

Understanding Vasculitis

A Guide for Families

“ *I'm sure as a newly diagnosed family you are feeling incredibly overwhelmed. Be patient with yourself. It's a long process, and it's okay to go through that grief. But there are wonderful days ahead. There are good things to come.* ”

~ Kacey Ableman (Son Spencer diagnosed with anti-GBM disease & MPA in 2021)

You Are Not Alone

The Vasculitis Foundation (VF) is here when you are ready – providing the **EDUCATION, RESOURCES, AND SUPPORT** you need as you navigate your child's vasculitis diagnosis. When you connect with the VF, you connect with real people who respond quickly and are invested in helping you and your family.



The VF can connect you with other families who have children with vasculitis, guide you to educational resources that can give you the information you need to make treatment decisions, and keep you informed on advances in vasculitis research.

Call us at 1-800-277-9474, or reach out by using the Contact Us form on our website: www.vasculitisfoundation.org



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Learn About Your Child's Vasculitis Type

Vasculitis is a general term that refers to inflammation of the blood vessels. There are more than 20 types of vasculitis that share common characteristics but are unique in the impact they have on the body. Some types of vasculitis such as Kawasaki disease

and IgA vasculitis (formerly Henloch-Schönlein purpura) occur mostly in children. Kawasaki disease typically does not recur once successfully treated. While children with IgA vasculitis can have recurrences, these are usually milder and typically do not need long-term treatment. Other types of vasculitis such as granulomatosis with polyangiitis (GPA), microscopic polyangiitis (MPA), Takayasu arteritis (TAK), and polyarteritis nodosa (PAN) occur in both children and adults. GPA, MPA, TAK, PAN, and many other types of vasculitis are considered chronic vasculitic diseases for which there is currently no cure. However, chronic vasculitis has many treatment options and can be well managed.

It is not possible to share everything you need to know about vasculitis in this guide. More information on the types of vasculitis as well as additional information on all of the topics covered in this guide can be **FOUND ON OUR WEBSITE**. There, you will find advice on explaining your child's diagnosis to their siblings, tips for managing symptoms, information on lung and kidney involvement in pediatric vasculitis, and much more.

Additional sources for reliable vasculitis information include the American College of Rheumatology, Pediatric Rheumatology European Society, and National Institutes of Health.

Find pediatric vasculitis resources on our website



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Online Research and Outdated or Non-Relevant Information

Researching online to familiarize yourself with vasculitis can be scary. Much of the information is dated and may be based on studies conducted on older patients that may not apply to children. Life-expectancy, disease recurrence, and treatment best practices are NOT necessarily applicable to your child's situation. Read to become aware, but consult with your doctor for up-to-date information that applies to your child.



Educate Yourself on Vasculitis Treatments

Treatment Guidelines

Healthcare providers use treatment guidelines to help them select the most effective treatment, monitor how well the treatment is working, and determine whether they need to switch to a different treatment. You can find treatment guidelines for most types of vasculitis on the VF website. Remember that guidelines are only recommendations for healthcare providers to consider. Each child with vasculitis is unique and their treatment plan needs to be tailored to their individual needs.



Glucocorticoids (Steroids)

In most cases, the initial treatment for vasculitis is high-dose glucocorticoids (steroids) such as prednisone. Steroids quickly control inflammation, protecting vital organs and limiting damage to blood vessels.

Learning what side effects may occur while your child is being treated with steroids, and being prepared with strategies to help minimize side effects, can help you and your child feel more in control as you navigate treatment.

Possible side effects of high-dose steroid treatment include:

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

High-dose steroids are the first line of defense to prevent vasculitis from causing severe, irreversible damage, but they are not a long-term treatment; thus these side effects, although unpleasant, are not long-term either. Once your child has safely tapered to a lower dose of steroids, the moon face, insomnia, and many other side effects associated with being on high doses of steroids will improve.

Consider tracking steroid side effects using a tool such as Steroids and Me (SAM). SAM is an online tool built by doctors, scientists, and patients that provides free education and practical tips from experienced medical experts to equip you with the knowledge to manage side effects and work with your child’s doctor toward a safe steroid taper.

Learn about steroid side effects and tools such as SAM.



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Additional Treatments

Other medications that may be used to treat vasculitis include chemotherapy medications, disease-modifying antirheumatic drugs, biologics, and complement inhibitors. You can find information on these medications, including common side effects, and questions to ask your doctor on our website.

Some treatments for vasculitis, for example cyclophosphamide, may impact your child's fertility.

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The **REPRODUCTIVE HEALTH** section of our website contains videos and other resources to help guide your conversation with your child's doctor.

