

A JOURNAL OF WESTERN OKLAHOMA

W E S T V I E W



Volume 31
Issue 1 *Fall/Winter*

Article 6

11-15-2015

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Recommended Citation

Landrum-Geyer, Denise (2015) "Nature's Tattoos," *Westview*: Vol. 31 : Iss. 1 , Article 6.
Available at: <https://dc.swosu.edu/westview/vol31/iss1/6>

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Nature's Tattoos

Denise Landrum-Geyer

I.

I never know what I'll see when I look in the mirror. Usually, all I see are the bright pink patches inching up from my neck and down from my scalp, ready to swallow my face. Sometimes, the patches change color from pink to white; I'm not sure if that's better or worse. I refuse to leave the house without putting foundation on, as I want to avoid questions about my skin. I have psoriasis, a skin disorder that takes the form of multiple patches of itchy scales—pink, white, and silver—covering random areas of my body. My husband used to call me Leopard Girl because of my spots; I say that I have nature's tattoos.

II.

When I was in seventh grade, I decided I wanted to become a dermatologist to find a cure for psoriasis, so I used the upcoming science fair as an opportunity to find out what I could about my disorder. My science fair project, entitled "Psoriasis: No, You Can't Catch It," was, my twelve-year-old self hoped, an enlightening look into psoriasis as a disorder. I researched all eight types of psoriasis, typical treatments, and common misconceptions about the disorder, including the idea that psoriasis is merely a cosmetic inconvenience. Yes, the patches itch and the medications stain my clothes, as does the blood that comes to the surface after scratching the scaly patches. Yes, it's unattractive, I've been told, but can't I just wear a turtleneck and be done with it? While I appreciate this "advice," all it offers is a mask—another way to fade into the background and hope nobody notices.

Psoriasis is the disorder that is not taken very seriously, as the phrase "the heartbreak of psoriasis" has ironically suggested in advertising campaigns since the 1950s: it is the thing that kept Kevin Arnold's brother out of Vietnam on *The Wonder Years*, the thing Kim Kardashian complained about on her reality show. At the science fair, I wanted to let my classmates know what it really was that they were making fun of every day. I wanted them to understand that I could not shave my legs like the other junior high girls because the razor made my psoriasis patches bleed. I wanted to show them that the patches on my arms and legs were more than dandruff but less than leprosy, although the biblical term *tsaraat* was used to name psoriasis as well as leprosy circa 70 BCE, according to *Psoriasis Connections* magazine. Most importantly, I wanted to let them know that they wouldn't catch it from me if they sat next to me in class.

My mom and I created a large display board that included photos of my psoriasis patches. The photos were blown up and glued to neon yellow and orange construction paper to attract people to my table, and I displayed samples of the various ointments I was using at the time to relieve the itching and scaling. I won

third place in the science fair, though that didn't matter to my classmate Kim, who shook her blond hair vigorously from side to side while pursing her lips and throwing her tan arms into the air as she exclaimed, "Eww. That is so gross. I don't want to see that stuff," when I walked up to claim my red ribbon at the PTA meeting.

III.

"The heartbreak of psoriasis" is a real phenomenon. My grandpa had it. My dad has it. I have it. Though my brother does not have it, my niece Courtney might have it: already, there are scaly patches that pop up on her limbs and then quickly disappear. The first time I saw a perfectly-formed circle of pink and silver scales on her forearm, I cried. When my dad saw my reaction, he cried, too. Whenever these patches pop up on her arms, Courtney will show me her arm while pointing at my stomach. "It's like you, She-She," she tells me. Despite Courtney's self-diagnosis, Dr. Hinkebein, the pediatrician who also first diagnosed me with psoriasis, is not ready to diagnose her patches just yet: "Let's wait and see what happens," he told my brother the first time the patches appeared, much like he told my mom when we first visited him about my patches.

I was in the fourth grade when I discovered a scratch behind my left ear that scabbed over for no reason. My mom and Dr. Hinkebein knew better, though the official psoriasis diagnosis was not made for a few months. Dr. Hinkebein put off the diagnosis due to my age; most psoriasis patients are first diagnosed as adults in their twenties or thirties, and I was nine years old. He held out hope that I was having an allergic reaction until three months passed with no improvement, at which point he told my mom, "She has it, too." Because I was so young when the psoriasis first appeared, the scaly patches and potential treatments quickly became part of my everyday routine.

