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Message from the Chair

It has been another promising summer, with a number of new and potential treatment therapies coming down the pipeline for melanoma patients. GlaxoSmithKline has two new drugs for treatment of melanoma that have already approved in the US by the FDA. Health Canada approved both Mekinist (Trametinib in the US) and Tafinlar (Dabrafenib in the US) in mid-July and both drugs will be used as an oral monotherapy for the treatment of patients with unresectable or metastatic melanoma with a BRAF V600 mutation. Currently, these two drugs are in the pan-Canadian Oncology Drug Review (pCODR) process and we are waiting on recommendation to have these drugs covered under provincial drug plans.

Mekinist is the first drug to inhibit the mitogen-activated protein kinase MEK enzymes – a fancy way of saying that it stops another avenue of cancer cell production. Both of these drugs have had some pretty impressive results and fewer side effects than some previous therapies. Canadian clinical trials have started to use the drugs in combination



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

and the results for patients are even better. These are more welcome tools in our arsenal to fight this disease and we are hoping for positive news on both therapies in early fall.

Health Canada is also reviewing a first in class drug for the treatment of disfiguring or potentially life threatening advanced basal cell carcinoma. Erivedge (vismodegib) by Roche has recently been approved in the U.S. and we expect more good news this fall, as there are few drug options for this advanced disease.

Upcoming Events

September 29th
**Strides for Melanoma -
Walk For Awareness**
Register online today at:
melanomanetwork.ca/walk2013

Patient Education Sessions:

October 28th
Hamilton, Juravinski Cancer Centre

November 5th
Toronto, Odette/Sunnybrook
Cancer Centre

December 7th
Toronto, Princess Margaret Cancer
Centre

Peer Support Teleconference
4th Wednesday of each month

To register for any MNC events visit
www.melanomanetwork.ca

Message from the Chair continued...

There are also three new anti PD1 therapies in the pipeline from Bristol-Myers Squibb, Hoffmann-La Roche and Merck. Anti-PD1 therapies can help the immune system recognize and attack melanoma cells. These new therapies are showing great promise for treatment and provide an indication of the future potential for targeted therapies.

How You Can Help to Have Drug Therapies Approved

MNC plays a critical role in getting new drug therapies approved. We advocate on behalf of patients to ensure new therapies are not only approved, but also are covered in provincial drug formularies in each province and territory so that all patients have fair and equitable access. You can help us help you and other patients by sharing your experiences with new therapies.

If you are on a clinical trial, please contact me directly (905) 901-5121 ext. 101. All information collected is confidential and will help in our submissions to the pCODR process for all patients. This is a required process for us as your advocates and part of the standards set by pCODR in reviewing and making recommendations for provincial coverage of cancer drugs.

We also actively link patients to clinical trials available both in Canada and abroad (if applicable), which many patients find very helpful in their journey. MNC is also actively involved in many national cancer committees including the Canadian Cancer Action Network (CCAN) and the Canadian Cancer Research Alliance (CCRA) to ensure that melanoma remains on radar for funding and research.

We need your help. Volunteer or contribute financially - to continue to make a difference, increase awareness and improve the lives of melanoma patients and their families. We strive to promote prevention, awareness and to ensure that melanoma remains a focus for research. If you haven't already done so please consider joining us on Sunday September 29th as we make **Strides for Melanoma** across the country. This is our largest fundraising event of the year and we need your support, energy and commitment. Walks are planned across the country but you can also join a virtual team and walk right in your own community!

We look forward to seeing you at one of our upcoming patient information sessions or connecting with you on a free patient teleconference. As always, I welcome your comments and feedback.

Help us make *Strides for Melanoma!*

Lace up your trainers, grab a friend, and join us on Sunday, September 29th as we make Strides for Melanoma. Walks are already planned in several cities across the country including; Victoria, Vancouver, Calgary, Edmonton, Hamilton, Mississauga, Toronto, Ottawa and Dartmouth.

