

# World IBD Day 2024

# IBD Has No Borders

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Mexico City, 17 May 2024



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**Isabella Haaf**

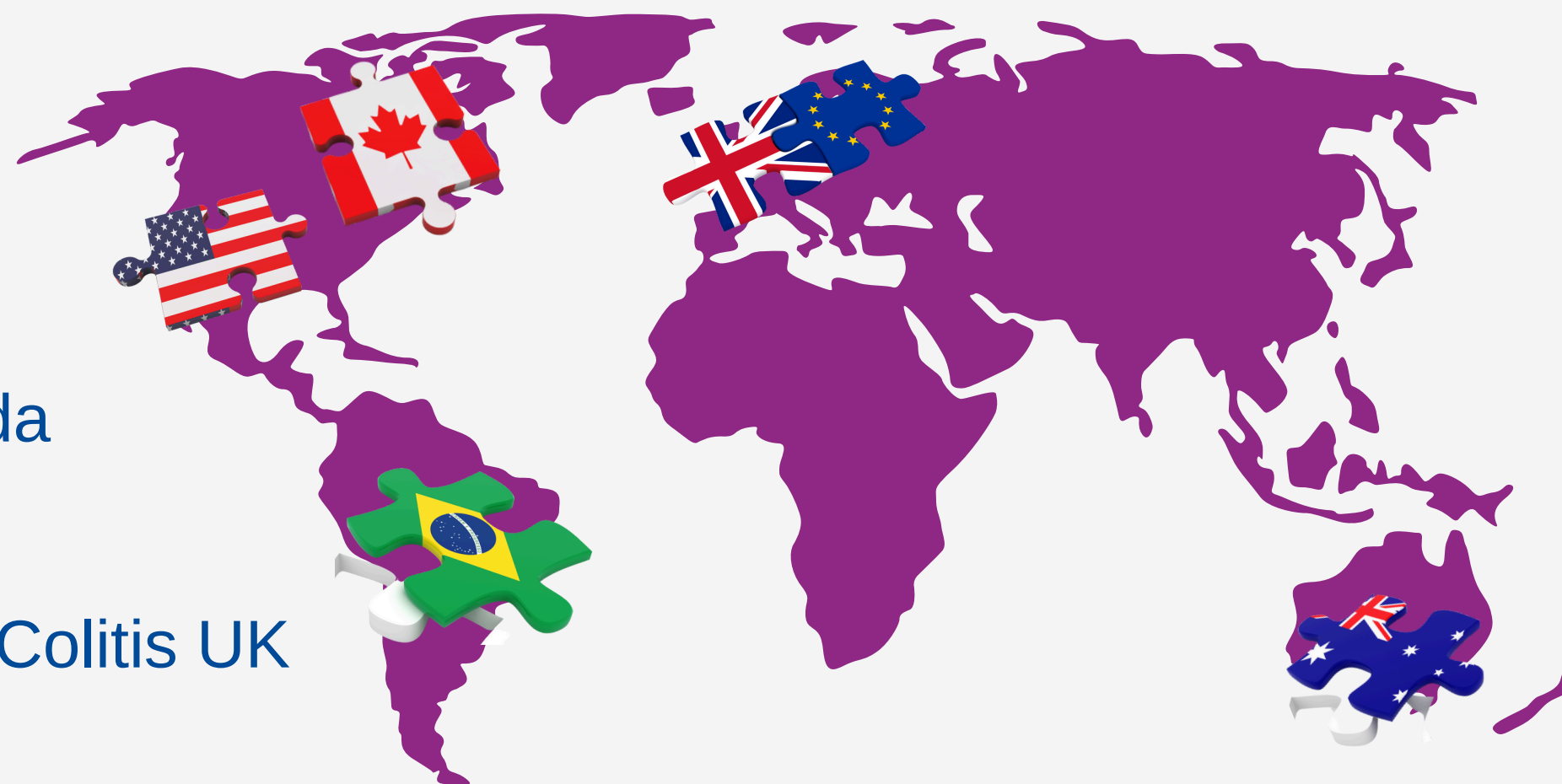
**Coordinator World IBD Day**  
EFCCA Head of Communication

