

## Alumna in a Fight for Life

For a long time UES alumna Amy Farber (class of '81) has been interested in making a positive difference in the world. Being diagnosed with a rare, incurable lung disease has inspired her to make a difference in a way she never could have anticipated.

Farber's social awareness was nurtured early. While in high school she travelled as an AFS exchange student to Venezuela. As an undergraduate she spent time working for Senator Ted Kennedy in Washington, where she said she "learned everything I could about South Africa and civil rights." Also as an undergraduate she received funding to visit 13 cities that were landmarks in the American civil rights movement. In each location she met with past and present political and grassroots leaders and took documentary photographs of the landmarks and people she interviewed. Henry Louis Gates, Jr. was her advisor on "Voices of Change—Bringing the Civil Rights Movement Forward," a multimedia project that included many of the photographs and interviews she compiled. In graduate school she trained as a social/cultural anthropologist focused on "issues of access to healthcare for children in South Africa after apartheid officially ended."

Then last year, after a frustrating series of medical tests and uncertainties, Farber learned she has Lymphangioleiomyomatosis (LAM), a rare disease caused by a defect in a gene that regulates cell growth. Experts believe the number of cases of LAM worldwide ranges up to 250,000, but only about 1,000 have been definitively diagnosed because it is so little known. LAM affects mostly women in their childbearing years.

Unwilling to passively accept her fate, Farber and her husband, Michael Nuroc, founded the LAM Treatment Alliance, an organization dedicated to raising awareness and finding treatment for LAM in the fastest time possible.

With the support of friends, scientists and family (including Farber's sister, Tricia Sirkisian, UES class of '79), Farber and her husband have assembled programs aimed at bringing together people who can "identify gaps in the research, brainstorm new therapeutic approaches, and recruit other scientists into this work."

Because the abnormal cell growth that causes LAM is similar to that in diseases such as breast cancer, prostate cancer, melanoma, diabetes and obesity, the work can have a broad impact.

"The danger is to see rare diseases as irrelevant because they affect so few people," Farber said. "But in addition to the moral and ethical reasons for not ignoring them, it is important to understand what rare diseases teach us about common diseases."

When asked how she finds courage for her fight, Farber said, "I'm convinced that each of us does not really know what we have in us until confronted with challenges we would have never thought we could or would have to take on." She added that she draws on a sense of



Photo courtesy of Amy Farber

Amy Farber and her husband, Michael Nuroc, at their wedding in Temescal Canyon in August 2004.

self "developed through relationships with loved ones, friends and colleagues; learning experiences throughout my travels; the wisdom of my many mentors; and the courage of those whose stories I learned from in South Africa and the American South—many stories of courage and faith under fire."

To learn more about LAM and how to help in the search for a treatment, visit <http://www.lamtreatmentalliance.org>, or email Farber at [afarber@post.harvard.edu](mailto:afarber@post.harvard.edu).

## Special Thanks to Visiting Author Linda Sue Park

Dear Ms. Linda Sue Park,

I was really excited when I heard you were coming to UES. I asked and asked my mom when it was and then you finally came. My mom and I were really excited because we have never met a Korean American author who writes children's literature.

It was interesting how you said that you read books and got inspired to write your books. I always liked to read but I hated writing.

I thought about how you said you wrote 32 drafts until the final one. You have to keep changing it and changing it until you have it perfect. That is sort of what we do in school, make everything perfect.

I thought your dog giving you inspiration was also a surprise. My dog also kind of gave me ideas to write about, but they pretty much didn't help me. It was funny how your dog always wanted you to write about a superdog and you never listened to him.

You inspired me to read a lot of books. I've read five of your books—six if you count rereads. My favorite is *Project Mulberry*. The book told me a lot of things I didn't know about you, like how you're afraid of worms. It's cool how you added one of your fears in a character.

My mom thought *When my name was Keoko* was really informative. That was the first book I've read written by you. I thought it was an interesting topic you chose. It was like a history book about a girl and her family and their life in Korea during World War II.

Even though I still hate writing, your advice made me read a lot of books and reread interesting books. I don't hate writing as much as before. You helped me like it because I heard you say that you got ideas from books and I have read a lot of books.

Sincerely,

Eunice Lee, Upper Elementary