



The LAM  
Foundation  
A BREATH OF HOPE

# CURRENTS

[The LAM Foundation](#)

August 2015

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## A Note from Sue Sherman, Executive Director

Imagine being 10 years old, [riding your bike](#) on one of the last, hot days of summer, humid air in your face, laughing off the prospect of school. You are pedaling with a [new friend](#) out beyond the subdivision, heading to a party where kids will be [hanging out poolside](#), and parents will be cooking up burgers. The excitement of backyard chaos beckons you to ride faster. You are part of something big – a party that’s happened every summer for [20 years](#) and you know that everyone will smile when you arrive. You wind toward the neighborhood, ignoring the vast green fields of [soybeans](#). From a distance you hear faint [music](#) and, as you cruise around a bend, you see [balloons](#) bobbing and swaying, fighting to break free from the mailbox. You and your friend nearly miss a group of [walkers](#) as you careen straight into the front yard, barely stopping before jumping off and depositing your bicycles in the front lawn. Without a knock, you are through the front door, your friends are everywhere. As you spy the fastest path to the back door, you see a crowd in the family room, video cameras on, kids [daring each other to dance](#), and screeching with delight at the next awesome move. You jump into the mix, mugging for the camera, and performing your famous front walkover. Coins jingle to the floor -- your last [.65 cents](#), saved for what? Will it be at the ice cream truck, or perhaps a gift for the girl asking for donations at the grocery store? Your mom said she would [match you penny for penny](#)... No matter, the fun has begun, and you are in the thick of it. The end of summer has never been so sweet and you intend to experience

## Visit our site:

[Foundation Publications](#)

[Sue Byrnes Legacy Fund](#)

[View Our Regional Map](#)

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## 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:**

@TheLAMFoundation

every moment.

To say that the camaraderie and joy of a childhood party is similar to news from the LAM community may feel like a bit of a stretch – and I hope you will indulge the impulse. Please read this edition of Currents and make the connections to the references in bold above. The hope, generosity and creativity of our “neighborhood” never ends. Enjoy the final weeks of summer!

## WELCOME - Anne McKenna



The LAM Foundation is pleased to welcome Anne McKenna to our staff, as the new Patient Services and Education Manager.

“We are thrilled to welcome Anne to Foundation,” said Susan Sherman, Executive Director of The LAM Foundation. “With her work in the Buffalo area with The LAM Foundation, she knows personally the struggle LAM patients face because a family connection. We feel she will be a terrific advocate for LAM patients and clinicians.”

You may have met Anne at previous LAMposiums -she has been to five of them.

She is the Co-founder and Volunteer Director for the Western New York Friends

### **Unsubscribe:**

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of The LAM Foundation. Every winter for the past 10 years, the McKenna Family has held a successful “Evening of Hope” fundraiser, where all proceeds go to The LAM Foundation.

She would love to hear from you; you can reach her by phone at 513.777.6889 or by email at [amckenna@thelamfoundation.org](mailto:amckenna@thelamfoundation.org)

### **A Special Thank You!**

Thank you Pfizer, the FDA and every individual and organization instrumental in the FDA approval of Rapamune for the treatment of Lymphangioliomyomatosis (LAM).

The registration database at The LAM Foundation contains nearly 2,000 women diagnosed with LAM. For a growing number, Rapamune is the drug therapy they count on to slow the progression of the disease. Until 2015, many were paying for therapy out of pocket or spending countless hours educating their physicians and insurance companies that this drug could make a difference.

Because these wonderful people took the time to listen, crunch the numbers, believe in the data, and care; the FDA approved Rapamune and gave these women hope.

This presentation was created by The LAM Foundation with letters from women with LAM, and sent to our friends at the above organizations. We hope you are inspired as they were. [Click here](#) to view.

### **LAM Week at the American Thoracic Society**

Last week was LAM week with the American Thoracic Society. All week long the ATS website, <http://www.thoracic.org/>, posted Lymphangioliomyomatosis information for researchers, clinicians and women diagnosed with LAM. This is an

area of the ATS website where members of ATS can review research studies, learn about how to diagnose and how to support women with LAM.