If you are interested in organizing a walk in your community we would love to help you! Please contact Jessica Bowes at 905-901-5121 ext. 104 or email jbowes@melanomanetwork.ca.

You can even sign up as a virtual walker! Register and walk anytime you choose, anywhere you choose, by yourself, with your family and friends, or with a team.

STRIDES for **MELANOMA** Walk for Awareness

SUNDAY, SEPTEMBER 29, 2013



Help us to raise much needed funds which allow us to continue to provide support services for patients and families, research and create education initiatives!

REGISTER TODAY!

www.melanomanetwork.ca/walk2013

2nd Annual Tee Off for Melanoma Awareness a Huge Success!

On May 31st under blue skies (and no rain), we held our 2nd annual *Tee Off For Melanoma Awareness* golf tournament and raised a phenomenal \$49,000! Dollars raised on the links will be used to support our ongoing commitment to a five year melanoma research grant and the development a youth sun safety awareness program – both critical in the fight against melanoma.

Education and research are two very important pillars of why we exist as an organization. Both improve the journey for those affected by melanoma and work towards a future without melanoma. As both of these initiatives are long range commitments, we will need to continue to raise funds. We hope that you will continue to support events like these and help us as we make advancements in the fight against this disease.

This year we added a sun awareness component for our non-golfing supporters. Our guests browsed displays from LaRoche-Posay, Columbia Sportswear, Puffin Gear, SunVeil, Jane Iredale, Tilley Endurables, Investors Group, and listened to a sun safety presentation from Dr. Sapro.

Everyone enjoyed a delicious BBQ lunch, refreshing cocktails, and awesome silent auction items. If you golf (or even if you don't) come on out and *Tee Off* with us next year on Thursday, May 22nd 2014 at Glen Abbey Golf Club in Oakville!

Thank you once again to our volunteers, golfers, supporters, silent auction donors and of course our very generous corporate sponsors!

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Save the Date!

3rd Annual Tee Off for Melanoma Awareness
Thursday, May 22nd 2014 • Glen Abbey Golf Club, Oakville

MNC
Volunteers
Rock!



Annette Cyr with MNC volunteer Tanya Hesser

MNC is pleased to acknowledge the many hours that Tanya Hesser has volunteered with our organization. Tanya has been involved with MNC from the very beginning and we appreciate the hours, commitment and expertise she has shared with us. Every month, patients from across the country are encouraged to call in to our free teleconference Peer Support Teleconference session which is facilitated by Tanya. Your volunteer support has helped so many Tanya – thank you!

Welcome Anne to the Peer Support Teleconference!

Tanya will now be joined on the Peer Support Teleconference by Anne Rajesparam. Anne has recently completed a Master of Social Work and she is passionate about volunteering. Anne is a very empathic listener and hopes to be the best of support to callers on the Peer Support Teleconference line. Welcome to Anne and thank you for joining us!

And the Winner Is....

Last newsletter we invited you to visit our newly updated website and register with us for a chance to win a new electronic tablet. We were pleased so many of you checked out the new site! The lucky winner was Chloe Gravelle who very generously donated the tablet back to MNC. **Thank you Chloe!!** We hope you continue to enjoy the website and check back frequently!

Peer Support Teleconference Look What's New!



The Peer Support Teleconference will be undergoing some exciting new changes this upcoming fall! We are pleased to announce that the structure of the teleconference will now combine both education and discussion.

The first half of the call will be allotted to a specific topic related to melanoma or cancer and feature an expert speaker who will provide valuable information and insight on that topic. The second half of the teleconference will be open for patient discussion, questions, and concerns.

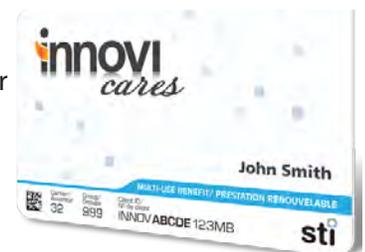
This change in format comes as a result of our users' feedback and we look forward to providing this revamped service. MNC will post a calendar of topics and easy online registration for teleconferences. More information will be coming soon at www.melanomanetwork.ca.

