



C . A . R . F .

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Wow! CARF Conference—the Best Ever!

The 4th International Patient Doctor Conference in Los Angeles was a rousing success! All 90 attendees from 14 U.S. states, the UK and Canada experienced unique moments that left them filled with inspiration and hope that cicatricial alopecia will be conquered.

The coming together of patients, their families, doctors and CARF sponsors was an unparalleled bonding experience that proved informative and fun for everyone. The medical speakers were outstanding. See pages 4, 5, 7 and 11 for summaries of talks by Vera H. Price, MD, Wilma F. Bergfeld, MD, FAAD, Sandra Dubose-Gibson and

Sharon Dunas, MFT. The Q & A session was a highlight of the event, during which the world's leading hair experts shared their individual treatment protocols and points of view. The audience was spellbound. Patient Sandra Gibson wowed the audience with her inspirational words and song. Sharon Dunas, MFT, skillfully led a breakout group where everyone shared feelings that were validated. Emcee Ken Washenik, MD, PhD, outdid himself at the Saturday dinner and auction proceedings. The Liars Club game was a hilarious hit. Nancy FitzGerald gave encouraging closing remarks and led attendees in a song from *Glee*, "Lean on Me,"

as the audience embraced and sang along.

We were honored and appreciative to have the support of our sponsors who attended the Conference: Procter & Gamble, Johnson & Johnson Consumer Products, Wells Fargo, Allergan, Bosley, Soroptimist International of Chico, and DermaGenoma. We are thankful also to the CARF sponsors who were unable to attend: Stiefel (SKG), Corn Products US, Follica, Galderma, L'Oreal USA, Skin-Medica, Toppik, Leiter's Pharmacy, and the UCSF Department of Dermatology.

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6th World Congress for Hair Research June 16-19, 2010 Cairns, Australia



The World Congress for Hair Research is held every three years and is the premier event on the international hair research calendar. The first Tricontinental Meeting was held in Brussels in 1995, and since then new member societies have joined. In 2010, the meeting was hosted by the Australasian Hair and Wool Research Society with partici-



pation of the North American Hair Research Society, the Japanese Hair Research Society, the European Society for Hair Research, and the Korean Society for Hair Research. Three hundred participants came from all parts of the globe: 50 of them from the US, 60 from Europe, and the rest from Asia, Australia and New Zealand.

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6th World Congress for Hair Research

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The 6th World Congress brought together hair biologists, wool scientists, dermatologists, and hair transplant surgeons in their common pursuit of better understanding of the science of hair growth in health and disease. Both basic science and clinical topics were presented at workshops, plenary lectures, and poster presentations. Sessions were devoted to:

- ◇ Cicatricial alopecia
- ◇ Morphogenesis, neogenesis and tissue engineering
- ◇ Genetics and genodermatoses
- ◇ Stem cells, stem cell niches and cicatricial alopecia
- ◇ Structure, biology and hair curl, color and luster
- ◇ Hormones, hair growth and pattern hair loss
- ◇ Comparative biology
- ◇ Immunobiology, alopecia areata
- ◇ Emerging technologies

CARF was an active participant and supporter of the Congress and was featured on the opening day as sponsor of the Cicatricial Alopecia Research Foundation Symposium. The hour-long

Symposium was chaired by Vera Price and co-chaired by Rodney Sinclair (Convener of the entire Congress) and Kurt Stenn (Chair of CARF's Scientific Advisors). Speakers included:

- Dr. Pratima Karnik, Case Western Department of Dermatology, USA: *Stem cells, environmental factors and lipid metabolism in cicatricial alopecia: A riddle wrapped in a mystery inside an enigma.*
- Prof. Ralf Paus, University of Lubeck, Germany, and School of Translational Medicine, University of Manchester, United Kingdom: *Possible pathogenic factors in primary cicatricial alopecia: new lessons from lichen planopilaris.*
- Dr. Vera Price, University of California, San Francisco, Department of Dermatology, USA: *Treatment of lichen planopilaris with hydroxy-chloroquine, mycophenolate mofetil, and PPAR gamma agonists.*

Summaries of the talks presented at the CARF-sponsored Symposium will appear in future CARF newsletters.

