



A YEAR OF EDUCATION & SUPPORT

2017 ANNUAL REPORT



LYMPHOMA
CANADA



A LETTER FROM THE CEO AND BOARD CHAIR

A YEAR OF EDUCATION AND SUPPORT

Lymphoma is one of the least understood cancers, yet it is the 5th most common among Canadians.

Too often when someone receives a lymphoma diagnosis, they are unaware that it is a form of cancer. This is why it is our mission at Lymphoma Canada to raise awareness and provide support for the over 100,000 Canadians currently living with lymphoma. We strive to empower patients and the lymphoma community by promoting early detection, finding new and better treatments, and ultimately, finding a cure.

In 2017, with the support of healthcare professionals, partners and volunteers, we have raised awareness of lymphoma. Lymphoma Canada is an integral part of the conversation that is helping decision makers identify effective new therapies and seek equal access to treatments across Canada. Nine government submissions were made in 2017, representing the experiences of over 1,300 patients and caregivers from around the globe. This input, provides a vital lens to decision-makers as they determine which therapies to fund.

Our patient support and education programs, available across the country, assist patients and their caregivers through the difficult journey of diagnosis,

treatment and survivorship. Throughout the past year, we have held twelve educational forums, three webinars and eight patient support groups. In September, our inaugural patient conferences on lymphoma, in both Montréal and Toronto, were well received.

In 2017, Lymphoma Canada distributed over 3,500 patient resource manuals to professionals, patients and caregivers from coast to coast. Each manual provides a comprehensive overview of one of the three main subtypes of lymphoma; Hodgkin, Non-Hodgkin and CLL (Chronic Lymphocytic Leukemia).

Our achievements and outreach to stakeholders across Canada are possible because of the support of our corporate partners, individual donors, volunteers and staff.

**Thank you for supporting Lymphoma Canada.
Together, we are working to fulfill our vision of life
unlimited by lymphoma.**



SHARLENE SMITH
BOARD CHAIR



ROBIN MARKOWITZ
CEO



PATIENT SUPPORT

HELPING PATIENTS GAIN ACCESS TO NEW LYMPHOMA THERAPIES

As part of our mission, Lymphoma Canada strives to educate decision-makers on the realities and needs of lymphoma patients. In 2017, Lymphoma Canada prepared a submission for each emerging lymphoma cancer therapy being assessed for public funding in Canada, through the pan-Canadian Oncology Drug Review (pCODR), the Common Drug Review (CDR), and Institut national d'excellence en santé et en services sociaux (INESSS). We are grateful to the more than 1,300 patients and caregivers from around the globe who shared their experiences to help lymphoma patients in Canada gain access to effective new therapies.

4

**4 pCODR
SUBMISSIONS**

1. Brentuximab-vedotin (Adcetris) for R/R Hodgkin lymphoma
2. Venetoclax (Venclexta) for R/R CLL (joint submission with CLL-PAG)
3. Pembrolizumab (Keytruda) for R/R Hodgkin lymphoma
4. Nivolumab (Opdivo) for R/R Hodgkin lymphoma

4

**4 INESSS
SUBMISSIONS**

1. Obinutuzumab (Gazyva) for R/R Follicular lymphoma
2. Brentuximab-vedotin (Adcetris) for R/R Hodgkin lymphoma
3. Venetoclax (Venclexta) for R/R CLL
4. Pembrolizumab (Keytruda) for R/R Hodgkin lymphoma

1

**1 CDR
SUBMISSION**

1. Letermovir (Prevymis) for anti-viral prophylaxis, post-allogeneic transplant (joint submission with Myeloma Canada)



2017 HIGHLIGHTS

EDUCATION

REACHING A WIDER COMMUNITY

At Lymphoma Canada, we strive to provide lymphoma cancer patients, family members and caregivers with information to better inform decisions regarding diagnosis and care. In addition to educational forums in many local communities, we host a webinar series to help individuals who may not have first-hand access to learning opportunities with lymphoma experts.

One of the highlights in 2017, was a webinar presented by Dr. Harold Atkins. This video addressed CAR-T cell therapy, a cutting-edge cancer treatment that has shown great promise in patients with diffuse large B cell lymphoma (DLBCL), the most common type of lymphoma in adults.

