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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  
**LMSAlerts - AUGUST 2014**

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## **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!**

### **LIVE IT UP!**

Renew your spirit and hope by: meeting inspiring survivors, learning about the newest treatments and trials; finding



out how you can "personalize" your own treatment to target your own LMS cells and learn about complimentary therapies. Conference fees include a sunset dinner cruise on the San Francisco Bay!

Last year, 90 of us met for the first time at Copper Mountain near Denver, Colorado. The response was so overwhelming positive that we're doing it again,

## Paraffin Block Drive for LMS Research



350 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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and donate to  
LMSdr

**Buy DVDs of the 2013  
LMS Retreat  
Presentations**

Visit Our Website  
[LMSdr.org](#)

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one more time! We anticipate 100-150 participants this year.

The Retreat kicks off with a buffet dinner reception with introductions and presentations. Each morning, speakers are scheduled. From noon to dinner, your afternoons are free to go play in San Francisco. Come back for our sunset dinner cruise and our final dinner where we'll have more motivational speakers and presentations.

We suggest you schedule a few extra days to see all the sights or take side trips to the Napa wine country, Monterey, Yosemite or Lake Tahoe.

Register and read all the details [HERE](#).

### Retreat Message Board Open!



Want to find someone to share a ride with from the airport? A room? A bike ride? Find other attendees and start planning

your free time and getting to know each other.

LMS Retreat Message Board [HERE](#)

## **REGISTER HERE**

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

## **FDA Testimonies on Uterine Morcellation for Fibroids / ULMS**

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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.

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Read past issues of  
**LMSeAlerts**

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LMSdr advocates for  
and funds LMS specific  
research. We've been

Regardless of what the final outcome is from the FDA Hearing on July 10th & 11th, the LMS community successfully stood up, spoke out, and got the attention of the Advisory Panel Members. [See Dr. Norchasm's testimony](#)

Speakers, both pro and con, acknowledged several facts:

1. There is no definitive way to identify ULMS with MRI or biopsy before surgery.
2. Morcellation scatters both benign and malignant fibroid tissue into the sensitive peritoneal cavity where it can grow and thrive.
3. The best possible surgical method for any cancer is surgical removal in-tact with wide margins.
4. Morcellation within a bag impairs vision and risks breakage or spillage.
5. With an open abdominal surgery, 50-55% of women with ULMS at stage 1, will never see it again and are considered cured.
6. Woman who undergo morcellation are considered to have as the same risks as those at stage 4.
7. Morcellation compromises the pathologist's ability to find and diagnose a hidden cancer.
8. There's not enough education and disclosure about the risk of ULMS before morcellation. Even if there is, women trust and rely on their doctors to know what's safe and best for them. Studies have shown how poorly people tend to comprehend medical risks.
9. Legally a case of upstaging by morcellation fails two tests: Was it preventable and was it predictable?
10. Laparoscopic hysterectomy is a safe alternative and minimally invasive causing only a 4-5 inch incision.

Next, the Advisory Panel will give their recommendations to the FDA. Public comments to the FDA is open until Aug. 11th. We expect the FDA to make their ruling within 30 days.

I deeply admire everyone who traveled to Washington DC to express their own heartfelt stories. Drs. Amy Reed, Hooman Norchasm and their family especially showed

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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great courage and tenacity which inspired us all and undoubtedly made a huge difference in moving this mountain! And our gratitude goes out to all of you at home who watched, sent their letters, shared photos and cheered us on. I'm truly proud of our LMS community!

"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*

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## **Johnson & Johnson Recall Their Morcellators**

Breaking news reported by the Wall Street Journal on 7/30/14. Johnson & Johnson is asking for all morcellators to be returned to them. It is expected that the other manufacturers, Storz, Wolfe and Lina will also recall their devices in response.

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## **Investigative Story on Uterine Morcellation to Air in September**



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

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## **[Treatment of Hormone Positive Uterine Leiomyosarcoma with Aromatase Inhibitors](#)**

Clin Sarcoma Res. 2014 Jun 26;4:5. doi: 10.1186/2045-3329-4-5. eCollection 2014.

