

LYMPHOMA **FACTS**

Lymphoma Canada was founded in 199 with a mission to **SUpport**, **educate**, and **advocate** for people in the lymphoma community and to eradicate lymphatic cancers.

Lymphoma is the being diagnosed in young adults,

discriminate with respect

of Canadians do not know that to race, gender, or age. lymphoma is a form of cancer.

Close to are diagnosed each year with lymphoma

are living with lymphoma

MESSAGE FROM THE CHAIR & EXECUTIVE DIRECTOR





APPROXIMATELY **80,000** CANADIANS ARE LIVING WITH LYMPHOMA AND, IN 2014, ANOTHER **9,000** WILL BE DIAGNOSED.

lymphoma remains the fastest rising cancer in young adults, and the fifth most common overall. Yet, in spite of this prevalence, many people have not even heard of lymphoma and, while promising new treatments continue to emerge and improve outcomes, its causes and cures are yet to be discovered. These sobering statistics are what drive our ongoing passion and commitment to our mission to empower lymphoma patients and the lymphoma community through education, support, and research.

As we reflect on 2013, we are proud of the many people we were able to touch in the lymphoma community. This report highlights some of the many ways our dedicated staff and volunteers have been able to make a difference:

- 2013 saw the development of our new Patient Support Strategy resulting in expansion
 of our patient education and support services, through conferences, seminars, online
 presentations, and support groups. For the first time, Lymphoma Canada has been
 able to provide these in both languages, to meet the needs of the French and
 English communities.
- We released the Report Card on lymphoma in Canada, a comprehensive report on patient and caregiver experiences from diagnosis onward. This Report Card will serve to further inform our programs and services, and ensure they are meeting the needs and improving the lives of the Canadian lymphoma community.
- Our commitment to healthcare professional education continues, and our first accredited continuing medical education program to help improve early diagnosis among primary care physicians wrapped up with over 1,450 physicians completing this important learning. Lymphoma Canada presented an abstract on these results at the Canadian Association of Nurses in Oncology conference in October.
- Lymphoma Canada sponsored a new research fellowship in 2013 and added distinguished members to our Scientific Advisory Board. While we were sad to see the eminent Dr. Joe Connors retire as Chair, we are excited about Dr. John Kuruvilla's acceptance to come on in this important role.

2014 promises continued momentum. Lymphoma Canada is committed to expanding our patient services through new programs, already under development. Our ceaseless advocacy work to secure equal access for all Canadians to new life-saving treatments remains a priority, as does supporting individuals to advocate individually. It is through reflecting on our past that we can encapsulate our recent successes and reaffirm our commitment to our mission as we begin to undertake some of these new and exciting initiatives.

None of these accomplishments would have been possible without the support of the dedicated individuals who form part of the lymphoma community. We are pleased to share information about those accomplishments with you as we look to our past, and remain steadfast in our focus on the future.

Paul Weingarten
Chair, Board of Directors

Paul Wergents

Sue Robson Executive Director

RESEARCH

1998-2013



LOCATIONS



LYMPHOMA AREAS RESEARCHED



SCIENTIFIC ADVISORY BOARD

Dr. John Kuruvilla, CHAIR; MD FRCPC

 $\hbox{Dr. David MacDonald, MD FRCPC}$

Dr. Doug Stewart, MD FRCPC

Dr. Matt Cheung, MD FRCPC SM

 $\hbox{ Dr. Tony Reiman, MD, SM, FRCPC}$

Dr. Sarit Assouline, MD

Dr. Kerry Savage, MD

Dr. David Hodgson, MD MPH FRCPC

Dr. Isabelle Bence-Bruckler, MD FRCPC

DRIVING LYMPHOMA RESEARCH

Supporting Canadian research is an integral part of lymphoma Canada achieving its ultimate vision of eradiating lymphoma. The bi-annual Fellowship awarded to a research supervisor with a project proposal in the area of lymphoproliferative disorders is LC's way of attracting more people to the field and also contributing annually to research.

