CELEBRATES
RARE DISEASE DAY
28 FEBRUARY 2023

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 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 >

Listen to the RDDC Podcasts

- **Building a Healthcare Pipeline for Diverse Rare Communities**
  - [https://youtu.be/i175bjm0D1g](https://youtu.be/i175bjm0D1g)

- **Rare Diseases in Communities of Color**
  - [https://youtu.be/qCDHiJt-rQ](https://youtu.be/qCDHiJt-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.

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.
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

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/
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 #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 #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