



RARE DISEASE DIVERSITY COALITION

**CELEBRATES
RARE DISEASE DAY
29 FEBRUARY 2024**

**RARE DISEASE DAY
TOOLKIT**

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 29th, 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 2024 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.



2024 Rare Disease Day Rise Awards Reception

FEBRUARY 28, 2024

Please join the RDDC on the eve of Rare Disease Day as we present the inaugural **RISE Awards** (Resilient, Impassioned, Strong, and Empowered) to a handful of rare disease health equity champions forwarding the mission and vision of RDDC. Food and refreshments will be provided.

[Register for Rise Awards Reception >](#)

Diversity, Equity, and Inclusion (DEI) Organizational Readiness Quiz

Are you DEI ready?

Meeting the needs of diverse populations is critical to serving the rare disease community. The Rare Disease Diversity Coalition (RDDC) is here to help you and your organization implement diversity, equity, and inclusion strategies and tactics to ensure that you are serving all patients, caregivers, and communities. Diversity extends beyond race and ethnicity to include age, gender, geographic location, sexual orientation, disability, etc.

Take the short anonymous quiz below to find out if your organization is "DEI Ready".



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



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Call to Action #LightUpForRare

If you want to join in the effort to **#LightUpForRare** in honor of Rare Disease Day on February 29th, 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 (@rarediseasediversitycoalition), X/Twitter (@rarediseasediv1), 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

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](#)

Watch GeneClips



GeneClips

[Informed Consent](#)

[Understanding Consent](#)

[Institutional Review Board and Your Protection](#)

[Difference Between Clinical and Research Genetic Testing](#)

Social Media

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RDDC Rare Disease Day Social Media 2024

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