



# JOURNEYS

A COMPREHENSIVE JOURNAL ON LAM RESEARCH, PATIENT ADVOCACY, EDUCATION AND AWARENESS PROVIDED BY THE LAM FOUNDATION

## Innovation is the Key to Maintaining Momentum in LAM

BY FRANK MCCORMACK, MD, LAM FOUNDATION SCIENTIFIC DIRECTOR



LAM is blessed with the fastest moving science in all of pulmonary medicine. There are four reasons for this gift, in my opinion, which include: 1) fantastically effective patient advocacy, 2) involvement of a molecular pathway that is fundamental to cell biology and cancer, and which attracts interest from the highest caliber scientists, 3) synergies with the tuberous sclerosis community, which laid the groundwork before the Foundation existed and continues to innovate and inspire, and 4) reciprocal collaborations with rare lung disease communities. I want to expand the last point a bit more, because it probably gets less press in Journeys than the other three.

When The LAM Foundation was just getting started, Sue Byrnes and I visited Bob Beall of the Cystic Fibrosis Foundation and connected with John Walsh, founder of the Alpha-1 Foundation, to learn what we could about effective approaches to advancing the science in a rare disorder. Both organizations were unfailingly generous with advice and sharing of documents and policies. Interactions between Sue Sherman and the COPD Foundation, the brain-child that John Walsh created to accelerate the diagnosis and treatment of COPD and Alpha-1 patients, have continued on an almost daily basis to this day. They have invited LAM and other rare lung diseases to piggyback on their epic effort to develop a web-based platform for communication (patient to patient, patient to physician and physician to physician), data collection and disease management. They are developing apps for smartphones that will enable patients to easily track their own data and to participate in research. Physicians around the world will be able to share cases complete with x-ray and pathology images to get immediate input about rare and difficult to diagnose diseases. Patients can discuss issues with each other and with physicians in a searchable and monitored environment that focuses discussion and censors uninformative chatter. These tools of the future would likely have been beyond the immediate reach of the LAM community, which has a finite budget for large scale projects.

The LAM Foundation has reciprocated with welcoming invitations for collaboration to other rare lung disease communities. The LAM Clinic Network (LCN) is an excellent example. The

LCN has been an extremely successful platform to focus LAM patients to referral centers, nurture expertise, improve quality of care and facilitate research. Patients with other cystic and chylous lung diseases that turn out not to be LAM have been correctly diagnosed with Birt-Hogg-Dube (BHD), pulmonary Langerhans cell histiocytosis (PLCH) and lymphangiomatosis in LAM clinics. We have now invited these rare lung disease communities and over a dozen others to 'deliberately' refer their patients to LAM Clinics, and they have now each posted the LCN on their own websites. As it has grown to over 55 sites and 15,000 patients (including >3,000 with LAM), the LAM Clinic Network has become the platform for the Rare Lung Disease Clinic Network (RLDCN). Due largely to its expanded scope, has attracted over \$3 million dollars in NIH funding and provided a mechanism to establish registries, and conduct trials and other studies in LAM, Hermansky-Pudlak Syndrome, PLCH, BHD, and pulmonary alveolar proteinosis (PAP), to name a few. The diversity of pathology keeps LAM Clinic Directors interested and engaged, and elevates the profile of their unique expertise at their own institutions. We are all learning together how to diagnose and treat the rarest of disorders, and accelerate trials by developing a central Institutional Review Board and innovative approaches to contracting. It's important to also remember that the first iteration of the Rare Lung Diseases Consortium provided critical infrastructure and expertise that made the MILES trial possible.

Innovation is the key to maintaining momentum in LAM. So for the second time in history, LAMposium will be held in conjunction with the Rare Lung Diseases Consortium meeting (Sept 22-25, 2016 in Cincinnati). The meeting, titled RLDC•2016, is uniquely focused on providing value to LAM Clinic Directors and to patient advocacy organizations. The first day, Friday, will be devoted to a medley of presentations about rare and ultra-rare lung diseases that could potentially be referred to the RLDCN. On Friday evening, Frank Sasinowski, former Director of the National Organization of Rare Disorders, will deliver an address about the promising future for rare lung diseases. On Saturday, there will be a one day LAMposium devoted to lung matrix chaired by Drs. Robert Kotloff and William Parks. There will also be workshops devoted to PLCH, genetic lung disease and PAP; disease communities that are poised for rapid progress. A patient

and family track on Friday and Saturday will present topics of broad interest to all patients and families affected by rare lung diseases. The LAM Breath of Hope Gala will occur, as always, on Saturday night. On Sunday morning, patients will be updated about LAM progress by conference chairs, and the first ever LAM and Rare Lung Disease Clinic Director Congress will be held to discuss in roundtable fashion the opportunities for collaboration and progress in the RLDCN. This will be the largest conference devoted to Rare Lung Diseases ever held, and promises to attract interest from federal agencies and pharmaceutical companies that would not have been possible for an individual disease conference.

LAM has been the focus of a lot of attention since the FDA approved sirolimus for LAM in May 2015. LAM was a centerpiece of recent addresses by Dr. Chris Austin, Director of National Center for Accelerating Translational Science (NCATS), and Dr. Francis Collins, Director of the NIH, who opened the Rare Disease Day Conference with the LAM community achievements. The LAM story has been prominently featured on the NCATS website as well.

I am convinced that the next 'day in the sun' for LAM will be how the LAM community has advanced the cause of all rare lung diseases, and in the process, advanced itself.

## New Lungs, New Life, New Discovery

BY SUSAN E. SHERMAN, LAM FOUNDATION EXECUTIVE DIRECTOR



Women in the LAM community who have survived lung transplant are wonderfully grounded, joyful and abundantly generous. Without exception, they share their joy of living, their delight with children and loved ones, and a special warmth and gentle wisdom. When in the presence of a woman with LAM who also has new lungs,

life slows, time has meaning, smiles matter. It is an exquisite experience to share moments with those who know what it means to count each one.

In my conversations with post-transplant survivors, they emphatically cherish their LAM sisters, and share a desire to pave a smoother road to health, whether it be through transplant or other-, less invasive methods. They uniformly support efforts to harvest and distribute tissue to further research. In the words of one woman with new lungs, "...my LAM lungs gave me all they had, and it was an absolute necessity in my mind that they would be donated for research, so that others might avoid what I had to go through." From her perspective, the gift of new lungs meant her LAM lungs would contribute to new discovery for others.

Current animal and cell models for LAM are very useful but also have serious limitations, and there is no substitute for studying the disease in humans. If we are ever to develop a cell line that authentically mimics the behavior of LAM cells, it will come from fresh tissue. New techniques that can be used to sequence every gene product in individual cells from freshly isolated lungs promise to unlock new secrets about LAM. While in Philadelphia recently, I asked Vera Krymskaya, PhD, MBA and LAM researcher, what it meant to her as a scientist to have access to lung tissue, and she replied, "Everything. It meant everything to the discovery of the LAM gene and it's what paved the way for the current treatment of LAM. We must have access to fresh explanted LAM lung tissue to find a cure for LAM."

In 2015, the good news was that the annual number of lung transplants for women with LAM was at the lowest level in 17 years, with just 6 procedures in the U.S. While we don't know for certain, we suspect that this is a result of the effectiveness of sirolimus, the only FDA approved treatment for LAM. Yet, our LAM scientists still need fresh and frozen tissues to continue the search for a cure, and there were only six opportunities in

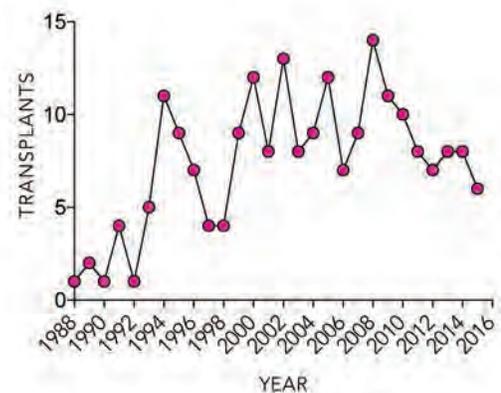
all of 2015. With only one transplant every other month, we cannot afford to miss a single opportunity to capture precious tissue from every procedure, which is otherwise simply discarded. While a lung transplant is the most abundant source of LAM tissue for research, it is only performed on patients with advanced LAM, and cannot yield critical information about earlier stages of the disease. LAM researchers also desperately need fresh tissue from lung biopsies, kidney tissue from resection, and chyle samples.

