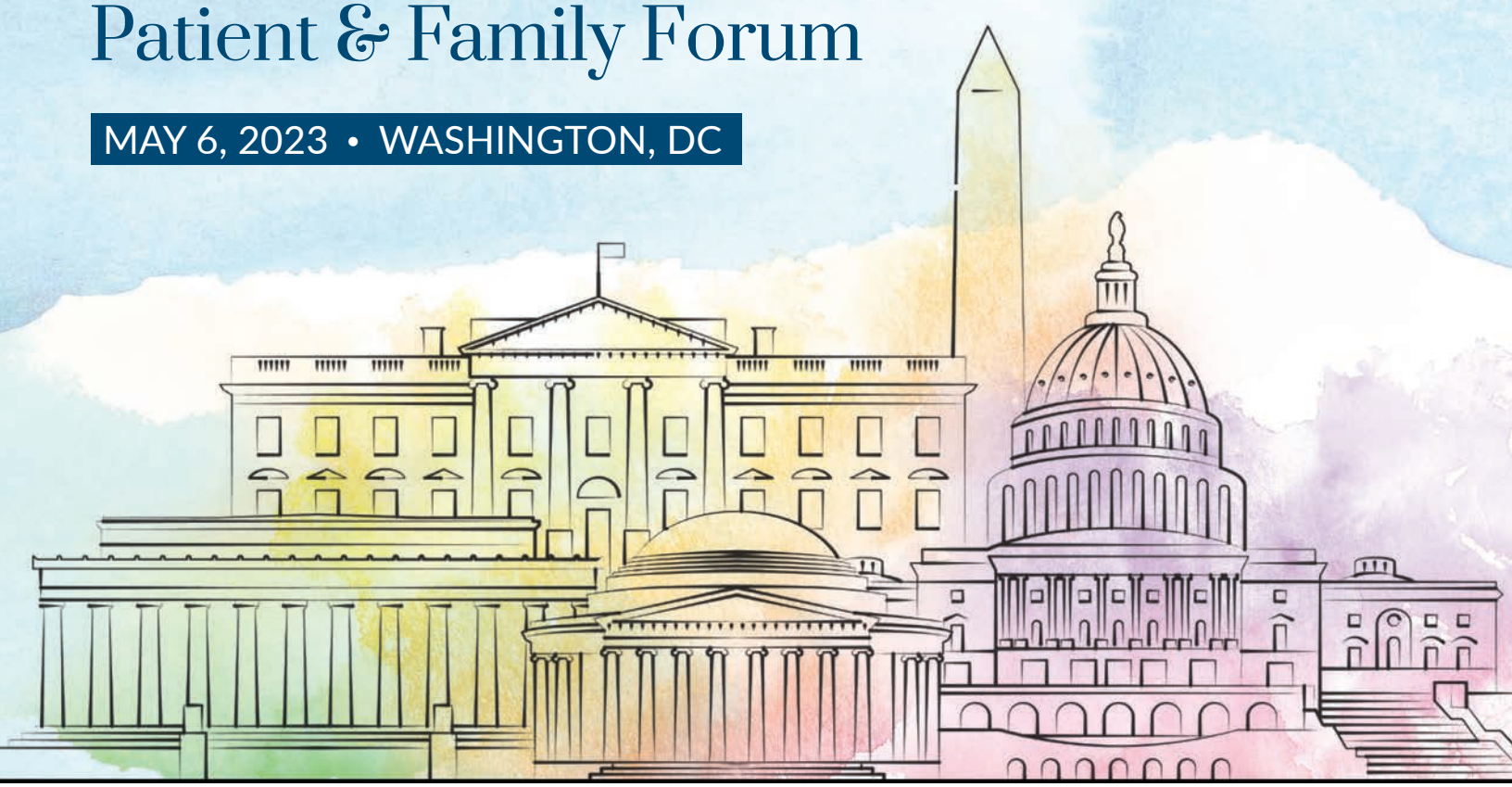
VIRTUAL PROGRAM GUIDE

NORD's Living Rare, Living Stronger® Patient & Family Forum

MAY 6, 2023 • WASHINGTON, DC



Friends,

I would like to welcome you to the 2023 Living Rare, Living Stronger NORD Patient and Family Forum. As we celebrate 40 years of NORD's impact and look ahead to the future, I can think of no convening that is more important for grounding this work than this, NORD's signature event for rare disease patients and their families, who have been the driving force behind our advocacy from the start.

