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History of LMS Paraffin Block Drive
Video

Working not Wishing for the Cure

LMSarcoma Direct Research Foundation
LMSAlerts - June 2014

The Power of Connecting

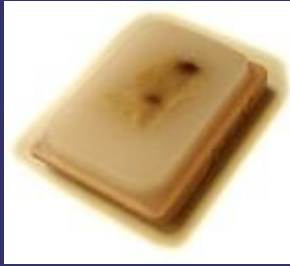


The Ladybugs and visitors

I'll never forget the surprised look on their faces when a group of LMS Colorado families discovered each other at the 2013 LMS Retreat. They've been meeting monthly ever since. There's a group of LMS women in the Washington D.C area, who call themselves the Ladybugs. Then there's the "Sac Pack" in Sacramento, California. San Francisco had the very first LMS support group in 2003, which is still active today.

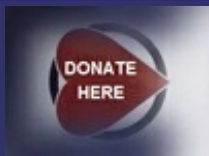
How do you find or start a local LMS support group? Best place is to find each other is on [ACOR LM-Sarcoma](#) group list serve. The upcoming [LMS Retreat](#) in October is another. Some people give their contact information to their oncologists to share with LMS'ers.

**Participate in the
Paraffin Block Drive
for LMS Research**



335 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

Support groups come in many forms: casual lunches, get-togethers at each other's homes and structured sharing and problem solving circles. But just being with others who have been affected by LMS, is both comforting and empowering. Daryl Brown shares her experience below...

**ACOR Want Ad: Baltimore Washington ULMS
Support Groups?**

"Anyone there? I'm feeling like a cork bobbing in the Atlantic far from shore, nothing in sight. Just me..."

-- Daryl Brown

Left to my own devices to learn about Uterine LMS, I scoured the internet. The articles frightened me. I was on my own and terrified. I was a walking time bomb with a 24-month expiration date....at least that is what I thought.

Less than 24 hours after the above post on ACOR, Laura of the "Ladybugs" invited me to lunch. Lady Bugs? Woo Hoo! I'm having lunch with 3 other LMS survivors. Hey! This is a big deal! I brushed up the wig, put my make-up on and headed out the door while dragging a 50-lb ball and chain. Found the restaurant, check! Looked inside for a group of sad sacks like me....none found. Instead I found a table with 3 vibrant, lively ladies welcoming me with open arms and hearts. We all shared our stories of diagnosis, treatment, and resources available to us. We talked (and laughed) non-stop for 3 hours. Somehow, the 50-lb ball and chain shackled to me for 7 months disappeared! My life as an LMS Survivor changed from that afternoon on. My heart was uplifted and soared for the first time since my diagnosis.

Support Groups Contacts

Denver, Colorado vickisun@comcast.net

Sacramento, California langhome@pacbell.net

Washington DC klk2410@yahoo.com

San Francisco Area 2SharonAnderson@gmail.com

FACEBOOK GROUP



LMSdr T-shirts and
water bottles
available
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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. M, L, XXL.

Read past issues of
[LMSeAlerts](#)

LMSdr advocates for

And meet more LMS families at the LMS Retreat - registration is below!

REGISTRATION OPEN

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

Open to Options

Ask Questions - Gain Confidence - Be Empowered

Open to Options is a free service by telephone to help patients identify important questions about your treatment options based on your personal needs.

Participants have reported:

- Decreased feelings of distress and anxiety
- Increased confidence in working with their medical team
- The ability to hold productive discussions with their doctor
- Satisfaction in having most or all of their questions answered



To schedule a session with an Open to Options facilitator, please call **888-793-9355**

Monday through Friday 9am - 8pm ET.

ULMS Patients To Testify with FDA

The FDA hearing on morcellation has been scheduled for July 10-11 in Washington DC. If you were a victim of morcellation please tell the FDA your story. If you can not

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

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attend, please send your photo or video. As many affected women, families and concerned individuals are asked to attend to protest the use morcellation. Come show your support and help save lives. This hearing will be the most important battle to ban morcellation on fibroids. Contact Sarah Salem-Robinson for details.

ASCO 2014

[The American Society Clinical Oncology](#) (ASCO) conference is underway May 30th - June 3rd in Chicago. You can search the abstracts on sarcomas [here](#).

Phase I Lambrolizumab is Full

10 spots in the Phase I lambrolizumab have all been filled with LMS patients. 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.

We will post any updates as they are officially reported, most likely at LMS Retreat in October.

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

Clinical Trial ID: NCT02054806

Need a drug from Europe?

[Durbin PLC](#) is a business in the UK that helps American patients legally attain cancer drugs that are available in Europe but not FDA approved in the US. Your oncologist must write the prescription and you send it to Durbin. Only your doctor may administer the drugs under their supervision. For more information contact Robert Donnell r.donnell@durbin.co.uk

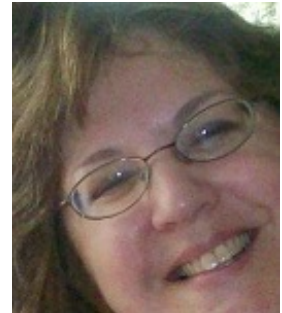
[Phase I Dendritic Cell Vaccine With or Without Gemcitabine Pre-Treatment for Adults and Children With Sarcoma](#)

In this trial, the patient's tumor is first resected and then a dendritic cell vaccine is made with the patient's own tumor. This type of vaccine is used to "teach" the immune system to recognize and attack the cancer cells. This study is offered only at the University of Miami Sylvester Comprehensive Cancer Center.

10 Year Thriver, Laura Penny

Another Grateful Ladybug

My GYN had been monitoring a 4 cm "fibroid" starting in 1997, when I was 37. But in 2004, I got a very heavy period and found the fibroid had grown to 10 cm. My GYN said it was time to take it out. I opted for a myomectomy. He warned me about LMS, but said it usually happened when the growth was more pronounced.



On July 1, 2004, I got results: low-grade LMS. I was devastated, especially because I had three young children. I got a TAH/BSO in 2 weeks. After surgery #2, I went to Sloan Kettering (MSKCC) for a consult, and all they told me was to watch and wait. My emotions were raw, but I got through this agonizing time by reading Lance Armstrong's books and holding onto every shred of hope I could find.

It recurred a year later, 2005, with two smaller tumors in the same place. I had another surgery. I went on Femara. Three months later, my follow-up scan showed a tumor in the same place again, widespread lymphadenopathy, and eight lung nodules.

In early 2006, I had VATS, a bronchoscopy, and a mediastinoscopy, all of which indicated sarcoidosis, not LMS, in my lungs and lymph nodes. Apparently the mesh used in a previous surgery caused an autoimmune reaction.

The pelvic tumor remained. The surgeon told me the previous

doctor had missed the second tumor in 2005. He removed that tumor in late 2006, and found and removed a second 2 cm tumor.

In early 2007, my onc started me on Faslodex. I still get those shots monthly. My scans are all clear.

In 2010, I started having lunch with others in Maryland with ULMS. Soon the "Ladybugs" were born, giving me a place to support others and voice my own fears.

I will celebrate 10 years since diagnosis on July 1, 2014. My kids were 11, 9, and 2 when I was diagnosed, the youngest adopted from Cambodia after already losing one mom. Now they are 21, 19, and 12. I know no one's future is certain, but I am thankful I've seen my kids grow up.

If you are a long term LMS survivor who would like to give hope to others by sharing your story, please contact
2SharonAnderson@gmail.com

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