How Do We Define Success? Cure? Remission? Chronic Suppression?

BY FRANK MCCORMACK, MD, SCIENTIFIC DIRECTOR

We have an effective treatment for LAM, sirolimus. We know that sirolimus does not cure LAM, however, because it only seems to have beneficial effects on lung function while the drug is being taken. In most cases, it stabilizes rather than improves lung function, so it does not meet the most rigorous definition of cure, that is, a “complete restoration of health”. Lance Armstrong’s course is a good example of a cure. Treatment completely eradicated his fatal, metastatic testicular cancer and completely restored his health. We don’t think that lung function in LAM, once lost, can be completely restored (at least not in 2013).

We don’t think sirolimus by itself can induce a remission, either. That is, we don’t think it can completely eradicate LAM cells from the body, even temporarily. We believe that although it reduces serum VEGF-D levels dramatically, they do not return to normal, so there must still be LAM cells around secreting VEGF-D into the blood even while sirolimus therapy continues. In addition, sirolimus only shrinks angiomylipomas (which are composed of LAM-like cells and are valuable surrogates for the effect of drugs on LAM) by about half, and when the drug is stopped, the tumor size increases again-so sirolimus is not killing cells, it is suppressing or shrinking them.

Robin Robert’s (GMA Co-anchor) course is a good example of a complete remission. There is no sign of her breast cancer after aggressive treatment—i.e. all breast cancer cells are presumed dead—and it hopefully will never return. She may have paid a price for her deliberately aggressive treatment choices, however, since she subsequently developed myelodysplasia and required a bone marrow transplant. There may be a lesson here for LAM as well. More on that below.

We think that sirolimus is partially restoring cellular order and suppressing bad LAM cell behaviors—their tendency to move, invade and secrete VEGF-D and lung dissolving substances. Not curing, not inducing remission, but suppressing. LAM cells seem to be shrinking and behaving, but not dying, on sirolimus. When sirolimus is stopped VEGF-D levels again rise, AMLs increase in size, and lung function decline resumes, suggesting the disease has been released from suppression.

Recently, on a trip to Los Angeles to talk about LAM, a scientist in the audience asked me if I was disappointed by the limitations of sirolimus in patients with LAM. The first thought that came to my mind was that I must be delivering the message poorly, because in fact I am delighted that we have this therapy to offer patients and I have been impressed with its efficacy and safety profile. Compared to the other drugs we have to treat diffuse lung disease, it performs extremely well. The fact that it is suppressive rather than remission inducing or curative does not mean that it is inferior. Indeed, many highly successful therapies are based on suppressive rather than curative strategies, including diabetes, depression and chronic myelogenous leukemia (CML). CML has been transformed from a uniformly fatal illness to a chronic manageable illness with the use of an exquisitely targeted therapy called Gleevec. Kareem Abdul Jabbar who was diagnosed with CML in 2008 is planning on living a long and healthy life on the drug. Sirolimus is an exquisitely targeted therapy for LAM, and it is entirely possible it may turn out to be our Gleevec.
So let’s not throw the baby out with the bathwater. This drug works for LAM, at least in the short term. The fact that it is suppressive rather than curative or remission inducing is only a problem if resistance can develop or if the drug can only be tolerated for limited periods. We need more research to determine if the drug is effective at lower doses, if it can be started earlier to prevent progression rather than later to stabilize advanced disease, and if it can be taken for long periods without serious side effects or development of resistance. So while we swing for the fences looking for drugs that promise cures and complete remissions, let’s remember that sometimes aggressive therapies have consequences (i.e. Robin Roberts) and that one very appealing definition of success for LAM could be ‘making it a chronic disease’ with sirolimus rather than curing it.

The LAM Foundation—“The Model for Rare Diseases”

BY LAURA LENTZ, CHAIR, BOARD OF DIRECTORS

When I was first diagnosed with LAM, I experienced two distinct emotions. First, I experienced the fear of being diagnosed with a potentially fatal disease. Second, I felt alone, as LAM is a rare disease and so few people, including doctors, understood what I was going through. The shock of a rare disease diagnosis is very difficult, but the truth of the matter is, we are not alone. We are a part of a broader rare-disease community. There are close to 7,000 rare diseases impacting about 25 million people in the U.S. That is about one in 10 Americans.

The LAM Foundation has been called “The Model for Rare Diseases” by the NIH and the “Model for Patient Advocacy” by the New England Journal of Medicine (NEJM). How did The LAM Foundation and the LAM community achieve this success? We achieved this success by creating a sustainable model of collaboration between patients, researchers, and clinicians. The result of this collaboration was the first treatment for LAM. Dr. Chris Austin of the NIH recently stated that of the approximate 7,000 rare diseases, there are treatments for only 500 of them. With the success of the MILES Trial, the LAM community has been able to add to that number. Given the adversity facing rare diseases, this accomplishment is truly amazing.

The touch-point for our collaboration is the LAM Clinics. The LAM Foundation has partnered with 26 medical institutions across the country to form the LAM Foundation Clinical Research Network (LAM Clinics). These LAM Clinics are incredibly important to our future success. Not only do they provide expert care for our LAM patients, but they also facilitate meaningful research and clinical trials. The LAM Foundation has invited other rare-disease partners such as the Histiocytosis Association to participate in the LAM Clinics and take advantage of the existing network and infrastructure. This is another way that we are giving back to the rare-disease community.

This rare-disease community offers many opportunities in our quest to find effective treatments and ultimately a cure for LAM. There are wonderful organizations such as the National Organization for Rare Disorders (NORD), The Office of Rare Diseases Research (ORDR), and programs at the National Institutes of Health (NIH) that provide us with funding, education, and infrastructure to accomplish our goals. The government appears to be focusing on rare diseases, recognizing the large number of Americans that have a rare disease, and the difficulty smaller organizations encounter obtaining the necessary resources to develop drugs and execute treatment trials.

Even though we have experienced success, we all know there is still much work to be done. I am confident that the passionate and dedicated members of the LAM community will continue to drive us forward to find effective treatments that will improve and extend the lives of women with LAM. We are committed to continue to work with the rare-disease community to accomplish these goals.
Amazing Progress Continues in LAM Research

BY JOHN BLENIS, PHD, AND STEPHEN RUOSS, MD, SCIENTIFIC CONFERENCE CHAIRS

The 2013 International Lymphangioleiomyomatosis Research Conference brought together a diverse group of scientists engaged in basic research, preclinical and/or clinical studies that are directly relevant to LAM. The symposium, also known as LAMposium, covered several general areas of investigation ranging from understanding and taking advantage of changes in cellular signaling and metabolism in cells with mutations in the tuberous sclerosis complex (TSC) genes, to identifying new biomarkers, improved imaging methods and new potential therapeutic strategies for LAM.

Several investigators presented their recent discoveries of altered metabolic processes found in cells and animals with inappropriate regulation of mTOR.

