June 23, 2025 Patient Education Webinar - Corticosteroids For Pemphigus and Pemphigoid and How to Manage Side Effects

Becky Strong: Welcome everyone. I'm Becky Strong, IPPF Outreach Director, and I'm so glad you're joining us. Before we dive in, just a quick reminder that this webinar is being recorded. “Information is absolutely essential when it comes to managing and living with any condition, but especially pemphigus and pemphigoid. But remember, everyone's journey is unique. The IPPF encourages you to always check out the information that you hear today or found anywhere online with your doctor or healthcare team to make sure it applies specifically to your situation”. Now, onto the exciting part, you've been asking to hear more about treatment options in Pemphigus and Pemphigoid and we're happy to deliver. Today, we're excited to have Dr. Rachel Lipman here to discuss corticosteroid use in pemphigus and pemphigoid and their side effects. So let me introduce you all now to Dr. Lipman. Dr. Rachel Lipman is a dermatologist and internist at Northwestern Memorial Hospital in Chicago, Illinois. She completed her undergraduate training at the University of Pennsylvania. While in medical school at Emory University, she was inspired to help patients with immunobolus disease under the clinical mentorship of Dr. Ron Feldman. She subsequently completed a combined residency in internal medicine and dermatology at Northwestern University where she served as the chief resident of the Med Derm program, as well as the chief resident of community engagement. She was the recipient of the Medical Dermatology Society Mentorship Award, enabling her to work alongside Dr. Daniela Kroshinsky to gain further expertise in inpatient dermatologic disease. Dr. Lipman sees patients with autoimmune blistering disorders in her weekly complex medical dermatology clinic. She serves as a core faculty member in the inpatient dermatology consult team, caring for those hospitalized with dermatologic diseases. She continues to practice internal medicine as a member of the hospitalist division of internal medicine. She enjoys using her dual training on a daily basis to provide holistic care to her patients and collaborate with colleagues.

Then Becky reviews the housekeeping slides… Now let’s welcome Dr. Lipman.

Dr. Lipman: Hello. Thank you so much for that wonderful introduction and let me get started by sharing my screen. I have a couple slides for us to go through during today's talk. Okay, Becky, can I ask you, can you see my screen okay?

Becky Strong: Yep, I can see it. Thank you.

Dr. Lipman: Okay, well, thank you again for having me here today. I just love the IPPF and I think it's such a wonderful resource for all of our patients, and thank you for doing everything you do to support people on a very difficult journey. It's always important to know who you're getting your information from. So I want to mention that I have no conflicts of interest related to today's talk, but I do participate in research, specifically to clinical trials related to cutaneous lupus and pemphigus vulgaris. But I receive no compensation for that work and I won't be discussing those treatments today.

Dr. Lipman: So by the end of today's discussion, I want everyone in the audience to understand the role of corticosteroids in the treatment of pemphigus and pemphigoid. I want you to familiarize yourself with potential side effects of steroids and to consider best practices to minimize these side effects..

Dr. Lipman: For reference, here's the skin underneath the microscope. I'm going to point out two major areas that we're going to be talking about today because I think it's important to understand the basis of why we prescribe the drugs we prescribe. So here we see the skin and we have the top layer all the way here, which is the epidermis, and then the bottom layer here, which is the dermis. The dermis is full of blood vessels, and in the case of bullous pemphigoid or some of our pemphigoid family disorders, a lot of the action is happening between the base of the epidermis and the dermis. Whereas for pemphigus family disorders, follicaous might be in the more superficial layers of the epidermis, and then pemphigus vulgaris is in the deeper layers of the epidermis. So that's just a little bit for your thought of, what are these conditions.

Dr. Lipman: Pemphigus and pemphigoid are families of autoimmune diseases, and while I don't really need to tell this community what blisters are, I think it's important to understand that the basis of these blistering conditions is that your body is under attack from self. And so we normally create antibodies as a way of protecting ourselves from the outside world. Whether that's viruses, bacteria, or cancer cells, our body's immune system is really honed in to create the best balance to protect us from the outside world. But sometimes in the case of autoimmune diseases like pemphigus and pemphigoid, the body produces signals to attack some very important parts of our skin. In the case of pemphigus, it's these desmoglein proteins that can hold our keratinocytes together. In the case of pemphigoid, it's one of a variety of structures within the basement membrane, that area between the epidermis and the dermis we were talking about. And so a lot of our treatments are seeing ways we can reduce this self inflammatory response.

Dr. Lipman: So like we talked about, here's a picture of pemphigus vulgaris, but we see that acanthalytic or breaking apart of the epidermal cells targeting these desmogleins, and that's a population of B cells that are making these antibodies.

Dr. Lipman: In disorders of bullous pemphigoid, mucus membrane pemphigoid or wider pemphigoid family disorders. We might see that there are antibodies against these proteins called BP 180 and 230, but oftentimes it's a complex system of multiple, various antibodies that are not those two, and there's a lot of other inflammatory cells that are active as well.

Dr. Lipman: But that's not the purpose of today's talk. The purpose of today's talk is really to talk about steroids. So I want to start by saying, what are they anyway? Corticosteroids are hormones that are produced by our adrenal glands. And so here we have our adrenal glands sitting atop our kidneys and they're relatively small, but they do a lot of work for their size. They have two major layers. They have the internal medulla and the external cortex, and the medulla is making hormones such as epinephrine and norepinephrine. Maybe you've heard about adrenaline before and they control a lot of things for our fight or flight responses. But what we're interested in are the hormones created by the adrenal cortex, specifically cortisol. Also the

adrenal glands create a lot of other important hormones including androgens and aldosterone, which help regulate our blood pressure.

Dr. Lipman: So our bodies normally make steroids, and I think that's an important thing to consider, that we're using medication to replicate what our body does and also to help overcome what our body is unable to control with our endogenous steroids alone. Our body makes different amounts of cortisol throughout the day, but on average we make about 7 to 10 milligrams worth of prednisone every single day.

