

Spring 2017 Newsletter

Message From Our Chair

Spring is here and soon Sarcoma Cancer Awareness Week will be upon us. It's a great opportunity each year for our community to come together and raise awareness, support each other and fundraise for sarcoma cancer research and other SCFC priority projects.

We are very lucky to have many wonderful advocates, survivors, patients and families across Canada who get involved each year, not only in June during the awareness week but throughout the year. Over the past six years it has been my pleasure to meet and speak with so many of you about the friends and family members you are supporting and fighting for and the memories of those you have lost.

Our community lost a fierce advocate and a funny, warm and caring friend on December 15, 2016 when we lost Teresa Bell, whose inspiring blog [can be found here](#).



I remember the first time I met Teresa - she and her husband were in Toronto for an annual visit to enjoy theatre and a night out and we sat and talked for hours about all of the challenges facing sarcoma patients but also the opportunities to get involved and to help. What struck me about Teresa then and in our conversations over the years that followed was her hope, her positivity and her belief that we could beat this disease. I think of her often as I know many of you do and marvel at all the lives she touched. I had the pleasure to see Teresa a few months before she died and that same twinkle was in her eye as she talked about all the projects she wanted to be a part of and all the ways we could continue to make a difference. Her work on behalf of sarcoma patients and families was inspiring, especially as she dealt with the challenges of her own illness and continued to be a force of nature. As we prepare for Sarcoma Cancer Awareness Week this year, I will certainly think of Teresa, my mother Vera and all the wonderful people I've met - both in person and through your stories - that have been lost to this disease. We continue to work in their memory and in honour of all of you living with sarcoma.

Thank you to our many friends and supporters - without you, we would not be able to do the work that we do. Please feel free to reach out anytime if we can be of help or if you'd like to get further involved.

Diana Arajs
Founder and Chair, SCFC



Patient Information Session

The Foundation is currently planning a Patient Information and Discussion Session for the Fall in Toronto. Stay tuned for details and let us know by emailing info@sarcomacancer.ca if you would be interested in participating.

Fertility Counselling Low Among Those With Young Adult Cancer

Over 7,000 Canadians aged 15-39 are diagnosed with cancer every year. Young adulthood is a period of key developmental milestones that are fundamental to a person's overall well-being for the rest of their life, and a cancer diagnosis means additional challenges during this period of development.

On April 24th, The Canadian Partnership Against Cancer released a report on Canadian adolescents and young adults living with cancer. The report identified fertility as a primary concern for men and women in this group, and that the emotional and financial impact of the inability to become biological parents, as a result of cancer treatment, can be devastating.



"Most fertility clinics get very few referrals from AYAs with cancer, suggesting that the majority are not being referred for counselling," said Dr. Anne Katz, Sexuality Counselor at CancerCare Manitoba. The report provides data on the burden fertility clinics would experience if all AYAs with cancer were referred for fertility counselling, and includes insights from AYA cancer patients on fertility concerns. It identifies the gaps in care and steps to be taken to ensure equitable access to fertility preservation counselling and services for young men and women across the country.

A full copy of the report is available at systemperformance.ca

Stories From Our Community

Carmela Caravaggio shares with SCFC a family perspective on her young niece's hope in the face of a sarcoma diagnosis.

"My lovely niece, Annie, the ballerina, felt a pop in her knee on April 24, 2015 while performing in a dance competition. I knew immediately

something was wrong. Annie was hurt and in pain. Weeks later, after meeting with specialists, undergoing tests, scans, MRI, blood work, and x-rays, the specialists knew what was wrong. We were perplexed and devastated beyond belief that Annie our beautiful niece had sarcoma cancer.

On her uncle's retirement celebration on June 24, 2015, what was supposed to be a joyous occasion became a sorrowful one: we were told that Annie had a malignant tumor in her distal femur, osteosarcoma, just like our hero Terry Fox. Chemo was imminent. It was going to be a very long road ahead.

Annie was merely 15 years old! It was horrendous for everyone. I wish I had words to make it all go away but the only words I knew were, "God help her". God answered my prayers when Annie was connected with Dr. Wunder at Mount Sinai Hospital.

