April 23, 2020- COVID-19 Part 2 Patient Education Call

Becky: Welcome everyone. This call is now being recorded. I would like to thank you for being on the call this evening and a big thank you to our sponsors Genentech and Principia Biopharma for making today's call possible. Today's topic is a Q&A on COVID-19 pemphigus and pemphigoid with the IPPF's medical advisory council members. Our speakers this evening, starting with Dr. Aimee Payne at the University of Pennsylvania. Dr. Payne serves as the Albert M. Kligman Associate Professor of Dermatology, Director of the NIH-funded Penn Clinical Autoimmunity Center of Excellence, Core Director for the Skin Biology and Disease Resource-based Center, and Associate Director of the Medical Scientist (MD-PhD) Training Program. Dr. Payne's clinical practice specializes in the diagnosis and treatment of patients with autoimmune blistering diseases. Our next panelist is Dr. Mary Tomayko. She is a physician scientist who specializes in the diagnosis and treatment of autoimmune blistering diseases and other immune-mediated skin disease. Dr. Tomayko is a director of dermatology education at Yale University School of Medicine. Our third speaker is Dr. Emanual Maverakis immunology researcher and an Associate Professor at the University of California, Davis Department of Dermatology. There, he runs a clinic that specializes in the treatment of patients with severe immune-mediated diseases involving the skin. So now, it is my pleasure to introduce Dr. Aimee Payne, Dr. Mary Tomayko and Dr. Emanuel Maverakis to answer your questions and to tell us about COVID-19.

Dr. Payne: Great. Thanks so much.

Dr. Tomayko: Thank you for that introduction.

Dr. Payne: Yeah, this is wonderful. So this is Aimee Payne and we will go to the overview slide now for the presentation and walk you through it. So some of you may have been on our call two weeks ago. And so we're not going to do a complete repeat of the call two weeks ago, but Dr. Tomayko took the lead to sort of update the presentation with some new guidances and some new data that's emerged over the last two weeks. And also we've added in some new topics that have come up about how to protect yourself as a community opens up and vaccines in the future. So I'll first go over a primer on terms, how the virus spreads, risk for serious disease. Dr. Maverakis will cover how to protect yourself now and as the community and society starts to open up again and then Dr. Tomayko will finish with what you should do if you can contract COVID-19 and talk a little bit about what we might expect from vaccines in the future and we did want to leave some time for a panel discussion Q&A at the end. So we can go to the next slide.

Dr. Payne: So for terminology review this is a review of what we went over two weeks ago, but wanted to make sure that everybody was on the same page in case you weren't able to attend that webinar. So coronavirus is a general term for the family of viruses that causes respiratory illness. So some of the more infamous ones have been known as SARS, MERS and the current outbreak which is caused by SARS-CoV-2 which we'll get to in a minute, but what I think a lot people may not realize is that there are coronaviruses circulating every year. There's about four or so that are common, they cause flu-like illnesses. For example, they may be a reason why some people feel like they got the flu even though they got the flu shots, you know, it's possible that they actually got one of these seasonal coronaviruses instead. So they are quite common and they circulate that there's a new one this year which on the next line is known as SARS-CoV-2. So that is the official name for the virus that's causing the global pandemic. Now, it stands for severe acute respiratory syndrome coronavirus two, SARS-CoV-2. That's a mouthful so we also call it the novel coronavirus which is what you hear most on the news and that's meant to distinguish it from the SARS 2003 outbreak. Okay, and then COVID-19 stands for Coronavirus Disease 2019. So that's the official name of the disease caused by SARS-CoV-2, it doesn't mean that it's the 19th virus that's been out there but rather that it's just named after the year. So that's basically the terms that will be using novel coronavirus to refer to the virus, SARS-CoV-2 is the official name for the virus and COVID-19 is the disease that the virus causes. Okay next slide.

Dr. Payne: So going forward on the next slide. This is a little bit of a review on how the novel coronavirus spreads but we added in one extra bullet. So person to person spread is the major transmission route and it's primarily from respiratory droplets that happen when you sneeze, cough, or talk. In general those are large droplets that pretty much kind of fly out of your mouth when you sneeze. You've probably seen that on the news and some of the talk shows when they show how far a sneeze can travel it goes about six feet away and then falls to the ground. But you know for those who are healthcare workers and working in different areas, smaller aerosolized particles that remain in the air for up to hours can also be possible that most often occurs with medical procedures. So, for example high risk procedures like suctioning and certain lung procedures that they do to very sick patients that have COVID-19 in the ICU. But there are isolated examples where they feel that certain things such as singing in a choir and various different things can also create these smaller particles that can remain so there are some everyday activities. if you will, that are thought to be a little bit higher risk. Virus can be spread by asymptomatic carriers and furthermore traces of virus can be found on solid surfaces such as door knobs, elevator buttons, bathroom fixtures, office fixtures. So COVID-19 is a serious disease, but most people will recover eventually and we'll get to a little bit later in the talk how you end up protecting yourself from the virus, but I did want to pause here for just a minute and go through some of the questions that you had put in before the call. So one question was can mosquitos carry COVID-19? So we think the answer to that is no because when they've looked in blood there's really no virus significant amounts of virus that are in the

blood. So we call that virania and that really doesn't seem to be the case. So we don't think mosquitoes can pass on COVID-19.

Dr. Payne: The second question was can a flu shot or pneumonia shot prevent COVID-19? So the answer to that is no, in the sense that there's not enough cross reactivity between this new coronavirus and the flu or pneumonia that we think that that would cause protection. Another question came in, can you get coronavirus from a toilet seat? I guess the easiest way to answer that is that that's the not the most common way that the virus is probably transmitted, but the answer is probably not a zero chance in the sense that if somebody sneezes all over the toilet seat and then you touch it and happen to touch your face, theoretically that is possible. So I think the general idea is if you use a public toilet or even a toilet in your home where somebody in the house is sick. So this is an issue that's coming up commonly where people have to quarantine in their home and there's only one bathroom. So in that case the recommendation is that if you go in and use the restroom, wipe down everything that you've touched including the toilet flusher, the knob for the handle so that the next person coming in doesn't have any risk of contracting it from you. And then one other question came in, do asymptomatic carriers of COVID-19 ever stop spreading the virus? Yes, in the sense that there's only a certain period of time when you're thought to be infectious. The highest values vary. So the thought is that if you're immunosuppressed you may actually have the virus a little bit longer than if you're not in your suppressed, but the range is somewhere in the order of 7 to 21 days. So that's basically the argument for quarantine and general for the average person it’s 14 days, which is why that's generally the length of quarantine if you've been exposed to somebody or if you've done high-risk activities such as traveling internationally. That's the reason for that 2 week quarantine. Final two questions on a slide was is it true that warmer weather will slow or stop the spread of coronavirus? That is a prediction that has been made but I will say that we don't think that that will bring it to zero in the sense that a lot of countries where this virus has spread are on the equator where it's quite warm. So places like Singapore and other places. So it doesn't mean that the risk is zero in the warmer climates. Finally one question was, is spraying buildings and streets effective for combating COVID-19? And we think the answer to that is yes in the sense that the virus is actually not very hardy. If you spray it with 70% ethanol or dilute bleach solution, it's dead within a minute. So it's not an incredibly hardy virus in that regard. But of course it's just the mass of people that are walking through that could sneeze or cough or do something that would be the source of new infection. So we can go to the next slide.

