



HONORS RARE DISEASE ADVOCACY

YEAR-ROUND AWARENESS

TOOLKIT



RDDC: ADVANCING EQUITY FOR THE #RAREWITHINRARE

The Rare Disease Diversity Coalition (RDDC), a signature program of the Black Women's Health Imperative was launched in 2020 to address the inequities faced by individuals living with rare diseases, particularly the #RareWithinRare in historically marginalized communities. While more than 10,000 rare diseases impact millions of families nationwide, 95% of rare conditions still lack an FDA-approved treatment. RDDC brings together rare disease experts, health equity advocates, community leaders, researchers, and industry partners to develop evidence-based solutions that reduce disparities and improve outcomes across the rare disease ecosystem. By centering lived experience, advancing policy, and dismantling systemic barriers, RDDC works to ensure equitable access to diagnosis, care, research, and treatment.

THE HISTORY OF RARE DISEASE DAY & RDDC'S RARE DISEASE AWARENESS TOOLKIT

Rare Disease Day was established in 2008 as a patient-led global movement to raise awareness and advocate for equitable access to diagnosis, care, and treatment. Observed annually on February 28 (or February 29 in leap years), the day brings together more than 70 national patient advocacy organizations, coordinated globally by EURORDIS, in solidarity with the 300 million people worldwide living with rare diseases. Through our awareness themes #RiseForRare (in support of RDDC) and #ShareYourColours (in alignment with the global campaign), RDDC utilizes its Rare Disease Awareness Toolkit to equip advocates, partners, and community members with resources to amplify rare voices and advance equity for the #RareWithinRare all year long.

WHY DIVERSITY, EQUITY, AND INCLUSION MATTER NOW MORE THAN EVER

The Rare Disease Diversity Coalition (RDDC), a signature program of the Black Women's Health Imperative was launched in 2020 to address the inequities faced by individuals living with rare diseases, particularly the #RareWithinRare in historically marginalized communities. While more than 10,000 rare diseases impact millions of families nationwide, 95% of rare conditions still lack an FDA-approved treatment. RDDC brings together rare disease experts, health equity advocates, community leaders, researchers, and industry partners to develop evidence-based solutions that reduce disparities and improve outcomes across the rare disease ecosystem. By centering lived experience, advancing policy, and dismantling systemic barriers, RDDC works to ensure equitable access to diagnosis, care, research, and treatment.



HOW INTERSECTIONALITY IMPACTS THE RARE DISEASE COMMUNITY

The Rare Disease Diversity Coalition (RDDC) was proud to present this poster at the 2025 APHA Annual Conference, expanding on research from the Inequities in the Rare Disease Community report. Kimberlé Crenshaw's concept of intersectionality explains how overlapping identities (such as race, gender, disability, sexual orientation, income, and geography) interact within systems of inequity to shape lived experience. For people living with rare diseases who also hold marginalized identities, barriers are compounded, affecting diagnosis, access to specialists, genetic testing, and quality care. Recognizing this reality requires us to move beyond one-size-fits-all standards and reject the idea that patients are a monolith. Honoring and humanizing each patient's unique journey demands collaborative, equity-centered solutions, reflected in the formal recommendations that follow.

RDDC *Intersectionality leads to more inequity in rare diseases.** — "The better we understand how identities and power work together, the less likely our movements for change are to fracture."
RARE DISEASE DIVERSITY COALITION Kimberlé Crenshaw

Acknowledging the Silent Crisis

Belonging to more than one marginalized group compounds barriers. Individuals who identify with more than one historically underrepresented group (e.g., Black/African-American, LatinX/Hispanic, Asian/Pacific Islander, LGBTQ+, Rural, Underinsured, etc.) report higher barriers to access, delays in diagnosis, and exclusion from clinical trials.

