Becky Strong: Welcome, everyone! This webinar is now being recorded. I'm Becky Strong, IPPF Outreach Director, and I will be your host for today's webinar. Thank you for joining us. I would like to thank you for being on the call with us and for the support provided by Sanofi and Regeneron, for making today's call possible. I would like to start off today with a quick poll.

Let us know, Do you struggle with knowing how to take care of your skin since your diagnosis? And while you are answering the poll, I would like to introduce you to our speaker for today. Dr Heather Holahan graduated residency training from the University of North Carolina (UNC) Department of Dermatology in 2019. She joined UNC faculty that same year and led an immunobullous clinic, under the expert guidance of Drs. Louis Diaz and Donna Culton. In June 2022, she joined the Dermatology Department at UCLA, where she treats both general and complex medical dermatology including immunobullous diseases.

It looks like we're still answering the poll. And I appreciate everybody joining. It looks like about 82% of the people who are on our call today. 83% have struggled with their skin care. So thank you for participating with us and thank you for taking the poll.

Now I would like to go over a few housekeeping items. You will remain in listen-only mode through this webinar. For those of you who are on their computer for this webinar, you will see on your screen that you can access the audio either by using your telephone to call in or from your speakers on your computer. Click on the little carrot or up arrow next to "audio settings" in the bottom left hand side of your screen. As you see on my screen right now you have the option to select your computer speakers or to dial in by telephone. Please be sure to select the method that you will be using. If you would like to ask a question please click the Q&A button on the bottom of the screen and then type your question into the text box. We will try our best to answer as many questions as we can within the hour. Please feel free to type your questions into the text box throughout the presentations. Dr. Holahan will be answering your questions at the end of the presentations.

On the webinar today we will be specifically discussing Skin Care for pemphigus and pemphigoid. If you ask a question that does not pertain to the webinar subject I will have to ask you to email me after the webinar.

For those of you on the call that aren't on the web, you will not be able to ask a question. So if you would like to ask a question, please click on the link that was provided to you in your confirmation email. Now, it is my pleasure to hand it over to Dr. Heather Holahan.

Dr. Heather Holahan: Thank you so much for having me. It's a pleasure. And thank you, Becky, for all your help in organizing this. I'm gonna share some tips that I've learned and I'm looking forward to having some questions and to go over anything. This is pretty informal, so we'll do questions after. So I'm going to share my screen and we're going to talk about skin care and Pemphigus and Pemphigoid. So this quote reminded me of what my experience was and is treating immuno bullous patients. And this quote says, "Let the young know they will never find a more interesting, more instructive book than the patient himself." And the reason I bring this

up is because nothing for the most part that I'll be talking about. I learned in a textbook. The majority of the tips and recommendations came from you all from my patients and listening, and I can say, like many things in medicine. it's not a one size fits all. Some of it is trial and error which can be frustrating when you have a new diagnosis. But the role of us in this is the team and to help you through that. Just for completeness in Pemphigus and Pemphigoid. So this is umbrella terms for many conditions that affect the skin and the mucus membranes, the oral, the nasal, the conjunctival, and the genital mucous membranes, and some of you know this, and many of you already know this, that our body creates inflammation against skin and the attachment, and this causes blisters and vesicles and ulcerations and this in turn creates chronic wounds that can be symptomatic on and off. I know Dr. Culton, who recently spoke about Rituxan as a way to prevent the formation of blisters and put disease activity into remission. So we're gonna focus on the prevention of infections and what we do to promote wound healing.

So I just put this schematic up because patients with Pemphigus and Pemphigoid were asked to do surveys about their quality of life, and how much these different factors impacted it. And so symptoms, as you can see, really impacted their quality of life a great amount. So did embarrassment based on the physical appearance of the disease. Being in public places, close social time or leisure sports, work, and school. And the point is that a lot of the symptoms are on our skin. And so people can see them. And we're just trying to focus on how we can better that for you, and how we can make them less painful, less draining so that your quality of life is restored. So again, not surprising, a lot of quality of life is impaired in our patients because of how symptomatic and how visible the wounds are.

So these are kind of to me, the symptoms that are alarming, and that we need to do something for. If you can't eat, if you can't move certain body parts without pain, or reduced range of motion, if you're unable to sleep, or you're unable to see. This greatly impacts your functioning, quality of life and can cause significant depression when you're starting with your disease, which most people, when they develop their bullous pemphigoid or their pemphigoid diseases, or their pemphigus will have some variant of this, and that's when they want you to come in to see someone.

We're going to start with the oral cavity. So many these recommendations did not come from a reference textbook. And like I said, there's not one universal management. Every patient is unique. and that's what I've learned. And so part of finding a doctor that can treat you is you want to look for someone who's going to listen to what you're telling them and who's going to be flexible with how you care for your wounds. I learned that gels are easier to put in the mouth because they're less kind of gooey, and they adhere better. But for every one patient that I give a gel to the next will say no, I didn't like it. It doesn't stick. It didn't work for me. I prefer the ointment version, or I didn't like any of the ointment, the cream or the gel. And so we have to be flexible with that, and not say, you know, keep trying that, keep doing that if it's not working for them. So this is one of my favorites. It's just a very easy kind of concoction to make that you can make at home with the help of your doctor. This is what we call magic mouthwash. Historically, this was being used for chemotherapy patients. But for these diseases, when your mouth is

