

**THE L·A·M
FOUNDATION**



TAKING THE FIRST STEP:

**A Fundraising Guide for
LAM Patients, Families & Friends**

The LAM Foundation
4015 Executive Park Drive
Suite 320
Cincinnati, Ohio 45241
877.CURE.LAM
www.thelamfoundation.org

THE L·A·M
FOUNDATION



Friends,

As a friend of The LAM Foundation you are aware of the tremendous impact of lymphangi leiomyomatosis (LAM) on individuals. Perhaps you are a LAM patient, a parent, sibling, family member or friend of a patient or perhaps you are a LAM Foundation advisor or trustee. You, as we do, envision a world where LAM is treatable. You may also realize that for this vision to become reality awareness and funds must be raised.

Taking on the challenge of raising funds may be scary. It is also empowering.

In the 12 years since The LAM Foundation began its work much has been accomplished. More than \$12 million dollars has been raised with the help of LAM patients, family members, friends and supporters.

The Foundation has poured more than \$7 million into cutting edge research and provided the seed money that has helped researchers and scientists garner additional research funds of more than \$20 million. From 9 known patients in 1995, to a database of over 1,200 patients worldwide, The LAM Foundation has connected LAM patients with researchers, scientists and physicians toward the common goal of finding a cure for LAM.

Through the LAM Foundation, LAM patients worldwide have found a network of support and reason for hope. There is still much to be done. It is with your help that we will fulfill our mission to seek an effective treatment and ultimately a cure for LAM.

This fundraising guide is meant to support your fundraising efforts. Where your talents and passions lie so does your ability to motivate people to support this cause. We welcome you and support you as you engage in raising funds for LAM research and the work of The LAM Foundation. We are grateful for your passion, commitment and contribution to this compelling cause.

Sincerely,

The LAM Foundation Staff & Board of Directors

The LAM Foundation

Contact Information

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

Telephone: 513.777.6889
Toll Free: 877.CURE.LAM
Fax: 513.777.4109
www.thelamfoundation.org

Tish Davey
Interim Director
tdavey@thelamfoundation.org

Laureen McCorkle
Development Director
lmccorkle@thelamfoundation.org

Sue Byrnes
Director of Research
sbyrnes@thelamfoundation.org

Joanne Chappell
Director of Finance
jchappell@thelamfoundation.org

Sally Lamb
Director of Patient Services
slamb@thelamfoundation.org

Amie Powers
Development Associate, Patient Fundraising
apowers@thelamfoundation.org

Brigid Higgins
Administrative Assistant
bhiggins@thelamfoundation.org

Talking Points about LAM and The LAM Foundation

Lymphangiomyomatosis (LAM)

- Lymphangiomyomatosis is pronounced *lim-fan je-o-lio-mi o-ma-to sis* and is more commonly referred to as LAM.
- LAM is a rare lung disease that affects almost exclusively women between puberty and menopause. It was first described in the medical literature in 1919.
- LAM results in progressive destruction of healthy lung tissue caused by cyst formation and abnormal growth of smooth muscle cells not usually found in the lungs.
- Symptoms may include shortness of breath, cough, collapsed lung, chest pain, or fatigue.
- LAM usually does not appear on an x-ray. A high-resolution CT scan of the chest, and often the abdominal area, is required for accurate diagnosis.
- Women often go undiagnosed for years, and are frequently misdiagnosed with asthma, bronchitis, or emphysema.
- The precise number of people who have LAM is not known. Scientists estimate there may be up to 300,000 women with the disease worldwide.
- There is no cure and no treatment proven to be effective at this time. A treatment trial to test a drug called sirolimus (rapamycin) is currently underway and made possible by the work of The LAM Foundation.

The LAM Foundation

- The LAM Foundation was founded in 1995 by Sue Byrnes, mother of Andrea Byrnes who was diagnosed with lymphangiomyomatosis (LAM) in 1994.
- The LAM Foundation has identified women with LAM worldwide and developed a patient database that has grown from 9 patients in 1995 to nearly 1500 patients in 2006.
- Research achievements include:
 - Convinced the National Heart, Lung, and Blood Institute (NHLBI) to establish a National LAM Registry and to initiate an intramural research program, resulting in a \$20 Million investment by the NHLBI.
 - Fund research projects that have led to clinical breakthroughs enabling treatment trials to begin.
 - Leveraged LAM money by awarding seed grants that generated preliminary data, resulting in additional awards for LAM scientists and 6 NIH grants (RO1s) that total more than \$6 million.
- Education and patient support achievements include:
 - Conducted the first-ever LAM patient/family conference in 1997 and co-funded the first LAM scientific meeting held at Columbia University in 1999.
 - Organized and executed 12 international LAM Research Conferences, co-funded by the National Heart, Lung and Blood Institute, and sponsored the Boston LAM Seminars at Harvard University in 2006.
 - Providing an extraordinary network of support to women with LAM worldwide through telephone calls, emails, patient newsletters, an Advocacy Program, "Personal Journeys", "Journeys with Lung Transplantation," and a LAM patient ListServ.

