*The following is an email that you can send to your patients and families. 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.*

**Subject**: Join the Living Rare Study and Help Drive Change for [the Rare Disease Community]

Dear [Advocacy Organization Name] Community,

You are already making a real difference for people living with [Disease Name] and we’re excited to share another opportunity to help support your ongoing mission to improve their lives. The National Organization for Rare Disorders (NORD) has launched the **Living Rare Study**, the first large-scale, long-term research project in the U.S. focused on the rare disease community as a whole. This study is designed to gather real-world data on the lived experiences and challenges faced by rare disease patients and caregivers.

This kind of information currently doesn’t exist across the broad spectrum of rare diseases – but is needed if we want to improve healthcare policies, access to care, treatments and expand resources and support for those with [Disease Name] and other rare diseases. The more people who participate in the Living Rare Study, the more powerful the data becomes – helping fuel changes that the rare disease community deserves.

Study Fast Facts:

* For Patients and Caregivers: The Living Rare study is open to people living in the U.S. who are diagnosed with or suspect they have a rare disease, as well as their caregivers.
* Comprehensive Research: NORD will collect patient experience data over several years to see how the impact of rare diseases changes over time.
* Holistic Approach: Covers several topics including healthcare access, daily life impacts, emotional and physical well-being, and financial challenges.
* Secure and Flexible: The survey is confidential, takes about 1 hour to complete, and can be done at your own pace. NORD will send you a reminder each year to update your information.
* **Start Here**: For more information and to join the Living Rare Study, visit [www.livingrarestudy.org](http://www.livingrarestudy.org).

Your experience matters. Together, we can drive progress and shape the future of care for the [Disease Name] community.

Thank you for your support and commitment to making a difference for those with rare diseases