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Cicatricial Alopecia Research Foundation
PO Box 60158, Los Angeles, CA 90064

CARF Communiqué

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Issue V

CARF Conference Sizzles!

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“Beyond our expectations” best describes CARF’s Third International Patient Doctor Conference that took place in Washington, DC this past September.

We had the largest conference attendance ever, as eighty-five enthusiastic folks gathered from seventeen states and as far away as Perth, Western Australia, Vancouver, Canada and London, England.

There were twenty-seven doctors present, including fifteen dermatology residents, fellows and medical students. These medical representatives came from institutions such as Boston

University, Henry Ford Hospital, Howard University, the National Institutes of Health, and the University of California, San Francisco.

The event included a potpourri of activities. Medical speakers discussed new insights, the latest available treatments, and cutting edge research about cicatricial alopecia.

Ten world-renowned hair loss specialists comprised an outstanding panel, providing new information and answering questions from the audience.

Most important, patients had an

opportunity to socialize with each other and meet in small groups to discuss intimate questions concerning their disease.

Among the entertainment highlights were the raffle drawing for a deluxe vacation package for two and the Liars Club game that took place after dinner on Saturday, which elicited great excitement and laughter. It was a memorable time for all.

Following are speech summaries and the comments of those who attended this successful conference.

Management of Cicatricial Alopecia

Vera Price MD



The first step in the management of a cicatricial alopecia is to establish the diagnosis. This is done through a combination

of careful clinical examination by a dermatologist and a biopsy of the scalp. Clinically, the hallmark is the loss of follicular openings on the scalp. A biopsy of primary cicatricial alopecia is characterized by inflammation that specifically targets the hair follicle, with scar tissue and progressive, permanent hair loss ultimately replacing the follicle. At present, the cause of these rare disorders is unknown.

A workshop sponsored by the North American Hair Research Society in 2001 proposed a working classification of the primary cicatricial alopecias based

on the biopsy findings and the predominant cellular infiltrate, whether lymphocytic, neutrophilic, mixed, or end stage and non-specific.

Working classification of primary cicatricial alopecia*

Lymphocytic group: Lichen planopilaris (LPP) and variant frontal fibrosing alopecia, central centrifugal alopecia, pseudopelade (Brocq), chronic cutaneous lupus erythematosus

Neutrophilic group: Folliculitis decalvans, tufted folliculitis, dissecting cellulitis

Mixed group: Folliculitis keloidalis, erosive pustular dermatosis

End stage and non-specific

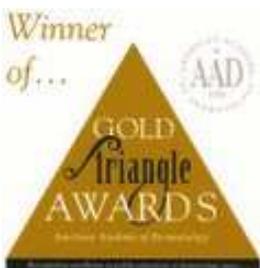
*Modified

The scalp biopsy does not distinguish the various clinical forms beyond separating them into the predominantly lymphocytic, neutrophilic, mixed group, and end-stage. That is why a dermatologist has to correlate the biopsy findings with the clinical picture. Nevertheless, this classification is a useful first step in guiding selection of treatment. The most helpful biopsy information is the type, location, and extent of the inflammatory infiltrate as well as the presence or absence of follicles and sebaceous glands.

The goals of treatment are to relieve signs, symptoms, and halt spread, but regrowth is impossible since there is destruction of follicles. Current therapies do not influence the underlying process nor necessarily arrest progression. Moreover, clinical activity may recur.

Keep your subscription to CARF’s news-letter up to date!

Only those who have made a donation or attended a CARF event will continue to receive this publication for the coming year.



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Spotlight on Central Centrifugal Scarring Alopecia

Amy McMichael MD

Patient Conference Feedback

"I just wanted to say how much I was enlightened by attending this year's conference. It really opened my eyes to the condition and, thanks to you guys, I am going to actively pursue getting my condition looked at by specialists."

Austin Daboh, patient from London, England

"I met so many people who are as passionate as I am in helping to raise awareness, provide support and ultimately find a cure for this disease. . . all in one place. I walked away from the conference with information, hope, and most of all a positive outlook on my own journey to self-acceptance."

Annette Moore, patient from Philadelphia, PA



What is CCSA?

For years, a scarring form of alopecia has been observed in African

American women, first called "hot comb alopecia" then later referred to as "follicular degeneration syndrome." Since no clear connection to hot combing seems to exist and hair specialists are still debating follicular degeneration, the more descriptive terms "central centrifugal scarring alopecia" (CCSA) and "cicatricial alopecia" (CCCA) were introduced for this type of hair loss.

This disease is most often seen on the crown of the scalp of African-American women, but can also be seen in men and Caucasian patients. It most often starts in African-American women between the ages of twenty-five and sixty-five years of age.

What does CCSA look and feel like?

CCSA is a scarring alopecia that usually occurs on the top center or crown of the scalp.

"The meeting was awesome, no doubt about this! Congratulations."

