



I am Amy

My name is Amy Farber. I am 35 and not ready to die.

In December of 2004, my husband Michael and I were nearing the end of our extensive academic training. I had finished a PhD in Social Anthropology and half of law school. Michael was nearing the end of his residency in Anesthesia at Brigham and Women's Hospital at Harvard in Boston and finishing his PhD in Sociology. We wanted to start a family. I have always been active and healthy, but I had a vague pain in my back and felt especially tired. I wanted to be sure I was healthy for pregnancy. After months of testing and profound uncertainty, I received a diagnosis of lymphangi leiomyomatosis (LAM) at the National Institutes of Health last April. Suddenly, Michael and I could no longer talk about building a family and growing old side by side.

I have LAM

LAM is a fatal disease that affects women during their childbearing years. Researchers believe that LAM is more sex-linked than breast cancer and Lupus. In LAM, aberrant circulating smooth muscle cells destroy normal lung tissue through the development of cysts. We don't know how many women have LAM. Many physicians have never heard of the disease, and it requires a CT scan and sometimes a biopsy for diagnosis. On average, LAM goes undiagnosed or misdiagnosed as asthma, bronchitis or emphysema for four years. LAM is especially cruel in that women are often diagnosed during pregnancy and learn that they may not live to see their children grow up. There is currently no effective treatment.

My goal is to be well

I left the NIH with my diagnosis of LAM, a supply of multivitamins and a recommendation to think hard before getting pregnant because it might accelerate the disease. The diagnosis and its implications are devastating, but I will do everything I can to stop LAM in its tracks. I am coping through action. For the past 15 years I have committed my life to advancing civil rights and social justice both in the United States and South Africa. I have lived my life as an activist and a voice for people in need, recently focusing on improving access to basic health care for impoverished groups in the United States and abroad. I drew on all of my experience and skills to launch a fight against LAM.

Here is my plan

I began by learning everything I could about LAM and related diseases, and then I launched a multi-pronged attack against LAM, seeking to find an effective treatment and ultimately a cure. Since my diagnosis, I have learned much about the dearth of attention paid to fatal women's diseases with no treatments. I have learned a great deal about rare diseases, which number over 6,000 and affect more than 25 million Americans, or 1 in 10.

With the support of family and friends, I have managed to have LAM included in U.S. Senate appropriations language in an effort to increase funding for research. I have met with legislators and lobbyists to advocate for increased funding for fatal women's diseases without treatment. My family and friends raised more than \$282,000 for LAM research in three months through a personal letter-writing campaign.

We are now embarking on a new phase of this journey, with unique opportunities and resources in Boston, where Michael and I live. In December of 2005, we convened a meeting of 10 internationally acclaimed scientists. Half of these scientists are leaders in LAM research, and the other half are widely recognized as leaders in developing effective treatments for disease. This dream team's goal was to define and prioritize a set of research projects, which will be structured to find a treatment for LAM in the shortest possible time. We seek to find an effective treatment within the next four years, at the latest.

In a complementary stream of work, I have organized a monthly seminar series at Harvard Medical School. The seminar series provides a forum for Boston-based researchers in disciplines relevant to LAM for collaboration, presentation of new data, and identification of novel therapeutic approaches and gaps in research that might shape a future research agenda (<http://www.bostonlamtscresearch.org/>).

Our third stream of work involves mobilizing vital resources to fund the research projects most likely to yield a treatment for LAM in the shortest time. The opportunity to have a dream team of scientists apply their minds to LAM is priceless, but fast-tracking this research process requires funds. Each of the projects identified by the scientists will require approximately \$150,000 per year of funding over the course of two to three years. Our aim is to begin the first project in early 2006 and then to raise sufficient funds to launch the others within the year. We are in the process of founding a new non-profit organization with the mission of finding a treatment for LAM as quickly as possible. To accomplish this mission, the organization will fundraise to support LAM researchers and researchers in related fields in a way that fosters accountability, collaboration and ongoing dialogue.

I need your help

LAM provides a unique opportunity for research. It is well understood at a molecular and cellular level. It lies at the intersection of pathways involved in more common yet serious diseases including breast cancer, prostate cancer, atherosclerosis and tuberous sclerosis. Finding a treatment for LAM will also promote understanding and treatment for these diseases. Solving multiple disorders that involve a common pathway requires a multidisciplinary systems biology approach, bringing together laboratory and clinical researchers interested in cell signaling, estrogen biology, pulmonary pathophysiology, vascular biology, and cancer, among other disciplines. Such an approach is directly in keeping with the dream team's composition, the thinking behind our seminar series, and the multidisciplinary perspective outlined by the NIH Roadmap for Medical Research as a guiding principal for research funding and support (<http://nihroadmap.nih.gov/>). It is also the way I have had success in the past in bringing about significant, lasting, and positive change.

I could not do all of this without mobilizing the support of a diverse and broad network: family, friends, former high school classmates now working in medical PR; Harvard Business School students; former public interest law employers; fellow graduate students and faculty; volunteer recruits from Craig's List; and families I knew from religious school in my youth. Despite the generous outpouring of resources, our critical challenge is money. In January 2006, experts will finish mapping out a list of research priorities, and the sooner these can be funded, the faster a treatment for LAM will be developed. I need your help.

To donate to the LAM Treatment Alliance, you can send a check payable to the "Boston Foundation/LAM Research Fast Track Fund" c/o Boston Foundation, 75 Arlington Street, Boston, MA 02116, or make a tax-deductible donation online at: www.CommunityRoom.net. Click "Make a Donation." Next, scroll down to the blue "Nonprofit" bar and "select a nonprofit": "Boston Foundation, Inc." Under the blue "Special Instructions" bar below, be sure to type in: "LAM Research Fast Track Fund." The LAM Research Fast Track Fund at the Boston Foundation was created to accelerate the pace of promising LAM research. Funds will support scientific research and collaborative and interdisciplinary work among scientists to develop effective therapeutic options or cures for LAM. Funds are being raised on behalf of the Boston Foundation for this component fund.

Thank you!
Amy

afarber@post.harvard.edu