

# *The Dragon Slayer*

Volume 5- Spring 2010

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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

## **Volunteering: Why is it Important?** *by Becky Fixel*

There is no doubt in anyone's mind that all of our lives were changed the moment someone we knew was diagnosed with Leiomyosarcoma. Whether it was you, your mother, your father, sister, brother, or friend- LMS has touched us all in one way or another.

The NLMSF is quickly approaching its 10th anniversary. It was founded in order to spread awareness of this rare cancer that has shaken us all. But without members and supporting volunteering, this would almost be impossible to do.

You may ask how you can volunteer? The Board of Directors consists of members from all over the country, and the main office is located in Michigan. It might seem like there isn't anything you can do from where you are- but that's where you are wrong! You can do the smallest things and help the out the cause of the foundation!

Volunteering can come in many forms and it can even be something you are passionate about. The foundation is always looking for people who might want to do graphic work, legal help, fund raising, planning events and a variety of other things.

Volunteers don't have to be an adult. Hanna Lynn, who is the NLMSF Treasurer Jane Mould's great daughter, helps out by licking closed the envelopes for the Foundation Mail. This small act lets Jane focus on balancing the books and setting up new funds within the foundation.

And age should never be a factor in volunteering. Anyone, of any age can help out. The foundation is always looking for someone to help, volunteer for a directors position . One simple act, can mean a difference to the foundation.

For volunteering opportunities email: [admin@nlmsf.org](mailto:admin@nlmsf.org)



Hanna Lynn, 5 years old helping with the NLMSF mail.

## **Tissue Boxes for a Cause:**

*by Theresa Miller*

As you can see in the picture I have way too much time on my hands. hahaha.

OK so I don't. I make tissue boxes to keep my hands busy when I am watching TV at night time. That way I stay out of the cookies and chips. Hey works for me and in the last year I have lost 50 pounds. (gotta replace that fat picture of me on the ribbon site).

I have taken these to Hugfest and we used them as center pieces. I have been asked if I could make them and we could sell them and the money go to research. Well I of course said YES.

I have a lot of different sayings and try to be original. Any suggestions on that please send them directly to me at [treesa5585@yahoo.com](mailto:treesa5585@yahoo.com) cuz my brain is running out of new and exciting things to put on these boxes.

When ordering know that they will be mailed to you without the tissue. You are on your own. Figure it is cheaper for everyone to get their own then to pay postage to mail a box of tissue.



I have tried to reach out to those who would join the list that were in somewhat close proximity to where I live. Now I would like the opportunity to give back to others in a different way, by serving as a board member of the NLMSE.

For the last 12 years I have worked for a general surgeon in our town. I have mostly done medical billing and coding, however, I was also the office manager for a period of time. This doctor retired at the end of 2009, thus I now have the time to commit to this position. Prior to doing medical billing I taught music at our local Christian school. I was also a member of their school board for at least 10 years.

My husband and I have been married for 33 years and reside on the beautiful Oregon coast. We have been blessed with 3 adult children, 1 son and 2 daughters.

If elected to this position I will work to spread awareness and help to facilitate others who are researching for a cure. I would appreciate the opportunity to give back to those who have helped me along my journey.

**Pam McNamara - Michigan**  
riverplm@netpenny.net

I am a native Michigianian and currently reside in Michigan. I grew up in Dearborn Michigan and graduated from high school in 1962. After marrying and having a family I worked as a bank teller for several years, took several basic college accounting courses, and then pursued a career in the insurance industry becoming a licensed insurance agent in Life, Health and Disability, Property and Casualty working for an independent insurance agency.

I retired in 1998 as we were building our retirement home in northern Michigan. Unfortunately, my husband passed away very suddenly in 2001 and never realized his dream I have two children and three grandchildren, all wonderful of course! I am now in a committed relationship, he is a survivor of colon and pancreatic cancer and is currently being treated for prostate cancer and is doing well at this time. This has been quite a journey and we are grateful for each day.

My interest in being a board member would allow me to interact with

the other foundation members, learn more about the foundation and help promote awareness of LMS which is a very important part of being involved along with fundraising activities.

