

EFCCA MAGAZINE

EUROPEAN FEDERATION OF CROHN'S AND ULCERATIVE COLITIS ASSOCIATIONS

FEBRUARY 2024

Reflections from the 3rd ECCO Council Meeting of National Representatives

page 6

FIBROTARGET: A potential new pharmacological target for IBD treatment?

page 16

Study highlights link between IBD and axSpA

page 33

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Content

EFCCA News 4

Project News 14

Member News 18

News from Partners 33

Medical Review Corner 36

Clinical Trials 38

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Foreword



Dear members and stakeholders,

The last few months have been a dynamic period of advocacy, collaboration and patient empowerment as we have implemented many exciting activities to achieve EFCCA's mission of improving the lives of those living with Inflammatory Bowel Disease (IBD).

One highlight was our participation in the United European Gastroenterology Week in Copenhagen which is an excellent hub for ideas, experiences and visions on matters of digestive health. EFCCA's presence was more than just about participation; it was about making our voices heard in the global dialogue. From the Digestive Health Roundtable to the 3rd ECCO Council Meeting of National Representatives, our representation was strategic and impactful.

You will find further instances in this issue highlighting the relentless efforts of the entire IBD community in progressing our mission and providing support to people living with IBD.

Join us as we provide you with the details, the insights and the steps taken not only at the transnational level but also at the national levels in order to advocate for every individual who is living with IBD.

Salvo Leone,
EFCCA Chairperson

Editorial



Dear readers,

I am pleased to present you with this latest issue of the EFCCA Magazine, a comprehensive compilation of articles that provide a detailed insight into our recent activities, and the dedicated efforts of our members, partners and various stakeholders.

In particular, I would like to draw your attention to an in-depth interview with patient representative, R. Campanella, who shares his thoughts from the recent ECCO Meeting of National Representatives.

In addition, I invite you to take a look at a study shared with us by ASIF, the global association uniting patient associations focused on assisting individuals with axial Spondyloarthritis (axSpA). Their study reveals a connection between IBD and axSpA, offering important, new perspectives on these conditions.

Beyond these highlights, this issue is filled with numerous other captivating stories that showcase the commitment of our IBD community. A big thank you to all of those who have made valuable contributions to this edition. I am confident that you will find it both informative and inspiring. Enjoy your reading!

Isabella Haaf,
Editor-in-Chief

Highlights from UEG Week 2023

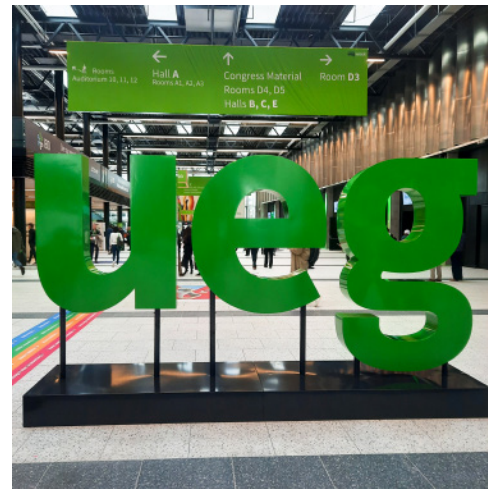
Bringing the Patient Perspective to Digestive Health

Once again, EFCCA was present at United European Gastroenterology Week, held last year in Copenhagen from 14-17 October. With over 11,200 attendees from more than 120 countries, it was an excellent event to share and discuss the latest research findings, clinical advancements and innovations in digestive health.

For EFCCA, this event served as a platform to communicate our visions for the IBD patient community and to explore collaborative initiatives to improve the quality of life and care for individuals living with Crohn's Disease and Ulcerative Colitis.

Our EFCCA booth became a hub for engaging discussions, attracting members, healthcare professionals and industry representatives alike. Here, we shared our perspectives on the IBD patient community, fostering dialogue on collaborative approaches and presenting our upcoming initiatives. Furthermore we had the opportunity to share information on some of the exciting Horizon Europe projects in which EFCCA is involved in and which investigate innovative IBD treatment options.

Our milestone events included our participation in the Digestive Health Roundtable on 15 October, where leading experts and patient advocates in digestive health gathered. Another notable event was our active involvement in the 3rd ECCO Council of National Representatives Meeting on 14 October. These engagements underscored EFCCA's commitment to driving positive change in the landscape of digestive health. For more information, see the following articles and interview.



Advancing Digestive Health: Roundtable discussions with key stakeholders

UEG Week 2023 served as the ideal backdrop for a range of engaging activities, one highlight being the Digestive Health Roundtable titled “Advancing Digestive Health: Collaborating for Better Outcomes” held on 15 October 2023.

EFCCA played an important role alongside leading UEG experts and patient advocates in launching this groundbreaking initiative, intended as the inaugural event in a series of multidisciplinary meetings.

As co-chairs Patrizia Burra and Ana Dugic outlined, the primary focus of the meeting was to emphasise the importance of learning from patient advocates about their experiences with digestive diseases. The shared objective of these gatherings is to address challenges, identify opportunities and create consensus on joint actions aimed at enhancing digestive health throughout Europe.

Our chairman, Salvo Leone, actively participated in one of the discussion groups, centred on Quality of Life. The group looked at issues such as stigma, lack of understanding leading to feelings of guilt and the impact of strained healthcare systems on both doctors and family members.



Salvo underscored the necessary steps required to improve the quality of life for patients with digestive diseases, highlighting the critical significance of meaningful collection of patient-reported outcomes. This, he argued, would provide direct insights into the patient experience, showing the true impact of the disease and its treatments.

In conclusion, the Digestive Health Roundtable at UEG Week 2023 facilitated significant discussions and also laid the foundation for ongoing collaborative efforts to improve digestive health across Europe. The commitment of participants, from patient advocates to leading experts, signifies a united front in addressing challenges and championing positive change in the field of digestive health.

3rd ECCO Council Meeting of National Representatives

EFCCA together with many of its members participated in the 3rd ECCO Council of National Representatives meeting which took place in Copenhagen during UEG WEEK on 14 October 2023.

This event which brought together representatives from ECCO, N-ECCO and EFCCA was a great opportunity to align our visions and discuss collaborative projects that will pave the way for better care and quality of life for people living with IBD.

It also confirmed our long-standing partnership with ECCO and N-ECCO which we have developed over the years and which has resulted in many collaborative projects that have the potential to reshape the landscape of IBD treatment and support. By fostering such events aimed at collaboration and cooperation, we are setting the stage for a more unified community, where the patient's voice is not just heard but valued.

Please read our following interview with Raffaele Campanella, a participant at this meeting sharing his insights and thoughts.



Reflections from the 3rd ECCO Council Meeting of National Representatives

Interview with Raffaele Campanella

After the 3rd ECCO Council Meeting of National Representatives on 14 October 2023 (held in Copenhagen during UEG WEEK 2023), we spoke with Raffaele Campanella from AMICI, the Italian IBD patient association, to share his insights and reflections on the meeting.



Raffaele Campanella is the president of AMICI's regional group in Friuli Venezia Giulia and has been actively engaged in efforts to improve the lives of individuals living with Inflammatory Bowel Disease (IBD).

1) *Can you share your overall impressions of the 3rd ECCO Council of National Representatives meeting during UEGWEEK23 and its importance in advancing the cause for people living with IBD?*

My overall impression has been very positive. I strongly believe in the power of meetings where we can share information, learn new things and exchange ideas.

The meeting in Copenhagen was an eye-opener, helping us understand the broader trends affecting ECCO and EFCCA. However, I think it's important to focus on a few key topics rather than having a long list of items on the agenda.

Also, I was wondering during the meeting how we can translate these high-level discussions into tangible actions at the local level, reaching both the medical and patient IBD community. In general, I feel that often important decisions and initiatives are discussed in capital cities or international congresses, involving top officials like for example from the Ministry of Health, international IBD specialists etc. But how do we then make sure that these discussions are effectively disseminated to local communities, especially those in remote regions? In my view the outcomes of such discussions need to reach and resonate with the grassroots level for them to have a successful implementation and impact.

“...the outcomes of such discussions need to reach and resonate with the grassroots level for them to have a successful implementation and impact.”

