

## Research in the Real World: COVID Vaccines and Pemphigus/Pemphigoid Patient Education Webinar Transcript

**Amethyst:** Welcome everyone. Thank you for joining us today for our Patient Education webinar to discuss “Research in the Real World: COVID Vaccines and Pemphigus and Pemphigoid”. This call is now being recorded. I would like to thank you for being on the call with us today. And to our sponsors, Genentech, argenx and Cabaletta Bio for making today's call possible. “Information is a key factor in treating and living with any condition. However, every patient situation is unique. The IPPF reminds you that any information found on the internet or during presentations should be discussed with your own doctor or health care team to determine if it applies to your specific situation.” Before we begin, I would like to take a quick poll to see how many of us on the call today have received the COVID vaccine. And while you are answering that, let me introduce you to our speaker for today. Dr. Michael Kasperkiwicz is from the University of Southern California. Formerly an Assistant Professor of Dermatology at the University of Lübeck, he currently is a Clinical Associate Professor of Dermatology in the Department of Dermatology at the Keck School of Medicine. Dr. Kasperkiewicz will be presenting on his recently published articles, “COVID-19 vaccine acceptance and hesitancy in patients with immunobullous diseases: a cross-sectional study of the International Pemphigus and Pemphigoid Foundation” and “Case Report: Circulating Anti-SARS-CoV-2 Antibodies Do Not Cross-React With Pemphigus or Pemphigoid Autoantigens”

**Amethyst:** Thank you all for taking the poll. It looks like most of those on the call have been vaccinated. We have one other poll and we want to know if you had any hesitation prior to getting either the vaccine or the booster. If you don't mind answering that real quick, we would appreciate that. And that goes hand-in-hand with Dr. Kasperkiwicz's study that he will be presenting on today. I'm going to close the poll real quick. It looks like a lot of you did not have any hesitation but there was a good amount that did. So thank you for taking that. Before we begin, I would like to go over a few housekeeping slides... (Reviews housekeeping rules). It is now my pleasure to introduce doctor Michael Kasperkiwicz to discuss his recently published studies. Thank you so much for joining us today doctor.

**Dr. Kasperkiewicz:** Yes, thank you so much for having me today and I apologize you cannot see me because of some technical issues but the IPPF staff will help me. Second of all, I would like to thank all of the patients who participated in these very important studies and I would like to send out my thanks because all the data that I presented would not be possible without you who participated. So, thanks again. Next slide, please.

**Dr. Kasperkiewicz:** So, I would like to start with recent recommendations from an expert panel that we have published a few months ago regarding the vaccination for patients with autoimmune blistering diseases. And these are some points that are summarized here. And, as you can see in the first part, it is in fact recommended that every immunobullous disease

patient without contraindications to vaccination is immunized with one of the authorized vaccines, such as the m.R.N.A. vaccines from Pfizer or Moderna, or the adenoviral vector vaccines from AstraZeneca or Johnson & Johnson. Of course, it would be great if patients are vaccinated when they're free of disease, if that is possible. However, it's not recommended to decrease the patient's immunosuppressive medication before or during the vaccination because there's in fact a risk of disease aggravation. And in the case of Rituximab you're probably all aware of this medication that is a first line treatment for moderate to severe pemphigus. This medication, it is suggested that, to complete the entire vaccination series at least a month prior to the initiation of the infusions, or at least three months after completion of the Rituximab. Now, there are high rates of vaccination worldwide to establish good immunity, and to stop the pandemic. But, in fact, hesitancy is a major barrier in achieving herd immunity across different populations. Next slide.

**Dr. Kasperkiewicz:** This is a slide showing the vaccine acceptance rate worldwide. As you can see here, with red colors, low acceptance rates ranging from about 27% and the green ones indicate high acceptance rates up to 94%. So, it varies across the countries. Next slide.

**Dr. Kasperkiewicz:** What we did, we were very interested, how this applies to the community with pemphigus and pemphigoid patients because that was so far unknown. Next slide.

**Dr. Kasperkiewicz:** So we have performed this IPPF study with pemphigus and pemphigoid patients from the IPPF. We included English speaking patients aged 18 years and above. Patients were asked to complete a COVID vaccine vaccination-related web based survey throughout August last year. Electronic informed consent was obtained from all patients and the questionnaire was completed anonymously. This study was granted an exemption by the IRB of the University of Southern California. Next slide.

**Dr. Kasperkiewicz:** So, the primary outcome of the study was the rate of patients reported in COVID-19 vaccination willingness or hesitancy, and secondary outcomes were vaccination coverage, safety, as well as factors associated with vaccination willingness and hesitancy. And the covariates included gender, age, country, ethnicity, education income, type of immunobullous disease and concomitant diseases. Next slide.