For its sponsorship role, CARF was given a prominent booth in the poster room, where CARF brochures were distributed and publicity was given to the \$1.77 million awarded to Pratima Karnik for continuing her excellent research on cicatricial alopecia. Brochures were distributed for the 2010 CARF Patient/Doctor Conference in Los Angeles and the 2011 Cicatricial Alopecia Research Symposium in Washington, DC. A sign-up sheet was available for participants who wished to receive more information about CARF and its activities.

Two speakers at the Congress, both closely affiliated with CARF, gave keynote addresses:

- Dr. George Cotsarelis, a CARF Scientific Advisor, spoke about fair follicle stem cells in alopecia;
- Dr. Ralf Paus, one of CARF's Symposium speakers, spoke about neuroendocrinology of the hair follicle.

In summary, CARF was well represented at the Congress for Hair Research and its activities were promoted to a global audience.

Multicultural Outreach

Gwen Powell Todd, PhD



Gwen Powell Todd,
PhD

In June, I represented CARF at the first meeting of the newly formed National Multicultural Outreach Initiative African American Work Group of the National Institutes of Health in Washington, DC. This was the most well organized meeting I have attended in recent years. We were welcomed by Dr. Stephen Katz, but Dr. Janet Austin was in charge and Dr. Robert Carter moderated the large group meetings. The more than 50 participants included representatives from the National Institute of Arthritis and Musculoskeletal and Skin Diseases Coalition, NIAMS Advisory Council, health professional organizations, community-based organizations, federal and local health agencies, and NIH staff.

The four ethnic groups (African Americans, Hispanic/Latinos, Asians/Pacific Islanders, and American Indians/Alaska Natives/Native Hawaiians) were tasked with developing re-

search-based, culturally relevant health messages and materials for the respective ethnic groups based on the culture, tradition and history of these groups. After the messages are developed, NIAMS will present them in tool-kit fashion and offer them to their partners, such as CARF, and recommended agencies. Each partner will personalize the messages according to their diseases. The recommended agencies can be any that would be relevant for that particular group. For example, our group recommended black and satellite radio stations. We all agreed that we listen to them consistently, and my African American communication friends who work for large firms endorse this decision.

This meeting was our kick-off. We will be meeting monthly by conference call to refine and expand our messages.

Cicatricial Alopecia

Lily Talakoub, MD, and Naissan Wesley, MD



Lily Talakoub, MD

A great victory for our patients suffering from cicatricial alopecia—Dr. Pratima Karnik, assistant professor of dermatology at Cleveland's Case Western Reserve University, received a \$1.77 National Institutes of Health grant to fund a five-year study on hair follicle, stem cell specific, PPAR-gamma deficiency in scarring alopecia.

Her research, published in the *Journal of Investigative Dermatology*, linked a defect in lipid processing and peroxisome biogenesis to cicatricial alopecia. As a result, it paved the way for a breakthrough finding in understanding the pathophysiology of the permanent hair loss disorder (*J Invest Dermatol*. 2009 May;129(5):1066-70).

Dr. Karnik and her colleagues found that unprocessed lipids are responsible for developing scarring hair loss. Their research suggests that processed lipids are necessary for hair growth and unprocessed lipids are toxic to hair. The bench-side research has led to clinical findings that treating patients with drugs that enhance lipid processing may relieve the clinical symptoms of the disorder.

Central centrifugal cicatricial alopecia, a scarring hair loss prevalent in African Americans, has no well-defined cause and has been difficult to understand and frustrating for patients.

Dr. Karnik's research, and the work of the Cicatricial Alopecia Research Foundation

(www.carfintl.org), is helping patients and physicians understand the biology, natural history, and treatment options for patients.

I personally attended a session with NIH Director Dr. Francis S. Collins, on behalf of CARF, where underrepresented and underfunded organizations had a chance to voice their opinions to the NIH and gain the well deserved attention they need.

