



FMDSA 2009 Annual Report

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 organization 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.

Statement of Activities

| Revenue and Support | 2009 | 2008 |
|---|---------------------|--------------------|
| Contributions and Grants (including events) | \$ 72,102 | \$ 57,812 |
| Program Revenue | \$ 3,711 | \$ 8,299 |
| Investment Income | \$ 958 | \$ 2,117 |
| Income Adjustment | \$ 321 | \$ - |
| Total Gross Revenue | \$ 76,771 | \$ 68,228 |
| Expenses | 2009 | 2008 |
| <i>Grants and Contract Service Expenses</i> | | |
| Patient Registry | \$ (45,964) | \$ - |
| Fundraising Fees | \$ (866) | \$ (314) |
| Accounting Fees | \$ (706) | \$ - |
| Legal Fees | \$ (6,164) | \$ (5,389) |
| Temporary Help - Contract | \$ (4,798) | \$ (2,155) |
| <i>Salaries and Related Expenses</i> | | |
| Salaries and Wages | \$ (10,665) | \$ - |
| Payroll Taxes | \$ (5,207) | \$ - |
| <i>Nonpersonnel Expenses</i> | | |
| Supplies | \$ (881) | \$ (2,171) |
| Telecommunications | \$ (2,187) | \$ (3,017) |
| Web Hosting | \$ (156) | \$ (253) |
| Information Technology | \$ (4,058) | \$ (3,939) |
| Postage and Shipping | \$ (1,320) | \$ (988) |
| Printing and Copying | \$ (1,847) | \$ (835) |
| <i>Facility & Equipment Expenses</i> | | |
| Rent Parking and Other Occupancy | \$ (4,998) | \$ (4,915) |
| Computer Purchase | \$ (825) | \$ - |
| Software Purchase | \$ (143) | \$ - |
| <i>Travel and Meetings</i> | | |
| Travel | \$ - | \$ (5,911) |
| Conferences, conventions, meetings | \$ (6,694) | \$ (6,758) |
| Airfare | \$ (1,327) | \$ - |
| Rental car | \$ (107) | \$ - |
| Taxi | \$ (142) | \$ - |
| Gas/Tolls/Parking | \$ (223) | \$ - |
| Mileage | \$ (984) | \$ - |
| Meals | \$ (699) | \$ - |
| Hotel | \$ (2,088) | \$ - |
| <i>Other Expenses</i> | | |
| Insurance | \$ (1,755) | \$ (1,078) |
| Membership Dues - Organization | \$ (100) | \$ (50) |
| Credit Card Transaction Fees | \$ (253) | \$ - |
| <i>Business Expenses</i> | | |
| Fines, Penalties, and Judgements | \$ (114) | \$ - |
| State Registration Fees | \$ (1,750) | \$ (1,179) |
| Other | \$ (274) | \$ (243) |
| Total Expenses | \$ (107,295) | \$ (39,195) |
| Total Net Revenue | \$ (30,524) | \$ 29,033 |
| Total Cash Assets as of 12/31/2009 | | \$ 115,276 |

| Program Categories | 2009 | 2008 |
|-------------------------------|--------------------|--------------------|
| Website Education | \$ (656) | \$ (253) |
| Grassroots Awareness Program | \$ (2,028) | \$ (776) |
| Physician Education Program | \$ (8,984) | \$ (6,868) |
| Patient Registry | \$ (46,652) | \$ (836) |
| Annual Member Conference | \$ (9,203) | \$ (5,765) |
| Patient Support | \$ (6,810) | \$ - |
| Research | \$ (2,934) | \$ - |
| Public Awareness | \$ (1,559) | \$ - |
| Total Program Expenses | \$ (78,826) | \$ (14,498) |



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 Sinai 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

Molly Clark and Kay Tanner
Kari & Dr. Michael Ulrich
Elizabeth Willmore
Robert and Lisa Zborowski

Benefactor Level - \$500

Millcent Allen
Bruce Bidnick
Kelly Connelly RN
Amy Fisher
Richard and Susan Gould
Muhammad Nashatizadeh
Jeffrey Olin, DO, FACP, FACC
Charlotte Rosenberg
Universal Solutions, Inc.
Douglas & Mariruth Webster

Patron Level - \$250

Liz Augusta RN
Bonita Benefield
Ronni Herrick & Mavin Goldstein
Brett Andrew Gooden
Rebecca Hoetger
David Johnson
Anne Karmon
Thomas Oberhausen
Stacey Rosenberg
Kellie Smiddie
Tracy VanDenBerg
Greg and Leigh Van Den Berg
Philip Verveer