



Lupus Canada

Lupus Canada Annual Report

October 1, 2007 – September 30, 2008

Working together to conquer lupus



Vision

Life without lupus.

Mission

Lupus Canada is a national voluntary organization dedicated to improving the lives of people living with lupus through advocacy, education, public awareness, support & research.

Values

The following values serve as guidelines for our conduct and behaviour as we work toward our vision and mission:

- quality of service
- equal access for all individuals
- accountability and transparency
- dignity and respect for all individuals
- collaboration and consultation

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President's Report

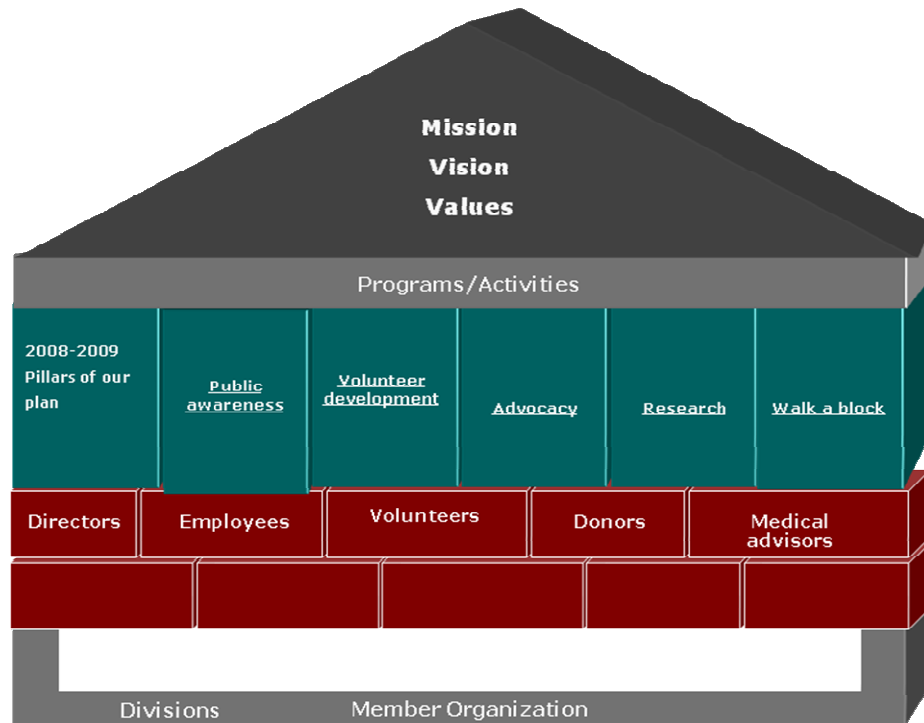
On behalf of the Board of Directors of Lupus Canada, I am pleased to present the annual report for the 2007-08 operating year.

Respectfully submitted on behalf of the Board of Directors

Lupus Canada is more determined than ever to make a difference in the lives of people living with lupus. The Member Organizations and Divisions are working with the National organization to make lupus better known to the public, to gather and circulate information on lupus and to contribute to research.

André Vincent, CPA, CMA, CA

One of the best examples of both cooperation and achievement is the Walk a Block fundraising campaign. Again this year, the Walk a Block campaign has not only raised money, it has raised awareness, brought new volunteers to our organizations and proven that working together to conquer lupus is more than an objective - it is the journey that we live every day.



In April 2008, the Member Organizations and Divisions thanked long serving volunteers who had devoted many years to the Board of Directors of Lupus Canada. Pat Leece (Lupus Foundation of Ontario), Miriam Gaudelli (Lupus Quebec), Josephine Fromm (Lupus Society of Nova Scotia) and Jerry Payne (Lupus Newfoundland & Labrador) have not only been leaders and devoted directors, but they brought wisdom and experience to our young organization. Mae Boa retired

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after many years as President of the organization. We celebrated her accomplishments and devotion to Lupus Canada during the last Annual General Meeting. We will be eternally grateful to all of them for they have changed the face of lupus in Canada.

We also welcomed new directors Michelle Leece (Lupus Foundation of Ontario), Iris Scallen (Lupus Society of Nova Scotia), and Lucy Stoyles (Lupus Newfoundland & Labrador). They have already made their mark with their deep knowledge of lupus and of the needs of people living with lupus. I am grateful for their support and commitment.

