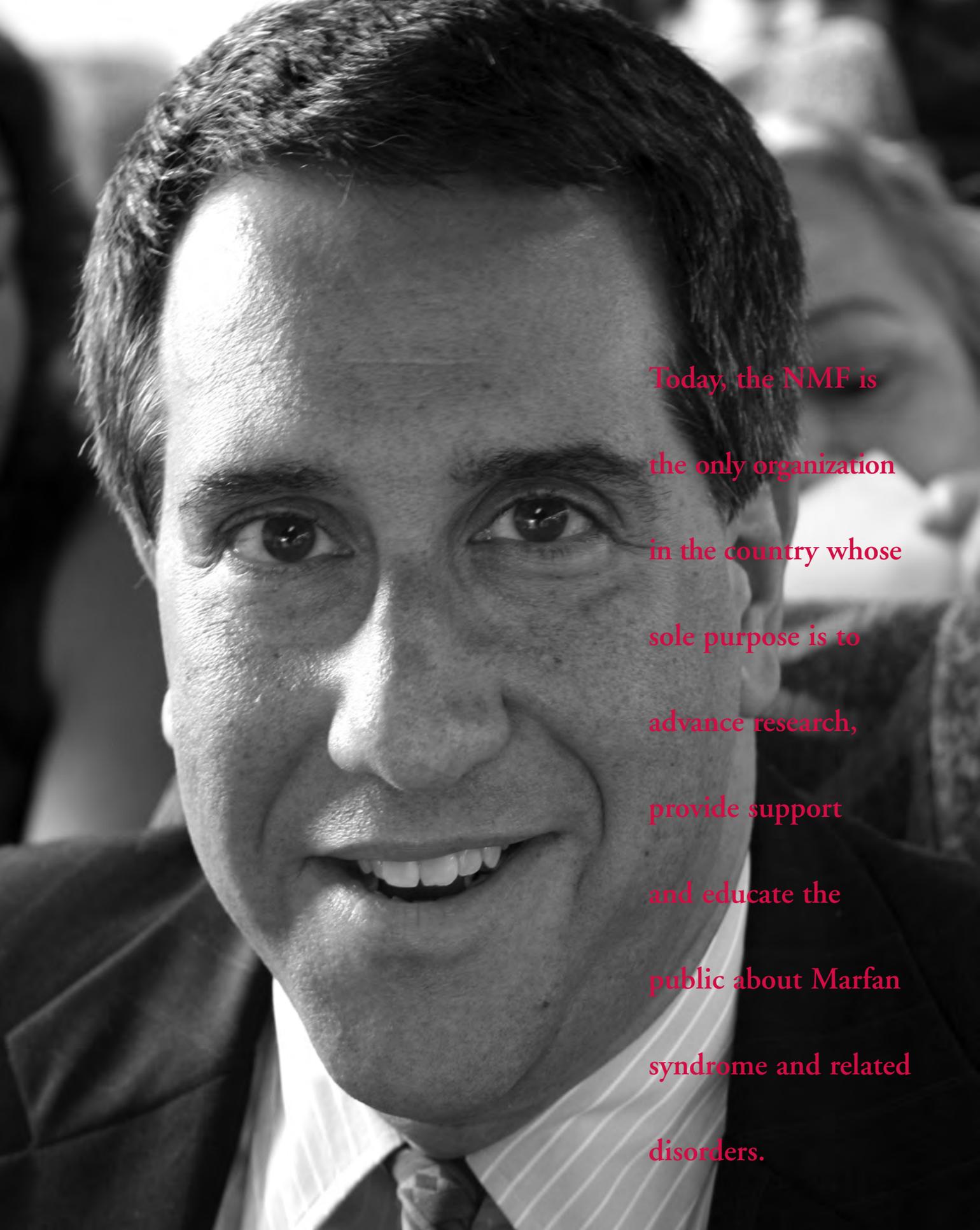


NATIONAL
MARFAN
FOUNDATION

Annual Report 2006



THE NATIONAL MARFAN FOUNDATION'S 25TH anniversary year inspired much nostalgia on the part of the organization and membership, highlighting the tremendous momentum that the NMF has built over the years and the last decade, in particular. The NMF has achieved so much in so little time; we are at a critical moment in our history. In 25 years, we have seen an expanding demographic, extraordinary media coverage, celebrity acknowledgement and new faces—young and old—from across the U.S., all of which underscore our growing national presence. Through research, support and education, we have stayed true to our mission to save lives and improve the quality of life of all individuals affected by Marfan syndrome and related disorders. Indeed, it has been the synergy among our three core work areas that has propelled the NMF with such remarkable velocity.



