


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

MARCH WAS FULL ON as individuals, groups, Organisations and many stakeholders swung into action to raise awareness of endometriosis. April is the month for Adenomyosis Awareness, though many of you included both in the March campaign. From social media and other platforms, WEO have been active raising funds, creating opportunities for community involvement, delivering workshops, engaging media, marching, supporting and making a political stand. Many of you painted the town yellow or may have worn yellow at your various activities. With that in mind, we bring you a short piece about the origin of the colour yellow for endometriosis awareness and will showcase some of the global activities from March 2024.

The following piece is from Mary-Lou Balweg about the origin of yellow as the colour for endometriosis awareness.



"In 1980, when I was preparing the first version of what became known as the "yellow brochure," I read in a graphic arts publication that black ink on yellow paper had been shown to be most eye-catching. So we printed the brochure on yellow and as over 32 translations developed and requests from around the world for the "yellow brochure" poured in, it became a trademark color. Over 3 million have been distributed in English in print; more in other languages and online. In 1993, while planning our first awareness month and designing the ribbon, it was only natural to make it yellow. I've noticed people wearing plain yellow ribbons; I'd respectfully suggest using the original design which has the words, "Ask me about endometriosis" or "Ask me about endo" which won't be confused with other yellow ribbons and furthers awareness. I'm delighted that our endo community worldwide has a unifying color and so proud of what women with endo and their families have accomplished. Anyone wanting ribbons, stickers, or brochures (specify language) can email support@EndometriosisAssn.org."

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



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Newsletter Highlights

A MESSAGE FROM THE
PRINCIPAL

INTERNATIONAL HIGHLIGHTS
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WCE2025

TALK TO US

CONT: MESSAGE FROM PRINCIPAL

GO YELLOW



What we know

1980: The Endometriosis Association was founded by Mary-Lou Balweg in Milwaukee Wisconsin. Their first brochure was printed on yellow paper on the advice of the printers.

1993: The brochure was written in multiple languages, all printed on yellow paper. Yellow became the colour of endometriosis.

There is no compulsion / rules to use YELLOW for Endometriosis Awareness

The yellow ribbon also represents:

Returning Military Personnel, Sarcoma, Bladder Cancer, Suicide Prevention, Protecting all Road Users (in NZ), Adoptive Parents, Carbon Monoxide Poisoning, Complimentary / Alternative, Equality Awareness, Gulf War, Missing children, Obesity Awareness, Remembrance Awareness, Spina Bifida

Image is a slide from a presentation on Awareness 2024, by Deborah Bush, MNZM, QSM

WEO acknowledges Mary-Lou Balweg's tireless commitment to the Endometriosis Association and to her dedicated efforts to advance the cause worldwide.

INTERNATIONAL HIGHLIGHTS FROM MARCH 2024

The Endometriosis-Adenomyosis Society of Bangladesh (ESB) in collaboration with Asian Society of Endometriosis and Adenomyosis (ASEA) celebrated at Dhaka, Bangladesh as part of EndoMarch. The ESB-ASEA Dhaka Declaration 2024 was announced and signed by both the presidents, Prof Sameena Chowdhury president of ESB and Dr Al Jefot Moamar, President ASEA with unanimous acceptance of all the participants. What a milestone. Congratulations!

Dhaka Declaration March 2nd 2024

"This declaration is our commitment." Prof. Sameena Chowdhury

MBBS, MCPs, FCPS, FICS(USA), FICMCH(Ind), DRH(UK)

- 2nd International conference hosted by Endometriosis-Adenomyosis Society of Bangladesh (ESB) in collaboration with Asian Society of Endometriosis and Adenomyosis (ASEA) celebrated at Dhaka, Bangladesh
- 600 participants: Bangladesh, India, Japan, China, Philippines
- Will develop endometriosis out-patient clinics in Gynaecology Depts, Medical Colleges and dedicated center for endometriosis



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INTERNATIONAL HIGHLIGHTS FROM MARCH 2024 CONT...

This informative, inspiring and moving film was created to support and provide a voice for individuals and couples with endometriosis and adenomyosis; it also details their related impact on infertility.



Quote: “....over a number of years, endometriosis just stopped me from living my own life.”

Quote: “As a physician myself, I am very aware of the stigma of chronic pelvic pain..... I encourage you to have a health pathway....”.

This film is for educational purposes only and must not be shared without the express consent of:

Rebecca Kerner Psychotherapist & Senior Counsellor

Chair, ANZICA; Chair, ASPIRE Psychology & Counselling SIG.

Contact Rebecca through WEO deborah@epp.nz

EARLY DETECTION BREAKTHROUGH IN ENDOMETRIOSIS

**BREAKING
NEWS**

On 18th March 2024, the study, led by **Professor Christian Becker** and **Professor Krina Zondervan**, involved imaging patients with known or suspected endometriosis using a SPECT-CT camera, followed by laparoscopic surgery. Results indicate that 99mTc-maraciclatiside holds promise as a non-invasive tool for detecting early-stage endometriosis.



