

February 26, 2026 Patient Education Webinar- Support that Understands with the IPPF Peer Coaches

Marc Yale: Welcome everybody. My name is Marc Yale and I'm the IPPF Research and Policy Advisor for the International Pemphigus and Pemphigoid Foundation, also known as the IPPF. And I'm so glad you're joining us today. But before we start, just a quick reminder that this webinar is being recorded. And we'd also like to remind you that "information is essential when it comes to managing and living with any condition. But remember that everybody's journey is unique. And the IPPF does encourage you to always check with your doctor or healthcare team to make sure that the information that you hear today or that you may have found online applies specifically to you and your situation". So today I'm very excited to have the IPPF peer coaches here and the IPPF peer coaches, just so you know, are volunteers who have learned how to manage their diseases and are willing to share their personal tips with you on what they have found helpful while learning to navigate with pemphigus and pemphigoid.

Marc Yale: Now reviews the housekeeping slides...

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Janet Segall: So my name is Janet Segall. I was diagnosed with pemphigus in 1983, pemphigus vulgaris. And in 1992, I started the IPPF. I've been working with the foundation since then. And I am now a peer coach trying to help people get through their issues that they're dealing with with these diseases. So I'm here for that. Semi-retired.

Marc Yale: Thank you Janet. Thank you for being here. And Scott, how about you?

Scott Taub: My name is Scott Taub. I live outside of Chicago. I came down with symptoms of pemphigus vulgaris, or what I eventually found out to be pemphigus vulgaris, in early 2013. After 3 or 4 months of going to many, many doctors, I finally got a diagnosis. I have been in remission and off all medication for over 9 years and no flares for me, so knock on wood, hopefully it stays that way. And I'm one of the few based on patients I've talked to that actually got to remission without ever using rituximab. So when I've stayed in remission, I used just Prednisone and Imuran.

Marc Yale: Great. Wonderful. And how about you, Mei Ling?

Mei Ling Moore: Let me think. In 2002, after 5 months, I got diagnosed with pemphigus vulgaris and found Janet through an online group that she had started in the very, very beginning. And the IPPF guided me through this challenging time. I reached remission in 2012, have been a volunteer since then, and I help organize the California support group meetings online and soon to be in person. Yay, after the pandemic. So hopefully we'll have an in-person meeting soon. And I'm one of your coaches, so if you need one of us, just go ask a coach. It's under the patient section on the website. Thank you.

Marc Yale: Great. Thanks, Mei Ling. Thanks to all of you. All right. Well, we've got a long list of questions here, so I'm going to go ahead and dive right in. Again, feel free to type your question into the Q&A box. We'll try to get to your question. I'm happy to read it out loud and then one of our wonderful coaches can answer it for you. And if, again, we don't get to your question, please feel free to submit it on the website. So Janet, I'm going to start with you. And the reason I want to start with you is I just want to rip the band-aid off, so to speak. And I want to talk a little bit about mental health because we know mental health is a huge component, a large component for this disease. So I wanted to just ask you, have you experienced anxiety or depression related to your diagnosis, and how did you cope? How did you deal with it?

Janet Segall: Well, it's such a complicated question because I was 36 years old when I was diagnosed and raising a child by myself, and yes, I got very depressed. And I was only on prednisone so not only was my situation difficult to begin with but I had a wonderful family helping me, so that was really good. And I think that was definitely something that helped get me through it, was having my family there to be supportive of me. The prednisone made me a little nutty.

Marc Yale: It can do that.

Janet Segall: They can do that. So it was a difficult time, but it took a long time, but I put my head around it. I mean, at one time I just didn't want to do it anymore. I really remember saying that to my sister-in-law and I said, "I don't want to do this anymore." And she said, "You have to or you'll die. And it hit me like, "Yeah, okay, I have to and otherwise I won't live." And at that time, people didn't have the medications they have now that help get you through it. So it was a tough time, but I found a way to let the support and make sure that the doctors understand that I was going to be a part of my recovery. I had one doctor say, "Well, you got to do what I say." And I said, "Bye." And I went and found another doctor because I knew that I had to be part of my recovery. I needed to know what he wanted to do, why he wanted to do it. I had to have all those questions answered. And I think it's really important. Knowledge is power. I think the more you know about what's going on for you. I think not being afraid to tell your family or people who support you on a regular basis, what you're going through and how you're feeling. And there's nothing wrong with going to a therapist. I did everything. I did hypnotherapy and biofeedback and whatever I could to help myself and meditation. So there are a lot of things that are available to people that can be very helpful. And there's us. We are here for you as well, so call us if you need to.

Marc Yale: Great. Thank you. Well, and it sounds like you had your sister too. Having that support there is critical. And like you said, knowledge is power. So by understanding the disease, it helps you get that control back because when you get this disease, you feel like your body's out of control, everything's out of control. So that's great. Thank you. Scott, I'm curious, I wanted to ask you, do you have any tips for talking to your doctors to make sure that they understand your situation, give better advice and really truly understand your journey? What would you recommend to doctors?

