

Becky: Welcome everyone! This call is now being recorded. I would like to thank you for being on the call this evening. Our Speakers today are the IPPF Peer Health Coaches Marc Yale, Mei Ling Moore, Janet Segall, Rudy Soto and Jack Sherman. Thank you for joining us today! The call today will be a question and answer session and will focus on patient to patient support. Let me introduce our coaches:

Marc Yale is the Executive Director of the IPPF and also works as a Peer Health Coach. Marc was diagnosed in 2007 with Cicatricial Pemphigoid, a rare autoimmune blistering skin disease. Like others with a rare disease, he experienced delays in diagnosis and difficulty finding a knowledgeable physician. Eventually, Marc lost his vision from the disease. This inspired him to help others with the disease and in 2008, he joined the IPPF as a Peer Health Coach. He works with people to improve their quality of life, and encouraged them become self-advocates. In 2009, he helped develop the Pemphigus and Pemphigoid Comprehensive Disease Profile giving experts insight into the patient perspective. He is a two-time Rare Voice Award Nominee, a Global Genes RARE Champion of Hope nominee and a national advocate for rare diseases.

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 Peer Health Coach in the fall of 2012 when she went into remission. In addition to being a Peer Health Coach, Mei Ling along with Marc Yale organize the Southern California Patient Support Group meetings. Prior to getting PV, she had spent over twenty-five years in the entertainment industry and ten years as Administrator for an award-winning architect.

Janet Segall is the Founder of the IPPF. She was diagnosed in 1983 and started the Foundation in 1994 with the express purpose of giving people living with this very rare disease a place to go to find information and others also living with pemphigus. Janet graduated with a Bachelor of Science degree in Psychology. After college she worked at Pilgrim State Mental Institution on Long Island. Upon moving to San Francisco she volunteered at the San Francisco Mental Health Department assisting the psychiatrist in the psychodrama group. She also worked at the Women's Refuge in Berkeley, CA. In 2009, Janet received her certification as a hypnotherapist and began working with the Foundation as a Peer Health Coach in 2015.

Rudy Soto is from the great state of Texas. He was diagnosed in 2009 with Pemphigus Foliaceus and has been in remission since November 2016. Rudy likes the outdoors, cooking

and spending time with his loving supportive family. He has been married to his wife Jennifer for 25 years and has 4 children, range in age from 6-25 years old.

Jack Sherman is a Seattle native. He's been a High School band director, IT technician and an award winning photographer. In 2002 Jack was diagnosed with pemphigus vulgaris within a week of seeking a provider. Jack is grateful for remission and all the help, fellowship and guidance he has received from the IPPF.

Becky: Now, it is my pleasure to introduce the IPPF's Peer Health Coaches to provide peer support and to answer your questions. So we have already had a few questions submitted before the call and Ryan says that he is in his late 20's and he has been battling localized bullous pemphigoid his hands, feet and face for two and a half years. He says, "I've not seen results from Tetracycline and Nicotinamide or Cellcept up to 3000mg/day and my dependency on Prednisone continues to worry me about my long-term health. I would like to hear the panel's personal experiences with Rituxan, the treatment I'm hoping to pursue next. After remission is reached, is this a drug something you have to continue taking throughout your life? Does it restore your quality of life?" He really is kind of asking if he will feel like a normal person after Rituxan? So Rudy I know that you had Rituxan and Jack. Rudy would you like to start?

Rudy: Sure I would like to start. I had seven treatments of Rituxan over a span of 2 and a half years. I did what they call a Rheumatology treatment where I did full treatments, 2 weeks apart and I did a "manage" treatment every 6 months. As far as any side effects, I did not experience any side effects from the treatments, from the Rituxan. I did experience some lack of energy only because the Benadryl and the other medications that they give you while you are doing those treatments. But you also asked about the quality of life, I am greatly happy with the results. I reached remission in 2016 from the Rituxan treatment and if I had to do it all over again I would do this treatment instead of messing around with all the other medications if I had that option. I do everything that I used to before I was diagnosed, I get to have my normal life doing everything I used to.

Becky: Great, Jack do you have anything to add?

