LIPOSARCOMA SUPPORT NETWORK

NEWSLETTER

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SEPTEMBER 2025 | VOLUME 3

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.

This newsletter is in loving memory of ***Carissa Marie Wascher.***

Carissa faced her myxoid pleomorphic liposarcoma diagnosis with grace, resilience and deep faith. Her remarkable strength and courage will continue to inspire us.

We hope that her story serves as a powerful reminder of the importance of the relentless need to push forward in the fight against this disease.

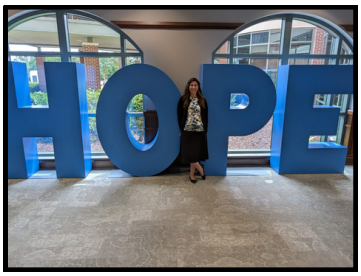
UPDATE FROM THE EXECUTIVE DIRECTOR

Sara Rothschild, MPH

Dear Friends,

I hope you are enjoying the start of the fall season! I'm writing to share a few exciting updates and milestones as we continue to push forward with purpose and passion.

Over the past few months, we've made great strides expanding our programs, deepening our partnerships, and reaching new members. Most notably, we hosted our very first Liposarcoma Medical Advisory Board meeting in conjunction with the American Society of Clinical Oncology (ASCO) Annual Meeting this past May. The meeting consisted of thoughtful discussions, strategic insight, and a shared sense of urgency and purpose among our Board members. It is clear that these clinicians are deeply committed to advancing care, treatment, and the understanding of liposarcoma.



This year, I have committed to meeting with doctors nationwide, including most recently, stops in Houston and Dallas, TX; Tampa, FL; Atlanta, GA; Baton Rouge, LA; San Diego, CA; Portland, OR; Salt Lake City, UT; Ann Arbor, MI; Birmingham, AL; and Baltimore, MD to raise awareness about liposarcoma. These conversations have not only opened doors for collaboration but also underscored how critical our work is in filling gaps in education, research, and patient support. Many clinicians shared their desire for better resources to guide patients, and they see our organization as a trusted ally in helping bridge that need. All of the physicians we met with expressed enthusiasm and appreciation that we are stepping up for the liposarcoma community.

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UPDATE FROM THE EXECUTIVE DIRECTOR

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We are working to formalize several of these relationships, laying the foundation for shared initiatives, clinical engagement, and expanded reach to ensure every liposarcoma patient receives the care and information they deserve.

Thank you to all of the physicians who generously took time to meet with the LSN team!

Last, but certainly not least, we are in the early stages of launching a patient registry dedicated to liposarcoma. This development is one of the most important steps we can take to drive progress in liposarcoma research and care. This will allow us to collect critical information about patients' diagnoses, treatments, outcomes, and experiences over time. This data can help researchers identify patterns, uncover unmet needs, and accelerate the development of better treatment options. It also gives patients a voice in shaping the future of care by ensuring that real-world experiences are reflected in the science. By creating this registry, we are laying the groundwork for smarter research, stronger advocacy, and ultimately, better outcomes for the liposarcoma community.

These accomplishments reflect the incredible work of our team, the dedication of our partners, and the unwavering support of individuals like you! As always, thank you for being part of our mission. Your engagement, feedback, and encouragement fuel everything we do. Let's keep moving forward—together.

With gratitude,

Sara Rothschild

REGISTER NOW

Life Fest is a unique event where patients and caregivers come together for a weekend to interact with each other and the medical and scientific communities that serve them.

Faced with a rare form of cancer, liposarcoma patients have a great need for information about this disease, particularly as the science evolves and our understanding reveals a complex set of subtypes of liposarcoma, each responding differently to available treatments. Each year brings a wealth of new information, and patients are eager to learn about the latest treatments.

Life Fest workshops provide patients and caregivers with emerging medical information. Participants leave with a stronger understanding of the disease, available treatments, and how to manage side effects. In addition to our traditional educational workshops, Life Fest 2026 will feature scientific presentations highlighting the newest research and the latest treatments.

The Liposarcoma Support Network emerged in recognition of the tremendous need for support in the liposarcoma community. Life Fest 2026 will provide liposarcoma patients and caregivers the opportunity to gather for the very first time. Coming together with fellow patients from around the world is a meaningful and powerful experience.

