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LMSeAlerts is an eNews service for families and professionals

History of LMS Paraffin Block Drive

[Video](#)



Participate in the Paraffin Block Drive for LMS Research



318 LMS patients have donated a primary

Working not Wishing for the Cure

LMSarcoma Direct Research Foundation LMSeAlerts - April 2014

What's Li-Fraumeni Syndrome?

LMS survivor Daryl B. was diagnosed with Li-Fraumeni Syndrome (LFS) after getting four different types of cancers.

The LFS is a very rare hereditary condition (estimated to occur in one person in 5000 to 20,000) where families have an early predisposition to cancer. The most common types of cancer found in families with LFS include sarcomas, acute leukemia, breast cancer, brain cancer, and adrenal cortical tumors. About 70% of families with LFS will have a mutation in the TP53 gene, which is the blueprint for a protein called p53.

Classic LFS is diagnosed when a person has all of the following criteria:

- A sarcoma diagnosed before age 45
- A first-degree relative (parent, sibling or child) with any cancer before age 45
- A first-degree relative or second-degree relative (grandparent, aunt/uncle, niece/nephew, or grandchild) with any cancer before age 45 or a sarcoma at any age

There is also a condition known as Li-Fraumeni-like Syndrome (LFL), where 22% of these families also have TP53 gene mutations.

Having LFS complicates treatment for LMS; radiation is less effective and some chemotherapy treatments are less effective as well.

paraffin tissue block for research - please [join us](#) and build our tissue bank.

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LMSdr

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LMS Retreat
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LMSdr T-shirts and

[Recruiting: Li-Fraumeni Syndrome Study](#)

[Recruiting: Metformin for Li-Faumeni Study](#)

[Create Your Own](#) Family Health History Tree

SAVE THE DATE!

October 30th - November 1st

LIVE IT UP! LMS Retreat 2014

San Francisco

(Registration opens in May)

Phase I Trial for Clostridium Novyi-NT Spores

Safety Study of Intratumoral Injection of Clostridium Novyi-NT Spores to Treat Patients With Solid Tumors That Have Not Responded to Standard Therapies.

[Trial Protocol](#)

Review article, "[Clostridium Spores for Cancer Therapy: Targeting Solid Tumour for Microenvironmet.](#)" Journal of Toxicology 2012,

14 Year LMS Survivor in Paralympics 2014

Watch this inspirational [YouTube Video](#) of
Augusto "Goose" Perez!

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. M, L, XL, XXL.

Read past issues of
LMSeAlerts

LMSdr advocates for and funds LMS specific research. We've been a nonprofit 501 (c) (3) since 2006. For details



Update on Nivolumab Advocacy for ULMS

The LMS patient community and LMSdr joined forces to support a proposed Phase II Trial of Nivolumab the week of March 17th. Emails were sent to both NCI and Bristol Myers Squibb (BMS) asking that they approve the application co-submitted by Dana Farber and Memorial Sloan Kettering. Sharon Anderson, Executive Director of LMSdr, spoke on the phone with representative from NCI and BMS. She reinforced the email messages which expressed that despite being a very rare cancer, the LMS community was well-organized and could put the word out for recruitment if the trial was approved. With so few treatment options, Phase II Nivolumab would be a very desirable clinical trial.

Nivolumab: a targeted (human antibody) PD-1 blocker drug that can bind the PD-1 protein so it can no longer function. As a result, the exhausted T lymphocytes continue to destroy foreign invaders (cancers). PD-1 blockers appear to free up the immune system only around the tumor, rather than more generally, which could mean they can have fewer side effects as well. Produced by Bristol-Myers Squibb (BMS). [See Wikipedia](#)



The Cancer Support Network has its own radio station, W4CS. You can listen to their cancer support shows on the Internet at <http://w4cs.com/>

of our past grants go
to LMSdr.org

[Forward this
message to a friend](#)

Morcellation Campaign Update

The war against uterine morcellation continues!
Please write your Senator and ask for a hearing.
[Details here](#)

Light a Virtual Candle



Coming Up!

