

A LETTER FROM THE **CEO AND BOARD CHAIR**





CLAUDIO GROSSI I Board Chair

Working Together

Thanks to the dedication of the Lymphoma Canada team as well as the Board of Directors and advisory bodies, 2022 was about being resilient together and building a stronger lymphoma community for all Canadians impacted by the disease.

In 2022 we worked at establishing relevant objectives as an organization that focused on empowering patients and the lymphoma community. With each new resource we developed, educational webinar we held, support group we hosted, peer mentorship relationship we forged, patient voice we amplified, and research grant we awarded, Lymphoma Canada continued to grow as the Canadian leader in the lymphoma space — the only national charity focused solely on lymphoma.

In 2022, our goals were many, and we are so thrilled to share with you in this report our accomplishments. Not only did we see a growing online audience in 2022, but we also disseminated more Hodgkin lymphoma, Non-Hodgkin lymphoma, and Chronic Lymphocytic Leukemia Patient Guides and other patient resources than ever before. Our collective team continued to understand the challenges and unmet needs of the patients we serve and to respond to each of the needs identified.

We could not have accomplished what we have without your ongoing support. We would like to extend our thanks to our donors, supporters, sponsors, and volunteers whose generosity and contributions of time, dollars, and skills make our work possible. It is only through our collaboration that we continue to build a strong lymphoma community.

As we near the end of 2022 and look to 2023, we look forward to celebrating the 25th anniversary of Lymphoma Canada. Our history has provided the solid foundation upon which we can base our future.

Our Vision

Life unlimited by lymphoma.

Our Mission

Empower patients and the lymphoma community through education, support, advocacy and research.

BOARD & COMMITTEES

Empowering patients and the lymphoma community.

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ABOUT US

For more than two decades, Lymphoma Canada has been serving the lymphoma community, and 2022 has been a year of achievements for the organization.

As the only national Canadian organization focusing entirely on lymphoma, our mission is to empower patients and the community through education, support, advocacy, and research. We strive to create a community of support and understanding for those affected by lymphoma and to provide resources and information to help them make informed decisions about their care. We also fund lymphoma-related research studies that can improve the quality of life for those affected by the disease.

Over the past year, we have made significant strides in our mission to provide education and resources to those affected by lymphoma. We have disseminated over 4,700 resources free of charge to hospitals and cancer centers across Canada; this is the highest number of resources we have ever shared. Additionally, we hosted our National Conference over three days, with over 600 registrants attending and expert speakers presenting on new and relevant lymphoma and Chronic lymphocytic leukemia (CLL) topics. We participated in all patient submission opportunities concerning lymphoma and CLL therapies to the Canadian Agency for Drugs and Technologies in Health (CADTH) and the Quebec equivalent Institut national d'excellence en santé et services sociaux (INESSS). We received several excellent research award applications in 2022 and awarded two research grants.

We are proud to have supported thousands of individuals and families affected by lymphoma. We are grateful for the generous support of our donors, volunteers, and partners, without whom none of this would have been possible.

We look forward to continuing our work in the coming years and to making a positive impact on the lives of those living with lymphoma.

From all of us at Lymphoma Canada, thank you for your continued support.



PROVIDING EDUCATION

Your donations give lymphoma patients and caregivers access to easy-tounderstand educational materials tailored to the Canadian healthcare system.



OFFERING SUPPORT

Your contributions allow us to provide a safe space for patients, family members, and caregivers, to share their experiences about lymphoma.



ADVOCATING FOR PATIENTS

Your gifts allow Lymphoma Canada to advocate for lymphoma cancer patients and their families for equitable access to innovative therapies in Canada.



RESEARCHING LYMPHOMA

Your donations fund research dedicated to improving health outcomes for lymphoproliferative malignancies in Canada.



We are stronger when we work together. Your generous contributions of time, skill, and action have empowered us to amplify the voices of those impacted by lymphoma!

