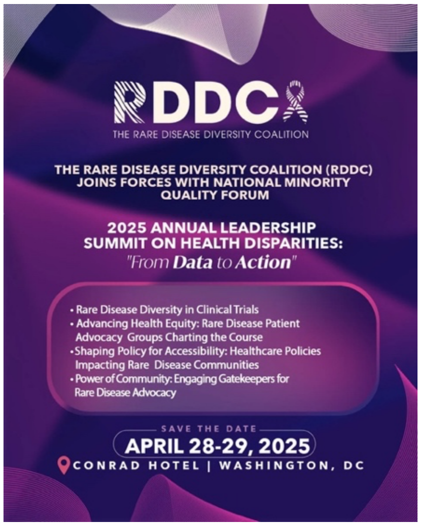
RDDC™
RARE DISEASE DIVERSITY COALITION

RDDC & NMQF LEADERSHIP SUMMIT ON HEALTH DISPARITIES 2025

SUMMIT MEETING SUMMARY

Event Theme	Driving Inclusion, Advocacy, Policy, and Community Power in Rare Disease
Key Date	April 29, 2025
Location	Conrad Hotel, Washington, DC



RDDC
THE RARE DISEASE DIVERSITY COALITION

THE RARE DISEASE DIVERSITY COALITION (RDDC)
JOINS FORCES WITH NATIONAL MINORITY
QUALITY FORUM

2025 ANNUAL LEADERSHIP
SUMMIT ON HEALTH DISPARITIES:
"From **Data** to **Action**"

- Rare Disease Diversity in Clinical Trials
- Advancing Health Equity: Rare Disease Patient Advocacy Groups Charting the Course
- Shaping Policy for Accessibility: Healthcare Policies Impacting Rare Disease Communities
- Power of Community: Engaging Gatekeepers for Rare Disease Advocacy

SAVE THE DATE
APRIL 28-29, 2025
CONRAD HOTEL | WASHINGTON, DC

Pictured above: 2025 RDDC x NMQF Summit Flyer

ABOUT THIS CONFERENCE

RDDC partnered with National Minority Quality Forum (NMQF) and hosted a Rare Disease Track at the annual NMQF Leadership Summit on Health Disparities & Spring Health Braintrust, which took place April 28-29, 2025 in Washington, DC. The Summit on Health Disparities is a premier event dedicated to advancing healthcare equity, bringing together nearly 1,000 leaders annually - including healthcare providers, researchers, policymakers, community advocates, and faith-based organizations - all united in the mission to advance health equity. The summit has played a critical role in educating and mobilizing thousands of health leaders in the fight against disparities.

On April 29, RDDC led a 4-panel series focused on rare diseases - shining a spotlight on underserved communities and the voices that matter most:

- Rare Disease Diversity in Clinical Trials
- Advancing Health Equity: Rare Disease Patient Advocacy Groups Charting the Course
- Shaping Policy for Accessibility: Healthcare Policies Impacting Rare Disease Communities
- Power of Community: Engaging Gatekeepers for Rare Disease Advocacy

For more information about the 4-panel series, visit the RDDC x NMQF Leadership Summit Program.

ABOUT THE PARTNERS

The Rare Disease Diversity Coalition (RDDC) is an initiative launched by the Black Women's Health Imperative (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. Find more information about RDDC at www.rarediseasediversity.org.

The Black Women 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. Find more information about BWHI at bwhi.org.

The National Minority Quality Forum (NMQF) is a U.S.-based healthcare research, education, and advocacy organization dedicated to reducing patient risk and advancing health equity. As the nation's largest minority-focused health organization, NMQF leads efforts to turn data into action - working to ensure optimal care and improved access for all, especially the most vulnerable. Find more information about NMQF at nmqf.org and nmqf.org/annual-summits/2025-annual-leadership-summit.

