

## October 26, 2020 Patient Education Webinar- Peer Support with the IPPF Peer Health Coaches

**Amethyst:** Hi everyone, welcome to the call, this call is now being recorded. We're gonna go ahead and get started with today's call. I'd like to thank everybody for joining today, and for being on the call. And thank you to our sponsors, Genentech, Principia Biopharma a Sanofi Company, argenx and Cabaletta Bio for making today's call possible. Today's topic is peer support, and our peer health coaches are here today to answer your questions about living with pemphigus and pemphigoid. Before we begin, I'd like to take a quick poll and see how many of you have connected with one of our peer health coaches, either by phone, or by email. So, if you just take a quick second, to answer the poll to see how many of you have connected with our great peer health coaches, We greatly appreciate it. In the meantime, I'd like to go over a few housekeeping rules and also introduce our peer health coaches. So let's get started to introduce our peer health coaches. Today on the line we have Marc Yale, Becky Strong, Janet Segall, Mei Ling Moore, and Scott Taub.

**Amethyst:** Marc Yale is the former Executive Director of the IPPF and is now the Advocacy and Research Coordinator and also works as a PHC. Marc was diagnosed in 2007 with Cicatricial Pemphigoid. 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 with PV in 1983 and started the Foundation in 1994 with the purpose of giving people living with this very rare disease a place to find information and connect with others. Janet graduated with a Bachelor of Science degree in psychology. After college, she worked at several jobs in the mental health field. She was also the executive director of the IPPF until 2008.

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.

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

**Amethyst:** I'm going to show the results here to see how many of you have connected with our peer health coaches. So it looks like about 50/50. So, some of you have and some of you haven't. So, hopefully after today's call, you'll feel comfortable maybe reaching out to a peer health coach in the future and know that we are always here to help you. So it is now my pleasure to introduce the Peer Health Coaches to answer your questions. And we're going to just get started here right away because we've got a lot of questions. So, I'm going to start off with this question that was submitted before the call. Cindy says that she's currently a few weeks into her steroid treatment, and she has three more weeks to go, she sees a definite improvement. She asks how will she know if she's eventually in remission? Marc, Janet, or Scott, would you like to answer that question?

**Scott:** Well, I'm one of the people who claim to be in remission, so I suppose I can explain what I mean. When I say I'm in remission, I mean that I don't have any constant symptoms, and I'm not on any medication. I do have a passing blister that happens maybe once every 3 or 4 months it goes away on its own. So I'm not completely free of disease activity all the time, but 99% of the time, I have nothing going on and I'm on no medication. To the question, how do I know when I'm in remission? I think what I've heard from most doctors, is that if you don't have any disease activity, and it remains that way for a period of a few months, you ought to think of yourself as in remission, but that doesn't mean that you can't have any disease activity and then you won't have any flare-ups. So it's more of a symptomatic thing if you're not suffering and it stays that way, then you're in remission. And if you can achieve a long period of time, with no symptoms and on no medication, then we've achieved our goal. I think others will also look to levels of antibodies using desmoglein 1 and 3 as the main test points. But, I know I've heard from all the doctors who are experts here that you could have low antibody levels and still have lesions. So, you would not be in remission in that case. On the flip side, some people have high antibody levels, but don't have any symptoms. If you're not having any symptoms, then, well, we've kind of met our goal. So, it's a long answer to the question of, how do I know I'm in remission, but I think it's basically if you're not suffering from it and it stays that way for a long period of time.

**Amethyst:** Great, thank you, Janet.

**Janet:** The doctors have also come out with definitions, and you can look it up, of what remission is and what's partial remission and what's full remission. And I think it's on the website, or you can look it up on the NIH website or PubMed. They did put together a remission discussion or detail, I suppose.

**Amethyst:** Great. Thank you. I got another question here, how do I know what subset of pemphigus or pemphigoid do I have? Marc, do you want to take this one?

**Marc:** Sure, so that's a great question and I think Scott kind of alluded to this a little bit is the way that you can determine or the physicians determine what subset you have is based on the antibodies that are present in your system. So, as he mentioned for pemphigus if it's desmoglein 1 or 3 then you know and that would determine whether or not you have pemphigus or pemphigus foliaceus. And the same type of thing for pemphigoid. You would have what they call BP180 or BP 230 which are the antibodies that would be present in your system for pemphigoid. So, the best way to determine that is through an indirect immunofluorescence test or an IFF, and that's a blood test. So they don't actually have to do a biopsy to determine that. It's done through a blood test. So I recommend that if you want to know exactly which subset you have after you've been diagnosed to get that blood test to find out which antibodies are present in your immune system.

**Janet:** I just want to say one thing to that. There's also the C3 to make a difference. But you could, they look for it in the biopsy as well. When I was diagnosed, I had no antibody count, but I had a lot of blisters from pemphigus. So sometimes they look at the biopsy and they see what antibodies are attacking which part of the blister.

**Marc:** So that C3 that Janet was talking about, is what they call a complement level. So, it's a complement to the other antibodies that might be present.

**Amethyst:** Great, thank you. And, I know we've been talking a little bit about desmoglein so I'm gonna jump onto this question. Pam asked, how many treatments of IVIG should be done before testing desmoglein levels again? What is the average amount of treatments before you see improvement with IVIG? I Think maybe Marc, you've had IVIG, if you'd like to answer that.

**Marc:** Sure, absolutely. I think it's always good to get a baseline test done at the beginning to see kind of where those antibody levels are. Again, as Janet kind of mentioned, the antibody level is not always the best indication but it can help doctors kind of determine how aggressive or where your disease is at but there's still such a thing as you can have low numbers and high activity or high numbers and low activity. So, it's not kind of the be all of information, but I

always recommend that you have that baseline antibody level test to see where you're at. As far as the number of treatments of IVIG, it really just varies. It varies per individual. So, IVIG, generally speaking, takes a long period of time to work, it doesn't happen overnight. So you may have to go through several treatments, multiple treatments. I was on IVIG for a year and a half. It works slowly because it's an immune modulator, so it modulates your immune system. The number of treatments varies by patient. So I think the best thing to do, is kind of what Scott was saying is really be in tune and be aware of you know your disease activity. And if your activity is getting better then that means that your disease is getting better and then you may not need as much, IVIG, or as much medication or therapies as as you begin to improve.

