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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 - November 2015

undefined

Back from CTOS!

November 4-7, LMSdr sponsored and trained 6 advocates at the Connective Tissue Oncology Society (CTOS) Conference in Salt Lake, City.



The first day, LMSdr Scientific Advisory Board Members, Debra Simons, Sarah Robinson and Executive Director Sharon Anderson gave presentations to the advocates on How to Understand Research, Patient Coaching and how to navigate the conference and advocate with the researchers.

The first evening concluded with a welcome reception and special invite to the Advocate's Dinner hosted by Sarcoma Alliance. Our new advocates networked with other sarcoma foundation members.

For the next 3 days, advocates attended the sarcoma research presentations. At meals and on breaks, they talked with researchers and medical professionals from Europe as well as the US. about the need for more research on LMS.

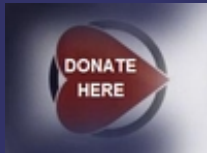
The Advocates will continue their training with monthly webinars on topics such as legislative advocacy, fundraising, patient rights and lawsuits and effective advocate models and foundations.

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

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

Visit Our Website
[LMSdr.org](#)

Join Our
[FACEBOOK GROUP](#)

Advocates were selected by their commitment to "pay it forward" and volunteer to help the LMS community. Several are Face Book moderators, some are designing and writing for the new website, launching fundraising campaigns, planning our next LMS Retreat as well as providing awareness, education and outreach. Thank you Advocates!

Join LMSdr's Patient Registry

Why should I join?

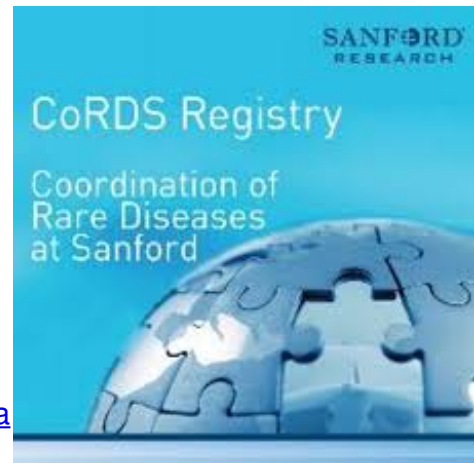
[watch video](#)

[JOIN HERE](#)

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.



REGISTRATION



LMS RETREAT 2016

April 7th, 8th and 9th

**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](#)

Speakers include Drs. Martee Hensley, William Tap, Matt van de Rijn, and more! Topics include ULMS, Team Approach to Treatment Planning, Immunotherapy, LMS Patient Registry, What's New with LMS Research, Trials and Treatments, Coping Strategies and much more. Our own Amy Regenstreif will open the welcome reception with stand-up cancer comedy. Friday night discount theater tickets available. Great food, views of NY City skyline, ferry rides and more. Come learn, laugh and connect with others!

Space is limited, so register today
[DETAILS AND REGISTRATION HERE](#)

FDA Approves Yondelis for LMS!



The FDA has approved trabectedin (Yondelis) for the treatment of patients with unresectable or metastatic soft tissue sarcoma—specifically, liposarcoma

and leiomyosarcoma—who have previously received chemotherapy that included an anthracycline. Now your local oncologist can prescribe it, rather than it only being available in a trial. Another BIG WIN for the LMS community!

[Read more](#)

Trial With Molecularly Profiled Drugs

[TAPUR](#) (Targeted Agent and Profiling Utilization Registry) by the American Society of Clinical Oncology (ASCO) and the National Cancer Institute's [MATCH](#) (Molecular Analysis for Therapy Choice) trial offers patients with advanced cancer access to best-in-class molecularly-guided therapy in their own communities.

[See more](#)

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

[Forward this message to a friend](#)

Brian Van Tine MD PhD Explains Molecular Profiling

Need to understand what molecular profiling is and why it's important for LMS?

