Called to Action: NORD’s Response to COVID-19

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*The COVID-19 education series is made possible with support from:*
This webinar is being recorded.
Question and Answer Session

Submit your questions using the chat function. It can be found at the **left hand side** of the window.
Upcoming Webinar

COVID-19: Current Status of Testing, Treatments and Vaccines

May 5, 2:00pm EDT

Rishi Desai, MD, MPH

Register: https://bit.ly/3cC1JoQ
Vanessa Boulanger, MSc  
Director of Research  
NORD

Jill Pollander, RN, MSN  
Director of Patient Services  
NORD

Rachel Sher, JD, MPH  
Vice President of Regulatory and Government Affairs  
NORD
Understanding and Responding to the Rare Disease Community During COVID-19

Vanessa Boulanger, MSc
Director of Research
NORD
How has the coronavirus (COVID-19) pandemic impacted you and your family? We are inviting the US rare disease community to contribute their experiences through a brief NORD survey designed to study the nature and extent of issues rare patients are facing due to the spread of the virus. This survey closes on April 8.
Submit your answers and share: https://bit.ly/2WVORFC
Snapshot: COVID-19 Community Survey

• Survey was open for 1 week
• 772 people responded
• 2/3 of survey participants had a rare disease themselves
  (vs caregiver or family member)
• 3/4 of survey participants were over the age of 40

Age of Respondents

- 18-24
- 25-40
- 41-55
- 56-75
- 75+

rarediseases.org
98% of participants are worried
  • 67% very or extremely

95% of participants have been impacted to some degree

69% of participants are concerned about medication and medical supply shortages

“I worry about being able to tell the difference between COVID symptoms and my norm.”
Snapshot: COVID-19 Community Survey

- 39% Have had challenges accessing medical care or treatment
- 74% Had medical appointment cancelled due to COVID-19
- 59% Have been offered a telephone or video call as an alternative to an in-office appointment
29% have lost jobs temporarily or permanently due to COVID-19

40% of households have been impacted by loss of income due to COVID-19

11% of job losses resulted in loss of health insurance
Patient Services: Supporting Our Rare Disease Community

Jill Pollander, RN, MSN
Director of Patient Services
NORD
How is Patient Services Supporting Our Rare Disease Community?

NORD and the RareCare Patient Services team has and will continue to provide uninterrupted support

• Communication Center hours remain unchanged
  • Monday – Thursday, 8:30 am – 7:00 pm EST
  • Friday 8:30 am – 6:00 pm

• Patient & Information & Resource Services answer an average of 1736 calls per week
• And process an average of 1148 emails per week
NORD’s RareCare Team
How is Patient Services Supporting Our Rare Disease Community?

NORD’s programs and services have for over 37 years assisted the rare disease community to overcome obstacles and access to care.

• 80 programs across 51 rare disease states
  • 6025 (and counting) enrolled in NORD assistance programs for 2020
• Rare Caregiver Respite Program
• COVID-19 Rare Disease Critical Needs Non-Medical Assistance Fund
  • Phone: 203.242.0497
  • Email: covid19assistance@rarediseases.org
COVID-19 Rare Disease Critical Needs Non-Medical Assistance Fund

Provides eligible individuals with financial assistance for unexpected or emergency, essential expenses.

- Assistance is based on eligibility and funding availability
- Review criteria includes
  - Confirmation of a rare disease diagnosis
  - Evidence that the need is driven by COVID-19 pandemic
  - Confirmation that the assistance requested is consistent with non-medical program criteria
  - Financial eligibility

- COVID-19 Rare Disease Critical Needs Non-Medical Assistance Fund
  - Phone: 203.242.0497
  - Email: covid19assistance@rarediseases.org
Top Needs During this Crisis

• Information & resources
• Premium assistance
• Access
• Educational support services
• Communication
Now as always, we’re here to help:

• NORD Information & Resource Services:
  Email: informationservices@rarediseases.org
  Phone: 800.469.0283

• There are a lot of websites, links and webinars out there:
  For reliable user-friendly, all-in-one-place information:
  rarediseases.org/covid-19
Overview of NORD’s COVID-19 Policy Work
A look at what we have done and how we can help you going forward

Rachel Sher, JD, MPH
Vice President of Regulatory and Government Affairs
NORD
NORD COVID-19 Policy Work

COVID-19 Resource Center

The health and safety of those with rare diseases and their caregivers are always our top priorities at the National Organization for Rare Disorders (NORD). We stand in solidarity with the rare community and would like to extend support for those impacted by COVID-19, directly and indirectly. By sharing resources on how to be prepared and seek proper care under these unusual circumstances, we hope to educate and empower the community during this unprecedented time.

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

NORD COVID-19 Resources

- Upcoming Webinars
- On-Demand Videos
- On-Demand Webinars
- Advocacy Opportunities and Tools
- NORD COVID-19 Policy Statements
  - Coalition letter in support of Including the Protecting Seniors Through Immunization Act in the next COVID-19 response legislative package
    - Learn more >
  - Coalition letter to Congress to further strengthen health insurance coverage, affordability, and accessibility in the next COVID-19 relief package
    - Learn more >
  - Coalition letter to HHS and CMS urging decisive action to slow the spread of COVID-

• Access to Medical Treatment
  - Telemedicine
  - Home infusion
  - Prescription Refills

• Nondiscrimination

• Paid Leave

https://rarediseases.org/covid-19/
Advocacy Opportunities and Tools

NORD COVID-19 Resources

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- On-Demand Webinars
- Advocacy Opportunities and Tools

COVID-19 Policy Issues Contact Us Form
The NORD policy team wants to hear from you! Share the concerns you are hearing about that are impacting the rare disease community at large during the COVID-19 pandemic.

COVID-19 State by State Resources
Learn more >

COVID-19 Virtual Discussion Groups
Learn more >

Join the Rare Action Network
Learn more >

https://rarediseases.org/covid-19/
COVID-19 Resources for You

- Webinars
- On-Demand Content
- Assistance Programs
- Mental Health and Stress Relief Resources
- And More!

https://rarediseases.org/covid-19/
Question and Answer Session
Questions?

Submit your questions in the chat box.

Our presenters will answer them in the order in which they came in and based on relevance to the discussion.