

Becky: Welcome everyone. This call is now being recorded. I would like to thank you for being on the call with us this morning. Our speaker today is Dr Joel Laudenbach, associate professor of oral medicine at Atrium Health in Charlotte, North Carolina. Thank you for joining us today. The call will focus on treatment of oral pemphigus and pemphigoid. So first let me introduce you to our speaker. Dr. Joel Rodenbach received his DMD from the University of Pennsylvania School of Dental Medicine in 1998. Dr. Laudenbach completed his post doctoral residency in general practice at Cedar Sinai Medical Center in Los Angeles and oral medicine at the University of Pennsylvania. He also completed a fellowship in geriatric dentistry at the University of Pennsylvania. In April of 2018 Dr Lautenbach was appointed to Atrium health as an associate professor of oral medicine and attending medical staff in the department of oral medicine in Charlotte, North Carolina. He practices oral medicine at the Carolina Center for oral health, is a diplomat of the American board of oral medicine and is attending a faculty at the Carolinas Medical Center for oral medicine and general practice residency postgraduate programs. Dr. Laudenbach is also a speaker, expert witness consultant and published author. Dr. Laudenbach provides educational courses to dental, medical and health care professionals, societies, study clubs and postgraduate training programs locally, nationally, and internationally. So now it is my pleasure to introduce Dr. Laudenbach to answer your questions about treatments for oral pemphigus and pemphigoid. Dr. Laudenbach, welcome.

Dr. Laudenbach: Thank you very much Becky. Thanks everyone for joining on the call today.

Becky: Great, did you just want to hop right in and start answering some questions from our community?

Dr. Laudenbach: Yeah, certainly. I think we've got a lot of great questions submitted and I know time is short. There'll probably be some add on so yeah, let's go right to it. I don't know if you want to choose from a list or something that can go from there.

Becky: Great, so Judy asks, "What do you recommend as an oral rinse to control the pain of oral lesions from pemphigus vulgaris?"

Dr. Laudenbach: Okay. One thing I've learned over the years is, asking my own patients what works best. And then I pass that along to my future patients as well so, very good question. Controlling the pain of oral lesions from really pemphigus or pemphigoid can involve various strategies. So there's the old fashioned rinse for the mouth and numbing medication, something like viscous Lidocaine. I've learned that not, and that's usually the medicine that's similar to what we applied before we give a dental injection, or like over the counter and abissol, but prescription strength. There can be times where patients, a lot of patients come back and tell me, yeah, that was great. Swishing with it was not great, but dabbing it on to specific areas was more helpful. And then occasionally I have the patient that says, yeah, it feels really strange for my whole mouth to be numb or I don't like it. So that's one strategy. When you use one medicine as opposed to a combo, or a compounded rinse I find that at least we know which medicines helpful. So viscous Lidocaine. Another one is a compounded rinse MBX, Maalox, Benadryl, liquid viscous Lidocaine. And so, that can be mixed up at the pharmacy depending on what state you're in. Some states very finicky about having pharmacists mix anything and others have no

problem. So with Maalox, Benadryl and Lidocaine mixed together, those are usually pretty benign and the pharmacist can mix them and those are not active treatments for the condition. So if you use them, at least as a provider, I know that you're not treating with a steroid or, or something else. And then those topicals, of course they're more options. But topicals combined with a systemic pain medicine together can actually help control the pain. So not just topicals, but analgesics that you might take for a headache or joint pain or prescription strengths. Pain medicine, like an Ibuprofen, Tylenol, something like that.

Becky: Great. And just a question that I have, I can, the medicine that you mentioned for pain can use before and after I dental treatment for rinse or is there something else that you would prefer?

Dr. Laudенbach: Okay, great question. And just to clarify, so you mean, can we use these right before we treat with a topical medicine in the mouth, right, like a topical steroids?

Becky: Even before a dental treatment for dental cleanings.

Dr. Laudенbach: Okay. Got it. Yeah, so certainly before a dental procedures you could use these medicines to help you get through the appointment and they're only going to last, um between a 15 to 30 minute kind of max time frame. But it is something that will, you know, be helpful. And we try not to repeat these too frequently in terms of being close together. So we usually say every three hours, up to about five times a day. We don't want too much absorption of it. But yeah, before a procedure, you know, and, or after would be another way to help.

