



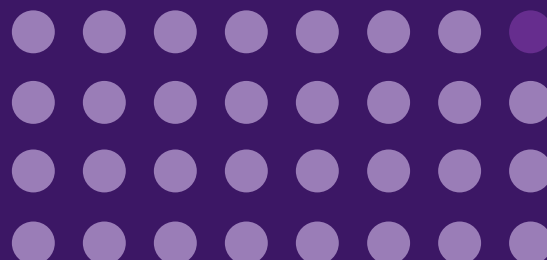
11,400 new cases in 2016



9 people will die each day



5th most common cancer



31 people diagnosed each day



LYMPHOMA  
CANADA

## A YEAR OF EVIDENCE & ACTION

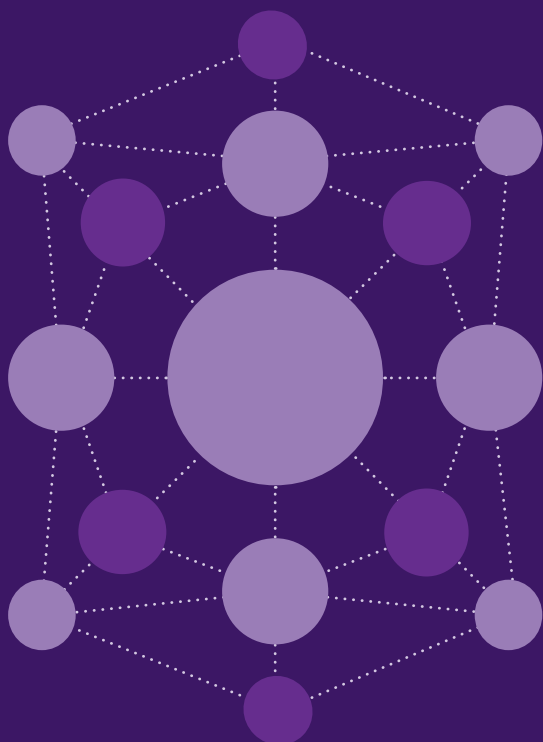
### 2016 ANNUAL REPORT



One new case  
every 45 minutes



3,500 deaths  
in 2016



Over 60 subtypes



There are over 100,000 people  
living with lymphoma



# A LETTER FROM THE CEO AND BOARD CHAIR

## A YEAR OF EVIDENCE AND ACTION

2016 marked an unprecedented year for new lymphoma therapies. Lymphoma Canada prepared a submission representative of the patient voice for every emerging lymphoma therapy being assessed for public reimbursement in Canada, through the pan-Canadian Oncology Drug Review (pCODR) and Institut national d'excellence en santé et en services sociaux (INESSS). These ten reports included carefully aggregated and analyzed patient data gleaned from our lymphoma community via online surveys and in-person interviews. The number of new treatments for lymphoma, with many of these therapies having reduced side effects and easier administration, is bringing hope to patients that they will live long, productive lives after a lymphoma diagnosis.

Over the course of 2016, our team also created three new patient resource manuals that have been extremely well-received by patients and clinicians alike: *Understanding Hodgkin lymphoma*,

*Understanding NHL* and *Understanding CLL & SLL*. Two new brochures, also available in both official languages, provide patients with valuable information about clinical trials and *Watch & Wait* for follicular lymphoma.

In addition, 13 live educational forums held across Canada and webinars available nationally provided 550 patients and healthcare professionals the opportunity to learn more about lymphoma and the cancer journey.

Lymphoma Canada continues to act as the voice of the lymphoma community, both nationally and provincially. Thanks to your support, we are empowering our patients to live a *Life Unlimited by Lymphoma*.

