



## Letter from the President

*“Faith is taking the first step, even when you don’t see the whole staircase.”*

*- Martin Luther King Jr.*

Dear Members,

We have come a long way in less than three years and I am pleased to say that in 2005 we made some big leaps in education and awareness of FMD. Through our new Grassroots Awareness Program, Physician Education Program, and Public Awareness Initiatives we brought more awareness to this disease in the last year than any other time in history. We are making a difference! Here are some of the 2005 highlights:

- We educated (face-to-face) more than a thousand medical practitioners at the medical conferences we attended.
- Website visitors grew to more than 1,500 per month and the primary page they download is the “About FMD” page.
- FMD information and links to our website can now be found at other related websites like the National Stroke Association and the American Association of Kidney Patients.

Our success is due to the many people that freely give their time and talent to our cause. I want everyone to know how incredibly proud I am of our board, our medical advisors, our volunteers, and our members. With your help, we will continue to take more steps up the staircase until we have found the answers every FMD patient needs to live a long and care-free life.

Thank you,

Richard E. Gould  
President, 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.

## Table of Contents

<i>Mission Statement</i>	1
<i>Letter from President</i>	1
<i>2005 Accomplishments</i>	2
<i>2005 Financials</i>	3
<i>Board of Directors</i>	4
<i>Heroes and Benefactors</i>	4

## 2005 Accomplishments

### Medical Advisory Board

In 2005, the FMDSA added two members to our Medical Advisory Board. Kevin E. Meyers, MD from The Children's Hospital of Philadelphia and Nazli McDonnel, M.D., Ph.D. from the National Institute on Aging/National Institutes of Health. Both members bring a wealth of experience and have already made contributions to the organization. Dr. Meyers treats a number of children with FMD and is very interested in developing CHOP into a center of excellence for hypertension. He has been very active in helping us develop educational materials for physicians. Dr. McDonnel is a medical research scientist specializing in genetics. She is currently conducting a study on hereditary disorders of connective tissue in which a number of FMDSA members are participating.

### Launched Grassroots Awareness Program (GAP)

We developed the Grassroots Awareness Program (GAP) to educate the healthcare community about FMD. This program provides FMDSA volunteers with GAP packets that include our brochure, an FMD Facts pamphlet, a comprehensive medical article written for physicians, FMDSA pens, and FMDSA post-it notes. By distributing these packages face-to-face, we are able to ensure that our information is reviewed by the physician. We have also been distributing these packets to new FMD patients to improve communication between that patient and their medical team.

### Launched Physician Education Program

In 2005, we attended three conferences including two National Stroke Association regional meetings and the annual American Society of Nephrology meeting. We not only educated more than a thousand healthcare professionals, but also built a number of key relationships in the medical community.

Another focus of this program will be continuing education for healthcare professionals. We developed a "For Physicians" section on our website that provides educational materials including a PowerPoint presentation developed by Dr. Kevin Meyers (Medical Advisory Board) with assistance from FMDSA volunteer Cheryl Golden. The materials provide the latest information on diagnosis and treatment of FMD. We have received great feedback from the medical community and will continue to grow this section of our website.

### Research

Dr. Nazli McDonnel is conducting a study at the National Institute of Aging to further define the overlap of FMD with other hereditary connective tissue disorders. The FMDSA has been notifying FMD patients about the study, thus providing them with the opportunity to participate in this critical research. The study is currently underway and more than 50 FMD patients have enrolled.

### Bracelet Program

The FMDSA launched a bracelet program in 2005 to help build awareness of FMD and to build a sense of unity between FMD patients. The bracelet was designed specifically for the FMDSA by jewelry designer, Katie Janoch. We distributed more than 135 bracelets in 2005 at a net cost of \$19.98 to the organization.

### National Organization for Rare Disorders (NORD) Associate Membership

The FMDSA was accepted as an Associate Member of NORD. The National Organization for Rare Disorders (NORD), a 501(c)3 organization, is a unique federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them. NORD is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and service. NORD has strict governance requirements to be recognized as a member. We thank NORD for giving us guidance and helping us establish a strong foundation for our organization.

## 2005 Accomplishments

### Online Education

We have received many thanks this past year from new patients looking for information on FMD. In addition to the frequently asked questions information we posted on our website last year, we added a downloadable FMD Facts Brochure developed by Dr. Susan Begelman with assistance from board member Marie Yeh. All of the information posted on our website follows guidelines set by Health On the Net Foundation.

