

## July Patient Education Call

Please note: There was an error with the recording of the beginning of the call. The beginning of the call is not available for listening. We are very sorry for any inconvenience that this may cause. All answers are provided in the opinion of Dr. Neil Korman, Dermatologist.

Question: I am a patient who has had PV for 4 years. I started on 50mg of Prednisone, and was eventually weaned completely off of it. I was completely lesion free, and now recently I have lesions all over my body. I had severe side effects on Prednisone, and would like to avoid going back on it. Is there any other medication that I can go on?

Answer: Without knowing more of your medical history, I would possibly try putting you on Prednisone with a steroid-sparing agent such as Methotrexate, Imuran, or CellCept. I may even consider treatments such as IVIG or Rituxan.

Question: I have mucous membrane pemphigoid and have had two Rituxan treatments, and I will get a few lesions here and there from time to time. My Dermatologist said not to touch this out, and that scarring could lead to Squamous Cell Carcinoma. Do you agree with this?

Answer: I don't agree. There is no evidence to support that theory. Blisters in the mouth I generally treat modestly. If it isn't largely negatively impacting your life I wouldn't worry. Topical steroids may be a good plan for you.

Question: I've heard that autoimmune diseases occur in pairs. Is this true?

Answer: There are so many old wise tales around the world, and this is one of them, in my opinion. No, this is not true. You could get another autoimmune disease, but it doesn't mean that you are going to.

Question: Is there a standard point in ones treatment that infusion therapy should be used? Or it is determined by the severity of disease activity?

Answer: There is no standard. All doctors do different things. For me, it is very patient specific. It also depends on insurance. If a patient has severe disease activity I would consider putting them on infusion therapy.

Question: I am currently on Prednisone, and am experiencing side effects such as dizziness, light-headedness, and headaches. They get worse as the day goes on. Is this a side effect from the Prednisone? Could it be a balance problem in the inner ear?

Answer: It is not likely to be a side effect from the Prednisone, or your disease. It could be a completely separate problem. I would suggest consulting your general practitioner.

Question: Could you please explain more about false positives and false negatives. I was diagnosed with pemphigus, and now am being told that I may not have it. Is there any diagnostic test that is better than others?

Answer: We like to think that we have definitive tests, but the answer is that we do testing along with examination of the patient. There is no "gold standard." It is about trusting your physician and their confidence in working with the disease.

Question: Is there any connection with pemphigus/pemphigoid and Lyme disease?

Answer: No, totally unrelated

Question: I have had quite a bit of hair loss since being on Prednisone, Dapsone, and Rituximab. I am going to get scalp injections to slow hair loss. Have you had experience with this?

Answer: Scalp injections can work quite nicely for patients. It seems to work well.

Question: Is it normal to be on Prednisone for over a year?

Answer: Yes

Question: Why is it more common that disease activity occurs in the mucous membranes rather than other areas of the epidermis?

Answer: More trauma occurs in the mucous membranes (i.e. eating food)

Question: For pemphigus patients who may be experiencing disease activity or who may not, and are thinking about getting pregnant, are they at risk of a dangerous pregnancy?

Answer: I have had pemphigus and pemphigoid patients who have gotten pregnant, and they have done just fine. The one thing that I do sometimes see is that around the time of delivery the mom can experience a breakout. The babies do generally just fine. If the mom has some active disease at the time of delivery sometimes the baby can be born with blisters because the mother passes down her immunoglobulins. Then it usually goes away. I've never actually seen this happen, however. It is very rare.

Question: Is it normal that the side effects of medication get worse as the day goes on?

Answer: No, there is no evidence of that.

Question: I have Pemphigus Vulgaris. How long until I will go into remission?

Answer: Unfortunately, there is no answer for that. It is very patient specific.

Question: How much research is being done on this disease?

Answer: Yes, a lot of research is currently being done. Lots of things to be very hopeful about for patients.