



Sarcoma Cancer
Foundation of Canada

SUMMER 2018 SNAPSHOT NEWSLETTER

A Message From Our Chair

As summer draws to a close, we wanted to thank everyone for their participation in this year's annual Sarcoma Cancer Awareness week as well as the ongoing passion we see from many of our donors and supporters through the year. Our community continues to grow each year and it is because of your participation that we can support sarcoma patients and families across Canada.

Our survey this year indicated that awareness about sarcoma cancer in Canada is increasing. There is still much work to do but these results were encouraging. We must make sure that any increase in awareness leads to increased dollars for sarcoma research. Working with patients and families every day continually underscores the dire need to find new treatments and eventually a cure for this disease.

Over the summer, we lost a brave fighter and wonderful advocate - 19 year old AnnFrances Tropea. Annie lost her battle with sarcoma after years of fiercely fighting the disease with the support of her large community of friends and her loving family. Our hearts go out to them as they grieve this terrible loss and I know that all of us will continue to be inspired by her courage and tenacity as well as her grace and sense of humour throughout her journey. It has been a privilege to come to know her family who have worked so hard to fundraise and help raise awareness over the past few years - we look forward to continuing to work with you to fight this disease in her memory.

Though June's awareness campaign has ended, we encourage you to find ways throughout the year to increase awareness about sarcoma cancer. Please reach out if you have ideas, questions, need to connect to our community or are in need of support.

Best,

Diana Arajs

As part of this year's Awareness Week, we asked Innovative Research Group to conduct a national survey to see what Canadians know about sarcomas. **You can read the full press release here.** The below results highlight the importance of raising awareness for this little known cancer.



Even among Canadians with direct cancer experience, one quarter (25%) have never heard of sarcoma cancer. For those without direct experience with cancer, this increased to 43%.



Sarcomas are perceived to receive the least amount of funding for research (3%). Breast, lung, and prostate cancer perceived to receive the most.



47% of those with some knowledge of sarcoma did not know where the next research innovation for sarcoma would be.



Of those who have at least heard of sarcoma cancer, 50% did not know who was most at risk of diagnosis.

Reflections on Sarcoma Awareness Week 2018

By Mark J. Stewart

"Every Sarcoma Awareness Week, I think back to the summer of 1995.

I was 18 years old and attending Cadet Camp on an Air Force base in northern Alberta.

Given the temporary rank of Corporal, for sixteen hours each day, it was my job to march other cadets around, look after their health and welfare, and make sure they understood the finer points of military leadership and drill. I still remember it as one of the best summers of my life.



In both the 23 years I've been a cancer survivor and the four years I've served on the Board of Directors of the Sarcoma Cancer Foundation of Canada, I've seen how research and education is making a difference. In the late 70s and early 80s someone with osteosarcoma had a slim chance of survival.

What I didn't understand was that it was also my last summer with two normal, working legs. You see, earlier that year, while throwing a baseball in my backyard, I twisted my knee in a way I never had before. I still remember the sting! After a month of the pain coming and going, (and the forceful encouragement of my frustrated mother) I finally went to the doctor. I was subsequently given anti-inflammatory medication, and was off to Alberta. When my pills ran out in August, the pain came back, and with it, a bump the size of a grapefruit above my left knee. Shortly after returning to Ontario, I went to Mt. Sinai Hospital and was diagnosed with osteosarcoma, the same cancer as Canadian icon Terry Fox.

My treatments started in September and on December 1, 1995 I had the tumor removed and a titanium prosthetic inserted to replace the infected bone and tissue. I have walked with a limp ever since.

Now, that number is orders of magnitude higher. We still have too many people passing from osteosarcoma, but positive change happens every day, and much of this is because of money raised during Sarcoma Awareness Week.

We still have a long way to go: too many people don't understand the damage sarcoma cancers have. But with your support, the Sarcoma Cancer Foundation of Canada will continue its great work. So, if you supported us this Sarcoma Awareness Week, thank you!