sore, and you can't talk, and you can't eat, not sure about something that's more miserable than that. And so this is something that you can easily make at home. So I recommend children's benadryl liquid and then maalox mylanta and then viscous lidocaine. And so what you do is you use a little medicine cup, and you just take equal parts of each. You swish it around the mouth and then you spit it out and you wait about 30 min prior to eating so that it can adhere to the surfaces and it can create some good numbness and the ability to coat the surfaces so that you can eat. And we'll go into why eating is so important during this time in addition to general life for nutrition. But this is a great one. So 2 of these 2 of the parts of this prescription are available over the counter and easily made I bring up just as we're talking about the oral cavity. If you're experiencing any hoarseness or sore throat you want to tell your doctor during this time, because it's not typical for hoarseness or sore throat to indicate disease activity here. When I first started practicing and treating patients I was just very naive and second guessing myself and didn't really think about hoarseness and sore throat. And then, you know, after a couple of times. It's like, of course it could be the condition. And so it's important for many reasons, if your mouth is clear, but your throat is still hurting, or your horse that's telling me you still likely have disease activity. Your doctor might send you to an ear, nose and throat doctor, so that they can take a better look at the throat alternatively. Sometimes when we're treating the mouth and putting you on medicines, you can get co-infection with yeast, and that can cause hoarseness, sore throat. And so we just want to be mindful of that, and treat you for that as well. So the alternative to the magic mouthwash is an equally easy solution to make. It's a tablespoon of salt, or about 6 grams of salt, 2 tablespoons of baking soda and about 8 fluid ounces of water. and you just switch this around your mouth and spit. And this is a nice way to just clean the mouth and soothe those areas. There's not a lot of salt per the formula. So initially, it sounds very terrible putting salt in a wound, but it's very dilute, and it's an anti-bacterial way to clean the mouth, and it's been shown to actually help healing in the mouth. So when you have those erosions and the reason why it helps healing is because when we have poor hygiene in the mouth, the blisters can actually get worse and not heal. And so, talking about the oral cavity, some things that I've learned over time that can trigger chronic wounds or give new life to healing wounds are caffeine, orange juice, hot tea, any kind of citrus, spicy foods, acidic foods like tomatoes. And then I learned through my patients which again was not in a textbook. Any kind of crunchy or firm food can flare you. So, I've had patients tell me I had some tortilla chips, just plain old tortilla chips, and it hit my gum, and then I got a sore there. So you want to avoid these when you're in the acute phase of healing, because they can not only give some energy to some healing erosions, but they can start new erosions in the mouth.

Then, back to hygiene. So, as I just mentioned, poor oral hygiene can worsen mouth sores. And so you want to tell your doctor, prior to dental care, because dental care, when you have open sores in your mouth, sounds worse than normal dental care which I don't love going to. So it's just terrible. And so sometimes what I've done is I've given my patients some prednisone. If they're already on prednisone, then I might increase their dose to get them through the dental appointment. Sometimes I'll use a medicated cortisone mouthwash to use preemptively a few days before the appointment, and a few days after because the dental cleaning alone will flare you, and it's incredibly painful. If you have inflammation in the mouth, you know, they're using those fast moving brushes. They're flossing the areas. They're hitting the gums. It's just not a

pleasant experience. I have a picture of a baby toothbrush. It's a very soft bristle, and I've recommended this for patients who have erosions and soreness in the mouth because it's just you think about it. If you're brushing your teeth, the natural tendency would be to avoid brushing the teeth because of the discomfort and pain, and that is very understandable. But as we just said, oral hygiene can make this worse, so we pick the softest toothbrush we can find, so that you can still maintain hygiene in the mouth. I've had patients who develop gingivitis from not brushing. And so I want to avoid that, and some have lost teeth because of the poor oral hygiene during the acute phases. Very understandable. But there are ways to go around this so that we can keep your hygiene intact and not keep the pain ongoing. So I recommend a baby toothbrush. And you want to find a dentist, and there's many dentists available on the IPPF website. It's a wonderful reference, as you all know. You want to, if you can find a dentist that has some comfort in and manages patients with immunobullous disease. Some dentists over time, I've learned, have created little trays with some cortisone to help put in the mouth. They've helped with other solutions to use for the pain or discomfort. So ideally, if you can find someone who has some experience. You can be the first patient that your dentist sees, and you can teach them about immunobullous disease. But sometimes, when you're in the thick of things. Your energy is low and fatigue is very high, and you might not feel up to par to, you know, really have the energy to teach them about your condition. So sometimes, starting with the dentist, or orthodontists or oral surgeon who has experience, it can be very helpful and lift some of that weight off of you.

So, ocular symptoms. You want to tell your doctor about any blurry vision you're having. Any light sensitivity, any double vision, drainage, discharge, or pain. And you may need to wear your glasses more and less contacts because of this. You might need to sit in a darker room and wear sunglasses inside if you're having photosensitivity. Sometimes you might need some rewetting eye drops to keep the moisture in the eye, because you're losing more because of the inflammation. And so this is not uncommon in the diseases that we treat in pemphigoid and pemphigus. It’s ok to sit in the darker room or wear some glasses. Use some rewetting drops. There are over the counter ones, systane is one brand that I like to provide that moisture back. But most importantly, you want to tell your doctor. These symptoms can be super vague. Sometimes I'd ask patients about eye symptoms, and they'll say, you know what, I have had some increased redness in my eyes, or they've been drier. And we want you to get in. We send you to someone, an ophthalmologist, usually with experience treating these diseases, but not always, to get a good eye exam. They can help us with some supportive care, with eye drops and sometimes they'll do some light soft washes with baby wash, or mineral oil, and so again, just important to keep us updated on that.

