

EFCCA MAGAZINE

EUROPEAN FEDERATION OF CROHN'S AND ULCERATIVE COLITIS ASSOCIATIONS

MAY 2023

IBD HAS NO AGE

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EFCCA makes the difference**

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Closing the conversation gap in IBD

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www.oemccv.at

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

Bulgaria - BCUCA
www.babkuk.org

Croatia - HUCUK
www.hucuk.hr

Cyprus - CYCCA
www.cycca.org

Czech Republic - Pacienti IBD
www.crohn.cz

Denmark - CCF
www.ccf.dk

Estonia - EPSS
www.ibd.ee

Finland - IBD ja muut
www.ibd.fi

France - AFA
www.afa.asso.fr

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

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Iceland - CCU
www.ccu.is

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Crohn's and Colitis Ireland
www.iscc.ie

Israel - CCFI
www.ccfi.co.il

Italy - AMICI
www.amiciitalia.org

Latvia - LKKSBB
www.lkksb.lv

Lithuania - CCLA
www.draugija.info

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

Malta - MACC
www.macc.org.mt

Montenegro - CUKUK
www.cukuk.me

New Zealand
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www.crohnsandcolitis.org.nz

Netherlands
Crohn & Colitis NL
www.crohn-colitis.nl

Norway - LMF
www.lmf Norge.no

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

Portugal - APDI
www.apdi.org.pt

Romania - ASPIIR
www.aspiir.ro

Serbia - UKUKS
www.ukuks.org

Slovakia - SCC
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Slovenia - SAIBD
www.kvcb.si

Spain - ACCU
www.accuesp.com

Sweden - MOT
www.magotarm.se

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

Turkey - IBHDYD
www.ibhportali.com

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

Associate Members:

Argentina - Mas Vida
www.masvida.org.ar

Brazil - DII Brasil
www.facebook.com/diibrasil

Lebanon - I Battle Disease
www.ibattledisease.org

Kazakhstan - FPVZK
www.vzk.kz

Mexico - CUCI
www.crohncuci.org.mx

Russia - Trust
www.vzk-life.ru

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

Trinidad and Tobago -
NACCTT
www.crohnsandcolitistt.org

Ukraine - Fulfilling life
www.gofulllife.com.ua

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Foreword

It is my pleasure to introduce you to the latest edition of the EFCCA Magazine, which showcases our commitment to empowering and supporting people with Inflammatory Bowel Disease (IBD) and improving their quality of life.

As we celebrate World IBD Day this month, we want to acknowledge the strength and importance of working together to raise awareness about the challenges faced by people living with IBD. This year, we are excited to focus our efforts on a group that is often overlooked: IBD adults aged 60 and over. As we age, the challenges of managing chronic illnesses become increasingly complex, and this is especially true for those with IBD. Our goal is to gather information through a survey to improve the care and support provided to this population.

The magazine also features our new working methodology, DIVA, and its innovative approach to address the real needs of patients with IBD that represents a vital step forward for our organisation. Furthermore, you will have the opportunity to read about the consultation process for our new strategic plan 2023-2026, which reflects the collective effort of all 46 EFCCA members and which is due to be ratified by our General Assembly in Bratislava on 9-11 June 2023.

As we enter this new era for EFCCA, we are excited about the future and the possibilities that lie ahead. We believe that our innovative approach and strategic plan will help us to serve the needs of patients with IBD better and make a meaningful difference in their lives.

We look forward to working together with our partners and supporters to achieve our shared vision. Thank you for joining us on this journey as we believe that together we can make a difference.

Salvo Leone,
EFCCA Chairperson



Editorial

Welcome to our May issue of the EFCCA Magazine where you will find the latest news and insights from the world of Inflammatory Bowel Disease (IBD).

In our EFCCA news section you can read detailed accounts about our activities in recent months in particular our focus for World IBD Day 2023, our new working approach, DIVA, and our networking efforts with the European Crohn's and Colitis Organisation (ECCO) as well as the European Association of Hospital Pharmacists (EAHP).

EFCCA has launched five significant research and development projects this year, as part of Horizon Europe. We are thrilled to introduce these initiatives and highlight how they fit into our organisation's overall objective.

We are also proud to feature examples of some of the incredible work our members are accomplishing at the national level. From the organisation of summer camps, advocacy work for children with IBD to awareness raising efforts, our members are making a meaningful impact in their communities.

In the Living with IBD section, Oona Liikanen, a volunteer with our member IBD ja muut (Finland) shares her personal story of studying abroad "despite" IBD. These stories serve as a reminder that IBD is not just a disease, but a journey that affects every aspect of a person's life.

Last, but not least, we bring you the latest in scientific news and developments in the world of IBD research. We believe that staying up to date is essential to advocate for better care and treatment of those with the disease.

We would like to thank our readers for their continued support and encourage you to stay engaged with our organisation.



Isabella Haaf,
EFCCA Head of Communications

World IBD Day 2023

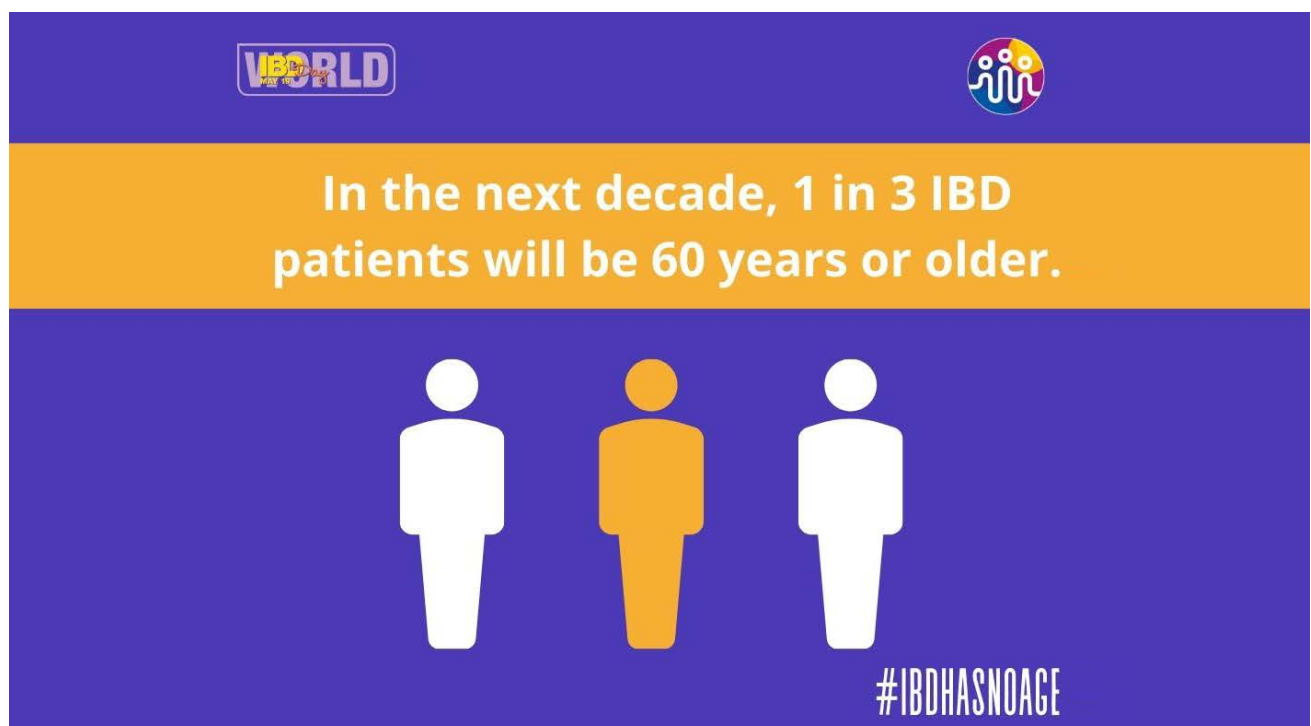
IBD HAS NO AGE

On 19 May, World IBD Day 2023, EFCCA is launching a survey on IBD in people aged 60 years and over. We want to find out more about how IBD impacts this age group. Help us spread the survey and our campaign!

IBD HAS NO AGE is an EFCCA campaign that started in 2022 in order to raise awareness of how Inflammatory Bowel Disease (IBD) is impacting on the life of people aged 60 years and over.

Why people with IBD aged 60 years and over?

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



Our Key messages of the IBD has no age campaign are:

Equal access to best treatment options

Currently, clinical data to inform treatment options practices are based on observational data or indirect evidence because people with IBD aged 60 years and over are underrepresented in clinical studies. Therefore, there is a risk of IBD patients in this age group not benefitting from best treatment options. We need a better understanding of the disease epidemiology among the older population and specific knowledge for the management and treatment of IBD in advanced age. There needs to be more research on specific issues related to comorbidities, polypharmacy, drug effectiveness and interactions.

Being better prepared - personalised medicine

The fact that the IBD population is shifting towards an older age calls for comprehensive actions to meet these challenges and better prepare our healthcare systems for an ageing IBD population. As such, health systems must be capable of providing older person-centred and integrated care and focus on maintaining capacities as people age. The approach to treatment must be tailored to the individual.

Our mindset

Our mindset around ageing needs to change!

Ageism – discrimination against a person based on their age – has severe consequences for older people and societies at large. Older people are often assumed to be frail or dependent and a burden to society. Health professionals, patient associations and other stakeholders must tackle this discrimination and strive towards comprehensive approaches and policies to enable a good quality of life for elderly patients.



Get involved!

Help us become more visible. Share the IBD has no age campaign on social media, using our graphics and hashtags (#ibdhasnoage, #worldibdday2023).

[Read more about the campaign](#)

[Download the toolkit](#)

Empowering Patient Representatives

EFCCA has been developing and refining the tools we announced last quarter to standardise and strengthen patient representation. We are excited to share the latest updates and new features on our data analysis platform, DIVA, as well as our manual for reviewing clinical trial protocols from a patient's perspective.

