Activating Your Medical Advisors for COVID-19 Response

Monthly Webinar
A NORD Members-Only Resource

For audio, use your computer speakers or dial: 866-966-0043 * passcode: 8750-1160#
Activating Your Medical Advisors for COVID-19 Response

Katie Kowalski
Senior Manager of Education Programs, NORD

Kristin Smedley
Chief Executive Officer, Curing Retinal Blindness Foundation

Josephine Grima, PhD
Chief Science Officer, The Marfan Foundation

Elyse Gellerman
Chief Executive Officer, Neuroendocrine Tumor Research Foundation
Your NORD Membership Team

Allie Crafton
Membership Associate

Debbie Drell
Director of Membership

Will Whitman
Membership Senior Program Manager

Membership@RareDiseases.org
Agenda

Welcome & Updates
Will Whitman, NORD Membership Senior Program Manager

Speakers
Katie Kowalski, NORD Senior Manager of Education Programs
Kristin Smedley, Curing Retinal Blindness Foundation CEO
Josephine Grima, PhD, The Marfan Foundation Chief Science Officer
Elyse Gellerman, Neuroendocrine Tumor Research Foundation CEO

Q&A
All Panelists
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.
National Updates
New Member Welcome
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 Resources

- **Upcoming Webinars**
- **On-Demand Videos**
- **On-Demand Webinars**
- **Advocacy Opportunities and Tools**
- **NORD COVID-19 Policy Statements**
- **Resources for Non-Profits**

**Additional Resources**

*Information and links here are not necessarily endorsed by NORD but are shared for your consideration.*
Member Benefit: Social Media Promotion

Let us promote your news!
NORD Members – Please Email Us for the Link!
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Activating your Medical Advisors for COVID-19 Response

Katie Kowalski
Senior Manager of Education Programs
NORD

Alone we are rare. Together we are strong.
NORD’s Education Committee

Role of Education Committee:
• Recommends new educational programs and initiatives to NORD
• Helps identify strong potential partners for educational initiatives
• Assists NORD staff in evaluating the organization’s educational programs
• Serve as a NORD Educational Initiatives champion when engaging in the community
• Provide expertise on standards and best practices in education, as well as in the latest trends for educational methods

Constituency of Education Committee:
• Medical Sciences (clinicians, researchers)
• Representatives from NORD Member Organizations
• Representatives from the rare Disease Community at large
• Social Sciences (education, social work, psychology, law)
High-Speed Recruitment for COVID-19 Webinar

- Leveraged Network of NORD’s Education Committee
- Outreach to Centers for Disease Control and Prevention
- Outreach Office of Rare Disease Research, National Center for Advancing Translational Sciences (NCATS), National Institutes of Health (NIH)
- Outreach to NORD staff for qualified individuals in their networks
Speakers

Marshall Summar, M.D.
Chief, Genetics and Metabolism
Director, Rare Disease Institute
Children’s National Hospital

Bernhard Wiedermann, M.D., M.A.
Attending, Infectious Diseases
Children’s National Hospital

Albert Freedman, Ph.D.
Counseling Psychologist
Freedman Counseling Associates
Rare Parent
COVID-19 Resource Center

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NORD Resources
- Upcoming Webinars
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Additional Resources
- [Information and links here are not necessarily endorsed by NORD but are shared for your consideration.]
- Official Resources
- Emergency Preparedness
- Mental Health Support
- On-Demand Videos
- On-Demand Webinars
- Online Events
- Resources for Non-Profits
- Stress Relief
Serving the CRB1 LCA/RP Community during COVID-19

Kristin Smedley
Chief Executive Officer
Curing Retinal Blindness Foundation

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Advocacy for Accessibility in Online Learning

Checking in on the Community
The CRBF team hopes this finds you and your family doing well.

REMINDER:

We are hosting a first ever
CRB1 VIRTUAL Family Meet Up
March 26, 2020 from 8:00-9:00pm Eastern Time USA

ALL CRB1 PATIENT FAMILIES FROM AROUND THE WORLD ARE INVITED TO JOIN!
Due to our commitment to protecting the privacy of our families, you MUST be a CRB1 affected family to participate and you MUST register in advance. All instructions to log into the meet up will be given upon registration confirmation.
NOTE: We realize the time may not work for some families around the globe. We will be adding additional Virtual Meet Ups very soon to accommodate other time zones!