FUNDRAISING FOR THE LAM FOUNDATION

We invite you to become a part of the miracle that is LAM fundraising. We know it may seem a little frightening, but if you'll take that first step, you'll never regret it. Are you thinking that fundraising is outside of your comfort zone? Do you have a fear of rejection? Dare to take that first step, and we promise you **empowerment**, a sense of accomplishment, and an amazing glimpse into the generosity of those around you. At The LAM Foundation, we are constantly amazed by the fundraising efforts of the LAM community. Here are a few examples of amazing women with LAM, their families and friends:

PUSHY FRIENDS

LAM patients *Michele Leatherbury* (Dayton, OH) and *Jane Markham* (Columbus, OH) each hosted a Breath of Hope Chari-Tea. Initially, Michele and Jane both shared the sentiment that they were far too shy to spearhead a LAM fundraising event. Then they realized they each had a secret weapon at their disposal...a close, pushy friend. With their permission, we are using the term "pushy" in the most complimentary sense! Michele's friend, *Patti*, and Jane's friend, *Madeline*, accepted the call to action. They not only gave of their time and talents - but more importantly, offered the kind of support that makes anything seem possible. These assertive women united with a larger circle of friends to raise over \$18,000 to honor Michele and Jane.

DYNAMIC LAM PATIENTS

Perhaps you are a natural leader who can inspire and attract participation from all of your friends and family, like *MaryKate Mundell* (East Lyme, CT). MaryKate's Breath of Hope walk attracted a crowd of caring individuals from two states! Thanks to her indomitable spirit and support from her husband Chip, this dynamic mother of two raised over \$13,000.

FAMILY TIES

Shar Van Winkle (Bellingham, WA) was diagnosed with LAM on Valentine's Day, 2002. Shar said she didn't think she could ask people for money. But her daughter Krista was willing to give it a try. Less than three years from that conversation, more than \$60,000 was been raised in Shar's honor through a letter writing campaign and three wine tasting/silent auction fundraisers. Krista did not do this alone. This effort included other family members, friends of Shar's, friends of Krista's, and generous local businesses. Newspaper articles were written which spread LAM awareness. As a direct result of her event, two women were diagnosed with LAM within one month. One of these young ladies was undergoing chemotherapy for an incorrect lung cancer diagnosis. If you asked Shar and Krista if their efforts were worth it and if they had fun in the process, the answer would be a resounding YES!

Michele, Jane, MaryKate and Shar do not have extraordinary powers. They are just LAM patients who allowed loved ones and people in their communities to change the world for LAM women everywhere. Please don't be intimidated by the amounts mentioned above. Fundraisers come in all types and sizes...letter writing campaigns, LAM-n-Aid Stands, car washes, walks, marathons, car shows, etc.

You can do it - we can help!

Are you tempted to join the fight? Are you thinking that you can't do this alone? You don't have to. *The LAM Foundation* is here to help you succeed. We can assist you with ideas, planning and implementation. We can also put you in touch with the LAM Liaison in your area. We will share our inspiration, calm your fears, connect you with other patients, family and friends in your area, and provide you with the necessary tools to make the most of your fundraising effort.

If you can imagine a future where LAM is treatable, or even cured, please contact the Foundation to help make it a reality!

LETTER WRITING AND EMAIL CAMPAIGNS

THE #1 MOST EFFECTIVE LAM FUNDRAISING EFFORT!

HOW YOU CAN INSPIRE OTHERS TO HELP THE LAM FOUNDATION

Not yet ready to spearhead a black-tie dinner auction or run the New York Marathon to fund LAM research? Think about doing a letter writing or email campaign.

MINIMAL TIME COMMITMENT + NOMINAL EXPENSE = TREMENDOUS BENEFITS FOR LAM

The letter writing campaign is the single most effective fundraising tool used by LAM patients, friends and families. Some letter writing campaigns raise \$500 - some \$5,000 or more.

- The mother of a LAM patient raised \$8,650 in five weeks with a short, hand-written letter.
- A LAM patient in Pennsylvania writes letters to all of her family and friends for the first time - giving the people in her life a way to help - and raises more than \$25,000.
- A woman decides to write a letter on behalf of her sister with LAM. Her heartfelt letter raises \$3,000 in just two weeks.

Will all letters raise that much? NO - but absolutely every gift to The LAM Foundation will make a difference to women with LAM. \$5, \$15, \$50 - every gift impacts the work of the Foundation and the advancement of LAM science and patient support.

"I have been diagnosed" or "My daughter" or "My Friend" are powerful words.

It is so simple - and we can help you tell your story. The LAM Foundation can supply you with sample letters, brochures and donation envelopes. A letter writing campaign can be from you as a LAM patient, or from your mother, your husband, your friend - anyone who cares about you and wants to help make a difference for women with LAM.

EMAIL CAMPAIGNS

Email is the main source of communication for most people, and messages are forwarded, copied and passed around the globe. An electronic request for funds has the potential to circle the world and keep on giving.

Create your email and write your story just as you would compose a letter. Some items to consider including in your email are:

- A picture of you and your family
- A link to The LAM Foundation website - www.thelamfoundation.org

- A link to The LAM Foundation's secure donation website:
<http://secure.skipjack.com/transactive/LAM/donate.asp>
- A YOUTUBE link. The LAM Foundation video and Public Service Announcements are posted on www.YouTube.com. To include the link, go to www.YouTube.com and search for The LAM Foundation or The LAM Foundation PSA (public service announcement) and cut and paste the link into your email.

