

JDPA

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SDPA NEWS AND CURRENT AFFAIRS

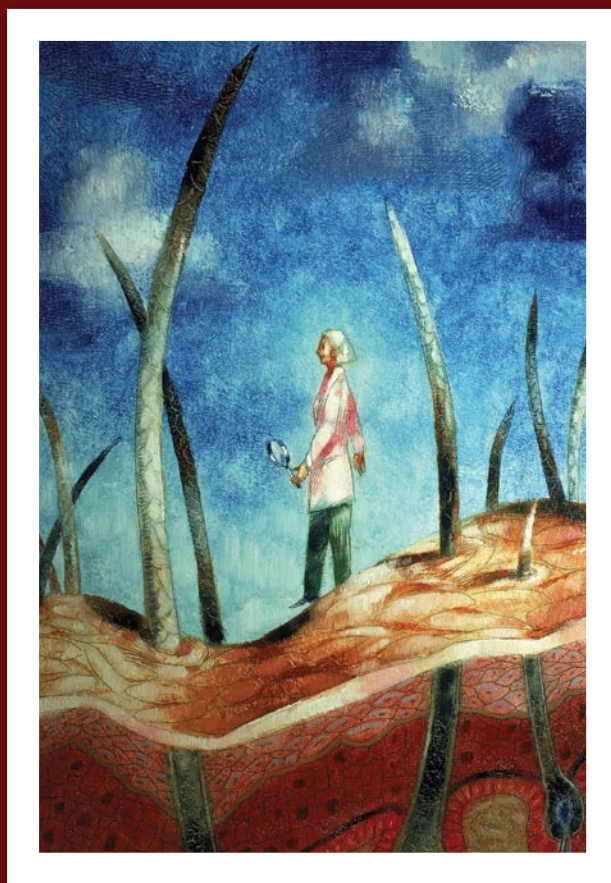
DERMATOLOGY PA NEWS AND NOTES

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JDPA

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FROM THE PATIENT'S PERSPECTIVE

My Roller Coaster Ride with Pemphigus

By Miki Pangburn

My pemphigus symptoms began in February. I awoke to find a mouthful of painful ulcers and swishing warm salt water made it worse. My primary care physician (PCP) said I had a yeast infection and he prescribed an oral rinse. Weeks later I was still eating Jell-O and mashed potatoes. My provider suggested that we let it run its course, but still continue to use the oral rinse along with a tapered dose of prednisone. Around May, he said it was a 'viral/fungal' infection. I thought that he meant that fungus, as in mold and mildew, was in my mouth. The ulcers in my mouth never completely healed. They would diminish but were replaced with torn skin. It felt as if I had corn cob pieces floating around in my mouth. My gums were inflamed and raw, and brushing my teeth hurt so badly that I wanted to squeal like a pig in mud!

Eight months later there was still no solution in sight. My hair was beginning to thin and fall out and other areas of my scalp were becoming very tender. I had developed what appeared to be a horn (nickel sized and sort of squishy) growing out of my scalp. My mother always said I was a 'bambino di diavolo' (devil child). In a brief moment I could almost hear her voice saying that from the other side; I was losing it! My PCP said this was a cyst and poured what felt like an acid on it. He insisted that I use this treatment for about a week until it cleared up. My toes would curl with the painful treatments and I decided that I was not going to do it. I would rather walk barefoot across hot coals.

Almost a year into this ordeal, the cuticles on both my hands and feet had erupted with tiny blisters that were red, swollen, itchy, and oozing. I had to change bandages daily, even at work (I should have purchased stock in Johnson & Johnson). My PCP continued to pursue the 'viral/fungal' infection by prescribing yet another course of tapered prednisone. All this time, my mouth and scalp had not completely healed and now my hands and feet were erupting. When bathing, it was like having a mixture of shards of glass and hot lava beating against my skin.

