

The Dragon Slayer

Volume 3 Winter Edition December 21, 2008

HAPPY HOLIDAYS!

The past year has been full of challenges for our foundation and our membership, yet friendships through LMS have been made across the United States and the world. The National Leiomyosarcoma Foundation, Inc. has worked hard to try to meet the needs of the members while remaining compliant with all of the Federal and State laws. Changes in leadership and the implementation of new policies and procedures will make the foundation stronger as it continues to grow. The growth of the NLMSF will allow the mission of spreading awareness and funding LMS research for all present and future LMS patients to be achieved.

The internet continues to be a great source for research and building a community among those of us touched by LMS. Tragically, we have lost

many loved ones in 2008 and have reached out to greet new families who find themselves newly acquainted with this rare disease. If one takes the time to look back and try to find a silver lining to a diagnosis of LMS, it will be the friendships made because of our association with LMS.

The Board of Directors of the National Leiomyosarcoma Foundation offers the best holiday wishes to all members of the foundation, their families and all touched by LMS. As we transition into a new year, let us pray for increased discoveries in LMS research and treatments so we may finally say that LMS is a chronic disease instead of the Dragon we currently fight.



In This Issue:

Happy Holidays	1
A Letter from the Board	2
Upcoming Events	2
Red Bank Entrepreneur	
Named Team Survivor	
TriState's Thrive and Survive	
Honoree	3
Attention Artists	3
Research Update	4
Slay The Dragon 5K	5
New Foundation	
Policies	6
HugFest 2009	7
Committee Corner	7
Poetry Spotlight	8
Fund raisers	8
NLMSF Cruise	9

The National Leiomyosarcoma Foundation, Inc.

Our Mission: Is to provide leadership in supporting research of Leiomyosarcoma, improving treatment outcomes of those affected by this disease as well as fostering awareness in the medical community and general public.

A Letter From the NLMSF Board

Dear Active NLMSF Member,

The National Leiomyosarcoma Foundation is seeking nominations of individuals to serve on its Board of Directors. The mission of the foundation is to provide leadership in supporting research of Leiomyosarcoma, improving treatment outcomes of those affected by this disease as well as fostering awareness in the medical community and general public. Board Members are passionate about increasing awareness and raising money to support research into finding a cure, while also supporting individuals and families affected by Leiomyosarcoma. The foundation began in 2001 as a grass roots effort by a group of individuals whose families had been affected by Leiomyosarcoma. Since that time the foundation has experienced remarkable success in raising money for research into this rare disease. Today the foundation continues to be financially and legally sound, as well as dedicated to its original goals of increasing awareness and

finding a cure for this disease.

The foundation currently has two openings on its Board of Directors. If you, or someone you know, reflects the passion, vision and commitment reflected by the foundation, please consider submitting a nomination to serve on the Board of Directors. All nominations must be received by email to Dr. Jen Croce Smith, NLMSF Board Member, Membership to jen@nlmsf.org) by January 15, 2009. Nominations should include the following:

- The name of the nominee
- The nominee's experience as it relates to being a Member of the Board
- The nominee's vision for the foundation over the next 2-10 years

On January 31, 2009, you will be able to read about each nominee on the foundation's website (www.nlmsf.org), and at that time active members will be able to vote. In order to vote, you must

be an active member, and have paid your 2008 dues by February 1, 2009. If you have any question about this, or would like to pay your 2008 dues, please contact Dr. Smith jen@nlmsf.org. The results of the election will be announced in April 2009 at Hugfest in Clinton, New Jersey. Once filled, the Board of Directors will be made up of 9 Board Members.

Again, please send nominations to Dr. Jen Croce Smith, NLMSF Board Member, Membership at jen@nlmsf.org by January 15, 2009.

Respectfully,

The National Leiomyosarcoma Foundation Membership Committee

A copy of this letter will be sent to the NLMSF community through the mail in early January 2009.

Upcoming Events

04/16/2009

HUGFEST 2009- See article enclosed for information! We look forward to seeing you there!

