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 support 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**

<table>
<thead>
<tr>
<th>Description</th>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cash and cash equivalents</td>
<td>$44,586.00</td>
</tr>
<tr>
<td>Contributions receivable</td>
<td>$0.00</td>
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</tbody>
</table>

**Total Assets**

<table>
<thead>
<tr>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>$44,586.00</td>
</tr>
</tbody>
</table>

#### LIABILITIES AND UNRESTRICTED NET ASSETS

**CURRENT LIABILITIES**

<table>
<thead>
<tr>
<th>Description</th>
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<tr>
<td>Accounts payable</td>
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**UNRESTRICTED NET ASSETS**

<table>
<thead>
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<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>$44,586.00</td>
</tr>
</tbody>
</table>

**Total liabilities and net assets**

<table>
<thead>
<tr>
<th>Amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>$44,586.00</td>
</tr>
</tbody>
</table>

### STATEMENT OF ACTIVITIES AND CHANGES IN NET ASSETS

#### SUPPORT AND REVENUE

<table>
<thead>
<tr>
<th>Description</th>
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<tbody>
<tr>
<td>Contributions and Grants</td>
<td>$106,541.00</td>
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<tr>
<td>Programs</td>
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**Total Public Support**

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<th>Amount</th>
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<tbody>
<tr>
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**Other Revenue**

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</thead>
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<td>Investment Income</td>
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**Total Unrestricted support and revenue**

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<thead>
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<tbody>
<tr>
<td>$126,664.00</td>
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#### EXPENSES

<table>
<thead>
<tr>
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<tbody>
<tr>
<td>Program Services</td>
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<tr>
<td>Management and General Expenses</td>
<td>$29,642.00</td>
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<tr>
<td>Fundraising Expenses</td>
<td>$8788.00</td>
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**Total Expenses**

<table>
<thead>
<tr>
<th>Amount</th>
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<tbody>
<tr>
<td>$162,474.00</td>
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**Unrestricted net assets at beginning of year**

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<td>$80,396.00</td>
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**Unrestricted net assets at end of year**

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<tr>
<td>$44,586.00</td>
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## Audited Financial Statements

### Statement of Functional Expenses

<table>
<thead>
<tr>
<th></th>
<th>Total Expenses</th>
<th>Program Service Expenses</th>
<th>Management and General Expenses</th>
<th>Fundraising Expenses</th>
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</thead>
<tbody>
<tr>
<td>Grants and other assistance to organizations and Registry</td>
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<tr>
<td>Salaries and Wages</td>
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<td>$32,231</td>
<td>$8662</td>
<td>$3275</td>
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<tr>
<td>Payroll taxes</td>
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<td>Accounting</td>
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<td>Advertising and Promotion</td>
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<td>$966</td>
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<td>Occupancy</td>
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<td>$5,100</td>
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<td>Travel</td>
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<td>$6,561</td>
<td>$35</td>
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<tr>
<td>Conferences, conventions, and Meetings</td>
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<td>$16,546</td>
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<tr>
<td>Insurance</td>
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<td>Supplies</td>
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<td>Postage and Mailing</td>
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<tr>
<td>Telecommunications</td>
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<td>$1947</td>
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<tr>
<td>Printing and Publications</td>
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<tr>
<td>Other expenses</td>
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<td>$2207</td>
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<tr>
<td>Total Functional Expenses</td>
<td>$162474</td>
<td>$124044</td>
<td>$29642</td>
<td>$8788</td>
</tr>
</tbody>
</table>
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
Brad.daar@fmdsa.org

Sara Bailey
Director-At-Large
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Cheryl Bailey
Vice President
FMD patient
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Mimi Petersen
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FMD patient
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Cheryl Golden, CPA
Treasurer and FMD patient
Cheryl.golden@fmdsa.org

Richard Gould
Chairperson
Rich.Gould@FMDSA.org

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

Kellie Smiddle, LISW-S
Director-At-Large
kelliesmiddle@fmdsa.org
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Director, Vascular Medicine
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Mount Sinai School of Medicine

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Associate Professor of Neurology
Nationwide Children's Hospital
Columbus, Ohio

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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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Assistant Professor of Pediatrics
The Children’s Hospital of Philadelphia and University of Pennsylvania

James C. Stanley, MD
Professor of Surgery
Handleman Research Professor of Vascular Surgery
University of Michigan Health System

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

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Division of Cardiovascular Medicine
University of Michigan Health System

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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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Chief of Clinical Cardiovascular Medicine
Director and Education Lead, Cardiovascular Center
Ann Arbor, Michigan

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

20325 Center Ridge Road, Suite 620
| Rocky River, OH 44116

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