

JOURNEYS

OUR COMPREHENSIVE JOURNAL ON LAM RESEARCH, PATIENT ADVOCACY, EDUCATION
AND AWARENESS PROVIDED BY THE LAM FOUNDATION FALL 2014

Better Together

BY FRANK MCCORMACK, MD, LAM FOUNDATION SCIENTIFIC DIRECTOR



There are now 47 LAM Clinics around the world from Beijing to Boston following over 2500 LAM patients. The number of LAM patients seen in each clinic ranges from 15 to 300. Within these centers, LAM awareness is rising among all specialties, expertise is being nurtured, and trials (such as TRAIL) are being conducted.

LAM Clinic Directors are also sharing challenging cases, important papers, best practices and critical issues in patient care in real time via the Internet. A recent example was a discussion regarding the use of sirolimus and everolimus in patients approaching lung transplantation. Three LAM Clinic Directors wrote a provocative opinion piece about the topic in the medical literature that was shared electronically with the rest of network within days of publication. A lively email discussion ensued, and it became clear that LAM Clinics in different counties and countries approach this issue very differently. Many U.S. centers prohibit the use of mTOR inhibitors in listed patients, because of the risk of effects on wound healing. However, some U.S. European and Australasian centers allow their use in low doses right up to the date of transplant. The jury is still out, but I think all involved were surprised at the range of experiences and biases expressed. This is a very healthy way to approach consensus in an area where the data are too sparse to reach definitive scientific conclusions, at least until a proper trial can be conducted.

The MILES trial was funded by the Rare Lung Disease Consortium (RLDC) grant from the Office of Rare Disease (ORD)

and the National Center for Research Resources (NCRR) that ended in 2008. We recently heard that the National Center for Advancing Translational Sciences (NCATS), the successor to the ORD and NCRR, would fund the sequel to the RLDC grant to support projects in LAM, pulmonary alveolar proteinosis (PAP) and Hermansky Pudlak syndrome (HPS). The objective of the LAM project is to follow patients who are on sirolimus to determine if the long-term risks and benefits are favorable. We also hope to conduct a trial of early, low dose, long-term sirolimus in patients with normal lung function, to determine if progression of mild LAM can be arrested before symptoms develop. The HPS project focuses on early detection and biomarker discovery, and the PAP project on refinement of the primary diagnostic test and defining the natural history of disease. The platform for all of these studies will be the LAM Clinic Network (now the Rare Lung Disease Network), which has embraced several rare pulmonary disease populations beyond HPS and PAP including lymphangiomatosis, pulmonary Langerhans cell histiocytosis, Sjögren's cystic lung disease, and Birt-Hogg-Dubé syndrome. We are sharing infrastructure including the data center in Florida and online data acquisition tools, and together developing educational tools for the public and a training program for future rare lung disease scientists. Working together enhances our chances of acquiring funding, conserves resources, and distributes new ideas. As an example, at the NCATS meeting in September 2014, other foundations shared their innovative processes for facilitating trials and registries with us, and it is highly likely we will adopt some of their approaches. Incorporating other diseases into the Clinics enriches the professional experience for Clinic directors and focuses referrals of the most challenging rare disease cases to academic health centers where they belong. Because

CONTINUES ON NEXT PAGE ›

the volume of rare disease patients is generally small compared to the overall clinical duties of any given Director (less than 10% of all annual clinic visits on average), there is little risk of becoming overwhelmed. In the end, everyone benefits. And it's the right thing to do.

In other news, LAM Clinic Directors and others are gearing up for the Biomarker Summit in Atlanta next month. An impressive roster of more than 50 scientists will spend a day and a half developing tools to conduct trials more rapidly, to help LAM patients reach a diagnosis without biopsy and make

decisions about treatment. We hope to leave the meeting with concrete plans for projects, but will need everyone's help to raise money for the scientists to carry them out. Please contact the Foundation if you are able to support this effort. And if you see him, thank John Adler for his unfailing generosity in making this exciting meeting a reality.

Oh, and one last thing- On July 7, 2014 sirolimus was approved by the Japanese Ministry of Health, Labor and Welfare for the treatment of LAM based on data from MILES and a trial called MLSTS still underway there. This is a major milestone for LAM.

Diversity and Solidarity

BY SUSAN E. SHERMAN, EXECUTIVE DIRECTOR



“Such progress is attributable to the toil and commitment, or solidarity, of passionate people working together.”

As I sit to compose this article, a beautiful October day hovers outside, promising cooler days and the soon-to-arrive beauty of crisp, brightly colored leaves. The seasons have begun to change in the Ohio Valley.

This year's transition to fall brings with it good fortune for me, as I celebrate my first year as executive director. In other words, I have now experienced the entirety of the “seasons of service” at The LAM Foundation. Our seasons include extraordinary projects such as planning the International Research Conference & LAMposium, the research grant award cycle and fundraising appeals, as well as all-season activities such as patient education & outreach, supporting community events, building awareness and connecting with the global LAM community. As with the weather, each day brings unexpected turns; moments of inspiration and heartache, keeping us firmly grounded in the importance and urgency of our work, even amidst the more predictable activities of any particular month, week or day.

As I reflect upon my first year, the heart of the people and experiences I've come to know as the LAM community are best described by the words: diversity and solidarity. Without fail, the women with LAM who have shared their story with me have detailed diverse and remarkable journeys about how LAM invaded their lives, stealing what they formerly took for granted and transforming

their futures forever. Their stories impress upon me that life with LAM is never predictable, and each woman and her family navigate their own experience, shaped by her unique circumstances such as her age, family dynamics, diagnostic misadventures, diversity of symptoms, differing responses to treatment and other co-existing health conditions.

Yet consistently, this disease creates solidarity and a resolve to fight that I would argue, is unparalleled in rare disease communities. What makes an even greater impression is that LAM solidarity is not limited to those affected or their families and friends. It is readily transmissible to doctors, nurses, caregivers, scientists, surgeons, donors and caring strangers, inspiring a potent mix of determination and compassion. The achievements of the larger LAM community are vast, including raising \$17 million for research and patient support, identifying the gene responsible for LAM, discovering an effective treatment and a powerful biomarker, and sustaining strong momentum toward a clear (albeit steep) path forward. Such progress is attributable to the toil and commitment, or solidarity, of passionate people working together.

Looking toward the Foundation's third decade, I have great hope and confidence that the LAM community's record of success, its diversity and solidarity are not merely our history, rather, a current, vital and expanding vision that is carrying us daily toward a cure.

Diversity in the LAM Research Portfolio

BY DAVID PLAS, ASSOCIATE PROFESSOR VONTZ CENTER FOR MOLECULAR STUDIES,
UNIVERSITY OF CINCINNATI MEDICAL CENTER



“The light bulb was not invented by perfecting the candle.”

- Source unknown

LAM is a disease that teaches courage in response to challenge. At the 2014 LAM Research Conference held in Chicago, remarkable women inspired one another and the entire LAM community with stories of how they have encountered and continue to overcome this condition. The response that unifies patients, supporters, physicians, and researchers is: “How can we strengthen one another to overcome LAM?”

We know that there are critical questions in LAM that require deeper research and understanding. What is the LAM cell? What explains the link between reproductive hormones and LAM? Most importantly, what can be done to better restrain and even eliminate LAM cells?

Discovery research (sometimes called “basic research”) partners with translational and clinical research in the search for breakthroughs. Many new therapies have origins in discovery research. In LAM, critical steps towards sirolimus therapy were derived from research on soil bacteria, yeast, and fruit flies. Discovery research in these seemingly unrelated areas, coupled with the landmark identification of the LAM genes, revealed the potential benefit of sirolimus therapy for LAM.

One of the important functions of The LAM Foundation is to continually monitor the latest findings in discovery research while constantly seeking to identify and apply promising new ideas for LAM-directed applications. The new partnership with the Rare Lung Diseases Alliance strategically increases research opportunities. Overall, the strategy of partnering with related research communities results in a large and diversified research portfolio, increasing the potential to bring breakthrough discoveries from unexpected directions for patients with LAM.

There are clear short-term objectives in LAM research, such as investigating second-generation LAM therapeutics, LAM biomarkers, LAM cell metabolism, and LAM hormone responses. Just as importantly, there are new ideas in partner research communities that have the potential to revolutionize LAM therapy.

