Studying LAM biological behavior in the laboratory is difficult because the model-based approaches that have been so vital to progress in other diseases have simply not been very good in LAM. There are many reasons for the inadequacy of LAM cell models, including that we don’t know the origin of the LAM cell, and that LAM cells grow slowly, change their signature functions with time in a dish, are often outcompeted by other cells in culture, and do not survive well through multiple passages. Immortalizing LAM cells with viruses can keep them alive but alters them in unpredictable and inauthentic ways. LAM animal models are also problematic; there is no known naturally occurring model of LAM other than in humans, and because we don’t know where LAM starts in the body, we don’t know what cell to target with our genetic manipulations. Tumor xenograft models, in which LAM cells are injected or implanted into mice, are also suboptimal because they are typically done in mice with compromised immune function (so they won’t reject the tumors), colonize and metastasize to the lung in an un-LAM-like manner, and induce reactions that are not typical in humans. Because the LAM models we have are imperfect, it has been difficult to be confident about how findings made in them can be translated to humans.

Said another way, although we know a lot about the genetic basis of LAM, the laboratory limitations above have left us with a gap in our understanding of what those mutations do to LAM cell functions. Enter single cell RNA sequencing (scRNAseq), a technique that allows us to comprehensively study the genetic programs of all cell types in a diseased human lung. We are fortunate to have a strong core facility that offers this sophisticated technique in Cincinnati, through the efforts of Drs. Steve Potter and Jeffrey Whitsett. The LAM Foundation has provided funds to perform approximately 10-12 scRNAseq experiments in LAM, angiomyolipoma (AML) and normal human tissue to map the ‘transcriptome’ of the LAM cell; that is, to produce a catalog of their most highly expressed genes. In this technique, tissues that are harvested at lung transplant, biopsies or resections are immediately placed on ice, rapidly dissociated into single cells and labeled in a manner that allows them to be easily identified. Using the 10x Chromium scRNAseq method, about 2,000-4,000 genes in each of up to 10,000 of the dissociated cells are sequenced and identified. The genetic profile of each cell sequenced is displayed as a dot on a two-dimensional plot in which distances between dots reflects differences between gene programs (see figure).
The dots segregate into ‘island like’ clusters representing different cell types, such as lymphocytes, macrophages, fibroblasts, endothelial cells, airway epithelial cells and alveolar epithelial cells. When this process was followed for the two LAM lungs that have been completed, small islands of cells that were not present in normal human lung, and which expressed several of the ‘usual suspects’ known to be made in LAM cells (such as VEGF-D, gp100, cathepsin K, osteoglycin, etc.) were identified (see pink circle in the figure). By studying these LAM clusters, we can validate the few dozen or so genes that we strongly suspected were being expressed in LAM cells, and identify hundreds of new ones with may become future drug targets or useful biomarkers. We might also learn something about where the LAM cell is coming from—for instance, if the LAM cluster is found to express many of the genes that are commonly found in the uterus or the ovary, perhaps our attention will be focused to those potential sources. We can also determine what effects LAM is having on other cells in the lung, such as the fibroblasts they are recruiting, the alveolar epithelial cells they are inducing to proliferate, and the immune cells that are trying to kill them. scRNAseq allows us to study these processes in LAM cells ‘where they live’ and in their natural state, and does not suffer from the many pitfalls that occur with isolation and manipulation, and other limitations that plague the study of cultured cells.

This is an incredibly exciting time for LAM research. Many of us feel as if we are entering a new era, and have been given a precious new window into the LAM cell playbook. Based on the advice of the Scientific Advisory Board, The LAM Foundation devoted $80,000 to scRNAseq on the condition that the raw data would be immediately available to all interested researchers. Four donors have already generously provided tissues, from three LAM lung transplants and one from an angiomyolipoma (AML) resection.

As it has always been, the success of this effort depends on the patients. If you are approaching a procedure where LAM or AML tissue will be obtained, please contact amckenna@thelamfoundation.org and sign all necessary paperwork early. It is vitally important to make your wishes regarding research known to your surgical team. The logistics of timely acquisition, processing and shipping of the samples are complicated and easily overlooked on transplant day. The time from resection to scRNAseq processing is key to success.

Hats off to our first four donors, to our future donors and to The LAM Foundation Board of Directors for immediately recognizing the promise of this cutting-edge technology and for being nimble with generous support.

A Legacy of Funding Scientific Advancement

The LAM Foundation continues its legacy of funding advancements and discoveries in LAM science with the 2018 Annual Grant Program. Arnold Kristof, MDCM, will serve as the 2018 Grant Program Chair, leading the process of grant submissions and reviews by the Scientific Advisory Board. Since 1996, The LAM Foundation has awarded more than $11 million in funding to LAM scientists and allocated an additional $3 million to research related projects.

Arnold Kristof, MDCM, 2018 Annual Grant Program Chair

2018 LAM Foundation Grant Program schedule:
June 15 — Deadline to submit Letter of Intent (LOI)
July 15 — Invitations are extended to investigators with competitive projects
Sept. 15 — Deadline for invited investigators to submit LAM grant proposal
Dec. 30 — Applicants are notified by this date
January — Once all paperwork has been signed and returned, funding begins.
Recently, I attended an awards dinner hosted by the National Disease Research Interchange (NDRI). The keynote speaker was Dr. Francis Collins, Director of the National Institutes of Health (NIH). In his acceptance remarks, he addressed an audience comprised of healthcare professionals, scientists, patient organizations and academicians, all working together to address complex rare diseases. He said, “Where there is no action, there is no hope.” He went on to say that hope requires responsibility.