DIVA: A Comprehensive Data Analysis Platform for Patients

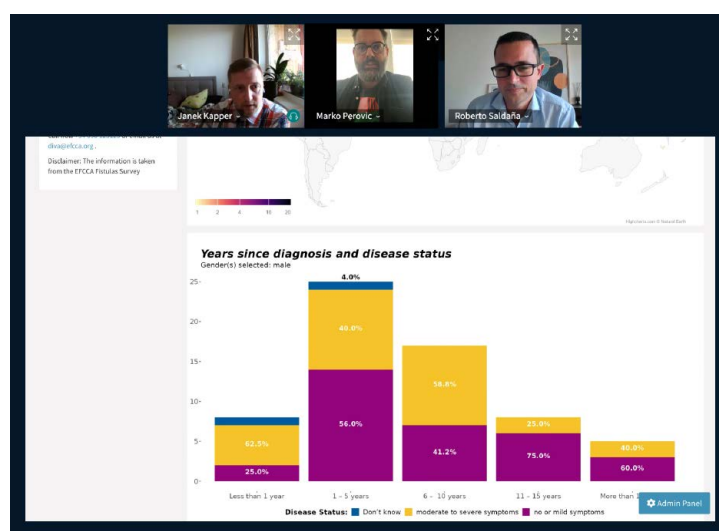
On 19 April 2023 we publicly launched the first version of DIVA, which includes the following features:

- A multimedia library with instructions for use, ensuring accessibility for all users.
- A European search engine for clinical trials, enabling exploration of:
 - ▶ The evolution of new clinical trials by period and conditions.
 - ▶ The current status of clinical trials in Crohn's disease and ulcerative colitis.
 - ▶ The location of clinical trials and their temporal and geographical evolution.
- A search engine for IBD drugs in the EU, with filters to explore:
 - ▶ By conditions and regulatory status.
 - ▶ Availability by country (Spain has been the first to be included).
- A patient status finder by topics of interest, allowing browsing of:
 - ▶ Different datasets (we have initially added the fistulas dataset).

Additionally, we have been collaborating with EFCCA member associations to gather feedback and identify potential new features, such as incorporating other territories and surveys conducted by our members in their respective countries.

The screenshot shows the DIVA web application interface. At the top, there are navigation links: Home, Trials, Market Access, and EFCCA surveys. Below this, there are filters for Date (01/01/1999 to 12/04/2023), Agency (EMA), and Disease (All). A sidebar on the left provides contact information and a disclaimer. The main content area displays a table of 15 entries for IBD drugs. The table columns are: Date, Name, Type, Active substance, Status, Orphan, Company, and IBD. The drugs listed include Hukydria, Libemrys, Jayempi, Yuflyma, Jyseleca, Zeposia, Amsparity, Rinvoq, Skyriz, Idacio, Kromeysa, and Hulio.

Date	Name	Type	Active substance	Status	Orphan	Company	IBD
2021-11-15	Hukydria	biosimilar	adalimumab	authorised	no	Stada	both
2021-11-12	Libemrys	biosimilar	adalimumab	authorised	no	Stada	both
2021-06-21	Jayempi	original	azathioprine	authorised	no	Nova Laboratories	both
2021-02-11	Yuflyma	biosimilar	adalimumab	authorised	no	Celltrion	both
2020-09-24	Jyseleca	original	filgotinib maleate	authorised	no	Galapagos	ulcerative colitis
2020-05-20	Zeposia	original	ozanimod hydrochloride	authorised	no	Bms	ulcerative colitis
2020-02-13	Amsparity	biosimilar	adalimumab	authorised	no	Pfizer	both
2019-12-16	Rinvoq	original	upadacitinib	authorised	no	Abbvie	ulcerative colitis
2019-04-26	Skyriz	original	Risankizumab	authorised	no	Abbvie	crohn's
2019-04-02	Idacio	biosimilar	adalimumab	authorised	no	Fresenius Kabi	both
2019-04-02	Kromeysa	biosimilar	adalimumab	authorised	no	Fresenius Kabi	both
2018-09-17	Hulio	biosimilar	adalimumab	authorised	no	Watris Limited	both



For more info please write to:
diva@efcca.org

The Protocol Review Handbook: Standardising Patient Perspectives in Clinical Trials

We have drafted a handbook designed to ensure a standardised review of clinical trial protocols from the patient's point of view. The structure of this document is as follows:

- Introduction
- Clinical trials
- The clinical trial protocol
- The Role of Patients in the Design of clinical trials
- Critical aspects of reviewing:
 - ▶ Rationale
 - ▶ Population
 - ▶ Design
 - ▶ Primary and secondary objectives
 - ▶ Inclusion and exclusion criteria
 - ▶ Tests and interventions
 - ▶ Patient-reported outcomes (PROs)
 - ▶ Timing
 - ▶ Safety
- Protocol review:
 - ▶ Requirements before starting
 - ▶ Review form (checklist)

We want to emphasise that all our comments and suggestions in this handbook arise from previous work by EFCCA with scientific literature references.

The following steps involve a review of the document by patients who wish to contribute their perspectives, followed by sending it to EFCCA associations to gather their opinions.

These tools will significantly enhance patient representation and collaboration with key stakeholders in the healthcare sector. By providing comprehensive

Protocol review checklist

Rationale

- ☐ Unmet need
- ☐ Stratification solution
- ☒ efficiency improvement
- ☐ safety improvement
- ☒ Subgroup without alternative
- ☐ Other

☐ Real World Evidence (RWE)

This clinical trial is aimed at Crohn's disease patients with **fistulas**: the subgroup with the worst quality of life because they lack specific **treatments**.

We agree that current clinical practice consists of surgeries and trying treatments off-label, which results in poor disease control and a life of continuous physical and mental suffering.

and accessible information, we empower patient representatives to make informed decisions and contribute meaningfully to developing treatments for their conditions. We look forward to the continued growth and improvement of DIVA and the Protocol Review Handbook, and we welcome feedback from all users and stakeholders to help us improve these tools.

Roberto Saldaña
EFCCA Innovation and Patient Engagement
Coordinator

EFCCA Strategy Plan 2023 – 2027: A consensus exercise

The EFCCA Strategy Plan 2019 – 2022, also titled Anti-DiscriminAction, is coming to an end. Its main goal was to tackle discrimination at work, to access treatments, to access health information, and to share decision-making and it focused on 4 priority areas, IBD & Quality of care (2019), IBD & Work (2020), IBD & Well-being (2021), IBD & Life cycle (2022).

The plan was developed by the board through a strategic planning process, presented, discussed, and approved by the General Assembly. The plan was successfully implemented and beyond. In fact, the secretariat implemented several activities that were not in the original plan but are very strategic for EFCCA, such as the work done to be part of large EU-funded research projects and the collaboration started with IBD patients' associations outside of Europe, not to mention the work done to face the pandemic and the war in Ukraine.

For the new period, the current Board and secretariat were brave enough to undertake new consensus-building method to develop the EFCCA Strategy Plan for the years 2023-2027.

They decided to involve all EFCCA delegates in the decision-making process. The journey started on the 10 June 2022 when the EFCCA Board and Secretariat kicked off the work. EFCCA delegates met in Barcelona to establish the roots of the EFCCA 2023 – 2027 Strategy Plan.

The objective of the day was to build on what was done in the past, strategize for the future, share ideas to improve IBD care, share ideas to improve EFCCA benefit to people with IBD, and overall reduce the burden of IBD on people, carers, healthcare systems, and the society. The discussion was very lively, and many ideas were generated and fed the work to develop the next Strategy Plan.



The ground was well prepared to move on involving all the members via online consultations. The EFCCA Board and Secretariat wanted to give the opportunity to all EFCCA members to actively contribute all along the process. They trusted the membership was mature to move to the next level.

Three consultations were set up using Survey Monkey. The first consultation was about EFCCA's Vision, Mission, and Values and was open in August and September 2022. 37 delegates representing 77% of the EFCCA membership answered the consultation and the absolute majority confirmed the current Vision, Mission, and Values.

Based on the discussions and reflections with the delegates during the meeting in Barcelona last year, the Board identified the strategic objectives for the next period and redefined the structure of the strategic areas into: Networking, Advocacy, Research & Development, Empowerment and Awareness raising.

The second consultation was organised in October and November 2022 and aimed at getting more inputs under each Strategic Area. The turnout of the delegates was again very high, with 77% of respondents.

The third round of consultations ran between December 2022 and January this year and the turnout of the EFCCA delegates was even higher with 79% of the respondents.

We will not disclose the details of the final strategy, yet. That will be presented to the General Assembly for its formal endorsement and then published on our website.

We believe that the high turnout of EFCCA delegates to each round of consultations is by itself a success and shows the high commitment of the membership and the motivation to move a step forward.

Antonella Cardone, Strategy Plan Adviser

Value through
innovation



*Transforming lives for generations
– Our purpose.*

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

ECCO Congress

EFCCA participated in the 18th ECCO Congress, an annual scientific conference organised by the European Crohn's and Colitis Organization (ECCO), that took place in Copenhagen, Denmark, from 1 to 4 March 2023.

It is one of the largest gatherings involved in managing and treating inflammatory bowel disease (IBD). This year, it garnered over 6946 participants, including healthcare professionals, researchers, patient advocates, and industry representatives from 93 countries around the world.

The congress featured a wide range of sessions, including keynote lectures, symposia, workshops, and poster presentations, covering the latest developments in IBD research and clinical practice. Attendees also had the opportunity to learn about new findings, share best practices, and network with other professionals in the field.

In addition to the scientific program, the ECCO Congress included various activities and events, such as an exhibition hall showcasing the latest medical products and services, social events, and career development and training opportunities.



Elise Schoefs during the poster presentations



EFCCA also set up a booth to meet and greet its community and members. EFCCA CEO, Luisa Avedano and Deputy Director, Isabella Haaf participated in key meetings and networked with our stakeholders. EFCCA's Innovation and Patient engagement coordinator, Roberto Saldaña participated in the 8th ECCO National Study Group Meeting where he presented a roadmap concerning EFCCA's role in supporting independent researchers to generate the evidence needed in clinical practices.

In addition, Elise Schoefs, PhD Researcher–KU Leuven who is collaborating with EFCCA on the Patient Preference study presented the highlights of the qualitative study published in Journal of Crohn's and Colitis (JCC) during the poster presentation session.

On 2 March the General Assembly of ECCO took place where elections to the future ECCO leadership took place. EFCCA would like to congratulate Fernando Magro for being elected as the New President Elect of ECCO and we look forward to a fruitful cooperation.



