

Fall 2017 Newsletter

A Message From Our Chair



Greetings,

A warm thank you to everyone who has supported SCFC's work this year. We have been able to provide critical support and information to patients and families, as well as groundbreaking research, due to the donations that we have received from individuals, families and corporations across Canada.

Together we will continue this work in 2018 and beyond. The holiday season is bittersweet for many in our community and 2017 will be no exception. It is a time to come together to celebrate successes - our survivors and all those living with sarcoma who are fighting their battle with dignity and strength every day. It is also a time to reflect and celebrate the lives of those we have lost.

This summer, our community lost a long-time friend and advocate with the passing of Lucian Yaron Panov, who bravely fought his battle with liposarcoma for seven years. His wife Rochelle's incredible tenacity, supported by the fundraising work of his family, helped to bring groundbreaking precision chemotherapy to Canada, so that Canadian patients and physicians can now access this treatment. We will miss Yaron's kindness and the message of hope he brought to patients across Canada. His family continues to be an inspiration to all of us, and to spread this message of hope in his memory as they continue to fight for research progress in sarcoma.

To all in our community, we wish you a peaceful holiday season, and health and strength in 2018.

Diana Arajs
Founder & Chair, SCFC

*please
join us*

SCFC Presents: An Interactive Panel Discussion on Living with Sarcoma

Join others in the sarcoma community for an informative and candid discussion about sarcoma from the perspectives of survivors and some of the country's leading experts.

Date: Tuesday, December 5th, 2017

Time: 6:00 pm - 8:30 pm

Location: 15 York Street (2nd Floor - Stonegate/CI offices), Toronto, Ontario

Moderated by: SCFC Board Member and sarcoma survivor, Mark J. Stewart

Panelists include:

Dr. Rebecca Glady, Sarcoma and Gastrointestinal Surgical Oncology,
Assistant Professor of Surgery, Mount Sinai Hospital

Judi Perry Brinkert, Executive Director of Wellspring

Registration is **FREE**. Please contact Jessica at
jessica@sarcomacancer.ca
or call us at 647-255-8123 (toll free at 1-800-487-1364)

New National Resource - The Launch of SCFC's New Website

The screenshot shows the SCFC website homepage. At the top left is the logo for Sarcoma Cancer Foundation of Canada. To the right is a navigation menu with links: About Sarcoma, About SCFC, Stories of Hope, Find Support, News & Events, and Donate Today. Below the navigation is a large blue banner. On the left side of the banner, the text reads: "Sarcoma Affects All Ages". Below this, a paragraph states: "Sarcoma cancer is a cancer that affects nerves, muscles, joints, bone, fat and blood vessels, or the body's 'connective tissues'. A cancer that affects individuals of all ages, sarcoma cancer is especially prevalent in children and young adults." At the bottom left of the banner is a small blue button that says "learn more". On the right side of the banner is a photograph of a woman with dark hair, wearing a bright green short-sleeved shirt, standing with her hands on her hips.

Through the dedicated work of our volunteers, SCFC is excited to announce the

launch of our revamped website. Over the years we have recognized the desperate need for increased information and accessible resources for Canadians, and through this online platform we are committed to providing you with the very best information as it becomes available.

Some of our new features include a robust catalogue of support groups across the country, more complete information about sarcoma types, and a new easy-to-print donation form.

However, there is always more work to be done, and we're not finished yet! Stay tuned in the upcoming months for our new third party event kit - designed to help you easily plan and hold your very own fundraiser or event - and for the addition of detailed sarcoma specialist information, allowing patients to access the best care regardless of where they live in Canada.

We would like to send a huge thank you to Clear Space Design for their incredible work, and we invite everyone to visit the site by clicking on the link below. We encourage you to share your feedback with us either through social media or by emailing us at info@sarcomacancer.ca.

Visit Our
Website

Research Into More Targeted Sarcoma Treatments Could Improve Patients' Outcomes

SCFC is pleased to announce our support for a brand new research initiative that will give patients with rare forms of soft tissue sarcoma (STS) faster, simpler, and more accurate diagnoses, so that treatment can get started sooner.

Since STS is not just one disease - there are over 50 types - patients often need to undergo a great deal of invasive testing, including surgical biopsies, to be diagnosed accurately.

