

OUR MISSION

Liposarcoma Support Network is a patient-focused foundation 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.

SARC041: A PHASE 3 RANDOMIZED DOUBLE-BLIND STUDY OF ABEMACICLIB VS. PLACEBO IN PATIENTS WITH ADVANCED DEDIFFERENTIATED LIPOSARCOMA

ASCO, May 31, 2026:

Abemaciclib, a CDK4/6 targeted inhibitor, was shown to improve progression-free survival in people with advanced Dedifferentiated Liposarcoma (DDLPS), a highly aggressive cancer with few effective treatment options.

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UPDATE FROM OUR EXECUTIVE DIRECTOR

Sara Rothschild, MPH



Dear Friends,

As LSN approaches its two-year anniversary, I want to take a moment to reflect on what we've accomplished together and to share my gratitude for each of you who continue to make our mission possible.

We are constantly reminded of the power of this community. Through shared experiences, advocacy, education, and support, we continue to show up for one another and that commitment has made a real difference. Whether you engaged with our programs, shared your story, volunteered your time, or supported our work behind the scenes, you have helped move our mission forward in such meaningful ways.

We entered the year with strong momentum and a clear vision for growth including launching a patient registry to accelerate research, increasing membership to amplify the patient voice, and introducing new programs that provide education and support. While challenges remain, we are inspired by the progress that is possible when patients, caregivers, advocates, and researchers work together.

Thank you for believing in the Liposarcoma Support Network and our mission. We are deeply grateful for your trust, your voice, and your continued support.

With gratitude,

Sara Rothschild

Life Fest 2026

A Landmark Weekend of Connection, Education & Hope

by the LSN Staff

LIPOSARCOMA
SUPPORT  **NETWORK**

Life Fest 2026 was held in Nashville, Tennessee in July. This was the first of its kind - an in-person event dedicated to the liposarcoma community. The weekend was an extraordinary success, exemplifying the power of bringing people together to share experiences, learn from sarcoma experts, and build lasting connections that strengthen the community. Individuals traveled from around the globe to participate, providing many with their first opportunity to meet others, face-to-face, with the the same diagnosis.

Throughout the weekend, participants engaged in a variety of educational sessions designed to provide the latest information on disease management, treatment options, and emerging therapies. Patients and caregivers had the unique opportunity to hear directly from leading sarcoma experts, gaining valuable insights into current and emerging treatment options. The addition of scientific presentations highlighted the newest research developments and innovative therapies, further enhancing the educational experience, empowering attendees with knowledge and hope.

One of the most impactful aspects of Life Fest, was the opportunity for patients and caregivers to connect with others who truly understand their journey. These personal connections fostered encouragement, understanding, and shared strength. Attendees exchanged experiences, practical advice, and emotional support, creating bonds that will continue long after the event concluded.



As the event came to a close, participants left with more than just information, they left with renewed confidence, stronger support networks, lasting friendships, and a greater sense of hope for the future. Life Fest demonstrated that when a community comes together, remarkable things happen. The weekend served as a powerful reminder that no patient or caregiver faces this journey alone, and that through collaboration, education, and connection, we can continue making meaningful progress for the liposarcoma community.

Life Fest 2026 will be remembered not only for its educational excellence, but also for the extraordinary sense of unity, resilience, and hope that filled every session, conversation, and connection throughout the weekend.



We look forward to seeing you at Life Fest 2028!



Strength in Love: A Personal Caregiving Journey

by Lindsay Marsh, *Caregiver*

When my husband Darnell was diagnosed with liposarcoma in January 2022, he had just turned 34 and we had been married for less than 18 months. Cancer was not on our radar. A rare cancer was definitely not on our radar. I remember feeling like we had been dropped into a world where everyone else knew the language except us.

From the beginning, humor became one of the ways we survived the fear. We jokingly named Darnell's first tumor "DeAndre," because somehow giving it a name made it feel a little less terrifying. At the end of February 2022, DeAndre was removed. It was too large to weigh in the operating room, and we later learned it was 27 pounds. Darnell's surgeon, Dr. Malcolm Bilimoria, was able to remove it completely and save all of his organs. That outcome is something I will be grateful for forever.

