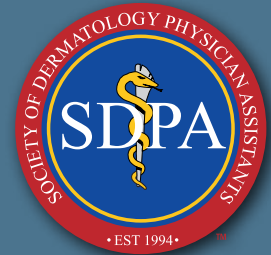


JDPA

Journal of Dermatology for Physician Assistants



DERMATOLOGY PA NEWS & NOTES

Certification Review 13

CLINICAL DERMATOLOGY

Clinical Snapshots 27

SURGICAL DERMATOLOGY

Surgical Wisdom 32

COSMETIC DERMATOLOGY

Journal Club 34

PROFESSIONAL DEVELOPMENT

Workplace Excellence 48



»» From The Patient's Perspective

A Tiny Part of Who I Am 23
By Vanessa Jennings

SUPPLEMENT
The Foundation for Ichthyosis
& Related Skin Types, Inc.
(FIRST)



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FROM THE PATIENT'S PERSPECTIVE

A Tiny Part of Who I Am

By Vanessa Jennings

My name is Vanessa. I was born with lamellar ichthyosis fifty-six years ago in Brooklyn, New York. When I was born, there was a gelatinous sac around me, which some cultures call a veil (also known as a collodion membrane). When the sac was broken and removed, the hospital staff saw that my skin was scaly and I was transferred to the intensive care unit. Eventually my parents were allowed to bring me home, although at that time there were no effective treatments for the condition. They managed the best they could, worked hard, and sacrificed to give my brother and me a parochial school education.



My earliest recollection of being “different” was when I was about five years old. People would point, laugh, or whisper to their companion(s) while staring at me. Once, while standing at a bus stop, a woman asked my mother if my condition was contagious and then she and her children moved away from us. We lived in public housing for about fifteen years and the children there could be very cruel

with their teasing and ostracizing. I got into a lot of fights! Although I was very self-conscious, I was not always timid. The desire to have positive attention made me a vociferous and gregarious (albeit moody) young person. In retrospect, my self-esteem was low and this led to some negative life experiences.

I attended college and my experiences there with co-eds were much more positive than in grade and high school. Eventually I married and had a daughter (who has a bit of eczema, but skin that is otherwise “normal”). The marriage did not last, but my daughter is, quite honestly, my best friend. Mistakenly believing that I was never going to be in a healthy relationship due to my skin condition was the basis for many disastrous (romantic and otherwise) relationships.

One of the psychological and emotional aspects of being seen as an outsider is that of self-loathing. When I made the decision to love myself more than anyone else

ever could, my entire life changed. Eventually at the age of fifty, I decided to attend graduate school and there I met many people who accepted me for who I am. That’s when I decided to totally accept myself for who I am as well! This change in attitude was an important step in my personal growth and has greatly diminished (but not erased) my self-consciousness. Getting my Master’s degree afforded me the opportunity to work part-time in a teaching position, which has given me a lot of personal and professional satisfaction.

“On the outside we may have skin of different colors or textures, but on the inside we are all people with feelings, dreams, desires, and hopes trying to reach our fullest potential.”

When I finally was able to relax about my condition and have more pride in myself, I met a wonderful man, fell in love, and moved to his state in order to be with him. He’s an incredible partner who cares for me. One way he demonstrates it is by helping me manage my skin disorder. He makes thoughtful and encouraging suggestions like installing a steam shower and he’s always asking me what I would like to drink, since hydration is so critical to me. He never complains about the flakes or the time I spend on personal care regimens. Lamellar ichthyosis is a tiny part of who I am according to him. It is an organ with a disorder, nothing more. Every human has seventy-eight organs in their body, so an affliction of at least one of them is inevitable.



The Foundation for Ichthyosis & Related Skin Types, Inc.® (FIRST) is the only national non-profit organization dedicated to helping families with the genetic skin disorders collectively called the ichthyoses. Our mission is to educate, inspire, and connect those touched by ichthyosis and related disorders through emotional support, information, advocacy, and research funding for better treatments and eventual cures.

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FROM THE PATIENT'S PERSPECTIVE



Very few doctors even knew what my condition was in the 1960's, and sometimes even now they are unfamiliar with the condition. Doing my own research led me to the Foundation for Ichthyosis & Related Skin Types (FIRST) and helped me to discover the products that make my skin look close to normal, and contributed to making me feel more comfortable with myself.

When I bathe, I add salts from the Dead Sea to the water, lathering with Dead Sea salt shower gel (imported from Israel), and scrub off scales with a ceramic pumice stone/sponge. Another topical product that has made a remarkable difference is 100% natural, unrefined African Shea Nut Butter. The smell of it is not appealing; I mix it with lotions of my favorite perfume scents or essential oils. However, I'm now utilizing much less expensive over-the-counter products to manage this disorder and rarely rely on expensive prescription medications, which have cost me thousands of dollars over my lifetime. On special occasions I go to a local day spa and treat myself to an exfoliating body scrub comprised of an oil and salt combination that is followed by a deep tissue massage with an emollient cream. If I'm early enough for my spa appointment, I get to utilize the dry sauna and steam-room, which seems to help as well.

I am very grateful to FIRST for promoting research and sharing profiles of other people with this same disorder. When you look different from the general public it can be very lonely. Now I feel like I have a huge community of people who understand what I've experienced and how I feel. I hope to attend FIRST conferences in the future to give support to parents and encourage confidence in those children who are affected. On the outside we may have skin of different colors or textures, but on the inside we are all people with feelings, dreams, desires, and hopes trying to reach our fullest potential. We express ourselves through art, science, and sharing the love in our hearts with family, friends, and strangers. **J**



Vanessa Jennings resides in Hackensack, NJ and works in New York City. She holds a BA in Economics from the City College of New York (CCNY) and a Master of Policy and Administration from the Metropolitan College of New York. A ten-year employee of the Sophie Davis School of Biomedical Education at the CCNY, she has risen from a secretarial function – Assistant to the Dean, to management – Director of Academic Affairs and Medical

Education. Ms. Jennings is also an instructor for the CCNY School of Continuing and Professional Studies. Her hobbies include reading historical based fiction, jogging, collecting cookbooks, cooking, indoor and outdoor gardening, and attending a variety of cultural performances when time allows. She and her life-partner enjoy traveling and hope to revisit Europe together again soon. Her best friend is her daughter who recently obtained her MBA and is engaged to be married this spring. Vanessa is also fortunate to have a wonderful set of parents who will celebrate their 60th wedding anniversary this fall.

Take Home Points for Derm PAs:

By Steven K. Shama, MD, MPH

- 1. Imagine Vanessa's parents' fear when their child was transferred to the intensive care unit at birth. When we do hospital consults with newborns, infants, or for that matter any child brought in by his or her parents, it is our responsibility to know enough about the skin condition as well as the future of this condition to make sure that parents are well counseled and that they are given hope, no matter how small it might seem to you, the clinician. The skin is simply our outer "wrapping," but as Vanessa says, "on the inside we are all people with feelings, dreams, desires, and hopes of trying to reach our fullest potential."*
- 2. You must also realize that even young children can feel deep emotions. At the age of five, Vanessa can recall feeling "different" and being stared at and whispered about. Let us remember empathy and compassion.*
- 3. My how Vanessa has been challenged in her life! She has been amazingly brave because of her deep belief of feeling that she was important in this life. She has got to be one of our teachers. Learn her message and tell her story to others who need your embracing words.*

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.

