

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

Welcome to 2024. We trust you had a well-deserved holiday whether you're in freezing temperatures and huddled inside keeping warm or enjoying winter activities, or like me, enjoying these hot summer days. Whatever the case, we hope you're well and getting into the swing of 2024.

We are pleased to cover two recently published research articles in this issue. Both articles are very relevant given March Awareness is looming quickly. As an author of the social media study, I remain staggered that, after decades of work to change the narrative, create unique services and programmes, develop resources, speak to schools, communities and workplaces, GP's and scientific meetings, we still find publications and articles supporting old myths and inaccurate information across social media platforms. Let's not become so accustomed to the misinformation, disinformation or misleading information within the global endometriosis community, that we accept this as the status quo. The information we disseminate should be peer reviewed, evidence based and accurate.

March is dedicated to Endometriosis Awareness and whether you are concentrating on one event or a month of activities and fund raising, we wish you every success for your 2024 Awareness Campaign.

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



WORKING TOGETHER TO INCREASE AWARENESS AND ACTION CHANGE



Newsletter Highlights

A MESSAGE FROM THE
PRINCIPAL

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WES WORLD LIAISON
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WCE2025

IN MEMORIAM: ROBERT
TAYLOR, MD, PhD

TALK TO US

RESEARCH: SOCIAL MEDIA, ENDOMETRIOSIS, AND EVIDENCE-BASED INFORMATION: AN ANALYSIS OF INSTAGRAM CONTENT:



an Open Access Journal by MDPI

Social Media, Endometriosis, and Evidence-Based Information: An Analysis of Instagram Content

Hannah Adler; Monique Lewis; Cecilia Hoi Man Ng; Cristy Brooks; Mathew Leonardi; Antonina Mikocka-Walus; Deborah Bush; Alex Semprini; Jessica Wilkinson-Tomey; George Condous; Nikhil Patravali; Jason Abbott; Mike Armour

Healthcare 2024, Volume 12, Issue 1, 121



Healthcare 2024

Quote from the publication: 'This study suggests that health communicators, clinicians, scientists, educators, and community groups trying to engage with the endometriosis online community, need to be aware of social media discourses about endometriosis, while also ensuring that accurate and translatable information is provided'.

Of the alarming results, **only 18.9%** of comments/posts made on Instagram during the study period that related to surgery, were scientifically accurate.

Quote from the conclusion: 'Given the fact that we found a considerable amount of mixed and non-evidence-based claims, future research prospectively determining the impact of social media on medical decision-making in those with endometriosis would provide further insight into the real-world consequences of potentially misleading content.'

EndoActive in collaboration with the University of Sydney launched the **Endometriosis Patient Experience Survey (EPES)**. Patient experiences of being advised by a healthcare professional to get pregnant to manage or treat endometriosis: a cross-sectional study. Diksha Sirohi, Sylvia Freedman, Lesley Freedman, Gretchen Carrigan, Alison J. Hey-Cunningham, M. Louise Hull, Rebecca O'Hara BMC Women's Health **volume 23**, Article number: 638 (2023)

EndoActive says 'over half of the 3,347 eligible participants had received advice to get pregnant or to have a baby to manage or treat their endometriosis.

1,692 received advice from a health professional and of those, 72% were advised by gynaecologists and 45% by GPs.

Pregnancy as a cure for endometriosis is a myth and it's often traumatising for a patient to be advised that they should become pregnant to treat the condition.



WEO congratulates co-authors Lesley and Syl Freedman from EndoActive, on this insightful publication.

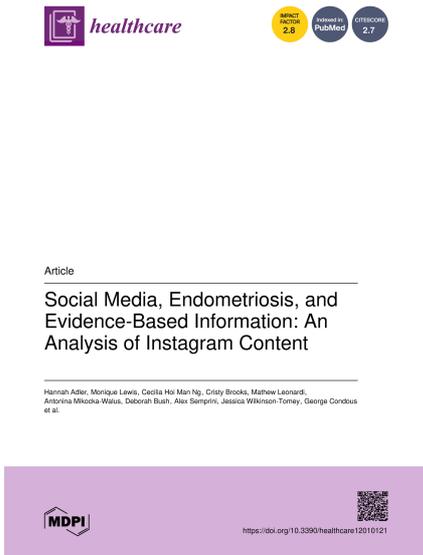


World Endometriosis
Organisations

WORKING TOGETHER TO INCREASE AWARENESS AND ACTION CHANGE

ENDOMETRIOSIS PATIENT EXPERIENCE SURVEY (EPES) CONT...

The research methodology considered 7 themes which included Health Literacy, Accepting the Advice, Rejecting the Advice, Life Implications, Healthcare Impacts, Mental Health, and Adverse Impact on Relationships. Each theme included patients' experiences of being told to get pregnant, such as this quote from the Mental Health theme:



“It [having a baby] was in my mind every day and added a significant amount of stress to day-to-day life. It is a huge decision to make, endometriosis or not. I was very confused and depressed.

Depressed at the prospect [I] may never have children.

It was a nightmare for me and something that impacted me greatly on an emotional level.

