



ADVANCING EQUITY IN RARE DISEASE CARE

FIRST OF ITS KIND

Since its formation under the visionary leadership of Linda Goler Blount and the **Black Women's Health Imperative** (BWHI), the **Rare Disease Diversity Coalition** (RDDC) has made monumental strides in addressing the extraordinary challenges faced by historically underrepresented rare disease patients.

Highlights - 100+ partners:

Over the years, RDDC has led and contributed to numerous publications, shared its expertise on international platforms, awarded scholarships to support emerging leaders in health equity, advocated for policy change through legislative outreach, and hosted a fellowship program to train the next generation of rare disease equity champions.

2020

PATHWAYS TO PROGRESS: RDDC'S 5 YEARS OF IMPACT

Black Women's Health Imperative launched the Rare Disease Diversity Coalition™ (RDDC™)

to address the extraordinary challenges faced by underserved populations with rare diseases. The coalition brings together rare disease experts, health and diversity advocates, and industry leaders to identify and advocate for evidence-based solutions to alleviate the disproportionate burden of rare diseases on historically marginalized populations.

The coalition was established to identify and advocate for evidence-based solutions to alleviate the disproportionate burden of rare diseases on communities of color.

LEARN MORE

MAY 2020 LAUNCH OF RDDC

The coalition was established to identify and advocate for evidence-based solutions to alleviate the disproportionate burden of rare diseases on communities of color.

LEARN MORE

NOVEMBER 2020

Undertook a six-month study to assess the most pressing challenges faced by people of color with rare diseases and identified potential solutions.

