



ADVANCING EQUITY IN RARE DISEASE CARE

FIRST OF ITS KIND

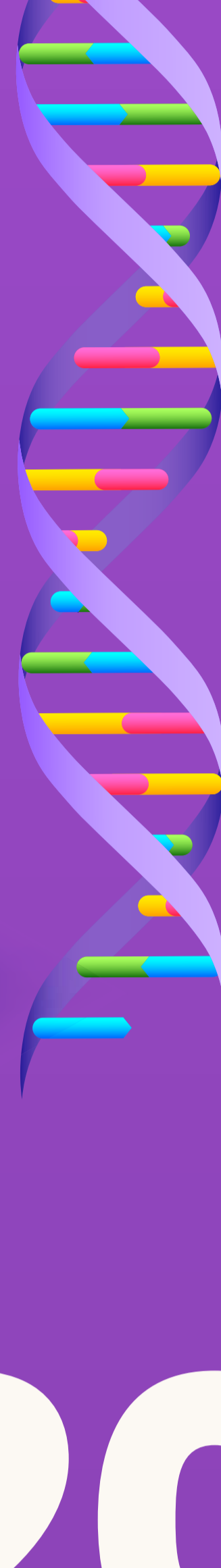
Since its formation under the visionary leadership of Linda Goler Blount and the **Black Women's Health Imperative** (BWHI), the **Rare Disease Diversity Coalition** (RDDC) has made monumental strides in addressing the extraordinary challenges faced by historically underrepresented rare disease patients.

Highlights - 90+ partners, 15 Publications, 14 speaking engagements, 9 rare disease health equity conference scholarships, 4 letters to state legislators, 4 rare disease fellows

PATHWAYS TO PROGRESS: RDDC'S 4 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.

2020



MAY 2020

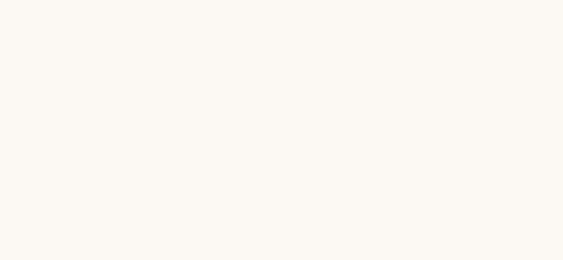
LAUNCH OF RDDC

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.



