

Join **NORD** in supporting

RARE DISEASE DAY 2017 U.S.



LIVING WITH A RARE DISEASE

On **February 28, 2017**, millions of people around the world will pay tribute to the many family members and friends whose daily lives are impacted and who are living day by day, hand in hand with rare disease patients. Please join the National Organization for Rare Disorders (**NORD**) - the official sponsor of Rare Disease Day in the United States - in supporting this important awareness effort on behalf of the 30 million Americans with rare diseases!

WHAT CAN YOU DO?

Events and activities will take place on or around February 28 at schools, hospitals, community centers, companies, 30 state capitol buildings and other locations across the U.S. You can read about these and find other suggested ways to get involved at **RareDiseaseDay.US**, the official national website for Rare Disease Day.

On the website, you can find:

- Information about how to promote awareness among your state legislators
- A sample proclamation and letter to send to your governor, asking that February 28 be declared Rare Disease Day in your state
- A press kit with materials you can download free and use to promote awareness in your community and among your social media networks
- A **"Handprints Across America"** gallery where you can share a photo and brief message of support
- A state-by-state listing of events
- Information on how to keep the momentum going year round
- ...and much more! Visit the website often to be sure you get the latest updates

HOW DID RARE DISEASE DAY GET STARTED?

NORD introduced Rare Disease Day in the U.S. in 2009 in partnership with EURORDIS (the European Organization for Rare Diseases). EURORDIS launched the first-ever Rare Disease Day in Europe in 2008.

Each year since then, Rare Disease Day has been growing and spreading to more countries around the world. In 2015, 80+ countries participated! On the global website, hosted by EURORDIS at RareDiseaseDay.org, you can see what others around the world are doing.

Want to know more?

Learn more and download our social media badges at RareDiseaseDay.us

Connect and Share

 [/RareDiseaseDayUS](https://www.facebook.com/RareDiseaseDayUS)

 [@RareDayUS](https://twitter.com/RareDayUS)





WHAT IS A RARE DISEASE?

IN THE UNITED STATES, ANY DISEASE AFFECTING FEWER THAN **200,000** PEOPLE IS CONSIDERED RARE.



DID YOU KNOW?

Nearly
30 MILLION AMERICANS
have a rare disease.



That's **1 in 10** Americans.

A map of the United States with a silhouette of a person standing on the right side. The text is overlaid on the map.

TWO THIRDS of Americans affected by a rare disease are **CHILDREN**.

It can take **several years** to receive an **accurate diagnosis**.

Rare diseases tend to be **serious** and **lifelong** or even **life threatening**.

Rare diseases are present across the broad spectrum of **medical conditions**.

All but a few types of cancers are rare. Other examples of rare diseases include PKU, ichthyosis, histiocytosis, Rett syndrome, and Huntington's disease.

Many rare diseases are **not being studied** by any medical researcher at this time.

Studying rare diseases often leads to **improved understanding** of more common diseases.

THERE ARE ABOUT 7,000 RARE DISEASES...

and less than 400 FDA-approved treatments.

WHAT IS NORD?

Since 1983, the **National Organization for Rare Disorders (NORD)** has been improving the lives of all people affected by rare diseases and those seeking to help them with programs of educations, advocacy, research and patient/family.

NORD was established by leaders of rare disease patient organizations who realized that **"Alone we are rare. Together we are strong."**

Learn more: rarediseases.org



NORD[®]
National Organization for Rare Disorders