



NORD[®]
National Organization
for Rare Disorders

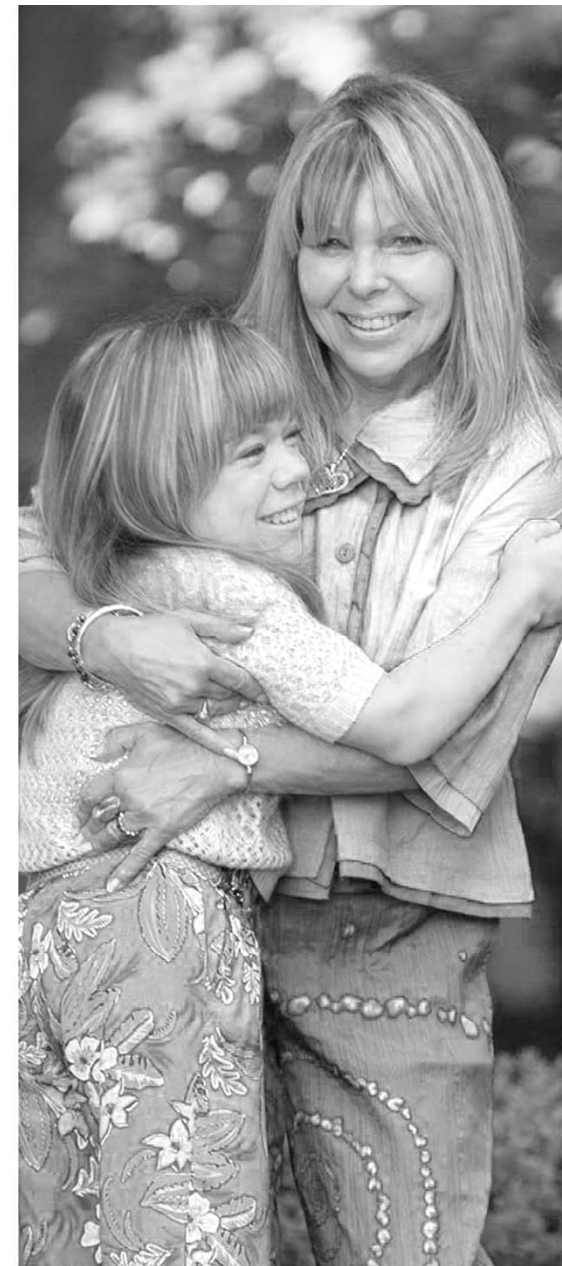
Called to Action

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

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



Issues & Concerns for U.S. Families

772 Individuals with a rare disease, caregivers, and family members responded to the survey

98% are worried about COVID-19



74% Have had a medical appointment **CANCELED** due to COVID-19

59% Have been offered a telephone or video call as an alternative to an in-office appointment



95% of individuals and families have been impacted due to COVID-19



69% Concerned about medication and medical supply shortages

29% Have lost jobs temporarily or permanently due to COVID-19



11% of job losses have resulted in loss of health insurance

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”



rarediseases.org

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

NORD RARE EDU

HOW TO PREPARE FOR YOUR TELEHEALTH APPOINTMENT
Content developed with assistance from Norelle Shul, MD and Elizabeth Lawrence, MD of Children's National Hospital

WHAT IS TELEHEALTH?
Telehealth is generally described as a virtual communication, such as a phone or video visit, used to deliver care outside of a typical or traditional health care facility. During the COVID-19 pandemic, "social distancing" is critical to minimize the spread of the coronavirus. Since many rare disease patients need to receive ongoing care, telehealth is increasingly being used as an alternative to in-person health care. If you are interested in telehealth, check with your individual provider and insurer to see if it is available to you.

HOW TO PREPARE FOR YOUR TELEHEALTH APPOINTMENT

spot
arent that you find a spot that allows for an uninterrupted appointment that is:
ate
re
list
a strong WiFi signal

appropriate app/software before your appointment
providers use various applications for telehealth. Ensure that you have
led the correct application for your appointment.
th your provider if it will be a video or audio-only appointment.

Video
chnology with a buddy. It may be possible for someone from your
office to test it with you.
ew process for many of us. We are all learning and need to
flexibility is key!

ustainable-development/health-sector/strategies/telehealth/en/

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COVID-19 COMMUNITY SURVEY REPORT
95% of Rare Disease Patients Affected
May 5, 2020

NORD RARE INSIGHTS

For more information, please contact: osp@nordfoundation.org
rarediseases.org

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