

WORLD IBD DAY REPORT 2023



"An opportunity to show support for people living with IBD."

WHAT IS WORLD IBD DAY

World IBD Day was created in 2010 by EFCCA and other 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).

Over the years, many other IBD organisations and stakeholders have joined the initiative. Today, World IBD Day is led by patient **organisations representing over 50 countries** on five continents, coordinated by EFCCA.

World IBD Day takes place on 19 May each year and it serves as a

powerful platform that unites people worldwide in their fight against Crohn's disease and ulcerative colitis.

It is an opportunity to show support for people living with these conditions as there is still **little public understanding of the pain and chronic suffering** with which IBD patients bravely cope every day of their lives.

Various national and local campaigns and activities are organised to raise awareness and engage communities, aiming to achieve the goal of **increasing understanding and support** for individuals affected by IBD.

Despite the progress made, there is still a significant lack of public awareness surrounding **the true impact of IBD on the lives of affected individuals.**

World IBD Day strives to change this by fostering greater empathy and

understanding among the different communities.

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

A GLOBAL CAMPAIGN



"Over 40 national associations shared their events and activities."

This year, EFCCA has made a significant effort to disseminate and promote the numerous activities of the different associations for World IBD Day.

Once again, along with social media outreach, **worldibdday.org** website has provided us with a great tool to compile and showcase these activities. The website served as a unique platform for sharing worldwide activities:

over 40 national associations shared their events and activities, which we ensured were reflected in the dedicated section (2023) of the World IBD Day website.

While 19 May, the official World IBD Day date, was the busiest day, many associations carried out activities throughout the week or even during the entire month.

In numerous countries around the globe, buildings, monuments, or famous landmarks were **illuminated in purple** to highlight the daily challenges faced by individuals living with IBD, inviting countries, cities, and people worldwide to join our fight against the disease.

Furthermore, patient associations and activists in Argentina, Cyprus, Egypt, Greece, Hungary, Lebanon, Mexico, Portugal, Singapore, Slovakia, Slovenia, Sweden, or Switzerland organised **local events** to support and inform about

IBD through lobbying efforts and information dissemination.

Associations in Brazil, India, Italy, and South Korea organised **walks or races** in different cities to engage as many citizens as possible on this day.

For example, in Malta, a "Walk of Warriors" marched through La Valetta accompanied by percussion instruments. While in Paris, the "Microbiota, Intestine and Inflammation" research team organised a flashmob that surprised passersby.

"Buildings, monuments and other landmarks were illuminated in purple, inviting people worldwide to join our fight."





Our colleagues in the Netherlands, New Zealand, and Norway encouraged individuals living with IBD to **share their stories**, whether through written form, videos, or photographs. In the Czech Republic, this initiative translated into a large format photo exhibition in the heart of Prague.

Other associations, such as our members in Croatia, Denmark, Iceland, Serbia, and Turkey, also contributed to the awareness efforts of this day, either by organising **public gatherings** or using their **social media platforms** to raise awareness about IBD among the public. In Flanders, Belgium, for example, several volunteers visited hospitals

on the days leading up to and following 19 May.

Lastly, countries like Ireland, Spain, the United Kingdom, and the United States carried out their own **awareness campaigns**. Others, like Hungary, Poland, and Romania, extended the motto "IBD Has No Age" to people of all ages, organising recreational and educational activities targeting both adults, kids and seniors.

We invite you to explore the **"World IBD Day events"** section on worldibdday.org to find out the specific activities and to discover how extraordinarily active our members have been this year.

As part of the World IBD Day Activities, a successful **regional meeting** took place on 20 May in **Vilnius**, bringing together IBD patient associations from Latvia, Lithuania, and Estonia.

There were special events, such as lectures, interviews, public performances, or lighting the chamber of Grand dukes of Lithuania in purple.

Magda Sajak Szczerba, board member of EFCCA and the Polish IBD patient association "J-elita," participated and extended EFCCA's support to this regional initiative.

BALTIC STATES REGIONAL MEETING



THE ROLE OF NURSES AND HEALTHCARE PERSONNEL

We must highlight and celebrate the solidarity displayed by **nurses** and **healthcare personnel**, who actively joined World IBD Day.

In countries like Belgium, France and others, they showcased their unwavering support further emphasizing their crucial role in the lives of IBD patients.



"Healthcare personnel
showed their solidarity."

Their example serves as an inspiration and a testament to their dedication to providing holistic care and improving the well-being of those impacted by this challenging condition.

Finally, we must express our gratitude to other collaborators, including **pharmaceutical companies**, who not only support us on this significant date but throughout the entire year.

PHARMACEUTICALS AND OTHER STAKEHOLDERS



Many of them actively participated by endorsing EFCCA's theme for this edition, "IBD Has No Age," or by creating awareness raising campaign, as seen with Celltrion and their initiative "Where is CC."

We also extend our appreciation to the teams involved in the **Horizon Europe**

research projects, who wholeheartedly provided their support and promoted World IBD Day and our survey aimed at individuals aged 60 and older with IBD (see page 8).

Their collaboration has been instrumental in advancing our mission, and we are sincerely thankful for their involvement.



"Consortium partners involved in our common Horizon Europe projects promoted World IBD Day and supported the launch of our survey."



Shine A Light World IBD Day

19 May 2023



Thank
you all!

Bedankt!



