



featuring the
Rare Impact
2019 Awards

HOUSTON ★ JUNE 21-23, 2019

Frequently Asked Questions

Who will I meet over the weekend?

NORD's Living Rare, Living Stronger Patient and Family Forum is open to all members of the rare disease community. You can expect to meet rare disease patients, caregivers, medical professionals and students, industry representatives and members of the government.

What is the schedule for the weekend?

A link to the agenda is available [here](#).

Will it be possible to switch tracks throughout the Forum on Saturday?

During registration, you will be asked to select which workshop during the Living Rare, Living Stronger Forum you will be attending. You will be able to select one track, however, we understand that you may want to switch workshops throughout the day for certain sessions. That is fine, with the exception of the medical professional track ("Caring for Rare"), which is reserved.

Can you tell me more about children's attendance at Living Rare, Living Stronger?

All children are invited to attend Living Rare, Living Stronger, however, the conference sessions are intended for adults. In an effort to avoid disrupting others attending the sessions, childcare services will be provided by licensed providers. The provider that has been chosen will have age appropriate activities available to keep the children safe and engaged all day. Children with special needs are encouraged to attend and the child care special needs director will contact parents prior to the conference to understand each child's needs. Snacks will be available in the center but breakfast and lunch for the children will be provided with the adults during designated meals times. Children ages 12 and under are \$69 and this includes their time in the childcare center.

Friday Night BBQ is family friendly, no childcare to be offered.

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Living Rare, Living Stronger Forum on Saturday—childcare is required for children under the age of 12.

Rare Impact Awards at Space Center Houston on Saturday evening—the staff at Space Center Houston will make the exhibits sensory friendly with advance notice. They will also facilitate child-friendly activities during the awards portion of the event. The children will eat with their parents.

Sunday Bon Voyage Brunch is family friendly, no childcare to be offered.

What is included in the Living Rare, Living Stronger registration price?

Friday Night BBQ—dinner and beverages

Saturday Conference—breakfast, morning break, lunch, conference materials, access to the Wellness Center

Shuttle service to and from Rare Impact Awards

Rare Impact Awards—private access to Space Center Houston, cocktail reception, formal plated seated dinner with beverages, Rare Impact Awards ceremony, dessert cocktail reception

Bon Voyage Brunch—food and beverage, materials as needed

What is not included in the registration price?

You are responsible for all of your own travel and lodging costs as well as parking, with the exception of free shuttle service being offered to/from the Rare Impact Awards.

Is a family rate available?

The rates offered for this conference are the best available, as they are already subsidized by NORD. Be sure to register before April 26 to lock in the lowest price!

I'm interested in learning more about scholarships to attend. Where can I find more information?

Applications close on April 1st. Please click [here](#) for more information.

Questions? Contact scholarships@rarediseases.org.

Will CME credits be available?

At this time, the Living Rare, Living Stronger Forum is not accredited for CME credits. We apologize for any inconvenience.

I have some ADA needs. How can I be sure that they are met?

We are happy to accommodate your ADA needs, however, advance notice is requested. Please email events@rarediseases.org or note your needs during the registration process.

Is there additional information about the hotel room block?

Please use this [link](#) to book your hotel room prior to May 28, 2019. The room rate is \$174.00 per room, per night plus taxes when you mention NORD's 2019 Living Rare, Living Stronger.

What amenities are available at the hotel?

A list of amenities at the Hilton Americas-Houston is available [here](#).

What can I expect in the Wellness Room?

A dedicated wellness room will be available to all forum attendees on Saturday from 8a.m. to 3p.m. Please stay tuned for more information on what services are being offered.

What will the weather be?

The weather in Houston in June can be hot and humid. The average high is 88 degrees and the average low is 74 degrees. All of the planned events are in climate controlled facilities, with the exception of moving between buildings and if you wish to visit [Independence Plaza at Space Center Houston](#).

Tell me more about extending my trip to Houston.

There is lots to do if you are visiting Houston for the conference and planning to extend your trip. Please visit www.visithoustontexas.com for more information. Hilton Americas-Houston may be able to extend our discounted group room block rate for a couple of days after the conference; be sure to ask about this when you are making your reservation. Please note that this is solely at the hotel's discretion and based upon availability.

I'd like to spend more time at Space Center Houston. Is a discount code available?

Space Center Houston is very cool and we understand that you probably won't have enough time to see all of the exhibits during the Rare Impact Awards event. You are in luck! Discount tickets are available through online booking only at www.spacecenter.org/grouppromo. Please use the promo code: NORD2019. The promotion will expire on July 31, 2019.

I need more information about transportation to/from Space Center Houston.

NORD will provide chartered busses to transport you to and from the Rare Impact Awards. The shuttles will depart the Hilton Americas-Houston for Space Center Houston at 6 pm on Saturday evening and return to Space Center Houston at approximately 10:30 pm. Anyone planning to use this service must make this request in your registration. There are a limited number of wheelchair accessible busses available for this, so please let us know during the registration process if you will need this accommodation. There is ample parking at Space Center Houston should you choose to drive on your own.

What is the attire for the weekend?

Attire for the Friday BBQ, Saturday Forum and Sunday Brunch is casual. The meeting rooms can be cool, so please bring a sweater. The attire for the Rare Impact Awards is black tie suggested.

Is there additional information about parking and getting to the hotel?

Please click [here](#) for directions and information on parking at the hotel.

