

# 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

WELCOME TO JUNE. WEO proudly welcomes Ms Surita Morgan from Malaysia to the WEO Steering Committee. We are delighted about this appointment and we know Surita will represent those in Malaysia who have endometriosis well, and join us in supporting the cause and those with the disease globally. We would like to introduce you to Surita.

**Ms. Surita Mogan** is the founder and president of the Endometriosis Association of Malaysia (MyEndosis), a registered association since 2014. She is also an endometriosis patient. This association's primary goal is to reduce the stigma surrounding endometriosis, thereby enabling women and girls to receive a comprehensive diagnosis, high-quality medical care, and essential peer support.



Additionally, she has 20 years of experience as a senior lecturer at Universiti Tunku Abdul Rahman (UTAR). She is currently pursuing her PhD at Universiti Teknologi Malaysia (UTM) in health communication and endometriosis. On June 15, 2021, she was awarded a Silver Medal for her "Empathy in Healthcare" topic in a competition organized by UTM. She is also a member of the Asia Pacific Expert Panel team, and the result of her work is a journal article titled "Improving the diagnosis of endometriosis in Asia-Pacific: Consensus from the Asia-Pacific Endometriosis Expert Panel for Endometriosis" published in the International Journal of Gynecology & Obstetrics (2023). She has contributed journal articles to the Malaysian Journal of Public Health Medicine, International Journal of Nursing Practice, Asian Women, and a book chapter titled "An Intersectional Case Study Analysis of Malaysian Indian Women with Endometriosis: Coping with Discrimination."

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## Newsletter Highlights

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PRINCIPAL

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FOR EARLY INTERVENTION

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## CONT: MESSAGE FROM PRINCIPAL

During March, many Organisations launched a new initiative and are now developing and implementing that further.

In this issue, we would like to acknowledge and highlight the work being achieved by WEO in educating young people in menstrual health and endometriosis. We are pleased to bring you updates from Ireland, Sri Lanka, Canada, Australia, and New Zealand, the latter being the first country in the world (1997/98) to initiate and deliver menstrual health and endometriosis education for young people and communities.

We will continue to provide information on this important and critical topic, which is fundamental to reducing the diagnostic delay, improving menstrual health literacy, knowledge and encouraging early intervention. This is a snapshot only. We are aware of other programmes in the world also.

We are pleased to bring you some related research and a brief update on Imaging presented by Mathew Leonardi MD PhD from a recent WESinar.

Lastly, we pay tribute to Mary Njambi Koikai, better known as Jahmby Koikai, a former Kenyan radio host who dedicated her short life to advocating for those with endometriosis.

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## ADOLESCENT EDUCATION FOR EARLY INTERVENTION

### IRELAND

The recent launch of MISE, a menstrual education program specialising in endometriosis, marks a significant milestone in Irish schools.



Inspired by New Zealand's successful ME program developed by Deborah Bush, MISE (Menstrual Information, Specialising in Endometriosis) aims to provide crucial information about menstrual health and endometriosis to teenagers. This initiative is essential, as endometriosis is a common yet often misunderstood condition that can significantly impact those affected. MISE was launched as a pilot program in March, reaching 500 pupils across multiple schools, with Cate and Kathleen traveling over 2000 kilometers to deliver the program.

## ADOLESCENT EDUCATION FOR EARLY INTERVENTION CONT...

The presentation is delivered in a relaxed and approachable manner, and the feedback and questions received have been fantastic. By fostering an environment of awareness and openness, MISE aims to improve the quality of life for young individuals dealing with menstrual health issues. The program's ultimate goal is to contribute to better health outcomes and reduce the stigma surrounding menstruation and endometriosis in Ireland.

Through education and understanding, MISE hopes to empower students and create a supportive community for those affected by these health issues.



## EARLY INTERVENTION AND EDUCATION: EMPOWERING YOUNG GIRLS AGAINST ENDOMETRIOSIS IN SRI LANKA

### SRI LANKA

Endometriosis is a complex, painful, and often misunderstood condition that affects young girls and women. Awareness programs within schools and parallel discussions with primary care medical levels are essential for promoting early symptom recognition and targeted treatment plans by experts. Sri Lanka's data for adolescent endometriosis is limited due to a combination of a lack of awareness among healthcare providers and cultural taboos. This adds to the negligence and dismissal of patients who are turned away by caregivers at every level such as schools, offices and clinics.



