Patient Recommendations for People Living withVasculitis

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RARE DISEASE DIVERSITY COALITION

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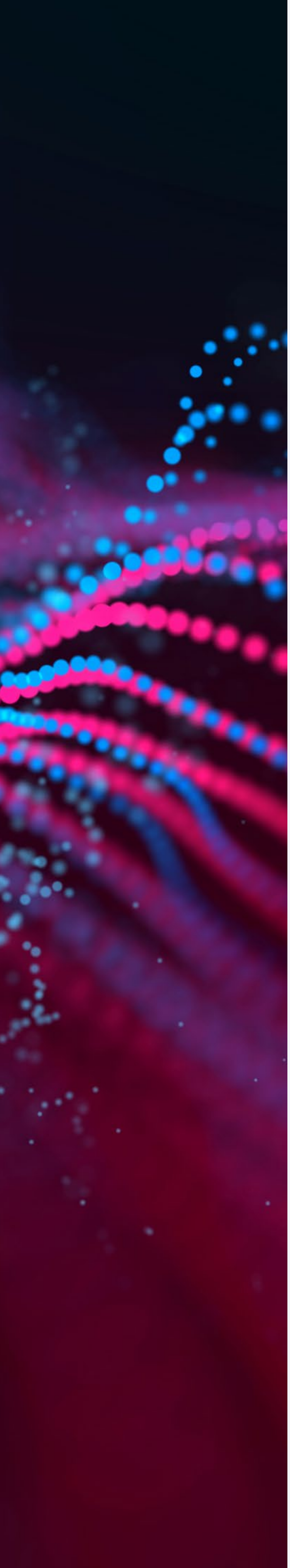


Contents

Patient Recommendations for People Living with Vasculitis

This recommendations report is built on the voices of the vasculitis community. Through group discussions and one-on-one interviews, Steering Committee members shared their insights on where current care and support fall short—and what a better future could look like for people living with vasculitis. This report brings together their ideas, hopes, and real-world experiences to offer powerful patient-driven recommendations for change.

Barriers to Care

I. Gaps in Patient-Centered Care
  a. Biases and Stereotypes
  b. Trust and Communication Gaps
  c. Healthcare Systems
  d. Delays in Diagnosis and Misdiagnosis
  e. Community vs. Academic Care

II. Lack of Access and Affordability
  a. Inadequate Insurance Coverage
  b. Impact of Federal Trends and State Politics on Medicaid
  c. Employment and Education Disparities
  d. Geographic Barriers
  e. Lack of Access to Specialists
  f. Limited Specialist Availability

Improving Vasculitis Care: Visualizing Better Outcomes

1. Advance health equity through trust-based care, cross-state telehealth access, and reimbursement reform.
2. Encourage healthcare providers to build trust and demonstrate cultural competency by being “compassionate listeners.”
3. Ensure healthcare providers support shared decision-making by encouraging patients to ask questions, and by offering referrals or consultations when they lack knowledge of vasculitis.
4. Improve affordability and accessibility of life-saving vasculitis treatment for patients of all backgrounds, with care navigation support as necessary across all treatment settings.
5. Center equity in all policy and program decisions and involve the patient voice in determining equity needs, including acknowledging current inequities in rare disease care.
6. Expand each patient’s network of support so that vasculitis treatment is possible even if someone does not have access to a friend, family, or paid caregiver.

Consensus-Developed Patient Recommendations

1. **Expand Academic and Community Provider Knowledge and Awareness of Vasculitis**
2. **Encourage People Impacted by Vasculitis to Advocate for Better Care**
3. **Advocate for System-Level Change to Improve Access and Affordability of Patient-Centered Care**

About This Project

In early 2025, the Rare Disease Diversity Coalition (RDDC) and the Vasculitis Foundation convened a patient-led **Vasculitis Health Equity Steering Committee** to develop Patient Recommendations for People Living with Vasculitis. This initiative brings together individuals with vasculitis, particularly those with ultra-rare forms of the condition, along with healthcare providers and other key stakeholders to co-create patient-led recommendations addressing access to care and support within the vasculitis community.

The Steering Committee identified three goals for its work:

1. **Raise Awareness:** Committee members shared their unique, lived experiences with vasculitis through Committee meetings and one-on-one qualitative interviews, reflecting the diverse journey that people and families living with vasculitis face in getting a diagnosis and treatment.
2. **Foster Multi-Stakeholder Collaboration:** The Committee represented multiple domains of vasculitis, including patient care, patient advocacy, provider care, and advocacy expertise. Representatives are from geographically diverse areas, represent different genders, ages, races, and ethnicities, and represent different stages of disease. Together, their insights offer new strategies to foster collaboration across disciplines and deliver better care to people living with vasculitis.
3. **Develop Practice Recommendations:** The Committee has developed recommendations that are "actionable and impactful," guiding patients and providers who are not experienced in vasculitis to recognize its warning signs, diagnose the disease, and get access to care.

We gratefully acknowledge Amgen's generous support for the development of the RDDC Patient Recommendations for People Living with Vasculitis Report. With this support, the Rare Disease Diversity Coalition (RDDC) engaged Links2Equity to lead a patient-led steering committee that brought stakeholders together to develop comprehensive, patient-centered recommendations to improve care and outcomes for individuals living with vasculitis.

