

In this Issue....

1 Message from the Chair: Annette Cyr	2 Ontario Bans the Tan!	3 Strides for Melanoma 2013 - Thank you!	4 An Open Letter of Thanks
5 Patient Spotlight: Andrea Miller	6 2014 Peer Support Teleconference Coming Soon - Youth Sun Awareness Program	7 Coping with Cancer During the Holidays Volunteer with MNC	2014 Tee Off For Melanoma Awareness
			8 Give the Gift That Gives Back: Donate Today!

Message from the Chair

2013 has been an incredibly busy year for MNC and the melanoma community:

- We assisted over 1700 patients and families dealing with the challenges of this disease.
- We submitted 4 advocacy group submissions for access to new drug therapies.
- We led the charge for the successful passing of a ban on youth access to tanning beds in Ontario.
- We have introduced an expanded teleconference service with guest speakers each month. This is free of charge to patients across Canada.
- We launched two new booklets in our information series for patients, *Melanoma – What you need to know* and *Managing Lymphedema for the Melanoma Patient*. In 2014 we will have a ground breaking publication on uveal (ocular) melanoma – stay tuned for this.
- We provided information sessions on new therapies for patients across the country and the first in Nova Scotia.
- We updated our website and registration for events to make it more robust and user-friendly as well as providing French translation.

Well, you get the idea. For a small organization, we have been active and growing.



Annette Cyr
C.Dir., M.B.A, C.C.P, S.H.R.P
Chair of the Board of Directors

While we are still waiting for every province to fully cover Zelboraf and Yervoy for metastatic melanoma patients (namely PEI, Newfoundland and New Brunswick), two new drug therapies from GlaxoSmithKline have received positive recommendations from the pan-Canadian Oncology Drug Review (pCODR). Trametinib (Mekinist) and Dabrafenib (Tafinlar) are both used for the treatment of patients with unresectable or metastatic melanoma with a BRAF V600 mutation.

On November 6th the pCODR Expert Review Committee recommended funding for Trametinib (Mekinist), conditional

on the cost-effectiveness of trametinib improved to an acceptable level. The pCODR decision on Dabrafenib (Tafinlar) is expected in early December. MNC strongly believes that every patient should have coverage of approved therapies regardless of where they live. We will continue to advocate on behalf of patients until all Canadians have fair and equitable access. As a result of these new and innovative therapies, more clinical trials are now being offered to melanoma patients. There are even some trials opening for some Stage 3 patients to hopefully prevent future progression of disease. We encourage you to keep lines of communication open with your oncologist and consider clinical trials if you are eligible.

MNC also presented pCODR with a patient submission for Vismodegib (Erevedge) for the treatment of adult patients with histologically advanced basal cell carcinoma

Message from the Chair continued...

inappropriate for surgery or radiotherapy. pCODR's decision for this new therapy is expected early in the new year. For more information visit the pCODR website at www.pcodr.ca.

MNC continues to strive to improve the services we offer. Our new Peer to Peer Support program – 'Within Reach' will launch in the New Year. We need all you willing supporters out there...If you would like to give back and help a newly diagnosed patient or caregiver, I encourage you to contact Diane at dharty@melanomaneetwork.ca or 905-901-5121 ext. 102. It may only involve a couple of hours a month by phone. We will be offering training and do not foresee this being too time consuming for volunteers.

We are also excited to be moving forward with our Youth Education Sun Awareness program in 2014. The program will be piloted in Ontario in collaboration with the Ontario Camp Association and will focus on simple and practical sun safety messaging to encourage youth to adopt sun awareness practices. After the initial launch the program will be offered nationwide.

As the year draws to an end I look back with gratefulness and pride. Pride at what we have been able to accomplish – outreach we have provided, lives we have touched and the difference we are making.

I am grateful for the wonderful people that we have had the pleasure of working with. MNC has amazing volunteers that help us in every aspect of our reach. Our Board of Directors is like none other – a collaboration of professionals who work hard to ensure MNC is successful in all undertakings. In addition I would like to thank the small but mighty staff at MNC (Diane and Jessica) for all their hard work throughout the year.

To our patient community, our friends and supporters: on behalf of everyone at MNC, thank you for all of your support and as we look forward to the New Year. I wish you peace and good health.

Ontario Finally Bans the Tan!

On October 9th, after years of advocacy and lobbying, Annette Cyr, MNC Chair stood proudly next to Health Minister, Deb Matthews as the Ontario government unanimously passed Bill 30, *the Skin Cancer Prevention Act*. This legislation will prevent youth under 18 years of age from accessing indoor tanning equipment.

