LMSarcoma Direct Research Foundation

LMSeAlerts - January 2016

REGISTER!
April 7th-

Come laugh, get educated and connect with others in NEW YORK! Read all details and how to register HERE.

LMS Patient Registry

LMSdr is proud to announce our new LMS Patient Registry in partnership with CoRDS!

JOIN HERE

What is a patient registry?
A central place for LMS patient donated histories that researchers can use. All patient data is de-identified and anonymous. The more we have, the better researchers can understand LMS.
Why participate?
Patients can collaborate with researchers to:
* Describe the natural history of disease
* Determine clinical effectiveness of treatments
* Locate potential volunteers for studies and trials

Who is CoRDS?
Coordination of Rare Diseases at Sanford (CoRDS) is based at Sanford Research, a not-for-profit research institution. CoRDS is a centralized international patient registry for all rare diseases. The goal of the CoRDS registry is to connect as many patients and researchers as possible to help advance treatments and cures for rare diseases. The CoRDS registry is free for patients to enroll and for researchers to access. See FAQs Video about CoRDS

Who can access the data?
Researchers must have approval from their own Institution Review Board (IRB) and then approval by CoRDS’s own IRB Scientific Advisory Board. LMSdr’s Scientific Advisory Board may also, if desired, use their discretion to allow or deny access, once the first review requirements are met.

How is my identity protected?
Your information will be de-identified by CoRDS. If you are eligible for a research study or trial, only CoRDS will contact you. They will also contact you annually to update your data.

Should I also join SFA’s Sarcoma Registry?
YES! LMSdr’s and Sarcoma Foundation of America’s (SFA) registries compliment each other. The main difference is that when you join SFA’s registry, you give them permission to access your medical records from your doctor. This provides more detailed and accurate data. LMSdr’s registry doesn’t access your records. While LMSdr’s also collects histories, it also serves as resource for researchers to find potential volunteers for their research studies, and helps to offer new trials to patients.

Put Your Heart Into It!
Olaratumab + Doxorubicin Extends Survival

The addition of adding olaratumab to doxorubicin extends survival one year in patients with advanced soft tissue sarcomas according to results for a phase II trial. This monoclonal antibody is being now tested in a phase III study and has received an FDA Breakthrough Therapy Designation. According to Dr. William Tap, the of the sarcoma program at Memorial Sloan Kettering, "It's a very nontoxic drug." Researchers are excited to potentially add olaratumab with other chemo agents.

See phase III trial

TAPUR TRIAL UPDATE

ASCO’s Targeted Agent and Profiling Utilization Registry (TAPUR) Study is expected to open in early 2016. This trial will profile your tumor and attempt to match it to drugs already approved by the FDA. The object of this study is find how effective the drug is for your specific tumor indicated the profiling. This trial is free. You do not need to get approval from your insurance.

FAQ HERE

NCI-MATCH TRIAL

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

We'll send you the 8 x 10 canvas, paints, brushes and return shipping box. You sent us your hearts to be donated to our silent auction. Art can be any media, paint, fabric, paper, etc. Both patients and caregivers can submit. Details on Silent Auction page.
NCI-Molecular Analysis for Therapy Choice (NCI-MATCH) is a clinical trial that analyzes patients’ tumors to determine whether they contain genetic abnormalities for which a targeted drug exists (that is, “actionable mutations”) and assigns treatment based on the abnormality. NCI-MATCH seeks to determine whether treating cancers according to their molecular abnormalities will show evidence of effectiveness.

Phase II Entrectinib Open

Ignyta Inc. based in San Diego, California has just opened their Phase 2 trial testing their drug entrectinib that targets the gene translocations of NTRK, ROS1 and ALK. It's estimated that 1 in 20 LMS patients will have these gene rearrangements. Ignyta will work with your oncologist to test your tumor tissue to determine if you have these gene alterations to qualify for the trial. It's offered at 30 sites in the US. See trial protocol. Contact Lisa Schecht t. 858-332-0785 lschechet@ignyta.com

Evofosfamide (Th-302) Fails Phase III Trial

Merck announced that they will not pursue Evofosfamide (TH-302) further in soft tissue sarcomas. Results from the phase III trial did not meet expected end points. Read more HERE

MD ANDERSON CONFERENCE

Please join NLMSF at their all day conference on April 2nd, 2016 at MD Anderson Cancer Center in Houston, Texas. Speakers are impressive! Details HERE

LMS Researchers Collaborate

November 6th, seven researchers gathered together for
cocktails and discussed how to work together on LMS research. This private event was sponsored by Dr. Mitch and Annie Achee at the Grand America Hotel in conjunction with the CTOS sarcoma research conference in Salt Lake City, Utah. Mitch and Annie Achee plan to make this "LMS Research Initiative" an ongoing event every other year when CTOS is held in the U.S.

