

EFFCCA

magazine

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Foreword



As I reflect on our recent General Assembly, I am filled with immense pride and gratitude. Being reelected as Chairperson of EFCCA is not only a personal honour but a testament to the collective strength and dedication of our entire EFCCA community.

The activities and milestones highlighted in this magazine are a clear indication of how EFCCA is emerging as an important force on the international stage. Our efforts to promote IBD patients' rights and raise awareness are more crucial than ever. Through our initiatives, we are committed to enhancing the quality of care and improving the quality of life for every individual living with these chronic conditions.

Our recent achievements, from the international Roundtable "Uniting for Access to IBD Care" in Mexico City on World IBD Day to the release of our new Guidebook on Health Technology Assessment (HTA) and presentation during UEG WEEK this month, underscore our ongoing mission. We are committed to not only advocating for better treatment options but also making a tangible difference in the daily lives of those affected by IBD.

Thank you for your unwavering support and dedication. Together, we are making significant strides and solidifying our role as a leading advocate in the fight against IBD. Let us continue to work with passion and purpose as we advance towards a future where every patient's voice is heard and valued.

*Salvo Leone,
EFCCA Chairperson*

Editorial



I'm excited to present the refreshed look of the EFCCA Magazine, along with this issue's insightful interview featuring James Lee, where he discusses his UK research team's groundbreaking discovery of a biological pathway driving Inflammatory Bowel Disease (IBD). This pathway could be targeted by existing drugs, paving the way for potentially transformative treatment options and better outcomes.

We're also proud to introduce our newly established EFCCA youth group, a milestone achieved through the EFCCA Youth Academy. Maria Stella de Rocchis, our Youth Programme Coordinator, and Vaso Vakouftis, the new EFCCA Youth Coordinator, share their vision for this dynamic initiative. Their efforts will empower young people to better champion their rights and raise awareness about IBD, planting the seeds for a new generation of advocates and change-makers.

Furthermore, this edition features updates on recent EFCCA activities, including World IBD Day, our General Assembly, the DIVA Training Academy and the release of our new guidebook on Health Technology Assessment (HTA) as well as exciting stories from our Members and Partners.

We hope these stories inspire and engage you as much as they have us.

*Isabella Haaf,
Editor-in-Chief*

EFCCA General Assembly 2024: A Year of Progress and New Beginnings

On 8 June 2024, the European Federation of Crohn's & Ulcerative Colitis Associations (EFCCA) held its annual General Assembly in Brussels. This year's gathering was a significant event, marking both the election of new leadership and the celebration of achievements in our ongoing mission to support and advocate for those living with Inflammatory Bowel Disease (IBD).

We are pleased to announce the re-election of Salvo Leone as EFCCA Chairperson and Marko Perovic as Treasurer, affirming their dedication and the confidence of our members in their leadership. Alongside, Ciara Drohan continues as Vice President and Magdalena Sajak-Szczerba as board member. Additionally, during the General Assembly former board member Lucie Laštíková announced her departure from the current board.

The composition of the newly elected board is as follows:

Salvo Leone - Chairperson

Ciara Drohan - Vice President

Marko Perovic - Treasurer

Magdalena Sajak-Szczerba - Board member

Congratulations to our dedicated team! We look forward to another exciting year of advocacy, support and progress for people living with IBD.



Celebrating Our Collective Achievements

The General Assembly brought together 38 member IBD patient associations from across Europe and beyond, providing a platform to exchange information, strengthen our community and review EFCCA's progress over the past year. Attendees were given an overview of EFCCA's top projects and activities during 2023-2024, reflecting our commitment to making a difference.

Highlights included:

World IBD Day: A global effort to raise awareness about IBD, reaching millions and sparking important conversations.

EFCCA Academy: An innovative initiative providing specialised training for IBD patients, empowering them with knowledge and skills to manage their condition effectively.

DIVA Project: A groundbreaking project aimed at empowering patient representatives living with IBD, ensuring their voices are heard in all aspects of healthcare decision-making.

Re-established Youth Group: A revitalization of our youth engagement efforts, bringing fresh energy and ideas to EFCCA's mission.

All these projects underline EFCCA's commitment to improving the lives of those affected by IBD and the Assembly provided an opportunity to reflect on these activities while setting the stage for future projects.



Key Decisions and Approvals

In addition to celebrating our achievements, the General Assembly (GA) also focused on the important task of governance. It approved the Minutes of the previous GA, the Annual Report 2023 and the Treasurer's Report 2023. With these approvals, the board was formally discharged, paving the way for new initiatives and strategies. Furthermore, the Assembly approved the Provisional Budget and Work Plan for 2025.

A Future Full of Promise

The EFCCA General Assembly 2024 was more than just a meeting; it was a reaffirmation of our shared commitment to making a tangible difference in the lives of those affected by IBD. With a renewed board, agreed strategic direction and the active participation of our member associations, we are well-positioned to continue our international work.

We extend our heartfelt thanks to all our members for their participation and to everyone who has supported EFCCA's efforts. As we conclude the institutional part of the General Assembly, we look forward to a year full of new opportunities, continued advocacy and support for the IBD community.



World IBD Day 2024: Mexico Roundtable Unites Global Voices for Improved IBD Care

On 17 May 2024, EFCCA organised the Roundtable **"Uniting for Access to IBD Care"** in Mexico City. This gathering, held as part of the World IBD Day 2024 campaign under the theme "IBD Has No Borders", marked a significant milestone in EFCCA's global effort to address the growing challenges of Inflammatory Bowel Disease (IBD).

The Roundtable brought together over 30 representatives from diverse regions, including founding members of World IBD Day (Australia, Canada, Europe and USA) and IBD associations from six Latin and Central American countries (Brazil, Chile, Colombia, Costa Rica, Mexico and Uruguay).

It was an essential platform for dialogue and collaboration in tackling unique regional challenges and shared global objectives in improving IBD care.

The discussions were guided by three primary objectives:

- Identifying and addressing barriers to quality IBD care.
- Advocating for increased awareness and resources.
- Formulating actionable recommendations to enhance patient care worldwide.

Keynote presentations from important figures in the field, including Professor Claudio Fiocchi of the Cleveland Clinic (USA) and Professor Dr. Britta Siegmund, President of the European Crohn's and Colitis Organisation (ECCO), underscored the critical need for a coordinated approach to overcoming disparities in healthcare access. Their insights highlighted the importance of recognising both the universal and region-specific challenges in delivering effective IBD care.



The Roundtable in Mexico City was a powerful reminder that our collective efforts can truly make a difference in the lives of those affected by IBD. The connections made here will undoubtedly lead to lasting change.

*Beatriz Capdevielle Gómez
Vivir con Crohn y CUCI A.C,
Mexico*

The Roundtable underscored the importance of advocacy and networking in the global effort to improve IBD care. Establishing strong relationships with healthcare providers and medical societies was identified as a critical step in ensuring that patient needs are adequately addressed. Additionally, enhancing visibility at both local and global levels was considered essential in creating a powerful, unified voice for IBD patients worldwide.



The success of this event, which was live-streamed and has garnered significant online engagement, is a testament to the growing momentum in the global IBD community. EFCCA's commitment to fostering international collaboration and sharing best practices is crucial in the ongoing effort to improve the quality of life for IBD patients worldwide. Watch the [video transmission here!](#)

For more details and information about the Conference, you can [read the full report, available in English and Spanish, on the EFCCA website.](#)



It was an enriching meeting and I hope it is the beginning of a new stage where we will be united in this great cause.

*Milka Pallas
Asociación Crohn - Colitis
Ulcerosa, Uruguay*



A Global Movement on World IBD Day 2024



This year's World IBD Day campaign, **"IBD Has No Borders,"** has truly resonated across the globe, thanks to the concerted efforts of patient associations and supporters worldwide. In 2024, EFCCA has once again undertaken a significant effort to disseminate and promote the diverse activities organised by patient associations and other IBD stakeholders.

A central element of this year's campaign has been coordinating and managing the World IBD Day website www.worldibdday.org. This platform is an important hub for showcasing impactful activities undertaken by countries involved in

the campaign. We are proud that new countries joined the campaign this year. Their inclusion amplifies our message and extends our reach to a broader audience.

Many associations have embraced EFCCA's theme for this year, translating our materials and sharing the "IBD Has No Borders" campaign across their websites and social media platforms. We extend our deepest thanks to all of them for their continued support - **United We Stand!**

In the lead-up to World IBD Day and on the day itself, numerous activities, public conferences and seminars

were hosted by national associations, encouraging citizens to participate and spread the message. While it is impossible to include every initiative in this article, we invite you to explore the [World IBD Day website](#) and the [full report of World IBD Day 2024](#), which provides a detailed account of the inspiring activities and collective efforts from our members, IBD activists, healthcare professionals and diverse stakeholders during this year's event, held on 19 May and throughout the month.

Together, we continue to push boundaries, raising awareness and advocating for the global IBD community.

Guidebook on Health Technology Assessment (HTA)

EFCCA is excited to introduce the Guidebook on Health Technology Assessment (HTA), a valuable tool created to support and inform our patient community.

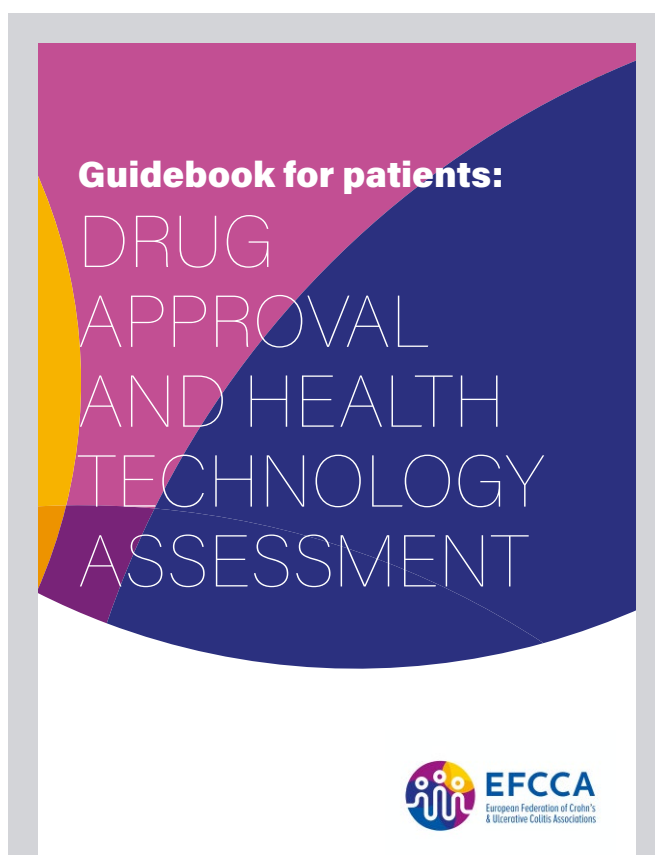
This resource is the result of months of dialogue with regulators and evaluators and it is launched at an important time when healthcare decision-making is changing rapidly, with patient perspectives playing a more significant role than ever before.