All Lymphoma Canada webinar videos can be viewed online at lymphoma.ca

SUPPORT

LYMPHOMA AWARENESS DAY AT QUEEN'S PARK

On October 25th, at Queen's Park, Lymphoma Canada, CanCertainty and The Canadian Cancer Society joined forces to speak up on behalf of all Ontario cancer patients. Navigating the process of obtaining access and authorization of approved cancer medications can be time-consuming, and overwhelming without the added stress of financial limitations. Take-home medications are increasingly becoming the go-to treatment for cancer, yet Ontario – unlike many other provinces – hasn't kept up with funding options to make the drugs accessible to all patients who need them. Together we delivered more than 15,000 signed postcards to the Ontario government asking the province to fund take-home cancer drugs.



L to R: Daniel Glazerman, lymphoma survivor; MPP France Gélinas, NDP Health Critic; Robin Markowitz, CEO, Lymphoma Canada; MPP Bill Walker, PC Critic Long Term Care, Seniors Affairs & Accessibility Issues; Sharon Dennis, leukemia patient.

RESEARCH

THE 2016-2018 LC RESEARCH FELLOWSHIP AWARD

The 2016 - 2018 LC Research Fellowship Award was presented to Dr. Anja Mottok in support of her research, investigating how Hodgkin lymphoma cells manipulate their cellular environment to proliferate and survive:

Classical Hodgkin lymphoma (cHL) is a cancer derived from white blood cells and typically occurs in young adults under the age of 30. Even though most patients can be cured with chemotherapy, 30% still experience relapse and eventually succumb to their disease.

There is now increasing evidence that not only tumour cells, but also normal cells surrounding them ("microenvironment"), are of importance for tumour progression. Over the past years, several studies have contributed to the current knowledge about the mechanisms by which the tumour cells in cHL recruit cells to form the tumour microenvironment and manipulate them to be non-functional.

Dr. Mottok proposed to characterize the composition of the tumour microenvironment in cHL. To explore which genetic changes in the lymphoma cells might have an impact on microenvironment composition, novel techniques will be used to decode the genetic makeup of ~1000 single cells per tumour. Results from these studies will provide the unique opportunity to relate how the gene mutations in Hodgkin lymphoma cells may influence the normal cells surrounding them.

EDUCATIONAL SESSIONS

After a lymphoma diagnosis, patients and their families often have questions about available treatments, support options and symptom management. In 2017, Lymphoma Canada was proud to host over twelve educational sessions and five webinars serving patients, caregivers and healthcare professionals.

