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January 2016

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A Note from Sue Sherman, Executive Director

I am excited for you to read this edition of Currents, our monthly e-newsletter. If you can believe it, we are already 1/12 of the way through the New Year. As you will see, we are making fast progress on our goals for 2016. This makes me think of a quote I recently read on Instagram:

“Time is free, but it’s priceless. You can’t own it, but you can use it. You can’t keep it, but you can spend it. Once you’ve lost it you can never get it back.”

Working together, The LAM community always makes the most of its time. In this edition of Currents you will read examples of what I mean:

- The 2015 LAM Foundation Research Grants have been awarded— funding the newest, most promising research;
- An exciting new Challenge Grant Program called LAMplify has been launched to “lamplify” the impact of community fundraisers;
- A “Virtual March on the Hill” is being organized that will train and empower LAM families across the country to reach out to their Congressional Representatives to sustain critical LAM research funding;

Time is our friend and our enemy. Each passing day without a cure puts those we love at more risk. Please join with me and The LAM Foundation staff to translate the momentum and accomplishment from our first 20 years into a future with a cure. Reach out, get involved, and make a difference. Thank you for all you do!

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)

Follow us on **Twitter:**

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P.S. Be sure to read the [New Year/New Vision letter](#) sent last week that recaps our accomplishments in 2015 and vision for the future.

Rare Lung Disease Consortium Inquiry

Dr. Frank McCormack continues to lead efforts to secure grant funding for our next important LAM Clinical Trial.

He needs YOUR HELP to include up-to-date information about women with LAM who could potentially participate for inclusion in future clinical trials. Please take a moment to complete the two questions survey. [Click here](#) for the survey. Thank You!

Board Appointment Advances LAM Awareness



The beginning of the New Year brings along a new platform to share LAM awareness. Beginning this January, Susan Sherman has been appointed to the board of directors of the National Health Council. The mission of the National Health Council (NHC) is to convene diverse stakeholders within the health community to work for health care that meets the personal needs and goals of people with chronic diseases and disabilities.

"NHC focus is all about the patient voice, this is something we have known at The LAM Foundation since the beginning", said Sue Sherman. "I am honored to further this important work of bringing the patient voice into research efforts." By joining the board of the National Health Council Sue Sherman advances The LAM Foundation onto a platform with national health-related organizations such as the National Multiple Sclerosis Society.

New Development Manager Katie Jensen



The LAM Foundation is pleased to welcome Katie Jensen to our staff, as the new Development Manager.

Katie is moving from Chicago, IL to join The LAM Foundation.

She learned about The LAM Foundation from her previous position as an Associate Director of Strategic Partnerships at the Foundation for Sarcoidosis Research.

We are thrilled to welcome Katie to The LAM Foundation as she is well versed in working with a community who is passionate in finding a cure for a rare lung disease.

Katie starts at the Foundation on Monday, February 1, 2016. You can reach her at kjensen@thelamfoundation.org or by calling her at 877.287.3526.

New Year New Vision Letter

A few weeks ago the Foundation sent out a “New Year New Vision” letter to The LAM Community. This email was crafted by the Foundation’s Executive Director Sue Sherman, Board Chair, Andrea Slattery and Scientific Director, Frank McCormack, MD.

If you would like to read the letter and share it with your family and friends, please [click here](#).

We thank you. Every gift, every helping hand, every commitment from you and other dedicated individuals like you brings us closer to a cure.

The LAM Foundation Offices are Moving

The LAM Foundation will be moving into its new facility March 1, 2016. The new office building is a bit closer to the University of Cincinnati where Dr. Frank McCormack’s offices are located.

Our new address is:

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

You will begin to notice our address change on our next issue of Journeys and on our thank you notes to our donors. Please make note of the change when you are mailing in your LAMposium registration and future donations.



Educational Webinar: Intimacy and LAM

Save the Date for our first LAM Foundation Educational Webinar, February 11, 2016 at 8:00pm EST.

Lisa Larkin, MD, from the University of Cincinnati Health Women's Center will offer an interactive discussion on "Intimacy and LAM".



Join in the conversation by clicking on the link below on February 11 at 8:00pm EST:

<https://thelamfoundation.adobeconnect.com/lisalarkinmd/>

YOUR PARTICIPATION WILL BE CONFIDENTIAL; all you need is a smartphone, laptop, desktop computer or an iPad to join in the discussion.