Dr. Collins suggested that a new structure of communication was being established at the NIH, noting that any organization can send a brief summary of issues it would like to bring to the attention of the NIH. The e-mail address is [nih-listens@nih.gov](mailto:.nih-listens@nih.gov). He ensured us he would look at every e-mail and respond to each one.

Often, rare diseases are difficult to study given the lack of attention and funding. The work of Dr. Karnik and her collaborative team, and organizations like CARF, give hope to the thousands of people suffering from cicatricial alopecia.

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Naissan Wesley, MD

The La Brea Tar Pits and Laboratory



Tar pits are rare, and the tar pits in the heart of Los Angeles are the most famous. The bubbling asphalt lake and the museum are a dramatic testament to the mammoths, mastodons, saber-toothed cats, camels and other fascinating creatures that roamed the area tens of thousands of years ago. Conference guests who arrived early had a special treat – a private tour at the world-famous “fish-bowl” laboratory, normally not accessible to visitors, where the research supervisor demonstrated the work being done with newly discovered fossils. Everyone loved this adventure.



Research Update

Vera H. Price, MD



Vera H. Price, MD

The management of cicatricial alopecia currently centers on the working classification of primary cicatricial alopecia that separates two main groups: those with predominantly lymphocytic inflammation and those with predominantly neutrophilic inflammation. This is based on examination of scalp biopsies with light microscopy, which cannot separate the various clinical subtypes in these groups.

It became clear that molecular studies were needed to understand the cicatricial alopecias. Microarray analysis of lichen planopilaris (affected and unaffected scalp biopsies) was compared to normal control biopsies. These studies revealed major biological pathways that were up-regulated, including inflammatory and cell-death pathways, whereas lipid metabolic and hair follicle cycling pathways were down-regulated. Abnormal lipid metabolism and cholesterol biosynthesis, and buildup of pro-inflammatory (toxic) lipids were noted in both affected and unaffected scalp biopsies in lichen planopilaris (LPP), whereas the inflammatory changes and hair follicle

and sebaceous gland destruction were marked in affected scalp biopsies only. This suggested that the inflammatory changes may not represent the primary events in the pathogenesis of LPP. Amongst the down-regulated genes in LPP was the significantly decreased expression of the peroxisome proliferator-activated receptor gamma (PPAR gamma) in hair follicles and sebaceous glands. Further experiments pointed to a key role for PPAR gamma in the pathogenesis of LPP. The role of PPAR gamma in the hair follicle changes in LPP was supported by the creation of a mouse model. Targeted deletion of PPAR gamma in hair follicle stem cells in mice resulted in a progressive, pruritic, scarring alopecia. These studies all suggested that PPAR gamma is crucial for healthy pilosebaceous units, and it is the loss of this function that triggers the pathogenesis of LPP (Karnik et al, 2009). However, the triggers for initiating this loss, such as environmental, genetic, microbial, or dietary triggers, are not known.

In frontal fibrosing alopecia (FFA), another predominantly lymphocyte-mediated cicatricial alopecia, similar PPAR gamma dysfunction was noted in gene expression studies. In central centrifugal cicatricial alopecia (CCCA), PPAR gamma was not decreased, although a co-activator of PPAR gamma was decreased. In the predominantly neutrophilic primary cicatricial alopecias, further molecular study is needed.

Other studies have also pointed to the importance of normal lipid pathways in maintaining healthy hair follicles. The nursing pups of mice that had targeted deletion of PPAR gamma in their mammary glands

developed hair loss, whereas the mothers themselves had no visible changes. The PPAR gamma deficiency caused toxic lipid accumulation in the lactating mammary gland, and the inflammatory lipids in the milk caused hair loss in nursing pups. When the pups were weaned, their hair loss was reversed (Wan et al, 2007).