Frustration. Feeling invisible. Feeling irrelevant. Angry. Disappointed. Deflated. Seen as a baby making oven instead of being seen as a person.”

The Guardian article, January 2024, draws attention to Medical Gaslighting, a serious health issue in our field, that has spanned centuries. While the cause and therefore the cure for endometriosis still eludes us, it is inexcusable for doctors to perpetuate myths and inaccuracies.



In the article, responders from NHS said;

“The health service is committed to meeting women’s individual healthcare needs and is rolling out dedicated pelvic health clinics – bringing together specialist healthcare staff – to provide further support for women living with endometriosis.”

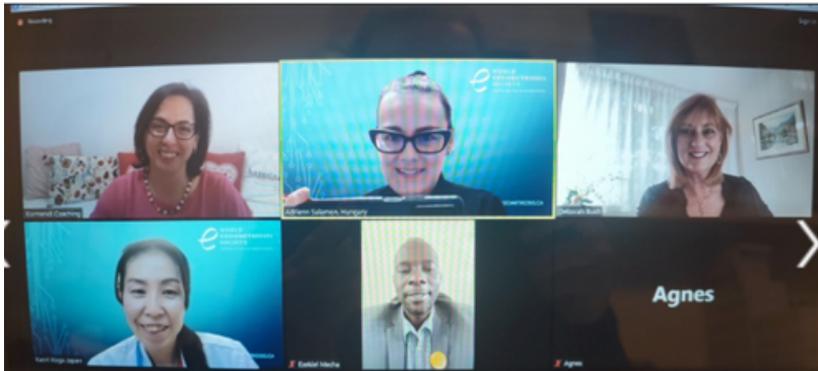
In 2022, a lead media source in New Zealand conducted a campaign for better health services titled ‘In Her Head’. This is not a country-specific issue faced by those with endometriosis. WEO is sure you have encountered similar stories.

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

INAUGURAL MEETING OF THE WES WORLD LIAISON COMMITTEE: JANUARY 2024

It was an honour to be invited on to the World Endometriosis Society (WES) Board, World Liaison committee, led by Adrien Salamon from Hungary (Centre).

The first meeting was marked by an in-depth discussion of our strategic plans leading up to May 2025. While the exact details of these plans will be communicated at a later date, the board expressed great enthusiasm for the exciting initiatives ahead.



“The involvement of civil organizations will be pivotal at certain points, emphasizing our collaborative approach,” said Adrienn. Stay tuned for more updates on this journey towards our goals.

ENDOMETRIOSIS AWARENESS MARCH 2024

WEO wishes each of its members a successful 2024 Awareness campaign. Endometriosis doesn’t start and end with March but it is the time to *‘shine a light on endometriosis: time to listen and take action’*



Some of you will be raising funds to invest in research and education, engage in patient advocacy and public awareness through various social media platforms, media, activities and events.

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



Sri Lanka 2023, with their SUCCESSFUL campaign UNSTOPPABLE, with a variety of outstanding, well planned events.

ENDOMETRIOSIS AWARENESS MARCH 2024 CONT...

ITALY 2023:

“LET’S SIT ON YELLOW ENDOPANK®”.

This time last year their project had more than 170 yellow benches throughout the country. The project involves a yellow bench with a QR code on a plaque.

A video explaining endometriosis is played when scanned. They plan to colour the whole of Italy yellow and would like to hear from other WEO members interested in this special project.



MYENDOSIS MALAYSIA



MyEndosis Malaysia started its campaign in early, January 2024. Congratulations to Surita Morgan for sharing her views on being a woman, researcher, and advocate on endometriosis awareness from the patients' perspective. This was a Dunia Wanita podcast headed by Nadiah Ibrahim, who also has endometriosis.

Surita said she “loved the vibe.”



Please share your awareness activities or campaign themes with us so that we can showcase and share your wonderful work, inspire others, and raise the WEO profile.

KEEP THE WCE2025 ON YOUR CALENDAR!



IN MEMORIAM. ROBERT N TAYLOR MD, PHD.

WEO pays tribute to the exceptional life of, Robert Taylor who died tragically on January 22, 2024.



Dr Taylor was a revered clinician and scientist and was committed to finding pain-relieving solutions for those with endometriosis. 'He led much of the foundational discoveries in cytokine activity and angiogenic underpinnings of endometriosis. Professor and Dean, Dr. Taylor served WES as a Senior Board member from 2005-2017, holding the Executive Board office of Secretary from 2011-2017, after which he has continued to serve as a WES Senior Ambassador.' (WES release, January 29, 2024)

Our thoughts are with his wife, Dr. Sarah Berga, and their family at this difficult time.

We encourage you to read this special tribute to Professor Robert Taylor MD [here](#) to gain a deeper appreciation of our brilliant colleague, a scientist who worked tirelessly and passionately to understand the complexities of endometriosis so that those with the disease would have improved care and management. "Thank you Rob for your amazing contribution. We will build upon your work and hope you will rest in peace." (www.endometriosis.org)

We don't always know what's happening for others. While we've posted this before, we'd like to leave you with this gentle and timely reminder. Take care everyone.

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

People don't always need advice. Sometimes all they really need is a hand to hold, an ear to listen, and a heart to understand them.

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