"COVID, Vaccines and the Safety of my Child who is DHH 'Plus'"

Summary of <u>Hands & Voices Deaf/Hard of Hearing Plus</u> Family Facebook Group* Chat

Thursday, January 14th, 2021 8 PM ET/7 PM CT/6 PM MT/5 PM PT

Patty Manning-Courtney, MD/Chief of Staff & Susan Wiley, MD from Cincinnati Children's Hospital Medical Center respond to questions from the H&V DHH Plus Facebook group about safety concerns related to COVID-19 and questions about vaccines.

"Is my child at greater risk to catch COVID? Is my child at greater risk for COVID complications, including worsening of hearing loss?"



Dr. Patty Manning-Courtney (PMC): Children who are deaf or hard of hearing are not at any greater risk for catching COVID than other children. Children in general may have a harder time keeping distance, wearing masks, or practicing hand hygiene, but in general children have had overall lower rates of COVID than adults.

Dr. Susan Wiley (SW): This question is a good one and we can think about how well a child can follow general precautions that are in place for all people which include:

- Handwashing
- Ability to wear a mask
- Understanding and following social distancing
- "Speaking up" when others are not respecting the rules

Another factor that can also come up for some children is:

• Frequent mouthing objects or hands as this can also put an added risk for exposure.

If a child cannot easily follow these strategies, another question to ask is "how well can adults help facilitate safe behaviors?" Adult-guided behaviors that facilitate safety include things like:

- Keeping children separated
- Cleaning objects that children have mouthed
- Reinforcing mask wearing among those who can wear masks

We don't have any information to suggest COVID will worsen a child's hearing loss. We recognize there is still a lot to learn.

"With regard to our DHH plus kiddos, what are some of the "pluses" that might be at a higher risk of contracting COVID and have more complications?"

PMC: We've also been very fortunate that children with a variety of developmental or pre-existing medical conditions are not at greater risk for complications. It's been hard to predict which adults and children have more complications from COVID, but there is no documented increased risk of complications for children who are DHH.

The "pluses" that increase the risk of COVID contraction are really not too many, and are primarily related to the ability to maintain safe practices, like handwashing, etc. The pluses that place children at greater risk for complications have more to do with medical factors like underlying lung disease, obesity, diabetes, immunosuppression, cardiac disease.

SW: We have to look at the medical conditions that can go along with the Plus. The CDC has a list of conditions which is helpful. Down syndrome recently was added to the CDC list of conditions. This is likely related to the many health issues that can come along with Down syndrome.

"Do children with additional conditions tend to have a higher risk for MIS - Multisystem Inflammatory Syndrome?"

PMC: We've not seen any association between children with additional conditions and higher risk of MISC. The very few MISC cases we've seen at Children's have been in almost exclusively previously healthy children. And I'll add that those cases of MISC have been fortunately generally mild.

"What have you all done to try to keep your children safe from infection? We can learn from each other." (question to the parents)

Parent: We talk a lot of about how we act differently in public now. Don't touch things, just look. Use elbows to push automatic door openers and such.

Parent: Resource: For any British Columbian / Canadian families online, our BCCDC has provided this resource for parents with more complex kids. I found it reassuring & informative. http://www.bccdc.ca/.../Children_medical%20complexity.pdf

"I have been reading asthma is NOT a risk factor which seems weird. We also were told by our allergist that they have not seen asthma as an increased risk factor. Has anyone else been told the same thing? Doctors Wiley and Manning-Courtney, what have you seen? I know this isn't hearing related per-se."

Parent: We were told that asthma patients have actually been faring pretty well because they are usually on a preventative med for their asthma that mitigates some of the lung effects. (One of my non-DHH kids has asthma) It would be interesting to know if that's true.

SW: While asthma is not in the highest risk category for COVID, the Centers for Disease Control (CDC) does list asthma as a condition with some evidence to suggest greater risk. With any child with asthma, it is important to address symptoms early rather than later!

If you want to keep track of information as we learn more, the CDC has a web-page. The page talking about risk categories is:

https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/index.html

"What should we be considering about the COVID-19 vaccine?"



SW: The current vaccines that are available for emergency authorization use are only approved for those 16 and older. There are vaccine trials occurring in children now.

People have a lot of questions about the safety and how well the vaccine works. It is safe and there are very few reasons a person should not get the vaccine. The main concern would be if a person is allergic to any of the ingredients in the vaccine.

The vaccine does not cause COVID. It is not a live vaccine. That means it should be safe for people with immune problems.

"In some states, young adults with complex medical conditions or special needs are being prioritized for vaccine. The vaccine has been safe for these populations?"

SW: While the vaccine testing did not include children with complex developmental and medical conditions, the people who were in the studies did have health conditions. The vaccine seems like it was developed quickly but it is because how people worked together instead of competing. The current vaccines were tested on many more people than other vaccines. The vaccine is safe.

