



# CONNECTING WITH PATIENTS

2021  
ANNUAL  
REPORT

*A Year of Community Empowerment*

| Education | Support | Advocacy | Research |



LYMPHOMA  
CANADA

# A LETTER FROM THE CEO AND BOARD CHAIR



*Antonella Rizza*

**ANTONELLA RIZZA**  
CEO



*Claudio Grossi*

**CLAUDIO GROSSI**  
Board Chair

## Words of Gratitude

The COVID-19 pandemic has continued to amplify public health concerns around timely and effective access to treatments and innovative therapies. Many patients and caregivers faced difficulties, including accessing adequate information, lack of consistent follow-up care or management, increased isolation and mental health impacts, and reduced availability of support services throughout the pandemic.

At Lymphoma Canada we believe that interconnectedness is the key to overcoming many of these issues. That is why we have worked tirelessly to disseminate a wide range of resources that bring Canadians together and help to improve patient outcomes. We have prioritized the connection of patients, caregivers, and their families with one another via support groups and peer to peer programs.

This year, we focused on supporting the lymphoma community through virtual educational forums, our annual patient and caregiver conference, and webinar series where individuals gain access to first-hand learning opportunities with lymphoma experts. We have disseminated upwards of 11,500 copies of patient resources in both official languages in print and digital formats. We advocated for equitable access to lymphoma and chronic lymphocytic leukemia (CLL) therapies across all provinces and where there are provincial funding delays, and lobbied for priority access to COVID-19 vaccines for lymphoma and CLL patients and their caregivers.

Our accomplishments in 2021 highlight the strengths of our community and the impact of your support. We cannot thank you enough for standing with us to further lymphoma education, support, advocacy and research for Canadians. **For this, we thank you.**

### 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.*

## 2021 Board of Directors

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## LYMPHOMA CANADA ANNOUNCES APPOINTMENT OF HOCKEY LEGEND, PAUL HENDERSON, TO HONORARY GOVERNORS



Lymphoma Canada announced the appointment of Paul Henderson to our Honorary Governors. Mr. Henderson has served as an ambassador of Lymphoma Canada for over eight years. He has participated as a celebrity representative for the 2017 Creighton Classic Par for the Cure, shared his patient story in a Canada-wide mailing to raise funds for lymphoma research, and participated in advocacy efforts to have the Ontario government assist with funding take-home cancer medication for lymphoma patients. He is best known for leading Team Canada to victory at the 1972 Summit Series against the Soviet Union. Paul has now been living with chronic lymphocytic leukemia (CLL) since his diagnosis in 2009.



## Scientific Advisory Committee

**Dr. John Kuruvillea** | *Chair*; MD, FRCPC  
Princess Margaret Cancer Centre  
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Saskatchewan Cancer Agency  
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**Dr. Graeme Fraser, MD, FRCPC**  
Juravinski Cancer Centre  
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Princess Margaret Cancer Centre  
Toronto, ON

**Dr. Jean-Francois Larouche, MD, FRCPC**  
Centre hospitalier affilié universitaire de  
Québec Québec, QC

**Dr. David MacDonald, MD, FRCPC**  
The Ottawa Hospital  
Ottawa, ON

**Dr. Tony Reiman, MD, SM, FRCPC**  
Saint John Regional Hospital  
St. John, NB

**Dr. Kerry Savage, MD**  
BC Cancer Agency  
Vancouver, BC

**Dr. Pamela Skrabek, MD, MSc, FRCPC**  
CancerCare Manitoba  
Winnipeg, MB

**Dr. Doug Stewart, MD, FRCPC**  
Tom Baker Cancer Centre  
Calgary, AB

## ABOUT US

As an organization, we have served the lymphoma community for well over 20 years. Lymphoma Canada brings awareness to this disease and its subtypes as well as promotes the need for new and innovative therapies for lymphoma patients and equal access to these treatments across Canada. We invest in Canadian research that may one day lead to better outcomes for patients. With the help of our community of supporters, we continue to offer education and support programs across the country that assist patients and their care partners through the difficult journey of diagnosis, treatment, and survivorship.