Red Bank Entrepreneur Named Team Survivor TriState's Thrive & Survive Honoree

Red Bank, NJ:

DonnaLyn Giegerich, MBA CIC RYT, has always squeezed the most out of every day. A successful entrepreneur, she grew and sold one insurance agency, launched another and taught Economics and Finance at Monmouth University as an adjunct professor. She started her career in sales at IBM and honed her analytical skills as an analyst on Wall Street before establishing her insurance career. A nationally Certified Insurance Counselor, she has served on the Business Council at Monmouth University and on the boards of The Community YMCA and the Eastern Monmouth Area Chamber of Commerce.

To relieve work and life stress, DonnaLyn teaches yoga, trains for triathlons and has run

marathons. Upon returning from a yoga teaching assignment in October 2006, her world suddenly changed when she was diagnosed with Leiomyosarcoma, a rare cancer that affects 4 in one million diagnosed with cancer. In 2007, she underwent an 8-hour surgery to remove the tumor, surgical rehabilitation, general radiation, cyberknife, and chemotherapy with no definitive efficacy due to the rarity of her cancer.

During the journey, DonnaLyn never lost her vibrant personality and sense of humor. She donned various wigs and began entertaining others with tumor humor and survivorship antics. She spoke to audiences for the American Cancer Society, the Wellness Community, and the Sarcoma Foundation of America, and

delivered the keynote address for the Cancer Institute of New Jersey's Annual Public Forum at The Robert Wood Johnson Medical Center in New Brunswick.

Bald yet still bold, she started and helped develop Monmouth County's Team Survivor Tri State Chapter to provide free fitness programs for women with cancer. She taught yoga to survivors. Since then, her efforts have helped countless women reclaim their bodies and psyches from the devastating effects that cancer can have.

Reprinted with permission from Spark Logo

For more information please go to www.donnalyn.org

Attention All Artists!

The NLMSF is announcing it's first ever Logo Contest! The foundation is looking for an image that can be used on items for events and for sale! The logo must represent the mission of slaying the Dragon of LMS and graphically convey that LMS is the Dragon we are fighting.

All artists are asked to submit!

Submissions Due 2-28- 2009

Winners Announced: 3-31-09 (or sooner!)

Digital Files can be submitted to the Dragon Slayer or to NLMSF Board members.

Research Update

By Rob West, MD, PhD

An army invading into a new land often has to rely on the goods and services of that land for its proper operation. Research over the years has identified a similar theme in cancers. As a cancer grows beyond a certain size, it needs to recruit cells from the surrounding normal tissue to provide support, such as nutrients. The vast majority of studies that looked at the role of normal cells in the support of malignant cells have focused on common cancers, such as breast and colon cancer. However, a recent study in Clinical Cancer Research has identified a similar relationship between the cells of Leiomyosarcomas and macrophages.

Macrophages are cells that migrate through the body and that are best characterized for their roles in inflammation, immune response and tissue remodeling. If we think of the human body as one big party, macrophages would be the people who come in and clean up with large plastic bags afterwards. We and our research collaborators at Stanford University, Vancouver General Hospital and the Netherlands Cancer Institute identified variations in ex-

pression of genes associated with macrophage function in Leiomyosarcomas through global gene expression profiling. Global gene expression profiling is a technique that allows researchers to simultaneously study the expression of almost every gene in the human genome for any tumor.

Spurred by this observation, we looked at a new series of 149 patients with Leiomyosarcomas on a tissue microarray. Tissue microarrays contain very small samples of tumor collected from patient tissue that was either biopsied or removed in a surgical procedure. After these tumors have been fixed (with formalin) the tissue can be preserved for a long period of time. These tissues, which typically reside in the pathology departments of the hospitals in which the surgical procedure was performed, can provide a tremendous resource for researchers studying these tumors. Using this tissue microarray, we studied the expression of two genes associated with macrophage function, CD68 and CD163, to identify and quantify the amount of macrophages within the Leiomyosarcomas tumor. While macrophages were pres-