Gene expression profiling at Case Western Reserve University is continuing for all types of cicatricial alopecia. The clinical variants of the lymphocytic and neutrophilic groups probably reflect differences in the underlying gene expression patterns. In future, a new classification of the cicatricial alopecias may be possible based on molecular features:

- Disorders with abnormal lipid/metabolic changes due to decreased PPAR gamma expression (LPP, FFA). This may lead to uphill treatment strategies with the use of PPAR gamma agonists (Mirmirani et al, 2009).
- Other nuclear receptor or metabolic changes.

Recent observations suggest that some collective brainstorming might be helpful to unravel the cicatricial alopecias. One striking observation is the increased incidence of FFA since it was first described in Australia by Kossard in 1994. The recent increase has been noted worldwide. Another observation is that the aryl hydrocarbon receptor is up-regulated in microarray analysis. This xenobiotic receptor (receptor for foreign substances), in response to dioxin-like substances, is known to suppress PPAR gamma.

Dioxin is generated from automobile emissions, industrial waste and forest fires. Dioxins seem to accumu-

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Medical Treatment of Cicatricial Alopecia

Wilma F. Bergfeld, MD, FAAD



Wilma F. Bergfeld, MD,
FAAD

There are many alopecic disorders that are classified as scarring alopecia that differ in both their clinical appearance as well as their histological changes. Common to all, however, is the destruction of the hair follicle and oil gland and its follicular growth centers, the primary bulge area. The exact trigger for the inflammation is poorly understood but is hypothesized to be initiated by infectious agents, hair follicle proteins, or products of the hair follicle metabolism.

The current therapies for all the scarring alopecias are aimed at reducing or altering the inflammation, and, in turn saving the hair follicle and oil gland from destruction. Basically, the targets for therapy are to: 1) reduce inflammation; 2) reduce follicular infectious agents and control the host's response. The clinical targets of therapy are to: 1) reduce scalp discomfort such as itching, pain and burning; 2) improve scalp health; 3) stop hair loss; 4) improve hair growth.

Basic therapy includes scalp care and cleansing, medical evaluation for concomitant disorders such as thyroid, diabetes, autoimmune diseases and nutritional deficiencies, especially low iron, calcium and vitamin D.

The specific active therapies are divided into: 1) antibiotics; 2) steroids, topically, intralesional and orally; 3) anti-inflammatory agents such as steroids, natural antioxidants, retinoids, antimalarials, antihistamines; 4) meta-

bolic agents to control local lipid metabolism; 5) immunologic modulating agents such as cyclosporine, mycophenolate mofetil, tacrolimus/pimecrolimus; 6) new biologic agents that interfere with inflammation on a molecular basis. Hair growth stimulation is accomplished by reduction of inflammation and use of topical minoxidil.

Therapies for end-stage "burned out" scarring alopecia include surgical intervention, such as scalp reduction and hair transplants. Camouflage procedures and prostheses are continuously helpful.

In summary, the scarring alopecic disorders overlap in their clinical and pathological presentation. Inflammation is common in the acute stage and scarring in the later end stage. With the inflammatory destruction of the hair follicle and oil gland, the hair loss is permanent. All efforts in therapy should emphasize the saving of the hair follicle and oil gland so that regeneration can occur. CARF and the North American Hair Research Society are actively developing a strategy to define, evaluate and treat this complex group of disorders. Understanding the mechanism of induction of these disorders is essential to developing more effective therapies. Continued research is underway and needed.

Research Update

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late in animal fat and fish, and food seems to be the major source of dioxin exposure in humans. Once in the body, it has a slow rate of metabolism and remains for long periods. Agent Orange is dioxin and causes loss of sebaceous glands. These observations suggest that plotting zip codes and cicatricial alopecia, specifically FFA, may be informative.

Karnik P, Tekeste Z, McCormik TS, Gilliam AC, Price VH, Cooper KD, Mirmirani P. Hair follicle stem cell-specific PPAR gamma deletion causes scarring alopecia. *J Invest Dermatol* 129; 1243-57, 2009.

Wan Y, Saghatelian A, Chong LW, Zhang CL, Cravatt BF, Evans RM. Maternal PPAR gamma protects nursing neonates by suppressing

the production of inflammatory milk. *Genes Dev* 21:1895-908, 2007.

