

Newsletter

Together we can end endo.

www.endometriosisaustralia.org



Endometriosis Australia enjoyed a happily hectic March in Yellow awareness month of events, elevation and engagement about all things endometriosis.

Thank you for Marching into Yellow with us and participating in our social media awareness campaign #morethanjust.

On behalf of Endometriosis Australia and the 1 in 9 #endowarrior girls, women and AFAB, a big yellow heartfelt thank you to those who hosted or attended high teas, shared photos with your personal messages and in front of the yellow Endo Enlightened structures, and everyone who participated in awareness and fundraising activities.

We've had an exciting month and we look forward to sharing a summary of it with you!

*Here's some mood music while you read through....Endo Warrior and Endometriosis Australia volunteer **Shara Rose** singing her fabulous song about the power of not giving up, [Hold On](#).*

Maree Davenport
CEO Endometriosis Australia



Photo: Board Members Naomi Seddon, Assoc Prof Anusch Yazdani, Co-founder Donna Ciccia, CEO Maree Davenport, 'Minister for Endo' Hon Ged Kearney MP, Ellie Angel Mobbs and former MP

and previous Chair Gai Brodtmann at Parliament House, Canberra.

We missed our Chair Monica Forlano and Board Treasurer Mariana von Lucken.



Endometriosis and pelvic pain clinics to open nationally

ENDO NEWS: Endometriosis Australia's Maree Davenport was delighted to be invited by Assistant Minister Ged Kearney MP to the announcement of 16 Endometriosis and Pelvic Pain Clinics in November 2022 and we welcome the extension to 20, with at least one clinic in every state and territory and a mix of regional and metropolitan locations.

- The Clinics will each receive more than \$700,000 over four years, to support hiring specialised staff, including nurse practitioners and allied health professionals, investment in equipment or fit-outs such as pelvic physiotherapy areas, as well as resources, training and development.
- Working in existing general practice, the clinics will strengthen what is often the first point of contact in the health system to reduce diagnostic delays and promote early access to multi-disciplinary intervention, care and treatment.
- As well as directly helping patients, the clinics will raise awareness of endometriosis and pelvic pain, build professional knowledge and skills in this area, and improve access to information and care pathways.

- Patients will be able to access the clinics by booking an appointment at one of the 20 attached clinics.

Endometriosis is the peak national body for endometriosis and will be supporting the clinics in their ongoing efforts.

VIEW THE FULL LIST ON OUR WEBSITE

Locations of Australian Government-funded Endometriosis and Pelvic Pain GP Clinics

State / Territory	Successful Clinic	Location	PHN
NSW	Orange Family Medical Centre	Orange, NSW	Western NSW PHN
	Hunters Hill Medical Practice	Hunters Hill, NSW	Northern Sydney PHN
	Leichardt General Practice	Leichardt, NSW	Central and Eastern Sydney PHN
	The Women's Health Centre Southern Highlands	Mittagong, NSW	South Western Sydney PHN
	Milton Medical Centre	Milton, NSW	South Eastern NSW PHN
	Coffs Harbour Women's Health Centre	Coffs Harbour, NSW	North Coast PHN
VIC	EACH Practice	Ringwood East, VIC	Eastern Melbourne PHN
	Bendigo Community Health Services	Bendigo, VIC	Murray PHN
	Kardinia Health	Belmont, VIC	Western Victoria PHN
	Lyndoch Medical Hub	Warnambool, VIC	Western Victoria PHN
QLD	MATSICHS (Institute for Urban Indigenous Health Ltd)	Morayfield, QLD	Brisbane North PHN
	Benowa Super Clinic	Benowa, QLD	Gold Coast PHN
	Family Planning Queensland	Cairns, QLD	Northern Queensland PHN
	Neighbourhood Medical	Bardon, QLD	Brisbane North PHN
WA	Pioneer Health Albany	Albany, WA	Country WA PHN
	The Garden Family Medical Clinic	Murdoch, WA	Perth South PHN
SA	Kadina Medical Associates	Kadina, SA	Country SA PHN
TAS	Family Planning Tasmania	Glenorchy, TAS	Tasmania PHN
ACT	Sexual Health and Family Planning ACT (SHFPACT)	Canberra, ACT	ACT PHN
NT	Northside Health Darwin	Coconut Grove, NT	Northern Territory PHN