My dad was first diagnosed with psoriasis in his early twenties; by the time I was diagnosed in 1989, he had been living with psoriasis and the cornucopia of suggested treatments for almost twenty years. Depending on the day, scaly patches cover 50-75% of his body. People often ask if he was burned in a fire, as the scaly patches turn bright pink and are raised off the normal-looking surrounding skin, like permanent scars. I've never seen my father without those roaming pink patches of scales, and when my own patches first appeared, I became his research partner.

IV.

My status as permanent guinea pig is written on my body in fuchsia. Dad shares the joys of experimentation. He has been wrapped in cellophane; I have been dipped in tar. He has given up eating pork; I ate yogurt once a day for years. He goes in for colonics; I go to the tanning bed. He drinks a tablespoon of cod liver oil every day; I meditate to relieve stress and strengthen my immune system. Despite all this, Dad and I are not usually described as "ill" because of our psoriasis. At one point in the 1980s, psoriasis was explained as being skin that was simply too healthy: my skin works so well that it regenerates nine times faster than normal skin.

Typically, skin cells regenerate and degenerate in a 28-day cycle. The new skin cells develop and mature as the old skin cells begin to weaken and slough off the

skin. In psoriatic people, the skin cell cycle accelerates. My skin cells regenerate on a 3- or 4-day cycle; the cells are immature and malformed, and when the surrounding normal skin cells become stubborn and refuse to move, the psoriatic cells begin to pile on top of one another, forming scaly patches. These patches then shed themselves, leaving little pieces behind, especially on dark-colored furniture or clothing. I have always been one of those “accelerated” students, on the fast track in school. I am also stubborn. So is my dad. So are our skins.

Right now, my own psoriasis is on the mild side, covering less than 10% of my body. Despite this mildness, I know that Dad still regrets the close connection we have because of the disorder. When I come home to Louisville, I feel his eyes follow me around the kitchen as we catch up on the latest college basketball and football gossip. At the beginning of every visit, he sits on the stool closest to the television as I wander around the white island in the middle of the room under his gaze. I wait for him to give me the result of his evaluation: “You look good,” means that I’ve been managing—or covering—the patches well. “Are you okay?” is his way of suggesting I make an appointment to see our dermatologist Dr. Young. For the past few years, I’ve received the “good” bill of skin health from Dad whenever I go home, though that does not stop our discussions of potential treatments for our skin.

I was Daddy’s girl growing up, though it was not the stereotypical adoring, do-no-wrong father-daughter relationship. Although I would accompany my dad to University of Kentucky basketball games while I was in grade school and my mom still tells me that Dad is wrapped around my finger, more often our relationship appears clinical: we are researchers studying ourselves and each other. I accompany him to dermatologist appointments. We share medicine and yogurt. We talk about diet and exercise. We take turns in the tanning bed. We share bits of information, much like we share similar bits of skin. I watch Dad deal with his psoriasis and psoriatic arthritis, which is a specific form of arthritis connected somehow to psoriasis. Psoriatic arthritis has made Dad’s feet and hands deformed, his joints swelling up so much that he has shoes specially made to fit his feet. Whenever I feel a jab of pain in my knees, I think of my dad’s slow, painful gait, and the arthritis that led to a knee replacement nine years ago.

About 20% of psoriasis patients develop psoriatic arthritis, but there is no definite way to tell whether or not a patient will develop this ailment; genetics seem to play a part, which means my chances of developing psoriatic arthritis are better than those psoriatic patients who have no family history of arthritis. I’ve had “weak” knees and ankles since my days as a high school athlete and dancer, which has led to many evening knee ice-downs, though none of the doctors I’ve been to are yet willing to tell me that psoriatic arthritis is in my future. Once again, it is a matter of wait-and-see. When I think of this possible future, I focus more closely on the present, reading articles and trying alternative treatments, which I then share with him.

