





# THE EDS MOVEMENT

*Charging forward. Saving lives.*

Need-to-Know Information for the  
**TEACHER**



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# Introduction

**Vascular Ehlers-Danlos Syndrome (VEDS)** is a life-threatening genetic condition that causes some physical problems that can interfere with a student's ability to perform in the classroom without modifications. These physical limitations cause many students living with the condition to feel isolated and alone. We hope this guide enables educators to:

- Understand the basics of VEDS and its impact on a student
- Learn recommended educational and classroom accommodations to ensure the best learning environment for students with VEDS
- Create a supportive classroom environment for students with VEDS
- Identify ways to incorporate VEDS and/or genetic diversity into lesson plans

Some students with VEDS suffer from low self-esteem. In some cases, this is because they may look different, and sometimes it's because they are unable to participate in many of the activities of their peers. This can reinforce intense feelings of isolation. Physical limitations usually mean that physical education requirements need to be modified.

## ► What is Vascular Ehlers-Danlos Syndrome (VEDS)?

VEDS is a life-threatening genetic condition of the body's connective tissue, specifically collagen, which helps hold the body's cells and tissues together. Due to a lack of functional collagen in the body, a person with VEDS has fragile tissue. This makes them prone to life-threatening events, including arterial dissections and ruptures, aneurysms, hollow organ ruptures, carotid cavernous fistulae, and lung collapses. These can happen with minimal trauma or spontaneously in someone with VEDS.

There are also several conditions related to VEDS that cause people to struggle with similar physical problems, and anyone affected by these conditions also needs an early and accurate diagnosis.



## ► What are the features of VEDS?

Some features of VEDS are easier to see than others, although not everyone with VEDS has these features. These include:

- Hypermobility or “double-jointedness” of the small joints (typically the fingers and hands)
- Thin, translucent skin with easily visible veins
- Small, narrow nose
- Small chin
- Large or sunken eyes
- Thin lips
- Easy bruising
- Aged appearance of the skin, usually on the hands
- Early onset varicose veins
- Sleeping with the eyes open or partially open

Harder-to-detect signs include:

- Artery dissections and aneurysms

Other signs include:

- Sudden collapse of a lung
- Congenital hip dislocation
- Clubfoot
- Rupture of the hollow organs, typically the colon



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## ► What causes VEDS?

VEDS is caused by a change (mutation) in the gene that tells the body how to make collagen III, a protein that is an important part of connective tissue. These mutations result in a reduced amount of functional collagen III in the body. Collagen III is like the “glue” in the body that holds the hollow organs and arteries together.



## ► Who has VEDS?

It is estimated that about 1 in 40,000 to 60,000 people have VEDS, but many people do not know they have it. This includes people of all genders, races, and ethnic groups. People can inherit VEDS; that is, they get the mutation from a parent who has it. This happens in about half of people with VEDS. Other people have a spontaneous mutation, meaning that they are the first in their family to have it. People are born with VEDS, but many people are not diagnosed until a major life-threatening event due to under recognition of the condition. People with VEDS have a 50 percent chance of passing the mutation on each time they have a child.



## ► How is VEDS diagnosed?

A VEDS diagnosis can often be suspected after exams of several parts of the body by doctors experienced with connective tissue conditions, including:

- A detailed medical and family history, including information about any family member who may have the condition or who had an early, unexplained, death.
- A complete physical examination and tests to identify VEDS features that are not visible during the physical exam.

Genetic testing is crucial to making an accurate diagnosis and differentiating between other conditions which may resemble VEDS.

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## ► What is life like for someone with VEDS?

Most people with VEDS can work, go to school, and enjoy active hobbies, although they will need to adapt their physical activity to reduce their risk of arterial events. With an early diagnosis, helpful medical monitoring and activity adjustments can begin early in life. In general, they should not play active team sports that have a risk of collision. In addition, they should not lift heavy objects when at work, home, or the gym. Someone with VEDS may have a reduced quality of life due to the nature of the condition, unpredictable presentation of medical emergencies, lack of a cure or treatment, and reduced life expectancy.

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## ► What emergencies could arise for someone with VEDS?

People with VEDS are at increased risk for emergencies involving the aorta, eyes, arteries, lungs, uterus, and hollow organs (like the intestinal tract). These include:

### **Arterial Dissection and Rupture**

Arterial dissection is a tear between the layers of the artery wall, and arterial rupture is a full tear of all the layers of the artery wall. Dissection or rupture can occur in any artery in the body, including the aorta, the large blood vessel that carries blood away from the heart. Aortic dissection can be fatal if not treated immediately, and any arterial dissection can be an emergency. An evaluation is needed immediately. Arterial dissection and rupture are uncommon in children with VEDS, but the risk may increase after puberty. Symptoms include:

- Sudden onset pain; may be “severe,” “sharp,” “tearing,” or “ripping” and may be located anywhere in the body, depending on which artery is affected. Sometimes, the pain is less severe, but a person still has a feeling that “something is very wrong.”
- Nausea
- Shortness of breath
- Fainting or lightheadedness
- Loss of pulse
- Tingling, numbness, burning, prickling of the skin (parasthesia)
- Paralysis

The presentation of an artery dissection may be very different depending on where the artery dissection occurs.