STRONGER TOGETHER: LSN MEDICAL ADVISORY BOARD UNITES AT ASCO

TOGETHER FOR PROGRESS, TOGETHER FOR PATIENTS

LIPOSARCOMA SUPPORT NETWORK

A Historic First Step: LSN Medical Advisory Board Holds Inaugural Meeting at ASCO 2025

CHICAGO, IL. We are honored and excited to share another significant milestone in the journey of the Liposarcoma Support Network: the LSN Medical Advisory Board (MAB) held its inaugural meeting on May 30th prior to the 2025 American Society of Clinical Oncology (ASCO) annual meeting in Chicago. This powerful moment officially launched our collaborative work with some of the leading minds in liposarcoma care and research.

L to R: *Dr. Mrinal Gounder, Memorial Sloan Kettering Cancer Center; Dr. Emily Jonzack, Sylvester Comprehensive Cancer Center; Dr. Inga-Marie Schaefer, Brigham and Women's Hospital; Sara Rothschild; Dr. Neeta Somaiah, MD Anderson Cancer Center; Dr. Sydney Stern, Director of TGCT Support*

Laying the Groundwork for Impact

This first meeting was the beginning of real, focused action for our community. Bringing together leading oncologists, surgeons, radiologists, and pathologists, we discussed research priorities, patient advocacy needs, and how best to ensure that LSN continues to serve as a reliable source of support and education for individuals and families affected by liposarcoma.

Setting the Stage for Progress

This meeting focused on establishing key goals and priorities for the year ahead, including (but not limited to):

- Clinical trials
- Consensus papers
- Opportunities for collaboration
- Patient education initiatives
- Urgent areas for research and advocacy

Building a Vision Together

The energy in the room was clear: each expert brought not only deep knowledge, but also a shared passion for changing the future of liposarcoma care. Their willingness to guide and partner with LSN represents an extraordinary step forward for our community.

SARAH HUNT: FINDING STRENGTH IN THE STRUGGLE

By Tara Ruggiero, LSN Program Coordinator

LIPOSARCOMA SUPPORT NETWORK

While checking for ticks during an eight-day, back-country canoe trip in Northern Ontario with her dad, celebrating the completion of graduate school, Sarah Hunt discovered something unexpected: a lump deep in her upper arm. She didn't panic. Assuming it was just a cyst, she made a mental note to mention it at her next doctor's appointment. A lifelong athlete and synchronized skater who had represented Canada on the world stage, Sarah was used to her body working hard and working well. Cancer was the last thing on her mind.

At age 29, the lump didn't go away. After several delays, multiple ultrasounds, an MRI, and the lump growth from the size of a pea to a 3-inch tumor, Sarah finally received her diagnosis: *myxoid liposarcoma*. This is a rare and aggressive soft tissue cancer, even rarer in the nerve bundle of the upper arm where hers was located. It was the day before her 30th birthday.

A New Reality

"I thought you did the treatments and then life went back to normal," Sarah recalls, "but I was kind of wrong."

> *"I didn't know what was ahead. I just knew I had to keep moving."*

Sarah underwent 25 rounds of radiation, followed by surgery to remove the tumor and then a second surgery to deal with healing complications. The radiation helped shrink the tumor to make surgery feasible, but also caused lasting damage: nerve pain, reduced mobility, and dystonia, a condition that requires regular Botox injections to manage painful spasms in her arm. Despite these challenges, Sarah considers herself a survivor, not because the cancer is gone, but because she continues to live fully and intentionally.

"I remember at a Young Adult Cancer Canada conference, they said 'you're a survivor from the moment you survive hearing you have cancer' and that stuck with me," Sarah shared.

The Hardest Part No One Talks About

About a year after treatment ended, Sarah hit an unexpected low.

"When you're in survival mode, you don't have time to feel. But when the dust settles, that's when it hits you." Her mental health became a major hurdle. "I felt isolated. No one around me had liposarcoma. I didn't know what was normal or what to expect. And no one warned me that this mental crash was coming."

It wasn't until she attended a patient conference and heard others share similar experiences that she began to feel less alone.

Reclaiming Purpose Through Action

Determined not to let cancer define her, Sarah decided to take part in Canada's Ride to Conquer Cancer, a 200+ km cycling event to raise funds for cancer research. Her dad had once said they couldn't do it because they didn't "have a story."

From that hospital bed, she turned to him and said, "Do you think we have a story now?"

They registered on the spot.

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SARAH HUNT: FINDING STRENGTH IN THE STRUGGLE

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Six months later, Sarah completed the ride, covering 220km (~137 miles) in two days. Over the years, she and her family have raised over $130,000 for sarcoma research.

