



**Lymphoma Foundation Canada:  
uniquely lymphoma, uniquely Canadian**

## Facts:

- Lymphoma develops when an error occurs in the production of lymphocytes, a type of white blood cell found in the lymph nodes, and results in abnormal cells that become cancerous.
- Lymphoma is the fifth most common cancer and the most common blood cancer in Canada
- Lymphoma has one of the fastest rising incidence rates worldwide.
- An estimated 8600 people will be diagnosed with lymphoma in 2011 and 3310 succumbed to the disease in 2010.
- Lymphoma affects men, women and children and the incidence is on the rise in young adults and children.



## Symptoms of Lymphoma:

Symptoms of lymphoma are similar to those of other diseases and afflictions. People often first go to the doctor because they think they have a cold or respiratory infection that will not go away. Most people who have nonspecific complaints such as these will not have lymphoma. However, it is important that any person who has symptoms that persist see a doctor to confirm that no lymphoma or serious illness is present.

- Painless swelling in the upper body lymph nodes, i.e., the neck, collarbone region, armpits or groin. (A swollen lymph node is normally *NOT* as painful as an infected lymph node, which is common and can be painful.)
- Chills/temperature swings
- Fevers (especially at night)
- Unexplained weight loss
- Loss of appetite
- Unusual tiredness/lack of energy
- Persistent coughing
- Breathlessness
- Persistent itch all over the body without an apparent cause or rash
- General fatigue
- Enlarged tonsils
- Headache



Paul Weingarten  
Chair, Board of Directors



Sue Robson  
Executive Director

*uniquely lymphoma, uniquely Canadian.*

Our new tagline highlights the distinct strength of Lymphoma Foundation Canada: We are proud to be the only organization dedicated to lymphoma in Canada. These words inform our initiatives and inspire the work that we do.

2010 was a year of growth and development for Lymphoma Foundation Canada. We each took on new roles with the organization in 2010 and are honoured by the opportunity to serve lymphoma patients and their families from coast to coast in Canada.

We worked together this year to invest in the infrastructure that we need to advocate for and provide services to those living with this disease, and to build financial sustainability for Lymphoma Foundation Canada to carry out our mission.

Through our close ties with the medical community and the support of our extraordinary Scientific Advisory Board, we have provided advanced medical information about the more than 35 different types of lymphoma cancer for patients in Canada.

We would like to thank our Lymphoma Foundation Canada team - the inspiring Scientific Advisory Board and Board of Directors, and our dedicated staff and volunteers - for their enthusiasm and commitment to advancing our mission. On their behalf, we extend our heartfelt thanks to the community for your unwavering support of the work that we do to support the lymphoma community across the country.

Paul Weingarten  
Chair, Board of Directors

Sue Robson  
Executive Director

## About Us

The Lymphoma Foundation of Canada has its roots in two distinct, regional organizations, which were both founded in 1998.

**The Lymphoma Research Foundation of Canada (LRF)** was founded in Vancouver in early 1998 by Patricia Manson after she was diagnosed with non-Hodgkin lymphoma in 1997. Following her diagnosis, she searched in vain for a Canadian organization which focused on lymphoma research and ultimately established the LRF as an organization that might help others living with lymphoma. Pat passed away a short time later on May 29, 1998.

**The Canadian Lymphoma Foundation (CLF)** was founded in 1998 by Deborah Sterritt in Toronto. Deborah was diagnosed with an indolent form of non-Hodgkin lymphoma in 1995. In early 1998, Deborah also discovered that no group existed in Canada which could provide patients with the information they needed and with the help of Dr. Brent Zanke, Terry Creighton and Jane Mingay, founded the Canadian Lymphoma Foundation.

The two organizations merged in 2000 as **Lymphoma Foundation Canada**.



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

**Mission:** Lymphoma Foundation Canada provides leadership by:

- Increasing awareness within the public and health communities about lymphoma cancer;
- Educating Canadians about the signs and symptoms of lymphoma;
- Supporting individuals and families touched by lymphoma;
- Advocating for the best treatments and care for lymphoma patients; and,
- Funding medical research to discover the cause and ultimately the cure for lymphoma.