- If the dissection occurs in the arteries in the head or neck, pain may be accompanied by stroke symptoms, including a droopy eyelid with a small pupil on the same side. A room spinning sensation or dizziness may be present, as well as difficulty seeing.
- If the dissection occurs in the coronary artery, the symptoms may be similar to or cause a heart attack, or cause abnormalities in heart rhythm.
- If the dissection occurs in the aorta, severe pain usually in the chest (front, back or both) but occasionally in the abdomen if the tear begins there.

Additional symptoms that may occur with full arterial rupture include:

- Rapid swelling of the area
- Nausea, which may be accompanied with vomiting
- Clammy skin
- Stroke symptoms may occur if the ruptured artery is in the brain

### **Collapsed Lung (Pneumothorax)**

Collapsed lung happens when air or gas collects in the space between the lungs and the chest and prevents the lung from inflating completely, 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

### **Ocular**

Carotid Cavernous Sinus Fistula formation (CCSF) is a medical emergency which may occur without injury or trauma. CCSF is an abnormal connection between an artery in your neck and the network of veins at the back of your eye. This formation happens as a result of a small tear that sometimes occurs in one of the carotid arteries. Signs of a CCSF are:

- Sudden onset of a swooshing sound in the head
- Redness of the eye
- Pain around the eye
- Bulging of the eye
- Slow onset of blurred vision

## **Bowel Perforation**

Bowel perforation occurs when the wall of the bowels (typically a hollow organ, such as the intestines) tears. This allows fecal matter to enter the abdominal cavity, and can result in sepsis and death. In patients with VEDS, a bowel perforation may occur in the sigmoid colon (lower left quadrant of the abdomen). Esophageal and gastric rupture have rarely been reported.

Symptoms of an intestinal perforation include:

- Abdominal pain that gradually increases and becomes severe or debilitating. This is usually in the lower left quadrant of the abdomen, because usually the perforation is in the sigmoid colon.
- Nausea
- Vomiting
- Chills
- Rectal bleeding
- Fever

## **Uterine Rupture**

Pregnancy is an uncommon occurrence in childhood or adolescence. However, emergencies with VEDS pregnancies do occur. Uterine rupture can occur in the third trimester. A uterine rupture occurs when the wall of the uterus tears. The baby may move into the abdominal cavity outside of the uterus. This is a medical emergency for both the baby and the mother. Signs of a uterine rupture may include:

- Discomfort in the lower area of the belly or lower back pain that is intermittent (like uterine contractions)
- An acute, severe pain in the lower abdomen (can feel like ripping pain), sometimes shoulder pain.
- Blood in the urine.
- Bloody vaginal discharge with dark brown or bright red bleeding.
- Change in the contour/shape of the belly- where the baby bump has been located.
- On fetal heart rate monitor, there are abnormalities in the fetal heart rate pattern.
- New low blood pressure, dizziness, fainting, maternal pulse is barely palpable and fast heart rate.

# ▼ Special Considerations for Students Living with VEDS

Barriers to learning and classroom participation arise from the multiple body systems affected by VEDS. Issues that may need accommodations are listed in sections below. Appropriate interventions are needed according to the difficulties each child may face.

Students with VEDS usually spend a lot of time with doctors, in hospitals, and getting medical tests. In some cases, they may miss school for surgery, physical rehabilitation, or other treatments. Some students take this in stride, while others are stressed and/or frightened. In some cases at-home lesson plans may need to be provided for long term recoveries. The school should be inclusive with all school activities and other information of what is happening at the school so the child feels like they are still a part of their class and school community.



## ► What are Individualized Education Plans (IEP) & 504 Plans?

VEDS does not cause cognitive disabilities, but 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.

Therefore, a student with VEDS may require an Individualized Education Plan (IEP) or a 504 Plan.

An Individualized Education Plan (IEP) is required by the Individuals with Disabilities Education Act (IDEA) so that eligible students can 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. However, the eligibility requirements are many and, in some cases, carries stigma because of the special education component.

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

Both types of plans may include accommodations ranging from an extra set of textbooks to leave at home to wheelchair ramps. They should be reviewed and updated annually.



The purposes of instituting an IEP or 504 Plan are to:

- Enable the student to be independent in school
- Support the student's acceptance and self-esteem
- Allow the student to adapt and cope at school within their limitations
- Keep the student safe from predictable physical injury
- Facilitate communication between the student, parents/guardians and school staff about health needs and accommodations in school

Teachers, administrators, and parents should work together as a team to determine which plan is better for a student and work together to develop it.

The plan works best when each member of the team includes all other members in general correspondence. However, any member can update parents about the student without including other team members. This is to allow for candid, open, and unfiltered communication about the student as often as possible. Team meetings should be held as often as necessary in response to any changes in the student'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. There are many common issues that affect students with VEDS that should be considered in the development of either type of plan.

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## ► What are Individualized Health Plans (IHP) & Emergency Care Plans (ECP)?

In addition to an Individualized Education Plan (IEP) or 504 Plan, a student with VEDS should have an Individualized Health Plan (IHP) and an Emergency Care Plan (ECP), coordinated by the school nurse. Classroom teachers should be aware of these plans, as well.



The Individualized Health Plan (IHP) outlines the healthcare services a student needs during the school day. Prepared by the school nurse in collaboration with the student, parents/guardians, teachers, school officials, and healthcare providers, it includes 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.

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, hospitals, and an ambulance service 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. It may be beneficial to include a picture of the student in the ECP to assist a new or substitute teacher identify the student.

## ► What is the impact of medical problems on the student and what are the suggested accommodations?

Overall, students with VEDS may require a modified curriculum and/or alternative to physical education class. It is also important for school officials and teachers to understand and tolerate extended absence for medical treatments and/or surgery. Collaboration with the entire educational team and family is important to ensure the student does not fall behind.

Here is a breakdown of the different parts of the body affected by VEDS and suggested accommodations.

### Heart and Blood Vessels

#### *Medical Problems*

- Aortic root enlargement/aortic aneurysm (rare)
- Aortic dissection (relatively rare in school-aged students, but it is a medical emergency and should be taken seriously if symptoms occur)
- Arterial dissection, which can occur in any artery in the body, and may occur in the absence of trauma or injury. This is a medical emergency which may present as sudden onset severe pain.
- Arterial rupture, which can occur in any artery in the body, and may occur in the absence of trauma or injury. This is a medical emergency which may present as sudden onset severe pain and/or rapid swelling of the area.
- Heavy bruising
- Frequent headaches

#### *Impact on the Student*

- Fatigue
- Restrictions on lifting (backpacks, textbooks, boxes, etc.)
- Restriction on activities, i.e., those that can increase heart rate or raise blood pressure
- Medication regimen may require taking doses at various times throughout the day
- Sudden, intense pain

#### *Accommodations*

- Take all medical complaints seriously
- Provide unlimited access to the nurse's office
- Adjust school schedule to allow for rest during the day while still meeting academic requirements
- Adjust class schedule and/or group classes together to limit movement between classes
- Provide additional time to get to classes
- Provide extra set of books for home use and/or second locker to accommodate lifting/carrying restrictions
- Modify physical education curriculum or offer alternative to physical education class
- Provide an escort, if necessary, when adjusting to new schedules or changing to new schools.

*Note: Excessive activity increases heart rate and blood pressure, which increases stress on the heart and blood vessels. This could contribute to sudden artery dissections and aortic dissections, which are life-threatening complication of VEDS. Arterial emergencies are relatively rare in school-aged students, but chest pain should always be taken seriously. The risk of arterial and aortic emergencies may increase during puberty.*

## **Bones and Joints**

### *Medical Problems*

- Loose and flexible joints
- Pain (often chronic)
- Poor coordination due to issues with proprioception
- Frequent headaches

### *Impact on the Student*

- 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
- Prone to joint injuries
- Muscle fatigue
- Body image issues
- Severely affected students may require use of a wheelchair (rare)

### *Accommodations*

- Provide a special desk and/or chair
- Allow student to stand if unable to sit comfortably
- Provide additional time to get to classes
- Schedule classes in rooms near each other
- Assign homeroom and locker near to classes students will attend; alternatively, assign a second locker in another part of the building
- Allow access to nurse for pain management, as necessary
- Modify curriculum or offer alternative to physical education class (sample modified curriculum and physical activity guidelines are included in section III, 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 books for several classes
- Grade handwriting with leniency
- Provide additional time for handwritten tests
- Offer options for handwritten assignments, such as an aide who can write for the student or a laptop or tablet
- Wheelchair accessibility if required
- Provide a separate changing room for physical education class

## **Lungs**

### *Medical Problems*

- Asthma
- Sleep apnea
- Collapsed lung; this should be treated as a medical emergency. See section on Emergencies.
- Shortness of breath



### *Impact on the Student*

- 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*

- Provide additional time to get to classes, and scheduling classes in nearby classrooms
- Allow access to nurse for medication or rest as necessary
- Provide for access to emergency inhaler if needed for asthma
- Modify physical education class or provide alternative to physical education class
- Adjust school schedule to allow for more free time for resting without relaxing academic requirements

## **Gastrointestinal**

### *Medical Problems*

- Frequent urination
- Difficulty passing a bowel movement, or constipation
- Gastrointestinal perforation, usually of the sigmoid colon
- Heartburn or other stomach upset

### *Impact on the Student*

- May need additional bathroom breaks
- May feel ill frequently

### *Accommodations*

- Provide additional bathroom breaks
- Allow access to nurse for medication or rest as necessary
- Allow student to complete school work at home in the case of gastrointestinal distress

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## **► What social and psychological problems do students with VEDS face?**

Students with VEDS may look different from their peers. They may be bruised frequently, have visible veins, have an aged appearance to their skin (especially the hands), and have difficulty with their joints. They may sometimes require a brace or other device for joints that dislocate, or may tear their ligaments very easily.

