MARFAN SYNDROME AND TREATMENT

What causes Marfan syndrome?

Marfan syndrome is caused by a genetic defect. The affected gene is called **fibrillin-1 or FBN1**. It contains information about making fibrillin and elastic fibers, which are a large part of the connective tissue in your body.

Marfan syndrome is usually inherited. It can be passed onto children by just one parent with the condition. If you have Marfan syndrome, you have a 50 percent chance of passing it onto your children. But, 25 percent of patients with Marfan syndrome do not have a parent with the condition, and the cause of the genetic defect is not known.

The condition is congenital, which means it is present at birth, but some patients are not diagnosed until they are adolescents or young adults.

What is Marfan syndrome?

Marfan syndrome (also called Marfan's syndrome or Marfans syndrome) is a condition that affects your connective tissue. Connective tissue holds your body together and acts as support for many structures. Patients with Marfan syndrome have abnormal connective tissue. As a result, many body systems are affected, including the heart, blood vessels, bones, tendons, cartilage, eyes, nervous system, skin and lungs.

Who is affected by Marfan syndrome?

Marfan syndrome affects 1 in 10,000 to 20,000 people of all races and ethnic backgrounds. It is just as common in men as it is in women.

What are the signs of Marfan syndrome?

Not everyone with Marfan syndrome has the same symptoms and appearance to the same degree. Some patients have few, if any symptoms. In most cases, the disease gets worse with age, and symptoms appear when there are changes in the connective tissue.

Physical Appearance

People with Marfan syndrome are often very tall and thin. Their arms, legs, fingers and toes may seem out of proportion and too long for the rest of their body. Their spine may be curved and their breastbone (sternum) may either stick out or be indented. Their joints may be weak and easily become dislocated. Many people with Marfan syndrome have a long, narrow face, and the roof of the mouth may be higher than normal, causing the teeth to be crowded.

Dental and bone problems

Patients with Marfan syndrome often have a narrow palate. Because of this, they often need a palate expander or have teeth removed. Other common problems are bone problems, such as flat feet, hernias and dislocated bones. Other signs of Marfan syndrome are an abnormal arm span-to-height-ratio and the ability to stick the thumb out past the palm of the hand when they make a fist.

Signs of Marfan syndrome (continued)

Eye problems

More than half of all people with Marfan syndrome have eye problems. These include being nearsighted (trouble seeing objects in the distance), lens subluxation (lens of the eye moves away from its normal position), a difference in the shape of the eye, and other issues.

Changes in the heart and blood vessels

The majority (about 90%) of people with Marfan syndrome develop changes in their heart and blood vessels.

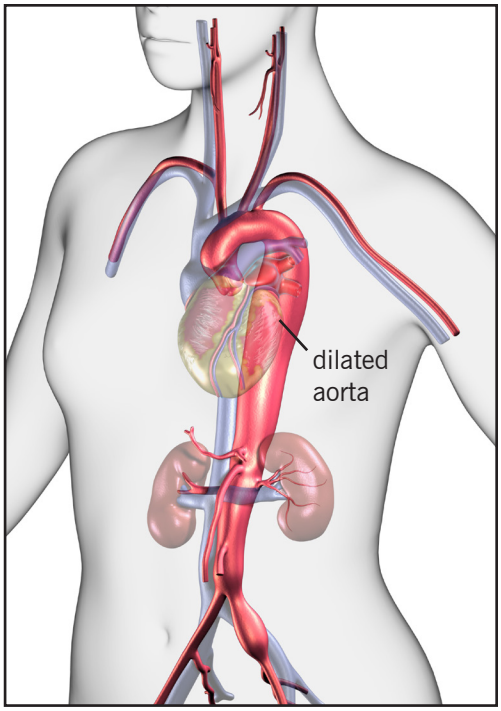
- **Blood vessel changes:** Marfan syndrome causes the walls of the blood vessels to become weak and dilate (stretch). These changes often affect the aorta, the major artery that carries blood from the heart to the rest of the body. When the walls of the aorta become stretched, there is a greater risk of aortic aneurysm, aortic dissection or rupture (bursting). Any section of the aorta can dilate or dissect. These conditions can lead to a medical emergency and can be life-threatening.