What I will never forget are the 20 minutes I spent alone in a small hospital room waiting for Dr. Bilimoria to speak with me after surgery. Because of pandemic restrictions, it was one of the first times family members were allowed back in the hospital, and even then, access was still very limited. The surgery had gone much faster than expected, and in that waiting room, every possible version of our future ran through my mind. When Dr. Bilimoria arrived and began listing the organs he had been able to save, I realized something humbling: even though I work in healthcare consulting, I was still completely unprepared to know what questions I should have been asking.

"I also had to learn that caregiving is not only about doing. Sometimes it is about sitting in uncertainty, making room for fear, and still deciding what we are having for dinner."



After surgery, Darnell completed preventative chemotherapy, and then our lives became measured in three-month increments. Every CT scan brought anxiety. Every good scan felt like we could breathe again. For three years, we received good news. We let ourselves hope that maybe this would become a chapter we looked back on instead of one we were still living.

Then the cancer came back.

I remember how quickly the ground shifted under us. One scan changed the

tone of everything. The language changed. The questions changed. The way I listened in appointments changed. I became more aware of every pause, every word choice, every "we'll keep an eye on it."



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Recurrence brought a different kind of fear than the original diagnosis. The first time, everything was shock and urgency. The second time, I knew too much. I knew what surgery meant. I knew what waiting felt like. I knew how long the days between a scan and a result could be. I knew how easily a normal Tuesday could become the day everything changed again.

And because Darnell looks healthy, the experience can feel strangely invisible. He still looks like himself. He still makes jokes. He still goes to work, travels, and lives his life. To the outside world, he often looks fine. But caregivers know that “looking fine” and “being fine” are not the same thing.

That has been one of the hardest parts for me: learning to live in the space between gratitude and uncertainty. We are grateful for good care, grateful for slow growth, grateful for options, grateful for every good scan and every ordinary day. We are grateful to have each other. But we are also always aware that the next scan is coming.

My role as a caregiver has changed over time. At first, I was the person trying to organize appointments, understand terminology, take notes, and ask questions without falling apart. Over time, I became the keeper of timelines, scan dates, medication lists, insurance details, and the emotional temperature of our household.

I have become more comfortable over time with the term “caregiver,” but it still does not feel completely accurate. Lately, I have been using “care partner.”

I am still walking beside him through every scan, every setback, every leap forward, and

every uncertain stretch in between. We are in this together, even though our roles are different.

“What I wish more people understood is that caregivers live in the in-between. We are grateful and scared. Hopeful and exhausted. Strong and overwhelmed. We celebrate good news while bracing for the next scan. We want information, but not too much. We want support, but do not always know how to ask for it.”

My advice to a new caregiver is to write things down, ask the questions, accept help, and find doctors who understand rare cancers. Also, let yourself laugh. Humor does not mean you are not taking it seriously. Sometimes it is what helps you keep going.

For now, we continue to monitor closely with Darnell’s care team. We take things one scan, one appointment, one decision at a time. And in between, we try to live — really live — because if liposarcoma has taught us anything, it is that no time is promised.

Liposarcoma has changed our lives, but it has also shown us the power of research, specialized care, community, and love. 



The plenary at ASCO 2026 (Chicago, IL) featured **abemaciclib**, a targeted CDK4/6 inhibitor, as a *promising new therapy for advanced dedifferentiated liposarcoma (DDLPS)*.

Treatment options for recurrent or metastatic DDLPS remain limited. Surgery is common but DDLPS has a risk of recurrence and current approved drug treatments have not prevented or significantly delayed disease progression for prolonged periods.

Since tumor growth in DDLPS is driven by an overactive CDK4 gene, researchers tested abemaciclib to block CDK4 and hopefully lead to DDLPS stability or shrinkage.

