

JDPA

Journal of Dermatology *for* Physician Assistants

VOLUME 5 NUMBER 2
SPRING 2011

SDPA NEWS AND CURRENT AFFAIRS

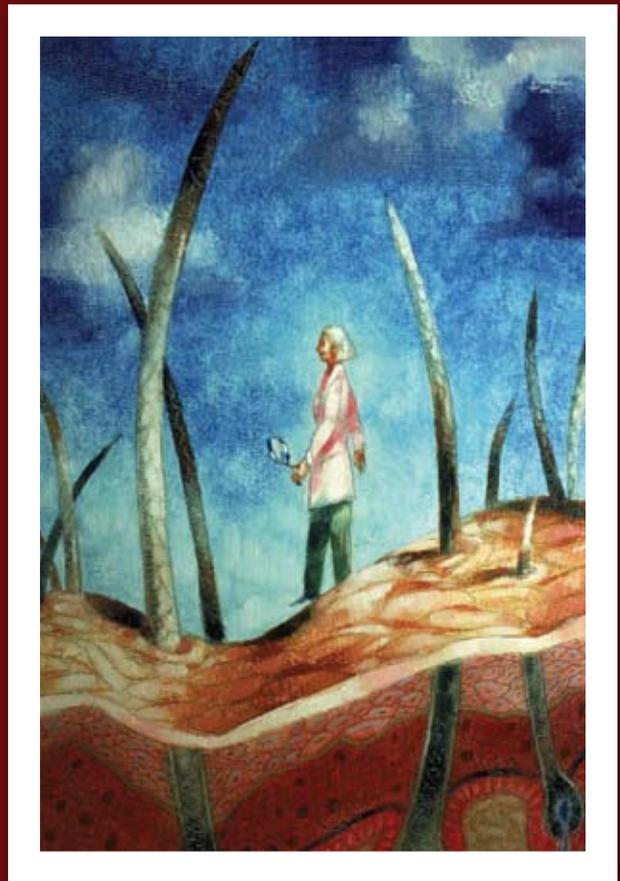
DERMATOLOGY PA NEWS AND NOTES

CLINICAL DERMATOLOGY

SURGICAL DERMATOLOGY

COSMETIC DERMATOLOGY

PROFESSIONAL DEVELOPMENT



SUPPLEMENT
for the
Basal Cell Carcinoma Nevus
Syndrome (BCCNS)
Life Support Network



Official Journal of the Society of Dermatology Physician Assistants

JDPA

Journal of Dermatology for Physician Assistants

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EDITORIAL MISSION: The JDPA is the official clinical journal of the Society of Dermatology Physician Assistants. The mission of the JDPA is to improve dermatological patient care by publishing the most innovative, timely, practice-proven educational information available for the physician assistant profession.

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JDPA/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 5, Number 2, Spring 2011. 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. P.O. Box 701461, San Antonio, Texas 78270; 1-800-380-3992.



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PHARMA

FROM THE PATIENT'S PERSPECTIVE

A "PA"tient with Basal Cell Carcinoma Nevus Syndrome

By Julie Ammen Breneiser, PA-C (Retired)

Back when I was in 8th grade, after having three large keratocystic odontogenic tumors removed from my mandible and maxilla, I was diagnosed with Basal Cell Carcinoma Nevus Syndrome (BCCNS), aka Gorlin Syndrome, BCNS, and Nevoid Basal Cell Carcinoma Syndrome (NBCS). Subsequently, at the age of 18, I had huge, calcified, ovarian fibromas removed just prior to starting college. At the time, neither my parents nor I had been informed that ovarian cysts are a manifestation of this syndrome. Feeling something hard in my lower abdomen and menstruating every two weeks for months prior to this surgery, I was too naive and scared to say or do anything. The good, the bad, and the ugly of BCCNS have shown their faces regularly since then.

BCCNS is an autosomal dominant genetic syndrome that affects all body systems. Most prominently, these can include the heart, nervous system, skeletal/orthopedic, gynecologic, and dermatologic problems. There are other manifestations that can develop as well.

In retrospect, signs of BCCNS were present at birth when my large skull size led to an air ventriculogram. Diagnosed with mild hydrocephalus, careful monitoring was all that was required. As a child (growing up in the country), I had numerous pits on my palms and soles, which were always dirty and hard to get clean. My pediatrician had no idea why the pits were present or what they were.

After my diagnosis in 1970, my mother volunteered me to participate in many Grand Rounds at Massachusetts General Hospital. Physicians would examine my pitted palms, which I was required to stick through the cubicle curtain. The vast majority of practitioners had no clue about the diagnosis despite these clear, pronounced clinical signs.