Then the blisters. This is a patient with Bullous Pemphigoid, and Bullous Pemphigoid is characterized by having those tense, intact large bullae. Pemphigus patients can also have large bullae, but oftentimes they're a little bit more fragile. And so what we see on the skin is just ulcerations or inflamed areas without the top layer. So with a large blister, or sometimes we call them bullae. They can be poked with a sterile needle. But you want to keep that overlying coverage on, because it's gonna serve as a physiologic band aid for you. And what does that mean? It's going to protect the skin and prevent infection. When you take that off the barrier of

the skin is interrupted, and so you can have bacteria that get in through the breaks of the skin. And you can also have bacteria that kind of lives on the surface. So when we're treating these blisters and bullae and ulcerations, our goal is to primarily, of course, prevent infection. We want to protect the wound. We want to create a moist environment. And we want to minimize scar. I'm a big proponent of vinegar. So because they're easy. I use them a lot with my patients, both for an immuno bullous disease, and also in my clinic just for general dermatology. Dr. Diaz taught me about this a lot in Residency. You want to take one to 2 tablespoons of household white vinegar which is also acetic acid, 4 to 5%, or cooking vinegar in 2 cups of lukewarm water. And so you make a solution. You can use gauze and or you can soak the area in this solution one to 2 times a day. It's antibacterial, it doesn't burn. Even though there's vinegar in it, it's very dilute and that's what you want to put on the blister after you poke it, or the ulceration on the skin. And next, you probably heard many of your doctors talk about this. You want to use bland emollients like vaseline or aquaphor. You want to keep the area very moist there to promote wound healing. We used to think we wanted to dry wounds out but that's actually not true. Keeping them moisturized actually helps with healing and keeps the skin barrier intact. So lower risk of infection. Then, when you cover them, you want to use a non-adherent dressing. It makes sense when you think about it. When we use gauze that's adherent. We rip the scab off where we rip the roof off every time we change the dressing, and so it's re-traumatized each time let alone, is incredibly painful. So, non adherent gauze is a big one, and this is just over the counter at any pharmacy, but it won't stick, and it won't traumatize the wound. Also they can be called telfa pads. You might have heard the called that. Sometimes patients will put that on after they put vaseline or aquaphor and they'll adhere it with some paper tape. So the paper tapes a little gentler for the skin, so you won't rip it off. When you rip the adhesive off, you can tear the skin, especially in fragile areas. And some of the medicines you might be on can increase skin fragility. So we really want to make a concerted effort to use paper tape. The only downside of paper tape is it doesn't stick quite as well as adhesive. But that's okay. And then hydrocolloid dressings. For example, if your wounds are really draining a lot. Then you want to use something called a hydrocolloid dressing. It'll help absorb a lot of the fluid. If the wounds are very dry. You don't need hydrocolloid dressing. You want to use something like a hydrogel. You need hydration. You want to think about the adhesive quality. Is it going to be too strong and take off skin with it? Are you going to keep it on for one to 2 days? Is it going to be in a kind of a joint area where you're bending? Is it gonna move with you? If the area is very painful, or in a painful area, like on the foot. Silicone dressings can provide comfort. They can be bordered and help with that, and if your doctor is concerned for infection or colonization. Colonization is where bacteria live on the surface of the wound. So there's not a true infection, but it's colonized with bacteria, and when things are colonized with bacteria it prevents wound healing, and so you can have a resultant very slow healing. And so silver impregnated dressings are very good, and iodine. Sometimes you can have a thick kind of coating on the wound, and we'll use something called Alginate dressings to basically remove that thick crust on top every time we change the dressing. And I just told you we don't want to rip off the roof of the area, but the alginate dressings are good because they help remove thick crust that can prevent the wound from healing.

Infection. Infection is a big concern when we're treating these wounds for many reasons. They can appear on the feet, on the lower legs. Those are areas of healing that are very slow. When I do a biopsy and clinic if it's on the leg or the foot I kind of cringe inside a little bit, because I know wound healing is just going to be slower. Some of that is because the blood just has to get down there, and the nutrients and new tissue factors just take longer to go there. Some of the other reasons we're concerned for infection is because we often put you on prednisone to begin with, and other medicines that can increase the risk of infection, and sometimes cause slow wound healing. Some of the signs of infection. You can have redness around the wound. Sometimes redness is okay. But in the constellation of these other factors you really want to let your doctor know. So if you have redness, swelling, pain or worsening odor or increased wound drainage. Then, you want to let your doctor know, because that would be different. You can have drainage with these wounds. Drainage does not always mean bad, but if it has a mal odor. and the drainage is increasing, those are pretty good signs that something else might be going on like an infection. The most common bacteria on the skin is staph aureus. And so when we're concerned about infection, we have you come back to the office and we swab the area with a little q-tip because that'll tell us. We send it to the lab, and it'll grow some bacteria if they're present, and we check to make sure the antibiotics we put you on, or the topical antibiotics we might use are going to work against that bacteria. As I mentioned, sometimes bacteria hang out on the wound surface. They're not causing a true infection, but they're preventing wound healing. And so sometimes we need to numb up the area and remove some of that thick crust, or sometimes we use a dressing that'll do it for you to help the wound heal fully.

Nutrition. Nutrition is very important in general, but also when you're undergoing wound healing, and this has been shown when they've examined burn patients who are in the hospital. You need a lot of protein for wound healing. You're losing a lot of fluid and nutrients with your wounds and with the drainage. So you want to talk to your doctor about this. Sometimes they might send you to a nutritionist to help with your nutrition, especially if you're also having inflammation in the oral cavity and having a hard time tolerating food and eating as well as you normally would. You want to avoid traumatizing the skin with very tight clothing, contact sports, and eating inflammatory foods because they'll cause irritation of the oral cavity and cause more drainage and fluid loss and nutrient loss. This isn't forever. This is just more during the active phase, when we're trying to control things and help you heal. So, loose clothing can be very helpful sometimes for the soothing areas when just the touch of clothing is excruciating. You can soak in a lukewarm or warm bath, with or without epsom salt. An oatmeal bath can be very soothing. Sleeping or sitting without a lot of clothing on just a loose shirt, if at all. Some people can't wear clothing during the acute phase when they're at home. And that's okay, too. I think whatever you can do to soothe the area is okay with me sometimes. What I'll also have you do is if you have a large area, let's say on the leg where there's multiple healing areas, I sometimes have you use a cortisone ointment and put vaseline over it, and a lukewarm towel on top of it. We call these like modified wet wraps, and you do that for an hour. I joke that it's kind of like going to the Spa for a little bit. You turn on the TV, keep it on. It just helps when you cover our medicine. It helps it get absorbed into the skin. And so we do this in the hospital, when someone comes in really with a generalized eruption of their fullest pemphigoid or pemphigus. It can really help very quickly in those areas, so you can do it up to 3 times a day. You put the