Maria Hordinsky MD, from Chair of Department of Dermatology, University of Minnesota School of Medicine, Minneapolis, MN

The area may start as a small area of itchy scalp with breakage of hair, and usually progresses to a large circular area of hair loss. Later, the hair loss often extends centrifugally in all directions. The scalp may become shiny smooth. Redness, pustules, and scaling may occasionally be present. CCSA may resemble other types of hair loss, such as female pattern hair loss. A scalp biopsy will clarify whether it is a scarring alopecia or not.

Some patients describe soreness, pain and itching, and others have no symptoms at all.

What causes CCSA?

The cause of CCSA is unknown, but suggestions have been made to relate it to traction on the hair, or chemicals used for styling, or chronic irritation from dandruff. For now, we do not have the answer to this question.

How is CCSA treated?

Most dermatologists will biopsy the scalp to diagnose CCSA, but sometimes the examination reveals CCSA so clearly that a scalp biopsy isn't necessary. In the active, spreading stage,

the biopsy shows white blood cells attacking the hair follicles. This attack leads to the destruction of follicles and eventual scarring, which, in turn, leads to hair loss in the area.

Once the diagnosis of CCSA has been made, the approach to management typically begins with prescription topical steroids and injectable steroids. Sometimes antibiotics or other oral medications are used to relieve symptoms, decrease the inflammation, and slow the spreading.

It may be warranted to decrease chemical exposures, treat underlying seborrheic dermatitis (dandruff) aggressively, and increase frequency of hair washing.

On-going Research for CCSA

There are many dermatologists interested in helping to find the cause and a good treatment for CCSA. For now, there is little funding for such research, but awareness is increasing, and groups like CARF will help granting agencies to recognize the importance of scarring hair loss and increase donations for research.

"The meeting was a huge success because of your wonderful planning and attention to detail. Great fun. Thank you for including me."

Amy Mc Michael, MD, physician from Wake Forest University School of Medicine, Winston-Salem, NC

"Our interactive conference was outstanding. It may be the best conference we have ever had. Everyone was 'abuzz.' It was a wonderful sight to behold and experience."

Gwen Powell Todd, patient from Jacksonville, FL

Research Update: Scarring Alopecia—New Breakthroughs

Pratima Karnik PhD



Primary cicatricial alopecias (CICALs) are immune disorders caused by an inflammatory attack on the hair follicle. Because the inflammation results in destruction of hair follicle regenerating cells, hair loss is permanent. Very little molecular information is available regarding the triggers that lead to CICAL.

To understand better the molecular signals, we carried out microarray analysis, using pairs of unaffected and affected scalp biopsies in patients with lichen planopilaris (LPP). Microarray technology allows the measurement of activity of thousands of genes at once.

This measurement helps to generate a global picture of the sample being tested. If biopsies from normal scalps (that is, of individuals without the disease) are used as references or controls, measurement allows us to compare multiple samples, including those of unaffected and affected areas from the same patient, those from different patients, and those of different cicals.

Using microarray technology, we have generated global pictures of unaffected and affected LPP. The global picture is a list of genes that show increased (up-regulated genes) or decreased activity (down-regulated genes) compared to normal activity.

Our microarray results showed that the majority of up-regulated genes in affected LPP tissue were either signals for tissue remodeling and cell death or inflammatory genes. These findings were expected because in-

flammation and scarring have been seen in routine pathology analysis. What was new and unexpected was that the microarray data also showed decreased activity of multiple genes in the lipid pathway: fatty acid β -oxidation, fatty acid desaturation, cholesterol biosynthesis and peroxisome biogenesis. This pointed to a new cause for disease and a possibly new treatment. However, we first have to understand why these lipid pathway genes behave differently in LPP.

Another interesting observation we made was that the increased activity of inflammatory genes was seen only in affected and not unaffected tissue. In contrast, the decreased activity of lipid metabolic genes was seen in both unaffected and affected LPP tissue.

This suggested that the lipid pathway changes are *early* or primary changes in the pathogenesis (that is, the origination and development of the disease) of LPP. Our results also suggest that the lipid pathway changes may be the major trigger-- the *cause* rather than the effect, of the inflammatory changes in LPP.

Using powerful computer analysis models of biochemical pathways, we identified the "master regulator" of these lipid pathway changes in LPP to be a protein called PPAR γ . PPAR γ controls the activity of other proteins that cause inflammation and those that control the lipid pathway. Such proteins are called transcription factors or master regulators.

This provided the first hint as to why the activity of inflammatory and lipid pathway genes are altered in LPP. To confirm our suspicion, we first measured the activity of PPAR γ in LPP and found that there is indeed a deficiency

(or decreased activity) of PPAR γ in both unaffected and affected LPP.

