

**Becky:** Welcome everyone. This call is now being recorded. I would like to thank you for being on the call with us. Afternoon. Our speaker today is professor Jennifer Harmon. Thank you for joining us today.

**Professor Harmon:** Thank you so much. It's so great to be here.

**Becky:** The call today we'll focus on oral health care and pemphigus and pemphigoid. First let me introduce you to our speaker for this evening. Jennifer Harmon is an assistant professor in the dental hygiene program, department of periodontology at the University of North Carolina at Chapel Hill School of dentistry where she is also the director of clinical hygiene in the first year of dental hygiene students. Professor Harmon also co-directs the practice of dental medicine for the first year dental students as well as the clinical and laboratory teaching for the graduate dental hygiene students. She received her bachelor of Arts in Exercise and Sports Science and from UNC Chapel Hill in 2007, her Bachelors of Science in Dental Hygiene from UNC in 2013 and completed her Master's of Science in Dental Hygiene Education at UNC in 2015. Professor Harmon currently serves on the board of directors for the North Carolina Caring Dental Professionals and the International Advisory Board for the National Center for Dental Hygiene Research and Practice. So now it is my pleasure to introduce you to professor Jennifer Harmon to answer your questions about oral health and care with pemphigus and pemphigoid. Welcome.

**Professor Harmon:** Wonderful. Thank you so much Becky. I am just so excited to be here today to answer questions about oral health and maybe some recommended products for people who, you know, do have the diagnosis of pemphigoid or pemphigus. So I can't wait to answer your questions and if I don't have the answer, I'll be honest. Just so you guys know, I am a dental hygienist. I am not a dentist, so I have gone to dental hygiene school. I have not gone to dental school. I know some people were sending some questions earlier about osseous surgeries and different types of things. I will give you the best information I can and if I don't answer your questions, I'll work with Becky to maybe have some questions written up and see if I can improve on some of those answers at a later time. So, yeah, let's get started. I wanted to touch on a couple of the questions that stood out to me and a lot of them were about products. So I'd like to start with speaking about some dental products that are going to be tailored for you guys' types of issues as far as dealing with oral manifestations. So one thing I want to start off with is just what you guys are using as your toothbrush. And some questions I always receive have been, do I use a manual toothbrush or I use a power toothbrush. My advice to you is, especially during flare ups, you're going to want to use a manual toothbrush. And the key thing about using a

manual toothbrush is going to be extra soft bristles. I want you guys to make sure that when you're looking on any packaging for dental products, especially something with bristles, you want the extra soft. Do not buy anything that says medium or coarse just because that's going to be a little bit of an issue with your disease and how that affects a lot of your tissues. And you guys know that better than I do. And another thing that a lot of people have complained to me prior about is they don't like how big, sometimes the manual toothbrush heads are. Guys, it's totally fine for you to get a kid's toothbrush... (Cuts out)

**Professor Harmon:** And that's exactly what this population needs. And the curaprox bristles are not nylon. It's made of a filament that is incredibly gentle and they're very fine, which is going to be very good for your tissues. Now I'm not saying that you can't use a power toothbrush, especially in times of remission or when you know you have zero oral lesions, you're not suffering from any gingivitis issues. If you're not suffering from any sloughing of the tissues or oral blisters, feel free to try at that time a power toothbrush. But again, when you're using that power toothbrush, make sure you have extra soft, replaceable toothbrush heads. And then the last thing I'll say about that, I do know that a lot of power toothbrushes are right now are coming up with replaceable heads that actually are much geared towards sensitive gums and they also come and different power modes. Make sure you're using a slow mode... (Cuts out)

**Professor Harmon:** The brushes. Are there any questions right now about actual toothbrushes? And Becky, keep me on point if people are sending it questions. I'm a little bit unfamiliar with this, so I don't know if I can see the questions. All right Becky, are we good to go still? Yes, I can hear you.

**Becky:** There was a question about is it okay to use a water pick?

**Professor Harmon:** Wonderful. Okay. Let's, let's move on to that then. So now that we've kind of talked about manual toothbrushes, and I gave you the example of the small curaprox soft brush, we've talked about power toothbrushes. Let's talk about interdental cleaning. And let's first off, start with Waterpik. My thing for Waterpik is making sure to use it on a very slow mode. You want to use it on the lowest pressure setting because you're not going to want a lot of force coming to your gum tissue, especially if you're having some issues with sloughing or blisters at the time. But I do recommend using a Waterpik as a water flosser. Sometimes waterpik can be a little bit of a nuisance just because you kind of have to leave over the sink and you know, you have some splashing around with water. But really it's nice, if you

put it on a low power setting with limited pressure and it's just very light, it should actually just kind of soothed the tissues. Now again, if you're using a waterpik and you're putting it on the most forceful pressure setting, that actually is going to do some damage. So using these certain types of oral care aides correctly is what's going to be most important.