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the only organization
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MESSAGE FROM THE CHAIR AND PRESIDENT/CEO

Dear NMF Members and Friends,

With tremendous pride, we reflect on 2006—the year marking our 25th anniversary. Our quarter century of service has helped generate hope in the lives of many children and adults affected by Marfan syndrome. This is in no small part due to the efforts of our visionary boards and the energy and dedication of our staff and membership.

The National Marfan Foundation (NMF), which began at Johns Hopkins University as a local support group under the direction of Reed E. Pyeritz, MD, PhD, protégé of Victor McKusick, MD, the “Father of Medical Genetics,” has blossomed into an organization of national scope and diverse activity. Today, the NMF is the only organization in the U.S. whose sole purpose is to advance research, provide support and educate the public about Marfan syndrome and related disorders. With a growing membership of more than 30,000 individuals and 53 volunteer groups in 39 states, as well as ties with leading medical colleges and national health organizations, the NMF has rightly earned its title as a lead advocate for people with aortic disease.

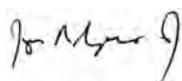
The past year’s noteworthy achievements include numerous examples of national media coverage, high profile exposure in contemporary culture, new outreach and educational materials targeting more diverse populations, and the expansion of our medical education initiative. In addition, a doubling of the number of children and teens attending our national conference and an explosion in the number of local network groups in 2006 serves as testament to the remarkable success of our national outreach.

Perhaps most significantly, there were medical breakthroughs in 2006 that could revolutionize the treatment of Marfan syndrome. In April, a study, partially supported by the NMF, was published in the prominent journal *Science* showing that losartan, a drug commonly prescribed to lower blood pressure, reduced aortic growth in Marfan mice. This was followed by an announcement of a clinical trial in humans. If the results of the clinical trial are positive, there will be evidence of a treatment that could prevent the life-threatening aspect of Marfan syndrome —aortic enlargement.

This trial comes as a timely tribute to the hard work of NMF leadership and members throughout the past 25 years. The study holds tremendous potential but will require a major commitment from the NMF in areas ranging from patient recruitment and support to overall funding to extend the scope of the research. We need you now more than ever before!

We invite you to share our pride because, without your help, we could not have achieved what we see before us today. We have never had so much reason for optimism, yet there is still much work to be done. We have a five-year strategic plan, building a solid foundation for future growth, and we look forward to your continued partnership in the years to come.

Sincerely,



Joseph Gagliano
Chairman



Carolyn Levering
President and CEO



Chapters and
network groups
offer more
intimate venues
for connecting
people locally.

SUPPORT

AT THE HEART OF OUR WORK IN THE SUPPORT DOMAIN IS OUR INFORMATION RESOURCE CENTER, comprised of a national hotline and website based at NMF headquarters and our annual conference, during which children, teens, adults and families affected by Marfan syndrome and related connective tissue disorders gather from across the country to get the latest information on Marfan syndrome from leading medical experts. The conference is much more than an educational experience; it is a time when the entire Marfan family comes together to learn, to see old friends, make new ones and enjoy the warmth of community.

The NMF National Hotline and Website

This year, the NMF provided customized responses to 4,000 inquiries through its toll-free number (800-8-MARFAN) and email. Additionally, the NMF website (www.marfan.org) received approximately 425,000 visits in 2006. The NMF's database of members, physicians, researchers, hospitals and clinics now totals more than 30,000.

In addition to answering questions about Marfan syndrome and related disorders and providing information about living with the disorder, the professionally-staffed Information Resource Center serves the equally critical role of connecting those affected to each other. The NMF maintains lists of members and volunteers across the country who are willing to speak with others who share their interests and concerns. This enables us to link callers with peers at the local or national level who can help on their Marfan journey.

Left: Jan McCarthy, of Pittsburgh, was one of 30 group leaders representing five chapters and 20 local Network Groups who participated in a training session held at the 2006 Annual Conference to strengthen the NMF's National Volunteer Network.

National Volunteer Network

The NMF has a strong and growing National Volunteer Network of members who carry out the Foundation's mission on the local level. These volunteers are the life-blood of the organization, providing support and implementing national programs in their own backyards.

Chapters and Network Groups

While the telephone volunteer program serves to bridge vast geographic divides, chapters and network groups offer more intimate venues for connecting people locally. This year the number of network groups exploded to a full 53 (a significant growth from the more modest 3 in 2003), with another 9 in formation. In addition to the role they play in raising awareness and providing support, NMF volunteers also engage in fundraising activities. In 2006, volunteers raised \$107,000 through chapter events, network group events and individual fundraisers.

