

Dear _____:

I have observed that _____ has the features checked at right. Because people with these features sometimes have a medical condition called Marfan syndrome, I strongly suggest further evaluation for this condition by a geneticist who knows about Marfan syndrome.

Marfan syndrome is a genetic disorder of connective tissue. Connective tissue is found throughout the body, so Marfan syndrome can affect many different body systems, including the skeleton, heart and blood vessels, eyes, lungs, nervous system, and skin. Approximately 75% of people inherit the condition from an affected parent, but about 25% have no family history at all.

Having the features noted here does not always mean a person has Marfan syndrome, but it does mean a person should have an evaluation by a doctor familiar with the syndrome.

For more information about Marfan syndrome, including what is needed for an evaluation, you can contact The Marfan Foundation at 800-862-7326, ext. 126 or go to marfan.org

Sincerely,

Name _____

Telephone _____

Referral:

For more information about Marfan syndrome and related disorders, contact The Marfan Foundation:



**THE MARFAN
FOUNDATION**

Know the signs. Fight for victory.

22 Manhasset Avenue
Port Washington, NY 11050
800-8-MARFAN
marfan.org

Please keep in mind that any of the features at right taken individually does NOT mean a person has Marfan syndrome. However, when observed in combination, further evaluation by a doctor familiar with connective tissue disorders and testing may be necessary.

Marfan Features Checklist:

Skeletal System

- tall, thin stature (often but not always)
- indented or protruding chest bone
- long arms and/or legs
- wrist and thumb signs (a measurement of loose joints and long fingers)
- scoliosis or kyphosis
- reduced extension at the elbows
- flat feet and/or hammer toes
- joint hypermobility
- high-arched palate and/or crowding of the teeth
- long, narrow face (dolichocephaly)
- underdeveloped cheekbones (malar hypoplasia)
- deep set (enophthalmos) or down slanting eyes
- receding jaw (retrognathia)

Cardiovascular System

- dilated aorta
- dissected aorta
- mitral valve prolapse
- dilation of main pulmonary artery
- calcification of the mitral annulus
- descending aortic dilation or dissection
- heart murmur

Pulmonary System

- spontaneous pneumothorax
- apical blebs

Ocular System

- dislocated lens (ectopia lentis)
- abnormally flat cornea
- under-developed (hypoplastic) iris or dilator muscle causing increased miosis
- severe nearsightedness (myopia)

Skin

- unexplained stretch marks
- recurrent incisional hernias

Central Nervous System

- lumbosacral dural ectasia (swelling or bulging of the dura)

Family History

- family member with early cardiac death, unexplained or identified as Marfan syndrome
- family history of aortic aneurysm
- height unusual for family
- height unusual for age

Other Observations

- _____
- _____
- _____