*The following is an article that you can use for a blog or an e-newsletter. Please note that this copy has been approved for use by an Institutional Review Board (IRB) and the wording cannot be changed. We ask that if you use the information below, please include the Living Rare Study logo that is provided in the toolkit.*

**Participate in the Living Rare Study: Share Your Experience, Help Shape the Future**

Living with [Disease Name] often brings challenges that affect every aspect of your life. Yet, despite the serious struggles that impact millions of those with rare diseases, due to a lack of data, rare diseases are not recognized as a public health issue. The National Organization for Rare Disorders (NORD) is addressing this information gap with the launch of the **Living Rare Study**, and we need you and everyone in the [Disease Name] community to participate. The more people with rare diseases and their caregivers who join Living Rare Study, the more powerful the data become - helping fuel improvements in policy, healthcare and resources for our rare disease community.

**What is the Living Rare Study?**

The Living Rare Study is the first large-scale, long-term research project in the United States dedicated to capturing the comprehensive experience of living with a rare disease. This study will collect data from thousands of people over several years, providing essential insights into the real-world challenges and needs of individuals and families faced with rare diseases - from accessing care and treatments to managing daily tasks, finances, and emotional well-being.

**Your Perspective Counts!**

For our community, the data from the Living Rare Study is more than just statistics—it’s the foundation for pushing forward critical healthcare changes. The more participants from our community who share their lived experiences, the stronger our case for support and change. This information will help us advocate more effectively for policies and resources that directly benefit those living with [Disease Name] and other rare diseases.

**Key Facts About the Living Rare Study**

* The Living Rare study is people living in the U.S. who are diagnosed with or suspect they have a rare disease, as well as their caregivers.
* The study’s survey questions explore healthcare access, daily life impacts, emotional, physical and social well-being, and financial challenges of living with a rare disease. It takes about 1 hour to complete, and you can do it at your own pace. The study is currently available in English and will be available in Spanish in 2025.
* You’ll get a reminder once a year to update your information.
* Your privacy is a priority—data is stored securely on NORD’s HIPAA-compliant platform, and responses are confidential.

**Join Today!**

By participating in the Living Rare Study, you are helping to shape the future of care for the [Disease Name] community and the estimated 30+ million Americans living with a rare disease. Sharing your experiences and how they evolve over time is vital in driving the change we need. For more information and to participate, visit [www.livingrarestudy.org](http://www.livingrarestudy.org).