In the editorial, "Chilean Miner's and Biomedical Research, A Modest Proposal," published in the American Journal of Respiratory Care Medicine, 2010, Bill Martin and his co-authors, patient advocates John Walsh and Sue Byrnes, argue that the approach to biomedical research should become more like that of the response to the underground crisis in Copiapo, Chile where trapped miners were dramatically rescued after 69 days. In that case, a team of experts was assembled, a strategy was developed, and the plan to solve what some had considered to be an insurmountable problem was executed in an urgent, coordinated and effective manner. One could imagine all members of the Copiapo team gathered for hundreds of hours around a large whiteboard with branching algorithms and alternative approaches, all converging on the goal of “solving the problem.” Save the miners.

The modern approach to solving human disease, in contrast, is much more incremental. To paraphrase Martin, “the engine behind scientific progress is publications, grants, commercialization and promotion”. “Solving the problem” in a deliberate and urgent manner is often considered to be beyond our reach, grandiose thinking, or worse, shameless hype. And indeed, for complex pulmonary disorders such as asthma or lung cancer, these criticisms may well apply. But not all diseases are in the same place in the discovery spectrum. For some rare diseases, clues of nature are abundant, molecular targets are known, FDA-approved drugs are available for repurposing, and patient communities are well organized, making rapid progress uniquely possible. LAM was in exactly this position in the early 2000s, yet the responsibility for capitalizing on the opportunity was left largely to the affected. I agree with Martin, Byrnes and Walsh that when these opportunities arise, the medical and research communities should rally around, get out the whiteboard, and dare to solve the problem. I am not proposing that translational research should take precedence over basic or discovery research into fundamental biological processes, after all, where would LAM and Tuberous Sclerosis be without the spectacular genetic and fruit fly breakthroughs in the 90’s? I am only saying that when research findings align in a manner that suggest a palpable opportunity to alleviate human suffering, we in the biomedical research community have a solemn obligation to pursue it, no matter how rare the disease.

Examples of rare lung disease studies that I believe have met that benchmark are trials of the new anti-fibrotic therapies in Hermansky-Pudlak syndrome, of inhaled GM-CSF in pulmonary alveolar proteinosis, and BRAF inhibitors in refractory pulmonary Langerhans cell histiocytosis. For LAM, refining the approach to use of mTOR inhibitors is a high priority, especially determining if early low dose, long term sirolimus prevents progression to more advanced lung disease.

This is a long-winded introduction to a proposal being considered by our Board of Directors for the next thematic research conference for LAM, affectionately called, ‘Patient Benefit’. Like the highly successful LAM Biomarker Innovation Summit last November, this meeting will bring together the brightest minds in LAM science; this time to brainstorm about projects that have the potential to produce patient benefit in less than five years. Examples of proposals that could emerge include development of VEGF-D as a tool for personalized sirolimus dosing, pilot trials of safe and available therapies that are well supported by findings from the
In previous editions of Journeys and in my presentations, I often talk about the many wonderful qualities of the LAM community. How, by working together, you have helped improve the lives of women living with LAM and provided answers to many of the medical and scientific questions presented by the disease. When speaking of patients and families as well as scientists and clinicians, I have used words like resilience, self-sacrifice, ingenuity, perseverance, curiosity, collaboration, compassion and synergy. If you believe in the idea that, "you get what you give," the LAM community could be described as perpetual circle: giving and receiving and giving again. The following are a few examples of how we, as a rare disease community, are investing in projects and people now that will lead to the future we desire – one filled with better treatments, diagnostics and ultimately, a cure.

Beginning this fall, the Foundation is launching several technology upgrades and projects. Historically, the Foundation has kept up-to-date with new software, using it to improve efficiencies while keeping a personal and responsive connection with our community. In 2015, we find that it is time to step forward again, and catch up with the constantly advancing tech world. The first phase, beginning this fall, will include a transition to a new cloud-based contact database. Through a generous program for nonprofits, The LAM Foundation will join 26,000 other nonprofits using Salesforce.com, the world’s largest cloud-based CRM platform. With this software we will have access to the most current technology available, giving us a single and secure means of communicating and tracking our activities -- including important conversations and information shared by patients, families, friends, donors, clinicians, investigators, government and industry. Salesforce Foundation provides the first 10 licenses to nonprofits at no cost, making our transition to Salesforce affordable.

The conference will include a Gala-like event, called the ‘Patient Benefit’ and will ideally include a call for ‘Patient Benefit’ grant applications, like Biomarker Innovation Grants (BIG) of the LAM Biomarker Innovation Summit. To geographically distribute access to LAM events, a California venue is under discussion, perhaps for 2017. This program will complement our annual grant program, and will not affect the funding or the broader scientific focus that is offered through that mechanism. We hope that families with LAM will help fundraise around this concept, and generate a war chest that scientists can use to translate their discoveries to ‘Patient Benefit’ in the shortest time possible.

The Future is not Something We Enter, it is Something We Create

BY SUSAN E. SHERMAN, EXECUTIVE DIRECTOR

The new Salesforce database will integrate with a LAM Foundation website upgrade, to be launched in 2016. The new site will provide updated information for everyone seeking to learn more about LAM. It will offer resources for new patients, clinicians and for those looking to take action by becoming an advocate, organizing educational events or fundraising. The new site will also provide secure and searchable discussion forums for clinicians and patients – helping to share case studies and Q&A sessions. Both the new database and the website will be mobile-device friendly, again improving our connectivity with everyone around the world. Together, these two projects will give us more power to connect women with LAM, inspire donors and facilitate better treatment, diagnostics and communication globally.

With regard to LAM research, we continue to innovate as we actively fund the most promising new investigators and research projects. This November, the Foundation will sponsor the first-ever, face to face meeting of our Scientific Advisory Board (SAB) for our annual Grant Study Section. As in every year since 1996, LAM scientists submitted their research proposals for projects that they believe will answer the next important questions about LAM.

SAB reviewers volunteer their time to read and discuss all 17 applications, offering their expert opinion about which ones should receive funding. Their recommendations will be submitted to The LAM Foundation Board of Directors to approve up to $350,000 in research funding. This year these extremely busy individuals have agreed to give us a weekend of their time for the study section and to participate in a visioning discussion for the overall grant program.

