

WORLD IBD DAY REPORT 2024





"World IBD Day unites people globally in the fight against Crohn's Disease and Ulcerative Colitis."

Walk near Celje, Slovenia

WHAT IS WORLD IBD DAY

World IBD Day was established in 2010 by the European Federation of Crohn's and Ulcerative Colitis Associations (EFCCA) along with five founding members: the Crohn's and Colitis Foundation (US), the Crohn's and Colitis Foundation Canada, Crohn's and Colitis Australia, Crohn's and Colitis UK and ABCD (Brazil).

Since then, numerous other IBD organisations and stakeholders have joined the initiative. Today, World IBD Day is spearheaded by patient organisations from over 50 countries across five continents, all coordinated by EFCCA.

Held annually on 19 May, World IBD Day is a powerful platform uniting people globally in the fight against Crohn's and Ulcerative Colitis. It offers a chance to show support for those living with these

conditions, as public awareness of the daily pain and chronic suffering IBD patients endure is still limited. Many national and local campaigns and activities are organised to raise awareness and engage communities, aiming to increase understanding and support for individuals affected by IBD.

Despite the progress achieved, there remains a significant lack of public awareness regarding the true impact of IBD on the lives of those affected.

World IBD Day seeks to change this by promoting greater empathy and understanding within various communities.

Through education, advocacy, and collaborative efforts, we aim to ensure that IBD patients receive the support, care, and respect they deserve.

A WORLDWIDE MOVEMENT



In 2024, EFCCA has made again a significant effort to disseminate and promote the numerous activities of the different associations for World IBD Day. Some of these are European entities, but many are from the rest of the world, something especially relevant to EFCCA in a year where our motto has been “IBD Has No Borders.”

EFCCA coordinates and manages the www.worldibdday.org website, which serves as an excellent hub for showcasing the most impactful activities undertaken by the involved countries.

This year, we are delighted to welcome four new countries/regions participating

in global World IBD Day awareness raising efforts: Scotland, Indonesia, Chile and Costa Rica. Their inclusion amplifies our reach and help us deliver our message to an even broader audience.

Finally, many associations have embraced EFCCA’s motto for this year. Whether by translating our kit or sharing the IBD HAS NO Border campaign on their websites and social media.

We would like to take this opportunity to extend our most sincere thanks to all of them for their continued support United We Stand!

UNITING FOR AWARENESS: DIVERSE EVENTS AND ACTIVITIES ON WORLD IBD DAY

On World IBD Day and in the days or weeks preceding it, many activities and public conferences/seminars were hosted by national associations, encouraging all citizens to participate and spread the message. In this section, we have aimed to share some of the most notable ones.

Due to the large number of initiatives undertaken by organisations worldwide, it has been impossible for us to include them all. We invite you to visit the World IBD Day website and social media channels of the associations to discover more!

TURN ON THE PURPLE!

On 19 May, many cities around the world illuminated their most iconic buildings and monuments in purple to draw global attention to the daily challenges faced by individuals living with IBD. Notable initiatives included the

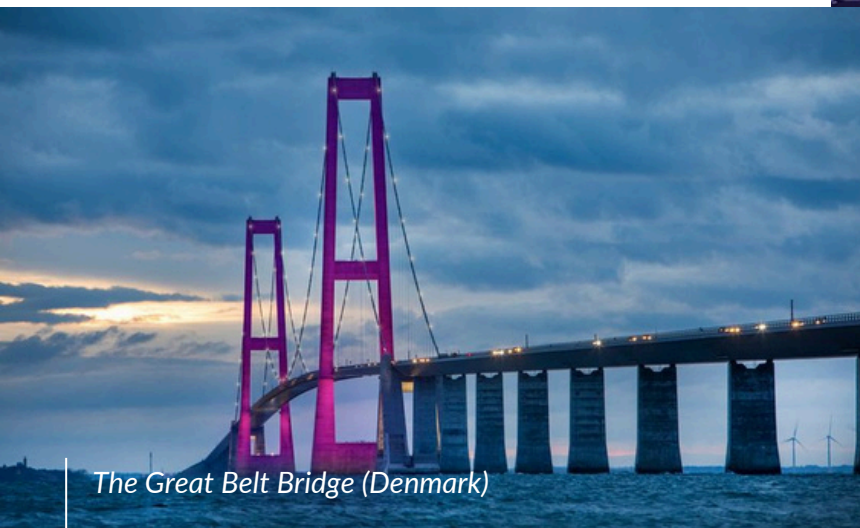
traditional “Shine A Light” in Australia and also the “Let Love Shine” campaign in China, where no fewer than 50 buildings in 32 cities were illuminated in purple, achieving great resonance for the day across the vast country.