You are making a difference."



thank you!

Though our June campaign is over, we encourage you to continue to post your Faces of Sarcoma through the use of our hashtags [#knowsarcoma](#) and [#facesofsarcoma](#) - in order to keep providing encouragement and courage to those across Canada.

We are happy to share with you some of the Faces of Sarcoma we received throughout awareness week!



Response to Immune Checkpoint Inhibition in Patients with Alveolar Soft Part Sarcoma



SCFC is proud to support important strides being made across Canada! Some recent work on Alveolar Soft Part Sarcoma has now been published in the prestigious journal entitled Cancer Immunology Research, a publication of AACR (American Association for Cancer Research). Although involving a small number of patients, this is a phenomenal paper that may hopefully be used to justify access to checkpoint inhibitors for these patients.

[Read The Full Paper Here](#)

Patient Spotlight: Fiona Ross

**"Sarcoma. Very rare. Chronic.
Incurable. Stage 4.**

I think every single one of those words is enough to strike fear in your heart, but in combination, it is enough to change your life. It certainly did mine. It was November 1st, 2017.

I had had a dry cough. Nothing horrible, but it persisted for a couple of years. My first visit to a respirologist



In my case, I take it to mean

had me diagnosed with Idiosyncratic Pulmonary Fibrosis. The first CT scan proved that diagnosis unlikely, but did discover “nodes” on my lungs. A fine needle biopsy missed the biggest node, so finally I was wheeled into the OR on Oct 24th for a wedge biopsy. In the meantime a PET scan showed nothing unusual and the surgeon told me after the surgery that what she took out didn’t look like cancer.

So, when I got the pathology report on Nov 1st that told me it was cancer, a very rare sarcoma in fact, I was totally unprepared. Even less so for the numbers. My sarcoma is approximately 1 in 3 million, and my specific presentation puts me at approximately 1 in 8 million or so. With those odds, I could have won a lottery. I was alone at the time. The doctor’s office hadn’t warned me to bring someone.

The sad truth is that rare sarcomas are underfunded, under-researched and even the experts don’t have the knowledge that exists in other more common or “popular” cancers.

My particular form of sarcoma is called Epithelioid Hemangioendothelioma or EHE for short. A recent medical publication from February 2018 puts my life expectancy at 6 months to 30 years. You could take those numbers to be hopeful, or as an indication of how little the medical community knows.

both. Initially I was put on the most common “treatment” plan for EHE. It is called “watch and wait,” in other words nothing at all. Just live.

“Soft tissue sarcomas are the quiet kids, left to themselves in the corner of the classroom.”

There are active foundations in America, the U.K. and Australia. In the last 5 years there has been specific EHE research in those countries with world leaders in sarcoma. In Canada, there has been little or nothing.

I am a secondary teacher librarian. Research and communication are basically what I do every day. Social justice is another lifelong passion of mine. Now I am turning my skills and passion in a different direction.

Thanks to the SCFC and my own advocacy, I now have raised about \$15,000 for EHE since January. I also have a Canadian sarcoma oncologist who is hoping to use Mt. Sinai’s biobank to look at EHE and other sarcomas for specific genetic signatures. Please help us raise the resources to research EHE and other rare soft tissue sarcomas. The life you save could well be mine.

[Read Fiona's Full Story Here](#)



Congratulations to Tina, friends, and family for another successful Spike 4

Ready, Set, SPIKE!

Tim loved afternoons spent on patios with friends, sun, and fun, and that’s how Spike began. With over 120 attendees each year, it’s a great way to remember a friend and raise money for those fighting the same battle Tim fought.

Through the community's endless

Sarcoma event! Spike 4 Sarcoma is a co-ed volleyball tournament that is held annually in memory of Tim Yeates, who lost his battle with sarcoma in 2010, at the age of 27.

love and support, and Tina's tireless work, Spike has raised and donated to SCFC over \$40,000 in the last 8 years. Way to go all teams!

Learn more at their FB page!

Donate Today

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