

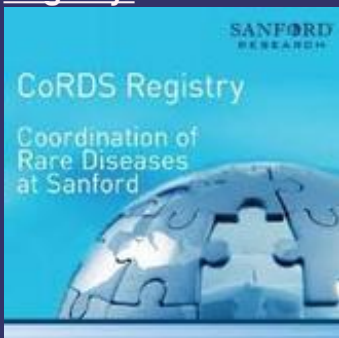


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LMSAlerts is an eNews service for families and professionals

**JOIN the LMS Patient Registry** with CORDS



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

## Working not Wishing for the Cure

### LMSarcoma Direct Research Foundation LMSeAlerts - July 2016

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#### American Society of Clinical Oncology



Every June, oncologists from around the world meet and present their latest research to each other. This year, ASCO declared immunotherapy as the most significant [clinical advance of the year](#). Immunotherapy is also called biologic therapy and is a cancer treatment designed to boost the body's natural defenses to fight cancer in the body. Two main strategies are now being explored, and both have achieved major successes over the past year. The first strategy involves unleashing the body's natural immune response to cancer. The second helps the immune system find and destroy cancer cells. Although exciting advances have been made, research will focus on making these benefits extend to more and more patients. Scientists are also exploring how they can predict who will respond best to certain immunotherapy regimens.

#### LMS and immunotherapy abstracts from ASCO:

[Anti-PD1 therapy with nivolumab in sarcoma.](#)

[Safety and efficacy of PD-1 blockade using pembrolizumab in patients with advanced soft tissue \(STS\) and bone sarcomas \(BS\): Results of SARC028—A multicenter phase II study.](#)

## History of LMS Paraffin Block Drive

[Video](#)

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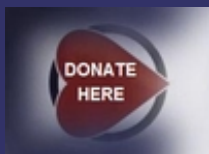
## Participate in the Paraffin Block Drive for LMS Research



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

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Shop at  
[SMILE.Amazon.com](#)  
and donate to  
LMSdr

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

## Clinical Trials with immunotherapy open to LMS or solid tumors:

[Phase I Safety Study of MGA271 in Combination With Pembrolizumab in Refractory Cancer](#)

[Study of REGN2810 \(Anti-PD-1\) in Patients With Advanced Malignancies](#)

[Study to Evaluate MEDI0562 in Combination With Immune Therapeutic Agents in Adult Subjects With Advanced Solid Tumors](#)

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## URGENT - Call Your Representatives!

Contact your [Representatives](#) and urge them to support HR5404 **Medical Device Safety Bill.**



Without support, this bill will die in the House of Representatives. This bill strengthens federal requirements for hospitals and device manufacturers to report adverse outcomes caused by medical devices like the power morcellator.

In the case of the morcellator, the FDA said they received no reports of it spreading uterine LMS until Drs. Noorchasm and Reed reported it in Dec. 2013. Such a bill could potentially save lives.

The LMS community has fought hard to get this bill sponsored - please do your part to help!

[VIDEO](#)

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**July 15th - LMS Awareness Day!**

## Presentations

Visit Our Website

[LMSdr.org](http://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,



We have declared the 15th for LMS in July, the sarcoma awareness month. This is the day to give out ribbons and cards to let your friends and family know how they can support you by making a donation for LMS research. The goal is to raise \$100 each.

Order your ribbons/cards from Heidi

[HeidiHarlin@gmail.com](mailto:HeidiHarlin@gmail.com) Send us photos of your events!

## 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 others, if you make a donation towards LMS research [HERE](#) you will receive the video as our thank you gift!

(photo: Dr. Martee Hensley at LMSdr Conference )

## LMS Blood Drive a Success!

The LMS blood drive has been a success with over 167 samples collected for the circulating DNA research project. This project by Drs. Kristen Ganjoo and Matt van de Rijn



XXL.