Welcome and Remarks

Gary A. Puckrein, PhD
President and CEO, National Minority Quality Forum

Jenifer Waldrop, MS
Executive Director, Rare Disease Diversity Coalition
Black Women's Health Imperative

Key Insights: In the opening remarks, Gary and Jenifer emphasized the importance of coming together to create a stronger, more equitable and just healthcare system - a theme that resonated throughout the sessions.

Session 1: Rare Disease Diversity in Clinical Trials

Moderator: Jenifer Waldrop, MS, Executive Director – RDDC at BWHI

Panelists: LaVarne Burton, President & CEO – American Kidney Fund
Jamie Freedman, MD, PhD, Chief Medical Officer – Sobi
Dr. Harsha Rajasimha, Founder & CEO – Jeeva Clinical Trials, Inc.
Dr. Marshall Summar, CEO – Uncommon Cures

Session Overview

This session explored bold, coordinated efforts to eliminate health disparities in the rare disease community. Speakers examined how underrepresentation in clinical research impacts trust, trial design, and patient outcomes - and shared actionable strategies to close these gaps. They deep-dived into the reshaping of the research ecosystem to reflect the true diversity of the communities it aims to serve, building a future in which equity is at the core of rare disease research.

Session Summary: Expanding Access and Equity in Clinical Trials

This session focused on actionable strategies to improve diversity, accessibility, and retention in clinical trials - particularly for underrepresented communities. Key recommendations included:

- **Engage Early & Build Trust**
  Invest in communities before trials begin by establishing strong relationships and understanding local needs. Long-term engagement - including communication after trials end - helps build trust and encourages ongoing participation.
- **Community-Based Recruitment**
  Reach beyond large hospitals to partner with community-based centers, ensuring access for

broader populations. Jamie Freedman, MD, PhD, Chief Medical Officer, Sobi, highlighted success recruiting underrepresented patients for a COVID-19 pneumonia trial by engaging participants directly in their local emergency rooms at the community hospital.

- **Address Barriers to Participation**
  Barriers such as geography, overly complex trial protocols, and time away from home were identified as root causes of low participation, especially among African American communities. A study shared by Dr. Marshall Summar, found that African American participation rates among 12,000 participants were less than 50% of other groups.
- **Participant-Centered Design**
  Treat participants with a "white glove" approach from the first contact, ensuring forms and materials are clear and accessible. Prioritize participant convenience and respect to build trust and retention.
- **Decentralized & At-Home Trial Models**
  Incorporate telehealth, mobile nursing, and medication delivery to increase convenience and improve data collection. While technology can enhance participation, it's essential to maintain a human touch and address the digital divide to avoid additional barriers.
- **Combat Isolation Through Community Building**
  For individuals living with rare diseases, building a connected community is vital to reducing isolation and foster support networks.

Closing Summary
The session emphasized that true equity in clinical trials requires proactive, sustained efforts to make research more accessible, inclusive, and human centered.

Session 2: Advancing Health Equity: Rare Disease Patient Advocacy Groups Charting the Course

Moderator: Pam Rattananont, MPH, Senior Patient Advocacy Consultant – Links2Equity

Panelists: Paula Eichenbrenner, Executive Director – The Myositis Association
Mary McGowan, CEO – Foundation for Sarcoidosis Research
Deborah Requesens, Co-Founder & President – Hispanic Society for Rare Diseases
Nicole Rochester, MD, Health Equity Medical Advisor – Immune Deficiency Foundation (IDF)
Dionne Stalling, Founder & Executive Director – Rare and Black

Session Overview
Advocacy organizations are at the forefront of advancing health equity and pushing for more inclusive healthcare systems. This session dived into the biggest barriers to clinical trial participation and shared proven strategies for meaningful community engagement. It also highlighted innovative collaborations between advocacy groups, government agencies, and industry partners - spotlighting real-world programs that are driving change in the rare disease community.

Session Summary: Driving Heath Equity in Rare Disease Advocacy

Rare disease advocacy groups are leading efforts to embed diversity into healthcare systems. This dynamic panel featured representatives from top advocacy organizations sharing actionable initiatives that tackle health disparities, promote equity, and strengthen diversity within the rare disease community. Attendees gained practical insights into successful models for improving patient outcomes and strategies to weave equitable principles into every aspect of organizational work.