Led by a collaborative team of scientists at Sinai Health System's Christopher Sharp Cancer Centre and Princess Margaret Cancer Centre, the research uses Next Generation Sequencing technologies to analyze the blood of patients with sarcoma, seeking distinctive 'signatures' that reveal their tumours' specific mutations. With this detailed insight into the tumour's characteristics and weaknesses, oncologists will be able to develop a blood test that allows oncologists to diagnose rare types of STS with precision, and that guides treatment decisions.

This simple and minimally invasive "liquid biopsy" could spare patients from undergoing invasive surgical biopsies to diagnose their tumour. Not only will treatment get started sooner (and with less stress), but oncologists will be able to monitor the patient easily, using a simple blood test to determine if the tumour is shrinking.

This is an exciting project for all of us, and SCFC is launching a new directed fundraising campaign to raise \$100,000 towards this cutting edge research. Join us in this exciting project!

Patient Profile

Andy Bertrand

"This is a tale of a lengthy medical journey full of surprises.

It was May 11, 2016, the day before my birthday. I was explaining to my family doctor about pain radiating along my lower abdominal area. He expressed concern and immediately recommended an ultrasound for a further examination. This would be surprise number one and lead me into a prolonged series of medical visits for the next six months. The ultrasound concluded I had a serious liver condition - Two masses were found on the liver and cirrhosis was rather presentable. He arranged for me to meet the liver specialist at the local hospital for a consultation. This was surprise number two.



The liver specialist prioritized my name onto the list of patients and a bone scan and CT scan were performed. Just two days later I meet with her to discuss the findings. The good news was I did not have any liver disease, but the better news was I have contracted cancer. I shook my head in disbelief. This was surprise number three.

How could I have cancer? And, how could that be classified as a good sign? This has to be the ultimate oxymoron of all times! After I regrouped mentally, she calmly supplied the explanation. If I had those liver ailments, my future would be a constant array of clinical visits and a certain liver transplant which would probably seriously dampen how I live my life. At least, the cancer is treatable and the chances of a 'normal' life were considerably better. but I did not have a common cancer. It was diagnosed as a sarcoma. Surprise number four. The sarcoma was classified as a retroperitoneal, meaning it was located in the abdominal region, up against the back abdominal wall.

On August 4th, at PMH, my radiation schedule was established. It would consist of 25 daily sessions, commencing August 15th, to shrink the tumour, leading to an easier surgery. At this meeting, Dr. Charles Catton, a noted radiation oncologist, stated, based on the CT scan, my tumour was the size of a softball. That was the next surprise. A softball? I played softball, so I knew all about the size. That's pretty big.

Sunday, August 28th, contributed another surprise. I was consuming some chicken noodle soup when my stomach indicated it was time to rush to the porcelain throne. Who says chicken noodle soup is good for what ails you? After emptying my contents, I began feeling dizzy and promptly fainted. Upon

wakening, a firefighter was shining his flashlight into my eyes. Off to the right were two paramedics. This necessitated an ambulance trip to the Emergency department. After transferring to the sub-ICU station, at about 5:45 a.m., I am informed I had a pulmonary embolism, which is why I fainted. I met again with Dr. Catton and explained what transpired the previous week. He then notes that my tumour is now the size of a football - NFL not CFL! Wasn't the purpose of radiation to shrink the tumour, not expand it?

I resumed the treatments September 6th and continued until September 29th. Whew, the last session! Surgery is scheduled for November 17th!