The new Executive Committee which includes Julia Kane as Chair of the Audit Committee, Tom Koor as Chair of the Governance Committee, Kendra MacDonald, Vice-President and Tina Sarta, Treasurer is my dream team. Together they offer technical expertise, knowledge of lupus, knowledge of the medical environment and of research. Most of all, they make this journey rewarding and enjoyable. I could not do my job as President without them.

During the year, we also welcomed our new executive director, Catherine Madden. Catherine comes to us after many years of experience in the not for profit sector. She had the very challenging role to build a new staffing complement and adjust all job descriptions and the operational focus of our volunteers to match our five pillar focus. We are very pleased to have her with us. Catherine can also count on Leanne Mielczarek, to second her in the office. We are also delighted to welcome Leanne to our team.

Lupus Canada remains primarily a volunteer organization. As you can imagine, it would be impossible for me to name all the volunteers who have devoted time and efforts to helping the lives of people living with Lupus. To all of them, and to all our financial supporters, I want to say 'thank you'. Not only have you helped the more than 50,000 people affected by lupus, but by helping research, public awareness and advocacy, you have also helped the lives of all the people impacted by lupus including their families and friends.

I would also like to thank our colleagues at the Canadian Network for Improved Outcomes in Systemic Lupus Erythematosus (CaNIOS), in particular, Paul R. Fortin – Chair, Janet Pope – Vice Chair, Joan Wither - Translational Research Director, Christine Peschken – Secretary, Jaime Claudio – National Scientific and Development Coordinator, Cathy Chau – Business Administrator. The collaboration between the medical association and Lupus Canada proves its value to people living

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with lupus when we understand better the research projects, the clinical trials, and the information shared at jointly held sessions such as Café Scientifique and the National Patient Symposium. We are grateful for their commitment to people living with lupus. Specifically, I want to thank Dr. Paul R. Fortin, Chair of CaNIOS for his commitment to the ongoing development of Lupus Canada.

The year 2007-2008 is a new beginning to what we can accomplish with our Member Organizations and Divisions. I am truly grateful for their support.

A handwritten signature in black ink that reads "André Vincent". The signature is written in a cursive style with a long, sweeping underline.

André Vincent
President, Lupus Canada Board of Directors

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Executive Director's Report

Respectfully
submitted by
Catherine
Madden

The Board of Directors of Lupus Canada embarked on a journey of change in 2007-2008. That change came at all levels... the Executive Committee, the Board of Directors, our Staff, our budgeting process, our operational style and most significantly, in the refocusing of our perspective on what we can do for the tens of thousands of Canadians living with lupus.

John F. Kennedy once said 'Change is the law of life. And those who look only to the past or present are certain to miss the future'. To some, change can be frightening, to others, an exciting new challenge. The Board of Directors of Lupus Canada took on the challenge of change and embraced it openly and with enthusiasm. At every turn this year we have asked ourselves 'what impact does this have on people living with lupus'?

***'If nothing
ever changed,
there'd be no
butterflies'.
~Unknown***

With a strong foundation put in place for Lupus Canada through the efforts of a team lead by Mae Boa, Lupus Canada, its Member Organizations and Divisions sought to achieve a new level of excellence with an exciting and aggressive plan for Lupus Canada. With Mae's retirement from the Board came change – in the form of a new President, André Vincent, a leader with a vision and passion for change.

In May of 2008, Lupus Canada held its Leadership and Annual General Meeting in Montreal. The goal of those meetings was to focus our energy, our efforts and our organizational resources on establishing key priorities for people living with lupus. The result of those meetings was the engagement of our Member Organizations and Divisions in our shared priorities - or 'pillars' as they are referred to – Advocacy, Public Awareness, Research, Walk a Block National Campaign and Volunteer Management.

Advocacy

For those living with lupus, the complexities of the various government programs, available benefits and related information can be overwhelming. Lupus Canada has worked to ensure that information is readily available to people living with lupus, their caregivers, family and friends that is current and relative.

