**Municipalities Proclamation Toolkit**

**DATE**

Dear **<TITLE & NAME OF ELECTED OFFICIAL>**

I am writing to ask you to declare February 28, 2023, as **Rare Disease Day** in **<STATE>.** On that day, millions of people across the United States will join the National Organization for Rare Disorders (NORD) in observing this special awareness day.

As your constituent, I believe this is important because national statistics indicate that approximately 1 in 10 people in our state are living with a rare disease. According to the National Institutes of Health (NIH), there are an estimated 25-30 million Americans living with a rare disease.

 **<INSERT 2-3 BRIEF SENTENCES OF YOUR PERSONAL JOURNEY WITH RARE DISEASE AND WHY IT IS IMPORTANT TO YOU TO ADVOCATE>**

A disease is considered rare if it affects fewer than 200,000 Americans. There are approximately 7,000 known rare diseases. These conditions are often lifelong, and many are terminal. Moreover, approximately two-thirds of those affected with a rare disease are children.

This Rare Disease Day, special events and activities are planned for February 28th. Individuals and families affected by rare diseases will be sharing their stories on social media; in radio, TV, and newspaper interviews; and at community events here in **<STATE>** and across the U.S.

**<STATE>** has a strong history of support for its citizens’ causes. By declaring February 28, 2023, Rare Disease Day in **<STATE>** you will help us raise awareness within our community. I hope that you will join me and let our neighbors living with rare diseases know that while their diseases are rare, they are not alone.

With best regards,

**Your name**

**Your organization (if applicable)**

**Your address**

**Your email, Your phone**

**Proclamation**

**Whereas,** there are approximately 7,000 rare diseases and conditions (each affecting fewer than 200,000 Americans) in the United States, according to the National Institutes of Health (NIH);

**Whereas,** while each of these diseases may affect small numbers of people, rare diseases as a group affect an estimated 25-30 million Americans;

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

**Whereas,** while more than 620 drugs and biologics have been approved for the treatment of over 1,000 rare diseases according to the Food and Drug Administration (FDA), 90% of rare diseases do not have an FDA approved treatment;

**Whereas,** individuals and families affected by rare diseases often experience problems such as delays in obtaining an accurate diagnosis, difficulty finding a health care provider with expertise in their condition, and a lack of access to treatments or ancillary services;

**Whereas,** residents of **<STATE>** are among those affected by rare diseases because nearly one in ten Americans have rare diseases;

**Whereas,** the National Organization for Rare Disorders (NORD) is organizing a nationwide observance of Rare Disease Day on February 28, 2023;

**Therefore,** be it resolved that February 28, 2023, will be observed as Rare Disease Day in **<STATE>.**