

December 10th, 2021 Oral Health and Care Patient Education Webinar

Amethyst: Welcome everyone to our Oral Health and Care Patient Education Webinar. This call is now being recorded. I'd like to thank you all for being on the call with us today and to our sponsors, Genentech, Principia Biopharma, a Sanofi Company, argenx, and Cabaletta Bio for making today's call possible. "Information is a key factor in treating and living with any condition. However, every patient's situation is unique. The IPPF reminds you that any information found on the internet or during presentations, should be discussed with your own health care team or doctor to determine if it applies to your specific situation." Before we begin, I would like to take a quick poll to see how many of you on the call have an oral care specialist involved in your treatment currently, or while you are being treated for your condition. I'm going ahead and launching that poll for you and you should see it pop up on your screen. And while taking that, I would like to introduce our speakers for this afternoon. Dr. Tanya Gibson, is a tenured Associate Professor at the University of Missouri Kansas City School of Dentistry. She graduated from Meharry Medical College School of Dentistry in 2001 and completed her residency in Oral and Maxillofacial Pathology at Long Island Jewish Medical Center in 2004. She is a Fellow of the American Academy of Oral and Maxillofacial Pathology and a Diplomate of the American Board of Oral and Maxillofacial Pathology. Dr. Gibson is an ad hoc reviewer for Triple O and Head and Neck Pathology and has published a number of manuscripts in peer reviewed journals. She maintains an active practice in diagnostic surgical and clinical oral pathology and provides oral and maxillofacial pathology continuing education programs on a local, regional and national level.

Dr. Rashidah Wiley is currently a dental instructor at the Carrington College Dental Hygiene Program and clinician at Lifelong Pinole Health Center. Dr. Wiley attended college at California State University, Sacramento where she majored in Biology. Dr. Wiley attended dental school at Meharry Medical College in Nashville, TN then completed a one-year Advanced Education in General Dentistry at Shasta Community Health in Redding, CA. She completed her oral pathology residency at New York Presbyterian in Queens in 2015 and continued on to work as an Assisting Clinical Professor at the University of New England and an Assisting Professor at the University of Kentucky. Dr. Wiley enjoys treating and providing dental education to practitioners and the greater community. Thank you both for being on the call with us today.

Amethyst: I'm going to go ahead and quickly share our results. So it looks about 50/ 50 split here, so a good amount of you have not used an Oral Care Specialist in the treatment of your disease. So today, we have these great speakers with us who are going to educate us about what they do and how oral care specialists can also be a great part of your treatment. So, before we get started, I would like to go over a few housekeeping rules... (Reviews

Housekeeping information). Now it is my pleasure to introduce Dr. Tanya Gibson and Dr. Rashida Wiley to present to you information about Oral Health and Care for pemphigus and pemphigoid and answer your questions. And I will go ahead and turn it over to you Dr. Wiley.

Dr. Wiley: So we would like to thank everybody for coming to hear our presentation today, and we hope that you'll learn a lot. I'm just going to share the screen. We will be discussing the oral health care regimen in patients with pemphigus and pemphigoid. Some of the things that we want to consider when we discuss the health of this particular group is the status of the disease process, so whether a patient has active disease, or whether the disease is in remission. Because we know that for those who have active disease, daily home care can be a little bit more of a challenge and sometimes may be ignored, just depending on what stage of the disease process you're in. We also want to consider whether a patient has their full dentition or whether they are partially missing teeth. Unfortunately if oral health care is not maintained over time, patients are more likely to get cavities, periodontal disease and unfortunately, in the long run tooth loss. For those who have completely lost their teeth, we need to discuss the ability for patients to be able to wear dentures and whether those dentures will be the conventional removable dentures that you can take in and take out or whether these patients can use implants to help retain those dentures.

Dr. Wiley: Here we can see a patient in this photo. You can see that the gingival tissue is very red. This is what we call disjunctive gingivitis and you can imagine with a patient like this, brushing their teeth, flossing, and even using mouth rinses can be very uncomfortable. So this is at a point where patients may decide to not brush and unfortunately, if they don't have a provider that they can seek help with, this can lead to further dental disease. When we talk about home care, this is what you as an individual can do at home to help prevent cavities, prevent periodontal disease and eventual tooth loss. Not only that, but also having immaculate home care will also help with the control of ulcerative conditions. So when we think about home care, one of the first things we're going to talk about is brushing. When patients can brush, you want to make sure that you're using a soft or an extra soft toothbrush. Many patients, some that I've actually talked with believe that using a hard toothbrush will kind of help with getting the plaque off the teeth but in reality, it's really causing more damage, not only to the tooth structure, but to the gum tissue in itself, and especially for someone who has an ulcerative condition. You really want to make sure that you're having a soft or extra soft brush. Also with the technique, a lot of patients like to kind of do the back and forth, sawing technique. What you really want to do is make sure that you're actually holding the toothbrush at about a 45 degree angle and just gently rubbing against the gum tissue as well as the teeth. There's actually a nice little video that you can check out on YouTube that will help you learn how to do that. That way you're making sure that you're cleaning your teeth and you're not doing further damage. Also, when you consider what type of toothpaste you want to use,

