

OUR MISSION

Liposarcoma Support Network is committed to enhancing the survival and quality of life for people living with liposarcoma through patient-powered research, education and empowerment, and global advocacy efforts - guiding their journey toward a cure.



LETTER FROM THE EXECUTIVE DIRECTOR

Sara Rothschild, MPH

We are thrilled to introduce you to the Liposarcoma Support Network, a new program of The Life Raft Group, dedicated to providing support and creating awareness for the liposarcoma community.

Supporting Each Step, Empowering Every Patient

The Life Raft Group has a long history of supporting rare cancer communities, and this new initiative reflects the organization's commitment to expanding resources for underserved populations.

With the help of partners in the patient advocacy community, the LRG aims to broaden awareness of liposarcoma and foster collaboration across organizations to better meet the needs of patients.



Our mission is simple: to empower patients by providing them with the resources and support that they need to navigate their liposarcoma journey. Whether it's through patient education, personalized support, or patient advocacy, we are here to bridge the gap and empower individuals to make informed choices and navigate their journey with confidence.

Thanks to our dedicated team, volunteers, and donors, we are already making headway with the liposarcoma community. But this is just the beginning!

Stay tuned for more updates on our upcoming webinars and events, volunteer opportunities, and the impact we're making together.

Thank you for being a part of this exciting new chapter in patient & caregiver support!

With gratitude,

Sara Rothschild

GET INVOLVED!

As a supporter, you can help us create lasting change in many ways:

Donate

Your contributions can make a tangible difference. Every dollar helps us reach more in need.

Volunteer

Join our growing community of volunteers and lend your time and skills to our mission.

Spread the Word

Share with friends, family, and colleagues to help raise awareness.

RECLAIMING LIFE AFTER CANCER: MY JOURNEY AND HOW YOU CAN TOO

by Loretta Mostofi, Australia

In January 2023, I had a 4.1 kg dedifferentiated retroperitoneal liposarcoma removed from my stomach cavity, along with my right kidney. Now, almost two years post-surgery, I'm 51 years old and grateful every day to be here sharing my journey.

My symptoms included weight gain, bloating, stomach tightness, weak bladder, loss of appetite, and pain when lying on my stomach. I assumed it was menopause and tried various diets to lose weight, but I kept gaining despite eating less. Finally, after my sister urged me, I decided to get it checked.

The day I was diagnosed with cancer was the most surreal experience of my life. It felt impossible — cancer happened to other people, not me. I came from a family of longevity; my grandparents lived well into their late 90's. I'm a personal trainer, eat well and exercise regularly. How could I, of all people, end up here?

After hearing the news, I locked myself in my room, sobbing uncontrollably, feeling utterly alone. I didn't want to hear, "You've got this," or, "You're strong." All I felt was shock, fear, and overwhelming sadness. I didn't know if I'd need chemo, if I'd ever feel like myself again, or if my life was about to end. I felt like I was already mourning a life I hadn't even finished living.

I'm a practical person by nature, and once the initial shock wore off, I needed a plan. I wanted to record my journey, initially as a diary for my sons, because at that point, I was convinced I wouldn't survive. As a self-described "control freak,"

feeling so powerless was terrifying. My surgeon called my cancer "bad luck"—no link to genetics or lifestyle, just a random occurrence that made me question everything I'd believed about health and wellness.

The month leading up to my surgery the fear and helplessness was intense, especially at night, but I clung to what I could control. I kept going to the gym, using exercise as a way to prepare my body for the upcoming surgery and its aftermath. Exercise became my lifeline, a way to channel my fear into something tangible and constructive.



Cancer changed my perspective on fitness. Before, exercise was about aesthetics—sculpting my body and competing in figure competitions. In the brief time before surgery, my workouts became less about how I looked and more about preparing for the hardest battle of my life. Today, it's about reclaiming strength and preparing for whatever comes next, focusing on functionality and control.

Exercise has major benefits in cancer recovery. The American Cancer Society and the National Cancer Institute (1), report that exercise reduces inflammation, boosts energy, improves mental health, and helps manage weight—factors that may reduce recurrence risk. This journey now goes beyond physical health; it's about building mental and emotional resilience too.

“Cancer, for me, feels as though life tapped me on the shoulder, forcing me to look at the path I was on and take a different one. Before my diagnosis, I drifted through life, convinced I had all the time in the world. Cancer changed that.”

Emotionally, the journey has been even harder. Fear of recurrence looms large, especially given the high recurrence rates for dedifferentiated liposarcoma. The Cleveland Clinic (2) emphasizes that this cancer often returns even after complete removal.

This isn't just a statistic—it's a reality that I live with every day. Balancing fear with wellness and resilience is a constant effort. I focus on what I can control, practicing meditation, mindfulness, and breathing techniques to keep a positive mindset.

Early on, I began sharing my journey to cope and leave something meaningful behind. I quickly found that sharing wasn't just helping me; it was helping others who were also struggling. People began reaching out, sharing that they, too, felt lost and alone. This connection transformed everything—my story became a source of hope and guidance. Through social media, I found purpose as a "survival guide," offering tips, exercise routines, and wellness strategies.

