

## February 10, 2021 Patient Education Webinar- Peer Support with the IPPF Peer Health Coaches

**Amethyst:** Hi, everyone, welcome to the webinar today. This call is now being recorded. I'd like to thank you for being on the call and to our sponsors, Genentech, Principia Biopharma, a Sanofi Company, argex 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 doctor or healthcare team to determine if it applies to your specific situation." Today's topic is Peer Support with the IPPF's Peer Health Coaches. Before we begin, I do want to take a quick poll to see how many of you have ever either spoken with one of our peer health coaches, or any other pemphigus or pemphigoid patient? I'm going to launch that poll real quick here. We like to collect this information because we know that many times people say that they feel very alone, especially when they're first diagnosed. And sometimes, they've never even spoken with or met another person with pemphigus or pemphigoid. But, we do want you guys to know that the IPPF and our Peer Health Coaches are always here to help you. It looks like, most of you say that you have actually spoken with either a peer health coach or another patient, so that's great. Like I said, we are always here to help you, and so are our Peer Health coaches. A great tool is to connect with us and the coaches.

**Amethyst:** I would like to introduce our speakers for today, Becky Strong is the IPPF Outreach Director. She was diagnosed with pemphigus vulgaris in 2010 after a 17 month journey of multiple appointments with many specialists and wrong diagnosis. She's been in remission and off all medications since 2013. Becky joined the IPPF as a Patient Educator in 2014 and became full time staff in 2016. Helping others with what she's learned on her journey has helped to give meaning to what she went through and has allowed her to pay it forward. Becky lives in Michigan with her husband, Timothy and their children.

Mei Ling Moore was diagnosed with Pemphigus Vulgaris in February of 2002. After dealing with the challenges of the rare autoimmune disease for 10 years, she became a PHC in the fall of 2012 when she went into remission. In addition to being a PHC, Mei Ling along with Marc Yale organize the Southern California Patient Support Group meetings.

Rudy Soto is from the great state of Texas. He was diagnosed in 2009 with Pemphigus Foliaceous and has been in remission since November 2006. Rudy likes the outdoors, cooking and spending time with his loving supportive family. He has been married to his wife Jennifer for 26 years and has 4 children.

Scott Taub is our newest peer health coach, having just started in the role in late 2020. He was diagnosed with pemphigus vulgaris in 2013, by the 11th doctor he saw after his symptoms started. Scott achieved remission in late 2016 with prednisone and azathioprine and has maintained remission without any systemic medications since 2017. Scott is an accounting and financial reporting consultant, helping large companies deal with complex transactions and accounting standards, and has been able to continue to be successful in his career while dealing with pemphigus vulgaris.

Marc Yale is the IPPF's Research and Advocacy Coordinator. In 2007 he was diagnosed with Cicatricial Pemphigoid. Like others with rare diseases, he experienced delays in diagnosis and difficulty finding a knowledgeable physician. Eventually, Marc lost the vision in his left eye from the disease. This inspired him to help others with the disease. In 2008, he joined the IPPF as a Peer Health Coach and from 2016 to 2020 Marc served as the IPPF's Executive Director. Marc continues to work with people to improve their quality of life, and encourages them to become self-advocates.

**Amethyst:** Thank you all for being here. Before we get into our questions, I'd like to go over a few housekeeping slides... (Continues with Housekeeping Information)

**Amethyst:** We have received many questions before the call, so we will try our best to answer as many questions as we can. So it is now my pleasure to introduce our peer health coaches and answer all your guys' questions today. Thank you all for being on the call with us. We're going to jump right in, since we got a lot of questions. I think since it's a new year, and maybe some new patients and new faces in our community, let's start off with the difference between pemphigus and pemphigoid because I know we get a lot of questions about that. Becky, can you explain the difference between the two diseases?

**Becky:** Sure, so pemphigus and pemphigoid are rare, autoimmune blistering diseases of the skin. And really, the big difference between pemphigus and pemphigoid is the layer of the skin that it happens in. So pemphigus happens in the more superficial layers. And so therefore, patients like us, typically see open lesions and don't see as much of the tense blisters that you would see with patients with pemphigoid. Depending on the variation, both pemphigus and pemphigoid patients can have lesions on their skin, in their mouth or other mucous membranes or the lucky ones get both. So it's possible to have some variation of that. In very, very rare instances, it is possible for patients to have both pemphigus and pemphigoid but, again, from what I've heard from our experts, this is a very, very rare phenomenon. So, in a nutshell.

**Amethyst:** Great, thank you. Todd wrote in and he said his doctor thinks he has PV. He's wondering if a biopsy is required for a diagnosis, or can he be diagnosed through blood work. Marc, do you want to go ahead and answer that?

**Marc:** Sure, absolutely. So, you can actually be diagnosed both ways through a biopsy or through bloodwork. So with the biopsy, it's called a direct immunofluorescence test, and that's when they do a punch biopsy of your skin. They put it in a fluorescent solution, and then they're able to determine looking underneath the microscope, what the disease looks like, the presentation of the disease. If it's done through a blood test, it's called an indirect immunofluorescence test and that's when they're actually looking at the antibodies that are present in your system. So it can be done both ways. The gold standard, at least currently out in the dermatological field, is a biopsy. The direct immunofluorescence test is a little bit more reliable than the indirect test. So, I would just make sure you consult with your doctor, on which test they feel is appropriate, but it can be done both ways.