you really want to stay away from things that have very bold taste and very bold flavors and also things that tend to be abrasive. A lot of toothpastes that are on the market have sodium lauryl sulfate, which is a chemical that can kind of help with cleansing the teeth and whitening. But for anybody who has an ulcerative condition, it can actually make the problem worse. So you may want to consider using a toothpaste that's meant for children, something that's a little bit less abrasive. Anything that has mint or a strong flavor you also want to avoid. So maybe using more bland toothpaste. Then also, you want to make sure that the toothpaste that you're using is fluoridated, because that's going to help with decreasing the risk of cavities and making your teeth stronger. For those patients, where toothpaste may just be a little bit too abrasive, especially if you have an active condition, you might want to consider using a mixture of baking soda and water. It will be a little bit more comfortable and it still helps make sure that the teeth are nice and clean.

Dr. Wiley: These are just some examples of different types of toothpaste that you may want to use from brand names. I just mentioned children's toothpaste and also very natural, different types of toothpaste that are going to be very mild and very sensitive on gingival tissue. When we talk about home care, we like to have patients who can floss. Flossing is going to be very important in helping to keep the surfaces in-between the teeth clean as well as kind of helping to massage the gums and stimulate them and keep them healthy. However, during periods of active disease, flossing may be a little bit hard. So, for these patients you may want to wait for the disease processes to calm down a little bit and then get back to flossing. But, whenever you can, you want to make sure that you're making flossing part of your normal daily health care regimen. Also, using a Waterpik to kind of help clean between the teeth and remove large areas of plaque and build-up and debris but just be mindful of the pressure. So with the Waterpik you have different settings, all the way from the lowest to the highest. You want to make sure that you're using more of the low setting so that way you're not creating blisters or if you already have blisters, you're not making them worse. You can also use different types of mouth rinse. So anything that's antiseptic, meaning that it's cleaning up the bacteria that's in your mouth. Chlorhexidine can be a good one, however it does contain alcohol, so it's one that you don't want to use for long periods of time so use for maybe shorter stints of time until you can get the periodontal health back in control. Once again, just like the toothpaste you want to make sure that the rinse that you are using at home has more of a mild flavor. Something that's not going to irritate the gingival tissues or cause the disease process to become active.

Dr. Wiley: There were actually quite a few questions about magic mouthwash. It's a palliative mouth rinse that can be used to make it a little bit more comfortable for patients to not only be able to do their oral health care but also when it comes to eating. There's various different types of ingredients that you can find in magic mouthwash. Some dentists like to use all of

these different ingredients where some will just use a few. But most of the time in mouthwash, you're going to have some type of magnesium hydroxide which is going to help coat the tissues. You may have an antihistamine, then an antifungal, usually Nystatin, and different types of antibiotics. Then, in addition to that you may also have corticosteroids, especially for our pemphigus and pemphigoid patients, to try to kind of help manage some of the ulcers. In addition to that, many different types of magic mouthwash contain a viscous lidocaine, which is an anesthetic that can once again coat and numb those tissues, so that way it makes it a little bit easier to get through the day, eating, brushing, all those kind of things. And then also topical gels can also be used to help with comfort with brushing.

Dr. Wiley: Another very important thing that a lot of patients have a question about when it comes to pemphigus and pemphigoid is the diet and oral health. We all know that our diet plays a big role in how our teeth and gingiva, how healthy they are. So for us, we really want to make sure that patients maintain a healthy mouth. You're not eating diets that are high in sugar and other types of carbohydrates because we really want to decrease the risk of getting cavities. In addition to that, unfortunately, poor diet and poor oral health can lead to flare ups with ulcerative conditions. So, we really want to make sure that we're having a healthy diet. This usually includes things like cheese, nuts, fish, fresh fruits, and vegetables, which kind of has a little asterisk by it because, some of the things like citrus fruits and nuts can be very hard to eat when patients are having a flare-up. So, definitely, things like oranges and even in some patients I've heard things like grapes can be a little bit irritating to the soft tissues. For instance, if you have a patient who comes in like this, where you can see that there's ulcers all over the border of the tongue, you can imagine that eating anything that has citrus in it or something that's crunchy like nuts or crackers can really cause a lot of disturbance and a lot of pain. For these patients, we usually suggest that there are certain foods that you kind of want to avoid, especially if you're having a flare up. For any patient, anything with a high amount of carbohydrates and sugars, you really want to decrease the amount that you're eating of that, because you don't want those sugars to sit on your teeth, leading to cavities and causing other issues. Also carbonated beverages, soda's can be really painful, really disturbing, and can actually lead to ulceration in the oral cavity. Highly acidic snacks and drinks go along with the carbonated beverages. You really want to avoid those types of substances, citrus fruits, really spicy, heavily seasoned food, especially a lot of things with tomato paste and a lot of different seasonings. During a flare up, you may want to have a little bit more of a bland diet, lots of smoothies with other healthy types of products. So that way, you're still getting the nutrients you need but you're not causing any disturbance at the oral cavity.

