Rare Disease Diversity Coalition Toolkit

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.

PRESS RELEASES

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/Ee2OmNUcT9tAuz0PgGChG0gBS4Ko5g0CXRPiTual73liw?e=BVMnDs

BWHi 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

Social Media Sites:

- Instagram: instagram.com/blkwomenshealth
- Twitter: twitter.com/blkwomenshealth
- Facebook: facebook.com/BlackWomensHealthImperative
- LinkedIn: linkedin.com/company/black-women%27s-health-imperative/
- YouTube: youtube.com/c/BlackWomensHealthImperative

Social Media Graphics:

Graphics Folder Link

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.