**Amethyst:** Great. Thank you. Let's see, next question here. I'm going to direct this to Carolyn, and I'm sorry Carolyn I didn't introduce you. I didn't realize you'd be joining us today, but for those of you on the call, Carolyn is a bullous pemphigoid patient who lives in Virginia and also a support group leader for the Virginia/Mid-Atlantic area and a great volunteer in our community and an advocate as well. Carolyn, what type of doctors should a pemphigus or pemphigoid patient see for their condition?

**Carolyn:** Well, that's a good question. Really, I'll look back at my own experience. First, a dermatologist to really see them. I have bullous pemphigoid as you mentioned and a dermatologist first fall, to see them, to be able to appropriately diagnose the patient, either with bullous pemphigoid or pemphigus vulgaris. I've found that very helpful to get the patient on appropriate treatment. Other doctors that the individual may be seeing, as they're referred out by their dermatologist. And in my case, if you have activity in your mouth, an oral surgeon or an oral pathologist to help with the treatment of the mouth, particularly for the symptoms that can be unpleasant to really maintain that oral hygiene and also that treatment. Other things, sometimes an ENT is often employed if there's activity going on in the back areas of the mouth and into the throat and the esophageal area. It can be very helpful to see an ENT if there is activity also in the sinuses and nasal area. And sometimes, if it's deeper into the ear, sometimes an ENT. Other times too, if the patient is affected with the eyes, as Marc knows, an ophthalmologist to be seeing. If it's more, as we say below the belt, a GYN for those vaginal areas. Gastroenterologists sometimes if it's affecting the rectal or more deeper in the rectal area or they think the digestive system is affected. Something also that patients can employ I think, is very helpful and the other coaches may also want to chime in on, seeing someone else who can also help not only you but also your family in terms of seeing a license therapist, social worker, psychologist, or a psychiatrist. Sometimes some of those medications you are on can make life difficult especially when using the steroids. Sometimes you can be having a lot of those types of feelings that you need to make sense of not only with the steroids, but with your personal life. So employing a psychiatrist, psychologist, a therapist, social worker, or also seeing someone of your faith to help you through some of the difficulties as well. And I know, for me, I know for me, I see a dermatologist and I also see an oral pathologist now and then to help me with my mouth as well. So, those are a few of the things to think about and to discuss with your health care team.

**Amethyst:** Great, thank you. I think an important question to follow up with that is, we talk a lot about, like you said, a whole healthcare team, and there are a lot of doctors that you listed there. How does a patient find some of these doctors, or how do they know where to find somebody in their community? Mei Ling do you want to answer that or Becky?

**Mei Ling:** So on our website under the “Patients” tab, there's “Find a Doctor”, which is a form that you can fill out and answer all the questions, and then you have access to the map. And you can pinpoint practically where you are. If I were a patient looking for a doctor right now, you can enter in your zip code or you can look under your city and find a dermatologist closest to the area. If, by chance, you happen to live 5 or 6 hours away from the closest doctor to you, I also suggest to patients that have your own dermatologist, who's not fully educated about pemphigus or pemphigoid or your doctor, your primary care, to go through the list and perhaps find a doctor closest to your state who they could call and get a consult. That would be the best and my suggestion or e-mail any one of us and we can try to help you with our Medical Advisory Board to guide you in the right direction to finding a doctor.

**Scott:** I'll just add on to that. Before I was diagnosed, of course, I didn't know to go to the IPPF's website and it didn't exist in my mind, because I didn't know what I was supposed to be looking for. But once I saw several, what I would call regular doctors, my primary care physician, and then a couple of people that they referred me to and they said they had never seen anything like this. I kept trying. It was recommended to me by one of those doctors that this thing you have appears to be rare enough, Scott, you need to be looking at large educational hospitals. Medical centers affiliated with universities. They are more likely to be able to recognize what you have. So, with that as a tip, I started looking. I live in the Chicago area so I started looking for doctors at Northwestern and University of Chicago. Once I started doing that, I finally started talking to people who had ideas of what they were looking at, and it didn't take long from there that I got a diagnosis and the team. So that would be my other tip if you're looking for somebody who knows about pemphigus and there isn't anybody on the IPPF list, start with University affiliated medical centers near you. And you may have some success there.

**Amethyst:** Thank you. Did you have something you want to add, Marc?

**Marc:** Yeah. Just just to add on to what Scott was saying. One of the tips I always recommend is that if you've been diagnosed and you had a diagnosis through biopsy or a blood test and you're looking to build that team of doctors or find an expert in the field. I recommend that you get a copy of the biopsy or copy of the documentation of your diagnosis because you will find that this will be very important when you are going to new doctors or you're looking for these doctors because that's the first thing they're going to ask for is, do have a definite diagnosis? They're going to want to see that documentation of this diagnosis, otherwise they're going to just go start from scratch and do the biopsy again. And you don't want to have to go through all

that again. So, I know sometimes it can be a challenge to even just get a hold of your medical records but it's something that I highly recommend. Get a copy of that biopsy. Carry it around with you like you do your driver's license. Just have it in case you need it.

**Amethyst:** Great. Thank you. Rudy, I know a lot of people say once they've got their diagnosis and they found a doctor now, they're kind of intimidated when they go into the doctor. They're not quite sure what questions to ask or to make sure that they have a meaningful appointment with their doctor. Can you speak to any suggestions on tips for talking to their doctor to make sure that they're doctors hearing? That they're getting their questions and concerns answered and that they're truly leaving their doctor feeling informed.