Collectively across the Country, Lupus Canada, our Member Organizations and Divisions have created a forum for the exchange and dissemination of information related to lupus. We have:

- Distributed thousands of our Living Well With Lupus Fact

Sheets, Introduction to Lupus brochures and information in the form of bookmarks, flyers and other literature;

- Made information available on our website www.lupuscanada.org and through links to our Member Organization and Division websites;
- Offered hours of telephone support and fielded a variety of inquiries through local and toll free numbers at both the National and Provincial levels;
- Responded to thousands of email requests for information, support group locations and general support;
- Presented medical symposiums for lupus patients, their families and caregivers;
- Brought lupus and related issues to the forefront through conversations with members of parliament, local politicians and through print, television and radio media coverage;
- Offered support groups for youth, people living with lupus and their family members and friends;
- Maintained a presence in hospitals and other medical facilities through speaking engagements, visits with newly diagnosed patients, seminars and the distribution of information to doctors and nurses.

Public Awareness

While lupus is known as the ‘disease with a thousand faces’ and affects an estimated 50,000 Canadians, the reality is that it is relatively unknown to the general public. Therefore, it is imperative that we continually strive to bring knowledge and awareness of lupus to the public in as many ways as we can. We must ensure the disease itself is better known and better understood.

Public Awareness has increased over the past year due to a variety of approaches taken at both the National and Provincial levels:

- Our new Public Service Announcement (PSA) was developed to increase awareness of the signs and symptoms of lupus. This piece ran nationally on the W Network and on RDI in Quebec in a variety of time slots during the month of October and resulted in an increase in the number of calls and website visits during that time. The PSA has now been revised to reflect Provincial contact information so it can be taken out by every Member Organization and Division to their local media for distribution on local networks and cable;
- Our direct mail campaigns have been streamlined to place stronger focus on awareness of lupus and the priorities of

- Lupus Canada;
- Creative advertising strategies have been undertaken which include television and radio interviews, inclusion of the media at events as both participants and for media related coverage, signs on local transportation vehicles, flag raising ceremonies to recognize Lupus Awareness Month and World Lupus Day, and participation on social networking and related sites;
 - Opportunities for awareness are sought regularly through presentations at schools, hospitals, volunteer fairs, and participation in other events like craft and bakes sales;
 - Our Online Boutique offers people the opportunity to promote Lupus and raise awareness through the wearing of lupus clothing items, the displaying of car magnets, the use of pens and other useful daily use items like travel mugs and water bottles.
 - Lupus Canada and its Member Organizations and Divisions actively utilize their websites to share information, promote their cause and create the opportunity for interaction with visitors to their sites through e-newsletters, youth newsletters and message boards. The number of visits to our sites continues to rise and we hear from people regularly who have found us online and who want to get involved, learn more or share their story with us.

Research

Over the last year our Member Organizations and Divisions have invested over \$400,000 to support research. This clearly illustrates the importance of research, not only to Lupus Canada, our Member Organizations and Divisions, but to people living with lupus, as they are the motivation behind all we do.

Our strong and ongoing relationship with Canadian Network for Improved Outcomes in Systemic Lupus Erythematosus (CaNIOS) has provided significant opportunities to fund research and is fostering new relationships with other organizations so we may, in the future, reach and assist even more Canadians living with lupus with resources and information. Access to key medical advisors, the presentation of our Annual Patient Symposium and various other information forums are only some of the examples of the benefits of our collaboration.

At our meetings in the spring of 2008 the Board of Directors of Lupus Canada challenged ourselves to allocate more money to research and to designate a portion of our fundraising efforts directly to research. In partnership with CaNIOS, Lupus Canada presented the 7th Annual

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Patient Symposium “Living Well with Lupus” in Montreal, Quebec. The event was well attended and continues to be a tremendous opportunity to share the results of research efforts across Canada happening on behalf of people living with lupus.

In addition to the strong relationship between Lupus Canada, our Member Organizations, Divisions and CaNIOS, research is supported across the country in a variety of other ways:

- Member Organizations and Divisions support lupus clinics in their provinces;
- Fellowships are granted to researchers studying a vast array of lupus and lupus related issues;
- Local researchers are supported in their work to learn more about lupus in an effort to improve the lives of people living with lupus through more effective disease treatment and eventually, a cure;
- Researchers are assisted in the distribution of study requests to members.

We are all clearly working together to achieve our vision of life without lupus.