**Jane Moulds - Foley, Alabama**  
jane@nlmsf.org

I am a ten and a half year Leiomyosarcoma survivor. If you do not know about LMS being diagnosed will get you an education in a real hurry. The best resource I found was right here with NLMSE. I guess that is the main reason I continue to be involved with the foundation. I will never forget the original feelings of lonely, lost, scared, unknowing. Then the more I learned the worse I felt, as nothing I was learning was good news. I hope to be able to help make it a little easier for newly diagnosed and their families. I know that just being a survivor has given many hope when they didn't think there was any. If I can help educate and save a life, then I have accomplished my mission.

Now for my history pre LMS. I was born and raised in Michigan, and my husband my son, and I moved to the Alabama Gulf

Coast in 1998. I have three children, four granddaughters, and four great granddaughters. Two of my great granddaughters live here so I get to see them quite often. Before moving to Alabama I was in Banking for 20 years. I started out as a teller and when I left I was in charge of the Credit Card and Debit Card department.

I have served one term on the board of directors, and I am running for another term. I have been the treasurer for the last year and a half. I am willing to continue in this capacity if re-elected to the board of directors. I now have all the records into quick books in the computer.

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## How to Vote!

This year the Board of Director election will be mostly held online. If you are a current NLMSF member cast your vote online at:

<http://www.nlmsf.org/vote.html>

If you are unable to vote online, or would prefer a paper ballot- please contact the Foundation at :  
(888) 449-6805

## Board Members: How and Why? *by Joni M. Fixel*

What is important about the Board of Directors? All of the Board of Directors once asked themselves “How can I help?” And eventually each became a Board Member. The NLMSF Board has 9 (nine) Directors. Every year 3 (three) positions are open and come up for election. The NLMSF, like other non-profit organizations, is legally required to follow the original intent and bylaws of the organization as it was when founded. One thing that is important is that each Board member actively participates in the governance of the foundation.

The Board of Directors meets to discuss legal issues, medical grant requests, financial issues, fundraising requests, etc. The Board meetings typically last 1-2 hours quarterly and the individual time devoted throughout the year is really minimal as long as each Board Member stays actively involved. But don't trivialize the importance of the Board or the decisions that are made for the future of the NLMSF – very little time is needed to make certain that the foundation is running smoothly and growing according to the original mission. We are seeking Board members who will actively participate in the future of the NLMSF.

The National Leiomyosarcoma Foundation, Inc. is here to serve those touched by LMS nationwide and we look forward to your questions, comments and participation.

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*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*

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## Stay Connected to the NLMSF

Twitter: [www.twitter.com/NLMSF](http://www.twitter.com/NLMSF)

Facebook search for: National LeiMyoSarcoma Foundation

Google Groups: <http://groups.google.com/group/nlmsf/topics>

Yahoo: <http://health.groups.yahoo.com/group/LMSarcoma/>

## Technology and the Foundation: How we've Grown! by Becky Fixel

In the last year the NLMSF has taken steps to grown in leaps and bounds and keep up with the latest trends. There is a growing trend in businesses, organization and foundations using social networking sites to help grown awareness and membership.

As many members can have seen our website has had yet another face lift. The new site not only allows for more interaction, it even has it's own chat forum. We are trying to make connecting our organization and other survivors and supporters of LMS- quick and easy for everyone.

Beyond the update website, the foundation has also joined Twitter, and Facebook. Both of these social networking sites help us keep our membership up-

dated at a moments notice. These sites also allow the Foundation to connect with members, as well as non-members.