To prove that it is the decreased activity of PPAR γ that causes LPP, we created a mouse model where the PPAR γ gene is inoperative ("knocked out") in hair follicle regenerating cells. To our great surprise, this PPAR γ knock-out animal has hair loss as well as other biologic findings that are seen in humans with LPP. This confirms the role of PPAR γ (or the lack of PPAR γ) in causing LPP.

One question that we have yet to answer is what causes the decreased activity of PPAR γ in LPP. Whether the decrease in PPAR γ activity in LPP is the result of exposure to an environmental toxin or is caused by dietary or genetic factors will require further study.

However, the activity of PPAR γ is known to be increased by certain drugs called thiazolidinediones or glitazones. In the laboratory, we have shown that pioglitazone can increase the activity of PPAR γ in hair follicle cells. Thus, it will be interesting to see if increasing PPAR γ -activity by glitazones could decrease inflammation, loss of hair follicles, and scarring seen in LPP.

In summary, our work suggests that decreased activity of PPAR γ may be a possible cause of scarring alopecia. However, most human diseases are caused by changes in activity of multiple genes, and further studies in the PPAR γ knockout mice should help us understand how exactly PPAR γ deficiency causes hair loss and scarring in primary cicatricial alopecia. We are currently taking a similar approach in order to understand other cicals and to determine if PPAR γ is responsible for them as well.

CARF Successes

Sheila Belkin



Since its inception in 2004, CARF's achievements have been truly exceptional. We continue to uphold our mission to support research that will find more effective treatments and an eventual cure for cicatricial alopecia. We also support education, advocacy, and efforts to raise public awareness about this rare set of diseases.

Among our key successes is the contribution we have made to funding ten research projects since 2002. CARF-sponsored research is at the cutting edge of new insights into cicatricial alopecia. For example, CARF has just awarded Dr. Pratima Karnik a \$20,000 grant to test the hypothesis that PPARgamma regulation and function are critical to prevent inflammation, fibrosis and permanent hair loss in scarring alopecia (see Dr. Karnik's article on PPARgamma in this issue).

Another success occurred in 2005, when CARF Scientific Advisors spearheaded the First Cicatricial Alopecia Research Colloquium in Bethesda, MD. Eighty researchers from various scientific and medical disciplines gathered from around the world to share ideas and discuss the focus of future research.

There are more than six hundred patients and five hundred doctors in the CARF database. Each day, our volunteers provide email and telephone support, make doctor referrals, and send out educational materials to our patients. We ask physicians to tell their patients about CARF, and we find dermatologists who are willing to treat patients with hair loss.

CARF is a member of national organizations such as the Coalition of Skin Diseases, NIAMS Coalition (National Institute of Arthritis and Musculoskeletal and Skin Diseases) and the National Organization of Rare Disor-

ders. These memberships give us the opportunity to meet, share information, and educate others about cicatricial alopecia. In addition, our team of scientific advisors speaks at medical meetings to educate other dermatologists.

An important advocacy event that members of CARF attend each year is "Skin Disease Research Day," sponsored by the American Academy of Dermatology and the Society of Investigative Dermatology. At this meeting, CARF representatives meet with legislators to petition for more funding of research at the NIH (National Institutes of Health) for all types of skin diseases.

Descriptions of the creative ways that CARF has raised awareness about cicatricial alopecia may be found on CARF's award winning website, in our newsletter, *CARF Communiqué*, on our newly produced video, and in articles appearing in professional magazines such as *Dermatology Times*, *SID News* and *Skin and Aging*.

Producer Frank Zamacona directed and shot the first CARF video, "Cicatricial Alopecia," in San Francisco. It received rave reviews and can be seen on our website and on YouTube. After viewing this short film, one patient remarked, "When I saw the video, I heard someone talking about feelings that I was having about my disorder. I realized that I am not alone. This is a video from which patients, families, and friends can benefit. It tells the *whole* story of cicatricial alopecia."

CARF has also made great strides in educating nurses about this disease. Two in-depth articles about cicatricial alopecia, written by a doctor and a patient, appeared in the *Dermatology Nurses Association Journal*. Vera and I have been invited to speak at the 2009 Annual Dermatologic Nurses Association Conference. This is another way CARF continues to bring awareness to health professionals.

Other recent achievements include:

1) Two Gold Triangle Awards in 2006 from the American Academy of Dermatology for excellence in public education of dermatologic issues: one for the CARF website and one for the First CARF International Patient Conference.

2) Recognition and special commendations for CARF's founders by Congress for outstanding and valuable service to the community.

Last year, a fundraiser honoring Vera Price boosted CARF's income to \$124,000, which went up fivefold from the previous year. In addition \$46,455 was donated in-kind and by pro-bono services. This means that fifty-two percent of our necessary expenses in 2007 was funded through donations. We always welcome and appreciate such donations. CARF became fully operational on August 1, 2005, when we received 501(c) 3 status. Donated monies received prior to that time have been held in a fund at UCSF, which is restricted for research only. Since our researchers donated their time and charged very little for the various components of their studies, CARF has spent relatively little of its income. In December 2007, in fact, CARF had \$30,000 remaining at UCSF, and \$104,481 in the CARF bank account. Still, as we look ahead to future projects, we realize how much more funding we'll need in the years ahead, and we count on you, our community of supporters, to help ease this burden.

