



February 15, 2014

The Honorable Martin O'Malley, Governor  
100 State Circle  
Annapolis, MD 21401

Dear Governor O'Malley,

On February 28th, millions of Americans will observe Rare Disease Day, an awareness event that takes place on the last day of February each year. Since approximately 1 in 10 of the residents of your state has a rare disease, we ask that you join us in observing this day and recognizing rare diseases as an important public health challenge.

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.

Many important decisions related to rare diseases are made at the state level, and the implementation of the *Affordable Care Act* has highlighted the increasingly important role of state policies and programs in assuring that the healthcare needs of the American public are addressed.

For that reason, we hope you will join NORD and its over 200 members this Rare Disease Day in recognizing the importance of public health issues such as newborn screening, support services for families coping with complex medical needs, an environment that promotes innovative medical research and product development, and insurance practices that assure patient access to medically necessary therapies.

Please consider showing your support for the rare disease community on social media, your website or any other communications platform. And please know that NORD stands ready to support your efforts to serve the rare disease community in any way we can.

In many states and local communities, Rare Disease Day events are being organized at hospitals and universities, in schools, and even at State Capitol Buildings. To find information about events being organized in your state, visit the official national Rare Disease Day website ([RareDiseaseDay.US](http://RareDiseaseDay.US)) and click on your state on the events page.

Sincerely,

Peter L. Saltonstall  
President and CEO