



Impact Report 2021

Community empowerment in unprecedented times



Message from the Executive Director

Dear Friends:

Thinking back on 2021, I can't help but feel overwhelmed with emotion and filled with inspiration to have been able to experience how truly incredible this community is, especially during such unprecedented times as living through a pandemic.

Upon my return in 2021, I was grateful to be once again working alongside this incredibly special and unique team of volunteers and staff members here at The Endometriosis Network Canada (TENC). (For those who don't know, TENC is fuelled by the power of our amazing volunteers with only two part-time staff. Without the help of our volunteers, we would not be where we are today!)

An element of what makes the TENC team so special is the fact that we are a group of individuals affected by endometriosis ("endo") ourselves. We bring that lived experience to the work we do, fuelling our drive and passion to further our mission across Canada. This past year with its collective challenges highlights what TENC and the endometriosis community at large are capable of accomplishing together!

I am so proud to say that The Endometriosis Network Canada has grown over the last year as we (to name a few fundamental developments):

- Welcomed **four new board members**
- Expanded our network of support and welcomed a new support group facilitator
- Developed **new online resources** including the **2SLGBTQIA+ resource page** for patients and clinicians as well as a **comprehensive guide to disability programs across Canada**
- Established several new committees including the Grant Writing Committee and the Teen / Young Adult Advisory team
- Hosted **our annual awareness and fundraising events**, the (Virtual) EndoMarch Canada and The Endo Network's Run To End Endo™
- Hosted **an educational webinar about endometriosis care in Canada**

We'd like to invite you to join this year's The Endo Network's Run To End Endo™, taking place virtually and in person at select locations across Canada from Saturday, June 4 to Monday, June 13, 2022. As in 2021, we look forward to coming together, connecting, and raising vital awareness!

On behalf of TENC, thank you to everyone who has generously donated and supported our mission. We will continue to work hard for everyone in Canada to raise endometriosis awareness and to provide support and educational resources for those whose lives the disease touches. I look forward to another exciting year together and to sharing all of our accomplishments with you.

Sincerely,
Katie Luciani (she/her)



Photo by Jackie Gladman, EndoMarch Canada 2018, Toronto, Ontario

Mission, Vision and Values

The Endometriosis Network Canada (TENC) is a charitable, grassroots organization, founded by people with endometriosis, run by people with endometriosis, for people affected by endometriosis. We gratefully acknowledge the many traditional, ancestral and unceded territories of First Nations, Inuit and Métis Peoples whose land we live, work and gather on.

Our mission is to promote awareness while providing education, support and resources for people with endometriosis and those whose lives it touches in a safe and inclusive environment.

Our vision is to inspire hope by building an informed, compassionate, strong community. We aim to cultivate a community of hope in collaboration with the endometriosis community: endo fighters, support persons, healthcare providers, students, teachers, researchers, advocates, and more.

Our values:

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

Since its founding in 2012 until 2021, TENC has been funded entirely by individual donations. In 2021, 95% of TENC's funding was from individual donations with 5% from a grant received from the Lawson Foundation. TENC does not accept sponsorship or funding from pharmaceutical companies. The leadership team, including board members and the executive director, have no affiliations with pharmaceutical companies. You can find a complete summary of interests and affiliations for our leadership team at: endometriosisnetwork.com/interests-and-affiliations-summary



Impact Highlights from 2021

Cultivating an inclusive community

TENC believes that everyone with endometriosis should have access to timely expert diagnosis and treatment as well as to endometriosis resources and support. TENC is committed to building a community that includes and serves the needs of everybody with endometriosis in Canada, with a focus on communities that have been disinvested, as well as historically and intentionally excluded. These include: Black, Indigenous, Asian, Filipino, Arab, Hispanic, Latine, Latinx, multi-racial, and other non-white populations, 2SLGBTQQIA+ communities, rural communities, isolated communities, and newcomer communities.

To work towards equity in the diagnosis and treatment of endometriosis in Canada, TENC has launched the Endo Ambassador Program, an outreach initiative designed to help give a voice to the needs of these communities, and to help inform the development of further endometriosis support and educational resources based on their unique needs. We are excited to grow our resources to serve these communities by listening to what they need and taking action.

Facilitating compassionate support

TENC was founded by a group of people with endometriosis who met at a support group and quickly realized that being in the same space as others who understand the challenges of living with the disease is critical for combatting the feelings of isolation and despair that endometriosis can cause. As such, providing support in a compassionate and inclusive environment has always been a key part of TENC's mission.



With a support community of over 7500 people and growing daily, we understand that people are coming from different places in their endometriosis journey, from different backgrounds, in different parts of the country, and have their own individual goals and preferences. Empathy requires us to try and understand the thoughts and feelings of others, even if we ourselves think and feel differently. At TENC, we are committed to providing safe spaces where people can respectfully disagree with each other while still being kind.



