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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 - January 2016

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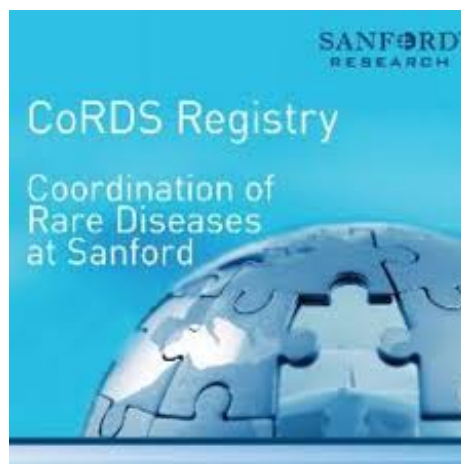
## REGISTER!

April 7th-



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

## LMS Patient Registry



LMSdr is proud to announce our new LMS Patient Registry in partnership with CoRDS!

[JOIN HERE](#)

**What is a patient registry?**

A central place for LMS patient donated histories that researchers can use. All patient data is de-identified and anonymous. The more we have, the better researchers can understand LMS.

## 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

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LMS Retreat  
Presentations

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[LMSdr.org](#)

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## Why participate?

Patients can collaborate with researchers to:

- \* Describe the natural history of disease
- \* Determine clinical effectiveness of treatments
- \* Locate potential volunteers for studies and trials

## Who is CoRDS?

[Coordination of Rare Diseases at Sanford](#) (CoRDS) is based at Sanford Research, a not-for-profit research institution.

CoRDS is a centralized international patient registry for all rare diseases. The goal of the CoRDS registry is to connect as many patients and researchers as possible to help advance treatments and cures for rare diseases. The CoRDS registry is free for patients to enroll and for researchers to access.

[See FAQs](#)

[Video about CoRDS](#)

## Who can access the data?

Researchers must have approval from their own Institution Review Board (IRB) and then approval by CoRDS's own IRB Scientific Advisory Board. LMSdr's Scientific Advisory Board may also, if desired, use their discretion to allow or deny access, once the first review requirements are met.

## How is my identity protected?

Your information will be de-identified by CoRDS. If you are eligible for a research study or trial, only CoRDS will contact you. They will also contact you annually to update your data.

## Should I also join SFA's Sarcoma Registry?

YES! LMSdr's and Sarcoma Foundation of America's (SFA) registries compliment each other. The main difference is that when you join SFA's registry, you give them permission to access your medical records from your doctor. This provides more detailed and accurate data. LMSdr's registry doesn't access your records. While LMSdr's also collects histories, it also serves as resource for researchers to find potential volunteers for their research studies, and helps to offer new trials to patients.

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**Put Your Heart Into It!**



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.

Read past issues of [LMSeAlerts](#)

LMSdr advocates for

We'll send you the 8 x 10 canvas, paints, brushes and return shipping box. You sent us your hearts to be donated to our silent auction. Art can be any media, paint, fabric, paper, etc. Both patients and caregivers can submit. Details on [Silent Auction](#) page.



## 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](#)

## TAPUR TRIAL UPDATE

ASCO's Targeted Agent and Profiling Utilization Registry (TAPUR) Study is expected to open in early 2016. 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

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](http://LMSdr.org)

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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.



NATIONAL  
CANCER  
INSTITUTE

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## Phase II Entrectinib Open



IGNYTA

Ignyta Inc. based in San Diego, California has just opened their Phase 2 trial testing their drug

entrectinib that targets the gene translocations of *NTRK*, *ROS1* 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](mailto:lschechet@ignyta.com)

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## Evofosfamide (Th-302) Fails Phase III Trial

Merck announced that they will not pursue Evofosfamide (TH-302) further in soft tissue sarcomas. Results from the phase III trial did not meet expected end points. Read more [HERE](#)

