March 2018 Patient Education Call- Transcription

Becky: Hello everyone! Welcome to this call! Our speakers for today are Dr. Donna Culton and IPPF Director, Marc Yale. Thank you both for joining us today!

Marc: Thank you for having us.

Becky: The call today will focus on current research being conducted within the Pemphigus and Pemphigoid community as well as advocacy efforts which the IPPF and you too can participate in.

Becky: Dr. Donna Culton completed her medical degree at the University of North Carolina at Chapel Hill. While there she also received her PhD in the Department of Microbiology and Immunology where she studied autoreactive B cell development and regulation in systemic lupus. She continued her training at UNC and following her Dermatology residency she completed a postdoctoral fellowship applying her knowledge of autoreactive B cell pathophysiology to pemphigus by studying B cells and autoantibodies from patients. Her laboratory has generated a novel murine model of pemphigus allowing for a better understanding of mucosal pemphigus vulgaris. In her current position as Assistant Professor of Dermatology at the University of North Carolina at Chapel Hill, she serves as the Director of the Clinical Immunofluorescence Laboratory at UNC and sees pemphigus and pemphigoid patients from North Carolina and neighboring states in her specialty Autoimmune clinic. She has served as an investigator in clinical trials in pemphigus and has contributed to consensus statement publications as part of the International Pemphigus and Pemphigoid Committee. She currently lives in Chapel Hill with her husband and daughters.

Becky: Marc Yale was diagnosed in 2007 with cicatricial pemphigoid, a rare autoimmune blistering skin disease. Like others with a rare disease, he experienced delays in diagnosis and difficulty finding a knowledgeable physician. Eventually, Marc lost his vision from the disease. This inspired him to help others with the disease. In 2008, he joined the IPPF as a Peer Health Coach. 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. Marc currently resides in Ventura, California and is the Executive Director for the IPPF.

Becky: Now, it is my pleasure to introduce Dr. Donna Culton and Executive Director of the IPPF, Marc Yale, to discuss a bit about research, advocacy and efforts from the IPPF and the rare disease community and to answer your questions. Welcome everyone!

Becky: Our first question is from Ralph and he is asking if there is any new research with bullous pemphigoid (BP) to show any relationship with diet and flare-up?

Dr. Donna Culton: It's a good question and it's a question we get a lot from patients. There is always a question if diet could be influencing the trigger of the disease itself or flares. At this point we don't have any clinical studies or research that shows that any particular foods will cause the disease or trigger flare ups. I think certainly when there are open sores in the mouth, things you eat can aggravate open areas and the tissue of course in the mouth is very frail so to speak. So sometimes things you eat- crunchy foods can lead to open sores. For skin lesions, bullous pemphigoid, so far there is nothing to suggest that anything in the diet can trigger a flare-up. I think most physicians do encourage their patients if there is something you identify as a definite trigger for yourself, we encourage you to actively avoid that and just listen to your body. In general, for all patients with pemphigoid there is no relationship with diet and flare-ups.

Becky: Great, thank you. Naheed is asing pretty much the same question about how diet affects patients with pemphigus and if there is any recommendation for patients with pemphigus on any food, drinks or fruit that can be triggers?

Dr. Donna Culton: Yes, I would say the same answer for patients with pemphigus that there are no obvious triggers we know of at this point to cause the disease or trigger flare-ups. Again, with open sores in the mouth one of the most commonly reported things that aggravate pemphigus would be crunchy foods and also acidic foods- raw citrus fruits, vinegar, all of those types of things that are acidic in nature can aggravate open sores and certainly make it feel like they're causing the disease to worsen. But the actual cause of the disease as most of you know at this point and the B-Cells and those autoantibodies. Nothing specific with diet causes a flare up of disease with pemphigus either.

Becky: This is also a medical question- why do some patients get extra energy with prednisone and I get tired with brain fog? Is this a real thing that is recognized by the medical community and is there any research being done to see who and why some people get weighed down and other people just feel extra tired or with more energy?

Dr. Donna Culton: Great question. Prednisone is a wonderful drug when you need it because it acts quickly and is very powerful, but, it is also very difficult to be on and it affects patients differently. I hear all the time some patients feel super raved up while other people feel very tired and brain fogged. I do think that's a real thing recognized by the medical community. Right now we've had Prednisone around for so long and it's been a lifesaver for many patients with autoimmune diseases. But most physicians goal is to get patients off prednisone, it certainly is not anyone's long term answer. There is no active research as to why some people get hyped up and some people feel brain fog or tired. But I think it's a well recognized side effect and hopefully the physician that is managing the medication is actively working to get patients off of Prednisone whenever possible.