**Dr. Kasperkiewicz:** So, these are the results. We have collected valid questionnaires from a total of 707 patients, 532 females and 175 males, age range between 23 and 97 years, with a mean about 60 years. Most of them were pemphigus vulgaris, 338 patients, followed by bullous pemphigoid, 144 patients, also 144 mucous membrane pemphigoid patients. 63 pemphigus foliaceus patients and 18 other immunobullous, non-specified diseases. As you can see, the

responses came primarily from North America, almost all 88.4%. Only 6% are from Europe and about 1% from Australia. Next slide.

**Dr. Kasperkiewicz:** These are interesting results, 73% of the participants reported to be willing to accept the COVID vaccination. 18% were undecided and about 9% refused it. And the factors positively associated with vaccination willingness were male gender, higher education level and concomitant coronary heart disease. Next slide.

**Dr. Kasperkiewicz:** 32% reported vaccination hesitations. So, it's interesting to see that as we just had this question before we started this talk, which is similar to that study, in fact. Those that reported hesitancy included, Acceptors with doubts, about 40%, Delayers about 36% and Refusers about 25%. Next slide.

**Dr. Kasperkiewicz:** Interestingly enough, the major reasons for vaccine hesitancy included worry that the COVID-19 vaccine could lead to a flare worsening of the immunobullous disease, about 71% of patients. Followed by concerns regarding safety, 35%, concerns regarding efficacy, 27%, and a factor positively associated with vaccination hesitancy was younger age. Next slide.

**Dr. Kasperkiewicz:** A total of 90% received the COVID-19 Vaccine. So similar to what we just had in our questionnaire before the talk started. 88% had the m.R.N.A. vaccine and only 9% of the adenovirus vector vaccine from AstraZeneca or Johnson & Johnson. Next slide.

**Dr. Kasperkiewicz:** About 44% of the vaccine acceptors had side effects with 12% experiencing a flare or worsening of their autoimmune disease, 30% after the first dose and 45% after the second dose, and 24% after both the first and the second dose. Other side effects included muscle aches, injection site reaction, sleepiness, headache, chills, weakness, fever, nausea, and vomiting. Next slide.

**Dr. Kasperkiewicz:** To summarize that study, the COVID-19 vaccine hesitancy is in fact prevalent in patients with immunobullous diseases, about 1/3 . But, the acceptance rate, about 73%, was within the upper range of the vaccine willingness reported in the service of the general population, which is about 55 to 75%. The actual vaccine rate of 90% was generally satisfactory. Interestingly, concern regarding a flare or worsening of the immunobullous disease was a major factor contributing to hesitancy. The limitations of this study included potential bias associated with subjective patients' health reporting, relative overrepresentation of the U.S. population, and underrepresentation of the general population worldwide. Next slide.

**Dr. Kasperkiewicz:** So, the conclusion of this study is that communications are important targeting patient concerns, such as information about risk-benefit ratios, a necessity to tackle the COVID-19 vaccine hesitancy among immunobullous patients, particularly in light of the recent recommendations for the booster immunizations. Next slide.

**Dr. Kasperkiewicz:** Now, I would like to show you very new data that we've gathered and submitted to a journal. This is very new. It was a systematic review on the COVID-19 vaccines and patients with pemphigus and pemphigoid. Dr. Woodley and I have been gathering information that has been available in the PubMed Database, which you know is the most relevant for publication for researchers and MDs. What we did is search for literature from conception of the database until this month, using this PubMed database and we type in the keywords pemphigus or pemphigoid or blistering combined with COVID-19 vaccination or COVID-19 vaccine or SARS-CoV-2 vaccination, or SARS-Co-V-2 vaccine. Additional other searches included screening of bibliographies to find further relevant publications. The inclusion criteria were peer-reviewed English language articles about autoimmune bullous disease cases in association with the COVID-19 vaccination. Only reviews or basic research studies, as well as articles, not meeting the inclusion criteria were excluded. Next slide.

**Dr. Kasperkiewicz:** So at the end of our selection process, with critical screening of titles, abstracts and full text, we have included 30 papers. These included 27 case reports or series with 272 vaccine recipients, one prospective observational case control study with 8 vaccine recipients, one registry based study with 12 vaccine recipients and one cross-sectional study with 640 vaccine recipients. Among 932 immunized individuals, the patients who present clinically with new onset of immunobullous diseases about 6%. Then those that flared or had a worsening of preexisting autoimmune bullous diseases, 10%. However, the majority, 85%, had no negative influence of the vaccination on their clinical course. So it was mostly well tolerated. Next slide.