Dr. Payne: Which is talking about risk factors. And we did cover this two weeks ago, but this has actually been updated on new data that was posted on the CDC website. So thanks to Dr. Tomayko for running this updated list. So the risk factors for severe COVID-19, officially on the website, CDC website are listed as being age greater than 65 years, but as we sort of look through the data increased risk for hospitalization from COVID-19 does take a tick up after the

age of 60. There is a higher percentage of men that are hospitalized compared to women and emerging data is also showing that black and Latin Americans, those with morbid obesity or poverty have more severe COVID-19 disease than people not in those categories. They also posted updated data on the CDC website about the risk of hospitalization if you have various chronic medical conditions. So this list is actually ranked in order but again, it's not what we call a multivariate analysis where it means that having this condition in and of itself is, will be the only thing that predicts risk. But generally those risk factors are kidney disease on dialysis, neurologic disease, heart disease, diabetes, being a former smoker, liver disease, immunocompromised state, lung disease, current smoker and pregnancy. So that's basically what, essentially any poorly controlled disease. So pemphigus and pemphigoid in and of itself is not known to increase the risk of COVID-19 disease. So it's really the medicines that you're taking rather than your pemphigus and pemphigoid in and of itself if that makes that determines your risk. So I think the take-home messages from this list is that an immunocompromised state is actually in the middle of the list. So one question that arose was do multiple underlying medical conditions increase your risk? The CDC did analyze that in their list they put in one or more conditions and meaning if you have more than one of the conditions that's on this list. In general, the risk averages out where it's just about the same as being immunocompromised. But, kidney disease on dialysis is definitely the number one risk where that is something that does fall as being higher. So I would say that, your risk is driven by a number of issues and being immunocompromised is only one of those. So we have a few questions that came in one is, should I stop taking Losartan for my high blood pressure since data suggests that there are more complications with people who get COVID-19 are on an Ace inhibitor or ARB which is the type of drug that Losartan is? So the recommendation right now would be no, not to change your medications without the advice of your doctor. The rationale for that is, that people are starting clinical trials right now to look at that issue. The one thing that I guess I've learned in medicine is that whenever you think something sounds good, you don't realize the law of unintended consequences. So that's really the need for basically doing clinical trials to understand that because having uncontrolled hypertension is probably not a good idea either. So basically, what I would recommend is just talk to your primary care doctor about these issues before you do that. But right now there's no data to suggest or provide doctors with guidance on what to do with that. Another question was, would non-alcoholic steatohepatitis also known as NASH be considered an additional risk factor? That probably depends on the level of the severity so it is a form of liver disease and chronic liver disease is a risk factor. So, if it's extremely mild, then I would say that the risk might be mild if it's obviously severe than that would bump you into that sort of higher risk category of chronic severe liver disease. One person asked about exercise induced asthma. Asthma, COPD, emphysema, these are all risk factors that fall into the lung disease category. Exercise induced asthma is considered like a milder form of asthma so, it's a mild risk, it's not a huge risk. So hopefully that I know that's a little hand wavy but hopefully that helps you put into context. I think I covered all the questions so we can go on to the final slide for my section. Sorry the

next to final slide for life section, which is how the risk of severe COVID-19 disease increases with age.

Dr. Payne: So this is the data on hospitalized patients and what you can see is that really relatively few people under the age of 50 are hospitalized but it's really starts to go up, particularly age 65 and greater and highest in those over the age of 85 but still overall a relatively low number per 100,000 people. Then if we go to the next slide.

Dr. Payne: People are asking about the immune response and there are thought to be two phases to the infection. So the first is when the virus is replicating in your body and the second is when your body starts trying to fight that infection. It's very important for your immune response to activate and clear the infection, but sometimes the problem is that if your immune response is overactive then that can actually be associated with severe disease. So basically you want it to be just right where you exhibit enough of an inflammatory response to kill the virus. But if your immune system goes overboard that is actually associated with severe disease and some of the complications and death that have been observed with COVID-19. So we have two questions surrounding this, one is somebody noticed that on the COVID registry of the patients with inflammatory bowel disease that patients taking anti-TNF medicine seem to have a lower hospitalization rate than other immunosuppressants and asked if the drugs can be used for mucous membrane pemphigoid. So I guess if we take those questions one by one. The anti-TNF medicine, this would be things like Humira, Etanercept, Remicade etc. Those drugs are not FDA approved for mucous membrane pemphigoid. So they can't be formally recommended. There are anecdotal data that some patients can improve with their mucus membrane pemphigoid on those medications. The data that we do know about anti-TNF medicines is that there was a trial of infliximab, which is Remicade in pemphigus vulgaris that was run several years ago. It was not a positive trial in a sense that the pemphigus improved. They did notice a little bit of a drop in the pemphigus antibody levels that were in the blood. But ultimately it was determined not to be strong enough data to support, for example an FDA approval or using that drug in regular clinical practice. The next question we had was a patient with pemphigus vulgaris, I'm not currently on any medications and the last Rituximab infusion was in February of 2019. This patient was noticed to have an extra immune response in the blood with a consistently positive test for something called VDRL. So the question was if I have an overactive immune system am I less likely to get the COVID-19 disease or will I get it less severely? So this is a little bit of a tricky question because the first thing is that the VDRL blood test is actually something that tortures medical students across the country every year. There's multiple questions on the board exams on that because there are multiple causes of false positive VDRLs. One of them is something as common as just a viral infection. So if you happen to have a viral infection and you go for that blood test, it can be a false positive. So you have to make sure that it's falsely elevated multiple times. And if that's true, where there are some patients with for example, lupus who have multiple false positive VDRL blood test. So then the question becomes does that mean that I'm less likely to

have severe disease? I think that there'd probably be no relation. It's too hard to be able to predict, blanket, whether or not you'd be less likely to have severe disease or more likely to have severe disease from that in and of itself. It's just very, very difficult to predict who's going to have that overreaction and who won't. So that's the end of my part.

