

AUGUST 2023

# WEO Newsletter

ISSUE 10

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.

Three months on since the WCE2023 in Edinburgh, there is progress being made around the world, new and exciting research being undertaken, advances in clinical diagnosis and treatment, and far more awareness, but it's slow. This requires us to be tenacious, persistent, and committed to the cause whilst navigating through barriers to find the best way to progress.

In this issue, we celebrate the work being achieved in Australia and a webinar, the Swedish education programme on endometriosis in children and adolescents, a summary from the Reframing Endometriosis Conference in Birmingham, and feedback you can give us about WEO. Enjoy the read and our very best to each of you.

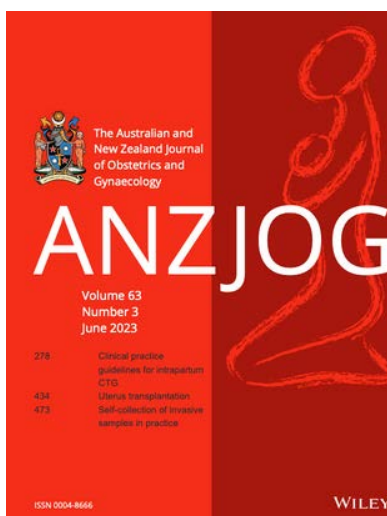
Deborah and the Steering Committee, Emma, Ambah, Elsie, Michelle, Philippa, and Femke.

## AUSTRALIA NATIONAL ACTION PLAN ON ENDOMETRIOSIS (NAPE)

Australia introduced its first National Action Plan on Endometriosis (NAPE) in 2018 and is now 80% of the way through the first five-year plan. The NAPE recommended three key directions: (i) awareness and education, (ii) clinical care and (iii) research.

The overarching aim of the NAPE is: 'a tangible improvement in the quality of life for individuals living with endometriosis, including a reduction in the impact and burden of disease at individual and population levels'.

You can read more about the [NAPE in ANZJOG](#), the Australian, New Zealand Journal of Obstetrics and Gynaecology.



Connect to the World Endometriosis Society online



WORKING TOGETHER TO INCREASE AWARENESS AND ACTION CHANGE



## Newsletter Highlights

A Message from the  
Principal

Australia National  
Action Plan on  
Endometriosis (NAPE)

Machine Learning in  
Medicine

Swedish Educational  
Program on Endometriosis  
in Children and  
Adolescents

Reframing Endometriosis:  
Power, Politics, and  
Potential Futures

TALK TO US

## CONT. AUSTRALIA NATIONAL ACTION PLAN ON ENDOMETRIOSIS (NAPE)

Following on from our webinar last year where Professor Jason Abbott introduced the NAPE, our WEOs requested a webinar to learn more about the NAPE. We are pleased to announce a webinar in November.

We look forward to hearing from the Pelvic Pain Foundation of Australia; EndoActive; QENDO and Endometriosis Australia.

**WEBINAR: Wednesday 1st November 2023 at 8:00 am UK GMT.**

MORE DETAILS TO COME. You'll appreciate that it's tricky finding a universal time that suits our global community. The time we have scheduled limits those from Canada and the USA joining as it is the middle of the night for them, but for those night owls – no problem. However, we hope to record the session so that no one misses out.

Save the date and REGISTER HERE: <https://us06web.zoom.us/meeting/register/tZUvf-6spzgtHt02vRsXSFxWIMqph9nGNcCd>

## MACHINE LEARNING IN MEDICINE



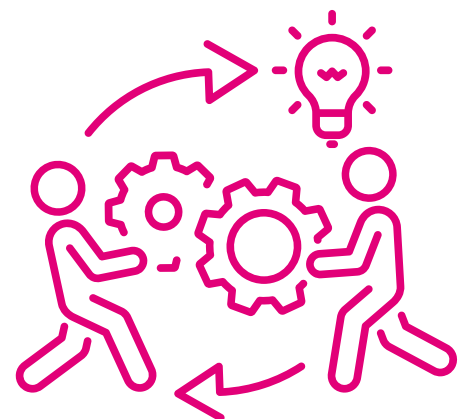
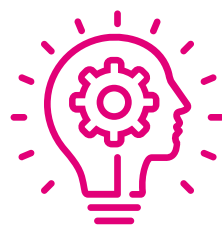
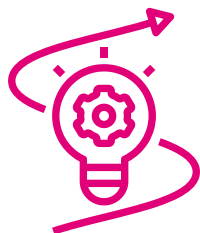
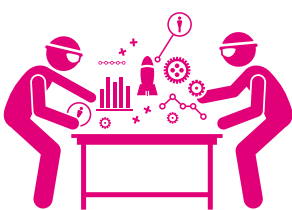
This article about harnessing artificial intelligence to help change the way endometriosis is diagnosed is most interesting and something that has enormous benefits to our global community. Some of you may have met Dr. Jodie Avery (a lead author) from the Robinson Research Institute (Australia) at the WCE2023 in Edinburgh.