Becky: Great, thank you. Someone has written in and says that many, including on our IPPF website say that tannins can have an effect for disease in the mouth and polyphenols. Do you have any information on what that does to the body or to the mouth?

Dr. Donna Culton: Nothing specific. I have had some patients mention that those things are triggers for them or things that aggravate their mouth. I know that this is certainly one of the areas I see more active research going into to figure out. I think that patients are providing the most up-to-date information on what it's like to live with these diseases and what patients recognize as to what triggers the disease may give us more insight as to what is going on in the deeper level of the skin and the pathways that cause pemphigus. I'm not aware of any specific or well-published research studies, but again I think it's an area that needs more active investigation.

Becky: Janice is asking- What research is currently being done for mucous membrane pemphigoid (MMP) treatments or BP treatments? Is there anything close to coming to the market to help us as there might be for pemphigus vulgaris (PV) patients?

Dr. Donna Culton: That's a great question. I think that there is a lot of research being done in Rituximab for patients with MMP, but also BP. I think Rituximab works pretty well for MMP and like in pemphigus, it takes a while for the medication to show it's ethicacy what it can do and how helpful it can be. It doesn't work immediately. Especially since MMP has issues with scarring, that becomes a more difficult thing to treat. While Rituximab may help with the disease inflammation, the scarring is more permanent and so that can be difficult to tease apart. There are plenty of studies going on right now using Rituximab and MMP. MMP is really interesting I think because there is such a specific environment in the mouth and the pathways that cause the end result disease in MMP are very different from pemphigus. So there is a lot of research that's going on into what other pathways cause the scarring. We know that antibodies are important, but we know that there are obviously other things going in to cause the scarring in ocular mucosa and oral mucosa as well as in the genital and anal mucosa as well. I'm a big proponent on having models to test. Certainly many patients have gotten Rituximab using animal models potentially to investigate those pathways and come up with new targets, not just be self depletion as Rituximab does, but other targets that might be helpful in treating MMP.

Becky: Great, thank you so much, that's very helpful. Marc, it's been kinda quiet for you but here is a question for you- Kyle said that he would like to start advocating for patients like him. What are some ways you can recommend for somebody to start?

Marc: Great question! Obviously the first thing is just recognizing the fact that you want to share your voice and advocate. Most importantly advocating for yourself is key. Contacting the IPPF is a great start and we can provide lots of information on ways to advocate, whether it be your local community, it could be on the state level or it could be in the federal government. Right now the IPPF advocates on all three of those fronts, but we also advocate on other governmental organizations such as Medicare, the Food and Drug Administration, we advocate

with other groups to help research funding, promote researching funding particularly for the National Institutes of Health (NIH). That's what I would recommend, reach out to us at the IPPF, and we can help provide the tools and some of the basic information you need to get started. We are here as a resource and we're happy to help.

Becky: Dr. Culton, with patients really suffering and going through a lot physically, emotionally, mentally. Joel's question is about Rituxan being fast tracked and what exactly that means to us as a patient?

Dr. Donna Culton: The FDA when reviewing different medications has different tracks to accelerate approval, and with Rituximab being the first medication to actually be submitted to the FDA for approval of treatment with pemphigus, it got priority review which was fantastic. What priority review means, there is actually a great website that's a part of the FDA website that you can get to if you just google fast track FDA and it brings you to all the definitions. Essentially, what Rituximab got was priority review. Priority review means that the FDA plans to take action within 6 months. It doesn't seem fast by regular standards these days, but for the FDA that's very fast. Typically it can take years for something to get approved but when a medication, especially when it's the first medication that's being FDA approved to treat a particular disease, priority review is a wonderful thing. We are really excited that we got priority review and we hope to hear something by mid-year somewhere in the fall regarding whether the FDA is going to approve it or not.

Becky: Another patient, Kate said that she's heard of CAR-T therapy and said that it might actually be the cure for patients with pemphigus or pemphigoid would you explain what CAR-T therapy is and what research is being done and how it works?

