



National Marfan Foundation

National Marfan Foundation Annual Report 2010

The National Marfan Foundation, founded in 1981, is a non-profit voluntary health organization dedicated to saving lives and improving the quality of life for individuals and families affected by Marfan syndrome and related disorders.



The Foundation accomplishes these goals through:

RESEARCH Promoting research to improve diagnosis and treatment and to find a cure through:

- A grant and fellowship program for all Marfan-related disciplines
- Medical and Scientific Symposia
- Advocacy for federal funding and policies that support the NMF mission
- Partnerships with government agencies and other voluntary health organizations

EDUCATION Providing accurate and up-to-date information about Marfan syndrome and related disorders to:

- Patients and families
- Health care professionals
- The general public

SUPPORT SERVICES Helping individuals and families with Marfan syndrome and related disorders through:

- The NMF Information and Resource Center, which provides access to personalized service through a toll free helpline, 1-800-8-MARFAN, and email
- The National Volunteer Network, consisting of Chapters, Network Groups, Support Groups and individual volunteers, which carries out the NMF mission at the local level
- The NMF Annual Conference
- The NMF newsletter, *Connective Issues*, and website, www.marfan.org



This annual report covers programmatic and financial information for fiscal year 2010 (July 1, 2009–June 30, 2010).



Dear Friends,

We are proud to share with you the National Marfan Foundation's 2010 Annual Report, which showcases our strength, our community and our progress in each of our mission areas: education, research and support.

What we have accomplished during the period of July 1, 2009, through June 30, 2010, is significant considering the size of our patient population and moderate size of our organization. Our ability to mobilize our constituents, maximize the availability of our medical and scientific advisors, and utilize the tools available to us given our limited resources enabled us to put a national focus on the issues that are important to the people we serve.

Our research initiatives continued to accelerate, with a primary emphasis on improving treatment for aortic enlargement, the most life-threatening aspect of Marfan syndrome and many of our related conditions. Through direct research, a therapeutics meeting, support of a multi-year study on aortic surgery titled *Aortic Valve Operative Outcomes in Marfan Patients*, an Aortic Summit, and an ongoing clinical trial on therapeutics that is still in the recruitment phase, we are tackling this issue from every conceivable angle.

Our education efforts have also focused on reduction of aortic tragedies, most notably with the TAD (Thoracic Aortic Disease) Coalition which the NMF convened to generate awareness of the new diagnosis and treatment guidelines for aortic dissection that were published this year.

We celebrated many milestones this year, most notably the growth of our online support services, our coast-to-coast volunteer network, the 10th anniversary of our Heartworks gala in New York City and our 25th Annual Conference.

Celebrating these achievements gave us pause, as we could reflect on how far we had come. How the flagship gala has grown and is now being replicated in other parts of the country. How our conference has grown to provide more than just information, but also friendship, self-esteem and hope for the future. How these events—and more—are garnering attention for us in the media, and how social media is taking our message to the public even further.

The cost of research is greater than any other program the NMF initiates. With this knowledge, the Foundation aggressively raised monies over the past several years to fund these life-saving projects. In 2010, as the momentum of the clinical trial, its ancillary studies and aortic surgery research continued, the Foundation's research expenditures continued to draw on previously raised funds. As a result, the NMF had a planned deficit as these previously raised monies were spent.

So many people have been instrumental in the successes of this year, from our volunteers and members to the Board of Directors, the Professional Advisory Board and the Scientific Advisory Board, to the staff. As part of this strong community, we thank you for your ongoing commitment.

A handwritten signature in black ink, appearing to read "Jon Tullis".

Jon Tullis
Chair

A handwritten signature in black ink, appearing to read "Carolyn Levering".

Carolyn Levering
President & CEO

Our Leadership: Research

There has been extensive progress made in research on Marfan syndrome and related disorders this year, in large part due to the leadership provided by the NMF and the strength of the Marfan community.

The Foundation continues to take a leading role in research on aortic surgery. In the absence of a cure for the aortic enlargement caused by Marfan syndrome, aortic surgery is a crucial part of the treatment plan. The NMF has an ongoing commitment to a major multi-year research study entitled *Aortic Valve Operative Outcomes in Marfan Patients*, which is investigating the pre-operative indicators of successful surgeries.

Parallel to this research, the Foundation is an active sponsor and supporter of the National Registry for Genetically Triggered Thoracic Aortic Aneurysms and Cardiovascular Conditions (GenTAC), through which data can be collected to help doctors and researchers better understand the link between genes and aortic aneurysms and heart disease. Better understanding and more research will lead to better treatment.