2) *Could you highlight some of the key discussions or initiatives that were addressed during the meeting, particularly those that hold the potential to make a positive impact on the IBD community?*

For me, the discussions around the ECCO Patient Guidelines were particularly interesting. I was surprised

to learn from Dr. Fiorino, a member of the E-learning task-force of the European Crohn's and Colitis Organisation (ECCO) and member of the ECCO Guidelines Committee, that the ECCO guidelines for doctors are less known among physicians than expected.

I therefore reached out to gastroenterology centres in my region after the Copenhagen meeting to organise online sessions where an IBD specialist can explain these guidelines to patients. I also think local congresses organised by IBD doctors could be an effective way to disseminate information about these guidelines. In Italy for example the IBD doctors organisation IG-IBD organises regular national and regional events where the guidelines could be presented.

Another important topic we discussed in Copenhagen was concerning the collection of patient needs as a vital aspect for healthcare systems to effectively organise and provide services. This topic has been a longstanding issue and I am afraid to say that not much has changed in the last decade.

In my opinion, we need to start setting specific targets and measuring them to ensure we're making progress. It's not just about discussing needs; it's about finding and implementing solutions!

Patients are the primary informants of their own needs and one of our key roles as an association is to encourage them to communicate these needs consistently during their interactions with healthcare professionals. While it may be challenging for some patients to fully open up to a doctor, they often find it easier to communicate with nurses. Therefore, nurses can play a critical role in collecting this information. It's important that both doctors and nurses are trained not just to listen, but also to understand and address these expressed needs.

At our association, we carried out a project a few years ago called AMICI We Care which revealed that there clearly is a different perception about patient needs (from the patient and the doctor's point of view). So what is important for the patient might not be important for the doctor. That's why we need to fine-tune the whole definition of patient needs.

3) *From your perspective as a patient representative, how do you see the outcomes of this meeting translating into real improvements in the care and quality of life for individuals affected by IBD and what role can patients play in these efforts?*

As I mentioned previously, ensuring that the outcomes of these high-level meetings translate into real improvements at the local level is a significant challenge. We need to prepare better for these meetings by focusing on a few well-documented subjects and setting concrete targets. It's about leaving the meeting with something tangible, not just words. This approach, I believe, would greatly benefit our patients who prefer facts over words.

4) *What are your hopes and expectations for the future of IBD advocacy and support, especially considering the organisation of such meetings? How can patients and organisations continue to work together to achieve positive change for the IBD community?*

I feel quite optimistic about the steps we are taking in IBD advocacy and support. Particularly considering

“we need to start setting specific targets (about patient needs) and measuring them to ensure we’re making progress. It’s not just about discussing needs; it’s about finding and implementing solutions!”

the organisation of such meetings, I hope to see a more integrated approach where patients, healthcare professionals and organisations collaborate closely.

My expectation is for these meetings to not only be a platform for discussion but also for actionable decision-making and that patients should be seen as active participants, not just recipients of care.



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Launch of EFCCA Empowerment Academy

This January we launched our new online training programme called “EFCCA Empowerment Academy – Everything you need to know about EFCCA” which is addressed to new EFCCA national associations, new delegates, new board members and staff.

As introduced during our General Assembly and as part of the 2023 Work Plan, this training will provide a comprehensive orientation and familiarisation with EFCCA and its operations. Taking part in this Academy is not mandatory for our new delegates (from 2020 onwards), but we really suggest it. We understand that joining a new organisation can be both exciting and disorienting and therefore, this training programme will help you understand EFCCA better and contribute more effectively to EFCCA’s mission and strategic objectives.

Teaching subjects include:

1. Understanding how EFCCA works under the Belgian law: An easy guide
2. The history of EFCCA: Mission, values and strategic priorities
3. Protect our values: Ethics & Transparency for Patients’ organisations
4. In-depth exploration of EFCCA’s strategic areas (Advocacy, Empowerment, Networking, Awareness Raising, Research & Development)
5. Empowering Patient Associations: EFCCA Best Practices

The training programme will be accessible online through the EFCCA e-learning platform and it will take approximately 5 hours to complete. The video lectures are pre-recorded, offering participants the flexibility to watch them at their convenience, from any location. In addition to the learning program, you’ll discover inspiring stories from other members and explore the EFCCA Best Practices Corner - useful learning lessons to better understand specific topics common to patient associations. Participants are requested to complete the programme within 2 months from their initial login to the platform.

This initial phase of the Academy is reserved exclusively for recent members of EFCCA. However, we are pleased to announce that the programme will be available to all members in spring 2024.

If you would like to participate in this training (free of charge), please contact mariastella.derocchis@efcca.org

Leaders of Tomorrow - EFCCA Youth Academy final work assignments

At the end of 2021 we have launched our first Youth Academy with the aim to enhance youth representation, foster a cohesive group of future leaders and empower young representatives. Targeted at IBD patients aged 18 to 30, this training program saw 14 students successfully complete their course and embark on final assignments choosing from the following options:

- Implementing a youth engagement project
- Assisting the national association in implementing an awareness campaign
- Contributing to EFCCA’s upcoming Youth event



We have already featured two out of the fourteen assignments in the previous issue. Now, let's read more about two other contributions: Francesca Russo from Crohn's & Colitis UK and Sāra Zdanovska from LKKSB - Latvijas Krona un kolīta slimnieku biedrība.

In her [article](#), Francesca highlights the growing importance of digital accessibility for events, influenced by Crohn's & Colitis UK's hybrid model and lessons learned from the Covid-19 pandemic. She emphasises the importance of fostering connections within the IBD community and suggests incorporating virtual elements, such as discussions and a 'coffee roulette', into future in-person events for greater inclusivity. Collaborating with

Crohn's & Colitis UK and the EFCCA Youth Academy group, Francesca intends to prioritise safety, connection and digital inclusion in event planning.

Sāra in her [report](#) proposes a comprehensive plan for the next EFCCA Summer Camp for young people living with IBD. Sara envisions a week-long event, focusing on creating a supportive community and providing opportunities for personal development. The proposed activities include team-building exercises, workshops, lectures, excursions and collaborative project creation.

If you want to find out more about the Youth Academy please visit our website at: efcca.org/news/efcca-youth-academy



EFCCA Patient Talks on Guidebook for Patients to Review Clinical Trial Protocols

In a significant move towards improving patient engagement in clinical trials, Roberto Saldaña, EFCCA's Coordinator for Innovation and Patient Engagement, recently presented the "Guidebook for Patients to Review Clinical Trial Protocols" during two online EFCCA Patient Talks conducted in the last quarter of 2023.

The Guidebook's Purpose and Key Features

The Guidebook serves as an advocacy tool, facilitating the active engagement of patients in the evaluation of clinical trial protocols. At the same time, it empowers

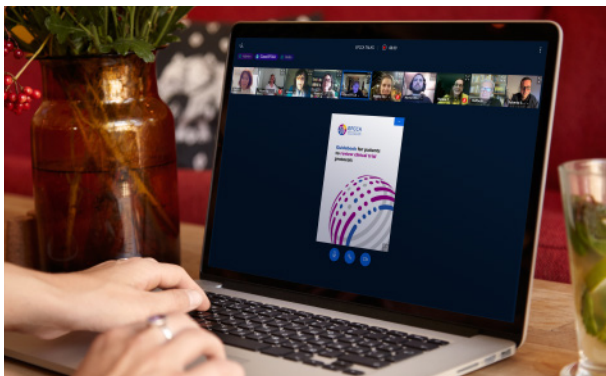
patient representatives to offer thorough and well-informed feedback, minimising variability and enhancing the overall quality of their input.

EFCCA has created this manual with the aim of aiding patient representatives in better understanding the strategies employed by sponsors and health authorities in drug research and assisting them in identifying key aspects that should be considered when providing feedback on protocols.

Connecting Patients and Industry to our Guidebook

The guidebook was presented during two virtual sessions in order to demonstrate its functionalities and to gather insightful feedback from both patient representatives and industry stakeholders:

- The EFCCA Patient Talk on 8 November 2023, was addressed to EFCCA Members and sparked a lively discussion, with patient representatives actively engaging in conversations about the use of the Guidebook and seeking clarity on its practical applications. Specific questions were raised, demonstrating the eagerness of patient advocates to employ this resource in their work to contribute meaningfully to clinical trial protocol reviews.
- The EFCCA Patient Talk meeting on 26 October 2023, was a closed meeting aimed at those industry stakeholders supporting EFCCA on this project, including representatives from Pfizer, Lilly, Takeda and Galapagos. This interesting session deepened into the context behind developing the Guidebook and the detailed methodology employed in its creation. The gathering provided a platform for industry leaders to share valuable insights, fostering a collaborative environment of patient engagement in clinical trials.



