

TMA Patient Conference & COVID

Protect Yourself, Protect Your Friends, & Enjoy the Conference!

(with TMA MAB interview!)

(Adapted from CDC Advisement with Myositis-specific Detail from the TMA Medical Advisory Board)

Masks Are Recommended



A well-fitting mask protects you and those around you during travel and in public places.



Help keep travel safer for everyone.



cdc.gov/covid19travel

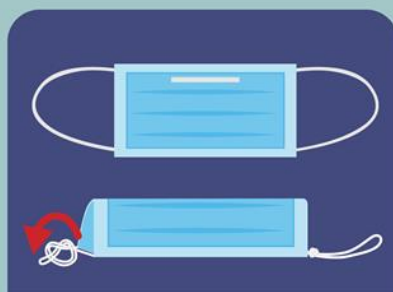
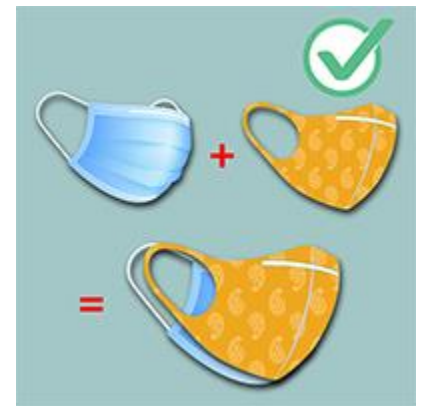
Wear a Mask to Protect Yourself and Others

- Masking is a critical public health tool and it is important to remember that any mask is better than no mask.
- Wear the most protective mask you can that fits well and that you will wear consistently. **KN95** is preferred when possible.
- Wearing a high-quality mask along with vaccination, self-testing, and physical distancing, helps protect you and others by reducing the chance of spreading COVID-19.

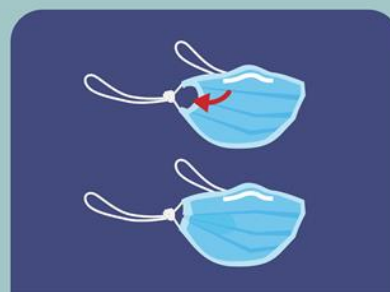


Ways to have better fit and extra protection with cloth and disposable masks

- Wear two masks (disposable mask underneath **AND** cloth mask on top)
- If possible, it's best if one of the masks is a **KN95** mask
- Combine either a cloth mask or disposable mask with a fitter or brace
- Knot and tuck ear loops of a 3-ply mask where they join the edge of the mask
 - For disposable procedure masks, fold and tuck the unneeded material under the edges. (For instructions, see the following <https://youtu.be/GzTAZDsNBe0>)



Knot the ear loops



**Fold and tuck in
unnneeded material**



Check for close fit

Use masks that attach behind the neck and head with either elastic bands or ties (if preferred instead of ear loops)



Before You Travel:

Make sure to plan ahead:

- Get [up to date](#) with your COVID-19 vaccines before you travel.
 - Find out [when](#) and where to get a [booster](#).
 - COVID-19 vaccines are effective at protecting people—especially those who are boosted— from getting seriously ill, being hospitalized, and even dying.
- If you have a [weakened immune system](#) or [are at increased risk for severe disease](#), take multiple prevention steps to provide additional layers of protection from COVID-19 **even if you are up to date with your COVID-19 vaccines**.

Testing:

CDC RECOMMENDS:

- Getting tested with a viral test as close to the time of departure as possible **on day of travel** (and no more than 3 days) **before** travel.
 - Make sure you know your test results before travel.
 - Don't travel if your test result is positive.
 - Find a COVID-19 testing location near you or use a self-test.

Can I travel if ...?

(think: Can I attend conference sessions if...?) 😊

We have all been inconvenienced in so many ways because of COVID-19; however though we may be disappointed by testing positive for COVID, we have learned to 'roll with life' - *we know we must honor safety first.*

I am sick with or [tested positive](#) for COVID-19 and am recommended to [isolate](#)?

- **Do NOT** travel.
- Follow recommendations for [isolation](#).

I ended isolation but still need to continue wearing my mask per [CDC's guidance](#)?

- Do not travel on public transportation such as airplanes, buses, and trains if you will not be able to wear a high-quality mask or respirator when around others indoors for the full duration of your trip.
- If you travel, wear a high-quality [mask](#) or respirator the entire time you are around others indoors.
- Traveling by private vehicle (if possible) can lower the chances of spreading COVID-19 to others.