Denise Campbell

(she/her)

Relation to TENC: Board Director

Relation to the endo community: diagnosed with thoracic, umbilical endometriosis and catamenial pneumothorax

"I had never heard of this chronic and debilitating disease until I was diagnosed in 2016 after a one-week stay in the hospital in December 2015. I sent an email to TENC in March 2016 in desperate need of help. I was having a tough time with both emotional and physical pain. The fantastic Katie M. responded the same day and encouraged me to attend the Toronto Endometriosis Support Group. Once-strangers who became my circle of support and cared for me intensely!

I received a free, world-class education, with resources and unconditional support as well as guidance from a support group. I know it sounds unbelievable but it's true. I was sad, lost and felt like my world was turned upside down. I lost my sense of self, and I wished that I met these remarkable people before starting my treatment plan.

I'm sure I would have gone into a deep depression without the TENC support group. TENC's board members and facilitators like Philippa, Katie L, and Jan encouraged and empowered me to take good care of my health. They helped me to stop glorifying work and prioritizing my career over my health and well-being. **Because of TENC, I no longer feel alone, I don't live in silence, and together we are advocating for systemic change. These real-life superheroes saved my life!"**

Stories of Impact

Stephanie

(she/her)

TENC Volunteer

“I began engaging with TENC nearly six years ago when I was first diagnosed with endometriosis and I have been a volunteer with TENC for over four years. Volunteering and being involved with TENC has given me the opportunity to participate in countless opportunities and events to raise awareness, including being a virtual support group and illuminations team volunteer. It has also allowed me to connect with so many dedicated and incredible people.

TENC has been an instrumental part of my support system and has helped me find meaning in my life. Having an organization like TENC in Canada provides not only resources and education, but the support needed throughout your endometriosis journey.”

Josef

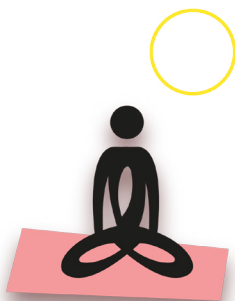
(he/him)

Husband of Stephanie

“TENC has given Stephanie the knowledge and guidance she needs to understand her endometriosis diagnosis and the ability to connect with others in the endometriosis community. This has provided her with a source of mutual support that she can’t find elsewhere.

I have seen how happy being involved with TENC has made her and it has given her a sense of purpose that she has not had since being unable to work. The friendships and connections she has made have given us the strength and support we need to get through the challenges that we face.”

In 2021, TENC’s wellness workshops reached over 370 individuals living with endometriosis.



