

The Dragon Slayer

Volume 2 Fall Edition September 28, 2008

Bridgefest 2008

The 4th Annual Bridgefest was held over the Labor Day weekend in Mackinaw City, Michigan. The weather was great and unusually warm for northern Michigan and where we usually wear jackets, it was warm enough for summer clothing all weekend.

Labor Day is the only day of the year that the Mackinaw Bridge is open to foot traffic and thousands gather to walk the 5.2 miles from St. Ignace back to Mackinaw. The NLSMF has found that this is the perfect opportunity to reach thousands of people in just a few short hours. The Village of Mackinaw City graciously granted permission for our foundation to have information and fundraising tents on Labor Day.

A great time was had by all who attended. Great weather, great

shopping and wonderful sharing of news and memories by survivors, caregivers and supporters led to another successful weekend.

Shortly before the holiday, we were contacted by Deanna Sundstrom, who is a LMS patient from Green Bay, Wisconsin. Deanna has been fundraising and with her supporters they have raised over \$3300.00. She presented the foundation with checks for over \$3000.00 on Labor Day and has

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Pictured from Left to Right: Jane Moulds, Jan Bariski, George Peters, Joni Fixel, Deanna Sundstrom, and Sharlene Zagozewski

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.

sent more since that time. While Deanna and her team of walkers were in Mackinaw, her husband and friends were organizing other walk teams back in Wisconsin. What an awesome sight to see Deanna and her team walking toward our tents!! The most remarkable thing is that Deanna is currently in treatment and still walked the Bridge. Thanks to Deanna and all of her supporters in raising funds for research.

As always.....we ended the day with sore feet, big hugs and thoughts of how we can continue to make Bridgefest an annual success. Join us on Labor Day weekend 2009 for our 5th Annual Bridgefest.

See you there!

Joni M. Fixel
VP NLMSF

Meet The Board!

Dr. Jen Croce Smith, DVM Membership

Hi. I am a board member and have been associated with the NLMSF since 2002 when my sister, Dawn Peragallo, was diagnosed. Originally from Madison, NJ, I now live in Perrysburg, OH with my husband, 2 children, 2 dogs and 2 cats. I graduated from Miami University with a BS in Zoology and received my Doctor of Veterinary Medicine degree from Colorado State University.

In 2000, my

family relocated to Ohio where I currently practice as a small animal veterinarian with a special interest in cancer diagnostics and treatment. Sadly, my sister lost her battle to LMS on April 6, 2007 and I continue to be active as a board member in the National Leiomyosarcoma Foundation as well as a medical advocate for LMSDr Foundation. My goal is to keep her memory alive and to continue to fight for a cure so that no other family has to go

through what we are all going through .

My other interests include cooking, hiking, fly fishing, and spending time



Jen Croce Smith with daughters Madeline and Giuliana.

Upcoming Events

- | | |
|--------------------------|--|
| 10/04/2008 | New England LMS Luncheon- Bertucci's Italian Restraunt, Westboro, MA for more info and RSVP: katiehunt@mac.com |
| 10/13/2008 | Nurses to Booth LMS- Hike in Devil's Den, Weston, CT for more Info: www.nursestobootlms.blogspot.com |
| 11/08/2008 | Annual Night at the Races in Memory of Angie McNeil- Smith Hanover Twp, PA. \$10.00 Donation you could win \$50! For tickets and info contact Susan at mistic1@aol.com |
| 12/6/2008-
12/11/2008 | Carnival Cruise
Meet in Mobile, AL and take a cruise to Mexico, Progresso, Yucatan and Cozumel. For More info call Carnival Cruises at 1-800-819-3902. Tell them you are with the Jane Moulds Party |

relaxing with my family. I am excited about the future of the foundation and look forward to serving you all in the future. There are exciting things in the works!

Jane Moulds
Treasurer

I am a nine + year LMS

survivor. I had surgery and radiation. I am originally from Michigan [Detroit area and Traverse City area] We moved to the Alabama Gulf Coast



Jane Moulds

10 years ago. I guess the hurricanes are better than the blizzards.

