

HAPPY NEW YEAR!

Welcome to our quarterly newsletter *Living Well with LupUS*—an opportunity for us at Lupus Canada to keep you, our stakeholders, up to date on the progress that is being made nationally to improve the lives of the tens of thousands of Canadians who are living with lupus.

With a new year comes the opportunity to reflect on the past and decide our goals and resolutions for the future. A new year is the opportunity to look forward with hope and renewed confidence that with new beginnings come new ideas, new successes and new joys. It is a time of renewal and is entered into with confidence.

At Lupus Canada we are building on the momentum that started last fall in a variety of areas. Momentum is powerful as it energizes us to keep moving forward with even greater enthusiasm and it sustains us when we meet roadblocks and detours along the way. Barack Obama is quoted as saying *“If you’re walking down the right path and you’re willing to keep walking, eventually you’ll make progress”*. I believe Lupus Canada and the collective Member Organizations and Divisions are making great progress. We’ve stayed the course, kept moving forward and now we are seeing success! I extend my congratulations to all of you for persevering and always keeping our purpose in mind... working together to improve the lives of Canadians living with lupus!

We are looking forward to 2010 and the opportunities before us in the coming months. We are building on successes of last fall and moving forward with enthusiasm and a renewed sense that we are on the right path!

As you know, Lupus Canada is a national voluntary organization comprised of Member Organizations and Divisions, dedicated to improving

the lives of people living with lupus through advocacy, education, public awareness, support and research. At Lupus Canada we have a very simple vision... *life without lupus*. Until such time as we can achieve that vision, we are working to ensure that Canadians are living well with lupus.

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. Much of our current success has come from focusing our energy and resources on those pillars and the underlying objectives of each.

“Progress always involves risks.

**You can’t steal second base
and keep your foot on first.”**

~ Frederick B. Wilcox

ADVOCACY – Questions about **H1N1** kept us busy in the fall as people living with lupus weighed the pros and cons of the decision to vaccinate. Through our colleagues at the Lupus Clinic at Toronto Western Hospital we were able to share the following position: *“It is recommended that that all persons with lupus receive H1N1 vaccine. There will be two types of vaccine one with adjuvant (booster) and one without. We would prefer the one WITHOUT the adjuvant. It may be difficult to obtain the vaccine without adjuvant, if this is the case we still recommend persons with lupus get vaccinated with the regular H1N1 vaccine.”*

We, like many in the lupus community, were interested in the news about a possible new drug developed by GlaxoSmithKline and Human Genome Sciences (HGS) for people living with lupus. **Benlysta** (belimumab) showed positive results in a phase 2 trial of the drug in patients with active systemic lupus erythematosus (SLE)

and, if successful in a phase 3 trial, "could represent a significant advance in the treatment of SLE" says Dr. William W. Freimuth, HGS Vice President, Clinical Research – Immunology, Rheumatology and Infectious Diseases. Lupus Canada will be working closely with GlaxoSmithKline in the coming months to keep the lupus community up-to-date on this issue.

The issues around the impending legislation regarding **Compact Fluorescent Lightbulbs** are of great concern to many people living with lupus. We are working to better understand the issues so that we may be able to advocate on behalf of people living with lupus regarding this issue.

PUBLIC AWARENESS – The importance of this pillar cannot be emphasized enough! We derive so many benefits from public awareness – an increase in awareness of this under-funded and under-recognized disease; education of the public as to what lupus is and how it affects those living with it; revenue to support research and other programs; and volunteers who assist our cause in a variety of ways. Our new **Celebrity Ambassadors** Colin Mochrie, Debra McGrath and Patrick McKenna are helping us secure more awareness of lupus through a variety of media opportunities as well as through their attendance at events held across the country designed to increase awareness and raise funds. We are constantly seeking additional awareness opportunities with the media where we can leverage the endorsement of these high profile Ambassadors for our cause.

Our **website** contains many and resources available to those living with lupus and those who simply want to better understand the disease with a thousand faces. We strive to keep the information relevant, current and easy to navigate and are pleased that our online subscribers continue to grow on a weekly basis and now number over 2,000. Watch for the launch of our website's new look in the coming months!



Lupus Canada Ambassador Meet & Greet

November 2009 (photo courtesy of SNAP Markham)

(From Left to Right) Kendra MacDonald (Vice President), Tom Koor (Chair, Governance Committee), André Vincent (President), Tina Sarta (Treasurer), Patrick McKenna, Debra McGrath, Catherine Madden (Executive Director), Julia Kane (Chair, Audit Committee) and Colin Mochrie.

We continue to receive many requests for our **Lupus Fact Sheets** and will soon be combining them into one booklet which will be available in either French or English. These Fact Sheets were originally developed under a grant by the Ontario Trillium Foundation and cover a wide range of topics. The Fact Sheets are also available on our website by individual title.