The event enabled

the NMF to reach

an audience of 3.5

million through

newspapers alone.



EDUCATION AND AWARENESS

PUBLIC AWARENESS OF MARFAN SYNDROME AND THE NMF REACHED NEW HEIGHTS IN 2006 WITH widespread media coverage featuring breakthrough research and the inauguration of the Foundation's *Music from the Heart* concert series.

In the first half of the year, there was extensive buzz in the media regarding the potential breakthrough in Marfan syndrome treatment published in *Science*. An Associated Press article spawned hundreds of articles in print and on the internet, while segments on CNN and WNBC-TV, which distributed a segment about Marfan syndrome and the study to all NBC affiliates nationwide, provided highly visible television coverage.

Awareness during the second half of the year focused on the NMF's first benefit concert featuring the Queen of Soul, Aretha Franklin. National name recognition, a memorable performance and effective leveraging of the event enabled the NMF to reach an audience of 3.5 million through newspapers alone. The extensive coverage on television (including Entertainment Tonight and NBC-TV), as well as on radio and the internet, led to the equivalent of millions of dollars in free publicity. This will go a long way in positioning the National Marfan Foundation as a leading not-for-profit and gaining recognition for Marfan syndrome among the general public.

In addition to public outreach, the NMF continues to advance its medical exhibit initiative to ensure that doctors and nurses are aware of the Foundation and the resources it provides. Among the national meetings at which the NMF exhibited this year were the Emergency Nurses Association, the American Heart Association, the National Association of School Nurses and the National Society for Genetic Counselors.

Dear NMF:

I am writing this letter to thank you for saving our son's life. In March of 2005, our son Nathan and his girlfriend, Melissa, watched the movie Rent on DVD. As you know, [the DVD] contained a very serious story about the needless death of Jonathan Larson and the plea for anyone with similar symptoms to get tested immediately. Nate, who is now 29, had been tested when he was 17 but to inconclusive results... [Melissa] told Nate that he exhibited a lot of the symptoms and that he should make arrangements to be tested immediately. Nate agreed to her request and went to the Mayo Clinic in Rochester, MN, to be tested. [The doctor] said he knew when Nate walked in his door that he had Marfan and sent him to their Marfan clinic. Once there, the doctor ran CT and MRI scans as well as genetic counseling. When the results of the tests came back, they told Nate two things: Yes, he had Marfan and, of more immediate importance, he had two aneurysms developing in his arteries. One was in his aorta, which I believe is where Jonathan Larson had his incident... The surgeon told Nate that he had less than a year to live if he didn't have surgery immediately. Nate had surgery three weeks later, got engaged, and this October 7 we [will] celebrate their wedding instead of attending his funeral.

*Thanks,
Barb and Steve, Nate's Parents*

ORGANIZATIONAL CAPACITY BUILDING

AS WE CELEBRATED THE ACCOMPLISHMENTS OF THE PAST 25 YEARS, WE ALSO LOOKED TO THE FUTURE and ways in which we can continue to grow and expand our services. By strengthening our membership, building relationships with a widening circle of partners and maximizing and diversifying our fundraising capabilities, we have been able to increase our organizational capacity so that we can build on today's achievements and accomplish even more in years to come.

Growing Partnerships

The NMF enjoys long-time relationships with the National Organization of Rare Disorders and The Genetic Alliance. In addition, the NMF continues to meet the stringent Standards of Excellence set by the National Health Council (NHC). Our continued active membership in the NHC has given us the opportunity to network with other leading voluntary health organizations.

Further bolstering our standing in the non-profit world, the NMF earned its third consecutive 4-star rating from Charity Navigator, America's largest independent evaluator of charities. This is the highest rating awarded; it indicates that the NMF, as compared to other charities in America, is successfully managing its finances in an efficient and effective manner.

Membership Development

The NMF's growing profile amid the general public and the medical community led to an increase in people with Marfan syndrome and related disorders joining our ranks. In 2006, we increased our database of affected people and family members, medical professionals, institutions and other interested parties by 15% to more than 42,000, while revenues from membership dues rose more than 45%.

Fundraising

The Foundation's annual fundraiser, *Heartworks: The Marfan Gala*, was held on April 18 at Cipriani 42nd Street in New York. More than \$1 million, including \$60,000 for patient support for the losartan vs. atenolol clinical trial, was raised at this star-studded event.

