Transcription for: "01PODCOVIDFLURSV.mp3" (Uploaded File) (New Transcription)

Emma Mertens: So again, this is one, doctor Keller. I think you covered this, but we're gonna ask it to the group so everyone can hear the answer. This individual wants to know. It is my understanding that there is no lab test that shows the protective levels of the COVID-nineteen vaccines. Is that true?
And if so, is there any work being done to change this?

Dr. Keller: It's a great question. I can press the start. So we can talk about the levels of antibodies. There's a couple of important things. Many tests really will look at total amount of antibody.
It really depends on the type of test that's being done. During the COVID-nineteen pandemic, the medical community realized that that antibodies, for the there's something binding domain on the spike protein, were the antibodies that were most important in neutralizing the virus. So when I say neutralizing, I mean, basically, that the the the antibody, the protein finding the virus in such a way that it's no longer infectious. That's really the gold standard for an antibody that's really effective against a given, you know, a free virus. So we actually can We can measure the amount of that receptor binding antibody.
Not all the commercial antibody commercial labs necessarily are doing that, but the absolute absolute cutoff for protection really depends I mean, it differs by by the individual test. Generally speaking, though, I mean, a a response that basically is is is within the the reference ranges for a given test. Usually would reflect that you have a good immune response to it and likely have some some quality of protection. So that said, I mean, we generally are not. We wouldn't necessarily kind of also what we're doing, like for instance, we would not recommend more vaccines to a given individual based on a given test.
Since again, these vaccines also generate a T cell response that's a little harder to track.

Emma Mertens: Thank you. All right. Next question. Again, one that I think everyone would benefit from hearing the answer. Should Vax seems to be taken relative to IVIG infusions and should this be done at the midpoint in between infusions or does it not matter?

Dr. Ward: Yeah. So there has been some concern raised about getting live vaccines in relation to to IVIG. In which case the line of viruses needed to kind of spread to generate the immune response. And so for those, there's some kind of indications to not give it. For other vaccines, it's not quite as clear that it makes as much difference.
And there, people get a good response to a number of inactivated vaccines kind of regardless of of being on IG or kind of when. So I would say that joined for live vaccines. There's a potential issue there. But for the vaccines, it shouldn't be as important.

Emma Mertens: Thanks, Dr. Ward. All right, next question in. So if I'm a patient and I receive protection from IG therapy, why are vaccines necessary? I'm still confused and in need of help.
Similarly, if one does not mount a response to vaccines, is there any point in getting them?

Dr. Keller: Yeah. This is a great question. Really, the only individuals, right, in Germany, so when we give immunoglobulin products, we're giving pooled plasma from thousands of donors. Catches those donors and generally for that product that you're looking at in front of you, be it sub q or IV, is from plasma that's generally been drawn and processed anywhere from nine to ten months or even perhaps even longer previously. So it's never totally kind of up to date, you know, I mean, response from a person who is seeing, you know, seeing the same circulating viruses that are happening in that season.
So that's one reason that we still usually would recommend that the annual vaccines for influenza and for COVID. Because again, these are rapidly changing viruses where the fact where the government you know, the country, how health officials and and the vaccine makers are really actually having to do some investigation work in terms of what's circulating for instance in Asia and in Australia, you know, in the, you know, during the early earlier in the year before our influence is season starts. So it's a bit of a guess, but nonetheless it's more reflective of the current viral mutations and the current shipments that happened in the virus. And obviously, you know, it's efficacy varies year to year. But even though there is, for instance, antibody against COVID-nineteen in immunoglobulin, having that additional booster and best we tell is saving most people with different types of immune deficiency.
And between the fact that it's that these vaccines usually do in gender, at least at least partial response in many individuals, and also can induce a T cell response that you wouldn't get from mitacobulin. It still may benefit you and it's very unlikely to do any harm.

Emma Mertens: Thanks, Dr. Keller. All right, next question, this individual says, before I was diagnosed with PI, I used to get live vaccines as a child. Broadly speaking, should I be worried about that? For me, that was over fifty years ago.

