

EFFCCA

magazine

ISSUE 01 | FEBRUARY 2025

UNITING THE IBD COMMUNITY

Treating IBD: Current drugs are only partially effective, how can we do better?

Prof. Claudio Fiocchi,
Lerner Research Institute

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ON THE COVER

**Building Momentum:
LATAM IBD Group
Leading the Way**

Beatriz Capdevielle

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Foreword



As we step into 2025, I am reminded of the remarkable resilience and determination of our EFCCA community. Each year, we come together to confront challenges, push boundaries, and champion the voices of people living with IBD. While our CEO, Luisa, has outlined in this issue the incredible milestones we've achieved, I would like to reflect on the principles that guide us: collaboration, innovation, and the unwavering belief in the power of patient voices.

2024 reminded us that progress is not just about meeting objectives—it's about building a network of empowered individuals and organisations that can inspire change at every level. Whether through the DIVA Academy, groundbreaking research initiatives, or strengthening regional collaborations, EFCCA has shown what is possible when we unite around shared goals.

The road ahead will not be without challenges, but I am confident that the collective strength of our community will lead us to even greater achievements. Together, we are shaping a future where people with IBD are heard, respected, and supported—wherever they are in the world.

Thank you for being an integral part of this journey. Let's make 2025 a year of even greater impact.

*Salvo Leone,
EFCCA Chairperson*

Editorial



Putting together this edition of the EFCCA Magazine has been a rewarding experience, offering a glimpse into the incredible work being done by many in our community. Every article and story reflects the dedication and strength of our members, and it's been a privilege to bring these voices together in one place.

On our cover, we feature Beatriz Capdevielle, EFCCA's LATAM Coordinator and founder of Vivir con Crohn y CUCI A.C. Beatriz is a driving force behind IBD advocacy efforts in Latin America, helping to build stronger networks and pushing for better care in the region. Her commitment is a great example of how much impact one person can have in mobilising others and creating real change.

This issue also highlights inspiring initiatives from our members—from youth-led activities in Finland to impactful awareness campaigns in Norway. It's encouraging to see how each of you is finding ways to support people living with IBD and challenge the stigma surrounding it.

One story that really struck me was my conversation with Nikhil Jayswal from India. His experience living with IBD in a country where access to care is limited and stigma is high was both eye-opening and heartbreaking. Hearing about his struggles—and his determination to advocate for others—was a powerful reminder of why our work is so important. There's still so much more to be done to ensure every patient has access to proper care and support, no matter where they live.

I hope this issue sparks new ideas and strengthens our shared commitment to improving the lives of people with IBD.

*Isabella Haaf,
EFCCA Head of Communication*

Celebrating 2024: Milestones Achieved and Exciting Skylines for 2025

As we reflect on the achievements of 2024, it's clear that last year has been a transformative one for our community, with significant milestones reached and new initiatives that will shape our future. We've worked together to create meaningful progress in advancing our mission, and with each success, we have set the stage for an even more impactful 2025. Let's take a moment to celebrate what we have accomplished, and to look ahead to the exciting journey that lies before us.



2024 Highlights: A Year of Progress

1. UEGW Conference:

The UEGW Conference was a major success this year, bringing together leading experts, researchers and healthcare professionals from around the world. It was a platform for sharing cutting-edge research and clinical innovations in the field of gastroenterology, with our community making its mark in discussions that will shape the future of IBD care.

2. DIVA Academy:

The launch of the DIVA Academy marked a new era for our community. Through tailored educational programs and resources, we've been able to empower healthcare professionals and IBD specialists, fostering continuous learning and growth in the field. The academy has been important in strengthening the expertise within our ranks, preparing our members to tackle the challenges of the future.

3. Two New Horizon Projects:

We're proud to announce that we've successfully secured two new Horizon projects, further solidifying



our position at the forefront of IBD research. These projects promise to bring innovative solutions and collaborative opportunities to improve patient care and management strategies across Europe and beyond.

4. DIVA Labs:

The establishment of DIVA Labs has provided a cutting-edge space for experimental research and clinical trials. This initiative has already shown great promise in advancing the understanding of IBD and testing new treatments, positioning our organisation as a leader in transforming scientific knowledge into practical, life-changing applications.

Empowering Patients Through Innovation



- New DIVA implementations
- Strategies for national-level adoption
- Key topics like patient testimonials, the ChatIBD platform and personalised clinical trial reports

5. World IBD Day in Mexico:

The celebration of World IBD Day in Mexico was a highlight for 2024, raising awareness of IBD issues and uniting our community to amplify the voices of those affected by these conditions. The event brought together 6 patient associations, the founders of World IBD Day, local stakeholders and healthcare providers, creating an atmosphere of solidarity and collective action and paving the way for a stronger and more effective community aiming at improving quality of life and care in the region.

6. LATAM Group – Latin American Patient Associations Group

Our growing LATAM group has fostered a sense of community and collaboration across Latin America, bringing together IBD patient associations, healthcare professionals and stakeholders interested in investing in the region and supporting our patients' community. The development of this network is vital for expanding our global reach and ensuring that we can share our expertise and insights with even more people who need it.

7. Establishment of the Purple Team & Constitution Renewal:

The creation of the Purple Team composed of people representing the different regional areas of the EFCCA community aiming at the renewal of our Constitution

was a landmark achievement this year. With the energy and expertise of this group, we are poised to refresh and modernise our organisational framework, ensuring that we remain adaptable and responsive to the evolving needs of our community, with special attention to the agreed internationalisation of our organisation.

8. The Re-Born Youth Group (YG):

A special mention goes to the revitalisation of our Youth Group. With renewed energy and a clear vision, the YG is embracing a more impactful role in shaping the future of our organisation. Their dedication and fresh perspectives are invaluable, and we're excited to see them continue to grow and lead initiatives that resonate with younger generations.



9. New Look of our Magazine:

In 2024, our magazine underwent a complete overhaul, reflecting our evolving mission and vision. The new design is more engaging, accessible and informative, ensuring that our members stay informed on the latest developments, breakthroughs and best practices in the IBD field.



Looking ahead to 2025: embracing new challenges and opportunities

As we step into 2025, our path forward is filled with exciting projects and initiatives that will build on the successes of the past year and elevate our work to new heights. Here's a look at the key steps we're taking:

1. Renewal of the Constitution:

The renewal of our Constitution is a priority for the coming year. The Purple Team has started working to ensure that the proposed changes reflect our evolving needs. This updated framework will be presented at our next General Assembly, and we are confident that it will enhance our organisation's responsiveness, inclusivity and effectiveness.

2. DIVA's Expansion and Pilots in New Countries:

2025 will see DIVA's expansion into pilot countries, with a range of new features and innovations aimed at improving the diagnosis, treatment and management of IBD. These country-specific initiatives will bring even more impactful solutions to communities that need them most while strengthening our global network.

3. ECCO Event in Berlin (February 2025):

The ECCO event in Berlin is an exciting opportunity that will bring together the world's leading experts in IBD care to debate the results of our study on Patient Preferences regarding treatment options, developed in partnership with KU Leuven. We look forward to engaging with our colleagues and sharing new insights that will shape the future of IBD research and patient care.

4. H2020 Events and Member Involvement:

2025 will see us more deeply involved in several H2020-related events, with our members playing an integral role in collaborative research and innovation. These events will offer fresh opportunities for cross-border cooperation, contributing to the advancement of IBD research and the development of new therapies.

5. Central Asian Countries Development:

We're excited to announce the continued expansion of our work in Central Asia. Over the coming year, we'll be building stronger partnerships with countries in this region, providing essential resources and knowledge to support local healthcare professionals and patients.

6. Strengthening Partnerships with N-ECCO:

Our partnership with N-ECCO will be crucial in 2025, with a focus on integrating IBD nurses into our broader network. This collaboration will help us ensure that nurses play a pivotal role in improving patient outcomes and enhancing the overall care experience. We aim to help our members to foster national debates on the topic, with the support of ECCO team and experts.

7. Revamped Youth Group (YG):

The re-establishment of the Youth Group as a formal part of our organisational structure is a significant step. In 2025, we will officially launch new initiatives driven by the Youth Group, ensuring that younger generations continue to have a voice in shaping the future of our field.

8. A New Website:

A revamped website will be launched in 2025, offering a dynamic and user-friendly platform for our members. This new digital presence will better serve our community by providing access to the latest resources, events and discussions in a more streamlined and accessible format.

A Year of New Opportunities and Impact

As we look ahead to 2025, it's clear that this year will be filled with new challenges and opportunities. We're energised by the momentum we've built and are confident that, together, we can continue to make a lasting impact on the global IBD community. Let's take on the new year with enthusiasm, collaboration and the determination to create a healthier, more inclusive future for all.

UNITED WE STAND
Luisa Avedano, EFCCA CEO

EFCCA at UEG Week 2024: Connecting and Collaborating

Last October, EFCCA once again had the privilege of participating in UEG Week, the important gathering of digestive health specialists from around the world. As always, our stand served as a vibrant hub for connecting with physicians, researchers, industry representatives and patient advocates.



UEG Week offers a great opportunity to present EFCCA's work, exchange ideas and strengthen collaborations with key stakeholders. Throughout the event, we met many inspiring individuals who share our commitment to improving the lives of people with IBD and discussed ongoing and potential collaborations.

We look forward to continuing the conversations started during UEG Week and building on the relationships formed at this exceptional platform. Thank you to everyone who visited our stand and shared their insights - together, we can make a difference!



Patients' Voices in Health Technology Assessment: EFCCA workshop

During UEG Week 2024, EFCCA proudly hosted a groundbreaking workshop: **Patients' Voices in Health Technology Assessment (HTA)**. This event marked a significant step forward in ensuring the voices of patients with IBD are heard and valued in the assessment of new treatments and health technologies.



