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## A Note from Sue Sherman, Executive Director

At the National Organization of Rare Disorders (NORD) 2015 Rare Diseases and Orphan Products Breakthrough Summit held in October, a keynote presentation was given by Christopher Austin, MD, head of the National Center for Advancing Translational Sciences (NCATS), part of the NIH. Many in the LAM community will remember Dr. Austin for his presentation at LAMposium 2014. In describing the work at NCATS, Dr. Austin coined the term, “Relentless Collaboration,” explaining that together we must pursue shared relationships, ideas, resources and discoveries, if we are to reach our goals. No longer are we able to function singularly, though there was a recent time when forward progress required pushing against the odds without partners to help.

In the same talk, Dr. Austin highlighted The LAM Foundation as a model for relentless collaboration and celebrated our history of working through partnerships to achieve important milestones like the MILES Trial and FDA approval of Rapamune for the treatment of LAM. To be highlighted in front of hundreds of rare disease organizations and industry leaders was indeed a tribute to you and everyone in the LAM community. If you are feeling alone, reach out. If you are unsure of your next steps on your journey with LAM, ask for advice. If you want to make a difference, get involved. Communicating and collaborating pay dividends for our future – in ways that have yet to be realized.

We are a rare disease “model to emulate” as cited in the New England Journal of Medicine (2010) for a reason. Enjoy reading this edition of Currents to find out why.

(LAM Patients Only)

Lammie Loved Ones

(Family/Friends Only)

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## **The Impact of Gathering Together as a Community and Making Personal Connections**

The Foundation has divided the United States up into **21** LAM Liaison Patient Network Regions.

Each region has **1 or 2** volunteer LAM Liaisons who dedicate their time by:

- Planning and hosting regional educational and support meetings
- Providing safe friendships to women who need support by phone, email, or in person
- Executing or participating in LAM community fundraising events
- Connecting those in need to professional support within their region
- Optimizing LAM awareness
- Supporting The LAM Foundation at all levels

LAM Liaisons planned **7** educational and support meetings during the month of October. That's one meeting every **4.5** days!

**191** women with LAM, family and friends attended these meetings.

**14** presenters shared updates on the latest LAM research, answered important questions and offered critical clinical support.

**21** of those women found a new sense of hope; because this was their **first LAM meeting**.

The numbers get even bigger if you count the following. At the NORD Rare Diseases and Orphan Products Breakthrough Summit in Washington D.C. the Director, National Center for Advancing Translational Sciences (NCATS), NIH, Christopher P. Austin, MD, spoke to a room of **500** people as mentioned in Sue's opening message above.

In the **31** days of October:

**191** Gathered in Person at LAM Regional Meetings  
**500** Gathered for a NORD Luncheon Keynote Address  
LAM Awareness has spread to **691** people across the

United States.

## **Regional Meeting Update**

### **Region 5 Kicks off a Month of LAM Education and Support Meetings.**

To kick off a month of LAM Liaison Meetings, women with LAM gathered in Bethesda, MD, where Region 5 (DE, MD, VA, DC) LAM Liaison, Mary Stojic, hosted a LAM Support Meeting at her home.

Mary noted, "The meeting was an incredible opportunity for women with LAM to connect and share their stories with each other. The range of symptoms and experiences was wide, but we learned from each other and supported our individual journeys with LAM." For six (6) women, this is the first LAM Liaison meeting they have attended. Thank you Mary, for opening up your home and providing a safe environment for women to meet for the first time.

### **Personal Connections are Made in Stanford**



Region 19 (Northern CA and NV). Over 25 women with LAM, family and friends gathered at Stanford University Medical Center on the first Saturday of October.

Women who attended had some homework to complete before they came together for this meeting. LAM Liaisons, Shellie Owens and Susan Jacobs, RN, MS, gathered everyone onto the same topic, by sending out two relevant journal articles to everyone who sent in their RSVP. At the meeting Susan Jacobs, RN, MS, gave everyone an update on the current LAM clinical trials. Then LAM Clinic Director Stephen Ruoss, MD, from Stanford University Medical Center joined Susan for a

lively interactive discussion on the articles; “UK prospective on LAM” and “Stuck with LAM”.