Project Team

Steering Committee

Antonio Salazar-Hobson, patient advocate, Small-Vessel Vasculitis (SVV)

Betsy Gemmecke, patient advocate, granulomatosis with polyangiitis (GPA)

Caleb Lounsbery, patient advocate, granulomatosis with polyangiitis (GPA)

Kimberly Fisher, patient advocate, Behçet's disease

Molly Terrenoire, patient advocate, granulomatosis with polyangiitis (GPA) with renal involvement

Sarah Jones, patient advocate, eosinophilic granulomatosis with polyangiitis (EGPA)

Convenors

Deanna Darlington, Links2Equity

Kathryn Boxill, Links2Equity

Jocelyn Cooper, RDDC

Jennifer Wages, Vasculitis Foundation

Jodi Hall, Vasculitis Foundation

What Is Vasculitis?

Vasculitis refers to a group of nearly 20 rare diseases and conditions that damage blood vessels by causing inflammation, which can restrict blood flow and damage vital organs. It can occur as a primary condition when another cause cannot be identified, or as a secondary condition, resulting from diseases and conditions related to infections, trauma, autoimmune disorders, or side effects of some medicines.

Vasculitis may present in a number of different ways, and it can have a multi-system impact. For example, people living with vasculitis may experience:

- Fever
- Loss of appetite
- Unexplained weight loss
- Tiredness or fatigue
- Nerve problems, including numbness, weakness, and loss of strength
- Pain, such as severe headaches and joint pain
- Skin conditions such as a rash, redness, facial swelling, or skin ulcers

In fact, different types of vasculitis may impact different organ systems, as described below.

Type of Vasculitis	Organ System Affected
Anti-GBM disease (anti-glomerular basement membrane)	Small and medium-sized blood vessels, lungs, kidneys
Aortitis	Large blood vessels, heart, brain, kidneys, gastrointestinal tract
Behçet's disease	Arteries of various sizes, mouth, eyes, skin, joints, genitals
Central nervous system vasculitis	Small and medium-sized blood vessels of the brain, spinal cord, and protective membranes
Cogan's syndrome	Arteries of various sizes, but primarily large vessels (especially the aorta), eyes, inner ear, heart
Cryoglobulinemic vasculitis	Small and medium-sized blood vessels, skin, muscles, peripheral nerves, kidneys
Cutaneous-small vessel vasculitis (hypersensitivity/leukocytoclastic)	Small blood vessels, skin
Eosinophilic granulomatosis with polyangiitis (EGPA), formerly Churg Strauss	Small and medium-sized blood vessels, lungs, sinuses, kidneys, intestinal tract, skin, heart, and nerves
Giant cell arteritis (GCA)	Large blood vessels (typically arteries in the neck and scalp), eyes, brain
Granulomatosis with polyangiitis (GPA), formerly Wegener's	Small and medium-sized blood vessels, sinuses, lungs, kidneys
IgA vasculitis (formerly Henoch-Schönlein purpura)	Small and medium-sized blood vessels, skin, joints, intestines, kidneys
Kawasaki disease	Medium blood vessels, including coronary arteries
Microscopic polyangiitis (MPA)	Small and medium-sized blood vessels, particularly kidneys, lungs, nerves, skin, joints
Polyarteritis nodosa (PAN)	Medium blood vessels, nervous system, joints, kidneys, gastrointestinal tract, heart
Polymyalgia rheumatica (PMR)	Large blood vessels, muscles, joints
Rheumatoid vasculitis	Small and medium-sized blood vessels, skin, peripheral nerves
Takayasu Arteritis (TAK)	Large and medium-sized blood vessels including the aorta and branches in the heart
Urticarial vasculitis (normocomplementemic/ hypocomplementemic)	Small and medium-sized blood vessels, skin, joints, eyes, lungs, gastrointestinal tract, kidneys

Because of the multi-system nature of the vasculitis, individuals often have an arduous diagnostic journey, bouncing between primary care providers and specialists before finding the correct diagnosis and treatment. Patients often report a "whack-a-mole" experience where a provider treats one symptom only to have another arise in its place.

The role of specialists with expertise in the different organ systems of the body, such as rheumatologists, neurologists, nephrologists, and hematologists, becomes especially important given that there is no one defined pathway to a vasculitis diagnosis.

Among the Steering Committee members alone, patients often interacted with multiple types of providers before getting a diagnosis, including general and primary care practitioners, ENT (ear, nose, and throat) specialists, rheumatologists, neurologists, cardiologists, dermatologists, hematologists, and allergists.

References

1. National Institutes of Health (2023, May 22). *What Is Vasculitis?* National Heart, Blood, and Lung Institute. Retrieved June 3, 2025, from https://www.nhlbi.nih.gov/health/vasculitis.
2. Vasculitis Foundation. *Education*. Retrieved June 3, 2025, from https://vasculitisfoundation.org/education.

A Trusted Resource on Rare Diseases: The GARD Database

GARD (Genetic and Rare Diseases Information Center) is a program by the National Institutes of Health that provides free access to information about genetic and rare diseases. It gathers information from different research databases to create a simplified summary of known causes and symptoms, diagnostic resources, and information on where people may find a community of support for their rare disease.

GARD offers multiple entries on vasculitis, covering 15 forms of the disease, how it presents, and how common the symptoms are for that form of vasculitis. GARD is a reliable resource and should be considered as a supplemental tool to share with patients, providers, advocates, and others when discussing vasculitis broadly as well as specific types of the rare disease.

>> To learn more, visit the GARD database at https://rarediseases.info.nih.gov/.

