Vasculitis Patient Recommendations
Social Media Toolkit

The Rare Disease Diversity Coalition™ (RDDC) has developed a Social Media Toolkit to support the promotion of the ***Patient Recommendations for People Living With Vasculitis*** report. Created by the Vasculitis Health Equity Steering Committee, this report highlights patient-driven recommendations to improve care, advance equity, and strengthen outcomes for people affected by vasculitis.

The Toolkit includes ready-to-use content and graphics designed to help amplify these important findings. We encourage you to use these materials to share the patient-centered recommendations for change, highlight barriers to care, disseminate key insights from the report, and foster collaboration and support across the rare disease community. Together, we can raise awareness, spark action, and help drive more equitable care for people living with vasculitis.

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Report Overview

Core Takeaways

This recommendations report is built on the voices of the vasculitis community. Through group discussions and one-on-one interviews, steering committee members shared insights on where current care and support fall short and what a better future could look like.

Top Aims

- Center Patient Voices in Care: Shared decision-making, trauma-informed practices, and culturally competent care are essential to build trust and improve outcomes.
- Increase Equitable Access to Care: Expand telehealth across state lines, reform reimbursement policies, and ensure insurance covers both FDA-approved and off-label treatments.
- Ease Financial Burdens: Vasculitis medications can exceed $8,000 annually in out-of-pocket costs. Patients need Medicaid protections, reduced prior authorization barriers, and caregiver reimbursement programs.
- Strengthen Support Systems: Expand peer networks, mental health support, and care navigators to reduce isolation and provide real-world guidance.
- Advance Equity in Research & Policy: Include vasculitis in the Social Security Compassionate Allowances list and advocate for new billing codes to reflect rare disease care needs.

Key Messages to Guide Your Social Media Content

Headline & Purpose of the Report
RDDC has launched the ***Patient Recommendations for People Living With Vasculitis Report***, developed with active participation from patients whose lived experiences with vasculitis directly shaped the recommendations. The report captures the real-world experiences, challenges, and systemic barriers faced by people living with vasculitis, with a focus on perspectives from historically underrepresented and medically underserved populations. Patients on the steering committee played a central role in ensuring their voices were heard and reflected throughout the report.

Why This Matters
Individuals with rare diseases often face long diagnostic journeys and ongoing challenges in accessing equitable care. For those affected by social, cultural, and economic disparities, these barriers can be even greater. This report amplifies patient voices to inform resources, advocacy, and policy solutions that truly reflect the lived experiences and needs of diverse vasculitis communities.

Call to Action
Help elevate the voices of the Vasculitis community! We encourage all individuals living with vasculitis, along with their caregivers and family members, to explore and share the ***Patient Recommendations for People Living With Vasculitis Report***. Your voice and lived experiences matter, and amplifying them can help drive meaningful change in care, policy, and awareness.

Track Back to RDDC's Mission
The Rare Disease Diversity Coalition (RDDC), in partnership with the **Vasculitis Foundation**, works to eliminate health disparities in the rare disease community. By elevating patient voices and addressing systemic barriers, RDDC advances equitable access to diagnosis, treatment, and care for all individuals living with rare diseases.

Key RDDC Social Media Accounts (Please Tag Us In Your Post)

LinkedIn
Rare Disease Diversity Coalition: https://www.linkedin.com/company/rare-disease-diversity-coalition/
Instagram
Rare Disease Diversity Coalition: @rarediseasediversity
Facebook
Rare Disease Diversity Coalition:
https://www.facebook.com/p/Rare-Disease-Diversity-Coalition-100086789036888/
X (Formerly Twitter)
Rare Disease Diversity Coalition: @rarediseasediv1

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On behalf of the Rare Disease Diversity Coalition (RDDC) and the Vasculitis Health Equity Steering Committee, thank you for helping us share ***Patient Recommendations for People Living With Vasculitis!***

Sample Posts

Instagram, Facebook, X (Twitter)

Sample Post (Long)

Living with vasculitis shouldn't mean navigating endless barriers to care. Our new report, "Patient Recommendations for People Living with Vasculitis," shares real-world patient voices and solutions to build a better future.