**Rudy:** For one thing, if you get in touch with a Peer Health Coach you can get a patient checklist. And that sometimes helps out when you're going to the doctor, because it helps you outline what kind of questions to ask and what to look for. Another thing is, what I did is, I went through my mind prior to my appointment, and I wrote down questions, specific questions that I wanted to ask him as far as disease activity and treatment options. These are some other suggestions, maybe diets, food, things like that. That kind of helped me out, to write some questions down prior to my appointment. Whether it was seeing the dermatologist for the first time or going to your ophthalmologists or another specialists like that would be to kind of pre-write those questions down.

**Amethyst:** Anyone else have any good tips for talking to their doctors?

**Scott:** Another thing I would add as a tip. When I was having severe symptoms, my wife came with me to my appointments. So while I was in pain and discomfort and maybe not processing things as quickly as I might otherwise, she was there to remind me of the things that we had been dealing with over the last few weeks and make sure that we talk to the doctors about them. That was really helpful. There were some things that I certainly would have forgotten at some of those appointments without her there to remind me.

**Mei Ling:** That's really a good suggestion Scott because sometimes your partner, or your wife, your spouse, or your daughter, will hear things that remember things that you don't because you're right in the middle of the chaos in your brain of going to the doctor. Another thing I suggest is, if you have new blisters if you can take a photograph with your cell phone, so that you have it with you. So that, by the time you see your doctor a week could go by before you get an appointment, and at least you can show what the activity has been like up to that point, which can also be very helpful.

**Marc:** A couple of suggestions as well and I know the IPPF has what we call a checklist with a number of different things on it that you can take with you to the doctor and write down your questions in advance. Or, I like what Scott and Mei Ling are saying, if you're with somebody, designate somebody as the note taker. Somebody's taking notes during the meeting, that's really a good thing to do because trust me that doctor's appointment is gonna go by really fast. You don't get that much time with the doctor to begin with. So either you're gonna leave and you forgot to ask something or you can't remember what the doctor said. So having a note taker is really a good idea. Two other tips that I would provide. Something I kind of learned early on was, when I made my doctor's appointments I always asked for extra time upfront. Doctors actually schedule certain blocks of time for patients and unless you ask, they're not gonna give you extra time. So you can tell them, I want 15 minutes or I need 30 minutes for the doctor, and they'll actually schedule that time in advance for you when you make your appointment. So don't be afraid to ask for extra time because we all know we need extra time for these appointments because we're rare. Then the other thing I would do is I would always ask for my doctor's appointments, either first thing in the morning or right after lunch. And the reason that I did that is because I knew that as the day went on, doctors would get further and further and further behind because of patients like myself. So I always wanted to be the first one in line to talk to the doctor so that I didn't have to be the last one waiting. So I always made my appointment either very first thing in the morning, or right after lunch that way I could try to avoid being the last one dealing with the doctor or the doctor was dealing with it. Those are just some anecdotal tips that I used when I was seeing my doctors.

**Becky:** My tip would be, honestly, it's an advantage now is that we all have electronic records or most of us do for our hospital system. Make use of the messaging system and with the questions that you have in between appointments. If you show up with a long list of 30 questions, your doctor will probably tell you to pick your top 10% but if you do the messaging in-between, that's a great time to ask those questions. Also, make nice with the nurse's line. They are the gatekeepers in the office. So if you have a question, you can definitely send it to them. A lot of times they will call you back. I've had nurses tell me, and physician's assistants and nurse practitioners tell me, I really think we need to talk to the doctor about this, I'm going to shoot them a message. So it might not be as quick to do that, but use every resource available. Be nice to the office staff when you go in for your appointments. When you call, no matter how frustrated and in pain you are because, again, the more friends you have in that office the better off you're gonna end up being.

**Marc:** Nurses like sweets.

**Becky:** Nurses like anything.

**Marc:** I would bring sweets. They would remember me and they would always make sure if I had a question they were responses.

**Mei Ling:** I have one more thing to add. Not every patient goes in with just topical on your skin. Some of you will have oral blistering. So, if you see a dermatologist for the first time and you're going in regarding your skin, please tell them that you also have it in your mouth, who do you refer your patients to? So that it's not like on a Saturday, all of a sudden you get something in your mouth and then you have to wait until Monday to find out, and all of a sudden it's getting worse. So at least you would have a reference of an oral pathologist or dentist or hygienist, who they would recommend. So that's really important to find out. And then you can also let us know or let Becky know, your doctor referred you to a different specialist because this is also how we're able to help all of you all across the US and globally for a referral. But especially for your own peace of mind, you want to be able to have somebody that you know you can call right away.

**Carolyn:** Yeah, if I could add something, especially when COVID was active, I fell out of remission. And so we were kind of scrambling to contact my normal dermatologist and then the dermatologist at the hospital that I had worked with. And meanwhile, my mouth was blossoming in blisters. One smart thing that we did do, we immediately contacted our dental insurance. So we contacted our dental insurance provider and asked for a list of both oral pathologists and oral surgeons. We contacted our dentists, and we are a part of a large dental group here in Virginia. And once again, we asked for names of dental surgeons and dental pathologists and, of course, were those offices open as well. And also with the hospital, we asked, who was working especially for emergency situations. We also asked the dermatologist where they were referring or knew of any offices that were open. Again, even though I volunteer with IPPF, we were making calls and the IPPF team was looking on the map and also to see if they knew of information. So, when it comes to that dental situation, use all your tools and let them help you and ask those questions. We were immediately finding resources and getting me seen. So that's just something to put out there, I learned a lot about and I hope it benefits others.