Becky: Great. Thank you. Our next question says, "I was diagnosed, on 10/7, I have been on steroids, which I am tapering off of and I'm on 50 milligrams of Imuran a day, five milligrams of steroids a day and Fluconazol 200 milligrams on Monday and Friday. The Fluconazole so is for the candidiasis on my tongue, but I can't seem to get better. Is there anything else I can do? I do a swish and spit of equal part Maalox and Benadryl twice a day."

Dr. Laudенbach: Okay. And so this is a good question and it's a complex question. So I'm not really clear on the diagnosis for this patient. But certainly taking Imuran, steroids and an antifungal medicine, Fluconazole, twice weekly it sounds like this patient is struggling with a recurring yeast infection on the tongue and really can't seem to get it better. And so yeah, in all those medicines, the one that really is a treatment for a yeast infection in the mouth is Fluconazole and all the other medicines, Imuran, steroids, those actually put you at risk or a yeast infection. So this is a balancing act here. The Maalox and Benadryl are just handling discomfort. So, there are a lot of reasons why someone can struggle with a yeast infection that keeps coming back. Sometimes it's the other medicines that affect the immune system like steroids and Imuran but it's also important to look in the mouth and see how dry the patient is. So if you don't have much saliva in your mouth, that in and of itself is a risk factor for yeast or thrush and we can treat a yeast infection in the mouth effectively. But if the patient continues to have dry mouth, a yeast infection can come right back. So part of management isn't just medication like Fluconazole or other antifungal medicines, but it's also making sure that if there is dryness to try and help increase saliva flow which helps protect against future yeast infections. Another thing as a dentist I

will look for is, does the patient wear a night guard or a retainer or a denture plate? And yeast love to live on oral appliances. And so if you keep wearing an appliance but you do not disinfect it, that itself, the appliance can be a recurring source for yeast infections to keep coming back. So we have the patients soak the dentures in an antifungal solution while we treat them pretty aggressively the first time around for an active yeast infection and then put them on preventive Fluconazole and very good salivary stimulating protocol.

Becky: Great. Just a couple of follow up questions to what you said. And, I'm not holding you to any specific number, but would you say it's common to get a yeast infection when you're on treatment like steroids and Imuran when you're using more systemic medicine? Is it more common than not, or is it still pretty rare?

Dr. Laudenschlager: I would say it is more common than rare. And so, every patient's different. You can imagine if someone had really good salivary flow, was otherwise pretty healthy, not taking many other medications, and didn't use any appliance, it would be probably uncommon to get a yeast infection. Not surprising, but it would be less common. And then the flip side where it would be more common. Imagine somebody also has asthma, uses an inhaler, has a denture plate and their mouth's very dry taking antidepressant medicines. That person, I would say okay, that that would be more common and not surprising that that person got a yeast infection.

Becky: Great. And you mentioned disinfecting dental appliances on a regular basis. How often should that maintenance be done? Is it a daily thing or is it a weekly, to deep clean it?

Dr. Laudenschlager: Great question. In terms of actively disinfecting an appliance or a denture plate, there are daily sort of denture cleansers that are available over the counter for, you know, routine cleaning. But separate from that is when, what I was just talking about in the context of an active thrush or oral yeast infection, then you would want to actually have the patients soak the appliances in a fresh prescription solution, Chlorhexidine is a common one, which is a rinse usually used for Gingivitis. A fresh solution of that prescription Chlorhexidine, 30 minutes a day on a daily basis while you're actively treating the yeast infection, which is usually about two or three weeks. So we wouldn't want to disinfect an appliance with the prescription Chlorhexidine all the time. It can cause staining and whatnot on the appliances. But there's the daily management and then there's, when you would use the prescription solution.

Becky: Great, thank you. Since we're talking about thrush and yeast, can you describe how differently that thrush and yeast would present in the mouth? Compared to a pemphigus or pemphigoid lesion or sore?

