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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 - May 2015

undefined



As patients, it's your *right and responsibility* to attain and keep copies of your medical records, test results and history.

Why?

- Be informed and know your medical history to participate equally in treatment decisions.
- Review scans and reports for accuracy. Have errors corrected.
- Be able to supply missing information to any practitioner you are consulting.
- Preserve records and scans indefinitely.

Providers are legally required to share any notes or records they have created themselves, or any test results for which they have copies. They're also required to share any information provided to them about you by another doctor if that information was used for the diagnosis and/or treatment being discussed with you.

Effective as of October 2014, labs have up to 30 days to provide you with test results.

Providers, including doctors, hospitals, labs and other medical practitioners are required to keep most medical records, scans and paraffin blocks for 6 years or more. They can legally destroy them after that.

## 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](https://smile.amazon.com)  
and donate to  
LMSdr

Buy **DVDs** of the 2014  
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more, they can legally destroy them after that.

Pathology labs are required by Federal CLEO laws to keep your paraffin block tumor tissues for only 5 years. They may destroy them after 5 years but most keep them 10 years. You have a right to those tissues before they destroy them, if you ask. You want the very first and last tumor tissues as it has the most information.

Most medical facilities will charge you for the cost of the photocopies, retrieval and mailing fees. Each State has set a maximum amount you can be charged. [List of State fees.](#) If this is a hardship, you can ask the hospital for a waiver in writing.

Contact the Medical Records Department for copies of surgical, pathology, radiology reports and doctor's notes. Contact the Film Library to make you copies of your scans or Xrays, usually supplied on CDs.

Organize your own medical records. Most patients file them in a simple 3 ring notebook, divided into the following sections with the most recent reports on top of the past reports. Use a highlighter over the dates and specific findings. Bring it to all appointments.

- Surgical reports
- Pathology reports
- Radiology reports (scans, treatments)
- Doctor's notes or summaries
- Blood labs
- Contacts (doctors, labs, hospitals, etc.)
- Medication log

Further reading:

[How to Get Your Test Results](#)

[Why Does My Doctor Make Me Return to the Office to Get My Medical Test Results?](#)

[How to Correct Errors in Your Medical Records](#)

**A Big Win!**

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

The phase III trial tested Eribulin in sarcoma patients, and it extended overall survival in LMS patients compared to the control group. Eribulin is already approved for breast cancer. Odds are the FDA will approve the drug for LMS and allow patients to receive the drug in fairly short order. Read more [HERE](#)

## Calling all Patient Advocate WANNABES!

Cloud 1 10



LMSdr is sponsoring an **LMS Patient Advocate Training** on November 4th which includes attending the [CTOS](#) sarcoma research conference November 5th to 7th in Salt Lake City, Utah.

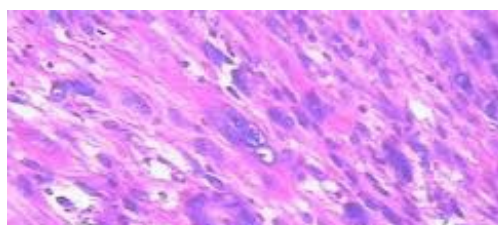
Speakers will teach you how to understand the research presentations and findings, patient advocacy 101, legislative advocacy and cancer patient coaching skills. We will also have 12 monthly webinar support sessions by internet.

Sponsorship includes hotel, meals and conference fees. Applicants will pay for their own transportation. This training is being funded by

Applicants will be selected by their desire and commitment to volunteer as an LMS advocate for a year. LMS patients, caregivers and friends of may apply.

Send an email to [Sharon 2SharonAnderson@gmail.com](mailto:Sharon2SharonAnderson@gmail.com) for an application and more details. Selections will be made by 7/1/15 and announced in the July LMSeAlerts.

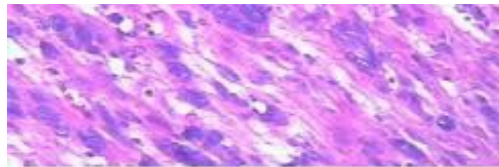
## Update on the LMS Tissue Collection at Stanford



In 2005, LMS patients Iqbal Ahmed and Sharon Anderson launched a paraffin tissue block drive of LMS tumors in collaboration with Dr. Matt

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](http://LMSdr.org)

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Marked cellular atypia in a leiomyosarcoma

van de Rijn at Stanford University.

[VIDEO - Story of the LMS Tissue Drive](#)

Since 2005, over 750 LMS patients have participated resulting in over 500 paraffin blocks.

