

# Newsletter

World Endometriosis Organisations



WEO MEMBERS AT WCE2025

## Final message from Deborah Bush MNZM, QSM, Principal WEO

### Dear WEO friends and colleagues

At the WEO Pre-Congress Course (May 21st 2025) held at the World Congress on Endometriosis in Sydney, Australia #WCE2025, I announced that I would be stepping back as Principal of the World Endometriosis Organisations #WEO. I advised the Steering Committee in 2024 and I appreciated having their wonderful support through the process.

Here's a snippet of the WEO story and how the Organisation came to be.

I founded #WEO at the 13th World Congress on #Endometriosis in Vancouver, Canada, in 2017.

Several people from Endometriosis Organisations around the world were present at that meeting. It was clear to me that the endometriosis NGOs needed a global representative entity, just as there is for clinicians, researchers, allied health professionals, industry and other stakeholders. My vision was to establish a global network of Endometriosis Organisations to collaborate with all stakeholders, advocate, educate, innovate, contribute to research and support its members. With the mandate of those present, I founded WEO, as that entity to advance the cause and influence change.

Over 8 years, which included navigating the Global Covid-19 Pandemic, WEO now has 45 member Organisations from around the world and has made its mark on the endometriosis community worldwide.

In this newsletter you can expect:

- \_\_\_\_\_
- Research Updates
- \_\_\_\_\_
- Global Events
- \_\_\_\_\_
- Webinars
- \_\_\_\_\_
- Member Updates
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- Photo Gallery
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- WEO Steering Committee
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## Final Message...cont

This was noticeably evident at the recent World Congress on Endometriosis in Sydney [#wce2025](#) where WEO was frequently referenced and its members totally engaged as delegates, speakers, presenting research, invited to Chair sessions and ensure that patients are front and centre of all thinking, [planning](#), [#advocacy](#), [#guidelines](#), [#support](#), [#publicity](#) and [#research](#) priorities.

In their own countries and regions, WEO Member Organisations have strived for better understanding of the disease, improved treatment and management and are making world of difference to those with [#endometriosis](#), their families, and communities. Some are working with governments and health decision makers to bring about legislative change. Now, the WEO Member Organisations can use their collective strengths to ensure the voices of those with endometriosis are heard and that they can champion the cause globally.

As any Founder will know, it's also important to plan your succession and know when to step back. After 8 years since I founded WEO and 40 years from when I founded Endometriosis New Zealand, the time was right for me to take the slogan from the 2017, 13th World Congress on [#endometriosis](#) where WEO began, and 'turn over a new leaf'. I am exceedingly proud of WEO and am excited about its future as an influential and key participant in our field.

People have said "but it's your baby." For me, the most joyous and satisfying sentiment is to see something you've initiated prosper and flourish when you step back. I have passed the precious WEO baton to the next team to lead and guide and I am delighted that they are carrying it forward. The World Endometriosis Organisations is now established as an integral entity alongside other global stakeholders.

The Steering Committee, is now ably led by [Elsie Wandera](#) (Kenya) and [Femke Jansen-van den Berg](#) (Netherlands). I was honoured to accept the role as Advisor to WEO and privileged to work with such professional, highly skilled and accomplished individuals, I now also call my dear friends.

I'd like to extend my very special thanks to: the WEO Steering Committee [Elsie Wandera](#), [Femke Jansen-van den Berg](#), [Philippa Bridge-Cook](#), [Emma Cox](#), [Surita Mogan](#), [Julia Mandeville](#) and [Ambah Grant](#). I also extend heartfelt thanks to [Lone Hummelshoj](#), [Stacey Missmer](#), [Andrew Horne](#), [Jason Abbott](#), [Neil Johnson](#), [#WorldEndometriosisSociety](#), [#WES](#) and all those, including WEO's incredible members for their support and friendship.

I am continuing to work in the field and am exploring some exciting endo projects and of course, will stay connected. I thank you from my heart for your own achievements and the wonderful work being done globally to improve health outcomes for the almost 200million world-wide with endometriosis. My very best wishes to each of you

Deborah Bush MNZM, QSM

*Deborah Bush*



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## Welcome from Your New Co-Chairs

Welcome to our WEO Newsletter! We are excited to share updates from across our global network and to begin a new chapter together.

As your new co-chairs, we're honored to step into this role and start this journey by listening to you. WEO was founded on the power of collaboration, and to take our coalition to the next level, we need to understand who our members are, what drives you, and what you need from us.

