Tips and Tricks for Living with Pemphigus and Pemphigoid with the IPPF Peer Coaches- Patient Education Webinar, February 26, 2024

Amethyst Yale: Welcome everybody. This webinar is now being recorded. My name is Amethyst Yale, IPPF Community Engagement Manager, and I'll be your host for today's webinar. I'd like to thank everybody for being on the call with us today, and especially to our coaches, for taking the time to be here with us. Before we begin. I'd like to remind everybody that, "Information is a key factor in treating and living with any condition. However, everybody's situation is unique. The IPPF reminds you that any information found online or during presentations should be discussed with your doctor or healthcare team to determine if it applies to your specific situation”. Also, this webinar is for informational purposes only, and the Peer Coaches cannot make recommendations for your physical or mental health or treatment regimens. For these specific types of questions, please refer to your healthcare team. Today we are excited to have a few of the IPPF Peer Coaches here to provide some of their personal tips and tricks for living with pemphigus and pemphigoid. But before we begin I would like to review a few housekeeping items… (Reviews Housekeeping Slides). Now, it is my pleasure to introduce the IPPF Peer Coaches and jump into some questions.

Amethyst Yale: But before we begin, I'd like to just quickly introduce you guys. So if you'd like to introduce yourself, tell us what disease type you have and how long you've been with the IPPF that would be great. I will start with Becky.

Becky Strong: Hi! I'm Becky Strong. I have Pemphigus Vulgaris. I was diagnosed in 2010, and that's when I first became involved with the foundation as a patient and later came on staff in 2016.

Amethyst Yale: Great, Marc.

Marc Yale: Hi everybody my name is Marc Yale, and I was diagnosed with Mucous Membrane pemphigoid with ocular involvement in 2007 and I've been with the IPPF for 15 years.

Janet Segall: Hi, everybody I'm Janet Segall. I have been living with Pemphigus Vulgaris since 1983, a long time. And I've been with the foundation since it started.

Marc Yale: 30 years.
Janet Segall: Yes, 30 years. It's been interesting. I'm happy to be a Peer Coach and helping others.

Scott Taub: Hi, everybody, my name's Scott Taub, and unlike in the rest of my life, I guess I'm the younger here. I was diagnosed in 2013, with Pemphigus Vulgaris and I have been a Peer Coach working with the IPPF for just 3 years.

Amethyst Yale: Wonderful, thank you all for joining us. I'm going to jump right into question. We have a lot coming in and a lot submitted ahead of time. We are going to start at the beginning. So starting at the beginning of someone's journey with these conditions, obviously it can be hard to get a correct diagnosis. Todd wrote in and said that his doctor said he thinks that he has PV and is wondering if a biopsy is required for a diagnosis or can the diagnosis be made through bloodwork? And, what doctors should be performing these tests to help him get a diagnosis? Scott or Marc, you want to take that one?

Scott Taub: Sure, I'll start. When I was diagnosed way back when, I had both a biopsy and blood work specifically, the blood test they performed was called indirect immunofluorescence. I had no idea what that was at the time, and frankly even now, I'm not sure how that differs from other blood tests. But the doctors did both. They suspected PV and indicated essentially that either one was sufficient for a diagnosis, but they wanted to do both just so that they could be doubly sure. And as it turned out, my biopsy was inconclusive, but the indirect immunofluorescence they said was conclusive for pemphigus vulgaris. Later on, a few months later, they actually did another biopsy just to make sure, and that one turned out to indicate PV as well. So I guess the answer to the question, Todd, is whatever your doctor feels most comfortable with. As for who should be performing those tests, I think the tests themselves are not unusual and don't require a particular specialty, but frankly, you do want to find a doctor that is experienced with PV because most are not. Our disease is rare enough and most doctors do not have experience dealing with it. Although you might have somebody who's inexperienced do the biopsy and run the blood tests, you're going to want to find someone with experience to manage your treatment.

Amethyst Yale: Great, thank you. So leading to that, somebody also asked, now that they have been diagnosed, what type of doctor should be managing their condition or
should they be seeing? And are there other doctors that they should look to find to treat
them?

**Janet Segall:** Yeah, patients that have been diagnosed should see a dermatologist and
there are special kinds of dermatologists called bullous disease experts. And if you can
find one, that's the kind of doctor you should see because they can deal with all kinds of
sores that are in your mouth and on your body. Sometimes you may be able to find an
oral pathologist who also knows about it. If the oral pathologist knows about it, that's also
a good doctor to see. And I would check on the IPPF website for Find a Doctor, because
it's very helpful in finding the experts that might be helpful for you.

**Amethyst Yale:** Great, that's a good recommendation. That led to my next question. So
besides maybe checking the Find the Doctor Directory, are there any other tips to find a
specialist or a doctor that knows how to treat you? Should they look at major medical
centers or something like that? Marc or Becky, do you have any suggestions or what you
did to find your specialist?