Dr. Maverakis: Doctor. I'm online, this is Dr. Maverakis. Should we go to the next slide?

Dr. Payne: Yeah, that would be great.

Dr. Maverakis: Okay, so we have protecting yourself from infection. Currently the CDC recommends hand-washing with soap and water but we also recognize that hand sanitizers are also an important component. Not everybody can wash their hands many times a day, depending on your own tolerance. Washing hands with soap and water with the 20 second scrub like the CDC recommends is probably a more thorough way of removing the virus but not everybody can wash their hands frequently enough. So we recommend washing your hands to tolerance and then to also using hand sanitizer if you're having difficulty with dryness or cracking of the hands. We should avoid touching our face, nose, eyes and mouth. I recognize that we do that subconsciously. It's not something that we're really aware of all the time. So it's best to wash your hands before you know you're going to touch your eyes and mouth like before you put in your contact lenses or before you put on your lipstick or something. And also when you think you have had contamination out there like you touch the doorknob that you saw many, many people touching things like that maybe you could focus on not touching your face or nose or eyes or mouth until you're able to wash your hands or to use some hand sanitizer. Disinfecting surfaces that are touched like door knobs, light stitches and rails, that's incredibly important. And wear face masks in public. So face masks are the newest recommendation by the CDC, but other countries like Taiwan have been doing it for a very long time. We highly recommend that everybody wear face masks in public. And then the other thing we want to mention is that there are no medications known to prevent infection. So do not take hydroxychloroquine as a preventative measure. Avoid supplements unless prescribed by your doctor. We don't have any good data that a supplement would help or harm you. Even if you think that the supplement is immune-boosting it's possible that your viral infection is going to damage you by an overactive immune response. So we don't know which direction would be best. So there's just not enough data on supplements so we don't recommend them at the time. Now, we had several interesting questions in this regard. Robin asks, how many times can I use my N95 masks? I use it when I get out of my car and when I go for a walk. So that's an absolute phenomenal question. So what we do know is that masks are reused in other countries that have done pretty well with coronavirus. N95 masks, when they compare N95 masks to surgical masks there seems to be no difference in influenza infection, but that's not because the N95 masks are not better. Obviously the N95 mask is superior, but there's something that is tolerability comes into play. So something very snug fitting and you're manipulating it and you're taking it off and stuff like that. Those are all things that contribute to

how well it's protecting you and if you contaminate your mask with hands that are contaminated then that's also going to be a component of how well that mask is able to protect you. So the N95 masks, it cannot protect you from aerosolized virus so we don't believe that aerosolization of the COVID virus is a problem in the general public. It's a problem for healthcare workers who are intubating and things like that. That's why they generally recommend N95 masks for healthcare workers who are doing these types of procedures that are highly contagious. But to go back and answer your question specifically, how many times can you use your mask? The virus will not last forever on that mask. So let's say you have seven different types of masks. Like you have a surgical mask, you have a nice cloth mask. You have different masks. You could probably cycle through those and reuse them. The fibers in the masks are not highly, highly stable, but you can give it a spray with 70% ethanol. That's also another possibility. They initially thought that these fibers would break down with autoclaving and other sterilization techniques, but it turns out that there's papers published where they're still pretty good when they're reused. So I do think that the N95 mask can be reused. Obviously if it's soiled you can't reuse it and depending on how many masks you have to cycle through them, I don't think you have to worry too much about having contaminated the mask and then getting infected because you're using a contaminated mask. I think the mask is going to hold up pretty well, it's just eventually going to get contaminated and you don't want to put a contaminated mask on your face. So some type of sterilization procedure, there ones on the internet. I don't want to necessarily recommend one or if you could just cycle them through. Leave one alone for about seven days. The coronavirus usually doesn't last for seven days. Okay. I'm sorry for taking so long on that one. We got another question. Will you explain how if somebody else wears a mask it won't necessarily prevent me from getting coronavirus but if I wear a mask it will help me from infecting others? Well you see the masks themselves are probably not the best way of preventing coronavirus. You need the mask plus something else like hand hygiene. If you have excellent hand hygiene, then that's good. And if you have excellent hand hygiene plus we're masks all the time that's great. The idea is that there are a lot of people who are infected and they don't know they're infected. I mean people shed this virus for many months sometimes and there's well-documented cases that people are shedding the virus for many months after infection. The question is are they still contagious? Just by having the virus detectable by PCR in your nasal, pharyngeal system does that mean that you're still contagious? So we patients were where the CDC says get two negative tests before you're considering not contagious and we've had people released from the hospital, like our very first case in California. She is still shedding virus and shee was released in March and she is still shedding virus. So by wearing a mask we don't know if you're contagious after you recover from symptoms but we do know that you're contagious before you get symptoms. Right before you get symptoms. You're pretty contagious. So by wearing a mask you prevent others from getting sick because you catch most of your virus in your mask. Then the question says that if I wear a mask and somebody else wears a mask it won't prevent me from getting coronavirus. So that's not true. If everybody's wearing a mask and you're the only person not wearing a mask you're going to be protected. The idea is to get as many people wearing masks as possible. I got another question from Carol, I stay home and have been home since mid February but my husband works outside the house. I wash my hands and sanitize our shared services constantly. Should I

