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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 LMSeAlerts - MAY 2014

2014 World Orphan Drug Conference Networking with Pharmas for LMS

North America's largest [World Orphan Drug Conference](#)

took place April 23-25th in Washington D.C. The event is dedicated to fostering collaboration with researchers, government and patient organizations to expedite drug development for orphan diseases, from discovery to patient access.



A disease is considered orphan when it affects less than 200,000 Americans. In Europe it is defined as less than 1 in 2000. LMS is a rare orphan disease, estimated to occur 1 in every 250,000 people.

Sharon Anderson, Executive Director and Sarah Salem-Robinson, Scientific Advisor for LMSarcoma Direct Research Foundation met with over 200 pharmaceutical representatives and researchers interested in developing orphan drugs.

An example of collaboration, Sharon Anderson and Sarah Salem-Robinson met for breakfast with Arthur Klausner CEO of [GemPharmaceuticals](#).

Gem Pharmaceutical's phase 1 study of their less cardiotoxic analogue of doxorubicin called [GPX 150](#), contained four LMS patients, of which three of these individuals responded. Because of this, they will be focusing on LMS patients in their phase 2 study fall of 2014.

Sharon Anderson advocates, "LMS can be a good candidate for researchers. There's a wide open market because we don't have drugs that work well and our

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

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patient population is very well organized. We can get the word out about promising drug trials and encourage enrollment to speed up the research.”

Photo: Sharon Anderson was nominated and chosen for the Patient Advocate Heroes Poster at the World Orphan Drug Conference.

REGISTRATION OPEN

October 30th - November 1st
LIVE IT UP! LMS Retreat 2014
San Francisco

Major Victories for ULMS Morcellation Campaign!

Thanks to Hooman Norchasm, Amy Reed, Sarah Salem-Robinson and many LMS families, the FDA has issued a [medical device warning](#) against the use of morcellation for uterine fibroids. Read NY Times April 17, 2014 "[FDA Discourages Procedure in Uterine Surgery.](#)"

As a result on April 29th, Johnson & Johnson, the manufacturer of power morcellators has suspended sales of their product. Read [Wall Street Journal 4/29/14.](#)

The FDA wants to hear testimonies from victims of uterine morcellation this month. Please contact Sarah sarahssr@gmail.com if you can help by telling the FDA your story in person, by letter, video or photo.

“Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it's the only thing that ever has.”

Margaret Mead

New... Cancer Coaching

Hospitals are beginning to add a new member the cancer team: your personal cancer coach. Different from a therapist, a cancer coach offers guidance in setting goals, making decisions and changes in your “new” cancer life. Perfect for those in remission



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

**Forward this
message to a friend**

who say to themselves, “now what?” But coaching is also for patients and caregivers at any stage of the journey who need that extra unbiased support.

If your cancer center does not yet offer this, there are certified cancer coaches who work with patients over the phone from any location in the world, like [The Cancer Journey](#).

Learn more

[Do You Need A Cancer Coach?](#) CureToday
9/13/11

[Panic to Powerful:](#) Live - every Wednesday 3-4pm Pacific Time) Cancer Coaching on Internet Radio W4CS by The Cancer Support Network

[“Cancer Coaches” Help Patients Navigate Choices.](#)
_ NBCnews.com 2/17 /08

Apply Now!



A free week-long outdoor experience at a Colorado ranch for individuals who have been diagnosed with cancer.

Experiences include outdoor adventure activities such as stand-up paddle boarding and kayaking. All expenses paid. Apply now online <http://www.epicexperience.org/attend-an-epic-experience-week/>.

Phase I Trial for Lambrolizumab

Lambrolizumab (similar to Nivolumab) is a monoclonal IgG4 antibody directed against human cell surface receptor PD-1. The patient must have a solid tumor which has the biomarker for this study.

Title: [Phase I Study of MK-3475 in Participants With Advanced Solid Tumors.](#)

Clinical Trial ID: NCT02054806

Coming Up!