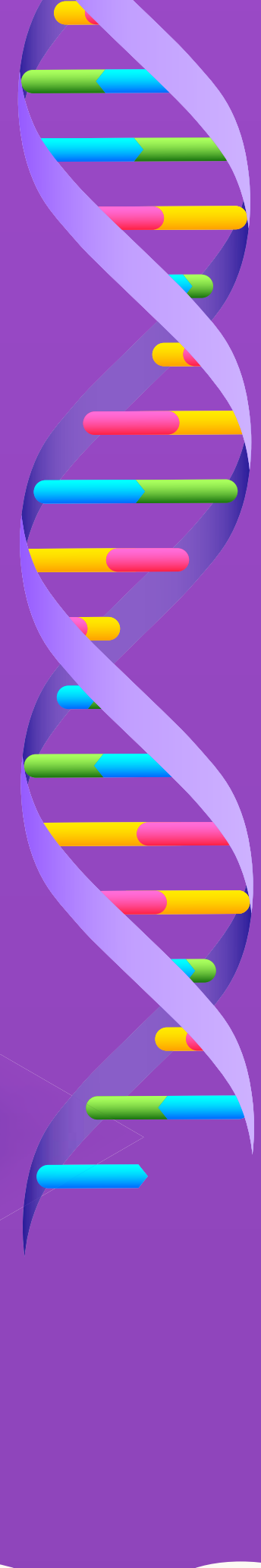
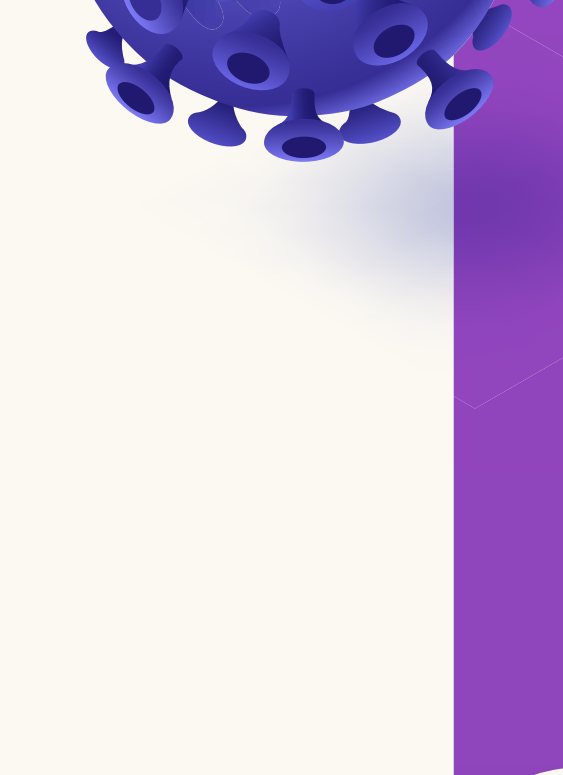
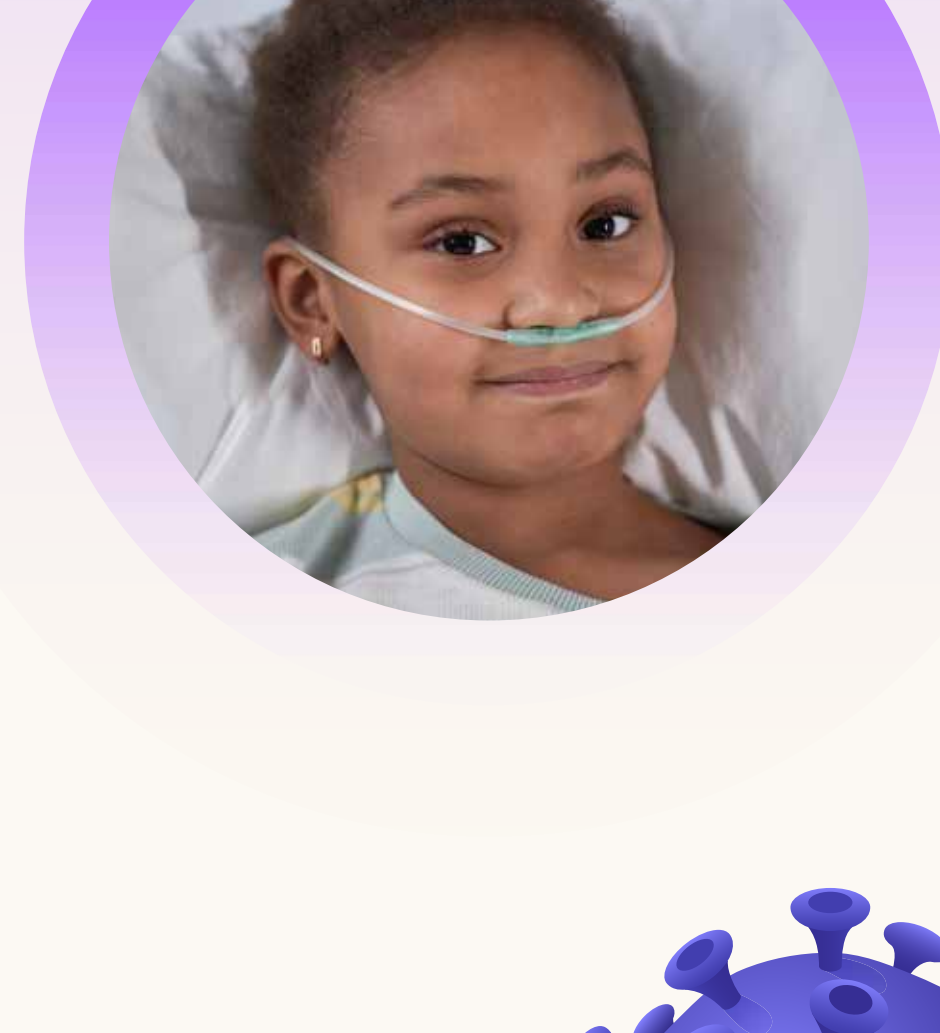
LEARN MORE

APRIL 2021

IDENTIFIED 75 RECOMMENDATIONS AND 5 AREAS OF FOCUS

Patient and Caregiver Journey, Delays in Diagnosis, Provider Education, Diversity in Research & Clinical Trials, Government Regulation, and Legislation & Policy.

