

AIR-P Presents: COVID-19 Vaccine, I/DD Populations, and the Needle Anxiety Program at UCLA  
Presentation Transcript

>> Good afternoon, everyone. We're just going to give it a couple minutes to let everyone join.

>> Hello, everyone. Welcome to the webinar series for the Autism Intervention Research Network on Physical Health, the AIR-P. My name is Kashia Rosenau. I would like to provide a few logistical details. I will provide a brief introduction for our speaker, and we will also reserve time for questions at the end of the presentation. Because of the number of participants, your audio will be muted throughout the call. However, you can submit questions at any point during the presentation via the chat box on your webinar console. This entire webinar is being recorded and it will be available on the website. There will also be a short evaluation survey at the close of the webinar. We invite you to provide feedback on this webinar and also to provide suggestions for future webinars as we appreciate feedback on the content of the monthly webinars hosted by the AIR-P. In the interest of time, let's get started. So, first we want to acknowledge our funding source. And now it is my honor to introduce the principal investigator and director of the AIR-P, Dr. Alice Kuo. Dr. Kuo is a professor from UCLA.

>> ALICE KUO: Thank you for having me. Let's get started because we have a lot to cover. As we know, we are going into the 12th month of a global pandemic. The COVID-19 condition is caused by the SARS-CoV-2, which was first discovered in Wuhan, China in December of 2019. The WHO, the World Health Organization declared the global pandemic on March 11, 2020. It's hard to believe it's been that long ago. As of today, there are over 109 million cases worldwide and over 2.41 million deaths. What is the best response during a global pandemic? For many of us, this is the first major global pandemic that we've been through. I want to credit the UCLA Health Marketing Team for putting together some of these slides. They are California specific or even Los Angeles. But during a pandemic, the best response is to follow the guidance of our public health officials. Nationally, this is the centers for disease control and prevention, or your state or local public health department. What we have learned over the course of the last year in managing our pandemic is to wear universal

masks, keep physical distance or social distancing, wash hands frequently, wipe down high-touch areas, and then symptom screening, meaning that if you are sick or have any symptoms, you should not leave your home.

A vaccine is a valuable tool for fighting a pandemic. So, with the news of the COVID-19 vaccine a couple of months ago, we now have a valuable tool to finally end this pandemic. The benefits of a vaccine is that with herd immunity, we can protect those among our community who cannot be vaccinated. How does the body fight an infection? In order to understand how a vaccine works, we need to understand how our immune system works. So, just like other systems in our body x our immune system is there to protect, our immune system is there to protect our total body against germs, which can be comprised of bacteria to viruses. The COVID-19 condition is caused by a virus. The immune system is stimulated to produce antibodies. I liken these antibodies to soldier cells. They will neutralize the

infection from causing any infection in your body. The way the vaccines work is they contain a code or a protein that stimulates the immune system to produce a particular antibody to fight the virus effectively. How are the COVID-19 vaccines should

to be effective? I just want to emphasize that these vaccines have been approved by our Food and Drug Administration, which is a regulatory body for all medications and drugs or injections in the United States.

So, in order for a new medication or vaccine to be proved, there are three phases of clinical trials. Phase I comprises of about 20-100 healthy volunteers. And the main focus of phase I is to know whether the vaccine is safe. We entered phase I for the COVID-19 in early summer of last year. In phase II, there were several hundred volunteers who started looking at the common side effects, as well as the actual immune response to the vaccine. And this was around June and July of 2020. Phase III comprises of thousands of volunteers. And for each of the FDA-approved vaccines, about 16-20,000 volunteers were used to determine the effectiveness of the vaccine. This is the most important phase of the clinical trial. This clinical trial phase III went from July 29th of 2020 into the fall. And around November, there were sufficient data to submit to the FDA for emergency use authorization. The FDA went through its complete regulatory process and the FDA will only license the vaccine if it's safe and effective and the benefits outweigh the risks.

To date, right now, there are two COVID-19 vaccines that have been authorized for emergency use by the FDA. The Pfizer-BioNTech one and the Moderna. These are the names of the pharmaceutical companies that produced the vaccine. They were both approved

relatively at the same time in the middle of December. The Pfizer vaccine is approved for individuals as young as 16 years of age, because there were 16 and 17-year-olds in the clinical trial, and the Moderna is approved only for adults, 18 and above. Both of these vaccines require two doses. For Pfizer it's 21 days apart. For Moderna, it's 28 days apart. The vaccine is administered as an injection into the muscle. Basically, if you go to the edge of your collarbone, the top of your shoulder and you feel the hard bone, you take two finger breadths below that and that will get you right to the belly of the deltoid muscle in either arm. And just to note, you must receive the same vaccine for both doses. If you start with the Pfizer vaccine, the second dose must be Pfizer. If you start with the Moderna vaccine, the second dose must be Moderna. You cannot mix and match. How effective is the vaccine? It is extremely effective. Based on the clinical trials, it is 95% effective after the second dose. People have asked, and this is a common question, how effective is it after the first dose? I have asked my infectious disease colleagues, and they said Pfizer is 50% effective after the first dose, and Moderna is 80-85% effective after the first dose. However, after receiving the second dose, which is a booster, both were 95% effective and a person is considered immune to COVID-19 two weeks after receiving the second dose. How does the COVID-19 vaccine work? Well, we know that COVID-19 is caused by a coronavirus, and "corona" means crown in Latin. So, if you see in the diagram the blue coronavirus. It looks like a crown because it's a circle and then there's pins, the spikey things, surrounding the circle. That is the virus. And if you are exposed to the virus, meaning the virus enters your body through one of your mucous membranes, then you have a likelihood of getting sick from it. The virus will bind to one of the receptors on one of your cells. The receptor is the little Y on the bottom. You can imagine how the spikey knob would go into the cup part of the receptor, and then the receptor draws the virus into the cell and then you have the likelihood to get sick because the virus can then replicate. The way that the vaccine works is because it stimulates your immune system to produce antibodies, those soldier cells that I was talking about. The antibodies are depicted by the yellow Y's. That's the shape of the proteins. What happens is those antibodies bind the spiking parts all around the virus. Once it's covered with antibodies, when the virus comes near one of your receptors on the cell, it can't get into the cup. It can't lock in. The antibody blocks that

receptor binding. And so the virus is neutralized in your body and can't get you sick.

Is it better to get vaccinated or contract the disease naturally? This is a common question and it is better to get vaccinated. What the scientists have seen is the immune response, the level of antibodies are much greater with the vaccine than people who just contract the virus naturally and then get over the illness. The new technology that is with this vaccine is mRNA. And this mRNA is a very effective code to instruct your immune system to create the right antibody, and not only does it produce the right antibody, but in large quantity.

You can imagine if you have a lot of virus that you've been exposed to, you need a big antibody response in order to neutralize all of those viruses. So, the definitive answer is that it is better to get vaccinated. Why get the vaccine if most people don't die from COVID-19?

Well, as of February, this month, COVID-19 has killed more than 485,000 in the U.S. And this is more than any other virus that we routinely vaccinate against, like influenza. This vaccine is needed, number one, as a long-term strategy to end the pandemic, but to protect ourselves

from any complications if we were to contract COVID-19 and to also protect those among us in our community that cannot get vaccinated.

What is the vaccine distribution plan? So, you may have heard this has been in the news a lot lately. And the CDC has recommended a tiered-approach in order to determine how the vaccine will be distributed because we currently have such

a severe vaccine shortage in the U.S. I'm sure that every community has some sort of prioritization scheme very similar to this one. This one just happens to be the one we're using in Los Angeles County.

