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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 for LMS Research

Working not Wishing for the Cure

LMSarcoma Direct Research Foundation
LMSAlerts - SEPTEMBER 2014

undefined

LMS RETREAT 2014

SPACE IS LIMITED - [REGISTER NOW!](#)

Come to beautiful San Francisco October 30th - November 1st for our second LMS conference for patients and professionals!



Retreat Message Board Open - Make Connections!



Want to find someone to share a ride with from the airport? A room? A



355 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**

Visit Our Website

LMSdr.org

Join Our

FACEBOOK GROUP



**LMSdr T-shirts and
water bottles**

bike ride? Find other attendees and start planning your free time and getting to know each other.

LMS Retreat Message Board [HERE](#)

Dr. Robin Jones at LMS Retreat!

Dr. Robin Jones

Dr. Robin Jones will be presenting on [Personalized Targeted Treatments for LMS](#).

Imagine having your tumor molecularly profiled and matched to actionable drugs which are currently FDA approved and available? You can do it now! Dr. Jones will help us understand the science and how to use your own test results to create a personalized treatment plan based on your very own unique cancer cells.



Robin Jones MD, Associate Professor of Medicine at the University of Washington/Seattle Cancer Care Alliance is a medical oncologist specializing in adult bone and soft tissue sarcoma. Dr. Jones' work is driven by the belief that providing patients up-to-date, disease specific information results in better care decisions. This vision and his interest in developing novel therapeutic strategies for the treatment of sarcomas have compelled his program's involvement in clinical research. He is currently the Principle Investigator on thirteen sarcoma clinical trials, including four phase one studies, that strive to cater towards the extensive range of sarcoma subtypes.

**Register now to hear Dr. Jones and other speakers at the
2014 LMS Retreat in
San Francisco [HERE](#).**

NEW! Intermountain Cancer Genomics

LMSdr is working in partnership with Dr. Lincoln Nadauld of Intermountain Healthcare to use genetic mapping to help develop personalized treatment options with you and your oncologist. This service analyzes your tumor DNA and identifies actionable mutations.



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

Intermountain Cancer Genomics utilizes a molecular tumor board of physicians and researchers to discuss each individual case and explore every possible treatment option. If a mutation is identified and a medication is available for that specific mutation, Intermountain Cancer Genomics works on obtaining the medication using a unique drug navigation program. While Intermountain Cancer Genomics can't match every patient with an effective medication every time, about 70 percent of patients have been matched with new drugs.

The current genomics treatment method is being used for patients who have failed standard treatments.

Intermountain Cancer Genomics will work you on an individual basis to bill Medicare, private insurance and offer financial assistance as needed.

If you are interested in this service, Intermountain Cancer Genomics will provide a letter to give to your oncologist to have them contact Intermountain Cancer Genomics.

A live teleconference for patients and doctors is scheduled to explain details and answer your questions on Sept. 26th at Noon (Pacific Time.)

Don't miss this opportunity to contribute to LMS research while getting your own personal recommendations for treatments based on your own tumor genetics.

JOIN THE LIVE WEBINAR!

How to join the Webinar

1. Go to:
<https://intermountainmeetings.webex.com/intermountainmeetings/j.php?J=624646580>

While you view the website, then...

2. Phone (Toll Free) [1-866-713-7506](tel:1-866-713-7506)
3. When asked, enter the Meeting ID:
624 646 580 followed by the (#) pound sign

There will be time for questions at the end of the webinar. This will be recorded for others to access via the website on LMSarcoma Direct

Forward this
message to a friend

Research Foundation www.LMSdr.org

Investigative Story on Uterine Morcellation to Air in September



Keep an eye out for the story on morcellation for uterine fibroids, this month TBA on CBS's 60 Minutes.

Surgery of First Single Recurrence Improves ULMS Survival

[Prognostic factors and survival in patients treated surgically for recurrent metastatic uterine leiomyosarcoma.](#)

Int J Surg Oncol. 2014;2014:919323. doi:10.1155/2014/919323. Epub 2014 Jun 22.

Hoang HL¹, Ensor K², Rosen G³, Leon Pachter H¹, Raccuia JS¹.