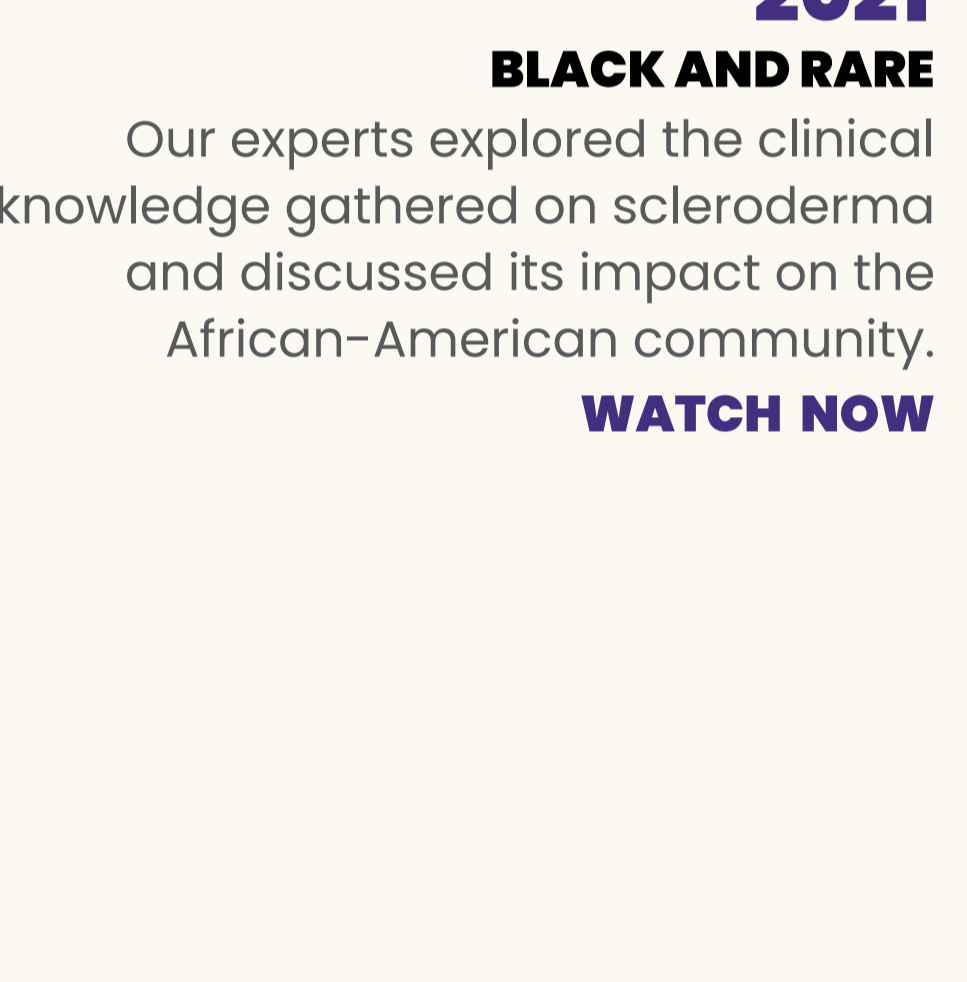
2021



APRIL 2021

IDENTIFIED 75 RECOMMENDATIONS AND 5 AREAS OF FOCUS

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

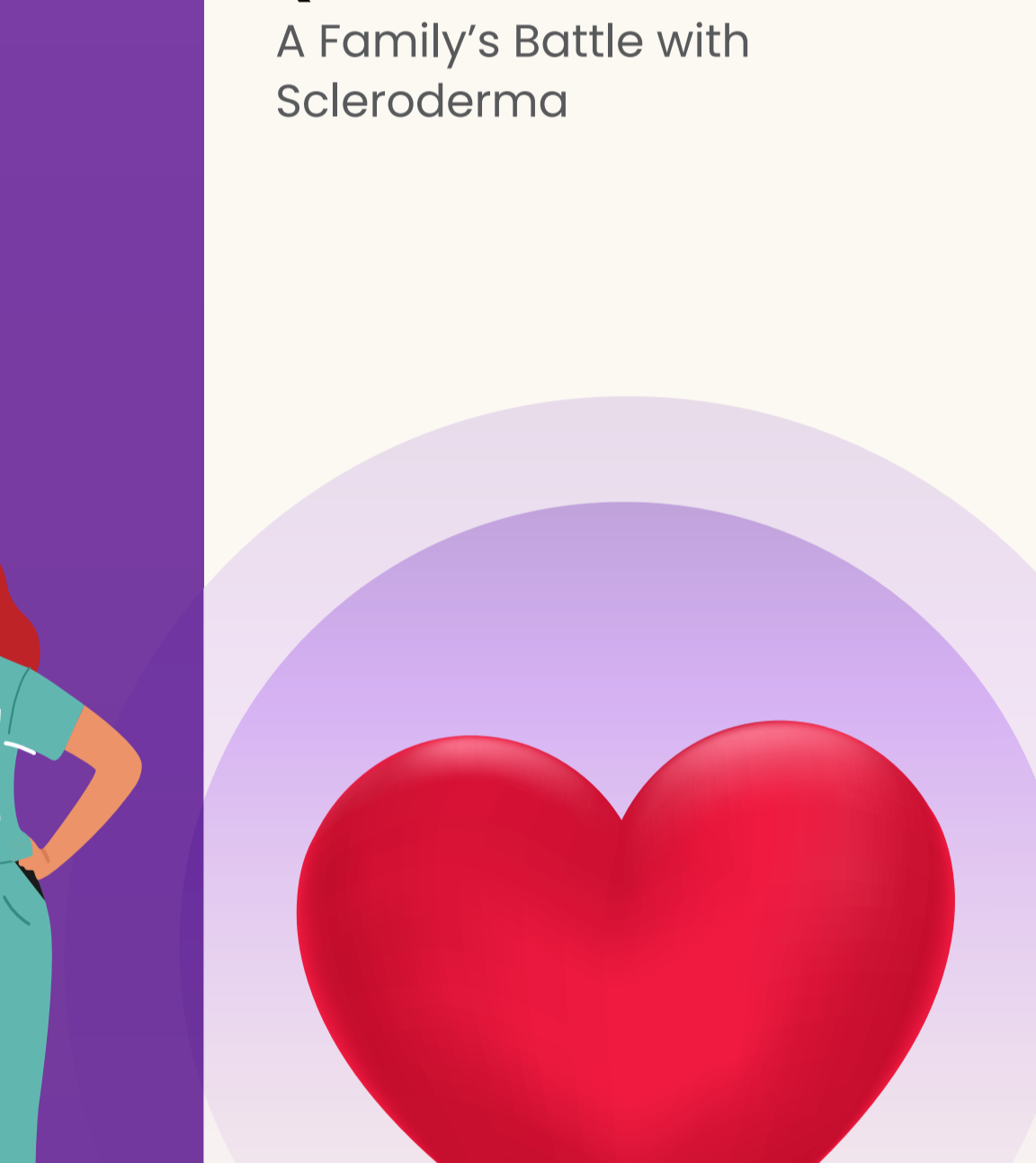