But the first group to be vaccinated were our healthcare workers, which are those frontline defense in the hospitals treating and taking care of patients. Healthcare workers needed to be vaccinated, and those who were at highest risk of death from COVID-19, which were nursing home residents. Those were the biggest priority in Los Angeles county. Now we're getting into other groups. A large percentage, about 85%, of those in our hospitals who have died of COVID-19 are individuals over the age of 61. And for that reason, senior citizens were prioritized next. There's recognition that essential workers need to be prioritized because they're at greatest risk for contracting COVID-19. And then individuals who have chronic illnesses or medical conditions or are developmental disability are prioritized next. These are the prioritization categories before the general public. So, we're here right now with a limited supply. We're sort of limited to additional. So, in many parts

of the country we have moved onto other priority groups. At least I can only speak to Los Angeles County.

In the last 2-3 weeks, we started doing senior citizens. We're still very early in the vaccine distribution plan before we can offer it to the general population. My understanding from the pharmaceutical companies is that they are capable of manufacturing about 12 million doses a week. And so as of today, in the U.S., about 53 million doses have been administered, but remember we have 331 million people in the country. Because it's a 2 dose vaccine, the 53 million doses is sort of mixed between whether they were first or second doses. 11% have received their first dose, and only about 4% of our country has been fully immunized. So, in order to reach herd immunity, the scientists are predicting anywhere from 70-80% or 85% of the population need to have been immunized. We're a little bit of a ways from that, but it's a great start. Other countries such as the U.K. and Israel are much further ahead.

So, turning to the populations that we care for, in December 2020, the Committee on Immunization Practices COVID-19 Working Group issued these recommendations that are on the CDC for prioritizing.

And the vast majority of individuals with intellectual or developmental disabilities were absent from these priority guidelines. If you go to the CDC website under certain medical conditions that should be prioritized, Down Syndrome is listed, but that is the only one.

I/DD populations are at risk, because early evidence suggests that the I/DD population is disproportionately susceptible to COVID-19. These individuals in these populations have more severe illness, are at greater risk for hospitalization, have twice the fatality rates, and they also may have difficulty with masking or following social distancing guidelines.

And so because of these reasons it would seem prudent to prioritize I/DD populations beyond just Down Syndrome for the COVID-19 vaccine.

When we look historically, the health outcomes for I/DD populations have always been challenging. This population has historically grappled with fragmented access to preventive care and primary care and that is probably at the root of a lot of the challenges that they face for their health. There's also been historic social and medical stigma and marginalization that continues to this day. And there's a higher prevalence of co-occurring medical, physical, or mental health conditions, which may affect their other chronic conditions. And if you have the sort of intersection of I/DD and other minority groups, such as racial and ethnic minorities, the conditions or outcomes can be even worse. So, we

became very concerned in AIR-P that the exclusion of I/DD populations on the certain medical conditions list from the CDC for vaccine prioritization represented yet another barrier to this population that would have significant health consequences. So, we anticipate this will have challenges for the vaccine rollout. We really wanted to join the effort to prioritize I/DD populations for the COVID-19 vaccine, because it seems as though advocacy is needed as with other groups that are concerned with the not being prioritized for the vaccine.

So, I just wanted to say that the advocacy has been pretty impressive. I just Googled disability and COVID-19 vaccine, and this is what came up on Google. So, this was just even in the last, you know, days to weeks. A lot of awareness being raised locally in order to change guidelines and to include I/DD populations in a prioritization for the COVID-19 vaccine. In AIR-P, we wrote our own commentary. I wanted to give a shout out to Emily Hotez, a member of our leadership team, one of our scientists for lead authoring this commentary that was recently published in a journal of The Lancet. This is a very concise sort of analysis of why the I/DD population should be prioritized. And we are hoping and we are hearing from disability advocates around the country that they're also penning similar commentary to be placing in scientific journals because we need to raise awareness so that the conditions can be changed. And the general I/DD population can be included other than Down Syndrome. In addition to Down Syndrome, I would say. So, once the vaccine becomes available, we want to make sure that all I/DD or populations receive the vaccine. And the challenge, I think, is that there is a fair amount of vaccine hesitancy in our country. So, vaccine hesitancy refers to a delay in the acceptance or refusal of vaccines despite having access to vaccine services. And it's very difficult to just say what one thing causes vaccine hesitancy. It's a complex issue and it's context-specific. As a primary care provider, I can tell you I have patients who are willing to get the COVID-19 vaccine, but not influenza. So, sometimes it can be very varying across time and place and the nature of the vaccine. It is influenced by factors such as complacency, concern, and confidence. I have had patients who have traditionally been very vaccine hesitant who are all ready to get the COVID-19 vaccine. When I try to ask if they will consider the other ones, they're like no, no, no, just the COVID-19 vaccine. Again, it's sort of an interesting and complex and complicated issue as to why a patient may be vaccine hesitant.

So, one aspect, one possible cause of vaccine hesitancy is actual needle phobia. So, this is known as trypanophobia, the extreme fear of medical procedures in the setting of injection or hypodermic needles. It's recognized in up to 10% of the population, which is higher than

I realized. It was recognized in the DSM in 1994, in DSM3, I believe. So, several iterations again. There is also the concern of patients altering health behaviors as a result. Not going to the doctor because you're afraid of getting a shot or needing to draw blood. So, then once those behaviors, we now see how individuals with needle phobia may have worse health outcomes because they won't get their cholesterol checked or they won't go to the dentist or things like that. And then we've also seen in patients with needle phobia that that can lead to more generalized fear of medical or dental healthcare providers. So, it starts with the fear of going to the doctor because you might get a shot and then it just generalizes to being afraid of healthcare in general.

So, we started an intervention at UCLA a few years ago that I would like to share with you. And a needle anxiety program developed out of a recognition that many of our, actually my I/DD patients did not receive the recommended medical services because of needle phobia. These included not getting immunizations, not having their routine screenings for diabetes or cholesterol, and even not having the recommended blood level checks for medications, such as seizure medications. That can be very concerning if we don't get the right levels of the seizure medications, that are too high or too low. I was actually quite astounded at the number of patients I had who were put on seizure medications by their specialists. And because of needle phobia had never had blood levels checked and I was concerned about that as their primary care provider. So, as UCLA, we had no official policy on what to do with these patients. The unofficial policy was to take them to the main laboratory in Westwood, and there would be enough people to restrain the patient. I was kind of horrified when I found out that was our unofficial policy. I find that very undignified for the patient and also not safe for the healthcare workers restraining the patient. That seemed like we should not keep that. We needed to change that. When I informally surveyed my colleagues, they seemed okay with deviating from the standard of care to accommodate the needle anxiety. One internist said the official recommendation for a patient with diabetes is to check their blood every three months, but it's okay to do it once every six months or once a year. But I said if the recommendation is three months, why would we change that for our needle-

phobic patients. I set out to try to do something. Some ideas in my journey to figure out what to do, I went to the emergency department. They were very good in drawing blood or doing procedures on patients who were needle-phobic. I asked if I had patients who needed blood drawn, could I send them to you? They basically said no. They said the volume is hard to predict. My patient might have to wait for hours

until somebody was free to do that. And then I turned away from the emergency department and I thought hmm, there are anesthesiologist in the same-day surgery centers. Could we just develop a mechanism where a patient who needed a blood draw could go see an anesthesiologist, and I was also told no, because they would get a bill for an operating charge. Because they would be in a surgery center and they could not just not charge for the resources used. Even though they would be willing to do it, it would cost too much for my patients and there

was a chance the insurance companies wouldn't cover that cost. I said okay, that's not going to work. So, I wanted to just clarify the difference between moderate sedation and procedural sedation, because we're talking about procedural sedation. Moderate sedation used to be known as conscious sedation. This is sort of the type of thing where you receive sedation because they may need to set a broken bone or they may need to do stitches or sutures for a laceration in a child more so probably. Or like if you are needing routine colonoscopies, and you receive a little propofol. And your breathing and cardiovascular system aren't impaired, but it can cause a decrease of your breathing, so it does require monitoring by a nurse. It's a little more intensive. This is over a couple of hours.

