Marfan syndrome is a life-threatening genetic disorder, and an early, accurate diagnosis is essential, not only for people with Marfan syndrome, but also for those with related disorders. Knowing the signs of Marfan syndrome can save lives.

About 1 in 5,000 people have Marfan syndrome, including men, women and children of all races and ethnic groups.

Our community of experts estimates that nearly half of the people living with Marfan syndrome don’t know it. Without proper diagnosis and treatment, they are at high risk for aortic dissection (a tear in the artery that takes blood away from the heart) and sudden death.

What are related disorders?
Related disorders are genetic conditions that, like Marfan syndrome, can cause the aorta to enlarge. They too require regular care.

Advances in diagnoses, treatments, care and research about Marfan syndrome will likely advance the diagnoses, treatments, care and research about related disorders—and vice versa.

THE MARFAN FOUNDATION

The Marfan Foundation, founded in 1981, is a non-profit voluntary health organization that creates a brighter future for everyone affected by Marfan syndrome and related disorders.

• We pursue the most innovative research and make sure that it receives proper funding.
• We create an informed public and educated patient community to increase early diagnosis and ensure life-saving treatment.
• We provide relentless support to families, caregivers, and healthcare providers.

We will not rest until we’ve achieved victory—a world in which everyone with Marfan syndrome or a related disorder receives a proper diagnosis, gets the necessary treatment, and lives a long and full life.

About 1 in 5,000 people have Marfan syndrome, including men, women and children of all races and ethnic groups.

Our community of experts estimates that nearly half of the people living with Marfan syndrome don’t know it. Without proper diagnosis and treatment, they are at high risk for aortic dissection (a tear in the artery that takes blood away from the heart) and sudden death.

What are related disorders?
Related disorders are genetic conditions that, like Marfan syndrome, can cause the aorta to enlarge. They too require regular care.

Advances in diagnoses, treatments, care and research about Marfan syndrome will likely advance the diagnoses, treatments, care and research about related disorders—and vice versa.

THE MARFAN FOUNDATION

Know the signs. Fight for victory.

22 Manhasset Avenue, Port Washington, NY 11050
516 883 8712  800 8 MARFAN
Marfan.org
HOW WE HELP

We provide a supportive community for everyone affected by Marfan syndrome and related disorders.

- We deliver expansive information for patients, family members, and healthcare providers through our website.
- Our help center, staffed by a registered nurse and a licensed social worker, is accessible by phone and email for personalized assistance.
- We provide special resources for children, teens, parents, and other specialized groups.

Get Connected

Connect with other people living with Marfan syndrome and related disorders.

- Our active volunteer network organizes support for individuals and families.
- Our online community provides a fun and engaging way for people to find each other and share experiences.

Annual Family Conference

Our annual four-day summer event is life-changing for patients and their families.

- Receive free patient health assessments by medical professionals with expertise in Marfan syndrome and related disorders.
- Hear about the latest research and medical issues and learn how to cope in general sessions and small group workshops.
- Participate in specialized programs for adults, young adults, children, and teens.

JOIN US IN OUR FIGHT FOR VICTORY!

We need your help to create a brighter future for everyone affected by Marfan syndrome and related disorders.

Volunteer

- Join one of our many community groups nationwide or start a project on your own.

Fundraise

- Throughout the year, many companies, community groups and volunteers join existing events or organize their own events to raise funds on our behalf. Visit our events calendar and explore our fundraising toolkits to learn more.

Team Victory

- Join our team and walk, run, or ride in an endurance event in your own community or choose one of the premiere events across the country where we are a charity partner. Can’t take part in an endurance event? Join us as a Spirit Runner!

Give

- Make a difference in the lives of people living with Marfan syndrome and related disorders by making a charitable contribution to support our life-saving programs of research, education, and support.

We create a brighter future for everyone affected by Marfan syndrome and related disorders.

We will not rest until we have achieved victory—join us!

KNOW THE SIGNS

Some features of Marfan syndrome are easier to see than others. These include:

- Long arms, legs, and fingers
- Tall and thin body type
- A curved spine
- Chest that sinks in or sticks out
- Flexible joints
- Flat feet
- Crowded teeth
- Stretch marks without weight change

Harder to detect signs include heart complications, especially related to the aorta, the large blood vessel that carries blood away from the heart.

Other signs include sudden collapse of a lung and eye problems, including severe nearsightedness, dislocated lens, detached retina, early glaucoma, and early cataracts.

There are also several disorders related to Marfan syndrome that cause people to struggle with the same or similar physical problems with their heart and blood vessels, eyes, bones and joints, and lungs, and anyone affected by these disorders also needs an early and accurate diagnosis.

Knowing the signs of Marfan syndrome and related disorders can save lives.