cortisone ointment on, vaseline over it, and a warm, damp towel. You wrap it, and you can do it if there's one area that's more problematic or more generalized. And again, it's just another way to maximize healing at home. And I just want to thank Dr. Fairley, Dr. Diaz and Dr. Culton. That's been very important in my learning and care of patients. They really are so caring for their patients, and they listen so well, and a lot of what I've learned is through my patients. Finding a good dermatologist as part of your treatment team as long as finding a dentist, and you want it to be with someone that you feel comfortable with. Who is up for going on this journey with you, because it is a journey. It's very hard when you're otherwise feeling healthy. And then all of a sudden you start breaking out with these chronic sores. And you're on multiple medicines. It takes time to kind of really get used to the idea that this, you know, we're gonna make it as asymptomatic as possible. But that takes time. And it's a lot and I think also on your treatment team having someone that you can talk to, whether it be a professional or the IPPF or members of the IPPF, because what you're going through is very unique, and not everyone can understand. And I think that some of the symptoms really impact your quality of life, not being able to eat or move well or sleep. Those are things that we take for granted every day. And so just finding a team, and it takes time. But finding a team, and you can use the IPPF as well to help you through this journey is important. With that thank you so much for having me. I hope some of these tips were helpful, but I'm happy to take any and all questions.

Becky Strong: Thank you, Dr. Heather Holahan. That was an amazing primer, and I couldn't ask for anything better. So thank you. We have gotten quite a few questions submitted ahead of time. And then we are getting questions submitted now. Elizabeth is asking, how does heat and humidity make bullous pemphigus blisters worse? And I know you gave some skin care and clothing tips. But is there anything that can help with the heat and humidity, especially with so much going on in so many areas of the country?

Dr. Heather Holahan: Yes, that's a great question. Heat and humidity make the blisters worse. They make them itchy and painful, and they can spread. And it's probably because sweating just helps in the inflammatory process. Wearing loose clothing like wide loose pants or a cotton longer T-shirt dress, anything you can do to stop the rubbing of clothing, and the friction is so helpful. If you are privileged and have air conditioning. Telling people I'm gonna have to hang back at home in the cooler environment. I think sleeping is a big deal. So you want to turn down that A/C at night, and if you need to sleep naked, you're sleeping naked. If you need to sleep in a loose kind of nightgown. Then that's fine. If you can't wear a bra right now, you can't wear a bra. Same with underwear. This is the acute period. And so that's okay but I think some of it is just trying. Unfortunately, you know, you might have to hang back from some record like social activities that are outside during the acute period, because it's just torture. I think vaseline on the areas iit doesn't have to be like cake frosting, as we say, just a lubricant of some kind on the skin can help with the friction and rubbing, and hopefully help with some of the irritation. Sometimes I have patients use a barrier cream or a powder just to help, because if you have an intact blister and any skin to skin contact, it's terrible. The barrier cream protects your skin a little bit. So people use desitin. There's a lot of powder. There's no sting barrier cream is another one we use in babies, and we use under like port sites, or for our Crohn's patients, we use them

under their Ostomy. It's a spray, and it just creates a film on the surface that can be super helpful.

Becky Strong: Can you use those if you're sticking to a bed sheet as well like some of those barrier creams that you mentioned?

Dr. Heather Holahan: Oh, yeah, just use sheets. You don't mind getting the barrier cream on so any sheet a white sheet. Anything like that. You can coat yourself up.

Becky Strong: Great. Thank you. So, I'm gonna kind of loop some of these questions together. We've gotten a lot of questions about scalp care, people being on different medications, whether it's prednisone or any of those immunosuppressives. And their scalps aren't healing. What can be done to help the scalp?

Dr. Heather Holahan: Yeah, that's a great question. So, for some of the thicker crust there, sometimes I'll use mineral oil just over the counter. It's in the baby section. You put it on the areas you leave it on. Put a cap on like a shower cap for at least an hour, and then you wash, and you do it. If you gently wash, you can even just use lukewarm water. It'll help break up some of that scale and help the wound heal a little faster. I have even had patients come in, and I've numbed the area and removed some of the scale. Sometimes that scale prevents it basically like freezes the wound and time and won't let it heal. So sometimes an intervention in the office can be helpful. I've even had patients. I've done some little cortisone pokes on the wounds. It's a little poke. Most of my immuno-bullous patients do very well with the poke, but it delivers cortisone right to the skin there, even though you're on prednisone. Sometimes those wounds need a little more of a nudge in the office. and that's okay. I've also used vinegar soaks there too. It's a little messy. But you can use non-stick gauze and you can even use like a little at the dollar store they have one of those bottles with a little dropper, and you just drop it around it can also take out some of that crust and help dry up things so that they heal, especially if they're weeping a lot.

Becky Strong: Well, great! Thank you for that. Jillian is asking if there is anything that can be done with the scarring that is left when lesions heal?