As we look toward the future, a plan is already in place for the first Monograph and Atlas on cicatricial alopecia. The book will be published and distributed to dermatology residents in every medical school in the country. It will also be sold to dermatologists.

CARF is a grass roots organization that works collaboratively. We have successfully enlisted the help of fellow patients and dedicated, empathetic doctors and friends. This is your organization. I encourage you to get involved to learn more about volunteering and fundraising opportunities. We need your help!

CARF International Patient Conference



Everyone is enjoying the patient conference



Speakers and panelist from front row: Sheila Belkin, Drs. Pratima Karnick. Amy McMichael, Maria Hordinsky, Lynne Goldberg, Kimberly Salkey, Len Sperling, Moderator, Drs. Valerie Callender. Vera Price, Donna Weaver and Ken Washenik.



Winners of Liars Club game with CARF mugs and candy kisses.



Wendell Primus, Senior Policy Advisor to the Speaker of the House discussed national health issues and is presented with certificate of appreciation.



Drs. Valerie Callender and Yolanda Lenzey.



CARF Board of Directors meet at the Conference: Front row, Dr. Jerry Shapiro, Sheila Belkin, Gwen Powell Todd, Rita Wanser, Dr. Vera Price and Dr. Ken Washenik. Absent are: James Aleveras, Richard Dunsay and Sharon. Absent are: James Aleveras, Richard Dunsay and Sharon **Potter**.



Residents with Dr. Amy McMichael on top right.

Turning It Around: A Patient's Perspective

Donna Dreher Weaver



I'm a Native New Englander and oldest of seven children. Raised and educated in Boston, various parts of New Jersey, and Chicago, I now live in northern CA, where I have taught marketing and management courses at the college and university level for twenty-seven years.

I'm also a newlywed, the mother of two, the stepmother of five, and the grandmother of four, going on five, children. I met my husband, John, after five years of on-line dating – and about ninety first dates! My hair loss served as a kind of litmus test: Could I ever imagine telling this guy about it? If not, next!

When John and I had been dating about two weeks, I told him that I had a rare hair loss disorder and wore a small hair-piece on the top of my head. His re-

sponse: "I wouldn't love you any less if you were as bald as I am!" Relieved and reassured, I laughed and told him that I couldn't promise that it wouldn't come to that.

I have also been a CARF volunteer for four years, almost since its inception.

The last eight months have been eventful. Besides recuperating from a car accident (which occurred just hours before I received an email from Sheila Belkin requesting the title of my talk for the 2008 Conference), I have been busy with the marriage of two of our daughters, a temporary relocation to the Bay Area, new jobs, and layoffs. You get the idea. I am glad to be turning a new page.

About my hair. When I was growing up, people often commented on my unruly, curly hair, and, in my elementary and junior high school years, it was the source of much teasing. In eighth grade, I saved up my babysitting money and had my hair straightened for the first time. That day marked the beginning of four years of high-maintenance hair

care: regularly-scheduled straightening and—to boot!-- sleeping on enormous curlers and juice cans each night. Still, my curly hair and frizz often overrode my efforts to keep them in check.

During my college years when I couldn't afford haircuts, my best friend nick-named me "Moptop." When I began online dating over three decades later, that was the name I used on my profile.

Several years ago, a friend asked me what my hair would look like if, instead of the controlled and cap-like coif I tried so hard to maintain, I wore it long and curly. I decided to see. Occasionally, someone who remembers my old hairdo will ask "What are you thinking?!" Echoing these notes of disapproval is the crack I imagine my grandmother would make if she saw me now: "Donna, your hair looks messy, like an unmade bed." Most days, however, I feel like my hairstyle suits me.

So, how did this wild-haired woman wind up as a speaker at the Conference? I first experienced symptoms of cicatricial

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Profiles in Giving: Super Volunteer Nancy FitzGerald

The accompanying photo shows Nancy FitzGerald, one of our many extraordinary volunteers, talking on her cell phone. She remarks that this is how we can "usually find her"—but the truth is, Nancy FitzGerald may be found just about anywhere, doing just about anything, when it comes to helping promote the field of dermatology.

Nancy received a B.S. in Speech Communications, cum laude, from Emerson College in Boston, followed by graduate management studies at New York University. She began her career in corporate public affairs at PepsiCo World Headquarters and then enjoyed many years in media, community relations, public relations consulting and coaching for professionals, non-profit organizations, and businesses. In between all this activity, Nancy has also produced and co-hosted various radio and television programs. She has also published

numerous articles in newspapers and magazines.

