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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
LMSAlerts - November 2014

undefined

LMS RETREAT 2014

LIVE IT UP!



2014 LMSdr Retreat a Success!

Over 120 people attended the Retreat in San Francisco Oct. 30th - Nov. 1st. Sharon Anderson's taiko drumming group set off the event with lively energy. We had a "laughter workout."

The presentations delivered important information on how to fight our LMS cancer and new methods to do it. We heard the most updated information on clinical trial drugs for LMS and the newest research being launched in the pathology laboratory of Dr. Matt van de Rijn's. Even the weather cooperated with the lovely sunset dinner cruise on the San Francisco Bay. What echoed all weekend was gratitude for meeting each other in person and the value of each other's support.

BUY DVDs of the PRESENTATIONS

for LMS Research



338 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 2013
LMS Retreat
Presentations

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Thanks to the generous donations of fellow LMS families, we have DVDs of the Retreat presentations.

To order:



www.2014LMSretreat.myevent.com

LMS Blood Samples Collected for Circulating 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 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.

[Phase 2, Alisertib in Treating Patients With Advanced or Metastatic Sarcoma](#)

Alisertib (MLN8237) is an oral, selective, inhibitor of Aurora A kinase. Aurora A kinase is required for cells to divide and has been shown to be over-expressed in a variety of cancers. The drug is made by Takeda in partnership with Millennium.

[Phase 2 Alisertib in Treating Patients With Recurrent or Persistent Leiomyosarcoma of the Uterus](#)

This phase 2 trial is for uterine leiomyosarcoma patients only is ongoing but is not recruiting patients at this time.

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
LMSAlerts

LMSdr advocates for
and funds LMS specific

Get Your Own Tumor Profiled for Targeted Treatments

What's Personalized Medicine? Dr. Robin Jones explained at the LMS Retreat that the future of cancer treatments will be based on the genomic profiling of an individual's specific tumor, instead of by the location, i.e. lung, uterus, breast.

There are many new laboratories offering this service. LMSdr has a special agreement with Intermountain Health Care to offer this test to the LMS community, at no cost to the patient.

To qualify, you must of had a biopsy or tumor surgically removed. It doesn't matter if you have had chemotherapy or not.

Intermountain's website explains to your doctor the benefits of this testing and how to make the referral. Intermountain has staff to work with your insurance. What your insurance will not pay, Intermountain will subsidize after you submit a simple waiver form to them.

While they can not promise that they will be able to match your tumor with drugs already on the market, over 70% of their participants do have matches.

Intermountain also has a drug procurement program to help you attain the recommended drugs.

At the same time of receiving your own personalized recommendations for chemo drugs, Intermountain will be able to collect LMS group (anonymous) genomic data for all researchers. You will contributing to finding treatments which work for others in the future.

Ready to get started? Ask your oncologist to go to www.PrecisionCancerCare.org and make the referral to Intermountain. You need to do nothing more until the results are back to discuss with your doctor. Intermountain will also consult with your oncologist about the results.

Webinar on the Affordable Care Act

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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Webinar on the Affordable Care Act for Cancer Patients

Wednesday, November 12 - 6 PM ET

Register:

<http://www.cancerandcareers.org/en/community/events/ACA>

Join Cancer & Careers for this FREE, 60-minute webinar where cancer survivors and their healthcare providers can learn key information about the Affordable Care Act. Topics include:

- the upcoming Open Enrollment Period (starts Nov. 14th)
- accessing coverage through health insurance marketplaces
- subsidies & tax credits
- Medicaid and more!

FREE CEUs are available for social workers and oncology nurses*

11 Year Thriver, Candace Berg

Retinoblastoma & ULMS
San Francisco Bay Area

In 2003 I went to the emergency room due to excruciating abdominal pain. An ultrasound showed a 10cm mass in my uterus. I had a complete hysterectomy, removing the tumor in one piece. Because of narrow margins I had pelvic radiation.



In 2005 my CT showed a tumor in my lung. The surgeon had to remove the lower lobe of my left lung. During the past nine years I have had probably fifteen lung mets treated. Most of these have been ablated with either radiofrequency or microwave ablation. If these less invasive techniques weren't possible, I had VATS surgery. I had a couple of very huge surgeries to remove the pancreas tumors and the tumor in my superior mesenteric vein. I utilized interventional radiology techniques of Y-90 and chemoembolization to control the liver

tumors. I tried doxorubicin in a clinical trial but it didn't work.

I currently have active disease in my lungs and liver. I hope to continue to treat my disease with modalities which balance tumor control with maintenance of my health and quality of life. I plan to continue to utilize complementary medicine as I have since my original diagnosis. If something won't hurt me and maybe help, I'll try it. Dr. Kossovo gave us some advice years ago which I try to follow; Stay as healthy and strong as you can for as long as you can, so you can utilize treatment advances as they come along.

The fear will always be there for me. I need to not let fear overwhelm me; and instead focus on people, activities and thoughts that fill me with gladness and appreciation for being alive.

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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