Dr. Donna Culton: CAR-T therapy is a very exciting therapy that is coming out. What it is, is using your immune system that is kinda out of control and attacking certain parts of your body which is causing pemphigus or pemphigoid. What CAR-T therapy is, is taking part of the cell out of our immune system. We think of B-cells as being kinda the main players of pemphigus and pemphigoid autoreactive to B-cells. Not all the B-cells are confused, but a certain subset are misguided. What CAR-T therapy does is it takes a person's own T-cells (which is just another part of the immune system) out of the body and kinda redesigns them and then extra bits of protein and molecules that help those T-cells fight against particular proteins. Right now it's being used CAR-T therapy there are certain ones out there that are used to eliminate B-cells, just like Rituximab does. More and more scientists are very clever and are using CAR-T cells to attack other proteins in the body. Proteins that are marking cancer, tumors and other autoimmune diseases. Right now, CAR-T cells for the use of pemphigus have been trialed in mouth models. To my knowledge, there is no trial going on right now in using humans, but certainly CAR-T are being used. Especially the ones that target the B-cells are being used to treat lymphoma. So, I think it's right around the corner. The important thing to remember is that this is a really difficult technology because the T-cells have to be removed from your own body,

re-engineered, and then put back in. It's not just a medication you can order at the local pharmacy, but it is very exciting and we are all very excited to see where this is going to go.

Becky: Great, thank you. Another patient is asking, how do you monitor if a patient is getting better while in a trial? Is there a titer or anything that can help or is it solely based on clinicals?

Dr. Donna Culton: I think most of us who treat pemphigus and pemphigoid use both. I am always looking at and listening to my patient to see if they are responding to the treatment that I'm using. Also occasionally we will use other tests. The titer is one used especially for pemphigus to track disease activity and it's used in different ways by physicians to treat pemphigus and pemphigoid. One particularly great way to use it is when you're coming down on therapy to see if you still have those circulating antibodies. I think we all understand that autobodies and antibodies, which is reflected by the titer, is what's causing the disease. There are also some tricky things that we have to consider when we interpret it so what's going on in your skin may not be reflected on a blood test. If antibodies on your skin are not circulating in your blood then the titers might not catch that. It's really tricky but I think that most clinical trials and most physicians in general who are seeing these patients rely on both a combination of blood tests and also the patient themselves, and listening to the patient, doing assessments. In clinical trials, the clinical assessment is rigorously scored by disease activity score. So a lot of the clinical trials will use the pemphigus disease activity or the BP disease activity index and now there is an MMP disease activity index. These are all helpful when you are comparing multiple patients through clinical trial.

Becky: Somebody is asking, I want to participate in the natural history study, what should I expect and what do I have to do to participate?

Marc: The first thing to do is go to our website to the natural history page and just sign up, it's just that easy. The history study itself, for the patient that's asking, the study itself is a series of questionnaires that will be asked over a series of time. This particular study is what we call a longitudinal study, so what it does is it measures the patient's disease activity over the history that they are involved in the study. So what it does is it really gives us an opportunity to see how the disease is when they join the study and what happens with the natural history of the disease as it progresses and as time goes on. It's a really extremely useful tool for us and for researchers to learn more about the disease so we can determine as Donna has been talking about pathways and key elements to the disease. Again, very simple, you sign up and then you'll get an email instructing what to do and you'll get reminders as to when you are suppose to take these periodic questionnaires. It's a very simple process and we try to make it as easy and the least time consuming as possible, but we definitely need everyone's information and I encourage all of you to join the natural history study so that we can learn more about the disease and so that we can find out better treatments and better cures for pemphigus and pemphigoid.

Becky: Dr. Culton, Ben is asking- What is happening with research and pemphigus in children and is there anything on the generic or biosimilar horizon?

Dr. Donna Culton: Great! That's two questions so I'll handle them one by one. In terms of research being done on pemphigus and children, most of us who have seen pemphigus have seen a handful of cases in children. Right now a lot of the clinical trials testing medication have not included children in the study for the safety of the children. In terms of clinical trials, most of the clinical trials will have inclusion or exclusion criteria to say how young a patient can be and still be in the study. But in terms of other types of research being done, I think that the pemphigus and pemphigoid community of physicians is trying to understand why some patients would get this in childhood because it's a terrible disease to have at any age but certainly I think we can all say that our hearts would go out to parents who have a child who has this disease.