Similarly, countries such as Bulgaria, Croatia, Denmark, Mexico, the Netherlands, New Zealand, Puerto Rico, Scotland, Slovakia, Slovenia and Japan (and their impressive illuminated castles), once again joined the initiative, bathing their night-time landscapes in purple.

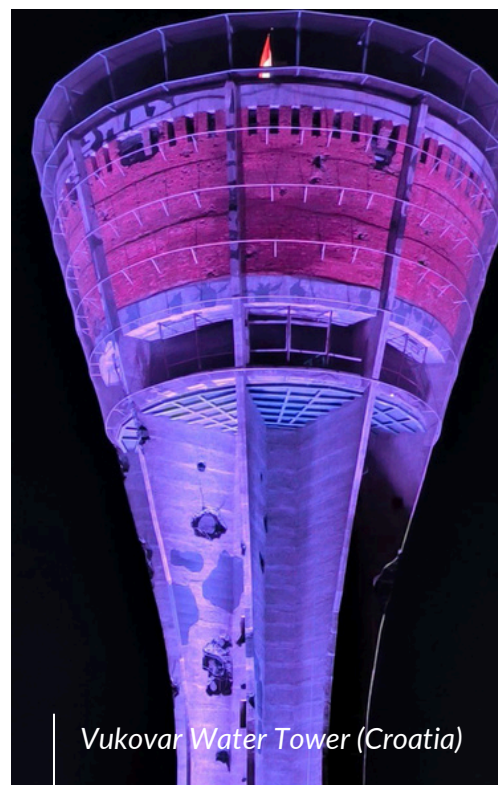


*Victoria Canopy Bridge
(Whangarei District, New Zealand)*



The Great Belt Bridge (Denmark)

Purple was also the prominent colour in numerous large-scale activities organised by the associations in public spaces, such as squares and parks. In the USA during Digestive Disease Week (DDW) provided an outstanding platform to spread awareness and support for the disease: our tagline IBD HAS NO BORDERS was displayed digitally and on congress banners and attendees were encouraged to wear purple on 19 May to show their support for those living with IBD.



Vukovar Water Tower (Croatia)



And of course, we cannot forget about the small and famous Manneken-Pis, whom our colleagues from ASBL Crohn RCUH and Crohn en Colitis Ulcerosa vzw., the two Belgian national IBD patient associations, dressed in purple once again on 19 May!

ON THE MOVE

Sport and being active was another theme used by some of our members during World IBD Day. Our partners at AFA Crohn RCH France took advantage of Paris hosting the Olympic and Paralympic Games to propose very sporty World IBD Day celebrations. Under the slogan "The IBD Enters into Play," the organisation focused on advocating for physical activity among patients and encouraging prevention strategies.

In Italy, our colleagues at AMICI organised their traditional IBD Run, where doctors, nurses, pharmaceutical and institutional representatives were all invited to participate in raising awareness about the disease.

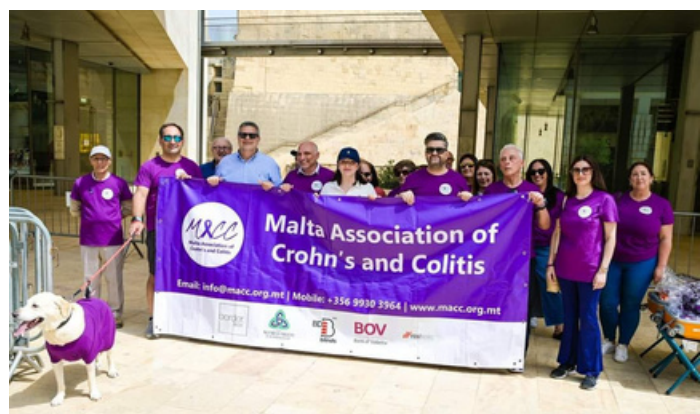


"Sports activities were a magnificent way to demonstrate that IBD is no obstacle to living active and fulfilling lives."