VOLUNTEER

Lymphoma Canada seeks enthusiastic volunteers to join our team and help in all facets of what we do. If you are eager to make a difference, we would love to have you with us!

SIGN-UP

Sign up to stay informed about the latest news, media updates, and other announcements from Lymphoma Canada by subscribing to our e-newsletter.

TAKE ACTION

At Lymphoma Canada, we depend on the kindness of donors, sponsors, and volunteers to provide us with ongoing support so that we can continue our services for patients and the lymphoma community. Act now by donating, participating in our patient surveys, signing up for our peer-to-peer support program, volunteering at an event, and or registering for our Laps Around Lymphoma fitness challenge.

THANK YOU!

We are grateful to our generous donors, sponsors, professional healthcare partners, and committed volunteers for their support in helping us provide care and assistance to lymphoma patients and their families. Your dedication has enabled us to be there for them in their time of need.

Your messages of appreciation are testimonies to the impact we have made. We are grateful for your support and are proud to share these messages.



Lymphoma Canada gave us options and hope.

Although we didn't get the result we wanted, I can't imagine having gone through the experience without the support and expertise offered by Lymphoma Canada.

- Anonymous



Grateful that Lymphoma Canada's patient conference exists. I don't feel so alone when I see how many other people there are with similar problems.

- Anonymous





Lymphoma Canada's webinars are very informative and do help me better understand the disease and treatments available. They also help the communication between my treating oncologist by my better understanding of the treatments involved, which in turn means that I can ask specific questions relating to my case. It encourages me to play an active part in my well-being.

- Carmen



I don't know what I would have done without the support from Lymphoma Canada. There was nothing I could do about my lymphoma diagnosis, but their educational resources were a huge help in learning about available treatment options.

- Anthony



PATIENT AND CAREGIVER EDUCATION

Whether you have been diagnosed recently, are currently undergoing cancer treatment, or are a survivor of lymphoma, Lymphoma Canada has many resources to support you and your loved ones. Every year, we provide Canadian-specific information to lymphoma patients and their caregivers to help them navigate the physical and mental health challenges they may experience. This information is accessible to all lymphoma patients across Canada and provided in both official languages, English and French. Patient resources and educational content can be found on our website.



PATIENT RESOURCE MANUALS

Every year, Lymphoma Canada ships patient resource manuals to cancer centers and hospitals across Canada to serve lymphoma patients in each province. The patient resource manuals are a helpful reference for patients who are newly diagnosed and want to learn more about the treatment options available for their lymphoma subtype. In 2022 we had an overwhelming number of requests and disseminated over 4,700 printed manuals and resource materials free of charge. Moreover, we developed a new educational guide called "Watch and Wait" for lymphoma patients that do not require immediate treatment. This reference, along with many others, such as *Life Beyond Lymphoma*, *Living with Lymphoma Brochure*, and *Side Effect Fact Sheet*, are available on our website lymphoma.ca/resources.



WATCH & WAIT GUIDE

In 2022 Lymphoma Canada developed a new educational resource for those diagnosed with slow-growing lymphomas. Patients diagnosed with CLL and some NHL subtypes often do not require immediate treatment as they do not experience any physical symptoms at the time of diagnosis. For many lymphoma patients, the "watch and wait" approach can be confusing or a time of high anxiety. To learn and help others understand why monitoring symptoms can be more helpful than receiving treatment, please read our Watch and Wait Guide.

EDUCATIONAL SERIES

For the first time, Lymphoma Canada hosted two educational series in 2022 for our lymphoma & CLL community. The two educational series consisted of three back-to-back webinars related to two subject areas. The first series focused on Novel Lymphoma Therapies, and the second series was on Lymphoma in the Adolescent and Young Adult (AYA) Population. In the Novel Lymphoma Therapy series, three wonderful educational webinars were hosted on Precision-based Medicine, Bispecific Antibody Therapy, and CAR T-cell Therapy. In the second educational series, Lymphoma in the AYA Population, we provided tailored information and support to young people living with lymphoma. In this series, disease-specific information regarding diagnosis, treatment, and follow-up care was provided in two of the educational webinars. Additional support was provided to patients in the third webinar, which focused on mental health challenges for AYAs living with lymphoma.

