

The Dragon Slayer

Volume 4 Spring/Summer Edition July 28, 2009

Team Sarcoma Initiative

This year the NLMSF took part in the Team Sarcoma Initiative on Saturday July 25th. The team Sarcoma Initiative was part of a world wide chain of events to raise awareness about Sarcomas and raise money to further research. The Team Sarcoma Initiative events took place during the week of July 18th to July 26th, 2009. The events were the result of a challenge from the Liddy Shrivery Sarcoma Initiative for groups and individuals to do something to bring awareness to Sarcomas in any way possible.

The preliminary count of all the events on Monday the 27th, just following the week was 12,075 participants world wide. This amazing number of people came together to help raise funds, raise awareness and help support each other through the battles with LMS and other sarcomas.

NLMSF's Part in the Initiative

On Saturday July 25th a group of 10 gathered at All Shapes and Sizes Grooming Salon in East Lansing Michigan to help raise awareness about Sarcomas and more specifically LMS. The small group was made up of survivors of LMS and family members and supporters.

All Shapes and Sizes is a luxury pet salon that features a variety of services. On the 25th they offered dog washes for a reduced price of a suggested donation of \$5.00. The shop's owner, Rachelle Anthony, volunteered her business, time and all money made that day to raise awareness and money for research.



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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 first \$5.00 donated for the dog wash went directly to the Team Sarcoma Initiative. Any other services, products sold, or NLMSF products sold went directly to our foundation.

The team washed over 25 dogs and handed out literature on both the Sarcoma Initiative and LMS. Each person who came into the shop for a dog wash came out touched by the

Team and our mission.

We truly appreciate everything the shop did for the foundation, and the hard work of all of the volunteers. For the first time our organization took part in the Team Sarcoma initiative, it was a great success. On the request of several of the customers we had that day, we will be holding this event again next year and look forward to more volunteers and



LMS Survivor Kelli Lambert found her second calling washing dogs with the NLMSF Team Sarcoma Initiative



Team Sarcoma Initiative Team 2009

Upcoming Events

- September 4-7, 2009 **BridgeFest 2009-** Mackinaw City, Michigan. Our highly successful (and fun) event is back for the 5th year in a row! We have a block of discounted rooms (book before 8/13) for our group again. Come join us walking the Mackinaw Bridge, or raising awareness.
- September 19, 2009 **Purple Affair- Dinner/Dance Fundraiser** Tenton, New Jersey Fundraiser to sponsor local survivor Daisy Rivera-Alicea. Donation of \$25.00- guests are ask to wear something purple in support. Contact information can be found on www.nlmsf.org
- September 26, 2009 **Slay the Dragon 5K Walk/Run in Memory of Richard Lloyd Ashlund**, Virginia. Sign up by August 1st for a reduced rate. All proceeds go to the NLMSF.
- February 8, 2010 **NLMSF Cruise-** Call Carnival Cruise Line 1-888-Carnival Group Code #86D5S2

We are constantly updating our events and more information can be found online.

A Message from the President: HugFest 2009 Recap

by Joni M. Fixel

Hugfest 2009 was held in Clinton, New Jersey over April 16-18th. It was set in a back drop of a quaint little town where participants could walk, talk and shop if they wanted to take a break from the planned events.

On Thursday evening as people arrived they were able to sign in and join everyone at a meet and greet session. Many of our participants were first time attendees and it was great for us all to put a face with a name. We got together and talked until the hotel told us it was time to close down for the night. Many of us continued to talk and visit over a late dinner.

Friday morning we met in the ballroom for a great presentation by Dr. Bob Dauchy. Dr. Dauchy is part of the research team with Dr. David Blask formerly of Bassett Research Institute. The project has moved and is now at Tulane University in New Orleans. Dr. Blask's team are studying the impacts of Melatonin (a natural substance) in inhibiting cancer cell growth. This project has been funded by the NLMSF through donations for research. The good news is that this project is soon moving from clinical research to testing on mice and rats. It is anticipated

that findings thus far will be published soon by the research team.

After the presentation by Dr. Dauchy, break out sessions lasted all day provided by the Wellness Community. Experts from various disciplines in cancer and health care treatment counseled members and attendees on nutrition, chemotherapy, radiation, caregivers support and coping with the stress for all members of the family. In the evening, we all met back in the ballroom for a great dinner and inspirational presentation by DonnaLyn Giergerich.

DonnaLyn Giergerich is a LMS survivor and beauty contest winner, (Ms. Red Bank 2009) and spreading the word about LMS across the nation. Everyone who hears her story of diagnosis and survival leaves with renewed hope that miracles can happen even with LMS. To learn more about Donnalyn's journey with LMS go to <http://donnalyn.org/>.

Saturday morning the NLMSF Annual Membership Meeting began with everyone met for a buffet breakfast and more presentations about the ongoing research funded fully or in part by the NLMSF. Ricki Gero was kind enough to give us all an update on the Tissue Bank Re-

pository and the progress made by Dr. Brooks. Her presentation reminded us about the time and effort that goes into a project such as this. It is through Dr. Brooks that a tissue bank has been created and housed that will provide researchers access to LMS tissues for decades to come. The NLMSF funds Dr. Brook's tissue bank. Ricki may have a new career in presentations!