Dr. Ward: So the the answer is in most people, it doesn't seem to to cause any long term sequelae if the the vaccine was originally received in and did well with it. So many people that develop common variability, for example, that develop it later on as an older child, teenager, or adult, and many of them seem to do pretty well. Nothing said, like Mike highlighted, there are some vaccine strains that can cause some problems. Usually, this is in more severe immune disorders that may present at an earlier age. But for most people that present kind of later in life with immune disorder, generally speaking, the risk is pretty low.

Dr. Keller: Clay, I'm not aware of any bad ruble associated granulose disease in CVID patients, at least not the date.

Emma Mertens: Thank you both. Alright, next question. Is there a relationship between COVID-nineteen vaccines and long COVID? Could vaccination help prevent long term effects?

Dr. Keller: Yeah. Great question to check, Ben.

Dr. Ward: I was just gonna say, yeah, so there has been some suggestion that it does seem to help prevent the development of long COVID. So I think we're still learning a lot about COVID and we don't know entirely what causes long COVID or really what long COVID is, but there are some hints that getting the vaccine does seem to decrease the risk for developing long COVID. And so yeah. So in that regard, it may be helpful. Howard Bauchner:

Dr. Keller: Yeah. I mean, there's a lot of work that's being done on what's being termed kind of infection associated chronic illnesses like chronic bronchovid and chronic fatigue syndrome and related diseases. And as we can tell, I mean, part of it is seems to be some mimicry between a given infection and and self proteins. But Certainly doing anything you can if you have myelco but to varenteral reinfection is a is a really good idea.

Emma Mertens: Thank you both. Alright, next question. This person wrote I'm a person who has had many and all caps, COVID vaccines, and boosters. Should there be a period of time that I should be waiting between vaccinations?

Dr. Keller: So yeah. I we certainly we certainly sympathize as healthcare providers. And and, obviously, in many people, then a day after can be a very ibuprofen driven day. But That said, I mean, if if you've tolerated vaccines, if you've tolerated prior vaccines well, and as long as eight weeks have elapsed since your last COVID nineteen booster, having the KP2 updated vaccine is probably a good idea because it should provide more accurate protection against the new circulating strains. So a short version is, you know, if if it's all your well, it's probably a good idea to get the newest run.
A minimum of two months after after your last vaccination or that matter if at least two months after last infection if you had it.

Dr. Ward: And I'll add to that there are some data to suggest that the severity you have kind of the secondary consequences that you feel from prior vaccines may not be the same with each subsequent vaccine. So some people might have a very bad reaction after their first COVID shot, for example, but do great after their second or vice versa. And they sail through the first one and and feel like they kind of run over for their second one. So it doesn't necessarily mean that you shouldn't get that that booster later on as well too.

Emma Mertens: Thank

Dr. Keller: you. That that fatigue and whatnot is what we call reactogenicity. And it's not it's not allergic as much as it is actually immune activation. And if any and miticase actually that kind of reflects that your immune system is doing what it's supposed to do.

Emma Mertens: Thank you. Alright. What is the latest information on monoclonal antibody treatment related to COVID-nineteen. Is that still being advised for immunocompromised patients? And if so, how could one locate or access this type of treatment?

Dr. Ward: Yes, yes. So yes, So Pembina Bart is the monoclonal antibody that's currently under authorization for the Emergency Authorization for for prevention of COVID-nineteen. So it is available like I mentioned, it is not available everywhere for reasons that kind of are not entirely clear to me, but it's mostly seems to be available kind of clustered in the center of the country. But is still available and it does seem to still be active against all the

Emma Mertens: –

Dr. Ward: most of the currently circulating viruses with the caveat that the newest KP3.1.1 may be a little bit less effective. But while there's still other viruses that are that it can effectively neutralize. I think it's still a good option to consider. Howard

Dr. Keller: Bauchner:

Emma Mertens: Thank you, both. And apologies. I had to turn my camera off. I wanted to make sure we weren't gonna lose connection here. Alright, next question.
What would be an effective antibody level after receiving the COVID vaccine? I know there is probably not a normal here, but trying to get some sort of idea as to what that might be?

