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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**

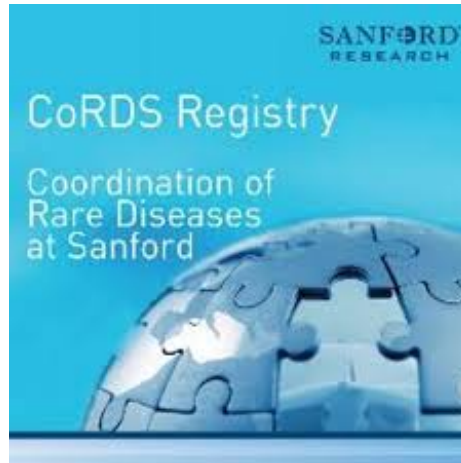
Participate in the Paraffin Block Drive

Working not Wishing for the Cure

LMSarcoma Direct Research Foundation LMSeAlerts - September 2015

undefined

NEW! 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.

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.

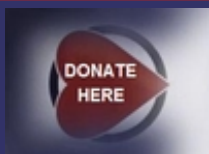
CoRDS is a centralized international patient registry for all rare diseases. The goal of the CoRDS registry is to connect as many patients and researchers as possible to help advance treatments and cures for rare diseases. The CoRDS registry is free for patients to enroll and for researchers to access.

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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LMSdr

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[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.

Update on SFA's Sarcoma Registry

[Sarcoma Foundation of America](#) (SFA) is currently working with Dr. Brian Van Tine from Washington University to get a IRB in place for his group to do a broad-based epidemiological study on the SFA's sarcoma patient registry. SFA will publish all findings that come from Prof. Van Tine's research and hope that it will spur others to utilize the patient registry for research.

SFA and LMSdr are also very excited by the push in the patient community and Congress for FDA guidance on the use of natural history as control arms for clinical trials. Such guidance could spur more drug development activity in the sarcoma community.

SFA intends to work with organizations that wish to use the registry data to help speed the development of new

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

therapies. LMS patients represent one of the bigger sarcoma sub-types in the registry. We appreciate the participation of LMS patients in making the registry a robust data-set for researchers.

Meet LMSdr's Political Advisor, Cat Moy

Catherine "Cat" Moy has been an elected City Councilwoman for the City of Fairfield, California since 2008. As a journalist, her investigating, reporting and lobbying in Washington D.C. helped lead to changes in federal law under President Bill Clinton. She has testified before the state's joint committee of the Senate and Assembly, and lobbies continuously on various issues. As an expert in marketing and political messaging, Moy has been hired by U.S. Senate campaigns and worked for Assembly, Gubernatorial, Supervisorial, Presidential and city campaigns.



In May 2013, Cat was diagnosed with ULMS. Since, she is driven to advocate for those who have been diagnosed with LMS. She is dedicated to change laws, find government money, and using what is left of her life to advocate for the end of LMS through research, education and political change.

Molecular Subtypes in LMS

The different molecular subtypes found in leiomyosarcoma show significant variations in gene expression levels, which suggests that they may respond differently to the novel targeted therapies being developed.

Read full research article [HERE](#)



Olaratumab/Doxorubicin Combination

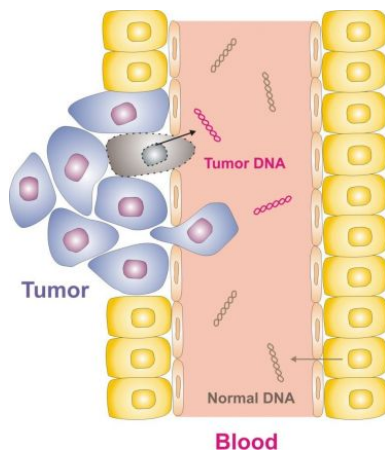
and funds LMS specific research. We've been a nonprofit 501 (c) (3) since 2006. For details of our past grants go to LMSdr.org

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Dr. William Tap MD of Memorial Sloan Kettering talks about the phase two trial results of the combination of olaratumab and doxorubicin with soft tissue sarcomas.

[Watch Here](#)

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.

Sept 12th - Dana Farber Sarcoma Symposium



DANA-FARBER
CANCER INSTITUTE

Dana-Farber will be hosting a free patient educational symposium on Saturday September 12th, "15 years GIST/Soft Tissue Sarcoma." Participants will receive free parking and lunch. Register by September 4th [HERE](#).

Sarcoma - Ask the Experts!

Sarcoma Foundation of America (SFA) is hosting two patient educational conferences. The conferences are free but you must register.

