

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

Warm greetings to all WEO members

The World Endometriosis Organisations would like to acknowledge the recent and unexpected passing of Dr David Redwine, a staunch pioneer in the field of endometriosis treatment. Dr Redwine headed the world-renowned Oregon Institute of Endometriosis at St. Charles Medical Center, Bend, USA. He made outstanding contributions to the understanding of endometriosis and pioneered minimally invasive laparoscopic surgery to excise the endometriosis. He was a tireless supporter of those with endometriosis, and a vocal advocate and assertive debater on the cause of endometriosis as a genetically driven disease of embryonic origin. He operated on thousands of women with endometriosis from the USA, Canada, and beyond.

His book 'Googling Endometriosis: The Lost Centuries', was released in 2012 and revised in 2016. It is a comprehensive history spanning eras not previously investigated. <https://endometriosis.org/resources/clinical-books/googling-endometriosis-david-redwine/>



From a personal perspective, I first met Dr. Redwine in 1998 when we travelled to Bend, Oregon following the WCE1998 in Quebec Canada. We wanted to see first-hand the work Dr Redwine was doing and look around the St Charles Medical Center. Soon after, several New Zealand gynaecologists also visited Dr. Redwine in Bend to train in the early practices of surgical excision of endometriosis. It was wonderful to later host Dr Redwine and his wife Laurie in Auckland, New Zealand where he was a keynote speaker.

We fondly remember Dr David Redwine, a global pioneer in endometriosis.

WEO extends its condolences to David's wife Laurie, his family and Nancy Peterson RN. RIP Dr David Redwine

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



WORKING TOGETHER TO INCREASE AWARENESS AND ACTION CHANGE



## Newsletter Highlights

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## PIONEERS IN ENDOMETRIOSIS

In our [October Newsletter](#), we called for all WEO pioneers to contact us and submit their stories to allow us to compile a dossier of those who have paved the way in our field. Thanks to those who have already submitted their inspiring stories. We look forward to hearing from others who founded an endometriosis, adenomyosis, or pelvic pain organisation and hearing about the work they have achieved to improve the lives of a few, or millions, and what impact this has had. Please note: stories can now be longer than 200 words.

We are delighted to bring you **Bianca De Bie's** tenacious and committed story titled: ***“Endometriosis pioneer in the Netherlands.”***



It is October 2002. I came into contact with other patients who have endometriosis through mailing lists. The internet is still quite new and not always accessible. What we collectively notice is that there is virtually no information about our disease. Quite a few of you have endometriosis and are unable to become pregnant. But nothing that describes the endless pain and impact on your life. The idea arises to jointly establish an organization for endometriosis. At the end of October 2002, we founded the Endometriosis Foundation, with the main aim of contacting fellow sufferers and providing information.

We then started looking for financial resources, medical input and ways to reach fellow sufferers. In the Netherlands there is a government fund for patient organizations. You can use this if you meet a number of core tasks and conditions. We certainly made efforts to comply with this in the early days. As a result, over the years we have continued to receive institutional funding, sometimes supplemented with project fundings. This makes us less dependent on donations.

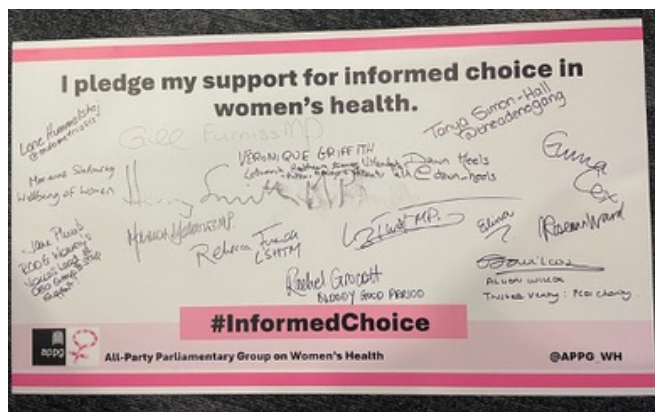
In this time 2002/2003 the internet and the forums emerged. This has benefited our flying start. As a result, we quickly got in touch with many patients. The first two years there was a storm with new donors, we had to look for a serious membership administration. We also became more adept at creating websites, brochures and setting up meetings. Ultimately, in 2012/2013, the forum made way for Facebook groups. During the Corona-virus period, on-site meetings were replaced by online meetings. Today these 2 types of meetings coexist! Over the years, our role as an advocate in the medical world and in politics has also changed. We were pleased with the establishment of the S.I.G. in 2010. Endometriosis within the department of gynecologists. We still work closely with this, and this collaboration has also changed endometriosis care in the Netherlands. From a single hospital with a gynecologist who focuses on endometriosis, there are currently about 25 hospitals where an entire endometriosis team works.