Dr. Laudenschlager: Certainly. So, the presentation of yeast or thrush in the mouth versus pemphigoid or pemphigus, it can be challenging because a lot of these conditions do look very similar, but in general, and realize there are several different kinds of a yeast infection in the mouth. They don't all look like little white plaques or white patches that just rub off and a coated tongue. There are sometimes when yeast or thrush infection looks like just redness, red patches on the mouth. And obviously red patches

in the mouth, pemphigus or pemphigoid, those can all look the same. Okay. So I'm in any event in general, the thrush infections more commonly have white patches that rub off and that's pretty diagnostics. And then the patient's usually describing some symptoms all of a sudden getting a dry mouth, bad taste and a coating on the tongue. Compare that with a pemphigus or pemphigoid patient, when those patients, we look in examine and usually when you rub on the gum tissue or the mucosa, we can actually cause a blister of the outer layers of the tissue or cause it to peel right off. And that's very different. So over the years you do get used to being able to tell that difference as a provider. I'm sure people familiar with that sign, it's the Nikolsky sign, where we take a cotton swab, we rub it along either the gum tissue or part of the mucosa and the mouth and we can actually cause a blister or peeling of the outer tissue. And right there, yeast and thrush doesn't do that. Very different.

Becky: Our next question says, "I've been on prednisone, since the last 40 or 50 days, but I'm down to 20 milligrams a day now with little to no symptoms. Could I get away with no systemic immunosuppressants?"

Dr. Laudenschlager: Okay, this is a great question I get often. So this patient's been on prednisone for 40, 50 days. Not really sure what the diagnosis is here, but the patient says they're down to 20 milligrams a day with little or no symptoms. Could I get away with no prednisone essentially? Right. Okay. So this really highlights the multidisciplinary care of patients. You know, here I am as the dentist, I'm not usually managing, you know, pemphigus or pemphigoid with systemic medicine that often, and especially not prednisone over 40, 50 days and choosing how to taper a patient down because certainly there's the science and the art of it. And this is a really the dermatologist and the Immunodermatologist specialty more so than mine. In my area with symptoms in the mouth and lesions in the mouth, there's a certain amount that we can do with topicals. So topical steroids, whether they're swishes or gels. We can also inject lesions with steroids to help get control. We can make trays, soft pliable trays that fit over the teeth and hold steroid gels onto the gums so that it gets absorbed. And then there are other medicines we can try. So we often work in connection, real closely with the dermatologist specialists so that we can see, okay, can this patient try and continue to taper down from 20 and go off the medicine, so to speak? Well, that's really a dermatologist question. Then the question becomes, well, what can I do to help the patient, if and when symptoms or lesions start up again in the mouth. And so we have to coordinate that real closely together. The other thing to keep in mind is when we have this affecting the gum tissue, all of the plaque that builds up with or without pemphigoid or pemphigus, plaque and our on our teeth causes our gums to be inflamed and red. But if you have a condition, pemphigoid or pemphigus, you have another reason for redness or inflammation of the gum tissue. So part of this coordination, is not just with me managing topical medicines is with you and your dentist, making sure that you're having good frequent dental visits to keep plaque from accumulating on the teeth. You have good home care. We have topical medicines and then the dermatologist, maybe they are able to start tapering down further to see what happens. But this is one of those that really depends and it's multidisciplinary.

Becky: Great, thank you. I think it's a followup question. Nina asked, "If I need to start on immunosuppressants, how long will I need to be on them?"

Dr. Laudенbach: Yeah, that's a great question. And I'm not sure if this is a clarification question about systemic immunosuppressants or the topicals. I come at this from the mostly topical management perspective. So I'll speak to, you know, patients who ask me often. So does that mean I'm going to have to swish with a steroid rinse every day for the rest of my life? Or am I going to have to apply a gel and the answer is it really depends for that patient and for the disease process and the specialist who's treating them systemically. So there are some cases where dermatology can push something into remission and if that happens, then we're really doing surveillance and making sure that home care, plaque build up, professional cleanings kind of keeping all that real nice and tight, more frequent than the rest of the world, you know, more than just twice a year. So that if and when, God forbid this starts to recur or flare up, we kind of get it early and get those medicines back on board. If the, the multidisciplinary group cannot push something into remission, then we're left with continuous management and that can be continuous topical management as well.