Similarly, female members of IBD EESTI participated in Estonia's massive spring women's race. Their purple shirts stood out among the more than 20,000 women who took part in the event, successfully showing that IBD is no obstacle to living active and fulfilling lives.

Traditional public walks were another successful activity. Notable examples include the walks held in Brazil as part of Purple May, open to patients, family and friends, or a walk near Celje, Slovenia, where association members distributed leaflets about IBD to raise awareness of the condition. Once again, our partners in Malta coloured Valletta streets in purple on 18 May, in a new edition of their Walk of Warriors.



BAGS AND BUZZ: CCU'S WORLD IBD DAY

distributed purple reusable cotton bags with their slogan, "You can't see it on me", each containing an informative leaflet, a roll of toilet paper, a scented spray and a cute poo figurine.

The first person to receive her bag was none other than Eliza Reid, the First Lady of the country, who gave tremendous publicity to the event by sharing it on her social media. In total, the association gave away 650 bags to attendees, providing extraordinary support for the CCU!



Eliza Reid, First Lady of Iceland, with Edda Svavarsdóttir, President of CCU, and other members of the association

Our members in Iceland, the CCU, started their awareness raising campaign on 3 May at Smáralind, one of the largest shopping centres in the Reykjavik area, where they

SHARING STORIES

This year, various associations gave voice to patients over several days or weeks throughout May.

Crohn's and Colitis Ireland launched the "It Takes Guts to Live with Crohn's and Colitis!" initiative: throughout the month, their social media channels and website highlighted the strength, resilience and courage of individuals who confront IBD every single day.

Crohn & Colitis NL organised a campaign featuring personal testimonials. Using the hashtag #levenachterdeschermen or "LifeBehindTheScreens," the initiative shared numerous stories through reels, posts, articles and swipes during World IBD Day week.



FINLAND AND IRELAND TURN 40!

This year, World IBD Day coincided with the 40th anniversary of two of our national associations.

IBD ja muut suolistosairaudet ry, our members in Finland, and Crohn's and Colitis Ireland took World IBD Day as an opportunity to celebrate their four decades of giving a voice and support to patients with IBD and their loved ones. We would like to take this opportunity to congratulate them for their effort over all these years!



Informative event organised by Greek association Hellecc



Crohn's & Colitis Society of Singapore 12th Annual Seminar

CONFERENCES AND SEMINARS

As part of the events for World IBD Day, numerous talks and conferences were held on 19 May, as well as in the days leading up to and following the occasion. Associations in Brazil, Bulgaria, Cyprus, Egypt, Greece, Hong Kong, Hungary, Italy, Norway, the Philippines, Indonesia, Poland, Singapore, Slovenia, South Africa and the United Arab Emirates invited doctors and experts in the field, as well as psychologists and dietitians.

The speakers shared their knowledge and often engaged in discussions with patients about issues important to the community.

Some of these conferences took place within the framework of significant annual events, such as the South African Gastroenterology Society Congress and Singapore's Annual Seminar IBD Patient Education and Public Awareness Seminar, which celebrated its 12th edition.

China, on the other hand, hosted IBD Science Week, a series of lectures given by experts and open to questions from attendees. These lectures, broadcast live, covered diet, exercise, lifestyle and treatment-related issues. APDI, the Portuguese IBD patient association, held



Conference held at the National University of Public Service in Budapest

a series of four free webinars throughout the month, aimed at patients, family members, friends and health professionals.

Educational activities were another highlight of the celebrations, often with the invaluable support of doctors and universities, as seen in Croatia, Cyprus, Hungary and Slovenia.

OTHER ACTIVITIES

Pacienti IBD, the national association in the Czech Republic, centered around the subject that diseases have no boundaries, neither within the human body nor geographically. An educational trail at publicly accessible locations in several regions was also organised.

The Slovak Crohn Club produced an educational video highlighting that IBD extends beyond the digestive system, with extra-intestinal effects.

In the United Kingdom, Crohn's & Colitis UK launched a targeted campaign to debunk common myths about IBD. Gathering insights from individuals with Crohn's or Colitis, they addressed misconceptions about diet, symptoms and managing fatigue and pain.