In conclusion I will say again that all of our efforts, whether they are related to technology, research, fundraising or communications, are dependent upon the compassion and generosity of everyone attached to the LAM community. By believing in a better future and taking action, we have the power to create short and long term successes that are more than dreams.
A Generous Gift Helps to Fund LAM Research

In May, Elizabeth Henske, MD, LAM Clinic Director for the Center for LAM Research and Clinical Care at Brigham and Women’s Hospital (BWH) in Boston, MA, received a $5 million dollar gift from Gregg and Molly Engles in honor of their 3 year-old daughter. With this gift, the Lucy Engles TSC/LAM Medical Research Program was started at BWH.

According to Dr. Henske, this generous gift will allow her and her colleagues at the Lung Research Center to use the strong foundation of knowledge about the functions of the Tuberous Sclerosis Complex (TSC) gene and develop more effective treatments, including treatments to eliminate LAM. Currently, there are no diagnostic tools to determine if a LAM patient’s disease progression will be slow or if progression will happen quickly. Dr. Henske and her team are working to develop biomarkers that may help determine the rate of progression for each individual LAM patient.

“We want to develop better LAM biomarkers to understand in which women the disease will become severe and in which women it will remain mild,” said Henske. “These biomarkers will allow us to do faster, more efficient clinical trials.”

Dr. Henske and her team are optimistic about the opportunities the new gift from the Engles family will provide to their research and to patients with LAM and TSC.

Update: Multicenter International Durability and Safety of Sirolimus on LAM Trial (MIDAS)

Rare Lung Disease (RLD) Clinics (also referred to as LAM Clinics) across the United States are preparing to participate in the Multicenter International Durability and Safety of Sirolimus (MIDAS) in LAM Trial.

Next year, women who enrolled in the MIDAS Trial through the Cincinnati Children’s Hospital Medical Center will have the opportunity to visit any of the 30 RLD Clinics near their home for their actual onsite visit. If you signed up for MIDAS earlier this year, you will be contacted in the coming months about next steps.

Participation in the MIDAS Study requires at least one visit per year to an RLD Clinic to receive standard treatment and testing for LAM. Standard of care exams at an RLD Clinic involve physical exams, blood and urine samples, and breathing tests. The study component of MIDAS involves a completion of questionnaires, and completion of an at home diary about any side effects of mTOR therapy.

The goal of the study is to refine the treatment of patients with LAM by determining if long term suppressive therapy with sirolimus or everolimus is safe and can prevent progression to more advanced stages of LAM.

This trial is supported by the efforts of women with LAM everywhere. We gratefully acknowledge all of the women who have volunteered to support clinical trials for LAM in the past. These women have advanced the treatment of this disease and the continued hope for a cure.

If you would like to sign up for the MIDAS Trial and need additional information, please contact the MIDAS Clinical Trial Manager, Tammy Roads.

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I don’t need to tell you what it’s like to live with LAM (or live with someone affected by LAM)—you’re the experts on that topic. Drawing on that expertise has created the underpinnings of my research program: go to the experts to try to fully understand how a chronic respiratory disease affects patients (and their loved ones). It is only through such understanding that we—as clinicians and researchers—are able to try to devise strategies to lessen the negative effects these diseases have on how patients feel and how they function.

How we human beings feel (physically and mentally), how we function (physically, in our homes and the swath of the world that we frequently “use”) and how we interact with the environment (people and places) within which, or with whom, we interact, to a great extent, determines our quality of life. My research mission is to understand how chronic respiratory diseases impact patients’ quality of life, to devise ways to accurately measure how patients feel and function and what their quality of life is, so that, ultimately, we can find ways to improve them.

As a patient with LAM, FEV1 is also important, right? We don’t want to see the FEV1 go down; and we’d love it if a drug (or other intervention) in our armamentarium made the FEV1 go up. But I’d argue such changes in FEV1 are really most important if they translate into something beneficial in the patient-centered realm…like fewer or less-severe symptoms…or improved physical functioning…the ability to be more active with kids or partners. Those patient-centered things are what I’m most interested in.

That, in a nutshell, is how ATAQ-LAM (A Tool to Assess Quality of life in LAM) was born. ATAQ-LAM is a questionnaire developed to assess quality of life, and those domains that are important for determining quality of life in patients with LAM. For those of you who don’t know, we developed ATAQ-LAM by conducting focus groups and interviews with several of women with LAM (and we thank you for your generosity and willingness to share your time and feelings with us). We asked you about the things that mattered most to you (in terms of LAM and how living with it affects your lives) and then formulated questions around them. My hope is that we can use ATAQ-LAM in research moving forward to determine if therapies on the horizon alter things—really important things—other than FEV1.

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that drove Dr. Yu to take her current position at the University of Cincinnati. She’s excited to work under Frank McCormack, MD because he understands both the scientific side of the research and the clinical aspects of the disease. She has also had incredible interactions with resources outside of her lab. She participated in a Rare Lung Disease Consortium Summit and has direct access to the Tuberous Sclerosis research lab at Cincinnati Children’s Hospital Medical Center, which is within walking distance. She’s also thinks it’s a huge advantage for her team to have such direct access with The LAM Foundation. “I think we can get so many things done with all the support and experience that is right here in Cincinnati. It is a true center for LAM research and success.”

Dr. Yu and her family are enjoying their time in Cincinnati. “It really is a nice city. I like Cincinnati. I want to learn more about it.” The city is a bit less congested than in Boston and she really appreciates the development that is happening in downtown Cincinnati.

One thing Dr. Yu wants LAM patients to know is that she is 100% dedicated to continuing her research to find more important discoveries about LAM. “Jane is here and Jane is your LAM sister! And I’m so glad to be here! It is a big life change for me and my family, but it’s worth it to provide hope for LAM patients and their families. And that’s the mission of the whole team. Everybody. I’m just so happy to be in Cincinnati. It’s special here. And it will always be special in my heart.”

A Session on LAM Featured at the Lymphatics Gordon Research Conference

BY GWENDALYN J. RANDOLPH, PHD, PROFESSOR, DEPT OF PATHOLOGY & IMMUNOLOGY HEAD, DIVISION OF IMMUNOBIOLOGY, WASHINGTON UNIVERSITY SCHOOL OF MEDICINE

The lymphatic vasculature participates critically in removal of fluid, molecules, and cells from all organs of the body. Lymphatic endothelial cells line all lymphatic vessels. A subset of these vessels are surrounded by specialized smooth muscle cells that confer contractile properties to the lymphatic system in order keep lymph moving. Both lymphatic endothelial cells and smooth muscle cells figure centrally in LAM, so a conference that allows cross-talk between physicians and scientists working on LAM and those carrying out fundamental research on the lymphatic vasculature will be mutually beneficial.

