

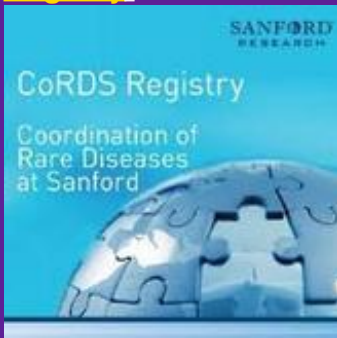


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LMSAlerts is an eNews service for families and professionals

**JOIN the LMS Patient Registry** with CORDS



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

## Wishing Working for the Cure

### LMSarcoma Direct Research Foundation **LMSAlerts - September 2016**

undefined

#### **\$1 MILLION INTERNATIONAL COLLABORATIVE LMS PROJECT TO START**

The Liddy Shriver Initiative visualized and coordinated an international LMS study by Drs. Fletcher, van de Rijn, Chibon, Bauer and Langenau. This study is funded by the Liddy Shriver Initiative (\$250,000), LMSarcoma Direct Research Foundation (\$125,000,) National LMS Foundation (\$125,000) and from the researchers' own resources (\$500,000.)

This is a comprehensive study. They plan to sequence the whole genome of 200 LMS tumors, investigate the PI3K-AKT-mTOR pathway and test new therapies with cell lines, mice and zebra fish. The ultimate goal is to test these in human clinical trials. [Details of the study](#)



Fletcher van de Rijn Chibon Bauer Langenau

The Collaborative Team

## 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 paraffin tissue blocks for research - please [join us](#) and build our tissue collection.

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## [DONATE NOW](#)

### Shop & Donate!

Shop at  
[Smile.Amazon.com](http://Smile.Amazon.com)  
and donate to  
LMSdr

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

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## 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.

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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 see it pass into law!

[VIDEO](#)

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## Sarcoma Patient Education Series

FREE conferences offered by Sarcoma Foundation of America (SFA) [Must register](#)

Raleigh-Durham, NC — **September 10**, 2016

New York, NY — **September 12**, 2016

Pittsburgh, PA — **September 17**, 2016

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, XXL.

Miami, FL — **September 24, 2016**

Salt Lake City, UT – **October 15, 2016**

Chicago, IL — **October 25, 2016**

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## Rare Patient Advocacy Summit

\$50 **September 22nd - 23rd** in Huntington Beach, CA. For patients, family and advocates.

Presented by Global Genes and the Rare Foundation Alliance. [More Info](#)

LMSdr is a member of the  
Rare Foundation Alliance



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## Dana Farber GIST/Soft Tissue Symposium

FREE for patients and loved ones.

**September 17th,**

7:30am - 2:00pm

Live webcast 8am - 12noon

Must register by Sept. 12th



[Details HERE](#)

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## Immunotherapy Patient Summit

Read past issues of  
[LMSeAlerts](#)

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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](#)

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[Forward this message to a friend](#)

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### **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](#)

FREE **September 24th**  
10am-5pm  
in New York City. Also available by live stream on your computer.  
[Details HERE](#)



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### **NLMSF Educational Conference for LMS**

FREE **October 7-8th**  
LMS conference at the  
Siteman Cancer Center in  
St. Louis, MO. Sponsored by National LMS  
Foundation.



Email [Annie](#) for registration & details

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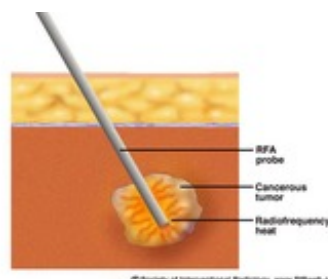
### **Slay Sarcoma 5K Run/Walk**



Saturday **October 15th** in Yardley, PA. Raise money for LMS research by running, walking or [supporting virtually!](#) Sponsored by the Slay Sarcoma Research Initiative.

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### **Percutaneous Thermal Ablation (PTA)**



PTA is a minimally invasive procedure using a special needle to deliver either heat, cold or chemical directly into a tumor to destroy it.

While it results in quick recovery time, PTA was not thought to be as effective in getting good margins as surgery. Therefore, recurrence of

growth has always been the concern. This new study below demonstrates that, of the 93 LMS metastasis tumors treated in 30 patients, the local control rate at 1 year was 95% and at 3 years was 89%. [\*\*Percutaneous thermal ablation: A new treatment line in the multidisciplinary management of metastatic leiomyosarcoma?\*\*](#)

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## July 15th - LMS Awareness Day!

Thanks to our LMS advocates, July 15th was officially legislated by Congress as LMS Awareness Day!

Patients and loved ones held fundraisers, gave out ribbons and shared their stories.

Don't wait for next year...

keep up the Awareness efforts. Order your ribbons/cards from Heidi [HeidiHarlin@gmail.com](mailto:HeidiHarlin@gmail.com)



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## 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](mailto: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: Dr. Martee Hensley at LMSdr Conference)

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## 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.