Dr. Heather Holahan: So some of the scarring is that discoloration there. And no one likes that. Everyone will have discoloration. The good thing about the discoloration is, it's not permanent scarring. The bad thing is that it takes. It's slow as molasses to heal. So sometimes when patients are completely healed and doing well. I've tried plus or minus a retinol or retinoid cream to try to lighten them. The other thing I'm a big proponent on are compression socks. I wear them in the clinic. They're not super tight. The idea often makes my patients want to strangle me, but they have a little device that you can pull them up with. So that's the hardest part about getting compression socks on. They're on Amazon. They're also called diabetic socks. They don't have to cut the circulation off, I promise you can use the lowest here, but what they do is they push blood back to the heart and help deliver nutrients back, and that can help when healing on the legs. If you're having a lot of discoloration there as well, and then when you're

outside in the sun, if those areas are exposed, you just want to be good with sun protection, and keep the area covered because the sun will make that discoloration compared to your normal skin more apparent. So there's no magic bullet right away. Unfortunately, a lot of it is time. But it will slowly fade. Sometimes patients will have milia scars, which are these little kind of bumps on the hands or forearms anywhere where they had an ulcer or blister. Sometimes they can be opened up just with a little poke in the office. If they were very bothersome they can be removed or off the skin. Those are kind of staying put. But again, my main message is, the discoloration will fade. It just takes time.

Becky Strong: Great, thank you. Tim is asking. Can clobetasol penetrate the PV scabs?

Dr. Heather Holahan: That's a great question. Yes, but you've gotta like many things. You've got to get some of that crust off. So you want to either use mineral oil or some vinegar. So because that crust is just, it's basically preventing that from getting through all the way. It's just an obstructive area there. So usually you need to remove some of the crusting. The other thing you can do is actually cover the area. So you put clobetasol on the pemphigus scab, and then you cover it with a little plastic wrap to help it get in at night and use a little paper tape. Again,anytime we cover something it gets in better so you could do that with the wet wraps with a damp wet towel and put it over the area as well. So you just want to maximize getting in this. We do this with conditions like psoriasis, too, when they have a lot of crust in there, it's just preventing some of our medicine from getting in. So to optimize that we want to take some of the crust off.

Becky Strong: Thank you. Our next question also comes from Tim, and he's asking if neosporin is better than vaseline?

Dr. Heather Holahan: No, Tim, no. So I grew up using neosporin but there's an ingredient in those called neomycin. And what's weird about it is that people develop an allergy to it. Okay? So you can use neosporin for your whole life. And then one day you put it on your wound, especially an open wound, and your body, your immune system sees more of it and decides that. Oh, I don't like this. It's an Allergen. And so what you'll hear is, people are using it for years, and then all of a sudden developed an allergy. So just because of that risk, I don't like it. Because Lord knows, I don't want to cause an allergy on top of your Pemphigus or Pemphigoid when you're flaring. So I prefer Vasilyn, the aquaphor. And for the antibacterial parts of that, so it's creating a barrier in the skin. So it's preventing the bacteria from colonizing the bacteria from getting in. So it helps with that. But we do those vinegar soaks or other things like new Parrison ointment is a big one we use. It just hasn't been shown to be as many allergens to those things. Becky Strong: Great. Thank you. I am going to lump a whole bunch of questions together, and patients want as much information as they can about what to do about itching. And so, if there's any tips or tricks, or over the counter treatments or prescriptions like people want the information.

I know you know the itching, especially in bullous pemphigoid is terrible. It's terrible. That's great, and I think what's hard about it is some of the medicines like Doxepen or atarax that can

help with the itching. I don't love using, and some of my more elderly patients, because it can cause grogginess, and I don't want them to fall. It's not that I haven't used them, but it's a little tricky, especially if you're getting up in the middle of the night to go to the bathroom or something like that. Some of the itching if you do those kinds of wet wraps where you put your cortisone ointment on, and then put a damp towel that can be helpful. Certainly people use Benadryl. It just makes you groggy and a little unsteady. So you have to be careful. I prefer someone family members around you that can keep tabs on you, or you take it before you go to bed, and you're going to stay in bed. We use dupixent, which is a medicine that does not impair the or affect the immune system. And then it affects the immune system. But it's not traditionally thought of as increasing the risk of infection and things like that. but it is used in eczema, and so it can help with a lot of the itching in bullous pemphigoid. It's approved for eczema. So you know, bullous pemphigoid carrier or eczema plaque, so we can sometimes get it approved, and it can be very helpful. It prevents some of the attractants for mass cells and eosinophils, and itching from getting to the site. Sometimes, if the itching will use an infusion called Ivig again, it's not kind of turning down inflammation. It's basically sticky, and it sticks and gets rid of all that those antibodies that your body is making. I use it temporarily, but can help a lot with the itch. I love and I hate prednisone but prednisone can help a lot with the itch. I curse it, and I love it because it works very fast. and so if you're not sleeping, not eating, I need something fast. Dupixent is, like I mentioned before, self administered. It looks like it's in a little pen, and you self administer you poke your thigh or your belly It works pretty quickly for some people within 2 weeks, and so that can be helpful. But I think, like immediately. I use a lot of prednisone.

Becky Strong: Well, thank you for sharing that. It's some really really great information. I hope I'm pronouncing this name right. I think it's Ruzbeh, who is asking a really great question. And are sunscreen she recommend for darker skin, with a sensitive face. And she's what they're saying is that mineral. The mineral sunscreens leave too much of a cast.

Dr. Heather Holahan: So they have now tinted sunscreens that are mineral to There's a sunscreen called black girl sunscreen. It's actually for darker skin types, or just dark or skin types like non white. And so it can blend in very well. Super goop has one, and it's translucent which I like. Trying to think what Ilia is another one. It's a tinted sunscreen which can be very helpful as well, so they're coming out with more tinted. I agree. The cast is even a lot on me, and I'm pretty pale myself, so I can get paler with the sunscreen so that those are helpful, but they think that a tinted. I would look for a tinted mineral sunscreen because they do have some.

Becky Strong: Great and is sunscreen enough when we're outside, or should we be wearing protective clothing as well? Or should we just stay inside.