Because we cannot predict the origin of the next big breakthrough, our mission in The LAM Foundation should be to confront the unknowns of LAM by seeking new ideas from all possible directions. Research is an investment in the future. One of our wisest investment strategies may be to continually diversify the LAM research portfolio.

LAM Biomarker Innovation Summit

This November, The LAM Foundation is hosting the first LAM Biomarker Innovation Summit in Atlanta, GA. Over 50 international biomarker experts from LAM and other diseases, such as breast cancer, will identify short and long term strategies that will accelerate discovery of new biomarkers for LAM. The meeting is generously funded by John Adler in honor of his late wife, Vi Adler.



After the Summit, investigators are invited to submit grant proposals based on their work at the meeting. Peer-reviewed projects will be funded by generous contributions from the LAM community, major donors and matching funds from The Sue Byrnes Legacy Fund. Monies will continue to be collected through the end of the year. Learn more about The LAM Biomarker Innovation Summit and how you can contribute to this important research, visit; <http://www.thelamfoundation.org/research/biomarker-innovation-summit>.

A Lay Description of a Two-Year Randomised Placebo-Controlled Trial of Doxycycline for Lymphangioleiomyomatosis

BY SIMON JOHNSON, PROFESSOR OF RESPIRATORY MEDICINE, DIRECTOR OF THE NATIONAL CENTRE FOR LYMPHANGIOLEIOMYOMATOSIS, UNIVERSITY OF NOTTINGHAM

Doxycycline is an antibiotic commonly used for respiratory and other infections over short periods of time. One of the features of doxycycline is that it inhibits enzymes called metalloproteinases, which are increased in the blood of patients with LAM, and it has been suggested that metalloproteinases contribute to the lung cysts that damage the lungs of women with LAM. As doxycycline is a safe and cheaply available drug, some patients with LAM started taking doxycycline to try and prevent decline in lung function. We therefore performed a randomised placebo-controlled trial to see if doxycycline could reduce the decline in lung function seen in women with LAM and indeed could be a potential treatment.

The study was funded by grants from the British Lung Foundation and LAM Action, the UK patients group. Patients with LAM and deteriorating lung function were recruited to take either doxycycline for two years or an identical matched placebo. In order to recruit as many patients as possible, other treatment was allowed other than rapamycin, providing treatment level stayed stable over the two-year study. When patients were recruited to the study they had baseline measures of FEV1 (forced expiratory volume in one second), a measure of airflow and one of the key markers for monitoring change in LAM over time, but also measurements of gas transfer (DLCO), exercise performance (assessed by shuttle walk test), and quality-of-life measurements, assessed by questionnaires.

We also took blood and urine samples to measure the effect of doxycycline on MMPs and other biomarkers over the course of the two-year study. Twenty-three patients were recruited and were randomised to take either doxycycline or placebo. For the first three months, patients took 100mg of doxycycline and, if tolerated, increased to 200mg for the remainder of the two years. Patients on placebo had their tablets increased at three months also. Every three months, patients attended the study centre in Nottingham and had measurements of safety MMP levels and



Doxycycline Trial Team, University Hospital Nottingham

FEV1. At one year and two years, patients had a full assessment, including full lung function shuttle walk test and quality-of-life assessment. In order to avoid patients taking placebo for two years if they had progressive disease, anyone who's FEV1 fell by 300ml or more was, on two occasions, withdrawn from the study. Patients were also withdrawn from the study if they had a pneumothorax or other severe adverse event.

Twenty-three patients started the study and whilst not all completed the two years, over this time, the main study outcome, the change in FEV1, did not differ significantly between the two groups, meaning that doxycycline had failed to reduce the decline in lung function in patients who were taking it. Similarly, although doxycycline did reduce the levels of MMP-9 protein in patients who took the active drug, there was no effect on vital capacity, gas transfer, exercise performance or quality of life by doxycycline.

As we are unable to recruit quite as many patients as we originally intended to the study, the conclusions are somewhat guarded, but from the work we have done, there is no evidence to suggest that women with LAM should take doxycycline to try and stop the progression of the disease. Although the drug was quite well tolerated by most patients who took it, side effects, including skin rashes, nausea, and tinnitus, were more common in the patients who took doxycycline than placebo, and overall we would not recommend people took this long term. Doxycycline remains a useful antibiotic for respiratory infections for women with LAM and other problems.

Although this is slightly disappointing news, we will continue to study mechanisms by which LAM damages the lung tissue and search for treatments to specifically target this. We are very grateful to the patients who participated in the clinical trials, those who fundraised for us, and the lung function department at our hospital, who worked very hard to make the study measurements. The paper is published in full in the European Respiratory Journal at erj.ersjournals.com.

Sirolimus Effects in the Ovary: Should We Be Worried?

BY STEPHEN R. HAMMES, MD, PHD, CHIEF, DIVISION OF ENDOCRINOLOGY, DIABETES, AND METABOLISM
UNIVERSITY OF ROCHESTER MEDICAL CENTER, ROCHESTER, N.Y. EDITOR-IN-CHIEF, MOLECULAR ENDOCRINOLOGY



Based on results from the MILES Trial,¹ more patients with LAM are being given mTORC1 inhibitors such as sirolimus in an effort to control progression of their disease. The positive results from the MILES Trial are exciting, as lung function in patients treated with sirolimus stabilized when compared to those treated with placebo, with a reduction in symptoms, improvement of quality

of life, and reduced levels of a possible marker for LAM called VEGF-D. However, as is the case for most chemotherapeutic reagents, sirolimus treatment is not without complications. Sirolimus has significant immunosuppressive abilities and leaves patients with increased susceptibility to infection. In addition, patients on sirolimus often have GI complaints that can result in discontinuation of the medication. Sirolimus can also cause fatigue, skin rashes, leg edema, high triglycerides or cholesterol, increased blood glucose, and elevated blood pressure.

Recently, another side effect of sirolimus was reported by a group in Switzerland.² In an un-blinded, randomized, controlled clinical trial held from 2006-2010, 21 women with a syndrome called polycystic kidney disease were treated with sirolimus for a median of 19 months. A matched group of 18 patients were treated with standard care that did not include sirolimus. Patients taking sirolimus had an increased risk of ovarian cysts as well as an increased risk of menstrual cycle irregularities. These risks were not small: 12/21 patients developed ovarian cysts (versus 5/18 in control patients), while 11/21 patients on sirolimus developed menstrual abnormalities (versus 3/18 control patients).

How might sirolimus be causing these effects? In the ovary, every ovulated egg starts in the fetus as part of a very small primordial follicle consisting of one oocyte (immature egg) and surrounding follicular cells. These follicles remain relatively dormant until puberty, at which point they start to grow. The vast majority of follicles die off before reaching maturity. In fact, a woman starts with millions of primordial follicles but only ends up ovulating a few hundred eggs over her lifetime. In addition to hosting oocytes/eggs, these follicles also play a critical role in producing the steroids that regulate the menstrual cycle; thus, anything that alters follicle development will also alter cycling. Interestingly, animal models suggest that mTORC1 is very important for the transition of follicles from the primordial to mature

state.^{3, 4} When Tsc2 expression is ablated in mouse oocytes, then primordial follicles prematurely progress within the ovary, leading to increased ovulation and premature ovarian failure.³ In contrast, when mTORC1 is blocked (for example, with sirolimus), then follicle progression and subsequent ovulation are reduced.⁴ Therefore, in humans, it is possible that sirolimus prevents follicles from developing normally, leading to cyst formation (excess fluid in abnormal follicles), and reduced ovulation. Without normal follicle development and ovulation, menstruation will be abnormal, as observed in the Swiss study.

So what does this mean for women taking sirolimus? At this point, we really do not know. Ovarian cysts are relatively common, rarely cause discomfort, and are almost always benign. Similarly, changes in ovulation and menstruation should pose minimal long-term health risks to women, other than potential negative effects on bone health if estrogen levels are chronically lower than usual. With regard to future fertility, again there are more questions than answers. Sirolimus is considered category “C” by the FDA, meaning that animal studies have uncovered evidence of embryo or fetal toxicity, but there are no controlled studies in pregnant women. With this in mind, most physicians recommend stopping sirolimus in women who desire pregnancy. Certainly the risks must be thoroughly discussed with any women on sirolimus. Finally, although we do not know for sure, presumably once sirolimus is stopped, follicle progression, along with periods, will normalize.

