There is a “translational roar” coming from the National Institutes of Health. By that I mean that the nation’s primary research institution is increasingly focusing support on research that has proximate potential to positively impact human health. Although the tremendous value of funding excellent, fundamental science should be apparent to all who know the fruit fly story in LAM, there is a collective sense that the time has come to apply what we have learned over the past several decades and turn the attention of researchers from the bench toward the bedside. I thought it might be helpful to review findings from LAM research, future research directions, and ways patients and families can help.

Here are 10 recent useful findings from LAM research, in non-technical terms:

1. Sirolimus stabilizes lung function in LAM, and improves some measures of quality of life.
   a. In Japanese studies, low-dose sirolimus appears to be effective too.
2. Sirolimus appears to be quite effective for chylous manifestations of LAM, including chylous pleural effusions and chylous congestion of lung tissue.
3. The annual rate of loss of lung function in LAM is about 2.5 to 4.5 times the normal rate of 30 cc of FEV1 per year in healthy adult women (about a shot glass full of air). The rate in the NHLBI Registry was about 72 cc per year, and in the placebo group of the MILES Trial was 134 cc/year. Decline slows after menopause.
4. High serum VEGF-D levels are associated with better response to sirolimus therapy.
5. Median survival of patients registered with The LAM Foundation is 29 years after symptom onset, meaning half of all patients who enroll live 29 years after the first LAM symptoms develop. Most women with tuberous sclerosis develop cysts in their lungs as they age, almost certainly due to LAM in most cases, but lung symptoms develop in only a fraction of female TSC patients.
6. The diagnosis of LAM can be made without surgical lung biopsy in most patients, using a tool kit composed of clinical guidelines, abdominal imaging, transbronchial biopsy, and serum VEGF-D levels.
7. Air travel is safe in most women with LAM.
8. In U.S. and European countries, about five women of every million women carry a diagnosis of LAM.
9. Pneumothorax tends to recur in patients with LAM, and pleurodesis should be performed on the first occurrence.

Here are 10 useful future research directions for LAM. We need to know:

1. How to predict rate of progression, using clinical clues, blood tests, and imaging studies.
2. Better and better ways to predict who is likely to respond to therapy.
3. How to determine if the sirolimus dose taken is optimal or can be reduced.
4. If disease progression can be safely arrested by starting sirolimus early and treating continuously.
5. Whether patients can safely remain on sirolimus for long periods of time.
6. Whether patients can remain on sirolimus while awaiting transplant.
7. Whether postmenopausal patients should be treated or followed conservatively.
In 1849, the French novelist Alphonse Karr coined the phrase, “Plus ça change, plus c’est la même chose.” The common translation is “The more things change, the more they stay the same.” Though Alphonse Karr was known for his bitter wit and satirical commentary, I think that there is an interpretation of this proverb that aptly fits The LAM Foundation and the greater LAM Community in the fall of 2013.

Let’s begin with “The more things change …” As you read the headlines of this edition of Journeys, you will encounter plenty of change. A first and obvious change is that I am writing to you as the new executive director. I arrive with both optimism and gratitude. First, I am optimistic for a future that connects my strengths and experiences as a healthcare executive, marketer, and fundraiser with the resiliency and clarity of purpose that exists at The LAM Foundation. I’m grateful for having found this opportunity and for the LAM Board of Directors who approved my hiring.

Looking externally, we are all watching the changes in Washington related to The Affordable Care Act. It is difficult for any of us to comprehend the sweeping reforms being implemented within our healthcare delivery system, much less the potential outcomes. We have more questions than answers about the priority of rare-disease research or the implications of patient-centered care.

Closer to home, another change is that, for the first time ever, LAMposium will be held in Chicago in March 2014. While moving to Chicago is a new endeavor, we anticipate that changing locations will help us take advantage of many benefits including lower airfares, better access for national and international speakers and patients, and hosting the event in an exceptional facility.

Advances in the science of LAM continue at a rapid pace, and our hope for continued success is bolstered by the expansion of the LAM Clinics nationally and internationally. Concurrent with clinic expansion is our partnership with other rare lung disease organizations, which you will read about in this edition. Aligning with other rare lung disease communities offers us a new model for sharing registries, enhancing data collection capabilities, transferring clinical expertise, and improving the clinic experience for patients and families.

So many changes could feel overwhelming. Yet I sense stability and clarity of purpose at The LAM Foundation. I believe this to be true because the fundamental elements of our success have stayed the same. What do I mean? Let’s go back to our list of changes. The first is leadership. Since the early days of the Foundation, the Board of Directors, Sue Byrnes, and Frank McCormack, MD, established a sustainable model for funding the most promising and impactful disease-related research. Even through the economic downturn, The LAM Foundation continued to fund grants at pre-recession levels. In hiring a new executive director, the Board expects continued advances from funded research, broader patient services programs, and more community awareness.

Below are 10 useful things that LAM patients and their families can do to help:

1. Enroll in LAM Clinics.
2. Participate in trials.
3. Donate your talents to the LAM effort.
4. Provide blood, DNA, and tissues to scientists and the National Disease Research Interchange.
5. Raise money for research.
6. Support the Foundation.
7. Get parents, spouses, children and siblings to join the fight.
8. Come to the International LAM Research Conference and Patient and Family LAMposium meeting in Chicago.
9. Respond to surveys and queries.
10. Welcome the new LAM Foundation Executive Director, Sue Sherman, and ask her how you can be useful.
Second is the change from Washington. One of the central tenets of The Affordable Care Act (ACA) is that the best care for our citizens requires their full and active engagement in their own health. You’ve heard the buzzwords, like patient-centered, person-focused, or patient–powered care. The authors of the ACA would have been smart to talk to the nearly 1,300 LAM patients and their families about what it means to take control of one’s health. In less than 18 years, you have raised $16 million to advance the understanding of LAM, its diagnosis, and treatment. The LAM Community is the definition of patient-powered. This has not changed, nor has the commitment of clinicians, scientists, families, or the Foundation.

The location of LAMposium may have changed, but the “magic” of bringing scientists, clinicians, and patients together is fundamental to the success of both the event and the Foundation. While I have not yet experienced LAMposium, my initial impression is that we could host it in Dr. McCormack’s back yard, and the education, camaraderie, and crucial connection between science, patients, and passion would be undeterred.

A final point related to “… the more they stay the same” is paradoxical. That is, when it comes to innovation, The LAM Foundation needs very little change. Innovation shines through every person and activity that this community pursues, such as developing and expanding the LAM Clinic Network, inviting other rare-disease communities to work with us, LAMposium, pursuit of new grants, and partnerships with industry. Many things are in the works—and all with a tireless focus on the path toward a cure.

