

COVID-19 and MYOSITIS, LIVE Q&A WITH DR. LISA CHRISTOPHER-STINE AND DR. CHRISTOPHER MECOLI

Additional Q&A from the session

Due to the large number of questions received during the live webinar, Dr. Lisa Christopher-Stine and Dr. Christopher Mecoli graciously agreed to provide written answers to questions they were unable to address. The answers to the patient and caregiver submitted questions are provided in blue below.

If you have not yet watched the recorded version of the live Q&A webinar, visit <https://understandingmyositis.org/covid-19-and-myositis-live-qa-webinar/>

Precautions

If someone inside your house gets sick and starts having COVID-19 symptoms, what should we do? Do we try and find somewhere else to stay (then possibly further spreading if we have it but are not yet showing symptoms?) or wait it out at home and possibly be exposed since we are in tight quarters.

This is a personal decision but ideally, staying in separate quarters as much as possible, having the sick person wear a mask around you and trying not to use the same bathroom is ideal. As always, clean high touch surfaces often. These include but are not limited to counters, kitchen/dining chair backs, doorknobs, faucet handles, and light switches.

What should we do, aside from the standard precautions to take, if we have interstitial lung disease (ILD) or pulmonary fibrosis?

There are no other known recommended precautions to take as far as we are aware.

How do we handle a family member if they show COVID-19 symptoms and get sick, especially if the individual is the main caregiver to a (polymyositis) patient? And how can we prepare to avoid this scenario, or at least know how to prepare if it happens?

These are individualized decisions and the best advice here is to have a plan in place BEFORE anyone gets sick – specifically who can help you in the event of such a scenario? You should designate another caregiver and get permission from that person

ahead of time. This may be a close friend or family member. Obviously, that person must recognize that they are also at risk and would need to be extra cautious with wearing a mask and practicing meticulous hand hygiene, etc.

Current Treatments

Should we stop immunosuppressive drugs?

No. There is no convincing data that says to do this. You may be slightly more susceptible to infection but it is possible that immunosuppressive drugs may dampen down the exuberant immune response that may be contributing to more severe disease. In addition, patients with unbridled autoimmune diseases are also a susceptible host to the virus so stopping medications, and potentially precipitating a flare, is surely not suggested.

Why are Plaquenil and IVIG not considered immunosuppressive?

They are considered immunomodulatory agents. They manipulate the immune system but do not actually suppress it in the traditional sense.

Should we continue our regular infusions?

Likely yes. This is an individualized discussion with your doctor, as some patients may be able to push out their infusion a little farther when it may be a bit more safe to do so as the number of community spread COVID infections will hopefully decline in the coming months.

Will there be drug shortages of life-saving medications?

There is always the possibility of drug shortages in a pandemic. These are unpredictable but everyone is aware of this possibility and trying to be anticipatory so it does not happen.

My UCSF team of doctors has tabled recommending Rituxan and IVIG during this period. At what point does this delay become harmful?

See above. This is an individualized answer based on each patient's unique circumstances and disease state.

Is it known to what extent Prednisone can have a beneficial effect on the airways and lungs in those affected by COVID-19. Is the benefit dose dependent?

No. This is not yet known. Large registry studies are underway to answer these types of questions, but this data will likely not be widely available for quite some time.

How can we continue to safely exercise at home?

We recommend utilizing YouTube videos or similar and always having someone nearby for safety reasons if you do not live alone. If you do live alone and you have the ability to have an Apple Watch series 4 or higher, you can enable fall protection on it and it will alert EMS (emergency services) if you fall unexpectedly.

What may be some steps for those not able to refill prescriptions? Aside from asking our own doctors, what are some thoughts?

It is not clear if you mean this is from a prescription shortage issue or a fear of utilizing a pharmacy due to possible infectious risk from exposure to others. If it is the first point, unfortunately there is little that we can do other than to try to enact procedures to prioritize these drugs for our patients and those who really need them. Such protocols are in place throughout the US in order to try to avoid this scenario. If it is the latter, many pharmacies have delivery services for your prescriptions.

COVID-19 Related: Treatments, Research, Testing

Regarding IVIG - Would this be helpful in treating COVID-19?

Not likely at this stage as there is no IgG with COVID antibodies in the product yet. There may be some benefit from passively transferred antibodies once the IgG supply includes donors who have recovered from COVID-19. IgG by itself may help the immune response in a generic fashion but it is unknown as to whether it will confer any benefit to COVID prevention or shortening the disease or lessening the severity if one were to contract the virus.