'Classroom awareness begins today', is a program planned by ESAF which advocates for classroom awareness promoting practices such as maintaining students' period diaries, rating their pain levels and discussing these records monthly with their class teacher.

If the record indicates abnormal pain levels and/or bleeding patterns exceeding three months we encourage the class teacher to connect the student to a family doctor to kickstart the diagnosis process. Availability of non-vaginal scans for young girls and such culturally sensitive aspects will be discussed so that parents will not resist testing.

## EARLY INTERVENTION AND EDUCATION: EMPOWERING YOUNG GIRLS AGAINST ENDOMETRIOSIS IN SRI LANKA CONT...

Early intervention of this nature can reduce the risk of complications such as subfertility, infertility, crippling pain, frozen pelvis, life-threatening infections, cyst ruptures, etc. Additionally, the psychosocial aspect of the patient can dramatically improve with improved pain management, lifestyle, and emotional support strategies.

By fostering open discussion about menstrual health with a special focus on endometriosis we can empower young girls to take care of their health confidently.

*Written by Rashani Meegama*

*(Attorney-at-Law)*

*Founder, The Endometriosis Support & Awareness Foundation (EASF)*

## THE WORLD VISION AWARENESS PROGRAM ON ENDOMETRIOSIS

The World Vision Awareness Program on Endometriosis was launched on March 3rd 2024, organised by the Endometriosis Support and Awareness Foundation (ESAF) and World Vision, headed by the National Director Dr Dhanan Senathirajah.

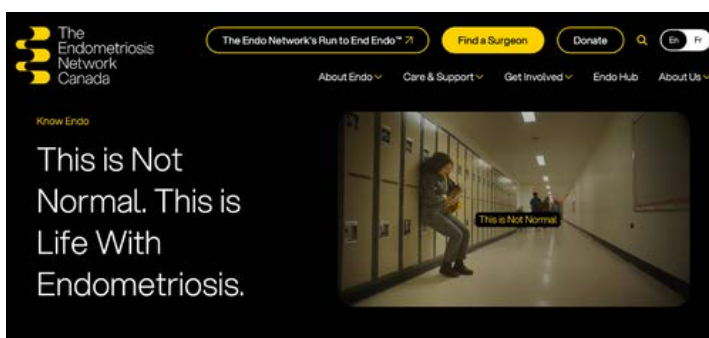
World Vision's support and collaboration were instrumental in reaching a wider audience and amplifying the impact of the awareness program, aligning with their commitment to women's health and empowerment.

The audience comprised World Vision employees, spanning ages approximately from 23 to 60 including both men and women. Additionally, the event was broadcasted via Zoom to individuals connected to World Vision, extending the reach beyond the physical venue. ESAF provided resources and informational materials to attendees, empowering them with knowledge to recognize and address endometriosis within their communities.

## HISTORIC FUNDING FOR PATIENT-LED ENDOMETRIOSIS AWARENESS AND EDUCATION IN CANADA

### CANADA

In 2023, the Canadian Federal Government made a historic investment in endometriosis awareness and education. The Endometriosis Network Canada received a large grant from Health Canada's Sexual and Reproductive Health Fund for a project titled **"Decreasing the Delay to Diagnosis: Endometriosis Education and Awareness."**



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## HISTORIC FUNDING FOR PATIENT-LED ENDOMETRIOSIS AWARENESS AND EDUCATION IN CANADA CONT...

The project had three objectives:

1. To develop and deliver a pan-Canadian digital endometriosis awareness campaign, #KnowEndo, that would reach millions of Canadians.
2. To develop a menstrual health and endometriosis curriculum enrichment resource for school and community programs to use with youth.
3. To create evidence-based resources on priority topics for people living with the disease.

Physicians from the Canadian Society for the Advancement of Gynaecologic Excellence (CanSAGE) provided clinical expertise across all of the objectives to ensure that the information presented was accurate, evidence-based, and up-to-date.

To ensure that the work met the needs of people with endometriosis, we engaged with our Endo Ambassadors. These individuals, with diverse lived experiences of endometriosis, including people of different ages, genders, sexualities, socioeconomic statuses, and ethnicities or races, and living across Canada, played a crucial role in shaping our project. Together, we identified topics that were chosen as priorities for patient education resources, including the impact of endometriosis, mental health, surgery, complementary and alternative medicine, pelvic physiotherapy, extra-pelvic endometriosis, and menopause.

