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**Message from the Chair**

The New Year holds a lot of promise on the treatment horizon for melanoma patients. The new drug therapies that were approved in 2012 - Zelboraf and Yervoy - have had a significant positive impact for many patients.

We are thrilled that GlaxoSmithKline is also anticipated to be launching two new drugs into the market this year. Glaxo's new dabrafenib drug works by blocking BRAF, a mutant gene that spurs cancer cell growth in about half of melanoma patients. Trametinib is the other Glaxo drug for melanoma and is designed to thwart a related protein called MEK that helps tumors resist an assault

on BRAF. MNC will again participate in the pCODR process to ensure patients across the country will have access. If you, or someone you know, is currently on clinical trial with either of these new drugs and would like to participate in this process by filling out a short survey for us so that we can ensure access for patients, please contact [acyr@melanomanetwork.ca](mailto:acyr@melanomanetwork.ca) or call 289-242-2010.

We remain concerned with the challenges for patients having timely access to dermatologists. Access to doctors and other effective diagnostic tools is imperative for timely and accurate diagnosis. We

were excited to learn that Verisante's Aura system has been placed in several clinics across the country for testing purposes. The new device uses Raman spectroscopy to rapidly scan and biochemically analyze the skin, provide immediate and accurate results, improving patient outcomes and comfort. It is technological developments like these that may help to improve timely access.

A major focus for us this year will be building a youth sun safety and awareness program. Over the past decade there has been a steady increase in the number of youth being diagnosed with melanoma.

## Message from the Chair

continued...



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

Changing sun habits and increasing awareness and education will be instrumental in reducing these statistics. We will also continue to pressure government on both municipal and provincial levels to enact legislation restricting youth access to indoor tanning beds, which we believe to be significant factor in the increase of melanoma cases in our youth and adult population.

The team at MNC is a small and dedicated one but we couldn't achieve as much as we do without your support. We look forward to working together to accomplish our goals, build a stronger patient voice and work towards a future without melanoma.

## Patient Spotlight – Susan Cox

Content and picture provided by Susan Cox

### *My story is like most stories I guess...*

I was blissfully unaware of Melanoma until it slapped me in the face in 2007. I was a sun lover, often bronzed in winter from frequent visits to the tanning bed and took no precautions with sunscreen. I admit it - I liked being tanned. I lived in B.C. and practically lived outdoors as a kid, winter and spring skiing, baseball, grass hockey, I swam in our pool - all of it in the heat of the day with no protection of any kind. It was the 70's and 80's and being tanned made me feel healthy and sporty. I was in for a big surprise.

An itchy mole on my shoulder blade turned into a little blueberry before I had it looked at. First to my GP then to a dermatologist who referred me to Princess Margaret Hospital in Toronto where I now live with my family. Honestly, I thought that maybe they'd have to cut a bit of skin out with it but hey, it can't be that bad I told myself. Don't you just cut skin cancer out and continue on with your day?

I was a little shocked to hear I would need a surgery to remove the

surrounding tissue. More shocked to see some 40 staples after I removed the bandage. I wondered aloud whether the surgeon knew it was just a mole? Shortly after we were told the cancer had in fact spread through the lymph nodes and that another surgery was in order to remove them. Ok, this was now getting real. Was I in trouble here? Surely not. I was in my 40's and untouchable by something like a cancerous mole, right? I was clear for 3 years when I started having minor bladder problems. Sure enough, I had a tumor now growing on my adrenal gland on my kidney. Another surgery to remove the tumor and that should be it right? No. Only 3 months later I had 3 new tumors growing and was now stage IV cancer and officially in trouble.

**It was then I was told about a clinical trial for GlaxoSmithKline's BRAF inhibitor, a drug that targets my specific kind of cancer**

by binding to it and inhibiting the activity of BRAF and effectively choking out the tumor - it just shrinks and dies. The trial was taking around 345 people. I thought, oh man - it

## Patient Spotlight – Susan Cox

continued...



seems like there is that many Melanoma patients hanging around the waiting room whenever I'm there, and I can never get parking... what are my odds I wondered? I've never been good at math and I was alarmed to learn it was 345 people from 8 countries, not just my country, not just my waiting room. I had to get in this study to save my life. I passed all the medical exams and I was told on April 29, 2011 that I was in the study. I had officially won the lottery! Forget about a chalet in Switzerland, a trip around the world or that red sports car, who cares, this drug would extend my life! My tumors

shrunk immediately and by the end of August 2011 I was cancer-free (as long as I take my BRAFF pills).