Brendan Manning, PhD (Harvard School of Public Health) described his work defining how the tuberous sclerosis complex suppresses cell growth and thus how loss of function changes several metabolic processes controlling growth and survival including lipogenesis, glycolysis and the pentose phosphate pathway. Issam Ben-Sahra, PhD (Harvard Medical School) described his discovery of how mTOR and S6K1 directly regulate pyrimidine synthesis, an essential requirement for cell growth. Ray Yeung, MD (University of Washington School of Medicine) continued this theme by revealing the role of mTORC1 and feedback-inhibited Akt, in regulating lipogenesis and steatosis in mouse models. mTORC1 drives protein synthesis in TSC-mutant cells which requires high energy supplies, shown by Alfredo Csibi, PhD (Harvard Medical School) to be provided in part by mTORC1-regulated glutamine metabolism. Proper protein folding is essential in cells with high protein synthesis and Dr. Csibi reported that interfering with protein folding and energy production with small molecules inhibitors selectively induces death in TSC-mutant cells, revealing a new potential therapeutic strategy independent of rapamycin. Elizabeth Henske, MD (Brigham & Women’s Hospital) discussed the importance of autophagy-mediated cell survival in LAM and provided evidence that targeting mTORC1 with rapamycin (sirolimus) in combination with inhibition of autophagy with hydroxychloroquine was significantly more effective than either agent alone in mouse models. This has led to the initiation of the Phase 1 SAIL (Sirolimus and Autophagy Inhibition in LAM) Trial. Carmen Priolo, MD, PhD (Brigham & Women’s Hospital/Harvard Medical School) demonstrated that targeting autophagy in LAM, stimulated upregulation of the pentose phosphate pathway to promote LAM cell survival. Her findings reveal a rapamycin-independent therapeutic strategy that can induce selective death in LAM cells. Continuing on the theme of identifying new strategies, Vera Krymskaya, PhD (University of Pennsylvania) provided additional evidence supporting the importance of targeting HMG Co-A Reductase with statins plus rapamycin as a future combination therapy approach for LAM.

Several studies are investigating the contribution of estrogen signaling to LAM, in the context of high mTORC1 activity. Joel Moss, MD, PhD (National Heart, Lung, and Blood Institute) showed that estrogen and mTORC1 signaling were intimately integrated to control cell size in TSC-null cells. Combining gene expression analysis and metabolomics, Jane Yu, PhD (Brigham & Women’s Hospital) showed that mTORC1 and estrogen work together to promote COX-2 expression and prostaglandin biosynthesis in TSC2-mutant cells in culture and in mouse models. She also found evidence of increase prostaglandin in serum of LAM patients. These studies reveal new therapeutic strategies such as the use of aspirin and estrogen signaling antagonists, and identify new potential biomarkers for LAM. Marina Kaufman-Holz, PhD (Albert Einstein College of Medicine, Yeshiva University) presented her work demonstrating the direct link between mTORC1 and S6K1 to estrogen receptor phosphorylation and signaling. She also showed that resveratrol inhibits S6K1. John Blenis, PhD (Harvard Medical School) showed that inhibiting S6K1 or its target the eIF4A RNA helicase, in combination with estrogen receptor antagonists, dramatically suppressed LAM cell migration and survival. Elena Goncharova, MD, PhD (University of Pennsylvania) showed that mTORC1 modulates E-cadherin trafficking and cell motility through Rac1 GTPase. Interestingly, the Blenis lab had earlier shown that Rac1 is also an upstream regulator of S6K1. Thus, combined with Dr. Ben-Sahra findings linking S6K1 to pyrimidine synthesis, these studies reveal S6K1 as an alternative therapeutic option for rapamycin, likely to be most useful in combination therapies, for example with inhibitors of estrogen signaling.

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Clinical observations in LAM were discussed by a number of speakers. Kuniaki Seyama, MD, PhD (Juntendo University, School of Medicine) shared the Japanese clinical experience with the use of low-dose rapamycin (2 mg/day or less) in the treatment of LAM. His presentation highlighted the great challenges and efforts undertaken by the Japanese physician-investigators to provide rapamycin for LAM patients in Japan, and their data suggest that low-dose therapy may provide significant clinical benefit. We have yet to fully understand the optimal dose of rapamycin for LAM, but these data provide added and important perspective. Lisa Young, MD (Vanderbilt University Medical Center) reviewed the rapamycin treatment data from the MILES Trial, which reveal an apparent correlation of reductions in serum VEGF-D levels with improvement in lung function (FEV1). This reinforces the importance of VEGF-D in the pathology of LAM, and suggests added options for the development of new therapies.

A useful and illuminating discussion of current imaging tools for lung disease was presented by George Washko, MD (Brigham & Women’s Hospital), with a focus on airways and cyst measurement and modeling, and the potential applications in LAM.

Addressing a vitally important aspect of LAM clinical management, Jeff Swigris, DO, MS (National Jewish Health) described his recent and ongoing efforts to develop better and specific clinical tools to accurately assess the quality of life of women with LAM. This is an important tool to have for clinical monitoring, and is critically important as a measure of treatment success in any therapy trial. Dr. Swigris’ work on quality of life tools had very real import for this meeting, as he took advantage of the presence of LAM patients at the meeting to involve them in the initial aspects of development of a LAM-specific quality of life measurement tool.

Elizabeth Thiele, MD, PhD (Massachusetts General Hospital) discussed lung manifestations in tuberous sclerosis complex (TSC), including multifocal micronodular pneumocyte hyperplasia, which is found relatively commonly in TSC and is characterized in part by a proliferation of type II pneumocytes along terminal airways (with micronodular pattern on chest CT). This is a very interesting and different phenotype compared with patients with sporadic LAM, and raises questions about differences in pulmonary effects of TSC1 vs. TSC2 mutations. David Kwiatkowski, MD, PhD (Brigham & Women’s Hospital) shared some fascinating data from the analysis of lung tissue specimens of women with sporadic LAM who had undergone lung transplantation. Surprisingly, there were relatively few cells that possessed TSC mutations in lung tissues clearly affected with LAM, raising the prospect that other genetic effects beyond simple TSC mutations were active in the pathological processes of LAM. Magdelena Tybuczy, PhD (Texas Tech University Health Science Center) presented data from her analysis of skin lesions from women with TSC, which reveal a complex picture of variability of mutations in TSC genes in these skin lesions. Her data demonstrates the presence of both inherited germine TSC mutations, as well as secondary and quite variable new mutations in both TSC1 and TSC2 genes.

Another important focus in the meeting this year was lymphatic developmental regulation and the participation of VEGF in lymphatic biology and pathology. Donald McDonald, MD, PhD (University of California San Francisco) presented evidence on the participation of VEGFs in lymphatic development. In mouse model studies, overexpression of VEGF-C (the principal lymphangiogenic VEGF in the mouse) produces abnormal lymphatic development predominated by lymphangiectasis and chylos fluid leak, similar to the lymphatic defects seen in LAM. Marc Achen, PhD (Ludwig Institute for Cancer Research) has also identified notable and variable plasticity of lymphatic vessels in response to VEGFs in his mouse studies, in agreement with the observations from the McDonald lab. The activity of microRNAs in the regulation of VEGF function was described by Calvin Kuo, MD (Stanford University School of Medicine). Data presented by Dr. Kuo revealed the possibility that relative dysregulation of VEGF actions may be induced by microRNA species with oncogenic capacity. Given the prominence of elevated serum and tissue levels of VEGF-D in LAM, and the central role of VEGF-D in the biology of lymphatic development and regulation, VEGF-D has emerged as a potential therapeutic target. Importantly, Dana Ault-Riche, PhD (Reflexions Pharmaceuticals) discussed the synthesis of D-amino acid polypeptides as stable protein interaction antagonists. A VEGF-A antagonist has been successfully developed and a VEGF-D antagonist is currently being developed with exciting possibilities for treating LAM.