Dr. Rob West gave everyone an update on the research at Stanford University. Dr. West is part of the research team led by Dr. Matt van de Rijn. The research at Stanford is producing some very exciting results. Through this research it is believed that LMS has subgroups which may explain why certain chemotherapy works on some people's LMS tumors but not on others. The subgroup identification may lead to future targeted treatments by tumor type. Other exciting results were reported in the last issue of the Dragonslayer. Publications are expected soon reporting more exciting research results. The Stanford research is funded by the NLMSF and LMSdr. The NLMSF Board presented Dr. West with a research grant of \$58,000.00 for the Stanford Research project.

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Next was a presentation by Dr. John Martignetti from Mt. Sinai Hospital on various cancer tumor markers the differences seen in Uterine LMS cancer cells. Much more work is being done but one exciting part is that cellular differences can be identified by the researchers. Dr. Martignetti's research is funded by the NLMSF and the Ellen McCullough foundation.

Maureen Kehoe attended with her parents, Tom and Pat. Each year since the passing of her 19 year old son, Derek, Maureen organizes a 5K run/walk in Derek's memory. The Kehoe's presented the NLMSF with \$15,000.00 to be used for research of the treatment and cure of LMS in memory of Derek Kehoe. It is through this and the many other fundraisers held every year that allows the foundation to fund the great research projects listed earlier in this article.

Finally, the Board of Directors presented the new Directors, Amy Rovi and Vicki Marrin. The new directors were selected and voted by the membership and presented at the annual meeting. New committees were formed with new committee heads and volunteers from the membership assisting and guiding each committee. Each Director told of their experience with LMS and how they got involved and their individual

reasons for involvement with the foundation. Goals for the future were presented by the Directors.

If anyone is interested in volunteering for any of these committees, we urge you to contact the Chair and let them know! We encourage your participation and ideas because it is through the membership that this foundation will continue to grow.

In closing our weekend, the memorial candle was lighted while names of those warriors who have gone before us were read aloud. Jen Smith provided a heart warming slide show giving us time to reflect. Bobbie Keller brought and displayed those beautiful LMS quilts for everyone to see and read the squares so lovingly stitched into quilts of memories. Sally Gagliano and her daughter, Laura brought their lovingly made bracelets and jewelry to sell for fundraising for research.

Finally special notes of appreciation must go out to those who put together such a wonderful weekend that allowed us to join together and learn about our disease, our battles and our support for each other. Mary Ann Croce and Patti Lloyd deserve all the thanks and recognition for pulling together a wonderful weekend. A thank you to Kristen Townsend and Jen Smith for creating a membership database. Thanks to Jill Andree, Ryan Belmont and Pamela Duval-Moore

for managing the sales tables. Thank you to Marge and Steve Rudloff for being our "official" photographers of our annual events. David Lloyd, Phil Keller and Bobbie Keller were great help in checking in our attendees. Bobbie Keller for keeping, sewing and transporting the LMS quilts to the Hugfest each year. Pamela Duval-Moore for creating social networking support for LMS. Thank you to Vicky Peters, Theresa and Ken Miller for creating the awareness ribbons and providing door prizes. If we have missed anyone in this list it is purely by accident and we want you to know that we truly appreciate each and every volunteer in the organization.

Finally, the Board of Directors would like to thank all members and supporters who give of themselves in time, lending an ear and in raising funds for the research and awareness of LeioMyoSarcoma. We cannot do anything without your help and support. Please consider offering suggestions to any Board member in how we can better serve you.

Hugs & Prayers,
Joni M. Fixel



**The National Leiomyosarcoma Foundation
Board of Directors and Officers are:**

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
Membership – Joni M. Fixel, joni@nlmsf.org
Fundraising – Dr. Jen Smith, jen@nlmsf.org
Audit Committee – George Peters, george@nlmsf.org
Communications – Amy Rovi, amy@nlmsf.org
Events – Vicki Marrin, Vicki@nlmsf.org

Letters from the New Board Members

Hello Board Members!
Here I am at a place I did not expect to be in the year 2000! It was then that I was diagnosed with the infamous LMS, a cancer that is aggressive, sneaky, rare, and not very well known. I had been waiting in the hospital for my doctor to tell me the results of the tests that had been done, and while I was waiting, I was reading *The Greatest Generation* by Tom Brokaw. The peculiar aspect of the doctor visit was that, as my doctor told me it was cancer, I felt like I was simply reading another story about someone else as had been written in the book. This was not me he was talking about!

I went through a hysterectomy and then almost immediately began chemotherapy, then two sets of radiation. As my oncologist said, “they threw

the kitchen sink at me.” Your life literally depends on the decisions you make as you face this terrible disease. Have chemo? Do radiation? What are the long-term effects? What are the side effects? And other questions – will I be able to perform my job? Will I be able to keep my job? What will my family say? How will they react in the long run? Who will really support me? And, of course, the big one – will I survive this?

When one is confronted with a problem, the advice is to research it to help in finding a solution. I went online after I was diagnosed. After an hour, I turned the computer off. “What did you find?” my husband asked. “Enough to make me sick. I don’t want to know any more.” I found out the low survivor rate for this terrible cancer; how it can recur; how it is aggressive.

