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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 - March 2015

Update on CD47 & ROR2 LMS Research at Stanford

Dr. Matt van de Rijn's laboratory continues to make progress on LMS specific research based on his [LMS paraffin tissue block collection](#).

In 2008, Dr. van de Rijn published [Prognostic Significance of Macrophage Infiltration in Leiomyosarcomas](#). He found that cells expressing CD47 drove macrophages to the LMS tumors and the macrophages drove tumor growth. The hope is that by creating an anti-CD47 antibody, it would stop the drawing of macrophages to the tumor and slow down tumor growth. Dr. Irving Weissman is currently testing this theory in a phase I trial with non-LMS patients. See below.

While Dr. van de Rijn is not involved in the Phase I anti-CD47 trial, he has continued to make vital discoveries on it's role with LMS. Please read past summaries of all his LMS work [HERE](#).

2015 Updates



CD47

Through a commercial vendor Dr. van de Rijn developed a rabbit antiserum against the CD47 protein and preliminary tests in his lab

indicate that this can be used on paraffin blocks to see if a tumor actually expresses CD47 or not. If all works out this could be used to make sure that patients that do not express CD47 on their tumor will not needlessly be exposed to anti-CD47 treatments.

ROR2

With a commercial vendor Dr. van de Rijn has made several

Paraffin Block Drive for LMS Research



LMS patients have donated over 600 primary paraffin tissue blocks for research - please [join us](#) and build our tissue collection.

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customized anti-ROR2 antibodies that inhibit the function of this protein; a protein that he previously has shown to be involved in LMS tumor growth. In the coming year he hopes to test the degree of inhibition by these antibodies in more detail. Ultimately the goal is to choose the most promising candidate and to develop this as a targeted drug for LMS. This will take many steps.

Second, Dr. van de Rijn has started a large gene expression profiling project meant to discover other genes that are involved in the ROR2 pathway. Very little is know about this pathway and we need to learn more in order to develop this as a promising target.

Phase I Anti-CD47 Vaccine Trial Update

In 2014, Dr. Irving Weissman at Stanford University began his [phase I trial using the anti-CD47 antibody](#) that he developed, on a small group of non-LMS patients. If there is good response, then LMSdr will advocate again to open the phase II to include LMS patients.

LMSdr Participating in Rare Disease Conference

LMSdr advocates will be attending the Rare Disease Conference sponsored by UC Davis on March 5-6 in Davis, California. The conference will look at rare disease research, the obstacles and new approaches that are shaping the future of research and how to treat difficult diseases. Speakers and panels from academia, industry and patient advocacy groups will share perspectives on driving innovation towards finding cures for people living with rare disease.



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

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
and funds LMS specific

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.

NCCN Guidelines for Patients!

[The National Comprehensive Cancer Network](#) (NCCN) is a group of the top 25 cancer centers who make recommendations for the "standard of care" which most oncologists follow. They also publish a patient version of the guidelines to help you make informed decisions and be an active participant in your own treatment plan. **Read the updated soft tissue sarcoma guidelines [HERE](#).**

Research

[Tissue collection](#)

Fundraisers

Blood samples

Participate!

and fund 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](#)

Calling all LMS Patient Advocate Wannabe's

LMSarcoma Direct Research Foundation will be hosting an educational patient advocate meeting at the [CTOS](#) sarcoma oncology conference.

LMSdr Patient Advocate Project

November 4-7, 2015

Salt Lake City, UT

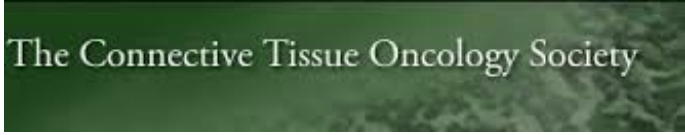
LMSdr will mentor new LMS patient advocates by conducting an orientation to the CTOS conference, research and advocacy. Then, LMSdr patient advocates will attend the CTOS presentations. Follow-up webinars will be provided.

We are accepting sponsorship donations to help your fellow patients learn how to be advocates for, and understand LMS research, in hopes of passing it forward.

Sponsorship entails CTOS conference fees, two additional meals to the meals included during the CTOS conference, workshop and speakers. Patient Advocates will provide for their own transportation and lodging.

LMS Patient Advocates can be patients or caregivers, long term survivors or newly diagnosed. Space will be limited. Decisions on who is selected will be based on your plans on how you will "pass it forward."

If you'd like to get on the email list for more information, or offer a sponsorship write 2SharonAnderson@gmail.com



The Connective Tissue Oncology Society

Yondelis Update

[U.S. FDA Grants Priority Review for YONDELIS® \(trabectedin\) for the Treatment of Patients with Advanced Soft Tissue Sarcoma](#)

Janssen announced that the U.S. Food and Drug Administration (FDA) has granted Priority Review for the New Drug Application (NDA) for YONDELIS® (trabectedin) to treat patients with advanced soft tissue sarcoma (STS), including liposarcoma and leiomyosarcoma subtypes, who have received

prior chemotherapy including an anthracycline. Janssen submitted the NDA to the FDA on November 24, 2014.

