TESTIMONY IN RECOGNITION OF RARE DISEASE DAY

VT Senate Committee on Health and Welfare
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Presented by:
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Good morning, Chair Lyons and Members of the Committee,

My name is Carolyn Sheridan, and I serve as Associate Director of State Policy at the National Organization for Rare Disorders, or NORD. In this role, I have the privilege of coming before state governments across the country to advocate alongside, and on behalf of, patients, caregivers, and providers in the rare disease community to advance policies that strengthen care, access, and coordination.

I am grateful for the opportunity to join you in recognition of Rare Disease Day and to share more about the rare disease community I serve and the work of NORD.

Rare disease is defined under federal law within the Orphan Drug Act as a condition affecting fewer than 200,000 people in the United States.

While each condition is rare individually, collectively rare diseases are not.

- NIH statistics report 1 in 10 Americans lives with a rare disease
  - That represents more than 30 million people nationwide
- There are more than 10,000 known rare diseases
  - Fewer than 5% have an FDA-approved treatment

Many rare diseases are chronic, complex, genetic, and life-threatening or severely debilitating. Patients frequently experience prolonged diagnostic delays, difficulty accessing specialists, fragmented systems of care, and

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significantly higher medical costs, sometimes 3–5 times higher than non-rare conditions.

Rare disease is not confined to one policy area. It intersects with newborn screening, Medicaid, commercial insurance, mental health, disability services, aging services, and public health infrastructure.

Thousands of Vermonters are living with rare diseases today

NORD was founded in 1983 by patient advocates who successfully fought for passage of the Orphan Drug Act.

Today, NORD is a national nonprofit organization and serves as an umbrella federation of more than 350 disease-specific patient organizations. While those organizations focus on individual rare conditions, NORD represents the rare disease community as a whole.

Main pillars of our work include:

- Patient Assistance Program (PAP): NORD administers one of the largest rare disease patient assistance programs in the country. Through these programs, we provide direct financial support to patients to help cover the cost of medications, travel to see specialists, and other disease-related healthcare needs. These funds are restricted and flow directly to patients; they do not support NORD's operational expenses. Similarly, a portion of our revenue supports research grants awarded directly to investigators and does not fund NORD operations.

- Education and Information: Our education team maintains a growing, medically reviewed rare disease database that provides evidence-based information for patients, caregivers, and healthcare professionals.

- Clinical Excellence: Our clinical team supports a nationwide Rare Disease Centers of Excellence network — a healthcare facility recognition program designed to elevate best practices in rare disease diagnosis and multidisciplinary care.

- Public Policy: Consistent with our origins in the Orphan Drug Act, our policy team works at both the federal and state levels to support legislative and regulatory solutions that improve access, affordability, research infrastructure, and care coordination for rare disease patients.

NORD operates with a fully remote workforce, allowing us to support communities across the country while remaining responsive to state-specific needs.

Rare Disease Day is observed annually on the last day of February; chosen because February 29th is the rarest day of the year. The observance began in Europe in 2008 and became a global movement in 2009 when NORD mobilized U.S. patient advocacy organizations.

The purpose of Rare Disease Day is to:

- Raise awareness
- Improve access to diagnosis and treatment
- Promote equity and representation in policy
- Highlight the lived experiences of patients and caregivers

Across the country and around the world:

- Landmarks "Light Up for Rare" in pink, purple, green, and blue
- Patients and families share their stories
- Communities gather to educate policymakers and the public

You may also see the "Show Your Stripes" campaign. The zebra is the symbol of rare disease. In medical training, physicians are often told: *"When you hear hoofbeats, think horses, not zebras."* But for families living with rare diseases, they are the zebras.

Finally, Rare Disease Day provides a moment of visibility.

But what patients need is year-round structural attention.

As you may know, Vermont is currently considering H.46, which would establish a Rare Disease Advisory Council within the Department of Health

I look forward to returning later this session in April, joining our Vermont advocates in raising awareness of the bill.

It is our hope that by that time, H.46 will be up for discussion here in Committee so that you all might meet them and we can explore together how Vermont can continue strengthening its support for the rare disease community.

Thank you for providing me with this forum to share more about Rare Disease Day, NORD, and the rare community.

NORD stands ready to serve as a resource to this Committee at any time.

Respectfully submitted,

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RARE DISEASE DAY RESOURCES

For those interested in learning more or participating, RareDiseaseDay.us offers downloadable toolkits, social media graphics, official hashtags, and sample messaging. The site also provides "playbooks" tailored for homes, workplaces, schools, and communities, with practical ideas for hosting events, engaging partners, and raising awareness at the local level.