**Dr. Kasperkiewicz:** The COVID-19 vaccines used were the m.R.N.A vaccines, just like I showed you from our previous IPPF paper, most commonly used about 80%, followed by the adenoviral vector vaccines and inactivated COVID-19 vaccines were information about vaccine type was not available in about 2% of patients. The reported time between receiving the first or second dose of the vaccine and the manifestation of autoimmune bullous disease ranged between one day and up to six weeks, with some patients experiencing degradation of the symptoms after the second dose. But the good thing about this was that the clinical courses of these post-vaccine of bullous disease were mostly well controlled with a standard immunosuppressive therapy. Next slide.

**Dr. Kasperkiewicz:** Now, finally, I would like to finish this with a very recent study that we have performed since we all know we're all anxious about the association between the COVID vaccines and induction of the blistering diseases. We wanted to have some more mechanistic

insight if this is really true or not. It has been hypothesized that the COVID-19 virus has the potential to elicit autoimmunity due to some molecular similarities between some proteins of the virus and human molecules. And what we did is we tested 12, 0 positive post-COVID individuals and 12 seropositive, healthy volunteers will receive two doses of the COVID vaccine from Pfizer and these have been included in the investigation. These were not bullous disease patients. These were just healthy volunteers that either had an infection or got the vaccine. The serum samples of these blood donors were tested for potential autoantibodies to the main target proteins of pemphigus and pemphigoid. What we found is that none of the 24 either infected or vaccinated subjects had a concomitant antibody reactivity with any of the tested autoantigens. And this is in fact reassuring, suggesting that there is no real relationship between the infection or vaccine and the autoimmune bullous diseases with respect to the previously hypothesized disease-trigger antibody cross-reactivity. Next slide.

**Dr. Kasperkiewicz:** So the conclusion is why causality between COVID-19 vaccination and autoimmune bullous disease remains unproven and should not affect present vaccination recommendations for this group of patients. Raised awareness and timely recognition of the rare post-SARS-CoV-2 vaccinal cases would be important for their optimal management. Next slide.

**Dr. Kasperkiewicz:** I would like to use this moment and advertise our potential study that we're currently working on with the IPPF to further learn more about safety of COVID-19 vaccines, particularly, we don't really know much about the booster shots that are now recommended in patients. And this would greatly advance our knowledge about the safety of these vaccines in general. I will be very happy as always if you would participate in the study. In this case both the researchers and the patients will profit from this new knowledge. Thank you very much for listening. I hope this was not too much data. I know there were a lot of numbers, but I have presented it and this is all about research. I'm happy to answer any questions.

**Amethyst:** Great. Thank you for sharing those studies with us that you've been working so hard on. Quick question for you, Michael, how did you get interested in studying and treating pemphigus and pemphigoid?

**Dr. Kasperkiewicz:** How did I get interested, I was always interested in complicated diseases. So boring diseases like acne, for instance, never really interested me. This is just a joke, but I really was interested in immunity in autoimmunity and always wanted to have some molecular basis research, which I did also in mice previously. And this is something very interesting, especially now with concerns regarding COVID-19 vaccines, which I could do some further research on.

**Amethyst:** Great, thank you. What made you look into the acceptance rate of the vaccine in the community?

**Dr. Kasperkiewicz:** Yes, the vaccine acceptance rate was very interesting to me considering this very particular patient population because there were some issues already from my patients in the clinic, who are always asking me whether they should get the vaccine or not. Regarding that, we would like to have some more robust data based on the IPPF collaboration so that we can provide patients with more data that is derived from questionnaires.

**Amethyst:** Great, were you surprised with the results of your hesitantly study, based on what you're seeing with your patients in the clinic?

**Dr. Kasperkiewicz:** Yes, I think that's very, very similar to what I see in real life, I have to admit. I also understand the patient's concerns. So, I think that we should still learn more about that, that's why the next study that we're planning is so important. But, overall, I think that, when you combine all the data, I think it's pretty much reassuring what we see. I can just conclude that recommendation for vaccines is in fact, the way to go, to recommend vaccines because the event of flares or worsening is rather low, and the benefit of vaccines far outweigh the potential risks.

**Amethyst:** Great, Thank you. We had a question come in from Debbie, and she said that a family member had first onset of PV after receiving two Moderna vaccinations, less than six months after first symptoms. How would cases like hers be counted in data studies to determine if there's any connection?

