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MYELOMA CANADA TODAY

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Lisa Ray was diagnosed with myeloma on June 23

Lisa Ray Launches Myeloma into the Public Spotlight

Actress, fashion model and “one of the 50 most beautiful people in the country” Canadian Lisa Ray was diagnosed with multiple myeloma on June 23. With the average age of diagnosis in the sixties, Lisa, who is only 37 years old, represents a growing population group that is diagnosed at a young age. Her diagnosis questions the perception that myeloma is a disease of “older people” and brings to light the fact that myeloma

can strike people who are in the prime of their lives.

Since her diagnosis, Lisa has taken the brave step of going public with her diagnosis and has begun documenting her journey on her blog called the Yellow Diaries. Her personal story has generated a worldwide reaction from people who have been touched with myeloma and has created an online community of sharing and support. To follow Lisa’s story, visit <http://lisaraniray.wordpress.com>.

With her new film *Cooking With Stella* slated for a gala premiere at the Toronto Film Festival in September, Lisa used her fame and celebrity to speak about this unknown and unnoticed cancer. Interviews with Canada AM, the *Globe and Mail*, Global TV and Entertainment Tonight Canada brought the myeloma into the spotlight by reaching millions of Canadians who had never heard of the disease, creating unprecedented awareness across the country.

With the excitement of the Toronto Film Festival behind her, Lisa valiantly continues her efforts on behalf the Canadian myeloma community. On October 18, Lisa joined Shane Saunderson for the 5K “M-Moving Together Toward the Cure” Walk in Toronto. Walking for Team Myeloma Canada, Lisa and Shane joined hundreds of others in raising funds for the Molly and David Bloom in Myeloma Research being established at Princess Margaret Hospital.

Myeloma Canada is deeply grateful to Lisa for the focus she has brought to the myeloma community and looks forward to collaborating with her to raise awareness and donations for much-needed research in Canada.

The Prairie Pedal for Myeloma Canada:

Shane Saunderson cycles 3500 kilometers to raise awareness and donations for myeloma

On August 1, Shane Saunderson, a determined young man from Manitoba, hopped on his bicycle and left Calgary to begin his 3500 kilometer trek across the Canadian Prairies en route to Toronto. His mission: to raise awareness and money in support of Myeloma Canada’s patient programs and the Bloom Chair in myeloma research – the first in Canada – being established at Princess Margaret Hospital.

Shane and his family were touched by myeloma two years ago when his dad was diagnosed with this relatively rare and unknown disease. Over that time,

Shane thought about how he could make a positive and lasting contribution to the Canadian myeloma community. This led to the idea of cycling from Calgary to Toronto and the inspiration for the “Prairie Pedal” fundraiser.

As he travelled across the country, Shane met many Canadians touched by myeloma and raised myeloma awareness through many media interviews in towns and cities along the way.

Despite strong headwinds, cold weather, unplanned detours and frequent mechanical problems, Shane reached Toronto, his final destination, on September 8, three days ahead of schedule.



Mission Accomplished



Shane sets off on his Prairie Pedal fundraiser

The generosity of Canadians from coast to coast helped Shane surpass his original objective of \$35,000. With donations still coming in, the Prairie Pedal, the first national myeloma fundraiser, has raised almost \$50,000! Myeloma Canada would like to thank everyone who contributed to the Prairie Pedal and acknowledge Ortho Biotech and Celgene for their generous financial support.

Myeloma Canada is deeply grateful to Shane for his remarkable initiative in helping all Canadians living with myeloma.

To read more about Shane’s journey, go to www.prairiepedal.com.

Myeloma Canada Welcomes Caroline Blanchard

Caroline Blanchard joined the Myeloma Canada team on September 1 as Administrative Manager – Planning and Development. Caroline’s professional career has included positions in account management and marketing after having earned her degree of Bachelor in Administration from the University of Quebec in Rimouski in 1999.

Since its founding five years ago, Myeloma Canada has been reaching out to the patients, caregivers and healthcare professionals with an increasing number of programs focused on education, awareness, access and research. Over this time, Myeloma Canada has successfully built a solid foundation through the work of many



Caroline Blanchard joined Myeloma Canada on September 1

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dedicated volunteers. Caroline's experience will build on the momentum that has been created and help develop programs to meeting the growing needs of the Canadian myeloma community.

Caroline can be reached at cblanchard@myelomacanada.ca or by phone at (514) 426-5885 or 1-888-798-5771.

Dr. Suzanne Trudel and Dr. Richard LeBlanc Join Myeloma Canada Scientific Advisory Board

Myeloma Canada is pleased to announce the appointment of Dr. Suzanne Trudel and Dr. Richard LeBlanc to the Myeloma Canada Scientific Advisory Board.



