

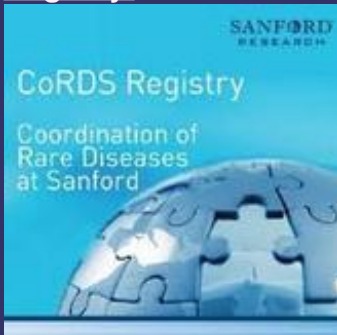


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LMSAlerts is an eNews service for families and professionals

JOIN the LMS Patient Registry with CORDS



New! Awareness ribbons for your events.

Working not Wishing for the Cure

LMSarcoma Direct Research Foundation LMSeAlerts - March 2016

undefined

REGISTER! April 7th-9th LMS CONFERENCE



Come laugh, get educated and connect with others in NEW YORK! Read all details and how to register [HERE](#).

--- Program Highlights ---

4/7 Reception dinner with our own Amy Regenstreif's one woman show, introductions and a light dinner buffet.

4/8 & 4/9 Presentations:

- Dr. William Tap, "What's New? LMS Treatments and Trials." Dr. Tap is the Chief of the Sarcoma Program at Sloan Kettering.
- Dr. Martee Hensley, "Uterine LMS." What do we know about ULMS, hormone therapies and response to other treatments?
- Dr. Sandra D'Angelo, "Immunology 101 and LMS." How can our immune systems learn to fight LMS? What are the current immunology trials for LMS and how do they work?
- Dr. Ting Bao, "Integrative Oncology." Can complimentary therapies help cure LMS?

History of LMS Paraffin Block Drive

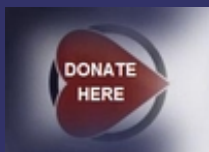
[Video](#)

Participate in the Paraffin Block Drive for LMS Research



LMS patients have donated over 500 primary 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

[Buy DVDs](#) of the 2014
LMS Retreat

- Dr. Majid Maybody, "Interventional Radiology for LMS." What is cyber knife, RFA, embolization and more? Learn how they can help destroy tumors.
- Dr. Matt van de Rijn MD, "LMS Research Projects Update."
- Angel Van Veldhuizen RN, "LMS Patient Registry."
- Sarah Green, "Sarcoma Inquiry Network Project."
- Donnalyn Giegerich, Emcee, motivational speaker and LMS survivor.

HURRY! Deadline March 7th for Hotel Room

We got an incredible group rate (for the NY area) from the Sheraton for \$189 for a single or double occupancy for April 7 & 8th! In addition, there are a few extra



reservations available for the evenings of 4/6 and 4/9 if you want to stay extra. You can cancel up to the day before. You must make your reservation by **March 7th**.

[See details here](#)

Deadline for conference registration is March 27th.

Conference is fully refundable until 10 days before the start April 7th.

Put Your Heart Into It

TIME TO BID! LMS Patients and caregivers have donated their artwork! Art Auction ends April 7th. Give generously, all donations go to support LMS research. Post on your Face Book page and send the link out. Details on [ART Auction](#) page.

Presentations

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,



Olaratumab + Doxorubicin Extends Survival



The addition of adding olaratumab to doxorubicin extends survival one year in patients with advanced soft tissue sarcomas according to results for a phase II trial. This monoclonal antibody is being now tested in a phase III study and has received an FDA

Breakthrough Therapy Designation. According to Dr. Willaim Tap, the of the sarcoma program at Memorial Sloan Kettering, "It's a very nontoxic drug." Researchers are excited to potentially add olaratumab with other chemo agents.

[See phase III trial](#)

Send Your Prayer Flags



A tradition at our LMS Retreats, we make and hang prayer flags to carry our well-wishes on the wind and bring us happiness, hope, health and strength. If you'd like to make your own to

XXL.

Read past issues of
[LMSeAlerts](#)

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

[Forward this message to a friend](#)

be displayed at the conference, please see directions on the [LMS Conference website](#).



TAPUR TRIAL UPDATE

ASCO's Targeted Agent and Profiling Utilization Registry (TAPUR) Study

OPENS MARCH 14th. This trial will profile your tumor and attempt to match it to drugs already approved by the FDA. The object of this study

is find how effective the drug is for your specific tumor indicated the profiling. This trial is free. You do not need to get approval from your insurance.

[FAQ HERE](#)



NCI-MATCH TRIAL

NCI-Molecular Analysis for Therapy

Choice (NCI-MATCH) is a [clinical trial](#) that analyzes patients' tumors to determine whether they contain genetic abnormalities for which a targeted drug exists (that is, "actionable mutations") and assigns

treatment based on the abnormality. NCI-MATCH seeks to determine whether treating cancers according to their molecular abnormalities will show evidence of effectiveness.

The logo for the National Cancer Institute, featuring the words 'NATIONAL CANCER INSTITUTE' in white serif font on a red square background.

NATIONAL
CANCER
INSTITUTE

STARTRK-2 Study Open



IGNYTA[®]

Ignyta Inc. based in San Diego, California has just opened their Phase II trial testing their drug

[Entrectinib](#) that targets the gene translocations of NTRK, ROS-1 and ALK. It's estimated that 1 in 20 LMS patients will have these gene rearrangements. Ignyta will work with your oncologist to test your tumor tissue to determine if you have these gene alterations to qualify for the trial. It's offered at 30 sites in the US. See [trial protocol](#). Contact Lisa Schecht t. 858-332-0785 lschechet@ignyta.com

TP53 and ATRX Common Mutations in LMS

Targeted next-generation sequencing of cancer genes identifies p53 and ATRX pathways being the main mechanisms for leiomyosarcomas.