Jack: Yes, first of all I was diagnosed in 2002 and back then Rituxan and IVIG for at least my dermatologist was a last-ditch effort type of drug. They were really concerned about dangerous side effects but after a few years of being on Azathioprine and Prednisone. By the way when I

did get diagnosed I wasn't covered in sores it was just mainly in my mouth and on my scalp. It wasn't fun but I know so many people who have it so much worse when they go to have their first Rituxan treatment. So my reason for not going was because it was considered a last resort, I don't know if I feel that way anymore, but that was what was explained to me. And my dermatologist told me, "You might get better, you might get worse, we don't know." So I didn't want to rock the boat and I will keep going as is but then it got to the point where I was never lesion-free. I started on a very high dose of Prednisone and tapered down to a low dose of Prednisone so finally I started thinking, "Well these sores are not going away and what are going to be the long-term effects of Prednisone even on a low dose?" So I finally decided to take a chance and go. My dermatologist had never worked with a Rituxan patient before but they were willing to help me and she knew that I had worked at the Foundation a little bit so we kind of took each other's strengths and acted like a team. She waited over a year of us going back and forth because she was afraid. She thought well if you take a pill and it doesn't work then your done but once you have an infusion you're along for the ride. So for me personally I had little side effects. One thing that did make me feel comfortable was that my dermatologist since she hadn't worked with Rituxan much, she referred me to an Oncologist and it is used daily for non-dermatology patients and most of the terrible warnings you see are geared towards the cancer patients that get the drug, not a fairly healthy pemphigus patient. So I was reassured and I got my first infusion and got 6 months of remission out of it and then a year or so later I was in California and I had a small flare and my dermatologist there thought that we should jump on it and I had another treatment that I got a year of remission out of. And I had my last treatment not last March but the year before that and I have basically been in remission ever since then. So each time I have got better and better.

Becky: Great, thank you. Kathleen asks, "Have patients found relief or remission by combining the prescribed allopathic treatment along with following an Autoimmune Protocol diet, acupuncture, chiropractic care, Traditional Chinese Medicine or any other complimentary treatments?" So Mei Ling do you want to answer that one?

Mei Ling: I am not sure that I can contribute much because I have never really followed any particular regime. I had activity in my mouth so I am still very careful not to have anything acidic. And homeopathic medicines don't really do much for our disease so I don't follow those. I don't think I can really contribute to this one but I wish I could though. But I think just following common senses and staying away from certain things. If you want to incorporate your favorite

foods little by little and keep a food diary if you have had oral activity, I think that would help you and then you would know what's best for you. Also, still be careful when you go out in the sun, use a SPF all the time because your skin is still sensitive. Sometimes I still get a feeling on my skin like it's a sunburn all of a sudden or as if somebody is pulling my scalp. As a matter of fact I am seeing my own dermatologist tomorrow to do a follow-up to see if there is anything that I should be worried about because I still have PV it's just not active at the moment.

Becky: Great.

Janet: I would like to add something if that is okay. You have to be very careful about homeopathic medicines. You have to be sure that if you want to take something homeopathic, or natural medicines of any kind, or herbs or spices you have to be really careful not to enhance your immune system. A lot of these homeopathic medicines try and enhance your immune system and you don't want to do that, you want to try and level it out, so be careful. There is nothing that we know of, of these other alternative medicines, that actually know will help get rid of pemphigus or pemphigoid but you can try and find something that will help you with side effects from the medication. Sometimes there are natural medicines that can help with side effects. You can also test yourself to see what might be problematic for you in terms of food and or alternatives. So be careful about any of that stuff.

Becky: Great, thank you Janet. Karen says she was diagnosed with mucous membrane pemphigoid. It is on her upper gum and doesn't bother her too much. She wasn't going to treat it because she didn't steroids for something tolerable. After attending the conference in Raleigh/Durham, a dental hygienist she met there told her she should get treated right away before it gets worse. So her question is does it always get worse? Should she treat now or wait?

Janet: You can have it in your mouth and not anywhere else or you can have it in your eye and not anywhere else. That is the thing about mucous membrane pemphigoid but I think that Marc could probably talk about mucous membrane pemphigoid pretty well.

