A YEAR OF EDUCATION & SUPPORT

2017 ANNUAL REPORT
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.

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

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

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

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

**MONTELL, 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.

**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

**LOCATIONS**
- Montreal
- Toronto
- Ottawa
- Quebec City
- Vancouver
- Kitchener-Waterloo

**SPEAKERS**

**MONTRÉAL, SEPTEMBER 15-16**

- DR. NATHALIE JOHNSON
  Jewish General Hospital, Montreal, QC
- DR. DAVID MACDONALD
  The Ottawa Hospital Cancer Centre, Ottawa, ON
- DR. APRIL SHAMY
  Jewish General Hospital, Montreal, QC
- DR. DENIS CLAUDE ROY
  Maisonneuve-Rosemont Hospital, Montreal, QC
- DR. KELLY DAVISON
  MUHC, Montreal, QC
- DR. ISABELLE FLEURY
  Hospital Maisonneuve-Rosemont, Montreal, QC
- DR. ROB LAISTER
  Princess Margaret Cancer Centre, Toronto, ON
- DR. CAROLYN FAUGHT
  The Ottawa Hospital Cancer Centre, Ottawa, ON
- DR. NATASHA KEKRE
  The Ottawa Hospital Cancer Centre, Ottawa, ON

**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.

**TOPICS**
- The Changing Landscape of Lymphoma
- New and Emerging Treatment Options
- Survivorship Issues
- 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
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- Understanding Clinical Trials
- Fear of Recurrence

**LOCATIONS**
- Toronto
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- Kitchener-Waterloo

**SPEAKERS**

**TORONTO, SEPTEMBER 29-30**

- DR. HAROLD J. OLNEY
  Hematologist-medical oncologist
  Head of the Department of Hematology-Transfusion Medicine
  University Hospital of Montreal (CHUM)
- DR. MALCOLM FARMER
  Professor of Medicine, University of Toronto
- DR. JOHN KURUVILLA
  Clinical Director of the Specialist Haematological Malignancy Diagnostic Service
  The Royal Marsden, London, UK
- DR. CLAIRE DEARDEN
  Assistant Professor of Medicine, University of Toronto
- DR. JOHN KURUVILLA
  Hematologist-medical oncologist
  Head of the Department of Hematology-Transfusion Medicine
  University Hospital of Montreal (CHUM)

**KEYNOTE SPEAKER**

- DR. ISABELLE BENCE-BRUCKLER
  Consultant Hematologist
  Head of the Chronic Lymphocytic Leukemia Unit
  The Royal Marsden, London, UK
- DR. CLAIRE DEARDEN
  Assistant Professor of Medicine, University of Toronto
- DR. JOHN KURUVILLA
  Hematologist-medical oncologist
  Head of the Department of Hematology-Transfusion Medicine
  University Hospital of Montreal (CHUM)
- DR. HAROLD J. OLNEY
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**SESSIONS**

- **EDUCATIONAL SESSIONS**
  - Treatment Options
  - Fear of Recurrence
  - Use of Medical Marijuana
  - Surviviorship Issues

**PATIENT CONFERENCES**

- **MONTREAL, SEPTEMBER 15-16**
  - Approximately 130 healthcare professionals, patients, and caregivers gathered to learn about the changing landscape of lymphoma.
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- **TORONTO, SEPTEMBER 29-30**
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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.
Life unlimited by lymphoma.

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

Over 60 different subtypes have been identified.
Over 100,000 Canadians live with lymphoma.

5th most common cancer in Canada.

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

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Dr. Pamela Skrabek | Winnipeg, MB
Cancer Care Manitoba
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Tom Baker Cancer Centre
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 initiatives. 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 “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.
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.