The analysis of mammalian lung development using mouse models was presented by two investigators, with emphasis on the emergence of very powerful research tools that can be brought to bear on better understanding pathology development in the lung. Tushar Desai, MD, MPH (Stanford University) described work on alveolar cell development and fates, with focus on understanding abnormal proliferation and tumor development in cells in the alveolar space. Maya Kumar, PhD (Stanford University) presented fascinating and elegant work exploring the behavior of progenitor cells in the developing mouse lung, with a focus on the presence of differential mechanisms for the development of distinct cell and tissue subtypes under complex genetic regulation. The work of Drs. Desai and Kumar demonstrate the very powerful tools that have now been created with potential to better examine the nature of lung pathology development, including in LAM.

Finally, Lewis Cantley, PhD (Harvard Medical School) gave an important and clear presentation detailing the path he has chosen to take basic research discoveries to the clinic using the development of PI3 kinase inhibitors as a model. This presentation
was provided to the scientists, LAM patients, and families. The presentation touched all of us and demonstrated that with drive and good science, quickly taking basic science discoveries to the clinic is a reality. The work of Drs. Frank McCormack, Joel Moss, Elizabeth Henske, Lisa Young and others in the LAM community is a testament to the power of dedication and drive.

As is becoming a tradition, Dr. Henske summarized the conference at the Saturday evening Gala. She likened the symposium to a developing “wave”, often observed at sports events. The wave starts small but soon grows and spreads to encompass many diverse participants, reminiscent of the coming together of the many scientists with unique skills now aimed at a common goal, to understand LAM at a basic level, discover new ways to improve the lives of women with LAM, and to bring us closer to the needed cure.

The amazing pace at which new discoveries are being made and translated into preclinical and clinical trials, and the excitement felt with each seminar and poster presented, clearly provides all of us with “a breath of hope” for all LAM patients. Next year’s symposium is eagerly awaited and will undoubtedly continue to feed into the positive energy felt at this year’s conference.

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LAM Cells Are Addicted to Glutamine

LAM Foundation-funded scientists Alfredo Csibi, PhD, and John Blenis, PhD (Harvard Medical School) recently reported in the journal Cell that mTORC1, the protein that drives cell growth in LAM, directly stimulates the uptake and metabolism of glutamine, the most abundant amino acid in the body. The authors showed that mTORC1 regulates glutamine metabolism by repressing the mitochondrial protein SIRT4, which inhibits one of the steps required to produce energy from glutamine.

Importantly, their study suggests that therapies aimed at targeting nutrient metabolism could be efficacious in diseases with deregulated mTORC1 signaling, including LAM. The article can be found in Cell (Cell 153, 1–15, May 9, 2013).

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Scientific Advancement Award

DAVID KWIATKOWSKI, MD, PHD, is the 6th recipient of The LAM Foundation Scientific Advancement Award. David is a professor of medicine at Harvard Medical School. He is a thoracic oncologist who has cared for women with LAM at the Dana Farber Cancer Institute, and a leading geneticist. He has served on the Scientific Advisory Boards of The LAM Foundation and the Tuberous Sclerosis Alliance for over a decade and twice as the basic science chair of the LAMposium. He has convened over a dozen major meetings for TSC and LAM. He cloned the TSC1 gene for tuberous sclerosis and developed the animal and cell models of TSC deficiency that are most widely used by the TSC and LAM community. The tools he developed and shared so generously were used to develop the scientific basis for clinical trials.

Dr. Kwiatkowski is a tremendous asset to the LAM community and a very deserving recipient of The LAM Foundation Scientific Advancement Award.

Past Awardees include Elizabeth Henske, MD; Vera Krymskaya, PhD; Frank McCormack, MD; Joel Moss, MD, PhD; and Kuniaki Seyama, MD, PhD.
Scientific Awards for the Study of LAM

Stephen Hammes, MD, PhD, is a Professor and Chief of Endocrinology and Metabolism at the University of Rochester Medical Center. He has received a three-year Established Investigator Award to further develop a mouse model of uterine-specific knockout in TSC-2. Dr. Hammes proposes that LAM tumors are basically uterus leiomyomas that have been made more aggressive through inactivation of the TSC gene. TSC signaling was shut off exclusively in the uterus and the mice developed uterine tumors that resemble leiomyomas, and some developed lung lesions that resemble LAM. These mice will become a model to develop novel strategies for LAM.

Arnold Kristof, MD, is an Associate Professor of Medicine at McGill University in Montreal, Canada. He has received a LAM Foundation Established Investigator Award to study the role of urotensin, a growth-promoting neuropeptide, in LAM tumors. His work is based on the observation that urotensin-II and its receptor are increased in the LAM nodules that cause progressive destruction of the lung. The main goal of this work is to understand the effect of urotensin-II on the growth and destructive properties of cells lacking the TSC2 gene. He will also test a drug that blocks urotensin-11 activity. Funding for this project is jointly provided by The LAM Foundation and the LAM Canada Fund at Tides Canada.

Robert Handin, MD, is a Senior Physician at Brigham and Women’s Hospital and Professor of Medicine at Harvard Medical School. He has received a one-year Pilot Award to study mTORC1 and S6K1 signaling in LAM. Dr. Handin has developed a technique to study angiogenesis (development of blood vessels) in other cancers by injecting tumor cells into developing zebrafish embryos. His goal is to determine whether using this technique with cultured LAM cell lines will induce blood vessel development, as well as lymphatic development (lymphangiogenesis), and whether blocking lymphatic or blood vessel production prevents LAM tumor growth.

Marina Holz, PhD, is an Assistant Professor at the Stern College for Women and the Albert Einstein College of Medicine of Yeshiva University. She has received a one-year Pilot Award to study mTORC1 and S6K1 signaling in LAM. Dr. Holz proposes that S6K1 may be an attractive target for LAM treatment. She hypothesizes that inhibiting specific components of S6K1 signaling downstream of the mTORC1 pathway may prove to be a more effective and less toxic treatment than current rapalog therapies. She also will study the connections between the S6K1 and estrogen functions in LAM cells as a basis to develop combination therapy approaches for treatment.

Pechin Lo, PhD, is a Postdoctoral Researcher at UCLA’s Center for Computer Vision and Biomarker Imaging. He has received a one-year Pilot Award to evaluate whether a computer-aided CT imaging biomarker might provide valuable outcome measurements for LAM clinical trials. Dr. Lo seeks to develop and evaluate a quantifiable and sensitive CT imaging biomarker for early detection of treatment effects of LAM. The goal of the imaging biomarker is to reduce both duration and population size of drug trials, thus lowering the cost and time required to develop safe and effective treatments for LAM.

