

SENATE HEALTH, HUMAN SERVICES AND SENIOR
CITIZENS COMMITTEE

STATEMENT TO

SENATE JOINT RESOLUTION No. 23

STATE OF NEW JERSEY

DATED: FEBRUARY 15, 2018

The Senate Health, Human Services and Senior Citizens Committee reports favorably Senate Joint Resolution No. 23.

This joint resolution would declare the last day of February of each year as “Rare Disease Awareness Day” in New Jersey to raise public awareness of rare diseases, to encourage support for patients and families affected by rare diseases, and to promote further research into rare diseases and their treatment.

The National Institutes of Health defines “rare disease” as any disease or condition that affects fewer than 200,000 persons in the United States. There are almost 7,000 rare diseases, affecting nearly 30 million Americans and their families. Many rare diseases are serious and debilitating conditions that have significant impacts on the lives of those affected. Patients with rare diseases often face challenges such as overcoming a sense of isolation, obtaining accurate and timely diagnoses, finding effective treatment options, or accessing or being reimbursed for treatment.

Rare diseases include genetic diseases such as cystic fibrosis, muscular dystrophy, Huntington’s disease, and amyotrophic lateral sclerosis (ALS, also known as Lou Gehrig’s disease), as well as rare cancers, auto-immune diseases, congenital malformations, and toxic and infectious diseases. Although some rare diseases are relatively well known, many other rare diseases are unfamiliar to the public, and patients and their families must bear a large share of the burden of promoting awareness and raising funds to support needed research. Raising public awareness of rare diseases as an important public health issue will help patients with rare diseases and their families obtain more timely and accurate information about their conditions, reduce the isolation of patients and their families, and promote policies and practices that facilitate further research into rare diseases and their treatment.