I have been married to my husband Doug for 24 years. I have three grown children, 2 daughters and my son Ryan, who lives at home with us. I have four granddaughters and two great granddaughters, 3 1/2 and 3.

My beginning interest in the NLMSF was as a survivor. I realized how important it was going to be to spread awareness of this very rare

cancer that affects 4 out of a million people. I need to share a little fact with you, when I was diagnosed and told I was being sent to an oncologist, I had to go home and look up oncologist on the Internet, and then I said "Oh Oh I have cancer." I have learned that each and every day is very important in my life and I want to make the very best of

each one. I have also learned a very valuable lesson on procrastination, don't put off until tomorrow what you can do today! I may not be here tomorrow, so let's get it done today. Since my surgery, I do not work outside the home [I was in banking for 20 years] so I thought

that I have some time on my hands to spend helping others with LMS. By being able to help others from home, my bad days were not an issue. Being a NLMSF board member has made me feel that I can really help others and I am thankful for the opportunity to do so.

Sharlene C. Zagozewski
Secretary/Fund raising

After living in Connecticut for 20+ years, I almost feel like a Yankee, but my roots are in Pennsylvania where my parents

and many friends still reside. It is from my Pennsylvania roots that I came to know the Dragon we are all working so hard to defeat. From a distance, I watched the courage and determination as well as the frustration of my good friends Janice and Jim Bariski, as they fought Jim's LMS. It is for them, their family and everyone like them who engages in this battle that I will do what I can to help.

My husband, Paul and I have been blessed with a wonderful family which now includes five grandchildren, Carter (5 years), Morgan (3 years) and Claudia (6 months) and their parents, our younger son, Scott and his wife, Melissa, and they are local! Our older son, Tod, is in New Jersey with his wife Megann and daughters Allyson (6 years) and Katherine (3 months).

Balancing family life, work life and spiritual life has always been a challenge. I have worked in the U.S. Pharmaceutical industry for 30+ years and now have responsibility for establishing and developing a Business Intelligence effort at Boehringer Ingelheim, Pharma. This includes organizing the people, processes and policies of the intelligence groups and creating a knowledge-sharing

culture within the company to support an intelligence effort. Prior to Business Intelligence, I led new product development teams as Associate Director, Project Management and spent six years as a Manager in Sales Training, following 12 years in Field Sales with Boehringer Ingelheim and Hoffmann La Roche.



Sharlene Zagowski

My job in pharma currently involves looking into the competitive environments for the therapeutic areas my company is researching. So I have access to public knowledge about new therapies, both ours and others. I hope to foster a collaborative process for LMS patients to gain knowledge about what may be coming in solid tumors, especially sarcomas. I believe that treaters, researchers, survivors and caregivers alike need to collaborate more, so that putting the pieces of this puzzle together is accomplished more quickly. After the Stand up to Cancer fundraising program, I realized that there is a groundswell of opinion regarding collaborations across the US. I

want the NLMSF to be part of that collaboration groundswell.

I am new to the Board this year. As Chair of Fundraising, I have a lot to learn. With the help of others, like Susan Smith in PA who will hopefully soon be my Co-Chair, I hope to figure out how best to support our members in their fundraising efforts. I envision putting together a FAQ guide and some do's and don'ts from the experts (our member who has successfully held fundraising events). Any other suggestions for what is needed, please send the ideas to me at sharlene@nlmsf.org. We are just getting started and need to plan for 2009.

**Joni M. Fixel, ESQ.
Vice President**

I was born in Allegan, Michigan and later moved to the Muskegon, Michigan area.

In Muskegon I met my husband and we had two daughters. In 1993, we moved to the Lansing, Michigan area where I began my education as I worked in the electric



Joni Fixel

industry. While finishing law school, I became the Vice President of Business Development and in-house counsel for a private corporation. A few years later I left the energy industry to open my own law practice in East Lansing, Michigan.