Sincerely,



Robin Markowitz



SHARLENE SMITH BOARD CHAIR



ROBIN MARKOWITZ CEO



3 new patient  
resource manuals



13 live educational  
forums



550 patients &  
healthcare professionals





## OUR VISION



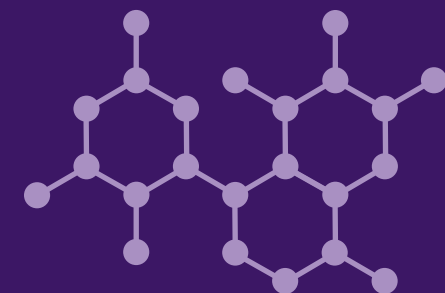
Life unlimited by lymphoma.

## OUR MISSION



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

## OUR STRUCTURE



We are Canada's only national organization focused entirely on lymphoma. As a registered charity, we are led by a volunteer board of directors from across Canada. Our board includes skilled professionals who are also lymphoma patients, family members, caregivers and doctors. A small, dedicated staff brings expertise in program implementation, communications, fundraising, and administration. We are guided by expert members of our Scientific Advisory Board and Nursing Advisory Board. Lymphoma patients and caregivers across the country help organize, and participate in, education events, support groups, and online forums.

Lymphoma Canada operates in both official languages, with staffed offices in Ontario and Quebec and a volunteer presence across the country.





2016/2017

## BOARDS

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Cancer Care Manitoba  
Dr. Douglas Stewart Calgary, AB  
Tom Baker Cancer Centre

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Julie Mendelson Toronto, ON  
Carol Peebles Prince George, BC  
Barry Reznick Thornhill, ON  
Diane Thibeault Laval, QC  
Tony Tse Toronto, ON



# EDUCATIONAL SESSIONS

In 2016, the World Health Organization (WHO) released an updated classification of lymphoid cancers, now listing over 60 subtypes. With a lymphoma landscape that is continuously changing, providing the most up-to-date information is more important than ever.

It is critical that patients and caregivers, especially those facing a new diagnosis, have quality, and current information on all aspects of their cancer.

This year, Lymphoma Canada was proud to host thirteen in-person educational sessions in Quebec, Ontario and British Columbia, serving over 400 patients, healthcare professionals and caregivers live, and over 150 individuals via 5 webinars.



## LOCATIONS

- Gatineau
- Sherbrooke
- Hamilton
- Toronto
- Kitchener
- Vancouver
- Montreal
- Waterloo



## TOPICS

- Connaissez-vous votre sous-type? Know Your Subtype
- Coping with Cancer — Mindfulness
- Dealing with Infertility
- Living Well with Lymphoma
- L'observation vigilante Watch and Wait
- Stress and stress reduction
- The Effects of Chemotherapy on Cognitive Functioning
- The Latest Treatments for Lymphoma



## SPEAKERS

DR. KARIM ABOU-NASSAR  
CISSS de l'Outaouais

MARYAM ALRIFAEI  
Oncology Pharmacist  
CISSS de l'Outaouais

GHISLAIN BÉRARD  
Oncology Pharmacist  
CIUSSS de l'Estrie – CHUS

DR. ALAIN BESTAVROS  
Hôpital de la cité de la Santé

DANY BEAULIEU  
Hematology pivot nurse  
CISSS de l'Outaouais

DR. JORGE CASTILLO  
Dana Farber Cancer Institute/  
Brigham and Women's Cancer  
Center

DR. CHRISTINE CHEN  
Princess Margaret Cancer Centre

DR. JOE CONNORS  
BC Cancer Agency

DR. KELLY DAVISON  
McGill University Health Centre

DR. JOANNA GRACYK  
Grand River Regional Cancer  
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DR. EMMA GUILD  
Jett Psychological Services

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Clinical Nurse Specialist  
Princess Margaret Cancer Centre

LINDA MORINELLO  
Certified Integrative Nutrition Health  
Coach and a Certified Life Coach

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Centre hospitalier de l'Université  
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DR. MICHEL PAVIC  
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DR. KERRY SAVAGE  
BCCA