**Dr. Kasperkiewicz:** If I understand correctly, that happened six months after the vaccine?

**Amethyst:** It looks like it. Yes.

**Dr. Kasperkiewicz:** So, in my opinion, this is highly unlikely that this is related, six months is a very long time, and this would not really go along with the data that I have presented here. Mostly, it has been shown that the time range is usually one day, up to six weeks. Six months seems very, very far away. And I think this is a rather random coincidence in my opinion.

**Amethyst:** Great. Thank you. And similarly to that, we received many questions prior to the webinar with people asking about, has there been an increase in prevalence of bullous disease or bullous pemphigoid since COVID-19 or the vaccine?

**Dr. Kasperkiewicz:** Yes, I think this is a great question and I cannot answer that. But this is something that we really should do research on and do some epidemiological data. It's a great question. It's too early to say and we still need to figure that out.

**Amethyst:** Great. Thank you. Well, we've got lots of questions coming in but we'd also like to invite our other panelists on the line. So if you guys don't mind joining us on camera, and while they're doing that, I want to take another poll here. We are wondering, after learning about Dr. Kasperkiewicz's current studies that he's doing and plans to hopefully continue to do in the future, does that research influence your decision on getting the COVID-19 vaccine or a booster? While you're taking that, I'd like to introduce you to our panelists for today.

**Amethyst:** Carolyn Fota is the Board Chair for the IPPF's Board of Directors, a peer health coach, the Mid-Atlantic Support Group leader and an IPPF advocate. She resides in Stafford, Virginia, with her husband of over 30 years. David Baron is a former IPPF Board of Directors Chair. David was diagnosed with pemphigus vulgaris in 2005 and suffered from a severe and refractory case, but was lucky to reach remission after three years of treatment with rituximab and IVIg. He is an airline pilot with a major airline company and graduated of Purdue University with a B.S. in Aviation Technology.

**Amethyst:** I'm going to share the results of our poll. Thank you all for taking that. It looks like definitely some of you feel a little bit more confident about the vaccine after learning more about the research that's being done in our community. Thank you all for taking that. Now, to continue introducing our speakers, Rudy Soto is from Texas. He was diagnosed in 2009 with Pemphigus Foliaceous and has been in remission since November 2006. Rudy is the leader of the Austin support group and an IPPF Peer Health Coach. Becky Strong is the IPPF Outreach Director. She was diagnosed with pemphigus vulgaris in 2010 after a 17 month journey of multiple appointments with many specialists and wrong diagnosis. She's been in remission and off all medications since 2013. Becky joined the IPPF as a Patient Educator in 2014 and became full time staff in 2016. Lastly we have Marc Yale who is the IPPF's Research and Advocacy Coordinator. In 2007 he was diagnosed with Cicatricial Pemphigoid. Like others with rare diseases, he experienced delays in diagnosis and difficulty finding a knowledgeable physician. Eventually, Marc lost the vision in his left eye from the disease. This inspired him to help others with the disease and in 2008, he joined the IPPF as a Peer Health Coach and from 2016 to 2020 Marc served as the IPPF's Executive Director. Thank you all for joining us today. It's great to have a patient perspective as well. We are going to jump into some questions here. The first one is for our panelists. How many panelists on the line today have been vaccinated with the COVID-19 vaccine and or boosted? *(All 5 panelists raised their hands)*

**Amethyst:** Great, thank you. I'm going to direct this one to Rudy. Rudy, did you have any hesitation prior to getting the COVID-19 vaccine?

**Rudy:** No, not really I think I was really excited to be able to get some kind of line of defense there between me and the COVID disease.

**Amethyst:** Was anyone else hesitant at all? Becky?

**Becky:** I was, I've been in remission for quite awhile. I wouldn't say it was a big hesitation for me. But at first, I had a little bit of fear and then I realized I knew doctors who could treat my disease, but I didn't know many doctors, by name, and by reputation that could treat COVID. So, I pretty quickly got over my hesitancy, but I did contact my doctor, asked one question. He said get it, and that was enough.

**Amethyst:** Great. Thank you. Did anyone else have any other steps that they took prior to getting the vaccine? Or did you consult your doctor?

**Carolyn:** Like Becky, I also talked to my doctor, both my internal medicine doctor and dermatologist. I had a checkup and both said get it. That's what I did too.

**Amethyst:** Great. Thank you. Becky had mentioned, I know she had a little bit of a concern about maybe having a flare. Did anyone else have any other concerns prior to getting the vaccine? It sounds like the major one was a flare.

**Dave:** Yes, the major concern was having a flare. I just made sure I spoke to my dermatologist. I came to the same conclusion that Becky did that. I know people that can treat my pemphigus and I know how to treat it, but I didn't know anyone personally wouldn't be able to treat my COVID.

