

## May 27, 2020 Patient Education Webinar- Peer Support with the IPPF's Peer Health Coaches

**Amethyst:** Welcome, everyone! This call is now being recorded. I would like to thank you for being on the call this evening and to our Sponsors Genentech, Principia Biopharma, Argenx, and Cabaletta Bio for making today's call possible. Today's topic is Peer Support to answer your question about living with pemphigus and pemphigoid with the IPPF's Peer Health Coaches.

Before we begin, I want to take a quick poll to see how many of you have connected with an IPPF Peer Health Coach (either by phone or email)?

While you are answering the poll let me introduce you to the IPPF Peer Health coaches:

- Marc Yale is the Executive Director of the IPPF and also works as a PHC. Marc was diagnosed in 2007 with Cicatricial Pemphigoid, a rare autoimmune blistering skin disease. Like others with a rare disease, he experienced delays in diagnosis and difficulty finding a knowledgeable physician. Eventually, Marc lost his vision from the disease. This inspired him to help others with the disease. In 2008, he joined the IPPF as a Peer Health Coach.
- Becky Strong is the Outreach Director of the International Pemphigus & Pemphigoid Foundation and also works as a PHC. She was diagnosed with pemphigus vulgaris in 2010 after a 17-month journey that included seeing six different doctors from various specialties. She continues to use this experience to shine a light on the average pemphigus and pemphigoid patient experience of delayed diagnosis and bring attention to how healthcare professionals can change the patient experience.
- Janet Segall is the Founder of the IPPF. She was diagnosed in 1983 and started the Foundation in 1994 with the express purpose of giving people living with this very rare disease a place to find information and others also living with pemphigus. In 2009, Janet received her certification as a hypnotherapist and began working with the Foundation as a Health Coach in 2015.
- 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.
- Carolyn Fota became a Peer Health Coach with IPPF in August 2019. Carolyn was a newly retired U.S. Army Lieutenant Colonel Medical Service Officer when she first experienced the undiagnosed symptoms of Bullous Pemphigoid in October 2015

following a simple same day medical procedure. Carolyn experienced body wide blistering to include oral lesions for almost six-months before being correctly diagnosed and treated. Carolyn has actively participated in Rare Disease Week on Capitol Hill since 2017, writing articles for IPPF's magazine, Mid-Atlantic Support Group Leader, Representing IPPF at various events and meetings and last year serving as a Peer Health Coach.

**Amethyst:** Welcome everybody to the call! Looks like about 59% of people have connected with a peer health coach in the past. That's great, and we hope that all of you can share all of your great knowledge with us this evening. Coaches are here today to answer your questions about living and managing Pemphigus and Pemphigoid and they're here to share their tips and tricks based on their personal experiences. If you do have a question that does not pertain to today's call subject, I will ask you to email me your question after the call. Also, if your question begins to exceed one minute and is linked, I will ask you to please proceed with your question to allow enough time to answer everybody's questions. So it is now my pleasure to introduce the IPPF's Peer Health Coaches to answer your questions this evening. Welcome, everyone!

**Amethyst:** Similarly to probably with family members, did anyone experience difficulty letting their family members know when you were first diagnosed?

**Mei Ling:** When I am speaking of a patient on the phone, whether it's a husband or a wife or a son or daughter. I always say, it would be a good idea to sit down with your family members and say, I know you're worried. I knew I was, too, but we don't have to be as secure about this. We have the International Pemphigus and Pemphigoid Foundation. They're available to us all the time. We have the best medical boards. So, we're available to them, and they don't have to be afraid. And I do stress, especially if you're a married person, and your partner, or your children and let them know, you're OK, because one of the biggest causes of a flare of stress and when a family member is worried about you, they are stressed, so we'll get into caregiving later. But when they're stressed then you stress because you're worried that they're worried and then it goes back and forth, like a ping pong ball. So, it's really a good idea to sit down with them and say, We don't have to worry as much anymore. We have the great support of the IPPF. Because you never know what they are thinking when they shut the lights out at night.

**Amethyst:** Great, great. Thank you. And when you say that stress can sometimes make the condition worse. How have you handled stress in the past? Or do you have any

recommendations for our listeners about how they can handle stress so that they don't have a flare.

**Mei Ling:** Ooo! Well, that takes some practice. Just like in the beginning with everybody else, all the wrong things on the internet. So, I would do deep breathing. I try to remember to breathe. If you can be calm and take your breath in, lower your blood pressure. Take our stress level down, you're ahead of the game. A lot of it has to do with support for your family. Maybe if you have a church pastor, for Spiritual. I happened to be spiritual, so I practice different things. Breathing, meditation. Listening to music, take your dog for a walk. Even today you can still take your dog out for a walk. Just try to relax and try to remember or worst-case scenario, you get really crazy, just send a text. Send an email to me, I'll call you back. We're here for you.

