

## May 19, 2022 Patient Education Webinar- Skin Care and Topical Treatments

**Becky:** Welcome everyone. My name is Becky Strong and I am the Outreach Director at the IPPF. Thank you for joining us today for our Patient Education Webinar to discuss Skin Care and Topical Treatments for pemphigus and pemphigoid. This webinar is now being recorded. I'd like to give a big thank you for being on the call and a big thank you to our sponsors, Genentech, argenx and Cabaletta Bio for making today's call possible. "Information is a key factor in treating and living with any condition, however everyone's situation is unique and the IPPF reminds you that any information found on the internet, or during webinars and presentations like today, should be discussed with your own doctor and health care team to determine if it applies to your specific situation." Now let me introduce you to our speaker for today.

**Becky:** Dr. Brittney Schultz completed her undergraduate, medical school, and residency at the University of Minnesota. She is a graduate of the Combined Internal Medicine/Dermatology program, where she served as chief resident. She now works at the University of Minnesota as an Assistant Professor and at the Minneapolis Veterans Affairs Healthcare System as a Staff Dermatologist. She is Director of the Autoimmune Blistering Diseases Clinic at the University of Minnesota. Her clinical and research interests are complex medical dermatology and autoimmune blistering disorders. Now, before we begin, I'd like to go over a few housekeeping items... (Reviews Housekeeping slides). Now it is my pleasure to introduce you to Dr. Schultz and to have her discuss topical treatment and skin care and answer your questions.

**Dr. Schultz:** Great, thank you Becky. Thank you for the nice introduction and for welcoming me to present today. So like Becky said, I'll be talking about skincare and topical treatments for pemphigus and pemphigoid. So my general overview is to cover some general skincare recommendations for all skin. People with pemphigus and pemphigoid and those who don't have those conditions. Then some specific considerations for those with pemphigus and pemphigoid and then to discuss topical treatments, after which we'll have the Q&A portion. I have a few disclaimers and I'll say this multiple times during the talk, everyone is different. So what I say, or recommend, may not work for you and that's okay. What works for you, might not work for others. What I recommend may not work for you. Things I advise against might be working really well for you and that's okay. Then your physician knows you better than me, so if your physician has told you something that is different from what I have said, I would trust them. They know you better than I know you. But these are just some general recommendations that I think can generally be true for many people, but not everybody.

**Dr. Schultz:** So, first, starting with just general skin care recommendations. Again, I'll say, everyone is different. But in general, from a dermatology standpoint, we recommend to bathe daily or every other day. We recommend putting a moisturizer to all the skin, and it's ideally

applied when damp. The idea behind that is that, after getting out of the shower, you pat dry, then you put that moisturizer on and that moisturizer then traps that water that you just put on your skin while you were showering or bathing. We recommend daily sun protection in all seasons. And even if you're not doing vigorous outdoor activities, you get a lot of sun through car windows, even in winter cloudy conditions, which we'll talk about. This is more of a personal recommendation, but I think less is more the skincare world, the beauty care world, there are all these different products designed to do different things for your skin. Toners and all kinds of things I don't even understand. I really think that less is more. I think those companies are often trying to get you to buy some more products or try some new products. And I really think you don't need much to take good care of your skin. So I'm a big fan of less is more, products that are affordable and things like that. Things that work for you.

**Dr. Schultz:** Thinking about good moisturization everyone is different, but in general, we like moisturizers that don't have a lot of fragrances or preservatives. And we also like moisturizers that don't have a lot of alcohol just because that alcohol can cause burning or stinging. So, I have no stock in any of these companies. These are many of the products that I will recommend to my patients, CeraVe, Vanicream, Eucerin, Aquaphor, Cetaphil and there's many other good ones but we know these products don't have a lot of fragrances or preservatives in them. A specific comment, products can be branded as unscented or branded as fragrance-free and that's a pretty big difference. What you should be looking for if you're trying to avoid fragrance is actually fragrance-free. So, fragrance free products can't contain any ingredients that have any kind of scent. The unscented products, they're formulated to have no smell. So, they can have ingredients if those ingredients neutralize another ingredient that has a scent. So, for example, you could have a product with lavender in it but if a chemical is added to obscure that lavender, then it can be branded as unscented. So if you're looking to avoid fragrances, you really want to look for fragrance free. We'll talk about this a little bit more when we get to topical steroids, but there's a big difference between ointments and creams, lotions, and oils. In general for good moisturization, if your goal is to moisturize the skin the best you can, you're gonna be looking for an ointment. Now ointment is greasy like vaseline, the difference behind the actual product is it has a higher oil content. More oil, more so than water, so they're really greasy but they really help trap that water into the skin. So if you have dry skin, if you're really looking for moisturization, ointments are the way to go. Now, some people understandably do not like how ointments make their skin feel because they're very greasy, they stick on clothing. So a cream is kind of the next step down in terms of how good it can absorb water into the skin. So a cream is another very good option. It works maybe a little less well than an ointment but can be much more appealing to use because it can rub in and smooth. These have a higher water content than the ointments that have the higher oil contents. Lotions are okay and they might be appropriate for some people, but they can have alcohol and that alcohol component can burn, so they're not great for everybody. Then for some people just oil, like think of an olive oil, think of a coconut oil. That texture, that can be really nice for some skin types. Again, it probably doesn't put as much water into the skin as ointments or creams, but we want to help you find something that you're going to use and be able to put on every day. So it's a good option. I alluded to this earlier, but I really think it's

important to not break your bank. The products on the screen I think are generally between probably \$5 and \$15. I think it's important to not spend a ton of money on these products when some good ones exist that are very affordable. Then it's nice to consider maybe getting a daily moisturizer that has an SPF in, has a sunscreen in it, just because as part of your morning routine, you wake up, you brush your teeth, you put your moisturizer on and your moisturizer already has sunscreen in it. Then you're set for the day. So, it's a nice 2 in 1 way to start your day.

