

OCTOBER 2023

WEO Newsletter

ISSUE 11

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

Greetings to all WEO members.

In this issue we bring you news and details of the forthcoming WEO webinar, introduce you to two new WEO member Organisations, highlight the work of one of the world's leading and respected researchers and the latest glossary on endometriosis plus more.

Enjoy the read and our very best to each of you.

Deborah and the Steering Committee, Emma, Ambah, Elsie, Michelle and Femke.

Last year, Professor Jason Abbott (Australia) introduced Australia's National Action Plan for Endometriosis (NAPE) at a WEO webinar. Our members said they wanted to learn more about the services and programmes that are now provided as a result. We will hear from those Australian Organisations who are part of NAPE including:

EndoActive, Qendo, Pelvic Pain Foundation of Australia and Endometriosis Australia.

See you there.

WEBINAR: Wednesday 1st November 8am UK GMT.
We hope to record the session so that no one misses out.

To attend, you must REGISTER HERE:
<https://us06web.zoom.us/meeting/register/tZUvf-6spzgtHtO2vRsXSFxWIMqph9nGNcCd>

When you register, the time in your location should show.

[Connect to the World Endometriosis Society online](#)



WORKING TOGETHER TO INCREASE AWARENESS AND ACTION CHANGE



Newsletter Highlights

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PRINCIPAL

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WELCOME TO NEW WEO ORGANISATION

It's our pleasure to welcome two new member organizations to WEO.

EndoWarriors Aotearoa

Endo Warriors Aotearoa was the first Endometriosis Charity in Aotearoa (New Zealand) to be inclusive of all genders! Endometriosis does not discriminate and neither do we!

*Kei roto i te pōuri, te marama e whiti ana
Through perseverance and hope, we will overcome*

Endo Warriors Aotearoa (EWA) believe that we can shorten the average 9-year wait for diagnosing endometriosis if we take teenage period pain, signs and symptoms more seriously. We believe that the stat '1 in 10 born female have endometriosis' is significantly higher, due to underreporting, misdiagnosis, & lack of nonsurgical & non-invasive diagnostics.



Endo Warriors Aotearoa was founded by CEO Jessenia Sandoval (front).

Webpage: <https://www.endowarriorsaotearoa.com/>

Facebook: <https://www.facebook.com/endowarriorsaotearoa>

Instagram: <https://www.instagram.com/endo.warriors.aotearoa/>



MyEndosis (Persatuan Endometriosis Malaysia)

Speaking up on Endometriosis – Surita Mogan, President of Persatuan Endometriosis Malaysia

“What is wrong with you? Period pain is normal”. I was often told that the period pain I experienced in my teenage years should be part of my life as a young girl. People around me especially women, ignored my painful periods constantly telling me that I should just bear the pain like everyone else. As the years went by, I started to slowly notice that my pain increased in intensity and it affected my daily routine to the point that I was unable to be productive. Back then, I was lonely and confused. I thought to myself, should I still bear the pain and toughen up? Besides the physical pain, Endometriosis comes with a great deal of emotional burden.

As awareness is low in Malaysia, not many can empathize with my condition. Furthermore, my unbearable pain and excessive bleeding affected my career prospects as I was always on medical leave. My employers truly believed that I was making up my pain to avoid my job responsibilities.

Now, frustrated with the unfair judgment on women with Endometriosis, I am part of the community in Malaysia, helping other women especially young girls break the barrier of speaking about menstrual health.

CONT: MYENDOSIS (PERSATUAN ENDOMETRIOSIS MALAYSIA)



As part of the community in MyEndosis, the mission of the association is to provide emotional support and information to women who suffer from Endometriosis in Malaysia. The biggest role of our movement in Malaysia is to highlight to our society the long-term damage Endometriosis does to a woman's physical and mental health. Coupled with the need to end the silence, MyEndosis believes women in Malaysia should have the right to choose the best option to deal with Endometriosis and most importantly a health care policy to help patients deal with their condition financially.

Let's end the silence on Endometriosis



Website: myendosis.org

Facebook group: [MyEndosis Malaysia](#)

Facebook page: [EndomarchMalaysia](#)

YouTube channel: [MyEndosis](#)

Instagram: [MyEndosis](#)

WCE2025 - SAVE THE DATE

16th World Congress on Endometriosis: put 21st - 24th May 2025 in your diary. 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. Knowledge and expertise will be shared, and professional networks strengthened across the globe as a result of the Congress.



World Endometriosis
Organisations

WORKING TOGETHER TO INCREASE AWARENESS AND ACTION CHANGE

RESEARCH

Discussions and published research around the genetics associated with endometriosis have been debated and researched for some years now. WEO would like to pay tribute to Professor Krina Zondervan and acknowledge this extract from [@FEMaLe Project LinkedIn](#) article of 14 September 2023

The [FEMaLe Project's](#) article highlights the extraordinary work of Professor Zondervan and a publication titled [‘The genetic basis of endometriosis and comorbidity with other pain and inflammatory conditions](#) 13 March 2023

“For over 25 years, Professor Zondervan has made globally recognized contributions to the field of endometriosis, pelvic pain, and benign gynaecology. Professor Zondervan has served as a Board Member of numerous charities and funding committees in the field of women’s health and genomics.



