

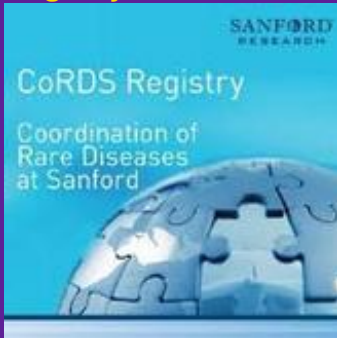


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LMSAlerts is an eNews service for families and professionals

JOIN the LMS Patient Registry with CORDS



New! **Awareness ribbons** for your events.

Wishing Working for the Cure

LMSarcoma Direct Research Foundation **LMSAlerts - November 2016**

undefined

'Tis the Season for Giving

How do you feel when you give toward LMS research? Joyful, fulfilled, hopeful? What could be more meaningful and heartfelt? *Please give generously this season to LMSdr to find a cure.*

There are lots of ways to give!



- Shop at [Amazon.Smile.com](#)
- Shop at [Giving Assistant](#)
- Ask your family and friends to donate in your honor in lieu of gifts
- Create a [Tribute Fund](#).
- Ask your employer for matching funds
- Promote us on [Giving Tuesday](#)
- Hold a [fundraiser](#)
- [Donate now](#)

Recent Fundraisers for LMS

Lemonade Stand for LMS



In honor of their grandmother, **Bernadette Hollis**, these children raised \$100 for LMS research. Bravo to **Shauna, Danny, Dylan and mom Amy Rovi**.

History of LMS

Paraffin Block Drive

[Video](#)

Participate in the Paraffin Block Drive for LMS Research



LMS patients have donated over 500 paraffin tissue blocks for research - please [join us](#) and build our tissue collection.

[DONATE NOW](#)

Shop & Donate!

Shop at
Smile.Amazon.com
and donate to
LMSdr

[NEW!](#)
[Videos of the 2016 LMS
Conference](#)

The 10/10 Club

On October 10th, these members asked 10 people for \$10 towards LMS research raising a total of \$2000.

Karen Trueman, Susan Titus, Barb Crews, Heidi Tate, Bonnie Haffajee, Jasmine Gilbreath Bonner, Mari Cinamon Miller, Vicki Hamrick Strong, Theresa Perales, Pamela Wheat Harrold, Debie Gurkin, Wendy Hyndman Christine Bruno and Lou Moan

Scavenger Hunt

In honor of Daryl Brown, daughter **Amy Brown Jubb** put some fun into fundraising, contributing \$2,600.



A heartfelt thanks to *everyone* who raised money this year by buying videos of the conference, organizing Art Auctions, Zumbathons, music concerts, tributes, T-shirt sales and more!

VOTES = \$10,000 for LMS RESEARCH!

Please vote every 24 hours for fellow LMS survivor and advocate Dr. Amy Reed and **help her win \$10,000 for her LMS research... it's EASY!**

[VOTE HERE](#)



Visit Our Website

LMSdr.org

Join Our

[FACEBOOK GROUP](#)



LMSdr T-shirts and
water bottles
available
[HERE](#)



Water bottles are BPA free, dishwasher safe, 30 oz. clear purple with gripper sides, easy to clean flip top cap.



T-shirts are unisex, preshrunk 50/50 cotton and polyester, color is blackberry. Sizes M, L, XXL.

Shop at Giving Assistant Stores!

The next time you shop online



Use Giving Assistant! They have 1600 stores including Target, Macy's, Groupon and more. With Giving Assistant, not only do you earn more cash back from your purchases, but you can easily donate your earnings to our LMSdr. Shop, earn, donate—all in one place.

[Shop online and donate to LMSdr](#)

Olaratumab + Doxorubicin Approved



On 10/19/16 the FDA approved olaratumab (Lartruvo) for soft-tissue sarcoma when used with doxorubicin (Adriamycin) as first-line treatment. This is the first “first-line” treatment approved for sarcoma in 40 years.