**Marc Yale:** Certainly, I think finding a doctor at a major medical center is helpful. They're
more likely to have some experience with the disease. As Janet said, some of these
centers have bullous disease clinics or bullous disease experts, and it will say so on
those websites. However, it can be a challenge because a lot of us are kind of at the
mercy of our insurance, and so sometimes we can only see doctors that our insurance
says we're able to see, which can be challenging. Or perhaps you're in a system like
Kaiser or an HMO where you're only allowed to see certain doctors. So that can always
be a challenge, but there's ways to work around that. So you can get referrals to outside
clinicians or experts, but you have to go through a process through your insurance
provider or the managed care organization that you're working with. But certainly I think
finding an expert at a major academic center is usually the best bet, but that's not always
an option, particularly if you live in a rural area or not close by an academic center. My
recommendation would be to reach out to the IPPF. Sometimes we can connect your
local doctor with an expert and they can work together and try to provide you with the
best care possible. And we certainly have connections with many experts that are willing
to help out. A great example would be one time I was talking to somebody in Hawaii and
their doctor had no idea how to treat this disease, so I connected them with a doctor in
Maryland and the doctor in Maryland helped that doctor figure out the best way to treat
the person that was in Hawaii. So that's an example of how the IPPF can help make
those connections and create that connection so that you can get the best treatment necessary.

**Becky Strong:** One other recommendation is, whoever you are currently seeing if they are suspecting pemphigus or pemphigoid, you're kind of above average anyway, but you may want to ask your doctor who they would recommend you go see. Many times, doctors have their own internal referral system and they might know a physician who is familiar with pemphigus or pemphigoid.

**Amethyst Yale:** Those are very good suggestions. So now somebody's been diagnosed, I think the next hard thing is how do you go about telling your friends, family, and coworkers about your diagnosis? So I don't know, Janet, you maybe want to share a little bit about what you did and what made you feel comfortable to talk to people about this?

**Janet Segall:** Yeah, I think it's really important to not keep it a secret. I mean it's hard to keep it a secret when you have sores, but I think it's really important to discuss what's going on with your family. I believe that it's empowering for you and your family to know what's going on, and I think knowledge is power. So the more information you know about your disease, the better it is for you. And I know how difficult this is and I know how overwhelming having a disease like this can be. I definitely feel that it's important to tell the people you know what's going on and let them help you, let them be there and support you. I think that's a very good way.

**Scott Taub:** I'll just add a couple thoughts there. I've talked to people who are concerned about telling others and feeling that they might get treated differently, that their friends and family might be wary of being around them. I think it's important to keep in mind these conditions are autoimmune. They are not contagious. You didn't catch them by doing anything wrong or going anywhere that you shouldn't have gone. It is bad luck, that's all. All of us that have this, we are victims of bad luck and not anything else. So there's nothing to be embarrassed by and there is no danger or reason for anybody to be concerned about being around you. So take that out of your mind. And if you tell people, they'll more than likely want to be helpful. I think that's what I found. Anybody that I told said, what can we do? Is there anything that we can do to help? Of course, some of them had recommendations for all kinds of remarkable treatments that were not going to be helpful, but you get that with any kind of health problem. So for me, it actually turned out to be very
easy to tell everybody because I went through 11 doctors before I got a diagnosis and I had been posting on Facebook about what was going on, just in the odd hopes that somebody who I was friends with on Facebook would have an idea of who I might talk to try and get diagnosed. So once I got a diagnosis, I published it on Facebook and everybody I knew knew right away and there was never any trouble with it.

**Amethyst Yale:** So somebody wrote in and asked, do you have any tips on how to make sure that you make the most of your doctor's appointments? Obviously at the very beginning it can be very overwhelming. There's a lot of medical jargon you maybe don't understand and you're just feeling very overwhelmed. So do you guys have any recommendations on what to do or any questions to ask?

**Janet Segall:** Yeah, I do know how overwhelming this is and it's not uncommon to feel that way. And the IPPF has questions that you can ask your doctor. If you go to the website and look for resources and scroll down and find that there's a whole list of questions that you can ask your doctor. You can also get a Peer Coach who can help you through that. And if you have an email, a Peer Coach can send you the questionnaire. And also if you have other questions, write everything down. Make sure you write something down and whatever other questions you might have, then what's on the list. It's important you only get 15 minutes or 20 minutes or however long you get with your doctor. So it's really good to write down the questions. I would also recommend, if you can take somebody with you to be a person who can help you and ask questions. I think that's a really good thing. You need an advocate if you can or someone to keep you on track so that in the time that you have there, it's helpful to have someone to help you do that. So that would be my recommendation for handling the doctors.