In summary, given the uncertainties and lack of strong data to guide us one way or another, decisions regarding sirolimus, LAM, and pregnancy should be dealt with on a case-by-case basis and will involve important conversations between patient and physician.

¹McCormack, FX et al. (2011) “Efficacy and safety of sirolimus in lymphangiomyomatosis,” *NEJM* 364, 1595-606.

²Braun, M. et al. (2012) “Low-dose oral sirolimus and the risk of menstrual-cycle disturbances and ovarian cysts: analysis of the randomized controlled SUISSE ADPKD trial,” *PlosOne* 7, e45868.

³Adhikari et al. (2009) “Disruption of Tsc2 in oocytes leads to overactivation of the entire pool of primordial follicles,” *Mol Hum Reprod* 15, 765-70.

⁴Tong, Y. et al. (2013) “Rapamycin-sensitive mTORC1 signaling is involved in physiological primordial follicle activation in mouse ovary,” *Mol Reprod Dev* 80, 1019-34.

Jane Yu, PhD, Receives Grant for TSC Study from NIH/NIDDK



Jane Yu, PhD is a principal investigator at the Brigham and Women's Hospital-Harvard Medical School. She received her B.S. from Peking University and PhD from The City University of New York. During her postdoctoral training in Dr. Lisa Henske's Lab at Fox Chase Cancer Center, Dr. Yu was funded by The LAM Foundation for three years. Dr. Yu's current research interests include the establishment

and characterization of the primary cell cultures derived from angiomyolipoma and pulmonary LAM, the investigation of the role of estrogen and anti-estrogen agents in stimulating LAM-associated angiomyolipoma cell growth and signaling pathways, the identification of molecular and metabolic signatures associated with estrogen-promoted metabolic alterations and survival of tuberin-deficient cells, and the development of animal models of LAM to test the efficacy of FDA-approved drugs.

Dr. Yu recently received a three-year \$450,000 NIH/NIDDK RO1 titled "Prostaglandin biosynthesis: a novel therapeutic target in TSC disorders." The major goal of this study is to investigate the molecular basis of prostaglandin biosynthesis and to determine the therapeutic efficacy of non-steroidal anti-inflammatory drugs

in tuberous sclerosis complex. The LAM Foundation provided seed money for this study through a LAM Foundation Postdoctoral Fellowship awarded to Dr. Chenggang Li. Department of Defense Tuberous Sclerosis Complex Research Program also supported the initial study related to this project.

Other key contributors on this project include David Kwiatkowski, MD, PhD, the co-Principal Investigator, Elizabeth Petri Henske, MD, and Bruce Levy, MD at the Brigham and Women's Hospital, John Bissler, MD, at the Le Bonheur Children's Hospital-University of Tennessee Health Science Center, and John Blenis, PhD, at Weill Cornell Medical College. Together, some of the initial work of this study has been published in *Journal of Experimental Medicine* 2014, representing the power of collaboration.

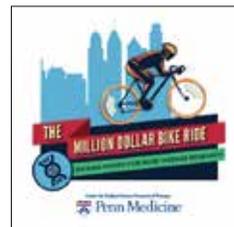
Members from Dr. Yu's Lab would like to thank the donors of The LAM Foundation, the patients and their families, and patient advocacy groups. Without their endless effort and strong support, this latest NIH/NIDDK grant may not have been possible.

Generous donations to The LAM Foundation provide seed money for fellowship grants that have generated an additional \$38 million in research support.

Million Dollar Bike Ride

On May 3, 2014 over 540 registered cyclists rode in the first Million Dollar Bike Ride and raised more than \$1.4 million for rare disease research. Money raised from this first Million Dollar Bike Ride, along with matching funds from donors and industry, resulted in 16 Pilot and Postdoctoral Fellowships Grants from Penn Medicine's Center for Orphan Disease Research and Therapy (CODRT).

The LAM Easy Breathers Cycling team rode in the Million Dollar Bike Ride and raised \$120,000 - which means that two \$60,000 pilot grants are available for Lymphangiomyomatosis (LAM) research! These research grants are focused on translational proposals with a strong likelihood of future federal funding. As of September 15, 2014, 21 scientists submitted LOIs for consideration. From that group of LOIs, 19 were asked to submit full grant applications.



A million thanks go out to those who supported the Easy Breather's Cycling Team and those who rode in the First Annual Million Dollar Bike Ride. Special thanks goes to Co-captains Patricia Ortiz and Kristin Gavin who worked non-stop, to make it a great ride for all 40 LAM riders on the Easy Breather's cycling team and also to Patti Bebie-Aronoff and Alanna Nelson for organizing, volunteering and helping the day of the race.

Kamyar Afshar, DO, has been named LAM Clinic Director at the USC Center for Advanced Lung Disease



Kamyar Afshar, DO

The LAM Foundation would like to welcome Dr. Kamyar Afshar and the University of Southern California Center for Advanced Lung Disease as the newest LAM Clinic.

Dr. Afshar is an Assistant Professor of Clinical Medicine specializing in advanced lung disease. He provides medical therapy in the various Intensive Care Units at the Keck Hospital of USC and is an active medical educator, serving as an associate program director of the pulmonary, critical care and sleep medicine fellowship program.

At USC, Dr. Afshar continues his research in the fields of cystic fibrosis, lung transplant, sarcoidosis and chronic obstructive pulmonary disease. He currently serves as a co-investigator on two studies. The first addresses development of a one-way endobronchial valve for patients with heterogenous emphysema. The second addresses the use of a cystic fibrosis transmembrane conductance regulator (CFTR) potentiator.

Dr. Afshar is also the Web Chair for the Clinical Problem Assembly of the American Thoracic Society and serves as a contributing editorial to various journals.

You can reach Dr. Kamyar Afshar at his office at 323.442.9590 or schedule an appointment with him by calling Haley Aldridge, RN at 323.442.9590.

Cleveland Clinic Welcomes Robert Kotloff, MD



Robert Kotloff, MD

Dr. Robert Kotloff is the new chairman of the Department of Pulmonary Medicine at the Cleveland Clinic and the Medical Director of its LAM Clinic. Dr. Kotloff has special expertise in the evaluation and management of patients with lymphangioleiomyomatosis (LAM) and other cystic lung diseases. Previously, Dr. Kotloff spent 23 years on the faculty of the University of Pennsylvania, where he was the

Craig and Elaine Dobbin/Nancy P. Blumenthal Professor of Medicine and Chief of the Section of Advanced Lung Disease and Lung Transplantation. At PENN, Dr. Kotloff was the inaugural director of their LAM Clinic, and during his tenure in

that position, the clinic evaluated over 80 women with LAM. He has worked in the field of lung transplantation for nearly 25 years and has extensive clinical experience in the evaluation of transplant candidates and in the care of transplant recipients. In addition to his involvement in lung transplantation, Dr. Kotloff also maintains an active interest in general pulmonary medicine and, in particular, in evaluating patients with complex pulmonary disorders.

Dr. Kotloff was named the 2013 recipient of the American Thoracic Society Assembly on Clinical Problems Educator Award given in recognition of outstanding clinical and educator expertise and significant contribution to clinical education in pulmonary and critical care. "Patients interested in seeing me at the Cleveland Clinic can call 216.444.6503 or 800.223.2273, ext. 46503, to make an appointment," said Dr. Kotloff. "We will get things set up for them."

There are 29 U.S. and 18 International LAM Clinics where women with LAM can seek expert care.

Save the Date:

LAMposium 2015 March 26–29, Chicago, IL

LAMposium 2015 is just around the corner. Save the date and join us in Chicago, March 26–29. As in previous years, LAMposium is three events in one: The LAM Foundation International Research Conference, the Patient and Family Educational LAMposium, and the Breath of Hope Gala. The Foundation is celebrating its 20th anniversary in 2015 and moving into its third decade of funding promising research and support of women with LAM.

STRONGER TOGETHER

This year's conference theme is, *Stronger Together*. In 2014, LAMposium brought together the largest gathering of LAM patients, families, physicians, and scientists in one location. In 2015 we are expecting more patients and their families to attend; over 20 percent more! At LAMposium, we are stronger together as we share experiences, create a forum for dialogue, and advance our mission to seek safe and effective treatments and, ultimately, a cure for LAM.