April 24 & 25th

[2014 World Orphan Drug Conference](#), Washington D.C.

This is an excellent networking event for advocates of rare diseases and pharmaceutical researchers. LMSdr will be represented by Sharon Anderson, Executive Director and Sarah Robinson, Scientific Advisory Committee Member.

April 24th

["Lady Bugs" LMS Support Group Meeting](#)

Washington DC, location TBA.

Contact Daryl darylbrown1858@verizon.net

May 4th

[San Francisco Bay Area LMS Support Group Meeting](#).

San Leandro, California.

Contact Sharon 2taikomom@gmail.com

May 30-June 3 2014

[50th Annual ASCO Conference, Chicago](#)

Debra Simons, LMSdr Scientific Advisory Committee Member will be attending the American Society of Clinical Oncology (ASCO) and bringing us back the most up-to-date sarcoma information.



Camp Kesem is a one-week overnight summer camp for kids with a parent who has (or has had) cancer. The camps are run by college students and are primarily for kids ages 6-13, with a few teen programs for campers ages 14-16. The camps are free and are intended to provide the campers with the extra attention and support they need. The camper to counselor ratio is 2:1. Find a camp near you!

<http://campkesem.org/>

Post Office Box 1113

Lafayette, CA 94549

925-212-9044; 925-550-5698

info@campkesem.org

16 Year Thriver, Deborah Gates

Not a moment to waste.

Attorney Deborah Gates was a powerhouse before she had ULMS, and true to her nature, she hasn't let her diagnosis rob her of one single second.

Successful and too busy to be sick, Deborah was an executive with a Fortune 500 corporation (in 1992, she had been appointed Vice President, the first woman at that level.) In her

spare time, she volunteered as the President of the Board of Directors of the local hospice, and on the Boards of Directors of the State Nature Conservancy, the state symphony, and the local hospital foundation.



"I regularly worked evenings and weekends so I scheduled an outpatient morcellation hysterectomy for Christmas Eve 1997, so I would not miss work" states Deborah.

When Deborah understood what the pathology report meant, she pledged, "If this damn leiomyosarcoma could come back and kill me in one year, I want to resume ballet and I want to lie on the grass and watch the clouds. I want to spend my time with my family and my friends and not in windowless conference rooms." And that's exactly what she did:

- * She resumed ballet and jazz and appeared in both ballet and jazz dance performances;
- * Completed fourteen triathlons and five marathons;
- * Learned how to play the harp;
- * Was certified as a mediator under Washington State law. (Presently in the process of adding a foreclosure mediation certification to assist homeowners in retaining their homes.)
- * With her husband Steve, she purchased their dream beach home on Puget Sound, complete with a nesting pair of bald eagles.
- * Steve and Deborah hiked together in the Olympic Mountains and travelled around the world snorkeling and scuba diving.
- * Became an elected officer on the Board of Directors of the Sarcoma Alliance.
- * With her collie dogs, she pursued agility, tracking, and appeared in TV commercials.
- * Was elected to the national board of directors of the Collie Club of America.

When Deborah's 53 year old husband died unexpectedly at work in 2006, she used her grief to make changes in the Washington State hospital safety standards. Presently, she is advocating for tougher standards on a national level. Her husband might be alive today if these safety standards had been in place in 2006.

Deborah's 16 years since diagnosis is an example of making every moment count. Life doesn't have to go on hold. Do what you've always wanted to do, what really matter to you and reach for the stars!

Join SFA's Sarcoma Patient Registry

Sarcoma Foundation of America (SFA) sponsors a professional patient registry to collect anonymous data for sarcoma researchers. Over **400** LMS patients are participating. [Join here](#)

Designate LMSdr as your charity when you shop



LMSarcoma Direct Research Foundation
Post Office Box 52697
Tulsa, Oklahoma 74152
tel. 1-866-912-2730
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