Roberto Saldaña at the 8th ECCO National Study Group Meeting

Patient-Centered Research in Drug Development for Inflammatory Bowel Disease

The development of new drugs is a complex and lengthy process that involves various stakeholders, including researchers, healthcare professionals, and regulatory agencies. However, one important stakeholder is often overlooked - the patients who will ultimately use these drugs. As patients are the ones who will experience the benefits and side effects of these drugs, their perspectives and experiences should be considered during the drug development process.

In recent years, there has been a growing interest in involving patients in drug development, and one way to achieve this is through the use of patient-reported



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outcomes (PROs). PROs are assessments of health-related quality of life that are completed by patients themselves, providing valuable information on the impact of a disease and its treatment on patients' lives.

This patient-centered research focuses on the use of PROs in the development of new biologic drugs for Inflammatory Bowel Disease (IBD). IBD includes ulcerative colitis and Crohn's disease, which are chronic conditions that can significantly impact patients' quality of life. The study examines the use of PROs at different stages of drug development, from clinical trials to regulatory approval and reimbursement decisions (Figure 1).

The research is conducted by patient organisations, including the European Federation of Crohn's & Ulcerative Colitis Associations (EFCCA), the Crohn's & Colitis Young Adults Network (CCYAN), and the Crohn's & Colitis Foundation. These organisations represent patients with IBD and aim to ensure that the patient voice is heard in the drug development process.

At the end of the study, the patient organisations will provide a statement outlining what the international IBD patient community considers to be patient-centric. This statement will guide other stakeholders,

such as healthcare professionals, industry, regulatory agencies, and health technology assessment (HTA) bodies, on the use of PROs in the development of new biologic drugs for IBD.

In summary, patient-centered research that incorporates PROs is crucial for developing drugs that truly meet the needs of patients with IBD. By involving patients in the drug development process and considering their perspectives, we can develop more effective and patient-centered treatments.

Gloria Macia, Health Policy Department,
London School of Economics (LSE)

Rocco Friebe, Health Policy Department,
London School of Economics (LSE)

Patient involvement in medicines R&D: a practical roadmap

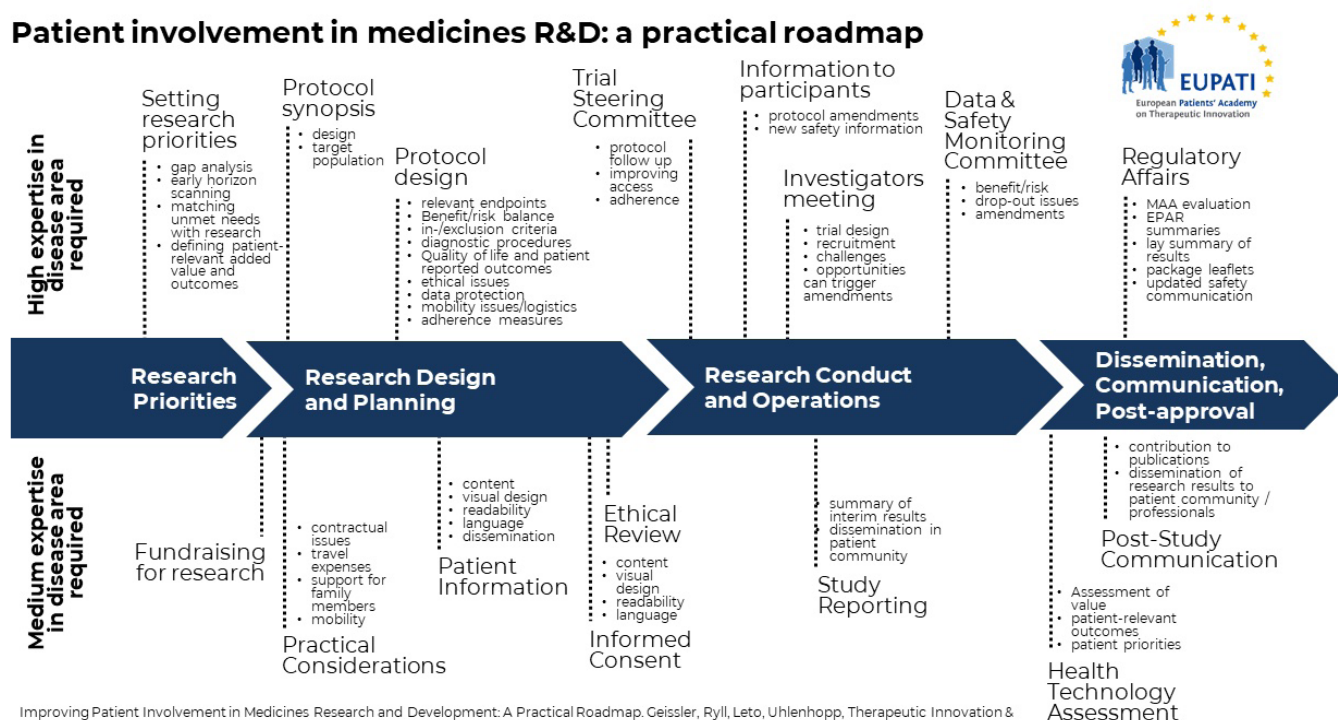


Figure 1.

A practical roadmap to improve patient involvement in medicines R&D

Collaborating for Better Care

On 22 to 24 March 2023, EFCCA had the opportunity to participate in the 27th Congress of the European Association for Hospital Pharmacists (EAHP) which took place in Lisbon.

The congress provided an excellent opportunity for EFCCA to learn more about the role of hospital pharmacists in healthcare and to share our experiences. We met with EAHP President, Andras Sule and his colleagues, to discuss common projects on how to improve awareness and collaboration with hospital pharmacists.

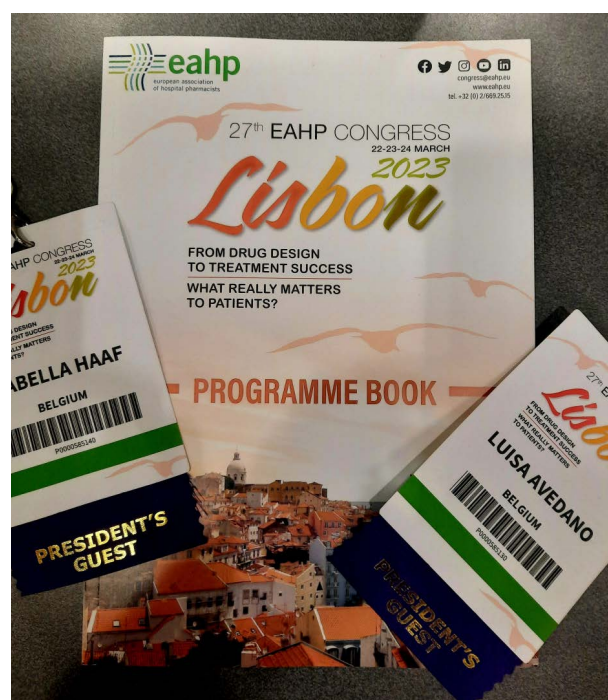
As a first instance we are planning to conduct a mapping exercise among our members to better understand their current level of involvement and knowledge about the role of hospital pharmacists in their country in order to pave the way and identify areas where more support and education may be needed.

We also discussed participating in next year's EAHP Congress in particular providing to a wider audience the perspectives of our IBD patient community.

We believe that hospital pharmacists play a crucial role in the healthcare system, particularly for people with chronic conditions such as IBD as they are responsible for ensuring that patients receive the correct medication and dosage, and that the medication is safe and effective.

Therefore, by working together, EFCCA and hospital pharmacists can ensure that people with IBD receive the best possible care and support they need.

Isabella Haaf
EFCCA Deputy Director



Knowledge and education: EFCCA makes the difference

In order to properly present the reflections contained in this article, I think it is important to start by defining the context that nurtured our participation in research and development projects over the past years.

Three elements have forged the backbone of IBD patients' federation's involvement in research projects under the IMI (Innovative Medicine Initiative) funds until 2020, and more recently under Horizon Europe.

The first is the clear mandate that our General Assembly gave us a few years ago: the necessity to diversify our sources of funding and reinforce our full independence from stakeholders and the need to gain a higher visibility in the European arena. Indeed, despite the steady and worrying increase in its incidence, IBD continues to be a second-tier priority on the European Commission's policy agenda and, more generally, in the investments of research institutes and investigators.

The second element is to strengthen the role that patients can play in research and, in particular, in proactively contributing to defining priorities and preferences at a very early stage with the purpose of improving clinical practice through collaboration across the entire pharmaceutical R&D cycle. This is the case of a meaningful and active collaboration in identifying unmet needs, co-designing protocols, and clinical trials, and in the subsequent knowledge transfer to a wider audience.

Furthermore, involving EFCCA patient representatives means also reinforcing the role of our EFCCA Academy and its main objective to train certified patients whose expertise reflects not only the priceless individual experience but also the legacy of evidence-based data resulting from in-depth analysis of the processed information.



Luisa Avedano, EFCCA CEO

The third element is the new European scenario that is fixing potential new roles to patients and offers some room to a more patient-centric approach to medicine and research.

On the one hand the new Pharmaceutical Strategy (initial resolution approved on 25 November 2020) is putting the patient at the centre and ensures Europe's supply of safe and affordable medicines to actually meet patients' needs.

On the other hand, with the recently approved "Engagement Framework: European Medicines Agency and Patients, Consumers and their organisations" the European Medicine Agency is committed to ensuring that the patient voice is included in the different regulatory activities of a medicine's lifecycle.

In this evolving context, EFCCA has made major organisational and financial efforts and, after selecting a few themes of great value to the IBD community, has applied for several Horizon Europe projects, working with large international consortia of research institutes, universities centres of excellence and private investors.

This effort was rewarded and between September 2022 and January 2023 5 large research and development projects were awarded and EFCCA became a full member of the 5 consortia that submitted them.

One of the selection criteria EFCCA applied for its participation is the potential role we can play in training our community. We have been taking into consideration how we could benefit from the outcomes and deliverables of these projects and transform some of them into training modules and/or ad hoc sessions dedicated to reinforcing skills and competences of our certified patients.

Among them the Genegut and Mi-gut projects (see below) include specific educational activities addressed to patients that will be held in the second half of the projects (between 2025 and 2026), while in others we are already working in shaping informative and communication actions that will translate into a patient-friendly language the most meaningful results of the different stages of the projects.