**Professor Harmon:** Now I also got some questions earlier about, you know, should I floss? Well, if you are having a lot of inflammation or pain inter dental care, which is just cleaning in between the teeth may not be on your top priority list and that's okay. Regular floss tends to be a little bit of a nuisance, but let's say that you're in remission and you don't have any oral blisters, by all means try flossing. I would recommend using a waxed floss. Something like maybe an example would be Glide, something very easy to kind of rope around your fingers and slip through those teeth. And you want to use it gently. You never want to kind of pop the floss in and out so to speak. You want to use it very gently. As you place it in between each teeth, you'll move from tooth to tooth. And using waxed floss would probably be the best. But again, if you're having a lot of inflammation and a lot of tenderness and a lot of pain with blisters, you may just want to lightly rinse with water and maybe just use a very low low setting on the waterpik.

**Becky:** Great, thank you. A lot of people are asking about what they should look for in a toothpaste. And a lot of things that patients are trying to avoid is the sodium lauryl sulfate or in trying to find one that has fluoride that isn't mint flavored, that is SLS free. So if you have any suggestions on different kinds of toothpaste that we can use, or even like a regime where we can still get the fluoride but not get the mint or the alcohol, that would be greatly appreciated as well.

**Professor Harmon:** Great question Becky, and thank you guys for being so specific with your questions. This is really helpful. So let's talk about different types of toothpastes out there. I will definitely give you some examples of toothpaste without sodium lauryl sulfate. I know that a lot of toothpaste do have that as an ingredient. For those of you who do not know what the ingredients sodium lauryl sulfate is, it's a detergent that actually gives toothpaste it's foaming lather. But for people who suffer from pemphigus, it's very difficult because a lot of times that can actually irritate the tissues of the mouth. So we're going to want to stay away from that. Let me give you some examples of some toothpaste that does not have sodium lauryl sulfate. The first one is a Biotene products and Biotene has actually come out with some toothpaste that has fluoride in it, which is wonderful because that's actually going to help reduce the risk of cavities. I actually do have some pictures, Becky, that I could possibly send you that might be

even more helpful. Biotene has one that is a fluoride toothpaste, it does not contain sodium lauryl sulfate, it's a low foaming firming formula, it's very gentle on tissues and it's formulated to protect the teeth. So again, that's a Biotene product. Make sure you read the ingredients. There is fluoride, but that does not have sodium lauryl sulfate. Another example is Pronamel, Pronamel is wonderful. It is actually created by the company's Sensodyne and Pronamel really helps to strengthen and protect the tooth enamel. Enamel is that outer surface that covers the tooth that we have inside our mouth, but not only does Pronamel help to strengthen and protect the enamel, it also helps to provide some relief from hypersensitivity. So there's some different types out there right now, guys. There's one called Sensodyne Pronamel Daily Protection. There's one called Sensodyne Pronamel Multi Action, and there's also one that's titled Sensodyne Pronamel Strong and Bright. Now the key thing with all of those Sensodyne Pronamel toothpaste, fluoride is a plus, so that's wonderful. There is no sodium lauryl sulfate in any of those Sensodyne Pronamel products. And then lastly, it's a gentle formulation and it has a very low abrasivity. So if you're looking for toothpaste, you want something that's going to be very, very gentle on the gum tissues as well as on the actual tooth surface. That's why a lot of people get frustrated. They tell me they want whitening toothpaste. Well, a lot of the heavy whitening toothpaste have a very high abrasivity, meaning they can be a lot more irritated to the tissues. So that's something to look for in the ingredients. And then I have two more examples I want to give. Another example of no sodium lauryl sulfate toothpaste is going to be Jason toothpaste. That's Jason Toothpaste and the one that I've actually used in presentations before is titled See Fresh. It's an anti cavity and strengthening Jason toothpaste. It does have fluoride. It does not have sodium lauryl sulfate, but it does have some aloe vera gel, a very tiny, tiny amount, which has actually been shown to help soothe some irritated gum tissue. So that's another one. And then if you guys are taking some notes, I'll tell you one more example of toothpastes...

