

## **October Patient Education Call** Panelists:

IPPF Founder, Janet Segall & Peer Health Coach, Marc Yale

Question: I was wondering about loose skin in my cheeks, is that normal?

Answer: It may just be allergies, or probably a regular symptom of pemphigus/pemphigoid.

Question: I'm going in and out of remission and whenever I come out of remission they put me on prednisone, but I feel like it's just causing problems. Recently I've started breaking out with lesions and treating it topically. Should I try to get stronger medications or keep treating it topically?

Answer: You can continue treating it topically, but if it keeps coming back and you're not going into remission you should have a talk with your doctor. There are many drugs to use and you don't have to use steroids

Question: (I have PV) Are there ways I can jumpstart my immune system to prevent future flare ups and start a longer remission?

Answer: I would suggest asking your doctor about stronger drugs such as CellCept, or Imuran. These are strong treatments, but this is a strong disease. You don't want to try to jumpstart your immune system too much because this is an autoimmune disease so the stronger your immune system the more reactive the disease will be.

Question: My doctor suggested that I go to a clinic, but I've heard that there is no cure for pemphigus, so how would I benefit from going?

Answer: Well there may be no cure for pemphigus, but there are treatments, and you can go into remission after using these treatments.

Question: I have some pinhead sized bumps on my arm what do you think it may be? I've just started taking two different prescriptions at the same time?

Answer: It may just be an allergic reaction or a side effect. You should talk to your doctor about stopping one of the medications to see if it's an allergic reaction or a side effect.

Question: Is there anything you can do to replace teeth? I haven't been treated by a doctor yet; I've only talked to dentists.

Answer: We have some dental physicians that can help you, but you should try to get the

disease under control before you get any implants.

Question: I have a lot of hair loss and I was wondering if that's a normal symptom or is it something else?

Answer: Well if you have lesions on your head and are prescribed prednisone you are most likely going to lose some hair. Some autoimmune diseases can trigger others so there may be a possibility that you may have a disease that when your hair falls out and doesn't grow back. You should have your doctor test to see if it is another autoimmune disease or if it is just part of the disease/treatment side effect.

Question: If a patient is given a prescription of prednisone what would be the typical dosage and duration of the prescription before the pemphigus would go into remission?

Answer: It depends on the individual and how serious the disease is.

Question: How do you know when you're in remission?

Answer: You would know when there is no disease activity, and you're off all treatments, however some doctors are classifying a partial remission when you have few to no lesions and less drugs.

Question: I am using Prednisone 1 mg a day is there anything that can replace this?

Answer: Well 1 milligram a day is a very minimal amount, so that is probably just keeping away any new blisters.