The event was a stellar success, with entertainment provided by Broadway Kids®, the only performance group composed of child stars of Broadway. Also in attendance were luminaries such as Brian Williams, host of *NBC Nightly News*, who served as master of ceremonies, and New York City Mayor Michael Bloomberg, the event's honorary chair.

The evening honored "Parents Changing the World for Children with Marfan," underscoring the growing numbers of children and families who have become a part of the Marfan community due to increased awareness and better diagnosis of the disorder.

Opposite, clockwise from top left: Susan Falco, Member, NMF Board of Directors, New York, with NMF President and CEO Carolyn Levering; Brian Williams, NBC-TV, Master of Ceremonies for Heartworks with Heather Holmes Floyd, Member, NMF Board of Directors; *(front)* Karen Murray, Corporate Host, Ann Reinking, Artistic Chair, Carolyn Levering, Susan Falco, Heather Holmes Floyd, *(back)* Joseph Gagliano, Paul Sponseller, MD, and Brian Williams.



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STATEMENT OF ACTIVITIES

YEARS ENDED JUNE 30, 2006 AND JUNE 30, 2005

	Unrestricted	Temporarily Restricted	Year Ended June 30, 2006	Year Ended June 30, 2005
Change in Net Assets:				
Revenues and gains:				
Contributions	\$ 2,119,378	-	\$ 2,119,378	\$ 3,250,607
Memorials	78,128	-	78,128	93,448
Membership dues	134,321	-	134,321	91,773
National Marfan Conference	201,102	-	201,102	147,659
Program revenue	28,235	-	28,235	53,789
Net investment income	189,519	-	189,519	144,929
Events, net of expenses of \$299,419 and \$218,362	800,654	-	800,654	820,372
Revenues temporarily restricted	<u>(1,641,715)</u>	<u>1,641,715</u>	<u>-</u>	<u>-</u>
Total revenues and gains	<u>1,909,622</u>	<u>1,641,715</u>	<u>3,551,337</u>	<u>4,602,577</u>
Expenses:				
Program services:				
Research and grants	1,041,049	-	1,041,049	990,789
Public information	608,509	-	608,509	347,903
Patient services	<u>608,515</u>	<u>-</u>	<u>608,515</u>	<u>561,054</u>
Subtotal	<u>2,258,073</u>	<u>-</u>	<u>2,258,073</u>	<u>1,899,746</u>
Supporting services:				
Management and general	233,551	-	233,551	196,149
Fundraising	<u>400,570</u>	<u>-</u>	<u>400,570</u>	<u>363,343</u>
Subtotal	<u>634,121</u>	<u>-</u>	<u>634,121</u>	<u>559,492</u>
Expenses temporarily restricted	<u>(1,075,203)</u>	<u>1,075,203</u>	<u>-</u>	<u>-</u>
Total expenses	<u>1,816,991</u>	<u>1,075,203</u>	<u>2,892,194</u>	<u>2,459,238</u>
Increase (decrease) in net assets	92,631	566,512	659,143	2,143,339
Net assets at beginning	<u>4,324,520</u>	<u>1,395,434</u>	<u>5,719,954</u>	<u>3,576,615</u>
Net assets at end	<u>\$ 4,417,151</u>	<u>\$ 1,961,946</u>	<u>\$ 6,379,097</u>	<u>\$ 5,719,954</u>

For a copy of the NMF's complete audited financial statements for the years ended June 30, 2006 and 2005, go to www.marfan.org or write to the National Marfan Foundation, 22 Manhasset Avenue, Port Washington, NY 11050.

STATEMENTS OF FINANCIAL POSITION

JUNE 30, 2006 AND JUNE 30, 2005

	June 30, 2006	June 30, 2005
Assets		
Current Assets:		
Cash	\$ 301,192	\$ 2,251,635
Short-term investments	2,336,512	1,185,624
Unconditional promises to give	337,819	506,452
Other current assets	53,060	40,388
Total current assets	3,028,583	3,984,099
Property and Equipment:		
Net of accumulated depreciation \$265,390 and \$224,179	858,432	822,999
Other Assets:		
Long-term investments	2,738,671	1,137,106
Total assets	\$ 6,625,686	\$ 5,944,204
Liabilities and Net Assets		
Current Liabilities:		
Accrued liabilities	\$ 166,537	\$ 161,498
Deferred conference income	80,052	62,752
Total current liabilities	246,589	224,250
Net Assets:		
Unrestricted:		
General funds	2,806,266	2,724,520
Board designated funds	1,610,885	1,600,000
Temporarily restricted	1,961,946	1,395,434
Total net assets	6,379,097	5,719,954
Total liabilities and net assets	\$ 6,625,686	\$ 5,944,204

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