2016 Rare Disease Week on Capital Hill

Monday February 29th to Thursday March 3rd is Rare Disease Week, on Capitol Hill, to let Legislators know our needs. The week is sponsored by RDLA - Rare Disease Legislative Advocates. Anyone is welcome to participate. Several LMS patients will be representing LMSDR. Read details HERE.

LMS Volunteers Needed for Survey/Interviews

Norvartis is conducting a survey about LMS tumor symptoms. IF you have LMS tumor related SYMPTOMS, not currently on chemo, and would be willing to complete a questionnaire and phone interview - you'll get $100. Call Sonya Stringer 1-800-242-2196 or email STS@evidera.com. Help researchers, help us!

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 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.

Dana Farber Opens New Anti-PD1 Trial

Nivolumab is an agent considered an “immunotherapy” which by blocking certain check-points in the immune system, aims to activate the immune system in hopes to control the cancer. This agent has shown benefit in other cancer types, but has not yet been studied in leiomyosarcoma. Enrollment will be 12 to 37 participants. ClinicalTrials.gov Identifier: NCT02428192

Contact Melissa Hohos  617-632-5204 or Mark Morley  617-632-3989

Pembrolizumab Anti-PD1 Trial Re-Opens

And more sites coming soon!

A Phase II Study of the Anti-PD1 Antibody Pembrolizumab (MK-3475) in Patients With Advanced Sarcomas

T-SHIRT SALE!
Only $15 (includes shipping)

Sizes left: M, L, XL, XXL

Shirts are unisex with a preshrunk 50/50 blend of cotton and polyester. Color is "blackberry."

Makes great gifts!

ORDER through the Donate Now web page.

Add a notation with your NAME, ADDRESS, TEL., EMAIL (and please include SIZE).

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Sale! DVDs of 2014 LMS Conference

Watch impressive speakers discuss LMS at the 2014 Conference in San Francisco. Set of 4 DVDs only $50!

Speakers discuss the most updated information and treatment options for LMS, complimentary therapies, our sponsored research projects at Stanford, interventional radiation techniques for LMS, coping strategies and much more... buy HERE.
CELEBRATE YOUR SURVIVORSHIP!

Give out ribbons to family and friends to celebrate your anniversary or birthday. Ribbons are free and have a business card attached to each one on how to donate to support LMS research. It's an easy fundraiser to stepping stone your battle. Email Sharon to order

Here's to another year!

LMS Artist Barb Soyka, dx 2010

FEAR, LOATHING, GRATITUDE and JOY

These four words describe my journey with LMS.

Fear: First, it was hearing the word cancer and then leiomyosarcoma of the retroperitoneal – it was ‘What?!!’ Next came fear of the unknown: scans and the results, recurrence, another surgery possibly affecting quality of life, chemo, blood transfusions, etc.

Loathing: I loathed the interference in my life. LMS arrived just after getting married and my career peaking. I
loathed: considering cancer when making decisions for the future, the feeling of exiting life while the world went on normally around me, the long-term fatigue, being defined by cancer.

Gratitude: At 67 and a 17 year survivor, I now look back with overwhelming gratitude (not to say I still don’t have twinges of fear). I am grateful for life, the love and support of my husband, sister, parents and friends, excellent doctors during my early journey, new friends, the ACOR listserv, getting real with being vain.

Joy: On a personal note in cancer defiance, Joy is my middle name. I decided to adapt it as my surname in 2000 for the listserv because I was adamant that cancer was not going to steal my joy.

Linda Joy
South Carolina
Diagnosed: 7/28/1998 at age 50
LMS Retroperitoneal
Surgery 7/28/1998
Surgery for recurrence 10/13/2000
AIM, Adriamycin 90 mg / m sq, 12/10/2000 – 4/25/2001, 6 cycles

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 you can designate a percentage of the proceeds to LMSdr!
If you no longer wish to receive these emails, please reply to this message with "Unsubscribe" in the subject line or simply click on the following link: [Unsubscribe](mailto:Unsubscribe)

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