**So, I'm winning my fight.**

Perhaps just for now, perhaps for the long term - no one knows. I'll find out as I go but one thing is for sure, I'm lucky, no matter what happens, because I have family and friends to support me, make me laugh and let me cry when I'm feeling the weight of this. Today, I'm pleased to say that I have been on the BRAF inhibitor for 1 year and 9 months with no re-growth, so far.

You know, maybe I won't be the last one to leave the party or maybe I'll be leaving early. Whatever lays in store for me, I'm just focused on moving forward, keeping a sense of humor and enjoying life, and along the way recommending that others do the same.

### Tee Off For Melanoma Awareness

This mild winter has us already thinking about golf! Our 2nd annual Tee Off For Melanoma Golf Tournament will be held on Friday May 31st at Rattlesnake Golf Club in Milton, ON.

We need your help to make it a success and there are several ways you can contribute;

- Register as a golfer (why not bring some friends or colleagues and make a foursome?).
- Donate an item for our silent auction. (most popular items last year were tickets to concerts and sporting events, memorabilia, and access to unique encounters/experiences)
- Become a corporate sponsor – there are several different levels available.
- Volunteer to help out at the tournament – many hands make light work!
- Join us for Lunch. If you don't golf, please consider joining us for the afternoon for lunch and the silent auction.

For more information about any of these opportunities or tournament itself please contact Diane [dharty@melanomanetwork.ca](mailto:dharty@melanomanetwork.ca) or 289-813-4303



## A Trip to the Salon Could Save Your Life

Content provided by Janet Gadeski

In April last year, I changed hairstylists. I walked into the new salon with nothing more on my mind than hope for a more manageable haircut. Debbie, the stylist to whom I'd been randomly assigned, began to section my hair – and paused.

**“Did you know you had an odd-looking mole back here?”**

she asked in a neutral tone. I did not. It was completely hidden by hair, imperceptible to my touch, and had never itched or bled. “You might want to show it to your doctor.” A little more conversation – no, there was no birthmark recorded on my birth certificate, better safe than sorry, you never know – and I visited my doctor, who sent me to a dermatologist right away for a biopsy.

Two weeks later, the dermatologist reassured me that though the mole was melanoma, it was one of the shallowest she'd seen. My prognosis, therefore, was good. She referred me to the head and neck cancer specialist at the Juravinski Cancer Centre in Hamilton. His explanation was full, evidence-based and reassuring. Within a few

days, I was booked for surgery the following week.

When I returned to thank Debbie, she introduced me to Margaret, another client who had been through the same thing. Sitting in the salon, Margaret reassured me with her own story of a happy outcome. In later chats with Debbie, I learned that she checks every client's scalp at every appointment, taking her time to go far beyond the requirements of her professional role. I now say that I have my hair done at a cancer detection and support centre disguised as a salon!

My surgery and skin graft were remarkably brief – just 30 minutes, plus a few hours of compassionate pre- and post-op care in the day surgery unit at St. Joseph's Hospital, Hamilton. In the following weeks, community nurses delivered wonderful care every day. They even taught my husband to change my dressings and gave us ample supplies so we could take the holiday we had previously planned.

Head and neck melanomas are especially dangerous because they occur so close to lymph nodes. But when I saw my surgeon for a follow-up, I learned that mine was just 0.4 mm deep and free of cancerous



cells in the margins he'd excised as a precaution. There was virtually no chance it had spread through my lymphatic system to undermine other parts of my body.

During the three months between that first haircut and the day I learned the outcome of the surgery, I was surprised by how little I worried. I believed that a story that began so wonderfully couldn't possibly end badly. My head knew that Debbie's early detection had boosted my statistical chances. Now I want anyone else with melanoma lurking under their hair to gain the precious treatment window that early detection provides.

Please have your scalp examined with every haircut and encourage your stylist to do the same for others. You may transform your hairdresser or barber into a lifesaver.



## Advanced Technology in the Fight Against Melanoma

*Content and pictures provided by Laura Davidson*

available at the Ottawa Hospital Cancer Centre. There are three cities in Canada that have Cyberknife technology: Ottawa, Hamilton and Montreal. It can be used to treat tumours in the brain, lungs and prostate. It is a relatively new treatment in Canada but has been used in the USA, UK, Sweden and other countries for some time.