The primary goal of this study was to determine whether abemaciclib could help patients have longer time between disease progression, calculated as progression-free survival (PFS).

How the Study Was Conducted

- Phase 3 clinical trial (SARC041)
- Randomized and double-blind (patients and researchers do not know who receives the drug vs. placebo)
- Conducted at 9 academic medical centers in the United States

Participant Requirements

A total of 108 patients with recurrent or metastatic DDLPS participated.

To join the study, patients had to:

- Have DDLPS that had returned or spread
- Show disease progression within the previous 6 months
- Have adequate overall health and organ function
- Have received any number of previous cancer treatments

NOTED TRIAL RESULTS

Versus placebo, abemaciclib:

- ✓ Delayed cancer progression
- ✓ Showed evidence of tumor shrinkage in some patients
- ✓ Showed a promising trend toward longer overall survival
- ✓ Maintained an acceptable safety profile

Key Results

1. Abemaciclib significantly extended PFS, where patients who received abemaciclib had 6x longer time without disease progression than those receiving the placebo.

- Specifically, patients receiving abemaciclib had: 9.67 months without progression longer than those on placebo (1.5 months)

The difference was both clinically meaningful and statistically significant, indicating the result was unlikely to be due to chance.

2. More tumor response with Abemaciclib was observed. Researchers measured how many patients experienced meaningful tumor shrinkage.

- 9.3% of patients receiving Abemaciclib had partial or complete shrinkage (response rate) compared to none with the placebo

Responses occurred only in the abemaciclib group.

3. Survival Results Were Encouraging

- The study duration has not been very long, meaning long-term follow-up is needed. Because of that, the overall survival for the abemaciclib group had not yet been reached, meaning most patients were still alive at the end of the data cut-off.
- The middle duration for overall survival for the placebo group was 25.45 months.

Many patients on abemaciclib were still alive when the study results were analyzed, while median overall survival in the placebo group was about 25 months.

4. Patients benefited after switching from placebo to abemaciclib. Patients whose cancer progressed on placebo were allowed to switch to abemaciclib, whereas:

- For patients that switched from the placebo to abemaciclib, on abemaciclib, they had 3.44 months longer without progression than the placebo.
- For patients that switched from placebo to abemaciclib, 4.3% of those patients had partial or complete shrinkage of their DDLPS
- **Median overall survival was 24.03 months**

This suggests abemaciclib can still provide benefit even after disease progression on placebo.

Safety Results:

- Rates of severe (grade 3 or higher) side effects were similar in both groups
- No unexpected safety concerns were identified
- No new safety signals were observed

Overall, the treatment was generally well tolerated.

What These Results Mean

This is one of the first studies to show a clear benefit from a targeted therapy in patients

with DDLPS. In patients with recurrent or metastatic DDLPS, abemaciclib significantly improved the time patients lived without disease progression.

The treatment was generally safe, produced some tumor responses, and showed encouraging signs of improving overall survival. And, based on these findings, the researchers concluded that abemaciclib should be considered a new treatment option for patients with dedifferentiated liposarcoma.

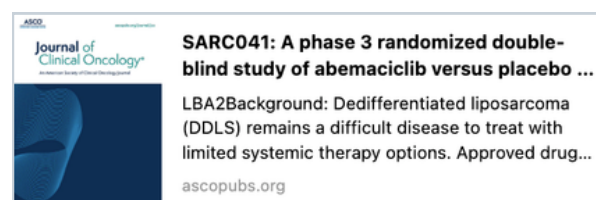


Next Steps

Researchers plan to further analyze the study results to better understand why abemaciclib is more effective for some patients with DDLPS than others.

They will also search for biomarkers (measurable characteristics in tumors or blood) that could help identify which patients are most likely to benefit from the treatment.

In addition, future studies may evaluate newer CDK4-targeting therapies to determine whether they can provide even greater or longer-lasting control of DDLPS.