At no other time in the history of our organization has a patient's need for our resources been greater. Not only have patients reached out with respect to their diagnoses, but also, how these diagnoses and their health will be impacted by the pandemic, vaccines, and delays to their healthcare. That's why we've made it our mission at Lymphoma Canada to stand together and to empower patients through education, support, advocacy, and research.

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



### PROVIDING EDUCATION

*Your gifts provide lymphoma patients and their caregivers with easy-to-understand resources that are specific to the Canadian healthcare landscape.*



### OFFERING SUPPORT

*Your gifts provide a safe space for individuals to share their experiences about lymphoma, including patients, family members, and caregivers.*



### ADVOCATING FOR PATIENTS

*Your gifts allow Lymphoma Canada to advocate on behalf of lymphoma cancer patients and their families, by helping decision makers identify effective new therapies and seek equal access to treatments throughout Canada.*



### RESEARCHING LYMPHOMA

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

## JOIN

*We are stronger together. It is concerned Canadians like you who have strengthened our voice with your gifts of time, talent, and action!*

### VOLUNTEER

Lymphoma Canada is seeking passionate volunteers to join our network and participate in awareness initiatives and fundraising activities.

### SIGN-UP

Stay current on the latest news, media updates and other announcements at Lymphoma Canada by registering for our e-newsletter.

### TAKE ACTION

At Lymphoma Canada, we rely on the generosity of foundations, corporations, and most of all, people like you, for ongoing support. Donate today, participate in our patient surveys, or enroll in our peer-to-peer support program.

# THANK YOU!

Providing support for lymphoma patients and their families is a team effort, and we have you to thank - our dedicated donors, sponsors, professional health care partners and committed volunteers - for enabling us to be there for patients and their families. Some of the thank you messages we received this year are included here. Every message is a testament to your commitment and generosity.



My biggest hope is that we can find a curative path for CLL in my lifetime. I'm lucky to live with a manageable case, but many are not as fortunate. Lymphoma Canada has been a wonderful resource for me during this time.

- Emily



Thank you for your ongoing support. As hard as it can be navigating the uncertainty that comes with cancer treatment and remission, I'm so grateful I don't have to travel this journey alone.

- Melanie



Our son has been fighting Hodgkin's Lymphoma for 13 months now. He has had many treatments, chemo, stem cell transplant, radiation and now he is on chemo for the next year. I hope our donation and the other donations will help find a cure that will work for him and all the other patients who are fighting this disease.

- Joan



Lymphoma has impacted my life a lot, with both my husband and mother. Your organization is very important to our family. Thank for all that you do.

- Cris



Lymphoma Canada and the support group I found through their website provided me with the strength needed to overcome this and it truly makes ALL the difference.

- Matt





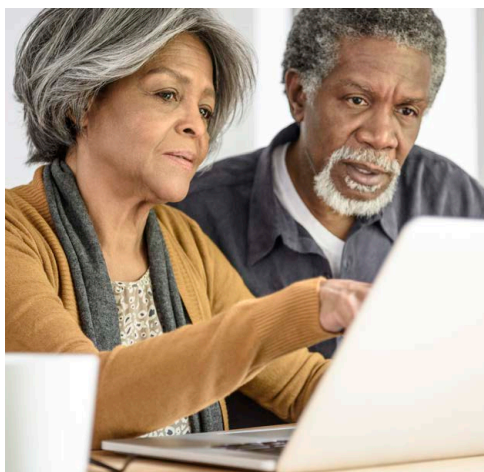
# PATIENT AND CAREGIVER EDUCATION

We know that navigating cancer care information can be overwhelming. That's why our team works with expert healthcare professionals, including our Nurse Advisory Board and Scientific Advisory Board which is comprised of Canadian nurses, researchers and clinicians, to develop accurate, clear, and reliable educational materials. We invite you to search our online resources, where you will find patient manuals by lymphoma subtype, videos, and interactive webinars and conferences.



