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Come and join us!



A Note from Sue Sherman, Executive Director

“Family is everything,” a simple statement, said in passing by a family member of Annette Roberts, of Kansas City, during the BLAM Golf Tournament, has remained in my thoughts. Simple and true, families form the backbone of the LAM community – rallying around the women they love to provide absolutely everything from unwavering love, emotional support and assistance with healthcare needs to organ donation and producing huge fundraisers to support the cause. While any one of these efforts might overwhelm a normal family, LAM families seem to take it all in stride. We routinely hear about husbands and friends qualifying to donate organs, parents reconfiguring homes to care for their daughters, and extended families reaching out to cousins, friends and neighbors to organize fundraising and awareness efforts. When traveling, I ask family members and friends what motivates them and the answers typically include the phrases...“because she asked...” “this is always a great event for a great cause...” and the above, “family is everything”.

Families, BIG families that grow beyond blood relations, provide hope for our mission and our future of finding a cure. The larger our reach to people who care, the more we can accomplish toward diagnosing women with LAM and sustaining research momentum. This is the drive behind our 20|20|20 Campaign, launched earlier this month.



In the simplest terms... 20|20|20 is an online template that is

[LAM Foundation](#)

[The LAM Foundation
Community](#)

[Lammies](#)
(LAM Patients Only)

[Lammie Loved Ones](#)
(Family/Friends Only)

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designed to help all of us reach more people and spread the word about LAM and our optimism about a new therapy or cure. It provides a simple means to ask for small contributions from lots of people, and inspire those who want to help with an easy way to participate.

It can be hard to ask our friends and family for money. Fundraising experts say that when someone makes a personal request, people are actually grateful for the opportunity to help. And, in many cases, when friends and families reach out to their friends, it can take pressure off those affected.

I hope you will join me in launching your family's 20|20|20 Campaign. If we find 50 families to reach out to their circles of friends and extended families, the effect will be exponential and we will easily reach our goal of increasing awareness and meeting our fundraising goal.

Don't hesitate if you are worried about a specific goal – all awareness is good and any money raised is a success. As an added bit of inspiration – watch our LAM Foundation Videos - [The LAM Foundation Overview video](#) and [Full Version](#).

I look forward to watching the LAM Community exceed expectations once again!

MIDAS Trial Update

Enrollment for the MIDAS Trial is just over 100!

In less than 3 short months, over 100 women with LAM worked through many questions and signed up for the MIDAS Trial. The first year enrollment goal was 100. It was hit the first week in June; an amazing effort, considering kickoff for the trial started March 27, 2015 at the International LAM Research Conference and LAMposium.

Thanks to the entire LAM community of strong, committed women who helped Dr. Frank McCormack and Tammy Roads through this process. Remember, our ultimate goal is 300 participants which will assure excellent data, answer important research questions and lead to new LAM studies.

Any woman diagnosed with LAM is eligible to participate. This study is primarily observational and requires a minimum of an annual visit to a LAM clinic site or to the NIH for LAM standard of

care testing. It is important that all women with LAM at least contact the study coordinator, Tammy Roads, to discuss the details of the study.

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University of Cincinnati
Department of Internal Medicine Pulmonary, Critical Care & Sleep
Medicine
Medical Science Building
231 Albert Sabin Way - Room 6053
Cincinnati, OH 45267
Phone 513-558-2148
Fax 513-558-4858
E-mail: roadst@ucmail.uc.edu

If you have already contacted Tammy Roads to sign up for the study, she will get back with you with next steps. She has the enormous task of having to speak with each individual in order to receive proper IRB approved consent.

THANK YOU Everyone!

Oxygen Users, Know Your Rights

Over the last 12 months there an increasing number of issues shared within our LAM community about access to liquid oxygen therapy. The LAM Foundation has teamed up with other rare and chronic lung disease organizations to fight for your rights to the most appropriate oxygen therapy. We are grateful to the COPD Foundation for sharing their educational/advocacy materials with us. If you are experiencing issues with your oxygen supplier, read and follow up with the following patent rights. Consider making the calls even if you are on commercial insurance. The COPD Foundation will track trends and issues with suppliers, no matter the insurance payer. It will help us build our case for better access and reimbursement.

The LAM community perspective is particularly important because we need to fight for the rights of active people who want to stay mobile – not tethered to a tank at home. Thank you to Susie Picart, Bev Jackson, Mary Harbaugh, Madeline Nolan and Laura Lentz for their input to this process and call to action.

So what should patients do?

