



The Dragon Slayer

Volume 6- January 2011

HugFest 2011

It's right around the corner!

Every Dollar is Appreciated

Edna's Hope

Events to Raise Awareness and Find a Cure

First Ever Sunset Stroll for LMS

Google's Gift to Non-profits

Second Annual Dog Wash for a Cure

Team Sarcoma Initiative

Models for a Cure

LEMATA

2011 Call for Board Members

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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.

The National LMS Foundation Inc. was formed on July 14, 2001. We were granted 501 c(3) status from the IRS as a non profit organization

HugFest 2011 - it's right around the corner!

HugFest 2011 is around the corner. I know, I am not ready for this either, but we must start working on this or it will not happen. Now, if you are thinking along the lines of spring travel or spring break, think BRANSON, Missouri on April 7, 8, & 9, 2011.

We will once again be staying at the wonderful Grand Plaza Hotel! Last year they honored our special price for three days before and three days after HugFest for anyone wanting to come in early or stay longer. IF YOU ARE A PAID MEMBER FOR 2011, the Foundation will pay for half of your room for Thursday, Friday, and Saturday. Full hot breakfasts are provided as a part of the room fee. The Foundation will provide dinner on Friday evening and lunch on Saturday after the annual membership meeting.

Thursday, April 7, 2011

Meet and Greet 4pm-8pm

Friday, April 8, 2011

Speakers 10am-11am

PLEASE start marking your plans now; I will need payment to make your

reservation. I will begin taking payment for rooms the first of March. Please keep watch on our website for updates to and for HUGFEST 2011! I will also post on the Google group.

If you think you are going to attend, please send me a quick email to jane@nlmsf.org and let me know who, how many, and what days. That will allow me to start a list for this year.

Thank you!

Love, hugs, thoughts, and prayers

Jane

jane@nlmsf.org

Reservations will be accepted after February 15, 2011. Please contact Jane to join us at HugFest this year.

Hugfest is an event that is open to all LMS members, non-members, supporters and survivors. We hope that you will join us this year in Branson.

This is our second year in Branson, MO. This location is centrally located for all members and supporters.



2010 HugFest Supporters



2010 HugFest Survivors



LMS Quilts, featuring squares made for and by local supporters and for LMS Angels. The LMS Quilt was started in 2000 and continues to grow and be added to by current LMS survivors and family members of Angels.

Every Dollar is Appreciated



One day last summer, a young boy Devin Torrez (9 years old from Holt, Michigan), went with his grandmother to take her dog to the groomers. At the grooming salon NLMSF wristbands were on display. Devin asked his grandmother to read him the tag with the information about LeioMyoSarcoma. After reading the information tag, he said “Gramma, that is so sad. I want to donate my allowance for this cancer”.

While the dog was being groomed, Devin had his grandmother take him home to get his allowance of \$1.00. When Devin and his grandmother picked up the dog, Devin brought his donation to the NLMSF and we were honored to take such a heartfelt donation. Devin has a wonderful giving heart and we are sure that he has a bright future with such a great personality.

The NLMSF appreciates every donation. It's donations like the one from Devin that reminds us that awareness is spread one person (or child) at a time!

A Special Engagement

Fundraising events can come in all different forms. This past May, NLMSF President Joni Fixel and her husband Bill had a very special day planned - they would renew their wedding vows for their 30th anniversary.

Pastor George Peters (NLMSF Chaplin) officiated the event with over 50 of the Fixel's closest friends and family in attendance. Feeling blessed in their marriage and their life they asked their guests to not give gifts for the occasion but instead make a donation to the foundation. The couple raised \$130 for the foundation that day. Thank you for your generosity and helping spread the word about LeioMyoSarcoma.



Bill and Joni Fixel (NLMSF) President renewed their wedding vows with Pastor George Peters.

Edna's Hope- Events to Raise Awareness and Find a Cure

On March 19, 2010, Edna's Foundation of Hope held its second annual “Shake Your Shamrocks” for Leiomyosarcoma at the Sheraton in Mahwah, New Jersey. The event was a great success having more than 150 people in attendance dancing the night away. Proceeds from this event will be used to promote funding and awareness about sarcomas, most specifically Leiomyosarcoma research and treatment of this rare, incurable and deadly disease.