Key Topics Explored:

- **Community-Driven Approaches**
  Panelists emphasized the importance of showing up in communities long before asking for participation in clinical trials - interested parties should start engagement by asking what improvements would truly enhance their lives. Delays in diagnosis, mistrust stemming from bias and medical discrimination, and gaps in engagement were cited as critical barriers. Sustained, culturally relevant education and communication - especially when it comes to clinical trials - are vital for lasting trust and retention.

- **Top Barriers to Clinical Trial Participation (Mary McGowan Insights)**
  1. People often never being asked to enroll
  2. Lack of accessible, clear information
  3. Financial concerns and fear of job loss
  4. Deep-rooted trust issues

- **Innovative Outreach Strategies (Nicole Rochester, MD Insights)**
  Creative platforms such as podcasts, patient advisory boards, and youth advisory boards are helping advocacy groups connect authentically with their audiences. Dr. Rochester highlighted her podcast, *Undiagnosed Primary Immune: Bold Conversations*, along with *Compromised: Life Without Immunity*, a documentary produced by IDF that provides an intimate portrayal of individuals living with primary immunodeficiencies (PIs). This documentary drew significant interest and helped amplify patient voices.

- **Other Engagement Tactics**
  - Podcasts like *More the Rare* (Deborah Requesens)
  - National registries to capture diverse data
  - Partnerships with HBCUs for education and recruitment
  - Caregiving conferences, with a focus on mental health

- **Sustainability & Advocacy**
  Speakers underscored the power of aligning with larger institutions to secure unrestricted funding - such as partnerships with hospitals - and the importance of legislative advocacy. Mary McGowan shared an initiative led by the Sarcoidosis Foundation that advocated for paid time off for employees to participate in clinical trials; it was very successful under the Family and Medical Leave Act (FMLA) and continues to reinforce the idea that a healthy workforce underpins a healthy society.

- **Memorable Example**
  Ms. McGowan cited an example of an initiative in which she participated with Burlington Coat Factory when she served as CEO for WomenHeart. This partnership speaks to the power of engaging larger partners to increase reach and patient engagement. Through this initiative,

WomenHeart was able to provide free blood pressure screenings, unexpectedly identifying critical health issues (people needing immediate ER care) and underscoring the impact of meeting people where they are.

Closing Summary
The session closed with a powerful reminder: Always ask, *"Who is missing from the table?"* and work tirelessly to bring them in.

Session 3: Shaping Policy for Accessibility: Healthcare Policies Impacting Rare Disease Communities

Moderator: Dr. Larry Bucshon, Senior Policy Advisor – Holland & Knight

Panelists:
Victoria Gemme, Director, Policy & Regulatory Affairs – NORD
Dr. Maggie Kang, Life and Healthcare Coach
Annie Kennedy, Chief of Policy, Advocacy & Patient Engagement – EveryLife Foundation for Rare Diseases
Chris Porter, Vice President of Government Affairs & Policy – Travere Therapeutics

Session Overview
This panel focused on current and emerging policies that directly impact diverse communities, highlighting how these initiatives can drive health equity. Panelists shared actionable insights on the steps needed to ensure equitable access to diagnosis, care, and treatment for rare diseases, ensuring that all populations have the support they need to thrive.

Session Summary: Advancing Health Equity Through Advocacy, Education, and Policy
This session underscored the essential role of advocacy, education, and unwavering persistence in improving health outcomes for rare disease patients.