**Becky:** I just want to add something to that. I haven't had IVIG, but no matter the treatment, a great thing to do is talk to your doctors. Sometimes they have a lot more knowledge than they tell us. So one thing that I always asked my doctor when they gave me a new treatment. "So when should I see results from this? How long in your experience, has it taken for patients to start getting better or to notice a difference?" And depending on the medication, whether it's prednisone or something topical or IVIG, or Rituximab those are a great question to ask your doctor.

**Marc:** Just to expand on what Becky said. I mean, log your disease activity as well. Write it down. If you have 2 or 3 blisters in your mouth, write down when it happened and how long that they last for, how long it takes to resolve. And if they're gone for two weeks, and then they come back then write it down, and that will really help you track, whether or not you're getting better, or if things are not getting better. The amount of activity that you're having, the length of the activity that you're having, and how long it takes for these blisters and the lesions to resolve and return really kind of indicates what's happening with your disease, and if it's improving or not improving.

**Amethyst:** Great. Thank you, Dee just submitted a question, and they ask, Can you give a simple explanation to describe what is happening when one has PV? What are the antibodies doing in PV, versus what should they be doing?

**Becky:** So my short answer to that is pretty much, my body thinks that the cells that hold my skin together is foreign and attack like it's the biggest enemy on the planet. In theory, our bodies should recognize these cells as ourselves and shouldn't fight them as something that is trying to attack us but that's what happens in our disease. So that's why our bodies get the blisters and that they're very fragile. A lot of times, you don't even see the blisters, you just see the open lesions in PV. So that's my life, my bottom watered down so I can understand it version.

**Amethyst:** Anyone else have anything? Janet?

**Janet:** What actually is happening is exactly what Becky says but it's actually attacking one molecule in the desmoglein. And that's what causes the blisters is the separation that the attack of one molecule does on the cell, in that particular area. So it's a process where the genetic markers tell the T cells to tell the B cells to make plasma cells, and it goes on and on, and on and then we get a blister. The plasma cells, they attack us because they don't think we're part of our body.

**Marc:** I think that's kind of hard to kind of wrap your head around. It's an autoimmune disease, right, so your body is attacking itself. So you have to be careful not to boost your immune system, or any of these types of things because it's an autoimmune disease. It's almost like your immune system is overreacting to something that's happening, and doing what Becky and Janet said. It's attacking itself, it's going after these particular cells and it doesn't know what to do so it attaches to these molecules and creates these blisters. So it's a really complicated thing that happens to our bodies, that they start attacking themselves. The biggest thing, I think one of the big takeaways, at least for me is to remember that because if you cause any trauma to your skin or trauma to your body, your immune system's gonna react. And then it makes the disease worse. So just remember that you don't want to cause any trauma to your body or your skin. And that can happen in lots of different ways. This trauma can happen from eating, could happen from stress, can happen from the sun, too much physical exercise. All kinds of things can cause trauma to make the immune system react and attack itself.

**Amethyst:** Great, Mei Ling did you have something to add?

**Mei Ling:** In reference to the trauma, it's important to also recognize that if you're going to have surgery of any kind, like a knee replacement, hip replacement, even oral surgery, having a tooth pulled, it is best that you let your dermatologist know ahead of time. Because depending on the level of your activity, she or he may want to increase your medications prior to the procedure or after because blisters can happen, because it's invasive. And this is a skin invasive blistering disease that we have. So you want to be very careful with that, as well.

**Amethyst:** Great. Thank you. Speaking of trauma and boosting your immune system. We get a lot of questions about this, and we had a question submitted beforehand what vitamins or supplements should I be taking? Or maybe even avoiding?

**Mei Ling:** You definitely want to take vitamin D and calcium because if you're on steroids such as prednisone, it depletes the bones of the calcium. So that for sure, I know all of us are going to also advise about magnesium, or potassium, or whatever. But please do not think that you have to go overboard and take every vitamin in the world. If you're concerned about this, ask your doctor to do a test to find out if you are actually deficient and need a B vitamin, or an A

vitamin, or K vitamin, or whatever because they do interact. And some of them react adversely to your immune system. So, double-check with your doctor before going out and buying every vitamin you can see.

**Scott:** I think when it comes to vitamins, there's one thing to know is that for a lot of us, we have disease activity in the mouth. So, we don't eat all the things that we might normally eat because they're painful. Well, if you're in that situation, you might want to think about taking just a regular multivitamin to make sure that your limited diet doesn't cause you to become deficient in something. But we also get asked what vitamins should we take to help us fight the disease? And I haven't heard of any vitamins that fight the disease and if you take an immune booster vitamin, that may be counterproductive because, as Marc alluded to, we may not want to be boosting our immune systems, because our immune systems don't always work right. So we don't want to trigger it unnecessarily but then the other category that Mei Ling alluded to is certain medications you may take might cause deficiencies and you might want to take vitamin supplements but you should talk to your doctor about those kinds of situations.

**Janet:** I also want to say that sometimes the medication can cause some irregularities. So that's another thing, make sure you get your blood tests from time to time because the medications can affect your kidneys or liver or something. I'm not on any medication right now and I'm in remission for a long time. I mean, don't ever do anything I say unless you talk to your doctor. But I take extra Vitamin D and I have to take magnesium and potassium because I'm low at it and I don't know if it's because I was on prednisone for 10 years and I was on Azathioprine like Scott. I don't take calcium because I have a heart condition. So I don't want to take calcium pills so I drink a lot of cashew milk and it seems to have really helped. It has a fairly high calcium level and I don't like regular milk. So there are different things that you can do naturally. I take milk thistle for my liver because I have a fatty liver. And I want to do whatever I can to stop that. So, there are different things that you need to talk to your doctor about before you do anything. But you don't want to do anything, again, to enhance your immune system. It's very dangerous.

**Marc:** I think that's a good point that Janet is making, making sure you get those tests and talk to your doctor. I was taking calcium and then my doctor said, your calcium is really high. And he said if I was having kidney or liver problems I could get kidney stones, or things like that because of too much calcium. So it really is important to make sure you talk to the doctor. And then the other note, kind of a cost thing is your doctors can prescribe these tests to test these vitamin levels. Make sure you check with your insurance company to make sure that all of these tests are covered by your insurance because sometimes they're not and make sure that your doctor is using the right diagnosis code, or test code, when they prescribe the test, to make sure that it is covered. So in other words, if you have a disease indication of pemphigus and they're ordering a specific test, make sure they say they order that test for this specific disease so that way the insurance company covers it because if they don't, then you might get a letter a surprise letter in the mail saying, this isn't covered and it could be hundreds of dollars.