Guidebook for patients to review clinical trial protocols



Promoting Patient-Centric Innovation in Clinical Trials

During both meetings, a solid exchange of ideas allowed for constructive feedback and perspectives. The positive response from both patient advocates and industry stakeholders underlines the significance of this initiative in promoting a collaborative and patient-centric approach to clinical trial development.

The discussion input from industries showed their commitment to ensuring that the Guidebook aligns with the needs and expectations of all stakeholders involved in the clinical trial process.

EFCCA's World IBD Day 2024 Campaign: "IBD Has No Borders: A Global Movement for Accessible IBD Care"

EFCCA has launched its campaign for World IBD Day 2024 with the theme: **"IBD Has No Borders: A Global Movement for Accessible IBD Care"**. The campaign aims to strengthen global alliances and amplify our collective impact in the fight against IBD.

The campaign's focal event is an international round table scheduled for the weekend of 19 May, titled **"Uniting for Access to IBD Care"**, which will bring together the founding members of World IBD Day as well as other stakeholders. During this event, we will discuss the various issues that are related to access to IBD care, such as its obstacles and potential solutions for ensuring that all IBD patients receive the essential IBD care they need.

We will be complementing this initiative with a social media campaign to raise awareness on the issue of access to IBD care and we will be calling on individuals with IBD to share their experiences through video testimonials.



We invite you to visit our website to find out more about our plans for World IBD Day 2024:

www.efcca.org/news/world-ibd-day-2024

Economist Impact: panel discussion on the future of IBD care

On 28 November 2023, EFCCA participated in the roundtable, "Soothing Systemic Challenges: Innovative Transformation for IBD Care Pathways" organised by Economist Impact, a think tank belonging to The Economist Group. The event took place in Brussels.

The session addressed the escalating challenges faced by healthcare leaders in Europe, such as constrained budgets, workforce shortages and delayed elective care. It also served to discuss the urgent need for timely diagnosis and treatment, particularly for chronic diseases like Inflammatory Bowel Disease (IBD). One

of the objectives was to position IBD care within the EU's health priorities, placing patients at the centre of the care journey and to underscore the importance of recognising the link between IBD and broader health policy concerns.

Our CEO, Luisa Avedano took part in the panel discussions alongside health-care policy makers, payers, physicians, researchers and a representative of the Flemish IBD Patient Association (CCV) to discuss some of the findings of the report "Inflammatory Bowel Disease; Addressing the "hidden" disease with innovative, multidisciplinary, and patient-centric care" published by the Economist IMPACT and supported by AbbVie.

The report provides an independent analysis of the growing global burden and unmet needs of Inflammatory Bowel Disease (IBD). It draws attention to the evolving burden, shines a light on the direct and indirect costs associated with IBD, maps current global practices that can be leveraged to promote effective and equitable care for IBD patients and produces unique insights that drive greater awareness of the unmet needs of IBD patients.

The lively panel discussions focused on questions around: Where are there gaps in the EU's current health priorities? How can IBD care be better positioned? From diagnosis to treatment, how can patients be better placed at the centre of care? What innovative



technologies can health-care providers use to improve patient outcomes, from diagnosis through to treatment? How can the link between IBD and wider health policy concerns be better recognised?

For more information please contact the EFCCA office.

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THERAPEUTICS

At the Forefront of Research: Horizon Europe Projects' Update

In the past few months, the Horizon Europe projects in which EFCCA is a partner have witnessed notable advancements in their common goals of improving inflammatory bowel disease (IBD) treatment. This short summary offers a glimpse into the most recent

developments. For more detailed information about our involvement in these Horizon Europe and Horizon 2020 projects, please subscribe to our [EFCCA PROJECT DIGEST](#), which provides regular and detailed updates on these projects.

GENEGUT General Assembly

GENEGUT held its third General Assembly in Budapest on 12-13 September 2023. The Assembly marked a year of substantial progress in the project's quest to develop an RNA-based therapy for Crohn's Disease, bringing together over 30 participants from all nine partner organisations. Coordinator Prof. Cairiona O'Driscoll (UCC) highlighted significant advancements in RNA-based therapeutics. As an initiative to provide resources for patients, in November, GENEGUT published a useful Factsheet for patients, an informative brochure tailored to patients summarising the most relevant information about the project.



Visit the GENEGUT website for more information about the project: <https://genegut.eu>

miGut-Health: Reflecting on One Year of Progress

Approaching its one-year anniversary, miGut-Health used the occasion to recap its significant milestones during 2023, which included the identification of patient cohorts, prioritisation of omics data collection and a clinical study showcasing the efficacy of a prolonged dietary intervention in modifying intestinal inflammation. The project also released an online leaflet summarising the project's work and objectives; you can read it here: www.migut-health.eu/media/miGUT_Leaflet_final.pdf

METHYLOMIC's Second General Assembly

Members of the METHYLOMIC Project Consortium gathered in Amsterdam on 13 December for the Second Network Meeting and Consortium General Assembly, during which leaders of the Work Packages provided updates on their current activities. METHYLOMIC aims to improve the effectiveness of medication in chronic immune-mediated diseases such as Crohn's Disease, Rheumatoid Arthritis and Psoriasis.

EFCCA and CCNL (the Dutch IBD patient association) highlighted their communication achievements, including the website, social media channels, podcasts and outlined upcoming plans for the online first Stakeholder Workshop in autumn.

Our association plays a vital role in Work Package 6 of METHYLOMIC by contributing to the implementation of dissemination, exploitation and communication strategies, in collaboration with Vita-Salute San Raffaele University and other partners. EFCCA's involvement is aimed to enhance the project's impact on scientific, economic and societal levels. Following the Consortium General Assembly, three break-out groups focused on the upcoming study to be launched by the Consortium, involving sites in the Netherlands, UK, Slovenia, Italy, Belgium and Hungary. EFCCA will share all details with our members in the mentioned countries once the survey is finalised and approved by the ethics committee.



Monthly Spotlight

METHYLOMIC initiated in November a monthly 3-questions interview series, featuring Professor Wouter de Jonge from Amsterdam UMC in its first edition and EFCCA's CEO Luisa Avedano in its second

one. The interviews provide insights into the project's motivation, challenges and hopes for enhancing the lives of Crohn's Disease. You can read Luisa's answers here: methyloomic.eu/artikel/three-questions-for-2



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FIBROTARGET: A potential new pharmacological target for IBD treatment?

Members from the FIBROTARGET project have just released a paper published in the Journal of Crohn's and Colitis under the title "NLRP3 Inhibition Leads to Impaired Mucosal Fibroblast Function in Patients with Inflammatory Bowel Diseases." The article is the latest to provide some insights about potential approaches that could help prevent severe complications due to intestinal fibrosis formation.

What research topics were explored?

Led by the First Department of Medicine and Deutsches Zentrum Immuntherapie at Friedrich-Alexander-Universität Erlangen-Nürnberg, the article delves into the role of NLRP3 inhibition in individuals living with inflammatory bowel disease (IBD). A multiprotein complex, NLRP3 influences how the body regulates the innate immune system and inflammatory signalling.

In cases of IBD, individuals with the disease can experience mucosal inflammation and fibrosis formation. Whilst NLRP3 could contribute to these processes, investigators remain unsure of its exact expression and function within this context.

What was done?

Investigators examined intestinal NLRP3 expression in mucosal immune cells and fibroblasts from individuals living with IBD. Using single-cell RNA sequencing and microarray analyses, they also looked at NLRP3-associated gene expression.

The study further explored the role of two other physiologic processes:

- Cytokine secretion - a type of protein that helps control inflammation - of NLRP3 inhibitor in treating blood and mucosal cells
- Proliferation, collagen production and cell death of NLRP3 inhibitor in treating intestinal fibroblast samples

What new results were found?

