



**Sarcoma Cancer**  
Foundation of Canada

## SCFC Spring Update

### A Message From Our Chair

As the spring weather lifts everyone's spirits, we move into preparations for Canada's national Sarcoma Cancer Awareness Week, which falls in the third week of June each year. Whether sending a message of support to those battling sarcoma cancer, remembering with a family who has suffered a recent loss or sharing your own story, we encourage you to get involved in this year's online campaign. Below you will read how you can get involved and make a meaningful contribution to our community.

Thank you to those of you who have already been in touch with plans for local fundraisers this year - the work that we do would not be possible without this passionate support from all of you across the country. From birthday celebrations to volleyball tournaments to evening galas, we are always inspired by the fundraising ideas put forward by all of you. If you'd like to get involved but don't know how to get started, we would be happy to help.

In this issue, we are thrilled to share some exciting updates about the research that SCFC is currently supporting. We launched the organization 9 years ago with a focus on raising awareness, providing patients and families with support and educational tools, and supporting Canada's world-leading researchers in their quest to find new treatments and ultimately, a cure. As we commemorate Mother's Day each May, I remember my own mother, in whose memory SCFC was founded, and as I celebrate with my own children, I hope that their generation does not have to suffer the same burden of loss from this terrible disease. Your contribution is making a difference. Thank you to all of you who have joined us in building and supporting this community and funding the important work that researchers are doing in Canada.

Happy Spring!

Diana Arajs  
Founder & Chair

## Sarcoma Research Underway!

SCFC is proud to be able to help fund numerous sarcoma research initiatives.



### Liquid Biopsy

In this highly exciting project, Dr. Shultz, Dr. Bratman, Dr. Razak (all at Princess Margaret Cancer Centre), and Dr. Wunder (Mount Sinai Hospital) aim to utilize a technology platform called ct-DNA. They aim to use blood samples to 'detect' cancer in patient who have early disease who undergo surgery. If successful, this method would be useful not only to determine whether surgery has eliminated the cancer completely, but this blood test can also be used as a tool to detect early recurrences.

Furthermore, this blood test can also be extended to people with advanced disease - in order to determine whether their drug therapy is working or otherwise.

### Drug ENMD

In this trial, the team investigated the utility of a drug called ENMD-2076. This agent has several anti-cancer properties against tumor blood vessel growth as well as cancer cell replication. In this study, notable anti-cancer activities are noted in a small and selected population, namely in patients with angiosarcoma or in those who harbour a mutation in the gene PTRB.

Further work using this agent will be warranted in these

### EHE

Epithelioid hemangioendothelioma is a rare sarcoma. In the advanced setting there is no known or established treatment, and the disease is invariably fatal.

Dr. Razak (Princess Margaret Cancer Centre), Dr. Dickson (Mount Sinai Hospital) and Dr. Shlien (Sick Kids Hospital) aim to decipher the immune landscape of this disease - by establishing the degree of 'inflammation' and gene profile of this rare cancer.

populations. This trial has now been published and a copy of the paper can be accessed using the below link.

<https://rdcu.be/bBKmS>

The aim of this project is to establish basis for immunotherapy for this rare disease.

## Upcoming Events



SCFC is excited to once again be participating in the Scotiabank Toronto Waterfront Marathon on Sunday, October 20th.

Lace up your sneakers and join Team Sarcoma in the Marathon, Half Marathon, and 5k walk/run this year! As part of our thanks for joining us and helping to raise funds and awareness for sarcoma, we are pleased to offer a discount to your registration fee for either the 5K, half, or full marathon.

Email us at [info@sarcomacancer.ca](mailto:info@sarcomacancer.ca) for our customized discount codes and information on how you can register and join us for race day!

[Register Here!](#)

## How to Participate

Do you want to run? Would you rather offer support from the sidelines?

If you've decided you want to run, consider starting a fundraising group in support of SCFC. Set a goal for your group, then reach out to friends and family to help you exceed your goal!

If you want to help out on race day but aren't sure you want to run, you can still make a one time donation or volunteer your time before, during, and after the race!

## Sarcoma Cancer Awareness Week

The third week in June is Sarcoma Cancer Awareness Week (June 16 - 22). SCFC wants to empower those who have supported the awareness week in your local communities before and those who are looking to recognize the important milestone in the calendar for the first time.



There is no wrong way to show your support for such an under-recognized cancer in Canada - everything we do as a collective community raises awareness and funds to support new research and important patient support programs. This year, whether it is a garage sale, bake sale, concert, or sports tournament, we encourage you to focus your fundraising efforts to leverage a week dedicated to sarcoma awareness. And don't forget to share photos with each other using the hashtag #knowsarcoma.

For more information or resources for your local event, please reach out for assistance. And don't forget to email us photos and details of your event so we can profile these in upcoming newsletters!

## Event Profile

### Belwood Grass Drags

Thank you to Kelly Woods for providing some insight into one of the most unique events SCFC has ever seen!



**'What do you get when you combine an empty wheat field, crazy creative adults and a barn filled with snowmobiles?'**

Answer: the annual Belwood Grass Drags.

Before this was an "official" event my cousins and their friends would race around the empty fields in almost any motorized vehicle that could handle it. My uncle Larry would come out to watch them after he was done in the fields/barns, he loved to watch them doing whatever crazy activity they had come up with that week. Talks around my family's dinner table usually started with "what crazy thing have the kids gotten up to this week/month?" He always replied with a laugh and then proceeded to tell us the latest stories. Seeing his kids being creative and enjoying life at the farm was one of the greatest joys of his life.

In 2011 my uncle was diagnosed with sarcoma, later that year he passed away. As a way to honor his memory, in 2015, my cousins decided to turn this informal get together into an annual fundraiser with the proceeds going to the Sarcoma Cancer Foundation of Canada.

The event draws not only close friends and family but people from all over Centre Wellington. To date the event has raised approx. \$8K. When I asked my cousins "why this event?" the unwavering and simple response was "because dad would have loved to watch this." "He loved seeing everyone get together at the family

farm."

I think anyone that goes through the loss of a loved one wonders how they can best remember them. The big questions being: how do you honour someone's life? How do you keep a memory alive? How do you make a difference? I think the answers to these questions are different for everyone. Maybe it's a bake sale, a family dinner, a dance party.

For my family the answer was in the sound of a snowmobile and the span of an empty wheat field.'

## Past Event



### Welcome to Glow Night!

On February 9th, more than 200 gym members joined Junction Climbing's annual Glow-in-the-Dark 'Glow Night' for an evening of rock climbing fun! Located in London, ON, one of their gym members has recently been given a clean bill of health after battling sarcoma.

After wondering how they could appropriately support her, they realized this event was the perfect opportunity to both celebrate her health and raise funds and awareness. This year they saw their donations almost doubled - Over \$1,500 was raised!

### Patient Profile Jane Cooper

November 5, 2009, is when cancer first impacted my life. After several operations and two years of misdiagnosis I finally had an answer to

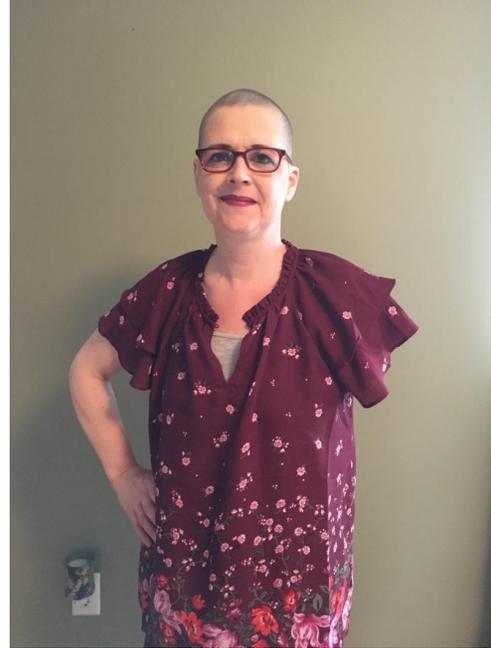
why I'd been in so much pain. I had a Synovial Sarcoma in my left arm, 2 cm in size. Although a great shock, I finally had an answer and realized I wasn't going completely insane.

The wonderful team at the Royal Orthopedic Hospital in Birmingham, England, headed by Dr. Roger Tillman, did an amazing job and I underwent removal of my radial head, then underwent 33 radiation sessions. Radiation was debilitating, but with being constantly kicked in the butt by my late husband John and family, I managed to kick cancer for the first time (Cidney as I now call it).

In February 2012 we took another curveball from Cidney when John was diagnosed with terminal inoperable bowel cancer. After battling the disease for just three months, with a legendary attitude, John sadly passed on May 31, 2012. His encouragement and his attitude and bravery has always stayed with me and always will.

Halloween, 2016 - After having a few more pains in my left arm I thought it was sensible to follow up with my GP and that's when Cidney hit for the second time. After some scans I was told that my cancer was back in my left arm, three times the size that it was originally. The amazing Dr. Ghert spoke with me and Chris and really there was only one option: amputation above the elbow. I was on board to get rid of this festering Cidney once and for all.

So that brings me to January, 2019. After undergoing a routine CT scan I was found to have a spot on my lungs and 2 on my pelvis. Seriously, Cidney must love me because it just keeps coming back. My diagnosis is to have chemotherapy as the tumours on my



A few weeks later I started to feel pain in my chest, head, neck, etc. so I contacted my oncologist to get checked out. Before we could meet, everything became so intense so quickly that I ended up in emergency again with a heart rate of 175 and felt so ill I think I fell asleep in triage with the pain. As always, the staff at Jurvinski Hospital in Hamilton, Ontario, were amazing, working quickly to assist me. They scanned me and could not believe that the mass which had shrunk was now doubled in size in just a few weeks. I was admitted and have just spent another week recovering.

***"People going through this journey all have different experiences and tales to tell. We should share where we can as it helps to talk and you learn from others and their loved ones. It is not just the patients who go through this horrible journey but all of our family and friends. I have the greatest support and feel honoured for that, never taking anything for granted."***

I hope my words can give comfort and help to people struggling with this disease. Sarcomas are a rare cancer and there is not much info out there so

pelvis cannot be removed.