Walk a Block

Walk a Block is our National fundraising initiative which takes place annually in communities across Canada in conjunction with World Lupus Day or Lupus Awareness Month. This event creates an opportunity for public awareness and volunteer engagement as well as the ability to raise funds to support research, organizational growth and development.

As our main fundraising initiative, Walk a Block is one of the most cost-efficient fundraising campaigns we can develop. With all Member Organizations and Divisions across the country already fully engaged, we established aggressive objectives and implemented strategies to make this an even bigger success. Walk a Block is a fantastic cooperative effort, not only between Lupus Canada and its Member Organizations, but also between the Member Organizations themselves.

With two walks held in fiscal year 2007-2008 we saw increased awareness, increased participation at all levels and certainly an increase in funds raised. In total, over \$500,000 was raised through the two combined walks, leading to an aggressive goal of \$500,000 set

at our meetings for the May 2009 walk.

The strategy for Walk a Block continues to be to increase participation as well as the profile of the walks which in turn would increase National awareness and secure corporate participation through sponsorships. Through the National Walk a Block Coordinator, direct support and consistent branding was provided to walks across Canada. The key to this events continued success and growth is the development of long term relationships with volunteers, walkers and partners. Re-development of the Walk a Block website provided a vehicle for secure electronic donation and receipting as well as creating a National link between participants who could share their stories, photos and successes.

Lupus Canada has committed to support the Member Organizations and Divisions through National coordination of materials, reporting, administration, charitable receipting and the recruitment of National Sponsors to raise funds, create walker incentives and provide services and supplies.

Our Member Organizations and Divisions continue to support this National initiative in a variety of creative and successful ways:

- Through the involvement of medical research team challenges;
- With specific focus on youth;
- By developing one-on-one rapport with team leaders which promotes retention of team leaders and mentoring of new leaders by identifying strengths and successes;
- Through creative events in addition to the walk – barbecues, musical entertainers and activities for kids;
- By involving local media as sponsors and as walkers.

Volunteer Management

Volunteers are the heart of Lupus Canada - delivering support, resources and energy to assist in our efforts to support people living with lupus. Our continued commitment to volunteers is reinforced through our focus on recruitment and recognition at both the Provincial and National levels as well as new opportunities for volunteers to participate and use their special skills on behalf of Canadians living with lupus. We recognize that volunteers are our most precious resource.

Sincere thanks and appreciation go out to all the volunteers across the country who give their time so generously to Lupus Canada, its

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Member Organizations and Divisions. Time is a precious commodity these days and certainly one of the most selfless gifts one can give. The services and support we are able to provide to people living with lupus, because of your efforts, is appreciated by us all.

In order to focus on volunteer development, Lupus Canada, its Member Organizations and Divisions endeavour to leverage our existing programs and materials as well as look at opportunities to recruit, retain and reward volunteers. We recognize that the development of support group leaders as well as the development of more volunteers to share the load has become critical. Many initiatives have been undertaken in that regard across the country:

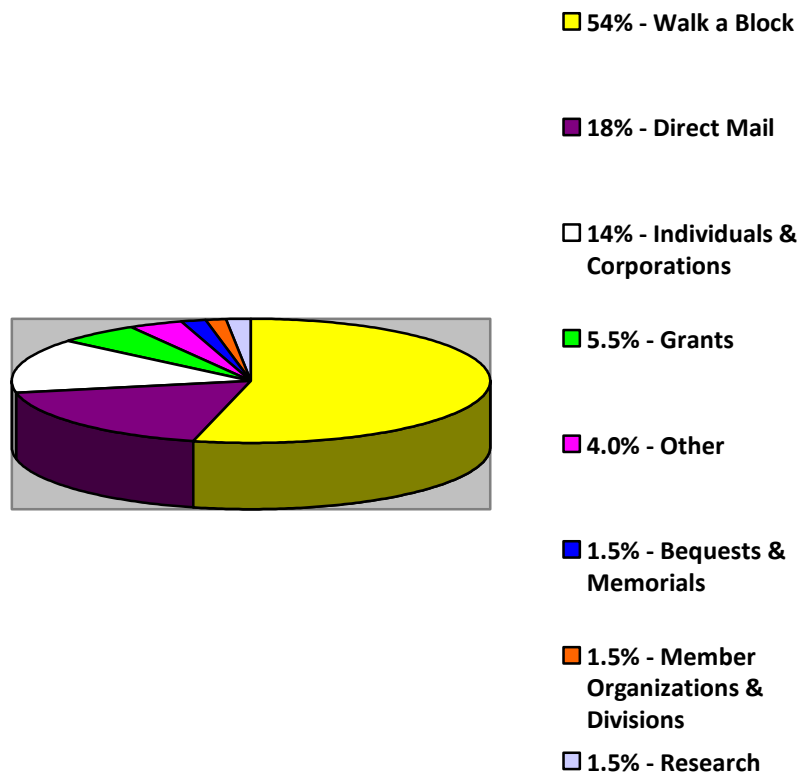
- Our Trillium Foundation material for Support Group Leader training has been utilized to recruit and train new support group leaders in both metropolitan and rural areas;
- Materials developed by our Volunteer Management Committee are being utilized to look at creative, streamlined methods to recruit new volunteers in all Member Organizations and Divisions;
- Lupus Canada developed a volunteer recognition pin program which will see our volunteers presented with pins recognizing their years of volunteer service;
- Member Organizations and Divisions are approaching schools to motivate youth into active, energetic volunteers;
- Recognition events are taking place to let volunteers know their time and service is appreciated;
- Walk a Block is being utilized as an opportunity to engage volunteers in the lupus movement as team leaders, walkers and volunteers to help on walk day;