It is early in my journey as your Executive Director, and I am inspired on a daily basis by your caring and support. For example, the LAMMIES initiated a campaign on their Facebook page to raise $5 from each of their members to celebrate their 500th member. This is the heart of the matter—and the motivation for us to continue to raise funds, innovate, and succeed in finding a cure. The Board of Directors has called the next five years of the Foundation “Mission-Critical Preparation.” The Foundation’s mission, in addition to patient education and advocacy, is to find personalized therapies that improve and extend quality of life.

For The LAM Foundation, the French proverb works in both directions. We know that the more we stay the same—in our passion, generosity, integrity, and focus—the more resilient we will be to change.

One great mystery of LAM concerns the origin of the abnormal smooth-muscle tumors within the lungs of affected individuals. Evidence suggests that LAM cells are derived outside of the lungs. For example, the genetic “signature” of LAM tumor cells in the lungs is often identical to TSC negative tumor cells found elsewhere in the body, suggesting that all tumors arose from a single source. More noteworthy are observations that some women redevelop LAM tumors in their lungs after lung transplantation, indicating that LAM lung tumors might migrate from elsewhere in the body.

A second mystery of LAM is why the disease affects almost exclusively women. Is it the estrogen in women? In support of this hypothesis, cultured LAM cells are derived outside of the lungs. For example, the genetic “signature” of LAM tumor cells in the lungs is often identical to TSC negative tumor cells found elsewhere in the body, suggesting that all tumors arose from a single source. More noteworthy are observations that some women redevelop LAM tumors in their lungs after lung transplantation, indicating that LAM lung tumors might migrate from elsewhere in the body.

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One hypothesis that could explain both of these mysteries is that LAM cells originate from a source unique to women: the uterus. The uterus contains a layer of smooth-muscle cells called the myometrium. Myometrial cells commonly form benign tumors of the uterus known as leiomyomas, or fibroids. Under a microscope, leiomyomas look much like LAM tumors. Furthermore, like LAM, leiomyomas are most common during women’s reproductive years (when estrogen levels are high), and leiomyoma cells proliferate in response to estrogen. Given these similarities, one could postulate that, if leiomyoma cells developed TSC mutations, they would respond even more dramatically to estrogen and possibly migrate to the lungs.

To test this postulate, Hen Prizant, a graduate student with Stephen Hammes at the University of Rochester, specifically knocked out TSC2 expression in the mouse uterus.
Remarkably, fibroid formation was also completely dependent on estrogen, as removal of the ovaries (where estrogen is produced), or treatment with an inhibitor of aromatase (a key enzyme in estrogen biosynthesis), blocked essentially all excess uterine growth. In fact, without estrogen, some signals that are usually turned on in TSC2 negative cells (such as the enzyme S6 kinase) were barely detectable. Finally, approximately 75 percent of uterine-specific TSC2 knockout mice developed myometrial tumors in their lungs. While the overall lung pathology in these mice was not completely identical to LAM in patients, the presence of lung leiomyomas confirms that LAM tumors could indeed arise from the uterus.

This study suggests an additional layer to previously described LAM models. In this model, TSC2 may serve as a brake that prevents myometrial cells from growing rapidly. In the absence of TSC2, the brake is released; however, myometrial cells will not proliferate and metastasize until an accelerator is also activated. These mouse data imply that the primary accelerator might be estrogen, and that aromatase blockade might therefore serve as a potent inhibitor of LAM growth. In fact, the TRAIL Trial is now under way to investigate the role of aromatase inhibition in LAM progression and the LAM community eagerly awaits its results (http://www.thelamfoundation.org/research/trials-a-studies).

Integration of mTOR and Estrogen-ERK2 Signaling in Lymphangioleiomyomatosis Pathogenesis

Xiaoxiao Gu, PhD, and a team of researchers in the lab of John Blenis, PhD, at Harvard Medical School and Brigham and Women’s Hospital are trying to understand why rapamycin slows LAM disease progression, but doesn’t stop it completely. Rapamycin works by inactivating a group of proteins called mTORC1. This mTORC1 protein complex is controlled upstream by a protein called tuberin. The tuberin protein is often inactive in LAM cells due to mutations in the gene that makes tuberin, called TSC2. Because rapamycin only slows LAM disease progression, scientists suspect that there are other active proteins that signal the smooth-muscle-like “LAM” cells to invade the lungs. Estrogen has been a prime suspect for driving disease progression because LAM often gets worse during pregnancy. A previous study using an animal model of LAM showed that estrogen played a role in LAM-like rat cells invading the lungs of mice. Gu’s group wanted to know if estrogen plays a similar role in human cells, and if estrogen activates the same pathway as mTORC1, or a different pathway. Instead of using rat LAM-like cells, they used cells from a LAM patient’s angiomyolipoma. These cells have mutant, or inactive, forms of the TSC2 gene, which is common in LAM patient cells.

Using a variety of molecular techniques in cell culture, the scientists showed that estrogen and mTORC1 affected the same downstream target, Fra1 messenger RNA (abbreviated mRNA), but through two different pathways. Fra1 mRNA is translated to make Fra1 protein, which turns on additional signals that tell the cells to migrate and invade the lungs.

When LAM patient cells lose the active form of the TSC2 gene, like the cells used in this study, the mTORC1 protein complex gets activated, and there is no tuberin signal to turn off the mTORC1. Rapamycin blocks mTORC1 activation, and shuts down the signaling from mTORC1 that drives transcription of the Fra1 mRNA. Estrogen, however, turns on a different pathway that increases Fra1 mRNA. This pathway also stabilizes the Fra1 protein made from the Fra1 mRNA. So while rapamycin inhibits mTORC1 and turns off Fra1 mRNA transcription, estrogen is activating another pathway that increases Fra1 mRNA and stabilizes the Fra1 protein.

These results are exciting because they present another pathway that scientists can target to slow LAM progression in patients. This research team is already thinking about the safest ways to test a combination of FDA-approved drugs that could be used to turn off both pathways, which would turn off the Fra1 mRNA and protein that signal cell migration and invasion into the lung.

The LAM Foundation has provided research support for four of the authors. Dr. Gu, the first author of this paper, received a three-year Fellowship Award to study these pathways in cells. Elizabeth Petri Henske, MD, received an Established Investigator award. Jane Yu, PhD, and senior author John Blenis, PhD, have also been supported by The LAM Foundation. The full article,
“Integration of mTOR and Estrogen-ERK2 Signaling in Lymphangioleiomyomatosis Pathogenesis,” can be found on the Proceedings of the National Academy of Sciences of the United States of America (PNAS) website at http://www.pnas.org/content/110/37/14960.