Dr. Lipman: And what are steroids? You might hear a wide variety of medications prescribed to you, and we're really talking about corticosteroids, and so I'm using the phrase steroid, but that could refer to a lot of different things. When I'm talking about steroids, I'm talking about things that replicate cortisol made by the adrenal cortex. Topically you may have been prescribed triamcinolone, betamethasone, hydrocortisone, clobetasol. Those are all topical steroids. And orally we have medications like prednisone, prednisolone, dexamethasone. Sometimes in the hospital especially, we may administer these medications through an IV and they might get the name methylprednisone, but these are all medications that are meant to replicate the natural cortisol that we create.

Dr. Lipman: Throughout today's talk, we're going to be talking about a lot of side effects of steroids. However, I really love this quote by Delaney Nothaft, who was a division one tennis player who was diagnosed with another autoimmune disease that's called myasthenia gravis, which is very similar to pemphigus in a lot of ways. And actually some of the research for myasthenia gravis inspired a lot of the research for pemphigus. She likes to say, “I'm talking a lot of trash about prednisone, but it is a lifesaving medication.” And I think it's important not to forget that about steroids.

Dr. Lipman: Prior to 1950, we did not have steroids widely available. And in fact, for their discovery and creation of exogenous steroids, Philip Hench, Edward Kendall and Tadeus Reichstein, they all received the Nobel Prize in 1950. So this is really a revolutionary treatment that is not that old. And if any of you are history buffs out there, I recently started this book here, “The Quest for Cortisone”, and so far I'm really enjoying it. It's a medical history about the discovery and development of cortisone in the lab.

Dr. Lipman: So this is Walter Lever, and he's one of the most important figures in the history of pemphigus. And this quote really stuck out to me. He said that, “In the treatment of pemphigus vulgaris, which he called hopeless up to then, it was revolutionized by the introduction of ACTH and cortisone in 1950. It was a thrilling experience to observe extensive eruptions clear within a few weeks when adequate doses were administered.” So this is the first time that hope was able to be delivered to patients suffering with this condition because prior to this, we did not have effective therapies for patients with pemphigus.

Dr. Lipman: Cortisone and corticosteroids work by reducing inflammation and they work quite broadly. So they act on multiple different pathways of the immune system. As you can see in this diagram, they're acting on multiple different types of immune cells. We have our natural

killer cells, we have our T cells, we have our B cells, we have our dendritic cells and our macrophages, and there's many complicated pathways in which corticosteroids reduce inflammation. However, we can see that it's pretty broad here. It's not very targeted to individual parts of your immune system. It's going to act in a lot of areas. And because of that, you can get pretty broad ranging side effects.

Dr. Lipman: We're talking about suppressing the immune system, but what is the immune system? Well, the immune system is a complex of tissues, organs, and blood cells, all with the hope of defending us from outside infection such as bacteria, viruses, fungus, recognizing foreign objects and detecting cancer cells. It involves the bone marrow, the spleen, our lymph nodes and our blood cells, our white blood cells, our thymus. So a very complex and integrated system.

Dr. Lipman: And what does it mean to be immune suppressed? Well, the immune system may not work for a variety of reasons. So there are some children who are born with immune deficiencies who don't produce part of their immune system, and those patients are considered immune suppressed. But there are also conditions that one can acquire throughout their lives that can make someone immune suppressed such as HIV, cancer, diabetes. And then immune suppression can also happen not from the disease itself, but from medications we give to treat diseases. So for example, chemotherapy can suppress the immune system and immune suppressants like steroids can suppress the immune system. So that is something that corticosteroids fit into the category of immune suppressants.

Dr. Lipman: I always tell my patients that corticosteroids are our best worst drugs. Best because they save lives, they can really turn around a really severe disease quickly, but worse because they come along with side effects and we really need to use them smartly. So here you can see a diagram of all the steroid side effects, but we're going to walk through some of the most important ones to know about today.

Dr. Lipman: The first thing that I know is on a lot of people's minds when they start therapies for pemphigus or pemphigoid is infection risk. If they're going to be starting a medication that suppresses their immune system, they want to be protected. There are certain infections that are higher risk with prolonged exposure to steroids. And I want to talk, one person submitted a really wonderful question, which is how much steroid will I be taking, for how long will I be taking it? And to think about this, oftentimes depending on the severity of your skin disease, we'll offer different doses. And so for our most severe skin disease, we may have the patient even in the hospital and giving high dose steroids that are based upon weights, and it may range from half of a milligram per kilogram all the way up to maybe 1.5 milligrams per kilogram. So you can think about if you're 150 pound person at one milligram per kilogram getting about 70 milligrams of prednisone. And in the world of rheumatology and dermatology, we consider high dose steroids to be anything higher than 20 milligrams of steroid per day. The risk for infections really go up when you're on more than 20 milligrams per day for more than one month at a time. And so within the rheumatology literature, there are certain recommendations especially to prevent this condition that's seen here to the right, that's called PJP pneumonia. It's a special type of pneumonia that is more risky for folks who have immune suppression. And we recommend

sometimes taking an antibiotic to prevent this when you're on high dose steroids for more than a month or you're also on another combination of immune suppressing medication. And that decision of whether to start this medication has a lot to do with your personal risk factors and your discussion with your doctor. And there's some good literature that actually some blistering patients are a little less at risk than other groups of patients, which is a really reassuring thing to know.

Dr. Lipman: So how can you protect yourself when you're immune suppressed? Well, there's no perfect answer here. And I get these questions every day for my patients of, is it safe for me to go on vacation? Is it safe for me to go to this event that I've really have looked forward to? And everything is about risk and benefit. So how can we reduce risks? We can have excellent hand hygiene. We can choose to avoid encounters when we know someone's sick. So if the grandchild is sick with runny nose, maybe we hold off on the visit today and we wait until they're feeling better. We can wear masks in crowded places and stay up to date with vaccinations to protect you the best you can from the things that we know may be higher risk, like COVID, influenza, pneumonia, RSV. Then trying to prioritize what's important to you. So for some of my patients going on that European vacation is a really big deal. They've been looking forward to it for a year. I am not going to stand in the way. We just want to make sure it's as safe of a trip as possible. And so thinking about those individual decisions together is important.