Successful collection of tissue for research requires careful planning. Operations tend to occur in the middle of the night. Patients and families are understandably anxious and preoccupied. Collection of the research sample is not at the top of the priority list for the surgical team. Pathologists loathe releasing precious tissue for research until they are certain that all clinical information needed has been extracted. Time is of the essence, since tissue starts to die as soon as it is removed.

Every member of the team, from patient, to surgeon, to pathologist, to the coordinator doing the preparation and shipping, needs to be fully apprised of the plan and faithfully execute their role. We heavily rely on LAM Clinic Directors and Coordinators for assistance when their site is involved with a transplant or other procedure.

If you are being evaluated for transplant, are on the transplant list or have other surgeries planned, please contact Anne McKenna at The LAM Foundation. Your tissues may help unlock new treatments or a cure for your LAM sisters.

UNOS TRANSPLANTS FOR LAM



# First Female PhD Tenured at UPENN Department of Medicine is LAM Investigator

BY NICOLE WIPP, DIAGNOSED IN 2015



This past summer, Vera Krymskaya, PhD, MBA, was named the first female PhD tenured professor at the Department of Medicine at the 251 year old Perelman School of Medicine at the University of Pennsylvania. She is a pulmonary disease researcher who has been instrumental in the advancement of LAM research.

Curiosity and solving puzzles has driven Dr. Krymskaya to become an accomplished investigator. She sees diseases as puzzles that need to be solved and uses her curiosity to drive her research.

When Dr. Krymskaya first heard about LAM, she remembers being very excited to solve this “puzzle” to help patients with a deadly disease. The gene mutation that triggers LAM had been discovered by Elizabeth Henske, MD. However, it wasn’t yet known how the mutation caused LAM. Dr. Krymskaya, captivated by the enigma before her, proceeded down the path of research investigation.

The LAM Foundation played an instrumental role in supporting Dr. Krymskaya as she investigated key pieces of the LAM puzzle. She wrote a pilot research project proposal and presented it to The LAM Foundation for funding. The LAM Foundation awarded Dr. Krymskaya a one-year, \$25,000 research grant in 2000. Conducting the initial experiments herself, Dr. Krymskaya discovered that the mTOR pathway in LAM patients is abnormally and excessively active. Using unique lung tissue donat-

ed by LAM patients, she derived LAM cells to demonstrate that treatment of these cells with rapamycin stops LAM cell growth. This discovery provided a year’s worth of data used to support her first NIH research grant proposal. She was awarded a four year grant from the NIH, providing approximately \$800,000 in additional research funding. Further breakthroughs, facilitated by the NIH grant, ultimately contributed to the first FDA approved treatment for patients with LAM.

“When I submitted my first application to The LAM Foundation, it was for a pilot study that ultimately generated important preliminary data that led to the NIH funding and the continuation of my research. I would say I am very lucky to be able to study LAM and work with LAM patients and be part of the LAM community”, says Dr. Krymskaya.

Being the first female tenured professor PhD at UPENN Department of Medicine is a huge accomplishment that Dr. Krymskaya is extremely proud of. While she acknowledges that women must work hard to excel in this male-dominated field, she says that by doing your best and being persistent, women can be successful. “There is a special place for women in academia. When women are authentic and follow their true passion, they can be very successful!”

The LAM Foundation is extremely grateful of all the hard work that Dr. Krymskaya has done to accelerate LAM research. To learn more about her current study and how you can participate, visit the Current Trials and Studies page on the Foundation’s website.

## The LAM Foundation Awards \$350,000 to LAM Researchers

The LAM Foundation is proud to announce their 2015 Grant Awardees. Because of your generous donations, the Foundation was able to award \$350,000 to advance LAM Research by offering four grants. Thank you to members of the LAM Scientific Advisory Board (SAB) for meeting in November of 2015 and recommending finalists to the Foundation’s Board of Directors.

### ESTABLISHED INVESTIGATOR AWARDS



**CAROLINE LE POOLE, PHD**

LOYOLA UNIVERSITY  
CHICAGO, IL

T Cell Receptor Transduced T Cells Supported by Anti-PD-1 to Treat LAM



**KUNIAKI SEYAMA, MD, PHD**

JUTENDO UNIVERSITY  
TOKYO, JAPAN

Exploring Pathobiology of LAM Through Isolation of Cellular Components



**MICHAEL BORCHERS, PHD**

UNIVERSITY OF CINCINNATI  
COLLEGE OF MEDICINE  
CINCINNATI, OH

NKG2D Receptor – Ligand Interactions in LAM Pathogenesis



**JOSHUA FESSEL, MD, PHD**

VANDERBILT UNIVERSITY  
NASHVILLE, TN

Use of 18F – Glutamine PET in the Diagnosis of LAM and other Pulmonary Diseases

## Two LAM Pilot Studies Receive Million Dollar Bike Ride Grants

In just two years, The LAM Foundation along with our LAM Easy Breather's cycling team raised more than \$200,000 that has been awarded to four LAM researchers for pilot studies.

Congratulations to the following 2015 LAM Researchers who were awarded \$50,500 for their pilot studies in 2015!



**DAVID KWIATKOWSKI, MD, PHD**

- Brigham and Women's Hospital, Boston, MA
- TSC2 Mutation Analysis as a Biomarker for Lymphangiomyomatosis (LAM)

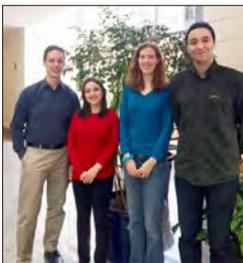


**NORBERT PERRIMON, PHD**

- Harvard Medical School, Boston, MA
- An shRNA Based Screening Method for TSC Synthetic Lethal Screens

## A New Function of mTOR with Implications for LAM Cell Growth

ARTICLE PUBLISHED FEBRUARY 2016 IN SCIENCE MAGAZINE, SUMMARIZED BY BRENDAN MANNING, PHD, AND ISSAM BEN-SAHRA, PHD, HARVARD T.H. CHAN SCHOOL OF PUBLIC HEALTH, BOSTON, MASSACHUSETTS

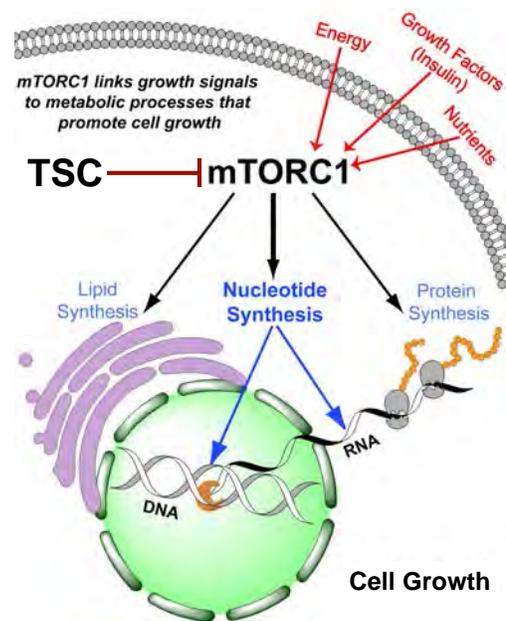


**THE "MTOR AND NUCLEOTIDE TEAM" IN THE BRENDAN MANNING LAB.**

**From the left to the right:** Brendan Manning, PhD, Gerta Hoxhaj, PhD, Jessica Howell, PhD, and Issam Ben-Sahra, PhD.

Cells in our body can be stimulated to grow and make more cells, such as during normal developmental growth, during the healing of wounds, and upon activation of immune cells in response to pathogens. Our recent studies show how the TSC-mTOR pathway controls the synthesis of pyrimidines<sup>1</sup> and purines<sup>2</sup>, which are nucleotides that are essential for making new DNA during cell growth. This work, coupled with previous studies establishing the role of mTOR in promoting protein and lipid synthesis, demonstrates that mTOR is a master regulator of biosynthetic metabolism, linking growth signals to the synthesis of the major materials needed to build more cells and bigger cells.