As part of LAM Week at ATS Francis McCormack, MD of University of Cincinnati School of Medicine presented a live webinar titled "LAM: A Model for Progress in Rare Lung Diseases". During the webinar researchers, clinicians and the public could ask Dr. McCormack questions related to his presentation or general questions about LAM.

The recorded webinar has been posted. [Click here](#) to listen to the webinar.

The American Thoracic Society is an international society with more than 15,000 members.

## **Clinical Trials & Studies**

**NEW STUDY** - 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 (Multicenter International Durability and Safety of Sirolimus in LAM)**

Do not let the title of the study confuse you. Any woman diagnosed with LAM is eligible to participate. It is important that all women with LAM contact the study coordinator to discuss the details of the study.

Dr. Francis X. McCormack

[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 including: 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](mailto:EHenske@Partners.org) or 617.355.9049 if you are considering any type of surgery or biopsy.

**BIG THANK YOU TO THE LAM COMMUNITY -**

Dr. Kwiatkowski has met his goal for the LAM Genome Wide Association Study (GWAS)

Dr. David Kwiatkowski

**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.

**The Tolerability of Saracatinib in Subjects with LAM (SLAM-1)**

Dr. Tony Eissa

[CLICK HERE](#) for more details.

**Million Dollar Bike Ride Grant Program Results**

The LAM Community launched Lymphangiomyomatosis to the tete de la course (front of the race) again this year for the Million Dollar Bike Ride. For the

second year in a row, The LAM Foundation Easy Breathers was one of the top rare disease teams, raising new funds for LAM Research.

LAM research will receive two (2) \$50,000 pilot grants, awarded to investigators who submit translational proposals with the strong likelihood of future federal funding, that use LAM samples, models or patient data, and which have the potential to favorably impact human health.

**Letters of Intent (LOIs) are due by 5:00pm (EST) on Monday, September 14, 2015.**

Thank you to everyone on the LAM Foundation Easy Breathers Team, generous donors, supporters, and volunteers who contributed to a fun event and successful fundraiser for LAM research.

We look forward to seeing everyone again in Philadelphia, PA, next year when the third annual Million Dollar Bike Ride will take place on Saturday, May 7, 2016.



## **Every Dollar Counts Twice Toward LAM Research**

This spring The LAM Foundation and its Easy Breathers Cycling Team participated in the Million Dollar Bike Ride (MDBR). More than \$130,000 was raised for LAM research and the UPENN Medicine Orphan Disease Center matched the first \$50,000, dollar for dollar.

In an attempt to make certain the surplus funds raised for the MDBR will be matched and have 100% directed to LAM research, a new fundraising opportunity has been developed.

For the final months of this year, the Foundation will match funds for qualifying community events.

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.

**Frances Saldivar-Morales** - \$10,000 [Breath of Hope 5K](#) on September 26, 2015

**Nicole Wipp** – \$10,000 [Wipp LAM](#) Online Campaign

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

**The Shaheen Family** – \$20,000 Dinner Fundraiser at Shaheen Modern and Contemporary Art Gallery on November 14, 2015

**Jennifer Fujikawa** – \$20,000 [Friends Ask Friends Online Campaign](#)

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

## **NEW LAM Awareness/Fundraising Campaign Has Popped Up**

UNC Eshelman School of Pharmacy students Laura Bowers and Libbie Dellinger are raising awareness about LAM and funds for the Foundation through a new social media campaign. In celebration of The LAM Foundation's 20th Anniversary, the women launched a Balloon Challenge on August 20. 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, a common symptom of all women with LAM. Laura would know; she was diagnosed with LAM halfway through her first semester of Pharmacy School.

The Balloon Challenge is taking place mostly on Facebook where videos can be viewed of friends and family members taking the challenge. With the encouragement of UNC and National Kappa Epsilon, the goal is to raise LAM Awareness, fund LAM research and support women with LAM. They are doing this by asking 3 others to take the challenge. Within the first 24 hours of the Challenge, nearly \$100 was donated online to the Foundation. .

[Click here](#) to view their introduction video.

Laura and Libbie hope you will help this Balloon Challenge by sharing this video with your Facebook friends!