## PATIENT RESOURCE MANUALS

Lymphoma Canada compiles information concerning diagnostics and treatment options in an easy-to-understand format. In 2021, we released updated French Patients Resource Manuals for Hodgkin and non-Hodgkin lymphoma patients as well as chronic lymphocytic leukemia and small lymphocytic leukemia patients. Over 3,000 printed manuals and resource materials were shared with cancer centres, hospitals, and patients, free of charge. In addition, Lymphoma Canada distributed many other resources, such as the Life Beyond Lymphoma Guide, Living with Lymphoma Brochure, Watch & Wait Pamphlet, Clinical Trial Brochure, and many more.

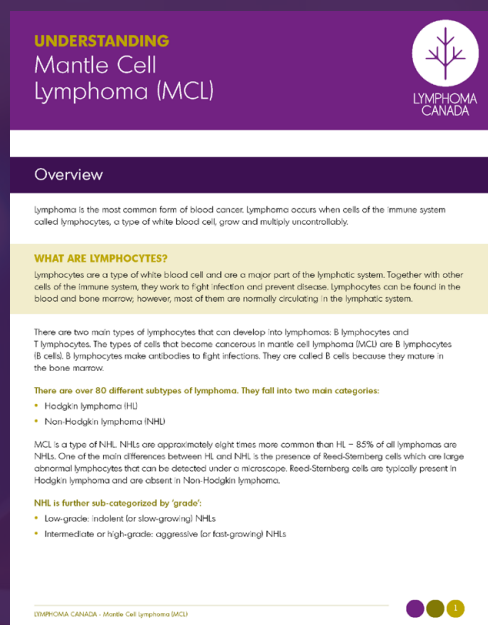


## WEBINAR SERIES

Lymphoma Canada hosted ten webinars in 2021, which were attended by over 2,300 registrants. These sessions were held in both official languages and led by professionals from across the country. Attendees learned about lymphoma as a disease, self-care methods and information on the latest research available. Topics of interest included Understanding your Lymphoma Subtype, Anxiety and Stress Management, How to Manage Fear of Recurrence, and COVID-19 and Vaccines for Lymphoma & CLL Patients.

## SUBTYPE FACT SHEETS

With over 80 lymphoma subtypes, each with their own clinical course, it is important for patients to understand their subtype from diagnosis. Fourteen lymphoma subtype fact sheets were developed to provide insights into treatment options, help patients to better advocate for their care, and connect with other patients who share the same subtype.



## NATIONAL CONFERENCE & FRENCH CONFERENCE

This year marked the fifth annual National Patient Conference and the second biennial French Conference. In 2021, it was the second year that Lymphoma Canada hosted the conference events virtually to allow for safe viewership and increased participation from coast-to-coast. The patient-focused conferences provided Canadians with meaningful presentations by expert faculty and specialists on the disease including treatment-specific information, clinical trials, the latest advancements in lymphoma research, and survivorship topics of interest.

### Thank you to our generous sponsors:

National Patient Conference  
on Lymphoma & CLL

Conférence nationale  
du Québec

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#### Bronze Sponsor



#### Silver Sponsor



#### Bronze Sponsor



## EDUCATIONAL FORUMS

Five educational forums for patients, caregivers, and families were hosted virtually and in collaboration with prominent medical professionals and healthcare/patient groups. These educational forums provided community-based learning and focused on specialized topics of interest within certain populations across Canada. Topics of discussion included CAR-T therapy in Alberta, Support in Coping with Lymphoma, Managing Fatigue, Oral Complications for Lymphoma Patients, and Patient & Caregiver Experience with Lymphoma.