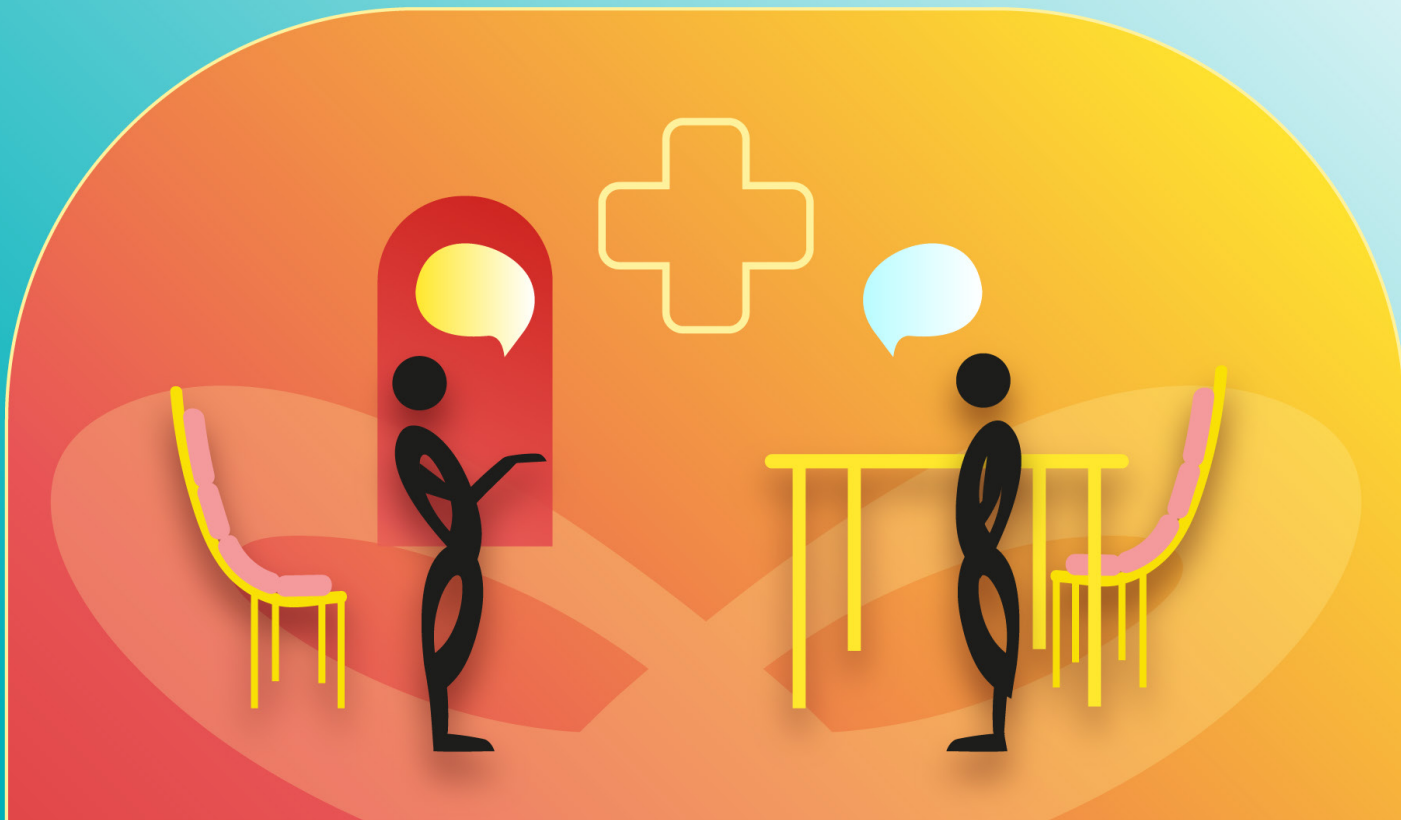
Laurelle Fullan

(she/her)

Yoga Instructor for the monthly Restorative Yoga for Endometriosis workshops

“I’ve been involved with The Endometriosis Network Canada community since 2019, teaching yoga geared towards those who live with endometriosis. The community has always been a huge support for me and my own endo journey, and it only continues to be a bright light. The members are incredible; I’ve never experienced a more welcoming community.

This organization is so important for those suffering with endometriosis, because it can feel so isolating and you can often feel misunderstood by friends and family. Talking and surrounding yourself with individuals who are going through what you are going through is incredibly impactful. I am so grateful I found this space.”



Enhancing and encouraging knowledge

The era of patients not having any agency over their own healthcare decisions is over (even if not all physicians realize it yet)! Patients should be respected as partners in decision-making about their healthcare. TENC firmly believes that informed patients are empowered to make decisions about their own health.

Having access to accurate information is essential to informed participation in your own healthcare decisions. In 2021, our online resources were accessed by over 40,000 people in Canada. At TENC, we aim to follow the science and peer-reviewed, published evidence, while acknowledging that for endometriosis, there are gaps in the scientific literature where more research is needed.



Erin Ball

(she/her)

Person living with endometriosis

“I found TENC at one of the most difficult and scariest points in my life; after almost a decade of questions and pain, my doctor had finally suggested endometriosis. TENC didn’t just fill in the information gaps for me. They also provided me with a community and an assurance that, while this condition can feel isolating, I was not alone. **TENC’s resources and events are absolutely critical to Canadians with endo, and the positive impact TENC has had on my life is immeasurable.**”

Honouring the individual journey

Although there are many commonalities in the shared experiences of endometriosis, each person experiences the disease differently. From the variety of possible body-wide and systemic symptoms, to the communities we live in, to our personal goals and preferences for managing the disease - as well as its various comorbid conditions that often come in tandem, each individual's journey is unique.

TENC has the utmost respect for everyone who is dealing with endometriosis in their own way and we are honoured to be alongside you in your journey. We are perpetually inspired by the strength and perseverance of every endo warrior in the community.



Nevan O'Grady

(she/her)

Member of the TENC Teen/Young Adult Advisory Committee / Endo Warrior

"I have been an active member in TENC since 2015, and as of 2021, I have been volunteering with TENC to provide better support for teens and young adults struggling with endometriosis.

TENC is the very reason I received my endometriosis diagnosis after nine years of fighting for it. I came across them in 2016 as a 15-year-old girl severely struggling, completely isolated with little to no information about endometriosis, no diagnosis, and not knowing a single soul who was "like me".

TENC completely changed my life. From meeting people who shared my exact experiences and stories, to people who were able to educate me and help steer me in the direction of doctors and next steps, to lifelong friends. Organizations like TENC are incredibly important as they pave the way for better care, support, and treatment for those battling endometriosis."

The Virtual EndoMarch Canada 2021 reached over 6,100 people and has since received over 1,600 views.