HTA is crucial for evaluating how well medical treatments work, how safe they are and whether they provide good value for money. This includes everything from medicines to surgical procedures. Recent decisions based on HTA have greatly affected patients' access to new treatments and care options. That's why patient advocacy groups like EFCCA are taking proactive steps to make sure that the needs and preferences of patients with Crohn's Disease and Ulcerative Colitis are heard and considered.

The Guidebook is a comprehensive effort to explain HTA processes and terms, giving our patient community the knowledge and tools they need to get involved in healthcare decision-making. By understanding how HTA works, the evidence it needs and what it looks for, patients can share their unique views, preferences and experiences with HTA evaluations. This helps make sure that HTA decisions better match what patients need and value.

EFCCA's launch of the Guidebook on HTA shows our commitment to empowering patients and making sure their voices are part of complex healthcare policies and decisions. Our goal is to encourage a more inclusive and patient-centered approach to HTA, leading to positive changes and better outcomes for people with Crohn's Disease and Ulcerative Colitis across Europe and beyond.

The Guidebook is part of the DIVA strategy, which aims to strengthen advocacy skills and the expertise of our community at a high level.



HTA is crucial for evaluating how well medical treatments work, how safe they are and whether they provide good value for money.

EFCCA to Present HTA Guidebook at UEG Week in Vienna

We are excited to announce that EFCCA will present the **HTA Guidebook** at our upcoming conference during UEG Week in Vienna. The event, titled "**How Can Patients Play a Crucial Role in Medicines-Related Decision-Making? An Open Dialogue with Stakeholders and the Presentation of the EFCCA HTA Guidebook,**" will take place on **12 October 2024** at **Messe Wien** and will highlight the importance of patient involvement in decision-making processes related to medicines and devices, fostering an open dialogue with stakeholders.

All EFCCA members are invited to join this significant presentation and discussion.

CONFERENCE:

How can patients play a crucial role in medicines-related decision making?

12 OCTOBER 2024 - VIENNA



An open dialogue with stakeholders and the presentation of the EFCCA HTA (Health Technology Assessment) Guidebook



uegweek

A large advertisement for Pfizer. It features a woman in a white lab coat crouching in a laboratory, looking at a whiteboard. The background is dark with blue lighting. The Pfizer logo is in the top right corner. The text 'SCIENCE WILL MAKE THE BREAKTHROUGH.' is in large white letters on the left. Below it, the text 'We believe science can cure every human disease.' and 'LEARN MORE AT PFIZER.COM' are visible.

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Insights from the EFCCA Youth Academy

In this interview, we speak to Maria Stella de Rocchis and Vaso Vakouftsi about the EFCCA Youth Group. Maria Stella, the overall coordinator of the EFCCA Academy, oversees both the Youth Academy and its initiatives, while Vaso has recently been appointed as the EFCCA Youth Group Coordinator. Together, they will share insights into the goals of the Youth training program and their visions for the future of the youth group.

Maria Stella, what inspired EFCCA to establish the Youth Academy and how do you envision it impacting young advocates within the IBD community?

For EFCCA, the Youth Group has always been a vital part of our organisation. Their support has significantly contributed to raising awareness about IBD among young people. Recognising the importance of their role, EFCCA is committed to further empowering this group, providing them with the necessary skills and capacity to advocate effectively for IBD awareness among their peers.

To achieve this, we identified the need to organise and structure a comprehensive training programme within our EFCCA Academy. This specific Youth Academy programme is designed to equip young advocates with the tools they need to represent their peers on a global scale more effectively. While experience is invaluable, having the right skills is

essential to making a meaningful impact. It's not just about being a patient advocate; it's about being equipped to lead and represent a large group of young people worldwide. In November 2021, we reached out to our 46 National Patient Associations, asking them to nominate one or two young individuals from their association to participate in the training.

It's important to remember that IBD often strikes at a crucial stage in life, typically around the teenage years. This disease has a profound impact on young people and it's essential to give them skills to cope with this life-changing diagnosis and the subsequent adjustments in their lives.

As Training Coordinator, what were some of the challenges you encountered while developing the Youth Academy?

The first challenge was designing an entirely online training programme that could effectively engage youth



patients from around the world. With participants from Europe and beyond, we embraced the opportunity to bring together a diverse group, even though they faced different schedules and time zones. While it required extra effort to foster a sense of unity among individuals who had never met before, this diversity also enriched the experience, allowing participants to connect with and learn from peers across different cultures and backgrounds.

Another challenge we encountered was maintaining participant engagement throughout the programme. While we started with 30 students, unfortunately only about one-third completed the training. It's essential for participants to recognise the long-term benefits of these trainings in managing their condition. Encouraging a stronger level of commitment and helping participants see the bigger picture is an area we definitely want to focus on when designing future training programmes.

Could you share any success stories or inspiring projects from the students who completed the programme, particularly those that highlight the impact of staying motivated and engaged?

Yes, one of the success stories revolves around the organisation of three online workshops with the European Youth Forum, aimed at empowering a youth group to advocate for their rights at an international level. Our students participating on behalf of EFCCA in this workshop became more engaged and recognised the value of their advocacy efforts. The interactive workshops provided practical skills in organising youth meetings, advocacy and engaging peers.

The decision to involve the European Youth Forum was based on their important role in advocating for

youth rights in Europe. The workshops showcased how young people could influence decision-makers and effect change on a larger scale. By the end of the training, participants understood the significance of youth rights and were inspired by the impactful work being done in Europe on issues like labour and inclusiveness.

What are your expectations for the Youth Academy's future? Will there be additional training programmes?

The Youth Academy will continue to welcome new generations of young people. Our goal is to provide them with essential skills in project management, advocacy and lobbying. We aim to inspire future leaders, much like Marco Greco, who founded the youth group and went on to become the president of EFCCA. Looking ahead, I hope the new group will actively seek out further training opportunities and I'm enthusiastic about providing them.

Let's turn our attention to Vaso Vakouftsi, who has recently been appointed as the EFCCA Youth Group Coordinator. Vaso, could you share a bit about yourself with us and how you got involved with the youth group?

Certainly! I'm Vaso from Greece and I've been living with Crohn's Disease for many years. For the past decade, I've been deeply involved in patient advocacy, currently serving as the



president of both the Greek Patient Association and the Hellenic Society of Crohn's Disease and Ulcerative Colitis Patients. Alongside my advocacy work, I am also a musician.

My involvement in the Youth Academy training showed me the impactful work being done there and after participating in various EFCCA activities, I was inspired to help establish a youth group to amplify the voices of young patients.

Now that you're the Youth Group Coordinator, what are your initial steps and objectives?

We've been quite busy since the conclusion of the Youth Academy. Immediately after the ceremony, we held an online meeting with most of the participants and two additional follow-up meetings. In the meetings we focused our efforts on drafting proposals for potential activities to present to the EFCCA board of directors.

Our primary objectives are to assess the specific needs and challenges faced by young patients, which can differ significantly from those of older patients or children. We would like to conduct a survey to assess the specific challenges and get a better picture of the needs of young patients. This survey will help us tailor our campaigns and advocacy efforts to address their real needs with evidence-based strategies.

How do you plan to engage with the group moving forward? Are there plans for regular meetings, a Facebook group, or other strategies to build cohesion and engagement?

Yes; we plan to hold monthly virtual meetings to stay updated, discuss activities and share ideas. The response from participants has been very positive, with a strong eagerness to re-establish and expand the youth group.

Recognising the importance of social media in reaching and engaging young people, we're considering various platforms to connect with our audience effectively. The group is eager to start a Discord server as a primary platform for communication, it is a promising idea and although

it's different from traditional platforms like WhatsApp or Messenger, it seems to be a fitting choice for engaging our age group.

To further enhance our group, we're also considering launching a campaign to recruit new members using existing EFCCA communication channels and our primary goal is to increase our membership from the current 12 to 20, which would enable us to conduct more activities and achieve better representation.

To conclude, what would you say to young people about the benefits of joining the youth group?

Joining the youth group offers valuable opportunities for connection and support. Members can engage with peers who are experiencing similar challenges, creating a network of understanding and empathy. This peer support is crucial as it allows them to share experiences and address common needs. Moreover, being part of the group provides a platform for advocacy, empowering them to speak out and advocate for their own needs and those of their peers, making a tangible impact in their community.



EFCCA Youth Academy Final Work Assignments

We are delighted to share the final two works from the "Leaders of Tomorrow - EFCCA Youth Academy": one by Martin-Kristofer Helgeland-Rossavik from the Norwegian association "Mage-tarmforbundet" and the other by Lisa Bechtum from the Italian association "Amici ETS".

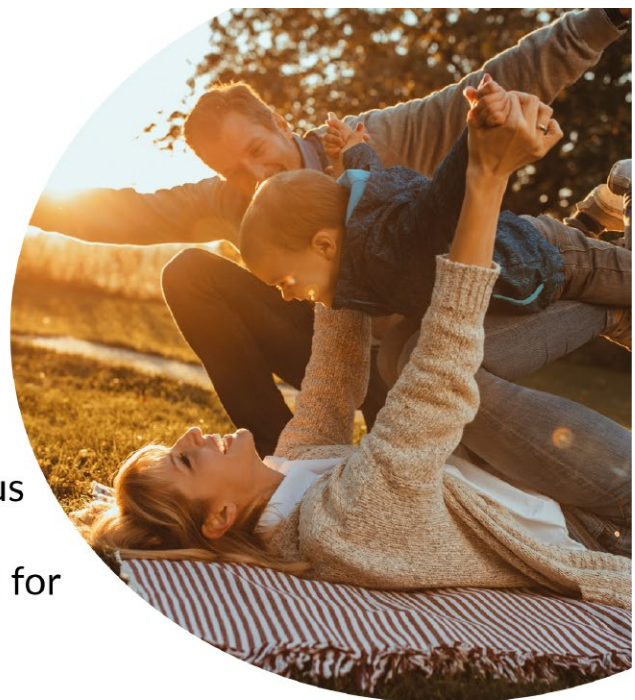
Martin-Kristofer Helgeland-Rossavik, Norwegian association "Mage- tarmforbundet":

Martin-Kristofer, in an in-depth interview with Norwegian youth group leader Martine Teigen, explores the role of youth groups in supporting young people with IBD. This dynamic group, catering to individuals between the ages of 18 and 34, organises a variety of activities, ranging from hut retreats in Norway to international gatherings across Europe. These events not only provide participants with essential health advice, but also offer opportunities to forge lasting friendships and gain support from peers

facing similar challenges. Teigen emphasises the unique benefits of youth groups: 'It's about camaraderie, finding people in the same life situation and age group with whom to share tips and advice to improve daily life and overcome health challenges'. One of the group's most successful initiatives, the Butterfly Project, offered young members the opportunity to learn how to stay active and engaged despite living with chronic illnesses.