EFCCA THEME FOR WORLD IBD DAY 2023

"IBD HAS NO AGE"



A MAJOR CHALLENGE: OUR SURVEY ON PEOPLE AGED 60 AND OVER

For World IBD Day 2023, EFCCA continued its mission of raising awareness about Inflammatory Bowel Disease (IBD) with a specific focus on the **population aged 60 and over**.

Building upon the success of our 2022 campaign, "**IBD has no age**," we aimed to shed light on how Crohn's disease and ulcerative colitis impact the individuals aged 60 and above.

Despite the increasing incidence and prevalence of IBD among older patients, this group had been underrepresented in discussions and research.

Unfortunately, there is limited scientific evidence available to fully comprehend how IBD affected the health outcomes and quality of life of this particular age group.

WORLD IBD Day

"Individuals aged 60 and above had been underrepresented in discussions and research."



Recognising the importance of this issue, on 19 May EFCCA launched a survey focused on these individuals with IBD.

The survey aims to delve deeper into this subject by exploring various aspects and to better understand the disease among this population on specific issues related to **comorbidities, polypharmacy, drug effectiveness, and interactions.**

We launched the survey on that very day to capitalise on the significance of WorldIBD Day in many countries.

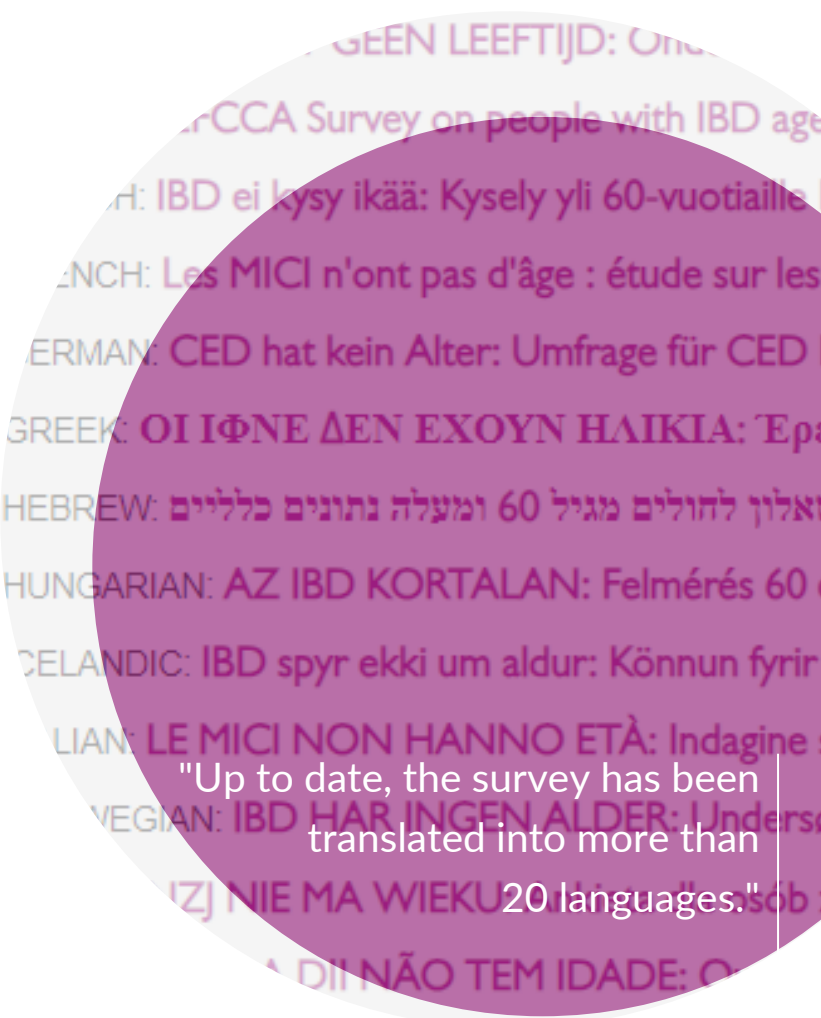
The survey represents our efforts to gather **valuable data** that we consider essential in order to shape future initiatives and ensure that the needs of these individuals are adequately addressed.

A SURVEY IN SEVERAL LANGUAGES

We are delighted to share that up to date the survey has been translated into **more than 20 languages** on our website. This allows us to reach a broader audience and facilitate the participation of individuals who might have otherwise been excluded due to language barriers, ensuring accessibility for a diverse range of patients worldwide.

This achievement would not have been possible without the contributions of **our dedicated volunteers**, who generously and enthusiastically devoted their time and efforts to translate the survey.

We are deeply grateful for their commitment, which serves as a testament to the power of collaboration and community-driven initiatives in advancing IBD research and representing patients.



During World IBD Day, numerous **patient associations** affiliated with EFCCA took proactive measures to **promote our survey** effectively.

OUR MEMBERS ARE GETTING INVOLVED

They leveraged their **social media** platforms and other channels to ensure its outreach to a larger audience, fully aware of the significance of the initiative.

In addition to the patient associations' efforts, several **pharmaceutical companies and research teams**, including those associated with the **Horizon Europe project**, collaborated with EFCCA in disseminating the survey. Their cooperation played a vital role in reaching a diverse range of potential respondents.



We extend our appreciation to our members from the Netherlands. Recognising that many of the elderly respondents might not be familiar with computers and electronic formats, they printed and distribute the survey via **traditional mail** to thousands of individuals.

A thoughtful approach that ensures inclusivity and enables a broader participation in the survey.



"Our members from the Netherlands printed and distributed the survey via traditional mail."

EFCCA's World IBD Day activities 2023 have been supported by the following companies:

abbvie

Boehringer
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