Not only did we demonstrate this new synthetic function of mTOR, we also show that nucleotide synthesis is uncontrolled when TSC function is lost. Loss of control over mTOR and these biosynthetic processes is what underlies the uncontrolled growth of LAM cells which also exhibit mTOR activation. More specifically, our study suggests that uncontrolled mTOR signaling in LAM and TSC cells contributes to the unrestrained growth of these cells, at least in part, by increasing the nucleotide pool required to meet an increased demand for RNA and DNA during growth. While we show that mTOR inhibitors such as rapamycin (sirolimus) block these new functions of mTOR, ongoing studies in our lab are testing the possibility that directly inhibiting nucleotide synthesis with available clinically safe compounds offers a therapeutic approach to LAM and TSC that is an alternative to mTOR inhibitors.



Courtesy of Jessica Howell

<sup>1</sup>Ben-Sahra I\*, Hoxhaj G\*, Ricoult SJH, Asara JM, Manning BD. mTORC1 induces purine synthesis through control of the mitochondrial tetrahydrofolate cycle. *Science* 12 Feb 2016; Vol. 351, Issue 6274, pp. 728-733 DOI: 10.1126/science.aad0489

<sup>2</sup>Ben-Sahra I\*, Howell JJ\*, Asara JM, Manning BD. Stimulation of de novo pyrimidine synthesis by growth signaling through mTOR and S6K1. *Science*. 2013 Mar 15;339(6125):1323-8. doi: 10.1126/science.1228792. Epub 2013 Feb 21.

# Multiple Benefits and Safety of Exercise Performance in Patients with LAM

ARTICLE PUBLISHED FEBRUARY 2016 IN THE EUROPEAN RESPIRATORY JOURNAL, SUMMARIZED BY BRUNO GUEDES BALDI, MD AND CARLOS ROBERTO RIBEIRO CARVALHO, MD, PULMONARY DIVISION, HEART INSTITUTE (INCOR), UNIVERSITY OF SÃO PAULO MEDICAL SCHOOL, SÃO PAULO, BRAZIL



BRUNO GUEDES, BALDI, MD



CARLOS ROBERTO RIBEIRO, MD

Several studies have shown that exercise intolerance and dyspnea are common complaints among patients with LAM, which are secondary to multiple mechanisms and contribute to decreased quality of life. The decision to conduct a study to investigate the impact and safety of pulmonary rehabilitation in LAM was based on our previous experiences in following patients that performed regular physical activities. It seemed to us that even those patients that had greater impairments in pulmonary function tests, but performed regular physical activities, experienced lower breathlessness and also had a better quality of life. Another relevant issue is that there is a myth, even among some respiratory physicians, that patients with cystic lung diseases, including LAM, should not perform exercise due to a higher risk of developing complications, mainly pneumothorax. However, during follow up of our patients over the years, we speculated that there was no increased risk associated with exercise in patients with LAM.

We performed a clinical trial that assessed the safety of exercise and impact of pulmonary rehabilitation in 40 patients with

LAM. We examined several variables, including exercise capacity, quality of life, level of dyspnea, symptoms of anxiety and depression, daily physical activity, pulmonary function tests, and muscle strength.

The pulmonary rehabilitation program consisted of 24 sessions of 1 hour duration (twice weekly) divided into 30 minutes of aerobic exercise on a treadmill and 30 minutes of muscle strength training. Patients also received education on different themes related to LAM, such as physiopathology treatment, self-management, and exercise. Our program had a high rate of adherence (at least 95% for all patients).

After pulmonary rehabilitation, LAM patients reported improved exercise tolerance and muscle strength and could exercise more frequently. In addition, they noted an improved quality of life with less breathlessness and fewer symptoms of depression. These changes occurred in the absence of any improvement in lung function tests, suggesting that the rehabilitation-induced increases in exercise capacity were due to an improvement in peripheral muscle function. Importantly, no pneumothorax or other severe complications during the program were observed.

We conclude that physical activity is beneficial and likely safe in patients with LAM. Although improvements in lung function are important targets in assessment responses to interventions in LAM, the impact on other outcomes, such as exercise capacity, quality of life, dyspnea and depression symptoms, is also highly relevant since all these variables improve after pulmonary rehabilitation. Women with a LAM diagnosis should consult with their pulmonologist or LAM Clinic about the benefits of participating in a pulmonary rehabilitation program. Insurance coverage and out-of-pocket costs should also be investigated when considering enrolling in a program.

## Study May Lead to Potential Drug Targets for Tumor Formation in Pulmonary TSC

ARTICLE PUBLISHED FEBRUARY 2016 IN THE AMERICAN ASSOCIATION FOR CANCER RESEARCH'S JOURNAL *CANCER RESEARCH*, SUMMARIZED BY JEANINE D'ARMIENTO, MD, PHD, LAM CLINIC DIRECTOR AT PRESBYTERIAN/COLUMBIA, NEW YORK, NEW YORK



In a new study published in the American Association of Cancer Research's journal, *Cancer Research*, the laboratories of Drs. Jeanine D'Armiento and Kiran Chada identified a gene, HMGA2, that may provide a new source of potential drug targets for tumors that arise in tuberous sclerosis complex (TSC).

Several years ago their group detected the presence of the gene HMGA2 in the lungs of patients with LAM. HMGA2 is a major molecular player in mesenchymal tumor formation. It is expressed only during development and is absent in normal

adult tissue. When mis-expressed in adult tissue, HMGA2 has also been shown affect mesenchymal differentiation, proliferation, and tumorigenesis.

Building on the prior research, LAM investigators Kiran Chada, D.Phil. (Oxon.) and Jeanine D'Armiento, MD, PhD, demonstrated in their new study that the HMGA2 gene and its signaling pathway are required to produce tumors in the lung and kidneys in a TSC mouse model. The study not only shows that HMGA2 is necessary for the formation of tumors, but its absence completely eliminated tumor formations in animal models of TSC. This new research contradicts the concept that mammalian target of rapamycin (mTOR) is the only molecule essential for tumor growth in TSC. Unlike the HMGA2

pathway, which was active in 100 percent of all the tumors in TSC, the mTOR pathway was not always active in animal and human tumors. Supporting this concept, tuberin, which is expected to be absent, was expressed in both human and mouse TSC-associated tumors.

“We were very surprised, but also excited regarding our investigations, which represent a radically different view on the

mechanism of tumor formation in tuberous sclerosis and presents a shift in our understanding of this syndrome”, said Dr. D’Armiento. The discovery of the role of HGMA2 in tumor development in TSC may have broader implications in cancer research. The studies also provide a new target for which therapies may be developed to suppress HGMA2 in individuals with TSC, LAM and other progressive tumor disorders.

## My Journey with Sirolimus Desensitization

BY LAURA BOWERS, DIAGNOSED 2013



My name is Laura, and I was diagnosed with LAM on December 22, 2013. That fall, I experienced three important milestones in my life: I turned forty years old, my five-year-old daughter started kindergarten, and I completed my first semester of pharmacy school. Receiving a diagnosis of LAM was quite a shock. Under the care of my LAM clinic doctor I started low dose sirolimus, and immediately

felt better, noticing an improvement in my breathing. Friends and family noticed my ability to participate in physical activities improved and my shortness of breath decreased.

For 8 weeks I thrived, experiencing minor side effects and breathing easier for the first time in years. I continued my busy routine of working, going to pharmacy school, and being a wife and mother. One morning I woke up and had difficulty seeing. Since I wear contact lenses, I immediately thought that maybe I needed to swap out my lenses. I continued through my morning routine, making a mental note to buy new lenses. Later, when I finally had time to look in the mirror, I realized that the reason I could not see was because my eyes were nearly swollen shut.