Accomplished professor in biochemistry and the oncology department at McGill University, Professor Jerry Pelletier, was awarded the 2013 fellowship. Mr. Pelletier's study "Validating Tumor Suppressor Genes in Burkitt Lymphomas" focusses on the variety of genes that cooperate with the CYMC gene to drive cell proliferation in lymphoid cancers.



GIVING TO ADVANCE LYMPHOMA RESEARCH

At the end of 2012, Lymphoma Canada gave \$450,000 to research at Princess Margaret Cancer Centre and Sunnybrook Health Science Centre for lymphoma research. These research grants were made possible through the funds raised from the June 2012 Romeo De Gasperis Tribute Dinner. These two leading research centres will use the funds towards research into and, ultimately, towards finding a cure for lymphatic cancers.

"I am happy to be involved with Lymphoma Canada because the organization helps to provide education and resources to patients with lymphoid cancers. Most importantly, Lymphoma Canada is able to advocate for patients on a national level and will help to ensure that all Canadians with lymphoma receive excellent state of the art care."





ADDING MORE KNOWLEDGE TO RESOURCES

"After 15 years I think that I have provided the ideas and guidance that I can come up with and I think it's good for organizations to move through leadership changes because that brings new perspective and new energy.

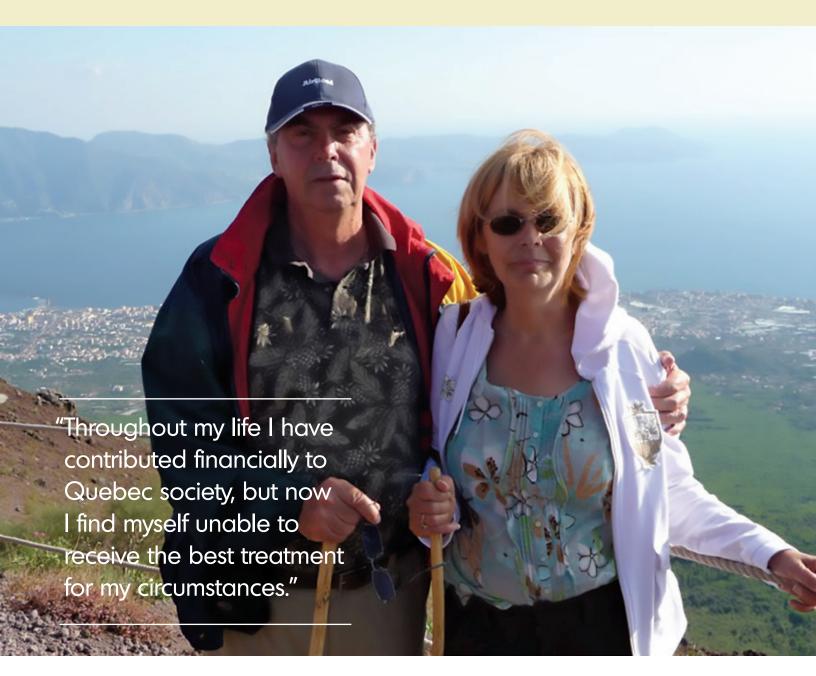
—Dr. Joseph Connors, Scientific Advisory Board, Past Chair

The outstanding contributions of the Lymphoma Canada Scientific Advisory Board (SAB) have helped the organization to stay credible and offer education to the lymphoma community that is relevant to their immediate needs. 2013 brought about change to the Scientific Advisory Board.

Eight new medical professionals from varying disciplines and regions in Canada accepted their position to provide support and new direction to the organization.

The entrance of eight new members and the one remaining member, Dr. Isabell Bence-Bruckler, marks a new era for Lymphoma Canada and the SAB. They take on more initiatives including the formation of standard treatment guidelines for lymphoma across the country, selection process for the research fellowship, presentations at education events, and review of medical resources.

SUPPORT



In 2007, I was diagnosed with Stage IV mantle cell lymphoma and then treated with six sessions of R-CHOP chemotherapy. The cancer subsequently fell into complete remission until Nov. 2012 when I underwent a routine scan. It showed a recurrence of cancer, located in the liver. This was confirmed with a biopsy on Dec 5, 2012. Since that time I have received three sessions of R-CHOP, which did not stop the lymphoma's progression. I also received six sessions of a fludarabine-based regime, which will be followed up with a regular scan as well as a PET scan.