# Creation of World IBD Day

*World IBD Day was created in **2010** during Digestive Disease Week (DDW) in San Diego, US*

## Founding Members:

- ABCD (Brazil)
- Crohn's and Colitis Australia
- Crohn's and Colitis Foundation Canada
- Crohn's and Colitis Foundation (US)
- EFCCA and its member Crohn's and Colitis UK



*World IBD Day is led by patient organisations representing **over 50 countries** on five continents*

# Why World IBD Day?

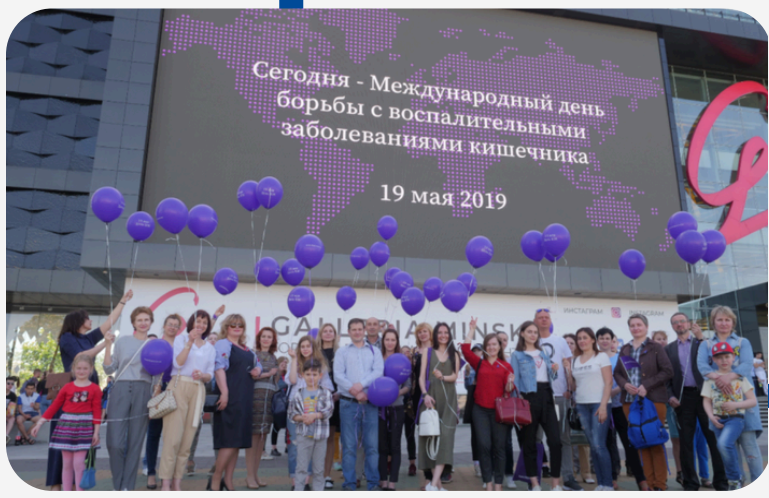
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➔ To raise **awareness about IBD** and to inform the public, healthcare professionals and policymakers about the challenges faced by those living with Crohn's disease and Ulcerative Colitis



# Why World IBD Day?



**➔ Unite and mobilise volunteers worldwide**

*Captions from different World IBD Day editions: (left to right and top to bottom) volunteers from Austria, Mexico, Lithuania, Belarus and Ivory Coast*



# World IBD Day website

## World IBD Day around the world

“It’s amazing to see so many people from different countries come together in order to raise awareness for these devastating diseases.” Salvo Leone, EFCCA chairman



Australia



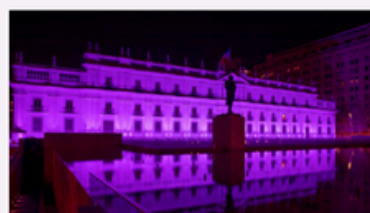
Belgium



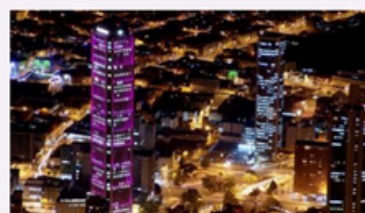
Brazil



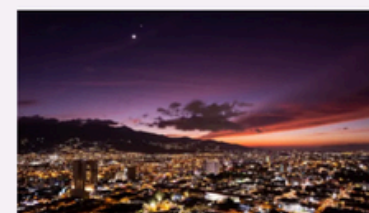
Canada



Chile



Colombia



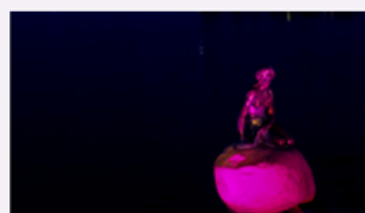
Costa Rica



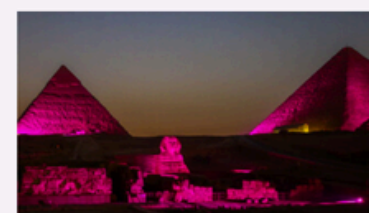
Cyprus



Czech Republic



Denmark



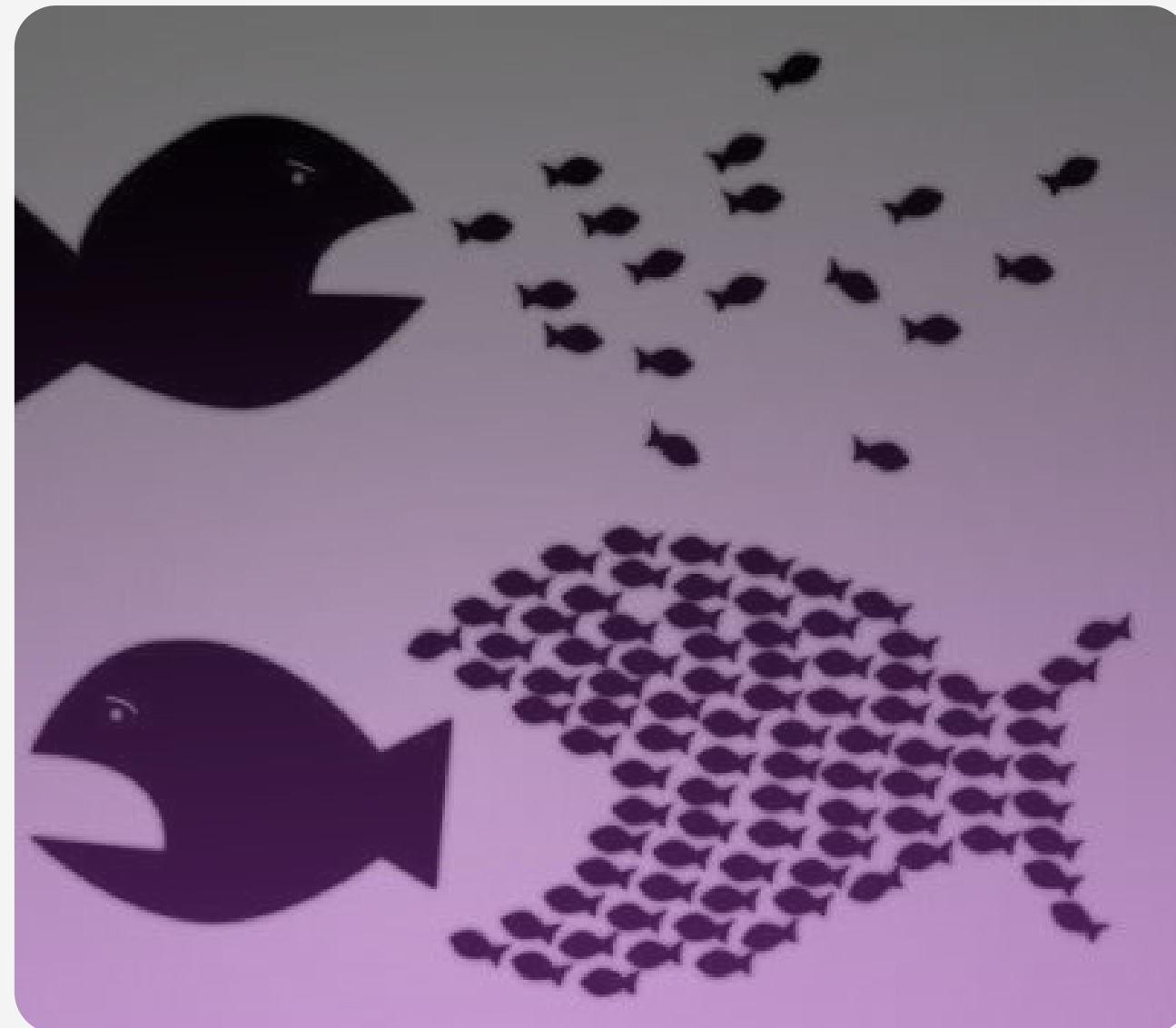
Egypt



Europe (EFCCA)

# Why World IBD Day?

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➔ **...Strength in numbers!!**

*In 2023, WIBDDAY united more than 60 patient associations on 5 continents*

- *More than 500 IBD information events took place*
- *1000s of volunteers participated*
- *Increased social media outreach and visibility in mainstream media*

# World IBD Day 2024

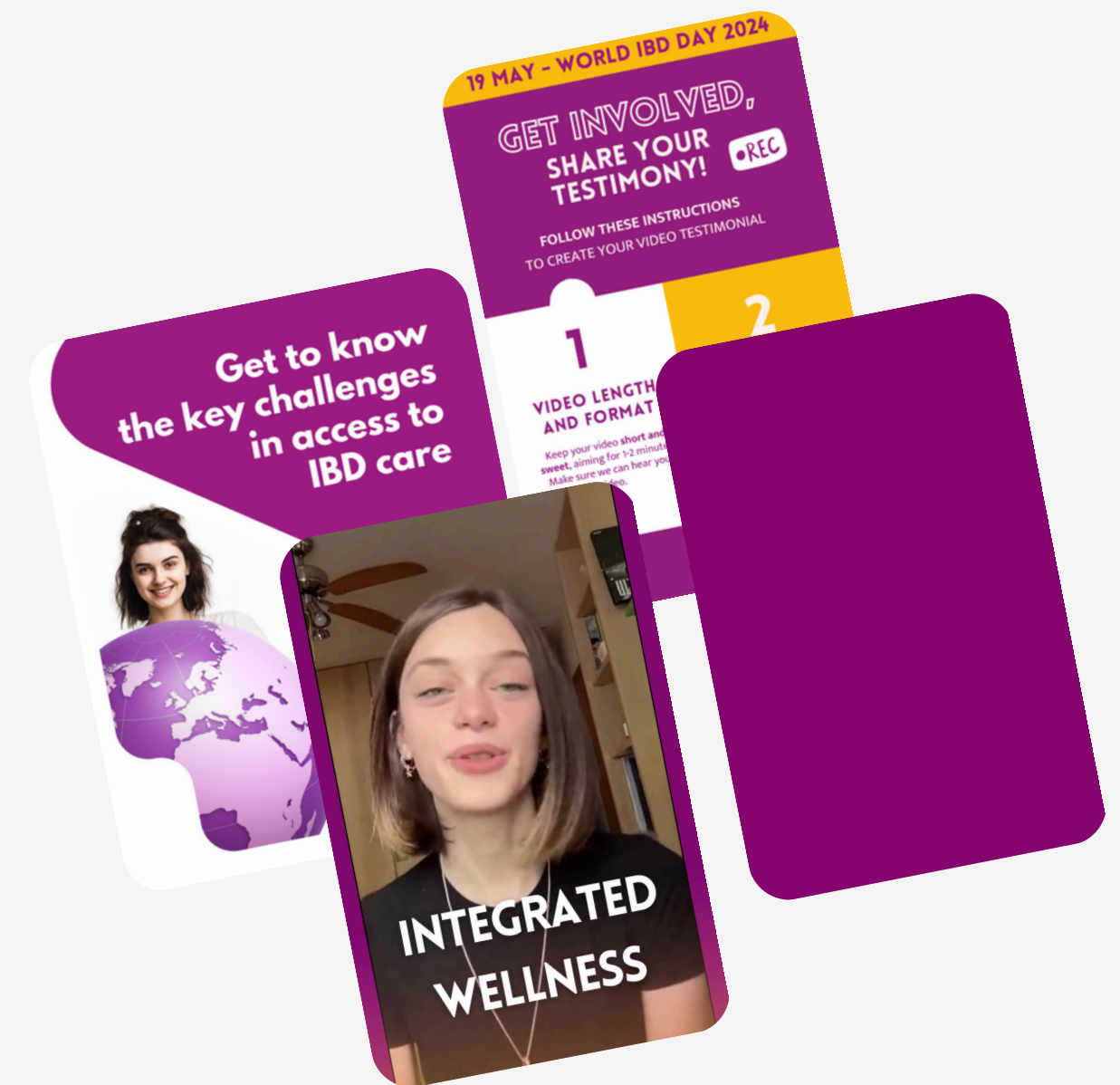


## “IBD Has No Borders”

- Universal nature of IBD, IBD on rise globally
- Need for collective action.
- Need for global response that prioritises awareness, support and equitable access to care for all affected individuals, regardless where they live

# Social media Awareness Raising campaign

- ➔ Hearing **voices** from people with IBD in **different countries**
- ➔ Highlight diverse **challenges and possibilities** of living with IBD
- ➔ Shed light on the importance of **improving access to care**





# Social media Awareness Raising campaign



*“It took over a  
year for doctors  
to find out what I  
had”*





# Uniting for Access to IBD care

## Roundtable discussion: Mexico, 17 May 2024



Roundtable discussion gathering World IBD Day founding members for the first time since DDW

**UNITING FOR ACCESS TO IBD CARE**

**MEET OUR SPEAKERS!**

**Claudio Fiocchi, MD**  
Dr. Fiocchi is Professor of Molecular Medicine at the Cleveland Clinic Lerner College of Medicine, Cleveland, and a member of the Department of Inflammation & Immunity in the Lerner Research Institute of the Cleveland Clinic. His lifelong interest is in IBD, where he has made numerous contributions. Dr. Fiocchi was the first investigator to study cytokines in Crohn's disease and ulcerative colitis and launched the study of intestinal immune-nonimmune cell interactions, which evolved into the field of intestinal fibrosis, and he was instrumental in establishing the new field of pediatric IBD. His most recent interest is the study of network medicine to understand IBD in greater depth. During his long career Dr. Fiocchi trained several investigators from the USA, Europe, Asia, and South America, many of whom went on to become leaders in IBD in their own countries. He has received numerous prestigious awards reflecting his outstanding contributions to gastroenterology and immunology.

**Prof. Dr. Britta Siegmund**  
Prof. Dr. Britta Siegmund is the current President of the European Crohn's and Colitis Organisation (ECCO). She is the Medical Director of the Division of Gastroenterology, Infectiology and Rheumatology at the Charité - University Hospital Campus Benjamin Franklin Berlin, Germany. Britta Siegmund has received her MD from the Ludwig-Maximilians-University in Munich and continued her training as Postdoc in the lab of Charles Dinarello in Denver, USA. She is widely recognised for her contributions to the field of gastroenterology and has published 482 scientific publications. She is known for her work in Inflammatory Bowel Disease and has focused her research on finding new and improved treatments for patients. In 2012 she was appointed as Heisenbergprofessor for "Translational Gastroenterology - IBD" and is one of the founders of the German IBD Study Group. She continues to provide excellent care and contribute to advancements in the field of gastroenterology.

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**Salvatore Leone**  
Salvo Leone is the Chairperson of the European Federation of Crohn's & Ulcerative Colitis Associations (EFCCA) and serves as the Director General of AIMEC Onlus, the Italian National Association for Inflammatory Bowel Disease (IBD). With over 20 years of dedicated involvement in patient associations, Salvo brings a wealth of experience to his roles. His longstanding commitment to patient advocacy, healthcare management, and research coordination underscores his passion for improving the quality of life for individuals affected by IBD.

**Laura D. Wingate**  
Laura D. Wingate is the Executive Vice President of Education, Support, & Advocacy of the Crohn's & Colitis Foundation (USA). She collaborates with the National Scientific Advisory Committee, the Board of Trustees and volunteers to develop programs and resources. She is an experienced non-profit professional. She has worked on quality improvement initiatives and patient experience redesign. Her desire to make a difference in patient care led her to join the Crohn's & Colitis Foundation seventeen years ago. Currently, Laura serves on the American Board of Internal Medicine Gastroenterology Specialty Board and as an advisor for Act4Biosimilars.

**Leanne Raven**  
Since 2018 Leanne Raven is the Chief Executive Officer with Crohn's & Colitis Australia and a fellow of the Australian Institute of Company Directors. She has been acknowledged for her innovation in the not-for-profit sector as the winner of the 2013 Telstra Business Women's Award. She has been the national CEO of Red Nose (formerly SIDS and Kids) and has led change and transformative growth in not-for-profit organisations to build capacity and sustainability, volunteering for many years in the disability and philanthropic sectors. She has been a self-employed strategy and management consultant with executive, non-executive director and senior management experience in primary health, community and human services, education and health professional regulation.

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**Kate Lee**  
Kate Lee is Vice President of Research & Patients Programs at Crohn's and Colitis Canada, where she oversees the organisation's research, patient and advocacy programs to find the cure(s) and improve the quality of life of everyone affected by Crohn's disease and ulcerative colitis. Kate has over 20 years of experience in the health sector, including Managing Director of the Canadian Arthritis Network - a Centre of Excellence funded by the tri-council funding agencies of CIHR, NSERC and SSHRC, VP of Research at the Arthritis Society, and as a scientist at a biotech company. Kate holds a PhD in biology from McGill University and an MBA from Rotman School of Management University of Toronto.

**Beatriz Capdevielle Gómez**  
Beatriz Capdevielle Gómez is a dedicated advocate and the director of Vivir con Crohn y Colitis (VCC), an organisation committed to supporting individuals living with Crohn's disease and ulcerative colitis (CU) in Mexico. Her journey with Crohn's disease has fuelled her passion for raising awareness and providing support for those affected by Crohn's and ulcerative colitis (CU) in Mexico. Beatriz's commitment to improving the lives of others shines through her advocacy efforts, educational initiatives and compassionate support network. Through Vivir con Crohn y Colitis (VCC), she continues to make a profound impact in the Crohn's and colitis community, offering guidance, resources and solidarity to those in need.

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**Roberto Saldaña**  
Roberto Saldaña is the Innovation and Patient Engagement Coordinator for EFCCA (European Federation of Crohn's & Ulcerative Colitis Associations). With a profound dedication to enhancing patient care and advocacy within the Inflammatory Bowel Disease (IBD) community, Roberto plays an important role in fostering innovation and empowering patients across Europe. Through his work at EFCCA, Roberto spearheads initiatives that promote patient engagement, access to treatment and advancements in IBD research.

**Isabella Haaf**  
Isabella Haaf is the Coordinator for World IBD Day and Head of Communications at the European Federation of Crohn's and Ulcerative Colitis Associations (EFCCA). In her role, she oversees EFCCA's advocacy and awareness programs, contributes to strategic organisational development and serves as the main editor of the EFCCA Magazine. Through these initiatives, Isabella provides comprehensive information on IBD-related projects, patient concerns, and the perspectives of individuals living with IBD.

**Luisa Avedano - Moderator**  
Luisa Avedano is the Chief Executive Officer of the European Federation of Crohn's and Ulcerative Colitis Associations (EFCCA) since 2009. She is in charge of the strategic, policy and daily management of the EFCCA's Secretariat as well as of the assistance and support of the Chairperson and the Executive Board members in fulfilling their responsibilities and tasks. She has an extensive experience in international NGOs and networking. She has been managing all levels of multiple and integrated projects including budgeting and administration. She is working on project design and development, advocacy and lobbying at EU level and she is responsible for the fundraising strategy.

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# Uniting for Access to IBD care

## Roundtable discussion: Mexico, 17 May 2024



### ➔ Objectives:

- Identify barriers to accessing quality IBD care globally
- Advocate for increased awareness, support and resources
- Formulate shared recommendations for improving IBD care worldwide



# Uniting for Access to IBD care

Roundtable discussion: Mexico, 17 May 2024

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## Take home messages

- Importance of addressing IBD as a global health concern
- Need for Strengthening collaboration with key IBD stakeholders
- Need for continued engagement beyond World IBD Day



**Thank you!**