V.

Psoriasis is a disorder of particularity. What works for one person will not work

for another. Because of this fact, Dad and I take turns experimenting on our bodies and fill each other in on the results: his experiments are usually under a doctor's supervision; I tend to combine typical treatments with alternative, homeopathic experiments. I once stained my body black with walnut juice because my husband's aunt, who also has psoriasis, went to a Cherokee healer who told her to coat her scaly skin with the oil from black walnut hulls gathered during the month of October. The treatment sent his aunt's psoriasis into remission—not so much for me. Instead, the silver and white patches on my stomach, chest, and face turned black, which made the lesions even more obvious. After a few weeks, I stopped the walnut juice treatment in favor of the coal tar ointment that I've often returned to over the years. Dad and I try to find things that kind of work, which we then share with one another. Despite our efforts, patches persist.

VI.

Since my initial diagnosis of psoriasis at the age of nine, I've only spoken with my father about the emotional fallout from psoriasis once. I was twenty-two at the time, and my psoriasis was particularly bad: bright pink patches covered the left side of my face, running from my hairline down the side of my jaw like a scaly sideburn. Pink, malformed splotches the size of silver dollars also covered my stomach, chest, back, and upper thighs. While it was easier to cover the spots on the rest of my body, I had trouble hiding the patches on my face: concealer and foundation muted the bright pink color of the patches, but the scales flaked off continuously, taking the foundation with them over the course of a normal day. I kept my hair long at the time, as it provided a curtain that hid the patches fairly well.

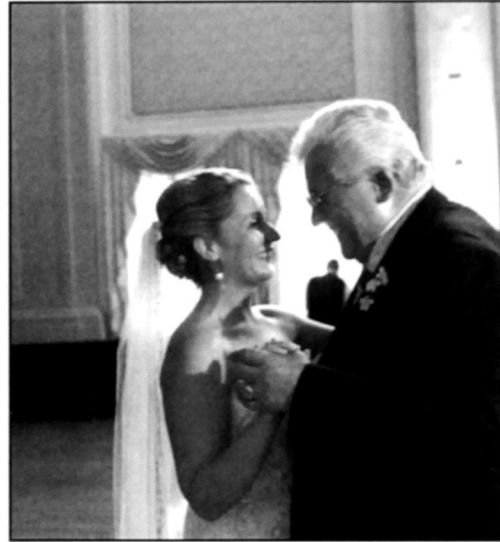
I was in my last semester of college and applying to graduate schools when I went home over fall break. I pulled my hair back in a ponytail for the hour-long ride from Lexington to Louisville, and, as I walked into the kitchen to see my parents, I pulled some strands of hair out of the ponytail in an attempt to cover the left side of my face. My dad was not fooled and asked me before saying hello, "How are your spots doing?"

"Okay." I didn't want to tell him how bad I let it get, that I was frustrated with the MG217 tar ointment because it stained my clothes yellow and made me smell like a freshly paved driveway. The thick, yellow coal tar medication was all I could use at the time because my prescription ointments ran out before I could make an appointment with Dr. Young, and, though the tar worked when I applied it to my patches two or three times a day, I did not have time to coat my body in the ointment and wait 30 minutes for the medication to seep into my skin. Instead, I applied the medicine once every morning and immediately dressed for class, which not only stained my tops and bras a mustard-yellow color but also wiped the medication off my body. My dad knew the trouble with this medication, as he used the same solution in addition to the treatments Dr. Young prescribed. He also knew the impatience I've had with topical treatments ever since I was first diagnosed.

"You using your medicine?" He arched his thick, white eyebrows skeptically as I shook my head. "You have to use your medicine. It won't just go away by itself."

"I know, Dad." The tears welled up in my eyes before I realized what was happening. "I just don't have time for slathering on that stupid ointment."