Additional Coverage for Your Prescription Drugs

MNC has partnered with reimbursement solutions provider, STI Technologies Limited, to provide patients with access to the innoviCares program.

InnoviCares is a single-card supplementary benefit that provides coverage for a variety of medications and healthcare products, providing patients with greater choice and access. The innoviCares card covers up to the difference in cost between many brand name medications and their generic alternatives allowing patients to remain on brand medication.

This free benefit program at www.innovicare.ca/mnc. Patients simply present their innoviCares card, along with their prescription, to their pharmacist to receive coverage on participating products.



Patient Spotlight: Trish Bentley



When I was 21 years old, I had a creepy looking mole that everyone kept telling me looked weird. It was on my back so I couldn't really see it for myself. After being urged, I finally went to see a dermatologist. This same mole had been already removed five years prior, but for some reason it had been burned off and never tested. It grew back, and this time with a vengeance.

I sat there in a little hospital gown with my toes dangling in mid-air as she told me it didn't look good. "It might be serious," she said. "Do you have someone to take you home or are you by yourself?" she asked. Of course I was by myself. I'm an adult, I thought. After leaving her office, I sat alone on the subway, listening to my music and studying the people around me. I thought about what it would be like to have cancer. I panicked and then decided that would be the last time I'd think about it. A few days later I found

out that the mole on my back was indeed melanoma. It was stage 2. I was scheduled in for surgery to remove a large section on my back and under my arm to test lymph nodes.

Before the surgery, I was to meet with an oncologist. My dad happened to be in Toronto, so he came with me to the Oncology appointment. I hadn't been to a doctor's appointment with a parent since I was 14 years old. We sat there dumbfounded as the doctor laid out the plan.

"Melanoma is the only skin cancer that can travel inside of your body. If this has happened, we will have to either do chemotherapy or radiation and as you were told previously, definitely the surgery. I have to tell you, this could be a fatal disease." His voice was stale and bleak.

All I could think about was how sorry I felt for my dad. He'd sat in offices like that hearing words like metastasized and malignant for years with my mom. We drove home in silence. I couldn't believe this was all from an ugly mole. I had never been one to bake in the sun. Although I have always loved how a tan looks, I would get so cagey in such heat that I could never stay long enough to get a fabulous glow. So how could I have gotten melanoma? I can't say for sure, but I often refer to that one time in the south of France. Yes, that one time.

I had been traveling with a friend who was beach lover. She had beautiful olive skin that tanned perfectly, and I remember how fresh and healthy she

looked after the beach in a dimly lit bar. I wanted some of that. Apart from the few times I had entered a tanning bed in the early '90s, this was one of the very rare times I actually spent 'baking' my skin. After falling asleep on the beach one afternoon I burnt my back badly, and when my skin grew back after blistering, I didn't think about it again. That was of course until I heard the word melanoma and chemotherapy and surgery all in the same sentence. As it turns out, it can take one time, as explained in the powerful "Dear 16 year old me" video from DCMF. If you burn before the age of 18, this can double your chances of getting melanoma.

When they tested my lymph nodes they found that there wasn't any cancer present in those nodes. I was one of the very lucky ones. They sent me home with strict instructions to never go in the sun again without protection and to see my dermatologist on a regular basis. I was to watch my moles carefully. But like trying to feel a lump in your breast, it's pretty hard not to freak yourself out every time you see an odd-looking mole. Still, I look at those little brown blobs every day and remember that I was much luckier than some others and to respect that by protecting my skin. As it turns out, that dark glow one gets from hours in the sun becomes embarrassingly meaningless when you're sitting under a florescent light being told you have cancer.

Content and photograph provided by:
Trish Bentley
@trishbentley
@thepurplefigmag

Thank you Green Shield Canada!