Relive the experience, or watch for the first time, by clicking on the image to the right >



Share how you're celebrating this EndoMarch by tagging:

#VirtualEndoMarchCanada

endometriosisnetwork.com



“ Living with endometriosis can be so isolating and most of the time, very challenging. Having events that help bring community members together and out of their isolation can be life-altering. ”



- KATIE LUCIANI

What to Expect in 2022

Reflection, learning, growing

Highlights of what's to come:

- The Endo Network's Run To End Endo™
- The first-ever Patient Education Day event in collaboration with the Canadian Society for the Advancement of Gynecologic Excellence (CanSAGE)
- Town hall meetings to discuss the needs of endometriosis patients in various regions in Canada
- TENC's Endo Ambassador Program
- Expanding accessibility with ongoing French translation work of resources
- Celebrating 10 Years of TENC

2022 is filled with opportunities for growth and expansion, and TENC is focused on taking the time to reflect, learn and grow as a team, an organization and as members of the endo community alongside you.

Full steam ahead, we are looking forward to hosting The Endo Network's Run To End Endo™, our annual awareness and fundraising run taking place virtually and in person at select locations across Canada from June 4 to 13, 2022.

For educational events, TENC's first-ever Patient Education Day in collaboration with CanSAGE is coming up in June 2022. We are also committed to offering virtual town hall meetings to discuss the unique needs of endometriosis patients in various regions across Canada.

As always, we are dedicated to creating safe spaces that are inclusive, compassionate and accessible to all. In addition to the ongoing development of the Endo Ambassador Program and growing our volunteer team, we are working to improve the accessibility of our resources for everyone in Canada through their translation into French.

TENC is thrilled to announce that 2022 marks our ten-year anniversary, and we look forward to celebrating with you! As we reflect on our first ten years as an organization, we are beyond grateful for everything we have been able to accomplish with the help and support of our volunteers and donors.

We are excited to experience what the next ten years will bring; what we will build together as the strong, informed, compassionate community we are; and the hope that comes with all of this.



Deanna Buttar

(she/her)

Endo advocate / patient

“TENC provides a trusted and inclusive environment that plays a pivotal role for those navigating endometriosis. TENC’s support gave me the motivation to get involved with The Endo Network’s Run To End Endo™. **There are far too many Canadians struggling and I believe it’s important to help the organization that is helping us. Change is vital; TENC is making that possible.**”



In Gratitude

We extend an immense thank you to all our donors for your support in 2021 and in years past, with special mention of:

- The Cooper-Friedrichsen Family
- The Lawson Foundation

To the wonderful individuals who make up TENC's team through volunteer and paid work:

- Bre Neufeld
- Ashley Barrett
- Taryn Linder
- Jane Walker
- Felicity Miller
- Leitz Facunda
- Nevan O'Grady
- Cassandra Earle
- Freya Blackie
- Madelaine Sallie
- Olivia Carriere
- Shay Freger
- Rachel Howard
- Kayla Penteliuk
- Hannah Young
- Amanda Gullace
- Paige Heffler
- Eden Bridge-Cook
- Stephanie Pezzimenti
- Nick Austin
- Shannon Philion
- Laurelle Fullan
- Heidi Lynch
- Roop Bassra
- Ashley Page
- Mary Luciani
- Alissa Santiago
- Marie-Josée Thibert
- Sevrina Haskett
- Stephanie Nikolich
- Guido Luciani
- Yvonne Murray
- Maia Leggot
- Mary Zawadzki
- Terris Schneider
- Kirsten Langereis
- Magali Gréani
- Noelle Solange Didierjean
- Kait Graham
- Meghan Marie Gates
- Alison Stark

To members of the 2021 TENC Board:

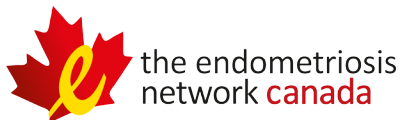
- Philippa Bridge-Cook
- Laura Diebolt
- Katie McLeod
- Alexis Nikolich
- Nelly Faghani
- Denise Campbell
- Desiree Lillie Adams
- Jennifer Wolter
- Michelle Avery

A special thank you to Jan Silverman for dedicating over 20 years to facilitating life-changing support groups for people with endometriosis and for supporting TENC's efforts from the very beginning. We will always have a special place in our hearts for you and everything that you have done for endometriosis awareness here in Canada.




Additional Notes

For the first seven years since its founding in 2012, TENC was entirely run by a team of dedicated volunteers, most of whom live with endometriosis. In 2019, TENC welcomed two part-time staff members who also live with the disease, to help further the support, educational and awareness initiatives, including the development of online resources, that TENC provides to people across Canada.

We extend our sincere gratitude to all who have dedicated their time and efforts to improving the lives of people with endometriosis.



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