When I was introduced to my oncologist (Dr. Abraham Mittelman), I told him, “Don’t give me facts and statistics; just tell me what we are going to do to get me through this.” I knew that if I were told I had three months to live, I would die 90 days later because I follow instructions really well! He simply grinned, shook my hand, and said “It’s a deal!”

Perhaps, as I’ve been told, attitude goes a long way toward getting better. Hard to say. After all, I did have a recurrence a year and a half later – a bump on my head that I knew hadn’t been there before. When I saw the dermatologist to have it biopsied, he said, “Bumps on the head are common. Do you really want it off?” I responded – with a sense of going “against” this doctor’s advice – “Yes; after the

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kind of cancer I had, I know that a bump on my head is not usual." The biopsy told us it was more LMS. After a long battery of tests, my body showed no more trace of LMS after the bump had been removed.

So now I live between doctor visits, the fear receding in the months between. I am so grateful to the men and women I have met along this path I would not have chosen. When my husband and I first visited the cancer treatment suite at Westchester Medical Center, my husband commented, "This is so awful!" But I said, "No – Thank God for this place; it is where I'm going to get better!" All of those people who work there are doing so to make me better! I have had many, many blessings.

In April 2008 I finally decided to learn about the cancer that changed my life. So I attended HugFest. And what an amazing experience. So many things I did not know; this was not just a "women's" disease – men get it too. It can appear in any part of the body. There is research on this dragon, but it is still in the beginning stages.. I was very interested to hear what our wonderful researchers had to say about the tests they are running and the results they have found; but they have such a long way to go. I admire their education, focus, and dedication to finding

a cure. The more we can help them, the more likely it is that we find a cure; and that cure will very likely help others who have other kinds of cancers as well. That is the light at the end of our tunnel.

HugFest was a wonderful experience; it is very comforting to talk to others who have experienced what you have. From 2000 to 2008 I had never met anyone who had it. I also learned what great people – and what a variety of people – get this disease. I am delighted to have met people like Joni, Loretta, and Jane.

Please forgive the rambling nature of this letter. It is just to give background to why I would like to become a board member of the NLMSF. I remember a slide that one of the research doctors showed; it was of a tiny car in a big parking lot. He said this was just like the amount of research that has been done on LMS. Then I realized that when I was diagnosed, there wasn't even a parking lot.

I am grateful to all of those who came before me who had to deal with LMS. I would like to "pay it forward" to those who have been diagnosed with LMS and need a little help - and to offer hope that we can and we will find a cure.

I've attached my resume to this letter. I think my relevant skills, besides being proficient in Word, Excel, and PowerPoint, and having many years of administrative experience is that I work well with people. I believe I listen well. I believe in collaborative effort. And I want to beat this terrible disease.

Please let me know what you think. I look forward to working with you.

Sincerely,

Victoria Marrin

Note from the Editor: Please see the next Page for Vicki Marrin's Resume. Contact her for any help with events or joining the events committee!

Work History

- 2002 – Present
Ossining Union Free School District Ossining, NY
Administrative Assistant to the Executive Director of Finance and Operations
Act as liaison for the Executive Director of Finance and Operations in extensive contact with administrators, central office personnel, business office staff, Board of Education, legal counsel
- . Write monthly Board resolutions for financial items and follow up
 - . Draft contracts between school district and vendors
 - . Responsible for District tax certioraris
 - . Write scholarships
 - . Active member of the Ossining UFSD Wellness Committee
 - . Manage insurance-related items for District; renewals, certificates of insurance
 - . Supervisor of the Free & Reduced Meal program at all District schools
 - . Handle state-mandated Free and Reduced Meal Verification process for the District
 - . Update of Districtwide Safety and Emergency Management books
 - . Supervisor of Mailroom Clerk
 - . Coordinate training of District personnel in CPR and use of the Automated External Defibrillator
- 1998 – 2002
North Salem Central School District North Salem, NY
Secretary to Principal – Middle and High School
Point person for teachers, staff, students and parents to principal; management and improvement of district-wide purchase orders. Typing, dictation, phone, letter creation.
- 2000 – 2002
Kenmar Advisory Group Greenwich, CT
Administrative Assistant to Chief Financial Officer
Office Manager; administrative work; managed a \$1MM+ futures fund.
- 1993 – 2002
Marrin Tax Service
Owner
Provided personal tax preparation service to clients.
- 1987 – 1990
General Foods Corporation Legal Department
Consultant
Researched, identified and individualized software system and supervised personnel to manage documents for a large legal case in preparation for trial.
- 1986 – 1990
General Foods Corporation Legal Department
Legal Assistant
Part of a small legal team that successfully defended against Federal Trade Commission charges of anti-trust activities in the Maxwell House Division; first in corporation to use large computerized database as well as Lexis Nexis for document research and location.
- 1983 – 1986
General Foods Corporation – Cereals Division
Logistics Manager
Coordinated the placement of products at retail with the timing of advertising. Visited Battle Creek, MI plant every six weeks to ensure timing accuracy. (Cereal products have the fastest advertising turnover of any on the market.)
- 1981 – 1983
General Foods Corporation – Main Meal Group
Administrative Assistant
Researched products and genre history and created product forecasts.