See [VIDEO](#) with Dr. Tapp discussing the benefits of

Read past issues of
[LMSeAlerts](#)

LMSdr advocates for and funds LMS specific research. We have been a nonprofit 501 (c) (3) since 2006. For details of our past grants, go to [LMSdr.org](#)

[Forward this message to a friend](#)

Review Us!

If you love our work, then tell the world! Please take 3 min to help us get Top-Rated status at Great Nonprofits by sharing your story. It's quick, easy & really helps us out. [Go here](#)

olaratumab.

Also see [VIDEO](#) of Dr. Mark Agulnik explaining benefits.

New Meta Study: Role of Adjuvant Chemo for ULMS Still Unclear

After a decade of debate, the effectiveness of adjuvant chemo for early stage ULMS was analyzed with a system review of all prior studies and meta-analysis. Findings are still unclear. Studies suggest a slight improvement in less distant metastasis but higher incident of local recurrence.

[READ MORE](#)

Current Immunotherapy Trials for Sarcomas!

Sarcoma specialist and researcher Dr. Robert Maki, of Mount Sinai Hospital in NY, explains the different types of immunotherapy trials in development. See the comprehensive list of the **current clinical trials for sarcomas** available using immunotherapy under each category.



[READ HERE](#)

Phase II Tivozanib Results

Out of 48 heavily pre-treated soft tissue sarcoma participants, 27 had LMS. Here are the responses of the 27 LMS patients at 16 weeks:

- 1 had partial response

- 14 had stable disease
- 12 had progressive disease

From Annals of Oncology Access published 10/22/16
Clinical Trial Information: NCT01782313

Immunotherapy patients/caregivers...

Are you an immunotherapy patient or caregiver? Participate in this conference **November 5th-6th in Philadelphia**. The Cancer Support Community will cover the cost travel, meals and lodging for volunteering to share your story and opinions. Get an overview in immunotherapy and advocacy training. [DETAILS](#)



Regorafenib Phase II Results

Another potential new drug for LMS! 56 LMS patients were in this international (France, Austria and Germany) phase II trial.

The median progression free survival for the LMS patients was 5.6 months with regorafenib vs 1.0 months with placebo. This [study](#) is ongoing but not currently recruiting new patients. [READ MORE](#)

What is



**CANCER
RESEARCH
INSTITUTE**

CRI offers free services to help you find the right immunotherapy clinical trial for you.

Search their data base at

cancerresearch.org/clinical-trials

or phone and speak to a trial navigator to search for you. **Call toll-free 1-855-216-0127**, M-F 8:30am to 6:00pm Eastern Time. Se habla español!

ClinicalTrials.gov

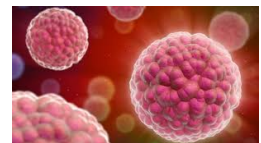
[Search for Trials](#)

New Immunotherapy Trial

MD Anderson Cancer Center announced its new phase II trial: [Immunotherapeutic Agents in Multiple Sarcoma Subtypes](#). This trial will combine two monoclonal antibodies: [Durvalumab](#) and [Tremelimumab](#). Enrollment is limited to 150 different types of sarcomas. Contact Somaiah at tel. 713-792-3626.

WATCH A WEBINAR - Immunology

Check out the recorded 30-minute webinars made for patients by the Cancer Research Institute (CRI.)



Sign up for new ones every month.

[Cancer Immunotherapy and You](#)

CD47 Studies Take Immunotherapy in New Direction

Onc. Live, Jane de Lartigue, PhD | October 31, 2016

During the past several decades, it has become increasingly clear that there is a complicated

relationship between a tumor and the patient's immune system. Although the genetic and epigenetic changes that fuel cancer development create foreign antigens that should trigger an immune response, one of the hallmarks of cancer is its ability to evade this immune recognition.

Read entire article [HERE](#)

New Scientific Advisory Member

LMSdr welcomes our newest Scientific Advisory Committee member! Dr. Gardner is an anatomical and clinical pathologist who specializes in bone and soft tissue sarcomas.