ent in nearly every single tumor studied, we were surprised to find that in Leiomyosarcomas there was a great variability in the number of macrophages between tumors from different patients. In other words, some Leiomyosarcomas were extensively infiltrated by macrophages while other LMS had few if any macrophages in them. When we grouped the tumors based on whether they had diffuse extensive macrophage infiltration versus sparse infiltration, we found that in tumors derived from non-gynecologic sites, patients with a dense infiltrate of macrophages in their Leiomyosarcomas did significantly worse over five years than patients with a sparse macrophage infiltrate. These tumors with a dense macrophage infiltrate made up approximately one-third of all non-gynecologic Leiomyosarcomas. The findings in this study imply that there is a functional interaction between macrophages and tumor cells of non-gynecologic Leiomyosarcomas.

In the next few years we hope that there could be new therapies aimed at disrupting key functional interactions between tumor cells and 4

Continued on Page 5

macrophages. This current research on LeioMyoSarcomas suggests that patients with these aggressive LeioMyoSarcomas could then benefit from these future therapies.

Footnote on Macrophages

Macrophages are versatile cells that play many roles. As scavengers, they rid the body of worn-out cells and other debris. They are foremost among the cells that “present” antigen; a crucial role in initiating an immune response. Unlike short-lived neutrophils, macrophages survive longer in the body up to a maximum of several months. Macrophages can digest more than 100 bacteria before they finally die due to their own digestive compounds.

Macrophages are believed to help cancer cells proliferate as well. They are attracted to oxygen-starved (hypoxic) tumour cells and promote chronic inflammation.

Dr. Rob West is an Assistant Professor at Stanford University. Together with Dr. Matt van de Rijn, they continue to do research on LMS. The NLMSF continues to provide grants to Stanford University for this continued research.

Slay the Dragon 5K

The 2nd Annual Slay the Dragon 5k Walk/Run was held on 9/27/08 in Ashland, VA in memory of Richard Lloyd, my dad. The first 5k in 2007 was such a huge success (raising over \$14k!!) we couldn't resist making it an annual event in our community. This year we raised over \$8k to send to the foundation—a surprising amount considering the economy!

Our lives were flipped upside down when my dad was diagnosed in January 2007 with this cancer we had never heard of. We immediately dug up all of the information we could to learn about LeioMyoSarcoma and were devastated to learn of its effects. My dad underwent surgery removing his bladder and prostate, as well as a large tumor in his abdominal cavity. He then had the usual radiation and very aggressive chemo. By the end of the summer in 2007 he had decided enough was enough and that his body couldn't take anymore of the chemo or the side effects. He was able to enjoy a month or so of feeling well enough to get out and about on his own, even making a trip to Carlisle, PA to a car show (he collected restored muscle cars). By Christmas 2007 the cancer

had started to grow again but he just couldn't handle any more treatments and decided let God take over. He passed away on February 24th, 2008 at home with his family by his side.

Our friends and family (and even strangers!) have been so supportive—the event wouldn't be successful without their support and participation. My dad was able to attend the first Slay the Dragon 5k in 2007 and was so touched by the number of people who showed up to participate and support our event—our first year we had 269 participants!! My family has vowed to continue the 5k fundraiser in memory of my dad so that research can continue and hopefully one day someone will find a cure, or at least a treatment, for this terrible disease. We have had positive feedback from participants and plan on hosting the 3rd Slay the Dragon 5k in September or October of 2009. Please check our website if you would be interested in attending or volunteering at our event, www.slaythedragon5k.com.

Kathy Landes and the Lloyd Family

New Foundation Policies

By: Joni M. Fixel, Esq. VP NLMSF

In early 2008, Board members of the National Leiomyosarcoma Foundation, Inc. (NLMSF) hired a prominent New York attorney to guide the Board in compliance issues, financial transparency, ethics, internal controls and to assist with corporate structure.

Legal Counsel

Daniel Alcott is a Partner in the Transactional Department of Duval & Stachenfeld LLP, a 50 attorney law firm with offices in New York and Los Angeles, and the founding member of the firm's Tax Exempt Organizations Practice Group, which was launched in May, 2006.