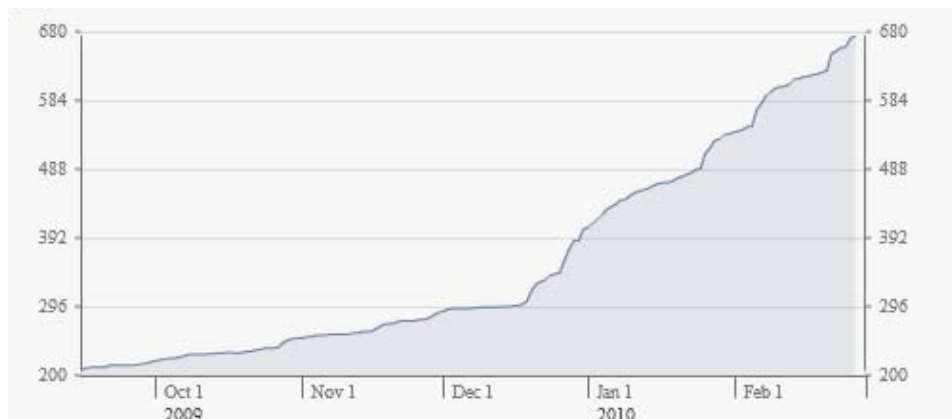
When the foundation joined these sites at the end of last summer they were slow growing in followers. We were slowly spreading the message, and updating on events, fundraisers and the upset. Once the website was fully updated in November we started to kick up the interaction with the people who are following us on both sites.

In October of last year, our Facebook page had just over 200 fans. At the end of February of this year- we were well over 600 members. Our fans on Facebook have been growing every day- and we're getting close to 700 fans now!

The most extraordinary thing about this connection is we are able to connect with others who don't know about our foundation, our cause or LMS. We have had the opportunity to reach out to people who don't even know what LeioMyoSarcoma is, and to educate them on the rare cancer.

Social networking sites make it easier for us to connect to the world, we have fans in the US where we're based, and as far away as Spain, South Korea and Malaysia.

We are growing in numbers, growing in awareness and finding better ways to stay connected. We want to be able to spread awareness throughout the world- and one update at a time we are starting to do just that!



Our Facebook Membership has more than tripled in the last 6 months!

Top Countries		Top Cities		Top Languages	
United States	655	Muncie	39	English (US)	655
Canada	5	Indianapolis	34	English (UK)	12
Taiwan	5	New York	34	Traditional Chinese (Taiwan)	5
United Kingdom	3	Chicago	18	Spanish (Spain)	1
Spain	2	Philadelphia	18	French (France)	1
South Korea	1	Houston	12		
Malaysia	1	Atlanta	11		
New Zealand	1				
Singapore	1				

The Fan page has helped spread awareness throughout the world! Top membership is still in the US, but numbers continue to increase weekly!



## **HugFest 2010** :All the Details you Need to Know *by Jane Moulds*

The NLMSF is very excited to be able to offer HugFest 2010 in Branson MO. We have found a very nice hotel in the heart of town and walking distance to restaurants and other attractions. The Grand Plaza. There are over 100 shows in Branson on any day. Branson is a beautiful place to visit. I went last Oct. and checked it out before picking it. One reason for looking at Branson is that it is pretty centrally located for most of the US.

The people there are warm lovely people who truly want us there, and want to make our visit the very best they can. Prices are much more economical. We are going to have a great time at much less the cost, beginning with the rooms, which are costing paid members \$35.00 a night.

Being in a new place will probably be a little different until we get used to it. Everything should be just about the same as previous HugFests with the exception of no brunch Saturday for the annual meeting. A full hot breakfast comes with your room so we will be having lunch after the annual membership meeting on Saturday. Then you are on your own, you can visit with others, you can sight see, you can take

in a show, or shop or whatever you want.

We hope to see as many as possible there, come join your fellow LMS'ers and learn about the support we can provide for each other. It is great online, but boy a hug and in person is so so much better!

### **Schedule**

#### ***Thursday April 15, 2010***

4:00 - 8:00pm: Meet and Greet

#### ***Friday April 16, 2010***

10:00am Dr. Dauchy

12:00pm Annual Board Meeting [Board Members Only]

3:00 - 6:00pm Group activity, City Tour

6:30pm Evening Dinner

#### ***Saturday April 17, 2010***

10:00am Annual Membership Meeting

For more information email  
jane@nlmsf.org

Reservation details can be found at  
[www.nlmsf.org/hugfest-2010.html](http://www.nlmsf.org/hugfest-2010.html)

## **NLMSF Board of Directors**

President – Joni M. Fixel, Esq.