1. Everyone using supplemental oxygen should download the [Supplemental Oxygen Guide](#).
2. When told that your liquid oxygen is being discontinued, IMMEDIATELY call the COPD Information Line and 1-800 Medicare and file a complaint. COPD will pull the complaints from the COPD Information Line at 866-316-2673 and get them fast tracked through CMS.
3. DO NOT allow the company to remove any of your liquid equipment (it is hard to get back once it is gone)
4. Contact your state and congressional reps advising them of the issue
5. Make sure your doctor has provided documentation to the oxygen company stating that Liquid Oxygen is “medically necessary and required for the patient”
6. Consider contacting the media
7. Tell everyone you know who uses liquid oxygen your situation and advise them of what to do.

LAM China



LAM China is pleased to announce they now have a full-time director, LAMBassador Eva Long. LAM China is a commonweal organization founded by Chinese LAM patients in 2008. With Eva as a full-time employee, now women in

China will receive treatment information. She will help bridge the gap between doctors and patients and provide an informational exchange between other LAM patients. Eva will guide patients to daily nursing care, as well as educate women on their diet and postoperative recovery.

LAM China aims to gain care and help from all walks of the society for the patients and their families to promote rare disease legislation, and promote social security related policies for LAM patients.

If you know of anyone in China who could use Eva's help, please direct them to LAM China at www.lamchina.org.

Blog: <http://blog.sina.com.cn/chinalam>

Twitter: <http://weibo.com/chinalam>

email: lam_china@sina.com

New LAM Liaison in Utah - Region 16

We are thrilled to welcome Lynnette Weese, our newest LAM Liaison in Utah and Colorado or Region 16. Lynnette will join Audrey Knipe in that Region to offer support to the women with LAM and program educational gatherings. Lynnette lives 40 minutes north Salt Lake City, Utah.



For years, Lynnette has been pillar of strength to women with LAM in her region, because Utah is hundreds of miles from Denver, Colorado, where Audrey lives. Lynnette, diagnosed in 2008, has volunteered her time to gather women with LAM for social events near her home town of Ogden, Utah. If you live in Utah, consider connecting with Lynnette by sending her an email note at lhweese@comcast.net.

Region 18 Gathering (OR, WA, AK)



L to R: Sharlene Dunn (Ashland, OR), Jennifer Mackey (Portland, OR), Lise Kaufmann (Seattle, WA), Shar Van Winkle (Bellingham, WA), Sid Taylor (Ashland, OR), Uta Damann (Port Townsend, WA), Keith Damann (Port Townsend, WA).

A small group of gals gathered on the evening of June 23rd at the fun and eclectic Blue Moon Tavern & Grill in Portland, OR. We discussed the MIDAS Study, and I was able to share my excitement stemming from the enthusiastic meeting I had had that morning with our new LAM Clinic Director, Dr. Matthew Drake, who will be building on the work Dr. Barker did for us in establishing the Oregon clinic. Welcome, Dr. Drake!

We also shared stories and answered LAM-related questions for one another--like all regions, there is always much wisdom and experience in the room when we gather. What a gift! The food and drinks were yummy, and the shuffleboard was a kick. Thank you,

Ladies, for yet another heartwarming get-together!

Our Regional LAM Meeting will be held on Saturday, October 17, in Tacoma, WA. Please mark your calendars now! We will be joined by our own delightful Sue Sherman and our wonderful Dr. George Pappas, and more. Watch your inbox for details. - Sharlene Dunn Brells

Region 19 TS Alliance Meeting



The Tuberous Sclerosis Alliance invited The LAM Foundation to their regional meeting in Stanford, California this past weekend.

Over 75 Tuberous Sclerosis adult and pediatric patients and their families gathered at the Li Ka Shing Conference Center at Stanford University,

where attendees were updated on TS research and had the opportunity to attend educational presentations.

LAM Liaisons from Region 19, (Northern California and Nevada) Susan Jacobs and Shellie Owens took the time out of their busy Saturday to help educate TS patients and families about Lymphangiomyomatosis. Susan and Shellie delivered good news to TS patients, including the FDA approval of Rapamune, and answered questions related to resources for adult patients with LAM, and the MIDAS Trial. Dr. Stephen Ruoss, Stanford's LAM Clinic Director, also gave a lecture on LAM and the lungs as part of the conference.

LAMposium Videos are Up!

Some of the most knowledgeable LAM scientist and clinicians in the world came to The International LAM Research Conference and LAMposium this past March.

Women with LAM family and friends had the opportunity to attend presentations from over 26 doctors, nurses, therapists and LAMMIES during LAMposium.