Photo: ACT EA Volunteers

Inaugural Canberra Breakfast Event at Parliament House

Endometriosis Australia's Inaugural Breakfast was hosted by the Parliamentary Friends of Endometriosis Awareness on Thursday 23 March. Endo Warriors were joined by MPs, Senators, clinicians, health professionals, Endometriosis Australia Ambassadors, including Emcee and Ambassador Ellie Angel Mobbs and supporters at Parliament House in Canberra.

We heard from **Assistant Minister for Health and Aged Care, The Hon. [Ged Kearney MP](#)**; **Shadow Assistant Minister for Mental Health and Suicide Prevention, [Melissa McIntosh MP](#)**; **Co-Chairs of the Parliamentary Friends of Endometriosis Awareness [Lisa Chesters MP](#) and The Hon. [Nola Marino MP](#)**; event emcee, radio announcer and Endo Warrior [Ellie Angel-Mobbs](#); Endometriosis Australia CEO Maree Davenport; and Medical Director and Board Member of Endometriosis Australia, Associate Professor Anusch Yazdani.

Attendees also heard from the effervescent **Emma Watkins**, our Ambassador, endo warrior, former yellow Wiggle and star of children's entertainment character Emma Memma, and our newest Ambassador, comedian, social media star and endo warrior **Tanya Hennessy**, **Associate Professor Mike Armour**, Chair of the Endometriosis Australia Clinical Advisory Committee, on a panel moderated by Ellie to talk all things endo. Local Endo Warrior and ACT volunteer coordinator **Caitlin Tough** was also welcomed as a new Ambassador.

[VIEW PHOTO LIBRARY](#)



Photo: VIC EA Volunteers

Melbourne High Tea

Our Melbourne High Tea event was a beautiful afternoon, celebrating the resilience of Endo Warriors and the support of Endo Allies. Emceed by **Candy Hertz**, guests heard from Endometriosis Australia Clinical Advisory Committee member **Professor Luk Rombauts - President of the World Endometriosis Society**, **Dr Helen Schiele**, an educational expert and Endo Warrior, **Patty and Joseph Pardillo - a couple navigating endometriosis**; and **Max Jahufer - an Endo Warrior navigating endometriosis as a transgender man**.

We welcomed special guests:

- **Julia Argyrou**, Foundation member of the Julia Argyrou Endometriosis Centre, Epworth
- **Janet Michelmores**, Co-Founder, Jean Hailes Foundation and fellow member of the Federal Government's Endometriosis Advisory Group
- **Sarah White** CEO Jean Hailes Foundation
- **Dr Sofie Piessens** – Women's Ultrasound Specialist and Endometriosis Australia Clinical Advisory Committee member; and
- **Vase Jovanoska** CEO Royal Australian and New Zealand College Of Obstetricians And Gynaecologists (RANZCOG).

[VIEW PHOTO LIBRARY](#)



Photo: NSW EA Volunteers

Sydney High Tea

Our Sydney High Tea Event was another beautiful and inspirational afternoon coming together to celebrate the resilience of Endo Warriors and the support of Endo Allies.

We had the privilege of hearing from MC and Endometriosis Champion **Naomi Fitzgerald de Grave**, Endometriosis Australia Chair, **Monica Forlano**, and Members of Parliament **The Hon Tara Moriarty MLC** and **The Hon. Emma Hurst MLC**.

Our Ambassador, retired Half Pipe Snowboard Olympian and Endo Warrior **Holly Crawford**, has us breathless with her inspirational and funny experiences. Singer/songwriter and Endo Warrior **Shara Rose**, performed a fabulous song about the power of not giving up, [Hold On](#).