One of the highlights of GenTAC this year was the Aortic Disease Summit, sponsored by the National Heart, Lung, and Blood Institute (NHLBI), which brought together prominent clinical and basic scientists to consolidate current information regarding disease pathogenesis, progression and treatment and to identify future directions for both GenTAC and the field.

While we remained focused on improving surgical options for Marfan syndrome and related disorders patients, we also continued to support major projects for identifying therapeutic strategies to prevent the life-threatening complications of these conditions. Following the Aortic Disease Summit, the NMF sponsored a meeting just for this purpose—a meeting of the minds for the development of a plan for potential therapeutic strategies for the disorder.

During this fiscal year, the NMF provided more than \$1 million in research funding.

Traditional Grants:	\$225,000
Fellowships:	\$200,000
Valve Sparing Study	\$97,500
Studies Ancillary to Clinical Trial	\$108,780
Donor Advised Grants:	\$450,000
Total	\$1,081,280



During this time, the NMF remained committed to the major clinical trial on Marfan syndrome that was begun in 2007. The clinical trial studying two medications—losartan and atenolol—and their ability to slow or prevent aortic enlargement in Marfan syndrome continued to enroll patients this year, and the NMF was a driving force, promoting the trial to its community and providing financial assistance to facilitate travel. This year, we progressed significantly towards our enrollment goal, a key milestone for the study. The Foundation’s leading role and dedication to this research continue to be recognized by the NHLBI, which is funding the trial, and the Pediatric Heart Network, which is conducting the research.



Jefferson Doyle, MBBCHIR, MHS, MA, and Christine Papke, PhD, NMF Victor McKusick Fellowship recipients (center) with their mentors, Hal Dietz, MD, Johns Hopkins University Medical Center, and Dianna Milewicz, MD, PhD, University of Texas Health Science Center at Houston

Our Power: **Advocacy**

The NMF’s advocacy efforts—specifically with the National Institutes of Health, Centers for Disease Control and Prevention (CDC), Social Security Administration, Congress and other government entities—have successfully enabled the Foundation to increase resources for its research, education and support programs. This year, with the support of Congressman Gary Ackerman (D-NY), the CDC announced that it will provide the NMF with a \$250,000 grant for education and awareness on Marfan syndrome. This funding, which will be awarded in FY 2011, will be targeted to consumer awareness and medical education for the purpose of early diagnosis and treatment of Marfan syndrome and related disorders.

Funding Research

In the 2010 fiscal year, the NMF’s Traditional Research Grant and Fellowship Programs funded the following projects, based on a review of proposals by the NMF’s Scientific Advisory Board.

VICTOR A. MCKUSICK FELLOWSHIP AWARDS*

Jefferson Doyle, MBBCHIR, MHS, MA

Johns Hopkins Hospital

The Benefits of Antagonizing ERK Signaling to Modify the Pathogenesis of Marfan Syndrome

Christine Papke, PhD

The University of Texas Medical School at Houston

Molecular Pathogenesis in Mouse Models of Thoracic Aortic Aneurysm and Dissections

Ami Bhatt, MD

Brigham and Women’s Hospital

Improving Aortic Health in Adults with Marfan Syndrome: Losartan vs. Atenolol

TRADITIONAL GRANT AWARDS*

Suneel Apte, PhD

Cleveland Clinic

ADAMTSL4, Fibrillin-1 and Ectopia Lentis

Joseph Coselli, MD

Baylor College of Medicine

Aortic Valve Sparing Operative Outcomes in Patients with Marfan Syndrome

Robert Mecham, PhD

Washington University

MAGP: Modifier of Microfibril Function

Jennifer Pardo Habashi, MD

Johns Hopkins Hospital

Exploration of Synergistic Therapeutic Strategies with Losartan to Improve All Cause Survival in an Exaggerated Mouse Model of Marfan Syndrome

**Paid in FY 2010, but awarded in 2008 or 2009.*



Our Empowerment: Support Services

The Information Resource Center helps strengthen the Marfan syndrome and related disorders community, providing help and hope to those who know something is wrong but don't know where to turn for proper diagnosis and treatment. In their greatest time of need, affected people and their families know they can count on the NMF. Medical professionals, too, turn to the NMF as a valuable resource and as a support organization for their patients.

The NMF's professional staff, including a licensed social worker and registered nurse, provides one-on-one customized assistance for people who contact us via phone or email. However, that's not all. The Foundation organizes phone support groups, including one specifically for parents and one for people who are over the age of 50; has a social networking site, NMFconnect, where people can "meet" others with similar issues; and connects people to chapters and network groups in their local geographic area. Support is literally available 24/7.