Education

- 1976 – 1981
Iona College
B.S. in Business Management - Summa Cum Laude
Minors: History, Psychology, Communications
Graduated in four years while continuing to work full time

Other

- Computer Knowledge: Microsoft Word, Excel, PowerPoint; Adobe Acrobat; Publisher; GroupWise; WinCap financial software; and others.
Notary Public
President of Homeowners' Association for 10 years

About Amy Rovi

Amy Rovi has over 15 years of medical education, training and corporate pharmaceutical experience with particular expertise in respiratory disease, pain management, metabolic bone disease, neuroscience, hematology, oncology and genetics. She has held numerous scientific, marketing and management positions with two global pharmaceutical companies from 2000-2006.

In 2007, Amy launched Medivor, LLC, a medical writing and consulting firm. Her firm develops and edits clinical study reports, scientific documents, slide presentations, medical marketing materials and consumer/health care practitioner website manuscripts. Clients include pharmaceutical companies, biotech firms, health care organizations, research settings, academic institutions, advertising agencies and the non-profit sector.

She has been a member of the American Medical Writers Association, Delaware Valley Chapter, since 2007. She currently serves on the Membership Committee of the National Leiomyosarcoma Foundation (NLMSF) and the Scientific Advisory Committee of Leiomyosarcoma Direct Research Foundation (LMSdr). Amy is currently the chair of Communications for the NLMSF.

Amy is a passionate caregiver and medical advocate for her mother, Bernadette M. Hollis, who was diagnosed with leiomyosarcoma (LMS) in June 2006. She maintains a deep personal interest in battling the disease and has devoted energy and resources to create awareness and funds for LMS research. Amy resides with her husband and son in suburban Philadelphia, PA.

Her Vision for her Board Position

As she was being discharged from the hospital, I was being admitted. She had a hysterectomy; I delivered a beautiful baby. In June 2006, my son was born and my Mom was diagnosed with ULMS.

No one prepares you for the moment when you first learn of such devastating news, especially after you've just been blessed with one of life's great miracles--having a healthy, happy baby. My husband, son and family members pulled me through the initial shock, and through subsequent steps along the grief continuum. In fact, we are still pulling each other along...

No one has endured more than my Mom, though. She has had numerous surgeries and chemotherapeutic/hormonal treatments while continuing to maintain her law practice in upstate New York. Despite Stage IV LMS, she continues to enjoy her profession at a full-time

pace, and spends time away from law visiting with her children, their spouses and her grandson.

It would be an honor to serve on the National Leiomyosarcoma Foundation (NLMSF) Board of Directors. I hold the nomination in high regard and would serve to pay tribute to my Mother, and all those affected by the disease. I maintain a deep personal interest in battling this disease and have devoted energy and resources to care for my Mom, ensure she has the best treatment, create awareness of the disease and raise funds for LMS research.

NLMSF has already touched the lives of so many through funding of research initiatives specific to LMS, by working to improve treatment outcomes for people affected by the disease and by fostering awareness through the website, annual Hugfest meeting and outreach initiatives. I have attended Hugfest for the past two years, serve on the Membership Committee of NLMSF and serve on the Scientific Advisory Committee of Leiomyosarcoma Direct Research Foundation (LMSdr).

My background and experience will serve useful if elected, as I have over 15 years of medical education, training and corporate pharmaceutical experience. In 2007, I launched Medivor, LLC, a medical writing and consult-

ing firm. We develop and edit clinical study reports, scientific documents, slide presentations, medical marketing materials and consumer/health care practitioner website manuscripts. Clients include pharmaceutical companies, biotech firms, health care organizations, research settings, academic institutions, advertising agencies and the non-profit sector.

My vision for NLMSF is consistent with its mission. Specifically, I would like to work with fellow Board members to identify and support a growing pool of LMS specific research. This requires new, creative ways to identify academicians and researchers and raise funds in support of LMS specific research, especially given the current economic environment. Guidance on fundrais-

ing posted to NLMSF.org may serve useful to those who wish to channel their energy into activism. And, we must continue to recognize and find new ways to support advocates and volunteers who raise funds and devote time and energy to our mission.

I would also like to work with fellow Board members and constituents to build an even more vibrant, transparent website which will energize and educate patients, caregivers and family members, the medical community and the general public. The site currently serves as a dynamic repository of information. We can leverage technology for greater efficiency on the site, registration to the site, membership tracking, two-way information exchange regarding events

and updates, and use of emerging social networking/blogging.

If granted the opportunity to serve on the NLMSF Board of Directors, I will continue to support the mission in a more direct leadership role, listen to feedback from our constituents and partners, and work to provide new growth opportunities for the organization that will ultimately improve the lives of all those affected by LMS.

Thank you for your consideration.