While I thought my swollen eyelids were very odd, I did not think much of it. I threw on my eyeglasses, took my daily dose of sirolimus, and left for school and work. After classes ended and before my night class began, I stopped in the bathroom and noticed that the swelling was worse and I now had red streaks across my face. I finally started to wonder if something bigger was going on. I called my LAM clinic doctor and asked, “Could this be an allergic reaction to sirolimus?”

Because I was just starting pharmacy school, I had not yet learned about allergic reactions to medications. I discovered that yes, you can have an allergic reaction months after starting a medication. It is called a type I allergic reaction. This type

of delayed allergic reaction is common with certain blood pressure medicines, and can happen after successfully taking a medicine for years. This type of allergic reaction generally progresses rapidly, causing redness and swelling of the face, mouth, or tongue over a period of hours or even minutes. The medical term for this is called angioedema, and it can lead to anaphylactic shock or even death if it goes untreated. Anyone with these symptoms should immediately call 911. Luckily for me, the progression of the allergic reaction was slower and therefore not a true emergency. That said, I quickly gained first-hand knowledge for how confusing and scary angioedema and anaphylaxis can be for patients. As a future pharmacist, this experience was both frightening and invaluable.

I was fortunate to avoid a trip to the emergency room; however, I now had a new problem. I could no longer take sirolimus. This treatment had improved my breathing significantly, and once I stopped taking it I noticed changes immediately. My shortness of breath increased, and I could feel the difference in my everyday activities. While I appreciated learning in a medicinal chemistry class the reason for this rapid decline in breathing upon stopping my sirolimus, my chief concern was how I could safely start taking this medicine again.

Working with my LAM clinic doctor, we made several medically supervised treatment attempts with sirolimus and then everolimus. Unfortunately between the allergic reaction and nausea, I was unable to find a way to safely take this important medicine. Almost one year later, I flew to the Cleveland Clinic to meet with a director of the LAM Clinic to discuss a drug desensitization process cited in the literature.

Over spring break in March of 2015, I checked into the ICU at the Medical University of South Carolina in Charleston. Under the close supervision of a team of physicians, I was given increasing doses of sirolimus over a 6 hour period. The procedure “desensitized” my body to sirolimus. Now as long as I take my medicine every day, without missing a single dose, I should not experience another allergic reaction to sirolimus.

Though my allergic reaction to sirolimus is considered extremely rare, I share my story with the LAM community to raise awareness of both the possibility and the positive outcome. I am grateful to the LAM clinic caregivers and all of my clinicians who listened and responded to me on my journey.

# Clinic Directors' Perspectives On Sirolimus Desensitization

BY DAN DILLING, MD, LOYOLA UNIVERSITY MEDICAL CENTER, ROBERT KOTLOFF, MD, CLEVELAND CLINIC AND FRANK MCCORMACK, MD, UNIVERSITY OF CINCINNATI

Rare diseases present many questions, complications and few clear answers. Women with LAM and more broadly, people affected by rare diseases are uniquely challenged to find and access clinicians with expertise in treating their



condition as well as in developing relationships that allow for comfortable dialogue in the face of uncertainty. Whether it be decisions about diagnostic procedures, treatment options, side effects, or quality of life, both the patient and caregiver are required to balance many variables: the known and unknown; advocating and listening; comfort and fear.

In the case of Laura Bowers' allergic reaction to sirolimus, all of these variables were in play. Importantly, she located

and had access to two LAM Clinics with caregivers who were familiar with both the disease and the treatment. Both she and her clinicians made a sincere effort to listen and explore the situation and possible solutions. While her allergic reaction became certain, how to proceed was unknown. Through searching the literature, and thoughtful consideration, they arrived at a solution that was ultimately successful. Comfort can be derived from this positive outcome.

Similarly, fear can easily be generated as patients read her story and wonder if they too might experience an allergic reaction. On the positive side, such reactions are extremely rare and only a handful have been reported during the last 20 years. Desensitization efforts are not always successful. Desensitization was followed by recurrent allergy to everolimus for a patient at another LAM clinic, and the medication had to be stopped once again.

These cases demonstrate that we continue to learn from each other as patients and caregivers and across the network of LAM Clinics and the patient community. When patients seek care at our clinics, they will find knowledgeable clinicians who will in turn advance the larger understanding with benefits for all.

## The LAM Clinic Lifeline

BY JENN TURNER-DOLD, DIAGNOSED 2010/ TRANSPLANTED 2012 AND LAM CLINIC DIRECTOR, MEILAN HAN, MD, MS, UNIVERSITY OF MICHIGAN HOSPITAL; DIVISION OF PULMONARY AND CRITICAL CARE, ANN ARBOR, MICHIGAN



So many doctors, so many tests, so few answers. The phrase "I have never seen this before" was becoming all too familiar. By the age of 28, I had racked up a long list of diagnoses including severe asthma, polycystic ovarian syndrome, endometriosis, thrombocytosis, and anemia. Then angiomyolipomas were found. As I researched these kidney tumors and read about LAM, I remember thinking, "This sounds a lot like me." I printed out some information and asked my family doctor if we should do a CT. He said, "You don't need a CT. This is super rare. You don't have this." Thank goodness. I really didn't want this incurable disease.

Fast forward six years to March 2010. I was having more frequent breathing problems. I started coughing up blood in the mornings and was finally referred to a pulmonologist. He ordered a long-overdue CT, then met us at the hospital and said to me, "Let's go down the hall and talk." He pulled up my scans and said, "I have only ever seen this in textbooks. I think you may have lymphangioleiomyomatosis. Can I share this with a few of my colleagues to confirm? And don't Google this." Well, I didn't have to. I knew we finally had our answer.

Within a week of this tentative diagnosis, I was provided sup-

plemental oxygen and referred to the LAM Clinic at the University of Michigan where I met Dr. MeiLan Han. She reviewed my medical history, my labs, and CT scans. She then confirmed that nearly all of my medical issues were related to LAM. For the first time in my life, a doctor knew what was wrong. It was such a relief to finally have an answer and yet I anxiously held my breath as she educated my family on the disease, statistics, and the long road ahead. I discovered my disease was already quite advanced. My best chance for survival was a double lung transplant. Dr. Han explained that I needed to lose weight and pass a multitude of other medical tests to be eligible for a transplant. She put together a plan for me to work with a local nutritionist, enroll in pulmonary rehab, and be followed by the University of Michigan LAM Clinic.

I know that I would not be alive today if I had not been referred to the University of Michigan LAM Clinic. For the first time, my family wasn't facing this battle alone. If you also have LAM and are not yet associated with a LAM Clinic, my advice would be to ask for that referral. One of the biggest benefits was to have a multidisciplinary medical team working for me. A LAM Clinic is more than just the pulmonologist. This is a disease that can affect your entire body. LAM Clinics have a team of experienced physicians in nephrology, urology, radiology, ob/gyn, pathology and more. This gives you the convenience of having all of your testing and treatments done within one medical team. Another benefit is access to the LAM network of physicians across the country. I know that Dr.

Han has tapped into this resource many times to assist with my care, whether it was to obtain advice from other physicians or find additional resources for me. There is a team of physicians waiting to formulate a personalized treatment plan for you.

It is teamwork that helped keep me alive until I received my double lung transplant in February of 2012. Once I became a transplant patient, my care was transitioned from the LAM Clinic to the Pulmonary Transplant Team at the University of Michigan. Luckily I was able to continue care with Dr. Han

because she is part of both teams. She has seen me go from a nasal cannula to non-rebreather to BiPAP, from transplant to tracheostomy and vent, to finally to breathing on my own. The continuity of my care with the LAM Clinic has been critical to improving my quality of life, my recovery, and my rehabilitation. I turned 40 this summer and just celebrated my 4th Breathday! Every day isn't easy, but every day is blessed with the help of my LAM Clinic Lifeline! **StrongerTogether**

## LAM, Menopause and Intimacy

BY LISA LARKIN, MD, UNIVERSITY OF CINCINNATI HEALTH WOMEN'S CENTER, CINCINNATI, OHIO



Management of menopause and sexual complaints in women with LAM is complicated because of the uncertain link between hormones and disease progression. What we do know is that LAM patients are usually diagnosed before menopause and LAM cells possess estrogen receptors (ER) and progesterone receptors (PR).