Dr. Heather Holahan: So yeah, that's a great question. I think there's no hard and fast rule. I would wear a large brim hat and sunglasses and sun protective clothing, because your skin is healing, and the sun is just, I think, irritating on healing skin. It's very hot. So you're going to start. You could start itching or getting inflamed, and it's just new, tender skin I don't want to say you have to stay at home, because I think part of living with a chronic condition is being adaptable, and learning to kind of fuse it into your life and do the things that you enjoy. But I

would say, being pretty liberal with a larger brimmed hat. Sunglasses, if you're having any eye sensitivity. They make great upf clothing. So that's sunscreen in the clothing. and so that's nice. Because then you don't have to really worry about putting in sunscreen in some areas. And, you know, rubbing the skin. If you're still irritated.

Becky Strong: That's great. A question that we get here all the time about SPF clothing, and I don't know the answer to is, does the SPF factor wear out of clothing over time, or it doesn't hold up until the clothing starts to break down.

Dr. Heather Holahan: That's a great question. I guess it depends how strong you wash it, and how often. I'm not sure but I will look that up for you.

Becky Strong: Great, thank you. Deborah has a really good question, too. She's asking if you have any tips for applying dressings to your back when you're alone, and how often should back dressings be changed?

Dr. Heather Holahan: Yeah, that's a great question. and that's hard. So someone invented it, I call it a sponge on a stick, but it's an applicator. You can make your own. You can take a ruler and a sponge and tape it, or you know, around, and you put a cortisone ointment and can touch the back with it, which is very nice. The other thing you can do is you can put ointment on a towel and flip it, and kind of do that. Dressings are really hard on the back, you know the mid to lower back. Lord, I feel your pain. So, maybe one hand can hold it, and a little bit of tape, or an adhesive dressing like a bordered kind of silicone dressing can be nice, because you just kind of smack it on there. That's hard, I think. Sometimes wound care centers are really great, and will help you with it. Even urgent care can help you with the application. It is fine to keep the dressings on for 2 or 3 days as long as you're not weeping through them. That is fine. Sometimes people have said as people we touch our wounds too much, and we expose them to our hands, even if they're clean. And we manipulate too much that we're probably introducing bacteria. So it's okay to let it sit like that. But I would feel free to talk to, to go to wound care or even urgent care to see if they can help you with that, because I've had patients also say that. Or even if there's a neighbor once a week that can help you change it. And then, if they're doing better, then I would just try like a sponge on a stick or a towel, anything you can do.

Becky Strong: Great. Thank you so much for that. Denise is asking what would be the best way to take care of lesions on her face? Are there any products that are better than others to use?

Dr. Heather Holahan: Yeah, some people, actually, they came out with the pimple kind of bandages. They're hydrocolloids. And so if there's drainage or anything, or it's a little wet, you can put those on. They come in cute little shapes and they have little designs. Sometimes it's just kind of a fun way of owning what's going on a little bit and taking back control. I think personally, a lot of the ointments. I'll tell patients if you hate it, I torture patients with ointments because the vehicle that something comes into in matters. What does that mean a gel can dry fast, but it's drying, so if you already have a very dry wound, it might not be the best way. A

cream is fine but if you have a dry wound, it's not super hydrating, and ointments are the strongest meaning they penetrate the best, and so I tend to use ointments. That being said, I usually give an ointment and a cream, and I tell patients during the day to try the cream. You can mix it with vaseline if you want, if it feels better to rub it in, and then at night I torture you with an ointment, because an ointment just penetrates better. We're going to bed, you know. You can cover it if you want with just non-stick gauze and a little bit of paper tape. You can rotate which side you do it. So maybe one night you do one side the next night you do the other so that you can still sleep well. I'm not against covering it with makeup, if you need to. I understand that these are wounds people see. I would say it's a fresh wound, probably not a great idea. And then vinegar soaks with a little gauze on the wound will help dry them out a bit, and so stop that drainage which will help them heal. And really you just hold the gauze like this you put you can put a TV show on anything you want for 5 or 10 min.

Becky Strong: Along those same lines. If you don't have any lesions if your skin is healed. But you have been diagnosed with pemphigus or pemphigoid, is it okay to exfoliate your skin?

Dr. Heather Holahan: That's a great question. If your condition is in remission, so to speak, whether you're on medicine or did an infusion. What I would say is.you know, it is probably okay. However, you know, patients taught me chips and crunchy things can create an erosion in their mouth. So I don't want to do that to you. So what I would say is, try a very small test area like the back of your hand or the back of your arm and don't use a brush or a loofa, because that is just they don't work so free yourself from that. But just try a little area

Becky Strong: Great along the same lines. If your skin is healed can you use products with an alpha, hydroxy acid or a retinol in?

Dr. Heather Holahan: Yes, I think you can. And I would again just trial a small area a few times, and make sure that you tolerate it, and slow and low. So once or twice a week, and a low amount of teeny, thin layers, and then you can always, and it's easier to add than to take away. So just test the area for a few, you know at least a couple of times.

Becky Strong: Great. Rebecca is asking a good question too. Can things like swimming like the chlorine from a pool affect the healing process of blisters that are now just spots of inflammation?

Dr. Heather Holahan: It actually can help. It's like, basically bleach. So chlorine. So it actually can kind of dry out things that can help them heal. It's antibacterial. You don't want to go swimming in a lake or a stream when you have open wounds, because there's lots of organisms and bacteria in there, but you certainly can go swimming in the pool. We think of the ocean as kind of being dirty, too, depending where you live but a pool is fine. It's chlorine. It's just like when we make bleach water soaks for patients, and so it can be very helpful.

Becky Strong: Great. Are there any particular ingredients that people should be looking for for their skin care when healing and fading the pigmentation from blisters.