Melanoma is one of the most commonly occurring cancers for Canadians aged 15-34 and tanning beds pose a significant risk for developing skin cancer or melanoma.

MNC has been urging governments across Canada, including Ontario, to pass this legislation in Ontario for over 4 years. In 2012, MNC spearheaded the campaign to ban tanning for teens in the municipalities of Mississauga, Oakville and in the Region of Peel.

By taking action to ban teens from tanning, Ontario joins Prince Edward Island, Quebec, British Columbia, Nova Scotia and Newfoundland that have already enacted similar restrictions for minors.

We are thankful to all three parties for putting politics aside and passing this life saving legislation. It is a turning point in the fight against melanoma. We are so proud this Bill has been passed!



**Hon Deborah Matthews,
Minister of Health and Long-Term
Care with Annette Cyr, Chair**

Strides for Melanoma 2013 Results!

The 2nd Annual Strides for Melanoma Walk was a great success! On September 29th hundreds of patients and supporters joined together, increased awareness and raised **over \$117,000** for MNC. Organized walks were held again this year in: Mississauga, Ottawa, Dartmouth. We also proudly welcomed new Strides for Melanoma sites in: Hamilton, Calgary, Edmonton and Victoria. It was truly a wonderful day, uniting the melanoma community across Canada from coast to coast.

Funds raised from the walk this year will enable MNC to continue to provide patient support services, research and education programs. The Walk will help fund a comprehensive youth sun awareness education program

geared to increase awareness, prevention and ultimately change sun habits.

The Strides for Melanoma Walk will continue to be held on the last Sunday in September. Please save the date and start to make your plans for **September 28th, 2014!**

Thinking of bringing a walk to your town? We would love to help you! Please contact walk@melanomanetwork.ca or call 905-901-5201 ext. 104.

Thank you to our local Mississauga sponsor:



Thank You For Your Support Canada!



An Open Letter of *Thanks*

I just wanted to let you know what a privilege it was to be a part of the 2nd Annual Strides for Melanoma Awareness Walk. My husband was diagnosed this past March and it has rocked our world. He is still young, just 39. This walk was a great way for our kids (9,11) to find ways to personalize what has been going on as well as to feel support from family and friends. They walked the event today with family and friends and came home excited having been a part of it all! I was unable to walk since I was needed at my husband's side today but sent our thoughts and prayers along with them. I was so proud of my kids and felt touched and supported by those who financially sponsored us as well as by those who walked.

The feedback I heard from everyone was that it ran smoothly and professionally...my daughter even got a massage which was a great bonus.

Thank you to all who worked hard at putting on this event, it will be remembered by my family forever...one small way we could show our love and support for my husband Jay.

Become MNC's Next Top Designer! Enter our Strides for Melanoma: Walk For Awareness T-Shirt Contest

Are you creative with a flair for design? Would you like to share your artistic talent for a great cause? Then we want **you** to enter our 2014 Strides for Melanoma T-Shirt Contest!

The winning design will be featured on hundreds of t-shirts across the country and will be credited to the designer. Our winner will also be awarded with a \$100 gift card to Future Shop!



MNC's 2013 Walk T-Shirts

No need to be a professional artist or designer – send in your design or the sketch of your concept and if selected we will help you refine it.

Please submit your design by 11 p.m. EST Monday, January 20, 2014 to walk@melanomanetwork.ca. For a full list of rules please visit www.melanomanetwork.ca.

Don't Miss Your Chance to Golf at the Home of the Canadian Open!

TEE OFF FOR **MELANOMA** AWARENESS
GLEN ABBEY GOLF CLUB, OAKVILLE

SAVE THE DATE

– THURSDAY, MAY 22ND 2014 –

• • • • *DETAILS TO COME* • • • •

VISIT WWW.MELANOMANETWORK.CA

OR CONTACT DIANE AT: DHARTY@MELANOMANETWORK.CA 905.901.5121 EXT. 102

Patient Spotlight: Andrea Miller

Growing up I was constantly complimented on my red hair, blue eyes and freckles. I didn't particularly find these qualities all that becoming and found kinship in our Canadian heroine, Anne of Green Gables. Eventually, I learned that these qualities allowed me to stand out in a crowd and I began to embrace my differences. Unfortunately, these characteristics are also risk factors for melanoma.

Over time, I developed a mole at the base of my neck and noticed progressive changes, however, I knew that when you are in your 30's and with pregnancies you often develop new moles so I didn't think too much about it. My intuition was telling me that there was something just not right with this mole, but being a busy working mom of two I kept putting off getting it checked.