Early Detection Breakthrough in Endometriosis: Oxford University Unveils Promising Imaging Study

Exciting advancements in the early detection of endometriosis have been unveiled by Serac Healthcare Limited and the Nuffield Department of Women's and Reproductive Health at the University of Oxford.

[ox.ac.uk](https://www.ox.ac.uk)

This study leads well into our next piece.

WEO INVITES YOU TO GET BACK TO US WITH YOUR IDEAS AND WHAT YOU ARE DOING IN YOUR COUNTRY TO ADDRESS THIS.



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INTERNATIONAL HIGHLIGHTS FROM MARCH 2024 CONT...

SECONDARY SCHOOL MENSTRUAL HEALTH EDUCATION PROGRAMME IN SCHOOLS LAUNCHES IN IRELAND.

The MISE team have been working on the project for a couple of years. Prior to this, we had sought support and funding and were unable to secure it in the positions we held.

Given our collective experience of #endometriosis #inmheatróis and education we have self funded this vital pilot programme to not only prove that it is needed, but to use audits and feedback to further refine and develop the programme.

It is an important topic, but one that needs to be handled with care and sensitivity. We built on the work of Deborah Bush with the published and praised ME Programme in New Zealand and have worked closely with Deborah in adapting it for Ireland. The pilot will allow us to take the feedback from students, teachers, parents and the team and evaluate what changes are required.

MISE.
MENSTRUAL INFORMATION SPECIALISING IN ENDOMETRIOSIS



Kathleen King (centre top) and her team in Ireland have adapted the 'me' (Menstrual Health and Endometriosis) education programme from New Zealand, for use in Ireland. MISE is Gaelic for the word me, making it personalised and purposeful while maintaining the core values and strengths-based approach, engaging pedagogical and clinical guidelines and learnings in consultation with an advisory team (including students and educationalists).

It has been my pleasure and privilege to work with Kathleen and her team. Deborah Bush

THE VAGINA MUSEUM LONDON CELEBRATED ENDOMETRIOSIS AWARENESS IN MARCH



Home | Vagina Museum | United Kingdom

The world's first bricks and mortar museum dedicated to the vagina, vulva, clitoris and...

Vagina Museum



Endometriosis: Into the unknown

The Vagina Museum, London commemorated March Awareness with an art / jewelry exhibition.



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INTERNATIONAL HIGHLIGHTS FROM MARCH 2024 CONT...

ENDOMETRIOSIS IN THE WORKPLACE



EndoAware
Workplace Accreditation Program

WESTERN SYDNEY UNIVERSITY Endometriosis Australia

The Program

- Endometriosis Australia Workplace Accreditation Program information is designed to work with workplaces committed to supporting their employees impacted by endometriosis.
- Based on the core pillars of Process, Policy and Promotion, EndoAware Workplace Accreditation benefits employees with endometriosis and employers, ultimately improving productivity and well-being for staff and their workplaces.

Eligibility Criteria

You must fulfil all the below requirements:

- Be a workplace with operations in Australia.
- Have employees (You can develop these guidelines regardless of whether employees have disclosed endometriosis)
- Be completely autonomous with your governance structure (e.g. have a CEO and board).
- Have authority to create and modify organisational policies and procedures.
- Appoint staff member/s as Endo Champion

Project Aims & Objectives

- Improved outcomes
- Increased staff retention and well-being
- Community Awareness

The Research

Endometriosis Australia has partnered with Western Sydney University's Endo@Work research project to deliver the world's first evidence-based endometriosis friendly workplace program. The data collected from the organisation ensures the continuous improvement and relevance of the program and accreditation.

www.endoaustralia.org



Congratulations to Endometriosis Australia and the Western Sydney University for their ENDOAWARE WORKPLACE ACCREDITATION PROGRAM. Guided by the Endo@Work research, ENDOAWARE delivers the world's first evidence-based, endometriosis friendly workplace program.

Contact: www.endoaustralia.org for more information or to be involved.

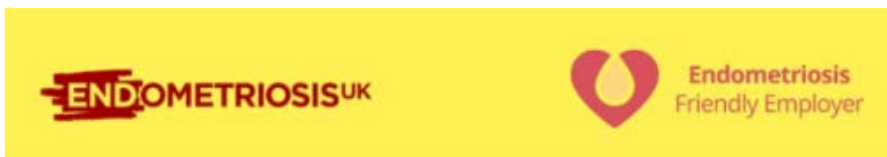
We'd be keen to hear what other workplace initiatives were undertaken during March.