Dr. Heather Holahan: Yeah. I like very like bland moisturizers. So Vanicream is a line that I really like. You're putting moisture back in the skin, and the last thing we want to do is irritate your skin with fragrances, and you know like those beads that kind of exfoliate because that'll cause more pigment. So I like something like that. There's another cream called ammonium lactate, which I really like 12% cream. It's just over the counter. The other name is amLactin. It's a gentle moisturizer, but it can kind of lift some of the pigment with time and be very helpful, and sometimes the skin gets dry when it's healing, because it was swollen, and then it's going back down to normal, and you can have a lot of superficial scaling, especially on the legs. And what amlactin and products like that do is they just gently exploit the scale off, but they also provide moisture at the same time.

Becky Strong: Great. One more question, and I'm going to loop some together. What can you offer in terms of relief for lesions in the genital area? Are epsom salts good or sitz baths or is there anything else that can be used?

Dr. Heather Holahan: I think sitz baths are great. I like lidocaine ointment, sometimes to put on the area during the acute phase to num it. I use clobetasol in that area. It's safe to use there. Sitz baths are extremely soothing. I think that's a great idea. So, Lidocaine I use because it's hard if you have to use those areas. You know, there's a lot of we can't just not go to the bathroom. Sometimes I'll have patients just gently rinse the area with a little saline just like a saline wash as well, and then again, a barrier cream and the surrounding kind of area can be helpful, or on top of the medicine you put on because we sit a lot, and we got a lot of sweat and moisture in those areas and that can aggravate the skin in addition to the pemphigus or pemphigoid. So sometimes I'll have you put desitin around the wound or on top of the wound or other barrier creams just to help with friction, because friction is impossible to avoid in those areas like the the buttock area too.

Becky Strong: I know we're over our time. Do you mind if I ask a few more questions? So we're getting a lot of questions about- Is it possible to dye your hair, wax your eyebrows and continue with botox injections? And I was just wondering your opinion on those activities as well.

Dr. Heather Holahan: Yeah. So my goal with our patients and all of our goals when treating this is to get you back to your normal life. And what brings you happiness? So I would say, it is fine to dye your hair. You don't want to do it during the acute phase, but you probably wouldn't want to do it, anyway, because you don't feel so great. And you have open areas. If you still have a healing area you can tell your hairdresser. This is healing. If we're going to do anything we need to be extra gentle, or let's avoid this spot right here. For right now you could even put vaseline over it as a cover. Botox is also fine from my point of view. Again, you want the skin to be intact when you're doing it just as good hygiene. Eyebrows, like microblading. People will get done like more. It's not permanent, but it's essentially like a semi. It's a non-permanent tattoo on the skin. Yes, but I usually say, I want your pemphigoid or pemphigus to be quiet for at least 6 months before you're tattooing that area. Just because I don't want the trauma to the skin to provoke anything. If you've never had lesions on your face, it's probably fine.I think we just want the skin to be fully healed before we start manipulating it.

Becky Strong: Thank you. And I would imagine the same would be true for waxing or laser hair removal as well?

Dr. Heather Holahan: Yeah, you just want the skin to be healed, and I want you to not have had a flare in recent times, because if you're still having activity, it's just telling me likely you could have a flare in that area. If you've had flares there and then you're waxing. It's a recipe for discomfort.

Becky Strong: Great. I really appreciate the information. I'm trying to look through questions here. Jeff is asking if there's any recommendations to keep the skin healthy to reduce future outbreaks.

Dr. Heather Holahan: Yeah, that's a great question. Just a good moisturizer. It sounds so basic, I know, but I love vanicream. I like LaRoche pose that has a lip balm that I've tried that I really like, because I think it stays on the skin. Neutrogena has some as well, but it doesn't have to be anything fancy at all. Just a cream in a jar. Why a jar? Because we can take out more medicine once or twice a day on the skin that's just keeping the skin barrier intact. Why do we need that? Because it prevents infection and inflammation.

Becky Strong: Great. Thank you. Patrick is asking, is phototherapy useful in treating Pemphigus and Pemphigoid. And how many sessions would you need if it is successful?

Dr. Heather Holahan: It's a great question. I don't use phototherapy for this. It's not that I couldn't. I assume it could be helpful, because phototherapy decreases inflammation on the skin level. And so that's what you're having. The question then becomes though when we stop the phototherapy. Where's your pemphigus or pemphigoid? And that's the concern. Is it still active? Is it going to come right back? Is it going to relapse? Because if we're just doing phototherapy, then I'm afraid of that. And we don't know. These are for questions that we? We won't know until we do them. But is there? Is it going to flare again?

Becky Strong: Great. Thank you. Along the same lines? What about hyperbaric oxygen for the abdominal wounds,. Is it helpful?

Dr. Heather Holahan: It can be very helpful. I think what can be hard is that I have a very hard time getting insurance to cover that. So if you can get your insurance to cover it, hyperbaric oxygen can be very helpful for wound healing. The second kind of to jump on that. At the same time, we want to decrease the inflammation that your immune system is producing. So we want to use an agent that's going to help with that at the same time. So hyperbar can help with slow healing wounds. You also want to make sure if they're in an area of friction, what you can do to basically unload that friction. So if your pants are rubbing, if there's a belt, if it's skin on skin, we want to optimize the local environment with dressings, maybe having the doctor take off some of that crust or debridement and then we want to have some level of medical management, so that you're not set up to have more chronic abdominal wounds or other wounds.

Becky Strong: Great. Thank you. Shelly is saying that the skin on the back of her heels. Looks like it's healed, but she still can't wear shoes due to the sensitivity of the new skin. It's been 11 months, and is there an application or something that can help with the skin be less sensitive? So she's not locked into wearing only sandals or backless shoes?

Dr. Heather Holahan: That's a great question. Podiatry will sometimes make shoes or help you with inserts to help cushion that area. Vaseline is super helpful on that new skin. The problem isI don't want you sliding out of your shoes either. I want to be practical about it. Sometimes they make heels without a back. So you slip your foot in, and there's a cover here, but there's no back, so that's one option. But I would ask your doctor if they think that podiatry could add a role with some inserts or other. Vaseline can help soften the new tissue, but if it's more of like the little nerves in the skin are still kind of upset, then I would see Podiatry about it to see if they have anything else, because a lot of you know, our specialties have little tips and tricks that we all can learn from each other.

