

## ATS Acceptance Speech

I am humbled, to say the least, to have been chosen for this award. I'd like to thank Dr. Barry Fanburg for nominating me and for a decade of unwavering support.

When my daughter, Andrea, was diagnosed with lymphangiomyomatosis at age 22, the grim prognosis and the unbearable thought of losing her spurred me to launch a letter-writing campaign to lung doctors and to Congress to convince the National Heart, Lung, and Blood Institute to establish a LAM registry – a beginning step. I am so grateful to the pulmonary community for responding to my plea and embracing this cause.

After receiving thousands of letters about LAM, Dr. Claude Lenfant, Director of the NHLBI at that time, met with me in his office and agreed to form a LAM registry to define the natural history of the disease. In a speech later on, Dr. Lenfant said, "I knew I had to do something for this woman, or she would still be there." At Dr. Lenfant's direction, a longitudinal research study was initiated, collecting data on over four hundred LAM patients, which set the stage for clinical trials. The value of our partnership with the NHLBI over the years could never be overstated.

When I started The LAM Foundation in 1995, I became acutely aware that I would need someone with a scientific background since I was formerly a music teacher. I don't think it was an accident that Dr. Frank McCormack had just moved to the University of Cincinnati, and enlisting his help was one of the best decisions I have ever made. He has done a brilliant job of leading the science. Under his guidance, over 70% of the \$10.2 million raised has been committed to peer-reviewed research, leading to new understanding in the molecular mechanisms of LAM and a pivotal trial based on sound science.

The successes of The LAM Foundation have come hour by hour, dollar by dollar, and inch by inch – through hard work, determination and passion; and watching them unfold has been one of the greatest joys of my life. But the most gratifying part of this experience has been my relationship with the women with LAM. They have taught me all about courage and strength, and the value of maintaining a sense of humor. I've spoken to almost every one of them personally and I have been deeply touched by their stories and their lives. One of *my* greatest pleasures has been connecting *them* to one another.

... I have learned *so* much over the past eleven years. This journey has taken me to places I never thought I would go, provided experiences I never imagined that I would have, made me stronger than I ever thought I would be. I've gained an enormous respect for science, and an appreciation for the huge responsibility that comes with conducting clinical trials.

I have seen the power of science bring the best of minds to the most obscure of problems, bring the darkest of diseases into the brightest light, and provide precious hope to the most hopeless. It has been a privilege to offer the gift of hope to women with LAM, while making a strong effort to recognize the difference between false hope and hope that is real. Hope is essential; and keeping hope alive is a never-ending challenge when scientific advances never seem to move fast enough. One of my favorite quotes so eloquently reads: "Hope is like a bird that senses dawn and carefully starts to sing while it is still dark."

This Award is especially meaningful to me because it demonstrates that the ATS truly values the efforts of public interest organizations. I am so grateful for the vision of Bill Martin and the ATS for recognizing the importance of the significant role that patients can play, the impact they can have on research, and for providing a forum through the Public Advisory Roundtable for their voices to be heard. It's clear that there is a deep respect and appreciation for the patients you serve. I am deeply honored to be the recipient of the Public Service Award. Thank you!