Dr. Suzanne Trudel

Dr. Suzanne Trudel is an Assistant Professor of Medicine, in the Division of Hematology at the University of Toronto, and a Clinician/Research Scientist in the Department of Medical Oncology and Hematology at Princess Margaret Hospital. Dr. Trudel received her MD from the Faculty of Medicine at the University of Toronto in 1994. She then completed training in General Internal Medicine and subspecialty training in Hematology at the University of Toronto affiliated hospitals, followed by research training in malignant hematology at Weill Medical College of Cornell in New York. Her research focuses

on novel drug development for the treatment of multiple myeloma based on molecular targets, and the incorporation of novel treatments into the clinic. Dr. Trudel is a former recipient of the American Society of Hematology Scholar Award and holds a Clinician-Scientist Award from the Canadian Institute of Health Research.



Dr. Richard LeBlanc

Dr. Richard LeBlanc is a hematologist/oncologist at Maisonneuve-Rosemont Hospital in Montreal. He obtained his MD degree from Laval University in 1995 and was certified in internal medicine in 1998. He then continued his his training in hematology at Laval University until 2000. Thereafter, he spent two years as a research fellow at the Jerome Lipper Center for Multiple Myeloma, Dana Farber Cancer Institute in Boston from 2000 to 2002. He published many articles about multiple myeloma and several as a first author in journals such as *Blood* and *Cancer Research*. In 2004, he completed his training in medical oncology at University of Montreal. In 2006, he obtained a grant from

Le Fonds de Recherche en Santé du Québec for a project concerning multiple myeloma. In 2009, he was recruited by Maisonneuve-Rosemont hospital to focus on myeloma care, research and teaching.

Patient Advocacy – Getting What You Need

Ryan Clarke, LL.B.

As a patient with multiple myeloma or as a caregiver to someone facing this disease, you undoubtedly recognize the importance of getting the most from the health care system. Whether it's a referral, a second opinion or access to a particular treatment, being able to stand up and ask for what you need is critical to ensuring that you receive the best care. And yet few of us know how to do this effectively.

Fortunately, through some of the tremendous work that has gone on in provinces like Ontario and Alberta over the last few years, patients and caregivers have developed some proven methods to impact real change around multiple

myeloma. They've done this through advocacy, aimed at the provincial governments and focused on getting access to the newest medications like Velcade and Revlimid. Below I'll share with you the basic steps that one needs to follow in taking on any advocacy effort, with some examples specific to multiple myeloma patient advocacy.

Your Issues

Before getting started, you need to have a clear understanding of the issues that you want to raise and with whom you want to raise them. Think about the concerns and challenges you face around multiple myeloma and identify who can help you bring about the change you require. The more focused your issues are, and the fewer of them you have, the more likely you are to be successful.

As mentioned, a group of patients and caregivers in Ontario recently came together after identifying a very clear issue: two medications vital to the treatment of multiple myeloma, while approved for use by Health Canada, were not being publicly funded by the provincial drug plan. That lack of public funding meant that some patients were at risk of not being able to get Velcade or Revlimid despite that fact that their physician felt they would benefit. They had their issue.

Key Messages

You then need to take your issues and distill them down to their simplest form. I recommend writing out three key messages that explain the salient points in easy to understand language. Each of those key messages should consist of 25 words or less and be conveyed in a clear, compelling, concise and consistent manner. They represent the essence of what you want a decision-maker (like your member of provincial parliament) to remember and respond to around your issues.

On the Myeloma Canada web site (www.myelomacanada.ca), there is a good example of the key messages that patients and caregivers in Ontario and Alberta used to advocate for access to Revlimid. The information can be found under "drug coverage and access". The key messages are:

- a. In early October 2008, Health Canada approved the use of Revlimid for multiple myeloma, an incurable form of cancer.
- b. A life-threatening cancer of the plasma cells, multiple myeloma is nevertheless a treatable disease.
- c. Medications are an important cornerstone of treatment for multiple myeloma, and Revlimid is a vital treatment that must be made accessible to patients in Ontario and Alberta.

In addition to your key messages, it is also critical that you discuss your multiple myeloma issues in the context of your personal story. Articulate how the disease has impacted your life, and then link that impact back to why you're advocating for change.

Advocacy Tools

Advocacy tools are the means by which you will deliver your three key messages. They're the most important way for you make your voice heard and get what you need. Examples of such tools include web sites, newsletters, in-person meetings, petitions, letters, fact sheets, postcards and newspaper articles.

In Ontario, patients and caregivers advocating for access to treatments used many different tools in their communication with government officials, both politicians and bureaucrats. They gathered petitions, many of which were presented in the provincial legislature, they sent letters to their Members of Provincial Parliament and others, they visited their elected representatives and some were interviewed in their local newspapers. All of these activities played an important role in conveying their key messages around the need for publicly-funded multiple myeloma medications.