## 20|20|20 Campaign Update



The LAM Foundation has reached one third of its goal for one of the most important campaigns of the year, the 20|20|20 Campaign. Help us reach our halfway mark!

Dr. Francis McCormack is getting us one step closer to advancing LAM research and supporting women with LAM. He donated \$20 for the next 20 months to Sue Sherman's 20|20|20 Campaign. Will you join us?

In honor of The LAM Foundation's 20th Anniversary, consider giving \$20 one time, or 20 times by [clicking here](#): Or consider inspiring 20 friends to give \$20, 20 times – When you break it down, that's 65¢ a day.



[Consider supporting Patricia Bebien-Aronoff's campaign!](#)

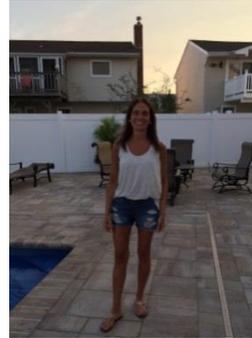
When I was first diagnosed with LAM in May 2012 I was fortunate to connect with The LAM Foundation right away.

I got the support and the information I needed to make the best decisions for my health. I am grateful for that and will do everything in my power to help find a

cure, educate the public about LAM and give my local LAM Sisters the support they need.

[Or supporting Tara Logozzo's campaign!](#)

I am participating in the 20|20|20 campaign because every donation will get us closer to finding a cure for LAM. Please donate whatever you can to my 20|20|20 campaign.



**You will be amazed at what can happen in 20 months!**

### **La Jolla Music Society SummerFest**



On a beautiful Sunday afternoon in July, The LAM Foundation was represented by Region 20 LAM Liaison Charm Perry Flint and Outreach and Events Manager, Maria Pearson at the La Jolla Music Society SummerFest.

They had the opportunity to talk with patrons of the Festival about the symptoms of LAM and the need for greater awareness and faster diagnoses. The concert included music composed in memory of LAMMIE, Deborah Hoffman, who passed away last year. The composition, "of Deborah, for Deborah", had its debut at SummerFest. It was commissioned by Deborah's brother; Joel Hoffman and performed by her brothers and her best friend.

You might remember Deborah; she played the harp at LAMposium in 2006. She was and double lung transplant recipient and the principal harpist of the Metropolitan Opera Orchestra.

If you would like to view a website in memory of Deborah Hoffman and listen to her work [click here](#).

### **Donations Come In All Shapes and Sizes**

A very heartfelt thank you to Rebecca Nissly's parents, Gerald and Regina Musser who donated 3000 bushels, the equivalent of 3 tractor trailer loads or 180,000 lbs of soybeans to The LAM Foundation. With this donation, the Foundation has the option to do whatever we might like with these soybeans.



You might be thinking, soybeans are not necessarily recommended for women with LAM, because they contain a natural estrogen hormone. And we are aware of this, so we are going to back away from serving edamame at LAMposium next year.

Within less than 24 hours of receiving this grain donation, The LAM Foundation sold the soybeans in the Commodities Market with the help of Rebecca Nissly. Rebecca sold the soybeans for the Foundation at \$8.38 per bushel for a grand total of \$25,140.00! That donation will go directly to The LAM Foundation to support women with LAM and find a cure faster.

This gift is just another example of gifting appreciated assets just like donors will sometimes gift appreciated stock to non-profits. The non-profit can sell the stock

and take the proceeds. Since they are tax-exempt, they do not have to pay any taxes on the transaction. The donor is able to give the value of the asset but since he/she didn't sell it, the Foundation doesn't have to pay the capital gains tax either--allowing the net amount of the gift to be larger. It is much better than the donor selling the asset (which will be taxed) and then giving the money. It's a well-known donation strategy, but usually it is done with stocks and not with grain!

So on behalf of the LAM Community, we love soybeans and we cannot thank Gerald and Regina Musser and their clever daughter Rebecca enough for the extremely hard work they put into growing these wonderful crops. You both are very generous.

### **Meetings from Around the Regions**



#### **Region 16 - Utah Lammie Luncheon**

Women with LAM in Salt Lake City, Utah, were pampered for an afternoon. Jill Bednark and Region 16 LAM Liaison, Lynnette Weese, hosted an afternoon of food, relaxing by the pool and massages.