Dr. Wiley: Here's just a picture that I like that shows when you're drinking carbonated drinks like sodas, they're very acidic, almost the same acidity that you can see in a car battery. So if you can imagine what this type of acid would do to your mouth, sodas and drinks like that are

not too far off. You really want to drink more things like water that are going to be a little bit more neutral and a little bit more comfortable to the oral cavity and overall more healthy for you.

Dr. Wiley: When it comes to dental care, the best thing that you can do is to really have a good relationship with your dentist and other dental professionals. So if you're seeing a dental hygienist, you want to make sure that they have a good idea of what's going on with your oral cavity, what state you're in, and when is the best time to be seen. Also, how long those appointments should be. You might need multiple appointments to clean the oral cavity, especially if you're having a flare up. Also, one thing that I really want to impress upon is really having good interprofessional relationships between your dental team, as well as your other healthcare providers. So that way we're all kind in the same place, we know what's going on with the patient. Hopefully, we're communicating with one another as far as what medications the patient is on, when they need to be seen, so that way we make sure the patient is getting the best care. So, communication is really going to be key. Making sure that we're communicating amongst each other as professionals and we're also keeping open communication with the patient. Essentially, the patient is going to be the center. You're the person that we want to take care of and make sure that you're okay and we're all going to communicate with each other and communicate with you. Whether that be your basic medical doctor, a primary care physician, your specialist, your general dentist, your hygienist, and then also other oral health care specialists that you may be seeing. So like I said, once again, we really want to create a team and have open communication, and make sure the patient is at optimal health.

Dr. Wiley: During this period, it is important to keep maintaining your regularly scheduled dental visit. You really want to make sure that you're seeing your dentist every six months. You're still going to the hygienist. Those appointments may change how they look. So as I mentioned before, you may have to go on more frequent visits to help with plaque control. So maybe instead of going to the dentist every six months, you may go every 3 to 4 months. It may take more appointments to clean the entire oral cavity because for some patients, especially if they're having active disease, there may be a lot of bleeding and discomfort when you're going to the dentist. So, if you could have a shorter appointment and then come back later when things are a little bit under control. Express that to your health care professionals, so that way you guys are all on the same page and they're doing what's best for you, as far as making sure that your mouth is still clean, but at the same time, trying to keep you as comfortable as possible. For some patients, they may need to increase their immunosuppressive therapy prior to dental visits so that way the disease process is a little bit more under control and you decrease the risk of trauma or ulceration to the tissue. In some cases, you can have patients who can wear these little plastic silicone coverings that contain

different types of gels and topical corticosteroids that you can wear prior to your visit. So that way the tissues can kind of be a little bit more under control and not as much in an ulcerative state before going to get dental treatment.

Dr. Wiley: For patients who wear dentures, whether that's fully or partially, you may have to wear partial dentures or complete dentures. One of the main keys for patients who are in this state is that you really want to make sure that you have good control of disease prior to starting the denture process. Just getting a denture by itself, in the average patient can take a long period of time. But, if you have a patient who has pemphigus or pemphigoid and the disease is active, going through the process of taking impressions, trying dentures or trying teeth can be really traumatizing to the tissues and may even take a little bit longer. So the better the control of disease, the shorter and better this process will be. Also, if you do happen to have flare ups during this period of time, whether it's during the fabrication of the denture, or after the dentures have already actually been delivered to the patient, you really want to talk to your doctors about different types of medications that you can use to try to get the flare ups a little bit more managed so that way that dentures fitting a little bit more comfortably and you're not getting tearing of the tissue as you're taking that denture in and out. When you can, you want to make sure that you leave any type of removable prosthesis, whether that be a full complete denture or partial denture out during active disease periods. I know for a lot of people, they really don't like being seen without their dentures in but that's what's really going to allow that tissue to heal. In addition to that, you're a dental professional should be sure to make adjustments that need to be made. So if there's any areas that are rubbing or causing pain, be sure to communicate that to your dental professional so that it can be fixed right away. In some cases the denture may actually need to be realigned, meaning that they need to maybe go and take some new impressions, add a little bit more material, or take away a little bit more material to make that denture a little bit more comfortable.

Dr. Wiley: We can see with this patient right here, this is a patient who is wearing, more than likely is wearing a complete denture, but you can imagine when you're in a state like this, where you have an active ulcer, this is very hard. So this is definitely a moment for this patient, where you should communicate with your dental professionals to try to get this disease process under control and then also leave your denture out as long as you possibly can until the ulcerations and areas of redness have cleared up.

Dr. Wiley: Another option for patients who wear dentures would be instead of having the removable dentures that you take in and out, are having implant-retained dentures. So actually have an implant placed, then have the denture adjust it to fit over the implants, so that way you're not having to take it in and take it out and causing so much friction to the tissues. Many clinicians actually prefer this because you're not having to take it in and out but once

again very much similar to the conventional denture, you really want to make sure that the disease process is under control prior to starting the process of placing the implants and fabricating the denture. One thing that's important to know about implants is that they have to become integrated into the bone once they're placed in order for them to be successful and last. If this process doesn't happen, unfortunately those implants are more likely to fail, cause infection, and maybe cause more damage to the tissues. So for this process of osseointegration to happen, you really need to be careful of the amount of plaque retention that the patient has. So if there's a lot of plaque and a lot of bacteria, it can cause an infection and really doesn't allow the implants to integrate the way they should. Also, some of the medications that are used for patients who have pemphigus and pemphigoid, for those who are using corticosteroids, corticosteroids can affect the bones in the body as well as in the oral cavity. Long term use can sometimes make the bone a little bit more weak and that can affect osseointegration as well. Once again, this is why we really want to have that team. You want to talk to your physicians as well as your dentist before having this process done, so that way they are able to make sure that you as a patient are a good candidate for either the implant-retained dentures or conventional dentures, and what are the different options that you may have?