I was speechless and dumbfounded. From July 2, 2015 to December 31, 2016 my sister and niece were in and out of Mount Sinai. It was sad to watch. We did our best to visit as often as possible. Annie had numerous blood transfusions and many obstacles from the chemo. It changed all our lives.

The Specialists at Mount Sinai saved her leg and her life. Dr. Wunder and his colleagues wasted no time to shrink the tumor with three rounds of chemo, pre and post surgery.

Presently, Annie is cancer-free! She continues to go for therapy 2-3 times a week to continue to improve her strength, mobility and range of motion. She is graduating with her class with honours and has been given early acceptance to the universities of her choice, praise God!

We continue to be grateful to all her doctors and therapists for the wondrous work they do. Furthermore, we are proud to fundraise for The Sarcoma Cancer Foundation of Canada in the hopes of raising awareness and money to help others who become victims of sarcoma cancer."

SCFC encourages the sharing of stories and experiences within the sarcoma community. To be featured in our newsletter or on our website, please contact us at info@sarcomacancer.ca

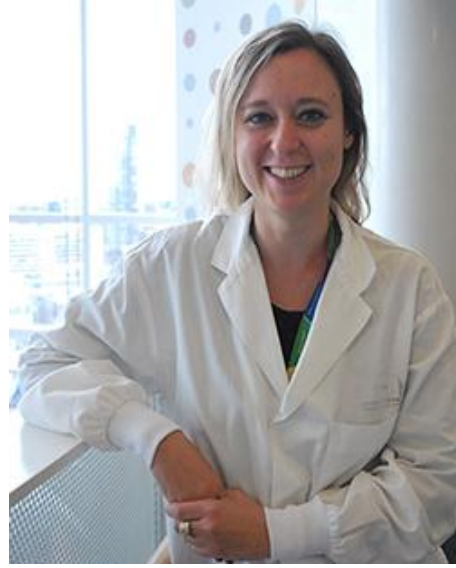
Mark your calendars: The third week of June will once again be Sarcoma Cancer Awareness Week. Stay tuned to our [Facebook](#) and [Twitter](#) channels for further information on this year's campaign and how you can get involved.

#knowsarcoma

Montreal Research

Initiative Looks at Stopping Sarcoma Spread

A new research initiative out of Montreal is focused on stopping the spread of sarcoma cancer. Dr. Livia Garzia told McGill University Health Centre's online publication that while 80% of sarcoma cancers are successfully treated at their primary site, the success rate is lower for metastasis.



"We have not made much progress in preventing or curing sarcoma that spread into metastases. The majority of deaths in patients initially diagnosed with sarcoma are due to the spread of tumour cells from the primary site," says Dr. Garzia. "When they colonize in other tissue they become resistant to therapy, and we do not have any efficient therapeutic intervention against them at this time." The report said Dr. Garzia's team will focus on better understanding how sarcoma cells move from the tumour out into the body, and how they circulate and survive to spread the disease.

[Read the full article here](#)



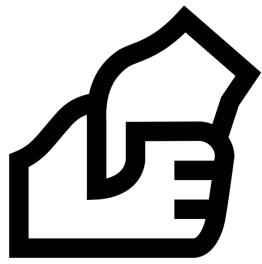
Sarcoma Karma Yoga Class

In May, the "Rock Steady" Sarcoma Karma Yoga Class was held in Halifax. Recognizing a lack of understanding for sarcoma, and specifically leiomyosarcoma, this event raised money for SCFC and brought people together with the aim of raising awareness and improving treatment options for sarcoma patients in Canada. The yoga class held 80 people and raised an incredible \$6,800. SCFC would like to send a huge thank you to organizers Guido Kerpel and his partner Sherry for all their work in organizing this event and their passion for raising

funds to support sarcoma research in Canada.

Looking for Fundraising Ideas?

With the warm weather fast approaching, SCFC is pleased to be able to offer a fundraising kit to those interested in holding a fundraiser or event in their community this summer but aren't quite sure how or where to get started. These



fundraisers have a tremendous impact as they promote sarcoma research, patient support programs, education, and awareness across the country. Whether you're looking to hold a gala, sporting event, or a bake sale, SCFC can help you plan your event. We also provide tax receipting and SCFC awareness materials to distribute free of charge to your guests. We're here to help in any way we can! For more

information or to request our fundraising kit, contact us at info@sarcomacancer.ca

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