

PRE-BUDGET SUBMISSION – ENDOMETRIOSIS AUSTRALIA



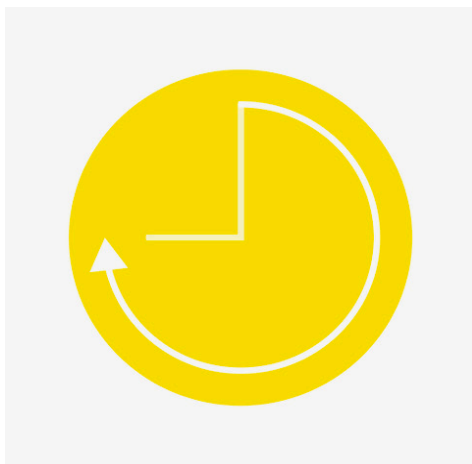
About Endometriosis Australia

Endometriosis Australia is a nationally accredited charity that endeavours to increase recognition of endometriosis and provide endometriosis education programs and funding for endometriosis research.

Endometriosis Australia is the leading not-for-profit advocacy organisation for the one in nine Australian women who suffer from endometriosis, and their families and carers.

Since 2013, Endometriosis Australia has worked tirelessly, and largely through a team of dedicated volunteers, to improve community and medical understanding of the disease through education, support and research programs.

“Endometriosis Australia has made a massive community of people supporting one another. It has saved my sanity quite a few times .” - Melissa



Our education and research programs have seen the delay in diagnosis reduce from 7 -12 years to 6.5 years¹.

Our support efforts mean we now have the largest reach and number of followers² of any endometriosis patient organisation in the country.

Endometriosis Australia is the only peak organisation with a multidisciplinary clinical advisory committee drawn from a team of internationally renowned medical, psychology, physiotherapy, allied and complementary health experts. These experts and feedback from our community assure the quality, efficacy, and accuracy of our programs.

¹ <https://www.nature.com/articles/s41598-020-73389-2>

² We have 87,000 followers on our social channels – more than any other endometriosis peak organisation

The 11.4 percent³

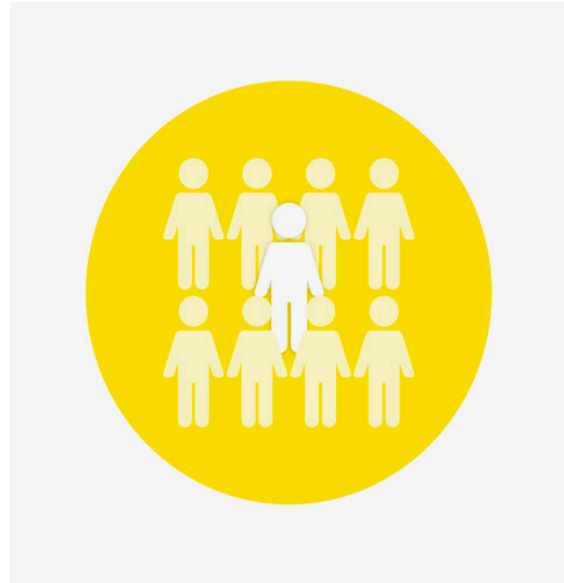
"It has been repeatedly demonstrated internationally that endometriosis has a long diagnostic delay, impacts people's health and wellbeing, including social activities, mental and emotional health, work/finances, and sexual relationships; and those with endometriosis report physical quality of life similar to that of cancer patients."

Endometriosis is a common disease in which the tissue that is similar to the lining of the womb grows outside it in other parts of the body.

One in nine women⁴ - or more than 830,000 Australians – suffer from endometriosis at some point in their life with the disease often starting in teenagers.

Symptoms are variable and this may contribute to the delay in diagnosis.

Common symptoms include pelvic pain that puts life on hold around or during a woman's period. It can damage fertility. While endometriosis most often affects the reproductive organs, it is frequently found in the bowel and bladder and has been found in muscle, joints, the lungs and the brain.



"I don't want someone else to wait fourteen years for a diagnosis they weren't aware they needed." - Mia

³ <https://obgyn.onlinelibrary.wiley.com/doi/abs/10.1111/1471-0528.16447>

⁴ <https://obgyn.onlinelibrary.wiley.com/doi/abs/10.1111/1471-0528.16447>



The direct and indirect cost of endometriosis to the Australian economy is estimated at \$9.7 billion annually. Two-thirds of these costs are attributed to a loss in productivity, with the remaining \$2.5 billion being direct healthcare costs⁵.

A recent large-scale epidemiological study has found women with endometriosis have an increase in the risk of cancer, particularly uterine cancer, ovarian cancer and breast cancer⁶.

This increased risk means greater attention needs to be focused on detection and treatment of the disease, as the risks to women suffering from endometriosis may in fact be far greater than previously thought.

Endometriosis Australia welcomes the opportunity to make this pre-Budget submission. Our submission focuses on three areas that medical evidence, government publications and community feedback have identified as requiring further investment to improve the level of endometriosis care for Australian women.

These are:

- Enhanced research funding
- Workplace education, and
- Mental health awareness and education.