Dr. Wiley: So on our end as dental professionals, it's best that we, for those of us who may not be familiar with pemphigus and pemphigoid, to really educate ourselves about that by attending meetings like this and any types of courses that we can go to to make sure that we have the knowledge to help our patients. Once your patient is in the office and you're actually doing treatment, you really, really want to be careful in how we manipulate the soft tissue. So, once again, being very gentle. Having extra gauze just in case the patient starts to get a little bit of bleeding. Making sure that we schedule enough time to really take our time and go slowly and then also, making sure that we have time to maybe do additional appointments for patients that may need it. Very important, you want to make sure that the soft tissues are lubricated because sometimes as you're getting dental treatment done, you can have that mouth open wide for a long period of time and unfortunately sometimes that can cause the lips and things to be dry and that's really not good. So we want to make sure that we have our patients properly lubricated before doing procedures. Prescriptions of fluoride are going to be very important. So once again, making sure that those teeth get the fluoride they need to be nice and strong. For a patient who may have active disease where they're not brushing as often, fluoride is really going to help keep those teeth nice and strong and free of decay. In some cases, there may need to be a prescription for chlorhexidine for periodontal health, but this once again is something that you want to use for only short periods of time because it does contain alcohol and it can cause staining of the teeth. So use this for a short period of time and then, when possible, brushing and flossing and using other types of mouth rinse to help maintain the oral health. For those who are wearing dentures, whether they be complete dentures, implant-retained dentures or partial dentures, going to quarterly recall visits so that

way, they make sure that the dentures are still fitting okay, it's not causing any disruption to the tissues, and if the patient does have active disease, coming together as a team to figure out how we can manage that disease so that way those dentures are fitting comfortably.

Dr. Wiley: For those who are looking for specialists that can help patients with pemphigus or pemphigoid, one of the sites that you may want to check out is the American Academy of Oral and Maxillofacial Pathology. There's actually a section for patients where you can go and find an oral pathologist, someone who can help you learn a little bit more and help with the control of your disease process.

Dr. Wiley: These are just some of the resources that I used for this. and I would like to thank you guys for listening to this presentation and we are more than happy to answer your questions.

Amethyst: Wonderful. Thank you, that was a great presentation. I know I learned a lot. We've had a lot of questions come in so I'm going to just start jumping right into those. We had a few questions come in about this prior to the webinar. Amy asked, how important is it that my dentist is familiar with pemphigus vulgaris? If it is important, how do I find a dentist that will help me? They've called several and they never heard of that condition.

Dr. Gibson: I think it's very important for your dental care provider to be aware of pemphigus and pemphigoid because it helps them to aid, to help them better to treat you. To find a dentist who's actually familiar with pemphigus and pemphigoid, there's not a resource that I know of that you can go to but I would continue to just call around to find someone who knows about pemphigus and pemphigoid. It's something that was taught in dental school, but they just may not have the experience and so it's something that's a little bit more removed from them.

Amethyst: Great, thank you. The IPPF does have the doctor referral list as well and those are doctors that have either been recommended to the IPPF from patients who are currently seeing the doctors, which both of you are on the list. We also have not only the dermatologist, but the oral specialists as well on the list. So, that's a great tool. Of course we don't have someone for everybody in every city, but we're always looking to grow the list. So, if you are seeing a specialist right now or a dentist that's familiar with the condition and not listed on the map, we ask that you recommend them to the foundation. We'd like to reach out to them and see if they'd be willing to join. Thank you. On the same lines, Tiffany said she was just diagnosed with PV and has pretty extensive oral disease. She's afraid to see her dentist but knows that she needs to. How should she educate her dentist about the disease if they aren't familiar with the condition?

Dr. Gibson: Well she should definitely see her dentist, and I think having that open, honest dialog with them to let them know things that make you comfortable and things that make you uncomfortable when they're examining your mouth. I think that's important for them to hear that. It's going to be painful if you have open sores. It's just a part of it, but if your dentist would take the care and the time to be gentle with you and to examine you so that way to minimize your discomfort. It's not going to be able to be avoided and you must go see the dentist, that's an absolute because it's just going to have a snowball effect of one problem leading to another problem.

Amethyst: Great, thank you. Ginelle asks while we're on these slides, Dr. Wiley, do you mind putting up the slide with the references backup?

Dr. Wiley: Sure, let's see.

Amethyst: Perfect. Thank you. Somebody asks, and I know you've covered a little bit about this, but topical treatments are used to treat oral pemphigus?