DR. LAURIE SEHN  
BCCA

DR. AXEL TOSIKYAN  
Hôpital du Sacré-Coeur de  
Montréal

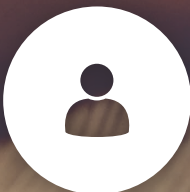
DR. DIEGO VILLA  
BCCA



13 educational  
events



400 + patients, caregivers  
and HCPs in-person



over 150  
individuals online



5 webinars



# PATIENT

# RESOURCES

To help navigate the ever-changing lymphoma landscape, patients need credible, useful information, presented in an easy to understand format. Lymphoma Canada made it a top priority in 2016 to launch 3 new patient resource manuals in BOTH official languages.

- **UNDERSTANDING CLL & SLL:** A Patient's Guide to Chronic Lymphocytic Leukemia and Small Lymphocytic Lymphoma
- **UNDERSTANDING NHL:** A Patient's Guide to Non-Hodgkin Lymphoma
- **UNDERSTANDING HODGKIN LYMPHOMA:** A Patient's Guide

In addition, Lymphoma Canada created 2 new pamphlets in response to clinicians' requests.

## 1 A PATIENT'S GUIDE TO WATCH & WAIT FOR FOLLICULAR LYMPHOMA

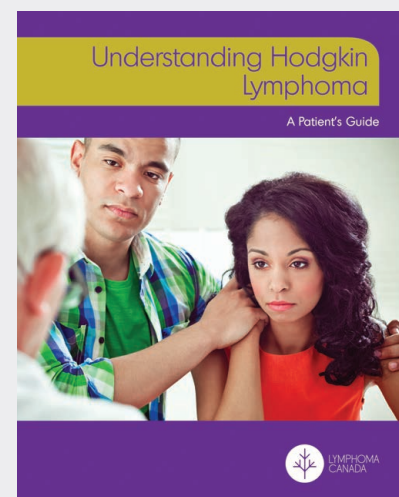
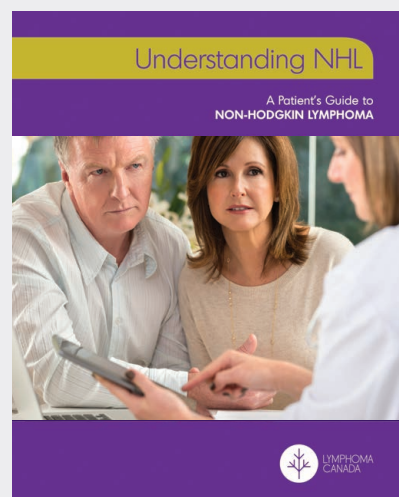
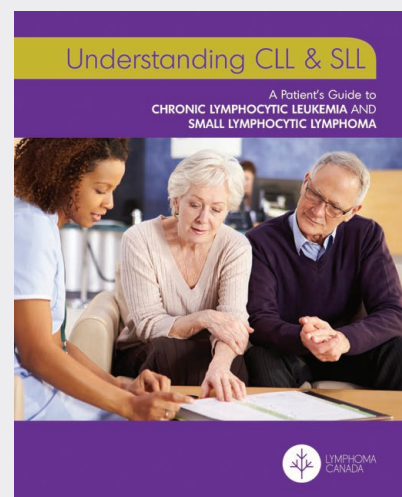
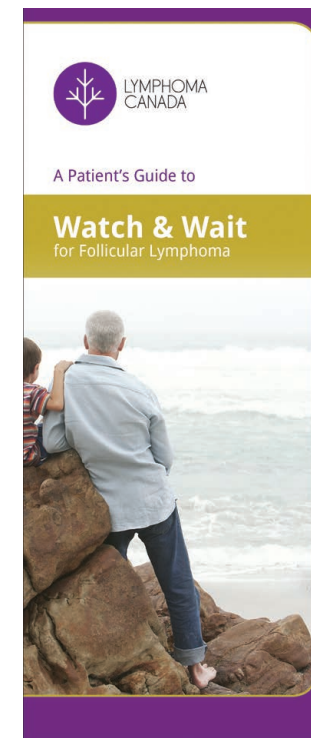
Watch & wait, or active monitoring, is a difficult concept for patients to understand as it goes against the global norm for cancer that says early diagnosis and treatment leads to better outcomes. Instead, for indolent lymphomas, some patients