Marc: I would definitely say with these diseases, left untreated, they generally get worse. I think it is a good idea to get some kind of treatment and certainly depending on the severity of the disease activity in her gums and in her mouth that would determine what type of treatment should be used. It could be something as simple as topical steroids to help treat the disease or certainly it could be something a little more aggressive depending on the extent of the disease.

But it don't think leaving the disease untreated is a wise choice so I would probably seek some kind of treatment from your physician.

Becky: Great, thank you. Gale want to know, how does she handle blisters on the top of her toes. She has tried toeless socks and going sockless doesn't help. She has tried Band-Aids but when she put socks on the toe box gets tight. Her biggest concern now is the need to wear compression hose according to the vein doctor versus the dermatologist's suggestion to wear socks because socks are easier on the skin. She had vein ablation and wear shoes with large toe boxes. All her current blister issues are in her toes and above the ankles. Any suggestions for Gayle?

Mei Ling: Yes, I used a toeless compression sock and I got it off of Amazon and I am looking it up right now for you. But there are toeless compression knee-highs that you can wear like if you wanted to wear sandals. So your toes won't be confined and they won't be irritated with anything rubbing against it. I would like to send you the link if you want to email me at meiling@pemphigus.org I would be very happy to help you with that.

Becky: Great, thank you. Rod said he has his first three IVIG infusions about 2 weeks ago. At the time he had headaches, nausea, fever and stomach pain for about three days but the nausea has continued. He says that he is trying to stay extra hydrated but was wondering if the coaches had any tips to reduce the side effects for what he is experiencing?

Marc: Becky, I can speak a little bit about this since I had IVIG. I would say that my biggest concern would be that he mentioned that he had a fever and that is not a normal side effect for IVIG. I think having nausea, diarrhea, and headache is normal but fever is definitely not a reaction that one would have with IVIG. So I think he might consult his doctor again and maybe reconsider IVIG. It sounds like he is having an awful lot of side effects and the side effects might be difficult to deal with and manage. So IVIG is not for everyone especially if you are having some pretty serious side effects, especially fever. So I definitely think that he should speak with his physician and maybe reconsider IVIG.

Becky: Great, thank you. Lawrence asks, "How do patients get included in clinical trials?"

Marc: I can speak to that. With clinical trials, all clinical trials have what you call a protocol and within that protocol are certain criteria that make patients eligible for clinical trials. There are exclusion criteria and inclusion criteria. So the best way to determine if you are eligible for these

trials is to contact the principal investigator directly and they will be able to determine whether or not you are eligible based on the inclusion and exclusion criteria and then you can participate if you are eligible. We certainly encourage patients to participate in clinical trials because we won't learn about the disease or learn whether or not treatments are working for pemphigus and pemphigoid without patients' participating but it really depends on the trial and that inclusion and exclusion criteria. One of the things the foundation is really working on is trying to become more involved in the early stages of the development of these trials, what they call the preclinical stage so that we, the IPPF, and the patient's perspective is included in that criteria, the inclusion and exclusion criteria, because a lot of times that criteria doesn't really reflect very well if patients can actually participate or not. The IPPF is really working on trying to improve that.

Becky: Great, thanks Marc. Wendy says that her husband was using Rituxan but it is no longer effective. Has anyone ever experienced that or is that a common side effect?

Jack: I mentioned that I had three total treatments and after the first two, my skin was completely clear. On my third infusion it seemed to take a little longer for everything to clear up than the other infusions. We did a different protocol on the third one but I don't really think that would have been the reason for it. But even to this day, you can't really see it but I have a little rough patch near my nostrils and that is one area that hasn't completely gone away. So for the first several months I might drink something like wine and I would get a little blister that would come and go very quickly in my mouth. Where in comparison to the other treatments, there were no problems. So I asked the dermatologist about it and he said what you just read off. He said that sometimes the more you have them, the less effective they can be. But personally I had never heard that before so that is the closest to that experience that I could mention.

Janet: Dr. Anhalt had said that it doesn't necessarily work for everybody especially if you have had the disease for a long time.

Jack: Which I did.

Janet: But it is certainly worth it to check the protocol that you are taking that you are getting it in the right protocol and how often you are getting it.

Jack: Just a note on the protocol since I mentioned it but I didn't explain, my first two treatments were with the RA protocol and the last one I had was with the lymphoma one. Which is a lot less convenient than the other one, by the way. Heading in once a week for four weeks.

