

JDPA

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SDPA NEWS AND CURRENT AFFAIRS

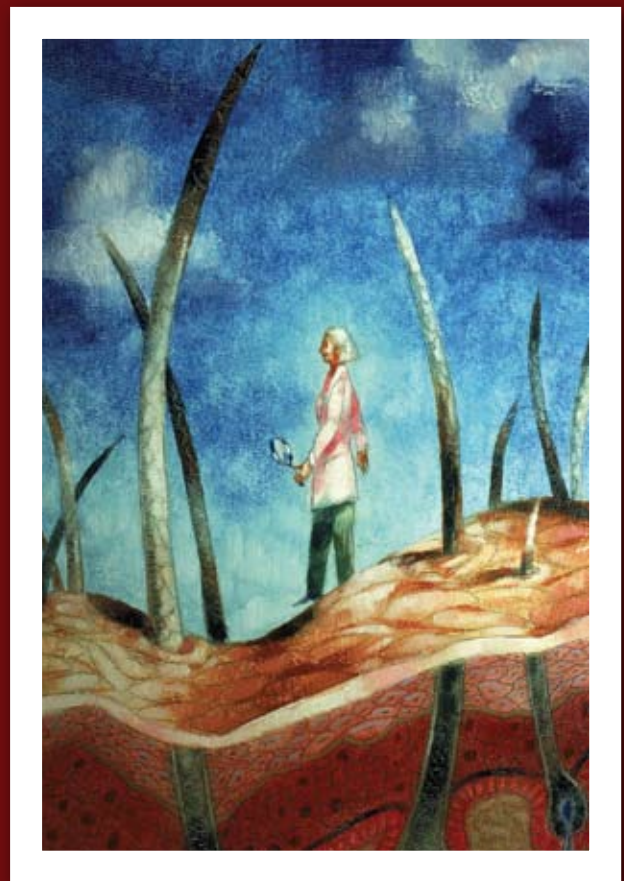
DERMATOLOGY PA NEWS AND NOTES

CLINICAL DERMATOLOGY

SURGICAL DERMATOLOGY

COSMETIC DERMATOLOGY

PROFESSIONAL DEVELOPMENT



SUPPLEMENT
for the
Cicatricial Alopecia
Research Foundation
(CARF)



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JDPA

Journal of Dermatology for Physician Assistants

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FROM THE PATIENT'S PERSPECTIVE

The True Measure of Beauty

By Sandra Dubose

I never knew how attached I was to my hair until I began to lose it. I recognize that in the big scheme of things if you have to get diagnosed with a rare autoimmune disease, not having a life-threatening situation is the most important factor. At the tender age of twenty-five, I began my journey with alopecia areata. Emotionally, it felt like a life-threatening situation. I was married and we had a one-year-old daughter. I always wore my hair very short, which made the bald islands that surfaced on my scalp impossible to hide. I immediately had to start wearing a wig. Since it was not by choice, having to wear a wig felt as if I were waving a red flag on my head and everyone was watching. If I got an honest compliment on my hairstyle, I could not receive it; I only wanted to run and hide. What I would not have given to be invisible during those days.

My dermatologist suggested I begin treatments of cortisone injections and topical ointments. None of these worked for me, and within the first six months of discovering my first bald spot, I had lost nearly 50% of the hair on my head. Discouraged and finding the injections painful, I decided to stop treatments and just let it be. Within a year my hair began to grow back on its own and so did my shattered confidence. When at least 95% of my hair had grown back, I thought the battle was over and that I had won.

It was all good until a year later, after I gave birth to my second daughter. The hair loss began again and was more aggressive. This time my condition progressed to alopecia universalis, and I lost all the hair on my body. I held on to every strand that I could until the last moment. I had to ask myself, "Who was I kidding?" The hair was gone and holding on to a few strands would not make other hair decide to come back. The most liberating thing I could do for myself was to take control of the situation and shave my whole head bald. No longer was I a victim waiting for the sting of alopecia to strike; I was fighting back by deciding not to let hair

define me anymore. The threat was not to my life, but to my self-esteem. I had to find a path to serenity by accepting the things I could not change and finding the courage to change the things I could.

For several years now I have learned to live happily as a bald woman. I have accepted this condition and myself but have secretly hoped that one day my hair would return. In 2009, I decided to see a dermatologist again and was diagnosed with central centrifugal cicatricial alopecia as well. With the reality of having cicatricial (scarring) alopecia, which causes permanent hair loss, my hope of hair regrowth was shattered.