Thank you Green Shield Canada! Once again MNC was delighted to receive a generous grant from Green Shield Canada to support our Peer Support Teleconference. The teleconference support line is highly valued as an incredible resource for patients dealing with what can be such an overwhelming diagnosis. One of the most useful means of support for patients is to be able to connect

with others going through a similar journey and to know they are not alone. Helping to reduce the stress and anxiety of patients and to contribute to their understanding of the disease helps both mentally and physically in fighting disease.

We are incredibly grateful to Green Shield Canada for their continued support of this resource!

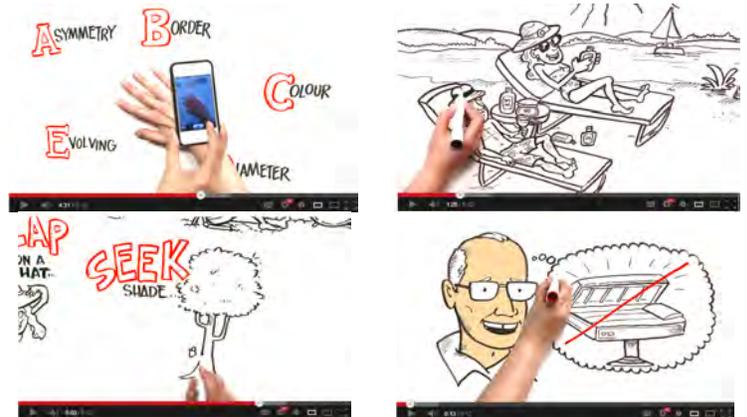


From left to right: Hareem Naveed, Katie Heckman, Laura from Green Shield Canada and Annette Cyr

Lights, Camera...Action!

In a joint initiative with the Douglas Wright Foundation, MNC is thrilled to unveil "What is the Best Way to Prevent and Detect Melanoma", a video by Dr. Mike Evans. We encourage you to check it out and share it with your friends and loved ones.

To watch the video, please visit our website: www.melanomanetwork.ca



Drug Therapies: Where are we now and what's coming?

The past few years have been breakthrough ones for the treatment of metastatic melanoma. 2012 saw the approval of two new therapies, the first advancements in treatment in almost forty years.

All proposed drug therapies are reviewed by the pan-Canadian Oncology Drug Review (pCODR). pCODR was established by the provincial and territorial Ministries of Health (excluding Quebec) to assess the clinical evidence and cost effectiveness of new cancer drugs and to use this information to make

recommendations to the provinces and territories to guide their drug funding decisions.

MNC is registered with pCODR as a patient advocacy group. In this capacity, MNC provides patient submissions and works diligently with each province to advocate for new therapies to be implemented and funded. MNC is aware that there remains some provinces in the country where approved therapies are not currently available. We find this to be unacceptable and puts the patient population at unnecessary

risk. We believe strongly that proven drug therapies should be available and funded for all patients across the country when it has been approved through the government established pCODR process.

We are actively engaging with those provinces who have yet to fund these approved therapies. If you are interested in helping, please contact Annette Cyr at 905-901-5121 ext. 101 or email acyr@melanomanetwork.ca to be added to our "Call to Action" list.

Vemurafenib (Zelboraf) – Notification to implement issued by pCODR: June 18th, 2012

Province	Status	Date of Decision	Funding Criteria
BC	Funded	October 1, 2012	Unresectable Stage III or IV melanoma; BRAF V600 mutation-positive *
AB	Funded	October 19, 2012	Treatment of BRAF V600 mutation-positive resectable or metastatic melanoma
SK	Funded	September 4, 2012	Melanoma – Advanced *
MB	Funded	September 24, 2012	For the treatment of patients with unresectable or metastatic (Stage IIIC or IV) melanoma *
ON	Funded	August 31, 2012	For the first line treatment of patients with BRAF V600 mutation-positive unresectable Stage IIIC or IV melanoma or metastatic melanoma *
NS	Funded	March 3, 2013	For the treatment of BRAF V600 mutation positive unresectable or metastatic melanoma*
NB	Under provincial consideration		
NL	Under provincial consideration		
PEI	Under provincial consideration		