Becky: Great. I think a follow up question, George asks, "How many times a year should I visited a dentist? But he asked, is it best to skip appointments when my mouth is really sore and I have lesions or is it best to actually go and see the dentist then?"

Dr. Laudенbach: Right. So, yeah, this old question, how many times a year and should you skip appointments? Well, I have to tell you after having gone to the annual meeting, the IPPF annual patient conference and working more with other specialists on the medical side, you know, there are times I understand from the medical side where patients have been told I don't want you going to the dentist for, and then they'll say, well, I was told one year, two years or, I mean, it does vary and I really hadn't heard that before. So, as I continue to get more clinical experience and work closer with experts over the years, I realize more and more, each patient's different. It needs to be tailored to you as the patient. Patients who don't have these conditions, sometimes they'll get a lot of buildup on their teeth quickly. So anyone who knows either someone or they know themselves, Oh yeah, I get tartar or calculus, calcified plaque build ups quickly or more quickly than the average person. Well, you can imagine if that's you and then you add pemphigoid. Okay, you're most likely, if we want this pemphigoid inflammation to be knocked down. We cannot have you walking around with calculus or tartar build up on your teeth, for six months straight. We want you at least every three months. And some patients in the beginning where we really want to get this under control, I'll tell them, look, I know it sounds odd to go to the dentist every two months for a cleaning, but have you talked to a gum specialist or a periodontist? There are some patients with gum disease that need to come in for cleanings more often than four times a year, three times a year. So it really is tailored to the patient. And there may be times where your physician doesn't want you to have dental cleanings and I don't always understand on the medical side when that is, it seems like it's in a pemphigus patient during the first initial management. But again, it's important to have a multidisciplinary group where everyone's communicating on the same page and you know, tailor it to you.

Becky: Great, thank you. We've had a few questions come in so I'm going to kind of lump these kind of together. Is gum scaling and appropriate treatment for pemphigus or pemphigoid?

Dr. Laudенbach: Okay, good question. Now as a treatment for the diseases themselves, right, so let's just clarify and make sure we're all on the same page here. The question would be, should you go to the dentist or hygienist to have a gum scaling, which is a cleaning below the gum line, to treat pemphigus or pemphigoid. And so that treatment, a deep cleaning is not going to treat the condition. The condition itself is autoimmune. The body is attacking the skin layers of the mouth, the lining and it's in two or a couple of different ways, but in any event, so that inflammation, the lesions in the mouth, that's really autoimmune. Your body is kind of attacking that area. And so the gum treatments are not gonna get rid of your body attacking those areas, but it is going to help manage the amount of inflammation, redness, gingivitis, or the response that your gums have since the gum tissue is affected by the disease. So, it's another strategy to help decrease things that trigger inflammation. And so, you know, you would be prescribed a medicine, whether it's by pill, infusion or a topical to help manage and treat the condition. But a deep scaling really is more of trying to manage the inflammation but not treat the condition. So hopefully that answers or clarifies.

Becky: No, that really does. Thank you so much for that.

Dr. Laudенbach: One other thing that I should say that gum scaling does do, whether you have pemphigoid, pemphigus or you have neither is it helps with gum disease. And so that may be stating the obvious, but it's important for everyone on the call to know, maybe you've never heard. You've gone to the dentist, you've had cleanings, and then all of a sudden they say, hey, you need a deep cleaning. Well, when you start having trouble with early gum disease, it's difficult for you as the patient and for the hygienist to clean very much below the gum line. And so usually when you start having early gum disease problems, the first treatment they're gonna do, and that is a true treatment is a deep cleaning to help treat your gum disease or bone loss.

Becky: Thank you. Do you think it's okay that when a patient is having no lesions to have like the deep cleaning of their gums done or should they just avoid that unless it's really necessary? I get a lot of questions at the foundation on this. So this is more for my knowledge.