Providing Answers

In response to a survey the NMF conducted among people who contacted the Information Resource Center:

96% stated that the information they received **helped them better understand Marfan syndrome or a related disorder.**

94% stated that the information they received **helped them or someone they care about.**

90% stated that the information they received **addressed their specific question/concern.**

87% stated that the information they received **increased their knowledge about management of Marfan syndrome or a related disorder.**

I wanted to thank you for all the information you provided. You are personable, supportive, knowledgeable, and genuine. I can not thank the National Marfan Foundation enough for all that you have done to assist me. You have been a great source of encouragement and help.

Debra Bouknight, South Carolina



In 2009, we were fortunate to go to Mayo Clinic for the NMF's annual conference and meet many amazing people and doctors in the Marfan community. The NMF gave us a scholarship to help offset the cost and offered a free echocardiogram to Joshua. We were shocked to find that Joshua has a defective aortic valve, called bicuspid, and also has an enlarged aorta. We would have never known this had the NMF not offered this test to us.

Jennifer Aguayo
Plainfield, IL

25th Annual Conference:

The NMF marked an important milestone this year with its 25th Annual Conference. This meeting of individuals and families with Marfan syndrome and related disorders was hosted by the Mayo Clinic in Rochester, NY. More than 500 people from all parts of the U.S. and from countries around the world to hear the latest medical information from experts in the field. They:

- Took advantage of the conference's free evaluation clinic provided by the country's leading clinicians on Marfan syndrome and related disorders
- Learned about medical management from doctors experienced with Marfan syndrome
- Heard research updates from the scientists on the front line of clinical and basic research
- Met with people who are just like them from all over the country
- Made connections to last a lifetime



Heidi Connolly, MD, Mayo Clinic, answers questions during Annual Conference Q & A session.

Our Knowledge: Education and Awareness

TAD Coalition

The NMF's successful track record in the media continued in 2010, bringing important messages about Marfan syndrome and related disorders to both a consumer and medical audience.

The most significant news this year was the first-ever publication of diagnosis and treatment guidelines for aortic dissection, which were developed by the American Heart Association, American College of Cardiology and several other leading medical organizations. Leading up to this publication, the NMF convened the Thoracic Aortic Disease (TAD) Coalition of medical groups and other like-minded voluntary health organizations for the purpose of leveraging these new guidelines.

This high profile collaboration—which involves the Ehlers-Danlos National Foundation, GenTAC (Registry for Genetically Triggered Aortic Aneurysm and Dissection), International Registry of Acute Aortic Dissection (IRAD), John Ritter Foundation for Aortic Health, Loews-Dietz Syndrome Foundation, National Marfan Foundation, and Nebraska Methodist Health System—devised Ritter Rules, named for the late actor John Ritter who died from an aortic dissection, and was very successful in garnering national attention. From national television shows, such as *The Doctors* and *CBS Early Shows*, to local programs and print media, to medical publications, such as *Physicians Weekly*, the guidelines and Ritter Rules put aortic dissection in the spotlight like never before.

While awareness is the first step in the process, the TAD Coalition continues to work hard to change clinical practice in hospital emergency departments, so that people who are at risk of aortic dissection—whether they know it or not—are diagnosed and treated quickly so that they do not die.

The TAD Coalition, by increasing public and care-giver awareness of Marfan syndrome and other conditions that put people at high risk of aortic dissection, offers the opportunity to dramatically improve care over the coming years. Too little attention has been paid to this and other genetically mediated aortic conditions, both in terms of national funding, physician and nurse education, and public visibility. The time is now to change this paradigm... and the TAD Coalition is doing it!

Kim A. Eagle, MD
Director
Cardiovascular Center
University of Michigan
Study Chair, GenTAC
Founder, IRAD





Social networking is allowing us to connect like never before. While the NMF website has been terrific, we really needed to take the next step and become involved in Facebook and Twitter to engage in the online communities where people are. A lot more people have found the NMF this way and can now take advantage of all the Foundation has to offer.

Maya Brown-Zimmerman
Milpitas, CA

Social Network Opportunities

The NMF's internet presence—its website, www.marfan.org—has long been an important resource for people with Marfan syndrome and related disorders. It is a reliable place they can go at any time of day or night to get information about their condition. Now, the opportunities on-line are expanding exponentially and the NMF has taken significant steps to have a presence on Facebook and Twitter. Connecting with affected people, the medical community and other people who are interested is essential to our mission and we have strategically and methodically expanded our foray into these social media platforms.