Mirmirani P, Karnik P. Lichen planopilaris treated with a peroxisome proliferator-activated receptor gamma agonist. *Arch Dermatol* 145: 1363-66, 2009.

Plucky Patient Takes the Initiative Represents CARF at the Baltimore Health Fair

Shakia Gullette



Shakia Gullette at the Baltimore Health Fair

I'm new to CARF and want to share my background with you all. I began to lose my hair at the age of 19, when I was a freshman in college. It was really hard to deal with it at the time because I was just starting to come into my own as a young woman. Being in college, I wasn't sure how I was going to adjust, but with God and supportive family I got through.

At first, I would still perm my hair and wear half-wigs, pieces, braids and sew-in weaves. It all worked well for a while, until I started to lose more hair. By age 20, I had been diagnosed with central centrifugal cicatricial alopecia. I was treated by my dermatologist with all types of pills, shampoos, scalp injections, you name it, all at an early age. I then went natural. I gave up perms and was able to wear my hair out when I was 23.

By this time, I was beginning to feel comfortable with myself but, unfortunately, I began to lose my hair in the front and had to go back to wigs. In 2007, I found my solution. I began to get my wigs custom made, and that is the way I have been wearing my hair since. Although I love that I get to wear the latest hair styles and trends, I miss my hair greatly and hate having to tell people my situation, but, hey, I have so many other things to be thankful for.

Currently, I'm not treating my hair because the last dermatologist I went to gave me more pills and shampoo and they have not worked. I cry a lot at this stage because I seem to be losing more hair and it makes me feel like less of a woman sometimes.

Determined to stay positive, on August 24, 2010, I took the first steps toward educating the public about CARF and the disease. The Baltimore Community Health and Wellness Fair was a collaborative event sponsored by Bethlehem Lutheran Church, Franklin Square Hospital, MedStar Donor Services, and community residents. The goals of the event were to increase personal health awareness, provide health screenings and educational materials to motivate behavioral changes, and increase knowledge of community resources.

I had a wonderful time representing CARF at the health fair. I educated the public on how to get a biopsy and the basic fundamentals of diagnosis. I spoke with many men and women who have been experiencing hair loss for years but have never been tested. Hopefully, the women I spoke with, who I could tell, just by looking at their hair, have some form of alopecia, will get tested and will become a part of our growing network.

I look forward to getting to know all of you very soon as we work to find a cure for this disease.



Baltimore Health Fair organizer
Shaquetta Chittams and Shakia Gullette

The Measure of Beauty

Sandra Dubose-Gibson



Sandra Dubose-Gibson

I never knew how attached I was to my hair until I began to lose it. I know that in the big scheme of things, if you have to get diagnosed with having a rare disease, not having a life-threatening situation is the most important factor. At the time, at just 25 years of age, when all of the hair on my body was falling out due to alopecia universalis, it felt like a life-threatening situation. What would I look like and how would others relate to me if I was forced to look different indefinitely? The threat was not on my life but on my self-esteem. In addition to having alopecia universalis, I was diagnosed with cicatricial alopecia. My dreams of having my hair grow back had been shattered. I had to find the path to serenity, the ability to accept the things I cannot change, and the courage to change the things that I could.

Looking back now, eleven years later, my attitude has changed. I am not the woman I used to be. I'm stronger, wiser and better. No one ever signs up to go through a life-changing, traumatic experience. We live and learn that in life many things will be out of our control. Life happens to the rich and the poor, the black and the white, the old and the young. We each have personal challenges along our path that are designed to teach us and shape us into who we are

meant to be if we stay present to the lesson. 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. Sometimes it seems that some have more than others, and some things we will just never understand.

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 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 those are taken away.

At some point, we have to find a way to turn it around and make it a positive. If you dig deeper, you can stand taller than you ever knew you could and 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. You will find that the true way to measure your own beauty is by the smiles you put on the faces of others.