**(Cuts Out)**

**Professor Harmon:** that based toothpaste. It does contain fluoride, but then again, we want stuff that does not have sodium lauryl sulfate. So again, that is another recommended toothpaste. So I'm just gonna kind of summarize that again. I know that was a lot. So we have Kiss my face toothpaste, Jason Toothpaste, there's a few different types of Sensodyne Pronamel just make sure that when you're looking on the ingredients list, it says no sodium lauryl sulfate and make sure that you get a gentle formulation and it should say gentle on it normally. And then another one that I gave you was an example of a Biotene fluoride toothpaste, which did not contain sodium lauryl sulfate. So those are kind of some examples that I am most familiar with. I'm sure some of you probably even have tried other things that I'm not familiar with, but you just want to make sure that you're staying away from any

toothpaste defaces and you want it to always be very gentle on your tissues and staying away from anything with alcohol in it. And in just a minute we'll talk about some, some mouth rinses as well. So Becky, how was that for the toothpaste products?

**Becky:** Perfect that is awesome. Thank you.

**Professor Harmon:** Yeah, absolutely. Well, another question I believe that was on the list of questions that I was sent prior to this was information about mouth rinses. And I know that that can be a tricky thing. I really urge you guys to stay away from mouth rinses that contain alcohol. That is, you know, contra indicated in the treatment of Pemphigus. So please, whatever you do, stay away from harsh mouth rinses with an alcohol content. There are so many available rinses now about are alcohol free and a lot of them are advertised right on the front of the bottle, For example, Listerine has a cool mint zero alcohol. However, the only downfall to that is sometimes I've had patients tell me that the mint is still too strong. So that's kind of a bummer on that one. But again, if you're not having a flare up, you might could try it. Then actually one that I have found several people to enjoy is the mouth rinse hat's actually from Tom's of Maine. And the one specifically that I have actually tried it as well, it's a Tom's of Maine Whole Care Mouthwash and it does not contain any flavoring agents. There is no alcohol and they're really good at making sure other, you know, harsh ingredients that might be irritating to oral tissues is left out. So again, that is Tom's of Maine Whole Care Mouthwash. As we continue on guys, it depends upon your dental home and what products your dentist carries. There can be some prescription options. Colgate makes a rinse called Prevident and it's sole purpose is a dental cavity prevention rinse. I do know that they make some without alcohol, but again, that's going to be a prescription option for you for a mouth rinse. And I urge you to just talk to your dentist about options for prescriptions. As a dental hygienist I'm not actually allowed to write prescriptions for mouth rinses in this state of North Carolina while at where I'm at. So if you want specific questions on prescription rinses, I'll just direct you to go to your dentist and see what the options are there.

**Becky:** Great. Just as a follow up question, there was a question submitted about using hydrogen peroxide, like Peroxyl. Is it okay to do that when you have blisters presence?

**Professor Harmon:** So great question and thank you for letting me know if that Becky. Now let me tell you what I do know. I know that Colgate makes a peroxy alcohol free rinse. If you're talking about a peroxy one with alcohol, stay away from that. I do know that the peroxy, alcohol free rinse does have

hydrogen peroxide in it. It's a pretty low percentage, but it doesn't have alcohol. And I know that they make some that is it with a very mild flavor. That is actually very good at helping to kind of alleviate some discomfort. I'm not sure if it would irritate a lot of oral wounds if someone had them all over. However, I do know that it does help in minor oral wounds. It's been shown to soothe the tissue and kind of provide a whole mouth cleansing feel for people who have minor oral wounds. It's really good for patients with sensitive mouths. But again, I'm not sure when it might be kind of overkill if someone was to have a lot of oral lesions, but I do know people who have used the peroxy alcohol-free rinse when they've had just a couple of lesions and it actually helped to kind of minimize and reduce bacteria. So that's what I know about that.

**Becky:** Great. Thank you. What are your recommendations for daily oral care? Like, how do you brush your teeth? How many times should a patient with oral lesions be brushing their teeth? And then what are some things, these are all kind of kind of mashing together. And so that's one question. And part B would be, and how do you, how can we deal with the pain of brushing? Is there anything over the counter that might be able to help with the pain to help us brush our teeth better?