Becky: Well thank you. Our next question is, "What can I apply to my lesions while I am sleeping or just relaxing in my chair so my lesions will not stick to my sheets or clothes."

Rudy: Because of my PF the blisters were all on the outside, the surface layers of my skin and the lesions were always open, so it was very difficult sometimes to sleep or fall asleep or just lay there in the bed or just relaxing on the chair. So what I would do is I would apply a topical ointment that would help the sheets not stick to me or it would help my shirts or undershirts not stick to me when I went to work. Or also when I slept I would put on something like a cornstarch and I would apply that to the lesions to give it barrier so when I was sleeping it wouldn't stick to the sheets and wake up the skin wasn't sticking to the clothes or the sheets. You can also apply some bandages that are non-stick to use also on your lesions while you are sleeping to keep them covered so they don't get crushed and get dried out and crack.

Becky: Great, thanks Rudy. So there are a lot of questions about nutrition that are starting to come in and they says that they avoid spicy and acidic foods and have heard that onions and garlic aren't good for them. Essentially people are asking if they cut foods out of their diets, after they go into remission are they able to eat those same foods again and are there any good sites to visit to get information on nutrition other than the IPPF website?

Mei Ling: I can answer one part of that. For the whole ten year that I had it and had it in the mouth, I couldn't have a tomato at all. I had to stay away from tomatoes for ten years. I would also get a blood blister like I'm sure a lot of people have and that could be due to the either the hard part of a lettuce vein or celery or a cracker. But now that I am in remission I am able to eat tomatoes and I can eat most anything I want. I still temper myself just in case. It would be a good idea to consult with a dietician or a nutritionist if you are concerned about your overall health but as far as putting foods back in just try and keep a little log and see if anything happens within forty-eight hours and if it doesn't then you are good to go.

Becky: Go ahead Janet.

Janet: I would like to say that one of the things I did with the onion and garlic was I tested myself when I was in remission. Before I was in remission about anything I would put in my

mouth would cause a blister. It is hard to know, there is no real evidence out there in terms of what the doctors say that proves that any foods will affect you. But I know that if you test yourself and I have done this myself and I have been dealing with this for a long time, that certain foods will instigate. But you have to find those foods for yourself. Some people can eat garlic, I can only eat a little bit of garlic, some people can eat a lot of garlic. So it really is a matter of finding the foods that you think are irritating you. Test yourself and see if there is something that works for you or doesn't work.

Jack: To add on to that, I know the warnings may tend to be more harmful but basically if there was something that I really wanted to eat I would try it and if it hurt too much or caused a blister I would stay away from it. Sometimes I would have a glass of wine and I might not get hardly any response at all and then other times I would get something and sometimes with other foods. I want to clarify that when people are talking about nutrition are they talking about nutrition to its ability to maybe help curb the disease or are we just talking about just avoiding painful things when you eat, it doesn't affect this disease getting better or worse it just makes it less painful to eat. As far as it making the disease get better I am not aware of any foods that will make you heal faster or anything else like that. Does anyone else have a comment on that?

Becky: I don't know of any foods that made me better but I did find foods that made it worse so I agree with Janet, it's trial and error. And the foods that made it worse aren't the onions and the garlic and tomatoes that we discussed, I could always eat those without making my disease worse. So I think you are all right, that it is something that we all need to trail and ourselves to figure out what is going to cause those lesions. Our next question is, "Has anyone on the panel ever had surgery? Did your pemphigus or pemphigoid become active at the site of the incision?"

Jack: I had surgery.

Janet: Me too, I had surgery.

Jack: I had my gallbladder removed and it didn't affect me one way or the other. Before the surgery I told the surgeon, I think at that time I hadn't had any Rituxan yet, but I was still active but I told them what drugs and immunosuppressants I was on and I wasn't that worried about it. He did mention that because it was a laparoscopic surgery there is even less chance of infection than if you had an open surgery.

Janet: Yeah, I also had surgery and I had my gallbladder out and I think I also had another surgery but I can't remember what it was. But I was on Prednisone so I stayed on the Prednisone during the surgery. Oh yeah, I had a partial hysterectomy also but that didn't really cut my skin. When I had the gallbladder out I was on Prednisone and I stayed on the Prednisone before the surgery and after the surgery and they did it laparoscopically and I had no lesions from that.