The Retreat That Roars

Rita Wanser



Rita Wanser, Sheila Belkin and Dr. Vera Price at the 2010 CARF Retreat

Over the past five years, CARF has made exceptional progress in accomplishing the objectives of our stated mission. To assure continued progress in fulfilling our mission, the CARF Board of Directors recently participated in a one-day retreat to review CARF's progress and set priorities for accomplishments in the next three years.

Priorities will focus on key areas that will provide a stronger infrastructure to advance CARF's mission. Priorities will be given to

streamlining the efforts of Scientific Advisors, Board members and patient members in fundraising activities and building patient and physician awareness and involvement.

We look forward to more of you becoming an active part of CARF's long-term growth, no matter how small or large the individual tasks, so you can make a great impact on other patients and the long-term viability of CARF. Stay tuned for more information!

Washington, DC, Area Support Group Up and Running

Beth Critchley

Thank you to everyone who attended our first meeting of the DC/MD/VA CARF support group. It was a great success.

We gathered at Valerie Callender's beautiful new office space and enjoyed tasty refreshments provided by Warner Chilcott, the pharmaceutical company that makes Doryx. There

were ten participants, plus co-leaders Alissa and myself, Dr. Callender, medical student Sophia Reid, and Corey Daniel from Dr. Callender's office.

We began with introductions. Going around the room, each person related their specific type of scarring alopecia and the challenges they are facing

with it. It was very powerful to be in a room for the first time with people who have the same problems as you. Everyone had similar stories, each with their own twist. We had a good mix of people representing different types of the scarring alopecias. It was impossible to tell from appearance alone that anyone there was suffering this type of hair loss.



Dr. Callender told us a little bit about her history and how, over the years, she has seen many patients with this type of hair loss. She learned more about it in order to help her patients but admits that many dermatologists still have a lot to learn about the disease. She told us of her involvement with CARF and also of the three clinical trials she is conducting on CCCA. She is excited for the future of this group and the things we can do.

Lastly, we fielded suggestions from everyone as to what they are hoping this group will provide for them. Many ideas were discussed, including:

- ◇ Patient support
- ◇ Developing lists of local resources

we can utilize, such as websites, listservs, hair stylists and wig shops

- ◇ Bringing in more experts to talk with us and discuss treatments that work
- ◇ Bringing in dermatologists who need to learn more about Cicatricial Alopecia and who can learn from us
- ◇ Presentations from wig experts and hair stylists with tips and tricks (and maybe discussions of insurance coverage for wigs, etc.)
- ◇ A presentation by a psychologist
- ◇ Presentations about nutrition (anti-inflammatory) and stress reduction

We talked briefly about the CARF conference and Dr. Callender mentioned

a Cicatricial Alopecia scientific conference coming up next spring, around which we might want to schedule some sort of event.

For the benefit of those unable to attend the CARF conference, we agreed to meet in early November to go over the information presented at the conference.

I think everyone will agree that we are very grateful that Dr. Callender has taken us under her wing by being our Medical Advisor and providing a very pleasant place to meet. A big thank you also to Sophia for helping us get organized and off to a great start and to Corey for her help with logistics and set-up.

Feedback from Conference

(continued from page 1)



“What a great time was had by all and what a fantastic panel of doctors.” *Patient from CA*



“Congratulations on a very successful meeting. The sessions were terrific - and patients were aglow with hope and having been heard/ shared their journey with those who truly understand.” *Patient from MA*



“So much information was packed into the conference and I met so many wonderful people that I didn’t want it to end. Many thanks to the doctors for taking the time to share their knowledge with us.” *Patient from CA*



“WOW. The patient conference was truly wonderful and I got so much from it. It was an honor to be there and to be a speaker. I was really inspired in many ways.” *Nancy FitzGerald, CARF friend*

Feedback from Conference

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“Thank you for a great conference. The information that we received was well worth the travel to LA from NJ. I learned so much about alopecia. I feel more confident in supporting my daughter as she deals with this disease, and I can already sense her greater confidence and empowerment in managing this very tough situation.” *Patient’s mom*



