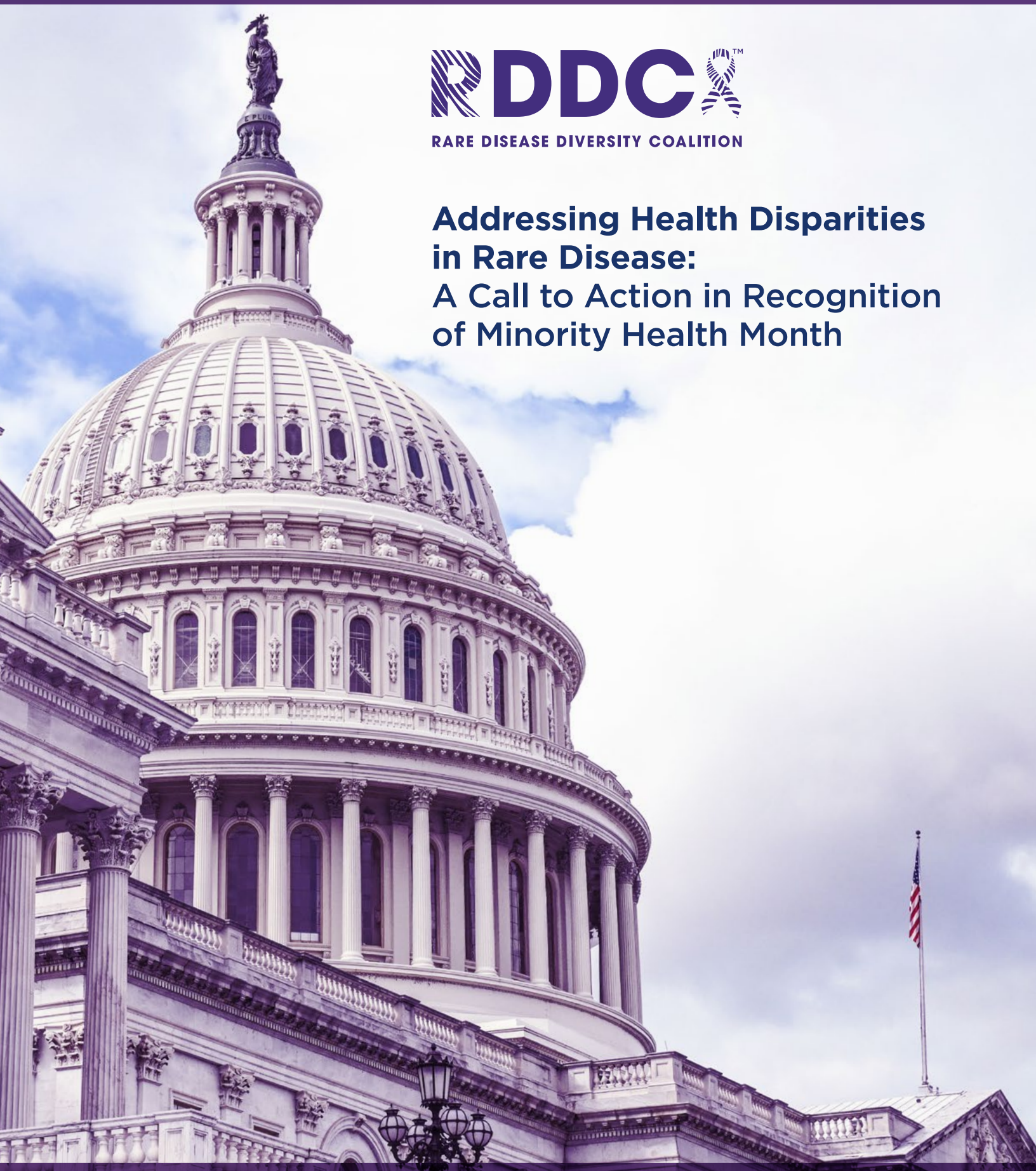
2025 Rare Disease Diversity Coalition (RDDC) Hill Briefing



RDDC™

RARE DISEASE DIVERSITY COALITION

Addressing Health Disparities in Rare Disease: A Call to Action in Recognition of Minority Health Month

April 30, 2025 | 11:30 AM – 12:30 PM ET | Room SVC-208

RARE DISEASE DIVERSITY COALITION

On behalf of the Rare Disease Diversity Coalition (RDDC), we extend our deepest gratitude to Senator Warnock's Office. The success of this briefing would not have been possible without your advocacy and the dedication of your team.