The menstrual health and endometriosis education program 'What you need to know. Period.' was developed with a strong focus on inclusivity and accessibility. A curriculum specialist, in consultation with diverse youth, educators, and clinician advisors, created the program. It follows guidelines for sexual health education as presented by the Sex Information & Education Council of Canada. The program is intended for use with young people of all genders, identities, and sexual orientations, whether or not they menstruate. The content was created through an anti-oppression lens and acknowledges different ways of knowing and doing, ensuring that it caters to the diverse needs of our audience.

All of this project's outputs were created in both English and French, Canada's official languages. This bilingual approach was a key aspect of our project, ensuring that our resources are accessible to a wide range of Canadians. With the financial support provided by Health Canada's Sexual and Reproductive Health Fund, all of the resources created by this project are available for free, further enhancing their accessibility.

As the one-year funding wrapped up, we are pleased to report on the incredible impact and reach of this work. Our bilingual awareness campaign, #KnowEndo, reached over 13 million people across Canada. 51 medical clinics, hospitals, and community organizations serving 770,000 people across Canada signed up to receive our endometriosis guides, and 71 schools, school districts, and community organizations serving 473,000 people across Canada signed up to receive our menstrual health and endometriosis curriculum enrichment program 'What you need to know. Period.'

We are also pleased to announce that The Endometriosis Network Canada recently received one-year extension funding for this project from Health Canada's Sexual and Reproductive Health Fund. With this additional funding, we aim to build upon all of the work that we have highlighted here to ensure maximum reach and benefit for Canadians across this country, especially in underserved communities.

*Written by Katie Luciani*

*Executive Director, The Endometriosis Network Canada*

## THE PERIODS, PAIN AND ENDOMETRIOSIS (PPEP TALK®) SCHOOLS PROGRAM

The Periods, Pain and Endometriosis (PPEP Talk®) Schools program is an Australian program provided by the Pelvic Pain Foundation of Australia.



PPEP Talk ® has programs for girls, boys, gender diverse, culturally diverse and indigenous students.

Additional programs for younger students, athletes, coaches, workplaces and health practitioners are also available



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# MENSTRUAL HEALTH AND ENDOMETRIOSIS ['ME'] EDUCATION

## NEW ZEALAND:

Where the world's first **Menstrual Health and Endometriosis ['me'] education** for young people in schools, began. <https://pubmed.ncbi.nlm.nih.gov/28349513/>



> Aust N Z J Obstet Gynaecol. 2017 Aug;57(4):452-457. doi: 10.1111/ajo.12614. Epub 2017 Mar 28.

**Endometriosis education in schools: A New Zealand model examining the impact of an education program in schools on early recognition of symptoms suggesting endometriosis**

Deborah Bush <sup>1 2</sup>, Emily Brick <sup>1</sup>, Michael C East <sup>2</sup>, Neil Johnson <sup>3 4</sup>

Affiliations + expand

PMID: 28349513 DOI: 10.1111/ajo.12614

## me<sup>®</sup> facts:

- 1st pilot in 1998
- Evaluated, revised and adjusted regularly to allow for clinical and educational knowledge, developments and advances
- Medically responsible, interactive and age appropriate with a well-health and wellbeing focus
- Reached over 300,000 secondary school students in NZ using an in-schools delivery model
- Reached single, co-ed, special character schools eg Muslim School for Girls and schools for teen mothers.
- Trialed successfully in: Mumbai; British Columbia, Ireland and South Australia (where it was included for expansion in the National Action Plan for Endometriosis in Australia - NAPE)
- Endorsed by WES
- 1st global publication on the impact of a Menstrual Health and Endometriosis Education program in schools.

2	Promote early education on women's health, delivered in school settings, and provided for all genders.	
	Action	Detail
	Update school puberty and sexual health curriculums to include a menstrual	Support the expansion of the Menstrual Education (ME) Schools Program to deliver this.