PATIENT SPONSORSHIP PROGRAM

The LAM Foundation has experienced tremendous success with its Sponsorship Program. This program is designed for LAM patients, families, and friends who wish to invite their family members, friends, and colleagues to sponsor a LAM patient for a specific amount for a specific time period - annually, quarterly, or monthly. This plan has tremendous potential. Think about it! If 50 LAM patients enlisted 50 people to donate \$10 each month for a year, The LAM Foundation would have \$300,000 to invest in research in just 1 year!

It's very easy. We can provide you with a sample letter, brochures and donation envelopes to approach your family, friends and constituents. They can become a sponsor in one of two ways:

- On the donation envelope they are given the option to make a recurring gift. They would complete this information and mail it to the Foundation.
- Suggest in the letter that they visit The LAM Foundation website and make a recurring donation in your honor. If you have questions, contact Brigid Higgins at 513.777.6889 or bhiggins@thelamfoundation.org.

THE LAM FOUNDATION CAN HELP WITH THE DETAILS

The most important thing that the Foundation can do for your letter writing campaign is read your letter to be sure it includes the most accurate, up-to-date information about LAM. Facts, figures, research funding figures and statistics change with time, so let us help you. Call Amie Powers at the Foundation at 513.777.6889 or apowers@thelamfoundation.org.

We can also help you put a personal touch on your stationary and provide sample letters to guide you in your fundraising effort.

Pick up the phone and let us help you - call 513.777.6889!

The next few pages include samples of letters written by LAM patients and family members.

There are as many different stories as there are reasons to give. Your story is unique. Share it with the ones you love - and others - and give them a chance to help you, and to help make a difference in the lives of all women living with LAM.

SAMPLE LETTER #1 – LAM FUNDRAISING

Names, Father and Mother of a LAM Patient
Address Telephone Email

Dear

March 2005

As LAM patient name's father and mother, we are writing to you because she was recently diagnosed, at the age of _____, with a rare lung disease known as lymphangioleiomyomatosis (LAM). LAM, which occurs almost exclusively in women of childbearing age, appears as cysts in the lungs, and progressively inhibits the infected individual's breathing capacity. Eventually the lungs fail. There is no known cause. There is no known cure. We have enclosed a brochure that contains additional information about LAM. We hope you will take the time to read it.

In September 2004, during her pregnancy, LAM patient name suffered a collapsed lung. Over the next six weeks everything possible was done to repair the lung in order to allow the pregnancy to come to term. As a result of doctors' care and lots of prayer, LAM patient name and her husband became parents to a daughter. One week later LAM patient name suffered another collapsed lung that required emergency surgery to repair. The findings of a biopsy taken during surgery disclosed the presence of LAM.

LAM patient name and husband name immediately began to research LAM. Some of what they found is frightening, some encouraging. There were various stories from people living with LAM and about people who died from the disease. There are very few doctors who have even heard of LAM, and even fewer know anything about it.

A wonderful resource that LAM patient name and husband name located was The LAM Foundation (www.thelamfoundation.org), which produced the enclosed brochure. There is much about the Foundation's website that is helpful, but what is most evident from reading the website information is that great strides are being made towards finding a cure for LAM. It is also clear that there is an urgent need for more research dollars in order to continue further progress. However, it is very hard to find funding for a disease that is so rare. The number of known LAM patients is about 1,000 worldwide, although researchers suspect that as many as 250,000 women suffer from LAM but have never been diagnosed.

After digesting the news about LAM patient name, we decided the best way to help our daughter and other women suffering from LAM is to raise money for research. So we are asking for your help. There has never been greater promise for a cure. Progress in LAM research has been astounding, which nourishes our family with hope that a cure for LAM will soon be discovered. But research and research trials cost money. Your immediate help is needed.

Enclosed is a donation envelope. Your gift goes directly to the LAM Foundation with a designation to LAM patient name. The Foundation will in turn send you a grateful "thank you" for your tax-deductible donation. As you consider whether to include this appeal among the charitable causes you support, please know that eighty-five percent of every dollar donated to the LAM Foundation goes directly towards research and the remainder supports the critical work and operations of the Foundation.

The Last Name family is deeply grateful to you for taking the time to read this letter, for your thoughts, and for any donation you can make.

With great hope for a cure,

Father & Mother

SAMPLE LETTER #2 – LAM FUNDRAISING

Your name and address



Dear Friends,

Happy Holidays! I am writing to you this holiday season to share with you a gift that I have been given. It is access to The LAM Foundation, a non-profit organization that is dedicated to finding a treatment and cure for LYMPHANGIOLEIOMYOMATOSIS (or LAM for short). LAM is a progressive and frequently fatal lung disease that affects women - usually during their child-bearing years. Healthy lung tissue is invaded by smooth muscle cells which block air passages in the lungs. Lung capacity, then, declines – resulting in the need for either oxygen therapy or lung transplant. Because LAM is such a rare disease, it often goes undiagnosed or misdiagnosed – leaving women to think their breathing problems are a result of asthma, bronchitis or emphysema.

Currently, there is no treatment or cure for LAM. There is, however, a foundation that is funding research, offering information and helping LAM patients cope with this devastating disease.

My LAM diagnosis came in September of this year. Since then, I have been in contact with The LAM Foundation and have made great use of their available resources. I have daily communication with my fellow “Lammies” via an online chat and I was given a patient handbook that has proven to be invaluable to me. The past 2 ½ months have been quite a challenge for the _____ family; fortunately, though, I have been blessed with a loving and supportive husband, two resilient preschoolers, and an extended family that has made my well-being one of their top priorities. I know that we will be facing more challenges together in the coming years, but I am hopeful that with the support of family, friends, and The LAM Foundation, we will be able to get through all of them a little bit easier.