Our most recent success is in politics. Due to, among other things, our request for attention, an amendment was adopted at the end of 2022 to set up an endometriosis campaign. We are currently working on shaping this.



## ALL PARTY PARLIAMENTARY GROUP (APPG)

In England, the All Party Parliamentary Group (APPG) on Women’s Health held a roundtable on 15 November focusing on the power of informed choice and decision-making - specifically for menstrual health conditions. Lone Hummelshoj ([endometriosis.org](http://endometriosis.org)) and Emma Cox (Endometriosis UK) represented the endometriosis community. This group came together to determine the asks of the UK government to improve informed choice and to address the barriers women in particular experience within the current healthcare system.



In 2017 the APPGWH found that two-thirds of women first found information about their condition from the internet - rather than from their healthcare providers. Dissatisfaction with not being presented with all treatment choices has led to 84% stating that they are not being listened to by healthcare professionals and that their treatment preferences are often ignored.

What do we need to do to change this?

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

## RESEARCH: ENDOMETRIOSIS AND DIET

In this issue, we chose to highlight an example of recent research on diet and endometriosis. It is misleading to say ‘the endo diet’ as the literature has yet to provide conclusive evidence. However, we now know there are certain foods or groups of foods such as FODMAPs, which can exacerbate commonly experienced bowel-related symptoms in those with endometriosis, adenomyosis, and pelvic pain. Dietary management can provide enormous relief by eliminating or minimizing these symptoms and improving well-being. It is reassuring to know that more research is being conducted in various parts of the world, on the interplay between food and painful symptoms.

This publication from September 2023 provides insight into the Mediterranean Diet.

**Mediterranean Diet and Oxidative Stress: A Relationship with Pain Perception in Endometriosis. Michela Cirillo, Conza Fatini et al** <https://pubmed.ncbi.nlm.nih.gov/37834048/>

The authors of this study concluded that the Mediterranean Diet ‘could be considered a new effective strategy for chronic pain management in the long term’. The authors acknowledge that the cohort was small with all participants being of Caucasian descent, and the study lasted only 6 months. Nonetheless, it may be something your members would appreciate learning more about.

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## ARTICLE IN THE GUARDIAN

There was an excellent article in The Guardian in August 2023; “It’s really only the beginning: are we on the cusp of a breakthrough in endometriosis?”. For decades it has felt like we are riding the wave of a breakthrough in endometriosis, but hopefully we are closer now than ever before. This article by Gabrielle Jackson, interviews Professor Andrew Horne and others and, while it says there has been ‘no single breakthrough’, it does highlight that ‘things are changing’. Enjoy the read.

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## WELCOME BACK

The Endometriosis Association of Iceland which was founded in 2006 are excited to rejoin WEO after a pause in membership while they took a break. They provide support, educate the community, and improve healthcare for people with endometriosis. Congratulations Anna Margrét on your appointment as their new Executive Director and welcome back to your Association.



## MASTERCLASS IN ENDOMETRIOSIS

Join us 'down under' at the **ASPIRE Masterclass in Endometriosis**, Auckland, New Zealand. The [programme](#) is exciting and inspirational. For more information and registration [click here](#).



## WCE2025

WEO is working with the Australian organisers and hope to bring some exciting news in 2024 for WEO members. In the meantime, mark the date in your diaries. It would be fantastic to have strong WEO representation at the next World Congress on Endometriosis in Sydney.



## 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)

We look forward to reconnecting in February 2024. **HAPPY HOLIDAYS TO YOU ALL!**