

Honoring the Rock Stars of the Rare Disease Community: NORD Announces the 2022 Rare Impact Award Honorees

NORD's Rare Impact Award ceremony on June 26 will honor all those making strides to improve the lives of patients and families in the rare disease community



NORD®

The National Organization for Rare Disorders (NORD)

WASHINGTON, D.C., USA, March 15, 2022 /EINPresswire.com/ -- [Today](#), the National Organization for Rare

Disorders (NORD®) announced the 2022 Rare Impact Award honorees. This list of outstanding individuals, organizations and industry innovators will be honored for exceptional work benefiting the US rare disease community during a live ceremony at the Rock & Roll Hall of Fame in Cleveland, Ohio on Sunday, June 26, 2022, at 7:00pm ET. The Rare Impact Awards program is part of the [Living Rare, Living Stronger NORD Patient and Family Forum](#).



The 2022 Rare Impact Award honorees represent a diverse and inspiring group, each making an impact on the rare community in a different way"

Peter L. Saltonstall, President and CEO, NORD

"The nearly 30 million Americans living with a rare disease are more often fighting for recognition rather than the care, access, research, community, or cures they deserve. In our society, as we strive to raise rare voices and bring everyone along in important decision-making, NORD is so thankful to partner with and elevate the individuals and communities out there fighting for advancement of the rare disease community," said Peter L. Saltonstall,

President and CEO, NORD. "The 2022 Rare Impact Award honorees represent a diverse and inspiring group, each making an impact on the rare community in a different way."

This year, the following caregivers, advocates, patients, and leaders are receiving a Rare Impact Award:

- Lesley Bennett; Connecticut Volunteer State Ambassador
- Bo Bigelow; Caregiver and Advocate
- Melinda Burnworth, Pharm.D., BCPS, FAzPA; Professor and Advocate

- The Honorable G.K. Butterfield; Congressman from North Carolina
- Rich Horgan; Industry Leader and Advocate
- Tammy Jones; Arkansas Volunteer State Ambassador
- The Kids Caring for Kids (KC4K) Youth Advisory Board of the Avalon Foundation; Patients, Caregivers and Advocates
- Michail Lionakis, MD, ScD.; Physician and Researcher
- The Honorable Kathleen Murphy; 34th District, Virginia
- Jack Timperley; Patient and Advocate
- Nora Wong; Caregiver and Advocate

Additionally, the Abbey S. Meyers Leadership Award will be presented to The Sickle Cell Disease Association of America and the Public Health Leadership Award will be given to Dr. Peter Hotez, MD, PhD and Dr. Maria Elena Bottazzi, PhD.

The 2022 Industry Innovation Award honorees include Apellis Pharmaceuticals, Inc. for Empaveli™; BridgeBio Pharma for Nulibry™; Bristol Myers Squibb and 2seventy bio for Abecma®; Enzyvant Therapeutics, Inc. for Rethymic®; Kedrion P BioPharma Inc. for Ryplazim®; On Target Laboratories, Inc. for Cytalux™; and PharmaEssentia Corporation for Besremi®.

NORD invites all to attend the Living Rare, Living Stronger Patient and Family Forum featuring the Rare Impact Awards. Registration is open now! For more information and to register, [visit livingrare.org](https://livingrare.org).

About the National Organization for Rare Disorders (NORD®)

The National Organization for Rare Disorders (NORD) is the leading independent advocacy organization representing all patients and families affected by rare diseases in the United States. NORD began as a small group of patient advocates that formed a coalition to unify and mobilize support to pass the Orphan Drug Act of 1983. Since then, the organization has led the way in voicing the needs of the rare disease community, driving supportive policies, furthering education, advancing medical research, and providing patient and family services for those who need them most. Together with over 300 disease-specific member organizations, more than 17,000 Rare Action Network advocates across all 50 states, and national and global partners, NORD delivers on its mission to improve the lives of those impacted by rare diseases. Visit rarediseases.org.

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