During routine visit to my family doctor to have my son's 18 month immunizations, I happened to ask the doctor to have a quick look at my neck, and thankfully he did. A few days later I was sent to the dermatologist and had a biopsy, only to discover that my "30 something" mole was actually melanoma.

I was diagnosed with a Stage 1B melanoma, which thankfully is still early stages, however my mitotic rate was higher, which meant that I should have my lymph nodes checked. After meeting with a number of different physicians and having a few more tests done, I had surgery to remove the skin



As a nurse I know that education is the key to prevention...

around the site and my lymph nodes. On June 21st, 2013 I received the great news that my lymph nodes were clear.

Although I thought that my melanoma experience would be over once I got the all clear, I was mistaken. For me personally, melanoma will be a part of my life forever. My journey with cancer has fundamentally changed me, and in fact I think it has been for the better.

My experience with Melanoma impacted my career. I am an RN and for the first time was able to see the health care system from another angle. I had the opportunity to walk in a patient's shoes and this has encouraged and motivated me to continue to provide exemplary care to others.

Melanoma has been known as a young person's cancer, and I feel blessed, not for having cancer in my 30's, but to

have been given the opportunity to re-evaluate my life at a young age. Very quickly I was able to realize the value of family, being present in the moment and enjoying the simple pleasures in life, which for me right now is watching my children grow and spending time with family and friends.

As a nurse I know that education is the key to prevention and what better way to educate people than through your own experience. It is because of my experience many of my friends and family have started to utilize their sunscreen on a more regular basis and have started to pay more attention to their skin and moles.

In August of this year my mother discovered that she also had a melanoma on her arm, fortunately hers was a Melanoma *in situ*; a very early stage Melanoma. I reflect on this situation from a positive perspective and know that it was my experience that encouraged my mother to have her skin checked and that her Melanoma was discovered early.

I know that my battle with Melanoma will be life-long, with monthly skin and lymph node checks, physician follow ups and dealing with the fear of the "what if". Although the prospect of finding another melanoma scares me, I have decided that I cannot live in fear and consider myself lucky that I have the knowledge of prevention and the support of family and friends to help me cope and persevere.

Content & photograph provided by Andrea Miller

Meridian Credit Union Hits the Links to Raise Funds!



We have been very fortunate to have had unbelievable support from Meridian Credit Union. We were thrilled when Zenon Iwachiw, Regional Vice President, Commercial Services nominated MNC to be one of the beneficiaries of the Greater Toronto Area and Simcoe Regions Meridian Credit Union charity golf tournament past summer.

We were, however, unprepared when his team came to our office to present us with a cheque for \$22,500. Through our tears, smiles and hugs we hope our gratitude was expressed. Our sincerest thanks to Zenon, his team, Meridian employees and their key partners – we are very grateful!



From left to right:
Diane Harty, MNC, Susan Cherry, Meridian Credit Union, Annette Cyr, Chair and Zenon Iwachiw, Meridian Credit Union.

Green Shield Canada Helps to Improve our Patient Support Teleconference

Thanks to the continued generosity of Green Shield Canada MNC is able to continue to offer and improve our monthly teleconference support line.



our monthly teleconference support line.

On the 4th Wednesday of each month MNC offers patients the opportunity to participate in a professionally facilitated support call. The call is offered free of charge for melanoma patients across the country. To improve on this unique opportunity we are now offering a guest speaker at the beginning of each call followed by an open discussion and questions afterwards.

Please contact Jessica at jbowes@melanomaneetwork.ca or call 905-901-5121 ext. 104 to register for sessions.

Melanoma Peer Support Teleconference Schedule 2014:

JANUARY 22, 2014

7:30 p.m. – 9:00 p.m. EST
New Drug Trials and Treatments
Speaker: Dr. Anthony Joshua

FEBRUARY 26, 2014

7:30 p.m. – 9:00 p.m. EST
Diet, Nutrition, Exercise & Mental Health
Speaker: Dr. Routledge

MARCH 26, 2014

7:30 p.m. – 9:00 p.m. EST
Coping with Cancer for the Caregiver
Speaker: Sarah Wood, Social Worker, Princess Margaret Hospital



Coming Soon! Youth Sun Awareness Program

As part of MNC's mission to provide funding support for public awareness and education we are currently developing a exciting new youth sun awareness education program. The program will be created to educate, breakdown myths of tanning, and ultimately change behaviour in a fun and engaging way.

The pilot program is geared toward youth aged 11 to 15 and will focus on simple and practical sun safety messaging to encourage youth to adopt sun awareness practices.