**Professor Harmon:** Okay, wonderful. So I was kinda writing down some things as you were speaking there. So give me just a little bit. I had made some notes before I started, so I'm just looking through my notes really quickly. Well one thing first, you were asking about how often should you be brushing? Because people who tend to have blistering issues and there can be ulcerated areas, you want to go ahead and brush at least two, three times a day. Three times a day would be amazing if that could be possible because a lot of times pemphigus vulgaris patients who have that, they are more apt to having cavities, especially when they have to change their diet to soft foods. So then what happens it's kind of like a terrible cycle, which I'm sure all of you are familiar with. But once you limit your diet to soft foods, if it's especially not of a nutritious value, that actually leads to even more plaque buildup on the teeth So basically getting rid of the plaque as often as you can is what's going to help these types of patients. We normally do say two to three times a day. And then again using toothpaste that does not have sodium lauryl sulfate. And guys, another thing I forgot to mention, you want to stay away from hidden flavoring agents. A lot of rinses and a lot of toothpastes these days puts flavoring agents like cinnamon, wintergreen, spearmint. If you can stay away from those. It's so hard these days because that's kind of how we get it sold. If you go to target and you walked down the aisle or in CVS or Walgreens. I'm a dental hygienist and it's evening overwhelming to me with how many different flavors things are these days. But a lot of times those additional preservatives can be a problem for some patients. So just keep

that in mind and then you guys were asking about how often we, we went over that and what was the next question, Becky? I'm sorry.

**Becky:** Oh, no, that's fine. How often should they be using the oral rinses as well? They should, they use it every time they brush?

**Professor Harmon:** If you are not in a flare up, I believe that that would be fine. I've also told some of my patients every other day. I know that patients that really suffer from a terrible amount of blisters, sometimes they complain that they can't even use a soft bristled brush. I know this might sound a little cheesy, but sometimes when, my grandma was in a nursing facility at one point in time, and I remember I would actually go in and clean her teeth with almost like a light little sponge. You can always just take a little washcloth, a very soft one and rub it around your teeth to wipe off some plaque if you ever have blisters that are covering all of your mouth. I know that that would be quite painful. But as a dental hygienist, what I recommend is to make sure that you can actually see your hygienist as often as you need to. If you recognize that once every six months is not enough. And let's say you have a lot of plaque buildup, you have a lot of tartar. A lot of times what we're teaching our students when they have their special care class, when you're tailoring treatment for patients that may have a special need such as pemphigoid and pemphigus, they actually may need to be going to their dental hygienist every three months or every four months. And that's okay. So having shorter recall visits with your dental hygienists to maintain and lower that bacterial count in the mouth, that's something that a lot of people forget. You know, and sadly, one of the questions that Becky sent me earlier was, do dental hygienist and dentist in dental school and dental hygiene school get thorough education on people who may be diagnosed with oral pemphigus? Sadly, that answer is no. We don't get enough textbook information and enough didactic lecturing with this disorder. We kind of get a run through, but we're definitely not experts in this field at all. I remember for me specifically, I learned about it when I took my pathology class and we talked about different oral lesions that could occur and we briefly went over how to help soothe those areas. And like we're saying right now, increasing their treatment appointments at the dental office. But a lot of times you guys are teaching us so what products that we've recommended work and we learn from you. But I really do encourage you, if you find that you're suffering from a lot of plaque a lot of inflammation in your gums, you'll want to see your dental hygienists more than just twice a year. So please remember to keep that open communication with your dental provider, whether it be your dentist or dental hygienist, because that's been proven to help the treatment for patients that have a lot of plaque buildup.

**Becky:** Great. Thank you. There are some questions about how should a patient instruct a dental hygienists that may not be as familiar with pemphigus or pemphigoid to clean their teeth? For example, like what should they use to clean their teeth or polish their teeth, kind of some do's and some don'ts. And, also like is there any type of anesthesia, either topical or systemic that can be used as well?