Finding Her Voice as an Advocate

During COVID, Sarah discovered another calling: *advocacy*. She became involved with the Terry Fox Foundation in Canada—particularly meaningful to her since Terry Fox also battled sarcoma.

She trained at the Health eMatters conference by Myeloma Canada learning how to engage with government, the media, and the public. She even returned to the program as a keynote speaker.

"I don't think getting cancer was 'for a reason,'" Sarah said, "but I do believe no one else should have to go through it alone. That's why I speak up. That's why I share."

Where She Is Now

Today, Sarah runs her own speech-language pathology practice and continues her advocacy work nationally. She's eight years post-surgery and still deals with ongoing effects of treatment, including nerve pain and limited use of her arm. But she's also thriving; professionally, personally, and a support for others walking the same uncertain path.

Sarah's Advice to New Liposarcoma Patients:

- *Breathe.* "Don't panic. You've already survived hearing the words - start there."
- *Talk to your medical team.* "The internet doesn't always help with rare cancers like liposarcoma. Your doctors will."
- *Don't go at it alone.* "Find a support group. Advocate for one if it doesn't exist."
- *Watch for the crash.* "Mental health struggles can hit hard when treatment ends. Be ready and get support."

~ Sometimes it is the struggle that reveals just how strong we truly are. ~

CLINICAL PRESENTATION, MANAGEMENT AND OUTCOME OF 11,132 PATIENTS WITH LIPOSARCOMA PATIENTS: A POPULATION-BASED STUDY FROM THE NETSARC+ REGISTRY

Blay, Jean-Yves et al. The Lancet Regional Health – Europe, Volume 57, 101403 https://pubmed.ncbi.nlm.nih.gov/40799506/

Article Background: Liposarcomas (LPS) are among the most common sarcomas, but gather a diversity of rare to ultra rare molecular subtypes whose presentations and natural histories are partially characterized. The aim of the work was to describe the presentation and outcome of the different LPS histotypes from the NETSARC+ registry.

"In addition to enable a more accurate description of the natural history of rare subtypes, such very large data sets provide new and unexpected information such as the interaction of age and sex for epidemiology and outcome of liposarcomas."

- Professor Jean-Yves Blay

COMING SOON

Prof. Blay will be hosting a webinar to discuss his findings with the LSN community on November 4th at 11:00am ET!

Registration Information Available Soon!

LIPOSARCOMA UPDATES FROM ASCO ANNUAL MEETING

By Catherine Wilbur, MD & Christian Meyer, MD, PhD
The Sidney Kimmel Comprehensive Cancer Center, Johns Hopkins Hospital

LIPOSARCOMA SUPPORT NETWORK

Each year, the American Society of Clinical Oncology (ASCO) Annual Meeting offers the opportunity to share cutting-edge research, explore novel therapeutic strategies and engage in multidisciplinary collaboration. Importantly, this meeting fosters connections between patient advocates, clinicians, and researchers, accelerating the translation of scientific discoveries into clinical practice. This is particularly crucial for rare cancer types, such as liposarcoma.

Liposarcoma (LPS) is a rare cancer type originating from lipocytes or fat cells. It is one of the more common subtypes of sarcoma, accounting for about 20% of all sarcomas. LPS arises commonly in the abdominal/pelvic area or the extremities and trunk. There are multiple different subtypes of LPS, including well-differentiated, dedifferentiated, myxoid and pleomorphic. Well-differentiated liposarcoma (WDLPS) and dedifferentiated liposarcoma (DDLPS) are the most common subtypes. Standard of care for localized WDLPS and DDLPS includes wide surgical resection. Perioperative chemotherapy is an area of active investigation with the field and is considered for patients with DDLPS depending on the location of the tumor and risk of recurrence. Anthracycline-based chemotherapy is considered first-line treatment for patients with advanced, unresectable, or Stage IV (metastatic) DDLPS.

ASCO Annual Meeting 2025 brought us exciting new research findings and updates about liposarcoma.