**Amethyst:** We appreciate that. Any other coaches have any great recommendations or things that they've done to help them relieve stress.

**Janet:** I find meditation of course is very good for helping with stress. Certain foods, cut down on the sugar. Try not to eat too much at one time. It can be healthful with stress. I do hypnotherapy, I do self hypnosis. That's really helped me a lot. It's just like a very strong meditation. And feeling grounded, ground yourself, which I think has been very helpful, too. Take a walk, if you can. Walk your dog, or walk yourself, or call somebody you love, and make sure that people you feel comfortable talking to you about your disease, knows about it, and you can call the IPPF always.

**Amethyst:** Great advice, especially during these stressful times. You know, I think it's very important to find something that is helpful for you, and helps you relieve some stress. We had a question come in and the question is: Once you've been diagnosed, what is the best specialist to see?

**Marc:** That's a great question. I think it really obviously depends on where the disease activity is. I also think that if you have disease activity in multiple locations, you really need to have a good team of physicians behind you to kind of help you navigate and manage your disease. It really depends on where the disease activity is. I would like with a caveat say, though, that most of the systemic therapies or medications that are being used for this disease are given through a dermatologist. So, sometimes, even if you only have disease in your mouth and you don't have disease on your skin, an oral physician may only be able to prescribe certain types of medication, systemic medication, to help you. And so, eventually, you may still end up

needing to see a dermatologist or a specialist who knows how to treat the disease systemically because it's an autoimmune disease. So, I always recommend, you know, make sure you've got a good dermatologist in your back pocket if you're not already seeing one. And, we, the IPPF can help, I refer you to experts in the field. Unfortunately, there's not experts in everybody's location or geographic area. But, you know, we'll do the best to try to refer you to a physician that has expertise in the disease to really help you manage and understand your disease. But, it just, just really depends. I mean, I saw a dermatologist and oral doctor. I saw several different eye doctors. And then, of course, I had a general practitioner, or my family doctor, that helped me manage not only the disease, but all of the side effects from the medications, and really helped me kind of just manage my general health. So it's important to have all of those doctors onboard, and hopefully they're communicating with each other, if not, you're that conduit, to really make sure that they're all communicating and they all are aware of what's happening with you.

**Amethyst:** Great, thank you. A few questions come in in regards to taking different supplements, whether they're vitamins. One person says, I've been taking supplements to build my immune system and sores began to get worse, is this because they're building their immune system?

**Marc:** Yeah, that's exactly the case. Because the last thing that you want to do is boost your immune system because in this case, we all have what they call an autoimmune disease. So that means the stronger your immune system is, the worse the disease will get. So, it's important that you're not boosting your immune system and so I would avoid supplements like echinacea or other types of things that boost your immune system. Now those supplements are different than vitamin supplements because the medications and the disease itself can deplete certain vitamins in your body. So, it's important to talk with your physician, that primary physician or whatever position you're seeing, to test your vitamin levels. To see if you have any deficiencies in vitamins, and if you do, then that would be where you would want to supplement those vitamins. But that's totally different than, say, an immune booster. And I think, Janet, you can probably talk about this, too, because I know you've worked with a lot of people that have tried to boost their immune system, and it just, you know, sometimes it can be fairly disastrous.

**Janet:** Yeah, I think it's really important, too. Try and normalize your immune system, if that's a real term. I think you don't want to do anything to increase it like Marc said. But I find that eating well can help with your immune system without over activating it. So, there's been some

studies that have shown certain foods, like spirulina. You don't want to take that because that's definitely shown to increase Pemphigus. Doctor Worth talked with me many years ago about somebody eating 5 pounds of chocolate and getting blisters. So, you know, you have to go with your own reality on how this is but don't be very careful about supplements that you take, especially herbs. Make sure that you're not overdoing your immune system because they say that there are some people out there that talk about autoimmune diseases. People with autoimmune diseases already have a ramped up immune system, so you don't want to make it more ramped up. So, yeah, watch your food, watch your supplements. Fish oils are good or eat a lot of fish.

**Becky:** I just wanted to add to that, if anybody is considering taking a supplement, it's always a good idea to run anything either over the counter or prescription by the doctor who's treating your disease. That way, you can make sure, you know, they can do a little research and help you might have knowledge, as well, that can help determine if whatever supplement that you're interested in taking will be doing exactly the opposite of what the medicine they're prescribing can do.