- An identified set of monocytes and macrophages as the main cell type involved in the NLRP3 signalling pathway
- Expression of the NLRP3 inflammasome was observed in the intestinal fibroblasts
- A significant reduction in proliferation of intestinal fibroblasts after NLRP3 was inhibited.
- This was associated with a marked decrease in collagen type I and type VI production
- NLRP3 inhibition in intestinal fibroblasts also induced autophagy, a cellular process involved in collagen degradation.

What impact could be expected?

NLRP3 activation has been well established as being crucial in regulating innate immune system processes. There are studies that suggest that overactivation of NLRP3 forms part of the immunopathogenesis of many immune-related diseases, like IBD. Yet, because investigators have not completely understood the exact role of NLRP3 in IBD, this current study adds much needed value to the field!

In fact, the findings imply that NLRP3 inhibition could serve as a pharmacologic target for IBD treatment. This could be exciting news for those living with the disease, given that no anti-fibrotic exists on the market. It could also pique the interests of industry and academia due to the still-to-be explored anti-inflammatory and anti-fibrotic properties of NLRP3 inhibition.

Indeed, NLRP3 inhibition as an eventual targeted treatment could translate into the possible prevention of fibrosis, intestinal structure remodelling and intestinal stenosis formation - all health conditions that continue to arise during IBD.

You will find more information about the article on the Journal of Crohn's and Colitis website:

<https://bit.ly/3SeSUcg>

Contact information

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Horizon 2020 Projects: IDEA-FAST Year in Review

Last December, the Horizon 2020 Project IDEA-FAST shared a “Year in Review” report, reflecting on the initiative’s achievements during the previous year. In the document, project leaders also express gratitude for the significant contributions and dedication of consortium members, with EFCCA among them.

With an enrolment of 920 participants by 18 December 2023, IDEA-FAST stands as one of the world’s largest

studies in wearable device research, notable for its comprehensive clinical and patient-reported outcome data. Looking ahead, the project aims to expedite COS recruitment, focusing on managing targets at each study site, ensuring high-quality clinical and digital data collection and advancing their data analytics pipeline.

You can read the review on the IDEA FAST project website at: <https://idea-fast.eu>

Italy

AMICI organises conference on diet and IBD

Food choices have a decisive impact on IBD patients. To reach common guidelines on this topic, AMICI promoted the organisation of a consensus conference to define the priority healthcare needs relating to diet.

Food and nutrition in Chronic Inflammatory Bowel Diseases have become crucial

The prevalence of malnutrition in IBD varies between 6% and 16%, a risk five times higher than in the healthy population. A balanced and healthy diet is a key factor as it plays a fundamental role in the homeostasis of the intestinal microenvironment. It can influence its composition and correct functioning, avoiding the exposure to malnutrition conditions.

The definition of nutritional needs

All this evidence about the importance of the diet during all stages of IBD has highlighted the role of nutrition in this area. AMICI, with a group of experts, promoted the organisation of a consensus conference. Its aim was the definition of practical indications to patients, such as all healthcare and psychological needs relating to diet and nutrition of people with IBD. But also, looking at good practices for social-welfare and psychological caregivers as well as quality of life indicators.

Nutrition education is needed

It is fundamental to spread greater awareness about daily food choices and the possibility of receiving nutritional assistance to maintain a psycho-physical well-being. A nutritional education process can lead to some essential abilities such as understanding and using information regarding nutrition, defining objectives for optimising the state of health and improving the quality of life.

Evidence-based recommendations

All these good practices will be collected in a document developed during several phases which then will be reviewed for unanimous approval.

Thanks to this project, medical recommendations will be produced based on the most recent scientific evidence. In recent years, enteral nutrition has been studied and adopted as a treatment for Crohn's Disease in paediatric patients. In adults, it still remains a topic to be explored further on a scientific level.

The danger of the Western diet

The World Health Organisation has detected a reduction in the quality of the diet globally. The Western diet (WSD) - typical of the industrialised world – differs from the past traditional regional diets (when the prevalence of IBD was significantly lower).

The most radical change was the transition from a predominantly plant-based diet to one rich in foods of animal origin containing saturated fats, industrial foods rich in additives and foods with a high density of refined sugars.

This dietary pattern includes components capable of causing both a direct and indirect pro-inflammatory effect on the intestine through the alteration of the regulatory mechanisms of the immune system, the composition of the microbiota and the integrity of the intestinal barrier.

Dr. Camilla Fiorindi - Dietician
Careggi University Hospital (Florence)

Publication on the link between Ulcerative Colitis and Hepatitis B

AMICI financed and supported a study recently published in the medical journal "GUT" that investigated the role of viral HBX Protein in the development of Ulcerative Colitis.

Chronic Inflammatory Bowel Diseases are characterised by incorrect functioning of the immune intestinal response and an altered composition of the microflora. If the components of the microbiota are not in perfect balance among themselves and with the organism, they can contribute actively to the development of IBD.

During intestinal inflammation, the continuous and persistent inflammatory state affects the microbiota causing alterations. Finding ways to counterbalance this symptom remains one of the most studied treatment options.

The role of hepatitis B infection

The hepatitis B viral X protein (HBx), (belonging to the Orthohepadnavirus genus), is very abundant in patients with Ulcerative Colitis when compared to healthy people and patients with Crohn's Disease.

Inflammation and cellular alteration

The research team published data on how HBx compromises the immune defences of the intestinal

mucosa. They also observed that HBx alters the functionality of intestinal cells, transforming them into inflammatory cells and unable to function properly.

Furthermore, 40% of the patients with Ulcerative Colitis carry this factor. In the future, it will be possible to think about a specific therapy inhibiting HBx, in order to fight colitis starting from its triggering factor.

Medicines, stress and bad habits affect the microbiota

The microbiota is a rich community of bacteria, viruses, fungi and other small microbes that are an integral part of our organism. It is a fundamental element for our health and its proper functioning is crucial for human well-being. However, the microbiota can be influenced by stress, diet, some drugs, poor physical activity and last but not least, by bad mood. This is why it remains fundamental to adopt correct and balanced lifestyles.

Dr. Federica Ungaro
Researcher at the Department of Gastroenterology
and Digestive Endoscopy,
San Raffaele Hospital (Milan)

France

Great success of our family camp!

Every year, AFA Crohn RCH France organises camps and weekends for IBD patients and their families. These include a summer course for teenagers, a camp for ostomates, a camp for seniors in September and finally, a family weekend at the end of October!

The family weekend is aimed for families with one or more children with Crohn's disease or colitis. For three days, parents, their child with the disease and siblings gather in Paris with other families to participate in workshops and get together under the guidance of AFA patient-experts.

A gastro-paediatrician and a dietitian are also on hand to answer any questions.

These information and dialogue sessions are separate for adults and children, allowing participants to speak openly and receive specific and relevant information.

From 27 to 29 October 2023, 10 families came together to talk about life with the disease, the difficulties encountered and in general to share their experiences. These are often intense moments, involving a great deal of emotions, but they are invaluable in boosting the mood and giving people new hope!

See you in 2024 for another edition!

Eve Saumier
AFA CROHN RCH FRANCE



Value through
innovation



*Transforming lives for generations
– Our purpose.*

Our curiosity, creativity and passion for science lead us to take the paths scientifically less travelled and the courage to face challenging journeys as we relentlessly pursue the next generation of breakthrough therapies that will transform lives now, and in generations to come.

UK

Breaking new ground – Crohn’s & Colitis UK: The Podcast

Crohn’s & Colitis UK’s new community-focused podcast is all about finding new ways to talk about Inflammatory Bowel Disease from a patient perspective.

There’s no doubt that it can be daunting to speak about life with Crohn’s or Colitis. When dealing with a lifelong condition, every day is different, but we know that sharing experiences can help people feel less alone.

In the media team at Crohn’s & Colitis UK, we feel very privileged that so many members of the IBD community contact us wanting to talk about their lives. Some of them choose to do that in the press, while others prefer to feature on our social media channels or in blogs on our website. They always get a warm reception.

We are always looking at new ways to reach people and to take our storytelling to the next level. So, after much planning, we have developed a brand-new initiative: a Crohn’s & Colitis UK podcast! Podcasting is such an intimate and engaging medium, it’s the perfect way to bring our fantastic case studies to life.