Dr. Lipman: Are there blood work or things I can do before starting steroids to help make it safer? Absolutely. So before starting any treatment with immunosuppressing agents, I recommend that everyone's screened for latent infections. So we want to make sure that there's no underlying hepatitis B or C or HIV or tuberculosis that you may have been exposed to at some point but is not active right now because you have a very robust immune system. Generally your doctor will screen you for these infections before starting any immune suppressing agents. Then we want to protect you against infections in the future. So for example, when you're not immune suppressed, that's the perfect time to get your vaccines. So COVID, RSV, shingles, pneumonia. Now we're seeing more measles out in the community and I've increasingly been checking to make sure my patients are immune to measles. And one of the questions was asked about whether you would be able to respond to vaccines if you were on prednisone. Well, that's a really great question, and there is evidence that there is reduced response to your vaccine if you're on more than 20 milligrams of prednisone. So it's a good time if you are able to get all of your vaccines before starting major immunosuppressant therapy.

Dr. Lipman: Okay, so next I want to switch gears a little bit. I put this towards the beginning because I really think it is so, so important. Mental health on steroids is a big deal, and there are the very severe side effect reactions from prednisone at high doses that we can see. And that's highest risk at the very beginning of therapy where someone might experience an event where they're really just not acting like themselves. And in that case, it's really important that we have a good support system. You can have someone to reach out to, friends, family, a mental health provider. I've included the link here. This is a national suicide crisis hotline that I want everyone to know if anyone in their lives is struggling with mental illness. This is a really important number to know about, but it's important to talk with your doctor about underlying issues with mental health before you start your prednisone therapy. So any underlying depression, anxiety, history

of psychotic disorders, history of bipolar disorder, because steroids don't necessarily make these happen, but they can certainly turn up the dial on things that you are feeling. And studies have shown that while only about 6% of patients will experience really severe psychiatric side effects of steroids, about 28% of patients will experience some degree of psychiatric symptoms, whether that's depression, anxiety, irritability. And so it's important to know who's in your support network. Is that a friend? Is it family? Is there a therapist? And check in with your doctor regarding your mood. I always like to say that having these symptoms throughout your experience with blistering diseases doesn't make you weak, it makes you human. And so it's important that you can share these feelings with your doctor, with your friends, with your family, and make sure that we're not ignoring them.

Dr. Lipman: Steroids can also make it hard to sleep, which can make people irritable too. And so an important thing to consider is taking your steroid early in the morning on a full stomach because some people get a little irritation to their stomach from their steroid. And considering the addition of medications that are non-habit forming. Melatonin is over the counter and that can be a really helpful sleep aid to help regulate your sleep cycle.

Dr. Lipman: There are risk factors to other aspects of your health. So specifically if you have an underlying diagnosis of high blood sugars or diabetes, it's important to let your doctor know when you're starting your steroids. And one thing to be prepared about this risk is knowing your baseline health history. So do you have a history of diabetes? And one way to check for that is looking through your blood work and seeing if you've ever had a hemoglobin A1C collected diabetes is defined as a hemoglobin A1C greater than 6.5. Are you taking medications for diabetes? So things like metformin, insulin, some of our newer agents like Ozempic or some of the GLP1 medications, those are all medications that can treat diabetes. And so it's important to let your doctor know about that. And then it's important to keep an eye out on your blood sugars during your routine blood work. Anytime that you're getting your kidney and liver and electrolytes checked, there will always be a blood sugar checked on there. And so it can be helpful to fast for your blood work and that way you can know what your fasting blood sugar is. If you're seeing it's going up up above the 120’s, above the 130’s, then you really should let your doctor know because the prednisone could be affecting your blood sugars.

Dr. Lipman: Prednisone can also increase the risk for weight gain and sometimes people feel just more puffy or fluid filled. It's important to surround yourself with healthy options at home. So healthy snacks can be really helpful and monitor your weight and let your doctor know if you're gaining a significant amount of weight that you think is more just puffiness and water weight.

Dr. Lipman: Heart health is always something else important that we need to check in on. So by knowing your health history, it's important to know do you have a history of high blood pressure? Do you take any medications for high blood pressure? So those are things including some of our beta blocker medications like metoprolol, carvedilol, some of our ACE and ARB medications like losartan or lisinopril, and so amlodipine. Those are some other medications you might see on your medication list. Check to make sure that you understand why you're taking every medicine that's on your medication list. And then when you go to your routine doctor's visits, keep an eye on your blood pressure and if you've noticed that it's going upwards, it's

important to have a blood pressure cuff at home So you can check in on that and let your doctor know if you're seeing high or elevated readings generally above 130 over 80.And then if you have any underlying heart health issues. This is something also that we should check in on before starting significant doses of steroids. So that includes issues with heart rhythms such as atrial fibrillation or heart artery disease if you've ever had a heart catheterization or a placement of a stent in the heart. And any abnormal testing that you've had in the past, maybe a stress test or calcium score. These are good things to have on your agenda when you're talking about your risks for heart disease related to steroid exposure.

Dr. Lipman: Okay, bone health. So this is one that I think is so, so important and we can do such a good job by doing prevention. So all patients receiving steroids should be taking calcium and vitamin D, No matter how long you're going to take the steroids for. It's really important because we know steroids affect bone formation and turnover. They do this by inhibiting bone forming cells and those are called osteoblasts and that leads to decreased bone formation. And this happens within the first three months of steroid therapy, but it peaks around month six. So even if you're only going to be on the steroid for a couple months, it's still really important to think about your bone health. The other effects include impaired bone repair and increased bone resorption, meaning loss of the bone. So the American College of Rheumatology recommends everyone takes 1500 milligrams of calcium and 800 to a 1000 units of vitamin D each day when you're on steroids. All patients should have a DEXA scan either before treatment during treatment, but this is going to let you know about your individual risk. Specifically women above the age of 65 should have a baseline DEXA scan anyway. So a DEXA scan looks at how strong your bones are, but if you have significant or even intermittent steroid exposure, it's a really good idea to get this DEXA scan to see if you are being affected by steroid exposure. There are other therapies that we can add on to help improve your bone strength and prevent fracture in the future. Here's a review that looked at why we use calcium and vitamin D, and it does improve and decrease the risk of weakening of the bones while on steroids.

