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## A Note from Sue Sherman, Executive Director

Definitions of belong:

- Be linked to somebody or something
- Be classified as part of something
- Be part of
- Be in right place
- Be accepted somewhere

Was there a moment in your life when you recall entering a crowded room, instantly making eye contact and feeling the warmth of a genuine welcome? A scene where each person wanted to know your name, your story and how you came to be there? A time and a place where you simply, **BELONGED?**

I have. I have found these beautiful encounters regularly when I attend LAM Foundation Regional Events. And, while people are always courteous and curious to meet me because of my position, the heartfelt love and support is reserved and delivered to women with LAM and their families as they embrace each other -- with their eyes, their arms and their shared connection. Regional LAM Foundation events are hosted across the country and in 2015 there are more events and more attendees than ever before, **24** gatherings in total. The LAM Liaison Patient Network is an active community of volunteers. They are women with LAM who organize educational events in partnership with LAM Clinics and other healthcare professionals.

At a LAM Regional meeting you will experience friendship and understanding. You will gain knowledge and insight, forging important relationships with experts. Lives change at these events -- through connection and caring. LAM is a **VERY BIG** small community -- and the people we meet may just change the world -- for all of us. [Click here](#) to read about one of the wonderful connections made within our community.

We now have Facebook groups.

Come and join us!



[LAM Foundation](#)

[The LAM Foundation  
Community](#)

[Lammies](#)

(LAM Patients Only)

[Lammie Loved Ones](#)

(Family/Friends Only)

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I am asking you to make time to attend your regional community events. They are always listed in this newsletter under [COMMUNITY EVENTS](#) and, besides LAMposium, are the best way to learn, help others and live well with LAM.

## **European Respiratory Society's Annual Conference in Amsterdam**



This past weekend, the 25th International Congress of the European Respiratory Society (ERS) held its annual conference in Amsterdam.

Respiratory professionals from around the world gathered with a goal of promoting lung health and combating lung diseases.

The LAM Foundation's Scientific Advisory Board member Dr. Jilly Evans gave a presentation on the key activities of the European LAM Foundation. The Europe LAM Federation also participated in the ERS World Village, an interactive space where scientific societies, patient organizations, international health agencies and government bodies gathered to collaborate.

## **LAM Spotlight Week at NORD**

The LAM Foundation was the spotlight member organization for National Organization for Rare Disorders (NORD) during the week of September 13-19. As a NORD spotlight member, the Foundation was featured prominently on the front page of their newly re-designed website [www.rarediseases.org](http://www.rarediseases.org). Viewers to the site, during this week, could learn about LAM and what it means to be a patient organization serving within the rare disease community. If you would like to view the blog, please [click here](#).

This is all a prelude to the NORD Rare Diseases and Orphan Products Breakthrough Summit taking place in Arlington, VA, October 21-22. There, The LAM Foundation will be represented

by our Executive Director, Sue Sherman, who is one of the spotlight presenters. Sue will be on a panel discussion called Focused Drug Development Research and Productivity-Innovations Around Drug Repurposing.



### **Region 13 Meeting in St. Louis**



Co-Liaisons Marla Dreyer Hamlin and Carmen Sanchez Iglesias organized their regional meeting in St. Louis at Barnes- Jewish Hospital. Dr. Adrian Shifren presented and took questions about LAM research and treatment. LAM families socialized and Sue Sherman gave updates from the Foundation.

Linda Patterson, a respiratory therapist provided tips on exercise and pulmonary rehab. Gifts and hugs were shared by all. Thanks to Annette Roberts and Patsy Koerperich for traveling from Kansas City and for bringing the beautiful Amelia. Also thanks to Ron Hamlin and Javier Iglesias for being fabulous LAM husbands. Many thanks to everyone who attended this event.

### **Join us for a LAM & TS Alliance Joint Board of Directors Luncheon on October 23**

As part of its annual Board of Directors meeting, The LAM Foundation, in partnership with the Tuberous Sclerosis Alliance, will host a Patient & Family Meeting and Luncheon for those affected by Lymphangiomyomatosis (LAM) and Tuberous Sclerosis Complex (TSC). All are welcome to join us to hear the

most up-to-date research and clinical advances in diagnosing and treating these two diseases, presented by leading experts in the field including:

- Frank McCormack, MD, Scientific Director, The LAM Foundation;
- Steve Roberds, PhD, CSO, TS Alliance;
- Darcy Krueger, MD, PhD, TSC Clinic Director, Cincinnati Children's Hospital Medical Center;
- Sue Sherman, MHA, Executive Director, LAM Foundation; and
- Kari Luther Rosbeck, President and CEO, TS Alliance

If you plan on joining us, RSVP by October 15, 2015 by contacting The LAM Foundation at: [info@thelamfoundation.org](mailto:info@thelamfoundation.org) or by calling us at 877.CURE.LAM (877.287.3526).