- Significantly longer diagnostic delays (7-12 years for diagnosis vs. 4-5 years for majority populations).
- Rural populations experience travel times twice as long to reach rare specialists.
- Low-income + private insurance = higher cost of care overall (high deductibles, limited coverage).
- LGBTQ+ community is twice as likely to see 20+ providers due to fragmented care and bias.
- 64% of Latinx respondents report spending >11 hours managing care weekly.
- 88% of Black and 86% of Latinx respondents were NOT offered genetic testing.

"I don't see color."

"We treat all of our patients the same."

"I just follow the guidelines."

"We don't ask about THAT because it doesn't matter."

Our Data Collection

- RDDC Rare Disease Inequities Survey Respondents (n = 2,848).
- Rare disease inequities mirror and magnify broader public health disparities.
- Analyzed experiences across single identity vs. multiple intersecting identities.
- Respondents identified by race/ethnicity, gender identity, LGBTQ+ status, income, geography, and caregiving roles.

*Coined by advocate, scholar, and attorney Kimberlé Crenshaw, intersectionality is the cumulative effect that multiple forms of marginalization have on the daily lives of individuals (particularly women and people of color) and its tendency to create unique experiences of oppression.

Implementing Practical Solutions

Customizing care is imperative, especially for underrepresented populations. People (even those with the same diagnosis) are not a monolith, and it's essential that psychosocial factors are considered as care and support are provided. Availability is not enough - we must make services accessible through intentional design and equitable delivery.

- Center lived experiences by listening to patients and caregivers and partnering on solutions.
- Require care team training that normalizes cultural humility and intersectional awareness.
- Bring care closer via telehealth and culturally relevant patient/caregiver support networks.
- Reduce costs, improve insurance coverage, and expand patient assistance programs.
- Offer low-cost testing and counseling through trusted community and safety-net clinics.
- Invest in paid leave and flexible work policies (applies to staff, patients, and caregivers).

"We support patients in making choices that fit their situation..."

"I'm listening..."

"I don't know, but let me do some research..."

"I respect your unique perspective and experiences."

Our Formal Recommendations

- Recognize and correct the profound impact discrimination and bias has on access.
- Collaborate with community health workers and public health agencies for outreach.
- Expand insurance coverage and support services beyond medical visits via policy.
- Address mental health challenges by providing support services regularly.
- Build bridges by promoting policies that normalize inclusion in daily practice.
- Normalize offering genetic testing and counseling to diverse communities.

METHODS

FINDINGS

Scan the QR code or visit bit.ly/4n7HS61 to explore RDDC resources and view the full report, [available in the Rare Disease Community](#).



OUR FORMAL RECOMMENDATIONS

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TO ACCESS THE FULL REPORT IN ENGLISH OR SPANISH, PLEASE CLICK YOUR PREFERRED LINK BELOW:

[RDDC Inequities in the Rare Disease Community Report](#)

[RDDC Desigualdades en la comunidad que tiene enfermedades raras](#)



PARTNERING WITH YOUR HEALTHCARE TEAM

Additional data from the RDDC inequities survey highlighted that a strong, trusting relationship between a patient and their care team is essential for timely diagnosis, coordinated care, and improved health outcomes. RDDC research highlights that every member of the care team (providers, nurses, community health workers, social workers, patient navigators, etc.) plays a meaningful role in supporting individuals living rare. Practical, open conversations that assess a person's full social context, not just their symptoms, can shape next steps and reduce barriers to care. Remember: an individual doesn't need a formal diagnosis to ask informed, assertive questions. Your healthcare relationship is a partnership. It is not only okay, but is your right to ask questions, write down answers, record information for clarity, or bring someone with you for support during appointments.

QUESTIONS TO ASK YOUR PROVIDER OR CARE TEAM

● UNDERSTANDING SYMPTOMS & DIAGNOSIS

- What could be causing my symptoms?
- What conditions are being ruled out, and how?
- Are there additional tests (including genetic testing) that should be considered?
- Should I see a specialist? If so, can you provide a referral?

