Dear Friends:

It is a tremendous joy to watch the organization grow and change each year. FMDSA made some great progress in 2009, and we hope the next few pages will provide a synopsis of our successes and challenges. Highlights of the year included:

Research and Treatment

- International Patient Registry, in cooperation with the University of Michigan became operational and started gathering data.

- University of Illinois opened FMD Clinic; joining the Cleveland Clinic in improving medical care for FMD patients. Massachusetts General is in progress and will be opening a clinic in 2010.

Awareness

- Wall Street Journal, June 27, 2009. Fibromuscular Dysplasia made the front page of the Wall Street Journal. This was the first time that FMD was presented in the national media.

- Mystery Diagnosis on Discovery Health Channel; First aired in September, 2009. Executive Director, Pamela Mace, was featured on this TV program and brought new awareness to the difficulty of being diagnosed.

- Kidney Beginnings Magazine (a publication of the American Association of Kidney Patients) published an article in their May 2009 issue. The article, “Fibromuscular Dysplasia, An Often Unrecognized Vascular Disease” was co-authored by Pamela Mace, RN and Jeffrey Olin, DO.

- First Public Service Announcement (PSA) created for FMDSA. Our thanks to Terri Provost for all of her hard work in creating the PSA.

Education

- Cleveland Clinic Heart and Vascular Institute held first live web chat for FMDSA patients in February and as well as a second web chat in November. This was the first opportunity that patients from around the world had to ask questions directly to FMD experts.

- The Doctor’s Channel. Dr. Heather Gornik (FMDSA Founder’s Award Winner) was featured in a series of short streaming video clips about FMD intended to help educate other physicians.

- 2nd Annual FMDSA Membership conference held June, 2009 brought together patients and physicians to discuss the latest on FMD progress.

- International Stroke Conference, San Diego, February, 2009. FMDSA continues to educate the medical community through face-to-face interaction.

Administrative

- Pamela Mace hired as Executive Director. Pamela Mace became the first official employee of FMDSA on Sept. 15, 2009. The organization has grown to require a full time representative of the organization. This change will also improve our ability to attract grant money in the future.

We would like to express our deepest gratitude to our donors and volunteers that support FMDSA and help to make our organizational successful. Working together, we will continue to make a difference in the lives of those afflicted with FMD.

Pamela Mace, RN
Executive Director

Richard Gould
Founder / President
About FMDSA

Mission Statement

The Fibromuscular Dysplasia Society of America, Inc. is a voluntary health organization dedicated to improving the lives of those afflicted with Fibromuscular Dysplasia (FMD) by raising awareness and developing funds to promote research towards new medical treatments and diagnostic tools.

FMDSA Programs

International Patient Registry
The patient registry has been developed in cooperation with the University of Michigan Health System’s Michigan Cardiovascular Outcomes Research and Reporting Program (M-CORRP). The purpose of the registry is to collect data on FMD patients seeking treatment at one of the initial nine centers. Until now, minimal research has been initiated on FMD. All studies have been regional in nature and based upon a limited population of patients. The registry will help us develop an incredible database of information with respect to the FMD population, genetics, treatment outcomes, and prognosis.

Healthcare Professional Education Program
This program is a combination of attending medical conferences and presenting training classes within hospital environments. This program has been a major focus of FMDSA over the past four years. These meetings are vital to the FMDSA expanding its influence in the medical community, educating healthcare professionals, and spurring action.

Website Education
One of the most important charters is to educate patients and family about FMD. Our website has grown exponentially since inception. FMDSA is the premier source of FMD information for the layperson. Our Honcode certification is a stamp of approval that verifies we are an unbiased organization providing only medically certified information. We saw about a 46% growth in pages downloaded in 2009.

Grassroots Awareness Program (GAP)
The GAP program was initiated in July 2005 to help FMD patients educate their healthcare providers about FMD. We have a number of valuable resources on our website to help communicate FMD in laymen’s terms as well as more in depth information for physicians that can help bridge the gap and build a better relationship.

Public Awareness
This program includes our work to get represented within the media. This past year was a great success with articles in the Wall Street Journal, Kidney Beginnings Magazine, and Cleveland Clinic newsletter as well as national TV coverage via the “Mystery Diagnosis” program on Discovery Health channel.

Patient Support
We are the first call for a number of newly diagnosed patients looking for educational information, how to connect with other patients, and how to find the best medical care. On average, we spend about 25% of our staff time assisting FMD patients.

Research
FMDSA participates in a number of research activities. Most of our actual work in 2009 was related to an NIH study focusing on the overlap between a number of connective tissue disorders. We have been planning a number of new programs for 2010 including tissue collection and a genetic study.