So, alongside the role EFCCA will play in the communication and dissemination of the outcomes, milestones and achievements of the Horizon Europe projects in which we are involved I believe that our Academy holds an important and absolutely unprecedented and original place regarding the services and support we are able to offer to our wider community.

We will also take great care of our members who will be involved in the different projects, and we are confident that the training we will offer through our Academy will contribute to increasing the knowledge and preparation of our representatives, who in turn will be able to train, inform and support their national associations according to the well-established formula of our Academy whereby each certified patient can transfer their know-how to the national context.

We are about to launch our 2023-2027 Strategy Plan and I think that our new positioning in the research and development domain will help us to achieve our goals and give us new energy to better answer the challenges of our growing community made by patients, relatives and families.

Making GENEGUT Science Accessible to Patients

Since the Kick-off meeting in January 2023 (see last issue of the EFCCA Magazine), EFCCA has been actively supporting the consortium's management team in various activities related to awareness raising around Crohn's disease.

EFCCA has been involved in the preparation of a project fact sheet which will provide patients with essential information about the project, its objectives and its potential of creating a first-of-its-kind, game-changing treatment for ileal Crohn's Disease. The fact sheet is being finalised and will soon be available on the GENEGUT as well as EFCCA's website.

EFCCA has also been instrumental in helping the consortium with social media activities, such



as promoting the project on various social media platforms, including Twitter, LinkedIn, and Facebook. In April 2023 the project launched a blog series about what it is like to live with Crohn's disease. Our first contribution from Deputy Director, Isabella Haaf, talked about the fact that here is no "typical" Crohn's disease patient. More stories will follow. Read [blog](#)

Finally, EFCCA has also provided its input into the communication and dissemination plan for the project making sure that the project findings are communicated in a way that is accessible and understandable to patients and other stakeholders.

Website: <https://genegut.eu>
follow via [Twitter](#) and [LinkedIn](#)

GENEGUT
Patient stories

#1

There is no typical Crohn's disease patient

Isabella Haaf
Deputy director EFCCA

EFCCA
European Federation of Crohn's & Ulcerative Colitis Associations



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HEALTHCARE
CELLTRION

Patient information important starting point for METHYLOMIC

What do people with Crohn's disease need to know when it comes to the METHYLOMIC project?

That is an important starting point for Crohn & Colitis NL, which is handling part of the communication activities of the four-year METHYLOMIC project, on behalf of EFCCA.

On March 31, 2023, the first communication activities were launched: the METHYLOMIC website and social media channels. The website has a separate section with information for patients with Crohn's Disease. This section will be filled with more information throughout the project, for example with information about participating in the OMICROHN trial, that is part of the project. There will also be podcasts aimed specifically at people with Crohn's Disease.

"We always follow two editorial lines in our activities" says Menne Scherpenzeel, director of Crohn & Colitis NL. *"In doing so, we always look at what is important and interesting for patients and what for healthcare professionals and researchers."*



Funded by
the European Union



Cooperation

The kick-off of the METHYLOMIC project was 18 January 2023 in Amsterdam. In attendance were Menne Scherpenzeel and communications consultant Barbara Davidson of Crohn & Colitis NL, alongside Luisa Avendano and Maria Stella de Rocchis of EFCCA.

Immediately after the kick-off, Crohn & Colitis NL went to work building and filling the website, setting up the social media channels, and writing the communication plan. This involved working closely with the 18 partners from 9 countries.

For all information about the METHYLOMIC project and the OMICROHN trial: <https://methylomic.eu>
And also follow the project via [LinkedIn](#) and [Twitter](#).

Barbara Davidson,
Crohn and Colitis NL (Netherlands)

miGut-Health: Personalised Health Blueprint to Prevent and Predict Inflammatory Bowel Disease

For the next 4 years, EFCCA will be part of a team of 11 other partners in the miGut-Health project, which is one of the 5 Horizon Europe projects focusing on IBD that started this year.

The goal of miGut-Health is to create personalised health plans that can help prevent and predict IBD.

The project wants to empower people who have IBD or are at risk of getting it by developing modern ways

to detect, prevent, and monitor the disease early on. The project aims to look for signs of gut health, assess personalised prevention measures, and find ways to encourage people to engage in healthier habits.

The researchers will use digital tools to collect information from patients and provide tailored recommendations for better management and prevention of IBD.

EFCCA will work together with Università Cattolica del Sacro Cuore (Milan, Italy) under the lead of Prof. Graffigna G. to support and involve people with IBD and those at a high risk of developing it in health and prevention programs. These programs will aim to encourage people to change their behaviour and follow a diet and nutrition plan to prevent IBD from developing. By shifting focus from treating the disease to preventing it, miGut-Health aims to reduce the negative impact IBD has on people's lives and society as a whole.



An online meeting was held on 27 February 2023 as a preliminary discussion before the official kick-off. The project partners, including EFCCA, will meet in person for the first time on 23 and 24 May 2023 in Kiel, Germany. This meeting will provide an excellent opportunity to discuss ways to optimise results and improve the quality of life for people living with IBD.



Website: <https://www.migut-health.eu>
follow via [LinkedIn](#)

FIBROTARGET: Validation of novel immunotherapeutic targets against fibrosis in inflammatory bowel diseases

The University of Leuven (Belgium) and 7 other partners have started a 5-year Horizon Europe project called FIBROTARGET. The project will improve the prevention, diagnosis, and treatment of fibrosis in the intestines associated with IBD.

FIBROTARGET aims to discover and validate early detection biomarkers, develop advanced diagnosis techniques, and test immunotherapeutic drugs for IBD and other fibrosis-related diseases.

The project hopes to create personalised immunotherapies for fibrosis to reduce the burden of IBD, costs, and improve the quality of life for patients. EFCCA will help ensure patients' voices and insights are considered throughout the process.



The kick-off meeting was held on 28 April 2023 in Leuven, Belgium.

Website: <https://fibrotarget.eu>



GlycanTrigger - Glycans as master triggers of health to intestinal inflammation transition

EFCCA will be one of the 9 consortium partners coming from 7 different EU and non-EU countries of GlycanTrigger, an Horizon Europe project led by the Portuguese researcher in Immunology, Cancer & GlycoMedicine, Salomé Pinho, from the “Instituto de Investigação e Inovação em Saúde (i3S)”.

In IBD, and in particular in Crohn's Disease, there seems to be an early phase where the disease is triggered by a combination of genetic susceptibility and environmental risk factors. As the disease progresses, it goes through various stages of development.

By understanding this early phase, the GlycanTrigger project aims at developing better treatments and ways to predict and prevent the disease from progressing and understanding how changes in sugar chains called glycans can cause inflammation in the digestive system. The team is exploring the idea that certain molecules can simulate the sugar code found in our body, tricking our immune system and causing inflammation.

The kick-off meeting took place in Porto, Portugal, where the project coordinator is based, on 13 and 14 March 2023. Luisa Avedano and Maria Stella De Rocchis represented EFCCA at this meeting which included an introduction of the host institute, a general presentation of the project and its various work packages, as well as discussions on project management. During a roundtable session, all partners had the opportunity to introduce themselves and their teams and establish expectations and goals for the project.

Over the course of the next six years of the project duration, EFCCA is committed to actively promote the dissemination, exploitation, and communication of the project's outcomes among its members, with the ultimate goal of significantly improving the health and well-being of people living with IBD.



Funded by
the European Union

As part of this effort, EFCCA will work closely with project partners to develop and implement innovative strategies aimed at predicting and preventing IBD, and will leverage its extensive knowledge and experience in the field to help ensure that the project's findings are widely disseminated and effectively utilised by stakeholders across the EU and beyond.

Follow the project via [Twitter](#) and [LinkedIn](#)

At the time of publication the project's website was still under development.

Maria Stella de Rocchis,
EU Project Officer

IDEA-FAST: Digital endpoints to improve IBD patient care

EFCCA attended the 4th General Assembly (GA) of the IDEA-FAST project held on 16 and 17 March 2023 in Barcelona. The project is a 5½-year Innovative Medicines Initiative project that started in November 2019 and is run by a consortium of 46 partners across 15 countries in Europe

The GA brought together all partners of the IDEA-FAST project and EFPIA (European Federation of Pharmaceutical Industries and Associations) representatives to share the progress made by the project in the past year and plan for the upcoming year. The assembly featured presentations and discussions on various topics dealt with by the project's 9 work packages, including digital endpoints, patient involvement, data management, ethics, and regulatory requirements.

As part of the project, the Clinical Observation Study (COS) is now on-going. The COS study aims to identify digital endpoints to better assess fatigue and sleep disturbances. Recruitment to the COS will include 6 different cohort diseases, representing both Immune-Mediated Inflammatory Diseases (such as IBD) and Neurodegenerative Diseases.



Study participants are asked to wear a combination of 3-4 digital devices and will be asked to report on their experience over a course of a year. The study is set to take place in 9 European countries involving 20 recruiting sites. So far 13 sites have opened and are successfully recruiting patients, with 7 additional sites to be included soon. A total of 132 participants have been recruited so far. The sites in Kiel, Brescia, Stavanger, Newcastle, Lisbon, Münster, Madrid, Royal Devon, Innsbruck, and University of Glasgow have already started recruiting patients, and Leeds, Warsaw and London Barts will soon follow.



As a partner of the project, EFCCA strongly believes in the significance of involving patients in the development of digital endpoints and the need for transparent and secure data management. We appreciate the opportunity to share our experience in engaging patients with immune-mediated diseases and would like to highlight the importance of patient-centered care in clinical trials.

We look forward to further discussions on this important matter and working together towards a more patient-centric approach.

Isabella Haaf,
EFCCA Deputy Director



This project has received funding from the Innovative Medicines Initiative 2 Joint Undertaking (JU) under grant agreement No 853981. The JU receives support from the European Union's Horizon 2020 research and innovation programme and EFPIA and PARKINSON'S DISEASE SOCIETY OF THE UNITED KINGDOM LBG.



We innovate in gastroenterology
so patients can live in the moment



Patient Preference Study

Since 2021 EFCCA has been partnering with KU Leuven University in Belgium on a project to better understand the preferences and needs of patients with IBD when it comes to their treatments.

The main objectives of this project are to quantify the importance of relevant treatment attributes, evaluate monoclonal antibody resistance, and investigate how preferences are influenced by participants' characteristics.