In 2004, I was told that I needed a routine hysterectomy for some large fibroids. Assured that they were benign 99% of the time, I was surprised to wake up to a new doctor advising me I had a rare cancer. I feel blessed that I have my gynecologist/oncologist who had seen and treated LMS in some of his other patients. It was truly a blessing that Dr. Meunier was on call the day of my surgery. His skill in removing a football sized tumor with wide margins is the reason that I have been NED (No Evidence of Disease) since the original surgery.

As a board member it is my goal to raise funds and promote awareness to find the treatments

and cure needed for this dragon. I have been personally enriched by the families, friends

and patients of LMS that I met through this foundation. We have lose some members and my heart has been broken too often by the loss of my friends to allow this dragon to continue unchecked.

On a personal note, I am so proud of the involvement of my family and friends who have become personally involved in this battle to find a cure.

Dr. Lucy-Rorke Adams
Scientific Advisor

Dr. Lucy Rorke-Adams is a native of St. Paul, Minnesota. She is the youngest in a family of five girls of Armenian parents. Her mother was a survivor of the Turkish massacre of the Armenians during the first world war. Although the family was of modest means she was raised in an intellectually rich, loving and secure environment. As the family had limited resources she had to work while attending the University of Minnesota. She was one of five women in her class of 110 medical students. All professors except for one were males.

She left Minnesota in 1957 following graduation and was an

intern at Philadelphia General Hospital, the 1800 bed City hospital, which provided her with remarkable exposure to a large variety of patients with both common and unusual diseases.



Dr. Lucy

She remained at that Hospital for specialty training in Pathology and Neuropathology and then joined the staff there after completing her formal training.

Her subsequent career encompassed diagnosis and research experience in a number of areas, namely viral diseases of the nervous system, brain tumors, and developmental problems, both congenital and acquired, in children. In addition, she dealt with the special problems in the field of forensic pathology.

Her first husband, Robert Rorke, died in 2002 (after a marriage of 42 years) and two years later she married Boyce Adams, whose wife had succumbed to leiomyosarcoma. That marriage was tragically short as he died 2 years and 2 months later. It was because of her marriage to Boyce that she became involved in the Foundation.

Jan Bariski
Outreach and Awareness

Early in our 6 year battle with Jim's leiomyosarcoma we were introduced to the NLMSF by Karen Gibson. The members of the foundation became our friends and provided us with a wealth of information and resources. While attending the past 6 Hugfests I came out of my comfort zone by wanting to make sure people who were attending the events were introduced to others with similar diagnoses and treatments.

A year ago I became a member of the NLMSF Board of Directors. My area of interest is patient advocacy, caregivers and end of life issues. Near the end of Jim's courageous 6 year battle, he was denied a chemo trial that gave him 30 percent shrinkage of his multiple tumors. I don't want this to happen to anyone else. I fought the doctors telling us that the drug company would never change their decision on giving Jim the drug. These same doctors learned that I might be quiet but I am persistent. Just before Jim died, the doctor in charge of this trial personally contacted me and said Jim could have the drug if I could get him to Philadelphia. Unfortunately by then Jim's disease had progressed to the point that he couldn't tolerate a two

our ride from our home in south central Pennsylvania.

This week a friend asked me to speak about my breast cancer at fundraiser she is organizing. I told her that my breast cancer was a nonevent compared to Jim's



Jan Bariski

leiomyosarcoma.

I have committed my future to spreading awareness of Leiomyosarcoma, helping to raise money for funding research, providing a place where caregivers can vent their concerns, and seeing that no one is denied a treatment because the researchers don't want their "numbers to look bad."

I grew up in New England, where at the age of 3 I decided I wanted to be a dental hygienist. Years later I earned a Bachelor of Science in Dental Hygiene and have been practicing in the same office for 34 years. I love knowing my patients so well and I have learned so much from them.