His comments led me to reflect on our tagline, “A Breath of Hope”, and the role of rare disease patient organizations as leaders of action and hope. We know that families who receive an unexpected rare disease diagnosis face futures that are nearly always uncertain, frustrating, financially taxing, emotionally draining and lonely. Their desperation to find answers for themselves or their loved ones drives them to take action, such as asking questions, finding other patients, educating clinical care teams, raising awareness and more. These actions generate a sense of purpose and the hope of progress.

Hope and progress instill a sense of responsibility and it’s something we see frequently within the LAM community. We see families and friends sharing knowledge, volunteering, participating in research and expressing compassion and joy for shared experiences. Every day, we witness warmth and caring along with a sincere willingness to “take on” the responsibility of moving things forward, and building upon progress.

LAM patients led the opening session, told their stories and, most importantly, posed their questions to an audience of thought leaders. Family members and patients joined physicians and scientists in designing solutions for the most vexing issues facing LAM patients every day. I watched as unscripted workshops revealed a treasure of ideas and momentum and the closing plenary bubbled with a Price Is Right gameshow enthusiasm.

The HOPE component of the event is harder to describe. There was something special about the courage it took for people to walk into workshops without a speaker or a script and to participate by sharing their individual expertise, as doctor, patient, spouse, scientist, or innovator. Every voice made a difference. With each idea, conversation and sticky note, we saw the energy build, possibility morph into probability, problems into solutions and enthusiasm into real, hard cash. At the Breath of Hope Gala, more than $200,000 was raised to support the solutions developed during the conference. In April, 14 initial letters of intent were received at the Foundation based on ideas generated at the Patient Benefit Conference. Final proposals will be reviewed and awarded funding by June 2018. I encourage everyone to stay engaged and energized, offer input to our teams and share your stories and insights. You may have the next idea or question that will improve the lives of women with LAM in five years or less.
The LAM Foundation 2017 Grant Awards Recipients

The LAM Foundation is proud to announce the 2017 Grant Award winners, which provided funding for four LAM research projects in the amount of $440,000. One of the grants was awarded in partnership with the Tuberous Sclerosis Alliance, helping us to increase our overall funding and to expand the LAM research portfolio. These projects were all peer-reviewed by The LAM Foundation’s Scientific Advisory Board and approved by The LAM Foundation Board of Directors.

ISSAM BEN-SAhra, PHD, NORTHWESTERN UNIVERSITY
Career Development Award
Defining the mTORC1-dependent Signaling Mechanisms Mediating Epigenetic Modifications

NISHANT GUPTA, MD, UNIVERSITY OF CINCINNATI COLLEGE OF MEDICINE
Pilot Award
Home Spirometry to Evaluate Disease Progression and Treatment Response in Patients with LAM

MICHAEL BORCHERS, PHD, UNIVERSITY OF CINCINNATI COLLEGE OF MEDICINE
Established Investigator Award
Natural Killer Cell Phenotype and Function in Lymphangioleiomyomatosis

YOU FENG, PHD, BRIGHAM AND WOMEN’S HOSPITAL
Career Development Joint Grant (Given in combination with the Tuberous Sclerosis Alliance)
Targeting Novel Regulatory Mechanisms of Phosphatidylcholine Metabolism in LAM

DAVID KWiatkowski, MD, PHD, BRIGHAM AND WOMEN’S HOSPITAL
Targeting Transcription in LAM

JANE YU, PHD, UNIVERSITY OF CINCINNATI MEDICAL CENTER
The Impact of Estrogen-Promoted Extracellular Matrix-Degrading Programs on LAM Progression

LAM Researchers Awarded 2017 MDBR Research Grant Awards

The Penn Medicine Orphan Disease Center also announced the winners of the 2017 Million Dollar Bike Ride Research Grant Awards. We extend a sincere THANK YOU to The LAM Foundation’s Easy Breathers Cycling Team and all those who donated to the Million Dollar Bike Ride to make these research projects possible. 2017 was the fourth consecutive year for the Million Dollar Bike Ride (MDBR), which has awarded more than $420,000 to LAM research projects.

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The LAM community of researchers, clinicians and patients has made incredible progress over the last 20 years. Frank McCormack and I were honored to be invited to write a review article “Lymphangioleiomyomatosis: A Monogenic Model of Malignancy” for the Annual Review of Medicine, which covers significant developments in various fields of medicine since 1950.

This review highlights the journey made by the LAM community in transforming LAM from an obscure disease to a well-recognized, well-resourced disease with a proven treatment and exciting new therapeutic options on the horizon.

The treatment options available to LAM patients of the last century included watchful waiting, unproven hormonal therapies and, in advanced cases, lung transplantation. Remarkable progress in our understanding of LAM—driven by patient advocacy, abundant clues from nature (restriction to females, recurrence in transplanted lungs, occurrence in patients with tuberous sclerosis complex (TSC), etc.), and intense scientific interest in the cellular pathway that is deranged in LAM—has yielded an effective therapy in under 20 years since efforts began in earnest. In the process, the study of LAM and tuberous sclerosis complex (TSC) has yielded unique insights into neoplastic growth that are informing our approach to cancers of all types.

