

Spring Update

A Message From Our Chair

As we welcome a much anticipated spring season, we are hearing from many people that they have taken to mindfulness practices during the pandemic and have found solace in focusing on the small things to be grateful for. This is something that has always been present in our community. Experiencing a sarcoma diagnosis and treatment journey often causes one to reflect, re-prioritize and appreciate small victories and small gestures. To celebrate this notion, we will be launching a campaign later this year about the little actions we can take that add up. We invite everyone to share ways that they have supported or been supported by their community by what may seem to be small things. One of the members of our Board of Directors, Fiona Ross, currently living with sarcoma, shares one of her own examples of how small actions can have a large impact in this newsletter.

We're also thrilled to share with you our support of the CanSaRCC initiative, an incredible effort spearheaded by Dr. Abha Gupta, oncologist and hematologist at Sick Kids and Princess Margaret hospitals. CanSaRCC is an initiative to provide physicians and researchers across the country with a comprehensive clinical database and virtual biobank to improve the understanding of the biology, treatment options and patient impact for sarcoma. Having supported Canadian sarcoma research for over a decade, we at SCFC know the critical nature of this work and the impact it will have on research projects nationally and globally.

For those of you that celebrate Easter, it marks the beginning of a second year of holidays shared virtually instead of in person. Our community continues to be hard hit by COVID-19, both physically and emotionally. Please reach out with a call, e-mail or via social media if there is any way that SCFC can support you. It's more important than ever to remember that you are not alone. We have peer counsellors available to speak one on one about their experiences and are always happy to connect you to information or resources to support your journey.

Wishing you a hopeful spring,

Diana Arajs
Founder & Chair
SCFC

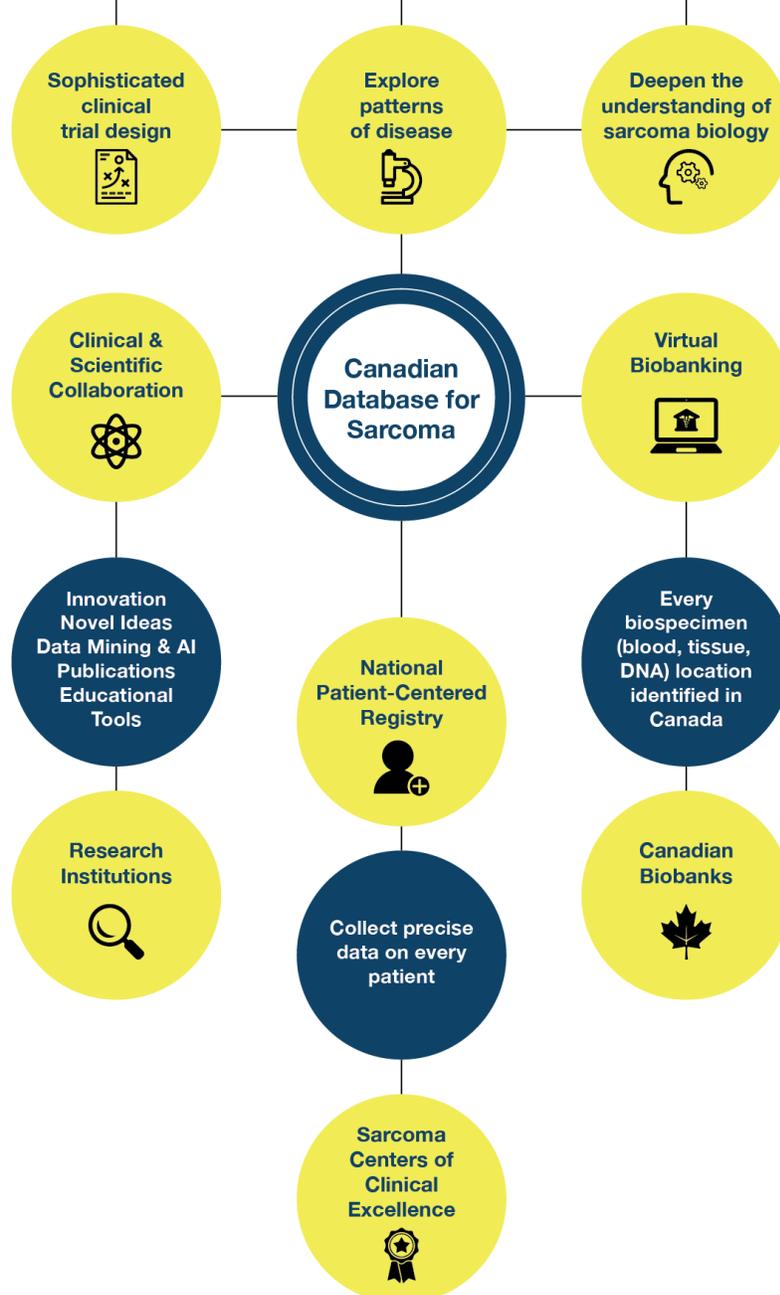
Canadian Sarcoma Research and Clinical Collaboration (CanSaRCC)

