RDDC™

RARE DISEASE DIVERSITY COALITION

CELEBRATES RARE DISEASE DAY 28 FEBRUARY 2025

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 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 2025 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.

History of Rare Disease Day

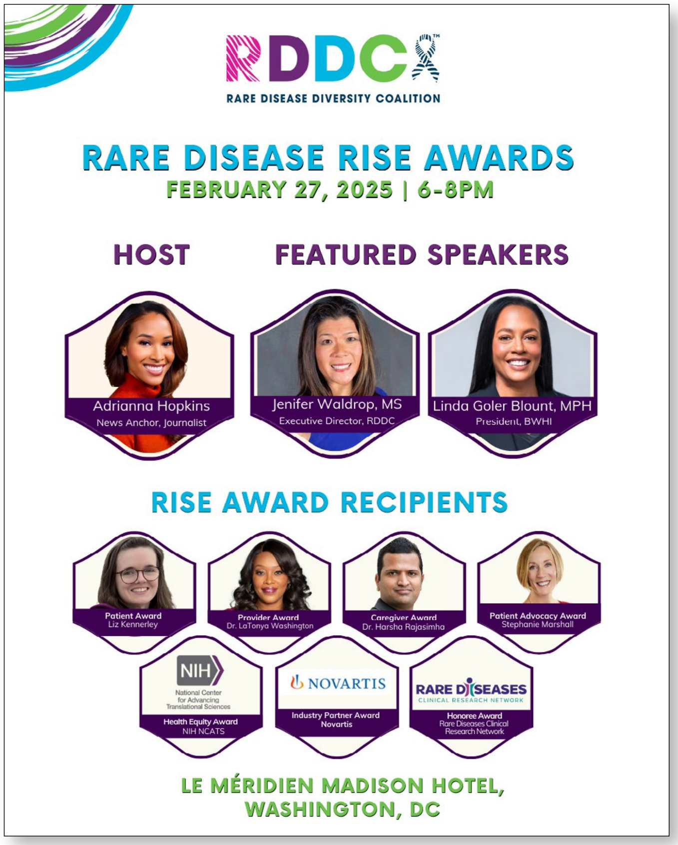
Rare Disease Day is the official international awareness-raising campaign for rare diseases which takes place on the last day of February each year. The main objective of the campaign is to raise awareness amongst the general public and decision-makers about rare diseases and their impact on patients'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

2025 Rare Disease Day Rise Awards Reception

FEBRUARY 27, 2025
6:00 - 8:00 PM
LE MÉRIDIEN MADISON HOTEL
1177 15TH ST NW
WASHINGTON, DC

Please join the RDDC for its third annual Eve of Rare Disease Day Reception. We are thrilled to share that Adrianna Hopkins, news anchor and journalist, will be hosting this year's second annual **RDDC RISE Awards** that recognizes rare disease health equity champions who have been Resilient, Impassioned, Strong, and Empowered towards the mission and vision of the RDDC. Food and refreshments will be provided.

Register for Rise Awards Reception >



RARE DISEASE DIVERSITY COALITION

RARE DISEASE RISE AWARDS

FEBRUARY 27, 2025 | 6-8PM

HOST

FEATURED SPEAKERS

Adrianna Hopkins
News Anchor, Journalist

Jenifer Waldrop, MS
Executive Director, RDDC

Linda Goler Blount, MPH
President, BWHI

RISE AWARD RECIPIENTS

Patient Award
Liz Kennerley

Provider Award
Dr. LaTonya Washington

Caregiver Award
Dr. Harsha Rajasimha

Patient Advocacy Award
Stephanie Marshall

Health Equity Award
NIH NCATS

Industry Partner Award
Novartis

Honoree Award
Rare Diseases Clinical Research Network

LE MÉRIDIEN MADISON HOTEL,
WASHINGTON, DC

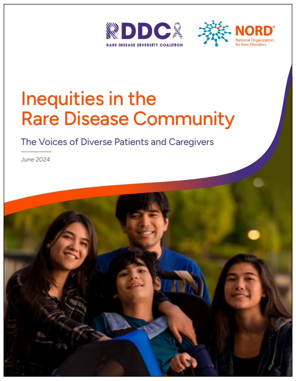
Inequities in the Rare Disease Community

The Rare Disease Diversity Coalition (RDDC) and the National Organization for Rare Disorders (NORD) partnered on a groundbreaking national survey aimed at illuminating the barriers faced by underrepresented patients with rare diseases. This pioneering research involved over 2,800 participants, revealing critical insights into the challenges of accessing necessary healthcare.