In preparing the content of this newsletter, I am delighted that some Organisations around the world are developing and delivering professional workplace programmes. IN 2010, I established an Endometriosis Workplace Wellness programme known as WISE (Workplaces Initiatives and Solutions for Endometriosis). Air New Zealand were the first in the scheme. In March 2024, it was my privilege to deliver my own sessions to the New Zealand Department of Corrections during March. Feedback has been rewarding and validating. *Deborah Bush*

Comment from Participant: *"someone like you setting this up so that people like me can benefit. Now so many people can talk about it openly, it's socially acceptable and people like me can get help."*

INTERNATIONAL HIGHLIGHTS FROM MARCH 2024 CONT...

ENDOMETRIOSIS IN THE WORKPLACE....CONT:



Endometriosis UK continued with their 'Endometriosis Friendly Employer' programme presenting Menstrual Health at Work events during March.

Photos: Emma Cox, CE of Endometriosis UK, hosting an event at the Northern Ireland Assembly. They were pleased to share findings of the Diagnosis Report and highlight the urgent need for improved care and support for those with endometriosis. An enthusiastic Cheer Squad from Endometriosis UK gearing up to support those running in the London Half Marathon early in April and the London Marathon 2 weeks later.



READ: "Dismissed, ignored and belittled" The long road to endometriosis diagnosis in the UK: March 2024.



INTERNATIONAL HIGHLIGHTS FROM MARCH 2024 CONT...

THANK YOU BARBADOES ASSOCIATION OF ENDOMETRIOSIS AND PCOS

for highlighting this serious issue.

Source: LinkedIn (March 2024)



"Historically endometriosis was associated with women of affluent backgrounds, who have private health insurance and have delayed marriage and childbearing. This description implies that the disease is rare and suggests that it would be less likely to occur in Black women (Farland and Horne, 2019).

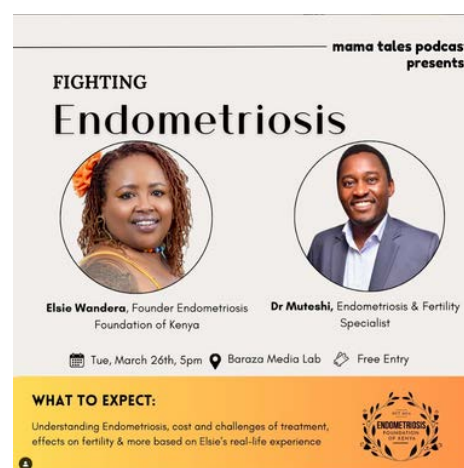
Recent studies have found that due to certain health disparities, endometriosis is underdiagnosed in black and Hispanic women. They tend to experience worse clinical and surgical outcomes compared to their White counterparts.

Racial and ethnic disparities play a significant role in women of color receiving poor pain management due to the misconception that they have a higher pain threshold."

Sources: (Bougie, Nwosu and Warshafsky, 2022). Revisiting the Impact of Race/ethnicity in Endometriosis. *Reproduction and Fertility*, 3(2). doi:<https://lnkd.in/dqz3Rjmg>. Farland, L. and Horne, A. (2019). Disparity in endometriosis diagnoses between racial/ethnic groups. *BJOG: An International Journal of Obstetrics & Gynaecology*, 126(9), pp.1115-1116. doi:<https://lnkd.in/dXtp5JWN>.

WEO WERE INVOLVED IN WEBINARS, SEMINARS, MEETINGS, CONFERENCES, SUMMITS AND GET-TOGETHERS around the globe during March as demonstrated here in Kenya with their week of empowerment and enlightenment.

Elsie Wandera, Founder of Endometriosis Foundation of Kenya is on the WEO Steering Committee.



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INTERNATIONAL HIGHLIGHTS FROM MARCH 2024 CONT...

Congratulations to the **Endometriosis Foundation of America (EndoFound)** whose combined efforts led to the **momentous occasion** of \$12 billion in funding to advance women's health research and innovation. EndoFound said "no one should suffer in silence. This move marks a significant victory for everyone who has advocated for more attention and resources for women's health issues.



RESEARCH:



SOCIAL MEDIA RESEARCH

In our last issue we presented [research analysing content on Instagram](#).

Social Media, Endometriosis, and Evidence-Based Information: An Analysis of Instagram Content: Findings from that study showed only 18.9% of comments / posts made on Instagram during the study period that related to surgery, were scientifically accurate.

In contrast, for this issue, we present another viewpoint. The authors say *"This content analysis provides preliminary evidence that the Instagram hashtag "#endometriosisawarenessmonth" is a meaningful conduit for communicating evidence-based information about, and experiences of, endometriosis."*

Endometriosis Awareness Month on Social Media: A Content Analysis of Images and Captions on Instagram. B. Le Busque, S. Mellish: Justice & Society, University of South Australia. Women 2023, 3(1), 82, 94;_



RESEARCH CONT...