Barriers to Care

> **“This is not a fun disease to live with… waiting three months to see a specialist can be torturous. When you’re going through it, it’s really important to get patients in as soon as possible.”** – Caleb

Gaps in Patient-Centered Care

- **Biases and Stereotypes:** Prejudices that affect the quality of care and patient experiences, including language barriers, socioeconomic status, racial and gender disparities, and others based on social determinants of health (SDOH).
- **Trust and Communication Gaps:** Barriers to effective communication between patients and healthcare providers, including issues related to language and interpreters.
- **Healthcare Systems:** Navigating various healthcare systems and the lack of sharing medical records between providers.
- **Delays in Diagnosis and Misdiagnosis:** Lack of knowledge of vasculitis led to misdiagnosis of the condition and/or late identification of the disease, leading to worsened health outcomes.
- **Community vs. Academic Care:** Patients experience important diagnosis, treatment, and care continuity differences, depending on their access to community-based or academic medical settings.

Lack of Access and Affordability

- **Inadequate Insurance Coverage:** Challenges in obtaining insurance that covers necessary treatments and services without barriers such as high deductibles or utilization management practices.
- **Impact of Federal Trends and State Politics on Medicaid:** Variability in Medicaid programs affect access to healthcare services.
- **Employment and Education Disparities:** Challenges that impact the socioeconomic status of individuals with vasculitis.
- **Geographic Barriers:** Limited access to care due to geographic location and the restrictions of state-bound insurance plans, such as not reimbursing non-emergent care.
- **Lack of Access to Specialists:** Limited availability of healthcare professionals with expertise in vasculitis, particularly ultra-rare forms of vasculitis.
- **Limited Specialist Availability:** Even when a specialist is available locally, many vasculitis patients face long wait times for treatment. Existing providers may also delay care for other chronic health conditions because of uncertainty around vasculitis.

> **“If I felt more comfortable, I would have gotten treated much faster…I had a really bad hospital visit and could hear the nurses talking about me the whole visit, making jokes. I was afraid, I felt ashamed, I felt harassed.”** – Kim

Improving Vasculitis Care: Visualizing Better Outcomes

The Steering Committee discussed how vasculitis care could be improved, visualizing what better outcomes would look like based on their lived experiences. That directly informed the recommendations below and is reflected in the rationale provided in each section.

1. Advance health equity through trust-based care, cross-state telehealth access, and reimbursement reform.

Recommendation: Implement policies and clinical practices that expand access to FDA-approved and off-label treatments, while supporting cross-state virtual care. Incorporate HCPs to advise legislators on effective Medicare guideline suggestions that promote improved healthcare by simplifying coding, creating new taxonomies, and expanding reimbursement for off-label and alternative treatments. This should include telehealth reimbursement parity and licensure reform to allow patients with rare conditions, like vasculitis, to maintain consistent access to preferred providers, regardless of geography or ability to travel. Advocate for and support proposed federal legislation targeting these goals, such as the proposed Access to Rare Indications Act of 2021 (H.R. 6160).

Events, such as the RDDC Capitol Hill Briefing, are key opportunities to make a cohesive and unified ask for policymakers to support and legislate health equity improvements.

Rationale: There are substantial navigation barriers to reimbursement and access to physician-administered treatments (e.g., infusions) as well as prescriptions available through pharmacies or community-based therapeutics. The lack of physician knowledge, the complex reimbursement process for off-label treatments, and the difficulty in reimbursing physician time related to approvals present issues to access and affordability.

Most people with a rare disease face barriers to meeting with knowledgeable providers, as medical professionals with expertise in their condition may be few and far between. This barrier can be amplified for people living in rural areas who may be out of reach from academic and specialty medical centers and lack access to regional specialists such as neurologists or hematologists. Many individuals face multi-hour drives each way to and from specialists, while others must travel to different states to receive care. Telehealth presents the most immediate way to address this gap while considering longer-term solutions to add more specialists in rural areas.

> **"Health equity means treating that patient as a new patient every time. If someone says they're in pain, you believe they are in pain until you have proof that they are not."** – Kim
>
> **"Make sure everybody is on an even playing field in a medical situation. That includes people who are Black, indigenous, or people of color; those in the LGBTQ+ community, and people living with rare diseases. It also includes communities that lack funds to access FDA-approved treatments and off-label treatments for vasculitis."** – Jodi
>
> **"I don't understand why doctors can't care for patients virtually across state lines. Doesn't make sense why I had to stop seeing my preferred specialists – my current doctor could do lab draws locally and communicate virtually."** – Caleb

2. Encourage healthcare providers to build trust and demonstrate cultural competency by being "compassionate listeners."

Recommendation: Embed health literacy, cultural competency, and communication standards into clinical practice and reimbursement policy. Create materials to better help practitioners understand vasculitis so they can focus on the individual patient instead of disease novelty, cultivating an environment of trust and safety.

Literacy areas should include:

- Understanding biases related to mental and behavioral health needs, substance use disorders, experiences of pain, and feelings of hopelessness that often coincide with chronic rare diseases.
- Why patient requests are focused on improving quality of life, while avoiding assumptions related to "drug-seeking behavior." This should include how to have conversations with other care professionals, such as ENTs, who have limited exposure to vasculitis and other rare diseases.
- How to reduce patient trauma related to loss of trust. This often occurs when overhearing negative assumptions, biases, etc. from providers.
- The need to address more common healthcare biases, such as assumptions related to age or socioeconomic status like the use of Medicaid programs.

Develop clinical protocols and reimbursement policies that require and incentivize culturally competent care, individualized communication approaches, and health-literate patient education as part of every visit, particularly for patients living with rare and complex diseases like vasculitis.