"I know. I'm sorry." At first, I misunderstood the apology, and when I looked across the counter, I was surprised to see him dabbing the corner of his right eye with a napkin. "I'm sorry." When he repeated those two words, I dropped my head and left the room without responding. I couldn't tell him it was okay: it wasn't okay, but I did not know how to tell him this without also suggesting that I regretted the mysterious genes we shared. I didn't want him to think that



my psoriasis was something he should apologize for, even though every doctor we visited pointed out that psoriasis was a genetic disorder that I had because of him. I avoided being in the same room alone with him for the rest of the weekend because I wasn't sure how to respond to his apology. As I was leaving to return to school on Sunday, Dad handed me a bag full of medication samples he had gotten from Dr. Young. "These should do the trick," he said as he walked me to my car. "They're corticosteroid creams. No staining." When I whispered "thank you" as I hugged him, he said simply, "I don't need all that medicine. And you're so much smaller than I am, one little tube could last you a week." As I now prepare for the birth of my first child, I sometimes wonder—and worry—if I will be having a similar conversation in a few decades. I cannot help but see psoriasis as a mysterious bad gene that I will probably pass on, though there is no way of knowing this until it happens.

VII.

Psoriasis is a perpetual in-between: the disorder usually does not prevent people from completing everyday tasks, so it is dismissed as unimportant. Yet when healthy people see psoriasis, they want to move as far away from it as possible because it looks like something that is contagious, as Brett, the blind date I took to the Christmas Dance my senior year of high school, reminded me.

Brett and I were set up by my friend Lonni after I broke up with my boyfriend two weeks before the dance. When I met Brett at Lonni's house, all he could do was stare at my chest, which was covered with a large patch of silver scales.

"It's psoriasis. You can't catch it." I smiled self-consciously and flipped my hair over both shoulders in an effort to cover some of the afflicted area. I was wearing a scoop-necked black dress with spaghetti straps that I had bought six weeks before. In the interim, my skin flared, partly due to the stress of breaking up with my boyfriend while I was also filling out college applications. The night of the dance, I was desperately looking for a replacement dress with a higher neck, but my mom

convinced me that I should wear the dress I had bought. "It's so pretty," she told me. "And really, your skin doesn't look that bad."

"Yeah. Okay," I thought to myself as I folded my arms over my chest while I was talking to Brett. He would not stop staring at my chest, and I wished I had stayed home instead. The evening progressively degenerated from there, as my "date" spent the entire night on the other side of the gym making out with another girl. When I drove him home, he looked me up and down one more time and told me, "If you covered yourself, it wouldn't be so bad. But, I don't want to touch that stuff. What if it happens to me?" My cheeks flushed, and a hot, mascara-laden tear slid down my face as I pulled into his driveway. Before he could close the door, I threw my car into reverse and began hitting my palm on the steering wheel as I cried loudly. Although I had dealt with negative reactions to my psoriasis before, this was the first time I was deemed undesirable by a member of the opposite sex because of it. I had gone out on dates in high school and had a steady boyfriend for a few months prior to meeting Brett, but my psoriasis had been rather mild for most of my high school career, only showing up on my stomach, upper arms, and back. I usually managed to avoid questions by covering the patches with clothes, but I was so keenly aware of my skin that I avoided any intimate contact beyond kissing. I worked hard to avoid the rejection that Brett delivered after that dance.

Most of my significant others have been understanding about my disorder, and, after giving them the obligatory abbreviated version of my seventh grade science fair presentation, I have become increasingly comfortable with allowing people close to me to see my spots. After presenting my psoriasis spiel to Dave and showing him the patches on my stomach, he shook his head and exclaimed, "If that's all that's wrong with you, I think I got the better end of this deal." I appreciated his sentiment at the time, but I still worry about his reaction if I have an especially bad flare-up. Dave is not worried: "They're kind of cute, really," he tells me all the time. "And I have spots, too, you know."

"Those are freckles. Not the same thing," I always shake my head violently at this argument.

The spots will always be there. There is no real explanation for where psoriasis comes from; researchers know it is passed down genetically, though they are still trying to isolate the chromosomes responsible. They are close, Dr. Young tells me every time I visit her office, which is usually twice a year. The most important part of this knowledge lies in one fact accepted within the dermatological community: psoriasis is not contagious. You cannot catch it. It is an autoimmune disorder that has something to do with the way people need to release toxins through the skin.