VISIBILITY FOR A RARE CANCER COMMUNITY

Every July, Sarcoma Awareness Month brings patients, caregivers, advocates, researchers, and healthcare professionals together to shine a light on sarcoma. The month serves as an important opportunity to increase public understanding, encourage earlier diagnosis, advocate for research funding, and celebrate the strength and resilience of those affected by these diseases.

This year, awareness efforts featured a wide range of activities, including educational campaigns, patient stories, advocacy initiatives, fundraising events, and landmarks illuminated in yellow (the color of sarcoma awareness). Organizations around the world encouraged communities to participate in events such as the Wear Yellow Wednesday campaign, advocacy events, educational programs, and social media outreach designed to amplify awareness of sarcoma and its many subtypes.

For LSN and the broader liposarcoma community, Sarcoma Awareness Month provided a valuable platform to increase understanding of this rare soft tissue sarcoma. Throughout the month, LSN shared educational resources and personal stories to help patients and families feel connected and informed.

Highlights included:

- Sharing of patient experiences to help others navigate diagnosis, treatment, and survivorship.
- Educational campaigns focused on recognizing symptoms, understanding treatment options, and connecting patients with sarcoma specialists.
- Expanded outreach through social media, webinars, and advocacy efforts aimed at driving research and improving support resources for those living with liposarcoma.
- Greater recognition of the need for continued research into rare sarcoma subtypes, including liposarcoma, to develop more effective therapies and improve quality of life for patients.

While Sarcoma Awareness Month may have come to a close, the momentum continues. The awareness raised, stories shared, and advocacy efforts throughout July all contribute to a stronger and more connected sarcoma community.

For patients living with liposarcoma, this serves as a reminder that while this cancer may be rare no one has to face it alone. Through continued education, research, and advocacy, the community can move closer to earlier diagnoses, better treatments, and improved outcomes for all.



The Supportive Benefits of Palliative Care

by the LSN Staff

Living with a rare disease can bring physical, emotional, and practical challenges for patients and their loved ones. Palliative care can offer an additional layer of support through a patient-centered approach focused on enhancing comfort and quality of life through treatments and services that can manage and relieve symptoms for patients living with rare diseases, such as sarcoma. This approach focuses on reducing the burden of illness, which is why it is often referred to as *supportive care*, *symptom management*, or *supportive oncology*.

If you or a loved one has been diagnosed with a rare cancer and is referred to palliative care, it is important to understand that all palliative care is not the same as hospice.

What does it mean when my care team recommends palliative care?

Being referred to palliative care simply means that additional support is available to help manage symptoms, address concerns, and enhance quality of life throughout the cancer journey. **A referral to palliative care does not necessarily mean that a patient is in the final stage of their illness.** Palliative care can provide extra support at any time during an illness and may even be suggested at the time of diagnosis and/or alongside continuing cancer treatments.

The current palliative care model maintains that supportive care and pain management should be available to patients from the beginning, not to replace other forms of treatment, but as a supplement. A palliative care team collaborates with a patient's oncologists and other clinicians to offer relevant, ongoing support that is proactive rather than reactive.

Facts

ABOUT PALLIATIVE CARE

Extra support. Better quality of life. For you, alongside your care.



1 Palliative care may be offered at any point during a serious illness, including at diagnosis.



2 Palliative care is diverse and addresses physical, mental, social, and emotional symptoms.



3 The palliative care team does not replace existing care teams and commonly works together with them.



4 Palliative care does not subtract from existing treatment and can add extra support alongside anti-cancer interventions.



5 Palliative care can be given alongside sarcoma treatments.



6 Palliative care is not the same as hospice care.

What are palliative treatments that might be offered for support during treatment?

There are a number of interventions that could fall under the umbrella of palliative care for a patient with sarcoma, including:

Physical Symptom Relief

Some patients with sarcoma report a higher baseline symptom burden than other cancers and increased toxicity associated with some treatments can increase overall discomfort.

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Palliative care exists to reduce this burden, target the symptoms and any potential side effects from treatment.