> **"The pulmonologist minimized my experience and treated me like a 'sweet old lady.' Even when I was really sick, they didn't understand my pain and told me, 'I think by now that you should be better.'"** – Betsy
>
> **"Providers need to make sure patients feel safe. Not everybody is medical. People are different kinds of learners and need different kinds of knowledge."** – Kim
>
> **"Some doctors don't have a good bedside manner – communication is where everything needs to start, communication on the care team… My primary care provider treats me like a human being."** – Molly
>
> **"Patients become activated when they reach radical acceptance of the situation, the realization that 'no one else will fight this the way I will fight it.' Sometimes this happens after diagnosis, because the validation allows them to trust themselves."**
> – Jennifer
>
> **"So much is on the patient–patients have to be willing to say, 'Not good enough.'"** – Sarah

This includes:

- Reimbursable time for patient education during visits (advocating for the development of new ICD/CPT codes).
- Required training in cultural humility and trauma-informed communication.
- Standards for health-literate, multi-lingual/language minority materials and shared decision-making tools tailored to diverse learning styles and backgrounds.
- Materials focused on other members of the care team who may face different knowledge gaps or burdens related to vasculitis care.

Rationale: Diagnosing a rare disease is often a long, arduous process. Patients worry that rare disease symptoms can compound other stigmas and biases already present in the medical system, such as those around age, race, geography, and gender. Practitioners need tools to help evaluate patients, and those tools should be designed around the patient experience to foster conversation and avoid negative labels or dismissiveness of symptoms.

According to patients, they feel more confident under the care of a practitioner who treats them as a new patient with new symptoms, instead of a "typical" case.

An Educational Example and Opportunity from RDDC

In January 2025, RDDC, in partnership with the Vasculitis Foundation, delivered a three-page vasculitis fact sheet titled "Living Well with Vasculitis: Essential Topics to Discuss with Your Provider." It serves as both a strong example of materials that can be made available to providers to share with patients and an example of existing materials ripe for translation to benefit the larger vasculitis community.

Living with vasculitis requires a proactive approach to managing health. Building a strong relationship with a healthcare team is essential to ensuring that patients receive the best possible care. This fact sheet is designed to help patients navigate important conversations with their healthcare providers, empowering them to take an active role in their care and treatment. It explores key topics to help patients and their healthcare teams create a personalized plan that addresses the patient's unique needs and improves their quality of life.

Resources like this, which offer a list of questions, can also help providers consider vasculitis from the patient's perspective, thereby improving their ability to be present as a compassionate listener.

➤ For more information, see the *Living Well with Vasculitis Fact Sheet* included at the end of this report.

3. Ensure healthcare providers support shared decision-making by encouraging patients to ask questions and by offering referrals or consultations when they lack knowledge of vasculitis.

Recommendation: Advance health equity by embedding health literacy, cultural competency, communication standards, and second opinion access into clinical practice and reimbursement policy.

Require and incentivize patient-centered care practices, including cultural competency, health literacy, individualized communication, and access to second opinions through clinical protocols and reimbursement policies. This is especially critical in the care of patients with rare, complex conditions like vasculitis. Look for opportunities to join or provide guidance to organizations like the National Quality Forum, which plays a role in developing standards designed to improve healthcare quality. Educate patients more thoroughly about the importance of second opinions in rare disease, using resources such as podcasts and other new media. For example, the Rare Candor podcast episode "More Information Please: A Second Opinion Can Change Your Life" covers this topic.

This includes:

- Reimbursable time and coding (ICD/CPT) for HCPs treating persons living with rare diseases that include patient education, care coordination, and interpreter services.
- Mandatory training in cultural humility and trauma-informed communication.
- Provision of health-literate, accessible educational materials that meet diverse learning needs.
- Coding and reimbursement support for out-of-network specialist consultations when clinical uncertainty exists or when a patient requests further input.
- Incentivize HCPs to communicate to persons living with vasculitis to seek a second opinion through reimbursement/coding and value-based payment models that reward, including second opinions in quality outcomes. Second opinion office visits can also be a part of quality recognition, provider performance standards, and guidelines.