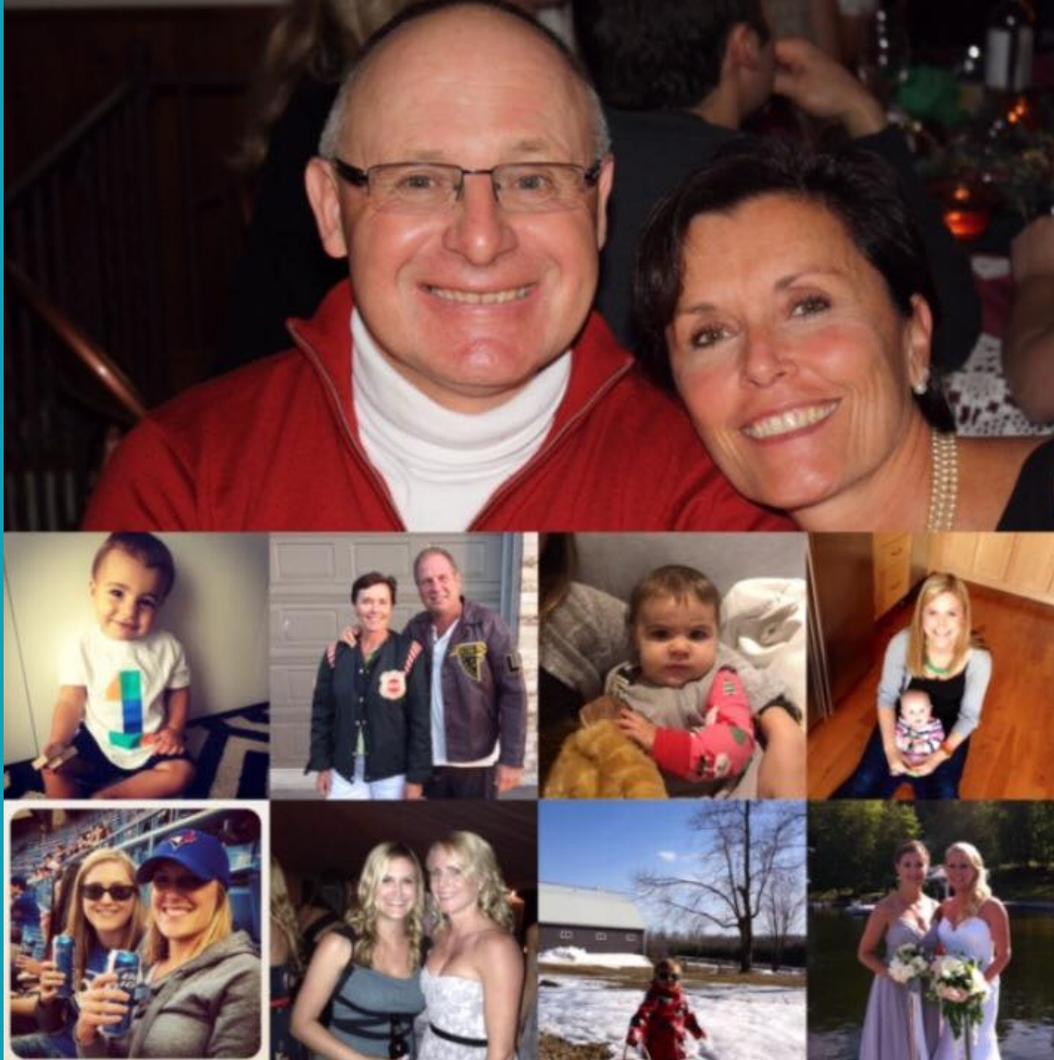
When all is said and done, I 'delivered' a 20-25 pound tumour, measuring approximately 30 inches in length by 24 inches in width. I refer to it as 'triplets'. It resembled a giant baked potato! I am so glad I asked for photos because knowing the sheer size of the tumour has become a hot conversational topic. The only reason I asked in the first place is because I was curious about what tumours were and what they looked like. Mine was an unexpected bonus!

I am a humble person who takes things in stride. Yes, it was a major ordeal healthwise, but I did not 'strain my brain' over it. My pursuit of perfection has diminished considerably and I do not allow little things to bother me. This Friday (November 17th) will mark the one-year anniversary of my operation. It is hard to believe how fast time has passed!

I am hoping that by sharing my story it will act as encouragement to lead more fulfilling lives for people; to pursue meaningful accomplishments that have been neglected up to now. That is the key to life: participating in activities that resonate with peoples' values. It is never too late to improve one's life."

[Read Andy's full story here.](#)

Sarcoma Cancer Awareness Week



Community is a powerful word. This June SCFC kicked off Sarcoma Cancer Awareness Week by inviting Canadians across the country to face sarcoma cancer by helping us share the Faces of Sarcoma Cancer. We wanted to bring together the ways in which we #knowsarcoma.

In an outpouring of support through social media, people from different walks of life have shown that when you bring a community together, whether within a city, across a country, or online, great things can happen.

SCFC would like to thank everyone who donated or supported the sarcoma community throughout Sarcoma Cancer Awareness Week. It is through the involvement of individuals like you that we can do the work we do to make strides in eradicating this disease.

While June has passed, we're already gearing up for 2018's Awareness Week and will be sharing details early in the new year. In the meantime, we encourage you to continue to post your Faces of Sarcoma through use of our hashtag #knowsarcoma - in order to keep facing sarcoma and to provide encouragement and courage to those across the country.

Above, we are happy to share with you some of the Faces of Sarcoma we received throughout awareness week.

STAY CONNECTED:

