Marfan Syndrome:
Need-to-Know Information for the Teacher

National Marfan Foundation

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INTRODUCTION

Marfan syndrome affects an estimated 200,000 men, women and children in the United States regardless of sex, race or ethnicity. It affects the heart, eyes, lungs, bones and other parts of the body and is potentially life-threatening.

Living with a serious medical condition is not easy for anyone, but dealing with it during childhood can be particularly challenging. As demonstrated by the thousands of inquiries received by the National Marfan Foundation (NMF) Information Resource Center, parents of children with Marfan syndrome experience a great deal of anxiety about sending their children to school. They are concerned that teachers are not adequately equipped to deal with their child's special needs. Typical activities of childhood can be profoundly affected by the disorder, with school-based activities such as recess, the pressures of social relationships and rigors of classroom participation made more difficult and sometimes overwhelming.

Many children with Marfan syndrome suffer from low self-esteem because they look "different" and are unable to participate in many of the activities of their peers, reinforcing intense feelings of isolation. Physical limitations can require special accommodations at school to ensure that children receive the education to which they are entitled. An adaptive physical education plan is a necessity.

This resource will provide teachers with the information and tools they need to:

- **Know the basics** of Marfan syndrome and its impact on the child.
- **Provide necessary educational and classroom accommodations** to ensure the best learning environment for students with Marfan syndrome.
- **Create a supportive environment** for students with Marfan syndrome.
- **Develop lesson plans** to incorporate an understanding of Marfan syndrome and/or genetic diversity into the classroom.

OVERVIEW OF MARFAN SYNDROME

What is Marfan syndrome?

Marfan syndrome is a genetic disorder of the connective tissue. Connective tissue is the glue and the scaffolding of the body and helps control how the body grows. All organs contain connective tissue, so Marfan syndrome can affect many parts of the body, including the bones, eyes, lungs and heart. It does not affect cognitive functions.

Marfan syndrome is caused by a variation (mutation) in the gene that tells the body how to make fibrillin-1, a protein that is an important part of connective tissue. About three quarters of people with Marfan syndrome inherit it from a parent; the remainder are the first in their family to be affected.

People are born with Marfan syndrome but may not notice any features until later in life. Marfan syndrome features can appear at any age, including in infants and young children. They often get worse as people age.

About 1 in 5,000 people have Marfan syndrome. This includes men and women of all races and ethnic groups. There is no cure for Marfan syndrome, but with early diagnosis, proper treatment and careful management of the disorder, it is possible for people to live a normal life span.

Features of Marfan syndrome

Marfan syndrome features occur in many different parts of the body. A person rarely has every feature. Some features are easy to see, while others, such as heart problems, are hidden and need special tests to find them. It is important that a person with Marfan syndrome features see a doctor who is familiar with the disorder. Following are the most common features of Marfan syndrome:

Heart and blood vessels (Cardiovascular system)

- Enlarged or bulging aorta, the main blood vessel that carries blood from the heart (aortic dilation or aneurysm)
- Separation of the layers of the aorta that can cause it to tear (aortic dissection)
- "Floppy" mitral valve (mitral valve prolapse—MVP)

Bones and Joints (Skeletal system)

- Long arms and legs
- Tall and thin body type
- Curvature of the spine (scoliosis or kyphosis)
- Chest sinks in (pectus excavatum) or sticks out/pigeon breast (pectus carinatum)
- Long, thin fingers
- Flexible joints
- Flat feet
- Teeth that are too crowded

Eyes (Ocular system)

- Severe nearsightedness (myopia)
- Dislocated lens of the eye
- Detached retina
- Early glaucoma or cataracts

Other body systems

- Stretch marks on the skin, not explained by pregnancy or weight gain
- Sudden collapse of the lung (spontaneous pneumothorax)
- Widening or ballooning of the dural sac surrounding the spinal cord (dural ecstasia)

Living with Marfan syndrome

While people with Marfan syndrome can in many ways live a normal life, there are areas in which they need to adapt their lifestyle to minimize risks. For children, this means that the adults in their life also need to be aware of their condition and make accommodations where necessary.

Physical activity is one important area of concern. Due to the strain it places on the heart and lungs, students with Marfan syndrome should not participate in certain competitive or contact sports, such as volleyball, football, soccer, or basketball. They should also not lift heavy objects, including book bags. Because athletics often play a large role for young people and in a school at large, students who cannot participate in them may struggle with disappointment or feeling left out.

Students with Marfan syndrome usually spend more time with doctors, in hospitals, and getting medical tests than their classmates. They need to see specialists, such as cardiologists and opthalmologists, that many people do not see until they are much older. Some students may take this in stride, while for others it may be highly stressful or frightening. For a smaller number, it may go further, entailing surgery, physical rehabilitation, and other types of treatment.

Because of these medical issues, students often miss a substantial amount of school and require additional help in catching up. Teachers may also find that they must mitigate comments and perceptions by other students of special treatment.

Since some of the features of Marfan syndrome are visible, students often get unwanted attention for their appearance. Their height is commonly commented on, by adults as well as their peers, and wearing thick glasses at an early age can provoke curiousity, at best. Dealing with the effect their appearance has on other people is another adaptation people with Marfan syndrome must make.

Children with special needs sometimes receive other types of special treatment in ways they would rather not (and do not need). In most cases, living with Marfan syndrome does not mean living in a cocoon, but there are some people who would regard them as weak or frail in ways they are not. Students with Marfan syndrome have the same mental capacity as anyone else, the same emotions, and the same interests. Except for in rare cases, they can participate in most of the activities their classmates do and should be held to the same standards.

To learn more about Marfan syndrome, visit the NMF website at www.marfan.org for a variety of fact sheets covering many Marfan-related topics. You will find them on the “About Marfan Syndrome” page. The NMF Store also features a comprehensive collection of resources available for purchase for a nominal charge.

2 Special Needs of a Student with Marfan Syndrome

ISSUES AND ACCOMMODATIONS

Individualized Education Plans & 504 Plans

People with Marfan syndrome are frequently, but not always, very tall and thin and experience problems throughout their whole body, most importantly their hearts, eyes, lungs, bones, skin, tendons and ligaments. Even though there are no cognitive disabilities associated with Marfan syndrome, some students experience learning disabilities, emotional trauma and mental instability secondary to the condition. These effects can relate directly to dealing with difficult physical traits, operations and pain, or they may occur as side-effects of medication. Marfan syndrome has an array of medical problems that should be accommodated in school settings.

Children with Marfan syndrome can face the following difficulties:

- poor vision
- fatigue
- shortness of breath from heart and or/lung involvement
- difficulty holding a pencil because of loose hand ligaments
- chronic pain
- headaches
- restrictions on physical activity, including the amount of weight they can lift

Because of these special needs, a student with Marfan syndrome may require an Individualized Education Plan or a 504 Plan. Both types of plans may include such things as wheelchair ramps or an extra set of textbooks and should be updated annually.

Individualized Education Plan

The Individualized Education Plan (IEP) is required by the Individuals with Disabilities Education Act (IDEA) for students to receive special education and related services. It requires a thorough evaluation, provides the widest range of services and accommodations, and entitles parents to be active participants. It also has more barriers to eligibility and may in some cases carries the risk of stigma attached to special education.

504 Plan

The 504 Plan derives from Section 504 of the Rehabilitation Act of 1973 and is for students who require accommodations be made by their school but are not eligible for special education. It is easier to get than the IEP but offers fewer services and legal protections to ensure compliance. Unlike the IEP, a 504 Plan may be adopted and changed with little to no parental involvement.

Goals

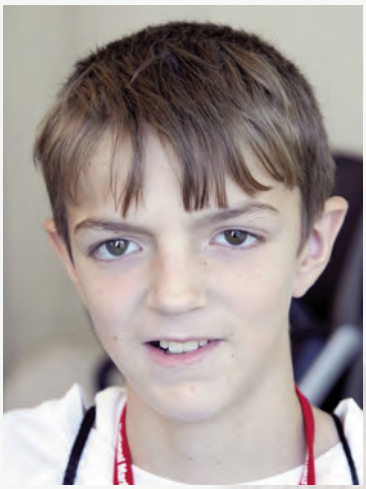
Both types of plans share the following goals:

- The student will be independent in the school setting
- The student will increase acceptance and positive self-esteem
- The student will increase his/her knowledge of the disease process
- The student will utilize healthy adaptation and coping skills
- The student will prevent predictable physical injury
- The student will communicate effectively with parents/guardians and school staff about school-day health needs

In developing an IEP or 504 Plan, teachers, other school staff, parents and specialists should work together as a team.

- Together, this team—teachers, school personnel, parents and specialists—must determine which type of plan best suits the needs of the student.
- Each member of the team should include all of the other members in all general correspondence. However, any member can update parents about the student without including other team members in that communication. This is to allow for candid, open and unfiltered communication about the child as often as possible.
- The entire team should meet as often as necessary and especially in response to any changes in the child's condition or specific events at the school.

Your school district should have readily available a template for developing an IEP or a 504 Plan. The following pages list issues commonly seen in students with Marfan syndrome which should be considered in the development of either type of plan. While not a complete list, it highlights many of the issues most likely to impact the classroom setting. Each person experiences Marfan syndrome differently. "Variable expression" of the disorder means that not all people have the same features. This document should serve as a guide to determine the specific needs of your student.



Medical Plans

In addition to the possible Individualized Education Plan or 504 plan, a student with Marfan syndrome should have an Individualized Health Plan (IHP) and an Emergency Care Plan (ECP). These are coordinated by the school nurse but it is important for teachers to be involved in their formulation and familiar with their contents.

Individualized Health Plan

The Individualized Health Plan (IHP) is a written document that outlines the provision of health care services intended to achieve specific student outcomes. It should be prepared by the school nurse in collaboration with the student, family, teachers, school officials and health care providers, and provide a thorough assessment of the student's physical and mental health and educational activity, along with guidance for school personnel. It should be reviewed and revised as needed at least once a year. A sample IHP is included in the NMF's "Marfan Syndrome: Need-to-Know Information for the School Nurse."

Emergency Care Plan

The Emergency Care Plan (ECP) is a shorter document, typically one page, that contains information about the student's condition and provides contact information for family, physicians, hospital and ambulance service to be accessed in the event of a medical emergency. Teachers, as well as the school nurse, principal, and other adults in the student's life should have a copy of it readily available. A copy of an ECP tailored for Marfan syndrome is included in section 4, Additional Resources.

MEDICAL ISSUES, IMPACT ON THE STUDENT AND ACCOMMODATIONS (by Body System)

Cardiovascular system	
Medical Issues	• Irregular/erratic heartbeat • Mitral valve prolapse • Aortic root enlargement/aortic aneurysm • Aortic dissection (relatively rare in school-aged children, but is a medical emergency and should be taken seriously if symptoms occur) [see section on Emergencies]
Impact on the Student at School	• Fatigue • Restrictions on lifting, including backpacks, textbooks, boxes, etc. • Cannot participate in certain activities that increase heart rate or raise blood pressure • Medication regimen may require taking doses at various times throughout the day
Accommodations	• All medical complaints should be taken seriously • Unlimited access to the nurse's office • Adjustment of school schedule to allow for resting during the day while still meeting academic requirements • Adjust class schedule to group classes together thus limiting movement between classes • Additional time to get to classes • Extra set of books and/or second locker to accommodate lifting/carrying restrictions • Modified physical education curriculum, or alternative to PE class (sample modified curriculum and physical activity guidelines are included section 3, Special Resources for the PE Teacher)

Note: Activity that increases heart rate and blood pressure, be it physical or emotional, increases stress on the cardiovascular system. This is a major contributor to enlargement of the aortic root, the most serious and life-threatening complication of Marfan syndrome.

Skeletal system

Medical Issues	• Tall stature, with disproportionately long arms and legs (students may be significantly taller than their peers) • Hyperextensive, easily damaged joints • Underdeveloped muscles • Pain (often chronic) • Long, loose jointed fingers • Chest wall deformity (indented or protruding breast bone) • Scoliosis or kyphosis (curvature of the spine) • Flat feet or hind foot deformity • Inhibited fine motor skills
Impact on the Student at School	• Difficulty fitting in standard size desks/chairs • May not be able to sit comfortably for long periods of time • Difficulty walking long distances • May not be able to participate in regular physical education or field day activities • Inability to carry heavy books long distances • Difficulty with penmanship and/or writing for long periods of time • More prone to joint injuries • Muscle fatigue sets in quicker • Bracing for back and foot issues is not unusual • Frequent surgeries with often long and painful recovery • Severely affected individuals may require use of a wheelchair (rare) • Possible psychosocial implications/body image issues

Skeletal system continued

Accommodations	• Special desk and/or chair
	• Allow student to stand if unable to sit comfortably
	• Additional time to get to classes, and scheduling classes closer together
	• Reassignment of homeroom and locker access can also cut down on excess walking and distance of walking; consider assigning a second locker
	• Allow the student extra time to get to his/her classes
	• Access to nurse for pain management as necessary
	• Modified curriculum and/or alternative to physical education class (sample modified curriculum and physical activity guidelines are included in section 3, Special Resources for the PE Teacher)
	• Provide an extra set of books at home and a set of books in each classroom in order to cut down on the student having to carry s everal classes' worth of books
	• Leniency regarding handwriting and penmanship
	• Additional time for handwritten tests
	• Limit the need for handwriting
	  • Classroom aid so student can dictate answers rather than write for long periods
	  • Use of computer and/or assistive software to cut back on the amount of writing
	• Understanding and tolerance of extended absence for medical treatments and/or surgery; collaborative efforts with entire educational team and family to ensure student does not fall behind
	• Wheelchair accessibility if required
	• Sensitivity to psychosocial/body image issues (privacy in changing rooms)

Ocular system	
Medical Issues	• Severe myopia (near-sightedness) is common • Dislocated lens • Risk of detached retinas (less common, but should be considered an emergency if it occurs) *See section on Emergencies.*
Impact on the Student at School	• Visual function may fluctuate from one minute to the next • May have difficulty reading for long periods of time • May have difficulty reading small or light colored fonts • Difficulty seeing the chalk board/smart board/projection screen, etc. • Potential absence for medical or surgical treatment of the eyes (and recovery time)
Accommodations	• Large print books (can be obtained from vision resource libraries) • All materials should be dark and clear • Seating in class close to the blackboard and close to instruction • Tests and homework may need to be large-print • Accessible computers (software or settings for visual disability) • Understanding and tolerance of extended absence for medical treatments and/or surgery; collaborative efforts with entire educational team and family to ensure student does not fall behind

Pulmonary system	
Medical Issues	• Asthma • Sleep apnea • Spontaneous pneumothorax (collapsed lung); this should be treated as a medical emergency. *See section on Emergencies.* • Pectus Excavatum (indented breast bone) and scoliosis can reduce lung capacity, reducing pulmonary function; can result in chronic respiratory acidosis, shortness of breath and fatigue
Impact on the Student at School	• May need additional time to get from class to class • May not be able to participate in regular physical education or field day activities • May experience mental or physical fatigue
Accommodations	• Additional time to get to classes, and s cheduling classes closer together • Access to nurse for medication if required • Access to emergency inhaler if used for asthma • Alternative physical education class with minimal aerobic activity • Adjustment of school schedule to give him or her more free time for resting during the day while still meeting academic requirements

Neurological system	
Medical Issues	• Dural ectasia (widening or ballooning of the dural sac surrounding the spinal cord), which can cause headaches, back, abdominal, or leg pain
Impact on the Student at School	• Pain (often chronic) may interfere with ability to focus or sit for long periods of time • May not be able to participate in regular physical education or field day activities • May have difficulty completing assignments on time
Accommodations	• Access to nurse as needed • Adjustment of school schedule to give him or her more free time for resting during the day while still meeting academic requirements • Extended time to complete school work due to severity of headaches • Allow student to take medication or take any other additional steps to relieve discomfort • Modified curriculum and/or alternative to physical education class (sample modified curriculum and physical activity guidelines are included in section 3, Special Resources for the PE Teacher)

EMERGENCIES

First and foremost, children with Marfan syndrome are still children. They should be allowed and encouraged to participate in classroom activities and appropriate adaptive PE as determined by their family, physicians and school.

Teachers should be aware of signs that a child is experiencing a medical situation that should be addressed. Additionally, listen to the student. Take their concerns seriously and involve the school nurse right away. Be aware, but do not be unnecessarily anxious.

Children with Marfan syndrome are at increased risk for three specific types of medical emergencies:

1. Aortic Dissection

Aortic dissection (AD) is a tear between layers of the aorta, the large blood vessel that carries blood away from the heart. If not immediately treated, an aortic dissection can rupture leading to immediate death. While relatively rare in school-aged children, AD is a medical emergency and should be taken seriously if symptoms occur. If AD is suspected, a person needs to go to a hospital emergency room right away.

Possible symptoms include:

- Pain in the center of their chest, abdomen (stomach), or back; may be "severe," "sharp," "tearing," or "ripping" and may travel from the chest to the back and/or abdomen. Sometimes, the pain is less severe, but a person still has a feeling that "something is very wrong."
- Nausea
- Shortness of breath
- Syncope (fainting)
- Loss of pulse
- Parasthesia (tickling, numbness, burning, prickling of the skin)
- Paralysis

2. Spontaneous Pneumothorax (collapsed lung)

Spontaneous pneumothorax is when air or gas collects in the space between the lungs and the chest that "collapses" the lung and prevents it from inflating completely.

Possible Symptoms include:

- Chest pain, sudden onset; sharp and may lead to feelings of tightness in the chest
- Shortness of breath
- Rapid heart rate
- Rapid breathing
- Cough
- Fatigue
- Skin may develop bluish color (cyanosis) due to decreased blood oxygen level

3. Detached Retina

A detached retina is a separation of the light-sensitive membrane in the back of the eye (the retina) from its supporting layers. If left untreated, retinal detachment usually results in permanent, severe vision loss or blindness.

Possible Symptoms include:

- Translucent specks of various size, shape and consistency in the eye
- Bright flashes of light, especially in the peripheral vision
- Blurred vision
- Shadow or blindness in a part of the visual field of one eye
- Symptoms may occur gradually or quite suddenly

Partner with your school nurse to ensure that an appropriate Emergency Care Plan is in place.

SOCIAL AND PSYCHOLOGICAL ISSUES

Students with Marfan syndrome often look different from their peers. They are often taller than average and very skinny and lanky. Many wear glasses or have stretch marks. Skeletal problems can cause scoliosis or kyphosis (curvature of the spine), foot problems and an indented or protruding chest bone. Treatments like back braces and orthotic shoes further affect their appearance.

Because they look different, students with Marfan syndrome can be highly self-conscious and are frequently targets of teasing and bullying. Special accommodations made for their disability, such as using large print books or not being able to participate in regular sports, often make the situation even more challenging.

It is important for teachers and school officials to be aware of this and to take steps to try to prevent it. Because teasing often comes from ignorance, educating other students about Marfan syndrome can help to prevent teasing and bullying. A teacher or guidance counselor can set up a classroom or school-wide presentation about Marfan syndrome in conjunction with the affected student and/or the affected student's parent(s) to educate the student body and help prevent teasing or bullying before it starts.*

It should also be noted that some teachers and school officials may suspect that a student with Marfan syndrome has an eating disorder such as anorexia or bulimia because they are so thin. People with Marfan syndrome are often unable to put on weight no matter how much they eat. This inability to gain weight is directly linked to their Marfan syndrome diagnosis and is not caused by an eating disorder.

Having Marfan syndrome doesn't change the usual questions about the future that students typically have. Will I go to college, get a job, find someone to spend my life with, have children? However, for students with Marfan syndrome the answers to these questions can be more complicated.

Older students may be concerned about going away to college because of their medical needs or lack of knowledgeable Marfan syndrome doctors throughout the country. Students may be concerned that they won't have the same job options others have because of physical limitations or eye issues. Students with Marfan syndrome can be concerned about how to tell friends or potential boyfriends and girlfriends about their condition. Teens with Marfan syndrome may be concerned about having children in the future because of the risk of passing their condition onto their child.

**The National Marfan Foundation has a number of resources that can be helpful in educating other students about Marfan syndrome, including age appropriate books and DVDs. See the Resources section of this document.*

All of this should be considered by teachers and school officials as they observe how a student with Marfan syndrome interacts with their peers in the classroom and at other school activities. At times it may be appropriate to involve the school social worker or guidance counselor. These potential concerns should also be considered in classes such as health or sexual education. The student with Marfan syndrome may have different questions or concerns than other students and their questions should be handled with sensitivity to their medical condition.

3 Special Resources for the Physical Education Teacher

PHYSICAL EDUCATION AND ACTIVITY GUIDELINES

Prepared by the NMF
Professional Advisory Board

This document is an overview of physical activity guidelines for people who have Marfan syndrome. A separate document is included in the additional resources section to provide detailed curriculum modifications for PE teachers.

Exercise is important for people with Marfan syndrome just as it is for everyone. It instills a sense of physical and psychological well-being, improves exercise endurance, lowers blood pressure, reduces weight, regulates metabolism and gastrointestinal function, increases bone density and physical strength, and often leads to beneficial lifestyle changes, such as smoking cessation, moderation of alcohol consumption and improved nutrition.

People with Marfan syndrome and their families, as well as physical educators and healthcare professionals charged with overseeing the physical activity of people with Marfan syndrome, should be aware of the following:

- Changes in connective tissue that give rise to the medical problems of Marfan syndrome.
- Different forms of exercise and their impact on Marfan syndrome.
- Basic guidelines for physical activities that should enable people with Marfan syndrome to participate safely.

Changes in connective tissue that cause Marfan syndrome

Marfan syndrome is a genetic disorder that affects the body's connective tissue. Connective tissue is found throughout the body and has various functions; it serves as the glue and scaffolding of all cells, giving structure and shape to organs, muscles, blood vessels and, in turn, the entire body.

One of the many ingredients of connective tissue is a protein known as fibrillin. In Marfan syndrome, a diversity of problems occur in fibrillin, all caused by genetic mutation. As a result, the structure it provides to the body is weaker than normal. Because of this inherent weakness, some modifications in exercise are required in affected individuals. There is variation in the weakness of tissue among individuals, particularly in the wall of the aorta, the ligaments, the joints and the eyes; therefore, recommendations can be tailored to some degree.