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THERAPEUTICS

Lisa Bechtum, Italian association "Amici ETS":

Lisa discusses the challenges faced by adolescents living with IBD, particularly during their school years. She introduces the IBD Bridge project by Amici Italia, which aims to close the knowledge gap about IBD in schools. The project educates both students and teachers about the condition, fostering empathy and inclusion. Through educational sessions led by gastroenterologists, psychologists and students living with IBD, the initiative seeks to create a more supportive, discrimination-free environment in schools. Lisa highlights that the project's impact goes beyond education, transforming schools into more inclusive spaces that accommodate students with chronic illnesses like IBD.

You can read both articles and other end-of-course assignments from the EFCCA Youth Academy on our website: www.efcca.org/news/efcca-youth-academy

At Sandoz, our Purpose is to pioneer access for patients. It shines through in our rich heritage, as in our plans for the future. The Sandoz brand, established in Switzerland in 1886, can look back on many scientific breakthroughs, from the world's first oral penicillin to the first biosimilar medicine.

An illustration on a blue background shows a woman with long brown hair, wearing a green top and blue pants, assisting an elderly woman with grey hair. The elderly woman is wearing a brown jacket and a blue hat, and is seated in a grey armchair with a cane. The woman in green is holding a brown teddy bear for the elderly woman. The word "SANDOZ" is written in large, white, bold, sans-serif capital letters across the middle of the illustration.

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Launch of DIVA Academy

In May this year, EFCCA proudly launched the **DIVA Academy: Unlocking the Power of Data Insights for Added Therapeutic Value**, an online training programme designed to enhance the use and understanding of DIVA, EFCCA's flagship methodology. DIVA (Data Insights for Added Therapeutic Value) is a powerful EFCCA working methodology that enables members to explore patients' unmet needs based on scientific data and propose new initiatives and campaigns to find meaningful solutions.

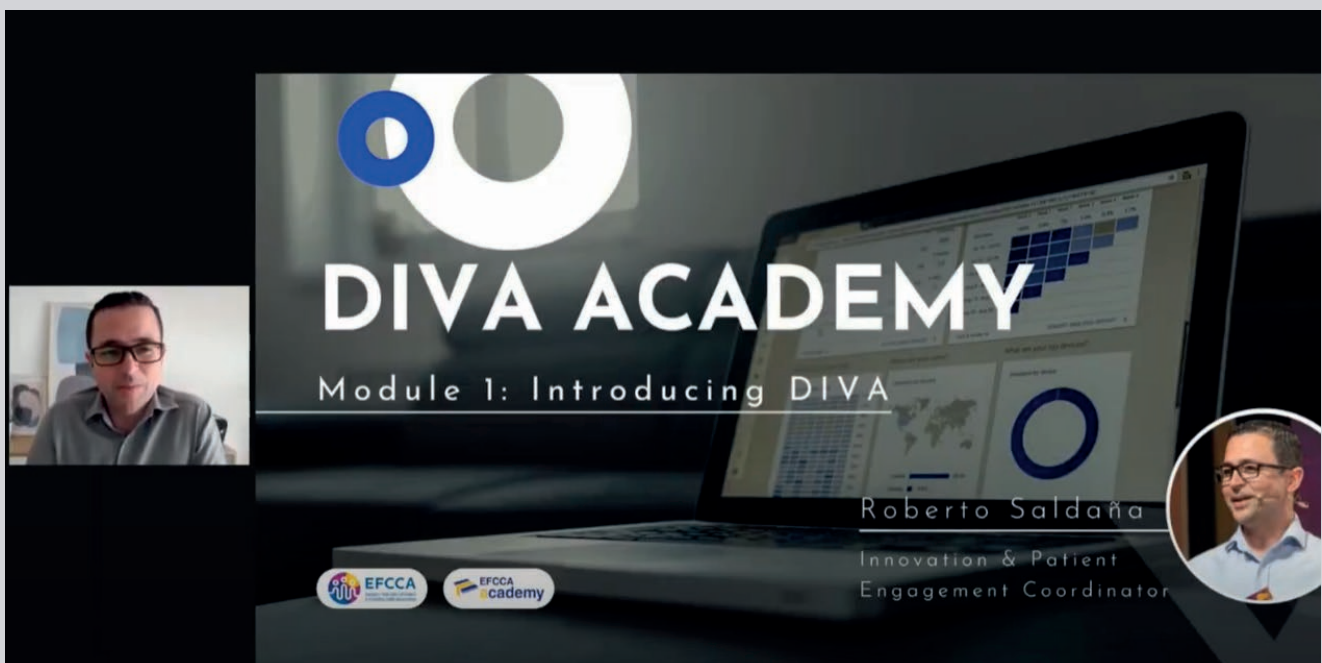
The DIVA Academy offers a three-module programme, each consisting of a combination of pre-recorded sessions and live online workshops. These sessions provide participants not only with theoretical knowledge, but also with practical insights into how DIVA can be applied to real-world scenarios encountered by patient representatives.

The inaugural edition was attended by 13 delegates representing a diverse range of countries, including Mexico, Romania, the Czech Republic, New Zealand, Estonia, Greece, Finland, Hungary, Ireland, Israel, Poland

and Italy. Throughout the programme, participants explored DIVA's features and functionality in a hands-on, engaging learning environment. The Academy is designed to foster deep engagement, enabling EFCCA members to confidently navigate the platform and utilise its data-driven insights to advocate for the unmet needs of IBD patients. By the end of the training, participants will have gained a thorough understanding of DIVA's capabilities and learned how to apply them in the everyday scenarios faced by patient representatives.

For more information, please contact me at:
mariastella.derocchis@efcca.org

Maria Stella De Rocchis
EFCCA European Project Officer



Romania

ASPIIR Receives Prestigious Award: Championing Human Rights and IBD Patient Support in Romania

We are pleased to announce that Isabella Grosu, President of ASPIIR, has been honoured with the Order "Merit for Human Rights and Social Commitment" in the rank of Knight during the Romanian World IBD Day 2024 event.

This prestigious distinction, bestowed by the President of Romania, acknowledges ASPIIR's significant contributions over the past 14 years to supporting patients with Inflammatory Bowel Diseases (IBD) and ostomies in Romania. Their collaborative efforts with medical societies such as the Romanian Club for Crohn's Disease and Ulcerative Colitis and the Romanian Society of Gastroenterology and Hepatology, have been instrumental in achieving this milestone. Here, we talk to Isabella Grosu about the journey, challenges and future of ASPIIR's mission.

Isabella, congratulations on receiving the "Order of Merit for Human Rights and Social Commitment". What does this recognition mean to you personally and to ASPIIR as an organisation?

The distinction represents a recognition of the results and social commitments at the national and international levels, it is particularly honourable for ASPIIR and, at the same time, it motivates us to continue and develop the ability and capability to support patients with Inflammatory Bowel Diseases and ostomates in Romania.

We know that there is a certain limited number of such presidential distinctions that can be awarded over time; new merits cannot be issued whenever a potential winner may appear and therefore, the decision of granting such a distinction is made after careful consideration and according to rigorous criteria. Under these conditions, the fact that the Presidency of Romania chose to award ASPIIR is a confirmation of the value of the association and its contribution to improving care for patients.

ASPIIR has succeeded enormously over the past 14 years. Could you share some of the key challenges you faced initially and how you managed to overcome them?

At the time of founding the association, we were entering an empty field, with not much expertise on how to approach patients with these needs - a situation somewhat similar to that of the gastroenterologists who were faced with huge challenges in managing some lesser-known diseases in Romania, namely Inflammatory Intestinal Diseases (IBD). Currently, after 14 years full of activity and efforts, we are in a position where the Presidential administration recognises ASPIIR as a factor of social commitment at the national level and awards it the title of Knight for the promotion of human rights.

It wasn't easy at all in the beginning. It was quite common to avoid talking about a disease that can destroy your personality and transform you physically and sometimes mentally. Overcoming these barriers and changing the mentality were serious challenges. Since then, thanks to ASPIR's IBD awareness raising campaigns, both for patients and their relatives or the general public, the understanding of these diseases has increased significantly. Starting from a small group of volunteer patients 14 years ago, we managed, over time, to attract partners, develop and implement campaigns at the national level and become a valuable partner of the Centers dedicated to the care of IBD in the country. Most importantly, we are now influencing medical care legislation in Romania today, in favour of our patients.

I think the defining keyword for how we have achieved all this is "perseverance" - there is a Romanian saying: "If someone kicks you out of the door, try to enter through the window".

Collaboration with medical societies has been crucial for ASPIR's success. How has partnering with organisations like the Romanian Club for Crohn's Disease and Ulcerative Colitis and the Romanian Society of Gastroenterology and Hepatology impacted your work and the support you provide to patients?

From my point of view, the support of specialists' societies is crucial indeed for a patient organisation, it is a circle that must be closed and it is a vital collaboration that must be based on trust and mutual respect. Each one has a well-defined role that the other cannot do. Therefore, understanding each other's role and complementing and endorsing each other, led to the achievement of common objectives (education of patients and the public, legislative approval of new services for IBD, etc.). The Romanian Club for Crohn's Disease and Ulcerative

Colitis and the Romanian Society of Gastroenterology and Hepatology were two bricks in our foundation of support at the moment we started ASPIR and they have been continuing to respond positively and join us in all the association's campaigns.