In 2004, the Gordon Research Conference hosted the first international meeting devoted to lymphatics. This meeting has played a key role in advancing the state of knowledge in the growing area of lymphatic-related research.

In 2016, the Lymphatics GRC will feature an entire session on LAM. Three prominent investigators will present the latest research related to LAM, including Frank McCormack, MD, from the University of Cincinnati (Lymphatic manifestations of lymphangioleiomyomatosis), Lisa Henske, MD, from Harvard University (Role of Cellular Metabolism and Autophagy in LAM: from pathogenesis to targeted therapy), and Kuniaki Seyama, MD from Juntendo University (Isolation and characterization of LAM cells). The entire conference will be filled with speakers who focus on lymphatic endothelial or smooth muscle biology, and many of the signaling pathways relevant to LAM will be discussed in other contexts during the meeting. The conference welcomes applications and participation from members throughout the LAM community.

Applications to attend must be made online at: https://www.grc.org/programs.aspx?id=13268

Event Details:
Basic Science and Disease Mechanisms in Multiple Organ Systems
March 20-25, 2016 Ventura Beach Marriott, Ventura, California
Applications for this meeting must be submitted by February 21, 2016
For additional questions please contact:
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Definition and Mechanism of Pneumothorax

Pneumothorax is defined as the presence of air within the pleural space, the space between the outer surface of the lung (lined by visceral pleura) and the rib cage (lined by parietal pleura on the inner surface). Normally, the pleural space contains a small amount of fluid and no air.

Most common mechanism of pneumothorax is leakage of air from the lung into the pleural space. In some situations, air enters the pleural space from the gastrointestinal tract such as in esophageal rupture resulting from severe vomiting. Air may also be introduced from the outside as in penetrating traumatic injuries or surgical procedures. Rarely, air can form within the pleural space from gas-producing infections.

Spontaneous (not associated with trauma or invasive medical procedures) pneumothorax can occur in patients with or without identifiable underlying lung disease, e.g., LAM or emphysema. In the presence of an underlying lung disease the term “secondary” spontaneous pneumothorax is used in contrast to “primary” spontaneous pneumothorax in those with normal-appearing lungs. This distinction has management implications since those with underlying lung disease are at higher risk of pneumothorax recurrence compared to those without lung disease. Thus, more aggressive measures are warranted in preventing recurrence in those with secondary spontaneous pneumothorax.

Effects of Pneumothorax

The main symptoms of pneumothorax are shortness of breath and chest pain which can be pleuritic (sharp pain that worsens during breathing; pleurisy-like). The pain may radiate to the shoulder on the side of the pneumothorax. Some patients may also experience a cough.

The severity of the symptoms will depend on the size of the pneumothorax and the patient’s health status, particularly in regard to the lung and heart. With a small pneumothorax some patients may experience minimal or no symptoms.

Although the air leak causing pneumothorax is commonly transient with spontaneous closure of the leak, air leak can sometimes be persistent leading to gradual enlargement of the pneumothorax and increasing breathing difficulties. Rarely, continued air leak may cause a medical emergency termed “tension pneumothorax” wherein a unidirectional flow of air (check-valve mechanism) into the pleural space leads to a large pneumothorax with buildup of air pressure in the pleural space. This results in a shift of the heart and associated blood vessels (the mediastinum) to the opposite side which can be demonstrated on chest radiography. The patient will experience increasing shortness of breath and heart rate along with decreasing blood pressure. Tension pneumothorax requires immediate medical attention with insertion of a needle or chest tube into the pleural space to release the pressurized air buildup.

Management of Pneumothorax in LAM

Pneumothorax is estimated to occur in 60% to 80% of patients with LAM. This high risk is related to the presence of diffuse cystic changes in the lung that characterize LAM. Some of these cysts are located just under the outer surface of the lung (visceral pleura) where they can rupture to cause air leakage from the lung into the pleural space. Once a pneumothorax occurs in a patient with LAM (secondary spontaneous pneumothorax) the risk of future recurrence remains similarly high. Thus, the management of pneumothorax in patients with LAM needs to take into account not only the treatment of the current episode of pneumothorax but also prevention of possible recurrence.

Management of Pneumothorax

In general, the initial management of pneumothorax will vary depending on the size of the pneumothorax, associated symptoms, available expertise/resources, and patient preferences. The management options include observation alone (no intervention), simple needle aspiration, and chest tube insertion. Most patients with LAM who experience a symptomatic episode of pneumothorax undergo chest tube insertion and drainage over the course of several days in hospital. Sometimes chest tube drainage of pneumothorax can be managed as an outpatient with the use of a Heimlich valve (one-way valve attached to the external end of the chest tube). Some patients with a small pneumothorax or no symptoms may choose to be managed conservatively with observation alone.

For patients treated with chest tube drainage, additional therapeutic measures will need to be considered depending on whether the air leak is continuing and to prevent recurrent pneumothorax. Continuing air leak (more than 5 days or so) generally requires a referral for surgical intervention which typically includes oversewing the leaking site and pleurodesis (see below). Most surgical procedures for the management of pneumothorax are performed by video-assisted thoracoscopic surgery (VATS)
which entails smaller surgical incisions compared to traditional thoracotomy. Expertise of a thoracic surgeon rather than a general surgeon should be sought for these types of procedures.

Pleurodesis is a procedure to adhere the two pleural surfaces, obliterating the pleural space. It is usually performed surgically by mechanical abrasion of the pleural surfaces, pleurectomy (partial removal of the pleura), or instillation of a sclerosing agent. Talc is the most commonly used sclerosing agent and is instilled in the form of a slurry or poudrage (sprayed into the pleural space in the powder form). For patients who are considered to be at high risk for surgery, talc slurry can be instilled into the pleural space via the chest tube to achieve pleurodesis. Pleurodesis reduces the risk of recurrent pneumothorax but does not completely eliminate this possibility.