Friday, October 23, 2015

11:30 am - 1:30 pm

Kingsgate Marriott Conference Center at the University of Cincinnati

151 Goodman Drive

Cincinnati, Ohio 45219

[Click here](#) for directions



## **LAM Experts are Set to Gather in Scottsdale, AZ in November**

Members of the LAM Scientific Advisory Board (SAB) will gather in Scottsdale, Arizona in November, giving women in that region a chance to meet personally with LAM experts.

For the first time ever, some members of the LAM SAB will gather at The Scottsdale Resort at McCormick Ranch to discuss their reviews of 2015 LAM Research Grant applications for the 2015 grant cycle.

Before the SAB gets to work with the review process, women with LAM, their family and friends are invited to join them for an evening reception at the McCormick Ranch. All will have the opportunity to hear from LAM experts, Elizabeth Henske, MD, Vera Krymskaya, PhD, MBA, and Frank McCormack, MD, as they address those in attendance.

If you live in that region, and would like to attend the evening reception, RSVP by October 26, 2015 to The LAM Foundation by phone 877.CURE.LAM (877.287.3526) or by email at [info@thelamfoundation.org](mailto:info@thelamfoundation.org).

November 5, 2015 from 5:00pm – 7:00pm  
The Scottsdale Resort at McCormick Ranch  
Apache III & IV  
7700 East McCormick Parkway  
Scottsdale, AZ 85258  
For directions [click here](#).

### **Educational Luncheon at the Cleveland Clinic**

In partnership with The Cleveland Clinic, women with LAM, friends and family can attend a LAM educational luncheon hosted by LAM Clinic Director, Robert Kotloff, MD, chair of Pulmonary Medicine. Daniel Raymond, MD, Thoracic Surgeon and Richard Fatica, MD, Nephrology & Hypertension, also from The Cleveland Clinic along with Sue Sherman from The LAM Foundation will be there for this informational meeting.

Topics covered will include:

- Treatment of LAM – Sirolimus and Beyond presented by Robert Kotloff, MD
- The Surgeon's Role in LAM – Management of Pneumothoraxes presented by Daniel Raymond, MD
- Management of Angiomyolipomas of the Kidneys presented by Richard Fatica, MD

Dr. Kotloff is thrilled to show everyone his LAM Clinic and introduce you to a team of experts who can help you through your journey with LAM.

If you would like to attend please RSVP to [www.clevelandclinic.org/lam](http://www.clevelandclinic.org/lam)

Here are the details:  
Cleveland Educational  
Meeting  
Region 9  
November 14, 2015 from  
11:00am – 2:00pm



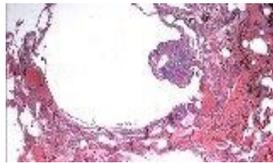
The Cleveland Clinic

9620 Carnegie Avenue, Cleveland, OH 44195  
N Building – Education Building & Lerner Research Institute

**Viabie Tissue is Needed for Research**

Dr. Elizabeth Henske's laboratory has a new project to develop cellular models of LAM and angiomyolipomas to catalyze translational research. The Henske lab is actively seeking tissue specimens from LAM, angiomyolipomas, lung transplantation, chyloous fluid, uterine fibroids or tumors, or any other tissue or specimen from individuals with LAM or TSC. If you would like to donate tissue for research purposes, advance notice is needed so that tissue can be properly collected.

If you are listed for lung transplantation or any type of surgery please contact Dr. Henske's office or Anne McKenna, Patient Services & Education Manager at the Foundation. They will make all of the arrangements for you.



Contact information for Dr. Elizabeth Henske's office is [EHenske@Partners.org](mailto:EHenske@Partners.org) or 617.355.9049.

Contact information for Anne McKenna, Patient Services & Education Manager [amckenna@thelamfoundation.org](mailto:amckenna@thelamfoundation.org) or 877.CURE.LAM (877.287.3526)

**LAM Research Needs You**

Finding a breakthrough therapy for LAM faster can only happen with research; and LAM research cannot happen without valuable data. Researchers and investigators are constantly challenged with finding the best data available to prove or disprove a theory.

They are also challenged with finding the right people who can submit data, statistics, samples, tissue, and all the other information needed to support their research.