Taking the Show on the Road: Chicago 2014

Have you heard the big news? For the very first time, the International LAM Research Conference and Patient and Family Educational LAMposium is moving to a new location. That’s right, after 16 years of hosting the conference in Cincinnati, Ohio, we are excited to be moving to a new venue in a new city! The 2014 conference is being held at the sophisticated, upscale Hyatt Regency in Chicago, Ill.

This year’s conference theme is Collaboration: Key to the Cure. In 2014 The LAM Foundation will celebrate our long held tradition of bringing patients, scientists and clinicians together. Collaboration is key to finding the cure and essential as we advance our mission to seek safe and effective treatments and, ultimately, a cure for LAM. Similarly, and on a larger scale, the global rare disease community is experiencing new and unprecedented collaboration across key constituents including patients, families, scientists, clinicians, industry, global advocacy groups, governments, and venture capital firms. By working together, the key to a cure is within our reach.

The LAM International Research Conference brings together researchers from diverse disciplines to discuss the scientific basis of LAM. The conference will integrate the ideas of top scientists who have parallel interests in fields that are relevant to LAM. The objectives of this conference are to discuss what is known, identify the most critical new research directions, and move the field forward. The Clinical and Basic Science sessions will be chaired, respectively, by MeiLan Han, MD, and Marc Achen, PhD. Session topics will include Biomarkers, Clinical Trials, Lung Biology/Lung Cancer, and Lymphatic Biology. Some of the confirmed speakers include Drs. Jeanine D’Armiento, Michael Detmar, Dan Dilling, Marilyn Glassberg, Steven Hammes, Daniel Hayes, Guillermo Oliver, Stephen Rennard, Stanley Rockson, Stephen Ruoss, and Kai-Feng Xu.

The Patient and Family Educational Symposium (also known as LAMposium) is an opportunity for LAM patients and their family members to spend time with others who can relate to what LAM patients experience. A patient described her LAMposium experience by saying, “I always learn something new and interesting at LAMposium, whether it’s related to the science and research behind the disease, or how someone else is handling a certain issue. It’s always good to connect with other women who share the same struggles and hopes. LAMposium is always a very positive experience!” The patient sessions will be chaired by Dr. Jay Ryu, Medical Advisor; Susie Picart, Patient Advisor; and Sally Lamb, Patient Conference Chair. Some of the session topics will include Benefits of Exercising, Importance of Clinical Trials, Nutrition and Diet, How to Manage My LAM, Understanding EFT, Oxygen: Why, When and How Much, and Transplant: Before and After. Some of the confirmed speakers include Drs. Charles Burger, Maryl Kreider, Frank McCormack, Sue Morter, George Pappas, Bruce Schwartz, and Gordon Yung.

Physicians, scientists, patients and family/friends will all come together on Friday evening for the Awards Banquet and again on Saturday evening for the annual Breath of Hope Gala. The Awards Banquet will honor our 2013 scientists and also LAM patients who have inspired donations over $10,000 for research since last year’s conference. LAM Leader Awards will be given to individuals who have consistently made extraordinary contributions to the LAM community. The evening ends with a dessert social, giving patients, physicians, and scientists a chance to meet and mingle. The Breath of Hope Gala offers a delicious dinner with complimentary beer and wine, open seating, a silent auction, music, and entertainment. It’s a wonderful celebration of life and hope.

Conference registration will be open by January 1, 2014. Be sure to mark your calendars. We hope to see you in Chicago next spring!

The Hyatt Regency O’Hare
Chicago, Ill.
March 28th–30th

Every year there is a patchwork quilt on display that is made up of individual quilt squares that are created by LAM patients or a family member or friend. This quilt is placed in the silent auction at the Breath of Hope Gala. In years past, the quilt has been purchased by LAM patients, who pool their money together to purchase and then present it to a member of the LAM community in appreciation of their dedication. If you would like to create a square to be included in the LAM quilt, please contact Stacey Wheelus at staceywheelus@gmail.com.
LAM Conference Keynote Speaker: Christopher P. Austin, MD, Named National Center for Advancing Translational Sciences Director

We are excited to announce that Christopher P. Austin, MD, will be the keynote speaker at the Friday evening Awards Banquet. Dr. Austin is director of the National Center for Advancing Translational Sciences (NCATS), the National Institutes of Health’s newest Center that was established in December 2011. He initially served as NCATS’ Division of Pre-Clinical Innovation director.

NCATS is a distinctly different entity in the research ecosystem. Rather than targeting a particular disease or fundamental science, NCATS focuses on what is common across diseases and the translational process. The Center emphasizes innovation and deliverables, relying on the power of data and new technologies to develop, demonstrate, and disseminate improvements in translational science that bring about tangible improvements in human health.

Dr. Austin came to NIH in 2002 from Merck, where his work focused on genome-based discovery of novel targets and drugs. He began his NIH career as the senior advisor to the director for translational research at the National Human Genome Research Institute, where he initiated the Knockout Mouse Project and the Molecular Libraries Roadmap Initiative.

International LAM Research Conference: Top 10 Reasons for Scientists and Clinicians to be There!

BY ELIZABETH HENSKE, MD, BRIGHAM AND WOMEN’S HOSPITAL, HARVARD MEDICAL SCHOOL

For scientists doing LAM-related research and physicians providing clinical care for women with LAM, the International LAM Research Conference is the most important weekend of the year. During the conference, unpublished translational and clinical data is discussed, clinical observations and “curbside consultations” are exchanged, and new concepts and ideas are debated.

Here are 10 reasons why you and your research team members should not miss this event:

1. To hear the latest and best scientific advances related to TSC, LAM, and related diseases, much of it unpublished, chaired this year by Marc Achen, PhD, from the Peter MacCallum Cancer Centre.
2. To hear the latest clinical advances and learn about ongoing and emerging clinical trials for women with LAM, chaired this year by MeiLan Han, MD, from the University of Michigan.
3. To meet our “next generation” of LAM physicians and scientists at the poster session, with a glass of wine and a lively poster discussion.
4. To spend a moment (or more) with a truly remarkable group of women who are living every day with LAM.
5. To meet the spouses, partners, children, friends, and family who support these women and who support LAM research.
6. To expose members of your research team to the reason why we do what we do—to improve the lives of women with LAM; this can be an inspiring event for young scientists attending for the first time.
7. To experience one of the most unusual and effective meetings that most of us will ever attend; scientists who attend for the first time regularly convey a lasting impact on their lives and careers through interactions with women with LAM.
8. To enjoy the collegial, interactive, and collaborative spirit of the LAM research community.
9. To relax with your colleagues at the annual Breath of Hope Gala, and perhaps take home a door prize.
10. To jump-start your own research and clinical care through a weekend of great talks, animated discussion, and thoughtful idea-generating.
The weather is just starting to change and soon it will be winter, but it's not too early to start thinking about attending next year's LAMposium, The LAM Foundation’s annual research and educational conference. For those who have never gone, LAMposium is a weekend filled with opportunities to learn more about LAM, to attend educational sessions led by scientists and doctors, to spend time with LAM specialists and ask questions, and meet other LAM patients and family members. The conference will be held in Chicago at the Hyatt hotel, which is a new location for us! It’s close to a large major airport and much easier to get to, which is a huge plus! There will even be a free shuttle from the airport to the hotel. And Chicago is home to wonderful museums, shopping, and restaurants, so if you can squeeze in an extra day, there’s so much to do there. For those women who desire to go but don’t think they have the means to do so, please contact the Foundation and ask for assistance; every year the LAM Family Network has some funds available to help those in need so that they can also have the experience of attending the conference.

