



2012 ANNUAL REPORT

A LETTER FROM THE PRESIDENT

Dear Friends of the FMDSA,

I have had the honor of serving as President of the FMDSA since my election to the board this year. To be part of such a wonderful organization has allowed me to meet many wonderful people, among them patients, Doctors, and various friends of the organization. My wife is an FMD patient, and that is how I initially began my affiliation with the FMDSA. After attending my first meeting quite a few years ago, I decided that it was important that I do more than just attend an occasional meeting and provide some financial aid.

Starting out as merely a support group, I have seen the FMDSA evolve into an International presence in just under a decade. Nowadays when someone has a need for information or wishes to pursue scientific study in the area of the disease (FMD) itself, we are the organization people turn to. The dedicated members of the Board, Advisory council, medical advisory board, and our loyal supporters have made great strides in studying the disease and are bringing us closer to understanding FMD, learning how to deal with it, and hopefully one day finding a cure.

Our most impressive accomplishment has been the formation of the FMD Registry, the data we have collected is astounding. Here are a few amazing facts about the Registry and our other accomplishments over the past year:

The Registry has allowed new data to be released: "The United States Registry for Fibromuscular Dysplasia Results in the First 447 Patients" was published in May in *Circulation*, the journal of the American Heart Association.

Circulation also published a "Patient Page" on Fibromuscular Dysplasia in 2012, with new data from the FMD Registry.

Multiple abstracts discussing new data from the registry were shared at medical conferences throughout the year.

We continue to add centers to the Patient Registry and assist in organizing FMD Programs, including helping the Fibromuscular Dysplasia Australian Association to develop their organization. They started out meeting through FMDSA and wanted to work on raising awareness of FMD in their own Country.

There is almost a daily increase in newly diagnosed patients contacting us or participating in our supports groups.

We have been working with Researchers and Organizations from around the world to continue collaboration.

Our 5th annual meeting was our best meeting to date with great speakers and the opportunity for patients and first degree relatives to participate in the blood draw for the FMD Bio Repository.

Executive Director, Pam Mace, had the opportunity to speak at the European Society of Hypertension meeting in London along with Dr. Pierre Plouin and several other FMD researchers

Dr. James Stanley, University of Michigan vascular surgeon joined our Medical Advisory Board.

There have been multiple television, magazine, and newspaper interviews.

FMDSA continues to organize Regional Network Groups throughout the U.S. so that patients have the opportunity to talk with and meet others that live locally.

Our Facebook and Inspire support groups continue to grow, offering patients a place to learn and share.

We have created a strong affiliation with NORD and other groups supporting rare disease organizations

In 2013 we will celebrate our 10 Year Anniversary! The accomplishments over the past nine years are too numerous to mention. Likewise those that have contributed to the FMDSA with money, their time, and efforts is astronomical. The organization has received help from many and touched the lives of thousands.

I have come to realize over the past year that the FMDSA is not just the Board members, the Doctors, and many supporters and volunteers. The FMDSA is you!! Whether you are a patient, a Doctor, a relative or spouse of a patient, a co-worker or a friend. Each and every one of you has helped us to get where we are today. Likewise, it is up to you to see that we continue to grow and prosper.

Thank You,

Bradley J Daar

President-FMDSA



STATEMENT OF FINANCIAL POSITION

ASSETS

CURRENT ASSETS	PREPARED FROM DATA IN AUDITED ANNUAL REPORT	
Cash and cash equivalents		\$44,586.00
Contributions receivable		\$0.00
Total Assets		<u>\$44,586.00</u>

LIABILITIES AND UNRESRICTED NET ASSETS

CURRENT LIABILITIES

Accounts payable		\$0.00
UNRESTRICTED NET ASSETS		\$44,586.00
Total liabilities and net assets		<u>\$44,586.00</u>

STATEMENT OF ACTIVITIES AND CHANGES IN NET ASSETS

SUPPORT AND REVENUE

Contributions and Grants	\$106,541.00
Programs	<u>\$ 20,033.00</u>
Total Public Support	\$126,574.00
Other Revenue	
Investment Income	<u>\$ 90.00</u>
Total Unrestricted support and revenue	\$126,664.00

EXPENSES

Program Services	\$124,044.00
Management and General Expenses	\$ 29,642.00
Fundraising Expenses	<u>\$ 8788.00</u>
Total Expenses	\$162,474.00
Unrestricted net assets at beginning of year	\$80,396.00
Unrestricted net assets at end of year	\$44,586.00



