

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

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



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 lung disease. Amy's efforts to find a cure have involved her family, Westlake classmates, Harvard Medical School doctors and new non-profit organizations.*

Last 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, 35, had been feeling a little funny.

She'd been experiencing bouts of back pain and fatigue, which was unusual for a 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 Farber 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 for further tests.

A CAT scan revealed a tumor near her kidney and scattered cysts near her lungs last February. Terrifying but not definitive, the results began a long journey of what Farber called "profound uncertainty."

An in-patient stay at the National Institutes of Health brought her earth-shattering news: she had Lymphangiomyomatosis (LAM), a rare, progressive and fatal lung disease that almost exclusively affects women of childbearing age. According to Farber, "researchers think LAM is even more sex linked than Lupus or breast cancer," Farber said.

Uncommon and difficult to diagnose, the exact number of LAM sufferers is unknown. It is reported at about 400, although it is thought to be significantly higher than that.

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, enduring 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 the next day," Farber said. Right now, there is no way to treat LAM.

"Nothing has proven effective," Farber said. "There is nothing I can take to slow it down," she said, but, "my goal is to stop it in its tracks as soon as possible."

She and her family were acutely aware that unlike more well-known diseases, LAM has no multi-million dollar foundations backing research on the disease. If they wanted to see the necessary progress, they would have to accomplish it themselves.

Along with a summit of both LAM and interdisciplinary experts held in early December, she has organized a monthly seminar series at Harvard Medical School where top researchers gather to collaborate on LAM and related diseases like prostate cancer and Tuberous sclerosis (TSC), a more common 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 work on LAM."

"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 "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, but her work is far from done.

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 been directing funds prior to mobilizing Boston based researchers.

"We've had Westlake alumnae 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 they feel is almost as strong as when they were in school. Alumni have also provided tremendous amounts of personal man power hours, volunteering and taking charge of various aspects of the cause.

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 always celebrated Thanksgiving together with the same family friends, also Westlake alums.

"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."

— Julia Wick '07