For a vaccine or a blood draw, that's probably not really feasible. But procedural sedation, also known as minimal sedation, there's no effect on breathing or cardiovascular function and you may have some cognitive or coordination function, but you're able to respond. And procedural sedation would be something like nitrous oxide.

So, procedural sedation guidelines have existed since 1985 for dentists and some pediatricians.

And in October of 2014, the American Society of Anesthesiologists recommended new guideline to allow expansion to other specialties. They recognized the need for mild sedation, and it started to be used in emergency medicine at that time.

So, our needle anxiety program

is an adaptation of an emergency medicine protocol to be used in our urgent care clinics, which would make it much more accessible. So, at UCLA, we're

fortunate to have higher level urgent care clinics called Evaluation and Treatment Centers. The original purpose of these clinics was to keep people out of the emergency department in the hospital. They are staffed by RNs. They can give IV fluids and give IV medications and do higher-level nurses functions that prevent patients from having to go to the emergency room. The only place that I could base this needle anxiety program was the ETC. So, after some discussion with a committee and a committee focused on creating this needle anxiety program, which included actually a psychologist who was experienced in procedural anxiety, we decide on a three-tiered approach. So, it's not that we wanted to go straight to inhale it for all patients who have procedural anxiety, but we wanted to try to address procedural anxiety in as many of the population as we could. So, on the bottom, the orange part of the pyramid is what I call tier one. We just needed better training for our medical assistants on how to approach needle phobia. So, teaching our medical assistants who usually give most of the vaccines it's not to say it's not going to hurt. For patients who are needle-phobic, they can immediately have a sense of distrust, because they know it's going to hurt. When the nurse says it's not going to hurt, it sort of undermines that relationship. The first tier is just to have all of our medical assistants have better training. That's been one of the things we've undertaken over the past year. The second tier is anything before we have to get to procedural sedation. Numbing cream, a buzzy bee, which is this vibrating device that we keep in the freezer so it's not only vibrating, but it's cold. If you put it proximal or near the place where you're going to give the vaccine, oftentimes it's so numb that they don't feel the needle go in. Techniques like that. Or even a distraction video. We have a video that we show patients to teach them how to do deep breathing during the procedure or they can watch a video of their choice to take their minds off of what's going on. Those are all non-medication approaches to needle anxiety. And finally, there's that small, small population of needle-phobic patients who may require the inhaled Medazalan. This is our procedure. The protocol. It took us two and a half years to get this approved. I think I started looking into this in the summer of 2017. And it has gone through I can't tell you how many committee meetings at UCLA Health. First we had to get the Departments of anesthesia and medicine to sign off on it. This protocol kept coming back. They would make a change and then they

would need sign-off. Many, many levels of approval. And the biggest hurdle was ambulatory nursing. Nurses

16:37:11 in the hospital and emergency room are used to doing this type of procedure and using these medications, but nurses in the outpatient setting or primary care office are not. And there was a lot of anxiety among the nursing staff, a lot of pushback, a lot of training that needed to be had, and so this was a very large task and I have to thank everybody who helped support me in getting this passed. But I'm proud to say that three years after starting the process in August last year, 2020, we started it on two patients on the same day. So, the first patient was a woman in her 30s that just had needle phobia. And she came in and it was fine. The second patient was an 18-year-old with I/DD who was minimally verbal. And actually his family drove from two hours away to be able to receive this procedure in order for him to get his blood drawn and get his vaccine. And it worked like a charm. And we have successfully used this intervention in patients to date. So, it's not a huge number. It's a couple of patients a month. So, we're extremely happy to be able to not have

to send these patients to the main lab to be restrained in order to get their minor procedures.

So, our next steps are to continue to track our outcomes and refine our protocol. Already in the last six months we've realized that the doses that the anesthesiologists recommended were on the high side.

So, right now, for example, the anesthesiologist recommended two sprays of the inhale Versed, one in each nostril, but we found that half the spray would be enough. One amendment to the protocol would allow for a little ramping up of the dose and not

having to give the whole dose all at once. We also want to disseminate this to our other evaluation and treatment centers within UCLA Health. We have three, but there is currently only one in Santa Monica. Which is in the middle of the county. We have one in the south and the north, so we would like to have them in all three locations. We want to develop better training for nurses. They're incredibly anxious about this procedure. I have one who is wonderful and believes and understands it. And I have others who are very reluctant to do it. And finally, we're going to raise awareness among the providers at UCLA that this service is available. We sort of told our friends, meaning neurology and genetics, because for our I/DD populations, we often recommend genetic testing and that requires a blood draw. So,

the specialists who work with us with our patients are aware, but then when we have solidified the protocol and the procedure, we want to raise awareness among all providers at UCLA.

So, thank you for your attention, and I'm happy to entertain any questions.

>> Thank you Dr. Kuo for a great presentation, and definitely very timely. If anybody has any questions, you can put those in the chat box and we're happy to go through and answer them.

And in the meantime, I'll also drop a link in the chat box for a survey to give some feedback on our webinar. This is our monthly webinar series, so, we'll love to hear from you on the webinars that we've already done and then suggestions for future ones, as well.

>> ALICE KUO: So I see questions starting to come in. The first is, is it possible for other states to use this protocol? So, I have shared it with people who have asked me for a copy of our UCLA protocol. I believe that you'll have to go through all the issues at your own

institution, right? So, as I mentioned, there was a fair amount of work trying to get buy-in and to get people to understand that this was an important topic.

And so I don't think it's an issue of the state. I probably is more of an issue of the individual health system.

So, I'm happy to share the protocol. Because maybe it would jump start the conversation at other health systems to see that a place like UCLA Health adopted a system like this, and it may shave some time off of the three years that it took me to get this implemented.

Another question. Is needle-phobia only associated with the person seeing the needle? I know of a person with ASD who is blind is restraint the only support she receives? It's very interesting. I have a son, a 12-year-old who is a bit neurodivergent who also has significant, significant needle phobia. It's not necessarily even about seeing the need. I think it's actually an anxiety response. Because he in his head knows that it's a teeny tiny needle and it feels like a mosquito bite and just observing over the years his challenges

with needle-phobia. It's also an irrational fear, but it's a fear that they cannot control. I think it can manifest in many different ways. Whether it is seeing the needle or just knowing that it's coming. Oftentimes parents will report to me that it's not about the needle

actually. It's just the fear of it or the anxiety surrounding it. Were Certified Child Life Specialists involved at all? Yes, they were concerned about the use of a medication and obviously would advocate for non-invasive interventions.

However, they recognized and, I think

one of the reasons we added the different tiers on the pyramid was we wanted to make clear that the inhaled medication was a last resort. That we were going to try to address needle phobia or needle anxiety in any other way other than the medication. And so there was definitely advocates for making sure that it wasn't that we were going to overmedicate and use this too widely. Yes, these have been used with patients with autism and they were effective. The hardest part, I think, is actually getting the spray in the nose. So, sometimes the process, you know, technically if the patient comes to the clinic and we're able to give them the nasal spray because the other techniques have not worked, then it should take 10-15 minutes to both have the onset of the medication and complete the shot, the vaccine, or the blood draw.