Dr. Lipman: Eye health is another important factor to think about. So stay up to date with your eye health screenings and if you can't think of when your last time you had your eyes examined, it might be a good time to go and do that. Steroids can increase your risk of cataracts. Now, I'm sure there might be some folks in the audience who've had cataracts regardless of steroid exposure, but it can increase the risk of getting cataracts and speed up their development, making it more likely that you'll need an intervention to help with them. Also, if someone has an underlying diagnosis of glaucoma or an eye pressure issue, it's really important to both tell your dermatologist and your eye doctor that you're going to be taking steroids because we can know that steroids really can affect the eye pressures and may change your glaucoma treatment. For patients who have ocular cicatrical pemphigoid, which is a subset of our mucus membrane population, the discussion of whether steroids are the right decision really should be a partnership between their eye doctor and their dermatologist when deciding what's going to be the best therapy for me.

Dr. Lipman: Okay, I also received a wonderful question about how do I get off of steroids? How

do I taper off of them? How quickly can I do it? What should I do if I miss doses? And the big thing we worry about is this problem called adrenal insufficiency. So as we discussed at the beginning, our adrenal glands create cortisol and they create about 7 to 10 milligrams worth of steroids per day. But if we take steroids for months and months, we kind of tell our adrenal glands, okay, time to take a vacation because I'm getting my steroid elsewhere. So when we are getting off of steroids, we have to give our adrenal glands some time to wake up to do their job. And if we don't give them time to wake up and do their job and we go straight from high dose steroids to nothing, people can feel pretty ill and that's called adrenal insufficiency. So the symptoms of that are having low blood nausea, vomiting, fatigue, just really feeling quite unwell, muscle pain. And so that's why it's so important that we slowly give yourself time to let your adrenal glands wake back up and do their job. And so this will be guided by your response, but essentially your dermatologist should be guiding you on this taper. For some patients, we taper by, when we're getting to lower doses I even taper very slowly by a milligram every month to allow your adrenal gland to wake back up. But at higher doses we might go down by 5 or 10 milligrams per week. It really depends on your individual circumstances. So definitely a question to ask your doctor. Who's at risk for this? Well, if you've been on high dose steroids and that means more than 20 milligrams for more than four weeks, then there is a risk. And so we shouldn't just turn them on and off really quickly after it's been about four weeks on steroids. Another good thing to know is it's never safe to change your own steroid dose without talking about it with your doctor because we want to prevent things like this. If you miss a dose, it's usually okay just to take the next dose as scheduled. You can even take it later that day. However, you might have some trouble sleeping that night if you take it later in the day. So not so much a risk if you miss one dose, but it's if you go from a 100 to zero all at once and we don't account for it.

Dr. Lipman: So now that I've thoroughly scared you all about all the potential bad sides of steroids, I know you're probably thinking, well, can I get around steroids? Is there anything else I can do? And one thing we can think about is are there ways that we can use topicals instead of oral steroids? So this was a really great study in a pretty foundational one by Dr. Joly's group in France back in 2002. They looked at a group of bullous pemphigoid patients and they had patients who had moderate bullous pemphigoid and then severe bullous pemphigoid, and they divide severe as having more than ten blisters in the previous three days. So that's a lot of blistering. And of these patients, they divided them into two groups. And the first group got traditional therapy with oral prednisone at 1 milligram per kilogram per day. So that's for 150 pound person, somewhere around 70 milligrams of prednisone to start with. Then they looked at the same group of severity and they said, well what happens if instead of giving you oral prednisone, we gave you topical clobetasol, which is a very high potency topical steroid. They had them use 40 grams, so a pretty medium-sized tube per day. They found that a year later, those patients had fewer complications, had better survival, and had fairly similar disease control. So we can use topical steroids to help reduce the amount of oral steroid you need. That's a really good thing. So if your doctor's offering you topicals, think about, okay, how can I use this tool to help me reduce this other part of my medication treatment?

Dr. Lipman: I like to say that prednisone is not all of your therapy, right? It's not the entire bridge going from sickness to health, but it's part of your therapy. It might get us started and the reason

why as in the beginning we talked about that steroids work quickly and they act on a broad function of the immune system. So if you are having severe pemphigus and you're not able to swallow and you're not able to eat appropriately, that's an emergency we need to treat really quickly. So prednisone can help us while we wait for some of our other medications, the steroid-sparing agents to get time to work up in your system. Some of these steroid-sparing agents you may have heard of before are things like rituximab for pemphigus or mycophenolate, Azathioprine, Dupixent, which is very newly approved for bullous pemphigoid. Yay. So prednisone can help us to get to the other therapies.

Dr. Lipman: My goal when I prescribe steroids is I want to use the lowest effective dose for the shortest period of time needed to help us. So what have we learned about steroids today? They help decrease inflammation quickly and they do save lives, but they have serious side effects. Infectious side effects, heart health, bone health, metabolic risks like diabetes, mental health side effects, eye health side effects. And the best thing to do is to be proactive, to stay up to date with your screenings with your primary care doctor. To know and be familiar with your health history, to know what medicines you take and why you take them and to discuss your symptoms you're concerned about with your doctor.

Dr. Lipman: Everything in our treatments are always about balancing risks and benefits, and when we use steroids, we feel like the risk of the side effects may not be as high as the risk of untreated disease, but that's always a balance that changes. And so your individual journey is one that your doctor can help you through.

Dr. Lipman: Here are a couple of references.

Dr. Lipman: I want to leave up my contact information. I am here and available and I appreciate your attention. I'm open for questions.

Becky Strong: Thank you. There are a lot of questions that have come in. The first question, Andrea is asking, do you treat patients with ocular mucous pemphigoid in Illinois?

Dr. Lipman: Yes, I do. And I have a fabulous team of ophthalmologists that I partner with and I think that is, it's such a challenging disease to treat, but it takes a team approach. So I work with a oculoplastics physician, a corneal physician, and several of my ocular pemphigoid patients also have other underlying eye diseases. So there may be even a retina specialist who's involved or sometimes even a uveitis specialist involved. So yes, we have a really wonderful group here at Northwestern and I'm happy to see any patient.

Becky Strong: Great, thank you. We have somebody else saying that they have suffered from neck disc issues and they need to take gabapentin for it. Is it okay to take prednisone and the rituximab with all of this, or are there any medicines that you shouldn't take with a steroid?