LAM is an elegant model of malignancy because mutations at a single genetic location on the chromosome are sufficient to transform healthy cells into LAM cells with remarkably cancer-like capabilities, including the ability to multiply with controls, migrate through the circulation, and invade the lungs, causing distortion of the delicate structure of gas exchanging elements and impairing their function. The direct benefit of the study of this rare disease has been the rapid identification of an effective FDA-approved therapy in the form of sirolimus, and the collateral benefits have included improved understanding of the roles that the mTOR pathway (the central pathway involved in LAM and TSC) plays in the regulation of cellular metabolism. For instance, we have learned that mTOR is a master regulator that senses the nutrition and energy status of cells, and that dysregulated activation of the mTOR pathway leads to abnormal cell survival, migration and invasiveness. The progression of scientific discoveries from genetic studies in humans with TSC and LAM, to astute observations in the eyes of flies and effective therapies for both diseases has occurred with astounding speed, and has joined the ranks of triumphs of twenty-first-century medicine. Perhaps even more remarkable, the fact that these advancements were driven largely by patient advocacy is a source of inspiration and hope for all rare disease communities and a testament to the motivating force of patient voice.

Dr. Nishant Gupta Named Director of the LAM Clinic Network

The LAM Foundation is pleased to announce that Dr. Nishant Gupta, MD, of the University of Cincinnati Medical Center, has been named the Medical Director of the LAM Clinic Network and has been appointed to The LAM Foundation Scientific Advisory Board. Dr. Gupta, a pulmonologist, is board certified in internal medicine. He earned his medical degree from the University College of Medical Sciences in Delhi, India, and completed his residency at University of Tennessee College of Medicine and a fellowship from the University of Cincinnati Medical Center.
Sirolimus Prescribing Guide
BY FRANK MCCORMACK, MD AND NISHANT GUPTA, MD

CLINICAL

Based on groundbreaking basic science research and the pivotal MILES trial, we now have an effective treatment option for LAM patients in the form of sirolimus. Sirolimus was recently approved by the United States FDA for the treatment of LAM. Sirolimus has also received approval from the regulatory agencies in other countries such as Japan, Russia, South Korea and Brazil. There are certain precautions and instructions that LAM patients as well as clinicians need to recognize while using sirolimus for the treatment of LAM. This guide provides a highlight of the basic safety instructions, and provides answers to some of the frequently encountered scenarios that LAM patients may face with regards to the use of sirolimus.

Before Beginning Sirolimus:
• Obtain baseline labs: complete blood count (CBC), comprehensive metabolic profile (CMP), lipid profile, urinalysis.
• Begin drug at 1-2mg daily.

While Taking Sirolimus:
• Instruct patients to take drug at the same time every day.
• After 14 days of treatment, perform a serum trough level. Instruct patients to wait 24 hours (20-28 hours) after taking the medication (and just prior to the next dose) prior to drawing a serum trough level.
• Check sirolimus level, CBC, CMP, lipid profile, urinalysis every month for the first 3 months. If levels are acceptable, extend repeat testing to every 3 months.
• Inquire about other adverse effects such as acne, oral ulcers, worsening of pulmonary symptoms (to evaluate for drug-induced pneumonitis) at every visit.
• Encourage patients to get annual influenza vaccinations, and pneumococcal prophylaxis, including both Pneumovax® and Prevnar®. Avoid live vaccines (such as shingles vaccine) while on sirolimus.
• Hold drug for at least 1 week before and 1 week after a surgical procedure or after an injury.

Other useful tips:
Dosing: We typically begin at low-dose sirolimus (1mg daily) for most patients, unless disease is rapidly progressive. In general, most patients respond well with stabilization of lung function with a trough around 5 ng/ml, and we should strive towards prescribing the lowest effective dose in order to minimize adverse effects, especially given the need for long-term treatment. For rapidly progressive patients, it may be better to start at 2-3 mg per day, and titrate downward once a response is assured.

Oral ulcers (mouth sores): In general, oral ulcers are uncommon at low sirolimus doses. Local corticosteroid based applications are very effective in treating sirolimus-induced oral ulcers.

Acne: In general, acne is not a common occurrence in patients taking low-dose sirolimus. Over-the-counter medications such as benzoyl peroxide and/or salicylic acid are quite effective, and reasonable first-line treatment options, in treating acne.

Hyperlipidemia: Treatment of hyperlipidemia should be undertaken as per existing guidelines, with dietary modifications and statins being the first-line treatment options.

Common interactions: Over-the-counter medications

Disclaimer:
This content was created for general informational purposes only. The content is not intended to be a substitute for professional medical advice, diagnosis or treatment. Always seek the advice of your physician or other qualified health provider with any questions you may have regarding a medical condition. Never disregard professional medical advice or delay in seeking it because of something you have read in this paper.
such as St. John’s Wort, grapefruit juice, CYP3A4 inducers (rifampin, carbamazepine, barbiturates, phenytoin), CYP3A4 inhibitors (ketoconazole, clarithromycin, Itraconazole, Erythromycin, Gemfibrozil, Nefazodone).

**Other advice for patients:**
- Use sunscreen, hats, and similar precautions due to an increased risk of skin cancer.
- Do not split tablets.
- Hold sirolimus for fever requiring antibiotics or serious infections. Call your physician if you are uncertain about stopping. Hold sirolimus for any event that requires optimal wound healing, such an accident with injuries.
- Spirometry (PFTs) should be obtained at regular intervals, every three months for those with disease progression, to every year or so for stable patients. Consider obtaining VEGF-D levels at least annually.

This article and guide reflect the opinion of the authors and is not an endorsement from The LAM Foundation.

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### 2018 AIR WE BREATHE CAMPAIGN

Raising awareness and promoting advocacy: What you need to know about the new clinical practice guidelines, free continuing medical education and physician conferences

**BY LAURA KING BOWERS**

In 2017, a supplement to the Official American Thoracic Society/Japanese Respiratory Society Clinical Practice Guidelines: Lymphangioleiomyomatosis Diagnosis and Management was published by the American Thoracic Society (ATS) and Japanese Respiratory Society (JRS). The new set of guidelines addresses four important recommendations for the proper diagnosis and treatment of LAM.