However, sometimes the patient is in our clinic for up to 45 minutes or an hour. And most of that time is actually figuring out how to get the spray into the nose. So, from the Q&A, I see have you considered expanding the system statewide or nationwide? That's sort of the purpose of this webinar. I think I wanted to see who was interested, if this seems like it filled a need in the community. I do think that many health systems

have the unofficial policy of the lab that will be able to restrain a patient in order to get needed studies. I'd like to put out there that perhaps we should recognize that that is not allowing our patient to have very much dignity and self-determination quite frankly.

And so expanding the system statewide or nationwide, I think it's more about disseminating this idea and helping individual health systems to adopt this kind of a policy. Other than training, have any other environmental modifications been considered to reduce anxiety?

Absolutely. As I mentioned in tier two, the part where we use non-medical interventions. So, other than training, you know, the cream, if the needle anxiety is truly due to the sensation of the needle entering into the skin, then numbing the surface of the skin

obviously would address that issue. Both numbing cream and the Buzzy Bee device, both of those are ways to numb the surface of the skin so that the patient does not feel the needle going into the skin, the injection itself. So, that's one.

When the issue is the actual

prick of the needle. If the needle phobia is because of the anxiety or the fear of getting an injection, then the other techniques like distraction. We have, again, a psychologist, who is experienced in procedural anxiety and will talk patients through their anxiety and that additional support is sometimes enough to overcome the anxiety. We definitely try other techniques before getting to the inhaled medication. And that is at the, you know, urging and with the

participation of for example as mentioned previously the Child Life Specialist and the psychologist.

Do you have a brochure or a short briefing that we can share with our healthcare administrators? Not yet. But I think as part of our AIR-P primary care node, we are happy to put that together. This is something that I did here at UCLA and I wanted to see if it would be useful

to others. But if there is interest, I would be happy to put together a package to make it easier to disseminate throughout our AIR-P network.

Are there videos or social stories geared for I/DD regarding the COVID-19 vaccine? You know, this is a really important point, and I'm glad we're getting questions referencing that part of the presentation. So, here in Los Angeles, so, I'm going to share some information

and then say we definitely need to do this. So, here in Los Angeles County, you know, we've had the rollout of the vaccine now for about two months or a little less than two months.

And what we're seeing is already sort of disparities. So, even though Los Angeles County is a non-majority county, which means there is no ethnicity that is more than 50%, what we see as far as who is receiving the vaccine in Los Angeles County is that white

members in our county are getting the vaccine at a rate of 2-1 compared to our Latino and Black populations. So, understanding that there is a component of vaccine hesitancy, as well as vaccine access, the Department of Public Health has partnered with our local

partners, so UCLA, as well as the University of Southern California to try to address the vaccine hesitancy. Number one is allowing the vaccine to be distributed directly in the community so that they don't have to for example go to Dodger Stadium, which many people have heard about. And the other is that a lot of the information was not available to them in their language or in their culture the way they would receive these messages or information. And so I think that with our I/DD populations, we do need some targeted messaging around the COVID-19

vaccine. Because I think many of our patients are in sort of the intersection of being a member of the I/DD population, but also having either low income or being from a minority background. And so I think we do need to try to tailor messages and make them more accessible

to these communities because I think there's a lot of misinformation out there about the COVID-19 vaccine. I've heard people be afraid of it because they think it will cause them to, you know, mutate their DNA.

I've heard so many rumors that it involved nanotechnology that will like, you know, somehow turn against you in your body. There's a lot of misconceptions. I'll just say both of those are not true.

But those stories and those rumors are out in the community. So, when there is so much misconception about the vaccine, I think it really does behoove us to clarify messaging to our I/DD populations and maybe from trusted sources. So, you know, identifying where those populations want to receive information and then partnering with those sources to be able to distribute and disseminate that information I think would be really crucial. Have you experienced vaccine hesitancy from those who may have had a severe adverse reaction in the past and have made an informed decision not to take a vaccination due to this adverse response? Again, no vaccine is mandatory. Even the COVID-19 vaccine is not mandatory.

So, when I have patients, I wouldn't say the scenario would be vaccine hesitancy. I think they just decided not to take the vaccine. To me they just declined. They decided not to take the vaccine. If they made that decision based on their previous experience,

I have to admit I don't really push. Each patient can make the decision for themselves. Vaccine hesitancy is really about patients who have questions, who are not sure, or for whom the reason not to get a vaccine is like an external issue, whether it's the needle, whether it's the anxiety so to speak.

>> I think there might be one up above. Are there any procedures for patients who are resistant to inhaling the spray?

>> ALICE KUO: That's a good question. There was a comment later on about using oral medications. Some parents have done that, as well. In some cases we've had parents who said it would be difficult to do even the nasal spray. Sometimes by the time they took the oral

Adivan to come to the office to get the nasal spray, they were relaxed enough that we didn't need to do the nasal spray. I think it's a situation in which you can't rush things. Everybody involved needs to be open to the fact that it may not happen that day. And so I

think when the approach to either giving the vaccine or doing the blood draw is much more of one that we want to make sure that everybody is comfortable and nobody is being, you know, pushed or forced or hastened or rushed, then I think the entire experience is much more pleasant and much more acceptable. And I think it's just much more dignified for our patients.

>> There is another question, but I also want to direct people's attention to the chat. Not surprisingly, because AUCD always has really helpful information, but Don included links to two different resources. One from the Bogg Center on Developmental Disabilities in New Jersey who has a social story related to the COVID vaccine, and another from the the University of Cincinnati Center for Excellence and Developmental Disabilities, sorry that's a mouthful. And they also included a social story and a fact sheet from them. And there's another question, Dr. Kuo.

>> ALICE KUO: Yes, that's very possible. So, here in the state of California, I can't speak to all of the other states, but at least here in the state of California, caregivers of individuals with I/DD were prioritized together with healthcare workers. So, they were considered to be in the top tier of prioritization for the COVID-19 vaccine. And I actually did have parents who were sort of surprised that they would be prioritized over their adult child who happened to have I/DD, as well. But we did vaccinate the caregivers before we vaccinated the individuals with I/DD because at this time in at least Los Angeles County, we have not yet opened our COVID-19 vaccine to anybody below the age of 65. And so I do think that having the caregiver be eligible will hopefully help them consider vaccinating the I/DD individual that they care for.

>> There was a comment on be more inclusive with language. That's a good point and always something really important to think about. About the wording that's used for describing it. So, this fact sheet and the social stories might be helpful for all individuals, right? And not just I/DD individuals.

>> ALICE KUO: Absolutely. I agree.

>> I dropped this survey link in the chat. Feel free to add more questions if you missed anything. I dropped the survey link in the chat. I want to be conscious of time as we have just a few minutes left. And also remind you all that you can register for our next upcoming webinar, which will be Using Autism Research to Inform Policy, which will be done by our colleagues at Drexel University. And there's a link to register on the next slide please, Anna. Thank you very much. And this would be Lindsay, Anne, and Paul who will be presenting on that on Monday, March 15th at 4 p.m. Eastern, 1 p.m. Pacific. I will drop the link in the chat to make it easier for you all.

