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LMSAlerts is an eNews service for families and professionals



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

History of LMS Paraffin Block Drive [Video](#)

Participate in the Paraffin Block Drive

## Working not Wishing for the Cure

### LMSarcoma Direct Research Foundation LMSeAlerts - July 2015

#### LMS Patient Advocate Training!

LMSdr is sponsoring an LMS Patient Advocate Training on November 4th and includes attending the [CTOS](#) sarcoma research conference November 5th to 7th in Salt Lake City, Utah.



Funding for this project has been donated by an anonymous supporter.

Our speakers will teach on how to understand the CTOS research presentations and patient advocacy 101. We will also have 12 monthly webinars support sessions.

Applicants have been selected by their desire and commitment to volunteer as an advocate for a year on their selected projects.

#### LMSdr Patient Advocates



**Karen Fisher (Reno, Nevada)**  
**Fundraising Campaigns**

Karen's mother and aunt both have ULMS

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**

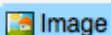


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LMSdr

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LMS Retreat  
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**Peggy Lussier (Alexandria, Virginia)**  
**Legislative Advocate and Face  
Book Moderator**

Peggy is a 3 year ULMS survivor



**Daryl Brown (Crofton, Maryland)**  
**Community Outreach and Face  
Book Moderator**

Daryl is a 4 year ULMS survivor



**Kathy Goodwin (Athens, Georgia)**  
**LMS Conference Organizer and  
Face Book Moderator**

Kathy is a 9 year ULMS survivor



**Karen Kozlowski (Boise, Idaho)**  
**Genetics Advocate and Face  
Book Moderator**

Karen is a 5 year ULMS survivor



**Kelly Maigaard (Clive, Iowa)**  
**Website Writer/Editor**

Kelly is a 6 year LMS survivor

insert your image, click the placeholder to the right, then click **Image**. You can also modify the link below to point to your website or place where additional information can be found.

[Link to my website](#)

**Visit Our Website**

[LMSdr.org](http://LMSdr.org)

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**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.



**And honorary advocate...**

**Janine DiTullio (NY, NY)**

**Website Coding/Design Manager**

Janine's best friend and business partner is a 1 year survivor

## Rare Disease Legislative Advocate's Conference

July 31st, LMSdr will join other patient advocates for the Rare Disease Legislative Advocates's Inaugural West-Coast Conference. The crucial goal of this conference is to update advocates about important legislation advancing through Congress and to prepare them to meet with their Representatives during August Recess.

Why Advocate?

"Unless someone like you cares a whole awful lot, Nothing is going to get better. It's not."  
- Dr. Seuss, The Lorax



This year Congress is working on legislation that will have a huge impact on drug development and approval, and as a community we must join together to ensure the legislation benefits rare disease patients and is passed in both the House and the Senate.

## Dana Farber Opens New Nivolumab Anti-PD1 Phase II Trial for ULMS

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](https://clinicaltrials.gov/ct2/show/study/NCT02428192)

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



T-shirts are unisex, preshrunk 50/50 cotton and polyester, color is blackberry. Sizes M, L, 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](#)

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## 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](#)

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### LMS Blood Samples Collected for Circulating DNA



Dr. Kristen Ganjoo and Dr. Matt van de Rijn at Stanford University are collecting blood samples from LMS patients to research circulating DNA.

They hope to identify the levels of LMS DNA to know whether a drug is killing tumor cells much earlier than a CT scan could. This potentially could identify LMS from non-malignant uterine fibroids before surgery.

To participate, patients must first watch an online video explaining the project and instructions. Then sign and return the enclosed consent. A blood collection kit will be shipped to you. Inside the kit are instructions for the lab. It also includes a pre-paid label for the lab to ship the blood back to Stanford.

You must have blood drawn only at a Quest Diagnostics Lab. The service is billed to Stanford, not to you or your insurance. There are no costs to the patient.

[Find a Quest Diagnostics Location](#)

Any LMS patient can participate, including those in remission or undergoing treatments.

**If you would like help out by donating a blood sample please contact Dr. Ganjoo [kganjoo@stanford.edu](mailto:kganjoo@stanford.edu) for the video and consent form.**

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### Aldoxorubicin Trials

Phase 1 Study to Investigate the Safety and Activity of [Aldoxorubicin](#)

[Plus Gemcitabine](#) in Subjects With Metastatic Solid Tumors

Phase 1 Study to Investigate the Safety and Activity of [Aldoxorubicin Plus Gemcitabine](#) in Subjects With Metastatic Solid Tumors

Phase 1 & 2 Study to Investigate the Safety and Activity of [Aldoxorubicin Plus Ifosfamide/Mesna](#) in Subjects With Metastatic Soft Tissue Sarcoma

Phase 3 Study to Treat [Patients With Soft Tissue Sarcomas](#)

For more trials go to [ClinicalTrials.gov](http://ClinicalTrials.gov)

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## Welcome LMSdr's

### New Scientific Board Members

#### Thierry Jahan MD

Oncologist at University of California in San Francisco (UCSF), Comprehensive Cancer Center



Dr. Thierry Jahan specializes in the treatment of lung cancer, mesothelioma, sarcomas and endocrine tumors and the use of multiple treatments. In addition to caring for patients, Jahan is involved in studying new treatments for malignancies related to the chest.