JUNE 2021

BLACK AND RARE

Our experts bring 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

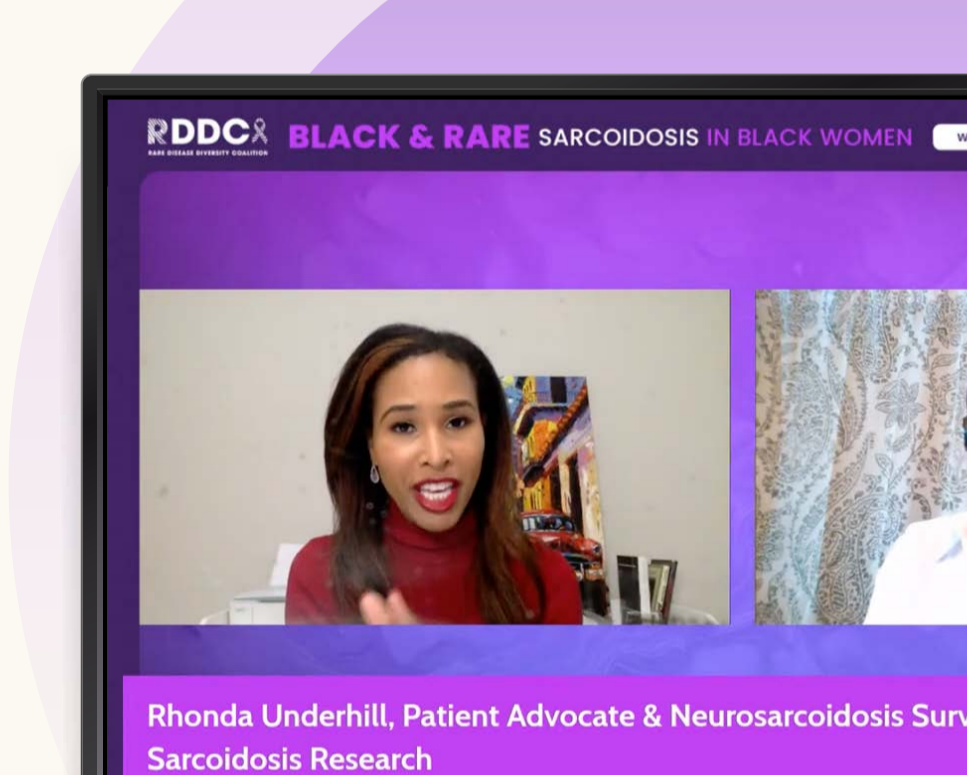
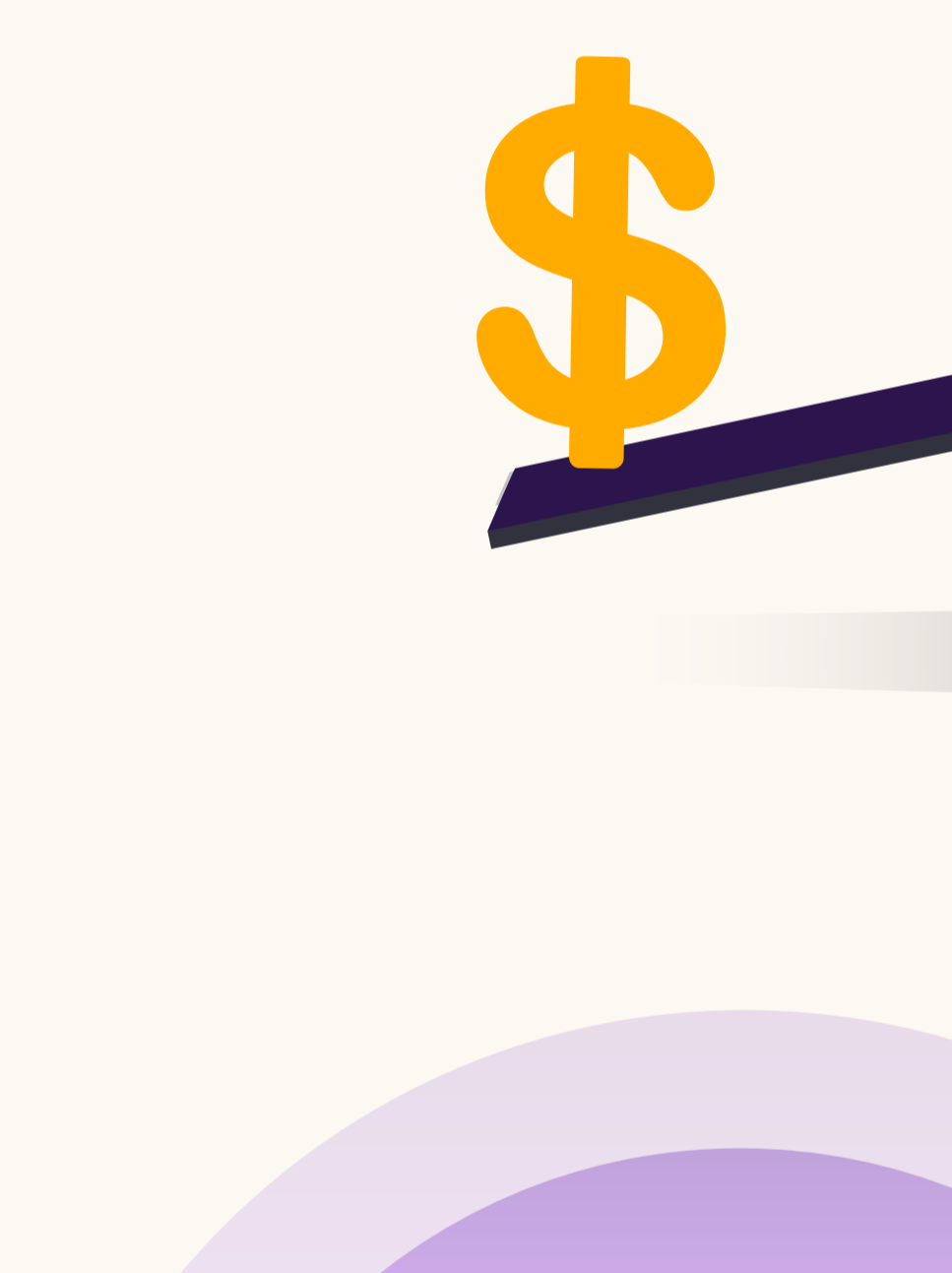


