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[LAM Foundation](#)

A Note from Sue Sherman, Executive Director

Greetings from The LAM Foundation! We hope that the warmth of summer brings you some relaxation, good health and time with children and grandchildren enjoying their freedom.

In this issue of Currents you will find many interesting updates from our very active LAM community -- including busy scientists with new clinical trials, energetic fundraisers and passionate volunteers – helping families and women with LAM.

The next LAMposium is merely 13 months away, and we are actively planning our 19th annual event. What will be new at LAMposium in 2016?

Here are the top five things that will be different at LAMposium 2016:

1. LAMposium 2016 will be hosted in KENTUCKY for the first time ever. Don't be fooled, we are just a bridge away from downtown Cincinnati and will have beautiful views of the skyline from our hotel: [The Marriott Rivercenter](#).
2. LAMposium 2016 will be held in the FALL for the first time ever. September 22-25, 2016. September is a beautiful time of year in the Ohio Valley.
3. In 2016, LAMposium will be combined with the Rare Lung Disease Consortium Research Conference. Scientists and Clinic Directors will collaborate and share knowledge about several rare lung diseases – expanding their expertise and advancing research activities on a broader scale. We did this in 2004, so it's not new but even more exciting and important 12 years later.
4. Patients, Families and Caregivers from our sister Rare Lung Patient Advocacy Groups will participate so, like

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our researchers, we can share knowledge and friendship with others who face similar journeys.

5. Many new technologies for streaming the conference online are being explored. Our goal is to make LAMposium and the Research Conference accessible to as many people around the world as possible. Stay tuned!

We hope you will **SAVE THE DATE** for the 2016 LAMposium and we look forward to keeping you informed. In the meantime, we wish you good health and happiness.

20|20|20 Campaign Update

The 20|20|20 Campaign is a fundraising drive of The LAM Foundation to heighten awareness of LAM and to fund a breakthrough therapy for LAM...faster.

In recognition of The LAM Foundation's 20th anniversary, our goal is to inspire as many \$20 gifts over the next 20 months as possible. You can give \$20 one time, or 20 times, or find 20 friends to give \$20, 20 times – THAT'S 20|20|20!

Below are some of the participants of the 20|20|20 campaign.



Beverly Jackson - Participation in the 20|20|20 Campaign is my way of giving back to The LAM Foundation. I am so grateful to The LAM Foundation, Dr. McCormack, and LAM researchers for bringing us Rapamune as a treatment drug.

It has been a miracle drug for me. I want to help make the next step happen. Not just slow the progression but kill the LAM cells.

I want a cure in my lifetime! [Click here](#) to support Beverly's campaign.

Zack and Shelby Garner -

Your donation to our campaign, no matter the size, means so much to our family and to other LAM patients and their families.



Together we CAN find a cure! [Click here](#) to support Zack and Shelby's campaign.



Trish Martin - The LAM Foundation gives hope to those of us affected with LAM.

When I was diagnosed ten years ago there was no effective treatment.

This year, herculean efforts presented LAM patients with the drug Rapamune.

Since 2012, this treatment has kept me off the lung transplant list.

Regardless of this progress, **IT IS NOT ENOUGH.** Not all of my LAM sisters tolerate or respond to this treatment. [Click here](#) to support Trish's campaign.

Every \$20 gets us closer to a cure. We need your help!

Donate \$20 to their campaign **TODAY** or [start your own campaign](#).

MIDAS Trial Update

Dedicating your time toward LAM research can accelerate scientific and medical breakthroughs and help to improve quality of life for women with LAM.

Enrollment for the MIDAS Trial continues. Researchers need over 300 women with LAM to participate in this observational study. Currently 120 women with LAM are signed up and are currently participating.

Have you taken the time to connect with Tammy Roads to see if the MIDAS trial is an option for you?

If you sent her a note or left her a voice mail a while ago and have not heard back – please contact her again. Now that the initial sign up load has eased up a bit, she will want to hear back from you.

Here is her contact information:

Tammy Roads, CCRC

513.558.2148

Tammy.roads@uc.edu

Anyone diagnosed with LAM can sign up for the MIDAS Trail, including women who are post-transplant.

Oxygen Users, Know Your Rights

Certificate of Medical Necessity for Oxygen Therapy

Have you talk with your doctor about a Certificate of Medical Necessity for Oxygen Therapy?

Women with LAM like to be active and do not want to be tied to their homes with large oxygen tanks. Talk with your doctor about types of oxygen delivery systems would work best for you. Talk about your needs not only at home, but also what you needs are when you're being active or otherwise exerting yourself. Your doctor needs to provide you with a certificate of medical necessity, saying that you require supplemental oxygen. The certificate of medical necessity will need to include exactly what you and your doctor spoke about in your appointment.

Next, find an oxygen supplier that can provide you with supplies that are required within the certificate of medical necessity.

Know that your oxygen supplier is not your doctor and cannot make decisions about the type of equipment you require. Only you and your doctor may do this!