There is no cure for psoriasis, only treatment to soothe the condition and lessen the visibility of the patches. Often, the treatments are more dangerous than the psoriasis itself. The most successful treatments for the largest number of psoriatic patients have included intense UV treatments in tanning beds, steroid creams, and coal tar applications. The potential side effects of all of these treatments include cancer and infertility. More recently, dermatologists discovered that Enbrel, an

arthritis medication that is injected into the bloodstream twice a day, also clears up psoriasis in some people. Dad and I have both considered Enbrel, despite the fact that this medication only appears to work 60% of the time and its side effects include skin cancer, nervous system damage, and death. While other people go to dermatologists to preserve their skin, patients with psoriasis are searching for something to destroy their skin, to make it stop, or at least slow down, before they can look forward to normal skin renewal.

VIII.

Dad and I took part in a research study at the University of Tennessee-Memphis for almost two years when I was in junior high. Every month, my entire family, including my mom and younger brother Trey, would pile into our blue Dodge Caravan and go down to Memphis for two or three days, where smiling men and women in white coats would give us a new list of treatments and suggestions. It was on my second visit there that a doctor suggested I begin to take 500mg of penicillin a day. Researchers there had recently discovered a connection between strep throat and psoriasis. Initial psoriasis outbreaks often occur in patients who have recently had a severe case of strep throat, and the doctors in Memphis suspected that some psoriatic patients might be carriers of the streptococcal bacteria that causes strep throat. After testing my saliva, the doctors triumphantly returned to tell me that I was, in fact, a strep carrier, and handed Mom a brown medicine bottle full of penicillin pills the size of bullets. I took the penicillin pills for four months, until the doctors in Memphis decided that it would be more effective to take my tonsils out rather than build up my immunity to penicillin through the large doses I was taking every day.

While the doctors were treating me from the inside out, Dad was given a selection of ointments to apply at different times of day to different areas of his body. Many of the treatments also required my mom's help: at one point in the study, I remember Mom wrapping Dad's legs and arms in Saran Wrap in order to force the ointment to soak into his skin while he wore special gloves and socks to seal in some kind of moisturizer. Although I hated swallowing the huge horse pills every day, I was quietly thankful that the doctors had not suggested turning me into a plastic mummy as a form of treatment.

We stopped going to Memphis during my eighth grade year. I'm not exactly sure why. Maybe it's because we had seen enough of Graceland and the surrounding museums of Elvis memorabilia. Maybe it was the lack of time and money for monthly trips. Maybe the study ended. Maybe it's because the treatments never worked.

IX.

When I was twelve, my family went to Florida for vacation. Sunlight and salt water seem to "dry" up psoriasis spots for many people, so my family made an effort to travel to Panama City Beach in the Florida panhandle on the Gulf of Mexico

every summer. We always stayed at the same condominium: a small, family-friendly complex that is about a mile away from the main strip of hotels and rental homes. I always appreciated the quiet atmosphere and small crowds because I could wear a two-piece bathing suit without feeling too self-conscious, which was especially important since Dad and I planned to spend as much time as possible outside, either at the beach or at nearby pools. One morning, we both decided to go to the smaller outdoor pool on the outskirts of the complex. My dad ambled slowly down the pool steps in the deeper end of the pool while I waited behind him, absentmindedly observing the women in the shallow end of the pool. I suddenly felt a set of eyes bore into my stomach, the source of which I located in a young mother, who gathered up two small boys and hurriedly pulled them out of the water. I looked around, ready to leap back from the offensive object that aroused this mother's fear and anger. Then, I heard her words: "I can't believe those people...spoiling the pool for the rest of us." It was me. It was my father. We "spoiled" the pool. We set foot in the same water as her children. Our skin—the rough, itchy patches that often resemble some form of mutated poison ivy—threatened to float over and infiltrate her children's bodies. My face flushed with embarrassment, which then turned to anger.

Dad didn't seem to hear her words. At least, he didn't acknowledge them. Instead, as the other pool-goers took their cue from the vigilant young mother, my dad smiled and said to me, "Looks like we have the pool to ourselves now."

I wasn't sure then if I wanted the pool to myself. I'm still not sure if I do.