In the fall of 2012, I was put on a new and very promising medication, a bendamustine and rituximab combination (BR). The drug not only increases my life expectancy (by an average of six years) but it has already given me a better quality of life.

I was shocked to learn that BR has not been approved by Quebec's provincial health services evaluation body, the INESSS (Institut national d'Excellence en santé et services sociaux). Despite the fact I was in treatment at the time, I took part in the first public awareness campaign on this issue.

SUPPORT

2 LOCATIONS



Hope&Cope Wellness Centre / Lou's House of the Jewish General Hospital



5 patients 2 caregivers Lymphoma support group



West Island Cancer Wellness Centre

6 patients 2 caregivers

TOPICS



FEAR: WHAT IT IS AND HOW DO WE MANAGE IT



INSIDE BODY/ OUTSIDE BODY EXERCISE

SOCIAL NETWORKS



FACEBOOK **~** 184.2%

TWITTER **~** 80.7%

GOOGLE+ **~** 1600%

LINKEDIN **~** 13.88%

YOUTUBE **~** 150%



IT'S THE CONNECTING THAT MAKES AN IMPACT

More than 5 years ago, a dedicated group of lymphoma patients came together to form a Lymphoma Canada Connection group. They knew the importance of support and wanted to offer it to as many people impacted by lymphoma, like themselves, in Waterloo-Kitchener and surrounding areas. The Waterloo Region Connection organizes 4 free meetings a year at HopeSpring Cancer Support Centre in February, May, August, and November.

SUPPORTING IN WAVES

Montreal was a pilot for Lymphoma Canada's support group model. The groups included a cross-section of genders, cultures, and ages. The regular support groups met at two locations between March and June at Hope & Cope and West Island Cancer Wellness Centre. Various topics were covered during the sessions including: communicating and coping skills, managing fear, and staying positive. From the information gathered from these two support groups, LC was able to develop a 6 session LIAISE patient support program designed to offer practical and coping skills, peer connection, and learning for patients across the country.

ADVOCATING FOR THOSE THAT AREN'T SUPPORTED.

INESSS, the drug review body in Quebec, has gone against pCODR and the rest of Canada and has neither recognized the therapeutic value of bendamustine in combination with rituximab nor recommended it for funding for the treatment of indolent NHL. In spite of a press conference highlighting this inequity and much support via a letter written by Dr Pierre Laneuville and 30 of his hematology-oncology colleagues, backing by our own SAB, and a FB page created especially for the crisis, the Quebec Minister of Health has so far refused to reverse the decision or to meet with Lymphoma Canada

representatives. While the initial response has been unfavourable, Lymphoma Canada will not abort its efforts to ensure that all Canadians have equal and timely access to the newest effective treatments for lymphoma.

Please help LYMPHOMA CANADA help you and other lymphoma patients living in Quebec to gain immediate access to this treatment that extends survival without disease progression and have the same chance as other Canadian patients. QUEBECKERS DESERVE ACCESS TO THE BEST CARE TOO!



ACCESSIBILITY SO NO ONE HAS TO FACE LYMPHOMA ALONE

lymphoma Canada has seen a large increase in social media engagement in 2013. It has given the organization the opportunity to respond to inquiries, drive sign-ups for education events, and encourage more interaction on a regularly with the lymphoma community and key community partners.

AWARENESS EVENTS THROUGH CANADA

- · Montreal, QC
- · Moncton, NB
- · Halifax, NS
- · Mississauga, ON
- · Oakville, ON

- · St. Catharines, ON
- · Oshawa, ON
- · Toronto, ON
- · Vancouver, BC





MONTREAL

Awash in purple, the Rialto Theatre in Montreal was the setting for **One Voice/ D'Une seule voix,** the first event of its kind to celebrate World Lymphoma Awareness Day in Quebec. Gifted songstresses and homegrown talents Angela Galuppo and her St. Ange musicians and Juno Award winner Lorraine Klaasen rocked the house with jazzy tunes and South African township melodies. Attendees were treated to wonderful music and tasty hors d'oeuvres, and a generous benefactor made it possible for some patients and their caregivers to attend thanks to the *Table For Two* sponsorship initiative.