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Read past issues of  
[LMSeAlerts](#)

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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](#)

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at Stanford, hopes to identify when a treatment is working or not, by looking for tumor DNA in the blood. This could potentially help patients long before they get their next CT scan. A second goal is to be able to tell if a uterine fibroid is a leiomyosarcoma tumor with a blood test. Thank you LMS blood donors!

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### **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](#)

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### **Anlotinib for LMS?**

News from ASCO! [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 was 11.7 months for LMS.

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### **Nivolumab Fails with ULMS**

[Phase 2 study of nivolumab in metastatic leiomyosarcoma of the uterus.](#)

**Conclusions:** Nivolumab as a single agent failed to



demonstrate antitumor activity among ULMS pts without any biomarker selection. The study is currently being amended to explore combination treatment with nivolumab among pts with metastatic ULMS. Clinical trial information: [NCT02428192](https://clinicaltrials.gov/ct2/show/study/NCT02428192)

### Tell Your Friends!

**zumbathon**<sup>®</sup>  
MAKE EVERY MOVE COUNT  
**CHARITY EVENT**  
Let's Party For A Great Cause

**LMSARCOMA**  
DIRECT RESEARCH

LMSarcoma Direct Research funds research for Leiomyosarcoma a rare and aggressive cancer.

**July 10th 2016**  
9:00am - 11:00am  
Hips & Salsa Fitness  
3911 Amboy Road Staten Island, NY 10308  
**\$20 Admission Fee** Free Refreshments - Raffle Sales - Post Class Mingling

All proceeds will be donated to LMSarcoma Direct Research. For tickets, donations, volunteering, and more information, contact: 917-848-6104 or via email at [lmsawareness@hotmail.com](mailto:lmsawareness@hotmail.com)

*No One Fights Alone*

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### 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!

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## 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](mailto:info@thrumyeyes.org) or call [914-725-1836](tel:914-725-1836).

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T-SHIRT SALE!



Only \$15 (includes shipping)

**Sizes left: M, L, XL**

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).**

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### **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](#).



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**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!**

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### **10 Year Thriver, Melody Yamaguchi**

My children were 10 and 12 when I found the lump in my left upper arm. It was a hard lump that felt like a small marble. I went to my general practitioner, who sent me to a dermatologist, who sent me to a surgeon, who sent me to an orthopedic surgeon, Dr. Ashe. All of this run-around cost me three months.



After examining my arm, Dr. Ashe exclaimed, "You have a lump in my arm and it doesn't bother you." As an advocate for my health, I demanded tumor removal and biopsy.

I received a call from Dr. Ashe's office. They told me to come in immediately, even though I had an appointment scheduled for the next day. My sense of foreboding increased when the staff hustled me into an exam room without collecting my copy.

Dr. Ashe informed me I had leiomyosarcoma. I asked, "How do you spell that?" He handed me a referral to the orthopedic oncologist and patient support center at UC of San Francisco, then abruptly left.

I went home with the intention of holding it together in front of the children, but I lost it. I gathered them up and we all snuggled together in my bed and watched stupid movies. We laughed sometimes and we cried sometimes. This is my sweetest memory of cancer.

My over-riding emotions though were sorrow and anger.



Anger. Huge. I didn't want some other woman in my bed, sleeping with my husband and raising my kids if I passed away. Mine!

It is 10 years later. My husband and I just celebrated our 26<sup>th</sup> wedding anniversary. Our children are now independent young adults and continue to be the joy of my life. We have grandchildren.

Sometimes curious people ask me about my upper arm, which looks like a smallish shark took a bite out of me. Completing the look is a 3 1/2 inch straight white scar, radiation tattoos and skin mottling from the radiation. If my curious onlookers will listen, I tell them the importance of being a strong advocate for your health.

Having cancer wasn't great. It sucked. But it has made me a more compassionate and kind person. And kindness is always a good thing.

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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

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## 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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fax: 1-413-502-2241  
Email: [Contact@LMSdr.org](mailto:Contact@LMSdr.org)

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