SEPTEMBER 2021

INAUGURAL RARE HEALTH EQUITY SUMMIT

Initiated a multi-year partnership with Global Genes

[WATCH HIGHLIGHTS](#)



NOVEMBER 2021

BLACK & RARE:

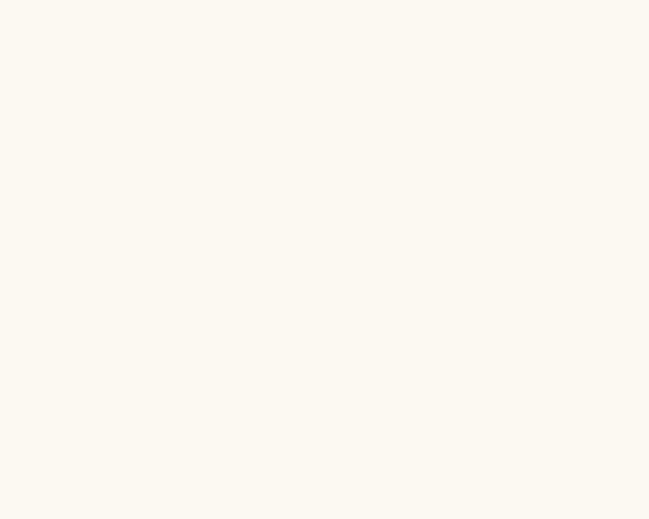
Sarcoidosis in Black Women Webinar

[WATCH NOW](#)