**Amethyst:** Great. Thank you, guys. Those are great tips and like Mei Ling said for those of you that are on the call, if you have a doctor that maybe isn't listed on the list yet. And you consult with them and they say they are comfortable or they're familiar with treating the disease. We'd like to know about them because we'd like to expand our list and help others in the community. So if you guys have a provider that you know you're really comfortable with and you think is great, feel free to contact Becky or myself, and we'd like to reach out to that doctor and see if they'd like to be added to our list as well. We had a few questions come in about MMP. Rhonda asked, what is the incidence of having blisters on your scalp with MMP? She's unable to find a lot of information about this and currently has oral and scalp lesions. Marc would you like to answer that since you are our MMP patient today?

**Marc:** Certainly, as far as the incidence rate, I don't have those numbers offhand. But I can speak from my own experience. Having MMP I also had blisters on my scalp. It can be really challenging having those blisters on you on your scalp and finding a doctor that really understands how to manage it. A couple of things that I learned along the way with these blisters on my scalp, and it's not uncommon, by the way to have blisters on your scalp if you have PV (pemphigus vulgaris) or PF (pemphigus foliaceus) or even bullous pemphigoid. Having blisters on your scalp is pretty common across all of the diseases so it's not just MMP. But I think there's certain things, some interventions, that will help with blisters on the scalp. There certainly are topical therapies that will help with the scalp. Whether it be a corticosteroid gel or ointment. If the blistering is persistent and doesn't go away there's the option of intralesional injections. Not very comfortable and certainly not the best option but it certainly is an option if you can't get those blisters on your scalp to go away. Then there's some things I think that you can do to try to help mitigate some of the blisters on the scalp. The first thing is try to avoid really hot water and have the water from your shower beat down directly on your scalp. That will cause trauma to your skin and then the blisters won't heal. Then there's also some medicated shampoos that you can use that can help with the blisters on your scalp. One is called Clobesol it's a prescription shampoo that you can get from your dermatologist and that's like a steroid shampoo. But otherwise, you should really use just really mild shampoo and conditioner, nothing with lots of chemicals in it. You'll hear a lot of us talk about baby shampoo and things that are really easy to use on the skin. Those are things that you could do to help mitigate some of those blisters on your scalp.

**Mei Ling:** If you have scalp activity which I did. If you're a fella and you go out and play golf or ladies tennis, please wear a cloth hat, no straw hats because the sun's rays filter through the straw. Even on a cloudy day it filters through and you should wear sunscreen anyway, but also don't forget your ears and the back of your neck and your scalp and your forehead. So, that will help you to kind of avoid some blistering activity when you go out in the sun.

**Marc:** One thing I remembered, Mei Ling just reminded me of something. And I know she's seen a couple of posts lately and I know that I've talked to some people about this, do not pick the blisters on your scalp. I know it's really hard when they are itchy. It's really hard to resist picking at those blisters but do not pick at them because any trauma that you cause to your scalp, the blisters won't heal. And the same goes for popping blisters. So if you have tense blisters like in MMP or BP and it's a tense blister, it's not like an open lesion, don't pop the blisters. Do not pop the blisters. It can cause an infection and it can be really bad. So don't pop the blisters. You can go see a doctor and they will lance the blister and they will remove any fluid that's in the blister, but you need to resist from popping the blister.

**Amethyst:** Great thank you. Karen wrote in before our call and she said that her doctor detected MMP in her left eye last July. And then in November she noticed some symptoms in her right eye. She's been on 25 milligrams of Prednisone since October of last year, and is now tapering off after two infusions of Rituximab with three more treatments planned over the next



18 months. What's the chance of the second eye being unaffected permanently by the MMP given that she's been receiving her treatments and hopefully they caught the problems in her other eye quickly.

**Marc:** That's a good question. I think I could probably take that since I've had experience with ocular disease. I think the key is what she said, that she had early and quick intervention with the eyes. I had ocular disease in both eyes but I had it worse in one eye than the other. And because of the early intervention and the early therapy and treatments that were provided, the disease didn't progress in the other eye. I still had it but it didn't progress. I think it's just important to have that early intervention. The sooner that you can be treated, the less likely it will be that you will have problems in the other eye.

**Amethyst:** Great. Thank you. Going back to the skin lesions, Miriam just wrote in and she said, does it help to use antibiotic creams like polysporin on the skin blisters?

**Scott:** I can perhaps start with that, and then the others can weigh in. So there are a couple of reasons you might want to use something like that. Number one is if you fear there's actually an infection. If you have blisters on your skin, you have an open wound they could get infected. So certainly if that's the case, polysporin or neosporin or something like that would likely be something that the doctors would recommend. If you're talking about using it just to help the lesions heal, I'm not aware of there being a benefit of that. Although I will tell you that most of those ointments have vaseline or aquaphor or something similar as a base and just putting on vaseline or aquaphor or something like that onto the lesions can help with pain and discomfort because it keeps things moist and helps the lesions to not dry out and crack as much so it might be helpful in that regard as well. But if you're looking for something that might actually help heal the lesions in terms of an ointment or cream you're probably looking for something with a steroid in it. Clobetasol is something that you can get in ointment form or cream form and it's often prescribed for skin lesions as a topical treatment, in addition to oral treatment if you're on anything like that.