Dr. Laudенbach: Yeah, and so that's a great question too. So, um, so patients not having active lesions in the mouth, should the patient have a deep cleaning? And so we've just spoke about how gum disease can occur in patients and gum disease is bone loss around teeth. If you start losing bone that holds your teeth in, the next steps are your teeth can get loose, you lose more bone, more gum disease and teeth get even more loose and then unfortunately they either fall out or we have to remove them or you get infections. And so preventing or stopping that process. Often the first treatment I just mentioned is this deep cleaning. And so just because you have a condition like pemphigoid or pemphigus, it doesn't mean you can't get gum disease. And if you do start getting some gum disease areas, maybe it's not the whole mouth, maybe just the upper right. You have a couple of teeth. All you need is a crown or a tooth not to be fitting next to a couple of teeth properly. You get food packed in there, you can't clean it. All of a sudden you have a little gum disease between a couple of teeth. Well, normally we would have a deep cleaning of that area and try and improve it so it doesn't keep happening because we wouldn't want you to get more build up around the teeth and have them get loose and of course eventually have to come out. So that's scenario

can still happen. So even if you don't have active lesions in the mouth, it's important to still get your teeth and gums check, have them measured for the pocketing or checked for gum disease, which is measuring around the teeth. And then if there is one or two or a couple of areas that I, how I just described, they're kind of breaking down and you're starting to get bone loss, which has come disease, you would still need probably a deep cleaning in that area, but you don't have any active pemphigoid or pemphigus lesions. I would still work with the medical team to make sure that this is still a good time to go ahead and have the deep scaling. As I've come to learn over the years, there are some points in treatment that the physician does not want. I think, my understanding is some antibodies or something can be triggered them. I think it was Dr Grando, I'm sure some of his patients have told me and he and I spoke briefly before. This is a good question Becky. Maybe on the medical side we should save for our future medical call, when one of the physicians is on. When that time frame is so I can learn better and all of us can. So usually I would check in with the physician who's the quarterback on managing medically. And then you also want to make sure, I tell all patients, I want you to go to the dental office that has a good respect for these conditions because the last thing that you want, and a lot of patients I've seen them come in, they say, I go to the dentist or the hygienist and they either don't clean because it's going to be bleeding too much or they don't want to cause trouble. Or they don't care and they just go in and start stirring up and tearing tissue. And so you're really, sometimes I'll say, look, you can blame it on me, tell the hygienist and then I'll write out exactly what I'd like them to do or what not to do. Or I'll pick up the phone I've called and I said, look, this patient's coming in next week. They have this condition. Make sure they know what it means, not every practice as many patients with these conditions. So you know, you could be seated in the dental chair and you could be the pemphigoid or pemphigus patients that they see maybe one or two a year. And so they're just ready for their next appointment at the top of the hour and so they need to slow down and make sure they know how to help you. So you have to be your own advocate there. That's real important.

Becky: Great. That's some really great advice. I'm going to move on to our next question. Carol says, my dentist recently did a biopsy and diagnosed me with pemphigoid and is treating me with Clobetasol. How do I know when is try time to try other medications?

Dr. Laudenschlager: This is a good question. So it's great the dentist did a biopsy, we got a diagnosis. Any folks here who know how challenging that is, that those are all important steps. And then here's a medicine that really the strongest, one of the strongest topical gels that we can use. Clobetasol and here are the patients already talking about when is it, when do I know it's time to try other medicines? So it's really important that, since the question has to do with pemphigoid, you want to make sure that all patients get an opportunity to meet with a physician specialist to see if that patient wants to explore stronger systemic medicines to try and push something into remission. Or if that patient just gets educated on their options, the risks from the physician side, and then if they choose to really only get topical medicine, you know, it's only affecting the mouth. There's been a full medical workup and the patients aware of the other medical options, but really just wants to have followup care and topical treatment. Then in my world, we're trying Clobetasol gel, a patient comes to me, they've been using Clobetasol, the first thing I'll ask as well, is it an ointment or in a gel? If it hasn't been in a gel formulation, gel is absorbed much better than ointments. So I might switch them to something that gets absorbed better. Medication trays are one way to hold the medicine right onto the gum tissue. So I'll