Crohn’s & Colitis UK: The Podcast is hosted by me and producer Luke Bligh. I have a background in radio and I was diagnosed with Colitis 30 years ago in my early teens, long before people had podcasts or even the internet. Luke has been living with Crohn’s since his teens. The first episode features IBD advocate Lauren Golightly as well as other members of the Crohn’s and Colitis community who speak about their experiences. This podcast isn’t just for the newly-diagnosed, it is for everyone with Crohn’s or Colitis and all those who support them. Each episode is fact-checked by our Knowledge & Information team and we direct listeners to the expert resources on our website.



The feedback has been really encouraging, with lots of people getting in touch to ask if they can appear as guests on future episodes. Just as we had hoped, we are connecting with the Crohn’s and Colitis community in a whole new way. It’s good to talk and it’s good to listen, too.

Crohn’s & Colitis UK: The Podcast is available on [Apple](#), [Acast](#), [Spotify](#) and all major podcast platforms.

Geraldine Cooper
Senior Media Lead at Crohn’s & Colitis UK

Czech Republic

A New Chapter for Pacienti IBD: Lucie Laštíková Takes the Helm

In the midst of the Svatováclavská IBD conference, a moment unfolded as the membership assembly and elections for the Pacienti IBD z.s. association marked the commencement of the 2023–2027 term. Stepping into the role of the new president is Lucie Laštíková.

PhDr. Martina Pfeiferová, the outgoing president, expressed her continued commitment to the association: *“I have been involved in the leadership of our patient organisation since its inception in 2008. With a touch of humour, it’s like my first child, which I, along with my colleagues, have guided through its teenage years to the age of 15. I am delighted that, within the executive committee, we have agreed that my dear colleague Lucie Laštíková will assume the role of president in the upcoming term. Lucie has been actively contributing to the association for over 10 years and I am confident that she will bring fresh ideas and initiatives to our patient organisation. I will continue to support the association’s activities, projects and initiatives from the position of vice president. I want to express my gratitude to all current colleagues who stand behind the activities of our patient organisation. I thank them for their excellent cooperation, support and the friendships that hopefully extend to our activities for you.”*

With this announcement, the Pacienti IBD community anticipates a new era under the leadership of Lucie Laštíková. The transition symbolises continuity and growth, with the assurance that former president PhDr. Martina Pfeiferová will remain actively involved in the association’s endeavours.

As the association embarks on this exciting journey, members can look forward to a wave of innovative activities and projects. The commitment and collaboration of both outgoing and incoming leadership promise a vibrant future for Pacienti IBD.



The association extends heartfelt thanks to its former president and expresses gratitude for the support, cooperation and friendships that have enriched its endeavours thus far.

Highlights from the 18 Annual IBD Conference in Prague

On Saturday, 23 September 2023, Prague hosted the 18 Annual Saint Wenceslav IBD Conference, drawing nearly 150 participants eager to delve into expert lectures on topics related to Inflammatory Bowel Diseases (IBD).

The event commenced with an opening address by Bc. Lenka Slabá, the manager of educational events at the organising entity, Pacienti IBD z.s. The series of expert lectures kicked off with a presentation by Doc. MUDr. Martin Bortlík, Ph.D., from Nemocnice České Budějovice a.s., who explored myths and facts about IBD. Subsequent talks were delivered by Prof. MUDr. Milan Lukáš, CSc., from the clinical and research centre ISCARE, highlighting advancements in IBD treatment, and Prof. MUDr. Michal Zikán, Ph.D., from FN Bulovka, addressing gynaecological issues in IBD patients.

Following a coffee break, MUDr. Jaroslav Vobořil from Vojenské lázeňské a rekreační zařízení presented the options for spa therapeutic-rehabilitation care for IBD patients. Psychotherapist and educator Mgr. Martina Hazuková focused on fatigue in IBD patients, offering advice on coping strategies. The management of pain in IBD was then explored by Prim. MUDr. Štěpán Bejvančický from ARO FN Plzeň. The morning session concluded with a presentation by Bc. Veronika Ivančíková, the president of Slovak Crohn Club, sharing insights into the club's 30th anniversary and activities for patients in Slovakia.

The afternoon session commenced with JUDr. Michal Sýkora informing participants about travel insurance options for IBD patients. This was followed by Ing. Veronika Hanzlíková and her husband Pavel Hanzlík announcing the winners of the summer photo competition – “Summer with IBD” – and presenting awards. Ing. Jana Komrsková then shared her patient journey with IBD. The conference concluded with Lucie Laščíková, the vice president of Pacienti IBD, providing updates on the activities carried out for patients throughout the year.

In addition to the enriching presentations, attendees had the opportunity to visit booths from Coloplast, Symprove, StomiQ cz and the organising entity Pacienti IBD z.s. These booths offered promotional items and professional publications. Celiak.cz – Bezlepková dieta SpBD z.s. and Prim. MUDr. Štěpán Bejvančický were also present, discussing gluten-free diets and pain management options, respectively. Attendees also took advantage of free consultations, including nutritional, legal, gastroenterological and psychotherapeutic advice. The conference provided a comprehensive experience, combining education, networking and support for the IBD community.

Pacienti IBD

Cyprus

Raising IBD Awareness

The Cyprus Crohn's and Ulcerative Colitis Association (CYCCA) organised information stands at the "Mall of Cyprus" on 26 November 2023 as well as a Christmas event on 17 December 2023 in the capital city, Nicosia, to provide information and raise awareness about Inflammatory Bowel Disease (IBD).

We were handing out leaflets and information to people of all ages and genders and asking them if they knew what Crohn's Disease and what Ulcerative Colitis was.

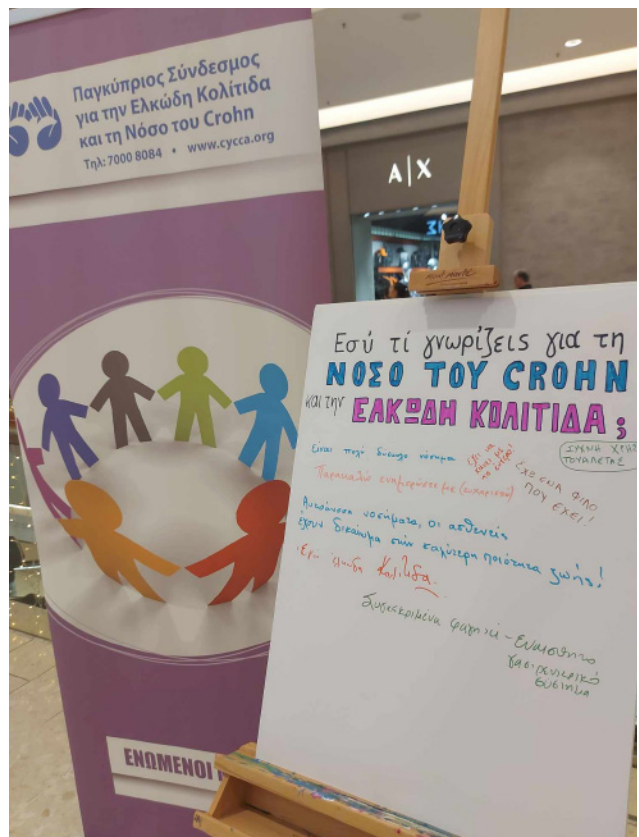
We have all learned to be strong and put on a brave face even when we are hurting inside. You cannot see it, but we sure feel it. You do not understand it, but we deal with it every day.

Just take some time to listen to us and try to understand us without judging us.

We deserve all that other people take for granted, a better quality of life at all levels. Our disease is invisible, but we are not! Do not be afraid to talk about Crohn's Disease and Ulcerative Colitis! Speak up now and break the silence!

United We Stand!

Cyprus Crohn's and Ulcerative Colitis Association
(CYCCA)



Austria

MY LIFE - Infodays in Austria

In June 2023 our Austrian IBD Patient Association, ÖMCCV, initiated through our service-platform CED-Kompass an information tour across six Austrian cities.

This info-tour called “MY-LIFE-Days for intestinal health” started with a press conference on 30 June 2023 at the Johannes Kepler University Hospital in Linz, the federal capital of Upper Austria, located in the north of our country. Following the press conference an information day with medical lectures and patients/doctors discussion exchange took place. The introductory question “Why are our intestines so necessary?”, followed by different themes, from dealing with the diagnosis of IBD to other intestinal diseases such as the irritable bowel syndrome or cancer of the colon.