Supported by more than twenty-five years of experience in these areas, Nancy has made invaluable contributions to the field of dermatology. Currently, she is the Director of Communications for the Women's Dermatologic Society (WDS), a position she earned after working with WDS and the Women's Dermatological Society Foundation (WDSF) on the "Play Safe in the Sun" campaign beginning in 2004. She now handles a variety of communications duties for this dynamic organization.

Nancy has served as a volunteer and board member for several non-profit organizations over the years. She especially enjoys working with the CARF family to support the growth of what she calls "this wonderful organization."



Nancy FitzGerald,
CARF Volunteer

Turning It Around

Continued from page 7

alopecia in 1995. A biopsy one year later indicated that I had LPP (lichen plano pilaris). During the course of eight years of treatment with topical medications and, occasionally, injections, I became anxious and sad as my symptoms increased: itchiness, pain, and increasing hair loss in an elliptical pattern on the top of my head, requiring that I wear a small hairpiece.

In the spring of 2004, I learned about Dr. Vera Price at UC, San Francisco. Dr. Price's examination and treatment were a turning point for me. She told me I have "central elliptical" alopecia and provided me with appropriate treatment.

Dr. Price also invited me to join a recently founded volunteer organization (CARF) to provide patient education and support and raise funds for cicatricial alopecia research. In August 2005, a small group of CARF volunteers (including co-founders Sheila Belkin and Dr. Vera Price) organized and facilitated our first patient conference in San Francisco. I was hooked on the prospect of continuing our good work.

In early 2006, my cicatricial alopecia was relatively "quiet." Dr. Price spoke about my condition to Dr. Ken Washenik, Medical Director of Bosley. Dr. Washenik examined my scalp and recommended

that I first have "scalp reduction" surgery, which involved cutting out the bald area.

In October 2006, Dr. Sheldon Kabaker of Oakland, CA performed the scalp reduction. Now, two years later, I'm experiencing little ongoing hair loss. My bald area is about half the size it used to be. I no longer wear a hairpiece. I am lucky! Now, a couple of bobby pins and my curls cover up the spot.

I have recently added another tool to my "health and wellness" arsenal: adopting a more anti-inflammatory lifestyle. Upon the advice of my "functional medicine" physician, I am following a low glycemic index diet, taking nutritional supplements, exercising and attempting to reduce stress. My scalp seems to be benefiting and I am experiencing very little crustiness or inflammation.

I know that each of us is unique in many respects, including the type of cicatricial alopecia we have, our personality, and our support system. Without preaching, I simply want to share what works for me:

Allow yourself to feel what you feel: sadness, anger, frustration, confusion, uncertainty, hope, relief. To the extent you can, try to put cicatricial alopecia in perspective, relying on your sense of

humor, if possible.

Learn what you can about cicatricial alopecia – and the experts treating it -- so you are informed adequately about your condition. Rely on and partner with the experts.

Make decisions with your physicians about medications you're able to tolerate. Choose aesthetic solutions that fit your needs and lifestyle.

Focus on restoring and maintaining your health -- and, perhaps, reducing your hair loss symptoms -- by committing to a healthy, anti-inflammatory lifestyle.

Volunteer for CARF. Network. Help to educate others. Join or form patient support groups. Help raise funds to support cutting-edge research projects.

Recently, while vacationing in North Conway, NH, I laughed aloud while walking past a store display. I saw a magnet depicting a wild-haired redhead that said, "You can't control everything. Your hair was put on your head to remind you of that." How appropriate. We can't control our hair or our hair loss – or much in our lives. But, we can try to have a positive impact on our health, on our lifestyle choices, and on the lives of others facing cicatricial alopecia.



Host Dr. Valerie Callendar with other happy guests.



On site "A" Team, Latasha Stephens, Beth Adeson and Janet Wisian.



Ken Washenik leads "Liar's Club" game.

Tips and Tricks for Dealing with Cicatricial Alopecia

Attendees at this year's physician/patient conference took part in a "Tips and Tricks" session where they shared ideas for dealing with cicatricial alopecia. While CARF does not endorse any specific products or practices, we do support patients helping and learning from each other. To this end, we include the following suggestions:

Topical Treatments and Shampoos:

The frequent dryness, scaling, and itching were discussed by many. Several patients recommended Neutrogena's T/Sal Shampoo to help limit scaling. Other patients liked "Head and Shoulders Intensive Solutions Shampoo," which contains zinc and helps control dry scalp itching; some commented that it produces very little friction when rubbed into hair. Others recommended shampoos with dimethicone for conditioning hair. The use of scalp brushes and vigorous shampooing were recommended to combat the scaling that often accompanies cicatricial alopecia.