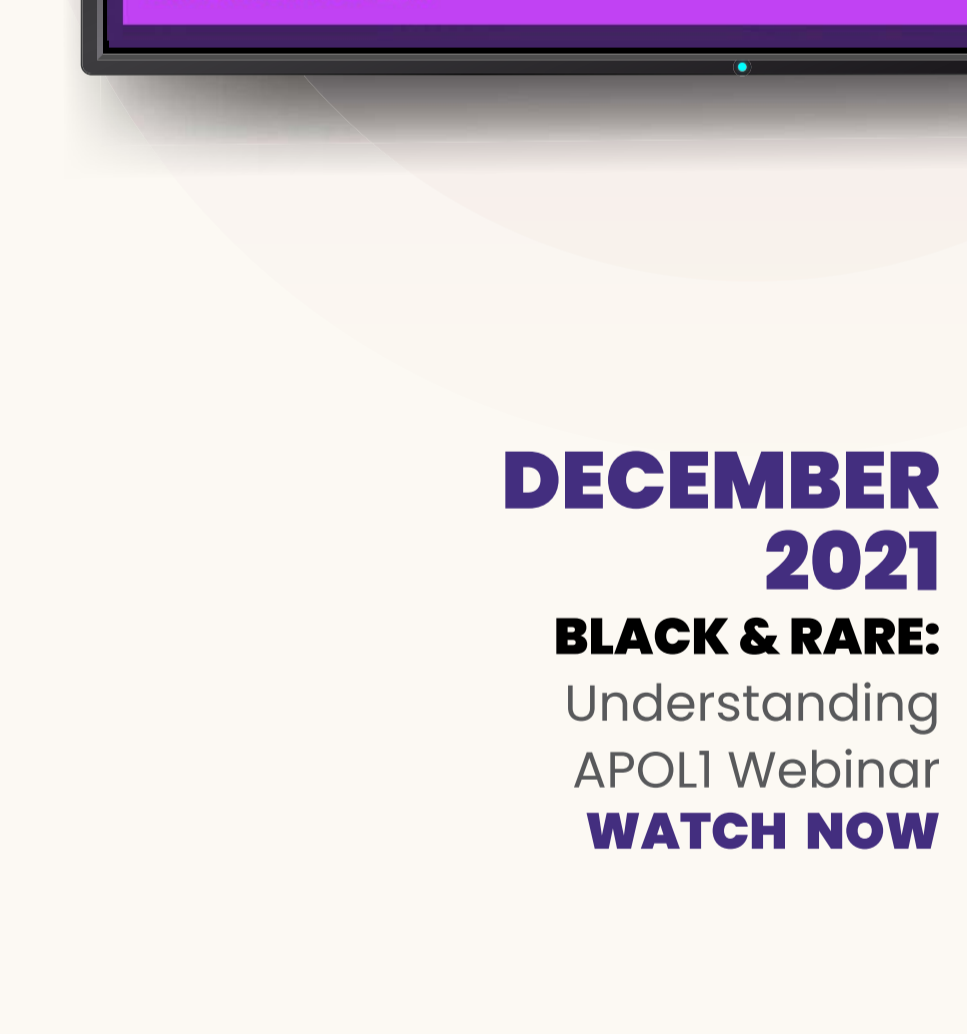
BLACK & RARE:

Thyroid Eye Disease Webinar

[WATCH NOW](#)



Mediated Kidney Disease



2022

FEBRUARY 2022

CONGRESSMAN G. K. BUTTERFIELD

Recognized in the congressional record for its mission, membership, and initiatives

RARE DISEASE DAY

Programming with Tischele Turner, Larenz Tate and his brothers Lahmard and LaRon

[WATCH NOW](#)



FEBRUARY 2022

RARE INSIGHT WEBINAR

Understanding gMG and the Barriers of Diagnosis Through a Lived Experience

[WATCH NOW](#)



JUNE 2022

RARE DISEASE DIVERSITY COALITION (RDDC)

Know Your Options: Careers in Clinical Trial Research Webinar

[WATCH NOW](#)

THE GLOBAL IMPACT OF SICKLE-CELL DISEASE

[WATCH NOW](#)



SEPT 2022

THE RARE HEALTH EQUITY SUMMIT

[WATCH HIGHLIGHTS](#)

OCTOBER 2022

LAUNCHED THE KNOW YOUR FAMILY HEALTH HISTORY CAMPAIGN WITH GLOBAL GENES

[LEARN MORE](#)

LAUNCHED GENECIPS CLINICAL TRIALS EDUCATION

Partnered with Children's National Medical Center

[WATCH NOW](#)



DECEMBER 2022

EFFECTING CHANGE:

Diversity & Cultural Competence in Research Webinar

[WATCH NOW](#)

2023



FEBRUARY 2023

GROUNDBREAKING SURVEY RESULTS

Diversity, Equity, and Inclusion Efforts in Rare Disease Organizations In partnership with Upequity

DOWNLOAD NOW

INCLUDED PROGRAM

GRADUATED 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



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



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

Insights into Barriers to Care in the Rare Disease Community in collaboration with NORD® Patient and the Caregiver workgroup



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 celebrate four years of the Rare Disease Diversity Coalition, we are reminded of the significant strides we've made in raising awareness and advocating for equitable care for those impacted by rare diseases. Our commitment to centering diversity and equity in every aspect of our work is unwavering. Together, we are breaking down barriers and creating a future where every patient, regardless of their background, receives the care and support they deserve."

Jenifer Waldrop, Executive Director, RDCC



JENIFER WALDROP

Executive Director, RDCC