Some of the greatest achievements start with a single question. Patrick Wilson, an 18 year old diagnosed with embryonal rhabdomyosarcoma, asked his physicians about the possibility of capturing information from all patients diagnosed with sarcoma across Canada, with a hope to ultimately improve their outcomes.

We are now happy to announce our support in helping to fund the development of the Canadian Sarcoma Research and Clinical Collaboration (CanSaRCC) – A Canadian Database for Sarcoma. Led by Dr. Abha Gupta, CanSaRCC is a group of physicians, scientists and other health care providers across Canada who have joined together to form a team to facilitate interdisciplinary scientific collaborations and perform clinical and translation research in sarcoma.

The goal: In one year, to be able to define the total number of adults that were tested for and diagnosed with a specific rare sarcoma subtype across the country. Knowing their disease stage, treatment, and outcome, health care providers will be in a position to advance knowledge in sarcoma and its treatment, and to conduct clinical research and design trials.

The vision:



Due to knowledge gaps, the scope and objectives of rare disease registries are often broader than in a typical disease registry. The major goals of the patient-centred registry are to improve understanding of the biology of soft tissue and bone sarcoma in order to:

- Support multidisciplinary research
- Connect patients, families, clinicians, scientists, investors and stakeholders
- Learn the natural history, evolution, risk, and outcomes of sarcoma
- Explore hidden patterns by using Data Mining tools and machine learning
- Using interdisciplinary knowledge to develop new diagnostics tests and therapies
- Identifying the ideal patient sub-population for novel drugs and identifying an inclusive cohort of patients that would benefit the most from a particular medicine.

[Learn More About CanSaRCC](#)



[Read Patrick's Story](#)

Tumour-Agnostic Treatment for Cancer

In an era of increased focus on precision medicine, tumour-agnostic therapies have emerged as a revolutionary new approach to cancer treatment. These therapies target specific genomic anomalies or molecular features regardless of tumour site of origin. The below infographic has been developed to help you understand this exciting new concept:

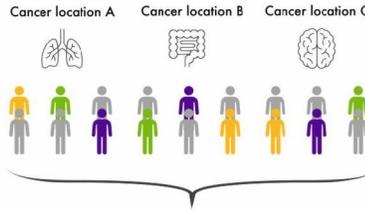
INTRODUCING

Tumour-Agnostic Therapies

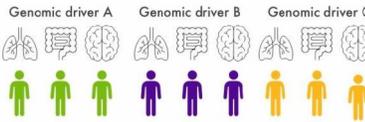
Advances in precision medicine have brought therapies that specifically target what is driving a patient's cancer



Treatment with more **traditional** cancer therapies is based on where the tumour is located in the body



Tumour agnostic therapies target a specific genomic change in the cancer cells regardless of where the tumour is located in the body



Genomic changes in cancer cells are identified through diagnostic testing of the cancer cells. The results help clinicians decide on a treatment for each patient.



