



## Letter from the President

Prior to writing this year's letter, I looked back on previous letters for inspiration. I found that inspiration in the letter I wrote for the first annual report in 2003.

*"Susan and I are the parents of a young daughter who was diagnosed with Fibromuscular Dysplasia (FMD) at age 5. We quickly learned that it was very unusual for someone so young to be diagnosed.*

*We asked our doctors many questions about FMD; is this life threatening; what is our daughter's prognosis; what causes this disease? To all of our questions, we received nearly the same answer, we don't know. My wife and I were desperate for answers, but we soon realized that these answers don't exist yet, that FMD has no known etiology, and information on FMD is difficult to find."*

The letter brought back the memories of how helpless Susan and I felt the day Alayna was diagnosed with FMD as well as the struggles we had in finding a treatment program. At that time, there were few physicians that had experience with FMD and there was very little information available for the layperson.

I imagine how different our experience would have been if there had been an organization like FMDSA there to help us.

Instead of searching the Internet and weeding through complicated medical text, amateur theories and student papers, we would have found the FMDSA website. The website would have immediately answered the majority of our questions. Our physicians would have likely already heard about FMD due to the many medical conferences FMDSA attended, the many Grand Rounds by our Medical Advisory Board, and the many publications and airtime FMDSA has garnered through the media. Even if our physician did not have any prior experience with FMD, he/she would also search the web and immediately find FMDSA where the latest medical papers on FMD are available as well as contact information to reach out for additional help.

Finally, I would take comfort in the fact that there is active research into FMD and that my participation can help drive further research to find better diagnostic and treatment options for FMD.

This has been quite a journey and I am deeply grateful to the many volunteers, physicians, and donors that have helped FMDSA make a difference in the lives of those afflicted with FMD. Our success is due to the sheer commitment and determination of others who share in our mission.

All of us involved with FMDSA are inspired to participate for one reason or another. For many of us, it's for a loved one. My daughter Alayna (now 15 years old) is my inspiration.

She's receiving the best medical care and because of FMDSA, she's learned more about her disease than she could have possibly known 10 years ago and all of this helps her to live the healthiest life possible.

We have come a long way, but we still have a long way to go. The ultimate goal is to find a cure for FMD. In 2010, we shifted our primary focus towards research. In the report to follow, you will see that we invested over half of our 2010 program budget into research (FMD International Patient Registry and the Genetic research at Erasmus MC in Rotterdam). With everyone's continued support, we will continue to make research our number one priority.

My heartfelt thanks to all that help us in the fight against FMD. I take comfort in the fact that it is easier than ever for those diagnosed with FMD to find the support and information we so desperately needed when Alayna was first diagnosed. I look forward to continuing the journey together and discovering a healthier, brighter future for all.

Sincerely,

Richard E. Gould, Founder / Chairperson



# 2010 Annual Report

## FMDSA Accomplishments

### Research and Treatment

- *First FMDSA Funded Genetic Study*

FMDSA took our first foray into directly funding research activity in 2010. This study will help us answer questions about FMD and may help us identify genes that play a part in FMD. The study results are expected to be available in 2011.

- *Patient Registry grows to be the Largest Database of FMD Patient Information*

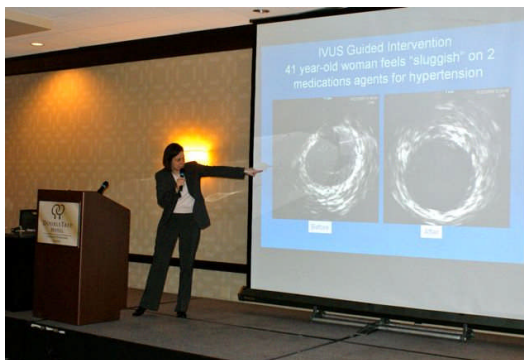
The patient registry has been developed in cooperation with the University of Michigan Health System's Michigan Cardiovascular Outcomes Research and Reporting Program (M-CORRP). The purpose of the registry is to collect data on FMD patients seeking treatment at one of eight medical centers in the United States. Until now, minimal research has been initiated on FMD. The database grew in 2010 to be the largest repository of information on FMD patients to date. At about 400 patients, this database grew to a size that is significant to researchers. The registry will help us develop an incredible database of information with respect to the FMD population, genetics, treatment outcomes, and prognosis. Collected data will be made available to the research community for analysis. The patient registry will be the foundation for future research efforts; making its success of the utmost importance to our organization.

The first presentation of the study data is planned to be released at the American College of Cardiology (ACC) in April, 2011. The database is garnering interest from the research community and we expect increasing study of data.

### Education

- *Third Annual Conference*

The annual conference has become one of the most important services we provide to our membership. It is an opportunity for members to learn the latest on FMD treatment and research, for members to build relationships with other FMD patients, and for FMD board members and medical advisory board members to collaborate. We have been fortunate to have great sponsors that help us offset the expenses of the conference. In 2010, the annual conference was a tenth of our working time and expense budget.