The workshop brought together physicians, patients and key stakeholders to engage in lively discussions about the evolving role of patients in HTA. The message was loud and clear: **patients must not miss the opportunity to provide their insights.** As new HTA regulations emphasise the importance of patient perspectives, our input is now a critical component in shaping how new drugs and health technologies are evaluated.

For too long, patients' lived experiences have been underrepresented in the decision-making processes that directly affect their lives. This workshop was a reminder that our voices are essential - not only for improving individual treatments but also for transforming healthcare systems to better address the realities of chronic conditions like IBD.



Hosting this workshop during UEG Week is an achievement worth celebrating. UEG Week is renowned as the leading event for specialists in digestive health, drawing experts from around the world to discuss innovations and challenges in the field. Securing a space at such a prestigious forum underscores the growing recognition of the critical role patients play in advancing healthcare.

The discussions during the workshop didn't just emphasise the

importance of patient involvement; they also called us to action. *"It's time to step forward, share our experiences and ensure that our insights shape the future of health technologies"* said Salvo Leone, EFCCA Chairperson, concluding the event. Through initiatives like this, EFCCA is paving the way for meaningful patient involvement in healthcare decision-making because nobody understands the impact of treatments better than those who live with IBD every day.

A woman in a white lab coat is crouching in a laboratory, looking at a whiteboard. The lab is filled with various pieces of scientific equipment, including refrigerators and shelving units. The lighting is dim, with a blue tint. The Pfizer logo is in the top right corner.

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DIVA LABS N.1

Second Module of the Diva Academy

On 14 December 2024, following the launch of the DIVA Academy in May 2024 and the completion of its first online module, we organised the first in-person Lab in Madrid as part of the second module of the **DIVA Academy: Unlocking the Power of Data Insights for Added Therapeutic Value**. This training programme is designed to enhance the use and understanding of DIVA, EFCCA's AI methodology. A group of five students participated in a four-hour workshop, led by Roberto Saldaña, Innovation and Patient Engagement Coordinator at EFCCA.



The first module covered the theoretical aspects of DIVA, including its functions and characteristics. The in-person event focused on national customisation, presenting

and exploring new features of DIVA and providing a platform to discuss strategies for its nationwide adoption.

New features introduced

The first new feature introduced was the integration of a **national ChatIBD platform** within the most commonly used communication channels of national patient organisations. ChatIBD is designed to serve as a reliable and trustworthy source of information for patients, offering a credible alternative to other AI-based sources where misinformation can often be encountered.

A second new feature, **Patient Testimonials**, can also be implemented at the national level. A pilot version was successfully conducted with our members in Mexico and demonstrated its potential to support the IBD community in identifying and addressing unmet needs. This

feature allows patient organisations to respond to targeted questions, enabling the collection of valuable data directly from the community. The collected information is organised and displayed through visual formats, simplifying analysis and facilitating following-up actions.

The final feature discussed was **the personalisation of clinical trial reports** based on patients' needs.

Clinical trials can end prematurely for various reasons, one of which may be that they do not address the aspects that matter most to patients, such as their real needs. It also establishes clear criteria and provides researchers with the necessary support to enhance trial success rates.

For each feature, Roberto and the group of students engaged in interactive discussions, brainstorming ideas and exploring each topic from various perspectives to determine how to implement it at the national level. They also started planning future activities to bring these ideas to life. It was inspirational to see the enthusiasm and commitment to activities that will ultimately benefit the entire community!

In 2025, we plan to hold a second Lab for the remaining group of students. Stay tuned for more updates.

If you would like to learn more about the DIVA Academy or are interested in enrolling, please send an email to mariastella.derocchis@efcca.org

A Participant's Perspective

Szabolcs Szentmihályi, a participant from EFCCA's Hungarian member association, shared his reflections on the first in-person DIVA Lab, highlighting its innovative impact on patient advocacy.

"The DIVA tool captured my imagination from the very first moment I saw it," Szabolcs remarked. He appreciated the workshop's practical focus, especially exploring how DIVA could be integrated into their national website and using patient testimonials to engage the community. Discussions on national implementation strategies were particularly inspiring.

Szabolcs sees significant potential for DIVA within his organisation. *"I plan to discuss with our team how we can implement DIVA on our website and create more*

visibility around it," he noted. However, he emphasised the need to consider legal aspects, especially regarding patient data and the use of Chat IBD insights.

One feature that stood out to him was the Chat IBD function. *"During our National IBD Day, dietary concerns are often a big topic. I was impressed that Chat IBD could provide clear, research-based answers directly from studies and papers,"* he explained. He believes this tool will resonate with their community once localised into Hungarian.

"I'm truly happy EFCCA made this initiative happen," Szabolcs concluded, recognising the DIVA Lab as a meaningful step toward empowering patient organisations through innovative technology.

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AGOMAB
THERAPEUTICS

Building Momentum: LATAM IBD Group Leading the Way

The success of the "Uniting for Access to IBD Care" Roundtable in Mexico City during [World IBD Day 2024](#) set the stage for something bigger—the launch of EFCCA's LATAM IBD group. Since May, this dynamic network of patient associations and medical professionals across Latin America has been making significant progress in improving the lives of people living with IBD.

A standout initiative was the 5 December webinar, "**LATAM Unida por la EII**" hosted by Latin American IBD associations. The event featured Dr. Beatriz Gros who presented on International Guidelines for IBD. The session attracted 140 participants and was later [shared on YouTube](#) to reach a wider audience. Feedback was overwhelmingly positive—81% of attendees appreciated the presentation, and 79% reported an improved understanding of IBD.

The enthusiasm generated from this event led to a follow-up video conference on 8 January 2025, where participants agreed to continue hosting webinars every two months. These sessions will focus on crucial topics, such as "Diet and Nutrition" for people with IBD, engaging both healthcare professionals and patients to share valuable insights and strengthen networks across the region.

Further advancing these efforts, a key meeting took place on 10 January in Mexico City. Roberto Saldaña,



representing EFCCA, met with Dr. Guillermo Veitia, president of PANCCO, and Dr. Jorge Luis de León from GAICCU. This meeting laid the groundwork for exciting joint projects, including the creation of a regional IBD database. This database will track symptoms, treatments and quality of life, helping improve clinical care.



Beatriz Capdevielle stands out as a dedicated IBD patient advocate and key contributor to the success of EFCCA's LATAM initiatives.

Her commitment, combined with her valuable network of regional contacts and EFCCA's support, has been instrumental in transforming the vision of a united Latin American IBD community into a tangible reality. Beatriz's collaborative spirit and leadership have helped build bridges between patient associations, healthcare professionals and researchers across Latin America. Beatriz continues to inspire and empower others, ensuring that the patient voice is at the center of every initiative.

Looking ahead, the group is already planning a brainstorming session to explore more collaborative opportunities. By uniting patient associations, healthcare professionals and researchers, the LATAM group is building a strong, supportive community dedicated to addressing IBD challenges with practical, patient-centered solutions.

Thanks to EFCCA's support and the hard work of the LATAM team, this growing network is already making a real difference-and they're just getting started.

Beatriz Capdevielle
EFCCA LATAM Coordinator
Founder of Vivir con Crohn y CUCI A.C

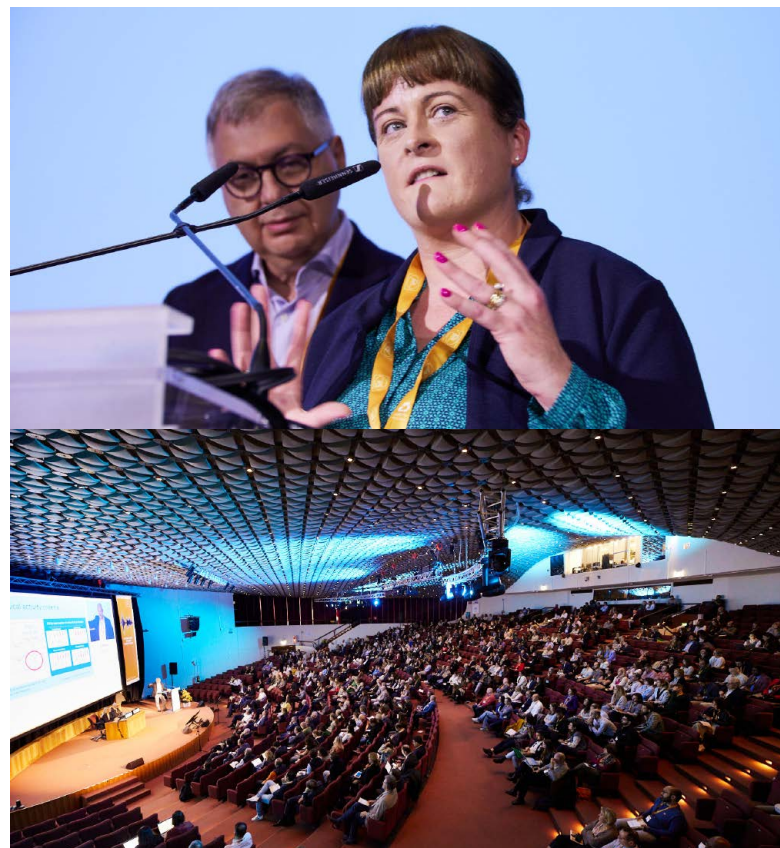


Left to Right: Roberto Saldaña, Beatriz Capdevielle, Dr. Guillermo Veitia and Dr. Jorge Luis de León.

Highlighting Patient Voices at the Falk Symposium

On 9 November 2024, EFCCA's Vice President, Ciara Drohan, represented the patient perspective at the Falk Symposium 238 in Florence, Italy. The event, titled "**Immuno-Mediated Diseases of the GI Tract: Where do we stand?**", brought together leading experts to discuss advances in the field.