**Amethyst:** Great. That's a really good perspective. Marc, did you have something to add?

**Marc:** I was just going to say, too, I think at the beginning, when we got the first vaccination there were still a lot of questions about vaccination. But now, as time has gone on I think, it's pretty well documented the effectiveness of the vaccination itself. The other thing that I found that was helpful to me when I was considering getting that vaccination, was to do a little research about the trials that took place and what it actually took for the vaccination to become available for everybody. There was a huge collaboration between researchers around the globe to bring the vaccination to people that need it. Just seeing that and just the fact that everybody was so focused on understanding and doing the research and doing the trials, really put me at ease when it came time for me to get the vaccination.

**Amethyst:** Great, thank you. Dr. Kasperkiewicz, we had a question come in from Robert. He's asking for patients who have had Rituximab recently. Do you think that the Evusheld is a good idea?

**Dr. Kasperkiewicz:** So, I have to admit I'm not very familiar with the monoclonal antibodies, Evusheld. So in fact, I cannot really tell. What I presented is that the COVID vaccines should be performed at least four weeks before giving Rituximab or three months after. Whether there is some interaction between the Rituximab and those infusions you were talking about, I'm not sure if there's any good data on that. I think it also depends on how severe the COVID is and it depends on different factors. But I don't really know the details about this.

**Marc:** I was just gonna say, I've been looking into the Evusheld because a lot of people have questions about it. One of the facts that I found was that there was a clinical trial that was done on Evusheld last summer with 5000 participants that had some type of comorbidity or autoimmune diseases. And the treatment results from that trial showed an 80% reduction in COVID. So I think when you look at it the Evusheld is designed to really protect people against the virus that don't have that initial immune response from the vaccine. I definitely agree, you would want to talk to your doctor about it, but I think there's some data that's coming out now about Evusheld and its efficacy.

**Amethyst:** Great, thank you. Somebody asked, has there been any studies or anything to be able to determine the efficacy of the vaccine for pemphigus or pemphigoid patients that are on immunosuppressants?

**Dr. Kasperkiewicz:** Not really any good designed studies. Most of the studies are derived from patients with rheumatologic diseases, just like rheumatoid arthritis or studies with transplant patients. What we know from the studies is that the immune response to the COVID vaccines is less, about 50% less than usual. So most patients that have a bad response, meaning no good response to the vaccine with regards to immunity are those with who received a transplant. All the other patients that have an autoimmune disease responded a little bit better. But with regards to pemphigus and pemphigoid there's not much data on that. But what we can tell from these studies is that they surely have an immune response, but it is less than the normal, healthy patients. But it's still recommended to get the vaccines. That's why it's so important to give the booster shot and even the fourth shot that is coming up most likely, in order to cope with this problem.

**Amethyst:** Great, thank you. We did receive several questions about a fourth shot. Patty says that she heard the CDC announced that immunocompromised patients should now receive a

fourth booster, three months after the third vaccine. She is currently on Mycophenolate and is wondering if the drug will affect the way the vaccine works in her body, even if she gets the fourth booster?

**Dr. Kasperkiewicz:** Yes, that's a good point. We usually do not recommend to stop medication during the vaccination period because we know that there is some response. I think it is substantial enough so I would not recommend lowering or stopping Cellcept because there is a risk of flare actually. This is also an important question whether we see flares after vaccination because patients are scared that they will not have a good immune response to the Covid vaccine and then just either make a break from their immunosuppressive therapy or go down with the dose and then it's kind of a bias because we don't know if it's really from the COVID vaccine or interruption of the immunosuppressive therapy which is important for patients with pemphigus and pemphigoid. So, it is recommended to continue with the medication and it is also dependent on a disease activity. So, it's hard to tell. It's always a case by case scenario, but overall it's recommended to continue with the medication.

**Amethyst:** Great, thank you. Did any of you get tested after your first vaccine to test if you mounted an immune response?

**Dave:** Yeah, I did my. My treating Dermatologist was testing all his patients and after my first full course, the first two m.R.N.A. vaccines, I did not have an detectable antibody response. I received my first dose of the vaccine, 9 months post-Rituxan.

**Amethyst:** Thank you for sharing that Dave. Speaking of responses, how did everybody respond to the vaccine? Did any of you get any symptoms afterward or any sickness, and how did you feel?