Becky Strong: Great information and great idea. So thank you so much. We also got a couple of questions about if you have itching around your eyes. What is the best way to address that and to help soothe that area.

Dr. Heather Holahan: Yeah, I again use a lot of cortisone there and it's okay to use Cortisone. Rarely someone had a patient had a very specific underlying condition, and her ophthalmologist did not want cortisone on there. So sometimes I've tried a non cortisone containing anti-inflammatory ointment. It depends on the cause of the inflammation, because sometimes it's actually blepharitis which is something that can happen when the oil glands get clogged. Sometimes your pemphigus or pemphigoid can bring that out. And so we use like Johnson and Johnson. Baby washes to wash that area a few times a week. We also there's Bruder is on Amazon, and they make a little mask, but you can heat it up, not super hot, but it's a warm, compressed mask, which is very soothing. If you're having discomfort on the eyes. What else? I just always with the eyelids. I always make sure it's the pemphigus or pemphigoid and there's no other contributing factor. Some people will supplement and give you all omega 3 supplementation, because that can be helpful for that area as well. So just kind of figuring out what the exact etiology of it is, if it's pemphigus or pemphigoid I often use cortisone there and vaseline, but sometimes I'll add a wash or the warm compress just feels really nice.

Becky Strong: Great great information. Thank you. I know you had mentioned before about rinses with baking soda in it. Does drinking it help with autoimmune disease?

Dr. Heather Holahan: You can drink the saline soak and sometimes it can be helpful. It’s antibacterial. So hygiene often takes a back seat when we have ulcers in the mouth right? Who wants to brush their teeth when you're having open areas in your mouth. Totally understandable. So the saline soaks help actually with the wound healing. Hygiene helps with wound healing. So they work together. So it's important to keep that soak, the rinses can be very helpful for hygiene which can promote wound healing. You can drink like even the magic mouthwash. You just

might get a little drowsy because it has benadryl in it. So you just want to be mindful of that but you certainly can drink it.

Becky Strong: Great. Thank you so much. Sherry is asking if there are any tips and tricks to shaving your legs after you've been diagnosed with pemphigus and pemphigoid?

Dr. Heather Holahan: Sherry, if there's ever a time not to shave your legs and a needed excuse. That's it. I would say. You want to, really, in all seriousness. You want to avoid shaving your legs if you have any open skin areas, because the razor can create micro injuries in the skin. And so if you're just healing. Wait. If anyone gives you a hard time, you tell them that you're a warrior, and you've been through a lot, so they need to take a back seat. But I would say, wait till the inflammation is very much healed, because I just don't want to open you up for infection and things like that. I like using a conditioner like a hair conditioner as in a like the source for inside a shaving cream, I just think it's more moisturizing and aluminum razors can be very gentle. So that's another idea to use and try not to go over the same area more than once just gentle shaving and then again, moisturizer on top, because it helps seal everything in.

Becky Strong: Great. Great tips. Thank you. Laura is saying that her hair and nails are falling out, and she's asking if this is normal for bullous pemphigoid?

Dr. Heather Holahan: It is normal, and it's because hair falling out can be a sign of just a stressful event, obviously having a new autoimmune condition in our body, can throw the body off. And so more of our hair goes into the falling out phase. It's stress induced, and medicines can do it. You're likely on new medicines. Dietary changes can do it. This should all normalize as things go on, and you get treated. If your doctor, oftentimes, when you're on systemic medicine, we're checking labs all the time. They can check your just like your B vitamins, your vitamin D, ferritin, just to make sure there's nothing else. Vitamin deficiency levels or vitamin deficiency that we need to supplement for. but can be very normal and should normalize with time. Truly.

Becky Strong: Great, a lot of great information there and I really appreciate the extra time that you gave to us. I know we still have some questions that are unanswered, but I do want to be respectful of your time as well. It has been very quick, but there has been a lot of great information, and I sincerely appreciate you and everybody joining us today for our call.

Dr. Heather Holahan: Yes, and, Becky, you can send me any remaining questions. I'm happy to answer them.

Becky Strong: Great. Great! I'll do that. I would also like to give a huge thank you to for the support provided by Sanofi and Regeneron for helping to make today’s call possible.
Our next Patient Education Webinar will be on August 3rd with Dr. Victoria Werth, Professor of Dermatology at the Hospital of the University of Pennsylvania and the Veteran's Administration Medical Center and Chief of Dermatology, Philadelphia V.A. Hospital to discuss Supplements in

Autoimmune Disease and Vaccinations. Registration is now open and you can register online today using the QR code on the screen.

We are excited to announce that this year's Patient Education Conference will be held virtually from October 27th- 29th! We have invited leading bullous disease experts to present on research and trends, educate on disease management, and answer your tough questions. We hope you will join us for this exciting event! Registration will be opening soon.

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, 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! Visit www.pemphigus.iamrare.org and join today.

It's your turn to pay it forward to other patients just like you in our community by becoming a Healing Hero. Our Healing Heroes make much-needed monthly donations to allow us to provide free programs and services like today's webinar and our Peer Coaches. With your monthly donation of only $15, you help the IPPF screen and add new doctors to our Find a Doctor map which increases patients' access to care. Or a $30 contribution allows our Peer Coaches to support you and other members of our community by providing resources and tips on how to live and thrive with their disease. Scan the QR code or visit www.pemphigus.org/hero to become a Healing Hero.

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. It's easier than it sounds to start a support group and you can help connect others in your area with other patients.

This call recording will be sent out with the survey following this call. Thank you all for joining us.