LEARN MORE



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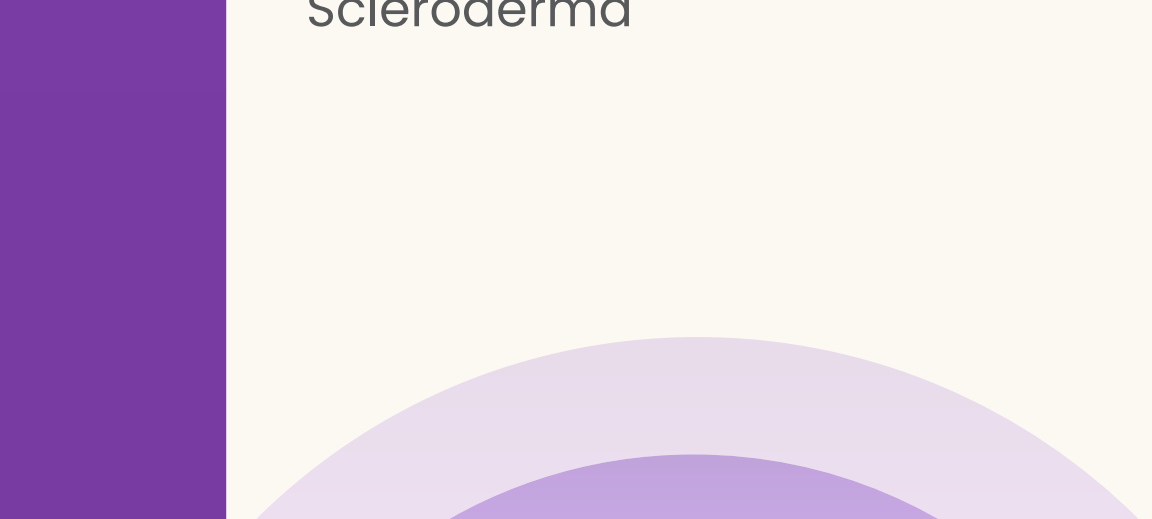


JUNE 2021

BLACK AND RARE

Our experts explored the clinical knowledge gathered on scleroderma and discussed its impact on the African-American community.

WATCH NOW



QUEEN LATIFAH

A Family's Battle with Scleroderma

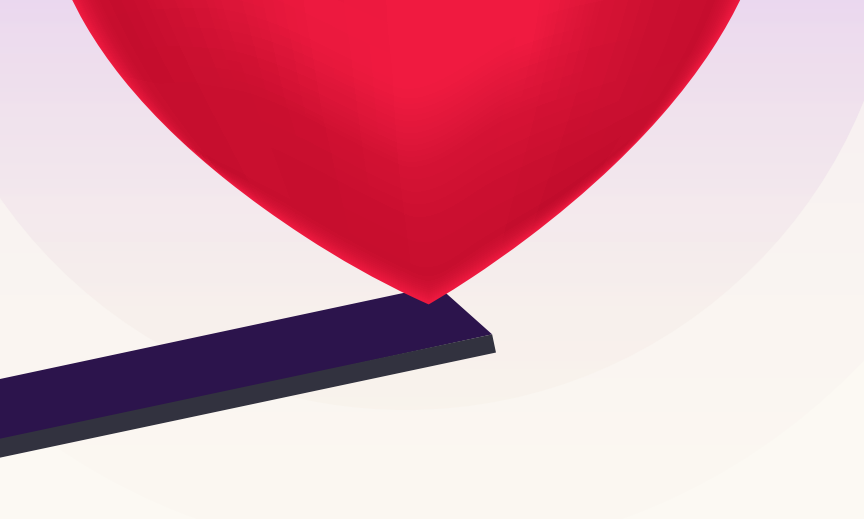


SEPTEMBER 2021

INAUGURAL RARE HEALTH EQUITY SUMMIT

Initiated a multi-year partnership with Global Genes.

