MONTHLY NEWSLETTER

Vol 1 Issue 06



World Endometriosis Organisations

WELCOME

THIS IS THE SIXTH ISSUE OF THE WEO MONTHLY NEWSLETTER

EACH ISSUE WILL COVER AREAS OF INTEREST, INCLUDING:

RESEARCH | MEETING(S) | GLOBAL EVENTS | AWARENESS | UPDATE FROM YOUR ORGANISATION AND WEO

NEW MEMBER

The Endometriosis Support and Awareness Foundation Sri Lanka (ESAF Sri Lanka) was founded in March 2021 by Corporate Lawyer Rashani Meegama, who herself has been a warrior of fourth-stage endometriosis.

The objective of this non-profit foundation is to create a loud voice of awareness and support on endometriosis to all social strata in Sri Lanka.

Despite the trials posed by COVID and Sri Lanka's economic crisis, ESAF Sri Lanka has managed to hold both online and in-person campaigns, such as the Endo Walk (the first of its kind in Sri Lanka) and participation in many interviews with doctors, newspapers, and influencers. ESAF was also represented at the Asian Conference on Endometriosis 2021. We were also instrumental in choreographing an oriental ballet dedicated to endometriosis awareness titled "THE YELLOW RIBBON DANCE."

We now have a panel of doctors onboard, specializing in Western medicine, Ayurveda, and nutrition, to provide as much help as possible.

As we initiate larger projects, our mission stays the same: Her Fight is My Fight.

They've included for you below their Social Media handles and a few photos and video links to some of the projects they have conducted in the past year.

INSTAGRAM - <u>@esaf.srilanka</u> FACEBOOK - <u>E S A F Sri Lanka</u> WEBSITE - <u>www.esafsrilanka.com</u>

WES/WERF FACT SHEET

This WES/WERF fact sheet will be helpful to share with groups or your members. We need to bear in mind the misinformation, disinformation, and inaccuracies repeatedly being seen. One slide in a recent presentation compared diabetes and asthma with endometriosis, all showing an incidence of 9% of the population! Further, supporting information from a recent documentary claimed that 1-2 in 10 of ALL women have endometriosis (which results in 200 million affected). However, this doesn't add up; the 190-200 million are based on ~10% of those during reproductive age – not of all women, as claimed. Adding another 10% would spiral the number to half a billion!

Click here for more information

SPECIAL NOTICE

NOTE: THERE WILL BE NO NEWSLETTER IN JANUARY 2023. Whatever you do to celebrate this time of year and welcome in the New Year, we wish you all a safe and fun holiday break. We will be back in February as we countdown to the World Congress on Endometriosis in Edinburgh in May.

Best wishes to all of you, your families, friends, and members.

The WEO Steering Committee: Deborah, Philippa, Emma, Ambah, Elsie, Femke and Michelle

Connect to the World Endometriosis Society online



WORKING TOGETHER FOR CHANGE AND PREVENTION

BI-ANNUAL MEETING NOVEMBER 22

It was an enormous pleasure to present this meeting to our WEO members. We aimed to have a meeting to inspire others on what we can collectively do to drive change. The outcome proved that it is possible and supported the old adage, "where there's a will, there's a way". There also has to be a financial investment, collaboration, and collective engagement where differences can be put aside for the cause and our vision. high interest in this initiative.

The following speakers provided a wonderful opportunity to understand some outstanding achievements in countries where WEO is represented:

- Professor Jason Abbott FRANZCOG FRCOG Ph.D.: 'The Australian National Action Plan for Endometriosis'
- Doris Murimi, CE Endo Sisters East Africa Foundation: • presented her book 'When Something is Wrong.'
- Emma Cox. CE Endometriosis UK: 'The Scottish **Government Initiative'**

The breakout groups provided time to discuss the presentations and ask questions of the speakers. We were fortunate that several representatives from the Australian Organisations were able to speak to the National Action Plan as Professor Jason was unable to stay on. A brief round-up of the groups follows:

- 1. There was significant interest in the PPEP Talk schools programme run by the Pelvic Pain Foundation in Australia. This programme is aimed at 15/16-year-olds, and is positive and support-based, to educate all children (male and female) and to help students identify where they are on the pain spectrum. In the UK, menstrual well-being has been included in the school curriculum following campaigning for this, however, this still needs to be a WEO webinar could be education in schools,
- 2. Several issues were discussed regarding the development of **Doris' book**. For instance, members were interested in knowing how long the process of writing the book took, the cost of publication as well as the ideal number of books to publish in the first round, and avenues of marketing or publicizing the book. It was refreshing to learn that others have already published books on endometriosis, and two others were in the process of publishing a book and medical papers.

3. Emma Cox spoke to the Scottish Government initiative. One of the aims embedded in the new Women's Health Strategy is to reduce waiting times for diagnosing endometriosis from over 8 years to less than 12 months by the end of the parliament and look to improve the experience and diagnosis of women who visit their GPs with other menstrual problems. There is

We acknowledged Lone Hummelshoj for hosting our website at no charge and Adrienn Salamon FROM Hungary, who provided this wonderful video of the activities of the Hungarian Endometriosis Association in 2021. This is a fine example of how your Organisation might consider presenting a visual overview of a project or a summary of what has been achieved.

We also acknowledged and thanked Emma Cox, CE of Endometriosis UK, and Lois Morehen for providing administrational support to WEO.

There was no time to give feedback on our current tagline, which is 'working together for change and prevention.' We like this suggestion, 'working together to increase awareness and action change.' We'd appreciate your input/feedback before the Steering Committee decides.

It gives great hope that considerable changes are happening globally and educating young people is now a hot topic. I remember when I first introduced 'the me® programme' in schools in 1998, how challenging it was. At that stage, it was not generally accepted that adolescents could have endometriosis. We knew better! The Menstrual Health and Endometriosis or me® programme was delivered to 300,000+ students in NZ implemented. It was suggested that a future topic for schools until it was paused for assessment in 2021. Our findings show a significant difference in early looking at the different models in different countries. presentation and diagnosis. To see other programmes now being introduced from the success of me® is brilliant. I can't wait to share the new online learning resource called What about me®?

> The meeting was 1.5 hours and closed on time. Thanks to all who presented and attended. I loved seeing familiar faces and those very new to WEO. Lesley Freedman from EndoActive in Australia kindly sent me these pics of the day WEO was founded in Vancouver in 2017. Thanks, Lesley.

Deborah Bush, MNZM, QSM, Dip Tchg, LSB: Principal WEO, **Director WES**

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These photos were taken at the WCE Vancouver 2017 when WEO was founded. Thanks Lesley Freedman of EndoActive Australia New Zealand for sending them through. Anyone recognise anyone? ☺





REMINDER: IT'S TIME TO REGISTER! NOTE THE KEY DATES. FOR THOSE WHO SUBMITTED SPONSORSHIP PROPOSALS - IT'S STILL ON THE RADAR. YOU HAVE NOT BEEN FORGOTTEN.

ENDOMETRIOSISUK



www.endometriosis-uk.org

Endometriosis UK: 'The Scottish Government Initiative'







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