The research team says “We hope that an earlier diagnosis enabled by the **IMAGENDO**® technology will lead to prompt treatment and better quality of life by avoiding unnecessary hospitalizations and repetitive surgery”.

The article concludes, “**IMAGENDO**® is increasingly recognized nationally and internationally for the way it has used AI to integrate digital data from ultrasound and MRI scans to formulate new diagnostics for endometriosis. The program is expanding nationally in Australia and internationally with collaborations in North America, South America, and in Europe.

You can read more about the article [here](#).

Just imagine how this would change our world!



World Endometriosis  
Organisations

WORKING TOGETHER TO INCREASE AWARENESS AND ACTION CHANGE

## SWEDISH EDUCATIONAL PROGRAM ON ENDOMETRIOSIS IN CHILDREN AND ADOLESCENTS

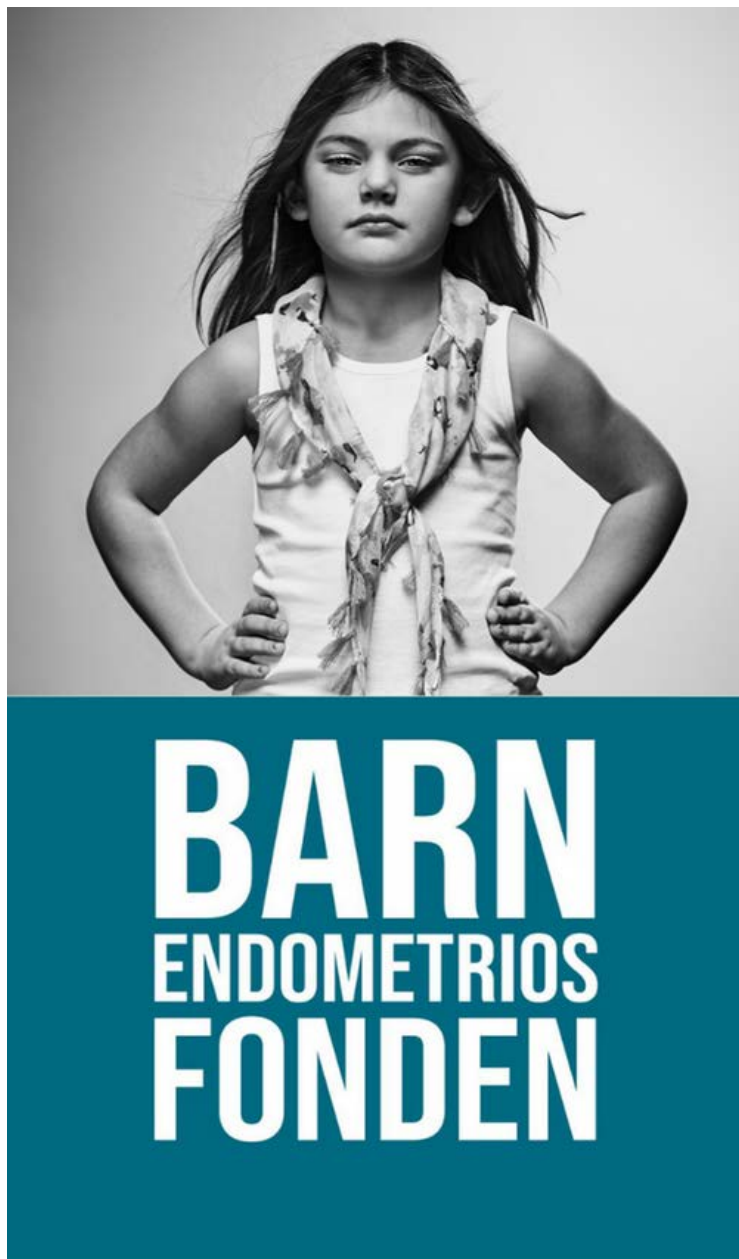
Katarina Steinfeldt Olbers, Chair of the Child Endometriosis Foundation in Sweden says “the knowledge that children get endometriosis is enormously low. No child becomes a "young woman" at menarche. A child is a child!” Katarina has prepared this summary of the work her Organisation is doing in Sweden. We look forward to receiving updates on this project.

