



**RARE DISEASE DIVERSITY COALITION**

**CELEBRATES  
RARE DISEASE DAY  
28 FEBRUARY 2023**

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**RARE DISEASE DAY  
TOOLKIT**

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# RARE DISEASE DIVERSITY COALITION Rare Disease Day Toolkit

The Rare Disease Diversity Coalition (RDDC) advocates for solutions to address the inequities that diverse and vulnerable communities face with respect to rare disease. On February 28th, Rare Disease Day, we join the globally-coordinated movement on rare diseases, to work towards equity in social opportunity, healthcare, and access to diagnosis and therapies for people living with a rare disease. **The key message for Rare Disease Day 2023 is #RiseForRare in support of RDDC and #ShareYourColours in honor of the global movement.**

The purpose of the Rare Disease Day Toolkit is to provide members with educational and engagement tools and resources which can be shared across owned platforms and networks.

## Rare Disease Day Reception

Please join the RDDC on the eve of Rare Disease Day as we unveil a report of survey findings developed in collaboration with Upequity:

### Diversity, Equity, and Inclusion Efforts in Rare Disease Organizations

Hear from the survey author and other esteemed speakers. Food and refreshments will be provided.



RSVP required (*space is limited*)

[Register for Rare Disease Day Reception >](#)



**IN SUPPORT OF RARE DISEASE DAY**

**RARE DISEASE DIVERSITY COALITION**

**RARE DISEASE DAY RECEPTION**

**FEBRUARY 27, 2023  
6:00 - 8:00 PM EST  
LONG VIEW GALLERY  
1234 9TH ST, NW  
WASHINGTON, DC 20001**

Please join the RDDC on the eve of Rare Disease Day as we unveil a report of survey findings developed in collaboration with Upequity:

**Diversity, Equity, and Inclusion Efforts  
in Rare Disease Organizations**

Hear from the survey author and other esteemed speakers. Food and refreshments will be provided.

**FEATURED SPEAKERS**

- Jennifer Waldrop, MS, Executive Director, Rare Disease Diversity Coalition
- Shonta Chambers, MSW, Executive Vice President, Health Equity and Community Engagement, American Red Cross
- Stephanie Marshall, Director, Rare Disease The Assistance Fund
- Tenasha Washington, PhD, MPH, MEd, Survey Author, University of Alabama at Birmingham
- Kevin Clayton, Senior Vice President, Head of Social Impact and Diversity, Cresswell Careers

**GUEST SPEAKER**

RSVP required (*space is limited*)  
<https://bit.ly/rarediseaseday23>

POWERED BY **BLACK WOMEN'S HEALTH MATTERS** and **upequity**

This is a widely attended event and complies with applicable House and Senate rules.

## Listen to the RDDC Podcasts



**RARE DISEASE DIVERSITY COALITION**

**BUILDING A HEALTHCARE PIPELINE FOR DIVERSE RARE COMMUNITIES**

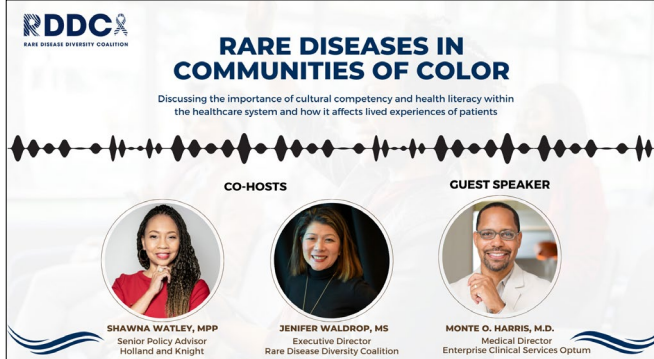
Discussing the importance of how HBCU creates a diverse healthcare workforce and opportunities for future contributions.

**HOST**

**PANELISTS**

- SHAWNA WATLEY, MPP**  
Senior Policy Advisor  
Holland and Knight
- DAVID CARLISLE, MD, PHD, MPH**  
President & CEO  
Charles R. Drew University
- JENIFER WALDROP, MS**  
Executive Director  
Rare Disease Diversity Coalition

**Building a Healthcare Pipeline for Diverse Rare Communities**  
<https://youtu.be/i175bjmODlg>



**RARE DISEASE DIVERSITY COALITION**

**RARE DISEASES IN COMMUNITIES OF COLOR**

Discussing the importance of cultural competency and health literacy within the healthcare system and how it affects lived experiences of patients

**CO-HOSTS**

**GUEST SPEAKER**

- SHAWNA WATLEY, MPP**  
Senior Policy Advisor  
Holland and Knight
- JENIFER WALDROP, MS**  
Executive Director  
Rare Disease Diversity Coalition
- MONTE O. HARRIS, M.D.**  
Medical Director  
Enterprise Clinical Services Optum

**Rare Diseases in Communities of Color**  
<https://youtu.be/qCDiHiJt-rQ>



## RDDC Rare Disease Day Logo

This logo features a custom colored RDDC logo to celebrate Rare Disease Day. It is available for light and dark backgrounds.