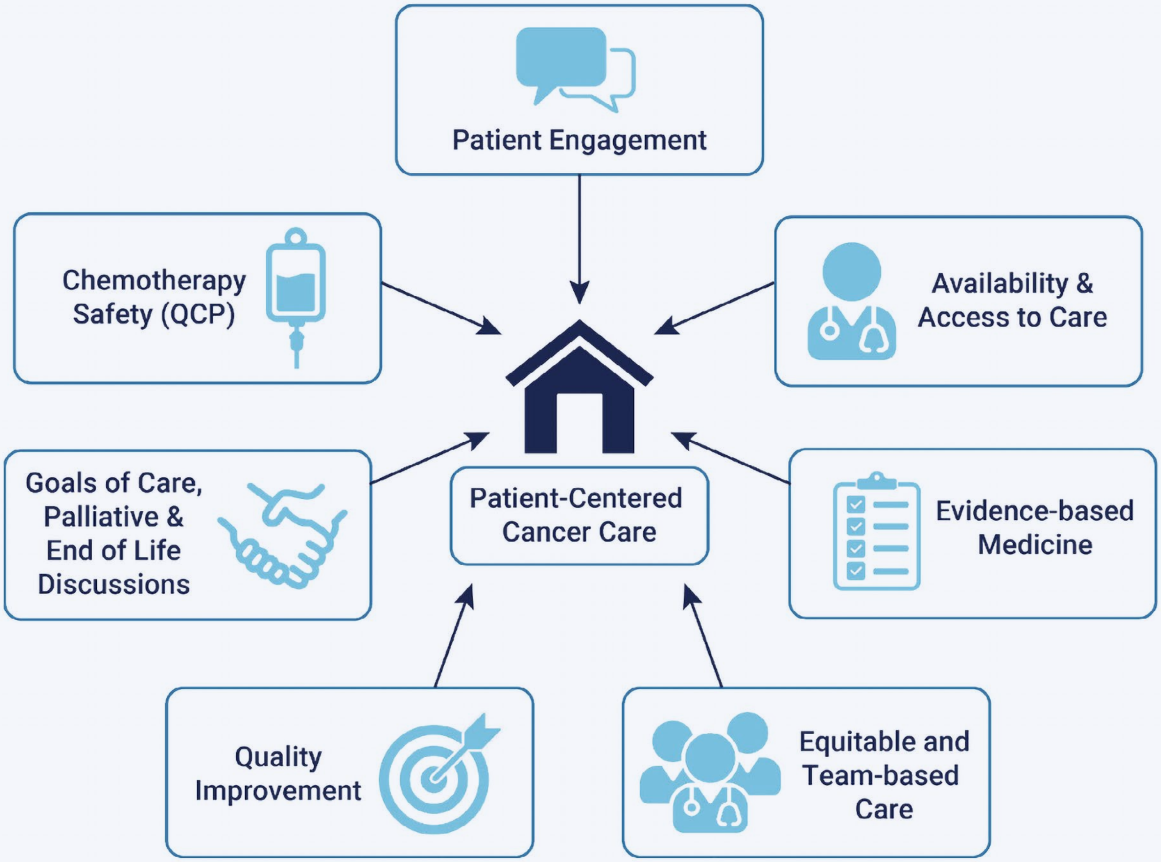
> **"I live in a tiny rural community and all the experts are ninety minutes away. My nurse practitioner pushed for a pulmonology appointment. She figured out what it was and pushed for the visits."** – Betsy
>
> **"I have a really great primary care physician; she knows me very well. She's one of the ones who will fight for their patients. She referred me to an oncologist, who biopsied my lymph nodes."** – Molly
>
> **"[Academic centers like Stanford create an] environment that is pro-patient. They have a complete willingness to provide specialists who are unique to vasculitis...They have been proactive at every point."** – Antonio
>
> **"[The Mayo Clinic] is curious about anything that looks interesting or different."** – Sarah
>
> **"[My physician at the MUSC Vasculitis Clinic] was very human in all of it, sometimes doctors are very transactional....she educated me, she told me the treatment plan."** – Caleb

Rationale: Standardizing the care approach will make patients more comfortable with requests like seeking a second opinion, helping them improve self-advocacy in this and other care settings. An individualized approach to care will help build patient trust and comfort with a practitioner while also assisting the practitioner when dealing with a novel symptom or diagnosis. Providers need reimbursement support to have adequate time to review patient concerns, especially when a rare disease is involved.

Pursuing a Patient-Centered Approach to Rare Disease Care

The complex diagnostic requirements for vasculitis and frequent delays related to treating symptoms mean most people with vasculitis will see a broad network of care providers in their lifetime. To account for this reality and use it to benefit patients, care should mirror other areas where this approach is proven beneficial, such as oncology, when specialist treatment is required.

One model to consider mirroring is the Oncology Medical Home model, which serves as "a guide to identify and implement a comprehensive oncology care delivery system that is focused on quality of care." Its goal is to ensure quality outcomes by focusing on patient-centered care coordination, and it encompasses patients, care teams, and payers. The model positions the specialist—oncologist for cancer, rheumatologist for vasculitis—as the focus for coordination to avoid adverse events.



Reference: Community Oncology Alliance (COA). "What is the Oncology Medical Home?" https://medicalhomeoncology.org/about/, last accessed June 27, 2025.

4. Improve affordability and accessibility of life-saving vasculitis treatment for patients of all backgrounds, with care navigation support as necessary across all treatment settings.

Recommendation: Advocate for pricing transparency, insurance coverage reforms, and financial assistance programs that make vasculitis medications and treatments accessible, regardless of a patient's socioeconomic status. Integrate nurse navigators or dedicated care coordinators into vasculitis care teams, both in community and academic settings, to assist with insurance navigation, care coordination, and communication.

> **"Most families in America have less than $1,000 in savings. That's it.... That's a real struggle. If we didn't have resources, we wouldn't be getting all the medicine we needed. Can I pay an additional $8,000 for a pill over the year? That's a hard choice. Most of us can't make that choice. That should frame the entire discussion."** – Antonio

Rationale: As Antonio shared, most patients cannot afford high out-of-pocket costs. Cost should not be a barrier to receiving necessary care. Betsy's experience underscores the need for a centralized advocate who can bridge the gap between patients and complex care systems, especially given the multi-symptom nature of vasculitis.

5. Center equity in all policy and program decisions and involve the patient voice in determining equity needs, including acknowledging current inequities in rare disease care.

Recommendation: Apply an equity lens to all decisions regarding rare disease treatment such as vasculitis care—from clinical research participation to resource allocation—ensuring rare, diverse patient populations have equal access to timely, high-quality, and culturally responsive care. Fund and support programs that bring patient advocates and voices to practitioners and specialists.

Rationale: Financial hardship, geographic location, and limited support infrastructure disproportionately affect underserved communities. These issues are compounded for patients with rare diseases who face further barriers to care due to a limitation in specialists, longer diagnostic journeys, and greater difficulty earning provider trust due to misconceptions of symptoms and diseases. Patients in these communities also expressed frustration with a lack of opportunity to share their experience with outside practitioners and believe this advocacy could encourage new practitioners to become relevant specialists in their community.