>> ALICE KUO: Great. I think for next steps, we'll take the interest in this presentation as an indication that we'll try to put together a brochure that people can share with their own health systems and maybe with a copy of our UCLA health protocol as a sample. Let me just

## AIR-P Presents: COVID-19 Vaccine, I/DD Populations, and the Needle Anxiety Program at UCLA Presentation Transcript

>> Good afternoon, everyone. We're just going to give it a couple minutes to let everyone join.

>> Hello, everyone. Welcome to the webinar series for the Autism Intervention Research Network on Physical Health, the AIR-P. My name is Kashia Rosenau. I would like to provide a few logistical details. I will provide a brief introduction for our speaker, and we

will also reserve time for questions at the end of the presentation. Because of the number of participants, your audio will be muted throughout the call. However, you can submit questions at any point during the presentation via the chat box on your webinar console. This

entire webinar is being recorded and it will be available on the website. There will also be a short evaluation survey at the close of the webinar. We invite you to provide feedback on this webinar and also to provide suggestions for future webinars as we appreciate feedback on the content of the monthly webinars hosted by the AIR-P. In the interest of time, let's get started. So, first we want to acknowledge our funding source. And now it is my honor to introduce the principal investigator and director of the AIR-P, Dr. Alice Kuo. Dr. Kuo is a professor from UCLA.

>> ALICE KUO: Thank you for having me. Let's get started because we have a lot to cover. As we know, we are going into the 12th month of a global pandemic. The COVID-19 condition is caused by the SARS-CoV-2, which was first discovered in Wuhan, China in December of 2019. The WHO, the World Health Organization declared the global pandemic on March 11, 2020. It's hard to believe it's been that long ago. As of today, there are over 109 million cases worldwide and over 2.41 million deaths. What is the best response during a global pandemic? For many of us, this is the first major global pandemic that we've been through. I want to credit the UCLA Health Marketing Team for putting together some of these slides. They are California specific or even Los Angeles. But during a pandemic, the best response is

to follow the guidance of our public health officials. Nationally, this is the centers for disease control and prevention, or your state or local public health department. What we have learned over the course of the last year in managing our pandemic is to wear universal masks, keep physical distance or social distancing, wash hands frequently, wipe down high-touch areas, and then symptom screening, meaning that if you are sick or have any symptoms, you should not leave your home.

A vaccine is a valuable tool for fighting a pandemic. So, with the news of the COVID-19 vaccine a couple of months ago, we now have a valuable tool to finally end this pandemic. The benefits of a vaccine is that with herd immunity, we can protect those among our community who cannot be vaccinated. How does the body fight an infection? In order to understand how a vaccine works, we need to understand how our immune system works. So, just like other systems in our body x our immune system is there to protect, our immune system is there to protect our total body against germs, which can be comprised of bacteria to viruses. The COVID-19 condition is caused by a virus. The immune system is stimulated to produce antibodies. I liken these antibodies to soldier cells. They will neutralize the

infection from causing any infection in your body. The way the vaccines work is they contain a code or a protein that stimulates the immune system to produce a particular antibody to fight the virus effectively. How are the COVID-19 vaccines should

to be effective? I just want to emphasize that these vaccines have been approved by our Food and Drug Administration, which is a regulatory body for all medications and drugs or injections in the United States.

So, in order for a new medication or vaccine to be proved, there are three phases of clinical trials. Phase I comprises of about 20-100 healthy volunteers. And the main focus of phase I is to know

whether the vaccine is safe. We entered phase I for the COVID-19 in early summer of last year. In phase II, there were several hundred volunteers who started looking at the common side effects, as well as the actual immune response to the vaccine. And this was around June and July of 2020. Phase III comprises of thousands of volunteers. And for each of the FDA-approved vaccines, about 16-20,000 volunteers were used to determine the effectiveness of the vaccine. This is the most important phase of the clinical trial. This clinical trial phase III went from July 29th of 2020 into the fall. And around November, there were sufficient data to submit to the FDA for emergency use authorization. The FDA went through its complete regulatory process and the FDA will only license the vaccine if it's safe and effective and the benefits outweigh the risks.

To date, right now, there are two COVID-19 vaccines that have been authorized for emergency use by the FDA. The Pfizer-BioNTech one and the Moderna. These are the names of the pharmaceutical companies that produced the vaccine. They were both approved relatively at the same time in the middle of December. The Pfizer vaccine is approved for individuals as young as 16 years of age, because there were 16 and 17-year-olds in the clinical trial, and the Moderna is approved only for adults, 18 and above. Both of these vaccines require two doses. For Pfizer it's 21 days apart. For Moderna, it's 28 days apart. The vaccine is administered as an injection into the muscle. Basically, if you go to the edge of your collarbone, the top of your shoulder and you feel the hard bone, you take two finger breadths below that and that will get you right to the belly of the deltoid muscle in either arm. And just to note, you must receive the same vaccine for both doses. If you start with the Pfizer vaccine, the second dose must be Pfizer. If you start with the Moderna vaccine, the second dose must be Moderna. You cannot mix and match. How effective is the vaccine? It is extremely effective. Based on the clinical trials, it is 95% effective after the second dose. People have asked, and this is a common question, how effective is it after the first dose? I have asked my infectious disease colleagues, and they said Pfizer is 50% effective after the first dose, and Moderna is 80-85% effective after the first dose. However, after receiving the second dose, which is a booster, both were 95% effective and a person is considered immune to COVID-19 two weeks after receiving the second dose. How does the COVID-19 vaccine work? Well, we know that COVID-19 is caused by a coronavirus, and "corona" means crown in Latin. So, if you see in the diagram the blue coronavirus. It looks like a crown because it's a circle and then there's pins, the spikey things, surrounding the circle. That is the virus. And if you are exposed to the virus, meaning the virus enters your body through one of your mucous membranes, then you have a likelihood of getting sick from it. The virus will bind to one of the receptors on one of your cells. The receptor is the little Y on the bottom. You can imagine how the spikey knob would go into the cup part of the receptor, and then the receptor draws the virus into the cell and then you have the likelihood to get sick because the virus can then replicate. The way that the vaccine works is because it stimulates your immune system to produce antibodies, those soldier cells that I was talking about. The antibodies are depicted by the yellow Y's. That's the shape of the proteins. What happens is those antibodies bind the spiking parts all around the virus. Once it's covered with antibodies, when the virus comes near one of your receptors on the cell, it can't get into the cup. It can't lock in. The antibody blocks that receptor binding. And so the virus is neutralized in your body and can't get you sick. Is it better to get vaccinated or contract the disease naturally? This is a common question and it is better to get vaccinated. What the scientists have seen is the immune response, the level of antibodies are much greater with the vaccine than people who just contract the virus naturally and then get over the illness. The new technology that is with this vaccine is mRNA. And this mRNA is a very effective code to instruct your immune system to create the right antibody, and not only does it produce the right antibody, but in large quantity.

You can imagine if you have a lot of virus that you've been exposed to, you need a big antibody response in order to neutralize all of those viruses. So, the definitive answer is that it is better to get vaccinated. Why get the vaccine if most people don't die from COVID-19?

Well, as of February, this month, COVID-19 has killed more than 485,000 in the U.S. And this is more than any other virus that we routinely vaccinate against, like influenza. This vaccine is needed, number one, as a long-term strategy to end the pandemic, but to protect ourselves from any complications if we were to contract COVID-19 and to also protect those among us in our community that cannot get vaccinated.