Now you can have access a majority of these presentations. By [clicking here](#) you can view these presentations. Also included is Dr. Frank McCormack's Friday Night Awards Banquet Address, "Twenty

Years of Progress in LAM- What's Next?"

Plus, Dr. Vera Krymskaya summarizes the Basic Science and Dr. Jeffrey Swigris summarizes the Clinical Science presentations that took place within the International LAM Research Conference.

Share these videos with the entire LAM community. There is so much to learn from the most knowledgeable LAM experts in the world.

Thank you to all of the doctors, nurses, therapists, experts, and women with LAM who gave their time to us for the weekend.

Chairs for Charity

Oregon LAM patient, Carrie DeRosia hosted her third annual "Chairs for Charity" event in the garden at The Wade Creek House on Saturday, June 6th. This event was created to spread LAM awareness while guests peruse an eclectic grouping of chairs donated by local supporters. The chairs were then purchased via silent auction.



This year over 20 painted, planted, antique and upholstered chairs were up for bid. The top bid getter was a chair inspired from the TV Series "Grimm"; it was signed by two of the actors from the show. This chair was purchased and shipped to an Indiana fan, who lives thousands of miles away from Oregon. While they won't have the final tally until the end of the month, it looks as if the Chairs for Charity event raised nearly \$2000 for The LAM Foundation.

3rd Annual BLAM Golf Tournament



The Roberts family hosted the 3rd Annual BLAM (Beat LAM) Golf Tournament in Topeka, KS on June 20, 2015. More than 100 golfers braved 99 degree heat and lots of sunshine to raise money for The LAM Foundation in honor of Annette Roberts. The golf tournament was followed by a banquet with prizes and an impressive group rendition of American Pie. Sue Sherman was honored to join the entire Roberts Family for the festivities.

Trials & Studies

NEW PROJECT IN HENSKELAB:

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 617-355-9049 if you are considering any type of surgery or biopsy. Thank you!

LAM Genome Wide Association Study (GWAS)

Dr. David Kwiatkowski

[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.

Upcoming Events

Region 16 (Colorado & Utah)

Donor Dash 5K

Sunday, July 19, 2015

Washington Park Denver, Colorado

8:00 am

The Donor Dash is a 5K run/walk to honor the lives of organ and tissue donors, celebrate the lives of organ and tissue recipients and recognize those who continue to wait for a lifesaving transplant.

Donate at <http://thelamfoundation.kintera.org/ColoradoLammies15>, registering to walk in the Donor Alliance 5k, or create your own personal fundraising page to support our LAM Foundation fundraising efforts.

-Register for the 5k walk, go to

<http://www.donoralliance.org/programs/donor-dash>

-\$35 Registration Fee helps the Donor Alliance raise funds for the Mountain States Region

-Picnic to follow race

Contact: Audrey Knipe at aknipe@denvest.com for more details.

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

KE Balloon Challenge Launch

Saturday, July 25, 2015

Chapel Hill, NC

Up for a challenge? Experience breathless.

Take the challenge and dare someone to do the same and/or give a donation to find a cure.

More details coming soon.

Contact Laura Bowers at lkbowers@email.unc.edu.

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

Regional Meeting

Saturday, August 1, 2015

12:00pm-2:30pm

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 jpica788@aol.com

South County Regional Library

5801 Rea Road

Charlotte, NC 28277

(704) 416-6600.

Parking is free with several handicapped spots available in front of the library.

Worldwide LAM Awareness Day, June 1, 2015



Worldwide LAM Awareness Day continues to be a spectacular success. Thank you to everyone in the LAM Community who took the time to spread LAM Awareness throughout your social circles. Here are just some of the Worldwide LAM Awareness highlights: June 1, 2015 was the perfect day to debut a LAM Awareness video that took 5 years of planning and rehearsing. Students from Crosby High School in Waterbury, CT helped to produce this video to support their teacher Mrs. Madeline Nolan, who was diagnosed with LAM in 1999. [Click here](#) to view this video.

Further south in Virginia, Kat Steele decided to share LAM awareness on Facebook and in her community by wearing a different LAM t-shirt each day for 5 days.

279 women with LAM, family and friends took the time to raise money for The LAM Foundation by hosting online WWLAD fundraising pages through the Foundation's website. Currently a over \$17,000 has been donated from these pages and counting.

WWLAD garnered a total online audience of 59,485,368
Worldwide LAM Awareness day was also celebrated around the

world, LAM Australia celebrated with a fundraising walk on Sunday, May 31. Their walk took place at Sydney's Centennial Parklands. Their goal for this walk is to raise \$20,000 for LAM Research. Congratulations to the LAM Community for making the 5th annual WWLAD one to remember!

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