As always, personal connections were made over a potluck lunch which is a major high point of their meetings and left people wanting more!

### **Hope for Women with LAM in Minnesota**



A Saturday afternoon regional meeting brought a sense of hope to four newly diagnosed women in Eugene, Minnesota. Women with LAM, family and friends gathered for an educational luncheon with Jay Ryu, MD and Misbah Baqir, MD, LAM Clinic Directors from the Rochester Mayo Clinic. In all, over 19 people gathered as Region 12 (ND, MN, SD, and WI) LAM Liaison, Sharon Hovland hosted the luncheon for women in that part of the country. Some of the women, who had never been to a regional LAM meeting, were able to spend time and talk with our LAM experts and get answers to some of their most important questions, as they begin their journey with LAM.

Thank you Mayo Clinic for supporting The LAM Foundation and a special thanks to Drs. Ryu and Misbah for traveling from Rochester, MN to Eugene, MN to be with us for a few hours on your day off.

### **A Sense of Community in Tacoma, Washington**



Co-LAM Liaisons, Sharlene Dunn and Renia Endo, hosted a day of community for 44 people in Tacoma, Washington. Nearly 20 women with LAM gathered with their family and friends for educational discussion on LAM and participated in simple strength exercises.

LAM Clinic Director, George Pappas, MD, from the Swedish Medical Center in Seattle, Washington presented on the latest in LAM Research and answered questions on LAM Clinical trials taking place. Physical trainer, Morgan Blackmore, came back for a return engagement, to present an interactive demonstration on Functional Fitness. Executive Director, Sue Sherman also made her way to the Pacific Northwest to share some of the strategic initiatives taking place at the Foundation.

It wasn't all business; a majority of the group took the time to continue the conversation at a nearby restaurant. Connections and lasting friendships were made at this event. LAM Liaison Sharlene Dunn summed up this meeting in this one sentence, "Hope is what made the meeting magical for me."

Thank you Dr. Pappas and Morgan Blackmore for dedicating your time to the LAM Community.

### **A Regional Meeting at UPenn is Time Well Spent**



Region 4 (Eastern PA and NJ) LAM Co-Liaisons, Patti Bébien Aronoff and Alanna Nelson welcomed 29 women with LAM, relatives and friends to their latest educational meeting. University of Pennsylvania Medicine hosted the meeting and LAM Clinic Director, Maryl Kreider, MD and Vera Krymskaya, PHD, MBA, provided very informative presentations on Recent Clinical and Scientific LAM Updates.

Jason Christie, MD, MS Chief of Pulmonary Medicine at UPenn gave a warm introduction to the audience and Andrea Slattery, LAM Foundation incoming Board Chair provided closing remarks.

For seven (7) women this is the first time they have ever attended a LAM Education Meeting. One of those women noted, "This is my first formal exposure to LAM, other than what I found on the internet. To me the entire presentation was very valuable."

Patti and Alanna would like to thank UPenn Medical Center and Drs. Kreider and Krymskaya for their continued generosity and support of women with LAM. They also want to thank all of the women who traveled; one woman came all the way from Virginia to attend this evening event.

### **The LAM Foundation and the TS Alliance combine meetings**

There are similarities between Lymphangiomyomatosis and Tuberous Sclerosis Complex (TSC). Both diseases have the same fundamental cell biology and most women with TSC develop lung cysts. Those similarities, plus the fact that The LAM Foundation and the TS Alliance have the same devotion to our patients, is more than enough reason for our two foundations to gather for a combined regional meeting and Board of Directors meetings.

Last week nearly 70 patients, family members, LAM and TSC Researchers, Clinicians, and Board Members gathered on the campus of University of Cincinnati Medical Center to kick off two days of meetings with a regional education luncheon.



