Question and Answer Session

Question: Why is it so difficult to be weaned off of Prednisone?

Answer: Your body naturally makes 5-10 mg of corticosteroids every day. When you start to take Prednisone your body stops making it naturally. In order for your body to start making corticosteroids again you have to wean off of it, so that your body can readjust itself.

Question: As I wean off of the Prednisone I start to get really bad mouth sores again. Why is this happening?

Answer: You should consult your doctor about tapering off of the prednisone more slowly. If you taper off too soon you can experience a flare. Most doctors tend to taper by mg, but it can be helpful to look at tapering by percentage. If you can figure out with your doctor a certain percentage (i.e. 20%) make sure to taper off at that percentage each time. It can be easier on the body.

Question: During the tapering off process of Prednisone, what do you consider a flare up? How large should they be? How long should they last?

Answer: Every time you taper down off Prednisone your body has to readjust to the amount of corticosteroids that your body needs to make. The body's response to the taper down process is usually inflammation. If the inflammation occurs for more than 7-10 days you could be experiencing a flare up. Then you should discuss with your doctor whether you should increase the dosage on Prednisone, or what action should occur now. A flare is a significant amount of new disease activity. New blistering activity where there wasn't activity before. Also, make sure to discuss in depth with your doctor what they consider to be a flare. If you experience 1 or 2 lesions you may want to talk to your doctor about taking clobetasol.

Question: I was given a Rituximab treatment about 8 weeks ago. I haven't experienced any difference in my pemphigus vulgaris. Has anyone had experience with Rituximab?

Answer: Everyone is different. For most people it can take 3-6 weeks to see any results. we suggest that you talk to your doctor about checking your B-cell level. Your doctor can perform a blood test called an amino panel, where they can test your B-cell count, and then they can determine whether you may need another round of Rituximab. Sometimes you need multiple cycles of Rituximab. Keep a journal of your activity level, so that you can really see if you are getting better. Sometimes you may see a slower progress instead of complete remission. After a cycle you may just see that the amount of blisters has decreased, and the duration of the blisters might not last as long. Just keep in mind you may need multiple infusions of Rituximab.

Question: Are there any foods that I need to stay away from with this disease?

Answer: What foods may affect one patient may affect another patient completely differently. We recommend that you keep a food journal. Keep track of the foods you eat and your activity level. As time goes on and you experience lesions you may be able to attribute them to occurring when you eat certain foods. Some foods that trigger a lesion in a patient may not affect another patient at all. Our physiological make-up is all different.

Question: I have mucous membrane pemphigoid. I am starting to see issues in my nose and throat. Should I see a different specialist for this?

Answer: It is possible that you could be having activity in those areas. I would recommend that you talk to your current doctor to see if they can recommend an ENT.

Question: When the blisters first started occurring in my mouth the blister would form, harden, and then fall off. Is this normal with this disease?

Answer: This is very common. Particularly with pemphigoid, the blisters tend to form scarring tissue, and then fall off. Then a blister can form over that scar tissue, and then that scar tissue tends to build up. That is a big difference between pemphigus and pemphigoid. Scar tissue can be very troublesome, and cause a lot of issues. This is why getting the disease under control sooner is better.

Question: I have been on and off prednisone for a few years. My doctor now wants to try me on Imuran. Has anyone had any experience with Imuran?

Answer: It can take 4-6 weeks for Imuran to take effect. Imuran can make you a little tired and/or a bit nauseous. You can take it at different times of the day depending on your side effects. Just make sure to consult your doctor about that. Also, make sure to keep up with your blood tests while on Imuran to make sure everything looks okay.

Question: When I was first diagnosed with bullous pemphigoid I began to lose vision in my left eye. I still haven't regained vision. Is there anything specific about this disease that makes it go towards the eyes?

Answer: Pemphigoid can affect the eyes. We recommend seeing an eye specialist.

Question: I had inflammation in my sinuses, so I was put on Vera mist. Has anyone experienced using this product?

Answered: Inflammation in the nose is common, so nasal mists can often be prescribed. It works like a topical treatment. It will help, but other treatments are going to be what ultimately helps you. The nasal sprays can take the pain away though. The other thing that we would recommend is a nasal saline rinse. You want to either go to the store to buy the saline rinse, or you can make your own at home by mixing 1 tablespoon of salt, 1 tablespoon of baking soda, and 8oz of warm water. Then put it into a nasal bowl. This eliminates any of the mucous and bacteria, so it gives the lesions an opportunity to heal. If you are going to make your own saline solution at home make sure to boil the water for about 5 minutes to make sure that you have killed off all bacteria. Then of course let it cool to room temperature before administering it.

Question: I have pemphigus vulgaris, and I have sought advice from a natural medicine doctor. What is your opinion of a natural medicine with this disease?

Answer: You have to be very careful with natural medicine, because some of it can enhance your immune system. You have to be careful about enhancing your immune system. For example, echinacea can actually stimulate pemphigus. Just make sure that they aren't going to interrupt the current medications that you are on, and that they won't enhance the immune system. The whole idea is to suppress it, and to normalize it. Probiotics are great though, omega 3 is great, so things that can help stabilize your body are great.

Question: Does pemphigus vulgaris eventually go into remission? Do you have to take medication for the rest of your life?

Answer: You can go into remission. You may still experience minor lesions here and there. It is possible to go off completely of all medications.

Question: My mom has pemphigus, and needs to have open heart surgery. How many days before surgery should she go off of her medication? How long can they be off of the medication while recovering from a major surgery?

Answer: You can have surgery and be on immunosuppressants. There may some medications that you have to go off. Doctors may want her on prednisone.

Question: I was diagnosed with pemphigus vulgaris 2 months ago. I am on 80 mg of prednisone every day, and it doesn't seem to be working. My doctors want to put me on Rituxan next month if I don't improve. Is that too soon?

Answer: Dr. Anhalt says that it is better and safer to go on Rituxan first before using a lot of different medications. You should consult your doctor with that first. You should maintain stability with whatever you are on first before you switch medications.

Question: I have a raspy throat and soreness on my gums, and that soreness seems to move around my mouth. In my upper gums there is an elastic particle. Is that the pemphigoid?

Answer: There is a corticosteroid swish that may help your pain in your mouth. There also is a clobetasol gel that can help for gum pain. Also, we recommend not using a straw. The sucking motion that you use when using a straw can cause pain.

Question: What are titers?

Answer: It is the level of antibodies in your system. Your titer level will not always correlate with the activity of your pemphigus. For example, if your titer level is low you may be experiencing activity, and if your titer level is high you may not be experiencing any disease activity. You should focus more on your disease activity then necessarily focusing on your titer level.

Question: What advice do you have to give to people when they ask about the disease?

Answer:

- Tell people that it is a rare auto immune disease, it is a challenge, and that it is not contagious.
- Look at it as an opportunity to educate others.
- Try not to get too personal or emotional when telling people about it, unless you know them well.
- Stay positive about it
- Know your audience
- I tell people that, “My body is confused, and that the glue in my skin isn’t holding well.
- Deal with it with a sense of humor.