Dr. Lipman: A great question. So in that particular situation, so gabapentin, the real risks of gabapentin can be sometimes we dose it renally, so according to your kidney function. So make sure that your doctor is looking out at your kidney function, making sure it's the appropriate dose. There is no interaction with the steroid, so that's okay to take it at the same time with the

rituximab and with the prednisone, however, the risks of gabapentin in general can cause some dizziness, drowsiness, and so you want to make sure that those things, you're taking them in a safe setting so you know how you react to the medication.

Becky Strong: Great, thank you. This next one you kind of touched on during the webinar, but maybe you could discuss it a little bit more. When using a corticosteroid, does it interfere or lessen the positive effects of a semaglutide treatment for weight loss? And if so, once off the corticosteroid, should the glide return to its previous effectiveness?

Dr. Lipman: That's a wonderful question, and I can think of my initial thought, which should be, I don't think it should, but I really think I need to do a literature search on this question because it's a fabulous question because the two are kind of battling two different aspects of the endocrine system. So my thought is that you'll have the side effects of the steroid, which are maybe some fluid retention, some weight gain in that respect, but the semaglutide, oftentimes when folks are taking semaglutide, they might find that their appetite is a little bit suppressed. And so my hope is that that would not change and maybe it would reduce some of the risk factors of overeating while on steroid. But I will say that this is a great question for even a research project and I don't have a perfect answer for you. But I would say that if you are prescribed semaglutide for either diabetes, for weight loss, for any other reason, that you should talk to either your primary care doctor or your endocrinologist who you're taking it with to make sure that they feel like the dosing is correct with your concurrent steroid therapy and that likely it's for a really good reason. So not to stop the medication unless directed by one of those physicians.

Becky Strong: Great, thank you. Cecilia asks, is it okay to take an antidepressant well on treatment?

Dr. Lipman: Absolutely, a hundred percent, yes. Mental health is so important. I've once heard this statistic that one out of two people will experience anxiety or depression in their lifetime. I tend to think that's closer to one out of one person. And so absolutely, if you are taking a medication that is helping with anxiety, with depression, there is no interaction with the steroid. But it is important to let your psychiatrist, your therapist, your primary care doctor and your dermatologist know how you're doing because sometimes we need to make changes to medications while going through steroid therapy and you might need a little bit more support while on high dose steroids and maybe a little less support when on lower dose steroids.

Becky Strong: Great, thank you. Our next question is talking about oral symptoms and which medicine helps best with mucosal pemphigoid. Is it the dexamethasone or a magic mouthwash? This person says, it seems that my mouth seems to burn more with the dexamethasone, but which helps more to comfort this disease.

Dr. Lipman: That's a fabulous question as well because the two are doing two distinct things. The magic mouthwash, which can have different recipes depending on who's making the magic mouthwash, but sometimes it has lidocaine in it, sometimes it has Benadryl in it, Maylox, some various things in there. That is really symptom control. It masks the pain you're feeling, but it

doesn't treat your disease because the disease is caused by inflammation and none of those ingredients treat inflammation. So the dexamethasone is the steroid, which is calming the inflammation. However, sometimes the dexamethasone is made in such a way that it contains alcohol in it as the substrate for which it's floating in. And so in those cases, I would recommend reaching out to your dermatologist prescribing it and seeing if you can get it compounded in a different solution so it doesn't have that burning sensation when you're using it. Because like we were talking about, if we can use more topical steroids, we can hopefully avoid the need for oral steroids. And so being able to tolerate the dexamethasone or sometimes we use a triamcinolone paste in the mouth, a gel of steroid, if you can get to targeted areas, if they're closer up. It's harder when you have more things involving your soft palate or your hard palate, it's really hard to get topicals to stick there and that's where the mouth washes can really help. In that case, I'd make sure that we're doing everything to reduce the discomfort with the use of the dexamethasone, but they two have two different functions. One is for comfort and one is for treatment.

Becky Strong: Great, thank you. Kelly is asking about the side effects and the symptoms that you discussed. Do they come with just the systemic or can you experience them with topical steroids as well and which ones are the most common with the topicals?

Dr. Lipman: So the topical steroids are more directed to the location of application. So in general, you can get some similar side effects. For example, we didn't talk about it today, but systemic steroids can lead to stretch marks, they can lead to skin thinning, they can lead to easy bruising, and those are hard to avoid when you're taking oral steroids. The best thing is sun protection, but it is quite difficult to prevent that from oral or IV steroids. But for topical steroids, that is the major risk. If you repetitively applied topical steroid to the same area of skin multiple for multiple weeks on end without breaks, you could thin the skin. And so that's where generally I always recommend if you're using triamcinolone, clobetasol using the right strength on the right area of skin. So in general, no one's going to recommend that you're putting clobetasol on your eyelids because that's the thinnest skin on the body and the strongest steroid. So we want the steroid and the the body part to be a good match. And then we also want to make sure you're using it with times for breaks. In general, if I'm using triamcinolone on the arm, I might say, okay, we're going to apply it to that spot twice a day for two weeks, then take a week off. Or if I'm using it chronically on the lower legs, maybe you're using it one week on one week off. But if you're having to use a lot of topical steroids, that's where it's a good time to revisit with your dermatologist and say, you know what, is this the right medication for me? Do we need to add on additional therapies so I can use less and get less of these side effects?

Becky Strong: Great, thank you. Another question that came in is in general, how long do the side effects of steroids take once you start treatment to start showing up? And once you are off of the medicine, how long does it stay in your system?

Dr. Lipman: Okay, so it depends on the type of side effects. For example, steroids start working pretty quickly within hours of taking them. So some of the issues with mood, irritability, sleep disturbance, hunger, those can happen pretty quickly after taking steroids within that first week, you might experience some of those things. Like we talked about for bone health, some of those

changes can happen in the both first three months of therapy. In fact, bone health changes have been demonstrated in folks with severe asthma who take intermittent courses of steroids off and on. For bone health I would always recommend being proactive with bone health, but for some of the later diseases like progressive heart disease, those are silent sorts of things. Same thing with bone health. Sometimes we don't see and we don't feel those things. And so that's why the goal is to take the smallest amount of steroid for the least amount of time needed to help your disease. But these are things that need to be continued to be monitored after steroid therapy. Your bone health after steroids is also important and your cardiac health after steroids is also important for them to continue to monitor moving forward.