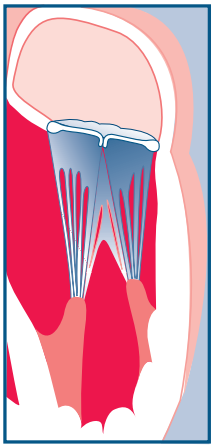
  The condition also increases the risk of bleeding in the brain and brain aneurysms called Berry aneurysms.

- **Aortic root dilation:** The aortic root is the area where the aorta meets the aortic valve. Marfan syndrome can cause the aortic root to get wider. This can cause the aortic valve to become stretched and leak. Aortic root dilation is the most common aortic problem among patients with Marfan syndrome.

- **Heart valve problems:** The heart's valves, especially the mitral valve, can be affected by Marfan syndrome. The valve leaflets become floppy and do not close tightly. This lets blood leak backwards across the valve (mitral valve prolapse, also called MVP). When MVP gets worse, the valve leaks and the condition is called mitral valve regurgitation.

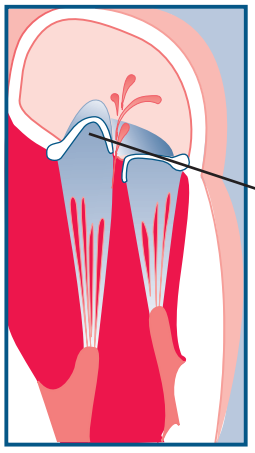
  Mitral valve prolapse and regurgitation can cause mild to serious valve leakage. Mild valve leaks do not create extra work for the heart, but if you have one of these problems, you need routine follow-up care. More serious valve leakages cause the heart to work harder and can cause symptoms such as shortness of breath, feeling overtired or heart palpitations (fluttering in the chest). The abnormal blood flow may cause a heart murmur (abnormal heart sounds heard through a stethoscope). Over time, the heart can get bigger and lead to heart failure.





Normal mitral valve

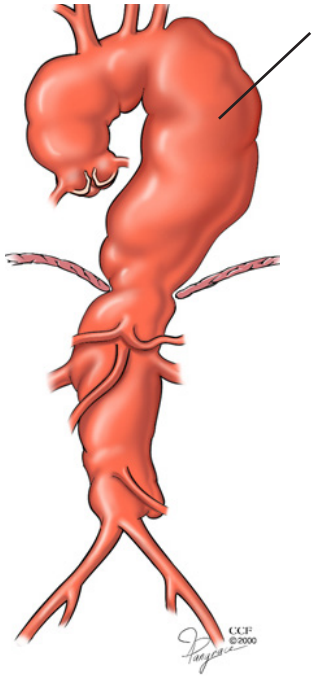
Leaflets close tightly



Mitral valve prolapse

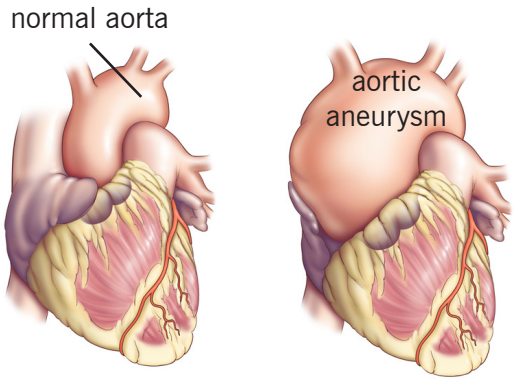
Leaflets are stretched and flop back into the left atrium with each heartbeat

Aortic Aneurysm



An aortic aneurysm is an abnormal enlargement or bulging of the wall of the aorta. An aneurysm can form anywhere in the vascular tree.