Since the rate of recurrent pneumothorax is high in patients with secondary spontaneous pneumothorax including those with LAM, pleurodesis is generally advised with the first episode of pneumothorax rather than second or third episode. Assuming relevant expertise and resources to perform a pleurodesis are available, the decision as to whether to move ahead with the procedure or not should take into account the downsides including risks, costs, potential implications for future lung transplant surgery for those who may experience continued progression of LAM, and patient preferences.

A Contraception Conversation: The Benefits and Drawbacks of Available Therapies

Women in the LAM community continue to have questions on the varied and evolving subject of contraception and how hormones and menopause play a role in choosing contraceptive methods. Women’s health specialist Lisa Larkin, MD, FACP, NCMP, IF, Associate Professor Obstetrics and Gynecology Director, Division Midlife Women’s Health and Primary Care Director, UC Health Women’s Center and Endocrinologist Stephen Hammes, MD, PhD, Chief of the Division of Endocrinology and Metabolism at University of Rochester Medical Center, provide their perspectives on contraceptive options for women with LAM.

PATIENT QUESTION: I am a 30 year old woman with LAM. I am newly married and need contraception, but I understand there are concerns about hormones and LAM progression. What are my options? Can I take birth control pills?

Oral contraceptive pills (OCPs): Estrogen and Progestin

Dr. Larkin: Most oral contraceptive pills contain an estrogen and a progestin in various doses. Ethinyl estradiol, a synthetic estrogen is combined with one of several synthetic progestins. They are highly effective when taken daily, without missing doses. They work to prevent pregnancy by suppressing ovulation. In the US they are the most frequently prescribed form of birth control. In most women they are well tolerated. Because there is data to suggest that hormones, and estrogen in particular, may be associated with LAM disease progression, LAM patients are often instructed not to use oral contraceptives.

Dr. Hammes: As Dr. Larkin mentioned, oral contraceptive pills (OCPs) contain various forms of estrogen which, based on what we know at this time, is contraindicated in LAM. Since we don’t know enough about the potency of these synthetic estrogens in OCPs, but there is a great deal of evidence to suggest that any estrogen can be detrimental in LAM, these would be my LAST choice for contraception. There are many other excellent methods that do not contain estrogen, so, in my opinion, OCPs are not necessary and should be avoided in LAM.
Progestin-only drugs (Depo-Provera injection or oral progestin only birth control)

**Dr. Larkin:** Progestin-only medications, either as an injection every 3 months in the form of Depo Provera, or as a daily pill, are effective for contraception. Although there is a somewhat clear association of estrogen and disease progression in LAM, the data is much less clear with progesterone.

**Dr. Hammes:** The fact that there is no estrogen makes progestin only medications a better option in LAM patients compared to combined oral contraception. Progestins will suppress ovarian androgen production and ovarian estrogen production, which, as mentioned previously, might actually be good for LAM. However, the problem is that we don’t really know if progesterone is good or bad for LAM. Most historical evidence suggests that it is neutral, but we don’t know for sure.

**Dr. Larkin:** I have almost completely stopped using Depo Provera for contraception in women because of significant weight gain, and bone health concerns. In my opinion there are better options for contraception. The weight gain, bone loss and the nagging question about progesterone and LAM progression makes Depo Provera in my mind another last choice recommendation for LAM women. The progestin only pills have less weight gain and would be my choice over Depo Provera, but would still fall low on my list.

**IUDs**

**Dr. Larkin:** IUD’s, or intrauterine devices, are an excellent choice for contraception for almost every woman, including both women who have not had children and women who have had children. They are used widely worldwide and are in fact the most common form of contraception in Europe and Asia. In specific populations of women, such as women where there is a concern about hormones (LAM patients and breast cancer patients) they are the preferred choice.

IUD’s are considered to be a LARC- a form of Long Acting Reversible Contraception. There are several types of IUD’s available. All are highly effective. Mirena and Skyla IUD’s contain small amounts of progesterone in the tips of the device. Skyla has less progesterone than Mirena. Mirena lasts for 5 years, while Skyla lasts for 3. Paraguard IUD’s are completely non hormonal and last 10 years.

As mentioned, Mirena and Skyla contain a small amount of progesterone. For most women, this small amount of progesterone is well tolerated and over time women’s menses will often go away completely, or at the very least menstrual bleeding will become much lighter. In LAM women, the progesterone is a theoretical concern, even though it is low dose and works mostly locally in the uterine cavity, Skyla has less than Mirena, but with both IUD’s serum levels of progesterone do increase slightly. Given the uncertain association of progesterone and LAM, my preference would be to use a non-hormonal Paraguard IUD as first line for contraception in LAM.

**GnRH agonists**

**Dr. Hammes:** An example of a GnRH agonist would be Lupron. Lupron is administered as a once a month shot. GnRH agonists suppress ovarian estrogen and progesterone production and women’s hormone levels drop into the post-menopausal range. Again, loss of estrogen (and possibly progesterone) is likely beneficial for LAM patients. The downside is that GnRH agonists cause menopause associated symptoms such as hot flashes, night sweats, sexual issues and bone loss. However, we have many terrific medications to control bone density, and there are other options for controlling hot flashes that work very well in many patients. For a LAM patient in her late 40’s, close to menopause, these agents might be a good option. For younger women the side effects may outweigh the benefits.

**Dr. Larkin:** I would only consider GnRH agonists in a younger (i.e. less than 45) premenopausal woman simply for contraception as a last resort. It is well established that early menopause results in earlier cardiovascular disease, negatively impacts cognition and bones and all cause mortality is increased. In my opinion, GnRH agonists should only be considered in young rapidly progressing LAM patients as a potential treatment for their disease and not simply for contraception. As I said earlier, I feel IUD’s are the best option and should be first line for contraception for LAM patients.
LAM and TSC Diagnostic Codes are Changing

The World Health Organization has published the 10th revision of the medical classification list of the International Statistical Classification of Diseases and Related Health Problems. The start date to use the new codes began Thursday, October 1, 2015.

Lymphangioleiomyomatosis ICD 10 Code - J84.81
Tuberous Sclerosis Complex ICD 10 Code - Q85.1

The LAM Foundation has Emergency Medicine Quick Facts for Lymphangioleiomyomatosis cards printed with these codes on them. If you would like updated cards to share with your physicians, give us a call at 877.CURE.LAM (877.287.3526) send us an email at info@thelamfoundation.org.

