**South Carolina General Assembly**

125th Session, 2023-2024

**H. 4054**

**STATUS INFORMATION**

House Resolution

Sponsors: Reps. Herbkersman, Alexander, Anderson, Atkinson, Bailey, Ballentine, Bamberg, Bannister, Bauer, Beach, Bernstein, Blackwell, Bradley, Brewer, Brittain, Burns, Bustos, Calhoon, Carter, Caskey, Chapman, Chumley, Clyburn, Cobb-Hunter, Collins, Connell, B.J. Cox, B.L. Cox, Crawford, Cromer, Davis, Dillard, Elliott, Erickson, Felder, Forrest, Gagnon, Garvin, Gatch, Gibson, Gilliam, Gilliard, Guest, Guffey, Haddon, Hager, Hardee, Harris, Hart, Hartnett, Hayes, Henderson-Myers, Henegan, Hewitt, Hiott, Hixon, Hosey, Howard, Hyde, Jefferson, J.E. Johnson, J.L. Johnson, S. Jones, W. Jones, Jordan, Kilmartin, King, Kirby, Landing, Lawson, Leber, Ligon, Long, Lowe, Magnuson, May, McCabe, McCravy, McDaniel, McGinnis, Mitchell, J. Moore, T. Moore, A.M. Morgan, T.A. Morgan, Moss, Murphy, Neese, B. Newton, W. Newton, Nutt, O'Neal, Oremus, Ott, Pace, Pedalino, Pendarvis, Pope, Rivers, Robbins, Rose, Rutherford, Sandifer, Schuessler, Sessions, G.M. Smith, M.M. Smith, Stavrinakis, Taylor, Tedder, Thayer, Thigpen, Trantham, Vaughan, Weeks, West, Wetmore, Wheeler, White, Whitmire, Williams, Willis, Wooten and Yow

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Introduced in the House on March 1, 2023

Adopted by the House on March 1, 2023

Summary: Rare Disease Awareness Day in SC

**HISTORY OF LEGISLATIVE ACTIONS**

 Date Body Action Description with journal page number

 3/1/2023 House Introduced and adopted (House Journal‑page 41)

View the latest  [legislative information](https://www.scstatehouse.gov/billsearch.php?billnumbers=4054&session=125&summary=B)  at the website

**VERSIONS OF THIS BILL**

[03/01/2023](https://www.scstatehouse.gov/sess125_2023-2024/prever/4054_20230301.docx)

A house RESOLUTION

TO DECLARE FEBRUARY 28, 2023, “RARE DISEASE AWARENESS DAY” IN SOUTH CAROLINA AND TO ENCOURAGE ALL CITIZENS TO learn about, connect with, and champion people living with rare diseases.

Whereas, February 28, 2023, marks the fifteenth annual Rare Disease Day to show support for nearly three hundred million people worldwide living with a rare disease and to encourage participants to showcase their individual characteristics that make them unique. While each rare disease is indeed unique, there are commonalities that unite the rare disease community; and

Whereas, approximately seven thousand rare diseases and conditions are recognized in the United States according to the National Institutes of Health, each of which affects fewer than two hundred thousand Americans. Even though each of these diseases may affect small numbers of people, rare diseases as a group affect an estimated twenty-five to thirty million Americans; and

Whereas, many rare diseases are serious and debilitating conditions with significant impact on the lives of those affected, and individuals and families affected by rare diseases often experience challenges, such as delays in obtaining an accurate diagnosis, difficulty finding a healthcare provider with expertise in their condition, and a lack of access to treatments or ancillary services; and

Whereas, while more than six hundred twenty drugs and biologics have been approved for the treatment of over one thousand rare diseases according to the Food and Drug Administration (FDA), ninety percent of rare diseases do not have an FDA approved treatment; and

Whereas, the South Carolina Rare Disease Advisory Council was established by Act 94 of 2021 to provide research, diagnosis, treatment, and education supports for South Carolinians impacted by rare diseases. The South Carolina Rare Disease Advisory Council, along with the patient-advocacy community, supports the rare disease community by recognizing Rare Disease Day through awareness events. Now, therefore,

Be it resolved by the House of Representatives:

That the members of the South Carolina House of Representatives, by this resolution, declare February 28, 2023, “Rare Disease Awareness Day” in South Carolina and encourage all citizens to learn about, connect with, and champion people living with rare diseases.

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