Right now I think that the natural history study would be a great one to understand, or other studies that might be looking at genetics for these patients and why they might be prone to these diseases at a young age. That's about all the information I have on trials or studies being done on children with pemphigus. A quick update on what biosimilars are is a generic form of biologic medication. So, right now there are none for Rituximab which is the only biologic medication that's really actively being used to treat pemphigus and pemphigoid. Most of the biosimilars out there are medications that are used to treat psoriasis at least in the dermatology field, so nothing right now for that.

Becky: Kevin is asking- Do you know of any research being done to look into long-term non physical effects of pemphigus and or any chronic autoimmune disease in general?

Dr. Donna Culton: Long-term non physical, right now there is a study going on in the quality of life. In pemphigus and potentially in pemphigoid, (and Becky you may be able to speak to that because I know the IPPF is sponsoring that study or heavily involved in that study as well). I know that the study focuses on quality of life issues surrounding that disease, but also quality of life issues that are due to the medications because we know that the medications used to treat these diseases are not benign medicine. So, that study is very important to help us understand the long-term effects with living with these diseases.

Becky: To speak to that, I think that study that you are talking about is from the University of Minnesota and the University of Oregon. It's a joint research project. If you email me, I can definitely get you the link after the call to participate in that study and you can also ask the researchers any questions. I believe their contact information is in that link as well. Please feel free to reach out to me after the call.

Marc: Becky, we do also have some upcoming studies as well on the quality of life issues. There is one that will be taking place in Boston and a couple others upcoming. I just wanted to give a quick shout out and let people know to keep their eye out for that and if they get an email or something from the IPPF asking them to participate in these quality of life studies. Again, as Dr.

Culton mentioned, it's very important for us to really understand the disease better and those long-term effects of the disease. If you do get those emails or requests to join these studies, I encourage patients to join.

Becky: Great, absolutely Marc. Our next question- Is pemphigus vulgaris (PV) a genetic disease? They were breast fed from breast milk and their other two children have problems which were not investigated properly. And this patient does have PV.

Dr. Donna Culton: To answer the first part as to whether there is a genetic component, we certainly feel that there is a genetic component in pemphigus. There have been lots of studies predominantly many of them in the labs of Dr. Ani Sinha in his group in Buffalo. But looking at genetic markers of disease. As you've already heard some families have a representation of disease, where in other families it's very sporadic. There certainly is a genetic component, and we potentially feel that there is an environmental component as well. You kind of have to have both the genetic background as well as the environmental trigger. We don't know what the environmental trigger is for patients in the U.S. That's an active area of investigation.

The second part of the question looking at and considering breast milk. So, antibodies are passed through the breast milk both good antibodies, which is why most physicians encourage breastfeeding children to pass on the good antibodies, but also autoantibodies could be passed through the breastmilk. There have been cases reported of newborns who are being breastfed having pemphigus. Also, the antibodies passed to the child while the child is in the womb. So there are, like I said, case reports of babies being born that show those signs of pemphigus. However, the babies immune system and the B-cells are actually healthy. It's just the antibodies that get passed and the antibodies have a half life of a couple of months. So, typically, in those cases, the disease resolved because it's really just the antibodies that just kind of have their own half life and the babies are fine. I do think it's important if babies have a skin disease that they be evaluated by a dermatologist, especially if the parents have a history of pemphigus.

Becky: Marc, Mary is asking a question to I think when you were talking about the Natural History Study- How do you access the index study?

Marc: You could either go to our website and access the research tab, or https://pemphigus.iamrare.org/

Becky: Another patient says- I have felt very alone throughout my whole disease process, how could I find out if my path is similar to others with pemphigoid? Will I be able to find this out if I participate in the Natural History Study?

Marc: Well, that's a good question. I think it will be helpful for them to participate to be able to get that information.

Becky: Dr. Culton, Carol is asking- how does a placebo trial work and the second question is- how closely will I be monitored during a clinical trial?