- **Educating Healthcare Providers**
  Panelists emphasized that when healthcare professionals - especially those in emergency departments - are well-trained in recognizing and managing rare diseases, it leads to significantly improved care practices and better patient outcomes.
- **Navigating Today's Policy Landscape**
  The discussion addressed today's challenging policy climate, marked by budget cuts, Medicaid reductions, and shrinking incentives. Speakers underscored the ability of grassroots advocacy - constituents sharing personal stories and pain points directly with policymakers - to powerfully influence legislative change. Medicaid's impact goes beyond medical care, supporting individuals' ability to work, live independently, and avoid institutionalization.
- **The Importance of Local Engagement**
  While the current environment presents challenges, panelists noted that disruption also creates opportunities for renewed advocacy and program protection. They encouraged attendees to engage both at the state and federal levels, highlighting that state-level advocacy is just as impactful as federal. Building strong relationships with local legislators early helps pave the way for more robust support when these leaders advance to federal roles. Resources like NORD's advisory councils were mentioned as valuable tools for supporting state-level engagement.

- **Reducing Barriers to Clinical Trial Participation**
  The session also explored micro-level strategies to improve clinical trial access, including the use of translators, patient advocates, and caregiver involvement to reduce participation barriers.
- **Persistence with Insurance Appeals**
  For insurance challenges, speakers stressed persistence, advising patients and advocates not to give up after initial denials. Successful strategies include submitting extensive documentation - such as patient stories, relevant articles, and letters from medical experts - to strengthen appeals and improve the chances of approval.

Closing Summary
The session concluded with a powerful reminder: Effective advocacy requires preparation, persistence, and community. By educating healthcare providers, building strong legislative relationships, and pushing for patient-centered policies, advocates can create lasting change for rare disease communities.

Session 4: The Power of Community: Engaging Gatekeepers for Rare Disease Advocacy

Moderator: Deanna Darlington, Founder and President – Links2Equity

Panelists: Oya Gilbert, Founder & CEO – Health, Hope & Hip-Hop Foundation
George Kerr III, Elder – Westminster Presbyterian Church DC
Rob Long, Executive Director – Uplifting Athletes
Tiffany Scott, Co-Founder & President – Maryland Community Health Workers Association
Stephen Thomas, Professor of Health Policy & Management, Director of Maryland Center for Health Equity – University of Maryland

Session Overview
This powerful panel explored the vital role of community gatekeepers and trusted leaders in bridging the gap between rare disease advocacy and local populations. Speakers shared practical strategies for building strong, authentic relationships with trusted figures and discussed how grassroots-level engagement can enhance awareness, education, and access to care within diverse communities. The panel also demonstrated how groups focused around broad diseases can replicate these strategies to support diverse rare disease communities.

Session Summary: Building Trust and Community Partnerships
This dynamic session highlighted innovative, grassroots strategies for connecting rare disease advocacy efforts to local communities. Panelists emphasized the power of culturally rooted initiatives and the essential role of community health workers (CHWs), barbers/hair stylists, pastors (faith-based organizations), sports figures, and community-focused and -led patient advocacy organizations in building lasting trust and improving access to care.

- **Hyper-Local Engagement Through Trusted Spaces**
  Dr. Stephen Thomas, a professor at University of Maryland, shared his highly effective initiative, The Health Advocates in-Reach and Research (HAIR) Campaign, which recruits Black and Brown participants for clinical trials and disease education and awareness through barbershops and

salons - spaces that long have been pillars of trust and community connection. By being engaged during their visits or being hosted at clinic events that feel like celebrations, participants leave both informed and intrigued. Barbers and stylists involved in the initiative become Certified Community Health Workers (CHWs), deepening their role as trusted health advocates.