Different forms of exercise and their impact on Marfan syndrome

Exercise can be classified by a number of characteristics. Aerobic activities are conducted at an intensity that permits oxygen to be used to generate energy. There is a balance between the needs of the muscles and the ability of the body to provide oxygen to the muscles. If you can carry on a conversation while you are exercising, you are at an aerobic level.

In an anaerobic activity, there is insufficient oxygen, and cells have to rely on internal sources, which become depleted quickly, leading to fatigue. Anaerobic activity is usually of higher intensity, and is thus more stressful to tissues and the cardiovascular system.

When a muscle contracts through much of its full range of motion, such as the arm muscles when throwing a ball and the leg muscles when running, the exercise is called isokinetic. When the muscle is contracting without moving, such as when straining to lift a heavy weight or pushing a heavy piece of furniture, the exercise is called isometric. An increase in blood pressure, which stresses the heart and aorta, is greater with isometric exercise.

Most exercises and athletic activities involve combinations of isokinetic and isometric muscle work and aerobic and anaerobic energy use. The proportion of work and energy is determined by the nature of the activity, how strenuously a person is participating and, in team sports, even the position being played.

Sports are classified based on the risk of collision (contact) and on how strenuous they are. The following table shows one classification scheme.

Classification of sports & activities*

Before you apply this chart to your specific situation, it is important to realize that many sports can fall within several categories, depending on the intensity of your participation. It is essential to consult a doctor about the sports and activities that are safe, and how to monitor exertion level so that exercise remains safe.

Contact/collision high potential: strenuous	basketball, boxing, field hockey, football, ice hockey, lacrosse martial arts, rodeo, skiing (water), soccer, wrestling
Limited contact: strenuous	baseball, bicycling (intense), gymnastics, horseback riding, skating (ice & roller), skiing (downhill & cross-country), softball, squash, volleyball
Noncontact: strenuous	aerobic dancing (high impact), crew, running (fast), weightlifting
Noncontact: moderately strenuous	aerobic dancing (low impact), badminton, bicycling (leisurely), jogging, swimming (leisurely), table tennis, tennis
Noncontact: nonstrenuous	golf, bowling, riflery, walking

* Modified from a classification devised by the American Academy of Pediatrics.

People with Marfan syndrome should always avoid contact sports because of the risk of damaging the aorta and injuring the eyes. Strenuous activities also should be avoided because of the stress placed on the aorta. Every activity has gradations, and no recommendation holds in all circumstances. For example, shooting baskets in the driveway is different from playing a full-court basketball game, and bicycling 10 miles in one hour on a level course is different from competing in a triathlon. To maximize safety of low intensity, non-contact activities, it is important to take necessary precautions, such as not carrying a heavy bag of golf clubs, and to avoid intense competitive efforts. In short, it is essential for each individual with Marfan syndrome to discuss physical activities, and specific activity levels, with his or her physician(s) so that exercise can be incorporated safely into the regular healthcare routine.

Effects of medication

Before beginning or increasing any exercise program, it is important that a person assess their current level of physical fitness, health and medications. The advice offered here is general, and is not meant to substitute for the recommendations of a personal physician.

Many people with Marfan syndrome take a beta-blocker or other medication to reduce stress on the aorta. This medication lowers the pulse at rest and with exercise, and makes it somewhat more difficult to achieve a given level of physical fitness for the amount of physical work performed. Beta-blockers do permit a person to improve their endurance and strength while protecting the aorta. They do not, however, allow a person to perform very strenuous exercises or to play contact sports.

People who have artificial heart valves usually take an anticoagulant medication, Coumadin®. This medication interferes with blood clotting and increases the chances of bruising and internal hemorrhages. People taking Coumadin® should avoid contact sports and any activity with a moderate risk of a blow to the head or abdomen. High-quality helmets should always be worn while bicycling.

Guidelines and modifications for safer exercise for people with Marfan syndrome

Physical activity modifications for people with Marfan syndrome include the following:

- Favor non-competitive, isokinetic activity performed at a non-strenuous aerobic pace. Especially suited are sports in which the student is free to rest when they feel tired and in which there is a minimal chance of sudden stops, rapid changes in direction, or contact with other players, equipment or the ground. Some beneficial activities are brisk walking, leisurely bicycling, slow jogging, shooting baskets, slow-paced tennis, and use of 1–3 pound hand weights.
- Choose an activity the student can perform three or four times per week for 20–30 minutes. If time is a major constraint, three 10-minute sessions are nearly as effective as one 30-minute session.
- Stay at an aerobic level of work (about 50% of capacity). If a student is on a beta-blocker or verapamil, their pulse should stay under 100 beats per minute. If they are not on a beta-blocker, their pulse should remain at less than 110. Tip: It is often easier to feel the pulse over arteries in the neck than at the wrist.
- With everyday activities, students should ask for help, make several trips carrying parcels rather than trying to carry them all at once, use their legs rather than their back to lift, exhale when lifting, and refrain from straining to do anything.
- Avoid activities that involve isometric work, such as weightlifting, climbing steep inclines, and pull-ups. If using a stationary cycle or a step-climber, keep the tension low. Multiple repetitions with a low resistance or weight are better than a few repetitions with a larger weight.
- Do not test their limits. This is particularly difficult for children during physical fitness tests in school and for people who once were competitive athletes. Be sure any student with Marfan syndrome has an adaptive physical education program in place.
- Avoid activities that risk rapid changes in atmospheric pressure, such as scuba diving and flying in unpressurized aircraft. People with Marfan syndrome are prone to collapse of a lung.

PHYSICAL EDUCATION GOALS FOR CHILDREN WITH MARFAN SYNDROME

Helen D. Iams, MD, MS

What is Marfan syndrome?

Marfan syndrome (MFS) is a genetic disorder of connective tissue. Because connective tissue is found throughout the body, Marfan features can occur in many different parts of the body. Marfan features are most often found in the heart, blood vessels, bones, joints, and eyes. Sometimes, the lungs and skin are also affected. Marfan syndrome does not affect intelligence. It occurs in both boys and girls and in all racial and ethnic groups.

General approach to physical education for students with Marfan syndrome

Children with Marfan syndrome require modification to their physical activity for a variety of reasons that we will address below. Even though they have physical limitations, it is important for each affected child to remain as active as possible to maintain both physical and mental health.

Marfan syndrome causes a wide variety of physical problems in both type and severity. Each child has a different combination of these problems. Because of this great variability of physical problems, most children with Marfan syndrome will need a custom-designed exercise program in lieu of standard physical education. The information provided below is designed to give physical educators the information they need to create gym programs that help children with Marfan syndrome be as active as possible. The information can also serve as a guide for persons responsible for a child's physical activity outside of the school setting, at, for example, summer camp or an after school program.

Parameters for exercise should be set by the child's physicians. The physical educator can then select activities for the child based on that child's needs, abilities, and limitations. These children are often seen by a number of different specialists, such as a cardiologists, orthopedists, and ophthalmologists. Each specialist should be consulted individually to find out what limitations would be prudent from their perspective.

How Marfan syndrome affects students' ability to exercise

Marfan syndrome affects connective tissue throughout the body. Because connective tissue is a component of many parts of the body, Marfan syndrome affects the body in many ways. We will identify in greater detail the features of Marfan syndrome and discuss how they can affect the child's ability to be physically active.

Musculoskeletal System

The most obvious features of Marfan syndrome are in the musculoskeletal system.

- The child may be tall and have elongated extremities.
- The child may be very thin and may lack muscle bulk and strength.
- Joints may be hyperextensible and prone to dislocating. Joint contractures may also be present.
- The combination of underdeveloped muscles and joint hypermobility can contribute to poor coordination and delay in acquiring gross and fine motor skills.
- The spine may be curved, resulting in scoliosis or kyphosis which can greatly limit the range of motion of the back. The child may need to wear a brace to support the spine and this brace may limit range of motion even further.
- The chest wall might be deformed, creating a sunken or protruding chest. Most often, chest deformities are merely a cosmetic problem. Occasionally these deformities will impair normal functioning of the lungs. To address the problems with lung function, the child may have had surgery or may need to wear a brace. Both of the solutions may cause problems by limiting exercise capacity and range of motion.
- The child may have a very narrow and highly arched palate and may not be able to use a standard mouth guard.

Ocular System

The eyes are commonly affected by Marfan syndrome.

- The lens may dislocate.
- The retina can tear.
- The cornea is often flatter than usual, making it difficult to fit contact lenses. Contact lenses, if worn, tend to fall out easily.
- The child may be near-sighted and may require corrective lenses.
- In some cases, bifocals may have to be worn over contact lenses.
- The child may have difficulty with visual perception and with eye-hand coordination.
- The child may have difficulty in following the flight of an object.
- The child may have difficulty tolerating bright light.

Cardiovascular System

The cardiovascular system is affected in approximately 90% of people with Marfan syndrome. Cardiovascular features include:

- Enlargement (dilation) of the aorta
- Leaking of the aortic valve (aortic regurgitation)
- "Floppy" mitral valve (mitral valve prolapse)
- Leaking of the mitral valve (mitral regurgitation)
- Dissection of the aorta that occurs if the aorta becomes too large

Aortic dilation is of major concern because a severely dilated aorta can tear (dissect) or rupture. Children (and adults) with Marfan syndrome have regular echocardiograms to monitor the size of their aortas. When the aorta reaches a certain size, prophylactic repair of a dilated aorta can prevent life-threatening aortic dissection.

Spontaneous aortic dissection (in the absence of trauma) is rare in school-aged children, but a gradual increase in aortic size is common. Exercise modification and beta-adrenergic blocker medications are important components of cardiac management that seek to help slow the rate of aortic growth. Medication and exercise modification help reduce the force with which blood is pumped from the heart, thus reducing stress placed on the aorta. Beta-blocker medication may have side effects including fatigue, feeling sleepy, and reduced ability to concentrate.

Repair or replacement of a leaking mitral valve may be needed in a school-aged child.

If the correction required valve replacement, the child will be on a blood thinner medication to keep any clots from forming on the replacement valve. This will leave the child prone to spontaneous bleeding and easy bruising.

Pulmonary System

The lungs can have defects called apical blebs. These are weakened areas of tissue that over inflate, much like a weak spot in a balloon. These blebs can break, causing the lung to suddenly collapse. Improper breathing techniques during activities put further stress on lungs and may lead to a lung collapse.

The lungs may be underdeveloped with reduced capacity for gaseous exchange. Children with this lung problem may have reduced exercise tolerance.

Emergencies and how to recognize them

People with Marfan syndrome can suddenly develop symptoms that signal the need for immediate medical attention. There is need for rapid transport to a hospital if the child suddenly develops such symptoms. Both the school nurse and the physical educator should be alert for signs of distress in the child that indicate a medical emergency.

