

JDPA

Journal of Dermatology for Physician Assistants



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KEEP CURRENT:



JDPDA.org

JDPDA/Journal of Dermatology for Physician Assistants (ISSN 1938-9574) is published quarterly (4 issues per volume, one volume per year) by Physician Assistant Communications, LLC, P.O. Box 416, Manlius NY 13104-0416. Volume 7, Number 2, Spring 2013. One year subscription rates: \$40 in the United States and Possessions. Single copies (prepaid only): \$10 in the United States (Include \$6.50 per order plus \$2 per additional copy for US postage and handling). Periodicals postage rate paid at New York, NY 10001 and additional mailing offices.

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POSTMASTER: Send address changes to Society of Dermatology Physician Assistants, Inc., 4111 W. Alameda Ave. Suite 412, Burbank, CA 91505, 1-800-380-3992, email SDPA@dermpa.org, www.dermpa.org.

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FROM THE PATIENT'S PERSPECTIVE

If Only I Had Listened

By Sharon Swanger

Forty years ago (I'm 59 now) having a tan was an absolute necessary "fashion accessory." Unfortunately, I have blonde hair, light green eyes, and very fair skin. I simply didn't tan. I burned. My mother was always lecturing me that spending too much time in the sun was bad for me. So, much to my mother's dismay, from the time I was fifteen years old my mission every summer was to get as tan as possible. Sunblock wasn't a concept back then, so I used suntan lotion or at times, even worse, baby oil with iodine. I found the most effective time to lay out was between 10:00AM - 2:00PM. Of course, I had to get an even tan, so I would set a timer and "flip" every hour on the hour. I did this every single day in the summer that I could when I wasn't working.

Fast forward to the fall of 2002. I had a suspicious mole removed from the back of my left shoulder. Thankfully, the dermatologist was "certain" that he got it all. I was fine, the "horse hadn't left the barn," and I was told it was a very good prognosis. All remained well until July of 2008. I began to develop a dry, unproductive cough that I just couldn't seem to get rid of. Then on July 30th, 2008 (funny how there are some dates you just never forget), I ended up in the emergency room because I couldn't stop coughing, and my chest had become very tight. I thought I might be having a heart attack and didn't want to take any chances. After about five hours in the ER and a multitude of scans and tests, the ER doctor on duty told me that I had cancer - tumors in my brain, lungs, uterus, and an especially large one that was growing and pressing against my windpipe, which was causing the cough.

I was admitted immediately into the Milton S. Hershey Medical Center (about 5 minutes from my house). Based on my past history of the melanoma that had been removed, they were guessing that the spots they were now seeing were metastatic melanoma. It turned out they were right, and my world began to come crashing down on me. Gratefully, the doctors at the hospital acted very quickly. Within a day of my discharge, the brain oncologist called me personally and asked me if I could come in the next day; he wanted to meet with me. The oncologist specializing in melanoma was on vacation, and the brain oncologist wanted to address the brain "mets" ASAP so that my treatments with the melanoma oncologist could start as quickly as possible upon his return. I met with Dr. Wagner who discussed my

options and suggested that they perform Gamma Knife surgery to "knock out" the spot on my brain. I agreed, and within just a few days I found myself having a metal "halo" screwed into my skull (a device used to calibrate the radiation rays and make sure that as little brain tissue as possible is damaged, focusing the treatment on the cancer metastasis).

Next stop was to meet with my melanoma oncologist, Dr. Drabich, who was back from vacation. The first time I met with him I forbade him to give me a prognosis (I knew it was grim from all that I had read). I told him that all

"I forbade him to give me a prognosis... I told him that all I needed to know was what we were going to do next to move forward."

I needed to know was what we were going to do next to move forward. My daughter was a senior in high school and my son a junior in college. Nope. Don't have time for this. Let's get moving and I want the most "kick-ass" treatment you have. He smiled and said he had one for me called Interleukin

2 (IL-2), a biotherapy that is very effective on a small number of patients (less than 6%), but works well on those patients who respond favorably to it. He explained that I would have to have both heart and lung screenings before attempting the treatment because it is "pretty rough." (That was the biggest understatement I think I've ever heard). I "passed" both tests and was approved for treatment. However, before I started, I did go for a second opinion at Johns Hopkins Hospital. I met with Dr. Scharfman, who is a recognized expert in the treatment of metastatic melanoma. He examined me, looked at all of my scans and test results, and



The mission of AIM at Melanoma is to increase support for melanoma research; to promote prevention and education among the general public and medical professionals; and to provide comprehensive and easily accessible melanoma resources for patients, survivors, and caregivers.