NOVA SCOTIA

Travis Saulnier cares about his community in Amherst, NS. And as a lymphoma survivor himself, he cares about bringing awareness of the signs and symptoms as well as the need to support Lymphoma Canada. Travis brought the community together to Dance Lymphoma Away, as his first fundraiser in honour of World Lymphoma Awareness Day. Travis began his planning 6 months before the event and took great care to attend to every detail. His months of planning and coordinating resulted in an incredible evening and fabulous show of support from his Amherst family, friends, neighbours, and colleagues. The Lions Club, decorated in purple, was the perfect venue for the fun family games, delicious dinner, and a night of dancing and coming



TORONTO

A unique World Lymphoma Awareness
Day campaign afforded us the opportunity
to engage Toronto in an up close and
personal way. It's Worth Noding was
an awareness campaign that drew
attention to the number of nodes in
the human body. With the support of
3 models and numerous Lymphoma
Canada ambassadors, the organization
was able to educate the community on
the importance of knowing their nodes.
The mini campaign drove people to
Lymphoma Canada's website, Facebook
page, Twitter, Instagram, and Know Your
Nodes quiz.



CHANNELS FVFNTS

together for a great cause.







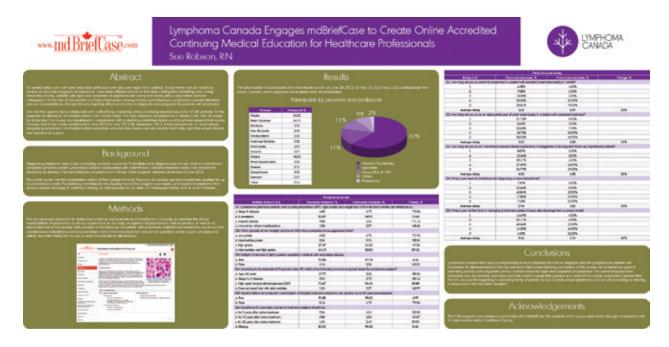


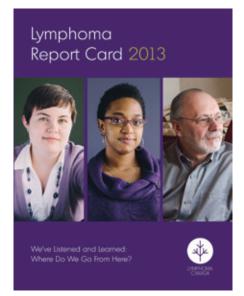
EDUCATION

PROVIDING EDUCATION TO PRIMARY CARE PHYSICIANS

The eCME program was created in partnership with mdBriefCase, and in consultation with lymphoma experts Dr. John Kuruvilla and Dr. Matthew Cheung. This was just the beginning of lymphoma's Canada's efforts to educate Canada's family physicians, and 2014 promises to see more initiatives in LC's passio to ensure physicians have the tools they need to follow evidence-based practices in their diagnosis and treatment of lymphomas patients. In the program's first three months, over 908 physicians participated.

Of those participants, 64 per cent were GPs. Of the 454 physicians who completed the pre-course survey, 36.25 per cent said they were likely to screen for lymphoma in a patient with persistent lymphadenopathy. After completing the course, that number increased to 78 per cent. These preliminary results show a very promising response from physicians in their understanding of diagnosing lymphoma.





LYMPHOMA REPORT CARD/ PATIENT SURVEY

"I remember telling my mom that I think I needed to see a shrink because if nothing was wrong physically then obviously it was all in my head."