“We continue to adjust our guidelines to keep pace with the evidence from clinical research,” said Joel Moss, MD, PhD, co-chair of the guideline committee and deputy chief, Pulmonary Branch of the National Heart, Lung and Blood Institute. “Patients are individuals and clinicians look at their specific cases when making treatment decisions. Their awareness of the guidelines and of the level of confidence in the potential effects of any course of treatment informs a doctor’s decision making, without constraining it. That is the key benefit to patients.”

Frank McCormack, MD, co-chair of the guideline committee and director of the Division of Pulmonary, Critical Care and Sleep Medicine at the University of Cincinnati, said, “Our hope is that these additional recommendations regarding diagnostic approach and pleural disease management can help protect patients from inappropriate drug exposures, unnecessary surgical procedures and recurrent pneumothoraces.”

With the release of these new clinical guidelines, healthcare providers and patients can gain a better understanding of the appropriate diagnosis and treatments for LAM. But these vital guidelines must first reach the right individuals, the physicians who are most likely to see patients presenting with signs and symptoms. The LAM Foundation is working to ensure today’s pulmonologists, obstetricians, gynecologists and emergency room physicians receive this important information.
To inform healthcare providers about the new ATS/JRS Clinical Practice Guidelines, The LAM Foundation is taking a holistic approach to help medical professionals diagnose and treat LAM. The LAM Foundation is:

• **PARTICIPATING** in professional education conferences

• **PARTNERING** with the University of Cincinnati to offer free virtual CME (Continuing Medical Education) about LAM

• **PROMOTING** the Foundation’s Global Clinic Network which gives patients and clinicians access to LAM experts

This spring The LAM Foundation will attend professional conferences for pulmonologists, obstetricians/gynecologists and emergency medicine physicians to ensure these specialties know about the new ATS/JRS LAM Clinical Practice Guidelines, the virtual LAM Continuing Medical Education (CME) activity, and the LAM Global Clinic Network: ACOG (The American College of Obstetricians and Gynecologists): April 27-30 in Austin, TX; SAEM (Society for Academic Emergency Medicine): May 15-17 in Indianapolis, IN; ATS (American Thoracic Society): May 18-23, in San Diego, CA.

The ACOG conference in Austin, Texas, was a huge success. This year we created information cards that provided targeted guidance to help obstetricians and gynecologists identify and diagnose LAM patients. The response was incredibly positive. We met with approximately 150 providers. The doctors especially enjoyed meeting LAM patients and family members. Researchers, faculty and pharmaceutical representatives asked engaging questions about how LAM is different than more common gynecological conditions such as endometriosis, catamenial pneumothorax and leiomyomatosis.

A new virtual CME course that teaches clinicians about how to diagnose and treat LAM is now available online to healthcare professionals. It addresses all eight topics from both the 2016 and 2017 ATS/JRS Clinical Practice Guidelines. The course is available through the joint providership of the University of Cincinnati and the RLDC for 1.0 AMA PRA Category 1 Credit™ and 1 ABIM® MOC point. This activity is available electronically online so that providers can login from any location, and it is structured in modules allowing participants the flexibility to view the one hour program continuously or in short, two to five minute segments.

This activity has been designed to meet the educational needs of pulmonologists, obstetricians and gynecologists, emergency room physicians, family medicine physicians, internal medicine physicians, nurse practitioners and physician assistants, and respiratory therapists involved in the management of patients with LAM.

The LAM Foundation needs your help letting healthcare providers know about the new virtual CME course. We are asking patients, friends and family members to share the link with their health care team. For a shareable link to the virtual CME, visit https://www.thelamfoundation.org/Healthcare-Providers-Diagnosis-Treatment-Treatment-Guidelines.

In addition, information cards with the link to the activity will be provided to LAM Liaisons and distributed at upcoming regional meetings, or you can call The LAM Foundation to request copies.
LAM clinical trials are critical for progress toward new treatments. Patient participation is the key to well-run studies with clear results.

The MILED Trial is a research study led by Dr. McCormack at the University of Cincinnati. There will be 11 study sites across the country. Currently enrolling locations include Cincinnati and Cleveland, OH; Chicago, IL; Stanford, CA; St. Louis, MO; Philadelphia, PA; Seattle, WA; Denver CO. Three additional sites in Nashville, TN; Atlanta, GA; and Boston, MA are opening in May. The study has four participants currently enrolled with plans to enroll a total of 60 women across the country.

Women who participate will be helping LAM researchers answer a very important clinical question about early treatment of LAM. That question is: “Should we use low-dose sirolimus early in LAM to slow progression of disease?” The answer to this question will benefit patients with LAM all around the world. Potential participants are adult patients with a LAM diagnosis, post-bronchodilator FEV1 of > 70%, DLCO above 60% predicted, resting room air saturation of 90% or greater (at sea level), and not currently taking sirolimus.

What to expect during MILED
Participants in the research study will attend 7 study visits over approximately two years (about one visit every four months). Study visits will include blood tests, a physical exam, and pulmonary function tests and questionnaires about breathing, fatigue and quality of life.

Study Drug
The study is a double-blind, placebo-controlled trial. This means that study participants will have a fifty-fifty chance of getting a placebo instead of sirolimus.

Participants will not know what they have received and neither will their study doctors until the study is complete.

MILED participants will be given study medicine (sirolimus or placebo) with instructions to take one pill every day and to record their pill taking and any side effects they may experience. The study staff will stay in contact between visits to monitor safety.