The International LAM Research Conference brings together researchers from diverse disciplines to discuss the scientific basis of LAM. The objective is to discuss what is known, identify the most critical new research, and move the field forward. This year's Clinical and Basic Science sessions will be chaired respectively by Jeff Swigris, DO, MS, and Vera Krymskaya, PhD, MBA. Session topics will include Biomarkers, Research and Clinical Trials, and Lymphatic Biology. Some of the confirmed speakers include John Blenis, MD, Kuniaki Seyama, MD, PhD, Lisa Young, MD, Jeanine D'Armiento, MD, PhD, Joel Moss, MD, PhD, Kristen Holm, PhD, Max Itkin, MD, and many more.

The 2015 Patient and Family Educational LAMposium is being designed by a steering committee that includes George Pappas, MD, Susan S. Jacobs, RN, MS, Peggy Haupt, Mary Haughey, RN, BSN, and Sue Sherman, MHA. To appeal to a diverse audience of longtime attendees and those new to LAMposium, we will offer more translational science talks, panel discussions, interest groups/roundtable discussions, and more integrated time for patients, clinicians, and scientists.

Specific session topics will include Breathlessness: Causes and Solutions, Understanding Social Security and Disability, Treatment Options: Integrative and Regenerative Medicine, and Emerging Treatments: mTOR Inhibitors, and Beyond. A few confirmed speakers are Lisa Henske, MD, Dan Dilling, MD, Lisa Larkin, MD, George Pappas, MD, and Jeff Swigris, DO, MS. Informative panel discussions

will cover topics such as Women's Health, Nutrition and Exercise when Living with LAM, and Lung Transplantation. This year we will be offering more opportunities for women with LAM and their families to get together for interactive shared interests groups such as "International Meet Up," "Asthma and LAM," "High-Impact Exercise and LAM," and more.

Patients, family, and friends, along with physicians and scientists, will all come together Friday evening for the Friday evening banquet and again on Saturday evening for the "**Breath of Hope**" Gala. Both events offer unparalleled education, recognition, and fun for the entire LAM family. Together, we will celebrate the strength we have by being together. We are *Stronger Together*.

Conference registration will open **December 1, 2014**. Be sure to mark your calendars. We hope to see you in Chicago in March!

The Hyatt Regency O'Hare

9300 Bryn Mawr Avenue
Rosemont, IL 60018

Conference Sponsors

LAMposium is possible because of the support of our loyal sponsors.

We would like to extend our heartfelt thanks to:

PLATINUM FEATHER SPONSOR:



THE ROTHBERG INSTITUTE
For childhood diseases

The Gift LAMposium Gave Me

BY KAT STEELE

Fear. Anxiety. Dread. Sadness. Isolation. Those are just a few of the feelings I experienced after learning of my LAM diagnosis last July. I was 28 years old when I was diagnosed, and like many of the other LAM patients I've met, I was devastated to hear the news.

My story began Memorial Day weekend of last year. Following a trip to the Eastern Shore of Virginia with my husband and 1-year-old daughter, I came down with what I thought was bronchitis. After seeing a doctor, I was told I should go have chest X-rays done to rule out the possibility of pneumonia. Upon having those X-rays, the discovery was made that not only did I have pneumonia but also a completely collapsed right lung. I was immediately rushed to the hospital, where I spent the next five days recovering after my lung was reinflated. As a standard follow-up to my initial lung collapse, my pulmonologist ordered additional chest X-rays a month later to ensure that I was healing properly. As it turns out, I was not. Those X-rays showed that I now had suffered not one but two collapsed lungs. I was again admitted to the hospital, where I underwent lung surgery to repair the right lung. In addition, a biopsy was performed to ascertain what was causing all these collapses to occur.

The findings of the biopsy revealed the presence of lymphangiomyomatosis, the name of a disease I could hardly pronounce, let alone comprehend. I will never forget the day I found out I had LAM; it was July 9, 2013. I had spent my Fourth of July in the hospital instead of spending it with my family, celebrating our country's freedom and independence. I found it all a bit too ironic, considering that my freedom, my independence, and my life as I knew it, would never be the same.

In the months that followed, I experienced many of the different stages of grief: denial, anger, loss, and depression. It wasn't until the holidays rolled around that I slowly began to find acceptance. For Christmas that year, my parents gave me a card. In it, I found a heartfelt note and a check. The money, they explained, was to cover the cost of two plane tickets to Chicago, and my husband's trip to LAMposium.

Right about now, you're probably thinking "good grief," or "why on earth would they send her there?" And considering the fact that I had been recently diagnosed with a fatal lung disease, I admit I probably would have preferred a trip to some remote tropical destination. However, my parents have always done their best to be supportive and guide me through life, so I knew they thought this was important not only for me but also for my family.

In hindsight, I can confidently say that attending LAMposium was one of the best decisions I ever made. While I was certainly



Kat and Adam Steele at the "Breath of Hope" Gala

nervous to attend, I gained so much from going. Having the opportunity to meet so many other women, both young and old, who are afflicted by this devastating disease helped me with the healing process. Sitting in on roundtable discussions with other LAM patients and being able to personally communicate with doctors about my own symptoms and current conditions was incredibly beneficial. Listening to researchers and other experts present their latest findings and information was not only informative, but it was also encouraging. Attending the Breath of Hope Gala and witnessing the immense generosity and outpouring of support was, without a doubt, one of the most moving and inspirational events I have ever had the privilege of seeing.

It's been over a year since I was diagnosed with LAM, and it sure has been a long, hard road getting to where I am today. I feel as though I have finally reached that acceptance stage and I can confidently move forward with my life, while still accepting the harsh reality of my circumstances and what my future may entail. Had I not attended LAMposium last March, I'm not certain I would be where I am right now in terms of my outlook and sense of hope. I know that I will return to Chicago next year for a number of different reasons, but most importantly to reconnect with so many of the incredible women I met last year who have inspired me to be strong and to keep moving forward.

The LAM Family Network

Bring More Women with LAM Together: Donate to the LAM Family Network

The LAM Family Network (LFN) is a resource available to women with LAM who need financial help to cover the cost to travel to LAMposium. For many women with LAM, especially newly diagnosed women, LAMposium is the most informative and inspiring meeting they will ever attend. LFN funds are offered as partial travel grants to LAM patients who qualify.

Many LAM patients and their families and friends have experienced LAMposium and want others to have the same opportunity. Because of their generosity, in the past 11 years, contributions to the LFN fund have exceeded \$71,500 and have helped 95 LAM patients attend LAMposium, a testament that the LAM community is truly a family of caring individuals. In the words of a LAMposium attendee:

LAMposium was an awe-inspiring event and I am so glad that I was able to participate. I now know that there are wonderful doctors and scientists who understand what we are facing and they are working very hard to find a cure. Being able to interact personally with many of these doctors and scientists was a dream come true!

It was great connecting with other women with LAM. Family and friends try to be supportive, but they don't know the full impact of what we go through with this disease. Being able to share our stories gave us an opportunity to know that there are others who can relate completely to our situation. I loved talking to so many intelligent, funny, accomplished, and resilient women. With Eternal Gratitude!

—Martha Wainscott, LAM Patient

SUPPORTING THE LAM FAMILY NETWORK

The LAM Foundation strives to help as many LAM patients as possible discover the benefits of attending LAMposium. In 2015, we expect to have more patient applications for LFN travel grants than ever before.

Your gift to the LAM Family Network fund could help a newly diagnosed LAM patient travel to LAMposium for the first time, or give a longtime patient an opportunity to personally connect with friends, doctors, and others in her support network. Your donation will have an immediate impact on the life of a LAM patient and her journey with LAM.

If you feel inspired to give a gift “above and beyond” to help a LAM patient experience LAMposium, please do so by making a donation @ thelamfoundation.org. To make sure your gift goes directly to the LFN fund, please make a note on your personal

check, or enter “LFN” in the comment field when making an online donation at www.thelamfoundation.org.