**Marc Yale:** Yeah, I have a couple of suggestions that I found helpful, at least in my case. One is that I try to schedule my appointments either first thing in the morning and be like the first patient there or right after lunch. As we all know, the doctors fall behind and so if you're the first patient there or the first patient right after lunch, then your doctor will have the time and pay the most attention to what you have to say. The other thing that I would do is, when I called and made an appointment, I would specifically ask for a 30 minute appointment because as Janet said, when they make these schedules, they schedule appointments every 15 minutes. So I would tell them that I need extra time and I need 30 minutes. So I'd
ask them for a 30 minute appointment so I would make sure that the doctor had enough
time to talk with me. Otherwise, you don't have enough time to ask all your questions
because you’ve got a million questions and you might have that checklist that Janet
mentioned from the website, but you may not be able to get all of your questions answered,
so you might have to prioritize your questions as well. Those were just a couple of things
that I would do. Lastly, I would say that don't wait to make an appointment. It's easier to
cancel an appointment than to get an appointment. So the longer you wait to call and make
an appointment, somebody else is going to take that spot. So call as soon as you feel like
you need to see a doctor or you're having a flare or whatever the case might be, call and
make the appointment and at least get on the books, you can always cancel it. Even if
you're going to see a doctor and get another doctor to get a second opinion, that's okay too,
but call and make the appointment. It's easier to cancel than it is to get the appointment.

**Becky Strong:** Yeah, my tips are, I have a couple. One, make use of your patient portal.
You can write all your questions down and save them until your appointment, but that's
going to take a lot of time. If you have questions, you can put them in the portal. The other
thing is, if you don't understand something that the doctor is saying, you may need to wait
until they finish their breath, but tell them you don't understand. I don't get it, I don't
understand. Doctors are really smart people a lot of the time, but they know not everybody
knows all of the medical terms and how things work. And so don't be intimidated and afraid
to ask the questions that you have.

**Amethyst Yale:** Those are really great tips. Thank you. Are there any other resources as
well? I know Janet had mentioned the checklist. Becky, are there any other resources too to
help patients learn about their disease and educate themselves more?

**Becky Strong:** Yeah, so these webinars are a great tool or resource. We put all of the
archives on our website so you can go back and visit those. There is a patient resource
section as well on our website and that's where you'll find the guide to pemphigus and
pemphigoid in English, Spanish and French. But there's things about wound care and
mouth ulcers, calcium and vitamin D, gene therapy, sunscreen, and a lot of different topics
that you can look at. So the website is a great resource. The other thing is that we do have
regional support groups and work with international organizations and we're happy to make
introductions if you're in the support group area or if you would like to be connected to one of our international organizations as well.

**Amethyst Yale:** Thank you. Real quick, going back to sharing with your friends and family, Doreen wrote in and said she has PF and when she informed her family that she had the condition, a lot of them were saying, are you sure it's not monkeypox? How do you respond to people like that? Naysayers or people that have really negative, rude, mean comments and don't really understand what's going on with you?

**Scott Taub:** I had a couple of questions like that and I just responded, matter of factly, yes, I'm sure. I've had the tests and we know what it is, we know how to treat it, and move forward. Most of the time they're asking that just because of what they've heard on the news or they know somebody that might've had a condition. And I think if you just respond that yes, you're confident, you know what it is and what needs to be done for it, my experience was they said, oh, okay, good. They're happy that you're sure what's going on.

**Amethyst Yale:** Great advice. So obviously being diagnosed with a rare disease can make people very isolated. In fact, one person wrote in and they just are very grateful for actually being on this webinar today. This is the first time they've ever even seen anybody with their condition. So obviously it's very isolating to be diagnosed with a rare disease. How important is it for you to find somebody to connect with who also has the disease and where can patients find other pemphigus and pemphigoid patients to talk with? I know Becky mentioned support groups, but what did you guys do when you were first diagnosed to find those people?

**Janet Segall:** I started the Foundation.

**Scott Taub:** The first thing I did was see if there was a group on Facebook because I figured there's a group on Facebook for everything and there was. That's how I wound up finding the IPPF. I found Facebook people first and then eventually found the IPPF. And as much as social media can be a bad thing for lots of reasons, the Pemphigus Vulgaris group on Facebook is probably the first place that I found anybody who could answer questions about what I was going through from experience. Obviously the doctors were able to give me some advice, but it's not until I found the other patients that I actually talked to people
who did it from experience. And there are other online groups as well. There are rare disease groups online where you can find people talking about it as well. But frankly, the Facebook group is still extremely active and that's where I always tell the people that I talk to go, if they're looking for a large volume of other patients.

**Amethyst Yale:** Great. Let's move into some questions about treatments and things like that that you guys experienced. Janet, somebody said that they're on prednisone. Is it normal to feel a lot of joint pain? And what about irritability and sleeplessness? What can be done to manage some of those side effects with prednisone?