Ciara joined Dr Fernando J. Magro in the session "**TANDEM: Discrepancy between treatment goals of physicians and patients in IBD**", emphasising the importance of aligning treatment strategies with patients' real-life priorities and needs. The symposium also covered critical topics such as the microbiome, innovative therapies and dietary approaches, underscoring the significance of collaborative efforts in improving IBD care.

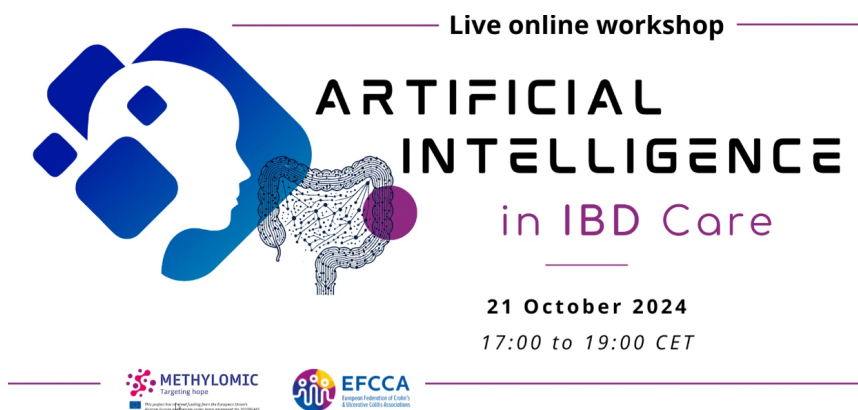


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Exploring the Intersection of AI and IBD Care: Highlights from METHYLOMIC Workshop

On 21 October 2024, EFCCA, in collaboration with the METHYLOMIC consortium, hosted the *Artificial Intelligence (AI) in IBD Care Workshop*. This pivotal event brought together researchers, clinicians and patient representatives to explore the potential of AI-driven advancements in Inflammatory Bowel Disease (IBD) management. The workshop, moderated by Antonella Cardone, opened with an overview of the METHYLOMIC project, a Horizon Europe initiative aimed at improving treatment for immune-mediated diseases like Crohn's disease, rheumatoid arthritis and psoriasis through the identification of predictive biomarkers such as DNA methylation.

Three insightful presentations followed, each offering its perspective on how AI is revolutionising IBD care. Dr Sarah van Zon introduced the OmiCrohn Study, which focuses on the application of next-generation sequencing (NGS) and AI to predict therapeutic responses in Crohn's disease. By leveraging DNA methylation profiles, this groundbreaking research aims to transition from the traditional trial-



and-error approach in treatment selection to AI-guided therapy. The study's innovative trial design promises to assess whether this AI-driven method can outperform conventional physician-led strategies, potentially reshaping personalised medicine in IBD.

In his presentation, Dimitrios Nikolakis delved into the application of AI in identifying anti-fibrotic treatments through transcriptomic data analysis. With fibrosis being a critical unmet need in IBD care, his research utilises AI-powered bioinformatic tools to uncover potential drug candidates that target fibrosis at the molecular level. By identifying key pathways and gene targets, this approach

accelerates the development of therapies addressing scarring and tissue damage, paving the way for a more comprehensive treatment strategy beyond inflammation control.

Finally, Roberto Saldaña provided insights into how patient organisations are integrating AI into their initiatives. From actively listening to patient testimonies to tailoring clinical trial information, these applications of AI offer a personalised approach to understanding and addressing patient needs. By simplifying access to complex data, AI ensures that patients remain at the centre of research and innovation.

The workshop concluded with a Q&A session, where participants engaged in discussions about the challenges and future opportunities of AI in IBD care. The event underscored the transformative potential of AI in advancing scientific understanding and also in enhancing patient

engagement and care delivery. As the METHYLOMIC project continues its journey, events like this serve as a vital platform for collaboration and innovation in the fight against IBD.

To watch the full workshop, click [here](#).

1st GlycanTrigger Patients Symposium

On 19 November 2024, EFCCA, in collaboration with SPI (Sociedade Portuguesa de Inovação), organised the inaugural Patients Symposium, part of the GlycanTrigger Horizon Europe Project. This two-hour online event brought together patients, experts and healthcare professionals to deepen understanding of IBD and foster patient engagement.

The first hour featured a webinar by Dr. Joana Revés (Hospital Beatriz Ângelo), addressing risk factors, prevention strategies and patient counseling in IBD management.

This was followed by a co-creation workshop led by Prof. Guendalina Graffigna (miGut-Health project), who highlighted the critical role of nutrition and stress in IBD progression. The session also included personal stories from Candida Cruz, Vice-President of APDI, and Filipa Cunha, APDI board member and EFCCA Youth Group, who shared their experiences as IBD patients, the need for better patient education and the vital role of healthcare professionals in supporting patients.

In the second part of the symposium, Dr. Joana Torres (Hospital da Luz Learning Health) discussed the importance of health literacy in empowering patients to make informed decisions and engage actively in their care. She shared strategies for improving health literacy, including fostering open communication and keeping informed through reliable support groups, such as patient organisations.

Alexandra Roventa and Olivera Culibrk (EFCCA Youth Group) offered their personal insights on managing IBD and the clarity of available information. They discussed helpful resources, tools they wish were available, and challenges in using them, underscoring the need for improved health literacy to support IBD patients.

This first GlycanTrigger Patients Symposium offered valuable insights and stimulated meaningful discussions, serving as a platform for knowledge sharing, linking research and patient care, and promoting dialogue within the IBD community. Many thanks to our members for their presence and active participation in the discussions!

To watch the full Symposium, click [here](#).



Finland

The Youth Team provides support and organises activities

When a young person is diagnosed with Inflammatory Bowel Disease, it can shake their whole world and identity. It is important that youngsters get support from peers who can relate to their life situation. That is why, at the Finnish association IBD ja muut suolistosairaudet ry, we organise several activities and events aimed at young people.

Our Youth Team consists of five trained volunteers: Lydia, Aleks, Enni, Eeli and Vilma – the current members of the Youth Team – are committed to supporting young peers with intestinal disease. They greatly help our association and offer us new insights from a young person's perspective.

"It is important to have activities for young people so that they can talk to peers who are in the same age group. Becoming ill at a young age

is a different experience than being diagnosed with a disease later in life," explains Vilma and Aleks.

The members of the Youth Team participate in organising activities that are mainly aimed at people aged 18 to 35 years. People who fall into this age range may be studying, planning their future, working, starting a family, searching for their path in life and so on. "Young people tend to think about the future as well as their present challenges.

Mental health is also a common topic among them," Eeli mentions.

Volunteer work is not only about giving but also about enjoying what you do. "I became a volunteer because I had gotten peer support when I needed it. I wanted to provide the same support to others," Enni says. Lydia adds, "I especially like when I get to organise events and use my creativity."



Young people tend to think about the future as well as their present challenges. Mental health is also a common topic among them.

An annual weekend that gathers young adults with intestinal disease is an event where the Youth Team plays an invaluable part. They plan the activities for the weekend together with our staff and support the participants. The Youth Team also takes part in maintaining our server on Discord. All in all, having active volunteers is what enables us to arrange various youth activities. For that, we thank all the awesome members of our Youth Team!

Iiris Heikkinen

Assistant at IBD ja muut suolistosairaudet ry



Greece

Attending ISPOR Europe 2024 in Barcelona was a transformative experience, especially as the Hellenic Society of Crohn's disease and Ulcerative Colitis Patients (HELLESCC) had the opportunity to present four posters on critical topics for patients. These research efforts focused on the experiences of patients with Crohn's disease and Ulcerative Colitis in Greece, shedding light on the disease burden, unmet medical needs and treatment preferences.

At HELLESCC, we are honoured that one of these posters was recognised among the top 5% of participant submissions. This recognition reflects the importance of patient-centred research and the impact of amplifying the voices of those directly affected by IBD.

Our posters were:

- Disease Burden and Unmet Medical Need in Patients with Crohn's disease in Greece: A Cross-Sectional Patient Survey
- Treatment Preferences of Patients with Crohn's disease in Greece: A Cross-Sectional Patient Survey
- Disease Burden and Unmet Medical Need in Patients with Ulcerative Colitis in Greece: A Cross-Sectional Patient Survey
- Treatment Preferences of Patients with Ulcerative Colitis in Greece: A Cross-Sectional Patient Survey



ISPOR Europe 2024 was a powerful reminder of the ongoing work needed to bridge the gap between research and patient experience. The feedback, discussions and partnerships fostered during the conference will help guide future research initiatives and advocacy efforts, ensuring that patient needs remain at the forefront of healthcare innovation.

