**FOR IMMEDIATE RELEASE**

**[Insert Town] Resident Explains Life with a Rare Disease and
Promotes Awareness for Rare Disease Day® on February 28**

**[CITY], [STATE]—[Month] [XX], 2019—**[Write out age]-year-old [insert town] resident [insert name] has a rare disease and will take part in a global movement to raise important awareness for **Rare Disease Day** on February 28.

[Include 3-5 sentences about your personal story. It will be helpful to share the name of your disease, symptoms, when you were diagnosed and how long it took to get your diagnosis, prognosis, if this runs in your family, and anything else that makes your story unique]

[Insert quote from patient/patient’s parent about why it is important for other people to know about rare diseases and what those living with a rare disease experience.]

According to the National Institutes of Health (NIH), a disease is rare if it affects less than 200,000 people in the United States. Approximately 25-30 million Americans have a rare disease—and nearly half of these patients are children. For the more than 7,000 known rare diseases, 90% are still without FDA-approved treatments.

[If applicable, include event information, such as: In honor of [insert patient name] and Rare Disease Day, [insert organization or person and relationship to patient] will host an event at [insert location], [insert address], at [insert time]. The event is open to the public. To register or purchase tickets in advance, visit [insert website] or call [insert phone number].]

Rare Disease Day is marked globally every year on the last day of February—the rarest date on the calendar—to underscore the nature of rare diseases and what patients face. The National Organization for Rare Disorders (NORD) is the sponsor of Rare Disease Day in the United States. This year, NORD launched the “Show Your Stripes” campaign; the campaign’s core message is to wear stripes on Rare Disease Day to raise awareness and show support for those living with rare diseases.

For more information about Rare Disease Day in the U.S. or “Show Your Stripes,” go to [www.rarediseaseday.us](http://www.rarediseaseday.us). For information about global activities, go to [www.rarediseaseday.org](http://www.rarediseaseday.org)). To search for information about rare diseases, visit NORD’s website, [www.rarediseases.org](http://www.rarediseases.org).

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**Media contacts:**

[If applicable, insert your organization’s media officer with contact information)

Laura Mullen, NORD, media@rarediseases.org