find out if they used Clobetasol gel in a tray. They may not want to do it, but these are things that will help me decide, should we move on from Clobetasol. And then the other questions I'll ask if lesions are on the inner cheeks or on the tongue or other areas, I'll ask, how have you applied it? Have you just rubbed it with a q-tip, your finger or have you actually taken it and put the Clobetasol onto something like a gauze pad and then laid the gauze pad with the gel right onto the area, treat it for five or 10 minutes, twice, three times a day. And how long? So I'm going to try and max out how much I can find out from the patient how they've tried to use it. The other thing is how long have they been using it? It is well known that topical steroids at some point lose their effectiveness and it doesn't mean they'll never work again. But it's known that at some point when they use it long enough, it's possible that you have to stop that one and try a different one. So we'll kind of assess the patient for all those perspectives and then it might be time, we'll decide it's time to try a different medicine. So it's a complicated question but that's usually when I'll make a determination if we should try something else. Also insurance, right? How much something costs. Sometimes it's clear that we should try something different when the pharmacy says that's going to be \$300.

Becky: Oh, that's great. That's a lot of great information there. Our next question comes from Janet and she says, my dentist told me I need to have an implant done. When is it safe to do so? Is it okay to do when I have lesions?

Dr. Laudenschlager: Okay. And this brings up, I wouldn't say a common question but it is a question that we've had at your presentations I think in San Francisco last year. The year or year before we got this question. So dental implants have a certain success rates. For those that don't know, a dental implant is now possible in the mouth. So if you lost a tooth and you have enough bone remaining, it is possible to place a titanium little post into the jaw bone. And so it goes into the jaw bone and it actually integrates with the bone first and then of course you need the gum tissues surrounding it to basically be happy sitting next to this titanium post and crown. And so with the gum tissue, when we have a setup where there's enough gum tissue, we have enough bone and then we look and this patient would benefit from getting a dental implant but there happens to be a pemphigoid lesion sitting right there. What do we do? And less common would be pemphigus. But over the years I've had oral surgeons or periodontists try and help with these patients. We try and ideally get the tissue as controlled as possible before you do any sort of surgical procedure. Even if you're going to forget an implant, go have the gum tissue specialists clean out an area, debrided the gum tissue. Ideally we'd like to get the pemphigoid tissue under best control possible using the topical medicines or whatever we can to get it as healthy as possible. And then once that happens, putting an implant in, again, you need the bone to react well and then you need the gum tissue around it to adapt. The success rate on implants is these days in the 90 to 95% range. So success is defined a lot of different ways. I think from the patient's standpoint, you would agree, if it can stay in there, you can put a crown on it, a cap and use it without a problem, that's success. Having an implant be successful, that's really hard because we don't have a lot of data on it, but we try and set up the tissue so that it has the best chance of healing. And that occurs when the lesions in the area are well controlled. But a success rate of 90 to 95% still means that we have failure. So implants can fail in someone who doesn't have these conditions. I think you can gather that having the conditions probably decreases that success rate.

We just don't have good numbers on that right now. So, it's kind of like root canals that anyone who knows about having a root canal or the inside of a tooth that's infected, kind of cleaned out and sealed off, those are very predictable, here's a high success rate. But you've probably heard of people having root canals that failed and they had to do them again or lose a tooth and implants are kind of at that same point, now. They're pretty predictable, especially if you have enough bone and the gums are healthy around there. But there, there are plenty of people that have had some failures and that's still within 90 to 95% success rate.

Becky: Great. My follow up question to that is do cavities follow the same rules like where you would want to have as much disease in the area under control or can you get a cavity with active lesions in the area or cavities?

Dr. Laudenschlager: Yeah, great question. And um, this is more of something that would be common, right? I mean, we all, I'll admit it, having had a cavity here and there. Right. When would be the best time to treat that cavity? If your lesions are active or if you're under control? And one of the problems with waiting on a cavity is that as we wait it is possible for those to get worse. Whether it's just more the tooth breaks down or if it gets worse and causes infection and then becomes an abscess or real trouble acute type of thing. So there's only so much time you want to wait on treating cavities. So an implant is usually more of an elective procedure, cavities of course still elective. You can wait and do absolutely nothing but, so we don't want to wait too long on cavities. So there's probably a certain amount of reasonable time a couple of weeks to try and get some particular area under control where you're going to treat it. The dentist is gonna want that area, let's say it's pemphigoid and the gums are really red and inflamed, but you have a cavity right at the gum line. Well if they go ahead and remove the cavity and put a filling in there and it bleeds a lot and they can't keep it dry, well that filling's going to fail earlier rather than later. So we don't want to wait too long on treating cavities. You could even have a temporary filling put in so that you have some time. You can stop the cavity now with a temporary filling, take several weeks or two months to get the gums under control before you put something more permanent, like a final cap or crown where you're investing a lot more time, money and you want it to obviously not only be successful but being long term successful. So you could stage it a little bit.