**Janet:** Also, ask your pharmacist. They understand drugs and supplements very well. Better than some doctors. There are some doctors where I go that are Integrative Medicine, doctors, TA, MDs, but they also are in natural medicine. So, if you have an Integrative Medicine doctor in your program, you might be able to consult with them if they know how to treat or what's best for autoimmune diseases.

**Marc:** One more thing, too, that I would say is that, you know, as Janet mentioned, I mean, there are some natural, anti-inflammatory things, like cumin, or cinnamon, or things like that, that you can put into your diet to help supplement, you know, and help bring down the inflammation in your body. So there's definitely things like that, that you can do, as well. The other thing that I would caution people about is, if you go onto Google, which everyone does, when you type in Pemphigus you will find some claims on the Internet that there are supplements or natural drugs that will cure this disease. And I just want to let people know that though that is not true, that those people are unscrupulous and just trying to basically get your money. So, I would just caution people to not pay attention to those things and really deal with what Becky said, and that is, talk to your doctor and consult your doctor. These people are experts on the disease.

**Amethyst:** Great, Thank you, guys. Looks like we have a question from Ashley. We're going to unmute you, Ashley, if you're on the line. If you'd like to ask your question to the coaches.

**Ashley:** Ok, yes, I'm Ashley. I'm from New Orleans, and I have Pemphigus Foliaceus and I actually did have COVID-19 and I was in the middle of receiving Rituximan and my doctor actually stopped treatment. So only had two infusions and I had a really bad flare, and she's not really sure what to do. Between the flares, she's just basically done the narrowest, but it has weakened more of my immune system. So I was trying to take some vitamins and things to boost it back up. At this point, I'm not really sure how many infusions and she's not really sure, but we can't really do anything with the antibodies. She's going to test but we're just kind of at a standstill of what to do. So, I'm not sure if I should boost my immune system after having it or another round of infusions. She was going for four, but we only did two and I've been having really bad flares.

**Marc:** So, Ashley, you did have COVID-19, and you recovered from that, is that correct?

**Ashley:** Correct.

**Marc:** I would say it's it's it's a very good question, Obviously, There's a lot that we don't know right now about COVID-19. And you know how it affects your treatment and your therapy. Are you seeing a doctor in New Orleans, an expert in New Orleans?

**Ashley:** Yes, Dr. Bow

**Marc:** Dr. Bow is obviously very familiar with disease. So, that's good. You're in good hands with Dr. Bow. But, it's a, it's a really good question. So, you know, I don't think you want to, just going back to what we were saying before. You don't want to boost your immune system. Because, it's going to, it's going to make the disease worse. But, maybe, stopping that therapy when you did was probably a good thing, because, if you've had COVID-19, or you're having COVID-19, and it's attacking your immune system, the more suppressed your immune system is. The worst COVID-19 will be.

**Carolyn:** I think the suggestions are really great, especially what Rudy said. One thing we did, we would put sheets down, and just cotton sheets, and I would look almost like an athlete walking around our home, which is wearing loose shorts, and that are breathable athletic shorts, T- shirts. Something that Becky was alluding to my doctor really emphasized was keeping my fingernails short, my toe nails short. And I wore socks on my hands at night because I would itch and like Marc was saying, that first itch and that was comfortable for me, the gloves made my hands too warm. And I did take cool showers and just very gently dry, and I think Becky was also sharing about that. All those little things really add up over time. And then just something distracting to listen to to fall asleep too and then if you wake up, you're not that old habit of itching. You're listening to something familiar and falling back asleep, again, getting drowsy and something that will assist you to relax and fall asleep and stay that way. So, you're not getting up and getting excited and itching, and you're walking the house. And just those kinds of things. Additionally helped me and those distractions and those calming influences that would help keep me asleep.

**Amethyst:** Great, thank you. And on the same lines, as far as skincare goes. Can patients with Pemphigus and Pemphigoid go out in the sun and if they do it is a physical sunscreen better, or a titanium dioxide or zinc oxide versus like a chemical sunscreen. Becky, if you want to maybe answer that.

