

NORD® EVENTS FREQUENTLY ANSWERED QUESTIONS

What is the NORD Living Rare, Living Stronger® Patient and Family Forum?

The Living Rare Forum is an annual patient-focused conference providing people living with rare diseases and their families with practical tools for living their best lives with rare diseases. We offer sessions with perspectives from patients, caregivers, and healthcare professionals.

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

The 2024 Living Rare Forum is heading to the west coast! The event will be held at the Hilton Universal City Hotel, 555 Universal Hollywood Dr, Universal, CA 91608 and everyone is welcome to attend! Join us on Friday, June 7th for an evening Welcome Reception and Saturday June 8th starting at 9:00am for the program and networking opportunities.

What does it cost to attend?

Registration to The Living Rare Forum is available free of charge for patients and caregivers! Full event pricing details can be found at <u>livingrare.org</u>. Guests are responsible for their own travel and lodging; A block of rooms has been reserved for Friday, June 7 and Saturday, June 8 for our conference attendees at a discounted rate of \$259/night. Reservations should be made directly from the <u>travel & pricing page</u> of the website. We are also working with certain airlines to provide discounted airfare. You can find more information on the <u>travel & pricing page</u>.

Money is tight. Are there any opportunities for support to attend?

NORD offers assistance to help offset the costs of travel and lodging associated with attending the Forum. The window to apply for assistance will be open from January 9, 2024 – February 6, 2024. Additional information, including qualifications for travel and lodging assistance and the application form, can be found on the website. Please note that assistance will only be provided to first-time attendees.

Is the event in person or virtual?

The 2024 Living Rare Forum will be held in-person in Los Angeles, CA with a virtual option available for those who are unable to travel. You can register to participate in person or virtually at <u>livingrare.org</u>.

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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 hotel ballrooms 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 if you are not feeling well, please participate virtually so that you are not putting other community members at risk

What is the agenda for the program?

Visit the website often as the agenda is coming together. It will be updated regularly.

Will sessions be recorded?

Yes, sessions will be recorded. After the conclusion of the conference, content will be made available online, and participants will be notified via email with instructions on how to access. After the conclusion of the conference, recorded content will be made available online, and participants will be notified via email with instructions on how to access.

Will CME credits be available?

At this time, the Living Rare Forum is not accredited for CME or professional continuing education credits. Though healthcare professionals are invited, all program content is designed for a patient and caregiver audience.

I have some ADA 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 in the registration form when you register. If your needs impact your hotel room reservation, please notify the hotel when you make your reservation as there are a limited number of ADA rooms available.