● TREATMENT & CARE PLAN

- What are my treatment options, and what are the risks and benefits of each?
- How will this treatment affect my daily life?
- What side effects should I watch for?
- How will we measure whether this plan is working?

● CLINICAL TRIALS & RESEARCH

- Are there clinical trials or research studies I may qualify for?
- What are the benefits and risks of participating?
- How would participation affect my current care?

● CARE COORDINATION & SUPPORT

- Who is my main point of contact if I have questions?
- Can I be connected to a patient navigator, social worker, or community health worker?
- Are there financial assistance programs or support resources available?
- How will my care be coordinated across specialists?

● REFERRALS & SPECIALISTS

- Do I need to see a rare disease specialist or center of excellence?
- How do I prepare for that appointment?
- Can my records be shared directly to avoid delays?

Empowered conversations help ensure that care plans reflect your lived experience, needs, and goals. Equitable rare disease care and support starts with listening and maintaining an informed partnership.

PATIENT VOICES THAT ILLUMINATE THE #RAREWITHINRARE JOURNEY



DIAMOND DESHIELDS

WNBA Champion and All-Star Diamond DeShields shares her deeply personal journey with keratoconus, a rare eye disease that nearly derailed her professional basketball career. In this powerful story, she reflects on the emotional toll of delayed diagnosis and the life-changing difference that came with finally receiving the right care. Her experience underscores the importance of visibility, advocacy, and equity in the rare disease space.



HOLLY JONES

Holly Jones was diagnosed with polymyositis at 19, after symptoms began disrupting her college life. Her journey, further complicated by interstitial lung disease and pulmonary hypertension, has been marked by both significant challenges and powerful transformation. She now channels her lived experience into advocacy, founding HER Story in Color and serving on The Myositis Association to uplift women of color living with chronic illness.



NICHOLAS (NICK) KELLY

Nicholas (Nick) Kelly was diagnosed with cystic fibrosis at just three months old but has never let that define him. A dietitian by training with a bachelor's and master's from Bowling Green State University, Nick is also a poet, educator, dancer, and motivational speaker, using his experience to advocate for the CF community and inspire others to reclaim their power. For Nicholas, living with CF isn't about limitations, it's the foundation for a life of purpose, passion, and resilience.

ARAYA AND HER PARENTS, DARIUS AND SHAMEUGA

Araya, a young girl living with ANCA vasculitis, a rare autoimmune disorder that affects blood vessels, shares her journey alongside her parents, Darius and Shameuga. After a difficult path to diagnosis, their story reveals the strength of a family navigating a rare disease with resilience, love, and determination to be heard in a complex healthcare system.

RDDC POLICY REPORT



The lived experiences shared in the Patient Voices that Illuminate the #RareWithinRare Journey reminds us that personal stories are shaped by the policies and systems that influence healthcare access and research. Healthcare policy is shifting rapidly, with changes that could directly impact rare diagnosis, treatment access, and innovation. The [2025 RDDC Annual Policy Report](#) outlines major federal developments, including FDA pathway updates for rare therapies and Medicare and Medicaid reforms under the One Big Beautiful Bill Act. Amid workforce reductions, drug pricing reforms, and rollbacks of equity initiatives, the report highlights both risks and opportunities for rare communities. Read the full report, share it with your network, and stay engaged as we work together to protect equitable access, early diagnosis, and innovation in rare disease care.

ELEVATING PATIENT VOICES: POLICY & PRACTICE RECOMMENDATIONS

Grounded in disease-specific health equity research, RDDC's recommendations center the lived experiences of patients and caregivers. These insights translate community voices into actionable solutions to improve diagnosis, access, and care, ensuring that the #RareWithinRare are not simply heard, but meaningfully included in the policies and practices that shape their health outcomes.