**Dr. Schultz:** A little bit more on branding. We already talked about the difference between fragrance free and unscented. And, again, if you're looking to avoid fragrances, fragrance-free is the way to go. I think a lot of products will brand themselves as natural or emphasize how natural they are, and I think it's important to keep in mind, natural doesn't always mean best for skin. Poison ivy is one of the most natural things in the world, and can cause a lot of rash problems on the skin. So just because something is natural, doesn't mean it's going to be the best thing for your skin. In general, essential oils can be great for some people but if you have an active skin disease, I would tend to steer away from them. There's actually a case report of two patients who use some essential oils and it was thought to have contributed to their development, or their flare of their pemphigoid. Essential oils can also cause allergic contact dermatitis just like poison ivy causes. If you have a normal skin barrier, there's no skin problems that you're dealing with, essential oils can be very nice. But in general, if someone has an active skin condition whether it's pemphigus or pemphigoid, psoriasis, eczema, I think it's good to stay away from them just because they can flare some of these different conditions.

**Dr. Schultz:** A few tips on bathing. In general, we like gentle soaps. So, probably, one of our favorite gentle soaps is a dove bar soap. You notice in the diagram here, it says fragrance-free, it also says hypoallergenic meaning there are few things that can cause allergies. We like bar soap because it really has very minimal fragrances, preservatives, and chemicals. Liquid soaps that bubble, which are probably nice to use, contain chemicals that make those bubbles and those chemicals can be irritating. Again, if you have a normal skin barrier and no active skin conditions, that might not be a problem but if you're dealing with some of the no troubles with the skin barrier it can be important to reduce any possible irritants so that could be a liquid soap. So we like Dove bar soap. You really don't need soap all over your body head to toe. You really only need to wash your nooks and crannies. Under your armpits, in your groin, hands and feet. That's all you really need the soap for, the water can do the rest for the other places. An exception to that might be if you were just out, sweating very vigorously, maybe that's not always going to be the case. But in general, the nooks and crannies are really all you need. I think it's good to have a warm, comfortable temperature. You don't have to take a really cold shower. I wouldn't take an extremely hot shower. I think, be comfortable. That should help not dry your skin too much because then you're going to pat dry, and do your moisturizer right after. That moisturizer is going to trap that water in the skin.

**Dr. Schultz:** Changing gears a little, we're going to talk about sun protection. Just a few basics on sunscreen and sunlight. Sun gives off a couple different types of UV lights. UVA is mostly responsible for aging. It passes through windows, such as car windows and house windows. UVB, ultraviolet light B is mostly responsible for sunburn. It does not pass through windows but again, the light that comes through windows can contribute to aging. There's also a UVC but that doesn't really come through the atmosphere. We talk a lot about SPF and what does that actually mean? SPF stands for sun protection factor. There's actually an equation that's used to calculate SPF. But essentially, it's the amount of sun your skin can get before your skin turns red if you have the sunscreen on and the amount of sun your skin can get before it turns red if you don't have the sunscreen in place. For example, if you have no sunscreen on and you're pale like me and sensitive to the sun like me, if you go out for 5 minutes, you're gonna get a sunburn. Now if you have SPF 30 on, you times that SPF 30 times 5 minutes, now I have 150 minutes before I'm going to turn red and sunburn. I think there's some misconception about SPF, that it blocks 30% of rays or 70% of rays or something like that. But it's really the time factor for how long it's gonna take you to get sunburnt. If you have darker skin than me, less sensitive skin than me. Your no sunscreen time to a sunburn might be more like an hour and your SPF 30 could last you longer. That number for someone to burn is really variable between people. The sunscreen SPF factor is adding more time before you're gonna get burned. That's assuming I haven't gone swimming or sweating and it hasn't come off. But in general, if it was that long, that's how much time I would have. There's also two big categories of sunscreens, physical or mineral sunscreens that actually block sun rays from entering the skin. The little hand on the left side of my screen is kind of blocking the sun from absorbing into the skin. This is also called sunblock. I use sunscreen interchangeably but this is technically sun block. These sunscreens are generally better for more sensitive skin and they're going to have ingredients like zinc oxide and titanium dioxide. They sit on the top layer of skin and deflect rays, simplistically. On the other side, you have chemical sunscreens, which actually absorb the sun but then prevent it from entering into the skin. It's called a sunscreen, not a sun block. These ones are usually much easier to rub into the skin and some examples are listed, oxybenzone, avobenzone, octisalate, octocrylene. They can be very good, again, for people that don't have troubles with their skin, they can work lovely. If you are having issues with skin sensitivity, definitely the physical or mineral sunscreens can be better. The physical or mineral sunscreens are probably also more effective as well, just because they don't have to rely on that chemical process to inactivate the sun, it's physically blocking it. One important qualifier I should say to the chemical sunscreens, is sometimes they only block sun UVA or sun UVB. So, you might actually have to mix and match the chemical sunscreens to get your full coverage where the physical blockers will block both UVA and UVB. So, it's just easier to know that you're getting full protection with the physical sunscreens.

**Dr. Schultz:** So in general, our recommendations, we recommend using a broad-spectrum sunscreen, that's a physical blocker or if you're doing a chemical sunscreen, make sure it covers UVA and UVB. We recommend SPF 30 or higher. You probably do get more protection if you use a higher SPF, but the difference between 10 and 30, it's much more dramatic between 30 and 50. So we generally just say 30 or higher. We recommend waterproof

sunscreens, it's good to apply about 15 minutes before going outside. You really do need to apply every two hours or after sweating or swimming and that's just because the sunscreen at that time wears off. Many people do not use as much sunscreen as they need. Most adults need an ounce so think of a shot glass to cover the whole body. You really do need a decent bit of sunscreen. Then better yet, if you are having sun sensitivity or you don't like sunscreen, wear sun protective clothing, avoid the peak hours of sun 10 am and 2 pm and then be careful when there's water, snow and sand because those materials can reflect the sun's rays back onto you. You can get a lot of sun when it's cloudy, so I remind everyone that daylight is sunlight. So if it's between 10 am and 2 pm or anytime it's daylight the sun's rays can come through the clouds.