At last year's third Annual Gala “Crusin for a Cure” we had over 500 people in attendance. The success of the evening enabled us to present a grant to the NYU Sarcoma Project headed by Dr. Eva Hernando for their continued research. In 2009, in keeping with our mission, the Foundation was proud and honored to present gifts to three families affected by this disease. We are looking forward to thanking our supporters and community at our first annual “Family Fun Day and Leiomyosarcoma Awareness Festival” on June 12, 2010. It will be a great day for everyone to come together and enjoy the day's festivities. Sadly our beloved founder and friend, retired NYPD



officer Edna Curley, lost her battle with Leiomyosarcoma on October 1, 2009. Her dream and hope for a cure lives on!

Edna's Hope also hosts an annual Gala. Last year's Cruising for a Cure, had over 500 people in attendance held on November 6th, 2009. And what a night it was! The outpouring of love and support added to the success of the evening. As a result of the generosity, a check for \$35,000 was presented to the NYU Sarcoma Project for their continued research. In 2009, in keeping with our mission, the Foundation was proud and honored to present gifts to three families affected by this disease.

www.ednashope.org

Bridgefest 2010

by Jane Moulds

A great time was had by all in attendance. We stayed in two different locations this year and we had a great time. We had a picnic dinner ordered from Kentucky Fried Chicken and lots of good fun and fellowship. Thankfully we were led in prayer by our Chaplin and board member George Peters, who by the way has had a wonderful recovery from his double knee replacement surgery. We all give thanks for that! The day of the bridgewalk was great for the walkers, it was cloudy and cooler with a breeze. We didn't sell as much water as in the past when it was hot and sunny. I think our booth was a huge success once again. Thank you Becky Fixel for designing another great patch for



2010 BridgeFest Patch



NLMSF Booth for BridgeFest 2010. This was the sixth annual Bridgefest that the NLMSF has participated in. Details for Bridgefest 2011 will be coming soon.

2010. They sold out very quickly. I had to get mine early before they were gone, and save one for my life long friend, Pam, who was walking the bridge for me. Pam and I went to school together, and have remained friends throughout the years, and she has been a part of bridgefest from the beginning and also came to HugFest in Branson this year. It means a great deal to have the love and support of family and friends. My mom and dad came to the picnic along with my daughter Laurie who also attended HugFest with me this year, and my son Ryan who is my greatest support person. Ryan is with me for everything. He is my rock!

A Student's Perspective

by Sharon Gates, RN

Please allow me to introduce myself. I am a registered nurse who is currently an online learning student at Drexel University working towards a degree in Health Services Administration. One of the core courses for this degree was Non Profit Organizations in Health Care. My assignments for each week were to search for national or local nonprofit organizations and write about the organization. For one week's assignment during that semester, I chose the National Leiomyosarcoma Foundation.

There were two main reasons for choosing this organization. First, my life has been affected by leiomyosarcoma. My father, Richard Bosley, was 54 years old when he lost his six month battle to this silent killer. He had no symptoms of the growing tumor in his small bowel and its metastasis until the tumors became large enough to affect his bodily functions as well as his brain. Upon diagnosis, we were informed of the rarity of this disease. We were also informed of the lack of treatment for this disease. Chemo was tried but to no avail. Radiation did shrink his brain tumors but it was a lost cause.

His death was untimely, like most who die too young. My family and I said our last loving goodbyes to him on October 4, 1989.

The second reason for my choice, was that I wanted to see if such an organization existed for this rare cancer. As a healthcare major, I am aware of the fact that non profits do so much to assist the healthcare community and professionals to carry onward in research, finding causes and cures to diseases. Non profits are also instrumental in creating public awareness and assisting patients and their families to obtain much needed support, whether it is education, financial, or hope. What is so important in your foundation is the mere vital importance of achieving your mission because of its rarity. It does not share popularity with cancers such as colon, lung, or breast which affect a larger populations and demand government attention to find cures. However, it does not make this disease any less damaging to those it affects or any less demanding for a cure. Your foundation is the key to opening the doors to research, treatment, and cure. Your foundation is the hope to those few who dream for a journey to renewed health.