> **"I wish there was a social worker or a nurse who could be an advocate, work with the insurance company, and help improve communications. I had cancer before – they had a great system. They had a nurse navigator. I could call her and she could find out the information. One diagnosis, and the team was around that. With vasculitis, there are so many different symptoms. If I was more of a passive person, I wouldn't get the care I need."** – Betsy
>
> **"Rare patients need support systems in place and tools to address social isolation... Resilience, a sense of community, and self-care are important."** – Kim

6. Expand each patient's network of support so that vasculitis treatment is possible even if someone does not have access to a friend, family, or paid caregiver.

Recommendation: Develop and fund accessible peer networks, support groups, mental health services, and telehealth infrastructure to ensure vasculitis patients, especially those in rural areas or without strong family/caregiver support, have consistent access to emotional, social, and clinical resources. Expand support systems that combat isolation, build resilience, and promote self-advocacy regardless of a patient's home situation. At the same time, advocate for improved support outside of patients, such as education and utilization of the Medicaid HCBS (Home and Community Based Services) 1915 (c) waiver programs for caregiver reimbursement. Share medication assistance resources that may be available. For example, the Eosinophilic and Rare Disease Cooperative offers a complete Medication Assistance Program list for vasculitis patients that is regularly updated and accessible.

Rationale: Many patients face vasculitis without local support or access to specialized care. Peer connections and virtual services can fill critical gaps in care and community. Having an opportunity to speak openly and share their personal experiences and offer suggestions seemed to mean a great deal to many, if not all, of the participants.

Kim and Molly, among others, highlight that resilience and a sense of belonging are critical to managing a rare disease like vasculitis, which can often feel isolating and overwhelming.

Patient Voices:

> **"There's a need for peer support if someone doesn't have family or a caregiver. That gets you through the hard days. Hope that there is life after this."**
> – Molly
>
> **"I moved back to Michigan after being diagnosed to be closer to family."**
> – Caleb
>
> **"Transportation in rural areas is a major issue. I rely on my husband for transportation to specialists and appointments. When it comes to vasculitis, my local hospital wasn't sure what to do. Telehealth has never been offered."**
> – Betsy

Consensus-Developed Patient-Recommendations

> **"Most of my fellow patients have also wandered in the forest for a very long time. If you have questions and are living with an unknown disease, what do you do? Do you stick in your local pond or do you go to the national clinics that understand what you have?"** – Antonio

When asked what kind of support they needed and solutions they wanted, persons living with vasculitis shared recommendations in three main policy areas:

1. Expand Academic and Community Provider Knowledge and Awareness of Vasculitis

a. Encourage knowledgeable providers and specialists, such as the Vasculitis Center professionals, to consult with peer medical professionals who lack familiarity with vasculitis.

b. Invest in ongoing continuing medical education (CME) on vasculitis to increase awareness of the disease, particularly among rheumatologists, neurologists, and primary care practitioners. Possible partnerships could be formed with the American Thoracic Society's Public Advisory Roundtable (PAR), American Society for Nephrology (ASN), or the American College of Rheumatology (ACR).

c. Education with medical professionals at specialty societies and events, such as ASN's Kidney Week, ACR Convergence, or the international ACR/APLAR Research Exchange Program. Encourage medical professionals to identify strategies to improve care through forums like the annual Vasculitis Quality Care Summit.

d. Encourage more frequent updates of vasculitis guidelines or addendums for interim periods when new treatments become available.

2. Encourage People Impacted by Vasculitis to Advocate for Better Care

a. Expand peer-to-peer support networks, such as Vasculitis Voices (Inspire), disease-specific virtual support groups on platforms such as Facebook, and in-person conferences, to help newly diagnosed or undiagnosed individuals learn from more experienced advocates. Incorporate peer-to-peer media, such as "Diverse Faces of Rare Disease" stories, to foster the sense of community and encourage sharing of resources.

b. Research the viability of a toll-free number or other service manned by volunteers who also suffer from vasculitis to build connections and help people navigate aspects of the disease.

c. Promote existing services, especially the Find A Doctor program, on more materials, support networks, and private channels. Update materials when new services launch, such as a decision tree for best practices and guidelines for finding care and accessing medications and treatment.

d. Create materials for caregivers, care partners, and family and friends to support people with vasculitis in treatment and home settings. Include services provided by other groups, such as disease-specific free Hospital Emergency Advocacy & Treatment (HEAT) kits.

e. Expand materials on vasculitis into non-English languages, such as Spanish, and include information on global efforts to support people with vasculitis.

f. Ensure quality of life is a component of all patient self-evaluation and communication with doctors, and encourage the use of currently available tools. For example, the Eosinophilic and Rare Disease Cooperative offers a free, personalized Quality of Life Tool for Rare Disease and accompanying video.

g. Continue to provide materials for patients to share with providers on vasculitis and resources needed to diagnose and treat the disease.

h. Help patients request care support services, such as care navigators, ER support, and care coordinators in rheumatology offices.

i. Include patient voices and stories in broader advocacy work, such as giving Sarah Jones, a patient and advocate, a chance to speak at the RDDC Capitol Hill Briefing in April 2025. Then, share recordings, recaps, and other materials to highlight different advocacy opportunities and needs.

