



LYMPHOMA
CANADA

2014
ANNUAL REPORT

EDUCATION • SUPPORT • RESEARCH

JOINING THE BOARD 10 YEARS AGO WAS PERSONAL.

My little sister was battling cancer.

Like most people, I was only vaguely familiar with lymphoma. Then, my sister was diagnosed and that, along with everything else, rapidly changed. I am from a close extended family. We banded together to support my sister through her treatment. Along the way, we developed an in-depth understanding of lymphoma cancer and the impact it has on the patient and their loved ones.

"Why her?" I often asked myself. I soon learned that lymphoma is an equal opportunity cancer. It strikes randomly and doesn't discriminate on account of age, gender, ethnicity or socio-economic level. No one is immune.

My family's search for information led us to Lymphoma Canada. Their resources shed light on many of complex issues faced by lymphoma patients. Ten years ago I decided to lend my expertise to building this volunteer driven organization that played an integral role in my family's journey and I have never looked back.

I was honoured to accept the role of Chair of the Board of Directors. This past year has been one of innovation. We developed new tools to educate and support patients and health care professionals. We spoke to decision makers on behalf of lymphoma patients and imparted their needs. We watched as

science provided new, more efficacious treatments and the respective regulatory bodies heard our pleas and ensured they were reimbursed and thus accessible.

Lymphoma is the 5th most common cancer in Canada and yet awareness is low. Through our events like *take it to the mat*, it is our aim to heighten awareness of this disease to improve the current reality – it takes most patients an average of six months to obtain a proper diagnosis; many patients are misdiagnosed time and time again.

Thanks to Lymphoma Canada, my family was not alone in our time of need. My sister has been in remission for over 10 years and enjoys an excellent quality of life. We are among the lucky ones. Lymphoma Canada continues to fund Canadian research to improve treatment and ultimately, find a cure.



Nick Iozzo
Chair, Board of Directors



A YEAR OF UNPRECEDENTED HOPE

In 2014, Lymphoma Canada found ourselves sharing in the excitement of a changing Canadian landscape for lymphoma patients. New and emerging therapies provided unprecedented hope.

In addition to our traditional education and support curriculum for patients, caregivers and health care professionals, we embarked on developing new collateral to address the treatments. Educational forums on new and emerging therapies were developed to facilitate a better understanding of these therapies including: data from clinical trials, availability and access.

Our distinguished Scientific Advisory Panel (SAB) recognized the importance of incorporating the new treatment options into the standard of care. Lymphoma Canada's SAB created the first National Guidelines for follicular lymphoma first-line. Published in the journal of Lymphoma, Myeloma and Leukemia, the Guidelines address the best standard of care in Canada for the most common type of lymphoma.

Our comprehensive patient portal "Life Beyond Lymphoma", launched in November, speaks to the patients in their off-treatment phase of their cancer journey; a phase fraught with

uncertainty. Voice navigated, complete with first person patient stories via video, the Portal assists patients in navigating the issues they confront as survivors such as loss of fertility, sexuality, returning to work and fear of relapse.

Lymphoma Canada continues to make inroads as we make the voice of the lymphoma community heard at the provincial and federal level and provides volunteers with the clinical background to garner support for those public policies most important to the lymphoma community.

Thanks to you, our thoughtful and generous supporters, Lymphoma Canada continues to ensure that the lymphoma community is empowered with comprehensive resources that enable them to make informed decisions through their patient journey.



Robin Markowitz CFRE
Chief Executive Officer



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We are Canada's only national organization focused entirely on lymphoma.

A registered charity, we are led by a volunteer board of directors drawn from the Canadian lymphoma community. Our board includes lymphoma patients and medical and research professionals. A small, dedicated staff brings expertise in program implementation, communications, fundraising, and administration. We are guided by expert members of a Scientific Advisory Board. Lymphoma patients 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.

MISSION

We empower lymphoma patients and the lymphoma community through education, support, and research.

VISION

To support and educate people in the lymphoma community and to eradicate lymphatic cancers.