So, it's definitely important to communicate with your doctor. Make sure that they're ordering those tests properly, and all of those types of things because nobody likes surprise billing.

**Mei Ling:** Since Marc brought up doctors. This is October. We are now into renewing your insurance coverage. It started a couple of weeks ago, and it ends in December, so definitely, check your policies. If you have an insurance agent double-check with him or her about what you're covered for so that you can go right into next year without a hitch. You may have a procedure that needs to be scheduled but there's a waiting period or because of COVID, there's a backlog. So double-check that you got your insurance covered going into next year.

**Amethyst:** Great, thank you. Julie asked, Do any of you take turmeric?

**Scott:** I definitely don't take turmeric. Before I started having symptoms of PV, I had discovered I was allergic to turmeric. And it actually produced symptoms in me that were more dangerous than PV. Oddly enough, after taking immunosuppressants for several years for PV, I am no longer allergic to turmeric, which I suppose, is one of the weird side benefits of having gone through all my PV symptoms.

**Janet:** I put turmeric in my Chinese food when I make it, other than that I don't take that separately.

**Amethyst:** If anyone does have a question, please feel free to raise your hand. I'll go ahead and unmute you and then you can ask your question live to any of our coaches. So, moving on, I know we've talked a little bit about remission and does desmoglein and everything like that. For those of you that are in remission, how long has it been, and how many treatments, or how many months did it take before you went into remission?

**Janet:** Woo, well, I can say, I was diagnosed in 1983, I was on prednisone for three years, at 30 milligrams, went into remission. And as soon as I saw a sore I went right back on prednisone for three months. Went into remission again and then 1994, I think it was, because that's when I started the Foundation, I broke out again. And this time they had to Immuran, so I was on prednisone at a low dose, and Immuran and for five years. Since 2002, I have been in remission, although, like Scott, I get lesions from time to time in my mouth, depending on my foods, I know what triggers me. Certain foods will trigger me if I eat too much of it, like chocolate. It comes and goes, from time to time, but it goes away. As long as it goes away by itself, I'm good.

**Scott:** I was diagnosed in 2013. Was on prednisone and Cellcept and then switched from Cellcept to Imuran. I was on prednisone for close to three years and then stopped that and for another year I was on only on Imuran. Then for the last three years, I've been in remission on no medication. It took me over three years to get to the point where I really had no disease activity to speak of. So I was on multiple treatments during that time, but the last four years I've been in remission and the last three, without any medication.

**Becky:** For me, I started giving symptoms in 2008 diagnosed in 2010, and I took my last dose of prednisone on September 30th of 2013. I saw rather quickly, probably within about nine months, I got to a place where I didn't have any lesions. And then, every time we would start to wean down on my medicines, I would have lesions and flares and have to go back up on my dosages and stay there for a little bit. So I would like to tell you like it happened, and it was so smooth, and I got off of it really quickly. That process took three years and by the end, the joke was that I had a nibble of prednisone a day, because even taking a quarter milligram or three quarters of a milligram of prednisone and trying to cut that out would make a difference in my life. So, then, I would have to be on that, and I was getting to a point where I was weening, from every two weeks, going down on, dosages to every three weeks to even a month. Like I said, going down by a nibble of prednisone at a time. Because you all know when you cut prednisone crumbles in your hand, especially when you're trying to cut it into four pieces. So, it wasn't a smooth process, but it's there, and the important thing is to never lose hope. The whole point of being on the treatments and the medicines that were on is to find something that works, to get us to remission.

**Amethyst:** Great, let's try to do another live question. We've got Julia Moua. Julia, you've raised your hand, so I'm gonna go ahead and unmute you. You are now unmuted, if you'd like to go ahead and introduce yourself and ask your question.

**Julia Moua (patient):** Hi. Yes, My name is Julia. I was just recently diagnosed with Bullous Pemphigoid. I'm 32 years old, and, to my knowledge, that's a really young age to be considered having this autoimmune disease. I don't know if that's something that anyone's ever come across. It's really new to me. I started having these little bumps in the beginning of September, 2 little bumps on my feet and I thought it was a spider bite so I didn't think much of it. And within that month I ended up having a rash on my stomach. And I thought it was my eczema that I found out I had at the beginning of this year. So I used some steroid cream and it was slowly going away but then more bumps came onto my body. And now I have blisters all over my body. I've seen three different dermatologists. I've gone to the ER three different times within this month alone. And I'm just trying to figure out what I need to do and what I should focus on and what are my steps here?

**Amethyst:** Great question Julia, we're gonna go ahead and see if the coaches want to answer. Input?

**Julia Moua (patient):** Yeah because I really don't know what I need to do.

**Becky:** So Julia I was diagnosed like you in my early thirties, the gray hair has suddenly come out thanks to the pandemic but I was in my very early thirties when I got diagnosed as well. You're doing everything right. You're talking to a dermatologist, making sure that they are familiar or have treated patients with pemphigus or pemphigoid before is very helpful. Finding out, just from their experience, what treatments that their patients have used, and have been successful for your disease. And then, again, having those conversations with your doctor. One thing that pemphigus has surely taught me is I need to be my advocate. Like when should I be seeing the results? Kind of like we talked about earlier. And talking to your doctor. Okay, if I'm on this treatment now, what's my next step? Right? If this works, great. We know that this is going to be my treatment plan, but what if it doesn't? When do I call you? My doctor wants me to call when I have five lesions lasting longer than five days. So, those are conversations I had with my doctor very early on. Those are contacts that I still keep in touch with. Even though I am in remission, I do still see my dermatologist just about once a year just to keep on track. Then, if you're using a medicine and it's not working and especially if you're getting more lesions like Marc said, really tracking your disease seems to really be helpful information to give to the doctor as well.

**Marc:** Julia, you got me beat. I was 38. So, I just have a quick question for you, what therapies are you on now?

**Julia Moua (patient):** So, right now, they have me on all sorts of stuff. Right now, they have me on, of course, the prednisone and I'm taking about 80 milligrams a day. Then they also have me taking vitamin C, Potassium and Vitamin D. Then, they have me taking either Narco or high dose of Tylenol because at night I have not been able to sleep since September. It's so bad at night, I'm really itchy and have really burning skin. They also give me Atarax to help and Melatonin but that's not really working. I mean, it gets me sleepy but that doesn't help with the itch or the burn.

