



Executive Summary

IBD Africa has strengthened its position as a leading organisation dedicated to improving the lives of people living with inflammatory bowel disease across South Africa and sub-Saharan Africa. Over the past year, the organisation has expanded its research portfolio, deepened its educational impact, strengthened patient advocacy and grown its global partnerships.

Key achievements include the continued growth and analysis of the IBD Africa Registry, now exceeding 4 000 patients and yielding important insights into the epidemiology, phenotype and health disparities of IBD in South Africa. The organisation joined the African IBD Research Endeavour (AIRE), contributing to the first genome-wide association study of IBD on the African continent. A landmark qualitative research project, led by Dr Sara Cooper, has commenced recruitment and will provide the first in-depth exploration of patient experiences and health system barriers in the region.

Education initiatives expanded significantly, including the 7th IBD Africa-SAGES Patient Meeting, a dedicated Paediatric IBD Day and the launch of a weekly multidisciplinary clinical forum. Patient engagement through social media continues to grow, with increasing outreach from across sub-Saharan Africa.

Advocacy efforts have been strengthened through the 3rd IBD Africa Patient Advocacy Summit. On the foundation of previous summits collaborative patient-led initiatives to address care deficits have been expanded.

Global collaborations accelerated through participation in the GLIDE initiative, the IBD Emerging Nations Consortium and IBDacadME, as well as contributions to major international publications and conference presentations. Notably, sub-Saharan Africa was represented in the Global IBD Phenotype Study published in *Journal of Crohn's and Colitis*.

The organisation expanded its internal capacity with the appointment of Dr Zozibini Mhlaba, who now leads key research and education initiatives and embarked on a Master's in Public Health in 2026.

IBD Africa enters the coming year with strong momentum and a clear trajectory: to advance African IBD research, strengthen

patient-centred care, broaden access to treatment and amplify African representation in the global IBD community.

Introduction

IBD Africa, registered as a non-profit organisation in 2017, has grown into a recognised and trusted presence within the inflammatory bowel disease community in South Africa, sub-Saharan Africa, and internationally. Over the years, our organisation has evolved with a sharper focus on programmes, projects and research aimed at improving the lives of people living with IBD across the continent through Research, Education and Advocacy.

New Board

In line with legislative requirements governing non-profit organisations, IBD Africa reconstituted its Board in July 2025.

The new Board comprises:

Dr David Epstein – IBD patient, founder and director

Mr Peter Marais – IBD patient

Sr Karin Davidson – IBD Nursing

Prof. Dion Levin – Gastroenterologist, academic

Ms Katherine Megaw – IBD Dietitian

Dr Lesego Ndhlovu – Paediatric IBD

Dr Sara Cooper – IBD patient and qualitative researcher

Dr Zozibini Mhlaba – IBD patient, research officer and company secretary

Research

IBD Africa's research agenda has crystallised into three strategic themes.

1. IBD Africa Registry

The IBD Africa Registry has evolved significantly since its origins in 1999, when the first 200 patients from the Groote Schuur Hospital IBD Clinic were recorded on an Excel spreadsheet. A major step forward came in 2016 when Takeda funded the

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Peter Marais

development of a customised database specifically designed for African IBD.

Today, the Registry includes over 4 000 patients, revealing a distinctive and increasingly well-defined pattern of IBD in South Africa. Key insights include:

- An exponential rise in IBD over the past 50 years
- A transition from a “developed world” to “developing world” disease phenotype
- High rates of both latent and active tuberculosis amongst IBD patients
- Clear disparities in IBD health outcomes between socioeconomic groups in Cape Town
- Distinctive epidemiology within the Cape Town Coloured community and Durban’s Indian community
- Patient-Reported Outcomes (PROs) highlighting substantial gaps in the quality of IBD care

IBD Africa has set an ambitious goal to complete the epidemiological update of IBD in Cape Town—last published more than 50 years ago.

2. Genetics of IBD in Africa

In March 2024, the African IBD Research Endeavour (AIRE) held its inaugural meeting in Lusaka. IBD Africa was invited to join this multinational, ECCO-funded collaboration involving 11 African centres, TROPGAN in Lusaka, and Cedars-Sinai in Los Angeles.

The initiative is undertaking the first genome-wide association study (GWAS) for IBD on African soil, with plans to expand the project modularly to include microbiome analyses and proteomics. Ethics approval was granted this year and recruitment is progressing well. This landmark study promises to unlock new understanding of IBD genetics in African populations.