Jeff Swigris, DO, MS, is an Associate Professor of Medicine at National Jewish Health. He has been awarded a Special Project grant to work with LAM patients to develop a questionnaire to assess quality of life specifically in women with LAM. Focus groups were conducted during this year’s LAMposium conference to gather input from LAM patients. A questionnaire will then be carefully developed using scientific methods. Once developed, the LAM community will have a useful instrument to determine whether new drugs or other therapies improve not only breathing, but things most important to women who suffer from LAM, for example, how they feel and function and how they rate their quality of life.
The 2013 International Lymphangioleiomyomatosis Research Conference and Patient and Family Educational LAMposium

This one-of-a-kind conference provides a place and time for the LAM community to come together and become stronger, and more determined, to find a cure. It offers patients the chance to learn about LAM from the experts and to connect with one another while physicians and scientists meet to share knowledge, exchange ideas, and collaborate on how to advance LAM research in the coming year.

This year’s conference was a huge success and was described by many patients and doctors alike as educational, inspiring, meaningful, and fun. Attendance boasted a record number of LAM patients—110 from eight different countries. Also attending were 84 family members and friends and 92 physicians and scientists. Thirty-one patients attended for the very first time. LAM patient Cary Shaw described her experience by saying, "LAMposium is the bright light for me while dealing with a disease that can be lonely and dark at times. The sisterhood and support keep me inspired throughout the year. These conferences have changed my life and my outlook on LAM.”

The Keynote Speaker at the Friday evening Awards Banquet was Lewis Cantley, PhD, the director of the Cancer Center at Beth Israel Deaconess Medical Center and the William Bosworth Castle Professor of Systems Biology at Harvard Medical School. He is a world-renowned scientist who studies the mechanisms by which cells respond to growth signals. His laboratory discovered the PI3-Kinase pathway that plays a critical role in insulin signaling and in cancers. Afterwards, achievement awards were presented to the following:

- The 2013 LAM Foundation Scientific Advancement Award was presented to David Kwiatkowski, MD, PhD, professor of medicine at Brigham and Women’s Hospital/Harvard Medical School. Past awardees include Elizabeth Henske, MD; Vera Krymskaya, PhD; Frank McCormack, MD; Joel Moss, MD, PhD; and Kuniaki Seyama, MD, PhD.
- The Distinguished Fundraising Award was presented to the WNY (Western New York) Friends of LAM for all of their hard work and efforts to raise awareness and funds. This group is spearheaded by the McKenna family and inspired by LAM patient Katie McKenna. They have been holding their annual fundraiser for eight years and have raised over $70,000 for The LAM Foundation.
- LAM Leader Awards were presented to Richard and Karyn Schad, Susie Picart, Peggy Haupt, and Gene Sullivan, MD, for their dedication and support of the LAM community.

During the three-day conference, two groups met to ensure that The LAM Foundation continues to grow and offer support; the LAM Liaisons met to share ideas from their regions, and the Foundation’s Board of Directors met to continue discussions about the Foundation’s strategic plan and initiatives.

Focus group studies were conducted at LAMposium by investigators Jeffrey Swigris, DO, MS, and Amanda Belkin. These focus groups, with participation of 37 LAM patients, met throughout the conference to help investigators understand how LAM affects the quality of patients’ lives. The information gained continues on next page ›
from each participant will be used to develop a questionnaire to measure the kinds of thoughts, feelings, and experiences individuals with LAM encounter throughout their daily lives. This questionnaire is needed to determine whether and how medicines—or other interventions—affect patients.

Patient session presentations are available on the Foundation’s website. All patient sessions were audio recorded and some were video recorded as well. The link to follow is http://thelamfoundation.org/patients/lamposium.

Pictures taken at the conference are available on the Foundation’s website for viewing and purchase (all proceeds benefit the Foundation). The pictures can be found on our home page under Current News (if prompted, the password is all4lam). A special thank you goes to Jurgen and Gina Lorenzen for donating their time and talents and for taking such great pictures.

Have You Heard?
The 2014 International Lymphangioleiomyomatosis Research Conference and Patient and Family Educational LAMposium will be held in Chicago, Ill.

Be sure to mark your calendar for March 28–30!

Sponsors of the 2013 International Research Conference and Breath of Hope Gala

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The LAM Foundation would also like to thank the following individuals for their support of the 2013 International Research Conference:

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Giving levels range from $250 to $20,000.
The Breath of Hope Gala Spent “A Night in Vegas”!

Over 280 guests joined us this year for a celebration of life and hope at the Breath of Hope Gala themed “A Night in Vegas.” Guests enjoyed a fabulous dinner, an eclectic silent auction, and a fantastic night of friendship and fun. Our guest speaker for the evening was Dr. Lisa Henske, who is part of the scientific community and the Director of the Center for LAM Research and Clinical Care at Brigham and Women’s Hospital, Professor of Medicine at Harvard Medical School, and a practicing medical oncologist at the Dana-Farber Cancer Center, in Boston.

During the three days of LAMposium, the conference organizers worked really hard at bringing the LAM patient and the scientific and medical communities together. During the final night of the conference, at the Breath of Hope Gala, was another great example of this. Everyone enjoyed trying their “luck” at the gaming tables, and bidding wars took place during the silent auction on items such as an Apple iPad mini, Windsor vacuum, and several adorable stuffed lambs. Thank you to everyone who generously donated 51 silent auction items, helping the Foundation raise over $8,000.

Over 400 raffle tickets were sold during the month before and at the night of the Gala, raising over $11,000. Ticket holders waited eagerly to see if their name would be called, announcing that they were the winner of one of the three fabulous travel packages to either Hawaii or California. Thank you to Aaron and Edith Dichter for securing these wonderful packages and to all those who helped sell the tickets before and during the Gala.

The Fund-A-Cure auction was an inspiring end to the evening’s program. Those in attendance watched as 110 women with LAM were called to the stage one by one to be recognized and presented with a rose. Afterwards, the inspired crowd lifted their bid paddles as the emcee announced each level of giving. And just a short time later, a record-breaking $122,000 was raised for LAM research! It was an amazing, awe-inspiring evening of generosity and HOPE.

We’d like to thank all of our sponsors who helped make the Breath of Hope Gala a great event!

If you’re interested in donating an item or volunteering on the Breath of Hope Gala committee for 2014, please call the Foundation at 513.777.6889 and ask for Sylvia. No matter what part of the country you live in, your volunteer time can make a difference!

Supporting Your Loved One Living with LAM

BY LACI HARPLE

Helping your loved one cope with a diagnosis of LAM can be challenging. How do you offer support without taking over for them? In what ways can you best help your loved one and be the most supportive? Notwithstanding, how do you deal with all of this change and your own feelings regarding the situation in a healthy manner?

We all want to do what we can to make this better. We rack our brains trying, scheming, and praying for a solution. We cannot turn back time, so we must move forward and assist our loved ones in the best ways possible. The more you educate yourself on your loved one’s symptoms and severity of this disease, you can ascertain the degree of onset and thereby understand what their strengths and limitations are. Gaining this information, this knowledge, will help you define your role in their support system.

Validation of their symptoms is a way to show your support. When validating your loved one, it is very important to ask them how they are feeling. Too many times we want to “fix things,” and LAM is something we cannot fix. It is important to separate what you want from what they need. Everyone has their own method of dealing with something like this and both sides need to respect each other’s process.