Looking ahead, what are ASPIR's main goals and priorities for the future in continuing to support patients with Inflammatory Bowel Diseases and those with ostomies?

Our vision and our plans for the future are quite long-term. Of course we want to continue the information and education programmes for patients, which have already become a tradition in recent years such as ASPIR's free psychological counselling programme, monthly webinars and forums. Apart from this, we are targeting improvements in the legislative regulations for IBD care (eg: the free calprotectin test for patients through the state medical insurance system, changing the frequency of issuing medical prescriptions from monthly to quarterly, obtaining approval from the Minister of Health for the introduction of psychologist and nutritionist positions in all gastroenterology clinics, etc.), as well as strengthening the Association's role as a reliable partner of the medical societies of gastroenterologists, surgeons and anaesthetists.

Our "to-do" list is a long one and we hope that the ASPIR community will grow and prove, once again, that it fully deserves the presidential recognition recently awarded.



Leaders, visionaries and doers

As a member of the Global IBD Patient Council of Pfizer since 2020, I had the opportunity in June to contribute to organising the team of the first Global IBD Community Summit initiated by Pfizer, in Warsaw and to give two presentations based on our experience in Romania. The first presentation was titled "Uninhibited health equity: multi-stakeholder collaboration to effect change, Using patient advocacy to drive health equity" and the second was "IBD and me: a unique perspective, ASPIIR survey: Transition of young people into adult IBD care".

One of our recent achievements was influencing legislation and obtaining new medical services included in the national social insurance system:

concretely, the administration of parenteral nutrition at home for patients with Short Bowel Syndrome (SBS) (compared to the previous situation when it was only done under the management of the anaesthetist in the hospital) through home care companies. This result came after a consistent advocacy campaign for almost two years and I was glad to share this with the participants. The summit was a platform for insightful discussions and valuable exchanges on patient care and advocacy.

The second topic discussed was the results of an ASPIIR national-level analysis regarding the challenges faced by adolescents with IBD during the transition period from paediatric to adult gastroenterology care. This brought a new collaboration and

a proposal from Polish paediatric specialists to make a comparative analysis of the transition situation of paediatric patients in Romania and Poland. So very exciting outcomes which make us believe that such meetings have a valuable role in encouraging collaborative initiatives between patient associations, as well as between patients and doctors.

One of the most important challenges is positioning ASPIIR at the top of the leaders, visionaries and doers, recognised at the international level. Thinking uninhibited helps IBD patients rise above stereotypes!

Isabella Grosu
ASPIIR - Association of People with
Inflammatory Bowel Diseases in
Romania



Netherlands

Vaccination information on Crohn & Colitis NL website

These days there is increasing discussion in the consulting room about the usefulness of vaccinations. In addition, it is not always clear to doctors and patients which vaccinations are important for people with IBD. Therefore, two gastroenterologists and a physician-researcher approached Crohn & Colitis NL. They asked us if we would be willing to add a page to our website with important information about IBD and vaccinations. This page has since gone online, we published an article about it in our magazine Crohniek and organised an online consultation for patients on the subject.

To vaccinate or not to vaccinate is, of course, always your own choice. However, IBD patients taking immunosuppressant medicines sometimes have a higher risk of contracting certain infectious diseases. And also often a greater chance of a more serious course of these infections. Vaccinations can help counteract this risk. In addition, unfortunately sometimes the immunosuppressant medicines can make the vaccination less effective. Nevertheless, the advice is to take the vaccine even then.

Two types of vaccines

There are two types of vaccines: inactivated (dead) vaccines and live attenuated vaccines. People on immunosuppressant medicines should always get inactivated vaccines and not live attenuated vaccines, such as the mumps, measles, rubella vaccine, Rota vaccine, salmonella vaccine or yellow fever vaccine. If an IBD patient needs to be vaccinated with a live attenuated vaccine while on immunosuppressant medication, this should always be discussed with the gastroenterologist at an early stage, as this can be dangerous and is therefore often discouraged. For example, if a person is going on a faraway trip and the yellow fever vaccine is mandatory. Then that person should first stop taking immunosuppressant medication keeping in mind that many medications take months to fully wear off.

Percentage of patients with vaccinations

92% have received childhood vaccinations according to National Vaccination Programme

62% have received annual flu shot

16% have received five-year pneumococcal vaccination. (This vaccine is unknown to most patients)

93% have received a full COVID-19 vaccination

Figures from research conducted by Natasja van de Pol and Annemarie de Vies among 1,390 patients with inflammatory diseases in the departments of gastroenterology, rheumatology and dermatology at Erasmus MC and Franciscus Gasthuis & Vlietland Rotterdam, Netherlands.

Information on the website

Together with the gastroenterologists and the physician-researcher, we decided to start on our website with the four key moments during IBD treatment when the topic of vaccinations should be discussed with the gastroenterologist or nurse practitioner. In general, most vaccinations work better if the patient receives them before starting immunosuppressant medicines. This is not always feasible, so the classification below is based on when the vaccination can be safely given. The four moments are:

1. Childhood (0-18 years): this is the period when vaccination programmes are offered. These may vary from country to country. If an adult has not had certain vaccinations, it is important to notify the gastroenterologist.
2. Before starting immunosuppressant medication: if someone is going to take this medication, but that person did not have certain vaccinations or diseases during childhood, it may be wise to take certain vaccinations before starting the immunosuppressant medication.
3. While taking immunosuppressant medication: consider the flu vaccine, COVID-19 vaccine, pneumococcal, HPV and shingles vaccinations. Vaccinations that are especially important because of reduced immunity.
4. If you are going to travel: this explains what you can do if you are taking immunosuppressant medication and need certain vaccinations for your trip.



Other topics

We also answered the most frequently asked questions about vaccinations and IBD on the website. For example, we address why it is important to vaccinate against certain diseases, the types of vaccines available, whether you can get all the vaccines if you are on immunosuppressant medication and whether you can catch up on vaccinations if necessary.

Information

The information on our website about vaccinations can be found by scanning the QR-code or by clicking on the link below.

<https://bit.ly/advies-over-vaccinaties-en-ibd>

The text can also be read in English. Please choose English in the menu.

*Barbara Davidson
Crohn & Colitis NL*



France

A look back at the Teen Summer Workshop!

For more than 10 years now, afa Crohn's RCH France has been offering teenagers affected by IBD the chance to enjoy an enriching experience with other young people. A new edition of the teenager camp took place, as it does every year, at the end of July in Dinard (Brittany, France).

There were 20 teenagers aged 12 to 17 enjoying the idyllic setting of the Château of the Marie-Thérèse Solacroup Foundation. A place and a time to themselves, among young people, without their parents and supervised by a motivated team of professionals and patient-expert volunteers.

The tailor-made programme of workshops, discussion sessions and entertainment was an opportunity for them to share their experiences of their illness with no taboos. It also allowed them to explore their own abilities to manage IBD and to reflect on how they see themselves, others and their relationship with their body.

In the mornings, IBD workshops were run by our volunteers Sylvie, Marine, Isabelle and Karim, covering day-to-day life with the disease, treatments, diet, self-esteem and a cooking workshop, as well as relaxation sessions focusing on movement,

well-being and adapted physical activity (Afghani walking, meditation, art therapy).



We innovate in gastroenterology
so patients can live in the moment



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In the afternoons, activity leaders Amélie and Camille, proposed a range of outings: a beach trip, visits to the surrounding area and to Saint-Malo, a tree top adventure park, kayaking and unforgettable evenings of laughing and sharing.

Being confronted with other teenagers with similar experiences can be disturbing and even painful for some young people. The role of our trained volunteers was to accompany them on their journey during the stay, so they could emerge happy, independent and more confident in life and in their future. Like all teenagers, they have plans and dreams, which are also possible with IBD.

"We regularly find during these workshops that teenagers with IBD find it difficult to talk about their illness with their friends and family. They sometimes feel misunderstood when it comes to the physical and psychological repercussions: pain, fatigue, social and emotional life, self-image and other people's opinions. So we were delighted to see them leave reassured, united and smiling, with the desire to see each other again soon", says Irina Lépany, coordinator of community life.

Louise, 13, has Crohn's Disease. She shares her experience at this year's Teen Summer Workshop:

"My gastro-paediatrician and my nurse coordinator talked to me about it because I felt very lonely with this disease and I didn't know anyone else



who had it. I learnt a lot and above all, I felt less alone. It's not a taboo topic here. You can talk about it whenever you want, wherever you want. You can talk about your symptoms, but no one will tell you it's a "little tummy ache". We feel listened to here. In the mornings, we do activities related to the disease, but in a very fun way. We share, listen to others and express

ourselves freely. In the afternoons, we do activities just like a normal camp! Kayaking, tree climbing, the beach - it's really great!"

She adds: "The teenage camp is an event you really have to experience and when you're old enough, you really have to do it!"

Mik@do: the new online mentoring programme for teenagers!

With the number of cases of IBD among children and teenagers on the rise, the association has developed in-depth expertise in their needs and offers long-term support to these young people and their families. This year, afa is setting up an innovative new service to go even further in supporting teenagers, who

we know are particularly vulnerable to the disease. Starting in October 2024, we will be launching "Mik@do", online workshops for teenagers with IBD aged 12 to 17. The programme will cover topics such as understanding the disease, diet, managing pain and fatigue and physical exercises. Supervised by expert patients and

specialists, these online workshops will enable young people to discuss and share their tips for living better with the disease. In addition, young people will have access to a dedicated module on MICI Connect, afa's platform, where a range of tools will be available, including stop-motion videos on MICI and schooling.

Eve Saumier
AFA CROHN RCH FRANCE

Brazil

Fighting Fake News: DII Brasil's Campaign in 2024

The spread of false and misleading information regarding Inflammatory Bowel Diseases (IBD) has become an increasing challenge in Brazil, particularly with the rapid dissemination of "miracle cures" and rumours on social media. In response to this growing threat, DII Brasil (IBD Brazil) has launched a campaign focused on combating fake news, reaffirming our commitment to providing the public with accurate and reliable information.

The image shows a screenshot of the Instagram profile for 'diibrasil'. The profile name is 'diibrasil' and it has 1,846 publications, 20,7 mil seguidores, and 2,543 seguindo. The bio identifies it as 'DII Brasil - IBD/EII BR' and 'diibrasil', an 'Organização não governamental (ONG)'. It lists affiliations with '#Enfrentamento ao #Crohn e #Retocolite', '#EFCCA', and 'da Rede @gerandofalcoes'. It also includes a link to a YouTube playlist: 'www.youtube.com/playlist?list=PLwzf-I74cqxMWwwYY_k9pxsGunCptQQnG + 4'. A note states '176 mil contas alcançadas nos últimos 30 dias. Ver insights'. At the bottom, there are six circular icons representing different content categories: 'Histórias', 'Filiadas', 'Amigos da ca...', 'Doações', 'Benefícios', and 'Ações'.