wait years before starting treatment. During watch & wait, the cancer is monitored by a medical team, who will determine the best time to initiate treatment. The new brochure, **A Patient's Guide to Watch & Wait for Follicular Lymphoma**, has been created to help patients and caregivers understand and adapt to this treatment phase.

## 2 CLINICAL TRIALS: IS PARTICIPATING THE RIGHT CHOICE FOR YOU?

For some patients, the best treatment option is participation in a clinical trial. To help patients facing this decision, Lymphoma Canada created the pamphlet **Clinical Trials: Is Participating the Right Choice For you?** This brochure explains what clinical trials are, addresses misconceptions, and explains participants' rights.




All materials created by Lymphoma Canada are vetted by our Scientific Advisory Board, Nursing Advisory Board and Patient & Family Advisory Committee. This ensures information is medically accurate, up-to-date, comprehensive and user-friendly.



# PATIENT

# SUBMISSIONS

New therapies for lymphoma are vital to allow patients to live long, healthy lives with limited disease impact. Lymphoma Canada remains committed to gaining Canadian patients access to new drugs that will improve survival rates with fewer side effects than currently available treatments. In 2016, Lymphoma Canada prepared **7 pCODR** and **3 INESSS** patient submissions for new therapies for chronic lymphocytic leukemia, Hodgkin lymphoma, follicular lymphoma, mantle cell lymphoma, and Waldenstrom's macroglobulinemia.

The experiences of		
		
732 Patients	100 Caregivers	Over 8 Countries
were captured in these submissions to ensure that patient values were represented in the drug review process.		

Lymphoma Canada engages Canadian patients and caregivers via online surveys and in-person interviews, and also captures international patient voices. This ensures that there is input from individuals who have had experience with the new therapy, as Canadians often have had limited exposure to the treatment.



# LYMPHOMA CONFERENCES, EVENTS & NETWORKS

Staying abreast on the most current information in the lymphoma community is integral to supporting patients and caregivers across the country. Thanks to the support of our donors, dedicated volunteers and staff of Lymphoma Canada were able to contribute to the following events and networks in 2016:

<p><b>1</b> CANADIAN CONFERENCE ON LYMPHOPROLIFERATIVE DISORDERS (CCOLD)</p> <p><i>Lake Louise, Alberta</i> March 2016</p>	<p><b>2</b> CANADIAN AGENCY FOR DRUGS AND TECHNOLOGIES IN HEALTH (CADTH) SYMPOSIUM</p> <p><i>Ottawa, Ontario</i> April 2016</p>	<p><b>3</b> THE CANADIAN CANCER TRIALS GROUP ANNUAL SPRING MEETING</p> <p><i>Toronto, Ontario</i> April 2016</p>
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<p><b>4</b> ONCOLOGY ROUNDTABLE OF PHARMACARE, hosted by CCSN</p> <p><i>Toronto, Ontario</i> April 2016</p>	<p><b>5</b> CANADIAN HEMATOLOGY CONFERENCE</p> <p><i>Toronto, Ontario</i> September 2016</p>	<p><b>6</b> CANADIAN CLL MEETING</p> <p><i>Winnipeg, Manitoba</i> September 2016</p>	<p><b>7</b> LYMPHOMA RESEARCH FOUNDATION CONFERENCE</p> <p><i>Chicago, Illinois</i> October 2016</p>
<p><b>8</b> HEALTH TECHNOLOGY ASSESSMENT hosted by CCAN</p> <p><i>Toronto, Ontario</i> October 2016</p>	<p><b>9</b> 2016 CANADIAN ASSOCIATION OF NURSES IN ONCOLOGY (CANO/ACIO) ANNUAL CONFERENCE</p> <p><i>Calgary, Alberta</i> October 2016</p>	<p><b>10</b> BEST MEDICINES COALITION ANNUAL CONFERENCE</p> <p><i>Toronto, Ontario</i> November 2016</p>	
<p><b>11</b> LYMPHOMA COALITION GLOBAL SUMMIT</p> <p><i>San Diego, California</i> November 2016</p>	<p><b>12</b> CLL 'HORIZONS' hosted by CLL ADVOCATES NETWORK (CLLAN)</p> <p><i>Belgrade, Serbia</i> November 2016</p>	<p><b>13</b> ASH (AMERICAN SOCIETY OF HEMATOLOGY) ANNUAL MEETING</p> <p><i>San Diego, California</i> December 2016</p>	