What is the vaccine distribution plan? So, you may have heard this has been in the news a lot lately. And the CDC has recommended a tiered-approach in order to determine how the vaccine will be distributed because we currently have such

a severe vaccine shortage in the U.S. I'm sure that every community has some sort of prioritization scheme very similar to this one. This one just happens to be the one we're using in Los Angeles County. But the first group to be vaccinated were our healthcare workers, which are those frontline defense in the hospitals treating and taking care of patients. Healthcare workers needed to be vaccinated, and those who were at highest risk of death from COVID-19, which were nursing home residents. Those were the biggest priority in Los Angeles county. Now we're getting into other groups. A large percentage, about 85%, of those in our hospitals who have died of COVID-19 are individuals over the age of 61. And for that reason, senior citizens were prioritized next. There's recognition that essential workers need to be prioritized because they're at greatest risk for contracting COVID-19. And then individuals who have chronic illnesses or medical conditions or are developmental disability are prioritized next. These

are the prioritization categories before the general public. So, we're here right now with a limited supply. We're sort of limited to additional. So, in many parts of the country we have moved onto other priority groups. At least I can only speak to Los Angeles County.

In the last 2-3 weeks, we started doing senior citizens. We're still very early in the vaccine distribution plan before we can offer it to the general population.

My understanding from the pharmaceutical companies is that they are capable of manufacturing about 12 million doses a week. And so as of today, in the U.S., about 53 million doses have been administered, but remember we have 331 million people in the country. Because it's a 2 dose vaccine, the 53 million doses is sort of mixed between whether they were first or second doses. 11% have received their first dose, and only about 4% of our country has been fully immunized. So, in order to reach herd immunity, the scientists are predicting anywhere from 70-80% or 85% of the population need to have been immunized. We're a little bit of a ways from that, but it's a great start. Other countries such as the U.K. and Israel are much further ahead.

So, turning to the populations that we care for, in December 2020, the Committee on Immunization Practices COVID-19 Working Group issued these recommendations that are on the CDC for prioritizing. And the vast majority of individuals with intellectual or developmental disabilities were absent from these priority guidelines. If you go to the CDC website under certain medical conditions that should be prioritized, Down Syndrome is listed, but that is the only one.

I/DD populations are at risk, because early evidence suggests that the I/DD population is disproportionately susceptible to COVID-19. These individuals in these populations have more severe illness, are at greater risk for hospitalization, have twice the fatality rates, and they also may have difficulty with masking or following social distancing guidelines.

And so because of these reasons it would seem prudent to prioritize I/DD populations beyond just Down Syndrome for the COVID-19 vaccine.

When we look historically, the health outcomes for I/DD populations have always been challenging.

This population has historically grappled with fragmented access to preventive care and primary care

and that is probably at the root of a lot of the challenges that they face for their health. There's also been historic social and medical stigma and marginalization that continues to this day. And there's a higher prevalence of co-occurring medical, physical, or mental health conditions, which may affect their other chronic conditions. And if you have the sort of intersection of I/DD and other minority groups, such as racial and ethnic minorities, the conditions or outcomes can be even worse. So, we became very concerned in AIR-P that the exclusion of I/DD populations on the certain medical conditions list from the CDC for vaccine prioritization represented yet another barrier to this population that would have significant health consequences. So, we anticipate this will have challenges for the vaccine rollout. We really wanted to join the effort to prioritize I/DD populations for the COVID-19 vaccine, because it seems as though advocacy is needed as with other groups that are concerned with the not being prioritized for the vaccine.

So, I just wanted to say that the advocacy has been pretty impressive. I just Googled disability and COVID-19 vaccine, and this is what came up on Google. So, this was just even in the last, you know, days to weeks. A lot of awareness being raised locally in order to change guidelines and to include I/DD populations in a prioritization for the COVID-19 vaccine. In AIR-P, we wrote our own commentary. I wanted to give a shout out to Emily Hotez, a member of our leadership team, one of our scientists for lead authoring this commentary that was recently published in a journal of The Lancet. This is a very concise sort of analysis of why the I/DD population should be prioritized. And we are hoping and we are hearing from disability advocates around the country that they're also penning similar commentary to be placing in scientific journals because we need to raise awareness so that the conditions can be changed. And the general I/DD population can be included other than Down Syndrome. In addition to Down Syndrome, I would say.

So, once the vaccine becomes available, we want to make sure that all I/DD or populations receive the vaccine. And the challenge, I think, is that there is a fair amount of vaccine hesitancy in our country. So, vaccine hesitancy refers to a delay in the acceptance or refusal of vaccines despite having access to vaccine services. And it's very difficult to just say what one thing causes vaccine hesitancy. It's a complex issue and it's context-specific. As a primary care provider, I can tell you I have patients who are willing to get the COVID-19 vaccine, but not influenza. So, sometimes it can be very varying across time and place and the nature of the vaccine. It is influenced by factors such as complacency, concern, and confidence. I have had patients who have traditionally been very vaccine hesitant who are all ready to get the COVID-19 vaccine. When I try to ask if they will consider the other ones, they're like no, no, no, just the COVID-19 vaccine. Again, it's sort of an interesting and complex and complicated issue as to why a patient may be vaccine hesitant.

So, one aspect, one possible cause of vaccine hesitancy is actual needle phobia. So, this is known as trypanophobia, the extreme fear of medical procedures in the setting of injection or hypodermic needles. It's recognized in up to 10% of the population, which is higher than I realized. It was recognized in the DSM in 1994, in DSM3, I believe. So, several iterations again. There is also the concern of patients altering health behaviors as a result. Not going to the doctor because you're afraid of getting a shot or needing to draw blood. So, then once those behaviors, we now see how individuals with needle phobia may have worse health outcomes because they won't get their cholesterol checked or they won't go to the dentist or things like that. And then we've also seen in patients with needle phobia that that can lead to more generalized fear of medical or dental healthcare providers. So, it starts with the fear of going to the doctor because you might get a shot and then it just generalizes to being afraid of healthcare in general.

So, we started an intervention at UCLA a few years ago that I would like to share with you. And a needle anxiety program developed out of a recognition that many of our, actually my I/DD patients did not receive the recommended medical services because of needle phobia. These included not getting