**Janet Segall:** Yeah, so you can get joint pain as a side effect with prednisone. I mean it's a very individual thing what some people will get. I personally had joint issues with prednisone when I was on it. That was the only thing that could cure me back in 1983 or I would say treat me, not cure me. So I was on a lot of prednisone for a lot of years straight and I did develop some joint issues. My joints would lock and I had MRIs and they didn't find anything, so who knows what it was. There are a lot of ways to deal with the prednisone side effects and I would definitely talk to your doctor or the pharmacist about anything you might want to do organically or supplements or things like that. So you could do alternative and traditional ways to deal with it. There are supplements that might be able to help with the side effects. There are other drugs that might be able to help with the side effects. A pharmacist is a good one to see, sometimes the doctor doesn't know about supplements. But if you want to take supplements, you really need to investigate. Make sure that there are some that are not going to interact with your medication, with the steroids. And there's also things that you can do to take care of yourself. Take time for yourself, take a bath or if you bathe, if you like to bathe rather than shower, take a bath. Listen to radio, walk out the door, take a walk, give yourself some time to relax. And I think that's really important. You can do alternative things like meditation, hypnotherapy and other things like that to help you deal with some of the emotional issues that come with prednisone. And there are, and there's also the weight gain issue and a lot of people, including myself, I gained a lot of weight because I'm an emotional eater and I had no idea in 1983 what I was dealing with. I gained a lot of weight and then I realized, I got to a point in my weight that I said, okay, I can't gain anymore. I was just too fat. So I went on a diet and I was able to, even on the prednisone, eat properly and lose the weight that I had gained. So there are ways to do it, but always check with your doctor on whatever you might be doing just to make sure that it's okay and it is important to do that. But there are a lot of things you can do to help with
the side effects of prednisone. And let me just say this, get a bone density test if you can before you start taking prednisone so you can have a baseline and also any vaccines you may need to take beforehand, check with your doctor. But yeah, that's my thoughts.

**Amethyst Yale:** And what's the reasoning why patients would need the bone scan before they start a prednisone or during their treatment?

**Janet Segall:** Yeah, prednisone can cause bone loss and the doctor may want to put you on bone therapy. I did not need it because actually the one thing that kept my bones strong was the weight because weight keeps your bones strong. So all that weight I had on me kept my bones strong. So even today I'm not on prednisone anymore. But yeah, I think the dense bone density test is important to get a baseline to see where you're at. For me, as soon as I started taking prednisone, I started getting cataracts, but it took 20 years before it actually made a difference. So just make sure you get checked out with everything and if there's anything you are looking into when you look on the internet, you want to do something, you can always go to the NIH website and PubMed always has some interesting stuff if you can understand the language. There's also integrative medicine, which are doctors and they give supplements. And so there's a whole range of places to go to find out what you might be able to work with with the prednisone.

**Amethyst Yale:** Great, thank you. Scott, somebody asked if they don't like the way their medicine is making them feel specifically in this case prednisone, is it okay to just stop taking their medicine without consulting their doctor, whether it's prednisone or another medicine, what do you recommend?

**Scott Taub:** Not prednisone in particular. Do a Google search on can I cold turkey, stop taking prednisone and all the warning messages come up. Prednisone is one, you cannot just stop. Even if you have concluded and your doctor agrees that the side effects are worse than the disease, they will tell you you cannot just stop taking prednisone. Prednisone does some things to your endocrine system, stops you from producing certain things that the body normally produces. You need to taper off of prednisone, sometimes very slowly, in order to make sure that your body resumes producing cortisol on its own. Because if it does not, then the effects of that can be quite dangerous. So for prednisone, you absolutely cannot just stop. You need to talk to your doctor about how quickly you can taper off it. For
many other drugs, I was on CellCept for a while and Imuran for a while as well. I talked with my doctors about those, what could I do if I felt like I needed to stop taking them for some reason? And I talked it through with my doctors and what they actually told me on those two drugs, which are pills that you generally take once a day, that if I felt I was getting a cold or a flu, it was okay to stop taking those drugs for a while to hopefully allow my immune system to fight the virus faster. But they said that was basically something I could decide for myself on those drugs because for those, there's not a withdrawal problem if you stop taking them. So talk about it with your doctor based on a particular medication you are on and how bad your symptoms are. The other thing to worry about if you stop taking your immunosuppressive drugs is, chances are that your pemphigus or pemphigoid is going to flare up and you need to weigh the dangers of that with what you hope to gain by stopping the medication for a while.

Janet Segall: I just want to say something about that. I was on prednisone, 30 milligrams for three years, and so at the end of three years we decided to try and wean me off. The doctors wanted to start taking me down the way they know how to take down prednisone, but I found from my own self that I needed to go down slower than what they recommended. Instead of 5 or 10 milligrams every other week or whatever. And then they wanted me to go to alternative days and that didn't work for me. And so you have to advocate for yourself in a lot of ways when it comes to this disease because it's rare and even the doctors don't really know. And especially with prednisone because it can cause your mind to get a little weird sometimes. And so for me, I found that one milligram, I'm not saying anybody should do this, but you should discuss it with your doctor. And I said to my doctor, I want to do one milligram at a time and until I get to something like 10 milligrams and then I would do one milligram every other day and I had no major problems doing one milligram, but I did when I was going down the other way. I'm not saying everybody's going to have that problem, but I'm just saying whatever you're feeling when you're reducing prednisone, make sure you discuss it with your doctor that maybe you need to change your dose a little bit differently and don't be afraid to do that because you're the one who understands your disease better than the doctor does actually. So

