

First-of-Its-Kind Decision Tree Gives ANCA Vasculitis Community a Map Through a System Built Without Them in Mind

Navigating a rare disease is tough. This tool helps people find their way through a system not built for them — for patients, care partners, and physicians.

GRAND RAPIDS, MI, UNITED STATES, September 2, 2026 /EINPresswire.com/ -- A new diagnosis of ANCA vasculitis usually arrives the same way: fast, frightening, and with no map. Most people have never heard of the disease before it lands on them, many have lived a healthy life and they suddenly find themselves in a [healthcare](#) system that offers little to help them find their footing.

Eosinophilic & Rare Disease Cooperative (ERDC) convened a

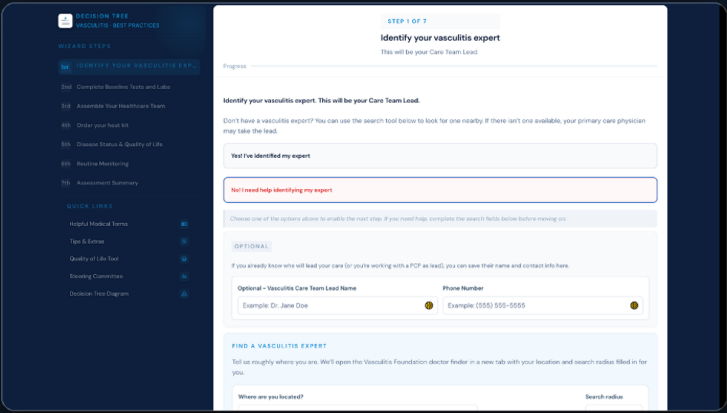
comprehensive ecosystem-based steering committee to develop a tool that leaves people less alone. Today, ERDC announces the launch of the ANCA Vasculitis [Decision Tree](#), the first patient-facing navigation tool of its kind available to the ANCA vasculitis community available at www.rarediseasedecisiontree.org.

The Decision Tree is a free, interactive computer-based tool (or downloadable map) developed with rheumatologists, nephrologists, pulmonologists, pharmacists, primary care clinicians, insurance billing specialists, care partners, and patients themselves. It helps people, regardless of where they are in their disease journey.

The Decision Tree walks a person through the questions that otherwise go unanswered: When does a new symptom mean urgent care instead of watching and waiting? Which specialist owns which piece of the disease? How does someone build a care team when their diagnosis is one most clinicians have never treated? For a disease this rare, those answers have never before

WHAT IS THE DECISION TREE?

A free, step-by-step guide through an ANCA vasculitis diagnosis — in plain language.



RareDiseaseDecisionTree.org

It all starts with finding the right provider to lead your care

existed in one place, built for the person living it.

Specifically, the tool helps locate physicians, ensure baseline testing, pull a care team together, assess quality of life and explore treatment options, order a free disease specific HEAT Kit (Hospital Emergency Advocacy & Treatment Kit), and ensure proper ongoing monitoring. After completing the tool, the user is able to print a copy of all of the materials, including outstanding labs and tests to bring with them to their doctor.

The Decision Tree is grounded in real patient experience. It will be shared at will be the subject of its own Interactive Scientific Session ACR Convergence 2026 in Orlando, Sunday, November 8.

HOW IT WORKS

Answer a few questions, and it maps out what to ask next — then prints a summary for your next appointment.

Decision Tree - Vasculitis Assessment (GPA, MPA, EGPA, ANCA)

DECISION TREE

WALK-THROUGH

WALK-THROUGH

1. Identify your vasculitis expert

2. COMPLETE BASELINE TESTS AND LABS

3. Assemble your healthcare team

4. Order your heat kit

5. Disease Status & Quality of Life

6. Baseline Monitoring

7. Assessment Summary

8. ACTION CHECK

9. Helpful Medical Terms

10. Test & Extra

11. Quality of Life Tool

12. Booking Connection

13. Decision Tree Diagram

STEP 2 OF 7

Complete Baseline Tests and Labs

Work with your team lead to complete baseline evaluation.

Below is a checklist of important baseline tests and optional tests your care team may recommend. Check off the tests you have completed or discussed with your clinician. Remember all of this will be compiled at the end in a printable report.

IMPORTANT BASELINE TESTS FOR ALL VASCULITIS

☐ ANCA blood panel (ELISA)
To identify if a person is ANCA positive. ANCA negative does not necessarily exclude the possibility of vasculitis.
• ANCA (anti-neutrophil cytoplasmic antibody) - common in MPA, occasionally in EGPA.
• PR3 (proteinase-3) - common in GPA.