So, what can you expect? There will be a mix of medical and health-related topics, from understanding LAM on a cellular level, on symptoms and what one can expect, on oxygen use, drug therapies and transplant, to sessions on the benefits of exercise and ways to reduce stress and anxiety. There will be an opportunity to sign up for individual one-on-one sessions with LAM doctors and other specialists. On Saturday evening, we will have a Gala, a social evening filled with an auction fundraiser, entertainment, music, and dancing. The conference is quite unique from other research conferences in that there are concurrently running sessions for the researchers and clinicians (which patients can also sit in on if desired) while at the same time there are separate sessions with topics designed specifically for LAM patients and family members to attend.

Patients and researchers comingle at the conference and during meals (which are provided). On more than one occasion, I have heard the scientists say that meeting and talking with LAM patients in person helps motivate them in their search for a treatment and a cure for LAM. It becomes so much more personal. What an opportunity for us to help shape our own future! And as a patient, I can’t overemphasize how encouraging it is to be able to come away with a feeling of hope; I personally find it very uplifting. In addition, I find the opportunity to form friendships and be surrounded by other women who “get it” very rewarding to me. I no longer feel alone with a very rare disease. It’s what keeps me coming back repeatedly. I can’t wait to see my LAM sisters and make new connections, and this time I’m also looking forward to having an opportunity to explore some of Chicago’s many wonderful venues. I hope you will also make an effort to attend and participate in this wonderful, fun weekend of learning and hope. Save the date!

The LAM Family Network: How You can Make an Impact

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

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

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

With Eternal Gratitude!
Martha Wainscott, LAM Patient
Board of Directors: Working Behind the Scenes

The governing body of The LAM Foundation is our Board of Directors. They work “behind the scenes” to make sure that the Foundation is successful. Each member of the Board is dedicated, hardworking, and enthusiastic. These volunteers have submitted applications and have been screened and then elected by that year’s current Board. They are responsible for guiding the Foundation to achieve our goals. They keep themselves fully informed about the work and progress in LAM; setting policies that establish the groundwork for the Foundation; developing and implementing strategic plans; ensuring that our funds are used in the most effective way possible; adopting and supporting a responsible annual budget; and working in concert with the Foundation staff.

In addition to the Board of Directors, the Foundation has a very active and knowledgeable Scientific Advisory Board, chaired by Frank McCormack, MD. This Board is the cornerstone of The LAM Foundation’s research program. They advise the Foundation on all scientific matters and they lend their expertise to formulate the direction of LAM research which is fully supported by the Board of Directors. See our website for a complete list of all Board members.

THANK YOU to our Board of Directors for all that you do to make a difference in the lives of those affected by LAM.
COMMUNITY

WELCOME TO OUR NEWEST BOARD MEMBERS:

CHRISTINA HAMILTON:
Christina is a Senior Vice President at Gephardt Government Affairs in Washington, D.C. With nearly two decades of experience in Washington as a congressional staffer and now as part of the Gephardt Group, she has a great deal of experience working on policy and legislative strategies to enact desired outcomes; navigating the budget process particularly as it relates to the health and medical research activities; and working with businesses, advocates, and coalitions to communicate their priorities to Congress and other stakeholders. As a member of the Board, Christina will be sharing this expertise as part of the advocacy team.

MARY HARBAUGH:
Mary is an “old, but new” member of the Board. She was previously on the Board and served for over four years. Recently retired from teaching college-level biology and microbiology for 14 years, she is excited to now rejoin the Board. Mary brings to the Board her perspective as both scientist and a woman with LAM. She has had LAM for over 31 years, although diagnosed just 12 years ago. Mary has been a regional LAM Liaison since the beginning of the program. When asked why she wanted to serve on the Board again, Mary said, “I have always been impressed with the intense dedication of the Board members who are concerned with what is the best for the LAM patients and The LAM Foundation. I am very excited and honored to be working with them again.”

DANIEL ROCHE:
Dan has been the Director of Finance for Regina Dominican High School in Wilmette, Ill., for the last 10 years – a not-for-profit, Catholic college preparatory school for young women. His prior work experience has been 30 years in investment banking, working with and for large money center banks. He has a Bachelor of Finance degree from the University of Illinois and an MBA from Loyola University of Chicago. Dan became involved with The LAM Foundation through his late sister-in-law, Jean Togikawa, who had LAM. He is eager to work with all persons associated with the Foundation to achieve an effective treatment and ultimately a cure for LAM.

ANDREA DOTTER SLATTERY:
Andrea is the Director of Research and Partner at Symmetry Peak Management, an investment firm that specializes in high-growth technology and emerging-growth companies. She has worked in the investment management industry since 1998, when she graduated summa cum laude with a BSBA from Washington University in St. Louis. In addition to her professional pursuits, Andrea is also a wife and mother and resides in the Philadelphia suburbs. She looks forward to contributing her skills from the business world to the LAM community to increase awareness, to raise funds, and to find a cure.

Collaboration is Key: The LAM Foundation Welcomes New Rare Disease Partners

Not all patients referred to LAM Clinics turn out to have LAM. The cystic and chylous lung diseases that are most commonly confused with LAM in our clinics are pulmonary Langerhan’s cell histiocytosis, Birt-Hogg-Dube syndrome, Sjogren’s cystic lung disease, and Lymphangiomatosis. Our LAM Clinic Directors have been “collecting” increasing numbers of these interesting patients, more by accident than design. The organizations representing each of these orphaned illnesses asked the Foundation to provide a home for their disease, to access our scientifically curious directors and their clinical and investigative teams, and to enable their patients to use our data and sample gathering systems, repositories, and data management center. Our LAM Clinic Directors have unanimously approved welcoming all of these partners.