Becky Strong: Great, thank you. We've got a lot of questions coming in and I'm trying to scan them. Roz is asking, can prednisone cause problems with your handwriting?

Dr. Lipman: Well, so we can get muscle strength issues from prednisone, which we didn't talk too much about today. Steroid myopathy is something where for folks who've taken high dose steroids for some time, they might just feel weak and that is something to definitely report to your doctor. And also as people taper down off of steroids, some people report muscle pain and joint pain. So I would definitely report any of those symptoms to your physician. As far as handwriting specifically. So if you're having muscle weakness to the hand muscles, I could see that changing. The other thing is that we do know that there's a high incidence, and I don't know in your particular case your treatment, but we do know that sometimes for our pemphigoid family disorders, there's a higher incidence of essential tremor in that patient population. So it is possible that there could be a different reason if you didn't have a tremor prior, but maybe you developed a tremor, is that due to the prednisone? Perhaps not. There's other medications that are more likely to cause tremors, but it's hard to say in your experience as individual. So if you find that you come off of your prednisone as directed by your physician and your tremor goes away or your handwriting gets better, then I think we have our answer.

Becky Strong: Great, thank you. Sarah is asking regarding using topical clobetasol for BP, how can we help a patient apply the prescribed dose correctly to the whole body? It looks like they have a 30 gram tube that they are using.

Dr. Lipman: So this can often be very challenging, especially if the patient is having difficulty with mobility, they need someone else to help them apply it. Becky, can you repeat the beginning of the question as far as.

Becky Strong: Let me go back. I'm sorry. So they are using topical clobetasol for bullous pemphigoid and they want to help to know how much to apply of the prescribed dose correctly on the whole body.

Dr. Lipman: I see. So you want to definitely apply to areas with active blisters and redness. So those would be the areas. When I'm telling patients to use topical steroids, I'm often describing that we're not being shy about it. We're going to use a nice thick layer, not quite like you're icing a cake, but you want to have a good thick layer on your skin because we want the medicine to do its job. Sometimes if it's an area that you say, well, if I put this on and then I put on my t-shirt,

it just goes right onto my t-shirt and my clothing is a mess, you could also think about putting on a bandage and that actually increases the potency of the steroid because it kind of helps it sit in. For some of my most severe patients who have, let's say they have blisters all up and down their arms, you can apply a good thick layer of clobetasol and then a layer of saran wrap, which sounds really silly, but it actually really works to help the medications stay in place. So it really depends on how many blisters there are because you can probably just do spot treatment, but if it's getting to the point where there's really almost the full arm, the full leg, the full stomach is blistered, then you should really be applying it very liberally. And of course if there's open skin, you might not want to apply the steroid there. You might want to and always be on the lookout for signs of infection. So redness, puss, drainage, fevers and chills, that's really important too.

Becky Strong: Great. Our next question says almost 10 years ago, I had to be hospitalized for close to three weeks in a psychiatric unit due to a bad psychotic reaction while on 80 milligrams of prednisone. They were prescribed a high dosage during a severe outbreak. They haven't had an outbreak since, but they're worried about what the future holds, should they do have a flare. How would you handle another outbreak and how do I tell my doctors about this experience?

Dr. Lipman: Well, thank you for sharing this, and I think it's such an important thing that we bring to light that these severe psychiatric reactions, they do happen in about 6% of the case. So the first thing is doing exactly what you're doing, which is talking about it. And then the second thing is that, while I think the pemphigus and getting a diagnosis is so scary, but relapse for a lot of patients is also incredibly anxiety provoking. And I always like to tell my patients that we know what the diagnosis is now, we don't have to start from scratch. And if we need to treat again, we can go hopefully, and generally we know the speed at which it's going. So hopefully show up with weeks and weeks and weeks of severe issues with eating and drinking because we know what the problem is. The first sign of a blister, you tell your doctor so we can check your desmoglein levels, we can know what's happening in your body. Then have a discussion about do we restart therapy with rituximab, with a steroid-sparing agent with extensive topicals? But for your individual case, that's a goal, a risk and benefit discussion of saying, you know what, maybe we try to avoid steroids if we can. Or we start steroids at a lower dose and have really close check-ins with my psychiatrist, with my therapist, with my dermatologist so that we have a safety plan.

Becky Strong: Great, thank you. Stuart is asking about, you've talked about infection risks, so how long after you're off steroid will your infection risk return to normal?

Dr. Lipman: Great question. So I think first it depends on if you're taking any other medications that affect your immune system. So if you are off the steroid but you're still taking mycophenolate, azathioprine or rituximab, those medications have other effects to the immune system that we should think about. But if it's just the steroid, the first thing is looking at your blood work and saying, do I have signs of immune suppression? The big one I look at is the lymphocyte count and something called lymphopenia. For patients who have very suppressed lymphocytes, that tells me that they have relative immune suppression. But generally when you've been tapered off high dose steroids, and if you've been on high dose steroids for long enough to be immune suppressed, meaning more than 20 milligrams for more than four weeks,

then we're likely not going to have you go from a 100 to zero all at once. We're going to taper you down slowly. And so by the time that you are at your physiologic levels, your 10 or 5 milligrams of prednisone, I would consider you not immune suppressed if it's just the steroid.

Becky Strong: Thank you. Our next question asks how long can a person stay on minimal therapy?

Dr. Lipman: So minimal therapy, it depends on how we define it. So is minimal therapy a certain dose of steroids? So less than 7.5 milligrams of prednisone, is it topical therapy alone? In those cases, I do have some patients who they require very small doses of prednisone to prevent flareups, maybe 3 milligrams or 5 milligrams, and we work towards getting them off. But there are patients in both the pemphigus world as well as in other rheumatologic communities that do have some chronic steroid use. Those patients may require a small dose of steroids in the long term. So it is possible, but we know that the side effects at more minimal at lower dose still exist. Bone health side effects still exist when you're on low dose steroids. It's important to make sure that we choose the best medication regimen for you in the long term. And sometimes that might be talking about rituximab therapy where it has maybe risks to discuss upfront, but it gives a chance of full remission off of medications.

Becky Strong: Great, thank you so much. Brynn is asking if your eyes start to be affected while on prednisone, what type of medications are then generally used?