SPEAKERS

DR. NATHALIE JOHNSON
Jewish General Hospital, Montréal, QC

TRACY REGIMBALD
Research Nurse Manager,
Jewish General Hospital, Montréal, QC

DR. MICHAEL REID
Kitchener, ON

DANIELLE MOREAU-AMARU
RD, CHUM, Montréal, QC

DR. HAROLD OLNEY
CHUM, Montréal, QC

DR. APRIL SHAMY
Jewish General Hospital, Montréal, QC

DR. DENIS-CLAUDE ROY
Maisonneuve-Rosemont Hospital,
Montréal, QC

DR. STÉPHANE DOUCET
CHUM, Montréal, QC

DR. KELLY DAVISON
MUHC, Montréal, QC

DR. ISABELLE FLEURY
Hôpital Maisonneuve-Rosemont, Montréal, QC

JEAN-PHILLIPE ADAM
Oncology Pharmacist, CHUM, Montréal, QC

DR. DOUGLAS STEWART
Tom Baker Cancer Centre, Calgary, AB

DENISE GABRIELSON
RD, St. Michael's Hospital, Toronto, ON

DR. ROB LAISTER
Princess Margaret Cancer Centre,
Toronto, ON

RUTH TURNER
RN, Princess Margaret Cancer Centre,
Toronto, ON

TINA CROSBIE
Pharmacist, The Ottawa Hospital Cancer
Centre, Ottawa, ON

DR. NATASHA KEKRE
The Ottawa Hospital Cancer Centre,
Ottawa, ON

ANGELA BOUDREAU
RN, APN, Odette Cancer Centre,
Toronto, ON

DR. PETER ANGLIN
Stronach Regional Cancer Centre,
Newmarket, ON

DR. KEVIN IMRIE
Odette Cancer Centre, Toronto, ON

DR. LAURIE SEHN
BC Cancer Agency, Vancouver, BC

DR. CLAIRE DEARDEN
The Royal Marsden, London, UK

DR. ANCA PRICA
Princess Margaret Cancer Centre,
Toronto, ON

DR. MICHAEL CRUMP
Princess Margaret Cancer Centre,
Toronto, ON

DR. MARTINA TRINKAUS
St. Michael's Hospital, Toronto, ON

DR. LISA DEL GIUDICE
Sunnybrook Health Sciences Centre,
Toronto, ON

DR. HAROLD ATKINS
Ottawa Hospital Research Institute,
Ottawa, ON

DR. ISABELLE BENCE-BRUCKLER
The Ottawa Hospital Cancer Centre,
Ottawa, ON

DR. CAROLYN FAUGHT
The Ottawa Hospital Cancer Centre,
Ottawa, ON

DR. MELISSA TOUPIN
The Ottawa Hospital Cancer Centre,
Ottawa, ON

DR. DAVID MACDONALD
The Ottawa Hospital Cancer Centre,
Ottawa, ON

LOCATIONS

- Montréal
- Toronto
- Ottawa
- Québec City
- Vancouver
- Kitchener-Waterloo

TOPICS

- The Changing Landscape of Chronic Lymphocytic Leukemia (CLL)
- Integrative and Lifestyle Treatment Options
- Survivorship Issues
- CAR T-Cell Therapy
- Know Your Subtype
- Managing Side Effects
- New and Emerging Treatments for CLL
- New and Emerging Treatments for Aggressive Lymphomas
- New and Emerging Treatments for Indolent Lymphomas
- Managing Nutrition and GI Health
- Use of Medical Marijuana
- Coping with Cancer-related Brain Fog
- Survivorship Care
- Lymphoma Biology and Common Lymphoma Terms
- Understanding Clinical Trials
- Fear of Recurrence

NATIONAL PATIENT CONFERENCES

This year marked the launch of Lymphoma Canada's two National Patient Conferences.

MONTRÉAL, SEPTEMBER 15-16

In honour of World Lymphoma Awareness Day, **over 130 healthcare professionals, patients and caregivers** gathered to learn about the changing landscape of lymphoma. Over a day-and-a-half, participants heard from leading lymphoma experts in both official languages and took part in personalized disease breakout sessions and valuable one-on-one interactions.



CONFERENCE CHAIR: DR. HAROLD J. OLNEY

Hematologist-medical oncologist
Head of the Department of Hematology-Transfusion Medicine
University Hospital of Montréal (CHUM)



KEYNOTE SPEAKER: DR. DENIS CLAUDE ROY

Director of Research
Maisonneuve-Rosemont Hospital
Montréal University

TORONTO, SEPTEMBER 29-30

Approximately **150 healthcare professionals, patients and caregivers** gathered to learn about the changing landscape of lymphoma from experts from around the globe.



CONFERENCE CHAIR: DR. JOHN KURUVILLA

Hematologist, Princess Margaret Cancer Centre
Assistant Professor of Medicine, University of Toronto



KEYNOTE SPEAKER: DR. CLAIRE DEARDEN

Consultant Hematologist
Head of the Chronic Lymphocytic Leukemia Unit
The Royal Marsden, London, UK
Clinical Director of the Haemato-Oncology Department
Clinical Director of the Specialist Haematological Malignancy Diagnostic Service
The Royal Marsden Biomedical Research Centre,
London, UK

OUR VISION

Life unlimited by lymphoma.

OUR MISSION

Empowering patients and the lymphoma community through education, support and research.

OUR REALITY

1 2 3 4 5 5th most common cancer in Canada.

Over 60 different subtypes have been identified.

In Canada, one new case is diagnosed every 45 minutes.

Over 100,000 Canadians live with lymphoma.

OUR VALUES

COMPASSION

Our work is rooted in empathy, respect & kindness.

INTEGRITY

We are honest and transparent, & adhere to high ethical standards, equality and fairness.

EXCELLENCE

We are passionate and determined & committed to being highly efficient & effective.

INFLUENTIAL

We are credible and professional, & dedicated to making an impactful difference that is evidence-based and legacy-worthy.

INNOVATIVE

We are resourceful, empowered & progressive. We deliver results through teamwork.

OUR STRATEGIC PRIORITIES

EDUCATION

To provide education to lymphoma patients, their families & healthcare professionals.

SUPPORT

To support and advocate on behalf of lymphoma patients, their families and healthcare professionals for universal access to the best care.

RESEARCH

To fund research that improves the outcomes for patients with lymphoma.