Testing is obviously good, especially if the results are positive, but why is nobody pointing out that a negative is not necessarily a negative. One could have the virus, but have a viral load not high enough yet to test positive. Also, anyone who tests negative could still contract the virus. It could be bad if people took it as an excuse to let their guard down.

This is all true! We know that there are certainly false negatives but essentially no false positives.

Is there any new timeline for the availability of a vaccine or a serology pinprick test?

Unfortunately nobody knows this. The average time to a vaccine is one year. Even with heroic efforts, I do not think we are likely to see a vaccine in this calendar year, as it must be adequately tested for safety and efficacy. In the rush to get a vaccine to the public, you cannot compromise the safety of others in that process. It is a fine balance but everyone appreciates the urgency with which a vaccine is desperately needed here.

Is the research supportive of a patient immunity once they've had the disease? How can we be reasonably safe without being SO stressed out about everything COVID related? (It is kind of exhausting). Is there a sense in the medical community about when we might be able to achieve "herd immunity?" In other words, when can we begin to hope (emphasis on hope) that things will start to simmer down a bit?

These are all questions without clear answers right now. The best advice for stress is to distract yourself with a new skill, academic course on line etc. Limit news viewing, as it is very anxiety provoking and can most definitely contribute to an altered immune response.

There are too many unknown variables to predict herd immunity with any precision, as we still do not have widespread serologic testing to find out who has already been exposed and how many asymptomatic resolved infections are in the community.

It is also unknown whether once someone recovers from COVID infection how long, if at all, they will remain immune to the disease. There are isolated reports of reinfection in some Asian countries but this is poorly understood.

What is the infection rate compared to the general population vs. immunocompromised and then the death rate once an immunocompromised person gets COVID-19 if those statistics are available? Realizing this information would likely be from foreign countries.

This is unknown.

Question about Advance Care Directives

Mine currently states that I don't want to go on a ventilator. Given CV patients may end up on a ventilator, where can I get some thoughts and advice and guidance on updating my ACD – what are the chances of coming off the vent? This is my main worry at the moment.

This is an excellent question and again is variable by patient. In general, "do not intubate" (DNI) and "do not resuscitate" (DNR) orders are in place for conditions with a poor prognosis. COVID is unpredictable, and while older patients with comorbidities do

less well, many can still recover. You may want to alter your advanced directive to state that withdrawal of care should occur after a certain amount of time, with lack of improvement, etc. Many patients with COVID are on ventilators upwards of two or three weeks, yet some of those patients are recovering. Thus, thinking about this, your advanced directives should reflect your wishes. It is much harder to withdraw care than not to intubate in the first place, but there is clearly still a chance of survival and it is not negligible, so short term ventilation (under one month, for example) may be an option to consider. But be clear about withdrawal of care instructions. Loved ones want to know that they are honoring the person's wishes and withdrawal of care creates the largest conundrum for both healthcare workers and patient's healthcare decision makers. Having a discussion with your health care proxy/designee about your wishes is also important.

Additional in-webinar Q&A

Is it true that comorbidity is more important than age although with age often comes comorbidity?

This is not known.

Thoughts about immunosuppressed patients working in direct patient care as health care providers?

Only if you must. This is a high risk and if you are required/essential, then make sure you have adequate personal protective equipment (PPE).

I'm recently diagnosed with DM vs Polymyositis and was put on 100 mg of Prednisone. Now I'm on 80 mg. Since being on Prednisone I developed tachycardia and restrictive airway disease. I'm a very proactive type of person. Is there anything I can suggest or present to my Provider to prevent any other risks. Also, what medication do you typically prescribe for newly diagnosed DM vs Polymyositis patients?

Unfortunately without a clinical evaluation, I cannot adequately address these questions.

Could you address DM and Plaquenil allergies? Should it be avoided if needed to treat COVID-19?

It depends on what is meant by "allergies" If a severe skin rash develops then yes, it likely should be avoided if one were to contract COVID.

During the webinar it was mentioned that steroids such as Prednisone can mask a fever. Is this true for many. The higher the dose, the more likely to have this happen. Is this true for all/majority of people? Does it mask it at low doses (5mg) as well as higher doses?

It is true for most but higher doses are likelier to be associated with this phenomenon. 5mg of prednisone is close to physiologic levels of cortisone so it is less likely to blunt a fever than a higher dose, for example 20 mg and above.