



It's Time to Take Action! Your Rare Experience Matters!

The Living Rare Study is the first long-term U.S. study focused on the real-life experiences of individuals with rare diseases.

The Living Rare Study is instrumental to:

- **Show** the true impact of rare diseases to key healthcare leaders and policy decision makers
- **Inform** programming that improves well-being and quality of life
- **Advocate** for a better future for everyone affected by rare diseases

Key Facts About the Living Rare Study

- **Who Can Take the Survey:** Anyone living in the U.S. diagnosed with or suspected of having a rare disease, as well as their caregivers
- **What Topics Does it Cover:** Healthcare access, daily life impacts, emotional and physical well-being, financial challenges and more
- **How Much Time Does It Take:** About 1 hour to complete and it can be done at your own pace
- **How Your Data is Protected:** Your responses are kept confidential and the data you provide is stored securely on NORD's HIPAA-compliant platform.

Join Today!

For more information and to participate, visit www.livingrarestudy.org.