By Thanopoulou E, Thway K, Khabra K, Judson I.

This newly published study by Dr. Ian Judson reviewed the

medical records of patients with ULMS treated with an AI, in the 1st or the 2nd line setting, at the Sarcoma Unit of the Royal Marsden Hospital between 2001 and 2012.

It concluded that with hormone positive ULMS, AIs achieved a significant CBR -clinical benefit rate (62.5%) in 1st line, which was retained in 2nd line (CBR: 50%). The relatively prolonged median PFS – progression free survival (14 months), along with the favorable toxicity profile could place AIs among the first choices of systemic treatment in hormone positive ULMS, preferably in strongly positive (>90%), and/ or low grade and low volume disease.

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### Help with Housework

Are you struggling through treatment?

That's where [Cleaning for a Reason](#)

steps in. As a nonprofit serving the entire

United States and Canada, they partner

with maid services to offer professional house cleanings to help women undergoing treatment for cancer, any type of cancer. To date, they have provided more than 17,000 cleanings for women with cancer with a value of more than \$4 million in donated cleanings, and partnered with over 1000 maid services.



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### Diagnostic Radiology



What's my radiation risks with CT, MRI, PET scans and X-rays?

What's the advantage of a combined CT and PET scan?

Who should request MRIs? Can someone help me understand my radiology report? Can I learn to read my own CT scan?

Mitchell Achee MD, a 3 yr. LMS survivor himself, will be presenting and answering these

important questions at the [LMS Retreat](#) Oct. 30th - Nov. 1st, in San Francisco.

Dr. Achee is a Board Certified Diagnostic Radiologist in private practice for over 25 years with Diversified Radiology of Colorado. He has served in many leadership roles through his career including Vice-President and Chief of Hospital Operations of his Radiology Group, Chairman of two different hospital imaging departments, Chief of the Medical Staff at a hospital and as a member of the Board of Directors of the Denver Medical Society and the Medical Advisory Board of United Healthcare in Colorado.

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## **20 Year ULMS Thriver, Helga Lavigne from Ontario, Canada**

Coping with long term side effects from radiation therapy.



In December 1993, age 58, after an emergency hysterectomy, I was told I had LMS. The oncologists told me I had a 50/50 chance of survival. I was shell shocked.

I went for 25 radiation treatments after being told the potential side effects would not show up for at least 10 years. Follow-up was only pap smears, pelvic exams and a periodic lung x-ray.

To deal with my mental anguish I saw a psychiatrist and took an antidepressant for several years. To this day I am still expecting the other shoe to drop. This cancer can return at any moment.

In July 2001, 8 years after my diagnosis, a metastasis showed up on a lung x-ray and was surgically removed. I declined adjuvant chemo much to the dismay of my doctor.

At this point, my daughter found the ACOR Listserv. I found so much valuable information unavailable here in Canada.

In February 2004, I had a total mastectomy for carcinoma which had spread to a lymph node. I turned down chemo and radiation.

From 2004 to 2010 I had CT scans every six months and took Arimidex to block estrogen and Metformin for my diabetes. My doctors suspect that it helped my remission.

This March, the radiation side effects caused a bowel obstruction and resulted in surgery. I now live with a colostomy. Obviously the radiologist back in 1994 never thought that I would survive 20 or more years.

So after many years living with a roller coaster of emotions, giving away my clothes, planning my affairs, praying to God, whose existence I had doubted on occasion, I am pleased to still enjoy life with my family and friends. I admire members who carry on so valiantly from one treatment to the next. I must thank the ACOR listserv for giving me a sense of belonging. It has allowed me to feel empathy for and kinship with so many individuals, some of whom are no longer with us.

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If you have an LMS long term thriver story 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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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](mailto:Contact@LMSdr.org)

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850 Pointe Pacific #5  
Daly City, California 94014  
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