APPLYING FOR A LAM FAMILY NETWORK TRAVEL GRANT

LAM patients with a strong financial need are encouraged to apply for a LFN travel grant for LAMposium 2015. To request a travel grant, please contact Maria Pearson at mpearson@thelamfoundation.org or at 513.777.6889, and she will send an application to you. Be sure to complete and return the LFN application by Friday, January 9, 2015.

Applications will be evaluated by an anonymous committee who will keep all information confidential. Committee volunteers will consider financial need, previous conference attendance, and the amount requested. The goal of the committee is to support as many patients as possible when granting funds for travel. The Foundation will notify all applicants by January 19, 2015, as to whether or not their request has been funded.

For those of you considering attending LAMposium, please let me encourage you to do so. The various meetings, sessions, and discussions will enlighten you to every aspect of our disease, including symptoms, treatment, research, and many others. But the greatest benefit you'll receive will be meeting and becoming friends with the most dedicated staff, the most courageous patients, the most comforting friends and families, and the most caring physicians and researchers. You will be changed in profound ways for the better. Please come join us!

—Janet Fredericksen, LAM Patient



Priceless Time Together at LAMposium

2015 LAMposium: Why Should You Join Us?

BY VERA P. KRYMSKAYA, PHD, MBA, PERELMAN SCHOOL OF MEDICINE, UNIVERSITY OF PENNSYLVANIA



Each year since my very first LAMposium, in 2000, I eagerly look forward to the next conference. As a scientist of LAM, I believe it is the most important event of the year. I will never forget my first trip from the Cincinnati airport, riding with LAM patients from other parts of the country. Meeting one on one with LAM patients established a special connectedness and gave meaning to what I, as a basic and translational scientist, do every day.

If you are a woman with LAM or a family member of someone with LAM, and you're debating whether you should go to the 2015 LAMposium, here are some reasons to attend that you should consider:

- You will meet other LAM patients, their families, and doctors, with whom you can share your story, your needs, and your hopes.

- You will learn about LAM from the best clinical and research doctors in the world: what causes LAM; how to manage and treat the disease; what are the potential future developments for treatment.
- You will celebrate with everyone at an awe-inspiring party called the "Breath of Hope Gala."

If you are a professional working with or interested in LAM, going to the conference, you will:

- Learn or advance your understanding of LAM.
- Hear about the latest developments in basic translational and clinical LAM research.
- Have inspiring meetings with LAM patients and their families.

Whatever your reasons are for attending the 2015 LAMposium, you will most certainly benefit from sharing in our collective and unifying goal to find a cure for LAM.

LAMposium Is a Unique International Conference

BY GEORGE PAPPAS, MD



With the International LAM Research Conference coming up, I want to take this opportunity to discuss why this meeting is so important and what makes it so special. This conference is a unique event, where women with LAM, expert clinicians, and leading researchers from around the world convene with the goal of furthering our understanding of LAM and finding a cure.

For women with LAM, the conference not only provides formal education about LAM from top doctors, nurses, and therapists, but it also is a place to learn from others living with the disease. It's an opportunity to get questions answered from the best and brightest in the field. It is a chance to talk with other women

who bravely share their experiences and make connections with the LAM community. The meeting format provides not only lectures and question-and-answer sessions but also the time to talk informally in the hallways or over lunch with national experts, others with LAM, and their families. New research and future areas of investigation are presented, with time to meet with the investigators and learn details about the trials.

For clinicians and researchers, the conference highlights the most recent scientific advances related to LAM, TSC, and related diseases – much of it unpublished. The conference is a wonderful opportunity to share ideas, build relationships, and develop collaborations.

It truly is an inspirational scientific meeting. The LAM community is amazing. And this meeting highlights the incredible strength and determination of those living with LAM and those who work in the field to work together to find a cure.

The meeting format provides not only lectures and question-and-answer sessions but also the time to talk informally in the hallways or over lunch with national experts, others with LAM, and their families.

- George Pappas, MD

Your Support Assures a Phenomenal Success

BY VEL HUX, DEVELOPMENT DIRECTOR

Join in the Celebration and Make the 2015 International Research Conference, LAMposium and Breath of Hope Gala the Best Ever

Planning has already begun for our annual “Breath of Hope” Gala. This well-attended and much-loved evening will include auctions, raffles, food, fun, and entertainment – a night filled with celebration and recognition of all powerful and brave women with LAM.

You are invited to join the festivities in Chicago at the Hyatt Regency O’Hare. We know that not everyone can travel to Chicago; however, you can still make a difference and help advance LAM research efforts worldwide. There are some ways that you can help. Here’s how:

SPONSORSHIPS

Consider asking your place of employment to sponsor the conference or be a sponsor yourself. Sponsorship levels range from \$2,500 up to \$50,000. Some of the sponsorship benefits include your name and logo placement in banquet and gala event programs, science and patient conference programs, event signage, recognition on The LAM Foundation’s website, and more. Pre-event promotion deadline is November 15, 2014. Conference and gala sponsorship deadline is February 1, 2015. The earlier you decide to sponsor, the more promotion you will receive. Details are online at www.thelamfoundation.org, or call Vel Hux, Director of Development, to discuss customization of your package.

HOST A TABLE OR PURCHASE A TICKET

If you are planning to attend, you may want to host a table of 10. By hosting a table, you ensure that you will be seated with

your invited guests. Your table purchase will be listed in the Breath of Hope Gala program and a special recognition at the event. Have friends in the Chicago area? Invite them to attend the gala with you. It is a perfect opportunity to show them the great work of The LAM Foundation. Please purchase tables or tickets by February 28, 2015.

BE A FRIEND OF LAM

You may want to be a special friend of LAM with a fully tax-deductible gift of \$250–\$500. Details are online at www.thelamfoundation.org. Please respond by February 28, 2015.

FUND-A-CURE – FUND RESEARCH!

Fund-A-Cure, one of the main events at the Breath of Hope Gala, takes place in a live auction setting to raise money to fund research. There are no auction items – just monetary bids to support LAM Foundation research efforts. In 2014, more than \$170,000 was raised! Fund-A-Cure is an awe-inspiring 20 minutes of generosity.

Whether you are able to attend the conference or gala or not, a donation or challenge grant from you can inspire donations. No amount is too large or too small. You can support Fund-A-Cure at a level that is comfortable for you.

Details are available online at www.thelamfoundation.org. If you have questions, please contact Vel Hux at vhux@thelamfoundation.org. Thank you for being an outstanding community of supporters.



One to One with Andrea D. Slattery Chairperson, Board Development Committee

INTERVIEW WITH VEL HUX, DEVELOPMENT DIRECTOR



Andrea D. Slattery

As a successful investor in the fast-paced world of technology, Andrea D. Slattery is no stranger to the often exhilarating nexus of innovation, entrepreneurship, and high finance. It is precisely this perspective that makes her perfect for her new role as chairperson of the Development Committee on The LAM Foundation Board of Directors.

Following a combination of personal interest and a passion to make a difference, Andrea joined the Board in 2013, and her energy and enthusiasm have been felt throughout the organization. Having already made a considerable impact on our fundraising efforts, Andrea's new role promises to elevate her contribution to The LAM Foundation's fundraising and resource development profile.

We took a few minutes with Andrea recently to discuss her background and her plans for the committee.

Tell us about your history with The LAM Foundation.

I first became aware of The LAM Foundation in 2007 and the more I learned about the Foundation, the more excited I became. One obvious and important factor for me was that several years ago, I was diagnosed with LAM, so all of the Foundation's work resonates on a very personal level with me. Even more important, though, my family and I have always believed that giving back is critically important, and The LAM Foundation is one of a number of charities where we have been involved over the years.

What really set LAM apart from the others, and ultimately motivated me to become even more involved, is the commitment of the Foundation's staff and constituents – especially the contribution made over time by Sue Byrnes – and the Foundation's long-term success in pursuing its mission. The energy behind that kind of impactful advocacy is infectious. I wanted to learn from that experience, to be a part of that success story, and eventually to explore whether LAM can be a template for similar organizations in the rare-disease space. Fortunately, I had the opportunity to join the board last year, and I'm thrilled by the opportunity to become more involved through the Development Committee.

What do you think have been the highlights of the Foundation's success to date?

The tangible results achieved in treatment over the past 20 years have been phenomenal, and I think due in no small part to the work undertaken by the Foundation. Several FDA-approved pharmaceuticals, like sirolimus, have been repurposed for other rare diseases, and drug development advances currently hold promise for potential breakthroughs that are very exciting.