Best regards,
Amy
Medivor, LLC
Writing and Consulting Firm
amyrovi@MedivorLLC.com
267.259.5599

License Plate Raises Awareness

My name is Theresa Miller and I have survived LMS for five years now. I am truly one of the blessed ones. BUT I will never forget about those that have lost the battle and those who are just hearing the word leiomyosarcoma for the first time. I will never give up the fight. For my birthday this year I got myself a present. I got this personalized license plate. I carry ribbons in my car for anyone who ever asks me about it. I will get the word out anyway I can. Please please please do the same. We have GOT TO find a CURE!!

Hope - Always,
Theresa



Hugfest 2009 From the Organizers

HugFest 2009 was held April 16-19 at the Holiday Inn Select in the lovely, historical town on Clinton, New Jersey.

The festivities began Thursday evening, April 16. Every attendee was greeted with a hug and received their nametags and welcome bags complete with water, snacks and the agenda for our weekend. Everyone met and warmly welcomed those that were attending HugFest for the first time. A vegetable crudité, cheese & cracker platter, flavored coffees, tea and soft drinks were enjoyed as the conversations and laughter flowed.

Our day on Friday, April 17 began early. After a short welcome, Dr. Robert Dauchy of Dr. Blask's team reported on the ongoing research being conducted at Tulane University on the effects of melatonin on tumor growth.

The day continued with the Wellness Community of Central N.J.'s programs led by Ellen Levin, Program Director. The programs were designed to give all the attendees, whether surviving LMS or supporting a survivor, with the tools necessary to help them live with cancer. We all learned about making decisions about complimentary care. There were break out groups de-

signed specifically for patients to learn strategies for talking with their health care team as well as one for the caregivers to aid them in healing and coping with loss. We also learned some tools for reducing stress. Our full day of programs ended with an informative presentation on nutrition. Each attendee received a packet from the Wellness Community with all the information presented to us that day. I know the "Guide for Reducing Stress" will be used by all!

Our day concluded with a sit-down, served dinner highlighted by our own Donnalyn Giegerich with her inspirational and motivational talk about her journey with LMS. Donnalyn recently was named "Mrs. Red Bank" and is vying for the title of "Mrs. New Jersey". We wish her luck (and our votes) as she continues to promote awareness of LMS.

Saturday morning began with a wonderful breakfast followed by a presentation by Dr. West of Dr. Matt van de Rijn's team from Stanford University. Dr. West began his presentation with first hand experience of what all those gathered go through as he related his own frustration after his wife's cancer diagnosis. His presentation was very informative as we were able to understand all the "scientific words"

as he used many metaphors, which allowed us to actually get it!! We are inching along in our goal to successfully pinpoint and treat LMS.

Dr. John Martignetti from Mt. Sinai's research department in New York reported on their work in LMS research.

Ricki Gero spoke about the status of the tissue bank project being run by Dr. Brooks from Philadelphia Hospital. Ricki was able to give us a rundown on how and why the bank began and what we hope to accomplish with the bank. Researchers will use these tumor tissue samples for use in their LMS research.

After our lunch break, the Annual NLMSF meeting was held. Joni Fixel updated the entire membership with the status of the Foundation and introduced the Board of Directors. Maureen Keho presented the NLMSF with a check for \$15,000 which was raised from the fundraiser held in memory of her son, Derek. The NLMSF presented Dr. West with a research grant of \$58,000 for next year's funding of the project.

Our HugFest weekend ended as it began with hugs, tears, laughter, renewed friendships and the

knowledge one is not along in this fight to “Slay the Dragon”!! A number of us stayed an extra night and thoroughly enjoyed the town of Clinton before heading home.

Special thanks go to David Lloyd for all of his work with the nametags, registration and organizational skills; Vicky Peters and Theresa Miller for the unbelievable “Dragon” centerpieces and all the gifts given to our survivors; George Peters for his prayers offered and his eloquence during our “Remembrance of our Lost

Warriors” and to Vicky, our own “American Idol”; Marge Rudloff our “official” photographer; Bobbi & Phil Keller the “quilt keeper” and all that it entails (sewing, protecting, shipping); Sally & Rachel Gagliano for the beautiful jewelry they hand make and sell to raise money for research in honor of Sally’s sister; Kathy & Karen McCullough for co-sponsoring the research project at Mt. Sinai with Dr. Martignetti in honor of their Mom, Ellen; Jill Andree, Pamela Moore and Ryan Belmore for their help running our “gift store”. Ryan and Jill

are the son & granddaughter of Jane Moulds and Pam pitches in wherever she is needed in honor of her Mom.

It was an honor to run HugFest 2009. We thank all who attended and hope you all went home with more information than you came with, many new friendships, lots of hugs and a renewed spirit until we meet again at HugFest 1010!!

Maryann Croce & Patti Lloyd

NLMSF Remembers Patti Lloyd



Last month, June 2009, we lost another angel to Leiomyosarcoma, Patti Lloyd. She worked very hard to promote awareness for LMS and raise money for the NLMSF. If you attended this year’s Hugfest, you knew how hard she and MaryAnn Croce worked to ensure everyone had an informative, memorable and supportive experience. Patti’s hard work and smile will truly be missed but her spirit will always be present. The NLMSF gives our condolences to Patti’s family.

The previous and following articles were written before her death. The next article is a biography Patti wrote before her death. During her life she did great things for the NLMSF. We would like to honor her by including this biography so we can all understand what she did for all of us in our battle against LMS.