## 2010 Critical Initiatives

### Patient Education & Support

#### Resources

2010 saw the completion of a large-scale project to re-launch the Lymphoma Foundation Canada website, [www.lymphoma.ca](http://www.lymphoma.ca). The newly-developed website is a comprehensive resource that offers dynamic interaction, up-to-date information and opportunities for social engagement, all within a consistently-branded, user-friendly look and feel. This exciting new bilingual website provides an online gathering place and source of information for Canadian lymphoma patients, their families, healthcare professionals and anyone seeking information about lymphoma or professional or personal support.

The organization also invested in software to update and improve accounting processes. These investments will pay dividends for years to come.

#### Patient Education Sessions

One of Lymphoma Foundation Canada's most integral programs is to provide topical and timely information to lymphoma patients and their caregivers. In addition to a patient help line at which patients can speak directly with Lymphoma Foundation Canada staff to get support and answers to many of their questions, Lymphoma Foundation Canada hosts workshops with oncology centres across Canada about key issues following a lymphoma diagnosis including: treatment, clinical trials, bone marrow and stem cell transplant, and after treatment/survivorship. Lymphoma Foundation Canada proudly hosted seven such sessions in 2010:

*June 24, 2010*

*Chronic Lymphocytic Leukemia (CLL) Education Forum  
Juravinski Cancer Centre, Hamilton, Ontario*

Featuring CLL expert Dr. Michael Hallek with special guest Paul Henderson, Member of the Canadian Sports Hall of Fame.

*September 17, 2010*

*Lymphoma & CLL: Ottawa Forum  
Hampton Inn Conference Centre, Ottawa, Ontario*

This full-day event featured many lymphoma experts including Dr. Robert Rutledge, author of "The Healing Circle".

*October 6 and October 7, 2010*

*Lymphomas & LLC (leucémie lymphoïde chronique)  
& Lymphoma and CLL*

*Dr. Léon-Richard Oncology Centre, Moncton,  
New Brunswick*

Featuring Hematologist Dr Ève St-Hilaire from l'Hôpital Georges-L Dumont.

*October 16, 2010*

*Lymphoma Education Day  
World Trade and Convention Centre, Halifax, Nova Scotia*

This full-day event featured many lymphoma experts including Dr. Robert Rutledge, author of "The Healing Circle".

*November 3, 2010*

*Mindfulness Meditation, Waterloo, Ontario  
Hopespring Cancer Support Centre, Waterloo, Ontario*

Featuring Holistic Counsellor, Tracy Rowan.

*November 10, 2010*

*Chemotherapy and The Cancer Journey  
Wellspring Chinguacousy, Brampton, Ontario*

Featuring Dr. Sandy Sehdev, Oncologist at the William Osler Health Centre.

## 2010 Critical Initiatives

### Patient Education & Support

#### Young Adult Support Group

In 2010, the Canadian Cancer Society announced that the increase in incidence rates of lymphoma in young adults aged 18-35 is highest in this age group in Canada. This disease can be particularly difficult to manage in this cohort of patients, largely because the early symptoms of lymphoma (swollen lymph nodes, persistent cough, night sweats and/or fatigue) mimic other illnesses commonly encountered by patients at this age such as mononucleosis. In addition, this population of Canadians is either in the process of moving away from home or living on their own, tend to have limited doctor visits and have generally low awareness of lymphoma symptoms.

Lymphoma Foundation Canada supports efforts to reach and support the needs this unique group of lymphoma patients.

“  
**When I first felt a lump in my neck, I thought it must be related to the canker sore in my mouth, and I ignored it – until I found a second lump just beside the first. I booked a doctor’s appointment for four weeks later – the next time I was home to stay at my parents’ house, but the word cancer never crossed my mind. Sitting in that office all those weeks later, I was stunned to find out that I had lymphoma. My life changed forever at that moment.**”

Lymphoma patient, 21 years old.

