



FMDSA
The Fibromuscular Dysplasia
Society of America



FMDSA 2008 Annual Report

Thanks to the many volunteers and donors that support the FMDSA, we had another exciting and successful year.

The International FMD Patient Registry was our most important project in 2008. Dr. Jeffrey Olin has been heading a project with the Regents of the University of Michigan on behalf of MCORRP (Michigan Cardiovascular Outcomes Research and Reporting Program) to build the first registry of FMD patients. The Patient Registry will help us develop an incredible database of information that will help us understand FMD population, genetics, treatment outcomes, and prognosis. The collected data will then be made available to the research community for research analysis. A registry of this quality will not only provide a critical base of information, but will also spur new interest in FMD research. The initial launch will include nine institutions from around the world. The registry will go into production during the first quarter of 2009.

On June 21, 2008, the FMDSA held its first annual members conference in Westlake, Ohio. The conference was attended by more than 100 participants from every region of the United States. This was the first time in history where FMD patients and FMD experts were together in the same room educating one another. Key speakers for the event included Dr. Jeffrey Olin, Dr. Nazli McDonnell, and Dr. Michael Ulrich. The meeting also included a panel discussion with question and answer from the audience. The event also gave FMD patients an opportunity to meet and share experiences with other FMD patients. After the meeting, Dr. McDonnell had an opportunity to collect saliva samples from most of the FMD patients for DNA analysis.

In 2008, we attended a number of conferences including: the International Stroke Conference in New Orleans; the American College of Cardiology Conference in Chicago; and the Society of Vascular Medicine Annual Meeting in Minneapolis, MN. The purpose of these meetings are to educate the medical community about FMD and to build partnerships within the medical community to advance our goals.

Our website continues to grow and is the primary source of FMD information for patients. We owe a great deal of thanks to Rochelle DesRochers-Moreau. Rochelle is a professional web designer and she volunteered to redesign our website. Our new site is much easier to navigate and more aesthetically pleasing.

We welcome approximately 3,000 unique visitors to our website each month. In 2008, we added a "Patient Stories" section to our website that helps patients with FMD share their experiences. This is now the most visited page on our website. The other top visited pages on our website are educational materials include: "FMD Fact Sheet", "What is FMD", "Recognizing and Managing Fibromuscular Dysplasia" by Dr. Jeffrey Olin, and "Fibromuscular Dysplasia PowerPoint for Medical Professionals". All of the information posted on our website follows guidelines set by Health On the Net Foundation to ensure our educational information is accurate, unbiased, and timely.

Our GAP program has grown from members distributing information to physicians to more broadcast opportunities. This past summer Fibromuscular Dysplasia was the highlight story in "Keeping in Circulation", the official publication of the Vascular Disease Foundation. Cheryl Bailey wrote an article on FMD for The Atlantic County Woman in their Health & Wellness section. She also spoke on behalf of FMDSA to the Atlantic Charter Chapter of the American Business Women's Association. Dr. Michael Ulrich helped us spread awareness by speaking at Grand Rounds at Albert Lea Medical Center and at a medical school alumni event.

The FMDSA added two members to our Medical Advisory Board. Warren D. Lo, MD is an Associate Professor of Pediatrics and Neurology at the Ohio State University College of Medicine and an attending physician at Nationwide Children's Hospital in Columbus, Ohio. Dr. Lo is very interested in studying the effects of stroke in infants and children. He began the Stroke Clinic at Nationwide Children's Hospital in 2007. We also welcomed Dr. Heather Gornik, MD



of the Cleveland Clinic. She is a Staff Physician in the Robert and Suzanne Tomisch Department of Cardiovascular Medicine, Sections of Clinical Cardiology and Vascular Medicine and Medical Director of the Non-Invasive Vascular Laboratory. Dr. Gornik's clinical specialty interests include general cardiology, atherosclerosis, peripheral vascular disease, Fibromuscular Dysplasia, and vascular ultrasound.