However, the impact of hormones on LAM progression remains unclear. Studies of hormones in LAM show mixed results. In the placebo arm of the MILES trial, the rate of decline in lung function decreased dramatically in the year after menopause supporting a possible negative impact of estrogen on disease progression, but the link is uncertain. Studies of LAM progression in high estrogen states, such as pregnancy, are mixed. Last year at the International LAM Research Conference and LAMposium, data was presented showing stability of lung function in 8 women before, during and after pregnancy. This is in contrast to prior case reports of pregnancy in LAM patients leading to disease exacerbation. Additionally, studies of anti-estrogen approaches, such as oophorectomy, progestins, GnRh agonists (leuprolide, goserelin) and selective estrogen receptor modulators (SERMs) have shown mixed and inconclusive results. In fact tamoxifen, a SERM with estrogen antagonist and agonist properties, has been linked to exacerbation in some patients. A multicenter trial of estrogen suppression with letrozole, an aromatase inhibitor, is underway in the United States and will hopefully shed more light on the relationship between estrogen and LAM disease progression.

Taken in totality, current evidence suggests a link between estrogen and LAM progression. With this understanding, clinicians caring for LAM patients do not encourage pregnancy, and are reluctant to prescribe any form of hormone therapy to LAM patients for menopause symptoms. As a result, menopause management and management of sexual health complaints in LAM patients are often not addressed by patients or their physicians because of the perception that there are no treatments available.

Menopause by definition is no menstrual bleeding for 12 months. It marks the end of fertility, and a low estrogen state as a result of loss of ovarian function. The average age of natural menopause in U.S. women is 51 years, and 60-90% of women experience menopause related symptoms. The most common symptoms are vasomotor symptoms, which include hot flashes and night sweats, and for many women these symptoms lead

to significant physical discomfort and impaired quality of life. Other common symptoms include mood disturbances, such as increased anxiety and depression, cognitive and memory complaints, hair and skin changes, and sexual complaints including decreased libido, vaginal dryness, and pain with intercourse. Menopause symptoms are related to the decline in estrogen levels, and the most effective treatment for menopause related symptoms is estrogen.

Menopause related symptoms peak in the year prior to through the year after the final menstrual period. Women who transition through menopause abruptly, either due to chemotherapy or surgery, have the most severe symptoms. For the majority of women, menopause symptoms related to menopause will gradually improve and resolve within 5 years. The notable exception is sexual complaints which increase with time from menopause. However approximately 15-20% of women will have persistent vasomotor symptoms throughout their lifetime.

The primary indication for hormone therapy is to treat menopause related symptoms in healthy women close to the menopause transition (NAMS 2012 Position Statement). Standard hormone therapy reduces the frequency and severity of hot flashes and night sweats by 90%. Thanks largely to 13 years of data from the Women's Health Initiative (WHI) we understand the other benefits and the risks of hormone especially as it relates to breast cancer and cardiovascular disease. Hormone therapy has beneficial effects on bones, reduces insulin resistance, and in younger, but not older women, decreases cardiovascular risk. For most women the most worrisome risk of hormone therapy is breast cancer. Data from the WHI demonstrates a small increase in breast cancer risk with short-term combined estrogen and progestin therapy, which increases with duration of use. In total, the risk benefit profile is favorable for short-term hormone therapy in young healthy women and is the most effective option.

Estrogen therapy is, however, contraindicated in women with a history of breast cancer, stroke, heart disease, clotting disorders and by extrapolation from existing data suggesting an association between LAM and estrogen, LAM patients. In patients with contraindications such as LAM patients, lifestyle, complementary and alternative medicine (CAM) and non-hormonal pharmacologic options are the only option available for symptom management.

Studies support the benefit of lifestyle measures such as wearing layered clothing and setting the room temperature lower. Avoidance of alcohol and regular exercise positively

impacts the frequency and severity of hot flashes and night sweats. CAM approaches such as paced respiration, yoga, mindfulness, meditation, massage and acupuncture have all shown modest benefit. Studies of supplements have in general been negative, with the exception of studies of soy. Soy, a phytoestrogen, weakly binds the estrogen receptor and has weak estrogenic effects. When soy is consumed in large quantities it does reduce the frequency and severity of hot flashes in some patients but only modestly. In patients with a contraindication to estrogen, excessive soy intake is controversial.

Mechanistically, hot flashes are attributed to a malfunction in the area of the brain, the preoptic nucleus

of the hypothalamus, which controls thermoregulation. This area is densely innervated with serotonin and estrogen receptors. Core body temperature is regulated by the balance of neurotransmitters, serotonin and norepinephrine. The preoptic nucleus of the hypothalamus is estrogen and non-hormonal medications that improve hot flashes appear to act centrally. Non-hormonal pharmacologic options for treatment of vasomotor symptoms include SSRI and SSRI antidepressants, clonidine and gabapentin. Until 2013 there was no FDA approved non-hormonal medication and their use was “off label”.

## Navigating Common Surgical and Diagnostic Procedures

BY ELIZABETH HENKE, MD, LAM CLINIC DIRECTOR, BRIGHAM AND WOMEN'S HOSPITAL AND FRANK MCCORMACK, MD, THE LAM FOUNDATION SCIENTIFIC DIRECTOR AND LAM CLINIC DIRECTOR, UNIVERSITY OF CINCINNATI MEDICAL CENTER



**W**hat should you know or ask when faced with the more common surgical or diagnostic procedures related to LAM?

Biopsies and/or surgery are sometimes necessary in LAM. In general, before undergoing a procedure, it is important to know why the procedure is being done, what the risks are, and whether an alternative should be considered.

An expert opinion from a specialized LAM Clinic is always the most important step, when possible, prior to any biopsy or surgical procedure. It is also important to be aware that sirolimus and everolimus inhibit wound healing, and need to be held in the perioperative period.

**Lung biopsy** A lung biopsy may be recommended to establish a definite diagnosis of LAM. Often a diagnosis of LAM can be established without a biopsy. For example, if the CT shows cysts characteristic of LAM and there is a diagnosis of tuberous sclerosis complex (TSC), a chylous pleural effusion, a renal angiomyolipoma, or an elevated VEGF-D level in the blood, a biopsy may not be needed to make a diagnosis of LAM. A transbronchial biopsy can often be used to establish a diagnosis of LAM vs. a video-assisted thoracic surgical (VATS) biopsy. It is estimated that the diagnosis of LAM can be made in more than 75% of patients without biopsy, and in general, the least invasive path to a definite diagnosis is best. **An expert opinion from a LAM Clinic is always advised prior to lung biopsy.**

**Kidney surgery** Angiomyolipomas are slow growing tumors that don't generally spread, but can bleed spontaneously as they become larger. Usually, the diagnosis of angiomyolipoma can be made by a CT scan or MRI scan alone, when it reveals fatty tissue within the tumor. If the kidney tumor has a more solid appearance, without the tell-tale fat signature of angiomyolipomas, a needle biopsy of the tumor may be recommended to be sure it is not a more aggressive type of growth. Treatments for angiomyolipomas are very different than those for other kidney growths, so it is important to be sure of the tumor type. The size of the

angiomyolipoma is important in decisions regarding treatment. Guidelines state that treatment with an mTOR inhibitor is the first line approach to angiomyolipoma treatment. However, a kidney procedure may be recommended to treat an angiomyolipoma in certain circumstances. Catheter-based embolization is the most common approach to reduce the size of angiomyolipomas. If surgery is recommended for the treatment of an angiomyolipoma, it is important to ask the physician if other possible treatments such as embolization have been considered. If kidney resection is required, a “nephron-sparing” approach that preserves as much normal kidney as possible should be used. If there is active bleeding, an urgent procedure may be required. **An expert opinion from a LAM Clinic is very important prior to kidney surgery unless it is an urgent situation.**