- **Historical Context and Empathy in Action**
  George Kerr highlighted the historical success of using barbershops to distribute condoms during the height of the HIV epidemic, reinforcing the value of these spaces for public health efforts. He also raised concerns about the current climate and the harmful policies that threaten the health of vulnerable communities, as there is an increased fear that these changes could lead to deaths. This underscores the need for empathy and continued advocacy and for urging advocates to build one-on-one connections that can expand into broader, lasting networks of trust and care.
- **Empowering CHWs to Lead and Educate**
  Tiffany Scott, a CHW, emphasized the importance of creating spaces that foster curiosity and continuous hunger to learn. She described the CHW role as guiding patients through every step of their health journey - from initial visits to surgery and beyond - while dispelling myths and building bridges of trust. CHWs do not only show up to bring the light and provide resources but also empower patients by amplifying their voices.
- **Bringing Hip-Hop Culture to Health Advocacy**
  Oya Gilbert of the Health, Hop & Hip-Hop Foundation spoke about leveraging hip-hop culture to promote health education through music, dance, swag, and community events. His approach bridges gaps from the BBQ to the boardroom, using creativity and cultural pride to engage diverse audiences. He stressed the importance of trusting ourselves to have the power to make impactful change, forming alliances, maintaining humanity over metrics, and centering love as a driving force for creating trust and meaningful change. Additionally, he shared a powerful and impactful story of his own delayed diagnosis with multiple myeloma (MM), which has inspired him to build bridges with the community through hip-hop.
- **Staying the Course and Investing in Community**
  Rob Long emphasized the need to continually invest in researchers and ensure opportunities are accessible. Both Mr. Gilbert and Mr. Long shared personal stories of transforming their own health challenges into powerful platforms for giving back, reminding attendees that personal experience can fuel impactful advocacy.

Closing Summary

The session highlighted the fact that community leaders are bridges to education and awareness about both large and rare diseases, and that through this engagement we can create “rare” and powerful moments for patients. The panel concluded with Dr. Thomas describing it as a "masterclass" in community-centered advocacy. This underscores that sustainable change begins with trust; cultural relevance; and deep, authentic relationships.

Topline Learnings and Final Summary

Closing Summary: RDDC x NMQF Leadership Summit on Health Disparities 2025

Driving Inclusion, Advocacy, Policy, and Community Power in Rare Disease

The 2025 RDDC x NMQF Leadership Summit on Health Disparities, held April 28–29 in Washington, DC, brought rare diseases to the forefront of the national conversation on health equity. In partnership with the National Minority Quality Forum, RDDC led a compelling 4-panel series on April 29 that amplified the voices of underserved communities, addressed systemic barriers, and charted a bold path forward for inclusion and equity in rare disease advocacy.

With a collaborative effort of patients, providers, researchers, policymakers, faith leaders, academia, industry partners, and community advocates—the summit underscored a shared mission: to dismantle health disparities through actionable policy, grassroots engagement, and innovative advocacy.

Key themes from the rare disease track included:

- **Diversity in Clinical Trials: Engage Early & Build Trust:** Invest in communities before trials begin by establishing strong relationships and understanding local needs. Long-term engagement - including communication after trials end - helps build trust and encourages ongoing participation.
- **Strengthening Advocacy and Policy Impact:** Panelists explored how education and persistent advocacy can reshape policy and improve patient outcomes, particularly when healthcare providers and emergency settings are equipped with rare disease knowledge.
- **Advancing Health Equity:** Patient advocacy groups shared proven strategies for embedding diversity and equity into their missions - highlighting how intentional outreach, innovative communication, and deep community partnerships drive real change.
- **Policy for Accessibility:** Experts unpacked the current policy landscape, emphasizing both the challenges and opportunities ahead. From state-level engagement to Medicaid protections and clinical trial accessibility, speakers called for coordinated, grassroots action to ensure equitable access to care.
- **Power of Community Engagement:** Advocates showcased how trusted local spaces - like barbershops, salons, and cultural hubs - can be leveraged to build lasting trust and spread awareness. Certified Community Health Workers and cultural advocates illuminated the critical role of grassroots leadership in driving health literacy and fostering long-term engagement.

Together, these sessions demonstrated the power of intersectional advocacy - where education, policy, culture, and community converge to advance equity in rare disease care.

The summit concluded with a resounding call to action: Health equity is not a passive goal but a collective responsibility. By deepening trust, strengthening local and national alliances, and staying relentless in advocacy, we can create a future where all rare disease patients - especially those in historically underserved communities - receive the diagnosis, care, and support they need to thrive.