This kick-off event was followed and will continue until 24 June with information days consisting of a varied program with specialist lectures by leading doctors and representatives of various health professions throughout further five big cities, namely: Graz, Salzburg, St. Veit/Glan, Innsbruck and Vienna.

Apart from the specialised informative lectures, there will also be time allocated allowing participants to share personal stories and concerns. People with IBD and their relatives will be supported and informed about different health information related to general health and intestinal diseases.

One highlight of the kick-off event was the possibility to walk through a huge model of an intestine in order to see the insides and experience processes such as the eversion of an intestines.

As mentioned, the information tour will be continued across Austria until mid of 2024, ending in Vienna with a big event close to World IBD Day.

Christine Gmeinder
Editor of Austrian magazine
ÖMCCV – Austria
www.oemccv.at

EMBRACE LIFE

Celltrion Healthcare will continue its innovation to promote better and happier lives for humanity.

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



Netherlands

Water weekend with youngsters

If you're a secondary school pupil, you probably don't have anyone else at school who also has IBD. That is why Crohn & Colitis NL thinks it is important to organise special activities where young people meet peers with the same disease. Everyone understands each other. One such activity last year was the Watersports Weekend on the Loosdrechtse Plassen.

At the end of September, board member Lisanne Trouw (27) joined Crohn & Colitis NL's watersports weekend for young people aged 14-18 as a volunteer. "You see the forming of real friendships. The youngsters arrived as individuals and left as a group".

The weather was perfect for the weekend which was all about sailing, surfing, canoeing and water-skiing and of course socialising with peers with IBD.

Sailing at night

The youngsters arrived at the jetty on the Loosdrechtse Plassen at 8 pm on Friday evening and were taken by boat to Robinson Crusoe Island. "It was a beautifully clear evening, with a full moon. Half the group went sailing immediately that night. At 11 pm the next evening, the other youngsters were also eager to take a night sailing trip. There was very little sleep that weekend. Everyone really squeezed out their last piece of energy."



Toilet

The atmosphere was very relaxed. “If someone got up during dinner to go to the toilet, no explanation was needed. Everyone understood. Furthermore, we went on a four-hour boat trip, on a boat without a toilet. I was worried beforehand that this might be a problem, but it turned out to be unjustified. Nobody needed to go to the toilet during the trip.”

Experiences

Lisanne does not have IBD herself, her husband does. He was diagnosed at 22. As a board member, Lisanne has young people in her portfolio. “I joined the sailing weekend for a slightly older group of young people earlier this year. Now it was especially special to hear the stories of these young people. The conversations were less about their illness, but about things like having to spread your final exams over two years or choosing a suitable education. It was good to be there and hear what is going on with this age group. And, as a plus, I learned how Snapchat and BeReal work,” Lisanne concludes with a laugh.

Cool weekend

Samuel (16) was one of the participants during the weekend. He has had Crohn's since he was 6 years old. “I actually had no expectations of the weekend and met everyone for the first time during the trip. That might be exciting, but it was mostly really cool! It was nice that everyone has the same disease and understands each other. I had a great time and enjoyed canoeing the most. I met Chayton there and went to stay with him recently.”

Barbara Davidson
Crohn & Colitis NL



Norway

The year 2023 – Norwegian Gastrointestinal Association

2023 has been a year characterised by renewal, interest-based political influence and a high level of activity for the Norwegian Gastrointestinal Association. These are some of the most important issues from the year.

In 2023, the Norwegian Gastrointestinal Association worked actively to get the law changed to give people with digestive diseases access to use toilets on board buses even while the bus was in circulation. Bus companies previously had closed access to toilets while driving as they believed that using the toilets could be dangerous to traffic and referred to the law.

Our argument that the law discriminates against those who have an urgent need to use a toilet was approved and the law was amended ensuring that no one can be refused to use the toilet on board regardless of whether the bus is moving or parked. The Norwegian Gastrointestinal Association finally prevailed after many debates, meetings and press reports, and we are satisfied with the result and pleased that IBD patients can now safely use buses for longer trips.

Public toilets on the agenda

It is not only on buses that we have had the spotlight on toilets. In 2023, we have also put the general lack of public toilets on the agenda. In a review on the availability of public toilets in Northern European capitals carried out by the largest daily newspaper, Aftenposten, Oslo came out worst. There is no reason to believe that the situation is better in other Norwegian cities and towns, quite the opposite.

The Norwegian Gastrointestinal Association published the case both in a TV report, an online case and a debate on TV2. We have also advocated for national investment in public toilets, with earmarked funds and a minimum standard for public toilets.

Name change of our association

After 35 years under the name of the National Association for Digestive Diseases (LMF-Norway), the organisation made a brave choice and changed its name to Norwegian Gastrointestinal Association in autumn 2022. In 2023, the new name has really gained a foothold. A new graphic profile is in place on new rollups, brochures, posters, jumpers, websites, social media and member magazines. Our new slogan "We fight for you" has also become a common thread in all communication. We are now working on developing a new website which will be launched in 2024.

The celebration of World IBD Day

In 2023, the Norwegian Gastrointestinal Association carried out a grand celebration with a physical event at Kulturhuset in Oslo with a live stream. The theme of the event was "IBD has no age". With the event, we wanted to highlight that children, young people, adults and the elderly live with IBD and to highlight the similarities and differences between the age groups. The presenter of the event was a well-known journalist who interviewed IBD patients and their families. The older participant was a man aged 69 who was diagnosed after turning 60. This was also the theme for other EFCCA members. In addition, we had a medical lecture about the differences in medical treatment of the elderly versus the young and which medical assessments create the difference.

Large IBS survey

In the spring of 2023, we conducted a large survey for people with irritable bowel syndrome (IBS). The survey aimed to assess the quality of life of people with IBS and how they experience the encounter with healthcare, working life and education. The survey received over 2,700 responses and shows a gloomy picture. 63% of respondents do not feel that the treatment offered by the public health system has helped with IBS. In contrast, more than half answered that treatment options they have tried on their own have helped.

A large proportion of the respondents were also dissatisfied with the competence of GPs (66%) and specialist health services (39%) in IBS. These are worrying numbers that the Norwegian Gastrointestinal Association will try to do something about. We are now working to get the survey published in a journal and will in the future enter into a dialogue with politicians, the media and the healthcare system to present the figures from the survey. IBS is an important area for us as IBS affects many people and close to 50% of patients with IBD also have IBS.

Huge gift for research

In 2021, we started a fundraising campaign where the money would go to a research project on irritable bowel and faecal transplantation. The fundraising campaign has yielded great results and in 2023 we received a private donation of around 100,000 Euro earmarked for this research under the direction of Professor Magdy El-Salhy. We are very humble and grateful for all the contributions that have been made to the research and it shows that we have an important role in fronting new ground-breaking research.

Information work and member meetings

In 2023, we published useful information on our website, our podcast Tarmkanalen and in the member magazine Fordøyelsen. We have also organised many physical and digital gatherings for members of all ages. All activities (of 13 county teams) are the result of volunteer members who want to help others in the same situation.

Nationally, we have also maintained a high level of activity with both gatherings for families with children, young people aged 18-35 and members over 35. In addition, we have arranged new physical peer-to-peer information work and member gatherings. Never have we had so many approved qualified peers!

We have also arranged twelve digital lectures/member meetings in 2023. These are published on our website, usually on the member pages.

The administration of the Norwegian Gastrointestinal Association amounts to 3.5 man-years divided among 8 employees. In addition, we have all our volunteers who are responsible for a large part of activities around Norway.

By Mads Johansson, General Secretary and Arne Schatten, senior advisor at the Norwegian Gastrointestinal Association



Mads Johansson
General Secretary



Arne Schatten
Senior Advisor

New Zealand

An invitation to EFCCA members to attend Camp Purple Live in NZ in 2025

With 2024 approaching quickly¹, there's one event on the horizon that is eagerly awaited by campers, volunteers and families alike – Camp Purple Live

Crohn's and Colitis NZ is extending an invitation to our fellow EFCCA members to attend our tenth annual Camp Purple Live in January 2025. This is an opportunity to learn first-hand about organising and running a camp, specifically designed for children and teens with Crohn's and Colitis. CCNZ will cover accommodation and catering expenses while at the camp, which will be held in Hunua, just outside Auckland.