The LAM Foundation has a rich history about how newly



diagnosed women stepped up and volunteered their time to LAM Research. Because of this, the MILES Trial was completed in 2010. From that research trial, we now have an FDA approval of Rapamune as a treatment therapy for LAM. Quite possibly those volunteers never questioned if they qualify for the study. They made the call, talked with a research associate and donated their time.

Currently there are 5 LAM research trials taking place. You can review them by clicking here:

<http://www.thelamfoundation.org/research/trials-a-studies>

Most of these research studies, like the MIDAS Trial, cannot continue to be funded by the NIH without the LAM population supporting the trial. So do not disqualify yourself from a research trial, educate yourself first by talking with the study's research associate. You may qualify and help in finding a breakthrough therapy for LAM faster.

Here is how:

- Update your registration information at The LAM Foundation's website. All women with LAM need to be counted.
- Call Tammy Roads and sign up for the MIDAS Trail. If you are diagnosed with LAM, you qualify, 513.558.2148.
- Educate yourself on the trials taking place. Click here <http://www.thelamfoundation.org/research/trials-a-studies>
- Call the research associate listed within each study. Let them determine if you qualify.

### **ICD-9 will be changing to ICD-10**

The World Health Organization has published the 10th revision of the medical classification list of the International Statistical Classification of Diseases and Related Health Problems. The start date to use the new codes begins on Thursday, October 1, 2015.

Lymphangioleiomyomatosis ICD 10 Code - J84.81

Tuberous Sclerosis Complex ICD 10 Code - Q85.1

The LAM Foundation has Emergency Medicine Quick Facts for Lymphangioleiomyomatosis cards printed with these codes on

them. If you would like updated cards to share with your physicians, give us a call at 877.CURE.LAM (877.287.3526) or send us an email at [info@thelamfoundation.org](mailto:info@thelamfoundation.org).

To learn more about the change in the ICD-10 [click here](#).



## Upcoming Events

[Click here](#) to read more information on all of our events listed below!

### **October 3, 2015**

Region 5 LAM Support Group in Bethesda, MD  
Region 19 LAM Educational "Fall Fling!" in Stanford, CA

### **October 17, 2015**

Region 12 Educational Meeting in Eagan, MN  
Region 18 Educational Meeting in North Tacoma, WA  
Region 5 Backyard Bull Roast in Street, MD

### **October 20, 2015**

Region 4 LAM Educational Meeting at UPENN

### **October 23, 2015**

Region 9 Educational Meeting at LAM Foundation Board Meeting in Cincinnati

### **October 24, 2015**

Region 19 7th Annual Chowchilla Laps for LAM Walk-a-Thon

### **November 1, 2015**

Region 1 in Portsmouth, NH Educational meeting with Dr. Henske  
Region 10 LAM Support Group in Woodstock, IL

### **November 5, 2015**

Region 20 Educational Meeting with the SAB in Scottsdale, AZ

[Click here](#) to read more information on each event!

## The Balloon Challenge has Taken Off



We are less than two months into the Balloon Challenge and raising awareness about LAM is reaching new heights. To celebrate the 20th anniversary of The Foundation, UNC Eshelman School of Pharmacy students Laura Bowers and Libbie Dellinger, launched their social media campaign and are inspiring people across the country to take the Balloon Challenge.

The challenge is to blow up as many balloons as you can in 30 seconds. By doing so, people will have a better understanding of what it feels like to be breathless. Laura would know; she was diagnosed with LAM halfway through her first semester of Pharmacy School.

A few weeks ago one of her professors, Dr. Jay, issued a challenge to the students at their school: if the students make a balloon challenge video and donate to The LAM Foundation, he would match up to \$1,000 in student donations. Currently \$880 has been donated to the Foundation. Check out Dr. Jay's video here: [Dr. Jay's Balloon Challenge](#).

Share your participation in the LAM Balloon Challenge today and challenge your friends on Facebook to take the Balloon Challenge for The LAM Foundation. They can also easily donate the Balloon Challenge by going The LAM Foundation's donation page and designating "KE Balloon Challenge".

## We are Inspired by Beverly Jackson and Rhonda Fell



Huge shout out to Beverly Jackson and Rhonda Fell for inspiring friends and family to give to their 20|20|20 campaign. Both Rhonda and Beverly are leading the pack of over 20 people who are participating in this year's most important fundraiser. Both women have leveraged Facebook to inspire most of the donations to their campaign. You will find that it is easy to do. Once you set up your campaign page, click on Social Fundraising Facebook and begin sharing with your Facebook friends. Posting your inspirational stories on Facebook will help to fund a breakthrough therapy for LAM...faster.

