalajara, chief of service in Jimenez Diaz Foundation, shared their vision from the equity and accessibility perspective for patients and the need of more accessibility and equity in access to clinical trial and treatments and to place the patient's voice and benefits in the centre of the clinical opinion.

The following delegates also were spokespersons of the event. The coordinators of GETECCU social area, Dr Barreiro and Dr Pilar Noos, the president of GETEII, Ester Navarro, the GETEII board member, Paula Sánchez, the director of ACCU España, Ruth Serrano and finally Antonio Valdivia from ACCU España. The group analysed the synergy between patients and professionals as a motor of change, where both patients' representatives and scientific societies aligned in need of working together to achieve the necessary changes in society and the national healthcare system to improve the life quality of IBD patients.

From the social side, Carina Escobar, president of the Spanish Patients Platform (POP); Daniel Aníbal García, Secretary of COCEMFE; Pilar Martínez, president of Diabetes Madrid; Julio Zarco, president of the Humans Foundation and Julio Roldán, president of ACCU, were part of a debate about the future of patients' associations.





They exchanged ideas and impressions about the associations' professionalisation and participation as decisive agents in health management. They emphasised the need for a paradigm change when it comes to patient-doctor shared responsibility where patients' voice is taken into account in decision-making affecting them.

Last but not least, Ana Sampaio, president of the Portuguese association APDI and Fabiana Miele,

president of the Argentinian association Fundeccu and Amaranta Cantero, from ACCU España, shared the different programs and approaches to working with the IBD community of their organisations and also exchanged views about cooperating with other associations at an international level.

The event was funded by Abbvie, Janssen, Pfizer, Takeda and the Spanish Ministry of Social Rights and 2030 Agenda.

## 27th National Youth Meeting

From 1-4 September, ACCU España celebrated the 27th edition of their National Youth Meeting. Every year since 1995, ACCU España gathers young people with IBD in a four-day event in different parts of Spain; only missing it once last 2020 because of the pandemic. This year was extra special since we could bring back the whole event with minimal restrictions to Aguilas (Murcia) after two years of limited attendance, mandatory masks and rigid but COVID-19 safe measures to guarantee safety.

Our 47 participants were diverse: young IBD patients, their friends, relatives, significant others, dietetic students, and even two members of the Portuguese association APDI. All of them came with an open and positive attitude to receive from and give back to our IBD community. They participated in water sports, outings and formative workshops tailored to their health needs in a safe space designed for them.



As we all know, a huge part of the IBD community receives their diagnosis of Crohn's or Ulcerative colitis in their younger years, which will impact their physical, emotional, and social development. ACCU's founder, Dr Leon Pecasse, believed that mutual aid was fundamental for patients, and youngsters were no exception. Hence, he started taking them together in the first meetings, providing a much-needed respite and fun time for the participants. Over the years, the event has evolved but never lost its spirit: Participants came to socialise but also they get in touch with different realities and perspectives related to IBD, which helps them normalise possible outcomes such as changes in their medications or surgeries; it provides opportunities to explore activities that might seem challenging for them such as new sports in an IBD friendly environment; the workshops explore different empowering topics such as patient or student's rights, non-IBD participants became more aware of the IBD struggles.



## Czech Republic World IBD Day Czechia

This year we showed that IBD patients can handle their disease at every age. As a symbol, we took a historical road through life - Prague in the last century tram. Almost 100 patients from different parts of the

Czech republic were dressed in purple and shared their stories via a special campaign. Raising awareness is essential, so why not have fun while doing it!

More info: [www.crohn.cz/about-us](http://www.crohn.cz/about-us)



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GastroImmunology™

# New Zealand

## World IBD Day 2022! IBD & Life Cycles

### #IBDhasnoage

This year's Crohn's and Colitis New Zealand's World IBD Day event featured the unveiling of a professional video in which patients across the age spectrum speak candidly about living with IBD. While their symptoms are the same, their challenges at different stages of their lives are very different.

Please follow our YouTube Channel and view the video on YouTube.

YouTube Channel: [Crohn's & Colitis NZ](#)

YouTube Video: [#ibdhasnoage - World IBD Day 2022](#)

#ibdhasnoage - [Charlotte](#)

#ibdhasnoage - [Hannah](#)

#ibdhasnoage - [Pete](#)

In the video, three patients with IBD tell their stories: Hannah, a mum in her 40's. Pete is in his early 70's, and Charlotte, age 15. Over 100 people attended the event, including several Parliament members and the Wellington mayor.

A powerful exhibit was set up to accompany the film in the Grand Hall of Parliament. Over 130 New Zealanders shared the enormous impact these diseases have on their lives.

The event was hosted by Brooke Van Velden, New Zealand Member of Parliament and Deputy Leader of the ACT party. Ms Van Velden delivered a compelling address about the IBD patients she has met and the need for increased funding for new medications.

The final words of the video are, *"There are new medications that offer hope. We need these in New Zealand"*. We hope this event raised awareness within Parliament, and we will see new medications funded soon.

Thank you to AbbVie Limited and Pelorus Trust, whose generous grants supported this project.



*Brooke Van Velden, Member of Parliament and host of the event delivers her speech*



*Dr Richard Stein, Chair of CCNZ; Brooke Van Velden, Member of Parliament and Belinda Brown, CEO of CCNZ*

# Poland

## How we celebrated World IBD Day

Photo exhibition, Polish landmarks and buildings illuminated in purple, visit to a children's hospital, picnic and integration meeting - this is how the "J-elita" Association celebrated IBD Day in Poland.

Our country's most recognisable landmarks and buildings lit up in purple on World IBD Day to raise awareness about the daily challenges of living with IBD. Our colour proudly illuminated Warsaw (the bridge over the Vistula river and the palace), stadiums in Kraków and Wrocław (where the Polish national football team played their matches), the Philharmonic in Szczecin and the building of public radio in Kielce." J-elita" volunteers visited the gastroenterology ward of the University Children's Hospital in Krakow and donated purple gifts to hospitalised children and teenagers: plush owls, unicorns, octopuses, and water bottles. We also thanked the doctors, nurses and medical students who help people with IBD during their daily struggles. In the evening, we all met to take a group photo, spread the feeling of joy and happiness, and forget about the disease.

