



The
Endometriosis
Network
Canada

2023 IMPACT REPORT



Promoting awareness, and providing inclusive education, support and resources for people living with and affected by endometriosis.

Decreasing the delay to diagnosis

Letter from the Executive Director



2023 was a year of opportunity and change for The Endometriosis Network Canada. We were honoured that Health Canada's Sexual and Reproductive Health Fund granted us the largest non-research federal investment to date in endometriosis. This marked a special moment in history for the Canadian endometriosis community. The funding gave us the opportunity to expand our efforts to raise awareness of endometriosis and educate people about this disease, while continuing to offer unwavering support to those living with endometriosis.

We started working on our Health Canada funded project *Decreasing the Delay to Diagnosis: Endometriosis Awareness and Education* in April 2023. Our team—which expanded from two to six paid employees—has been hard at work preparing patient education resources, a menstrual health and endometriosis curriculum enrichment program for youth, and a pan-Canadian campaign to raise public awareness of endometriosis. We can't wait to share the final products in 2024.

There was so much to celebrate in 2023! Highlights included presenting to family physicians, hosting a symposium for patients at the International Continence Society conference, a screening of the *Below the Belt* documentary in Ottawa, and briefing the House of Commons Standing Committee on Health about endometriosis. To make all of this happen, we continued to rely on our amazing, passionate team of volunteers.

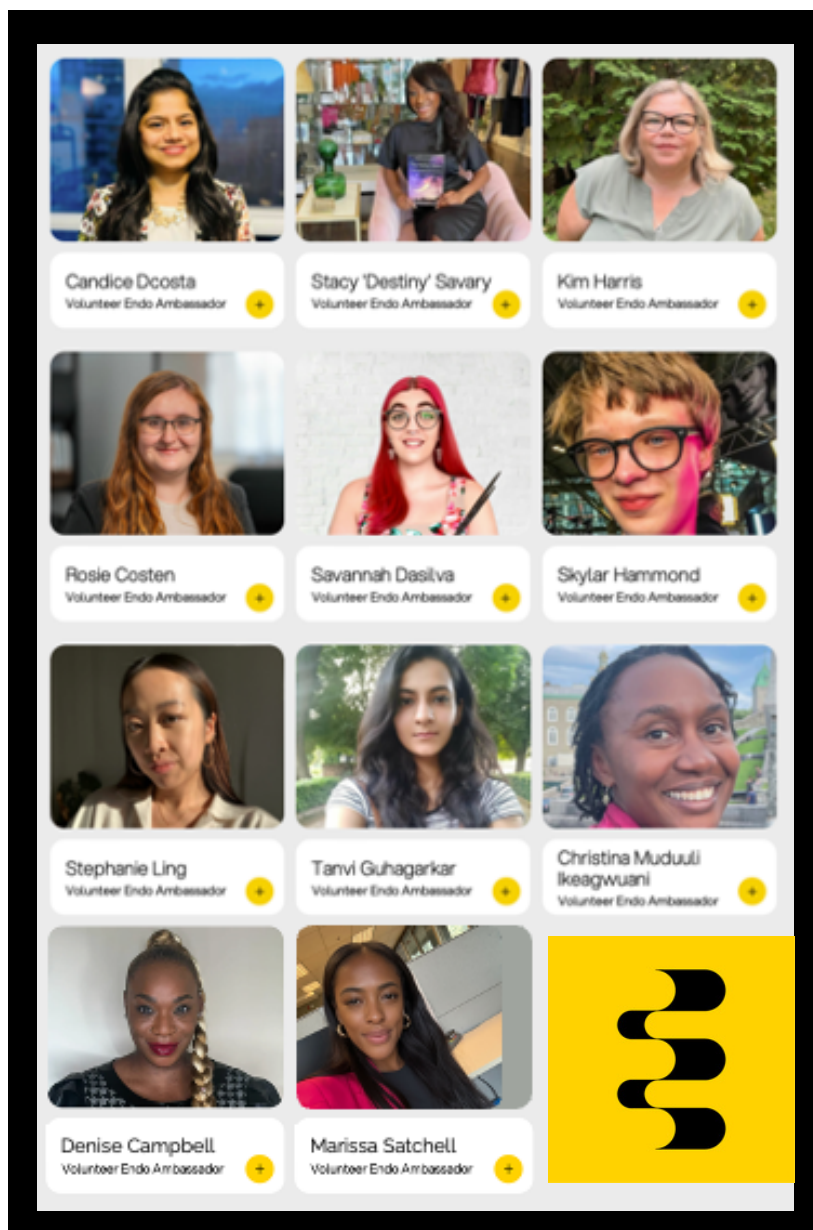


In 2023, we also launched our Endometriosis Ambassador program. This initiative was designed to connect with people who have endometriosis from communities that need urgent attention. We welcomed ten ambassadors from underserved communities to guide the development of endometriosis support and educational resources based on the needs of their communities. As The Endometriosis Network Canada was growing, I appreciated the opportunity to take a pause and connect with our new ambassadors as they shared their unique experiences.