Rare Lung Disease Partners to Join Us at LAMposium in 2016

We are less than a year away from gathering at the 2016 International LAM Research Conference, LAMposium & Breath of Hope Gala. Planning is underway for the 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, including a title change for the conference to Rare Lung Disease Conference, LAMposium & Breath of Hope Gala. 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

We welcome LAM Clinic Directors from all 54 of the Rare Lung Disease Clinics across the United States and around the world to join us in September 22-25, 2016. The goal is to inspire scientists and clinicians as they connect with patients and each other to find better treatments, diagnosis and ultimately a cure for all rare lung diseases.

JOIN US!

For the 2016 Rare Lung Disease Research Conference, LAMposium & Breath of Hope Gala
at the Cincinnati Marriott at RiverCenter Covington, Kentucky
September 22–25, 2016
For the first time ever, an anonymous donor has offered a DOLLAR FOR DOLLAR MATCH, up to $10,000, to boost the LAM Family Network (LFN) Fund. This means that $20,000 will be available to bring more women to the 2016 LAMposium in Cincinnati, Ohio.

The LAM Family Network (LFN) makes it possible for women with LAM to travel each year to the three-day Rare Lung Disease Conference, LAMposium and Breath of Hope Gala.

Last March, $11,000 in travel grants were awarded to 21 women with LAM who could not have traveled to Chicago without support. Grants are awarded based on financial need and previous conference attendance.

As of October, we are at 90% of our $10,000 goal. Consider donating to the LAM Family Network Fund. Your gift of $50, $100, $250 will be doubled and will assist in:

- Supporting women with LAM in their search for knowledge;
- Providing them access to expert clinical advice;
- Expanding awareness of clinical trial opportunities;
- Connecting women with LAM to each other.

You can help bring more women to LAMposium in 2016! You can give two different ways:

1. Online at www.thelamfoundation.org by clicking on the DONATE NOW button and choosing LAM Family Network in the drop down menu.
2. Mail a check to The LAM Foundation and indicate LFN MATCH. Call or email us at info@thelamfoundation.org or 877.CURE.LAM (877.287.3526).

Every gift – no matter the size – will help a woman with LAM to attend LAMposium.

Our friends, Dana Garrett and Dave Butz from Trailhead Films along with LAM Foundation Board Member, Eden Pontz, produced a fabulous video for The LAM Foundation while they attended the 2015 International LAM Research Conference, LAMposium and Breath of Hope Gala in Chicago. The Foundation is pleased to share this video; you can view it from the front page of The Foundation’s website, www.thelamfoundation.org.

Please share this video with your family, friends or a woman you know who is diagnosed with LAM. We are certain, after you had a moment to view the video, you will be compelled to join us at the only international conference where expert LAM researchers and patients gather to learn about advances in LAM research and to be inspired by each other.
March 2014

Three months after my initial diagnosis, I attended my first LAMposium in hopes of gaining better knowledge of LAM and connecting with others affected by it. Although I had a remarkable support system from family and friends, I was looking for a reciprocal support system that consisted of those who knew exactly what I was going through.

The LAMposium experience gave me something tangible. It was interactive on so many levels, and I had the opportunity to share it with individuals who were both new and experienced with LAM. My husband and I gained knowledge at the seminars, connected with other LAM patients and their families, and I finally felt like I “fit in.” As I spoke to other women diagnosed with LAM, I could see that, like me, some gasped for air between words. It was gratifying to be surrounded by those who knew exactly how I felt; I was not alone.

I was intrigued by the seminars being offered and wanted to learn more about lung collapses, pregnancies, oxygen, Rapamune, lung transplants, fundraisers…there was so much! Not only did I explore physical factors, but emotional factors as well. In addition, I was astounded to see and have access to physicians sharing their time and knowledge while discussing topics of interest with patients.

Above all, I realized how therapeutic it was to connect with those who were fighting the same battle, and to see first-hand The LAM Foundation, physicians and scientists who were dedicating time and efforts to our cause. This experience gave me so much optimism, and motivated me to take an active role in advocating for LAM.

March 2015, I returned to LAMposium with a fire in my belly! I was armed with more knowledge about LAM and new experiences. Only 7 months after initial diagnosis, my mild case of LAM had quickly progressed to a moderate-to-severe case. I had experienced 2 lung collapses, a pleurodesis, multiple chest tubes, began supplemental oxygen, taking Sirolimus, and pre-lung transplant consultations. I raised awareness in my community via the Movie Madness 5/10K to benefit The LAM Foundation, which made over $6,000. This time, I was not only eager to learn about new research findings and breakthroughs, I also wanted share my experiences with newly diagnosed patients and my optimism with everyone.

Our theme was “Stronger Together” and we celebrated The LAM Foundation’s 20th anniversary. LAMposium was a true example of solidarity and it showcased The LAM Foundation’s achievements over 20 years. The Awards Banquet was proof of all collaborative efforts; funds raised for and by women with LAM were awarded as grants to scientists for scientific advancements. The Breath of Hope Gala featured two decades of The LAM Foundation’s accomplishments with Brian Kleps discussing the early years. In honor of his late wife Dawn, a LAM patient, Brian joined Sue Byrnes when there was no treatment for LAM or much understanding of the disease. Shelby and her husband Zack Garner discussed the second decade, when their lives were touched by LAM. During this time, the LAM community began treatment trials and a drug therapy was obtained. I was honored to speak about the LAM community’s future and capitalize on the momentum that will lead to better treatment and a cure.

In retrospect, I not only gained knowledge from attending LAMposium, I gained a new family, a sense of empowerment to advocate for myself and others, and hope for a future that will cease to consist of daily accommodations for LAM in my life. LAMposium has been and will continue to be an annual validation of the lives impacted by The LAM Foundation and the hope it renders.
LAM Education and Regional Meetings Across the Country

This past year, LAM education was a top priority for the Foundation and LAM community. Our LAM Liaisons were extremely busy coordinating regional educational meetings and gathering women with LAM and families to connect and share experiences. Here is a short list of how women across the country are sharing their journey.

- In January, The American Thoracic Society, in partnership with The LAM Foundation and the COPD Foundation, sponsored a U.S. Congressional Briefing on Women's Lung Health: Advances and Challenges, in Washington, DC. Kat Steele courageously shared her LAM journey in front of a packed room of congressional staff. The panel also included the head of the NHLBI, Gary Gibbons, MD.

