

2015 May Patient Education Call

Patient to Patient Call

Marc Yale, Hannah Heinzig, Esther Nelson, Rudy Soto, & Rebecca Van Hout

Introductions:

Marc Yale: My name is Marc I was diagnosed in 2007 with mucus membrane pemphigoid. As far as treatment is concerned I was put on high dose of steroid's initially and then I went through a regimen of quite a few of different immunosuppressants, medications including Imuran. I also did therapies such as Cytoxan, rituximab, and IVIG infusions which helped me go into remission for 3 years. Then I had a small flare and then went back into remission, and now I'm back into a flare again. I have experience with the common presentation of the disease coming and going. In addition I am a Peer Health Coach and have spoken with numerous patients about their condition and treatment. Whatever kind of questions you have for me, please don't hesitate to ask.

Hannah Heinzig: My name is Hannah Heinzig, I'm 25 years old, and I have pemphigus vulgaris. I was recently diagnosed in July of 2014. I'm still learning about my disease. I have mainly ulcerations in the mouth and some activity on my scalp. I started on prednisone right away. It cleared up almost everything except for a few mouth ulcers and some gum sensitivity. I have also tried Dapsone and I had an allergic reaction to that. At this point I am not on any medication and I am looking into starting some Rituximab and IVIG, similar to Marc.

Rebecca Van Hout: I am Rebecca Van Hout and I'm 44. In 2008 I had my first symptoms and I was really fortunate and I got diagnosed within about a month of my first symptom. I did go to the IPPF Conference right in the beginning of my first flare and I was really fortunate to get some really good advice. I was on high doses of prednisone at first. I saw Dr. Morrison and she was very helpful. I was very lucky; I did retrieve remission in 2011. Then I actually finished nursing school about the same time that I went into remission and had a baby. A lot has happened in the last couple of years. I have the occasional small flare in my mouth, especially after dental treatment. But in general I am pretty much off of all medication at this point except for occasional use of Clobetasol.

Rudy Soto: Hello my name is Rudy Soto and I am 43 years old. I am from Georgetown, Texas; a small town about 20 minutes north of Austin. I have pemphigus foliaceus. Pemphigus started in 2009. I wasn't diagnosed properly until 2010. My symptoms began in the chest and torso area, some scalp and facial area also but never in my mouth or nose. I've been on prednisone, CellCept, Imuran, Clobetasol, and shampoo for my scalp. I am currently on rituximab. Doctors say I haven't had any flare-ups. I do

occasionally get a blister or so. That is something, however, that I could use an ointment for and it'll go away within a day or two. I've been on rituximab since 2013. They did 4 treatments and I am currently doing maintenance treatments every 6 months. I have my last treatment in April of this year.

Esther Nelson: My name is Esther and I live in New York City. I have pemphigus vulgaris. I found out about it in August 2013. I got diagnosed almost 4 weeks after I found out. They sent me to a hospital by where I live in a city called North Shore. They handed me a piece of paper from Wikipedia and they said "we think you have this." It was after the skin biopsy that I got the immunofluorescence biopsy. To make a long story short after I got home I decided I need to do something immediately. I found the International Pemphigus Foundation online. I contacted them and they gave me a coach; Marc Yale is my wonderful coach. With that I got a list of doctors. My doctor is Dr. Annette Czernik, who was the leader of the conference in New York City. With her very important help and staff I am doing very well. I've had two major rounds of rituximab. I've been on prednisone since the day I was in the first hospital. I was diagnosed September 7, 2013. I was on prednisone for over a year with two rounds of rituximab, a lot of IVIG every month. I knew I was getting better because now she said now every two months and three months. I still have two more three months to go. I'm only on one pill of the immunosuppressant, instead of 4, which is CellCept. Things are going very well. I would consider that I am in remission. Some people would say "I'm almost in remission." I went back to work 4 months after this happened. I thank all the people who have given me a lot of hope and health, and that includes the Pemphigus Foundation.

Question: Hi my name is Lorainne. I was just diagnosed in the beginning of April with pemphigus vulgaris. I have it on my scalp and in my mouth. The only thing I am on is the Clobetasol steroid cream on my head in and my mouth. You know is this the beginning of it and he is hesitating on giving me anything stronger. Do you think I should go get a second opinion and maybe go to someone that is going to start me on something heavy that's actually going to help more efficiently?

Hannah: I actually tried the topical oral clobetasol. Similar to you my doctor was also hesitant. However, he did start me on higher doses of prednisone and that's what cleared me up. My scalp cleared within two weeks as well as all the ulcers in my mouth on the high doses of prednisone.

Rebecca: What I was told when I was first diagnosed was often times the systemic medication goes through your entire body as necessary to get on top of the initial outbreak. I would recommend getting a recommendation from IPPF for a specialist that

has achieved remission from patients that is in your area and then go see them. Also, your dermatologist can call and ask for a patient with one of those experts if you're comfortable with them and don't want to have a provider treating you. I find that getting that specialist involved, somebody that's really experienced can be the key of getting on top of that initial outbreak. Then later once the systemic medication is moved down the topical ointments can be more effective in clearing up those little flares but a topical by itself doesn't seem to be that effective for people.

Esther: I had great sores in my mouth on both sides. I couldn't eat normally for about a year and a quarter. My doctor put me on high levels of prednisone and two months after rituximab. 6 months later a few rounds, two times. So I really had it four times. It made a difference.