ANNUAL NATIONAL PATIENT CONFERENCE

This year's National Patient and Caregiver Conference was the most well-attended conference Lymphoma Canada has hosted to date. Over 600 participants registered to attend the conference virtually from the comfort and safety of their own homes. This conference, held over three days in October, brought together numerous hematologists, oncologists, and lymphoma specialists to speak about treatment-specific information, clinical trials, the latest advancements in lymphoma research, and survivorship topics of interest. Recordings of the entire conference are available on our website.

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WEBINARS & EDUCATIONAL FORUMS

Lymphoma Canada hosted numerous virtual webinars in 2022 for lymphoma patients and their caregivers. These sessions were held in both official languages and led by lymphoma specialists from across the country. Attendees learned about relevant and specialized topics, including Watch & Wait for Lymphoma, Integrative Cancer Care, and How to Help Yourself as a Caregiver and a Patient. Webinar recordings can be accessed on our website under the "Resources" section.

SUPPORT FOR PATIENTS, FAMILIES, AND THEIR CAREGIVERS

Lymphoma Canada offers a variety of support programs for lymphoma & CLL patients and their caregivers. We provide our community the opportunity to connect with other individuals who have had a similar lymphoma experience via a peer-mentoring program and a monthly support group. Lymphoma Canada provides further support to patients by answering questions via phone or email and directing them to information, resources, and connections that help them to cope at any stage of lymphoma.

LYMPHOMA LINKS PEER-MENTORSHIP PROGRAM

In 2022, Lymphoma Canada updated our 1-on-1 peer support program for lymphoma patients and their caregivers. We frequently hear of the benefits patients receive from speaking with someone who has lived a similar lymphoma journey. Connecting with someone who knows what it is like to live with lymphoma helps reduce feelings of isolation. In our "Lymphoma Links" mentorship program, patients and their caregivers can apply to be a mentee, someone requiring help with their lymphoma diagnosis, or a mentor, someone giving support based on their lymphoma experience. To apply, please follow this link: Lymphoma Canada Peer-to-Peer Mentorship Program - Lymphoma Canada.

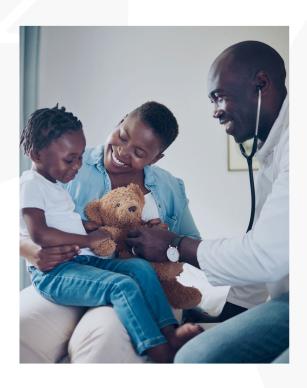
ONLINE SUPPORT PROGRAMS

Lymphoma Canada provides information for patients and caregivers in numerous ways, including email, by phone, and a virtual monthly support group co-hosted with Wellspring Young Adult Program, a Canadian non-profit that provides cancer support. These points of contact offer a friendly and safe environment for patients and their caregivers to receive the help and support they need. For more information, please visit our website, lymphoma.ca/resources/support.

ADVOCATING FOR EQUAL ACCESS **TO EFFECTIVE THERAPIES**

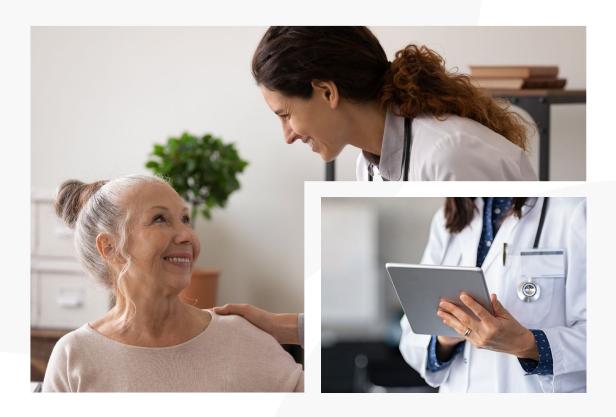
Lymphoma Canada is committed to improving outcomes for lymphoma patients by advocating for equal access to innovative therapies across Canada. We believe that every lymphoma patient should have the care and treatments they need to thrive. We provide decision-makers with objective and evidence-based patient feedback submissions on all emerging lymphoma and CLL therapies that are being assessed for public funding in Canada.