DOWNLOAD  
LOGOS



CELEBRATES RARE DISEASE DAY  
28 FEBRUARY 2023



## Call to Action #LightUpForRare

If you want to join in the effort to **#LightUpForRare** in honor of Rare Disease Day on February 28, you are encouraged to share your colors and shine a beacon from your home, office or your town. Your participation will raise awareness and show solidarity. Tag us on Instagram (@rareDiseaseDiversity,) Facebook (Rare Disease Diversity Coalition,) or LinkedIn (@RareDiseaseDiversityCoalition) so that we may also amplify your efforts and feature you in our Rare Disease Day activation. Download the [#LightUpForRare Toolkit](#).

## Global Rare Disease by the Numbers

There are some universal challenges faced by those living with a rare disease.

1. The lack of scientific knowledge and quality information on the disease often results in a delay in diagnosis;
2. Research needs to be international to ensure that experts, researchers and clinicians are connected; and
3. The need for appropriate quality health care engenders inequalities and difficulties in access to treatment and care. This often results in heavy social and financial burdens on patients.
4. Owing to the broad diversity of disorders and relatively common symptoms which can hide underlying rare diseases, initial misdiagnosis is common. In addition, symptoms differ not only from disease to disease, but also from patient to patient suffering from the same disease.
5. Research needs to be international to ensure that experts, researchers and clinicians are connected.

**Globally 300M+ people live with rare disease, approximately 3.5% - 5.9% of the population.**

**Of those affected 72% have genetic diseases.**

[Rare Disease Statistics >](#)

## RDDC Website

The Black Women’s Health Imperative launched the Rare Disease Diversity Coalition to address the extraordinary challenges faced by rare disease patients of color. The Coalition brings together rare disease experts, health, and diversity advocates, & industry leaders to identify and advocate for evidenced-based solutions to alleviate the disproportionate burden of rare diseases on communities of color. [www.rarediseasediversity.org](http://www.rarediseasediversity.org)

## Fact Sheet

Rare diseases are more common than they sound. It is estimated that **25-30 million Americans—nearly 1 in 10—have a rare disease. While individual rare diseases affect fewer than 200,000 people, there are over 7,000 different conditions.** Some rare diseases, like lupus, sarcoidosis, sickle cell anemia, & thalassemia disproportionately impact people of color. [Fact Sheet Document](#)

## Rare Disease Day Website

Rare Disease Day is the official international awareness-raising campaign for rare diseases which takes place on the last day of February each year. The main objective of the campaign is to raise awareness amongst the general public and decision-makers about rare diseases and their impact on patients’ lives. Rare Disease Day was launched by EURORDIS Rare Diseases Europe and its Council of National Alliances in 2008. [Rare Disease Day Website](#)

## Social Media

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## Follow RDDC on Social Media



Twitter:

<https://twitter.com/rarediseasediv1>



Instagram:

<https://www.instagram.com/rarediseasediversity/>



LinkedIn:

<https://www.linkedin.com/company/rare-disease-diversity-coalition/>

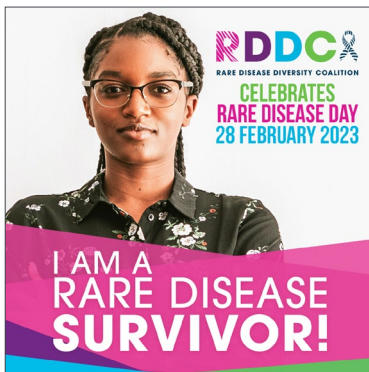
## Social Media

DOWNLOAD  
SOCIAL MEDIA



The RDDC is charting the path forward for equity in rare diseases as we celebrate **#RareDiseaseDay**.

To learn more about our plan of action, check out our website.  
[www.rarediseasediversity.org/action-plan](http://www.rarediseasediversity.org/action-plan)  
**#RiseForRare**



Join the RDDC on February 27th as we recognize **#RareDiseaseDay** and unveil a report of survey findings developed in collaboration with Upequity.  
<https://bit.ly/rarediseaseday23>  
**#RiseForRare**



If we are to make an impact, we must **organize, mobilize and fight** in order to reduce disparities in the rare disease community. This **#RareDiseaseDay**, pledge to get involved and join our coalition.

Go here to learn more:  
[www.rarediseasediversity.org/get-involved](http://www.rarediseasediversity.org/get-involved)  
**#RiseForRare**



**#RiseForRare** with the RDDC on **#RareDiseaseDay** by sharing your story of how you or a family member are rising above a diagnosis and navigating the complexity of the medical establishment. Be inspired by others that have shared their stories...  
[www.rarediseasediversity.org/our-mission](http://www.rarediseasediversity.org/our-mission)