**Marc:** The first round, I didn't really have any reaction at all but on the second vaccination I did feel symptoms for probably about, maybe 24 hours with chills, headache that sort of thing but I didn't have a fever or anything like that. Then when I got my booster shot, I actually had my booster shot the same time I got my flu shot. In hindsight, I don't know if I would recommend it just because you're getting a double dose of stuff in your body. I didn't really feel sick, but I just felt tired and just kind of under the weather, but didn't really have any major symptoms. Really it was that second second shot where I really felt something. But the reality is, you're supposed to feel that way. That means that your immune system is reacting. And fortunately I didn't have any type of flaring activity that went along with that. But, going back to what Becky and David said earlier, if I was to have a flare at least I would know what to do, but if I was to get COVID, I wouldn't have any idea what to do. So at least I had that "card in my back pocket" so to say.

**Becky:** For me, I got a Moderna vaccine and after my first shot, I felt awful. I developed the stereotypical fever, the swollen glands through my neck that went down my back. Extreme joint pain, loss of appetite, headache, nausea. When I got my second vaccine I was pretty much convinced that I would never survive COVID. With both of them, at about the 36 hour mark, I really turned a corner. And I went literally, in almost an hour from feeling like I was going to have to crawl for the rest of my life because I couldn't stand up, to maybe I'm going to make it through this. When I did get my booster, I did get the third shot, I still was achy and I was tired and got a headache but I didn't have near the response to that one as I did to the first two.

**Rudy:** So for my first one, I experienced, probably like everybody else, the sore arm near the place of injection, but that was it. I was able to get up. I went up to work the next morning. After the second one, that one hit me hard. With the second one, I had all the body aches. I didn't have any fever, my body ached and I could barely get out of bed. That lasted, kind of like for Marc, 24 hours and that was it. When I got the Moderna booster, that one hit me really hard. I had everything, I had the flu like symptoms, I woke up with a fever, chills, body ache. I didn't really lose my appetite, but I was drinking a lot of fluids and water because I had a fever so I wanted to make sure that I stayed hydrated. But that lasted again, about 24 hours, and I was good to go to work the next morning.

**Carolyn:** I think my story is kind of like Rudy and Marc's. I took the Pfizer vaccine, with the first shot just a sore arm. For the second shot my symptoms only lasted 24 hours, with a sore arm, chills, sleepiness and feeling forgetful. So I was sure to drink a lot of water and took a lot of naps. I wasn't very hungry. For me, I felt it was very minor and after 24 hours it passed and I went to work the following day.

**Amethyst:** Dave, you mentioned that you were non-respondent for that first vaccine. Did you notice any symptoms after it?

**Dave:** So I had the Moderna vaccine. After the first injection, nothing, no, not even a sore arm. The second one I had, what seems to be a pretty typical reaction, a fever, chills, body aches, flu like symptoms. And, like Becky, mine was about 36 hours, then it was like a light switch, I went from feeling awful to almost instantly feeling back to normal. Then with the booster, I only felt a little rundown, not too bad.

**Amethyst:** Thank you. Dr. Kasperkiewicz, Stephen wrote in prior to the webinar, and said that he's 77 and he was recently diagnosed with PV. His doctor recommended that she should not get the booster at this time, as he's seen patients flare in his practice. He wants to know what you would recommend, and maybe why you think that doctor may have made that suggestion for him.

**Dr. Kasperkiewicz:** It's hard to tell now, because I don't know the disease activity. I would need to have more information about the patient to give you some clear advice. So, depending on the clinical disease activity of the patient, what he's taking or the immunosuppressants or any comorbidities, I would need to have some more information unfortunately, to answer this question.

**Amethyst:** Thank you. Madaline just wrote in, were any of you on medication for your pemphigus or pemphigoid during the time of your vaccination?

**Amethyst:** No. Okay, Good to know. I know we get a lot of questions about vaccination when you're first diagnosed. Is there any recommendation, Michael? Should a patient get vaccinated before starting their treatment for pemphigus or pemphigoid, whether that's immunosuppressants, IVIg, or prednisone?

**Dr. Kasperkiewicz:** Before starting the vaccine?

**Amethyst:** Getting vaccinated before starting their treatment, if they're just newly diagnosed?

**Dr. Kasperkiewicz:** So, yes, the best thing would be to get the vaccine while not being on immunosuppressive therapy. But, this again depends on their clinical disease activity of their pemphigus or pemphigoid, to see what is more important. If they have severe disease, then of course, we should not wait for the vaccine and just give immunosuppressive therapy. So, it's really hard to tell and it's always a case by case suggestion. But again, I can just repeat myself regarding Rituximab because this is the main issue because it's the drug that kind of disturbs the immune response of vaccines. So it's important that we complete the vaccination at least four weeks before the infusion, or at least three months after Rituximab, this is the fact.