I think there are a number of elements to the Foundation's programs that I see as significantly advancing the cause. The first of these is the LAMposium, which in 2009 was my first opportunity to see the Foundation's mission in action. It's an incredible event that pulls together patients, doctors, families, and clinicians. It is a fabulous resource for all patients. Patients talk with clinicians, leading thought experts, and scientists about LAM and its effects on their lives. It's incredible how much collaboration takes place. Also, it's a place where patients can share their experiences and feel supported by an incredible group of strong women. There is something for everyone. I was really struck by how powerful LAMposium was.

More recently, the University of Pennsylvania's [PENN] Million Dollar Bike Ride was held in May 2014. The Foundation partnered with Penn's efforts to fund rare diseases, and Penn matched \$50,000 in donations so that a total of \$120,000 was raised in just over three weeks for LAM research. It was a great success for Penn and for the Foundation. The pre-event dinner was a microcosm of LAMposium – bringing together clinicians, scientists, patients, and major donors in the Philadelphia area and connecting them all.

And you took a leadership role in the Penn event. Do you expect more similar events in the future?

Yes! I was fortunate to be involved in the Million Dollar Bike Ride in addition to the success in raising money and building awareness; I think we learned a lot from the event. First and foremost, there is strength in numbers – the benefits of collaboration were incredible in the Million Dollar Bike Ride.

There really is an opportunity to do much more on a broader scale, particularly if we work with other rare-disease charities. In actuality, rare diseases aren't all that rare – one in 10 people will have a rare disease in their lifetime. And of 7,000 known rare diseases, only 500 have effective treatments. There's a lot of work to be done, and this is an increasing focus for us as we look forward to the next decade at the Foundation.

So what do we do from here?

There are so many exciting opportunities. I've been incredibly fortunate that I've been able to spend virtually my entire career working in direct contact with some of the world's leading innovators and entrepreneurs. And as you may know, the notion of "social entrepreneurship" has been very much in vogue in Silicon Valley over the past 20 years. The upshot is that a lot of the creativity and entrepreneurial spirit that has driven the technology revolution of the last three decades has recently been brought to bear on social challenges. The ferment of those ideas, combined with enabling technology, is taking charitable development far beyond traditional approaches like parties, direct mail, etc. I'd like to be able to bring some of those ideas and approaches to what we're doing for LAM.

As we begin the next decade, what type of investments do you feel the Foundation should make?

- Offer more patient services and more resources in our clinics. The more data we collect, the closer we will be to the cure. We should be the first call when someone is diagnosed and work towards building something like a "Starbucks Model for Clinics" with as much uniformity and consistency as possible.
- Showcase the fundraisers. Highlight other independent fundraisers and how they captured success.
- Embrace challenge gifts.
- Place more content in multiple channels – print, audio, Facebook, website, e-blast, etc.

- Create special fundraising projects – for example, mini-trials. Major donors like to see the impact and know how their dollars are going to be used.
- Discover the passion of Board members, major donors, volunteers, and annual donors.

Thank you so much, Andrea. It has been delightful interviewing you. I love your enthusiasm and look forward to working with you. Is there anything else you would like to share?

I'm excited about the opportunity to serve. The collaboration among scientists, patients, and clinicians is one of the most impressive communication models that I have seen in my lifetime.

It is truly unusual and amazing to see these many talented people come together. Talented people – Sue Byrnes laying a strong foundation, bringing Sue Sherman in as executive director, Frank McCormack, MD, working as scientific director, involving National Institutes of Health [NIH] and all of the major clinics around the world – are what makes us stronger and gives me hope that a cure will be found. That is why I wanted to get involved so directly. I think that we are looking into a much brighter future in the next 10 years. I am excited about what lies ahead.

Andrea D. Slattery has worked in the technology investment industry since 1998. She is married and lives with her husband and their 6-year-old son in the suburbs of Philadelphia, Penn.

The LAM Foundation Welcomes Vel Hux



Vel Hux

The LAM Foundation welcomes Velvette "Vel" Hux as its new Development Director.

As the Foundation's Development Director, Vel will develop and expand the fundraising capability of the Foundation and direct fundraising programs. "Her background will be enormously helpful as we pursue continued research funding for LAM. We are delighted to have her as part of our team," said Sue

Sherman, Executive Director.

For more than 20 years, Vel has accrued a depth of non-profit, corporate and educational experiences. Prior to joining The LAM Foundation, she held corporate positions with Westinghouse Electric Corporation and nonprofit positions most recently with Warren County Community Services (WCCS).

As a Development Officer, she developed successful annual and capital campaigns, intriguing special events, and secured innovatively funded grants.

She earned her Bachelors in Mathematics from the University of Florida in Gainesville and her Masters from Duquesne University in Pittsburgh, PA. Her formal education combined with frequent seminars and workshops have provided her the skills to enhance the Foundation's fundraising effectiveness. Vel is an active member of the Association of Fundraising Professionals.

Vel and her husband, James, live in Springboro, Ohio. They are the proud parents of two daughters and two sons. Vel enjoys spending time with her family, cheering on the Pittsburgh Steelers, and making a positive impact in her job, community, church, or wherever you find her. She likes inspiring "ordinary people to do extraordinary things."

You may contact Vel via e-mail at vhux@thelamfoundation.org or by phone at 513.777.6889.

The LAM Foundation Welcomes Maria Pearson



Maria Pearson

The LAM Foundation is pleased to welcome Maria Pearson to its staff as the Foundation's Outreach and Events Manager. Maria is a media and communications specialist, who, for the past 15 years, has helped a variety of clients and small businesses plan and implement their communication and outreach activities. As a trusted consultant for her clients, Maria has been the lead on many complex projects. She has expertise in managing teams, timelines and tasks in order to produce live stage events, videos, audio recordings, social media campaigns and associated educational and print materials to promote and enhance events.

Working for the LAM Foundation is a dream of Maria's. After being contacted by Sue Sherman at Foundation to consult on LAMposium and the 20th Anniversary of the Foundation, Maria realized she could use her project management skills to

help other women while contributing to a meaningful and urgent mission. She will be leading the planning activities for the LAM International Research Conference & LAMposium and will manage Foundation outreach projects such as Journeys, Currents, online communications and educational events.

"After years of helping my corporate clients solve their communications needs, I know I can put my skills to greater use, helping to educate, build awareness and find more resources to accelerate the search for a cure for LAM."

Currently Maria is an Advisory Board Member of Portaluca, the sustainable funding arm for the Cincinnati chapter of Dress for Success. In her role, she is working to help Portaluca with their social media strategy.

Maria and her husband Greg live in Cincinnati. They have two energetic and athletic boys. The entire family enjoys traveling with and supporting the boys' soccer teams.

You may reach Maria via e-mail at mpearson@thelamfoundation.org or by phone at 513.777.6889.

My Next Chapter: A New Adventure



Sally Lamb

In August, 2014, Sally Lamb retired from The LAM Foundation and her role as Patient Services Director. Sally provided hope and endless compassion for women with LAM for more than 13 years. The Board of Directors and staff are extremely grateful to Sally for her years of service and wish her much happiness in her new adventure. The following letter was written by Sally in August 2014.

My LAM chapter started in 2001 when Sue Byrnes hired me as an Administrative Assistant. At that time, The LAM Foundation had a staff of 5 and we each had an office in the lower level of Sue's home. Two years later, my responsibilities changed and I became the Patient Services Administrator. In 2006, the Foundation moved into an office building and the staff grew to 7. My role changed once again and I became the Director of Patient Services.

Now, 8 years later, I am facing another change and also a new adventure. My husband has accepted a new position in northern Ohio and we are both excited about buying a new home and beginning our next chapter there. As such, I have resigned from the Foundation and I am officially retiring. My last day at the Foundation will be August 15th.

During my time at the Foundation, I have enjoyed getting to know and work with some of the most amazing people I have ever met. The strong bond that the LAM community shares is truly unique. I will always treasure the relationships I have built with so many women with LAM. They gave me purpose and a reason to come to work every day. The care and compassion shown by the LAM staff and the commitment and dedication shown by LAM physicians and scientists has been inspiring. I also feel honored and privileged to have worked for an organization whose Board of Directors is so focused on its mission.