The *Know Your Nodes* Campaign was launched in Canada to celebrate World Lymphoma Awareness Day on September 15, 2006.



The Know Your Nodes campaign was built on the insight that people know little about their lymphatic system, and in turn, lymphoma. An international survey conducted by the Lymphoma Coalition showed that, in spite of the fact that the incidence of lymphoma in Canada has increased by an estimated 60 per cent since the 1970, nearly three-quarters (74 percent) of people did not know lymphoma was a kind of cancer and less than half (49 percent) knew anything about lymphoma at all.

This campaign was developed as an awareness campaign with a 21-question quiz to help educate people about the lymphatic system. In 2007, the campaign was introduced as a global initiative of the Lymphoma Coalition. Today, Know Your Nodes operates in over 30 countries worldwide.

#### *World Lymphoma Awareness Day – September 15*

World Lymphoma Awareness Day is marked on September 15 every year as a day dedicated to raising awareness of lymphoma. Launched in 2004 and now an established date in the health calendar, World Lymphoma Awareness Day provides a focus for doctors, nurses, patient support groups, patients and their families to join forces in a united campaign to inform the public about lymphoma, its signs and symptoms and how it affects lives of thousands of people around the world. World Lymphoma Awareness Day is a global initiative with participation from over 53 member organizations in 38 countries around the world.

In 2010, Lymphoma Foundation Canada was grateful to Anwar Knight, the popular Anchor of news updates during Canada AM and Weather Anchor on CTV News at Noon for CTV Toronto, for sharing his personal journey following his diagnosis with Hodgkin lymphoma early in the year. Pauline Chan’s interview with Anwar and Dr. Mary Gospodarowicz, Oncologist at Princess Margaret Hospital and one of Anwar’s physicians, aired on CTV on September 14 and promoted World Lymphoma Awareness Day.

## 2010 Critical Initiatives

### Advocacy

#### Government Relations

In 2010, Lymphoma Foundation Canada worked to develop relationships with the Ontario Ministry of Health and Long-Term Care and Cancer Care Ontario to build awareness of Lymphoma Foundation Canada and to advocate for timely access to the best treatment options for lymphoma patients.

#### Partnerships

Lymphoma Foundation Canada is a founding member of Lymphoma Coalition and partners with the Lymphoma Research Foundation.

Lymphoma Foundation Canada is also a participating member of other cancer support networks which support best and consistent healthcare access to treatment for patients. These include Canadian Cancer Action Network (CCAN) and Best Medicines Coalition (BMC). In addition, Lymphoma Foundation Canada participates in the Joint Oncology Drug Review sessions.

2010 provided many opportunities for Lymphoma Foundation Canada to collaborate and engage in some key partnering initiatives, including advisory board work, national and provincial advocacy efforts. In addition, Lymphoma Foundation presented at several conferences across Canada that bring together lymphoma healthcare professionals, and at the North American Patient Education Forum at which Lymphoma Foundation Canada proudly stood as a co-host.

Lymphoma Foundation Canada highly values collaboration and sees partnering as a key component of its work to further its mission.

## 2010 Critical Initiatives

### Fundraising

Lymphoma Foundation Canada uses three programs to raise funds to maintain and further develop the ability to deliver on its mission.

1. A Corporate Fundraising Program through which companies make a long-term financial commitment
2. Event Fundraising – including a gala night and other third party events
3. Foundation Grants and Individual Donations.

In 2010, Lymphoma Foundation Canada formed a relationship with a professional fundraiser to strengthen our ability to reach out to corporate and individual donors in Canada.

This year, Lymphoma Foundation Canada raised \$597,375 to support its work. Fundraising events included:

#### *Charity Fashion Show by King's University College at University of Western Ontario*

London, Ontario - March 20, 2010

The King's University College Student Council's 2010 Charity Fashion Show took place in March. Lymphoma Foundation Canada was the proud recipient of the \$3,000 proceeds from this special event.

