

SPRING IS HERE!

Welcome to the spring edition of our quarterly newsletter *Living Well with LupUS!* We've designed this periodical with you in mind as it gives us an opportunity to keep you up-to-date on our five pillars and how our focus of energy and resources towards them keeps us ever mindful of what's important—improving the lives of people living with lupus across Canada.

While the winter has been anything but a period of hibernation for Lupus Canada, the spring season brings with it promise of more activity and more opportunities to come face to face with our stakeholders so we can ensure they are benefitting from our pillars and are living well with lupus. It gives us a chance to get out and talk to people, to share stories, get new ideas and talk about what people living with lupus need from us. It's a busy and exciting time and we are looking forward to it!

Spring is my favourite time of the year bar none. The days get longer and brighter and it just feels like there's more oxygen in the air. There is a sense of renewal, a longing to venture outdoors again after a winter spent in hibernation. I love these early days of spring when you can open the windows for a few hours to let in the fresh air and hear the cheerful songs of the birds. Even better are the days when it's comfortable enough to sit on the back deck and listen to the rustle of the newly opened leaves in the breeze, the hum of a lawn mower and the most pleasant of sounds - children laughing and playing.

One of the simplest things we can do in life is to listen... simply listen. Too often though we are doing or thinking of several other things at the same time or anxiously waiting for our opportunity to reply. True and active listening takes work and focus but is one of the sincerest gifts we can offer. Our goal at Lupus Canada has

been, and will continue to be, to actively listen to our Member Organizations, Divisions and supporters to ensure that we are hearing your needs and acting upon them.

**"To learn through listening,
practice it naively and actively.
Naively means that you listen openly,
ready to learn something, as opposed to
listening defensively, ready to rebut.
Listening actively means you acknowledge
what you heard and act accordingly."
~ Betsy Sanders**

Our five pillars—Advocacy, Public Awareness, Research, Volunteer Management and Walk a Block—reflect the collaborative work being done nationally on behalf of people living with lupus.

ADVOCACY

Advocacy means two things at Lupus Canada— "educating people about their legal rights and entitlements and working with politicians and government to enhance policies and legislation affecting people living with lupus".

In addition to ensuring that our website is as current as possible in terms of resources available to people living with lupus, we are working on the issue of **compact fluorescent lightbulbs** (CFL's) and the impact they have on some people living with lupus. The federal government has mandated that traditional incandescent bulbs are to be eliminated by 2012 and replaced by CFL's which are widely touted worldwide as being more energy efficient as well as being more environmentally friendly. Several lupus health organizations around the world have identified the bulbs as a potential risk for people living with lupus due to the increased exposure to UV radiation similar to unprotected exposure to direct sunlight. For people living with lupus who experience sensitivity to the

sun, this is of significant concern. More research is necessary and Lupus Canada is working to better understand the health implications so we can present an informed opinion to Health Canada, if necessary.

Lupus Canada receives many calls daily from people living with lupus across the country who are looking for **information** and **support**. We are pleased to be able to assist those callers with their enquiries as well as being able to provide the opportunity to connect those callers to their local Member Organization or Division for support in the communities in which they live. This is the true value and impact we provide in working together to conquer lupus.

We continue to monitor news of the Phase 3 trials of **BENLYSTA™** (belimumab) and encourage people living with lupus to keep informed by reading the coverage and press releases on our website as they become available.

Our lupus **Fact Sheets** continue to be requested through calls to our office and downloads from our website. Due to their popularity and the increase in requests for information, Lupus Canada has designed **Living well with lupus FACTS**, a booklet containing all fact sheets in one concise source. These booklets will be available in the coming weeks and are available free of charge by contacting the Lupus Canada office.

PUBLIC AWARENESS

At Lupus Canada, public awareness is defined as “informing and educating the public about what lupus is”. It’s a simple enough definition but rather diverse in its delivery.

There’s been so much happening at Lupus Canada in terms of the promotion of public awareness it’s hard to know where to start! Let’s begin with our audience—our Member Organizations and Divisions and their members as well as our **online subscribers** and website visitors. With the

support of our Member Organizations and Divisions, the work happening at Lupus Canada has been shared with thousands of their members through emails, newsletters and at meetings. We are honoured to have an online subscriber list of 2,200 people who receive our electronic newsletter and e-blasts on a regular basis. And just think... if each of those subscribers forwards it on to just one person that number doubles! The power of electronic public awareness is incredible and as such we are venturing beyond traditional email and also utilizing social media like Twitter™ YouTube™ and Facebook© to share our message.

We are thrilled to be working with Jergens Canada as part of their **Skintervention.ca** campaign. Through the Skintervention.ca microsite and the Jergens Canada Facebook© fan page, the Natural Glow Daily Moisturizer product campaign is creating awareness and raising money for Lupus Canada. For the first 5,000 people who become fans of Jergens Canada on Facebook© and write “**Shed Light on Lupus**”, Jergens Canada is donating \$1 to Lupus Canada. Our celebrity Ambassadors Colin Mochrie and Debra McGrath helped us out by creating three really great ads to promote the campaign and share facts about lupus. This multi-faceted program brings awareness specifically to the issue of sun sensitivity and lupus but through reciprocal links on their site and ours, allows us to capture an audience who are interested in learning more about the disease.

Lupus **flags** have been made available at no charge to all Member Organizations and Divisions across Canada in the hopes they can be utilized to promote awareness in May for World Lupus Day and in October for Lupus Awareness Month.