In 2022, Lymphoma Canada completed two advocacy campaigns on behalf of lymphoma patients and their caregivers. The first initiative involved drafting a letter submitted to the National Advisory Committee on Immunization, alongside other non-profit organizations, to formally recognize lymphoma and CLL patients as immune-compromised before, during, and after treatment. In 2022 Lymphoma Canada also advocated for equitable access across Canada to CAR T-cell therapy for mantle cell lymphoma patients.



CADTH & INESS SUBMISSIONS

In Canada, lymphoma therapies are approved on a federal basis by Health Canada. When a novel treatment is submitted for review, two non-profit organizations are responsible for reviewing the economic, clinical, and perspectives of the drug for the patient population it serves. The Institut national d'excellence en santé et en services sociaux (INESSS) is responsible for Quebec residents, and the Canada's Drug and Health Technology Agency (CADTH) for all other provinces. Lymphoma Canada helps elevate the patient's voice by creating and promoting patient experience surveys for all lymphoma drugs and treatments up for approval by CADTH and INESSS. These surveys are disseminated through our national emailing list. For more information, please contact info@lymphoma.ca. The input we receive from patients' responses provides vital information for decisionmakers as they determine which therapies to fund.



UPDATE TO NATIONAL CLL FRONTLINE TREATMENT GUIDELINES

Chronic lymphocytic leukemia (CLL) is the most diagnosed form of lymphoprofilerative disease in North America. In 2018, Lymphoma Canada led a project which resulted in the development of the first unified national guideline for the front-line treatment of CLL. National guidelines help provide healthcare professionals with a standardized, evidence-based approach to CLL treatment. In 2022, Lymphoma Canada and a group of Canadian clinical experts updated the guidelines to include new and innovative therapeutic options for CLL patients in the front-line setting. Recommendations were provided based on the review of available evidence for the first-line treatment of CLL.

LYMPHOMA RESEARCH & DISEASE AWARENESS

Lymphoma Canada is committed to improving outcomes for lymphoma and CLL patients by investing in well-defined research studies that have the potential to effect improvements in healthcare, health systems, and health outcomes as they pertain to malignant lymphoproliferative diseases.

2022 LYMPHOMA CANADA RESEARCH GRANT

This year several fantastic research grant applications were received. Our research grants are provided to Canadian researchers to support small, well-defined research studies that have the potential to effect improvements in healthcare, health systems, and/ or health outcomes as they pertain to malignant lymphoproliferative diseases.

Recipients of the 2022 Lymphoma Research Grant include:

Dr. Kerry Savage BC Cancer, BC

Dr. Savage's research focuses on the study of nodular peripheral T-cell lymphoma to describe the clinical presentation and outcome of this rare lymphoma subtype.

Dr. Abi Vijenthira University of Manitoba, MB

Dr. Vijenthira's research focuses on the risk of developing secondary cancer for Chronic Lymphocytic Leukemia patients treated with chemoimmunotherapy treatment in comparison to those treated with novel therapies.



PARTNERSHIP WITH LYMPHOMA PATIENTS TO RAISE FUNDS FOR RESEARCH

Throughout 2022, more than \$25,000 was raised to support well-defined Canadian research projects. Gilles and Larry, two lymphoma patients, shared their stories to raise awareness of the importance of an ongoing need for research funds that could potentially improve patient outcomes.