I was exposed to a person with COVID-19 in the past 10 days?

- Follow [CDC guidance](#), including getting tested at least 5 full days after your last exposure.
- Do not travel on public transportation such as airplanes, buses, and trains if you will not be able to wear a high-quality mask or respirator when around others indoors for the full duration of your trip.
- If you travel, wear a high-quality [mask](#) or respirator the entire time you are around others indoors.
- Traveling by private vehicle (if possible) can lower the chances of spreading COVID-19 to others.

During Travel: In-Flight and Airports

Protect Yourself and Others

RECOMMENDED

- Follow CDC's [recommendations for wearing masks in travel and public transportation settings](#).
- Follow [recommendations for protecting yourself and others](#).
- Follow all [state, tribal, local, and territorial health recommendations and requirements](#) at your destination.

TMA COVID PRECAUTION MEDICAL ADVISORY POD



Cheilonda Johnson



Julie Paik



Malin Regardt



Lesley Ann Saketkoo



Chrissy Thornton

Chrissy Thornton (TMA CEO) Interviews Dr. Lesley Ann Saketkoo (TMA Medical Advisory Board Member):

on Protecting Yourself, Protecting Your Friends, & Enjoying the Conference!

Chrissy Thornton: Welcome, Lesley! Very much looking forward to seeing you at the conference!

Lesley Ann Saketkoo: Chrissy Thornton – me too! Thank you and the TMA team so much for this great opportunity to learn together! I LOVE the motto: **Protect Yourself, Protect Your Friends, & Enjoy the Conference!**

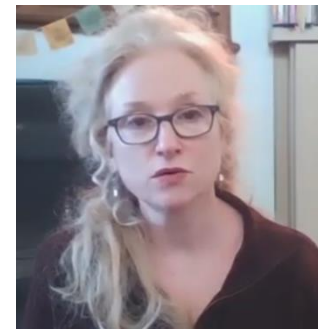
Chrissy Thornton: Lesley, can you tell us how COVID-19 has influenced the way you support your patients with myositis?

Lesley Ann Saketkoo: So, the past couple years have been particularly more challenging than usual in trying to support our patients in living their lives as fully as possible. This is obviously because of the very extreme risks presented by having COVID-19 in our world. At first it was tremendously shocking and we all went into hypervigilance mode because our patients are so vulnerable.

Since then we have learned a lot on how to protect ourselves and patients– and how to support their desires to live a fulfilling and contented life during COVID-19. My friend **Dr. Julie Paik**, who will also be at the conference, has been a major contributor of our current knowledge regarding vaccines and patient vulnerability. Now we can feel more confident advising patients on travelling even internationally - and be able to attend important events like the TMA Annual Patient Conference 😊

Chrissy Thornton: Lesley, can you explain a bit why people with myositis are considered a more vulnerable group in terms of COVID-19?

Lesley Ann Saketkoo: Chrissy, that is an important question. People with myositis are considered vulnerable for multiple reasons. Having an autoimmune disease (unless it's absolutely controlled) is a condition of a disorganized and dysfunctional immune system. So even though 'auto-immune' sounds like the immune system is 'over-active', it really is sometimes 'too un-coordinated' to protect us. On the flip side, some of the medications



used to control most types of autoimmune myositis, also depress the immune system. Thus, making people with myositis vulnerable in yet another way.

Many people living with myositis possibly have several types of lung challenges, that make them vulnerable in yet another way. In addition to interstitial lung disease (ILD), a proportion of patients may have a weakened diaphragm or chest wall muscles that may cause the strength of ones breathing to be somewhat impaired. There are also other heart and lung difficulties that a person with myositis might have that makes them further vulnerable.

Further, we are uncertain why, but it seems that people living with myositis ILD have a higher infection risk than other people with autoimmune-related ILD. I've had several patients with myositis who contracted COVID and did okay; but I've also had patients whereby COVID made their myositis much worse and required rehabilitation after hospitalization. So obviously it is crucial that ***we are protecting patients – and protecting each other.***

Chrissy Thornton: So Lesley, what do we know on how to protect patients?