avoid him to be on the safe side? We have a big enough house that we can easily keep our distances. So I would say that depends on how high risk your husband is. Is he doing something where he has a high chance of getting coronavirus? And it also depends on what state you are living in to see what the endogenous rate of coronavirus is right now. Many states that there's not too many cases so the chances of you getting coronavirus from your husband, if you're in one of those areas where the incidence is low is going to be low and if your husband doesn't engage in any high-risk activities and he does his hand washing and he wears his masks his chances of getting coronavirus are low. Now if your husband is like a bus driver or is out working in the grocery store or something, Costco or something like that then yeah, it might be reasonable to isolate yourself from him. But I think it would be a little bit extreme to do it otherwise, but it's personal preference. If I think it'll be okay, it doesn't it doesn't hurt to isolate yourself from your husband. The next question is a pretty good question. Should I be covering my open lesions when I need to go to the grocery store? In general I don't think it's a bad idea to cover your open lesions. I think that's probably a good baseline that you don't have erroisions everywhere. You are immunocompromised. But in terms of can you get COVID through a skin ulcer, a skin erosion, from your pemphigus or bullous pemphigoid? As far as I know, they're not talking about that type of mode of transmission. Even that it's in stool, I don't think that there's a lot of cases of fecal coronavirus infection from contact with somebody. So absolutely there's not enough data to say for certain but I would imagine that not a natural route of entry for the coronavirus. So it’s probably not terribly dangerous if you accidentally have your arm coughed on or something and some coronavirus went on your arm. With that said, in general I would say that it's a good idea to cover your open lesions when you're outside. I'm not sure if the other doctors would disagree with that. So I got another one from Kathleen, I'm an otherwise healthy 70 year old woman, am I more susceptible to catching the coronavirus and experiencing more severe symptoms. Are there any additional precautions I should take over and above what is recommended for the general public? I think that if you are a healthy 70 year old woman you're going to have a better chance than if you're unhealthy because obviously the comorbidities are what increase your mortality not just your age. But all the different comorbidities are probably as or more important. I don't know if you should take additional precautions because of your age. Now if you're a pemphigus or pemphigoid patient and you're on immunosuppression then I would recommend that you use high degree of caution. Probably be more strict with the recommendations. I don't know about taking additional recommendations, but be more stringent with your hand hygiene and those types of things. Marion says that she has read that the president of the U.S. keeps suggesting zinc to help COVID-19. What are the thoughts and research to suggest this could be helpful? Well zinc is helpful for other types of infections. I am unaware if there have been any good randomized control trials for zinc so I doubt that, I mean I think if zinc was well established it would be as part of our established regimen for patients in our hospital. And as far as I know, it's not on our standard of care to give zinc. Now with that said I think zinc can give you some stomach ache. And if you do want to take zinc you might want to take zinc echinacea because they'll probably be less hard in your stomach then zinc sulfate and I would stay within a reasonable amount of zinc because it can be very harsh on your stomach. I personally don't think that zinc would be very harmful if you want to try it, and it might have some benefit because it has been in other

infections, but I don't think it's been worked out well for COVID-19. Now I did hear Dr. Payne talking about zinc yesterday, and I just didn't really listen to her. So maybe she has something to chime in here?

Dr. Payne: I think that you know, a lot of the data on zinc is in petri culture dishes where they can artificially keep the zinc high at all times and that perticulture dish and they can show that it decreases the rate of infection. I don't think that in clinical trials the data is very strong. And I think that's because you can't take zinc frequently enough to keep the levels high enough in your blood to really make a difference. It's also very expensive nowadays. So I personally don't recommend it. Yeah, that was it.

Dr. Maverakis: Okay, perfect. So the next question says, how should a patient going through IVIG handle the in-home infusion therapy. Are there extra precautions I should take even in my home while getting my infusion? Should the nurse and myself be wearing masks the whole time? How long can it be delayed? I don't know what delayed maybe the IVIG therapy. That would depend what dose you're getting of IVIG. IVIG is pretty good for immunobullous diseases, but in my experience, it's something that I give every month for at least 3 months. I don't just give a little bit of IVIG I have to use high amounts of IVIG. I don't know if delaying it like every other month or something like that. I'm not sure how effective that would be if it's possible. But we typically do a pretty aggressive regimen of IVIG to get the immunobullous diseases under a little bit of control. I would say absolutely that you and your nurse should be wearing a mask. I mean those are the recommendations now that we all have a face covering. So when your nurse comes in she should wear the mask. Besides that I think your normal daily precautions, like good hand hygiene and those types of things. So Vicki asks, is it safe at this time to go into a lab for blood tests and I start Rituxan treatment during the pandemic. So those are all excellent questions, obviously going in for a blood test is a little bit worrisome because you're going to be in a crowded waiting room possibly but at the same time these types of questions depend on where you're at. So if the prevalence of COVID is high where you're at, it's going to be at a slightly increased risk. But in general I think if you take hand sanitizer, wash your hands after coming out, don't touch your face, wear your mask it's probably safer to get your blood drawn then to not get your blood drawn if you're on medication that requires monitoring by blood draw. So I don't think there's any reason to forgo and needed blood draw. I mean if it's just like an annual blood draw where the doctor didn't have any suspicion that there is anything going on, in that case you might want to delay a month or two. But if it is something like you're on a specific medication and they want to monitor you for that medication, like if you're on Dapsone, you need to get your blood drawn because Dapson can do really weird things with your blood. So if you're being monitored for medication adverse events, I would say it's safer to get your blood drawn regardless of the prevalence in your area. If it's just a routine blood draw, maybe you could ask your doctor if you could push that out a little bit. Then the next question was can you start Rituximab during the pandemic? So I personally believe that Rituxan is a great medication and that it should not

be withheld during the pandemic if you are symptomatic. So if your pemphigus and again, let me let me dial back a little bit. Obviously your doctor knows you best and if you have a dermatologist who's taking care of you or rheumatologist, or whatever type of doctor that's taking care of you that's been managing you it's highly likely that they know you best and they know when you should get your Rituxan. But in the generalist way of thinking about this, Rituxan is usually given and then it's given in six months, often given in two doses two weeks apart, 1,000 milligrams. So if you are in remission and you're up for your next dose of Rituxan it's reasonable to talk it over with your doctor if you could push out the Rituxan a little bit. I mean the doctor might say no because you don't react well to prednisone, you have horrible diabetes and if you're pemphigus flares up really bad you're going to be in much more trouble than you are if you encounter COVID. I don't know your particular story, but it's a reasonable conversation to have with your doctor whether or not you push back your Rituxan if you're asymptomatic. Now if you have pemphigus and it looks like your pemphigus is getting worse or if you have bullous pemphigoid and it looks like it's not going to getting better and if anything it's going to start getting worse, then I think in that setting Rituxan is a reasonable medication to get during the pandemic. And just because you have your B cells wiped out does not mean that you will lose all of your B cell response to the COVID-19 virus. It is possible for your B cells that are resistant to Rituxan to respond to the COVID-19 virus. So I would say that it's not ideal to have Rituxan and to get COVID absolutely not but if I had to pick between a horrible pemphigus flare and getting Rituxan, I would pick getting the Rituxan and like I said, there's many other complicating factors that you do you have to have a discussion with your doctor. Okay. I think we could go to the next slide.