Here are three accounts of other lung diseases being seen in our LAM Clinics. The first is by Charlie Strange, MD, who recently helped a patient with Sjogren’s. The other accounts are by the presidents of two lung organizations who are grateful for this partnership.

CONTINUES ON NEXT PAGE ›
The expansion of LAM Clinics to include the “other” diseases such as Birt Hogg Dube, Dipnech, Gorhams Disease, Sjögrens Syndrome, Langerhans Cell Histiocytosis, Lymphangiomatosis, Pulmonary Alveolar Microlithiasis, and Pulmonary Alveolar Proteinosis was met with a bit of trepidation by some LAM Clinic Directors. Do I really know anything about these diseases? Am I enough of an expert to make a difference in the lives of these rare disease patients? Will patient expectations be higher than I can deliver? Therefore, I agreed to share our experience with a rare disease clinic at MUSC to let you know this can work.

First of all, patients generally do not like to be seen as a “great case.” So when every patient in a clinic has a rare disease, the aura of fascination disappears and the clinic staff can focus on treating the patients as individuals. My approach to the rare clinic population includes the following four rules:

1. The patient needs an intensive education in their own disease because any interaction with the rest of the medical community will require the patients be teachers to their primary care practitioners and specialists once they leave the rare disease clinic. Be honest about what you know and don’t know but can look up.

2. The patient needs to hear what is known and not known about his/her symptoms. One of the most common questions is whether some symptom is related to the rare disease, and often there is not enough known about these systemic diseases to know definitively whether it is or is not related. All of us have stories in the LAM community in which we were fooled by a clinical presentation. The same happens in all diseases.

3. The patient needs to know that you will work with his/her physicians closer to home. Geographic isolation seems to be the rule for rare diseases. Therefore, the lines of communication need to stay open, even if the patient is seen infrequently. This model of communication is clearly not the way to make money in medicine. Our clinic revenues are small, but physician satisfaction is large.

4. Every patient needs to help build the infrastructure to advance the cure for his/her rare disease. Some time is necessary in clinic to discuss joining a registry, personally participating in a research study, or earning money to support his/her disease specific foundation. Physicians don’t see patients with rare diseases because it is the only way we can make a living. The professional and personal satisfaction of being the best physician for a rare-disease patient is the motivation for expanding the LAM Clinic experience. To date, I have met individuals engaged in their disease, eager for knowledge, and willing to push the limits of what is known in medicine. This is the reason all of us went into medicine in the first place. As an ordinary physician, I have been given an extraordinary opportunity and hope that our clinics succeed.

Gaining Clinical Support for Adult Diffuse Pulmonary Lymphangiomatosis

When a person with a prevalent disease visits a physician and is examined, he or she is usually given a diagnosis, a range of treatment options, and a prognosis—a time to heal, or a plan to manage and live with their illness. For a rare disease, like pulmonary lymphangiomatosis, it’s more than a visit to a clinic. It’s a journey—a nomadic experience crowded with uncertainty. Finding a doctor who understands the disease and can make a firm diagnosis can take several years.

Lymphangioleiomyomatosis and lymphangiomatosis—similar sounding words that are often confused with each other—both have commonly checked symptoms and characteristics. Both present with lymphatic lung disease, can experience shortness of breath, can be multi-systemic, can have long-term management burden, have abnormal proliferative factors, may involve pleural effusion, ascites, or diaphragm impingement, and can be life-threatening, or can lead to morbidity. Pulmonary lymphangiomatosis can be misdiagnosed as asthma or emphysema—and, not surprisingly, a number of cases are reported to have been mistakenly thought to be LAM—and vice versa. While similar is some aspects, they are two distinct, rare lung diseases for which biomarkers in LAM help to distinguish.

Lymphangiomatosis can affect male or female, a large number of the cases being small children and adolescents. There are documented patients from all over the globe. Pulmonary involvement can be clinically challenging. The “gold standard” for pediatric care has been the Vascular Anomalies Center (VAC),
a clinical model pioneered at Boston Children's Hospital. Other centers, such as in Cincinnati, Milwaukee, Seattle, and in Europe, comprise a VAC Network for pediatric care. For adults, there has been a huge gap—with only a smattering of expertise. There is usually an age cutoff for continuing care. As adolescents reach adulthood, the hunt is on again to find an experienced team who can accept their case. The newly formed partnership of The LAM Foundation with the LGDA—made possible through the leadership and support of Frank McCormack, MD, University of Cincinnati, and Denise Adams, MD, Cincinnati Children’s Hospital—provides an adult patient with apparent pulmonary lymphangiomatosis to go directly to a treatment team in the LAM Clinical Network. Today there are nearly two dozen adult pulmonary lymphangiomatosis patients who receive ongoing treatment and care management in the LAM Clinical Network!

Offering Hope to PLCH Patients

BY JEFFREY TOUGHILL, PRESIDENT OF THE HISTIOCYTOSIS ASSOCIATION

Lymphangioleiomyomatosis and pulmonary Langerhans cell histiocytosis: Both are words that are so far apart but so close.

Langerhans cell histiocytosis (LCH) is a rare disease that is caused by an overproduction of a certain cell in the body, a histiocyte. When these cells accumulate in certain places, they damage good tissue—skin, bone, liver, lungs and spleen. For many years, physicians thought that only young children had this disease. Although not considered a cancer, LCH may be treated with chemotherapy, radiation, or surgery.

As more and more information was published in medical journals, this disease became more recognized in adult patients. Consequently, the Histiocytosis Association has experienced a significant increase in new contacts from adult patients. We are now contacted by as many adult patients as we are by families of children.

For several years, it was next to impossible to offer any hope to adult patients. They (and we) were unable to find knowledgeable physicians who understood this disease. Essentially they were lost, alone, and without hope. Then we were contacted by The LAM Foundation, suggesting that we collaborate. Because adult pulmonary Langerhans cell histiocytosis (PLCH) is often confused with LAM, physicians at the LAM Clinics have taken an interest in PLCH.

The Histiocytosis Association has partnered with The LAM Foundation to establish pulmonary Langerhans cell clinics within the LAM clinical settings to address the issues outlined above. Potentially, these clinics will assist PLCH patients with access to relevant experts in histiocytic lung diseases and promote increased awareness within the medical community. It is also hoped that such a network will facilitate future studies, increase knowledge, and improve future care for patients with PLCH.