It is also very important not to pressure your loved one into treatment they may not be ready to face. When my sister, Lisa Palmateer, was diagnosed, I wanted her to have a lung transplant right away. But this is what I wanted, not what she was ready for. Observe your loved one so that you may take your cues from them. “Everyone needs to feel that they have some control over their own life.” (Schad, 2012) While our intentions may be the best, we must watch our actions as there is a fine line between helping and taking over. This is not supportive or validating, but is in fact detrimental to both of you. They must retain a sense of control over the circumstances that have befallen them. The only thing you will do by trying to impose your will on them is to push them away. Remember, this isn’t about you, and you will never truly understand what it is like to walk in their shoes.

When LAM loved ones impose limitations regarding visitation due to illness in the family, it is important to “be okay” with these

CONTINUES ON NEXT PAGE ›
conditions and to understand that it is not because they don’t want to see you (or your children), but rather because it can be injurious to their health. Their health has to be the priority in their lives. It is in the best interest of your loved one to decrease the chances of exposure by any means necessary because of the serious, potentially life threatening issues that can arise from such contact.

There are some positive actions that you can take on your own to help both yourself and your loved one. Take that feeling of helplessness and channel it into constructive activities that help your goals. You can become an activist and help to spread the word around the world. This helps to make the public aware of the symptoms and treatment of LAM and may help to reduce the number of women being misdiagnosed.

It is also very important to take care of yourself during this trying time. “No one should face the unknown by themselves. That was a great lesson. That I was not alone, that I could lean on others for help, and that I could help others when I felt weak and lost and confused.” (Schad, 2012) There is a network of help and support for loved ones. There is a special “LAMMIE LOVED ONES” group on Facebook, where we reach out to others just like us and take/lend support. A sense of community and belonging is key to the overall function of a support system, and you need support too. You can gain peace and a sense of self through helping others. I would recommend more family members become involved in this group.

Reference:

Thank you to Richard and Karyn Schad for allowing me to use quotes from their book. I recommend reading this as you will gain insight through the documentation of their trials and tribulations. And all proceeds from this book go directly to The LAM Foundation.

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**Poster Awards Presented at the International Research Conference**

**BASIC SCIENCE AWARD**  
Integration of mTOR and Estrogen-ERK2 Signaling in Lymphangioleiomyomatosis Pathogenesis  
Xiaoxiao Gu, PhD  
Brigham and Women’s Hospital/Harvard Medical School  
This project is focused on defining the Estrogen-ERK signaling pathway in LAM and how it collaborates with the mTOR pathway to promote disease progression.

**TRANSLATIONAL SCIENCE AWARD**  
A Remarkable Cell Line Derived from LAM Lung with Intense Pigmentation  
Emily Gilbert, MD  
Loyola University Medical Center  
This project introduces a cell line derived from a LAM patient that displays significant pigmentation. The cell line she derived is valuable in that it should help us better understand how LAM cells and cells that are derived from a melanoma cell line are connected.

**CLINICAL SCIENCE AWARDS**  
Outcomes of Patients with Lymphangioleiomyomatosis Treated with Sirolimus  
Yoshikazu Inoue, MD, PhD  
National Hospital Organization Kinki-Chuo Chest Medical Center, Osaka, Japan  
This project found sirolimus to be effective and tolerable for most patients with LAM in their study cohort. Sirolimus improved pulmonary dysfunction, prevented pneumothorax and chylous effusion, and abdominal tumors.

Multicenter Lymphangiomymomatosis Sirolimus Trial for Safety (MLSTS) in Japan  
Koh Nakata, MD, PhD  
Niigata University Medical and Dental Hospital, Japan  
After the completion of MILES, a multicenter trial is being conducted by Japanese investigators with the goals of providing access to sirolimus for patients in Japan and to obtain approval from the Japanese regulatory agency, the PMDA.
2013 LAM Leader Awards

LAM Leader Awards are given to individuals who have consistently made extraordinary contributions to the LAM community. These individuals go above and beyond when it comes to giving of their time, talent, energy, and commitment.

**LAM PATIENT KARYN SCHAD AND HER HUSBAND, RICHARD SCHAD,** received the LAM Leader Award for their many years of support of The LAM Foundation. They have hosted several fundraisers and have raised over $140,000 for the Foundation. Karyn is a past Board member and currently serves as a LAM Liaison for Region 16. Richard recently wrote and published a book about their experiences while waiting for Karyn’s double-lung transplant, which she received in 2009. The book, called The Taste of Air: A Love Story, is a memoir in which Richard shares their story, combining his recollection of events with Karyn’s diary entries. The Schads are donating all proceeds from the sale of the book to the Foundation. Congratulations, Karyn and Richard.

**GENE SULLIVAN, MD,** received the LAM Leader Award for his selfless service to the LAM Foundation. He is a pulmonary physician who has served on the Board of Directors of the Foundation for 10 years. Gene trained in Pulmonary and Critical Care Medicine at the University of Colorado in Denver and spent his early faculty years at the Cleveland Clinic. He went on to serve as the Deputy Director of the Pulmonary and Allergy Products Division at the FDA, then into industry as the Medical Director at United Therapeutic and he now has his own company, EJS Consulting. Gene is an invaluable adviser to the Foundation on a broad range of issues that have arisen over the years, including key aspects of trial design for CAST, TRAIL, and MILES. Most recently, he played a major role in the Foundation’s effort to obtain FDA approval for sirolimus in LAM, based on the results of the MILES trial. Congratulations, Dr. Sullivan.

**LAM PATIENTS PEGGY HAUPT AND SUSIE PICART** received the LAM Leader Award for their dedication to helping other women with LAM. Two years ago, they recognized that patients needed a way to support each other by sharing their feelings and experiences. Together they decided that a group solely for LAM patients would be a great solution and so they created the group Lammies on Facebook. This group, which currently has over 425 members, is a great way for patients to receive words of encouragement and hope when they are feeling fear, sadness, or despair. It’s also a great place to share good news about doctor visits, personal accomplishments, and stories about family members. The feeling of sisterhood among LAM patients grows stronger every day because of Peggy and Susie. Congratulations, Peggy and Susie.

**The Distinguished Benefactor Award**

In 2012, The LAM Foundation initiated a program called “Lifetime Giving Clubs.”

As members of the giving club, Vi and John Adler are a true inspiration. Vi’s commitment and dedication to patient services is perceived by the LAM community as both compassionate and inspirational. John’s continued commitment to the Foundation and to moving LAM science forward is both meaningful and motivating. Together they provide a “Breath of Hope”.

In appreciation for their extraordinary contributions to the advancement of LAM Science and Patient Services, The LAM Foundation is proud to honor Vi and John Adler through the creation of the **Vi and John Adler Distinguished Benefactor Award**. This award will be given to top benefactors who help the Foundation fulfill its mission for years to come.