Becky: Great, thank you. Our next question asks, How do pemphigus and pemphigoid differ in the mouth? Is it possible to have both diseases in your mouth? And how do I know if I do?

Dr. Laudenschlager: Well, I'll tell you this is a great question that highlights, especially for me as the provider, some of the benefits I've had from participating with the foundation. I didn't meet someone who had, I hadn't really come across patients with pemphigus and pemphigoid until going to the meeting, the annual patient meetings. So, I know firsthand that that's possible, to have both conditions. And, here's that question. How do you know if you have both? But first let's answer how do they differ when they're in the mouth? And that's a tough one. But pemphigus, the tissue on the outside, outermost layer of the tissue or lining of the mouth with pemphigus peels so easily and just a touch easier than pemphigoid. And part of the disease processes are different whether the body is causing inflammation in pemphigus right at the top outer layer, where pemphigoid is just a little bit lower. So it's a very subtle difference. I wouldn't expect the patient to notice as much. But things that patient might

tell you are different is getting blisters. Sometimes there's a little bit more of blistering in a pemphigoid type of finding whereas a pemphigus tissues kind of scraping off or sloughing off cause it's affecting the outer tissues. So those are some subtle differences that I look at. Certainly my understanding is, and I haven't had patients in my practice with both. I have other patients that have one of these conditions and we suspect there's another condition. Canker sores, lichen planus something else. And of course we've talked about yeast, right? Or thrush. So the question about how do you know if you have both? The diagnosis, with surgical biopsies are really the way. And that's really the starter. There's often doing the biopsies, both a regular old fashioned sample I call it. And then a second one we call it immunofluorescence. And those together, those even can be difficult because these tissues peels so much. Once we get those first and biopsies, we work with a physician specialist to help with the medical diagnosis. There are blood tests that can be ordered, to really hone in on which of the conditions this patient has to help make that diagnosis of, you know, either one or both or something else.

Becky: Great, our next question says, my dentist gave me Clobetasol and told me dissolve a piece size amount in half ounce of water and told me to swish with this. Is this the right way to be getting Clobetasol on my lesions or is there a better way?

Dr. Laudenbach: Okay, great question. This question highlights the how to, how do we get topical medicines absorbed into the tissues in the mouth? And that's a challenge. There's no doubt about it. And each one of us is different. You can imagine if someone's mouth was really dry, then it might be easy to take some medicine, a gel, put it on a gauze pad and lay it right on a sore spot. And since the mouth is so dry that gauze pads gonna stick right there and hold it. And someone who has a lot of saliva, you try the same thing and within minutes the gauze pads very wet, it's starting to move around and whatever gel was there is pretty quickly washed away. And then there's everyone in between. So there are different strategies to try and get absorption. I am less familiar with this type of strategy, telling someone to take a gel and then mixing it on their own in water and then swishing with it. That to me is a less predictable way to treat somebody. So doesn't mean it doesn't work. We all have our sort of, there's an art and science to what we all do. And so this may be just a strategy that I'm not familiar with. But if I'm gonna try and prescribe absorption of medicine via a rinse, then there are some standardized rinses, like a steroid dexamethasone solution. So that's more of a predictable way to go ahead and get someone some absorption of that medicine. If I use something like Clobetasol gel, trying to get the Gel absorbed right into the spot that has a lesion, there are two strategies that I'm familiar with. One is to take gauze pads, little squares, fold them up once, maybe twice, put a good thick amount of gel on the gauze pad and then put the Gel side of that Gauze, pad the Gel right onto the lesion and Tuck it in there and let it sit for about five, or ten minutes. Once you're done, you take the gauze pad, you throw it away, try not to eat or drink for about a half hour. No rinses, no brushing, just trying to let whatever gel was in that area, in the mouth to continue to just finished with absorption and then do that, you know, twice or three times a day. The other strategies are some people use cotton rolls, which are in dentistry, that little cotton cylinders. And you can kind of dampen them and squeeze out some water, put some gel on those and put those kind of in the folds of the mouth and those kind of fit in there. Some patients like those. And then if you are going to prescribe a steroid rinse, I usually have the patient swish up to about three minutes. Kind of do their best with that, trying to get as much absorption in the mouth and then spit out and try not to eat or drink for about a half hour. So those are some strategies.

