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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 2015

As of January 2015, LMSeAlerts will be published every two months instead of monthly. If you have LMS news to submit please send to Sharon Anderson 2SharonAnderson@gmail.com



Happy 2015!

LMSdr had a productive and inspiring year. We are always thankful to those who have contributed to our efforts and success: the Face Book moderators, tissue bank volunteers, advocates for the morcellation campaign, those who hold fundraisers and of course all the donors.

In 2014, we saw the LMSeAlerts newsletter grow to 1650 subscribers. The LMSdr Face Book has 728 members.

The Tissue Bank has over 600 LMS paraffin blocks. We learned and loved a lot at the LMS Retreat in San Francisco. We wrote letters, met with Senators and testified at the FDA hearings. We've raised over \$110,000 awarded for promising LMS research. [History of LMSdr Grants](#)

What's next for LMSdr? Our first goal is to update the website. We encourage you to volunteer in the Circulating DNA research project (below.) We'll continue the Tissue Bank drive and advocate against uterine morcellation. We have a few major fundraisers planned to fund the best LMS research projects.

Here's to a healthy and prosperous 2015!

LMS Blood Samples Collected for Circulating

Paraffin Block Drive for LMS Research



LMS patients have donated a primary paraffin tissue block for research - please [join us](#) and build our tissue bank.

DONATE NOW



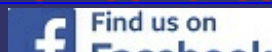
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LMSdr

Buy DVDs of the 2014
LMS Retreat
Presentations

Visit Our Website
[LMSdr.org](#)

Join Our
FACEBOOK GROUP



DNA Study at Stanford

Dr. Kristen Ganjoo and Dr. Matt van de Rijn at



Stanford University are collecting blood samples from LMS patients to research circulating LMS tumor 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 also could potentially identify LMS from benign

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.

Yondelis to be Available in the U.S.

On 11/24/14, Janssen the makers of Yondelis (trabectedin) submitted a new drug application to the U.S. Food and Drug Administration (FDA) for the treatment of patients with leiomyosarcoma (LMS), who have received prior chemotherapy including an anthracycline.

Janssen also announced plans to amend the Phase 3 randomized, open-label study ET743-SAR-3007. The protocol will be revised to offer patients who were randomized to the dacarbazine arm the option of receiving trabectedin.

Facebook

LMSdr T-shirts, water bottles & pins 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.



Janssen will be revising the trabectedin compassionate use program ET743-SAR-3002, to allow entry of patients with LMS. Interested patients should discuss accessing trabectedin through the compassionate use program with their physician.

There's An App for That



Apps for Cancer Patients

Keep all your info handy so that you have everything you need ready for doctor's appointments – and you can spend your time at work focused on work, not scrambling to find paperwork pre-appointment.

- iChemoDiary – a free application from Merck to help you track your chemotherapy schedule, manage medication and record symptoms and side effects. Lets you create reports to share and discuss with your healthcare providers. (Free)
- Cancer Terms Pro – this database of thousands of treatment, prevention, diagnosis and oncological terms can help you, your coworkers and your employer understand all the complicated language involved. (\$1.99)
- My Medical -- a mobile database for your medical history and information, including lab results, medications, immunizations, contact info for all healthcare providers and insurance. (\$1.99)
- iHealth Log – aimed at those with chronic disease, this app tracks appointments, medication, doses, test results & lab values. Also has a diary for jotting down notes and questions. (\$4.99)
- ExpressWell – designed to help simplify and clarify communication between you and your doctor. Tracks meds, physicians and treatment. (\$0.99)



Uterine Leiomyosarcom

NEW! LMSdr

[Awareness Pins](#)

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](#)

[Forward this message to a friend](#)

[Medscape Interview with Dr. Martee Hensley 11/19/14](#)

[Distinctive outcome in patients with non-uterine and uterine leiomyosarcoma](#)

[BMC Cancer](#). 2014 Dec 18;14(1):981.

This study concludes: At time of diagnosis ULMS were larger and more often metastasized. Therefore patients with ULMS showed unfavorable outcome when compared to NULMS. Later diagnosis might be caused by differences in symptoms and clinical presentation or a more aggressive biological tumor behavior.

