



# A MESSAGE OF GRATITUDE

2020  
ANNUAL  
REPORT

*A Year of Community Support -  
Standing Together for Patients at Risk*

| Education    Advocacy    Support    Research



LYMPHOMA  
CANADA

# A LETTER FROM THE CEO AND BOARD CHAIR



**CLAUDIO GROSSI**  
Board Chair



**ANTONELLA RIZZA**  
CEO

## Words of Appreciation

This past year has been unlike any other.

Since the earliest days of Canada's response to the COVID-19 pandemic, our community has stepped up to support Lymphoma Canada's efforts to be there for patients and their families.

There has been a lot of change and a lot of progress over the last year. Despite the chaos and multiple pivots resultant from working remotely, lockdowns and adaptation to virtual educational webinars and patient conferences, we are so proud that we were unwavering in our goal to serve lymphoma and CLL patients through the past year. The steadfast support we have received from our volunteers, Board of Directors, Scientific Advisory Board, Nursing Advisory Board and Patient, Family and Caregiver Committee have helped us to continue to drive forward our mission of empowering patients and the lymphoma community through education, support, advocacy, and research.

You have been there with us, from providing donations to supporting advocacy initiatives and ground-breaking research, to volunteering with online support groups, to sponsoring our events and providing grants in support of our programs, to responding to surveys or even finding creative ways to host virtual fundraisers.

Your generosity and words of hope have been felt by lymphoma patients across Canada. In these trying times of physical distancing, where staying connected has felt more challenging than ever, you showed us the true meaning of community and togetherness. **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 for over 20 years.

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As an organization, Lymphoma Canada has focused on lymphoma education, support, advocacy, and research for over 20 years. We bring awareness to the disease and its subtypes and provide support for patients and their families as well as promote the need for new and innovative drugs for lymphoma patients and equal access to these treatments across Canada.

Our purpose stands stronger now more than ever. We are grateful to you, our community of supporters, for your commitment to those affected by lymphoma. Your efforts ensure that Lymphoma Canada is there when it is needed most.

We acknowledge the many donors and sponsors who have generously provided support for at risk patients during the COVID-19 pandemic. Lymphoma patients have faced heightened challenges, including balancing the need to receive proper care in an overburdened healthcare system while protecting themselves from a deadly virus. Because of you, patients were able to receive much needed resources to better navigate the changing landscape of cancer care.

**From all of us at Lymphoma Canada, thank you.**

 <b>PROVIDING EDUCATION</b> <i>Your gifts provide reliable Canadian lymphoma and CLL resources, free of charge, for patients and caregivers.</i>	 <b>OFFERING SUPPORT</b> <i>Your gifts provide a safe space for individuals to talk about their experiences, including patients, family members, and caregivers.</i>
 <b>ADVOCATING FOR PATIENTS</b> <i>Your gifts allow Lymphoma Canada to advocate on behalf of lymphoma cancer patients and their families, to enact policies that will address equal access to effective new therapies throughout Canada.</i>	 <b>RESEARCHING LYMPHOMA</b> <i>Your gifts fund ground-breaking research that helps to determine lymphoma's many causes and ultimately one day find a cure.</i>

**JOIN** *We are all needed to help empower the lymphoma community. It is concerned Canadians like you who have strengthened our voice with your gifts of time, talent, and action!*

### **VOLUNTEER**

Lymphoma Canada is always seeking active and passionate volunteers to join our network.

### **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.

### **SIGN-UP**

Our e-newsletter keeps you up to date on our latest campaigns and lymphoma research.

# THANK YOU!

Without the support of our community of donors, of sponsors of our programs, of health care professionals and of committed volunteers, we would not have been able to power through the challenges that 2020 brought to continue to serve patients and caregivers. Some of the thank you messages we have received from our patients this year are included here and are extended to you - our exceptional community of supporters.



I was very impressed by the depth of information provided in the [National Conference] sessions. I've been a pediatric oncology nurse for many years, but now as a patient, I had a lot to learn about lymphoma!

- Mag, lymphoma patient



I am so grateful for the support I received after being diagnosed with NHL. 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, lymphoma patient



I'm struggling to find ways to cope and get used to this "new normal" that is my life, but I am slowly feeling a bit more like me each day. Thank you for sending a patient resource manual and support group information when I needed it most.

- Jess, lymphoma patient



Thank you so much for the information. You have made it so much easier during this very difficult time.

