

Breaking Barriers in Rare Disease Equity:

RDDC 2026
Capitol Hill Briefing &
Eve Dryer RISE Awards
Reception



September 17th | 4:00–7:00 p.m. ET
Rayburn House, Room 2044
45 Independence Ave SW, Washington, DC 20515



RDDC

RARE DISEASE DIVERSITY COALITION



On behalf of RDDC, we extend our deepest gratitude to **Congresswoman Doris Matsui**. The success of this event 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.

Capitol Hill Briefing Agenda

4:00 pm – 4:45 pm

Welcome & Opening Remarks

- [Joy D. Calloway](#), President & CEO, Black Women's Health Imperative

Panel Presentation on the [Current state and demographic trends of medically underserved populations in rare disease research in the United States: a systematic review](#)

Moderator

- [Josie Villanueva](#), Principal – Health Sector Lead, Fulcrum Public Affairs

Speakers

- [Dr. Harsha Rajasimha](#), Founder & CEO of Jeeva Clinical Trials, Founder & Chairman of IndoUSrare
- [Nate Milam II](#), Person living with Histiocytosis
- [Nitasha Sarswat, MD](#), Associate Professor of Medicine, University of Chicago

Closing Remarks / Call to Action

- A member of Representative Marilyn Strickland's office

Call to Action:

Drive systemic change by supporting the *Health Equity and Rare Disease (HEARD) Act of 2025 (H.R. 1750)* and advancing policies that improve demographic data collection, representation, and inclusion for medically underserved populations in rare disease research.



Join Us to Advance 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 researchers, caregivers, advocates, and healthcare leaders—are a powerful reminder: equity in rare disease care is not a privilege—it is a right. The continued underrepresentation of medically underserved populations in rare disease research—paired with critical gaps in data and access—are unacceptable and require immediate action. It's time to act.

Here's how you can make a difference:



Support the *HEARD Act of 2025 (H.R. 1750)*. RDDC proudly champions and helped shape 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>



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.



Advocate Year-Round. Use your platform—whether in policy, medicine, community leadership, or advocacy—to champion inclusive and equitable healthcare solutions.



Stay Informed. Visit rarediseasediversity.org to access research, tools, and ways to get involved.

Recently, RDDC and IndoUSRare collaborated to conduct this unprecedented initiative: a first-of-its-kind, cross-national effort examining rare disease disparities across the U.S. and India, culminating in a peer-reviewed publication that elevates critical insights on equity, access, and representation in rare disease research and care. **Use the QR code to view the full publication:**



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

Eve Dryer RISE Awards Agenda

5:15 pm – 7:00 pm

Opening Remarks

- [Joy D. Calloway](#), President & CEO, Black Women's Health Imperative

Moment of Remembrance

- [Stephanie Marshall](#), Director of Patient Advocacy, The Assistance Fund

Eve Dryer Tribute

- [Sika Dunyoh](#), Sr. Director of Patient Advocacy, Travers Therapeutics

Award Presentations

- Health Equity RISE Award - [TSC Alliance](#)
- Industry Partner RISE Award - [BridgeBio](#)
- Patient Advocacy RISE Award - [Shruti Mitkus](#)
- Provider RISE Award - [Dr. Aditi Kantipuly](#)

Keynote Remarks

- [Donna R. Cryer](#), JD, Patient Officer, CryerHealth

Award Presentations

- Caregiver RISE Award - [Gloria Rodriguez](#)
- Patient RISE Award - [Nate Milam II](#)
- Eve Dryer Legacy RISE Award

Closing Remarks

- [Deanna Darlington](#), President, Links2Equity

Community Connection & Networking



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