- In February, Region 13 (MO, IA, NE, KS) LAM Liaison, Marla Hamlin, created an awareness opportunity by speaking at a Respiratory Therapy Conference in St. Louis, MO. She has been going to a respiratory therapist for 16 years and is passionate about the importance of staying active and educating more clinicians about LAM.

- Stanford University Medical Center hosted the Region 19 (Northern California and Northern Nevada) LAM Support Group Meetings in April and October. LAM Clinic Director, Dr. Stephen Ruoss and Susan Jacobs, Nurse Coordinator at Stanford’s Interstitial Lung Disease (ILD) Program both presented.

- In April, Region 4 (Eastern PA, NJ) Co-Liaisons, Patti Bebien-Aronoff and Alanna Nelson, met with New Jersey LAMMIES and friends for Dim Sum in Middletown, New Jersey.

- In May, a Region 16 (CO, UT) meeting was held in downtown Denver, CO, during the American Thoracic Society’s annual conference. LAM families plus Foundation staff members Sue Sherman, Judy Sheridan and Kerri Morgan joined Drs. Joel Moss and Frank McCormack who presented on LAM research, clinical trials as well as treatment and diagnostic updates.

- A small group of gals from Region 18 (AK, OR, and WA) gathered on a spring evening in June at the eclectic Blue Moon Tavern & Grill in Portland, OR. They discussed the MIDAS Study and the news that new LAM Clinic Director, Dr. Matthew Drake, will be building on the work of Dr. Barker who established the Oregon LAM Clinic.

- The Tuberous Sclerosis Alliance invited The LAM Foundation to their regional meeting in Stanford, CA, in June. LAM Liaisons from Region 19, (Northern CA, NV) Susan Jacobs, RN and Shellie Owens, took time out of their busy Saturday to help educate TSC patients and families about LAM.

- The Region 10 (IL) meeting was held in June at Loyola University Stritch School of Medicine. LAM Clinic Director, Dr. Dan Dilling along with Loyola dietician, Rachael Dunn presented to everyone who attended.

- Region 11, (MI) met in July at a beautiful conference room on the campus of University of Michigan at Mott Children’s Hospital. LAM Clinic Director, Dr. MeiLan Han gave an overview of the basic and clinical science discussed at LAMposium. LAM Foundation Executive Director, Sue Sherman, joined the meeting and Julie Woodward, MSW provided a workshop on breathing, relaxation, and mindfulness.

- Also in July, Region 20 (Southern CA, NV, AZ), held their meeting at the Keck School of Medicine at USC in Los Angeles. USC LAM Clinic Director, Dr. Richard Lubman, gave an informative presentation on LAM.

CONTINUES ON NEXT PAGE ›
The LAM Foundation is thrilled to welcome Anne McKenna as the new Patient Services and Education Manager. Anne moved from Buffalo, New York to Cincinnati, Ohio to be a part of the Foundation’s staff.

“We are thrilled to welcome Anne to The LAM Foundation as Patient Services Manager,” 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. We feel she is a terrific advocate for LAM patients and clinicians.”

If you have attended LAMposium in the past, you may have run into Anne or recognize her name. She has been to five of them, attending with her parents and her sister Katie McKenna who was diagnosed with LAM in 2004.

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

SEVERAL MORE MEETINGS ARE PLANNED FOR THE LAST PART OF THE YEAR. MANY THANKS TO EVERYONE WHO MADE THESE EVENTS A SUCCESS, FROM ORGANIZERS, TO PRESENTERS TO ATTENDEES. WE ARE STRONGER TOGETHER!
Kate Slattery joins The LAM Foundation’s Board of Directors

Kate Slattery joined The LAM Foundation’s Board of Directors in August, 2015. Kate is a fundraising professional and is currently the Annual Giving Programs Coordinator at the Barnes Foundation in Philadelphia, PA. Having built a career as a development professional, Kate is passionate about helping nonprofits cultivate strong and giving communities through relationship building and excellent communications. Kate’s experience includes donor relations, capital campaigns, stewardship and new program development. She has cultivated her fundraising expertise in the greater Philadelphia area, having worked for the Philadelphia Orchestra and The Franklin Institute prior to the Barnes Foundation. You may recognize Kate as a competitive ice dancer who toured with the International Team for US Figure Skating for 3 years and for the US national team for 6 years.

Kate is keenly interested in contributing her knowledge, experience and skills to The LAM Foundation Board of Directors because her sister-in-law, Andrea Slattery has LAM. Kate has been a key organizer in planning a LAM fundraiser connected to the Million Dollar Bike Ride, raising more than $70,000 in 2015.

The LAM Foundation Board of Directors is pleased to welcome Kate to the LAM community!

My 10 Year Journey with LAM

BY MICHELE HANSEN

My name is Michele Hansen and I live in Anchorage, AK. Almost 10 years ago I ended up in the ER with shortness of breath and chest pain. You know the rest of the story… I was fortunate to be diagnosed quickly because the pulmonologist I saw knew about LAM. He was seeing the only other LAM patient in Anchorage at the time.

As I reflect, the one thing that has stuck with me was the thought that I had 10 years left to live. That is the one number I never forgot. Experiencing my 10 year anniversary is an empowering place to be. Ten years ago it was tough to look ahead to the future. Many questions clouded my thoughts. Why contribute to my retirement? Will I even make it to that age? What will that look like? How debilitated will I be? Could I still fly? My job demanded that I fly on a weekly basis. Would I still be married?

I revised my bucket list, removed climbing Kilimanjaro and skiing the Haute Route in the Swiss Alps. Now I joke that they looked good on the list, and I did not have to do them. Seems overwhelming when I look back, but very real thoughts at the time.

One piece of advice my pulmonologist gave me was, “don’t let this disease define who you are”. I have used those words as my guide. My inner circle of family and friends know my circumstance and while that circle has broadened over the years, I am still Michele and LAM is a piece of who I am.

Living in Alaska, we are already somewhat isolated from the rest of the world, but that doesn’t stop me from having connections with other women with LAM. I have been to a couple of LAMposiums. I have traveled to the NIH a number of times, first to contribute to the research and second to gain a better understanding of my situation. The NIH has been of huge value to me. Even though I ran away from the hospital that first night, I returned the next morning (much to the surprise of staff!). I have come to appreciate these visits. There are a few of us living with LAM here in Alaska and we connect on an informal basis to support each other.