We look forward to chatting with you.
The CRBF team wishes your family good health during this challenging time.
THE CRBF TEAM IS PROUD TO ANNOUNCE THE FIRST EVER GENE THERAPY CLINICAL TRIAL FOR CRBI RETINAL DISEASE!

We hope this news bring you and your family joy in this unprecedented time as we are all handling the challenges the COVID19 pandemic is causing.

The CRBF Family is so very grateful to Dr. Jan Wijnholds and his team for the dedication to our CRBI patients for a number of years. Thanks to their dedication, and with support from several sources including CRBF, the clinical trial for gene therapy to treat CRBI retinal disease will open in 2023!
MOVING FORWARD:

- Monthly Zoom Meetings with Families and specialists
- Create an online fundraising event for the entire CRBF community
- Collaborate with other blind/Visually Impaired/Rare Eye Disease organizations to advocate for accessible resources for
  - Assistance during Social Distancing/Quarantine
  - Accessible Online education
  - Accessible COVID-19 testing
Rapid COVID-19 Community Response: The Marfan Foundation Experience

Josephine Grima, Ph.D.
Chief Science Officer
The Marfan Foundation

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## TIMELINE: COVID-19 Rapid Response

<table>
<thead>
<tr>
<th>Date</th>
<th>Information Type</th>
<th>Vehicle</th>
</tr>
</thead>
<tbody>
<tr>
<td>March 6</td>
<td>General CDC Guidelines, Reminders of Adverse Drugs</td>
<td>Database Email, social media links</td>
</tr>
<tr>
<td>March 12</td>
<td>Medical Advisors Statement: Defining High Risk</td>
<td>Posted on Website, social media links</td>
</tr>
<tr>
<td>March 13</td>
<td>Medical Advisors Q &amp; A Webinar</td>
<td>Zoom</td>
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<tr>
<td>March 16</td>
<td>Updated Medical Advisors Statement – Add’l High Risk</td>
<td>Posted on Website</td>
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<tr>
<td>March 20</td>
<td>Coping and Mindfulness Webinar – Social Worker</td>
<td>Zoom</td>
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<tr>
<td>March 31</td>
<td>Medical Advisors Q &amp; A Webinar – Personalized High Risk Info; Standard of Care Drugs and COVID; Possible Treatments</td>
<td>Zoom</td>
</tr>
<tr>
<td>April 6</td>
<td>Medical Advisors – Ventilator Information</td>
<td>Website</td>
</tr>
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</table>
March 6 – General information from CDC – News Article

• Inform community that our medical advisors are monitoring the information to determine how this might affect this community. Helped to ease anxiety for the community to know that their organization is looking into this situation for them.

• Included important Information and reminders for community
  • Provide information on how virus spreads
  • Echo CDC guidelines on hand-washing, social distancing
  • Remind patients about dangerous drug indications
  • Provide patients with general information on managing flu like symptoms

**TIP:** Prepare statement internally – then send around for approval from medical advisors
What Informed Our Content?

- March 12 – Medical Advisory Statement
  - Clarified who is at high risk – Basic question that many physicians and patients did not know
    - Which cardiovascular disease indications?
    - Which lung disease indications?
    - Are there specific issues for certain conditions?
  - Outline General Protective Strategies
    - Pneumonia vaccine and who should get it
    - Flu vaccine
    - Safe cold medications and antibiotics if needed
    - CDC Guidelines

- **TIP:** Prepare statement internally outlining important points, note controversies, make comments in document to clarify information – Then ask for edits, comments, changes and approval.

- **Words matter:** There will always be much discussion about “may” or “will”

- Always include point that patients need to consult with their physicians about their individual situation to get the best care.
Alerted medical advisors early in development of 1st medical statement and we wanted to do a webinar based on statement

First Webinar
- Included three physicians – Pulmonologist, and Adult and Pediatric Cardiologist

Schedule late in the evening – 7:00 or 8:00 pm Eastern

Zoom/Require registration to determine numbers of participants

Provide ability for members to ask questions ahead of time

Organize webinar to answer those questions and have them on slides

Prepare slides internally so medical advisors don’t have to.

