Called to Action
NORD's Response to COVID-19

For more information please visit the NORD COVID-19 Resource Center on our website:

www.rarediseases.org/COVID-19
Issues & Concerns for U.S. Families

Most Common Issues and Concerns

- Not being able to access PPE (masks & gloves)
- Not able to access testing and risk of false negatives
- Drug shortages
- Access to medical services (home infusions, lab work, therapies)
- Financial stability (paying for medications, mortgage/rent, utilities)
- Equity of care for patients with chronic conditions in ERs
- Returning to work if they or a family member are immunocompromised or at high-risk.
- Staying safe now and when this is “over”
COVID-19 Advocacy & Resources for Families

Advocating on Behalf of the Rare Community
  • Access to medical treatment: Home infusion services, telemedicine, prescription refills
  • Discrimination in COVID triaging and emergency response protocols
  • Paid leave

COVID-19 Non-Medical, Premium and Medical Relief Programs
  • Financial assistance for rare families in the U.S. impacted by COVID-19

Webinars and On-Demand Videos
  • NORD’s Ask a Rare Disease Expert About COVID-19 Video Series
  • Maintaining Your Physical and Mental Health
  • Current Status of Testing, Treatments and Vaccines
  • Drug Supply in the Time of COVID-19
  • Telehealth and Rare Disease Treatment

Webinars and Resources for Patient Organizations
  • How to Activate Your Medical Boards to Respond to COVID-19
  • Virtual Fundraisers: How to Raise Money During COVID-19