#### *Cancer Can't Dance Like This*

Ottawa, Ontario - September 17, 2010 and Mississauga, Ontario - October 22, 2010

In March of 2008, Daniel Stolfi was diagnosed with acute non-Hodgkin T-Lymphoblastic lymphoma, an aggressive form of cancer that would need equally-aggressive chemotherapy treatment over the following two years of his life. Just when his acting career was starting to take off, he needed to put it all on hold to embark on the most physically, mentally, and emotionally draining journey of his life.

In this travelling comedy show, Daniel invites the audience into his fight with a number of comedic monologues, musical numbers and character portrayals of his lost attributes to the disease in response to one question: can cancer out-dance the Dancing Machine?

#### *Party in Purple*

Ottawa, Ontario - October 29, 2010

Hosted by Lymphoma Survivor, Sabrina Liberatori

This special fundraising dinner and silent auction was hosted by the Liberatori family in honour of Sabrina and raised over \$31,000 for Lymphoma Foundation Canada.

Lymphoma Foundation Canada is also grateful to its corporate and individual donors without whom its programs could not exist.

## Research Fellowships

The original Lymphoma Research Foundation Canada established a research fellowship in 1998. Lymphoma Foundation Canada proudly awards these fellowships to encourage applicants to pursue careers in lymphoma basic, translational and clinical research. Since 1998, 15 research fellowships have been awarded to facilitate and support worthy research projects.

To ensure that the money Lymphoma Foundation Canada raises is directed toward the leading-edge of lymphoma research, applications are rigorously reviewed by the Lymphoma Foundation Canada Scientific Advisory Board, a volunteer group of scientists distinguished in fields related to lymphoma research. Each project is judged based on the scientific merit of the research, and the demonstrated ability of the Primary Investigator and the Primary Investigating Institution. The members of the Scientific Advisory Board review the applications independently, and make their recommendation to the Lymphoma Foundation Canada Board of Directors.

Lymphoma Foundation Canada Research Fellowships are awarded for two years and consist of an annual stipend of \$45,000 plus \$7,500 in each of the two years to support travel, publication and laboratory supply costs.

In 2010, Lymphoma Foundation Canada supported two Research Fellowships.

**The Philip Lavorgna LFC Research Fellowship Award** was granted to **Dr. Stuart A. Berger** of University Health Network, Toronto General Research Institute.



Dr. Stuart A. Berger  
Senior Scientist, Division of Cellular & Molecular Biology  
Title: c-Myc-dependent targeting of lymphoma in vitro and in vivo

Lymphomas often involve the c-myc oncogene. It was found that inhibiting an enzyme called calpain causes c-myc-transformed cells, but not normal cells to die. The goals are to evaluate how c-myc sensitizes human lymphoma cells to calpain inhibition and to optimize its use in a lymphoma model. This project provided information on the function and potential of calpain as a lymphoma target.

“  
With the LFC Research Fellowship grant, we were able to expand our work to the study of lymphoma. We found that calpain is indeed critical for lymphoma cell viability. Therefore our work has identified a new and potentially important target for lymphoma treatment.”

Dr. Stuart Berger

## Research Fellowships

The Terry Creighton LFC Research Fellowship Award was granted to Dr. Philip Hieter of Michael Smith Laboratories, University of British Columbia.



Dr. Philip Hieter  
 Professor and Director of the Michael Smith Laboratories and Professor, Department of Medical Genetics at the University of British Columbia  
 Title: Understanding and exploiting chromosome instability associated with non-Hodgkin lymphoma for the discovery of broad spectrum therapeutics.

This research is significant both in the context of understanding the basic biology of chromosome instability underlying the onset of non-Hodgkin lymphoma, and the potential to identify novel therapeutic targets and drugs that could dramatically improve the quality of life and treatment of non-Hodgkin lymphoma.