Because of these physical differences, students with VEDS may be highly self-conscious and become the target of bullies. Special accommodations made for them sometimes make the situation even more challenging.

Educating classmates about VEDS can reduce the stigma and prevent bullying. A classroom or school-wide presentation about VEDS can be helpful. Teachers can try to include the student with VEDS, as well as his or her family, in the presentation.



# Physical Education & Activity Guidelines

Regular exercise improves both physical and emotional well-being and can be incorporated safely into the routine of students with VEDS. A student with VEDS should have a physical education and activity program that is individualized to ensure safety.

Physical activity should be modified to help eliminate undue stress on the arteries, avoid physical injury, and avoid potential damage to loose ligaments or joints.

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

## ► What should I know about physical activity for students with VEDS?

In general, most students living with VEDS should exercise regularly through low-intensity, low-impact activities adapted to meet their specific needs. They should avoid collision sports because of the risk of damaging the arteries. Strenuous activities, such as competitive sports and weightlifting, also should be avoided because of the stress placed on the arteries.

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 parent or guardian of a student with VEDS to discuss physical activities and specific activity levels with their student's physician so that exercise can be incorporated safely into physical education at school and in their regular healthcare routine.

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## ► What if VEDS is not formally diagnosed but suspected?

Sometimes VEDS is suspected, but has not been firmly diagnosed. In other cases, a diagnosis of VEDS has been made, but the individual currently doesn't have any serious symptoms. In these instances, determining whether to follow the physical activity guidelines is particularly confusing.

Several factors are considered in determining which activities are safe and which are not. These are: how strongly a diagnosis is suspected; whether there is family history of VEDS or a family history of early death; the age of the person; and level of activity planned. The individual's skeletal, heart, aortic, arterial, and lung condition are important to consider when deciding on safe levels of physical activity.

It is best for parents to speak with their child's vascular surgeon, cardiologist, geneticist, or specific medical specialist to determine what is considered safe.

## ► 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 the person exercising can carry on a conversation while exercising, it is 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 straining to lift a heavy weight or pushing a heavy piece of furniture. An increase in blood pressure, which stresses the heart, arteries 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.

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## ► 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 participation. It is essential that parents talk to their student's doctor about the sports and activities that are safe, and how to monitor exertion levels so that exercise remains safe throughout 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.

<b>Contact/collision high potential: Strenuous</b>	Basketball, boxing, field hockey, football, ice hockey, lacrosse, martial arts, rodeo, skiing (water), soccer, wrestling
<b>Contact limited: Strenuous</b>	Baseball, bicycling (intense), gymnastics, horseback riding, skating (ice & roller), skiing (downhill & cross-country), softball, squash, volleyball
<b>Noncontact: Strenuous</b>	Aerobic dancing (high impact), crew, running (fast), weightlifting
<b>Noncontact: Moderately Strenuous</b>	Aerobic dancing (low impact), badminton, bicycling (leisurely), jogging, swimming (leisurely), table tennis, tennis
<b>Noncontact: Nonstrenuous</b>	Golf, bowling, walking



## ► How does a student's medication impact physical activity?

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

Many students with VEDS take a beta-blocker medication to reduce stress on the arteries. 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 VEDS to perform very strenuous exercises or play contact sports.

Some individuals with VEDS take medications called angiotensin receptor blockers or angiotensin converting enzyme inhibitors. Neither of these medications protect the aorta or arteries from strenuous exercise.

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## ► What are some guidelines and modifications that permit safer exercise for students with VEDS?

Physical activity modifications for students with VEDS include the following:

- Favor non-competitive activity performed at a non-strenuous aerobic pace. Especially suited are sports in which the student is free to rest whenever 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 light hand weights.
- Choose an activity the student can enjoy that can be performed 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.
- Avoid activities that involve intense isometric work, such as weightlifting, climbing steep inclines, and doing pull-ups. When 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 limits. This is particularly difficult for students during physical fitness tests in school and for students who once were competitive athletes.
- Wear protective gear. For example, high-quality helmets should always be worn while bicycling.

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## ► How can parents and the school 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 students with VEDS are to avoid competitive and contact sports that

would put added stress on the arteries, cause abdominal 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 VEDS because aortic or arterial dissection in a young child with VEDS 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 they have 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 and teachers 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 student 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 the student is having difficulty adjusting to the restrictions or has become depressed about necessary lifestyle changes, speaking with a therapist may be helpful. The VEDS Movement offers opportunities for parents of affected children to speak with other parents in our online support groups, or connect with others one-on-one. We also offer specialized programs for children, teens, and young adults at our annual family conference.

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## ► What are the suggested accommodations for students with VEDS?