The Adler’s continued dedication and compassion is an inspiration to women with LAM around the world.
LAM Clinics Welcome Partners

BY FRANK McCORMACK, MD

LAM Clinics have been highly successful and effective. The practice of distributing expertise to dozens of academic institutions has been more than a convenience for patients who can now see their expert closer to home, it has resulted in an explosion of interest in LAM from consultants and investigators at centers throughout the country. Our radiologists, pathologists, nephrologists and thoracic surgeons are becoming expert in recognizing and managing LAM, and our clinical and basic scientists are engaging and requesting data and samples. Volumes of LAM patients seen in individual clinics have risen from the single digits to as high as 70 or more in some of the larger clinics, and we are conducting our first trial through this network. Unlike the Rare Lung Disease Network that hosted the MILES Trial, the LAM Clinical Research Network survives the ups and downs of federal funding because the primary ‘glue’ is investigator altruism and inquisitiveness rather than financial support.

Not all patients referred to LAM Clinics turn out to have LAM, however. The cystic and chylous lung diseases that are most commonly confused with LAM in our clinics are emphysema, pulmonary Langerhan’s cell histiocytosis, Birt-Hogg-Dube syndrome, Sjogren’s cystic lung disease, and Lymphangiomatosis. For the last several years, LAM Clinic Directors have been ‘collecting’ increasing numbers of these interesting patients, more by accident than design. Now the organizations representing each of these orphaned illnesses have asked us to ‘adopt’ them, 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. We have discussed these proposals in our quarterly LAM Clinic Network conference calls, and LAM Clinic Directors have unanimously approved welcoming all of these partners. More recently, we have received interest from organizations representing patients with lung diseases that do not mimic LAM, such as The Pulmonary Alveolar Proteinosis Foundation. These requests will be considered in upcoming calls, but I predict that the vote will be to embrace these disease communities as well.

It is fitting that these rare and complex lung disorders are seen in academic medical centers that have the expertise and interest to provide multidisciplinary care and opportunities for research. Once sufficient numbers of non-LAM patients accrue in these clinics, trials will become feasible for disease communities that have never before dared to hope for meaningful research. LAM was in their shoes not so very long ago.

Adding these disease communities will not overwhelm or cause congestion in LAM Clinics. To put things in perspective, of the tens of thousands of annual outpatient pulmonary clinic visits occurring in each of our major academic medical centers like the University of Cincinnati, California, Michigan, etc., only dozens or maybe a hundred are for LAM. In individual clinics, the few new referrals for non-LAM patients will not add substantially to our clinic volumes. They will make our practices more stimulating, however, and in aggregate across all LAM Clinics will provide many new opportunities.

Indeed, extending invitations to other disease communities will benefit the network tremendously. It will enable us to apply for federal grants for patient focused initiatives, including some that are becoming available now from the National Center for Translational Science and the Patient Centered Outcomes Research Institute. The NIH is very receptive to models that lift all boats, and result in benefits for multiple disease communities. Opportunities like these will hopefully provide a durable source of funding for the trials, data center, staff support and repository for all partners, and will keep our directors and investigators stimulated and engaged. We have invited each partner to represent the LAM Clinical Research Network as their own, as the Birt-Hogg-Dube Foundation has done (see the web at bhd-pulmonary-centres).

These are exciting times for rare lung disease research. Thank you for participation in your regional LAM Clinic. I am confident that the next major advance in LAM will come from the LAM Clinical Research Network.

LAM Clinic Locations

- UAB Birmingham, AL
- Mayo Clinic Scottsdale, AZ
- UCLA, CA
- UCSD, CA
- UCSF, CA
- Stanford University Medical Center, CA
- National Jewish Health, CO
- Mayo Clinic Jacksonville, FL
- University of Miami, FL
- Emory University Hospital, GA
- Loyola University Medical Center, IL
- Brigham and Women’s Hospital, MA
- University of Michigan, MI
- Mayo Clinic Rochester, MN
- Barnes Jewish, MO
- Presbyterian/Columbia, NY
- URMG/Strong Memorial Hospital, NY
- UC Medical Center, OH
- Cleveland Clinic, OH
- OHSU, OR
- University of Pennsylvania, PA
- MUSC, SC
- Vanderbilt University, TN
- UT Southwestern, TX
- University of Texas Health Center, TX
- Swedish Medical Center, WA

WWW.THELAMFOUNDATION.ORG
Emergency Medical Quick Facts for Lymphangioleiomyomatosis

The LAM Foundation is excited to offer LAM patients an easy way to provide doctors in the ER with information about LAM. We have created a small card (the size of a typical business card) that is easy to carry and contains helpful information that LAM patients and their family can share with the doctor when they go to an ER. The card can be easily inserted into a luggage tag and then attached to a purse for easy reference.

The front of the card has a QR code that can be scanned with a smart phone or tablet. The scan goes directly to a special page, written by Dr. Frank McCormack, to help the ER staff understand the disease and the best way to treat it. The Foundation’s website URL is also printed on the bottom of the card for quick access to information on LAM.

The back of the card has a place to put the name and phone number of a pulmonologist or LAM Clinic Director. This information will help the ER staff to quickly contact someone who is more familiar with LAM. The back of the card also includes the ICD-9 Code for LAM, to hopefully help with tracking the LAM patient’s situation and billing.

The ER card is available on our website as a PDF file under “Patients/Patient Resources” (http://thelamfoundation.org/patients/patient-resources). You can print as many cards as you’d like on Avery 5881 business cards (perforated) or on card stock (and hand-cut to size). You can also email the Foundation at info@thelamfoundation.org and request card(s) to be sent to you.

The Sirolimus and Autophagy Inhibition in LAM (SAIL) Trial is Seeking Women with LAM

Brigham and Women’s Hospital, in Boston, Mass., is currently enrolling women with Lymphangioleiomyomatosis (LAM) in a clinical trial to test the safety of sirolimus (rapamycin) in combination with hydroxychloroquine. All subjects will receive a study drug provided by the trial. Participation requires seven visits over one year and involves physical exams, blood and urine samples, X-rays, CT scans, MRIs, breathing tests, exercise tests, questionnaires, and an at-home diary.

For more information, including risks and study procedures, please contact Betsy Peters, RN, at 617.525.9331 or at epeters2@partners.org.

LAM Foundation Cited as a Model for Patient Advocacy in NEJM

In the November 1, 2012, edition of the New England Journal of Medicine (NEJM), there is an interesting article titled “How Much Would You Give to Save a Dying Bird? Patient Advocacy and Biomedical Research.” The author, Lisa Rosenbaum, MD, wanted to write an article about the importance of advocacy in clinical trials. She was given some advice to “talk to The LAM Foundation.” Dr. Rosenbaum contacted Sue Byrnes, who is the Founder, and Frank McCormack, MD, the Foundation’s Scientific Director, about the role of patient organizations in research.

The article is a true testament of what patients go through when making the decision to participate in research. LAM patients certainly exemplify the courageous example of what must happen in order to move LAM science forward.
Making Connections: The LAM Liaison Patient Network

The LAM Foundation’s mission, in addition to funding promising research, is to provide support for women with LAM and to help create a sense of community among LAM patients and their families. One of the ways in which we are striving to do this is through the LAM Liaison Patient Network. According to Webster, a “liaison is one who establishes and maintains communication for mutual understanding and cooperation.” According to The LAM Foundation, “a liaison is a compassionate, understanding, caring individual who has volunteered to serve as a link between women with LAM (and their families) within their geographic region.”

