PHYSICAL ACTIVITY GUIDELINES

Everyone—including people with Marfan syndrome—benefits from exercise. Regular exercise improves both physical and emotional well-being and can be incorporated safely into the routine of people with Marfan syndrome. Due to early diagnosis and treatment, many people with Marfan syndrome can now expect to live a normal life span; therefore, they are encouraged to adapt health measures that protect them not only from Marfan features that can worsen, but also from medical conditions that are simply part of the aging process.

Most people living with Marfan syndrome should exercise regularly through low-intensity, low-impact activities adapted to meet their specific needs.

Why does physical activity have to be modified for people with Marfan syndrome?

Physical activity should be modified to help eliminate undue stress on the aorta, avoid chest or eye trauma, and avoid potential damage to loose ligaments or joints.

The goal of these physical activity guidelines is to help people achieve the benefits of safe levels of exercise and, at the same time, ensure that they don't add to medical problems related to Marfan syndrome.

What should I know about physical activity if I have Marfan syndrome?

In general, most people living with Marfan syndrome should exercise regularly through low-intensity, low-impact activities adapted to meet their specific needs. They should avoid contact sports because of the risk of damaging the aorta and injuring the eyes. Strenuous activities, such as competitive sports and weightlifting, also should be avoided because of the stress placed on the aorta.

However, it's important to keep in mind that every activity can be done at different intensity levels, and no recommendation holds true in all circumstances. For example, shooting baskets in the driveway is different from playing a full-court basketball game, and bicycling ten miles in one hour on a level course is different from competing in a triathlon.

It is essential for each person with Marfan syndrome to discuss physical activities and specific activity levels with his or her physician so that exercise can be incorporated safely into the regular health-care routine.

What if Marfan syndrome is suspected?

Sometimes Marfan syndrome or a related disorder is suspected, but has not been firmly diagnosed. In other cases, a diagnosis of Marfan syndrome has been made, but the individual currently doesn't have aortic enlargement. In these instances, determining whether or not to follow the physical activity guidelines is particularly confusing.

Several factors are taken into account in determining which activities are safe and which are not. These are: how strongly a diagnosis is suspected; whether or not there is family history of Marfan syndrome/related disorder or a family history of early cardiac death; the age of the person; and level of activity planned. The individual's particular eye, skeletal, heart, aortic, and lung condition are important to consider when deciding on safe levels of physical activity.

It is best to speak with your cardiologist (heart doctor), medical geneticist, or specific medical specialist to determine what is considered safe for you.

What are the different types of exercise and competition?

Exercise can be classified by several 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.
- Isokinetic exercise is 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.
- Isometric exercise is when a muscle is contracting without moving, such as when you strain to lift a heavy weight or push a heavy piece of furniture. An increase in blood pressure, which stresses the heart and aorta, is greater with isometric exercise.

Most exercises and athletic activities involve a combination 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 how strenuous they are.

What are the classifications of sports and activities?

The following table is modified from a classification devised by the American Academy of Pediatrics. Please note that many sports can fall within several categories, depending on the intensity of your participation. It is essential to talk to your doctor about the sports and activities that are safe for you, and how to monitor your exertion level so that exercise remains safe throughout your involvement.

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 avoiding intense competitive efforts.

Contact/collision high potential: Strenuous	Basketball, boxing, field hockey, football, ice hockey, lacrosse, martial arts, rodeo, skiing (water), soccer, wrestling
Contact limited: 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: Non-strenuous	Golf, bowling, walking

How does your medication impact your physical activity?

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

Many people with Marfan syndrome take a beta-blocker medication to reduce stress on the aorta. This medication lowers the pulse at rest and during exercise, and makes it somewhat more difficult to achieve a given level of physical fitness for the amount of physical work performed. They do not, however, allow a person with Marfan syndrome or other aortic aneurysm syndrome to perform very strenuous exercises or play contact sports. Some patients with Marfan syndrome take medications called angiotensin receptor blockers (like losartan) or angiotensin converting enzyme inhibitors. These medications do not protect the aorta from strenuous exercise.

People who have artificial heart valves usually take an anticoagulant medication, warfarin (Coumadin®). This medication interferes with blood clotting and increases the chances of bruising and internal hemorrhages. People taking this medication should avoid contact sports and any activity with a moderate risk of a blow to the head or abdomen.

What are some guidelines and modifications that permit 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 you are free to rest whenever you 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 you enjoy that you 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 percent of capacity). If you are on a beta-blocker, keep your pulse under 100 beats per minute. If you are not on a beta-blocker, keep your pulse at less than 110. Tip: It is often easier to feel the pulse over arteries in the neck than at the wrist.
- Take your time and choose your activities wisely. With everyday activities, ask for help, make several trips carrying parcels rather than carrying everything at once, use your legs rather than your back to lift, exhale when lifting, and refrain from heavy straining.
- Avoid activities that involve isometric work, such as weightlifting, climbing steep inclines, and doing pull-ups. If you are using a stationary cycle or a step-climber, keep the tension low. Multiple repetitions with low resistance or low weight are safer than a few repetitions with a larger weight.
- Do not test your limits. This is particularly difficult for children during physical fitness tests in school and for people who once were competitive athletes. Be sure your child with Marfan syndrome has a physical education program in place that is adapted to minimize his/her health risks.
- 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 in these situations.
- Make sure you wear protective gear. For example, high-quality helmets should always be worn while bicycling.

How can parents guide a child to safe physical activity and exercise?

Adults who are newly diagnosed are usually able to reconcile the need to modify their exercise; however, modifying activity is a greater concern to parents who have a child who is newly diagnosed.

Sports are a big part of childhood in many families. Being part of a team helps develop social skills and self-esteem. It is understandably frustrating or upsetting to children who suddenly have physical activity restrictions (and for their parents), particularly if the child already has a passion or talent for a particular sport.

The general guidelines for people with Marfan syndrome are to avoid competitive and contact sports that would put added stress on the aorta, cause chest or eye trauma, or be potentially damaging to loose ligaments and joints. However, there are also concerns that go beyond the potential physical dangers.

Consider youth soccer, which is not an intensely competitive sport; it's more recreational and is not regarded as dangerous for children with Marfan syndrome because aortic dissection in a young child with Marfan syndrome is very rare. However, youth soccer leads to more competitive soccer in middle school and beyond. Asking a child to give up a sport after he or she has been involved for

many years impacts their social circle and their self-esteem, and removes from their life an activity for which they have developed a passion and talent.

When children are diagnosed at a very young age, parents are encouraged to provide guidance for activities that are appropriate for the long-term. Golf, bowling, archery, piano, art, and music are just a few alternatives that can provide an outlet for creativity and competition while still providing the interaction and socialization a child needs.

When a diagnosis is made when someone is on an athletic scholarship in college, the new physical activity restrictions can be particularly devastating and life-changing. Yet, the alternative can be deadly.

If you or your child is having difficulty adjusting to the restrictions or has become depressed about necessary lifestyle changes, speaking with a therapist may be helpful. You can also talk to others in the same situation as you are through our in-person and online support groups and at our annual family conference.

Do you have questions? Would you like more information?

- Call our help center, 800-862-7326, ext. 126 to speak with a nurse who can answer your questions and send you additional information.
- Visit our website at marfan.org. You can print information that interests you and ask questions online.