In Sweden, an estimated 50,000 adolescents between the ages of 13 to 23 suffer from endometriosis. For them, the delay in diagnosis is far more than 8 years. The Child Endometriosis Foundation (Barnendometriosfonden) initiated a project together with LÖF (The Mutual Insurance Company for The Regions) and representatives from several patient organisations and healthcare professions.

The project was created as there is a need to increase awareness in the whole society that children and adolescents suffer from endometriosis. The knowledge among healthcare professions that meet children also needs to increase. The delay in appropriate treatment can have severe consequences resulting in decreased quality of life and health, as well as disease progression. [Barnendometrios.se](http://Barnendometrios.se) aims to disseminate information to three important users: persons under 18 years of age, persons over 18 years of age and healthcare professions. Images, language and information is adapted in accordance with the three user groups. The whole project is based on The United Nations Convention on The Rights of The Child.

[Barnendometrios.se](http://Barnendometrios.se) is a national educational program that aspires that all children and adolescents with endometriosis will receive early help and appropriate treatment. The educational platform will be launched in August 2023 and continuous updates will be made every 6 months.

Katarina Steinfeldt Olbers  
Chairman, Child Endometriosis Foundation  
[info@barnendometriosfonden.se](mailto:info@barnendometriosfonden.se)



**CONGRATULATIONS**



World Endometriosis  
Organisations

# REFRAMING ENDOMETRIOSIS: POWER, POLITICS, AND POTENTIAL FUTURES



## Reframing Endometriosis: Power, Politics and Potential Futures



Image: Endometriosis in Wall of Fallopian Tube, photograph by Ed Uthman. Used with permission from the creator and under CC by 2.0

Reframing Endometriosis: Power, Politics, and Potential Futures, the British Academy/Wellcome Trust international, hybrid social science conference on endometriosis, took place last month (July 6th&7th). It was the first-ever academic conference to bring together the UK and internationally-based social science and humanities researchers alongside (bio)medical researchers, third-sector representatives, and independent researchers and authors. President of the World Endometriosis Society Professor Stacey Missmer, a moderator at the event, called the conference “paradigm shifting” in its approach to bringing together social scientists, biomedical/clinical researchers, and patient advocates to address silos in the field.

Speakers focused on practices of exclusion in past and present approaches to endometriosis, as well as potential inclusive futures. Panels (see the full programme here: [Programme. Reframing Endometriosis \(thebritishacademy.ac.uk\)](https://www.thebritishacademy.ac.uk)) discussed historical framings of endometriosis, lived and marginalized experiences, what social and biomedical divides that must be addressed to improve care, and future framings of endometriosis. The final panel, with leads of key patient organizations, including Deborah Bush MNZM, QSM (World Endometriosis Organisations), Lauren R Kornegay (EndoBlack, Inc.), Emma Cox (Endometriosis UK), and Neelam Heera-Shergill (Cysters), addressed why the language we use to talk about endometriosis matters and what new ways of talking about the condition are needed.

Reframing Endometriosis is the start of ongoing public and government engagement. Illustrator Justnya Green was commissioned to create a special art piece based on conference themes, which will be exhibited at The Wellcome Trust and British Academy. Conference conveners Dr. Annalise Weckesser, Dr. Andrea Ford, and Dr. Veronique Griffith will present outcomes from the conference to the UK's All Party Parliamentary Group on Endometriosis and the Women's Health Strategy in September.

For those who could not attend and would like access to panel recordings/transcripts, please contact [Annalise.Weckesser@bcu.ac.uk](mailto:Annalise.Weckesser@bcu.ac.uk).



# 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.

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.

This is a photo of a slide taken at the WCE2023 closing ceremony.  
Start planning to attend WCE2025 in Sydney.  
Let's aim for a strong WEO presence.



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



World Endometriosis  
Organisations

WORKING TOGETHER TO INCREASE AWARENESS AND ACTION CHANGE