NMFconnect, the Foundation's social network, has more than doubled this year:

1,300+ participants

3,647 photos shared

279 forum discussions

70 online support groups

Our Strength: National Volunteer Network

Moonlight strolls and cookbook fundraisers, poetry readings and carnivals, memory walks and marches, casino nights and health fairs... These are just a sample of the activities that our National Volunteer Network performed this year, all with the goal of advancing the cause of the NMF. Our 50 groups, including 7 chapters, 41 network groups and 2 support groups, along with our 89 telephone contacts stepped up to conduct fundraising and awareness events, implementing tried and true strategies and using their own creativity to devise unique events.

In this fiscal year, our dedicated volunteers held 79 events and raised close to \$175,000 for the NMF's programs and services. Equally important, they raised extensive awareness about Marfan syndrome and related disorders in cities, small towns and rural areas throughout the country.

The dedication of the Marfan syndrome and related disorders community is vital. They are the lifeblood of the organization, helping us advance our mission from coast to coast.



Volunteering has helped Daniel come to terms with his own diagnosis and has given him a way of turning a negative into a positive. He has matured greatly just by taking ownership of his health through volunteering.

Amy Speck
Knoxville, MD



10th Anniversary Circle of Honor

Hero with a Heart Award
Recipients 2000-2010

2000:

O. Wayne Isom, MD

2002:

Valentin Fuster, MD

2003:

Mary Roman, MD

Richard Devereux, MD

2004:

Leonard Girardi, MD

Paul Charron

Allan Larson

2005:

Karen Murray

Victor A. McKusick, MD

2006:

Susan Falco

Heather Holmes Floyd

Paul Sponseller, MD

2007:

Antonio M. Gotto, Jr, MD, DPhil

Ann Reinking

Ben Carpenter

2008:

Hal Dietz, MD

Merck & Co.

2009:

Randy Falco

Michael L. Weamer

2010:

Duke Cameron, MD

Herbert Pardes, MD

Our Community: Gala Support

The Heartworks gala in New York City continues to be a beacon for the NMF, reaffirming each year the commitment of our New York area friends and colleagues to the Foundation's mission. In April 2010, the NMF celebrated the 10th anniversary of its Heartworks Gala, securing funding for core programs and services for the Marfan syndrome and related disorders community.

New York City Mayor Michael Bloomberg was again on-hand as the honorary chair of Heartworks. He presented the Founder's Award to NMF Board member Karen Murray, President, VF Sportswear, who has served as corporate host of Heartworks since its inception.

Hero with a Heart Awards were presented to two distinguished doctors: Dr. Duke Cameron, Professor of Cardiac Surgery and Pediatrics, Johns Hopkins, and Dr. Herbert Pardes, President and CEO, New York Presbyterian Hospital. The NMF also recognized the 10th Anniversary Circle of Honor, all previous recipients of the Hero with a Heart Award.

Events in other cities also demonstrated commitment and support for the NMF. NMF Professional Advisory Board member Alan Braverman and his wife, Becky, hosted the second annual Heartworks St. Louis honoring the esteemed surgeon Dr. Gregorio Sicard, Executive Vice Chairman of the Department of Surgery and Chief of the Vascular Surgery Section at Washington University School of Medicine, Barnes-Jewish Hospital. In Westchester, NY, NMF members Barbara and Jonathan Lerman, held the third annual Heartworks Westchester in honor of their seven-year-old daughter Sydney who has Marfan syndrome.



Duke Cameron, MD

Our Support: Donors

The NMF extends sincerest gratitude to all those who contributed financially during our 2010 fiscal year. We list here those who have contributed amounts of \$1,000 and above from July 1, 2009, through June 30, 2010.

Platinum Circle

\$1,000,000 and above
Anonymous

Silver Circle

\$250,000 - \$999,999
Smilow Family Charitable Trust

Bronze Circle

\$100,000 - \$249,999
American Heart Association
Mr. & Mrs. James Fabiszewski
Vital Projects Fund, Inc.