1 Patients undergo a biopsy to obtain a sample for testing



2 Tissue is sent to lab to test for genomic changes



3 Results sent to clinician to help decide on treatment

Advantages of tumour agnostic therapies



1 Targets the genomic change that is the root cause of the cancer to suppress tumour growth



2 Harnesses our growing understanding of cancer biology



3 Offers an innovative, new and effective approach to treating cancer

Change required to adopt tumour agnostic therapies in Canada



1 A shift in mindset: this is a new concept that differs from the traditional approach of treating cancer based on tumour location



2 Access to genomic testing: Identifying patients who would benefit from treatments requires a robust testing infrastructure



3 An evolved, more adaptive assessment of treatments for public coverage is required that includes recognition of smaller patient populations, new clinical trial methods, and ability to examine new data over time

Research Update: The Panov Program in Precision Therapy

When a CT scan showed that Yaron Panov's rare abdominal sarcoma had returned, he was given months to live. He went on to have years added to his

life thanks to cutting-edge Precision Chemotherapy treatment he received internationally.

Oncologists grafted pieces of his tumor into mice avatars and then tested different chemotherapy drugs to see which would work best on his genetically unique cancer cells. Yaron, his wife, children, and family physician became passionate advocates for bringing this treatment to Canada.



SCFC's Vera Arajs Clinical Fellowship and Research Chair supported this important work in precision therapy, and thanks to the 650 individuals who have contributed, over \$1,500,000 has been raised to date. We want to thank all of our donors whose support made these advancements possible and the Panov Family for their incredible passion and leadership.

These funds have allowed Sinai Health System's Christopher Sharp Cancer Centre to join an international study to prove the value of this highly personalized chemotherapy approach, and for the establishment of a new sarcoma cancer research fund at Mount Sinai hospital to which researchers will be able to apply annually for critical funds to support their groundbreaking work.

Fundraising: Small Actions Make a Big Impact

By: Fiona Ross

EHE Patient/Advocate and SCFC Board Member

We are now heading into our second year living with COVID-19. People are tired. People are scared and many are under financial pressure. The same is true of charities. There are so many good causes that need our support and attention.

I have EHE (epithelioid hemangioendothelioma). It is literally a one in a million rare sarcoma. Until I started fundraising there had never been any EHE-focused research in Canada, ever. While I totally appreciate all the many reasons that fundraising had stalled in the COVID world, I couldn't just sit back and do nothing.

I wanted to find a small action that I could take in my daily life that would make a real difference, so I decided to make an old idea new again and simply run a never ending bottle drive. I take LCBO bottles, cans and bladders and return them for cash, which I then total up every month or so and send to the SCFC.



Sometimes friends and colleagues help too. As we are still in the midst of COVID we practice no contact drop offs in order to prevent the sharing of germs. I have gone to parking lots in various institutions and have loaded empties into my van. I have had people drop off on my driveway in the dark of night, but mostly I use our community Facebook page to remind people so that they can drop them off when they can. It's not a huge amount of work. Maybe an hour to sort, count and drop off once or twice a month.



I have been doing this since June 2020 and I am pretty sure that by the time June 2021 comes around I will have donated over \$2,500. Most people are happy to do it and it helps them declutter, but those \$0.10 cans and \$0.20 bottles can make a real contribution to fundraising for EHE research in Canada.

So, if you want to help, or are thinking of trying to raise money, sometimes it is not the big, splashy gestures that are needed. An involved community, a little PR and a few hours a month can all become something much bigger. Little things add up!

What little things have you done in your community that add up to make a difference? Share with us on social media!



Patient Profile: Dana Levanto

I'll probably never know when exactly I boarded this involuntary roller coaster. It was a series of minor circumstances and events that unfortunately, or fortunately, led me to where I am today.

In late 2018 and 2019 I was complaining of fatigue and shortness



of breath. Many would have attributed it to the fact I was out of shape, and needed to lose some weight. However, my family physician insisted we get some answers.

