A Rare Response: Addressing the COVID-19 Pandemic

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Alone we are rare. Together we are strong.
Responding to COVID-19

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.

In these uncertain times, remember:

Alone we are rare. Together we are strong.
This webinar is being recorded.
Submit your questions using the chat function. It can be found at the **left hand side** of the window.
NORD, an independent nonprofit, is leading the fight to improve the lives of rare disease patients and families.

We do this by supporting patients and organizations, accelerating research, providing education, disseminating information and driving public policy.
Speakers

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Rare Parent
Responding to COVID-19

Marshall Summar, M.D.
Division Chief, Genetics and Metabolism
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Chairman, Board of Directors
NORD
Nothing in life is to be feared. It is only to be understood.

— Marie Curie
What the Rare Community Already Knows

• Most rare diseases already come with risk greater than everyday life and COVID-19.

• The Rare Disease Community has dealt with this for many years and our folks have better than average coping skills. We are resilient.

• While there are things for us to learn we also have things to teach everyone else.

• We can help make changes that benefit our community and countless others.
So How Does COVID-19 Affect the Rare Disease Community

• Who is at greater risk than normal?
• What can we do about it?
• How do we manage a complex medical condition when panic is in the air?
• How do we change the medical paradigm to help now and later?

Communication is key.
• To date, the younger a patient, the less effect COVID-19 seems to have.
  • Dr. Wiedermann will have more.

• Older patients with underlying medical conditions are at greater risk for severe disease, particularly those with underlying immune or respiratory illness. This includes rare diseases involving these systems.

• Patients on immunosuppression have a greater risk.
What Can We do About It?.... A Lot

• Listen and obey public announcements about social separation, staying away from others, and self-quarantine.

• Make sure you have refills and a good stock of all medicines, formulas, etc. Unlike toilet paper, this can stave off disaster.

• Check to see if your regular hospital has diverted non-COVID-19 patients elsewhere. Find out who at that facility you might need and how to connect them to your regular care team.

• Make sure any treatment letters are up to date.
How do we manage a complex medical condition when panic is in the air?

• First, **DON’T PANIC.** You’ve dealt with things like this more than almost anyone you know. **Stop, Think, Plan.**

• If you absolutely have to go to the hospital, **plan ahead.** Visitation is limited. Make sure you’ve got phones/tablets/portables AND the chargers that go with them. Have a kit ready to go if the hospital is a frequent stop for you.

• Take a supply of your medications. If the facility isn’t used to you (even if they are) they may not have your meds/formulas/etc. The distribution network may be slower to respond. Be as self-sufficient as you can in this regard.

• Don’t let fear drive you to the Emergency Room. Be objective about symptoms and what they are. ER’s will be crowded. If admission is a must then discuss direct admit with the team.

• Don’t let fear drive you away either. If you need it, get seen and treated. Your rare disease may be the greater risk than the virus.

• Lot’s of people will be wearing masks. Don’t freak out. Ask if you need one too. You may or may not. The hospital/clinic will probably seem a lot more chaotic than usual.
Changing the Medical Model in the Middle of Pandemic

• Telemedicine is and can be your friend. If someone doesn’t absolutely have to poke, image, or lay hands on something, see if they can do it remotely.

• You need to be the center of your medical care, not your medical center.

• Regulations like cross-state licensure are easing during this crisis. If your expert is elsewhere, they can see you from almost all states in your home.

• The Rare Action Network (NORD’s State Organizations) is mobilized to see that this happens in your state. Help if you can. And let’s hang onto this ability.

• This is a good opportunity to find out what parts of your regimen are habit and what parts are necessary. That is different from inconvenient.

• Programs like NORD’s undiagnosed registry and IAMRARE program are places you can store data and it belongs to YOU! The Medical Record should center on you not the medical center.

“Never let a good crisis go to waste”
Winston Churchill
Telemedicine or Why Shirts are Outselling Pants
Final Thoughts

• This is a great time to join a NORD rare disease group. Or have your group join NORD. Network, trade stories, meet folks who have walked in shoes like yours.
• Remember your healthcare team. They are likely to be almost as stressed as you are.
• When vaccines are ready. Get them.
• Stay informed but don’t let it drive your fear. Use knowledge to prepare.
• We will get through this. Doesn’t mean it will be easy or quick.
COVID-19: The Basics for NORD Families

Bernhard L. (Bud) Wiedermann
Division of Infectious Diseases
Children’s National Hospital

Professor of Pediatrics
The George Washington University School of Medicine and Health Sciences
What I’ll Cover Today

• Basics of the virus and the disease
• How to stay safe
• What about masks and other PPE?
• Predicting the future
• Internet resources
A Crash Course in Coronaviruses!