Over the years, DII Brasil has been dedicated to educating and supporting patients, families and healthcare professionals with trustworthy content on topics such as diet, medications, complementary treatments, physical activity and patients' rights. However, the rise of pages and profiles spreading inconsistent information, often preying on the hope of patients seeking a cure, has driven us to intensify our communication efforts.

Our campaign against fake news aims not only to debunk false information but also to emphasise the importance of seeking knowledge from reliable and specialised sources. We are highlighting our work to ensure it reaches a wider audience, surpassing the negative impact caused by misinformation.

As part of this initiative, we are restructuring the DII Brasil website, which will soon be relaunched with a new design and features to make accessing accurate and up-to-date information easier. Additionally, we are making significant investments in our social media presence, including Instagram, Facebook and LinkedIn, to broaden the reach of our work and strengthen our communication with the community.

We believe that strengthening communication is, in fact, strengthening our entire cause. By expanding our impact across digital platforms, we aim not only to educate more people about IBD but also to build a more informed and united community, capable of facing challenges with knowledge and mutual support.

DII Brasil will continue to be at the forefront, promoting responsible information and fighting fake news. With the support of our partners and the community, we are confident that we can amplify our results and protect patients from misinformation.

We invite everyone to learn more about our work by visiting our website at: www.diiBrasil.org.br and following us on Instagram [@diiBrasil](https://www.instagram.com/diiBrasil).

Patricia Mendes, CEO of DII Brazil
Translated by Thiago Carvalho
Board Member of DII Brazil
Communication

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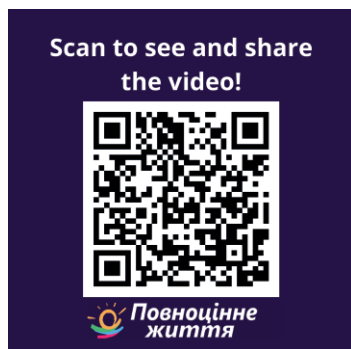
Ukraine

IBD Doesn't Define Your Future

It's no secret that Ukraine is going through the most difficult times in its modern history. The war waged by Russia against Ukraine has not spared a single Ukrainian. Everyone has suffered and continues to suffer from this war, which we did not start and did not want.

This war affected every IBD patient; many Ukrainian patients lost their homes, loved ones, jobs and income. Many have gone abroad and found temporary refuge somewhere in the world. Since the beginning of the war, more than 2,000 people in Ukraine have been diagnosed with Crohn's Disease and Ulcerative Colitis. Those newly diagnosed with IBD are desperate, despairing and believe that their normal life is over forever.

Over the past two years, our organisation has received higher number of requests for help compared to before. To support every Ukrainian suffering from Crohn's disease or Ulcerative Colitis, we decided to create [this video](#).



This video contains thousands of stories of IBD patients, who have gone through pain, despair and a sense of hopelessness. The prototype of the heroine is our psychologist Kristina, who has Crohn's Disease but has found a way out, learned to live a full life and now helps other IBD patients find their way.

We wanted to show that illness is not a life sentence, that people with serious incurable diseases can do a lot for themselves and others, that they should not despair. They can find their doctor, connect with like-minded people and most importantly, find themselves and their place in this world.

The Ukrainian public organisation "Association of Patients with Inflammatory Bowel Diseases "Fulfilling Life" was established in 2018 to support Ukrainian patients with IBD.

Since the beginning of the war, our organisation has been distributing tons of humanitarian aid for IBD patients, which we receive from all over the world. We also provide strong information support and do a lot of advocacy work. We have a website with more than 700 popular science articles that we have translated and adapted for people, a YouTube channel and a Facebook page. We have a therapeutic psychological support group for people with IBD, we also provide peer-to-peer mentoring support, where more experienced patients help newcomers cope with the challenges of the disease.

You can also get involved in helping Ukrainian patients and donate here:

www.gofulllife.com.ua/donate

Olena Sotskova
Association of Patients with
Inflammatory Bowel Diseases
"Fulfilling Life"

Portugal

APDI, the Portuguese IBD patient association, provides ongoing support and advice to people living with IBD. The organisation regularly publishes articles by a psychologist, offering patients valuable insights and strategies for coping with this chronic condition. We are pleased to reshare their recent article, which explores some insightful considerations about different stages of an IBD diagnosis.

Manage or be managed by IBD

Both Crohn's Disease and Ulcerative Colitis, as chronic conditions, require a self-management lifestyle directly linked to symptom severity, hospitalisations, absenteeism and other health factors¹.

What's interesting is that general doubts and discussions on disease management only consider time after the diagnosis. Whether it occurs in adolescence, in your thirties or to an older person, many people say *"I had some symptoms before, but they never told me what those were!"* or *"Now that I know about IBD, I remember having similar problems as a kid."*

So, do you believe that someone with IBD only starts dealing with abdominal pain, fatigue, diarrhoea, bleeding, or mucus only after receiving a diagnosis?

The unpredictable nature of IBD symptoms has a bidirectional relationship with our mental health² starting right from the first run to the bathroom, or the first time you doubted your own tiredness, to the day your instincts were telling you something was wrong.

Considering that the severity and perceived causes of a disease are

strong predictors of social stigma³ that goes with it, we can assume that managing IBD begins long before the day you feel like the ground has opened a hole under you.

It's true... Long before we feel judged telling others about our IBD, we are the first ones to reject the idea that those symptoms might be signs of something more serious. Starting from *"it must be stress"* or *"something I ate"* to *"I need to rest more"* or *"I'll sleep and feel better tomorrow"*, until we realise something is different and we really should be looking for professional help.

Some took longer than others, but many have managed, invented and lived - alone or with their families - through sleepless nights, pain, nausea, diarrhoea, days without work, self-medication, changes and cuts in diet, hoping a trendy intolerance would solve the problem. And... no.

Having the diagnosis isn't going to solve the problem all on its own, or teach us how to manage this entire "undertaking." Doctors and nurses provide manuals, guides, communication strategies and literacy courses, but that moment is just ours.



Article written by Jorge Ascensão - Clinical Psychologist
APDI - Associação Portuguesa da Doença Inflamatória do Intestino

The relief of finally knowing, for some, the punch in the stomach for others and the earth-shattering quake in everyone's life doesn't allow us to learn much on the day we're supposed to be reborn as chronic patients.

"Supposed to", because, as I think you can understand, just because reality changes around us, it doesn't mean we automatically start acting according to what's expected from us. And as strange as it may seem, what saves the vast majority from a more severe collapse after receiving such a diagnosis is the "good old Denial".

But not that cinematic, or social media "denial" of someone that doesn't care about their own disease, or refuses medication and dramatically runs away as far as

the horizon or their thoughts can take them. Nothing like that.

I'm talking about newly diagnosed people who are excellent at taking their medication, don't miss appointments and keep track of all necessary exams. But not because they "get the message" about the severity of the disease they now have, but as an alternative way of controlling a reality they don't yet understand, allowing them to keep their world unchanged and their life untouched by illness. Or at least that's what they want to believe.

How good it would be if a physiological perspective on self-management was enough for something as complex as an autoimmune disease like IBD, where we would take medication, control the symptoms and endure the usual side effects with ease⁴.

However, when a change is too fast and/or intense, physically and/or mentally, the result tends to be traumatic. Denial, here, is the mental mechanism that allows us, in the face of a catastrophic change in our reality, to gradually and progressively learn and feel, at our own pace, in our own way, the new version we will one day become.

The new identity we need to develop.

This is where you're used to reading or hearing about stress, anxiety and depression. But beyond that, there are also a series of important negative psychological consequences, including agitation and emotional confusion, that seriously compromise self-esteem⁵.

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And from that day, since the diagnosis, waking up, getting dressed, going out, studying, working and simply being who you were, ceases to be guaranteed and becomes a general feeling of loss of identity⁶. A lack of belonging to yourself.

Sure. We move forward, but half-in-the-air, half-groundless, clinging to our stomachs, to the bathroom, or to our knees, where the importance of the "rest" is no longer the same, so much so that we are empty of who we are to others. Of what is expected of us, of what remains after the collapse of our social identity⁷.

We are, fortunately, in reality, "many things," to close ourselves off in just one identity.

We are our personal characteristics and our various social roles, we belong to this and that group of people. We see ourselves – and are seen – in the sum of all these images and self-concepts, in how we imagine ourselves in the eyes of others. And now? How can we imagine

ourselves capable, possibly the same, but adding to this global identity of who we were and who we are, a new self-concept of disease and being a chronic patient? How can we add to the tower of our life, to the floors of our history, an entire floor dedicated to this pitfall it gave us?

We need to discover and will learn (whether we want to or not) this new mental reference.

Integration is more than just a conformist acceptance!

But only if we want to understand and know how to act, with some control, in this new part of our identity, charged with new thoughts, behaviours and emotions⁸.

More than being swallowed by a disease that dominates our identity, more than rejecting IBD because we consider it unacceptable in our life project. It's already there, regardless of your acceptance, your plans, or everything that you really deserved and surely it didn't include an autoimmune disease.

Why, then, a constant "arm wrestle" with an entity that cannot be dominated by force but by strategy? Where escaping symptoms is only effective through changing the course of the disease.

A course that only changes when the person carrying the disease invests in knowledge about it, without getting overwhelmed by it.

Better knowing where IBD became part of your identity, but that it didn't erase it. Day after day, appointment after appointment, one crisis after another, you know more, understand more about yourself and the disease. And even more wisdom lies in the future ahead.

There's no hurry. We have time. A chronic disease isn't going anywhere alone. It will go with us wherever we decide to go. We're stuck with it for the journey ahead.

The real question is how to be there for the disease. Because that's how we'll be there for our health too. And our health will be there for us.

