

THE LAM FOUNDATION ACHIEVEMENTS

The LAM Foundation has identified women with LAM worldwide and developed a patient database that has grown from 9 patients in 1995 to over 1300 patients in 2007. Hope is provided for all women with LAM through research, education, awareness and support. Our accomplishments are a testament of the dedication of The LAM Foundation staff and the LAM community.

Research

- Convinced the National Heart, Lung, and Blood Institute (NHLBI) to establish a National LAM Registry and to initiate an intramural research program, resulting in a \$20 Million investment by the NHLBI;
- Developed a system to acquire and distribute LAM tissues obtained at lung transplantation for research;
- Developed a robust research program based on investigator-initiated projects and rigorous peer review by an outstanding international LAM Scientific Board;
- Dedicated 67% of funds raised to research; 17% to patient and education programs;
- Funded 75 research projects that produced 3 major breakthroughs that made clinical trials possible, including the genetic basis of LAM, its relationship to tuberous sclerosis, and the identity of molecular targets for therapy;
- Conducted the first-ever LAM treatment trial!
- Granted seed money through LAM Awards that generated preliminary data, resulting in additional awards for LAM scientists and 6 NIH grants (ROIs) that total over \$6 Million.

Education

- Conducted the first-ever LAM patient/family conference in 1997 and co-funded the first LAM scientific meeting held at Columbia University in 1999;
- Organized and executed eight annual International LAM Research Conferences, co-funded by the National Heart, Lung, and Blood Institute, and sponsored the Boston LAM Seminars at Harvard University in 2006;
- Created the primary forum for scientific discussion in LAM through outstanding annual meetings that attract 100 conference attendees, including an average of 100 investigators.
- Gave presentations and managed exhibits for the last 9 years at the International American Thoracic Society (ATS) Conferences, the American College of Chest Physicians (ACCP), European Respiratory Society (ERS), Tuberous Sclerosis Alliance (TSA), American Lung Association *Catch Your Breath* conferences, and the Canadian Lung Conference, to educate the medical community;
- Delivered LAM research and educational presentations to investigators and patients in New Zealand, Australia, Japan, England, Canada, at the United Nations, and all over the United States;
- Developed a plan to educate pulmonologists, nephrologists, gynecologists, internists, neurologists, and ED Physicians, to identify women with LAM, and to acquire LAM patient referrals.

Advocacy/Awareness

- Testified before Congress on behalf of rare diseases;
- Lobbied through Congress to convince the NHLBI to form a National LAM registry, followed by a LAM protocol;
- Successfully lobbied House Appropriations Committee in years 2000 through 2005, and Senate Appropriations Committees in 2006 to have report language on LAM included in the Labor, HHS and Education Appropriations Bills;
- Sponsored "Tour for a Cure", a 13,000-mile trip around the US by the Development Director, to raise LAM awareness;
- Spoke about LAM at the United Nations;

- Featured in national magazines & newspapers, including American Respiratory Care, Advanced Respiratory Magazine, Family Circle, Woman's Day, Philanthropy World, Washington Post, and Wall Street Journal;
- Cultivated a successful, collaborative relationship with the National Heart, Lung, and Blood Institute
- Received invitation for National Health Council (NHC) membership and created productive affiliations with the TS Alliance (TSA), American Lung Association (ALA), and American Thoracic Society (ATS);
- Gave LAM presentations in Australia, New Zealand, Japan, and provided patient speakers for the American Thoracic Society International Conference;
- Launched a major national awareness campaign through Spectrum Science Communications.

Patient Support

- Provided an extraordinary network of support to women with LAM worldwide through telephone calls, emails, Breath of Hope patient newsletter, an Advocacy Program, "Personal Journeys", "Journeys with Lung Transplantation," and a LAM patient ListServ;
- Inspired and assisted in the founding of 13 other LAM organizations abroad, including France, Germany, England, New Zealand, Switzerland, Australia, The Netherlands, Japan, Italy, Spain, China, Romania, and Canada, three of which are raising funds for The US LAM Foundation;
- Developed a LAM patient handbook and brochures that have been translated into Japanese, Chinese, German, Spanish and French;
- Formed the Worldwide LAM Patient Coalition (WLPC) to enable collaboration with patient organizations around the globe.

Fundraising

- Raised over \$10.2 Million since inception;
- Enlisted over 50% of registered LAM patients to participate in fundraising efforts;
- More than 90% of all funds raised were in honor of a LAM patient;
- Increased number of annual donors from 1,438 to over 15,609;
- Increased number of LAM fundraisers from 3 to 170 events;
- Raised funds in all 50 states, the Commonwealth of Puerto Rico, and 25 foreign countries;
- Approved by the Better Business Bureau for national membership.

LAM Foundation Leadership Roles

- National Heart, Lung, and Blood Advisory Council – Sue Byrnes
- American Thoracic Society Public Advisory Roundtable – Sue Byrnes
- Co-Director, Rare Lung Diseases Consortium – Frank McCormack, MD
- LAM Registry Tissue Committee – Frank McCormack, MD and Sue Byrnes

Awards Presented to Founder Sue Byrnes

- American Thoracic Society Public Service Award
- National American Lung Association Founders Award
- American Lung Association of Chicago Change the Numbers Award
- Fatima El-Fehria International Award for Women in Science
- Speaking of Women's Health Award
- Leading Women Award
- Health Care Heroes Award
- Woman's Day Award
- Freedom Heroes Award

The LAM Foundation is proud to have been selected as a member of the National Health Council.