That's why we're inviting you to complete a short survey that will shape WEO's direction in the years ahead.

Tell us about your organization, your goals, and how WEO can better support your mission. Your insights will guide our leadership and ensure that WEO continues to grow as a vibrant, relevant, and member-driven community.

 **Take the Survey ==> [Click Here](#)**

We are deeply grateful for the passion and dedication each of you brings to this movement. Together, we can continue to advance education, advocacy, clinical care, and research, improving the lives of everyone affected by endometriosis and related conditions.

Thank you for being part of WEO. We're looking forward to building the future of this coalition together.

With warm regards,  
Elsie & Femke  
WEO Co-Chairs

*Elsie & Femke*

## WEO Webinar: Coming Soon

We are excited to announce that WEO will be hosting a special webinar featuring Deborah Bush, our outgoing chair, at a date to be shared.

During this session, Deborah will reflect on her journey with WEO, sharing key learnings, insights, and the next steps as she transitions from her role. It will be an inspiring opportunity to celebrate her leadership and hear her vision for the future of our global community.



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**WORKING TOGETHER TO INCREASE AWARENESS AND ACTION CHANGE**

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## WEO at WCE2025: Key Takeaways and Reflections

### World Endometriosis Congress 2025: Working Together for Better Care

From May 21 to 25, the World Endometriosis Congress 2025 took place in Sydney, Australia. This congress is held every two years, each time on a different continent.

#### Wednesday: International Collaboration

The first day, Wednesday, May 21, featured several pre-congress courses. For us, the day revolved around a special meeting of the World Endometriosis Organizations (WEO).

Unfortunately, not everyone could attend, but the discussions with those present were incredibly valuable.

We exchanged experiences, projects on menstrual and endometriosis education were presented, patient involvement in scientific research was discussed and cool campaigns were shown. Very interesting were the insights shared on fundraising and endometriosis in the workplace. We talked about differences in care between countries, the focus of patient associations, and the challenges they face. Together, we explored how to raise awareness, improve diagnosis and treatment—even in countries with fewer resources.

A key topic was inclusivity in research. Much scientific research is conducted in Western countries with predominantly white participants. This means we know less about how endometriosis presents in people of color, which can lead to misdiagnoses or incorrect treatments. Future research must be more inclusive. Here is a link to the [recorded sessions](#).

At the end of the day, Deborah Bush stepped down as principal of the WEO after eight years of dedicated service. Her role will now be shared by Elsie Wandera from Kenya and Femke Jansen from the Netherlands, who will lead the WEO for the coming years.

#### Thursday & Friday: Lectures and New Insights

The congress days on Thursday and Friday started early—first lecture at 8 AM, last one around 5 PM. This year's program was more streamlined, with many keynote lectures in the main hall, allowing us to attend more sessions without tough choices.

Topics were diverse but shared a common theme: the impact of endometriosis on daily life. Highlights included:

- How patients can better manage pain
- The role of supportive therapies like physiotherapy and psychological care
- Why surgery isn't always the best solution
- Advances in imaging techniques for diagnosis
- The importance of interdisciplinary care—specialists working together based on patient needs

There was also a significant focus on Artificial Intelligence (AI). AI can aid in faster diagnosis, data analysis, and discovering better treatments. But if certain data is missing, AI can't compensate—so collecting data from diverse countries and populations is essential.

#### Saturday: The Future of Care

Saturday started a bit later. Though the lectures were more technical or less relevant to our work, important themes emerged. The afternoon focused on the future of endometriosis care: how can researchers and patient organizations collaborate better? How can we design care that truly meets women's needs?

There was also discussion about differences in healthcare systems worldwide. Some countries have strong collaboration between researchers, doctors, and patients—others are still developing this. Sharing experiences helps us learn from one another.

#### Sunday: Research Agenda and Priorities

The final day centered on the research agenda for endometriosis—a plan outlining which topics should be studied and get priority in the coming years. Key questions included:

- What's the best way to diagnose endometriosis? Is laparoscopy with biopsy always necessary, or is imaging sufficient?
- How can we better identify mild forms of endometriosis?
- How do we secure funding for large-scale research?
- How do we align the goals of patients, doctors, and researchers?