**Pleurodesis** Pleurodesis is often recommended to prevent future pneumothoraces or chylothoraces. The European Respiratory Society Guidelines concluded that pleurodesis should be performed on the first pneumothorax to prevent recurrences and future hospitalizations. There are several ways in which pleurodesis can be performed. Some of these may influence the likelihood of bleeding during a future lung transplant, if that were ever to be required. **Ideally, input from a LAM Clinic should be obtained prior to pleurodesis.**

**Ovarian removal (oophorectomy)** LAM is a disease which primarily affects women and we know that there is an increased risk of lung function decline during the premenopausal years. Removal of the ovaries was a common approach to treating LAM in the past, but is not frequently employed today. Similarly, treatment with anti-estrogen strategies such as progesterone was once common but is now rarely used. It is important to emphasize that neither ovarian removal nor hormonal therapy has yet been proven to have efficacy for the treatment of LAM. **As a result, most LAM physicians do not routinely employ either of these approaches.**

CONTINUES ON NEXT PAGE >

**Anesthesia for Surgeries** LAM patients may require routine surgeries for gall bladder problems, appendicitis, abnormal uterine bleeding and other common indications. The anesthesiologist should become informed about LAM prior to surgery, and make every attempt to maintain low airway pressures during the procedure. In addition, if blood pressure drops in the operating room, it is important for the anesthesiologist to consider the possibility of tension

pneumothorax as a cause (although this is a rare event). Sirolimus is a potent inhibitor of wound healing, and should be stopped at least one week before and held for at least one week after surgery. **In addition, if surgery is likely to provide access to LAM involved tissues in the abdomen or chest, LAM patients should consider registering with NDRI and notifying The LAM Foundation to facilitate the collection of tissue for research.**

## LAMposium 2016: Share, Learn, Inspire, and Collaborate



RLDC•2016  
CINCINNATI  
LAMPOSIUM

In a few short months, we join together in Cincinnati for our 19th Annual LAMposium. Planning is moving full speed ahead.

Simultaneously, researchers and clinicians studying rare lung diseases are receiving invitations to present at the International Rare Lung Diseases Research Conference (RLDC•2016). This conference will be the largest and most comprehensive scientific research meeting focused on rare lung diseases ever held! Patients and families with rare lung diseases are encouraged to attend and to share, learn, inspire, and collaborate.

RLDC•2016 will take place September 22 - 25, 2016, at the Cincinnati Marriott at RiverCenter and the Northern Kentucky Convention Center, directly across the Ohio River from Cincinnati. Registration will open the first week of June.

### Here is a glimpse of what we are planning:

- New topics are being added to both LAMposium presentations and our Roundtable Discussion sessions
- Families and caregivers will have more topics and events to attend
- A yoga class lead by Kat Steele

- Thursday evening joint reception with a Keynote Speaker
- All LAM Clinic Directors are strongly encouraged to join us this year

**Even though we are back in Cincinnati and inviting members from the RLDC, you will recognize familiar elements:**

- 2 days of LAM education for women with LAM, family and friends
  - You can connect with researchers and clinicians at our combined breakfast and lunches
  - LAM researchers will be available to answer your questions and help you sign up for LAM research and clinical trials
  - LAM community fundraisers and researchers will present posters
  - Stacey Wheelus is working diligently on the newest LAM quilt
  - The Oxygen Station will be available on Friday and Saturday
- Sharlene Dunn is going to bring back the Remembrance Room

We hope you will join us. The goal of this conference is to inspire researchers and clinicians as they connect with patients and each other to find better treatments, diagnosis and ultimately a cure for all rare lung diseases. **We are Stronger Together.**



## LFN Travel Grant Applications are Available

The LAM Family Network (LFN) Travel Grant helps fund travel for women with LAM to LAMposium every year. Thanks to the support from generous LAM community donors, more women can receive financial assistance for their travels to Cincinnati, Ohio for the RLDC • 2016 • LAMposium and Breath of Hope Gala in September.

If you are a woman with LAM and want to attend LAMposium, but have limited finances, you can apply for a LAM Family Network (LFN) Travel Grant. The LFN Travel Grant only assists with travel expenses and partial hotel costs. Registration for LAMposium is free for all women with LAM.

Applications must be received by June 30, 2016. To apply for the travel grant contact Anne McKenna, Patient Services Manager, at [amckenna@thelamfoundation.org](mailto:amckenna@thelamfoundation.org). She can provide you with an application or help if you have questions.

## LAMposium – A Conference for Everyone

BY CAROL SEE, DIAGNOSED 2012



Every woman has a story about her path to a LAM diagnosis. My story began with a case of mononucleosis. In October/November of 2011, I was feeling so tired and weak that I could barely stand up. After a series of blood tests, my doctor sent me to the hospital to check myself in, but the ER staff sent me home with a diagnosis of mono. Being 48 years old, the obvious jokes ensued. However, my doctor was not amused

and was convinced there was something additionally wrong. His consultation with an endocrinologist led to a new finding: adrenal insufficiency, aka Addison's disease. I was given a prescription for daily corticosteroids that I will take for the rest of my life, and instructions to return in three months for a re-check of suspicious lung nodules that had shown up on an abdominal CT.

Fast forward to February 2012. I was feeling pretty well after adjusting to the new medicine. I did have some unusual pain when lying on my right side, but I brushed it off. The next surprise came when the follow-up scan showed a large pleural effusion on my left side. I was sent back to the hospital for a thoracentesis, which showed that the fluid was chyle. Thankfully my pulmonologist was familiar with LAM, so that was his working diagnosis after seeing the fluid. To confirm this, he sent me for a lung biopsy. My surgeon said he'd seen a chylous effusion after a gunshot wound, but I was pretty confident that wasn't the case with me! It was during my nine-day hospital stay post-biopsy that I received the official diagnosis of LAM. The date was March 28, 2012. My pulmonologist was on vacation, so his uninformed partner gave me the news, including the "you have ten years to live" line, speaking as if that was going to make me feel better.

Within a week, I saw Dr. Dilling at the Loyola LAM Clinic who quickly dispelled the "ten-year" misinformation that I was given. He also encouraged me to contact The LAM

Foundation. Looking back today, I now realize that first call to Cincinnati was one of the most important phone calls I have ever made. Sally Lamb, then the Director of Patient Services, asked me if I wanted to attend a special conference known as "LAMposium" which was to be held just a few weeks later. At the time I didn't feel ready, either physically or emotionally, to face this unknown conference. But after a year of processing the diagnosis and meeting some wonderful women through regional events, I was ready to attend in 2013. My husband Dave and I have attended all the LAMposium conferences since then, and have found them to be extremely worthwhile.

LAMposium is an educational conference, in that you learn about new research, clinical trials and studies, the meaning of test results, and how to manage symptoms. LAMposium is also an encouraging conference. You see so many people donating their precious time, talents, and resources toward finding a cure. A cure is bound to happen soon! And LAMposium is a social conference, where you will reconnect with dear friends and meet some of the most wonderful people, who all speak the same "LAMguage". There is no need to have to explain "pneumothorax", "chyle", "PFT", "FEV1", etc. What a comfort that can be!

Dave finds that attending LAMposium helps him too. He feels that education is power, and that learning about the disease, how it affects me on a daily basis, and how other patients' loved ones cope and live with LAM, is helpful to both of us. He also loves the fact that the researchers and doctors are just as passionate about finding a cure for LAM as we are!

**We both encourage you to attend LAMposium in September - we are looking forward to seeing you there!**

# From the Board Chair

BY ANDREA SLATTERY – LAM FOUNDATION BOARD CHAIR



As the incoming Board Chair of The LAM Foundation, I am pleased to write my debut article for Journeys. Let me begin by offering my heartfelt thanks to the people and community who have not just supported the Foundation, but who are, in many cases (and here I have to thank our Scientific Director, Frank McCormack, MD) directly responsible for saving my life –

and the lives of so many other women with LAM.

As the new Board Chair, I have big shoes to fill. Laura Lentz, our immediate past Board Chair, performed above and beyond the call of duty, creating a strong foundation upon which I'm excited to build. And I am also fortunate to work with our leader and Executive Director, Sue Sherman, who represents a rare combination of tenacity and compassion, to take us forward.