**Dr. Schultz:** I like to include this because I get a lot of questions from my patients about a base tan. They're going to Florida, they're expecting a lot of sun so they want to get a base tan to prevent sunburn and it's really not necessary, it's not recommended. Every UV exposure is damaging your skin so whatever you have to do to get that base tan, damages your skin and having a base tan is about an SPF 3. So for me, that buys me 15 minutes instead of 5 minutes but I had to damage my skin to get the SPF 3, so better yet, just use sunscreen.

**Dr. Schultz:** Another question I get a lot is what about vitamin D? I get a lot of vitamin D through the sun and I don't wanna miss out on that. Vitamin D is very important and you actually do get a fair amount of vitamin D through sunlight. You can see a few examples there. An 8 ounce glass of milk is 100 international units of Vitamin D, a small helping of salmon is 360 international units, and sunlight is 430 international units. So, you do get a fair amount of vitamin D through sunlight. I tell my patients that vitamin D supplements do not carry a risk of skin cancer or photo aging, or potentially exacerbating or worsening a skin condition such as pemphigus or pemphigoid. So bottom line, I say, sun is not the answer for your vitamin D, we should supplement to get it through the diet.

**Dr. Schultz:** I thought it'd be nice to maybe give you some sunscreen recommendations. I think the most important thing is to not break the bank again and to find something you'll use. So, if I give you a recommendation and it's something you really hate putting on your skin, that isn't a very good recommendation because I want you to be able to put it on every day and re-apply it. As I mentioned before, in general prefer physical sunscreens over chemical sunscreens. One particular type of sunscreen I didn't mention is called a tinted sunscreen. I'm circling it right now with my cursor and it's the CeraVe Hydrating Mineral Sunscreen with a brown or tan color and it has a bit of a tint to it. That tint actually protects against visible light and visible light causes a lot of this skin aging. But it can also be nice if you have a little bit of a darker skin tone. It doesn't look so chalky white. So some of my patients really like these tinted sunscreens, so I just have a couple of examples. Again, these are not very expensive sunscreens. I don't have stock in these companies but they're mostly mineral sunscreens and they're not too expensive. Most importantly, find something you're going to use.

**Dr. Schultz:** Changing gears a little bit, so you might be thinking, what about me? I have pemphigus and pemphigoid so how should what I just told you be different for me? I think, in general, the recommendations can be pretty similar but some things are going to maybe have to be modified or become even more important. So protecting your skin from the sun is maybe more important. Putting a good moisturizer on, a good barrier on your skin, avoiding fragrances, might even be more important just because your skin can be more sensitive to the things worsening it. Then you might need to modify it. It might be really tough to get into a shower every day so you might want to do a bath instead of a shower. You might want to do soaks with wash cloths or towels, something that's a little more gentle on the skin where the shower isn't beating down on your skin. Modify as you need to, and every day might be really tough so every other day, I think it is still very good. The sunscreen might actually irritate your skin no matter what product you find, so then you might want to just opt for sun protective clothing, staying in the shade, things like that. There are some reports of pemphigus being worse with sun exposure. There's some conditions that we know are worse with sun. Lupus is an autoimmune condition that we know is worse with sun. Not everyone with pemphigus or pemphigoid will notice that their skin can be worse in the sun, but I would say it can be. So, if you notice that the sun is a trigger for you, that's very valid and then definitely do your best to avoid it. If you don't notice it being a trigger, still do your best to avoid and protect yourself because it can cause a lot of other problems down the line.

**Dr. Schultz:** Some other wound care tips, this one I mentioned already and many of these, I have to say, came from my patients. Some of them are from Becky Strong, these are things that people have shared with me that worked well for them. I don't have pemphigus or pemphigoid, but I hope that my patients can help me give you some ideas. A bath might be better tolerated than showers. If you have oral lesions, oral sores in the mouth, consider a toddler toothbrush or toddler toothpaste, use a manual toothbrush, not an electric toothbrush just because it'll be a little less aggressive on the gums. If you have troubles with sores in the eyes or the mouth, use saline drops to keep things moist. Flossing tape, which is down here on the left, is a little kind of thicker and fluffier can be less painful than the thin floss. If you have genital sores, this is for women after they've had a baby and it's called a peri bottle. Water goes down in here, and you squeeze the bottle and water comes out the spout, or even just using a small watering can with a long spout then using that bottle or that can to run water over the genital area while you're urinating can kinda help dilute that urine and prevent the skin from being sore or irritated by urine. If you have a lot of sores on your back, I'm going to talk about a few dressings at the end of this. But there's a dressing that doesn't stick to the skin that's called telfa. I'll show an example of it. You can put that on your back and then wear a tighter T-shirt to kinda secure it in place. Or on your legs, if you could wear some leggings and secure things in place. So being creative about how to secure dressings.

If you have a lot of thick scales on the scalp. It can help to do an oil overnight. There's some steroid oils we're going to talk about, but even just like coconut oil or something like that. Put it on overnight, cover it with a shower cap and then rinse it off in the morning. Keeping it moist overnight, can really help get that scale off that's so uncomfortable. It can be very helpful to do

antimicrobial soaks. In many different skin conditions, Eczema is probably the classic one that we first started thinking about these in, they can be very helpful because they're anti-inflammatory and they're also antimicrobial. So it's normal to have bacteria on your skin, but if you have bacteria on your skin, if you have too much of it, or if it's in the wrong place, it just makes it harder for your skin to heal. Wounds can become colonized with bacteria and they just can't heal, because there's just too much bacteria in them. So you can do a bleach bath, which might sound a little goofy but it's kind of like a swimming pool. It's very dilute, a quarter to a half cup of bleach in a full tub or a half to one teaspoon in a large bowl. If it's in a bathtub, you can soak in the bathtub for maybe 5 to 10 minutes, then rinse off with some just plain water, and then pat dry and put your moisturizer on. If you're doing a soak, you could put a little towel in the bleach soak, and then put it on your arm or your neck or your head. Leave the washcloth in place for about 5-10 minutes, and then rinse it off. You can also do vinegar soaks, which is one tablespoon of vinegar with about a cup of water. And again, you can do that in a small basin. Vinegar soaks are especially good for fingers and toes because there's a little bit of different bacteria that live in those places, but either can be very beneficial.