Dr. Wiley: Usually with pemphigus, I would say for me, I like to use more of the stronger steroids topical rinses or topical gels. Although, depending on where the patient is, like if they have more expansive oral disease, I think usually with that group we would go systemic. Where sometimes with patients with pemphigoid I am more likely to try topical medications than more so with the pemphigus patients because usually with them a lot of clinicians like to do systemic treatment. Then once it's a little bit more under control, then maybe Clobetasol for a short period of time, either as a rinse or a topical gel.

Amethyst: Great, thank you. Maureen asked, is a Dexamethasone elixir 0.5 milligrams per milliliter suggested as a swish and spit treatment?

Dr. Gibson: It can be. Some prescribe it as a swish and spit and others prescribe it as a swish and swallow. Both ways are effective.

Amethyst: Great, thank you. Benita just wrote in and asked, who is best to handle and manage these diseases? Is the oral pathologist the primary caregiver to manage the prescriptions for the illness? She's been trying to manage with a dermatologist without success.

Dr. Gibson: Where are the lesions located? If it's just in the oral cavity then maybe, the oral pathologist. If it's the oral cavity and also the skin, probably a combined approach would be the best. So it depends on your extent of the disease.

Amethyst: Great, thank you. Dr. Wiley, I know you had mentioned the website for the Oral and Maxillofacial Pathologists. Is there a location there to find an oral specialist on the website?

Dr. Wiley: Yes, I believe if you go to the website and you go to the section for patients they actually have a list of clinicians and where they're located.

Amethyst: Great. Thank you. Pauline wrote in before the call and asked for sores in the mouth and on the tongue, what can be used to clear it? She lives in Australia and at the moment, is getting Rituximab. She heard in the U.S. that we have the magic mouthwash and can you go over again what that's made of? She also said her teeth are hurting, is that

Dr. Wiley: So, these are just the different ingredients that can be seen in magic mouthwash to help with numbing, coating, and getting rid of fungal infections. Also the corticosteroids to help with the management of the ulcers. So most regiments of magic mouthwash don't necessarily have all of these products but there's different formulations that doctors will use.

Dr. Gibson: From my personal experience, I had never prescribed a patient magic mouthwash for the management for their pemphigus or pemphigoid. My strategy for treating pemphigus and pemphigoid is to prescribe a medication that is targeted for that specific disease process. With the magic mouthwash, it's kind of like grandma's soup, it has a little bit of this and a little bit of that in it and we throw it out at you. So, I prefer to use a medicine that is going to be effective in treating the pemphigus or pemphigoid directly.

Dr. Wiley: I think sometimes you can tend to see that with patients who may have seen other dental professionals they will prescribe magic mouthwash.

Amethyst: Real quick, Robina wrote in and asked can you explain why the antihistamine is important in the magic mouthwash?

Dr. Wiley: For me to be honest, I'm not really sure. Personally, in the few cases, not pemphigus or pemphigoid patients, where I have prescribed magic mouthwash, I don't usually tend to put an antihistamine in my mixture, but I have seen it in other mixtures before.

Dr. Gibson: Again, I don't prescribe magic mouthwash, but my guess would be, if they think that maybe the oral condition that they're seeing is some type of allergic or hypersensitivity reaction. Maybe the antihistamine will help decrease that reaction, but that would just be my best guess.

Amethyst: Great. Thank you. Can the magic mouthwash swishes that you prescribed be made at the normal pharmacy? Or do they have to get them at specialty pharmacy?

Dr. Wiley: So for those who prescribe it, you can get it at most of your like CVS or Walgreens. It has to be a prescription from an oral health care or medical healthcare professional. It's not something that you can buy over the counter.

Amethyst: Great, thank you. Augustine wrote in and said that they recently had a deep cleaning of all of their teeth. They're curious if the deep cleaning actually strengthens the gums or weakens them with the condition?

Dr. Gibson: The deep cleaning, what that would do is help decrease the inflammation that's in the gum tissue and if we can decrease the inflammation that's in the gum tissue, when I do my follow up for my patients, I know that the redness that I'm seeing is a manifestation of the pemphigus or pemphigoid. If they have what I think is active disease and they have lots of plaque, calculus buildup, I don't know if that redness is the manifestation of a disease or from them having those irritants. So having a good cleaning done, it just helps me in my clinical follow up of the patient so I can know whether or not the treatment that I'm prescribing has been effective.

Amethyst: Great, thank you. Somebody wrote in and said that their gums are receding from the disease. What can they and their dentist do to prevent further recession?

Dr. Gibson: So I would question as to whether or not your gums are receding as an effect of the pemphigus or pemphigoid or do you have periodontal disease in addition to the pemphigus or pemphigoid?

Dr. Wiley: Like I mentioned in my lecture, if you have patients who unfortunately have active disease and they may not really want a brush, floss, that leads to periodontal disease, which further complicates the pemphigus or pemphigoid that you have. Patients think, this is just the disease that's causing this, but it's a little bit more complicated.

Amethyst: Great. Thank you. Going back to some of the oral maintenance that people can do at home. Catherine said that she uses an oral B electric toothbrush. I know you talked about the different kinds of toothbrushes to use. But do you think that toothbrush is a good idea?