1.Long-term follow-up of palbociclib for the treatment of WDLPS and DDLPS

Gene amplification of mouse double minute 2 (MDM2) and cyclin-dependent kinase 4 (CDK4) are present in nearly all well-differentiated liposarcomas (WDLPS) and dedifferentiated liposarcomas (DDLPS) and have become attractive therapeutic targets. Previously, two phase II clinical trials assessed the use of palbociclib, a CDK4 and CDK6 inhibitor, for the treatment of WDLPS and DDLPS. Due to the clinical activity of palbociclib for WDLPS and DDLPS, palbociclib is now listed in the National Comprehensive Cancer Network (NCCN) guidelines for treatment of these tumor types. The long-term follow-up of approximately 8.5 years from those clinical trials was presented. Palbociclib in advanced WDLPS and DDLPS demonstrated median progression-free survival (PFS) of approximately 18 weeks and median overall survival (OS) of 24–26 months. Patients with pure WDLPS had longer PFS, but OS did not differ significantly by subtype of LPS. This long-term follow-up shows that palbociclib was well tolerated and provides an alternative for patients who cannot tolerate standard chemotherapy. This data reaffirms the role of palbociclib in advanced WDLPS and DDLPS, though outcomes remain modest and highlight the need for novel treatment strategies.

2. New treatment strategy with low-dose combination chemotherapy and immunotherapy

In the setting of advanced or metastatic liposarcoma, chemotherapy is the primary treatment. Anthracycline-based chemotherapy, such as doxorubicin, is often used as first-line treatment. An alternative regimen utilizes the combination of gemcitabine and docetaxel. A phase II clinical trial investigated the combination of multiple chemotherapies, including gemcitabine, doxorubicin and docetaxel, in combination with an immunotherapy called nivolumab.

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The chemotherapy agents were given in lower doses than what is standardly given. The study enrolled 11 patients with liposarcoma and 30 patients with leiomyosarcoma, which is a cancer of smooth muscle. While only a limited number of patients with LPS were enrolled, the study showed promising results with approximately 20% of patients experiencing a decrease in size of their cancer and 87% of patients experiencing either a decrease or stability in the size of their tumors. The treatment was generally well-tolerated without unexpected side effects. Given the small number of liposarcoma patients in this trial, a larger clinical trial is needed to further investigate efficacy and safety, but this may be an effective treatment strategy in the future.

3. Further molecular insights for liposarcoma

Changes in DNA, called gene fusions, play a significant role in how cancer develops, grows and behaves. Researchers used a technique called RNA sequencing to identify these gene fusions in different subtypes of liposarcoma. Biopsy samples taken from 150 patients with liposarcoma were analyzed. The results confirmed the presence of known gene fusions and revealed new gene fusion hotspots. This study improves our understanding of how liposarcoma develops, increases our diagnostic accuracy, and may lead to more personalized treatments in the future.

4. Updates on current clinical trials enrolling patients with liposarcoma

Two national clinical trials are being conducted through the National Cancer Institute's (NCI) Experimental Therapeutics Clinical Trials Network and are enrolling patients with liposarcoma. The first clinical trial is entitled "Phase I/II study to evaluate the feasibility and efficacy of sequential abemaciclib and gemcitabine treatment in patients with retinoblastoma (Rb)-positive leiomyosarcoma (LMS) and dedifferentiated liposarcoma (DDLPS)." Eligible patients must have a protein called retinoblastoma (Rb) expressed in their tumor. The first part of the trial aims to find the best dose of abemaciclib, a CDK4 and CDK6 inhibitor, and gemcitabine, a standard chemotherapy agent, when given in combination. The second phase of the trial aims to determine how well abemaciclib and gemcitabine controls the cancer compared to standard chemotherapy with gemcitabine and docetaxel. The second clinical trial is entitled "Phase I study of peposertib and liposomal doxorubicin for advanced or metastatic leiomyosarcoma and other sarcomas". This trial is enrolling patients with advanced or metastatic DDLPS during the first portion of the clinical trial only. The trial is evaluating liposomal doxorubicin in combination with peposertib, a targeted therapy that blocks one way that cancer cells repair themselves after being damaged. The main goal of the study is to find the safest dose of peposertib that can be given with liposomal doxorubicin and to see if this combination could help control the cancer.

Overall, the findings from this year's ASCO Annual Meeting mark important steps forward in the fight against liposarcoma and bring hope for better treatments and brighter outcomes for patients living with liposarcoma.

TREATMENT OF DEDIFFERENTIATED LIPOSARCOMA IN THE ERA OF IMMUNOTHERAPY

LIPOSARCOMA SUPPORT NETWORK

DISCLAIMER: This is a plain language summary of this scientific article provided by Priyanka Reddy, Clinical Research Coordinator Associate at Stanford Medicine.