**Dr. Schultz:** Itching, I wanted to mention, is just really, really tough. Especially our patients with pemphigoid but also our patients with pemphigus can have a lot of itching and it's just really hard to treat that. In general, if you have dry skin, that's itchy skin. So moisturizing daily can help anyone with itch even for those who don't have pemphigus or pemphigoid. There are some anti itch creams that can be helpful. Two examples are Sarna or Cerave with pramoxine but these can sometimes also be irritating so you really have to do what works for you. The most important thing for itching if it's from your pemphigus or pemphigoid is treating your underlying pemphigus or pemphigoid. Whether that's with Prednisone, Cellcept or Rituximab or what have you. That's probably going to be the most effective thing that's actually treating your itching, but these are some things that can help a little bit along the way.

**Dr. Schultz:** Afterwards, you might be saying, I haven't had any active pemphigus or pemphigoid for a long time, but I have all these other things on the skin. Just to mention that these happen and unfortunately, there's not great treatment options. So let's say you had a blister on your skin, as that blister is healed up it often looks very pink or it might look very dark brown depending on what color your skin is. We call that post inflammatory erythema or hyper pigmentation. Basically, it's a pigment scar so the skin looks red or brown because there had previously been a ton of inflammation there. These can fade over time, and protecting yourself from the sun can help prevent it from worsening. But they're kind of a scar from what you've dealt with. So there's not a great way to reduce that scar other than just treating the underlying condition and preventing new scars. Some of you may have also noticed you get these little white bumps in places where you used to have blisters. These are called Millia and it's essentially a small cyst. It's a normal part of the scarring process. It's not anything worrisome or dangerous, but it can be annoying. Sometimes these Millia just fall off and go away on their own. I had a few patients where I made a little nick on the skin and pushed a little cyst out, so your doctor could consider removing them. But you also want to be careful because anytime

you're doing that you're making a nick in the skin and injuring the skin so you want to make sure that person is under really good control, because you wouldn't want to flare of their pemphigus or pemphigoid.

**Dr. Schultz:** There's a few other miscellaneous things you might be dealing with. Some of these are a little bit outside of what we're talking about today, but I just wanted to mention them. Many of you may have had to deal with hair loss, it's common. We see it from medications. Prednisone or methotrexate are probably two big ones, but also stress of a chronic illness can cause a lot of hair loss. Let's say you have an insult from a medicine or stress, that can also unmask a tendency towards male or female pattern hair loss. So maybe you never would have never had a problem with male or female pattern hair loss but then you had the second hit of a medicine or stress and now it exposed that. Sometimes the hair loss can improve with control of the condition, or being able to stop the medicine but sometimes it never goes back to normal and that's a hard thing. Doing things like rogain can sometimes help, but hair loss can be really challenging. If you've been on prednisone, or if you take blood thinners, you may notice this easy bruising. This is a forearm. You might not even remember getting an injury but these bruises can show up on your arms from the slightest little tap and these bruises can show up on the arms. I tell my patients, this can be from wisdom or normal aging but definitely medicines like prednisone or blood thinners can make it worse. There's not too much to do other than if you can get off prednisone great but many of you might have to be on it for a while or you might have to be on blood thinners for another reason so unfortunately, sometimes you're kind of stuck with it. So doing a moisturizer as a barrier repair can sometimes help prevent this from happening. Then you can get side effects from the medicines you're dealing with and that can show up as things on the skin or in the mouth. Yeast or thrush in the mouth is very common when you have to be on medicines that suppress your immune system. Just to mention, some other things you might have to deal with on your skin that aren't necessarily from the pemphigus or pemphigoid, but maybe from the treatments or just having to deal with the condition itself.

**Dr. Schultz:** Then, lastly, we're going to talk about some topical treatments for pemphigus and pemphigoid which really consists of topical steroids. It's kind of our mainstay of treatment. But there's actually a lot to talk about for steroids because there's different strengths or potencies. There's all these different formulations or vehicles and then we want to talk about how to apply them. You may recognize a couple of these. So, here's a cream, here's an ointment, here's an oil, and here's an elixir. There is Clobetasol, Triamcinolone, Fluocinolone, and Dexamethasone, so what does all this gibberish mean? There's actually seven groups of steroids from least potent to most potent and I just put a couple of examples that you may have used from your physician but they range from over the counter, Hydrocortisone 1% cream to our strongest steroids Clobetasol, Augmented betamethasone, and then all the ones in between. Depending on where your skin lesions are, your doctors are likely giving you either a lower potency, a middle potency, or a higher potency. The potency and how it translates into how it affects your skin is influenced by a number of things. Number one, what is the steroid



you are using? Clobetasol is the strongest, Triamcinolone is the middle, Hydrocortisone is the end and the least potent. Are you covering it with dressings or not covering it? If you cover something with a dressing that can make the steroid work better. Then, how is it formulated? What's the vehicle it's in? Either an ointment, cream, lotion or oil. So we'll talk a little bit more about that, which one's the most potent. And then is your skin barrier intact or do you have an active lesion? If your skin is intact the steroid might not absorb as well then if you had an active sore and the medicine can get in there very easily. In general, we use higher potency steroids on really thick sores and thick skin, like hands, feet, knees, and we use lower potency steroids on thinner lesions, thinner skin, like face, eyelids, armpits, groin, places like that.