Intermountain LMS Genetic Profiling Project

Get your tumor tested and potentially matched to targeted drugs.

Please Note: *There has been a change. Intermountain's genomic profiling is NOT a free service. After a patient's insurance has been billed, patients are financially responsible for any deductibles and co-payments. Those patients left with a balance bill will have the opportunity to apply for financial assistance and charity, on a generous sliding scale. Medicare usually pays for 100% of the cost.*



LMSdr is working in partnership with Dr. Lincoln Nadauld of Intermountain Healthcare to complete profiling for LMS patients.

They will test a tissue sample from your last surgically removed tumor. It doesn't matter if you have or haven't had chemotherapy. You can be with or without tumors at this time of testing.

You will receive your own test results with recommended drugs already FDA approved, to discuss with your oncologist. Intermountain will

consult directly with your oncologist.

They also have a Drug Procurement Program to help you attain the drugs indicated by the profiling.

Intermountain will work with patients on an individual basis to bill Medicare or commercial insurance as well as offer financial assistance on a sliding scale as needed.

The first step is to have your oncologist make a referral for you.

For more information go to [Intermountain's website](#) , call [435-251-5780](tel:435-251-5780) or email genomics@imail.org

These trials are currently open for solid tumors

[Tumor Genomic Profiling in Patients Evaluated for Targeted Therapy](#)

Memorial Sloan Kettering, NY NCT01775072

[Tumor Genomic Profiling in Patients Evaluated for Targeted Cancer Therapy](#)

Memorial Sloan Kettering, NY NCT01775072

[Genomic Profiling in Recommending Treatment for Patients With Metastatic Solid Tumors](#)

Stanford University, CA NCT02215928

[Molecular Testing of Cancer by Integrated Genomic, Transcriptomic, and Proteomic Analysis](#)

Rhode Island NCT02213822

[Feasibility Study of Genomic Sequencing to Find Potential Targets for Personalized Therapy](#)

University of Colorado, Denver NCT01869218

CAMP DATES ARE SET FOR 2015
[APPLY NOW](#)



JOIN FACE BOOK GROUP: Campaign Against Morcellation- Help Us Save Women's Lives

<https://www.facebook.com/campaignagainstmorcellation>

Did your hysterectomy or myomectomy involve using laparoscopic morcellation? Join this group to learn about the issues!

13 Year Thriver: Sharon Anderson

No chemo or radiation, just surgeries and adjuvant Arimidex



I opted for a myomectomy to remove a large uterine fibroid in January 2002. I had no symptoms or problems... but a close friend had just died from ULMS that year, so something inside urged me to get it out. It was LMS, 6 x 9 cms. with a mitotic rate of 10/10hpf. I was 43 and never thought I'd make it to now... 56 years old.

My gyn onc said I only needed an annual chest X-ray. I joined the ACOR support group and was immediately warned to get CTs of the chest, pelvic and abdomen every 90 days. It saved my life. There was a 1 cm. lung metastasis growing. I had VATS - video assisted thoracic surgery to remove it. I was hiking two weeks later.

I volunteered for a vaccine clinical trial at Dana Farber. I flew from San Francisco to Boston every other week. During the trial I developed a fast growing tumor in a chest lymph node - which was surgically removed.

Next, I asked my onc to test my original tumor for hormone receptors. When we found them to be 99% positive for estrogen and progesterone, I fought my insurance to get my ovaries removed. Then I started an aromatase inhibitor, Arimidex, to prevent any estrogen being made post menopause.

I have been NED - no evidence of disease - since then, 11 years. I stopped the Arimidex a few years ago because my

bones were thinning. I take calcium, vitamin D3 and exercise.

My big battle has been depression after I lost my ovaries/estrogen. I saw a psychiatrist who finally helped me with 3 different anti-depressants. Each one helped replace a low "happy chemical." It was a life saver. I really mean it.

Two "therapies" help me stay sane. I play and teach taiko drumming. The other is my advocacy work for LMSarcoma Direct Research Foundation. People thank me a lot, but I'm the one so grateful for being able to work, not wish, for a cure. Being able to do something makes me feel better.

Have you been an LMS warrior for 7 years or more? Share your story! 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!

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