June 2015 Patient Call
Pemphigus & Pemphigoid in Women
Dr. Vanessa Holland, UCLA, Dermatologist

<u>Dr. Holland:</u> Pemphigus is a condition that is not very common, as you all know. When it comes to being a women and dealing with pemphigus it can be hard. The genital area rubs quite a bit. It's an area that can have much sweat and moisture. We are now finding that urethral involvement can occur. I'm happy to discuss and answer any questions.

Question: I have hoshi motis disease and pemphigoid. I am 44 years old and live in Greece. I lost my baby 2 years ago and cannot get pregnant even when trying IBF. Could this difficulty I am facing be related to the auto immune diseases I have or is there anything I could do in order to help me overcome these issues?

Dr. Holland: That is a tough question. But, first of all I am very sorry for your loss. Auto Immune disease is a very complex set of disorders. Both hoshi motis and pemphigoid are auto immune diseases. With regard to fertility I am not aware of the diseases decreasing fertility, however, I will say any auto immune disease that is poorly controlled can play into a number of different things, such as hormone and stress levels. What I would recommend is trying to just manage both to the best that you can. You can work with an optician who does specialize in fertility. I would proceed with IBF. Also, a lot of the medications for pemphigoid are not used when in pregnancy.

Question: One of the side effects of my steroid treatment is facial hair as well as thinning of the skin. Is dermaplaining a safe treatment? Are there any other options?

<u>Dr. Holland:</u> There are a lot of procedures that dermatologists will perform. I'm not familiar with that procedure but prednisone definitely can cause atrophy and thinning of the skin. The best way to avoid it is to get off the prednisone.

Question: If there is an involvement in the urethra is it painful to urinate? How do you numb the pain there?

<u>Dr. Holland:</u> Urine generally has a PH that tends to be acidic. One thing I have found is trying to dilute that urinal as you urinate. Following urination, a nice ointment would be good as to act like a barrier.

Question: What are your recommendations on the use of Imuran during pregnancy? Is CellCept safe to use during pregnancy?

<u>Dr. Holland:</u> Imuran is pregnancy category D. It is not recommended. The thing with pregnancy is there are 2 lives on the line. No CellCept either.

Question: My name is Linda and I am 65 and live in Florida. My gynecologists and dermatologists have proscribes different medications. Which is the best for a blister right inside the genital area?

<u>Dr. Holland:</u> If you're not on prednisone I would go with the higher potent steroid, clobetasol. This will be the most effective one.

Question: My name is Bonny and I am 56 years old from New York. I have sickitristual Pemphigoid on the volva. I was diagnosed in 2010. A lot of doctors didn't know what to do. I cannot have intercourse and am feeling hopeless. Any suggestions?

<u>Dr. Holland:</u> This is even less common than pemphigus. Generally when it occurs the primary area of activity is in the mouth. I would start thinking about prednisone, immune suppression, and oral medication or Rituximab. It is very unusual for this to localize to the genital area. Make sure the diagnosis is right. The thing with having sores you're open to infection because you lose the barriers. You have to make sure the doctor is swabbing the area and make sure there is no secondary infection. For the intercourse part of this the best thing you can do is use lubrication. Generally I recommend clean Vaseline.

Question: Is it typical to have a discharge for your referral involvement? When I was tested they said my PH was off and I had BV and treated me with a cream but that made my condition worse and painful. Was this simply an outbreak that was misdiagnosed?

<u>Dr. Holland:</u> This type of involvement is a hot spot. The best study had 77 patients and 50% of them had documented activity and pain and discharge. It is very possible that it is Pemphigus. I would medicate it.

Question: Is there anything different than we discussed that we need to do about lesions involved in the anal area?

<u>Dr. Holland:</u> Anal skin definitely can be involved. Infection is really important to be aware of too. People can become carriers very easily and commonly. When you do become a carrier one of the hotspot areas are the anal skin.

Question: Is it true that during the pregnancy Pemphigoid is under control but it becomes active again after delivery?

<u>Dr. Holland:</u> It depends. Pemphigoid does occur most commonly in the third trimester. They tend to get very itchy and then the blisters start. In some people the condition will be worse. Being pregnant is very stressful which will trigger for some people. There are cases where pemphigus improves during pregnancy. It depends on the person.

Question: Does PV increase the risks of urinary continents in humans?

<u>Dr. Holland:</u> Not that I know of. There are studies that there are inflammation and swelling of the blatter. If the disease is fairly active it can affect it. I have not ran into that with my patients.

Question: Is there connection with the cycle in pre menopause symptoms and disease activity?

<u>Dr. Holland:</u> Smoking decreases disease activity. It lowers the estrogen levels. In theory, yes it could potentially increase the risk.

Question: Is there any concern in regards to breast feeding and having an active disease with pemphigus or pemphigoid?

<u>Dr. Holland:</u> If the disease requires medication breast feeding would not be good.

Question: Are frequent and urgent urination both side effects of prednisone? If so are there any reductions to these side effects?

<u>Dr. Holland:</u> The blood sugar needs to be monitored. It can affect your blood sugar. Without the diabetes element it's not a major concern.

Question: What level of pemphigus activity is rituximab recommended for? How bad does it have to be?

Dr. Holland: Rituximab is probably the first drug that has changed the nature of the disease, next to prednisone. It does have side effects and fatalities. It does suppress the immune system for year timeframes. Because of the seriousness of the medication dermatologist are reluctant. I have been using it for the past 5 years and it's getting safer and safer. Because this is such a rare disease the evidence is not that great but it is looking better and better. I reserve it for moderate and severe diseases.

Question 15

Any recommendations for bi phosphonates for treating ospiperosis to avoid the possibility of irritation to the esophagus, particularly with mucous membrane dominant PV?

Vanessa: All patients need to be on calcium and vitamin D. You need to have regular routine desk scans. I try to perform them every 6 months but at least every year. There are scary side effects. I do recommend if there are any osteoporosis signs. There are injectable forms for treating ospoperosis.

Question 16

My doctor recommends a sea section and I am currently taking amino suppressants. Will this slow the healing?

Vanessa: A suppressed amine can potentially slow healings. I don't think it will be a significant flow but yes.

Question 17

I was diagnosed with pemphigoid at 35 and my main medication was and still is when there is a need for prednisone. My main concern is how likely is it to get diabetes at some point even though my weight is normal. Is there something I could do to avoid diabetes possibly?

Vanessa: Once you're off the prednisone the risk is not great but once you are on the risk can elevate your blood sugar. It's not triggering type 1 diabetes. If you're on prednisone chronically and it does look like your sugars are consistently elevating then you need to get on an oral motoric.