Becky: Great. Our last question comes from Linda and she asks, “how do you heal the ulcers on your tongue and why is it that your tongue becomes painful at times but you don't see any lesions on it?”

Dr. Laudenbach: Okay, good question. Question about how do you heal ulcers on the tongue? And this could be an age old question here, right? Whatever kind of lesions you have the tongue is an area that if you're going to try and get absorption, I had just mentioned the strategy of using a gauze pad to hold the gel right where it needs to be. So my first response would be, well to heal an ulcer on your tongue, you would want to try and use that strategy. If the gauze pad is not effective there's also doing something like an injectable steroid on the tongue since that's a pretty readily available site. And so injecting some steroid can be helpful. And then, um, you know, why does the tongue become painful at times, but you don't see any lesions on it? You can't see all the way back and underneath the tongue. So a good clinical exam is really going to be helpful. You could be having some symptoms on the tongue, not see much and have a low grade yeast infection. You could have pain on the tongue and there's no lesions on it, but your mouth's real dry. It's a tongue gets dried out, it can become sore and painful. And I have to tell you there's a long differential diagnosis on tongue pain when there are no lesions. So that's something that would be worked up separately to make sure that you don't have any other sort of causes for like a burning tongue or something like that.

Becky: Well, great. Thank you Dr. Laudenbach. That was a really quick hour for, as you provided us with a lot of great information. So I just want to say thank you for being on the call with us today. It was extremely educational and thank you so much for all that you do for our community. I'd also like to give a huge thank you to everyone who is on the call with us today joining in and listening in and a big thank you to Genentech and to Celgene for helping to make today's call possible. To wrap things up, I just have a few announcements. To let everybody know we need your help. We only have two days left to raise money for the IPPF new awareness program. This program stresses the importance of a biopsy when diagnosing pemphigus and pemphigoid to help accelerate diagnosis time, go online today and help us reach our goal to raise \$15,000. You can make a difference in the lives of pemphigus and pemphigoid patients and their families by helping us spread awareness and accelerating diagnosis times. Your tax deductible donation will support our biopsy saves lives campaign that will educate and encourage dental professionals to consider a biopsy sooner in order to diagnose faster.

If you've not already registered, please register for the IPPF natural history study. The IPPF Natural History study is a patient registry sponsored by the National Organization for Rare Disorders (NORD) and the US Food and Drug Administration (FDA). You can register today at www.pemphigus.iamrare.org. This online data system collects, stores, and retrieves patient data for analysis in research studies. The more data we can collect, the better the information we can give to researchers, the sooner they can find better treatments, earlier diagnosis, and one day – **A CURE!**

The IPPF is also pleased to announce the date and place of the 2019 IPPF Annual Patient Education Conference. The 2019 conference will take place in Philadelphia from October 11-13th. This is our 25th year as an organization and we hope that you will join us this year for an educational and fun weekend

in the city of brotherly love! More registration details to come in the next few months. Mark your calendars, We hope to see you there!

Our next Patient Education Call will be on Monday, July 8th. We will be having a question and answer session with the IPPF's Peer Health Coaches. This is a great time to have your questions answered from a person who knows exactly what you are dealing with. Registration details for the July call will be on our website.

Lastly, If you have a question that didn't get answered on the call, or have additional questions please e-mail out to me, Becky, at becky@pemphigus.org, or call me at (916) 922-1298 x:105, and I would be more than happy to help. This call recording will be sent out with the survey following this call. Thank you everyone.

Dr. Laudенbach: Goodbye. Thank you. Bye Bye.