

By Jenny Thorn Palter

# SKIN

## STORIES

Caroline McLean, 32, of Atlanta, was working for Sen. Johnny Isakson (R-GA) in Washington, D.C., when she was diagnosed with lupus in 2011. “I was a young, single professional,” she says. “I didn’t want to change anything about my life.” Yet a trip to Puerto Rico with friends did just that. “It was a poor decision to travel there, knowing how the sun affected my skin,” she admits. “I developed a horrible lupus rash all over my body—from the top of my scalp, all over my face, neck, and chest, to my stomach and legs—that looked like a badly peeling sunburn, for weeks and weeks.”

A dermatologist diagnosed Denan (DEE-nun) Lance with discoid lupus in 2008. Lance, 38, an account executive with Clear Channel Media + Entertainment in Richmond, Virginia, had heard of lupus, but she didn’t know it could involve the skin. Early 2014 brought complications. What started as a rash on Lance’s back and shoulder began to spread across her chest, stomach, and legs, until two-thirds of her body was covered. “I looked like a burn victim,” Lance says.

Quenaria (kwa-NAYR-a) Hayes, 25, an elementary school teacher in Orange Park, Florida, was diagnosed with lupus in 1995 when she was 7 years old. “I don’t remember not being sick,” she says. During her sophomore year at Bethune-Cookman University, a rash that started on her scalp gradually spread across her face and left scars. “And because the rash damaged my hair follicles so badly, I had to completely go bald. As a young lady, that was a hard decision to make.”

**Learning  
to cope  
with  
visible  
signs of  
disease**



LEARN MORE

[lupus.org/resources/15-questions-skin-issues-and-hair-loss-with-lupus](http://lupus.org/resources/15-questions-skin-issues-and-hair-loss-with-lupus)

Audra Melton







***“Don’t give up. ... And don’t be ashamed.”*** —Caroline McLean

### FACE TO FACE

David F. Fiorentino, M.D., Ph.D., associate professor of dermatology at Stanford University and a member of the Lupus Foundation of America Medical-Scientific Advisory Council, notes that recent studies have shown that individuals with lupus skin involvement have a worse quality of life compared with those suffering from other dermatologic conditions.

“People with skin lupus can have a form of disease that leaves quite a bit of damage to the skin—scarring, pigmentation changes, enlarged blood vessels, and areas of atrophy. These can be permanently disfiguring if not treated with surgical modalities. Unfortunately, the face is a common site of involvement for cutaneous lupus.”

As with other inflammatory skin conditions, Fiorentino says, lupus skin involvement can adversely affect social confidence, self-esteem, and interactions in the workplace.

McLean recalls that the bright red, raised rash was especially bad on her neck and scalp. “People would avoid sitting next to me on the subway,” she remembers. “I would often get

uncomfortable smiles when I took meetings with people at work. It was emotionally hard to handle. Even though I knew they didn’t understand, it was extremely trying on my self-esteem.”

Lance remembers, too. “Being an outside salesperson, this was a very traumatic experience,” she says. “I was lucky to have wonderful people around me, and they all commended me on my great attitude, but no one will ever know how scary and upsetting this was.”

### TRIAL AND ERROR

Efforts to treat McLean’s skin were unsuccessful at first. “There were a lot of medications my rheumatologist tried,” she says. “Each time I would have the worst side effects you could have.”

Like McLean, Lance went through a trial-and-error period, first trying steroids and then methotrexate, but neither was effective for her. In the meantime, she resolved to do what she could to help

her body. “I wanted to try as many natural things as I could.” When a nurse friend suggested a salt spa, Lance checked it out. “I went weekly for about three months,” she says. “The redness of my skin went way down, and every time I would leave there, I felt more healed.” Treatment with dapsone began to work at the same time.

Fiorentino acknowledges that certain risk factors appear to impact an individual’s responsiveness to therapy. “Having widespread disease appears to be more difficult to treat. Some studies suggest that if a person has systemic lupus, then certain forms of their cutaneous lupus are harder to bring under control. We also know that tobacco smoke increases the risk that skin lupus will be difficult to control. Finally, patients who do not protect themselves from sunlight are in general going to have skin disease that is more difficult to treat.”

