

N L M S F E –BULLETIN

September 15, 2016

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THE NLMSF PATIENT EDUCATION SYMPOSIUM - SITEMAN CANCER CENTER

USEFUL WEBSITES:

Health-cost finder: Enter your zip code to obtain estimates for common medical and dental procedures, including the out of pocket costs for individuals without insurance coverage. Free apps are available for Android and Apple devices.
FairHealthConsumer.org

Food-additive safety: You can find safety ratings for caramel coloring (carcinogenic), malodextrin, olestra, transglutaminase (“meat glue” previously in the news), other flavorings, preservatives, etc. From the Center for Science in Public Interest. **CSPINet.org/eating-healthy/chemical-cuisine.**
Note: I have heard it said: if you can’t pronounce it and can’t spell it . . .don’t eat it.

The skinny on diet plans: check out the facts about such diets as African Mango, Jenny Craig, South Beach, and other popular plans. **WebMD.com/diet/evaluate-latest-diets.**

Free art instruction - If you need to . . .beat the blues, and get your mind in a different place to mentally feel better - explore art talent . . .more than 2,000 videos demonstrate how to create landscape paintings, portraits, pottery, sculptures, and other types of art. **JerrysArtarama.com/free-art-instruction-videos.**

THE NIH CANCER GENOME ATLAS – its focus for our future:

The Cancer Genome Atlas (TCGA) is the NIH research program that has helped establish the standards for characterizing the genomic mapping of many cancers on a large scale, and is now moving to the next phase. This initiative was launched in 2006, with the first symposium in 2011, and the most recent in 2015. The program grew to include samples from 11,000 patients across 33 tumor types, and represents the largest tumor collection ever to be analyzed for key genomic and molecular characteristics. Findings for 13 cancer types have already been published, and SARC is working on sarcomas. Scientists are completing sequencing protein coding regions (exomes) for most tumor types, and completed whole-genome sequencing for 1,000 tumor samples, which characterizes complete DNA sequence in the genome. In 2013, sample collection ended the data continues to be analyzed and papers continue to be published.

From this NIH program has come the International Cancer Genome Consortium (ICGC), launched in 2008, coordinating 70 international research projects across five continents with the shared goal of generating a comprehensive catalog of cancer genomic abnormalities. 60% of patient data is housed at the ICGC's Data Coordination Center.

The future of genomics research - Two projects are underway: PanCanAtlas and Pan-Cancer Analysis of whole Genomes - amplifying the use of the TCGA generated data to focus on discovery of more complex relationships across cancer types. Another program is kicking off: the Cancer Driver Discovery Project (CDDP), which will focus on characterizing driver genetic events that occur in two percent or more cases of three common tumors – sarcoma is not yet included. However, many of these cases will be drawn from completed clinical trials allowing the program to determine molecular features of tumors influenced by therapeutic response. Cancer research centers are participating/involved in the NIH's Atlas program components.

All cancers / sarcomas will benefit from all of this – to fulfill the TCGA's original goal of improving the ability to diagnose, treat, and prevent cancer.

LMS SPECIFIC RESEARCH PROJECTS - promising for survivorship

The #1 million dollar LMS International collaborative LMS research project, under the direction of the Liddy Shriver Foundation launched, with support from the National Leiomyosarcoma Foundation.

This has come on the heels of the recent July 15 National Leiomyosarcoma Awareness Day which was coordinated with Senator Stabenow's office (D-MI), with our new Legislative Liaison Steve Baker, mayor pro-tem in Berkley, Michigan, who initiated the draft Resolution for this.

This research project is discussed by all four researchers involved in the international research project And you will want to hear their exciting information: http://sarcomahelp.org/leiomyosarcoma-http://sarcomahelp.or/leiomyosarcoma-collaborative-research.html#?tpm=1_3. There is more research funding needed for an additional research component of this research effort. The Foundation needs your help!

Also, **the M D Anderson LMS Research Workgroup**, is comprised of four dedicated research oncologists, one of whom is no longer seeing patients so he can devote himself to LMS / sarcoma research, and lead this Work Group – Dr. Vino Ravi. The Workgroup is asking for Foundation funding support. The research project involves the study of LMS tumor cell testing on LMS cell lines (growing tumor on mice) to apply special “inhibitors” for potential anti-tumor effect on LMS tumor cells. Evaluation of responsiveness of LMS tumor cells using the inhibitor alone is the evaluation focus of this study. The Foundation is in close contact with the researchers on this project, which was presented at the April 2nd NLMSF Patient Education Symposium.

Dr. Gonzalo Lopez of the Solove Cancer Institute, James Cancer Center, Ohio State University, under the direction of Dr. Raphael Pollock, a world renowned sarcoma surgeon and researcher of sarcoma and Leiomyosarcoma, and the Foundation's Medical Advisory Committee Member, is also in need of support for his LMS specific research project to grow LMS tumors on mice and test various chemotherapy agents to identify which type of treatment agent(s) combined, or singular response best, in addition to studying the capability to progress toward expansion of treatment options for patients.

IF WE in the LMS COMMUNITY do not stand behind these types of research projects, and the dedicated researchers involved, who will? It is up to us . . .we are the “stakeholders” – that have the

vested interest in the success of any and all of these projects to make all the difference in advancing treatment breakthroughs so patients can live longer and better.

Please help us . . . a monthly paypal donation of \$5, \$10, \$15, \$25 can be a “game changer” for research support – accelerate research toward the breakthroughs that we are all hoping for and needing badly.

Please consider a contribution to the NLMSF - a monthly, bimonthly, quarterly, semi annual, annual contribution can mean so much. We need everyone coming together – to continue “Reaching for The Cure- Together!” For the sake of the being able to survive for a long time and changing the statistics!

DANA FARBER ANNUAL SARCOMA CONFERENCE in Boston on Sept. 17. Registration closed on Sept. 12th, but you may still be able to register through Dana Farber by calling 617 632-5368 or emailing ptobie@partners.org.

NLMSF PATIENT EDUCATION SYMPOSIUM AT THE SITEMAN CANCER CENTER in ST. LOUIS – October 8th

We would very like to see you at either of these educational programs. Contact Annie at 303 783-0924 or annieachee@aol.com to register for the St. Louis program. Go the www.nlmsf.org to see the video featuring Dr. Brian Van Tine, who is the coordinator of this program.

NOTE: IF YOU ARE UNABLE TO ATTEND EITHER EVENT AND WOULD LIKE TO SUBMIT QUESTIONS FOR DISCUSSION DURING EITHER PROGRAM: PLEASE EMAIL YOUR QUESTIONS AND I WILL TAKE THEM TO BOTH PROGRAMS: annieachee@aol.com.

Thank you for being a part of the NLMSF Family and supporting the ongoing efforts to help the LMS Community . . . You and your family/caregiver.

Note: FaceBook has regular posts almost daily, include Caregiver inspirational messages.

IF you would like special information researched to discuss with your oncologist, please let me know. Information provided does not take the place of your oncologist’s guidance or recommendations for your care.

Annie Achee