

*"I go to sleep many nights terrified that I'm not going to be able to breathe well the next day," Amy Farber '87 says.*

# When she set out to save lives as a social activist, she never knew she'd end up fighting for her own.

By JULIA WICK

**L**ast January, all the pieces were falling into place for Amy Farber '87. She was a newlywed. She and her husband Michael Nurok were finally approaching the end of their extensive academic training, poised to begin a family and the next stage of their lives.

The world was her oyster.

But Farber had been feeling a little funny.

She'd been experiencing bouts of back pain and fatigue, which was unusual for a 35-year-old woman who said she "never gave a second thought to my health," and described herself as "very active."

"She figured it was just something little, some kind of stress from school," Trisha Sarkisian '85, Farber's older sister, said.

Nonetheless, since Farber was planning on getting pregnant she opted to go through some testing to make sure she was entirely healthy. At first everything checked out fine, but Farber still couldn't shake the feeling that something wasn't right, so she pushed the doctor to do further tests.

A CAT scan revealed a tumor near her kidney and scattered cysts near her lungs last February. Terrifying but not definitive, these results were just the beginning of a long journey of what Farber called "profound uncertainty." An in-patient stay at the National Institutes of Health in April brought her earth-shattering news: she had Lymphangioleiomyomatosis (LAM), a rare, progressive and fatal lung disease that almost exclusively affects women of childbearing age. According to Farber, "researchers believe that LAM is even more sex-linked than Lupus or breast cancer."

Extremely uncommon and difficult to diagnose, the exact number of LAM sufferers is unknown, but reported at about 400, though it is thought to be higher.

LAM's effects are devastating on the body. The disease causes smooth muscle cells to overproduce within the lungs, destroying the surrounding lung tissue and creating cysts that make it impossible for the body to get enough air.

Women with LAM suffer from an inability to breathe and endure symptomatic shortness of breath that is often misdiagnosed as asthma or bronchitis, and which can be temporarily alleviated by the use of an oxygen tank.

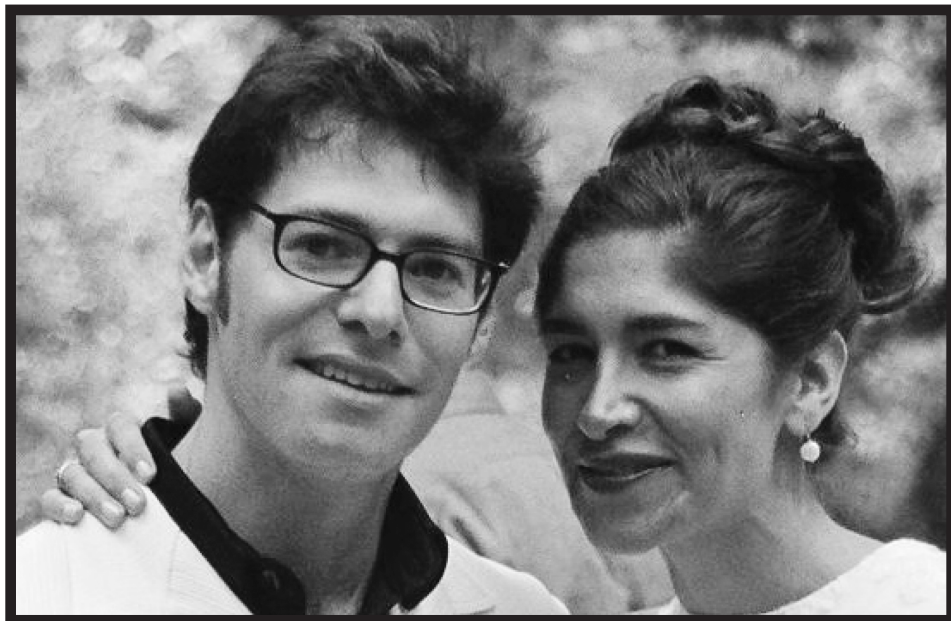
Ultimately, victims of LAM, women like Farber in the prime of their lives, will die from suffocation, most within a decade or two of their diagnosis.

"I go to sleep many nights terrified that I'm not going to be able to breathe well the next day," Farber said.

Right now, there is no treatment for LAM whatsoever.

"There is nothing I can take to slow it down. My goal is to stop it in its tracks as soon as possible," Farber said.