**Marc:** And, of course, the prednisone doesn't know either. That doesn't help you sleep either. I think the high dose prednisone, and I don't know how long you've been on the high dose prednisone but that should help with some of the initial inflammation. It doesn't sound like you're on any immunosuppressant medicine, which would probably be the next step if things aren't getting better from the prednisone. They have to treat this disease systemically, so some sort of immunosuppressant medication might be the next step. I would probably recommend, if you haven't already, reach out to the IPPF and we can put you in touch directly with a Coach to kind of help you walk through the next steps and what kind of questions you should be asking your doctor, as Becky talked about, and just provide some more information about all these

different therapies that are available. Because there are a lot of therapies that are available. There's a list of them on our website but we can also provide that to you directly so you can go through those with your doctor and say well, hey, what about this? You know what about this? And just make sure you kind of move through that list of potential recommended therapies to try to get you into a better state faster and get you off of that high dose prednisone as soon as possible. Because as you have probably heard, prednisone can cause lots of problems. Prednisone plays an important role in reducing that inflammation in the beginning but you don't want to be on the prednisone for a really long time. And I think Janet was going to say something.

**Janet:** If you're on 80 milligrams of prednisone, that's a lot of prednisone and it can cause a lot of problems like sleeping and other issues. So, you need to really talk to your doctor about adding in something else, because you have to make sure the doctor understands the disease. And don't be afraid to talk to them because they're people. Some know more than others, and some don't know all that much. So you have to sometimes be aware of them. There's also a checklist on the website, you can go to the front page of the website and scroll down, it says a checklist, you come up with a checklist for the questions you should ask. I was 36 when I was diagnosed with pemphigus so yes, some of us get it young. But bullous pemphigoid that young, that's pretty young for BP but it happens.

**Amethyst:** Marc, you kind of alluded to it, and I was going to ask it at the end. But let's ask it now. If patient's want to get in touch with one of you, coaches, what's the best way to do that?

**Marc:** Yeah, definitely go to the website, as Janet mentioned, you can go to the website and just scroll down, it says "Ask a Coach", and you click on that. You'll be put in touch with one of us or one of our other colleagues, within a couple of days. And we're here to help, as Janet said, help provide information and support and guide you through this journey that you're just embarking on or have been on. The beauty of it is, of course, is we've experienced it firsthand. Some of us are in remission, some of us are still experiencing disease activity and we're here to help. That's what we're here for.

**Amethyst:** Great, thank you. Got another live question coming in from Elizabeth Ceranowski, I think I am pronouncing that correctly. Elizabeth, I'm going to unmute you if you go ahead and ask your question.

**Elizabeth Ceranowski (caller):** Okay, can you hear me?

**Amethyst:** Yes, we can.

**Elizabeth Ceranowski (caller):** Okay, I actually have two questions, but, if I can only ask one, I totally understand. So, I'm the parent of somebody, my son, is 11 and he has pemphigus. We think he's had it since he was 3. He was diagnosed with it two years ago, after lots of misdiagnosis. But my question is, is there something that you wish you could have told the people that love you back when you first started out, and you were struggling with this, that would have made your life easier, or just been nice to hear? Or, just, as you were beginning your journey, way back then? It's hard for him to articulate. So, I'm just looking for information, as you can imagine, this isn't a large group of folks, so any support that you would have to provide would be really helpful.

**Janet:** I'd like to respond to that, actually. So, I met another child some years ago with pemphigus vulgaris. Does your son have pemphigus vulgaris or pemphigus foliaceus? Do you know?

**Elizabeth Ceranowski (caller):** Pemphigus herpetiformis.

**Janet:** Okay, so he was a 9 year old young man . I'm sorry, I was thinking of somebody else. There are a couple of kids. This little kid had pemphigus vulgaris, and the mother was worried more about the disease than the child was and he had a lot of stores all over his body. He would sit and watch TV, and he was in some pain, but they don't think the same way we do. So, when children have a disease like this, they think of it in a different way. So, it's probably a good idea to talk to him about it and see if you can get him to talk about it, but not in the scary way, where he feels comfortable and where he can express to you how he's feeling. And it might help give you a little bit of understanding or relaxation about how he's dealing with it and how you can help him deal with it. I would say, try and talk with him about it, even though he is young.

**Marc:** And I think, like Janet's saying, children or kids think about it in a different way such as, can I go out and play with my friends? What are they going to say if I have a blister on my face? So there's all of these stigma things. Or am I able to participate in sports? Or, I can't go out in the sun. So there's all of these limitations and burdens that come along with this disease, and they're different for kids than they are for adults, right? My heart goes out to you, because this has got to be extremely challenging and everybody's going to experience it differently so having that open dialog with him or making sure he has somebody to talk to, if it's you, or even a counselor, or somebody. I think that's really important. Just making sure he expresses himself, that's the key.

**Scott:** Elizabeth, you asked if there was something we wish we could have told our loved ones. My family was supportive and helpful. I've heard some people with this disease have stories of

families that shunned them and refused to understand the disease. I didn't have any of that, but the one thing it took my family some time to understand, was just how tired I was. Even when I got past the not sleeping due to prednisone. Even when I was getting 8 or 9 hours of sleep Fighting this disease and dealing with the pain all the time, I was just absolutely exhausted all the time. It took my wife and particularly my kids, some time before they got it. Before, if Dad didn't clean up the dishes from dinner, it's not because he was being a lazy bum, although I do that sometimes. But at that point, it was not because I was being lazy, it was simply because eating took all my energy, and that was it. So, if your son sometimes in dealing with this is sometimes refusing to do things, he may just be completely exhausted, even if nothing in particular happened that day.

**Becky:** So tagging on to what Scott said, my family whenever something would happen, and I would get upset would say, "Oh, Becky, I know it's the prednisone." And one time I snapped back to my husband, "Well no, sometimes you're just a jerk." So, a lot of times we try and make excuses, that it is the prednisone and probably a lot of times it is the prednisone. We are a little bit more touchy or cry or whatever, right? But sometimes, he's just going to be a kid too. So don't be quick to blame on medicine but keep that in the back of your mind. The other thing I was going to say is, normalize it with his friends for him. I have a friend whose daughter needs to get laser treatments for her disease. And then it results in visible on her face and her neck and her arms, polka dots. So, they call the laser treatments, Marissa's polka dots and that's what makes her special. And then they have a song that has a little bit to do with the holiday season, called the Penguin Poca, and they play that for her in the car on the way there and on the way home. So, make it normal amongst the friends, right? And it's to the point where some of her daughter's friends have said, "I wish I could have polka dots like that." Make it so special and a normal part of the vernacular, not something different and scary but really make it what it is in a very level appropriate way for him and his friends.