Travel Expenses
Reasonable travel expenses to enable participants to travel to and from study visits will be reimbursed by The LAM Foundation. In order to minimize travel, sites are open in Atlanta, Boston, Denver, Chicago, Cincinnati, Cleveland, Nashville, Philadelphia, Seattle and Stanford. For inquiries about travel expense support, please contact Anne McKenna, Patient Services Director, to request more detailed information. Anne can be reached at amckenna@thelamfoundation.org or at 513-777-6889.

For additional study information or to be connected with the study team at your local LAM clinic, please contact Susan McMahan at susan.mcmahan@uc.edu or 513-558-4376.

The safety of LAM patients is paramount to the caregivers conducting this study. The study team will plan to stay in close communication with study participants throughout the trial. A description of this clinical trial is available on www.clinicaltrials.gov, as required by U.S. Law. ClinicalTrials.gov is a registry and results database of publicly and privately supported clinical studies of human participants conducted around the world.
Pneumothorax (collapsed lung from accumulation of air between the lung and the chest wall) is a significant problem in patients with LAM. Up to 70% of patients will ultimately develop at least one pneumothorax in their lifetime and this is often the first sign of LAM. Most commonly, the pneumothorax occurs spontaneously without inciting factors (such as vigorous exertion). Unlike patients with Primary Spontaneous Pneumothorax (which occurs in patients without apparent underlying lung disease) who have about a 25% risk of recurrent pneumothorax after a first episode, three-quarters of women with LAM suffer from recurrence if nothing is done to prevent it. In a survey conducted from The LAM Foundation database, participants reported an average of 3.5 episodes of pneumothorax resulting in an average of one month total spent in the hospital.

There are a variety of treatment options for a spontaneous pneumothorax including simple observation, chest tube placement, chemical pleurodesis through a chest tube and surgery. Conservative management with observation until air is naturally resorbed by the body or simple chest tube placement alone has a very high rate of recurrence (about 65%) in patients with LAM. Because of this, most thoracic surgeons recommend pleurodesis (a procedure which obliterates the pleural space to prevent future pneumothoraces) after the first episode of pneumothorax. Pleurodesis can be done mechanically (using physical abrasion) or chemically (using talc, doxycycline, bleomycin or other agents). While chemical pleurodesis through a chest tube can be successful, this may result in incomplete pleurodesis due to uneven distribution of the chemical. Surgical treatment, using video-assisted thoracoscopy (VATS), is the preferred approach. In this procedure, cameras, forceps and other instruments are inserted through fingertip-sized incisions in the chest wall, rather than through the large incisions with rib-spreading that are used in thoracotomies or open procedures. The recurrence rate after surgical pleurodesis in patients with LAM is reported to be about 25-30%; however, there are strategies to help optimize success. First, surgical intervention should ideally be performed by a thoracic surgeon (rather than a general surgeon or heart surgeon) experienced in minimally-invasive surgery, pleurodesis and LAM (if possible). An aggressive mechanical pleurodesis which involves abrading the pleural surfaces with a piece of gauze or rough pad to promote an intense inflammatory response is the most common first intervention. Resection of the offending bleb or cyst is a common part of pleurodesis for patients without underlying lung disease or those with emphysema. However, this should generally be discouraged in patients with LAM because it is often impossible to tell which cyst is the culprit and staple lines placed in LAM lung tissue may lead to prolonged air leaks that are difficult to manage.

The procedure is done under general anesthesia and it is important that the anesthesiologist be experienced with thoracic surgical procedures in patients with lung disease so that protective lung strategies are used such as maintaining low airway pressures during surgery. An epidural catheter for postoperative pain control is standard in our practice, and provides excellent post-operative pain control. The chest tube is usually kept to suction for 48 hours after surgery and the typical hospital stay is about 3 days. Most patients can return to normal activity in 2-3 weeks. Patients should avoid anti-inflammatory agents such as ibuprofen or naproxen for 3 weeks. Sirolimus should also be stopped for at least a week before surgery and for 3 weeks after surgery. These medications may prevent effective pleurodesis from occurring. In addition, patients should avoid flying for one month after surgery.

For patients with recurrent pneumothorax after surgical intervention, there are several options.

CONTINUES ON NEXT PAGE >
For patients with a total or near total collapse, repeat surgical intervention is recommended. Options include a repeat mechanical pleurodesis if it is unclear whether an appropriate mechanical pleurodesis was done initially or pleurectomy in which the pleura overlying the ribs is actually removed. Another option to consider for refractory pneumothorax is chemical pleurodesis in which a drug or other agent is used to create an inflammatory response that results in pleurodesis. Talc is the most commonly used agent due to its effectiveness. Historically, talc pleurodesis was considered a contraindication to future lung transplantation because of the intense inflammatory response that made surgery very difficult. However, in the 2014 consensus document for the selection of patients for lung transplant by the International Society for Heart and Lung Transplantation, pleurodesis was not considered a contraindication for transplantation. They recommended that “pneumothorax in a patient who may become a future transplant recipient should be given the best immediate management... and “the choice of intervention is unlikely to affect future acceptance for transplantation.” Patients who undergo lung transplantation after a pleural intervention are at higher risk of bleeding complications; therefore, a strategy of optimizing successful treatment of pneumothorax while minimizing the impact on potential future lung transplantation should be undertaken. Given the potential that any intervention could have an impact on future lung transplantation should this become necessary, it is critical that the patient, pulmonologist and surgeon work together to develop the best treatment plan for each individual patient. It should be noted that talc has recently become less available due to manufacturing delays and it is unclear when adequate supplies will return. Alternatives, which are generally thought to be less effective, include bleomycin, doxycycline or iodine.