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## Immunotherapy and Sarcomas

ASCO 2016 - Seth Pollack, MD, from the Fred Hutchinson Research Center and the University of Washington Cancer Center talks about the promise of immunotherapy for sarcomas, but more research is needed. [VIDEO](#)

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## 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.

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## 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.

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## INTEGRATIVE ONCOLOGY



Donald Abrams, MD, of the University of California in San Francisco describes what integrative oncology offers cancer patients.

You'll hear Dr. Abrams use the metaphor of the *body as a garden* to explain integrative medicine. While conventional oncologists 'weed' out cancer through powerful, fast methods, more holistic approaches look to fortify the 'soil' of our immune system to become less susceptible to disease over time, and to strengthen the body's own healing abilities. This "both-and" approach toward treatment is the crux of integrative medicine and offers many patients comfort in not having to choose one over the other.

[VIDEO HERE](#)

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## WHO IS SARC?



Sarcoma Alliance for Research Through Collaboration (SARC) are sarcoma specialists worldwide working together to offer clinical trials to sarcoma patients. The problem in the past was that there were not enough of these rare sarcoma patients in any one location to complete a trial. Sarcoma oncologists from several independent institutions got together to solve the problem. After years of legal issues and red tape, we now have triple the amount of trials available to us... PROGRESS! Read more about [SARC](#) and their plans for immunotherapy trials.

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## 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](#)**

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## **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](#)**

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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.

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### **LMSdr Top-Rated Nonprofit Award!**

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



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### **JOIN THE LMS 10/10 Club!**

On 10/10/16 get 10 donations of \$10 for LMS research. Just tell people your own LMS story and how we need better treatments for LMS. Give them a purple ribbon to show their support. The cards have directions on how to donate to LMSdr. Order your free ribbons from [Heidi](#) now!

Members of the 10/10 Club will have their names listed in the November 1st LMSeAlerts.

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**1276**

is the number of LMS patients diagnosed in any given year.

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**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).**

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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, 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!**

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## Michelle Dillion, 8-Year Thriver

### Beating the Odds

In the beginning, prior to a hysterectomy, my gynecologist said there was a slim chance it may be cancer. In surgery, he cut my "fibroid" into sections, and also nicked a ureter. He told me later there was some cancer, but assured me it was contained in my uterus.



The oncologist told me they had found Leiomyosarcoma, and I would need six weeks of radiation and six months of chemo (Gemzar and Carboplatin). A CT scan prior to beginning treatment showed "multiple" lung mets (metastases). Luckily, I had discovered ACOR, and knew I needed a second opinion. So I had my records sent to Memorial Sloan Kettering.

At MSK, I saw Dr. Koehan, whose first words to me were: "It's not as bad as it looks." I left her office feeling like I could live with this disease. I had a plan, and knew there were more options. Nine months later, I was on top of the world when my scans came back with no evidence of disease (NED)!

My first recurrence, a 1 cm lung met, was easily removed with surgery. The next recurrence was painful -- a tumor wrapped around my ureter, causing kidney blockage, and I had to get a

temporary nephrostomy and a stent. My local oncologist told me I was inoperable, and that he would make me comfortable, So I once again traveled to MSK, where a surgeon agreed to do the tricky surgery. That was five years ago.

Since then, I've combated LMS with chemo, surgery and radiation. I live with two ostomies now, but my quality of life is good. My attitude is a combination of denial, hope and faith. I started out believing that once a person had a recurrence, that was the end. Now I see cancer as a chronic disease. Most of the time, I try to pretend I'm not sick, and that I have a normal life. My life *is* normal; it just involves doctors and chemo. I'm realistic, but I don't dwell on having LMS. I believe each new treatment will work and research will find a treatment to control my LMS.

In the meantime, I love my life – I read, knit, color, play with my critters, work on my crafts, cook and enjoy every moment with my loved ones. I also read the stories of my online friends, and laugh with their successes and cry with their failures, for they are the ones to whom I truly owe my life. I would not be here today without my online support. My advice is to read everything you can get your hands on, be cautious of what you believe, and research, research, research!

Michelle Dillon  
Charleston WV  
April 2008  
ULMS

Discovered Stage IV from hysterectomy for fibroids. Gemzar with complete response. Thoracotomy for lung met. Pelvic resection, bladder and ureter rebuilt. Unsuccessful Doxil, successful Ifosfomide and later Gemzar. Complete response. Pelvic resection, colonostomy and urostomy. Stereotactic radiation. Stable lung mets. Lung mets grew, antiangiogenic protocol, more lung mets. Aldoxirubicin, Votrient, Temodar and Erubilin all failed. Yondelis with shrinkage

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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!](#)

LMSarcoma Direct Research Foundation  
Post Office Box 52697  
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tel. 1-866-912-2730  
fax: 1-413-502-2241  
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