The next day, another event took place to celebrate World IBD Day. The long-awaited photo exhibition - organised by the branch of "J-elita" in Lublin - was opened. The must-see pictures depict IBD patients, photographed by the gastroenterologist Professor Rafał Filip and the photographer Krzysztof Pisarek.

The exhibition shows the two sides of IBD. The creators took two pictures of each patient: a black and white portrait symbolises fear and a sense of uncertainty at the time of diagnosis, while the colour, full-length one portrays life with joy and passion despite the disease.

On Saturday, 21 May 2022, residents of Warsaw and the surrounding area met at a picnic in a charming forest education centre near the capital, where many attractions awaited children and adults.

Everyone eagerly participated in the day's events: the birds of prey show when participants experienced the excitement of each bird flying free, long conversations and jokes during the barbecue dinner.

World IBD Day in Poland every year brings more and more participants that gather together to show how to cope with this invisible disease.

"J-elita" Association



*Philharmonic in Szczecin*

# Austria

## World IBD Day 2022

60.000 – 80.000 Austrians suffer from Inflammatory Diseases (IBD), either Crohn's Disease or Ulcerative Colitis. Because of that, this year, the CED-Kompass – the patients' service platform of the Austrian IBD Organisation ÖMCCV - implemented an extensive awareness campaign on Viennese tram lines for World IBD Day.

In 2020, this campaign under the slogan #makeitvisible started a photo shoot with bare facts of unveiled bodies intending to visualise the Invisible: carrying a stoma or bellies with all their scars. Photos of twelve female and male persons and their personal stories of their fate after several operations were posted on social media (we reported about it in EFCCA-Magazine 2/2020). The following year the ÖMCCV continued the campaign via CED-Kompass (English: IBD-Compass). A glossy magazine of this photo event was produced, and an exhibition gallery with twelve roll-ups, each showing an IBD-affected person.

In 2022 we continued this campaign with the same protagonists. However, this time, we “brought the project to rails”: in our capital city – Vienna – two long tram-trains with photos and slogans were crossing the town on seven different tram lines for one month, from 21 April to 20 May 2022. It was about showing these chronic diseases to the general public. “To give Crohn's Disease and Ulcerative Colitis a face and to break taboos” as the photo artist Dr Barbara Wirl formulated.

Gastroenterologist Univ. Prof. Dr Alexander Moschen, PhD, Kepler Universitätsklinikum Linz, confirms: “There is no doubt of the importance of IBD awareness as IBD patients are faced with a lot of everyday life limitations. Qualified information for the public is vital. Only in this way is it possible to reduce stigma and that's why we call all our IBD-specialists to fully support this campaign.”

IBD-Nurse Tobias Mooslechner, MSc, Medical University of Vienna, emphasises: “There are important issues related to everyday life where patients should be



supported. Best-practice includes IBD-Nurses as an integrated part of the interdisciplinary treatment teams to assist besides long-term therapy support on individual problems such as sexuality, pregnancy or nourishment.” Tobias Mooslechner acts as Vice-President of IBD-Nursing Austria. Since 2018 our CED-Kompass operates a telephone-hotline in cooperation with this IBD-Nursing society. The free-of-charge hotline is a contact point besides official channels and can be called up to four times a week for several hours. More information can be found on [www.ced-kompass.at](http://www.ced-kompass.at).

CED-Kompass (CED is the German short form for IBD) has existed for four years. Besides several patients' services (telephone hotline, social media accounts, newsletter, event implementation), the main task of CED-Kompass is to raise awareness amongst the general population as the stigma around IBD is still very high.

Subjects such as intestinal bloating, diarrhoea or artificial bowel outlets are still big taboos. “There are long periods of sick leave, a lot of pain or the problem of searching for a toilet in the public domain. The ÖMCCV – the Austrian Patients’ Organization – is working on more understanding of our situation. Only then can we feel as an integrated part of society”, explains Ing. Evelyn Gross,

President of ÖMCCV. She further adds “As a matter of fact, far too few people know about IBD. But early detection of the symptoms plays an important role in the course of the disease.”

Christine Gmeinder  
Editorial Staff of the Austrian News Magazine “Chronicle”  
[www.oemccv.at](http://www.oemccv.at)

# Denmark

## Election of new CCF board

CCF - the Patient Association for Bowel Diseases in Denmark - had to find a new main board at the national general assembly. We are proud to announce that we are now again up and running.

The new main board is a mix of new and old members and some have a history of 20 years in CCF Denmark. There will be a continuing replacement of the board. The chairman is nominated for two years, deputy chairman, treasurer and secretary are nominated for three years. Thereby the stability of CCF Denmark is secured, and

we will continue the development for the benefit of our members and cooperating partners nationally and internationally.

In Denmark, we marked World IBD day – 19 May 2022, in different ways.

We had several buildings lit up in purple, introduced a free



video on how a member of CCF lives with IBD and asked our members to show their purple day on Facebook.

We have had theme days with different patient associations in Denmark, doctors, nurses and several medicine manufacturers. A member of the main board has appeared in the national news. In week 35, the Denmark and Faroe Islands national meeting took place.

The meeting included workshops on our mission and the vision for CCF Denmark's future. Among the objectives is a focus on transparency and terminology every member will be able to understand. CCF Denmark is associated with all bowel diseases, including Colitis and Crohn's, Microscopic Colitis, Bile Acid Malabsorption, Irritable Bowel Syndrome and other related intestinal diseases.

Faroe Islands is the place in the world where IBD is most frequent in the population. Currently, the Faroe Islands focuses on testing the treatment of Colitis by being in a pressure chamber, and a private person has agreed to cooperate with the government when testing the treatment in his/her private pressure chamber. The Faroe Islands CCF association has made three videos combining Knowledge Sharing and Nordic Humour.



There is a lot of new and existing planning for the year, including new courses and new toilet cards. CCF Denmark has initiated cooperation with a worldwide association for people with hidden disabilities. We are looking very much forward to the future.

Benthe Bertelsen & Vera Slyk  
CCF Denmark





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# Lebanon

## Breaking the silence!

Interview with Nathalie Jbeily, President of the Lebanese IBD patient association “I Battle Disease”.