Here's what patients recommend:
➡️ Expand telehealth to reach rural patients
➡️ Reduce out-of-pocket medication costs
➡️ Train providers in cultural humility
➡️ Strengthen peer and mental health supports

Tap the link in our bio to read the report. Together, we can build equity in vasculitis care.
#Vasculitis #RDDC #BWHI #RareWithinRare #RareDisease #HealthEquity #PatientVoices #RareCommunity

Sample Post (Short)

Vasculitis can affect nearly 20 different organs, from the lungs and kidneys to the brain and skin. Patients deserve faster diagnosis and compassionate care. Read more: [insert link]
#Vasculitis #RDDC #BWHI #RareWithinRare #RareDisease #HealthEquity #PatientVoices #CommunityVoices

Many patients wait over 3 months to see a specialist for vasculitis. Delays can be life-threatening. Our community is calling for expanded telehealth and fair access now. [insert link]
#Vasculitis #RDDC #BWHI #RareWithinRare #RareDisease #HealthEquity #CommunityVoices

Patients with vasculitis often drive 90+ minutes each way to reach specialists. No one should have to cross state lines for care. Let's push for telehealth equity. [insert link]
#RuralHealth #HealthEquity #RDDC #BWHI #RareWithinRare #RareDisease #HealthEquity

Out-of-pocket costs for vasculitis medications can exceed $8,000 a year. Most families have less than $1,000 in savings. Patients need relief. [insert link]
#AffordableCare #Vasculitis #RDDC #BWHI #RareWithinRare #RareDisease #HealthEquity

People living with vasculitis describe their journey as "whack-a-mole." One symptom treated, another one appears. Patients need providers who listen and believe them. [insert link]
#PatientAdvocacy #Vasculitis #RDDC #BWHI #RareWithinRare #RareDisease #HealthEquity

Bias and stigma based on race, gender, income, or age can delay diagnosis. Our recommendations call for trauma-informed and culturally competent care. [insert link]
#EquityInCare #Vasculitis #RDDC #BWHI #RareWithinRare #RareDisease #HealthEquity

Telehealth is one of the fastest ways to bridge the access gap for rare disease patients, but it's rarely offered to those with vasculitis. We can change that. [insert link]
#TelehealthForAll #RDDC #BWHI #RareWithinRare #RareDisease #HealthEquity

Patients with vasculitis see multiple specialists before diagnosis, including: ENT, rheumatology, neurology, dermatology.. It's time for earlier detection and coordinated care. [insert link]
#EarlyDiagnosis #Vasculitis #RDDC #BWHI #RareWithinRare #RareDisease #HealthEquity

Care isn’t just clinical. Patients need peer networks, care navigators, and mental health resources to truly thrive. [insert link]
#SupportSystems #Vasculitis #RDDC #BWHI #RareWithinRare #RareDisease #HealthEquity

Vasculitis must be recognized as a Social Security Compassionate Allowance condition. Faster disability approval can mean faster support for families. [insert link]
#PolicyChange #Vasculitis #RDDC #BWHI #RareWithinRare #RareDisease #HealthEquity

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LinkedIn

Sample Posts (Long)

🔍 Making Health Equity Real for Vasculitis Patients

For people living with vasculitis, care is often delayed, fragmented, and unaffordable. This patient-driven white paper highlights the barriers like long wait times, lack of telehealth, and high medication costs, and delivers solutions to create a more equitable future.

Read Patient Recommendations for People Living with Vasculitis and join us in advancing health equity: [insert link]
#Vasculitis #RareDisease #PatientAdvocacy #RDDC #BWHI #RareWithinRare #HealthEquity

Sample Posts (Short)

Diagnostic delays in vasculitis often last years, with patients bouncing between multiple specialists. Our report shares solutions to speed up access to care. [insert link]
#Vasculitis #RareDisease #HealthEquity #RDDC #BWHI #RareWithinRare

Financial barriers prevent many patients from accessing vasculitis treatments that can exceed $8,000 annually. Policy change is overdue. [insert link]
#AffordableCare #PolicyChange #RDDC #BWHI #RareWithinRare #RareDisease #HealthEquity

Patients in rural areas may travel 90+ minutes to see a vasculitis specialist. Expanding telehealth across state lines is one way to close the gap. [insert link]
#RuralHealth #TelehealthAccess #RDDC #BWHI #RareWithinRare #RareDisease #HealthEquity