On the business side, we officially outgrew our information systems infrastructure. We implemented a new donor management system that helped us automate much of our day-to-day work, enabled distributed processing, as well as improved security and data integrity. We also outsourced nonprofit registration in all 50 states. This enables us to fundraise in all 50 states and to automatically process online donations through our donor management system.

Financial Summary:

We also had a good year financially. We received \$68,228 in donations against our 2008 goal of \$56,000. Thank you to the many donors who supported our organization in 2008 and helped us exceed our fundraising goal.

We significantly undershot our 2008 expense plan of \$83,999. We had included \$46,500 for the International Patient Registry into our 2008 plan, but development of the registry took a little longer than expected and we did not incur any charges in 2008. Subtracting the anticipated \$46,500 expense, our expenses were in line with plan. We spent \$39,195 in 2008. Our expense plan minus the patient registry was \$38,335. Expenses in most categories were lower than previous years. As usual, we are very prudent spenders and we have been able to meet all of our program goals with minimal funds. Spending increases in 2008 included registering in all 50 states (\$5,389 in legal fees and \$1,179 in registration fees), our first full year in our office space (\$4,915), and temporary contract work to keep up with the growing business (\$2,155). You will also notice an increase in IT spending. We spent \$3,939 to implement the new donor management system. However, implementing this system saved us money in other areas including supplies, postage, and copying. The net cost of the system is closer to \$1,000.

The negative impact of the delay in the patient registry is that our program spending was lower than expected. Our goal was to increase our program to management expense ratio to 70%, but finished the year at 37%. We did spend \$14,498 on the programs previously highlighted.

We ended the year with \$145,158 in cash assets. As mentioned in the last annual report, we have been building our savings in preparation for funding the International Patient Registry. We want to have sufficient cash on hand to fully fund this project for the first couple years of operation. The registry will be our primary funding priority and the success of our other programs will depend greatly on how well we fundraise over the next few years. Our balance sheet is very simple. We have \$145,158 in cash and savings and \$0 liabilities.

We increased membership by 51% last year to more than 160 active members. In 2008, we increased membership another 87% to 318 members. It is very important for us to keep expanding our donor list and this is a very healthy sign for our organization.

In summary, the FMDSA continues to build momentum. We are making tremendous strides in learning more about FMD, educating patients and physicians, and building awareness of our disease. Our finances are stable, even in the difficult economic climate, and we are well funded for the next few years.