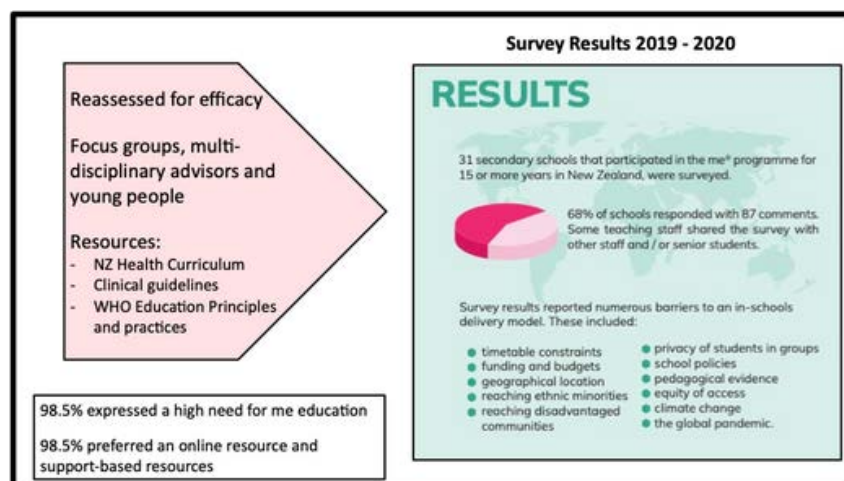
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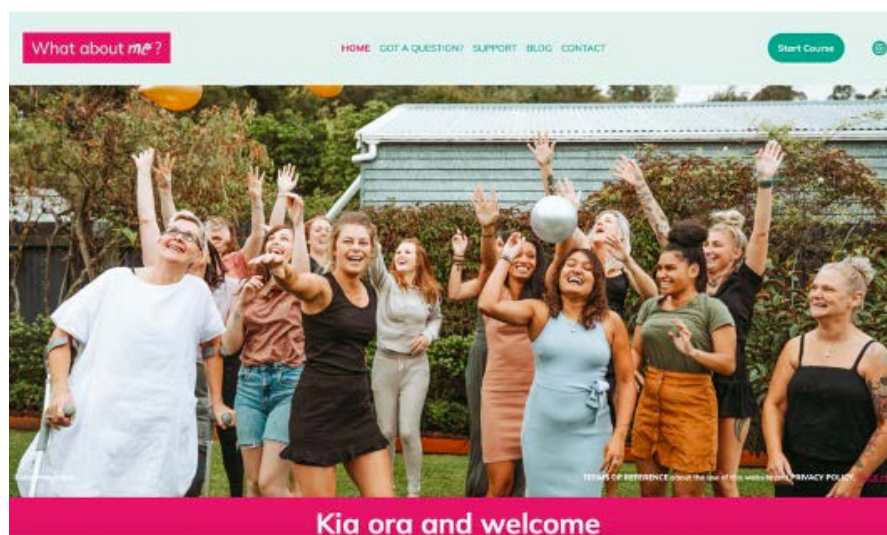
## MENSTRUAL HEALTH AND ENDOMETRIOSIS ['ME'] EDUCATION CONT...

In 2020 / 21, the program was paused and assessed for efficacy. This was natural timing given COVID19 lockdowns. We surveyed our school and student community and many barriers to delivering an in-schools programme were noted including climate change and fiscal responsibility. It's a very expensive way to connect. Here are some results:



We therefore adapted and moved the program online to maximise learning opportunities for adolescents, families and communities.

The new online program is called **WHAT ABOUT ME?** and in 2023 was launched from its [website](#)



While it has a strong Māori (indigenous people of Aotearoa) focus, it is interactive (games & activities), fun, strengths based, medically responsible and follows the neuroscience of pain, clinical guidelines and health literacy. Advisors to the programme included students, teachers, educationalists, Māori and Pasifika, gynaecologists, allied health professionals, GPs, and researchers in our field

We encourage you to check it out, enjoy and share it with your young people and communities.

**You are welcome to contact Deborah Bush for advice or help in establishing your own educational programme for young people.**

**EARLY INTERVENTION IS VITAL. MENSTRUAL HEALTH EDUCATION CANNOT BE LEFT TO CHANCE.**

This will be discussed in a WEO webinar later in the year.