The following researchers have also used this collection for their own LMS studies:

Matt Anderson, MD, PhD  
Baylor College of Medicine, Houston

Torsten Nielsen, MD, PhD  
University of British Columbia, Canada

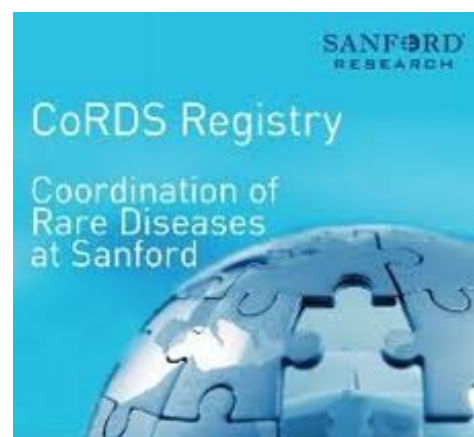
Jonathan Fletcher, MD, PhD  
Harvard Med School, Boston

Alexander Lazar, MD, PhD  
MD Anderson, Houston

The collection is ongoing. You can read the details and get the consent form [HERE](#). You simply return your consent and we take care of the rest! If we are able to attain a paraffin block, then Sharon Anderson will phone you to get your LMS history to go with the sample. All patient identities are anonymous to researchers. You will find all the details at the above link.

## LMS Patient Registry... coming soon!

We are excited about our new partnership with [CoRDS](#) of Sanford Research. Expected to open this June 2015, the LMS Patient Registry will be available to help collect patient data (deidentified) for researchers. Our LMS



registry will compliment but [not](#) replace the Sarcoma Foundation of America's (SFA) patient registry, of which LMS is largest subgroup. [SFA's registry](#) collects more detailed history from your medical records. The LMSdr registry is available for researchers to find patients that might qualify for their own studies. We hope you join both registries and help us work toward finding treatments that work.

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### **Selumetinib with Temezirolimus Active for LMS**

A new phase II trial demonstrated activity against LMS. An improved median progress free survival (PFS) was observed in the combination arm (N=11) over single agent (N=10) in the prespecified leiomyosarcoma stratum (median 3.7 vs 1.8 months; P=0.01). Four-month progression free survival rate (PFS) was 50% with the combination vs 0% with selumetinib alone in the leiomyosarcoma cohort. Read more [HERE](#)

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### **SBRT Provides Excellent Local Control**

[Stereotactic body radiation therapy for lung metastases from soft tissue sarcoma.](#)

Eur J Cancer. 2015 Feb 13. pii: S0959-8049(15)00105-7. doi: 10.1016/j.ejca.2015.01.061.

SBRT provides excellent local control of pulmonary metastasis from soft tissue sarcoma (STS) and may improve survival in selected patients. SBRT should be considered for all patients with pulmonary metastasis (PM) and evaluated in a multidisciplinary team. [Read more at the above link]

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### **PD1 Trial Re-Opens**

**And more sites coming soon!**

[A Phase II Study of the Anti-PD1 Antibody Pembrolizumab \(MK-3475\) in Patients With Advanced Sarcomas](#)

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## **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](mailto:kganjoo@stanford.edu) for the video and consent form.**

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## **NLMSF Connect Conference - August 6-8th**

National LMS Foundation is sponsoring a conference for LMS patients in Columbus, Ohio. The Connect Conference was formerly known as "HugFest." Keynote speakers are Drs. Matt van de Rijn and Raphael Pollock. For hotel and program details contact Lori [lori@nlmsf.org](mailto:lori@nlmsf.org)

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## **Aldoxorubicin Trials Available**

Phase 1 Study to Investigate the Safety and Activity of [Aldoxorubicin Plus Gemcitabine](#) in Subjects With Metastatic Solid Tumors

Phase 1 & 2 Study to Investigate the Safety and Activity of [Aldoxorubicin Plus Ifosfamide/Mesna](#) in Subjects With Metastatic Soft Tissue Sarcoma

Phase 3 Study to Treat [Patients With Soft Tissue Sarcomas](#)

For more trials go to [ClinicalTrials.gov](http://ClinicalTrials.gov)

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## **Management of Advanced Uterine LMS**

[Curr Opin Oncol.](#) 2014 Jul;26(4):422-7.

[Hyman DM](#)<sup>1</sup>, [Grisham RN](#), [Hensley ML](#).

RECENT FINDINGS: The management of patients with advanced uterine LMS is divided between those with localized and those with disseminated disease. Selected patients with localized or single-organ oligometastatic disease may benefit from surgical resection. For patients with disseminated disease, fixed-dose-rate gemcitabine plus docetaxel is an appropriate first-line chemotherapy regimen. Other active cytotoxic agents include doxorubicin, ifosfamide, and dacarbazine. The role of trabectedin (approved by the European Medicine Agency to be marketed for advanced or metastatic soft tissue sarcoma) is being explored. Trials are also underway for targeted therapy in uterine LMS. Currently, the only approved targeted therapy for advanced soft tissue sarcoma is pazopanib. In patients with small volume and slowly progressive estrogen receptor/progesterone receptor-positive disease, antiestrogen therapy with an aromatase inhibitor is a reasonable alternative to observation alone. [Read more at the above link]

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# Research

Community  
Volunteers Patients  
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Retreat Advocate  
Tissue LMSarcoma  
LMSeAlerts  
Foundation

## LMSdr supports the Open Act

LMSdr has joined the Rare Disease Legislative Advocates (RDLA) to pass The Open Act HR 971.



It takes the average of 14 years and two billion dollars to develop a drug, of which 90% fail.

The Open Act can provide incentives for industry to invest in "re-purposing" existing drugs for potential use in the rare disease community.