The LAM Foundation Executive Director, Sue Sherman and President and CEO of TS Alliance, Kari Luther Rosebeck kicked off the regional meeting by sharing the amazing accomplishments taking place within each community.

They also took the time to share initial plans for combined regional meetings taking shape for next year.

Darcy Krueger, MD, PhD, TSC Clinic Director at Children's Hospital Medical Center presented on the great strides taking place within the TSC research community. Chief Scientific Officer for the TS Alliance, Steve Roberds, PhD, presented on symptoms that most concern caregivers and TSC patients. Controlling seizures and LAM symptoms ranked highest on the list of TSC patients.



Then our very own Scientific Director, Frank McCormack, MD, shared his thoughts on now that we have an FDA approval, how do we optimize the treatment and how both Foundations can boost awareness through our web presence and in social media.



Women from southern and eastern Ohio and from West Virginia enjoyed re-connecting with each other and with LAM researchers and clinicians who came for what looks to be a partnership of communities working towards one goal, a cure for LAM.



### **Upcoming Regional Events- Let's Continue the Personal Connections**

Sunday, November 1, Regional Meetings are taking place in Chicago, IL and Portsmouth, NH.

**LAM Liaison in Region 10 (IL), Kathy Peiffer** is hosting a LAM Support meeting in Woodstock, Illinois. They will practice Yoga to focus on ways to improve and sustain good health while managing the symptoms of LAM.

**On the East Coast, LAM Liaison, Madeline Nolan** is hosting a LAM Education Meeting in Portsmouth, NH. LAM Clinic Directors, Elizabeth Henske, MD and Souheil El-Chemaly, MD from Brigham and Women's Hospital will both present.

There is still time to RSVP to LAM Education Events in Scottsdale, AZ, Cleveland, OH and Brooklyn, NY.

Women with LAM, family and friends who live near Scottsdale, AZ have an opportunity to connect with some members of the LAM Scientific Advisory Board (SAB) on Thursday, November 5, 2015 at the The Scottsdale Resort at McCormick Ranch. To RSVP contact the Foundation at [info@thelamfoundation.org](mailto:info@thelamfoundation.org).

**The Cleveland Clinic and Robert Kotloff, MD**, are hosting a Regional LAM Education luncheon event on Saturday, November 14, 2015. The Cleveland Clinic has a line-up of LAM experts, who will present on; Sirolimus Treatment, Management of Pneumothoraxes, Management of Angiomyolipomas of the Kidneys and an Overview of Pulmonary Rehabilitation and Supplemental Oxygen. To RSVP, click here [www.clevelandclinic.org/lam](http://www.clevelandclinic.org/lam).

**In Region 3 (NY), LAM Liaison, Sarah Poitras** is hosting a LAM educational meeting in Brooklyn, NY, where LAM Clinic Director, Jeanine D'Armiento, MD, PhD, from the Center for Rare Lung Diseases at Columbia University will give an update on treatment and management of symptoms related to LAM. This meeting is also taking place on Saturday, November 14, 2015. For more information or to RSVP email Sarah Poitras at [sarahpoitras@gmail.com](mailto:sarahpoitras@gmail.com).

LAM Liaisons are available to offer support and are happy to take topic suggestions for future meetings. If you would like to connect with a LAM Liaison in your region, [click here](#) for a list of names and contact information.

You can also see the full list of Events and Meetings taking place within The LAM Community by [clicking here](#).

## Fundraising Update

### Backyard Bullroast

Crystal Windsor's Backyard Bullroast was a great success! Crystal and her family hosted the Backyard Bullroast in Street, Maryland for the first time this year.



Over 20 items were donated and on display for the silent auction, the dance floor got a bit crowded and of course all who attended were served Pit Beef and Pit Ham throughout the evening. The Backyard Bullroast helped to raise nearly \$3,000 to support women with LAM and LAM Research. Everyone had a wonderful time and plans for the Second Bullroast are being discussed.



