



## 10th Anniversary Newsletter

### A Message From Our Chair

Ten years! It doesn't seem possible that a decade has passed since we launched SCFC in November 2010, and yet it also seems impossible to imagine a time before we had the opportunity to connect with and learn from the incredible community of patients, families, survivors and advocates across Canada. We are forever grateful to the talented group of physicians across Canada who have made it their life's work to support and treat sarcoma cancer patients, while creating visionary research projects that continue to give us hope. Your generosity with your time, your kindness and your dedication to this group of patients is extraordinary and it makes a real difference every day. We are also grateful to our wonderful community of donors across the country. Without your generosity and support through good times and bad, we would not be able to do the work that we do.

Sarcoma cancer continues to be an incredibly difficult disease to treat, given its over 70 subtypes, and we have seen quite a marked increase in the level of awareness about this disease and the number of Canadian research projects that are being funded over the last 10 years - both things which have a significant impact on our understanding of sarcoma and the ability to give patients a better quality of life, and increase survival rates. SCFC has been proud to be a part of this work and also of our ability to support patients and families through often frustrating and difficult times. Over 1700 Canadians are diagnosed with sarcoma each year and we still lose far too many of them. This work is not always easy - we feel each loss deeply - but those losses motivate us to keep going and keep memories alive. It also makes the celebrations that much sweeter - the successful surgeries, the clear scans, exciting research results, the announcement of new, promising treatments all move us one step closer to our goal of one day eradicating sarcoma cancer altogether.

Here's to the next 10 years and beyond. Whether you have been with us since the beginning or have recently connected or supported our work for the first time, we thank you. We will continue to do all that we can for this community and encourage you all to continue to spread the word and share your stories.

Happy anniversary,

Diana Araj  
Founder & Chair  
SCFC



This year we are celebrating a major milestone. Check out our Facebook, Twitter, and Instagram to catch the latest announcements and follow along as we celebrate.



## 10 Years At a Glance

Check Out Some of Our Major Milestones From The Last Decade!



*Sarcoma Cancer Foundation of Canada is Canada's national organization dedicated to providing patient support and education while working with Canada's leading researchers to eradicate the disease.*

### **FEB 2010**

Received charitable registration number - SCFC was born!

**APR 2010**

First meeting of Board of Directors. A huge thanks to this dedicated and visionary group of 10 founding board members

**JAN 2011**

SCFC launches first Canadian sarcoma cancer-focused website with information and resources at [www.sarcomacancer.ca](http://www.sarcomacancer.ca)

**MAY 2012**

SCFC establishes toll free patient support line, first dedicated to sarcoma cancer in Canada

**JUN 2014**

Federal Health Minister Rona Ambrose officially announces Sarcoma Cancer Awareness Week as the 3rd Week of June and includes a pledge of \$1.2M from CIHR to support a 5-year research project on alveolar rhabdomyosarcoma

**DEC 2017**

SCFC celebrates first \$1M raised and millions of dollars donated in pro-bono and volunteer services to support sarcoma patients and families

**DEC 2019**

Generosity of transformational private donors and continued community support launch critical SCFC Canadian EHE Research Fund

**NOV 2010**

Official launch of the Sarcoma Cancer Foundation of Canada and initial pledge of \$250K to establish the Vera Arajs Clinical Fellowship and Research Chair at Mount Sinai hospital in Toronto

**MAR 2012**

Advocacy efforts begin to declare a national Sarcoma Cancer Awareness Week

**OCT 2013**

SCFC becomes the first patient group to submit to CADTH's pCODR process, advocating for equal access to treatment for all patients

**SEPT 2015**

SCFC sends first mailing of printed materials to sarcoma clinics across Canada to support patients and physicians

**DEC 2016**

SCFC holds first patient information session bringing together a panel of physicians, survivors and patient support services

**MAR 2018**

Updated online resources at [www.sarcomacancer.ca](http://www.sarcomacancer.ca) providing patients, families, and all Canadians access to news, events, resources and a way to come together as a community

**NOV 2020**





## Our Board of Directors Through The Years

A huge thank you to every member of our Board, past and present, for your passion and hard work. Ten years on, you've made our successes possible and have helped shape the SCFC we are today.

**Adrianna Boyko**  
2012 - 2020

**Angela Stawecki**  
2019 - Present

**Candice Best**  
2010 - 2012  
*Founding Director*

**Christa Favot**  
2010 - 2013  
*Founding Director*

**Christie Love**  
2010 - 2013  
*Founding Director*

**Claire Macnamara**  
2010 - 2012  
*Founding Director*

**Diana Arajs**  
2010 - Present  
*Founding Director*

**Eric Arajs**  
2018 - Present

**Ethan Pigott**  
2012 - Present

**Fiona Ross**  
2020 - Present

**George Arajs**  
2012 - 2018  
*Founding Director*

**Jasmine Ighneski**  
2012 - Present

**Joann Brnjas**  
2011 - 2013

**Jodi Kovitz**



I joined SCFC before it even had a name. It was born out of the sadness of loss, but has proven over and over again that the community we build around a shared cause is the greatest tribute to the memories of our loved ones.

