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Working not Wishing for the Cure

LMSAlerts

LMSarcoma Direct Research Foundation

January 2014

Phase I CD47 Trial Update

Dear Drs. Weissman and Volkmer,

I am writing to urge you to include leiomyosarcoma (LMS) patients into your phase I trial.

There are several reasons which make LMS patients excellent potential candidates.

As you know, Dr. Matt van de Rijn demonstrated that mice with LMS lung metastasis had a very dramatic response to CD47 in the 2012 paper you co-authored, Flipping the script on macrophages in leiomyosarcoma.

Second, the LMS patient community is already very aware and eager to join such a trial. Dr. van de Rijn presented his CD47 work at an LMS conference in Sept. 2013, which was also viewed by a hundred more patients on DVD.

I have access to daily communication with hundreds of LMS patients for recruitment. I moderate several LMS online support groups and LMS Facebook groups. In addition, I publish a monthly LMSAlerts Newsletter to a subscribership of 1105 LMS families.

Every week, patients are asking for an update on your CD47 trial, hoping that they might be a future participant. On their behalf, I urge you to include LMS patients in the upcoming CD47 trials.

Thank you in advance for your consideration! Please do contact me if you would like to discuss this further.

Sincerely,

Sharon Anderson MSW
Executive Director, LMSarcoma Direct Research

Join Our
FACEBOOK GROUP

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. M, L, XL, XXL.

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

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

Foundation & Patient Tissue Coordinator, LMS Paraffin Tissue Block Repository

Dear Ms Anderson,

Thank you for your interest—as you point out, we have done some work that indicates the the anti-CD47 therapy would be useful in LMS in addition to the other cancers we have tested, at least in animal models.

We are moving toward phase 1 trials, but we don't yet know what sorts of patients will be included. The first trials will be very small safety trials with perhaps 10 patients.

Because the therapy seems to be effective against so many types of cancer, there has been a huge amount of interest. Right now, we are trying to communicate that we are hopeful, but also try to manage expectations that this will be a miracle cure or that they personally will be able to get into the early stage trials. We don't know yet if this works in humans, and there will be a lot of people interested in a very few slots in the early stages.

But I'm glad to make a connection with you and will keep you in mind as we get closer to trials. I'm sure that at some point, LMS patients will be involved in trials.

Below I have pasted the standard letter that we are sending out to people.

Christopher Vaughan
Communications Officer
Stanford Institute for Stem Cell Biology and Regenerative Medicine

Message from Irving Weissman's Office

Thank you for your interest in our research on using anti-CD47 antibodies as a cancer therapy. While we are very excited about the potential of this research, we are unfortunately not able to start human trials for this therapy now. We are projecting that human phase I clinical trials will begin in the first half of 2014, if all goes well. We are not enrolling patients at this time and don't yet have information about who will be eligible to enroll. Please keep in mind that the initial clinical trial will be a very small safety trial with only tens of patients, and at this early stage of testing, we cannot practically or legally administer the treatment outside of the clinical trials. We are advising all patients to continue with the therapies advised by their physicians at this time.



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

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Those who are interested in this experimental therapy are also advised to check our website for current information about clinical trials. When and if clinical trials begin, we will post information about enrollment there:

<http://stemcell.stanford.edu/>

We are proceeding as rapidly as possible, although we know this fact does not make it easier for those who have cancer right now. Many researchers are working nights and weekends to move this along, and our progression toward clinical trials is actually faster than is typical for experimental cancer therapies.

Those who are interested in finding current clinical trials in the United States may also find it useful to search the National Institutes of Health Clinical Trials Database:

<http://clinicaltrials.gov/ct2/search>

To search for other clinical trials at Stanford, you may search this website: <http://med.stanford.edu/clinicaltrials/>

SAVE THE DATE!

October 30th - November 1st

LMS Retreat 2014

San Francisco

Macrophage attacking bacteria



Macrophages are white blood cells within our tissues. Their job is phagocytose (engulf and then digest) debris and pathogens.

Macrophages can also drive LMS tumor growth. Drs. Weissman and Matt van de Rijn's current research is turning off this action and "teaching" it to destroy tumor cells.

Learn more [HERE](#)

ULMS and Morcellation

Drs. Noorchashm and Reed continue their tenacious campaign to end uterine morcellation with daily letters to the FDA, support of Drs. Hensley and George, and media coverage. Was your hysterectomy performed with morcellation? You might be able to join a class action law

suit. Read more [HERE](#).

Meet the 18 Year Thriver: Jim Matthews

Faith, Juice and Really Wide Margins!

I am a 18 year LMS survivor and I still think about the day they marked me for radiation in 1996.

Memorial Sloan Kettering in New York City, had already removed a grapefruit sized tumor from my chest. They also removed 1/3 of the right lung, right diaphragm and 3 inches of esophagus around the tumor. They even removed some pericardium around my heart. Talk about getting wide margins!



I was grateful for the two fellows who were maybe 40ish, a woman and man. They sprayed saline solution into my chest cavity and sucked out the fluids. It sounds so simple like an oil leak on the floor of a garage. Even after that, the tumor ruptured and they all grabbed it out in pieces. It harkens me to picture a Three Stooges skit as they worked around my open side.

I really had planned to do radiation because my surgeon, Dr. Bob Ginsburg, the son of a butcher, told me it was necessary to do as a precaution. I believed him but, Laura my wife, Ellie my Mom, Meghan my sister the RN, all seemed to think I was crazy to have the radiation.

Even my local Doctor asked, why did I have to do anything? He was like the 1960's American Doc who enjoyed a mild diet of Marlboro's during his evening hours.

Well they all got to me. I did nothing because the fear of radiation... the gift that keeps on giving.

I prayed, juiced and lived a relaxed lifestyle. It seems to suit me. I think prayer and a balance of opinions helped me find the answers.

My daughter Tara Lynne is not 4 months old now, but finishing her senior year. My wife Ellie says my two boys just came along after my surgery. I either had faith that I

would survive or I perhaps was a tad overzealous thinking I would dodge another bullet.

Growing up, I was the accident prone kid: a shovel to head wrecking a snow fort, hit by a car at 60 mph down the Jersey Shore, fell off Buttermilk Falls Cliff in New Jersey, and a few car jaunts... rolling a '74 Pinto wagon as we raced from the Jersey Devil down the Monkey Town Road in the pine barrens of South Jersey.

They say God watches out for fools, babies, drunks, and well...

So vaya con Dios! Live today and ask for peace and healing. Shalom!

Jim the Juice Man

If you'd like to share your long term thriver story, contact Sharon 2SharonAnderson@gmail.com .

Cancer Companions Pets



Cancer Companion Pets is a nonprofit that matches cancer patients with pets from their local rescue shelters.

Services include: matching, dog

walking services, transportation to vet appointments and if needed, assistance rehoming your pet.

Visit their website at CancerCompanionPets.org

Join SFA's Sarcoma Patient Registry

Sarcoma Foundation of America (SFA) sponsors a professional patient registry to collect anonymous data for sarcoma researchers. Read more and join [HERE](#).

Pay It Forward

Who or what has helped you along your cancer journey? How will you pay that forward to make a difference?

Send your comments to LMSeAlerts to share with others!
2SharonAnderson@gmail.com

[site](#)

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