She is among the most highly cited authors in reproductive sciences; was recognized in 2013 as Outstanding Female Scientist by [AcademiaNet](#) ([Wellcome Trust](#) nomination); and in 2019 through an honorary professorship at the [Aarhus Universitet](#) University, Denmark. Krina is Professor of Reproductive & Genomic Epidemiology and Head of the Nuffield Department of Women’s and Reproductive Health at Oxford University. She trained in biomedical sciences (MSc 1995, Leiden University, the Netherlands); epidemiology (DPhil 2000, Oxford University); and genetic epidemiology (MSc 2001, Erasmus University, the Netherlands).” Krina herself says “Great science is achieved by Team Work”.

WEO thoroughly agrees. Working as a team, sharing knowledge, supporting each other, and collaborating our expertise with respect and conviviality, will lead to success and better health outcomes for those we represent.

If you haven’t had the chance to read [Nilufer Rahmioglu](#) et al and Professor Krina Zondervan’s article in Nature Genetics, follow the link above. It is the largest study on the genetics of #endometriosis and a ‘mammoth collaboration’ between 25 global centers with data from more than 60,000 women with endometriosis and 700,000 population controls

Let's Celebrate



World Endometriosis
Organisations

GLOSSARY ON ENDOMETRIOSIS:

www.endometriosis.org in collaboration with the FEMaLe Project, has developed an extensive and comprehensive [glossary](#) for endometriosis ensuring we have one place to find correct terminology and definitions for phrases and words associated with endometriosis.

Glossary

In this glossary there are phrases and/or words which refer specifically to the female (woman) and the male (man) biology. Whereas we recognise that some individuals, who use this site, do not identify as either female or male, the biologic processes, however, are gender specific and are therefore described as such.

A · B · C · D · E · F · G · H · I · J · K · L · M · N · O · P · Q · R · S · T · U · V · W · X · Y · Z

WEO UPDATE

In our August WEO newsletter, we asked how best we can meet the needs of our members. Thanks to those who responded, we appreciate your feedback and positive comments. There was one query asking whether WEO could run clinical courses and training programmes. This is outside WEO's purpose but the information you require will be available through the various medical associations both globally such as WES and your local / regional Societies.

WEO SURVEY: HEADS UP

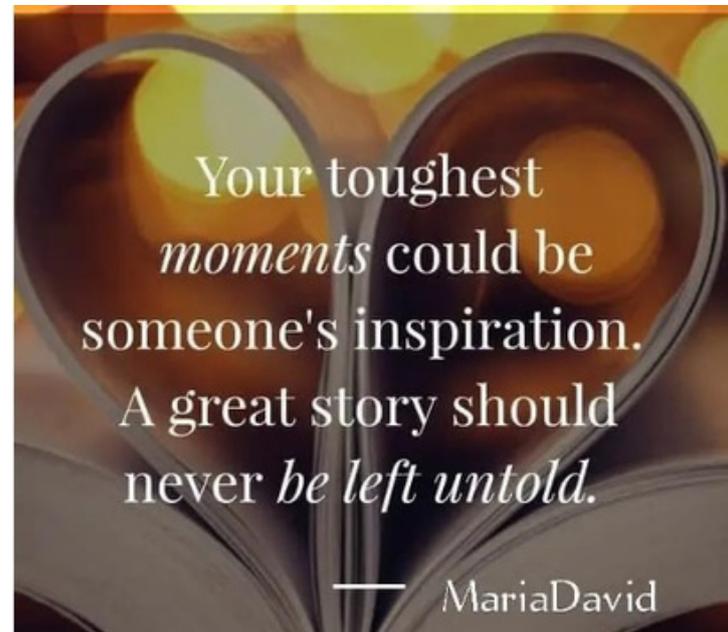
We will be circulating a brief survey in November about the World Congress on Endometriosis (WCE) in Sydney, in May 2025. We are hoping to attract funding for those WEOs who would like to attend, but are unable to do so without funding to cover travel, accommodation, and registration. The information from the survey will help us present WEO's case for funding on your behalf. If we are successful in being granted funds for this purpose, we will advise you and Organisations may apply.



No action is required at this point.

CALLING ALL PIONEERS

We are reaching out to ALL pioneers in our WEO community. This includes anyone who founded or co-founded your Organisation. We want to highlight your work and allow others to learn from your experiences. We want to know what drove you to establish your Organisation, the skills you had, the hurdles and barriers you met, and the challenges you faced. We want to know about your successes and how these have influenced change or are contributing to improving the situation for those with endometriosis in your country, region, or worldwide and we'd like you to tell us about your future goals. This may include those of you who, like me, are endometriosis pioneers from the last century, or others who are recent pioneers.



Please keep your script to less than 200 words and include one or two images. This information will build a wonderful story about the modern history of WEO pioneers, endometriosis advocates and innovators.

TALK TO US

Let us know how WEO can best meet your needs.

- *webinars*: what topics would you like covered?
- *partnering and supporting*: would you like to partner with another Organisation for support, advice, or mentoring?
- *ideas*: provide us with a brief overview of a project, service, research, or network you're involved in that would be of interest to all.



Please share this newsletter on your socials to raise awareness about WEO as a global endometriosis community.

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 on deborah@epp.nz