

August 2015 Patient Call

Noelle Madsen: Janet Segal, as most of you know, is a pemphigus vulgaris patient. She is the founder of the IPPF. She founded it 21 years ago. I think I speak on behalf of the entire community in saying that we are very grateful for all that she has done.

Marc is a mucous membrane pemphigoid patient. He is our senior peer health coach. He talks to a lot of patients and caregivers. Marc and Janet are both really great resources and both single handedly helped many people through this Foundation.

Question 1

I have seen you mention the use of herbal medicine to reduce steroid levels? Long term side effects?

Janet: I don't know if anything has been actually tested herbal that can reduce the side effects of steroids. Try to see what works for you, what herbs. Be careful you don't take herbs that incite your pemphigus because that can happen.

Marc: Don't take any herbal remedies that will make your immune system stronger because you don't need that. You can use herbal supplements, turmeric, and anti-inflammatory herbs. Just consult your position. Don't try it alone, maybe in combination with.

Noelle: Always make sure to keep your doctor in the loop.

Janet: One person that could be very knowledgeable for you regarding your herbs and medication is your pharmacist. Sometimes the doctors just don't know.

Question 2

I just had blood work and it shows my lumfosites are low and that she has large platelet. Are you aware of anything that I can do to remove these results?

Janet: To me it seems that the medication could be causing problems with your platelet. You may want to think about changing medication. To me, you should check with your doctor. Maybe this medication is not the right one for you.

Question 3

Hi. I am 58 years old and I have had bullet pemphigoid for 3 years. I take one gram of celcept per day and it suppresses the disease so that I only get a few small spots from time to time. Is there anything I could do to lessen the chances of bullet pemphigoid to be triggered, for example, changes in health or lifestyle?

Janet: I think anything anti-inflammatory may be good. You have to test yourself and see what works for you. Natural stuff would be good. Don't do anything without finding out for sure whatever you're taking will not interrupt your healing.

Marc: We don't really know what triggers the disease. I recommend trying to find some balance in your life, addition to the medication. Stress can be a trigger. I would watch my stress level, diet and nutrition; do some sort of physical activity, and vitamin supplements. Talk to the doctor and maybe increase the dosage a little bit. If that doesn't work you should try another medication.

Question 4

My sister is 25 years old. She's been suffering from pemphigus vulgaris for the last 2 years. We have tried a couple of things like rituximab and now she is on conditional steroids. I have read an article on canada overgrowth in the intestine related to pemphigus vulgaris. Do you have any suggestions or history regarding that?

Marc: A lot of patients do get canada in their mouth, It is a side effect. It can be caused by the antibiotic or steroids. Talk to the physician about introducing an anti-fungal to try to get rid of those canada. It sounds like the rituximab is helping the pemphigus so I think I would continue to stay with that treatment to help the pemphigus. I would just result the physician.

Janet: First of all, I would check if it is yeast or canada because sometimes it can just seem like it is something but it's not. Yogurt helps if it is yeast.

Marc: Canada is a fungal affection that can be caused or aggravated by pemphigus. It typically presents itself in the mouth.

Question 5

Can you both please explain what you know about rituximab? Pros, cons? It is my next step in treatment and I would like to know more about it.

Janet: It seems like its been pretty successful in a lot of cases. Sometimes it takes more than one time. I know many people that have been successful with it. It's showing up to be a pretty good drug to help pemphigus.

Marc: I have used rituximab and have had very good success with it, as well of many other patients. I would recommend you contact one of our coaches or me and we can further talk about it.

Noelle: Rituximab used to traditionally be used as a last defense. That is not what we're seeing these days. Quite a few doctors use rituximab and see results that get patients into remission. Be sure to talk to one of our coaches.

Question 6

My name is Trisha Hill and I'm from Virginia. I was diagnosed with pemphigus vulgaris when I was 17 and I am now 40. Rituximab and all the other medications have not worked for me. The only thing that is working for me is prednisone and that's a bad drug to be on for so many years. I have been battling with thick scalp dandruff and I don't know what to do about it. My doctors usually give me fx shampoo but that's a long painful process. I was wondering if you had any ideas of what I can do. When I took rituximab I broke out really bad.

Janet: Some people when they take rituximab they get a rash. I know people who took prednisone and Benadryl for a couple days and it went away.

Marc: You can try clobisol, tea tree oil, and IBIT.

Question 7

I have mucus membrane pemphigoid. Any suggestions for gentle, low mint toothpaste for teeth?

Marc: I use the biotene toothpaste. Any one of the dry mouth toothpaste would work good. Anything that doesn't have alcohol in it works well. The more time you take and the more gentle you are the better it will be.

Question 8

Do you know anyone who has tried benlista?

Marc: I think this medication is in clinical trial right now but I haven't seen results.

Question 9

My question is about disease activity in the mouth. What are your suggestions about how to get a cleaning done? I have a lot of issues in my mouth because of pemphigus.

Marc: I think it's important to get your teeth cleaned. However, I also think you should see a physician. If you're looking for physicians that know this disease we have a whole list of them all around the world.

Janet: Dentists can clean your teeth with them being careful.

Question 10

Hi. I am Christine from Florida. I have been diagnosed with bullis pemphigoid. I have been on Imuran for 6 weeks. I am feeling very weak and have a slight cough. My doctor is lowering my dosage because of the side effects.

Janet: Imuran is not the kind of drug you can take for just a little. I took it for 5 years. It can make you tired. There are some side effects for the drug itself. Definitely you can not just be on the drug for just a couple of weeks.

Marc: I would confirm the diagnosis.

Question 11

My husband has mucus membrane pemphigoid in his airways and lungs. He is having another rituximab infusion soon. He is taking incyclofacimine infusions. Any advice for diets?

Janet: A liquid diet might be a good idea for him. Whatever he can eat that's non inflammatory.

Marc: If it's a lung and airway issue that's pretty serious. I would recommend you contact the foundation.

Question 12

I have chronic thrust. I have many mouth olsurs on my tongue. I am starting retuxin soon. Do you think it will affect it?

Janet: I don't know if those two are connected. The pemphigus and pemphigoid is independent of the retuxin.