This year, Camp Purple Live takes place at El Rancho in Waikanae, on the stunning Kapiti Coast in the Wellington region from 9 to 14 January. Camp Purple is set to make memories that will last a lifetime.

71 campers have registered to attend and will be arriving from all corners of the country. The Camp Committee has been very busy organising an exciting array of activities, from adrenaline-pumping outdoor adventures like kayaking and raft building, to more relaxed pursuits such as arts and crafts. All expenses for the children, including transportation to and from camp, are paid for by CCNZ.

One of the most valuable aspects of Camp Purple is the opportunity for campers to form lasting friendships. Through team building, group activities and shared experiences, participants will have the chance to connect with fellow campers, all of whom have Inflammatory Bowel Disease (IBD). These connections usually extend far beyond the camp.

In addition, Camp Purple Live is thrilled to welcome six "Experience Camp for a Day" families of children who are too young to attend but want to get a taste of camp life in one day.

Our dedicated volunteers, all of whom also have IBD, will attend an all-day training session on the 8 January. The day is dedicated to ensuring a smooth and safe camp experience, supported by a medical team of five doctors, five nurses and a child psychologist. One of the highlights of the training day will be a special guest speaker, Charlie Whitmarsh, a former camper. She will share insights on the importance of camp and the role it has played in her life. Her mother will also be speaking, providing perspective on the impact the camp has on campers' families.



Flights are booked, apparel is ordered, the program is set, name badges are made, our away day has been arranged and only have a few last-minute tasks to tidy up. 9 January can't come soon enough!

If you are interested in attending Camp Purple Live next year, contact Belinda Brown, CEO, at ceo@crohnsandcolitis.org.nz.

Share and learn from this extraordinary gathering in the lively heart of New Zealand and enjoy six days of New Zealand summer with our IBD community.

Want to find out more about Camp Purple Live?
https://youtu.be/uin88vOE7_s



Belinda Brown
Crohn's & Colitis NZ Charitable Trust

¹ Note from editor: the article was submitted in late December 2023



We innovate in gastroenterology
so patients can live in the moment



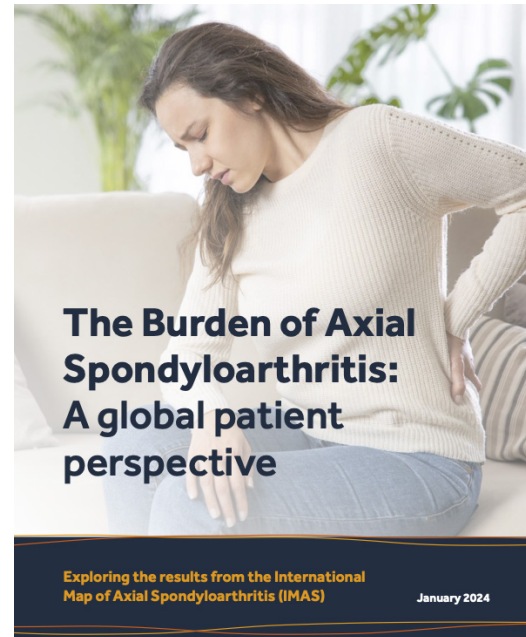
International study highlights link between IBD and axSpA

Joanne de Bry

Did you know that Inflammatory Bowel Disease is one of the conditions that also commonly affects people living with axial Spondyloarthritis (axSpA)? AxSpA is a painful, chronic, inflammatory disease that has no cure; it primarily affects the sacroiliac joints and spine. First symptoms tend to occur earlier in life, usually between the ages of 20 and 40. The main symptoms are lower back pain, sometimes with hip and buttock pain; pain and stiffness that get worse with rest, but better with movement, and often significant fatigue. AxSpA can also manifest in other areas of the body, such as the eyes (uveitis), other joints (peripheral arthritis) and, as already mentioned, in the bowel. If the symptoms above sound familiar, ask your doctor if it might be axSpA.

In recent results from the International Map of Axial Spondyloarthritis (IMAS), 14% of respondents reported also having IBD. We also know from IMAS that associated diseases, such as Crohn's and Colitis, are more common in people with more active axSpA disease. And alarmingly, 75% of participants reported their disease was not well-controlled. This underlines the need for multidisciplinary care to assess and treat the range of physical and psychological conditions faced by many people living with axSpA.

IMAS is a comprehensive survey of people diagnosed with axSpA covering many themes beyond the physical symptoms. The questionnaire collected information from 5,557 respondents from 27 countries across five continents. Its purpose is to better understand the impact and burden of living with the disease from the patient's perspective. By disseminating evidence of how people with axSpA experience the disease, ASIF aims to ensure this perspective is captured in health policy and treatment decisions.



In late January 2024, Axial Spondyloarthritis International Federation (ASIF) will publish a comprehensive report on the IMAS results. The burden of axial spondyloarthritis: a global patient perspective details the varied and far-reaching impacts of living with axSpA, including the associated physical and psychological conditions. It will be a tool for ASIF and its members to advocate for changes in health policy and treatment for people living with the disease around the world.

We know many people living with IBD will relate to the impact that axSpA has, not only on physical health but a range of other life-changing challenges. Respondents to IMAS reported delays in diagnosis; significant psychological distress; issues with working life; deterioration of relationships; difficulties in undertaking common daily activities; and living with the uncertainty of what the future holds, all negatively impacting their lives.

As a contributor to the IMAS global report, ASIF Trustee and person living with both axSpA and IBD, Andri Phoka commented: *“Living with both axSpA and IBD is not easy. Managing both conditions can be challenging as sometimes the solution for one aspect of one disease negatively impacts the other disease. I had to change many things in my life when I was diagnosed with axSpA and 15 years later I had to make more changes due to my IBD diagnosis. I've had to find new ways to manage both conditions, but it's not unachievable. The IMAS Global Report is an invaluable tool that brings the patient experience to the forefront and can be used to advocate for the changes needed to improve the lives of people suffering from axSpA and related conditions.”*

ASIF is a global umbrella organisation bringing together patient organisations working to support people living with axSpA. It is proud to support EFCCA's work.

To find out more about axSpA and ASIF's work, visit asif.info or follow us on social media. Read the IMAS Global Report on our website from 29 January.

“This underlines the need for multidisciplinary care to assess and treat the range of physical and psychological conditions faced by many people living with axSpA”



Together we are living innovation

We don't think it is good enough that countless people affected by immune-mediated conditions are still living with debilitating symptoms. That is why we are determined to change this. We are relentlessly searching for medicines to tackle the progression of the disease itself. We are driven by thinking about the positive impact this could have, not only in changing the lives of those affected, but also on their families, friends and societies in general.

European Disability Card

The European Disability Forum (EDF) welcomes the European Parliament's official position on the proposed Directive for a European Disability Card and a European Parking Card adopted by unanimity in [a vote at the Employment and Social Affairs Committee](#). The position clearly reflects the demands of persons with disabilities. It also means that negotiations between the EU institutions on the final text can now begin, the final phase of the EU decision-making procedure.

EDF thanks the European Parliament for actively involving organisations of persons with disabilities while drafting it. We especially welcome:

- the demand for the European Disability Card to grant temporary access to allowances, support and social security when moving for work and study.
- the provisions to access support when taking part in EU Mobility Programmes.
- the proposal to reduce the time of transposition and implementation of the European Disability Card – the Card must not take too long to become a reality.

This is, overall, an excellent position. EDF thanks the lead negotiator, MEP Lucia Ďuriš Nicholsonová and

all the Members of the European Parliament who advocated for the rights of persons with disabilities in this file.

EDF now calls on the negotiators from the European Parliament and the Council of the EU to achieve a speedy, ambitious agreement on the European Disability Card and European Parking Card. A deal without loopholes that ensures little delay between the publication of the text and its transposition and issuance of the Cards. The final text also needs to deliver ambitious Cards underpinned by funding and clear information in multiple languages on how to access their different benefits and discounts.

Yannis Vardakastanis, President of the European Disability Forum, said: *"We thank MEP Nicholsonová and all the Members of the European Parliament involved in advancing our demands in this file – the European Parliament proves, once again, to be on the side of persons with disabilities. We now ask for a strong and speedy agreement that ensures persons with disabilities can use these Cards as soon as possible!"*

For more information please visit:

www.edf-feph.org/parliaments-position-paves-the-way-for-ambitious-european-disability-card



What if there was the possibility of predicting and preventing IBD? Would you accept it? If yes, to what extent?