Enclosed you will find a LAM Foundation brochure and donation envelope. In the spirit of the season, I am asking you to please consider giving a tax-deductible gift to The LAM Foundation in my name. It will help this wonderful organization fund more research and offer more resources to women with LAM around the world. And that would give us all a much needed breath of hope.

Thank you!

Patient name

__ years old

Wife, mother, daughter, sister, aunt, cousin, friend.....and LAM patient.

SAMPLE LETTER #3 – LAM FUNDRAISING

Dear Friends and Family,

I am writing this letter to let you know about what has taken place in my life in the past few years, provide an update on recent developments, and ask for your help.

In the spring of 2004, in trying to discover the cause of my persistent shortness of breath (a condition I had attributed to being out of shape), I was diagnosed with an extremely rare lung disease called lymphangioleiomyomatosis, or LAM. A high-resolution CT scan of my lungs revealed the presence of thousands of tiny cysts within my lungs, drastically reducing the amount of oxygen reaching my blood. Although I have numerous physicians in my immediate family, none of us had ever heard of or knew anything about this obscure disease.

An initial study of conventional textbooks and current literature provided a very poor prognosis. There is no known cure, or even treatment, for this progressive disease. LAM affects only women, mostly during their child-bearing years, causing a progressively worsening shortness of breath, often accompanied by collapse of the lung(s). Many patients will need to use supplemental oxygen, and some will ultimately require lung transplants. Again, no cause has been determined, no cure for this disease has been found, and only the very beginnings of some possible treatments are in view.

Needless to say, we were quite shocked and dismayed at this diagnosis. But because I am past child-bearing age (I always knew there were advantages to being old!), the doctors feel that my LAM is probably a slowly progressive form, for which we are very thankful. Although my lung function has deteriorated somewhat in the past three years, I am still able to perform most of my responsibilities at home. (Alas, no more hiking in the Rockies!)

Because LAM is so rare – only about 1500 women in the world have been diagnosed – it remains largely ignored, an orphaned issue among so many competing for attention. The sole advocacy group for patients with LAM, The LAM Foundation, is raising money to fund research toward discovering a treatment for this disease. My personal goal is to raise \$25,000 – the minimum size of a single research grant. Please consider making a tax-deductible contribution to help me meet this goal; you may use the enclosed envelope or go online (www.thelamfoundation.org)

Most of all, this experience has been an opportunity for me to put my trust in the Lord. I am also very grateful for the love and support of my husband, _____, and my children. I am deeply grateful to you for taking the time to read this letter, for your kind friendship, and for any donation you might make.

Towards making a difference together,

We make a living by what we get, but
we make a life by what we give.

—NORMAN MACEWAN

HOW YOU CAN HELP THE LAM FOUNDATION

MAKE A PERSONAL DONATION

The LAM Foundation is a 501(c)(3) nonprofit organization and all donations are tax-deductible to the extent provided by law. Our Federal Tax ID number is 31-1438001.

WAYS TO DONATE

BY MAIL

- Mail your check or credit card information to:

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

- You will receive a gift acknowledgement and a tax-exempt receipt by mail. If you would like your gift to be acknowledged to another party or for a special reason (LAM patient, birthday, wedding, etc.), please stipulate clearly on the LAM donation envelope or by enclosing a note.
- You may call the Foundation at 513.777.6889 to request a brochure and donation envelope.

ONLINE

- Visit our website (www.thelamfoundation.org) and make a one-time or recurring online donation on our secure web donation page. You will instantly receive a receipt by email. If you wish for someone to receive an acknowledgement of your donation, please include that information in the *Acknowledgment/Comments* space provided.

TELEPHONE

- Call Brigid Higgins at The LAM Foundation at 513.777.6889 to donate by credit card.

WIRE TRANSFER

- Call or email Joanne Chappell at jchappell@thelamfoundation.org. or 513.777.6889 to receive wire transfer instructions.

GIFTS OF STOCK

Gifts of stock are an excellent way to support The LAM Foundation and earn a significant tax deduction. This is especially true if you have assets that have appreciated in value. When you donate stock instead of cash, your benefits are two-fold: you get a charitable deduction for the stock's full market value and you avoid paying capital gains tax on the appreciation.

HOW IT WORKS

- Let's begin by assuming that you plan to donate \$10,000 to The LAM Foundation. Let's also assume that a stock investment you made several years ago for \$5,000 has appreciated in value to \$10,000. If you were to sell the stock and then donate the proceeds, you would probably pay \$1,000 in capital gains tax (20% capital gains tax on the \$5,000 in appreciated value), leaving \$9,000 for the charity.
- An alternative strategy calls for giving the appreciated stock directly to the charity. In this scenario, The LAM Foundation gets the full \$10,000 in stock which it can turn around and, as a tax-exempt entity, sell without paying taxes on the gain. You get a deduction for the fair market value of your donated stock and avoid paying tax on the appreciation. (The fair market value of securities listed on a public exchange is the average of the high and low sales price on the date the donation is made.) Although your total charitable deduction is limited to 30% of AGI, you may use any remaining deduction over the next five years.
- The LAM Foundation can also accept mutual fund shares. You may direct the fund to transfer your shares to The LAM Foundation. To maximize your tax savings, be sure to have the fund transfer the shares that cost you the least. Those shares will usually have accumulated the largest capital gain.

