

2014 SESSION

ENROLLED

HOUSE JOINT RESOLUTION NO. 108

Designating February 28, in 2014 and in each succeeding year, as Rare Disease Day in Virginia.

Agreed to by the House of Delegates, February 5, 2014

Agreed to by the Senate, March 4, 2014

WHEREAS, there are approximately 7,000 diseases and conditions considered rare, each affecting fewer than 200,000 Americans in the United States; and

WHEREAS, rare diseases affect an estimated total of 25 to 30 million Americans; 80 percent of rare diseases are genetic in origin, and it is estimated that about half of all rare diseases affect children; and

WHEREAS, rare diseases can become chronic, progressive, disabling, and life-threatening conditions, significantly impacting the lives of those affected; and

WHEREAS, relatively common symptoms can hide underlying rare diseases, leading to misdiagnosis and delayed treatment; individuals and families affected by rare diseases often face challenges, such as a sense of isolation and psychological burden, few treatment options, lack of support services, and problems related to accessing treatment; and

WHEREAS, while more than 300 orphan drugs and biologic medical products have been approved for the treatment of rare diseases by the Food and Drug Administration, millions of Americans with rare diseases still have no treatment specific to their disease; and

WHEREAS, some rare diseases, such as Lou Gehrig's disease and Huntington's disease, are relatively well known; however, many other rare diseases are not well known by the public, leaving patients and their families to bear a large share of the burden regarding critical issues, such as raising funds for research, education, and awareness outreach; and

WHEREAS, on the last day of the month of February, patients and their families, medical professionals, researchers, government officials, and companies developing treatments for rare diseases join together to focus attention on rare diseases as a public health issue; and

WHEREAS, it is important for Virginians and all Americans to support those affected by rare diseases and to promote annual health care visits to help ensure screening for rare diseases; now, therefore, be it

RESOLVED by the House of Delegates, the Senate concurring, That the General Assembly designate February 28, in 2014 and in each succeeding year, as Rare Disease Day in Virginia; and, be it

RESOLVED FURTHER, That the Clerk of the House of Delegates transmit a copy of this resolution to the National Organization for Rare Disorders, the sponsor for Rare Disease Day in the United States, so that members of the organization may be apprised of the sense of the General Assembly of Virginia in this matter; and, be it

RESOLVED FINALLY, That the Clerk of the House of Delegates post the designation of this day on the General Assembly's website.

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