Benefactor

\$50,000 - \$99,999
Mr. & Mrs. Benjamin Carpenter
Randy and Susan Falco
St. Jude Medical Foundation

Patron

\$25,000 - \$49,999
Allen & Company, Inc.
Frank J. Antun Foundation
Centene
The Chu and Chan Foundation
Alex McLean Jennings 13.1 for Cassie
Fundraiser
Gary & Mary Kauffman
Mr. & Mrs. Allan Larson
Mr. & Mrs. Jay Levine
Massachusetts Chapter of the NMF
Karen Murray & Harry Steinmetz
Drew & Laurie Rayman
Ms. Ann Reinking
Sholton Foundation
VF Sportswear
Estate of Joan Wheeler

Sponsor

\$10,000 - \$24,999
Akin, Gump, Strauss, Hauer & Feld, LLP
American Legion Child Welfare
Foundation
Jenna & Neil Bloomgarden
Ernst & Young LLP
Express Scripts
Genzyme
GQ Magazine
Josephine Grima, Ph.D.
JAFGO Fundraiser
Johns Hopkins Hospital
KPMG, LLP
Mr. & Mrs. Jerry Lerman
The Levy Group
Lord & Taylor
Macy's and Bloomingdales
Merck & Co., Inc.
Neuco, Inc.

Mrs. Barbara Neustadt
New York State Department of Health
NewYork-Presbyterian Hospital
Northern Illinois Chapter of the NMF
Peerless Clothing
Estate of Ronald Pimpinella
PricewaterhouseCoopers LLP
Randa Accessories
Ross Stores
Mrs. Edmond J. Safra
Ms. Elna Schonholtz
Smart Apparel U.S.
Syms Foundation
Peter & Marjorie Troob
Mr. Jon Tullis
VF Corporation
Tanja & Peter Vogel
Weill Cornell Medical College,
Department of Cardiothoracic Surgery
Weill Cornell Medical College
Weiser, LLP
Eric & Susan Wiseman
Mr. & Mrs. Robert C. Wright

Supporter

\$5,000 - \$9,999
Mr. & Mrs. Scott D. Avitabile
Mr. R. Douglas Barnhart
Belk, Inc.
Estate of David Bressen
Caxton-Iseman Capital Inc.
Century 21 Associates Foundation
Charmer Sunbelt Group
Mrs. Lillian Confino
Michele Cripps' Casino Night Fundraiser
Deloitte LLP
Anne & Patrick Dooley
Emerson
Rachel Epperson Strides for Sarah
Fundraiser
FirstService Williams
Mr. Charles Galli
Michael Goldstein &
Therese Vandenberg
Heart of Iowa Chapter of the NMF
Mr. & Mrs. Mark A. Heller
Ms. Pamela Kohlberg
Mr. & Mrs. Seth Kornblau
Ms. Hoda Kotb
Mr. & Mrs. Adam Leibner
Mr. & Mrs. Jonathan Lerman
March of Dimes Foundation
Harold & Ellen McElhinny
New England Motor Freight
O'Melveny & Myers
R P Lumber
Mrs. Cindy Rains
Mr. & Mrs. Andrew Roos
Ron & Pam Rubin
Paul & Alison Savage

Mr. & Mrs. Roland Strick
TJX Companies
Mr. Chris Vogel
Mr. & Mrs. John Witte

Partner

\$1,000 - \$4,999
Douglas & Sharon Aach
Mr. Richard Adamski
Alberici Foundation
Felice & Jeffrey Anikstein
Mr. & Mrs. Luis Arias
AstraZenecaPharmaceuticals
Amy Avitabile Triathlon Fundraiser
Baker Street Trust
Barnes Retina Institute
Barnes-Jewish Foundation
Barnes-Jewish Hospital
Ms. Helaine Baruch
Daniel & Mindy Bass
Mr. & Mrs. Michael W. Baumgartner
Dr. & Mrs. Charles Berst
Ms. Irene Bishop
Theodore Blackston & Rhiannon Kubicka
Bloomingdale's
Mr. & Mrs. Scott Boilen
Diana & Peter Boodell
Mr. Paul R. Boudreau
Mr. & Mrs. Bob Bower
Robert & Martha Bowlus
Dr. & Mrs. Alan Braverman
Mr. & Mrs. Michael Buck
Mr. & Mrs. Roger Burrus
Mr. & Mrs. Glenn Carr
Karen Castellano & Jerry Newirth
Casual Time Ltd.
Paul & Dorothy Cayo
Raymond & Joanne Chevallier
Mrs. Priscilla C. Ciccariello
Mr. Ron Cohen
Ms. Karen Compton
Mr. & Mrs. William Conger
Conger Family Foundation
Heidi Connolly, MD
Ms. Judith Consigli
Mr. Michael J. Day
Teri and Ken Dean
Ms. Sarah Deckey
Pamela Deering Fundraiser
Mr. & Mrs. Urmil Desai
Mr. Peter Diamond
Doneger Group
Mr. & Mrs. Jonathan Dulman
Heather Earnhardt Fundraiser
Mr. Cory Eaves
Ehlers-Danlos Syndrome Network
C.A.R.E.S.
Bruce English & Laurie Hammel
Esquel Group
Estate Motors