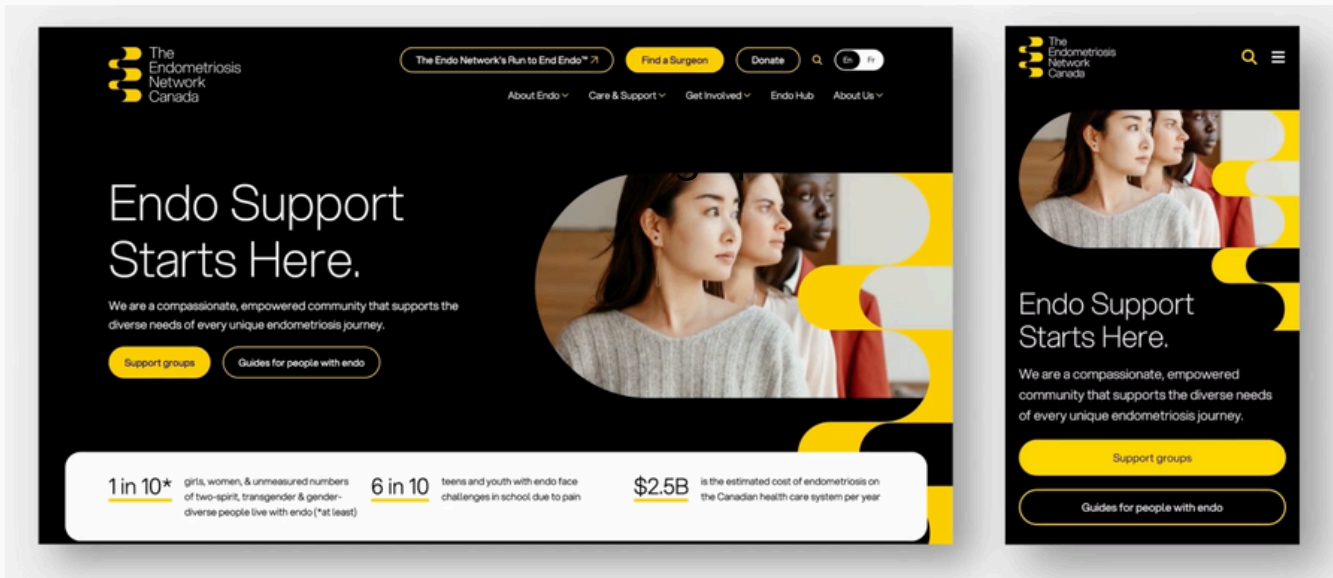
We are truly grateful for your support and belief in our mission to improve the lives of people with endometriosis in Canada. Thank you for being an essential part of our journey. Together, we are inspiring hope and changing lives.

With heartfelt gratitude,

Katie Luciani (She/Her)



Charity overview



The Endometriosis Network Canada is dedicated to enhancing the lives of individuals living with endometriosis across Canada. As a patient-centered registered charity in Canada founded in 2012, our measurable impact includes providing support and education to thousands of Canadians, developing dedicated programs for underserved communities, raising awareness, and impacting policy across Canada.

Our mission

To promote awareness, and provide inclusive education, support and resources for people living with and affected by endometriosis.

Our values

- To cultivate an inclusive community
- To facilitate compassionate support
- To enhance and encourage knowledge
- To honour the individual journey



Support

Providing essential support for people with endometriosis in Canada



This year, we continued to grow our Facebook support group, which provides a community for thousands of Canadians with endometriosis to connect, no matter where they are on their endometriosis journey—at any time, and no matter where they live in the country. The Facebook support group is moderated by incredible volunteers who help to ensure evidence-based information is shared, while providing compassionate support to members. Given the rapid growth of the Facebook support group, we plan to increase the number of moderators.

We know that connecting face-to-face can make a big difference in the endometriosis journey. We also know that for many people, in-person support groups are inaccessible because they live too far away or feel too unwell to attend. To bridge this gap, we offered bi-monthly virtual support groups facilitated by two experienced social service workers.