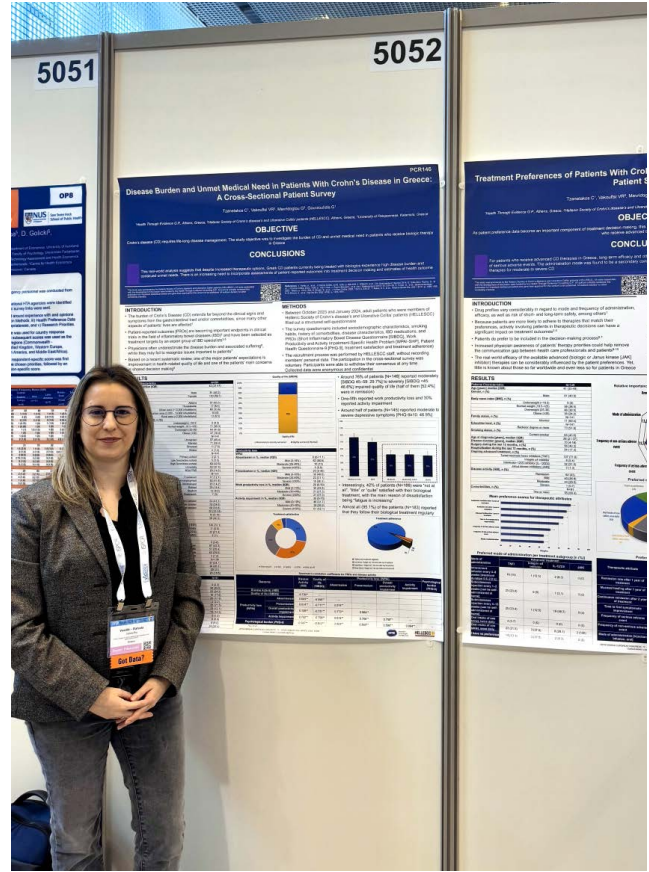
We are excited to continue sharing these findings with the EFCCA and other stakeholders. Together, we can work towards improving the lives of individuals with IBD, advocating for access to better treatments and, ultimately, better care.

For those who would like to see the full posters, please feel free to contact us via email at info@crohnhellas.gr.

Vasiliki Vakouftsi

EFCCA Youth Coordinator

President of Hellenic Society of Crohn's disease and Ulcerative Colitis' Patients (HELLESCC) and the President of Greek Patients' Association



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.

Belgium

We were unaware of how many IBD patients were among us. What about your country?

In Belgium, the last official scientific study on the number of IBD patients dates back to the early 1990s. At that time, 30,000 patients were recorded as living with the condition.

Given the slow but steady increase in visits to gastroenterology clinics for IBD, healthcare providers estimated a figure of 40,000 patients in the early 2000s. However, in the absence of updated Belgian studies, this estimate has been repeated for nearly 25 years.

That is until our association uncovered a study from 2021 (Kaplan et al.), which throws a cat among the pigeons. While, as recently as the last Belgian IBD congress on 24 November, gastroenterologists were still estimating the number of IBD patients in Belgium at around 40,000, Kaplan's study indicates that the actual figure had already more than doubled by 2020.

This suggests that by early 2025, the number of IBD patients in Belgium will likely reach 90,000!

In light of these new figures, the scientific community in several countries, including Belgium and France, expects that by 2030, approximately 1% of the population will be living with IBD. For Belgium, with a population of 11 million, this equates to 110,000 IBD patients.

In response, BIRD (Belgian IBD Research & Development) has decided to conduct its own study to count the number of IBD patients in Belgium officially. This effort aims to confirm the alarming increase and present these findings to our National Institute of Public Health (Sciensano).



Projection:
1 français sur 100 en 2030

Table 1 | Projected IBD population in selected industrialized countries of the Western world

Region	Prevalent IBD population			Increase 2010–2030 (%)
	2010 (0.5%)	2020 (0.75%)	2030 (1%)	
Australia	110,158	192,060	283,930	258
Austria	41,817	66,622	90,170	216
Belgium	54,477	86,535	119,040	219
Canada	170,024	282,630	402,853	237
Denmark	27,738	43,800	60,470	218
Finland	26,816	41,610	56,560	230
France	325,137	505,822	695,090	214
Germany	408,884	620,085	815,200	199 ^a
Greece	55,606	79,987	103,550	186 ^a
Hungary	50,000	72,712	90,920	182 ^a
Ireland	22,800	36,997	52,550	230
Italy	296,387	451,875	591,960	200
Netherlands	83,077	129,975	177,390	214
New Zealand	21,753	37,282	53,420	246
Norway	24,446	40,665	58,540	239
Portugal	52,865	76,462	98,320	186 ^a
Spain	232,884	350,332	462,740	199 ^a
Sweden	46,890	77,392	109,330	233
Switzerland	39,124	64,807	91,450	234
UK	313,831	504,180	702,770	224
USA	1,546,630	2,489,362	3,544,480	229

Kaplan et al. *Nat Rev Gastroenterol Hepatol*. 2021

And Belgium isn't alone in underestimating these figures. Not long ago, an article from a non-profit organisation active in IBD cited 300,000 patients in their country. Yet Kaplan's study estimates the actual number to be nearly double that.

In the image are the figures from the Kaplan et al. study for industrialised countries in the Western world.

So, are you, like us, surprised by these findings? Or were you already aware of the dramatic rise in this relentless disease in your country?

Xavier Donnet
President, Belgian French-Speaking Association
CROHN-RCUH

France

How Afa develops narrative approaches in Patient Therapeutic Education (PTE)

Medical care is increasingly patient-centred and is even beginning to evolve into a patient-care partnership. First, this is because science alone does not answer all the challenges in an IBD patient's life. Second, the human dimension must remain at the heart of the care relationship. Finally, the patient is the one who lives with the disease daily and is therefore best placed to provide insight into it.

One of Afa's core objectives is supporting patients, relatives and healthcare professionals. Its expertise in this area is widely recognised. Afa has been deeply involved in PTE for the past twenty years.

Patient Therapeutic Education, beyond its pedagogical intent, advocates and supports medical practices that challenge and enhance the care relationship for IBD patients. Narrative approaches—such as those pioneered by Rita Charon in the United States—share common values with PTE. Both approaches honour life stories, using them as a foundation and method for improving the care relationship between patients living with chronic diseases and healthcare professionals.

Encouraging patients to share their life stories about their experiences with the disease is a key starting point. It helps healthcare professionals learn from patients, establish a quality care relationship, and build trust, especially during the early stages of the educational process. For patients, this exercise also offers a learning opportunity, enabling them to discover new perspectives on their lives and experiences, which can positively impact their self-esteem.

It is therefore natural that Afa has embraced these narrative approaches to enhance the practice of PTE. Afa has established training programmes in narrative medicine for PTE experts, health professionals, patients, relatives and other stakeholders in healthcare.

This training programme is led by Dr J.M. Benattar, M. Schoene, and L. Flora of the CI3P (Centre d'Innovation du Partenariat avec les Patients et le Public), Faculty of Medicine, Université Côte d'Azur, in Nice. The programme consists of four virtual workshops, held one month apart and is inspired by narrative medicine principles. Each session begins with the presentation of a work of art—such as an excerpt from a film, book, or comic—that serves as a basis for shared reflections and discussions among participants. This is followed by an introduction to narrative medicine and practical exercises involving writing and sharing texts. At the end of each workshop, participants collaborate to produce a summary or joint conclusions from the session.



The success of this innovative training programme has brought together over 40 participants. Afa strongly supports the development of narrative approaches within the care relationship, aiming to improve support for IBD patients.



*Corinne Devos
President Afa Crohn RCH France*

Spain

ACCU España holds its 3rd Congress under the guiding principle "Together We Achieve More"

On 25 October, ACCU España hosted its 3rd ACCU Congress: Together We Achieve More at the Pablo Ruiz Picasso Cultural Centre in Torremolinos, Málaga, Spain. The event, held under the Honorary Presidency of His Majesty King Felipe VI, brought together more than 150 in-person attendees, while its live stream has already exceeded 1,000 views.

The Congress focused on crucial issues for individuals with Inflammatory Bowel Disease (IBD), their families, healthcare professionals and the broader community. Its main objective was to strengthen the role of patient organisations in healthcare and social systems. By including the patient voice in strategic discussions, ACCU España promotes increased participation in research, improved healthcare quality and adaptation to digital healthcare challenges.

The event began with remarks from Dr. Lucía E. Legarza, President of ACCU España, alongside Marta Huete, Deputy Mayor of Torremolinos, and other notable speakers such as Encarnación Peláez from the Health Department and Claudia Zambrana, President of ACCU León Pecasse Málaga. Their speeches highlighted the importance of collaboration in improving patient care and advocating for people with IBD.



The Congress opened with a panel on Preventive Medicine and Vaccination for People with IBD, featuring nurse Julián Ojanguren, Patient Relations Representative for the Spanish Vaccination Association (AEV), and Dr. Lucía E. Legarza, President of ACCU España. The discussion addressed the importance of preventive measures, accessibility and recent updates from Spain's Ministry of Health.

Immunology took centre stage during the presentation by Dr. Alfredo Corell, Professor of Immunology at the University of Seville, who offered an engaging exploration of the immune system and its interaction with lifestyle factors such as nutrition, physical activity and sleeping habits.

The third panel, Disability and Rights for People with IBD, moderated by sociologist Juanjo López, included lawyer and disability consultant Juan González-Badía, psychologist Carolina Medina, and social worker Josefa Bohórquez, both from the Málaga



Inclusiva Federation. The session discussed the distinction between disability and incapacity, their legal frameworks and the daily challenges faced by individuals living with these conditions.

The closing discussion, Coordination and Continuity: Transforming the Healthcare System, addressed the need for integrated, multidisciplinary approaches to managing chronic and complex illnesses. Moderated by Antonio Valdivia, Director of ACCU España, the panel featured various specialists: Dr. Yamile Zabana, President of GETECCU; Dr. Ester Navarro, President of GETEII; Dr. Marina Gras, GP of SEMERGEN; Dr. M^a del Carmen Ordóñez, Rheumatologist and IBIMA researcher; and Elena Sánchez, hospital pharmacist and SEFH representative.

The Congress was supported by GETECCU, GETEII, AEV, Málaga Inclusiva, SEFH, SEMERGEN, and IBIMA, with funding from the Ministry of Social Rights, Consumption and Agenda 2030, as well as AbbVie, Biogen, GSK, Lilly and Takeda. ACCU España extends its gratitude to all participants, collaborators and sponsors for their indispensable role in this event.