Multiple hospital experiences and the opportunity to shadow a young pediatrician during my senior year in high school, led me to believe that I wanted to do something in medicine, yet without the hours and responsibility of being a physician. After applying to both the Nurse Practitioner Program at Yale University

and the PA Program at Emory University, I decided to attend Emory and the rest is history. What a great choice this has been.

"Those of us with rare syndromes need all the information we can get. I am grateful and relieved to have the BCCNS Life Support Network to go to for information."

While practicing as a PA, I underwent a number of surgical procedures including frequent and extensive MOHS procedures, followed immediately by plastic surgery reconstruction and repair. These procedures were particularly difficult, since I would see patients or scrub in

the OR a day or two after being treated myself. Having this disease while being a PA increased my ability to empathize with patients as they did with me. This ability was further enhanced after my two children were born, each inheriting BCCNS. My friends called me the "Energizer Bunny" because I kept on going. What choice was there?

Last year I joined an 18-month clinical trial of the Genentech drug Vismodegib, an oral inhibitor of the hedgehog pathway. For me, the results have been positively incredible. In the twelve months that I have been on the drug, 60% of the basal cell carcinomas present at the study's initial exam have disappeared. The hundreds of pits on my palms and soles have vanished. The side effects including loss of taste of food, hair loss, and muscle cramps are significant. When I get frustrated with these, I think back to 2009 when I required minor or major skin cancer surgery (biopsies, MOHS, plastic surgery reconstruction and repair) every month for the first six months of that year. There is NO comparison. For decades prior to 2009, these surgeries had occurred every three months. Years ago, I realized that I would probably never be cancer free. Now, thanks to Vismodegib, that potential exists! This is amazing.

Even though I retired from the world of medicine about ten years ago, I am still learning about the many manifestations of BCCNS. I do not know everything about the syndrome, but I do know that it is best to ask, inform, listen, and communicate. In addition, the websites noted below are excellent information sources.

One of, if not the most valuable statements I was taught at Emory was, "to listen is to communicate." From my perspective as a "PA"tient, I would like to add that "knowledge is power" in caring for oneself. Those of us with rare syndromes need all the information we

can get. I am grateful and relieved to have the BCCNS Life Support Network to go to for information; this is a patient oriented, advocacy, non-profit organization. Even though I was a PA for almost twenty years, I still think this is a wonderful source.

Given that it is impossible to go to one medical provider for comprehensive care, patients with BCCNS need an “orchestra conductor.” Since regular dermatology visits are essential, it makes sense that these providers take up the baton. As PAs in dermatology, it is critical to provide all the information needed to help your patients and their families get the care they need from all the appropriate physicians. 🗣️



Julie Ammen Breneiser was a practicing PA from 1981 to 2000. The specialties in which she worked included orthopedics, neurosurgery, cardiac surgery, and otolaryngology. After retiring for a few years, Julie now works as an assistant teacher of children with multiple disabilities. Over the past few years, she has become actively involved in the Basal Cell Carcinoma Nevus Syndrome Life Support Network, and was elected to their Board of Trustees in 2010. Julie is a strong advocate of this organization, participating in fundraising and recruitment of clinical trial participants. She feels strongly that active involvement in clinical trials will lead to improvement in the quality and quantity of life of those with BCCNS. After all, simply put, life comes down to quality and quantity.

Julie lives in Pennsylvania with her husband of 22 years and two teenage children. She enjoys traveling, exercising, reading, and spending time with her family and friends. Community Service is important to Julie. Along with her volunteer work for the Network, she is an active volunteer at her local community library.

Helpful Websites for Patients:

www.bccns.org

www.gorlinsyndrome.org

TAKE HOME POINTS for DERM PAs:

By Steven K. Shama, MD, MPH

1. **“To listen is to communicate.”** As health care practitioners we were taught in school that in order to make the right diagnosis and provide the best treatment, we need to truly listen to the patient... simply listen. We must allow the space when with a patient for him/her to feel that the environment is a trusted and confidential one. It is in that sacred space that patients tell us what is truly going on and how we can help.
2. **“Knowledge is power.”** Patients should be given as much information as possible so that they feel in as much control of their disease as possible. Refer patients to websites with good up-to-date scientific knowledge, and also include addresses of local support groups. In situations with complex syndromes, you often can’t do it alone.
3. **“Be the orchestra conductor.”** When treating patients with complicated syndromes like BCCNS, you may involve many specialists from totally different disciplines. Patients deeply appreciate the fact that you are still the “clearing house” for referrals and general advice, and that you are still there to simply listen. After all, you still are their caregiver. Never forget that.

**Let them know
they’re not
alone...**

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your patients.**

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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.