Provide outline and expectations of webinar to advisors

Use interview style to prompt advisors to answer questions

Record webinar
2nd Q & A Webinar

• Answered more detailed medical questions
• Addressed members personal medical situations if they weren’t sure about their risk
• Addressed questions on possible therapies
• Used statement and patients questions to guide content
• Based on discussion at this webinar, prepared third statement on patients with connective tissue conditions and ventilators.
Engaging Your Medical Advisors
Tips and Best Practices

• Explain what you need and why you need it.
• Reduce burden on them by assisting as much as possible.
  • Doing research ahead of time, preparing draft statements
• Engage them often and regularly.
  • Have only one or two people that consistently reach out to them.
  • Chief Science Officer – main liaison with medical advisors
  • RN on staff answering patient questions and consults with medical advisors when needed.

• Anticipate Important News
  • Significant publications
  • FDA drug approvals – prepare statements for both approval and denial scenarios.
  • Clinical trial results
Responding to the NET Community during the COVID-19 Emergency

Elyse Gellerman
Chief Executive Officer, Neuroendocrine Tumor Research Foundation

Alone we are rare. Together we are strong.
NETRF Response to COVID: Key Considerations

• What do patients and families need/expect from NETRF?
• What can we share and not duplicate? How can we collaborate with other NET groups?
• How can we focus the involvement of our Board members and experts, at a time they are on the front lines?
• How can we maintain transparency with our community?
• How do we communicate effectively and with sensitivity?
First Steps to Assess the Needs

• Source patient questions and concerns about their risk and treatment
• Survey all active, funded researchers
• Check other NET organizations’ activities
• Develop an initial plan
• Maximize existing channels
  • Creation of a landing page on netrf.org for all COVID-related materials
  • Social media promotion of landing page materials
  • Monthly e-update focus
  • Plan for short email communications on 3/16, 3/27
COVID-19 and cancer resources for NET patients and families

NEW 4/13/20
NETWise podcast special episode on COVID-19 and NETs: What You Need to Know. Hosted by Laran Hyder, NETRF Director of Education and Outreach.

NEW 4/8/20
Julie Hallet, MD, shares information and discusses treatment protocols during COVID-19 for Canadian NET patients during the Canadian Neuroendocrine Tumor Society (CNETS) Webinar.

NEW 4/3/20
Mark Lewis, MD, oncologist at Intermountain Healthcare and member, NETRF Board of Directors, talks to Elyse Gelberman, NETRF Chief Executive Officer on how COVID-19 is affecting NET patient care.

NEW 4/2/20
NANETS panel discussion on shifting risk/benefit calculations for NET treatment due to COVID-19

Information on COVID-19 and Cancer

Reducing Risk

3 Ways COVID-19 is Changing NET Treatment

Social Distancing

Facing the Risk of Serious Illness

When Someone is Sick
I hope that all of you and your families are safe and well. Our hearts go out to everyone trying to meet the challenges of stay-at-home orders, remote work, homeschooling, and maintaining one's physical and mental health. We especially recognize the health care providers on the front lines, first responders, and all essential workers serving our needs.

Some of you have asked me about what happens with research during this international crisis, particularly NETRF-funded projects. Our grantees in the US and throughout the world tell us their projects are paused and labs have been closed to protect the staff. "Mission-critical" work to maintain cell cultures and other animal models continues so these essential resources will not be lost. Some of the researchers can continue their data analysis research activities from home. Work may be delayed but our grantees are committed to their NET research.
Lessons Learned

• Focus on what your community needs from you and can’t find elsewhere.
• Time stamp the materials because information changes quickly.
• It’s okay if you do not have all the answers—patients understand that but want to make sure they haven’t missed anything.
• Make it easy for your Board members and experts to help you.
• Focus on mental as well as physical health.
• The plan should be flexible as needs change.
Questions?

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Senior Manager of Education Programs, NORD

Kristin Smedley
Chief Executive Officer, Curing Retinal Blindness Foundation

Josephine Grima, PhD
Chief Science Officer, The Marfan Foundation

Elyse Gellerman
Chief Executive Officer, Neuroendocrine Tumor Research Foundation

rarediseases.org
Thank you.