*Paul Cantin 2010-2019  
Founding Member*



I'm proud to be part of a foundation that helps support patients and their families through a really challenging time in their lives.

*Kelly Woods 2014-Present*

2014 - 2016  
John Ratchford  
2014 - 2018

Judy Danis  
2011 - 2012

Kelly Woods  
2014 - Present

Kurt Tiltack  
2010 - 2012  
Founding Director

Maggie Duvnjak  
2014 - 2016

Mark Chalifoux  
2010 - 2014  
Founding Director

Mark Stewart  
2014 - Current

Mary Ng  
2011 - 2015

Mike Mallinos  
2010 - 2017  
Founding Director

Mike Sharp  
2011 - 2013

Nancy Dale  
2010 - 2012  
Founding Director

Paul Cantin  
2010 - 2019  
Founding Director

Sahand Sojoodi  
2011 - 2016

Tamara Breukelman  
2017 - 2019

“

I'm incredibly proud to have been involved in supporting SCFC during its early years as we laid the foundations for this important organization. The work accomplished over the past decade has been transformational.

Marc Chalifoux 2010-2014  
Founding Member

“

I was most proud of the impact on individual families that we had and our ability to enable and drive innovative research that otherwise never would have been funded.

Jodi Kovitz 2014-2016

“

Even among sarcomas, the type I have is the rarest of the rare. It is important to me to serve a community that has been neglected and give a voice to those who have not been heard.

Fiona Ross 2020-Present

Check out our social media for all quotes from current and past Board members!

Throwing it Back:  
Our First Recognized

## Awareness Week!



In 2013, SCFC celebrated our first Sarcoma Cancer Awareness Week, held annually during the third week of June to bring national awareness to sarcoma cancers.

While our first Awareness Week was held in 2013, we and the sarcoma community took a collective giant step forward in 2014, as The Honourable Rona Ambrose, Minister of Health, officially marked and federally recognized Canada's Sarcoma Cancer Awareness Week. During this inaugural and official year the Minister visited with researchers, clinicians, sarcoma cancer patients, and survivors at the Ottawa Hospital Research Institute (OHRI). She was joined by Diana Arajs, Founder and Chair of SCFC, Dr. Jane Aubin, Chief Scientific Officer and Executive Vice-President, Research and Knowledge Translation, Canadian Institutes of Health Research (CIHR), Dr. Duncan Stewart, Chief Executive Officer and Scientific Director of OHRI, and Dr. Shailendra Verma, a medical oncologist and sarcoma expert at The Ottawa Hospital.

As part of the visit, the Minister announced funding of \$1.2M from CIHR to support a five-year research project on aveolar rhabdomyosarcoma, a type of sarcoma that affects children and adolescents, and most often occurs in the arms, legs and torso.

*"I applaud the Sarcoma Cancer Foundation of Canada for its ongoing work to raise awareness, promote research and support patients and their families. Our Government is pleased to support innovative research that will contribute to our shared goal of improving cancer treatment for Canadians."*

- The Honourable Rona Ambrose, 2014

## Patient Profile: Monique

I was in Orlando visiting my parents with my husband and our two sons in December 2015, when I realized something was not right.

I was 38 years old and was experiencing what I thought was an excessive menstrual cycle, only two weeks after my last one. This time was different though as I was passing clots and the flow was so bad one day that I couldn't leave the



bed. My gut told me something was wrong, but I didn't want to worry my husband, my kids or my parents. We returned from Disney and over the course of the next 6 weeks, I was rushed to the hospital via ambulance twice, received blood transfusions twice, received uterine artery embolization to minimize the bleeding and was hospitalized for almost 3 weeks total. On my first hospital visit they took a biopsy of a mass they thought was a fibroid and it was sent for a rush pathology.

It took almost 30 days before the pathology came back to confirm it was cancer. I was called in to the OB/GYN's office and before we could even sit down in our chairs, he announced "you have cancer, it is one I have never heard of before, and I don't even know how to pronounce it". He told us that the pathology was performed at the Mayo Clinic in Rochester, MN because they couldn't determine what kind of cancer it was in Manitoba, which is why it took so long to get the diagnosis. We were crushed. I had an Endocervical Fibroblastic Malignant Peripheral Nerve Sheath tumour (MPNST) , high-grade sarcoma, and it was classified as Stage IV.

I completed 20 sessions of pelvic radiation and underwent a radical hysterectomy. This was followed by intracavitary brachytherapy treatments. My pathology had good margins.

It wasn't until June 2019, three years later, after a routine CT scan, that I was told that the cancer had returned. This time it had metastasized to my left lung and there were three tumours. I was in shock. It caught us so far out of left field that my husband fainted in the appointment. After leaving to have some blood work done, we got called back to see the oncologist and he advised us that there was a research article that had been published a few months prior that described a woman with the same type of tumour as me, in a similar location, and how her tumour had tested positive for a NRTK gene fusion. He advised that there was a new drug, Vitrakvi (Larotrectinib), which had just been approved for use in Canada at the end of July that attacks these genes. We returned to his office and I signed the consent to test my tumour for the gene fusion and we waited.