**Amethyst:** Great. Thank you.

**Carolyn:** If I could add something, I think that, from my own experience with bullous pemphigoid, I had a few serious bouts of infection, skin infection, that actually placed me in the hospital and it was a really long delayed time of care. One thing I learned from my dermatologist was good wound care. What is a sign of infection? And if I suspect I have an infection, what's the plan going to be? Should I come into the office and you take a look at me and decide if we are going to systemically treat you with some oral antibiotics? Or something topical, to add to that? I also was using both vaseline and Clobetasol topically on my skin that my doctor prescribed for me. And I was taking doxycycline and nicotinamide as well to include a couple of other medications. But we always discussed good wound care and what would an

infection look like and what would be the plan? Was there going to be something or should I come into the office? Early on into my journey, the doctor would say, this is what an infection of the wound would look like. And, if it does look like this, I want you to come in so I can take a look and we can either prescribe or decide if something topical was needed. Now that I'm a little bit more experienced, something that Becky shared, I'll send a portal note to let the doctor know, I think I might be dealing with something on my skin or in my mouth that's just taking a little bit of a turn that I'm not too sure about. But, I've always worked with my dermatologist and oral surgeons as far as either complications or infections. I kind of have a few plans of attack but mostly I'll follow up with them. Always mindful like Marc was saying, good wound care means let's not go creating more open skin lesions and leaving that open to infection. Taking good care of it and if something's going south, contacting my healthcare provider to let them know, besides keeping a good clean and good wound care. And I had to learn the hard way. I stick to the straight and narrow now and work of my health care team.

**Amethyst:** Great, thank you. Becky, can you put Clobetasol on an open wound?

**Becky:** Great question. I would definitely ask your healthcare provider. Me, personally, my doctor told me that I could, but I would defer, answering that as a broad answer to everybody not being a doctor. I did in my case, but again, I would ask your healthcare provider just for a definitive answer on that.

**Scott:** My doctors told me, and I only had lesions in my mouth, my doctors told me it was fine to put Clobetasol right on them but they said, if you suspect an infection, then you ought to be talking to somebody about that because Clobetasol, being a steroid, can inhibit the fighting of the infection. So you would not want to put only Clobetasol on if you thought that you might have an infection. You want to talk to your doctor and make sure that you're treating the infection as well.

**Amethyst:** Great, thank you. So Missy just wrote in and she said that her husband was diagnosed with PV and has multiple lesions in his mouth and at all times has constant nosebleeds. He started a course of medications, and is improving, although she did not write what he is on right now. But can you speak to the drugs that have been on anyone's road to remission, or even maybe some oral tips because those are a lot of a lot of questions that we get?

**Scott:** I can give a few. Personally, systemically what I took to get me into remission was a combination of prednisone and Imuran, or Azathioprine. It was slow, it took awhile until I was in complete remission, but I did get there. Others have had other experiences with Cellcept, Rituximab and other drugs. But specifically regarding the nosebleeds, I had that. And it wasn't

the kind of nosebleeds that you get when you get punched in the nose where it kind of is dripping blood. Rather, it was just the open wounds in my nose. If I sneezed, that would be a little bit bloody and it was painful and uncomfortable. In addition to the prednisone and Imuran which gradually cleared that up along with everything else I did get a steroid nasal spray, which at the time that I started using it was prescription but is now available over the counter. I think the brand name is Flonase but it has a steroid in it, triamcinolone I think is the steroids that's in it. And that can help heal things in the nose a little bit faster, and I don't want to oversell it. It's not like I sprayed it for a few days and I was all better. But I think gradually it helped things heal up in the nose better than not using it anyways. So that might be something to look at for the nasal symptoms.

**Becky:** For my PV, it was oral, and I just had a few lesions on my skin but it did affect my mucous membranes like my nose. For me, it was high dose prednisone and Cellcept. That was back in the day before Rituximab was widespread. And now it's FDA approved for a moderate to severe pemphigus vulgaris. So I think if I were to have a relapse today, I would lean toward looking at Rituximab. I also used the Clobetasol on 4x4 squares in my mouth. This is going to sound gross but shoving them up my nose as well, just to keep it in contact. Then the thing also that I used was a nasal saline spray in between to make sure that my mucous membranes were staying moist. My nose was extraordinarily painful from having my lesions. So one thing that I did was use the nasal spray to keep it moist, so it didn't dry out. Then there are some mouth moistening products that are over the counter that have glycerin in them. So I kept the glycerin swabs that you can get at the hospital, they're kinda lemon flavored, and would suck on those occasionally as well. About that time too Biotene came onto the market. Now, Act has mouth rinses as well. But those things were very helpful for me as well.

**Mei Ling:** Could I add a little notation here for all of you. I know a lot of you are on some of the Facebook groups, and you will ask others what have you taken, or what can somebody suggest? If you happen to take something over the counter, please write it down. Anything over the counter that you take, so that when you see your doctor you let them know because they need to know everything you're taking. And it might be that you're buying something over the counter that may have one of those long names that you can pronounce but the doctor will know and they might say I don't think that's a good idea because... so whatever it is, as minor as it seems to you, please let your doctor know what you've bought that's over the counter at the drugstore to treat whatever's been bothering you because they need to know everything you take.