Dr. Maverakis: Okay. So how should these recommendations change as community life opens up? So the recommendations don't really change as community life opens up. I think you still do your best to do your social distancing. Like of course if you're working at a bar and then they open up the bar, you have to make a decision if that's a great job to have. But if possible, when possible you should still practice social distancing the best you can. You should still wear your mask, you should still practice good hand hygiene, you should still try to avoid touching your face. In the short term it is possible that we will get one of these medications that pan out that help us from the clinical trials that we're doing now. They're doing tons of clinical trials and hopefully something will work out. The testing for coronavirus is going up dramatically, so there should be some contact tracing and these types of things that are going to be improved upon shortly. Testing for covid antibodies, now this is a very tricky thing because we don't know the prevalence and when you don't know the prevalence you're going to have a lot of false positives for the antibody testing when you don't have a gold standard, but this is going to maybe change of how we're looking at COVID and then aggressive contact tracing. Now herd immunity is not going to happen for a while because there's not enough people who have been infected by covid virus and it would also depend on your area, but even York, I don't think New York has enough people infected to start getting herd immunity. But herd immunity hopefully will reach some level to provide us herd immunity with people who have asymptomatic infection. It would be horrible if we relied upon herd

immunity, how it is now where some people are getting really sick. But the ultimate thing is that when we get a vaccine that's when things are going to be the most safe when we have an effective vaccine for this and that remains to be seen. It is very difficult to develop a vaccine and hopefully we're on the right track and hopefully the virus doesn't mutate and these types of things. Okay, so we have several questions. My state will start opening up next week, should I continue to quarantine at home for how long? I think this is a question that would depend upon if you have the means to quarantine at home and how much that affects you personally. So if you don't mind being quarantined at home, it's not a bad thing to continue the home quarantine. If you are relying upon a job for your health insurance and these types of things, I don't recommend quitting your job because you're too afraid to go outside. I do believe that wearing masks and practicing extreme hand hygiene you're probably going to be much safer than before, especially now that more people are wearing masks and things like that. So what precautions should I continue to take as I re-enter society. I think even if they say don't wear masks or masks are not needed anymore, if you're on immunosuppression I would say continue wearing masks. If possible I would have hand sanitizer on me at all times, continue washing your hands, especially when they come in contact with contaminated surfaces, continue to wash your hands when they're soiled but do it to your tolerance and then use hand sanitizer multiple times throughout the day just pretend like everything's infected. So do your best to keep your hands sanitized, plus a mask should go a very long way. What precautions should I take to get a haircut as wearing a mask is difficult? So when you're getting your haircut it might be difficult because your mask is going to go around your hair. You can have masks that go around your ears. I don't think that that would necessarily inhibit your haircut, but I'm not like a stylist. I'm not like an expert. But if you had one that didn't go around your hair, but when around your ears, I would probably be reasonable. The other thing is that if your hair stylist has a mask on then that's also nice. Like if you can't wear a mask yourself, but she wears a face mask, that is not ideal but that would be better than both of you not wearing the face mask. But I think that you should be able to wear a face mask while you get your haircut, I don't see a problem with that. But again, I'm not a hair stylist. Why are some states opening while other states remain under stay at home? Well, I think that that is because in some states, there's many reasons to open up and there's many reasons to not open up. One reason to open up is if your state is prepared to handle what it needs to do when it opens up. For example can they do 100,000 tests a week, can they do good contact tracing or do they have a means to dial back to quickly go back into quarantine if they're able to detect a resurgence? How quickly can they detect a resurgence, how quickly can they act? These are all reasons and also you would not want to open up unless you have a serious downturn in the number of cases. Any state that is still getting a lot of cases that doesn't have a good decline in the cases, it would be kind of stupid to open up. The 1908 influenza pandemic, I think it's 1908, was when they had the tale of the two cities like Philadelphia, they never closed down well might have closed down eventually, but while the other sister city had quarantined the other state had bond rallies because they're selling war bonds or bonds and they had a horrible infection and like everybody got sick. But that city then did not get a resurgent but the city that quarantined the resurgent was worse than the initial one prior to the quarantine. So long story short is that coming out of quarantine does not mean that this virus has gone away.

It means that we feel that we're better prepared to deal with the virus. So one of the reasons why we went into quarantine was because we weren't prepared. The hospitals are going to be overrun like they are in New York and these types of things and we don't have personal protective equipment, we don't have ventilators, we don't have all these things. So there's a good reason to go into quarantine. Eventually, when we feel that we can do contact tracing and all these other things it might be reasonable to come out of quarantine. And if we did come out of quarantine, hopefully we could go back into quarantine very quickly if things are getting out of control again. I think I just talked around in a circle but hopefully I answered that.

Dr. Maverakis: So the next side are medications for pemphigus and pemphigoid that may increase risk for severe COVID-19 disease and then what the time dose of effect and what's the effect on the virus? So the first one we have Rituxan and we already spoke about this. When you get Rituxan it's going to knock out all of your CD20 positive B cells. There are some B cells that don't have CD20 so you're going to be left with some of unity and then it's highly variable when those cells come back in people. Sometimes they're gone for well over a year, sometimes they're back in a couple of months. So it's hard to pinpoint exactly but I would say most patients by one year have titers again of their CD20 positive B cells. These are the cells that Rituxan kills and then of course Rituxan is going to weaken your immune system and without your B cell response you might not be able to clear the virus. Then there's Cellcept and Cellcept you might think it's safer, but it's not necessarily safer. One reason being is that it’s hard to wear off the effects of the Cellept. So even though you might be taking it twice a day, if you stop taking it then you don't regain your immune system overnight it will take about 3 months and this medication again is going to weaken your immune response to make you more susceptible. Azathioprine basically mimics Cellcept and so does Methotrexate. Now prednisone doesn't last very long so if you stop prednisone very quickly your immune system will bounce back but it might bounce back horribly and you might have a horrible pemphigus or pemphigoid flare. The other thing is that your body will stop making its own prednisone, its own mineralocorticoid, when you're taking it. So if you stop suddenly you won't have any of these endogenous prednisone like molecules to keep you going because we need them. So it's very difficult even though its effect on the immune system is rapidly reversed, it's not a drug that you can easily stop quickly. IVIG is a great medication because it's not going to have much immunosuppressive effects and it takes a while to get out of your system because some of this is going to be recycled. There's a recycling mechanism for the IVIG, so that would be about 4 weeks. Dapsone, Doxycycline, and Nicotinamide don't last very long in your system and then probably not that much of an effect on the virus. Then Xolair and Dupixent we don't quite know about Dupixent yet but Xolair shouldn't have much of an effect on the virus and it'll take a little bit of time to get out of your system but I don't think it's going to have much effect at all. Probably zero effect on the body's ability to fight off the virus. Dupixent in theory shouldn't have much of an effect but since it's blocking one pathway, it might contribute to a more robust immune response to the virus, but in general we think Dupixent is pretty safe. So let me just answer about two questions because I'm spending too much time answering these questions. So what is the daily dose of Mycophenolate Mofetil that can be taken by pemphigus

