

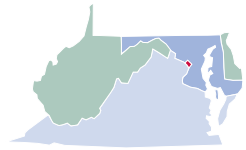
## Getting Connected

Become part of the Marfan syndrome and related disorders community by joining the NMF. As a member, you will receive a subscription to the newsletter, *Connective Issues*, which contains the most up-to-date and accurate medical information available on Marfan syndrome and related disorders.

In addition, members receive discounted registration for the NMF's Annual Conference, which is held in a different city each year. The conference provides a wonderful opportunity to connect with others and hear presentations from leading experts on physical, emotional and other aspects of living with Marfan syndrome and related disorders.

You can also connect by signing up for the NMF's Email Network to receive "action alerts" on research breakthroughs, event updates, legislation and other news of interest.

By joining the Mid-Atlantic Chapter you have the opportunity to help make a difference in our local area which includes Delaware, Maryland, Virginia, Washington, DC, and West Virginia. You will also be included in our email network and mailings to receive information about events and happenings in the Mid-Atlantic area and invitations to our support, education and fundraising programs.



### Mid-Atlantic Chapter

Amy Speck, President

301 371-5660 • siberianspring@hughes.net  
marfan.org/marfan/4337/Mid-Atlantic-Chapter

### National Marfan Foundation

800 8 MARFAN • staff@marfan.org  
www.marfan.org  
22 Manhasset Avenue  
Port Washington, NY 11050

## Knowledge Is Power

Marfan syndrome, a life-threatening genetic connective tissue disorder, affects the skeleton, lungs, eyes, skin, heart, and blood vessels. It does not affect intelligence. About 1 in 5,000 people are affected, including men, women and children of all races and ethnic groups. 75% of cases are inherited from a parent. The remaining cases are caused by a new gene mutation. Those affected have a 1 in 2 chance of passing it on each time they have a child. Its life-threatening aspect is due to the effect on the aorta, the body's largest artery that carries blood away from the heart. The condition makes the aorta prone to enlarge and tear, which could be fatal.

### Physical Characteristics That May Indicate Marfan Syndrome

- Tall, thin stature
- Flat feet
- Nearsightedness
- Lens dislocation
- Curvature of the spine
- Disproportionately long arms
- Long, double-jointed fingers
- Unusually long lower half of body
- Chest bone that curves inward or outward

### Diagnosis

Early diagnosis and careful management of a Marfan patient are essential. Diagnosis requires a multi-system evaluation by a cardiologist to examine the size and function of the aorta; an orthopedist to measure the skeleton; an ophthalmologist to examine the eyes; and a medical geneticist. There is no simple blood or skin test to make the diagnosis, however, genetic testing is helpful in some cases.

### Going Forward

People with Marfan syndrome and related disorders can live a normal life span if they are diagnosed, monitored and treated. Treatment includes frequent monitoring of the aorta and medication to slow its enlargement. Surgery can prevent an aortic tear or rupture. The other affected body systems require ongoing monitoring as well. Lifestyle modifications should also be made to reduce the strain on the fragile aorta and reduce the impact on the eyes and joints.



National Marfan Foundation  
Mid-Atlantic Chapter  
Delaware • Maryland • Virginia  
Washington, D.C. • West Virginia



*Serving the Needs of People with  
Marfan Syndrome and Related Disorders*  
800 8 MARFAN (800 862-7326)  
www.marfan.org

## Who We Are

The National Marfan Foundation (NMF), established in 1981, is the primary source of accurate and up-to-date information on Marfan syndrome and related connective tissue disorders. The NMF provides the Marfan syndrome and related disorders community with education and support, and fosters research on these conditions. It maintains a valuable Information Resource Center accessible via a toll-free number (800 8 MARFAN) and a website ([www.marfan.org](http://www.marfan.org)). The Foundation has an annual conference for patients, families and healthcare providers.

The Mid-Atlantic Chapter is part of the NMF's National Volunteer Network and acts as an extension of the NMF locally by providing support, education, awareness and fundraising.

## Our Chapter's Mission

The Mid-Atlantic Chapter is dedicated to implementing the mission of the National Marfan Foundation at the local level: to save lives and improve the quality of life for affected individuals and families through education and awareness, advocacy, support services and research.

## Chapter Programs, Support, Events

### Annual Awareness and Advocacy Events

- NBC4 Health & Fitness Expo, Washington, DC
- NMF Lobby Day, Capitol Hill
- University of Maryland Basketball Game Awareness Event, NMF Information Table with Chapter Volunteer Greeters, Main Concourse, Comcast Center, College Park Campus

### Service

- Heartfelt Taste of Home  
*Support for Extended-Stay Families*



Our newest program supports patients and their families from out of the area who experience ex-

tended stays at Johns Hopkins University (JHU) Hospital in Baltimore while undergoing Marfan-related care. The Chapter provides gift baskets of comfort items and a get well card. As the project expands, the Chapter will also provide dinners.

*An Open Invitation* If you or someone you know will be coming to the Baltimore area for Marfan-related medical care and have an interest in learning more about this program, please contact Cindy Amdur at 301 879-1602, [amdurclark@yahoo.com](mailto:amdurclark@yahoo.com).

*Calling All Volunteers* We are seeking Chapter volunteers, particularly from the Baltimore area, to help. If interested, please contact Cindy.

### Meetings and Networking Opportunities

Our area is very large. Would you like to host a meeting? Please contact Amy Speck, 301 371-5660, [siberianspring@hughes.net](mailto:siberianspring@hughes.net).

### Chapter Meetings

- Annual Expert Medical Speakers Presentations and Chapter Spring Meeting  
JHU Hospital, Baltimore, MD
- Chapter BBQ & Potluck Meetings, varied locations
- Chapter Fall Social, varied locations

### Networking Groups

- Tidewater Networking Group, Norfolk, VA  
Contact: JD Oliver, [oliverva@aol.com](mailto:oliverva@aol.com),  
757 962-4823

### Annual Fundraisers

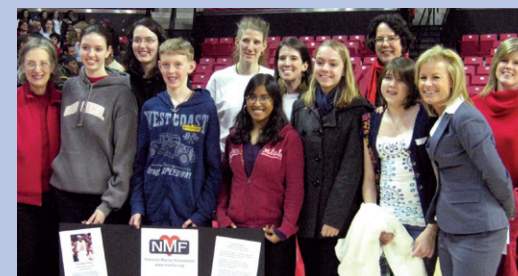
- Annual Golf Tournament, South Riding, VA
- Hard Times Café, College Park, MD

### Previous Programs, Projects and Events

- Heart & Soul Music for Marfan, Wolfsville, MD
- Hounds Helping Hearts Dog Walk, Sharpsburg, MD
- Foster's Grill Fundraiser & Raffle, Chantilly, VA
- National Institutes of Health (NIH) Rare Disease Day Awareness Event, NMF Information Booth Support, Bethesda, MD
- Genetic counseling publication project, in collaboration with NIH and JHU Hospital



*NBC4 Health & Fitness Expo, left  
NMF Lobby Day, below*



*University of Maryland Basketball Game Awareness Event, above; Annual Expert Medical Speakers Presentations and Chapter Spring Meeting, below*



*above, Chapter Planning Meeting; far left, Annual Golf Tournament; left; Heart & Soul Music for Marfan*