**Marc:** Just real quick, to expand on what both Scott and Becky mentioned, at least for the nasal disease activity. I had some pretty extensive nasal disease activity and I actually ended up with a perforated septum from the nasal activity so it was pretty aggressive. But definitely what Scott said, there's Nasacort or Flonase, so there's that steroid nasal spray and it is over the counter now. What Becky said about the saline solution, to me that was probably the lifesaver. It was very uncomfortable but I did it three times a day and it worked. Then the last

thing that my doctor recommended was a steam inhaler and Becky kind of alluded to this, your nose gets very dried out from this disease. You can buy a steam inhaler at the drugstore and you plug it in a little bit of distilled water in it and it creates steam and then you just put your face over it and your nose. And it will create that moisture that you're lacking to help with the healing process with those nasal lesions. My doctor recommended it and it really helped. So I just wanted to mention that.

**Amethyst:** Wonderful. Thank you. For oral lesions, does anyone have a good recommendation for the best toothbrush to use?

**Mei Ling:** Soft.

**Becky:** Not an electric toothbrush. That really tore up my mouth. Some of the ultrasonic action was really, really harsh for me. When I get oral lesions my goto toothbrush is a toddler toothbrush. They are relatively inexpensive. They last a little bit longer than a surgical toothbrush, but they're softer, smaller and a little bit more rounded than the typical toothbrush. Being a little bit softer too helps. I also used kids toothpaste. For me, the mint was really bothersome and cinnamon was something I couldn't even think about. I will give the disclaimer, it takes a little bit for tooty frooty or bubblegum flavor to feel clean in your mouth. But the Children's toothpaste is generally a gel and has a little bit less abrasives. So those were things that really worked well for me. I also used a finger brush. And, again, those glycerin swabs have a little bit of a sponge and I would brush my teeth with that. One of the biggest tips that I got was actually from another patient. We think we know how to brush our teeth, right, since we've been doing it since we were little kids. What another patient told me was to stop thinking about having to brush the inside and the outsides of the teeth, instead focus on brushing a tooth. You don't need to brush your gums. You need to brush your teeth. Really take the time to focus. It's going to take a little bit longer, but focused on brushing a tooth and then moving on to the next one.

**Carolyn:** I think I could share a little bit on the oral hygiene too. Like Becky was saying, and I really learned going to some of the recent conferences, the child's toothbrush, soft toothbrush. Make sure you use a wet toothbrush. I usually use warm water. Generally, I'll first rinse my mouth out so it's not dry. In the morning you tend to have a dry mouth, so I rinse my mouth gently. It was Becky who shared this with me, brushing your teeth in the morning shouldn't be a race but that's what we do. We're half awake and going at it, going to town and all of a sudden we're in a bad way. Really take your time and just slowly brush your teeth. Again I use a child's tooth brush. Child's toothpaste sometimes or Biotene. Something else that Becky and Marc mentioned and Biotene has a spray. I'll even use that if my mouth has been a little bit on the sore side and then do my oral hygiene in the morning. Then as you're directed to and it just seems to go a little bit easier. Make sure the brush bristles are even. A lot of times the bristles

are uneven. I try to avoid brushes that are uneven or have some rubber or plastic. Just a plain child toothbrush in which the bristles are even and soft. And it just seems things go easier.

**Amethyst:** Great. Thank you. Renee asked, is it the norm or the exception for MMP patients to need ongoing dental or periodontal work for the rest of their lives?

**Marc:** I think it's pretty common that you're going to be experiencing issues, ongoing issues. It just has to do with the nature of the disease, unfortunately. You can do lots of things to try to mitigate it. Of course, see your dentist often, make sure you get your teeth cleaned, have good oral hygiene, all of those things. But it's just kind of likely that you're going to continue to have ongoing issues. One of the things that I think is good to remember is that, I think when you get diagnosed with this disease you learn that you have to take extra care with the oral cavity. How you brush your teeth, the toothpaste to use, the mouthwash. As Becky was saying, take your time and focus on one tooth at a time and go slow. Do all of those things because you have this disease. The challenge is, if you're lucky enough to go into remission, to remember that you still have to do those things, even though you don't have any active disease. Because if you do that, if you continue to have those behaviors, then you will be less likely to have more problems down the road. So, it's really easy to slip back into the old ways that you used to do things, if you go into remission. You go back to eating the things you used to eat, go back to doing all the things you used to do. It's really easy to take those behaviors that you were forced to do and not continue to do them. But the bottom line is, if you take those behaviors and they become habits and you continue to do the things you're supposed to do, then it will be less likely to have those problems going forward. That's my experience, anyway.

