



2011 Annual Report

Letter from the President

Dear Friends,

Nine years already....where do I start? As your President, first I am very honored to represent the FMDSA this year. Since volunteering in 2004 (when I was first diagnosed and searching for any information I could find on this rare disease), FMDSA has taken me on quite a journey. I remember feeling helpless and alone...that is when I found the FMDSA web site and met our (now) Executive Director, Pam Mace. I immediately found a friend and a sister...someone who shared my deepest fears and greatest hopes, and I knew at that moment that I wanted to be part of this organization to help raise awareness of our disease and hopefully one day find a cause/cure for FMD.

It is a long road when you embark into research, but as with anything worthwhile, it takes time and dedication. Thanks to the dedication of the FMDSA Board of Directors, Advisory Board and Physicians and especially to the members who donate their time to help raise money to fund our programs including the Patient Registry and office operations, our uphill journey has been quite a learning experience with amazing results. Yes, we still have a long way to go, but let's look at our accomplishments this past year.

- The 4th Annual FMDSA Conference was held May 13-14, 2011 at the Doubletree Hotel in Downtown Cleveland. Over 60% of those who attended were new to FMDSA.
- The fifth HEGP (Hopital Europeen G Pompidou) meeting on FMD was held on October 21st in Paris, France; Dr. Jeff Olin and Pam Mace were in attendance.
- The FMDSA represented at the NORD conference in Washington DC, October 11-13th.
- Nearly 150 patients with FMD have been recruited in our Biorepository project between the Cleveland Clinic Foundation and Mayo Clinic by July 2011.

- 2011 Conferences included the International Stroke, American Cardiology Conference (ACC), the Society of Vascular Medicine and the 1st annual US Conference on Rare Diseases and Orphan Products. Fibromuscular Dysplasia Registry results were presented at the ISET Meeting in Miami by Dr. Jeffrey Olin.
- The FMDSA has had increased media coverage over the past year, as well as joining the Social Media by launching our FMDSA Facebook and Inspire FMD Group Support pages. This year we also launched our first Patients United Fundraising Campaign.

At the end of the day, it's all about achieving our goals and fulfilling our Mission. Thank you to the FMDSA Boards, Physicians, and all of you, the members who freely devote your time to volunteer for the FMDSA. Without your help we could not have come this far, and with your continued support we can continue this journey! I recently read a quote that said "Snowflakes are one of nature's most fragile things, but just look at what they can do when they stick together." Together we can achieve our goals! I look forward to "sticking" with you to continue to grow the future of the FMDSA.

Thank you,

Cheryl Bailey,

President - FMDSA



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Audited Financial Statements

Statement of Financial Position

ASSETS	2011	2010
CURRENT ASSETS		
Cash and cash equivalents	\$ 80,396	\$ 116,045
Contributions receivable	2,885	2,558
Total Assets	<u>\$ 83,281</u>	<u>\$ 118,603</u>
LIABILITIES AND UNRESTRICTED NET ASSETS		
CURRENT LIABILITIES		
Accounts payable	\$ 11,184	\$ 31,156
UNRESTRICTED NET ASSETS	72,097	87,447
Total liabilities and net assets	<u>\$ 83,281</u>	<u>118,603</u>

Statement of Activities and Changes in Net Assets

	2011	2010
SUPPORT AND REVENUE		
Contributions and grants	\$ 124,093	\$ 126,088
Programs	22,199	4,895
Total public support	146,292	130,983
Other revenue		
Investment income	201	403
Total unrestricted support and revenue	146,493	131,386
Expenses		
Program services	115,906	115,552
Fundraising	6,452	6,334
General and administrative	39,485	35,862
Total expenses	161,843	157,748
Change in unrestricted net assets	(15,350)	(26,362)
Unrestricted net assets at beginning of year	87,447	113,809
Unrestricted net assets at end of year	<u>\$ 72,097</u>	<u>\$ 87,447</u>



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Statement of Functional Expenses