Marc Yale: Yeah, just to build on what Janet's saying, you're the one that understands your disease the best. You're the expert on your disease. But the one thing I just wanted to mention is that it's very common that when you taper off prednisone because you're tapering, you're naturally going to have some inflammation because you're tapering off your
prednisone. That's normal. So my point is, not to freak out and be like, oh, I'm having a flare or it's getting worse. It's normal that you're going to have some inflammation. You need to kind of wait it out a couple of days and see if that inflammation subsides and then your body can kind of regulate the amount of prednisone or cortisol in your body and normalize that and then your body has to get used to that before you do that next taper. So just because you taper doesn't necessarily mean your disease is getting worse. It's normal to have that inflammation as a response to the taper itself.

**Janet Segall:** I also found for myself that I started out with like 40 milligrams of prednisone. They wanted to put me on more and I said, no, let's try it at lower dose. So we tried the 40 milligrams and about a month later we got to 30 milligrams and then I went down one milligram at a time to 28 milligrams. At 28 milligrams, not 30, 28 I broke out all over the place. And that's another reason to go down slowly because you're not sure where you are if you're going to have to take prednisone. But usually now, people are taking prednisone with other drugs, so it's sometimes hard to know where that baseline is. For me, it was 28 milligrams and I broke out. I had to go back to 30 milligrams and stay there for three years at that time anyway, maybe not that long. So I think that don't go down too fast. Even if you break out, you may not know what your threshold is. So I think that's important.

**Marc Yale:** And to that point on prednisone, I think if you go to your doctor and your doctor says, oh, I'm going to put you on 40 milligrams and then in three days we're going to go to 30, and then in three days we're going to go to 20 and then on three more days down to 10 and then 5 and then you're off within a week or two. That's not how prednisone is used in this particular condition, in these conditions, in these diseases. And that may indicate to you that maybe your physician doesn't have a lot of experience treating these diseases and you might need to find someone that has a little bit more expertise because that regimen for prednisone is not how it's used in these particular autoimmune bullous diseases. It might be used in other conditions, but that's not how it's used in these conditions.

**Amethyst Yale:** Great, thank you. Somebody wrote in and they want to know if anybody has experience using IVIG, how did it work for them and just overall what was their experience?
Marc Yale: I did. I have experience using IVIg. Overall my experience was pretty positive. It certainly helped my condition. IVIg is what they call an immune modulator. What it does is it changes the ratio of good cells to bad cells in your body. So what you're doing is you're infusing, through this plasma infusion, good cells into your body while your old cells or the other cells in your body are dying. And so you're changing that ratio of good cells to bad cells. So overall the experience was positive. However, you have to think about some of the burdens that come along with IVIg. One in particular is that you have to do IVIg for a very long time. So it's not like you get one infusion and then everything's great. You have to do it over a long period of time because it's slowly modulating your immune system. For example, I had to be on IVIg for probably three years in total and I would go once a month. It's not just one day a month, you have to go three to four times a week in that month period. There's things like taking off work, finding childcare or transportation to and from the infusion center. So there's a lot of logistical things that can be very challenging and burdens that it puts on you if you're going to get IVIg. However, you can also get IVIg at home, so there's home infusion companies that will come to your house and actually do the IVIg. But I would say probably the most burdensome thing is the cost. IVIg is very expensive and not all insurances want to pay that kind of money. They might say, well, we'll do it, but we want you to try all these other therapies first. So it is very expensive therapy, it's something that takes a long time. I kind of look at it as almost like an investment. You have to really invest your time and your energy into it. But I mean overall it has a very positive effect, particularly when it's also combined with other therapies like Rituxan or Rituximab or CellCept or other immunosuppressive medications. It can be very beneficial because it kind of expedites or increases the efficacy of those drugs. It also makes you get better faster. And IVIg also works as a prophylaxis, so it works to help guard against secondary infections. So there's a lot of positive things about IVIg, but I would certainly talk to your doctor and consult your doctor on whether or not it's the best option for you. There's certainly other options out there, but I would talk to your doctor and just kind of decide whether or not it's the best option for you.

Amethyst Yale: Great, thank you. Speaking of infusions, Elliot asks, do you have any tips or tricks for writing medical insurance claims appeals specifically for trying to get Rituximab?

Marc Yale: I guess I could talk about that as well. I think obviously the most important thing is to make sure that your doctor is on board because the doctor, your physician, is going to
be the person that's going to be definitely working with the payer or the insurance company to make sure you can get it. Sometimes you need a letter from your doctor. My tip is to try to get as much information about the safety and efficacy of the drug through peer review journals so you have evidence to show that it works and send all that information also to the insurance company. Then also ask for an expedited appeal because the insurance company has to do that within a certain amount of time if you ask for an expedited appeal. But the biggest thing is just to make sure that your doctor is willing to go to bat for you because in the end it's going to be up to the doctor and whoever they're dealing with with the insurance company to really make sure that you're able to get that. I think we have an example letter or a template letter that you can use to write your insurance company. So if you need something like that, just reach out to the IPPF or reach out to one of the coaches and we can help you with that.