KU Leuven researchers and EFCCA representatives have already worked on a shared understanding and definition of attributes and structure of the study and launched the pilot phase last September 2022. This involved interviewing English native speaker patients to get honest and direct feedback on attributes and the survey.

The findings from the qualitative study were presented by researcher Elise Schoefs during the poster presentations at the ECCO Congress 1-4 March 2023 (see ECCO article in the EFCCA news section).

Now we are working on the quantitative study and are targeting the countries to be involved and arrange for translations. We have the survey available in the following languages: English, French, Dutch, Portuguese, Finnish, Greek, Hungarian, Italian, Spanish, Poland and Romanian.

If you want to have the survey translated also in other languages, please reach out to Maria Stella at mariastella.derocchis@efcca.org

After having all the translations done, we will be ready to launch the survey which will be online. The recruitment of participants will be done through physicians and patient organisations. Please stay tuned for more news!

Maria Stella de Rocchis,
EU Project Officer

Netherlands

Top 10 research priorities for IBD in children and adolescents: a Dutch James Lind Alliance priority setting partnership

It's high time for more research on children and adolescents up to 18 years with IBD. With that message, director Menne Scherpenzeel of patient organisation Crohn & Colitis NL visited Károly Illy, chairman of the Dutch Society for Pediatrics.

Scherpenzeel handed over the leaflet “Research Agenda for Children and Adolescents with IBD up to 18 years of age”, containing the top 10 research questions that need to be researched as a priority. That top 10 is the result of a unique collaboration between Crohn & Colitis NL, James Lind Alliance (JLA) and Kids with Crohn & Colitis (K-ICC), children and adolescents with IBD, parents and healthcare professionals.

Why a Top 10 research agenda?

There are still too many questions that healthcare providers cannot answer in the consulting room. With the Top 10, it is now clear what needs to be answered as soon as possible. According to Scherpenzeel, research among children and adolescents up to age 18 lags far behind research among adults with IBD.

“Moreover, outcomes of research among adults cannot be translated 1-to-1 to children and adolescents. After all, they are not little adults. Children and adolescents have specific questions related to their specific stage of life.”

Method

This process was conducted in collaboration with the James Lind Alliance (JLA), the patient organisation Crohn & Colitis Netherlands and the Kids with Crohn's Colitis (K-ICC) Working Group for Collaborative Pediatric IBD Research. A steering group including four children and adolescents with IBD, four parents



and eight healthcare professionals was established. Research “uncertainties” were gathered by using an online survey completed by 222 respondents (patients, parents and healthcare professionals), and categorised into 13 themes. Overlapping “uncertainties” were refined into 64 indicative questions. The uncertainty of these questions was reviewed in the current literature, resulting in a list of “answered uncertainties” and “verified uncertainties”. In an interim prioritisation survey, patients, parents and healthcare professionals were requested to identify their top 10 questions from the list of 59 “verified uncertainties”. This survey was completed by 236 respondents. The resulting top 25 of most ranked items was carried forward to a stakeholder workshop for reaching consensus on the “top 10” research priorities. In March 2023, the final “top 10” priorities were reached in the final workshop.

Top 10

1. What are the causes of fatigue in children/young adults with IBD and what can they do to feel less tired?
2. How can healthcare professionals better predict the disease course (flares, extension/ complications of disease) in children/young adults, and can this help prevent disease progression?
3. What external factors such as diet, infections, medication, and living environment play a role in the development of IBD in children/young adults?
4. What are the long-term effects of medication in children/young adults with IBD?
5. When and how is it best to taper medications in children/young adults with IBD?
6. What role does the gut microbiome play in the development of IBD in children/young adults?
7. Which foods/nutrients/eating habits are good for the course of IBD in children/young people?
8. Is it possible to predict on an individual basis which medications will work best?
9. How can children and young adults with IBD be helped to better cope with their disease?
10. Is there a less invasive procedure for children/ young adults with IBD other than endoscopy?

Follow-up

In the coming period, Crohn & Colitis NL and K-ICC will bring the agenda to the attention of important stakeholders. The Top 10 agenda will also be published (inter)nationally to draw attention to this important topic. The initiators hope that this will free up more money in the future for research into IBD in children and adolescents.

Daniëlle van der Horst, Barbara Davidson
Crohn & Colitis NL (Netherlands)



New Zealand

Camp Purple Live 2023!

For those of you who are unaware of what Camp Purple is, Crohn's & Colitis New Zealand sponsors an annual six-day camp for children and teens with Crohn's disease and ulcerative colitis. Entering its eighth year, our 2023 camp had a record number of campers attend.

93 children arrived in the Christchurch area this year from all corners of our country, more than double the number who attended our first camp in 2015. Thirty five volunteers, all with IBD, also arrived, along with

five gastroenterologists, five nurses, and a child psychologist. This year we even had an international volunteer from Lithuania.



All expenses, including transportation, are covered by our organisation as we do not want cost to be a barrier for any child to attend.

All sorts of exciting activities were planned in our schedule including a waterslide (run by the local Fire Brigade), tree climbing, rope courses, shooting and archery. But by far everyone's favourite was our away-day activity. We left camp for the day and ventured out for a day of Blo-Karting and Drift-Karting.

We also incorporate our "Experience Camp for a Day" with our carnival on the last full day of camp. This day creates an opportunity for children aged 5 and upwards with IBD who may be too young or unsure about attending the week-long camp, to get an idea of what Camp Purple is all about.

Our carnival featured a mechanical bull and a dunk tank where campers could dunk fellow campers, volunteers, and medical staff!

That night we also had another highlight, our disco. The theme was "Beach Day" and all attendees came in costume. Some of our favourite costumes were lobsters, lifeguards and there was even a jellyfish.

One of the key components of Camp Purple Live is a two-day seminar for parents and caregivers. The programme is organised by Professor Andrew Day, a paediatric gastroenterologist in Christchurch. It focuses on education and dealing with the challenges of being a parent of a child with IBD. Most importantly, it gives parents the opportunity to meet, share experiences, network with other caregivers, and establish lasting friendships.

Camp Purple, supported by medical staff and volunteers, gives the campers a chance to experience fundamental elements of childhood – to learn independence, nourish self-esteem, challenge themselves physically, and be proud of their accomplishments. Incorporated into the camp activities, the children also learn about their diseases. They learn coping skills through group activities such as Q&A sessions with the medical team and group sessions with our clinical child psychologist (who also has IBD).

To find out more about Camp Purple Live, watch the [video](#) or head over to our webpage www.crohnsandcolitis.org.nz



Crohn's and Colitis New Zealand Charitable Trust Announces Two New Ambassadors

We are pleased to announce the appointment of two new Ambassadors of our organisation. Ambassadors are the face of our organisation, they speak on our behalf, raising awareness to support the 20,000+ New Zealanders living with these chronic diseases.

Nicole Thornton, our first ambassador, is well-known for her advocacy work, both in the community and in Parliament. Nicole, now a young woman and pursuing a career in nursing, was diagnosed with Crohn's disease at the age of eight. At the age of 12 she presented a petition to Parliament and gave nationally televised testimony to the Health Select Committee to allow workplace toilet access to those that might need a bathroom urgently. She is also the author of our national "I Can't Wait Campaign", a campaign to promote toilet access and to normalise the lives of people living with IBD. Nicole was recently recognized by New Zealand's prestigious Kiwibank's Local Heroes' Awards. Her campaign and work has been endorsed by several city councils throughout the country.

Our second Ambassador, representing the many children and teens with Crohn's and colitis, is 15-year-old Charlotte Livingstone. Charlotte has been an instrumental member of the young IBD community, sharing her story and advocating for greater understanding and support for those living with the condition. On World IBD Day in 2022, Charlotte shared her experiences of living with Crohn's disease at Parliament and appeared in the video "IBD Has No Age".

On 25 January 2023, a presentation at Camp Purple Live was held to celebrate these appointments. Brooke van Velden, a prominent member of Parliament, known for her advocacy work in the health sector, and Charlotte's home-town mayor, Ashburton Mayor Neil Brown, spoke to the children and volunteers and presented certificates to the new Ambassadors initiating their new roles.



Introducing Our

Ambassador

Nicole Thornton



Introducing Our NEW

**Youth
Ambassador**

Charlotte Livingstone





We are confident that Nicole and Charlotte will be instrumental in raising awareness for Crohn's disease and ulcerative colitis throughout New Zealand, and we look forward to working with them and celebrating their successes.

Belinda Brown,
Crohn's and Colitis New Zealand

*Brooke van Velden, ACT Party Deputy Leader and MP;
Nicole Thornton, Ambassador; Mayor of Ashburton,
Neil Brown and Charlotte Livingstone, Youth Ambassador*



Together we are living innovation

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



www.glp.com



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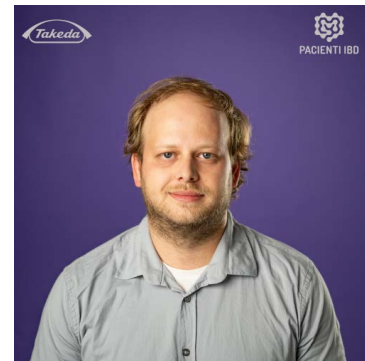


[Galapagos](https://www.linkedin.com/company/galapagos)

Czech Republic

We are handling it at every age!

That's the name of a Czech campaign which is this year continuing to promote World IBD Day



Patients across the age spectrum revealing their stories will be the highlight of the large format photo exhibition which will be located in the centre of Prague for the whole week.

Inflammatory Bowel Disease can be diagnosed at any age of patients' lives. That's why we are focussing on showing what priorities patients have when they are diagnosed in different periods of their lives and how their needs change when they are getting older. While explaining all the struggles and highlighting the growing numbers of IBD patients in the society.

Our campaign yet remains positive, showing to the public that with access to innovative care patients can have and should have regular lives.

Lucie Lastikova
Pacienti IBD



Lebanon

The Patient Journey in IBD: Obstacles and Opportunities

Inflammatory Bowel Disease (IBD) is a complex disease that usually affects individuals at the prime of their lives. This journey is at times complex, affects nearly all aspects of the patient's life, and is generally highly personal.