Our co-founder **Donna Ciccio** spoke about 10 years since she founded Endometriosis Australia with **Prof Jason Abbott** and inaugural Director **Dennis Robertson**, then joined **Dr Cecilia Ng** to discuss her study for Endo@Work.

We had the opportunity to farewell **Alexis Wolfe**, acknowledging her resignation as CEO, and welcomed her words of support for Endometriosis Australia as we wished her well for the future.

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Merck Healthcare's Endo Warrior High Tea

CEO Maree Davenport was a guest speaker at **Merck Healthcare's Endometriosis Australia High Tea** during March, sharing her personal experience with endometriosis. Having a daughter who started having symptoms at the age of eight, Maree knows only too well the challenges around getting a diagnosis and improving community understanding of the condition. Maree, alongside three other Endo Warriors, shared their moving stories of diagnosis, managing decisions around treatment, impact on family and fertility. The event helped raise awareness of endometriosis and its impact on fertility in particular.

Talking Pineapples Podcast

Endometriosis Australia's co-founder Professor Jason Abbott features on Talking Pineapples, a new fertility focussed podcast which delves into the realities of an endometriosis diagnosis and its impact on fertility. Designed with expert insights from IVF nurses, Merck Healthcare worked with Access Australia, the National Infertility Network, to develop the new 4-part podcast series.

[LISTEN HERE](#)

Einstein A-Go-Go Podcast

To coincide with Endometriosis Awareness Month, Radio Triple R and Einstein A Go-Go did an Endometriosis Special Broadcast, hosted by Triple R's esteemed science presenters Dr. Shane and Dr. Jen, live from the Triple R Performance Space, with guests:

- **Maree Davenport, CEO Endometriosis Australia***
- **Ali Deslandes from Robinson Research Institute, University of Adelaide IMAGENDO using MRI scans to improve diagnosis, which received an Endometriosis Australia Grant in 2020 and then went on to be funded by the Federal Government for \$1.9M dollars.**
- **Dr Fiona Cousins from Hudson Institute of Medical Research; and**
- **Dr Kate Tyson CEO Julia Argrou Centre, Epworth.**

****Note:** At one point during this broadcast, endometriosis was incorrectly defined as "endometrial tissue that can grow anywhere in the body". The correct description is "Endometriosis is a condition in which cells that are similar to the ones that line your uterus start growing in other areas of your body".*

LISTEN HERE



The 2023 Endometriosis Australia Symposium

Endometriosis: Spotlight On Research

WATCH ON DEMAND



Endometriosis Australia Symposium 2023

Our annual Endometriosis Australia Symposium took place online Saturday 25 March. This engaging and informative virtual event, emceed by Candy Hertz, shone a spotlight on the wonderful research currently being conducted in Australia with questions and answers provided by patients and researchers.

Our panellists:

- **Associate Professor Anusch Yazdani, Endometriosis Australia Medical Director**
- **Dr Kate Tyson, Researcher, Julia Argyrou Endometriosis Centre, Epworth VIC**
- **Professor Louise Hull, Researcher Adelaide University, SA**
- **Dr Brett McKinnon, Researcher University of Queensland QLD**
- **Professor Caroline Gargett, Researcher Hudson Institute, VIC**
- **Antara Mascarenhas, Endo patient and Endometriosis Australia Ambassador**

Don't worry if you missed out! Hit the button below to watch (or rewatch!) the 2023 Symposium on demand.

WATCH NOW

NEWS NEWS NEWS NEWS

Research Grant Winners Announced



2022 ENDOMETRIOSIS AUSTRALIA RESEARCH GRANT

Swipe for the winners >




Dr. Jacquie Mills

PROJECT: Let's Talk About Sex: The Development of Communication Tools for People Living with Endometriosis





Dr. Kate Tyson

PROJECT: Consumers and health professionals' views on what a multidisciplinary team care model for endometriosis should include: MDT Care Study

Dr. Thomas Tapmeier

PROJECT: Validating small extracellular vesicles as non-invasive biomarkers in endometriosis



Exciting Endo News - Research Grant Winners Announced!

