WEO Newsletter

Each issue will cover areas of interest, including:

Research | Meeting(s) | Global Events | Awareness | Member Updates

A MESSAGE FROM DEBORAH BUSH MNZM, QSM, PRINCIPAL WEO

Warm greetings to all

As we approach the end of 2024, we have a lot to be grateful for and much to look forward to in 2025. Gratitude goes to all WEO members for your tireless efforts to advance the cause, provide support and services to those with endometriosis and advocate for change.

We are excited about the World Congress on Endometriosis (WCE2025) 21 – 24 May in Sydney. We hope you will join us at the WEO Pre-Congress Course (PCC) on Wednesday 21st May. We've been working hard to deliver an exciting and relatable programme which will be helpful to each of us.

In this issue we show gratitude and bring you further details about the WCE2025 and the WEO PCC.

WEO farewells one of our first Steering Committee members, Michelle Marvel USA. from the Michelle. accomplished business professional, founded the **Endometriosis Research** Center in the USA in 1997 with her vision of addressing the ongoing need for international endometriosis awareness. advocacv. support, education, legislative efforts and research facilitation.

We send our thanks and gratitude to Michelle for her commitment to the cause for over two and a half decades. Michelle said it's been her pleasure working with WEO and believes a 'terrific team' is in place to move forward.



MICHELLE MARVEL

Connect to the World Endometriosis Society online









Newsletter Highlights

A MESSAGE FROM THE PRINCIPAL

WEO WEBINAR

'RUN FOR HER' SRI LANKA

RESEARCH

16TH WCE2025

WEO PRE-CONGRESS COURSE EVENT 2025

TALK TO US

WEO WEBINAR

The WEO webinar was held on October 23rd with a focus on Endometriosis in the Workplace, with speakers, Donna Ciccia, Director Endometriosis Australia, and Emma Cox, CE Endometriosis UK. We were delighted to also hear from Suram Jayetileke from the ESAF Sri Lanka.



People from the following countries attended: Turkey, USA, Malaysia, Japan, Canada, Kenya, Denmark, UK, Netherlands, Australia, Hong Kong and Norway. Those who missed out can view the webinar from our website here.

We are delighted to bring you recent snippets from WEO members and acknowledge contributions from others.

This heartwarming extract from Carolyn Ricci, CEO ENDOMETRIOSIS FOUNDATION OF AMERICA was taken from their e-news on 29th November 2024.

"Your unwavering support reminds us every day that **Every Story Matters** — because every journey with endometriosis deserves to be heard, valued, and supported. Together, we're not just driving progress — we're creating a community of compassion, empowerment, and hope."



'RUN FOR HER' IN SRI LANKA BY THE ENDOMETRIOSIS SUPPORT AND AWARENESS FOUNDATION (ESAF)

We are continually inspired by the work being achieved in SRI LANKA by the ESAF (Endometriosis Support and Awareness Foundation). Suram Jayetileke, Head of Projects, was the 'highlight' speaker at our recent WEO webinar on 23rd October and spoke to their planned Marathon. Here's a brief overview and a wonderful pictorial on the RUN FOR HER 5km marathon which took place on November 24th 2024.

Almost 200 runners and walkers participated in this meaningful fundraiser and awareness event. Suram said that "it was heartening to see so many people from different parts of Sri Lanka join us, not just individuals, but entire families, foreign nationals, school children as well as clinical and academic dignitaries, leading hospitals in Sri Lanka and the reigning Miss Sri Lanka for Miss Universe 2024. It was a true reflection of how the community came together to help spread the important message about endometriosis including an Ayurvedic perspective." The powerful and empowering speeches included one by ESAF Founder Rashani Meegama. The photos and recap of the occasion certainly capture this fabulous event. Congratulations to ESAF. Check out their Instagram page for more.













RESEARCH

We are, as a community, hugely grateful to the research into endometriosis that is being undertaken around the world. Despite endometriosis being a major global public health problem, attracting funding for research to the level that's required, is difficult and usually inadequate. We are grateful to researchers around the world for their commitment to unravel the complex enigma of endometriosis, in a highly competitive research world.

It was a privilege being co-author of this research <u>The Language of Endometriosis prevalence: How can Gender Inclusivity and Accuracy Co-Exist?</u>

The Language of Endometriosis Prevalence: How Can Gender Inclusivity and Accuracy Coexist?

Hannah Adler

□, Sam Jeffrey, Louis Max Ashton, Danielle Howe, Michelle O'Shea, Cecilia Hoi Man Ng, Lanna Last,
Genester Wilson-King, Deborah Bush & Mike Armour ...show less
Received 14 Feb 2024, Accepted 19 Aug 2024, Published online: 10 Sep 2024

Quote from the abstract "Through this research, we explore the challenges associated with defining "whom" endometriosis affects, describe the current barriers to use of accurate language, and provide some possible solutions to inaccuracies." Further, we congratulate the lead author <u>Hannah Adler</u> on receiving the Christopher Newell Award for a presentation based on this research.