In an attempt to develop a complete and integrated patient journey, a group of patients, psychologists, and healthcare providers (including IBD experts) in Lebanon met on several occasions, organised relevant webinars, and went through a systematic process of collecting information from patients over social media platforms relying on patient experience and expertise of the professional healthcare team. The result was the map shown in Figure 1.

Pre-diagnosis and diagnosis

For many patients with IBD, the pre-diagnosis stage can be a confusing and frustrating time. The lack of awareness of IBD in society may lead to social isolation and stigmatisation. The diagnosis stage is a critical milestone in the patient's journey, as it begins to bring a sense of clarity and direction for effective treatment and management of their condition.

Treatment decision and initiation

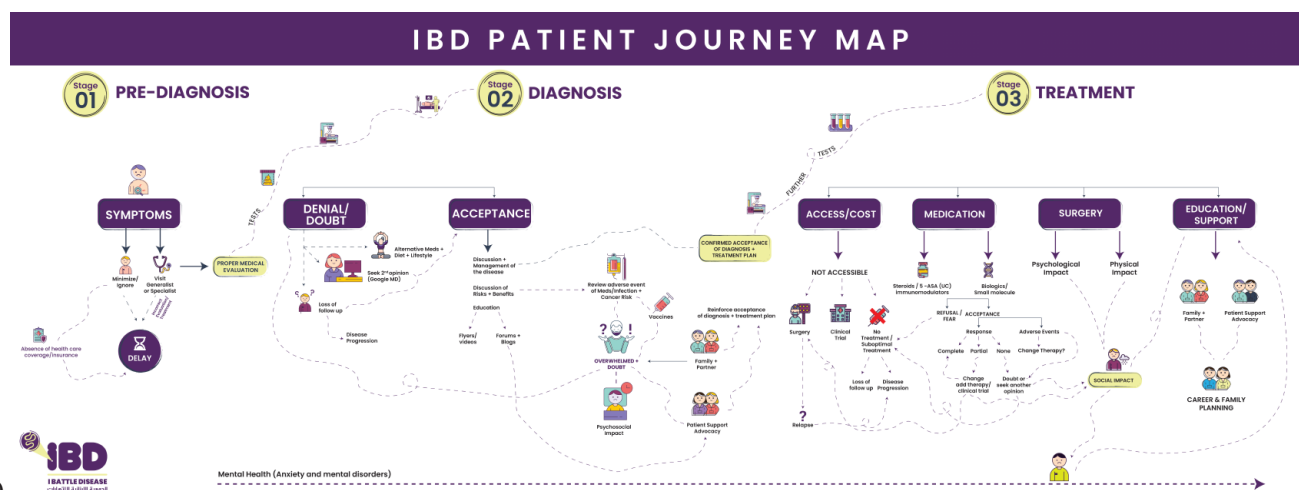
After diagnosis, patients work with their doctor to develop a personalised treatment plan. This requires a therapeutic alliance and a trustful relationship

between the doctor and the patient in a process of shared-decision making. A discussion regarding treatment options available for IBD, from dietary and lifestyle modification to medications is expected. Doctors should acknowledge the social, financial, and psychological factors that determine the optimal treatment plan based on each patient's unique needs. With the elevated cost of IBD care, it is not surprising that financial constraints are the leading setbacks for successful long-term treatment and remission of IBD.

Impact of IBD on professional and family life

For patients with IBD, managing their disease while maintaining a professional work to life balance can be challenging. At the core of finding solutions to such problems is education and raising awareness to reduce stigma and refine perceptions towards the disease. Students enrolled at schools or universities face similar difficulties. Schools and universities should provide support, such as unlimited access to restrooms, accommodations for missed classes, and counselling services to help them manage the emotional impact of dealing with the disease.

Figure 1



Family planning

Patients with IBD may face unique considerations when it comes to family planning, especially women. While many women with IBD have successful pregnancies, it is not uncommon for women with IBD to report a higher rate of voluntary childlessness. This stems from a variety of factors including heritability of IBD, risk of congenital abnormalities, medication teratogenicity, and the risk of complications in pregnancy.

There has yet to be a comprehensive description of the complete IBD patient journey. Several factors contribute to this shortage such as geographic and socioeconomic limitations which prevent the appropriate funding and awareness needed to elucidate the journey of IBD patients. It is imperative that a holistic framework of multidisciplinary IBD patient-centered care (Figure 2) be set in place encompassing all aspects of the patient journey, from pre-diagnosis to continued life-long care.

Jad Allam, Darine Daher, Nathalie Jbeily,
Sara Zeidan, Caroline Chalhoub, Rita Francis,
Mohamad Ali Ibrahim, Ala I. Sharara
From I Battle Disease Patient Association
and the American University of
Beirut Medical Center, Beirut, Lebanon

Patient support and advocacy

The psychosocial impact of IBD on patients' lives should not be underestimated. The journey of living with IBD may be very challenging, and patients often require support and advocacy to navigate the hurdles that accompany their journey. IBD patients worry about the disruption the disease will bring about in their work and social lives.

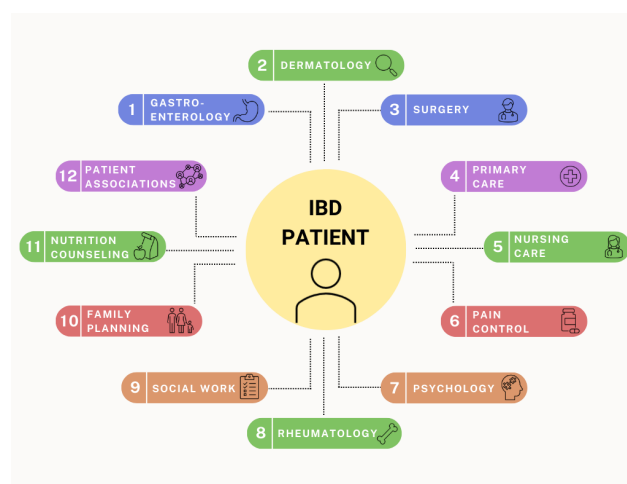


Figure 2

Lebanon - a healthcare tragedy with heavy impact on IBD patients

Lebanon is facing an unprecedented crisis. A complex set of macro environmental factors have contributed to the detrimental exacerbation of the economic aspect of this crisis

Starting in late 2019 with nationwide protests against political corruption, followed by systematic collapse of the banking sector, and economic collapse. Gross public debt peaked at an alarming value of \$86.2 billion and the crisis was fueled further with the COVID-19 pandemic and the catastrophic Beirut Port blast in August 2020 (Figure 1A) compounded by restrictions on cash withdrawals, strict informal capital controls and deductions on deposits.



Figure 1A. Beirut Port after the 4th of August Blast

According to the World Bank, GDP per capita plunged by around 36.5% between 2019 and 2021. This is reflected economically by continuous reduction in purchasing power, precipitated by the progressive decrease in average income, galloping inflation, and currency devaluation (Figure 1B), benchmarking the evolving financial instability.



Figure 1B. USD to LBP Market Rate from end of 2019 till start of 2023

These events have affected the poor and middle classes in an inordinate manner. The rate of unemployment increased from 11.4% in 2018-2019 to 29.6% in 2022. In addition, Lebanon was reclassified as a lower-middle income country, as opposed to an upper-middle country previously. A large section of the Lebanese are no longer able to meet soaring prices of basic drugs and medications, most of which cannot be produced locally. Specifically, the overall CPI (defined as the index number that measures changes in prices of goods and services), and the health CPI show a steady increase in inflation over the first quarter (Q1) of 2021, followed by a much steeper increase due to the slow withdrawal of subsidies (Figure 2).

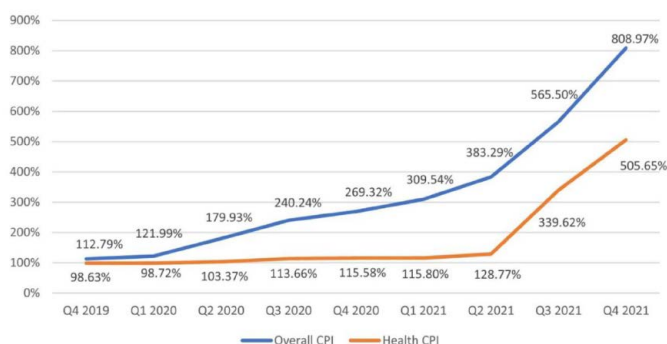


Figure 2. Average consumer price index (CPI) progression per quarter (Q) from 2019 to 2021

This highlights the inability of people to afford their living and health expenses following the crisis. Patients with chronic diseases, including those with IBD, have been impacted most given their need for costly and chronic treatment with biologics.

It has become almost impossible to find medications across the country. At a time where basic drugs like NSAIDs, anti-hypertensives, paracetamol, and aspirin are unavailable, biologic agents have only become a luxury. A recent survey that was disseminated on the social media platforms of I Battle Disease, the IBD patient association in Lebanon, investigated the impact of the crisis on IBD patients. Specifically, it explored the ability to acquire necessary medications, the need to alter or completely stop treatment (Figure 3), and the resulting complications on their disease course.

How long did you stop or interrupt your treatment?

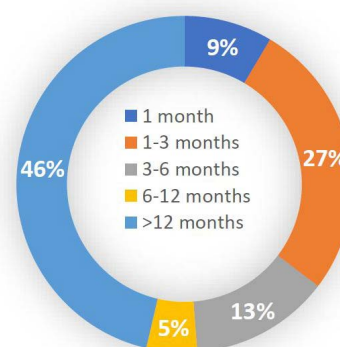


Figure 3. Duration of treatment interruption

The majority of patients (69%) declared stopping or interrupting their treatment in the past 3 years, resulting in a deterioration of their condition; 36% were forced into steroid use, 36% reported switching to secondary medications, and 15% were admitted to the hospital for disease flares (Figure 4). Further, 12% of the patients even reported immigrating or seeking employment abroad due to difficulty with drug access.

Amidst the catastrophic situation in Lebanon, patients with IBD in Lebanon face a very harsh reality. Recent events have exposed significant challenges on IBD patients, affecting adherence to therapy and control of their disease. There is an urgent need for action within the public health context to improve IBD medication availability and accessibility for the Lebanese population.

Did your condition worsen when you stopped treatment?