**Becky:** Sure. So, what my doctors told me is that physical sunscreen is better. They make clothing that is on SPF clothing, shirts, pants and hats, and so that's always really good. There was breathable fabric as well and so that helped quite a lot. My dermatologist preferred the titanium oxide sunscreen or the physical barrier rather than the chemical barrier since I did have some open lesions. So going out in the sun can exacerbate our condition from my understanding, so don't limit your life but just be smart about it, right? I think that tips that worked for me were not going out during peak hours, and going out in the morning or a little bit later when it wasn't so hot wearing my sunscreen. I'm a big advocate for sunscreen for many reasons including like my dad had skin cancer. So, definitely, It's something that I look for in make-ups and different formulations. I will spray it on. I will use the creams and the biggest thing with sunscreen is to remember to re-apply it. The average adult needs one ounce. Or, the equivalent of a shot glass of sunscreen to cover their body when they go out into the sun. So, that's something to remember a lot of us don't use enough. Another thing is my dermatologist, you go to your dermatologist for your condition, but also have them do his skin check. Look for new moles. A lot of times with everybody wearing flip-flops, moles can develop underneath at

the end of our toes or between our toes. So definitely be checking all your surfaces for any changes in any skin condition and let your doctor know.

**Amethyst:** Great, thank you. And kind of along the same lines, I know that summer is right around the corner and we're all really excited, Rudy, you live in Texas and it's very warm there. So we had somebody ask, is it ok to go swimming, especially if you're having any open lesion?

**Rudy:** What I used to do is, I'm not a real big swimmer, but I do tend to sometimes get in the pool with the kids. It's not always, it's not really safe to go in. Especially in the pool with an open lesion because there's chlorine in it and the chlorine will burn. It will sting your open lesion if you have any open lesions. Now, once you're in remission, there's nothing that says you can't go to the pool, but like Becky alluded to, be sure that you're wearing sunscreen and you re-apply and they also make swimshirts to use while you're swimming. And I believe there's a lot of surfers and things like that that they use those swim shirts and that's an option to go with. They have them in long sleeved shirt and short sleeves and they also have some SPF protection in. And also be sure to wear a cap or hat or something to cover your head from the sun if you have any lesions on your head.

**Mei Ling:** I have three things, like Rudy says to have a hat. I always caution people, Straw hats, are out because the sun filters through the straw. So have a cloth hat or a baseball cap. If you're driving in the summertime, you always get that driver's arm. The one that gets the sun on the window. Also, need to remember to put sunscreen on your ear lobes on the back of your neck. A lot of people, especially the guys, forget the back of the neck, the ear lobes are really important, because you can get skin cancer there. And if you happen to have lesions that are on shoulders, or arms, you want to be able to protect them.

**Amethyst:** Great. Thank you. That's great advice. We're going to move on to some oral care and maintenance because many patients are affected in the oral cavity. Does anyone have any good recommendations of a toothbrush and toothpaste that they used?

**Becky:** When I had active lesions in my mouth, I would use a toddler's toothbrush. They tend to be a little bit smaller, and a bit softer and rounder, so, they weren't poking in my mouth as well. As a grown up now and in remission, I do use an extra soft toothbrush that my dentist specially orders for me. I think it's my crest, but a lot of different brands make very, very soft toothbrushes. I also was very irritated by mint flavor, so I would use a children's toothpaste which is a gel more than a paste. And the gel is usually a little less abrasive than a tooth paste. It did. I will warn you, take a little bit to get used to strawberry or tooty fruity or

bubblegum to equal clean. But it definitely didn't burn like some of the mint toothpastes do. There's a lot of toothpaste on the market that are natural toothpaste. Just watch the ingredients. One thing that I find, that even in remission, that the sodium sulfates can cause issues in my mouth or some of the whitening agents that they put in different toothpastes can also be very irritating. For those of you who are on the call and don't know, that's the sodium moral sulfat that makes all the foaming in your mouth to dental companies a lot of forming equals a lot of clean, and that's why they put it in there, but really it's not an unnecessary ingredient. I've also heard some patients talk about using a surgical toothbrush. Surgical toothbrushes are meant to last, real long. So, you may need to replace them every couple of weeks. And another recommendation that I've heard is that with oral lesions, it's best to avoid the ultrasonic or electric toothbrushes because it can remove extra tissue. My dentist and oral medicine specialists also stress technique. We don't need to get in there and be kinda sawing at it and brushing our gums. Really the important part is brushing our teeth. And my dentist encouraged me to focus brushing one tooth at a time, not like a side or my tops, or my bottoms, but to focus on brushing an individual tooth at a time.

**Mei Ling:** Little suggestion- if in the meantime, you haven't found a toothpaste that works for you, there is the old-fashioned soda water which you can make a paste out of. And if you want to do what they call, pulling, which you can do with coconut oil which can ease the gums but you need to remember to spit it out in the trash can. Because if you spit it up in your sink, you're going to end up calling a plumber. Also, we've been told by one of our oral experts at UCLA when you go for a high gel screening, if you can ask for hands rather than the machine, and tell them to be very, very careful. So they have to be very careful around your gum area. Hand scaling is a lot better.