Scott Taub: Well, I think that with respect to talking to doctors, and the most important thing is make sure you find a doctor that has experience with patients with pemphigus and pemphigoid. And that may not always be easy. In fact, if you live outside a major metropolitan area, you might well have to find a local doctor who's willing to consult with somebody who's more experienced. And when I say experienced, I don't mean they necessarily have to be experts at it because even those who treat pemphigus and pemphigoid frequently probably only have a dozen patients at a time that have these diseases. It's just not that common, but a little bit of experience goes a long way. So if you feel like your doctor just can't answer your questions because it's the first time they've ever been asked that question, you might need to look around and find another doctor. But I tell all the patients that I talk to, particularly that are new in dealing with pemphigus and pemphigoid, when you go to your doctor, if you can bring somebody with you, that can be very helpful because you are uncomfortable, you're tired, you're fatigued, you're suffering the effects of the medication in addition to the disease. And when I would go, I would sometimes forget to bring things up, things that had been bothering me, but my wife never forgot. They were bothering her too, and probably I was bothering her. So my wife came with me to all of my appointments until things were really under control. And almost every appointment, she remembered to ask something that I forgot, or she was able to better remember my doctor's response than I did, remembered the nuances and remembered the instructions. And that's really my best tip for dealing with doctors is to bring somebody with you so you've got a second mouth, a second pair of ears, and there's less chance of missing something. And the other thing I will say is a lot of people are intimidated by doctors, and there's a good reason for that. They have a lot more experience with these medications and all of these things than you do. Even if a doctor has only seen a handful of patients with pemphigus, you've only seen one, you. So they do know more, but it doesn't matter. Don't let them gloss over something, go quickly past something and you don't understand, but you're embarrassed to ask for more information. Stop them and say, wait a minute, I didn't get that. There's something else I really need to talk about. The doctors are busy. They're trying to get onto the next patient, but ask your questions. Most doctors, I think when they realize that you are interested and you did your research and you learned a lot about this disease, they're actually more than willing to have that conversation because they actually learn as well. I mean, I've had three different doctors during my period. They've all been experienced with pemphigus and pemphigoid, but every one of them, at some point, I told them something they didn't know because I had experienced it. I had talked to others on Facebook. So by all means, get your doctor talking and don't feel embarrassed to bring something up. Even if you think it's dumb, bring it up because it's important to you managing and living with your disease.

Marc Yale: I love that. That's great. That's wonderful. Mei Ling, I know that you often recommend that people keep a journal to help use it when you go see the doctor like Scott's talking about, or just even to cope with the stress and anxiety of having this disease. I'm curious, what advice would you give someone that's really struggling with self-confidence, dealing with the symptoms, how maybe their appearance, dealing with that doctor and the anxiety? What advice would you give to somebody that's struggling with that?

Mei Ling Moore: Well, definitely keep a daily journal of thoughts. I mean, just even if you're rambling, because we have over 75,000 thoughts a minute, if you can believe that. I mean, we really have a lot of thoughts or maybe 750, but if you write it down, then also in looking back, you can kind of see where you've gone from point A to point B. But taking your thoughts to your physician is helpful. Also, I suggest checking with the insurance carrier if you have coverage for mental health, and I am going to make a statement here now that might even shock my fellow peer coaches. I went to see a therapist last Saturday at UCLA. I've been having different struggles physically. And of course, I'm much older now, but I had 10 or 12 years of prednisone, which affected my bones. And aside from getting older and going through old age stuff, I didn't realize that, even though I appear happy, I get depressed. And I'm also concerned that having a health issue, it can be detrimental to hold your thoughts inside. So I do suggest, even for myself, to see a professional who's objective, who is learning in their profession to be objective and make suggestions. And getting it out is much better because stress is a huge factor in blistering activity. So if you could talk to a family member, that's great. If you could talk to a church advisor, that's great. If you go to a group therapy, that's even better. If you go to the support groups, we have the support groups in different regions, which you could check on our events calendar on the IPPF website. But other than that, also check with your insurance because if you do get coverage, it is so helpful. And you'd be able to speak with a professional privately. So it's not like you're going to be embarrassed in front of a family member. You can absolutely get out your thoughts, and that's helpful. And do write down every day what you're feeling. And also, I recommend when you have a blister, take a photograph. Take a photograph of it because by the time you see your physician, they may have dried up and they need to see the activity that you've been going through. So it all helps. And I'm not ashamed to say I'm seeing a therapist because it's helpful. It's keeping me sane because I do worry about, "Oh my God, am I going to lose my remission? I'm going through this. What's going to happen?" Getting it out there is a great stress relief.

Marc Yale: Absolutely. Thank you. I'm going to shift gears a little bit, and I know I have lots of questions about medications and side effects, and I know a lot of people are submitting questions about that. So I'm going to come back to you, Janet, and I'm just going to ask you, have you experienced side effects? I'm sure you did, from the medications. And tell us, how did you manage those side effects? What did you do?

Janet Segall: Well, prednisone was the only thing I was on. So I can't really talk about side effects from Rituxan except from what I've heard from other people. So maybe if it comes to some questions about that, certainly maybe somebody who's been on Rituxan could answer that. But I can say with the prednisone, I had a lot of side effects. Mainly I gained a lot of weight because it made me hungry and I'm a person who likes to eat. So I just went pretty crazy.

Marc Yale: You and me both.