He trained under Dr. Sharon Weiss, a world renowned expert in bone and soft tissue sarcoma pathology. Currently, he is an Assistant Professor of Pathology and Dermatology at the University of Arkansas for Medical Sciences (UAMS) in Little Rock, Arkansas. Dr. Gardner is also a Deputy Editor-in-Chief of the Archives of Pathology & Laboratory Medicine.

Connective Tissue Oncology Society



November 9th-12th is the 2016 CTOS Conference in Lisbon, Portugal. This annual event brings together sarcoma researchers and specialists from around the world to connect and learn. CTOS was first organized in 1993 by a sarcoma patient who wanted all the

doctors meet each other and collaborate on a cure. Today, there are over 400 members, including patient advocacy groups, of which LMSdr is included.

At CTOS, researchers present their latest sarcoma discoveries and treatments.

LMSdr advocates attend CTOS every other year when hosted in the US. (LMSdr is very frugal with our research monies.) It's not only important for learning about new research, but to talk with these researchers and promote studies on LMS. We report the findings of LMS studies as soon as they are presented and then released.

ASCO's Patient Advocate Membership



The American Society of Clinical Oncology meets annually to present new cancer research. You can now be a member of ASCO for much less money as an "advocate." Membership allows you to get the presentations and papers earlier.

[See more benefits & join](#)

RARE DISEASE WEEK on CAPITOL HILL



Plan to join us for [Rare Disease Week on Capitol Hill](#), to be held February 27 through March 2, 2017, in Washington, DC. The week of events brings together rare-disease community members from across the

country to be educated on federal legislative issues, meet other advocates, and share their unique stories with legislators. There will be new members of the House and Senate next year, and it is critical for them to meet members of their communities affected by rare disease.

The EveryLife Foundation is now accepting applications for travel stipends! We awarded more than \$55k in stipends this year, and hope to enable even more advocates to join us in Washington, DC, next year. Patients, caregivers, and others in the rare disease community can [apply online](#). **The deadline to apply is December 18**, and all applicants will be notified in early January. Please note that stipends are limited to one per family, and attendance at the Legislative Conference and Lobby Day is required.

All events are free for patient advocates, and registration will open in early January.

P A T I E N T S T O R I E S

Can't travel to RARE DISEASE WEEK?
You can still advocate for LMS!

[Click here to submit your story to be hand-delivered to your Members of Congress](#). Please submit your patient story by February 12, 2017.

**LMSarcoma Direct Research Foundation is
a member of the Rare Foundation Alliance!**



VIDEOS! Rare Patient Advocacy Summit

LMSdr representatives Sharon Anderson, Sarah Robinson and Amy Regenstreif attended **The Rare Patient Advocate Summit** held on September 22-23, 2016, sponsored by Global Genes. 589 people attended, representing 173 rare diseases.

Now you, too, can virtually attend this conference by watching the recorded [VIDEOS!](#)

2016 LMSdr Conference Video


If you attended the LMSdr Conference in New Jersey/NY in April, the video of the presenters is now available! Email [Sharon](#) to get your **VIP code** to view the video [HERE](#).



For those who did not attend, if you make a donation toward LMS research [HERE](#) you will receive the video as our thank you gift!

(photo: Drs. D'Angelo, Tap and Hensley at LMSdr Conference)

STARTRK-2 TRIAL

 **IGNYTA** Looking for new options? Have your doctor [order this free test](#) to see if you have the gene rearrangement that might respond to the new drug Entrectinib by Ignyta.

Anlotinib for LMS?

[Phase 2 study](#) from China shows promising efficacy for

LMS. The study included a range of soft tissue sarcoma subtypes. 15.66% (26 patients) had LMS. Of those LMS patients, 69.2% were progression-free at 12 weeks. The median progression-free survival rate was 11.7 months for LMS patients.

Alisertib Offers Stability for LMS

10 LMS patients in the [phase 2 trial for Alisertib](#) had 11.7 weeks of PFS (progression-free survival) but no response in tumor reduction.