Review > Womens Health (Lond). 2024 Jan-Dec:20:17455057241248121. doi: 10.1177/17455057241248121.

Assessing the Utility of artificial intelligence in endometriosis: Promises and pitfalls

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Brie Dungate <sup>1 2 3</sup>, Dwayne R Tucker <sup>2 3 4</sup>, Emma Goodwin <sup>2 3</sup>, Paul J Yong <sup>2 3 4</sup>

Affiliations + expand

PMID: 38686828 PMCID: PMC11062212 DOI: 10.1177/17455057241248121
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Artificial Intelligence is part of our world and it should be no surprise that the impact is being felt and explored in the field of endometriosis. Here is the link to this research published in <u>Women's Health (Lond) 2024.</u>

Quote from the abstract: "AI holds significant potential in advancing the diagnosis and treatment of endometriosis, but it must be applied carefully and transparently to avoid pitfalls and ensure reproducibility. This review calls for increased scrutiny and accountability in AI research. Addressing these challenges can lead to more effective AI-driven solutions for endometriosis and other complex medical conditions."

RESEARCH - UNPRECEDENTED MOMENTUM FOR ENDOMETRIOSIS IN THE EUROPEAN UNION AND BEYOND

The FEMaLe Project has created an unprecedented momentum for endometriosis advocacy and research in the European Union and beyond. With a remarkable organic reach of 12 million views across various media platforms, we have effectively raised awareness and driven action.

Two co-created social media campaigns, developed in collaboration with endometriosis patient associations in Denmark and Sweden, have yielded significant results: four visits to the Danish Parliament, one to the Swedish Parliament, and one event in the European Parliament. Notably, endometriosis has now been included in the Danish state budget for the first time.

To date, we have published 11 peer-reviewed articles (cited 179 times) and delivered 42 presentations at international conferences. By applying the Half Double hybrid project management methodology, we have accelerated our impact while maintaining a systematic focus on learning and evaluation. The Lucy App has been enhanced and launched in eight countries, enabling the largest-ever study on endometriosis. This platform is poised to grow into a start-up and seek EIC Accelerator funding, aiming to provide an inclusive digital solution to advance endometriosis research further.

Meanwhile, SurgAR has established a secure pipeline for data collection and annotation, resulting in the world's largest dataset on endometriosis, annotated by expert surgeons. The team has also designed, implemented, and validated a deep neural network for automated lesion and incision boundary segmentation in laparoscopic surgery. Following a successful €11 million Series A funding round, SurgAR is now closer to integrating its technology into clinical practice, aiming to standardize and improve laparoscopic surgical procedures for endometriosis.



FEMaLe



16TH WORLD CONGRESS ON ENDOMETRIOSIS 2025



"Hosted by the World Endometriosis Society, this truly global event will advance the understanding of patient treatment, patient care and the causes and consequences of the disease on the lives of countless women."

Co-Presidents Professor Jason Abbott and Professor Gita Mishra



WORLD ENDOMETRIOSIS ORGANISATIONS (WEO) PRE-CONGRESS EVENT 2025



WEO is excited to announce further details of our WEO Pre-Congress Course hosted by Endometriosis Australia. This is a wonderful opportunity for our WEO global leaders and changemakers to unite to advance the future of endometriosis care and awareness.

The inspirational program includes presentations from our Organisations and others with an emphasis on how we can be agile and responsive in our changing global landscapes and the importance of adaptability in an evolving world.

The program provides an opportunity to:

- · meet, share, learn and network
- engage in thought-provoking discussions on diversity and inclusion to highlight the need for equitable care for all
- explore education trends in menstrual health focussing on young people
- consider cool campaigns designed to empower, inform, engage and reshape the narrative around endometriosis
- dive into research, emphasising the significance of co-design with consumers to create resonating outcomes
- find out about fundraising to fuel progress
- be inspired together, to build a future where awareness, understanding, and support for those impacted by endometriosis reaches new heights.

Further details about registering, posters and extended invitations will be sent to you early in 2025. There is no cost to attend this Pre-Congress Course thanks to a much appreciated grant from Endometriosis Australia. We hope your funding to attend Congress is positive and can't wait to meet you all in Sydney.





WEO wishes everyone in our global community, warmth, safety and memorable moments with your family and friends at this special time of year.

Best wishes to all Deborah and the Steering Committee



















TALK TO US

WEO is committed to its members and is working globally for the good of its members and all those with endometriosis. To respect our collective aims, please make sure that your organisation shows its affiliation to WEO by visibly displaying the WEO logo and tagline on your website. Sharing this newsletter via website and social media is a great way to show your support, grow our network, and raise awareness.

Also, remember to share your articles, research, and photos with captions with a max of 100 words for the upcoming issues sent to Elsie Wandera at info@endofoundke.org and Deborah Bush at deborah@epp.nz