Unlike a traditional radiation treatment machine, which delivers radiation in a linear fashion, the CyberKnife system has a robotic arm, which moves around the patient to deliver radiation from any direction. High-dosage, multiple beams attack the tumour from many directions using extreme accuracy.

The precision of CyberKnife radiosurgery results in minimal damage to healthy tissues surrounding the target. Also, it is often a safer option than traditional brain surgery. CyberKnife radiosurgery is usually a one-time therapy completed in a single day.

The technology tracks the minute movements of the patient--breathing, shifting--and makes adjustments. It's so accurate that it can be targeted within .5mm of the tumor.



Cyberknife may increase life expectancy because it's done in a non-invasive way. For many, it also improves quality of life. Patients aren't exposed to the risk of surgery, side effects are reduced and sometimes almost non-existent. We need to spread the word of the wonders that this machine can do.

It is now 2013 and my father is not only alive, but feeling great! He has returned to his usual activities such as boating and golfing and even attempted water-skiing this past summer!

Cancer changes your life. It can often make your life better because we start to realize what is truly important. We learn not to waste our time. We remember to be grateful to our friends and family. We start prioritizing. My father, my hero!

My father was diagnosed in July, 2011 with Stage IV melanoma that had metastasized to his brain. Prognosis was grim; doctors gave him 3-5 months to live. There were 3 tumors in his brain. He underwent Whole Brain Radiation Therapy (WBRT) in July 2011 and the side effects of this treatment were devastating. Radiation sickness included weight loss, loss of appetite, nausea, dizziness, extreme fatigue, lack of mobility and decreased strength, to name a few.

By September another follow up revealed three additional tumors. We were devastated to learn we had run out of options as WBRT is a one-time only treatment and there was no chemotherapy that crossed the blood brain barrier. My Dad was informed to get his affairs in order and to enjoy the next months.

In November 2011, we learned of a new treatment option, Cyberknife,



## Heading South this Winter? – You need the Skinny on the Screen

With so many sunscreen products available, it can be confusing selecting the best one for your skin's protection.

SPF on your sunscreen stands for Sun Protection Factor and refers to the theoretical amount of time you can stay in the sun without getting sunburned. It is a measure of how much ultraviolet (or UV) radiation it takes to burn your skin when it's unprotected compared to how much it takes to burn it when it's slathered in sunscreen. For example, an SPF of 15 allows you to stay in the sun 15 times longer than without protection. So, if your skin starts to redden in 20 minutes without sunscreen, applying a product with SPF15 increases that time by a factor of 15, meaning you could stay in the sun for 300 minutes. Generally speaking, a higher SPF blocks out somewhat more rays—a product with an SPF of 15 filters out approximately 93%

of UVB rays; SPF 30 filters out about 97%. Always use a sunscreen that has the words "broad spectrum" on the product label for filtering both UVB and UVA cancer causing rays.

And there are other factors to consider:

If you are in the sun during peak hours (10 am to 3 pm), you will burn more quickly; reapply every two hours and limit time in the sun. Intensity of the UV radiation (the UV index that you hear on the weather reports) also impacts the amount and SPF of sunscreen you should apply. An hour of sunlight at 9:00 am is equivalent to 15 minutes of sunlight at 1:00 pm. So if you're only looking at how long you're out in the sun you might drastically underestimate how much sun exposure you're really getting.

Don't skimp! You should use at least an ounce of SPF 30 sunscreen with every application, so in a full day at the beach you'd go through half of an eight ounce bottle. Also check expiry dates – last year's product is likely no good and if it has passed the expiry, then it will not be effective.

But remember, sunscreen can't do the job alone! Wear sun protective clothing that covers as much of your body as possible, wear a broad-brimmed hat that shades your face, neck and ears, wear wrap-around sunglasses and always seek shade!

## A Royal Nod for a Job Well Done



It is not often that the Chair of our Board of Directors is left speechless but at the last Board meeting in December Annette was just that: speechless. City of Mississauga Councilor, Bonnie Crombie was an invited guest to the meeting to talk about the recently enacted tanning bed bylaw in Mississauga but unbeknownst to Annette, Councilor Crombie had another surprise. Councilor Crombie's office had nominated Annette as a candidate to receive the Queen's Diamond Jubilee Medal!

Annette is an amazing individual who works tirelessly and passionately. She has devoted her time, resources, professional expertise and dogged determination to improve the journey of Melanoma patients and their families across the country. On December 3rd 2012, in recognition of Annette's determined and passionate service to her community and country, she was awarded the Queen's Diamond Jubilee Medal. Congratulations Annette – We are very proud of you!