We are honored to partner with a champion like you in the fight for a more equitable healthcare system. Thank you again for standing with us and for your continued support of the rare disease community.

— The Rare Disease Diversity Coalition

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 of the best strategies and organizations that accomplish its goals. You can find more information about BWHI at bwhi.org.

The **Rare Disease Diversity Coalition (RDDC)** is a signature program launched by BWHI to address the extraordinary challenges faced by historically underrepresented populations with rare disease. 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.

Agenda

11:30 AM – 11:35 AM **Welcome & Opening Remarks**

Shawna Watley, Sr. Policy Advisor, Holland & Knight

- Acknowledgment to our Congressional Sponsors
- Introduction to RDDC and its mission
- Overview of the HEARD Act and RDDC's commitment to addressing health disparities in rare disease

11:35 AM – 11:50 AM **Presentation: RDDC Patient & Caregiver Gap Survey**

Jenifer Waldrop, Executive Director, RDDC

- Findings from the RDDC and NORD report, *Inequities in the Rare Disease Community: The Voices of Diverse Patients and Caregivers*
- Key insights on barriers to diagnosis, treatment, and care for rare disease patients in marginalized communities
- Analysis of Rare Diseases Clinical Research Network (RDCRN) data on patient representation

11:50 AM – 12:20 PM **Rare Disease Perspectives: Navigating the Burden of Rare Diseases & Health Disparities**

Personal Journeys

- Challenges in rare disease diagnosis and care
- Impact of Social Determinants of Health (SDOH) and geography on accessibility

Oya Gilbert, *Person living with Multiple Myeloma*

Sarah Jones, *Person living with Eosinophilic Granulomatosis with Polyangiitis (EGPA)*

Diamond DeShields, *Person living with Keratoconus*

Rare Disease Stakeholder

Dr. Rutvi Doshi, OD FAAO, *Optometrist*

12:20 PM – 12:30 PM **Q&A & Closing Remarks**

Q&A Session – Moderated discussion with speakers and attendees

Closing Remarks

Shawna Watley, Sr. Policy Advisor, Holland & Knight

- Final thoughts on advancing health equity for rare disease patients

Call to Action: Continue the conversation, support the HEARD Act, and advocate for equitable rare disease policies.

Speakers

Diamond DeShields
Founder, 3-D Foundation and
WNBA Guard for the Connecticut Sun

Diamond DeShields is a WNBA champion, gold medalist, and founder of The 3-D Foundation—a philanthropic initiative dedicated to expanding access to vision care and mentorship for underserved communities. Diagnosed with keratoconus, a degenerative eye disease, Diamond has navigated the complexities of elite athletics while managing a rare condition that nearly ended her career. Her personal experience fuels her commitment to ensuring that youth, particularly those in marginalized communities, receive the vision support and life guidance they need to succeed. Through her foundation, Diamond champions both literal vision—providing critical eye care services—and figurative vision—offering mentorship, career exposure, and programs that help young people see and believe in their future. Her mission is rooted in equity, compassion, and purpose, with the belief that no one should be held back by the things they can't see.

Dr. Rutvi Doshi, OD FAAO
Optometrist

Dr. Rutvi Doshi is a board-certified optometrist with over 15 years of leadership in clinical care, academia, and biotech, focused on advancing innovation in ocular rare diseases. She has led national initiatives in care and education for complex ocular surface conditions, including keratoconus, and played a key role in launching first-in-class therapies in ophthalmology. A former Director of Optometry at the University of Chicago, Dr. Doshi is a recognized advocate for patient-centered care and equitable access to diagnostics and treatment for rare eye diseases. In the pharmaceutical industry, she has overseen medical strategy for therapeutic launches and led real-world evidence studies. Dr. Doshi actively partners with advocacy groups to promote early diagnosis, research equity, and policy support for keratoconus and other rare ocular conditions.

Oya Gilbert
Founder
Health, Hope & Hip-Hop Foundation

Oya Gilbert, aka "Grand G," is a father, podcaster, and key figure in Delaware's hip-hop scene who turned his cancer diagnosis into a mission for change. After years of misdiagnoses, he was diagnosed with multiple myeloma in 2017 and underwent a stem cell transplant in 2018, continuing treatment with daily chemotherapy. He hosts the podcast *Hip, Hope, Hooray! Black Men Talking Health*, which tackles health disparities and raises awareness in the Black community. In 2024, he founded the Health, Hope & Hip-Hop Foundation to teach health literacy and use hip-hop culture as a force for grassroots change. Backed by major health organizations, Gilbert champions diversity, equity, and patient advocacy.