and pemphigoid patients before making us immunosuppressant and other immunosuppressants? So Mycophenolate Mofetil/Cellcept will make you immunosuppressed at any level. Obviously if you are only on 500 mg a day the effect is not going to be that much compared to something like a 1000 milligrams twice a day. I believe the top dose of Cellcept/ Mycophenolate Mofetil is 2.5 or 2,500 milligrams a day you can take. If you're on the low dose your immune system obviously is not going to be nearly as immunosuppressed. But then again you don't want to be in the situation where you're dosing so low that you get a horrible pemphigus flare because going back up the dose of Mycophenolate Mofetil you're not going to get overnight relief. It's going to take a while to reach back maximum effectiveness again. So let's say you're on 1000 milligrams twice a day and you're doing great, you don't have any lesions and then you go down to 500 milligrams twice a day. Then like a week later, you're thinking that's great, I went down and I don't have any new lesions. Well, it takes time for it to wear off. So like three months later you might be getting horrible lesions and then if you go back up on the dose and might take some time to kick back in. But these are things that you can talk to your doctor about to see if maybe you could do a hybrid therapy with a little bit of Mycophenolate and you could ask other treatments that are less immunosuppressive like my Doxycycline or Nicotinamide or IVIG or Dupixent or something like that. Often, it's hard to get insurance approval for Dupixent because it's a very expensive medication and it would only be used for bullous pemphigoid. I don't think it would work at all for pemphigus but the point is that there's no dose of Mycophenolate Mofetil that you will not be immunosuppressed it's just a gradation. Okay, so I'm taking Cellcept, 1,000 milligrams twice daily and prednisone 5 milligrams daily for pemphigus vulgaris. I'm an otherwise healthy 70 year old woman. Am I more susceptible to catching the coronavirus and having more severe symptoms? I would say absolutely. So you are on prednisone and you are on a good dose of Cellcept so you are very immunosuppressed and if you caught the coronavirus you would have a harder time to mount your immune response to the coronavirus. Now everybody's immune system is different. It is possible that a little bit of immunosuppression would prevent your body from having the over aggressive response to the coronavirus but I would think that that would be the minority of cases. I would think that people who are on high-dose Cellcept like you are would be much more susceptible to getting severe coronavirus infections. Okay, so maybe I just do one more or should I call it there Aimee?

Dr. Payne: Maybe let's go on to the final slides and then we can go back to questions.

Dr. Tomayko: So I can take over from here. So thank you everybody for your patience. We do have some more slides and I will try to be efficient as we go through these because I know it's getting late.So many, many people are wondering what if I develop COVID-19 disease? And are asking how do I know that I have COVID-19 or how do I have influenza? Somebody asked, are there skin lesions that could be symptoms of COVID-19? So let's address both of those. If

you have any symptoms suggesting that you might have COVID-19, please call your doctor immediately. Call don't just go in because if you have an infection, you don't want to share it. You don't want to go into the Health Care system if you don't need to, so call. So what are concerning symptoms? As we know, there is fever, cough, shortness of breath. It can be loss of smell, it can be diarrhea, it can be red eyes. And yes, you can have tender bumps on your toes. This is not a common presentation. And from what we know so far this tends to be healthy young people and children. So that's that. However, we say call if you are severely short of breath, you don't call then you call 9-1-1 and you go straight. People are asking, if we get sick should we stay at home until we're so sick we can't handle it at home anymore since we're immunocompromised? What should we do? Here we can't be afraid of the Health Care System. The hospitals are set up to take care of you. You do not want to stay at home and try to handle this by yourself until the very last minute. The more we understand about this disease the more we realize that earlier intervention, even without super aggressive interventions can be very important. That's why, Boris Johnson if anyone followed his study, that his situation in the UK you can read about that. So after you talk to your doctor if the decision is made you're going to stay in and you're going to monitor at home, take your doctor's recommendation. That's going to probably include having a home pulse oximeter to be measuring your own oxygen and be talking back and forth with your doctor. There is a pulse oximeter that you can get as an app on your iPhone. It's good for a range of maybe really early disease. Usually about 99 or a 100% percent. If your oxygen drops below 90% your iPhone app is not good enough and you need another pulse ox, but really by that point you should be in your doctor's office or maybe even the emergency room. So another question is should I stop my medications? No, please don't. Don't stop your medications unless you're directed to by your physician. We even now have formal recommendations by the National Institute of Health on this so we have specific recommendations for people with autoimmune disease that says if you require prednisone for your autoimmune disease, you do not stop the prednisone even If you're diagnosed with COVID-19. One question was, I've been advised to take prednisone if I'm flaring. Is this recommendation still valid? I'm worried that prednisone is not a good idea if I become infected with the COVID-19 virus. So in the end the basic principle is, if you don't have COVID-19, we need to keep your skin disease under control. So you're going to call your doctor, you're going to discuss and if your doctor says yes, you should do your extra prednisone to take care of your skin disease, you're going to take care of your skin disease. And right now that is your primary concern. If you get COVID-19, then we're going to deal with it. So next slide, please Becky.