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3217 Bob O Link Court, Plano, TX 75093

Patient support: nurseoncall@aimatmelanoma.org
877-AIM-2ME

Patients and caregivers can call or e-mail for answers about early detection, diagnosis, treatment, and follow-up.

FROM THE PATIENT'S PERSPECTIVE

agreed with the treatment plan that had been laid out by Dr. Drabich at the Hershey Medical Center. Since I lived so close to the hospital in Hershey, I elected to get the treatment done there.

IL-2 is such a toxic treatment that it is administered inpatient. At the time (and now I'm finding that they are "tweaking" the protocol in some clinical trials, so the treatment delivery varies, to some degree these days), the plan was for me to be admitted to the hospital and "offered" fourteen treatments (one every eight hours) each hospitalization. The times they "offered" the treatments were 7:00AM, 3:00PM, and 11:00PM. I was monitored around the clock for blood pressure, heart rate, and blood oxygen levels. Assuming everything looked ok, I would be "offered" another treatment. I knew that my best chance was to get as much of this stuff in my system as possible, so I never refused a treatment. The ones I missed were because my vital signs were questionable, and the physician monitoring this process would pass until the next treatment time. The nurses told me they considered seven treatments out of fourteen a success. As I recall, the first week I was able to tolerate twelve of fourteen sessions. IL-2 is not chemotherapy or radiation but a biotherapy which is designed to "ramp up" the patient's immune system to attack the cancer cells. Unfortunately, the patient feels as though it's the worse flu they've ever had. Your body is wracked with tremors (for me, lasting about a half an hour after treatment, with unbelievable chills and sweats). About the only thing that gave me relief was a shot of Demerol administered at exactly the right time.

So, the plan was to have one week in the hospital, one week off, and then back in to do it all again. I would wait two weeks and then have scans to determine if I was responding. Side effects after being discharged from the hospital (for me) were a water weight gain of about thirty pounds, bloating, itchy skin, and very sore joints. After I completed the first successful round of IL-2, I started my second. During the second round, I was only able to tolerate eight treatments the first week. After seven treatments during the second week, I developed a very serious infection in my port. That was it. I was done with IL-2. They removed the port, and I was sent home - sick, stiff, sore, and feeling that I had failed. Scans showed that the tumors were still shrinking, and I was definitely moving in the right direction. My melanoma oncologist then put me on an oral chemotherapy drug called Temodar. I had regular three-month checkups and scans that showed both no new evidence of disease and the tumors continuing to shrink.

One bump in the road was that the spot on my brain had reappeared. In retrospect, knowing that IL-2 causes swelling, doctors believed that the effects of the IL-2 caused the "dead tissue" left by the Gamma Knife surgery to swell and grow. The spot began to cause problems with

my judgment, memory, and depth perception. I had to stop driving. They tried a second Gamma Knife surgery to address this issue, but it didn't help. The spot continued to increase in size and cause problems. The good news was that there wasn't anything new showing up, just the same stubborn area. It was decided that I would have brain surgery to remove the spot. Around July of 2009, I had the brain surgery to remove what turned out to be "dead tissue" with no signs of cancer at all.

Recovery from the brain surgery took me about three months, but brain scans (I have them every two years) look good with no evidence of disease or further problems. Since that time, the only treatments I have had are regular six month scans and appointments with my melanoma oncologist, and two year follow-ups with the brain oncologist. July of this year will mark five years since my diagnosis! After my next scan, my oncologist has stated that he will most likely put me on a one year schedule. He even hinted at the using the word cure. I've since read that patients with my diagnosis generally have a less than 10% chance of living five years. I've learned not to focus on these numbers.