I suffer occasional itching, which is one of the typical symptoms of cicatricial alopecia, and the color of my beautiful, baldhead is compromised of blotchy discoloration. This is nothing that a little MAC makeup cannot fix.

Experiencing hair loss has changed me in many ways and even though the process was painful at times, I am grateful for the invaluable life lessons it has taught me and for the amazing people I have been able to meet while on this path. I am not the woman I used to be. I'm stronger, I'm wiser, and I'm better - bald, bold, and more beautiful than I ever knew I was with hair. No one ever signs up to go through a life-changing traumatic experience. We live and learn that in life there are many things that will be out of our control. We each have personal challenges along our path that are designed to teach us and shape us into who we are meant to be. Whining and wondering, "Why me?" is an effort in futility because no one person deserves emotional pain over another, and yet we each will have our own unique share of it.

Being challenged by unwanted changes in our self-image provides us with a unique opportunity to learn a deeper lesson about our identity. We pick apart what we thought made us who we are and get to the root (no pun intended) of our true identity. We are forced to learn this lesson if we are going to survive. Dare we believe that our greatness and

"I'm stronger, I'm wiser, and I'm better - bald, bold, and more beautiful than I ever knew I was with hair."

beauty exists in our external attributes alone? We can no longer allow hair to define us, or our weight, or our skin, or even our limbs if they are taken away. At some point we have to find a way to turn it around and make it a positive. I learned that if you dig deeper, you can stand taller than you ever knew you could. Find a way to give back, even when you feel you have nothing to give. There is always someone in need of a kind word of encouragement. Through it all, I have realized that the true way to measure my beauty is not counted by the hair follicles on my head but by the smiles I can put on the faces of others. 🕒



Sandra Dubose knows firsthand what it is like to struggle with low self-esteem and a lack of confidence as a result of hair loss. She has lived as a completely bald woman for the past eight years due to alopecia universalis and in 2009 was diagnosed with central centrifugal cicatricial alopecia as well.

Sandra is the Founder and President of the Alopecia Community of the Triangle,

a support group for people living with medically related hair loss in and around Raleigh, NC. Sandra was the inspirational patient speaker at the Cicatricial Alopecia Research Foundation's (CARF) Fourth International Patient Doctor Conference in 2010 and is a leader of CARF's patient support group in Winston-Salem, North Carolina.

As an advocate for alopecia awareness, Sandra has become a leader in the alopecia community, speaking out to educate others by sharing her song and story on television, radio, and at speaking events all over the US. Sandra is an inspirational speaker, recording artist, actress, and independent filmmaker. Her self-documentary film entitled, "Project Liberation; My Alopecia Experience" is available on DVD as an educational tool in libraries throughout the US, as well as through Amazon.com. The accompanying music soundtrack has songs she wrote and performed that uplift and inspire both those with hair and without. It is currently available on iTunes and other online record stores. For more information visit: www.SandraDubose.com.

Sandra uses all of her creative talents to inspire and encourage others to liberate themselves from the pain of hair loss and reclaim the joy in their lives by uncovering the origin of their true beauty. She says that her mission in life is to live her song and make manifest the glory of God that is within her in spite of the challenges of life. Her hope is that as she is continually liberated from her own fear, her very presence will automatically liberate others.

TAKE HOME POINTS for DERM PAs:

By Steven K. Shama, MD, MPH

1. I only wish I could use the inspirational thoughts contained within this article initially with all patients. There is a time and a place for us to introduce to patients the concept of, "It is not a threat to your life but to your self-esteem." All patients may one day embrace those feelings, but we need to be sensitive about when we might introduce these and other perspectives.
2. Our author mentions that while she has accepted her condition and herself, she still "secretly" hoped her hair would return one day. If we are conscious of this secret wish that many patients probably have, we might be even more sensitive to how they express their expressed emotional adjustment, wondering if they ever do completely adjust.
3. What can we learn about our own personal body image and how we would feel if it changed? I have said this before in my writings in our journal - patients are messengers from the universe trying to teach us a lesson. We need to listen.

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

**Share a story with
your patients.**

Visit the *Patient's Perspective*
library of articles at
www.jdpa.org/advocacy.html

If you know a patient who would like to share his/her story, please contact us at editor@jdpa.org



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.