One 'Ask'

The goal of any advocacy effort should always be to ask a decision-maker for the *one* thing you *need* them to do. It's here that most people fail to be specific enough. It may sound contrary to what some think, but the less you ask for and the more specific you are, the more likely you are to succeed through advocacy.

And remember that your ask needs to be tangible, something that you can clearly see or measure.

In the case of the advocacy work that's gone on in Ontario and Alberta in multiple myeloma this year, the 'ask' has been succinct – that the provincial government provide access to Revlimid through public funding. That 'ask' has now been fulfilled in both provinces.

Making our voices known to people in power is not a typically Canadian thing to do. We're more likely to accept things, not questioning or disagreeing. But to bring about change, the change we need, sometimes we need to speak up. And in the case of government, every one of us has the right under Section 2 of the *Canadian Charter of Rights and Freedoms* to make known our personal thoughts, beliefs, opinions, and expressions. I encourage you to do so for yourself and for the benefit of everyone affected by multiple myeloma.

Ryan Clarke is the founder of Advocacy Solutions, a business committed to providing a voice to organizations and individuals through the development and implementation of advocacy strategies. He can be contacted at ryan@advocacysolutions.ca.

Celgene Presents TEAM Award at Calgary Conference

At the recent Myeloma Canada Conference held in Calgary, The Ontario Advocacy Team was honoured for their determined efforts in leading the initiative to persuade the Ontario government to approve funding for Revlimid. Last July, after many months of meetings, letter-writing campaigns and petitions, the Ontario government finally announced that Revlimid would be included on the provincial formulary.



Pictured from left to right: Jill Lang-Ward, Dr. Donna Reece, Alan Patt, Marion Hunter, Don Hunter.

The recipients of the first-ever TEAM (The Excellence in Advocacy Medal) award were Carolyn Henry, Cindy Leder and Dr. Donna Reece.

Mr. Alan Patt, Director of Government Relations and Market Access for Celgene Canada, also presented a cheque for \$5,000 to Myeloma Canada in recognition of the efforts of the Ontario Advocacy Team.

Myeloma Canada thanks everyone in Ontario who were part of the successful effort to have Revlimid funded.

Introducing ChemoReady.ca: A valuable new resource for people living with cancer

While many people have heard of chemotherapy, few may know where to find information they need to be well informed. Amgen Canada has sponsored a new web site to support people living with cancer – and their caregivers – through the chemotherapy journey. **ChemoReady.ca** helps people prepare for chemotherapy by explaining the treatment process so they know what to expect and informs them about potential risks and side effects such as nausea, fatigue, anemia and neutropenia.

Every chemotherapy experience is unique. ChemoReady.ca includes **MyChemoPlan**, a step-by-step program that guides people through chemotherapy with information, tools and other resources customized to each individual needs. Visit www.ChemoReady.ca today to see MyChemoPlan in action.

In addition, ChemoReady.ca also offers the eChemoCare Program. This program consists of a series of emails that provide facts and advice at each stage of treatment, so people can feel in control every step of the way. To sign up for the eChemoCare Program, visit <http://www.chemoready.ca/public/treatment/emailprogram.jsp>.

M-Moving Together Toward the Cure

On October 18, a record number of patients, caregivers and friends gathered in downtown Toronto to participate in the annual 5K Walk to raise funds for the Molly & David Bloom Myeloma Research Chair. With donations still coming in, the myeloma team has thus far raised \$287,500. Donations can be made at www.mm5k-walk.ca until December 31. Congratulations to Shane Saunderson and Lisa Ray who led Team Myeloma Canada and raised over \$28,000!



Lisa Ray, David Bloom and Shane Saunderson



Jennifer McLaughlin, Mike Kaczor, Cindy Leder and Carolyn Henry



Promoting the Montreal March for Myeloma

Montreal Myeloma Support Group Organizes First Fundraiser

The Montreal Myeloma Support Group organized its first 5K "March for Myeloma" on October 18, to coincide with the Toronto 5K Walk. Thanks to the leadership of Sylvie-Chantale Duquette and Maryse Bouchard, the entire event was organized in six weeks! Almost 300 participants from Montreal and beyond walked along the picturesque Lachine Canal under sunny skies, raising over \$25,000 in support of Myeloma Canada's patient programs. The Montreal March for Myeloma will become an annual event, and planning is well underway for 2010 in support of myeloma research.



Enjoying a beautiful fall day while raising money and awareness for myeloma

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Myeloma Manager™ Personal Care Assistant™: Canadian Edition

The Canadian edition of the Myeloma Manager™ was developed by the International Myeloma Foundation (IMF) in collaboration with Myeloma Canada to help patients and caregivers deal with the growth of information and increasing complexity of myeloma treatment programs. It runs on the user's computer and stores all personal data on the user's computer. None of the data are transmitted to anyone. Access to the Myeloma Manager™ is password protected and the data is encrypted (scrambled) so that it cannot be accessed from outside of the Myeloma Manager™.