**Amethyst Yale:** Thank you. Jumping around here, Carlos sas. Are there any specific moisturizers that anyone recommends for dry skin or helping with their itch while they're dealing with their disease?

**Scott Taub:** The itch can be particularly bad I think with Bullous Pemphigoid, although those of us dealing with PV sometimes get it as well. And what we typically hear about moisturizers is kind of the simpler, the better. Less fragrance, less special ingredients. Vaseline is actually one that I think people say feels good. It's also kind of oily, so I think people don't like to use it, but it typically does the trick. Otherwise I've heard people have good luck with Cetaphil and other sort of simple moisturizing creams. The other thing is you might try something that has an antihistamine in it like you would use on bug bites. For some people that helps with the itch. Not everybody, but for some people that kind of cream actually helps with the itch.

**Amethyst Yale:** Anyone else? Any suggestions? I know Becky wanted to say something.

**Becky Strong:** Yeah, I was going to say the Vaseline thing helped me with my skin. I put it on when I got out of the shower when my skin was still a little damp and you're a bit of a slimy mess for a couple minutes, but it dries relatively quickly. My doctor actually recommended Crisco if I didn't want to deal with the petroleum products because it's food grade, there's no perfumes or dyes or anything like that. And I can tell you it works again,
you just want it to absorb. I have found that some of the eczema creams out there or the eczema balms, like the thicker balm, ointment kind of things tend to help hold in the moisture a little bit better for me.

**Amethyst Yale:** Great, thank you. Scott, do you have any recommendations for patients for pain management, whether it's just overall general pain or maybe specific to pain that they're experiencing in their mouth?

**Scott Taub:** So when my pemphigus was very bad, my mouth was a complete mess. I could barely eat and frankly I found very little that could completely take care of the pain. What helped was certainly keeping my mouth moist. If it got dry, the pain was much worse. And the big thing I think that I found that could give me a little bit of relief was a magic mouthwash that had lidocaine in it. My doctor prescribed it. It was actually something of an effort to find a pharmacy that could compound it for me, but I used a mouthwash that had lidocaine and that kind of numbed things up for a little while. You can get some of the same results using cough drops that have benzocaine in it. Benzocaine is also a numbing agent and as things improved a little bit and I wasn't in constant agony, I could use the cough drops to numb the pain enough to allow me to eat a real meal without causing pain. For more general pain, the things you do for other kinds of pain. Take Tylenol, Advil, whatever works for you for other kinds of pain can be helpful here. The one thing I'll note here is that after some trial and error, I came to believe that NSAIDs were actually triggering my PV and so I stopped taking aspirin and ibuprofen and stuck only with the Tylenol. Apparently immune system reactions to NSAIDs are not all that uncommon. And when I mentioned to my doctor that it seemed like that might be triggering, they agreed it was a possibility. So at that point I had to try different pain relievers.

**Becky Strong:** Another suggestion is to ask for a referral for a pain specialist. That's one thing that I didn't do and in hindsight I really wish I would've done because they have a lot of different medications. There's topical anesthetics that might be helpful as well, and they're really somebody in the know with what might work the best for you with the least amount of side effects.

**Janet Segall:** Also, if you don't want to take a lot of pain medication, you could try things like meditation and hypnotherapy. Sometimes you can even do self-hypnosis and
sometimes it works, sometimes it doesn't. And I've been doing it for a long time and I think it's been really helpful. So it's another way, an alternative to adding on to whatever else you're doing that might be helpful.

**Amethyst Yale:** Wonderful. Somebody wrote in and they're asking about food. I know Scott, you had mentioned a lot of the oral pain and blisters, difficulty eating. So I'll start with Janet, was there anything, you specifically, in your diet either removed or found painful to eat that you tried to avoid?

**Janet Segall:** Yeah, I've been in remission now 20 years without medication. I occasionally do get a lesion because I know my triggers. I think when you first start having lesions, it's really hard to find foods that you might consider triggers because anything you eat could trigger. I remember when I had a lot of lesions in my mouth, anything I ate was a trigger. Just the process of eating caused a lesion. The IPPF has a great webinar on foods that you should listen to and information there. I think for me, I have issues with garlic, I can still eat it. I did a little test on myself once I went into remission and I ate garlic for a week, a lot of it, and I got a lesion in my mouth and a couple lesions and then I stopped eating it and it went away. I did the same thing about three weeks later and the same thing happened. So I knew I couldn't eat a lot of garlic. I can have garlic, I just can't eat a lot of garlic. Onions I'm okay with, I have a problem with sourdough bread. I do want to recommend healthy eating and I think it's really important to watch the sugar. Chocolate will do it to me and I remember one of the doctors telling me 20 years ago that they had a patient who had five pounds of chocolate and got pemphigus. So don't eat five pounds of chocolate at one time. Once you can find a time when you're not getting mouth sores, when you go into remission, you may want to just work with foods and find what might be triggering you. But watch your diet, try to eat healthy and I think that will be helpful too. Anybody else?