It is estimated that 63 percent of adults with LCH have lung-only disease, pulmonary Langerhans cell histiocytosis (PLCH), although it can also occur with other involvement, such as bone, skin, or diabetes insipidus. Although the cause is unknown, it is believed that 90 to 95 percent of adults with this disease are past or current smokers, suggesting that smoking is related. It has also been reported that children with LCH in organs other than the lungs, who acquire the habit of cigarette smoking in adulthood, may develop PLCH, sometimes years after the initial diagnosis. Relatively few studies have explored the natural history of PLCH and the care of patients is often fragmented among hematologists, oncologists, pulmonologists, and other medical specialists with expertise in histiocytic disorders. For patients afflicted with this disease, the identification of appropriate care providers can be a very frustrating journey, as relatively few specialists have expertise in the management of histiocytic lung disorders such as PLCH.

We are very grateful to be part of the journey that The LAM Foundation has set, and for the support from the VAC Network and the LAM Clinical Network for this breakthrough in addressing the adult-care gap for pulmonary lymphangiomatosis.

The writer is president of the Lymphangiomatosis and Gorham’s Disease Alliance, founded by his late daughter, Jana K. Sheets (1974-2010). His sister, Dorothy Pedrero, succumbed to LAM (1951-1990). For more information, go to the LGDA website: www.lgdalliance.org.
The LAM Foundation developed the LAM Foundation Clinic Partners program to focus care of LAM patients to expert clinics, provide access to multidisciplinary clinical care, collect data for research and quality improvement purposes, and embrace a coordinated approach for clinical care to LAM patients worldwide.

To continue to improve the care and treatment of LAM patients worldwide, we expanded the LAM Foundation Clinic Partners program to include 11 international sites:
- Australia (Sydney)
- Brazil (São Paulo)
- Canada (Montreal)
- China (Beijing)
- China (Guangzhou)
- Israel (Petah Tikva)
- Japan (Niigata City)
- Mexico (Mexico City)
- Spain (Barcelona)
- Switzerland (Lausanne)
- United Kingdom (Nottingham)

We have also added two new LAM Clinics in the United States, increasing the number of U.S. clinic sites to 28. The new sites are located in Missouri (Kansas City) and Kansas (Kansas City).

Our LAM Foundation Clinic Partners have knowledgeable physicians and staff members who exemplify hope, support, and encouragement, and aggressively manage symptoms with strategies designed to maximize health and independence. Our partners participate in clinical trials, advocacy projects, educational programs, support groups, research, and quality improvement initiatives.

In partnership with the LAM Foundation Clinic Partners, and to ensure their success, The LAM Foundation continues to make non-exclusive patient referrals to regional LAM Clinics and elevate the exposure and awareness of the regional and international clinics through The LAM Foundation’s website, e-blasts, online publications, and communications with LAM organizations across the globe.

Please visit The LAM Foundation website for a complete list of the clinics, including the Clinic Director name(s) and the number to call to schedule an appointment.

Influenza, or “the flu,” is a highly contagious viral illness characterized by fever, chills, severe aches, cough, headache, sore throat, and runny nose. The virus is spread by coughing, sneezing, and close personal contact. Influenza can lead to pneumonia, an especially severe complication in people with lung disease. Thousands of people in the U.S. die annually from the flu and its complications, and many more are hospitalized. Vaccination against influenza is the best protection to prevent this disease.

The influenza vaccine works by exposing people to proteins contained in the virus’ outer wrapping or envelope. After being exposed to these proteins, a person’s immune system builds a defense response that allows them to subsequently recognize and destroy viruses that contain these proteins. The influenza virus is remarkable for its high rate of change in characteristics of these envelope proteins.

As the envelope proteins change, new vaccines are needed to prompt an appropriate immune response. For this reason, influenza vaccines have to be produced each year against anticipated viruses. The decision of what to put in each vaccine is based on global surveillance of influenza viruses and spread of new strains. Influenza vaccines have been traditionally produced in chicken eggs and take up to nine months to develop. If there is an outbreak of a virus with an unanticipated envelope protein, a major flu epidemic can occur. Sometimes the vaccine can offer a degree of protection against unanticipated viruses.

Influenza vaccines are now available. This year there are more choices than ever for options to prevent the flu. There are two major categories of flu vaccine.

The first category is the inactivated flu vaccine. The inactivated vaccines contain fragments of inactivated viruses including their envelope proteins. Inactivated flu vaccines are recommended for people with lung disease, including LAM patients. They are safe for immunosuppressed individuals, including lung transplant patients and those taking sirolimus/rapamycin. Inactivated flu vaccine options this year include:
The traditional “trivalent” flu vaccine contains fragments of three viruses. This year’s vaccine includes envelope proteins from influenza A/California/7/H1N1, influenza A/Texas/50/2012 H3N2, and influenza B/Massachusetts/2/2012. This vaccine is produced in eggs and cannot be used in people with egg allergies. It is administered as a shot.

- A “quadrivalent” vaccine contains the aforementioned proteins and also contains influenza B/Brisbane/60/2008.
- A high-dose trivalent vaccine is targeted toward seniors over 65 years of age, where there is concern the standard dose may not convey sufficient immunity.
- An intradermal low-dose trivalent vaccine uses one-fifth the amount of vaccine antigens and an ultrafine 1.5-mm needle.
- A trivalent vaccine produced in cultured cells provides a new option for those with egg allergies.
- A trivalent vaccine produced using recombinant DNA technology is also an option for those with egg allergies.

Some of the new production techniques may make it possible to develop flu shots more rapidly, allowing for quick adjustments to changes in the makeup of envelope proteins.

The second category is of vaccines is the live attenuated vaccines, which contain weakened live viruses that contain appropriate envelope proteins to elicit an immune response. There are both a trivalent and quadrivalent live attenuated vaccines available. These are typically administered not by needle but by nasal inhalation. The live attenuated vaccines are not recommended for people with lung disease (such as LAM), pregnant women, or immunocompromised individuals, including transplant recipients (and their household contacts).

It is important for women with LAM to get a flu shot annually to help reduce their risk of flu. Please consult your physician to determine which flu vaccine is best for you.

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LAM Support Through Facebook
BY CATHERINE CHENOWETH, LAM PATIENT

I was first diagnosed with LAM over 17 years ago. So much has changed since that time. The LAM Foundation had just been formed, the NIH protocol just started, and there was a growing network of patients, thanks to Sue Byrnes. When asked what the most important and relevant changes were that I observed over the years, probably the first things to come to mind are all the advancements in medicine—the changes in treating and diagnosing LAM, in particular.

But there is another big change that I have seen take place over the years, and that is a change in the way we communicate. The first place I remember being able to connect with other LAM patients was the Listserv. I was on it for a while, but I found the volume of emails cumbersome and overwhelming after a while, so I left.

Facebook was created in 2004. I already had an account when they announced the idea of the Facebook “group.” In October 2010, on the very day the new feature was launched, I woke up and found myself in two LAM groups. Susie Picart and Peggy Haupt had each started a LAM group, and after some scrambling around and figuring out how things worked, we combined the groups and the two administrators joined forces. The group “Lammies” emerged, and it has been gaining momentum ever since. We now have over 500 members as I write this.

