

2022 DIGITAL PROGRAM AGENDA



LIVING RARE, LIVING STRONGER[®] NORD[®] PATIENT AND FAMILY FORUM

JUNE 26, 2022
Cleveland, Ohio

Featuring the Rare Impact Awards[®]

livingrare.org | 475.289.6850

WHO SHOULD ATTEND?

- Patients and their families
- Students from medical, genetic counseling and related fields
- Patient organization leaders and advocates
- Industry, researchers and academics
- Healthcare professionals (clinicians, nurses, pharmacists and more)

KEY TOPICS:

- Building and Quarterbacking Your Care Team
- Beyond Coping: Resiliency While Rare
- Rare Breakthroughs: Hope Now and on the Horizon

HONOR STARS OF RARE DISEASE!

Join us as we celebrate our 2022 Rare Impact Award honorees on June 26, 2022! Honoring those individuals and organizations doing remarkable work on behalf of the rare disease community.

2022 LIVING RARE, LIVING STRONGER® AGENDA

As of: 6/1/2022

SUNDAY, JUNE 26

| | |
|---------|---|
| 9:00am | Registration, continental breakfast, and exhibitor booths open |
| 9:45am | Welcome to Cleveland! Peter L. Saltonstall - President and CEO, National Organization for Rare Disorders |
| 10:00am | Opening Keynote Address - Bitter to Better: My Invisible Rare Disease <i>This session will explore one person's perspective of living through a diagnostic odyssey and living with an invisible, rare disease. Sarah will share the positive and encouraging life lessons she has learned throughout her journey and how her experiences changed her outlook on life with a rare disease.</i> Sarah Tobias - Founder, Living Well with Sweatpants Sarah |
| 10:20am | Building and Quarterbacking Your Care Team <i>Identifying the right team of health care providers and getting specialists to communicate with one another for effective, comprehensive care can be a challenge. This session will explore strategies patients and caregivers can leverage to establish a knowledgeable care team and to connect them appropriately.</i> David Flannery, MD - Director of Telegenetics and Digital Genetics, Cleveland Clinic Jim Kuhn - Patient Advocate, Foundation for Sarcoidosis Research Ashley Santana, MSW LISW - Complex Care Social Work Care Manager, Cincinnati Children's Medical Center |
| 11:05am | Stretch break and music |
| 11:20am | Beyond Coping: Resiliency While Rare <i>A rare disease diagnosis is often accompanied by an array of physiological and psychological challenges for both patients and caregivers. In this session, rare disease patients and a licensed social worker who supports people with complex illnesses will share firsthand experiences, strategies for coping and skills to help people with rare conditions live meaningful and impactful lives.</i> Maggie Adair - Community Member, Hao-Fountain Syndrome Jodi Taub, LCSW - Private Practice Psychotherapist Kyle Underwood, MHA - Program Manager, Cleveland Clinic |
| 11:30am | Continuous lunch service begins |
| 12:05pm | Transitioning from Childhood to Adulthood with Rare Disease <i>As children with rare diseases approach adulthood, their families often worry about what the future may hold. This session will explore how families can work with their care teams to navigate this transition successfully.</i> Carrie Cuomo, DNP, CPNP - Director APRN/PA Services, Pediatric Institute and Pediatric Nurse Practitioner, Cleveland Clinic Kelleigh Gustafson - Pediatric Occupational Therapist; President, Kelleigh's Cause Jamie Jackson, PhD - Assistant Professor of Pediatrics & Psychology, Nationwide Children's Hospital |

2022 LIVING RARE, LIVING STRONGER® AGENDA

As of: 6/1/2022

SUNDAY, JUNE 26 (continued)

| | |
|---------|---|
| 12:55pm | Overcoming Ableism While Parenting with a Rare Disease <i>This session will discuss ableism as experienced by disabled parents with rare diseases from an individual, community and systemic perspective. The presenter will speak from both professional and personal experience.</i> Kara Ayers, PhD - Associate Professor, Associate Director, Cincinnati Children's Hospital Medical Center |
| 1:15pm | Rare Disease Onset and Diagnosis in Adulthood <i>Some patients with rare conditions do not receive an accurate diagnosis until they are adults, and some rare conditions do not manifest until adulthood. Speakers in this session will discuss the unique challenges of living with a rare diagnosis after years of uncertainty or relatively good health.</i> Daphne Jones - Community Member, POEMS Syndrome Pam Mace, RN - Executive Director, Fibromuscular Dysplasia Society of America Robert Myrick - Kentucky Volunteer State Ambassador, NORD Rare Action Network |
| 2:00pm | Stretch break and music; lunch service concludes |
| 2:15pm | Rare Breakthroughs: Hope Now and on the Horizon <i>Healthcare providers, researchers and patient organizations are working to improve the diagnosis, treatment, and care of rare disease patients. This session will highlight approaches to collaborative care that benefit rare disease patients and their families, currently available technologies and treatments, and possible advances in the future.</i> Kelly Lehman, MSN, CNP - Research Nurse Practitioner, Center for Gene Therapy/Mendell Lab, Abigail Wexner Research Institute, Nationwide Children's Hospital Edward Neilan, MD, PhD - Chief Medical and Scientific Officer, NORD Loren Peña, MD, PhD - Clinical Geneticist, Associate Professor, UC, Department of Pediatrics Cincinnati Children's Hospital Medical Center |
| 3:00pm | Closing Keynote Address - A Mother's Story: How My Son's Life Inspired Me to Make a Difference <i>There is nothing more powerful than being a parent who understands the complexities of life with a rare disease and is focused and driven. Patricia will share about the struggles and triumphs of the diagnostic odyssey and highlight the importance of the role of the caregiver.</i> Patricia Burks - Director of Clinical Trial Affairs, Cystic Fibrosis Foundation |
| 6:30pm | Shuttle service to Rock & Roll Hall of Fame for Rare Impact Awards begins |
| 7:00pm | Rare Impact Awards begin |
| 10:00pm | Return shuttle service begins |
| 11:00pm | Rare Impact Awards conclude |

FREQUENTLY ASKED QUESTIONS

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

Living Rare Living Stronger (LRLS) 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 the healthcare professional community.

When is the event and who can attend?

LRLS 2022 will be held Sunday, June 26, 2022 at the Intercontinental Cleveland Conference Center in Cleveland, Ohio and everyone is welcome to attend!

What does it cost to attend?

The Living Rare Forum is free of charge for patients and caregivers! The full event pricing details can be found on the event [website](#). There are also several options available to apply for lodging or travel assistance.

Money is tight, are there any opportunities for support in order to attend?

NORD offers many scholarships to offset the costs of travel and lodging associated with attending LRLS. Please be sure to fill out a sponsorship application – Visit the [website](#) for more information and application deadlines.

Is the event in-person or virtual?

2022 Living Rare, Living Stronger will mark the first time in more than two years that NORD is hosting an in-person event. 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. NORD is committed to the health and safety of all attendees. NORD is abiding by local, state and national guidelines, which are updated as needed, so please visit our [website](#) for the latest information on the Forum's health and safety protocols. A virtual option is now available for those who are unable to join us in-person.

I want to attend but can't visit Cleveland; are sessions recorded?

Sessions will be available via a live-stream virtual option and are also being recorded. Registration will include on-demand access for all content after the program concludes. All participants will be notified by email with details how to view.

Will CME credits be available?

At this time, the Living Rare, Living Stronger Forum is not accredited for CME credits. Though health care professionals are invited, all program content is for a patient and caregiver audience.

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. If your needs impact your hotel room reservation, please be sure to notify the hotel at the time that you make your reservation as there are a limited number of ADA rooms available.

Tell me more about extending my trip to Cleveland.

There are lots of activities to do if you are visiting Cleveland for the conference and planning to extend your trip. Please visit www.thisiscleveland.com for more information.



HEALTH AND SAFETY GUIDELINES

Attendees should be aware that while the Living Rare Forum and Rare Impact Awards are taking place we will make every effort to reduce the risk of COVID-19 transmission, it is possible that attendees will come in contact with people in airports, on public transportation, and in other public areas with individuals who could potentially carry the virus, which is why NORD strongly encourages those, who are able, to be fully vaccinated for their own safety, as well as the safety of others ahead of attending the event.

At this time, **ALL attendees of the Living Rare Forum featuring the Rare Impact Awards must be fully vaccinated against COVID-19 prior to arrival in Cleveland or have received a negative PCR or antigen (rapid) COVID-19 test within 24 hours of picking up their registration badge at the conference venue.** If you cannot or choose not to comply with NORD's health and safety protocols, we hope to provide you with other ways to enjoy the program at a later date.



Proof of vaccination or a negative COVID-19 test may be submitted via an email with a link to a secure, HIPAA-compliant verification site ahead of the conference. More information on that will follow your registration for the event. NORD staff will have no access to the information submitted via the verification site; NORD will only receive notification that the attendee has or has not completed the verification process.

***** COVID VERIFICATION MUST BE SUBMITTED PRIOR TO ARRIVAL, NO COVID DOCUMENTS WILL BE ACCEPTED ONSITE*****

In addition, it is mandatory for ALL persons within the meeting and event spaces to wear a face mask covering BOTH their nose and mouth at all times while they are indoors. This includes attendees and all accompanying persons above the age of two (2).

By attending Living Rare, Living Stronger featuring the Rare Impact Awards 2022 in person, you are confirming that you:

- Are fully vaccinated or have received a negative PCR or antigen COVID-19 test within 24 hours of picking up your registration badge at the conference venue;
- Are not experiencing any symptoms of COVID-19 identified by the Centers for Disease Control and Prevention at CDC.gov;
- Are not under any self-quarantine orders; and
- Acknowledge and will abide by all applicable regulations and health and safety protocols.

If you will not be fully vaccinated by the time of Living Rare Forum and Rare Impact Awards and are registered for the LIVE meeting, you may cancel your registration and watch the recorded content when it becomes available shortly after the program.

OFFICIAL NATIONAL / STATE GUIDELINES

NORD will comply with all state and federal requirements, and NORD reserves the right to modify or eliminate the option of negative testing at any time should federal or state mandates change.

Fully vaccinated means that either three weeks have passed since receiving the second dose of an FDA- or WHO-authorized double-dose COVID-19 vaccine or that three weeks have passed since receiving the one dose of an FDA- or WHO-authorized single-dose COVID-19 vaccine.

Booster shots are strongly recommended by the CDC if it has been more than five (5) months after completing the primary COVID-19 vaccination series.

NORD is committed to maintaining the health and safety of all Living Rare Forum and Rare Impact Awards attendees, and the latest Centers for Disease Control and Prevention and World Health Organization guidelines as well as industry best practices will be followed as closely as possible. NORD will be coordinating with the venue spaces, the InterContinental Cleveland Conference Center and Rock Hall, to actively monitor local conditions, risk factors, and any applicable laws, regulations, and guidance. Because these factors are frequently changing, this page will continue to be updated as new guidance is released.

ADDITIONAL HEALTH & SAFETY GUIDELINES

No Onsite Registration

- Due to requirements to submit proof of vaccination and negative test results PRIOR to ARRIVAL at Living Rare, Living Stronger featuring the Rare Impact Awards 2022, there will be NO ONSITE REGISTRATION for Living Rare, Living Stronger featuring the Rare Impact Awards 2022.
- Please plan to register well in advance, to allow for the HIPAA-compliant COVID screening and approval process to be completed prior to your arrival.

Testing

- NORD is unable to provide resources for on-site COVID-19 testing on arrival, or prior to departure for attendees. Please complete your COVID-19 screening test prior to arrival at the Living Rare Forum and Rare Impact Awards. NORD is not able to provide COVID-19 testing, you are required to make your own arrangements.
- For information on testing locations, contact your state or local government, or your health care provider to determine the options available for testing in your area.

Venue and Hotel

- The InterContinental Cleveland Conference Center will be monitoring and following the CDC, WHO, and local health department's guidelines. Please visit the [InterContinental Cleveland Conference Center website](#) and view [IHG Hotels & Resorts Way of Clean](#) website for detailed information about the steps IHG is taking to protect meeting attendees.
- Meeting room set up will be coordinated and planned with appropriate social distancing. Please note that social distancing guidelines may continue to change and evolve based on direction from the CDC and the state of Ohio. The InterContinental Cleveland Conference Center and NORD are committed to full compliance and safe social distancing in all meeting areas.

Masks

- At this time, the wearing of protective masks is required of all attendees, faculty, and staff, regardless of whether or not it is required by law at the time of the meeting.
- Masks must be worn properly (covering both mouth and nose) at all times indoors, except as noted below. The indoor mask requirement applies to all indoor areas of the InterContinental Cleveland Conference Center and Rock Hall. Masks are not required outdoors.

- Masks may be removed briefly in the following situations:
 - > When actively eating or drinking.*
 - > When speaking at the lectern (as the distance between the speaker and audience will be greater than six feet). Speakers should put their masks back on when not actively presenting.
 - > When being photographed or interviewed on camera by registered media or staff.*
 - > *PLEASE NOTE: Attendees should maintain a distance of at least six (6) feet from others when unmasked in the above-mentioned situations if possible. Food and beverages will only be permitted in designated areas.
- While surgical masks and additional cloth masks will be provided on site, attendees are welcome to bring their own mask of choice. Surgical, N95, and KN95 masks are strongly preferred. Gaiters, bandanas, and masks with exhalation valves will not be accepted.
- Attendees who are not properly masked will be refused admittance to sessions and events and may have their badges revoked. [Please see CDC guidance on masking.](#)

Hand Sanitizer

- Hand sanitizing stations will be available in multiple locations throughout the InterContinental Cleveland Conference Center for all attendees to use.

Health and Safety in Ohio

- Please refer to [Ohio's COVID-19 webpage](#) or the most up-to-date information about requirements for traveling to Ohio.

Individual Accountability

- *By choosing to attend any in-person component of an event, you agree to comply with all safety protocols NORD or the venues may have in place. This is to ensure everyone is cared for and met in a way in which respects their health needs to the extent possible.*
- *To preserve a safe environment, should any participant fail to comply with such protocols, NORD may take immediate steps including, but not limited to, denial of entrance to the event or removal of the non-compliant participant from the event space. Unless otherwise determined by NORD in its sole discretion, any participant who is denied access/entrance to or removed from an event based on this policy will not be eligible for a refund of any registration fees paid for access/entrance to or participation in the event.*

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By attending this event, I am granting the National Organization for Rare Disorders (NORD) permission to use my image(s) and quotes from the program, whether in a screenshot, photo, or as a recording, for purposes including but not limited to enduring archived recording and/or transcript of event, marketing and/or promotions.

To book your sponsorship or for more information, please contact:
Julie Manus, Associate Director of Business Development, at 617.249.7304
or jmanus@rarediseases.org.

For more information regarding the event, sponsorship opportunities
or ticket purchases, visit: livingrare.org.

Questions? Email events@rarediseases.org or call 475.289.6850.

