



FMDSA 2003 Annual Report

President Abraham Lucchin

Letter from the President

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.

After many discussions with the National Organization for Rare Disorders (NORD) and the director of rare diseases at the National Institutes of Health (NIH), they convinced us that most voluntary health organizations begin around the kitchen table and that we did have the "right stuff" to be successful. We enlisted the assistance of a health educator, Marie Yeh, and began the arduous task of incorporation as a public charity. The three of us founded the Fibromuscular Dysplasia Society of America, Inc. (FMDSA) on March 11, 2003.

*"Faith is taking the first step, even when
you don't see the whole staircase."
...Martin Luther King, Jr.*

The past year has been about taking those first steps up the staircase and we thank you for taking those first steps with us. We have also done our best to lay the groundwork that will encourage everyone to become involved and help us take the next steps towards finding the answers we all desire.

We thank you for your support in 2003 and we look forward to a successful 2004.

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.

2003 Accomplishments

...Laying the Foundation for Success

Our first year has been dedicated to filing government forms and building the foundation for a strong organization. Our major accomplishments for 2003 are as follows:

Corporate Governance – The FMDSA Bylaws were established to ensure that every member of the FMDSA has a vote in who directs the affairs of the organization as well as any changes made to the Bylaws. The Bylaws are our constitution and detail the governance of every aspect of our organization. A copy of the Bylaws is available upon request.

Tax-exempt Status – In October, the FMDSA was given tax-exempt status as a "public charity" based upon preliminary review by the IRS. All donations to the FMDSA from the date of incorporation are tax deductible. This was an important milestone for us as well as for those that wish to contribute and participate.

Organizational Plan – We established a five-year plan that details our financial goals and program objectives.

Program Objectives

- Promote research towards better treatments and ultimately a cure for FMD.
- Provide accurate medical information to FMD patients.
- Define treatment protocols for FMD.
- Build public awareness of FMD.
- Provide an online center of education for physicians.

(continued on page 2)

2003 Financial Report

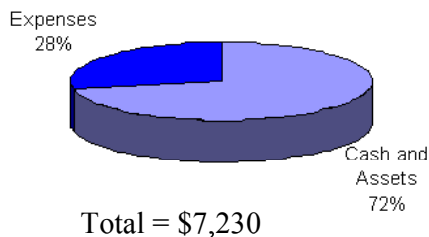
The first year of any startup is very difficult and we are proud to say that we did exceed our 2003 contribution goal.

The FMDSA raised a total of \$7,230 versus our intended goal of \$7,000. We also came very close to meeting our expense goal of \$2,100 spending only \$2,195 (see FMDSA Financial Summary – 2003).

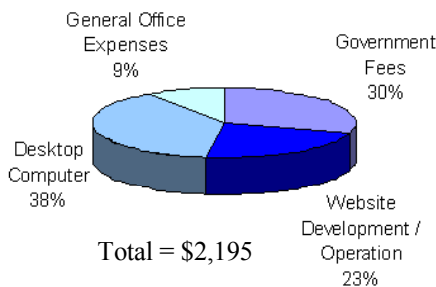
We ended the year with a total of \$5,597 in cash and assets. Our first year goal was to finish the year with \$4,900 in cash and we finished the year at \$5,038. We also acquired a desktop computer to develop our website and run our membership and financial software. The total cost of the computer was \$842.34. We are depreciating this asset over three years. This accounts for the \$561 in assets listed at year-end.

Our total expenses of \$2,195 were relatively low considering that 68% of those total costs were from one-time start-up fees (government filing fees and desktop computer) that we will not incur in 2004.

FMDSA Financial Summary - 2003



FMDSA Expenses - 2003

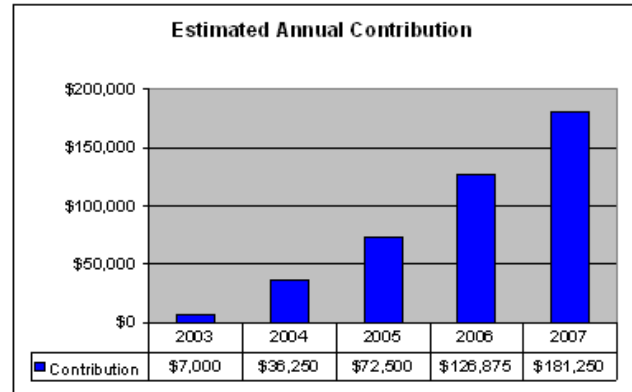


2003 Accomplishments

...Laying the Foundation for Success

Financial Goals

Our financial goals for each of the next 5 years are detailed in the graph below. We are proud to say that we exceeded our 2003 goal of \$7,000 by raising \$7,230. We will continue to grow as an organization and expect to exceed \$181,000 in annual contribution in the year 2007.



State Registration – In 45 of the 50 states, a nonprofit organization must register in order to solicit funds within that state. In most states we are exempt from registration until our annual contributions exceed \$25,000. We do expect to exceed \$25,000 in 2004, therefore are proactively registering in states where we have received significant direct contributions. In 2003, we completed registration in Connecticut, Florida, Ohio, New York, and Michigan. In 2004, we will continue to directly register in states from where we are receiving direct contributions.

We also partnered with another 501(c)(3) organization, Groundspring, to enable the FMDSA to solicit contributions online. Groundspring's charter is to assist other 501(c)(3) organizations to solicit funds online via the Internet in all 50 states without directly registering in each state. Groundspring accepts online donations on our behalf and distributes those donations to the FMDSA at the end of each month via a grant. Groundspring does charge a small transaction fee (3%), but this fee costs far less than registering in every state.

FMDSA Website – We launched the FMDSA website in December to an active support group on yahoo and have received some very good feedback on how to improve the site. Our goal is to implement those recommendations during the first quarter of 2004 and formally launch our website to the public.

INTERIM BOARD OF DIRECTORS

Our organization has been incorporated as a not-for-profit. The initial three incorporators (listed below) have acted as the interim board of directors in 2003 and will serve until the first annual meeting scheduled for March 30, 2004.

- Mr. Richard Gould
- Mrs. Susan Gould
- Mrs. Marie Yeh

A formal Board of Directors will be elected to 2-year terms at the first annual meeting. In 2004, the FMDSA will also appoint a Medical Advisory Board as well as a number of special committees in which our members may participate.

FMDSA Benefactors

The FMDSA appreciates and wishes to recognize our generous benefactors for 2003.

- Dr. and Mrs. Marvin Wiener
- Mr. and Mrs. Charles Wiener
- Mr. and Mrs. Paul Gould
- Mr. and Mrs. Richard Gould



*Fibromuscular
Dysplasia Society
of America, Inc.*

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

Phone Number: 330-653-8416

Email: admin@fmdsa.org