Janet Segall: I gained a lot of weight. And I got to a point where I said, "Okay, I'm not going to do this anymore." But it also made me angry a lot. I didn't want anybody to come near me. I didn't want anybody to touch me. It took a while before I got really used to the prednisone. And I told my family, I was living with my brother he took me in and my daughter because I was raising

a child by myself. And I said, This is how I feel and I'm letting you know that I might yell at you or get angry or whatever. And so I had to learn how to deal with those. And what I did with the mental part of it, as I mentioned before, was I went to biofeedback and hypnotherapy. And as Mei Ling said, having a therapist is really helpful. And also I tried to find foods that wouldn't hurt me. And that is a very difficult thing to say generally because everybody's different. And what foods that may affect you that affected me, may not affect you. I did my own trip with garlic. I ate it for a week every day. And after I went into remission, when you're not in remission, it's hard to know anything you put in your mouth could actually cause a blister. So when I went into remission, I did a whole thing with garlic and I found that, yes, if I eat too much garlic, then I'll get a sore throat. And then it stopped when I stopped eating the garlic. So I had to be very careful about how much of certain foods that I was eating. Right now, I have one blister in my mouth that's been sitting there. It goes away when I don't eat for a couple of hours. And as soon as I put anything in my mouth, it comes back. So it's just one. And so far I keep a very good eye on it. It's been 40 years for me, and I still think about it, but I don't make it the center of my life. I'm aware all the time of what's going on in my body. I try to make sure that I'm eating as healthy as I can, and sometimes I don't, and sometimes I get a blister that will pop up when I'm eating too much chocolate because that'll happen for me. So there are certain foods that you have to find for yourself. And I found also, and I'm not saying anybody else should take it, but you should discuss with your doctor if you're on a lot of prednisone about taking a mild, what do you call it? A benzo like Xanax. That's just what I took Xanax because it really helped. It's short-lived and they don't give it very often anymore, but there were other drugs out there that they could give with prednisone. It worked very well for me for prednisone, and it calmed me down quite a bit. But very small amounts and just now and then. I did not want to take it on a regular basis. So there are certain ways that foods help you relax. There are teas, chamomile teas and things like that. There are so many different ways that you have to figure out what's bothering you and how that might work for you with food and therapy and whatever else that might be bothering you. Also it depends on how much medication you're taking and the tiredness sometimes and getting enough sleep and trying to figure ways to make that happen for you. So biofeedback really helped me and meditation. I found that really helpful. So sometimes natural things can be very helpful for side effects.

Marc Yale: Thanks for that advice. It's great. So Scott, I wanted to ask you, Janet, you kind of mentioned remission. I know a lot of people have questions about remission, like what is it and so forth. So I'm going to pass this over to you. What is remission and is it a reasonable goal to go into remission? And what does that mean? Does it mean you don't have any symptoms? Maybe you have some symptoms. Are you on medication? Are you off medication? Maybe some of us go to get our labs done and that can be misleading sometimes. So tell us about what you've learned about remission, because you mentioned you were in remission.

Scott Taub: I did, and I do make that claim. So what I learned surprisingly early on is that there is no accepted definition of remission. We all say remission, but there isn't an accepted definition. In different studies of different drugs and the effects of different drugs, within the study, they might define remission as the goal, and then they will describe what they mean by it, but there is not an accepted definition. So I will say, certainly based on my experience and

based on the experience of patients that I've worked with, it is a reasonable goal to think that you could get to a point where you have no symptoms and are on no medication because that's me. I don't have any symptoms. I haven't been on any medication for over 8 years, almost 9 years, so it's possible. Other people are comfortable saying that they're in remission, even though they're still on a low dose of prednisone or are getting rituximab infusions every 6 months because they have no symptoms and they feel like that is remission. So if your doctor tells you that he or she thinks that you could get to remission within a certain amount of time, ask them what they mean and tell them what your goal is. If your doctor says, well, I think we can get you to remission, but then on clarification say, on 10 milligrams of prednisone every day to keep things under control, you can decide whether that would be satisfactory to you. It is satisfactory to some people. And from my research, being on a low dose of prednisone is not likely to have any huge side effects, but you might be shooting for more and you ought to make that clear to your doctor. And I will say that over the six years that I've been a peer coach, the majority of patients that I have worked with have gotten to a point where they're off medication, they don't have symptoms, and it lasts for a while. Now, I've been lucky. I haven't had a flare in over 8 years off medication. Most people do have flares after 2, 3, 4, 5 years, but I will say most patients that got to remission once, they get there again if they have a flare. So yes, I think that it's a reasonable goal to have no symptoms and no medication. Not everybody gets there, but most do. And I always tell the folks I'm talking to, don't lose hope, but also be patient. It took me 3 years to get to remission, but since I got there, I've stayed.

Marc Yale: Great. That's great advice. I'm curious, Mei Ling, just kind of feeding off what Scott has talked about, how can a patient tell or how can someone tell if their condition is improving or if it's getting worse? How do they know? How do they know they're on the road to remission or how do they know that things are getting worse? How do they know that?