May 4th

San Francisco Bay Area LMS Support Group Meeting

San Leandro, California.

Contact Sharon 2taikomom@gmail.com

May 30th - June 3rd

50th Annual ASCO Conference, Chicago

June 18th Noon-1:30 pm

Sarcoma Patients Support Group at Cedar Sinai

Comprehensive Cancer Institute in Los Angeles. 3rd

Wed of every month starting in June. Lunch is served on

the Mezzanine level of the cancer center. Contact Pauline

(310) 423-8045 for details.

October 30th - November 1st

LMS Retreat in San Francisco (Registration open!)

www.2014LMSretreat.myevent.com

Warren Bailey, 13 yr. Thriver

Back in the Game

In March 2001, at age 55, I got the bad news from my primary doctor in Anchorage, Alaska, that the 6 cm lump in my thigh was

Leiomyosarcoma. There

literally wasn't an oncologist

in the entire State that knew anything about treating this

cancer. The closest sarcoma center was the Seattle Cancer Care Alliance.



My wife and I traveled to Seattle in our motor home, 2500 miles with winter still going strong down the Alaska Alcan Highway. Little did we know that Seattle would be our home for the good part of the next 5 1/2 years, with many treatments including many surgeries, AIM for chemo, radiation, and hyperbaric treatments and more. After a lung surgery in July 2005, I have been NED (no evidence of disease.)

I finally got back to the Sport that I love so much,

racquetball. I used it to bring awareness and raise money for LMS. I recently became the number one racquetball Player in the country over 65 years old, by winning the National Masters Racquetball Championships in Tucson, Arizona and made it into the Alaska "Hall of Fame".

Photo: Huntsman World Senior Games where Warren won a Gold, Silver and Bronze metal.

Mushrooms for May



May is mushroom month! Easy to add to almost anything: pasta, rice, chicken, meat, eggs, salad and veggies. But did you know that they are a proven natural aromatase inhibitor? And more [studies](#) cite mushrooms as an anti-cancer agent.

But always cook them. [Dr. Donald Abrams](#), Director of UCSF's Osher Center for Integrative Oncology, warns that mushrooms should not be eaten raw.

Mushroom are considered a "super food." They provide essential amino acids, vitamins, fiber and potassium. It's low in calories, fat and sodium. They contains antioxidants, boost the immune system and lower blood pressure.

Hungarian Mushroom Soup

Makes 6 servings

What You'll Need:

- 4 tablespoons unsalted butter
- 2 cups chopped onions
- 1 pound fresh mushrooms, sliced
- 2 teaspoons dried dill weed
- 1 tablespoon paprika
- 1 tablespoon soy sauce
- 2 cups chicken broth
- 1 cup milk
- 3 tablespoons all-purpose flour
- 1 teaspoon salt
- ground black pepper to taste
- 2 teaspoons lemon juice
- 1/4 cup chopped fresh parsley
- 1/2 cup sour cream

What To Do:

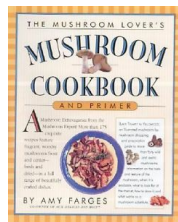
- 1. Melt the butter in a large pot over medium heat. Saute the onions in the butter for 5 minutes. Add the mushrooms and saute for 5 more minutes. Stir in the dill, paprika, soy sauce and

broth. Reduce heat to low, cover, and simmer for 15 minutes.

2. In a separate small bowl, whisk the milk and flour together. Pour this into the soup and stir well to blend. Cover and simmer for 15 more minutes, stirring occasionally.

3. Finally, stir in the salt, ground black pepper, lemon juice, parsley and sour cream. Mix together and allow to heat through over low heat, about 3 to 5 minutes. Do not boil. Serve immediately.

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!

LMSarcoma Direct Research Foundation
Post Office Box 52697
Tulsa, Oklahoma 74152
tel. 1-866-912-2730
fax: 1-413-502-2241
Email: Contact@LMSdr.org

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