**Amethyst:** Great, thank you. We have another question: Renee says she has MMP patient with multiple oral lesions. Her dentist, her periodontist and her dermatologists have all recommended that she get her teeth cleaned every three months rather than every six months. How often do you guys get your teeth cleaned? And once she goes into remission, does she need to go less frequent?

**Carolyn:** I think I can answer that. When my condition was very active, I was getting dental cleanings every three months. Then, when I went intermission, we changed that to about every four months. And recently, I've had some recent activity with my mouth and we've got that under control. One thing, both the oral surgeon and the dental hygienists and a dermatologist said was, Let's go back to every three months. And, again, not doing the scaling kind not with the electrical kind of treatment and what's also helped us when they put a little bit of that gel on your gums. It's not so sensitive and you don't feel everything, and taste,

everything. You can feel a little more comfortable with that. But every three months there was a very noticeable difference. I'm glad I was doing it, kind of getting back into that, too.

**Marc:** I would say that the reason that you want to do it every three months versus every six months, is because there's a lot of bacteria, and your mouth can build up over a short period of time when you have this disease activity. And they know that not having your teeth cleaned will actually make the disease worse. So if you have a lot of activity in your mouth, it's a really good idea to switch to that every three months at clean versus every six months.

**Carolyn:** I have to agree with Marc, where I had an appearance is, where I'd had a lot of heavy dental work before everything happened with COVID-19, and I was supposed to have a dental cleaning, we put that off and put that off. And then the first thing, the oral surgeon said, was, Wow, wish we could have stayed on top of the dental cleanings and with some of the heavy dental work. When we may not have encouraged some of this activity to happen. And so, Marc is absolutely right. We got back on scheduling, and things quickly got turned around, and it really proved to me that aggressive dental hygiene really is worth the time and effort.

**Marc:** It's painful, but it will pay off.

**Amethyst:** Becky, you had mentioned a little bit more about the hand brushing. Cheryl asks, do you recommend a water pik?

**Becky:** Great question. I think it's how bad your diseases are. When I started to heal like Carolyn and Marc alluded to, I was going to the dentist every three months, and I come from a long line of heavy plaque filters and it was something that my dentist suggested. I've been in remission since 2013, I'm very proud to say my water pik is all the way up to three right now. I use it just enough to get through. Again, you just have to be very careful with your technique. I don't make any recommendations for anybody else. I always tell people to talk to their dentist about it, and their dermatologists even though the lesions are in their mouth, and they can help determine if it's right for them. But I do use it, I just use a little bit of not quite warm temperature water, not cold, but kind of at that temperature where you can't even feel it. And then I'm very careful when I do, like I said, I am very careful to get it just between my teeth because that will remove tissue. And the other thing I was gonna say about just going to the dentist. My dentist used topical anesthetic for my cleanings as well. And I'm very proactive at telling my dentist, when I have oral lesions. They use different things like a topical lidocaine gel and they'll let it sit on the area that's really inflamed before we start working on it. And then that

way it's not such a tortuous option as well. If you have to go in, and if you've really got some lesions talk to your doctor about it.

**Amethyst:** Great, great advice. If any of you had any experience being prescribed any clean medications, such as an antibiotic before they did go in for a dental visit, she recently had a knee replacement. Her doctor has told her that she might need to take antibiotics before she goes in for her dental cleanings.

**Becky:** That's a great question. Generally, there's different standards of care for, like the College of Orthopedic Surgeons and the American Dental Academy. So, that's something really that they should talk to their dentist about their dentists and their surgeon for the knee replacement. I don't know what the current standards are, so it's always a good idea to check with the doctor before any sort of procedure or cleaning, just to make sure. And it's also good to, if you can get your dentist and your orthopedic surgeon who did the knee replacement, to talk to one another. Sometimes, we, as the patients need to be the conduit, like Marc alluded to earlier, but one thing I did very early on, again, with my team of doctors. If the dermatologist prescribed something, I had them send a note to my internists, my dentist's, my oral medicine specialists, and the same for the other doctors. Could you send my appointment note to the other ones to try and keep it in a loop? I also requested copies of my office notes and kept the papers that came with my prescriptions and kept a notebook. I started with a two ring, two inch binder that progressed to a four inch binder. Sometimes then I would take it with me to other doctors appointments, so that everybody was in the loop. And if they needed to copy it, they could do that, too.

**Amethyst:** Great advice. Asking that she seems to only be having a couple of oral lesions at a time. Is it better to treat her pemphigus now? Or is it better to wait to see if it gets worse? And then go for treatment?