## Making a Difference One Cookie at a Time

MNC was honoured by the fundraising efforts of Thalia and Julia, both 11 from Mississauga, ON. The girls sold lemonade, cookies and oranges outside their house with the proceeds going towards melanoma research. They had decided to raise funds for the cause after seeing many articles linking the disease to tanning beds.

When interviewed by the Mississauga News, Julia said; "We know some people who have been diagnosed with it (melanoma) before so we really wanted to raise some money to help find a cure,". Thalia added: "We like to tell people that any donation can make a difference. Even if only one person donates, it still helps." Thalia and Julia – We are deeply touched by your efforts! Thank you for helping to spread awareness and for raising much needed funds for research. You have made a difference!



## Save the Date - Strides for Melanoma 2013!

In October 2012 hundreds of our friends and supporters from across the nation laced up their trainers and walked in their communities to raise awareness and funds. We raised over \$100,000 to support our melanoma research grant and youth education initiatives – Thank you!



You may remember from the recap in our last newsletter that a team in Calgary braved the elements and walked in the snow! We are hoping to avoid the snow this year and have moved the date up. Please join us

**Sunday September 29th, 2013**

Walks are being planned in Calgary, Mississauga (Toronto), Ottawa and Halifax. If you are interested in volunteering at one of these walks or helping us to organize a walk in your community, we would love to hear from you. Please contact Diane [dharty@melanomanetwork.ca](mailto:dharty@melanomanetwork.ca) or call 289-813-4303.

## Upcoming Events

### HALIFAX PATIENT EDUCATION SESSION

March 6th

### MONTREAL PATIENT EDUCATION SESSION

April 16

### TEE OFF FOR MELANOMA AWARENESS

May 31st – Milton ON

### STRIDES FOR MELANOMA – Walk for Awareness

September 29th

Want to volunteer for these events? We want to hear from you! Email or call Diane – we have plenty of volunteer opportunities for these events and others.

[dharty@melanomanetwork.ca](mailto:dharty@melanomanetwork.ca)

289-813-4303



## Stop the Presses! Have You Seen the Publications for Patients that Are Coming Your Way?

### Melanoma – What You Need to Know

Coming this month is a new and detailed melanoma booklet for patients.



A team of outstanding professionals was assembled to create this new 35 page booklet that provides current information on diagnosis and treatment approaches for patients in Canada. It will be available at all major cancer centres across the country, thanks to the generous support of Bristol Myers Squibb. We also want to thank our medical advisory team that reviewed the book for accuracy and content, including Dr. Anthony Joshua (Princess Margaret Hospital), Dr. Teresa Petrella (Odette Cancer Centre, Sunnybrook), Dr. Judy Wismer (Ancaster Dermatology) and Annette Cyr, Chair, MNC.

### Lymphedema – Overcoming the Challenges

We are fortunate to have two medical interns assisting us on two very important projects. Annie Liu has been working on the development of a pamphlet to create awareness of lymphedema for patients, caregivers and medical professionals. She conducted surveys and interviews of patients to aid in the development. For those of us who have been through some significant surgeries and lymphadenectomies (surgical removal of lymph nodes), we are often faced with the lasting issues of secondary lymphedema. Secondary lymphedema is caused by a blockage in the lymphatic system - often caused by the removal of or damage to lymph nodes as a part of cancer treatment. The blockage prevents lymph fluid from draining well, and as the fluid builds up, tissue in the limb or affected area begins to swell and retain fluid. It affects each of us differently – some have mild discomfort that is easily manageable, while others are significantly impaired and may have their daily life and mobility impacted.

There's no cure for lymphedema, but it can be controlled. Controlling lymphedema involves diligent care of the affected limb. We hope that patients, caregivers and medical professionals will be alerted to the challenges and management of lymphedema.

### MNC Patient & Caregiver Satisfaction Survey – Help Us Help You

Every three years, MNC conducts a survey of the patients and caregiver population that we support to provide us with feedback and guidance as to services we provide. **Melanie Kalbfleisch** is our other medical intern who has undertaken this project and created an outstanding survey. The survey was just released last week and is easy to complete. You should have received an email notification with instructions for completion. If not, please check your email or even spam filter. We need your feedback to help direct our efforts and all of the precious dollars that are raised in support of education, research and advocacy.