Finally, on the Friday of Thanksgiving weekend, we got the news we were hoping for, my gene tested positive for the NRTK fusion and they were rushing me the medication and I would start on Tuesday. As for the delay in waiting for the results, I was told that I was the first in Canada to test positive under the new testing regime after the drug received its approval and that they had triple tested it to make sure they had the proper results.

Within a week of starting this new drug, my pain was significantly reduced, my energy was improved, and I was able to attend a Winnipeg Jets game with my family. After one month, my CT scans had showed shrinkage, I was completely weaned off my pain meds and by January my CT scan showed further shrinking. I went snowboarding with my kids for New Years and I was able to return to work on part-time basis mid January. Having my independence back and feeling well enough to return to work part-time is something that is very important to me.

In August of this year I had another PET scan, and I have 3 tumours that are still showing activity, the same three tumours that I originally started with. I just completed 15 sessions of radiation on my left lung. I continued to

work half-time through out my treatments. Work has given me an outlet for me and socialization, even though I have been working from home since March because of COVID.

I am grateful that cancer research continues to happen and that new drugs are being brought to the market so that patients like myself have choices and have hope. Four years ago, Vitrakvi wasn't an option for me. We need more drugs to be subsidized by the Health Canada and our provincial drug plans in order to make these kinds of drugs more accessible for cancer patients.

I never anticipated that at age 43, that I would be on this journey I am on and sometimes I can feel resentment, but it is never for very long. I can only control what I can control. Our boys are now 15.5 and 14 years old, and I want to continue to watch them grow. I have been with my husband for 25 years, married for 18 of those years, and I want to celebrate 25 more years together. Continuing cancer research and making new drugs accessible will be required in order to make that happen.

[Read Monique's Full Story on Our Website](#)

We'd love to hear from you - share your story through our social media platforms or by emailing us at [info@sarcomacancer.ca](mailto:info@sarcomacancer.ca)

## Holiday Fundraising

### Chocolate Holiday Fundraiser

We're selling Linda Lee Chocolate bars! Each delicious bar sold will help us fund patient care programs and critical research initiatives.

Orders will be delivered or shipped after sales close on Dec 11, and all orders from Toronto, the GTA and London are guaranteed to be delivered before Christmas.

[Order Yours Here!](#)



Donated by Linda Lee Chocolates

### CHOCOLATE FUNDRAISER

Proceeds support Sarcoma Cancer Foundation of Canada

**ORDER BY DEC 11 AT 10PM EST**

Each bar purchased will help fund patient support programs and critical research initiatives



Chocolate bars were generously donated by Linda Lee Chocolate! For more information on these unique and delicious bars, check out [lindaleechocolates.com](http://lindaleechocolates.com)

# Virtual Fundraising During COVID-19

COVID-19 is taking so much from us, but it is also giving us the opportunity to come together, work together, learn together and grow together. This crisis serves to illustrate the deep and interwoven connection between all human life.



This connection is something we at SCFC are honored to experience and witness continuously. This is no more obvious than through fundraisers. Although we aren't currently able to gather in person for events, we encourage you to leverage this opportunity to connect with your community virtually, in new and novel ways.

If you were already planning a fundraiser or event, consider converting it to a virtual fundraiser through a platform like Facebook Live rather than cancelling. Were you planning a gala? Virtual dinner parties are a great and fun alternative, and you can even include silent auctions and prize raffles. Get creative with online contests, giveaways, and incentive items that can be run completely in a virtual environment or delivered via mail delivery. If you want to get a little more physical, create a virtual run/walk where participants collect pledges and complete a physical challenge from home.

We encourage everyone to stay home, stay safe, but stay connected during this time. We believe that with your help we can lessen the impact of COVID-19 on our mission to support sarcoma patients and their families.

## Tips for Healthy Holiday Cooking

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 ways you can tweak your recipes to keep you and your family healthy over the holidays.



Chicken broth and fresh herbs are a delicious butter/margarine substitute for vegetables. Toss the vegetables with sauce made from chicken broth and herbs such as dill, basil, oregano, and



Adding horseradish and/or garlic to mashed potatoes gives you a very rich flavor. Fresh basil and other herbs also add a gourmet touch to this old holiday classic. Chicken broth can also



Cooking sweet potatoes in orange juice adds a natural sweetness and great flavor to these holiday favorites. Use a calcium fortified orange juice and you will add an important nutrient to this

thyme. Add a little marmalade to bring shine to your vegetables.



Try silken tofu in place of some, or all, of the cream cheese in dip recipes.

Silken tofu is low in saturated fat and adds a smooth creamy texture to dips.

take the place of whole milk in mashed pot.



Use applesauce instead of oil when baking cake and brownie recipes.

You'll cut down on calories without losing flavor or texture.

dish.



Sweeten winter squash with apple juice concentrate, light syrup, fruit preserves or maple syrup. Season with cinnamon, cloves and nutmeg.

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**Donate Today**

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