**Mei Ling:** I'd like to add in here, that it isn't just MMP. You could have BP, you could have CF or CP or PV, like I did. I had it on my upper back. I had it on my scalp, in the larynx, I had it in the gums. And when I first got it in the gums I thought my teeth were going to fall out, which most of us have that reaction when we see it. Whether you have or have not, any oral activity, you still need to take care of your mouth. You still need to be like other patients all around the US and the world, you need to see your dentist at least twice a year. Hopefully somebody who knows how to treat PV patients. You still need to floss, as hard as that might be for some of you, and you still need to be able to rinse and do everything else. The other thing that I would like to suggest because not everybody knows this, when you go to have your teeth cleaned, it is recommended that your hygienist does hand scaling and not use the electronic method. Your gums are very sensitive and if they slip and just one tiny millimeter of you could have a reaction on your gums. You might not but it is always safest to do hand scaling. So try to remember that when you go for a cleaning and let your dentist. And if your dentist doesn't know what pemphigus is, I always let my dentist know, and take some information. Take a screenshot off of our website for oral health care and let them know, this is what I have, and this is why we need to be extra careful. You need to let your dentist know about this as well.

**Amethyst:** Great, thank you, Scott. Did you have something you'd like to add?

**Scott:** Yeah. Since we were talking about dentists and keeping the mouth clean and all that. One thing that I think helped me a lot early on, I happened to have a dentist appointment and I was afraid because I was in a lot of pain and I was afraid that it would be painful. I grew up with two uncles who were dentists and never allowed me to miss a dental appointment. So I said, all right, I've got to go. The hygienist obviously realized there was something going on and I told her what it was and she had never heard of it. But I explained what was happening and even though she didn't know about the disease, she had a couple of ideas to help. So she did do what Mei Ling suggested, she did the cleaning a little bit differently and it didn't hurt. The other thing she suggested was, maybe instead of coming twice a year, come for cleanings three times a year because she correctly figured out, you're probably not going to be brushing quite as long as you might otherwise because it'll be painful. Plus, if the skin is coming off your gums, there's more chance of food getting caught and getting infected. Since then, I've had cleanings every four months instead of every six and it's definitely helped keep things calm in my mouth, and even when I went into remission I kept doing it because it's one last thing to worry about if I do get to a point where I'm not brushing or flossing as well as I could, well, at least I'm getting an extra cleaning a year and I think it's really helped keep things calm in my mouth.

**Marc:** Scott, you took the words right out of my mouth, no pun intended. For a regular person, a normal person, they should go every six months, right? None of us are normal people, so you should go more than every six months. So by going, as you suggested, every four months you're going to just be one step ahead. You're going to be better off by taking extra preventative measures. Every six months is for normal people but we're not normal people. So, you should go more often and that will help of course, prevent any long term issues. I'm with Scott.

**Amethyst:** Great, thank you guys. We had a few questions come in, in light of what's happening with the global pandemic about the COVID vaccine. I know these might be hard to answer and if you guys don't have the answer that's fine too. Somebody asked, should I be afraid of the COVID vaccine as possibly triggering a flare for my disease? If I'm on immunosuppressants, will that affect whether the COVID vaccine works or not? I don't know if any of you have experience with the vaccine, if any of you have taken it or not? Or any advice about should you be afraid to get the vaccine?

**Mei Ling:** I've had my first shot, and I'm going on the 19th for my second and I am getting the Moderna. It didn't hurt, it was like a regular flu shot, so there was nothing but I've been in remission. So, I don't have, as yet the same concerns about being on an immunosuppressant. I would discuss it with my dermatologist and say, I might be in the next tier group to get it. Should I get it? What can I expect? Because only your dermatologist can have this conversation with you. We do have on one of our webinars, actually three webinars, the subject

was COVID. So you might want to go to where the webinars are and go scroll down to those conversations and listen to them. But I know that there's a time period too where, if you're on Imuran, IVIG or Rituximab, there is a timeframe for before and after getting the inoculation. But, again, have a conversation with your dermatologist.

**Scott:** The Patient Education webinar on December 9th, 2020, I think I got the date right. You can access on the IPF'S website, there was probably 20 or 30 minutes of discussion about the vaccines including how they interact with immunosuppressants. There were some slides and a chart about how far apart you should be with respect to any immunosuppressants and getting the vaccine. And that was about making sure the vaccine would work, not suggesting it was dangerous to get them closer together, but it was more about efficacy of the vaccine. But when people have asked me, as a Peer Health Coach about the COVID vaccines, that's pretty much the go to spot that I'm aware of and the most discussion that we've had on it.

**Amethyst:** Great, Becky, Terry wrote in and asked about the vaccine as well. They wanted to know if they should get the vaccine, if they have active BP?

**Becky:** Again, it sounds like such a cop out answer, but I'm gonna defer you to your doctor. I think vaccines, any sort of treatment is a very personal decision. And in order to make the best decisions, you need to have some really great conversations with your doctors. There is a COVID page on our website and I'm happy to send that out to anybody if you want to follow up with me and ask me or you can look for it on the PEM Press page of our website. Our medical advisors did make a broad statement and said that they, along with an organization from Europe, do think that the vaccine does benefit our community. But, again, I'm going to defer to your providers. We're all a little bit different. We all color outside the lines in a different way. Otherwise, we wouldn't have these diseases, right? So I think it's a great thing to talk to your doctor, especially to discuss if you have active lesions. If there's open lesions, your infection risks are all great questions to ask by your doctor and how your current treatment is going to affect the effectiveness of the vaccine if it's going to tamper it down or have any issues at all. Please have these really meaningful discussions with your doctor. If it's hard to have those conversations talk to the nurse. Use that message box, but really get all the information you can from your provider and have that information be as specific as it can be to your particular case, to make sure it's the right decision for you.