**Janet:** I just want to say one more thing. I think it's also important for you to take care of you in this kind of situation. You need someone to talk to, if your husband you can talk with him. Or a neighbor friend or therapist, or one of us, or whatever. I really believe that if you're doing okay, if you can communicate with him okay and you're feeling no anxiety about it all, because parents can feel that way when something happens to children. I can tell you that too. So take care yourself. I think that's really important.

**Elizabeth Ceranowski (caller):** Thank you, that's really helpful

**Marc:** Yeah, that's really. That's really good.

**Elizabeth Ceranowski (caller):** My other question was around food. I've noticed with my son when he eats corn, although he has not tested allergic to it, but when he does have corn, it causes a flare up for him. The doctors act like we're crazy when we bring that up. Have any of you all had that in your experience where certain foods are a trigger for you for this condition? Look at all those heads nodding, oh my gosh, I wish the doctors could see this right now.

**Janet:** Let me say one more thing about the doctors. There's no, quote unquote proof. Doctors will not say yes at all unless there has been written proof because they didn't want to get sued. So you have to sort of go with your own gut about what foods may or may not trigger you. I know what triggers me, chocolate. If I eat too much of it will trigger me, and some other things. So if it triggers him, don't give it to him.

**Scott:** I think, just about all of us who've been through this disease have eventually figured out that we have triggers. For me, I figured out that for a while alcohol was a trigger and I didn't drink for two years because when I did, I got a blister and didn't seem worth it. Other people have said other things like onions and tomatoes. There's all kinds of research on things that are more likely to be triggers. There's a doctor that's presented at the IPPF Annual Conference a few weeks ago, Dr. Kyle Amber who did a good session on foods and he basically said, if you kept track of your food and you come up with something that appears to be a trigger for you, yeah, it probably is. So if that's a trigger then just avoid it. And even if medical science hasn't yet figured out how or why triggers, it doesn't matter. Just avoid the things that cause problems for you because why make this disease worse? Unless it turns out that your son really, really likes corn in which case, you will have more difficulty getting him to avoid it.

**Marc:** And it can be different for everybody. That's the other thing. So corn might be a trigger. That's okay.

**Amethyst:** Great, thank you. Thanks Elizabeth, for asking those great questions. Let's take another live question. Humaira Hannan, are you there?

**Humaira Hannan (patient):** Hi, how are you? My question is, you know, because I was diagnosed when I was 26 years old and I'm turning 29 at the end of this year. In the March and April, I had my first Rituximab infusion, that's when I severely had it in my mouth area and also in the genital area. So I was a bit of a severe case, and I had a very tough time. I went through Rituximab infusion, once in 2018, once in 2019 and this year, I actually had it twice. I headed once in February 2020 because I had one little lesion on top of one tooth. And then, again, I think 5 months later this year, I started having blisters to be around 10, 11, 12 or teeth, so I had to get another Rituximab infusion in October. So, my question is because I am diabetic and I have PV, I badly wanted to plan a family plan with my husband because I also recently got married two years ago. I wanted to get pregnant, but I'm scared. I don't know with PV how it is,

as a diabetic patient, since I can take prednisone. Is it possible to go through a normal pregnancy cycle and give birth to a normal healthy baby with any treatment?

**Becky:** It's a great question and that was one of my concerns being diagnosed in my early thirties and I had just gotten married. One of the best pieces of advice my dermatologist gave to me was to see a high risk OB, also known as the Maternal, Fetal Medicine doctor who is familiar with patients with autoimmune diseases like lupus. Those are commonly found at University Medical Centers or teaching institutions are a little bit more common. And, while my doctor had never had a patient with pemphigus vulgaris they had had lots of patients that had lupus and other autoimmune diseases like rheumatoid arthritis and those kinds of diseases. So the same medicines that are used for those diseases are also used to treat our disease. There's not a real straight forward, like, yep, go for it. Nobody ever told me Becky, this is the best idea ever. But I had what they referred to as a preconception consultation and it's a mouthful but it gave me an opportunity to meet with the doctor and my husband was there as well. We went over the pros and the cons of having an autoimmune disease and being pregnant, the birth defects and the black warnings and the absolute, well, you can be, but there's a slight risk with this, or up until this dose, it's probably okay. And it gave me a real sense of is this worth it? Should we go through with this? Should we hold off? And then the high risk OB talked and worked with my dermatologist about when would be the best time. Back in like 2012/2013 when I went through it, they wanted me to start fertility treatments. Normally, they make you wait a period of time but because I had this autoimmune disease that had a chance of coming back, they wanted me to start fertility treatments right away. So you can get all of this information at that appointment before you and your husband even set out on a journey of starting to have a baby. Again, having those conversations with doctors, and talking to people that have been through it are probably the two best tips that I can get you. It's a lot of talking, ahead of time but the more knowledge that you have, you can make the better decisions if it's a risk that you're willing to take and what needs to happen if you're not ready right now, what risks and what you can do with your doctor, what medication changes can you make now, in preparation for having a family.

**Janet:** Also you may want to talk to your doctor since you can't take prednisone and you're diabetic. If you're going to do Rituxan to maybe add IVIG, because there are some indications that IVIG and together, I don't know if they give at the same time, it has a better remission chance than just doing one. There are a lot of people on prednisone and some other drug when they do Rituxan. So, you should talk to them about IVIG along with the Rituxan and Marc may know more about that.

**Marc:** Yeah, the combination therapy works really well with Rituxan and IVIG. That's what I actually used to go into remission several times. The one thing about IVIG though, is you have to make sure because you're diabetic that you get the formulation that either has no sucrose or low sucrose because there is sugar in there. So, just make sure, again, if your doctor does do

IVIG and that they're getting the right formulation. Then, sometimes when you get IVIG or even Rituxan, which it sounds like you've already had, they will give you an injection of corticosteroid right before the infusion as a premedication to make sure that you don't have any reactions. And, of course, that can make your blood sugar spike, but it will go away. So, they do that, same thing with IVIG. So it's a short term spike in your blood sugar, but you definitely want to be aware of it so you don't think, "what's going on with my blood sugar, I have diabetes and I just got this infusion and now my blood sugar went up." It's because of that corticosteroid that they give you in the premedication. But Janet's right, I'd talk to your doctor about the IVIG as well.