**Amethyst Yale:** Anyone else want to add anything that they maybe avoided?

**Becky Strong:** Just general advice is I kept a food journal and if it really hurt my mouth while I was eating it or if I developed blisters after, I would make a note. Now you can do it very easily on your phone, take a picture of your plate, write whatever your reaction was in the caption and that way you can kind of monitor it. We're all a little bit different. Janet said she has a problem with garlic and chocolate. I can eat those, but I have issues with sharp
foods like biting into apple skin or having a pita chip or something. I have to be pretty careful about things like that. But I can eat the garlic that Janet was saying was an issue for her.

Scott Taub: I think the real message on foods, if you do research on diets to treat pemphigus or autoimmune conditions and you follow all of the things you find, you'll eat water and maybe an egg now and then. Because there are people who legitimately I think have concluded that they have problems with just about any kind of food. And I think that that's the real thing I've come to believe about food in this disease is that yes, you may have foods that trigger lesions or sores in pemphigus or pemphigoid, but there isn't a common list of triggers that applies to everybody or even a large portion of patients. So you need to figure out for yourself what your triggers are. For me, I eventually determined NSAIDs and alcohol. I actually had to lay off alcohol for several years because it seemed like every time I had alcohol I would get blisters about a day and a half later. So for a while I didn't drink and eventually I found that I could drink again without causing problems.

Marc Yale: I think the best advice that I got from my doctor, especially in the beginning, was it needs to be soft, boring, and bland. If you stick to those three things, you're going to have less pain. You're still going to have lesions obviously, because you have to treat this disease systemically, but you also have to eat and drink. So it needs to be soft, boring, and bland. And to your point, Scott, actually I couldn't drink water because it felt like I had razor blades in my throat because I had esophageal lesions. So it can be a really tough challenge, but try to keep things soft, boring and bland. That would be my recommendation.

Amethyst Yale: Thank you. Well, we are quickly nearing the end of our webinar, which is amazing how quick the time goes. There's lots of questions. So I'm going to just kind of wrap this webinar up with kind of a multi-twofold, maybe threefold type question. So somebody asked, remission, what does that mean? What does that mean to you guys specifically? Maybe individually as a person? Are any of you in remission? So everyone's in remission, so does that mean remission on medication or off medication? So what does that mean to all of you guys? And maybe that'll give some hope to our community.

Becky Strong: I was going to say, for me I am in remission. So right now I don't have any lesions and I am off all medication. With that said, stress is also a trigger for me and my hormones and I will get what they refer to as transient lesions. There have been times when
it has been severe enough, I will say that I have used topical clobetasol or a
dexamethasone rinse, but generally my lesions will go away within a day or two on their
own, maybe a week with medication. But truly define what a flare is with your doctor, figure
out what they mean by a flare, what they mean by remission. So you guys are all on the
same page?

Janet Segall: Yeah, there is a standard of remission with or without drugs that was decided
on many years ago. I have been in remission since 2002, although I was diagnosed in
1983. I had three years on medication, three years off medication, six months on
medication, another two years off medication, five years on medication and then I've been
off. I don't know how that adds up. But anyway, since 2002 I've been in total remission.
Today I actually have a lesion on my gums, which is a little scary, but I have clobetasol and I
put it on my finger and I hold it there for a few minutes and I do that twice a day if I get a
lesion. And for me, I know that I'm having a lesion because of some foods that I've been
eating that I shouldn't be. So okay, I have to get in my head that I can't eat that stuff. It's
been a long time since I have been in remission and knock on wood that I am going to be in
remission for another 20 years if I'm alive that long. And yeah, I mean that's remission for
me.

