



RARE DISEASE DIVERSITY COALITION

**CELEBRATES
RARE DISEASE DAY
28 FEBRUARY 2022**

**RARE DISEASE DAY
TOOLKIT**

RARE DISEASE DIVERSITY COALITION Rare Disease Day Toolkit

The Rare Disease Diversity Coalition (RDDDC) advocates for solutions to address the inequities that communities of color 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 2022 is #RiseForRare in support of RDDDC 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 Insight:
Understanding gMG and the Barriers of Diagnosis Through a Lived Experience

**FRIDAY
FEBRUARY 25, 2022
1 PM EST**

SPECIAL GUEST
Marvin Figueroa
Director, Intergovernmental and External Affairs (D&E)
U.S. Department of Health and Human Services

SPEAKERS
Raphael Gervais, MD, PhD
Neurologist
St. Elizabeth's Epilepsy Program Group
Wendi Huff
Vice President
Program & Clinical Care
Myasthenia Gravis Foundation of America
Adrijia Smith, JD, LL.M.
gMG Patient & Advocate

LIVE ON YouTube
RSVP at www.rareinstitute.org

POWERED BY **ALEXION**
Advancing Rare Disease

Rare Disease Day Webinars

Rare Insight: Understanding gMG and the Barriers of Diagnosis Through a Lived Experience

This webinar is produced in collaboration with Alexion Pharmaceuticals. Our panel of healthcare experts and rare disease patients will address important issues regarding generalized Myasthenia Gravis (gMG), including: signs and symptoms, barriers that can delay diagnosis, how to manage gMG, and strategies that can be used to raise awareness among our stakeholders.



Panel One: Knowledge is Power: A CONVERSATION WITH THE TATE BROTHERS AROUND RARE DISEASE

**MONDAY
FEBRUARY 28, 2022
12 PM EST**

HOSTED BY
Nischelle Turner
Co-Host
Entertainment Tonight

SPEAKERS
Lamar Tate
Actor
Tate Brothers Foundation
Larenz Tate
Actor
Tate Brothers Foundation
Laron Tate
Actor
Tate Brothers Foundation

Panel Two: How to Advocate for Your Health as a BIPOC Patient

**MONDAY
FEBRUARY 28, 2022
12 PM EST**

HOSTED BY
Richard Lui
Actor & Activist
NBC News/TEEN

SPEAKERS
Olga Lucia Torres, MD, MPH
Chief, Department of Community Medicine
Columbia University
Yves Duroseau, MD, MPH
Chief, Department of Community Medicine
Columbia University
Sachet Waller
Comedian for Rare with PGO

LIVE ON YouTube
RSVP at www.rareinstitute.org

POWERED BY **MMCA**

How to Advocate for Your Health as a BIPOC Patient

This two-part event will feature discussions surrounding rare disease from the perspective of clinicians, activists, and patients. In the first panel, we delve into the topic of sickle cell disease with Hollywood stars turned philanthropists; the Tate brothers. They will educate our audience importance of knowing one's family medical history and give us a glimpse at their own personal motivation for joining the fight against rare disease.

In our second panel, our key experts will explore why symptoms of rare diseases are often dismissed by physicians and how rare disease patients of color can best advocate for themselves, so they can reap the benefits of an early diagnosis.

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

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.



[CLICK LOGO TO DOWNLOAD](#)

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. Send your **#LightUpForRare** images to Berlyn Neumann (berlyn@theburnsbrothers.com) 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.

**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](#)

Social Media

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.

Follow RDDC on Social Media



Twitter:
<https://twitter.com/rarediseasediv1>



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

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

#RiseForRare



Join the RDDC on February 28th as we recognize #RareDiseaseDay through stories of survival, encouragement and triumph. Register here to attend:

www.rarediseasediversity.org/rsvp

#RiseForRare

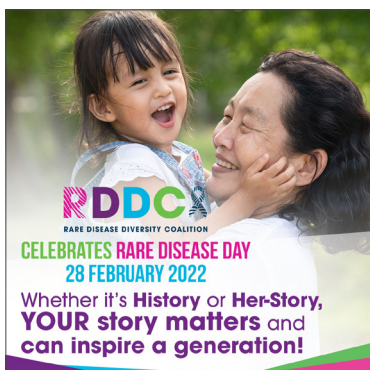


If we are to make an impact, we must organize, mobilize and fight in order to reduce disparities in the rare disease community. This #RareDiseaseDay, pledge to get involved and join our coalition.

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

CLICK IMAGE TO DOWNLOAD