Family Management Corporation
 Mr. Jay Farbstein
 Alison & John Ferring
 Fishman & Tobin
 Mr. & Mrs. Marc Flamino
 Walter & Leona K. Friedrichs
 Mr. & Mrs. Thomas Gaston
 Mr. Jeff Gennette
 Mr. & Mrs. Alan Gerstein
 Ms. Judy Gibaldi
 Gibson, Dunn & Crutcher, LLP
 Mr. Mark Glasberg
 Global Export Marketing Co.
 Mr. & Mrs. Alan Grainger
 Mr. & Mrs. Ron Grant
 Mr. & Mrs. John M. Grimshaw
 Ms. Patricia Gronell
 Mr. Stephan Gross
 Ms. Bernadine Hagnauer
 Mr. Timothy Hall
 Ms. Mary Hanson
 Gordon & Mary Harnett
 Mr. & Mrs. Albert P. Harris
 Ms. Phyllis Troupe Hawkins
 Hecht and Company
 Mr. Daniel Heflin
 Ms. Dorothy Helphand
 Mr. David Hickman
 Lucy & Ken Hicks
 Anne H. Hinds
 Anne H. Hinds Fundraiser
 Roy & Sandra Hoffman
 Dawne Hostetter Fundraiser
 John Houston & Kathy Read
 Mr. Clifton Hyatt
 Mr. Christopher Ihde
 Ms. Karene Infranco
 Doug Jakubowski & Joe Conforti
 Alexandra McLean Jennings &
 Ezra Jennings
 Suzanne Nora Johnson &
 David G. Johnson Foundation
 Mr. & Mrs. Michael J. Johnston
 Thomas & Joanne Jordan
 Kaiser Permanente Foundation
 Kappa Kappa Gamma-Epsilon
 Omega Fundraiser
 Adam & Kate Kauffman
 Alice Kelly Fundraiser
 Ms. Colleen Kelly
 The Kiev Foundation
 Mr. Bryan Knepper
 Randall & Amy Knox
 Tricia & Ronald Kordalski
 Arleen & Phil Korenblat
 Dr. & Mrs. Yamil Kouri
 Anne Laffoon Fundraiser
 Mr. & Mrs. Steven Lefkowitz
 Amy & Adam Lehrhoff
 Mimi & Jonathan Leibner
 Tom & Betty Leininger
 David & Danielle Lerner
 Ms. Carolyn Levering
 Mr. & Mrs. David Litvinsky
 Loeys-Dietz Syndrome Foundation
 Mr. Robert E. Lotwin
 Richard & Susan Madris
 Kathy Magee Big Hearted Texans
 Fundraiser
 Mainstream Inc.
 Ms. Marissa Marlin
 Harry & Anna Masi

Steven & Toby Mayer
 David & Sheila McLean
 Mr. & Mrs. Bruce Michelich
 Dr. & Mrs. John Middelkamp
 Lori & Adam Miller
 Minnesota Twin Cities Chapter
 of the NMF
 Missouri Baptist Medical Center
 Mr. & Mrs. Edward J. Mooney
 Mrs. Dorothy Moore
 Morgan Stanley Children's Hospital
 Mr. C. J. Murray
 Gregg & Carol Myers
 Alan & Karen Nadel
 Nassau County Association of
 School Nurses
 Sharon Nasutovicz Fundraiser
 Mr. & Mrs. David Neal
 Nebraska Methodist Health System
 Mr. & Mrs. Michael Neidorff
 Jon & Julie Neustadt
 Mr. & Mrs. Paul Neustadt
 New York Hospital Queens
 Northern California Ford F100 Elite
 The Linda Sue Pfarrer Nortillo
 Foundation
 Ocean Sky International Ltd.
 Ms. Catherine O'Keefe
 James & Karen O'Keefe
 Bernard & Rosemarie Oliveri
 P. Morrissey Contracting Inc.
 Mr. Matthew Parker
 Stephanie Parkinson Fundraiser
 Yogesh R. Patel, MD
 Ms. Anna Lee Pearson
 Peebles/Stage Stores
 Gary & Rebecca Perlow
 Perry Ellis Menswear
 Jillian & Michael Pohly
 Glenn & Ayelet Pollner
 PolyOne Corporation
 Dennis & Jill Prestia
 Mr. & Mrs. Michael Prober
 PVH Neckwear
 Josephine Ragusa Fundraiser
 Dr. & Mrs. John Reckner
 Mr. Carl Reisner
 Ms. Blair Ritchie
 John Ritter Foundation for
 Aortic Health
 Dr. & Mrs. Paul Robiolio
 Rock Bottom Foundation
 Michael & Gwen Rohrer
 Rollex Corporation
 Mr. & Mrs. Peter Roos
 Theo T. & Hilda Rose Foundation, Inc.
 Eric Rosee Fundraiser
 Courtney & Jonathan Rothstein
 Mr. Peter Sachse
 Stacey & Marc Saiontz
 Mr. & Mrs. Harvey Sanders
 Mr. Richard Savitt
 Ms. Teresa Schell
 Mr. & Mrs. Robert Schwarzenbek
 Mr. & Mrs. Terence Seery
 Mr. & Mrs. Andrew Serenyi
 Mr. Steven Shapiro
 Gregorio A. Sicard, MD
 Ms. Cynthia Simmons
 Ms. Candace Singer
 Mr. & Mrs. Howard Socol
 Daniel Speck 4-H Fundraiser