In Her Own Words..
By Patti Lloyd

My name is Patti Lloyd and after 30 years in Texas, I now live in Gilbert, Arizona. I was diagnosed with Leiomyosarcoma in October, 2005, which, basically, changed my life as well as my family's. Before my diagnosis I worked for 23 years for the University of North Texas Health Science Center in Fort Worth, Texas. I have been married to my husband, David, for 40 years and have two sons, Jim and Maki, five amazing grandchildren, and two daughter-in-laws which I consider my very own.

In my pre-LMS life, I served as Executive Director in the President's office of the UNT Health Science Center. My duties included serving as a liaison between the President and the various administrative arms of the institution. In addition to working directly with our numerous Vice Presidents and Deans, I had five areas reporting to me which included Special Events, Faculty Affairs, Community Service, Scheduling, and coordination of information between our institution and our governing Board of Regents. I was also responsible for a multi-million dollar budget as well as budgeting for areas that could not be funded by dollars provided by the state.

The areas I enjoyed the most were in my role as community liaison and working with our Foundation and Alumni office to raise awareness of our mission as well as helping to raise funds for various projects and research efforts in our institution. I also had the opportunity to work with our medical and bioscience students as they went through the rigors of learning to be physicians and scientists. I have reviewed grant applications and served on committees to improve patient care to insure our institution provided the best quality of care possible.

These experiences have served me well since my own diagnosis and have helped guide me in my own journey to find the best and most successful treatment in my personal battle against LMS. It is my hope to help spread awareness of LMS and to coordinate with any other organization who can possibly help us with our quest.

It would be my honor to serve as a member of the Board of the National Leiomyosarcoma Foundation and work in any way I can to get our word out to those who can help us to accomplish our goals of awareness, research, patient care and most importantly, supporting and helping each other.

Yours truly,

Patti Lloyd
Gilbert, Arizona



EVER BEEN A HERO?

by Theresa Miller

Recently at work I got to be a hero. (I work at a car dealership. I am the operator and do a lot of clerical work.) I answered the phone to hear a very upset woman say she had locked her keys in the car and she wanted to know how long it would take someone to get there and open her vehicle. I could hear in her voice that she was trying oh so hard not to cry. She then frantically says YOU DON'T UNDERSTAND! MY 3 MONTH OLD BABY IS IN THE CAR! The police are here and they are going to break the window (while she is talking I got my computer to the right place to get the needed information). I asked her does your vehicle have keyless entry? She said yes but she never used it and didn't know the code. Now as fate would have it I am the one who programs all of this info into the computer. I looked up her info and she was getting oh so irritated with me. I kept saying trust me I have to make sure it is you. I can't give this info to just anyone. Once I was sure (took all of two questions) I said you ready? I said the number. She punched it in and TA DA the door opened. Her baby was fine and the window wasn't broken out. She cried and thanked me over and over. I am a hero to this woman. I have to be totally honest. DANG IT FELT GOOD!

You want to know what else I do to feel good? I make LMS ribbons and mail them to whoever asks for them. As I pack them (anywhere from two to a bazillion) I listen to my heart. I sometimes put surprises in with the ribbons. I do whatever my heart tells me to do. I don't question it I just do it. When the person gets their package I usually get an email full of thanks and a question of "How did you know I needed that?" I hear that kind of remark a lot. I respond my heart knows even when my head doesn't. I also send cards to fellow LMS'ers and friends. I hear so often how do you know when to send me a card? I needed that so much today. I send funny cards, serious cards or just plain cards and I write a word or two. I never know why I pick what I do. Like I said my heart knows when my head doesn't. Be a hero to someone. Write a note, send a card or even just say a prayer. Do what your heart tells you to do.

You will like yourself for it.

Hope - Always,

Theresa

survivor

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

The Story of the NLMSF Quilt

The LMS Quilt project started about eight years ago and is the brainchild of Karen Gibson, a mother whose daughter was diagnosed with LMS. Karen made a block for her daughter. It is in the first completed quilt displayed at our first Hugfest in Lancaster in 2002. The idea behind this quilt project was similar to that of the AIDS quilt and in response to the growing need to increase awareness of LMS. We all had heard of the AIDS quilt but Karen believed we didn't need to go to that extreme. A secondary thought crossed her mind--make the LMS quilt small enough to be shipped around the country to important events which could increase awareness of this "dragon." Also, the smaller size would enable it to be sent to anyone who might be nearing the end of their battle or just going through a tough time so they could feel enveloped by the love emanating from the quilt.

Upon completion of the first quilt, Cana Machine Quilting of Oyster Bay, New York machine quilted it for us after which Karen Gibson completed it with the binding. The second quilt was machine quilted by Marge Geary of the Evening Star Quilters of Mineola, New York. In addition Marge hand stitched

the binding on this second quilt. The third quilt was sewn together, machine quilted and bound by Bobbie Keller, a quilter, a survivor of LMS and currently the "Keeper" of the quilts.