Immediately after her diagnosis, Farber voraciously began to learn everything she could about LAM. She and her family, were acutely aware that unlike more well-known diseases, LAM has no large multi-million dollar foundations backing research on the disease. If they wanted to see rapid progress, they would have to accomplish it themselves.



COURTESY OF TRISHA SARKISIAN

**FINDING A CURE:** Michael Nurok and Amy Farber '87 recently wed. They were ready to start a family when Amy was diagnosed with a rare, incurable and fatal lung disease. Amy's efforts to find a cure have involved her family, Westlake classmates, Harvard Medical School doctors and new non-profit organizations.

Farber and her family saw the lack of structure as a call to action.

Farber had been an activist long before her diagnosis, having spent time in Venezuela with AFS and working on a grant in South Africa.

"She's always been a global thinker," said Sarkisian, who added that her sister has always focused her energies towards helping people who need it.

"She never really thought it would be herself and she'd end up advocating to save her own life, but that's exactly what she's doing."

Along with a summit of LAM and interdisciplinary experts held in early December, Farber has organized a monthly seminar series at Harvard Medical school where top researchers gather to share ideas and further collaborate on LAM and related diseases like Tuberous sclerosis (TSC), a more widespread disease that shares a common gene defect with LAM.

Farber said that she hopes the shared pathway involved in LAM and more common diseases like breast cancer, prostate cancer, melanoma, diabetes, atherosclerosis and TSC will act as "a magnet for drawing researchers to LAM."

Despite it being what Farber described as an "ultra orphan disease," insight into LAM will undoubtedly help researchers make leaps of progress within the study of other diseases, in part because LAM is in many ways similar to a slow-growing cancer.

"Based on the momentum that we've developed working with scientists on a regular basis, we've worked to develop a research agenda," Farber said.

She has worked to set up a fund at the Boston Foundation, the LAM Research Fast Track Fund, which will be run by a scientific advisory board and will "allow us to begin fundraising to support the research that these scientists think is necessary... so we can get the work done in the shortest time possible."

Farber has "moved mountains in a period of months," Sarkisian said.

Her efforts with the Fast Track fund have laid the groundwork for serious LAM lab research to begin in January, but \$300,000 is needed to finance the project. Only \$50,000 is currently in the bank.

"She has this desperation, because she has this priceless brainpower organized, but what she doesn't have is the financial piece," Sarkisian said. "We need to fund the scientists or else all her effort will have been for nothing. It's so rare to get the top thinkers in the world excited about something."

A personal letter-writing campaign, in part from letters sent to Westlake alumni by Sarkisian and friends, raised \$210,000 for the LAM foundation, where the family had previously been directing funds prior to mobilizing Boston-based researchers..

Sarkisian started by sending a letter to all the members of both her and Farber's graduating classes, and "the idea... blossomed into other friends who were in different classes saying 'I want to write to my classmates,' and it grew from there," Sarkisian said, with letters having been sent to almost every graduating class from '80 to '90.

"We've had Westlake alumni come out of the woodwork; it's just been incredible," said Sarkisian, who noted that she and her sister were both surprised and grateful by the pull of the community, which is almost as strong as when they were in school.

Beyond financial support, alumni have provided tremendous amounts of personal hours. Among other things, alumni have helped to review the organization's business plans, manage health related PR, raise awareness and help Farber get media exposure.

"The only way any of us in our family are coping is by action," Sarkisian said, "That's just how we do it; everybody's pulled together."

The Farber clan has even found a way to turn the 3,000 miles and three time zones separating them into an advantage: "If I'm working on things until one in the morning and my mom is as well and then Amy gets up at five in the morning her time and starts cranking on different parts of this problem, there's really not a lot of hours that this operation isn't working," Sarkisian said.

After taking a four-day train ride across the country because flying increases her chances of lung collapse, Farber was at her family's Thanksgiving dinner this November for the first time in five years.

The Farbers have been "doing Thanksgiving forever together, since they were kids," with the same family friends, also Westlake alums, and the Farber sisters "cooked together all day, it's sort of a tradition," Sarkisian said.

"And certainly, we had a lot to be thankful for this year," Sarkisian said. "That's just how we have to move through this. We've had such support in fighting this."

To support LAM research, go to [www.communityroom.net](http://www.communityroom.net). Click on The Boston Foundation and reference the LAM Research Fast Track Fund, and for further information, to help, or to donate, contact: [trishasarkisian@yahoo.com](mailto:trishasarkisian@yahoo.com)