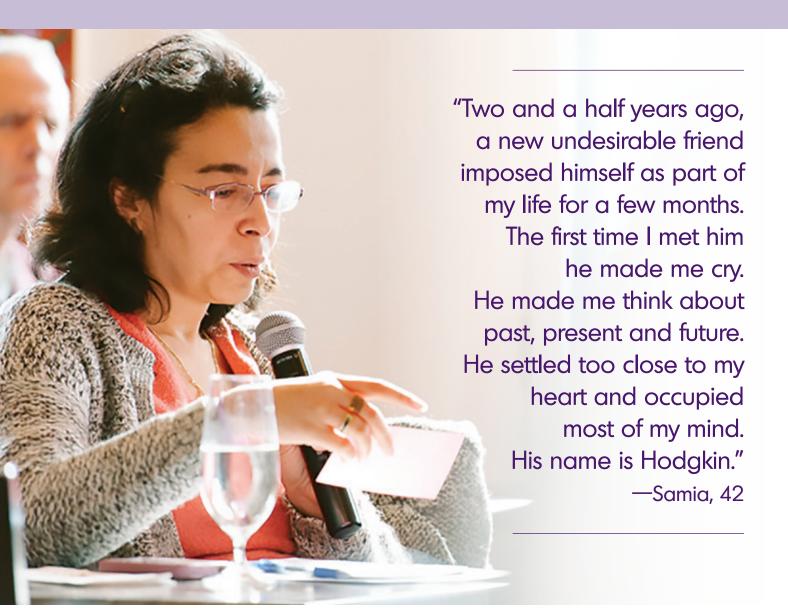
- Ryan Leal, Hodgkin lymphoma survivor

The 2013 Lymphoma Report Card was the first one from Lymphoma Canada that came out its 2012 patient survey. The results of the patient survey that were highlighted in the report card showcased how far the lymphoma community has come over the years and encouraged the organization to remain aware of areas that need to be improved.

We know that education is essential to improving early detection and ensuring that the public is aware of this disease that impacts many Canadians, young and old. And with support, no one will have to face this alone.

REPORT CARD OUTCOMES:

- · 81% of respondents were diagnosed with something other than lymphoma
- More than half of respondents had 2 or more diagnoses before a lymphoma diagnosis.
- · Fatigue and cough are common lymphoma symptoms
- · Lymphoma is the most common cancer for people 18-39 years of age



I had never heard about Hodgkin until 2 years ago. At that time, I have been tired for some months, had itchiness and a bad cough but still I haven't ever thought it was so serious. And all in sudden, I got formally introduced to Hodgkin, first by an internal doctor, then by one of the most competent, nice and helpful oncologists.

Am here to say the road is really feasible. For sure, dealing with Hodgkin was not a pleasure. I had 16 ABVD treatments through IV, the usual side effects were nausea and tiredness, my veins took time to recover, I had pneumonia in the middle of the treatment, I had joint pain for some time during and following treatment,

there were some days I felt so tired, some moments I felt so lonely, some occasions I felt so desperate not being able to do the things I was able to do before. There were also some moments where I felt really good, some days there were no pain at all..., some months I just felt how lucky I was to get support from family and friends.

Then, after 8 months, I saw the light at the end of the tunnel, I reached THE moment I was able to tell Hodgkin 'Bye, get OUT of my life', the moment my doctor said 'You are in Remission'. That was a GREAT moment.

EDUCATION

EDUCATING THE COMMUNITIES ACROSS THE COUNTRY

Education is important to Lymphoma Canada as a result the organization conducted lymphoma education events, conferences, and online session in more than 8 locations across Canada to educate patients, caregivers, healthcare professionals, and the general public about this complicated type of cancer.

12 DOCTORS

- Dr. Rena Buckstein, FRCPC
- Dr. Pike
- Dr. John Kuruvilla
- Dr. Alain Bestawros
- Dr. Sarit Assouline
- Dr. Harold Olney
- Dr. Ronan Foley
- Dr. C. Tom Kouroukis
- Dr. Joy Mangel
- Dr. Olga Vujouic
- Dr. Eugenia Pilliotis
- Dr. Ralph Meyer



12 PARTNERS

- Hôpital Notre-Dame
- Sunnybrook Odette Cancer Centre
- HopeSpring Cancer Support Centre
- Juravinski Cancer Centre/Hamilton Health Sciences
- BC Cancer Agency
- Lymphoma Research Foundation
- Hearth Place Cancer Support Centre
- London Health Sciences Centre
- Grand River Rapids Cancer Centre
- Cedars CanSupport
- Jewish General Hospital
- Canadian Cancer Society