Mei Ling Moore: If you're more comfortable in your own skin and feel like you're almost back to "normal", then you're on the road if you don't stress as much. If you realize, "Oh, I haven't had a blister in a week," or, "It's been a couple of weeks." Oh, that's great. On the other hand, if you do get one blister, don't panic, because I've been in remission since 2012, and occasionally I will get one little blister here or something in the mouth or my scalp will itch, but I use a topical for a day and then it's gone. If you get more than 5 at once, 10 at once, then that's a cluster, then I would call my dermatologist to say, "Hey, this has happened. Take a picture and this is happening." And I think we need to take a blood test, do a panel. But otherwise, if you aren't anxious and you don't have an itch and you don't have something festering, a blister, you haven't had any activity, you're able to move physically, you can wear your clothes without irritation, you can get in and out of bed easily without worrying about lying on the sheets. You can do more physical activity. You're able to eat better, the foods you like as you introduce one at a time, then you're improving.

Marc Yale: Yeah, that's great. I like what you're saying. I think you have to expect small incremental changes. It's not just going to happen overnight. So like you said, if the blister's not lasting as long, it resolves faster or you don't have as many, then obviously that means things are improving. And if you have more energy or you can do things more physically or you're not

even psychologically, if you're not as worried, things like that. But it is small, right? It's small incremental change and doesn't happen overnight, unfortunately.

Mei Ling Moore: I think one of the biggest indicators is clothing because I remember for me, my upper back looked like I got hit with shrapnel, like a war. I couldn't wear clothing that touched me without it hurting. And my hair, being Asian, I have thick hair, so I had to cut it off as short as scots because a single strand of hair felt like a razor blade going down my back. So when you're able to grow your hair again, or you're able to wear a shirt again without flinching, your skin is getting better, so are you.

Marc Yale: Go ahead, Janet.

Janet Segall: I just want to say that it could be a little bit different between pemphigus and pemphigoid. With pemphigus, you got to really watch it carefully and little bit differently. I mean, you have to watch the pemphigoid too, but, with the pemphigoid it usually starts with a lot of itching but it is certainly worth monitoring. When that starts happening, if you've already had bullous pemphigoid with blisters, sometimes it doesn't go to blisters. Pemphigus vulgaris or pemphigus foliaceus usually doesn't stop. I mean, once you go in remission. I've been in remission since 2002 and I get a blister occasionally here but they go right away or they go away by themselves within a day or two, as long as that happens. But I'm very careful because I have pemphigus vulgaris that if I notice for me, I get a blister in my head or on my body, I know it's time because that's what happened with my second remission. When I got out of my first remission, it was three years and I noticed I had mouth sores and I said, "Okay, this is it again." And I was right. And I went right back on medication. It took me three months and I was in remission again because I caught it very early. So you got to watch carefully and decide whether you should. And like I said, pemphigoid may be a little bit different and you may not get the same breakout as you do with pemphigus, but you may also. It just depends. I mean, Marc, maybe you can talk to the pemphigoid side of it for the mucus membrane pemphigoid side of that.

Marc Yale: Yeah, certainly. I think again, it takes time and it even varies by person. Everybody's a little different, but I definitely think you make a really good point. So I wanted to ask you, Scott, because you talked about remission and we talked a little bit about flares. So I'm just thinking about flares. Are there any changes that you had to make to your lifestyle in order to keep the disease in check and try to avoid those flares? Did you have to change your diet? I know some of us have talked a little bit about diet and what we eat. I know Janet, you specifically talked a lot about that and even your level of physical activity or exercise, I know for me it really affected my work. I was unable to work. So what lifestyle changes did you have to make to really help you avoid those flares?

Scott Taub: So while my pemphigus was bad and before I got to remission, there were two kind of dietary changes that I thought about. And as I've talked with patients over the years, I think the dietary stuff falls into two different categories. Number one, if you have sores in your mouth, there are lots of things that you shouldn't eat because they hurt. And you can pretty well predict most of them, citrus, not good, spicy things, not good, cinnamon, not good, pointy things, sharp

things, not good. I didn't have a potato chip for a couple years, but that was just to avoid pain. That wasn't necessarily making the disease worse. That just hurt. Then there are the foods that you think might actually be affecting your disease activity. And I will say that I've talked to lots of patients that have tried all kinds of diets, keto, no carbs, no gluten, no meat, all kinds of things. And some people have had success with all kinds of those different diets. Based on talking to people and looking at studies and talking with doctors, what I believe, although doctors have not proven any of this, I think this is a little bit like an allergy in that different people are sensitive to different foods. And if you can identify a food that triggers your symptoms, triggers your pemphigus or your pemphigoid and eliminate it, it may well help. I believe that early on as I was getting to remission, I discovered that alcohol seemed to be a trigger for me. And so I did not drink for two years leading up to remission and then the first couple of years that I was in remission because I didn't want to risk anything. So I believe that alcohol was a trigger for me, but by no means do I recommend to all the patients that I talk to that you avoid alcohol. If you think alcohol might be a trigger for you, then sure, avoid it. But I have talked to patients who have believed that strawberries were a trigger. Okay, don't have strawberries. And I think if the people who've had success with these very limited diets, I think it's because they happened to choose a diet that eliminated their trigger. And if you can do that, that's great. If you go on a limited diet and that helps your disease activity, then you start adding back foods one by one and see what triggers it. I'll give one caution there. I discovered when I thought that alcohol was a trigger for me, it took 24 to 36 hours for the blisters to appear. So it wasn't like I drank it and then within an hour I started feeling it. So it took me a while to figure it out. Your trigger may affect you only for only some period of time after. But I'll say since I have been in remission and other than avoiding alcohol, I have no lifestyle changes. Once I got off the medication, my energy went back to normal. I happened to have a job that was not physically demanding and is not physically demanding. I'm an accountant. I was able to continue working and continue to work as I have. My job is stressful.