Priority Review is a designation for a drug that treats a serious condition and may offer major advances in treatment when compared to existing options. A priority review designation means the FDA's goal is to take action, following the two month period for the validation and acceptance of the NDA, within six months as compared to 10 months under standard review. [Continue reading entire announcement at the above link]

Eribulin Extends LMS Survival in Phase III



Treatment with eribulin mesylate significantly extended overall survival (OS) compared with dacarbazine in patients with advanced soft tissue sarcoma,

according to topline results from a phase III clinical trial. The open-label study, titled Study 309, enrolled 452 patients with locally advanced or metastatic adipocytic sarcoma or leiomyosarcoma who had progressed on two prior therapies, including an anthracycline. The primary endpoint of the study was OS, with progression-free survival (PFS) as a secondary outcome measure. [\[Read the rest of the article here\]](#)

May 2nd Patient Education Conference



[Ask the Experts: Advances in Sarcoma Treatment and Research](#) hosted by Sarcoma Foundation of America will be May 2nd, 11 am to 3pm in New York City. The event is free but you must register.

This event includes a panel of sarcoma experts, Q & As and buffet luncheon. For all types of sarcoma patients and supporters.

When Cancer Comes Back

[Thrive Summer 2014](#)

U of Michigan Comprehensive Cancer Center

Leiomyosarcoma survivor Jennifer Kelly gives inspiration on how to deal with fear of recurrence



Jennifer Kelley never lets go of the idea she has cancer. She does not want to let her guard down. However, as she moves forward with no evidence of disease, she is able to focus more on living and less on worrying.

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:

Bevacizumab Fails to Improve Gem/Tax Treatment

[Randomized Phase III Trial of Gemcitabine Plus Docetaxel Plus Bevacizumab or Placebo As First-Line Treatment for Metastatic Uterine Leiomyosarcoma](#): An NRG Oncology/Gynecologic Oncology Group Study.

Phase II evaluation of [ixabepilone](#) - not effective with ULMS

Gynecol Oncol. 2014 Oct;135(1):44-8.

CAMP DATES ARE SET FOR 2015

[APPLY NOW](#)

CAMPS FOR SURVIVORS

- March 1-7 Fred Hutchinson Cancer Center and Northwest
- May 31-June 6 University of Colorado Cancer Center
- June 7-13 Shaw Regional Cancer Center
- July 26-Aug 1 UCSF and Stanford Cancer Centers



Attend our **free** week-long outdoor experiences for individuals who have been diagnosed with cancer. We welcome those that were diagnosed at any time in their lives. It could be last month or 10 years ago.

Conference



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.

Free Patient Help

Do you need someone to help you battle your insurance? Need help with your medical debts or prescription co-pays?

The [Patient Advocate Foundation](#) offers free caseworkers, live chats and webinars for patients. Call them at (800) 532-5274.

GINGER FOR NAUSEA

Some people with cancer find that



the taste or aroma of beverages and foods with ginger helps soothe their nausea. There's been some research to validate this, although more needs to be done. Ginger should never be used to replace your anti-nausea medications and with any herb, you should consult a health care provider qualified in the field of botanical medicine.



Here are two good sources of information on Ginger:

[University of Maryland Medical Center](#)
[American Cancer Society](#)

There are zillions of recipes to add ginger to any dish, including dessert. Ginger cookies, candy, lollipops and lozenges are easy to buy online. The simplest way to make tea is to cut 4-5 slices of fresh ginger root and add to 1-2 cups hot water!

A Pot of Ginger Tea

INGREDIENTS

1/4 cup grated fresh ginger root

4 cups boiling water

4 teaspoons honey

Optional: lemon, cinnamon stick, or mint leaves

DIRECTIONS

Put the grated ginger into a teapot and pour in the boiling water. Allow the mixture to steep for 4 minutes. Strain and serve the tea with a teaspoon of honey in each cup. Stir and serve.

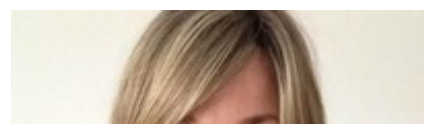
Join Face Book Group: Campaign Against Morcellation &

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

Did your hysterectomy or myomectomy involve using laparoscopic morcellation? Join this group to learn about the issues and what you can do!

14 Year Thriver, Suzy Allen

Moving Forward
San Francisco, California



When I was diagnosed with uterine LMS in June of 2001, I had 10% chance surviving 5 years. I believe diet is a big part of my survival. I have survived 14 years “against the odds” and the only thing that has been consistent since 2008 is eliminating sugars and gluten (celiac dx 2008.)



Between 2001 and 2004, I had lung mets. My treatments were AIM, Gemzar/Taxotere, Iressa and five thoracotomies.

In 2003, I stopped eating sugar of all kinds for 90 days. They were monitoring another lung met. After 90 days the PET/CT showed the tumor cavitated. My doctor was shocked. I was not undergoing any chemo and the only thing I changed was my diet. Due to stress, I started to have my Starbucks chai lattes and scones again and the next 90 day scan showed my tumor was growing.

2004-2008 I had 4 years of NED (no evidence of disease) until 2008 when I had another thoracotomy. When lung mets returned in 2013 I had cyber knife and took Tamoxifen for a few months. I've been NED since.

Set boundaries on how you will discuss your cancer with people. It's OK to not discuss it if you don't want to. Many times I would be out at a party having fun and someone would discuss my illness. I went home feeling bad. I had finally forgotten about it and there I was rehashing and reliving my nightmare, when I really wanted to move forward.

I chose to stop focusing and discussing my illness and treatments 90% of the time, and instead focused 90% on living, health and wellness. I started to journal my thoughts. I wanted to experience joy, fun and make new memories with family and friends and not spend lunch or dinner discussing cancer. It made me feel bad and I didn't want to feel bad anymore.

Focus on what you have, not what is lacking. I spent many years angry about what cancer had taken away from me. I fought so hard to live my life, and I realized I was not living that life. I learned to forgive, move on and appreciate the life I fought for.

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](https://www.smile.amazon.com) you can designate a percentage of the proceeds to LMSdr!



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