### TALK THERAPY

After a severe allergic reaction to dapsone landed McLean in the hospital for two days, “I really broke down with my rheumatologist,” she says. “That’s when she suggested it might be beneficial for me to talk with a psychiatrist or psychologist.” McLean took the advice. “He helped me to talk through what I was feeling and to find perspective.”

Being able to talk to someone about your feelings and emotions is as necessary to healing as finding the right medication. Clinical psychologist Francine Rosenberg,

***“I was lucky to have wonderful people around me, and they all commended me on my great attitude, but no one will ever know how scary and upsetting this was.”***

—Denan Lance



## ALTERNATIVE *Therapies*

“Because treatments for skin lupus are not always effective, it is understandable that many patients seek alternative (e.g., non-Western) methods,” says David F. Fiorentino, M.D., Ph.D., associate professor of dermatology at Stanford University and a member of the Lupus Foundation of America Medical-Scientific Advisory Council. “My first and foremost goal is to make sure there are no obvious safety concerns, either because of a medication interaction or due to potential side effects of the therapy on its own.”

Fiorentino stresses that many alternative treatments have not been specifically tested for safety in humans, let alone humans with skin lupus. Therefore, when using such treatments, patients should be aware that they might be putting themselves at unknown risk.

“It is often much easier to tout efficacy in a blog or online ad or by word of mouth than to put that efficacy to rigorous medical testing and evaluation,” he says.

“Patients should always have hope—but that hope needs to be tempered with a sense of reality and skepticism, especially when the results sound too good to be true.”

Psy.D., a member of Morris Psychological Group, P.A., in Parsippany, New Jersey, says that people who are struggling can benefit from additional support, whether from a mental health professional or a support group. “With acceptance of a newly defined life, people can overcome the feelings of depression and some of the other negative emotions associated with those changes,” she says.

It’s one thing to talk privately about lupus and its consequences. It’s another to take it public. “When people would ask me about the scarring, I started using that to spread awareness,” Hayes says. “I also am a teacher to some very honest elementary school kids. They want to know, ‘What happened?’ and ‘Does it hurt?’ When I tell them, ‘I have an illness that sometimes makes me sick,’ their next question is, ‘Are you better?’ They don’t care about the scars. They just want to know that their teacher is OK.”

McLean had similar experiences. “I started telling people what the rash was from, and turned it into an educational opportunity. I started a blog, and I joined a young adult support group run by the Lupus Foundation of America.”

“Talking to people can give a feeling of empowerment,” explains Rosenberg. “It acknowledges what’s probably apparent and shows that you’re comfortable talking about it. By giving people permission to maybe ask a question, it helps them understand that this is something you can’t necessarily control. It’s also showing your sense of courage.”



***“Yes, I have some scars on my face, but that means I’m a survivor. I know it can be a lot worse, because I’ve experienced a lot worse from lupus.” –Quenaria Hayes***

### ADJUSTING TO CHANGE

Rosenberg notes that there are stages of acceptance in dealing with visible signs of an illness. “When you’re dealing with a serious illness like lupus, there is a grieving of certain losses that goes along with it. It could be the loss of physical abilities, the loss of employment, or the loss of your looks. If you previously felt very good about the way you looked and now you don’t, there is a loss associated with that, and it’s not so different than the kind of grief one experiences after a death,” she says.

Hayes says that a poem a friend wrote for her, called “Beauty Marks of War,” helped her feel less self-conscious about her scars and her baldness. “Yes, I have some scars on my face, but that means I’m a survivor. I know it can be a lot worse, because I’ve experienced a lot worse from lupus.”

She also credits her mother, Willette Hayes, with providing emotional support. “Her favorite thing to say to me is, ‘You’re so pretty. You look just like me.’ With someone telling you that your whole life, you’re going to feel good about yourself regardless of what’s happening on the outside,” Hayes says.

McLean moved back to Atlanta to be closer to family, and she now works as the senior analyst for public policy for a natural gas company. “Therapy and hard work, along with a trial and error of multiple medications, helped me get my skin mostly into remission, although I still look like I have a slight sunburn,” she says. “It was a difficult path, but it made me much more aware of other people with visual illnesses or flaws.” Her advice? “Don’t give up. Keep looking for that medication that will work for you, and that person who will listen. And don’t be ashamed.” ■