To ensure the safest environment for a student with VEDS that allows them to participate to the greatest/safest extent possible, the physical education teacher should partner with the student's medical team) and parents.

It is not possible to create a single exercise program that is safe for all students who have VEDS. Each student's physician should provide the physical education teacher with information about safe activity levels for that student. The physical education teacher can then design activities within these levels. It may be helpful for the physical education teacher to provide the physician with a list of planned activities in the physical education curriculum.

In addition, a student may need assistance in developing a realistic self-concept of abilities and limitations.

### *General accommodations and suggestions*

- Encourage the concept of the "personal best" to minimize competition between students and limit peer pressure.
- Instruct the student in safe levels of intensity and duration.
- Be receptive to a student with VEDS who reports certain symptoms, such as chest pain and difficulty breathing.
- Provide adequate time for gradual warm-up and cool-down.
- Monitor the student's level of exertion more closely in extreme weather conditions because heat and cold may add additional stress and may affect the student's endurance and exertion level
- A child with VEDS should be encouraged to take part in noncompetitive activities performed at a mild to moderate level, e.g., they aren't out of breath.

Physical education teachers who are monitoring the exertion level of a student with VEDS should be aware of the student's medication. Some medications slow the heart rate and therefore measuring heart rate is not a true indicator of exertion level.

Students with VEDS often have joint laxity or tightness and may struggle with chronic pain, fatigue, or joint dislocations.

Muscle strengthening can be helpful for these students. Focus on activities that increase strength of both muscles and ligaments. However, the student should only do exercises with a weight that enables 15-20 repetitions comfortably. Avoid activities involving heavy weights or intense isometric exertion. The student may be doing physical therapy outside of school; ask parents about coordinating with the student's physical therapist so that in-school physical education can complement it.

### *Modifications for required equipment*

- If the student needs a brace during sports activities, his or her maneuverability, flexibility, speed, and endurance may be affected. The physical education teacher should be informed by an orthopedist what restrictions the brace creates. When a back or body brace is worn, the head and neck should be protected during physical activity by suitable padding.
- If hernias are present, the student 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.

### *Addressing fatigue issues*

- Decreasing duration of an activity
- Decreasing size of playing area
- Allowing frequent "time out" periods
- Permitting participation at the student's own rate, with freedom to rest as necessary
- Eliminating competitive and emotional stress factors

### *Collision and contact concerns*

- Assign zones of play
- Use individual activities
- Change nature of implement (e.g., foam balls instead of hard balls)
- Group students according to size, abilities, and needs
- Provide clear and concise directions, rules, and regulations
- Provide play area free of obstacles, barriers, or hazards
- Ensure proper padding of facilities and equipment according to 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, horseshoes, relaxation exercises, shuffleboard, walking, aquatics/water activities (safety skills, swimming strokes, pool exercises)



# Additional Resources

## **The VEDS Movement Publications**

*VEDS Need-to-Know Information for the School Nurse:* A companion resource to this school teacher guide, this contains a wealth of information and resources tailored to the school nurse. Find it at [TheVEDSMovement.org/resources-and-answers/parent-toolkit/school-safety](https://TheVEDSMovement.org/resources-and-answers/parent-toolkit/school-safety).

*Vascular Ehlers-Danlos Syndrome:* This brochure contains more detailed information about VEDS. Find it at [TheVEDSMovement.org/veds/what-is-veds](https://TheVEDSMovement.org/veds/what-is-veds).

## **Emergency Care Plan**

The Emergency Care Plan (ECP) attached is customizable and will help record information about the student's condition and provides contact information for family, physicians, hospitals, and an ambulance service 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.

See page 19.

## **VEDS Medical Action Plan**

The VEDS Medical Action Plan attached is customizable and can be used as a quick reference guide for the teacher or nurse. It was designed to be used as a complement to the ECP for the School Nurse, and as a quick reference guide for the Teacher.

See page 20.

## **Classroom Activities**

The attached classroom activities include a word search, crossword puzzle, and word cloud. These tools were developed to help teachers educate their students about VEDS.

See pages 21-24.

## **The VEDS Movement/The Marfan Foundation Help and Resource Center**

Staffed by a registered nurse, you can reach the Help and Resource Center by submitting your question at [TheVEDSMovement.org/resources-and-answers/ask-a-question](https://TheVEDSMovement.org/resources-and-answers/ask-a-question).

Note: **The following may be signs of a trauma situation.**

Sudden instances of chest, neck, abdominal, back, or flank pain; blood pressure/heart rate that is erratic; altered mental status or stroke symptoms; cold limb; eye pain or visual disturbance, shortness of breath/dizziness; sudden collapse or loss of consciousness.