Marc Yale: The numbers don't change.

Scott Taub: But my job is stressful, but it has not caused me too many problems. And I eat what I have always eaten. And again, I tell all my patients that ought to be your goal, that you get to a point where you're living your life the way you did before pemphigus or pemphigoid. And don't give up on that until you have tried to get there and decided, "Nope, I can't make it." Then you might have to accept something less than that. But certainly for me, my life is the same.

Marc Yale: Great advice. Thank you for sharing that. Mei Ling, I saw you had your hand up, so I'm assuming you had something you wanted to comment on that.

Mei Ling Moore: Well, yeah, it's like Janet said there's a difference between pemphigus vulgaris and bullous pemphigoid. Now, when we're talking about oral activity, yes, the diet is very influential. I couldn't eat roma tomatoes for two years. Now I can eat all the tomatoes I want and garlic. But I've also seen on Facebook groups, people asking, "What about this diet or the keto diet or the whatever diets there are? We're not saying that diet specifically affects the blisters throughout the body. We're only discussing oral activity when we mention these foods,

like the highly acidic ones or like red wine has tannins, so that could definitely irritate. But I know there's a fine line between diet and the entire body as opposed to just oral activity.

Marc Yale: Yeah, you're right. And so like Scott said, like you're saying, food perhaps could trigger some disease activity. So you obviously have to be very conscientious about which foods you're eating because it certainly could trigger the disease. I'm curious, since we're talking about oral activity, I know there's obviously many of us that have that issue. And maybe I'll ask you, Mei Ling, how do you deal with going to the dentist?

Mei Ling Moore: I am going tomorrow as a matter of fact for a cleaning. I swear I'm going tomorrow. But also keep a food diary, whatever you're eating so that you eat something every day. You could eat three meals a day and two snacks and nothing will happen or something will happen. So you could look at what you ate and decide, was it too acidic? Was it too sharp? Was it spicy? So when you go to the dentist, we do recommend, and all of our oral experts recommend, if you're having a cleaning that you ask for a manual cleaning, not the electronic. The electronic method can nick your gums. You don't want that. If you're going to have major work done like an extraction or root canal, or even a fitting for a crown, let your dermatologist know because depending on the level of activity that you're having, he or she may want to increase your daily dosage if you're on a steroid or if you're on an immunosuppressant, that's as a prophylactic. Use soft toothbrushes, very soft. And you don't have to be vigorous when you're brushing your teeth just softly every day. Rinse your mouth out after every meal, that always helps too. Flossing is important. I know that a lot of patients have oral activity and they feel, "Oh, I don't want to put that dental floss in my mouth. It's going to hurt. Try the best you can or get a water pick. That could be very, very helpful. Do try to see your dentist a minimum of twice a year, four times a year is what hygienists recommend. I know it's expensive, especially if you don't have dental coverage, but maybe you could go to a dental clinic or a teaching school that has a dental unit in it, but definitely keep up your dental visits and prevention is the best for everybody in general, but especially for us. But like I said, if you're going to go and have major work done, definitely let your doctor know.

Scott Taub: And I will add on to that. I agree with everything you said, Mei Ling. And another thing that I discovered early on in my disease, I obviously was not brushing very well because it hurt. And I had a dentist appointment about 3 or 4 months after the disease started and I explained what was going on in my mouth before I opened it. I didn't want to scare the heck out of the hygienist when she saw what was happening with my gums, but the hygienist and the dentist came in and talked to me and I explained what was going on. They'd heard of the disease, never seen anybody with it. So it was cool for them to see somebody with oral involvement with pemphigus. But they assigned me to the gentlest hygienist and she did it all by hand. No vibrating instruments or anything like that. And I will tell you what they recommended that turned out great for me was to come in for a cleaning every 4 months instead of every 6. And they said, "You won't have to worry as much about the brushing with that point." And that first appointment after I had pemphigus, I had 2 cavities and I have not had a cavity in 10 years since then because I have continued going 3 times a year instead of 2. And now I make my kids just go 3 times a year instead of 2, even though they don't have pemphigus or any other

problems. So I do think the dentist can really help overcome some of the problems we have with oral involvement.

Marc Yale: Yeah, that's great. Oh, go ahead Mei Ling I see you have your hand raised.

Mei Ling Moore: Yes. In the beginning, and I know we don't have a lot of dental referrals on our ask a doctor, mostly they're dermatologists or pathologists, whatever. If your dentist isn't aware, what I used to do in the beginning was I would go to our website, I would take a screenshot of our dental information, oral activity. You could use a little magnifying glass and look up dental, tooth, whatever, and print it. And I would tell the hygienist, "Here's some pages for you. And if you have any questions, call at that point, call Becky or Marc or any of us to get more information and we can put you in touch with another dentist who you can consult with". We do have quite a few dentists who we are familiar with. That way they become more familiar. You can go to our YouTube where I think we have a video on oral care too. So that could be helpful if your dental hygienist and your dentist is not aware of pemphigus or pemphigoid or MMP.