WORLD LYMPHOMA AWARENESS DAY

On World Lymphoma Awareness Day, Lymphoma Canada illuminated more than 30 monuments nationwide to raise public awareness of lymphoma cancer. This day also marked the start of our third annual Laps Around Lymphoma event, where Canadians from across the country raised awareness and funds to support the lymphoma community.



Nathan Phillips Square, Toronto, ON



Vancouver Convention Centre, Vancouver, BC

VOLUNTEER **SPOTLIGHT**







HOST A FUNDRAISER

Consider hosting a fundraiser for Lymphoma Canada to raise awareness and support for those affected by lymphoma. Your gifts provide reliable Canadian lymphoma and CLL resources free of charge for patients and caregivers.

For more information on how to host an event in support of Lymphoma Canada, visit: www.lymphoma.ca/get-involved/host-a-fundraising-event.

LYMPHOMA CANADA'S GOLF COMMITTEE

Claudio Grossi

Sam Sapera

Anthony Iozzo

Kathy Sotirakos

Cary Chapnick

Nadim Youakim

Par for the Cure 2022

Since 2011, Lymphoma Canada has hosted its annual Par for the Cure golf tournament in the Greater Toronto Area. Over this time, the golf tournament has raised awareness about lymphoma and generated funds to support Lymphoma Canada's mission and the patients we serve. These tournaments were only possible with our volunteer golf committee, who selflessly give their time yearly.

The golf committee members put in a significant effort to make these golf tournaments successful. They help plan the event, obtain sponsorships and donors, and ask their friends, family, and colleagues to register and play golf to support Lymphoma Canada.

Thank you, Claudio, Sam, Anthony, Kathy, Cary, and Nadim, for your contributions to the 2022 Par for the Cure golf tournament. We so value and appreciate your continued commitment to the values and mission of Lymphoma Canada.

With the support and contributions of volunteers like the golf committee, Lymphoma Canada can advance its mission year after year.

PATIENT **SPOTLIGHT**



GILLES

For lymphoma patients like Gilles, a mantle cell lymphoma patient, the availability of treatment options like CAR-T (Chimeric Antigen Receptor T-Cell) therapy is essential and potentially transformative.

Gilles' cancer journey began in 2017 following some mild but unsettling symptoms, weight loss thought to be caused by leading a healthier lifestyle, night sweats, and pain in his neck and shoulder that led to the discovery of some lumps. He had been experiencing these symptoms for about a year, but he and his wife Francis had attributed them to other causes.



Only when I had found the lumps did I know something was serious and booked [Gilles] a doctor's appointment the next day. - Francis



Gilles was sent for blood work and then referred to an ear-nose-throat specialist by his family doctor. The specialist felt Gilles' neck, stepped back, and said very matter-of-fact, "you have cancer," and referred him to oncology. There was no further explanation – Gilles and Francis were shocked.

Gilles was referred to an oncologist at a cancer centre who determined, after a biopsy, that he had mantle cell lymphoma, a highly aggressive cancer. He could not wait a day longer to receive treatment. He needed it now. There were not many treatment options available for mantle cell lymphoma, and Gilles and Francis were told what the treatment plan would be.

To receive treatment, they would have to travel to a cancer centre, the closest of which was 220 km away. The trip took a toll on Gilles. On arrival, he had jaundice and felt extremely unwell. However, Gilles needed to begin treatment immediately. He was provided with a combination of chemotherapy and immunotherapy. The immunotherapy, unfortunately, led to a severe reaction. His temperature skyrocketed, his blood pressure increased, his heart rate became irregular, and he began having extreme rigors (shaking). This was incredibly challenging for Gilles and Francis.

Gilles had to stop treatment temporarily, wait until he recovered, and then try again. Thankfully things went smoother the second time around. Again, there was not a cancer centre close enough that could conduct the procedure, so Gilles and Francis had to travel over five hours by airplane and car to come to Toronto.