Mrs. Catherine Spillman
 St. Louis Children's Hospital
 Mr. & Mrs. Jeffrey Stein
 Stone Hedge Day Spa
 David Striker, MD
 Stanford Sullum, MD
 Tau Kappa Epsilon Fundraiser
 Ms. Nancy Taylor
 Mr. & Mrs. Jeffrey Tochner
 Mr. & Mrs. Michael S. Tracey
 Robyn & Douglas Troob
 Keith & Catherine G. Turner
 Mr. & Mrs. Charles Vago
 Valspar Foundation
 Mr. & Mrs. Mike Van Eekeren
 Peter Varga, MD
 Jennifer & Robert Vecchio
 Wal-Mart Stores, Inc.
 Mr. Marc Warm & Ms. Meredith
 Tanowitz
 Washington University School of
 Medicine, Marfan Syndrome Clinic
 Washington University School of
 Medicine, Division of Cardiothoracic
 Surgery
 Washington University School of
 Medicine, Cardiology Division
 Washington University School of
 Medicine, Department of Surgery
 Mr. Henry J. Wasiak
 Nate & Marion Weeks
 Weill Cornell Medical College
 Mr. & Mrs. Michael Weisman
 Debra & Mark Wells
 Wika Family & F100 Elite Fundraiser
 Cheryl & Dave Williams
 Willkie, Farr & Gallagher LLP
 Mr. & Mrs. Henry Wilson
 Julie Winch, Ph.D.
 Andrij Witiuk & Susan P. James
 Caroline & Mark Yeager
 Zegar Family Foundation
 Mr. J. Joseph Zimmerman
 Mr. & Mrs. John Zuckerman



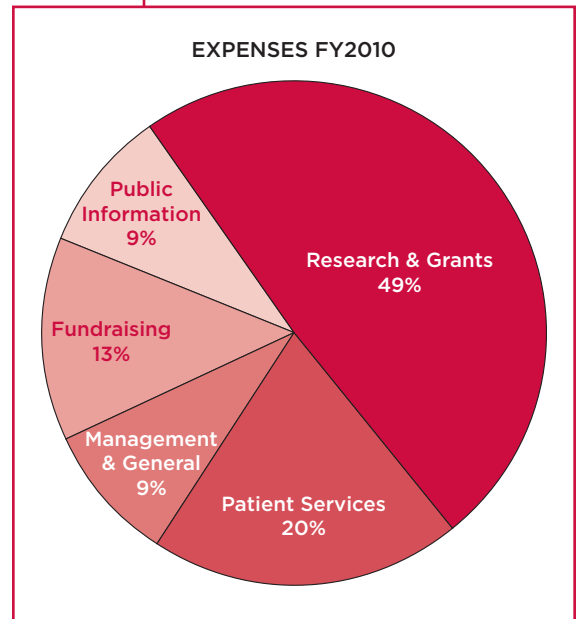
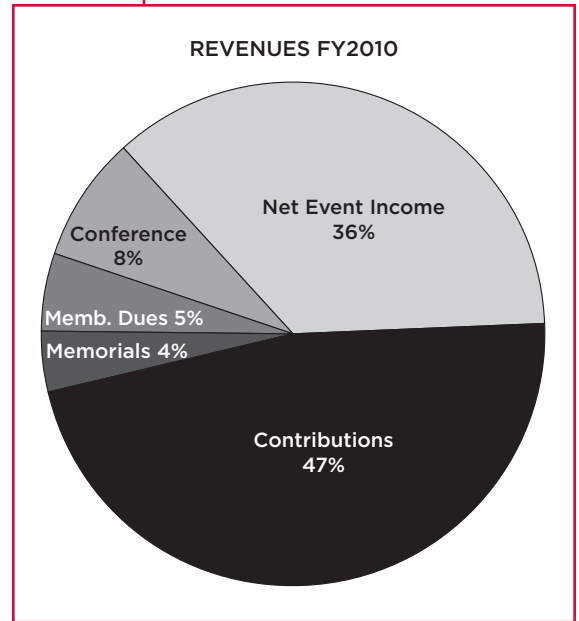
Our Stewardship: Financial Information