Treatment may be needed, depending on the size of the aneurysm. Emergency surgery to stop the bleeding is needed if an aneurysm ruptures.



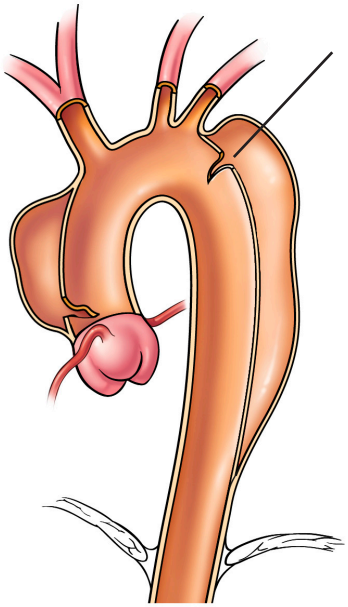
Symptoms of Aortic Aneurysm

- **Symptoms of a thoracic aortic aneurysm** (affects upper part of aorta in chest): Pain in the jaw, neck, upper back or chest; coughing, hoarseness or trouble breathing
- **Symptoms of an abdominal aortic aneurysm** (affects the lower part of the aorta in the abdomen): Pulsating enlargement or tender mass felt by a doctor during an exam; pain in the back, abdomen or groin that does not get better if you change positions or take pain medication

Early diagnosis of an aneurysm is critical to best manage the condition and reduce the risk of rupture.

If you have symptoms of an aneurysm, call your doctor right away.

Aortic Dissection



The aorta has many layers. Aortic dissection is a tear in the inner layer of the aorta. This causes blood to flow between the layers. The layers then separate, interrupting the blood flow, and the artery wall can burst.

Aortic dissection is a life-threatening emergency that requires immediate treatment.
Surgery is done to repair or replace the damaged section of the aorta.

The goal is to perform surgery **BEFORE** there is a dissection. This reduces the risk of death and improves long-term life expectancy.

Most patients who have surgery before a dissection happens do not need more surgery. But, surgery after an aortic dissection increases the need for future surgeries to repair other sections of the aorta.

Symptoms of Aortic Dissection

- **Most common symptom:** Severe pain in the chest (front, back or both)
- **Less common symptoms:** Pain in the abdomen, numbness or weakness in one or both legs, loss of consciousness or symptoms of a stroke (sudden weakness, numbness, dizziness or loss of balance; sudden vision changes; sudden confusion, trouble speaking)

If you have symptoms of an aortic dissection, call 911!

Signs of Marfan syndrome (continued)

- **Cardiomyopathy:** Marfan syndrome can cause the heart muscle to get bigger and weaker over time, causing disease of the heart muscle (cardiomyopathy). This can happen even if the valves are not leaking. Cardiomyopathy can lead to heart failure.
- **Arrhythmia** (abnormal heart rhythm): Some patients with Marfan syndrome develop an arrhythmia. This is often related to mitral valve prolapse, but can also happen if you have a dilated ventricle.
- **Lung changes:** The changes in lung tissue related to Marfan syndrome increase your risk of asthma, emphysema, chronic obstructive pulmonary disease (COPD), bronchitis, pneumonia and a collapsed lung.
- **Skin changes:** Marfan syndrome causes the skin to become less elastic. This can lead to stretch marks, even without changes in weight.

How is Marfan syndrome diagnosed?

Accurate diagnosis of Marfan syndrome requires a multidisciplinary approach because the condition affects many organ systems. Your healthcare team will review your family history and any symptoms you have. You will have a thorough exam that includes your eyes, heart and blood vessels, spine and bones.

You will have tests, such as a chest X-ray, electrocardiogram (ECG) and echocardiogram (an ultrasound of your heart's valves and chambers). These tests show changes in your heart, blood vessels and heart rhythm.