Liaisons organize regional meetings to bring people together to hear the latest in LAM research, patient care, and activities of The LAM Foundation. These meetings offer women a chance to meet face to face with others dealing with LAM and its effects. There is definitely a special sisterhood among women with LAM. Meeting others who have been down the same path gives hope, inspiration, and support.

Whenever possible, a LAM Clinic Director, a member of the LAM Clinic team, or a Foundation staff member will attend these meetings. Throughout the year the LAM Liaisons communicate via email, phone, Facebook, and in person with LAM patients in their area. Smaller, less formal luncheons or coffee hours are often held throughout the regions.

The Foundation is working very hard to ensure that every region has a Liaison and in some of the larger regions, a Co-Liaison.

Please welcome our newest LAM Liaisons and Area Lead:
A Life Surprise: Learning I Have LAM
BY KAROLINA CARAVELLI CAMPOS, LAM PATIENT

My name is Karolina Caravelli Campos and I am 20 years old. I grew up believing that I was invincible. Even though that belief is partly true today, I am now aware that my lungs suck at being lungs, which means that I have some physical limitations.

Prior to my first lung collapse in July 2011, I never set foot inside a hospital. I was the healthiest person in my family, or so I thought. I remember feeling a strange pressure on the left side of my chest. At first, I dismissed the pain and assumed that I had strained a muscle. Three weeks passed and the pain worsened. I couldn’t lie on my left side, and I would cough whenever I bent down. I went to the emergency room, thinking that something was wrong with my heart. After some X-rays, I innocently believed that my problem would be solved with some prescription medication. To my surprise, I was told that my left lung had collapsed 40 percent and that I’d need to have a tube inserted into my chest wall to reinflate it.

After a lung biopsy and further evaluation, I was diagnosed with TSC-LAM. In less than two years, I’ve experienced two lung collapses and an embolization for a benign kidney tumor. Nevertheless, I’m very optimistic about my future. I have been fortunate to meet incredible and heartwarming doctors and nurses, such as Dr. Taveira-Dasilva and nurse Amanda Jones at the National Institutes of Health. In addition, I’ve met other patients with LAM and learned that we each have our own struggles.

My newfound health diagnosis has helped me realize that life surprises you in many ways. Some of these surprises will be good, while others will challenge you physically, mentally, and emotionally. Yet despite your circumstances, you should always learn and grow from your experiences and believe that you’re a better person because of it all. As I usually say, “It could’ve been worse,” and because of that, I can’t find a reason to complain too much.

A Taste of Air: LAM: A Love Story

In 1999, Karyn Schad became the 200th woman in the world to be diagnosed with LAM. Muscle-like cells grew out of control in her lungs, stealing her breath away. She struggled with the disease until finally receiving the gift of life, her new lungs on May 17, 2009, delivering her from the foggy line where life rubs shoulders with death.

On their wedding day 40 years before, neither Karyn nor Richard could possibly have foreseen the tremendous trial in their future. Together, they found the courage to brave LAM and are truly grateful for the wisdom they’ve gained.

A Taste of Air: LAM: A Love Story is a memoir combining Richard’s recollection of events with Karyn’s diary entries. Richard considers the joy they have now and the lessons they have learned from the experience—how it opened their eyes to the beauty surrounding them. Although the disease exploded in Karyn’s body, it never touched her heart, and that’s where hope lives.

“Some things you take for granted, like the love of your spouse and your children, the rising of the sun tomorrow, and the breathing of fresh air from your lungs. Once I crossed over into LAM world in 1999, I became a stranger in a strange world. Nothing, not anything, no longer, is taken for granted.”

—Richard Schad

A Taste of Air: LAM: A Love Story can be purchased online at: http://www.barnesandnoble.com/w/the-taste-of-air-richard-schad/1113879669

All net proceeds from the sale of the book benefit The LAM Foundation.
Having FUN. Having a FUNdraiser!
BY SYLVIA RICHARD, DEVELOPMENT DIRECTOR, THE LAM FOUNDATION

Have you ever thought about holding a fundraiser and then thought, “I just don’t know how”? If you have, you’re certainly not alone. If you’re reading this Journey’s publication, there’s no doubt that you care about finding an effective treatment and a cure for LAM and that you’re very aware that fundraising is a key component to funding our mission. We need your help to raise funds.

What do you like to do? Are you a runner? Do you love to sew, play board games, or check out new local music? Almost anything can be made into a fundraiser! Here are some examples of fundraisers that members of the LAM community conducted this past year: Laps for LAM walkathons, food and wine tastings, crawfish boil, golf outings, LAMonade stand, run/walk events, craft shows, concerts, and much more!

Once you’ve settled on an activity or event, think about all of its components and make a list. This will help you put the event into detailed perspective and gain insight into how many other people you may need to involve in the planning process. When recruiting people to help throughout the planning process, remember to be direct about what you need them to do. In most cases, committee members want to do a good job; they just need to be told (specifically) what they are responsible for.

Use the list you created to build a fundraising budget. This will help you and your team members see all of the potential event revenue sources as well as monitor the parts of your event that will become expensive. A fundraising budget can be helpful even for fundraisers that have a short planning timeline.

Work with your team members to develop a timeline. This visionary road map will be helpful and inspiring when you and your team are in the midst of planning. Checking completed items off of the timeline can also be a great motivator for the fundraising team during meetings.

Use your team members, your family and friends, your co-workers, etc., to market your event. Emails, flyers, social media postings like Facebook … all of these things can help you create energy around your event. The more you talk about the upcoming event, the more participation you’ll have. This is relevant even for bake sales at work! Be sure to include information about LAM in your marketing pitch.

It’s very important to remember to have fun! Planning a fundraiser is a great excuse to hang out with the people you care about and a chance to make new friends. If everyone is working together toward a common goal, fundraising can be a walk in the park.

The Tools You’ll Need – The Resources The LAM Foundation Can Give You:

- Annual Report
- Donation Tracking Sheet for Walks and Runs
- Fundraising Guide Book
- How to Set Up Your Online Fundraising Page
- LAM Awareness Flyer
- LAM Foundation Regions
- LAM Overview and Talking Points
- Quick and Easy Fundraiser Ideas
- Sample 5K or Walk Budget
- Sample Committee Roles
- Sample Event Planning Timeline
- Sample Gala Budget
- Sample Letter for Letter-Writing Campaign

Please feel free to contact us if you have any questions about The LAM Foundation or any of the topics covered here today including fundraising strategies, matching gifts, or to donate your time and services to our organization.

I encourage you to contact me directly at srichard@thelamfoundation.org or at 513.777.6889.

I look forward to talking with you.

Sylvia Richard
Development Director
The LAM Foundation
Other Ways to Give

Many of you already support The LAM Foundation in so many ways. But some of you may not know of other ways to give. For example, did you know that The LAM Foundation is an approved organization with a designation code through the Combined Federal Campaign (CFC)? Have you looked to see if your employer offers matching gift donations? These are just two options that you can choose to support the Foundation. Please see other ways to support below.

COMBINED FEDERAL CAMPAIGN (CFC)
Are you a federal employee? Do you have a family member, friend, or neighbor who works at a federal agency? As the CFC kicks off this fall, please remember that The LAM Foundation is eligible for inclusion on the national part of the Combined Federal Campaign charity list. The CFC code that federal employees should use to designate their contributions to The LAM Foundation is 10886. Please share this information with every federal employee you know.