The LAM community will always be near and dear to my heart and I hope to stay in touch with many of my "friends" on Facebook. I look forward to following your stories and watching the Foundation as it continues to grow. I hope we can stay in touch for many years to come. Please feel free to contact me at sallygollnitz@gmail.com.

Thanks to all of you for making my life richer!

With gratitude and admiration,

Sally Lamb

The Hudsonville “Breath of Hope 5K” – Birthing a New Idea

BY CINDY DEBOER

Once a year, at Christmastime, I get together with my friends from high school. We share stories about our kids, our jobs, our passions, and our lives in general. But this year, the focus was more on my health. As I shared with my friends about my recent diagnosis of LAM, they were so intrigued and compassionate. I told them that because of the stage of my disease, there was essentially nothing I could do in response to it: no treatment, no medication, no surgery, nothing. Then someone said, “Could you at least raise awareness for the disease, or money for research? I mean, it seems to me your gift is communication. Maybe that’s the thing you can do, Cindy!” And because several of them are runners, they suggested that together we put on a 5K fundraiser for The LAM Foundation. Voilà! An idea was born!

My three sisters joined “the team,” and we started to meet monthly at our local pizzeria. Over beer and nachos, we planned the event. None of us had any experience whatsoever with this kind of endeavor and so we talked a lot, laughed a lot, and hoped a lot! We hoped we weren’t in over our heads! We wanted to be realistic in our expectations and since LAM is so rare and unknown, we knew that promotion of this event would be a challenge. We decided that whatever God wanted the event to be is what it would be, and we would be okay with that. We hoped that at least 50 people would show up and that maybe, possibly, hopefully, we could raise a few thousand dollars. We set the date for August 9th and started praying.

We sent a few letters to local businesses and made phone calls to our “connected” friends, in order to find some corporate sponsors. Within two weeks, we had over \$2,000 donated to cover the expenses of the event! We primarily used social media to advertise the event, but we didn’t get a lot of “feedback” from that. We tried to advertise in the local paper, but they were unable to do an interview in time. And even though we had a wonderful website designed by The LAM Foundation for registering, registrations came in very slowly. Instead of getting discouraged, we remembered that the goal had always been to just raise awareness and maybe a few thousand dollars.

Then August 9th arrived. It was a gorgeous Michigan morning with no humidity in the air, a gentle breeze, and full sunshine. Participants were lined up at the registration table an hour before the event. Laughter, lively music, and the aroma of coffee filled the air as people just kept coming and coming. We ran out of T-shirts – something we never expected would happen because we had ordered so many extras! After an inspirational talk from a friend and a rigorous warm-up from my personal trainer, at 9 a.m. the horn blew and the race began. My kids and their cousins hid in the bushes and squirted runners



from squirt guns. We had signs all along the route that gave facts about LAM and also had funny things on them, like “Run, Forrest, Run!” and “No matter how slow you go, you’re still lapping everyone on the couch!” After the race, participants were treated to bagels and fruit and given a goody-bag loaded with coupons. It felt like nearly everyone commented on what a wonderful time they had at our 5K.

When we finally sat down later that day and counted registrations and donations, we were brought to tears by the success of the event: 275 participants and over \$13,000 raised for The LAM Foundation! Our “realistic” goals were blown completely to pieces! Apparently, God sent exactly the people He wanted to send, and the event was exactly what He wanted it to be. It was unbelievably fun and we, my team of organizers, hope to make it an annual event!

We ran out of T-shirts – something we never expected would happen because we had ordered so many extras!



My Way of Coping

BY JANUARY BUTLER

My sister was diagnosed with LAM in October 2006. Devastated and overwhelmed by the news, I began to search for a way to cope. Since her diagnosis, I have organized over 15 different fundraising events.



LAM at THE LINKS, now in its seventh year, has been the most successful and also gets easier to orchestrate each year.

What makes it successful? Consistency, community support, and great volunteers: Our teams and sponsors come back year after year, the mailing list continues to grow, and the engagement of our community and friends is heartfelt.

The event has definitely evolved over the years, and through it all, we rely on family and friends, and they really step up!

“Consistency, community support, and great volunteers make for success.”

- January Butler

They are our golfers, volunteers, and they help us find and keep our sponsors.

In the spring, we send letters to all past participants and local companies, asking for donations. Over the last seven years, the list of golfers has grown to over 250! Everyone is so generous; donated items for the door prizes raffle or sponsors total more than 200. The third year of the outing, we were fortunate enough to secure a title sponsor. This was a definite game-changer. The title sponsor guaranteed 10 teams and a cash donation. The sixth year we were able to sell out teams and added a 50/50 raffle to increase proceeds.

Each year, we raise more money and the outing tends to grow a little more. Undoubtedly, without the determination of our volunteers to find a cure and eradicate LAM, none of this would be possible!

The LAM Foundation would like to thank our many generous donors for their support.

This list reflects gifts made between January 1, 2014 and June 30, 2014.

GIFTS OF \$20,000 AND ABOVE

Liz and Fred Hoy, MD
Peggy and Francis McCormack, Sr
MSL Group
Novartis Pharmaceutical Corp
Ed Plocharczyk
The Bard Family Foundation
The J C F Foundation

GIFTS OF \$10,000 - \$19,999

MG Covidien Employee Matching Gift Program
Cindy and Chris Hughes
McCabe Pub, Inc.
William Reese
Wilfred & Esther Lam Family Fund
of the Community Foundation
for the Land of Lincoln
WNY Friends of The LAM Foundation

GIFTS OF \$5,000 - \$9,999

Karen Barth
Mary Brown and John Riparetti
Sue Byrnes
Edith and Aaron Dichter
Barbara and Tom Laurenzi
Kim and Andrew Romanosky
Ann and Jack Struthers
Swanton Foundation
Charles Wehland

GIFTS OF \$1,000 - \$4,999

Kori and Patrick Aldrich
Barbara and Jerry Marcotte
Sarah Bacon
Jack G. Blair
Kathleen and Richard Callahan
Carol Connor
Joanne and A.J. Dearlove
Delmhorst Instrument Co.
Terrence Demos, MD
Daniel Dilling MD, FCCP, FACP
MG Dominion Foundation
Sharon and Joel Eaves
Clara and Ron Erickson
Jilly Evans, PhD
Geraldine Finlay, MD
Janet Fredericksen
Christina Hamilton
Mary and Tom Harbaugh
Mary Ann Harrington
Peggy and Eric Haupt
Kathi Hawn
Lisa and Danny Haynes
Elizabeth Henske, MD
His Venture
Jennifer Hust
Hyatt Shared Services
Incandescent Technologies, Inc.
Carmen and Javier Iglesias
J.V. Henik, Inc.
Beverly Jackson

Susan and Richard Jardine
Jenay and Raymond Javorcky
Lewis A. Kingsley Foundation
Brenda Kirby
Peg Krengel
Patricia La Sala
Carol Langelier
Christopher Laurenzi
Young and Jung Lee
Laura and Chris Lentz
Frank Liesner
Thomas Lowder, PhD
Florence and Calvin Lu, MD
Mihaela Mattes
Holly and Frank McCormack, MD
Mary McAuliffe
Medtronic Volunteer Grant Program
Susan and David Mennillo
Susan Milligan
Carolyn Nowell and Mike Croyle
Patricia Ortiz
Chris Perez
Eden and Douglas Pontz
Corey and Ari Pontz
Beth and Mark Porst
Rachel and Roy Rosin
Angelo Santoro
Karyn and Rich Schad
Michele and Tim Hansen
William Schulman
Judy and Jeff Schwartz
Carol and David See
Diane and David Sheill
Teresa Smolarek, PhD
Teresa Stoker
Eugene J. Sullivan, MD
Terri and Paul Svendsen
Shahpar Vafamand and Houshang Falahatpour
Mary and Joe Van Brackel
Anneke and Gerrit van den Dool
Jane and Bill Venell
Patricia Venters
Barbara Venters and Bruce Yarnick
Janette and Richard Verhey
Jason Whitney
Madeline and Darrin Williams
Margaret and Pete Williamson
Clarice Wong
Lisa Young, MD
Deborah and Alfred Yudes

GIFTS OF \$500 - \$999

Andrea Alaimo
Patti and Burt Aronoff
Kristy and Brent Benefield
Danielle and Ken Benich
Nadia Cavnar
Jordan Chalmers
Stanley Chenoweth
Choctaw Nation Bicycle Team
Cooperative Food Sales, Inc.