	Program Services	Fundraising	General and Administrative	Total
Patient registry	\$ 28,311	\$ -	\$ -	\$ 28,311
Grant erasmus	5,000	-	-	5,000
Fundraising fees	-	466	-	466
Contracted employees	250	-	-	250
Salaries and payroll taxes	53,976	5,438	16,378	75,792
Supplies	2,075	480	774	3,329
Telecommunications	13	-	2,628	2,641
Information technology	5,889	-	3,679	9,568
Insurance	-	-	1,566	1,566
Postage and mailing services	636	49	780	1,465
Printing and copying	777	-	-	777
Facility and equipment expenses	36	-	4,505	4,541
Travel and meetings	18,943	-	-	18,943
Miscellaneous	-	-	330	330
Business registration fees	-	19	8,845	8,864
	<u>115,906</u>	<u>6,452</u>	<u>39,485</u>	<u>161,843</u>

Statement of Cash Flows

	2011	2010
CASH FLOW FROM OPERATING ACTIVITIES		
Change in unrestricted net assets	\$ (15,350)	\$ (26,362)
Adjustments to reconcile change in net assets to net cash provided by (used in) operating activities:		
Contributions receivable	(327)	929
Accounts payable	<u>(19,972)</u>	<u>28,957</u>
Net cash provided by (used in) operating activities	<u>(35,649)</u>	<u>3,524</u>
Net increase (decrease) in cash and cash equivalents	(35,649)	3,524
Cash and cash equivalents - beginning of year	<u>116,045</u>	<u>112,521</u>
Cash and cash equivalents - end of year	<u>\$ 80,396</u>	<u>\$ 116,045</u>



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FMDSA Board of Directors



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



Richard Gould
Chairperson
rich.gould@fmdsa.org



Cheryl Bailey
Vice President and FMD patient
cheryl.bailey@fmdsa.org



Cheryl Golden, CPA
Treasurer and FMD patient
cheryl.golden@fmdsa.org



Kay Tanner, JD
Secretary
kay.tanner@fmdsa.org



Glenn Graham, MD, PhD
Director-At-Large



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



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

FMDSA Medical Advisory Board



Jeffrey W. Olin, DO, FACP, FACC
Board Chairman
Professor of Medicine
Director, Vascular Medicine
Zena and Michael A. Wiener Cardiovascular Institute
Mount Sinai School of Medicine
New York, New York



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



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



Warren D. Lo, MD
Associate Professor of Pediatrics
Associate Professor of Neurology
Nationwide Children's Hospital
Columbus, Ohio



Nazli McDonnell, MD, PhD
Medical Genetics
Laboratory of Genetics
National Institute on Aging
National Institutes of Health
Baltimore, Maryland



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, Illinois

FMDSA Business 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



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FMDSA Giving Honor Roll

Champion—\$5,000

Cheryl Golden
Jodi Roth
Molly Clark & Kay Tanner
Tracey Toto

Hero Level - \$1,000

Busch & Hutchison, PLLC
Capital One
Martha Clark
Betty Conway
Manchester Family Dental
Lisa Foster & Geno Likins
Suzann H. Murphy
Mimi Petersen
Dorine Catherine Secrest
Pete & Joyce Streelman
Maureen Womack
Angeline Young

Benefactor Level - \$500

Kara Arthur
Eve Brooks
Carolyn Cusick
Karen Hartman
Johnson & Johnson
Robert Kubic
Pamela Mace
Jeffrey Olin, DO, FACP, FACC
Peace Unique
Kellie Smiddie
Bonnie E. Rhinehart
Ron Vinder
Douglas & Mariruth Webster
Nikki Esserman Wolpe

Patron Level - \$250

Liz Augusta RN
Phyllis Labatut Baker
Bonita Benefield
Robert and Brenda Brodrick
Patricia Brock
Chesser Financial
Lisa Curley

Patron Level - \$250 (Cont.)

Fifth Third Bank
Google
Richard and Susan Gould
Kadi Hodges
Alice Faye Hubbard
Linda Mary Koelz
Bernard Ray Koogler
Donna Lanza
Nicolette & Teo Maus
Bonnie McClinton
Nicole McCombie
Mike Miller Auto Park
Elizabeth Pancoe
Nancy Pook
PJ Quinn
Stacey Rosenberg
Karen Schiff
Liz Schimmel
Bronte Sterk
Gina Summers
Jason Wrone
Joan White

FMDSA Contact Information



FMDSA

Fibromuscular Dysplasia
Society of America

FMDSA

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