**Amethyst:** Great, Thank you. Laurance just asked, is there a difference in symptoms to the vaccine for patients who are treated with Rituximab from patients who didn't receive Rituximab?

**Dr. Kasperkiewicz:** With regards to the side effects of the vaccines? This is a good question. I don't have data on that. But what we know is that there is some confusing data about the COVID infection, while being on Rituximab. Some papers show that there is a more severe disease, some papers show that there is no effect. But, there's a trend showing that Rituximab may provoke a more severe COVID infection. But regarding the COVID-19 vaccines and

Rituximab, there's only a little bit more data on the immune response, not the clinical response. So the immune response is a little bit lower in patients receiving Rituximab, but still there is some response. We didn't really mention that antibodies are very important and testing is also maybe an interesting idea to do, but they're also T cells that are important. So even if you don't have detectable antibodies in your blood, you still have most likely T cells that will fight the disease after the vaccine. And this is something that we don't really test by commercial assays but it has been shown in studies that the T cell response is there, even though you got Rituximab which can negatively affect your antibody response. So there is some hope that even if you are on immunosuppressive therapies like Rituximab, there is some good protection for you.

**Amethyst:** Great. Thank you. Somebody wrote in and asked if you developed a flare after getting the first shot or even the second shot. Should they consider still getting a booster?

**Dr. Kasperkiewicz:** Yes, this is also a very, very good question. I think that it all depends, it also depends on a case by case basis. It depends on how bad the flare was and was it related to the vaccine or was it because the patient was not on immunosuppressive therapy. Overall, just my gut feeling for that patient is that the third shot is still recommended but the patient needs to be closely monitored on immunosuppressive therapy.

**Amethyst:** Okay, thank you. Somebody said that they had COVID and didn't get a flare, should they get a vaccine? So maybe they haven't had the vaccine yet.

**Dr. Kasperkiewicz:** So they didn't get a flare after the infection, right?

**Amethyst:** Yes, they did not.

**Dr. Kasperkiewicz:** Yes, so that sounds like a promising event. So, surely, yes, they should get a vaccine and a booster. Chances sound low to flare if they haven't experienced any effect from the COVID.

**Amethyst:** Great, thank you. I'm curious, after knowing our panelists vaccination status, have any of you had COVID? And what was your experience with it?

**Dave:** Well, It's funny you should ask that because after two years COVID finally found me and I'm dealing with as we speak, I'm on day six after I tested positive, and the vaccine is doing its job. It's been like a mild head cold for me. It's exactly what you can hope for with the vaccine. I think there's some confusion out there that vaccines prevent infection when I heard the best analogy recently from a vaccine expert, that a vaccine is like a fire extinguisher in your kitchen, it won't prevent the fire, but it will help put it out, and it's exactly what it's doing for me. So, I'm pretty happy so far.

**Carolyn:** I'd also say, just very recently, six weeks ago, I saw my provider. We were both wearing masks, he was every now and then sneezing and excused himself a few times. And he told me it was allergies and that he had been vaccinated and boosted and he was okay. After 24 hours, I was contacted by his office, he had indeed had COVID. During that time, I was wearing my mask and washing my hands, and I've had both vaccines. We were monitoring my temperature and I was tested and I tested negative. But that just proves the confidence and I believe that the vaccine helped me in addition to following CDC guidance and I did not develop COVID as a result of I think being vaccinated and following CDC guidance.

**Amethyst:** Has anyone else had any exposure and noticed that they did not get it?

**Marc:** I think at this point, I know I've had notices that I've been potentially exposed. I went to my doctor yesterday, and one of the things he said to me was at this point, everybody's probably been exposed to it. It's just a fact of whether or not your body is reacting to the virus. So some people aren't reacting to the virus or if they have been exposed, they're mounting a response, but at this point we're literally two years in, I think everybody's probably exposed at some point, it's just a matter of how well your body reacts to that exposure.

**Becky:** To kind of build on what Marc said, I live with two vectors of death. There are lower elementary school children who go to school and they wear masks. We have taught them the importance of washing their hands and at school they have to sit so far apart at lunch and that kind of thing. I really think Dr. Payne in one of our webinars used this swiss cheese analogy that, yes, like masks alone won't work, vaccines alone won't work, distancing alone won't work, but if you line up all the slices of swiss cheese, the holes generally get covered by another slice in the pile. So working together, it works really well. My children are big cheese eaters as we all are in this house so that was something that I could physically show them. This alone isn't going to protect us, or that alone is not going to protect us but all these things working together will help. We're careful about who we're around and whether we're inside or outside, and how cautious they are. They also know that it's important to protect my mother and my husband, who are at high risk if we're to get this disease. So, I think Marc's right, we've probably all been exposed at some point, but it's the number of particles we might have been around, and those in our inner circle, and how well they protect not only us, but our circle as a whole.