Rudy: So I had to have reconstructive shoulder surgery and at that time I was in remission, I had just gone into remission, and going into the stress of going into the surgery it kind of caused a little bit of a flare-up around that area of the surgery. Plus also, if you have to have anesthesia, make your anesthesiologist aware and your doctor aware and your surgeon aware of your skin disease and your pemphigus because a lot of times when they put the tape on for your breathing tube if you have to have a breathing tube, when they go to remove that tape you can have the skin come off with it and cause a lesion. That happened to me when I did my shoulder surgery. So there are other options that they can do like if you take a shoelace and tie it around the tube and have the anesthesiologist tie it around the back of your neck to hold the breathing tube in. It eliminates having the tape on your face or anything.

Becky: Great.

Janet: I also want to say Rudy reminded me that they put a tube down your throat. The first time I had surgery when I had my partial hysterectomy they put a tube down my throat and I got lesions down my throat because of the way they did it. During the second surgery I specifically told them do put the tube in very carefully and very slowly, taking it in and out because of the fact that it can cause lesions in my throat. So the second surgery I did not have a sore throat at all and I hope that they listened to me. So you have to ask them specifically if you have to have surgery if they are going to put a tube down your throat to please be very careful about it.

Becky: Great thank you. Our next question is, "Is it safe to take a probiotic or an immune system booster?"

Janet: No

Rudy: I was actually on a probiotic also and when I first became properly diagnosed the dermatologist wanted me to get off of the probiotic right away because it enhances your immune system and that is something that we don't need our immune system enhanced we need it to

kind of be suppressed and come down. So he took me off probiotics and told me not to take probiotics or immune system booster ever again.

Becky: Great thank you. Our next question is, “After my first Rituxan treatment, how long will it be before I begin to notice any type of peeling or any type of difference in my lesions and activity?”

Jack: I would say four weeks. I can’t remember but I thought that there was a standard number the doctors use to see how you actually respond and I can’t remember if it was four weeks or six weeks but I get reluctant to mention myself because I was an unusual case. But after my treatment, within two weeks it was almost gone and basically I was healed within two to three weeks which is kind of unheard of. I was just going to add on that that was the difference between my third infusion where not only did I not completely clear up. It took a little longer but not as long as a lot of patients have to deal with but it did take longer than my other two for some reason.

Rudy: I think it varies from patient to patient how they react to the treatment because everybody is going to react to it differently. For me it took me about four, four and a half weeks after my second treatment to actually see the lesions begin to heal and if I did get another lesion it wasn’t as pronounced or as big as the ones previously and if they did come up they wouldn’t last as long, it would heal a lot quicker. So I think it varies from person to person and how they react. It could be four weeks, it could be six weeks, it could be a little less than four weeks, it could be eight weeks. It think it all just depends on how that patient takes that treatment in.

Becky: Great, thank you. There is another question about clinical trials and they are asking, “How do patients find out about clinical trials?”, Marc do you want to speak to that one? Marc are you here still? Does anyone want to speak to that?

Mei Ling: You can go to clinicaltrials.gov

Janet: On the website too, I think I found on website too, on the pemphigus website.

Becky: So absolutely to both so thank you. How long does it take the average patient in the U.S. to get diagnosed.

Janet: Becky you should be able to answer that one.

Becky: So yes, according to a study done by the IPPF back in 2011, it take the average patient five health care providers over the course of ten months to find a diagnosis. And in that study, ten percent of patients reported having to see about ten health care providers. So that is data from a few years ago, about five or six years ago, but I think that is pretty standard. I think that everyone on the panel except for lucky Jack took a little bit to get diagnosed.

Janet: I think it also depends on where you live. I think where you live can make a difference and the kind of doctors that are familiar with the disease. It took me a long time but it really didn't. It didn't really have a lot activity when I had my first biopsy so although it took a year before I was actually diagnosed, there wasn't a lot of activity that I had. So by the time it actually looked like pemphigus the doctors pretty much knew what it was. So I didn't have to go through a lot but I think it was because of where I lived and I was lucky to have a good doctor. But some people I know it has taken a very long time.