SCIENTIFIC ADVISORY BOARD

- | | |
|----------------------------|---------------------|
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| Dr. David Hodgson | Dr. Doug Stewart |

THERE ARE OVER 100,000 PEOPLE LIVING WITH LYMPHOMA (INCLUDING CLL) IN CANADA

EVERY
45
MINUTES
one Canadian
is diagnosed with
lymphoma

OVER
11,400
CANADIANS
will be
newly diagnosed
in 2015

There are over
3,500
DEATHS PER YEAR
due to lymphoma

That is
9 PEOPLE
PER DAY
or one person
every 2.5 hours

There are over
60
different kinds
of lymphoma

In Canada,
lymphoma is the

5TH

most common type of cancer in adults and the
MOST COMMON TYPE
among teenagers and young adults.

Lymphoma patients
often relapse and often
MORE THAN ONCE

PATIENTS & CAREGIVERS

Patients and their caregivers have questions, lots of questions and a burning desire to learn more about all aspects of lymphoma. Lymphoma Canada’s live Educational Forums provide a forum for patients to learn from oncologists, nurses, social workers, psychologists and other patients. Last year we hosted 16 forums for patients in Ontario and Quebec along with two webinars that were available to patients across Canada on a variety of topics.

FROM INNOVATION TO ACTIVATION - MONTREAL

Participants assembled at the Delta hotel in downtown Montreal to gain information about new and emerging therapies in the pipeline for Hodgkin lymphoma, non-Hodgkin lymphoma and CLL (Chronic Lymphocytic Leukemia).

Dr. Nathalie Johnson, clinician scientist and hematologist-oncologist at the Lady Davis Institute for Medical Research of the Jewish General Hospital gave a detailed presentation on how medication works on a cellular level prompted an enthusiastic Q&A period afterward. Dr. Johnson was joined by Dr. Pierre Laneuville, former Head of Hematology for the McGill University Health Centre (MUCH) and Mrs. Nicole Giroux, member of Coalition Priorité Cancer au Québec.

WEBINAR: NEW AND EMERGING THERAPIES - TORONTO AND WATERLOO

The banquet room at the Hilton downtown was packed with patients eager to hear vital information on new drugs therapies for Hodgkin, non-Hodgkin and CLL lymphomas and how to gain access to them. Dr. John Kuruvilla, medical oncologist/hematologist at Princess Margaret Hospital, introduced eight new drugs and their innovative approach to lymphoma treatment. Louise Binder, lawyer and advocate, explained the Canadian/Ontario drug approval and reimbursement process and the role of patients and organizations in advocacy. The SW Ontario Chapter gathered at the Waterloo Inn and Conference Hotel to participate via webinar. Their questions and comments sent electronically were addressed by the speakers in Toronto.



Robin Markowitz, CEO and Samia Hadj Zoufir, Montreal Chapter Member



Dr. Nathalie Johnson, Dr. Pierre Laneuville, Nicole Giroux



2014 EDUCATIONAL FORUMS

TOPICS

- Community resources 🌿 Symptom management 🌿 Meditation 🌿 Lymphoma survivorship 🌿
- A brief history of cancer 🌿 Watch & wait 🌿 A patient perspective from Nepal 🌿
- Stem cell transplants 🌿 The caregiver experience 🌿 Payment of medication in Canada 🌿
- Health Canada vs. reimbursement 🌿 Benefits of yoga for lymphoma patients 🌿
- Reimbursement of oncology drugs in Quebec 🌿 What survivorship means 🌿
- Current issues in drug access 🌿 Evaluation of new drugs (INESSS) 🌿
- The challenges that accompany surviving lymphoma 🌿
- Tips and tools for thriving as a survivor 🌿

The Drug Review Process in Quebec

- Quebec City
Marquis Nadeau, Pharmacist

Incorporating Yoga into your Lymphoma Journey

- Waterloo
Maggie French, yoga instructor

From Innovation to Activation: New and Emerging Drug Therapies and How to Gain Access to the Best Treatments Available

- Waterloo, Toronto
Dr. John Kuruville,
Princess Margaret Hospital
Louise Binder, B.A., LL.B., LL.D (hon)
- Montreal
Dr. Pierre Laneuville, Royal Victoria Hospital, Dr. Nathalie Johnson, Jewish General Hospital, Nicole Giroux, patient advocate

Living Well With Lymphoma

- Montreal
Dr. Harold Olney, head of hematology, Hôpital Notre-Dame and Lymphoma Canada Board Member

Restoring Balance

- Waterloo
Robin McQuillan and Shawn Sajkowski, lymphoma survivors

Surviving and Thriving with Lymphoma

- Hamilton
Robin McQuillan, lymphoma survivor

Quality of Life: A Global Perspective

- Kitchener
Karen Van Rassel, Executive Director, Lymphoma Coalition

The Latest Advances in Treating Lymphoma

- Oakville
Dr. Ronan Foley, hematologist, Juravinski Cancer Centre

"Mom, Dad, Don't Worry - I Can Deal With This. Remember, I'm An Adult!"