**Professor Harmon:** Excellent. Thank you. So first things first, always keep that line of communication open with your dental hygienist. If you're comfortable, talk to them and educate them. Maybe talk to them prior to your appointment, maybe a week before. I always think that's really helpful. If I know that I'm going to see a patient that might have some special needs where I need to maybe do some research on or find some better products, I might want to be prepared for that. And we want to give you the best care possible. So maybe alert your dental hygienist a week before or the office manager that would be just fine. And just tell them, say, you know what, I want to let you know that the past few times when it seems to have been most successful with my dental hygienist is when appointments are conducted in a gentle fashion. Let's say that your gum tissues are just really inflamed, there's a lot of gingivitis going on. You might actually have to have a couple of appointments to finish everything and that's okay. So if you need to divide your appointment up into two or three appointments, that's just fine. I think as a dental hygienist, ideally I would want to disrupt the tissues as little as possible and just focus on probably using some simple hand scaling instruments to remove the plaque and be effective at removing the plaque. As far as polishing, do not let your dental hygienist polish with any type of medium or coarse paste. It's just not necessary. Quite honestly, we have found that simply polishing with a non abrasive toothpaste is really all that's needed. Now if you are concerned with aesthetics as far as you having deep staining, that may be something that you want to talk to with your dentist about. But just ridding of any bacteria and biofilm, which is just another word for a plaque, we have seen that... (Cuts Out)

**Professor Harmon:** before when I was teaching a CE course, they were like, well, I don't like the stain on my teeth can I use an air polisher? And I said, no air polishers they have a lot of harsh abrasives that come out of them and your tissue, it might be in a state where it's so fragile, it could actually do more damage than good. So I encourage you guys to stay away from air polishers just because a lot of times the abrasives that come out of that are so harsh, it would really, really, really irritate the tissue and actually probably cause more damage. When we talked about the frequent maintenance appointments for that meticulous plaque control, that's going to be the best. And as far as brushing something you were asking Becky, I believe, like how should you actually brush. Be gentle. A lot of people think that in order to remove plaque off the teeth, do you have to get in there and scrub so hard. You don't, it's a

very light pressure. In fact, when you use a automatic toothbrush, you're not supposed to actually maneuver the brush like you would a manual brush. You just let the bristles do the work in a rotate on their own. Now, if you're using a manual brush, just very soft, soft light circles is going to be fine. Angling the soft bristles bristle towards the gum line and just gently massaging them, kind of like a vibration motion, but very gentle, not putting a lot of lateral pressure on the tube. That's going to be the best bet as far as just getting that plaque out of the way. Once you disturb that plaque that's all it needs. You just need to get the plaque removed.

**Becky:** Great. Thank you. What are some types of anesthesia that can be used to help patients and have you ever used hypnosis before in treatment to help patients?

**Professor Harmon:** Okay, wonderful. Thank you. So, I do think that using a local anesthetic to have a cleaning done if you're that sensitive, that actually may be very beneficial. That way you are less sensitive during your appointment with your hygienist. Making sure that if your dental hygienist uses a little bit of topical anesthetic, if you guys can kind of picture being in your dental chair with your hygienist sometimes they have like a little Qtip and they have like a little gel that's fine. But I will tell you sometimes those topical anesthetics can cause gingival irritation if it sat on the gum tissue too long. So if you are using a topical anesthetic during a dental appointment, just use the exact amount that's needed. You don't need to slap a ton on there. And then if there's any residue that's left, just gently wipe that off because sometimes if you leave it on long term, it actually can cause some gingival irritation even on someone like me who is not diagnosed with oral pemphigus. So yes, local anesthetic can be used and when you're in there with your dentist or your dental hygienist, they're probably going to be having suction going and they may be using gauze and stuff like that. Here is a hint for you to tell your dental hygienists and your dentist. Dry gauze sometimes, imagine if you're opening up your mouth and you have blisters or even maybe no blisters, but that dry gauze can sometimes just stick to your cheek tissue on the inside of your mouth. So it's a simple hint and helpful tip is just to add some water and coat that gauze before you put it into your mouth... (Cuts out)

**Becky:** You had mentioned about talking to a dentist afterward would invasive dental work cause a flare up?

**Professor Harmon:** Well this is what I do know. If you're in remission and there's no types of oral lesions present, then I think a lot of dentists are willing to try and help. And let's say you have a cavity that

needs to be filled. Well that's active dental disease in your mouth that needs to be taken care of. So you know, if there was a one tooth that needed to be treated, absolutely that doesn't need to be ignored. Somebody wrote on there, invasive treatments such as dental implants. The one thing that I do know about dental implants, if someone who has pemphigus or pemphigoid is treated with any type of immune suppressant for a very long period of time, which I know probably many people on this call are. Sometimes that makes people kind of a poor candidate for dental implants because dental implants actually have to like integrate into the bone and sometimes people who are on any type of immune suppressant medication implant failure can happen. I don't know how often and what the actual statistic of that is. But implant failure can happen if immune responses are altered. So that's one thing but as far as like having a filling done, Becky, that's totally fine. That needs to be taken care of. If it's something more invasive, like a getting a dental implant done, that would mean you would need to have a conversation with your medical provider and your dental provider. Maybe even see a specialist like a periodontist instead of a general practitioner or someone who has treated patients with with more tailored needs. I would say there would need to be some communication between medical and have that cross communication. That would be helpful.