Leaflets distributed by Pacienti IBD

The idea was to initiate a comprehensive myth-busting effort to provide accurate information: a crucial educational initiative during World IBD Day, aiming to dispel widespread misconceptions and improve public understanding of Crohn's and Colitis.

A UNIQUE QR CODE



For World IBD Day, the Catherine McEwan Foundation in Scotland raised awareness with their #shoottheshitonibd campaign, highlighting challenges faced by those with IBD. They used a QR code billboard made from 100 toilet rolls, symbolising UK's 1 in 100 IBD sufferers. The QR code linked to their film "Shoot the Shit on IBD," a straight-talking film about living with the disease.

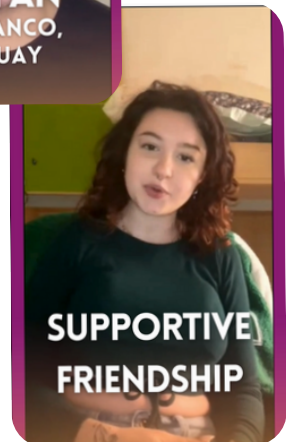
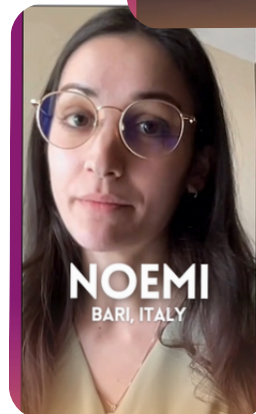
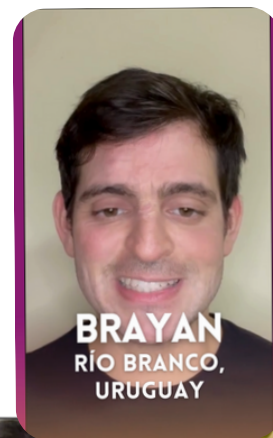
A COLLECTIVE CALL TO SHARE IBD STORIES IN SOCIAL MEDIA

As part of its "IBD Has No Borders" campaign, EFCCA carried out a social media campaign to amplify the voices of those living with Inflammatory Bowel Disease worldwide.

During the months leading up to World IBD Day, individuals with IBD were invited to share their personal stories, bringing together voices from different countries and cultures, each sharing what access to IBD care means to them..

These stories shared by many countries, told through video testimonials, provided valuable insights into the various aspects of IBD care and fostered a sense of unity and shared purpose within the global IBD community.

When people identify with stories similar to theirs, they get inspired to continue advocating for better resources and support systems for IBD patients



everywhere. These narratives not only showcase the resilience and strength of the IBD community but also underscore the universal need for enhanced care and understanding of this condition.

To find out more go to:

<https://www.efcca.org/news/world-ibd-day-2024>

EUROPEAN RESEARCH PROJECTS AND OTHER STAKEHOLDERS

Finally, we must express our gratitude to our other collaborators, especially to the teams involved in several EU-funded research projects in which EFCCA is a partner. They supported our awareness raising efforts and engaged many members of the scientific community.

The GENEGUT project organised an activity focusing on raising awareness and sharing perspectives on the global challenges of accessing IBD care and the future of innovative therapies. This initiative featured audio stories from both researchers and patients, aiming to highlight the disparities in healthcare access for IBD patients and to educate the public on the impact of the disease on individuals' lives.

On social media, FIBROTARGET provided significant exposure to our "IBD Has No Borders" campaign. Throughout the week, the consortium shared our videos featuring testimonies from IBD patients, in an effort



to spread our message among their followers. Their work was further enhanced by their blog, where they shared a short video highlighting the key challenges in IBD care.

Our appreciation is of course extended to pharmaceutical companies, who have supported us not only on this significant date but all year round. Their continued commitment and assistance are invaluable in helping us raise awareness and provide resources for those affected by IBD. We are truly thankful for their unwavering support year after year.



Maio Roxo

EVENTO OFICIAL ABCD

DIA DE ALEGRIA E UN

PARQUE DA INDEPENDÊNCIA
São Paul
EV



IBD.AFRICA

IBD AFRICA PATIENT MEETING

DATE: SATURDAY, 18 MAY 2024
TIME: 9.30-12.30
VENUE: CAPE TOWN ICC
RSVP: INFO@IBDAFRICA.ORG



المنتدى الخامس

IBD Alliance

EGYPTIAN IBD ADV. Day 2024

كروز... تفرج

Thank you all!