*Alex Herrera,
Confederación ACCU España
Crohn y Colitis Ulcerosa*



Norway

The Norwegian Gastrointestinal Association Wins Prestigious National Health Award for Groundbreaking Campaign

The Norwegian Gastrointestinal Association (Mage-tarmforbundet) has been awarded the prestigious Norwegian Health Award 2024, presented by the Minister of Health and Care Services, Jan Christian Vestre. This recognition celebrates their impactful campaign, "Not All Disabilities Are Visible," which has brought nationwide attention to the challenges faced by individuals with invisible disabilities and gastrointestinal diseases.

Redefining Accessibility Standards

The campaign's centrepiece has been the introduction of a new national signage standard for accessible (HC) toilets. The updated signs include the text "Not All Disabilities Are Visible" and depict a broader range of disabilities, going beyond the traditional wheelchair symbol. This effort aims to foster greater understanding and inclusivity for the 70–80% of invisible disabilities.

"This campaign has always been about more than just signs," said Mailiz de Ramecourt, Project Leader for the campaign. "They challenge societal attitudes, reduce stigma and create a more inclusive environment for the millions living with chronic conditions like Crohn's disease, Ulcerative Colitis, IBS and other gastrointestinal illnesses. A small change like this can have a profound impact on dignity, health and participation in society."



Honoured by the Minister of Health

"The approach is simple yet highly effective. Shopping centres, airports and amusement parks across Norway have already adopted the new signs, and they are now beginning to spread across Europe. It is, therefore, a great pleasure to announce the project "Not All Disabilities Are Visible" and the Norwegian Gastrointestinal Association as the

winner of the 2024 Health Award," elaborated Minister of Health and Care Services Jan Christian Vestre from the podium when he announced the Norwegian Gastrointestinal Association as the winner of the Health Initiative of the Year Award 2024 on 5 December, the UN's International Day of Volunteering.

The Health Initiative of the Year Award, presented annually, is a prestigious recognition of significant health projects led by voluntary organisations. The Norwegian Gastrointestinal Association joins a distinguished group of winners who have made meaningful contributions to public health.

Advocacy Beyond Signage

The Norwegian Gastrointestinal Association's commitment to improving toilet accessibility goes beyond this campaign. Over the past years, the organisation has been a vocal advocate for equitable access to public toilets:

- **2022:** Won a discrimination case against a regional bus company -AtB, which had closed toilets on long-distance buses, through Norway's Discrimination Tribunal.
- **January 2024:** Filed a complaint against Oslo Municipality for removing public toilets from parks and beaches.
- **August 2024:** Criticised major players in Scandinavian infrastructure – like the state-owned Norwegian railway company and other long-distance and regional rail services for operating long-distance trains with closed toilets, highlighting the impact on passengers.
- **Ongoing:** Campaigning against bus companies that introduced new long-distance buses without onboard toilet facilities.

This sustained advocacy underscores the organisation's mission to address one of society's most neglected issues: equitable toilet access.

Achievements and Impact

In just one year, The Norwegian Gastrointestinal Association has achieved incredible milestones:

- **National Adoption:** Major players such as Norway's largest shopping centres and amusement parks have adopted the new signage.
- **Increased Awareness:** The campaign has sparked widespread public discourse about invisible disabilities, with significant media coverage and social media engagement
- **Empowering Voices:** Through the accompanying campaign **#WhatPeopleDon'tSee**, over 20 individuals shared their personal stories, giving their faces to the invisible and highlighting the daily struggles of living with gastrointestinal diseases.

General Secretary Mads Johansson emphasised a key message when receiving the award, delivering a pointed reminder to the attending politicians:

"This campaign highlights a crucial issue. Access to toilets isn't about pipes and drains or mundane expenses—it's about health, dignity and inclusion. No matter how much we try to ignore these needs by closing or restricting access to toilets, they remain universal and essential. We must adapt our society to these needs, not the other way around."

From Grassroots to National Success

Despite being a small organisation with only 3.5 full-time staff, the Norwegian Gastrointestinal Association's efforts have led to significant changes. The campaign's success stems from close collaboration with passionate volunteers, members and supportive partners.



"Our team and volunteers worked tirelessly, contacting businesses, advocating for change and spreading the campaign's message through social media and media outlets," explains de Ramecourt.

The campaign also gained traction thanks to endorsements from high-profile advocates, such as Norwegian Member of Parliament Bård Hoksrud and TV personality Carina Olset Hovda, who lives with Ulcerative Colitis. Their voices helped amplify the message, reaching a broad audience and inspiring key stakeholders to join the cause.

A Broad Impact Beyond Gastrointestinal Diseases

While initially focused on gastrointestinal patients, the campaign's message extends far beyond this group. It addresses the needs of individuals with various conditions, including diabetes, fibromyalgia, endometriosis, ME and cancer patients experiencing fatigue or gastrointestinal challenges.

A Recognition That Inspires Inclusive Change

Winning the Norwegian Health Award is a testament to the Norwegian Gastrointestinal Association's relentless efforts to ensure that such fundamental needs are recognised and addressed.

With the award and national recognition, the Norwegian Gastrointestinal Association aims to inspire other countries to adopt similar standards and promote inclusive practices for all individuals, regardless of visible or invisible disabilities.

The campaign is originally an award-winning initiative launched by Crohn's and Colitis UK "Not every disability is visible"

Arne Schatten
Norwegian Gastrointestinal Association
(Mage-tarmforbundet)



This campaign highlights a crucial issue. Access to toilets isn't about pipes and drains or mundane expenses—it's about health, dignity and inclusion. No matter how much we try to ignore these needs by closing or restricting access to toilets, they remain universal and essential. We must adapt our society to these needs, not the other way around

Mads Johansson
General Secretary

Italy

Inflammatory Bowel Disease (IBD): discrimination and loneliness.

An investigation takes a snapshot of how hard school life is for young people with IBD in Italy

Discrimination, loneliness and shame

IBD students face a tough school life every day. Out of a sample of 362 young people with IBD, a quarter reported being teased at least once and/or to be direct victims of bullying due to their pathology. Among the main reasons for discomfort, the embarrassment about using school bathrooms emerges in over 60%, with access guaranteed for only half of the interviewees, even if 79% have communicated IBD pathologies to at least one person at school.

This is the snapshot provided by AMICI Italia IBD Patients Association that put the spotlight on a worrying phenomenon: the **discrimination** experienced in schools by Italian students with IBD.

The study revealed obstacles that go beyond medical difficulties, including social isolation, bullying and teachers' misunderstandings.

"Each student has the right to an education without discrimination," declares Salvo Leone, General Director of AMICI Italia.

"We ask schools and legislators to join us in building a school environment that focuses on respect and inclusion. This survey represents a starting point in breaking the silence on an issue that deserves attention and action. No young person should feel excluded due to their health condition" concludes Mr Leone.

"IBD represents an invisible disability that can become very burdensome, especially during school life." declares Dr. Lorenzo Norsa, a paediatric gastroenterologist at Buzzi Children's Hospital in Milan.

"Allowing unconditional and safe access to the bathrooms is an essential condition to guarantee emotional calmness for our young

people. Furthermore, absences linked to their IBD should not represent an obstacle to school success. The close collaboration between paediatric reference centres such as Buzzi and patient associations such as AMICI is essential to raise awareness among the institutions and the community."



IBD represents an invisible disability that can become very burdensome, especially during school life.

*Dr. Lorenzo Norsa
Paediatric Gastroenterologist at
Buzzi Children's Hospital in Milan*



We ask schools and legislators to join us in building a school environment that focuses on respect and inclusion. This survey represents a starting point in breaking the silence on an issue that deserves attention and action. No young person should feel excluded due to their health condition.

*Salvo Leone
General Director of AMICI Italia*

How to change the situation

AMICI Italia launches an urgent appeal to the Minister of Education, Giuseppe Valditara, to the Minister for Disabilities Alessandra Locatelli and to the schools to take concrete measures to protect IBD students' rights and well-being.

These are the proposals:

- **Training for teachers:** Raising awareness among school staff about the specifics of IBD and more generally on chronic conditions.
- **Personalised educational plans:** Ensure support for those who face frequent absences or limitations.
- **Anti-bullying campaigns:** Involving students and families to promote empathy and inclusion.

The **Psychological Burden:** The challenges faced by IBD students are not just physical, but even emotional. Many of them feel isolated from their peers and ignored by adults often perceiving school as a source of stress rather than a place for learning. This condition has a profound impact on self-esteem and psychological well-being, fueling a sense of inadequacy and loneliness.

*Cristiano Consorte
AMICI Italia*



**We innovate in gastroenterology
so patients can live in the moment**



Poland

"IBD Vacation" in the mountains

One hundred and fifty people from all over Poland—teenagers and adults alike—took part in a week-long mountain vacation at the turn of August and September 2024, organised by the "J-elita" Society.

One hundred and fifty people from all over Poland—teenagers and adults alike—took part in a week-long mountain vacation at the turn of August and September 2024, organised by the "J-elita" Society. For more than 12 years, "J-elita" has been providing recreation and integration opportunities for people living with IBD in the highest Polish mountains—the Tatras. This year's record attendance was achieved thanks to funding from a government agency; all participants with disabled status were able to join the trip free of charge.

As usual, we divided ourselves into several groups. The most active among us hiked along mountain trails and conquered numerous peaks. Living with IBD doesn't necessarily have to hinder such adventures! Rising on the Slovakian border with Poland is Kriváň (2,495 metres above sea level), one of the highest mountains in the Tatras which two centuries ago was a gold mine. The hikers' reward for the five-hour climb up its trails was a truly magnificent view from the top. On another day, climbing enthusiasts tackled Siwy Wierch (1,805 metres above sea level) and its rock chimneys, equipped with chain guardrails embedded in the walls.