Dr. Larkin presented at last year's LAMposium. If you would like to review her presentation on "LAM, Menopause and Intimacy" [click here](#).

Lisa Larkin, MD, Director, UC Health Women's Center, Associate Professor and Division Director of Midlife Women's Health and Primary Care, University of Cincinnati College of Medicine, Department of OB/GYN. She has a specific interest and expertise in women's health, particularly in the area of perimenopause and menopause transition, female sexual health and cancer survivorship. She is a breast cancer survivor and is committed to providing current, evidence-based care to her patients and is especially passionate about the care of women at midlife.

LAM and TSC Advocacy Training

Learn how to be an advocate for LAM and TSC research by participating in the 'Virtual March on the Hill' Training Call February 17, 2016 at 8pm EST. You will learn how and when to contact your congressional representatives this March so that you can influence key decisions that will sustain funding for important LAM research.

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 visiting their U.S. Representatives and Senators to urge them to continue funding the Tuberous Sclerosis Complex Research Program (TSCR). With your help, The LAM Foundation would like to support their efforts this year by joining our voices through a virtual campaign. Additional details on the training conference call for the 'Virtual March on the Hill' will follow in future emails.

We need volunteers willing to contact their U.S. Representatives and Senators by phone, email or even schedule a visit to a district office in their home state during the week of February 29 - March 4, 2016.

With your help we can sustain critical LAM Research.

Pilot Challenge Grant Success leads to LAMplify

Thanks to everyone who joined the Easy Breathers Cycling Team in raising money for last year's UPenn Million Dollar Bike Ride (MDBR). Funds raised in excess of the match provided by UPenn were used to help community fundraisers increase their impact.

Jennifer Fujikawa, Peggy Haupt, Frances Saldivar-Morales, Mitch Shaheen and Nicole Wipp accepted a challenge match to double their community fundraising efforts. Together these five Challenge Grant Heroes raised more than \$70,000.

Because of the tremendous success from this pilot, numerous donors have asked the Foundation how they can be a part of this initiative, hoping to amplify the impact of more community events in 2016.

Allow us to introduce



LAMplify will match the amount of money your donors give at your community fundraiser. And there is nothing better than **DOUBLING THE IMPACT** of your fundraising efforts.

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.

Call or send an email to The LAM Foundation for more details about how you can 'LAMplify' your efforts and **DOUBLE THE IMPACT OF YOUR NEXT LAM COMMUNITY FUNDRAISING EVENT!**

Call the Foundation at 877.CURE.LAM (877.287.3526) or send us an email at info@thelamfoundation.org.

TLF Grant Awards and MDBR Grants Awards

The LAM Foundation is proud to announce their 2015 Grant Awardees. Because of your generous donations, the Foundation is able to give \$350,000 to advance LAM Research by offering four (4) grants.

Established Investigator Awards - \$150,000 over three years



I. Caroline Le Poole, PhD

Loyola University
Chicago, IL

T Cell Receptor Transduced T
Cells Supported by Anti-PD-1 to
Treat LAM



Kuniaki Seyama, MD, PhD

Jutendo University
Tokyo, Japan

Exploring Pathobiology of LAM
Through Isolation of Cellular
Components of LAM Lesions,
Their Characterization, and the
Reconstitution of LAM Lesions by
Patient – Derived LAM Cells and
Lymphatic Endothelial Cells

Pilot Awards - \$25,000 for 1 year

Michael Borchers, PhD

University of Cincinnati
College of Medicine
Cincinnati, OH



NKG2D Receptor – Ligand
Interactions in LAM Pathogenesis

Joshua Fessel, MD, PhD

Vanderbilt University
Nashville, TN



Use of 18F – Glutamine PET in
the Diagnosis of LAM and other
Pulmonary Diseases

Thank you to the LAM Scientific Advisory Board (SAB) for taking the time to gather together in November of 2015 to review the grant applications and recommend these research studies to the Foundation's Board of Directors.

To read more about the grants [click here](#).

MDBR winners have been announced!

In just two years, The LAM Foundation along with our Easy Breather's cycling team raised more than \$200,000 that has been awarded to four LAM researchers for pilot studies from the UPenn Orphan Disease Center's Million Dollar Bike Ride.

Congratulations to the following 2015 LAM Researchers who were awarded \$50,500 for their pilot studies in 2015.