As a specialist in both nonprofit and business law, Mr. Alcott has provided a range of legal services to nonprofits. Mr. Alcott has extensive experience representing public charities, private foundations, trade associations, museums, commercial co-venturers, corporate sponsors, religious corporations and professional fund raisers. Mr. Alcott is recognized by his peers as an expert on nonprofit governance and parliamentary procedure.

Recommendations from Legal Counsel

We recommend that the Board review this memorandum, consider the roles and responsibilities of the Board of Directors and Officers, and review the attached policies: (i) Policy on Internal Controls; (ii) Audit Committee Charter; (iii) Reporting of Improper Conduct and Non-Retaliation Policy [Whistleblower Policy]; Record Retention Policy; Code of Ethics; Conflict of Interest Policy. We further recommend that the Board consider adopting, and following, these, or similar internal policies and practices. The 2008 IRS 990 will now ask whether the organization has an audit committee, a whistleblower policy, a record retention policy, a code of ethics and a conflict of interest policy. It is best to answer those questions in the affirmative.

Actions by the Board of Directors

On August 31, 2008, the NLMSF reviewed, voted on and unanimously passed the policies recommended by Attorney Dan Alcott. These policies are available for anyone who wishes to review the policies.

The implementation of these policies will allow the NLMSF to be compliant with the Internal Revenue requirements and at the same time have the policies in place required to apply for grants to the foundation for research projects.

HugFest 2009

This year's HugFest will be held at the Holiday Inn Select of Clinton, 111 W. Main Street, Clinton, N.J. 08809 which is located 3 minutes off Rt. 78 at Exit 15 and 45 minutes from Newark Airport. Historic Clinton offers boutiques, antique shops, bookstore, ice cream parlor, sushi & espresso bars, restaurants, a historic gristmill and museum. The hotel offers a full service restaurant, indoor pool, whirlpool and fitness center. There is plenty of free parking and is pet friendly!

We have planned what we hope will be a fun and informative HugFest with something of interest to everyone.

Thursday, April 16 - Meet & Greet 5:00 – 9:00 p.m. in the Petits Mill Square Room

Friday, April 17 - Programs throughout the day presented in conjunction with the Wellness Community of Central N.J. including topics such as "Tools for Reducing Stress for your Mind/Body", Healthy Nutrition, an overview of Complimentary Medicine/Therapies available, Caregiver and Bereavement program and "Looking Good/Feeling Good." Sit-down Served Dinner 7:00 – 9:30 p.m.

Saturday, April 18 - Hot Buffet Breakfast - 8:00 a.m. – 1:00 p.m.

Presentations by our researchers and our annual meeting followed by a question and answer session.

Foundation Members - \$50 per room, per night

Non-Foundation Members - \$99 per room, per night

Please make check payable to NLMSF and must include the following: names, addresses and phone numbers of all attendees, the date of your arrival and departure, the type of room you want (ie. One King bed or Two Double beds) and if you will be attending the programs on Friday. Please send your reservation

and information requested to Maryann Croce, 60 Enclave Blvd., Lakewood, N.J. 08701. All reservations must be received by March 1, 2009. Please do not make your reservation through the hotel as we are acting as the "booking agent" and our rates are tax-free.

If you are flying and need transportation to the hotel, please contact me with your flight information.

If you have any questions or suggestions, please contact Maryann at 732-363-4187 or Bandmcro1@aol.com or Patti at 480-686-9622 or lloydpd2007@yahoo.com.

Sincerely,

Committee Corner : Finance Committee

The finance committee has been meeting on a monthly basis except for December. I have all of the information available into the quickbooks computer program. This was not real easy without having access to the books that had been kept. This should help make year end reporting much easier. We should be able to just say print and it will be there.

I think we are on track now and this should be a much easier year coming up. Everything is in place and just needs to be entered.

D Jane Moulds
NLMSF Treasurer and Board Member

Poetry Spotlight: Christmas Poem

By Vicky and George Peters - 2006

O What A Night

Joseph & Mary went to Bethlem town
For them, no room at the inn was found.

O What a Night.

A stable stall a manger bed
for God's own Son to lay his head.