Aortic rupture or dissection is the leading cause of death in people with Marfan syndrome, and is therefore a medical emergency of grave concern. Although spontaneous aortic rupture or dissection is rare in school-aged children, it can occur. Therefore it is important to know how to recognize the symptoms. Aortic rupture or dissection is typically painful, described by people as "tearing chest pain that bores through" to their back. Much less commonly, acute dissection may present as sudden collapse or syncope. However, aortic dilation can be pain-free and the only symptom may be a shortness of breath.

Sudden shortness of breath and chest pain can also be a signs of spontaneous collapse of the lung. Spontaneous lung collapse is not life-threatening but does require immediate medical attention. Other possible signs of cardiac or pulmonary problems are fatigue and an irregular heart rate. Any of these symptoms are serious and if the child complains of these symptoms, he should be promptly transported to a local emergency room.

Children with Marfan syndrome are prone to retinal detachments. Affected children who complain of any vision problems, including flashing lights, spots in their vision, or sudden loss of vision, should be removed from physical activity and referred immediately to the school nurse.

Children who have had a valve replacement will probably be on a blood-thinner. Any child on a blood thinner can develop a spontaneous bleed or excessive bruising and should be sent to the school nurse for evaluation if these occur. The replacement valve may make a clicking sound that can be heard when standing near the child. This is normal and is the sound of the device working.

Activities that should be avoided

The physical demands of some sports can lead to devastating problems for students with Marfan syndrome. Although there are a number of safe activities for a child with Marfan syndrome, some activities and situations should be avoided. These include:

- Most competitive sports—as exercise is often done at maximal capacity during competition. Golf is generally an exception.
- Activities that place excessive stress across the joints could cause dislocations or damage to the joint surface.
- Wrestling and many gymnastic activities.
- Isometric sports, such as weight-lifting, that create high blood pressure.
- SCUBA diving—because the lungs may not withstand stress from pressure gradients.
- Contact sports and sports requiring sudden exertion, because a blow to the chest or the strain of jumping or stretching can result in serious injury and even aortic dissection.
- Sports with a risk of falling or impact, such as gymnastics, diving or skating.
- Demanding endurance activities, such as competitive running and bicycling.

Almost all physical activity involves some aspect of body collision if not presented safely. Therefore care must be taken with most activities. If the child is on a blood thinner, a collision could result in heavy bleeding. Exercise to the point of exhaustion should be prevented to avoid the increases in heart rate, blood pressure and force of muscular contractions that are present in an exhausted state.

Suggested physical activities and activity modifications

General Modifications

It is not possible to create a single exercise program that would be safe for all children who have Marfan syndrome. Each child's physicians should provide the physical educator with information about safe activity levels for that child. The physical educator can then design activities within these levels. It may be helpful for the physical educator to provide the physician with a list of planned activities in the PE curriculum. If possible, have the child help in selecting activities. This will increase their enjoyment of the program.

A child may need assistance in developing a realistic self-concept of abilities and limitations. It is important to recognize that the child's level of comprehension can be misjudged. Because of their increased height, children with Marfan syndrome may be treated as older than their actual age.

Modifications to address cardiovascular issues

- The child with Marfan syndrome should be encouraged to take part in noncompetitive activities performed at a sub-maximal level of effort.
- Select activities promoting the concept of self-competition to minimize the effects of peer pressure for the child to exceed physical exertion limits.
- Instruct the child in self-monitoring techniques and provide an exercise environment in which an affected child can practice self-monitoring.
- Instruct the child in safe levels of intensity and duration.
- Include instruction in relaxation techniques, safety, and correct breathing mechanics.
- A child with Marfan syndrome must be taught to never "push through" symptoms.
- Provide adequate time for gradual warm-up and cool-down.
- Monitor the child's level of exertion more closely under extreme weather conditions because heat and cold may add additional stress and may affect the child's endurance and exertion level.

Most children with Marfan syndrome receive beta-blocker medications. These medications depress the heart rate. Therefore heart rate will not be a true indicator of exertion level. Children on a beta blocker under age seven should keep prolonged heart rate under 120 beats a minute. Older children (and adults) on a beta blocker should keep heart rate under 100 beats a minute.

A "graded" exercise program may be recommended by the child's physicians. In such instances, use an estimate of the child's exercise tolerance to determine the maximal heart rate and functional capacity. The child must never be actually tested to identify the maximal heart rate. The estimation of the maximal heart rate should be based on the child's age. It is generally recommended that Marfan patients stay at an aerobic level of work at 50-60% of their maximal heart rate. If there is no evidence of aortic dilatation, the physician may permit activity at higher levels of intensity.

Modifications that address musculoskeletal issues

The student may have muscular underdevelopment and joint laxity or, conversely, contractures. Overall lack of bulk and muscle tone may need to be addressed with strengthening exercises. Muscle strengthening is also useful when working with individuals who demonstrate joint hyperextensibility. Focus on activities that increase strength of both muscles and ligaments. However, the child should only do exercises with a weight that enables 15-20 repetitions comfortably. It is recommended to avoid activities involving heavy weights or intense isometric exertion. The child's musculoskeletal manifestations may have required physical therapy so the child may already have prescribed exercises. Ask the family about any physical therapy the child is doing, as this may affect the physical educational activities at school.

Modifications to Improve Coordination

A child with Marfan syndrome may have difficulty with eye-hand and eye-foot coordination. Provide opportunities to practice visual tracking of objects in motion and to develop other sequential perceptual motor skills (fine motor, gross motor, balance, spatial and body awareness). The physical educator may be able to enhance the child's body mechanics and improve posture by providing appropriate exercise.

Modifications for Required Equipment

If the child needs a brace during sports activities, his or her maneuverability, flexibility, speed, and endurance may be affected. The physical education instructor should be informed by an orthopedist what restrictions the brace will create. When a back or body brace is worn, the head and neck should be protected during physical activity by suitable padding. If the child has had chest wall surgery, the surgeon will need to inform the physical educator about any further restrictions that are necessary. If mouth guards are required for an activity, the child may need custom-made mouth guards to accommodate the narrow mouth. If hernias are present, the child may need to wear a supportive truss and the student will need instruction in proper lifting techniques. The physical education program may need to minimize activities that involve lifting or climbing.

Provide instruction in selecting appropriate clothing for physical activity to insure comfort and easy movement. Unnecessary circulatory restrictions created by clothing or bracing must be eliminated or minimized. To decrease the potential for falling, only appropriate, well fitting, and supportive footwear should be worn. The equipment the child needs to wear may cause embarrassment so provide the child with privacy for dressing and showering.

As with any other student wearing glasses during athletic activities, the child will need glasses with shatter-proof lenses and rounded edges. If the child needs to wear contact lenses, there is a greater likelihood of their falling off during physical activity due to the flatter corneas. The child may need to wear sun glasses for activities taking place outside or in brightly lit places.

Suggestions for Modifying Activities

To address intensity, endurance and fatigue:

- Decrease duration of an activity
- Decrease size of playing area
- Use frequent “time out” periods
- Permit participation at the child's own rate, with freedom to rest as necessary
- Eliminate competitive and emotional stress factors
- Reduce weight of implement
- Use transportation or support devices
- Utilize sitting or lying position in place of standing
- Utilize greater numbers of participants
- Utilize aquatics for support during activity
- Utilize relaxation techniques and relaxing music during activities
- Incorporate proper breathing techniques

To address collision and contact concerns:

- Assign “zones” of play
- Use individual activities
- Use “singles” rather than “doubles” in racquet games, where appropriate
- Change nature of implement (utilize “Nerf,” foam, and “rag” items)
- Group children according to size, abilities, and needs
- Provide clear and concise directions, rules, and regulations
- Provide play area free of obstacles, barriers, or hazards
- Insure proper padding of facilities and equipment according to activity

Note: Special thanks to the late Tom Romeo who wrote the document from which this resource is adapted.

To address visual and perceptual motor limitations:

- Use brightly colored objects
- Use "soft" objects (foam, Nerf, rag)
- Use Velcro to assist in "catching"
- Decrease distances
- Change implement to decrease speed of flight and movement (e.g., a whiffle ball instead of a softball)
- Place child to insure a clear and close visual field
- Increase the size of the implement when necessary
- Provide playing areas that are free of hazards
- Utilize appropriate illumination
- Familiarize the child with the play area prior to the start of an activity

Curriculum suggestions

Grades K-3

Movement exploration activities, games of low organization (with limitations as described above)

Grades 4-12

Archery, billiards/pool, board games, bowling, bicycling (stationary and/or leisurely) croquet, dance/rhythms (rhythmic elements, singing games, folk, square, social), darts, golf, gymnastics (balance activities), horseshoes, relaxation exercises, shuffle-board, walking, aquatics/water activities (safety skills, swimming strokes, pool exercises)

Summary of key points

A child with Marfan syndrome should have a physical activity program that:

- provides opportunity for physical activity in order to optimize physical and mental health
- is individualized to acknowledge the Marfan features and limitations specific to the child
- creates exercise modification that
    - Reduces stress on the aorta
    - Minimizes opportunity for head or chest trauma
    - Reduces stress on joints
    - Accommodates possible reduced lung capacity

4 Additional Resources

Marfan Syndrome Facts

What is Marfan syndrome?

Marfan syndrome (MFS) is a disorder of connective tissue. Connective tissue holds all parts of the body together and helps control how the body grows. Because connective tissue is found throughout the body, MFS features can occur in many different parts of the body.

MFS features are most often found in the heart, blood vessels, bones, joints, and eyes. Sometimes, the lungs and skin are also affected. MFS does not affect intelligence.

What causes Marfan syndrome?

MFS is caused by a defect (mutation) in the gene that tells the body how to make fibrillin-1—a protein that is an important part of connective tissue. This mutation creates different MFS features and causes medical problems for people with MFS.

Who has Marfan syndrome?

About 1 in 5,000 people have MFS. This includes men and women of all races and ethnic groups. People can inherit MFS, meaning that they get the mutation from a parent who has MFS. This happens to about 3 out of 4 people with MFS. Other people have a spontaneous mutation, meaning that they are the first in their family to have MFS. People with MFS have a 1 out of 2 chance of passing the mutation on each time they have a child.

People are born with MFS but may not notice any features until later in life. However, MFS features can appear at any age, including in infants and young children. MFS features and medical problems can get worse as people age.

What are Marfan syndrome Features?

MFS features occur in many different parts of the body. Rarely, a person has every feature. Some MFS features are easy to see. Other features, such as heart problems, are hidden and need special tests to find them. It is important that a person with MFS features see a doctor who knows about MFS.

Here are the most common MFS features:

Heart and blood vessels (Cardiovascular system)

- Enlarged or bulging aorta, the main blood vessel that carries blood from the heart (aortic dilation or aneurysm)
- Separation of the layers of the aorta that can cause it to tear (aortic dissection)
- "Floppy" mitral valve (mitral valve prolapse—MVP)

over

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Port Washington, NY 11050

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516-883-8040 (fax)

www.marfan.org

Bones and Joints (Skeletal system)

- Long arms and legs
- Tall and thin body type
- Curvature of the spine (scoliosis or kyphosis)
- Chest sinks in (pectus excavatum) or sticks out/pigeon breast (pectus carinatum)
- Long, thin fingers
- Flexible joints
- Flat feet
- Teeth that are too crowded

Eyes (Ocular system)

- Severe nearsightedness (myopia)
- Dislocated lens of the eye
- Detached retina
- Early glaucoma or cataracts

Other body systems

- Stretch marks on the skin, not explained by pregnancy or weight gain
- Sudden collapse of the lung (spontaneous pneumothorax)
- Widening or ballooning of the dural sac surrounding the spinal cord (dural ecstasia)

What is life like for a person with Marfan Syndrome?