Becky: Great, thank you. So there are a couple questions, "How long do I need to stay on Prednisone and how long do I need to take immunosuppressants?"

Janet: Well that depends, it depends on how active your disease is, it depends on what immunosuppressant you are on. I was on Imuran for five years and I didn't do Rituxan because they didn't have it then and then I was on Prednisone alone for a very long time because there weren't any immunosuppressants. But I think in general you really have to be careful that you don't come off Prednisone too soon, it could take up to five weeks for the immunosuppressants to kick in and you want to make sure that they are working and then you can start reducing. A lot of doctors want to get you off really quickly but unfortunately if they get you off too fast, and I had that issue they took me off too fast after three months and I broke out really badly. So it really depends on the activity and how much of the medication you are on and how they are keeping you on that medication. I was able to get down off the Prednisone because I was on the Imuran but it took me a long time and I was actually off Imuran before I was off the Prednisone. Everybody has to handle that different but you have to be careful about getting off either one of those drugs too soon.

Becky: Great, thanks Janet. Our next question is from Carol and she says, "Right now I am only seeing my primary care doctor to manage my disease but I hear many people say that they see a dentist and a dermatologist or a rheumatologist and and an oncologist to manage their

disease. Should I go to a specialist or is my primary care physician good enough to manage the symptoms?”

Janet: I could say that a primary care doctor or any doctor can manage the disease as long as they understand the disease and what to do about it and how to handle it. Any doctor can give you medication for the disease, any doctor can do that. I only have a primary care doctor and a dermatologist but other than that I go to a specialist if I need something else but not for the pemphigus. But if your internist or your regular doctor is willing to know about it, learn about it and look into it. Actually rheumatologists are not for pemphigus and you can see a dentist because you have to get your teeth cleaned so if you need to have work. Having a dentist or a dental pathologist take a look at you too, that is always a good thing. But you don't have to go to them on a regular basis necessarily.

Jack: My dermatologist had a question about whether I would react to the Imuran and there were just some things popping up that he didn't understand. My dermatologist was the head of my treatment he would send me out to different specialists as needed and in this case he couldn't figure it out so he wanted to send me out to a primary care doctor and my primary care doctor when they walked into the room said, oh did you fall off a bike or something. He had been practicing for ten years and he had never seen a case of it. So that just gives you an idea of how often they might come across it.

Mei Ling: Becky, can I add one more note for everybody especially if you have oral activity if you go to our website, pemphigus.org/awareness then you will come up with the oral part of the disease and go to where it says patients. And there are patient resources, “How to talk to Your Provider” which is very good and find a doctor that is recommended. It is always good to have your dentist in loop with your dermatologist especially if you are going to have oral surgery and if you are going to have a cleaning because your mouth can be very sensitive at this time. So I just suggest that you look at the awareness site so that you are better prepared for your dental needs.

Becky: Great, thank you. Our next question is from Mike and he wants to know, “It is okay to get a tattoo?”

Janet: I wouldn't. I mean you could probably do it but it is probably not the best idea.

Mei Ling: I have seen that question a lot. I know some patients who have had one and they haven't had any repercussions but I think that we need to remember that number one that this is a skin invasive rare autoimmune disease and number two if you are thinking of getting one and you have been given the go ahead from your dermatologist at least be sure that you have had a tetanus shot in the last ten years because you need to protect yourself just in case. It needs to be a discussion that you have with your dermatologist because somebody else can have a tattoo and have nothing go wrong but then it might be your misfortune to have a tattoo and you will get an eruption that you don't want.

Becky: Great, thank you. Sue is asking, "Why does my doctor tell me I need to get a flu shot?"

Janet: Well, you should get a flu shot because if you are on immunosuppressants and you get the flu it could be really bad. Make sure it is not a live virus, but that is why they want you to get a flu shot.

Becky: Great, thanks Janet. Our next question comes from JoLynn and she says she has kept her struggle pretty much to herself but now feels that she is ready to start telling her family about what she is experiencing. How is the best way to tell your family?

Janet: Be honest, sit down and talk to them and tell them how you are feeling. Communication and honesty in your relationship with your family is the best solution and make them apart of your healing because family can be very helpful in healing.