Bias and stigma continue to erode trust between vasculitis patients and providers. Our recommendations call for culturally competent and trauma-informed care. [insert link]
#InclusiveCare #PatientTrust #RDDC #BWHI #RareWithinRare #RareDisease #HealthEquity

Specialist wait times often exceed 3 months for vasculitis patients, worsening outcomes. Our community says: access must improve now. [insert link]
#HealthEquity #AccessToCare #RDDC #BWHI #RareWithinRare #RareDisease

Caregivers of people with vasculitis need support too, from reimbursement programs to mental health resources. Read how patients recommend building these systems. [insert link]
#CaregiverSupport #Vasculitis #RDDC #BWHI #RareWithinRare #RareDisease #HealthEquity

Equity in vasculitis care means ensuring FDA-approved and off-label treatments are covered by insurance. No one should be denied care due to coverage gaps. [insert link]
#EquityInTreatment #RareDisease #RDDC #BWHI #RareWithinRare #HealthEquity

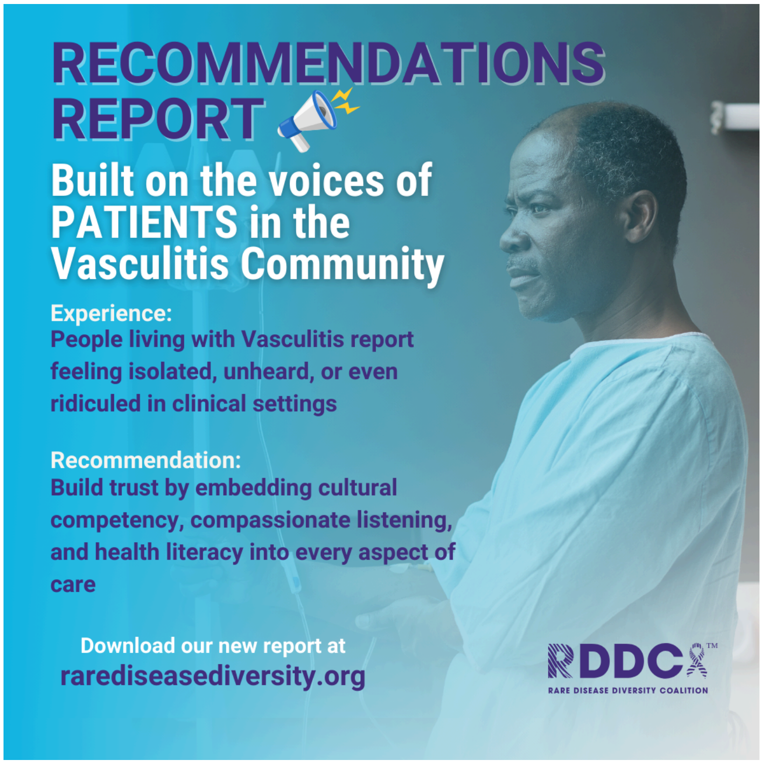
Patients living with vasculitis report feeling isolated, unheard, or ridiculed. Embedding compassionate listening and shared decision-making can rebuild trust. [insert link]
#PatientVoices #CompassionateCare #RDDC #BWHI #RareWithinRare #RareDisease #HealthEquity

Medicaid protections are critical for families with vasculitis, especially those facing high costs and long diagnostic journeys. Advocacy is key. [insert link]
#MedicaidMatters #RareDiseaseAdvocacy #RDDC #BWHI #RareWithinRare #RareDisease #HealthEquity

Improving equity for vasculitis patients requires collaboration across patients, providers, policymakers, and advocates. Read the patient-driven roadmap here: [insert link]
#HealthEquity #PatientCentered #RDDC #BWHI #RareWithinRare #RareDisease #HealthEquity

Graphics

Please find the downloadable graphics linked here



RECOMMENDATIONS REPORT 📢

Built on the voices of PATIENTS in the Vasculitis Community

Experience:
People living with Vasculitis report feeling isolated, unheard, or even ridiculed in clinical settings

Recommendation:
Build trust by embedding cultural competency, compassionate listening, and health literacy into every aspect of care

Download our new report at
rarediseasediversity.org

RDDC™
RARE DISEASE DIVERSITY COALITION