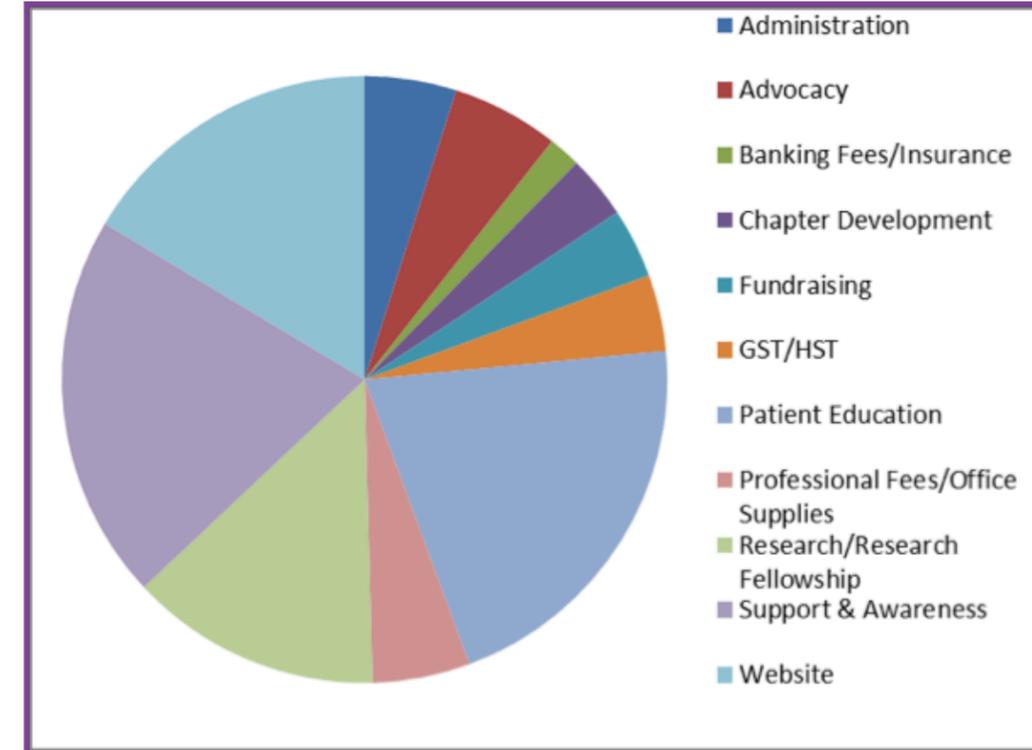
“ The support provided by the Lymphoma Foundation Canada Research Fellowship enabled me to make significant progress on my research into chromosome instability and also sowed the seeds for future research projects on related topics. I am grateful for the opportunity to have focused on this important segment of research. ”

Dr. Philip Hieter

The work conducted by these scientists and their laboratories contribute in a significant way to the understanding of and, ultimately, to finding a cure for lymphatic cancers.

## Financial Highlights for 2010

Total Assets at year end	\$564,001
Total Revenue (including Fundraising)	\$597,375
Total Patient Support (includes Education, Advocacy, Awareness)	\$218,144
Total Administration (includes Banking Fees/Insurance and other Admin)	\$30,580



Audited statements are available upon request.

Auditors: Grant Thornton, LLP, Suite 200, 41 Valleybrook Drive, Toronto, ON M3B 2S6

### Thank you: Alyssa Burkus Rolf, Past Chair

In May 2010, Alyssa Burkus Rolf presided over her final meeting as Chair of Lymphoma Foundation Canada. Over the course of her eight year history with Lymphoma Foundation Canada, Alyssa has devoted herself to our organization - as a Director and then Chair of our Board of Directors for seven years - all while focusing on beating the disease herself. In May 2011, Alyssa will reach the 10 year anniversary since her diagnosis with non-Hodgkin lymphoma and we proudly celebrate this significant milestone with her.

Alyssa has been a transformational leader with exceptional skills and an unwavering commitment to Lymphoma Foundation Canada. She has nurtured Lymphoma Foundation Canada through various transitions and challenges. Her vision and enthusiasm have been critical success factors in building the organization. Alyssa played a key support role in the development of the "Know Your Nodes" campaign, which now operates around the world.

Alyssa has become a regular blogger on the Lymphoma Foundation Canada website and her popularity among visitors has inspired the creation of a lymphoma community blogging site. As Past Chair, Alyssa is an invaluable contributor as well as a mentor to others on the Board of Directors. As a patient, she continues to motivate, inspire, and keep us focused on our cause.