Dr. Lipman: So if eye pressure issues are a major problem, and that's specifically the one that I take the most seriously with eye disease as well as of course if there was any sort of infection in the eye, corneal abrasions or things like that, we'd want to know about it. But eye pressure issues would be the biggest thing because we know that uncontrolled high eye pressures in glaucoma can lead to loss of vision, and that is so important to maintain vision and independence. We would then move to some of our steroid-sparing therapies. The steroid-sparing therapies that may work the fastest depending on the condition. So if we're in the bullous pemphigoid world, well Dupixent is now approved and that's great and a lot of patients see relief within weeks of taking it so that's a great opportunity. Now of course, some of you might know that Dupixent has some side effect warnings about eye irritation. Generally that's more of a pink eye type of experience. And generally my patients who have had that, they're able to get by with just some drops, over-the-counter drops and have never had to stop the Dupixent because of that reason. So that's one option if you're in the pemphigoid world. Other things that are faster onset that could take this place of steroids, you could think about IVIg therapy that works pretty quickly and does not have any ocular toxicities for us to think about, but it'd be very individualized. So I'd say know your baseline eye history. So do you have any history of glaucoma, any history of cataracts? And then if you are having symptoms, check in, let someone know. Let your eye doctor know. Let your dermatologist know.

Becky Strong: Great, thank you. James is asking, does high dose prednisone weaken teeth?

Dr. Lipman: So that's a great question. I know that prednisone can cause dental sensitivity. I will have to check in the literature about actual dental strength. I would assume to some degree,

yes, because we do know that calcium is so important for dental formation. So I would assume yes, there could be some increased risks to the teeth, but I would need to check on that.

Great. One quick question, and this is from somebody who lives in England. They said that there is a national shortage of betamethasone 500 milligram tablets and they are using a mouthwash at the moment, and the local doctors are always prescribing betamethasone. What would be a good alternative in the case of a medication shortage?

Dr. Lipman: And this is specifically for oral rinses or for oral medication?

Becky Strong: I am not sure. They mentioned that they used it in a mouth rinse, but I don't know if they're asking for.

Dr. Lipman: So I think for rinses, what's really great about dermatology is that we come out of a very proud background of compounding medications. So we can work really closely with pharmacists to be able to create the best medication for you, even if it's not something closely on the market. So for oral rinses, I frequently use a lot of dexamethasone. That might take the place of a betamethasone. And then for oral medications, I mean we have a slew of dexamethasone, prednisone, prednisolone, all of those could be considered. And the use of topicals in the mouth, which you have to make sure you're using a safe variety of the topical in the mouth, but there are pastes that can be made for steroid, which are also good alternatives.

Becky Strong: Great, thank you. Jacqueline says that she was given clobetasol, which felt harsh to her, and she was told that she could use it everywhere, but when she used it on the scalp it really burned and she lost patches of hair. Is there a suggestion for either how to use that better so that doesn't happen, or is there something else that can be used?

Dr. Lipman: I think the first question is making sure we're using, is it cream or is it ointment? I find that for folks who have any sort of blistering disorder, I always go for ointment because cream has other additives and it can really burn. That's the first thing is check if you're using an ointment. And then the second would be to make sure that you're applying it to areas that are not, maybe the area that you're applying to has some erosion, so maybe making sure there's no concurrent infection there. Are there other soothing treatments you can add as well? For the scalp, oftentimes if it's pemphigus we're dealing with on the scalp, which is what I'm going to guess, although we see plenty of mucous membrane pemphigoid and pemphigoid blisters on the scalp too. But I see a lot of scalp disease for pemphigus, sometimes doing gentle soaks with a dilute vinegar, a very dilute, so one part vinegar like four parts water, and that can help loosen up some of the scale and sometimes that can help with some of the sensation as well.

Becky Strong: Great, thank you. Cecilia says she sees a lot of conflicting information on the internet. Should we try to boost our immune system or not when we're taking prednisone such as using herbs or food or et cetera?

Dr. Lipman: This is tough because I think one of the things that is most difficult about these autoimmune diseases are they appear out of nowhere and we always wonder, why did this happen? Is there something I could have done to prevent this? And the answer is no. Nothing

about pemphigus or pemphigoid is any patient's fault, however, are there other things that we can do to help control it? So the medications are a big part of it and staying healthy is really important. That means eating a healthful diet. So avoiding the problem foods if you can, that can help with some of the weight gain side effects because we know that prednisone is going to be rough on that aspect of treatment already. And herbal supplements, what are tricky about them is a lot of them are not regulated by the FDA, and so we don't always know what is in them and we don't know if they could have potential interactions with your medications. So if you're thinking about starting another supplement, talk to your dermatologist and just have them take a look at it and make sure, yep, this is safe to use. For example, there's been a lot of reports about certain supplements actually causing dermatomyositis. We don't want to necessarily use a supplement if we don't know about it. However, taking a multivitamin, that's certainly a fine thing to do. Taking the calcium and vitamin D, that's a great idea and definitely being as engaged and proactive, staying healthy, trying to exercise, that will help with bone health issues as well. Those are all really good things to do.

Becky Strong: Great, thank you. Our last question is what treatment is used to stop the loss of calcium when dealing with severe osteoporosis as a result of a hormonal therapy for 10 years? What would be the first line medication?

Dr. Lipman: In general, if you have known bone loss, known osteoporosis, known osteopenia, and you're going to be starting steroid therapy, sometimes we think about starting a medication like a bisphosphonate, and those have various names, zoledronic acid, this and that. They are medications that help to prevent further bone loss and help strengthen and reformat tissue and bone. If you have known osteoporosis, I highly recommend chatting with your primary care doctor or your endocrinologist because there are a number of really good options on the market now. Some are oral pills, some are infusion medications, and not all are bisphosphate. So there's a lot of different things on the market for osteoporosis now, and it'd be really important to find the one that is best for you. It's for your bones today, but it's really for your bones in the future. Our goal is to prevent fractures of the spine, fractures of the hip, things that can help you stay mobile and independent and interactive in the decades to come.

