

## Half Empty or Half Full?

### In Hopes of Inspiring Resilience

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I've always considered myself an optimist. But I sure didn't feel the least bit cheerful on that day four years ago, when I held up a hand mirror to check out the rearview of a new haircut, only to discover a series of shiny snow-white, mangy-looking bald patches sweeping across the back of my head. I felt devastated.

As a freckled, green-eyed strawberry blonde susceptible to skin cancers and rashes, I had seen dermatologists routinely my entire life and during the previous six years had asked them to examine my scalp to see if the itching and crusty lesions I'd been experiencing were suspicious or malignant. Not a single doctor, even after several biopsies, had given me an accurate diagnosis. My panic and dismay were now mixed with anger and frustration that things had gotten out of control, even under the care of professionals. My glass seemed considerably closer to half empty.

Responding to my alarm and distress, my husband, Dennis, encouraged me to find a specialist and said we would "go to Switzerland" if necessary. We didn't have to go that far. After an Internet search, I discovered one of the world's foremost scalp specialists, Dr. Vera Price, nearby in San Francisco. Things were looking up! But I was still in for an emotional roller-coaster ride, particularly after learning that my hair loss was permanent and my disorder so rare that scientists have not yet discovered a cause, let alone a cure. More disheartening was the fact that some of the drugs being tried as first-line treatments produced mixed outcomes, and often came with serious side effects. I had to make some difficult decisions, weighing my desire to hang on to my hair with my fear of putting my body at risk.

So where was the silver lining in this cloud? Reflecting back today, I can actually count many blessings in the form of life lessons learned and things for which to be thankful. The best thing to come out of this process has been the deepening strength of my relationship with my husband, who routinely applies topical tacrolimus to my scalp, and in so doing we have maintained some control over the symptoms and rate of hair loss. While assuring me that he'd love me with or without hair, Dennis' emotional support continues to help me cope, and he has also become a supporter of CARF in its mission to fund research and raise awareness and advocacy.

Other good things have come out of having this disorder. I have long subscribed to several health/medical/nutrition newsletters and have followed research on a wide range of health-related topics—from the study of chronic diseases of aging to the many ways science is discovering how diet and lifestyle can affect illness and wellness. In the course of learning about the cicatricial alopecias and other hair loss disorders, I have

integrated theories and knowledge about these disease processes, such as autoimmunity, into my understanding of health issues in general.

In particular, I have become a proponent of an anti-inflammatory diet. Having already known that many diseases—including arthritis, heart disease and Alzheimer's—are thought to be inflammatory in nature, and then learning that the activity of cicatricial alopecia is likely also to be an inflammatory process, I have adopted a diet rich in anti-inflammatory nutrients and low in ingredients thought to contribute to inflammation. There's nothing like the motivation of not going bald to inspire a commitment to a diet that may slow the hair loss process! Rigorous adherence to my diet, along with dedication to regular exercise, has reduced much of my arthritic joint pain, made me slender, and may also be lowering my risk of developing some of the diseases that have afflicted my ancestors. Benefits indeed!

I have also gained more confidence in my ability to influence my health through exploring modalities that are complementary to Western medicine, including acupuncture and oriental and naturopathic medicine. I have learned how to have more productive clinical visits and more effective conversations with care providers, both for myself and on behalf of others. I am empowered knowing that my growing knowledge base will help me in the future to deal with other issues and illnesses that may arise in my family and am gratified at having become an ad hoc resource for information and support within my extended family and circle of friends.

Another look on the bright side concerns my hairstyle. I used to let my long hair flow, restraining it with a ponytail holder anytime I wanted it out of my face, which was most of the time. It was not the most becoming look for me, but it was utilitarian. Now, because of my need to train my hair to sweep back in order to cover the bald patches, I've been compelled to learn some styling skills, which, in my opinion, have resulted in a hairstyle that's more flattering to my face and functional as well. And I've strengthened my commitment to wearing hats and sunscreen as a result of using a medication that increases UV sensitivity. In the long run, my skin will look less aged.

And speaking of comb-overs, I have learned to be more compassionate in my attitude toward balding men whose attempts to reposition a few strands of hair across their hairless heads used to seem comical to me. I can now empathize with their desperation to cover their scalps, and I am more sensitive to anyone trying to minimize what they perceive to be personal imperfections of any kind.

Gaining a healthy perspective has also been an advantage of having this disorder. Although hair loss is horrid, it is not life-threatening. And I've found that staying busy with my work and my life, plus the passing of time, has helped me to place less importance on it too. I can honestly say that several days at a time can now pass without giving my scalp a second thought.

One of the most rewarding benefits that has resulted from having cicatricial alopecia has been my association with physicians and patients through the wonderful organization of

CARF. The exchange of support, information and friendship among the patients I've met and gotten to know through CARF continues to be invaluable. CARF, through its two patient conferences and the 2005 Colloquium, has provided Dennis and me opportunities to meet the world's leading dermatologists specializing in scalp disorders and to talk with them informally about their treatment approaches and their work. What a rare and valuable privilege this has been!

I look forward to seeing these folks and meeting new acquaintances at CARF's upcoming Diamond Affair fundraiser in Beverly Hills in July. Dennis and I hope to see you there!