Amy Rovi-Medivov, the Communication Director of the foundation, was amazing as she procured the information I needed about NLMSF for my assignment. Her ability to articulate her own passion about being a part of this foundation was inspiring. She shared the foundations mission, goals, and leadership's energy they shared to reach out and help all those affected by leiomyosarcoma. For all of the positive research attained, I applaud this foundation, for the work you do, the strong foundation you have built, and the day when all the efforts you have made, allow those afflicted to shout "I AM CURED!!!". Thank you for your example of an exemplary nonprofit organization

Sharon Gates RN
Drexel University Student
Thomasville, PA

*Would you like to write for the Dragon Slayer?
We are always looking for new articles and
new contributors from the LMS Community.
Please submit any articles to:*

dragonslayernewsletter@gmail.com

My New Steady Ned

by Janet Ringer

Hi everyone,

There's a new guy in my life and I'm crazy about him. I hope NED sticks around for a long time, because I don't think I can live without him. I saw the oncologist today to find out the results of my latest CT scan and there's No Evidence of Disease. You can understand now why I'm so enthralled with NED. I will continue to get checkups every 3 months just to make sure NED sticks around. As with any relationship, there are no guarantees. But here's hoping. Hope always.

And in many ways I have you, my dragon slayers, to thank for this moment. You have slayed, prayed, and made a difference in my life and I will never forget your love and support during my treatment. I still go to the web page Jay set up to look at your photos and I always feel so inspired by the sight of you in your dragon slaying T-shirts. Please wear them from time to time (or as often as you want) just to keep that nasty old dragon away from my new heartthrob Ned.

It's been a while since I sent out a group

email. I last wrote to tell you about my upcoming modeling opportunity at the Guardian Angels annual benefit fashion show. That happened on Nov. 1 and it was one of the best nights of my life. It was so much fun and I wasn't nervous at all on the runway. I wore false eyelashes for the first time in my life, didn't use my cane, and felt like a million dollars. I was pumped!

One of models who had undergone cancer treatment said there were 900 people in the audience. I said, "That's a relief. I only get nervous when there are more than a thousand."

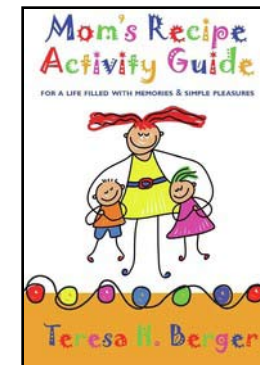
Among those 900 were my dear friends, Agatha, Greta, Alison, Karen, Sandy, Diane, and Sonja. They were standing and cheering and ROARING the whole time I was on the runway. At least that's the way I remember it. And the wonderful encouragement from the rest of the audience was exhilarating. It helped me realize just how far I've come in the last year. I've lived through the fear of dying, painful treatments, loss of hope, and no hair. In the end, though, fighting cancer has made life sweeter and more precious. I want to enjoy and experience so much and keep in touch with you all. Nothing

means more to me than the people in my life.

I still need to build more strength and energy by improving my health and fitness so I can do all the things I want to do. But most of all, I need to keep **ROARING**.

Hugs and hope,
Janet

This letter was shared with the Dragon Slayer by Theresa Miller. We want to thank Janet for such a wonderful letter!



Teresa Berger lost her mother to LMS in 2001. She has started a blog detailing her struggles with her loss and upcoming events to raise awareness.

In May 2010, Teresa released an activity guide with wonderful recipes and short stories as a tribute to her mother. Proceeds from book sales will benefit the NLMSF.

Soon the book will be added to the NLMSF store, but it can be found online at: <https://www.createspace.com/3412744>

First Ever Sunset Stroll for LMS Held in Abington, PA

by Teresa Berger

It all started with a book - a tribute to a mother lost to LMS - then led to a fundraiser bringing people throughout the greater Philadelphia area together for one special day. Over 50 people from the Philadelphia suburbs converged on October 10, 2010 for the first ever Sunset Stroll for LMS at Alverthorpe Park in Abington, PA.

With the generous support of the community, local retailers and businesses who donated food, drink, raffle prizes, entertainment or time, the Sunset Stroll raised \$500 for the National LeioMyoSarcoma Foundation. The goal of the event was to bring people together and raise awareness and funding for the foundation. And we successfully accomplished that!