REFERENCES:

SAVE THE DATE!
Join us for the 2018 International Rare Lung Diseases Conference (RLDC·2018) and LAMposium in Cincinnati, Ohio September 6-9, 2018

Modeled after the RLDC·2016, this unique conference is designed to accelerate the advancement of rare lung disease research by fostering scientific communication and collaboration, improving clinician knowledge about new diagnostics and therapeutics, and increasing patient understanding about diseases affecting them. In 2018, the conference theme is “Bringing Cutting Edge Technologies to Rare Lung Disease Research.”

LAMposium patient and family educational sessions will run concurrently, and will offer a variety of sessions and workshops, centered around research progress, treatment of LAM, improving quality of life and caring for caregivers. Conference participants will have the opportunity to interact with world-class clinician-scientists, other rare lung disease patients and family members. Topics will be presented by LAM clinicians and scientists.

REGISTRATION IS NOW OPEN
For more information, visit www.thelamfoundation.org/conference
2017 LAM PATIENT BENEFIT CONFERENCE & LAMposium LA HIGHLIGHTS:
Los Angeles, CA - November 9-12, 2017

One hallmark of The LAM Foundation is our annual research conference and LAMposium. A unique version of the conference was held in 2017 in Los Angeles, CA. The main goal of the Patient Benefit Conference was to identify and fund proposals for new products or services to benefit LAM patients in the shorter term: five years or less.

The format for the conference germinated from the idea that problem-solving for short-term challenges related to living with LAM need to be addressed, in addition to research efforts to find a cure.

In advance of the event, The LAM Foundation conducted two surveys – one for individuals with LAM, and one for LAM Clinic Directors. The collective feedback of 250 patients and 16 Clinic Directors enabled The LAM Foundation to identify the following six big topics that were addressed at the conference. They included:

- Biomarkers and Imaging for LAM
- Supplemental Oxygen and LAM
- Exercise and LAM
- Fatigue
- Coping and Mental Wellness
- The Clinic Experience and Patient Reported Outcomes

The Six Big Topics were considered by thought leaders and participants in moderated Solutions Workshops where they identified potential solutions. The momentum of this stimulating meeting was taken to The LAM Foundation’s Breath of Hope Gala where $200,000 was raised for a newly established Patient Benefit Grant Program. This grant program will fund proposals generated at the Patient Benefit Conference.
LAMposium Solutions Workshops – Six Big Topics

Imaging for LAM Workshop
Imaging experts discussed how to develop imaging tools such as new software platforms and low-dose radiation HRCT techniques that allow patients to understand more about their disease from using imaging technology and potentially receiving less radiation when tests are performed. Participants discussed the need for a biobank of validated LAM clinical data for deeper learning.

Supplemental Oxygen and LAM Workshop
Patients and clinicians focused on improving the quality and technology of supplemental oxygen therapy. Participants generated ideas for making supplemental oxygen devices easier to use, less burdensome and more adaptable for living an active lifestyle.

Exercise and LAM Workshop
Clinicians and patients discussed exercise and LAM and addressed the fact that few studies have been conducted on this topic. The group discussed the possibilities and limitations for self-initiated pulmonary rehabitation, novel avenues for making exercise and daily activities more manageable, and better tests to evaluate oxygen requirements.

The Clinical Experience and Patient Reported Data Workshop
Participants conceptualized tools for patients to use to track disease progression and communicate effectively with their clinical care team. Ideas included technology such as online apps and home spirometry as well as new ways to integrate patient-reported data into the clinical record and research trials.

Biomarkers for LAM Workshop
Clinicians and patients discussed how to find more accurate ways to track disease progression, monitor treatment response and improve time to diagnosis. Key takeaways included the need for more clinical trials to find and verify new biomarkers.

Coping and Mental Wellness Workshop
Patients and clinicians addressed the sensitive and important topic of coping, including topics such as anxiety, fear and depression; overcoming the stress; and dealing with limitations.
THE STATE OF LAM

BY FRANK MCCORMACK, MD

I have been privileged to be involved with this organization for 22 years, and serving the LAM community has been one of the great joys of my life. The pace of discovery in TSC and LAM has impressed the entire scientific world and has led to meaningful alleviation of suffering for many people. The LAM Foundation and its members have unequivocally been the driving force behind this progress.

From humble beginnings when Sue Byrnes started building this community, patient by patient, and investigator by investigator over 18-hour days and thousands of phone calls to now... The LAM Foundation keeps reinventing itself, with innovative meeting formats around the country that continue to attract increasing numbers of investigators and families.

The LAM Foundation has re-established the process of collecting and distributing LAM lung tissues at the time of transplant; advocated for FDA approval for sirolimus, which is now established in five countries; advocated for oxygen justice; and lobbied at the NIH and on The Hill. On the research side, the scientific and clinical expertise supporting LAM cannot be duplicated. World-class scientists and clinicians are focusing on the problems that LAM families told them were most important. They work day and night in labs and clinics to determine answers and make a difference for people they have met at conferences and in their clinics.

Last year's Patient Benefit Conference & LAMposium in LA has already started significant inroads into progress and shown rewarding results. The stories of inspiration abounded throughout the conference with familiar faces and numerous first-time participants. We saw lessons in resilience and courage and joie de vivre. I gained hope from solutions that the coping and mental wellness focus has suggested for newly diagnosed LAM patients. We saw scientists enthusiastically solving problems and sharing data as the NHLBI Registry platform that Nishant Gupta and Joel Moss developed and the single cell RNA-seq data that Anne-Karina Perl brought to LAM have provided a pathway for biomarker development we previously only dreamed about.