*Nathalie Jbeily is a psychotherapist, performance psychologist, and former athlete. After a series of medical procedures that halted her athletic career, she decided to combine her passion for sports and her desire to support warriors of this silent illness through her professional degrees. She is the co-founder of the “I Battle Disease” patient association which aims to advocate for the IBD community, and ensure patients’ medical, psychological and social stability are met.*



### What motivated you to establish the “I Battle Disease” patient association?

It all started back in 2011 when I got sick. It initially took some time for me to be diagnosed with ulcerative colitis. I was not reacting well to the medication available at that time and my disease became severe. After facing ongoing inflammation for over a year and a half, I finally had surgery.

It was a very challenging time in my life and I had to give up my career as an athlete. There was hardly any psychological support and when I got in touch with a group of other IBD patients we decided to set up “I Battle Disease”.

I felt that as a psychologist I should use my skills and personal experience to support people in similar situations. Our organisation was officially launched in 2020 to provide psychological support to patients, raise awareness, and pursue advocacy measures.

### Tell us a little bit more about your activities?

There is a lack of IBD awareness in Lebanon and in general in the Arab world. Hence, we work together with other Arab countries and have men, women,

children, workers and people from all walks of life share their IBD journey.

IBD, and what it comes along with it, is still a huge taboo which I think is due to a lack of information. Having our patient association is a way of reaching out to the masses and to educate them on IBD.

Of course there are also cultural factors that make it difficult to break the silence around the disease. Talks about toilets are considered ‘unclean’ and people are being shamed for not being able to ‘fulfil’ their role in society. For instance, if a man frequently visits the toilet people might see him as weak and tell him “if you are a man, you have to hold yourself”. It is even worse for a woman and her role as a mother. Society might see her as someone not able to completely fulfil her role, which is to have children and raise them. Women might fear that if people find out about their disease they might not be able to get married. In saying that, Lebanon is more progressive in comparison to other neighbouring countries.

In terms of other activities of our organisation, at the start of the COVID-19 pandemic we organised webinars to share information about IBD in regards to COVID-19. We also hosted webinars on Colon Cancer and IBD in order to address the myths and fears around the disease.

We create deliverables where we map the journey of an IBD patient with all the stages highlighting the difficulties and solutions. We do this as a way to provide lots of important medical information. For instance, we host group support sessions for patients with psychologists.

For World IBD Day we held two campaigns, one in May 2021 and another in May 2022. In 2021 it was all about “breaking the silence” and talking about the taboo of IBD, as mentioned above. Our campaign included people talking about their experiences and challenges with IBD on social media. The idea is also for our neighbouring countries to see that people are willing to show their faces and publicly talk about something so personal.

In May 2022, “I Battle Disease” joined World IBD Day by highlighting our famous landmark of Raouche rock in purple outside Beirut to raise awareness about the shortage of medications in Lebanon.

### **How common is IBD in Lebanon?**

There are actually no official IBD registries in Lebanon, but the estimates are that around 10 000 people have it, of which 7000 have Ulcerative Colitis and 3000 have Crohn’s disease. Currently we have around 20 percent of IBD patients being prescribed biologics and 80 percent taking the more traditional medications.

### **What are the main challenges that you are facing in Lebanon?**

One of our most pressing challenges is the financial crisis and shortage of medicines that we are currently experiencing. It started with the revolution in 2019 and at first we noticed a slight shortage in the availability of certain medicines but since July 2021 the situation is getting worse and worse.

On top of that, the few medications that companies have allocated for Lebanon are being sold on the black market in Syria and we are faced with other illegal activities such as thefts of medicines.

When we started our association we had good support from pharmaceutical companies that sponsored our webinars, giving our association much-needed financial support. However, because of the ongoing economic and financial situation in our country, more and more companies are pulling out of Lebanon, which poses a severe problem for us.

We try to support our members and buy medicines for them, and in terms of more traditional medicines this is still more or less possible, but in terms of much-needed biologics, there is a severe shortage. We had a tragic case where one of our members could not receive her biologic treatment for six months and had to have surgery for a colostomy.

**“One of our most pressing challenges is the financial crisis and shortage of medicines that we are currently experiencing ... We had a tragic case where one of our members could not receive her biologic treatment for six months and had to have surgery for a colostomy.”**

We are trying to advocate with our Minister of Health about this very urgent issue, but so far, we have had no real success. We hope that through our collaboration with EFCCA we can find some kind of solutions!

# Patient involvement in the development, regulation and safe use of medicines

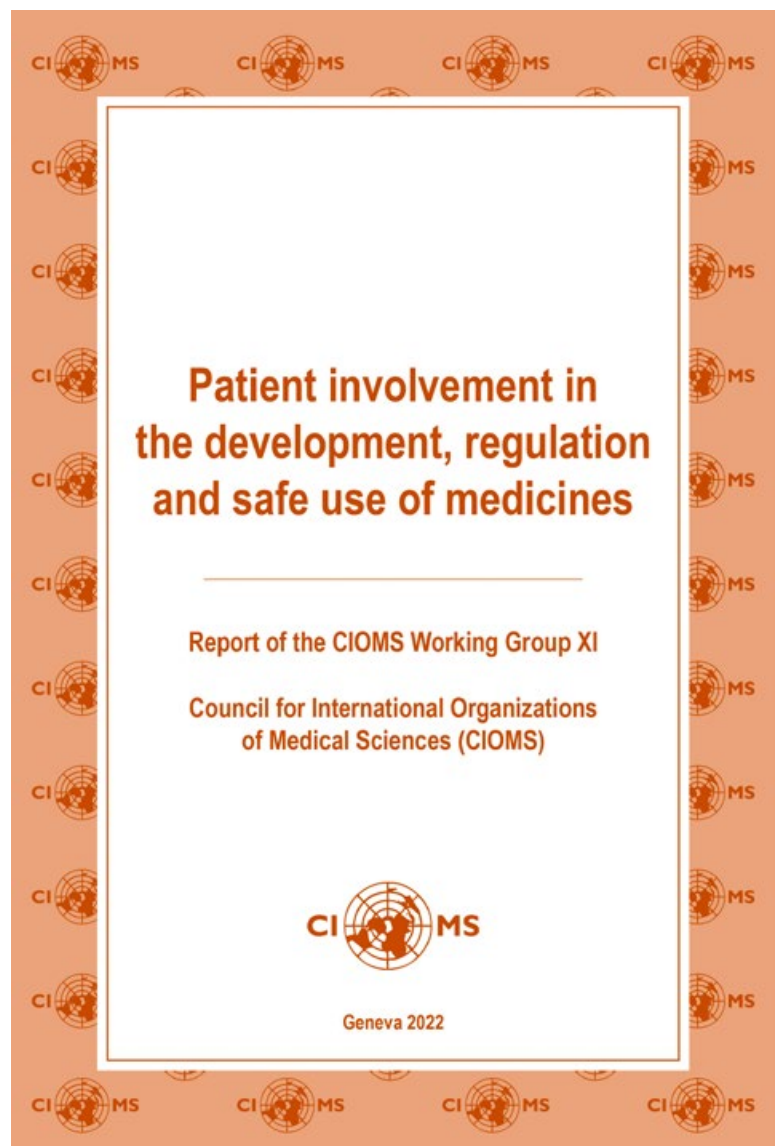
The Council For International Organisations of Medical Sciences (CIOMS) has published a report on [“patient involvement in the development, regulation and safe use of medicines”](#), which is available as a free download.