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## MD ANDERSON CONFERENCE

Please join NLMSF at their all day conference on April 2nd, 2016 at MD Anderson Cancer Center in Houston, Texas. Speakers are impressive! Details [HERE](#)



THE UNIVERSITY OF TEXAS  
MD Anderson  
Cancer Center  
Making Cancer History®

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## LMS Researchers Collaborate

November 6th, seven researchers gathered together for

cocktails and discussed how to work together on LMS research. This private event was sponsored Dr. Mitch and Annie Achee at the Grand America Hotel in conjunction with the CTOS sarcoma research conference in Salt Lake City, Utah. Mitch and Annie Achee plan to make this "LMS Research Initiative" an ongoing event every other year when CTOS is held in the U.S.

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## 2016 Rare Disease Week on Capitol Hill

Monday February 29th to Thursday March 3rd is Rare Disease Week, on Capitol Hill, to let Legislators know our needs. The week is sponsored



by RDLA - Rare Disease Legislative Advocates. Anyone is welcome to participate. Several LMS patients will be representing LMSDR. Read details [HERE](#).

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## LMS Volunteers Needed for Survey/Interviews

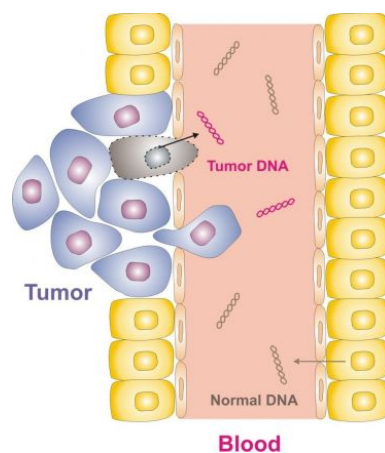
Novartis is conducting a survey about LMS tumor symptoms. IF you have LMS tumor related SYMPTOMS, not currently on chemo, and would be willing to complete a



questionnaire and phone interview - you'll get \$100. Call Sonya Stringer 1-800-242-2196 or email [STS@evidera.com](mailto:STS@evidera.com)  
Help researchers, help us!

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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 for the video and consent form.**

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## **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

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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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## **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).**

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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](#).



## 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 Sharon to order](#)

**Here's to another year!**

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## LMS Artist Barb Soyka, dx 2010



## 17 yr. Thriver, LINDA JOY

FEAR, LOATHING, GRATITUDE and JOY



These four words describe my journey with LMS.

Fear: First, it was hearing the word cancer and then leiomyosarcoma of the retroperitoneal – it was 'What?!' of

'What?!' Next came fear of the unknown: scans and the results, recurrence, another surgery possibly affecting quality of life, chemo, blood transfusions, etc.

Loathing: I loathed the interference in my life. LMS arrived just after getting married and my career peaking. I



loathed: considering cancer when making decisions for the future, the feeling of exiting life while the world went on normally around me, the long-term fatigue, being defined by cancer.

Gratitude: At 67 and a 17 year survivor, I now look back with overwhelming gratitude (not to say I still don't have twinges of fear). I am grateful for life, the love and support of my husband, sister, parents and friends, excellent doctors during my early journey, new friends, the ACOR listserv, getting real with being vain.

Joy: On a personal note in cancer defiance, Joy is my middle name. I decided to adapt it as my surname in 2000 for the listserv because I was adamant that cancer was not going to steal my joy.

Linda Joy

South Carolina

Diagnosed: 7/28/1998 at age 50

LMS Retroperitoneal

Surgery 7/28/1998

Surgery for recurrence 10/13/2000

AIM, Adriamycin 90 mg / m sq, 12/10/2000 – 4/25/2001, 6 cycles

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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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LMSarcoma Direct Research Foundation  
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Tulsa, Oklahoma 74152  
tel. 1-866-912-2730  
fax: 1-413-502-2241  
Email: [Contact@LMSdr.org](mailto:Contact@LMSdr.org)

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