Ipilimumab (Yervoy) – Notification to implement issued by pCODR: May 2, 2012

Province	Status	Date of Decision	Funding Criteria
BC	Funded	November 1, 2012	Unresectable Stage III or IV melanoma *
AB	Funded	October 19, 2012	Treatment of advanced melanoma (unresectable Stage III or IV melanoma) in patients who have received prior systemic treatment.
SK	Funded	September 4, 2012	Treatment of patients who have received at least one prior systemic therapy for advanced melanoma (unresectable Stage III or IV melanoma) *
MB	Funded	July 1, 2012	For the treatment of patients with unresectable or metastatic (stage IIIC or IV) melanoma *
ON	Funded	September 13, 2012	For the first line treatment of unresectable stage III or IV melanoma patient who have received at least one systemic therapy for advanced melanoma *
NS	Funded	January 1, 2013	For the treatment of unresectable Stage III or IV melanoma in patients who have received at least one prior systemic treatment for advanced melanoma *
NB	Under provincial consideration		
NL	Under provincial consideration		
PEI	Under provincial consideration		

*denotes additional funding criteria information is available - please visit <http://www.pcodr.ca>

Drugs Currently Under Review by pCODR:

Dabrafenib (Tafinlar)

For use as a monotherapy for the treatment of patients with unresectable or metastatic melanoma, with a BRAF V600 mutation.

Recommendation is expected fall/winter 2013

Trametinib (Mekinist)

For use as a monotherapy for the treatment of patients with unresectable or metastatic melanoma with a BRAF V600 mutation.

Recommendation is expected fall/winter 2013

Vismodegib (Erivedge)

For the treatment of adult patients with histologically confirmed metastatic basal cell carcinoma or with locally advanced basal cell carcinoma inappropriate for surgery or radiotherapy. **Recommendation is expected fall/winter 2013**

Information collected August 14, 2013, www.pcodr.ca

NEW!

'Within Reach': A Peer to Peer Support Program

Have you ever wanted to share your experience and provide support for another melanoma patient? MNC is proud to announce a new patient mentoring program called 'Within Reach.'

This program is designed to connect melanoma patients to a trained and certified peer who has also faced the disease. Peers will share their stories, act as a supportive mentor and provide support. This service will be offered by telephone and can connect patients anywhere in the country. Our hope is that patients can create a special relationship with one another and be able to relieve some of their stress, worries, concerns, and fears that come from living with cancer diagnosis.

Peer mentors will be assigned (based on availability) by similar geographic location, diagnosis, life situation, etc. To find out more, please contact Diane Harty at dharty@melanomanetwork.ca or 905-901-5121 ext. 102.

Diamonds, Daisies & BBQ!

Last year Taryn Fieldhouse of Kingston, Ontario approached us with an idea to host a themed "Girls Night Out" evening in memory of her mom, who sadly lost her battle with melanoma.

The big event came to fruition this summer and MNC was pleased to be invited to attend and speak. Taryn hosted a beautiful evening with a garden theme, surrounded by her friends and family. Guests enjoyed refreshing signature drinks, live music and a gourmet meal.

Taryn and her husband Chris also organized a charity BBQ at their new FreschCo store in Kingston over the Canada Day long weekend. Together both events raised over \$2,500! Thank you Taryn for all your hard work – we are very grateful for the support!

If you are considering hosting a fundraising event we would love to speak with you and support you! Please contact Diane Harty at dharty@melanomanetwork.ca or 905-901-5121 ext. 102.



MNC Has Moved!

Update your address book to:

**1155 North Service Road West, Unit 11
Oakville, Ontario
L6M 3E3
Phone: 905.901.5121**