**Dr. Schultz:** Looking at the formulation of the vehicle. We talked a little bit earlier about this, ointment is the thickest vehicle, it's the most potent and it's going to absorb the best into the skin and trap the medicine and the skin but you may like it the least because it's very greasy. So, creams are a little less potent but many people like them more because they can run smoothly. Then lotion is the thinnest and it's good if you have lesions on your scalp or someone where there's a lot of hair like your chest or your back or if you're spreading it over a wide surface. Just be careful with lotions because it can contain alcohol so it can sting. We already talked about oils. Oils can be really good for the scalps, sometimes, but some people don't like that oil feel in their hair. Gels can be really good for the mouth, the mucosal surface, the genital surface, hair-bearing areas but they can contain alcohol. Foam is really wonderful. It's very easy to apply especially in the scalp but it's often very, very expensive. Then solutions are also good for hair-bearing areas, but they can contain alcohol. So another caution. In thinking about applying steroids, I'll give my disclaimer that your physician may tell you something different here so keep that in mind, but in general we say to apply steroids 1 to 2 times a day. You can increase their efficacy by what we call a soak and smear. It was made for people with eczema. The soak and smear is when, let's say your hands are affected, if you soak your hands in a warm basin or your body in a tub. You get out pat dry and then put the medicine on and that initial soak for 5 or 10 minutes can really help prime your body to accept that medicine and kind of absorb it better. You can also increase efficacy by occlusion or covering your skin, so with a band-aid or dressing and I'll show you a couple examples of wet wraps. These pictures show a wet wrap. A wet wrap is when you get a little dressing, whether it's a towel, cotton pajamas, a washcloth, get the wrap wet and wring it out and put it over the affected area and then put a dry towel, cotton pajama, washcloth on top of it. Then leave that on in place as long as you can. You can sleep in it if that's comfortable or even just an hour while you're watching TV, but that water again, just helps the medicine absorb. You can apply steroids to open skin or active blisters that's very safe to do. The medicine might absorb a little more, which can be okay because we're trying to calm your skin down in these areas, but if it's too irritating, maybe you have a lotion and it's irritating your sore, maybe apply it at the edge of your blister or try a different formulation, like a cream or an ointment. There's lots of ways to use steroids and different strategies. The goal is to have enough control of your skin, but to try to reduce side effects in steroids. It's really balancing the use and what's going on with your skin with the side effects. Some doctors will tell their patients to use the steroid Monday through Friday and take a break on Saturday and Sunday. Some people will say two weeks on

two weeks off. My strategy is to try to hit things hard. I am the fire hydrant where I tell my patients to use this twice a day until the skin really calms down versus the other ways in my mind are more like the watering can that you sprinkle a little then you pull it back, then you sprinkle a little then you pull it back again. I think it's more effective to try to hit it hard and try to calm that skin down as fast as you can. Now that has the potential to get more side effects if you need to use it for a long time. So if we find that we're hitting it really hard but the skin really isn't budging, then I think it is really important to take some of those breaks and try something like Saturday and Sunday off, or take a week off or something like that. You just want to take too much time off because your skin can flare. You're going to probably hear a lot of different things from your doctors about how often to apply the steroids. I think it's important to know that you can use them when you need to, but we have to be careful if we're using them too long just because of the side effects. The side effects we mostly watch for is skin thinning, that can look like stretch marks on the skin or the blood vessels can become more prominent. Other side effects of steroids, you can develop acne. You can become allergic to the steroids. You can have easy bruising. There are theoretical risks if you're using a lot of steroids, your body kind of gets used to the steroid. Then when you stop it, you can kind of have a little bit of withdrawal, so your skin can kind of feel burning or stinging. It's rare to get, like full, body wide effects, systemic effects, like feeling flushed or having high blood pressure, or glaucoma or diabetes, like you might get from prednisone but it can happen especially if you're using a higher potency all over the body. Then there was a question, does your body get used to your steroids, and then it doesn't work as well. And that's a little bit debated if that actually truly happens. It might, so it's possible if you use a steroid for a long time and you get used to that one, you could consider switching to another one. But, everyone's a little different. That doesn't always happen, but if you're noticing you're using the same steroid and it starts working less than you're used to, that's something you could ask your doctor about if they think that's happened to you.

**Dr. Schultz:** If you have sores in the mouth or in the mucosal area of the genital skin there are different formulations, like gels or pastes can work nice for a single spot here and there. I shouldn't say a single spot, but an isolated spot around here and there. If you have diffuse lesions in the mouth, a swish and spit can be really nice especially for hard to reach lesions that are at the back of the throat. You can swish and then spit it out, that's a nice way to get the back of the throat. Some other tips I've heard from some of my colleagues or patients, put a little gauze on your cheek to dry the cheek, then apply the medicine, and then hold that gauze or telfa to the top of it for a few minutes over the top of it to help that medicine absorb. If your whole gum line is inflamed, think about getting a mouthguard custom fit for your gums and putting a little medicine along the guard and letting that sit on your gums for 5 to 10 minutes. It's also really important to practice good dental hygiene and keep seeing your dentist. I know that might be hard to hear when your mouth is so inflamed and going to the dentist aggravates things potentially but working with a dentist that's familiar with your condition. The IPPF has wonderful resources for people in your area that might be able to help. It's really important because if you have plaque or inflammation and gingivitis that can just worsen pemphigus and pemphigoid. So it's really important to maintain good dental hygiene.

**Dr. Schultz:** Then, there are a couple of non-steroid topical that we sometimes use such as Tacrolimus, Cyclosporine, they work similar to topical steroids but in a slightly different way. We use them less often in pemphigoid and pemphigus but they are potential nice options. Often that they can be expensive or need to be specially compounded so they're probably not used as frequently.

**Dr. Schultz:** Then the last little section is just a few slides on some different dressings and maybe you have encountered some of these. There's a lot of different categories of dressing, a few of the ones I'm going to mention, are ones that are non-stick. Telfa shown at the top here looks like a piece of gauze or a washcloth, and it has a little bit of absorbency to it. There's also an ABD or an abdominal pad, and that's even thicker. These are both dressings that don't have any adhesive to them. So they're really nice to put on the skin and then they can be fairly easily removed without pulling skin. They're also nice if wounds have a lot of drainage but they do need to be secured in place. This is Kerlix down at the bottom, it's a roll of gauze and you unroll it and wrap it around an extremity like your arm or leg or your back to keep it in place or you can use that type of clothing like you mentioned earlier. There's also some dressing called hydrocolloids that just means there's an adhesive layer that has like a little hydrated gel and it's a very moist environment, then there's an outer layer that kind of seals the skin and keeps the area protected. So two examples are Deoderm and Restore. If you squeeze them they are kind of squishy and they promote a moist environment. They're a little bit absorbent, not as absorbent as the others we just talked about. The nice thing about them is you can cut to fit them, so you can take this and kind of cut it in a little square, or cut it in a little circle. You can put it right on an open sore, put a little medicine on it and put it on the open sore and then leave it in place for a few days. Then when you remove it hopefully it shouldn't be too uncomfortable to remove because it's been a little bit moist. I maybe should have said this earlier, in general we do like having wounds be a little moist and covered because we know that that promotes wound healing. Dry, crusty, uncovered wounds do not heal as well as those that are a little moist and covered. Then the last type of dressing to mention is a film, so the classic example is Tegaderm. These also promote a moist environment. They're very flexible and pliable. You could put it over an elbow very easily. But they don't absorb really anything, so they're not great for wounds with a lot of drainage, but if you have a really superficial wound and it's on a joint and you just want to keep it covered and put a little medicine on it and put the Tegaderm on it and can leave in place for a few days. Some people have skin sensitivity, so these won't always be great for everyone but they're just some things to consider for some.