IMPORTANT INFORMATION YOU NEED TO KNOW

To ensure the maximum tax benefit for a contribution of appreciated property, be sure it has been held for more than one year. The deduction for ordinary income property (held for less than a year) is limited to your purchase price for the stock. If you are planning a year-end donation of securities, don't wait until the last minute. Generally, the gift is not considered complete until the properly-endorsed securities are mailed or delivered to the charity or its agent.

MAKING THE TRANSFER

Transferring a stock gift is easy. For more information please contact Joanne Chappell at The LAM Foundation at 513.777.6889 or jchappell@thelamfoundation.org.

OTHER GIVING OPPORTUNITIES

DONATE A USED CAR

Tax laws regarding vehicle donations have changed significantly. In the past, donors were able to claim the fair market value of their vehicle. Unless the charity sold the vehicle to the general public, the donor was allowed to determine the fair market value using Kelley Blue Book, NADA, etc. Under the new law, the donor can claim up to \$500 with just a simple receipt. Beyond that value, the donor can only claim the amount for which the charity sells the vehicle.

The LAM Foundation uses the services of Cars-4-Charities to process the donation of automobiles. The LAM Foundation receives a minimum of 65% of the sale price of the vehicle. Cars-4-Charities manages all aspects of the donation process including: processing vehicle titles; arranging for the pickup and sale of donated vehicles; providing donors with the forms they require to claim the tax deduction; and providing the IRS with the forms they require to verify the donation. This is done in compliance with IRS rules and regulations. To learn more, visit www.Cars4Charities.org or call the Foundation offices 513.777.6889.

IN-KIND DONATION

The term "In-Kind" refers to donations other than cash, like airline miles, computers, printing services, etc. Donors receive an acknowledgement letter for the donated goods or services to provide to their tax professional.

Airline miles are particularly helpful because we can use them to bring doctors and researchers to LAMposium, or pay for staff travel to significant conferences to represent The LAM Foundation. The Foundation can use almost any item or service, so please call us if you have any questions about in-kind giving opportunities.

PLANNED GIVING

A "Planned Gift" refers to plans to make a gift to an organization or charity in your estate plans. The most common planned gift is the "bequest", which means leaving a gift in your will. Would you, your family, or your friends consider leaving an estate gift to The LAM Foundation? We can also assist you with the purchase of a life insurance policy naming The LAM Foundation as beneficiary.

Other forms of planned giving are Life Insurance Policies, Charitable Remainder Trust and Charitable Gift Annuities. There are many income and tax advantages for planned gifts. We encourage you to discuss planned giving opportunities with your tax professional or attorney. If you would like more information, please contact The LAM Foundation and we will be happy to assist you.

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 magically turns into \$2 for the Foundation! The Human Resources

department at your place of employment will have information on this program. Usually there is a form that you must give to The Foundation in order to confirm your gift. Be sure to send us the form and we will handle everything else. Questions about matching gifts? Please contact Brigid Higgins at 513.777.6889 or bhiggins@thelamfoundation.org.

UNITED WAY

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 United Way Campaigns allow for the donor to write in The LAM Foundation on the "donor designated" portion of your United Way donation form. Ask your Human Resource representative or call your local United Way office for more information.

COMBINED FEDERAL CAMPAIGN

CFC is much like the United Way of the federal government. If you, your family, or your friends work for the federal government in the United States or internationally, please check to see if it is possible to designate The LAM Foundation as the recipient of your gift.

STATE CHARITABLE CAMPAIGNS

If you, your family, or your friends are employed by your state government, please request that the Foundation apply to become eligible for your state's charitable appeal.

FRATERNITIES, SORORITIES, CIVIC, RELIGIOUS, AND PROFESSIONAL ORGANIZATIONS

Women's clubs, Rotary clubs, Knights of Columbus, Jewish Federation, Daughters of Penelope, local churches, sororities, fraternities...the list of community, religious and professional organizations that give to nonprofits is never-ending. Consider organizations in your area.

GOODSEARCH

How many online searches do you do every day? GoodSearch is an online search engine that will donate a penny to The LAM Foundation every time you surf the web. Use it just as you would any other search engine. Since it's powered by Yahoo!, you get the same results. Please visit goodsearch.com and follow the instructions to name The LAM Foundation as your favorite charity. Now, tell your friends and family about GoodSearch and you're good to go! Everyone uses a search engine, so why not use GoodSearch? No matter how big or small, one person can make a difference.

LAM APPAREL

The LAM Foundation, with the help of LAM patient Jean Togikawa, is raising funds for research and building awareness for LAM. Jean embroiders the Foundation's logo on shirts, jackets, baseball caps, pique polo shirts, denim shirts, aprons, picnic blankets, tote bags and much more.

100% of all proceeds from your order are donated to the Foundation. Please take a moment to view the LAM Apparel by visiting www.thelamfoundation.org, click on donate and then click the SHOP LAM button for color pictures of items available for purchase.

Comments and suggestions for additional items and colors are welcomed. Please send those to lamapparel@earthlink.net. Also, please contact Jean if you are planning a fundraiser. There are many ways to use embroidered items to promote your event and raise funds. And, they make great gifts for the holidays and special occasions!

LAM BRACELETS

The popular LAM silicone bracelets are available for personal use or to fundraise. They are \$3 each or 2 for \$5.