The report is the result of four years of work with patient group leaders, academics, industry experts, regulators and other stakeholders.

It describes the importance of systematically involving patients throughout a medicine’s lifecycle, from early development through the regulatory process to ongoing monitoring and safe use in everyday healthcare and provides a comprehensive overview of current knowledge about the benefits of patient involvement and existing initiatives, with examples and recommendations, and addresses the remaining challenges and practice gaps. The aim of the report is to prompt readers to implement its best practice recommendations according to how well they fit in with their organisational and national needs.

## About CIOMS

CIOMS is an international, non-governmental, non-profit organisation with the mission to advance public health through guidance on health research and policy including ethics, medical product development and pharmacovigilance.





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Pioneering for patients

# European Medicines Agency

## Meeting of the Executive Steering Group on Shortages and Safety of Medicinal Products (MSSG)

The second meeting of the MSSG took place on 14 September 2022. The group was established by the European Medicines Agency in March 2022 in accordance with the [Regulation on EMA's Reinforced Role \(Regulation \(EU\) 2022/123\)](#).

The Group is also known as the “medicine shortage steering group” or MSSG.

### Responsibilities of the MSSG

The MSSG's responsibilities include:

- establishing lists of the main therapeutic groups of human medicines that are being used in emergency care, surgeries and intensive care;
- establishing lists of critical medicines that need to be monitored for supply issues during a major event or a public-health emergency;
- monitoring the supply and demand of critical medicines to identify any potential or actual shortages of these medicines;
- providing recommendations and coordinating activities that aim to prevent shortages or mitigate their effects;
- advising the European Commission on whether medicine shortages and other ongoing or imminent events should be recognised as ‘major events’;
- evaluating information on the quality, safety and efficacy of medicines affected by public-health emergencies and other major events, and consider the need for urgent and EU coordinated actions;
- providing recommendations on actions to be taken at EU level relating to medicine shortages and the quality, safety and efficacy of medicines, to the European Commission and to EU Member States.

[More information on this link](#)



EUROPEAN MEDICINES AGENCY  
SCIENCE MEDICINES HEALTH

# Corruption in Health Care Systems in Europe

A study on “Corruption in Health Care Systems” reveals an increase in informal payments from patients to providers even though the perception of corruption has decreased. The higher prevalence of informal payments has been associated with lower public health care expenditure.

In the article published in the latest issue of the Health Affairs Journal (September 2022) researchers from Imperial College London set out to investigate “Trends In Informal Payments Across Twenty-Eight EU Countries, 2013–19”.

The authors defined corruption as a major challenge in health care systems across the European Union (EU), where it manifests most visibly as informal payments from patients to providers. A higher prevalence of informal payments has been associated with lower public health care expenditure. EU member states have experienced significant changes in public health care expenditure throughout the 2000s.

The researchers found that informal payments increased in 2019 compared with 2013, whereas the perception of corruption decreased. Although higher public health care expenditure was associated with less corruption, the research shows a smaller effect size between informal payments and this expenditure throughout the study period.

The results suggest that informal payments may be driven by other factors, which require further investigations. The researchers also suggest that public health care investments may be insufficient to confront corruption unless coupled with measures to limit wasteful spending and increase transparency.

Policy makers should understand that factors external to health systems, including media coverage and cultural and political factors, should be explored to explain country-level differences in corruption.

More info: <https://pubmed.ncbi.nlm.nih.gov/36067438/>

The findings of the study also mirrors similar results for the [Global Corruption Barometer \(GCB\) – European Union 2021](#), which surveyed more than 40,000 people from 27 EU countries. The survey measured respondents’ views and experiences with corruption in their countries.

# Sir Fartalot - a tale for children

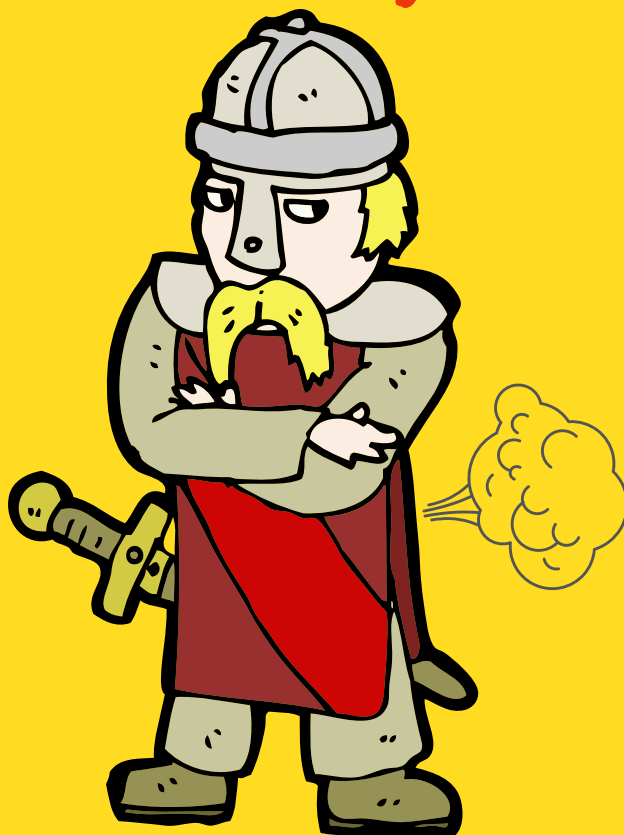
**By Dagmara Corrigan**

*"The story of Sir Fartalot is a simple one. It all started with my now 10-year-old son. Although he was three at the time and we were living in Scotland. We always loved books, and after learning the stories of Gruffalo, the Smartest Giant in Town, the Highway Rat and pretty much every other book written by Julia Donaldson - I decided to give it a go myself. Jack had issues with his stomach and digestion pretty much from birth - frequent visits to the toilet, sore stomach after eating and flatulence. And*