We saw advocates tackling topics such as oxygen justice and experts encouraging industry partners to improve products that allow patients to live life to the fullest. We saw ideas be developed, such as a practical remote-control oxygen flow rate device.

“LAM patients and families could not have a more effective organization to represent them, or a more impactful way to invest a charitable dollar.”

We saw a remarkable evidence-based approach for determining the biological basis of fatigue and exercise limitation in LAM with insights that may emerge to resolve this fatigue problem in LAM in the next five years. We were encouraged as the imaging group’s feasible strategies for enhancing the utility of CT as a way to safely track LAM disease progression and treatment.

This concept of solving problems together – with patients, scientists and physicians in the same room, working on the problems that patients say are most important to them – started as a fairly indistinct idea two years ago at a board meeting. The success of this innovative approach has changed The LAM Foundation’s approach to meetings for all time, thanks to the efforts of Sue Sherman and The LAM Foundation staff.

This event highlighted, once again, how the money that The LAM Foundation raises directly funds significant grants that solve problems and benefit families in under five years.
Could you briefly describe your background with LAM and how your experiences influenced this book?

I had my first pneumothorax in the fall of 2003. I realized later that I had been experiencing shortness of breath for some time, but had paid no attention! I had been so healthy all my life that it didn’t occur to me that something might be seriously wrong. After my second pneumothorax in the spring of 2004, I had a biopsy and a pleurodesis and was diagnosed with LAM. That first pneumothorax occurred during a trip to Montreal; the second, while I was living temporarily in Paris, so I received an unplanned international tour of medical systems and hospitals in the French-speaking world.

As a result of LAM, my life is far more sedentary than it once was, and that is perhaps what enabled me to do the writing in this book – fewer distractions! With an FEV1 now fluctuating between 25 and 30%, writing is one of the few things I can still do without discomfort. One of the pieces, “Climbing Montmartre,” focuses on my medical experiences in Paris and my reckoning with a serious diagnosis while in my thirties. Many other sections of the book refer to LAM and its effect on my life, intertwining it with my other obsessions, such as my work as a translator, travel, foreign languages and cultures, books, marriage/divorce and childlessness.

Could you please tell us more about your book and when it will it be available?

The book, which won the 2017 Iowa Prize for Literary Nonfiction, is entitled For Single Mothers Working as Train Conductors. (Don’t ask me to explain what that means! You’ll just have to read it.) The book has been described as a memoir, an essay collection and a story collection. It is a collection of mini-memoirs of a life in which LAM has played a major role over the past 15 years. The book will be released on June 1, but can be preordered now from any independent bookstore.

What inspired you to write this book?

I have always been a writer as well as a translator. I have always loved reading autobiographical works, going back to my childhood, when I read and reread The Little House on the Prairie series and Little Women, moving on later to more sophisticated works of memoir and essays. Writing has always been my way of making sense of the world and my life, of creating pleasure and meaning, and of connecting with people.

How long have you been working on this book?

I wrote the oldest section in 2002, and the most recent one in 2016. The book contains 13 sections, 11 of which were published as freestanding pieces in magazines and anthologies over the years, and some of which have won various honors and awards. After the book was accepted for publication, I spent months weaving the parts together.

What do you hope readers “take away” after reading your book?

Perhaps the best description of my book is from author Meghan Daum, the judge who bestowed the Iowa Prize for Literary Nonfiction on the book. As she says, it’s about the tensions between the lives we think we want and the ones we make or get. Who wants a rare, incurable illness? It’s about figuring out what to do when things go wrong.
What has been your favorite part about writing this book?

The sentences and stories in the book emerged from a well of solitude and interiority. The process of creation was a profound experience in itself. It is also profound, after the many years it took to write its various parts, to see the book reaching people and touching them.

Linda Grunberg

In early July 2017, LAM Patient Linda Grunberg received a much-anticipated call from the lung transplant program at the Hospital of the University of Pennsylvania (HUP), that it was her turn to receive new lungs. After living with LAM for nearly 20 years, she was certainly ready, “As a LAM patient, I’ve been coming to HUP for 19 years and had the utmost confidence that this would be the best place to have my transplant.”

Linda did all the necessary work to prepare for this day, including enquiring about how her LAM lungs could benefit other women with LAM. “My daughter, Robyn, called The LAM Foundation to get as much information as she could,” Linda says. Robyn spoke with Anne McKenna at The LAM Foundation who directed the family to the National Disease Research Interchange (NDRI). NDRI is a non-profit national tissue recovery network that connects medical research facilities to donor tissue.

Linda took care to give specific instructions to her lung transplant team about her wishes to donate her explanted lungs to LAM research. “It was quick and easy, I just filled out some paperwork.”

For scientists who study LAM, there is no more important resource than actual LAM tissue, which is only available from LAM patients who agree to donate their tissue from a hysterectomy, oophorectomy, pleurectomy, nephrectomy, biopsy or lung transplant. Jilly Evans, PhD, LAM Scientific Advisory Board Member says, “We work with fresh tissue immediately to characterize the different targets for future LAM therapy and to help us understand the mechanism of LAM growth. We can then use the LAM cells to find ways to slow or stop them from damaging the lung.”

The annual number of lung transplants for patients with LAM is lower now than in years past, with just five LAM lung transplants in all of 2017. Sue Sherman, MHA, CEO of The LAM Foundation points out, “While this is good news for patients, it also means that there are fewer opportunities to distribute LAM lung tissue to research.”

LAM Clinic Director, Lisa Henske, MD, from Brigham and Women’s Hospital adds this plea to women with LAM who may one day have surgery, “We need your help! Many of our LAM research questions require LAM tissue. Your donation of tissue (which would otherwise be discarded) can make a huge difference.