Marc Yale: Yeah, that's great. That's great. I mean, thinking about talking about the dentist, there's certain toothpaste and products, especially for the mouth, but also even for the skin, like lotions and perhaps shampoos. I know there's recommendations on types of clothing to wear. You mentioned clothing earlier Mei Ling. So I'm just going to open it up. Maybe I start with you, Janet. What do you recommend? Maybe we'll go around and ask everybody, when it comes to products, what do you always recommend?

Janet Segall: I'm not a good person. I don't use anything, so I'm not a good person. But I have colbetasol, which I use occasionally if I need to, or just regular hydrocortisone. I don't use makeup, really. I put a little bit of makeup on. I try not to put too much on my face. When I had disease activity, I didn't use any makeup whatsoever. What I should be using more of, and I don't, is keep your skin moisturized. Yeah, I think moisturizers are good. And I think the CV was recommended. I'm not sure. Yeah. And there are some really good ones out there. And check the website. I think there are some recommendations on the website. Mei Ling probably has a better idea than I do about.

Marc Yale: Yeah. What do you say Mei Ling? What do you always recommend?

Mei Ling Moore: What I send when I send out emails is, Tide is a recommended detergent. You need to get a detergent for your laundry that is non-scented, hypoallergenic, sensitive skin, any of those. Tide is endorsed by ... No, the word is going out of my head. It starts with an E.

Marc Yale: The eczema foundation.

Mei Ling Moore: Yes.

Yes. We don't think that maybe our laundry detergent has something in it that could be irritating and staying in our laundry.

Marc Yale: That's good advice.

Mei Ling Moore: Bubblegum, toothpaste. I understand. Children's toothpaste, I understand from everybody, is the least offensive.

Marc Yale: Anything children's is good.

Janet Segall: I know Sensodyne is recommended by the dental people at the IPPF, I think.

Marc Yale: Yeah. Scott?

Scott Taub: And I would say the dermatologists and other experts that we've heard from generally would say sensitive skin, sensitive oral products, that's the kind of thing you should be using. The least amount of fragrance, the least amount of added things. There's a brand that all the dermatologists I've talked to have been recommending lately of moisturizing cream called VaniCream that they all seem to be swearing by. Simple ingredients, no scents, no fragrance, and works very well. For toothpastes, if you can find toothpaste that does not have sodium laurel sulfate, that's the magic ingredient to avoid. It happens to be the ingredient that makes toothpaste foam. So when you start using toothpaste without sodium laurel sulfate, you may feel like it's not doing what it's supposed to do, but the foaming is not actually part of what makes it work. It's just part of what makes it spread across the teeth. So you might have to brush for a little longer, but if you can avoid SLS, that can be helpful. And with everything else, if you have open sores, keep them moist. It's a word a lot of people don't like to say I found out. My wife hates it when I say that word. But just even Vaseline over them can help keep them moist. And that is the most important thing for healing and for avoiding infection. Anything that keeps a good seal on the wound is helpful to avoid infection as well.

Marc Yale: So we had a question, this probably be one of our last questions, but we had a question about challenges with insurance. So I'm going to end on the heavy stuff here. Have any of you had challenges with insurance coverage for any of the medications that you have or been working with someone that's had challenges with coverage for the medications and treatments? And what do you recommend to them and how do we handle those challenges that we're dealing with medication and insurance?

Mei Ling Moore: Like Janet, I only had prednisone, so I just never had that. But I know that at one of our support meetings, one of our doctors from USC had said, He's got a stack like this, ready to go. He said, "Your doctor is your best advocate in fighting with the insurance companies to get you what you need." So your doctor working with you, that's all that I know. I mean, I'm not sure about anything else. Scott, do you?

Scott Taub: Yeah, I mean, I can go from experience. I also never had any trouble getting things covered. The biggest thing I had was one of my insurance companies, they changed their network and one of my doctors was no longer in-network. But I live in the Chicago area and it wasn't hard to find another doctor thankfully. But I would say I've talked to a lot of patients that have various insurance problems, and of course, mostly talking about the US here. If you're from abroad, you probably are saying, "What do you mean insurance problems?" Be thankful. So a couple of tips I can give, things you don't need to fight about. If your insurance won't cover

the brand name medication, but will cover a generic or a biosimilar, not worth the fight, the generic or biosimilar almost certainly will work just as well, not something worth fighting about. So if they won't cover Rituxan, but they'll cover Truxima or Ruxiencs, same drug, not worth the fight. In addition, we have experienced many less, many fewer insurance problems since rituximab got approved officially by the FDA for pemphigus vulgaris, and recently Dupixent has gained official approval for bullous pemphigoid. Most insurance carriers, once the thing is officially approved for the condition, are much easier about covering it. Before that, when they're using it off-label, insurance companies can be much more difficult, but it is easier. In addition, several of our doctors have worked very hard to get Medicare to cover certain treatment plans, including treatment plans with IVIg. IVIg is extremely expensive, and getting that covered by Medicare has been very helpful. Many insurance companies, if Medicare would cover it, they will also cover it, and so that's been helpful. And then if you do get a denial, absolutely your doctor is your best friend. Your doctor prescribed what they prescribed for a reason, and your doctor prescribed rituximab because they thought it would work best, not because they were looking for the most expensive drug, and your doctor will often be able to work with the insurance company on appeal and get them to reconsider. Now, the unfortunate thing is it takes time, and in the meantime, you're suffering, and I really wish there were better ways to deal with that. I will tell you that from time to time, the IPPF will send out an email saying, "Hey, we have an upcoming conference with members of Congress or the FDA. That's all to try to get things approved or get rules in place to make it easier for insurance coverage. So please participate, send us your comments, because the more we can show that this is a real issue, making us wait 6 months and try a less effective drug before insurance will pay for the more expensive one, that's a real burden, and we absolutely understand and we would like to do something about it.

