117TH CONGRESS
2D SESSION

H. RES. 948

Recognizing the extraordinary challenges faced by patients of color with rare diseases and the need to identify and promote evidenced-based solutions to alleviate the disproportionate burden of rare diseases on these communities and supporting the recognition of the last day in February as ''Rare Disease Day''.

IN THE HOUSE OF REPRESENTATIVES

FEBRUARY 28, 2022

Mr. BUTTERFIELD submitted the following resolution; which was referred to the Committee on Energy and Commerce

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RESOLUTION

Recognizing the extraordinary challenges faced by patients of color with rare diseases and the need to identify and promote evidenced-based solutions to alleviate the disproportionate burden of rare diseases on these communities and supporting the recognition of the last day in February as ''Rare Disease Day''.

Whereas a rare disease is defined as a condition affecting fewer than 200,000 people in the United States, and over 7,000 individual diseases are represented in the rare disease community;

Whereas 25,000,000 to 30,000,000 individuals in the United States, nearly 1 in 10, suffer from a rare disease, and the majority of rare diseases start in childhood;

Whereas rare diseases disproportionately affect people of color, and rare disorders such as sarcoidosis, sickle cell anemia, Kawasaki disease, and some forms of lupus are known to affect minority populations at higher rates than the general population;

Whereas a long history of discrimination and socioeconomic inequality has led to a health crisis for people of color in the United States, and both social and physical determinants of health, which disproportionately negatively affect people of color, contribute to this crisis;

Whereas the rare disease community continues to face hurdles generally and people of color face additional hurdles in their quest for care, and flaws across the entire system often have deadly consequences and a compounding effect on the care that Black, Native American, Hispanic, Asian, and Pacific Islander individuals with rare diseases receive;

Whereas the lack of information and knowledge about rare diseases by most medical professionals can result in fewer diagnoses, and it takes an average of 6 years to get a diagnosis of a rare disease, and even longer for people of color;

Whereas delays in diagnosis and treatment can result in serious disease progression, and many patients are misdiagnosed multiple times before receiving an accurate diagnosis;

Whereas over 95 percent of rare diseases lack Food and Drug Administration-approved treatments, and people of color have less access to specialists and innovative therapies;

Whereas people of color make up more than 38 percent of the United States population, but people of color comprise only 16 percent of clinical research study participants;

Whereas rare disease specialists are limited in number and are geographically scattered, compounding the challenge of securing a timely diagnosis and treatment from knowledgeable professionals, and access to these specialists, advanced diagnostic tests, and to the limited therapies available can be prohibitively expensive for many families and geographically out of reach;

Whereas innovative health management strategies and patient-centered care can improve access to care and treatment for all individuals living with rare disease, including people of color;

Whereas improving the state of research and clinical trials to address pipeline and systemic issues that inhibit communities of color from participating in research and clinical trials, increasing the number of rare disease researchers and medical students that come from communities of color, and increasing the participation of communities of color in research and clinical trials is necessary to improve care for patients of color with rare diseases;

Whereas 80 percent of rare diseases are genetic, and some genetic disorders such as sickle cell anemia, thalassemia, and hATTR amyloidosis are more likely to occur among people who trace their ancestry to a particular geographic area;

Whereas 80 percent of the participants in genome-wide association studies are of European descent, which has devastating implications for diverse populations with rare disease;

Whereas proper understanding of the genomics of diverse ethnic populations is critical to increasing the speed of diagnosis for rare diseases;

Whereas, relative to the number of diseases and scope of need, very few therapies for rare diseases, known as ''orphan drugs'', are being developed due, in part, to the limited prevalence of populations with rare disease;

Whereas the genesis of many inequities in the United States health care system stem from a precursor disparity in research and availability of new treatments;

Whereas patients and caregivers of color are underrepresented in the rare disease advocacy groups that have been so important in educating and providing resources to those newly diagnosed with a rare disease;

Whereas groups like the Rare Disease Diversity Coalition, comprised of rare disease experts, health and diversity advocates, and industry leaders, are dedicated to developing and implementing strategies to reduce inequalities and are working to improve the quality and accessibility of care by identifying the most pressing problems, and most promising solutions, in areas that include—

(1) delays in the diagnosis and treatment of rare diseases;

(2) research and clinical studies;

(3) education and engagement of providers, patients, and nursing staff; and

(4) public policy; and

Whereas continued education of policymakers on the importance of addressing racial disparities is needed: Now, therefore, be it

Resolved, That the House of Representatives—

(1) recognizes the importance of decreasing rare diseases among all populations, especially among people of color;

(2) recognizes the unique factors that impact people of color, including racism and historic bias and its lingering disparate social, economic, and health effects on these communities;

(3) recognizes the necessity of spreading awareness and improving patient and provider education and engagement as a means to reduce delays in rare disease diagnosis and improving rare disease treatment;

(4) supports continued research and development of drugs for rare diseases to address unmet medical needs of patients with rare diseases; and

(5) supports the designation of ''Rare Disease Day''.

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