Jim's death in December 2007 marked the second time I was widowed, as my first husband

died fairly suddenly when our girls were just 3 and 5. Jim was a remarkable stepfather to the girls, was so proud and in awe of our 4 grandchildren, ages 2, 3, 4 and 5 and truly loved our sons-in-laws.

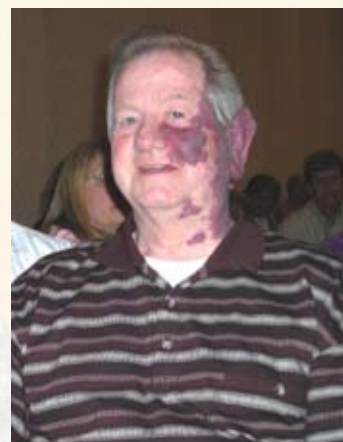
I am proud to say that my loyal friends have helped to make Susan Smith's "Night at the Races" a great fundraising event.

I recently returned from my second Bridge Walk in Michigan where we spent the weekend bringing awareness to Leiomyosarcoma.

I encourage anyone going through the LMS journey to contact me if they think I can to be of any benefit to them.

George Peters Chaplin

My name is George Peters, I live in Taylor, Michigan. I am the Associate Pastor of Emmanuel Baptist church, in Taylor Michigan. I also work for Rogers Electric Supply, as a warehouse worker and truck driver. My wife Vicky (alias LMS Idol) works there also.



George Peters

I became associated with NLMSF, when my sister-in-law, Theresa Miller was diagnosed with LMS. Her and Vicky found out about the Bridgefest and went and met the LMS Family. For two years I drove them to Hugfest and dropped them off and I went to visit friends. Then in 2006 I went to Bridgefest with them and met the LMS Family. As people came off the bridge I decided to meet them and pass out ribbons to help to make people aware of LMS. I was amazed at the amount of people came off that bridge. I soon ran out of ribbons. The next year I gave out even more ribbons and in 2008 even more. People need to know about LMS.

In 2007 I was asked if I would be the chaplain for NLMSF and I considered this an honor.

Then in 2008 I was asked if I would be on the Board of Directors and I was honored to be asked. I hope that I will be an asset to the Board in making decisions for the

good of the NLMSF.

I have been asked to be the chairman of the Awareness and Outreach Committee,

Jan Bariski is also on this committee. In making this committee work we will need your help. If you have had an event or a fund raiser, please let us know so we can inform others on how to go about organizing a fund raising event.

All the above articles were written by the members of the NLMSF Board. Their personal experiences and commitment to the foundation contribute to its success. We all thank them for their hard work and dedication!

Committee Corner : Outreach and Awareness Committee

by Jan Bariski

This committee was established to meet the emotional and spiritual needs of our survivors and caregivers as we travels through the Leiomyosarcoma journey. Whether you want to speak to one of us or be matched with someone who has been in a similar situation we want you to know that you are not alone.

Waiting for a referral or waiting for the results of a recent test, dealing with caregivers mental and physical exhaustion, wondering what to expect about end of life issues are all real big time issues what we want to address.

This year as we initiate this committee we look forward to hearing from all of you regardless if you are in need of support or want to give support.



I AM A LMS SURVIVOR by Theresa Miller

My name is Theresa Miller. I am on my fourth year of NED (No Evidence of Disease). I was asked to write about being a survivor. To tell the truth I have had a very hard time composing my point of view on this subject.

But I promised so I will give it a shot. So here goes.

When LMS was dumped in my lap I had never heard of it. Sound familiar? I eventually read up on it and thought well I will be gone soon. But I was wrong. I have survived for four years. Have had a scare or two but have never had a recurrence (hold on while I knock on some wood). I am a survivor. But I have to admit I am not a happy survivor. Oh don't get me wrong. I am thrilled that since my diagnosis I have had two grand daughters added to my life. I work daily and I am healthy. BUT being a survivor means I get to watch as so many friends that I have met through this group have lost the battle. I have walked bridges and

raised money to see it not be in time or enough. I have read letters from people requesting ribbons for loved ones that are fighting the battle or have lost that final battle. I get heart sick over each and every letter and send the ribbons with a card or gift or just a prayer and many times a tear.