Dr. Wiley: For me, I think definitely making sure that it's a soft bristle but also for me, I would think if you have active disease, I don't know if this has been research, but for me I would personally think that just the vibration and depending on how strong the vibration is, it might cause a little bit more harm. So I think it's a good idea to use it, but maybe when the disease state is a little bit more controlled, just to prevent any further damage to the soft tissues.

Amethyst: Great, Thank you. Sharon just wrote in and said that she needs to have a crown pulled sometime next month. Her dentist has researched PV, and is very good with working with her, and she goes for cleanings every three months. Is there anything that she should specifically know or the dentists should know prior to pulling the crown? She currently takes prednisone and Cellcept and she sees a dermatologist at Wake Forest.

Dr. Gibson: So she's having a crown removed or she's having a crown place?

Amethyst: It looks like she said she's having it pulled.

Dr. Gibson: So if she is having it removed, I'm going to assume that she's going to get a new crown to replace it. I think that will probably be best, if possible, to have the area in which the crown sits on the tooth to be above the gingiva. I would probably try to keep it away from the gum line, if possible. Now it also depends on the location of the tooth, whether or not it's an esthetic area. It also depends on the structural integrity of the remaining natural tooth structure, whether that can be something that can be accomplished.

Amethyst: Great, thank you. Neville also wrote in and says that from past experiences he's noticed that some antibiotic seemed to be a catalyst for flaring up his pemphigus. However, he needs dental surgery to remove a wisdom tooth because it's infected. He wants to know if

there's any specific antibiotics that you would recommend, and if you've ever seen anybody who's had reactions to the antibiotics causing worsening of their disease.

Dr. Gibson: I have not had that clinical experience.

Dr. Wiley: Neither have I but I guess this would be one of those cases where I'm not sure how long he's been seeing the dentist that's going to be doing the procedure but maybe having that discussion and mentioning the ones where he's felt that he's had flare ups in the past and seeing if they can come together to get a prescription that might be a little bit more safe and not cause as many issues.

Amethyst: Great, thank you. Darmesta says they have PV and pretty extensive activity on her gums. She found a dentist to go to who is not very familiar with the disease. They told the dentist that they are using a CPAP at night and the dentist told them that it damages the gums so they would like them to have a dental plate, but the dentist is not sure whether to make a plastic or a rubber one. He thinks that plastic might be too strong so he'd like to know your thoughts.

Dr. Gibson: That's a hard one. The problem that a person runs into is that if something is contacting the mouth and is causing any type of friction or rubbing that can make current sores worse for the patient or it can induce more sores to pop up. With that being said, if you do have any appliance made for the mouth, you want to make sure that it fits comfortably and that it doesn't rub on any areas to cause sores to form.

Amethyst: Great. Thank you. Nancy asked, can PV actually affect the enamel of your teeth?

Dr. Gibson: No.

Amethyst: Great, thank you. Mindy says that she has MMP and her gums have been receding, especially where she has a capped molar. One of her eye teeth actually has an exposed root. Is there anything that you recommend to remedy this?

Dr. Gibson: It's hard to answer that question without seeing the case clinically and also seeing the radiograph for the tooth or the root. If it's something that's exposed to the oral cavity, meaning that when you open your mouth you can see it, it's probably a good idea to

have that removed because that could be an entryway for infection and that I just complicate things down the line. You just have to be aware that when you go through the trauma of having a tooth surgically removed that can cause you to have a flare up, particularly in that area. You'll just have to go through the process of getting that disease back under control again. But if you have a tooth root communicating with the oral cavity, that's not a good thing. That could be a source of infection.

Amethyst: Great, thank you. Jeanie asks, are salt water rinses helpful?

Dr. Wiley: I think it more so depends on where you are with your disease state. I don't think that they are super helpful but maybe more so like a comfort. But I think really, as Dr. Gibson said, you really want to try to use a medication that's really targeting the disease process.

Amethyst: Great, thank you. We are getting a lot of questions about rinses. Paul just wrote, How long is it safe to use dexamethasone as a mouth rinse?

Dr. Gibson: If I'm using a topical steroid, I tend to keep the patients on that topical steroid until I get disease control, assuming that type of medication is working for the patient. So if I'm seeing an improvement using topical steroids, I would keep them on that medication until the sores have resolved. Then I would take them off the medication and only have them to re-use it again in an instance of a flare up. I've had patients who've been on topical steroids for an extended period of time and I have not seen any adverse effects but with that in mind I do understand that the steroid can cause thinning of the mucosa so I only keep the patients on it for the amount of time that is absolutely necessary.

Amethyst: Great, thank you. We have a question about being on steroids and bone density. What dose of prednisone is considered dangerous to have dental work and can bone density scans help determine if asked if there's any osteoporosis in the jaw?

Dr. Gibson: So there's not a magic number as to what dosage prednisone would be considered dangerous. It's going to be patient specific and the effects of steroids also be patient specific. A bone density scan can allow the provider to analyze the bone density of the jaw bones as well as the bones of the body. But a long term side effect of prolonged systemic steroids is decreased bone density.

Amethyst: So if a patient is on prednisone or any drug that causes a decrease in the bone density, how often should they be getting the scans?

Dr. Gibson: I'm not sure about that question. I don't keep patients on high dose steroids for an extended period of time, so I have not had to order bone scans to check the density of the patients bone. So I'm not sure about that question.