Fans of more leisurely recreation opted for walks, easy treks with cable car rides, swimming in the guesthouse pool and trips to the nearby aqua park with its thermal baths. Those unafraid of heights explored Slovak trailways, featuring hanging bridges, catwalks and ladders in rocky gorges. Adventurers could also jump into a pontoon and float down the 15-kilometre-long gorge of the Dunajec River, right below picturesque mountain peaks. Everywhere we looked, we were surrounded by beautiful nature, rocky summits, green slopes and crystal-clear mountain ponds and streams.



In the evenings, we all came together for bonfires and parties, accompanied by a folk band and delicious regional dishes. Late-night conversations about overcoming everyday challenges related to the disease and the friendships forged during the trip were the true highlights. No one understands a person with IBD or a caregiver of a sick child better than another person with IBD or caregiver. After all, those with similar experiences know best how to support each other.

"J-elita" trips create a safe environment for people. We always have a gastroenterologist and a psychologist with us who are available to provide consultations for anyone in need.

The wonderful atmosphere and all these experiences mean that every year our trips attract more and more eager participants. We look forward to meeting again in the same place in January 2025.

Jacek Hołub
J-elita Society



Czech Republic

Active Participation in the XXII Intensive IBD Course for Physicians and Nurses

On 12–13 December 2024, the XXII Intensive IBD Course for Physicians and Nurses took place in Prague, organised by the IBD Working Group of the Czech Society of Gastroenterology (ČGS ČLS JEP).

Our representatives Martina Pfeiferová and Lenka Slabá actively contributed to the Friday training session for nurses. The session was opened by MUDr. Petra Matějková, Ph.D., who also moderated the discussions.

Martina Pfeiferová began the session with a presentation titled What Patients Expect and Need from Healthcare Professionals. She was followed by Lenka Slabá, who introduced attendees to the activities of the patient organisation Pacienti IBD.

The presentations sparked an engaging discussion, and healthcare professionals had the opportunity to take home patient publications and other related materials.



Pacienti IBD

Austria

40 years of support for people with IBD

Last autumn, we celebrated the 40th anniversary of our patient organisation, ÖMCCV – the Austrian Crohn’s Colitis Association. The review of these 40 years was captured in a video that included special photo moments. Many remarkable individuals have supported us over the years, a wide range of outstanding events have been organised and smaller initiatives have been arranged, all reflecting our motto: “Affected persons help affected ones” and showing everyone “You are not alone.”



In the second part of the video, individuals responded to our call by sharing their thoughts on the importance of a patient self-help initiative.

To mark the occasion, we celebrated with a boat trip on the Danube during the last weekend of September. The beautiful weather added to the joy of the event, which was attended by around 100 people. Representatives from neighbouring countries joined us to toast our anniversary. We were delighted to meet familiar and new faces, have meaningful conversations and share laughter and joy.

This celebration has given us renewed strength and motivation for our future work, staying true to our motto: "You are not alone."

Christine Gmeinder
ÖMCCV – Austrian Crohn's Colitis Association



SERVING PATIENTS IS OUR INSPIRATION, AND WE ARE PASSIONATE ABOUT IMPROVING THEIR LIVES

Alfasigma is an international pharmaceutical company founded in Italy, operating in over 100 countries worldwide. Our mission is to improve peoples' health and quality of life through innovative solutions that meet the highest standards of quality and safety. Gastrointestinal therapeutics are our specialty. Everyday we strive to give a concrete answer to functional gastro-intestinal disorders, including IBD (Inflammatory Bowel Disease).



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Breaking the silence: An IBD journey in India and the fight for change

IBD remains a challenging condition worldwide, but in countries like India, where public awareness is low and access to advanced treatments is limited, the hurdles can be even greater. To understand more about the situation on the ground, Isabella Haaf, EFCCA's Head of Communication, spoke with Nikhil Jayswal, a young patient advocate and founder of India's first patient-oriented IBD organisation.

Diagnosed with Crohn's disease over a decade ago, Nikhil's journey has been marked by immense personal challenges—from dealing with an under-resourced healthcare system to overcoming societal stigma. Yet, his resilience and determination to help people like him led to the establishment of a platform that's giving a voice to countless IBD patients across India. In this conversation, Nikhil shares his experiences as a patient, how he got into advocacy work and his vision for improving the lives of people with IBD in India.



Nikhil, can you tell us about your experiences as an IBD patient in India? What were the turning points, challenges and moments of hope as you navigated the medical system there?

I was diagnosed with Crohn's disease over 10 years ago, at 20, while pursuing my undergraduate degree in mechanical engineering. During an internship, I suddenly developed symptoms like diarrhoea, fever and vomiting. Initially, we thought it was an infection and I was prescribed antibiotics. Over a month, the antibiotics didn't work, and I started losing weight rapidly.

First stop: the private hospital

When things got worse, a relative took me to a specialist at a super-speciality hospital. The fees were high, but we managed somehow to gather the money. For the first time, I heard the specialist mention Inflammatory Bowel Disease. The final verdict was Crohn's with Crohn's Colitis and I was put on Budesonide. For a year, things went well. I even graduated, despite missing a semester.

I got a field job in the oil and gas industry and moved to a new city. A few months in, my symptoms returned. When I saw the doctor, he explained that Crohn's is a chronic, relapsing-remitting disease and suddenly the truth hit me in the face: "I have a lifelong condition, not something that medications and diet alone could completely fix." The



doctor increased my medications but my symptoms worsened. The pain was unbearable, and I struggled to work.

Switching to a public hospital

After months of being sick, I quit and returned to Delhi. With financial issues and family problems, I couldn't afford the specialist anymore and started visiting AIIMS, a crowded public hospital. It was chaotic, and my complaints weren't taken seriously at first. My condition kept worsening. In 2015, two years after my diagnosis, I was hospitalised for the first time after spending a day in unbearable pain. During this stay, I learned about biologics, though they were beyond our means. However, with the help of friends and some crowd-funding, I started on an Adalimumab biosimilar, which initially helped, but within weeks, my symptoms worsened-20 to 30

bathroom trips a day, incontinence and unbearable pain. The pain became so overwhelming that I attempted to take my life.

By 2017, after years of failed treatments and suffering, I chose to undergo ostomy surgery, despite my doctor's concerns about societal stigma and its potential impact on my life. Waking up pain-free for the first time in years was a moment of clarity-it was never just in my head.

Life as an ostomate

Post-ostomy, new challenges arose. Complications kept me in the hospital for over a month, and adjusting to life with an ostomy was overwhelming-figuring out clothes, sleep and diet. Finding a job was even harder. Employers hesitated, and I settled for a modest night tutoring role.

Encouraged by supportive colleagues, I applied to graduate school and an IBD fellowship, astonished to be accepted into both. It felt like a turning point, but in reclaiming my life, I neglected my health. By 2021, Crohn's returned as a fistula, and I was also diagnosed with thyroid cancer, complicating treatment due to my suppressed immune system.

You had a very hard share of the IBD patient journey, what made you get involved in patient advocacy?

Amid these health struggles, the pandemic offered unexpected time for reflection. I had been exposed to global patient advocacy movements through my fellowship and wondered why similar efforts didn't exist in India. Patient groups in India were small, closed communities, often silent on critical issues like stomas. There were hardly any resources in Indian languages or tailored to local conditions.

Motivated to change this, I got in touch with a few patients and began planning a public campaign. Around World IBD Day 2020, we launched our first initiative: a series of public Facebook Live discussions addressing topics previously considered taboo. For the first time, IBD was being openly discussed in India.

After launching our initiative, I reached out to my doctor, who supported us and joined our platform. This opened the door for

more doctors to collaborate, and we evolved into a patient education resource, teaching people about IBD and addressing their concerns. Soon, patients began reaching out with questions like, "Where can I find a doctor?" or "What are the side effects of this medication?"

Over time, it became clear that people needed a formal organisation focused on patients—something that didn't exist in India. With help, we registered the first patient-oriented IBD organisation.

For me, it was deeply personal. My struggle was about access—finding the right care, resources and treatments in a system where IBD isn't covered by insurance or disability policies. Everything is out-of-pocket, and patients often feel lost. I didn't want others, especially kids, to go through what I did.

"I don't see this work as a burning passion but as a responsibility. If I can help prevent another teenager from facing the challenges I endured, I feel it's worth doing"

What is the general awareness of IBD in India, both among the public and the medical community?

Awareness of IBD in India is very low, both among the public and the medical community. Many doctors don't recognise IBD as a possibility, leading to delayed diagnoses, sometimes by years. Public awareness is minimal, compounded by the stigma of

discussing bowel-related issues, which is prevalent in both rural and urban areas.

What about access to treatment through public hospitals?

Most IBD treatment is limited to major centres in metro cities, leaving rural and suburban patients with little access. Public hospitals do provide free medication for the poorest, but the income cutoff is so low (about €30/month) that many who still can't afford treatment are excluded. Advanced therapies like biologics remain inaccessible to most due to high costs and limited availability, forcing some patients to resort to crowdfunding. Expanding affordable treatment options and including IBD in government policies or insurance frameworks is critical to addressing these gaps.

Are there any estimates of how many people in India have IBD?

No, unfortunately, there are no official registries or large-scale studies on IBD in India. However, based on patterns observed across both rural and urban areas, it's evident that IBD is prevalent nationwide. In Western countries, the prevalence of IBD ranges from 1 in 100 to 1 in 150. If we apply even conservative estimates to India's population, the number of IBD patients could range between 7 to 14 million! But more realistically, it's likely that at least 2 to 3 million people in India are living with IBD.

This lack of data poses a significant challenge because, without it, we cannot effectively advocate for government policies or support. When we approach lawmakers, the first thing they ask for is data—how many people are affected? What is the economic burden? How much funding is required?