Navigating endometriosis is hard, and we get daily messages from people looking for information about how to get a diagnosis and care, surgical wait times, and accessing care internationally. The volume and urgency of these emails and direct messages on social media underscore the importance of our personalized responses and up-to-date resources like our *Find a Doctor* page. To make sure the responses are timely, we plan to hire an empathetic and knowledgeable administrator.

8300+

Number of Facebook support group members

24

Number of virtual support groups held

8000+

Number of visits to *Find A Doctor*

Education

Building on our success delivering evidence-based, accessible information online and in-person

For people with endometriosis

Our website provides resources to help people through their endometriosis journey. This year, there were over 75,000 website visitors representing every province and territory. Our most visited pages were *Finding A Doctor*, *Support*, *Treatment*, and *Understanding Endometriosis*. In addition, 51 medical clinics, sexual health clinics, hospitals, and community organizations serving 770,000 people registered to receive materials about our digital resources.

The continued popularity of our resources indicates that our mission to provide support and education is still critical to our community. An audit of our website found that the number of resources made it difficult to navigate, so we rebuilt the website to enhance its accessibility. The new version will launch in 2024.

We held two events this year: an in-person screening of the documentary *Below the Belt* in Ottawa with 126 registrants (partners: EndoAct Canada and the University of Ottawa Endometriosis Education Fund) and the hybrid in-person and virtual symposium *Exploring Endometriosis & Pelvic Pain from Science to Solutions* with 227 registrants (partner: International Continence Society). It was a privilege to connect with the attendees and we continue to evolve our approach to delivering this type of event in an equitable, feasible way.

For teens and youth

We expanded our educational programming to include Canadian youth by designing a free, inclusive curriculum enrichment program about menstrual health and endometriosis: *What you need to know. Period.* 71 schools, school districts, and community organizations serving 473,000 people registered to receive these materials.

Awareness

Making endometriosis part of the conversation about health in Canada

Low awareness of endometriosis makes it harder for people with symptoms to access the care they need. Our goal is to make sure that healthcare providers, teachers, and employers know about endometriosis and its impact so they can offer support.

This year, we had several earned media features, including in the Globe and Mail, Global News, and CBC Radio. We used the opportunities to bring attention to the endometriosis crisis in Canada. Most of our media appearances happened in March for Endometriosis Awareness Month, and we are exploring opportunities to grow our presence at other times of the year.

To increase awareness of endometriosis among healthcare providers, we attended the Canadian Society for the Advancement of Gynecologic Excellence (CanSAGE) annual conference for Canadian surgeons with the expertise to manage advanced endometriosis. We also partnered with CanSAGE to present about endometriosis to the Ontario College of Family Physicians for their Family Medicine Summit and the staff of Prince County Hospital. Our 2022 presentation with CanSAGE to the Family Medicine Forum was selected to be a part of FMF LOVED 2023, a online showcase of the most popular talks from the Forum.

As we do every year, we recognized Endometriosis Awareness Month by coordinating illuminations of landmarks across Canada. This year, over 60 illuminations brought attention to endometriosis, including the CN Tower, Niagara Falls, Legislative Assembly of New Brunswick, City Hall, Regina, Fraser River Footbridge, Quesnel and Prince Edward Island Convention Centre. Many thanks to everyone involved.

In addition to our regular awareness activities, we worked with a creative agency to develop *Know Endo*, our first national awareness campaign. The campaign will launch on social media, display ads, sponsored content, and influencer accounts in March 2024 and is expected to reach more than 10 million people.

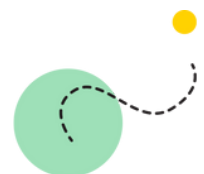
Calling on government to act on the challenges facing Canadians with endometriosis

Building on the success of the 2022 #ActOnEndo campaign—which resulted in our community sending 527 emails to all 338 Members of Parliament—we continued to work collaboratively with other organizations to advance policy action on endometriosis.

Federally, we partnered with EndoAct Canada and CanSAGE to prepare a brief for the House of Commons Standing Committee on Health, which is conducting a study on women's health. Our brief described the challenges facing Canadians with endometriosis and recommended investments in health care provider training, public awareness, research, monitoring, and access to surgical and multidisciplinary care.

Provincially, we supported grassroots activists to mobilize on endometriosis. On Prince Edward Island, we worked with Pam MacDonald and the government's Women and Gender Diverse People's Health Council to review a healthcare provider information sheet about endometriosis. In Saskatchewan, we attended meetings with the Health Minister and Deputy Leader of the Opposition alongside Tina Dolcetti.