Abstract

Background. Uterine leiomyosarcoma (LMS) is a rare diagnosis, which is seldom cured when it recurs with metastatic disease. We evaluated patients who present with first time recurrence treated surgically to determine prognostic factors associated with long-term survival. Methods. Over a 16-year period, 41 patients were operated on for recurrent uterine sarcoma. Data examined included patient age, date of initial diagnosis, tumor histology, grade at the initial diagnosis, cytopathology changes in tumor activity from the initial diagnosis, residual tumor after all operations, use of adjuvant therapy, dates and sites of all recurrences, and disease status at last followup. Results. 24 patients were operated for first recurrence of metastatic uterine LMS. Complete tumor resection with histologic negative margins was achieved in 16 (67%) patients. Overall survival was significantly affected by the FIGO stage at the time of the initial diagnosis, the ability to obtain complete tumor resection at the time of surgery for first time recurrent disease, single tumor recurrence, and recurrence greater than 12 months from the time of the initial diagnosis. Median disease-free survival was 14 months and overall survival was 27

months. Conclusion. Our findings suggest that stage 1 at the time of initial diagnosis, recurrence greater than 12 months, isolated tumor recurrence, and the ability to remove ability to perform complete tumor resection at the time of the first recurrence can afford improved survival in selected patients at the time of the first recurrence can afford improved survival in selected patients.

PMID:25045534

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<http://www.needymeds.org/index.htm>

NeedyMeds is a web-based information resource for people who need assistance paying for health care. NeedyMeds has information on patient assistance programs that provide free or low-cost medicine to people who are uninsured or underinsured. Patients are able to search a directory of drugs (listed by brand name or generic name) that are available through the Patient Assistance Programs (PAPs) of the respective drug companies. NeedyMeds does not supply medications or financial assistance but helps people find programs that provide these services. They also offer information on other assistance programs, such as discount drug cards, disease-based assistance (programs that help with costs associated with specific diseases), and free or low-cost clinics.

Send Us Your Prayer Flags!



At the LMS Retreat, we'll be offering flags to decorate again. If you can't come, please be part of the celebration by sending us your own homemade one. Flags can express heart felt encouragement, well-wishes or remembrance of those who have lost thier battles. We'll string your flags up with the rest of the groups!

Directions [HERE](#)

Uterine Morcellation Show

The Dr. Oz

The Dr. Oz Show on the Fox station will be airing a segment on the issue of uterine morcellation this month.

[Check your local listings for the times.](#)



Just published...

[Metastatic pattern, predictors and outcome of ULMS](#)

Tirumani SH, Deaver P, Shinagare AB, Tirumani H, Hornick JL, George S, Ramaiya NH.

J Gynecol Oncol. 2014 Aug 5.
PMID: 25142630

Thriver, Beth Grady

30 Years!

My story begins in 1983. During my hysterectomy for a fibroid, the surgeon removed an intact grapefruit-sized tumor weighing 1.5 pounds. It was a “stromal tumor of unknown malignant potential” or [STUMP](#) for short. The doctor explained that it would be considered cancer except that it had a low mitotic rate. I spent the rest of that day wondering whether or not I had cancer? But I soon forgot and no follow-up was advised.



Ten years went by. I experienced many changes during those years

ten years went by. I experienced many changes during those years including a divorce, a marriage and retirement. I started hormone replacement therapy (HRT.)

1995, during a pelvic exam my doctor discovered a large retroperitoneal tumor. Just prior to removing the mass it ruptured, spilling the fluid contents into my gut. They said it would "probably behave in a benign fashion."

Not until 1999 did I have my very first CT scan for another retroperitoneal tumor. Surgical pathology identified as low-grade leiomyosarcoma (LMS).

In 2000, I was again in surgery to remove a pelvic low-grade LMS tumor.

In 2003, my CT scan indicated one tumor in the pelvic area, but during surgery the doctor was surprised to find five. Scans don't always tell the whole story. I discontinued the HRT because it was evident that the estrogen was feeding the tumors.

About that time, I discovered the [ACOR](#) LMS website and an LMS support group led by other patients in the SF Bay Area. I also traveled for the first time to a sarcoma center for a second opinion.

My 2004 CT showed a large tumor in one lung and a small one in the other lung. Surgery revealed the larger one was predominately a low-grade *lipo*-sarcoma containing both low and high grade LMS.

I had no evidence of disease (NED) until 2007, when another LMS tumor was removed from my abdomen.

In late 2008 a new 2 cm mass in the abdomen was seen on the CT scan. I began taking letrozole (Femara), an anti-estrogen drug and just four months later the 2 cm thingy was now just a residual 3 mm. EUREKA!!

In 2009, the abdomen/pelvis scan showed a 3 cm mass. In 2012, I lowered my letrozole dosage to ½ tablet per day to help both the hot flashes and bone density. This pelvic nodule is still stable today and all lung scans continue to show NED.

I feel certain that if I had access to the ACOR website back in 1983 I wouldn't have gone through so many surgeries. I keep abreast of new developments in the LMS arena without dwelling on the subject. Many good things are happening. I'll see you at the LMS Retreat!

Shop for the Cause

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