Every year, Crystal and her family enjoy hosting new and innovative events to raise money for the Foundation. You might remember they hosted the successful Duck Pin Bowling last year raising \$1,500.

### Words of Thanks on the Huge Success of the Laps for LAM

#### By Peggy Haupt

Words cannot even begin to express my gratitude to so many of you who supported my cause at LAPS for LAM. Because of YOU, not only did we meet our goal, we SURPASSED it!!!! I don't have the final figures, but it looks like we hit approximately \$12,000, which now becomes a beautiful \$24,000 to go towards LAM research to help so many of my LAM sisters!! I cannot say thank you enough to all who walked, sought your

own donations, donated, bought raffle tickets, donated raffle prizes, prayed, offered words of encouragement, and also inquired about reaching the goal. This became important to some of you too, which touched my heart! Chowchilla, CA is a small community, but the love for others here is tremendous and I will always be thankful for that! God bless you and I love you all!!



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

#### **Goals have been set and surpassed!**

You may remember this summer we announced the Foundation had \$80,000 in funds available from the Million Dollar Bike Ride (MDBR). We invited new and annual community fundraisers to dream big, go for it, raise your expectations and raise \$10,000 or \$20,000 for LAM Research - using the \$80,000 the Foundation is able to double their event proceeds, matching dollar for dollar.

#### **Four women took on that challenge.**

Because of the generous support from their community of family and friends all four events have surpassed or are just on the verge of surpassing their goals. And all four are going with the positive momentum to raise even more money!

Here is where each fundraising event stands as of this week:

**Nicole Wipp** – \$9,294.90 of a \$10,000 goal Wipp LAM  
[Wipp LAM Facebook Page](#)  
[Wipp LAM Fundraising Page](#)

**Peggy Haupt** – \$12,000 of a \$10,000 goal 7th Annual Chowchilla Laps for LAM Walk-A-Thon on October 24, 2015

[7th Annual Chowchilla Laps for LAM](#)

**Frances Saldivar-Morales** – \$9,200 of a \$10,000 goal  
[Breath of Hope 5K](#)

**Jennifer Fujikawa** – \$21,460 of a \$20,000 goal Friends asking Friends Fundraising page

[Jennifer's Friends asking Friends Donation Page](#)

Thank these courageous women by donating to their event simply by clicking on the link provided by their name. Every dollar donated to their campaigns will be matched dollar for dollar. All money donated will go directly to patient services to support women with LAM and LAM Research.

## **[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**

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 at least contact the study coordinator to discuss the details of the study. NIH continued funding of this study is dependent on Dr. McCormack and the other site's ability to enroll as many women with LAM as possible in the first few months...Multi center International Durability and Safety of Sirolimus in Lymphangioleiomyomatosis Trial (MIDAS

Trial)

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 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](mailto:EHenske@Partners.org) or 617.355.9049 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.

**Save the Date for The International Rare Lung Disease Clinical Research Conference, LAMposium and Breath of Hope Gala**

Planning is underway for this one of a kind 3 day conference, which will include our Rare Lung Disease Partners (RLDP). Because we are so fortunate to have our Rare Lung Disease Partners with us at the conference, you will notice some changes to the Research Conference and LAMposium format. Rest assured that the tradition of sharing knowledge and building community will not change – it will only get better. Joining us in 2016 will be researchers, clinicians, patients, family and friends from the following

organizations:

- Alpha-1 Foundation
- Birt-Hogg-Dube Foundation
- Hermansky Pudlak Syndrome Network
- Histiocytosis Association
- Lymphangiomatosis & Gorham's Disease Alliance
- The Pulmonary Alveolar Proteinosis Foundation
- Sjogren's Syndrome Foundation

**SO SAVE THE DATE!**

**September 22 – 25, 2016** at the Cincinnati Marriott at RiverCenter Covington, Kentucky

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