Congratulations for a wonderful and memorable conference. I think it surpassed everyone's expectations; all of my patients thanked me for persuading them to attend - they had no idea how helpful it would be. Everyone's comments gave the same positive and enthusiastic reaction. *Vera Price, MD*



“What a wonderful, amazing, and eye-opening conference.” *Nicole Rogers, MD*

Find That Spark in Sheila's Shoes

Sharon Dunas, MFT



Sharon Dunas, MFT

A famous author who wrote *The Power of Myth* said, "We have to let go of the life that we had planned and be open to the life that is here now, waiting for us." But in the beginning stages of the diagnosis of cicatricial alopecia, one's sense of self can be shattered. The continual burning, itching and scalp discomfort take their toll on our sense of who we are. What we present to the world can be what is reflected back to us, and this is how we tell our story. Once we get a diagnosis, we can begin to believe that our story and life will never be the same. Words like anguish, torture, devastation, loss and pain are how we begin to describe our sense of self. The life you have now can still be a beautiful life. It just takes some time to recreate this possibility. Einstein said that the main question in life to ask is: "Is it still a friendly world?" Yes, I can easily say that people are basically good at heart. They really are. And you still can have a wonderful life in spite of hair loss and hair disease. How does one learn to live beyond loss?

Well, first of all, you have to give up

being critical of yourself. Diseases of the scalp are no-fault illnesses. It is not your fault that your head has been kidnapped by a hair disease. You can give up the guilt you experience with hair loss. You did not cause your hair disease and hair loss, you cannot cure your hair disease, and you cannot control the outcome of your hair disease. When you are competent and used to completing tasks, it is a new spiritual experience to admit your powerlessness over a situation.

When our scalp is first kidnapped by disease, we go into shock. No, no, not me! Why did this happen to me? I am being punished for what I did when I was 15 to the neighbor's lawn. The shock leads us through a kaleidoscope of images and ideas. Then, the second emotional experience we have is denial. If I just wash my scalp from left to right, instead of right to left, I can beat this hair disease. This is the stage of denial and bargaining. If I make myself a better wife, a better mother, this punishing hair disease will go away. Then we go into anger. This can't be happening to me, or absolutely everything bad happens to me and I am mad as hell and I won't take it. We get irritable and angry with our significant others. I've got hair disease, and now you yell at me about a dirty kitchen; that is the least of my worries. "Do the dishes yourself," we wail.

Then, after the anger and the irritability, comes the recognition that it is not going to go away, and we fall into sorrow and feelings of utter devastation and grief. How can this be happening to me? It is true, bad things do happen to good people. I don't deserve this. I don't want this. I must be somehow responsible for this. We begin to cry and grieve our loss of a beautiful head of hair. We do this quietly when we are locked in the bath-

room. Slowly, we begin to accept it a little more, and we begin to feel safe enough to share our feelings about this loss. The grieving goes on for a very long time—for some a few weeks, for some a few months, or even for a year or two. Finally, when we come out on the other side of grief and suffering, we find there is a gift. OK, so my scalp is imperfect, so it really hurts and itches sometimes.

There is a Buddhist fable: "Go and knock on the door of any house in the village, and if you can find one house without suffering, pain and loss, then," the Buddha said, "I will remove your suffering." Of course, we can never find even one house without pain, loss and suffering. So we have to wear our suffering like a mantle. This is what the universe gave me to contend with. It could have been cancer. It could have been diabetes. It could have been mental illness. I could have a relative with schizophrenia, bipolar disorder or borderline personality disorder. Yes, it could be worse. And when you put it in that context: yes, I am suffering, yes, I can endure, and yes, I still have worth, and yes, my life still has value. I am not an Afghanistan vet with severed limbs. I am not one of the polio victims of old being able to survive only in an iron lung. Wow! You notice there is suffering everywhere and in every family. Think of all the families that have been kidnapped by cancer. Every one carries a burden of suffering. OK, so now that I understand there is suffering everywhere, what can I do with my suffering over hair loss and hair disease?