**Becky:** And talking about Rituxan too, all of these medicines, just because we stop taking it today doesn't mean it's not in our system tomorrow or six months from now or a year from now. So, really, be sure you talk with your doctor that after you get your Rituxan infusion, how long should you wait to try and conceive a child as well. Same thing for any of the medications such as the immunosuppressants medication, to make sure that you're in a really good place to start trying to conceive.

**Amethyst:** Great, thank you, good input guys. We had somebody type in, speaking of Rituxan, how does an Rituxan infusion work and what's the difference between Rituxan and IVIG?

**Marc:** Rituxan is a targeted B cell therapy. What that does is it targets the B cell in your body which is creating the autoantibodies which is making your skin blister basically. So what the Rituxan does is it eliminates all of those B cells so that your body can't make those autoantibodies that attack your skin. And that's what Rituxan does. IVIG is a little different in that it, as I mentioned earlier, is an immune modulator. It's basically a plasma infusion and what it does is it slowly changes the ratio of good cells in your body and bad cells. As Rituxan eliminates the B cells, what IVIG does is it replenishes your body with plasma cells and creates more plasma cells in your body which aren't necessarily creating the autoantibodies causing your skin to separate. So, that's why sometimes they're done in combination with each other because as one is eliminating, the other one is repairing and adding, and that's why they're done together. Did I answer the question Amethyst? I don't know if I missed anything?

**Amethyst:** I think so, yeah. And then also kind of alluded to, somebody had asked, how do I know if I should get one or the other, or both?

**Marc:** That would be obviously up to the doctor, between you and your doctor to decide what is the best choice in therapy. One of the challenges, I think, with Rituxan although it's proven to be very successful with many patients, it doesn't work for everybody, but because it targets those B cells and eliminates those B cells it suppresses your immune system at a pretty high

level. So, it's important that you're aware of that. You're going to have an extremely suppressed immune system, or no immune system at all because you're eliminating those B cells. The other benefit of adding the IVIG to that is, when you add those plasma cells in, what that does is it creates a prophylaxis against getting a secondary infection that the Rituxan is causing. So, having the IVIG infusion at the same time, you're getting that Rituxan, again can, I wouldn't say eliminate, but help prevent any secondary infection or help guard against that kind of thing. So, there's a benefit to doing IVIG at the same time you're doing the Rituxan.

**Janet:** Let me just say when you get Rituxan it kills maturing B cells, it doesn't kill all the B cell and also, you have immunity from your T cells as well. The whole idea about Rituxan is it targets a certain molecule. And so don't have total loss of immunity, but I would suggest you talk to your doctor if you're gonna get Rituxan and about getting a pneumonia shot because pneumonia is one of those things that are B cell mediated. So if you get a flu shot or pneumonia shot as well, because it's B cell mediated.

**Marc:** Yeah, and on and on the pneumonia shot, just a side note, there's actually two pneumonia shots. There's one for the elderly, and there's one for folks that aren't elderly. So make sure you ask your doctor about that, as well, just in case.

**Amethyst:** On another side note too, what about thoughts on the flu shot? Is it okay to get a flu shot?

**Janet:** The thing about that, too, is, yes, it is. If you're immunosuppressed, and you're already taking some other drugs it's probably worth getting but you need to really discuss that with your doctor or dermatologists, or even your primary care doctor, because sometimes the dermatologists may not be so sure. If you're on a drugs like prednisone or an immunosuppressive, they say it's better to get it while you're on a low dose of that. But they say, it's better to get a flu shot anyway especially now with COVID.

**Scott:** The flu shot is an inactivated dead virus. And those ought to be okay. You're not at risk getting the flu due directly from the vaccine. If, for some reason, you are offered a live flu vaccine, which the nasal vaccine that was popular a few years ago was live. You should avoid live vaccines if you're on immunosuppressants, because you could actually catch the disease. But if it's the inactivated virus, it should be safe to get a flu shot. My doctors told me, I should not miss a flu shot, because, if I get the flu, my immune system will fire up to fight the flu and it could also cause a pemphigus flare. So I have not missed a flu shot in over 10 years and don't plan on skipping it in the foreseeable future.

**Janet:** Me too.

**Amethyst:** Great. Thank you. I know it's already been a very quick hour. If you guys don't mind hanging around I can maybe ask 1 or 2 more questions? Great thank you because we've got a lot of questions coming in still. So Tamalia asks, "What was your experience with the Rituxan infusion? Were you able to get it at home? And do you feel physically or emotionally strained after taking them, and what are the side effects?"

**Marc:** So it cannot be administered at home just because it's very potent medication, very potent therapy, so, normally, it's done in an infusion center or can also be done in the doctor's office, but there needs to be a nurse and a doctor available during the infusion. As far as the side effects, again everybody is different. At least, in my experience, the side effects were pretty mild. It certainly wasn't anything worse than any of the other medications that I was on such as the high dose prednisone of the Imuran or the cyclophosphamide or any of those other medications. I did have some mild, intermittent constipation and diarrhea, that sort of thing and little bit of a headache but nothing major. Basically, I mean, you can do what you normally do, you can eat during the infusion, drink a lot of water, read a magazine, and sleep if you're tired. I mean, They are going to give you some Benadryl anyway, So, you can sleep. That's one of the premedications they give you. I would expect after the treatment, and Scott kind of alluded to this earlier anyways, you're gonna be tired. You're getting an infusion, you're getting a therapy, you're introducing a new medication to your body. So, expect to be fatigued, expect to be tired. Take the next day off if you have to work. Take the time to let your body rest, and just really listen to your body. If you're tired, that's okay, that's normal. You're going to be tired but other than that, I wouldn't really expect too many things.

**Janet:** One of the things that several people have mentioned to me was that a lot of the times the major problem is with the infusion, especially the first time. Have it done slowly, the first time, especially the first time. To make sure it's over hours is, anywhere between 6 and 8 hours, depending on. Sometimes they'll push you to 3 or 4 hours, and that's really a little fast. So if you're going to have it the first time, make sure that you have it done slowly

**Marc:** Generally they're pretty good about that. There's going to be a nurse there. She's going to be monitoring you, checking your blood pressure, making sure you don't have a temperature. They're gonna give you those premedications to make sure you're not having any type of allergic reaction. And if you do have a problem, as Janet said, it's going to happen during that infusion and it's going to happen right away, and when that happens, you're gonna stop the infusion. So, if you notice something when you're getting the infusion, that just doesn't seem right, feels off. You're feeling itchy, or your throat is scratchy, or anything, let the nurse know and they'll stop the infusion because you don't want to have any type of reaction. Some people will have a reaction to the infusion and that can happen but you don't want to keep pushing ahead. You definitely want to do it slowly as Janet mentioned.