<b>EMERGENCY CARE PLAN</b>		
Student:		Date:
DOB:	Grade:	Homeroom:
Parent(s)/Gaurdian(s):		
<b>Contact Information</b>	Cell/Home Telephone Number	Work Telephone Number
Parent		
Mother:		
Father:		
<b>Healthcare Contact Information</b>	Name	Telephone Number
Primary Care Provider/Pediatrician		
Hospital Preference		
Ambulance Preference		
Health Insurance		
Cardiologist		
Orthopedist		
Geneticist		
Vascular Specialist		
Pulmonologist		
Other Care Provider		
<b>Health Conditions</b>		
Vascular Concerns		
Orthopedic Concerns		
GI Concerns		
Other Concerns		
<b>Signatures</b>		
Reviewed by:		Date:
Student:		Date:
School Nurse:		Date:
Parent/Guardian:		Date:

# VEDS Medical Action Plan

Name:	Date of Birth:	Effective Date:
Doctor:	Parent/Guardian:	
Doctor's Office Phone (Day):	Parent's Phone:	
Emergency Contact (After Parent):	Contact Phone:	
<b>Potential Trauma Situations:</b> <ul style="list-style-type: none"> <li>• Chest, neck, abdominal, back, or flank pain</li> <li>• Erratic blood pressure or heart rate</li> <li>• Altered mental status</li> <li>• Cold limbs (arms/legs)</li> <li>• Sudden muscle weakness or paralysis</li> <li>• Eye pain, change in appearance of the eyes, visual disturbance, or any unusual head symptoms</li> <li>• Shortness of breath or dizziness</li> <li>• Sudden collapse/loss of consciousness</li> </ul> <b>Any spontaneous onset of severe pain could be the sign of a medical emergency for this student.</b>	Student's Picture:	
<b>Emergency Protocols (Check all that apply)</b> <input type="checkbox"/> Call 911 Preferred Hospital: Preferred Ambulance Service/Department Identifier:  <input type="checkbox"/> Notify Parent or Emergency Contact <input type="checkbox"/> Notify School Nurse <input type="checkbox"/> Notify Doctor:	Other Protocols for this Student	
<b>Moderations at School and Circumstances to Avoid</b>		
<b>School Activities</b>	Collision sports, heavy lifting, heavy exertion, muscle straining. Other:	
<b>Medical Considerations</b>	Conventional catheter arteriography, endoscopy, and colonoscopy should only be performed if they cannot be avoided, as they can be life threatening. Information about VEDS should be given to emergency personnel in case of medical emergency.	
<b>Special Considerations</b>	More frequent bathroom breaks, or more breaks due to pain or exhaustion. May need second set of books for home or additional locker to avoid carrying a heavy backpack. Refer to the VEDS School Nurse Guide for more information. Other:	



# Classroom Activities

## ► Word Search

Vascular Ehlers-Danlos Syndrome (VEDS) is a genetic condition that affects many different parts of the body. Find the VEDS-related words and terms below in the puzzle and discuss how the different words are related to VEDS.

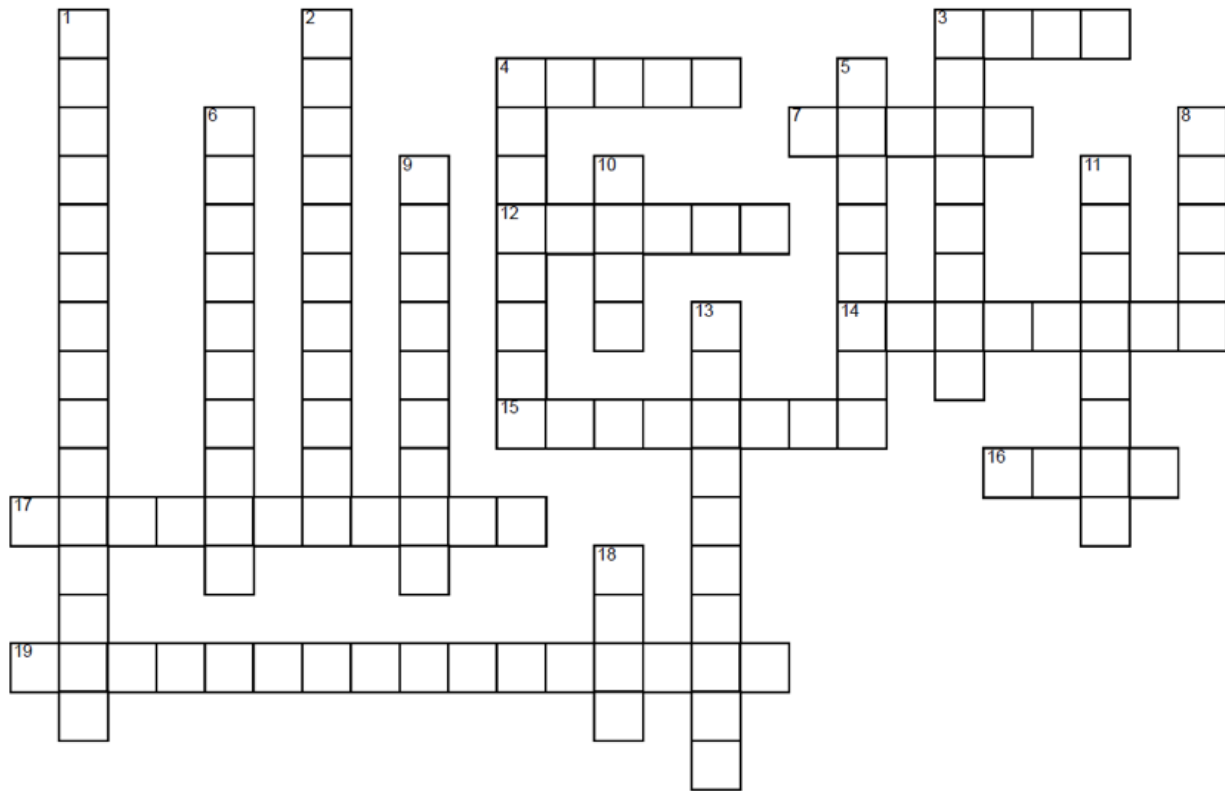
A	A	T	N	A	O	G	S	Y	E	C	U	T	S
N	U	O	N	M	E	T	A	L	L	V	E	A	L
G	K	S	N	N	S	I	N	O	G	R	S	Y	S
O	V	G	I	I	S	Y	N	D	R	O	M	E	U
A	O	N	K	S	G	A	S	O	S	R	M	Y	K
M	E	U	S	T	N	I	O	J	S	N	T	O	O
L	S	L	N	K	O	U	S	A	U	N	S	T	U
E	O	E	I	S	E	I	R	E	T	R	A	M	I
I	N	A	V	E	O	S	M	D	E	E	E	U	A
N	I	N	T	E	S	A	L	O	S	I	S	S	O
S	E	L	A	S	I	S	A	C	E	A	M	C	R
C	E	K	R	R	A	N	O	T	E	M	U	L	T
K	L	Y	L	T	N	V	S	O	N	S	G	E	A
S	E	N	E	G	O	G	O	R	G	A	N	S	M