The NMF is currently running three large research programs that involve substantial expenditures and are expected to take place over a number of years. Due to the size of the financial commitment that is associated with these programs, substantial fundraising was performed at the outset of each. The result has been that all three programs are now fully financed from either donations that have already been given or pledge payments that will be received over the next few years.

However, according to the accounting rules to which the NMF is subject, these gifts must be recorded as revenue in the year in which they were given or pledged, but the corresponding expenditures (most of which will be paid out over several years) are not recorded until the year in which they are incurred. As a result, the NMF is currently making substantial expenditures for which the associated revenues were recognized in earlier years. Although the money for these expenses is on hand (or expected from donors), the NMF's reported financial statements will nonetheless show a deficit for the years in which this reporting mismatch occurs.

This situation existed in the fiscal year ended June 30, 2010. During this year, the NMF experienced a deficit that was substantially financed from funds that had already been received for these programs.

For a copy of the NMF's complete audited financial statements for the years ended June 30, 2010 and 2009, go to www.marfan.org or write to the National Marfan Foundation, 22 Manhasset Avenue, Port Washington, New York 11050.



Statements of Activities

Years Ended June 30, 2010 and June 30, 2009

	Unrestricted	Temporarily Restricted	Year Ended June 30, 2010	Year Ended June 30, 2009
Changes In Net Assets:				
Revenues and gains:				
Contributions	\$ 1,291,478		\$ 1,291,478	\$ 1,010,110
Unrealized loss on land	(168,454)		(168,454)	
Memorials	98,457		98,457	93,485
Membership dues	112,538		112,538	117,428
National Marfan Conference	202,017		202,017	251,454
Program revenue	9,529		9,529	9,037
Net investment income	415,080		415,080	(572,061)
Events, net of expenses of \$302,211 and \$315,645	881,761		881,761	835,034
Net assets released from restriction	411,868	(411,868)	-	-
Total revenues and gains	3,254,274	(411,868)	2,842,406	1,744,487
Expenses:				
Program services:				
Research and grants	1,524,922		1,524,922	1,734,961
Public information	281,599		281,599	299,260
Patient services	638,213		638,213	808,128
	2,444,734	-	2,444,734	2,842,349
Supporting services:				
Management and general	266,326		266,326	417,175
Fundraising	406,989		406,989	411,619
	673,315	-	673,315	828,794
Total expenses	3,118,049	-	3,118,049	3,671,143
Increase (decrease) in net assets	136,225	(411,868)	(275,643)	(1,926,656)
Net assets at beginning	3,623,298	5,488,057	9,111,355	11,038,011
Net assets at end	\$ 3,759,523	\$ 5,076,189	\$ 8,835,712	\$ 9,111,355

Statements of Financial Position

June 30, 2010 and June 30, 2009

	June 30, 2010	June 30, 2009
ASSETS		
Current Assets:		
Cash	\$ 626,887	\$ 340,978
Short-term investments	1,021,228	775,921
Unconditional promises to give	1,041,033	1,158,658
Non cash contributions	235,000	-
Reserve for non cash contributions	(168,454)	-
Other current assets	113,558	38,891
Total current assets	2,869,252	2,314,448
Property and Equipment:		
Net of accumulated depreciation \$445,901 and \$405,823	790,150	819,729
Other Assets:		
Long-term investments	4,384,220	4,246,643
Long-term unconditional promises to give	1,024,587	1,990,345
Total other assets	5,408,807	6,236,988
Total assets	\$ 9,068,209	\$ 9,371,165
LIABILITIES AND NET ASSETS		
Current Liabilities:		
Accrued liabilities	\$ 112,727	\$ 123,279
Deferred conference income	119,770	136,531
Total current liabilities	232,497	259,810
Net Assets:		
Unrestricted:		
General	1,669,499	1,335,848
Board designated	2,090,024	2,287,450
Temporarily restricted	5,076,189	5,488,057
Total net assets	8,835,712	9,111,355
Total liabilities and net assets	\$ 9,068,209	\$ 9,371,165



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