Patient support is so important when you have a rare disease such as LAM. We have become a close-knit group of women who count on each other for support in so many ways. The group is the place to go with questions on unusual symptoms, common problems, what to ask the doctor, how to use the many resources available, and how to cope. Perhaps most important is having a place to just vent when we’re feeling down, depressed, anxious, or ill. Just having someone who genuinely knows how you feel and what you’re going through can be so helpful. For myself, I know I’m not a doctor and I know I can’t diagnose people, but at some point I realized that after 17 years, I know some stuff! And it’s great to be able to pass that on. I am always able to find the support and answers I need in return.

Seeing someone post to the group from the hospital emergency room, someone finding a resource on the LAM Foundation website for them, and posting it for the ER doctors to be able to print out really drove home how far we’ve come. We no longer get swallowed into the black hole of the hospital, only in contact when a relative on the outside passes a message along. People can be in touch with their support from almost anywhere. LAM truly no longer can be called “the loneliest disease.”

If you are a LAM patient and you would like to join the Lammies group on Facebook, please contact Susie Picart at jpicart788@aol.com or Peggy Haupt at phaupt@sbcglobal.net.
My LAMiversary
BY STEPHANIE NEMSER DREYER, LAM PATIENT

Recently reached my one-year LAMiversary. This time last year I was in the ER with my first lung collapse, about to learn that I had a rare, debilitating disease with no cure. About to ask myself: What changes about my life if I only have 10 years left?

I’m so grateful to be feeling better this year. I’m grateful for supportive friends and family. I’m continually impressed and humbled by the brave Lammie women who inspire me to truly appreciate the good stuff, and to live life to the absolute fullest.

Now I’ll be honest. I’d rather not have LAM, obviously. The physical implications are tough. I had three left pneumothoraces in a six-month span (while pregnant). Three hospital stays, four chest tubes, close to 100 X-rays, and a pleurodesis four days after delivery aren’t fun and can be extremely painful.

However, my diagnosis has changed my life—and for now, it’s for the better. My family and friends have rallied around me with unwavering support. I’ve met very inspiring Lammies who are honest and brave and caring. The doctors and nurses who have cared for me are encouraging and generous, and I’ve learned a lot from them, including a much, much better prognosis. Most importantly, my diagnosis has forced me to take a good look at my life, my priorities, and me.

I have chosen to be positive and hopeful—about LAM and about life in general. I have chosen to be a better mommy and wife for my family. I have chosen to sharpen my career focus. I have chosen to be as healthy as I can be, and not let any disease define me. I realize that some day I will likely have more significant physical symptoms, but I’m not focusing on that. Hey, medicine moves quickly, and a lot can happen in just a few years.

So for now, I’m just living my life pretty close to normal, with a refreshed perspective and greater appreciation. Aside from a few scars, some shortness of breath, and a little pain in my chest, I’m doing great—and I plan to keep it that way.

LAM can be scary, but LAM can also be a blessing in disguise. I’m grateful for the life I have. I’m choosing to make the most of it, and I look forward to many healthy years ahead with my family.

So in honor of my LAMiversary, I encourage you to take a step back to appreciate life. Be grateful for the things we take for granted. Hug your kids, your puppies, your love. Really enjoy that glass of wine or bite of chocolate. Listen to the beauty of the wind and take a look at the night sky. And take a deep breath of hope.

Personal Journeys With LAM: Stories to Inspire You

The LAM Foundation is pleased to offer LAM patients a collection of inspiring stories, called Personal Journeys With LAM, that were written by women who are living with LAM. It’s our hope that patients will feel inspired as they read these personal stories of courage and determination. Because these stories were written to be shared with other women with LAM, Personal Journeys With LAM is available only to LAM patients.

The stories are organized according to the 20 different regions defined within the United States for the LAM Liaison Patient Network. The number of stories in each region does not reflect the number of women with LAM in that area but just the number of stories submitted for this publication.

To receive an electronic copy, LAM patients can contact Sally Lamb at slamb@thelamfoundation.org. Once your request is received, she will email a PDF file to you.

LAM patients can order a hard copy of Personal Journeys With LAM for $30. This amount will help to cover the cost to print in full color, bind, and mail. LAM patients can place an order in one of two ways:

1. Go to the LAM Foundation’s website (thelamfoundation.org) and make an online donation. Be sure to put “PJWL” in the comments area.
2. Mail a check to the Foundation (make check payable to The LAM Foundation). Be sure to put “PJWL” in the memo area. Please mail your check to:

   The LAM Foundation
   4015 Executive Park Drive, Suite 320
   Cincinnati, OH 45241

   Once payment is received, a copy of Personal Journeys With LAM will be mailed to you. If you have any questions or comments, please contact Sally Lamb at slamb@thelamfoundation.org or at 513.777.6889.

   Please note: Personal Journeys With LAM is to be considered private and confidential. It’s very important that it’s not posted on any social media. We ask LAM patients to please be respectful to those who have written and shared their personal story so that other LAM patients can feel connected and less alone in their own journey with LAM.
Help Support the 2014 International Research Conference/LAMposium and Breath of Hope Gala!

BY SYLVIA RICHARD, DEVELOPMENT DIRECTOR

The planning for next year’s Breath of Hope Gala is in full gear. As in previous years, we will tantalize your taste buds with delicious food choices, entice your dancing shoes after dinner with great music, and last, but certainly not least, shine a light on The LAM Foundation mission by holding the Fund-A-Cure live auction, silent auction, and raffle drawing!

We know that not everyone can travel to Chicago to be a part of our conference, but you can still make a difference and impact LAM research efforts worldwide. Here are some ways you can help from home:

SPONSORSHIP
Consider asking your place of employment if they would sponsor the conference or consider becoming a sponsor yourself. Sponsorship levels range from $250 to $20,000. Some of the benefits that you’ll receive as a sponsor include your name or logo placement in banquet and gala event programs, science and patient conference programs, event signage, recognition on The LAM Foundation’s website, and more.

If you plan to attend the conference and the Breath of Hope Gala in 2014, consider hosting a table of 10 at the Saturday night gala for $1,000. By hosting a table of 10, you ensure that you’re seated with the guest of your choice. Your table purchase will be listed in the Breath of Hope Gala program, and a special sign will be placed on a significant table at the event to recognize your generous gift.

FUND-A-CURE – FUND RESEARCH!
Fund-A-Cure, one of the main events at the Breath of Hope Gala, takes place in a live auction setting to raise money to fund research. There are no auction items—just monetary bids to support LAM Foundation research efforts. In 2013, more than $122,000 was raised! Fund-A-Cure is always an amazing and awe-inspiring 20 minutes of generosity.