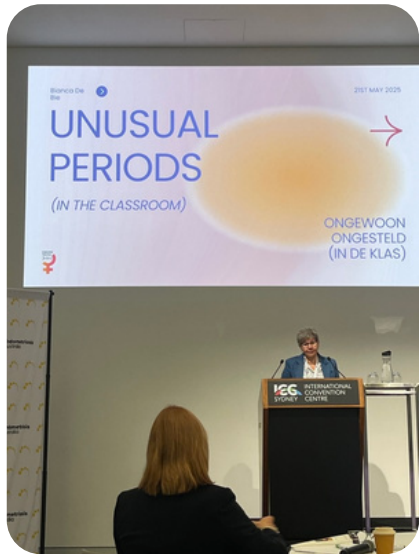
There were differing opinions. What a doctor finds important may not match what a patient values. By discussing these differences, we hope to build mutual understanding. These conversations will continue online in the coming months through meetings and surveys. The new research agenda will be finalized next year.

# Our Shared Commitment to Better Care

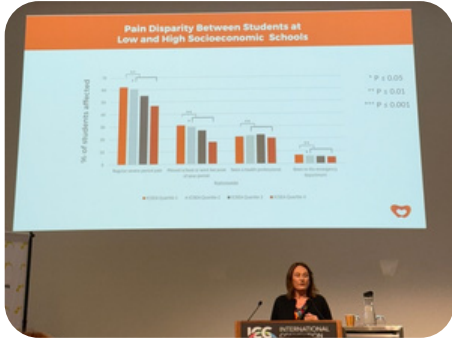
The World Endometriosis Congress 2025 was intense, educational, and inspiring. We gained new knowledge, met many people, and shared our own experiences. Together with organizations around the world, we remain committed to improving care for everyone affected by endometriosis.

## Photos from WCE2025

Thank you Endometriosis Australia for hosting the WEO Pre-Congress Course and the documentation of the event



# Photos from WCE2025



**What we do**

- Campaign** - for change and improvement in diagnosis time, treatment, care and support
- Empower** - information to help raise awareness
- Connect** - support groups, helpline online to help reduce isolation
- Influence** - policy and decision makers; health; education; employment



**Top 5 Tips for a Successful Fundraising Strategy**

1. **Identify your audience and their needs**
2. **Build trust and credibility**
3. **Build the right network and partnerships**
4. **Plan, track, evaluate**
5. **Build compelling stories**

**Addressing the Issue through Research**

The lived experiences of Black women and women of color in the Caribbean and the USA, who have been diagnosed with endometriosis have yet to be critically examined and characterized using community-engaged research.

**END! THE TABOO AROUND MY DISEASE**

**END! THE ISOLATION AND PAIN**

**END! THE PAIN**

# World Endometriosis Society WESinar

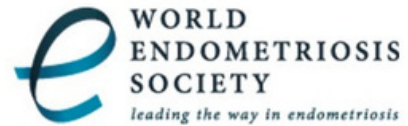
The **World Endometriosis Society** is excited to announce our next WESinar:  
**Management of endometriosis during peri-/post-menopause**

**Moderator:** Devon Evans

**Speakers:** Ludwig Kiesel, Engin Oral

**Date and Time:** 9 October 2025 - 12:00pm EDT/ 6:00pm CEST

To register for the WESinar, please [click here](#)



## Stay Connected & Share Your Voice

WEO is committed to its members and to improving the lives of everyone affected by endometriosis worldwide. To honor our shared mission, please ensure that your organization shows its affiliation to WEO by visibly displaying the WEO logo and tagline on your website.

Sharing this newsletter on your website and social media platforms is also a powerful way to:

- Show your support for the global endometriosis community
- Grow our network of engaged partners and advocates
- Raise awareness and reach those who need information most

We also encourage you to contribute content for future newsletters!

Please send articles, research highlights, and photos with captions (maximum 100 words) to:

✉ Elsie Wandera: [info@endofoundke.org](mailto:info@endofoundke.org)

✉ Femke Jansen: [f.jansen@endometriose.nl](mailto:f.jansen@endometriose.nl)

Upcoming Deadline:

- December Issue – submissions due by the end of November

Together, we can keep building a vibrant, collaborative, and member-driven community that amplifies our collective voice.

Best wishes to all  
from the Steering Committee



Philippa Bridge-Cook



Emma Cox



Ambah Grant



Femke Jansen



Julia Mandeville



Surita Mogan



Elsie Wandera

*Thank you for reading!*