#### Suzanne George MD



Clinical director of the Center for Sarcoma and Bone Oncology Senior Physician at Dana Farber Cancer Institute in Boston, Massachusetts

Dr. George's areas of expertise include soft tissue sarcoma, bone sarcomas, and gastrointestinal stromal tumor (GIST). She was a featured speaker at the 2013 LMS Retreat in Colorado.

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## Did You Know...

It takes an average of 14 years and two billion dollars to develop a drug in which 90% fail.

The **Open Act HR971**, proposed in November 2014, would help repurpose existing drugs to be used for rare diseases.

LMSdr has added our name to the list of foundations that support the passage of the Open Act.

Read more [HERE](#)



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## LMS - One disease or distinct biologic entities based on site of origin?

[J. Surg. Oncol. 2015 111:808-812.](#)

Although larger and higher grade, retroperitoneal and uterine LMS share similar survival and recurrence patterns with their trunk and extremity counterparts. LMS of various anatomic sites may not represent distinct disease processes based on clinical outcomes. The presence of metastatic disease remains the most important prognostic factor for LMS.

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## Six Flags Concert Benefit for LMS

August 22, 2015  
7:00 pm  
Northern Star Arena  
Six Flags, Jackson, NJ  
Band: [Foster The People](#)



Grammy nominated band, Foster the People will help us raise money for LMS research! Foster the People had their 2010 breakthrough hit, Pumped Up Kicks. They have appeared on Saturday Night Live as well as concert tours worldwide.

HELP SUPPORT THE CAUSE! Bring out your family and friends!

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## The influence of primary site on outcomes in leiomyosarcoma: a review of clinicopathologic differences between uterine and extrauterine disease

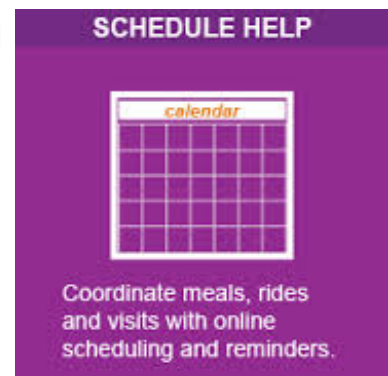
[Am J Clin Oncol. 2013 Aug;36\(4\):368-74.](#)

While demonstrating interesting clinicopathologic differences, the evidence for uLMS and eLMS being biologically distinct remains inconclusive. Disease stage is prognostically most important in LMS.

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## My Life Line

My Life Line provides free personal websites for people affected by cancer. You can invite friends and loved ones to follow your updates, find cancer resources and even post requests for help. "It's the power of emotional connections, together with practical day-to-day assistance that can see you through to more positive outcomes." [MyLifeLine.org](http://MyLifeLine.org)



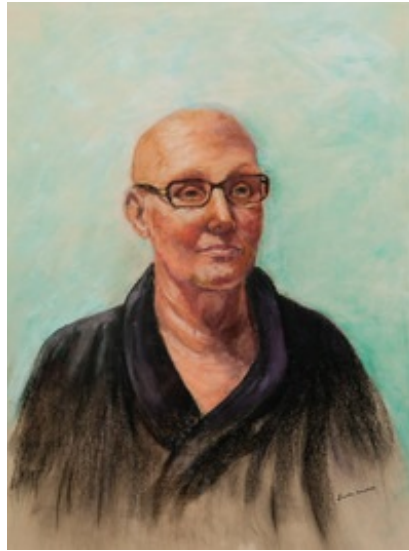
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## "Self Portrait" by Linda Maurer

They said I have cancer  
In my lungs  
Who? Me?  
Again? Still?  
The chemo, the port  
The scans, the tests.  
Am I still me  
Bald  
In a chair?

### About the Artist

The Self Portrait shows a determination to survive despite the



fact of losing a leg and being affected by chemotherapy. I have been bald three times and now don't worry about the hat unless it is for the weather. This is me, the new me, determined to survive this thing called LMS. Linda Maurer

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### **FBI Investigating**

Please read more [HERE](#).

If you had uterine morcellation during your hysterectomy, you have a higher risk of disease spreading. The FDA has issued a warning against the use of morcellation in routine surgeries.

Please contact Sarah Robinson, a fellow LMS victim of morcellation, to find out what you can do:

[sarahssr@gmail.com](mailto:sarahssr@gmail.com)

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### **Sarah Ailey, 12 Year Thriver in Chicago**



Part luck, part assertiveness

I was diagnosed with uterine LMS in April of 2003. My tumor was 6.5 cm and highly estrogen positive. I was lucky. I had a gynecologist who sent me for pelvic "ultrasounds" every two years. The gyn onc who did the surgery had been involved in ULMS studies and he knew what he was looking at right away, so the surgery was done correctly.

I flew to New York and consulted with Dr. Samuels at Memorial Sloan Kettering. He recommended a new chemo combination called Gem/Tax, rather than the traditional AIM (Adriamycin, ifosimide and mesna.) I opted for an adjuvant 6 cycles.

There were a couple of fellow LMS list group members with estrogen sensitive tumors, on a breast cancer drug Femara



(letrozole) with success. I brought everything I had on it and insisted the oncologist prescribe it for me after the chemo. I took Femara 5 ½ years with no recurrences.

At 8 years my onc suggested I stop scans. I told her the protocol was 10 years. And at 10 years, a precancerous lesion was found on my pancreas. I no longer have the pancreatic tail and dodged that bullet.

I have been NED (no evidence of disease) since.

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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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