Question: My name is Susan and I am from Florida and I have MMP, same as Marc. I wanted to ask Marc, did he find that staying away from citrus foods and drinks help?

Marc: Hi Susan. Yes, there are definitely some foods you should try and stay away from. Everyone is a little different and has a different tolerance level to different foods. Citrus oranges, grapefruits, and even tomatoes contain a high concentration of citric acid. Anything like this tends to exacerbate the disease. It certainly can be an issue. I would definitely try to avoid those types of foods.

Question: When you went in remission did you completely stop taking any type of medication?

Marc: I did actually. What I did was I was on a combination of therapy: rituximab and IVIG. As soon as I started Rituxan they took me off of all the other medications. Eventually I was just off of all those medications except for the Rituxan and IVIG. After the Rituxan was complete then I stayed on IVIG for a total of 3 years on a maintenance dose. Eventually, after that I was off of all medication. First, eliminate all the disease then the medications.

Question: Hi my name is Nancy and I am from Illinois. I have pemphigus vulgaris. I still have muscle and joint pain. I was wondering if I could go to see a dermatologist. If I could take it for these aches and pains I'm getting from the withdrawal to the prednisone.

Marc: The muscle and joint pain is pretty common with the steroid use. As far as seeing a dermatologist I wouldn't be able to tell you. I think it's definitely worth talking to a dermatologist about. They certainly can provide advice. They would have an idea of whether or not to certain things. It's for sure worth getting a second opinion.

Question: My name is Mimi and I live in Virginia. I've been seeing a pretty well-known doctor and I am taking topical steroids. I'm just wondering if this will not work I will have to start on Dapsone. I was wondering what my experience with Dapsone might be like/ what might I expect?

Hannah: I took dapzone for only two weeks. For me, I actually had a negative reaction. I became very anemic and had trouble going up the stairs. I started getting red dots on my shin. I had negative side effects and the doctor said it was unusual because a lot of people have not had reactions like that.

Marc: I also took Dapsone. One of the side effects is anemia. It is recommended to check your iron level. Second, Dapsone does take about 6-8 weeks to start working.

Question: My name is Robena from Florida. I have EBA. I was diagnosed back in 2006. I am nowhere near remission. What kind of protocol should I have?

Marc: Yes, it is rare. There are a couple programs specifically one called "Debora" and it works mainly with EBA. For Rituxan there is 2 different protocols. They are similar. The first one is twice a month and the second is once a week for four weeks. As far as IVIG, pemphigus and pemphigoid is given once or twice a month. It really depends on the physician. I did it twice a month then we started spreading it out every 10 weeks or so. For Rituxan I did every week for three months then every other week for the next 3 weeks. I did 6 cycles.

Question: My name is Vicky and I am from Florida. I have pemphigus foliaceus. It started in 2007-2008. I've been on two rounds of rituximab. I have been doing it every week for the last 6 months. I don't feel it working. What have you been successful in using?

Rudy: The doses they gave me were pretty strong. 5 doses I started at. I had 1000 units my first treatment and then another treatment the next week the same. 6 months later I did 500 units. I am now doing maintenance treatment every 6 months. It's been a blister here and there that I've been able to treat. I have done 4 rounds of Rituximab.

Question: This is Lauren and I am calling for Georgia. I have had pemphigus foliaceus. I have had it for 30 years. Why do some people get IVIG with rituximab?

Marc: Sometimes physicians prefer to use IVIG because it's considered an immune modulator. It slowly does it to your immune system and puts it back in order. The combination of the rituximab and the IVIG is two-fold. The rituximab kills all the bad b

cells. The IVIG basically feeds your body with good cells and the ratio is good over bad with IVIG. This is why most people use this.

Question: I have pemphigus vulgaris. I have 4 ulcers that won't heal. I am in remission. I was diagnosed in 2008. For some reason doctors might be resistant is because rituximab can wipe out all cells all at once. The allergic reaction can be pretty severe. If you are pre-medicated you will have less of a bad reaction.

Marc: Yes! If there is a patient that does want to talk to another doctor there are many doctors with us.

Question: I have bullous pemphigoid. Is there anybody else that has that particular pemphigoid?

Rebecca: I do, however, I was put on high doses of prednisone. I think this treatment was a better option for me. It put me in remission. It took me 3 years before full remission.

Mine is on my back and scalp. Is that why they put me on methotrexate because where it is?

Rebecca: Doctors stick to what they are comfortable with and think is best for their patient. There are many different routes but if you want to try other treatments you should go talk to your doctor about it.

Question: This is Stacy and I am from New Jersey. I have pemphigus vulgaris. I am being told that Rituxan can take 3 months to work and I haven't seen any improvement yet. I have also been experiencing some slight muscle twitches. Anyone could give me any advice?

Marc: With the time of it, it could depend. I've heard it could be from 3 weeks to 3 months depending. If you email me I can explain further about everything.

Question: Hi my name is Becky and I am from Indiana. I have pemphigus vulgaris. I was diagnosed in 2013. For a year I've been taking 10 mg of prednisone and 50 mg of Imuran. That is keeping me comfortable. We talked about doing rituximab. My insurance denied it saying that it is an experimental treatment. How can I go about that getting approval? Should I even go on rituximab?

Rudy: I guess it depends on your provider. I didn't have any issues. What you may be able to do is get with the financial aid advisor. He was able to help me write a letter.

Noelle: Get familiar with them because it does make a difference.

Esther: It took about a month for me. I called my doctor and they took care of the whole thing.