We are working together to conquer lupus!

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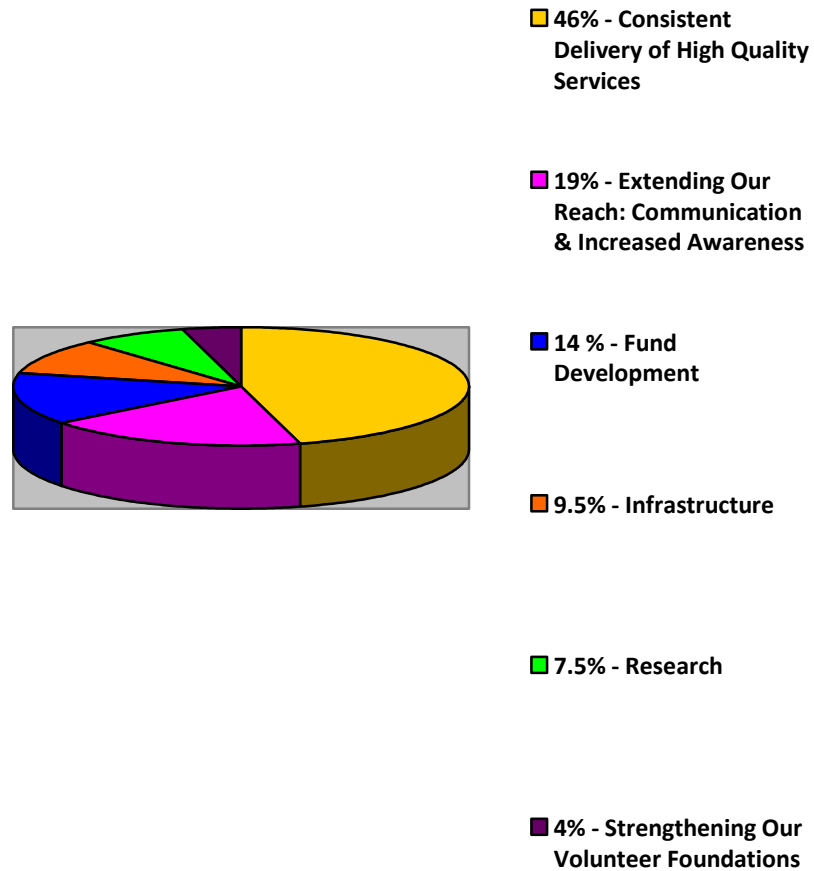
During the year, Lupus Canada undertook a strategic review of our infrastructure costs so as to ensure we were working as efficiently and effectively as possible. We have focused our staff and financial resources directly at our five pillars - Advocacy, Public Awareness, Research, Walk a Block National Campaign and Volunteer Management. Employee job descriptions and budgets have been built strategically around those pillars and every effort has been made to reduce costs and provide transparency to our stakeholders.