This year, as a celebration of my 10 years, I felt the need to do more. I decided to re-connect with my first roommate at the NIH, who is an amazing athlete and who was participating in the Million Dollar Bike Ride in Philadelphia. So I committed to raising funds and to ride with her. What an inspiring event! While both of us have put our days of being competitive athletes behind us, the ride created new memories. Every dollar raised by The LAM Foundation is matched by UPENN. I fortunately work for a company that has a matching grant program and in June they doubled the match. So for every dollar I contributed they matched two dollars. This company has a volunteer program; if I volunteer 25 hours, they will send The LAM Foundation $500. The Foundation has found a way for me to do this without having to leave Alaska.

Now that my journey is 10 years in, I am looking forward to the next 10 and to finding more ways to contribute. I encourage everyone in the LAM community to stay connected. Living in Alaska sounds remote, but it has not stopped me from being active and giving back to the many people and organizations that have help me along the way. Thanks to The LAM Foundation for being there for me, especially in those early days of my journey.
The 20|20|20 Campaign is Gaining Momentum

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

In honor of The LAM Foundation’s 20th Anniversary, consider giving $20 one time, or 20 times by donating on line or sending your donation to The LAM Foundation. Or consider inspiring 20 friends to give $20, 20 times – When you break it down, that’s 65¢ a day.

Or consider supporting one of the many campaigns on our website with these simple steps:

1. Click on the 20|20|20 Campaign logo on the front of the Foundation’s website
2. Click on the yellow “Sponsor a 20|20|20 Campaign” button
3. Type in the first or last name of the person you would like to sponsor then click “Search”
4. Find the name you would like to sponsor in the dropdown list
5. Click on the name
6. Enter your donation amount

Here are just a few of those participating in the 20|20|20 Campaign

**Patricia Bebien-Aronoff**

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.

**Zack and Shelby Garner**

Your donation to our campaign, no matter the size, means so much to our family and to other LAM patients and their families. Together we CAN find a cure!

**Beverly Jackson**

Participation in the 20|20|20 Campaign is my way of giving back to The LAM Foundation. I am so grateful to The LAM Foundation, Dr. McCormack, and LAM researchers for bringing us Rapamune as a treatment drug. It has been a miracle drug for me. I want to help make the next step happen. Not just slow the progression but kill the LAM cells. I want a cure in my lifetime!

**Tara Logozzo’s**

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.

**Trish Martin**

I’m participating in the 20|20|20 campaign to honor the researchers and clinicians who work tirelessly for a treatment and cure. The LAM Foundation gives hope to those of us affected with LAM. When I was diagnosed ten years ago there was no effective treatment. This year, herculean efforts presented LAM patients with the drug Rapamune. Regardless of this progress, IT IS NOT ENOUGH. Not all of my LAM sisters tolerate or respond to this treatment.

**Marna O’Connor Wende**

Before the Foundation there were no studies, no support group, no resources, no patient registry, and no research being done. It is truly amazing how far things have come in 20 years. This year the FDA approved a drug for treatment. But it is just a treatment, not a cure and it does not work for everyone. We need the research to help find a cure. There is finally a treatment, and there will be a cure!

YOU WILL BE AMAZED AT HOW MUCH RESEARCH YOU CAN BUY FOR $0.65 A DAY!
Every Dollar Counts Twice Toward LAM Research

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

With that match, two (2) $50,500 pilot grants will be awarded to investigators who submit translational proposals that meet the following criteria: have a strong likelihood of future federal funding, use LAM samples, animal models or patient data, and which have the potential to favorably impact human health.

For the final months of this year the Foundation is continuing to match funds for locally based LAM Foundation fundraising events and all proceeds will be directed 100% to LAM research.

The following five (5) participants are committed to the dollar for dollar match from the Foundation and will inspire others to help them reach a goal of contributing $10,000 or $20,000 in net proceeds to The LAM Foundation.

- **Nicole Wipp** – $10,000 Social Media campaign through her Facebook page Wipp LAM
- **Peggy Haupt** – $10,000 7th Annual Chowchilla Laps for LAM Walk-A-Thon on October 24, 2015
- **Frances Saldivar-Morales** -- $10,000 Breath of Hope 5K on September 26, 2015
- **Jennifer Fujikawa** – $20,000 through her “Friends asking Friends” webpage located on the Foundations Online Fundraising page.

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.

The LAM Foundation LOVES Soybeans!

A heartfelt thank you goes out to Rebecca Nissly’s parents, Gerald and Regina Musser who donated 3000 bushels, the equivalent to 3 tractor trailer loads or 180,000 lbs, of soybeans to The LAM Foundation.

Within less than 24 hours of receiving this donation, The LAM Foundation sold the soybeans at $8.38 per bushel resulting in a total gift of $25,140!

This is an excellent example of gifting appreciated assets - just like donors will sometimes gift appreciated stock to non-profits. In that case, a non-profit can sell the stock and take the proceeds. Since The LAM Foundation is tax-exempt, we do not have to pay any taxes on the transaction. The donor is able to give the value of the stock, and 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 stock (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!

On behalf of The LAM Foundation, we love soybeans and we cannot thank Gerald and Regina Musser enough for the extremely hard work and generous gift.

![Rebecca Nissly and her father Gerald Musser](image)
Educating others and raising awareness for LAM while funding LAM research is no small task. The LAM Community continues to inspire others to donate to the Foundation all while sharing individual journeys with LAM and having a great time. Here are highlights from a sample of successful community events that have taken place this year.

The Western New York (WNY) Friends of the LAM Foundation and the McKenna Family hosted a stellar 10th anniversary fundraiser – “An Evening of Hope.” Over the last ten years, the McKenna’s and their friends in Buffalo, NY have raised more than $100,000 for The LAM Foundation.

Andrea Byrnes launched a Dare to Dance for LAM campaign on Facebook this year. Dare to Dance is a LAM awareness campaign urging people to post a video of themselves dancing or daring others to dance.

The Newland Team and Kathi Hawn organized a successful Slam LAM 5K Walk in March at the Residents Club Central in Summerwood, Texas. In its inaugural year, SLAM LAM and many big-hearted Texans contributed more than $30,000 to the Foundation.

Over 700 people attended the 3rd Annual McCabe Pub Crawfish Boil in early April. The Dean Family organized the event in honor Stephanie Dean Brown.

