



NORD[®]
National Organization
for Rare Disorders

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

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The COVID-19 education series is made possible with support from:



HORIZON

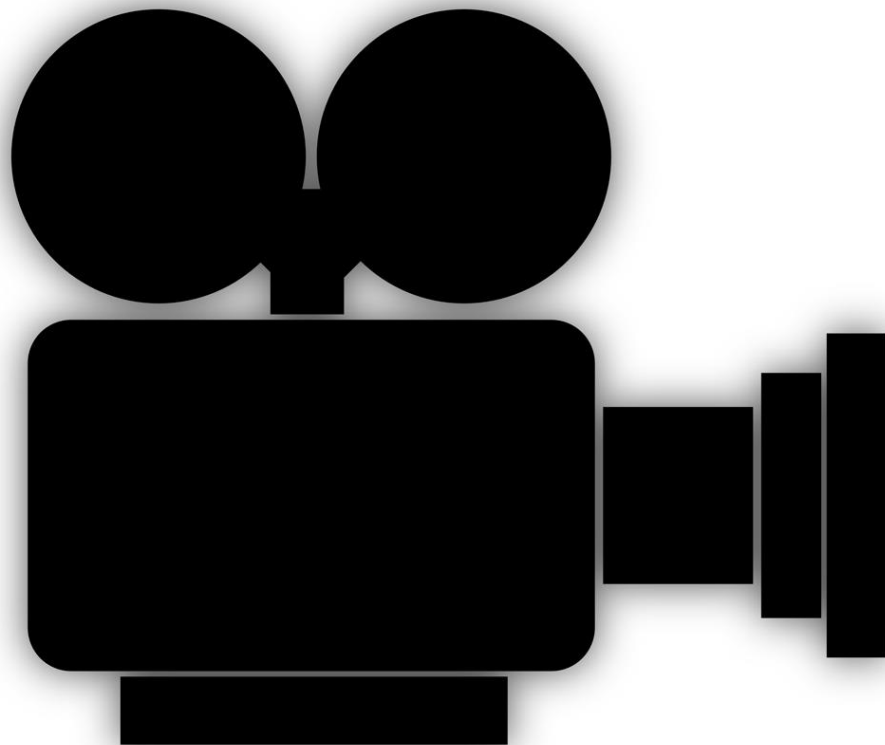
SANOFI GENZYME



STRONGBRIDGE
BIOPHARMA[®]



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>



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Speakers



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

Vaughn family: Son, Morgan (left), diagnosed with Necrotizing Enterocolitis at four days old



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NORD COVID-19 Community Survey



National Organization for Rare Disorders, Inc. (NORD)

April 8 at 6:48 AM · 🌐

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>



SURVEYMONKEY.COM

NORD COVID-19 Survey of the Community

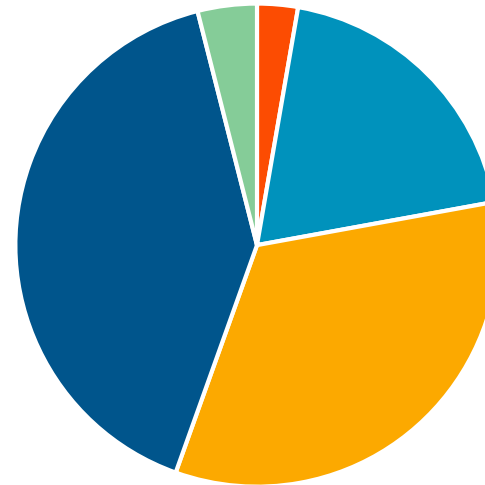


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Snapshot: COVID-19 Community Survey

- 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+

Snapshot: COVID-19 Community Survey

- 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



Snapshot: COVID-19 Community Survey

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





Marcia Galan and her daughter, Alena, diagnosed with Mucopolysaccharidosis type VI (MPS VI)

Patient Services: Supporting Our Rare Disease Community

Jill Pollander, RN, MSN

Director of Patient Services
NORD



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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