- Linda, lymphoma patient



It was a Lymphoma Canada, Know Your Nodes campaign that helped me get diagnosed after many years of being symptomatic. Education is so very important to make people aware of lymphoma.

- Linda, lymphoma patient



# PATIENT AND CAREGIVER EDUCATION

At Lymphoma Canada, we strive to provide lymphoma cancer patients with information to better inform decisions regarding diagnosis and care. In addition to educational forums, and our annual patient and caregiver conference, we host a webinar series for individuals to gain access to first-hand learning opportunities with lymphoma experts. All resources are available online at [lymphoma.ca](https://lymphoma.ca).



## PATIENT RESOURCE MANUALS

As new information is released concerning diagnostics and the most recent treatment options, Lymphoma Canada compiles this data in an easy-to-understand format. In 2020, we released updated Patient Resources Manuals, for Hodgkin and non-Hodgkin lymphoma patients as well as chronic lymphocytic leukemia and small lymphocytic leukemia patients. Over 3,500 printed manuals were shared with cancer centres, hospitals, and patients, free of charge.



## WEBINAR SERIES

Lymphoma Canada hosted 11 webinars in 2020, for those interested in understanding more about lymphoma as a disease, self-care, and the latest research available. These sessions were hosted in both official languages and led by leading professionals from across the country. Some topics included, Anxiety and Stress Management for Lymphoma Patients, Cancer Drug Access, and CAR-T Cell Therapy for Lymphoma Patients. A three-part series for adolescents and young adults was also featured to provide support for the specific challenges faced by the young adult population.

## NATIONAL CONFERENCE

This year marked our 4th Annual National Patient and Caregiver Conference, and our first national conference hosted as a virtual event. This patient-focused conference provided Canadians across the country with presentations by expert faculty and specialists about the disease and treatment-specific information, clinical trials, the latest advancements in lymphoma research, and survivorship topics of interest.



## EDUCATIONAL FORUMS

Lymphoma Canada facilitated three virtual educational forums for patients, caregivers, and families in collaboration with prominent medical professionals and healthcare/ patient groups. Topics of discussion included lymphoma diagnosis, stem-cell transplant, and coping strategies for patients.

## CAR-T SCIENTIFIC & PROTOCOL OVERVIEWS

These documents outline the processes involved in receiving Chimeric Antigen Receptor T-Cell (CAR-T) therapy. This is a type of immune therapy that engineers a patient's own T-cells to fight against their cancer. These resources include detailed steps beginning from the screening process, to T-cell engineering, CAR-T infusion, and the subsequent observation period.

## CLL TREATMENT ALGORITHM AND PATIENT TREATMENT OPTION RESOURCES

In collaboration with our partners, Lymphoma Canada created a number of chronic lymphocytic leukemia (CLL) specific resources, including a treatment algorithm for both frontline and relapsed/refractory settings, and an overview of prevalent CLL patient treatment options and their funding across the provinces and territories.

# SUPPORT FOR PATIENTS, FAMILIES, & THEIR CAREGIVERS

Lymphoma Canada is there to help patients navigate their cancer journey from diagnosis through to treatment and remission. We provide support materials and opportunities for individuals to meet with other lymphoma patients and caregivers to talk about the impact of their diagnosis, including the emotions and fears associated with cancer, its disruption to one's life and family, concerns for the future, and coping strategies.

## COVID-19 INFORMATION HUB

We created a COVID-19 Information Hub to provide Canadians living with lymphoma and their families the most up-to-date information related to COVID-19, including province-specific resources, vaccine related information, and available mental health programs. Lymphoma Canada, with the help of our Scientific Advisory Board comprised of leading hematologists and oncologists from across Canada, created a report to address questions from patients related to COVID-19 and the vaccine, and to provide guidance from clinicians at the policy level.

## CLL WATCH & WAIT APP

The CLL Watch & Wait app was relaunched with enhanced features to further assist CLL and SLL patients during the watch and wait period of the disease. This app allows CLL and SLL patients to track their symptoms over time. New features include a downloadable overview of tracked symptoms, an all-new log in and password recovery process, new treatment option information as well as the ability to bypass non-applicable tracking details.

## LYMPHOMA CANADA PATIENT COVID-19 SURVEY

Feedback was gathered to better understand the impacts of COVID-19 and improve resources for lymphoma patients during the pandemic. The collected data helped to address the challenges faced by lymphoma patients and caregivers and has driven the development of educational and support programs, such as those needed to address patient anxieties brought about by the pandemic.