*Dr. Heather Gornik and Dr. Iftikhar Kullo presenting at the Annual Conference.*

- *Physician Education Program*

This program is a combination of attending medical conferences and presenting training classes within hospital environments. This program is a major focus of FMDSA and has been an avenue to educate thousands of medical professionals. The end result is a greater awareness of Fibromuscular Dysplasia within the medical



# 2010 Annual Report

## FMDSA Accomplishments (continued)

- *Website Education*

One of our most important charters is to educate patients and the families about FMD. Our website has grown exponentially since inception. FMDSA is the premier source of FMD information for the layperson and an excellent place for physicians to easily find medical papers. Our Honcode certification is a stamp of approval that verifies we are an unbiased organization providing only medical certified information. Our website serves more than 100,000 page requests per month.

### Awareness

- *Media*

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 between patient and physician. GAP also includes our work to get represented within the media. 2010 was another successful year for FMDSA in the media. Articles were published in Fitness Magazine, Bottom Line Health, and Cardiac Consult.

### Support

- *Patient Support*

Patient support is becoming a bigger part of our responsibility. We spent 27% of our paid work time assisting FMD patients and the families in 2010. We will be expanding this program in 2011 to incorporate regional volunteer support networks that will be moderated by qualified volunteers in each region. This will ultimately provide a greater level of support for patients by providing more opportunities for patients to engage together regionally.

- *FMD Clinics*

FMD Clinics are a major breakthrough in treating FMD patients. Each patient requires a full team of doctors including vascular specialists, nephrologists, neurologists, etc. The concept of the clinic is to provide a streamlined process for patients to enable a full check up in a single day at one of the clinics. This is a vast improvement to the multiple appointments a patient would typically need to manage.

Participating Institutions:

- Cleveland Clinic Foundation
- University of Illinois
- University of Michigan
- Massachusetts General Hospital
- University of California Davis





# 2010 Annual Report

## Financial Summary

### 2010 Fundraising

FMDSA earned \$128,786, which is \$17,614 more than our 2010 revenue goal of \$111,172. We owe a great deal of thanks to the board of VIVA (Vascular Interventional Advances) Physicians for their \$50,000 contribution at the VIVA conference in October. Most of our revenue in 2010 (\$123,488) came from direct donor donations. Other revenue earned was for registration fees to the annual conference (\$4,895) and interest on our money market account (\$403).

### 2010 Expenses

FMDSA was \$21,850 under budget. We are always very focused on squeezing every bit of value we can from each dollar donated, and we did an exceptional job in 2010. We were able to renegotiate our contract with University of Michigan for the International Patient Registry (saving ~ \$8,000) as well as reduce planned staffing costs (saving ~\$9,000) and general management costs (saving ~\$6,000).

Although not a requirement for nonprofits of our size, we are tracking our functional expenses in an effort to consistently improve the percentage of donated dollars that go directly towards FMDSA programs and not towards management and fundraising costs. We do keep detailed track of how our compensated time is spent (see Time Allocation on page 3) as well as our functional expenses (see Functional Expenses on page 3). In 2010, we spent 73% of our time and 74% of our expenses on program related activities. A couple of important points:

- We spend most of our time helping patients, followed by educating the medical community, and educating patients at the Annual Member Conference.
- We are very focused on research. We invested \$59,666 on the Patient Registry and Erasmus MC Genetic Study. This is more than half of our program expense budget.

### 2010 Balance Sheet

By exceeding both our revenue and expense plans for 2010, we finished the year with about \$40,000 more in assets than we had planned. This is very important for us to maintain a healthy cash flow. As you will notice, we spent about \$30,000 more than we earned in 2010. This was planned into our long term cash flow targets. If you look at the 4 year cash flow plan at the bottom of the "Financial Statements" page, our goal over the next four years is to match earnings to spending very closely. In order to maintain our cash flow health, it is imperative that we raise at least \$150,000 in 2011.



# 2010 Annual Report

## Financial Statements

### Balance Sheet

#### ASSETS

##### Current Assets

Checking	\$7,977.15
Money Market	\$108,067.91
<b>Total Current Assets</b>	<b>\$116,045.06</b>

#### LIABILITIES

<b>Total Liabilities</b>	<b>(\$30,000.00)</b>
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#### EQUITY

Opening Balance Equity	\$115,275.78
Net Income	\$769.28
<b>Total Equity</b>	<b>\$116,045.06</b>

<b>TOTAL NET ASSETS</b>	<b>\$86,045.06</b>
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### Income Statement

#### REVENUE

Contributions	\$123,488
Program Service Revenue	\$4,895
Interest	\$403
<b>Total Revenue</b>	<b>\$128,786</b>