Teresa Berger coordinated this fundraiser and launched the event during a half-hour segment of Philadelphia Agenda, a radio talk show with Brad Segall of WOGL (<http://wogl.radio.com/2010/09/06/philadelphia-agenda-with-brad-segall-28/>) at the end of August. Teresa raised awareness of LMS,

NLMSF and her personal experience with her Mom's battle with LMS. NLMSF Board member Amy Rovi joined her on the show, too.

Corporate donors included Jules Thin Crust Pizza in Jenkintown, 4KidsinPA.com, Medivor, LLC, Romp 'n Roll of Willow Grove, and Megs Melodies.

Teresa plans to make the Sunset Stroll an annual event to raise funds for the NLMSF with the second event scheduled for the fall of 2011.

Teresa Berger lost her mother, Ellen Swain Haser, to LMS in 2001. She is one of four daughters Ellen raised with her husband of thirty-plus years. Ms. Berger recently published, Mom's Recipe & Activity Guide...

Teresa is currently battling LMS and she came along with her family from Delaware County

for a life filled with memories & simple pleasures, in honor of her mother, the life lessons she instilled and the memories she

The First Annual Sunset Stroll for LMS: Look for details soon for The Second Annual event coming Fall 2011.



Google's Gift to Non-Profits

by Becky Fixel

Early in 2010 the NLMSF was contacted by Google and MSU. It seems like an unlikely combination for our organization to be contacted by- but the news they had for us was exciting. When our foundation set up a Google Checkout Account, our Treasurer Jane Moulds also entered us for a grant.

Michigan State University had previously set up a program where graduate students volunteered to work Google and local Non-Profits to help them build an adwords campaign. This adwords account would be monitored by the students and tweaked to get the best results.

The students worked tirelessly on our account and built a great foundation for us to work with. Our campaigns received higher than expected CTR (Click Through Rates) for each ad they launched.

Videos from the students presentation can be found on our website. We are thankful for everything the students have done for the organization.

Read the students experiences:



The National Leiomyosarcoma Foundation is a recipient of a Google Grant from the Google Ann Arbor office. Google Grants is a unique in-kind donation program awarding free AdWords advertising to select charitable organizations. Google supports organizations sharing their philosophy of community service to help the world in areas such as science and technology, education, global public health, the environment, youth advocacy, and the arts.

NLMSF President Joni Fixel with MSU Grad Students Nupur Bihani, Kristyn Jones and Raymond Lee at Google's Office in Ann Arbor, MI

From the Students: Their blog, insight and input on working on the NLMSF Adwords Grant.

When we started this class, we had a group of organizations to choose from that ranged from land grant institutions to Weimaraner adoption. The National

Leiomyosarcoma Foundation was the one that we hoped to be able to work with the most because we felt that it was the one foundation where we could have a grander impact beyond just theoretical issues presented within the classroom. We had just left our first semester of the MBA program at Michigan State University and were enjoying our first few moments of relaxation since starting the program a little more than four months earlier. We received an email directed towards marketing students announcing the start of a class that would use the Google search engine to promote various organizations. We were excited to use this tool that was common to us all to raise awareness for our nonprofit organizations.

We got the charity we were hoping for, but now it meant that we had to do some research to become educated on the disease. We did some internet research, talked to members of the organization and called on some doctors. We were taken back by the fact that the disease affected four out of 1 million people. We also learned about the impact that it had on those with the disease, their family, and the amazing support system that had sprouted up across the nation as a result.

Nupur: I had actually worked with Google before going back to school. I had experience creating AdWords campaigns, but this was the first experience I had dealing with Leiomyosarcoma. I admit that I was a little excited. I was going to have the chance to use the skills I learned through my work experience and use them to support an organization that supported so many. It was a unique combination of work, school and charity.

We had done our research on the disease and the foundation. We read up on Google AdWords. Then it was time to be able to combine our research with AdWords and see just how effective of a campaign we could give life to. We tried to understand what the “user” went through in trying to find more information on the ailment. It was complicated when we learned that the rarity of the disease meant that some doctors weren’t even aware of it. We tried to put ourselves in the shoes of the patient, and walk ourselves through the learning process, and all of the scenarios one would find themselves in. It was really something of a humbling experience.