• COVID-19 = the disease
  • Fever, cough, other respiratory symptoms
  • Not much to distinguish from other viral respiratory illnesses
    • Changes in taste and smell?

• SARS-CoV-2 = the virus causing COVID-19
  • A coronavirus
    • Several cause the common cold, currently active in our community as usual
  • SARS 2002-3: ~6 month epidemic
  • MERS 2012 – present
    • Mostly in Middle Eastern countries
    • Travel-associated cases in many countries, including US
What’s Safe for Medical Care?

• Think of this as you might have done if your child had influenza
  • Difference – COVID-19 vaccine and specific treatment not available, no one has pre-existing immunity, don’t yet know if it’s seasonal

• Have a plan
  • Office visits, emergency visits, hospitalizations

• If you haven’t already
  • Check with your child’s provider – website, email, etc.
What’s Safe for Shopping?

• Delivery services, online shopping
• Try to shop at “off hours” if visiting a store becomes necessary
  • Some businesses have special accommodations for high risk
• Touch only what you intend to buy
• Avoid touching face
• Washable mittens?
What About Getting Out of the House?

• It’s difficult to stay indoors all the time, and not everyone has a giant personal yard to frolic in!
• Walking around the neighborhood is fine
  • General rule to keep at least 6 feet distance from others
• Avoid public parks/playgrounds
• Don’t go out if you are sick
Protecting Yourself

- Virus survival under various conditions
- Masks and other PPEs
Virus Survival Outside the Body

• PCR is different from living virus

Virus Survival Outside the Body

Graph showing the half-life of viable virus on different surfaces:
- Aerosols
- Copper
- Cardboard
- Stainless Steel
- Plastic

The graphs compare SARS-CoV-2 and SARS-CoV-1.
Personal Protective Equipment (PPE)
Dr. Bud’s Crystal Ball

• Seasonality
  • When will this go away?

• Treatment
  • What do we really know?

• Vaccine
  • Why does it take so long?
Help Us Help You – Flatten the Curve

• Social distancing
• Wash hands
• Don’t touch face
• Disinfect surfaces
• Sneeze/cough hygiene

• Have a plan
  • Well
  • Sick
• Take time to smell the roses
Internet Resources – The Best

• Centers for Disease Control and Prevention

• World Health Organization
  • https://www.who.int/emergencies/diseases/novel-coronavirus-2019

• Your Health Department
  • https://www.naccho.org/membership/lhd-directory
Internet Resources – Specific Groups

• National Organization of Rare Diseases
  • https://rarediseases.org/covid-19-resources-for-non-profit-leaders-and-the-community/

• Children’s National Hospital
  • https://childrensnational.org/

• American Academy of Pediatrics
  • https://www.healthychildren.org/English/Pages/default.aspx
Internet Resources - Data Overload!

- Nextstrain
  - https://nextstrain.org/ncov

- Worldometer
  - https://www.worldometers.info/coronavirus/

- Johns Hopkins U. CSSE
  - https://gisanddata.maps.arcgis.com/apps/opsdashboard/index.html#/bda7594740fd40299423467b48e9ecf6

- 1point3acres
  - https://coronavirus.1point3acres.com/en
Responding to COVID-19

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Counseling & Consulting Psychologist
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Rare Disease Parent
What I Plan to Discuss Today

- Why change is so stressful
- Why we are well prepared
- Focusing on what we can control
- “Fear distancing” strategies
- How we can be a model for others
Why is this situation so stressful?

Abrupt change triggers uncomfortable feelings.

Our sense of safety is threatened.

It’s normal to experience a range of strong emotions.
We are uniquely prepared.

Our rare disease community has experience with

unexpected change,

living with uncertainty,

and isolation.
We are experts at facing challenges and adversity.

We are adaptive.
We are resourceful.
We are resilient.
We are hopeful.
The anxiety we feel is real.

Many aspects of this pandemic do not feel in our control.

But we can choose to focus on what is in our control.
Focus on what **is** in our control

How we....

- Take care of ourselves
- Stay connected with others
- Choose to use our time
- Plan and prepare
A positive attitude, resilience, hope, and gratitude go a long way.

Our rare disease community models these qualities every day.
Resources

CDC: Managing Stress and Coping Resources

The Mighty: Online Community for Health Challenges
https://www.themighty.com

Massachusetts General Hospital Guide to Mental Health Resources
https://www.massgeneral.org/psychiatry/guide-to-mental-health-resources/

Apps: Calm, Headspace, Sanvello
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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.
Thank you.

Alone we are rare. Together we are strong.®

rarediseases.org