WATCH HIGHLIGHTS



NOVEMBER 2021

BLACK & RARE: Sarcoidosis in Black Women Webinar

WATCH NOW

BLACK & RARE: Thyroid Eye Disease Webinar

WATCH NOW

BLACK & RARE: Mediated Kidney Disease Webinar

WATCH NOW

BLACK & RARE: Sickle Cell Disease Webinar

WATCH NOW

BLACK & RARE: HIV/AIDS Webinar

WATCH NOW

BLACK & RARE: Mental Health Webinar

WATCH NOW

BLACK & RARE: Substance Use Disorder Webinar

WATCH NOW

BLACK & RARE: Diabetes Webinar

WATCH NOW

BLACK & RARE: Hypertension Webinar

WATCH NOW

BLACK & RARE: Asthma Webinar

WATCH NOW

BLACK & RARE: COPD Webinar

WATCH NOW

BLACK & RARE: Cancer Webinar

WATCH NOW

BLACK & RARE: Alzheimer's Disease Webinar

WATCH NOW

BLACK & RARE: Parkinson's Disease Webinar

WATCH NOW

BLACK & RARE: Multiple Sclerosis Webinar

WATCH NOW

BLACK & RARE: Rheumatoid Arthritis Webinar

WATCH NOW

BLACK & RARE: Osteoarthritis Webinar

WATCH NOW

BLACK & RARE: Osteoporosis Webinar

WATCH NOW

BLACK & RARE: Chronic Pain Webinar

WATCH NOW

BLACK & RARE: Depression Webinar

WATCH NOW

BLACK & RARE: Anxiety Disorder Webinar

WATCH NOW



DECEMBER 2021

BLACK & RARE: Understanding APOL1 Webinar

WATCH NOW



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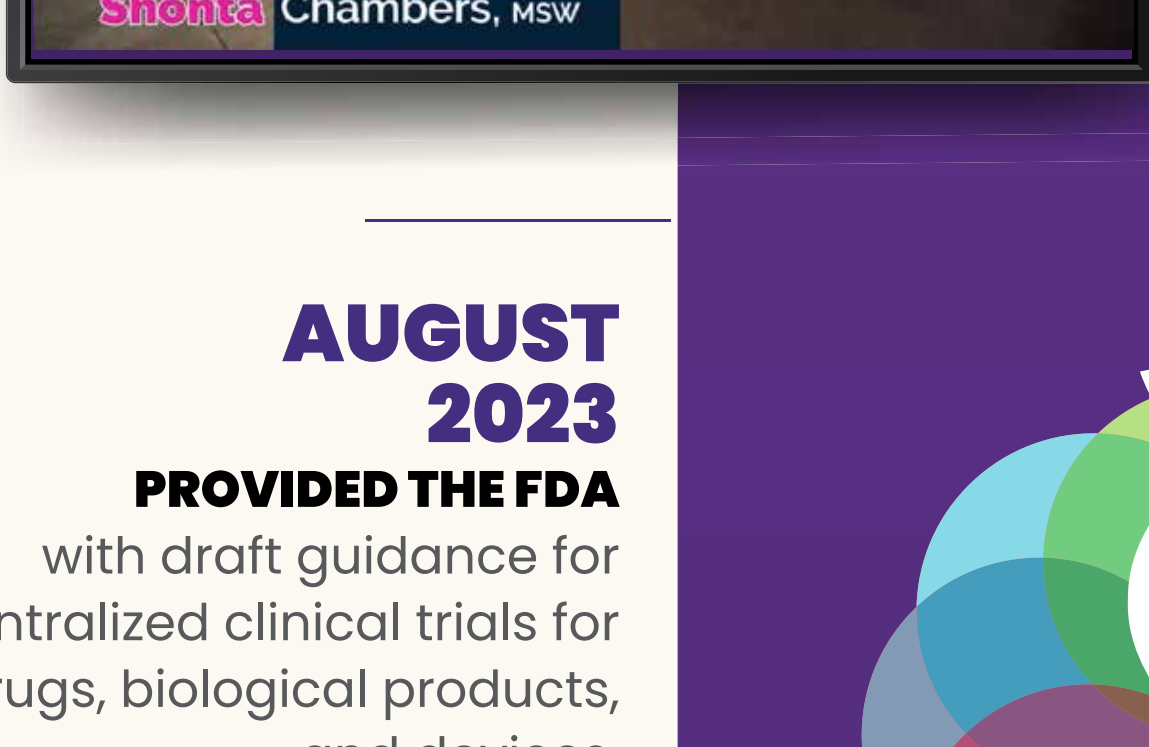
BLACK & RARE: Understanding APOL1 Webinar