Scott Taub: I'm also in remission. I've been in remission for seven years, off all medication
for about six and a half years. For me, I mean, I didn't think of myself as being in remission
when I was still on the drugs, even though I didn't have any sores and that didn't feel like
remission because I still was taking immunosuppressant. But once I got off, that felt like
remission to me. Like Becky, I do get a very small sore every now and then in my mouth. So
my doctor says, that probably means you're not completely in remission, but we don't need
to treat it if it goes away on its own, which it does. And for me, the random blister in my
mouth usually tells me I'm getting a cold because my immune system is firing up. And I
actually tend to get the blister before my sinuses start to feel full and I start sneezing and
coughing. So it's actually a warning sign for me now that I may have picked up a virus. But
like Becky, they go away quickly. My doctor's aware of them and says, if you ever want to
treat them, we can treat them, but it's not really necessary and it's been that way for six
years.
**Marc Yale:** Yeah, I'm currently in remission without any therapy, so I'm not on any drugs. Like Janet said, I've had over the years, since I was diagnosed 15 years ago, I've had lots of flares, a couple of periods of remission. So the disease waxed and waned, and I had a lot of recalcitrant disease activity. But as of now, I think this is close to my longest remission, almost four years now since my last flare. But to just expand on what Janice said, you can either be in remission on therapy or off therapy. So there's different ways to be in remission. I think one of the things that I try to explain is and a lot of people ask, how do you know if you're getting better? Or how do you know if you're getting worse? And how do you know if you're in remission? How do you know if you're not in remission? Again, to what Janet said, remission is technically defined as the absence of any lesions for more than four weeks. That's what the clinical definition is. But I always just tell people that, I think you can measure whether or not you're getting better or getting worse by the number of lesions you have and how frequently they appear. So if you're getting more lesions and they're appearing more frequently, then you're getting worse. If the lesions are, you don't have as many and they're not appearing as frequently, or the time in between lesions is getting less, then you're getting better. And I think that's the most important thing when you're trying to manage this disease, is to figure out, am I getting better or am I getting worse? Are the therapies and drugs working or are they not working? And that will really help guide you in how you manage your disease, but also with the discussions that you have with your doctors. I think that's really important.

**Amethyst Yale:** Great. Thank you. Well, thank you everybody for sharing. I know that we could continue on for probably at least an hour or two more. So if you did not get your question answered today, which I do know that there were probably many questions that did not, you can contact one of our peer coaches by visiting our website and they'd love to connect with you, share their experiences, and just provide some of the support that you need throughout this journey. Then also, I'd like to thank everybody for being on the webinar with us today, and then of course to our Peer Coaches for providing their personal insight and what worked for them. So yes, thank you all for joining us. Before we wrap up, I have a few announcements.

**Amethyst Yale:** If you'd like to stay updated about some of our upcoming webinars, which we have some in the works or about events, important news in our community, you can opt into our mailing list. You can join our mailing list by visiting our website [www.pemphigus.org](http://www.pemphigus.org).
Scroll to the bottom of the very first main page, and on the bottom you'll see a little area where it says, “Join our email list”. Enter your email in there, and you'll continue to get emails about future events that are going on in our community.

**Amethyst Yale:** Also, have you checked out the IPPF’S newest resource, the IPPF Guide to Pemphigus and pemphigoid. The guide is intended to provide medically reviewed information relevant to the most common questions people have when they're first diagnosed with pemphigus and pemphigoid, as well as educational information about ongoing disease management and treatment options. Through this guide and other IPPF resources, we hope that we'll be able to empower the community with essential knowledge to make living with pemphigus and pemphigoid much more bearable.

**Amethyst Yale:** As we mentioned today, we do have a Find a Doctor directory. We used to have a map and you guys spoke up and let us know that the map format was not working for many of you. So we've made some edits and we now have a directory that allows you to search by many criteria to find a doctor in your area who's familiar with pemphigus and pemphigoid. So you can find that on our website or scan the QR code on your screen right now to access the directory.

**Amethyst Yale:** Do you want researchers and doctors in our community to better understand these diseases? Do you wish that there was more FDA approved treatment and better treatments available? If so, here's your chance to get involved and make these goals a reality. You can join the Natural History Study today. The Natural History Study is a patient registry sponsored by the National Organization for Rare Disorders (NORD) and the U.S. Food and Drug Administration (FDA). Your information is private and the Natural History Study follows strict government guidelines to ensure patient information is protected. The IPPF will use your participation and the data we collect to help advance research, better understand the patient journey, find better treatments, and hopefully one day a cure. By sharing your information and journey and answering some questions, you directly affect the future of all of those affected by pemphigus and pemphigoid. So get involved today. You can visit www.pemphigus.iamrare.org, or you can scan the QR code you can see on your screen and you can join the study today.
**Amethyst Yale:** We’d also like to thank everybody in our community for their continued generous support to the IPPF. Your donations help connect patients with support services like our Peer Coaches, resources, and disease experts and raise awareness. With your support we also share patient experiences with medical and dental professionals and students, advocate at the government level and promote research. You can scan the QR code on your screen or visit [www.pemphigus.org/donate](http://www.pemphigus.org/donate) to donate today. By donating you ensure that all of our programs are available to all of those who need them today, to tomorrow and for years to come. And then, as Becky had mentioned during our webinar today, we do have various support groups throughout the country. If you're interested in attending a meeting, please check the IPFF’s event page to register. We have several meetings coming up in the future. Also, if you're looking for a support group and there's maybe not one in your area, we're always looking to expand our support network. So if you'd like to start a support group in your region, please contact Becky at becky@pemphigus.org. It is easier than it sounds to start a support group, and you can help connect others in your area to find the peer support that they're looking for. This call recording will be sent out with a survey following the call. We thank you all for joining us, and like I said, if you didn't get your question answered, feel free to reach out to one of our Peer Coaches. So thank you all for joining us. We really appreciate you being on the call with us today. Thank you.