O EDUCATION EVENTS

21 SPEAKERS

- Samantha Thiessen—Registered Dietitian
- Margaret Mayer—Nurse Practition
- Jennifer Finestone—Drama Therapist
- Natalie Seaall—Cancer Patient Educator
- Melisa Nestore—Kinesiologis
- Patricia Vincent
- Marita Poll—Clinical Counsello
- Oren Cheifietz—Physiotherapist, Clinical Specialis
- Deborah M. Evans—Clinical Nurse Specialis
- Jennifer Wiernikowski—Nurse Practitioner
- Mary Christie—Primary Nurse
- Patrycia Birbaum—Social Worke
- Dawn McKinnon—Chemotherapy Nurse
- Elaine Rapp—Social Worker
- Elain Posluns—Nutrition
- Stephanie Burlein Ha
- Greg Dafoe—lymphoma survivo
- Anwar Knight—lymphoma survivoi
- Dr. Giselle Salmasi—lymphoma survivor and docto
- Alyssa Burkus Rolf—lymphoma survivor
- Deanne Pederson—lymphoma survivor

over445

PATIENTS, CAREGIVERS, AND HEALTHCARE PROFESSIONALS

17 TOPICS

- Stem Cell Transplants
- Clinical Trials
- Nutrition
- Lymphoma and your medical care
- Managing Emotional Expectations
- Kinesiology: How movement can empower you
- · Cancer and Sexuality
- Return to work, return to life
- Managing Fear of Recurrence

- New and Emerging Therapies
- How to use exercise help? Research and practical tips
- Lymphoma 101
- Pain and Symptom Management
- Maximum Wellness as a lymphoma survivor
- Coping with lymphoma
- Diet
- Complementary Medicine

In addition to organizing lymphoma education events, the organization also attended event hosted by key community partners in an attempt to expand its reach to others that were unaware of lymphoma and the impact that it has on Canadians each day.

fundraising



A FIVE DOLLAR DONATION GOING A LONG WAY

It is thanks to the support of local communities, corporations, and individuals that Lymphoma Canada is able to continue offering information, help, and hope to lymphoma patients and caregivers across Canada.

In September, four Power Yoga Canada locations throughout Ontario together raised over \$1025.00 for the cause through their monthly Karma Sunday charity initiative. With over 180 people in attending hot yoga classes weekly during Blood Cancer Awareness Month, Power Yoga Canada joined the organization is raising awareness of lymphoma in their communities and encouraging students to wear purple and educate others about the fifth most common cancer in Canada.

Deepest thanks to the St. Catherine's, Oshawa, Oakville, and Mississauga Power Yoga Canada locations for their support of Lymphoma Canada in honouring all lymphoma patients, survivors, and caregivers during the month of September and especially on September 15th for World Lymphoma Awareness Day.

Celebrating the memory of a loved one or honouring a friend or colleague by making a donation goes a long way in helping Lymphoma Canada achieve its mission. Power Yoga Canada was one of the few organization that dedicated their time and resources to give back to the lymphoma community in 2013 and the organization looks forward to greater support moving into future years.

FUNDRAISING



VOLUNTEERS IN 2013

......Administrative
.....Event Ambassadors
....Photographer
....Committees
....Connections
....Bloggers
....Social media

...............Spokesperson



GETTING THE COMMUNITY INVOLVED

2013 was a great year with many new initiatives that allowed for the development of Lymphoma Canada's volunteer program. In March 2013, the organization hosted its first group volunteer and intern orientation at the head office in Mississauga with 10 volunteers and interns in attendance. Over the year, the number of volunteers interested in getting involved with the organization across the country grew, which allowed for Lymphoma Canada to reach more individuals in the lymphoma community.

Lymphoma Canada has been fortunate to have the dedication of amazing volunteers, supporters of the cause, and ambassadors of the organization. These selfless volunteers do so much, and ask for little in return.

PAR FOR THE CURE ANNUAL GOLF TOURNAMENT

The Annual Par for the Cure Golf Tournament was started in 2006 and has given lymphoma Canada the opportunity to connect with with local businesses across the Greater Toronto Area and to inform them of the needed support for the lymphoma community across Canada, while they enjoy a day of golf.

The support of CTV is greatly appreciated, as it allows the organization to expand our each of the golfing event by highlighting the themed activities taking place throughout the day.