This is one of the biggest challenges in our advocacy work. It's also an area where I feel medical societies and researchers need to step up and prioritise.

In your opinion, what changes would you like to see in the healthcare system or maybe in the public attitudes that would make the lives of patients with IBD better in India?

The first change I believe is necessary is creating more open discussions around IBD. In India IBD is still stigmatised. This is especially true for young people, children and teenagers, but even adults often avoid discussing their condition due to concerns about their career or social life.

Another important change I believe is needed is incorporating IBD into public policy, especially to ensure access to essential treatments. In India, advanced therapies are recommended, but we have very limited options—only four biologics, and new drugs are not immediately accessible. There needs to be a

policy framework that supports access to medications, perhaps by including them in insurance plans or offering government-funded biologics for at least a year. This could give patients a real chance at remission and a better quality of life!

It's important to ensure the involvement of local patients and patient leaders, who often get overlooked. We encourage doctors to collaborate directly with their own patients—those forming small groups and driving change within their communities. These efforts deserve recognition and support. Empowering local patients is crucial because no single person or organisation can address all of India's challenges. India is like ten countries in one, and meaningful progress requires a strong, community-based approach.

We need more patients to speak out and get involved in the cause. Motivation must come from both sides—doctors encouraging patients, and patients stepping up to take initiative. IBD is becoming rampant in India, Asia and globally. If we don't work together to improve the standard of care in the next decade, we risk failing future generations—and ourselves.

We have the knowledge and treatment options; it's unacceptable that people must resort to debt and crowdfunding to access care and feel better, because it doesn't always succeed,

delaying access to required care. No patient should have to endure this.

Things are moving in the right direction, but there's still much to do—though thankfully, we have dedicated people on our side.



Another important change I believe is needed is incorporating IBD into public policy, especially to ensure access to essential treatments. In India, advanced therapies are recommended, but we have very limited options—only four biologics, and new drugs are not immediately accessible.

Nikhil Jayswal

Treating IBD: Current drugs are only partially effective, how can we do better?

Claudio Fiocchi, M.D.

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Department of Gastroenterology, Hepatology & Nutrition

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It is undeniable that, in the last few decades, the treatment for IBD (both Ulcerative Colitis and Crohn's disease) has considerably improved. This is due primarily to advances in the field of immunology that led to the ability to target and block molecules (secreted or intracellular proteins) that mediate inflammation. This blockade is specific and has relatively fewer side effects when compared to older drugs like corticosteroids and broad-acting immunosuppressors. Despite this improvement, modern medications like biologics and small molecules are only partially effective because not all patients respond to them, or only respond in part and temporarily, and the cycle of partial response, loss of response and need to switch tends to perpetuate itself, frustrating the patients and the doctors alike. This has resulted in an overall therapeutic efficacy of merely 30-40%¹, motivating the need to look for alternative medications with the

hope, if not the certainty, of a better outcome. The quest for other IBD medications goes on and on, and the literature is full of "promising" but unproven drugs which seldom reach a formal clinical trial. In addition, we must accept the reality that the overall probability of success of new medications, for IBD or any other disease, is disappointingly low, around 15-20% overall². Further aggravating this state of affairs is the fact that pharmaceutical companies have progressively cut down their investments in research and development for several decades, while producing more and more drugs that block the same targets and fewer and fewer drugs that block new targets³.

Facing this disheartening reality, it is time to ask three fundamental questions:

1. why do we fail to cure IBD?
2. what are we doing wrong?
3. how can we do better?



There are three basic answers to these questions: 1) complexity, 2) variability and 3) conception. Let's briefly examine each of these answers.

Complexity: both Ulcerative Colitis and Crohn's disease are typical "complex diseases" with numerous contributing factors, unknown triggers and highly intricate mechanisms. The currently accepted factors conditioning IBD, i.e., the exposome (the surrounding environment in which we live), the genome (the complete set of genes we inherit from our parents), the microbiome (the enormous load of bacteria, viruses and fungi populating the intestine) and the immunome (the immune system) are not only infinitely complex, but they are closely interdependent and dynamically influence each other throughout the lifetime.

Variability: Humans are completely different from one another. Every person has unique genes (even identical twins), pregnancy, birth conditions, environmental exposures, microbes, lifestyle, diet, behaviour, education, etc. This immense variability is present in both healthy and sick individuals, and therefore two individuals with the same disease, including IBD, are not biologically the same even though superficially it seems so at the clinical and diagnostic level. This means that the reasons for having Ulcerative Colitis or Crohn's disease vary from patient to patient and so do the underlying inflammatory mechanisms. This also means that each IBD patient requires his or her specific anti-inflammatory management (the so-called precision medicine), something that is still not done and explains why the same treatment applied indiscriminately to all IBD patients, as we do today, can only benefit

some but not all patients and with different and unpredictable degrees of efficacy.

Conception: This refers to the way IBD is currently perceived by patients, stakeholders, doctors and researchers. Until now IBD is seen as an unrelenting inflammatory disease process that comes and goes and gets better and worse unpredictably. In reality, the inflammation present in chronic immune-mediated conditions like IBD, but also many others affecting diverse organs (like the joints in rheumatoid arthritis, the skin in psoriasis and atopic dermatitis, the lungs in asthma, the nervous system in multiple sclerosis), is not the disease proper, but the response to the disease. Thus, trying to control inflammation alone does not address the central problem which is the disease itself and its cause. In other words, it is like treating the manifestations of the disease but not the cause.

In view of these roadblocks that prevent a better management for IBD, it seems logical and timely to switch view and think of IBD and its treatment in a whole different way. Complex diseases, like IBD and the others mentioned above, are networks of multiple interacting molecules that can be studied, identified and manipulated using systems biology. System biology is the computational and mathematical analysis of complex biological problems and is based on a holistic integration, i.e., an all-inclusive approach instead of the reductionist approach where each component of the biological network is studied

in isolation, like we do today⁴. This approach has been applied to the field of oncology for decades and has led to major breakthroughs and whole new ways of thinking about cancer and its treatment⁵. It is time to try this approach in IBD and see what it might yield.

This novel way of approaching IBD is facilitated by a number of recent technical and methodological developments like machine learning (a type of artificial intelligence - AI) and the ability to study tissue and cells at an unprecedented level of detail and sophistication. Combined, these novel developments allow to much better define the status of a tissue, like the inflamed gut in IBD, identify the cell types causing inflammation, the products they secrete and how inflammatory cells induce tissue damage. This combination of thinking about IBD in a far more comprehensive way and applying systems biology-based methodologies permits to move from the traditional to an innovative approach for drug development.

In the traditional approach (conventionally used by pharma companies) a single factor (a molecule) is selected for investigation based on the assumption that this particular factor is relevant to the disease process and millions of new drugs are tested using standard models of disease (like mouse experimental colitis). When one of the drugs shows some experimental evidence of efficacy it is developed pharmaceutically and tested in patients with a specific clinical diagnosis, like IBD. This traditional approach takes 10-12 years to be completed.

In the innovative approach all factors considered relevant to the network of the disease process are integrated using AI, and a target is identified in an unbiased fashion without the subjective choice of the investigators. Computational chemistry is then used to develop a drug that singularly blocks that target, and this drug is then tested in vitro, ex vivo and in animal models of the disease of interest, like IBD. If preliminary evidence of efficacy is obtained, then the drug is tested in clinical trials, but given only to those patients that express the AI-identified target. In doing so, this target can also become a highly specific biomarker of a subgroup of patients. This innovative approach takes only 3-4 years to be implemented.

Switching from the traditional to the AI-based innovative approach for drug development offers a realistic possibility of “doing better” and generating drugs that are “custom-

made” for each type of patient, a key step toward precision medicine for IBD. Efforts in this direction are already underway and they will ultimately result in a switch from traditional doctor-based treatments to novel AI-based treatments. A doctor, no matter how competent, can only use limited medical tools to diagnose IBD and decide what medications to prescribe based on his or her knowledge and experience, both of which are variable and limited. In contrast, AI can use molecular tools (multi-omics) to identify and integrate all the molecular components of the IBD network (the so called “IBD interactome”)⁶ based on an immeasurably greater base of information, identify the most appropriate drug for each subgroup of IBD patients and develop specific therapies with a much greater degree of effectiveness.

New and exciting developments are underway in the field of IBD and the patients should actively contribute

to this progress. IBD patients should not only become aware of these developments that will revolutionise treatment options for Ulcerative Colitis and Crohn’s disease, but also become a unified force in promoting the push “let’s do better in IBD” and advocating for brand-new ways to restore health in IBD.

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Common perceptions of gut conditions: new report and survey highlight opportunity to drive change

Takeda GI Perceptions Audit. *Evaluating Awareness and Attitudes Towards Gut Conditions.*

Gastrointestinal (GI) diseases such as Inflammatory Bowel Disease (IBD) are a global issue, and their prevalence is rising across every continent. For instance, estimates by EFCCA show that as many as 10 million people worldwide and 3.4 million people in Europe are living with IBD.¹

Life with GI disease is anything but normal. For example, individuals with IBD often experience a substantial burden to their lives and routine, with an increased risk of psychiatric comorbidity.¹

Given this context and wanting to better understand the needs and challenges of people living with gut conditions, in 2023, Takeda initiated and commissioned a survey on GI perceptions. As part of this, the survey also captured insights into the levels of awareness and perceptions of gut conditions among the general population and policymakers in Europe and Canada. The survey aimed to generate supportive evidence to drive more meaningful conversations to identify solutions with policymakers and decision-makers and ultimately contribute to improvements for those living with gut conditions.