You may need a transesophageal echo (TEE), magnetic resonance imaging (MRI), or computed tomography (CT) scan if your doctor needs more detailed images or if it is likely you have an aortic dissection.

An MRI or CT can also be used to check for a condition called **dural ectasia.** This is a bulging in the lining of the spinal column. The condition can cause back pain, but often does not cause any symptoms. Dural ectasia is common in patients with Marfan syndrome but can also be caused by other connective tissue disorders.

A blood test can be used to help diagnose Marfan syndrome. This blood test is highly specialized and is used to detect changes in **FBN1**, the gene that is responsible for most cases of Marfan syndrome.

Blood tests also help diagnose other genetic mutations, such as Loeys-Dietz syndrome, that are similar to Marfan syndrome.

Genetic Testing

What is genetic testing?

Genetic testing is a specialized lab test that looks for changes (mutations) in your genetic material (DNA, genes or chromosomes) or in the products that the genes make. Genetic testing usually uses a blood sample, but other samples (like cheek cells or skin) are sometimes needed.

The FBN1 test is about $2,000. The cost of the test is often covered by insurance, but check your coverage before you have the test done.

More than 2,000 different mutations have been identified in FBN1; most mutations are unique to an individual family. Once a mutation is found in one family member, the same mutation is likely to be found in other family members who have Marfan syndrome. Sometimes more testing that may include other family members is needed to confirm Marfan syndrome.

Patients with Loeys-Dietz syndrome may have signs of Marfan syndrome, but are usually not as tall, have elastic skin, have an aortic valve with two (instead of three) leaflets, and a divided or abnormal uvula (the piece of flesh that hangs down at the back of your throat).

Who should have genetic testing?

You may want to have testing if:

- **You know you have Marfan syndrome and would like family members to be tested.** Genetic testing should start with the person who has been diagnosed with Marfan syndrome. Once a genetic mutation is identified, other family members can be tested for that mutation at a lower cost.
- **You want to confirm that you have Marfan syndrome.** Genetic testing may confirm a diagnosis of Marfan syndrome. But, genetic testing cannot confirm all cases of Marfan syndrome. If a clinical diagnosis is not confirmed with genetic testing, it does not mean you do not have Marfan syndrome. It just means that it was not possible to find the genetic reason for the condition.
- **If you were seen by your doctor to find out if you have Marfan syndrome, but were not diagnosed with the condition.**
- **If your doctor thinks you may have Marfan syndrome but is not sure.**
- **If a family member has a genetic mutation.**

Genetic counseling should be combined with genetic testing to help you fully understand your condition.

What treatments are available for patients with Marfan syndrome?

Patients with Marfan syndrome need a plan of care based on their individual needs. You may not need treatment, but you do need regular follow-up appointments. Treatment may involve medications or surgery.

Important considerations

- **Follow-up care**: You need to have regular follow-up care that includes cardiovascular, eye and skeletal exams, especially if you are still growing. Your doctors will let you know how often you need to be seen.

- **Activity:** The amount of activity you can do depends on the extent of the disease and your symptoms. Most people with Marfan syndrome can take part in some type of physical and/or recreational activities. You may need to avoid high-intensity team sports, contact sports, and isometric exercises (such as weight lifting) if you have a dilated aorta. Activities that involve fast movement involving the upper chest and arms while straining should especially be avoided. Ask your cardiologist about the activity guidelines that are right for you.
- **Pregnancy**: You should have genetic counseling before becoming pregnant since Marfan syndrome is an inherited condition. Pregnant women with Marfan syndrome are considered high-risk cases. If the aorta is normal size, the risk of dissection is lower, but still exists. Even a slight enlargement of the aorta causes a greater risk, and the stress of pregnancy can cause the dilation to progress faster than normal. Your doctor may recommend surgery before you become pregnant. Careful follow-up with frequent blood pressure checks and monthly echocardiograms are needed during pregnancy. If your aorta quickly gets larger or if you have aortic regurgitation, you may need to stay in bed or have surgery. Your doctor will talk to you about the best type of delivery and other details about your care during pregnancy.
- **Bacterial endocarditis prevention:** If you have Marfan syndrome and have had valve or aortic surgery, you are more at risk of getting bacterial endocarditis. This is an infection of the heart valves or tissue caused by bacteria in the blood stream. Talk to your doctor about ways to reduce your risk of bacterial endocarditis, such as by taking antibiotics before you have dental or surgical procedures. You can get a card with detailed information about taking preventive antibiotics from the American Heart Association.

