



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 ways in 2 years. We spent our first year, 2003, taking our first steps by building a strong organizational foundation that enabled the FMDSA to become an entity unto its own and establish the FMDSA as a democratic society that encourages everyone to become involved in its governance.

This past year was about taking our first steps into fundraising and education. I am very pleased to report that 2004 was a good year for the FMDSA. We finished ahead of our original five year plan in fundraising, established a medical advisory board, and delivered online educational information.

My personal thanks to everyone that helped the FMDSA take those next precious steps up the staircase. Everyone is vital to our success and I owe great thanks to our very dedicated board of directors whom freely volunteer their time and expertise; our very talented medical advisors that help to educate and direct our efforts; and most importantly our growing membership from which we have drawn many ideas and much inspiration.

This coming year, 2005, promises to be very exciting and challenging as we work to build sustainable fundraising programs and use the money we earned in 2004 to begin to develop formal awareness and research programs.

Again, I want to thank everyone for their support in 2004 and we look forward to working with you in 2005.

Sincerely,

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.

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2004 Accomplishments

Medical Advisory Board

In 2004, the FMDSA added the first two members to our Medical Advisory Board. We are very fortunate to have Susan M. Begelman, M.D. of The Cleveland Clinic and Jeffrey W. Olin, D.O. of The Mount Sinai Hospital on our medical advisory board. Both doctors have been very active in studying FMD and both have written comprehensive medical articles on FMD in the past 3 years. The purpose of the Medical Advisory Board is to create and disseminate accurate information regarding FMD, work with the FMDSA to define how best to spend our research dollars, and to actively engage the medical community on FMD education and research.

Online Education

We launched our website to the public in 2004. The primary goal of our website is to provide comprehensive, accurate information regarding FMD. To date, we have added a FAQ's (Frequently Asked Questions) page about FMD written by Susan Begelman, M.D., links to download two comprehensive medical documents free of charge, and a host of links to other pertinent organizations like the American Vascular Association. In addition, our website was accredited by Health on the Net Foundation (HONcode) for meeting their stringent guidelines for providing accurate medical information.

Brochure

We completed and printed 500 brochures to introduce people to the FMDSA and FMD. Thanks to the generosity of a local graphic designer and a local printer, the brochures were developed and created free of charge.

Annual NORD Conference

The FMDSA was awarded a scholarship through the National Organization of Rare Disorders, Inc. (NORD) to attend our first conference. The conference was co-sponsored by NORD and the NIH and focused on helping small health organizations to develop their programs and grow in their network of supporters. NORD hosted their annual meeting in Minneapolis in October and Susan and Richard Gould attended. The conference provided a wealth of information and speakers that explained the research process, organizational governance, interfacing with the medical industry and government agencies, and fundraising.

The \$20,000 Challenge

The FMDSA was able to raise more than \$20,000 in the third quarter of this 2004 business year. The money was raised thanks to a challenge made by a private donor who pledged to match all donations made between October and December up to \$10,000. Thanks to this offer, FMDSA raised more than \$15,000 to be matched by the donor bringing our actual total from the \$20,000 Challenge to more than \$25,000!

Pedal for Progress

We were absolutely overwhelmed by the response to our first fundraiser, "Pedal for Progress". "Pedal for Progress" was the brain child of Alayna Gould. Alayna is 8 years old and has renal vascular FMD. She decided to ride her bike around Mackinac Island, MI (8 miles) to raise money for the FMDSA. This was a fantastic experience. The Gould family was featured in the Mackinac Island newspaper; "The Town Crier" and in the local monthly magazine "Hudson Life". Alayna was able to raise \$6,596.



2004 Financial Summary

One of the fundamental goals of the FMDSA is to raise money to fund FMD research, awareness, and education. We initially established a five year plan in 2003 that would enable us to start funding these programs in late 2005. We are very happy to report that we have far exceeded our 2004 plan and will be able to begin investing in these programs earlier in 2005 than expected.

Our initial five year plan called for us to raise \$7,000 in 2003 and \$36,250 in 2004 for a total of \$43,250. Our initial plan also allowed for expenses of \$2,100 in 2003 and \$8,460 in 2004 for a total of \$10,560. Therefore, our total planned net revenue was \$32,690.

Our actual revenue was \$7,229 in 2003 and \$59,140 in 2004 for a total of \$66,369. Our actual expenses were \$2,195 in 2003 and \$1,704 in 2004 for a total of \$3,899. Therefore our total actual net revenue was \$62,470, or \$28,781 ahead of our initial 5 year plan.