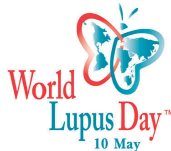
The **patient education program** is now available for the **9th International Congress on Systemic Lupus Erythematosus** and can be found online by visiting www.lupus2010.com. The congress will be held June 24-27, 2010 in Vancouver and will include a variety of topics that will appeal to peo-



ple living with lupus, their family and caregivers.

There are several new upcoming events being held within our Divisions that will bring added awareness to new audiences of our under-funded and under-recognized cause, but in more traditional ways. In Quebec, **Flare for Fashion Montreal** is taking place on Friday May 7th and will showcase multiple designers in support of **Lupus Quebec**. For more information on tickets or to volunteer your time, contact the Lupus Canada office at 1-800-661-1468. In Prince Edward island we are fortunate to have been selected as one of several charity recipients of the funds from the **Maritime Electric Golf Tournament** on June 4th. Our thanks to the organizers for their support of **Lupus PEI**.

World Lupus Day will be recognized on May 10, 2010. The following excerpt, reprinted from the World Lupus Day proclamation found at www.worldlupusday.org defines World Lupus Day as a day "on which lupus organizations around the globe call for increases in public and private sector funding for medical research on lupus, targeted education programs for health professionals, patients and the public, and worldwide recognition of lupus as a significant public health issue". We are proud to support and recognize World Lupus Day through national press releases and our social networking resources.



RESEARCH

"Funding to enable medical research to find causes, cures and treatment of lupus" is how we, at Lupus Canada, define our research pillar.

In January we were pleased to forward \$30,000 from our Member Organizations and Divisions to the **Canadian Network for Improved Outcomes in Systemic Lupus Erythematosus (CaNIOS)**. This revenue is matched by an anonymous donor and

supports infrastructure costs at CaNIOS that leverage hundreds of thousands of dollars of research grant funding in order for CaNIOS to continue their important work studying lupus. CaNIOS are feeling the economic crisis as funding for patient-oriented research is being scaled back but continue to look for alternate funding models and the support of independent activity and local funding of each member centre.

Lupus Canada is committed to supporting research across Canada and will allocate 10% of their net Walk a Block revenue to research. Work will begin to identify opportunities to support research in the coming months.

VOLUNTEER MANAGEMENT

When we talk about volunteer management, we mean the "recruiting, training and retaining of volunteers for Lupus Canada, our Member Organizations and our Divisions".

Volunteers are the heart of Lupus Canada and we celebrate our volunteers at both the national and provincial levels by recognizing them with a sincere "THANK YOU" during **National Volunteer Week April 18-24, 2010**. "Canada is a compassionate nation. There are 12.5 million Canadians volunteering in some form in this country," says Ruth MacKenzie, President and CEO of Volunteer Canada (on their website www.volunteer.ca). "The work of volunteering is essential to our communities as well as to our social fabric and recognizing their contribution is an essential part of keeping the volunteering energy vibrant." We at Lupus Canada could not agree more.

One of the most significant ways we are able to recruit and engage volunteers at both the national and provincial levels is through Walk a Block, our national fundraising and awareness campaign. Volunteers are needed to fill roles as team leaders and as walkers, or to help with registration, face painting and barbeques.



Please contact your provincial organization to find out how you can get involved.

Again, **thank you to our volunteers**—working in our Divisions and working at and for our Member Organizations—we couldn't do it without all of you! My sincere thanks also to the 2009-2010 Lupus Canada Board of Directors for their support, energy and time—a valuable and rare commodity these days.

Lupus Canada Board of Directors:

André Vincent—President
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Lucy Stoyles—Lupus Newfoundland & Labrador

“Never think that a small group of committed people cannot change the world. Indeed, it is the only thing that ever has”.
~Margaret Mead

WALK A BLOCK

Walk a Block is our National fundraising campaign involving walks across the country. It includes national and local sponsors as well as donations to individual walkers and teams.

Walk a Block is truly a 'team effort'! Coordinated from the Lupus Canada office, walks are happening in almost every province in the country—from BC to PEI. The last several months have been spent focusing on the recruitment of National Corporate Sponsors and in supporting the Member Organizations and Divisions with literature, ideas, supplies and a variety of other resources. We are well on our

way to almost 75 walks this spring and have already generated \$100,000 (33%) of our fundraising goal through online donations. Our Member Organizations and Divisions are all excited about the momentum that is being felt across the country for this year's walk. We are seeing increased donations, media support and participation. What better way to enjoy spring than to get out and Walk a Block? It's never too late to JOIN a walk, START a walk or DONATE to a walk by visiting www.walkablock.ca or by contacting the Lupus Canada office at 1-800-661-1468.

New this year is the addition of **virtual walks**. It's never been easier to donate to Walk a Block and support your local Member Organization or Division. Visit www.walkablock.ca and click on the "find a walk in your area" button to the left; select the Province of your choice and then from the drop-down menu select "virtual walk". Your donation will then be directed to support the Province of your choice.

We are grateful for the support of the following **National Corporate Sponsors** for 2010:



Good luck to all our Walk a Block participants for 2010. May you enjoy a beautiful spring day filled with the people, sounds and sites that bring you joy! We look forward to sharing your successes with the rest of the country!

Thanks for taking a step to conquer lupus!

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