So here it is in a nutshell. I am a survivor. My goal is to have each and every LMS person be able to say those words as they grow old and live a full life. We have got to get the word out. We have got to make it our life's goal to find a cure for this horrible disease.

Yes I am a survivor. I want all of you to be one too.

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.

Poetry Spotlight: Rainbows of Promise

By Vicky Peters

When those storm clouds of life gather
and the rains come tumbling down
When there's not one ray of sunshine
anywhere around
As the skies keep growing darker
and there's not one ray of light
Just remember at the dark storm's end
There will be a rainbow bright.
For God in loving kindness
has made a promise rare,
Whenever we face the storms of life
We will a rainbow share
For the rainbow is a promise
A promise from God above
That He will keep us in His care
by His blessed, precious love.

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

About the Dragon Slayer



The Dragon Slayer is a quarterly newsletter started by Jane Moulds. It is our hope that with continuing this newsletter and expanding our distribution of it we can spread the mission of Slaying the Dragon of LMS even further. This newsletter will be not only for members of the National Leiomyosarcoma Foundation but for any others interested in learning about LMS or would just like to help support our cause. Although the topics may vary in each edition, our cause is always the same: to raise awareness of LeioMyoSarcoma and to raise funds for medical research.

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

To Subscribe or Unsubscribe to this newsletter please contact us at:

Dragon.Slayer.Newsletter@gmail.com

NLMSF Wesbite News

The National LeioMyoSarcoma Foundation's website has always been a place to find posting about upcoming events and to gather information. In 2007 the website was given a "facelift" and made into a more interactive site. It has since taken on a whole new life. The website is an living site that is constantly updated by board members and helpers to provide you with the most relevant and up to date information.

Most recently the website was updated with the spectacular news of the latest BridgeFest and you can find pictures of this event on the photo album tab. Also the foundation store has grown since the beginning of this September. Custom T-shirts items can be ordered and sent out for events for members and non-membes. All profits will go directly towards LMS research.

The most important thing to know about the website is that is generated by the organization. This doesn't mean just the board members! If you are having an event, please send a board member the information so we can let everyone know. And please share photos for the events- they will be displayed for everyone to see. We also

ask that if there is anything you would like to see on the website, that you let us know! The NLMSF is for everyone who's life has been touch in any way by LMS and we would love to have your involvement. If you have ever wondered how to get more involved this is a great way- share your LMS experiences with everyone.



National LeioMyoSarcoma Foundation, Inc.
"Slay the Dragon"

If you have a fundraiser or awareness event
PLEASE let us know about it!
admin@nlmsf.net

Upcoming Events:

Slay the Dragon 5k Walk/Run
scheduled for 9/27/2008 in Ashland, VA
for information: www.slaythedragon5k.com
in memory of Richard Lloyd

The Norwalk Community College Nursing Club is sponsoring a 'Nurses to Boot LMS' Hike at the Nature Conservancy's Devils Den in Weston, CT at 10AM on Monday, October 13, 2008 to raise awareness of LMS. Guest speaker: Debra Simons, LMS Survivor and Nursing Professor. Suggested donation: \$5 for hikers, \$10 to sponsor a hiker and more is greatly appreciated. Make your check payable to: National LeioMyoSarcoma Foundation Inc. Slay the Dragon directed towards the Nurses to Boot LMS research fund.

More info and directions at www.nursestobootlms.blogspot.com
Questions, send an email to Jeff Wells at jwells45@hotmail.com.

4th ANNUAL NIGHT AT THE RACES, SATURDAY NOVEMBER 8th, 2008
in Hanover Twp, PA. In Memory of Angie McNeil-Smith. For more information and/or tickets, email Susan at mist11@aol.com
Donation \$10 - you need not be present to win!
Spend \$10, win \$50!
Support a great cause and help raise funds to "Slay the Dragon!"

The National LeioMyoSarcoma Foundation
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