While there is no cure for MFS, advances in medical care are helping people live longer and enjoy a good quality of life. Research is also finding new ways to treat people with MFS. Most people with MFS can work, go to school, and enjoy active hobbies.

It is very important that people with MFS get treatment and follow medical advice. One reason is that heart problems can cause sudden death if they are not treated. Early diagnosis means helpful treatment can begin early in life. People with MFS should not play active team sports such as football, soccer, or basketball. They should not lift heavy objects when at work, home or the gym.

What should you do if you suspect Marfan Syndrome?

Look for a doctor who knows about MFS so you can be checked for this disorder. Keep in mind that you can have MFS features but not have the disorder. The only way to know for sure is to be checked by a doctor who understands MFS.

How can you learn more about Marfan Syndrome?

MFS is a complex disorder, with many features that affect different parts of the body. Here are some ways to learn more about MFS:

- Call the National Marfan Foundation (NMF) Resource Center at 1-800-862-7326 ext. 126. When you call, you will speak with a staff member who can answer questions and mail you information. They can also suggest ways to find a doctor who knows about MFS.
- Go to the NMF website at www.marfan.org. You can find more information on the “About Marfan Syndrome” and “Living with Marfan Syndrome” pages.
- Talk with a doctor. Sometimes it helps to take MFS information with you when you visit the doctor. Your doctor can go to the special section for doctors on the NMF website by clicking on “Medical Professionals.”

Additional fact sheets are available at www.marfan.org/factsheets

How to Find Out if You Have Marfan Syndrome

People sometimes ask, "Do I or a loved one have Marfan syndrome?" Here are some ways you and your doctor can find out the answer to this question.

What YOU Can Do

Find a doctor who knows about Marfan syndrome (MFS)

Marfan syndrome (MFS) is rare and not all doctors know about it. You need to find a doctor who knows about MFS and how to tell the difference between MFS and the other medical conditions that look like it.

The first choice of doctor to look for is a medical geneticist (a doctor who specializes in genetic conditions such as Marfan syndrome).

A second choice is a cardiologist (heart doctor). Make sure the cardiologist has treated people who have MFS.

You can find a doctor by:

- asking your primary doctor for a referral
- calling the doctor referral service at your local hospital
- calling the National Marfan Foundation Resource Center at 800-862-7326, ext. 126

Learn the health history of you and your family. You might want to write this down in a health history notebook with lists of:

- your past illnesses, operations, and hospitalizations
- medications you are taking
- reasons why you think you might have MFS
- family members who have, or might have, MFS
- family members who died of a heart problem

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What YOUR DOCTOR Can Do

Talk with you about your health history. This is the time when you can talk about the information in your health history notebook and why you think you might have MFS.

Do a thorough physical exam. This includes looking for MFS features in your bones, joints, skin, and lungs.

Ask you to have medical tests. These common, painless tests include:

- Echocardiogram. This test looks at the heart, its valves, and the aorta (vessel that carries blood from the heart).
- Electrocardiogram (EKG). This test checks your heart rate and heart rhythm. Your doctor may want to do an EKG in addition to an echocardiogram.
- Slit lamp eye exam. This test, a part of most eye exams, helps your doctor see if the lenses in your eyes are dislocated (out of place).
- Other tests, such as a MRI or CT scan of the lower back. These tests can help your doctor see if you have dural ectasia, a back problem that is very common in people who have MFS.

What You AND Your Doctor Can Do

You asked, "Do I have MFS?" There are three possible answers to this question. Each answer has actions you and your doctor should take.

- **No, you do not have MFS**. Ask your doctor if you have any other medical condition that needs medical care. You should also ask how you can get this needed care.
- **Maybe, you have MFS**. Ask your doctor if you should repeat the echocardiogram in 1 to 2 years to find out if the valves of your heart and aorta have changed.
- **Yes, you have MFS**. Ask your doctor how to take care of yourself. It is very important to follow these instructions. Find out if other people in your family also have MFS. You may feel overwhelmed and have a lot of questions. Below are some ways to learn more about MFS.

Ways to Learn More about MFS

- Call the National Marfan Foundation (NMF) Resource Center at 1-800-862-7326 ext. 126. You will speak with a staff member who can answer your questions and mail you information. They can also suggest articles your doctor can read about MFS.
- Talk with your doctor. Sometimes it helps to use the information you have from the NMF when you speak with your doctor.
- Visit the NMF website at www.marfan.org. You can print out information from the "About Marfan Syndrome" and "Living with Marfan Syndrome" pages.

Additional fact sheets are available at www.marfan.org/factsheets

EMERGENCY CARE PLAN		
Student:		Date:
DOB:	Grade:	Homeroom:
Parent(s)/Guardian(s):		
Contact Information	Home Telephone Number:	
Parent	Work Telephone Number	Cell Phone Number
Mother		
Father		
Healthcare Contact Information	Name	Telephone Number
Primary Care Provider/Pediatrician		
Hospital Preference		
Ambulance Preference		
Health Insurance		
Cardiologist		
Orthopedist		
Geneticist		
Pulmonologist		
Ophthalmologist:		
Health Condition:		
Cardiac Concerns:		
Vision Concerns:		
Orthopedic Concerns:		
Signatures		
Reviewed by:		Date:
Student:		Date:
School Nurse:		Date:
Parent/Guardian:		Date:

Adapted with permission from Sunrise River Press

CLASSROOM ACTIVITY: WORD SEARCH

Marfan syndrome is a genetic condition that affects many different parts of the body. Find the Marfan-related words and terms below in the puzzle and discuss how the different words are related to Marfan syndrome.

G A O R T A L L O G T X L E H N

L O N G A R M S Y N D R O M E N

A D O C T O R M A R F A N N A L

S S E Y E S T R T G L Y G G R U

S K E L E T O N U R S E L E T N

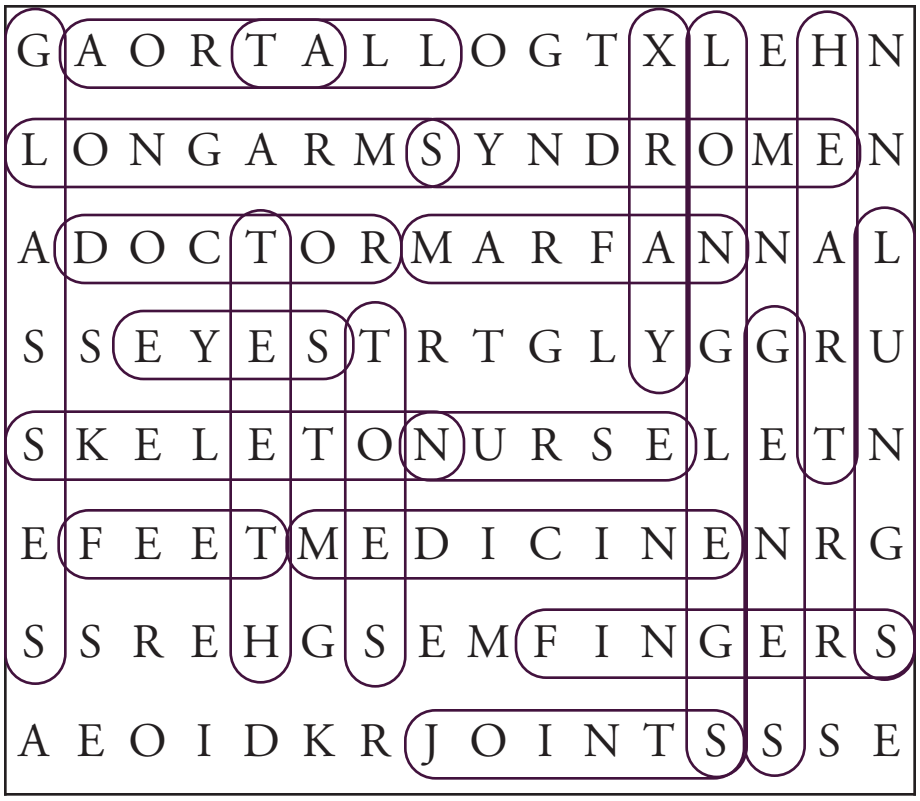
E F E E T M E D I C I N E N R G

S S R E H G S E M F I N G E R S

A E O I D K R J O I N T S S S E

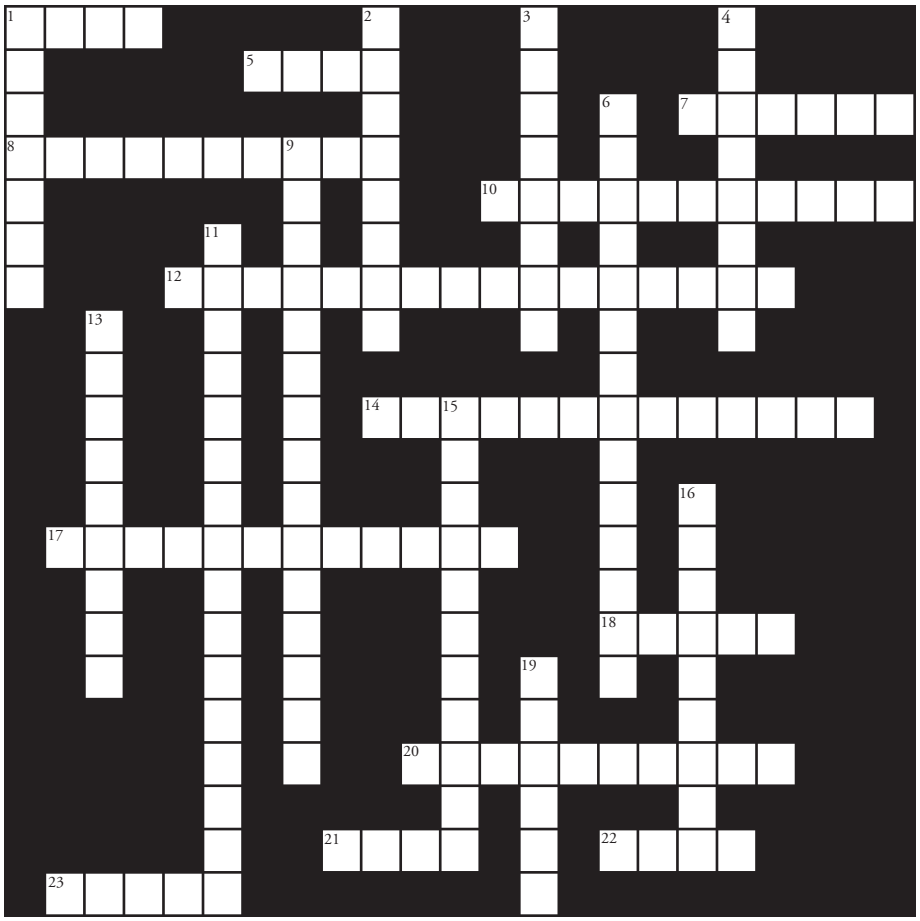
aorta
doctor
eyes
feet
fingers
genes
glasses
heart
joints
long arms
long legs
lungs
marfan
medicine
nurse
skeleton
syndrome
tall
teeth
toes
xray

CLASSROOM ACTIVITY: WORD SEARCH ANSWER KEY



CLASSROOM ACTIVITY: CROSSWORD PUZZLE

Marfan syndrome is a genetic condition that affects many different parts of the body. Learn common terms and facts about Marfan syndrome by completing this crossword puzzle.