Vice President – Jan Bariski

Treasurer – Jane Moulds

Secretary- Sharlene Zagazewski

Director – Dr. Lucy Rorke-Adams

Director – Dr. Jen Smith, DVM

Director – George Peters, Chaplain

Director – Amy Rovi

Director – Vicki Marrin

### **Committees and Chairperson:**

Scientific Advisory & Grant Writing

Dr. Lucy Rorke-Adams

[drLucy@nlmsf.org](mailto:drLucy@nlmsf.org)

Membership

Joni M. Fixel - [joni@nlmsf.org](mailto:joni@nlmsf.org)

Fundraising

Open - For more info, email: [admin@nlmsf.org](mailto:admin@nlmsf.org)

Audit Committee

George Peters - [george@nlmsf.org](mailto:george@nlmsf.org)

Communications

Amy Rovi - [amy@nlmsf.org](mailto:amy@nlmsf.org)

Events

Vicki Marrin- [Vicki@nlmsf.org](mailto:Vicki@nlmsf.org)

## LMS Greeter: Nancy Gayder

It was September 8, 2001 when Joe and I heard my gynecologist say those horrible words, “Nancy, you have cancer”. Our lives stopped. In a fog we heard her say “It’s called Leiomyosarcoma”. Thus began a new phase in our lives.

We entered what seemed like the world’s largest building. The sign on the wall read “University of Texas M.D. Anderson Cancer Center”. It can be described as a small city. Each weekday 150,000 people comprising patients, visitors and employees pass through its doors. This was not like any previous hospital I had been in. Everybody here had cancer. My first impression was “all these people are dying”. It was not until much later I learned “they were all living”.

For almost five years my husband and I battled the LMS Dragon on our own. We knew of no one else who had this rare disease with the name that was so hard to pronounce. Through radiation, chemotherapy and three thoracotomies we had the wonderful support of family and friends. It was not until the fall of 2006 when one day I decided to google Leiomyosarcoma that I found a whole

new family and support system, NLMSF. Since then we have learned more than we wanted to know about LMS. We have attended Hugfests and have been embraced by fellow survivors and caregivers. If it were not for Yahoo Mail, I would never have known to ask about Femara. No more mets. No more thoracotomies. I have been NED since May, 2008.

Last year I replied to a fellow LMS survivor who was coming to M.D. Anderson asking if she would like to meet for lunch during her visit. Little did I know that one gesture would lead to me being nicknamed “The LMS Greeter”. Over the past year I have provided numerous LMS patients with maps, transportation, restaurant and hotel information. Explained what a cat scan entails and how to prepare for the doctor’s appointment. Mainly, I try to ease those same fears I had experienced on my first visit.

I was asked to write about my experiences as an LMS Greeter with the thought of encouraging others to reach out to other LMS survivors in their local communities. I know it is easier for me since I am retired and have the extra time. With our busy

schedules I know it is difficult to even find “me” time some days. However, if you do find time, you will discover, as I have, the return on your investment is priceless.

Nancy Gayder  
“The LMS Greeter”

Do you have a story you’d like to share with our foundation and community? We are currently looking for any articles about your battle, something that can inspire others or just something that could bring a smile to our faces.

Please send all submissions to :  
[dragon.slayer.newsletter@gmail.com](mailto:dragon.slayer.newsletter@gmail.com)



## Cruise 2010: A look at Paradise by Jane Moulds

February 8th was the day of our NLMSF cruise. Part of fighting our disease is to try to stay stress free, but in this day and age it is near impossible. A cruise is the closest thing I can imagine to being stress free. It was five days of someone cooking fantastic meals for me, making my bed, and cleaning my room and bathroom, and being able to do what I wanted when I wanted to do it! I totally relaxed and loved every minute of it. I can't wait for the next one, which I understand may be in 2012.

We had a small intimate group of six, which worked out great for meals and etc. We were on a different ship than last time, and it was a very nice newer ship than the Holiday. But this one is on its way to North Carolina and yet another ship is coming to Mobile, so we will have to check out this one also.