UNITED WAY CAMPAIGN
Many companies encourage their employees to give to charities through their local United Way campaign. Even though The LAM Foundation may not be listed as a designated organization for your United Way, most campaigns allow you to write in The LAM Foundation on the “donor designated” portion of your United Way donation form. Ask your human resources representative or call your local United Way office for more information.

MATCHING GIFTS
Matching gift programs are a great way to increase the impact of your gift to The LAM Foundation. Many companies have matching gift programs that match your contribution. Every $1 you give can become $2 for the Foundation! Check with your human resources department for information on this program. Typically there is a form that you send to the Foundation in order to confirm your gift. Once you make your donation, send us the form and we’ll handle the rest.

Some companies that offer matching gifts currently participate by matching their employees’ donations to the Foundation. These companies include Microsoft, Hewlett-Packard, Macy’s, and IBM. Please go to our website (“Get Involved” section) to see a list of companies that currently match their employees’ donations. If your company (or a loved one’s) has a matching gift program and is not listed, please let us know and help us grow the list.

VEHICLES FOR CHARITY
If you are looking for a tax benefit and a way to help The LAM Foundation at the same time, consider donating any car, truck, RV, or boat that you don’t need or want any more.

The LAM Foundation has partnered with Vehicles For Charity to process donated vehicles. It’s fast, free, and friendly. Simply call 866.628.2277, and they can answer any questions you may have and make arrangements to pick up your donation. You can also learn more about Vehicles For Charity by visiting their website at http://www.vehiclesforcharity.org/.

IN-KIND GIFTS
Donating in-kind gifts is another great way to support The LAM Foundation. An in-kind gift can help generate revenue streams through silent auctions, raffles, and services provided. You can also help the Foundation spare expenses by donating office equipment that may be needed, such as printers, laptops, etc. Some of the types of services that are always in demand by the Foundation are graphic designers for brochures and appeals, experienced grant writers, and website reviewers.

GOODSEARCH
Here are 5 easy ways to earn donations for The LAM Foundation; 1) GoodShop - Great deals and coupons from over 2,800 top retailers and up to 20% of your purchase price will be donated to the Foundation, 2) GoodSeach - Great results powered by Yahoo! Search and we donate about a penny for every search you do, 3) GoodDining - Earn up to 6% donation for the Foundation when you dine or take out at over 10,000 restaurants nationwide, 4) GoodApp - Search, shop and earn donations right from your Internet browser, and 5) GoodGames - If you’re going to play online games, why not play games that give back? Start ‘fun-raising’ with new Goodgames and earn donations for the Foundation at the same time. Please go to GoodSearch.com to learn how you can help change the lives of women with LAM through your simple everyday actions.

BRAVELETS™
The LAM Foundation has been accepted as a supported charity by Bravelets. Bravelets are bracelets that are worn as a reminder to be brave during tough times and to never lose hope. As a supported charity, Bravelets will donate $10 to the Foundation for every bracelet sold. In just the last 3 months we have received $160! You can go to The LAM Foundation Bravelets page (http://bravelets.com/product/lam-bracelet/) to place an order.
The LAM Foundation would like to thank our many generous donors for their support.

This list reflects gifts made between July 1 and December 31, 2012.

**GIFTS OF $20,000 AND ABOVE**
- Tim & Lou Alexander
- Mitch & Sandra Shaheen
- Tim & Judy Rosenbaum

**GIFTS OF $10,000 - $19,999**
- National Heart, Lung, & Blood Institute
- Chris & Cindy Hughes
- Joan Kutems
- Earl Nemser
- John & Mary Riparetti
- Tides Canada Foundation’s LAM Canada Fund
- Fund of Tides Foundation
- Betty Togikawa

**GIFTS OF $5,000 - $9,999**
- Richard & Pam Bard
- Sue Byrnes
- Chrysalis Fund
- Bill Crispin & Maureen Mahoney
- Aaron & Edith Dichter
- Tom & Barbara Laurenzi
- Nuveen Investment Holding

**GIFTS OF $1,000 - $4,999**
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**GIFTS OF $500 - $999**
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- Pete & Margaret Williamson
- Betty Winkelman
- Barbara Yamashiro
- Jim & Marilyn Young
- Alfred & Deborah Yules

**GIFTS OF $250 - $499**
- Nicholas & Joyce André
- Alan Barker, MD
- Linda Bilmes
- Howard & Kathleen Brandeisky
- Sharlene Brells
- Jason & Stefanie Brown
- Loren & Christy Buntrock
- Eileen Calvey
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- David & Michelle Zimmermann
- Harold & Virginia Zito
- Jeffrey L. Zweibel
The LAM Foundation would also like to thank the more than 958 donors who contributed $5 - $149. We appreciate your support.

The pink feather denotes that a donor has included The LAM Foundation in their charitable estate plan. By doing so, they are now members of the Breath of Hope Legacy Society. To learn more about this, please contact Sylvia Richard at srichard@thelamfoundation.org. If you have made a planned gift to the Foundation, please let us know and earn your pink feather.

The MG denotes that these companies are matching gift companies. If your company matches gifts, please contact your HR Dept. to find out how to request a matching gift donation for The LAM Foundation.

The LAM Foundation has made every effort to be as accurate as possible when creating our list of contributors. If there is an error in the recognition of your gift, please contact the Foundation at 513.777.6889 or info@thelamfoundation.org so we may correct our records. Thank you.
The Breath of Hope Legacy Society

The Breath of Hope Legacy Society is a way for you to change the lives of women living with LAM by including a gift to The LAM Foundation in your will or estate plans. These special gifts take many forms, but they all represent hope for LAM patients and their loved ones. All Breath of Hope Legacy Society members share a common goal: to save lives and to create a world where a deep breath comes naturally for everyone, by fighting back against LAM, and by finding a cure.

WHY WE NEED YOU

By becoming a member of the Breath of Hope Legacy Society, you make an important decision to include a future gift to the Foundation in your financial or estate plans. Your gift will ensure that the Foundation can continue to fund LAM research and to help patients and their families throughout their journey with LAM. You establish a personal legacy that impacts the lives of those living with LAM, and you will receive lasting rewards for many years to come.

There are gift arrangements tailored to fit most financial circumstances. Some gifts—the charitable gift annuity, for example—offer you financial benefits in return. Many gift arrangements also provide significant tax benefits. Life insurance is one of the easiest ways to donate an asset. You can make The LAM Foundation a beneficiary of your policy by allocating a percentage of your asset. For example, a friend of the Foundation recently notified us that she allocated 10 percent of her assets to the Foundation. No matter what your income level, your planned gift will make a difference!

HOW TO JOIN THE BREATH OF HOPE LEGACY SOCIETY

Becoming a member of the Breath of Hope Legacy Society is easy! All you have to do is update your will (or living trust) so that it reflects your desire to support The LAM Foundation. This is the most important step in the planned giving process.

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; one that will achieve your charitable objectives and provide for your family.

If you have already included The LAM Foundation in your charitable estate plans, thank you. Please be sure to let us know and share what inspired you to make a contribution in the fight against LAM.