Cover-ups (hats, scarves): Patients discussed and demonstrated the use of scarves and hats to hide hair loss while looking stylish. These products may be purchased at local stores and are available online. The National Alopecia Areata Foundation (NAAF) has a "marketplace" (www.naaf.org/aamarketplace.html) where people with hair loss may purchase good-quality products. One NAAF marketplace site that provides a full line of headwear was recommended by an attendee: www.domadesigns.com.

Hairpieces: One patient reported that she covers the bald area on the top of her head with a hairpiece cut to the specific dimensions of her bare area; this is done by her hair stylist who works with American Hairlines products (www.americanhairlines.com). Made of human hair on an ultra light-weight backing, the piece was dyed to match her own hair color. It was then affixed to her scalp using dual-sided tape (TDI Dura-Flex tape or mini-contours). Depending on what hair products and topical medications you use, this particular type of tape may allow you to attach your hairpiece to your scalp for weeks at a time. Another source for hairpieces that was recommended by several

workshop attendees was www.extensionsplus.com. Located in Los Angeles, this company offers custom and ready-made products, including both hair extensions and wigs.

Camouflage Products: Workshop attendees were also provided with information about some cosmetic options for covering hair loss. Some patients choose to camouflage their hair loss with the use of hair-thickening, color-matched, keratin protein products, such as Toppix, Nanogen or Organin. Others use hair powders, such as Bumble and Bumble Hair Powder or Salon Graffix Powder Shampoo. Others recommended creams that match the color of your hair and may be applied to the scalp to make hair loss less apparent (for example, DermMatch, CRC Concealing Color, Shapley's Show Touch-Up or Tween Time Hair Color Touch-Up Sticks). Sites for purchase of these products may be found by "Googling" the product name.

One of the patients demonstrated her easy technique for "creating" very natural-looking eyebrows, using a wax-like base, then applying hair-like fibers infused in powder. She highly recommended a smudge- and water-resistant product purchased at www.ditzycosmetics.com; another patient described a similar product made by Smashbox.

Nutrition and General Health Tips:

Since cicatricial alopecia is an inflammatory condition, it makes good sense to reduce inflammation via diet, nutritional supplements, exercise and relaxation/ stress reduction. Several patients noted having experienced the stress-reducing benefits of yoga.

One of the facilitators recommended two books her physician had suggested: [The Anti-Inflammation Zone: Reversing the Silent Epidemic That's Destroying Our Health](#), by Dr. Barry Sears; and [The Inflammation Syndrome: The Complete Nutritional Program to Prevent and Reverse Heart Disease, Arthritis, Diabetes, Allergies, and Asthma](#) by Jack Challem. Both sources present dietary guidelines,

focusing on a low Glycemic Index diet, comprised of regular meals and snacks (consisting of fruits and vegetables, lean protein and healthy fats) throughout the day, including a first meal within an hour of waking. Further, these books recommend that individuals take nutritional supplements, including high-quality fish oil (Omega 3), to optimize health and reduce inflammation. Herbal teas including chamomile and green tea are considered anti-inflammatory, as are spices such as turmeric, ginger, oregano and garlic. A couple of participants noted that an herbal product Zyflamend (sold at health food stores) contains many of the herbs that are said to have anti-inflammatory properties.

Also recommended was Dr. Andrew Weil's website: www.drweil.com. On this site there are numerous dietary and lifestyle guidelines, including avoiding artificial sweeteners, high fructose corn syrup and various oils (coconut, corn, cottonseed, palm, soybean, safflower, sunflower, etc.). It is also worth looking at Dr. Weil's "Anti-Inflammatory Diet Food Pyramid," which recommends emphasizing fruits and vegetables, whole and cracked grains, healthy fats (such as extra virgin olive oil and freshly ground flaxseed) and lean sources of protein. While there is no promise that these anti-inflammation tips will affect cicatricial alopecia positively, testing them may be worth a try--especially since most of them have other important health benefits.

Exercise is so important in the management of many disorders, not to mention critical to a healthy lifestyle. Fourteen years ago patient Nancy Gates discovered deep-water exercise in a pool using a flotation belt. Noodles work too. A big advantage? You do not have to get your hair wet! Here is a photo of Nancy (in deep water, wearing a wetsuit jacket) doing her thing: http://www.ptinnovations.com/svc/pti_svc_02.html.

One Last Tip: If none of these suggestions seems appropriate for you (or even if they do), you might want to try to infuse your life with a little humor. The magnet "You Can't Control Everything. Your hair was put on your head to remind you of that." is available for purchase at the website www.shoplucys.com.

Management of Cicatricial Alopecia

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A standardized patient assessment chart is used to track response to treatment. We score symptoms (pruritus, pain/tenderness, burning) clinical signs (perifollicular erythema, perifollicular scale, erythema, pustules/crusting, anagen pull test (anagen hairs/total hairs), and clinical impression of spreading. The chart is used to follow three specific end-points at each visit: severity of patient-reported symptoms, physician assessment of disease activity, and progression of hair loss.