A year and three months into my ordeal, during yet another visit to my PCP, I had 'roid rage' (those of you who have taken steroids may know what I mean). While taking prednisone I experienced maddening mood

swings that could slip out at any time. During this visit I said some very choice words to him and he finally agreed to do a biopsy of the putrid ooze. This initial biopsy unfortunately came back as 'undetermined.' The following month, a small pea sized blister developed on my calf overnight and had become the size of a bottle cap by lunchtime. I felt as though I had bubble wrap growing out of my leg. My PCP immediately sent me to a dermatologist who did a biopsy of the blister.

"I have had to give up my 'normal' life, but it hasn't stopped me from getting a new one."

Almost a year and a half into trying to figure out what was happening to me, the dermatologist calmly stated that I have pemphigus vulgaris, an autoimmune disease characterized by large blisters on the skin and mucous membranes that are often accompanied by itching or burning sensations. To me, pemphigus vulgaris sounded

like 'supercalifragilisticexpialidocious.' An image of Mary Poppins with her umbrella came into my head. It did not roll off my tongue, and words are supposed to do that. I carried a piece of paper around for about a week until I could actually pronounce the diagnosis.

Prednisone and Dapsone were the recommended course of treatment. I had gained about 100 pounds while taking prednisone over the last year and a half and the dermatologist wanted me to take more at even higher doses. Physically I looked like a moon-faced bloated whale and I cried a lot. I had also experienced dizziness, nausea, double vision, swelling, steroid induced glaucoma, and mood swings. My PCP had put me on medications to counterbalance the side effects of the prednisone, which helped a little. I kept questioning my doctor about this disease and the course of treatment and then I was told that the office was no longer accepting my insurance.

It was the beginning of my second year dealing with this condition when I started seeing a new dermatologist. I did not like this provider from the beginning. He would stand at such a distance from me and would not touch me, acting as though what I had was contagious. It would be wonderful if providers who are not familiar with a condition would either research the disease or help the patient find another provider who could help them!

I conducted an Internet search and found the International Pemphigus & Pemphigoid Foundation (IPPF) at www.pemphigus.org. I was finally able to

FROM THE PATIENT'S PERSPECTIVE

connect with a community of pemphigus patients through an email discussion group. There were others out there like me going through what I was. This was the beginning of a new life for me. Talking with people within the IPPF was a lifesaver. They understood the importance of me needing to ask questions and share my experiences with them. My coworkers were so concerned that I had AIDS that they went to the human resource manager of the company and requested to be moved away from me. At work I was dealing with people putting latex gloves on my desk along with Lysol, coworkers whispering, and being excluded in meetings. I did have a few rages, but locked myself in my office during these outbursts.

Fortunately through the IPPF I was referred to Dr. Grant Anhalt at Johns Hopkins in Baltimore, MD. Dr. Anhalt is an expert in pemphigus and a member of the IPPF Medical Advisory Board. My husband drove me to see Dr. Anhalt. I had a legal pad filled with questions both front and back. Dr. Anhalt spent almost two hours with me. He spoke in medical terminology that gave me the 'deer in headlights' stare. Realizing this, he began to draw me pictures. Pictures! I can do pictures, my brain understands those! I love this man! Ok, but I did not like all the answers. He recommended high doses of prednisone and cellcept to get my pemphigus under control. I felt as though I was preparing to be on another prednisone roller coaster ride.

So this was my life now. My body was physically exhausted, I was in pain and limp, and I felt like I was a marionette puppet. During another visit Dr. Anhalt examined me and said that I was having an allergic reaction to cellcept (which I had been taking now for three years) and that I was only the second person he ever knew of to have a crippling reaction to it. Lucky me! The next course of treatment involved imuran and prednisone. For about a year, it felt as if all my body wanted to do was sleep.

I am now more informed and aware of my condition than ever before. I now understand that if you have an autoimmune condition there is a chance that you can develop other autoimmune conditions. When I go to a new provider, I tell them during my first visit about my pemphigus history and cycles of flare-ups. If I am uncomfortable with the response or lack thereof, I will search for another provider. I have had to give up my 'normal' life, but it hasn't stopped me from getting a new one. I have learned to listen to my body and, more importantly, my team of providers listens to it as well. I have stayed involved with the IPPF because they are my family, my spine, my venting place. I have lost some prednisone weight and I have learned to live like a bloated whale. I now have the attitude that I am me, take it or leave it. I usually run on four hours of sleep. Pain often wakes me up, but instead of popping more pills I go grocery shopping, clean, read, or do whatever I can.