References

1. Saibil, F., Lai, E., Hayward, A., Yip, J., & Gilbert, C. (2008). Self-management for people with Inflammatory Bowel Disease. *Canadian Journal of Gastroenterology*, 22, 281–287.
2. Mikocka-Walus, A., Hanlon, I., Dober, M., Emerson, C., Beswick, L., Selinger, C., . . . Hewitt, C. (2020). Lived experience in people with Inflammatory Bowel Disease and comorbid anxiety and depression in the United Kingdom and Australia. *Journal of Health Psychology*, 26, 2290–2303.
3. Crandall CS, Moriarty D. (1995) Physical illness stigma and social rejection. *British Journal of Social Psychology*. 34 (Pt 1):67–83.
4. Yeshi, K., Ruscher, R., Hunter, L., Daly, N. L., Loukas, A., & Wangchuk, P. (2020). Revisiting Inflammatory Bowel Disease: Pathology, treatments, challenges and emerging therapeutics including drug leads from natural products. *Journal of Clinical Medicine*, 9, 1273.
5. Sammut, J., Scerri, J., & Borg Xuereb, R. (2015). The lived experience of adults with Ulcerative Colitis. *Journal of Clinical Nursing*, 24(17–18), 2659–2667.
6. Matini, L., & Ogden, J. (2016). A qualitative study of patients' experience of living with Inflammatory Bowel Disease: A preliminary focus on the notion of adaptation. *Journal of Health Psychology*, 21, 2493–2502.
7. Byron, C., Cornally, N., Burton, A., & Savage, E. (2019). NII Patients' challenges of living with and managing Inflammatory Bowel Disease: A meta-synthesis. *Journal of Crohn's and Colitis*, 13 (Supplement 1), S561–S562
8. Burke, P. J., & Stets, J. E. (2009). *Identity theory*. Oxford, UK: Oxford University Press.

Mexico

Reflections on the Commemoration of World IBD Day 2024 in Mexico City

On 17 May, Mexico City hosted a historic event: the commemoration of World Inflammatory Bowel Disease (IBD) Day. For the Mexican association Vivir con Crohn y CUCI, this gathering was particularly special, as it was the first time that multiple organisations from Latin America, alongside colleagues from Australia, Brazil, the United States and Canada, came together. These countries were pioneers in advocating for a day dedicated to raising awareness of IBD and it was truly inspiring to have their presence at the event.

Organised by EFCCA, the day featured a keynote speech by Professor Claudio Fiocchi, who shared his expertise and insights with all attendees. This event was not only emotional but also a turning point in our ability to collaborate. Thanks to this opportunity, we were able to strengthen ties that will be essential for coordinating joint activities at a regional level, thereby reinforcing our presence and visibility as a united region in the fight against IBD.



One of the key objectives that emerged from this event is the creation of a series of panel discussions, where each country will nominate an expert to discuss and compare how IBD is managed in their respective contexts. This exchange of best practices among specialists will be crucial for patients in each country to know the treatments that are available and that are aligned with international guidelines.

In addition, we are launching a regional survey to understand how long it takes for patients in each

country to receive a diagnosis. This information will be vital in crafting more efficient, patient-centered strategies, ultimately improving access to timely diagnosis and proper treatment.

The May event opened many doors, positioning Latin America as a region that can and should contribute to international efforts. Furthermore, the networking opportunities generated during this reunion have strengthened local organisations by allowing us to establish valuable alliances with our peers in other countries.

For us, this is just the beginning. We will continue to organise events that not only allow us to learn from countries with better IBD control and management but also provide opportunities to share the best practices being implemented in our region. Our mission is clear: to improve the quality of life for patients and continue advancing awareness and education about IBD.

Beatriz Capdevielle Gómez
Vivir con Crohn y CUCI A.C.

Belgium

CCV-vzw and EFCCA Collaborate on Patient Expert Training

This autumn, Crohn- & Colitis Ulcerosa Association vzw (CCV-vzw) is proud to once again host a disease-specific training seminar for our dedicated patient experts. Following the successful completion of general training provided by the Patient Expert Center, this specialised seminar aims to deepen the knowledge and skills of IBD patients Belgium, equipping them to advocate and support others facing similar challenges.

In 2021, we had the privilege of seeing six passionate and engaged patients complete this programme. Now, in 2024, we are excited to welcome a new group of six patients, equally

committed to making a difference in the IBD community. Their journey will be supported by a range of expert-led sessions designed to address the complexities of living with Crohn's Disease and Ulcerative Colitis.

One interesting component of our previous seminar was a session delivered by EFCCA, which focused on the international IBD landscape. This self-study module provided participants with a global perspective on the advancements and challenges in the field, followed by a multiple-choice test to assess their understanding. The insights gained from this session were invaluable,

offering our patient experts a broader context in which to situate their advocacy and knowledge.

We are pleased to announce that EFCCA will once again contribute to this year's seminar, helping to enrich our training programme. The session is scheduled for Monday, 18 November, at 7:00 PM and will follow a similar format to the previous edition. By drawing on both local and international expertise, CCV-vzw aims to create a seminar that truly prepares our patient experts for the role they play in improving the lives of those affected by Crohn's Disease and Ulcerative Colitis.



Slovenia

20 Years of Progress: Celebrating Two Decades of the Slovenian IBD Association

This year, the Slovenian Association for Chronic Inflammatory Bowel Disease, KVČB, celebrates its 20th anniversary. Over the past two decades, all the programmes and activities we have implemented have been aimed at improving knowledge of the disease and enhancing the quality of life for individuals living with chronic Inflammatory Bowel Disease.

On Saturday, 7 September, to mark our 20th anniversary, we organised an international symposium titled: "I have had IBD since childhood. How do I manage the disease?"

Among the distinguished speakers was the renowned gastroenterologist Prof. Dr. Petar Mamula, MD, PhD, from Philadelphia. Following the symposium, we hosted a gala event, where we presented awards to the most dedicated members of the Association. The evening concluded with a social gathering and dancing.



With 20 years behind us, we now look towards the future. We are planning further initiatives and projects that will continue to fulfil our mission and improve the lives of people with IBD. We are building on the strong foundations we have laid and I am confident that together we can achieve even more, strengthening the Association further.

Mateja Saje, KVČB President (left)

As President of the Association, I would like to extend my heartfelt thanks to everyone for their trust, support and commitment over these past two decades.

Mateja Saje
President of the Slovenian IBD
Association

Italy

AMICI Italia shouts from Sardinia: "IBD has no borders!"

On 12 May 2024, AMICI Italy, the Italian IBD Patient Association, celebrated World IBD Day in Cagliari, Sardinia, focusing on optimising the quality of life and lifestyle of IBD patients.

The event was led by Dr. Gianmarco Mocci, medical director in Cagliari, who acted as the scientific director. It was supported by several sponsors, including the Sardinia Region, the Municipality of Cagliari, AIGO (Italian Association of Gastroenterologists & Hospital Digestive Endoscopists), EFCCA, IG-IBD (Italian Group for the Study of Inflammatory Bowel Disease) and SIGENP (Italian Society of Gastroenterology, Hepatology and Paediatric Nutrition).

The theme, "IBD has no borders", emphasised the importance of a holistic approach to care, encompassing medical, social, psychological and healthcare aspects and promoting a national response involving patients, doctors, researchers and policy-makers, in line with the principles of Value-Based Healthcare. It is important to consider the patient as a whole person.

Dr. Mocci declared: "In Italy, 250,000 people live with these conditions, with an estimated incidence of around 10-15 new cases per 100,000 inhabitants per year. It is predicted that in the next 10 years, the prevalence could

increase by more than 30%-40%. The impact of these diseases on quality of life and mental health is enormous. Hiding symptoms and pain does not help. Illness should not be seen as a limitation. Talking about it helps in accepting the disease and fighting it."

The president of AMICI Italia, Mara Pellizzari, added: "Raising public awareness about chronic conditions and the importance of comprehensive care is crucial. We want to collaborate with doctors and institutions to address the gaps that continue to create barriers in the daily lives of IBD patients. It is essential that we work together to strengthen prevention at all levels."



The event covered several key topics, such as early diagnosis and classification methods of IBD, personalised treatments with multidisciplinary teams, active patient involvement in decision-making and management and access to high-quality care.

The morning began with patient stories from various regions, highlighting the global impact of the disease. The second session focused on innovations in IBD research and

treatment in Italy, exploring the latest developments. The third session looked to the future of IBD, with a borderless vision, reflecting on how technology, national health policy and partnerships can shape the future of IBD management.

Addressing IBD without borders involved recognising that patients' care needs can vary greatly depending on cultural and socio-economic factors, available support and personal life experiences. The

aim of the initiative was to highlight and promote the importance of a national response to IBD, demonstrating how patients, doctors, researchers and policy-makers can collaborate across regional boundaries to improve research, access to care and support for patients and their expectations.

AMICI Italia - Associazione nazionale per le Malattie Infiammatorie Croniche dell'Intestino

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Poland

World IBD Day in the Polish Parliament

This year's celebration of World IBD Day in Poland was remarkable. The "J-elita" Association organised a photo exhibition featuring patients with Crohn's Disease and Ulcerative Colitis at the Polish parliament in Warsaw. Representatives of the organisation also spoke during the meeting of the Parliamentary Group for Intestinal Diseases.



The photo exhibition, entitled "Inflammatory Bowel Diseases: Faces", created by gastroenterologist Prof. Rafał Filip and photographer Krzysztof Pisarek, was presented by "J-elita" in the Polish parliament building in May 2024. The exhibition portrays two sides of patients: one showing pain and despair at the time of diagnosis and the other depicting joy, passion and determination to live despite the disease. The photographs feature 22 of Prof. Filip's patients and were taken over three years. Each photo is accompanied by personal testimonies from the patients themselves.

"World IBD Day is the perfect opportunity to highlight the challenges faced by patients", emphasised Agnieszka Gołębiewska, President of the "J-elita" Association, during the exhibition's opening.

Introductory speeches were also given by MP Żaneta Cwalina-Śliwowska, Chair of the Parliamentary Group for Intestinal Diseases, Prof. Filip and Deputy Minister of Health, Prof. Urszula Demkow. The event was attended by parliamentarians, gastroenterologists from across Poland, experts and representatives of patient organisations, including a large delegation from "J-elita" and Magdalena Sajak-Szczerba,

representing the EFCCA Board.

Visitors to the exhibition were able to read about the disease and the various barriers hindering patients with IBD, including:

- Lack of personalised care to provide comprehensive treatment.
- Regional disparities in access to innovative therapies and specialist centres.
- Financial barriers, such as the cost of treatment and travel.
- Difficulties in obtaining a quick diagnosis.
- Stigmatisation and a lack of awareness of IBDs.
- Limited access to public toilets.