Amethyst: Okay, thank you. At what point do you feel that a topical treatment maybe isn't working and a patient might need to discuss stronger medication or maybe even a systemic treatment with you or their other primary health care provider?

Dr. Gibson: So when I first see a patient who was diagnosed with pemphigus or pemphigoid my routine is to see them in one month. That way I'm able to assess whether or not we're getting any improvement from the medication and whether or not the patient is compliant with the recommended regimen. If the patient is being compliant and I'm not seeing any improvement in a month, I may give it maybe another month or two, to see whether or not I get any improvement. If not, then I will change courses and try something else.

Amethyst: Great, thank you. Is that the same protocol typically that you follow as well, Dr. Wiley?

Dr. Wiley: Yeah. So if you're just like Dr. Gibson said, the patient is being compliant and you're just not really seeing any change with both, but especially with pemphigus, I would probably maybe a little bit sooner suggest a systemic steroid for those patients.

Amethyst: Great. Thank you.

Dr. Gibson: It all depends on the extent of disease and how bad it is, as to how soon I will change directions.

Amethyst: Makes sense. Great, thank you. Sandra just asked again, can you clarify if using a CPAP affects the oral health of pemphigoid?

Dr. Gibson: There's no impact on the course of the disease for the pemphigoid. If your CPAP machine is such that it causes any type of friction or rubbing against your mucosa, then you know you can induce a flare up.

Amethyst: Great, thank you. Felix asks, what's the best treatment for lesions that occur on the sides of the tongue?

Dr. Gibson: I don't think it matters of the location whether it's the side of the tongue, cheeks, or the roof of the mouth, I think if it's going to respond to a medication protocol, it's going to respond to it regardless of the location. If a patient does not respond to that protocol, then you may need to switch directions.

Amethyst: What about maybe something to help with blistering on the lips? This patient, Sarah said that anything she puts on her lips seems to be sticky and pulls off the skin of the lips.

Dr. Gibson: So, if you're putting things on your lips and it's causing your skin to peel off or slough, then I wouldn't recommend putting things on your lips because whatever you're using, your body is not liking. I would recommend not doing that. If you have the need to have some type of lip balm on your lip because it's cracking and it's painful and you need something to help soothe it, I would recommend a wax based lip balm to be applied, not Vaseline or Petroleum Jelly. Something that's wax base.

Dr. Wiley: With this patient, I'm not sure if maybe she is using gels or anything like that, but I don't know if maybe in addition to using a wax based balm for a short period of time, maybe try try a rinse and you can take a 2x2 gauze and dip it in there and put it on the lips for a little bit. Then after that, before you go on about your day, then put on the lip balm.

Amethyst: Great, thank you. That's a great recommendation. Martha wrote in and said that her dentist had prescribed doxycycline to be used for 3 months, 100 milligrams twice a day for mouth flares. She's wondering if that is overkill.

Dr. Gibson: Not necessarily. The doxycycline that's helpful in helping the tissue re-epithelialize to get the skin inside your mouth to grow back so you don't have these active disease states.

Amethyst: Great, thank you. Somebody asked, have you seen tacrolimus oral solution used for MMP?

Dr. Gibson: Yes

Amethyst: Is there a typical dosage for that?

Dr. Wiley: 0.1% is what I usually use.

Amethyst: Thank you. Kelly asked, what constitutes the difference between an active state and remission? If there are any blisters at all, is that an active state?

Dr. Gibson: So what I tell my patients is that I want to reach the stage in which, when I examine you, I have no idea while you're sitting in my chair. So when I am doing my oral exam, I don't see anything whatsoever happening and that's when you are in a state of remission. I don't see any blisters, I don't see any sores, I don't see any erythema, I don't see anything that's happening. When you look normal, then it's remission. If you have anything, whatsoever then you're in an active state of disease and that's going to vary as to what level of activity that is based on the presentation.

Amethyst: Great. Thank you. This person asks, what happens when pemphigus moves just from the oral cavity to also include the scalp? They're wondering if the dexamethasone rinse has any effect on the pemphigus on this scale?

Dr. Gibson: No, because with the mouth rinse steroids, you use it as a swish and spit, so it only topically affects the area it contacts. So if you're swishing it in the mouth, it will have no effect whatsoever on your scalp. So at that point, you would need another mode of treatment.

Amethyst: Great, thank you. This person asked, what is immaculate oral health care? They said that it was mentioned in one of the slides.

Dr. Wiley: I guess when I put that, for patients who have the disease process, in order to try to decrease the disease you really want to make sure that you're brushing, flossing, and doing as much as you can to keep your oral health in check. Like I said, I know sometimes during active disease states it can be a little bit harder but really just making sure that you're paying attention. Brushing, flossing, using mouth rinses when you can and then also going to see your dental health care professional. I know immaculate is a broad term, but basically meaning putting in the most effort in order to get your oral disease, as well as the ulcerative of disease under control.

Amethyst: Great, thank you. This person asks, why does it feel like pemphigoid in the mouth has everything stick to the gums? Maybe they're asking, why do the blisters always appear on the gums?