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

SILENT AUCTION AND TAKE-A-CHANCE RAFFLE
We are looking for your help again this year for our silent auction and Take-A-Chance raffle. Please see our “wish list” of items that would help make the silent auction our best yet!

WISH LIST
• Use of vacation properties/ timeshare hotel accommodations
• Resort stays
• Cruise packages
• Airfare
• Wine / wine tours
• Food baskets (pasta, cookies, candy, cheese)
• Spa/pampering
• Theme baskets (Chocolate Lover, Coffee Lover, Book Lover, Music Lover)
• Tickets to sports games
• A day with a sports personality
• Signed items (footballs, basketballs, books)
• Entertainment or dining gift cards for national restaurant chains
• Ipads / Ipods / Netbooks / Kindles
• Wii/ Xbox
• Jewelry

If you have any questions or need a sample request letter, please contact Sylvia Richard at srichard@thelamfoundation.org or call 513.777.6889. Thank you so much for being an outstanding community of supporters! Please send your contributions to the Foundation by February 28th so that we may acknowledge your item in the Gala program.

We are confident that the 2014 Breath of Hope Gala will be in the spotlight of success! We look forward to seeing you there!
Breath of Hope Legacy Society

The Breath of Hope Legacy Society was created to recognize those donors who want to create a lasting legacy that will help shape the Foundation’s future through a planned gift. What is a planned gift? A planned gift is a philanthropic gift and legacy that is funded by individuals in their lifetime or after their death. No matter what your age or income level, there is a planned gift that can make a difference in the lives of women with LAM.

When you make a planned gift to The LAM Foundation, you are ensuring that the Foundation will be able to continue to fund LAM research and help patients and their families through their journey with LAM. Donors who make a planned gift can be recognized for their contribution while still living and leave behind a wonderful legacy of caring and support to the LAM Community. For your family, a planned gift removes property and assets from probate, reducing or eliminating probate expenses. The tax advantages can be substantial.

There are many types of planned gifts. The most common way is through a bequest. Many donors, after evaluating their family and philanthropic goals, make bequests through their wills and trusts. Life insurance and retirement plans are also easy ways to leave a legacy. Simply name The LAM Foundation as the first or subsequent beneficiary on your policy or plan. Charitable lead and remainder trusts, endowment gifts, and stocks are also ways in which you can provide for the future.

If you are interested in leaving a legacy and becoming a member of the Breath of Hope Legacy Society, we encourage you to contact a financial adviser to guide you in selecting the best type of planned gift option for you and your family.

Worldwide LAM Awareness Online Fundraising Campaign

Thank you to all of you who have participated in the Worldwide LAM Awareness Campaign. With your help, we have raised over $24,000 so far. We have extended the Worldwide LAM Awareness Online Fundraising Campaign until the end of this year. Our goal is to raise an additional $10,000 by December 31, 2013.

Are you interested in raising money for LAM research this year? Well, it’s not too late. You can still raise funds to support research from the comfort of your home. If you have already created a page, consider writing an end-of-year email to your family and friends, asking them to support your online fundraising page by making a donation.

If you have not created a page already, please visit www.thelamfoundation.kintera.org/WWLAD13. You can support this virtual event by making an online donation, sponsoring a participant, or creating your own online fundraising page.

HOW DO I RAISE FUNDS ONLINE?
- Click the Participant Registration button (registration is FREE!).
- Join your region’s team, create your own team, or join as an individual.
- Complete the required registration information. Be sure to remember your username and password. You’ll need it later.
- Now you’re in your personal headquarters. You can add a picture of yourself to your personal page and send emails to let people know that you’re raising funds for LAM.
- To log in after leaving the site, visit www.thelamfoundation.kintera.org/WWLAD13 and click any of the links listed under My HQ on the lefthand side of the home page.

Remember, this fundraising campaign will end December 31. Be sure to remind people to visit your personal fundraising page by consistently posting your page to your Facebook or Twitter account and by sending donation request emails from your personal headquarters.

If you have questions or need help, you can contact the Foundation’s Development Department at 513.777.6889.
On June 29, 2012, Paul and I became proud grandparents to beautiful girl named Amelia Michelle. Our son, Aaron, and his wife, Annette, beamed with joy at this new gift from God. Several weeks after the delivery, Annette started having a cough. She didn’t seem to be bouncing back easily after the birth, but we initially attributed her problems to fatigue of a new parent, and the demands of an infant. After seeing their family doctor, a round of steroids and an inhaler provided little or no relief. Upon returning to the doctor, a CT scan was ordered to make certain she hadn’t developed a pulmonary embolism giving birth to Amelia. The radiologist read the scan as advanced emphysema, which shocked us all since Annette was just over 30 years old, never smoked, and had never been around secondhand smoke. At this point, we knew something was seriously wrong, and her family doctor sent her to see a pulmonologist.

Meeting with the pulmonologist, we received the horrible news: Annette had a rare progressive lung disease that we couldn’t even pronounce! It was advanced far enough to cause ongoing problems with breathing, activities, and daily routines.

Imagine for a moment, you are first-time parents, only six weeks after the greatest bundle of joy comes into your life, and then you are told that one of you has a rare lung disease called LAM, which will probably result in your death in 10 to 15 years or less. News of that type can only take you from the highest euphoria toward the darkest despair. Annette and Aaron struggled, prayed, and ultimately decided not to give up.

They contacted The LAM Foundation and received so much support and information. They were directed to one of the world’s leading LAM doctors in Denver, Colo., for help and care. Through the Foundation, they have been able to have dialogues with other LAM patients and doctors from around the world with updates and support.

When Paul and I learned that Annette had LAM, we wanted to do something to increase awareness and raise funds for LAM research. Because we are a golfing family and nearly all our family lives in and around the Topeka, Kan., area, we decided to hold a golf tournament here. As we began planning the tournament, it quickly “morphed” into something much, much more!

BLAM! (Benefit for LAM tournament) developed into a golf outing, followed by dinner, dancing, and a silent auction for the attendees. The planning for the event began in January, and by June 22nd we had 82 golfers in the golf tournament and over 200 people who attend the dinner / dance. Awareness was raised throughout the community, and Annette was able to celebrate with those who have helped her through her first year of diagnosis. When all was said and done, thanks to the generosity of our friends, family, and other sponsors, over $10,000 was raised for The LAM Foundation! We plan to continue to hold BLAM! as an annual event with next year’s date already set for June 21.
The LAM Foundation would like to thank our many generous donors for their support.

This list reflects gifts made between January 1, 2013 and June 30, 2013.

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