When iron therapy didn't resolve my diagnosed anemia, she ordered a colonoscopy and endoscopy to determine if there was internal bleeding. Although no evidence of bleeding, scans did show a large hiatus hernia. I was given the option of surgical repair, and in order to assess if the surgery could be done laparoscopically Dr. Smith ordered CT scans.

I was told the CT showed "spots" in my lungs, liver, kidney and bones. In November of 2019 I saw a kidney specialist in Hamilton who said he could remove and biopsy the masses in the kidney by using a minimally invasive technique. In the meantime I had a liver biopsy. I was told I should have results around Christmas time. Well, Christmas, and New Years came and went with no results. I took this as a good sign. I mean, no news is good news, right? Besides, in the past few months my mother was diagnosed with Stage 4 Melanoma and my infant granddaughter with a heart condition. Surely, nothing else could go wrong.

On January 7th, 2020, I got calls from both my family doctor and my local surgeon and thus began the ride on an unpredictable roller coaster called 2020. The results from my liver biopsy were "a differential diagnosis of angiosarcoma or Epithelioid Hemangioendothelioma (EHE)". My reaction - what does that even mean? Basically it was one of two rare forms of cancer, but they weren't sure which one.

February, and another trip to Toronto, brought consultations with a team of sarcoma specialists at Mt. Sinai, and more tests and scans. March, 2020 was surreal. On March 11th I had a second liver biopsy, at Princess Margaret Hospital. When I went into the hospital Toronto was its usual busy, bustling self. 36 hours later I walked outside my hotel to a ghost town. COVID-19 had hit, and Ontario was going into lockdown. Another challenge to be considered. By the end of March; 6 specialists, 5 trips to Southern Ontario and seven months from my initial scans, I finally had a definitive diagnosis. Multifocal Hepatic hemangioendothelioma (EHE). Although this cancer of the blood vessels is very rare and treatment and prognosis is unclear, I welcomed this news with relief.

On September 24 I underwent major surgery which included a right hepatectomy, a partial left hepatectomy, a cholecystectomy and right partial nephrectomy. Dr. Trevor Reichman was able to remove all tumours except for one, although not all margins are clear. It took several weeks to recover and although I still experience significant fatigue and minor pain I generally feel well.

I know my ride on this rollercoaster is far from over. Next week I will return to Toronto for more scans and then we will decide how to treat the remaining tumour. Will I need more surgery? Chemotherapy? Ablation? What about the spots in my pelvis? Will the doctors take a watchful waiting approach, and if so how comfortable will I be? How many more times will I make the 2,800 kilometre (return) trip to access care? EHE is unpredictable, it doesn't follow a definite pattern, it could stay dormant for a long time, or suddenly become aggressive causing death within months. I don't know what to expect and I know I'm not alone. Without more research about this one in a million cancer, no one who lives with EHE can predict what their future may hold.

What I DO know, however, is that one year ago I thought I might not be alive today. Yes, 2020 was a roller coaster ride in many ways, but I cherish every moment. I am grateful for every conversation with friends and family, every visit with my children, every day I get to play with one of my young grandchildren. There are more trips around the track to come. The steep inclines, devastating drops, unpredictable corners interspersed with short periods of relative calm will continue. I am grateful, but not completely without fear. Today, as I held my newborn grandson for the first time I wondered if I will live long enough for him to remember me. One thing is for sure - I will travel a million miles, try every treatment, and explore every option necessary to ensure that he does.

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

Upcoming Events

Toronto International Sarcoma Symposium

The Sarcoma Program at the University of Toronto is pleased to host the 4th Toronto International Sarcoma Symposium to be held on April 9th, 2021 on a virtual platform.

The one day symposium will feature Clinical and Translational Research among other topics.

This multidisciplinary symposium welcomes the attendance of Faculty, Trainees, Allied Health Professionals as well as our Sarcoma patients and their families.