Dr. Donna Culton: We'll talk just briefly about clinical trials and just review. Clinical trials start with testing of a drug in healthy individuals primarily for safety. Once that's done, the drug will move into the next phases of clinical trials where it's tested in patients. Again, both for safety and ethicacy. Many studies will include a placebo arm. To make sure that we know, I think the placebo effect is the real thing and patients tend to get better when they think that they're getting the drug. It's very important to have placebo control trials done to understand what does it look like. The other word that comes up is blinded study, meaning the patient and occasionally the physician may not know which patient is getting the drug or the placebo. That's important again just to eliminate that placebo effect and really understand if the study drug is working well for the disease. So different clinical trials it's important if you are considering enrolling in a clinical trial to ask about whether there is a placebo arm and the breakdown of how many participants are enrolled how many of the patients are gonna get the placebo versus how many are gonna get the active drug. I think it's important to consider all clinical trials that may come your way but obviously you need to know what your chances are of actually getting the drug versus getting the placebo.

To follow up on the next question, which is how closely would you be monitored? I always tell my patients who are considering a clinical trial is that you are actually monitored almost more closely in a clinical trial. My joke is that even if you sneeze too many times in a row the study coordinator wants to know. So, I think a lot of patients are reassured by that. That you have almost direct access to the study coordinator and the physician while you're in a clinical trial, blood work being drawn all the time, and again, any side effect that you experience are being recorded and monitored whether it's related to the study drug or if it's unrelated. I would say that you are monitored very closely while you are in a clinical trial.

Becky: This is kind of my question- you mentioned that there's a lot of blood work to be done. If someone decides to participate in the clinical trial, do they have to do to the center or the doctor's office where the trial is being conducted to get that blood work or could they have that done anywhere?

Dr. Donna Culton: That's a great question. I think it depends on the study. Different studies have different protocols. Protocols is the term for exactly what is being asked of you when you are in a clinical trial. Often times that will detail the visits, the blood work. Some studies allow you to have the blood work done by a blood draw agency that will come out to your home, and there are protocols that would require you to come into the office. There is not one city that I know of that has a boat load of pemphigus or pemphigoid patients in one place. We all understand that patients that may enroll in this study are going to be coming from all over the place and we have to be able to accommodate and make it reasonable to be in a clinical trial. I do think that there are a lot of clinical studies that allow blood draw to be done closer to home.

Becky: If I was to apply for a clinical trial, what are some things that could get me excluded from participating?

Dr. Donna Culton: That again goes back to the study protocol that would have the inclusion and exclusion criteria. It all depends on the study sponsor who are kind of the group of people who are laying out the study and patients and physicians are the ones signing up to be part of the study. The study sponsor would come up with what they feel are reasonable inclusion and exclusion criteria. Most of the exclusion criteria would be if you have had some other drug to treat your pemphigus within the prior six months, it depends, that could interfere with the interpretation of your response to the study drug. If you just got Rituximab two weeks ago then you're probably not going to be able to enroll in a new study looking at B-cell depletion because you just had your B-cells depleted. They wouldn't be able to tell if the drug was working in you or not. Those are kind of the main things that would exclude a patient. It doesn't mean that if you had Rituximab two years ago that you can't participate in the study. Again, each study is different and it's important to ask when you are considering a clinical trial.

Becky: Since we are talking about it right now, maybe you could clarify a phase two and phase three trial?

Dr. Donna Culton: Phase two trials are predominantly looking at safety, ethicacy. In general, phase three would be a larger study with more patients, and comparing the study drug to standard of care or standard treatments. It's a larger study and comparing to other treatments that are already used to treat the condition.

Becky: If I participate in a trial and it's a bit of a distance away, will I have to pay for travel to the research center?

Dr. Donna Culton: Most studies, the sponsor will pay for your travel and again these are important questions to ask if a center that you live near to ask these type of questions. Most sponsors understand that you shouldn't have to pay for your own travel while you are going to be participating in clinical trials. So, usually travel is covered, any housing if you have to stay overnight is covered.

Becky: Bob is asking- Why should patient in remission participate in a trial or study like the Natural History study?

Dr. Donna Culton: If someone is in remission we want to know what led them to that remission. As we've already heard today, every patient has their own course of disease, their own story to tell and so the Natural History study like any other study is just more information about everyone who is living with pemphigus and pemphigoid. To have information on anyone who has gone into remission and what has led to that remission. I think we all see short term remission as well as long term remission. It may be that a person who has gone into remission is going to have a relapse. So, it's important to capture all of that information to help us better understand.

Becky: I'm not sure if there is an answer for this one- Why don't all treatments work on every patient?

Dr. Donna Culton: I wish that were the case too! It might make my job a lot easier.

