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February 2016

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Note from Sue Sherman, Executive Director

"I know of nothing so pleasant to minds as the discovery of anything which is at once new and valuable; for nothing so lightens and sweetens toil, as the hopeful pursuit of such discovery."

~Abraham Lincoln, 16th President of the United States

February is the birth month of Abraham Lincoln, one of my heroes. Many Americans admire him for his wisdom, conviction and humor, and I was delighted to find the above quote, proving again that Lincoln's vision is timeless. Our LAM scientists, fellows and students, exemplify intelligence, curiosity and enthusiasm, genuinely seeking answers to the questions presented by LAM. We are uniquely fortunate to have a large and talented team of professionals who are inspired by discovery of things *new and valuable* for women with LAM. With our help, they use the money we raise and insights we provide to advance the scientific understanding of LAM, while also contributing to a better understanding of other diseases, both common and rare. Please enjoy this edition of Currents, knowing that each educational event, awareness activity, fundraiser, scientific publication and award feeds the *hopeful pursuit of discovery*.

Join Us for Our Virtual March on the Hill



Join us elsewhere:

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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The LAM Foundation's 'Virtual March on the Hill' is being coordinated in partnership with the Tuberous Sclerosis Alliance. On March 2, 2016, advocates from the TS Alliance will spend the day on Capitol Hill in Washington, DC, visiting with their U.S. Representatives and Senators. They will urge them to continue funding the Tuberous Sclerosis Complex Research Program (TSCR) which also includes critical funding for LAM Research. Our goal is to 'virtually' support their efforts.

The LAM Foundation is looking for advocates who are willing to contact their U.S. Representatives and Senators during the week of February 29 - March 4 by phone, email or by visiting with your district office. [Click here](#) to get instructions and tools for helping us in this advocacy effort.

If you have any questions or would like more information about how you can help, please contact Anne McKenna at 513-777-6889 or amckenna@thelamfoundation.org.

Another Way to Give to LAM Research



Are you a LAM patient who is anticipating having a biopsy, lung transplant or other procedure which will result in tissue being removed? You can further LAM research by donating your tissue samples to our LAM scientists. The application process is easy and only takes a few minutes to complete.

If you are a LAM patient living in the United States:

You can donate tissue from a lung transplant, hysterectomy, oophorectomy, pleurectomy, nephrectomy, or biopsy. You can also donate chyle.

Once registered, please call NDRI as soon as your surgery is scheduled or as soon as you get the call for transplant.

NDRI can be reached at [800.222.6374](tel:800.222.6374), 24 hours a day.

ATS Webinar for LAM Week from Stephen Ruoss, MD



Rare Lung Disease Week at the American Thoracic Society (ATS) will highlight The LAM Foundation from March 6 – 12. During this week, the ATS will feature Lymphangiomyomatosis and The LAM Foundation. They will also foster interaction between patients, researchers and clinicians by hosting a webinar that will include a question-and-answer session.

Tuesday, March 8, LAM Clinic Director Stephen Ruoss, MD, from the Stanford University Medical Center will present a webinar on “Chest Pain: Insight into the Reasons Why Women with LAM Have Pain”. This webinar will take place at 2:00 pm EST. You can participate in the webinar by [clicking here](#) to RSVP and receive a link to the live presentation.

Elizabeth Henske, MD wins PAR Excellence Award



Congratulations to LAM Clinic Director, Elizabeth Henske, MD, from Brigham and Women's Hospital in Boston, MA. She is the recipient of the 2016 American Thoracic Society (ATS) Public Advisory

Roundtable (PAR) Excellence Award. The PAR Excellence Award is an honor given to a person who embodies many criteria including passion for patients, innovative spirit and outstanding leadership skills. Gregory R. Porta, Chair, ATS states, "Her exemplary service to patients with lung diseases and critical illnesses has been nothing short of admirable and praiseworthy."

Dr. Lisa Henske will receive this award at the ATS PAR symposium at the 2016 ATS International Conference in San Francisco, CA, Tuesday, May 17, 2016.

New Address for The LAM Foundation

The LAM Foundation has moved their office! Please take note of our address before you send any correspondence by mail.

Our new address is:

The LAM Foundation
4520 Cooper Road, Suite 300
Cincinnati, Ohio 45242

If you happen to be visiting or driving through Cincinnati, we would love to have you stop by for a visit so we can show off our new working space!

Support The LAM Foundation's Easy Breathers Cycling Team

The LAM Foundation's Easy Breathers Cycling Team is in full training mode for the 3rd annual Penn Medicine Orphan Disease Center (ODC) Million Dollar Bike Ride. The LAM Foundation and the Easy Breathers Cycling Team are fortunate to be one of the most successful disease teams to enter into the ride!