# SUPPORT FOR PATIENTS, FAMILIES, AND THEIR CAREGIVERS

Lymphoma Canada offers a support system for people with lymphoma and their family, friends, and caregivers. We provide opportunities for individuals to meet with others to discuss the impact of their diagnosis. We help answer questions about lymphoma, assist with coping mechanisms, work to find community and connection, and build overall wellness and resilience.

## LYMPHOMA & CLL PATIENT AND CAREGIVER REPORT CARDS

In 2020, a survey was conducted to learn about the current issues faced by the lymphoma patient and caregiver community. In 2021, Lymphoma Canada compiled the responses and released two report cards: the Canadian Lymphoma Report Card and the Canadian CLL Report Card. These resources bring awareness to challenges experienced by the Canadian lymphoma community. The information highlights unmet needs faced by patients and caregivers and serves as a call to action.

## CLL WATCH & WAIT APP

The Lymphoma Canada Watch & Wait app allows CLL and SLL patients to track their symptoms over time. There are over 390 registrants using the app to help monitor their wellbeing. Watch and wait is an approach your physician may recommend for those who feel well, have acceptable blood tests, have small lymph nodes that are not causing problems or growing rapidly, and have no significant problems with their liver, kidneys, or other organs.

## LYMPHOMA & CLL PATIENT AND CAREGIVER COVID-19 EXPERIENCE REPORT

Feedback was gathered to better understand the impacts of COVID-19 and improve resources for lymphoma patients during the pandemic. The collected data helps us to address the unique challenges faced by lymphoma patients and caregivers, including difficulties in accessing treatments, lack of consistent follow-up care or management, increased isolation and mental health impacts, and reduced availability of support services. Lymphoma Canada works to develop appropriate programming and services, and advocate for change on a national frontier.

## ONE-ON-ONE SUPPORT AND ONLINE SUPPORT GROUPS

Lymphoma Canada provides one-on-one information for patients and caregivers through direct contact and via support groups, including the SouthWestern Ontario Chapter and Wellspring Westerkirk support group. This contact offers a friendly and safe environment so that patients and their caregivers can receive the help they need. Lymphoma Canada also assisted with the transition of support groups to a virtual environment as needed.

# 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 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.



## MOLECULAR TESTING

Lymphoma Canada launched an informational campaign to raise awareness about molecular testing. Molecular tests identify the type of CLL you have and help to determine the best course of treatment moving forward. They work by determining what chromosome abnormalities and genetic changes are present in your CLL cells and can be performed on a blood sample or on a bone marrow sample if one is already being taken.



## LYMPHOMA PATIENT ACCESS TO COVID-19 VACCINES

The COVID-19 pandemic brought many challenges for lymphoma and CLL patients. Lymphoma Canada advocated for priority access to COVID-19 vaccines for lymphoma and CLL patients and their caregivers during the initial rollout of the vaccination program for first and second vaccinations. Letters were developed in partnership with our Scientific Advisory Board, comprised of Canadian researchers and clinicians, along with other cancer organizations and were sent to the government as well as shared via a Global News campaign.

## NATIONAL TREATMENT GUIDELINES FOR DIFFUSE LARGE B-CELL LYMPHOMA

Led by Lymphoma Canada, a group of hematologists and oncologists from across Canada have developed a national evidence-based treatment guideline to provide healthcare professionals and patients with best practices for the management of DLBCL in the frontline and relapsed/refractory settings based on treatments available in Canada.



## WHITE PAPER: IMPROVING ACCESS TO INNOVATIVE THERAPIES IN CANADA

In 2018, Lymphoma Canada led the development of a White Paper that called attention to the challenges in accessing innovative new cancer therapies in Canada. This paper highlighted the different pathways that deny or delay access and provided recommendations that would improve access pathways to potentially life-saving treatments for many cancer patients. Based on key issues that continued to impact the Canadian landscape, and with the support of 22 Canadian cancer organizations, these access pathways were reassessed in 2021 and new recommendations were developed to help cancer patients receive the most effective therapies available.