Our ports were Cozumel and Calica. Of course I think Cozumel is the shopping mecca of all ports. It was a very rough cruise, I am not sure what weather system we were in but it rained and was very windy, and rough. One definitely needed their sea legs. It does make it a challenge to walk through the dining room. I can-

not imagine having to carry those trays full of food in these conditions. It is a challenge to say the least! Of course we were entertained by our servers who sang and danced for us. Considering the fact that not one of them were Americans, we basically understood them with no problem. The crew was the friendliest I have encountered in 13 cruises.

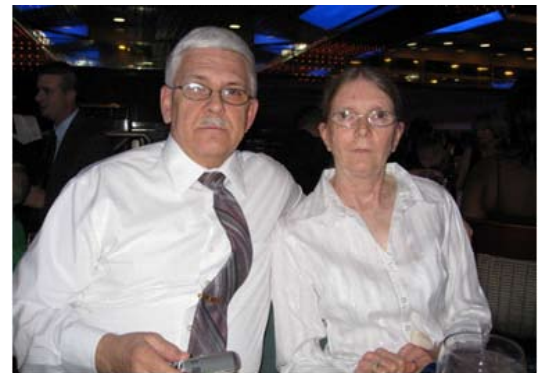
Understand I had never been on a cruise prior to diagnosis of LMS. I had always wanted to go. After diagnosis I decided to take my husband and my son and we were going. Well I have been making up for lost time and cruising ever since. I cannot imagine a better way to vacation. All one needs to do is whatever they want to, whenever they want to. If this your idea of fun, plan to join us for the next cruise!



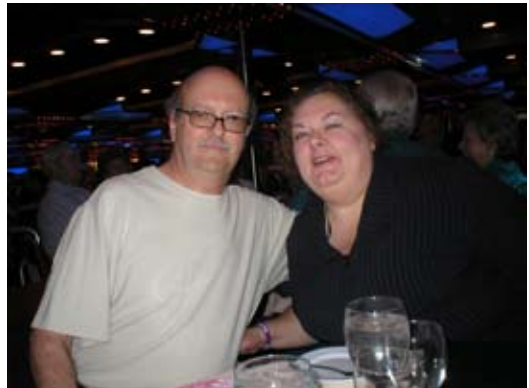
Jane Moulds and Ryan Belmore



Coconuts in the Palm Trees



Dave and Barb Jones



Bill and Joni Fixel

## NLMSF – How can you help or get Involved *by Joni M. Fixel*

The NLMSF is run by member elected Directors who volunteer their time to the foundation. Each of the current Board members asked themselves at one time “How can I help?”

As a foundation that continues to grow and serve those touched by LMS, there are endless opportunities for people to volunteer. We have a volunteer who meets others with LMS at MD Anderson to help navigate the hospital and internal processes of the hospital. Other volunteers make ribbons to send out or take calls from newly diagnosed LMS patients.

Our foundation needs your help in any way you want to help. There are several committees where you might be interested in lending a hand; Communications, Membership, Medical, Finance, Events, and Audit. NLMSF needs you to lend a hand (or two?)..... it is your assistance that helps us grow.

A strong volunteer force that is dedicated to helping educate and spread awareness of LMS is what we need. The fundraisers are invaluable to help fund

research to find treatments and eventually a cure for this rare cancer. If you have extra time or an idea, let us know.

### The Foundation Store has great New Products!

With the update of our website the NLMSF has a newly expanded foundation store. With a large variety of products the store features cookbooks, jewelry, artwork, photography, candles and much more! Every penny made from the items in the store goes towards funding research for Leiomyosarcoma. Help support the NLMSF by shopping in our online store!



Notecard Pack of 10 with Envelopes  
\$6.00 each set



Morning Hunt Painting  
\$20.00



Survivor Lapel Pin  
\$3.50 each



Hope Dream Believe  
Lapel Pin  
\$3.50 each



Dragon Slayer Hat  
\$12.00

## NLMSF Stamp by Theresa Miller

At Hugfest this year I get to present a stamp created by Kristina Johnson in memory of her mother who lost her battle with LMS in August. It will be passed (I have faith) and it will become our official stamp.

If you like what you see I will be the one ordering them and mailing them to you. They will become available shortly.

