

## Powerful Patient, 2009 week 22

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### Speeding Research on LAM

Amy Farber is the executive director of the LAM Treatment Alliance, which she founded when she was diagnosed with lymphangiomyomatosis. Hear her decision to be a fighter, not a victim. The LAM Treatment Alliance raises money for research into treatments and provides support for those diagnosed with the disease.



#### 1) About Amy Farber

Farber discovered she had LAM in 2005 just after she got married and was planning a family. Something in her upper abdomen was bothering her so she went for a checkup. When the discomfort didn't stop she went for a CT scan and discovered small cysts at the base of her lung and a lesion next to one of her kidneys.

Within four months she was diagnosed.

Her plans to have children were thrown into confusion because she was advised not to get pregnant. She was told the sustained levels of estrogen that occur in pregnancy might accelerate the disease so Farber made a surprising move.

"So I went through one cycle of IVF [in vitro fertilization] and my eggs and my husband's sperm were implanted in another woman who carried our daughter for us. She's two now, Charlotte. She's amazing. One of my convictions is that if science can help us make Charlotte, it can conquer LAM."

Because LAM is so rare, Farber was worried that no one would be interested in doing research but she has discovered that investments in LAM can pay off elsewhere.

"The good news is that rare diseases teach us about common diseases," she says. "And common diseases teach us about rare diseases so it's not a zero-sum game."

She thinks the challenge is not just in lab discoveries, but in pulling together the right group of scientists who might have some of the keys to directing the research. Farber has taken on the role of finding those scientists.

## 2) **About LAM**

Lymphangiomyomatosis (LAM) is a degenerative disease of the lung that affects about 250,000. Doctors don't know what causes it, there is no cure and it almost always strikes women in their child-bearing years.

It's often confused with asthma and emphysema, so doctors think it's probably under-diagnosed. The average time it takes to figure it out is about four years. Symptoms include:

- Shortness of breath.
- Chest pain.
- Collapsed lung.
- Abdominal discomfort.
- Frequent coughing.

In the worst case, a woman can die within a couple of years.

For more information on LAM, and how to get a differential diagnosis between LAM and emphysema, please contact one of the following resources:

LAM Treatment Alliance, <http://www.lamtreatmentalliance.org>

LAM Foundation, <http://lam.uc.edu>

My Life and Breath (blog), <http://lamchop.wordpress.com>