Memorial Sloan Kettering
Cancer Center.

Chaos Theory: Understanding the Genetic Chaos of Soft Tissue Sarcoma

A growing understanding of these mutations may lead to new treatments. [Cure Today](#)



CURE Wants Your Story



Cure Magazine is looking for stories from cancer patients. [Share Your Story](#)

TAPUR TRIAL PODCAST

Innovations in
Precision Medicine
Introduced at
ASCO 2015

By Lynne Lederman, PhD



In 2016, the American Society of Clinical Oncology (ASCO) launched its first clinical trial. The [Targeted Agent and Profiling Utilization Registry \(TAPUR\) Study](#) is designed to help doctors learn more about targeted drugs in people with

later-stage cancer.

[PODCAST](#) Learn more basics on TAPUR **[HERE](#)**

NCI's MATCH TRIAL

NCI - Molecular Analysis for Therapy Choice (MATCH) is similar to the ASCO TAPUR Trial. Both look at the genetics of your tumor and try to match it to drugs on the market. **[LEARN MORE](#)** about NCI's MATCH TRIAL.

[ENROLL NOW](#)



Title: Constant. This painting describes that constant feeling of the pit in your stomach, threatening cloud overhead and everyday feeling of "ugh" from being diagnosed with LMS.

Help raise \$500 for LMS research by voting every 10 days for this painting by 14-year survivor Sharon Anderson. [Vote Here](#)

Sponsored by the Rare Disease Foundation 2016.

LMSdr Top-Rated Nonprofit Award!

Thanks to our fans, we are one of the first winners of a 2016 Top-Rated Award from GreatNonprofits!



T-SHIRT SALE!



Only \$15 (includes shipping)

Sizes left: M, L, XL

Shirts are unisex in a preshrunk 50/50 blend of cotton and polyester. Color is "blackberry."

Make great gifts!

[ORDER](#)

Add a notation with your NAME, ADDRESS, TEL, EMAIL (and please include SIZE).

Sale! DVDs of 2014 LMS Conference

Watch impressive speakers discuss LMS at the 2014 Conference in San Francisco. **Set of 4 DVDs only \$50!**

Speakers discuss the most updated information and treatment options for LMS, complementary therapies, our sponsored research projects at Stanford, interventional radiation techniques for LMS, coping strategies and much more.



CELEBRATE YOUR SURVIVORSHIP!



Hand out ribbons to family and friends to celebrate your anniversary or birthday. Ribbons are free and have a business card attached to each one on how to donate to support LMS research. It's an easy fundraiser in honor of your battle. **Email Heidi to order!**

Here's to another year!

Milica Stefanovic, 10-Year Thriver

No Recurrence

In 2006, my doctor advised me to have a hysterectomy. I was insisting on removing the tumor only, not knowing that it was LMS. It was stage I, high grade ULMS. The mitotic count was 10/10, it was poorly differentiated and measured 9 cm. It also tested



with a high percentage for hormone sensitivity.

After the initial surgery, I had radiation therapy, which I believe kept the tumor from spreading. I followed with taking Femara (letrozole) for one year. I stopped Femara because of side-effects. My doctor wasn't so excited about that decision. But I wanted to save it for later if cancer returns.

I've never had a recurrence – I have been NED since.

I wouldn't do anything differently. The “watch and wait” approach could be risky for this stubborn disease. Even for stage I, I believe adjuvant therapy is needed.

I also believe improving insulin sensitivity (or reversing insulin resistance) is critical for this type of cancer. I keep blood sugar stable with several small snacks during a day. I also take chromium (100 mcg before every meal). Vitamin D3, and C with magnesium, B12 and selenium. I think this is what has kept me NED so far.

Have you survived with leiomyosarcoma for 7 years or more? Want to share your story and pass the hope forward to those who need it? Contact Sharon 2SharonAnderson@gmail.com



When you buy online via [Smile.Amazon.Com](https://www.smile.amazon.com) you can designate a percentage of the proceeds to

LMSarcoma Direct Research Foundation

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