SYNDROME  
 VEINS  
 JOINTS  
 AORTA  
 NOSE  
 ARTERIES  
 GENES  
 SKIN  
 EYES  
 GUMS  
 LUNGS  
 DOCTOR  
 MUSCLES  
 ORGANS

## ► Word Search Answers

A	A	T	N	A	O	G	S	Y	E	C	U	T	S
N	U	O	N	M	E	T	A	L	L	V	E	A	L
G	K	S	N	N	S	I	N	O	G	R	S	Y	S
O	V	G	I	I	S	Y	N	D	R	O	M	E	U
A	O	N	K	S	G	A	S	O	S	R	M	Y	K
M	E	U	S	T	N	I	O	J	S	N	T	O	O
L	S	L	N	K	O	U	S	A	U	N	S	T	U
E	O	E	I	S	E	I	R	E	T	R	A	M	I
I	N	A	V	E	O	S	M	D	E	E	E	U	A
N	I	N	T	E	S	A	L	O	S	I	S	S	O
S	E	L	A	S	I	S	A	C	E	A	M	C	R
C	E	K	R	R	A	N	O	T	E	M	U	L	T
K	L	Y	L	T	N	V	S	O	N	S	G	E	A
S	E	N	E	G	O	G	O	R	G	A	N	S	M