Jack: Or they can be very stressful.

Janet: Well yes they can be but if you want to include them then you have to talk to them because they might be wondering and scared for you knowing that something is wrong and if you are not talking to them.

Jack: Maybe if you have some literature possibly that you found helpful that you can share with them because if anything what you hear might be scarier than what you actually have so it might be another good thing to have on hand.

Becky: Great thank you. Our next question comes from Darren and he wants to know if pemphigus is genetic?

Janet: Pemphigus is genetically marked which means you have to have the gene to get the disease but if you do have the disease you might not get the disease. So there are a lot of people running around with the same gene but they don't ever get the disease because there is something that triggers the gene. So it is not really considered a genetic disease but genetically marked.

Becky: Great thank you. Our next question comes from Jeff and he wants to know, "How does stress affect this disease and how can I deal with stressors in my life?"

Mei Ling: I don't know how to articulate this very well because I don't know how the antibodies get the signal but they do when you are emotionally upset somehow the antibodies know it's time to react. I have often suggested to people that taking your mind off of disease and either going out for a walk or doing yoga or swimming or listening to music that is calming, doing deep breathing exercises, doing meditation they all help. The thing is to just try and remain balanced and I know this is difficult especially when you first get pemphigus or pemphigoid it's very difficult but maybe you can just talk to a friend and take some time out. And you can always call one of us, any one of our Peer Health Coaches we are available to talk with you. If at any time you feel really anxious and frustrated send us an email and your phone number and we'll be very happy to have a conversation with you. And also if you happen to live in one of the cities that we have a support group, if you attend those meetings you will be meeting other people who are patients and they have suggestions too and then you have your own little nucleus to help you through it.

Becky: Hey Mei Ling while you are at it since you talked about the Peer Health Coaches do you want to let people know how they can find us and send an email to the coaches? I think it is interesting to point out too that generally we live in different time zones so there is somebody almost twenty-four hours a day that you can talk with somebody just by reaching out and sending an email. So do you want to tell people how they can get in touch with a coach?

Mei Ling: Well if you go to our website www.pemphigus.org, then go to the header that says "Living with P/P", the pull down menu has "Ask a Coach". So you fill in the page and I will see it right away and so will a couple other of our coaches. I am on the west coast, I am in Los Angeles so I can take calls on the west coast. Becky is in the midwest, Janet is on the west coast, Rudy is in Texas, Jack is on the west coast. None of so far on the east coast but we can

adapt. I have patients that I call on the east coast. So just go the the “Ask a Coach” fill it out and let us know what you need because we are here for you.

Becky: Great thank you. Dorothy is asking, has Rituxan been successful with patients with pemphigoid?

Janet: Yes.

Marc: So it has been successful in pemphigoid as well as pemphigus. Currently it is only FDA approved for pemphigus. In June it was approved by the FDA for the use in pemphigus but it is still being used off-label for pemphigoid. Currently if patients are looking to get that approved and they need assistance, they can reach out to the IPPF and we can help them navigate the waters so to speak but it is being used for both pemphigus and pemphigoid and it is successful in both.

Becky: Great thank you. Jack, Julie is asking to know the name of the doctor who diagnosed you. What doctor diagnosed you?

Jack: Dr. Goffe, Bernard Goffe.

Becky: And they are located?

Jack: Probably not located anywhere that would involve helping someone anymore, I believe he is retired. He was getting close to retirement back in 2002 so if you are asking to try and contact him I don't believe he is working anymore.

Becky: Okay, thank you Jack. Marlow wants to know if we can speak to the long term effect of Cellcept? Am I the only one that took Cellcept? Yes, so one of the things my doctor told me about back in 2010 when I was diagnosed was that by taking Cellcept I was increasing my long term risk of lymphoma and it was a very mild increase over time. So far it has only been eight years but nothing has ever developed in me but that risk is always there. And also when I was taking Cellcept, I stopped taking it in 2013, I took it because its job is to lower the immune system, I was always at risk for infection. Any infection such as the common cold or the flu that we already spoke about, would be worse in a patient like me. At one point when I was on treatment I did get a pretty severe lung infection I was on eighty milligrams of Prednisone which is a drug they commonly give to people with respiratory or asthmatic symptoms and I was acting like an asthmatic and getting really bad attacks and a really bad infection. So I kind of scared

