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

What an absolute privilege it was to attend the World Congress on Endometriosis in Edinburgh in May. It was a marvellous opportunity for many WEO members to connect, collaborate, get excited about ideas, renew friendships, and develop new ones. We have put together a collage of photos from Congress for your interest. One question I was asked post-congress was my perspective on what WCE2023 offered differently from previous World Congresses on Endometriosis. For me Edinburgh offered a more diverse programme that captured the many facets and impact of endometriosis, adenomyosis, and pelvic pain. We heard from experts in sociology, psychology, social media, gut microbiota, diagnostics, aetiology, epidemiology, patient centric multi-disciplinary care, and aspects of pain. Seminars on 'State of the Art' surgery and medical management were well covered in the programme, but there was more diversity, cultural sensitivity and inclusiveness than we have had in the past which reflects current thought about endometriosis as a whole person's disease impacting families and society. There was good representation from those with endometriosis who articulated their experiences and challenged speakers on current treatment and management. I was impressed by the young enthusiastic clinicians and researchers who are bringing innovation and technology to our field to test theories against the evidence in pursuit of improving our knowledge, understanding and ultimately, improving the health and wellbeing of those with endometriosis, adenomyosis and pelvic pain globally. This was very apparent in the hundreds of posters on display which were chosen from submitted abstracts. It is also wonderful to see WES encouraging Early Career trainees and faculty and providing Tips and Pathways in a pre-congress meeting. In any 21/2 day World Congress, the programme scheduling is tight and with really interesting seminars running concurrently, it was sometimes hard to choose which to attend. However, the keynote lectures were inspiring and diverse. Our capacity to be more open, and transparent and engage in concepts that might just hold the key, or at least provide more insight into the enigma that is endometriosis was encouraging. This was my broad take and many who attended will have other responses or maybe this was their first WCE.

Connect to the World Endometriosis Society online











Newsletter Highlights

A Message from the Principal

Congratulations -Adrienn Salamon

Welcome New WEO Organisations

Research: Global Case Study

Research Grants

Meetings of Interest

WCE2023 - Photo Gallery

CONT. MESSAGE FROM THE PRINCIPAL

It was a pleasure and privilege to host the WEO networking session and present the research we conducted earlier this year. The link to this presentation is here. We want to acknowledge the academic expertise of Philippa Bridge-Cook from the Endometriosis Network of Canada who was instrumental in the development, dissemination, and collation of the survey. Emma Cox, CE of Endometriosis UK, gave a great talk on the significant work being conducted and achieved in the UK influencing others in the sector.

It was awesome to reconnect in person with so many colleagues who have become life-long friends over many decades in the field. It was a thrill to be immersed in all things 'Scottish' during the social events.

WEO was well represented and actively involved at WCE2023. We thank the organizing committee and particularly Professor Philippa Saunders and Professor Andrew Horne for providing an outstanding WCE in Edinburgh in May 2023. We congratulate Sydney on winning the Oceania bid to host the World Congress on Endometriosis in May 2025. We know that Sydney will continue with the superb efforts of all previous World Congresses and provide us with a super-charged Congress in May 2025. Start planning!



Emma Cox, CEO - Endometriosis UK, Deborah Bush, Principal - WEO & Julie Sjølin Kiil - Chairperson - Endometriose Fællesskabet

Deborah Bush MNZM, QSM, Principal WEO www.eppcoaching.com



WEO Member Organisations represented at the WCE2023 during our Pre-Congress Session on May 3rd, 2023 in Edinburgh, UK

CONGRATULATIONS - ADRIENN SALAMON



Adrienn Salamon - President - 'Together is Easier' Women's Health Foundation and Newly Appointed WES Board Member

Adrienn Salamon is the newly appointed member of the WES Board and was introduced at the Congress in Edinburgh. We send her our heartiest congratulations. Adrienn is President of the "Together it's Easier" For Women's Health Foundation, which is the only official NGO in Hungary to raise awareness and educate about endometriosis and support women suffering from the disorder. She started the Foundation in 2010 (member of WEO), after being diagnosed with endometriosis and she has been advocating for women's health ever since. Two of the many great achievements of her Foundation in Hungary have been:

- the diagnostic delay has been reduced to 4 years
- rules and laws have been changed in Hungary

Learning to live with the disease has undoubtedly been a great challenge, but now she has made it her mission to support endometriosis patients and their families. Her driving force is her dream, that not a single woman has to go through the same struggle she experienced due to endometriosis. She believes in the power of collaboration that "Together it's easier" which has wonderful synergy with the WEO tagline of 'working together to increase awareness and action change'.

Adrienn designed the WEO logo which you are able to use freely as long as you have signed the 'Licence to Use Agreement.'

WELCOME TO NEW WEO ORGANISATION

WE WARMLY WELCOME THREE NEW WEO MEMBERS.

There are now 42 WEOs reaching almost every corner of the world.



Endometriosis Society of Bangladesh (ESB)
 President Professor Sameena Chowdhry
 Check out their <u>Facebook Page</u>
 Website: under construction





Endo Turkey
 Co-founder Bahar Yuksel Ozgor, MD
 Website: https://endoturkiye.org



RESEARCH: GLOBAL STUDY SHOWS THE EXPERIENCE OF ENDOMETRIOSIS IS ROOTED IN A PERSON'S GENETICS

Researchers at the University of Oxford, in collaboration with 25 research institutions in 11 countries, have published the largest study to date on the genetic basis of endometriosis. <u>Find out more here:</u>

The full study: "The genetic basis of endometriosis and comorbidity with other pain and inflammatory conditions." is published in Nature Genetics here.

The question asked is: are we deep-wired to endure this pain? Pain and specific genes: what does that mean?

190 MILLION HAVE ENDOMETRIOSIS



RESEARCH IMPROVES LIVES

RESEARCH GRANTS: AN OPPORTUNITY TO EXPLORE

EndoFound is pleased to announce its 2023 research grants cycle, offering grants of up to \$50,000 (\$25,000/year) over a two-year period. Contact on the link here.



WEO Webinar: watch out for details to be sent to you in July

MEETINGS OF INTEREST

The British Academy/Wellcome Trust Conferences bring together scholars and specialists from around the world to explore themes related to health and wellbeing. Thursday 6 – Friday 7 July 2023.

For registration and more information, see the conference website: Reframing Endometriosis: Power, Politics and Potential Futures | The British Academy. Download the programme here

Topics to be discussed are:

- Reframing Endometriosis Histories;
- Experiential & Marginalised Endometriosis Framings;
- Beyond Biomedical and Social Divides;
- · Future Framings of Endometriosis;
- Speaking Differently About Endometriosis.

Emma Cox and Deborah Bush are presenting in this panel.

The questions to be discussed are:

- How could new ways of talking about endometriosis, introduced at the conference or elsewhere, lead to real-world changes?
- · What could & should these changes be?



WCE2023 - PHOTO GALLERY

















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