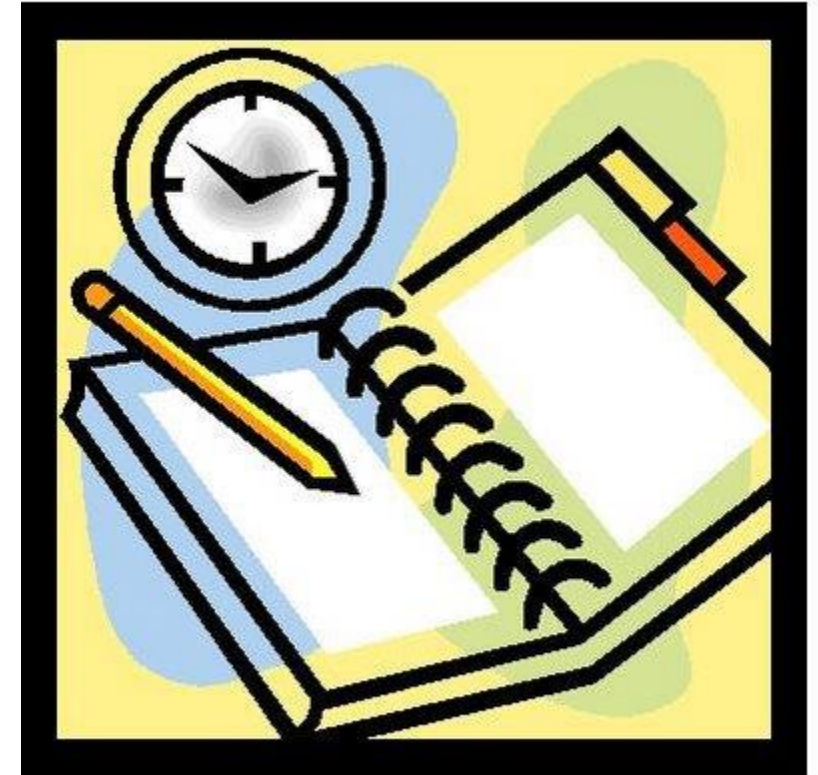
Provides eligible individuals with financial assistance for unexpected or emergency, essential expenses.

- 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**
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Top Needs During this Crisis

- Information & resources
- Premium assistance
- Access
- Educational support services
- Communication



Resources

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



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Madilyn Yang (far left) has been battling a rare breathing disorder since birth called Central Congenital Hypoventilation Syndrome (CCHS) or Ondine's Curse.

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-

**SUPPORT NORD'S
COVID-19 PROGRAMS**

There are many vulnerable people in our community who desperately need your support during the coronavirus pandemic.

DONATE NOW

**OPEN NOW!
COVID-19 CRITICAL
RELIEF PROGRAM**

FIND OUT MORE

**ACCESS
ASSISTANCE
PROGRAMS**



[Find out more >](#)

- Access to Medical Treatment
 - Telemedicine
 - Home infusion
 - Prescription Refills
- Nondiscrimination
- Paid Leave

<https://rarediseases.org/covid-19/>



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Advocacy Opportunities and Tools

NORD COVID-19 Resources

- + Upcoming Webinars
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- + **Advocacy Opportunities and Tools**

COVID-19 Policy Issues Contact Us Form

The NORD policy team wants to hear from you! Share the concerns are you 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 >](#)

OPEN NOW!

**COVID-19 CRITICAL
RELIEF PROGRAM**

FIND OUT MORE

**ACCESS
ASSISTANCE
PROGRAMS**



[Find out more >](#)

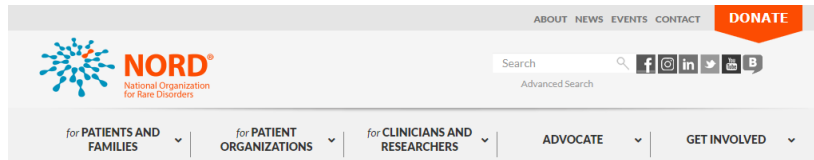
**RELIEF FOR
CAREGIVERS**



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<https://rarediseases.org/covid-19/>

COVID-19 Resources for You



COVID-19 Resource Center

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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
- Resources for Non-Profits

Additional COVID-19 Resources

* Information and links here are not necessarily endorsed by NORD but are shared for your consideration.

- Official Resources
- Upcoming Webinars
- Emergency Preparedness
- Mental Health Support
- On-Demand Videos
- On-Demand Webinars
- Online Events
- Resources for Non-Profits
- Stress Relief

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

<https://rarediseases.org/covid-19/>



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Question and Answer Session

Vaughn family: Son, Morgan (left), diagnosed with Necrotizing Enterocolitis at four days old



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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.





Thank you.



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