2012 Annual Report

Audited Financial Statements

Statement of Functional Expenses

	Total Expenses	Program Service Expenses	Management and General Expenses	Fundraising Expenses
Grants and other assistance to organizations and Registry	\$50,456	\$50,456		
Salaries and Wages	\$44,168	\$32,231	\$8662	\$3275
Payroll taxes	\$20,338	\$14,537	\$4346	\$1455
Accounting	\$2,500		\$2500	
Advertising and Promotion	\$966		\$966	
Occupancy	\$5,100		\$5,100	
Travel	\$6,596	\$6,561	\$35	
Conferences ,conventions, and Meetings	\$16,546	\$16,546		
Insurance	\$79		\$79	
Supplies	\$743	\$221	\$522	
Postage and Mailing	\$1044	\$595	\$449	
Telecommunications	\$1947			\$1947
Printing and Publications	\$850	\$690	\$160	
Other expenses	\$11,141	\$2207	\$6823	\$2111
Total Functional Expenses	\$162474	\$124044	\$29642	\$8788



2012 Board of Directors



Pamela Mace, RN
Executive Director
FMD patient
Pam.mace@fmdsa.org



Glenn Graham, MD, PhD
Director-At-Large



Bradley J Daar DDS
President
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Sara Bailey
Director-At-Large

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Cheryl Bailey
Vice President
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Mimi Petersen
Director-At-Large
FMD patient

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Cheryl Golden, CPA
Treasurer and FMD patient
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Chairperson
Rich.Gould@FMDSA.org



Douglas Webster
DO, FACOEP, FACEP
Director-At-Large



Kellie Smiddie, LISW-S
Director-At-Large
kelliesmiddie@fmdsa.org



2012 MEDICAL ADVISORY BOARD



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Medical Director, Non-Invasive Vascular Laboratory
Cleveland Clinic Heart and Vascular Institute
The Cleveland Clinic Foundation
Cleveland, Ohio



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The Children's Hospital of Philadelphia
and University of Pennsylvania



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Laboratory of Genetics
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Baltimore, Maryland



Santhi K. Ganesh, M.D.
Assistant Professor of Medicine
Division of Cardiovascular Medicine
University of Michigan Health System



Philip B. Gorelick, MD, MPH
John S. Garvin Professor and Head Director
Center for Stroke Research
Dept. of Neurology & Rehabilitation

University of Illinois College of Medicine Chicago, Ill



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2012 ADVISORY COUNCIL



Kim A. Eagle, MD

Albion Walter Hewlett Professor of Internal Medicine
Chief of Clinical Cardiovascular Medicine
Director and Education Lead, Cardiovascular Center
Ann Arbor, Michigan



Robert D. Kubic, MBA

Chief Operating Officer
Honigman Miller Schwartz and Cohn LLP
Detroit, Michigan



James Baranski, CEO

National Stroke Association. Member of various stroke-focused organizational advisory boards, including the Brain Attack Coalition, National Forum for Heart Disease and Stroke and the World Stroke Association



Joan M. Legraw, RN, JD, MPH

Cape Cod Research Institute
General Counsel & Consultant for Ethical & Regulatory Affairs
Barnstable, Massachusetts



Kay Tanner, JD Former FMDSA Board Member. Dell, Inc...Austin, Texas



2012 ANNUAL REPORT

FMDSA Giving Honor Roll

CHAMPION-\$5000

Jodi Roth
Cheryl Golden
Tracey Toto Fundraiser
Manchester Family Dental
Debra Koehler
Molly Clark & Kay Tanner
Dell Direct Giving Campaign
Andrea Spears
Cleveland Clinic

Hero Level - \$1,000

Johnson & Johnson
Martha Clark
Terri Jo Wetzel
Allina Heath System
Angeline Young
Greenville Hospital
Jeffrey Olin, DO, FACP, FACC
University of Michigan
University of Virginia
Wade and Yvette Ragas

Benefactor Level - \$500

Capital One
Denise Laman
Douglas & Mariruth Webster
Pamela Mace & Robert Kubic
Peace Unique
Rochelle DesRochers-Moreau
Anne Stapsy
Bernard Ray Koogler
Bonnie E. Rhinehart
Carolyn Cusick
Clayton Foundation
Julie Kasper
Linda Mary Koelz
Louise Tilzer
Michael D Short

Patron Level - \$250

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Maureen Womack
Patricia Brock
Carol Rogers
Thomas F Paolozzi III
Cherylann Bailey
Richard and Susan Gould
Karen Schiff
Mary Brodmerkel
Diane Dumit
Antonia Keg
Alice Faye Hubbard
Brent Johnson
Kellie Smiddie
Karen Hartman
National Organization for Rare Disorders
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Kathleen Martin
Pauline Standley
Diana Clark
Elizabeth Pancoe
Joan White
Kelly Connelly RN
Kelly Saunders
Mary Wright Baylor
Petersen Plumbing Services
Samuel W and Anne M Oliver
Tracy VanDenBerg



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