[Read more](#)

## **ACTION ALERT**

Sign a petition to The United States House of Representatives, The United States Senate, and President Barack Obama, which says:

1. Ban the faulty Power Morcellator , a surgical device, that spreads a deadly hidden cancer masquerading as a common fibroid.
2. Revise the FDA's 510K clearance process, that fast tracks approval of medical devices without clinical trials."

Will you sign the petition too? Together we are more effective.



[Click here](#) to add your name and pass it on to friends.

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## Update on Morcellation Campaign

On 4/21/15, Drs. Amy Reed and Hooman Norchasm testified at the FDA's workshop on post-market surveillance of medical devices. View each of their testimonies: [Hooman](#) and [Amy](#)

Congressman Mike Fitzpatrick (R-PA), also testified and called for immediate congressional oversight over FDA's CDRH to ensure patient safety. The congressman has stated that he is prepared to "introduce new legislation if that is what it takes to keep people safe". Watch testimony [HERE](#)

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## Free Summer Camp for Children



For children with a parent fighting cancer, Camp Kesem helps bring back a little magic to the summer while helping children find ways to cope. Camps are a week long, sponsored by Universities - check for a location near you. [Apply now!](#)

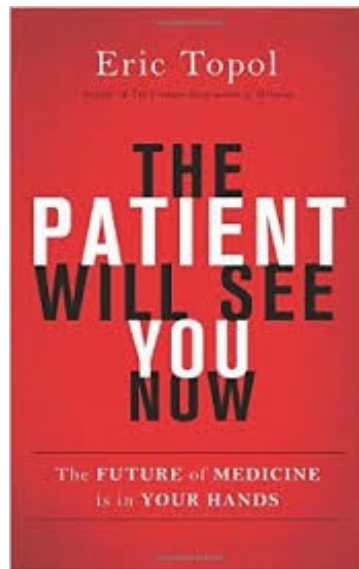
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The annual [National Conference on Work & Cancer](#) will be held on **June 12, 2015**, in New York City. The conference explores the challenges working people face — including **job search, health insurance, legal issues, working through treatment, job re-entry and more** — as they try to balance their cancer treatment and recovery with employment. Speakers will include oncologists, cancer rights attorneys, medical social workers, career coaches and other experts on the intersection of work and cancer.

This conference is FREE to attend for cancer patients, survivors, caregivers and healthcare professionals. [Travel scholarships](#) and [CEUs](#) available.

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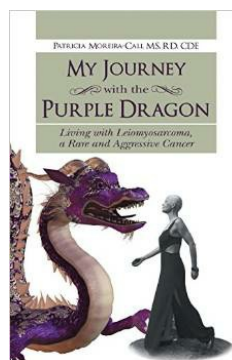
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**Amazon.Smile.com**

Much as the printing press took learning out of the hands of a priestly class, the mobile internet is doing the same for medicine, giving us unprecedented control over our healthcare. With smartphones in hand, we are no longer beholden to an impersonal and paternalistic system in which "doctor knows best." Medicine has been digitized,

Topol argues; now it will be democratized. Computers will replace physicians for many diagnostic tasks, citizen science will give rise to citizen medicine, and enormous data sets will give us new means to attack conditions that have long been incurable. Massive, open, online medicine, where diagnostics are done by Facebook-like comparisons of medical profiles, will enable real-time, real-world research on massive populations.

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## MY JOURNEY WITH THE PURPLE DRAGON



Written by LMS survivor, Patricia Cali, this book follows her inspirational journey as she learns to live with a rare and aggressive cancer...while battling back and winning every day. Part of the profits will be donated to LMSdr.

<http://www.purpledragonjourney.com/>

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### Caroline Abbey, 11 yr. Thriver



STUMPING LMS with  
Letrozole

I had a total abdominal hysterectomy in 2004 because of growing fibroids. A 5 cm.



tumor was found. Slides were sent to Harvard for a second opinion who deemed it “a most difficult case.” They reluctantly classified the tumor as STUMP - Smooth Muscle Tumor of Unknown Malignant Potential. I was told there was only a 1%

–2% chance of a recurrence. There was no follow-up at all. I continued taking hormone replacement therapy pills for the next 7 years.

Lucky for me, my company required a chest x-ray in 2011. Diffuse nodules were found in both my lungs, at least a half dozen between 1 to 2 cm, and many smaller. The following CT scan 3 months later showed considerable growth. A thoracotomy revealed these were leiomyosarcoma. The mitotic index was 6, much greater than the “less than 1” in the original STUMP tumor.

My tumor was 78% positive for estrogen receptors and 82% for progesterone receptors. Dana Farber put me on the aromatase inhibitor (AI) letrozole, a tiny yellow pill taken daily. Within a few months, there was considerable shrinkage, which eventually made most of the lung nodules cavitate. My tumors have become “indolent” and I’ve been progression free for the last 3 years.

The AI brings some joint pain, and of course, hot flashes. My bone density is now in the osteopenia range. I’ve been taking vitamin D, and my last bone density scan showed stability over the past two years. I’ve stayed active, golfing, kayaking and hiking.

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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

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## 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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**Shop Now!**

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