**Dr. Schultz:** With that, I just want to acknowledge the IPPF who's supported my career, in particular Becky Strong who I've worked with for several years now and then I have mentors across the country that I've taught me a lot of these things. I also want to thank and acknowledge my patients who give me their tips as well. This is one of my dear patients on the right who I've taken care of since I was in training and I'm happy to say he's doing very well in remission from his blistering disease and that was when we had good news and could stop

some of his medicine. So, thank you for your time and attention. At this time, I believe I'll stop sharing my screen and we'll open to the Q&A portion.

**Becky:** Thank you Dr. Schultz, that was a lot of really great information and I know that our community is going to be thankful. We did get some questions in, and I'm going to kind of group these together. Are the ingredients that patients with pemphigus and pemphigoid should use or shouldn't use. Some of the questions that are coming in are surrounding hyaluronic acid and retinol and those kinds of ingredients.

**Dr. Schultz:** Those are great questions. I think in general, I'll say this again, I think less is more. If you have active pemphigus or pemphigoid I think things like hyaluronic acids and retinoids could be irritating to your skin. Now, if you are in great shape from your pemphigus or pemphigoid, your skin is in remission, you're doing well and you're doing your anti-aging routine. I think hyaluronic acid and retinoids can be perfectly fine. Maybe you have active pemphigus and pemphigoid somewhere else but not your face, and you want to use hyaluronic acid and retinoids on your face, I think that's okay. But if you use them and you notice you're getting irritated, I would stop immediately. So again, they could be safe in the right scenario, they could be irritating in the right scenario. Are they actually helping make your skin look more youthful, I think is up for debate sometimes.

**Becky:** Great, thank you so much. We got a couple of questions about the clothing that you had mentioned labeled as sun protective. Are there different materials that they should be looking for that are truly protective? And if there's any brands or recommendations, that you find more helpful.

**Dr. Schultz:** That's a great question. I should have included a slide on that. So what you're looking for is clothing that has a UPF factor in it, and there's some very good brands. The one I'm thinking of off the top of my head is Coolibar, but there are many others. I'm going to see if I can find any while we're chatting, but you're really looking for UPF clothing. I think it's generally 50 or higher, 40 to 50. I know you can get them at athletics stores like REI or Athleta, but they can be a little pricey. So it's good to have maybe 1 or 2 pieces that you rotate. Maybe I can come up with a little list that I could send to you Becky?

**Becky:** Yes, that would be great. Thank you so much. We've also got a few questions, and I know it's a hot topic and some of the discussion groups on Facebook as well about getting tattoos. What are your recommendations for patients with pemphigus and pemphigoid? What if our lesions are only in our mouths? What if we're in remission? Kind of all of those, in a nutshell scenario?

**Dr. Schultz:** Yeah, that's another great question. As some of you may have experienced, pemphigus and pemphigoid can both be made worse by trauma. If you injure your skin, you can get a lesion where you injure your skin. If you have some trauma in your mouth, you can get some lesions where you have trauma. So a tattoo is a form of trauma. So, theoretically, if you got a tattoo, could you develop pemphigus or pemphigoid in that area? I think it's possible. If you've never had skin lesions, they've only been in the mouth or the genital area, you're probably a lot safer than someone who's had active sores all over their skin. If you're in remission, it's probably unlikely but I think that it is a possibility. That might be a really low possibility depending on your scenario so I think you have to just think about it. Would you be prepared to have a flare in that area if it happens? If you've only had it in your mouth, or if you're in remission, you're off medications or are well controlled on medications, that's probably going to be much lower risk. So I think you could consider it. But I could never tell you that it would never cause a problem but there are no never evens in medicine. So I think you just have to be as prepared as you can and be in control of your skin as well as you can. I think before proceeding with that. I would probably avoid it if you have active skin lesions or getting new sores or things like that

**Becky:** Great advice. Thank you. I'm going to ask you a follow up question, because we've got quite a few questions about laser hair removal And so kind of the same question is, is that recommended not recommended?

**Dr. Schultz:** Another good question. I think it's very similar to the tattoo conversation. It could be very fine especially if you've only had sores in your mouth or you're in complete remission. Laser hair removal like a tattoo is another injury to the skin so it's possible you could flare your pemphigus or pemphigoid in the area. It is probably less likely, again, if you're in remission and you haven't had it in that area but I think there is kind of a similar answer there.

**Becky:** Great, and getting back to the skincare products, do you recommend coconut oil on the face or is there a better oil when creams aren't helping?

**Dr. Schultz:** That's a good question. I think if the question is, if the steroid creams aren't helping treat active pemphigus and pemphigoid, I don't think coconut oil is likely to be the most effective thing. If your creams are working to treat active lesions for the condition, that probably means you need a different therapy whether that's pills or injections or infusions or things like that. If it's more for moisturization, I think coconut oil can be great but I think you have to be careful because coconut oil is something that has a natural fragrance and fragrance can be irritating for some people. So I think one thing that may have been good to include would have been, if you're ever in doubt about a product, it's always a good idea to test a small area. Maybe get a little coconut oil, and try it on your cheek and put it on once a day for a few days

just to see if you notice any irritation. If you don't notice any irritation, then you could maybe feel comfortable applying it to the whole face. I think coconut oil can be nice, but again, it depends on how your skin responds to it. And it's probably not going to be what's going to treat your pemphigus or pemphigoid the best.