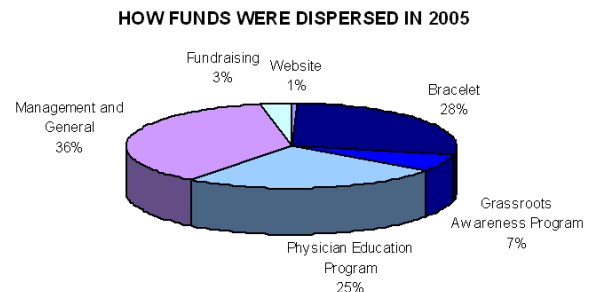
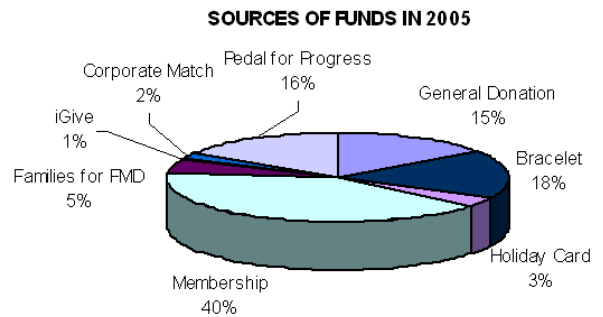
Our website is also easier to find. We consistently rank in the top 5 on major search engines like Google, Yahoo, and MSN. Our new programs in combination with our improved search engine rankings has steadily increased traffic to our website. In December, we had 1,666 visits to our website (average of 53 visits per day) compared to just 857 visits this past May.

### Public Awareness Initiative

We have been successful in distributing information about FMD to the public. Board member, Pam Mace gave our first interview on KFHX radio in Phoenix, AZ this past November. KFHX broadcasts via the Internet as well as locally on 1620AM. We have also been successful in getting web links and FMD information posted to other related websites like the National Stroke Association, the American Association of Kidney Patients, thekidney.org, National Women's Health Resource Center, and Kinetic Muscles.

## 2005 Financials

	2005	2004	2003
<b>REVENUE SUPPORT</b>			
General Donation	\$4,192.00	\$36,602.10	\$5,045.87
Bracelet	\$5,087.00	\$0.00	\$0.00
Holiday Card	\$867.50	\$0.00	\$0.00
Membership	\$11,523.74	\$15,867.38	\$2,183.95
Families for FMD	\$1,353.94	\$0.00	\$0.00
iGive	\$167.76	\$0.00	\$0.00
Corporate Match	\$500.00	\$75.00	\$0.00
Pedal for Progress	\$4,525.45	\$6,596.31	\$0.00
<b>Total Revenue and Support</b>	<b>\$28,217.39</b>	<b>\$59,140.79</b>	<b>\$7,229.82</b>
<b>EXPENSES</b>			
<i>Program Services</i>			
Website	\$99.00	\$268.95	\$494.59
Bracelet	\$5,106.98	\$0.00	\$0.00
Grassroots Awareness Program	\$1,235.19	\$0.00	\$0.00
Physician Education Program	\$4,609.77	\$0.00	\$0.00
<b>Total Program Services</b>	<b>\$11,050.94</b>	<b>\$268.95</b>	<b>\$494.59</b>
<i>Supporting Services</i>			
Management and General	\$6,757.06	\$1,150.71	\$1,699.81
Fundraising	\$540.00	\$347.22	\$0.00
<b>Total Supporting Services</b>	<b>\$7,297.06</b>	<b>\$1,497.93</b>	<b>\$1,699.81</b>
<b>Total Expenses</b>	<b>\$18,348.00</b>	<b>\$1,766.88</b>	<b>\$2,194.40</b>
<b>Total Net Revenue</b>	<b>\$9,869.39</b>	<b>\$57,373.91</b>	<b>\$5,035.42</b>
<b>Total Cash Assets as of 12/31/2005</b>	<b>\$72,278.72</b>		



## 2005 Board of Directors and Medical Advisory Board

### FMDSA Board of Directors

**Richard Gould**  
Chairperson

**Marie Yeh, MEd**  
Vice Chairperson

**Susan W. Gould**  
Secretary

**Michelle Moran**  
Treasurer

**Pamela Mace**  
Director-at-Large

**Ruth Love**  
Director-at-Large

### FMDSA Medical Advisory Board

**Susan M. Begelman, M.D., R.V.T.**  
Chairperson Medical Advisory Board  
Medical Director, Noninvasive Cardiovascular Laboratory  
Staff Physician, Department of Cardiovascular Medicine  
Cleveland Clinic

**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

**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

## FMDSA Heroes and Benefactors

### Hero Level of Giving \$1,000

Cheryl Golden  
Richard and Susan Gould  
Andrew and Deborah Madoff  
Marvin and Sondra Wiener

### Benefactor Level of Giving \$500

Amy Fisher  
Lehman Brothers (Matching Gift)  
Clifford and Dorcas Mace  
Mimi Petersen  
Peter and Jodi Roth  
Charles and Carolyn Wiener



**FMDSA**  
**P.O. Box 999**  
**Hudson, Ohio 44236-0999**