**Amethyst:** Great, thank you. And I know Marc you said that you can't get Rituxan at home, are you able to get IVIG at home?

**Marc:** Yeah, so, it depends on your insurance, of course, but IVIG is available at home. Again, it depends on the type of insurance you have and what their coverage is. You can get what they call a home infusion where a nurse comes out to your house and they can do the infusion right in your home. Right now, with COVID actually, that home infusion is becoming more accessible and more available just due to COVID and the fact that they don't want people going to the hospital or to the infusion center since you are at high risk, to maybe be in those types of environments during COVID so you can actually get the infusions at home a little bit more excessively now because of COVID. Talk to your insurance company if you have questions about that, and of course, again, reach out to the IPPF, reach out to us and we can help provide some names of some different infusion companies that provide this type of service. But the big thing is just make sure your insurance is onboard. Basically the doctor has to just prescribe it. They say, "Hey, they're immunosuppressed, they need to get IVIG at home", and that needs to be the prescription. Then that goes to the insurance company and from there, then all the arrangements get made.

**Amethyst:** Great, thank you. And ask another live question here, Julia Moua I just unmuted you, want to go ahead and ask your question.

**Julia Moua (patient):** Hi, again, you guys. So my main question right now, is the fact that this is new to me. I have all these new blisters and some of them have popped and some of them are sort of healing. How did you guys deal with it in the beginning? How did you guys self care for yourself? And what kind of clothing did you guys wear, what kind of soap did you guys use so that it doesn't irritate your skin? I'm just trying to navigate this right now, because I could barely wear any clothing. I'm trying my best to find the most sensitive soap out there to clean myself. I don't know if I need to shower once or twice a day to keep my wounds clean? I went to the ER because my dermatologist told me to go there so that they can have the wound team clean me up. When I got in and was admitted, they didn't even do anything like that. I was just there for two nights, and then they sent me right home. So I didn't even get to shower for those two days. They pretty much just told me, don't pop your blisters but if you pop them, make sure that you spray saline on it and put a bandage on it. That did not help me one bit.

**Amethyst:** Thanks for the question Julia. I know a lot of patients have issues with that. Cleaning and self care and soap. So, Mei Ling, did you want to answer the question?

**Mei Ling:** Yes, I can address some of them and I'm sure Marc, Scott, Becky and Janet can do the rest. I, myself, when I got it in 2002, I had it all over my upper back. Being Asian, I have very coarse hair and a single strand of hair, felt like a razor blade cutting me. So I understand about the sensitivity there. I cut all my hair off and I also cut out the clothing labels. If you have

anything on your back or your neck, you might want to cut the labels out of the clothing so that it doesn't irritate. Paper tape if you didn't use it successfully. There's several brands out at drugstores that have paper tape so that it doesn't pull on your skin. You might want to take lukewarm baths, instead of showers, because the pressure from the water hitting your skin can be painful. I had to do that for a year. Also, I don't know if you have it on your scalp but if you do and you want to wash your hair, I personally had to boil parts of water on the stove and then mix it with bowls of cold water to get lukewarm. So, I mean, there's a lot of steps. Also, one of our doctors had recommended that if you use a topical, if you're at home, which most of us are these days and you could wear minimal clothing, or none at all to apply your topical, or vaseline, and walk around naked for a while because that will speed up healing instead of putting on gauze. I'll let somebody else take it over from here.

**Janet:** You know, when they put you in the hospital, I don't know if you have bullous pemphigoid or pemphigus? What disease do you have because it sounds like you have pemphigoid because you are talking about bursting your blisters.

**Amethyst:** I think that she said she has BP Janet.

**Janet:** Yeah, okay, so that would make sense. You don't want to break your blisters, try not to break your blisters. Some doctors say to cover them, some don't. But when you go into the emergency room and you have a lot of blisters they don't know what to do about PV, I mean pemphigus or pemphigoid. They will treat you like a burn patient and you don't want to be treated like a burn patient. I've been through this with a couple of patients and actually went to hospital with one, who they put in a burn unit and they didn't know what to do with her, so we had to have a long discussion about that. So, when you go to the hospital, they have to really understand, if you have to go to the hospital, but hopefully, you're getting medication to help you get rid of these blisters so that you don't have to have coverings, and you don't have to do anything. When I had pemphigus and it covered my head I couldn't shower. Baby shampoo seemed to help with what Mei Ling was saying and tap water when washing it, very light water pressure. I don't know if you can turn the shower head to make it very misty instead of really hard and baby shampoo. I just dreaded going in and washing my hair. And my mom made me a bunch of clothing so something I could tie around my waist that was very loose clothing. Cotton is best. So that was my experience.

**Becky:** I was gonna say something similar. Breathable clothing, avoiding the synthetic fibers. For me, using liquid soap was a little bit better than using bar soap, and then making sure it was dye free and perfume free. Unscented is different from fragrance free. One has something in it to cover up the smell, and one is not scented. So to talk to your doctor about that. Also make sure that the skin that's intact, to protect it. So, for me, my doctor had me use ointments and creams, rather than lotions because they tend to be more moisturizing. One of our other

coaches that's not on the call, used tight T-shirts to hold dressings on when he went to work to hold dressings in place instead of using tape to keep the skin intact and I've heard of women using camis or leggings in the same way so that they don't have to use tape to hold dressings in place. One dressing that seems to be coming up time and time again in conversations with other patients is telfa. It's best described as the white part of the band-aid, that dressing in there, and it's meant to not and that stick to wounds. It can be found in a lot of drugstores. Sometimes you can get it from durable medical, and it's covered under your insurance plan sometimes. So check that out as well. Make sure you know what dressing supplies are covered, what are not? Or using gauze to hold on dressings like a role called Kerlix to hold on larger dressings as well. So those things are very helpful. I've had patients tell me that they sprinkle cornstarch on their sheets and their clothing before they put it on to help them sticking. All of these things I would run by your doctor, just before you try any of this, just to make sure if it's right for you and what your doctor recommends rather to cover, or to not cover. But those things kind of helped. And again, I hear a lot of patients say what Mei Ling already mentioned about walking around naked. You're in your house, the windows are closed anyway, who cares.