The Cancer Wellness House in Salt Lake donated time and free massages for everyone.

Lynnette Weese said, "It was a great opportunity for us to reconnect with each other and to get away from it all for an afternoon."





### **Region 6 Meeting**

On Saturday August 1, patients, family and friends in Region 6 (Georgia, North Carolina, and South Carolina) met for lunch in Charlotte, North Carolina at the South County Regional library.

Dr. Charlie Strange, LAM clinic director at the Medical University of Charleston South Carolina, was the guest speaker. Dr. Strange discussed the MIDAS trial, LAM research findings, along with other upcoming trials, oxygen modalities and insurance. He also answered questions about Rapamune. In all, fifteen patients and family members came together to connect and share their journey.

### **Region 4 Gathering**

On Sunday, August 23rd, 8 people gathered at the home of Patti Bebien-Aronoff to welcome new LAMMIE Deanna Zoog and enjoy a British tea with scones, clotted cream, lemon curd and jam.



We had a wonderful time sharing our LAM experience and answering all the questions Deanna and her mom had. We were also so happy to see our latest Region 4 lung transplant patient, Barbara Kaplan, who was 8 weeks post-transplant and looked absolutely wonderful.

## Upcoming Events

### **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.

### **Region 13 (Iowa, Kansas, Missouri, and Nebraska)**

#### **Regional LAM Meeting**

**Thursday, September 17, 2015**

**4:30 pm - 7:00 pm**

Washington University School of Medicine Pulmonary and Critical Care Division

15th floor of the Northwest Tower in our Atrium Conference room The conference room is located directly outside of the elevators.

Parking lot address

4990 Children's Place

St. Louis, MO 63110.

Marla Hamlin and Carmen Inglesias would like you to come and reconnect with everyone in our region for dinner.

LAM Clinic Director, Dr. Adrian Shifren from Washington University School of Medicine, Barnes Jewish will be there updating everyone on LAM research, and answering all of your LAM related questions.

Also, Lynda Patterson, Respiratory Therapist, will speak on the importance of pulmonary rehab, diet, breathing techniques and so much more.

A light dinner will be served as we catch up on all of the good news coming from The LAM Foundation from our Executive Director, Sue Sherman.

Please RSVP to Marla Hamlin email [Ron4Mar@aol.com](mailto:Ron4Mar@aol.com) by Sunday, September 13, 2015.

**Region 19 (Northern California, Northern Nevada)**

**LAM Support Group "Fall Fling!"**

**Saturday October, 3, 2015**

**11:00 a.m. - 2:00 p.m.**

Stanford University Medical Center

Dr. Stephen Ruoss will review LAM highlights from the May 2015 International Thoracic Society Meeting as well as some key publications related to LAM. (Links to publications will be sent out closer to time of meeting and we will have copies.)

There will also be time for socializing during a potluck luncheon.

Family and friends are welcome.

Please RSVP to Shellie Owens [saowens@earthlink.net](mailto:saowens@earthlink.net)

Also feel free to call her with any questions 650.862.6374

If you haven't been before, please check with the information desk at the front entrance and they will help direct you to our meeting room on the 3rd floor of the hospital in the Pulmonary Division. Look for signs on the 3rd floor. (If the escalators **aren't working, there are elevators immediately past them.**)

**LOCATION AND DIRECTIONS:**

Stanford University Medical Center  
300 Pasteur DriveStanford,  
CA 94305

**Region 2 (Western Pennsylvania and Western New York)**

**Regional LAM Meeting**

**Saturday, October 10, 2015**

**12:00 pm - 2:00 pm**

1344 McClellan Street

Schenectady, New York 12309

A respiratory therapist from the Sunnyview Rehabilitation Hospital will present

helpful tips on pulmonary rehab for LAM patients.

RSVP to Susan Mennillo by Wednesday, September 30, 2015 by phone (518) 382.5463 or by email: [smennill@nycap.rr.com](mailto:smennill@nycap.rr.com).