3. Advocate for System-Level Change to Improve Access and Affordability of Patient-Centered Care

a. Encourage the creation of a new physician fee (or billing code) for extended office visits for rare disease patients, to ensure adequate time for patient/provider education and shared decision-making.

b. Advocate for reduced use of health insurance utilization management tools like step-therapy and prior authorization for vasculitis treatments.

c. Protect expanded Medicaid coverage to allow individuals with lower income levels continued access to vasculitis care and treatment.

d. Support provider incentives to use secure messaging through programs like MyChart as one means to maintain “open lines of communication” with vasculitis patients.

e. Advocate for improved interoperability of medical records to allow providers to share medical records and clinical information freely between settings.

f. Advocate for the continuation of telehealth reimbursement to expand patient access to specialist care while ensuring proper reimbursement for provider time and expertise.

g. Advocate to add vasculitis to the Social Security Administration’s list of Compassionate Allowances.

h. Encourage the use of Chronic Care Management Services (CCM) supports and billing codes through CMS/Medicare to alleviate diagnosis, care coordination, and cost burdens of people with vasculitis when they have multiple chronic conditions. Explore the potential for making CCM services available beyond MCR and MCR replacement policies.

Living Well with Vasculitis: **Essential Topics to Discuss with Your Provider**

Living with vasculitis requires a proactive approach to managing your health. Building a strong relationship with your healthcare team is essential to ensuring that you receive the best possible care. This fact sheet, a collaborative effort of the Rare Disease Diversity Coalition (RDDC) and the Vasculitis Foundation, is designed to help you navigate important conversations with your provider, empowering you to take an active role in your treatment and explores key topics to help you and your healthcare team create a personalized plan that addresses your unique needs and improves your quality of life.

Building Your Treatment Team

When managing vasculitis, it's important to have a team of specialists who can address the different areas of the body that may be affected by the disease. An **ENT specialist** treats inflammation in the sinuses, nose, and throat. A **nephrologist** monitors kidney health to detect early signs of damage, while a **pulmonologist** assesses lung function and manages respiratory issues. A **dermatologist** addresses skin symptoms and monitors for treatment-related side effects, such as skin thinning. Having a treatment team is crucial for effective treatment and preventing complications

Kidney Monitoring

Regular kidney function monitoring is essential for vasculitis patients, particularly those diagnosed with **microscopic polyangiitis (MPA)** or **granulomatosis with polyangiitis (GPA)**. It's important to discuss various tests, including urine tests, blood tests (such as serum creatinine), and other monitoring tools. Early detection of kidney involvement is crucial, as it can prevent serious complications from arising.

Long-Term Medication Side Effects

Long-term treatment with **glucocorticoids** and other **immunosuppressants** can lead to several side effects. These include osteoporosis, which weakens bones from prolonged steroid use; increased risk of infections due to immunosuppression; and elevated cardiovascular risks associated with some medications. Understanding the long-term side effects of vasculitis medications is crucial for patients to manage their health proactively and minimize potential complications. To learn more about long-term side effects of medications and find information on the risks associated with steroids and other treatments, please visit the Immunity & Infection and Prednisone pages on the VF website.

Relapse Risk and Monitoring

Even during remission, the risk of relapse persists, making regular monitoring essential for early detection and treatment adjustments. Recognizing symptoms promptly can prevent complications and improve long-term outcomes.

Mental Health and Emotional Support

Living with a chronic illness like vasculitis can greatly impact mental well-being. Signs that support may be needed include feeling overwhelmed, isolated, or depressed. Seeking mental health resources, such as support groups or counselors, is crucial for managing these challenges and enhancing quality of life. For further insights into the challenges faced by patients and caregivers, consider visiting the RDDC website to read the latest report on inequities in the rare disease community: 2024 Report: The Voices of Diverse Patients and Caregivers. For additional support, connect with others living with vasculitis by joining the VF's virtual support groups and explore resources on the VF Mental Wellness page.

Lifestyle Adjustments and Infection Prevention

To lower infection risk and enhance overall health, discuss lifestyle changes with your provider, including vaccinations and a balanced diet. Gentle exercise can boost energy levels, while effective fatigue management strategies are vital for improving quality of life. For more resources and to get started, visit the VF Living Well page to learn more about the Victory Over Vasculitis Physical Wellness Program.

Clinical Trials Participation

Participating in clinical trials is a valuable way to contribute to vasculitis research. Understanding your rights and the trial process is crucial for informed decision-making. Resources like the Vasculitis Patient-Powered Research Network and RDDC YouTube channel provide important information on clinical trials and related topics.

Key Questions to Ask Your Provider:

By discussing these points with your healthcare team, you can take an active role in managing your vasculitis and improving your quality of life. Here are some key questions to start the conversation:

- → Does my care team include all the specialists needed to manage my vasculitis?
- → How will my long-term treatment plan incorporate regular kidney function tests, such as urine and blood tests?
- → How often should we review my medication plan to ensure we're effectively balancing disease control with minimizing side effects?
- → Could we develop a relapse monitoring plan, and what specific symptoms should I watch for that would indicate a need for treatment adjustments?
- → Can we discuss my emotional health, and could you provide referrals to mental health professionals if necessary?
- → What steps can we take to monitor my condition effectively and develop a plan for early detection of potential relapses?
- → How can we address my emotional health and explore mental health support options together?
- → Can we create a personalized plan to help me stay active, eat well, and reduce my infection risk?
- → Do you know of any ongoing clinical trials I might qualify for that could benefit my condition?

Key Questions for Caregivers to Ask Providers

- → What signs or symptoms should I monitor closely to help detect potential relapses or complications early?
- → How can I support the patient's treatment plan, especially with managing medications, appointments, and lifestyle changes? What resources are available for me as a caregiver to manage stress and prevent burnout while providing care?
- → What resources are available for me as a caregiver to manage stress and prevent burnout while providing care?
- → Are there specific ways I can help the patient manage their emotional well-being or access mental health support

By having these conversations with your healthcare team, you take an active role in managing your vasculitis, ensuring that you receive personalized, equitable care that supports your long-term health and well-being.