We are seeing that some people have a sore arm and a little flu-like symptoms with the first or second vaccine. This is not getting COVID but is because your body is building a response against COVID.

The two currently available vaccines are the Pfizer and Moderna vaccines. The main concern for getting the vaccine is if a person is allergic to any of the ingredients in the vaccine (the below chart is from a CDC presentation on the COVID vaccines).

Ingredients* included in mRNA COVID-19 vaccines

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Parent: We live in NC. Our son Malik who has CHARGE Syndrome was vaccinated 2 weeks ago and has been okay. We are so grateful!

SW: We can share some social stories about the vaccine as well for kids to better understand why they need a vaccine and what will happen. https://www.ucucedd.org/covid-19-info/

"What is the best way to monitor for reactions if the kiddo cannot self-report?"

PMC: The best thing to watch for is fever, irritability, or rash. But we've seen very little of this.

SW: I know you are all good at reading your child's cues. So, any changes in energy level, irritability, or behaviors might be a cue. With the vaccine, it is fine to give Tylenol if you think someone is having muscle aches or pains.

I do worry a lot about people who have conditions that could put them at greater risk with COVID. This is even harder if your child can't indicate what they are experiencing. This is a concern in the early phases of a COVID infection as well as with side effects from a vaccine. It is good to access information and talk to your care team to help with your decision-making.

The rates of allergic reactions is very low. Dr. Manning has helped get our hospital personnel immunized.

PMC: We've had a great experience with our employees getting vaccinated, over 6000 now, and little to no reactions of any kind.

"I hear anywhere from 60 to 70% of Americans plan to actively seek out the vaccine, while others have significant concerns about the lack of 100% approval by the FDA (Pfizer), the limited testing on teens (and certainly only short-term testing on anyone for this brand-new RNA vaccine) and pathogenic priming discussed by news outlets for those with already compromised systems. Is there anything nutritionally or otherwise that parents can do to mitigate effects?"



PMC: There really isn't any information on supplements or nutritional interventions that can help prevent COVID. General good health practices- eating a healthy diet, getting sleep, and all of the other safe practices are always good to follow. Handwashing is also good as a health practice!

SW: We know the vaccine will help prevent COVID. We have much less information about nutritional supplements. There has been some information about Vitamin D and if people have low Vitamin D levels, we want to supplement to the normal level to keep people healthy.

What we think we know is:

Vitamin D has been linked with many medical conditions and it is helpful to have a diet high in Vitamin D and supplement if Vitamin D levels are low. This is good for bone health and has been linked to other health conditions.

Factors that impact Vitamin D levels include: dietary intake, absorption issues by the gut, sun-light exposure, medications.

Taking Vitamin D is safe. It is a vitamin that can build up in your system so please discuss dosing and monitoring with your medical providers.

Some people use Vitamin C and zinc when they are feeling like they are getting sick. This is safe, but it isn't assurance that you won't get COVID or another illness.

PMC: I'll add here that in the medical community, we strongly support getting vaccinated when it becomes available. We know this is a personal decision, but I would encourage all to strongly consider getting vaccinated. The more protection we can get as a society, the more we can move out of this challenging chapter.

SW: This question also recognizes that for the vaccine to have the greatest impact, many people will agree to have it. I am hopeful that with time, those who might have been more concerned about it will have more information about vaccine safety and effectiveness with a lot more people vaccinated. Waiting to see how it goes is a strategy some people take. It is important to realize, someone might say no at first, and then perhaps later make a different decision.

"Has anyone already gotten the vaccine and want to share their experiences?"

Member 1: My brother got the first Pfizer dose. He got COVID two weeks later but he was mostly asymptomatic and can return to work tomorrow. I don't know if the vaccine helped reduce the severity. We have a lot of risk factors in my family. We are Latino and my brother is severely overweight. We feel so lucky. My mom who lives with him didn't catch it.

Member 2: My husband got his first dose. He was sore for 2 days but otherwise felt fine. The second dose should be in 2 weeks.

Member 3: I received the first Moderna injection on Saturday. My arm was sore and was a bit fatigued for about 24 hours. Very similar to the reaction I had to the flu shot back in November.

Member 4: [Our son who is] 25 who has CHARGE was vaccinated 2 weeks ago. He has been fine. We consulted a few of his docs for advice. The decision was not made in haste and certainly with trepidation and careful concern. To us, it was worth trying to prevent COVID than having him get it which could very well cost his life given how compromised his respiratory system is.

SW: It is always a good idea to talk to a doctor who knows your child! And will partner with you on decisions.

PMC: Definitely talk with your child's physician. Because we are still waiting on studies in younger children, approval right now is only for children over 16 for the Pfizer vaccine, and 18 for Moderna.