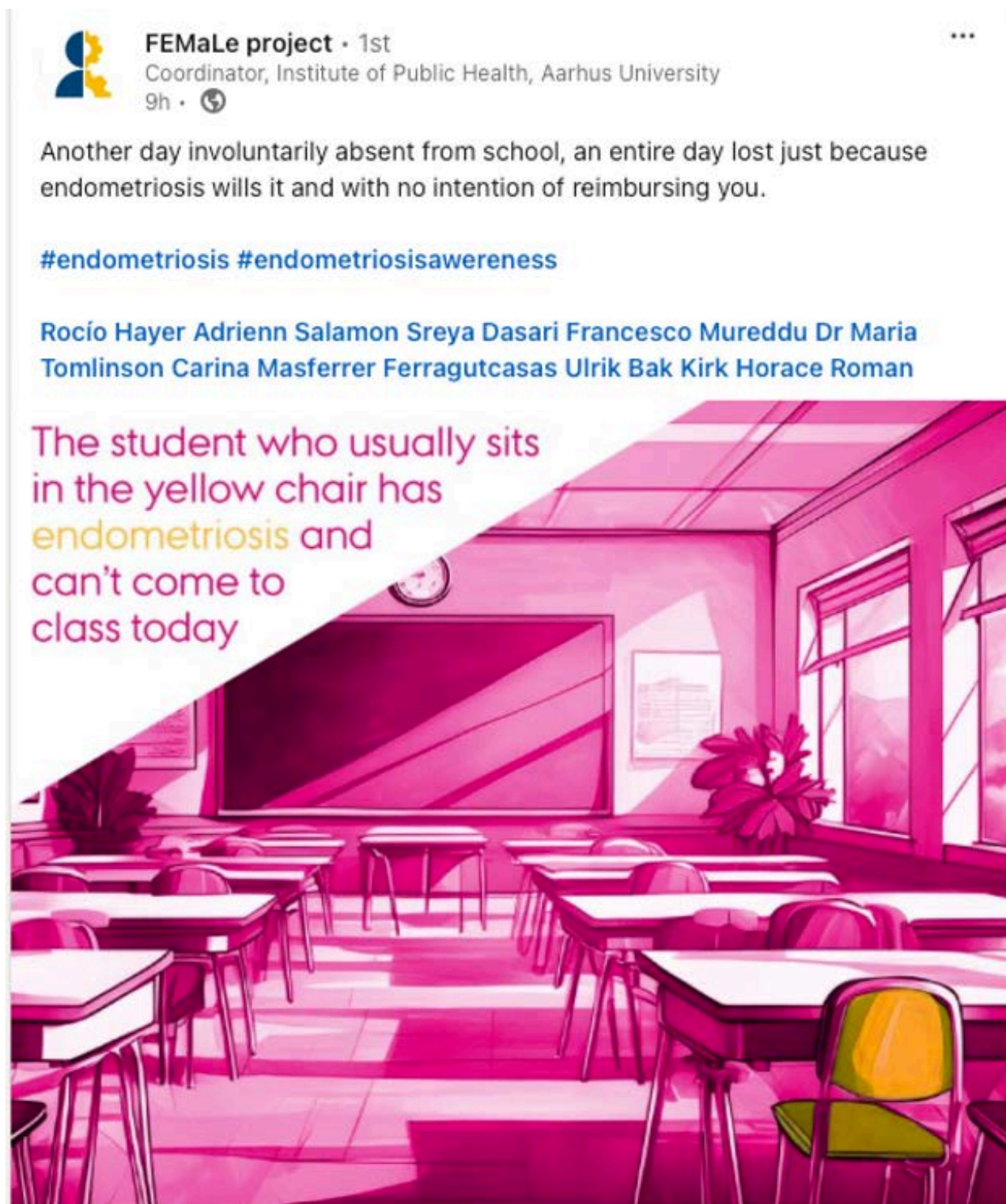
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## FEMaLe Project

### HATS OFF TO THE FEMaLe Project for this effective campaign



## RESEARCH

Recent studies relating to adolescents and young people.

This study was to investigate whether an early need of hormonal contraception (HC) of a failure to find a suitable method, are warning signs for endometriosis.

> BJOG. 2024 Mar 21. doi: 10.1111/1471-0528.17812. Online ahead of print.

### Endometriosis risk and hormonal contraceptive usage: A nationwide cohort study

Cerisa Obern<sup>1</sup>, Matts Olovsson<sup>1</sup>, Tanja Tydén<sup>1</sup>, Inger Sundström-Poromaa<sup>1</sup>

Affiliations + expand

PMID: 38511416 DOI: 10.1111/1471-0528.17812

**Conclusions:** The use of HCs at an early age and a failure to find a suitable HC were identified as warning signs of later receiving an endometriosis diagnosis. A longer duration of HC usage reduced the risk of receiving the diagnosis

This study evaluated the associations between peritoneal fluid color and volume at time of endometriosis-related laparoscopic surgery with patient characteristics, endometriosis type and lesion location in adolescents and young adults with endometriosis.

> Front Reprod Health. 2023 Dec 15;5:1297907. doi: 10.3389/frph.2023.1297907. eCollection 2023.