Dr. Keller: Yeah. That's a tough question. I think it really depends a great deal on the specific test that's being done. I got children, we use a diasorin, receptor binding IgG. It really depends.
So each lab usually establishes their own normative values for a given population. So I would I would talk to your provider and look look at the results relative to that specific tests that's being done to kind of get a better sense. But I would stress also though that it's only half the picture because again we can't test - we can't routinely test T cell responses to the mRNA vaccines, but they're definitely present. And So is that that latest European review that figured that which I I put in the in my slides showed T cell responses actually are more uniform than antibody responses in our PI population.

Emma Mertens: Thank you so much. Alright, next question. Do you recommend that a senior individual receives a double flu? This individual has CDID and or other primary mean deficiency. This person shares that they found that without the double flu vaccine, they get

the flu and but it is becoming harder and harder for them to get authorization, to get a double flu vaccine at the pharmacy, and they have to go to their primary care provider. Is this advice? I guess is the question.

Dr. Ward: Yeah. So in general, the evidence was pretty good to suggest that older individuals, the height strength, you know, quote unquote flu shot did seem to elicit a little bit better protective response. And so yeah. And generally, I would say we do recommend that if you if it's if you're in the age group or which it's indicated that it is good to to get. There's been some talk about whether people that are younger than that, but who have immunocompromised should get the high strength And to date, there's not really a lot of data to support it one way or the other.
And it can unfortunately be a little bit tricky to get those covered if you're not in the age group. But if you are in the age group, I do think it's a good idea to try and get it if you can because it does seem to to help kind of boost to the protected levels a little bit.

Emma Mertens: Thank you. All right, next question, this one's very interesting. Do you know if infants can shed the virus or a virus from a live vaccines through stool? For example, if a PI patient has a child who is still in diapers and this child received live vaccines, would diaper change diaper changes be a concern for the PI parent for a time period after the child has recently been vaccinated?

Dr. Keller: Great question. That is the case for rhododec, for the rhodovirus vaccine. That said, it's activated. I mean, it's activated. So, I mean, in most individuals with PI, it really shouldn't really only be a risk people with fairly severe disease.
So it wouldn't it wouldn't give me pause, for instance, and a patient with an outright deficiency to give it to their children. And then definitely, rodovirus can be quite even even in well children, rotovirus can be quite nasty in in infancy, responsible for over one hundred thousand hospitalizations in Europe, it's annual in the U. S. So I My my two cents I I think you talk you could talk to your provider certainly and determine if if I think, you know, if you're too immunocompromised, you can discuss your provider and your nutrition if it's worth worth holding off. But in most cases, it should be safe.
I don't know if that word, if you have

Dr. Ward: Yeah. No, I agree. And I was going to add the other one that might be a concern would be the oral polio virus or a vaccine that we don't routinely give here in the US anymore. But yes, I think it's less of a concern for our population here in the U. S.
But that one potentially could be spread to.

Emma Mertens: Thank you, both. All right, next question. Is there any science or legitimacy surrounding the concept of microdosing exposures? This person shares with masking, I seem to get sick more in the summer, and this is a person who has PI.

Dr. Ward: So it's a good question. And I I have to say I'm not aware of a lot of good evidence about micro dosing. I think, you know, there was, I think, a interesting kind of a side note about one of the Olympic athletes who tried to micro dose a little bit before swimming in the the sand during the Olympics didn't seem to work as well for for him. But see, I'm not entirely sure if there's a lot of good evidence to to support it. But I I think in in general, I think, you know, trying to prevent some illnesses that you know could be associated with severe disease, I think, is going to be the best bet.
And I would say, say that steer clear of it. So I would generally would say steer clear of of COVID, if you can. And and things like that. But I don't know. Patrick, do you have any other any other thoughts?

