

## **NEWS RELEASE – EndoAct pushes for national action plan during Endometriosis Awareness Month**

March 9, 2022

March is Endometriosis Awareness Month in Canada. Endometriosis impacts one million people in Canada. Approximately 1 in 10 women of reproductive age and an unknown number of transgender and gender diverse people are impacted by the disease.

EndoAct Canada is calling on the federal government to create a National Action Plan for endometriosis. Following in the footsteps of Australia, France and other peer nations, we want a concrete plan to tackle endometriosis on all fronts: awareness, education, diagnosis, clinical management, and research. To ensure solutions are tailored to the needs of the Canadian endometriosis community, the federal government must consult with people who live with this disease.

Endometriosis costs \$1.8 billion per year in Canada, a lot of this relates to productivity, people with the disease are too sick to work. Although the federal government does not deliver health care, it has the responsibility to address the substantial burden and cost of this health challenge through targeted funding support, health promotion, disease monitoring and research.

The Australian government was the first in the world to launch a [national action plan](#) for endometriosis in 2018 and committed more than \$22 million to support people with the disease through education, care, and research. In the plan, the Australian government also apologized “on behalf of the Australian Parliament and medical system for the historic failures that sufferers of endometriosis endured.” Just this January, France launched a [national endometriosis strategy](#), including designated centres of treatment in each region of the country.

A similar Pan-Canadian model must be developed to address the neglect of people with endometriosis in this country. As part of the #ActOnEndo, people from 11 provinces and territories have written 275 letters to 117 Members of Parliament demanding a national action plan for endometriosis.

EndoAct Canada is an unincorporated not-for-profit organization with the goal of driving public policy action on endometriosis in Canada that is based on science and grounded in the needs of the endometriosis community; our volunteers include people with endometriosis, health care providers, and researchers.

### **Background**

Endometriosis is a complex, chronic disease that occurs when tissue similar to the lining of the uterus implants outside of the uterus to form lesions, cysts, and deep nodules. Symptoms often start in early teenage years and include severe and chronic pain, infertility, and fatigue. When these symptoms are not managed, they cause frequent absence from school or work, disrupt milestones like going to college or starting a family, and negatively affect mental health.

Despite the burden of endometriosis, it takes approximately 5 to 11 years to be diagnosed. This diagnostic delay happens because awareness of the disease is low - many health care professionals

and members of the public think that the severe pain experienced by people with endometriosis is normal.

Before the pandemic, individuals in Canada waited 9 months to 2 years for specialized surgical and chronic pain care – this wait is now significantly longer. Because of the delay in access to specialized surgical care and limited accessibility certain regions of Canada, some people have even crowdfunded to get care internationally. Regardless of where they receive care, people with endometriosis may require lifelong follow up since there is no cure for endometriosis.

**Contact:**

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**People with endometriosis available to speak with media:**

- [Anna Mae Alexander](#), Calgary AB
- [Rosie Costen](#), Lethbridge AB
- [Lindsay McCray](#), North Saanich BC
- [Lan Randhawa](#), Abbotsford BC
- [Lauren Butler](#), Toronto ON
- [Philippa Bridge-Cook](#), Toronto ON
- [Katie Luciani](#), Toronto ON
- [Denise Campbell](#), Toronto ON
- [Emily Rowan](#), Toronto ON
- [Aditee Kissoon](#), Ottawa ON
- [Ruby Stickney](#), Saskatoon SK
- [Maria Arauz](#), Montreal QC

**Endometriosis specialists available to speak with media:**

- [Catherine Allaire](#), Vancouver BC
- [Liz Randle](#), Halifax ON
- [Jamie Kroft](#), Toronto ON
- [Mathew Leonardi](#), Hamilton ON

For an interview with any of these individuals, please contact Kate Wahl to obtain their contact information.