All participants received an exhibition catalogue containing the photographs and messages from patients. The exhibition, held in the Sejm, was viewed by high-profile figures, including all Polish parliamentarians and ministers.

Following the exhibition's opening, a meeting of the Parliamentary Group for Intestinal Diseases took place. The session began with introductions of special guests, including gastroenterologists and the President of "J-elita". The discussion covered the challenges faced by Polish patients, the rising incidence of IBD and the positive developments introduced on 1 April 2024, which the "J-elita" Association and clinicians had been advocating for over many years. By 2020, over 73,000 people in Poland had been diagnosed with Ulcerative Colitis and more than 23,000 with Crohn's Disease. Agnieszka Gołębiewska spoke about the urgent need to implement a personalised/coordinated care model in Poland. She also outlined other key demands from the patient community:

- Reimbursement of nutritional treatment for adults with Crohn's Disease.
- Reimbursement of faecal calprotectin tests.
- Equal access to biological treatments and specialist centres across all regions of Poland.
- An increase in the number of public toilets.
- Reinstating parking permits for patients with IBD, allowing them to park closer to public toilets in emergencies.



The Chair of the Parliamentary Group for Intestinal Diseases shared her personal experience of living with microscopic collagenous colitis for the past 20 years. She spoke candidly about the stigma attached to the disease and how it affected her ability to work as a teacher. She also described her struggle with severe depression, the strain on family relationships and the feelings of shame and lack of understanding she endured.

Deputy Minister of Health, Prof. Urszula Demkow, highlighted that Poland is working swiftly to introduce innovative medications for reimbursement under drug programmes. Currently, five modern treatments are available for Crohn's disease patients in Poland and seven for those with Ulcerative Colitis. The

Deputy Minister also addressed the demands raised by "J-elita", stressing that the ministry's role is to ensure equal access to healthcare across all regions. She expressed support for the personalised/coordinated care model and referenced the patient ID card, proposed by non-governmental organisations, to improve access to public toilets.

Additional events to mark World IBD Day were organised by the regional branches of "J-elita". On Saturday, 18 May, picnics were held for children with the disease and their families.

*Magdalena Sajak
Polish Society for Supporting People
with Inflammatory Bowel Disease
"J-elita".*

N-ECCO School Grant and Achievements

In February 2024, EFCCA awarded a significant grant to the N-ECCO (School of ECCO Nurses) to support their 15th annual educational course in Stockholm, Sweden. This initiative, part of ECCO's commitment since 2007, focuses on enhancing the educational opportunities for Inflammatory Bowel Disease (IBD) nurses across Europe and fostering a network for sharing best practices.

The grant enabled N-ECCO to provide a comprehensive one-day course, featuring lectures and workshops designed by expert committee members. This course prepares nurses, particularly those still in training and interested in IBD, to engage in advanced educational opportunities such as the N-ECCO Network Meeting and Research Forum, held biannually. In 2024, participation was extended

to 87 attendees, including 72 nurses from various ECCO member countries, 2 dietitians and 8 N-ECCO National Representatives. These representatives played a crucial role in supporting participants, many of whom spoke English as a second language. Additionally, 10 seats were allocated to dietitians and another 10 to global friends, reflecting the inclusive approach of the programme.





The course covered a broad range of relevant topics, including a detailed history of IBD, delivered by international clinicians and nurses. Feedback indicated a high level of satisfaction, with speaker evaluations averaging a score of 4.20. Participants praised the relevance of the topics to their clinical practice, underscoring the programme's success in enhancing nurse education.

EFCCA's grant also facilitated travel bursaries for participants from countries where industry sponsorship is restricted, ensuring that financial barriers did not hinder educational advancement. Learning materials, including PowerPoint presentations, are accessible online via the e-CCO Learning platform for all ECCO members, promoting continuous learning.

Overall, the N-ECCO School continues to serve as a vital platform for professional development and networking among IBD nurses and dietitians, ultimately improving patient care quality and welfare across Europe.

*Anna Thiel, MA
Junior Society Project Manager
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Organisation)*

EU-X-CT Cross-Border Clinical Trials Initiative: Request to Patients/Caregivers to Complete our Patient Questionnaire

For many patients, participating in a clinical trial is a vital lifeline. The lack of clinical trial options in their home country urges many patients, particularly those with life-threatening or rare diseases, to seek options across borders. Yet, despite high demand, it is rare for patients to gain access to clinical trials beyond their home country. The absence of an EU-wide legal framework or any guidance that defines the conditions for accessing clinical

trials in another country creates high barriers for patients and healthcare professionals.

The EU-X-CT Cross-Border Clinical Trials Initiative was born out of this unmet need and aims to improve cross-border access to clinical trials for patients in Europe. The initiative is a concerted effort by volunteers from patient organisations, academics, research networks, industry and not-for-profit organisations, led by EFGCP and EFPIA.

EU-X-CT hosted its first Public Stakeholders' Forum on 12 April 2024 in Brussels. This event gathered a diverse group of stakeholders to address the challenges of patient participation in cross-border clinical trials within Europe. At the end of the meeting, EU-X-CT leadership presented a six-point action plan as a way forward.

- Minimal Ethics Committee requirements: Collaborate with MedEthicsEU to work out the minimal ethics committee requirements for cross-border participation in clinical trials.
- Recommendations for sponsors and CROs: Develop a set of recommendations for industry and academic sponsors, as well as CROs, on how to approach cross-border trials in their protocols, when to inform the relevant ethics committees about the planned conditions and how to prepare and support sites for hosting patients from abroad.
- Guidance for investigators and sites: Develop a set of recommendations for investigators and sites on aspects they need to clarify when wanting to host patients from abroad.
- Cost coverage clarity: Reach out to payers and health insurance companies to get clarity on the cost coverage of cross-border trial participation.
- Liability insurance: Clarify with liability insurance companies how damages occurring to the patient in his/her home country could best be covered.
- Awareness and national contact points: Raise awareness among patients and treating physicians about the option of cross-border participation in clinical trials. Establishing national contact points for patients was also suggested.



Currently, EU-X-CT is gathering detailed information about the obstacles patients face when they want to enrol in a clinical trial in a foreign country. To achieve this, the initiative needs help in gathering crucial information from European countries (both EU and non-EU) on patient-related aspects of cross-border clinical trial participation.

A questionnaire has been created to collect valuable insights and experiences. Every response counts. Patients, carers and patient organisations are encouraged to share their experiences about accessing a clinical trial in another country. Whether they could or could not participate in such a clinical trial abroad, their contributions are vital.

Please take a few moments to share your country-specific experiences. The questionnaire is available in 24 languages in addition to English.

Important note: You don't need to be an expert on all topics—every bit of information helps, even if some or most answers are "don't know" or "N/A."

Once the survey is complete and the results are analysed, the information will be made available for free on the EU-X-CT website per country.

If you have experience with cross-border clinical trials as a patient or caregiver, help us by filling out our [patient questionnaire](#). Follow EU-X-CT on [LinkedIn](#) and [Facebook](#).

IBD PODCAST Feature for UEGW

EFCCA is pleased to share an insightful article about a recent AbbVie study focused on disease management findings in Inflammatory Bowel Disease (IBD). We believe this article will be of great interest to our patient community, offering valuable perspectives on potential improvements in IBD care. Our aim is to keep you informed about ongoing research and development that may impact your health and wellbeing.

Only half of people living with Inflammatory Bowel Disease (IBD) have achieved optimal disease control, according to data from a new global study

People with IBD, including Crohn's disease (CD) and ulcerative colitis (UC), not achieving optimal control, need improved approaches to disease management

Global Study Finds there is Room for Improvement in Patient Management of IBD

New findings from a global IBD study showed that 52.2% of patients with CD and 44.3% of patients with UC had suboptimal disease control – meaning that their disease management could be improved.^{1*}

In the IBD PODCAST study (**Proportion of Inadequate Disease Control and Strategy of Treatment in IBD**), researchers used the IBD STRIDE-II clinical recommendations to analyze charts and clinical tests of more than 2,000 patients with IBD across 10 countries and found that approximately half of patients were not meeting objective criteria for optimal disease management.^{1,2}

People with suboptimal IBD control can experience a range of unwanted health outcomes that lower quality of life, including increased extraintestinal complications, failure to achieve healing of the intestinal lining (mucosal healing), overuse of steroids (in UC), development of perianal disease (in CD) and more.¹

Take action: Learn what is happening inside your gut.

[Understand](#) how IBD impacts your gut and physical health. Even when you are feeling good, there may be more you can do to control IBD and achieve mucosal healing.

Beyond the Physical Symptoms of IBD

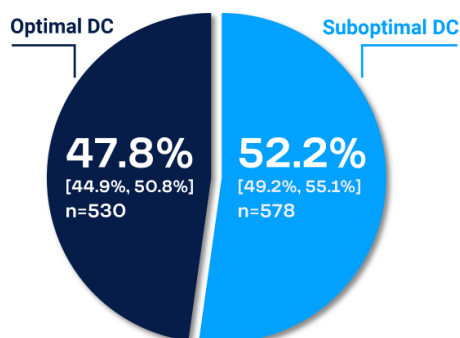
If you are living with IBD, or caring for a loved one with IBD, you know that this condition can impact more than just the gut – it can influence overall quality of life.¹

From mental health and social relationships to productivity and general wellbeing, IBD can impact many aspects of daily life. The IBD PODCAST study found that patients with CD or UC who had suboptimal disease control had substantially lower work productivity than patients with optimal disease control.^{3*}

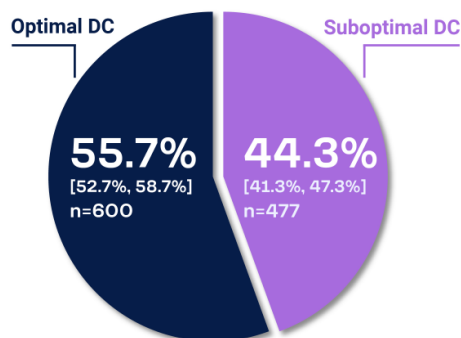
While achieving a better quality of life will look different for everyone, it is important to talk with your doctor and discuss what living life to the fullest with IBD means for you or your loved one.

IBD SUBOPTIMAL DISEASE CONTROL (DC) ACCORDING TO IBD PODCAST STUDY FINDINGS

Crohn's Disease (n=1108)



Ulcerative Colitis (n=1077)



abbvie

Take action: Track how you are feeling. Write down the ways CD or UC impacts your life, including physical symptoms and social and emotional well-being. Note when your day-to-day routine changes. Consider holistic monitoring in partnership with your care team using tools available in clinical practice.