Once you have your equipment, you cannot, in most cases, change the type of equipment or type of delivery system for a term of five (5) years. This is why it's important to choose the type of equipment and delivery system that will work best for your lifestyle! Note: If your oxygen requirements change or your doctor feels you require different equipment or delivery system, your certificate of medical necessity will need to be updated. With a new certificate of medical necessity your oxygen supplier must provide equipment that fits that need.

If your doctor decides that your oxygen equipment can no longer provide what you need, he/she may notify the oxygen supplier with a new letter of medical necessity for different equipment. The oxygen supplier must provide you with new equipment. In this case, your contract period does not change even after the 36 month period.

When your five-year contract is about to run out, your oxygen supplier is required to let you know. Your doctor will then need to provide a new letter of medical necessity. This may include an updated evaluation of your oxygen needs. This is the perfect time to talk with your doctor about other types of oxygen systems that might work better for you. **You should NEVER enter into a new contract period without first consulting the doctor who writes orders for your oxygen!**

The certificate of medical necessity from your doctor should address your mobility needs both inside and outside your home. Your oxygen supplier is required to supply the items you need for such mobility. Talk with your doctor about your concerns and request a new letter of medical necessity that details your needs.

To learn more about Medicare's rules and tell the COPD Foundation about your oxygen experience, please call 866.316.COPD (2673).

For more information and to read the entire Supplemental Oxygen guide provided to us by the COPD Foundation, please [click here](#).

Regional Meeting Updates



Region 10

The Illinois, Region 10 meeting was held in June at Loyola University Stritch School of Medicine. Despite busy Chicago traffic, women with LAM, family and friends had a chance to mingle and chat with Dr. Dilling, who could only stay for a short time. A light dinner was served while everyone introduced themselves and discussed the latest news from The LAM Foundation.

Loyola dietician, Rachael Dunn spoke on various issues involving diet and LAM, including controlling chyle through diet, bone health, dietary requirements both pre and post-transplant, drug-food interactions and soy consumption.

Attendees included four new patients and five family/friends who have never attended to a regional meeting.

Plans for upcoming regional meetings in Region 10 include a casual gathering without a speaker, a meeting with a presentation on exercise, and/or a co-regional meeting with Region 12.



Region 20

Region 20, Southern California and Arizona, held their meeting at the Keck Hospital at USC in Los Angeles, July 18th. It was a much needed rainy day in Southern California, and attendance was wonderful. Two newly diagnosed women joined us as well as one woman with LAM and her family who drove in from Arizona with her family to attend the meeting.

A light lunch was served and everyone had a chance to get to know each other, asking questions and sharing their journey with LAM. We welcomed USC LAM Clinic Director, Dr. Richard Lubman, who gave an informative presentation on LAM. He answered questions regarding Rapamycin, Pain Management, Stress, Diet and Menopause and LAM. Dr. Lubman pointed out the LAM Foundation Website and encouraged everyone to use the site.

Charm Perry Flint said, "Some women with LAM were not able to attend due to weather or illness. We missed them but we are planning an additional meeting in the fall for those who missed this event."



Region 11

Region 11, Michigan, met on July 25th in a beautiful conference room on the campus of University of Michigan at Mott Children's Hospital.

LAM patients, family members, and professionals including the Foundation's executive director, Sue Sherman, reconnected in a room overlooking the city of Ann Arbor. Dr. MeiLan Han, our LAM Clinic Director, gave an overview of the basic and clinical science discussed at LAMposium. During lunch, Sue Sherman covered exciting developments happening within The LAM Foundation. And Julie Woodward, MSW, an expert in yoga, relaxation, breathing techniques eased us into the afternoon. LAM Liaison, Gwen Pryor said, "It was a great source of empowerment and support to meet again outside of LAMposium with friends within our home state area. We encourage anyone who is from the Michigan area to join us at our next gathering. We would love to have you! "

Video Recordings of Sessions from LAMposium

If you were unable to join us, this past March, at the International LAM Research Conference and LAMposium or if you would like to review some of the presentations you attended while there, you are in luck. A majority of the LAMposium presentations can all be viewed from The LAM Foundation's website.

By [clicking here](#) you now have access to 20 presentations. Topics range from drug therapies, hormones and LAM, LAM patient experiences along with an overview of the International LAM Research Conference.

Once you have a chance to review these videos, please share them with your friends and family. Raising awareness about LAM makes us all stronger together.

Raising LAM Awareness



Attendees at the 50th National Kappa Epsilon Conference in Orlando, Florida sport the LAM Foundation bracelets in support of the Balloon Challenge launching this fall by Libbie Dellinger and Laura Bowers

Pharmaceutical College encourages LAM Awareness -

Laura Bowers and Libbie Dellinger are friends and colleagues enrolled in the UNC Eshelman School of Pharmacy PharmD program. Laura was diagnosed with LAM in her first semester of pharmacy school. Since then, Libbie has educated teams of medical professionals about LAM during her rotations. Last fall at a Kappa Epsilon meeting of the Beta Mu chapter, a professional fraternity for pharmacists, the two women talked with their colleagues about LAM and what it is like to live with such a rare disease. From that conversation the UNC fraternity decided they wanted to do more to raise LAM awareness nationwide. They are working on a new idea that will help build awareness about what it is like to experience breathlessness on a daily basis. This past July, Libbie took her LAM message nationwide at the National Kappa Epsilon meeting in Orlando, FL. Libbie says, with the encouragement of National Kappa Epsilon, "Everyone is very enthusiastic and interested to learn more about LAM. So stay tuned! The Balloon Challenge will launch this fall!"