For the predominantly lymphocytic group: immunomodulating agents:

Oral: hydroxychloroquine 200 mg BID* or doxycycline 100 mg BID, or mycophenolate mofetil 0.5 gm BID for 1st month, then 1 gm BID for 5 months, or cyclosporine 3 to 5 mg/kg per day, or 300 mg/day for 3 to 5 months

Topical: high potency corticosteroids, topical tacrolimus or pimecrolimus, Derma-Smoother/FS scalp oil

Intralesional injection: triamcinolone acetonide, 10 mg/cc, to inflamed, symptomatic areas on the scalp

*BID = twice daily

Using the standardized patient assessment chart, we have been able to gather for the first time evidence-based (objective) data on some of these treatments: hydroxychloroquine (Plaquenil) and mycophenolate mofetil (CellCept) are significantly effective in many, not all, patients with LPP.

For the predominantly neutrophilic group: antimicrobial agents:

Repeated culture and sensitivities of pustules & crusts to select antibiotic

For *staph aureus*: oral rifampin 600 mg daily and clindamycin 300 mg BID for 10-12 weeks. May substitute ciprofloxacin 500 - 750 mg BID, or cephalexin 500 mg QID, or doxycycline 100 mg BID, given with rifampin.

For dissecting cellulitis, folliculitis keloidalis: isotretinoin helpful in some patients. Starting dose must be small

Topical: clindamycin solution/lotion; Derma-Smoother/FS oil, corticosteroids, intralesional injection: triamcinolone acetonide as above *QID = 4 times daily

So far, this sounds straightforward, so why is management of the cicatricial alopecias so difficult? In reality, biopsy findings and clinical picture may change over time. The response to treatment is not always what is

expected: a predominantly neutrophilic inflammation may respond to immunomodulating agents and not to antibiotics. The fact that the cicatricial alopecias are rare adds to the difficulty. In a recent survey, the annual incidence of lichen planopilaris in four major hair centers is only 1.2% to 7.6% of all new hair loss patients. Consequently, patients are not always seen by dermatologists who have treated many cases. And biopsies are not always read by dermatopathologists who have seen many cases.

Because of the presence of CARF, the cicatricial alopecias are now the hot topic at national, regional and local dermatologic meetings. Dermatologists at this conference are amongst the experts who are teaching our colleagues how to diagnose and manage cicatricial alopecia. CARF's presence in Washington with the Coalition of Skin Diseases, and its work with the Women's Dermatologic Society, have all helped to bring these disorders to the attention of researchers. And researchers like nothing better than a field where little is known and there is lots of room for new discoveries.

And keep in mind the good news: these disorders do not affect general health, are not contagious, and occur in otherwise healthy, beautiful people.

Inaugural Wine and Cheese Fundraiser

Vino 100, 704 Mangrove Avenue, Chico, CA—Tuesday, December 9th, 2008, 5:30 p.m.—7 p.m.

We need your support! Believe it or not, this is the first CARF event of its kind in the country!

Please join us for an evening of relaxation and fun — enjoying good company, sipping fine wines, nib-bling yummy hors d'oeuvres and bidding on great prizes. **All donations are tax-deductible** and all proceeds will benefit CARF, the Cicatricial Alopecia Research Foundation. It's all for a great cause: educating and supporting patients as well as funding research to find a cure for cicatricial alopecia.

Cicatricial (or scarring) alopecia is a very rare inflammatory disease — with no known cause and no known cure. It's so rare that the average dermatologist may

see one case in his or her entire career. It's not contagious and doesn't have a genetic link. Patients experience permanent, generally progressive, hair loss and, often intense itching and painful "hair on fire" symptoms — plus a wide range of accompanying emotions, as you might expect.

CARF was founded less than five years ago by a patient and her physician. Since then, run entirely by a small group of volunteers, CARF has been awarded two prestigious "Golden Triangles" by the American Academy of Dermatology. A non-profit organization supported entirely by donations and grants, CARF now serves and advocates for approximately 800 patients around the country — and throughout the world.

CARF has sponsored a research colloquium and funded promising scientific research. CARF has also been instrumental in educating and supporting patients via its newsletters and website, San Francisco support group, and patient/physician conferences. Two Chico patients attended CARF's recent conference in Washington, DC, one of us a featured speaker and meeting facilitator. It was there that this fundraising idea was "hatched." We're committed to making a difference!

Please join us for an enjoyable evening, celebrating the successes of this remarkable organization — and supporting the important contribution CARF is making in the lives of cicatricial alopecia patients.

Yoga: the Practice of Awakening the Moment

Kim Fisch

Before you read this article, please do the following. Get comfortable in your seat. Root down through your pelvis and extend tall through your spine. Lift your chest and roll your shoulders onto your back. Slow down and deepen your breath. Fill your lungs slowly as you inhale- expand the breath inside your chest. Exhale, and move all breath out completely. Allow all thoughts and emotions to be quieted down by your breath. Close your eyes, and take at least ten more of these slow, sustained breaths. Once you have finished, pause for a moment to reflect on this experience.