We are thrilled to gather with you for a full day of programming, where you will receive insights from experts in our diverse rare community, gain practical knowledge and resources, and have networking opportunities with people who understand your unique journey. We thank you for being here with us today. Alone we are rare. Together we are strong.

Peter L. Saltonstall
President and Chief Executive Officer, NORD

PROGRAM GUIDE CONTENT:

THANK YOU TO OUR DIAMOND SPONSOR:

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Living Rare, Living Stronger® Patient & Family Forum

AGENDA

SATURDAY, MAY 6, 2023

All times are ET

9:00am — **Registration, breakfast, networking, and exhibitor booths open**

9:50am — **Opening Remarks**

Peter L. Saltonstall - President and CEO, National Organization for Rare Disorders (NORD®)

10:00am — **Opening Keynote Address: Resilient and Rare**

Connie Montgomery - Rare Community Member, CHES Foundation, Inc.

10:20am — **Plenary Session – Living with Uncertainty**

The journey through life with a rare disease is filled with uncertainty. Often times, this takes a toll on the mental health of people living with rare disease and their loved ones. This session will explore ways to navigate life while coping with uncertainty, feel affirmed that your thoughts and feelings are valid and normal, nourish yourself and have a productive life with contentment amidst the unknowns.

Moderator: Al Freedman, PhD - Psychologist, Freedman Counseling Associates

Speakers:

Col. Steven Coffee - MA, EMCQSL

Maggie Kang, MD - Life Coach

Joanne Sperando - Rare Community Member, Advocate

11:05am — **Break**

11:15am — **Breakout Sessions**

Beyond the Disability or Diagnosis: Rare Disease in Adulthood

Adults living with rare diseases are whole people with relationships, jobs, hobbies and responsibilities beyond managing their care. Many experienced or are still undergoing long diagnostic odysseys that include difficulty finding validation and accessing appropriate care. This experience can negatively affect quality of life and mental health or even be traumatizing. For adults with rare disorders from marginalized communities, the struggles may be even greater. This session will explore the unique challenges of adults with rare disorders and discuss coping mechanisms and approaches to overcoming barriers.

Moderator: Brittany Clayborne, MS, PsyD - Rare Community Member, Author

Speakers:

Lara Bloom - President and CEO, The Ehlers-Danlos Society

Rebekah Palmer - Vice President of Advocacy and Awareness, Next Generation of Cystinosis

Debunking the Myths of Palliative Care

Palliative care is often used as another word for hospice care or end of life care. However, palliative care is appropriate for people with diagnoses that are not terminal and can even be utilized alongside curative treatments! Palliative care helps focus a care team on the goals of the patient and what quality of life means to them while focusing on alleviating burdensome symptoms of disease. Come learn more about the spectrum of palliative care and how your family may benefit from this important service.

Moderator: Danielle Doberman, MD, MPH - Clinical Medical Director for Palliative Medicine, Johns Hopkins Medicine

Speakers:

Shannon McNeil, LMSW, LGSW - Pediatric Social Worker, Grief Therapist, Capital Caring Health

Beth Papanastasiou - Rare Community Member

12:00pm — **Grab lunch**

Living Rare, Living Stronger® Patient & Family Forum

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12:10pm **Networking Lunch** *(Table Topics/Facilitator-led)*

1:10pm **Laughter Yoga presented by the Laughing Lovebugs**

1:40pm **Breakout Sessions**

How to Participate in Rare Disease Research

There are many ways that rare disease patients can participate in research. Participating can benefit patients directly while also contributing to scientific knowledge about rare disorders. Many patient organizations drive clinical research forward by maintaining patient registries and biobanks, collecting data for natural history studies and funding research. This session will explore ways that members of the rare community can engage in research efforts to advance cures.