PARTICIPATE IN STUDY:

The following study is independent of WEO. We are sharing for your interest. If you are keen to participate, please circulate to your members.

Determining the relationship issues experienced throughout the infertility and fertility treatment journey: A consensus study.

QUES: What are the most significant relationship issues that people can experience throughout their infertility/fertility treatment journey?

We are looking for researchers, health professionals, and people with lived experiences to form an expert panel to help us answer this question in our consensus study run through Deakin University, Australia. The expert panel will participate by completing several short (10-20 minute, with a maximum time commitment of 60 minutes) anonymous, online surveys over time. Each round will seek the expert's opinions on relationship-related issues in the context of infertility and fertility treatments. The panels' insights will provide much needed direction for future research and will help professionals better understand how we can help ensure people have the positive relationship interactions and social connections they need through this time. The study has received Deakin University ethics approval (HEAG-H 193_2023).

[Click the link](#) to learn more from the Plain Language Statement and see if you are eligible to participate:



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[XM deakin.edu.au](https://xm.deakin.edu.au)

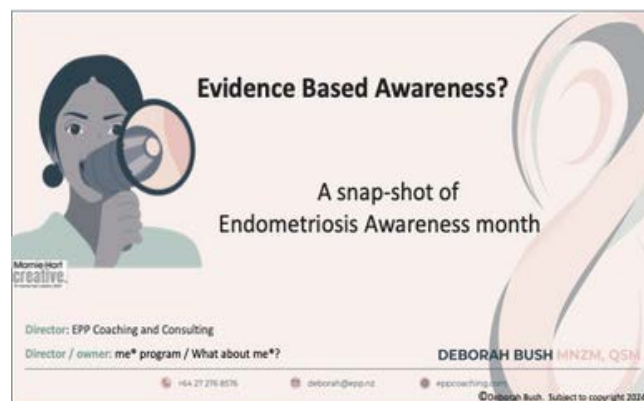
Share with other people who might like to participate! Please contact Dr Emma Marshall for more information or any queries, email: emma.marshall@deakin.edu.au

Let's advance the field together!

ENDOMETRIOSIS AWARENESS MARCH 2024

DEBORAH BUSH MNZM, QSM

During March, I presented to the ASPIRE conference in Auckland and the Menstrual Health Research Network about AWARENESS. Awareness simply means a concept about knowing. We should not presume or assume what is being presented in our communities around the world is evidence-based, inclusive, culturally sensitive and scientifically accurate.



I asked questions like, 'Do our plans also consider what happens once we've raised all this awareness? Does our country or regional setting have the capacity, expertise and resources to manage? What else do we need to do to encompass this? Are we embodying awareness activities into our strategic plan and action / alert campaigns?

Health advocates for every cause I can think of, set out to 'raise awareness'. Therefore, how do we make sure ENDOMETRIOSIS, our cause, is heard above the other noise and receives the societal, academic and clinical attention, it desperately deserves. I encourage you all to consider this challenge as an opportunity and collaborate and innovate. **AWARENESS** still has relevance, but let's be bold and consider how we can also **AGITATE FOR ACTION**.

As stated in our last issue:

'Working collaboratively, patients, advocates, healthcare providers, and researchers can significantly improve care for those affected by endometriosis and break new ground'.



World Endometriosis
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WEO WEBINARS

TOPICS:

- Education for schools, young people and communities.
- Workplace Wellness for Endometriosis.

We will advise on dates in the near future.



World Endometriosis
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KEEP THE WCE2025 ON YOUR CALENDAR!



WORLD ENDOMETRIOSIS SOCIETY WESINAR:

WES is proud to announce its next WESinar:

Speaker:
Dr Pinar Bahat

Chair:
Dr Jacques Maas

Simultaneous translation into: Mandarin, Portuguese, Russian, Spanish, Ukrainian, and Vietnamese

PROGESTOGENS' RECEPTOR BINDING PROFILE AND THEIR
ROLE IN ENDOMETRIOSIS
PAIN TREATMENT

May 21 - 14:00 CET (Paris) / 22:00 AEST (Sydney)

Supported by:

Progestogens' receptor binding profile
& their role in endometriosis pain treatment

Date: 21st May 2024:

Time: 14:00 CET/22:00 AEST

Speaker: A/Prof Pinar Bahat, Turkey.

Chair: Dr Jacques Maas, the Netherlands

REGISTER [HERE](#)

*We recognise that this has been a quick snapshot into the marvellous work that took place during March.
WEO wishes to extend its heartiest congratulations to all those involved in Endometriosis Awareness
Activities and Action during March 2024.*

Best wishes to all

WEO Steering Committee



Deborah Bush

Emma Cox

Michelle Marvel

Elsie Wandera

Ambah Grant

Philippa Bridge-Cook

Femke Jansen

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