Marc Yale: Janet, I see you wanted a comment. Go ahead.

Janet Segall: Well, I wanted to add also that sometimes the companies have foundations if they've approved the drug that you can go to because sometimes even the copays are too expensive for some people. So there are advocacy organizations out there that might be able to help as well as the companies that provide the drugs. Genentech did have a foundation, I am not sure if they still have it.

Marc Yale: They do.

Janet Segall: Make sure that if you're having trouble with your copay talk to someone.

Marc Yale: Dupixent has one as well now.

Janet Segall: So that they'll help you pay for the drugs.

Marc Yale: Yeah, that's great. And then there's things like even depending on what medication you're taking, even things like GoodRx and stuff, sometimes you can get a discount with those things. And then there's also another foundation called the PAN Foundation that the IPPF works with that helps with copay assistance. But Mei Ling, I saw you had your hand up as well.

Mei Ling Moore: Well, Janet and I were thinking the same thing. In addition to Genentech, which has rituximab, depending on what your immunosuppressant is that your doctor's recommending, if you're getting resistance, ask who is the manufacturer, which is the drug company making it? Go to their website and see if they have patient assistance because you never know. A lot of them do. And some of the commercials that I see on TV, which we are getting bombarded with, they do have patient assistance. So always try that as well.

Marc Yale: Yeah, that's great. That's great advice. Great advice. So listen, I know that a lot of you have questions. I see tons of them in the Q&A. We had a lot of pre-submitted questions as well. We didn't get to nearly all of them. We barely scratched the surface. So I do encourage you, we want to answer all your questions. Do encourage you again to go to our website, submit your question in the ask a coach section. We're happy to get back to you, reach out to you, talk with you personally, send you an email, whatever we need to do to help answer your questions. So please, please make sure if we didn't get your question answered, we just put the website there in the chat so you can click on that and submit your question and we will get back to you. We always try to get back to you as soon as possible within 48 hours. That's what the coaches are here for. That's what we do and we're here for you. As Janet said so eloquently earlier, we're here to support you. But that hour went very quickly. We could probably go on for several more. I do want to thank, first of all, thank all of you, Mei Ling, Scott, Janet, thank you for taking time today to share your stories, to share your experience, talk to us about your journeys and provide some really good advice. Just thinking back, for me 18 years ago, I reached out to the foundation and I talked to Janet, and Janet was there for me 18 years ago when I was first diagnosed. So I just want to thank you, Janet, for that, because I wouldn't be here today for it was not for you. But that's why we're here. I also want to thank everybody on the call today. Thanks for joining us and I want to thank all of you for being on the webinar. I do have just a few announcements to make before we say goodbye.

Marc Yale: We do want to extend our deepest thanks to all of you and the entire IPPF community, patients, caregivers, advocates, volunteers, clinicians, and partners. Together, we've witnessed some really impressive milestones for pemphigus and pemphigoid and for our community. Our community's commitment to supporting one another is extremely powerful. And the PPF coaches supported nearly 400 patient cases just last year. So we're truly making an impact. The coaches offer one-on-one guidance, provide empathy. We're very good listeners, and we also have lived experience that we can share to help you on every stage of your journey. We did host 7 free patient education webinars last year, and we also provided 21 free support group meetings, providing a safe, welcoming space for patients and caregivers to connect, share their stories, and really heal together. And your involvement and resilience and generosity are really what makes all of this possible and allows us to make this progress. So we do look forward to continuing this work with you in the coming year and the years ahead. So thank you again for what a huge impact that we had in 2025.

Marc Yale: As we alluded to earlier, the IPPF is excited to share that in June of 2025, the US Food and Drug Administration or FDA approved Dupixent, also known as dupilumab, as the first biologic treatment for adults with bullous pemphigoid. And this is a significant milestone for our community and others. And it offers a new treatment option for bullous pemphigoid patients. If

you'd like to learn more about Dupixent and the approval for BP, you can read more about Dupixent on the IPPF website by scanning the QR code on the screen. And do make sure that you read about the Dupixent MyWay section. That's that patient assistance program that we mentioned earlier. It is on our page and it does highlight that patient support program and it will help enable you to access Dupixent. It does offer financial assistance to eligible patients and one-on-one nursing support and a lot more. So make sure you go there.