immunizations, not having their routine screenings for diabetes or cholesterol, and even not having the recommended blood level checks for medications, such as seizure medications. That can be very concerning if we don't get the right levels of the seizure medications, that are too high or too low. I was actually quite astounded at the number of patients I had who were put on seizure medications by their specialists. And because of needle phobia had never had blood levels checked and I was concerned about that as their primary care provider. So, as UCLA, we had no official policy on what to do with these patients. The unofficial policy was to take them to the main laboratory in Westwood, and there would be enough people to restrain the patient. I was kind of horrified when I found out that was our unofficial policy. I find that very undignified for the patient and also not safe for the healthcare workers restraining the patient. That seemed like we should not keep that. We needed to change that. When I informally surveyed my colleagues, they seemed okay with deviating from the standard of care to accommodate the needle anxiety. One internist said the official recommendation for a patient with diabetes is to check their blood every three months, but it's okay to do it once every six months or once a year. But I said if the recommendation is three months, why would we change that for our needle-phobic patients. I set out to try to do something. Some ideas in my journey to figure out what to do, I went to the emergency department. They were very good in drawing blood or doing procedures on patients who were needle-phobic. I asked if I had patients who needed blood drawn, could I send them to you? They basically said no. They said the volume is hard to predict. My patient might have to wait for hours until somebody was free to do that. And then I turned away from the emergency department and I thought hmm, there are anesthesiologists in the same-day surgery centers. Could we just develop a mechanism where a patient who needed a blood draw could go see an anesthesiologist, and I was also told no, because they would get a bill for an operating charge. Because they would be in a surgery center and they could not just not charge for the resources used. Even though they would be willing to do it, it would cost too much for my patients and there was a chance the insurance companies wouldn't cover that cost. I said okay, that's not going to work. So, I wanted to just clarify the difference between moderate sedation and procedural sedation, because we're talking about procedural sedation. Moderate sedation used to be known as conscious sedation. This is sort of the type of thing where you receive sedation because they may need to set a broken bone or they may need to do stitches or sutures for a laceration in a child more so probably. Or like if you are needing routine colonoscopies, and you receive a little propofol. And your breathing and cardiovascular system aren't impaired, but it can cause a decrease of your breathing, so it does require monitoring by a nurse. It's a little more intensive. This is over a couple of hours. For a vaccine or a blood draw, that's probably not really feasible. But procedural sedation, also known as minimal sedation, there's no effect on breathing or cardiovascular function and you may have some cognitive or coordination function, but you're able to respond. And procedural sedation would be something like nitrous oxide. So, procedural sedation guidelines have existed since 1985 for dentists and some pediatricians. And in October of 2014, the American Society of Anesthesiologists recommended new guideline to allow expansion to other specialties. They recognized the need for mild sedation, and it started to be used in emergency medicine at that time. So, our needle anxiety program is an adaptation of an emergency medicine protocol to be used in our urgent care clinics, which would make it much more accessible. So, at UCLA, we're fortunate to have higher level urgent care clinics called Evaluation and Treatment Centers. The original purpose of these clinics was to keep people out of the emergency department in the hospital. They are staffed by RNs. They can give IV fluids and give IV medications and do higher-level nurses functions that prevent patients from having to go to the emergency room. The only

place that I could base this needle anxiety program was the ETC. So, after some discussion with a committee and a committee focused on creating this needle anxiety program, which included actually a psychologist who was experienced in procedural anxiety, we decide on a three-tiered approach. So, it's not that we wanted to go straight to inhale it for all patients who have procedural anxiety, but we wanted to try to address procedural anxiety in as many of the population as we could. So, on the bottom, the orange part of the pyramid is what I call tier one. We just needed better training for our medical assistants on how to approach needle phobia. So, teaching our medical assistants who usually give most of the vaccines it's not to say it's not going to hurt. For patients who are needle-phobic, they can immediately have a sense of distrust, because they know it's going to hurt. When the nurse says it's not going to hurt, it sort of undermines that relationship. The first tier is just to have all of our medical assistants have better training. That's been one of the things we've undertaken over the past year. The second tier is anything before we have to get to procedural sedation. Numbing cream, a buzzy bee, which is this vibrating device that we keep in the freezer so it's not only vibrating, but it's cold. If you put it proximal or near the place where you're going to give the vaccine, oftentimes it's so numb that they don't feel the needle go in. Techniques like that. Or even a distraction video. We have a video that we show patients to teach them how to do deep breathing during the procedure or they can watch a video of their choice to take their minds off of what's going on. Those are all non-medication approaches to needle anxiety. And finally, there's that small, small population of needle-phobic patients who may require the inhaled Medazolan. This is our procedure. The protocol. It took us two and a half years to get this approved. I think I started looking into this in the summer of 2017. And it has gone through I can't tell you how many committee meetings at UCLA Health. First we

16:36:53 had to get the Departments of anesthesia and medicine to sign off on it. This protocol kept coming back. They would make a change and then they would need sign-off. Many, many levels of approval. And the biggest hurdle was ambulatory nursing. Nurses

16:37:11 in the hospital and emergency room are used to doing this type of procedure and using these medications, but nurses in the outpatient setting or primary care office are not. And there was a lot of anxiety among the nursing staff, a lot of pushback, a lot of training that needed to be had, and so this was a very large task and I have to thank everybody who helped support me in getting this passed. But I'm proud to say that three years after starting the process in August last year, 2020, we started it on two patients on the same day. So, the first patient was a woman in her 30s that just had needle phobia. And she came in and it was fine. The second patient was an 18-year-old with I/DD who was minimally verbal. And actually his family drove from two hours away to be able to receive this procedure in order for him to get his blood drawn and get his vaccine. And it worked like a charm. And we have successfully used this intervention in patients to date. So, it's not a huge number. It's a couple of patients a month. So, we're extremely happy to be able to not have to send these patients to the main lab to be restrained in order to get their minor procedures. So, our next steps are to continue to track our outcomes and refine our protocol. Already in the last six months we've realized that the doses that the anesthesiologists recommended were on the high side. So, right now, for example, the anesthesiologist recommended two sprays of the inhale Versed, one in each nostril, but we found that half the spray would be enough. One amendment to the protocol would allow for a little ramping up of the dose and not having to give the whole dose all at once. We also want to disseminate this to our other evaluation and treatment centers within UCLA Health. We have three, but there is currently only one in Santa Monica. Which is in the middle of the county. We have one in the south and the north, so we would like to have them in all three locations. We want to develop better training for nurses. They're incredibly anxious about this procedure. I have one who is wonderful and believes and understands it.

And I have others who are very reluctant to do it. And finally, we're going to raise awareness among the providers at UCLA that this service is available. We sort of told our friends, meaning neurology and genetics, because for our I/DD populations, we often recommend genetic testing and that requires a blood draw. So,

the specialists who work with us with our patients are aware, but then when we have solidified the protocol and the procedure, we want to raise awareness among all providers at UCLA.

So, thank you for your attention, and I'm happy to entertain any questions.

>> Thank you Dr. Kuo for a great presentation, and definitely very timely. If anybody has any questions, you can put those in the chat box and we're happy to go through and answer them.

And in the meantime, I'll also drop a link in the chat box for a survey to give some feedback on our webinar. This is our monthly webinar series, so, we'll love to hear from you on the webinars that we've already done and then suggestions for future ones, as well.

>> ALICE KUO: So I see questions starting to come in. The first is, is it possible for other states to use this protocol? So, I have shared it with people who have asked me for a copy of our UCLA protocol. I believe that you'll have to go through all the issues at your own institution, right? So, as I mentioned, there was a fair amount of work trying to get buy-in and to get people to understand that this was an important topic. And so I don't think it's an issue of the state. I probably is more of an issue of the individual health system.

So, I'm happy to share the protocol. Because maybe it would jump start the conversation at other health systems to see that a place like UCLA Health adopted a system like this, and it may shave some time off of the three years that it took me to get this implemented.

Another question. Is needle-phobia only associated with the person seeing the needle? I know of a person with ASD who is blind is restraint the only support she receives? It's very interesting. I have a son, a 12-year-old who is a bit neurodivergent who also has significant, significant needle phobia. It's not necessarily even about seeing the need. I think it's actually an anxiety response. Because he in his head knows that it's a teeny tiny needle and it feels like a mosquito bite and just observing over the years his challenges

with needle-phobia. It's also an irrational fear, but it's a fear that they cannot control. I think it can manifest in many different ways. Whether it is seeing the needle or just knowing that it's coming.

Oftentimes parents will report to me that it's not about the needle

actually. It's just the fear of it or the anxiety surrounding it. Were Certified Child Life Specialists involved at all? Yes, they were concerned about the use of a medication and obviously would advocate for non-invasive interventions. However, they recognized and, I think

one of the reasons we added the different tiers on the pyramid was we wanted to make clear that the inhaled medication was a last resort. That we were going to try to address needle phobia or needle anxiety in any other way other than the medication. And so there was definitely advocates for making sure that it wasn't that we were going to overmedicate and use this too widely. Yes, these have been used with patients with autism and they were effective. The hardest part, I think, is actually getting the spray in the nose. So, sometimes the process, you know, technically if the patient comes to the clinic and we're able to give them the nasal spray because the other techniques have not worked, then it should take 10-15 minutes to both have the onset of the medication and complete the shot, the vaccine, or the blood draw.