Protect Your Child from Infection

Many of the medications used to treat vasculitis suppress your child's immune system. A child with a suppressed immune system is more likely to get an infection, less able to fight off an infection once infected, and more likely to experience complications from an infection than other children. Take these important steps to help protect your child.

- Make sure your child receives all recommended vaccinations. Some medications used to treat vasculitis may make vaccinations less effective. Discuss the timing of vaccinations with your child's pediatrician and pediatric rheumatologist.
- Frequently sanitize high-touch surfaces such as door handles and light switches.
- Remind your child to wash their hands often and to avoid touching their face.
- Encourage your child to stay away from anyone who seems sick.
- Ask your child's school to notify you about outbreaks of infectious diseases.
- Ask your child's school to provide alternative seating in crowded areas such as cafeterias or during assemblies.
- Have your child wear a mask when they can't avoid crowds.

Ask your pediatric rheumatologist about any additional measures you may need to take to reduce your child's risk of infection.

Build Your Child's Treatment Team & Plan



Treatment Team

In most cases, a pediatric rheumatologist will take the lead in developing your child's treatment plan. Rheumatologists specialize in the treatment of immune-related and inflammatory diseases such as vasculitis. Depending on how vasculitis is impacting your child's body, your child's treatment team may include other healthcare professionals such as:

- Nephrologist (Kidneys)
- Pulmonologist and/or Respiratory Therapist (Lungs)
- Otolaryngologist/ENT (Ear, Nose & Throat)
- Cardiologist (Heart)

Depending on the severity of your child's vasculitis and the availability of experts locally, you may want to consider traveling to a vasculitis center for a consultation. At a vasculitis center you will find specialized teams of medical professionals who have additional training and experience in treating vasculitis. The experts at a vasculitis center can work with your local healthcare team to help build your child's treatment plan. To find a vasculitis center, you can use the Find a Doctor tool on the VF's website or contact the VF for assistance.

Treatment Plan

Your child's treatment plan has several goals:

- Bring inflammation under control and keep it controlled
- Prevent damage to blood vessels and organs
- Prevent complications
- Ease symptoms



Medications are not the only pieces of a successful treatment plan. Occupational or physical therapy, dietary changes, good sleep routines, physical activity, and stress management are also helpful in managing symptoms and improving overall health.

Working with Your Child's School

Reach out to the administrators at your child's school and set up an appointment to talk about your child's educational needs. Explain what vasculitis is and how the disease and treatments may impact your child. Let them know that vasculitis symptoms may not always be visible, but their impact on your child may be severe at times. The VF's **GUIDE FOR TEACHERS AND COACHES**, "Understanding Vasculitis: Essential Information for Educators", is a helpful resource to share with faculty and staff at your child's school. The information in the guide can also help direct your discussions with school faculty, staff, and administration.

If you live in the United States, ask school administrators to start the process for qualifying your child under Section 504. (Similar statutes exist in many countries). For every student with a chronic illness, federal legislation requires schools to make any reasonable accommodations to allow the student to receive public education. A 504 Plan is designed for the student who can function in the general education classroom, but requires accommodations to enable an optimal learning experience. The good news is that the professionals at the school who are responsible for these plans are experts at what they do. They will take your request, gather the necessary information, and set up a meeting with you and any additional school personnel who will play an important role in your child's education.

Accommodations that may be helpful for your child include:

- Accommodation for absences/excused absences for medical appointments
- Notification if communicable diseases are present in the classroom
- Extra time for assignments, tests, and exams
- Rest breaks during the day
- Modified physical education curriculum

You can find a more comprehensive list of possible accommodations as well as more information on 504 plans and working with your child's school on our website at vasculitisfoundation.org/pediatrics-vasculitis/education-concerns/

While it is natural to worry that implementing a 504 plan might "label" your child, this is not the case. The accommodations provided by a 504 plan can protect your child's health and provide the tools and resources they need to succeed academically.

There's a Community Here to Support You

Your mind is probably swirling with questions right now. Will my child look or act differently? What will their future be like? Will they play sports again, go to college, be able to have kids, have a “normal” life? You may also be feeling lonely and scared. You had probably never heard of vasculitis until your child was diagnosed. You might be thinking there is no one else who can understand your worries and fears for your child. You may be wondering if there is even anyone working on curing this disease.

A group of parents who have children with vasculitis inspired this guide and they want you to know what they have learned. Yes, pediatric vasculitis is a rare disease, but you are not alone. Researchers and physicians are actively working on improving pediatric-specific vasculitis treatments. Other families are eager to support you. The Vasculitis Foundation is committed to advocating for you. Until there's a cure, there's community.

This guide was made possible through sponsorship from



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Learn More!

Learn more about VF virtual support groups at <https://www.vasculitisfoundation.org/living-well/find-support/>



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Early Diagnosis · Better Treatment · Improving Lives