**Janet:** I think it's better to be treated now before it gets really bad, because you may not need as much medication now as you might need later. Absolutely go to be treated now, don't wait because it will progress. Pemphigus does progress, like it or not. It just does. So, go now and get it fixed.

**Marc:** I agree with Janet. It's a progressive disease, so that means it can progress slowly or can progress rapidly, but it will progress and if it's left untreated, it will progress faster than it will be treated. So, I 100% agree with Janet it needs to be treated sooner than later.

**Carolyn:** If I could add to that too. oh, I gotta bite the bullet. You know, I've been doing so well. All of my coaches are here listening to me. And I even consulted with Becky. This past winter I bit the bullet and saw the dermatologist and the oral surgeon. And then I went to a dentist and I was glad I did because when we took care of it, a dental situation had gone undetected and they're all absolutely right. You really don't know if you're going to wake up with a real serious issue. Get seen, get medication on board, and they know what's going on with you. So, if you need further help, and I was glad I did it. Got it addressed real quick.

**Becky:** I know I'm going to sound like a broken record when I say this, but one thing is to keep your doctor in the loop. There have been times when I've had a couple lesions and kind of in that same place. I don't really want to go back on the prednisone. I don't want to go on this medicine. But, I'm going to tell my doctor now and let them know that you know how I'm feeling and what my concerns are that I don't want to go on these big doses of medicine for a long time. How about if I write this out for a week? Let's try some topical. And if it goes away, it goes away if not, I'll do it your way. And luckily, I had a doctor who realized there was a pretty good negotiator and that we worked well together. That we set some ground rules of when I should call them, and I think that's a question everybody should ask if your lesions are healing up and you're approaching remission or, if you're in remission, ask your doctor when I should call you when I should be worried. My doctor says that when you have five, you call five, because that's in his name. So he tells me if you have five lesions to to call him, and it's a really easy thing for me to remember. That's his threshold and his comfort, but I'll notify him if I only have a couple as well.

**Marc:** As coaches, I think this is a question we hear a lot is, how do I know it's getting worse? Or how do I know if it's getting better? How do you know? The way to really navigate that is to look at the amount of disease activity you have. So whether it's individual blisters or individual areas that are breaking in, then it has to do with the frequency. So the frequency of how long lasting and the frequency of how fast they're going away and maybe even reoccurring. If you're having more activity or more blisters that means it's getting worse. If the frequency is happening more rapidly or they're lasting longer, that means you're getting worse, just the opposite to the same thing to see you're getting better, less amount of activity. That means you're getting better or if the frequency is, like the amount of time in between the blisters is getting longer, they're not coming as quickly. That means you're getting better. So, those are

really ways that you can just judge on your own if you're getting better or if you're getting worse. But when in doubt, call your doctor.

**Amethyst:** And is there an actual way to know when you're in remission? What's that?

**Janet:** I was gonna say that. I think the Pemphigus Vulgaris and it might be different a little bit for Pemphigoid because certain Pemphigoid you can get it just in your mouth. You can get it on your body, you can get it both places. But sometimes it's just specific to certain areas of your body. With Pemphigus Vulgaris it won't stop. You start getting lesions, it'll just keep going. I've been in remission since 2002 without any drugs. For a very long time without blisters. Now I get blisters in my mouth from time to time but they go away by themselves. I use topicals sometimes. Sometimes I can go months without seeing a blister and then maybe stress and recent realities. So, maybe a couple of lesions have popped up, and so as long as they go away by themselves, I'm ok. If you start seeing blisters that won't go away by themselves within a couple of days or then you get another blister on top of that. It's time to call the doctor.

**Marc:** What Janet's talking about is transient lesions. And I think we as patients, we all get those transient lesions from time to time, maybe you ate something and it irritated your mouth or caused trauma and then you get a blister, but then it goes away right away. That's what we call a transient lesion. Or maybe you bump your arm and you get something on your skin or if something irritates your skin, and you get a transient lesion. It lasts for a very short amount of time and then it goes away. That's considered a transient lesion. So, remission is defined as, and Janet already really kind of alluded to this, is not having any cause any continued disease activity for at least two months. So if you don't have any disease activity, no lesions, no blisters for two months. Then you're considered to be in remission but you can be on medication or off medication. That doesn't really change, whether in remission or not, you're still in remission, either on or off medication.

**Janet:** Complete remission is without medication, and without transient lesion here and there. And, partial remission is with medication.

**Marc:** So, remission means no disease activity at all. So, if you're getting transient lesions you're not really quite in remission because you're still having disease activity.