**Becky:** Great. Thank you. There was a question that was submitted about, can you address the issue of adolescents with Pemphigus Vulgaris who need braces? This is actually coming from France and she says it's very expensive in France because the device has to be specially made since the gums are so fragile. How would it work in the U.S.?

**Professor Harmon:** Wow, okay. So, to my friends in France who were asking this question, thank you. Wow, let me try the best I can and then again, if I need to find out some more information I will try to help you. So one thing that I do know when I work with my orthodontist colleagues here at the UNC school of Dentistry, they are very big on home care. So let's say we had a teenager who only brushes once every other day that orthodontists will most likely not put braces on. So if someone doesn't have control of removing the plaque on a day to day basis, you're going to have a hard time no matter where you go. In the U.S. we're actually getting someone to agree to put braces on because a lot of teenagers, especially who put braces on, they don't floss as much, they don't brush as much and that actually can lead to a higher rate of cavities and a lot of decay on the tooth and demineralization. So I know my colleagues here in North Carolina, they're very big at making sure the teenager can prove to the orthodontist prior to putting the braces on that they can actually maintain their oral home care regimen on a regular basis before they even put the braces on. Now, that being said, I am not an orthodontist, so

I don't want to speak out of turn. But I imagine if someone did take care of their oral health and was very adequate at removing that plaque on a day to day basis and they weren't having a lot of issues. I don't see why that teenager can't have braces. Or now let's say if they had some slight, you know, gingival or gum tissue irritation depending upon their needs, maybe they don't have to have braces. Maybe they can have more of the clear retainer type Invisalign. So I think I'll turn that over to my orthodontic colleagues to answer that question probably a little bit better. But seeing what other types of options are out there, could they be a candidate for braces or could they be a candidate for having maybe an Invisalign type option done?

**Becky:** Great, thank you so much for that. There is a question and it has to do with gum recession that a lot of our patients have. If your roots are exposed due to gum recession, how effective is fluoride and helping cavities? And if so, what's the best delivery method for the fluoride?

**Professor Harmon:** Oh, wonderful. Yes if you have recession and let's say some of your roots are exposed, definitely fluoride is a must. And the reason I say this is because when you have recession and you have exposure of more tooth, you now don't just have enamel being exposed you now have another dental tissue exposed in the mouth called cementum. And that is different than an enamel and it actually is thinner and it is more susceptible to getting cavities. So a lot of dental hygienists are very big when you come to the dental hygienists for your cleaning, I recommend that you ask your dental hygienist about fluoride varnish. It's kind of like a little gel that they're able to kind of paint on almost like fingernail polish and they can actually put it right where they want it. Let's say for some reason you opt to not have fluoride varnish, any type of toothpaste or any type of the rinses that we went over make sure that it has some type of fluoride component to it because it really will have benefits on lowering your risk for getting cavities.

**Becky:** Great. Thank you.

**Professor Harmon:** Yeah, but that fluoride varnish is wonderful. It's very easy to put on is user friendly. People can eat right after they put it on. I know when I was a child, I only used to have the fluoride gel put on and you had to put those trays in your mouth for four minutes. Now they have a new concentrated version of that and it's literally so easy. It's user friendly for the dental hygienists, but also user friendly for the patient. You can drink right afterwards. The only thing you can't do after you have

fluoride varnish to put on is no alcohol and you want to stay away from like sticky, crunchy foods. But everything else, it's really a great thing to have when you go to the, to see your dental hygienist.

**Becky:** Great, thank you. They use that a lot in children too, right? Like it's, it's gentle enough that you'd say you said in kids?

**Professor Harmon:** Oh, absolutely. And I use it when I go see my dental hygienists. A lot of people I think, we don't hear about fluoride being used for geriatric populations and older adults and we just hear it for kids. Anybody who has had a lot of cavities in their life, anybody who has had recession with that root exposure, just because you're an adult doesn't mean you don't qualify for fluoride. Fluoride varnish is just as fine no matter what age.