*it was the flatulence that was my inspiration to write the story of Sir Fartalot! There is a sad part to the story as well. Jack was diagnosed with Crohn's disease only at the age of eight. Jack's early childhood stomach issues were dismissed by numerous doctors - with the words "it's just a phase". I sometimes wish I could visit our old doctors and ask them to listen to their mother's instincts. It might speed up the diagnosis!"*

## **SIR FARTALOT**

**and the Kingdom of  
Faraway**



A DAGMARA CORRIGAN STORY



In the distant land of Faraway  
Beyond a deep ocean and a witch's house made of clay  
There was a tiny Kingdom where lived a famous Knight  
Famous not for his sword, not for his height  
Not even for being extremely polite.



Sir Fartalot (as this was his name) was known for his  
fighting skills  
That gave every single one of his enemies the terrible chills.  
Even the dragons with huge teeth and terrible claws  
Avoided the Knight; they knew how fearsome he was!

The Knight himself trained very hard every day  
To keep all the baddies and dragons at bay.  
He ate beans for breakfast and broccoli for a snack  
And his favourite Brussel sprouts were the best form of attack!



As the Knight's best fighting skill  
Was a fart as powerful as a power drill!  
No sword, no bow and arrow could ever match  
The superhuman wind that was always up to scratch!

Sir Fartalot was always ready to defend his land  
His services were forever in very high demand  
But the Knight, as fearsome as he was  
He didn't have any friends because...

Well, you can guess why, can you?



Sir Fartalot's farts were forever so smelly  
They would turn even the King's legs to jelly.  
The whole tiny Kingdom of Faraway kept a safe distance  
As anyone found close to the Knight would require  
assistance!



The King was so grateful for Sir Fartalot's loyalty  
That he made a search for a companion his priority.  
The King's guard searched everywhere  
For a suitable young lady, with a bad sense of smell.

The quest was long and difficult but finally one day  
The King's guard found a young princess that wouldn't run away!  
Her name was Lady Guinevere Sneezalot and  
she was famous too!  
She sneezed so much that everyone called her Lady Achoo!

As poor Guinevere had a terrible hay fever  
And she was also allergic to a mountain beaver!  
Unlucky for her, it was always Spring in the Faraway land  
And the King loved beavers so much; he even had a ...  
beaver band!

Lady Guinevere moved in with the Knight  
She did not faint even once to everyone's delight!  
As Sir Fartalot of course would still fart every day  
To defend his home and the Kingdom of Faraway!



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Sir Faratalot - a tale for children  
By Dagmara Corrigan

# Cycling along the Danube

**By Jean-Baptiste Corboeuf**

This is about a six-week cycling trip - six countries on Eurovelo 6, from Basel to Belgrade, first along the Rhine, then along the Danube through Switzerland, Germany, Austria, Slovakia, Hungary and Serbia. On the program, a fabulous European sharing and the discovery of four capitals: Vienna, Bratislava, Budapest and Belgrade.

*We are pleased to share the story of **Jean-Baptiste Corboeuf**, a volunteer at the French IBD association afa Crohn-RCH-France. He decided to ride by bicycle from Basel to Belgrade crossing six European countries and meeting along the way representatives from various EFCCA members.*



## Switzerland (a few days only) - Germany

Two weeks after leaving Basel in Switzerland and crossing southern Germany, I am ready to return to Austria. A little bit of nostalgia for my years in Germany, I was happy to find the Germanic atmosphere again.

I loved the cycling network for its western design and its density. And as for the legendary German discipline, I

found that it has nothing authoritarian and is more a form of respect in community life. On my route, I fell in love with the Black Forest with its small roads that wind through wooded terrain, and of course, Bavaria with its pretty little towns with colourful houses.

## Austria to Vienna

I have seen Austria with the Danube winding through steep hills, a beautiful rural and urban architectural heritage, castles perched on hills, forest landscapes and a very comfortable cycle route. It is also the Mauthausen memorial, the first concentration camp I visited, from which I came out absolutely devastated. It's also the

accumulated fatigue of pedalling, the illness that bothers me and incessant daily storms. But ultimately, I feel the enormous satisfaction of continuing this journey to meet Europe and myself.



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## Vienna

Vienna is a beautiful city with historical monuments and palaces around every corner. I'm amazed at how well-maintained the city is with pure coloured facades.

However, the Austrian capital is not resting on its achievements, with multiple projects, including the recent construction of a new gigantic central station and the development of a business district. Behind this beauty hides another more intimate one at the bend of an alley or a pushed door which opens onto a flowery inner courtyard. I had the chance to discover all this during a day with Christine, a member of the ÖMCCV, the association for inflammatory bowel diseases.

Christine is in charge of the newspaper of the Austrian association. The next day, Evelyn, the president of the ÖMCCV, picks me up at my Airbnb. After a city tour by car, we meet up with Christine, Gérrhard (treasurer), and Rosa (secretary) for lunch, followed by a walk on the grounds of Schönbrunn Palace.



They make an incredible team. They are fully involved in the ÖMCCV, which operates exclusively voluntarily, that is to say, without employees. In addition to the support the association provides to patients, they carried out a powerful communication change on World Inflammatory Bowel Disease Day (May 19 - my birthday).

Purple lights were shone on the big wheel of Vienna, and photos were attached to two trams that travelled the city for a month. I leave Vienna with an enriched heart from this meeting.