World Lupus Day will be celebrated on May 10th, 2010. Lupus Canada intends to utilize our Ambassadors as a method to bring media awareness to this date, celebrated around the world.

Lupus Canada, its Member Organizations and Divisions are proud to be some of the many sponsors of the **9th International Congress on Systemic Lupus Erythematosus** to be held in Vancouver, B.C. June 24-27, 2010. The Congress will bring together international researchers and clinicians to discuss lupus with a goal of

improving lupus treatment worldwide. According to the Congress information *"The goals of the patient program elements are to inform attendees about the latest findings in lupus research and review current clinical practices, trials and treatments; as well as to provide multiple opportunities for patients and lupus experts to interact in formal and informal panel settings and joint plenary sessions"*. For more information visit the Congress website at www.lupus2010.com or contact organizers at 1-604-688-9655 x2.

Social networking is certainly a growing trend and allows us to increase awareness of lupus both in Canada and globally. So, we've joined Facebook® as both a cause and as a group, you can follow us as *WalkaBlock* on Twitter® and we've posted our awareness video on both our website and on YouTube®.

RESEARCH – While we work towards our vision of *Life without lupus*, we strive to ensure that today patients who are living with lupus are living *well* with lupus. Therefore, while we continue to support research into the disease, Lupus Canada, its Member Organizations and Divisions also supports a variety of studies being conducted by the **Canadian Network for Improved Outcomes in Systemic Lupus Erythematosus (CaNIOS)**. Most recently, \$30,000 has been provided to CaNIOS and those funds will be matched by a private donor. The matched funds allow CaNIOS to support the salaries of permanent administrative and research staff at the CaNIOS Coordinating Centre in Toronto.

Lupus Canada is looking for volunteers interested in serving on an ad-hoc **Research Committee**. The function of this committee would be to determine what opportunities exist in regards to supporting research in Canada, to understand what the needs are, as they relate to research, of people living with lupus and do recommend how research dollars should be allocated by Lupus

Canada. Meetings will likely be held once a month initially, via teleconference.

If you, or someone you know, would be interested in serving on this Research Committee, please contact Catherine at the Lupus Canada office at 1-800-661-1468.

Through a commitment by Lupus Canada and its Member Organizations and Divisions, research is also supported through a minimum contribution of 10% of net proceeds from our annual **Walk a Block** event.

VOLUNTEER MANAGEMENT – Lupus Canada is pleased to have recruited several new volunteers who are supporting us in a variety of different ways across the country from organizing walks in our Divisions to assisting us with language translations for some of our most often requested literature. We have been very happy to learn from our Member Organizations and Divisions that they too are seeing an increase in volunteer support within their local organizations.

Volunteers are vital to the work being done across the country as they provide support to deliver programs and provide services as well as spreading awareness through their efforts.

A simple way to get involved and provide support is through Walk a Block. You can **hold** a walk, **volunteer** at a walk or **join** a walk. No effort is too small!

WALK A BLOCK – Walk a Block is fast approaching with walks taking place across the country in May! We have a new tagline that is grabbing people's attention, engaging them to *'Take a step to conquer lupus'* and help us

reach our **fundraising goal** of **\$300,000** across Canada.



New literature has been designed to assist our supporters in gathering pledges, approaching corporate partners and to assist Team Leaders with planning their walks and setting their fundraising goals.

Lupus Canada has an aggressive plan to engage the corporate community in supporting our event on a National basis by offering them the opportunity to demonstrate **corporate social responsibility** while also promoting their business.

Our Walk a Block website www.walkablock.ca is an exciting addition to this year's event! It provides the opportunity to share information, photos of past events as well as register teams and donations online. This year we will also feature **Virtual Walks** in all provinces so even if you can't join a walk, you can donate to your home province in support of Walk a Block.

We encourage you to use the Walk a Block website as an opportunity to generate funds outside of a traditional walk too. What about asking people to donate to your walk or support a virtual walk in honour of your birthday, graduation, wedding, anniversary or other significant life milestone?

If you have any ideas to share, or questions to ask about Walk a Block, please contact Leanne Mielczarek, National Coordinator Campaigns & Development at 1-800-661-1468 x224 or via email at leanne.mielczarek@lupuscanada.org

Our efforts in the coming months will be focused on increasing the number of walks and in promoting Walk a Block through every media opportunity available to us.

Through your support, **Walk a Block** is the single, most focused way, to achieve success in all of our Lupus Canada pillars – it helps us create **awareness** allowing us to **advocate** for people living with lupus; it helps us fund **research** into a cure as well as ensuring studies continue as to how to live well with the disease; and, it provides the opportunity for **volunteers** to get involved and make a difference.

Remember... **"Success is a journey, not a destination"** (Ben Sweetland) and we are on the right path. Let's follow Barack Obama's earlier advice - let's keep walking and working together to conquer lupus!

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