[Am J Transl Res](#). 2015 Oct 15;7(10):2072-81

EPIC Adventure Camps



Time to apply for [Epic's free week-long summer camps](#) - for cancer patients who have been diagnosed at any time in their life.

Free Camp for Children of Cancer Patients



[Camp Kesem](#) is the only summer camp to support children through their parents' cancer and beyond. Many LMS families have highly recommended this FREE life-changing opportunity!

LMS Tumor Symptoms Paid Interviews



Norartis is conducting a survey about LMS tumor symptoms. IF you have LMS tumor related symptoms, not currently on chemo, and would be willing to complete a questionnaire and phone interview - you'll get \$25. Call Sonya Stringer 1-800-242-2196 or email STS@evidera.com

Help researchers help us!

ACTION ALERT - Please help

LMSdr has been a supporter of the Congress's 21st Century Cures Initiative and its companion legislation in the Senate. The OPEN ACT, a bipartisan legislation that could double the number of treatments available to rare disease patients, has been left off the list. [We are urging advocates to contact their representatives in the House and the Senate to ask that they step-up for rare disease patients and co-sponsor the OPEN ACT.](#)



Dana Farber Opens New Anti-PD1 Trial

Nivolumab is an agent considered an "immunotherapy" which by blocking certain check-points in the immune system, aims to activate the immune system in hopes to control the cancer. This agent has shown benefit in other cancer types, but has not yet been studied in leiomyosarcoma. Enrollment will be 12 to 37 participants. ClinicalTrials.gov Identifier: [NCT02428192](#)

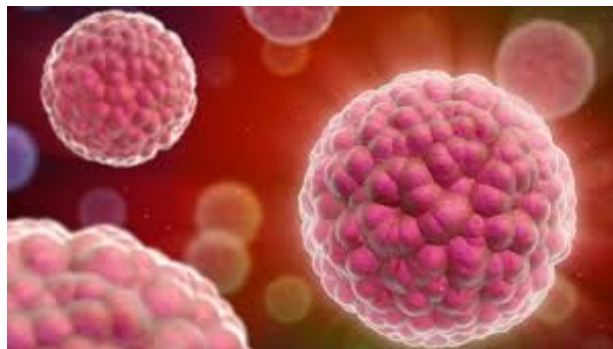
Contact Melissa Hohos 617-632-5204 or
Mark Morley 617-632-3989

Pembrolizumab Anti-PD1 Trial Re-Opens And more sites coming soon!

[A Phase II Study of the Anti-PD1 Antibody Pembrolizumab \(MK-3475\) in Patients With Advanced Sarcomas](#)

Immunotherapy Explained

This video has an excellent illustration of how the above Anti-PD1 antibodies help "tag" cancer cells so that your immune system will attack them. [Watch video](#)



[Listen to this podcast »](#)

Learn about **key research definitions**, categories of cancer studies, and tips for finding medical journals.

Create a Living Legacy Video



[Thru My Eyes](#) is a nationwide organization whose mission is to give individuals living with a life-threatening illness the ability to create a living legacy. Video recordings are done in the privacy of one's home at no cost and can be either in-person or via Skype, all with professional videographers and volunteer therapists to

ensure the highest quality video legacy. Bilingual services are available in Spanish, French, and Hebrew. For more information, contact info@thrumyeyes.org or call [914-725-1836](tel:914-725-1836).

Free Advocate Help



Solving Insurance and Healthcare Access Problems | since 1996

Do you need someone to help you battle your insurance? Need help with your medical debts or prescription co-pays? [The Patient Advocate Foundation](http://www.patientadvocatefoundation.org) offers free caseworkers, live chats and webinars for patients. Call them at (800) 532-5274.

T-SHIRT SALE!



Only \$15 (includes shipping)

Sizes left: M, L, XL, XXL

Shirts are unisex with a preshrunk 50/50 blend of cotton

and polyester. Color is "blackberry."

Makes great gifts!

ORDER through the [Donate Now](#) web page.
**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, complimentary therapies, our sponsored research projects at Stanford, interventional radiation techniques for LMS, coping strategies and much more... buy [HERE](#).



CELEBRATE YOUR SURVIVORSHIP!



Give 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!

11 year Thriver, Lisa Smith

Living with LMS

In 2005, at age 40, I got the ULMS diagnosis after a partial hysterectomy.

Every three years I've had a recurrence:



- 2008 near the remaining ovary. I had surgery followed by 6 rounds of Adriamycin;

- 2011 in pelvis and had cyber knife;
- 2014 near bladder and another wrapping around ureter. I got a ureter stent and 11 rounds gem/tax. I develop fistula between intestine and ureter due to damaged weak tissue from prior cyber knife. I started Temodar in February 2015.

So many times I thought this is it, I will keep getting worse and then die. But each time I got better and had years and now months of quality life. Don't fall into despair and give up. I've lived to see my 3 daughters grow to adulthood and to meet my grandsons. Remember to keep living with cancer not dying from it.

When I had periods of depression. Getting out into the sunshine, meditation and my gratitude journal got me out of it. I exercise and eat a vegan diet. Working and being around people helps a lot. I became an animal advocate and volunteer for a farmed animal sanctuary. This was the gift that cancer gave me. Focused on helping, not on myself and cancer.

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

Shop for the Cause

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

Shop Now!

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