LAM CAR MAGNETS

These large 5x5 car magnets are a great way to raise awareness of LAM. The magnets include The LAM Foundation logo and the website address. They are \$5 each and all proceeds go to support The LAM Foundation.

CORPORATE & FOUNDATION GIFTS

CORPORATE DONATIONS AND GRANTS

Corporate donations can be significant and have a huge impact on the work of The LAM Foundation. Companies give to charitable organizations, either through their company foundation or through their marketing budget, to enhance their image in the community. Either way, The LAM Foundation can benefit. If you have a corporate connection, The LAM Foundation can deliver a proposal to the company you have in mind, or we can forward one to you to personally present to them. If you prefer to remain anonymous we can forward a proposal without your contact information.

You may be surprised how many people you know that have ties to a local or national corporation. All we need is a name, a phone number, or a way in the door. If you can facilitate an introduction to a company, we can handle the rest.

Many national retailers such as Wal-Mart and Sam's Club are particularly generous. They do not make philanthropic decisions from their corporate headquarters. The giving decisions are made by the employees of your local store, and donations can only be given within your community. To help you make this or any other corporate approach, we can supply a corporate folder and regional LAM stationery with your name and address. We will do all the work...while you make all the difference!

PRIVATE FOUNDATIONS

A private foundation refers to a foundation that gets most of its funding from one particular source such as an individual, family, or corporation. Perhaps you know someone at a private foundation. We can help prepare a packet of specific information to appeal to any foundation for support of LAM and The LAM Foundation.

The LAM Foundation is here to help whenever you need us.

If you can open the door for us, we can make "the ask"!

MEDIA & PUBLIC RELATIONS

RAISING AWARENESS

Raising awareness of LAM is a very important part of our mission for 3 reasons:

- Research - Raising awareness leads to compassionate giving. With solid financial support from informed and invested donors, the Foundation will be able to fund more research that will lead to a cure.
- Education - Scientists estimate that there are more than 300,000 women with LAM who are currently undiagnosed or are misdiagnosed. Awareness efforts will help educate doctors to make more accurate diagnoses, thereby empowering women to make informed choices regarding their health.
- Patient Support - LAM is a lonely disease. Raising awareness of LAM and The LAM Foundation will help locate and connect LAM patients with one another. This will help further enhance a LAM patient network of hope and support.

MEDIA, PUBLIC RELATIONS AND SPEAKERS

Women with LAM have compelling stories to share with their local newspaper and TV news shows, or perhaps even a national TV show or magazine.

Have you considered contacting your local media sources? If that sounds like your worst nightmare, bring in another LAM patient to share the spotlight. We are happy to consult with you and send a LAM Foundation media packet to you or your media contact.

Any of the LAM Foundation staff, our Board of Directors or Board of Advisors, are available to speak with reporters. The LAM video is an excellent way to share the Foundation story with the media. Please contact the Foundation for further information.

The LAM Foundation would like to receive a copy of any published article or media interview if possible. These examples will help inspire other patients and may also be used in future awareness efforts.

PUBLIC SERVE ANNOUNCEMENTS

The LAM Foundation has a professionally produced Public Service Announcement (PSA) to distribute to TV, radio and print media. Our print PSA's are also in Spanish.

The public service announcements were designed to get the attention of women who are currently undiagnosed, and to inform the public of the symptoms of LAM and its impact on women. They are dramatic in nature and convey the seriousness of the disease.

If you would like copies of the PSA's please contact the Foundation offices.

PLANNING A FUNDRAISING EVENT

The thought of planning a fundraising event may seem overwhelming, but we are happy to share testimonials of members of the LAM community who have held successful events of all types and sizes and enjoyed the experience. We can also connect you with others in your community who may want to participate.

There are as many forms of fundraising events as there are grains of sand on the beach. Ask yourself this one question... "Where are my interests, talents and passions?" The answer that will lead you in the direction of an antique car rally, blue jeans Friday at the office, black-tie dinner auction, Chari-Tea, garage sale, wine tasting, euchre tournament, walk-a-thon, golf tournament, Academy Awards gala, hog-calling contest, snow golf, or reality show benefit...the sky's the limit!!

This information will help you get started in planning whatever event you want and, as always, The LAM Foundation staff is here to help you throughout your event. We can help inspire you and put you in contact with LAM patients, families and friends in your area to help spread the word about your event.

EVENT IDEAS

Here are a few ideas of fundraisers that have actually been used to raise funds to fight LAM:

Auction, Live & Silent	LAM Bracelet Sales
Accordion Band Concert	LAM Cookbook
Art Show or Auction	LAM-n-Aid Stand
Backyard Bash	Lunch/Fashion Show
Bake Sale	Marathons or Runs
Beach Party	Memorial (in lieu of flowers)
Beanie Baby Raffle	Motorcycle Race
Bike Ride	Pampered Chef Party
Birthday gifts (in lieu of)	Penny Wars
Book & Bake Sale	Pictionary/Board Game Tournament
Candle Sales	Pig Roast
Car Wash	Portrait Painting
Chari-Tea	Princess Bear Raffle
Comedy Night	Quilt Raffle
Cornhole Tournament	Reality Show Benefit
Current Catalog Sales	Run or Relay Races
Dinner/Auction/Dance	Restaurant Sales (% of)
Fashion Show	Reunion Raffle
Festival	Shop-to-Share Charities
Flower Sale	Snow Golf
Garage /Yard Sale	Sorority Breakfast
Gift Wrap Fundraiser	Split-the-Pot Raffle
Golf Tournament	Treats/Treasures Raffle
Gospel Sing	Trip Raffle
Happy Habits	Tupperware
Happy Birthday to Me	Variety Show
Holiday Bazaar	Walk-a-Thon
Inspire Art Auction	Wedding gifts (in lieu of)
Jeans Day at Work	Wine Tasting
Jewelry Sales/Party	