A survey about perceptions regarding the possibility of prediction and prevention of IBD

Inflammatory Bowel Disease encompasses a set of chronic diseases, which are incurable and have a significant personal and social impact. It mainly affects young adults and can have devastating consequences in terms of quality of life, healthcare resource consumption and productivity. While many advances have been made towards improving the care of IBD patients, there still remains a therapeutic ceiling and many patients, regrettably, still suffer from disability caused by the disease. Furthermore, the incidence of IBD continues to rise across the world, especially in areas where access to care may not be universal. Therefore, besides improving the treatment of IBD and continuing to search for its cure, it is equally important to predict and prevent new cases of IBD.

It is currently recognised that inflammatory bowel disease has a pre-clinical phase that begins many years before clinical diagnosis. Although the initial events of immune dysregulation leading to irreversible chronic gastrointestinal inflammation are currently unknown, they conceivably occur years before symptoms and diagnosis become evident.

However, all therapeutic interventions in IBD target an already established disease and even the most potent agents cannot prevent or reverse chronic damage often present at diagnosis. Therefore, to truly change the natural history and long-term consequences of the disease, intervention should occur at an earlier stage, targeting the processes that drive the disease from a pre-clinical phase (before the development of symptoms and gastrointestinal damage) to a clinical phase (when symptoms and gastrointestinal damage are already present).

However, even if IBD can be predicted and prevented, the decision to undergo a series of predictive tests or adopt preventive measures, which may involve risks, can be complex. To our knowledge, no study has been conducted on asymptomatic individuals at high risk of developing IBD to understand the factors that could be involved in the decision to adopt preventive measures or undergo predictive tests. However, this is a crucial aspect, because understanding people's perceptions of risks and benefits and their willingness to undergo predictive or preventive methods is essential for the future design and implementation of screening and prevention strategies.

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In this regard, we have developed a study aimed at asymptomatic individuals at high risk of developing IBD (first-degree relatives of patients with Crohn's Disease or Ulcerative Colitis) and prospective parents with IBD to assess the most important factors in the decision to undergo predictive tests or adopt preventive measures for IBD.

A survey has been distributed and we already have collected some responses from people from more than 25 different countries. However, we need to have your opinion and your first-degree relative opinion on this topic. Opinions may vary, depending on perception of disease, knowledge about disease and fear of tests or interventions.

We need to hear as many voices as possible, especially from first-degree relatives of people with IBD.

You still have time to participate, encourage your relatives and be part of IBD research!

To do so, you just have to fill out this survey. It is available in different languages and will take no more than 10-15 minutes:

For any questions related to this study, you can contact the Principal Investigator:
joana.torres@hbeatrizangelo.pt

Help us make a difference! IBD research counts on you!

Md. PhD Joana Torres
Md. Ana Catarina Bravo
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Hospital da Luz

Portuguese



French



Portuguese-Brazil



Spanish



English



Danish



Italian



German



EFCCA routinely shares information from external partners aimed at promoting clinical trial awareness. The activities and content below are not affiliated with EFCCA. However, EFCCA invites you to browse through the below sponsored clinical trials that might be of interest to the IBD patient community.

The Yellowstone Crohn's Disease Clinical Research Program

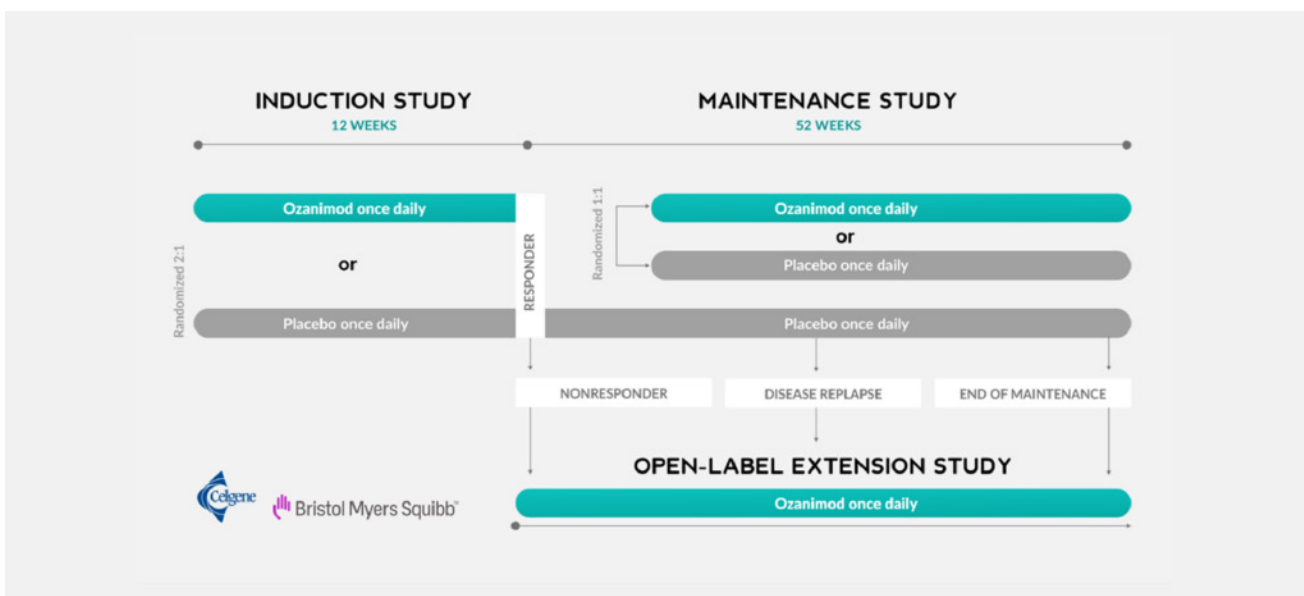
The YELLOWSTONE Program is a series of Phase 3 clinical studies for people with moderately to severely active Crohn's Disease. These studies will evaluate the safety and effectiveness of an oral investigational study drug (ozanimod) which is taken once daily.

Ozanimod is not a biologic, injection or infusion. Ozanimod is an immune regulator designed to change the body's immune system response (when the body defends itself), potentially reducing inflammation and overall disease activity. The goal is to potentially help people living with this disease reduce symptoms (remission/response).

The YELLOWSTONE Program is made up of four clinical studies:

- The Induction 1 study is a phase 3 study and is currently accepting new Crohn's disease patients. Participation in the Induction 1 clinical study is expected to last 12 weeks (3 months). The Induction 2 study has met enrolment.
- Depending on response and the study doctor's recommendation, participants may have the opportunity to continue participation in the
- YELLOWSTONE Maintenance or YELLOWSTONE Open-Label Extension Studies

For each study, patients can expect to have visits with a doctor every 1-3 months. The length of each visit may vary.



Who is eligible to participate in the YELLOWSTONE Program?

Crohn's Disease patients may be eligible to participate in these clinical studies if they:*

- Are 18 to 75 years of age
- Have been experiencing signs and symptoms of CD for at least 3 months where the diagnosis has been confirmed by endoscopy (a procedure where a doctor looks inside your digestive tract using a device called an endoscope).
- Have not improved on or have not been able to tolerate, at least one prior Crohn's disease medication such as corticosteroids or immunomodulators

* Other eligibility criteria apply

Only a study doctor can determine if a person meets all eligibility criteria.

To learn more about the YELLOWSTONE Program of studies visit:

Induction Study 1: <http://bit.ly/NCT03440372>

Is the YELLOWSTONE clinical trial available in my country?

There are YELLOWSTONE clinical trial sites around the world. For more information on clinical trial sites in the countries listed below, please visit ClinicalTrials.gov or <https://chorobacrohna-badanie.pl> (for Poland), or email Clinical.Trials@bms.com

This trial is recruiting in the following countries: Argentina, Australia, Belgium, Bulgaria, Canada, Chile, Croatia, Czech Republic, France, Georgia, Germany, India, Ireland, Israel, Italy, Korea, Republic of, Latvia, Mexico, Moldova, Poland, Romania, Saudi Arabia, Serbia, Spain, Switzerland, Turkey, Ukraine, United Kingdom, United States.





EFCCA

European Federation of Crohn's
& Ulcerative Colitis Associations

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