Thank you for helping us make all of this possible,

Richard E. Gould, Treasurer



Income Statement

Revenue and Support	2008	2007	2006	2005
Contributions and Grants	\$ 42,825	\$ 36,804	\$ 36,594	\$ 17,251
Fundraising Events	\$ 14,987	\$ -	\$ 13,087	\$ 5,879
Program Revenue	\$ 8,299	\$ -	\$ 1,666	\$ 5,087
Investment Income	\$ 2,117	\$ -	\$ -	\$ -
Total Gross Revenue	\$ 68,228	\$ 36,804	\$ 51,346	\$ 28,217
Expenses	2008	2007	2006	2005
<i>Contract Service Expenses</i>				
Fundraising Fees	\$ (314)	\$ (164)	\$ (194)	\$ (179)
Accounting Fees	\$ -	\$ -	\$ (240)	\$ -
Legal Fees	\$ (5,389)	\$ -	\$ -	\$ -
Professional Fees	\$ -	\$ -	\$ (150)	\$ (350)
Temporary Help - Cntract	\$ (2,155)	\$ -	\$ -	\$ -
<i>Nonpersonnel Expenses</i>				
Supplies ^(see Note 1)	\$ (2,171)	\$ (3,615)	\$ (2,313)	\$ (9,505)
Telecommunications	\$ (3,017)	\$ (2,211)	\$ (1,459)	\$ (821)
Web Hosting	\$ (253)	\$ -	\$ -	\$ -
Information Technology	\$ (3,939)	\$ -	\$ (288)	\$ (99)
Postage and Shipping	\$ (988)	\$ (1,329)	\$ (1,165)	\$ (1,094)
Printing and Copying	\$ (835)	\$ (1,784)	\$ (1,951)	\$ (563)
Books, Subscriptions	\$ -	\$ -	\$ (30)	\$ (129)
<i>Facility & Equipment Expenses</i>				
Rent Parking and Other Occupancy	\$ (4,915)	\$ (1,999)	\$ -	\$ -
Deprec & Amort	\$ -	\$ -	\$ -	\$ (1,270)
<i>Travel and Meetings</i>				
Travel	\$ (5,911)	\$ (7,134)	\$ (1,991)	\$ (823)
Conferences, Conventions, Meetings	\$ (6,758)	\$ (9,221)	\$ (3,645)	\$ (1,599)
<i>Other Expenses</i>				
Interest	\$ -	\$ (156)	\$ -	\$ -
Insurance	\$ (1,078)	\$ (1,158)	\$ (1,038)	\$ (1,038)
Membership Dues	\$ (50)	\$ (50)	\$ (50)	\$ (50)
Office Move	\$ -	\$ (140)	\$ -	\$ -
Outside Computer Services	\$ -	\$ -	\$ -	\$ (274)
<i>Business Expenses</i>				
Bad Debt Expense	\$ -	\$ -	\$ (21)	\$ (154)
Sales Tax	\$ -	\$ -	\$ (74)	\$ -
Taxes	\$ (1,179)	\$ (568)	\$ (227)	\$ (399)
Other	\$ (243)	\$ -	\$ -	\$ -
Total Expenses	\$ (39,195)	\$ (29,529)	\$ (14,837)	\$ (18,348)
Total Net Revenue	\$ 29,033	\$ 7,275	\$ 36,509	\$ 9,869
Total Cash Assets as of 12/31/2008	\$ 145,158	\$ 116,126	\$ 108,850	\$ 72,341

Expense Detail

Expense Categories	Total	Program	Management	Fundraising
<i>Contract Service Fees:</i>				
Fundraising fees	\$ (314)	\$ -	\$ -	\$ (314)
Legal fees	\$ (5,389)	\$ -	\$ (5,389)	\$ -
Temporary help - contract	\$ (2,155)	\$ (408)	\$ (1,748)	\$ -
<i>Nonpersonnel expenses:</i>				
Supplies	\$ (2,171)	\$ (939)	\$ (1,231)	\$ -
Telephone & telecommunications	\$ (3,017)	\$ -	\$ (3,017)	\$ -
Website	\$ (253)	\$ (253)	\$ -	\$ -
Donor Database	\$ (3,939)	\$ -	\$ (3,939)	\$ -
Postage & shipping	\$ (988)	\$ (33)	\$ (788)	\$ (168)
Printing & copying	\$ (835)	\$ (196)	\$ (159)	\$ (480)
<i>Facility & equipment expenses:</i>				
Rent, parking, other occupancy	\$ (4,915)	\$ -	\$ (4,915)	\$ -
<i>Travel & meetings expenses:</i>				
Travel	\$ (5,911)	\$ (5,911)	\$ -	\$ -
Conferences, conventions, meetings	\$ (6,758)	\$ (6,758)	\$ -	\$ -
<i>Other expenses:</i>				
Insurance - non-employee related	\$ (1,078)	\$ -	\$ (1,078)	\$ -
Membership dues - organization	\$ (50)	\$ -	\$ (50)	\$ -
<i>Business expenses:</i>				
Taxes - other	\$ (1,179)	\$ -	\$ (1,179)	\$ -
Other	\$ (243)	\$ -	\$ (243)	\$ -
Total expenses	\$ (39,195)	\$ (14,498)	\$ (23,735)	\$ (962)

Program Detail

Program Categories	Actual	Plan
Website Education	\$ (253)	\$ (250)
Grassroots Awareness Program	\$ (776)	\$ (1,000)
Physician Education Program	\$ (6,868)	\$ (4,000)
Patient Registry	\$ (836)	\$ (46,500)
Annual Member Conference	\$ (5,765)	\$ (2,000)
Total Program Expenses	\$ (14,498)	\$ (53,750)



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