WATCH NOW

DECEMBER 2021

BLACK

2023



AUGUST 2023

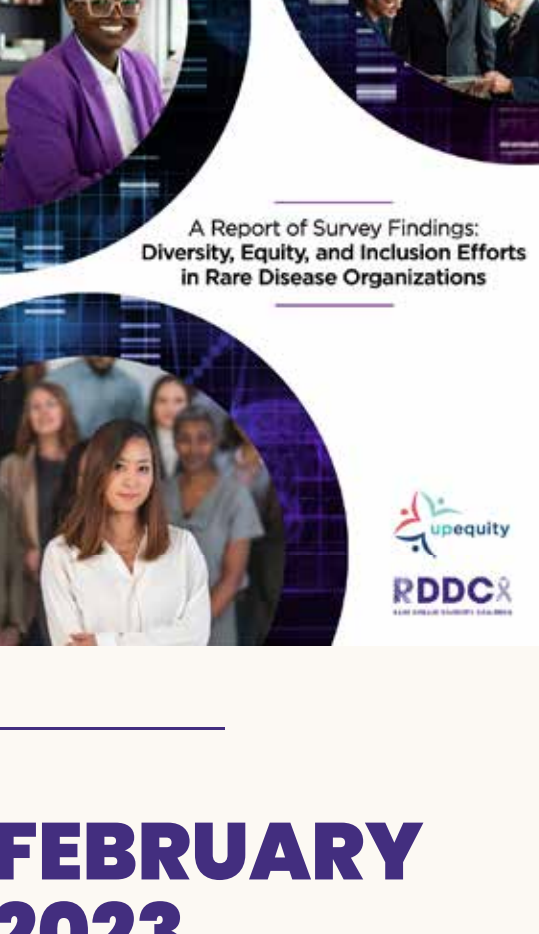
PROVIDED THE FDA

with draft guidance for decentralized clinical trials for drugs, biological products, and devices.

SEPTEMBER 2023

RARE HEALTH EQUITY FORUM

Partnered with Global Genes for a 2-day event with 10 speakers.



FEBRUARY 2023

GROUND-BREAKING SURVEY RESULTS

Diversity, Equity, and Inclusion Efforts in Rare Disease Organizations in partnership with Rare Rising.

DOWNLOAD NOW

FELLOWSHIP PROGRAM INAUGURAL 2 FELLOWS

Hosts include Gillette Children's Hospital in MN and the Alliance to Cure Cavernous Malformations.

WATCH EXIT PRESENTATION

FIRST ANNUAL RECEPTION WATCH HIGHLIGHTS



2024

FEBRUARY 2024

1ST ANNUAL RISE AWARDS IN CONJUNCTION WITH THE 2ND ANNUAL RARE DISEASE DAY RECEPTION

This event honored nine outstanding contributors to the rare disease community, including individuals, organizations, and legislative champions such as the FDA and Senator Cory Booker.

LAUNCHED THE DIVERSITY, EQUITY, AND INCLUSION (DEI) ORGANIZATIONAL READINESS QUIZ TAKE THE QUIZ

RELEASED THE EXECUTIVE SUMMARY OF GROUND-BREAKING NATIONAL SURVEY

Shared a preview of key insights into challenges faced by the rare disease community through a survey conducted by the RDDC Patient and Caregiver Workgroup in collaboration with NORD®

AVAILABLE HERE



AUGUST 2024

PUBLISHED GROUNDBREAKING RARE DISEASE NATIONAL REPORT

In partnership with National Organization for Rare Disorders (NORD®), RDDC published Inequities in the Rare Disease Community, a comprehensive report highlighting the barriers faced by patients and caregivers from medically underrepresented populations. The report focuses on challenges related to diagnosis, care, and support.

