Rare Disease Diversity Coalition Toolkit (Minority Health Month)

The Rare Disease Diversity Coalition (RDDC) advocates for solutions to address the inequities that communities of color face with respect to rare disease. The purpose of the RDDC Toolkit is to provide members with educational and engagement tools and resources which they can share across their platforms and networks. Components of the toolkit include: press releases, a fact sheet, logos, RDDC website, resource materials, and social media content.

SOCIAL MEDIA

Social Media Sites:

- Instagram: 
  [instagram.com/blkwomenshealth](https://instagram.com/blkwomenshealth)

- Facebook: 
  [facebook.com/BlackWomensHealthImperative](https://facebook.com/BlackWomensHealthImperative)

- LinkedIn: 
  [linkedin.com/company/black-women%27s-health-imperative/](https://linkedin.com/company/black-women%27s-health-imperative/)

- Twitter: 
  [twitter.com/blkwomenshealth](https://twitter.com/blkwomenshealth)

- YouTube: 
  [youtube.com/c/BlackWomensHealthImperative](https://youtube.com/c/BlackWomensHealthImperative)

Social Media Graphics:

- [Graphics Folder Link](#)  
- [Link to Office of Minority Health](#)

Character Limits:

- **280 characters** – is the character limit on Twitter
- **2,200 characters** – is the character limit on Instagram
- **Facebook** and **LinkedIn** do not have character limits, but shorter posts tend to be more effective.
SAMPLE CAPTIONS

• Today, only 10% of Rare Diseases have a treatment or therapy approved by the FDA. The Rare Disease Diversity Coalition seeks to increase awareness of rare diseases so more life-saving treatments and therapies can be developed.

• On average, it takes 5 years and consultations with over 7 clinicians to reach an accurate diagnosis for a rare disease. For Black and other minority patients, the journey from onset of symptoms to diagnosis is even harder because of various disparities. This Minority Health Month, let’s begin to dismantle these inequities.

• Not knowing family medical history can severely delay a rare disease diagnosis. This vital information saves time and saves lives. Start having those conversations within your family today.

• Although Sickle Cell Disease disproportionately affects the Black community, Black children are among the least likely to be included in Sickle Cell-related clinical trials. Lack of participation ultimately boils down to ineffective treatments for the overlooked group. Health advocates are fighting every day to increase minority participation in clinical trials. Find out how you can help at rarediseasediversity.org

• The RDDC is committed to increasing minority participation in clinical trials. Go to rarediseasediversity.org to educate yourself, your family and caregivers about your rights as a rare disease patient.

• This Minority Health Month, take some time to celebrate yourself and empower your community. Listen to what your body is asking for and treat yourself! #NMHM2021

SAMPLE HASHTAGS

• #minorityhealthmonth #bwhi #blackwomen #healthcare #bwhirare #bwhiequity #bwhipolicy #riseforrare #raredisease #healthequity #policy #blackfamily #research #funding #blackwomenshealth #discrimination #healthandwellbeing #wellness #recovery #culture #protectblackwomen #protectblackwomenshealth #blkwomenshealth #rddc
Black Women's Health Imperative Announces New Rare Disease Diversity Coalition

Black Women's Health Imperative Announces The Rare Disease Diversity Coalition's “RISE For Rare” Campaign

The Black Report: Linda Goler Blount Interview at the 10-minute mark
https://vods3-prod.franklyinc.com/foxb/foxb_1406_137_54327_54328_24510869_15159007_1.mp4

Good Morning Washington: Black Women's Health Imperative launches rare disease coalition

Media Coverage
https://netorg6204496-my.sharepoint.com/:w:/g/personal/india_theburnsbrothers_com/EE2OmNUcT9tAuz0PgGChG0gBS4Ko5g0CXRpiZTual73Iiw?e=BVMnDs

BWII Tackles Uterine Fibroids, Rare Disease, Vaccine Distribution
Women's Health Advocates Voice Optimism About Biden Administration

Rare diseases are more common than they sound. More than 30 million Americans—nearly 1 in 10—have a rare disease. While individual rare diseases affect fewer than 200,000 people, there are about 7,000 different conditions. Some rare diseases, like lupus, sarcoidosis, sickle cell anemia, & thalassemia, disproportionately impact people of color.

Fact Sheet Document Link
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

This document outlines key talking points regarding the Rare Disease Diversity Coalition and rare diseases in minority populations. It is intended to guide communications with the newly formed coalition, the media, and other stakeholders about the issue. These messages can be used to inform talking points, presentations, media briefings, and other materials.

Talking Points Document Link

The Guardian: COVID-19 lack of diversity threatens to undermine vaccine trials, experts warn.

The Guardian Article Link