

# Rare Disease Diversity Coalition Formed To End Racial Disparities in Rare Disease Diagnosis, Research and Treatment

*White House COVID Health Equity Task Force Chair Dr. Marcella Nunez-Smith, Alonzo Mourning and Rep. G. K. Butterfield Join on February 23rd for RDDC Launch*

WASHINGTON, DC, UNITED STATES, February 23, 2021 /EINPresswire.com/ -- Today, the Black Women's Health Imperative (BWHI) hosts the first public meeting of the [Rare Disease Diversity Coalition](#) (RDDC). RDDC seeks to address the pressing challenges faced

by marginalized populations and identify potential solutions. Led by BWHI and comprised of a diverse group of healthcare organizations, patient advocacy groups, and industry experts, the RDDC is poised to achieve action in the years to come by:



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Racial bias is entrenched in our healthcare system and deeply lowers the quality of care for patients of color. RDDC is working to educate, support and empower rare disease patients of color”

*Dr. Elena Rios, President & CEO National Hispanic Medical Association*

Reducing racial disparities in the rare disease community; identifying and advocating for evidence-based solutions to alleviate the disproportionate burden of rare diseases on communities of color; and Helping to achieve greater equality within the rare disease community

The RDDC was established at a pivotal time, as the United States continues to grapple with the impact of the COVID-19 pandemic, and the glaringly evident racial disparities that exist regarding infection rates, treatment and access to care.

The coalition's initial public meeting, will commemorate the upcoming international Rare Disease Day, and will tap into the collective expertise and experiences of various stakeholders to

raise awareness of the work. The meeting will take place virtually today, February 23, 2021, from 1:00 P.M.-3:00 P.M. EST. Moderated by Emmy Award-Winning anchor Lesli Foster, the meeting will feature participation by leading rare disease experts from top healthcare organizations including the American Medical Association, National Medical Association, the National Hispanic Medical Association, and the Asian & Pacific Islander American Health Forum. Remarks will also be offered by Congressman G. K. Butterfield (D-NC), Dr. Marcella Nunez-Smith, Chair of the White House Covid-19 Health Equity Task Force, and NBA champion Alonzo Mourning, who suffered from focal segmental glomerulosclerosis, a rare kidney disorder, and had a double kidney transplant in 2003.



RDDC has just released its 2021 Action Plan entitled “Charting the Path Forward for Equity in Rare Diseases”, that lays out priorities which the coalition will be undertaking to address the challenges that rare disease patients of color face. At [www.RareDiseaseDiversity.org](http://www.RareDiseaseDiversity.org), RDDC now has a website to share resources, promote patient stories, provide updates on their work, and otherwise engage with the rare disease community.

“RDDC has a huge mandate, but our work could not be more important. As COVID-19 sets its sights on people of color and patients living with rare and chronic diseases, the individuals who exist at the intersection of these two realities need dedicated advocacy and policy change now more than ever,” said Linda Goler Blount, BWHI President and CEO.

“Racial bias is entrenched in our healthcare system and deeply lowers the quality of care for patients of color. RDDC is working to educate, support and empower rare disease patients of color and their caregivers so they can be their own advocates,” said Dr. Elena Rios, President & CEO of the National Hispanic Medical Association.

“The work of RDDC is critical in order to address the health inequities that people of color with rare disease experience. RDDC is focused on raising awareness around these health inequalities, reducing racial disparities and advocating for evidence-based solutions,” said Juliet K. Choi, Chief Executive Officer of Asian & Pacific Islander American Health Forum.

RDDC Steering Committee Member - Organization - Position

Linda Goler Blount, MPH - Black Women's Health Imperative, President & CEO  
Lauren Lee - MA-NephCur, Executive Vice President, Stakeholder Engagement

Marshall Summar, MD - Children's National Hospital, Chief, Division of Genetics and Metabolism; Director, Rare Disease Institute; Board Chair of NORD

Juliet K. Choi, JD - Asian & Pacific Islander American Health Forum (APIAHF), Chief Executive Officer

Elena Rios, MD - National Hispanic Medical Association, President

Christian Rubio - Global Genes, Vice-President, Strategic Advancement

Brian Thompson, MD - Association of American Indian Physicians, Board of Directors Member

Aletha Maybank, MD, MPH - American Medical Association, Chief Health Equity Officer And Vice President

Garfield Clunie, MD - National Medical Association, Board of Trustees and Treasurer

Beverley Francis - Gibson, MA -Sickle Cell Disease Association of America President

Yousra Yusuf, MPH - South Asian Public Health Association President

Eric Dube, PhD -Travere Therapeutics CEO

Amy Hinojosa -MANA National, President and CEO

Eve Dryer - Travere Therapeutics, Executive Director, Patient Advocacy

Shonta Chambers, MSW - Patient Advocate Foundation Principal Investigator, SelfMade Health Network

Kimberly Haugstad, MBA - ACTion Partners President

Tamar Thompson, MS - Alexion Pharmaceuticals, Inc.,Vice President US Government Affairs & Policy

Rev. Anthony J. Brownlow, M.Div., MBA - Alfred Street Baptist Church Deputy Chief Operating Officer

Cassandra McCullough - MBA Association of Black Cardiologists, President & CEO

Pamela Price, RN - Balm In Gilead, Deputy Director

Ashley John, MS - Biotechnology Innovation Organization, Director, Patient Advocacy and Alliances

Tammy Boyd, MPH, JD - Black Women's Health Imperative, Chief Policy Officer & Counsel

John Burns - Burns Brothers, Managing Partner

Kim Smith-Whitley, MD- Children's Hospital of Philadelphia Clinical Director of Hematology and Director of the Comprehensive Sickle Cell Center

Laura Weidner, JD- Epilepsy Foundation of America, VP of Government Affairs and Advocacy

Julia Jenkins, MA- EveryLife Foundation, Executive Director

Donna Cryer, JD Global Liver Institute CEO

Rev. Matthew L. Watley, M.Div.- Kingdom Fellowship AME Church Senior Pastor

C. Grace Whiting, JD -National Alliance for Caregiving President and CEO

Millicent Gorham, MBA- National Black Nurses Association Executive Director

Lauren Lee, MA- NephCure, Executive Vice President, Stakeholder Engagement

Debbie Drell- NORD, Director of Membership Services

Saira Sultan, JD- PCORI Advisory Panel on Rare Disease Member

Courtney Pieczynski Keplinger, MBA- Vertex Pharmaceuticals Senior Director, Public Policy and Alliance Development (Pipeline)

About the Black Women's Health Imperative

The Black Women's Health Imperative is a national non-profit organization dedicated to advancing health equity and social justice for Black women across generations, through policy, advocacy, education, research, and leadership development. The organization identifies the most pressing health issues that affect the nation's 22 million Black women and girls and invests in the best of the best strategies that will accomplish its goals. For more information, please visit [www.bwhi.org](http://www.bwhi.org)

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To View The RDDC Meeting visit BWHI YouTube: <https://bit.ly/2ZLlvIV>

RDDC Website: <https://www.rarediseasediversity.org/events>

BWHI Social Media

Hashtag: #RiseForRare

Website: [www.RareDiseaseDiversity.org](http://www.RareDiseaseDiversity.org)

Instagram: <https://www.instagram.com/blkwomenshealth/> (@blkwomenshealth)

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

Facebook: <https://www.facebook.com/BlackWomensHealthImperative/>

YouTube: <https://www.youtube.com/c/BlackWomensHealthImperative>

LinkedIn: <https://www.linkedin.com/company/black-women%27s-health-imperative/>

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