## ONLINE SUPPORT GROUPS

Lymphoma Canada and our partners transitioned many in-person support groups to a new virtual format. This provided patients and caregivers with a friendly and safe environment to receive the help they needed when group gatherings were no longer possible.

# ADVOCATING FOR EQUAL ACCESS TO EFFECTIVE THERAPIES

We believe that every lymphoma patient should have the care they need to thrive. Each day, we advocate for new and innovative therapies for Canadian lymphoma patients and work to equalize, or increase, access to these treatments across Canada. We strive to provide decision-makers with objective evidence-based patient feedback submissions on all emerging lymphoma cancer therapies being assessed for public funding in Canada.

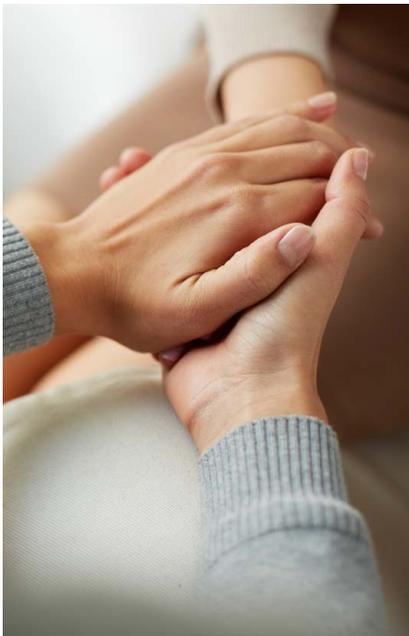


## **FOUNDING MEMBER, DR. JOSEPH M. CONNORS, CM, IS APPOINTED TO THE ORDER OF CANADA**

Dr. Connors, a founding member of Lymphoma Canada, and former Chair of our Scientific Advisory Board, was recognized in 2020 for his contributions to the study and treatment of lymphoid cancers, and for his role in the advancement of lymphoma care in Canada. A fierce patient advocate, Dr. Connors has touched the lives of countless lymphoma patients and trained scores of hematologists who are sharing their knowledge to benefit patients across the country as well as internationally.

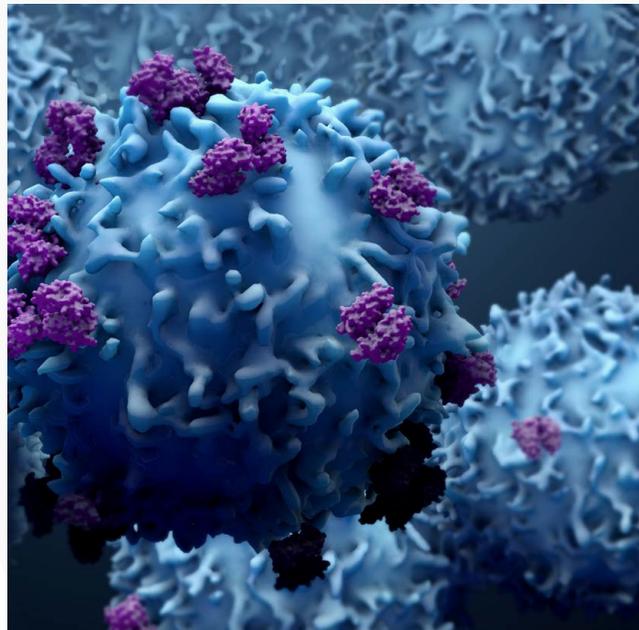
## **PATIENT FEEDBACK HELPS GUIDE PROVINCIAL AND TERRITORIAL DRUG FUNDING DECISIONS**

Lymphoma Canada prepared nine pCODR (panCanadian Oncology Drug Review) 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.



## **ACCESS TO CAR-T CELL THERAPY**

CAR-T cell therapy is an innovative immunotherapy which uses the patient's own immune system, through genetic modification of the T-cells, to attack their cancer. It is currently approved in Canada for use in Diffuse Large B-Cell patients. Lymphoma Canada applauds provinces that have made CAR-T cell therapy treatment available for patients inside their home province. We promote advocacy for equitable access to treatment across all provinces and territories. This year, Lymphoma Canada circulated letters to each of the provincial and territorial Ministers of Health and to leaders of Cancer Agencies across Canada about inequitable access to CAR-T treatments across Canada and the impacts it is causing to Canadian patients. We continue to work with patient groups to address the delays in funding for CAR-T therapy.



