



February 13, 2015

Office of Governor Nikki R. Haley
1205 Pendleton Street
Columbia, SC 29201

Dear Governor Haley:

On behalf of the 30 million Americans living with a rare disease, the National Organization for Rare Disorders (NORD) invites you to join us this February 28 in observing Rare Disease Day 2015. Held on the last day of February every year, Rare Disease Day is an important opportunity to raise awareness about urgent issues facing the rare disease community.

This Rare Disease Day, we need your help to:

- Educate your state about rare diseases. In the U.S., any disease affecting fewer than 200,000 Americans is considered rare. There are more than 7,000 such diseases that together impact nearly 30 million Americans. These diseases are medically diverse, but most are severe and many are life-threatening. Nearly two-thirds of rare diseases affect children.
- Prioritize health care policies that lead to better care for people with rare diseases in your state. Given the ongoing implementation of the Affordable Care Act, this is a critical time to raise awareness about important public health issues for people with rare diseases, such as newborn screening, support services for families coping with complex medical needs, and insurance practices that assure patient access to medically necessary therapies.
- Promote national solutions to the research challenge posed by rare diseases. Most people who have rare diseases have no treatment options; fewer than 400 of the 7,000 rare diseases have an FDA-approved treatment. As a country, we must foster an environment that promotes innovative medical research and product development.

If you are ready to join us, please consider showing your support for the rare disease community on social media, your website or any other communications platform. A press kit and other resources are available the official national Rare Disease Day website, <http://rarediseaseday.us/>.

In many states, Rare Disease Day events are being organized at local schools, hospitals, and even at State Capitol Buildings. Information about these events can also be on the official Rare Disease Day Website (click on your state on the Events page).

We look forward to you seeing you in action this Rare Disease Day, and please know that NORD is ready to aid your efforts to serve the rare disease community in any way we can.

Sincerely,

Peter L. Saltonstall, President and CEO