Kristyn: I worked in medical sales before heading back to Michigan State. There were a few similarities that I noticed between

my work experience and working with AdWords. In both, we had a brief window of opportunity to grab people’s attention and direct their efforts to the foundation’s Web site. We needed to be precise with our campaigns, content and verbiage.

We had a short learning curve, a few stumbles, but it wasn’t long until we were off and running with some relative success. A few things were learned was to avoid being too specific without being overly broad. We also had to learn how to take the many assets of the Web site and to use them to direct people to the foundation’s Web site. The two campaigns we created that were the most successful were awareness and ribbons. We found that what drove the most traffic were people wanting to learn more about the disease, its symptoms and its cures. In short, people wanted to learn what they were dealing with. We also utilized the foundation’s donation opportunities, so we created a campaign based on the ribbons that the foundation sold. We learned that people wanted to show their support for the foundation’s cause and for those who were “dancing with NED,” and that many thought that ribbons was one of the best ways to do so.

Ray: The Web site offers so many ways to help people who are suffering, not only through support, but also education, treatment and advancing the fight against the disease. The avenues towards success were there. The question became how we could leverage them.

One metric that we used to judge the success of our work and how it translated into real world success was Facebook membership. The foundation’s page, we are happy to say, more than doubled from 600 to over 1,200 since we started. Furthermore, sales through the site were going “bazurk.” We will always be proud to know that we were able to contribute to spurring some of this activity. To know that our effort went beyond campus grounds in a way that contributed to such a worthy cause.

Thank you again to the Students and to Google for all of your support and hard work!

Our Adwords Campaigns are still up and running, and we see positive growth every day. Our Facebook group has just crossed over 2000 fans because of the ads the students have set up from us. We are thankful for the growth and support!

Last Year's Hugfest: A letter from Dr. Robert Dauchy

Good morning, Jane!

Thank you for your kind thoughts and well-wishes!!

It's always such a great experience attending the Annual Hugfest and speaking! I cannot tell you how much it means to me, friend. This organization is so very important, in its mission, goals and achievements for our society and world as a whole. I know that I speak for Dave and all the members of our team hear at Tulane School of Medicine when I tell you and fellow LMS Foundation members, Jane, how truly honored we are to be associated with this grand institution. And, if in some small way, we are able to help move the organization's goals and mission forward, particularly in the area of basic LMS cancer research, then it doesn't get any better than this - we truly will have made a difference for everyone!

Jane, I'd love to attend the 2011 Hugfest next year and speak for how ever long you folks would wish! I've already marked my calendar and will plan on the event!

I've already taken care of the travel expense on this end (Limo and Courtyard Marriott room for Friday eve), so please not to fret about this!

Also, please pass along to everyone that our research presentation at the American Association for Cancer Research Annual Meeting the following week was also a great success! The work was extremely well received! We will not quit!

Best wishes, Jane, to you and everyone! Our thoughts, prayers and continued "hugs" to all!

See you next year!

Love to all!

Bob



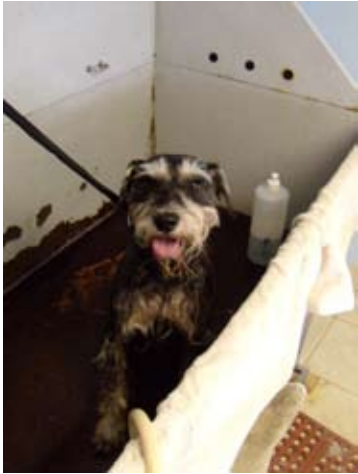
Second Annual Dog Wash for a Cure: Team Sarcoma Initiative

The NLMSF is proud to have been part of the Team Sarcoma Initiative again this year. Rachele Anthony, once again offered up her dog grooming salon as a venue for the event. All Shapes and Sizes Grooming greeted several LMS patients, survivors, their family members and local supporters throughout the day.

The shop invited the public in to learn about LeioMyoSarcoma. Dog washes were offered to the public for a \$5.00 donation that benefited the Team Sarcoma initiative. The NLMSF offered items for sale and all proceeds went to our foundation. This event was a great success and raised funds to go towards research.