Becky: The follow up question is- Why doesn't one treatment but also one dose work for everyone?

Dr. Donna Culton: Every patient is unique and individual and we see it all the time where some treatments work beautifully for one patient and don't even begin to help another patient. We don't understand why, and we are learning about that too as we understand how these drugs are processed in the body. It's also important to understand the people come in different shapes and sizes or are on different medications so it might be that someone needs a higher dose than somebody else. Especially for severity of disease. I think we all kind of have a sense that if you have a very mild with only a few spots, maybe a lower dose would work compared to someone who is covered with disease might need a higher dose. Those two questions really get to the part of medicine where it's really a part of art than an art of science where we really have to follow patients carefully. This highlights that we do not know why different people behave differently but it just goes back to the unique nature of each patient.

Becky: That's a great explanation, thank you. Bryan is asking a question for Marc- He would like to participate in Rare Disease Week on Capitol Hill next year. How do I sign up, and what if I can't come to all the events all week?

Becky: I guess I will answer that question- Rare Disease Week on Capitol Hill is sponsored by the Rare Disease Legislative Advocates (RDLA). They have a website that lists their upcoming activities and events including things like In-District Lobby Days that you can participate in. I think they started to post that on the website last fall.

Marc: Yes, usually they start posting it around September or October for the upcoming year. So, this September or October will be the time that we start planning and as you mentioned the Rare Disease Legislative Advocates will start planning for the upcoming year. If you are interested, certainly reach out to the IPPF and we can make sure you are notified once those events are announced.

Becky: For the person who feels like it's a little intimidating sounding, do you want to just give a brief synopsis of what it entails and how it's really not intimidating at all because you go to legislative boot camp?

Marc: Absolutely, thank you for mentioning that. Of course I do remember my first time up on the hill and I definitely felt intimidated. Once you get there, and particularly with this event it's fantastic because there were over seven hundred different rare diseases represented at this

year's conference in Washington D.C. Really you are amongst many rare disease patients and of course the IPPF likes to send quite a few representatives ourselves. So, you are not alone. As you mentioned Becky, that it can feel a little bit intimidating. The way that the conference is set up, we'll spend an entire day talking about what to expect when you get up on the hill, what the offices are like, what to expect when you get there, how to present yourself and how to make an appropriate ask of your congressional member. Then, we will let you practice too which is great. We want to give everyone the opportunity to practice. Although it seems like it could be intimidating, it's really not. To be able to go and speak to your congressional members and express yourself, share your story and also share your story on behalf of all of the pemphigus and pemphigoid community is extremely empowering. I would highly recommend it for anyone who is interested in sharing their story, particularly with their congressional members.

Becky: That was a very quick hour, and I just want to say thank you both for being on the call. I would also like to give a shout out to and thank you to everyone on the call for joining us.

I would like to remind everyone that the first fundraiser of the year started in January and runs through the end of March. During this time, the funds raised goes towards research. You still have a couple of weeks left if you would like to donate to this worthy cause and it ends at the end of March.

The IPPF is also very pleased to announce the date and place of the next IPPF Annual Patient Conference. The 2018 Annual Patient Conference will take place in Raleigh-Durham, NC on October 12-14 and Dr. Donna Culton will be one of our co-hosts this year along with Dr. Padilla. More registration details will come in the next few months. So, please keep your ears open and we definitely hope to see you there.

If you live in Michigan and would like to volunteer at the IPPF exhibit booth at the Michigan Dental Annual Dental Association Session, April 26-28, please email me after the call. It takes place in Lansing, MI.

Keep in mind that our next webinar is scheduled on Monday, April 2nd and we will be discussing the IPPF Awareness program with our Program Director, Kate Frantz, and Awareness Ambassador Coordinator, Bryon Scott.

Don't forget to register for the Natural History Study that we discussed on our call today. A patient registry sponsored by the National Organization for Rare Disorders (NORD) and the U.S Food and Drug Administration (FDA), register today on our website under the research tab.

Last reminder, the IPPF is still looking for Awareness Ambassadors to visit local dental offices and to help promote us on Facebook. Please click on the Awareness Ambassador link for more information.

Lastly, if you didn't get your question answered on the call today, I am really sorry. Or if you have additional questions, please email me at becky@pemphigus.org or call me at (916) 922-1298 x105 and I will be very happy to help. Thank you everyone, goodbye!