Medications

Medications are not used as treatment for Marfan syndrome; however, you may need to take medications to prevent or control complications. Medications may include:

- **Beta-blockers** help the heart relax, decrease the force of your heartbeat and pressure inside your arteries. This helps prevent or slow the enlargement of the aorta. Beta-blocker therapy usually starts at an early age.
  If you cannot take beta-blockers due to asthma or side effects, your doctor may prescribe a calcium channel blocker, which may help strengthen the aorta.
- **Angiotensin receptor blockers (ARBs)** are often used to treat patients with high blood pressure as well as heart failure. Research also shows that ARBs help slow the enlargement of the aorta as well as beta blockers do.

Surgery

You may need surgery to prevent an aortic dissection, rupture, or to correct a problem with your heart valves. Surgery may also be needed if you are pregnant.

The need for aortic surgery is based on the size of the aorta; expected normal size of the aorta; how fast the aorta is growing; your age, height, and gender; and family history of aortic dissection. Surgery involves replacing the dilated part of the aorta with a graft.

Surgery is not recommended until the aorta is more than 4.7 cm to 5.0 cm wide, depending on your height, or if the aorta quickly gets wider. Your cardiologist may also calculate your aortic root diameter-to-height ratio. Surgery is recommended if the ratio is greater than 10.

Recovery generally takes 6 to 8 weeks, including 5 to 10 days in the hospital. Most patients can return to normal activities after they fully recover. Your doctor will talk to you about restrictions.

You may need valve repair or replacement surgery if you have a leaky aortic or mitral valve (regurgitation) that causes shortness of breath, changes in the left ventricle or heart failure.

Surgical Treatment for Marfan Syndrome

The goal of surgery for patients with Marfan syndrome is to prevent aortic dissection or rupture and fix valve problems. Patients with Marfan syndrome should have the procedure done at a major center by a surgeon experienced in treating patients with Marfan syndrome. The combination of experience, early detection, careful follow-up and advanced technology to perform surgery leads to better outcomes.

At Cleveland Clinic, the surgical survival rate is 99% for patients who had surgery for marfan syndrome or related connective tissue disorders. And, the 10-year survival rate is 82%.

Aorta Surgery for Patients with Marfan Syndrome

Two surgical techniques can be used to replace the enlarged area of the aorta with a graft:

- **Traditional method:** The aorta is replaced with a graft and the aortic valve is replaced with a mechanical valve.
- **Valve-sparing modified reimplantation method:** The aorta is replaced with a tube graft and the patient's own aortic valve is put back in place. The valve-sparing method is done whenever possible and should be done by an experienced surgeon.

Traditional aorta surgery method

If you have traditional aorta surgery, your surgeon will remove the area of the aorta that has the dissection or aneurysm.

A mechanical valve, attached to the end of an aortic graft, is sewn to the opening (annulus) of the aortic valve.

The coronary arteries are reattached to the aortic graft through small holes cut into the graft. Then, the other end of the graft is sewn to the aorta.

Patients who have a mechanical valve need to take anticoagulants ("blood thinners") for the rest of their lives to prevent blood clots.