- Montreal
Dr. Sylvie Aubin, psycho-oncologist, Segal Cancer Centre, Jewish General Hospital



Dr. Harold Olney, National Board Member

Living Well With Lymphoma

- Niagara Region
Niagara Health System, Walker Family Cancer Centre

Lymphomation Conference 2014

- Montreal
Dr. Phil Gold, Dr. Harold Olney, Denis Ladouceur, Fabiola Desrosiers, RN, Anita Mehta, RN, Ph.D

What is a Clinical Trial and New and Emerging Drug Therapies for Lymphoma

- Ottawa
Dr. Isabelle Bence-Bruckler and Dr. Carolyn Faught, The Ottawa Hospital

LIFE BEYOND LYMPHOMA

Life Beyond Lymphoma is an online portal created for patients and caregivers, offering comprehensive resources related to the off-treatment phases of the lymphoma experience. Whether it's living with a lymphoma that is not curable, wondering when treatment (or re-treatment) will be needed, or dealing with the effects of chemo and radiation as a young adult, lymphoma survivorship carries its unique set of issues.

"When I was diagnosed with lymphoma, I had no idea how different my journey would be from what I knew of most cancer patients. To begin with, I was told that I wasn't even going to get treatment right away."
- CLL lymphoma patient

"Sometimes I feel so different from my friends at university. I am the only one who has had cancer, who has faced my mortality head-on. Sometimes I just can't relate to them, and of course not one of them can relate to what I have been through either." - Hodgkin lymphoma patient

Life Beyond Lymphoma addresses these types of situations that are unique to lymphoma patients, such as the protocol of Watchful Waiting.

It is the first healthcare initiative in Canada to use Interactive Conversation, offering the user a more "human" online experience.

1200 users per month, 25% of whom are returning visitors. Through their responses to the questions, we are able to collect important metrics, which are already helping us to plan upgrades and improvements to the site.

Lymphoma Canada has conducted 18 webinars and in-person presentations of the portal, to major cancer centres across the country and will continue through 2015.



The LBL Portal includes videos from patients sharing their first-person testimonials.

SUPPORT

SUPPORTING ACCESS TO THE BEST TREATMENTS AVAILABLE

Lymphoma Canada's role as the "patient voice" includes patient submissions to the regulatory bodies, pCODR and INESSS. Through our patient and caregivers surveys, we provide the patient/caregiver experience with their current therapies and their perspective on new treatments. Through our national and international network, we provide patients' commentary based on their experiences with the said therapies. Even the most compelling statistical empirical data cannot fully portray the effect on the quality of patients' lives and the lives of their caregivers.

PEER MENTORING PROGRAM

Lymphoma Canada's Peer Mentoring program matches patients and caregivers with survivors whose experience in some way mirrors their own. The program's success is in large part due to the flexibility it offers to patients and caregivers alike. Lymphoma is a complex cancer, with varied diagnosis and treatment experiences, and affects people of all ages, from youth to seniors. The program was created to recruit caring and gifted mentors with a wide range of diagnoses and experiences, in order to respond to the vast array of received requests over several years and provides for both extended mentoring relationships as well as one-time interactions.

A unique feature of the Lymphoma Canada Peer Mentoring program is in its provision for caregiver mentoring. Caregivers are an integral part of the cancer experience and find great comfort in being able to ask questions of other loved ones about their role in the lymphoma journey. In addition to the option of being matched with other caregivers, based on caregiver requests, our Peer Mentoring program allows caregivers to be matched with patient mentors as well, when they are seeking information about the patient experience that may help inform their role as support persons.

"Thank you for matching me with Tony. Before I spoke with him, I actually thought I was the only one who had gone through this. He really helped to ease my fears and help me face the next steps."