The Foundation's achievements over the past two decades are nothing short of incredible. With our collective effort and collaboration, The LAM Foundation has achieved something that 93% of the orphan disease community has not - an FDA approved treatment. This major milestone has intensified our quest for a cure.

While we've done extraordinary things, there's a lot more to do, and I'd like to share my vision of the places we'll go together. Twenty years ago we started with a little known disease diagnosed in just 8 patients - an orphan disease with no resources, no visibility, and no progress toward a cure. It is very fair to say the odds were terrible, and completely stacked against us. However, in my professional career as a technology investor, I have spent the past twenty years surrounded by exceptional visionaries

who routinely take on the odds and win... Their refusal to be deterred by long odds has rubbed off on me in an important way.

My personal drive informs my thinking when it comes to solving problems that others dismiss as "impossible" and my professional expertise informs my belief that we can and should deploy leading edge technology to improve patient outcomes and to accelerate scientific research. We have started by tackling the basics – changing the way we broaden awareness and deliver information about LAM, the Foundation, and our activities to all interested audiences. With our new website and database, we are now using the best available software to develop opportunities and manage relationships.

In my mind, these are the necessary building blocks upon which we can begin to develop our future. However, by themselves these pieces won't take us to the next level. So, what will?

In my opinion, the answer again lies in technology. Specifically, the application of technology to allow patients to own and understand their own data to improve health and outcomes; to give patients the tools that will allow them to more effectively contribute to scientific research; and to use big data and analytics to allow the scientific community to access, analyze and share data sets in ways never before possible, accelerating research efforts and moving us to accomplishing our goal: a cure.

Looking forward, I believe we will establish ourselves as one of the most effective organizations for treating orphan diseases, and I believe it will be our responsibility to share it with others – and the way we do this is in providing visible leadership. To borrow an old proverb, "we will make the path by walking".

**I look forward to sharing our future success with you, and thank you for your continued support.**

## Thank You, Laura Lentz, for Service as Board Chair

BY SUE SHERMAN, EXECUTIVE DIRECTOR



Late last year, Laura Lentz completed five years as Chairperson of The LAM Foundation Board of Directors. She is now serving as Immediate Past Chairperson and member of the Executive Committee. During her tenure, Laura provided thoughtful and intuitive leadership, guiding the Foundation through a several im-

portant milestones and transitions:

- In her first year as Chairperson, the results of the MILES Trial were published in the NEJM and in her final year, FDA approval of Rapamune for the treatment of LAM was announced.
- The LAM Clinic Network grew from 24 U.S.-based clinics seeing 650 LAM patients in 2011, to 55 global rare lung disease clinics treating 3,280 LAM patients and 13,085 additional rare lung disease patients.

- The Foundation distributed more than \$2 million in scientific grants directly to LAM researchers.
- LAMposium moved to Chicago, IL, for two years, drawing record numbers of researchers, clinicians and LAM families.
- A five year strategic plan was written and executed, culminating with the 20th anniversary of The Foundation and continued recognition as a highly respected patient advocacy organization with strong forward momentum.

Laura was the first person I met from The LAM Foundation, greeting me with warmth and strength of character that sparked my interest and attachment to the Foundation. Through two years of partnership she has been a friend and mentor. We at The LAM Foundation are better for her leadership and will continue to benefit from her counsel in the years to come. Thank you Laura for your generosity and for many years of priceless activism!

# Meet Katie Jensen, Development Manager



The LAM Foundation is pleased to welcome Katie Jensen to our staff, as our new Development Manager.

Katie moved from Chicago, IL, to join The LAM Foundation. She learned about The LAM Foundation from her previous position as the Associate Director of Strategic Partnerships at the Foundation for Sarcoidosis Research. The Foundation

for Sarcoidosis Research is dedicated to finding a cure for sarcoidosis and to improving care for sarcoidosis patients.

“We are thrilled to welcome Katie to The LAM Foundation as she is well versed in working with a community who is passionate in finding a cure for a rare lung disease,” said Sue Sherman, Executive Director of The LAM Foundation. “She comes from an organization that has experience in working with a multitude of stakeholders, including individuals, the pharmaceutical industry, academia and government.”

You can reach Katie at [kjensen@thelamfoundation.org](mailto:kjensen@thelamfoundation.org) or by calling her at 877.287.3526.

## New Website!

The LAM Foundation is proud to share our newly designed website! The new site offers a wealth of information about LAM, offers ways to connect with each other along with how communities are sharing LAM awareness and fundraising. It has taken us months to modernize the content for the site and we will continue to keep it up to date with the most valuable information. The LAM Foundation website will be a place where everyone from around the world can come to learn about diagnosing and treating LAM.



## New Address for The LAM Foundation



The LAM Foundation has moved to a new office! We will begin a new chapter of discovery and progress toward a cure in our new home.

Please take note of our address before you send any correspondence by mail.

### OUR NEW ADDRESS IS:

The LAM Foundation  
4520 Cooper Road, Suite 300  
Cincinnati, Ohio 45242

If you happen to be visiting or driving through Cincinnati, we would love to have you stop by for a visit so we can show off our new working space!

## Regional LAM Education Meetings

### NHLBI DIGNITARIES ATTEND A REGIONAL LAM/TSC EDUCATION MEETING

The Mid-Atlantic Region of The LAM Foundation and the TS Alliance hosted an educational meeting at the National Institutes of Health (NIH) in Bethesda, MD in November, garnering the attention from some top dignitaries at the National Heart, Lung, and Blood Institute (NHLBI). The visit by Gary Gibbons, MD, Director of the NHLBI was a rare opportunity for the LAM and TSC communities to thank the NIH and NHLBI for their continued support of the LAM protocol. The attendance of so many women with LAM/TSC and their family members on a weeknight during the holiday season highlighted the important of patient participation in research protocols.

A heartfelt thanks to Joel Moss, MD, PhD, Deputy Chief of Cardiovascular and Pulmonary Branch, NHLBI; Jean Berube, Legislative Analyst, Office of Science Policy, Engagement, Education and Communications, NHLBI; Lora Reineck, MD, MS, Medical Officer, Division of Lung Diseases, NHLBI, and Thomas Darling, MD, PhD, Professor and Chair of Dermatology, for speaking. And a special thank you to LAM Liaison Mary Stojic for generously giving her time and making everyone feel welcome with her amazing attention to detail.



### EVERYTHING IS BIGGER IN TEXAS

LAM Liaisons in Texas hosted the largest regional educational event on January 30, 2016.

In January, more than 60 women with LAM, family and friends gathered at the University of Houston for a day of LAM education and friendship. LAM Liaisons from Regions 14 and 15, Frances Saldivar, Maria Teniente, and Kathi Hawn welcomed people from Texas, Oklahoma, Louisiana, Arkansas and Mexico. LAM experts from the University of Texas LAM Clinic presented including LAM Clinic Director, Rosa Estrada-Y-Martin, MD, Hope Northrup, MD, Director, Division of Medical Genetics, and Sandra Oldham, MD, Chief of Radiology at University of Texas. Thomas Lowder, PhD from the University of Houston, Tony Eissa MD from Baylor and Sue Sherman from The LAM Foundation rounded out the speaker line-up. Priceless knowledge was shared among the professionals and patients present, creating new friendships and hope.

Thank you to our energetic LAM Liaisons and passionate clinicians for delivering memorable and important days for women with LAM.

## 2016 Regional LAM & TSC Conference Series

The LAM Foundation is pleased to partner with the Tuberous Sclerosis Alliance for the 2016 LAM & TSC Conference Series. The nation's top experts in the fields of lymphangioleiomyomatosis (LAM) and Tuberous Sclerosis Complex (TSC) will present on basic and translational research, the latest treatment, support, and upcoming clinical trials. Join us for any of these free one-day conferences in Nashville, TN, Seattle, WA and Cleveland, OH.

By collaborating, we can learn how these two rare diseases are connected, share updates on research and find ways to improve the quality of life for those living with LAM and/or TSC.