## LYMPHOMA CANADA'S NURSING AWARD OF EXCELLENCE

Cheryl Howe was announced as the recipient of this year's Lymphoma Canada Nursing Award in Honour of Estéphanie Jémus-Gonzalez. The award was presented at the CANO/ACIO Awards of Excellence Ceremony.

As triage coordinator at the Tom Baker Cancer Centre, Cheryl has taken a leadership role to ensure comprehensive care. She identified key areas to advance capacity when faced with a rapidly expanding hematology patient population, addressing gaps in service and establishing evidence-based, efficient patient care.

She has also spent six years volunteering her time to facilitate a monthly lymphoma support group at a local non-profit organization. Her colleagues describe her as a skillful mentor and visionary leader for oncology nursing. Cheryl's strong patient advocacy, program development and patient support reflect the criteria and spirit of this award.

## CANADIAN TASK FORCE ON AYA WITH CANCER

As part of our Adolescent and Young Adult Pilot Program, Lymphoma Canada's National Director, Education & Services participated in the Canadian Task Force on AYA with Cancer on February 22, 2016. The workshop primarily focused on a new Canadian governance model for cancer control within this age bracket. Lymphoma Canada remains committed to expanding resources and support for this community.



Cheryl shown at center.

## CANADIAN CANCER ACTION NETWORK

The CEO, Lymphoma Canada is a member of the board of the Canadian Cancer Action Network (CCAN) and is the CCAN representative on the CADTH - Patient Community Liaison Forum. Since 2001, CCAN has served as an umbrella organization dedicating to connecting member organizations from across Canada to work underway in cancer control. Today, CCAN represents the views and interests of diverse member organizations working together in support of the innovative “CCAN Collaborative Model of Engagement,” an approach that serves as a virtual bridge to connect organizations across Canada to one another ensuring work underway in cancer control moves forward in unison. Through partnerships and resource sharing, CCAN works collaboratively with stakeholders in order to maintain momentum, avoid duplication and advance shared areas of interest to patients, caregivers and their families.



## CLL ADVOCATES NETWORK

The National Director, Education & Services for Lymphoma Canada is a member of the board of the new CLL Advocates Network (CLLAN). CLLAN is a global network created to share knowledge and experience amongst patient groups with a full or partial focus on chronic lymphocytic leukemia, and advocate for equitable standards of care. Networks established for other diseases have led to numerous successes globally, including the establishment of treatment standards, an expanded number of patient groups dedicated to supporting patients, vast improvements in patients' understanding of clinical trials and the drug development process, and the facilitation of key knowledge sharing. CLLAN wants to see these same successes for CLL. The organization's mission is to enhance CLL patient care and improve outcomes.





# FUNDRAISING & COMMUNITY EVENTS

## | TAKE IT TO THE MAT, MONTRÉAL

The inaugural yoga and wellness event held in October at McGill University was a great success. Tara Schwartz, from CTV MC'd and introduced keynote Sandra Reich, from the Montreal Centre for Anxiety, who spoke on "Being Your Best Self", a topic that resonated well with the wellness crowd. Participants, sponsors and donors helped the event raise over \$50,000 to help support the mission of Lymphoma Canada.