Verdens IBD-dag!

19. mai



EFCCA THEME
FOR WORLD IBD
DAY 2024

IBD HAS NO BORDERS

19 MAY - WORLD IBD DAY 2024



WHY IBD HAS NO BORDERS?

This year, EFCCA's theme was "IBD Has No Borders" emphasizing the global nature of IBD and the need for collective action.

The global prevalence of IBD is on the rise, with cases surging not only in regions such as the European Union, the United States, Australia, and Canada, but also in newly industrialised countries like those in Latin America and Asia. This increase is closely linked to rapid industrial development, highlighting a concerning connection between IBD and societal changes.

Despite advancements in medical research, only 30-40% of IBD medications prove effective, and treatments that work today may not be viable in a few months for the same patient.

This unpredictability further complicates the management of IBD, making it imperative to raise awareness and mobilise stakeholders—including governments, healthcare providers, and the public—towards a more concerted effort in supporting IBD patients.

The global prevalence of IBD is rising. This trend is linked to rapid industrial development and societal changes.



UNITING FOR ACCESS TO IBD CARE:

EFCCA'S ROUNDTABLE IN MEXICO CITY HIGHLIGHTS GLOBAL COMMITMENT TO IBD ADVOCACY



On May 17, 2024, in the heart of Mexico City, EFCCA organised an important event within the framework of its World IBD Day "IBD Has No Borders" campaign. The Roundtable discussion "**Uniting for Access to IBD Care**" addressed the pressing global challenge posed by IBD in particular as concerns access to quality care.

The meeting saw attendance from over 30 participants, including representatives from the founding members of World IBD Day (Crohn's & Colitis Australia, Crohn's and Colitis Canada, EFCCA, and Crohn's and Colitis Foundation USA), as well as delegates from six Latin and Central American countries (Brazil, Chile, Colombia, Costa Rica, Mexico, and Uruguay), and other IBD stakeholders.

Recognising the **urgent need for a coordinated and comprehensive approach to IBD care**, the Mexico City roundtable was particularly notable for its inclusive approach, aiming to bridge regional disparities and unify efforts towards global solutions.

[SEE COMPLETE VIDEO](#)
[READ THE FULL REPORT](#)

The meeting was live-streamed and has been viewed over **1,000 times** to date!





The keynote speakers were **Professor Claudio Fiocchi** from the Cleveland Clinic, US, and **Prof. Dr. Britta Siegmund**, ECCO President, who joined via a virtual presentation.

CORE OBJECTIVES OF THE ROUNDTABLE

- Engage in meaningful dialogue about the **barriers to quality IBD care**.
- Advocate for **increased awareness, support, and resources** for IBD patients.
- Formulate and **share recommendations** to enhance IBD care on a global scale.

Keynote speakers and founding members of World IBD Day provided insightful presentations, detailing various challenges in accessing quality IBD care and proposing viable solutions. The discussions highlighted common obstacles, such as healthcare access disparities, insufficient funding, and the critical need for heightened awareness and education about IBD.

The event stressed the importance of greater awareness and the mobilisation of all stakeholders, including governments, healthcare providers, and the public, to effectively address the needs of IBD patients. Collaboration, realistic goal-setting, and the sharing of best practices were identified as crucial elements in the ongoing effort to enhance IBD care.

Thank you to all our sponsors who have partially contributed to World IBD Day through their support of EFCCA. Your generous contributions have played a crucial role in making our IBD HAS NO BORDERS campaign possible and in raising awareness about Inflammatory Bowel Disease through the World IBD Day website. We deeply appreciate your commitment and partnership in our mission.

abbvie

Boehringer
Ingelheim

Galápagos

Lilly

Takeda

AGOMAB
THERAPEUTICS

HEALTHCARE
CELLTRION

janssen

Pfizer

EFCCA WORLD IBD DAY REPORT 2024

Authors and Layout: Laura Cervetto, Francesc Esparza and Isabella Haaf

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Rue des Chartreux 33-35
B-1000 Brussels Belgium
Tel/Fax: +32 2 540 8434