To register for any of the three conferences send an email to The LAM Foundation at [info@thelamfoundation.org](mailto:info@thelamfoundation.org) or call the Foundation at 877.287.3526



### CONFERENCE SERIES SCHEDULE:

- Nashville, TN – April 16 at Vanderbilt University Medical Center
- Seattle, WA – June 11 at Swedish Medical Center
- Cleveland, OH – November 5 at Cleveland Clinic

# Virtual 'March on the Hill' Advocacy in Numbers



The first week of March ushered in the Foundation's first 'Virtual March on the Hill' when nearly 20 women with LAM, family and friends took the time to call, email and visit their local U.S. House of Representatives and Senators offices.

Our 'Virtual March on the Hill' was coordinated in partnership with the Tuberous Sclerosis Alliance's annual 'March on

the Hill', when advocates from the TS Alliance visited 326 members of the House of Representatives and 82 Senators in

Washington D.C. on March 2. Together, it was time well-spent urging our Congressmen and women to continue funding the Tuberous Sclerosis Complex Research Program (TSCR) which includes critical funding for LAM research.

The LAM Foundation's Executive Director, Sue Sherman and Patient Services Manager, Anne McKenna spent the afternoon visiting the local office of Sherrod Brown, senior United States Senator from Ohio. They had the opportunity to share LAM awareness and advocated to sustain critical LAM research funding.

If you would like to learn how to advocate continuing government funding for LAM research, give Anne McKenna a call at 877.287.3526. She will connect you with the tools you need to get started.

## LAMplify Doubles the Impact for Community Fundraisers



If you are planning a LAM Community Fundraiser this year and plan to raise \$5,000, \$10,000, or even \$20,000, 'LAMPlyfy' your event with a LAMPlyfy Challenge Grant!

LAMPlyfy was created as a challenge grant program to encourage local community-based LAM fundraisers to stretch their goals. All LAMPlyfy program donations go toward funding LAM research, supporting LAM patients and providing better access to expert healthcare.

The Foundation will give you all the tools you need to make your event a success. Just call us at 877.287.3526 or send an email to [info@thelamfoundation.org](mailto:info@thelamfoundation.org) for more details about how you can 'LAMPlyfy' your efforts and **DOUBLE THE IMPACT OF YOUR NEXT LAM COMMUNITY FUNDRAISING EVENT!**

**Thanks to generous donors, the Foundation has the ability to LAMPlyfy the following Community Fundraisers:**

- The McKenna Family along with The Western New York Friends of The LAM Foundation hosted the 11th annual "An Evening of Hope" Beer & Wine Tasting in February raising over \$15,000 for LAM research.
- Joanne Unger is raising \$10,000 to celebrate her 10 year post lung transplant anniversary through her Friends Asking Friends website.
- The Newland Communities hosted the SLAM LAM Charity Walk on April 9 in Houston, Texas, to raise over \$40,000 on behalf of longtime Summerwood resident and Newland employee, Kathi Hawn.
- Morphotek hosted their 3rd Annual Golf Outing on April 11 outside of Philadelphia. This year they are working to raise \$10,000, with all proceeds going to The LAM Foundation.
- Andrea Slattery, Board Chair of The LAM Foundation, hosted the 2nd Annual Merion Cricket Club Event, May 5, 2016.

- The Pontz family is hosting a "Day of Discovery" on June 11 in Philadelphia to raise \$10,000.
- Tee It Up for LAM! Golf Outing on June 24, outside of Chicago, hosted by The Woodstock and The Elgin Friends of The LAM Foundation are on their way to raise \$10,000 for the Foundation.
- Last year, Jen Fujikawa was very successful raising over \$20,000 with the Foundation's Challenge Grant. She is back at it again this year using her Friends Asking Friends website to raise another \$20,000.



*"This year LAMPlyfy helped us secure more sponsors, sell more event tickets, receive more donations, not to mention entice attendees to purchase more "Take A Chance" tickets and bid higher at our Silent Auction. Because our sponsors and attendees responded positively to the dollar for dollar match, we exceeded our goal! That's over \$30,000 toward LAM research and support. Thank you to The LAM Foundation for all of your assistance and support in helping us reach our goal!"*

– Katie McKenna

## How You Can Help: Alternative Ways to Give

The LAM Foundation relies on its many supporters to help make a difference in the lives of women living with LAM. There are many easy ways to give to The LAM Foundation beyond a traditional donation. We can't all give large gifts, but every little bit helps. Below are some of the programs where your help can make a big difference!

### GIVE WHILE YOU SHOP

#### Amazon Smile

You shop. Amazon Gives. Amazon will donate 0.5% of your eligible purchases to the charitable organization of your choice. To register for Amazon Smile, visit [smile.amazon.com](http://smile.amazon.com) and choose "The LAM Foundation".

#### iGive

Help The LAM Foundation at no extra cost to you, every time you shop online. With a plug-in button, iGive makes it easy to donate while shopping at over 1,700 online stores. A percentage of your purchases will be donated directly to The LAM Foundation. To learn more, visit [www.igive.com](http://www.igive.com).

#### Kroger and Fred Meyer Community Rewards Program

Donate to The LAM Foundation while you shop at your local Kroger and Fred Meyer grocery stores. Designate The LAM Foundation onto your Kroger Plus card or Fred Meyer Plus card to receive community rewards. Visit [www.kroger.com/communityrewards](http://www.kroger.com/communityrewards) or [www.fredmeyer.com/topic/community-rewards-4](http://www.fredmeyer.com/topic/community-rewards-4) to sign up.

#### eBay for Charity

Since 1999, eBay has been making it easy to give to The LAM Foundation whether you are shopping, selling or making a direct donation at checkout. To learn more about this program and how you can participate, visit <http://charity.ebay.com>.

### WORKPLACE GIVING

Many organizations offer pre-tax ways to give to the charity of your choice. Check with your employer to see if they have a workplace giving program, or if you qualify for one of the programs below:

#### United Way Campaign

Does your company encourage giving through the local United Way Campaign? Simply write in The LAM Foundation on the "donor designated" portion of your United Way donation form. Ask your Human Resource representative or call your local United Way office for more information.

#### Combined Federal Campaigns

The LAM Foundation is eligible for inclusion on the Combined Federal Campaign Charity List. The CFC code that Federal employees should use to designate their contributions to The LAM Foundation is 10886. Please share this information with every Federal employee you know.

#### Matching Gifts

Many companies have matching gift programs that will double your contribution – or more! Check with your Human Resources department for information on this program.

### UNIQUE WAYS TO GIVE

#### Sustained Giving

Sustained giving to The LAM Foundation has a continuous impact on the organization. By setting up an affordable donation on a regular schedule, you can help us fulfill our mission over the long term. Go to our Donate Now page and choose to give your gift monthly, quarterly, or annually. Every little bit will make an impact on our mission.

#### Gifts of Stock or Assets

Take advantage of the unique tax benefits associated with donating a gift of stock or asset. Ask your broker to make an electronic transfer of the shares to The LAM Foundation stock contribution account.

#### Planned Giving

Create a lasting legacy that will help shape the future of The LAM Foundation and improve the lives of women with LAM by joining the Breath of Hope Legacy Society. The most common planned gift is the 'bequest', or remembering The LAM Foundation in your will. Other forms of planned giving include the Charitable Remainder Trust and the Charitable Gift Annuity.

#### Sue Byrnes Legacy Fund

To preserve her vision, The LAM Foundation Board of Directors has created the Sue Byrnes Legacy Fund which will support the Foundation's strategic priorities to expand support of basic and clinical research, offer innovative ways to connect LAM patients and families globally, and improve clinical treatment and diagnostics for patients with LAM.

#### In-Kind Gifts

An in-kind gift can help generate revenue streams through silent auctions, raffles, and services provided. We can use most items or services that are national and can travel well. Gift certificates, services, gift baskets, jewelry, and even timeshares or vacation homes have been donated in the past. You can also help the Foundation spare expenses by donating office equipment that may be needed, such as printers, laptops, etc.

For questions on creative ways you can help The LAM Foundation, contact Katie Jensen, Development Manager at 877.287.3526 or [development@thelamfoundation.org](mailto:development@thelamfoundation.org).

# 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](http://www.thelamfoundation.org).

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January 1, 2015 through December 31, 2015

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