ACROSS

1 Pneumothorax, or collapsed ____, can be a serious complication of Marfan syndrome

5 The basic physical and funcational unit of heredity

7 _____ excavatum or carinatum, deformities of the breastbone, also called funnel chest or pigeon breast

8 Marfan syndrome is caused by a mutation in the fibrillin gene on _____ 15 in the human genome

10 Bone and joint doctor

12 A tear in the inner lining of the aorta (2 words)

14 Spider fingers

17 Heart doctor

18 The large blood vessel that carries blood away from the heart

20 Part of the heart that regulates blood flow by opening and closing with each heartbeat (2 words)

21 Dislocated ____ of the eye is a common feature in Marfan syndrome and can cause severe vision problems

22 Jonathan Larson, creator of the hit musical ____, died of Marfan-related causes before his show even opened

23 A curving of the ____ is called scoliosis

DOWN

1 U.S. President thought by some to have had Marfan syndrome

2 In biology, the study of inheritance

3 An abnormal ballooning of a blood vessel

4 Bones and joints

6 A painless test that uses sound waves to take pictures of the heart and blood vessels

9 Eye doctor

11 Tissue that provides support and structure throughout the body (2 words)

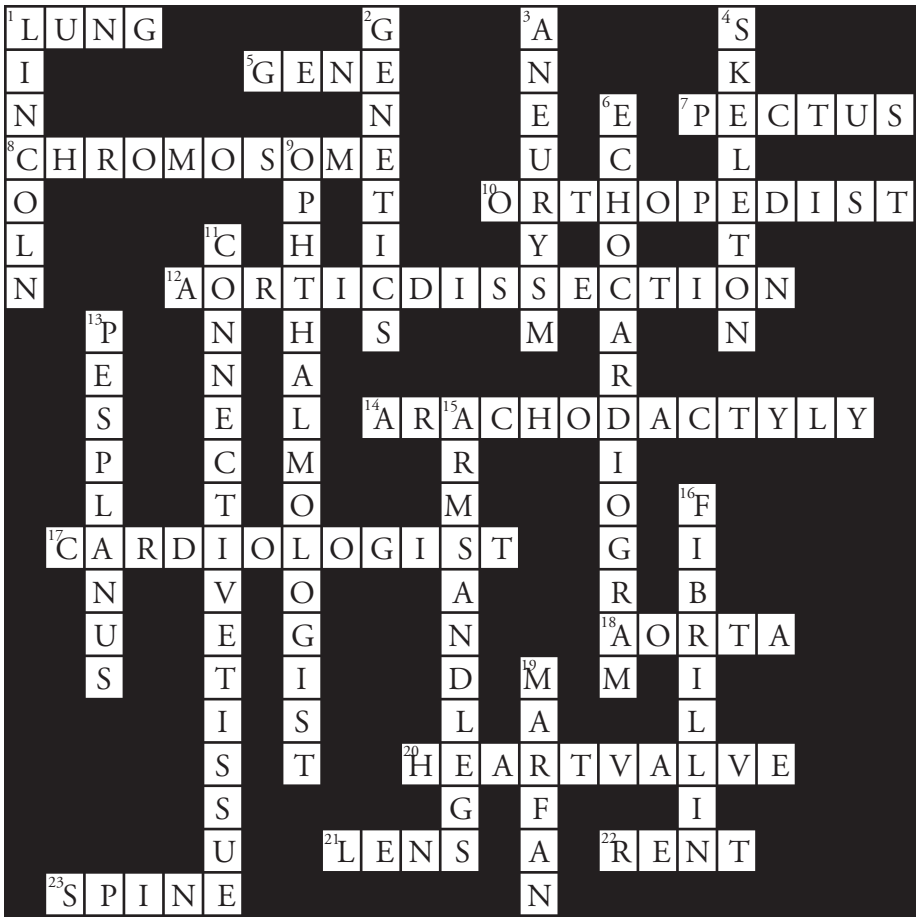
13 Flat feet, also called ___ ___, that may be larger than normal make it difficult to find shoes that fit (2 words)

15 Extremities (3 words)

16 A protein that is essential for the formation of elastic fibers found in connective tissue

19 Antoine ____ is the French pediatrician who first identified the disorder

CLASSROOM ACTIVITY: CROSSWORD PUZZLE ANSWER KEY

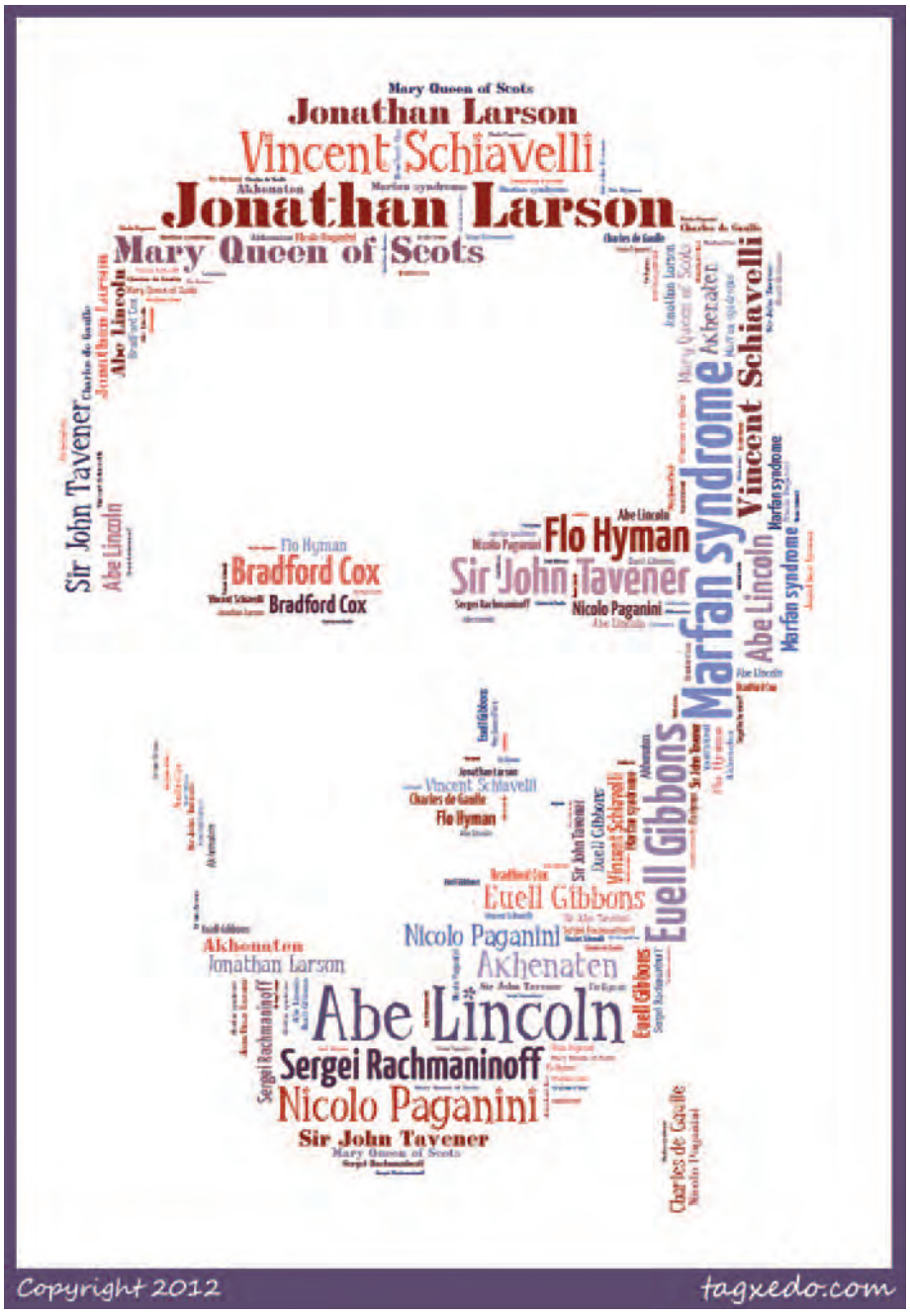


CLASSROOM ACTIVITY: WORD CLOUDS

A "word cloud" is a visual representation of text. Creating word clouds is an easy, fun, and creative way to enforce key points of lessons, reading assignments, or research projects, and to incorporate technology into the classroom.

The 21st Century Educational Technology and Learning Blog written by Michael Gordon includes a comprehensive list of how word clouds can be incorporated into the classroom. There are many free online word cloud generators, each with varying features. Tagxedo is one that provides numerous creative options and flexibility.

Here's a word cloud of celebrities and historical figures assocated with Marfan syndrome created by the NMF as an example.



Celebrities and historical figures

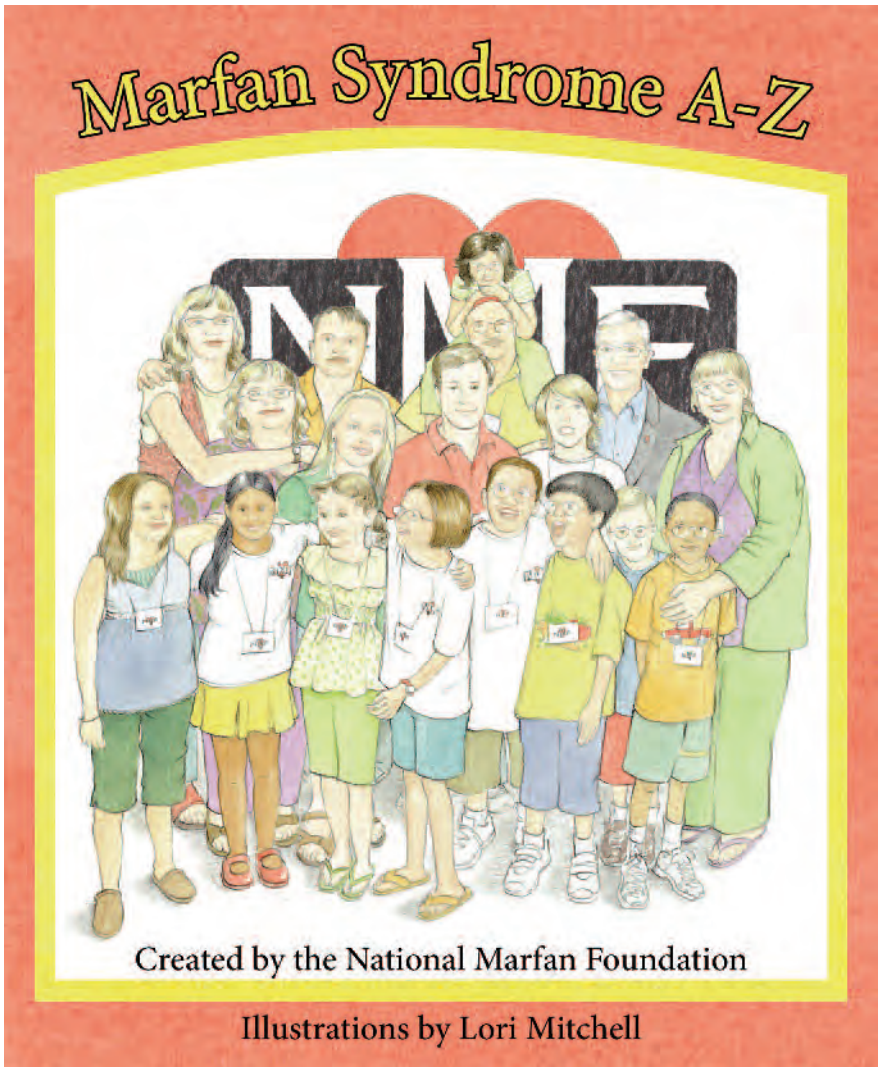
***Confirmed* to have Marfan syndrome or a related disorder:**
Jonathan Larson, Playwright
Flo Hyman, Athlete
Vincent Schiavelli, Actor
Euell Gibbons, Naturalist
Bradford Cox*, Musician
Sir John Tavener*, Composer