The Nagatuck community has embraced LAM Liaison Madeline Nolan’s fight against LAM by supporting her at the 11th Beer and Wine Tasting party in April at the Elks Lodge in Naugatuck, Connecticut.

Andrea Slattery, Board Development Chairperson, hosted a fundraising dinner at the Merion Cricket Club on the Thursday evening before of the Million Dollar Bike Ride in May.

More than 30 women came together for an Afternoon Tea fundraising event with Emma Murphy on a beautiful Sunday in May. Our hearts were broken when Emma passed away in September. Her generous spirit and good humor will live on forever.

A hot summer day in Topeka greeted hundreds of golfers for the third annual BLAM Golf Tournament in June. Family and friends of Annette and Aaron Roberts enjoyed golf, a silent auction and dinner all to raise money for The LAM Foundation. All told, the Roberts contributed over $22,000 to the Foundation from this golf outing.

In June, Carrie DeRosia hosted a “Chairs for Charity” event. A variety of painted, upholstered, antique, chairs were donated for a fabulous silent auction in Estacada, Oregon.

UNC Eshelman School of Pharmacy students Laura Bowers and Libbie Dellinger are raising awareness about LAM and funds for the Foundation by launching the Balloon Challenge on August 20.
Anyone who battles LAM on a daily basis, whether it’s yourself, a family member or a loved one, knows the unique story of your life—the triumphs and challenges. Every once in a while, you may have an opportunity to talk about LAM in front of a group that may know little to nothing about the organization.

Before you act upon your first instinct to say ‘no’ or ‘I could never do that,’ think about what your presentation might mean to others affected by LAM.

No one can tell the story of LAM better than you can, because you live it every day. It may be uncomfortable for you to get up in front of a group of strangers and talk about yourself, but it is the best way for others to understand LAM, the organization and our mission.

To make you feel more comfortable, here are some guidelines to help you tell your story. This type of outline or direction can also be used for a written story or social media post.

First, know your audience. Perhaps it’s a group of women who just received a LAM diagnosis or their family members. Is it a community group? Is it a women’s group? Tailor your talk to your audience. With the women, you can be personal. Family members might want to learn more about what they can do to help. A community group might just want to be more educated about a disease that targets them or their family. Do a little research—it never hurts to see who else has spoken to the group, to give you a better sense of their expectations.

Second, tell your story. Start at the beginning and tell the good and the bad, the funny and the sad. If you can help it, don’t use a typed-out speech. If you need them, bullet points are better than a script. As they say: A read speech is a dead speech. It’s your story and you can tell it better than anyone. Remember, they invited you—they want to hear about your experiences.

Lastly, give your audience three points to remember. Depending upon the audience, they may never have heard of LAM, so this is your opportunity to educate them. It may be something as simple as this:

- “About 2,000 women have been officially diagnosed with LAM; but that number is likely much higher because so many women are misdiagnosed and treated for other lung issues, like asthma or emphysema, instead of LAM.”
- “Because of worldwide research, much of which is connected to funds from The LAM Foundation, LAM today is very different than just a few years ago. Recent breakthroughs are giving LAM patients, and their families, new hope.”
- “But the work isn’t finished. Our 20|20|20 campaign asks for $20 donations over the next 20 months to mark The LAM Foundation’s 20th anniversary. The money continues to fund important research, and help to diagnose women who may not even know they have LAM. They can’t be helped, if we don’t know who they are.”

Once you’ve delivered your three points, make sure you ask for questions from your audience, if there is time. And then wrap it up with a message of hope.

“The LAM Foundation was founded, because a mother was determined to find help for her daughter who was diagnosed with LAM in the prime of her life. In the process she and the organization have helped fund research that has provided a treatment of hundreds of women. We continue to spread the word about LAM, and we hope you will join us.”

Betsy Ross, president of Game Day Communications, was one of the first women to break into national sports broadcast with ESPN where she was an anchor from 1997-2002. She is also an adjunct professor at Indiana University and Xavier University. Betsy Ross and Jackie Reau provide public relations services to The LAM Foundation, donating a large portion of their work.
Breath of Hope Giving Clubs

Thank you for your continued support of The LAM Foundation. To view our contributor list or the full list of individual and group Giving Club donors, please visit our website at www.thelamfoundation.org

INDIVIDUAL GIVING

BREATH OF HOPE FOUNDER’S SOCIETY $100,000 OR MORE
Vi Adler
Tim & Lou Alexander
Mary Brown & John Riparetti
Barry & Bev Crown
Aaron & Edith Dichter
Pat & Joe Harrington
Patricia Houghton
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Tom & Barbara Laurenzi
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GOLD FEATHER SOCIETY
$25,000 - 49,999
John Adler
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PLATINUM FEATHER SOCIETY
$50,000 - $99,999
Pam & Richard Bard
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THE LAM FOUNDATION HAS MADE EVERY EFFORT TO BE AS ACCURATE AS POSSIBLE WHEN CREATING OUR GIVING CLUB LIST. IF THERE IS AN ERROR IN THE RECOGNITION OF YOUR GIFT, PLEASE CONTACT THE FOUNDATION AT 513.777.6889 OR INFO@THELAMFOUNDATION.ORG SO WE MAY CORRECT OUR RECORDS. THANK YOU.
A National Day of Giving During the Holidays

December 1, 2015 is #Giving Tuesday, a national movement dedicated to giving, similar to how Black Friday and Cyber Monday are synonymous with holiday shopping. Whether you are finished with all of your holiday shopping or are working on your list, we hope you take a moment this holiday season to include The LAM Foundation as part of your holiday giving.

Three easy ways you can help on #GivingTuesday:

1. Make a donation to The LAM Foundation for #GivingTuesday. Your gift will help support women with LAM and fund a breakthrough therapy for LAM Faster. Donate at www.thelamfoundation.org and Click on the Donate Now button.

2. Post on Facebook, Tweet, e-mail, Instagram, and blog about the Foundation to heighten LAM awareness. Use #LAMGivingTuesday and #GivingTuesday within your posts.

3. Make a #GivingTuesday sign, “I’m giving to The LAM Foundation on #GivingTuesday because ________”. Take a picture with your sign and share it on Facebook, Twitter or Instagram using #LAMGivingTuesday OR e-mail it to info@thelamfoundation.org. We will share pictures throughout the day on our Facebook page.