

# The LAM Foundation Annual Report 2003

# Lymphangioleiomyomatosis

## **Our Mission**

*The LAM Foundation provides support, education, and hope to women with Lymphangioleiomyomatosis (LAM), a progressive, debilitating lung disease. Our goals are to organize, marshal the forces of the scientific community, raise LAM from obscurity, and conquer it in a decade.*



## **The LAM Foundation**

10105 Beacon Hills Drive

Cincinnati, OH 45241-1335

Phone: (513) 777-6889 Fax: (513) 777-4109

Email: [lam@one.net](mailto:lam@one.net) Website: <http://lam.uc.edu>



# THE LAM FOUNDATION

## 2003 ANNUAL REPORT

January 1, 2003 through December 31, 2003

### A Message from the Director



The LAM Foundation has transformed your donations into ideas, action and hope. There have been thousands of decisions and dilemmas along the way. The guiding principle at every fork in the road has been “to do what is best for the patients.” How fortunate we are to have this North Star on our horizon. First we built the infrastructure; organized patients, an accessible staff, a powerful database, and a mechanism to fund promising science. We chose wisely. The projects that we supported ideally positioned us for progress, which came with lightening speed and from directions that we never expected. Based on molecular targets that were affirmed in numerous laboratories, the Foundation embarked on the first ever LAM clinical trial; and did it first and before the ink was dry on the breakthrough publications. The early results have quickened the pulses of our investigators, who are hurriedly writing a bold global LAM trial. Without exception, the shared sentiment of the scientists who have raised our disease from obscurity is not pride or possessiveness, but how lucky they feel to have been part of this effort.

Make no mistake, this is a Cinderella story in progress. But the ending is yet to be written. The next trial is powered for proof, and will include a dozen states and foreign countries. It will be expensive. When it is over, you will have shown the world what aggressive, intelligent, proactive patients and families can do to help themselves. We need your help to sustain this momentum, and achieve our goal to conquer LAM in a decade. Look carefully at this document, and think about coauthorship on a happy ending for the LAM patient you love.

Sue Byrnes, Executive Director

### LAM Research Continues!

Thanks to LAM patients and their family and friends who have made this research possible! A special thanks to John and Vi Adler and the **Adler Foundation, Inc.** for funding two three-year LAM research fellowships! The LAM Foundation is grateful for their extraordinary support!



**Baldwin Mak, BSc, PhD**, a post-doctoral fellow in the laboratory of Dr. Raymond Yeung at the University of Washington in Seattle, was awarded a **\$40,000 pilot grant** to assess the role of the Wnt/beta-catenin pathway in LAM and to determine how the TSC genes control its activity in health and disease states.



**Hongwei Wang, MD**, is a research fellow in Dr. David Kwiatkowski's lab at the Brigham & Women's Hospital, Harvard Medical School. Her **\$150,000 fellowship award** is to develop a mouse model of LAM using mesenchymal stem cells that have been engineered to have lost functional TSC2 (or TSC1). This model will ideally help understand how LAM develops and permit assessment of potential therapies.



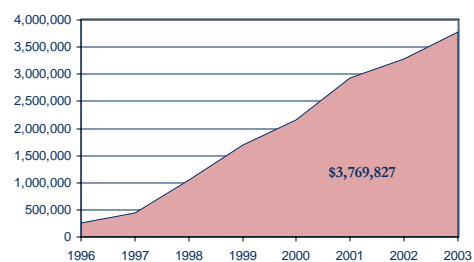
**David Kwiatkowski, MD, PhD**, and **Nisreen El-Hashemite, PhD**, Brigham & Women's Hospital, Harvard Medical School, have been awarded a **\$120,000 three-year special project award** to study the role of interferon-gamma, matrix metalloproteinases, and smooth muscle cell proliferation in both a TSC mouse model lesion, liver hemangioma, and in AMLs and LAM from patients.