As a result of the first two MDBR events, The LAM Foundation and Upenn raised more than \$200,000. This was awarded in the form of four research grants to LAM investigators. This is all due to the dedication and spirit the LAM Community brings to this event. And this year is no exception! We are excited to share with you the many ways you can help our team be successful again this year.

- Purchase a LAM Easy Breathers Tech T-Shirt or Team Jersey at the [Team Store](#). 20% of all proceeds from this Team Store will go to The LAM Foundation.
- Ride with the Easy Breathers Saturday, May 7, 2016. Register at the ODC Million Dollar Bike Ride Event site by [clicking here](#).
- Volunteer at the Million Dollar Bike Ride. Help the Penn Medicine Orphan Disease Center (ODC) at the event. [Click here](#) for more information.
- Add to the spirit of the event by cheering on our LAM Easy Breathers Cycling Team while they are taking part in the ride on May 7.
- Support a LAM Easy Breather participant by donating to their individual PENN Giving Page.
- Donate to the The LAM Foundation's giving page by [clicking here](#).

All donations, up to \$50,000, will be matched dollar for dollar by the Penn Medicine Orphan Disease Center.

For more information call the Foundation at 877.287.3526 or contact Patricia Ortiz at portiz_home@yahoo.com.



MDBR Volunteers

“LAM and Intimacy” Webinar



This past month, The LAM Foundation hosted its first educational webinar, offering over 25 women the opportunity to learn about “LAM and Intimacy”.

Lisa Larkin, MD, from the University of Cincinnati Health Women’s Center presented and took questions on hormones, intimacy and contraception options.

If you did not attend the webinar, you can review the presentation by [clicking here](#).

If you have additional questions for Dr. Larkin, please email them to Anne McKenna, the Foundation’s Patient Services Manager at amckenna@thelamfoundation.org and she will be happy to forward them to Dr. Larkin.

New Plans Taking Shape at LAMposium

In just under seven months, we will all come together in Cincinnati for our 19th annual LAMposium. Planning is moving full speed ahead. Simultaneously researchers and clinicians studying rare lung diseases are receiving invitations to present at the International Rare Lung Diseases Research Conference (RLDC•2016•Cincinnati). This

event will be the largest and most comprehensive scientific research meeting focused on rare lung diseases ever held! Patients and families with rare lung diseases are encouraged to attend and to share, learn, inspire, and collaborate.



RLDC•2016•Cincinnati will take place September 22 - 25, 2016, at the Cincinnati Marriott at RiverCenter and the Northern Kentucky Convention Center, directly across the Ohio River from Cincinnati. Registration will open the first week of June.

Even though we are back in Cincinnati and inviting members from the RLDC, you will recognize a lot of the familiar events that took place in Chicago:

- You can connect with researchers and clinicians at our combined breakfast and luncheons.
- In the Research Room, LAM researchers will be available to answer your questions and help you sign up for LAM research and clinical trials.
- LAM community fundraisers and researchers will exhibit posters.
- Stacey Wheelus is working diligently on the newest LAM quilt.
- The Oxygen Station will be available on Friday and Saturday.
- Sharlene Dunn is going to bring back the Remembrance Room.

We hope you can join us. The goal of this conference is to inspire researchers and clinicians as they connect with patients and each other to find better treatments, diagnosis and ultimately find a cure for all rare lung diseases. We are Stronger Together!

LFN Travel Grant Applications are Available

The LAM Family Network (LFN) Travel Grant helps fund travel for women with LAM to LAMposium every year. Thanks to the support from generous LAM Community donors, the LFN Travel Grant Fund is replenished. Now the Foundation can assist more women in their travels to Cincinnati, Ohio, for the RLDC•2016•Cincinnati,

LAMposium and Breath of Hope Gala in September.

If you have LAM, want to attend LAMposium, and need financial support, you can apply for a LAM Family Network (LFN) Travel Grant. The LFN Travel Grant only assists with travel expenses and partial hotel costs. Registration for LAMposium is free for all women with LAM.

Applications must be received by June 6, 2016. To apply for the travel grant, [click here](#) for an application or contact Maria Pearson at mpearson@thelamfoundation.org. She can provide you with an application or help if you have questions.

Board of Directors Luncheon in Boston

Join The LAM Foundation's Board of Directors for lunch in Boston, MA, on April 2. LAM Clinic Director, Elizabeth Henske, MD, and LAM Liaison, Madeline Nolan will host an educational meeting and luncheon at the Brigham and Women's Hospital on Saturday, April 2, 2016.

Dr. Elizabeth Henske and Dr. Souheil El-Chemaly will present the most up-to-date research and clinical advances in diagnosing and treating LAM.

[Click here](#) for more details.

RSVP by March 25th to The LAM Foundation at info@thelamfoundation.org

Everything is BIGGER in Texas



LAM Liaisons in Texas hosted the largest regional educational events ever on January 30, 2016.