**Janet:** When I first got Pemphigus I had a lot of transient lesions, they would come and go. It took about a year, then all of a sudden, they just kept coming and not going. And I think that if you're experiencing lesions, but have never been on any medication, you need to talk to your doctor, because even though they may be transient lesions at the beginning of a disease, if you've never had it before, it might be time to do something even if it's just topicals. That would be my suggestion.

**Marc:** And then conversely, if you're not having any disease activity and you're on medication, that would be the time to talk to your doctor about tapering the medication, but they need to taper it slow so you can get off of those medications and go into a complete remission where you're not on anything. And that happens. A lot of people go into complete remission and are never on drugs.

**Amethyst:** Great, thank you guys. I know we're running out of time here. I'm gonna, if you guys don't mind, just maybe ask a few more questions. I know that everybody kind of alluded to having a good relationship with their doctor. And, does anyone have any recommendations for tips when they go into the doctor? How to make sure that they're having meaningful conversations with their doctor?

**Janet:** First of all, write your questions down, Number one. If you can bring somebody in with you, an advocate with you could be a family friend, but let them come in the room with you and help you to understand what the doctor is saying. Because sometimes, you just can't. You're in that state that you can't. You're not really hearing what the doctor is saying, and if you can have somebody with you to write down the answers to your questions, make sure you have your questions written down. I do that even now, I go into the doctors and I always have my questions with me..

**Marc:** We have a checklist here that we can provide for patients. You don't have to use the checklist, but it gives you an idea of what some of the questions might be that you can ask your doctor when you're there. It's kind of lengthy so you probably won't be able to ask all of those questions, but we do have a resource that patients can ask their coach for a checklist of questions. The other thing that I would say kind of some tricks that I use when I was being seen is I would always try to schedule my appointments either first thing in the morning or right after lunch. Because that's the time when the doctor is not behind schedule. And they have more time to spend with you. And then I would also ask, when I called and made my appointments, I would specifically say, I need a 30 minute appointment. And they'd say, Well, we only do appointments for 15 minutes and then I'd say, ok, Well, then I want two appointments back to back. I need 30 minutes with that doctor. To have enough time to explain

to them, you know, what my situation is. My experience and really have enough time to really have a meaningful appointment with doctors. Those were just some things that I did, and I learned from the beginning, to make sure that I was trying to make sure that I had enough time with the doctor.

**Mei Ling:** Like Janet, I always take a list even today, because if not I'm walking out into the parking lot, and I forgot to ask. As you go on with your daily life and something comes up suddenly go write it down. The other thing I suggest to every patient if you're active, take a photograph with your phone. Because by the time you get your appointment, those blisters may have dried up. The doctor needs to see the level of activity that you're having. So, if you take a photograph, it's Tuesday, But you can't get to that until the following Wednesday. He may not, or she may not be able to see it. So it's always a good idea to take photographs at the same time.

**Janet:** Remember that your doctor is a human being. They may know some things about Pemphigus and Pemphigoid. You may know some things more than he knows. You can be nice, I see a doctor, but know that they may not know everything, and you have to question things that they tell you, as well. And you gotta look at them as human beings, they're not God's. I think it's really important to look at your doctor, that It's not a God, and that they don't know everything, and you have to treat them as human.

**Carolyn:** As a matter of fact, I think one thing that helped me, besides, like everyone said, going in with questions. One thing I would also do is a lot of health care organizations and doctors do have patient portals. And so, I would e-mail my questions ahead of time, if that was possible. I would also always have a record of pictures, and I would send in my most recent picture of what was going on. Those things helped me at times, and also historically, looking at progress I was making, or if there are problems going on, and reminding of my medication and schedule as medications. All of those things would really help track me and my care.

**Janet:** I want to make one more point with doctors. And that is that when you're emailing your doctors, they often don't read the whole email well. So whatever you need to email your doctor about, put it in the first two sentences, then you can go on a little more, because you'll find out that if you email your doctor and they don't answer all your questions or your answer fully, that's because they're not reading your email. So, ask your questions, and then you can go on.

**Marc:** You really have to advocate for yourself. And, you know, one thing I will say is, you know, the more educated you are about this disease, the better off you're going to be. And

that's really where the IPPF can help. We have lots of resources, lots of education, we can connect you with those resources that we can connect you with doctors. So, the more educated you are about this disease, you're gonna have a better outcome. Remember that we're here to help, and we're here as a resource. You have to advocate for yourself.

**Amethyst:** With that, I know a lot of patients say that they have a doctor who is not very familiar with the disease or they're having trouble finding a doctor that seems to know anything about it. Are there any resources that the IPPF has or where's a great starting point for them to try to find a doctor that's knowledgeable and in helping treat them?