# LYMPHOMA RESEARCH & DISEASE AWARENESS

Lymphoma Canada is committed to improving outcomes for lymphoma patients by investing in promising Canadian research studies. Research studies are critical to increase our understanding of lymphomas and to lead us to more effective treatment options for patients.

## PARTNERSHIP WITH PAUL HENDERSON TO RAISE FUNDS FOR RESEARCH

In 2020, Lymphoma Canada collaborated with Canadian hockey legend, Paul Henderson to raise \$25,000 in support of lymphoma research. Throughout 2020, over \$45,000 dollars was raised to support 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.

## 2020 LYMPHOMA CANADA RESEARCH GRANT

Drs. Rob Laister and Sam Saibil from the Princess Margaret Cancer Centre received the 2020 Lymphoma Canada Research Grant. Together they share an interest in targeted treatments for hematological malignancies and are collaborating to advance research on CAR-T cell therapy. The goal of their research project is to determine whether they can engineer different models of CAR-T cells to make them more effective at killing lymphoma cells. By increasing the effectiveness of CAR-T therapy, this can lead to longer remission times and higher success rates in a larger number of patients.

Photo courtesy of William Brock



Dr. Rob Laister



Dr. Sam Saibil



## RESEARCH BREAKTHROUGH FUNDED BY LYMPHOMA CANADA

Breakthroughs of a research study, funded in part by Lymphoma Canada, were published on February 24, 2020, in Nature Medicine. Researchers uncovered that the TMEM30A protein is present in every cell of diffuse large B-cell lymphoma (DLBCL), however cells with an altered gene were found to respond better to treatment when tested in the lab.

## BIOSIMILARS REPORT

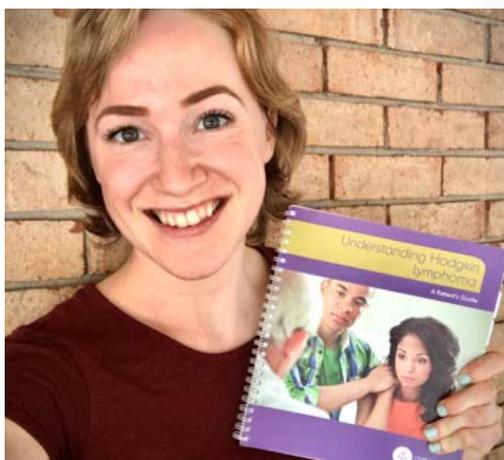
Lymphoma Canada surveyed clinicians and patients on their knowledge of biosimilars and the use of these in Canada. A biosimilar drug is medicine that is similar in structure and function to a biologic drug. The collected data was compiled into a report that included detailed information regarding responders' use and basic knowledge of biosimilars, their understanding of biosimilar development, and level of comfort with extrapolation and interchangeability.

## WORLD LYMPHOMA AWARENESS DAY

World Lymphoma Awareness Day (WLAD) is held on September 15 every year and is a day dedicated to raising public awareness of lymphoma cancer. In recognition of this day Lymphoma Canada illuminated 10 monuments across Canada. This day also marked the start of our inaugural Laps Around Lymphoma event where Canadians from across the country walked a total of 7,735,339 steps, that's over 5,350 km (the distance from Vancouver, BC to Fredericton, NB), in recognition of lymphoma patients.



# VOLUNTEER SPOTLIGHT



Every year we are fortunate to have the support of many volunteers. Many of these volunteers share their time, skills, and resources to help bring about disease awareness and to support others in their journey with lymphoma.

## GRACE COWLEY

### *A Benefit Concert for the Lymphoma Community*



Lymphoma Canada is thankful to have supportive donors and volunteers whose contributions continue to make a difference in the lives of so many. Because of the dedication of individuals like Grace Cowley, we continue to provide patients and caregivers with exceptional support and service.

Grace Cowley's journey with lymphoma began while she was living abroad after graduating from university. She began to feel increasingly unwell while abroad, and was diagnosed on November 28, just one month after her return to Canada.

On November 28, 2018, Grace received the devastating news that she was diagnosed with Stage four Hodgkin lymphoma. She underwent six months of chemotherapy at Grand River Hospital in Kitchener, and it was there that she was introduced to Lymphoma Canada's patient resource manuals and support materials. Grace scoured our brochures and survivor stories for inspiration, and to prepare herself for what was to come.