Across Canada, we see community advocacy is moving the needle on endometriosis. In Ontario, the Opposition called for a provincial plan on endometriosis. In Nova Scotia, the legislature passed the Endometriosis Awareness Month Act. Endometriosis was the only specific condition named within the priorities of the Health Canada call for proposals for sexual and reproductive health. These are steps toward a future where Canadians with endometriosis can access the care they need, where and when they need it.



Financial update

We are proud to do work that is aligned with the values of the Canadian endometriosis community. As an organization, we do not accept sponsorship or funding from pharmaceutical companies. Before 2023, The Endometriosis Network Canada was funded solely through individual donations from the endometriosis community and private foundations.

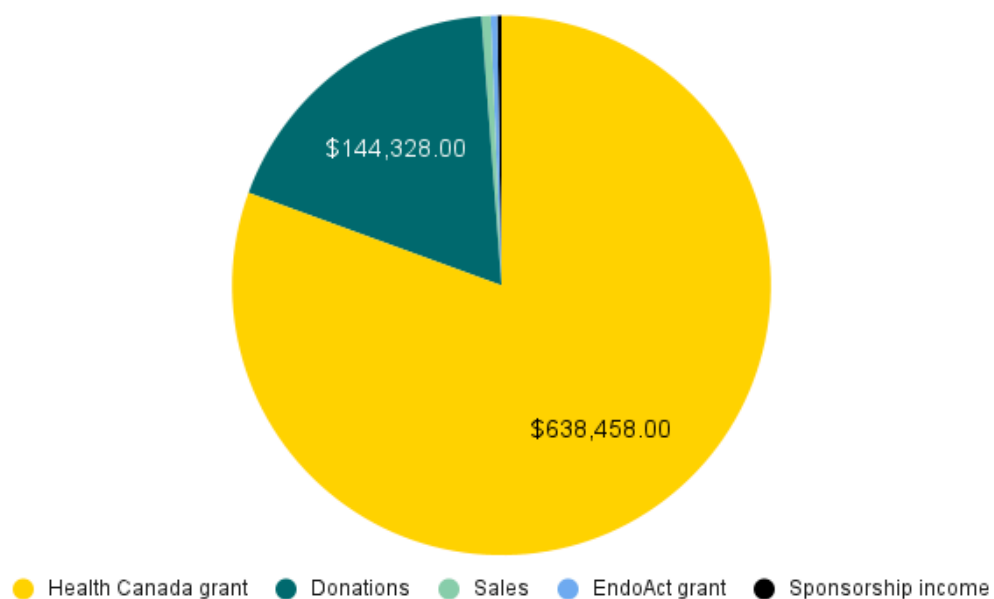
Our largest fundraising event, *The Endo Network's Run to End Endo*, is held every year in June. We were excited to expand the event to new locations, and we had in-person events in Toronto, Ottawa, Charlottetown, and Regina, as well as a virtual run, raising \$82,959.52.

In 2022, we were invited to submit an application for funding to Health Canada's Sexual and Reproductive Health Fund. In 2023, our application for the project ***Decreasing the Delay to Diagnosis: Endometriosis Education and Awareness*** was awarded funding. The project received a grant of \$874,988 and will run from April 2023 until March 2024..



\$792,518

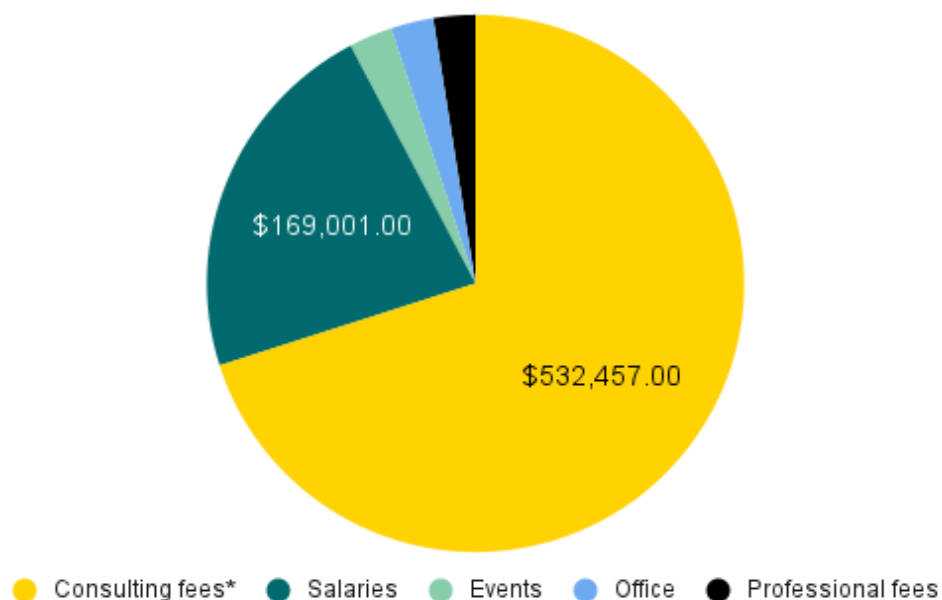
TOTAL INCOME
IN 2023



\$778,693

TOTAL EXPENSES
IN 2023

Top Five Expenses



Audited financial statements are available on request.