A significant part of the program is focused on sun safety to prevent the development of skin cancer and melanoma at summer camps. Initially the program will launch Ontario, and then on a Canada-wide basis.

MNC is proudly collaborating with the Ontario Camp Association to launch a sun safety certification program in 2014 to recognize camps that follow sun safe practices with children attending camp.

Coping with Cancer During the Holidays

Holidays are traditionally viewed as a time to celebrate. Many people enjoy reuniting with family and friends, giving and receiving gifts, and celebrating religious traditions during this time.

However, sometimes people with cancer and their loved ones feel “out of step” from the rest of the world during the holidays. In fact, the holiday season can prompt new questions, such as: How do I take care of the holiday rush and myself at the same time? How can I celebrate when I have so many other things on my mind? What will my life be like next year? Sharing these concerns with the people you love and who love you can help you feel more connected.

Here are some additional tips:

Make plans to get together with friends, family or co-workers over the holidays. Trying to celebrate alone can be very difficult, so accept some invitations from others, or join an organized group activity through your local YMCA, YWCA, church or synagogue. Find the right balance between celebrating with family and friends and spending the time you may need on your own. Give yourself permission to pace your activities

and to decline an invitation or two so that you have the energy to enjoy the gatherings that are most important to you.

Create a new holiday season

tradition that makes the most of your energy. Change your usual holiday activities so you relieve yourself of some of the pressures of entertaining. Have a “pot luck,” with family members each bringing a favourite restaurant.

Be an innovative shopper or gift

giver. Use mail order catalogues, shop over the telephone, or try online shopping this year. You can also make a gift of sharing your thoughts and feelings. Write a short note or make a phone call to let others know that you are thinking about them.

Express your feelings in ways that help you receive the support of the important people in your life.

Tears can bring a sense of relief. Laughter can be relaxing. Sharing can be comforting. It is common to experience a mixture of anticipation, talk them over with a loved one, friend or professional counselor.

From cancercare.org - Coping with the Holidays – November, 2013

Your Journey Can Change a Life! Make a Difference with MNC's Peer to Peer Volunteer Program: *Within Reach!*

Have you ever wanted to share your experiences with melanoma to help another patient or caregiver? MNC would love to have you join our new **Peer to Peer Support** Volunteer Program: *Within Reach!*

In the New Year, we are offering Peer Support training to those want to reach out and support caregivers and newly diagnosed patients. By offering encouragement, hope and compassion to someone when they need peer support most, you will make a difference!

It is not anticipated to take up too much time – an hour or two a month would go a long way. If you are interested in becoming a Peer to Peer volunteer please contact Diane at dharty@melanomanetwork.ca or 905-901-5121 ext. 102.



HAPPY
Holidays

This Holiday Season,
Give the Gift That



GIVES BACK

This holiday, donate to MNC! Your support makes a direct impact in the lives of Canadians affected by melanoma.

Here's how:

Providing Patient Support

- Patient Publications and Newsletters
- Patient Information Hotline and Monthly Teleconferences
- Education Sessions for Patients Across Canada
- Peer to Peer Support Programs

Prevention and Awareness Initiatives

- National Youth Sun Awareness Education Program (Coming 2014!)
- Prevention and Detection Publications
- Winter Sun Awareness Campaigns

Advocacy Work and Research Grants

- Drug Therapy Approval Advocacy
- Provide a Patient Voice for Government Health Advocacy

Donate online: www.melanomanetwork.ca, by **phone** at 905-901-5121 ext. 104 or by **mail**.

The Melanoma Network of Canada will send a holiday postcard to your gift recipient if requested! If you have any questions about your donation, please don't hesitate to contact us!

Did you know you can support Melanoma Network of Canada through the United Way?

Many of us support the United Way through automatic workplace donations.



United Way

Did you know that you can choose where your money goes? The United Way will direct your funds as a donation to the charity of your choice. Why not make Melanoma Network of Canada your *charity of choice*?

Agency Name: Melanoma Network of Canada
Address: 11-1155 North Service Road Oakville, ON L6M 3E3

Thank you for your continued support!

Celebrating Continued Health with a Backyard Party!

This past summer the McDonnell family wanted to celebrate their Mom being five years being cancer free. What a better way than to throw a party!



On a warm summer evening under the stars, the McDonnell's family and friends got together to raise a cheer to continued health. Wanting to mark the occasion and make a difference they raised funds at their party. They presented MNC with a cheque for just under a thousand dollars!

Thank you so much McDonnell family!