The Black Women's Health Imperative (BWHI) is a national non-profit organization dedicated to advancing health equity and social justice for Black women across the lifespan through policy, advocacy, education, research, and leadership development. The organization identifies the most pressing health issues that affect the nation's 22 million Black women and girls and invests in the best strategies and organizations to accomplish its goals. You can find more information about BWHI at bwhi.org.

The Rare Disease Diversity Coalition TM (RDDC) is an initiative launched by BWHI to address the extraordinary challenges faced by historically underrepresented populations with rare diseases. RDDC brings together rare disease experts, health and diversity advocates, and industry leaders to identify and advocate for evidence-based solutions to reduce racial disparities in the rare disease community. You can find more information about RDDC at rarediseasediversity.org.

Contact Information

For more information, visit our website or contact us:

Black Women's Health Imperative and Rare Disease Diversity Coalition ™

384 Northyards Blvd NW, Bldg 100/Suite 190,
Atlanta, GA 30313
Phone: 888.834.8451

Email: rddc@bwhi.org
Website: www.rarediseasediversity.org

The Vasculitis Foundation (VF) is the leading organization in the world dedicated to diagnosing, treating, and curing all forms of vasculitis. We work to inspire and empower those affected by vasculitis through education, research, clinical initiatives, and advocacy.

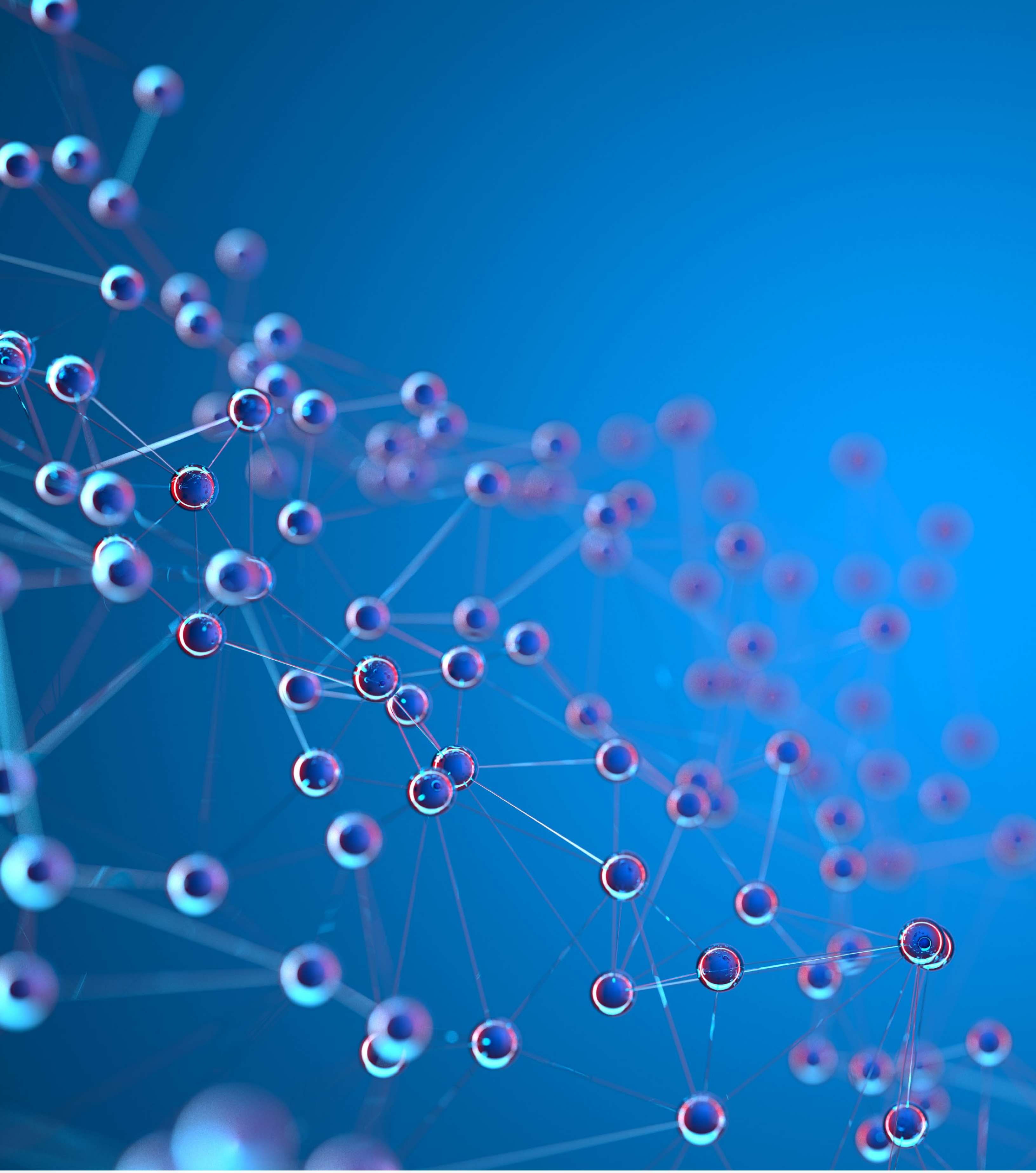
Contact Information

For more information, visit our website or contact us:

Vasculitis Foundation

PO Box 28660, Kansas City, MO 64188
Phone: 816.436.8211 | Toll Free: 800.277.9474

Email: vf@vasculitisfoundation.org
Website: www.VasculitisFoundation.org



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