Thank you Beverly and Rhonda...you continue to inspire us.

### **MDBR + Community Fundraising = \$250,000 for LAM Research**

Thank you to everyone who donated in support of The LAM Foundation's Easy Breathers Cycling Team who participated in the Million Dollar Bike Ride (MDBR). Because of your support more than \$130,000 was raised for LAM research.

UPENN Medicine Orphan Disease Center matched the first \$50,000, dollar for dollar and will give \$100,000 to two LAM researchers who will advance their study of LAM.

The LAM Foundation is putting the additional \$80,000 to great use by challenging community fundraisers to raise more money for LAM research; by doubling their event proceeds, matching dollar for dollar.

The following five (5) participants are committing to the dollar for dollar match from the Foundation and will strive to reach a goal of contributing \$10,000 or \$20,000 in net proceeds for The LAM Foundation.

Nicole Wipp – \$10,000 Wipp LAM [Wipp LAM Facebook Page](#)

Peggy Haupt – \$10,000 7th Annual Chowchilla Laps for LAM Walk-A-Thon on October 24, 2015 [7th Annual Chowchilla Laps for LAM](#)

Frances Saldivar-Morales – \$10,000 [Breath of Hope 5K](#)

Mitch Shaheen – \$20,000 Shaheen Family Fundraiser

Jennifer Fujikawa – \$20,000 Friends asking Friends Fundraising

page at [Jennifer Fujikawa Friends asking Friends Donation Page](#)

If you add it up, by the end of the year, with your help, we will advance LAM research by a quarter of a million dollars (\$250,000).

We hope you support these great events and help us double your dollars for LAM Research!

### **LAM at the Links**



August 1, was a perfect day for golf just outside of Indianapolis, IN, at the LAM at “THE LINKS” VIII Golf Outing. January Butler and her family hosted 128 golfers in early August for their 8th annual golf outing. Once the golfers finished their 18 holes of golf they were treated to a dinner and participated in a raffle. In all the golf outing raised \$17,804 for LAM Research and Patient Support.

### **Shaughne-Ski Golf Outing Continues to Support The LAM Foundation**

The 24th annual Shaughne-Ski Golf Tournament was held in Apalachin, New York on August 21. For the past 18 years, all proceeds from this charity golf tournament go to The LAM Foundation. 80 golfers participated in the tournament; a true testament to the people who come every year to support The LAM Foundation and the dedication of Co-chairman Rick Pulaski. It was a beautiful day and a lot of fun was had by all. New to the tournament this year, a memory hole for people that have had special meaning to the tournament in the past 24 years. Among those people remembered was Diane Shaughnessy who battled LAM symptoms for over 18 years and passed away in November of 2013.



## Breath of Hope 5k

On Saturday, September 26th, the Rio Grande Valley rallied in Edinburg, TX to heighten LAM awareness and raise funds for The LAM Foundation.



They expected rain that day, yet over 200 community members gathered to take part in the Breath of Hope 5K! Luckily, it was a beautiful morning filled with support, LAM awareness, and hope!

Congratulations to Frances Saldivar-Morales and many thanks to everyone that attended the event!

## Magic Happens at LAMposium

We are less than a year away from the Foundation's 19th annual LAMposium. We hope you can join us in Cincinnati, Ohio for the 2016 Rare Lung Disease Research Conference, LAMposium & Breath of Hope Gala. If you are still uncertain whether this event is for you, take a moment to watch this video produced from this past year's conference: [Magic Happens at LAMposium](#)

Our friends, Dana Garrett and Dave Butz from Trailhead Films along with LAM Foundation Board Member, Eden Pontz, produced the fabulous video for The LAM Foundation while they

attended the 2015 International LAM Research Conference, LAMposium and Breath of Hope Gala. Please share this video with your family and friends, so everyone will understand why this conference is so unique; gathering LAM Researchers and Clinicians together with women with LAM.

**SAVE THE DATE!**

Join us for the  
2016 Rare Lung Disease Research Conference, LAMposium &  
Breath of Hope Gala  
at the [Cincinnati Marriott at RiverCenter](#)  
Covington, Kentucky  
**September 22 – 25, 2016**

**The LAM Foundation** 4015 Executive Park Dr. Suite 320 Cincinnati, OH 45241  
Phone: 513.777.6889 | Email: [info@thelamfoundation.org](mailto:info@thelamfoundation.org)

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