**Becky:** Great. Good to know. A patient is asking, "My first flare up happened immediately after a deep cleaning by my hygienist. Will a deep cleaning bring on another flare up?"

**Professor Harmon:** Wonderful question. So to whoever is asking this question, I don't know. I don't want to make up an answer. Now I will tell for everyone in the audience who's listening, the quote unquote deep cleaning in hygienists terms, that's what we call scaling and root planing. Which is a different insurance code than a regular adult cleaning. A regular adult cleaning in the hygienists world is term and adult prophylaxis and that is different than a deep cleaning. So if that happened to someone I'm not sure if you had a flare up right afterwards, would that promote another flare up? Maybe this time it could be just focused a little bit more superficial. Staying above the gum line and removing any of the plaque. Or maybe they could follow up with like a chlorhexidine rinse afterwards to maybe promote some healing. I would suggest that person to talk to their dentist and dental hygienist about maybe some type of anti-bacterial rinse afterwards to maybe decrease the bacteria count in the mouth. I'm not positive though, but that would be my suggestion.

**Becky:** Great, thank you. There is a question from Dolores and she's asking, is it advisable to take an antibiotic before every cleaning, whether you've had blisters or if you're in complete remission?

**Professor Harmon:** That is a, that answer will change no matter who you talk to. Some people say yes, do it and some people say no. My thing right now is we have such an epidemic with antibiotic resistance going on, especially the United States. So, if you don't have to take an antibiotic, I would not. However,

if you know that that's a routine that you have done previously and it causes you to have less anxiety and it has seemed to work, then I just say talk with your medical provider and talk with your general dentist and get their opinion and see if that's something that you need to continue. I do not know what the research says on taking an antibiotic prior to every cleaning, specifically for dental management of pemphigus patients. I'm not sure what all the research says about that, Becky. I'm a little bit more familiar with antibiotic prophylaxis with patients that have undergone like hip replacements and knee replacements. But even with that...

**Becky:** I was gonna say that's part B of the question.

**Professor Harmon:** Okay, well let me continue. If you have had a hip replacement or a knee replacement and some form of total joint has been replaced in your body, always make sure to follow you or your orders from your orthopedic surgeon. There are some updated guidelines out there right now that say that people do not need to take premed for life anymore unless they do have more susceptibility to infection. And I do not know right now if pemphigus or pemphigoid qualifies as making that person have taking premed the rest of their life. Tell them to talk to their surgeon about that and see if they can find some more research on that.

**Becky:** Great, thank you. There is a question from Susan who is asking about a SLS free toothpaste that is non-mint or preferably unflavored and what are the cons of using baking soda to brush your teeth?

**Professor Harmon:** Wonderful. Excellent. So to those of you who are wondering about some non-mint flavor toothpaste, I think the example that I gave earlier, the last example that I talked about was called Kiss My Face. They have some toothpaste that actually do not have many sweeteners or flavorings. So my advice to that person, if you're looking for something without artificial flavors and without artificial sweeteners, try the Kiss My Face brand and see if you can find some from any of that. That would be my go to. And then, what was the last question, Becky, after the no flavoring or sweetener toothpaste?

**Becky:** Then the next question was about using baking soda, what are the pros and cons of using baking soda.

**Professor Harmon:** Sure, baking soda. I've had patients that have used that. My only problem with that is the abrasivity. I do not know if it might be too abrasive to irritate the tissues. So I therefore I would

just go to a toothpaste kind of like one of the Pronamels or that Kiss My Face because I know for a fact that the research has proven that there is low abrasivity. Now if somebody wanted to try that once or twice a week when they were in remission or would they didn't have any oral lesions, I don't see any harm in it. But if you notice that it causes any gingival irritation, then I would stop. And then also Becky, on a side note, I had wrote down that a lot of people suffering from pemphigus and pemphigoid during high flare ups, they have to have a soft diet. So I'm not a registered dietician, I'm not a nutritionist, but I have taken several nutrition classes in my career and I just wanted to encourage everyone when you feel that you have to have a soft diet, really try guys just for your overall health, tried to put in your body some nutritious options such as maybe some really dense fruit smoothies or some really nutritious type soups, high in veggies. And I know that's kind of off topic, but I just wanted to throw that plug in there because a lot of times what I see is people who get on soft diets are eating very high sugar content and they end up eating a lot of cakey type food. And I just want to encourage you guys to make some sound nutritious options for yourself if you ever find yourself having to eat on a soft diet for a little bit. So keep that in mind.