- Lymphoma patient, NHL

FOLLICULAR GUIDELINES

Follicular lymphoma (FL) is the most common form of indolent (slow growing) non-Hodgkin's lymphoma (NHL) — a disease that can, in many cases, grow to a more aggressive form of cancer. Up until now, there were no national guidelines for the treatment of this disease. Physicians and oncology centres across the country had dealt with FL on a purely provincial basis — evolving their own sets of best practices as they went. They faced many challenges, such as the question of when to start therapy, how to navigate through treatment options, and the end point to which success of the individual treatment should be measured.

The practical effect of the guidelines is that care for FL nationwide will be up-to-date, consistent and will ensure that patients with FL have equitable access to the best available care. Dr. John Kuruvilla is Staff Physician of Medical Oncology and Hematology at Princess Margaret Hospital in Toronto and sees the new guidelines as essential in ensuring effective, equitable treatment.

“When clinicians met across the country we noticed that there were similarities in how Canadians wanted to manage these diseases but there were limitations from provincial approvals and funding — particularly novel drugs et cetera. In a universal healthcare system, where healthcare is transportable we wanted to ensure some basic standard across the country, so that equity would be achievable.” *Dr. Kuruvilla*



The First-Line Treatment of Follicular Lymphoma in Canada

A Patient Guide to the 2014 Canadian Follicular Lymphoma Guidelines



CANADIAN ASSOCIATION OF NURSES IN ONCOLOGY

Lymphoma Canada knows all too well the impact and the importance a nurse has on the life of a patient and that of their loved ones. Nurses are a wealth of information, a source of comfort and reassurance, the liaison between the home life and the hospital life of a patient and an invaluable member of a team who always has the patient's best interest at heart.

Lymphoma Canada is proud to celebrate exceptional nurses through its Award of Excellence in Hematological Oncology. The award recognizes a nurse whose actions support the concept of patient advocacy and decision making, or who promotes change within the oncology/hematology community. This year's award, presented at the 2014 Canadian Nurses in Oncology (CANO) conference, was named in memory of Nicholas Benum, a young man who died of Hodgkin lymphoma. His family was moved by the compassionate care shown him by a nurse in hematology and shared their story with Lymphoma Canada.

Congratulations to the 2014 award recipient, Edith Putuskin, RN, PhD.

Each year Lymphoma Canada funds Canadian hematological research that is focussed on lymphoma. Lymphoma Canada's Scientific Advisory Board selects which grant applications will be funded. In 2014, a Research Fellowship was awarded to McGill University professor Jerry Pelletier and his graduate student, Alexandra Katigbak.

IDENTIFYING NOVEL ONCOGENIC DRIVERS IN BURKITT'S LYMPHOMA.

Burkitt's lymphoma (BL) is a type of non-Hodgkin lymphoma. It is characterized by a mutation in a gene called *myc*, which triggers the BL cells to grow uncontrollably. However, much is still unknown about the cause of the disease. Genetic studies of BL tumours have identified a number of genes that are mutated in these tumours. The goal of our research is to determine whether these mutated genes play a role in the development of BL.

In order to determine the role of the identified mutated genes, we used a mouse model of Burkitt's lymphoma to screen each gene. These mice normally develop lymphoma due to a mutation in the *myc* gene. Blood stem cells can be manipulated to include one of the mutated genes and then transplanted into the mice to repopulate their immune system. If the gene mutation contributes to tumour formation, B-cell lymphomas develop more quickly than usual. If the mutation has no effect on tumour growth, B-cell lymphomas will develop at the normal rate.