Annual Conference
The primary purpose of the FMDSA annual conference is to educate the patient population on the latest progress on FMD research and treatment. FMDSA held its second annual conference in June 2009 in Cleveland, OH. Speakers included Drs. Jeffrey Olin, Heather Gornik, Kevin Meyers, and James Froelich. The meeting is also a great opportunity for FMD patients to network with other patients and learn to get involved in spreading awareness of the disease. In addition, this is an opportunity for members of our Medical Advisory Board to meet and share information they have learned throughout the year.
Financial Summary

Thanks to all of our donors for helping us exceed our 2009 revenue goal of $76,130. The vast majority of our revenue comes from individual contributors and your continued support is vital to our success.

Operationally, we had some significant changes in 2009. The biggest expense for FMDSA is the International Patient Registry that became operational in 2009. As discussed earlier, this program will be the foundation for future FMD research and treatment progress.

Another big step forward was the employment of a paid staff. We hired Pamela Mace as our full time Executive Director in September, and contracted temporary help to assist us with project based work. As demand for our services continues to grow, it will be necessary to evaluate our need for additional paid staff.

Our net revenue for 2009 was ($30,524). We missed our initial expense goal for 2009, which was $95,446. This was primarily due to the patient registry becoming operational earlier than planned. We did expect negative net revenue in 2009 as we added staff and began production on the registry.

The FMDSA “Statement of Financial Position” is very simple. As of December 31, 2009, we have $115,276 in assets (all cash) and $0 liabilities.

Our five year plan factors in growth for all of our existing programs. In order to support this growth, our revenue needs to grow as well. Our revenue goal for 2010 is $111,172. This is a significant increase over 2009 and we hope that you will continue to support FMDSA.
Board of Directors and Medical Advisory Board

**FMDSA Board of Directors**

**Pamela Mace, RN**  
Executive Director  (as of 9/2009)  
Chairperson / President (Resigned 9/2009)

**Richard Gould**  
Chairperson/President (as of 9/2009)  
Treasurer (Resigned 9/2009)

**Cherylann Bailey**  
Secretary

**Cheryl Golden, CPA**  
Treasurer (as of 9/2009)

**Glen Graham, MD, PhD**  
Director-at-Large

**Kari Ulrich**  
Director-at-Large (Resigned 4/2009)

**Douglas Webster, DO**  
Director-at-Large

**FMDSA Medical Advisory Board**

**Jeffrey W. Olin, DO, FASC., FASS**  
Professor of Medicine  
Director of Vascular Medicine  
Zena and Michael A. Wiener Cardiovascular Institute  
Mount Sanai School of Medicine

**Philip B. Gorelick, MD, MPH**  
John S. Garvin Prof. and Head Director Center for Stroke Research  
Department of Neurology and Rehabilitation  
University of Illinois College of Medicine

**Heather L. Gornik, MD**  
Medical Director, Non-Invasive Vascular Laboratory  
Cleveland Clinic Heart and Vascular Institute  
The Cleveland Clinic Foundation

**Warren D. Lo, MD**  
Associate Professor of Pediatrics and Neurology  
Nationwide Children’s Hospital

**Nazli McDonnell, MD, MPH**  
Medical Genetics  
Laboratory of Genetics  
National Institute of Aging / National Institutes of Health

**Kevin E. Meyers, MD**  
Pediatric Nephrologist  
Assistant Professor of Pediatrics  
The Children’s Hospital of Philadelphia and University of Pennsylvania

**FMDSA Giving Honor Roll**

**Superhero Level - $5,000**  
Manchester Family Dental  
Sandra Pileggi  
Andrea Spears

**Hero Level - $1,000**  
Busch & Hutchison, PLLC  
Martha Clark  
Cleveland Clinic  
Carolyn Cusick  
Dell Direct Giving Campaign  
Cheryl Golden  
Rochelle DesRochers-Moreau and Phil Moreau  
Maureen Murley  
Mimi Petersen  
Wade and Yvette Ragas  
Jodi Roth

**Benefactor Level - $500**  
Molly Clark and Kay Tanner  
Kari & Dr. Michael Ulrich  
Elizabeth Willmore  
Robert and Lisa Zborowski

**Patron Level - $250**  
Liz Augusta RN  
Bonita Benefield  
Ronni Herrick & Mavin Goldstein  
Brett Andrew Gooden  
Rebecca Hoeftger  
David Johnson  
Anne Karmon  
Thomas Oberhausen  
Stacey Rosenberg  
Kellie Smidde  
Tracy VanDenBerg  
Greg and Leigh Van Den Berg  
Philip Verveer  
Douglas & Mariruth Webster