SCFC applauds Dr. Rebecca Gladdy, Dr. Abha Gupta, Dr. Joel Werier, and Dr. Philip Wong for their ongoing leadership in overcoming the current challenges to ensure that this conference takes place and allows sarcoma experts from around the globe to collaborate and share learnings.



Healthy Spring Recipes

Nutrition is an important part of life, cancer treatment, recovery, and prevention, and is fortunately one thing you can control. The below are some simple, delicious recipes to keep you and your family healthy.



Salmon and Veggie Egg Muffins

Ingredients:

- Nonstick cooking spray
- 2 tsp. extra-virgin olive oil
- 1/2 red pepper, diced
- 2 cups baby spinach, roughly chopped and packed
- 2 green onions, trimmed, sliced and chopped
- 5 large eggs
- One 2.6-ounce pouch wild-caught pink salmon in extra-virgin olive oil, flaked*
- 1/2 cup shredded Cheddar cheese
- 1/4 cup fresh basil, finely chopped
- Salt and black pepper, to taste

Directions:

1. Preheat oven to 350°F. Lightly coat 6-cup muffin pan with nonstick cooking spray and set aside.
2. Heat oil in skillet over



Breakfast Blueberry Oatmeal Cakes

Ingredients:

- 2 ½ cups old-fashioned rolled oats
- 1 ½ cups low-fat milk
- 1 large egg, lightly beaten
- ⅓ cup pure maple syrup
- 2 tablespoons canola oil
- 1 teaspoon vanilla extract
- 1 teaspoon ground cinnamon
- 1 teaspoon baking powder
- ¼ teaspoon salt
- ¾ cup blueberries, fresh or frozen

Directions:

1. Combine oats and milk in a large bowl. Cover and let soak in the refrigerator until much of the liquid is absorbed, at least 8 hours and up to 12 hours.
2. Preheat oven to 375 degrees F. Coat a 12-cup nonstick muffin tin with

- medium-high heat. Add peppers and cook, stirring, until tender, 5 minutes. Add spinach and onions and cook, stirring, until wilted. Set aside to cool slightly.
3. Crack eggs into large bowl. Whisk until well combined. Stir in salmon, cheese, basil, cooked vegetables and salt and pepper until combined. Use a 1/3 measuring cup to divide mixture evenly into prepared muffin cups. Bake until eggs are set, about 18 minutes.

[View Original Recipe](#)

- cooking spray.
3. Stir egg, maple syrup, oil, vanilla, cinnamon, baking powder and salt into the soaked oats until well combined. Divide the mixture among the muffin cups (about 1/4 cup each). Top each with 1 tablespoon blueberries.
 4. Bake the oatmeal cakes until they spring back when touched, 25 to 30 minutes. Let cool in the pan for about 10 minutes. Loosen and remove with a paring knife. Serve warm.

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No Bake Watermelon Cake

Ingredients:

- 1/3 cup whipping cream
- 12 oz. plain Greek yogurt
- 2 Tbsp. reduced-fat cream cheese
- 2 Tbsp. granulated sugar
- 1 tsp. lemon juice
- 1 tsp. seedless watermelon, well-chilled
- Blackberries, kiwi slices, red raspberries, for garnish



Directions:

1. Pour whipping cream in small mixing bowl and chill in refrigerator for about 10 to 20 minutes. (Cream is easier to whip when cold.) Meanwhile, in medium mixing bowl, mix together yogurt and cream cheese. Set Aside.
2. When cream is chilled, add sugar to cream and whip with whisk or electric mixer until moderately stiff peaks form. (Be careful not to overbeat because too much whipping will turn cream to butter.) Add whipped cream and lemon juice to yogurt/cheese mixture. Chill.
3. Slice off both watermelon ends to make a flat top and bottom. Set melon on one flat end and carve rind off sides to make a round, cake-shaped watermelon.
4. Place watermelon cake on serving plate and frost top and sides with chilled icing. Decorate with fruit on top and around the bottom. Keep

well chilled until serving.

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