Macy's "Shop for a Cause" Passes

THE LAM FOUNDATION PARTNERS WITH MACY'S FOR 10TH ANNUAL "SHOP FOR A CAUSE"

Purchase your Macy's "Shop for a Cause" shopping pass and raise money for The LAM Foundation.

Macy's "Shop For A Cause", takes place on Saturday, August 29, 2015. This unique one-day-only shopping event is created to support charities' fundraising efforts.

Macy's provides The LAM Foundation with shopping passes to sell for \$5 each. The Foundation keeps 100% of every shopping pass it sells. The more shopping passes the Foundation sells the more money it will raise!

Last year, the Foundation sold over \$1,600 in passes. Let's surpass that number and work to sell \$3,500 passes for the Foundation.

What a great concept, enjoying a day of spectacular discounts, entertainment and special events at Macy's, while raising money to support women with LAM. Pass holders will receive special discounts on most regular, sale and clearance purchases all day, but some exclusions apply.

You can purchase your passes online through our donate now button, [click here](#) (must purchase at least 2 passes). Make sure to put Macy's passes and the number you need in the comment box. If you have questions please contact Kerri Morgan at kmorgan@thelamfoundation.org or call 1.877.287.3526.

Current Trials & Studies

Here is a list of current LAM research trials, including Dr. Lisa Young's Biomarker Research in TSC and LAM (BUILD) study. Click on each link to get a description and eligibility requirements.

[Click here](#) for Dr. Young's Biomarker Study.

[Click here](#) for the MIDAS Trial.

NEW PROJECT IN HENSKE LAB: Elizabeth (Lisa) Henske's laboratory has a new project to develop cellular models of LAM and angiomyolipomas to catalyze translational research. Please contact us if you are considering lung transplantation or any type of surgery. We are actively seeking tissue specimens from LAM, angiomyolipomas, lung transplantation, chylous fluid, uterine fibroids or tumors, or any other tissue or specimen from

individuals with LAM or TSC. Please provide as much advance notice as possible so that the tissue can be properly collected. Please contact Lisa Henske at EHenske@Partners.org or 617-355-9049 if you are considering any type of surgery or biopsy. Thank you!

[Click here](#) for the GWAS Study.

[Click here](#) for SOS Study.

[Click here](#) for NIH Protocol.

[Click here](#) for SLAM Study.

Upcoming Events

Region 6 (North Carolina, South Carolina, Georgia, Eastern Tennessee)

Regional Meeting

Saturday, August 1, 2015

12:00pm-2:30pm

The meeting will be at the South County Regional Library in Charlotte. Parking is free with several handicapped spots available in front of the library.

Dr. Charlie Strange, LAM Clinic Director and Pulmonologist from the Medical University of South Carolina in Charleston, will join us to discuss LAM Clinics, current and upcoming research trials, supplemental oxygen use, rapamune (a drug treatment), and other cystic lung diseases which are similar to LAM.

We will have an open question and answer time with Dr. Strange and a time to connect with each other over lunch.

RSVP to Susie Picart at jpkaart788@aol.com.

Region 2 (Western New York and Western Pennsylvania)

Shaughne-SKI Charitable Open

August 15, 2015

8:00 am Shotgun Start

Apalachin Golf Course

Apalachin, NY

Food, Prizes, Fun!

Tournament/Event Co-chairpersons:

Matt Shaughnessy and Rick Pulaski

Entry fee is \$70.00

Non-golfers - \$15.00

Sponsorships Available.

Contact Matt at 607.768.2483 or

Rick Pulaski at 607.427.9748 for more details.

Region 9 (Indiana, Kentucky, Ohio, West Virginia)

LAM at "THE LINKS" VIII Golf Outing

Saturday, August 15, 2015

Registration: 11:30 am – 12:45 pm

Tee time: 1:00 pm

Florida Scramble, Shot Gun Start

The LINKS

11425 N. Shelby, 700 W

New Palestine, IN

Registration Deadline – August 1, 2015

Maximum 36 teams!

Player Registration - \$100 Individual; \$400 Foursome

Sponsorships available.

Contact January Butler at 317.250.5266

Region 15 (Western Texas, Western Oklahoma, New Mexico)

2015 Breath of Hope 5k in Honor of Frances Saldivar

September 26, 2015

8:00 am-12:00 pm

Edinburg Municipal Park

714 S. Raul Longoria Edinburg, TX 78542

Cost for 5k participants: \$25 Adults; \$15 ages 12-6; donations accepted for 5 ages and under.

Contact: Frances Saldivar – Fran_tx02@hotmail.com

[Click here](#) to register.

The LAM Foundation 4015 Executive Park Dr. Suite 320 Cincinnati, OH 45241

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