## | TAKE IT TO THE MAT, TORONTO

Lymphoma Canada's 3rd annual take it to the mat, The Great Yoga & Wellness Revolution fundraiser was held at the beautiful bright space at CBC, Toronto, The Glenn Gould Studio. The delightful Master of Ceremonies, Robert Hawke, and talented keynote speaker—Comedian Susan Stewart—had the group exercising their laughter muscles.

Collectively, our sponsors, participants and donors, who generously contributed to this one-of-a-kind pledge-driven fundraiser, raised \$145,000.



## BUFFA DISTRIBUTION'S PRO-AM BOWLING EXPO

On Saturday, August 13, 2016 in Boucherville, QC, close to 200 bowling enthusiasts came out to play with the best in the sport, in support of Lymphoma Canada. It was a fun-filled day with food, beverages, desserts (and of course bowling!) sponsored by Buffa Distribution. This event began in 2015, when Customer Service Director, Vince Gaudio, was diagnosed with mantle cell lymphoma. This diagnosis affected not only his immediate family, but his extended family as well, Buffa Distribution. Mark Buffa, CEO, Frank Buffa, Founder, and Vince Gaudio have been working with Lymphoma Canada to raise awareness and funds. The Buffa team has raised over \$13,000 over the past 2 years through the Expo, and a raffle and silent auction.



## THE CREIGHTON CLASSIC PAR FOR THE CURE GOLF TOURNAMENT

The sixth annual - Par for the Cure - "Wild Wild West" Golf Tournament helped raise over \$72,000 to support Lymphoma Canada's mission.



## WORLD LYMPHOMA AWARENESS DAY

On September 15, 2016, to mark World Lymphoma Awareness Day (WLAD), volunteers from the Southwestern Ontario Chapter went out to Conestoga Mall, Waterloo, ON, to help spread the word about Lymphoma Canada's mission.



Left to Right: Mary Jon Lachance, Tim Sperling and Robin McQuillan



## OUR SOCIAL

## IMPACT

In 2016, Lymphoma Canada reached more individuals than ever before through our social media and online channels. Lymphoma Canada has a plan that will see these figures dramatically increase over the next 2 years to expand our reach to patients and caregivers.



TWITTER



1,027 Followers



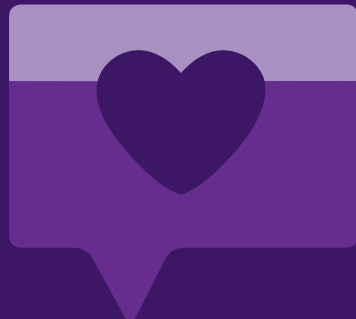
99,080 Impressions



FACEBOOK



2,702 Likes



11,030 Post Reactions



123,096 Post Reach



WEBSITE



563,717 Sessions

GENDER



72% Female



28% Male

LANGUAGE

EN



57% English

FR



43% French



YOUTUBE



9,750 Views



23,221 Minutes of Watchtime



466,075 Unique Users



# INDIVIDUAL

# DONORS

Lymphoma Canada relies on the generosity of its donors. We are grateful for the incredible support offered by these individuals in 2016. Below is a list of all individual donors who contributed over \$200 this year.

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Ronald Anthony	Frieda Dym	Julie McDowell	Marc St-Pierre
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Andrea Derby	Robin Markowitz	Carla Snaith	

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# & PARTNERS

Thanks to the commitment of our corporate partners, both in-kind and financial, we are able to provide patients and care-givers with exceptional support and services. Each year we are astounded by the overwhelming generosity of our partners.

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LYMPHOMA  
CANADA

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General inquiries [renseignement@lymphoma.ca](mailto:renseignement@lymphoma.ca) Website [lymphome.ca](http://lymphome.ca)

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