HEALTH EQUITY FOR PEOPLE LIVING WITH PNH REPORT

RDDC and Links2Equity are proud to present Health Equity for People Living with PNH: Creating a Leveled Playing Field. This paper was made possible through the insights and contributions of patient advocates, healthcare professionals, advocates, and others who have lived experience with Paroxysmal Nocturnal Hemoglobinuria (PNH). Please share with your PNH communities.



VASCULITIS PATIENT RECOMMENDATIONS REPORT

RDDC and the Vasculitis Foundation are proud to present the report, Patient Recommendations for People Living With Vasculitis. Built on the insights and lived experiences of patients, healthcare professionals, and advocates, this report reflects the real needs and priorities of those living with vasculitis. The recommendations offer practical guidance to improve care, strengthen support systems, and promote equity. We encourage you to read and share this report with your vasculitis communities and networks to help ensure the patient voice continues to drive meaningful change.



SOCIAL DETERMINANTS OF HEALTH AND MYASTHENIA GRAVIS REPORT

Developed by the Rare Disease Diversity Coalition (RDDC) in partnership with the Myasthenia Gravis Foundation of America (MGFA), this community-informed report examines how social determinants of health impact people living with Myasthenia Gravis and their caregivers. Grounded in lived experience, it highlights barriers to diagnosis, treatment access, and overall well-being. Read the report and use the social media toolkit to amplify voices and advance more equitable MG care.

ADDITIONAL PATIENT RESOURCES & SUPPORT

- [Rare Disease Care Line](#)
- [Know Your Family History](#)
- [Social Security Benefits](#)
- [Clinical Trials](#)
- [Project Teach](#)

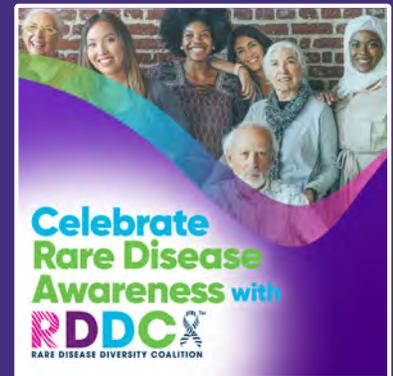
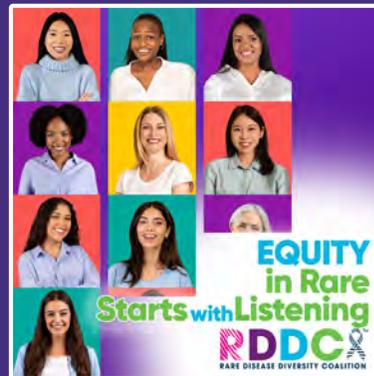
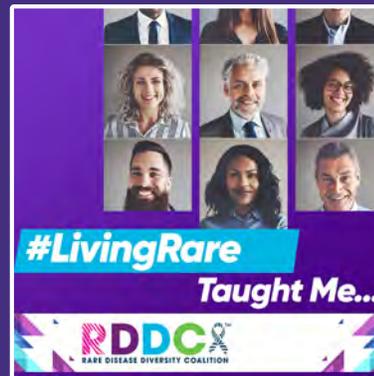


UTILIZE RDDC'S #RAREWITHINRARE AWARENESS SOCIAL MEDIA TOOLKIT...ALL YEAR LONG

Rare disease awareness isn't just a moment, it's a movement. We invite you to honor Rare Disease Awareness year round with RDDC by sharing your story, your strength, and your commitment to equity. Whether you identify as a Rare Disease Warrior, a Rare Care Partner, or a proud Rare Ally, your voice matters. Finish the sentence "#LivingRare Taught Me..." or "My Diagnosis Didn't Define Me, But It Changed Me..." and help spark meaningful conversation. Because equity in rare starts with access, listening, and representation, it's imperative that we advance equity for the #RareWithinRare, 365 days a year.

DOWNLOAD FREE GRAPHICS AND MORE...

[Click to Access the
Social Media Toolkit
and Share Your Story](#)



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