**Amethyst:** That's great. And actually, another patient wrote in Annemiek says, "Use seamless underwear or wear underwear inside out no seams on your skin." Good tip as well. Thanks Annemiek.

**Marc:** My two biggest suggestions would be, as Janet said, do not pop the blisters and do not go to the emergency room. Those are two things I think you want to avoid. If you need help finding a doctor that's a little bit more familiar with this disease, just reach out to us and we'll help you with that. Don't go to the emergency room. They will debride the wounds and it will just make it worse.

**Amethyst:** Great, Thank you. Let's try to get one more live question in before we end our call today. Khloe Tam I'm going to try to unmute you again. Chloe, if you're on the line, you are unmuted, if you'd like to go ahead and ask your question to the coaches?

**Khloe Tam (patient):** Yes, hello. How is everybody? This is so interesting. I'm from Montreal, Canada, and unfortunately, we don't have Mayo clinics. I've got pemphigus vulgaris, PV, it has been about nine months now. I asked for infusions because I read a lot about it on your sites, and my doctor seems to want to use that only as a last resort. I am 64. I have seen very, very bad side effects from the prednisone. I'm also taking Cellcept and all the other topical possible creams and I haven't been sleeping for the past seven months. Exhausted, like you all mentioned. Is there any requirement or anything that I can do to convince my doctor that it could be a right route without offending obviously their expertise? Thank you.

**Amethyst:** Thanks Khloe.

**Scott:** I would start out by saying, don't worry about offending them. And I don't mean that, because I think it's okay to offend them. It turns out doctors have pretty thick skin, I've found. Yes, that was a skin related pun since we have skin related diseases. I was nervous for awhile about this and I did research on Google and the IPPF and came up with all these possible new treatments and I was a little reluctant to bring it up to my doctor but then my wife who came with me to most of my appointments when things were bad basically said, "This is dumb, we have access to somebody who should know about this, we should bring it up." So one of my appointments, I started bringing these things up and a couple of them she'd never heard of, and you know what she did? She did research. Then the next appointment she knew more and had more recommendations. So, I wouldn't worry about offending your doctor, I'd say go for it. As for convincing them to go to Rituxan without some of these other treatments. I have heard all kinds of stories. Some people, their first appointment the doctor says, looks like pemphigus, and we should give you Rituxan. Others require you to try lots and lots of things before they're willing to go that route, and sometimes the insurance companies have something. You're in Canada, so you've got national healthcare. I don't know what the Canadian health care recommendations are. But, what I have found is that over time, the last few years, it's become easier and easier for people to go the Rituximab route. It's got official approval now, the cost is coming down because it's off patent. It has become easier, but that doesn't mean it's easy. And if your current doctor won't go that route, you may think about trying to see another doctor who may have different views.

**Janet:** Yeah, I think what Scott said is exactly right. Don't be afraid to talk to your doctor. Show them the literature, it's approved in the United States and I know in France and several other countries as a first line treatment. So I don't think it's something that you should not be afraid to talk to your doctor about. Especially, if you have to be on a lot prednisone and other drugs. I mean, a lot of doctors don't want to start people on Rituxan because they don't really know that much about it, some doctors. They think it's just a cancer drug so they don't want to give you a cancer drug but it doesn't work the same way. When you take prednisone and high doses that are more than 20 milligrams and you take Imuran and Cellcept, your whole entire immune system is going to be repressed but with Rituxan that's not actually true. So check it out. Talk to your doctor again, and see if you can sort of show in the literature that it's approved in the United States for first line treatment and in other countries.

**Marc:** We have the literature to share. If you don't mind taking a stack of literature in to your doctor and say, hey, look, here's the documentation that it works. We can help provide that.

**Amethyst:** Great, thank you guys. Well, that was definitely a very quick almost hour and a half. I thank you all for being on the call with us today. And hopefully, we can do another one of these calls very soon since we have lots of questions that went unanswered. And I know

everyone has many questions. Real quick, I want to launch one last poll for everyone that's still on the line. Do you guys feel that the information that you learned today from the coaches will help you better manage your disease in your daily life? So, if you guys don't mind, quickly taking this poll while we're wrapping today's call up. In the meantime, I'd also like to give a huge thank you to you guys for joining the call. 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, a Sanofi company, Argenx, Cabaletta Bio for helping to make today's call possible. It looks like most of you said that the information that you learned today will be helpful in your daily lives. So, thank you, again, Coaches for being on the call. I know that everyone really appreciated it, and if you didn't get your question answered, and you would like to submit your question, go online to our website. Like Marc said, scroll down to "Ask a Coach", and our coaches will try to get back to you as soon as possible. They are always here to help you guys, so, thank you again.

**Amethyst:** Before we go, I do have a few quick announcements. The IPPF needs your help, help us fund the future by becoming a Healing Hero. Healing Heroes fund the future of the IPPF community by making sustaining, monthly gifts to support our mission of improving the quality of life for all those affected by pemphigus and pemphigoid. No amount is too small, even a \$5 or \$10 monthly donation goes a long way and continues to allow us to provide for the greater good of our community. Your monthly gift allows us to not only sustain current programs such as today's Peer Health Coach call, but also expand our key areas of operation: patient support, education, awareness, research and advocacy. You can become a healing hero today by visiting our website today! And I am a healing hero. And I know some of you on the call today as well. So like I said, even a small monthly donation of \$5 or \$10 which is a cup of coffee, or two, it really goes a long way. We are a very small patient organization and a non-profit. We really do rely on the part of our community, so you can become a healing hero today by visiting our website.

Also, 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 and our doctors, the sooner they can find better treatments, earlier diagnosis, and one day – **A CURE!** So if you have not already joined, please go online today and register yourself on our Natural History study.

Our next Patient Education Webinar will be on Thursday, November 12th with Dr. Dolca Thomas, Chief Medical Officer at Principia Biopharma, a Sanofi Company to discuss the

Pegasus Trial pivotal, Phase 3 clinical trial for patients with moderate to severe pemphigus. This is a great opportunity to learn more about current research and a potential treatment option. Registration will be opening soon, keep an eye out for an email and our website for that.

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, or like I said, go online and find the "Ask a Coach" section of our website and our coaches and Becky would be more than happy to help. After this call and recording will be sent out as far as well as a survey. So, please feel free to fill out the survey, and let us know how we did today. Wonderful, guys. Thank you so much for joining us everybody. We hope to see you guys soon. Have a wonderful day. Thank you so much.

**Marc:** Thanks Amethyst, thanks everybody!