MAKING GREAT STRIDES FOR LYMPHOMA

Lymphoma Canada participated for its first time in the Scotiabank Toronto Waterfront Marathon. 13 determined individuals helped raise awareness and funds for the organization by wearing their race shirts and dressing in purple for the cause. Lymphoma survivors, supporters, and volunteers united on behalf of Lymphoma Canada and surpassed our \$5000 goal. With a small group of participants for the first year, the enthusiastic team morale could not be ignored as the announcer made a special shout out to Lymphoma Canada prior to the race.

It was only because of the motivated individuals who participated that in the organizations first year participating in the race that it was able to significantly surpassing the fundraising goal with a total of \$7226.00.

2014 is bound to be another thrilling year and we invite you and your loved ones to come out and actively support the cause.

Being diagnosed with lymphoma can be a devastating moment for a patient as well as their family. Yet, many people find this is an opportunity to rally behind their loved one and show incredible support. Many individuals decide to work together in support of Lymphoma Canada knowing that they are able to help others in this way. Whether it was a repeat event or brand new, using their own ideas or with the help of Lymphoma Canada, 2013 saw many creative initiatives on the part of the community to support Lymphoma Canada in its mission.



DAY TRIPPER

\$2,500.00





PARTY DISCO Quebec In memory: Michaël Dubé-Tanguay AMOUNT RAISED .230.00







13.1 FOR HEATHER CAMPAIGN Florida In honour: Heather Ruscillo

AMOUNT RAISED

\$1,415.00

DANCE LYMPHOMA AWAY Nova Scotia

AMOUNT RAISED:

\$730.00

GREEN SHIELD DRESS DOWN DAY

\$1,368.00

IBM CANADA Ontario

AMOUNT RAISED

\$2,040.00

POWER YOGA CANADA Ontario

AMOUNT RAISED

\$1,025.00

POWELL'S SUPERMARKET Newfoundland

AMOUNT RAISED \$500.00

ABOUT THE ORGANIZATION

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.

BOARD OF DIRECTORS

Paul Weingarten Chair

Mike Joyce Vice-Chair

Alyssa Burkus Rolf Past Chair

John Sutherland Treasurer

Nick lozzo Secretary

Dr. Laurie Sehn Research Fellowship Director

Loring Gimbel Director

Dr. Harold Olney Director

Amy Maraone Director

Anwar Knight Director Lymphoma Canada connects and empowers this community. Together we are promoting early detection, finding new and better treatments, helping patients access those treatments, learning lymphoma's causes, and finding a cure. 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 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.



"My personal experience had tremendous highs and lows and numerous people helped me along the way. Through battling lymphoma I have learned things that I would like to pass on to other patients and families. If I can help people receive the best care possible and help them navigate successfully through the experience; then I will have made a positive contribution to fighting this deadly disease. Fighting lymphoma demands operating on several fronts - LC is the only organization that provides a full spectrum of support!"

-Mike Joyce, Vice Chair, Board of Directors

INDIVIDUAL DONORS

\$100-\$499

Alcide DeGagne Aldo DeCarolis Anderson Joyce

Andrew & Shayna Gaunt

Angela lasenza Anne Marchildon Assunta Dicrescenzo Barbara Adamson Beatrice Jenkins Blake Frazer

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Ron Lewis

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Salim Haiee Sean Birt Shane Berhalter Shelagh Langford Sherry Bishop Storey Wilkins Sue Ann Choo Susan Bott Susan Down Tom Curry Tracey-Ann Curtis Ursula Boyer

\$500 - \$999

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Nicole Halasa Phillip Armstrong Ron Vandervecht Scott Taylor

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\$100-\$499

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PSCC661 Skymark West Phase II

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\$500-\$999

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\$1000+

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Giovanni & Concetta Guglietti

Foundation Green Shield Harvest Ball IBM Canada Informa Canada InterBase Consultants Investors Group Financial Lindvest Properties Limited

mdBriefcase

Minto Foundation Inc. South Simcoe Developments

Telus Corporation Wellington Laboratories

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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Charitable Registration Number: 87346 1040 RR0001

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