Valve-sparing aorta surgery

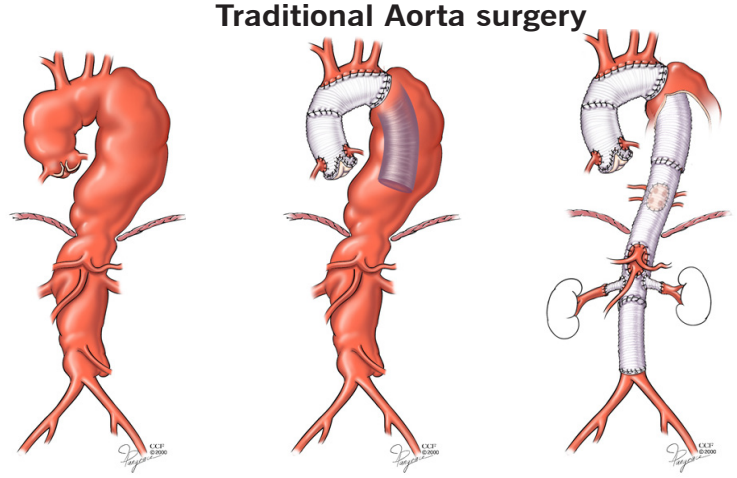
There are two ways to replace the aorta without replacing the aortic valve:

- Valve sparing reimplantation method
- Valve remodeling method

These techniques can be used in young patients if the aorta is not enlarged and if the aortic valve is not damaged.

Patients who have this surgery do not need to take "blood thinners" for the rest of their lives, unless they are part of treatment for another condition.

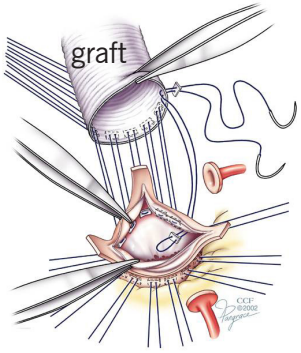
Traditional Aorta surgery



Aortic aneurysm

Repair of aortic aneurysm with graft

Valve-sparing modified reimplantation aorta surgery

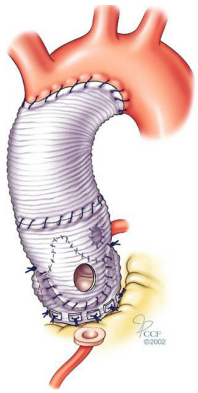


The surgery involves freeing and repairing the aortic valve and replacing the damaged section of the aorta with a synthetic tube graft.

Sutures are placed through the graft and just below the aortic valve, around the left ventricular outflow tract.

A custom-sized dilator device is placed in the left ventricular outflow tract, through the aortic valve. Sutures are tied around the dilator to shape the bottom portion of the aorta graft, similar to the natural aortic root.

The repaired aortic valve is reimplanted and the aortic graft is sewn to the annulus of the repaired valve. The valve is tested to make sure it opens and closes properly.



Small holes are made in the graft for the openings where the coronary arteries are reattached.

The graft is sewn to the aorta. If the aortic arch needs to be replaced, a separate graft is sewn from the aortic arch to the aortic root graft.

Valve Repair or Replacement Surgery for Patients with Marfan Syndrome

If you have a leaky aortic or mitral valve (regurgitation) that causes shortness of breath, changes in the left ventricle or heart failure, you may need to have the valve repaired or replaced.