In April 2018, Gilles' stem cells were collected, which was an intense process. It took nine days of continuous collection to obtain enough stem cells for the treatment. He then had a Hickman line placed to prepare for the transplant, which would take place at Gilles' local hospital. Unfortunately, there was an accident with a dressing change, and an infection was introduced. Gilles had to have his Hickman line removed, and the transplant was delayed while he recovered with antibiotics.

After another trip to Toronto to re-install the Hickman line, Gilles was finally able to start his stem cell transplant in July. Following the stem cell transplant, he lost 45 pounds. The mouth sores were awful, food tasted terrible, and everything smelled bad. After the transplant, Gilles began maintenance therapy to help the transplant succeed and prevent relapse. Thankfully this worked for almost two years, but then he began to have severe abdominal pain. A CT scan later revealed a mass the size of a softball. Gilles felt so down; he had been in remission and now had to start all over again with treatment.



We were so afraid there would be no treatment options left for us to try. Our oncologist introduced us at this time to the possibility of CAR-T therapy. We went online to learn more about this therapy, and hope crept into our hearts.

- Francis



Despite significant delays and challenges with therapy, Gilles and Francis both remain optimistic about CAR-T therapy and the potential holds for the treatment of mantle cell lymphoma.

By sharing your story, you'll help raise awareness of lymphoma and provide comfort to others going through similar experiences.

DONOR **SPOTLIGHT**

We are appreciative of all those who support Lymphoma Canada in achieving our mission, and we recognize that philanthropy is a crucial factor in helping to improve the lives of those affected by lymphoma.

TEAM COURAGE

We would like to thank Jenna Courage Baz and Team Courage for supporting Lymphoma Canada through their participation in the Oakville Half Marathon. Team Courage completed the half-marathon in honour of Todd Courage, who is currently undergoing chemotherapy for Non-Hodgkin's Lymphoma. Through the marathon, the team raised more than \$10,000 in support of Lymphoma Canada. The efforts of proud supporters like Jenna and Team Courage make it possible for us to continue advancing our mission to empower the Canadian lymphoma community.

Thank you, Jenna and Team Courage, for your support in honour of Todd Courage.

EVENT SPOTLIGHT

LAPS AROUND LYMPHOMA

This annual fitness challenge was hosted virtually across Canada to raise awareness and funds for lymphoma-related programs and resources. Throughout the 16-day challenge, participants are encouraged to take 100,000 steps in honour of the more than 100,000 Canadians living with lymphoma.

This year marked the third year of the Laps Around Lymphoma challenge, during which participants took a cumulative 8,207,313 steps and raised over \$100,000.

Thank you to our sponsors for making this day possible:

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Education Sponsors







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PAR FOR THE CURE

This year, Lymphoma Canada hosted its 11th annual Par for the Cure golf tournament. Thanks to the generous support of golfers, donors, and sponsors who participated, the event was a big success.

Through the tournament, we raised more than \$63,000. The proceeds from Par for the Cure will enable us to continue providing services to patients and their families through education, support, advocacy, and research.

Thank you to our sponsors for making this day possible:

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UPCOMING **2023**

In 2023, Lymphoma Canada will celebrate its 25th anniversary. Over the past two and a half decades, we have been dedicated to empowering patients and the lymphoma community. We are proud of the progress we have made and the services we have provided.

Throughout the year, we will share stories from our founding members, volunteers, supporters, and patients impacted by Lymphoma Canada. We will also share information about our ongoing contributions to lymphoma research and patient education.

Celebrate this milestone with us; please visit 25th Anniversary

We are committed to providing educational resources and opportunities to lymphoma patients and caregivers, maintaining our support programs, advocating for lymphoma patients and caregivers, and funding Canadian research in 2023.

To support Lymphoma Canada, please visit lymphoma.ca/donate

December 31, 2022, audited financial statements are available at **lymphoma.ca**La version française du rapport annuel est disponible.



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