**Becky:** Our Find A Doctor Map is an interactive international map of providers that we believe are familiar with Pemphigus and Pemphigoid from around the world. I will lay the disclaimer that it is not an exclusive list, that there may be other doctors out there, we're just not aware of them at this time. But it's a good place to start, and it's a great resource to help you determine if a doctor is right for you as a starting place. I always let patients know that they should call those providers to make sure that they take their insurance and to do their due diligence to make sure that those providers are right for them. There's also some other resources and other organizations like the American Academy of Oral Medicine (AAOM) and the American Academy of Oral and Maxillofacial Pathology (AAOMP). That they also have lists of providers that should be familiar with Pemphigus and Pemphigoid as well for those in the mouth. Our list has dermatologists, rheumatologists, ENT's as well.

**Carolyn:** One thing that helped me this past winter, and it was actually Becky, who had made a suggestion to me. I was having what we thought was some re-occurrence and my mouth. It was more of a dental situation. But there had been some irritation. COVID-19 was going on, I could not contact my own oral Maxillofacial surgeon or a pathologist. And quickly, got a hold of the list, looked at it, contacted my dental insurance company, and was soon comparing lists. And it was just a really rich resource in finding someone new who could see me, take a look at the dental situation. So, it was really a great resource, and, again, partnering with my own dental Insurance company, and even my dental office. And we were able to get me in and get some things looked at. And as a result of that, within just a couple of days I had those resources lined up. And I was getting seen. So it really worked. And it does.

**Amethyst:** Great, thank you. Well, that was a very quick hour, thank you all for being on the call. Before we go, I want to launch another poll. Just to get everybody's opinion, after listening in, do you feel like you will be more likely to connect with one of our peer health coaches in the future? So, I'm going to just launch that. If you guys can take a quick minute to answer that.

And while they are answering that question, what is the best way for our listeners and our patient community to connect with the pure health coach?

**Mei Ling:** On our website, there is “Ask a Coach” you can fill out the “Ask a Coach”. We have our IPPF page on Facebook, so you can definitely go there, and ask a question, and say, how do I get in touch with somebody, and one of our staff will answer you, so you can go there. Can I make one more suggestion? I know we're running out of time, but because of the COVID-19 and I know this won't work necessarily if you have oral lesions, but if you have lesions anywhere else like on the skin and if you're not able to get in to be seen. If they could do a teleconference with you and if you have that ability to do a teleconference phone call, a lot of the doctors are able to do that with you. You are just on the camera with them, like we are, and you can show them your activity. So that may be the third best way to try to get to see your dermatologist in case you can't get physically in if their offices are limited hours. But other than that, just go to the website or go to the IPPF on Facebook.

**Amethyst:** Great, thank you. Well, thank you guys for sharing all of your great knowledge. It looks like after the call, 96% of our listeners said that they will definitely be more comfortable connecting with coaches in the future. So, thank you for sharing all of your great information with us this evening.

I would also like to give a huge thank you to everyone on the call for joining us today and thank you to Genentech, Principia Biopharma, Argenx, Cabaletta Bio for helping to make today's call possible.

Before we go, I have a few announcements: Our next Patient Education Webinar will be on June 3 with Dr. Animesh Sinha from the University at Buffalo, of New York for a Pemphigus and Pemphigoid 101 session. You can register online today!

As you know, the IPPF's main focus is to improve the quality of life for all those affected by pemphigus and pemphigoid through early diagnosis and support. Day in and day out, we're here for you, whether it's by providing support through our peer health coaches, supporting the research of new treatment options, advocating on behalf of the rare disease community, or accelerating the diagnostic process. What you may not know is that we accomplish all of this with just 4 full-time and 6 part-time employees. Though our commitment is international in

scope, the IPPF operates as a small nonprofit organization. Due to the ongoing COVID-19 pandemic, the world is facing unprecedented challenges. Unfortunately, the IPPF is not immune. Recent donations are down, and our usual sources of funding are now unreliable. In short, we need your help and support to keep the IPPF operating in the way you've come to expect. Together, we can keep hope alive. All donations will now be tripled from our generous matching sponsorships from both Principia Biopharma and argenx. We only have a few days left to reach our goal to raise \$40,000 by June 2. You can go online and donate today at [www.pemphigus.org/hope](http://www.pemphigus.org/hope). Give today, and you'll triple your impact!

Also, for those of you that do online shopping through Amazon, you have the opportunity to give back all while shopping. Visit [smile.amazon.com](http://smile.amazon.com) and search for the International Pemphigus and Pemphigoid Foundation as your charity. Amazon will donate 0.5% of all purchases made through amazon smile to the IPPF.

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.

This call recording will be sent out with the survey following this call.