**Becky:** Great, a great tip too about doing a spot test. There was a question from Sarah who's asking, if the sunscreens you were talking about are they reef and sea life safe?

**Dr. Schultz:** Great question. So, I thought about including a slide on this, and I wondered about it. As you can see I had so many things I wanted to tell you. So I ran out of room. The studies that have come out about the sunscreens damaging reefs have been more for the chemical sunscreens. The chemical sunscreens like the Avobenzone and Oxybenzone, I can't remember which compounds were specifically studied, but were found in those chemical sunscreens. Usually the mineral sunscreens are going to be considered reef and sea life safe because they are that physical blocker and not that chemical. If you don't know if each sunscreen is labeled in that manner, but in general, if you're looking at the physical blockers, you're going to be more likely to find one that is reef safe. Whether or not they are labeled like that but I didn't specifically see if the ones I listed were certified reef safe. But in general, I think minerals are the way to go.

**Becky:** Great, thank you. I know you talked about hair loss a little bit. You presented a lot of information so if you're already covered this, I apologize. Natalie is asking, is there anything to help with hair loss or slow it down, or start to bring it back?

**Dr. Schultz:** Yeah, I think hair loss is so tough because sometimes it's from the chronic stress of your illness or the stress you have going on in your life, and there is no prescription that I can write to you to, say, be less stressed. That's really out of your control. Medications like prednisone or Methotrexate so if you can reduce those medicines as able, that's great too. Other than that, there isn't a ton you can do to prevent it from falling out. There are things that can help hair regrow so the most common is Rogaine or Minoxidil, which is just over the counter, it comes in 2% and 5%, we recommend the 5%. It comes in a liquid, it comes in a foam. The foam is probably less irritating to the skin but the downside to using things like Rogaine is that, if you start using it, you kind of have to keep using it because if you stop using it your hair will just go back to whatever it was, if you never started using it in the first place. If, once your skin is controlled and you're off your medicines or lower doses of your medicines, your hair would have come back anyway. It's almost like you started the Rogaine too early, if that makes sense. If you started the Rogaine and your hair gets better, was that because you started the Rogaine or because all these other things got better. So I often will tell my patients to try to work it out a little bit and see and then if over time it isn't getting better, maybe it's

unmasked your female pattern or male pattern hair loss, I think you definitely can try the Rogaine. But sometimes you may not have needed it, and then you started it, and now you're not sure if you should continue it or not, if that makes sense. So Rogaine is something that you can do but I would maybe wait and see first?

**Becky:** Great. Thank you. We're getting some questions about using hair dye. Is it safe to use hair dye when you have pemphigus and pemphigoid? If so, what type of product is best to dye our hair?

**Dr. Schultz:** You guys ask great questions. I think in general, dying your hair should be okay. If you have a lot of active scalp lesions, I would probably avoid it just because the dye can be irritating to your scalp. I could be wrong but I'm not aware of hair dye itself triggering pemphigus or pemphigoid but I think it could just irritate. If you don't have active scalp lesions, I think it would be safe to use. Now if you use it once and you have a flare in on your skin, then I'd say to not to use the dye again. In regards to a particular dye, I don't think I know enough about hair dyes to say for sure the best type of product to use. The other thing I'll say is that some hair dyes can cause other problems. So some people can be allergic to hair dye. If you ever get your hair dyed and then your scalp is really red or itchy afterwards, but not from your pemphigus or pemphigoid but more like an eczema rash, that could be a sign that you're allergic to hair dye. Something else just to keep in mind but if you don't have scalp lesions and you are not having problems with hair dye I think that it is okay to continue. If you're noticing that you're having any rashes develop on the scalp after hair dye or if you have active sores on the scalp, I would avoid hair dye.

**Becky:** There are some questions about the itch so if you wouldn't mind, can you put the itch creams back up? People want to know about those products. Also, we've got a few questions about using medications, such as Atarax or hydroxyzine and wanted your opinion of using those as well.

**Dr. Schultz:** Absolutely, if you are dealing with itch, I'm really sorry because it's just so hard. These are the two topical anti-itch creams that could be helpful, Sarna or CreaVe but I'll just say one more time that they could potentially irritate the skin so maybe try a test spot. I wouldn't put these directly on active regions just because the ingredients can be irritating. They may not help or they may be a game changer. What they have is kind of a cooling menthol ingredient, that as it dries, it kind of cools the skin and so it can be a little soothing. The medications like hydroxyzine, Atarax, Benadryl, Zyrtec, etc, I didn't include those because they are not topical treatments but they are absolutely something we can utilize. For some people, they can be extremely helpful. For other people, they don't do too much. The biggest thing to be careful with, especially the really sedating ones, like hydroxyzine, Atarax, Benadryl, doxepin, is that

sometimes if you take them at night you can get a little confused. People can have difficulty sleeping. If you have any mobility issues, you could potentially fall. As our patients get older and older, we worry about them a little more just for some of the side effects, but I do have many patients who very safely take them with some relief. I think the more important thing is treating the underlying condition. Things like prednisone, Mycophenolate, Dupilumab, and Rituximab are probably going to end up being more helpful for the ithc than kind these other “temporary band-aids”, but they are definitely things that are safe and okay to try and I'd use them carefully with your physician.

**Becky:** Great. Great advice, Thank you for covering that. Robert asks that you had mentioned about hyperpigmentation, but what about hypopigmentation? Patches on the scalp and the chest. Could it be from the Clobetasol and is there anything to make those scars go away?

**Dr. Schultz:** Yeah, absolutely. You guys are great. I can make this talk even better after these questions. So hyperpigmentation, which is darkness, redness or erythema, but you can get hypopigmentation too. Those are all just kind of pigment scars or pigment effects from the prior inflammation. Once that inflammation has happened there is not often much to do, unfortunately. Similar to the hyperpigmentation and the redness or the erythema, the hypopigmentation could fade over time. You probably also want to be talking with your doctor and making sure it's not a sign of a different condition. There are some very common fungal rashes, yeast rashes on the chest and back that can show up as hypopigmented spots. Now it's showing up on your pemphigus or pemphigoid spots it's probably not something else, but just something else the mind and consider. Unfortunately, there isn't too much to do other than tincture of time and try to avoid sunburns.