## Slovakia

I will only travel a few kilometres in Slovakia, but enough to visit its capital because Bratislava has the particularity of being located on the border with Austria and Hungary. Half a day, 80 km, and here I am, already immersed in the atmosphere of the old town. The centre is tiny, but I'm under its spell. I enjoy walking in the streets and sitting on its benches to observe the monuments and passers-by without being oppressed by noise or tourist activities.

I don't have to hang around because it's already time to meet Veronika, president for four years of the Slovak Crohn Club, freshly returned from a European meeting in Barcelona with the other European associations for inflammatory bowel diseases. Her association is made up exclusively of volunteers, having a board of seven women. Their actions support the sick with lectures from eminent doctors and cures.



## Hungary

Even if it's not apparent, I feel that Hungary is moving away from the standardisation of the Western world. I was surprised by the dense distribution of small towns, each with shops and services to live in autarky without having to reach a big city to go shopping or go to the hairdresser. The houses are generally pavilions with a small vegetable garden and a dog that loves to bark as soon as I stop pedalling to rest or take a picture. The travelling cyclists have been replaced by local cyclists who pedal slowly on old bicycles to go shopping. The bike trip is fabulous for its immersion.

I had several good contacts with Hungarians. This section of the trip is also the first where dogs had fun chasing me, children admiring my bike, temperatures that do not drop below 30°C, and the joy of paddling along the Danube. And unfortunately, I also experienced significant fatigue from this trip, with violent stomach aches caused by the disease and some side effects such as nosebleeds and skin problems. But I'm not giving up because I do not doubt that in a few days, it will be better with the bonus of the satisfaction of having done it.

## Serbia

I entered Serbia, a new stage of this cycling trip because the border also marks the exit from the European Union. When I was younger, I came to a party in Belgrade, I did not know Serbia, and it was a good surprise on this trip. I had a crush on the city of Novi Sad, all the districts of which are lively and with their own identities still untouched by tourism. The Serbs have a spontaneous contact, and everywhere, even in the countryside, local life is palpable: people sitting in the street, bars, grocery stores, children

playing, and fruit sales on the side of the road. Of course, I perceive all this with my foreign eyes, and I feel something more profound in Serbia that I can't grasp, but here I am already in Belgrade: the end of this trip, or almost because I have a friendly meeting with UCUK. The association supports people with inflammatory bowel disease through webinars and sporting events. The association has 700 members and only five volunteers, which is impressive when you see the work they accomplish.

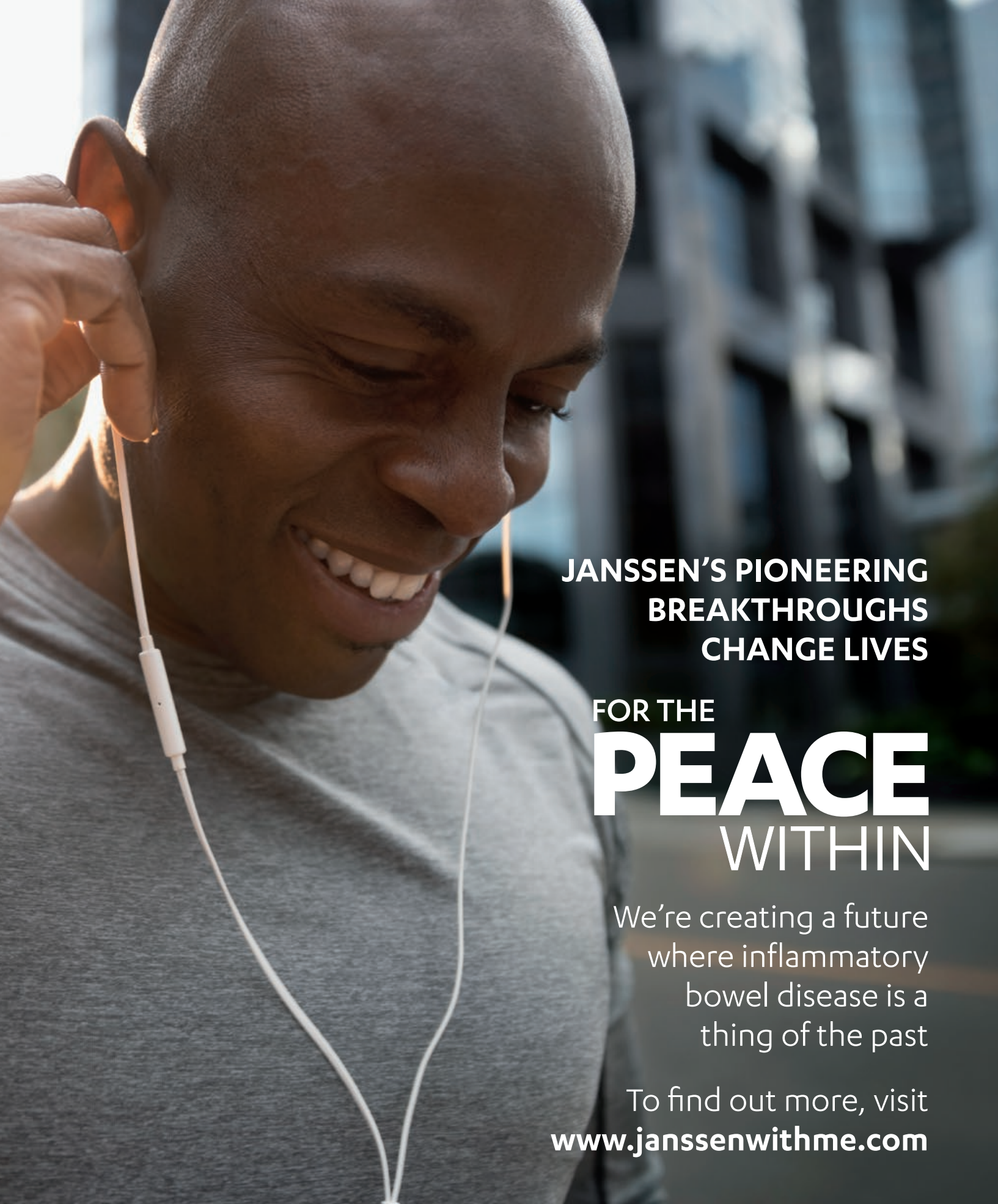


## Conclusion

I undertook this trip out of revenge for illness, a taste for challenge, for the well-being provided by physical effort, in response to a desire to immerse myself in Europe, and to raise awareness of chronic inflammatory diseases through extraordinary meetings of member associations of the EFCCA network. My bike carried me along the Danube, and like this river that grows bigger with the miles, I gradually took on emotions and knowledge of the world and the cultures surrounding us. By understanding them better, I learned to open my mind more to differences, a

real human wealth that should unite us rather than divide us. I relegated the worries of everyday life to focus on one thing: keep moving forward to enjoy life because the disease has already taught me that it may not be possible later. I hope you have found a small dose of escape through sharing this trip.