Marc Yale: When someone is diagnosed with pemphigus or pemphigoid, they often feel very scared. We've all been there, isolated, invisible, but the IPPF is there for you. And hopefully for the first time, you feel not so alone and you feel recognized and you feel seen. Hopefully you find answers and you find our community. We can provide hope to you. We only continue to exist with your support. So things that your generous gifts do is they help us reach newly diagnosed patients at their worst and vulnerable moment, and we help them connect with life-changing peer support and education. Your donation goes to help advocate for access to breakthrough treatments. So I want to remind everybody again, you are not alone. We're here to help you. The IPPF can be there from day one with trusted education, compassionate support, and the network of people who truly understand what you're going through. We help patients make sense of their diagnosis and connect them with others who've walked the same path. Only you make it possible though, and you make it possible not just to survive, but to thrive. So we ask that you donate today at www.pemphigus.org/donate, or you can scan the QR code on the screen. And together we're changing what's possible and no one should have to face the journey alone. We're all here for you.

Marc Yale: We are excited to share that the IPPF has added 6 new research questionnaires. The IPPF hopes that these new surveys will help us answer many more unanswered questions about pemphigus and pemphigoid through your help. Please join the IPPF Natural History Registry Study today at www.pemphigus.iamrare.org. We do recognize that these surveys take time and your time is valuable, and we really appreciate it. The critical research, however, is needed to really identify gaps in our understanding of these diseases, and only your participation will truly make a difference. The Natural History Study is now even easier to participate in because there's a new mobile app available. So the IAM Rare app, which is free to download, gives you more convenience to stay involved with the registry wherever you are. And with the app, you can manage your participation, complete surveys, receive updates, and much more all from your phone or tablet. You can download the I Am Rare Mobile app today from the Apple Store or from Google Play. Just type it in and you'll find it.

Marc Yale: I am very excited to share that the 2026 IPPF Patient Education Conference will be hosted from August 28th to August 30th in Chicago. This year we'll be in Scott's backyard at the Voco Downtown Riverwalk Hotel. And this is more than just a conference, if you've ever been. It's a powerful weekend of learning, connection, and community. Whether you're newly diagnosed or have been living with pemphigus or pemphigoid for years, this event is really for you. You'll hear directly from world-renowned experts and you'll get practical tips on how to use therapies the right way, things that you can do immediately to change your lives. And most importantly, connect with people who truly understand what it's like to live with the disease and go through what you're going through. I have to say, the patient conference for me was a turning

point for me in my disease, and it really was so impactful. It really made a difference in my life. It's going to be an informative, inspiring, and unforgettable time. Please keep an eye on your inbox because registration will open very soon, and we can't wait to see you all there. And I'm looking forward to meeting many of you in Chicago.

Marc Yale: Stay in the know by signing up for our email list. Many of you are probably on the email list, but if you're not, you can get exclusive updates on this year's patient education conference, upcoming webinars, events, and the latest news from the pemphigus and pemphigoid community. It's the best way to really stay connected and ensure that you never miss out on any important resources or updates. Joining is super easy. You just scan the code on the screen here and then click the menu bars on the upper right-hand corner. Click join our email list and then enter your info in the pop-up box. You can sign up today to stay informed.

Marc Yale: And not sure if everyone's had a chance to explore the IPPF patient resource page. Hopefully you have. If not, now is really the perfect time to do that. Whether you've just been diagnosed or seeking trusted guidance on managing and treating the disease, the guide for pemphigus and pemphigoid is really an essential resource. It's filled with medically reviewed answers, practical tips, and expert insights to help you navigate your journey with confidence. We've made the guide available in multiple languages, so it's now available in English, Spanish, French, Hebrew, and Arabic. So again, you can find that on the IPPF resource page.

Marc Yale: And if you're looking for a doctor who understands pemphigus and pemphigoid, be sure to check out the IPPF Find-A-Doctor Directory. That can be found on our website, and you can search for doctors in your area or anywhere in the world who are experienced and really understand these diseases. It's a great starting place, and you can filter your search using various criteria to help find the right doctor for you. And we've also added a section to the directory to keep it up to date. So if you notice that a provider's no longer available or if they've moved, there's an opportunity to make those changes and let us know so we can make those changes. So feel free to scan that QR code on the screen and you can visit the website to find a doctor today.

Marc Yale: The IPPF has several upcoming virtual support groups. If you'd like to join a meeting, visit the support group page to find out how to join the event and register. If you're looking to start a support group in your area or you're interested in starting a support group in your area, you can contact Amethyst Yale at amethyst@pemphigus.org. And it's really easy to start a support group. All it takes is two people, you and one other person, and then now it's a group. So if you're interested and would like to start a group in your area, we're here to help you do that and support you in that endeavor.

Marc Yale: And that is it for today. I just want to remind everybody that our next patient education webinar will be held on March 23rd. Dr. Marney White, Professor of Psychiatry and Social and Behavioral Sciences from Yale University will be with us, and she will be presenting on "Mental Health Support in Blistering Diseases. Why, When, What, and How to Find It". We hope that you will join us for this supportive and educational webinar. You can, again, scan the

code on the screen or visit the event page to register for the next webinar on Monday, March 23rd. And just want to thank you again today for joining us. Thank you again to our speakers and presenters today. And there will be a recording that comes out at the end of the webinar today with a survey. Please take time to fill it out and let us know how we're doing. And with that, I want to thank you all again and we'll see you next time.