



**LIVING  
RARE** Study  
YOUR EXPERIENCE CAN SHAPE THE FUTURE



Individuals & Caregivers  
Impacted by Rare Disease...

**HELP CREATE A  
BETTER FUTURE!**

The Living Rare Study is the first large-scale, long-term study in the U.S. to quantify the evolving experiences of individuals and caregivers impacted by rare diseases.

Make a difference by putting real-life data behind your lived experience with rare disease by answering a series of survey questions each year. Your insights will help shape NORD programming, inform national and local policy decisions, and support increased access to resources that improve quality of life.

**YOUR VOICE CAN MAKE A DIFFERENCE.**  
Alone we are rare. Together we are strong.®

### WHAT TO KNOW:



Information shared is confidential and secure



Takes 45-60 minutes to complete



Save your progress; take at your own pace



Receive annual reminders to update your survey information



Tell others in your community about the Living Rare Study



Take the survey today: [LivingRareStudy.org](https://LivingRareStudy.org)