

A CEREMONIAL RESOLUTION

25-20

IN THE COUNCIL OF THE DISTRICT OF COLUMBIA

February 7, 2023

To recognize the need to raise awareness for rare diseases, honor rare disease patients and families in the District, thank the National Organization for Rare Disorders and rare disease advocacy groups for their tireless work, and declare February 28, 2023 as Rare Disease Day in the District of Columbia.

WHEREAS, there are over 7,000 rare diseases that have currently been identified;

WHEREAS, a disease is considered a rare disease when fewer than 1 in 2,000 people are affected by it;

WHEREAS, 300 million people worldwide are currently living with a rare disease, or between 3.5 and 5.9% of the population. It is estimated that 25-30 million Americans are living with a rare disease;

WHEREAS, because rare disease research is underfunded, over 90% of rare diseases have no FDA-approved treatment available;

WHEREAS, the National Organization for Rare Disorders, or NORD, is the largest patient advocacy organization in the United States for individuals affected by rare diseases. NORD is comprised of over 330 nonprofit member organizations nationally.

WHEREAS, Rare Disease Day is celebrated annually on the last day of February and recognized in over 100 countries worldwide;

RESOLVED, BY THE COUNCIL OF THE DISTRICT OF COLUMBIA, That this resolution may be cited as the “Rare Disease Day Recognition Resolution of 2023”.

Sec. 2. The Council of the District of Columbia recognizes the need to raise awareness for rare diseases, honors rare disease patients and families in the District, thanks the National Organization for Rare Disorders and rare disease advocacy groups for their tireless work, and declares February 28, 2023 as Rare Disease Day in the District of Columbia.

Sec. 3. This resolution shall take effect immediately.