## ► Crossword



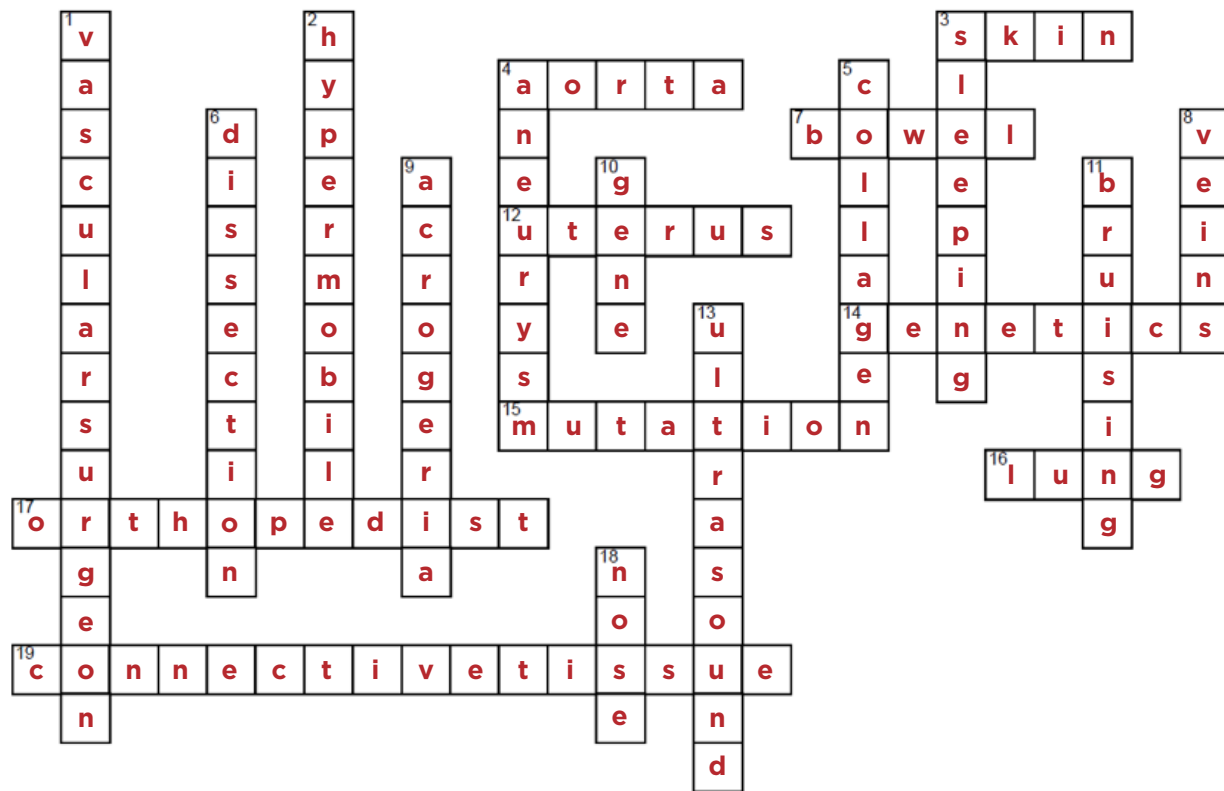
### ACROSS

3. Some people with VEDS have thin and fragile \_\_\_\_\_
4. The large blood vessel that carries blood away from the heart
7. \_\_\_\_\_perforation can be a serious complication of VEDS that can cause sepsis
12. The hollow organ that a baby develops in
14. In biology, the study of inheritance
15. VEDS is caused by a \_\_\_\_\_ in the COL3A1 gene
16. Pneumothorax, or collapsed \_\_\_\_\_, can be a serious complication of VEDS
17. Bone and joint doctor
19. Tissue that provides support and structure throughout the body

### DOWN

1. The type of surgeon that fixes problems in the blood vessels
2. \_\_\_\_\_ joints, or “double-jointedness,” can be present in some people with VEDS, but not everyone has this feature
3. \_\_\_\_\_with the eyes open is common among children with VEDS
4. Abnormal ballooning of a blood vessel
5. Protein that provides support and structure to the skin, blood vessels, and hollow organs
6. A tear in the inner lining of an artery or the aorta
8. Visible \_\_\_\_\_ are a common feature of VEDS
9. Aged appearance of the hands
10. The basic physical and functional unit of heredity
11. Often, people who have VEDS have unexplained \_\_\_\_\_, caused by breakage of very small blood vessels under the skin
13. A painless test that uses sound waves to take pictures of the heart and blood vessels
18. Facial features that some people with VEDS have are thin lips, a narrow \_\_\_\_\_, and large or sunken eyes.

## ► Crossword Answers



### ACROSS

3. Some people with VEDS have thin and fragile **skin**
4. The large blood vessel that carries blood away from the heart - **aorta**
7. **Bowel** perforation can be a serious complication of VEDS that can cause sepsis
12. The hollow organ that a baby develops in - **uterus**
14. In biology, the study of inheritance - **genetics**
15. VEDS is caused by a **mutation** in the COL3A1 gene
16. Pneumothorax, or collapsed **lung**, can be a serious complication of VEDS
17. Bone and joint doctor - **orthopedist**
19. Tissue that provides support and structure throughout the body - **connective tissue**

### DOWN

1. The type of surgeon that fixes problems in the blood vessels - **vascular surgeon**
2. **Hypermobile** joints, or “double-jointedness,” can be present in some people with VEDS, but not everyone has this feature
3. **Sleeping** with the eyes open is common among children with VEDS
4. Abnormal ballooning of a blood vessel - **aneurysm**
5. Protein that provides support and structure to the skin, blood vessels, and hollow organs - **collagen**
6. A tear in the inner lining of an artery or the aorta - **dissection**
8. Visible **veins** are a common feature of VEDS
9. Aged appearance of the hands - **acrogeria**
10. The basic physical and functional unit of heredity - **gene**
11. Often, people who have VEDS have unexplained **bruising**, caused by breakage of very small blood vessels under the skin
13. A painless test that uses sound waves to take pictures of the heart and blood vessels - **ultrasound**
18. Facial features that some people with VEDS have are thin lips, a narrow **nose**, and large or sunken eyes



# THE VEDS MOVEMENT

*Charging forward. Saving lives.*

## Our Mission

**The VEDS Movement** mission is to save lives and improve the quality of life of individuals with Vascular Ehlers-Danlos Syndrome (VEDS). By pursuing the most innovative research, educating the medical community, general public and affected individuals, and providing support to patients, families, and caregivers, we can charge forward and improve the outcomes for those living with VEDS.

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*A division of The Marfan Foundation.*



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FOUNDATION