Background: There are more than 10,000 different rare diseases[1], of which 95% lack any FDA-approved treatment[2]. Rare diseases impact small patient populations of fewer than 200,000 people in the United States - sometimes far fewer. These smaller patient populations make it difficult to diagnose and access clinical care and treatments.

Key Findings:

- The study participants were primarily adults and almost 90% of individuals with a rare disease were aged 18 or older.
- 1,259 respondents (48%) met the definition of belonging to one or more underrepresented communities.
- 40% of respondents had not received genetic testing and 61% had not met with a genetic counselor. Of those who reported not receiving testing, 85% indicated the reason was because it was not offered.
- 85% of respondent caregivers stated that they often felt physically exhausted and 71% stated that their life satisfaction has suffered because of caregiving.



RDDC NORD

Inequities in the Rare Disease Community

The Voices of Diverse Patients and Caregivers

June 2024

(English)
Download The Report

RDDC NORD

Desigualdades en la comunidad que tiene enfermedades raras

Las voces de pacientes diversos y sus cuidadores

Junio de 2024

(Spanish)
Descargar El Informe

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.
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.

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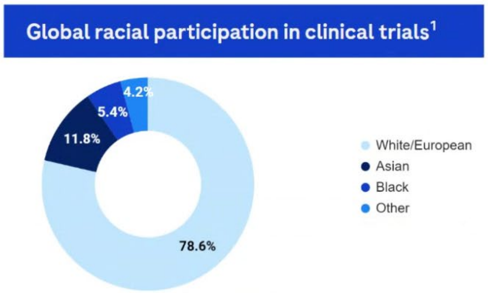
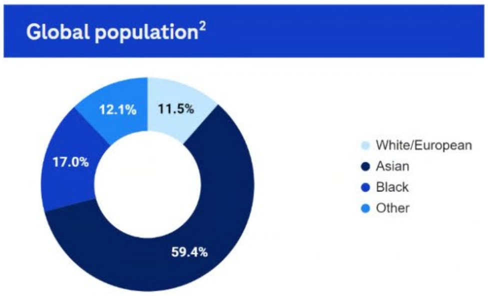
1. Rare-X. The power of being counted: A more accurate account of rare diseases and steps to getting counted. [Internet] 2022. [cited 2024 June 27]. Available from: https://rare-x.org/wp-content/uploads/2022/05/be-counted-052722-WEB.pdf
2. Fermaglich, LJ, Miller KL. A comprehensive study of the rare diseases and conditions targeted by orphan drug designations and approvals over the forty years of the Orphan Drug Act. Orphanet Journal of Rare Diseases (2023) 18:163.

The continued under-representation of racial and ethnic groups in clinical trials is of particular concern


Global racial participation in clinical trials[1]


Global population[2]

*~20% of newly **FDA-approved molecular entities** indicated **differences in exposure and/or response across racial or ethical groups** that resulted in **different prescribing recommendations** for specific populations*

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".

Virtual RDDC Appearances

[The Bonnell Foundation Podcast: Rare Disease Diversity, Jenifer Waldrop]

[C-Path Institute: New Findings on Inequities in Rare Diseases: How They Impact Research and Clinical Trials Processes]

[X-talks: Engaging Patient Communities: A Pathway to Clinical Trial Success]

Watch GeneClips

[Informed Consent]

[Understanding Consent]

[Institutional Review Board and Your Protection]

[Difference Between Clinical and Research Genetic Testing]

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https://www.instagram.com/rarediseasediversitycoalition/

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

RDDC Rare Disease Day Logo 2025

DOWNLOAD LOGOS

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

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RDDC Rare Disease Day Social Media 2025

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