Becky Strong: Great. Well, Dr. Lipman, that hour went by so quickly and we're so thankful that you have so grateful that you joined us today and shared such great insights with us and our community. Thank you to everyone who took the time to be with us too. Before we go, I do have a few announcements. So big news. I'm thrilled to announce that the US FDA has officially approved Dupixent or Dupilumab for the treatment of adult patients with bullous pemphigoid. This is a historic moment for our community, and it didn't happen overnight. The IPPF has worked hand in hand with our partners at Sanofi and Regeneron, alongside government agencies, medical experts, and dedicated advocates to bring us to this point. But most importantly, this milestone belongs to you. Whether you've participated in a clinical trial, shared your story, supported a fellow patient, spoken out at an event, joined a support group, educated others, or simply stood by with us, your voice made this possible. Even if you don't have BP, by being part of the IPPF community, you have helped to move the needle forward for rare disease patients everywhere. The approval of Dupixent represents a new era in treatment for bullous pemphigoid, a disease that until now has not had an FDA approved treatment. This means new

hope for patients and caregivers alike. We know many of you have questions about access, eligibility, and next steps. Although Dupixent has been approved, it typically takes some time for payors and insurance companies to add a new approval for coverage. As always, the best resource for your individual situation is your treating medical team. The IPPF staff are not doctors, so we cannot make recommendations on how to treat your specific case. However, we're here to be a clearing house of information about your disease, and we will share more details about Dupixent as they become available to us. To learn more about Dupixent and its approval for BP, you can read the press releases from Sanofi and Regeneron by scanning the QR codes on your screen.

Becky Strong: When someone is diagnosed with pemphigus or pemphigoid, they often feel scared, isolated and invisible, but then they find the IPPF, and for the first time they feel seen. We find answers and we find community, and most importantly, we find hope. That hope exists because of you. Thanks to your support, we're there from day one as a trusted source of education, compassionate support, and a network of people who truly understand. We help people make sense of their diagnosis and connect them with others who walk the same path. And now we stand at a turning point. The recent FDA approval for Dupixent, for bullous, pemphigoid, and existing approval for rituximab, for pemphigus vulgaris are giving patients like you and me, new treatment options, new reasons to believe in a brighter future, but these breakthroughs only matter if patients know about them and can access them and feel empowered to advocate for the care that they deserve, and that's where you come in. Your gift helps the IPPF reach newly diagnosed people at their most vulnerable moment and connect them with life-changing peer support and education. The IPPF advocates for access to breakthrough treatments, and to remind every patient, you're not alone. You can make it possible for people like us to not just survive but thrive. So please donate today at www.pemphigus.org/donate or scan the QR code. Together, we're changing what's possible and make sure that no one faces this journey alone.

Becky Strong: I'm also excited to share that the 2025 IPPF Patient Education Conference is happening November 7th through 9th in Atlanta, Georgia. This is more than just a conference, it's a powerful weekend of learning, connecting, and community. So whether you're newly diagnosed or have been living with pemphigus and pemphigoid for years, this event is for you. You'll hear directly from world renowned experts, get practical tips you can use right away, and most importantly, connect with people who truly understand what you're going through. It's going to be an informative, inspiring, and unforgettable weekend, so please keep an eye on your inbox because registration opens soon and we can't wait to see you there. We're also looking for a photographer to help capture the magic of our upcoming event, and we could really use your help. If you or someone has a great eye for storytelling through photos and would be interested in supporting a wonderful community, please let Amethyst Yale know via email at amethyst@pemphigus.org. This is such a special time for our attendees and having someone there to document these meaningful moments would truly make a difference.

Becky Strong: Stay in the know by signing up for our email list. You'll get exclusive updates on this year's patient conference, upcoming webinars like today's and the latest news in the pemphigus and pemphigoid community. It's the best way to stay connected, ensure you never

miss out on important resources and updates. Joining is quick and easy, just scan the QR code or visit www.pemphigus.org or click join our email list at the top of the page. Then enter your information in the popup box. Sign up today to make sure that you're part of the conversation.

Becky Strong: Have you had a chance to explore the IPPF's patient resource page? If not, now is the perfect time. Whether you've just been diagnosed or are seeking trusted guidance on treating pemphigus and pemphigoid, our guide to pemphigus and pemphigoid is an essential resource. It's filled with medically reviewed answers, practical tips and expert insights to help you navigate your journey with confidence. We've made the guide available in multiple language so it's accessible to as many people as possible. In addition to the guide, our patient resource page offers a wide range of educational materials to support you. We hope these resources empower you with the knowledge you need to live more comfortably and to talk to your doctor about pemphigus or pemphigoid. Visit the patient resource page today and explore all the information we have offer. A healthier future starts here.

Becky Strong: Are you looking for a doctor who understands pemphigus or pemphigoid? Well, be sure to check out the IPPF find a Doctor Directory. This easy to use tool allows you to search for doctors in your area or anywhere in the world who the IPPF believes are experienced with our rare diseases. It's a great starting place and you can filter your search using a variety of criteria to help you find the right doctor for you. We are also excited to announce that we added a section for you to help keep our directory up to date. You'll be able to notify us of if any of your doctor's information has changed. Plus we've added some tips and tricks to help guide you in finding the right doctor who's the perfect fit for you. Just scan the QR code or visit our website to get started.

Becky Strong: Do you want to help doctors and researchers gain a deeper understanding of pemphigus and pemphigoid? Are you hoping for more effective and FDA approved treatments? We'll join the Natural History Study today. Sponsored by NORD and the FDA, this patient registry helps to keep your information private and secure. Your participation will drive research forward, improved treatment option, and bring us one step closer to a cure. Share your journey and make a lasting impact on everyone affected by these diseases. Get involved today by visiting www.pemphigus.iamrare.org to join.

Becky Strong: Also, researchers at the Yale University of Medicine and Yale School of Public Health are seeking volunteers for a research study examining the psychological and social consequences of having an autoimmune blistering disease. Your experience matters. This anonymous survey will help advance our knowledge of the impact of living with pemphigus and pemphigoid. Visit the website on the screen or scan the QR code to participate in the survey.

Becky Strong: The IPPF has support groups nationwide. If you'd like to join a meeting, please visit our event page and then use the link on the calendar to register. We're also looking to expand our network, so if you're interested in starting a support group in your area, please contact me, Becky Strong at becky@pemphigus.org. It's easier than you think and a great way to help others find the peer support they need. To thank you again to everyone that joined us

today. A recording of today's presentation along with a survey will be sent out after the webinar. Goodbye.