I can be like our bright cicatricial alopecia star, Sheila Belkin. I can use my suffering, my knowledge and my understanding of hair disease to help others who are in the same boat. I really do know what discomfort of the scalp is like. I really understand. I can

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Find That Spark in Sheila's Shoes

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let others know I understand and know their pain. I will again find my worth in spite of hair disease and hair loss by helping others. I can listen. I can validate others' lived experience of hair disease. I can tell others how I got through a long and lonely night of weeping over hair loss. I can tell others how I feel, now that I have allowed myself to grieve. I may not be as cute as Sheila or as short as Sheila, but I can do what Sheila does, which is to understand another's suffering, reflect back the pain and anguish they share, and then give appropriate referrals to doctors.

Yes, I can follow in Sheila's shoes and be another bright star and help others. I better ask Sheila what color shoes she wears. Is it best to wear blue shoes so I can listen to the softness and the sadness when someone is grieving? Is it better to wear red shoes so I can step out in my wigs and sashay around, swinging my hips so that—yes, in my wig with the swinging hair—I can be as sexy and flirty as anyone. Is it better to wear yellow shoes, the color of hope, so I can help others feel lighter and throw away that suffering and the feelings of loss for today? There is hope as new pharmaceutical products come out that may help more than the options presently on the market. I will feel less despair when I can offer some hope to others. Or I might wear green shoes. Green is the color of healing. We all know that green soothes a weary and troubled soul. We can let go when we wear green, and then we can allow ourselves to grieve and then accept. Yes, wearing green puts us on the path of healing. Or perhaps I will wear white shoes, the most spiritual color of all. When I wear white shoes, I can offer the thought of forgiveness, forgiving the self because I did not cause this disease on my scalp, cannot control it, and cannot single-handedly cure

it. Or is it better to wear white shoes that speak of courage? Yes, you have to have a little courage to step out from behind the shame of having a chronic disease and let the world know you are a person of worth and a person of value in spite of the goofy tufts of hair that are on your head.

In the end, people are drawn to your sense of humor, your intellectual interests, your emotional power, your sweet nature, or your adaptable ways. People are drawn to your emotional soul, whether you are in white shoes or green shoes or yellow shoes. People are not drawn to our looks. You forget what someone looks like in about 24 hours. It is your essence that holds people, not the amount of hair on your head. Yes, I can share with others the importance of forgiving the self and being kind to the self. I am doing the best I can with the knowledge I have about my disease and accepting it and going on to have a life anyway.

There is a wonderful poem that is sometimes attributed to Mother Teresa but was actually written by author Kent M. Keith during his sophomore year at Harvard. It goes like this:

THE PARADOXICAL COMMANDMENTS

- ✦ People are illogical, unreasonable, and self-centered.
Love them anyway.
- ✦ If you do good, people will accuse you of selfish ulterior motives.
Do good anyway.
- ✦ If you are successful, you will win false friends and true enemies.
Succeed anyway.
- ✦ The good you do today will be forgotten tomorrow.

Do good anyway.

- ✦ Honesty and frankness make you vulnerable.
Be honest and frank anyway.
- ✦ The biggest men and women with the biggest ideas can be shot down by the smallest men and women with the smallest minds.
Think big anyway.
- ✦ People favor underdogs but follow only top dogs.
Fight for a few underdogs anyway.
- ✦ What you spend years building may be destroyed overnight.
Build anyway.
- ✦ People really need help but may attack you if you do help them.
Help people anyway.
- ✦ Give the world the best you have and you'll get kicked in the teeth.
Give the world the best you have anyway.

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Giving the best you have is the essence of generativity. It is the legacy of wisdom, love and true power you can leave in your wake that may sustain itself for 100 years after you are gone. There is hope and life after hair loss. You have come out of hiding and have found CARF, which offers you a sense of belonging and community. I encourage you to keep your head held high, to let the world know you are a person of worth and a person of value, and to follow in Sheila's shoes in making others feel less alone.



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