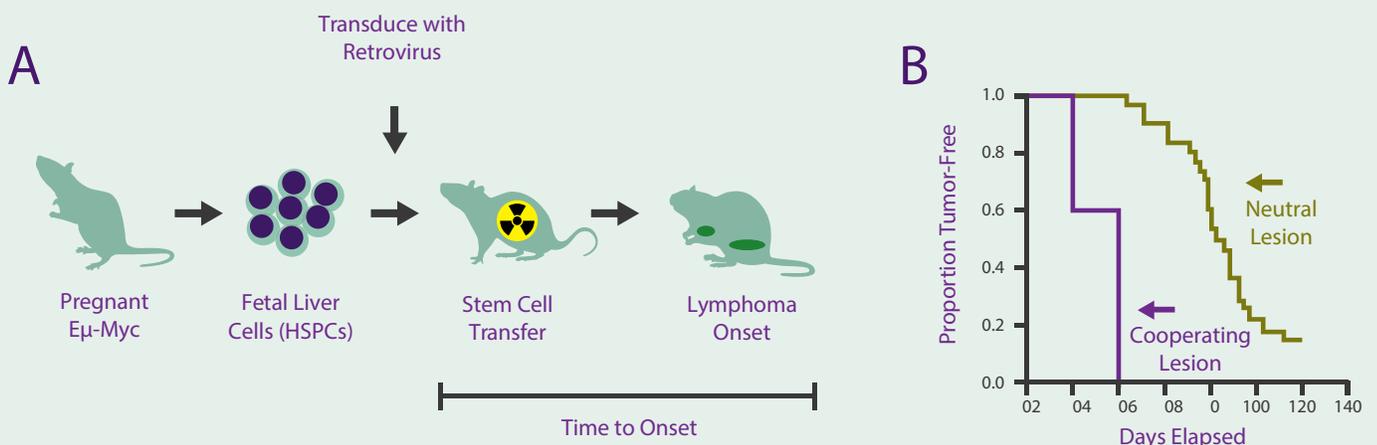
To introduce the desired gene mutations with precision we used a specialized genetic engineering tool. 91 genes that were identified from the BL genetic screening experiments were introduced into Burkitt lymphoma cells. These cells were then transplanted into mice and the time until the onset of lymphoma was monitored. The first round of experiments has been completed and we have identified genetic mutations that accelerate tumour development. Current work is directed at confirming our results and then characterizing the function of these genes. We will then conduct further experiments to identify how these genes contribute to tumour growth. Our hope is that these studies will illuminate the molecular processes involved in BL, potentially leading to future development of more effective and less toxic therapies.



McGill University Professor Jerry Pelletier



Graduate student Alexandra Katigbak





Lymphoma Canada presented its inaugural pledge-driven fundraising event, "Take it to the mat, The Great Yoga & Wellness Revolution" on Sunday, November 2, 2014, at the National Ballet School in downtown Toronto. Funds raised supported 100,000 Canadians living with lymphoma. The full day event furthered participants' knowledge on achieving optimal health through balanced nutrition, mindfulness, and the practice of yoga. Participants were encouraged to pursue their wellness journey using the tips and techniques they learned through joining the Wellness Revolution.



Trish Stratus, Fitness Icon was the MC of the inaugural titim

"It was an honor to participate in the first "take it to the mat" event. As a Lymphoma survivor who has benefited immensely from the introduction of yoga in my healing and recovery, I was ecstatic to participate in an event that truly resonated with me. From the opportunity to practice with renowned yoga instructors, the enlightening health and wellness presentations, and the touching survivor stories- this event was absolutely inspiring. It was incredible to be in the midst of so many people who wanted to make a difference. I will most certainly be participating in the event next year!"

- Alyssa Da Silva, 2014 Participant



PAR FOR *the* CURE

Terry Creighton is one of the founders of Lymphoma Canada. Terry was involved as a Board member since LC's inception in 1998 and chaired the Fundraising and Advocacy Committees. During her tenure, the organization has grown from a group of passionate volunteers to become a respected voice for lymphoma patients, and has expanded its mandate to include patient advocacy, caregiver support, and the funding of Canadian research. Terry has been a driving force over the last decade in organizing the annual golf tournament, Lymphoma Canada's signature fundraising event.

Terry is a non-Hodgkin lymphoma survivor. In 1994 after several months of uncertainty, Terry was diagnosed with an advanced stage of lymphoma and underwent chemotherapy. Years later in 2010, she relapsed and went through treatment again and she is currently in remission. Throughout this time, she has remained actively involved with Lymphoma Canada. Her commitment to increase funding for research and patient support programs led to innovative events that increased revenues and patient support vehicles.

Lymphoma Canada is deeply indebted to Terry Creighton. Her leadership and passion are responsible for the organization's growth.

The Board of Directors, staff, and volunteers unanimously voted to recognize Terry's contributions at the 2014 tournament by officially changing the name to "The Creighton Classic Par for the Cure" to reflect Terry Creighton's extensive support and tireless commitment.



GET INVOLVED. VOLUNTEER. DONATE.

It is because of the generosity and commitment of individuals, corporations, and foundations that Lymphoma Canada has been able to continue its work to achieve its mission. Thanks to you, we can ensure that no one with lymphoma has to face it alone.



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