David Vaughan Investments
Nancy Dickason, MD
Marilyn and Anthony DiLauro
Lisa and Tim Elo
Jeffrey Fieldhack
Angie and Joe Flanagan
Jan Fox and Bill Lock
Shelby and Zack Garner
Deanna Gaston
Jannine and Henry Givray
Marie and Dan Glasby
Barb and Mark Hair
Marla and Ron Hamlin
Pat and Craig Harmeling
Dawn and Bob Haugom
Gene Hawkins
Lesley Hoover
Alisha Hoover
Sharon Hovland and Joe Neumann
Jewish Federation of Greater Philadelphia
Dina and Ed Jennings
Zhengyu Jin
Jones Day
Cynthia and James Kinsella
Brian Kleps
Susan and Daniel Kocher
Rosalie Kosher
Marilou Kuczmiarczyk
Beth and Sean Landrette
Kim Langholz
Carole and Nicholas Laugavitz
Catherine and James Lawrence
Beverly and William Levy
Logar, Inc.
Pat and Bob Marcroft
MG Microsoft Matching Gifts Program
Nina and Kevin Molk
Sarah Morgan and Mark Oldani
Dawn Morrow
Israel Moses
Janet and David Neff
Brenda and Randy Nutt
Maureen and Jerry O'Hara
Melissa Overholt
Kathy and Duane Peiffer
Lisa Prevatte and Brad Ryan
Terri and Charles Rice
Annette and Aaron Roberts
John Roberts
Donna and Patrick Roche
Judy and Allan Rosenbaum
Stephen Ruoss, MD
Dannah and Jon Sauer
Emily and Lee Schnee
SE CT Friends of LAM
Timothy J. Shaughnessy
Lori and Jerry Siadek
Kathleen Speegle
Kathryn and Adam Steele
Charlie Strange, MD
Mr. and Mrs. Isaac Tam

Sharron Thompson
 Alexey Tyryshkin
 Pam and Doug Wallin
 Carol and Chuck Wehage
 Stacey Wheelus
 Tiffany Whitney
 Meghan and Tory Wierzbicki
 Patricia and Ronald Williams
 Linda and Robert Winter
 Karen and Don Wolnik
 Yanaco, Inc.

GIFTS OF \$250 - \$499

Ruth Guerrero and Sergio Aguirre
 Art Guild, Inc.
 Auburn Apple Market
 Kathy and Gary Avezzie
 Valorie and Jim Babb

MG BAE Systems Matching Gifts Program

MG Bank of America Foundation

 Pamela and Richard Bard

Bartlett & West
 Craig Becker
 Cindy Becker
 Belmont Group, Inc.
 Branda Bezuyen
 Dennis Billena
 Barry Blackmore
 Laura and Brian Bowers
 Bridgeport Athletics
 Mariele Briones, MD
 Caroline Brown
 Marguerite Brown
 Stefanie and Jason Brown
 Becky Brown
 Andrea Byrnes
 Kris and Tim Cada
 Louise and Charles Carrington
 Deb Carroll
 Mary and Stuart Carroll
 Mr. & Mrs. Joseph Chow
 Danelle Christensen
 Sheryl Cohen
 Jacquelin Davis
 Corinna Dewar
 Nicole Dinwiddie
 Genevieve Dorment

Mark and Brittan Dubose
 Kimberly Durbin
 Kathleen Eggers
 Karen Evers
 Constance and Mike Farkas
 Claudia and Colin Feeney
 Julie Fredericksen
 Carla and Matthew Galvanoni
 Ned Garinger
 Cathy Cuenin and Loren Gerhard
 Leah and Jack Goebel
 Barbara and John Granicher

MG Bronwyn Gray
 Group Benefit Specialists, Inc.

Kenneth Gulotta
 Leryn and Scott Hahn
 Stephen Hammes, MD, PhD
 Nancy and John Harris
 Michael Hatch, MD
 Debra and Neal Hedervary
 Barb Hustad
 Olatz Ibarra
 Ana and Enrique Irizarry
 Danielle Jacobs
 Maria and Manuel Inclan
 Brian Johnston
 Cheryl Jones
 Leah Karp
 Katherine and Gary Kaufman
 Kristin Kerwin and Mike Bila
 Karen and Bryan Kinsey
 Audrey Knipe
 Leslie Korbee
 Paul Laurence
 Caroline Le Poole, MS, PhD
 Alice Levy and Mordechai Seal
 Frances Lucas
 Joan Malliband
 Thomas Mandler
 Patricia Martin
 Angela McRoy
 Laura and Douglas Megill
 microIntegration
 Louise and Thomas Middleton
 Ramona and Louis Milioti
 Natalie Miller
 Kathryn and Les Miller

Mary Kate and Wayne Mundell
 Brian Nickel
 Sarah Noel Meyer
 Rhonda and Kevin Officer
 Angela Osborne
 Patricia Owens

MG Charm and Daniel Flint
 Susie and Josie Picart
 Sarah and Justin Poitras
 Barbara Powers
 Ann Provencher
 Gwen and David Pryor
 Jacqueline Putney-Bunt
 Jackie Rasmussen
 Jennifer Rausch
 Sylvia and William Richard
 Paula Romitelli
 Erin and Steve Ronhovde
 Raimonda and Fiqri Rapi
 Diana Rust and Troy Warner
 Frances Saldivar and Joe Morales
 Monique Samuels
 Mindy Scherr
 Marcy Schrank
 Patty and Stephen Segal
 Kathy Smetzer
 Carol and Donald Smith
 Soroptimist
 Tonisse Speech
 Mary and Steve Stojic
 Patricia Sullivan
 Ekaterina Surzhikova
 Lynne and Michael Terry
 Margo and Rob Thomas
 The Timken Company Charitable and
 Educational Fund, Inc.
 Warren Tompkins
 Kay and Craig Tuber
 Tuberosus Sclerosis Canada
 Ellen Ussery
 Holly VanNeste
 Susan Vasher and Eugene Poole
 Jennifer and Joe Velling
 Christine Westfall
 Linda Wiley
 Amanda Liora Zirkel

The LAM Foundation would also like to thank the more than 613 donors who contributed \$5-\$499. We appreciate your support.

 The pink feather denotes donors who have included The LAM Foundation in their charitable estate plan. By doing so, they are now members of the Breath of Hope Legacy Society. To learn more, please contact The LAM Foundation at info@thelamfoundation.org. If you have made a planned gift to the Foundation, please let us know so we can recognize your name with a pink feather.

MG The MG denotes companies that offer matching gifts. If your company has a matching gift program, please contact your HR Department to find out how to request a matching gift donation to The LAM Foundation.

The LAM Foundation has made every effort to be as accurate as possible when creating our list of contributors. 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.



4015 Executive Park Dr., Ste. 320
Cincinnati, OH 45241
513.777.6889
info@thelamfoundation.org
www.thelamfoundation.org

BLACK FRIDAY. CYBER MONDAY.

#GIVINGTUESDAY

DECEMBER 2, 2014

#GivingTuesday: A national day of giving back during the holidays

#GivingTuesday on December 2, 2014, is a national movement around the holidays dedicated to giving, similar to how Black Friday and Cyber Monday have become synonymous with holiday shopping. Whether you have finished your holiday shopping or are still working on your list, we hope you take a moment, this holiday season, to include The LAM Foundation as part of your holiday giving.

Here are four easy ways you can help on #GivingTuesday:

1. Make a donation to The LAM Foundation for #GivingTuesday. Your gift inspires new research, educates patients and families, and generates funds for a cure. Donate at www.thelamfoundation.org.
2. Post on Facebook, Tweet, E-mail, Instagram, blog about the Foundation and #GivingTuesday. Use #LAMGivingTuesday.
3. Make your own "I'm giving to The LAM Foundation on #GivingTuesday because _____" sign.
4. Take a picture with your sign and share it on Facebook, Twitter or Instagram using #LAMGivingTuesday OR e-mail it to vhux@thelamfoundation.org. We will be sharing these throughout the day on our Facebook page.