

Medical Management Plan of Care for Marfan's Syndrome
Green River District School Health Program

Student: _____ Date of Birth: _____

Date: _____ School: _____

Physician(s): _____

Marfan Syndrome is a rare inherited connective tissue disorder in which cardiac and other complications can cause sudden death or greatly impair life. Because connective tissue is found throughout the body many body systems can be affected including the skeleton, eyes, heart and blood vessels, nervous system, skin, and lungs.

Skeletal problems include kyphoscoliosis. Affected persons are typically very tall, slender, and loose jointed. Long bones may be disproportionate in relation to the rest of the body. Frequently there are visual problems that may cause dislocation of the lenses of one or both eyes, retinal detachment and often near-sightedness. Some may even develop glaucoma or cataracts. Heart defects include mitral valve prolapse, tachycardia arrhythmias, aortic dilatation or rupture causing sudden death. Dural ectasia can cause symptoms of mild discomfort or radiating pain in the abdomen, numbness, or weakness in the legs. The nurse may see stretch marks without weight change, an abdominal or inguinal hernia. There is a risk of pneumothorax if the alveoli becomes stretched and swollen.

There is no cure for Marfan Syndrome. With early diagnosis and proper management life expectancy is similar to that of the average person. Treatment is directed toward specific problems.

Problem: Cardiac Arrest

Goal: Prompt recognition and first aid

Action:

1. School staff members and school nurse that are trained in CPR should be readily available if needed and be up to date on the student's current physician orders.
2. Contact sports and overexertion should be avoided.
3. Physician permission to participate in PE and other physical activities is required annually.
4. Current physician recommendations for activity. See attachment.

Problem: Kyphoscoliosis

Goal: Early recognition

Action:

1. Kyphoscoliosis is the backwards and sideways curving of the spine. It can be severely disabling and deforming if not detected and treated early.
 - a. Encourage routine annual scoliosis screenings and during rapid growth.
 - b. Serious deformity can cause not only disfigurement but prevent the heart and lungs from functioning properly.

Problem: Visual disturbance

Goal: Early recognition

Action:

1. Regular eye exams are crucial.
2. Corrective lenses, contact lenses or glasses can correct acuity.
3. Surgery may be needed for lens displacement or detached retina.

Problem: Dural ectasia

Goal: Minimize pain

Action:

1. Administer medication as prescribed by physician to relieve pain.
2. Refer to physician to follow up care.

Problem: Spontaneous pneumothorax

Goal: Improve air exchange

Action:

1. Discourage smoking
2. Manage other respiratory symptoms as needed.
3. Call 911

CONTACT INFORMATION

Parent/guardian

Name: _____

Address: _____

Telephone: Home _____ Work _____ Cell _____

SIGNATURES

This health care plan has been reviewed by:

Physician Date

Parent/guardian Date

School Nurse Date