**Becky:** That's great.

**Dr. Harmon:** Yes. Thank you.

**Becky:** Leah says, when I'm having flare ups on her tongue it can be very painful in the back and she has an open cut that has never healed on her tongue from a bad flare up. Are there any cream or anything that she can help to reduce the pain and to help it heal at the same time?

**Professor Harmon:** Gosh, bless. I'm so sorry that you're suffering from that. There are some over-the-counter creams. I do know that there is like an over-the-counter Oral-gel. But the thing that we've seen with Oral-gel is a lot of times it's only solving kind of the problem at hand as far as it relieves it minimally. There is also a xylocaine 2% gel that patients can put on painful lesions. Ask Your dentist about that. Again, it's xylocaine gel. A lot of people I know have used that on painful cuts or painful ulcers and there they put that on there before meals or either right before they brush their teeth. So you might want to do some investigating with your dental professional with that. My only thing, they do have a chlorhexidine gel as well, Becky. But I don't know if that chlorhexidine gel helps with numbing or soothing. So that's also something that if people want it to look into, they could ask their dentist about.

But yes, a lot of times the painful lesions, they can use this really light, xylocaine gel and you know that that can help alleviate at least temporarily, long-term though I'm not sure.

**Becky:** Great, thank you. One last question, should a patient bother to treat a transient oral lesions?

**Professor Harmon:** Wow, sometimes I feel like you guys know this stuff better than I do cause you guys are suffering with a lot of these oral conditions. I think that that might be something where you have a general practitioner, I'm like your general dentist working with a medical provider, kind of doing some trial and error things to see if it helps. I do not have enough knowledge and research background to be able to tell you how to... (Call cuts out)

**Professor Harmon:** Experience that I've had with research and teaching and seeing patients that have had pemphigus or pemphigoid definitely make sure that you're keeping in touch with your dentist and your dental hygienist. If you need to increase the times that you've seen them, please make sure you do. Just make sure that you are getting dental care. I really do believe that your appointments with your dental hygienists can at least help kind of keep things at bay so to speak and get a better handle on reducing the bacteria and plaque in your mouth. But hopefully some of the products that I gave examples of today, you guys can actually use that and then hopefully some of them can benefit. We talked about a lot. We talked about manual toothbrushes, Waterpik remember on the lowest setting we talked about toothpaste examples, making sure we stay away from alcohol, staying away from spicy foods, staying away from sodium lauryl sulfate. Sometimes I realized the floss may be a little, a little bit tricky. Glide floss, something that's waxed may be a better option. I felt I was so pleased to be able to join you.

**Becky:** Thank you so much. It was extremely educational having you on our call. I would also like to give a huge thank you to everyone on the call for joining us today!

I would also like to remind you that there are only a few days left to help the IPPF's Research and Advocacy fundraiser. Help us reach our goal of \$15,000. Your tax-deductible donation enables the IPPF to advocate for patients and collaborate with stakeholders for the development of research of pemphigus and pemphigoid (P/P). We provide the most current information to clinicians treating these diseases, researchers investigating potential cures, and patients. With your support, we also maintain relationships with congressional representatives and other rare disease support organizations who

provide the IPPF with the opportunity to advocate for favorable state and federal legislation, research funding, and policies that benefit those affected by P/P. Your donation will help the IPPF continue to provide the promise of new therapies, improved access to treatments, and a better understanding of these diseases through our advocacy efforts, research grant program, clinical trial support, natural history study, and biobank. You can make a difference! You can visit our website today and click on the Donate button in the upper right corner to help support Research and Advocacy for all people affected with pemphigus and pemphigoid.

If you have not heard, the IPPF has a natural history study! If you have not registered for the IPPF Natural History Study, we encourage you to do so. The IPPF Natural History study is a new 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](http://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 Tuesday, April 16th from 5-6pm PST with Dr. Neil Korman, Professor and Faculty Director of the Department of Dermatology at Case Western Reserve University to discuss Immunosuppressives in pemphigus and pemphigoid.

Lastly, If you have a question that didn't get answered on the call, or have additional questions please e-mail our Outreach Manager, Becky, at [becky@pemphigus.org](mailto: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.