"Since then, I've had to quit my job and start freelance work. I've been through 13 months of a controversial treatment which puts your body into a form of chemical menopause, and I've had another 2 surgeries. My endometriosis is the kind that seems to like to hang out on my bladder, around my bowel, all over the outside of my uterus and associated ligaments causing quite some havoc". - Rachel

⁵ The cost of illness and economic burden of endometriosis and chronic pelvic pain in Australia: A national online survey (plos.org)

⁶ Markedly increased risk of malignancies in women with endometriosis, by Kyung Jin Eoh et al

Drivers of Change - Shaping the agenda in Australia

Since 2013, Endometriosis Australia has:

- **Lead the production of Australia's first National Action Plan for endometriosis, and the first for any disease** – which has served as the blueprint for other similar national action plans.
- **Improved patient understanding of the disease** – through webinars, podcasts, blogs and other educational materials.
- **Improved the medical community's understanding of the disease** – through webinars delivered by the medical community for the medical community.
- **Improved the national and international body of knowledge of the disease** – by privately funding research through donations, since 2017. Last year, \$100,000 was allocated to four research projects. However, there is significant unmet demand. Endometriosis Australia received 26 research submissions in the 2020 round, with a combined total budget of more than \$1,000,000.
- **Helped shape government policy** – through two Endometriosis Advisory Group members, Chief Executive Officer, Donna Ciccia and Medical Director, Professor Jason Abbott.
- **Normalised community discussion and understanding** – through our national Ambassador Program and the first peak association to have endometriosis identified and spoken about in Parliament in 2017.

“I've had to rely on my son, he's 14 in April, there has been quite a few times where my son has had to help me out of bed and get me to the toilet... or help me even get out of bed because I physically couldn't and that causes me such worry but he says 'mum, I wouldn't have it any other way'." - Melissa

Recommendations

Guided by the latest research findings, Endometriosis Australia is seeking \$600,000 to expand our education and research programs and address the gaps in detection, awareness and understanding of the disease.

Endometriosis Australia will match government funding for these programs with private donations.

Recommendation 1: Research

Problem

Last year's draft National Clinical Guidelines highlighted the paucity of high-quality research in all areas of endometriosis care.

Solution

Endometriosis Australia is Australia's largest provider of non-government research funding in the field.

A rigorous and transparent academic review process and multidisciplinary clinical advisory committee of experts assess our research funding program.⁷

Endometriosis Australia is seeking funding of \$300,000 over three years to enhance our existing annual research program of \$100,000.

The 2020 clinical guidelines, and experience with our own program – where demand outstripped funding by 1:10 – prove there is a significant gap in the endometriosis research market.

Sustained funding over three years would serve to fill this gap and improve the national and international body of knowledge and understanding of a disease that impacts one in nine Australian women, particularly in early detection.

PROGRAM	FINANCIAL YEAR	FUNDING
Endometriosis research	2021-22	\$100,000
Endometriosis research	2022-23	\$100,000
Endometriosis research	2023-24	\$100,000

⁷ [Endometriosis Australia | Advisory Committee](#)

Recommendation 2: Workplace education

Problem

The chronic nature of endometriosis means women with the disease find it hard to get and maintain work, placing them at considerable financial disadvantage. Those women with endometriosis who gain and keep jobs attribute their success to flexible and reasonable workplaces, and understanding and empathic managers and colleagues.

Solution

Over the next three years, Endometriosis Australia is seeking funding of \$150,000 to research and implement a workplace education program loosely modelled on the UK Endometriosis Friendly Employer Scheme.⁸

The Australian scheme would target small and medium businesses, large corporations and government agencies and the construction, engineering and mining industries.

Year 1 – Research and development

The first year of funding of \$50,000 would be invested in research and development to assess how the UK scheme can be applied to the Australian industrial relations regulatory environment, and the changed work patterns arising from COVID-19.

Endometriosis Australia will collaborate through existing partnerships with the University of Western Sydney, Southern Cross University, and industrial relations lawyers to conduct the research and establish a rigorous evidence base to inform the implementation of the scheme.

Years 2 and 3 – Implementation

The final two years of funding of \$50,000 each year would be invested in the implementation of the scheme, including training trainers and online education programs for small and medium business owners and human resource managers.

PROGRAM	FINANCIAL YEAR	FUNDING
Workplace education program – research and development	2021-22	\$50,000
Workplace education program – implementation	2022-23	\$50,000
Workplace education program – implementation	2023-24	\$50,000

⁸ [Endometriosis Friendly Employer Scheme | Endometriosis UK \(endometriosis-uk.org\)](#)

Recommendation 3: Mental Health Awareness and Education

Problem

Endometriosis is a disease that affects every facet of a person's life.

It impacts on the individual, the family, partner, friends, socially and at workplaces.

Endometriosis is a quality of life disease. It is a disease that takes its toll physically, financially and mentally.

Solution

Over the next three years, Endometriosis Australia is seeking funding of \$150,000 to enhance our education and awareness series to support mental health for those that have endometriosis.

This mental health series would fill the education gap and deliver to patients, families and practitioners information to help them relate, understand and support each other.

Endometriosis Australia has a strong track record in delivering relatable and educational awareness campaigns around the nation. This mental health series would include medical webinars, blogs, podcasts, and live streamed direct to the patient information.

This supplementation of our education program with sustained funding over three years would serve to fill this gap.

PROGRAM	FINANCIAL YEAR	FUNDING
Endometriosis Mental Health Education and Awareness Program	2021-22	\$50,000
Endometriosis Mental Health Education and Awareness Program	2022-23	\$50,000
Endometriosis Mental Health Education and Awareness Program	2023-24	\$50,000

"In my shame and embarrassment, I had told myself, 'You're being crazy and overly anxious', a view that was, unfortunately, shared by quite a few medical professionals. To wake up and be told that it was absolutely real was, and still remains, one of the best feelings of my life." - Lucy