Sarah Jones, MPA, MS
Person living with Eosinophilic Granulomatosis with Polyangiitis (EGPA)

Sarah Jones has over 25 years of experience leading nonprofits and health care programs. She has designed programs and led trainings for local, national and international audiences. She holds two Masters degrees: Masters of Science in Strategic Design Management from Parsons the New School and a Masters in Public Administration (healthcare). Her life irrevocably changed when diagnosed with EGPA, Eosinophilic Granulomatosis with Polyangiitis. Sarah and her wife of 30 years bring their shared passion to improving access to treatments, care and provide Hospital Emergency Advocacy and Training Kits for rare disease through their nonprofit - Eosinophilic & Rare Disease Cooperative.

Jenifer Waldrop, MS
Executive Director
Rare Disease Diversity Coalition (RDDC)

Jenifer Ngo Waldrop, the Executive Director of RDDC, joined the coalition in October 2022. Before leading RDDC, she developed models and programs for diversity, equity, and inclusion initiatives to support multiple business units with Fortune 500 companies and organizations in Asia, Canada, and the US. Jenifer received her undergraduate degree from Colby College and her Master of Human Resources Development from Villanova University. As the Professional Development Director of the National Association of Asian-American Professionals (NAAAP) of Colorado, Jenifer continues her outreach in society. Through this organization, she mentors formally and informally.

Shawna Watley, MPP
Senior Policy Advisor
Holland & Knight LLP

Shawna Watley is a senior policy strategist at Holland & Knight in Washington, D.C., and co-leads the firm's Education Team within the Public Policy & Regulation Group. With over 17 years of experience, she specializes in lobbying, legislative strategy, and regulatory counseling for corporate, nonprofit, and government clients. She has strong working relationships across all levels of government, including the Biden Administration, Congress, and key caucuses. Watley holds a B.S. from Howard University and an M.A. in Public Policy from Johns Hopkins University. Before joining Holland & Knight, she led her own firm, the Francis Group LLC, and held leadership roles at the Democratic Leadership Council. She has also lectured internationally and has deep expertise in a range of policy areas, including healthcare, education, energy, and homeland security.

Call to Action:
Join Us in Advancing Equity for Rare Disease Patients

As we conclude today's briefing, the Rare Disease Diversity Coalition (RDDC) urges you to take action and be a part of the movement to dismantle health disparities in the rare disease community.

The voices you heard today—from patients, caregivers, advocates, and healthcare leaders—are a powerful reminder: **equity in rare disease care is not a privilege—it is a right.** The barriers outlined in our survey findings and lived experiences are unacceptable. It's time to act.

Here's how you can continue making a difference:

- **Support the HEARD Act of 2025 (H.R. 1750).** RDDC proudly supports the HEARD Act of 2025 (H.R. 1750), and we urge you to join us in taking the next step. This critical legislation addresses the diagnostic and care gaps that disproportionately affect historically underrepresented communities.
  - **Make your impact. Speak up for the HEARD Act today.** https://www.govtrack.us/congress/bills/119/hr1750/comment
- **Partner with RDDC.** Collaborate with us to champion evidence-based solutions that prioritize diversity in research, access, and outcomes.
- **Elevate patient voices.** Share what you've learned today with your networks. Engage with communities, policymakers, and healthcare systems to ensure these stories lead to meaningful change.
- **Stay Informed.** Visit rarediseasediversity.org to access research, tools, and ways to get involved.
  - In 2022, RDDC and the National Organization for Rare Disorders (NORD) collaborated to conduct this unprecedented initiative: developing a national survey targeting underrepresented rare disease patients and caregivers across disease areas. The primary objective was to close critical knowledge gaps and gain insights into these individuals' unique perspectives and challenges in accessing and affording health care. By concentrating on underrepresented patients, the intention was to gather essential information that would facilitate a more profound comprehension of existing gaps and barriers in diagnosis, care, and treatment access. This pioneering research involved over 2,800 participants, revealing critical insights into the challenges of accessing necessary healthcare. **Use the QR code to view the full report.**
- **Advocate Year-Round.** This Minority Health Month, and beyond, use your platform—whether in policy, medicine, community leadership, or advocacy—to champion inclusive and equitable healthcare solutions.

This is more than a briefing. It's a call to action. Let's work together to ensure every rare disease patient—regardless of race, ethnicity, income, or geography—receives the timely diagnosis, treatment, and care they deserve.

Thank you for standing with us.

— The Rare Disease Diversity Coalition (RDDC)

Special Thanks

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