However, sometimes the patient is in our clinic for up to 45 minutes or an hour. And most of that time is actually figuring out how to get the spray into the nose.

So, from the Q&A, I see have you considered expanding the system statewide or nationwide? That's sort of the purpose of this webinar. I think I wanted to see who was interested, if this seems like it filled a need in the community. I do think that many health systems

have the unofficial policy of the lab that will be able to restrain a patient in order to get needed studies. I'd like to put out there that perhaps we should recognize that that is not allowing our patient to have very much dignity and self-determination quite frankly.

And so expanding the system statewide or nationwide, I think it's more about disseminating this idea and helping individual health systems to adopt this kind of a policy. Other than training, have any other environmental modifications been considered to reduce anxiety?

Absolutely. As I mentioned in tier two, the part where we use non-medical interventions. So, other than training, you know, the cream, if the needle anxiety is truly due to the sensation of the needle entering into the skin, then numbing the surface of the skin

obviously would address that issue. Both numbing cream and the Buzzy Bee device, both of those are ways to numb the surface of the skin so that the patient does not feel the needle going into the skin, the injection itself. So, that's one. When the issue is the actual

prick of the needle. If the needle phobia is because of the anxiety or the fear of getting an injection, then the other techniques like distraction. We have, again, a psychologist, who is experienced in procedural anxiety and will talk patients through their anxiety and that additional support is sometimes enough to overcome the anxiety. We definitely try other techniques before getting to the inhaled medication. And that is at the, you know, urging and with the participation of for example as mentioned previously the Child Life Specialist and the psychologist.

Do you have a brochure or a short briefing that we can share with our healthcare administrators? Not yet. But I think as part of our AIR-P primary care node, we are happy to put that together. This is something that I did here at UCLA and I wanted to see if it would be useful

to others. But if there is interest, I would be happy to put together a package to make it easier to disseminate throughout our AIR-P network.

Are there videos or social stories geared for I/DD regarding the COVID-19 vaccine? You know, this is a really important point, and I'm glad we're getting questions referencing that part of the presentation.

So, here in Los Angeles, so, I'm going to share some information

and then say we definitely need to do this. So, here in Los Angeles County, you know, we've had the rollout of the vaccine now for about two months or a little less than two months.

And what we're seeing is already sort of disparities. So, even though Los Angeles County is a non-majority county, which means there is no ethnicity that is more than 50%, what we see as far as who is receiving the vaccine in Los Angeles County is that white

members in our county are getting the vaccine at a rate of 2-1 compared to our Latino and Black populations. So, understanding that there is a component of vaccine hesitancy, as well as vaccine access, the Department of Public Health has partnered with our local

partners, so UCLA, as well as the University of Southern California to try to address the vaccine hesitancy. Number one is allowing the vaccine to be distributed directly in the community so that they don't have to for example go to Dodger Stadium, which many people have heard about. And the other

is that a lot of the information was not available to them in their language or in their culture the way they would receive these messages or information. And so I think that with our I/DD populations, we do need some targeted messaging around the COVID-19

vaccine. Because I think many of our patients are in sort of the intersection of being a member of the I/DD population, but also having either low income or being from a minority background. And so I think we do need to try to tailor messages and make them more accessible

to these communities because I think there's a lot of misinformation out there about the COVID-19 vaccine. I've heard people be afraid of it because they think it will cause them to, you know, mutate their DNA.

I've heard so many rumors that it involved nanotechnology that will like, you know, somehow turn against you in your body. There's a lot of misconceptions. I'll just say both of those are not true.

But those stories and those rumors are out in the community. So, when there is so much misconception about the vaccine, I think it really does behoove us to clarify messaging to our I/DD populations and maybe from trusted sources. So, you know, identifying where those populations want to receive information and then partnering with those sources to be able to distribute and disseminate that information I think would be really crucial.

Have you experienced vaccine hesitancy from those who may have had a severe adverse reaction in the past and have made an informed decision not to take a vaccination due to this adverse response?

Again, no vaccine is mandatory. Even the COVID-19 vaccine is not mandatory.

So, when I have patients, I wouldn't say the scenario would be vaccine hesitancy. I think they just decided not to take the vaccine. To me they just declined. They decided not to take the vaccine. If they made that decision based on their previous experience,

I have to admit I don't really push. Each patient can make the decision for themselves. Vaccine hesitancy is really about patients who have questions, who are not sure, or for whom the reason not to get a vaccine is like an external issue, whether it's the needle, whether it's the anxiety so to speak.

>> I think there might be one up above. Are there any procedures for patients who are resistant to inhaling the spray?

>> ALICE KUO: That's a good question. There was a comment later on about using oral medications. Some parents have done that, as well. In some cases we've had parents who said it would be difficult to do even the nasal spray. Sometimes by the time they took the oral

Adivan to come to the office to get the nasal spray, they were relaxed enough that we didn't need to do the nasal spray. I think it's a situation in which you can't rush things. Everybody involved needs to be open to the fact that it may not happen that day. And so I think when the approach to either giving the vaccine or doing the blood draw is much more of one that we want to make sure that everybody is comfortable and nobody is being, you know, pushed or forced or hastened or rushed, then I think the entire experience is much more pleasant and much more acceptable. And I think it's just much more dignified for our patients.

>> There is another question, but I also want to direct people's attention to the chat. Not surprisingly, because AUCD always has really helpful information, but Don included links to two different resources. One from the Bogg Center on Developmental Disabilities in New Jersey who has a social story related to the COVID vaccine, and another from the the University of Cincinnati Center for Excellence and Developmental Disabilities, sorry that's a mouthful. And they also included a social story and a fact sheet from them. And there's another question, Dr. Kuo.

>> ALICE KUO: Yes, that's very possible. So, here in the state of California, I can't speak to all of the other states, but at least here in the state of California, caregivers of individuals with I/DD were prioritized together with healthcare workers. So, they were considered to be in the top tier of prioritization for the COVID-19 vaccine. And I actually did have parents who were sort of surprised that they would be prioritized over their adult child who happened to have I/DD, as well. But we did vaccinate the caregivers before we vaccinated the individuals with I/DD because at this time in at least Los Angeles County, we have not yet opened our COVID-19 vaccine to anybody below the age of 65. And so I do think that having the caregiver be eligible will hopefully help them consider vaccinating the I/DD individual that they care for.

>> There was a comment on be more inclusive with language. That's a good point and always something really important to think about. About the wording that's used for describing it. So, this fact sheet and the social stories might be helpful for all individuals, right?

And not just I/DD individuals.

>> ALICE KUO: Absolutely. I agree.

>> I dropped this survey link in the chat. Feel free to add more questions if you missed anything. I dropped the survey link in the chat. I want to be conscious of time as we have just a few minutes left. And also remind you all that you can register for our next upcoming webinar, which will be Using Autism Research to Inform Policy, which will be done by our colleagues at Drexel University. And there's a link to register on the next slide please, Anna. Thank you very much. And this would be Lindsay, Anne, and Paul who will be presenting on that on Monday, March 15th at 4 p.m. Eastern, 1 p.m. Pacific. I will drop the link in the chat to make it easier for you all.