The survey included telephone interviews with 105 policymakers across eight countries: Spain, UK, Italy, Belgium, Canada, Sweden, Germany and France. 58% of these policymakers were either personally affected by gut conditions or had a family member living with them.²

In addition to this, 1,000 people from the general public, per country, were interviewed across the UK, France, Germany, Italy, Spain and Canada (6,336 total). Of these, 33% had been previously diagnosed with a gut condition. This split allowed the survey to compare the perceptions of gut conditions between people living with conditions and those who do not, which provided some useful and interesting insights.³

The potential impact of symptoms and exacerbations on quality of life

The survey findings showed that the respondents frequently experienced symptoms³:

- 6% suffer from exacerbations at least once per day
- 20% experience them on a weekly basis
- 43% experience them every two to four weeks

Additionally, more than 50% of respondents reported experiencing bowel-related symptoms such as bloating, frequent bowel movements and abdominal pain at least once a month.

Living with a gut condition can also cause substantial disruptions to an individual's work and career³:

- 48% of respondents noted that they had missed work due to their gut condition in the 12 months prior
- 40% believed that their illness has had a negative impact on their earnings and career progression



How has living with a gut condition affected your day-to-day responsibilities as a parliamentarian?

"I live my everyday working life under physical impairment and difficult conditions. It takes a lot of energy. And if I ignore my physical boundaries, I end up in bed for one or two weeks with a fever."

Policymaker, Germany

In terms of impact on social lives, 32% of respondents felt that they were unable to have a normal social, romantic or sex life due to their illness.³

Furthermore, when asked, many respondents shared insights on how their mental health had been affected by their gut condition: over 30% of respondents reported having anxiety and/or mood disorders; 24% noted experiencing depression; and almost 6% shared that they had experienced suicidal thoughts.

Regarding the experience of stigma, almost 30% of respondents noted being subjected to unfair comments and discrimination in their place of work due to their illness. 40% also felt that society does not take their condition seriously.

Challenges associated with care for gut conditions

People living with a gut condition mentioned experiencing several challenges with their care³:

- Poor access to services – 56% of respondents noted being able to access to the right specialist for their psychological needs. Additionally, 66% felt that their treatment plan was a shared decision between themselves and their clinical team.
- Emergency department visits – over 55% of respondents reported having visited the emergency department due to an exacerbation. 29% shared that they had visited in the 12 months prior.

- Long waits for diagnosis and referral to a specialist – 31% of respondents had to wait over six months to receive a diagnosis from a specialist and 27% waited over a year between experiencing their first symptoms and receiving a formal diagnosis.

Common perceptions across those without gut conditions

Among the general public respondents³:

- 22% were familiar with IBD, which was lower than awareness of coronary heart disease, rheumatoid arthritis, asthma and diabetes.
- While 35% of respondents understood that IBD could affect anyone, 27% believed that it was more likely to affect people with unhealthy lifestyle choices and 24% associated it with poor diet.
- In terms of age, 17% of respondents believed that IBD could affect working-age adults.

Among policymakers³:

- 40% of respondents were not personally affected by gut conditions and felt they knew little about them. However, when prompted, they were able to recognise that gut conditions can have a wide-ranging impact on people's lives.

Below are some quotes from policymakers highlighting their perceptions of the impact of symptoms:



In your view, what impact does living with a gut condition have on people physically, mentally and socially?

“The impact of a gut condition is quite big because it involves everything, from the mental aspect to the intestinal aspect with physical consequences.”

“It is very debilitating. It probably limits their ability to work. The psychological aspects of being out in public and then suddenly being overcome with the condition. Situations like that would be a constant worry.”

In contrast, the survey also highlighted some of the misunderstanding in relation to the impact of symptoms on people living with gut conditions, as shown through the quotes below³:



“They are certainly very annoying pathologies, although I would say they are not normally serious and disabling pathologies like others.”

“It is all about self-management. People who manage it well tend to be less affected. Some people who don't manage it well are more prone to being ill.”

“A poor lifestyle, a poor diet which could be the cause of poor digestion, illness or intestinal complications.”

The way forward: overcoming perceived lack of awareness and understanding to drive change

The findings from this survey highlight potential knowledge gaps that exist among the general public and policymakers on life with a gut condition, especially in terms of impact on quality of life, symptom management and causes.

However, most importantly, the findings reveal the scale of opportunity to drive change when it comes to the perceptions from the general public and policymakers, as well as clear unmet needs in terms of care that must be addressed around timely diagnosis, efficient referral to specialists and access to services.

These survey findings have been captured and summarised in a report: Takeda GI Perceptions Audit: Evaluating Awareness and Attitudes Towards Gut Conditions.

The hope is that this report serves as an additional support tool that may be used to raise more awareness and better familiarity with gut conditions when engaging with policymakers and decision-makers to drive meaningful change.

Read the report here:



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Beyond Symptoms: The Significance of Endoscopic Healing in IBD Management

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Over the past decade, treatment goals in Inflammatory Bowel Disease (IBD) have slowly transitioned from focusing on managing symptoms to prioritising long-term symptom control and healing of the intestinal tract.¹ In 2015, the International Organisation for the Study of IBD introduced the STRIDE recommendations to help manage IBD care – updated in 2021 as the STRIDE – II recommendations – to

include endoscopic healing as a key long-term treatment target, which is monitored through endoscopy procedures.^{1,2}

While there are several methods for measuring disease progression in IBD, endoscopy remains the gold standard for assessing disease activity, providing doctors with a comprehensive understanding of

patients' symptoms and becoming increasingly valuable in understanding and predicting long term health.³ Achieving endoscopic healing, which means that there are no signs of inflammation, ulcers, or damage of the colon, has become an important long-term target for managing IBD linked to fewer complications, lower risk of relapse and an improved overall quality of life.⁴

Endoscopic healing as an indicator of disease control

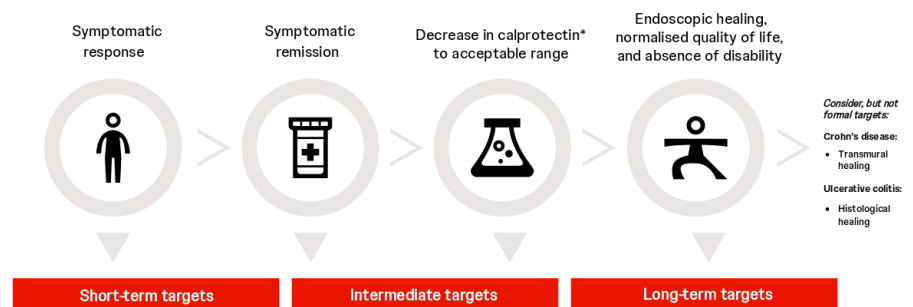
Recent research in Crohn's disease (CD), presented at the United European Gastroenterology Week congress in October 2024, showed that patients who have visible endoscopic healing in their gut (measured by an endoscopy) at the end of 1 year of treatment are much more likely to stay symptom-free nearly two years later.² In fact, 75.3% of those with endoscopic healing remained in clinical remission, compared to only 48.4% of those without it.² Data from the research showed that endoscopic healing is an important predictor of long-term health.² Patients who showed visible endoscopic healing not only had a better quality of life, but also faced a lower risk of having to undergo surgery related to their disease or being hospitalised.² Additionally, complete

endoscopic healing was linked to even better long-term outcomes and a lower chance of relapse compared to partial healing.²

Endoscopy refers to a group of medical procedures that use an endoscope – a thin, flexible tube with a light and camera – which doctors use to examine the inside of your bowel.⁶ The two main types of endoscopic tests used in IBD are upper endoscopy and colonoscopy,

with the specific procedure varying for Crohn's disease (CD) and Ulcerative Colitis (UC).⁷ These procedures allow doctors to see inside the digestive tract and check for signs of disease, such as inflammation, or damage to the lining of the colon.⁸ Endoscopies are also the only way to take small tissue samples (biopsies) from the colon, which support in monitoring IBD and checking for colorectal cancer, a risk that is higher in people with IBD.⁹

Treatment goals in IBD

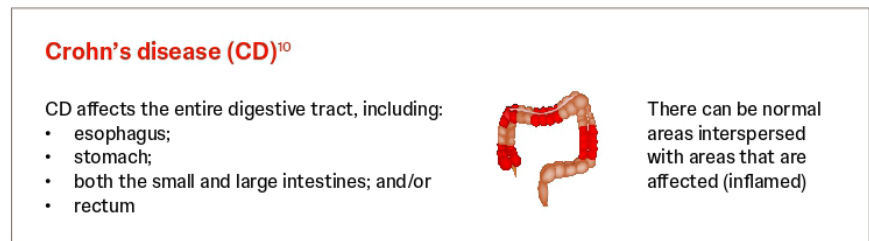


*Calprotectin is a protein biomarker that is present in the faeces when intestinal inflammation occurs.⁵

Figure 1. Adapted from: *Gastroenterology* 2021 Apr;160(5):1570-1583. doi: 10.1053/j.gastro.2020.12.031

Guiding treatment decisions

As our understanding of IBD evolves, endoscopic healing is becoming increasingly recognised as a significant marker in predicting improved long-term patient outcomes.¹¹ Recognised as the standard of care for managing IBD, endoscopy plays a key role in diagnosing the condition, assessing how well treatments are working, providing a deeper understanding of cellular-level changes and closely monitoring patients and their condition long-term to better manage flare-ups.^{11,12} These insights enable adjustments to be made to treatments, maximising the likelihood of endoscopic healing and prioritising long-term remission in treatment decisions.



While these procedures can be uncomfortable and anxiety-inducing, clear communication, empathy and support from your healthcare practitioners can help ease concerns, empowering you to make informed

decisions about your care and treatment options. If you are worried about endoscopy, ask your doctor to explain the procedure in more detail for you and why it is required for your care to help you make a more informed decision.

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