## EQUITABLE ACCESS TO CAR-T THERAPIES FOR DLBCL PATIENTS

CAR-T therapy is still considered a new and innovative therapy for the treatment of lymphoma. It was initially approved by Health Canada in 2018 for relapsed/refractory Diffuse Large B-Cell Lymphoma patients, and more recently in 2021 for Mantle Cell Lymphoma, however it is still not locally accessible for all patients across Canada. Lymphoma Canada continues to advocate for equitable access to CAR-T cell treatment for DLBCL and now for MCL patients. This year, advocacy efforts included a patient and healthcare experience story that was released alongside an article in *Macleans* (EN) and *L'Actualite* (FR), and an animation campaign to increase awareness.

## PATIENT FEEDBACK HELPS GUIDE PROVINCIAL AND TERRITORIAL DRUG FUNDING DECISIONS

Lymphoma Canada prepared nine CADTH (Canadian Agency for Drugs and Technology in Health) and INESSS (Institut national d'excellence en santé et en services sociaux) submissions, representing the experiences of patients and caregivers. This input provides vital information for decision-makers as they determine which therapies to fund.



# 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/or health outcomes as they pertain to malignant lymphoproliferative diseases.

## 2021 LYMPHOMA CANADA RESEARCH GRANT

This year, Lymphoma Canada received the highest number of research grant applicants in its history. This funding is provided to Canadian researchers whose work improves outcomes related to lymphoproliferative malignancies.

Recipients of the 2021 Lymphoma Research Grant include:

**Dr. Krysta Coyle** Simon Fraser University, BC

Dr. Coyle's research focuses on the effect of specific molecular mutations in mantle cell lymphoma to test a new treatment in this lymphoma subtype.

**Dr. Versha Banerji** University of Manitoba, MB

Dr. Banerji's research focuses on the feasibility and implementation of therapies for chronic lymphocytic leukemia within the healthcare system to improve access.



Dr. Krysta Coyle



Dr. Versha Banerji

## PARTNERSHIP WITH LYMPHOMA PATIENTS TO RAISE FUNDS FOR RESEARCH

Throughout 2021, over \$25,000 was raised to support well-defined, Canadian research studies. Two lymphoma patients, Filomena and John, shared their personal experiences with lymphoma to help raise awareness of the need for research funds that have the potential to impact patient outcomes.



## STORIES OF HOPE

A three-story campaign highlighting the importance of hope and the caregiver-patient relationship was launched on Macleans.ca and l'Actualité.ca. Patient stories such as these shed light on those living with lymphoma and CLL and offer valuable insight to those sharing a similar experience.



## WORLD LYMPHOMA AWARENESS DAY

World Lymphoma Awareness Day (WLAD) is held every year on September 15. It is a day dedicated to raising public awareness of lymphoma cancer. In recognition of this day Lymphoma Canada illuminated 15 monuments across Canada. This day also marked the start of our second annual Laps Around Lymphoma event where Canadians from across the country walked a total of 25,339,362 steps, that's over 19,308 km in recognition of lymphoma patients.



# VOLUNTEER SPOTLIGHT



We are fortunate to have the support of many volunteers who share their time, skills, and resources to help bring about disease awareness, raise funds and support others in their journey with lymphoma.

## LARRY SIMPSON

### *Don't Horse Around with Lymphoma*

Larry Simpson is President of PONIES 24-7 Inc., a media company that includes 'Ponies 24-7, THE RADIO MAGAZINE Show, heard Saturday mornings at 8:30 ET, on 105.9 The Region and a bi-monthly digital magazine.

Recently, Larry was diagnosed with lymphoma and after some research, soon discovered that the disease can also affect horses, which immediately became the brainchild behind a natural fundraising and promotional tie, between the two media properties and Lymphoma Canada.