#### EXPENSES

Grants	\$52,536
Salaries	\$60,282
Professional Fees	\$8,768
Office Rent	\$4,949
Print Publications	\$1,974
Other Expenses	\$29,507
<b>Total Expenses</b>	<b>\$158,016</b>

<b>TOTAL NET REVENUE</b>	<b>(\$29,230.00)</b>
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### Time Allocation

#### PROGRAM

Website Education	2%
Grassroots Awareness Program	2%
Physician Education Program	15%
Patient Registry	4%
Annual Member Conference	10%
Research	6%
Public Awareness	6%
Patient Support	27%
<b>Total Program</b>	<b>73%</b>

<b>MANAGEMENT</b>	<b>19%</b>
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<b>FUNDRAISING</b>	<b>8%</b>
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<b>TOTAL</b>	<b>100.0%</b>
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### Functional Expenses

#### PROGRAM

Website Education	\$1,408	1%
Grassroots Awareness Program	\$2,564	2%
Physician Education Program	\$13,802	9%
Patient Registry	\$45,341	29%
Annual Member Conference	\$16,527	10%
Research	\$14,325	9%
Public Awareness	\$4,908	3%
Patient Support	\$18,013	11%
<b>Total Program</b>	<b>\$116,887</b>	<b>74%</b>

<b>MANAGEMENT</b>	<b>\$34,657.44</b>	<b>22%</b>
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<b>FUNDRAISING</b>	<b>\$6,471.66</b>	<b>4%</b>
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<b>TOTAL FUNCTIONAL EXPENSES</b>	<b>\$158,016.48</b>	<b>100%</b>
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### 4 Year Cash Flow Planning

Year	Expenses	Revenue	Net Assets
BOY 2011			\$86,045
EOY 2011	\$158,016	\$150,000	\$78,029
EOY 2012	\$184,240	\$180,000	\$73,789
EOY 2013	\$223,621	\$220,000	\$70,168
EOY 2014	\$267,416	\$270,000	\$72,752



# 2010 Annual Report

## FMDSA Board of Directors



**Pamela Mace, RN**  
Executive Director  
FMD patient  
[pam.mace@fmdsa.org](mailto:pam.mace@fmdsa.org)



**Richard Gould**  
Chairperson  
[rich.gould@fmdsa.org](mailto:rich.gould@fmdsa.org)



**Cheryl Bailey**  
Vice President and FMD patient  
[cheryl.bailey@fmdsa.org](mailto:cheryl.bailey@fmdsa.org)



**Cheryl Golden, CPA**  
Treasurer and FMD patient  
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**Kay Tanner, JD**  
Secretary  
[kay.tanner@fmdsa.org](mailto:kay.tanner@fmdsa.org)



**Glenn Graham, MD, PhD**  
Director-At-Large



**Kellie Smiddie, LISW-S**  
Director-At-Large  
[kellie.smiddie@fmdsa.org](mailto: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



# 2010 Annual Report

## FMDSA Giving Honor Roll

### Champion—\$5,000

VIVA Physicians  
Cleveland Clinic  
Cheryl Golden  
Manchester Family Dental  
Jodi Roth  
Andrea Spears

### Hero Level - \$1,000

Busch & Hutchison, PLLC  
Michael Gordon Davern  
Massachusetts General  
Martha Clark  
Molly Clark and Kay Tanner  
Mark Herron  
Dr. Jeff Jazwa  
Peninsula Neurological Assoc  
Liz Schimmel  
Austerio H Sousa  
Tracey Toto  
Kari and Dr. Michael Ulrich  
University of California  
Nikki Esserman Wolpe

### Benefactor Level - \$500

Millcent Allen  
Jay Canell  
Neil Canell  
Carolyn Cusick  
Gay Leah Hardee / Tana Busch  
Honigman Miller Schwartz & Cohn LLP  
Maria Elena Jaramillo  
Johnson & Johnson  
Robert Kubic  
Pamela Mace  
Bonnie McClinton  
Cindy Musoff  
Mimi Petersen  
Bari Seiden  
Gerri Sommers  
Anne Stapsy  
Swinnett Hospital Systems  
Universal Solutions, Inc.

### Patron Level - \$250

Alan Adams  
Karen Andersen  
Liz Augusta RN  
Patricia Brock  
Mary Brodmerkel  
Richard and Karen Doll  
Jack Fleig  
Lisa Foster  
Leslie Goldfarb  
Antonia Keg  
C. Hope Poindexter  
Bonnie E. Rhinehart  
Stacey Rosenberg  
Linda Shattuck  
Kellie Smiddie  
Tracy VanDenBerg  
Joan White  
Andrew and Rosalee Zeniou

## FMDSA Contact Information



# FMDSA

Fibromuscular Dysplasia  
Society of America

### FMDSA

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