Endometriosis Australia is the peak body for Endometriosis sufferers and the [largest non-government funder of research into endometriosis in Australia](#).

Since 2019, it has provided a total of \$400,000 for 12 research projects, investing in Australia's knowledge of the disease. However, there continues to be significant unmet demand for seed funded research. The 2022 Research Grant closed on 31 August 2022 with 16 quality applications requesting a combined value of \$847,000. Regrettably, we could only fund \$170,000 this year and these were announced in March.

The research institutions we work with nationally also train the clinicians who contribute to Australia's and the world's knowledge on diagnosis, treatment and are working towards a cure for endo and adeno.

We are very proud to announce the winners of the 2022 Endometriosis Australia Research Grant:

- **Dr Jacquie Mills, Deakin University**

PROJECT: Let's Talk About Sex: The development of communication tools for people living with endometriosis

- **Dr Thomas Tapmeier, Monash University**

PROJECT: Validating small extracellular vesicles as non-invasive biomarkers in endometriosis

- **Dr Kate Tyson, Epworth HealthCare**

PROJECT: Consumers and health professionals' views on what a multidisciplinary team care model for endometriosis should include: MDT Care Study

Thank you to all those who applied for sharing our vision to improve the lives of those with endometriosis.

Workplace Assistance Program Endo@Work

Endometriosis Australia in partnership with experts from Western Sydney University, University of Technology Sydney, and Southern Cross University is developing an Endometriosis in the Workplace policy for Australian employers. Our Endo@Work project aims to develop a set of guidelines for Australian employers, that will provide advice and guidance specific to different industries.

It is reported to cost more than \$7.7 billion in healthcare, absenteeism and lost social and economic participation (National Action Plan for Endometriosis, page 2). In Australia, endometriosis is associated with absenteeism from work, along with significant reductions in productivity when at work (presenteeism), leading to a cost of illness burden of approximately \$9.7 billion per year, comprising two thirds costs due to productivity loss.

Many workplaces are challenging for sufferers and the development of an Australian workplace employer and employee education platform and set of guidelines, will help to equip employers and employees with resources and education tools to manage endometriosis in the workplace.

The [Endometriosis Australia research](#) completed with Endometriosis Australia Clinical Advisory Committee Chair Associate Professor Mike Armour (University of Western Sydney) found:

- one in six people with endometriosis will lose their employment due to managing the disease
- one in three will be overlooked for a promotion
- 70% have to take unpaid time off work to manage symptoms
- 50% said lack of workplace flexibility was a significant problem
- 79% reported that work from home protocols made managing their symptoms easier
- 60% said they will more productively working from home
- 90% thought flexibility in hours and working from home could improve their management of endo in the workplace.

Those with endometriosis who gain and keep jobs attribute their success to flexible and reasonable workplaces and understanding and empathic managers and colleagues. COVID-19 restrictions have demonstrated that for those with endometriosis, changes in working arrangements mostly around the ability to self-manage working hours and rest breaks, improved their quality of life and productivity. A global, multicentre study of 1418 women (aged 18–45 years) with endometriosis reported that each woman lost an average of 10.8 h of work weekly because of lower work productivity.

We will keep you up to date on development of the Endometriosis Australia workplace assistance program [Endo@Work](#).



The Women in Leadership Summit in Sydney on 30 March explored *The New Taboos: Women's health, leadership & supporting your team*. CEO Maree Davenport joined the panel with:

Sonya Lovell (she/her)

Menopause Advocate, Speaker, Podcaster & Founder

Stellar Women

Megan Spindler-Smith (they/them)

Chair, ABC Inclusive

ABC

Rebecca Featherstone

Relationship Manager

IVF Australia

Preet Brar (she/her)

General Manager, Victoria

Cleanaway

MAKE A LIFE CHANGING DONATION TODAY



jessnathan_



Liked by **monicaforlano** and others

jessnathan_ Thrilled and humbled to announce I am now an Ambassador for @endometriosisaustralia 🧡

Endo Warriors be the change!

The facts speak for themselves.



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