Dr. Tomayko: Okay, so what our experience with individuals who have pemphigus or pemphigoid who've gotten COVID-19 is quite limited to date. We have no published outcomes data yet. So you're asking how long does it take for somebody who has pemphigus or pemphigoid to completely recover? Is there any record of people who have pemphigus or pemphigoid who've had COVID? How did they do? We don't have any published outcomes data but our personal experience so far is encouraging. It's very small. This is a very, very limited experience that we have talking to one another about our individual patients. And what

I can say is in my own personal experience, although it's very limited, my patients with pemphigus or pemphigoid have done very well after being infected with COVID-19. They've done similarly to other people with their general age and health conditions. It's a small, small sample size however, I find it very encouraging and I hope that you will too. Furthermore these are very important questions and would just like to say that I think the IPPF community is really positioned to help address this so it's something that we consider doing as a group to come up with an answer to this. Another question related to this topic is, I've read that steroids may be helpful if someone has COVID and they are having acute respiratory distress. Is there any truth to this theory? That's very insightful question. So when people are having as Dr. Payne pointed out in the second. So the first phase of infection your body is going to mount an immune response against the virus. But if then you have an out-of-control inflammatory response that doesn't dampen down that's when you can get into trouble with acute respiratory distress. And so there are many, many trials and uses of prednisone to calm down that overly active inflammatory response. The data are not out there yet to say whether or not this is the most effective treatment but prednisone and many other immunosuppressive medications are being tested as treatments during this out-of-control inflammatory response that's giving people pneumonia. Similarly, another person asks, can medications that are used to treat pemphigus and pemphigoid be used to treat COVID? I would say right now, I don't I don't know of any studies or I can't even think of a good rationale for using pemphigus and pemphigoid medications to treat COVID. However other medications that we use to treat other autoimmune diseases are being used in trials to treat that second stage of the COVID-19 disease. Can we have the next slide?

Dr. Tomayko: Okay. So what about after you have an infection so we'll look at the second line first. So individuals who have recovered from COVID-19 will probably be protected against any new infection at least for a while. Probably we think based on what we know of other coronavirus, this will probably be at least a year and maybe longer. How do we know if a person who has recovered is immune? We don't have the answer to that yet. One way that we hope to gather that answer is to do tests for antibodies. So there are many many caveats to these antibody tests. So this is something that's in development and we can have more data for you later. Right now antibody tests are not readily available. There are many, many different tests and we don't have a good sense yet for the differences between them. It's also not clear yet which tests detect antibodies that are actually protective against the disease versus antibodies that were mounted during the disease that are irrelevant to protection. So we're going to need to get much more information about that. Can I have the next slide Becky, please?

Dr. Tomayko: Okay. So this slide I made to try to help us address a few questions. So one person asks can the coronavirus reactivate and get people who've already had it sick again? Another person says, is the general consensus that if you do get COVID that you cannot get it a second time? And another person says I'm on high-dose prednisone, if I get the virus and

recover will the prednisone prevent my immune system from developing antibodies so that I'm protected in the future? So these are really good questions. When we say viral reactivation we don't have any real reason to think that the coronavirus is reactivating. There have been some stories in the news that have suggested that it might and I won't say definitively that it doesn't but viral reactivation which means the virus never really went away and it stayed in your body and now it's coming out again doesn't seem to be common. However, can you get it a second time or not? So let's look at this graph and we're going to read it from left to right. Okay, so going across we're going to see time after infection and then going up and down we've got the amount. So first we're going to say this is when a person is infected. So a person is infected and they have a little bit of virus in their body and then the virus proliferates, and divides and divides and there's more and more of the virus. As there's more virus a person starts to feel sick. Eventually the immune system starts to get rid of the virus and the amount of the virus goes down, down, down. At some point as the virus is coming down the immune system also starts to make antibodies. So the immune system starts to make some antibodies and makes more and more and more and more and in that interval as a virus is coming down and there are more antibodies and other things are happening the person starts to recover from the infection. Then you've got this recovery period where the person is completely recovered and the antibodies start to drop off. So whether they go away completely or not is a question that we do not know the answer to. Now there are two types of tests that you're hearing about. So it's important to realize that these are different. There are viral tests, so that test this first stage and sometimes they're called RNA test and that says is there an active infection right now do we detect virus in you right now? Then there are antibody tests and those are the ones that are being developed and they're starting to be used. What the antibody test say is, did you have an infection before? So there are these outstanding questions that we don't know the answer to : how long do those antibodies last, how protective are they and if you get reinfected in the future, do those antibodies protect you or do you get disease? Okay, next that slide, please.

Dr. Tomakyo: And we are almost done. Okay, so in the future what we are all hoping for is to be able to have protection from vaccination. Development of a vaccine is going to take time. This is many months to years and we're all hoping for 18 months, like a year to 18 months would be terrific if that's the case. Once the vaccine is developed, there's also safety testing that is going to be absolutely critical. So for example, we have a question that says what's the probability that a vaccine that is developed might trigger a relapse in somebody who has pemphigus or pemphigoid. That's one example of a safety question. From what we know of other vaccines say influenza vaccines and shingles vaccines and hepatitis B vaccines, we do not see that these are common triggers for pemphigus or pemphigoid. So we do not anticipate that there will be a danger for people who have pemphigus or pemphigoid in being vaccinated. Another person says what if the virus continues to mutate and the vaccine is not very effective? It's another excellent question. Coronaviruses do mutate as all viruses do. They mutate not as quickly as others as in respiratory causing viruses, influenza mutates more quickly. What do we do for influenza? We make new vaccines every few years to try to keep

up with changes and anticipated changes in the influenza vaccine. So the coronavirus might mutate and it might mean that we need to have future iterations of the vaccine in the future. So some medications that we take for pemphigus and pemphigoid might make a vaccine less effective. Particularly, this is going back to what Dr. Maverakis was talking about., but Cellcept and Azathioprine really probably will make the vaccine less effective. Rituximab will probably make it less effective particularly in the first 4 months after an infusion is what we would anticipate. So a question that we have is, if a vaccine is developed in it's a live vaccine is it safe for a person on Rituximab, is a live vaccine safe for a person on Cellcept or prednisone? A live vaccine very well might not be but might not be safe for those. We're not anticipating that the vaccines are going to be live vaccines, it's much more likely that it will not be a live vaccine. So if it's not a live vaccine, it should be safe for people on these medications. And then finally and then this will be the last question and we can move on. So another person says, I've read that many COVID patients don't develop measurable antibodies, which is true. That's true especially, it could be that people with more mild disease don't and maybe for other factors. So going on though, does the depletion of B cells by Rituxan lead to a lower antibody response? And then another part of that question is if I only have half as many B cells does that mean I make half as many antibodies. So these are important questions. Depletion of B cells by Rituxan does not result in all of your B cells going away. Your B cells also regrow as they regrow their establishing a new B cell system. And as that B cell system is becoming established, it works a little bit differently. So if you have a vaccine 4 months after Rituximab and another person gets the vaccine 12 months after Rituximab you might have a slightly different type of response, but it's not clear that one's actually better than the other but immunologically they're not going to be quite the same. In the end, we're going to need to test. We will be giving you the vaccine to keep you as safe as possible and we will be watching as we can develop measures to test how effective that vaccine is. Okay, and then we can just go on to the next slide, please.

Dr. Tomayko: And say thank you very much. It's now much later than we intended. But how about I pass this back to Becky, please.