Lesley Ann Saketkoo: We know vaccines are SAFE and an important LIFE-SAVING opportunity for our patients. Now we have a better idea of how frequently our patients should be receiving COVID-19 boosters which is approximately 5 months after the prior COVID-19 vaccine administration – which is when vaccines begin to lose efficacy. We have also learned that vaccines for patients and their family lessen the impact of COVID-19 for patients. However, as great as vaccines are, they are not fully protective – and therefore masking in **public indoor places** and **crowded outdoor places is important.** And **social distancing** is still a key factor in prevention. 😊

Chrissy Thornton: Great, is there anything special you tell your patients, Lesley, to support them when they travel and gather in public places?

Lesley Ann Saketkoo: We want our patients to be able to travel and to have as many fulfilling life experiences as possible – like attending the TMA Conference 😊. And we also want them safe!

Firstly, get your VACCINE on!!! Make sure you're up to date – around 5 months since the previous vaccination ... it's time!

Secondly, **eating outdoors at restaurants** is not only pleasurable but the safest option for a person with an autoimmune disease. I always remind my patients to wear sun protection when dining outdoors during the day - regardless of skin color (!). This is

because autoimmune diseases and many of the medications used to treat them make a patient's skin more **photo-sensitive**.

When eating on a long haul flight, I advise patients to **drop their mask between sips and bites** 😊 . **Another tip:** regarding one's seat, one can easily splodge a bit of hand sanitizer on napkin (or use an anti-bacterial wipe) to wipe down their seat tray, knobs, buttons and arm rests.

Thirdly, I advise patients to double mask in public places which includes airport, grocery stores, conferences 😊 and on public transportation like buses, car services, trains, planes, etc. Multiple layers provide more protection. This can be a combination of cloth and paper type mask – or double cloth – or double paper type mask. As long as the seal is good, nose and mouth are covered with no gaps! I remind patients to **pinch the metal strip** to form a seal over their nose.

Fourthly, I let patients know about clear face shield visors that are the length of face from forehead to below the chin. It can be used on public transportation –**in addition to masking**. It creates an additional impermeable layer between one's face and the public which possibly adds a bit more protection – **but does not take the place of double masking!** I always travel with my shield – because I feel more secure that I won't be unknowingly passing COVID on to my patients.

Also at the top of the prevention list is, wash hands or sanitize before touching face – and visa versa – when touching your own face wash or sanitize hands afterward – this is also true to prevent transmission of other airborne viruses like the flu!

Chrissy Thornton: What are some of the barriers do you think people living with myositis face in relation to COVID-19 precautions.

Lesley Ann Saketkoo: One of the biggest problems is that people with chronic diseases can feel stigmatized and different or feel like their making a 'big deal' or focusing too much attention on themselves because of their vulnerability. So here we have YET ONE MORE WAY our patients have to muster their inner strength– and remember they are worthy and their lives are valuable – and that SELF-PROTECTION is REAL.

Chrissy Thornton: OK! I agree with that, Lesley!

Lesley Ann Saketkoo: I know you do, Chrissy!! You are an inspiration to me as a CEO! You always have the patients' best interest at heart!

Chrissy Thornton: Awww thanks, Lesley. But let me ask you this: What about testing before arriving to and during the conference?

Lesley Ann Saketkoo: Chrissy.. do you EVER ask a bad question?! I don't think so!

Well, ideally all attendees will test on their travel day, before heading to the airport. And ideally, all attendees (including faculty and staff) will test in the morning on each day.

And if positive, we know the drill >> **DON'T TRAVEL!** And if any of us test positive at the conference >>> **we ISOLATE!!!**

Chrissy... now let me ask you a question! What will happen if a person tests positive at the conference?

Chrissy Thornton: Great question, Lesley! It's our hope that the TMA Patient Conference will demonstrate **that vulnerable people can travel, congregate and live their lives fully despite COVID...** and also that **vulnerable people are awesome at protecting each other!** In the case of an attendee testing positive for COVID on any of the conference days:

1. we ask them to **let us know as soon as possible** by contacting tma@myositis.org
2. we ask them to **contact their physician immediately**, as they might be a candidate for oral treatment. In this case, the hotel will advise on pharmacies that deliver to the hotel.
3. we ask them to **stay in isolation**, do not socialize in-person. Do not feel ashamed be proud that you have done the right thing by isolating. Letting your co-attendees know through virtual methods is perfectly OK and is encouraged.
4. TMA will make sure the attendee can have meals delivered to their room

Lesley Ann Saketkoo: Wow, Chrissy! That is very forward thinking of TMA. So glad to be attending this meeting. Looking forward to a GREAT and SAFE conference!!

Chrissy Thornton: So glad to have you, Lesley! And thank you for our chat!