

# Understanding Vasculitis

## Essential Information for Educators

### What is Vasculitis?

Vasculitis is a general term that refers to **INFLAMMATION OF THE BLOOD VESSELS**. It describes a family of more than 20 rare autoimmune diseases, characterized by narrowing, weakening or scarring of the blood vessels, which can restrict blood flow and damage tissues and vital organs such as the lungs, kidneys, heart, and brain. With treatment, it can be well managed, but there is currently no cure.

Vasculitis symptoms can vary from person to person depending on the organs and tissues affected but may include:

- Fatigue/weakness
- Muscle and/or joint pain
- Lack of appetite/weight loss
- Rashes or skin lesions
- Eye pain and redness/blurred vision
- Chronic nasal, ear and/or sinus problems
- Cough & shortness of breath
- Abdominal pain
- Severe headaches
- Nerve problems (numbness, weakness, pain)



### TIP

Your student and their parents are likely feeling overwhelmed. Help connect them with the people in your school and education system who can help.

# Accommodations

There are different types of vasculitis and each affects the body in unique ways. Your student could be experiencing a variety of symptoms that impact their education including trouble with hearing or vision, weakness or numbness in hands and feet, brain fog and memory problems, and extreme fatigue. Your student is also likely to be immunocompromised due to the medications that are used to treat vasculitis. Accommodations will need to be made to protect them from infectious diseases.



## How You Can Help

**Collaborate with your administrative team to determine who will be the family's main point of contact at your school. The main contact will function as the liaison between the school and the family. Their role is to ensure that information, such as notification of extended absences, updates on health status, or changes to accommodations, is shared with all relevant parties.**



## Work with the family and your school's 504 team to make appropriate accommodations. Possible accommodations could include:

- Reduced course load
- Accommodation for absences/excused absences for medical appointments
- Notification if communicable diseases are present in the classroom
- Alternative seating for lunch or assemblies
- Flexibility in course schedules, tests, and exams
- Extra time for assignments, tests, and exams
- Breaks during class to go to the restroom or to move around
- Rest breaks during the day
- Teacher-provided outlines for presentations and lectures
- Verbal, visual, or technology aids
- Assistance from a tutor or lab assistant
- Preferential classroom seating
- Modified physical education curriculum
- Physical/occupational therapy consult at school
- Assistance with carrying books, lunch tray, etc.
- Water bottle and/or snacks as needed allowed in class
- A plan in case of emergencies

**TIP**

**Leave a note for substitute teachers explaining accommodations.**



Although this list does not include all possible accommodations, some of these options may be helpful. At the same time, your student may not need many, or most, of the listed accommodations.

# How Is Vasculitis Treated?

Treatment for vasculitis involves two phases: controlling the inflammation to achieve remission, and maintenance treatment to help prevent relapses. Glucocorticoids (steroids) such as prednisone are often the first line of treatment for vasculitis. Glucocorticoids are also immunosuppressive medications. In some cases, other medications that suppress the immune system such as chemotherapy medications, disease-modifying antirheumatic drugs, and biologics are prescribed.

Immunosuppressive medications restrain or lessen the body's immune response. When a child is being treated for vasculitis, they may be immunocompromised. As a result they are:

- More likely to get an infection.
- Less able to fight off an infection once infected.
- More likely to experience complications from infections.



## How You Can Help

1. Encourage frequent hand washing or use of hand sanitizer for all of your students.
2. Remind students to stay home when ill.
3. Sanitize high touch surfaces in your classroom.





## What You Need to Know about Glucocorticoids

Glucocorticoids quickly control inflammation, helping prevent further damage to vital organs. Unfortunately treatment with glucocorticoids results

in unpleasant side effects. It is helpful to be familiar with some of the possible physical and mental health impacts of treatment with glucocorticoids.

### Physical Impact

- Rapid weight gain, especially in the face (often referred to as “moon face”) along with fat redistribution to the upper back and midriff
- Red or ruddy complexion and/or acne
- Increased hunger
- Insomnia
- Upset stomach
- Muscle aches and pains

### Mental & Emotional Impact

- Mood swings/irritability
- Difficulty concentrating
- Hyperactivity
- Anxiety



**TIP**

Be prepared for any change you may see in your student. They may need extra emotional support in the classroom. Consider reaching out to the school guidance counselor for additional support.

# The Impact of Vasculitis on Your Student

While each child with vasculitis is unique, there are some concerns and struggles shared by almost all children with vasculitis.

- Appearance changes caused by treatment or by vasculitis can have a profound impact on a child's self-esteem.
- Vasculitis can cause extreme fatigue. Having to cut back on extracurricular activities and socialization increases feelings of isolation and loneliness.
- Dealing with a chronic illness can be challenging. Many children with vasculitis report increased anxiety and depression. Glucocorticoids can also have a profound impact on a child's mental health.



## How You Can Help

1. Reassure your student that you are in their corner. Your caring and support mean so much.
2. Make an extra effort to be on the lookout for teasing or bullying from other children who do not understand the reason behind the sudden changes in their classmate's appearance.
3. Be alert to troubling changes in mood, and share concerns with the child's parents.
4. With the permission of the parent and child, share age appropriate information with your class about vasculitis. Consider covering topics such as:
  - Illness or medications may change how someone looks, but it doesn't change who they are.
  - Vasculitis is not contagious.
  - Specific ways they can support their classmate.



## A Special Note for Coaches and Physical Education Instructors

Vasculitis causes extreme fatigue and negatively impacts strength and endurance. Vasculitis treatments can weaken bones and muscles. As a result, a child with vasculitis may need to avoid or modify certain types of physical activity. However, children with vasculitis need to maintain as much physical activity as possible to help lessen bone and muscle loss, preserve strength and cardiovascular endurance, and enjoy the physical and mental health benefits of being active.

It can be very hard for a child who has excelled in athletics to suddenly find themselves unable to compete and perform at their previous level. Remind them how incredibly hard their body is working to fight this disease. Help them to see that, for now, more of their body's energy and other resources need to be devoted to healing. Reassure them that in time they will have more energy for their athletic pursuits.



## How You Can Help

1. Suggest physical activities they can enjoy even with limited strength and stamina.
2. Find ways to allow them to safely participate.
3. Provide non-physical ways for them to be a leader and contribute to the team.

# Learn More!

Visit our website for more information and resources.

[www.VasculitisFoundation.org](http://www.VasculitisFoundation.org)



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