***Suspected* of having Marfan syndrome:**
Abraham Lincoln, U.S. President
Mary Queen of Scots, Scottish Queen
Niccolò Paganini, Musician
Charles de Gaulle, French President
Sergei Rachmaninoff, Musician
Akhenaten, Pharaoh

** Still living*

PUBLICATIONS
PRINT

Marfan Syndrome: A to Z



Featuring vivid illustrations of diverse children and families in real-life situations, **Marfan A to Z** normalizes the child's experience with Marfan syndrome. A specialized illustration style lets children complete coloring in the pictures (more coloring pages are available online) and have fun finding the hidden pictures on each page. A glossary of helpful terms is included for parents.

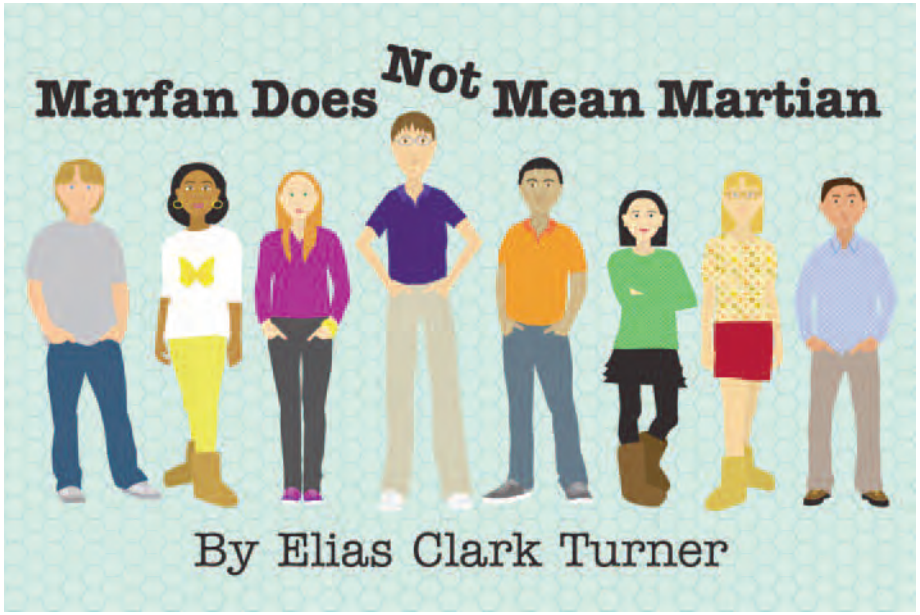
Written collaboratively by a committee consisting of parents of affected children, an affected adult, an elementary school teacher, a genetic counselor, social workers, and NMF staff members. The illustrations were created by award-winning author and illustrator Lori Mitchell. Book; 34 pages. Recommended for children ages 4–8.

Order your free copy online at www.marfan.org.

Funded by a grant from the American Legion Child Welfare Foundation

PUBLICATIONS
PRINT

Marfan Does Not Mean Martian

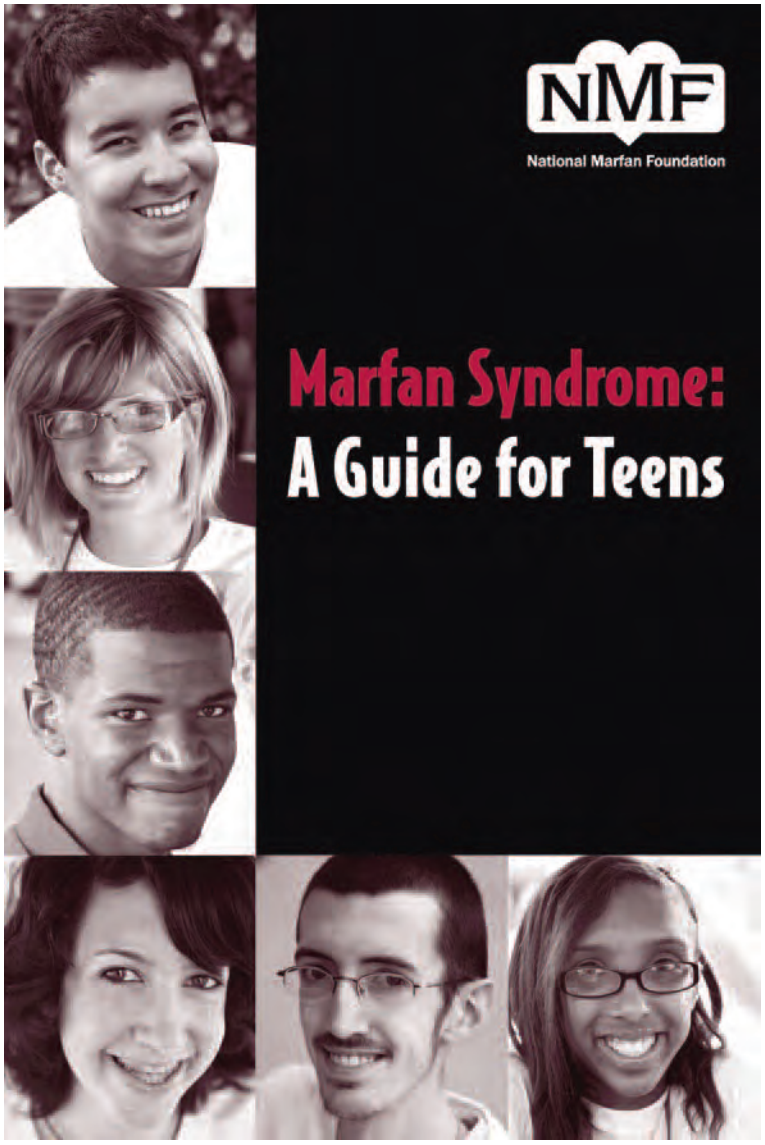


An inspirational story about Marvin, a boy diagnosed with Marfan syndrome, and the friendship he builds with his new neighbor Joe. The story educates children about Marfan syndrome while teaching them about diversity and acceptance. Written by a teenager who has Marfan syndrome, Elias Clark Turner, and illustrated by Alexandra Dubow. Book; 28 pages. Recommended for children ages 8–12.

Available for purchase for $5.00 online at www.marfan.org.

PUBLICATIONS
PRINT

Marfan Syndrome: A Guide for Teens



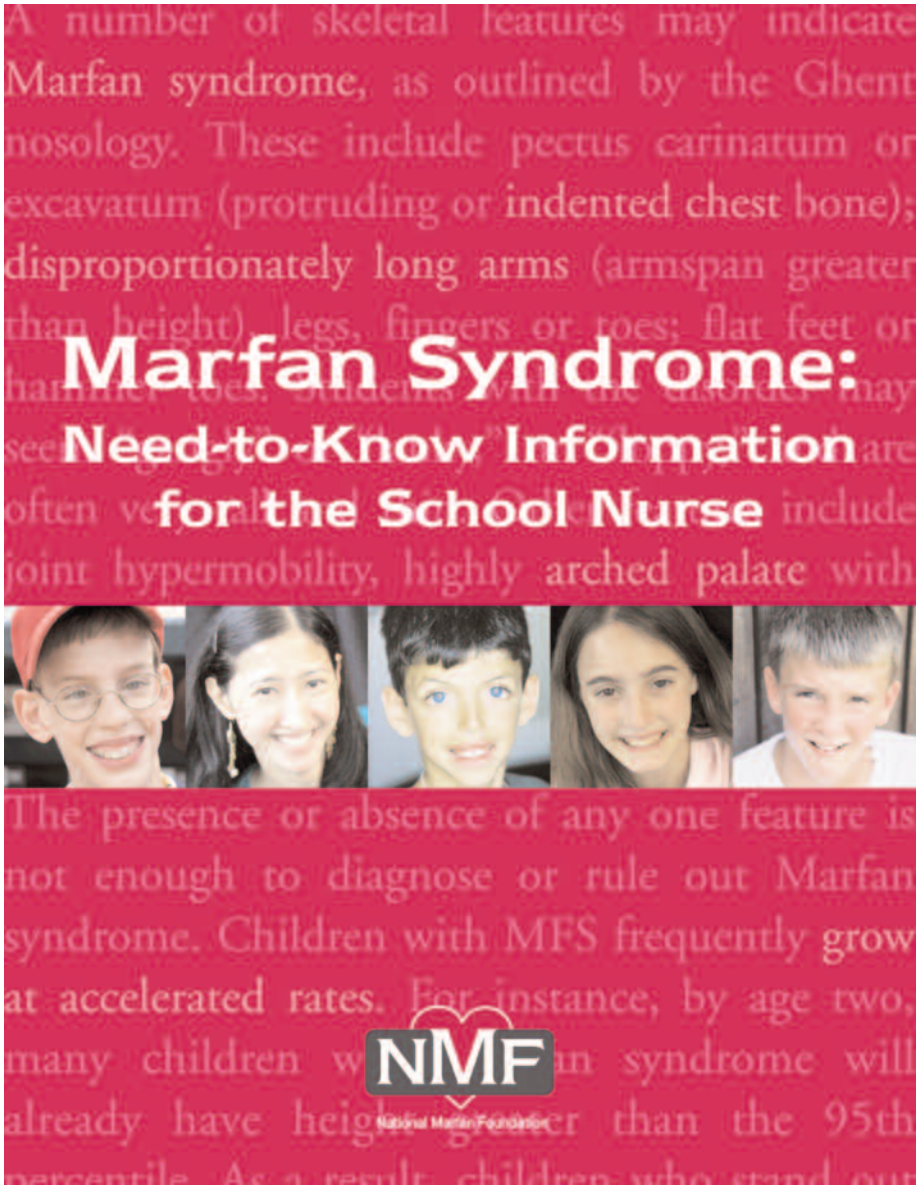
A comprehensive resource for teens, this booklet addressing all aspects of living with Marfan syndrome from diagnosis and treatment to psychosocial issues such as dealing with family, friends and school. It includes a glossary of Marfan-related terms and listing of additional resources, and features photographs of teens living successfully with Marfan syndrome. Book; 52 pages. Recommended for teens age 12 and above.