After completing her treatment regiment, Grace received a clean scan in July of 2019. It was then, that she began to look for ways in which she could give back to the lymphoma community in recognition of the support she received.

As a talented artist, Grace decided to host a benefit concert to raise funds for Lymphoma Canada. On January 11, 2020, at the Badenoch Community Centre in Puslinch, Ontario, Grace and several other artists performed in a coffee-house style show. Between the concert tickets, silent auction, and people's generous online donations, she raised a total of \$3,245 for Lymphoma Canada!

Grace continues to find ways to support the lymphoma community and we thank her for her commitment to helping those impacted by lymphoma.

# PATIENT SPOTLIGHT

## JULIA APRILE



Receiving a cancer diagnosis is an overwhelming experience. It is perfectly normal to be shocked by the diagnosis, anxious about the future, and confused about the medical information and decisions that need to be made.

Although each person is different and each response to therapy is unique, knowing someone who has been through the same treatment and who may have had similar concerns can be a source of great comfort. Take for example, Julia.

Julia was diagnosed with lymphoma at the age of 19 and shared her story as part of Lymphoma Canada's 2020 Holiday Campaign to encourage others facing a lymphoma diagnosis.

When Julia first started experiencing symptoms, she was attending university as an engineering student. Part way through her second year she went to see a doctor at the University Wellness Centre about some persisting symptoms. She had a few small bumps on her neck and her skin was itchy all over.

Prior to this doctors appointment, Julia was told that these symptoms could be related to a virus, but they hadn't disappeared in over several weeks. Concerned, the doctor at the Wellness Centre sent her for a neck ultrasound, a chest x-ray, and some blood work. However, the results didn't show anything conclusive, so a biopsy was conducted where a small sample was taken from her neck.

On January 22, 2020, Julia learned that she had Hodgkin lymphoma. That day changed everything. Julia made the difficult decision to leave school and isolate herself at home in preparation for her immediate start of treatment. This was well before the beginning of the pandemic and things would only continue to get more difficult. But she knew that she had the support of her friends and family and a highly successful treatment plan.

In February, she began ABVD chemotherapy and despite the ongoing challenges, including a deep fear of needles, she maintained a positive outlook, and even started her own blog.

The blog, titled, **Life as Me; my cancer battle**, was an important part of Julia's journey. It was cathartic for her to create, and she hoped that it would motivate others battling lymphoma. In her blog, Julia chronicled difficult decisions that she faced about fertility, the loss of her hair, and the effects of chemotherapy.



*Since the day I shared my story,  
I felt physically stronger.*



On July 31, 2020, Julia finished her final treatment of chemotherapy. And by September 15, she was well enough to be able to participate in Lymphoma Canada's Laps Around Lymphoma virtual fitness challenge. The way Julia sees it, it is important to raise funds for lymphoma research and patient resources, so that support is available to Canadians when it matters most.

That is why she also held her own fundraiser called Paint 4 Lymphoma where donors received one of her handmade paintings in exchange for their contribution to Lymphoma Canada.

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

## DONOR SPOTLIGHT

*Donors play an important role, allowing Lymphoma Canada to provide ongoing resources for patients and caregivers.*

### SUTHERLAND SCHOOL - GRADE EIGHT CLASS

In the fall of 2019, Jaycie, a grade eight teacher at Sutherland School in Saskatoon, ran community service events with her class. One of the class groups hosted a bake sale to raise money for cancer research without realizing what was in store for their teacher. In December of 2019, Jaycie was diagnosed with follicular lymphoma. In early 2020, the class decided to direct the funds they raised to Lymphoma Canada. We thank these students for their generous contribution and support of the lymphoma community.

# UPCOMING 2021

In 2021, we aim to provide patients with up-to-date, resources with the publication of subtype-related treatment guidelines and the Canadian Lymphoma and Chronic Lymphocytic Leukemia (CLL) Report Cards. We also strive to further the conversation surrounding the impacts of COVID-19 on lymphoma patients and will continue to advocate for the prioritization of immunocompromised cancer patients and survivors of cancer to receive the COVID-19 vaccine.

*All of this work is not possible without your support.*

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

We appreciate the foundations, corporations and funders who play an important role in our continued success, including those who sponsored our 2020 Events:

## NATIONAL CONFERENCE

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December 31, 2020, audited financial statements are available at [lymphoma.ca](https://lymphoma.ca)  
Version française disponible.



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