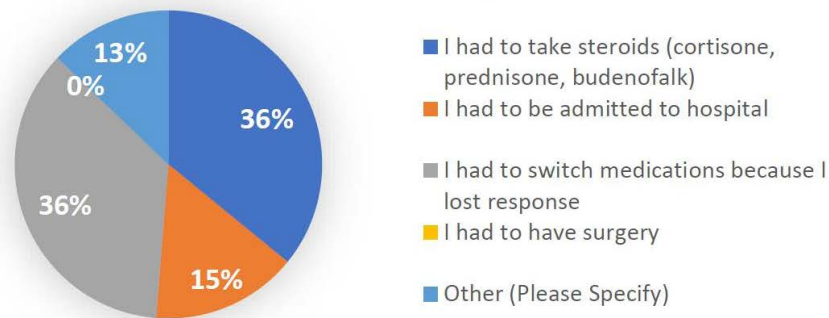


Figure 4. Consequences of forced treatment interruption

We hope our article drives IBD societies, non-profit organisations, and healthcare executives to support the untenable situation for IBD patients in Lebanon.

Amar Zeidan, Mohamad Ali Ibrahim, Dima Haidar-Ahmad, Rita Francis, Nathalie Jbeily, Caroline Chalhoub, and Ala I. Sharara
From I Battle Disease Patient Association
and the American University of
Beirut Medical Center, Beirut, Lebanon

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France

A memorable Annual Meeting for Afa Crohn RCH France

Saturday, 25 March 2023, marked a very important event, a turning point for Afa at its 41st Annual Meeting. This year was the first hybrid version of the event with some members present and others tuned in online, each group being allowed to ask questions and vote for all the motions of the meeting.

The mistress of ceremonies was the new Afa CEO, Anne Buisson, who presented the 2022 Activity Report, a particularly intense year filled with many activities and events, especially with the 40th Anniversary celebrations and the return to a normally active and dynamic life following the COVID lockdown period.

This was also the time to present the research projects supported by Afa through videos with each researcher, for a historic grant total of € 272 000! The meeting

was closed by an exceptional conference given by Prof. Jean-Pierre Hugot (Robert Debré Hospital – Paris) on the theme: Is Crohn's disease the price to be paid for having survived the Black Plague? This was an opportunity for the professor to talk about his work on the impact of food conservation and the way it can be contaminated by different bacteria; how the modification of certain genes in response to epidemics can lead to the predisposition in developing other pathological ailments.

Afa's new board of administrators

One of the most moving times of the Annual Meeting was Chantal Dufresne's announcement, as planned, to step down from her presidency of the Board, which she held for 15 years, since 2007. A daily commitment which she had made even before becoming president, as an Afa volunteer and donor as well as administrator. Chantal was a distinguished delegate as well since the beginning of EFCCA, with whom she worked with successive presidents, Rod, Marco and Salvo. Among the many lobbies she undertook with both Afa and EFCCA, were the recruitment of a CEO and the creation of one and only IBD Day, replacing all of the national celebration dates. Last but not least, Chantal pushed for European Research! Chantal hasn't abandoned the IBD Cause, therefore we can rest assured: her story isn't finished!

Life goes on at Afa with the election of Corinne Devos as the new President of the Board of Afa Crohn RCH France!



Corinne joined Afa 15 years ago as a volunteer for the Paris region. She has fulfilled several missions from being an administrative aid, to a trained active listener and patient management volunteer. She was the Paris regional delegate along with representation in national institutional positions. This experience allowed her to progressively gain the DNA which is what Afa is made of. Corinne has been Vice-President of Afa since 2018. She is particularly committed to patient-centered work in Patient management, which helps patients and their entourage learn how to manage their lives with as much independence as possible giving them the capacity to overcome their difficulties. By her side is François Blanchardon, the new Afa Vice-President, formerly Treasurer for many years and especially experienced in the development of patient representation with the health authorities. Marie-Hélène Ravel, Secretary general, and Bastien Corsat, treasurer, were also newly elected along with some new members of the Board.



A close-knit group of volunteers very motivated in fighting the continued battle against IBD!

Madeleine Duboe
Afa Crohn RCH France



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Brasil

IBD World Day 2023: partnership between DII Brasil and Academic Leagues will raise awareness of Inflammatory Bowel Disease

The World IBD Day 2023 in Brazil will feature an unprecedented initiative, resulting from the partnership between DII Brazil and the Academic Leagues of higher education institutions in the country.

The alliance will allow awareness about Inflammatory Bowel Disease to reach students from different areas, such as journalism, sociology, theology and law, in addition to courses in the health area.

Partnership is essential to disseminate information about IBD to as many people as possible. The expectation is to innovate in the celebration of World IBD Day, known as Purple May in Brazil.

The objective is to increase the reach of information and education about IBD in academic centers and also in the communities where universities are located. Thus, the campaign aims to give greater visibility to the cause, impacting a greater number of people and promoting awareness about Crohn's Disease and Ulcerative Colitis.

The joint efforts between DII Brasil and the Academic Leagues has the potential to transform the way society views diseases, bringing knowledge and support to patients and, at the same time, promoting actions that improve the quality of life of those affected by these diseases.

Therefore, DII Brasil is looking for sponsors to guarantee the distribution of informative pamphlets and banners in the events promoted by the Academic Leagues. The entity launched a fundraising campaign and created a website to facilitate donations:

With strategic actions, the campaign aims to positively impact the public and encourage discussions on the subject, enabling advances in the diagnosis, treatment and prevention of IBD.

<https://diibrasil.apoiar.co>



So far, 15 Academic Leagues have partnered with DII Brazil.

- LAGCID - University of Vale do Sapucaí (Pouso Alegre/MG)
- LIGASTRO - Paulista State University (Botucatu/SP)
- Clinical-Surgical Academic League of the Digestive System - University Center Cesmac (Maceió/AL)
- LAGH - State University of Feira de Santana (Feira de Santana/BA)
- Academic League of Gastroenterology and Hepatology - Catholic University of Pelotas (Pelotas/RS)
- LAGH - Bahia School of Medicine and Public Health (Salvador/BA)
- LAGH - Federal University of Amapá (Macapá/AP)
- League of Gastroenterology and Emergency - Federal University of Ceará (Fortaleza/CE)
- LAGHEB - State University of Bahia (Salvador/BA)
- Academic League of Gastroenterology and Coloproctology - Federal University of Ouro Preto (Ouro Preto/MG)
- LADII - FIPMoc University Center – UNIFIPMoc (Montes Claros/MG)
- Univates Academic League of Gastroenterology - University of Vale do Taquari (Lajeado/RS)
- LAGASTRO-BH - Liga de Gastroenterologia da Faminas (Belo Horizonte/MG)
- APLAG - Paulista Association of Academic Leagues of Gastroenterology (SP)
- GASTROLIGA - Academic League of Gastroenterology of the State University of Southwest Bahia - (Jequié/BA)

Review by journalist Ivanete Damasceno,
translated by Thiago Carvalho,
artwork by Kaylie Paruçulo
DII Brasil Communication Committee



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Act4Biosimilars: Increasing patient access to biologic medicines

Act4Biosimilars is a global initiative that aims to increase patient access to biologics by facilitating greater approvability, accessibility, acceptability and affordability (4As) of biosimilars

Its mission is to increase global adoption of biosimilar medicines by at least 30% in 30+ countries by 2030. The 12 goals have been identified under the 4As to achieve the mission, including ensuring equitable pricing, involving patients in treatment decisions and streamlining biosimilar development.

The initiative seeks to drive an ambitious, inclusive approach, bringing key stakeholders together to take actions to help people access the medicines they need. Act4Biosimilars is led by a multidisciplinary Steering Committee of patient advocacy leaders, healthcare professionals, biosimilar experts and industry leaders.

On 30 January 2023, Act4Biosimilars initiative hosted a virtual meeting with key stakeholders from across the healthcare space to discuss the Action Plan – its first key deliverable to aid the increase of adoption of biosimilars globally. This meeting brought together a group of experts to preview and input into the Action Plan, which will provide the strategies, tools and activities needed to equip and empower stakeholders to realize the 12 goals.

The Chairman of EFCCA, Salvo Leone joined this meeting to bring the patient perspectives, share comments on the Action Plan and highlight the points that are important for the IBD community in terms of access to biologics. The meeting was a huge success, and the fruitful discussion between stakeholders will be used to further refine the Action Plan to create maximum impact for patients.



Ensure to follow Act4Biosimilars on [LinkedIn](#) and [Twitter](#) to be among the first to read the Action Plan when it launches later this year.

For more information, you can visit Act4Biosimilars.com

EPF Turns 20!

The European Patients' Forum (EPF) is delighted to share with you the news of its 20th-anniversary! It has been a remarkable journey of two decades, and we take immense pride in all that we have accomplished

2023 is marked by 20 years of highly effective advocacy campaigns. 20 years of unique multi stakeholder collaboration. 20 years of ensuring that patients have a seat at the table in the design of medicines, technologies, practices, care, and the overall strengthening of the healthcare system. 2023 is the year of EPF's 20th anniversary.

On 28 April 2023, EPF celebrated key achievements, drew learnings, and co-designed a collective vision for the future of the European patient community. The event included a keynote address from Marco Greco, EPF President, panel discussions looking back at our experiences, achievements, and milestones, but also workshops looking forward towards the next 10 years of patient advocacy.

Two decades after its founding, EPF occupies a unique position as the only cross-disease umbrella patient organisation at the European level. We have achieved numerous milestones, working towards our vision of creating a Europe where patient organisations are valued partners in creating equitable, person-centred, accessible, and sustainable healthcare systems, based on patients' unique expertise.

To celebrate 20 years of EPF, EPF organised an engaging event that takes a retrospective look at the last two decades and uses this to drive meaningful conversations about patient-centred healthcare in Europe today. Attendees gained valuable insights into patient advocacy and how it can shape the future of healthcare. This event created a clear and inspiring plan for what the patient advocacy movement could accomplish over the next decade.

EPF believes that this celebratory time is an inspiring incentive to keep up the pace in shaping the future of patient engagement together. The theme for this anniversary year is based on just that: the future, with a particular focus on a new generation of young patient leaders.

You can keep up to date with our activities by listening to our anniversary podcast series.

[Click here](#) for the latest episode!