I have grandchildren now and enjoy them as much as possible. I enjoy making pictures with them out of the clouds in the sky. When they pick me flowers (dandelions), I put them in a vase on my table and when they leave I throw them out because they make me sneeze. I have a tight group of close friends outside the IPPF who truly understand me. They don't call attention to me when I have full-blown conversations with myself, they just chime in with their two cents. My husband and I have been married now for twenty-eight years and he has been through it all with me. This is my life and despite all of it, I would not change a thing. 🍷

Miki Pangburn lives in York, PA and has lived with pemphigus vulgaris for ten years. She is happily married and has two children and two wonderful grandchildren. Her pemphigus flares about three times a year and is currently treated with imuran and prednisone. She enjoys reading, cooking, sewing, and riding a Harley when she is feeling well. Miki worked until 2004 and then was placed on disability because of her pemphigus and complications relating to it. Regarding her life with pemphigus, Miki says, "I have good days, bad days, some in between and need to nap. I laugh at myself, at stupid stuff, and laugh even harder when people think I'm crazy. I have fun with me."

TAKE HOME POINTS for DERM PAs:

By Steven K. Shama, MD, MPH

- It was over a year of suffering before our patient was referred to a dermatology practice. We need to educate general medical practitioners that we are available to diagnose and treat disorders of the skin, hair, nails, and most mucous membranes. We need to encourage them to call us if they have a question. Perhaps if this were the standard, our patient would have been referred soon after her first oral symptoms.
- The example of the second dermatology provider standing at a distance and "would not touch me" should remind us all of the importance and power of touch. Physical touch is only one way of touching. One can "touch" a patient with the words we use and also with eye contact, to name two.
- When we see and treat patients with difficult diseases we need to make sure that we personally have the expertise. If we do not, a referral is imperative. Ironically, it was the support group of pemphigus patients who actually gave our patient the name of the dermatology specialist Dr. Anhalt. What patients need when they have a serious skin disease is a support group who is "my family, my spine, my venting place." How often can patients use those qualities to describe us? I wish it were more often.

Dermatology Physician Assistants



Physician Assistants (PAs) in dermatology play a number of varied and vital roles.

PAs are medical providers licensed to practice medicine with physician supervision. From patient care and education, to skin surgery, treatment of chronic skin conditions, and cosmetic procedures, PAs are dynamic members of the healthcare team. PAs practice in every medical and surgical specialty and have been collaborating with dermatologists for 30 years, providing a wide variety of services. These include diagnosing, prescribing medications, ordering and interpreting lab tests, wound suturing, and medical or surgical treatment of a wide variety of clinical diseases. As with all PAs, dermatology PAs are legally and ethically bound to practice only under physician supervision.

PAs are trained in intensive, accredited education programs.

Because of the close working relationship that PAs have with physicians, PAs are educated in the medical model designed to mirror and complement physician training. PAs take a national certification examination and to maintain their certification, they must complete 100 hours of continuing medical education every two years and take a recertification exam every six years. Graduation from an accredited PA program and passage of the national certifying exam are required for state licensure.

How a PA practices dermatology varies with training, experience, and state law. In addition, the scope of the PA's responsibilities corresponds to the supervising physician's scope of practice. In general, a PA will see many of the same types of patients as the physician. Referral to the physician, or close consultation between the PA and physician, is based on the dynamic relationship between the physician and PA.

The Society of Dermatology Physician Assistants (SDPA) is a non-profit professional organization, composed of members who provide dermatologic care or have an interest in the medical specialty of dermatology. Fellow members provide medical services under the supervision of a board certified dermatologist.

More information can be found at www.dermpa.org and www.aapa.org.