**Blanca Camoretti-Mercado, PhD**, works at the University of Chicago in the Section of Pulmonary and Critical Care. Her award is funded by the American Thoracic Society in partnership with The LAM Foundation. With her **\$100,000 two-year special project award**, “Modulation of Smooth Muscle Gene Expression by the TSC Gene Products”, she will investigate the role of TSC1 and TSC2 in the transcription-promoting activity of serum response factor through regulation of Rho signaling.



### Our Central Mission - Research!



Total monies committed to research

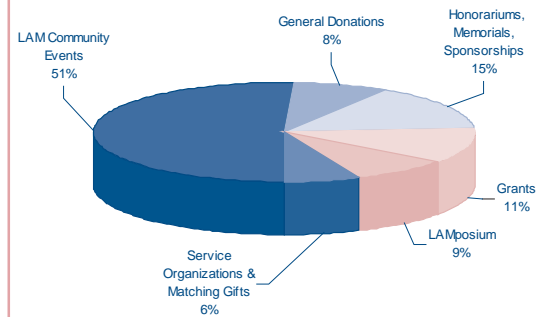
## STATEMENT OF ACTIVITIES

	2003			2002
	<i>Unrestricted</i>	<i>Temporarily Restricted</i>	<i>Total</i>	<i>Total</i>
<b>REVENUES, SUPPORT &amp; GAINS</b>				
Support	\$941,541	(\$6,186)	\$935,355	\$734,724
Dividends, Interest & Gains	12,767		12,767	(7,373)
<b>Total Revenues, Support and Gains</b>	954,308	(6,186)	948,122	727,351
<b>EXPENSES</b>				
Program Services	731,587		731,587	590,019
Management and General	64,971		64,971	47,935
Fundraising	86,616		86,616	55,859
<b>Total Expenses</b>	883,174		883,174	693,813
<b>Increase (Decrease) in Net Assets</b>	\$71,134	(\$6,186)	\$64,948	\$33,538

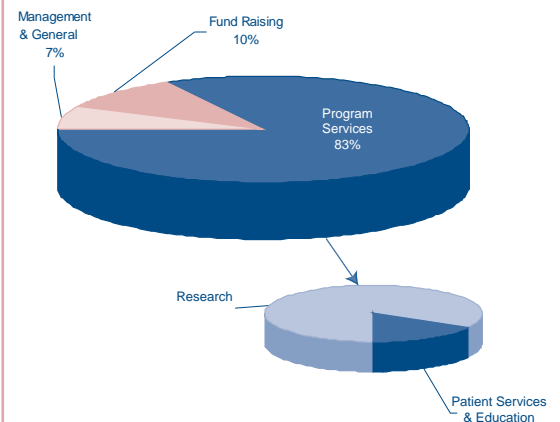
### STATEMENT OF FINANCIAL POSITION

	2003	2002
<b>ASSETS</b>		
Current Assets		
Cash	\$521,606	\$469,683
Accounts receivable	49,152	47,210
Other assets	15,929	7,530
Investments	102,209	56,624
<b>Total Current Assets</b>	<b>688,896</b>	<b>581,047</b>
Property and equipment, net	14,385	14,115
<b>Total Assets</b>	<b>\$703,281</b>	<b>\$595,162</b>
<b>LIABILITIES - NET ASSETS</b>		
Current Liabilities		
Accounts payable	\$12,552	\$14,084
Compensation payable	12,624	6,403
Payroll taxes payable	3,984	3,843
Fellowships payable	356,163	317,822
<b>Total Current Liabilities</b>	<b>385,323</b>	<b>342,152</b>
Net Assets		
Unrestricted	307,704	236,570
Temporarily restricted	10,254	16,440
<b>Total Net Assets</b>	<b>317,958</b>	<b>253,010</b>
<b>Total Liabilities and Net Assets</b>	<b>\$703,281</b>	<b>\$595,162</b>

### SUPPORT



### EXPENSES



*Copies of The LAM Foundation's complete 2003 audited financial statements are available upon request.*

