

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, which provide people with rare diseases, their families, and caregivers with practical tools for living their best lives. The focus of the 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 2025 Living Rare, Living Stronger forum is headed to the southeast! Living Rare, Living Stronger in Georgia will be held at the Georgia Aquarium, located at 357 Luckie Street, NW Atlanta, GA 30313 (parking address). Everyone is welcome to attend! Join us on Friday, June 27 for check-in, networking, and breakfast starting at 8:00 a.m. and programming beginning at 9:00 a.m. Lunch will also be provided. The second 2025 Living Rare, Living Stronger forum will be held in Milwaukee, Wisconsin on November 8, 2025. Stay tuned for additional details about the Living Rare, Living Stronger in Wisconsin event!

What does it cost to attend?

We are offering complimentary registration for the 2025 Living Rare, Living Stronger in Georgia forum for all Patients living with a rare disease or disorder and Caregivers! In addition, this year we will also be offering complimentary registration for NORD patient organization members, students, and 501c3 non-profit/professional advocates.

The cost of registration for healthcare representatives will be \$100.

The cost for bio/pharma, company representatives, will be \$250.

Is the event in person or virtual?

The 2025 Living Rare, Living Stronger in Georgia forum will be held in person in Atlanta, Georgia. There will not be a virtual option.

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 <u>website</u> often as the agenda is currently being developed and confirmed. It will be updated regularly.

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

At this time, the 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.