**Amethyst:** Great. Thank you. One last COVID question or COVID vaccine question. Tapas wrote in before the call and she wanted to know after she does receive the vaccine is it okay for her to travel outside the country? I think she said she's located in India right now, but looking to travel to the US. Or even begin to gather with people and see friends? Is there any consensus or did our medical advisory board speak to anything about that?

**Becky:** My guess is, when Dr. Fauci says it's okay for us to do it then I would have more confidence and do it. Right now, Dr. Fauci is saying that we need to wear, the general public needs to wear double masks and the best thing that we can do even after getting the vaccine, just because of all these new variances, to still keep our distance, let it die down, keep washing our hands. Being vigilant and proactive and preventing this disease. I think, personally, for me I still wear my mask, we wash our hands. It's very hard and my son is asking if we can go see his grandparents for his birthday because we haven't seen them in a year, other than through Facetime. So I know it's very hard, and it can be very isolating, especially when you have a rare disease. But I would contact your local health department, find out what they're saying about the disease in your area. Keep the numbers in mind and truly follow the data. Again, talk to your doctors. Listen to the local health department. Listen to trusted experts like Dr. Fauci and find out what truly is going on at both the broad level, but also in your smaller area as well.

**Amethyst:** Thank you guys. Well, that was a very quick hour. I know we have tons of questions that still did not get answered. We skimmed the surface and didn't really touch base on tons of medications, but like we said, we're always here for you guys. So if you guys still have questions that went unanswered and you'd like to talk to some of our coaches about them please connect with them. Marc, can you just let everyone know the best way to connect with the coaches after this call, if they have questions about either specific medications or anything like that?

**Marc:** Absolutely. So you can find that on the IPPF website, [www.pemphigus.org](http://www.pemphigus.org), the "Ask A Coach" button. Go to the main page, and scroll down, you'll see it says "Ask a Coach" and that will connect you with it with one of us. With a coach that can help answer your questions or just even chat with you and talk with you about whatever you're experiencing. That's what we're here for and we're here to support you and provide any insight that we can to help you deal with these conditions and learn how to improve your lives. That's the best way to get a hold of us.

**Amethyst:** Great, thank you. Well, before we go, I do have a few quick announcements. We have a lot going on in our community in the next few months, so I'd like to share that with you. I'd also give a huge thank you to you guys for joining the call and to our sponsors, Genentech, Principia Biopharma, a Sanofi Company, argenx and Cabaletta Bio for making today's call possible. So, starting next week we will be hosting a treatment mini series where they will be discussing common treatments for pemphigus and pemphigoid including: prednisone, IVIg, immunosuppressants, Rituximab, and anti-inflammatories. This series is meant to provide information for the newly diagnosed patients and increase their knowledge of treatments as well as provide insight into treatments for those of us who are "more seasoned" patients as well. The first webinar will be on February 24th to discuss prednisone with Dr. Donna Culton, Associate Professor of Dermatology at the University of North Carolina School of Medicine of Chapel Hill. Registration will open soon for the webinar. Following each webinar in the series,



you will be able to register for the subsequent webinar. So please make sure that you register for each webinar that you would like to attend once the registration is open.

The IPPF will be participating in Rare Across America at the end this month. During this event, the IPPF and advocates from our community will be meeting with our congressional representatives to spread awareness about pemphigus and pemphigoid and advocate for legislation that helps the rare disease community. Although registration is closed to participate in these upcoming events, there are still many ways that you can get involved and also show your stripes during Rare Disease Day, which is the last day of February. Rare Disease Day is a patient-led international awareness campaign that brings people together in solidarity with the 300 million patients impacted by rare diseases worldwide. You can learn how you can get involved in Rare Disease Day and how to “show your stripes” by visiting [www.rarediseases.org/rare-disease-day/get-involved/](http://www.rarediseases.org/rare-disease-day/get-involved/)

Are you interested in helping accelerate research? The IPPF is participating in GlobalSkin's Global Research on the Impact of Dermatological Diseases project, the Phase 3 – Patient Data Verification Delphi (the Delphi). GlobalSkin is calling on adult dermatology patients representing all diseases/conditions to participate in the study. By participating in, you will be helping to design a new and credible measurement tool (questionnaire) that fully explains the impacts and challenges that people living with dermatological conditions experience. Studies like this are a great way to help advance medicine and treatment for pemphigus and pemphigoid patients. If you are interested in participating in the survey, please contact Marc Yale, at [marc@pemphiugs.org](mailto:marc@pemphiugs.org) and he will send you the link to participate in the study.

The IPPF has been looking towards the future and how we can continue to help you and our community. We need your help to grow our community of Healing Heroes. Healing Heroes fund the future of the IPPF community by making sustaining, monthly gifts to support our mission of improving the quality of life for all those affected by pemphigus and pemphigoid. No amount is too small, even a \$5 or \$10 monthly donation goes a long way and continues to allow us to provide for the greater good of our community.

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](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!

Lastly, If you have a question that didn't get answered on the call, or have additional questions please e-mail Becky Strong, at [becky@pemphigus.org](mailto:becky@pemphigus.org), or call (916) 922-1298 x:105, and we would be more than happy to help. Or like Marc said you can contact one of our Peer Health Coaches and they would be more than happy to help as well. Go online to our website and find the "[Ask A Coach](#)" tab. Great everyone thank you so much for attending our webinar today and thank you coaches for all your great tips. It was very helpful and we hope to see you guys soon. Thank you so much, have a great day everyone. Bye.