SW: "Patty, on the last post someone asked about pediatric trials. Anything you can comment on that is happening at Cincinnati Children's?"

PMC: Children's is recruiting teenagers for the Astra Zeneca trial, but we are not yet recruiting younger children.

"What organization said that the FDA does not approve of the Pfizer vaccine 100%?"

Moderator: The FDA vote for Pfizer wasn't 100% unanimous but passed, 17 yes, 4 no, 1 abstained. Moderna was 20 yes, 1 abstained.

"I'm curious if you have treated more children with the latest strains of COVID? My son has CHARGE, and chronic lung issues, and we are much more concerned with the news of more children being impacted."

PMC: We haven't seen children with asthma struggle as much with COVID as we originally thought would be the case. I think this is related to the generally milder disease we see in children, even those with asthma and other pulmonary conditions.

"Do you think it is the inhaled steroids they are taking?"

SW: The goal of giving inhaled steroids to people with asthma is to try to prevent reactivity and decrease the severity of an asthma attack. We also use steroids in an asthma attack to try to limit the inflammation that can make the lungs continue to react and have the airways clamp down.

PMC: Since November, we have seen an increase in the number of children hospitalized with COVID, but these numbers are far lower than the number of adults hospitalized. And a number of children with COVID who are hospitalized are "incidentally" found to be COVID positive. They are hospitalized for something else, and tested because they might need surgery, and then we find out they have COVID. A number of children, as you've all heard, are asymptomatic. Adults can be asymptomatic as well, but that doesn't seem to be as common.

"Is there documentation readily available that goes into more detail as to the ingredients of the vaccine or what allergies would make you ineligible to take it?"

SW: Below is information from the CDC about the ingredients in the two available vaccines. There is not egg in either vaccine. There aren't preservatives either which is why it has to be kept very cold.

Ingredients* included in mRNA COVID-19 vaccines

Descriptio n	Pfizer-BioNTech COVID-19 vaccine	Moderna COVID-19 vaccine
mRNA	nucleoside-modified mRNA encoding the viral spike	nucleoside-modified mRNA encoding the viral
	(5) glycoprotein of SARS-CoV-2	spike (5) glycoprotein of SARS-CoV-2
Lipids	2[(polyethylene glycol)-2000]-N,N-	1 monomethoxypolyethyleneglycol-2,3-
	ditetradecylacetamide	dimyristylglycerol with polyethylene glycol of average molecular weight 2000 (PEG2000-DMG)
	1,2-distearoyl-sn-glycero-3-phosphocholine	1,2-distearoyl-sn-glycero-3-phosphocholine
	cholesterol	cholesterol
	(4-hydroxybutyl)azanediyl)bis(hexane-6,1-diyl)bis(2- hexyldecanoate)	5M-102 (proprietary to Moderna)
Salts and	potassium chloride	Tris buffer containing sucrose and sodium acetate
Sugars	monobasic potassium phosphate	
1576	sodium chloride	
	dibasic sodium phosphate dihydrate	
	sucrose	1
*As reserve	ed in the prescribing information	

Comment: I had a friend's family member who claimed they were denied vaccination in the UK due to a pretty common allergy that my daughter also has. (Didn't list it specifically as to not potentially spread false information) I realize the science is ever evolving and some things can vary by location, so I appreciate the info and clarification.

SW: If NPR is accurate, UK has had a different approach to approval process so I'm not sure. There is MiraLAX in the vaccine (yes, not sure why because I am not that big of a science geek) so if someone had a reaction to MiraLAX, that would prompt someone to say not to get it.

PMC: The only allergy concerns we've heard have been for individuals with severe food allergies, but even those individuals have had a very low rate of reaction, despite the initial news stories.

"Is there any information about when trials might start for children under 12? And do you have any idea how long the trials would last for children?"

PMC: Trials in younger children may start as early as March for Pfizer, and may be followed by Moderna, in children as young as 5. I can share that the trial my husband is in lasts 2 years, and I suspect that might be the length for children.

"My son is 18. So, he would eventually be able to get the vaccination. How long does the vaccine last? Is it something we will have to get every year like a Flu shot?"

PMC: We actually don't know how long the immunity from the vaccine lasts yet-that's something we will learn as these studies go one, and as we move through COVID ourselves. It's possible we may need to be revaccinated-just not sure yet.



Resources:

<u>Hands & Voices COVID Page</u>: information and resources about COVID and how it affects children who are DHH.

A Social Story about Getting the COVID-19 Vaccine by the University of Cincinnati Center for Excellence in Developmental Disabilities – Center for Dignity in Healthcare for People with Disabilities.

Cincinnati Children's Hospital web-page on COVID-19: https://www.cincinnatichildrens.org/patients/coronavirus-information

*780 Facebook Group Members