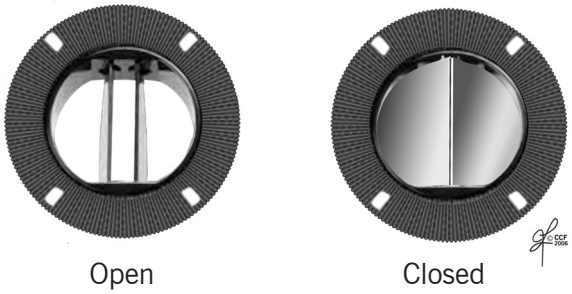
Your doctor will talk to you about available treatments and the best option for you. One option is the **modified David's reimplantation procedure**. This procedure involves an aortic graft and keeping the passageway out of the left ventricle and aortic valve in tact. More information about this procedure and surgical videos are available at: **www.clevelandclinic.org/marfan.**

Cleveland Clinic surgeons are experienced in combining valve surgery with other heart surgeries, such as repair or replacement of more than one valve, bypass surgery, aortic aneurysm surgery or surgery to correct atrial fibrillation. Your surgeon will talk to you about combining procedures if this is the best option for you.

Mechanical Heart Valves

Mechanical heart valves are made of metal or carbon and are designed to perform the functions of your own heart valve. A mechanical valve is very durable, well-tolerated by the body and is designed to last a lifetime.

The bi-leaflet valve is the most common type of mechanical valve and consists of two carbon leaflets in a ring covered with polyester knit fabric.



Open Closed

Follow-Up Care

Regular follow-up care is very important for patients with Marfan syndrome, even those who have surgery.

It is also important to take all your medications as prescribed and make lifestyle changes as needed to reduce your risk of developing further cardiovascular problems.

Please talk to your doctor or other member of your healthcare team about any questions or concerns you have about your condition, treatment, medications or prevention.

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Support is Available

We understand that learning you have a genetic disorder, such as Marfan syndrome, is concerning. You may be worried about making lifestyle changes, having surgery, the need for lifetime follow-up care or finances. You may also be concerned about the risk of passing the condition onto your children.

It is important to get medical care and information from a doctor who is experienced in treating patients with marfan syndrome. It may also be helpful to get genetic counseling to help understand the disease and the risks for your children.

In addition to the Marfan syndrome resources at Cleveland Clinic (listed below), these national organizations offer information and support:

National Marfan Foundation
www.marfan.org
800.862.7326

National Institute of Arthritis and Musculoskeletal and Skin Disease
www.niams.nih.gov
877.226.4267

American Heart Association
www.americanheart.org
800.242.8721

Marfan Syndrome and Connective Tissue Disorder Clinic

The multidisciplinary team of experts in the Marfan Syndrome and Connective Tissue Disorder Clinic includes cardiologists, pediatric cardiologists, cardiovascular and vascular surgeons, ophthalmologists, orthopedic surgeons and genetic specialists. Our goal is to help patients live longer and improve their quality of life. We provide:

- A thorough evaluation of patients using state-of-the art diagnostic testing
- Ongoing comprehensive care for patients with disease of the aorta, connective tissue disorder, and Marfan syndrome
- Genetic screening for family members of those with genetic disorders, such as Marfan syndrome
- Ongoing research and education to offer patients high quality and innovative therapies

For More Information

For more information about Marfan syndrome and treatments, please visit our website at: **www.clevelandclinic.org/marfan** or email us using the Contact Us form on the web at **www.clevelandclinic.org/heart**.

You can talk to a registered nurse about Marfan syndrome and treatment options. Please call the Heart & Vascular Resource Center Nurse line at **866.289.6911.**

To make an appointment, please call **800.659.7822.**

About the Sydell and Arnold Miller Family Heart & Vascular Institute

The Sydell and Arnold Miller Family Heart & Vascular Institute at Cleveland Clinic is one of the largest cardiovascular specialty groups in the world, providing patients with expert medical management and a full range of therapies. **Our cardiac care program has been ranked number one since 1995 by *U.S. News & World Report*.**

We combine research, education and clinical practice to provide innovative and scientifically based treatments for patients with cardiovascular disease. Our physicians and scientists are committed to the prevention and cure of cardiovascular disease. This commitment has led to innovative care, better outcomes and improved quality of life for patients with cardiovascular disease.

This information is not intended to replace the medical advice of your doctor or healthcare provider. Please consult your healthcare provider for advice about a specific medical condition.

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