EVENT FUNDRAISING POLICIES

The following information provides, in detail, the role The LAM Foundation will play in assisting fundraisers and fundraising events. It outlines legal information and financial obligations regarding fundraising for the benefit of The LAM Foundation and is designed to give credibility to all fundraisers. All questions and concerns may be addressed by contacting The LAM Foundation.

NOTIFICATION OF EVENT

The LAM Foundation must be made aware of all fundraisers and fundraising events (date, type, etc.) to benefit The LAM Foundation.

How The LAM Foundation Can Help

- The Foundation will supply you with these fundraising and awareness tools:
 - Brochures, displays or banners to help publicize your event
 - Donation envelopes, regional stationary and other LAM Foundation publications
 - IRS Determination Letter (proof of nonprofit status)
 - Fundraiser Accounting Forms
- With your permission, we will gladly advertise your event on the The LAM Foundation website, in our *Journeys* newsletter and in *Currents* - the Foundation's monthly e-newsletter and to the LAM community in your area.
- If you would like to invite LAM patients and members of the LAM community to your event, please contact Amie Powers at 513.777.6889 or apowers@thelamfoundation.org.

Event Planning Steps

- Gather together friends, family, and members of the LAM community in your area to help you plan your event.
- Choose the type of event - Remember, where do your interests, talents and passions lie?
- Find a venue suitable in size and appropriate to your event.
- Enlist local business to design and print an invitation, and to donate silent auction and raffle items, if appropriate.
- Create an invitation list. Don't forget family, friends, colleagues and your local LAM community.
- Contact your local media to promote the event and raise awareness of LAM.

DONOR LISTS, THANK YOU NOTES, AND TAX RECEIPTS

The LAM Foundation is an IRS designated 501(c)(3) nonprofit. We must provide all donors with prompt acknowledgement letters for their tax records. We ask that you provide all donor contact information and donation amounts to The LAM Foundation so that we can formally acknowledge all types of donations - money, services and materials.

It is important that all of your guests, donors and event participants receive information about The LAM Foundation. Throughout the year, your contacts can receive LAM Foundation newsletters, e-publications and more to keep them connected to you and the LAM Foundation. When donors know that their money was used wisely to fund LAM research, support patients and raise awareness of LAM it will make them more likely to give again.

In addition to receiving a formal acknowledgement from The LAM Foundation, *we highly recommend that you extend a personal thank you by card, letter or email.* This small effort will go a long way - nothing can replace that personal connection you have with your supporters.

FULL DISCLOSURE

It is possible that a portion of your event ticket price is tax deductible. Your guests may deduct, at least partially, their contribution on their tax returns.

Example: The ticket price, less the fair market values of the goods received (dinner, etc.) may be deducted as a charitable donation. For example, if the ticket price is \$100 per person with \$25 representing the actual cost of the meal they received, the guest may claim \$75 as a charitable tax deduction.

Event patrons may assume that the entire ticket price is tax-deductible.

Please do not promote a fundraising event as tax-deductible without providing full disclosure of the amount that is eligible for deduction.

You can provide that information in the event invitation or on the Invitation response card.

OPENING SPECIAL ACCOUNTS FOR A FUNDRAISING EVENT

The following account guidelines are in place to protect you and the Foundation. It is important that good records be kept of all fundraising transactions. Consider calling on a knowledgeable event co-committee member for assistance. We can provide you with our IRS 501(c)(3) determination letter and a letter of authorization, if needed.

- If you have a lot of expenses to manage your event, you may open a **non-interest bearing checking account** with the help of the Foundation.

- The social security number of the principal organizer is used to open this account. There should be no cost to open this account since it is a non-interest bearing account.
- The checking account should be opened as (or something similar):
Name of principle organizer
DBA (Doing business as) or FBO (For the benefit of) Friends of The LAM Foundation
Street Address
City, State, Zip code
- We recommend instructing your bank to send a copy of the monthly bank statement directly to The LAM Foundation.
- Have two members of the event committee as eligible signers (if applicable).
- All donations/checks received should be made payable to **The LAM Foundation**.
- **For Deposit Only** should be written or stamped on the back of each check. For more accurate record keeping, **checks must be deposited, not cashed**.
- **Withdrawals** may be made or checks written to cover event expenses.
- Please complete the **Fundraiser Accounting Worksheet** when your fundraiser comes to a close. Mail the form to the Foundation with the proceeds. If the fundraising event is ongoing, please provide quarterly reports and remit funds in excess of potential expenses.
- If future fundraising activities are anticipated, the account may be kept open year-round by leaving the necessary minimal funds in the account. You may keep up to 10% of event net proceeds as start-up monies for the next fundraising event. (see Fundraiser Accounting Worksheet, line 25).