On a sunny Saturday in January more than 60 women with LAM, family and friends gathered at the University of Houston for a day of LAM education and friendship. LAM Liaisons from two regions,

Frances Saldivar, Maria Teniente, and Kathi Hawn started planning their regional meeting two months ago, with an interest in welcoming people from Texas, Oklahoma, Louisiana, Arkansas and Mexico. They achieved their goal!

LAM experts from the University of Texas LAM Clinic presented including LAM Clinic Director, Rosa Estrada -y- Martin, MD, Hope Northrup, MD, Director, Division of Medical Genetics and Sandra Oldham, MD, Chief of Radiology at University of Texas. Thomas Lowder, PhD from the University of Houston, Tony Eissa MD from Baylor and Sue Sherman from The LAM Foundation rounded out the speaker line-up. Priceless knowledge was shared among the professionals and patients present, creating new friendships and hope.



Thank you to our energetic LAM Liaisons, passionate clinicians and their families for delivering a memorable and important day for women with LAM from Regions 14, 15 and Mexico.

Breaking Records



February 13, 2016 was a day for breaking records. The temperatures might have been record-breaking cold but that didn't stop the Western New York community from coming out to Asbury

Hall in Buffalo, NY to raise a record-breaking \$15,000 for The LAM Foundation.

The 11th annual "An Evening of Hope" Beer & Wine Tasting was a great success. With the support of wine and beer vendors from the area and the help of many wonderful volunteers, The Western New York Friends of The LAM Foundation were able to meet their stretch goal and LAMplify their event! By participating in the LAMplify program, they were able to double their donation to The LAM Foundation for a grand total of \$30,000.

"The LAMplify program motivated us and our wonderful community of fundraisers to dig a little deeper and give a little bit more this year. Knowing that their donation would be doubled was a huge incentive for our fundraisers to give more," said Katie McKenna.

If you are planning a LAM Community Fundraiser this year and plan to raise \$5,000, \$10,000, or even \$20,000, you too can "LAMplify" your event with a LAMplify Challenge Grant.



The Foundation will give you all the tools you need to make your event a success. Just call us at 877.287.3526 or send an email to info@thelamfoundation.org for more details about how you can 'LAMplify' your efforts and DOUBLE THE IMPACT OF YOUR NEXT LAM COMMUNITY FUNDRAISING EVENT!

Upcoming Regional Events

Region 20 (AZ, Southern CA, & Southern NV)

March 12, 2016

Taste of Aloha

1641 W. Redondo Beach Blvd
Gardena, CA 90247

Food, music, and magic all to benefit The LAM Foundation. For more information contact Liana Kuklinski kiyabu@hotmail.com.

Region 1 (CT, MA, ME, NH, RI, & VT)

LAM Educational Meeting

April 2, 2016

Brigham and Women's Hospital
Carrie Hall
75 Francis Street
Boston, MA 02115

11am - 2pm

As part of its annual Board of Directors meeting, The LAM Foundation, in partnership with Brigham and Women's Hospital will host a Patient & Family Meeting and Luncheon for those affected by Lymphangioliomyomatosis (LAM). Please join us to hear the most up-to-date research and clinical advances in diagnosing and treating LAM.

RSVP by March 25th to: info@thelamfoundation.org

Region 1 (CT, MA, ME, NH, RI, & VT)

Laughs for LAM

April 8, 2016

Club Comedy

585 South Main St

Naugatuck, CT 06770

Come join Madeline Nolan for a night of laughs. Tickets are \$20 and there is a set limit available to buy.

Contact Madeline Nolan at curelam@aol.com.

Region 10 (IL)

LAM Educational Meeting

Saturday, April 9th, 2016

Loyola Stritch School of Medicine

Presentations by the LAM Clinic Team

More information to come

RSVP to Kathy Peiffer kdpeiffer@ameritech.net.

Region 14 (Eastern TX, Eastern OK, AR & LA)

2nd Annual SLAM LAM 5k Walk

April 9, 2016

Residents Club Central in Summerwood

14111 Summerwood Lakes Drive

Houston, TX 77044

7:30am start time

Registration for SLAM LAM is \$25 for adults and \$15 for children 12 and under. All registrations received by March 18 will receive a goodie bag and event T-shirt. After March 19th registration will increase to \$35 for adults and \$25 for children.

[Click here](#) for more information or to register.

Region 8 (AL, MS, & Western TN)

Save the Date

2016 Regional TSC & LAM Conference Series

April 16, 2016

Monroe Carell, Jr. Children's

Hospital at Vanderbilt
2200 Children's Way,
Nashville, TN 37232
8:30am Registration - 4:00pm
More information to come.

Region 7 (FL)

Save the Date

LAM Educational Meeting

May 21, 2016

Mayo Clinic Jacksonville
Jacksonville, FL
More information to come.