✦ **Physical Symptoms.** There are many strategies to manage physical symptoms ranging from oral medication, surgery, and non-invasive tumor reduction (chemotherapy, palliative surgery, palliative radiotherapy or radiofrequency ablation). In addition, other examples of supportive care can combine medication management with non-pharmacological approaches such as physical therapy, massage, and relaxation techniques to increase comfort, function, and quality of life.

✦ **Treatment Side Effects and Other Cancer-related Symptoms.** Part of palliative care involves anticipating and mitigating other side effects and symptoms. Relief-focused strategies for medication use can involve pain relievers, anti-nausea medications, appetite stimulants, anti-anxiety medications, or other therapies designed to reduce symptoms, improve comfort, and support overall well-being. For example, working with a nutritionist can prevent weight loss due to cancer-related metabolic changes. Physical and occupational therapists can help maintain mobility. Addressing underlying contributors to fatigue, such as pain, sleep disturbances, medication side effects, can help improve energy levels and improve daily life.

Psychological and Emotional Support

Patients can experience a unique type of grief accompanying the loss of their daily lives and routines in the months following diagnosis and treatment, including anxiety, depression, fear, or emotional adjustment difficulties.

If you have experienced this, you are not alone. Thankfully, a palliative care team can help address this. Counseling, integrative medicine, creative therapy, and other interventions can all be leveraged to support a patient throughout their cancer journey.

In parallel, many palliative care programs encourage caregivers to use respite services (short-term relief of duties) early and throughout a treatment journey to help prevent burnout and maintain their own physical and emotional well-being.

Patients deserve relief at every stage of treatment.

While existing misconceptions of palliative care typically place the specialty in a small box, supportive care for sarcoma includes many possible interventions to help support patients throughout their cancer journey.

Patients are encouraged to ask their sarcoma team or a referring practitioner clarifying questions about palliative care options, what they can expect, and what measures might be integrated into their course of treatment.

For additional information, please refer to the sources below:

[Ewing Sarcoma and Palliative Care | Quality of Life | Get Palliative Care.](#)

[Mayo Clinic. Supportive Oncology: The Role of Palliative Care for People with Cancer.](#)

[Fred Hutch. Inside Sarcoma Care: New Therapies, Clinical Trials & Team-Based Treatment.](#)

[More Support, Fewer Symptoms: Palliative Care for Older Adults with Cancer | Dana-Farber.](#)

Reflections on Life Fest 2026

by Sara Rothschild, *Executive Director*

LIPOSARCOMA
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There was something really special about the inaugural Life Fest - Liposarcoma gathering that took place in July. Maybe it was the energy in the room. Maybe it was the way patients, loved ones, and physicians moved so naturally between conversations. Or maybe it was the feeling that, for one weekend, we weren't just talking about what it means to navigate a rare disease - we were navigating it together.

Friday evening set the tone. I had the chance to greet old friends and welcome new faces, and it was wonderful to see physicians mingling with patients in such a relaxed, social setting. These moments matter. They break down the distance that can sometimes exist between the person sitting in the exam room and the person sitting across the desk.



During Saturday morning's kickoff, our Board Chair, Gary Glasser, offered an analogy that stayed with me. Inspired by the FIFA World Cup and the power of Norway's fans rowing together in unison - that is The Life Raft Group (LRG) and Liposarcoma Support Network (LSN). We are all in the same life raft, and we move forward as we row together.

It isn't just patients and their loved ones who are in that raft. If you had the opportunity to engage with a sarcoma expert (and I hope all of you reading this have), you know that many of these physicians bring an extraordinary level of

passion and commitment to this community. They don't simply treat sarcoma. They care deeply about the people living with these diseases. They want to understand what patients are experiencing, what they need, and where the system is falling short.

They want to row with us.

You could feel that throughout the weekend. During the Q&A sessions, one patient would ask a question, one physician would respond, and another would build on that answer. The conversation became bigger than any one person or specialty. It was a powerful reminder of why communication and multidisciplinary care matter so much in rare disease. No single person has every answer. But when we bring the right people together, we can get much closer to finding them.