Loretta's story continued on Page 3

Loretta's story continued from Page 2

In terms of nutrition, I didn't overhaul my diet drastically because I already ate well, and lifestyle wasn't the cause of my cancer. However, because liposarcomas start in fat cells, I decided to cut out anything that manipulated fat metabolism, like fat burners, and stopped using low-fat products. Today, I focus on nutrient-dense foods, prioritize hydration, especially for kidney health, and practice intuitive eating. I include the occasional cocktail or pizza because enjoying life is part of my healing.



Cancer, for me, feels as though life tapped me on the shoulder, forcing me to look at the path I was on and take a different one. Before my diagnosis, I drifted through life, convinced I had all the time in the world. Cancer changed that. Today, I live with intention, purpose, and a renewed excitement for the possibilities ahead.

If you're just starting this journey, remember you're not alone—support is out there. Feel your emotions, but know that cancer doesn't have to be the end of your story. I'm proof things can improve. Focus on what you can control, be kind to yourself, and prioritize self-care. Don't let fear or cancer hold you back from living the life you truly deserve.

Follow Loretta's journey
& wellness tips:



¹ American Cancer Society. Guideline for Diet and Physical Activity for Cancer Prevention. <https://www.cancer.org/>
National Cancer Institute. Physical Activity and Cancer. Available at: <https://www.cancer.gov/>
² "Liposarcoma." Cleveland Clinic, <https://my.clevelandclinic.org/health/diseases/21142-liposarcoma>.

FINDING HER VOICE: CARISSA'S JOURNEY WITH SARCOMA

When Carissa Wascher noticed a lump in her abdomen during her last semester of college, she didn't think much of it. At 23, she was busy balancing school, work, and her commute—tiredness and small health concerns felt normal.

"In October 2021, I woke up feeling this pressure in my abdomen," she recalls. "It felt like something was pushing upward. A week later, I felt it again, and this time I noticed a lump in my pelvic area. But I thought it was hormone-related because I have PCOS. I didn't think it was anything serious."

But the lump didn't go away.

An ultrasound suggested it was a fibroid, but when further tests revealed a mass filled with fluid, Carissa's doctors began to suspect something more serious. An MRI later confirmed a seven-inch tumor.

"The doctor told my mom it wasn't a fibroid, and it looked cancerous. I had surgery in December 2021 to remove the mass, but even after that, they couldn't figure out what type of cancer it was," Carissa says.



"For over a year, her medical team referred to it as an undifferentiated sarcoma. Then, after a second surgery at City of Hope, the tumor was reclassified as myxoid pleomorphic liposarcoma.

It was such a relief to finally have answers," she explains. "I think a lot of people underestimate how long it can take to get the right diagnosis with sarcoma. It took time, but finding a team that really understands sarcoma made all the difference."

Carissa's story continued on Page 4

Navigating Uncertainty

As someone who didn't even know what sarcoma was before her diagnosis, Carissa has spent the past two years not only navigating treatment but also educating herself about the disease.

"I didn't get to choose this," she says. "You just have to be strong. You have to go through treatment if you want to live. But it's not always a choice—it's just what you do."

Reflecting on her journey, Carissa says cancer has shaped her into a more resilient person.

"I bounce back more, mentally and physically, than I did before. I think it's made me resilient in ways I wasn't before. Of course, there are parts of myself I miss about who I was before cancer, and I know I'll never be her again. But I've grown a lot, and that's not all negative."

Support and Connection

Through it all, Carissa's mom has been her biggest supporter.

"My mom is my number one," she says. "She's been there for me throughout my entire treatment, at every scan and doctor's appointment. It's really important to have someone else there as a second set of ears because, as the patient, you miss things or forget questions. It's been so nice to have her by my side."

Carissa also found strength in connecting with others who understood her experience.

"There's this app called CancerBuddy—it's like social media for cancer patients. You can meet other people your age with similar diagnoses. It's been really important for me because it helps you feel less alone. It makes you realize there are people out there who 100% understand what you're going through."



Finding Joy in the Midst of Suffering

Early in her treatment, Carissa adopted the motto "joy in the midst of suffering."

"I would always see the word 'joy' in the most random places," she says. "It felt like a reminder that my circumstances don't determine my joy. I even started making bracelets with 'joy' on them and giving them to friends, family, and strangers. My faith has shown me that beauty and goodness can still exist, even in deep pain and suffering."

For Carissa, this perspective didn't come easily.

"I had a strong faith even before my diagnosis, but I never thought it was possible to feel joy in the middle of something so hard. It's been a process, but that reminder helps me wake up every morning and gives me a passion for life."

Pursuing Her Dreams

Despite everything she's faced, Carissa has continued pursuing her goals.

"I was still able to graduate college," she says. "I majored in Rehabilitation Sciences, and now I want to go to grad school for a doctorate in occupational therapy. I've worked with OTs after my surgeries, and I'd love to work in oncology and pediatrics."

Carissa is starting a new treatment soon—a pill therapy—and hopes it will give her the stability she needs to move forward with school.