Order your free copy online at www.marfan.org.

Funded by a grant from the American Legion Child Welfare Foundation

PUBLICATIONS ON CD

Marfan Syndrome: Need-to-Know Information for the School Nurse



A companion resource to this teacher guide, this CD-ROM contains a wealth of information and resources tailored to the school nurse.

Order your free (for school nurses; $5.00 for others) copy online at www.marfan.org.

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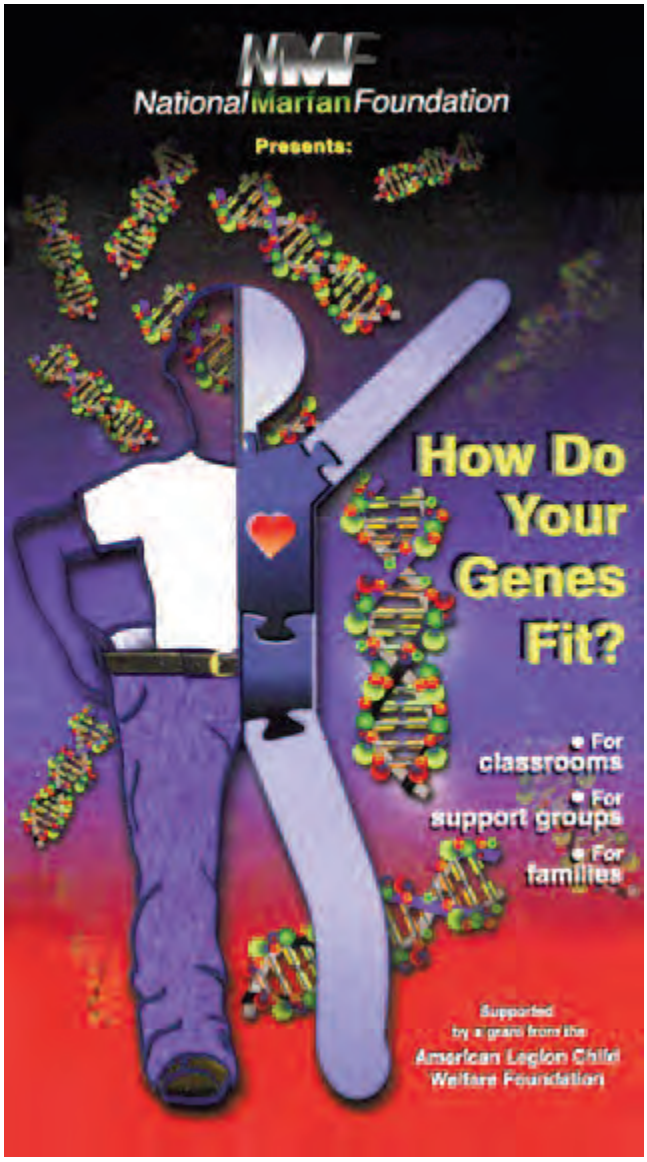
PUBLICATIONS ON DVD

How Do Your Genes Fit?



This 20 minute educational video and discussion guide, suitable for teachers, support groups and families, provides a genetics lesson, with Marfan syndrome as a case study, and teaches children to appreciate their differences. Teacher's Guide or Support Group Facilitator's Guide included. DVD.

Available for purchase for $20.00 at www.marfan.org.

PUBLICATIONS ON DVD

Marfan Syndrome: The Heart of the Matter

This 20 minute video provides an easy-to-understand general introduction to Marfan syndrome and a discussion of diagnosis and management of the disorder. Features interviews with physicians, parents and people living successfully with Marfan syndrome. NMF resources and services are also highlighted. DVD.

Available for purchase for $15.00 at www.marfan.org.

Rare Diseases and Scientific Inquiry

Rare Diseases and Scientific Inquiry is one of a series of National Institute of Health (NIH) Curriculum Supplements that includes a section entirely on Marfan syndrome and related disorders, prepared with participation by NMF staff. Geared towards students in grades 6–8, it provides a teacher's guide with two weeks of lessons and can be used to help students understand some of the challenges faced by a person living with the condition. Lessons include:

1. What Is a Rare Disease?
2. What Causes Rare Diseases?
3. The Difficulty of Diagnosis
4. The Importance of Medical Research
5. Communicating about Rare Diseases

Online and PDF versions are available free to all. Print versions are free upon request to educators in the U.S. Get it at: http://science.education.nih.gov/customers.nsf/MSDiseases.htm.

OTHER RESOURCES

Understanding Genetic Differences

The PEARLS Project

PEARLS Project is a ground-breaking educational tool by Positive Exposure which invites students to learn about their peers living with genetic, physical and behavioral differences through an image gallery and safe online blog.

This trailblazing interactive program enables student audiences to gain a deeper understanding and respect for human diversity, while empowering their peer group living with differences to become self-advocates and teach the world about life from their unique perspective.

For more information, please contact:
Liz Grossman, Program Director
liz@positiveexposure.org | 212-420-1931

Positive Exposure

Founded in 1997 by former fashion photographer Rick Guidotti and Diane McLean, MD, PhD, MPH, Positive Exposure is an innovative arts organization working with individuals living with genetic differences.

Through cross-sector partnerships with health advocacy organizations, governmental agencies and educational institutions, Positive Exposure utilizes the visual arts to significantly impact the fields of genetics, mental health and human rights.

Positive Exposure programs support and promote human dignity through the Spirit of Difference photographic image data bank and video interviews of persons, particularly children, living with genetic conditions.

For more information, please visit www.positiveexposure.org or contact:
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CREDITS

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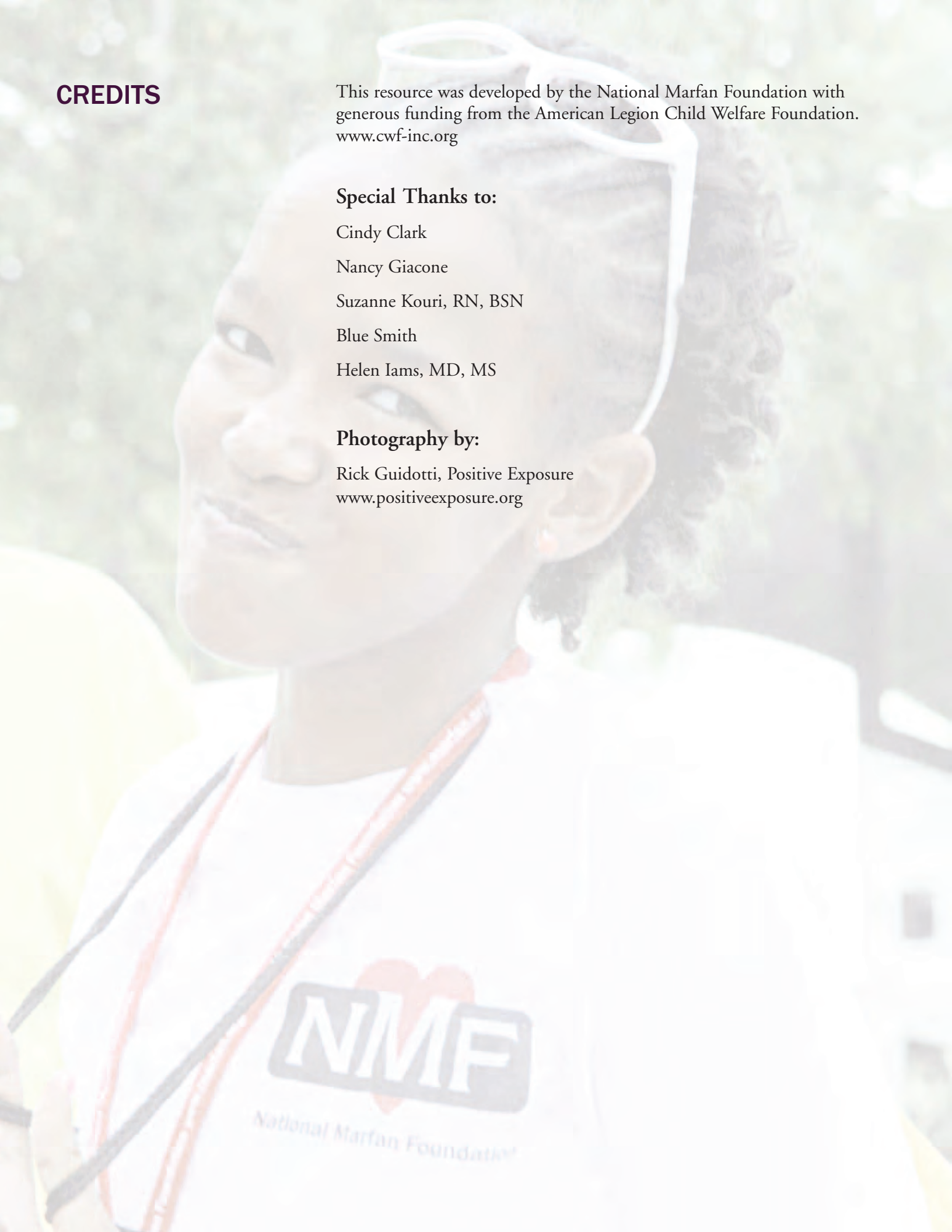

PRODUCED BY

National Marfan Foundation

The **National Marfan Foundation** is a non-profit health organization dedicated to saving lives and improving the quality of life for individuals and families affected by Marfan syndrome and related disorders.

The Foundation, which was founded in 1981, accomplishes these goals by:

- Educating patients, family members and the health care community.
- Advocating and funding clinical and molecular research into the syndrome's detection and treatment.
- Providing support services and a national network of local chapters and groups for patients and relatives to share experiences and improve their medical care.

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Marfan Syndrome: Need-to-Know Information for the Teacher

CD-Rom Evaluation

Please take a moment to share your thoughts about this resource. Your comments will help us develop new materials in the future.

On a scale of 1–5, please circle the degree to which you agree with the following statements:

Statement	1=strongly DISAGREE				5= strongly AGREE
The information is presented in clear and easy to understand language.	1	2	3	4	5
The tabs and bookmarks make the information easy to find.	1	2	3	4	5
After reading this information, I am more likely to recognize a student in need of an evaluation for Marfan syndrome.	1	2	3	4	5
This resource provides me with tools and information to make an appropriate referral.	1	2	3	4	5
The tools presented will help me to better manage the needs of an affected student in my school.	1	2	3	4	5
The "look" of the resource (photos, page layout, etc) is attractive and helps in conveying the information.	1	2	3	4	5
The CD-Rom format is convenient in allowing me to print the materials I need on a case-by-case basis.	1	2	3	4	5
The PowerPoint presentation is an effective tool to aid in educating others in my school about Marfan syndrome.	1	2	3	4	5
Have you ever had a student with Marfan syndrome in your school?	☐ Yes	☐ No	How many? _____		

Please share any comments you have about the resource:

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