How our dollars are raised:



Lupus Canada continues to receive strong support from the public through our Direct Mail Program, online giving through Canada Helps, Memorial Donations, In Honour Donations and third party events for which we are truly grateful.

How our dollars are spent:



It's been an exciting year and I am delighted to have had the opportunity to join the team at Lupus Canada in the newly created role of Executive Director. It's an honor and privilege to have been selected to assume that role at a time of such opportunity and growth for Lupus Canada. I have been impressed and encouraged by the strong support shown at every level – the Board of Directors, Member Organizations and Divisions, stakeholders, volunteers and staff – we truly are ***working together to conquer lupus.***

My thanks to André Vincent, President of the Board of Directors as well as the Officers and Directors of the Lupus Canada Board for their leadership. Through the dedicated efforts of our Board of Directors, our exceptional volunteers and our staff, we continue to focus on our vision of life without lupus.

Catherine Madden
Executive Director, Lupus Canada

Lupus Canada is truly the sum of its parts... the Board of Directors, Member Organizations, Divisions, volunteers, stakeholders and staff. We are grateful for the support of the following...

Lupus Canada Volunteer Board of Directors

Officers:

André Vincent, President (Nova Scotia)

Kendra MacDonald, Vice President (Québec)

Tina Sarta, Treasurer (Ontario)

Directors:

Tom Koor, Chair Governance Committee (Ontario)

Julia Kane, Chair Audit Committee (Ontario)

Michael Hinman, B.C. Lupus Society

Lloyd Driedger, Lupus Erythematosus Society of Saskatchewan

Darlene Garner, Lupus Society of Manitoba Inc.

Michelle Leece, Lupus Foundation of Ontario

Nancy Votour, Lupus New Brunswick

Iris Scallen, Lupus Society of Nova Scotia

Lucy Stoyles, Lupus Newfoundland & Labrador

Member Organizations & Divisions

BC Lupus Society

Lupus Erythematosus Society of Saskatchewan

Lupus Society of Manitoba

Lupus Foundation of Ontario

Lupus Ontario

Lupus Québec Division

Lupus New Brunswick

Lupus PEI

Lupus Society of Nova Scotia

Lupus Newfoundland and Labrador

Lupus Canada Advisors

Medical Advisors

Ann Clarke, MD, MSc ; Montreal General Hospital, Montreal

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Susan D. Denburg, PhD; McMaster University, Hamilton

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Vancouver

Earl Silverman, MD, FRCP(C); Hospital for Sick Children, Toronto

Legal Advisor

Lawrence Greenspon, LL.B.; Ottawa

Educational Advisor

Sasha Bernatsky, MD

Committees

Governance Committee

Tom Koor (Chair), Ontario

Michelle Leece, Ontario

Lloyd Driedger, Saskatchewan

André Vincent, Nova Scotia

Audit Committee

Julia Kane (Chair), Ontario

Michael Hinman, British Columbia

Kendra MacDonald, Quebec

Trillium Advisory Committee

Cheryl Magnusson (Chair), British Columbia

Anne Cymet, Toronto Hospital – Western Division

Jaclyn Law, Lupus Ontario

Denise Mehta, University of Ottawa General Hospital

Shelly Michano, Pick River Health Centre

Marketa Myatt, St. Joseph Health Centre

Erin Woodbeck, Thunder Bay Health Sciences Centre

Volunteer Management Committee

Glenn Outhwaite (Chair), Ontario

Shari Kennedy, Manitoba

Lorrie Powless, Ontario

Catherine Madden, Lupus Canada

Lupus Canada Major Supporters

Lupus Canada thanks all individuals and organizations whose generous support has funded the organization's programs and services. Those organizations who have made significant contributions are listed below:

Abbott
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Amgen
Aspreva Pharmaceuticals
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Bristol Myers Squibb
CAW Local 414
Canadian Institutes of Health Research
Delta Hotels
Desjardins Credit Union
Dundee Wealth
Florie Storr Lupus Endowment Fund
Grabber Warmers
ING Direct
Magnum Fine Printing
The Ontario Trillium Foundation
Revelstoke Community Foundation
Roche
Wyeth

Our sincere apologies for any names we might have missed.

Lupus Canada National Office

Catherine Madden, Executive Director
Leanne Mielczarek, National Coordinator, Campaigns &
Development

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