my doctors at that time and they quickly, I think I just stopped taking the Cellcept and they cut back pretty far with the Prednisone as well, as far as they could safely and then I had to go see a respiratory specialist, a lung doctor, and through pretty extensive testing. So those are some of my side effects that I had. If you are interested in other side effects, definitely talk to your doctor and you can also look up Cellcept on the internet. Most drug companies have an information page for patients that do talk about side effects. So a great thing to do is to take a look at those and you can use that to help you have pretty good conversations with your physician as well. So I hope that information helps you.

Becky: Our next question is, “When I was at the IPPF conference in Durham I heard a lot of talk about Healing Heros, can you explain what a Healing Hero is and how I can be more involved?”

Marc: So a Healing Hero is a program that we launched last year for Giving Tuesday and it is essentially a fundraising program that is a recurring donor program that helps us raise funds for research and awareness and all of the things that the IPPF needs to sustain itself. So it is a monthly donation, based on whatever you are willing to give and if you become a Healing Hero then we give you a few benefits like a conference discount and then we also send you periodic emails to keep you informed about what the IPPF is up to and all the things we are accomplishing. A Healing Hero is someone that really helps us make an impact and helps patients on an ongoing basis. And I encourage everybody to become a healing hero because we need your help to continue to provide great services to patients like everyone on the phone listening. It costs us money to do these Patient Education Series Calls so your generous donation helps to continue to provide services for you. So that is what a Healing Hero is.

Becky: Great thank you. We have another question, this is probably the last one because it has been a really quick hour. “My dentist has scheduled me for two extractions in preparation for implants. Are there any concerns that I should have about trauma to my mouth in healing?” She says she is going to an oral surgeon as both her upper teeth are very close to her sinus cavity.

Jack: I believe I had all four of my wisdom teeth out while I had active pemphigus and was taking Prednisone and I don't recall any special protocols for me. I guess my mouth was not in too bad of shape during that time but I'm trying to remember since it was a while ago but I suppose if you are having a lot of blistering going on then it might be a different story.

Janet: And if they are going to do implants then they are going to drill into the bone and it is going to bother your gum tissue but if you talk to the pathologist about the possibility of taking steroids while you're doing the procedure because even if you're in the remission it might be worthwhile to take a short course. So I'm dealing with that now, trying to decide whether to do an implant or a partial implant. Partial implants are a little less problematic but that is a difficult question and that depends on the person and depends on whether the doctor thinks that maybe you should do a course of steroids.

Marc: The other thing I would recommend is to space out the procedures. So one thing to keep in mind is any trauma that you have to your skin tissue or your mouth or your gums that is going to take a while for those things to heal so I would try and space out those procedures and definitely I agree with Janet you might want to consult your physician about maybe taking some sort of corticosteroid or anti inflammatory because the procedures are definitely going to cause inflammation.

Becky: Well great, thank you so much. Well that was a very quick hour and there are still a lot of questions that we hadn't got to and I apologize for that. I would like to thank all of the coaches for being on the call with us today. It was extremely educational having you on our call. I would like to give a thank you to everyone who took the time out to join us today!

I would also like to remind you that the IPPF's Community Engagement fourth quarter fundraising campaign has kicked off with a goal of raising \$15,000. Your tax-deductible donation enables our community to continue to receive; a physician referral service and map to help patients find the best medical care possible, local and regional support from others, our one-of-a-kind Patient Education Series webinars, and having a Peer Health Coach available to answer all your questions.

Please consider visiting our website today to make a tax-free donation to support the IPPF and our mission of improving lives and reducing diagnostic delays.

Don't forget to register for the IPPF Natural History Study, a new patient registry sponsored by the National Organization for Rare Disorders (NORD) and the US Food and Drug Administration (FDA). Register today at www.pemphigus.iamrare.org

Lastly, If you have a question that didn't get answered on the call, or have additional questions please e-mail our Outreach Manager, Becky, at becky@pemphigus.org, or call me at (916) 922-1298 x:105, and I would be more than happy to help. This call recording will be sent out with the survey following this call.