DOWNLOAD NOW



SEPTEMBER 2024

HEALTH EQUITY SERIES: A PROVIDER-FOCUSED INITIATIVE

RDDC partnered with Bluff City Medical Society to launch an initiative entitled Health Equity Webinar Series, an educational program focused on equipping healthcare providers with tools and strategies to deliver more equitable, culturally responsive care in rare disease diagnosis and treatment. This impactful series was approved for 1 AMA PRA Category 1 Credit, allowing participants to fulfill continuing medical education (CME) requirements while advancing their knowledge in health equity and rare disease care.

WATCH HERE

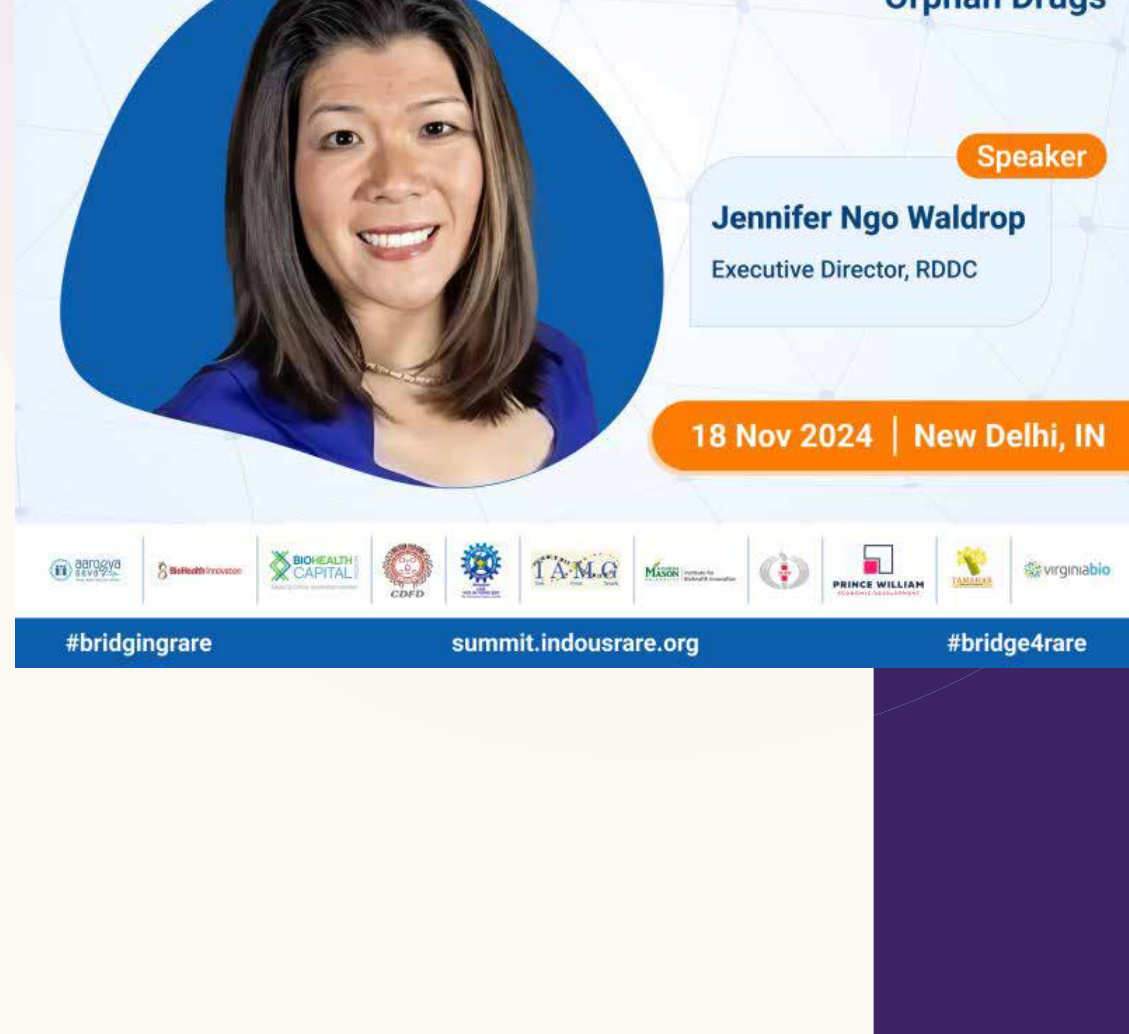


NOVEMBER 2024

RDDC GOES INTERNATIONAL

RDDC expanded its global reach by presenting at the Indo US Bridging Rare Summit in New Delhi, India, and the Clinical Trials in Rare Disease Europe Conference in Brussels, Belgium, sharing critical insights into the disparities faced by underrepresented populations around the world. Discussions focused on diagnostic barriers, the emotional toll on patients and caregivers, and healthcare system challenges—helping lived experiences to advance equity in rare disease care worldwide.

LEARN MORE



DECEMBER 2024

CENTERING PATIENTS IN ACTION: PNH HEALTH EQUITY GUIDELINES

RDDC released its first disease-specific health equity guideline focused on Paroxysmal Nocturnal Hemoglobinuria (PNH). Developed in collaboration with a patient-led steering committee, this white paper stands as a powerful example of how patient engagement drives equity in the rare disease space.

LEARN MORE



2025



FEBRUARY 2025

CONGRESSWOMAN MARILYN STRICKLAND INTRODUCES THE HEARD ACT

The Health Equity and Rare Disease (HEARD) Act aims to improve data collection, strengthen access to care, and expand support for underserved rare disease communities by addressing the systemic barriers that drive disparities in diagnosis, treatment, and research.

SUPPORT THIS BILL



APRIL 2025

PARTNERING WITH NMQF TO ELEVATE RARE DISEASE EQUITY

RDDC partnered with the National Minority Quality Forum (NMQF) to host a unique and innovative Rare Disease Track at their annual summit. Featuring four impactful sessions, the track brought together patients, caregivers, advocates, providers, and industry leaders to drive transformative conversations and actions around equity, access, and the lived experiences of underrepresented communities in rare disease care.