Region 18 (OR & WA)

Save the Date

2016 Regional TSC & LAM Conference Series

June 11, 2016

Swedish Medical Center
Seattle, WA
8:30am Registration - 4:00pm
More information to come.

Region 18 (OR & WA)

Save the Date

LAM Educational Meeting

June 12, 2016

Oregon Health and Science University
Portland, OR
Time - TBD
More information to come.

Region 10 (IL)

Tee It Up for LAM! Golf Outing to benefit The LAM Foundation

Friday, June 24, 2016

Whisper Creek Golf Club
12840 Del Webb Blvd
Huntley, IL 60142

Entry Fees: \$125 per Golfer / \$400 Foursome / \$30 Dinner only
Included: Lunch, 18 holes Golf w/cart. Course Games and Prizes,
Dinner

Schedule of Events:

Bag Drop & Registration: 11:00 am -12:45 pm

Warm-up: 11:30 am -12:45 pm

Tee Off: 1:00 pm

Dinner and Silent Auction: 6:00 pm

Questions, want to help, or register please call the Peiffers at 815-245-8616 or the Glasbys at 847-276-0572. You can also send emails to glasbyx5@yahoo.com or kialam07@gmail.com.

Region 9 (IN, KY, OH, & WV)

Save the Date

2016 Regional TSC & LAM Conference Series

November 5, 2016

Cleveland Clinic

Cleveland, OH

8:30am Registration - 4:00pm

More information to come.

Trials & Studies

NEW PHASE OPEN - "SAFETY AND EFFICACY OF SARACATINIB IN SUBJECTS WITH LYMPHANGIOLEIOMYOMATOSIS (LAM) 9SLAM-2)" - Dr. N. Tony Eissa at Baylor College of Medicine

Who will be included in this study? Women 18 years and older who have LAM.

How long will you be in the research study? You will be in the research study for up to 12 months. Study drug will be given for up to 9 months.

What is involved in the research study? You will be 125 mg saracatinib for up to nine months.

Study Visits: The study schedule will include about 7 visits

CONTACT:

Caryn O. Pope, BSN, RRT, RCP

Clinical Research Coordinator

Baylor College of Medicine - Ben Taub General Hospital

Medicine: Pulmonary/Critical Care

1504 Taub Loop - 6PF 80-02

Houston, TX 77030

713-873-2471 (office)

713-796-9351 (fax)

[cpope@bcm.edu](mailto:cpoppe@bcm.edu)

[CLICK HERE](#) for more details.

**"BUILD" Biomarker Utility in LAM Diagnosis - Dr. Lisa Young at Vanderbilt University - Do Not Need to Travel
PARTICIPANTS WANTED FOR BIOMARKER RESEARCH in TSC**

AND LAM

Who?

Females age 13 and older who have been diagnosed with LAM, either Sporadic LAM or TSC associated LAM

Please note: Diagnosis of TSC is not required

[CLICK HERE](#) for more details

MIDAS Trial

Any woman diagnosed with LAM is eligible to participate in the Multi center International Durability and Safety of Sirolimus in Lymphangi leiomyomatosis Trial (MIDAS Trial). It is important that all women with LAM at least contact the study coordinator to discuss the details of the study. NIH continued funding of this study is dependent on Dr. Frank McCormack and the other site's ability to enroll as many women with LAM as possible.

[CLICK HERE](#) for more details

Safety Study of Simvastatin (SOS)

Dr. Vera Krymskaya

[CLICK HERE](#) for more details.

Study of the Disease Process of LAM

Dr. Joel Moss

[CLICK HERE](#) for more details.

New Year, New iWallets



The LAM Foundation has new iWallets to hold your Emergency Medicine Quick Facts - Lymphangi leiomyomatosis cards. Stick the iWallets on the back of your cell phone for easy access if you are

rushed to the Emergency Room.

This is an easy way to make sure the doctors in the ER have the information they need about LAM. Ask your doctors to scan the QR code on the front of the card using their smart phone or tablet. The scan will take them directly to information, written by Frank McCormack, MD, The LAM Foundation Scientific Director, who explains the disease for ER professionals and the best way to treat it when you are in the Emergency Room.

Before using your card, be sure to write in the name of your pulmonologist or LAM Clinic Director on the back. This will allow the ER staff to quickly contact someone who is more familiar with your condition. The ICD-10 Code for LAM is also printed on the back to help the medical facility track your status and assist in billing.

If you would like updated cards and an iWallet, give us a call at 877.CURE.LAM (877.287.3526) or send us an email at info@thelamfoundation.org.

The LAM Foundation 4520 Cooper Rd. Suite 300 Cincinnati, OH 45242
Phone: 513.777.6889 | Email: info@thelamfoundation.org