**Marc:** My doctor's was like, it just depends on you know how much of a viral load you a person's body can take. Some people get sick, some people don't get sick. But I think by now, everybody has been exposed in one form or another. He said the best approach is, just to do everything that you can to make sure that your body can handle the viral load so that you don't COVID.

**Amethyst:** Great, thank you. We're quickly reaching the top of the hour. So I have a few other questions. Dr. Kasperkiewicz we had a lot of questions come in about patients asking about Cellcept. So many of them were just asking, what are the recommendations for the use of Cellcept and getting the booster? I'm not sure if we covered that yet specifically.

**Dr. Kasperkiewicz:** I think again, it depends on the clinical disease activity of the patient. But in general we recommend continuing with the immunosuppressive therapy because there is a risk of disease flare when you stop.

**Amethyst:** Great, thank you. Somebody asked, with many states and countries starting to lift their mask mandates, should our community continue to mask up and take those precautions?

**Dr. Kasperkiewicz:** Yes, so, I would recommend still wearing a mask because this particular community is on immunosuppressive therapies so we cannot compare with the general population. I would still wear a mask and do all the precautions.

**Amethyst:** Would you advise those same precautions for maybe a patient that is in remission and not on immunosuppressive therapy?

**Dr. Kasperkiewicz:** Yes, I would also do that because we know that if someone gets COVID that this could also lead to a flare of the pemphigus or pemphigoid. Not only protecting them from COVID but also from a flare so it would be advisable to wear masks even without the immunosuppressive therapy.

**Amethyst:** One last question, just to reiterate the fourth vaccine or the booster vaccine. What are the current recommendations for our community?

**Dr. Kasperkiewicz:** So I would advise you to get the fourth shot. Again, it's a little bit of a gray zone, we don't really know the safety of the third booster shot, that's why we're planning to do this IPPF study. I would be really grateful if you could participate so that we can answer that question. Yeah, but I think that overall, everything points toward that the community with pemphigus and pemphigoid should get the second boost.

**Amethyst:** Thank you. We have one last poll for you all to take today. So after today's webinar and hearing from our panelists and our doctor. Has it helped you to better understand the COVID vaccine? While you're answering that, I would like to give a huge thank you to everyone for joining us today and to our sponsors, Genentech, argenx and Cabaletta Bio for making today's call possible. A lot of you are loving these webinars, and we're here to help educate you and educate the community. So, thank you all for taking that poll and for being with us today.

**Amethyst:** Before we go, I have a few announcements. Do you wish there was a better understanding of our diseases by doctors and researchers? Do you wish there were more FDA-approved treatments and better treatments available? Well here's your chance to get involved and make these goals a reality - Join the IPPF Natural History Study today! The Natural History Study is a patient registry sponsored by the National Organization for Rare Disorders (NORD) and the US Food and Drug Administration (FDA). Your information is private and the IPPF Natural History Study follows strict government guidelines to assure patient information is protected. Your participation and the data will be used by the IPPF to help advance research, better understand the patient journey, find better treatments, and hopefully one day a cure. By sharing your journey and answering some questions, you directly have an effect on the future of all people affected by pemphigus and pemphigoid. So get involved today! You can find the Natural History Study by visiting [www.pemphigus.iamrare.org](http://www.pemphigus.iamrare.org)

**Amethyst:** The IPPF has a number of upcoming virtual support groups across the country. If you are interested in attending a meeting, please check the IPPF's Event Page to register for a meeting. Also, we are always looking to expand our support network. If you are interested in starting a support group in your region please contact Becky Strong at [becky@pemphigus.org](mailto:becky@pemphigus.org). It's easier than it sounds to start a support group and you can help connect others in your area with other patients.

**Amethyst:** If you are interested in continuing to help support the IPPF and allow us to continue to provide free programs and services like today's webinar, you can become a healing hero. Healing Heroes fund the future of the IPPF community by making sustaining, monthly gifts to support our mission of improving the quality of life for all those affected by pemphigus and pemphigoid. No amount is too small, even a \$5 or \$10 monthly donation goes a long way and continues to allow us to provide for the greater good of our community. This call recording will be sent out with the survey following this call. Thank you all for joining us and for sharing your patient perspective and also sharing the amazing studies that you're doing for our community. Thank you all for joining us, and we will see you soon and have a great night.