[Facebook](#) & [Youtube](#) (in French): “72 rayons d’espoir contre la maladie de Crohn”



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# Analysis of the Burden and Economic Impact of Digestive Diseases and Investigation of Research Gaps and Priorities in the Field of Digestive Health”

In September 2022, the United European Gastroenterologists (UEG) have published the “Analysis of the Burden and Economic Impact of Digestive Diseases and Investigation of Research Gaps and Priorities in the Field of Digestive Health” – in short “White Book 2” in the [UEG Journal](#).

This important study commissioned by UEG has been conducted over the course of two years by a team of researchers from the University of Liverpool led by Tanith Rose. Despite their substantial burden, many digestive diseases are poorly understood, attracting relatively little attention in terms of policy, funding or research.<sup>1</sup>

United European Gastroenterology (UEG) commissioned the first White Book, published in 2014, which revealed important insights regarding the public health and economic burden of digestive disorders and health services across Europe.<sup>2,3</sup>

In order to evaluate the current status, increase political and public awareness of digestive disorders and encourage digestive health research, UEG commissioned the White Book 2.

The White Book 2 updates analysis of the burden and determinants of digestive disorders, and explores unmet needs for digestive health research. It consists of two parts. Part one provides an international comparative analysis of the public health burden of digestive diseases and cancers, and analysis of the economic impact of digestive diseases amongst UEG national society member countries. In Part two, research gaps and priorities in the field of digestive health are explored by consulting UEG national society members and examining distributions of research activity and European Commission funding for digestive disease related research.

It is intended that the findings from these reports will assist UEG in accelerating progress in reducing the burden of digestive disorders, and in identifying priority areas where research and investment are required. It is also hoped that the reports will be of interest to others, including national and specialist gastroenterology societies and policymakers.

Some of the key findings (especially as concerns part two) of the reports are summarised below. The full reports are available via the UEG website and can be accessed here: [ueg.eu/white-book2-part1](http://ueg.eu/white-book2-part1) and [ueg.eu/white-book2-part2](http://ueg.eu/white-book2-part2).

## **PART 2 - Analysis of research gaps and priorities in the field of digestive health in the European Region**

### **Survey of the research priorities and preferences of UEG national society members**

To gain the views of UEG national society members whilst creating an opportunity for national societies to communicate their research priorities to UEG and other societies, an online survey was conducted. The survey collected information on prioritised research topics and

digestive disorders, and asked societies to rank the research areas previously identified as research priorities by UEG’s specialist society members<sup>5</sup> across three domains.



## Key findings:

- In total, 33 responses to the survey were received from UEG national society members—a response rate of 73%. The 33 societies submitted 120 research priorities.
- The most prioritised research topics included drug therapy, diagnosis, and disease prevention research.
- The most prioritised disease categories included inflammatory bowel disease, digestive cancers, chronic liver diseases, diseases of the pancreas, and irritable bowel syndrome.
- Overall, inflammatory bowel disease drug therapy research was the most popular disease and topic combination identified for prioritisation by the societies, followed by digestive cancer prevention research.
- Of the research areas previously identified as research priorities by UEG's specialist society members, life-style/nutrition/diet/obesity and primary prevention were, on average, the most highly ranked research areas in terms of relevancy to national health policy or national goals.
- EU trials/epidemiological studies/networks/surveys and primary prevention were, on average, the most highly ranked research areas in terms of the feasibility of conducting research in these areas.
- EU trials/epidemiological studies/networks/surveys and precision/personalised medicine were, on average, the most highly ranked research areas in terms of the potential to strengthen collaboration between partners from different organisations, disciplines or sectors.

## Distribution of research activity in the field of digestive health

To capture areas where research attention has been focused a bibliometric analysis was used to estimate quantities of published literature indexed within the MEDLINE database by topic and digestive disorder, and to identify areas that appeared under-researched in relation to disease burden.

## Key findings:

- A relatively large number of digestive disorder related academic journal publications were classified as pathology/physiopathology, diagnosis/diagnostic imaging, surgery, and drug therapy research.
- Amongst the digestive cancers, colon and rectum cancer and liver cancer had the greatest number of related publications, whilst oesophageal and gallbladder and biliary tract cancers had the fewest.
- Amongst the digestive diseases analysed, inflammatory bowel disease had the greatest number of related publications, and eosinophilic oesophagitis had the fewest.
- Inflammatory bowel disease appeared to be well researched in relation to burden compared to the other digestive diseases, whilst alcohol-related liver disease appeared to be under-researched in relation to the high level of burden associated with this disease.

## European Commission funding for digestive disease research within Horizon 2020

To identify and quantify European Commission funding for digestive disease related research, analysis of Horizon 2020 funded research projects was performed. Patterns of funding for digestive disease research in relation to disease burden in the European Union were examined and compared to funding granted for other diseases.

### Key findings:

- The digestive diseases that received the most research funding included inflammatory bowel disease, non-alcoholic fatty liver disease, chronic hepatitis B and coeliac disease.
- Most of the digestive diseases analysed, however, received relatively small amounts of research funding and appeared to be under-funded in relation to burden compared with other (non-digestive) diseases.
- Gastroesophageal reflux disease, dyspepsia, peptic ulcer disease, and paralytic ileus and intestinal obstruction were amongst the digestive diseases that each received around €50,000 or less in research funding.

