



## RARE DISEASE DAY EDUCATIONAL TOOLKIT

In the United States, rare diseases are defined as medical conditions that **affect fewer than 200,000 people**. Though these diseases are rare by themselves, collectively more than **30 million Americans** – close to 1 in 10 – live with a diagnosis of one of the over 10,000 recognized rare diseases.

**Rare Disease Day is an observance held on the last day of February** to raise awareness for rare diseases and improve access to treatment and medical care. Since its establishment in 2008, it has been observed every year in more than 40 countries around the world.

The National Organization for Rare Disorders (**NORD®**) is proud to be the official **US partner for Rare Disease Day**. We work with our sister organization EURORDIS (Rare Diseases – Europe) and others all around the world to drive an international campaign that shines a light on rare diseases and advocates for health equity for all those living with a rare disease.

It is critical for America's youth and students to recognize the challenges that patients and families across the country are facing when it comes to rare diseases diagnosis, treatment, and care. **Many of the over 30 million Americans who have rare diseases are children or teenagers**, and they often encounter bullying and lack of peer acceptance. Rare Disease Day is an important time to reflect about the journey our friends, peers and/or fellow students go on, and what we can do as a community and as a country to **encourage greater acceptance, inclusion, and advocacy**.

**The included NORD resources are designed to engage and educate all levels – Elementary, Middle School, High School and University.** Utilize the following toolkit for access to Rare Disease Day curriculum, facts, school activities, and more.

EURORDIS, the global sponsor of Rare Disease Day and NORD's sister organization, has developed a [school toolkit](#) to help you start a conversation with teachers or young children around Rare Disease Day. Please download, adapt, and translate these resources as you see fit.

Take a picture of your educational efforts and activities to share with NORD or on social media with the hashtags **#ShowYourStripes** and **#RareDiseaseDay**.

As we say at NORD, **"Alone, we are rare. Together, we are strong.®"** Thank you for your interest in Rare Disease Day and for helping the rare disease community learn and grow.