Dr. Keller: Yeah. For a lot of these a lot of these viruses, it's it's just I mean, if if you either had enough exposure that you get sick or you didn't? And you really You're not generally speaking. You're it's unlikely that you would generate a immune response if you didn't actually get an infectious dose. I would I would agree.
Yeah. I think there's mean, definitely, it's the case that when you when you stopped masking for a period thereafter, you were asked to get more sick than you were. I mean, that was pretty much the entire story of twenty twenty two for most of us. Even in otherwise healthy individuals. But otherwise, I think my only suggestion would be just talk to your provider about making sure that you're authorizing

Dr. Ward: all

Dr. Keller: other preventative medicines be it, you know, immunoglobulin or preventative you know, competitor boosters or what have you?

Emma Mertens: Thank you, both. Alright, we have a couple more. This individual wanted to confirm what the vaccine schedule is for RSV. So they wrote that they thought they were supposed to get it every two years, the RSV vaccine. Is that accurate or is it a one and done situation?

Dr. Keller: It depends on the type of vaccine or type. So the active vaccinations. So those those are those are basically a one time. The the date at least. Again, there are all all three of them are new.
So at and And for that matter, I mean, importantly, there's fairly limited information on the active RSC vaccines duration of efficacy in immunocompromised patients. But that said, I think for older individuals, if you're eligible for it, they certainly are safe and seem to be

effective in reducing the chance of a serious case. Pass for the passive dosing, probably I'll probably tag you out for doctor Ward for that one.

Dr. Ward: Yeah. Yeah. So for for the passive dosing, the the newest, you know, the before this the brand name is recommended to be given once for most infants. And then for those infants that have primary mean efficiency or other reason to have severe disease, they can get a second dose as long as they're younger than the nineteen months. So it's just kind of one and done or two and done potentially for with that.
And the older the older monoclonal antibody Synagis was given once a month. It was an injection once a month during the the season. So that's a little bit of a different different protocol. But again, that's not one that we recommend doing right now if the newer Bay Fortis is available. And right now, it's they're so new.
There's almost zero data on whether or not the passive immune deficient passive immunity preparations like Bay Fortis will be helpful in older people, older children or kind of middle aged adults or or those that have a PI. We just don't know yet. In theory, you you could, you know, say that it probably should be helpful. But again, there's zero data. And unfortunately, it's gonna be a very, very tough kind of hill to climb to try and get that approved by insurance to to pay for it or dispensed by a pharmacy.
If you're not in that that first year or second year of life. Howard Bauchner:

Emma Mertens: Thank you so much. And this is going to be our final question of the evening. Can you tell us what contributes to repeat COVID infections? And is there any literature to explain why these occur?

Dr. Keller: Sorry, Emma, we lost you for a moment there.

Emma Mertens: Oh, you guys hear me okay? Yes, we can hear you. This person wanted to know what contributes or what is the cause of repeat COVID infections? And is there any science literature that's been achieved to look at this top? Nick?

Dr. Keller: Sure. At a very kind of overview, just kind of a basic level. Repeat infections are a combination of kind of changes in the virus, and duration of immunity. And so as as we had, you know, the various Greek letters that have that's COVID has gone through to, you know, to achieve to to get to now that our current Omecon flirt variants. There's been specific changes in the virus that have allowed us to evade it both different types of antibody responses and to some degree even T cell responses.
So at the same time, our immune system is kind of thick and obviously we're getting exposed just to read the vaccination or when we occasionally get infected. So we're getting kind of snapshots of that virus as it's changing over time. And so the plus side is a lot of a lot of responses that we make, Julie, at least give you some production against the newer

variants, but they may not I mean, so it's largely why at least hospitalization rates have fallen pretty dramatically. But they may not, you know, there's very big difference between what what the level immunity in order to keep you from getting critically ill versus the level of immunity to get keep you from getting the infected at all. So that's why the duration of protection against infections is relatively short after vaccination, generally about three to four months, sometimes maybe a little longer at individuals, whereas the the protection against more severe disease is more lasting.