*98% of the consulting fees were for the Health Canada-funded project and included development of the digital media awareness campaign and associated advertising costs, curriculum development, educational resource development and outreach, and project management. These costs were defined within the scope of the approved Health Canada grant.

Future outlook

Understanding endometriosis



What is endo?

Endometriosis is a complex chronic disease that is challenging to manage and live with. It occurs when tissue similar to the lining of the uterus grows abnormally elsewhere in the body.

[More about endo](#)



Endo symptoms

Everyone's experience of having endometriosis is different, but there are common symptoms to look out for to get a diagnosis and start getting help.

[Learn about symptoms](#)



Pathways to diagnosis

There are several ways that doctors can get information that will help them make a diagnosis of endometriosis. Your symptoms, priorities, and specific needs will help you decide with your doctor how to approach investigating your symptoms.

[More about diagnosis](#)



Management options

While there is no known cure for endometriosis, there are many different management options to consider, including surgery, and medication. Holistic approaches, like how you eat, manage stress, and process difficult emotions can also help.

[Managing your endo](#)



We have so much to look forward to in 2024! We are excited to launch our new logo (previewed in this report) and bilingual website. We are making these changes to better reflect our mission and enhance accessibility for all.

In the coming year, we will also update our surgeon directory, which helps people with endometriosis find the specialized care they deserve. The update will provide more details about the surgeons who are listed, including information about their surgical management of endometriosis, their training, and the languages spoken.

Building on the success of past years, we are gearing up to host the *Run to End Endo* in new locations, as well as our virtual option, bringing communities together nationwide to support our cause.

One of our foundational goals is to raise awareness of endometriosis. We are especially thrilled to launch our pan-Canadian, bilingual digital awareness campaign, which is expected to reach over 10 million people.

With these initiatives, 2024 promises to be a transformative year as we strengthen our commitment to improving lives and driving awareness across Canada.



Thank you



The Endometriosis Network Canada wouldn't exist without the support of our community.

11 years ago, The Endometriosis Network Canada launched as a grassroots, completely volunteer-run organization. We continue to rely on our amazing team of more than 60 volunteers, including our support group moderators, teen and youth advisors, 2SLGBTQIA+ advisors, grant writers, visual content creators, event supporters, French translation team, and Endo Ambassadors. This year, we also welcomed four new team members who are working on our Health Canada-funded project.

While funding from Health Canada has allowed us to expand in an exciting way, our core support, education, awareness, and advocacy operations are driven by donations from the community. We are beyond grateful for the over 1000 donations to our organization this year, including the Ball family and long time donors Tracy Cooper and John Friedrichsen. Tracy and John's generosity since 2021 has allowed us to sustainably grow our support for Canadians with endometriosis.

Finally, thank you to the endometriosis community for continuing with us in this journey—your dedication fuels our mission and inspires hope for a brighter future for all those impacted by endometriosis. **Together, we are making a difference.**

Get involved

Every contribution makes a big difference

Your contribution offers hope and improves the quality of life for individuals living with endometriosis. With your help, we can continue to cultivate a safer and more inclusive community, and improve the quality of life for everyone affected by endometriosis in Canada.



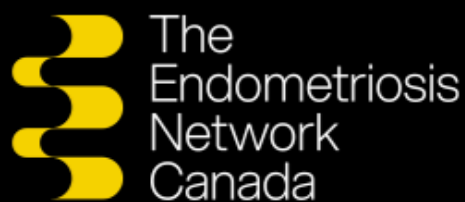
Make a donation



We do not accept funding from pharmaceutical companies. United by our vision and values, we are grateful for your support. It truly changes lives.

info@endometriosisnetwork.ca

EndometriosisNetwork.ca



The Endometriosis Network Canada acknowledges the many traditional, ancestral and unceded territories of First Nations, Inuit and Métis Peoples whose land we live, work and gather on.

Charitable Registration Number: 83997 6131 RR0001