[Watch Here](#)



Phase III Doxorubicin Plus Olaratumab (LY3012207) Now Recruiting

This study adds olaratumab to doxorubicin or a placebo to doxorubicin. In phase II, the addition of olaratumab resulted in medium overall survival of 10.3 months over doxorubicin alone without increased toxicity. If you get progression on the doxorubicin alone arm, you will be put on the olaratumab arm. Olaratumab is a human anti-platelet-derived growth factor α (PDGFR α) monoclonal antibody. PDGFR α is genetically altered and overexpressed in multiple tumor types, including certain sarcomas, and the expression is associated with increased metastatic potential. ClinicalTrials.gov Identifier: NCT02451943

[Read more.](#) [Clinical trial protocol.](#)

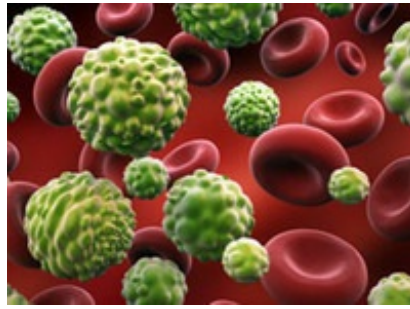
Save the Date!

THE UNIVERSITY OF TEXAS
**MDAnderson
Cancer Center**
Making Cancer History®

NLMSF is sponsoring a one-day educational conference on Saturday March 26th at the M.D. Anderson Cancer Center in

Houston, Texas.
Details to come out soon.

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.

Aldoxorubicin Vs. Doxorubicin

Single-agent aldoxorubicin therapy showed superior efficacy over doxorubicin by prolonging progression-free survival and improving rates of 6-month progression-free survival and tumor response. Aldoxorubicin therapy exhibited manageable adverse effects, without unexpected events, and without evidence of acute cardiotoxicity. [Read abstract](#) [Clinical trial info](#)

Clinical trial ID: NCT01514188

Nov. 13th - Work & Cancer Conference



First-ever [West Coast Conference on Work & Cancer](#) is on Friday, November 13th, 2015 in LA! The FREE EVENT will explore the complexities of balancing cancer with employment. Topics include: legal issues, health insurance options, job-search, taking time off and disclosure.

CEUs are available for oncology nurses and social workers. Click [here](#) for more information and to register today!

APPLY NOW FOR TRAVEL SCHOLARSHIP

RARE
DISEASE WEEK
ON CAPITOL HILL



Every Life Foundation for Rare Diseases is accepting applications for travel scholarships for Rare Disease Week on Capitol

Hill from February 29 through March 3, 2016. Travel stipends range from \$300-\$1,000 maximum, depending upon the distance the recipient has to travel.

The Foundation offers the stipends to enable more patient advocates to participate in the lobby day and other empowering activities during Rare Disease Week. [You can apply online here](#) through December 31st. They will grant as many stipends as possible, and notify winners on January 4th. Please contact Stephanie Fischer at sfischer@everylifefoundation.org with any questions.



donnabellasangels.org

My Life, My Choice

My Life, My Choice

Cancer can change my body,
but I choose my life...

I choose to embrace peace.

I choose to build friendships.

I choose to cherish sweet memories.

I choose to accept grace.

I choose to have courage.

I choose to believe in hope.

I choose to welcome faith.

I choose to know love.

I choose to want my life.

Feel beauty, My Life

Do you have an original work of art you'd like to share?

Contact 2SharonAnderson@gmail.com

Kay's Campaign for the Cure!



Buy cosmetics and Kay Browning will donate 50% of her 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!

Tee Shirt Sale!



November & December Only \$15 (includes shipping)

Sizes left: M, L, 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 for T-SHIRTS, please include SIZE).

Free Game Apps that Help Fight Cancer



Have fun and help cancer research by downloading and playing these games!

Go [HERE](#)

Life is a blessing

I was diagnosed in September of 2000 with a large retroperitoneal LMS tumor that involved my left ureter. Margins were not clear. My left kidney was removed in January 2002. Radiation followed. A recurrence in my colon was removed in April 2003.



After three rounds of MAID I stopped the infusions due to side effects. The next occurrence was removed from my right upper hip.

I retired on Social Security Disability in 2003 due to cognitive issues. I was a practicing registered nurse in a large urban hospital and my workplace sent me for testing. It took me a day and a half to complete what should have been 6 hours or so of testing. Needless to say I flunked!

The scanxiety in the beginning was awful. I felt as if I was on a gerbil wheel every three months. This went on many years. I have seen a therapist off and on for many years to help me deal with this anxiety.

My life is a blessing! My only son has married a wonderful woman and I have my first grandchild. I didn't think I would live

long enough to see that baby. I am active and involved in many things. I'm goofy but my family and friends have helped me through this journey!

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](#) you can designate a percentage of the proceeds to LMSdr!

[Shop Now!](#)

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Email: Contact@LMSdr.org

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