Understanding Dedifferentiated Liposarcoma

Liposarcoma is one of the most common forms of soft tissue sarcoma. There are different types, with well-differentiated liposarcoma (WDLPS) and de-differentiated liposarcoma (DDLPS) accounting for over 60% of all liposarcomas. WDLPS tends to be less aggressive with low risk of spreading, but it can sometimes turn into DDLPS which grows faster and may spread to other parts of the body.

Current Treatments

- Surgery and local radiation are the main treatments for WDLPS, as it does not respond well to chemotherapy.
- Chemotherapy can be used for DDLPS, but its effectiveness is limited with short duration. Common drugs include doxorubicin (or in combination with ifosfamide), gemcitabine (or in combination with docetaxel), trabectedin, eribulin, and pazopanib.
- Targeted therapy is being explored to block key cancer growth signals in both WDLPS and DDLPS.

Targeted Therapy

CDK4 and MDM2 are the two main genes that are amplified in WDLPS and DDLPS patients.

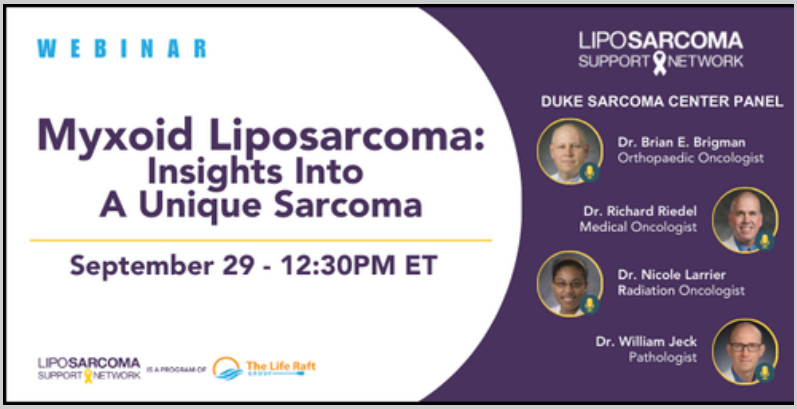
- **CDK4/6 Inhibitors:** These drugs slow cancer cell growth by blocking CDK4, a protein that helps cancer cells grow and divide. Clinical trials for palbociclib have shown to be effective in slowing progression for WDLPS and DDLPS patients and occasionally shrinking the tumor itself which is why it has become a recommended form of treatment. Another inhibitor currently undergoing clinical trials, abemaciclib, has shown promise that it may be more effective than palbociclib.
- **Immune Checkpoint Inhibitors:** These drugs help the immune system recognize and attack cancer cells. Clinical trial response rates for drugs like Pembrolizumab and Nivolumab have been limited for WDLPS and DDLPS patients but have shown activity. There have been additional laboratory studies which suggest that in combination with other drugs such as a CDK4/6 inhibitor, these immune checkpoint inhibitors may have enhanced efficacy. Still, further research is needed to determine the best biomarkers for WDLPS and DDLPS in order to develop more effective immune checkpoint inhibitors.
- **MDM2 Inhibitors:** These drugs target MDM2 which prevents the body from stopping cancer cell growth. Many clinical trials for these drugs are focused on other diseases, but there are several trials in their early stages, such as those for Milademetan and Brigimadlin, which have shown promising results for DDLPS.

Ongoing Research

While standard treatment for well-differentiated and de-differentiated liposarcoma remains limited, new targeted therapies are showing great promise. There are several ongoing and potential future clinical trials and research studies whose results are eagerly being anticipated for liposarcoma patients.

Zhou, Maggie Y., Nam Q. Bui, Gregory W. Charville, Kristen N. Ganjoo, and Minggui Pan. 2023. "Treatment of De-Differentiated Liposarcoma in the Era of Immunotherapy" International Journal of Molecular Sciences 24, no. 11: 9571. ***https://doi.org/10.3390/ijms24119571***

UPDATES



Join us for an expert-led discussion focused on Myxoid Liposarcoma, a rare and distinctive subtype of soft tissue sarcoma. More details and registration information provided here:

REGISTER NOW

Life Fest is a unique event where patients and caregivers come together for a weekend to interact with each other and the medical and scientific communities that serve them. More details and registration information provided here:

REGISTER NOW

VISIT LSN ONLINE

BECOME AN LSN MEMBER

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.

LIPOSARCOMA SUPPORT NETWORK

PATIENT SUPPORT GROUP

Click below to register for future support groups.

LIPOSARCOMA PATIENT SUPPORT GROUP

Follow us on social media for the latest updates & inspiring stories from our community: