2020 DIGITAL PROGRAM
Saturday, July 18: DAY 1
12:00pm- 1:00pm Opening Plenary: Stories of Hope When Doctors & Patients Collaborate
Jennelle Stephenson - Patient
John F. Tisdale, MD - Senior Investigator, Molecular and Clinical Hematology Branch, NIH
1:00pm- 1:15pm Break

Three tracks to choose for each workshop:

**WORKSHOP ONE 11:15am-2:00pm**

**LIVING RARE Beginners & Newly Diagnosed**
Diagnosing Rare: Terminology, Tests & Genetic Testing
Speakers: Kelly Kurrett - Patient
Marvin Naitzak, MD, PhD - Physician, Cleveland Clinic

**LIVING STRONGER Advanced Patients & Caregivers**
Long-term Survivor Panel: Tips, Tricks & Life Hacks for Living Your Best, Rare Life!
Speakers: Maria Belknap - Illinois Volunteer State Ambassador, Rare Action Network, NORD
Nicholas Meyering - Board Member, Congenital Hypersensitivity Syndrome Network
Sumanta Smith - President, GastricrectosPatient Association for Gums and Treatments, Inc.

**CARING FOR RARE Medical Professionals & Student Education**
Gene Therapy for Rare Diseases
Speakers: Christian Guadino - Patient
Kim McIlhine, MD, MS - Nationwide Children's Hospital
John Tisdale, MD - Senior Investigator, Molecular and Clinical Hematology Branch, NIH

**WORKSHOP TWO 3:00pm-5:45pm**

**LIVING RARE Beginners & Newly Diagnosed**
Drug Development, Clinical Trials & Investigational Therapies: Navigating Your Options
Speakers: Mary McKown - Executive Director, The Myotis Association

**LOVING RARE Caregivers Education & Coping**
Relationships: Dating, Divorce, & Managing Intimate Partner Relationships (Including Fertility Issues, Single Parenting)
Speakers: Michael Chippelli - Caregiver
Shannon Hutton - Founder & President, Mississippi Metavalks Foundation, Caregiver
Andme MacDowell - Co-Founder & COO, OffScrip
Trace Swa - Mother's Heart, Caregiver

**LOVING RARE Caregivers Education & Coping**
Fertility Issues, Single Parenting
Speakers: Orah Lasko - Fundraising Chair, Foundation for USP7
Effie Parks - Host, "Once Upon a Gene" Podcast; Caregiver

**CARING FOR RARE Medical Professionals & Student Education**
Break: Virtual Networking Roundtables
Speakers to be announced

Sunday, July 19: DAY 2
12:00pm-1:00pm Rocking for Rare Party
1:00pm-2:00pm Day 2 Opening: Fight Back Plenary: Join NORD in Fighting for Rare Disease Awareness and Advocacy and for Your Life
Colleen Brunetti, MEd, CHC, Patient Advocate; Author
Darlene Shelton - Founder & President, Danny's Dose Alliance

**WORKSHOP THREE 2:00pm-4:25pm**

**LIVING RARE Beginners & Newly Diagnosed**
Ending Isolation: Tips for Connecting & Resources for Support
Speakers: Amy Plaxuelle - Patient
Seth Hotting - Co-Founder and Head of Strategy & Engagement, Our Odyssey

**LIVING STRONGER Advanced Patients & Caregivers**
Psychology of Rare: PTSD, Depression, Evaluation, Diagnosis & Therapy
Speakers: Christopher Akselrud - Managing Intelligence Manager, Muscular Dystrophy Association
Deborah Byers - President, The Acanthus Foundation
Kathleen Hoyart, PhD - Associate Professor of Psychology & Social Interaction Lab, Oregon State University
Tessa Woodford - Patient Advocate, Sickle Cell Community Consultant

**LOVING RARE Caregivers Education & Coping**
Transitoning Care: Q&A with Parents & Top Specialists
Speakers: Linda Hampton Stanes - Caregiver, Florida Family Leaders Network
Marine Naitzak, MD - Physician, Cleveland Clinic
Mac Starnes - Patient, Florida Family Leaders Network

**CARING FOR RARE Medical Professionals & Student Education**
Health for the Caregiver
Speakers: Christian Guadino - Patient
Kim McIlhine, MD, MS - Nationwide Children's Hospital
John Tisdale, MD - Senior Investigator, Molecular and Clinical Hematology Branch, NIH

**WORKSHOP FOUR 3:00pm-5:45pm**

**LIVING STRONGER Advanced Patients & Caregivers**
Patient Self-Advocacy
Speakers: Brushep Rupaire - Blogger, "Beauty with a Twist"; CEO, The Design Foundation; Patient
Ranmeet Franco - Founder & CEO, Comparison Works Medical
Nicholas J. Nusco - Public Affairs Manager - STAIBLE; Ohio Treasurer of State
Osha Lakso - Founding Chair, Foundation for USP7 Related Diseases; Caregiver

**LOVING STRONGER Caregivers Education & Coping**
Stress Management: Self-Care & Emotional Health for the Caregiver
Speakers: Katie Dykman - Social Worker, Huntington's Disease Society of America Center of Excellence at Cleveland Clinic
Beth McKenna - Children's Tumor Foundation, Caregiver
Ellie Parks - "Herd, Once Upon a Gene" Podcast; Caregiver

**CARING FOR RARE Medical Professionals & Student Education**
Current Challenges & Opportunities in Rare Disease Research: What Every Physician Should Know About Research
Speakers: Philip Brooks, PhD - Program Director Office of Rare Disease Research, National Center for Advancing Translational Sciences, NIH
Cathy Khan, PhD, RN, MPH - Program Officer, Patient Centered Outcomes Research Institute (PCORI)
Camille Know - President & CEO, Plattert Disorder Support Association

3:45pm-4:30pm Forum Wrap Up: Show Us your stripes Zebra Pageant and Raffle Prizes
With the health and safety of the rare community in mind, we have made the decision to present the 2020 Living Rare, Living Stronger Patient and Family Forum as a virtual program this year (with the 2020 Rare Impact Awards now taking place at a later date in Washington, DC). Our goal is, as always, for the Forum to provide rare disease patients and their families with networking, education, hope and fun. That hasn’t changed for this year’s virtual event!

We will provide live educational sessions, interactive Q&As and inspiring online panels presented by patients, caregivers and top rare disease medical experts. Attendees will be able to participate in networking sessions, interact with our rare disease exhibitors and take part in some surprise activities. Please join us in July for this special virtual forum!

**REGISTRATION**

I already registered for the Living Rare Forum and now plan to attend virtually. Is there anything I need to do at this time?

Yes, you will need to register for the virtual event. More information will be coming soon.

I would like to participate in the virtual event. How do I sign up?

Registration for the virtual Living Rare Forum will open shortly. Sign up for updates here, watch your email, or check out NORD’s social media channels for an upcoming announcement. All attendees must be registered in order to participate and the first 200 paid registrations will receive a special Living Rare goodie bag!

Can I transfer my paid registration fees for the in-person conference to the 2021 Living Rare Forum in Cleveland?

If you already registered to attend the 2020 conference in Cleveland, your registration will be carried over to our 2021 in-person event.

Can I request a refund for my Living Rare Forum in-person conference registration fee?

Yes. Please email events@rarediseases.org.

**PARTICIPATION**

What is the location of this event?

This is an online event and you do not need to travel to any specific location. You can participate anywhere you have consistent internet access. The event is accessible from your desktop, mobile and tablet devices.

May I invite my friends to attend the event?

Absolutely! The Living Rare Forum will be open to everyone, and we are counting on you to invite others and help us spread the word. Once registration is open, you can simply share the link to this page and they can register too.

I applied to receive a travel and lodging scholarship. What happens now?

All scholarship applicants will receive an email within the coming weeks with expectations and next steps for the virtual program. In the meantime, please contact scholarship@rarediseases.org with any immediate questions.

**AGENDA**

Will the agenda for the Living Rare, Living Stronger virtual forum be the same as it was for the in-person conference? Will the content planned be announced soon?

Each year we strive for the Living Rare, Living Stronger Forum to provide a unique, impactful experience for the rare disease community, and that hasn’t changed! The evolving agenda is available for download on the Living Rare, Living Stronger webpage.

Will I be able to take away handouts, information, brochures or zebra goodies from the event?

Yes, all virtual registrants will be able to access digital information, brochures and documents. Be among the first 200 paid registrations and have a Living Rare goodie bag mailed to you!
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: rarediseases.org/living-rare-forum.

Questions?
Go to: events@rarediseases.org or call 203-744-0100.