



NORD® LIVING RARE, LIVING STRONGER®

FREQUENTLY ASKED QUESTIONS

What is NORD Living Rare, Living Stronger®?

The Living Rare, Living Stronger (LRLS) annual patient and family forums are regional events that provide practical tools to people with rare diseases, their families, and caregivers so that they can live their best lives. The focus of these events is reducing or eliminating the burdens and challenges of living with rare diseases. LRLS strives to address the need for candid dialogue around difficult topics, tools for self-advocacy, and connection to much-needed resources. We offer educational and interactive sessions with perspectives from patients, caregivers, and health care professionals.

When and where is the event, and who can attend?

The first 2026 Living Rare, Living Stronger forum is headed to the southwest! Living Rare, Living Stronger Arizona will be held at Grand Canyon University, 2600 W Camelback Rd., Phoenix, AZ. Everyone is welcome to attend! Join us on Friday, May 8, for check-in, networking, and light refreshments starting at 10:00 a.m. and programming beginning at 10:30 a.m. Lunch will be provided.

We will also be bringing our Living Rare Forum to Colorado and Florida in 2026.

What does it cost to attend?

We are offering complimentary registration for patients living with a rare disease, their caregivers, and families! In addition, we will be offering complimentary registration for NORD patient organization members, students, and 501c3 non-profit/professional advocates.

The cost of registration for health care representatives is \$100.

The cost for bio/pharma company representatives is \$250.

Is the event in person or virtual?

The 2026 Living Rare, Living Stronger Arizona will be held in person in Phoenix, AZ. There will not be a virtual option.

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What is the dress code?

We want all participants to be comfortable, so jeans and sneakers are welcome at this event. Keep in mind that air-conditioned buildings can be chilly, so bring a sweater if you feel the cold easily.

What health & safety precautions are being taken?

Your support is critical to NORD's ability to convene our community so that all attendees may participate in engaging sessions and networking opportunities in a safe, comfortable environment. While we no longer require proof of vaccination or the wearing of masks, we encourage you to take necessary precautions to help us protect the community. We encourage you to wear a mask if it makes you feel more comfortable and/or if you are not feeling well.

What is the agenda for the program?

Visit the [website](#) often as the agenda is being developed and confirmed. It will be updated regularly.

Will continuing medical education (CME) or other continuing education credits be available?

At this time, our Living Rare, Living Stronger forums are not accredited for CME or professional continuing education credits. Though health care professionals are invited, all program content is designed for a patient and caregiver audience.

I have some Americans with Disabilities (ADA) Act needs. How can I be sure that they are met?

We will do our best to accommodate your ADA needs; however, advance notice is requested. Please indicate your needs on the registration form when you register.