In January of 2021, PONIES 24-7 partnered with Lymphoma Canada and together they launched 'Don't Horse Around with Lymphoma', again a nod to the fact that lymphoma can touch both humans and horses. The campaign consisted of magazine advertorials in the PONIES 24-7 magazine and 30-second radio spots and show 'shut outs', while utilizing both PONIES 24-7 media properties. These advertisements encouraged Canadians to learn the signs and symptoms of lymphoma and the campaign itself, helped raise awareness and much needed funds for patient resources, including comprehensive patient subtype manuals, educational forums, webinars, and national conferences.

Thank you, Larry Simpson and PONIES 24-7, for organizing such an amazing fundraiser and thanks also to everyone who has supported the 'Don't Horse Around with Lymphoma' Campaign to date, including 105.9 The Region!

## HOST A FUNDRAISER

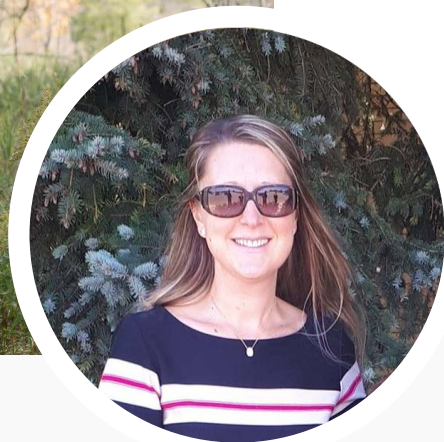
Consider hosting a fundraiser for Lymphoma Canada to raise awareness and support for those affected by lymphoma. Your gifts provide reliable Canadian lymphoma and CLL resources free of charge for patients and caregivers.

For more information on how to host your own event in support of Lymphoma Canada, visit: [www.lymphoma.ca/get-involved/host-a-fundraising-event](http://www.lymphoma.ca/get-involved/host-a-fundraising-event)



# PATIENT SPOTLIGHT

## FILOMENA FELTMATE



Filomena is a wife, a mother of two boys, an event planner, and a Hodgkin's lymphoma survivor.

Eight years ago, she developed a cough that took her breath away. It started when she was eight months pregnant with her first child. The cough came from deep in her chest and left her easily winded. She had a hard time going up and down stairs and picking things up – many symptoms which were easily attributed to being pregnant.

Filomena mentioned this to her family doctor, who thought that the cough was likely due to asthma, so Filomena was given an inhaler. But it wasn't working, and she kept coughing.

Two months following the birth of her son; however, the cough still hadn't gone away. Luckily, she had a routine allergy check-up scheduled. Her allergist immediately noticed how out of breath Filomena was when she went to pick up her son. And after seeing that, Filomena was sent to have a chest x-ray straight away.

The chest x-ray revealed that a tumour roughly the size of a volleyball had collapsed her entire left lung. Filomena was sent straight to the hospital emergency room. On arrival at the emergency room, she immediately had a catheter inserted to release the fluid buildup in the tissue surrounding her lung. In total, about four and a half litres were drained. Afterward, thankfully, the cough was gone.

The doctor believed that she might have lymphoma, so Filomena was sent for a biopsy to be certain. She was 29 and fell into the at-risk age group for Hodgkin's lymphoma, which is from 15 to 39 years old. Filomena was asked by the doctor if she experienced any other symptoms. Did she have night sweats? Was she tired and lacking energy? The only symptoms Filomena experienced, however, were coughing and weight loss. And even though she weighed less than before she was pregnant, Filomena didn't realize that there was anything seriously wrong because she was busy being a new mom.

Organizations like Lymphoma Canada are critical. "I remember picking up pamphlets while I was at the hospital. They're important for people who are newly diagnosed. And they're great for family members to have, especially so they can better understand what their family member is going through."