Two of the quilts have traveled all over the country and even to Canada. The very first quilt was present in Washington, DC to welcome a father who ran from the middle of the country to the nation's capitol on behalf of his daughter who was battling the "dragon" to bring awareness to the disease. They've been at Relay for Life events, golf tournaments and been on display in the Arts in Medicine studio of H. Lee Moffitt Cancer Center & Research Institute in Tampa, Florida during their Sarcoma Awareness Month. In addition, they have been present at memorial services at the request of family members. The recently completed third quilt will soon join the first two in journey around the country to help raise awareness to LMS. It is also hoped that sometime in the future the quilts would make their TV debut on a program like Oprah Winfrey or some other similar type program to bring more awareness to LMS. Each quilt block is made in honor of someone currently do-

ing battle or who had lost that battle. Those who made blocks for loved ones who lost the battle have commented it has helped with the grieving process. We tried to simplify the process for making a block so that sewing knowledge is not required. Blocks can be done in any way as long as they conform to the size needed and contain some pertinent information. Instructions have been developed which include these guidelines as well as some suggestions on how to go about making a block. While some of the quilt blocks are sewn, others use fabric paint or fabric pigment pens, photo transfers, been cross stitched, etc. Any medium is acceptable. There is also available some premade blocks upon which information can be printed with a pen. The finished blocks are then incorporated into a quilt which when completed is about the size of a twin size bed.

If anyone is interested in obtaining the instructions or have additional questions, please contact Bobbie Keller at kellerpjbw@aol.com.

A Recap of Night at the Races 2008

by Susan Smith

The Night at the Races 2008 was indeed another success, thanks mostly in part to the dedication of wonderful volunteers and great family and friends. We have been fortunate to raise almost \$25,000 for the Foundation over the past 4 years. The Annual Night at the Races, held in Wilkes-Barre, Pennsylvania every fall was started by Susan Smith, sister-in-law of Angie McNeil-Smith, who passed on in August of 2007 from LMS. It is now held in her memory, however all proceeds go toward research, in the hopes of one day finding a cure and "Slaying the Dragon." It is a great night full of fun, food and

festivities. For \$10, a person buys a ticket, otherwise known as their "horse," and is put into a race. If their horse wins that race, they win \$50 and \$50 goes to the Foundation. (Aside from the actual racing, you can bet on other horses that night as well as take chances on a Chinese Auction, Instant Bingos, participate in the Raffle, or even the 50/50 drawing.) The great thing about this fundraiser is that you need not be present to win, so we are very fortunate to have people participate, family and friends, from all over the United States! Angie and Andy's 7 year-old daughter, Maggie, has now taken over the job of open-

ing the festivities by welcoming everyone to the Annual Night at the Races, telling them that her Mom had passed on from LMS, and to please have fun and raise lots of money to "slay the dragon." And that's what we have done year after year. It started with one person's idea and dream of wanting to make a difference and, thru hard work and determination, has been a great success year after year! Thanks to everyone who became involved and supported this fundraiser -- we couldn't have done it without you! Together we can -- and ARE -- making a difference!

NASCAR Sponsors the NLMSF

TRG Motorsports has joined with the National Leiomyosarcoma Foundation (NLMSF) to raise awareness about Leiomyosarcoma! In an effort to support research into this very rare cancer, TRG has donated sponsorship advertising space on David Gilliland's #71 racecar for the Sprint Cup Series race in Pocono, Pennsylvania, on August 2nd at 1pm. Garage passes for the race were also made available for two LMS representatives, one a survivor

and the other a NLMSF Board member who lost her husband to LMS, as well as transportation and accommodations. The abundant generosity of this motorsports team has been spearheaded by Mike Brown, General Manager of TRG, and Slugger Labbe, Gilliland's crew chief.

LMS, along with "Sarcoma, The Forgotten Cancer" will have logos on the car and should be a topic of interest with MRN and

PRN racing network interviews. "Slay the Dragon" wrist bands will be available for the team and we are hoping to have T-shirts available for all the folks that have stepped up to the challenge of finding a cure for Leiomyosarcoma! Be sure to cheer for TRG Motorsports and David Gilliland on Sunday, August 2nd! Our thanks go out to Amy Elliott for being such a great coordinator (as well as a LMS survivor) for her great efforts in

giving all of those of us touched by LMS the opportunity to get nationwide coverage through NASCAR! This is truly a great opportunity for our LMS community to educate the world through this race.

We also want to thank Mike Brown and Slugger Labbe for supporting our foundation through the generous use of advertising space on David Gil-

liland's car - it is truly an opportunity that we could never afford without this donation.

Gratefully,
Joni (MI)
ULMS 7/03
NED 6 years
President NLMSF



Stanford Research Summary

By Matt van de Rijn, MD, PHD

In our laboratory (van de Rijn laboratory at Stanford University) we study sarcomas with a focus on LMS, GIST and desmoid tumors. In the past years we have analyzed the role of macrophages (a type of cells that is part of the immune system) in leiomyosarcoma. We initially found that the presence of macrophages influences the clinical behavior of LMS. As part of a project funded by NLMSF we next focused on the role CSF1, a powerful attractant for macrophages. We could determine that in some cases, CSF1 is secreted by the LMS tumor cells, leading to attraction of macrophages into LMS tumors. The coordinate expression of CSF and 3 macrophage genes was found to correlate with clinical outcome. Combined these results suggest that treatment with inhibitors for CSF1 could potentially benefit a subset of patients. However, additional studies on cell lines are needed to verify this possibility. The results of these studies were published in two papers: "Prognostic significance of macrophage infiltration in leiomyosarcomas. Clinical Cancer Research, 2008 14:1423-30" and "Coordinate expression of Colony Stimulating Factor-1 (CSF1) and CSF1 related proteins is associated with poor prognosis in gynecologic and non-gynecologic leiomyosarcoma. American Journal of Pathology, May 2009 Epub ahead of print."