“Exhale and move all breath out completely. Allow all thoughts and emotions to be quieted down by your breath.”

I am a yoga teacher and practitioner in Los Angeles. I believe firmly in yoga as a healing practice of self-knowledge, in which we awaken to the present moment. When Sheila Belkin asked me to contribute an article on yoga for CARF, I wasn't sure what I wanted to write. However, I knew that I wanted the article to offer inspiration. I know Sheila because she is a regular student in my yoga class (she is an inspiration to me, and if you have ever met her, I am sure you can understand why).

The main form of yoga I practice and teach is called Hatha yoga, which explores postures, movement, and breath. I was first introduced to yoga in 1997, after spending most of my life as a dancer. I noticed immediately that Hatha yoga offered a completely different way of experiencing movement in the body. Yoga has nothing to do with competition or performance. Rather, it is a therapeutic practice, which emphasizes balance between the physical, mental and spiritual aspects of being.

Yoga was developed in India thousands of years ago as a method of self-understanding. The word yoga means “union” or “integration.” Yoga is the harmo-

nious relationship between the body, the mind, and the spirit. It is a method that aligns the systems of the body with both steadiness and ease.

Some of the many benefits of yoga include developing strength and flexibility (in both body and mind); improving circulation for blood and lymph; enhancing digestion; strengthening the immune system; and calming the nervous system. Through yoga, practitioners cultivate clarity and joy, enjoying increased health, vitality, and overall well-being.

“Through yoga, practitioners cultivate clarity and joy, enjoying increased health, vitality, and overall well-being.”



Because of its soothing effects on the nervous system, practitioners experience reduced stress and anxiety. If done well, yoga should feel liberating, empowering, and relaxing.

If you tried the breathing exercise I described earlier, you may have experienced a unique change. When we close our eyes, slow down and deepen the breath, we are immediately brought into the present moment. Breathing consciously brings focus to the mind and relaxes the physical body from the cellular level. The running com-

mentary that is usually going on inside the mind is quieted. We enter a state of being that is fully engaged in the present moment and we may feel a connection to some deeper level of understanding.

When I practice yoga, I experience the wholeness of myself. I observe a deeper, knowing self, who is able to be fully present in the moment. When I practice yoga, I feel my entire being alive and connected to the world. I am firmly grounded in myself, and able to relate to others in a peaceful and respectful way. It is through daily practice that I enjoy the benefits of yoga- necessary vitamins and minerals for my soul!

My understanding of cicatricial alopecia is that it is a condition that requires a warrior spirit. It requires strength to be able to see beyond the forms in which it manifests itself, and then surrender to forces beyond our control. When we come to terms with any disease, injury, or weakness, we always have the choice about how to approach it. We can do our best to understand the condition, take appropriate methods for healing, and then appreciate the delicate balance of living in a body that is temporary and impermanent.

“When we come to terms with any disease, injury, or weakness, we always have the choice about how to approach it.”

It is with courage that we can see beyond the forms of disease, experience the beauty within, and sit comfortably with the way the world is.

Practicing yoga can be a healing process that involves self-acceptance and non-judgmental awareness. It is an empowering practice, which allows us to experience the joy of living in a body. With time, the practice of becoming present alters our perspective of ourselves, our concept of time, even our perception of the world. It is transformative because we make the conscious effort to move toward change and experience the truth of who we are.



C. A. R. F.

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Check out CARF's award-winning website: www.carfintl.org

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Sign Up Now for eScrip and Help CARF Fund Research

Just in time for the holidays -- CARF has enrolled in the eScrip fundraising program!

You can benefit CARF without any out-of-pocket expense.

Shop for groceries, airline tickets, holiday presents, and dine out.

eScrip is a simple, year-round fundraising program. Participating merchants contribute a percentage of your purchases made on your credit or debit/ATM card to CARF.

Invite your extended family and friends to support CARF by joining eScrip and designating CARF as the organization they wish to benefit.

Check out the eScrip website (www.eScrip.com) to view participating merchants.

How does the eScrip program work? In four easy steps!

1. Sign Up – It's Free! Go to www.eScrip.com and select CARF to be the beneficiary. CARF's Group ID # is **500020699**.
2. Shop – Retail or online. Visit the family of merchants for a complete list of eScrip partners.
3. Invite your family and friends to participate, too.
4. Review your monthly purchase report and see how

much you have contributed to CARF.

Funds generated with your purchases will be deposited directly by eScrip into CARF's bank account each month and will support CARF's ongoing patient support, patient education, and research to find better treatments and a cure for cicatricial alopecia.

Please sign up today. Thank you in advance for your help.

We'll be sure to keep you posted on the success of this new fundraising effort!

We're "On Fire For Research and A Cure!"