Now, about the tanning bed issue. When I was diagnosed, I retired so that I could battle my disease. As a result, I had a lot of free time on my hands and began reading quite a bit. I soon learned that young people (especially young women) were being diagnosed with advanced stage melanoma in "epidemic proportions." Why? From what I've learned, one reason is because of the increased use of tanning beds by our teens. I will admit that I have never set foot in a tanning bed. I abused my skin the free and old-fashioned way - laying out unprotected in the sun. However, my point is MELANOMA IS MELANOMA. The consequences are the same, no matter how you get the disease. This prompted a discussion with my sister-in-law, Pennsylvania House Representative RoseMarie Swanger. We talked about the status of tanning bed regulations (or lack thereof) in the state of PA. RoseMarie witnessed firsthand the horrors of the treatment associated with this disease and, as she learned more about the dangers that tanning beds pose especially to young people, she became determined to do something about it. She considers herself a public servant, sworn to protect the health and safety of the citizens of PA. In proposing her legislation, she has endured criticism from those factions who consider this type of legislation "inconsequential," infringing on the rights of parents to make their own decisions for their children, and of course, doing harm to small business owners (many of them women) in the state of PA. It hasn't been easy. I'm proud to tell you that on Monday, April 8th, 2013 she held a press conference to announce the introduction of HB 977 that will protect our teens in the state of PA from using tanning beds. She could cave to the criticism and walk

away. However, now that she knows what she knows, she simply can't walk away.

Sadly, in researching and learning about this issue, we've "met" too many parents who simply didn't know and/or understand the dangers posed by tanning beds. In fact, one of the voices that was heard on Monday at the press conference was that of Doreen Nortum-Buckel who lost her beautiful daughter Jen to tanning bed use. It was a needless death. Doreen promised Jen before she passed away that she would do everything possible to get the word out about the dangers of tanning bed use and better yet, support efforts to keep kids from using indoor tanning in the same manner that we don't allow them to make the decision to smoke before they're eighteen. There simply is no difference. The results of teen tanning and teen smoking are the same - illness, suffering, unnecessary medical expenses, and worst of all, in many instances, death.

And, I haven't even mentioned the cost. I checked with my insurance company a couple of years ago to find out how much they had paid out in treatment costs for me. About three years ago my treatment cost was up to \$860,000. I'm

guessing that by now I am a million dollar woman. Why? Because I didn't listen to my mother who knew better. More than likely, this could have been avoided; it didn't have to be. If only I had listened. 🙏



Sharon Swanger is retired after twenty-eight years of working with the Social Security Administration. She lives in Hershey, PA with her best friend, husband, and caregiver, Michael, with whom she will celebrate their 30th wedding anniversary this year. She and Michael

have two children, Philip age 25 and Sara age 21. Since her retirement, she has been working to help her sister-in-law RoseMarie Swanger push to get legislation passed in PA that would protect teens under the age of 18 from using tanning beds. She also serves as a "Voices of Hope" speaker for the American Cancer Society. In her spare time, she enjoys traveling and walking dogs for the Harrisburg Area Humane Society.

Take Home Points for Derm PAs:

By Steven K. Shama, MD, MPH

1. When you are dealing with a teenager, be aware of how you word your message. Sharon lets us know that her mother told her, "spending too much time in the sun was bad for me" so her "mission every summer was to get as tan as possible." While it is difficult to know exactly how to express your message about the dangers of tanning, let your young patients know that you understand why they may want to look more tan, that there is much information to suggest that the sun is not necessarily their friend, and that there are ways of tanning (e.g., using skin cream applied dihydroxyacetone products) that are not known to be harmful to the skin. Look for a buy-in, by asking, "Would you try this approach for me and let me know how it is working?"
2. It is difficult to know how a patient's positive attitude helps in terms of long-term survival but it would appear that Sharon certainly had a very positive one from the very beginning of being diagnosed with melanoma. She lets us know that she is the captain of her team by sharing

that she is meeting with "my" oncologist. She forbid her oncologist to "give me a prognosis... all I needed to know was what we were going to do next to move forward... Let's get moving and I want the most 'kick-ass' treatment you have." Can we help shape the energy a patient brings to the first meeting and direct it in a way that supports realistic hope?

3. I have written about this before in a previous piece about hope in the JDPA. Sharon states that she has learned not to focus on the numbers, given patients with her diagnosis generally have a less than 10% chance of surviving five years. May I suggest that you leave it up to your patients to decide whether they will focus on the 10% chance of surviving, or the 90% likelihood of dying in five years. While you can suggest the 10% survival numbers may be a positive way of looking at the future, our patients are the only ones who can define hope for themselves and can work with you on treatment options. It is only fair.

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.