On behalf of the Lymphoma Foundation Canada team, we thank you Alyssa!



### In Memorium: Helen Vavaroutsos

We were saddened by the loss of our wonderful volunteer and friend, Helen Vavaroutsos, in June 2010. Helen was an active volunteer and supporter of LFC throughout her illness, despite repeated rounds of treatment. She received the Deborah Sterritt Volunteer of the Year Award in 2009. Helen supported many of our events behind the scenes, and always had a kind word of encouragement for patients going through similar treatment cycles.

Helen's email signature always included the same passage which stood, for all of us, as a poignant reminder of how we must treasure every moment:

*Pessimists say alright, Optimists say alrighty!  
Life may not be the party we hoped for, but while we're here, we should dance...  
Be kinder than necessary, for everyone you meet is fighting some kind of battle.  
Life is short, appreciate the goodness in your life.*



Helen, we miss you and appreciate all the many ways that you contributed to Lymphoma Foundation Canada.

**Alyssa Burkus Rolf and Helene Vavaroutsos are representative of the outstanding volunteers and committed members of the community that we are privileged to work with at Lymphoma Foundation Canada. We thank you all.**

## Board Members and Affiliates

**Management** • Sue Robson: Executive Director • Jan Coleman, Program Coordinator • Tanja Loeb, Communications Manager • Angèle Ménard, Quebec Regional Manager • **Lymphoma Foundation Canada Board of Directors** • Paul Weingarten, Chair • Mike Joyce, Vice-Chair • Alyssa Burkus Rolf, Past Chair • Mary Hunt, Secretary • John Sutherland, Treasurer • Dr. Laurie Sehn, Research Fellowship Director • Terry Creighton, Director • Loring Gimble, Director • Mike Kleisinger, Director • Dr. Harold Olney, Director • Amy Maraone, Director • Nick Iozzo, Director • **Scientific Advisory Board** • Dr. Joe Connors, CHAIR; MD - Clinical Professor, University of British Columbia; Chair, Lymphoma Tumour Group, British Columbia Cancer Agency • Dr. Isabelle Bence-Bruckler, MD FRCPC - Hematologist, Associate Professor of Medicine, Member, Blood and Marrow Transplant Program, Ottawa General Hospital Campus • Dr. Spencer Gibson, PhD, Associate Professor, Manitoba Institute of Cell Biology, Department of Biochemistry and Medical Genetic, University of Manitoba • Dr. Mary Gospodarowicz, MD FRCPC FRCR(Hon) Professor and Chair, Department of Radiation Oncology, University of Toronto, Chief, Radiation Medicine Program, Princess Margaret Hospital • Dr. Kevin Imrie, MD FRCPC - Physician-in-Chief, Sunnybrook Health Sciences Centre, Vice-Chair, Education, Department of Medicine, University of Toronto, Professor of Medicine, University of Toronto • Dr. Ralph M. Meyer, MD, FRCP(C), Director of the National Cancer Institute of Canada (NCIC) Clinical Trials Group and Holder of the Edith Eisenhower Chair in Clinical Cancer Research at Queen's University •



# Lymphoma Foundation Canada

Lymphoma Foundation Canada  
16-1375 Southdown Road, Unit 236  
Mississauga Ontario L5J 2Z1  
Tel. (905) 822-5135  
Toll Free: 1-866-659-5556  
Fax: (905) 814-9152

La Fondation Lymphome Canada  
PO Box 56008, 1500 Atwater  
Montréal, Québec H3Z 3G3  
Tel. (450) 466-6955  
Toll Free: 1-866-659-5556  
Fax: (450) 466-8286

For more information about Lymphoma Foundation Canada or to make a donation, please visit:  
[www.lymphoma.ca](http://www.lymphoma.ca), on Facebook at [www.facebook.com/LymphomaCanada](http://www.facebook.com/LymphomaCanada), or on  
Twitter at @LymphomaCanada.

Charitable registration#: 873461040RR0001