[Pittsburg, PA September 19th](#)

[Miami, FL September 26th](#)

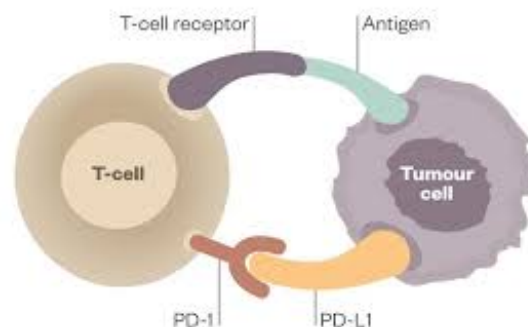


Nivolumab Anti-PD1 Trial

Dana Farber Opens New Phase II 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](#)

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](#)

Understanding Cancer Research Studies

[Listen to this podcast »](#)

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

Mixed Emotions



Mixed Emotions

The cancer has returned
In my lungs.
Inoperable.....they say.
Incurable.....they say.
Enjoy your time....they say.
I say.....Enjoy this moment.
I say.....Keep your hopes alive..
I say.....Believe in yourself
In your own light.

**Painting and poem by LMS survivor
Linda Maurer, 10/30/2012**

The [West Coast Conference on Work & Cancer](#) sponsored by Cancer & Careers, is on Friday, November 13th, 2015 in Los Angeles! This FREE event will explore various elements of balancing work and cancer, including legal issues, health insurance options, working during treatment and job-search.



Inspirational story

[Anything is Possible, Even Without Wine](#)

by LMS Survivor, Vicki Kelly

A year ago I was in pretty bad shape. In fact, a year ago I could hardly breathe. The tumors that invaded my chest cavity were growing out of control. They grew through horrific chemotherapy, through intense radiation and one grew so big that I could hardly breathe. Quickly it was determined that the only choice I had to save my life was a surgery so involved and so huge that my surgeon called it "The mother of all surgeries".

A year ago I was about to undergo a lifesaving, life changing operation that would change the course of my life. [continue reading story at the above link]

High School Fundraiser



Billy Woltz, a high school junior in Logan, Ohio rallied his friends to perform a benefit concert for LMSdr. It was in honor of Kelley Hoellrich, his friend's mother and school cross country coach, who was diagnosed with LMS in spring of 2014. Selling tickets for \$5, they raised \$4400.

“We decided to perform "The Wall" by Pink Floyd due to its message, tear down the wall. We thought that this was appropriate due to the lack of knowledge about cancer, and LMS specifically. I wanted to help break down those barriers and raise awareness, which I believe helps our cause against cancer so much more than any amount of money raised” stated
Billy Woltz

Calling LMS Artists!

Seventh Annual Rare Artist Contest Awards Over \$3000 to Creative Community



The EveryLife Foundation for Rare Diseases is pleased to announce the 7th Annual Rare Artist Contest, which celebrates the unique talents of the rare disease community. This year's contest will run until December 15th, 2015, with voting lasting until December 22nd, 2015. Entrants are allowed to enter one piece in the contest for their age group, and two awards will be given out in each category: One by popular vote and one decided by a panel of rare disease community leaders. For additional rules and contest information, please visit [the contest rules page](#)

San Francisco Bay Area LMS Gathering



Sunday 9/27/15

Join us for a beach bonfire, sunset and total lunar eclipse!

RSVP Sharon for details at 2taikomom@gmail.com

Kay's Campaign for a Cure!

Buy cosmetics and Kay Browning will donate 50% of the proceeds to LMSDR for research. Any product qualifies and orders over \$25 get free shipping!. You must order through



[HERE](#) to get the donation. Post this on your Face Book page and share with family and friends.

Thank you Kay Browning for this beautiful fundraiser!

11 Year Thriver, Peggy Chalk in Tucson

We cannot know

When I was diagnosed in 2004, I remember refilling my daily mini-legal pad notebook from the stack of Costco pads and thinking that this was the last pack of pads I'd ever need. The joy of needing another package made me giggle...the next year.



And the two throws I knit for my young daughters so they'd have something to snuggle with and remember Mom are now pretty worn. My younger daughter, whom I prayed to see graduate from high school, now uses it on her dorm couch where she and her roommates use substances for which they are not yet of legal age (disappointed mom). Oh, and now that I am off SSDI and back to work, I am thinking that I better save more for retirement that I expected not to reach (10 years away).

So, I understand the sadness, and hope you can focus on the moment and find joy. We cannot know the

length of our time here but we can do our best to make it good.

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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