Relationship between European Commission funding for Horizon 2020 research projects and disease burden in the European Union (measured as Disability-Adjusted Life Years)

### Recommendations for further research

- The analysis presented in the report is exploratory and intended to be used to initiate further discussions and more detailed investigations to further assist UEG in designing research agendas and advocacy strategies that are responsive to health needs and salient evidence gaps in the field of digestive health.
- Prioritised disease areas that appear under-funded or under-researched may represent

- Research investigating irritable bowel syndrome, one of the most common digestive diseases with limited available treatment options, was granted approximately €1.7 million in funding—equivalent to just over 1% of the amount awarded for inflammatory bowel disease research.
- Alcohol-related liver disease research appeared to be under-funded in relation to the high level of burden associated with this disease.
- If nine digestive diseases had received a proportionate amount of Horizon 2020 research funding relative to their disease burden, an estimated additional €283 million would have been allocated to these diseases in total, including almost €83 million for alcohol-related liver disease research.
- Of the digestive cancers that were available to analyse, colon and rectum cancer and pancreatic cancer appeared to be under-funded in relation to burden compared with some non-digestive system related cancers.

research gaps that warrant greater consideration. Digestive diseases, such as irritable bowel syndrome, pancreatitis, and alcohol-related liver disease, which received little in the way of Horizon 2020 research funding were highlighted as areas for prioritisation by the national societies. Additionally, disease prevention research appeared to be under-researched yet regarded as an important area for prioritisation and may represent a promising avenue for development.

- Due consideration must be afforded to developing equitable research agendas and investment strategies given the low levels of research activity and funding for alcohol-related liver disease a condition which disproportionately burdens more socioeconomically disadvantaged groups, contributing to health inequities.
- Refinement of the potential areas for prioritisation that have been identified, into specific research questions for investigation can be achieved using systematic review methods and/or focused priority setting exercises.
- Gaining insight from patient groups who represent the intended beneficiaries of the research will be particularly informative. Capturing the views of marginalised and disadvantaged patient groups who may be more difficult to engage but likely have greater unmet health needs is especially important to inform decisions regarding avenues for further research.
- Additionally, further investigations are needed to identify barriers to conducting research in neglected areas, which will inform the development of effective strategies to encourage increased research activity and funding.
- Institutional body funding could be oriented not only at research grants but also for networking pan-European activities with capacity-building objectives which may provide long-term benefits for digestive health research.
- Coordinated approaches to improve the surveillance of research activity and funding could also support research efforts by helping the research community to identify under-researched areas and opportunities for collaboration.

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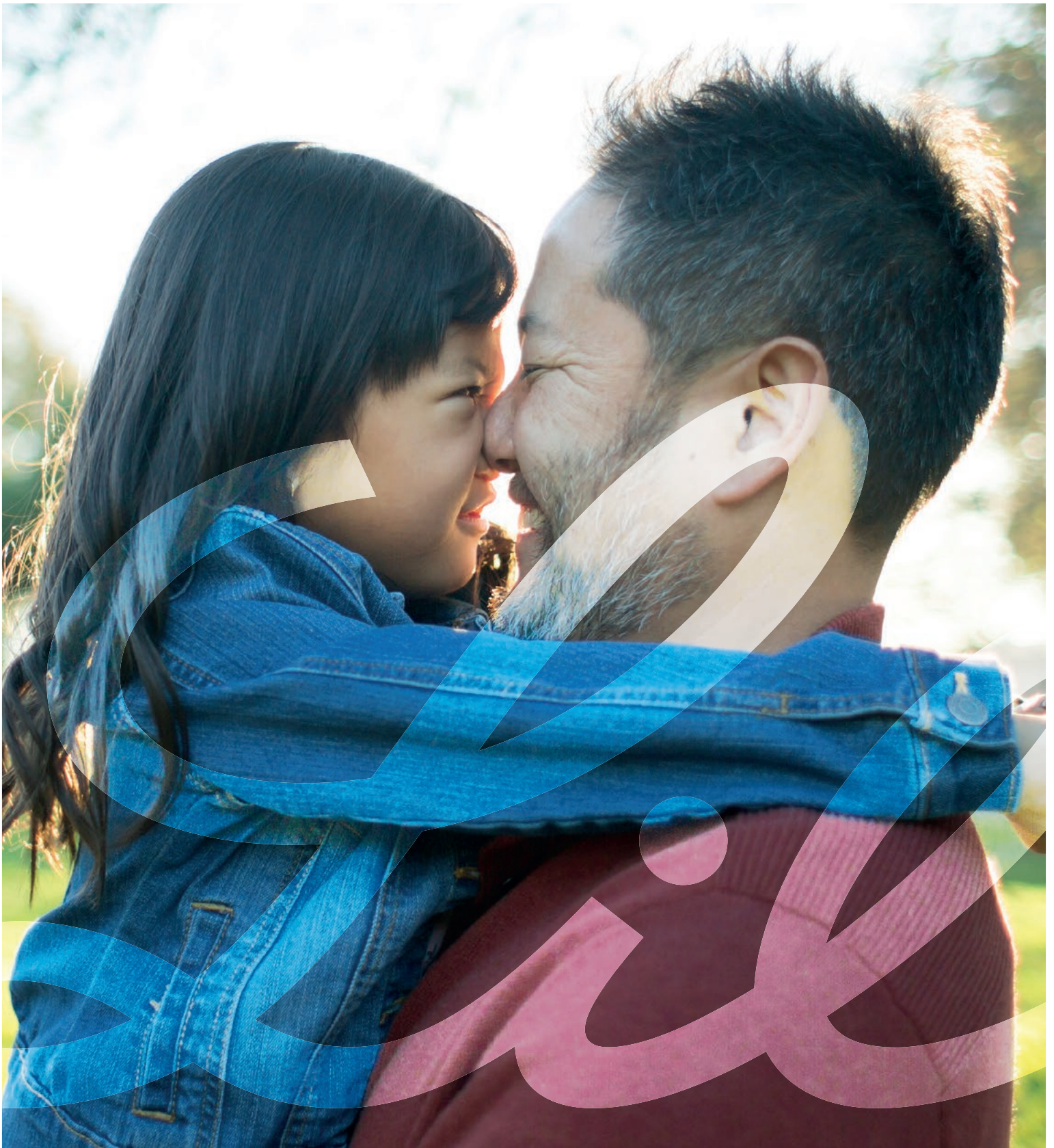
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