LINK TO PHOTO EVENT SUMMARY LINK

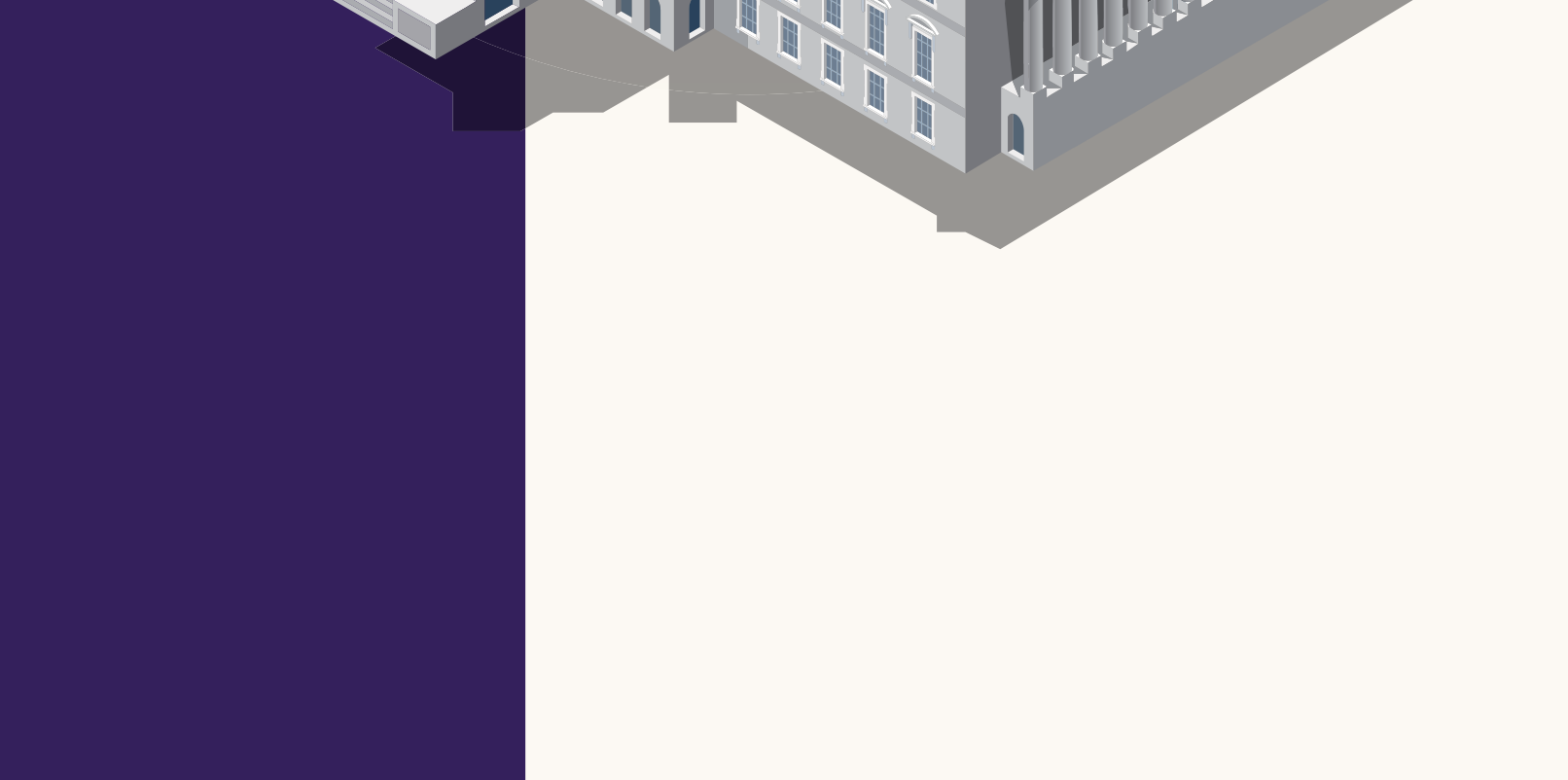


APRIL 2025

HOSTS INAUGURAL CAPITOL HILL BRIEFING

RDDC brought together policymakers, advocates, and healthcare leaders to spotlight disparities in rare disease care. The briefing emphasized the importance of elevating patient voices, underscoring the urgent need for equitable policies, patient-centered solutions, and increased representation of medically underserved communities in research, diagnosis, and treatment throughout the rare disease landscape.

WATCH NOW





THANK YOU

We wouldn't be where we are today without the support of the organizations and individuals listed below.

FOUNDING MEMBERS

Linda Goler Blount, MPH; Aletha Maybank, MD, MPH; Beverley Francis-Gibson, MA; Courtney Keplinger, MBA; Debbie Drell; Donna Cryer, JD; Elena Rios, MD, MSPH, MACP; Eric Dube, Ph.D.; Eve Dryer; Garfield Clunie, MD; Heidi Bjornson-Pennell; Julia Jenkins, MA; Juliet K. Choi, JD; Marshall Summar, MD; Millicent Gorham, MBA; Pamela Price, RN; Regina Hartfield; Saira Sultan, JD; Sika Dunyoh, Christian Rubio, MBA

As we mark this important milestone, the Rare Disease Diversity Coalition celebrates the meaningful progress we've made—together. Through collective action, we've raised awareness, amplified underrepresented voices, and championed more equitable care for individuals living with rare diseases. Our unwavering commitment to diversity, equity, and inclusion remains at the heart of everything we do. With each step forward, we continue to dismantle systemic barriers and reimagine a future where every patient—regardless of race, background, or diagnosis—is seen, heard, and fully supported.



JENIFER WALDROP

Executive Director, RDDC



RARE DISEASE DIVERSITY COALITION