A Proclamation

Whereas, There are nearly 10,000 diseases and conditions considered rare (each affecting fewer than 200,000 Americans) in the United States, according to the National Institutes of Health (NIH); and

Whereas, While each of these diseases may affect small numbers of people, rare diseases as a group affect almost 30 million Americans; and

Whereas, Many rare diseases are serious and debilitating conditions that have a significant impact on the lives of those affected; and

Whereas, While more than 450 drugs and biologics have been approved for the treatment of rare diseases according to the Food and Drug Administration (FDA), millions of Americans still have rare diseases for which there is no approved treatment; and

Whereas, Individuals and families affected by rare diseases often experience problems such as diagnosis delay, difficulty finding a medical expert, and lack of access to treatments or ancillary services; and

Whereas, While the public is familiar with some rare diseases such as "Lou Gehrig's disease" and sympathetic to those affected, many patients and families affected by less widely known rare diseases bear a large share of the burden of finding research and raising public awareness to support the search for treatments; and

Whereas, Thousands of residents of Massachusetts are among those affected by rare diseases since nearly one in 10 Americans have rare diseases; and

Whereas, The Orphan Drug Act, championed in Congress by the late Massachusetts Senator Edward M. Kennedy and now celebrating 35 years in existence, has encouraged and promoted the discovery and development of biopharmaceuticals designed to treat and even cure rare diseases; and

Whereas, Many of the world leading academic institutions, academic medical centers, biotech companies and pharmaceutical companies conducting research and seeking cures for rare diseases are doing so in Massachusetts; and

Whereas, Patients, medical professionals, researchers, government officials, and companies developing orphan products to treat people with rare diseases, and others in the state of Massachusetts will participate in that observance,

Now, Therefore, I, Charles D. Baker, Governor of the Commonwealth of Massachusetts, do hereby proclaim February 28th, 2019, to be,

RARE DISEASE DAY

And urge all the citizens of the Commonwealth to take cognizance of this event and participate fittingly in its observance.

Given at the Executive Chamber in Boston, this twentieth day of February, in the year two thousand and nineteen, and of the Independence of the United States of America, the two hundred and forty-second.

BY HIS EXCELLENCY

[Signatures]

Charles D. Baker
Governor of the Commonwealth

Karyn E. Polito
Lt. Governor of the Commonwealth

William Francis Galvin
Secretary of the Commonwealth

God Save the Commonwealth of Massachusetts