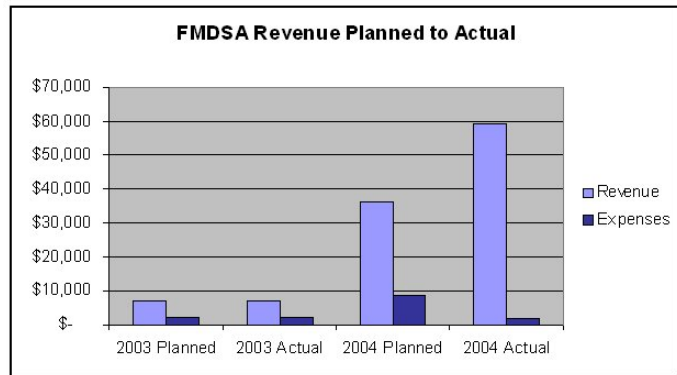
We have been very prudent with our money in 2004. In the world of public charities there are two ways to spend money, on programs (e.g. education and research) and on administration (e.g. office supplies, government fees). The goal of the public charity is to invest heavily on programs and spend as little as possible on administration.

Our only program goal for 2004 was to develop web based (online) education. We spent \$268 on developing and maintaining our website for that purpose and we will continue to fund this program in 2005 (see 2004 accomplishments).

In regards to administration, we kept our expenses very low. Our largest expense (\$743) is general office expenses. Our general office expenses included a software upgrade to Microsoft Office and miscellaneous office supplies like inkjet printer cartridges, printer paper, and filing folders.

Our next highest expense was for fundraising. Fundraising included the cost for using Groundspring for processing online donations and the cost of printing brochures for "Pedal for Progress" (see 2004 accomplishments).

The remaining expenses were minimal and include mailings to our membership, government filing fees and board meeting expenses.



Fibromuscular Dysplasia Society of America, Inc.
...2004 Financial Summary

Revenue	2004	2003
Gifts, Grants and Contributions Received	\$ 59,140.79	\$ 7,229.82
Total Revenue	\$ 59,140.79	\$ 7,229.82
Expenses	2004	2003
Fundraising Expenses	\$ 347.22	\$ -
Printing, publications, postage, shipping	\$ 126.00	\$ 106.45
General Office	\$ 743.93	\$ 943.77
Program - Online Education	\$ 268.95	\$ 494.59
Meeting Expenses	\$ 54.78	\$ -
Government Filing Fees	\$ 164.00	\$ 850.00
Total Expenses	\$ 1,704.88	\$ 2,194.81
Balance	\$ 57,435.91	\$ 5,035.01
Total Assets as of 12/31/2005	\$ 62,470.92	

FMDSA Board of Directors

The first annual meeting of the FMDSA was held on March 30, 2004. At the first annual meeting, the membership elected our first official board members to two year terms.

Mr. Richard Gould

Founder
Chairperson of the Board
President

Ms. Marie Yeh, MSED

Founder
Vice President
Chairperson, Public Awareness Committee

Ms. Susan W. Gould

Founder
Secretary and Treasurer

Ms. Michelle Moran

Chairperson Development Committee

Ms. Lydia Mackey

Chairperson Membership Committee

The Board of Directors appointed two members to our Medical Advisory Board in 2004. We are pleased and honored to work with such talented and committed individuals.

The primary role of the Medical Advisory Board is to establish research direction, keep the Board of Directors abreast of changes regarding FMD diagnostic and treatment options, and to actively engage the medical community on FMD education and research..

Susan Begelman, M.D., R.V.T.

Chairperson Medical Advisory Board
Staff Physician, The Cleveland Clinic
Cleveland, Ohio

Jeffrey W. Olin, D.O., F.A.C.P., F.A.C.C.

Member Medical Advisory Board
Director, The Mount Sinai Hospital
New York, New York

FMDSA Heroes and Benefactors**Hero Level of Giving \$1,000**

Cheryl Golden
Richard and Susan Gould
Larry and Ruth Love
Bernard and Ruth Madoff
Jeffrey Olin, D.O.
The Schlicker Foundation
Marvin and Sondra Wiener
Charles and Carolyn Wiener

Benefactor Level of Giving \$500

Paul and Janice Gould
Frank and Joanne Pascali



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