We especially need “fresh” tissue, obtained at the time of surgery or lung transplantation.”

Linda Grunberg shares, “I am one of the oldest living LAM patients, (72 years young) who has had a bilateral lung transplant. I am feeling amazing and I hope to live a long and healthy life.” The gift of giving her old lungs to LAM research is priceless. “Our laboratory is extremely grateful to those who have who have helped fast-track LAM research through tissue donation,” adds Dr. Henske.

You can make arrangements to donate tissue today! Please contact Anne McKenna at The LAM Foundation by calling her at 877-CURE-LAM or 877-287-3526.
We often hear about the power of advocates to take on a cause with the goal of influencing change. In June 2017, The LAM Foundation gathered a group of LAM patients and family in Washington, D.C., to advocate for LAM awareness and continued funding of the NIH, presenting an opportunity almost as rare as the disease itself.

A crowd of amazing, committed, somewhat nervous (I know I was!) members of our LAM community started the day with training from LAM Board Member and seasoned advocate, Christina Hamilton. We learned what we could expect upon arriving on The Hill at the offices of various representatives and heard about the challenges we’d potentially face in making an impression, such as telling the story of our individual experiences, while making important broader points in 20 minutes or less.

We were there as part of Worldwide LAM Awareness Month, but as it turned out, that very morning, Republican senators revealed their proposed Healthcare Bill. So, healthcare was on minds of everyone we’d be speaking to that day. This meant we’d have to work even harder to make sure our stories stood out. I was with a small group of fellow New Yorkers and together we cut across swaths of parkland, filled with historic statues and fountains. While en route, we found some great photo spots to capture the Capitol in the background. We walked to the buildings where we’d seek out our appointed representatives.

One fascinating thing we learned quickly – Washington is run by the youth. While many politicians may be the seasoned faces of the different states, the offices stay humming thanks to the hard work of young staffers. They would act as messengers, bringing word to senators and representatives who could choose to act upon them.

My brother, Evan, who joined us in our efforts as a member of The LAM Foundation Board of Directors, helped ease our fears by reminding us, “Think about it this way – we are here to help educate.” We told personal stories of life dealing with a rare disease. We talked about the broader issue of oxygen and pitfalls facing those who need it on a daily basis. We even taught a few folks how to properly pronounce lymphangioleiomyomatosis!

In the end, more than 40 of us managed 50 appointments in a single day. Not a bad tally on an important day in the world of healthcare and the LAM community.
There have been some moments (and by “some” I mean a lot) during this LAM journey that I have tried to avoid. For me, dealing with them meant that THIS was all real, and real was a scary word. At the top of my list: the decision to start taking sirolimus and going to the National Institutes of Health (NIH).

I was diagnosed on December 14, 2015, and it was not until September, during LAMposium 2016, that I seriously considered my trip to Bethesda. I felt it was time. I was given the information I needed, the tools to be ready, and I was lucky enough to meet friends to go with. I had a long nice chat with my monsters and we decided to be practical, to not over think and do what had to be done to be healthy. Everything felt right except a small financial issue which was solved as soon as I reached out to The LAM Foundation, when the amazing Anne McKenna told me it was possible to get a travel grant. After this, I contacted the NIH, sent my information and booked my flight!
Of course, I was nervous, but I was excited at the same time. My hometown doctor is an amazing pulmonologist, but he was the first one to encourage me to see an expert and get an official examination and follow up. It was clear to me where I would find this kind of rare species, and I felt lucky to have a free pass to THE place to be checked from head to toe while being part of research studies working to find a cure.

I’m sure you’ve heard interesting anecdotes with doctors sporting the Homer Simpson look, the one saying “I might buy some donuts on my way home” while taking a long, silent, clueless look at your CTs. Well, it was so refreshing to get the OTHER look, the one that made me feel understood and taken care of. They asked a lot of questions that finally made sense and the greatest thing was that I also got the answers to mine! I got information about phytoestrogens, a topic that was interesting to me since the beginning and I enjoyed a firsthand explanation by Dr. Joel Moss about how Rapamycin works with LAM cells. I love that I got a lot of information about my case, which helped me with my internal journey, but my highlight was to experience that we actually are stronger together. C, my week would not have been the same without you holding my hand when I needed the most.

Huge thanks to my husband for supporting this decision, to Mary, Tania, Amanda, all the nurses and staff, the Phlebotomy (ninja) team, Dr. Angelo Taveira-DaSilva, and Dr. Joel Moss for answering all my questions (yes, I even had a list) and to all the other women attending the program, because none of this would have been achieved without your help; and of course, to The LAM Foundation for making this possible for me, for us.

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TEAM EASY BREathers PEDAL FOR FUNDS AT THE MILLION DOLLAR BIKE RIDE

Joe and Mary Van Brackel rode their tandem bicycle in the Million Dollar Bike Ride (MDBR) this year to help The LAM Foundation Easy Breathers team raise funds for LAM research. Since 2014, the Easy Breathers have raised more than $420,000 for LAM research. With your support the total will surpass a HALF MILLION DOLLARS in 2018.

This year’s MDBR took place on May 20th in Philadelphia, PA. There’s still time to donate and help the Easy Breathers team reach their goal of $50,000. Don’t forget, every dollar will be doubled by Penn Orphan Disease Center for a total of $100,000 to LAM research!

For more information on future rides, visit: www.milliondollarbikeride.org.

Contact Katie Jensen, Development Director, to find out how to give today: kjensen@thelamfoundation.org.
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Thank you!
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Don’t forget to use the hashtag #WWLAM on social media.

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