They are not forever stamps so when the price hikes (as we all know it will) they will change right along with the rate. My husband is in charge of this part.

Kristina was kind enough to send me some stamps and gave me all the info to get them for ourselves. She has gone out of her way to spread the word about LMS. She is a soldier for our cause even after the death of her mother. WE SHOULD ALL SALUTE HER.

Remember contacting anyone but me over this is gonna get you no where. I don't mind being in charge of this. I see a way for lots of people to see what we are all about. I already have stamp collectors asking for them.

I asked my wonderful adoring husband Ken to print me a label to go along with the stamp. It says Learn More About Leiomyosarcoma at [www.nlmsf.org](http://www.nlmsf.org) I am putting this on the front of the envelope along with the stamp. Yes we will get some response and spread the word. That is our mission right?

We will let you know when the stamps are available. If you can't wait write me at [treesa5585@yahoo.com](mailto:treesa5585@yahoo.com) and we will work something out.



The NLMSF stamp features the dragon, slogan SLAY the Dragon and will feature our web address. What a great way to spread awareness!

**Fundraisers:** Recapping our latest events and fundraisers by our Members and supporters!

### September 19, 2009: Purple Affair for LMS

Location: Trenton, NJ

This event was coordinated by Diasy Rivera- Alicia as a way to spread awareness and raise money for cancer research. The event this year raised \$13,610.00! Thank you so much for your amazing efforts on behalf of everyone with LMS and their supporters.

### September 26, 2009: Slay the Dragon 5K Walk/Run

Location: Carter Park, Ashland, VA

This annual event was started by Kathy Landes in memory of her father Richard Lloyd who lost his battle with LMS. The 2009 Walk/Run raised \$10,000.00 for LMS Awareness! We thank Kathy all of the volunteers, walkers and runners for their hard work!

For more information on how to be involved in next years event please visit:  
<http://slaythedragon5k.com>

### **January 2010: Basketball game to raise Awareness**

Location: Ann Arbor, MI

Pioner Highschool Girls Basketball team used one of their games to raise awareness and funds for LMS. Their coach Crystal Westfield was diagnosed with LMS- and has continued to coach between her surgeries and treatments. The team made T-Shirts and sold them- all proceeds were donated to cancer research. The Foundation would like to thank the girls for their effort. We would also like to extend our supportive hand to Crystal as she continues her battle with LMS.

<http://www.annarbor.com/sports/high-school/raising-funds-and-shaky-cheerleaders-in-county-gymnasium/>

## **Upcoming Events**

### ***HugFest 2010***

The 10th annual HugFest event is back and in a new location! This year the event will be held in Bronson , MO. A more central location for the majority of our membership. For more information please check out our website [www.nlmsf.org](http://www.nlmsf.org) .

Questions and Registration information email: [jane@nlmsf.org](mailto:jane@nlmsf.org)

**Dates:** Thursday April 15, 2010 - Saturday 17, 2010

### ***Team Sarcoma Initiative: Dog Wash for a Cure***

After last years success raising money for the Team Sarcoma Initiative and the NLMSF, All Shapes and Sizes Dog Grooming Salon in East Lansing, MI will be offering \$5.00 dog washes and donating all proceeds towards cancer research. More details will be coming soon!

We encourage everyone to have a Team Sarcoma Initiative Team. during Sarcoma Awareness Week - Together we can Slay the Dragon!

**Dates:** Saturday July 25, 2010

### ***BridgeFest 2010:***

The Annual event at the Mackinaw Bridge is back! It is in its early planning stages. For more information on how to get involved or attend please email [admin@nlmf.org](mailto:admin@nlmf.org)

**Dates:** Saturday Sept. 4, 2010 - Monday Sept. 6, 2010

### ***Slay the Dragon 5K Walk/Run***

**Date: September 25, 2010**

Contact: [info@slaythedragon5k.com](mailto:info@slaythedragon5k.com)

If you have an upcoming fundraising event please email [admin@nlmsf.org](mailto:admin@nlmsf.org)



**The National LeioMyoSarcoma Foundation**

2843 E. Grand River #230

East Lansing, MI 48823