Becky: Thank you all so much that was so much information and we sincerely appreciate all the effort that you put in to answer a lot of the questions from the webinar. So we really appreciate that. I'm just looking through some of the questions now. And I think you've answered a lot of them that have come through. So I'm just reviewing them now. And we're pretty late. Would you guys mind answering just a couple questions? Let's see. So another question is is can a flu shot or a pneumonia shot prevent COVID-19?

Dr. Tomayko: Yeah, so it cannot. A flu shot will not prevent COVID-19. It will help prevent pneumonia, which is helpful, but it will not not prevent COVID-19.

Becky: Sure. Another question is is it possible to get COVID antibodies through an IVIG infusion?

Dr. Payne: I can take that one. So the answer right now is not just because we think that not enough people have been exposed to the SARS-CoV-2 virus to be able to develop protective antibodies. Theoretically if people go in and continue to donate plasma for IVIG after they've recovered from COVID-19, then theoretically those antibodies could be in there IVIG, but right now that's not the case.

Becky: Great. Thank you. One question goes back to when we were talking about the live vaccine and it wouldn't be safe for patients who are taking Rituximab. Why wouldn't it be safe?

Dr. Tomayko: So a live vaccine is a true infection so you're getting an infection and the goal is have the immune system respond to that infection quickly and to kill off that infection and then give you a robust response. So if you are immunosuppressed your response to that infection can be delayed and you run the risk of having the infection go on and on without mounting an effective response and having the infection take hold as a full-fledged infection. It won't necessarily do that but there's a risk of doing that. So the risk would not outweigh the potential benefit.

Becky: Great. Thank you. Another question is coming when you were talking about the oxygen levels and testing with the pulse oximeter. Deborah from Hawaii she has heard from a New York Times article that patients are having low oxygen levels without having other symptoms. Do you have an opinion on testing with the cheaper pulse oximeters that you can buy to test oxygenation levels?

Dr. Tomayko: I can take that since I'm the one who mentioned that. That was an excellent article that she's mentioning. So unfortunately a month ago you could get a pulse oximeter in the drug store for $20. Now, they're virtually impossible to find on the web and they're listed for many times that amount. So it's true that one of the things that we're seeing with patients with COVID-19 is that they can have very low levels of oxygen and not feel strikingly short of breath or strikingly uncomfortable. It's a very unusual situation. Usually if a person has an oxygen level that's a little bit below 90, 88 or 90, they're going to feel terrible and there are stories of people coming into the emergency room with oxygen levels of less than 85 even 40 and not being really symptomatic. So what this article was suggesting very thoughtfully is that there's this concern that individuals are having COVID-19, they don't realize they have COVID-19. They're not having that many symptoms and then all of a sudden they crash and when they crash it now becomes very hard to support them. And if you could make a diagnosis earlier and start giving them gentle support before that, they would do better. So this article is saying

one way to do that. I mean there are many ways more testing, having a lower threshold for calling your doctor. But another thing you can do is if you have a pulse oximeter at home and you're measuring your oxygen and you see that it's coming down then that's a sign to you that maybe you have COVID-19 and you didn't realize it. So if you can get a pulse oximeter in the drug store or online, that's terrific. But because this is hard to do a workaround is there are these apps you can put on an iPhone. They're not as sensitive as what you'll get in the drugstore. They only go from 100 down to about 90, but they lose their sensitivity after that. But if you're a person at risk you could consider taking, we call it a pulse ox, every day and if you notice that you're going from 100 now all of a sudden you're at 95, then you're at 93, that's a problem. And at that point that's a sign that you might have COVID-19 and you should call your doctor.

Becky: Great. Thank you so much. Dr. Payne, Dr. Tomayko and Dr. Maverakis thank you for being on the call with us today. We really appreciate the time that you gave us today. I know we're well over our hour but it was extremely educational having you here and I'd like to give a thank you to everybody who hung with us and sent in some really great questions to answer. And of course, thank you to Genentech and Principia Biopharma for making today's call possible. Before we leave I have a few announcements. We recently sent out at the IPPF a COVID-19 survey and those of you who responded I just want to say thank you. Not surprising but kind of surprising that 94% of our respondents to the survey said that they were worried about COVID-19 and 50% of the people that responded to the survey said that one of the things that they were looking for was to get updates from our medical advisors on how to handle this pandemic with our disease. So we all very much appreciate your being on the call with us. The IPPF is listening to you and we want our community to know that we are updating our COVID-19 webpage as new information becomes available and if you haven't checked it out yet we encourage you to do so. We are also planning webinars with our advisors and other health experts to help get the information that you're most looking for including the COVID-19 updates, mental health, peer support and even how the coronavirus is affecting clinical trials. Also know that the IPPF peer health coaches are here to offer support by sharing their experience with pemphigus and pemphigoid and as well as how we're preparing and protecting ourselves from COVID-19. Also know that we're also looking into additional ways to support you virtually. Our next patient education webinar will be on April 30th with Dr. Tanya Gibson, Associate professor from the University of Missouri, Kansas City school of Dentistry and Dr. Nasser Said-Al-Naief, Professor of Oral Pathology and Radiology at Oregon Health and Science University School of Dentistry to answer your questions about oral health with pemphigus and pemphigoid. So please register today. Also, we need your help to continue to spread awareness about pemphigus and pemphigoid. The IPPF's Awareness Program aims to accelerate the time it takes pemphigus and pemphigoid patients to get diagnosed by stressing the importance of a biopsy. Your tax-deductible donation will support our Biopsies Save Lives campaign that will educate and encourage dental professionals to consider a biopsy sooner in order to diagnose patients faster. We are counting on you to make a difference in the lives of P/P patients and their families by helping us accelerate diagnosis times. Donate today and

Help us reach our goal of $15,000. If you have not registered for the IPPF's natural history study we encourage you to do so. The IPPF Natural History study is a patient registry sponsored by the National Organization for Rare Disorders (NORD) and the US Food and Drug Administration (FDA). You can register today at www.pemphigus.iamrare.org. This online data system collects, stores, and retrieves patient data for analysis in research studies. The more data we can collect, the better the information we can give to researchers, the sooner they can find better treatments, earlier diagnosis, and one day – **A CURE**! Lastly, If you have a question that didn't get answered on the call, or have additional questions please e-mail Becky Strong, at becky@pemphigus.org, or call (916) 922-1298 x:105, and we would be more than happy to help.This call recording will be sent out with the survey following this call.