Flavia Topan,
Communications Manager
European Patient Forum



UEG: Pan-European study on digestive health

The United European Gastroenterologists (UEG) has recently commissioned a pan-European study on digestive health and associated research gaps, the [White Book 2](#)

A wide spectrum of digestive diseases were examined, including major diseases of the gastrointestinal tract, liver, pancreas and biliary system as well as digestive cancers. Findings from the analysis revealed a notable and concerning increase in the prevalence of several digestive diseases since 2000, including a rise in the incidence and mortality rates for all digestive cancers. In addition, health inequalities across Europe are widening and predicted to be further exacerbated by emerging economic challenges.

UEG conducted a similar study in 2014 which highlighted similar burdens and, with limited improvements since, the results and outcomes of this new UEG study will assist in accelerating progress in reducing the burden of digestive disorders. It will also help to identify priority areas where research and investment are required across the whole of Europe as well as individual nations.

On 26 April 2023, UEG brought together digestive health experts and key stakeholders from the European health community for a lively and solution-oriented discussion on the current state of digestive health across Europe.

UEG has drafted an open letter addressed to the EU leadership with broad policy recommendations addressed to EU and national key stakeholders. These recommendations result from the study's key findings and address different areas of action (disease prevention, health inequalities, research and funding priorities) to reduce the overall burden of digestive diseases and cancers across Europe. EFCCA is supporting this open letter which will be published beginning of May.

More information:

<https://ueg.eu/p/61#whitebook>



Hosted by
MEP Romana Jerković
(S&D, Croatia)

Bridging the gaps

A Pan-European study on digestive diseases across Europe

April 26, 2023 | 13:30 – 15:30 CEST
European Parliament, Brussels

I've Had The Time of My Life

By Oona Liikanen

“As sung in the soundtrack of the movie *Dirty Dancing* back in the 80’s, the lyrics still apply, except that we can still have it!” This is my story about being a student with IBD.

I’m currently 22-years-old and I’m doing my internship at the Finnish association for IBD and Other Intestinal Diseases. But more than anything right now, I’m a student and that is why I’m writing my story.

There are as many stories about living with IBD as there are patients diagnosed with it. A lot of the time people around the same age, in the same situations in life wonder similar things connected to their work, studies, relationships, or anything really. And because of that, it’s important to hear different stories that could affect someone else, light some spark inside that resonates that there are other people with IBD out there doing all the things I’m just here thinking about. Why shouldn’t I do it then?

I got my diagnosis back in 2018, when I had to go to the Emergency Room due to intense, getting worse by the minute stomach ache, fever and finally, vomiting. I was treated with cortisone and antibiotics but my intestine was already severely inflamed, with obstructions and abscesses. I ended up undergoing surgery and got left with a Crohn’s disease diagnosis and a temporary stoma all in just one week. After all that, I started azathioprine and since then I haven’t had nearly any problems with Crohn’s, major problems anyway.

At this point in life, in 2022, I had been studying my Bachelor’s degree in business service solutions and languages for a little over two years now. I didn’t always know in what area I wanted to specialise, or what would be my main languages, but one thing I have always been sure about is that I want to go on an exchange semester.



And just like people always say, your twenties are the time of your life! And that's exactly what I was living by. Summer was starting, exams were done, I was starting a new summer job in a week... I had a lot of plans with my friends for that summer because after that I was finally going to go on my exchange and leave Finland for half a year. But guess what? After four good and steady years my Crohn's popped back up again. Literally, out of nowhere.

It was the end of May when I got a fever of almost 40 degrees, intense stomach pain and everything I put inside of me came right out. I suffered like this for a good five days because I was told it's probably just a norovirus and they don't want me in the hospital infecting others. But eventually it was just so bad that I had to go to the hospital. I ended up being there over a week because my whole large intestine was inflamed. I started biological treatment and it started helping. The summer went by faster than any other time of my life and finally it was about time to go to Belgium.



Even though my biological medication was working excellently on the inflammation, with it came other side effects that did, and still do affect my life. One of the worst is being tired. I have energy to study and work, to see people and do activities but that requires a lot of sleep and rest. And I think for a lot of young people it isn't the case.

Other international students were able to go through the whole week on four hours of sleep while studying, partying, travelling and doing everything. For me a night out combined with studying and other activities requires at least twice as much rest. And that was one of the first things I told my new room mate there, to not be bothered if I need to take a nap or just don't feel like doing anything. The feeling of tiredness is really hard to explain to others. It's one of those things that if you know, you know.

How did I build up the courage to leave and change my whole life for six months after all the uncertainties I had during the summer? I have to be honest, I was scared. I know Belgium isn't far from Finland if things would have gotten worse, but my flares being so over to the top, seeking healthcare in a different country didn't sound very appealing.

But regardless of being scared, keeping an open mind, listening to your own body and feelings and being open about IBD was what really made my time there. When I was younger I felt a lot of shame about having IBD, I didn't really talk about it with many people, was always trying to hide my urgency to go to the bathroom and really just went through the pain if I had stomach aches and tried to ignore it. But only if you're honest with yourself and let yourself open up to others, they are able to understand that even if it's not visible, it's still possible to be in pain or feeling sick.

**“When I was younger
I felt a lot of shame
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even if it's not visible,
it's still possible to be
in pain or feeling sick.”**

Visiting the European Parliament, Brussels



And now, after going through all the emotions, fears, and questions about not knowing what and who was out there, I couldn't be more happy that I was able to experience it. I had bad days, tired days, days when I didn't have an appetite, days when I wanted to give up and leave. But those days are nothing in comparison with the days when I spent time with people from all around the world, learning about new cultures and languages. The days I spent time with friends, visiting places, eating, drinking and laughing. And yes, I went to nearly every lecture in university too and got good grades on every course!

Please, keep in mind that this is just my experience and applies to people whose condition allows them to go. If your IBD is worse, it's okay – there's nothing more important than your own health and wellbeing!

I had to consider, together with my doctors, me leaving Finland for quite a while as well, because of my medication change and the side-effects it was causing me. If you have the chance and willingness to go, I say go for it and if nothing else, at least you won't have regrets about not knowing!



On a daytrip with my new friends

Some tips before going on exchange:

- Talk to your doctors and IBD nurse before to consult them for any precautions! For me, the doctor prescribed cortisone just in case my Crohn's got worse, I would've had the possibility to try that before coming back home.
- Also if you have to get regular blood tests ask how those should be done. I did mine just before leaving, during Christmas in Finland and right after I came back.
- Take all the medication possible and look up for information for how to buy more and how much they cost in your destination country if you need to buy more from there.
- Also inform your insurance company and Social Insurance Institution, if needed.
- Remember to print out your prescriptions in English or in the language of the destination, if possible!
- Keep an open mind and stay easy with yourself. You can always go back home, but you will never know what it could have been if you don't try!

Peer support was the main reason I was encouraged to seek help after getting turned back home during the weekend at the ER last year. For me, it was a social media post on Facebook, moderated by the Finnish association for IBD and Other Intestinal Diseases, that I posted to ask advice from others. Without other patients pushing me to go see a doctor, I would have probably stayed at home longer, in pain.

If you don't have similar local social media platforms, I still suggest contacting your local IBD association for peer support. And as an advocate for peer support, feel free to contact me anytime via email liikanenoona@gmail.com.



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Closing the conversation gap in IBD

Eli Lilly and Company (Lilly) launched the CONFIDE Study (Communicating Needs and Features of IBD Experiences) to better understand the burden, barriers and care experience of those living with moderately-to-severely active Ulcerative Colitis (UC) and Crohn's Disease (CD) and how they communicate with their healthcare providers (HCPs). The study is a global, cross-sectional survey of more than 800 healthcare professionals and more than 1,600 adults living with UC and CD in Europe, U.S. and Japan.

Those living with IBD often experience debilitating symptoms such as bowel urgency, urge incontinence, increased stool frequency and rectal bleeding.¹⁻⁴

The full global data from CONFIDE has uncovered interesting insights, primarily highlighting the need for patients and healthcare professionals to have open and honest dialogue about symptoms. Here's a summary of some of the key findings:

- Impact of Bowel Urgency** - Bowel urgency, which is the sudden, immediate need for a bowel movement, can be emotionally exhausting and cause someone to worry about when they may suddenly need to use the bathroom^{1,2,5,6}. Bowel urgency was the second-most commonly reported symptom experienced by both Europeans and Americans living with moderately-to-severely active UC; however, it was not ranked among HCPs as one of the top three symptoms reported by patients⁷
- Impact on Sexual Health** - More than three-fourths of female patients and more than one-half of male patients surveyed in the U.S. reported avoiding or decreasing sexual activity due to moderately-to-severely active UC, with bowel urgency reported as the top reason for this impact⁹. Of those surveyed in the U.S. who reported avoiding or decreasing sexual activity in the last three months due to UC, more than two-fifths indicated bowel urgency as a reason for their avoidance of sexual activity and more than one-third ranked fear of bowel urgency related accidents⁹
- Fear of Urge Incontinence Due to Bowel Urgency** - Urge incontinence is defined as bowel urgency-related accidents in spite of efforts to make it to the bathroom in time³. In patients with UC in the U.S. and Europe, about two-thirds of respondents reported wearing diapers, pads or protection at least once a month in the past three months due to fear of having bowel urgency-related accidents⁸. These symptoms can make it difficult for people living with UC to participate in activities such as work and school and physical exercise. In fact, it was discovered in the CONFIDE Study that UC patients in Europe and the U.S. cited bowel urgency and fear of urge incontinence as the most common UC-related reasons for declining participation in these types of activities⁸
- Conversation Gap Between Patients and Providers** - Findings from the CONFIDE Study highlight the conversation gap between patient and healthcare provider that may contribute to outcomes that are less than optimal. More than one-half of patients in Europe and the U.S. (58% and 62%, respectively) who are not comfortable reporting bowel urgency to their HCPs cite embarrassment as a reason, but HCPs may expect patients to bring it up at their appointments⁷

By uncovering patient and provider perspectives tied to the IBD experience and by shining a spotlight on the impact of UC and CD symptoms, Lilly aims to remove stigma around the disease and inspire better dialogue between patients and healthcare providers.

These insights have led Lilly and stakeholders to have discussions about how best to help to drive awareness around the importance of patients and healthcare professionals having conversations about their symptoms. Through ongoing collaboration, the goal is to initiate a campaign that will help patients to explain their symptoms and ensure that they are getting the best care by having constructive dialogue around what they are experiencing.

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