Two weeks later, Filomena got the biopsy results confirming a lymphoma diagnosis. Right away, she was put in touch with an oncologist at my cancer centre. Soon after, the cough started to come back, and this meant that the tissue surrounding her lungs was filling up once again due to the tumour. Filomena's oncologist said that the cough would disappear throughout treatment as the tumour began to shrink. Chemo was tough for her, but that's how she knew it was working because the cough disappeared. In total, Filomena completed eight months of chemotherapy and one month of radiation.

As a new mom, being able to get treatment as soon as she could, so that she was able to be there for her son, was extremely important. "Two years ago, I got the all-clear from my oncologist. Even though I'm clear, not a day goes by where I don't think about the cancer coming back." Still, Filomena remains positive. Her goal is to increase awareness of lymphoma symptoms, as many of the signs she experienced were interpreted as simply part of being a new mom.

To help raise awareness and support for the lymphoma community, Filomena participated in Lymphoma Canada's Laps Around Lymphoma virtual fitness challenge for two years now. Participants are challenged to take 100,000 steps in honour of the 100,000 Canadians currently living with lymphoma. "Everyone's like – 100,000 steps! I'm like yeah, I can do it! This is something that is close to my heart, and I want to help spread the word about lymphoma. Hopefully next year I'll get a team together."

Filomena continues to share her experiences and provide support for the lymphoma community. She is a great inspiration to others.

## DONOR SPOTLIGHT

*At Lymphoma Canada, we are profoundly grateful for every donor who shares our vision of life unlimited by lymphoma. We believe philanthropy has an important role to play in improving outcomes for lymphoma patients and their families.*

### BEAUTY OF GIVING ~ In loving memory of Dany Jaber

We want to thank Modern Beauty, one of Canada's leading beauty suppliers, who, since 2015, has raised over \$30,000 in support of Lymphoma Canada. Through their annual Beauty of Giving Campaign, one hundred percent of proceeds from select product sales are donated to the lymphoma community.

"Dany was a true inspiration to those who knew him. Although he is gone, he will never be forgotten."

Dany undeniably gave every ounce of himself to his family, friends, clients, co-workers, and suppliers. There were no limits to his generosity and kindness as he had a heart of gold. His smile and laughter had the ability to fill an entire room with joy and happiness.

**Thank you, Modern Beauty, for your continued support in honour of Dany Jaber.**



# EVENT SPOTLIGHT

## PAR FOR THE CURE

This year marked the 10th Annual Par for the Cure golf tournament. To all golfers, donors, and sponsors who participated, you helped make this event a great success.

Together we raised over \$63,000 with proceeds from Par for the Cure benefitting lymphoma patients and their families, through research, support, advocacy, and education.



Thank you to our sponsors for making this day possible:

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## LAPS AROUND LYMPHOMA

This fitness challenge raises awareness of lymphoma and funds for lymphoma related programs and resources. Participants are challenged to walk 100,000 steps in honour of the 100,000 Canadians currently living with lymphoma.

This year was the second Laps Around Lymphoma event, raising over \$74,000.

Thank you to our sponsors for making this day possible:

### Title Sponsor



### Education Sponsors



### Challenge Kick-Off Sponsor





# UPCOMING 2022

In 2022, we will provide patients with leading-edge treatment guidelines for CLL and Hodgkin lymphoma in frontline and relapsed/refractory settings. A side effect fact sheet that provides insight into the short-term and long-term impacts of lymphoma treatments will be released in addition to a lymphoma storybook for children and adolescents.

*We look forward to continuing to provide educational resources and opportunities, support programs, advocate on behalf of lymphoma patients and caregivers, and support Canadian research in 2022.*

To support Lymphoma Canada, please visit [lymphoma.ca/donate](https://lymphoma.ca/donate)

December 31, 2021, audited financial statements are available at [lymphoma.ca](https://lymphoma.ca)  
La version française du rapport annuel est disponible.



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