Dr. Gibson: In one of the earlier clinical slides that was shown, was a picture of a patient with red gums and that's something we refer to clinically as formative gingivitis and patients with pemphigus or pemphigoid, their only oral presentation can be the gingivitis can you can also have other lesions but sometimes, they only have their red gums as their clinical manifestation of their oral pemphigus or pemphigoid. I'm not sure if that was the question that they were posing so I am not sure if I answered the question correctly.

Amethyst: I'm not sure either. Linda, if you want to clarify, please feel free to type your question again into the question box and we'll go ahead and ask that again. Jean asked, is drinking carbonated tap water okay? You had mentioned staying away from those carbonated soda.

Dr. Wiley: I mean for me, I would think that especially if you have open lesions, even though you're drinking water, which is pretty neutral as far as PH, just the action of the bubbles and things would probably cause irritation to the soft tissue. So I would probably just avoid anything carbonated and just drink water.

Amethyst: Great, thank you. Paula asked, do you have any recommendations other than just being toothless for a PV patient who has major bone loss that won't support implants or raised dentures? They're uncomfortable and feel that their mouth is kind of out of control right now. They saw several dentists that won't currently touch their mouth.

Dr. Gibson: That's hard. I don't do any general dentistry so I am not sure of all the techniques that would be available. I would recommend probably that you see someone who has an interest or whose practice has an emphasis on medically compromised patients. They may have some other options for you.

Dr. Wiley: In addition to that, I'm not sure if this patient currently has a dermatologist or other healthcare professionals that they're saying, but really working with someone to get the disease under control, in addition to finding an oral healthcare professional that's willing to work with them. So that way, hopefully, if they do have a new set of dentures made, the tissue will be a little bit in a better shape.

Amethyst: Great! Thank you! That makes sense. Linda wrote back and she said that she feels like her gums are actually sticky and that food tends to stick to her gums. Is that normal for patients with that condition?

Dr. Gibson: Is she experiencing some dry mouth in addition to that?

Dr. Wiley: Sometimes when you have open sores, the debris from the food kind of collects on them. For somebody like her, maybe after meals, finding a mild rinse or even just trying to rinse with water gently, just to try to loosen up that debris and get it out so that way it's not just collecting in those areas.

Amethyst: She said no dryness.

Dr. Gibson: I would tend to echo Dr. Wiley's comment.

Amethyst: Great, thank you. Well we have already passed our hour, so I'm going to ask one last question here. This person says that the blisters usually occur on the roof of their mouth. They get a red source that almost looks like acid has dissolved the gums and it's very painful. Is this a presentation of pemphigoid itself or is that caused by an irritation from something that she's either eating or using to clean her mouth?

Dr. Gibson: That sounds like a manifestation of pemphigoid to me. One last question that came in, somebody asked if you'll quickly show the toothpaste that you recommend if you don't mind popping back on the screen for us. Great. Well like I said, that was a very quick hour. We flew through a lot of questions. We still have a lot of questions that went unanswered. So, if you do have questions that you didn't get answered, feel free to contact me, Amethyst, amethyst@pemphigus.org or you can contact one of our peer health coaches, that will help you get your questions answered. I'd like to thank everybody for being on the call with us today and for Dr. Wiley and Dr. Gibson for answering everybody's questions. You both did an amazing job. I'd also like to give a huge thank you to all of you for being on the call with us today and to our sponsors, Genentech, Principia Biopharma, a Sanofi Company, argenx, and Cabaletta Bio for making today's call possible.

Amethyst: Before we go, I have a few announcements: The IPPF makes these resources available to patients, caregivers, medical professionals and others through the generous support of people like you. If you would like to support this work, please text IPPF to 24365 and follow the prompts to make a donation. Again that's text IPPF to 24365. Thank you for your support! Our next patient education webinar will be on January 31st with Dr. Aimee Payne, Dr. Neil Korman, and Dr. Nasser Said-Al-Naief. Our experts will answer your dermatologic and dental questions. Registration will be opening soon and you will be able to register online. We hope that you will join us for this amazing webinar. Are you ready to share your story and help make changes in real legislation that will impact our community's access to medications, access to high quality health care for patients, and increase federal funding for advances in medical research? If so, we encourage you to join us this year in participating in Rare Disease Week 2022. The IPPF will be participating in this year as we have in the past and we need your help! If you are interested in sharing your story with your Congressional Representatives please register for Rare Disease Week at www.everylifefoundation.org/rare-advocates/rare-disease-week/. This is a great way to not only get involved but really have your voice heard and make an impact. Both RDLA and the IPPF will provide training and help you learn how to share your story and about the bills we will be advocating for. If you have any questions or are interested please contact Marc Yale at marc@pemphigus.org and he would be happy to answer any of your questions about getting involved.

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

Lastly, if you have a question that didn't get answered on the call, or have additional questions please contact one of the IPPF's Peer Health Coaches on our website by visiting: www.pemphigus.org/peer-health-coaches/ or you can call (916) 922-1298, and we would be more than happy to help. This recording of the call will be sent out following today's webinar in an email tomorrow, and it'll also be posted on our website. Thank you all for joining us today, and thank you Dr. Gibson and Dr. Wiley for answering all of the questions from our patient community. Have a great day. Thank you so much.