We also heard about new and promising treatments on the horizon. That matters. For a community that has spent decades fighting for more options, scientific progress is more than an abstract concept- it is possibility. It means there are new paths forward, new questions to ask, and, increasingly, more choices to consider. Life Fest is not only about treatments.

Patients spoke honestly about the importance of communication with their care teams, the stress of managing an unpredictable disease, and the toll that cancer can take not only on patients but on the people who love them. Those conversations are just as important as the scientific ones.

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A treatment plan exists in the context of a person's life. We cannot separate the disease from the human being living with it.

Several physicians told us they had never attended a meeting quite like Life Fest and that the conversations with patients stayed with them, not just as physicians, but on a deeply human level.

That is exactly why we do this. LSN's role in this community is unique. We bring people together who may otherwise never have the opportunity to sit in the same room - to connect patients and loved ones with the clinicians and researchers who are working to change the future of these diseases. We create a place where questions can be asked openly, experiences can be shared honestly, and knowledge can move in both directions.

To everyone who attended: thank you for showing up, asking questions, sharing your experiences, and helping move this community forward.

To those who were on the fence about attending in person, I encourage you to watch the recordings. You will learn a lot. I also want to say this: you will not get everything from a video.

There is something intangible about being in that room. It is the hug from someone who understands without needing an explanation. It is the physician who stays after a session to answer one more question. It is hearing another patient say something you thought only you were experiencing. It is the energy that builds when hundreds of people who understand the weight of this disease come together and realize they are not carrying it alone.

You can watch a presentation later. You can read the slides. You can catch up on the science.

But you cannot replicate that feeling.

Life Fest reminds us that we are not rowing alone. And when we row together - with patients, loved ones, and physicians pulling in the same direction - we can move this community somewhere new.

That is the role of the Liposarcoma Support Network of the The Life Raft Group: to bring the right people into the life raft, give them the tools and information to keep moving forward, and make sure no one has to row alone.



STC-15 (a METTL3 inhibitor) is a Phase 2 monotherapy trial investigating the safety, tolerability, and anti-tumor activity of STC-15 in participants with selected, advanced sarcomas subtypes, including DDLPS.

The **upLIFT study** is a Phase 3 clinical trial for patients suffering from low blood sugar related symptoms (hypoglycemia) due to the over-production of hormones (e.g., insulin or similar substances) by certain non-removable tumors.

The **SA53-OS Study** is a phase 1/2a, open-label, dose escalation study. The objective of this MDM2 inhibitor trial is to assess safety and efficacy in adult participants with refractory solid tumors, including dedifferentiated liposarcoma.

The **ATLAS (Actinium Therapy for Late-stage Aggressive Sarcomas) Study** is an open-label study evaluating the safety, tolerability, and efficacy of the radiopharmaceutical, [Ac-225]-RTX-2358 targeting fibroblast activation protein-α (FAP) in patients with relapsed or refractory soft tissue sarcomas.

The **SARATOGA study** is a Phase 2, multicenter, open-label study of lifileucel (tumor-infiltrating lymphocytes [TIL]) in participants with previously treated advanced soft tissue sarcoma.

The **EA7222 Study** is a Randomized Phase 3 Trial of Doxorubicin (chemotherapy) + Pembrolizumab (immunotherapy) vs. Doxorubicin (chemotherapy) alone for the treatment of dedifferentiated liposarcoma (DDLPS).

[CLICK HERE FOR MORE INFORMATION ON THESE
TRIALS AND OTHERS ON OUR WEBSITE](#)



Visit

[Life Fest 2026 Photo Gallery](#)

[Life Fest Highlight Video](#)

[Walk for Hope Video](#)

[Liposarcoma 101 presentation \(PDF\)](#)

by Dr. Breelyn Wilky,

University of Colorado Anschutz

Recordings of all presentations
will be available in September.



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SUPPORT GROUP**



Connect with fellow
liposarcoma patients in a
safe, supportive space.

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**CAREGIVER
SUPPORT GROUP**



Find support and
connection with other
liposarcoma caregivers.

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