3. IBD Qualitative Research

A major strength of the organisation this year has been the addition of Dr Sara Cooper, a qualitative researcher at the SAMRC and Cochrane Centre who pivoted to IBD research following her own lived experience of the disease. Her personal journey—particularly the ease of access to advanced therapies—prompted her to investigate how other South Africans navigate the IBD care pathway.

Her work began as a situational analysis of IBD care in South Africa and sub-Saharan Africa, which has since evolved into a paper co-authored with international experts and submitted for publication. With ethics approval and funding secured, patient recruitment is now underway for one of the continent’s first qualitative research studies dedicated to IBD.

Education

IBD Africa continues to expand its educational footprint with meaningful, patient-centred initiatives.

7th IBD Africa Patient Meeting

The annual patient meeting took place on 2 August 2025 at the SAGES Congress in Durban. This hybrid in-person and online meeting—run in collaboration with GECHO—provided updates on global IBD developments, strengthened patient health literacy and offered a platform for patients to voice their experiences.

We thank SAGES, Equity Pharmaceuticals and Evolabs (Bio-Oil®) for their generous support.

Paediatric IBD Day

On 20 September 2025, IBD Africa hosted a dedicated day for children, adolescents and their parents. For many young attendees, this was their first opportunity to meet peers living with IBD. Themes of bullying, stigma and emotional

burden emerged strongly, reinforcing the need for focused support. Parents also engaged in open and deeply meaningful conversations about the challenges of caring for a child with IBD.

Social Media Outreach

Our social media platforms continue to expand, with increasing engagement from patients across sub-Saharan Africa seeking guidance on diagnosis, treatment and disease management.

Weekly IBD Multidisciplinary Forum

In 2025, IBD Africa launched a weekly multidisciplinary clinical forum where complex IBD cases and therapeutic dilemmas are discussed by gastroenterologists (adult and paediatric), IBD nurses, surgeons, rheumatologists, dermatologists and pathologists. This platform has become invaluable for collaborative decision-making and shared learning.

Advocacy

3rd IBD Africa Patient Advocacy Summit

The third summit took place in Cape Town on 25–26 October 2025, led by Lauren Pretorius from Campaigning for Cancer with support from IBD Africa facilitators.

While the programme serves as an introduction to healthcare advocacy, the “Advocacy in Action” sessions brought together past delegates and other immune-mediated disease advocates who shared their advocacy journeys and successes. Highlights included learning from the experience of Gaone Mawwa’s “Beyond Vitiligo” NPO, a talk on managing IBD in the context of Xhosa traditions and a talk by Discovery Health’s Darren Sweidan on “Why is healthcare so expensive?” Delegates concluded the summit with knowledge of patient advocacy principles, empowered through shared experiences and better informed of the challenges facing IBD patients in both the public and private sectors in South Africa.

Empowering patients through advocacy remains a core pillar of IBD Africa’s mission, and the impact of these summits is increasingly evident.

Global Partnerships and Presentations

IBD Africa continues to strengthen its international profile and partnerships.

We were invited to join the GLIDE initiative at the ECCO 2025 meeting in Berlin, contributing to a global platform for IBD registry data.

Dr David Epstein was invited to join the IBD Emerging Nations Consortium to support development of the ENC Biologics Registry.

IBD Africa joined IBDacadME, a Middle Eastern IBD network initiated by Prof. Ala Shahara from the American University of Beirut and Duke University Medical Center, USA. Dr Sara Cooper



and Dr David Epstein co-authored “The IBD Patient Journey” with Prof. Shahara and colleagues, accepted for publication in JCC Plus.

IBD Africa collaborated with Prof. Charles Bernstein and an international team on the Global IBD Phenotype Study, published in *Gastroenterology* in August 2025—the first global IBD study to include patients from sub-Saharan Africa.

At Canadian Digestive Diseases Week (April 2025), Dr Epstein delivered a lecture titled “Implications of Patient, Environment and Microbiome in IBD”. He subsequently visited Prof Bernstein’s IBD Unit in Winnipeg, presenting on IBD and TB, extraintestinal manifestations and participated in GI fellow teaching.

IBD Nursing

IBD Africa continues to raise the standard of inflammatory bowel disease (IBD) nursing in South Africa, largely through the dedicated efforts of board member Sr Karin Davidson.

Sr Davidson has represented South Africa as a low- and middle-income country (LMIC) delegate on both the ECCO LMIC IBD Management Consensus and the N-ECCO Nursing Guidelines.

She remains deeply committed to education through numerous national and international speaking engagements, one-on-one training of IBD nurses, and active participation in a weekly multidisciplinary IBD forum.

In addition, Sr Davidson has spearheaded an iron-deficiency anaemia awareness campaign for adolescent girls in the Western Cape and has joined global partners in a point-of-care diagnosis and intravenous iron treatment programme at antenatal clinics on the Cape Flats in Cape Town.

Dr Zozibini Mhlaba Joins the IBD Africa Team

Dr Zozibini Mhlaba grew up in Ugie, a rural town in the Eastern Cape, and studied medicine at the University of Cape Town. Diagnosed with ulcerative colitis in her first year at university, she completed her community service at the end of 2024 and, like many young doctors in SA, faced unemployment.





She joined IBD Africa in February 2025 for three-months supporting the African IBD genetics study. Her contributions quickly expanded, and she accepted a one-year renewable contract. Dr Mhlaba now:

- Leads the AIRE genetics project
- Serves as co-investigator on the qualitative IBD study
- Has significantly expanded the IBD Africa Registry
- Plays an active role in education and advocacy initiatives

Dr Mhlaba’s abstract “The burden of tuberculosis in an IBD cohort from an African, TB endemic, country” was presented at the ECCO Congress in Stockholm, Sweden, in February 2026.

Dr Mhlaba has also been accepted to participate in the ECCO Train the Trainer Programme in June 2026 in Vienna where a nurse-physician team meet with colleagues from around the world with the focus on “sustaining IBD networks and sharing knowledge in your country.” Dr Mhlaba will be joined by an IBD nurse from the Cape Town Gastroenterology Centre.

In her words:

“My work at IBD Africa has been transformative, both professionally and personally. From working alone at a rural primary healthcare clinic in the Eastern Cape, grappling with disillusionment and burnout, to being immersed in multidisciplinary research with IBD experts from across the globe... what a journey!”

IBD Africa Funding

IBD Africa wishes to thank Prof. Chris Kassianides and The Gastro Foundation, AbbVie, The Cape Town Infusion Centre, The Cape Town Gastroenterology Centre, Equity Pharmaceuticals, Evolabs, Janssen and Takeda for their support of our projects in 2025.

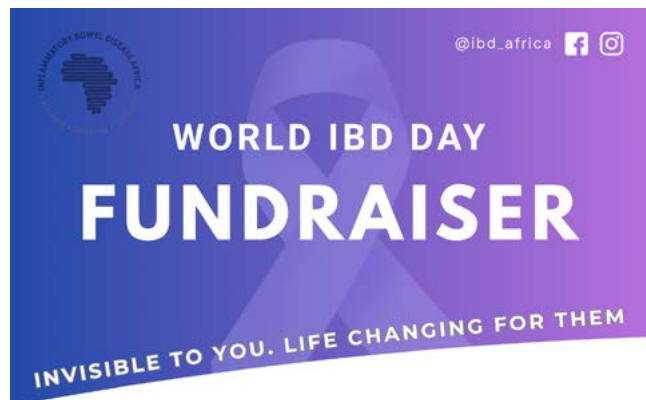
IBD Africa’s biggest challenge remains sustainable funding to future-proof our organisation. In contrast to our partner organisations in Europe and North America where budgets run into millions of US dollars (Crohn’s & Colitis Foundation, USA operating revenue in 2023 was \$92.8M) we survive on “a hand to mouth” existence.

We urgently need financial support for the day to day running of our organisation, to continue our research agenda, to expand

our patient education and advocacy projects and to fund our growing staff compliment. Our track record speaks for itself... we have changed the landscape of IBD in South Africa and we invite you to partner with us to continue this vital work.

2026 and Beyond

IBD Africa enters 2026 with strong momentum, expanded capability and deepened partnerships. Our priorities include completing the Cape Town IBD epidemiology study, scaling the AIRE genetics programme, broadening our patient education and advocacy footprint and continuing to strengthen multidisciplinary clinical support for IBD across the region.



Enjoy a memorable evening of education and entertainment over a three-course dinner while supporting IBD Africa. More than 6 million people around the world live with inflammatory bowel disease and the numbers are rising.

JOIN US IN AID OF IBD AFRICA’S RESEARCH, EDUCATION AND ADVOCACY WORK

Golfpark 4,
Raapenberg Rd,
Mowbray

Saturday 23 May

18:30