Dr. Ward: Yeah. So I'll add that it's very similar to why we can get flu. So in a similar kind of aspect of the flu is changing, the COVID by our as well. And the duration of the immunity that we have to those viruses, like the FGFRA we're saying, is not forever, unfortunately. It would be great if it was, but it's one of those things, it's constantly evolving, and so we're going to be constantly kind of an arms race to try and figure out who has the better, the virus, the better virulence, so to speak, ability to attack us, and then our immune system is the has a better ability to abate it, and it'll keep the keep going kind of in the arms race kind of in perpetuity.

Emma Mertens: Wonderful. Well, thank you so much to both of you for joining us this evening. Thank you so much to our audience for your thoughtful questions and being so engaged during the Q and A. Before we close out, I do have a few more slides just going over some resources and upcoming events with IDF, but Dr. Keller and Dr.
Ward, you've already dedicated your evening to us. If you have lives to get back to, we totally understand, but we wanna make sure you know how much we appreciate you joining us this evening and having you present this talk for our first decoding PI series. So thank you both so much. Alright. Alright, everybody.
Just a few more slides to get turned before we close out. Be sure to check out our website for additional resources, upcoming events, and more. All IDF materials are free to access, print, or have mailed directly to you, and we're going to share the link to our website that's primary immune dot org. That's where you can find all of our resources, upcoming events, and more. If your question was not answered this evening, you can contact our resource navigator through Ask IDF.
She's wonderful. She will personally connect with you to talk later question and direct you to appropriate resources. And the link to access ask IDF is also being shared in the chat.
You can even take IDF on the road with our engaging podcast series. You can find programs like bold conversations and undiagnosed by searching for the IDF podcast in your platform of preference.
I'm also really excited to share about some of our newest resources, very timely with this event is that we have updated our flu and COVID pages on the website, and we definitely recommend that you check them out after the webinar. The links to find those pages are

listed on screen, and they're also being shared now in the chat. We also have a brand new immune system self assessment tool. I'm really excited about this one. This is a ten minute questionnaire you can take from your laptop, from your phone, and it can be used to help identify potential signs of PI and help guide a conversation with your medical provider. Again, the link to access the new survey is on screen and also being shared in the chat. And finally, we have the healthcare provider template for letters of medical necessity for IG therapy. This is a tool that can be used by your provider to advocate on your behalf if insurance is denying coverage of your IG replacement therapy. Again, to access that template, you can either download it directly at primary immune dot org, and the link to access is also being shared in the chat. Are you looking for ways to connect with others who are navigating life with the PI?

You might be interested in joining one of our many get connected groups. These groups are free, virtual, and volunteer led opportunities to connect with others with PI all over the US. We offer location based groups, so what city you live in or nationwide groups. And because the groups meet virtually, you can join any group time leader that works for you. It's totally up to you.

And we also have a brand new men with PI group if that's of interest to anyone. IDF's new documentary, compromised life without immunity, offers an intimate look into the world of those living with primary immunodeficiencies. Screenings and private watch parties are available now by requesting the film at primary immune dot orgcompromised. And the walk for p I continues this fall with several more in person events and even a virtual option. And it looks like we have the St.

Louis Walk this weekend. Visit the walk for p I website linked in the chat to register and build your team. We offer webinars each month and we hope to see you at one of our upcoming programs. Here's a look at some of our upcoming programs in the next few months. And on that note, if you have a great idea for a topic or a presenter that you would like to see at a future IDF event, we want to hear from you.

Visit the link in the chat to submit your idea for consideration. And with that, before we close, we want to thank our incredible sponsors for supporting our education initiatives here at the immune deficiency foundation. We appreciate everyone's participation this evening and want to give a huge thank you again to Dr. Keller and Dr. Ward for their time and expertise that went into these talks this evening.

We hope to see you at our next webinar on October 24th Take care, and have a great evening.