Moderator: **Kyra Krass, PhD** - IAMRARE Implementation Co-lead, NORD

Speakers:

Pangkong Fox, PhD - Science Engagement Director, CACNA1A Foundation

Kevin Glinton, MD, PhD - Assistant Professor, Department of Molecular & Human Genetics, Baylor College of Medicine, Texas Children's Hospital

Rare in the Family: Family Planning and Decision-making

Since many rare diseases are genetic and diagnosed in childhood, parents often struggle with family planning decisions. Some rare conditions are associated with increased risks during pregnancy and may involve treatment that can impact fertility. This session will explore the important medical, social, psychological, and financial considerations relevant to these personal decisions.

Moderator: **Barbara Harrison, MS, CGC** - Assistant Professor, Department of Pediatrics, Howard University College of Medicine

Speakers:

Al Freedman, PhD - Psychologist, Freedman Counseling Associates

Beth Papanastasiou - Rare Community Member

Teonna Woolford - Co-Founder, Chief Executive Officer, Sickle Cell Reproductive Health Education Directive (SC RED)

2:25pm **Break**

2:45pm **Rare Breakthroughs: Hope Now and on the Horizon**

New innovations are helping to advance the diagnosis, treatment and care of rare disease patients. This session will highlight current government initiatives and new technologies that can benefit rare disease patients and their families, now and in the future.

Moderator: **PJ Brooks, PhD** - Acting Director, Division of Rare Diseases Research Innovation, National Center for Advancing Translational Sciences (NCATS), NIH

Speakers:

Jennifer Cohen, MD - Pediatric Medical Genetics Specialist, Duke Children's Hospital & Health Center

Peter Marks, MD, PhD - Director Center for Biologics Evaluation and Research (CBER), US Food & Drug Administration

3:30pm **Closing Keynote Address: Dented, Not Broken**

Jackson Goodrich - Rare Community Member; Teen Ambassador, Dent Disease Foundation

3:50pm **Closing Remarks/Program Concludes**

2023 Living Rare Forum External Planning Committee

We sincerely thank the members of our national planning committee for sharing their time, talents and expertise with us to assist with the careful selection of session topics and connection-making opportunities at this year's Living Rare Forum.

Brittany Clayborne, MS, PsyD
Brittany Speaks

Divya Desai, PharmD
Purdue University, FDA, Eli Lilly and Company

Al Freedman, PhD
Freedman Counseling Associates

Nakisha Isom, MA
Novant Health

Tammy Jones
Rare Action Network®

Natasha Shur, MD
Children's National Hospital, Rare Disease Institute

Kyle Underwood, MHA
Cleveland Clinic

Samantha Vergano, MD
Children's Hospital of The King's Daughters

Robin Yoon, MD candidate
Georgetown University School of Medicine

Enter to Win a Prize!

Don't forget to complete your event survey at the end of the forum! Once completed, you will be entered into a drawing to win a gift from the NORD store! We appreciate any and all feedback. To complete, scan the QR code or visit, **bit.ly/LRLS-2023-virtual.**

Get Social at the #LivingRareForum

Join the conversation, connect with others and let your friends know you're participating by:

- Using the hashtag: **#LivingRareForum** in your posts
- Tagging NORD on social media so we can reshare your posts
- Tagging your location on Instagram as Living Rare, Living Stronger
- Posting a picture from the forum and tagging NORD and using **#LivingRareForum**

Donate to NORD!

NORD is leading the fight to improve the lives of those impacted by rare disease. We do this by supporting patients and organizations, accelerating research, providing education, disseminating information, raising awareness, and driving public policy. Scan the QR code or visit **livingrare.org/donate** to support NORD today!

Get Involved!

Are you ready to take action? Join our community of volunteers, advocates, and fundraisers creating a healthier future for rare diseases. Sign up for the Rare Action Network to participate advocacy campaigns, share your story with legislators, and connect with others in your area. Visit: **rarediseases.org/get-involved**

Celebrate 40 Years of NORD's Impact

Alone we are **rare.** Together we are **strong.®**

Together, we are reimagining a healthier future for people living with rare diseases and their families.

In 2023, we are celebrating 40 years of community and working together to drive progress. Join NORD as we meet the challenge to create a better future for people living with rare diseases. Picture the next 10 years: what is one thing that would change your rare journey, or make a difference for the entire community?

Share your ideas with a video or photo today and see what others are saying on our Community Wall. Scan the QR code or visit: **rarediseases.org/nord40/**

RARE.
STRONG.
TOGETHER.
40 YEARS

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