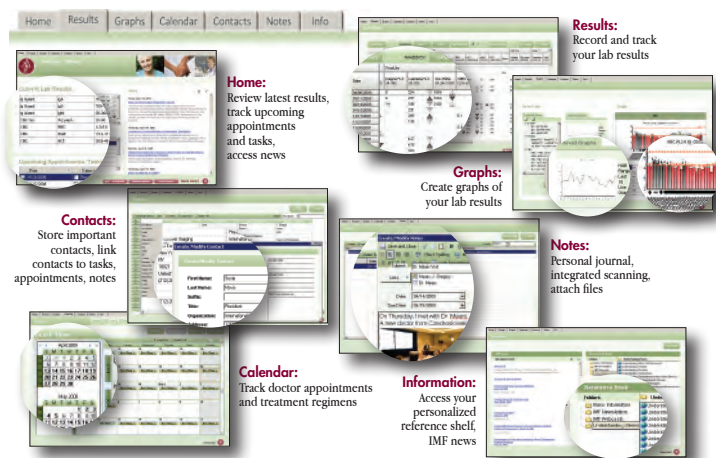
At its core, the Myeloma Manager™ provides a tool to capture laboratory results and display and print tables and charts to show how those results change over time. Other features include automatic backup of your data each time you shut down the program, calendars, and graph features such as plotting multiple tests on one graph and time-scaled graphs. The software also includes real-time news feeds from the IMF web site and a reference shelf, with links to useful publications and web pages.

At this time, the Myeloma Manager™ is available for Windows computers running XP or Vista. It is not yet available for Macintosh, although this is planned for the future.

We hope that you will find this new tool useful. As this software is the first product of its kind, we very much look forward to your feedback and suggestions. You can help us identify problems that we need to fix as well as understanding what we can do to make the software more valuable for myeloma patients and caregivers.

You can access the Canadian edition of the Myeloma Manager™ from the Myeloma Canada website (www.myelomacanada.ca) by clicking on the "myeloma manager" tab on the right hand side of the home page.

You can also download the Canadian version of the Myeloma Manager™ Personal Care Assistant™ at <http://camanager.myeloma.org>



Contact Information

To reach Myeloma Canada:

Telephone: (514) 426-5885 or 1-888-798-5771
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Mailing Address: PO Box 326
Kirkland, QC
H9H 0A4
Website: www.myelomacanada.ca

To reach the International Myeloma Foundation:

Hotline: 1-800-452-2873 (US and Canada)
Email: TheIMF@myeloma.org
Website: www.myeloma.org



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Please note that information contained in this newsletter is not intended to replace the advice of a qualified healthcare professional. Myeloma Canada is not engaged in rendering medical or professional services.



Telephone: (514) 426-5885 or (888) 798-5771

www.myelomacanada.ca

Multiple Myeloma Support Groups

Myeloma Canada is often asked by patients and caregivers if we know of support groups in their areas where they can meet others dealing with myeloma. There is presently a network of 15 patient groups across Canada that hold regular meetings for members of the myeloma community. Myeloma support groups are active in the following locations:

- **Alberta:** Calgary, Edmonton
- **British Columbia:** Campbell River, Vancouver, Victoria
- **Manitoba:** Winnipeg
- **New Brunswick:** Saint John
- **Ontario:** Hamilton, London, Ottawa, Sault Ste. Marie, Toronto, Windsor
- **Prince Edward Island:** Charlottetown
- **Quebec:** Montreal

Although these groups are independent from Myeloma Canada, we support their efforts and encourage you to seek them out. For more information, including contact information and meeting times, visit the Myeloma Canada website at www.myelomacanada.ca and click on "find support".

New Support Groups

In addition to the existing national support group network, two new support groups are in the process of being formed.

- **Regina, Saskatchewan**
Contact: Mona Dartige
Phone: (306) 949-7794; Email: mdartige@sasktel.net
- **Fredericton, New Brunswick**
Contact: Carol Coleman
Phone: 506-450-9935; Email: carolcoleman@rogers.com

Help Myeloma Canada Help You

Your generous donations will help Myeloma Canada continue its programs and extend its services to the myeloma community at large, promoting education, awareness, access and research. Your donations remain in Canada to support our ongoing activities that benefit you and the thousands of myeloma patients and their caregivers in this country.

Myeloma Canada is a registered charity providing tax receipts to donors. Donations can easily be made online at www.canadahelps.org. Simply indicate you want to give to Myeloma Canada and follow the instructions.

Alternatively, you can send a cheque or money order to:

Myeloma Canada, PO Box 326, Kirkland, QC H9H 0A4