### Visualized peritoneal fluid variation in adolescents and young adults with endometriosis: is there more to it?

Abdelrahman Yousif<sup>1 2</sup>, Mary DePari<sup>3 4</sup>, Allison F Vitonis<sup>3 4</sup>, Holly R Harris<sup>5 6</sup>, Amy L Shafir<sup>4 7 8</sup>, Kathryn L Terry<sup>3 4 9</sup>, Stacey A Missmer<sup>2 4 7 9</sup>, Naoko Sasamoto<sup>3 4</sup>

Affiliations + expand

PMID: 38162009 PMCID: PMC10757835 DOI: 10.3389/frph.2023.1297907

The findings highlight the importance of accounting for menstrual cycle phase and hormonal exposures when designing research using peritoneal fluid samples and inferring from biomarker results intended to advance our understanding of endometriosis and associated pathophysiology.



A proper educational programme may be necessary for these women and healthcare providers to understand the consequences of intractable cyclic/acyclic pain, in order to facilitate early detection and timely management of menstrual pain and its negative consequences, such as endometriosis.

*"If prevention is still better than cure, then I believe that early detection and timely management is very important to prevent the progressive cascade of endometriosis." Khaleque Khan, MD, PhD, Japan*



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## RESEARCH CONT...

## Did you attend this WESinar?



Hearty congratulations to Mathew Leonardi MD PhD from Canada who gave a fabulous talk on 'Advances in Imaging for Endometriosis'. Innovations in imaging is a rapidly growing area in our field and is changing the diagnostic / assessment tools available allowing the pelvis to be mapped thoroughly which allows for a planned approach to treatment and management being discussed with the patient.



Dr Leonardi often posts helpful video clips and information on social media.

**Social media handles:**

Instagram (@drmathewleonardi),  
YouTube (Mathew Leonardi MD PhD)  
Twitter/X (@mathewleonardi)

He suggested [this publication](#) for your interest.

We try to include the details of WESinars in our newsletters so you have access to vital learnings.



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## WEO TRIBUTE TO MARY NJAMBI KOIKAI

### A Tribute to Njambi Koikai: A Resilient Voice

Mary Njambi Koikai, a Kenyan Endometriosis advocate, passed away on June 4, 2024 at the age of 38, after a long struggle with endometriosis from the tender age of 13. She will be remembered as a beacon of strength and resilience to Kenyans and community around the world.

She was diagnosed with thoracic endometriosis and endured an unimaginable journey of 21 surgeries, with her final procedure taking place in 2018 at the Center for Endometriosis Care in the United States.

Beyond her fight with endometriosis, Njambi was a beloved figure in the Kenyan entertainment industry. Known for her vibrant personality and deep passion for music, she gained fame as a host of reggae shows on Metro FM and QFM, where her voice became a familiar comfort to many. Njambi was more than a media personality; she was a cultural icon who brought joy and reggae rhythms to the hearts of her listeners.

Her advocacy went beyond her personal struggle; Njambi used her platform to raise awareness about endometriosis, pushing for better understanding and medical care for others suffering from the condition. She was a warrior not just for herself but for many others, helping to lift the veil of silence that often surrounds women's health issues.

As we remember Njambi Koikai, we celebrate her life, her courage, and her incredible impact both on and off the air. Her legacy of resilience and advocacy continues to inspire and influence the community, driving forward the conversation on endometriosis and women's health in Kenya and around the world.

Njambi, your fight has taught us all the meaning of perseverance, and your voice continues to echo in the lives you've touched. Rest in power, Njambi, knowing your journey has made a difference.

*Written by Elsie Wandera  
Founder, Endometriosis Foundation of Kenya & Member of  
WEO Steering Committee*





## KEEP THE WCE2025 ON YOUR CALENDAR!

**WEO** WEO WEBINARS: Dates to be advised.

**AT WCE2025. MARK IT ON YOUR CALENDAR! Exciting news to come.**



*We would like to extend our heartfelt thanks to the entire WEO community for your continuous support and dedication to our cause. Your efforts and contributions are invaluable as we work together to make a difference.*

*Best wishes to all  
Deborah and the Steering Committee*



Deborah Bush



Emma Cox



Surita Morgan



Elsie Wandera



Philippa Bridge- Cook



Ambah Grant



Michelle Marvel



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](mailto:info@endofoundke.org) and Deborah Bush at [deborah@epp.nz](mailto:deborah@epp.nz)