"I never thought life would turn out this way," she says. "But I want to keep sharing my story, spreading awareness about liposarcoma, and pushing for better research and treatment options."

Carissa's journey is one of resilience, advocacy, and hope. Through it all, she's found a voice strong enough to inspire others and a sense of joy that remains unshaken, even in the midst of the hardest trials.

LIPOSARCOMA
SUPPORT NETWORK

PATIENT SUPPORT GROUP

4 Sessions | 6:00 PM ET
January 8, 22 & February 5, 19

For Members of the Liposarcoma Support Network
Max 10 Participants

bit.ly/LiposarcomaPatientSupportGroup

An illustration of a diverse group of seven people of various ages and ethnicities standing in a line, holding hands or arms, symbolizing support and community. They are set against a yellow background with a white sun-like shape behind them.

UPDATES FROM CTOS

CTOS is an annual meeting that brings together physicians and healthcare professionals, who specialize in sarcomas, from around the world, to discuss new developments, treatments and advancements in the field.

This November, we had the privilege of attending the Connective Tissue Oncology Society (CTOS) conference, an annual event that brings together sarcoma-focused medical professionals, advocates, pharmaceutical companies, and researchers to share the latest advancements and discoveries.

Representing The Life Raft Group and our new Liposarcoma Support Network (LSN) was Denise Evans (Senior Director of Data Management & Research), Christina Wang (Director, Liposarcoma Support Network), and Dr. Sydney Stern (Director, Giant Cell Tumor Programs).

The response to our expansion into liposarcoma advocacy was overwhelmingly positive, highlighting the critical unmet need for this effort.

We're excited to share a few highlights from the conference below.

1. Understanding Tumor Diversity

Not all liposarcoma tumors are alike and even areas within the same tumor may look very different. Researchers found that certain immune structures in low-grade areas (known as areas that are less aggressive) of tumors could improve responses to immune-based therapies, while high-grade areas (known as areas that are very aggressive) may resist these treatments. This highlights the importance of personalized care that considers the differences among areas of the tumor.

2. Better Surgical Outcomes Studies

This session emphasized that surgeries performed at high-volume sarcoma centers lead to better outcomes for patients. These centers are equipped with the expertise and resources needed for complex cases like retroperitoneal liposarcoma. Due to being high trafficked, these centers also tend to have more options like clinical trials.



3. Advancements in Drug Development

Promising clinical trials explored innovative drug combinations showing potential to improve tumor responses and duration of response time. While some trials face challenges with showing meaningful changes in patients survival, they lay the groundwork for future advancements and advocacy.

- **Brigimadlin (Brightline-1 Trial):** This investigational drug was tested as a first-line treatment for dedifferentiated liposarcoma (DDLPS). While it showed promising tumor shrinkage and stabilized disease in some patients, it did not outperform the current standard, doxorubicin, in preventing disease progression. Disease progression is often used as a measurement for overall survival (e.g., it's assumed that if patients don't progress in their disease, they will survive longer).

Therefore, it's unknown if this investigational drug would improve survival outcomes compared to doxorubicin. Advocacy can help ensure future trials and improve the design of the trial (e.g., if the trial was intended for patients who already received doxorubicin previously and needed a new option, it may work better in that population).

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Updates from CTOS continued from Page 5

- **Combination Therapies:** Trials combining MDM2 and CDK4/6 inhibitors demonstrated encouraging results for patients with advanced well-differentiated and dedifferentiated liposarcoma (WD/DD LPS). These therapies may offer new hope in targeting specific genetic pathways linked to liposarcoma.

These findings emphasize the importance of patient involvement in research and care. Be proactive—ask your doctor about emerging treatments, advocate for access to clinical trials, and stay connected with the Liposarcoma Support Network for updates, advocacy opportunities, and support. We're committed to keeping you informed about these advancements and how they could shape future treatment options.

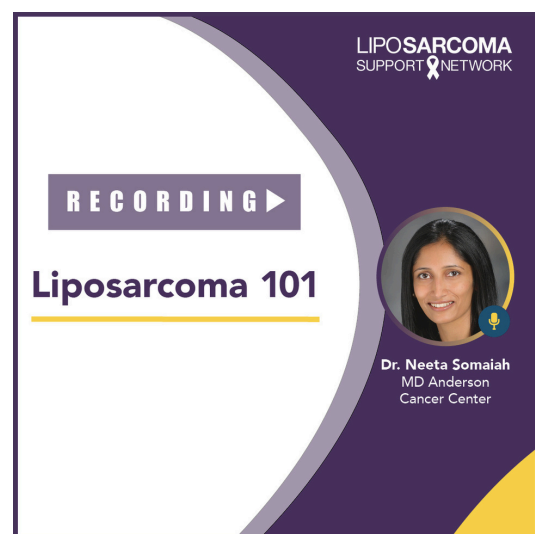
Email us with any questions: support@liposarcomasupport.org with any questions.

For a deeper dive on CTOS updates, check out Christina's takeaways:
bit.ly/CTOS2024LipoSummary



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