☐ Complete Blood Count (CBC) with Differential
Identify infection and elevated eosinophils (EOP), and elevated blood counts for ALL ANCA vasculitis.

☐ Comprehensive Metabolic Panel
Evaluate kidney and liver function, electrolytes and other key levels.

☐ Troponin, CK
To detect prior heart attack.

☐ Inflammation markers: ESR, CRP
Measure markers of inflammation in the body. ESR (erythrocyte sedimentation rate) and CRP (c-reactive protein).

RareDiseaseDecisionTree.org

Completing your baseline tests ensures you have the right starting point!

ERDC is making the Decision Tree freely available and unbranded to clinics, health systems, and care teams to integrate directly into routine care — no cost, no license, no barrier between the tool and the person who needs it.

“

When my wife became sick, it took 54 doctor visits to get diagnosed. With a rare disease, you're often the only expert in the room. This tool offers guidance through the healthcare system.”

Pam Squires, MSW

ANCA vasculitis is one of six rare disease communities served by ERDC, a patient- and care-partner-run nonprofit reaching more than 120,000 people. ERDC's mission is built on the belief: people living with rare disease deserve access to care and treatment.

To try the Decision Tree, visit www.rarediseasedecisiontree.org or find it at

EosinophilRareDisease.org.

Eosinophilic & Rare Disease Cooperative (ERDC) is a patient and care partner-run nonprofit serving people with ANCA-associated vasculitis (GPA/MPA, EGPA), IgG4-RD, Myasthenia Gravis, Hypereosinophilic Syndrome, and NMOSD, reaching more than 120,000 people across these

communities.

Resources available:

- HEAT Kits — Disease-specific kits for patients to use in healthcare settings. Kits include treatment history, labs, monitoring parameters, a medical snapshot, guidelines, medical history, infusion guidance, and more. Usable with any provider, it builds patient confidence, and transfers information quickly.

- Rare Disease Decision Trees — Visual, step-by-step guides through diagnosis, emergency care, and care-team building, developed with disease-specific clinical partners, patients, care partners, medical billing, pharmacists and the disease ecosystem. Currently available for ANCA Vasculitis only. IgG4-RD coming early 2027.

- Livestream education - Live sessions on treatment access, insurance navigation, and Medicare, and more archived so anyone can revisit them.
- Rare Candor podcast — Unscripted conversations with clinicians, advocates, care partners, biotech leaders, and people living with rare disease, on treatment, policy, and access (Spotify and Apple).
- Survey data — Original ethnographic surveys to understand patient experience and barriers to care, including our Medical Debt in Rare Disease Survey.
- Public policy advocacy — Legislative engagement and education to improve systemic access to quality care and treatment.

Our work is not seeking a cure. We work for access to the right treatment at the right time, every time.

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The screenshot displays the RareDiseaseDecisionTree.org website. At the top, a dark blue banner contains the text "NO LOGIN. NO COST. PERSONALIZED." in white. Below this, the main heading reads "The first interactive decision tree for ANCA vasculitis — free for anyone to use and share." The interface is divided into two main sections. On the left, a dark blue sidebar lists "WIZARD STEPS" with a checklist: "Identify your vasculitis expert", "Complete Baseline Tests and Labs", "Assemble Your Healthcare Team", "Order your test kit", "Evaluate Status & Quality of Life", and "Routine Monitoring". Below this is a "KNOWLEDGE SUMMARY" section with links to "Helpful Medical Terms", "Test & Treat", "Quality of Life Test", "Treating Complications", and "Decision Tree Diagram". The main content area on the right is titled "STEP 7 OF 7 Assessment Summary" and includes a "Print Summary" button. It features a "Vasculitis Care Plan Snapshot - GPA/MPA/EGPA, ANCA" section with a note: "You can print this page and bring it to your appointments to review with your care team." Below this is a "RECOMMENDATIONS SUMMARY TO REVIEW WITH YOUR CARE TEAM" section with three bullet points: "Consider completing all Important Baseline Tests for All Vasculitis that have not yet been completed listed below", "Continue assembling your healthcare team and discuss whether additional roles from the list could be helpful in your care. Potential team members are included below.", and "Work with your care team lead to revise your plan. The treatment resources below may be useful to share during your visit. Resources are included below." At the bottom of the main area, there is a "STEP 1 - VASCULITIS EXPERT" section with a "No - I need help identifying my expert." option and a "Search details you entered:" field with "Radius: 100 miles" below it.

RareDiseaseDecisionTree.org

After completing the Decision Tree the assessment will provide a guide for you and your provider

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