SUSTAINABILITY

To have the human & financial resources needed to achieve our mission.



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Thanks to the commitment of our corporate partners, sponsors and donors, we are able to provide patients and caregivers with exceptional support and services. Each year we are astounded by the overwhelming generosity of our partners.

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VOLUNTEER SPOTLIGHT JENNA'S LEMONADE STAND

A FAMILY HONOURS THEIR DAD BY GIVING BACK

We are grateful and humbled by those who have been irrevocably touched by lymphoma and have chosen to channel their experience to benefit others. The Zaracoff family are a wonderful example of this, as they continue to remember their husband and father annually by fundraising in his memory.

It all began when Jenna, who was eight years old at the time, decided to create a lemonade stand that would help keep her father's memory alive. Her goal was to donate the proceeds to Lymphoma Canada and promote awareness as well as advance research for other individuals living with lymphoma. With the help of family, friends and the community, they raised \$1,500 that very first year. They have continued to carry on this tradition every year since their inaugural lemonade stand back in 2011.

In 2016, CTV News hosted a segment that featured their event, and this brought attention to their ongoing initiative. That same year, Jenna was presented with an award from Vaughan Mayor, Maurizio Bevilacqua, in acknowledgment of her efforts as a "Civic Hero" for outstanding community service. Altogether, in 2016, they raised \$8,500 for Lymphoma Canada.

On June 11, 2017 the Zaracoff family held their 7th annual Lemonade Stand. Again, through the efforts of Jenna and her sister Jordyn, along with their mom Elise, the event has grown to include entertainment, the sale of baked goods, silent auctions, food trucks and much more.

To raise further funds for Lymphoma Canada, Jordyn spearheaded a splendid gala that took place in October

of 2017, with a beautiful sit-down dinner, open bar, entertainment and a huge silent auction. As a special surprise The Tenors created a video honoring their efforts. This event was a big success and \$10,492 was raised.

In 2017 Mayor Bevilacqua invited their family to Vaughan City Hall where he presented them with a cheque for \$2,500 in support of their fundraising initiative. Additionally, their family efforts were recognized by our MPP Gila Martow, on October 25, 2017, at Lymphoma Canada's "Lymphoma Awareness Day at Queen's Park".

On June 9, 2018, they held their annual lemonade stand and have had the honour of being invited to The Mayor's Gala In June 2018.

In Jordyn, Jenna & Elise's Words: "At the age of 45, my father, Stewart Zaracoff, lost his life to Lymphoma leaving behind our young family. His passing was extremely heartbreaking, as we no longer had our rock. My father's last words to my mom, sister and I were, if anything happens, you have to move on. He wanted my family to be prepared for what was to come. Since his passing, we have been inspired to carry on his legacy."

They have far surpassed their goals but continue to raise funds for this cause through their annual lemonade stand and gala. They are proud to say that "as a family, we have raised over \$46,419 for a cause that is so close to our hearts."

Thank you Zaracoff family for your continued support.



L to R: Jordyn, Jenna & Elise Zaracoff



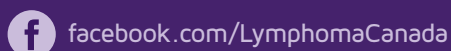
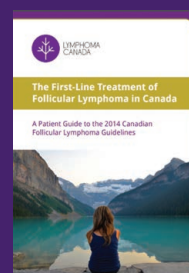
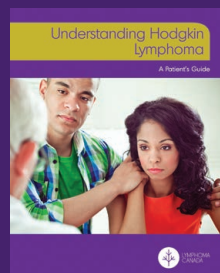
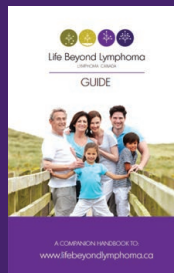
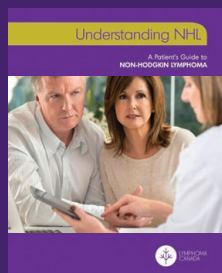
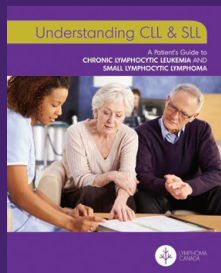
Dancing at Jenna's Lemonade Stand



Stewart Zaracoff

PATIENT RESOURCES

Lymphoma Canada offers a wide range of patient support and educational literature. Our resource materials are available in both English and French for patients and their families at no cost. To order your copy today, please visit our website at www.lymphoma.ca for further information, or call us at 1-866-659-5556.



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