**Region 12 (Minnesota, North Dakota, South Dakota and Wisconsin)**

**Regional LAM Meeting**

**Saturday, October 17, 2015**

**Time: 10:00am Meet and Greet**

**11:00am Presentation**

THINK Mutual Bank

4245 Johnny Cake Ridge Road

Eagan, MN 55122

2nd Floor Meeting Room (Please take the elevator)

Presentation and Q&A by LAM Clinic Directors Dr. Jay Ryu and Dr. Misbah Baqir from the Mayo Clinic, Rochester.

RSVP by Friday, October 2, 2015 to Sharon Hovland:

[sharonhovland@gmail.com](mailto:sharonhovland@gmail.com).

Sharon is taking topic requests. If you have a topic we should discuss, please send her an email note.

**Region 18 (Alaska, Oregon and Washington State)**

**Regional LAM Meeting**

**Saturday, October 17, 2015**

**1:00 pm - 5:00 pm**

The delightful Dr. George Pappas, LAM Clinic Director at Minor and James Medical will present on new and exciting LAM research. Sue Sherman will share all that is going on with the Foundation, plus physical trainer, Morgan Blackmore is back, for a return engagement, to present on Functional Fitness.

Join us for the meeting from 1:00 pm - 3:00 pm at:

Immanuel Presbyterian Church

901 North J Street

Tacoma, WA 98403

Then, let's continue the conversation from 3:00 pm - 5:00 pm at:

Cafe Divino

2112 North 30th Street

Tacoma, WA 98403

RSVP to Sharlene Dunn Brells: [sbrells@gmail.com](mailto:sbrells@gmail.com).

**Region 5 (Delaware, Maryland, Washington DC, and Virginia)**

**1st Annual Backyard Bull Roast**

**Saturday, October 17, 2015**

**6:00pm-10:00pm**

Darlington/Dublin VFW Post 10146

3430 Conowingo Rd

Street, MD 21154

Tickets are \$25 per person, must be 18 to attend.

Menu includes: pit beef & ham, home-style sides and soda

Cash bar, money wheels, basket raffles, and Ravens/Orioles memorabilia silent auction

For more info or to purchase tickets contact Crystal Windsor at

[clcwindsor@msn.com](mailto:clcwindsor@msn.com).

**Region 4 (Eastern Pennsylvania and New Jersey)**

**LAM Regional Meeting**

**Tuesday, October 20, 2015**

**6:00pm-8:00pm**

We are still working on the details, more information will be available to you in September.

In the meantime, if you have any questions, please contact Patti Bébien-Aronoff at [bebienaronoff@aol.com](mailto:bebienaronoff@aol.com).

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

**LAM Regional Meeting**

**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

As part of its annual Board of Directors meeting, The LAM Foundation, in partnership with the TS Alliance, will host a Patient & Family Meeting and Luncheon for those affected by Lymphangioleiomyomatosis (LAM). Please join us to hear the most up-to-date research and clinical advances in diagnosing and treating LAM, presented by leading experts in the field.

If you plan on joining us, please contact The LAM Foundation at:

[info@thelamfoundation.org](mailto:info@thelamfoundation.org) or by calling us at 877.CURE.LAM (877.287.3526).

**Region 19 (Northern California and Northern Nevada)**

**7th Annual Chowchilla Laps for LAM Walk-a-Thon**

**October 24, 2015**

Chowchilla Union High School Football Stadium

Humboldt Avenue and 10th Street

Chowchilla, CA

Day of Event Registration Start Time - 9:00am

Walk begins at 10:00am

Registration Fees:

Youth (under 18): \$20

Adult Pre-Registration (before 10/14/15): \$30

Adult Registration (day of event): \$35

Registration fee includes walk-a-thon registration fee and t-shirt. \*T-shirts are only guaranteed for pre-registrations submitted by October 14, 2015. If participant raises \$100.00 in walk-a-thon donations, they will receive a gift bag. Pre-register by 10/14/15 and receive 3 free raffle tickets!

[Click here](#) to register.

Congratulations to Dare to Dance for LAM (D2D4LAM) on all the awareness you are generating.

For more information or to view some of the Dare 2 Dance videos [click here](#) to visit their Facebook page.

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