Collaborating with Your Care Team

IBD is a complex condition that can be difficult to explain. How you talk

about your IBD may be different than how your doctor talks about it, but it is important that you understand each other and agree on your approach to managing the disease. Additional findings from the IBD PODCAST study show that when disease control was assessed with patient- or doctor-reported criteria, patients were less likely than doctors to report suboptimal disease control, and reporting from both patients and doctors was lower than the half of patients with suboptimal control identified per

STRIDE-II clinical recommendations. Overall, only a small percentage of patients with CD (10.9%) and UC (13.0%) and physicians (15.7% in CD and 17.9% in UC) reported suboptimal disease control.^{4*}

Take action: Talk to your doctor.

Set goals and be honest with your care team. Engaging in robust patient-doctor discussions can help with shared decision-making and timely action, potentially leading to improved health outcomes.

*Study funded by AbbVie

References

1. D'Amico F, Gomollón F, Bamias G, et al. Proportion of Inflammatory Bowel Diseases patients with suboptimal disease control in daily clinical practice—real-world evidence from the Inflammatory Bowel Diseases-podcast study. *United European Gastroenterol J.* 2024;12(6):705-716.
2. Turner D, Ricciuto A, Lewis A, et al. STRIDE-II: an update on the selecting therapeutic targets in Inflammatory Bowel Disease (STRIDE) initiative of the International Organization for the Study of IBD (IOIBD): determining therapeutic goals for treat-to-target strategies in IBD. *Gastroenterology.* 2021;160(5):1570-1583.
3. Gomollón F, Bamias G, D'Amico F, et al. Health care resource utilization of suboptimal control of IBD: IBD PODCAST study results. Poster presented at: *Digestive Disease Week (DDW) 2024; May 18-21, 2024; Washington, D.C., United States.* Poster Tu1106.
4. D'Amico F, Gomollón F, Bamias G, et al. Lack of concordance between patient-reported, physician-reported and objective criteria-based identification of suboptimal control in IBD patients: IBD PODCAST study results. Poster presented at: *19th Congress of the European Crohn's and Colitis Organisation (ECCO); February 21-24, 2024; Stockholm, Sweden.* Poster P732.

Revolutionising IBD Research: James Lee Discusses Landmark Findings

Interviewed by Isabella Haaf (EFCCA's Head of Communications)

In a groundbreaking discovery, UK researchers have identified a new biological pathway that drives Inflammatory Bowel Disease (IBD) and could potentially be targeted with existing drugs. This significant finding was the result of collaborative research conducted by the Francis Crick Institute, University College London (UCL) and Imperial College London. The team uncovered a region of DNA that enhances the activity of specific macrophages (white blood cells), thereby driving inflammation and increasing the risk of IBD. Today, we have the privilege of speaking with James Lee, the lead researcher of this study, to gain deeper insights into this discovery and its potential implications for IBD treatment and management.

The European Federation of Crohn's and Colitis Associations, representing 46 national IBD patient associations, is thrilled to hear about your research findings. Could you explain in simple terms what your discovery is about?

We know from numerous genetic studies conducted over the last 10 to 15 years that both Crohn's Disease and Ulcerative Colitis (collectively referred to as Inflammatory Bowel Disease) have a significant genetic component.

We have identified numerous regions in our DNA that contribute to the development of these diseases and know their locations. However, the challenge lies in understanding the specific mechanisms within these regions that lead to IBD. This knowledge is important because moving from identifying where the associations are to understanding what exactly goes wrong can potentially lead to new ways to treat the disease.

We began investigating a DNA region identified about 15 years ago that is known to increase the risk of both Crohn's disease and Ulcerative Colitis, as well as several other diseases. The function of this region remains unclear, partly because there are no obvious genes located at the site of the association.

You need to understand that in fact, only about two percent of our DNA is used for encoding genes; the rest

was once considered "junk" because its function was unknown. When genetic associations are found in large stretches of DNA without any genes, they are often overlooked in favour of associations that are easier to understand.

We initially realised that since this region not only increased your risk of developing IBD but also increased your risk of getting various other diseases, it must hold significant importance. When a region elevates the risk of multiple diseases, it indicates a crucial role in human health. Moreover, it likely influences the immune system because these diseases are all characterised by an abnormal immune response.

What exactly did you discover in this region that helps us to better understand IBD?

We basically discovered that within this region, there is something called an enhancer. An enhancer functions like a volume dial for genes—it can "turn up" or "turn down" the amount of a nearby gene. We observed that this enhancer is specifically active in a type of cells known as macrophages.



Macrophages are important in the context of IBD for two main reasons. Firstly, in IBD, there is a significant influx of macrophages into the intestine, where they contribute to inflammation. Secondly, some of the most effective treatments for IBD currently target the inflammatory chemicals produced by these macrophages.

Eventually, we identified the gene through a series of experiments where we could "deactivate" or "increase its expression". This discovery led us to realise that what we had found was actually the central regulator of inflammation in macrophages.

When "activated", macrophages became very inflammatory; conversely, when "deactivated", they lost their inflammatory capabilities. Interestingly, even in

resting macrophages that were not previously activated, 'activating' this gene caused them to look like the macrophages found in the inflamed guts of patients with Crohn's Disease and Ulcerative Colitis. So, by just turning on one gene made macrophages look like those found in patients with IBD. This discovery marked the initial breakthrough in uncovering this entire pathway.

This is really exciting news because, if I understand correctly, targeting this pathway could mean that patients won't have to endure the frustration of trying multiple treatments before finding relief?

Yes, the second exciting discovery we made is figuring out a method to

deactivate this pathway. Currently, some of the most effective drugs for IBD target individual molecules that macrophages produce, such as anti-TNF or anti-R23. However, we've learned that targeting multiple molecules simultaneously can sometimes be more effective than targeting just one. For researchers the ultimate goal has been to identify a single protein that, if targeted, could effectively switch off all these pathways, which would potentially be much more effective for treatment.

We have found a way of "switching off" this pathway using a drug already approved for use in people, though not yet for inflammatory diseases. However, this drug isn't yet ready for patient trials because it's not safe for long-term use and of course IBD is a chronic condition.

We are now working hard to make this drug more targeted and safer. We hope this effort will result in a much more effective IBD treatment in the near future. This could spare patients from the trial and error of current treatments, offering one drug capable of addressing multiple pathways and significantly improving patient outcomes.

When you mention the near future, could you provide a rough timeframe or specify how soon we might expect to see developments or changes based on your findings?

It's a crucial question and I believe we have a couple of advantages. First, transitioning from basic discovery to a drug typically takes 10 to 15 years. However, we have a significant head start because the drugs we're considering have already undergone comprehensive safety testing in humans. This prior safety testing gives us a substantial advantage compared to starting from scratch.

And fortunately, we have already begun developing molecules designed to specifically target inflammatory macrophages. These molecules are currently undergoing testing in the lab, with development having started approximately six months ago.

If these molecules prove effective, the next step will be to develop a drug suitable for human use. I am optimistic that within the next two

years, we will have a drug ready to undergo the necessary regulatory approvals for eventual use in patients. Following that, I hope to begin clinical trials shortly thereafter. Ideally, I envision dosing the first patient with a drug targeting this pathway within the next two to three years, initially through trials and eventually obtaining approval for broader use.

You previously talked about the genetic component related to your research. Does this have any implications for predicting the disease? As you can imagine, this is a major concern for individuals with a family history of IBD?

First and foremost, it's important to reassure people that discovering a strong genetic link does not mean everyone in the family will develop IBD. We have long understood that if someone has Crohn's disease or UC, the likelihood of any first-degree relatives—such as children, siblings, or parents—also developing Crohn's is only about 10% over their lifetime. There's no need for anyone to panic about this.

Another important aspect of IBD is that it typically involves multiple pathways being affected and then being triggered by environmental factors. This is why people don't usually develop IBD at birth but rather later in life, typically around 20–30 years of age. While this genetic pathway we've identified is significant, it alone isn't sufficient to

predict who will develop IBD.

Here's how I explain it to my patients in clinic: both genetics and an environmental trigger are necessary. I often use this analogy—a loaded gun represents genetics and the trigger being pulled represents the environmental trigger. If a gun is loaded but the trigger is never pulled, it won't fire and you won't develop the disease and similarly, if the trigger is pulled but the gun isn't loaded in the first place, it also won't fire.

We've received many questions through social media and other channels from individuals worried about their first-degree relatives but there is no need for concern. The main excitement about our work is that we've identified a central pathway involved in IBD that we believe can be targeted with drugs. This discovery doesn't have major implications for whether people's first-degree relatives or children will develop IBD in the future.

Talking about implications, it's correct to say that while this discovery is certainly going to be a game-changer for IBD, it doesn't have any direct impact on current treatment options at the moment?

That's correct. I've had many people contact me asking, "Can we join the clinical trial? Can I stop my medication now?" The answer is: if you're already on medication that's working for your IBD, you should continue with it.

At the point that we're ready for clinical trials, we will make it known and then people if they want to be involved in those clinical trials can have the opportunity to do that, but at the moment we don't have a drug that's ready to go into people just yet and so people should sit tight we're working as fast as we can on this and as the patient community, we'll

keep you posted in terms of where we get to.

When we're ready for clinical trials, we'll announce it and those interested will have the opportunity to participate. However, at this moment, we don't have a drug ready for human trials. Please be patient as we're working as quickly as possible.

We share your excitement about this work and are fully committed to putting our efforts into it.

We'll keep the patient community updated on our progress!

Glossary:

Association: *In the context of DNA, an association refers to a statistical relationship between a specific genetic variant and a particular trait or disease, indicating that the presence of the variant is correlated with an increased or decreased likelihood of the trait or disease.*

Regions in DNA: *Regions in DNA are specific sequences or segments of the DNA molecule that have particular functions, such as coding for proteins, regulating gene expression, or acting as structural components.*

Macrophages: *Macrophages are a type of white blood cell that helps protect the body by engulfing and digesting harmful bacteria, dead cells and other debris.*

Pathway: *In a medical sense, a pathway refers to a series of actions among molecules in a cell that leads to a certain product or a change in the cell, often involving processes like metabolism, signal transduction, or gene expression that are crucial for maintaining health and responding to disease.*



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