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*

Mount Sinai School of Medicine Research Summary

By John A. Martignetti, M.D., Ph.D.

The genetic causes underlying the development and progression of uterine leiomyosarcoma (ULMS) and, in general, leiomyosarcoma (LMS), remain largely unknown. Much work has been done to describe the expression of patterns of genes expressed by these tumors once they have grown and spread. Importantly, this is providing insight into the fact that major subtypes exist and this may explain differences in tumor behaviour and response to treatment. Despite these findings, no single gene has been identified as an initiator of the disease. Finding this gene will be important to better understand what initiates the cascade of events which result in tumorigenesis and spread and hopefully provide a powerful target for treatment.

Our studies have identified the first LMS initiator gene. Funding from the National Leiomyosarcoma Foundation, including a generous contribution from the Ellen McCullough Golf Classic, have allowed us to move these studies forward. Specifically, we recently demonstrated that female mice genetically engineered to overexpress the KLF6-SV1 gene result in mice which develop uterine leiomyosarcomas. We knew that the KLF6-SV1 gene is an oncogene and it is excessively produced in a number

of other cancers. When tumor cells make KLF6-SV1, they can grow, spread and metastasize more efficiently. To our knowledge, this mouse represents the first animal model for uterine leiomyosarcoma. This suggests two immediate consequences.

Therefore, and with the funding provided by the NLMSF, we explored this important first question: "If high-levels of KLF6-SV1 causes leiomyosarcomas to develop in mice, can it do the same in humans?" To answer this question, Dr. Analisa DiFeo an Instructor in my laboratory and Dr. Fei Huang, first examined uterine LMS tumor samples from our own pathology department. In each case, and in agreement with our hypothesis, we found that the KLF6-SV1 gene was more highly expressed in these patient-derived tumors than in adjacent normal tissue. Based on these findings, we then sought a larger collection of tissues to strengthen our results. In collaboration with Dr. Matt van de Rijn's group at Stanford University Medical Center and Dr. Douglas Levine's group at Memorial Sloan-Kettering Cancer Center we obtained additional tumor samples for analysis. Again, the KLF6-SV1 gene and protein were found to be more prevalent in tumor than normal

tissues. Based on these human tumor findings, we believe that KLF6-SV1 is involved in the development of human LMS. These findings, along with the mouse model of LMS, are currently being prepared for submission for publication. The generous funding of the NLMSF and the important role it played in allowing us to pursue these studies will be gratefully acknowledged.

The second and next important question for us to pursue in the future will be how to leverage these findings into an even better molecular and clinical understanding of LMS. For example: "Can KLF6-SV1 levels in a tumor sample predict the disease outcome or sensitivity to a particular drug regimen?" or "Can KLF6-SV1 be a predictor of disease in families with a history of LMS?" Finally, if high levels of KLF6-SV1 can initiate the growth and spread of LMS can we find a way to inactivate this gene and shut off tumor growth. In this regard, some of our work suggests that this may be achievable. We recently published our findings that a new class of drug molecule known as siRNA, that can shut-down or "silence" a gene, can be injected into mice which are burdened with ovarian cancer and by specifically

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and efficiently shutting-down the KLF6-SV1 gene, mouse survival was greatly increased.

The Tulane University School of Medicine has also published a research paper in the Journal of Pineal Research. That research brief is attached at the end of this newsletter. What a great milestone for the NLMSF!

Tulane University School of Medicine Research Summary

By David E. Blask, Ph.D., M.D.

Melatonin a hormone produced by the human pineal gland during the night provides a signal that inhibits the metabolism and growth of a variety of human cancers in the experimental setting. In a first of its kind study funded by the National Leiomyosarcoma Foundation the hypothesis was tested that melatonin can directly inhibit the growth and metabolic activity of human leiomyosarcomas grown in rats over the short-term as well as cause the regression of these tumors over the long-run. Our results demonstrated that mela-

tonin directly and almost completely suppressed the metabolic and growth activity of human leiomyosarcomas. Furthermore, melatonin was able to cause a substantial regression in the size of these aggressively growing tumors. These findings are the first to demonstrate a potent anticancer effect of melatonin on human leiomyosarcoma growth in rats by suppressing the metabolic activity of these cancers. The next step in this research process is to test the effects of melatonin on the growth activity of leiomyosarcomas (growing in rats) di-

rectly perfused with donor blood collected from human subjects following their intake of an oral melatonin supplements. These promising initial results indicate that melatonin may be a unique and effective potential new strategy for the treatment of leiomyosarcoma in future human clinical trials in leiomyosarcoma patients.



The National Leiomyosarcoma Foundation

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