However, I will not be beaten and I will do everything in my power to kick its butt.

if there is anything I can do to help, I will try.

[Read Jane's Full Story](#)

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## **Sarcoma - The Standard Bearer in Cancer Discovery**

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By: Jared W. Potter, Kevin B. Jones, Jared J. Barrott

for: Critical Reviews in Oncology/Hematology



Sarcoma is a rare tumor type that occurs most frequently in connective tissue. Despite its uncommon occurrence, sarcoma research has provided the means for groundbreaking research that has advanced our understanding of general cancer mechanisms. It is through sarcoma research that the pioneering efforts of cancer immunotherapy were explored, that we understand the inherent genetic nature of cancer mutations, and that we appreciate the

sub-classification of general cancer types to make more accurate prognoses. This review explores the brief history of sarcoma research and what sarcomas can still teach us about the future of cancer research, especially in regard to novel immunotherapy targets, the role of epigenetics in disease progression and chemoresistance, and the benefits of more focused clinical trials.

[Read the Full Publication](#)

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## **Sarcoma Infographic**

There's always a need for more educational materials, and we're pleased to release our newly redesigned sarcoma infographic. Updated with new statistics, we've started distributing to clinics across Canada.

Our infographic includes common questions and answers, Canadian statistics, and 'Fast Facts' such as:

- 55-60% of all soft tissue sarcomas are located in the limbs (arms & legs).

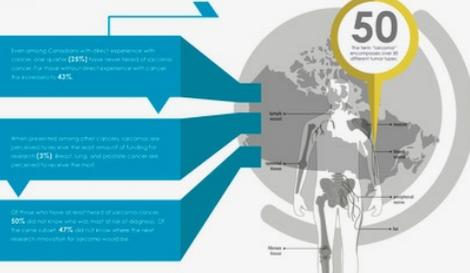
# Sarcoma Cancer in Canada

Sarcoma is a cancer that develops out of cells in connective tissues. It can begin in bones, cartilage, muscles, tendons, fibrous tissues, veins, arteries, nerves, skin, and fatty tissues.

Sarcomas can affect almost any part of the body, but commonly affect the arms, legs and torso. They also appear in the stomach and intestines, as well as behind the abdomen (retroperitoneal sarcomas) and the female reproductive system (gynae sarcomas).

1,285 Canadians are estimated to be diagnosed with soft tissue sarcoma each year.  
745 Canadians die from soft tissue sarcoma each year.  
700 men are diagnosed with soft tissue sarcoma and 254 die from it each year.  
565 women are diagnosed with soft tissue sarcoma and 249 die from it each year.

## What do Canadians know about sarcoma cancer? <sup>1</sup>



Sarcoma Cancer Awareness Week was recognized by the Federal Minister of Health during the third week in June.

### Causes of Sarcoma

The causes of most sarcomas are unknown. There are some hereditary conditions which have a predisposition to sarcoma but the number of cases is very small. Accurate data about the actual diagnosed number of cases of sarcoma is hard to find. This is because cancer is reported against the site of origin (the area of the body where the cancer is found). Sarcomas can develop almost anywhere on or in the body and many are only found following investigations for a condition which seems unconnected with cancer.

### Treatment

Despite the many different sub-types of sarcoma, the general pattern of treatment is similar. Treatment can include surgery, chemotherapy, radiation therapy depending on the particular type of sarcoma as well as new targeted cancer drugs.

### Fast Facts

The term sarcoma comes from the Greek word sarcoma, meaning "fleshy growth".

55-60% of soft tissue sarcomas are located in the limbs (arms & legs).

Sarcoma is a rare cancer that affects the connective tissue in the body. These tumors are divided into tumors of the bone or soft tissue.

Soft tissue sarcomas are an uncommon type of cancer in adults and account for about 1% of all adult cancers.

Sarcoma cancer is more common in children and makes up 15% of all childhood cancers.

Bone cancers can be divided into three groups – osteosarcoma and Ewing's sarcoma, primarily found in children and young adults from 10-25 years of age, and chondrosarcoma, most commonly seen in adults over the age of 50.

### Supporting Cutting-Edge Sarcoma Research in Canada

Through the Vera Arap Clinical Fellowship and Research Chair at Mount Sinai Hospital in Toronto, the SCFC supports the training of future sarcoma experts and the need for research across Canada.

### You are not alone.

Join Canada's sarcoma community today.

Have questions? Need support? Call us at: 1-800-487-1364.

Follow us on Twitter - @sarcomacancer.com and visit us on Facebook.

The Sarcoma Cancer Foundation of Canada is Canada's national organization dedicated to providing patient support and education while working with Canada's leading research institutions to eradicate the disease. It is our mission to connect patients and their families with the best medical information and community resources, to ease the process of dealing with a sarcoma cancer diagnosis and treatment.

### Sarcoma Cancer Foundation of Canada

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If interested in obtaining a physical or PDF copy please send us an email at [info@sarcomacancer.ca](mailto:info@sarcomacancer.ca)

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