The event caught the attention of Channel 6 News in Lansing. The segment lead to donations to the organization and more connections within the community.

Thank you so much to Rachele Anthony and her staff for their generosity and support!



All proceeds from dog baths were donated to the Team Sarcoma Initiative and NLMSF.



Models for the Cure

Legacy Model Agency based in Lansing, Michigan launched a unique idea for a fashion show: feature cancer patients and survivors and bring awareness to their causes.

The founder of Legacy Models and LEMATA (the new charity division) contacted Rachelle Anthony after the dog wash to invite her to join. Anthony is a recent survivor of Thyroid Cancer herself. NLMSF President Joni Fixel took part in this event as well bringing attention to LeioMyoSarcoma and the NLMSF.

Men, women and children of all ages, races and cancer types were highlighted on the stage and it was truly a magical night. NLMSF supporter Jessica French of Holt, Michigan also took part in the event. French is a survivor of Familial Adenomatous Polyposis (FAP) the only known cancer to be genetically inherited.

LEMATA has plans to make this an annual event and to take the runaway on the road. We applaud their support and their efforts to show the beauty of all of their models who grow stronger and more beautiful battling their cancers.



NLMSF President Joni Fixel in the LEMATA Models for a Cure Fashion Show



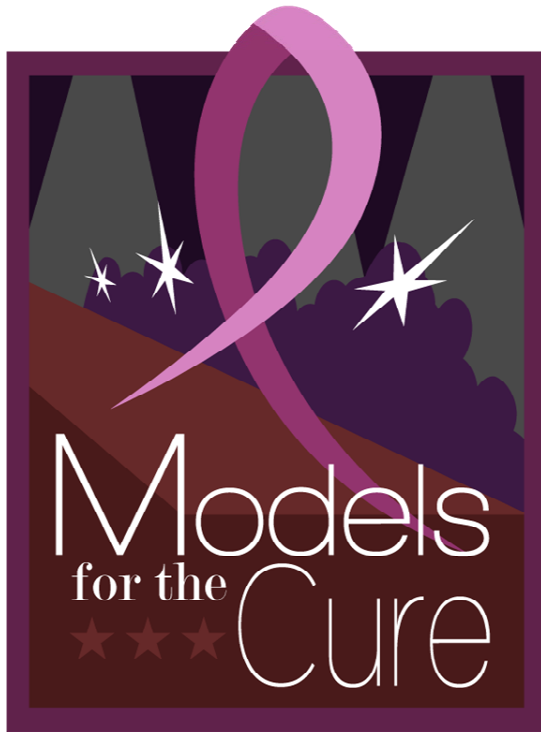
Rachelle Anthony is a Thyroid Cancer survivor.



Jessica French is a survivor of Familial Adenomatous Polyposis (FAP)



The event was featured on the Channel 6 WLNS News.



Thank you to Legacy Model and Talent Agency for all of their hard work and support towards different cancer groups.

More information on Lemata and Legacy Model and Talent agency can be found at:

<http://www.legacymodelandtalentagency.com>

2011 Call for Board Members

Have you ever wanted to become more involved with the NLMSF? We have a place for you! The 2011 Board Member elections are right around the corner and we will have openings for interested foundation members. Board positions are for 2 years and board members are required to take place in board meetings (physically or via the phone)

How do you apply?

Interested foundation members should email their resume, a statement of interest and their contact information to: admin@nlmsf.org

The Voting for the 2011 Board will take place online at: <http://www.nlmsf.org/2011-board-election.html>

If you would like to vote using a paper

ballot please contact us at: admin@nlmsf.org

Voting will take place online:
February 15th, 2011 - March 30th, 2011

If you have any questions regarding the upcoming election, what becoming a board member means, how you can help or other volunteering opportunities please contact us today! admin@nlmsf.org

Upcoming Events

HugFest 2011

Dates: 4-7-2011 to 4-9-2011

BridgeFest 2011:

Dates: 9-3-2011 to 9-5-2011

LMS Cruise 2012: Details Coming Soon!



The National LeioMyoSarcoma Foundation

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