RUNNING CREDIT CARD CHARGES

- Unless you are a large and recurring fundraising event, it is not necessary to open a credit card account at your local bank.
- Credit card transactions may be processed via The LAM Foundation website by clicking on the *Donate Now* tab on the Foundation's website www.thelamfoundation.org.
- Be sure to gather all of the necessary information from the donor to process the charge, including amount, credit card information, name on the card, address, daytime phone number and email.
- When running a charge through the website, please stipulate the purpose of the charge by using your event name and what the donation is for (raffle ticket, silent auction, ticket, etc...)

FORWARDING PROCEEDS

All proceeds (minus the amount withheld as “seed money” for a future fundraiser) should be forwarded to the Foundation within approximately 30 days after all accounts have been reconciled and all expenses have been paid. Please forward the proceeds along with a **LAM Foundation Fundraiser Accounting Worksheet** to the Foundation. You may forward checks and credit card charges to the Foundation and we will send acknowledgement letters and tax receipts as necessary.

EARMARKING PROCEEDS

Proceeds from fundraisers may be earmarked to fund LAM research in someone’s honor. For more information and possible recognition opportunities, contact Amie Powers at 513. 777.6889 or apowers@thelamfoundation.org.

SEED MONEY

Seed money to launch a fundraising event will not be provided by The LAM Foundation. After a fundraiser has been successful (produced more revenue than spent), a Friends of the LAM Foundation group *may keep up to 10% of the net proceeds* as seed money if it is included in the fundraising accounting worksheet submitted from the previous fundraising event. If there is no subsequent scheduled event within 18 months, the seed money must be forwarded to The LAM Foundation and the non-interest bearing account closed.

LAM FOUNDATION LETTERHEAD, REGIONAL STATIONERY AND LOGO

- The Foundation will gladly supply you with personalized regional stationery (see attached sample).
- If an organization, corporation, or individual you are soliciting requires a letter on official letterhead, please contact The LAM Foundation.
- Regional event stationery and LAM Foundation logo’s are available upon request. The regional LAM Foundation name/logo, when approved for use, may be used for invitations and advertising of your event.
- The LAM Foundation name/logo (without the regional tag line) may only be used with permission from the Foundation.
- The floating feather alone may be used on all correspondence and materials with other addresses besides that of The LAM Foundation. It may be used in any color and in any position.

BROCHURES AND DONATION ENVELOPES

The purpose of all fundraising events should be to raise funds AND awareness. The LAM Foundation will provide informative brochures and donation envelopes to be enclosed with invitations, solicitations, etc. Other LAM publications and materials are also available.

POSTAGE

The LAM Foundation cannot provide mailing services and postage. If you are interested in bulk mailing rates to mail your event materials, please contact your local post office. Please be aware that bulk mail is slower than first class and not as dependable.

ALCOHOL

If the fundraising committee assumes the responsibility of serving alcoholic beverages, a one-time insurance policy (liability) is usually required. Please check the permit requirements of the facility and the local government where the event is being held and contact The LAM Foundation regarding its insurance policy. We may be able to provide you with a certificate of insurance to cover your event.

SOLICITATION LEGALITIES

Depending on the type of event and the requirements of your city and state, a legal form for solicitation may be needed. Charity raffles and sweepstakes are not legal in certain parts of the country.

PUBLICITY

Public exposure has proven very effective in identifying individuals with LAM. It has also helped raise awareness in both the lay and medical communities. Publicity for your event is highly encouraged. Should any event, chairperson, or LAM patient be granted the opportunity for national and/or significant media coverage, the Foundation should be contacted. The Foundation will provide current information concerning both the disease and the Foundation. The LAM Foundation welcomes all media exposure and is available for that purpose.

LAM PATIENTS, FOUNDATION STAFF OR BOARD MEMBERS AT YOUR EVENT

If you would like a LAM Foundation speaker for your event, please contact The Foundation as soon as possible so that we can begin making arrangements. The Foundation has a very limited travel budget but, in most cases, we are able to secure another local LAM patient, a LAM Foundation board member, advisory board member or medical professional to speak to your group. We will work with you to provide someone who will "fit" with your group and represent the Foundation.

WE CAN HELP YOU HELP THE LAM FOUNDATION

The LAM Foundation is here for you and we want to help you succeed. Call or email us and we can talk with you about your personal fundraising effort or ideas. We can supply you with what you need to help you succeed. We are here to encourage you, calm your fears and pat you on the back along the way.

THE LAM FOUNDATION SUPPORT MATERIALS

FUNDRAISING AND RAISING AWARENESS

- Brochures
- Donation envelopes
- LAM logos in electronic format
- LAM PSA (Public Service Announcement) for TV, Radio or print media
- Additional sample letters for letter writing campaign
- IRS nonprofit determination letter
- Media packet, LAM newspaper and magazine articles
- LAM bracelets
- LAM Car Magnets
- A LAM Foundation display or banner for your event

APPROACHING CORPORATIONS FOR FUNDING

- Corporate packets and presentation folders
- Sample letters
- Regional Stationery

EDUCATING: YOURSELF, FAMILY, FRIENDS AND THE MEDICAL COMMUNITY

- LAM Patient Handbook
- LAM Public Service Announcements
- Physician's pamphlet to educate the medical community about LAM

For more information about how the Foundation can help you become a fundraiser for The LAM Foundation, please contact Amie Powers at The LAM Foundation at 513.777.6889 or apowers@thelamfoundation.org.

THANK YOU FOR YOUR SUPPORT OF THE LAM FOUNDATION!