O What a Night

The angels sang, the stars shone bright,
Can you imagine?

O What a Night.

The shepherds came, made hast to see
The place the angels said he would be

O What a Night

The wise men came traveling from a far
following the wondrous star

O What a Night

God's gift of salvation come down to earth
through a miraculous virgin birth

O What a Night.

*To Submit Poetry for upcoming editions please send an email
to: dragon.slayer.newsletter@gmail.com*

Fund raisers

Fundraiser for Betty

By Bonnie Benshoof

The fundraiser was for Betty Stieglitz who was diagnosed with Leiomyosarcoma in January she is my sister-in-law (husband's sister) my Kids favorite Aunt!! We all participated, myself (Bonnie Benshoof, husband-David Benshoof, kids, Alyson (13years and Jonathan 10 years old, it was a gorgeous sunny day in Ellettsville, IN, where the event was held there were 5,500 bicyclist from 40

states and foreign countries, it started at the Ellettsville High School and toured around the Ellettsville, IN area!

We completed the Hilly event and then we proceeded



Betty Stieglitz and her grandson Jonathan

Continued on Page 10

If you have any comments or questions about anything from this edition, please let us know!

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Dragon.Slayer.Newsletter@gmail.com

NLMSF Cruise

Our very first NLMSF cruise was on December 6, 2008. We had some excited people getting ready to go and enjoy their break from their regular daily lives. We had a group of seven. We set sail on Carnival Cruise Lines and sailed out of Mobile AL. It was a five day cruise to Mexico. The two ports we visited were Cozumel and the other was Progreso. At dinner we sat together and bonded while we learned more about each other's lives and how LMS affected each of us.

The Cruisers have returned to reality, sorry to say! We all had a wonderful time and thoroughly enjoyed ourselves. In fact we are planning another trip in February 2010.

What a wonderful way to spend relaxing time together and get to know each other outside of our usual functions. Everyone can do as they please all day long and then sit down to a wonderful gourmet dinner that none of us had to prepare or clean up after. Then maybe take in a live show and hit the casino for a while. Whatever you choose to do, this is a wonderful way to go. Then when you decide to turn in for the evening you will return to your cabin to find your bath spotlessly clean and your bed turned down with a cute towel animal and a chocolate on your pillow.

While in port everyone is free to go and do their own thing and see and do whatever they want to. We did some tours and some shopping. Cozumel is my very favorite place to shop! They have about anything you are looking for, and it is so much fun to bargain for your goods. Please think about joining us next time around.

D. Jane Moulds



Left side of table Vicky and Owen Marrin, Jane Moulds, Right side of table, Loretta and George Watkins, Bill and Joni Fixel



to spend time with my Betty by a game of cards and she treated us with cookies. She is taking a break from the Chemo at this point, she was at M.D. Anderson in Houston did 5 chemo treatments.. I've attached a picture of her and my son that was taken last December before the diagnosis, it was at my son's musical that she attends every year.



Nurses to Boot LMS groups gather

Nurses to Boot LMS

By Debra Simons

On October 13, 2008 the

Norwalk Community College Nurses Club campaigned for awareness and funds to give the "Boot" to LeioMyoSarcoma LMS . This was done in honor of two nurses, Betsy Vandall who lost her battle to LMS on October 3, 2008 and their College Professor Debra Simons a survivor of LMS. Thus the name "Nurses to Boot LMS". Jeff Well, Sanya West, Angelica Arteaga, Amelia Montiero all nursing students and many other nurses, student nurses, and residents of the state of Connecticut met at the Devil's Den Nature Preserve located in Weston, CT. Jeff Wells spoke briefly about the importance in



Devil's Den Nature Preserve, Weston, CT.

nurses leading efforts to raise awareness about rare cancers. Debra Simons spoke about some of the issues faced by LMS patients and families and about the latest strides made for LMS patients. Afterward, everyone set out to hike the beautiful trails.

Are you having a fund raiser for LMS you would like to share? Please let us know and it will be featured in the next edition.



The National LeioMyoSarcoma Foundation

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