David Kwiatkowski, MD, PhD
Brigham and Women's Hospital
Boston, MA

TSC2 mutation analysis as a
biomarker for
lymphangioleiomyomatosis (LAM)



Norbert Perrimon, PhD
Harvard Medical School
Boston, MA

An shRNA based screening
method for TSC synthetic lethal
screens

To read the entire list of award winning researchers from the 2nd Annual Million Dollar Bike Ride and The Orphan Disease Center [click here](#).

New Year = New MDBR Gear

A Note from the MDBR Easy Breathers Team Captain, Patricia Ortiz

For the third time in a row, The LAM Foundation Easy Breathers Team is invited by The Penn Medicine Center for Orphan Disease Research and Therapy (CODRT) to participate in the "Million Dollar Bike Ride" in Philadelphia on Saturday, May 7, 2016 to raise funds for LAM research.

In preparation for the event, the fabulous team at ZOCA Gear helped us to design a new outfit that will include cycling jersey, the popular tech tee, and new this year we are considering adding a long sleeve jacket to the collection.

Garments will be available for men and women. Check out the new design. Even if you are not a cyclist, the jacket and the tech tee are great for any type of activity! Jorge Linss from ZOCA Gear generously offered again to donate a portion of the proceeds from the sale to The LAM Foundation! He and his team are truly amazing!

The team store will open February 22, 2016. We are interested in finding out peoples' interest in purchasing items. Please take our quick MDBR garment survey to help us gauge the amount we might

need for ordering purposes. [Click here](#) for the survey.



Re-enroll your Kroger Community Rewards

It's a new year, time to re-enroll your Kroger Rewards Card. Enroll your Kroger Rewards Card and designate The LAM Foundation as your charity of choice. Kroger will donate a percentage of your total to the Foundation.



No extra money out of your pocket. Just by shopping at Kroger, The LAM Foundation will benefit.

The more of our Kroger shoppers that are signed up, the more The LAM Foundation will receive!

[Click here](#) to learn more and enroll your card.

Upcoming Regional Events

Region 15 (TX, OK, NM)

LAM Educational Meeting

Saturday, January 30, 2016

University of Houston

10:00am - 2:00pm

Women with LAM, family and friends are all welcome to a regional LAM education meeting on Saturday, January 30, 2016.

You will not want to miss this impressive line-up of speakers and their presentations; including a visit from Sue Sherman, Executive Director of The LAM Foundation.

- Rosa Estrada-Y-Martin, MD, LAM Clinic Director from UTHealth - "LAM 101"
- Hope Northrop, MD, Director, Division of Medical Genetics at UTHealth - "Genetics; How it Relates to LAM and/or TSC"
- Sandra A Oldham, MD, Chief of Radiology at UTHealth - "Radiology 101"
- Thomas Lowder, PhD, University of Houston - "Understanding Your PFT's and How They are Affected by Exercise"

Co-LAM Liaisons, Frances Saldivar and Maria Tentiente are hosting the meeting at the University of Houston

Garrison Gymnasium, Room 205

3875 Holman

Houston, TX 77204

Free parking and lunch will be provided to all who attend.

There will also be an elevator and plenty of electrical outlets.



Region 2 (Western NY & Western PA)

The WNY Friends of the LAM Foundation 11th Annual 'An Evening of Hope'

Saturday, February 13th, 2016

7:00pm - 10:00pm

Asbury Hall at Babeville

341 Delaware Avenue

Buffalo, NY 14202

The evening includes hors d'oeuvres, wine and beer tasting, silent and lucky numbers auctions, raffles, Wall of Wine, live music and complimentary valet parking.

Ticket Prices:- \$55 per person pre-sale; \$65 per person at the door.

For more information and to purchase tickets [click here](#).

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 the 5k 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.

MIDAS Update

Patient enrollment continues for the MIDAS Trial and LAM Clinic Sites are currently being signed up. The first ten sites should be up and going soon. If you have already registered for MIDAS, thank you. This is a vitally important study for all women with a LAM diagnosis. You will be contacted soon about next steps. If you have not enrolled, please consider doing so by calling Tammy Roads at 513.558.2148 or send her an email at roadst@ucmail.uc.edu.

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

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713-796-9351 (fax)
cpope@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.

NEW PROJECT IN HENSKE LAB

Elizabeth (Lisa) Henske's laboratory (HenskeLab.org) 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 857.307.0782 if you are considering any type of surgery or biopsy. Thank you!

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.

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