



HEREDITARY
NEUROPATHY
FOUNDATION

CMT & COVID-19 FAQ

**Disclaimer: This webinar content is not intended to be a substitute for professional medical advice, diagnosis, or treatment. COVID-19 is a real threat and people with neuromuscular disease are considered to be in the “high risk” category. Due to the nature of the content of this webinar, some may be sensitive to what is being presented. Always seek the advice of your physician or other qualified health provider with any questions you may have regarding a medical condition.*

Click Below for Full Webinar:

<https://www.hnf-cure.org/covid19>

Respiratory weakness is only recently being acknowledged as a symptom of CMT, so there is still a lot that we, as patients, need to learn regarding standard of care so that we (and our loved ones) can be our best advocates. Having CMT doesn't necessarily put you in the “high risk” category for COVID-19, but if you have a weak diaphragm and reduced lung capacity please keep reading for answers to the most frequently asked questions.

On March 20, 2020, HNF teamed up with Dr. John Bach (full credentials on pg. 4) of Rutgers Medical School to answer some of our community's most vital questions regarding pulmonary health and the specific risks and precautions pertaining to COVID-19.

DR. JOHN BACH, MD - RUTGERS MED. SCHOOL

CMT & COVID-19

CMT
CONNECT

HEREDITARY
NEUROPATHY
FOUNDATION



Should I be concerned about the effects of COVID-19 due to my CMT/HNPP diagnosis?

If you have respiratory issues, yes, you may be considered “high risk” and you should take proper precautions such as isolation, frequent hand washing (for a min. 20 seconds), disinfecting surfaces, staying at least 6-9 feet away from anyone who may have been exposed to COVID-19. It can be spread by someone who is asymptomatic. The incubation period is from 2-14 days.

Studies show that the COVID-19 virus remains:

- In the air for up to 3 hours
- On cardboard for up to 24 hours
- On plastic and stainless steel for 2-3 days

What are the classic symptoms of COVID-19?

- Fever (101°F)
- Muscles aches
- Shortness of breath
- Cough

What are the dangers of COVID-19 for people with neuromuscular disease?

The biggest danger is that if you are intubated, as you recover from the pneumonia the doctor will try to ween you from the ventilator. If the doctor feels it is not possible to extubate you quickly to CPAP or BiPAP (possibly with inadequate spans), it can be fatal. Let your family members know that they should NOT immediately accept a trach tube, but contact/use Dr. Bach’s procedures for extubation for neuromuscular patients. (see webinar at about 57:00 and attached .pdf)

Is it possible for people with CMT to have diaphragm problems without knowing it?

It may be possible, yes. Things that you can ask yourself to determine if you have a weak diaphragm include:

- Do you sleep mainly on your side because you can’t breathe well when you’re on your back (orthopnea)?
- Are you unable to take a deep breath and hold it for 20 seconds?
- Do you have fatigue, sleepiness during the day?
- Do you have morning headaches?

If you answered yes to these questions, you may consider visiting a pulmonologist (preferably one that understands neuromuscular disease - see Dr. Bach’s list of [centers](#))



Dr. Bach does *not* recommend a sleep study. Patients with a CMT diagnosis and limited lung capacity should be approved for Respiratory Assist Device (RAD) by insurance - [here](#) is a link to the Medicare guidance on treating with RAD.

What should I do if I'm short of breath and put on oxygen?

Dr. Bach suggests you let the HCP know that you have a neuromuscular disease that weakens your diaphragm and limits your ability to expel CO₂, so they'll need to be prepared to intubate you if you stop breathing. "No O₂ without ventilation" is the rule.

Is it safe to return to work next week?

Dr. Bach advocates isolation and social distancing for everyone at this time. The more quickly we stop the spread of COVID-19, the more quickly we can all go back to our normal lives.

What exercises can I do to increase my lung capacity?

Lung volume recruitment exercises include [breath stacking](#), and "[frog breathing](#)" or Glossopharyngeal Breathing. This will keep your lungs functioning at their best capacity.

Can COVID-19 cause further progression of CMT?

As with any virus, CMT patients often take longer to get over it completely and they often do experience progression of muscle weakness.

How do I use CoughAssist?

The CoughAssist settings are always the ones that give the highest flows. That is almost always 50 to 60 cm H₂O in and out to full chest expansion then full chest retraction. It is not complicated! Do it manually to determine times if you want to use automatic but manual is often better.

CoughAssist should also be used during extubation as per Dr. Bach's guidance (see .pdf)

What four tools does Dr. Bach recommend all clinics with neuromuscular patients have?

1. Peak Flow Meter (like [this](#)) to measure cough strength
2. Oximeter (like [this](#)) to measure oxygen saturation in the blood
3. CO₂ monitor (capnogram)
4. Spirometer (like [this](#))

Dr. Bach's instructions for use of cough assist with pneumothorax (collapsed lung) are at the 1:32 mark in the video.



HEREDITARY
NEUROPATHY
FOUNDATION

Our team at HNF remains as dedicated to the CMT community as ever. If you find this information valuable and can support our continued efforts towards providing education, programs and research to the CMT community, please make a donation here. <http://weblink.donorperfect.com/CMTConnect>

Book Info: **Noninvasive Mechanical Ventilation**

This book describes the use of inspiratory and expiratory muscle aids to prevent the pulmonary complications of lung disease and conditions with muscle weakness. It also describes treatment and rehabilitation interventions specific for patients with these conditions. This book is unique in presenting the use of entirely noninvasive management alternatives to eliminate respiratory morbidity and mortality and avoid the need to resort to tracheostomy for the majority of patients with lung or neuromuscular disease.

Philadelphia: Hanley & Belfus 2002, 600 pages, 200+ illustrations. Here is a [link](#) to buy his book on Amazon (1:47:30)

To buy this book directly from Dr. Bach at the reduced price of \$25, please send a check to:

Dr. John Bach
536-28th Street
Union City, N.J. 07087

More articles on extubation from Dr. Bach:

<https://www.hnf-cure.org/wp-content/uploads/2020/03/2010-197-Extubation.pdf>

<https://www.hnf-cure.org/wp-content/uploads/2020/03/2015-235-MIE-extubation-Resp-Care.pdf>

John R. Bach, M.D. has written 7 books and 450 articles and book chapters on managing people with neuromuscular insufficiency and failure and the extubating and decanulating of patients who are unable to breathe unaided. Dr. Bach is a professor at the UMDNJ-New Jersey Medical School where he is currently: (a) Professor of Physical Medicine and Rehabilitation, including Research in Physical Medicine and Rehabilitation and Neuromuscular-Pulmonary Rehabilitation; (b) Vice Chairman of the Department of Physical Medicine and Rehabilitation; (c) Professor of Neurosciences in the Department of Neurosciences; (d) Director of Research and Associate Medical Director of the Department of Physical Medicine and Rehabilitation at University Hospital, Newark, N.J.; (e) Co-Director of the Medical School's Jerry Lewis Muscular Dystrophy Association Clinic; and (f) Medical Director of the Center for Ventilator Management Alternatives at University Hospital, Newark, N.J. He is also a fellow of the Association of Academic Physiatrists, the American College of Chest Physicians, and the American Academy of Physical Medicine and Rehabilitation.

Have additional questions? Email us at info@hnf-cure.org

For more resources on Charcot-Marie-Tooth, visit hnf-cure.org