**Becky:** Great. Well, that's a good lead into the next question, because people want to know what to do about sunburns? And can having pemphigus or pemphigoid make the skin on your lip more susceptible to getting sunburned?

**Dr. Schultz:** That's a good question. You know, I did look this up. I wanted to know how common it was that the sun actually made pemphigus or pemphigoid more active. In the literature, there's only a few case reports of that, so it doesn't seem like it's as common as in other conditions such as lupus and some other conditions, as I mentioned, there is very clear proof or evidence that sun makes these conditions flare. That hasn't really been shown in pemphigus or pemphigoid but anecdotally, I've had patients tell me that that happens to them and maybe you've noticed that for yourself as well. I think it's possible, even if it's not well proven specifically if you get a burn on the lips. This is another thing I should have included they do make SPF lip balm. You can get a chapstick that has an SPF in it. That's something to consider adding to your routine especially if you notice the sun is flaring your pemphigus or



pemphigoid lesions. When you have an active sunburn, I say the best thing to do, and this goes for anywhere, your lips or your skin, is just to really moisturize that skin really well and protect it as a healing. Things like aloe vera can have a lot of alcohol in them and sting quite a bit so I'd probably steer away from those, especially if you have any active pemphigus or pemphigoid lesions. But I would just say moisturization is your friend. Otherwise, definitely a cream, not a lotion that has alcohol in it.

**Becky:** Great, Thank you so much. We did get a question about, should I be using the specific soaps and lotions that I use when I have blisters or open lesions after my skin is clear with no blisters?

**Dr. Schultz:** Yeah, great question. I think that when your skin is clear with no blisters, and you're not having skin sensitivities, you should feel the freedom to use what you want and go back to that life that you had before you ever had to deal with this. Now, let's say you go back to those products and they do irritate your skin maybe try that little spot test to see if it's going to irritate you and if it does, then you know your skin may have changed in the process of your pemphigus or pemphigoid so it is time to continue using your gentle products. But maybe your skin can tolerate it no problem and you can get back to another sense of normalcy.

**Becky:** Great. One more question for you, we've got a few questions about, is it okay to use public swimming pools or jacuzzis or hot tubs? Does anything make this contagious or make us more susceptible to anything from those things as well?

**Dr. Schultz:** Good question. I think, in general, it is safe to use the public swimming pools and the hot tubs and things. Now that being said, particularly the hot tubs or jacuzzis, those might have some strange chemicals or products that keep that water warm and clean. If you find out you get in the hot tubs and they irritate you to your skin, I would say don't do that again but if you use them without issue I think it's okay. From an infection standpoint, or a contagious standpoint you are obviously not contagious. And, really, I think they have so many chemicals in public swimming pools and hot tubs that there's probably not really a risk to you that any infection is going to transfer to you. If you have a lot of open sores, that might be the exception just because, there is bacteria floating around in those pools. I'd say, if your skin is clear or really well controlled with not a lot of active sores. I'd say give it a try. If it flares things up, then maybe take a break for a while and try it again later. If you have a lot of active sores it just might be more irritating to your skin. I think it is unlikely to be an infection risk, but if you have a lot of open sores, it just might not be very comfortable.

**Becky:** Thank you. I know I just said this but one last question. We're getting a couple of questions asking about, should clothing be tight to hold dressings in place or should it be loose? Is it dependent? What should we do?

**Dr. Schultz:** I think it is dependent. I think that's the good answer. If you're finding that you have large areas of your skin are sore or open, and you want to try that tip that one of my patients gave me about putting the dressing in place and then putting a tighter T-shirt around that can help secure it in place. If you are finding that that's just too uncomfortable and it's hurting your skin, then maybe having looser clothing is going to be better for you. It is nice to keep wounds covered, sores covered, so maybe experimenting with that dressing and tighter clothing could be a good idea, but if it doesn't work for you, it doesn't work for you so then, go looser. I think you can kind of play around and do what works for you.

**Becky:** Well great, that was an insane amount of information in a very short amount of time, and I sincerely appreciate you hanging with us and answering questions. I've learned a lot so thank you so much, I really appreciate that.

**Dr. Schultz:** It was fun for me too.

**Becky:** Good. So I would like to give a big thank you to everybody who joined us today. We had quite a large audience and I know this is probably going to be a popular one in the recordings as well. We're already getting great feedback and letting us know how great you were Dr. Schultz. I'd also like to give a big thank you to our sponsors Genentech, argenx, Cabaletta Bio for making today's call possible.

**Becky:** Before we go, I do have a few announcements. Our next webinar is going to be on May 31st. This was the webinar that was originally scheduled for May 10th but we had to reschedule. So on May 31st, on the webinar we'll be discussing PTSD in patients with pemphigus and pemphigoid. Please be sure to re-register in order to get the new link for this webinar, if you've already registered. If not, please register. It's going to probably be as good, if not better. So, thank you so much. 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! You can find the Natural History Study by visiting [www.pemphigus.iamrare.org](http://www.pemphigus.iamrare.org)

**Becky:** If you are interested in continuing to help support the IPPF and allow us to continue to provide free programs and services like today's webinar, you can become a healing hero. Healing Heroes fund the future of the IPPF community by making sustaining, monthly gifts to support our mission of improving the quality of life for all those affected by pemphigus and pemphigoid. No amount is too small, even a \$10 or \$15 monthly donation goes a long way and continues to allow us to provide for the greater good of our community. The IPPF has a number of upcoming virtual support groups across the country. If you are interested in attending a meeting, please check the IPPF's Event Page to register for a meeting. Also, we are always looking to expand our support network. If you are interested in starting a support group in your region please contact Becky Strong at [becky@pemphigus.org](mailto:becky@pemphigus.org). It's easier than it sounds to start a support group and you can help connect others in your area with other patients. Thank you, again, for joining us today. A call recording will be sent out of this webinar after the webinar today, so thank you again Dr. Shultz. Thank you to our sponsors, and thank you everyone for joining us.

**Dr. Shultz:** Thanks, Becky.