# THE L·A·M FOUNDATION



Non-Profit  
Organization  
U.S. POSTAGE  
**PAID**  
CINCINNATI, OH  
PERMIT NO. 1481

10105 BEACON HILLS DRIVE  
CINCINNATI, OH 45241-1335

Tel: 513-777-6889

Fax: 513-777-4109

Email: lam@one.net

Website: <http://lam.uc.edu>

## ANNUAL REPORT 2003

### The LAM Foundation

#### EXECUTIVE COMMITTEE

**Sue Byrnes, Executive Director**  
Cincinnati, OH

**Valerie Babb, Board Secretary**  
Minot, ND

**Aaron Dichter, Board Chairman**  
Bellevue, WA

**Richard Aquilina, PhD**

**Board Vice Chairman**  
Poquott, NY

**Francis McCormack, MD**  
**Scientific Director**  
Terrace Park, OH

#### BOARD OF TRUSTEES

**Cynthia Beasley**  
Overland Park, KS

**Jeffrey Caden**  
Seattle, WA

**Barry Crown**  
Chicago, IL

**Patricia Davey**  
Pelham Manor, NY

**Richard Denoyer, PhD**  
Cincinnati, OH

**Mary Harbaugh, PhD**  
Shoreview, MN

**Chris Hughes**  
Franklyn, MA

**Brian Kleps**  
Bridgeport, CT

**Gianni Migliorini**  
Occoquan, VA

**Susan Milligan**  
Cincinnati, OH

**Madeline Nolan**  
Naugatuck, CT

**Pat Rubadeau, PhD**  
Ann Arbor, MI

**Karyn Schad**  
Louisville, CO

**Eugene Sullivan, MD**  
Olney, MD

**Charles Wehland**  
Wilmette, IL

#### SCIENTIFIC BOARD CHAIRMAN

**Francis McCormack, MD**  
University of Cincinnati Medical Center, OH

#### BASIC SCIENCE ADVISORY BOARD

**Thomas Colby, MD**  
Mayo Clinic Scottsdale, AZ

**Jilly Evans, PhD**  
Merck & Company, PA

**Barry Fanburg, MD**  
New England Medical Center, MA

**Elizabeth Henske, MD**  
Fox Chase Cancer Center, PA

**Sharon Long, PhD**  
Stanford University, CA

**Reynold Panettieri, MD**  
University of Pennsylvania Medical Center, PA

**Alan Sachs, MD, PhD**  
Rosetta Inpharmatics LLC, WA

**Jeffrey Whitsett, MD**  
Children's Hospital Medical Center, OH

**Ray Yeung, MD**  
Washington School of Medicine, WA

#### ADVISORY BOARD

**Francis Byrnes**  
Cincinnati, OH

**Brent Jaquet**  
Edgewater, MD

**Sam Reynolds**  
Mason, OH

**Carol Vreim, PhD**  
National Institutes of Health (NIH), MD

#### CLINICAL ADVISORY BOARD

**John Bissler, MD**  
Children's Hospital Medical Center, OH

**Jean-Francois Cordier, MD**  
Hospital Louis Pradel, France

**David Franz, MD**  
Children's Hospital Medical Center, OH

**Janet Maurer, MD**  
CIGNA HealthCare, CT

**Sonoko Nagai, MD**  
Kyoto University Graduate School, Japan

**Thomas Raffin, MD**  
Stanford University Medical Center, CA

**Jay Ryu, MD**  
Mayo Clinic, MN

**Steven Sahn, MD**  
Medical University of South Carolina, SC

**Marvin Schwarz, MD**  
University of Colorado Health Sciences Ctr., CO

**Eugene Sullivan, MD**  
Olney, MD

**Anne Tattersfield, MD**  
The University of Nottingham, England

**Elbert Trulock, MD**  
Washington University Medical Center, MO

#### HONORARY MEMBERS

The Honorable Michael Bilirakis, MC

The Honorable Steve Chabot

The Honorable John Glenn

The Honorable Barbara Mikulski

The Honorable John Porter