



C . A . R . F .

Inside this issue:

- CARF Research Update: CARF AWARDS RESEARCH GRANT TO DRS. HARRIES AND PAUS 2
- Can You Recognize This Skin Disease? 2
- Clinical Aspects of Cicatricial Alopecia: A Quick Overview. Len Sperling, MD 3
- "Are We Close to Multiplying Hair Follicles? And Will it Help?" Ken Washenik, MD, Ph.D 4
- Scientific Advisor Profile: Valerie Dawn Callender, MD 4
- Bald Woman is "Crowned Regal". Annette Moore 5
- Why Am I Involved in CARF? Rita Wanser 6
- CARF Wine & Cheese Fundraiser 8
- CARF Donors for 2009 9
- Save The Date! 10

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

BREAKTHROUGH DISCOVERY IN HAIR BIOLOGY PAVES WAY FOR TREATING SCARRING HAIR LOSS

The press release printed below was distributed recently by CARF. It announces a major discovery that could well lead to better treatment for cicatricial alopecia. Read on and learn the inspiring news!

"BREAKTHROUGH DISCOVERY IN HAIR BIOLOGY PAVES WAY FOR TREATING SCARRING HAIR LOSS"

Collaborative scientific research reveals link between rare group of hair disorders and a defect in lipid processing.

SAN FRANCISCO, March 12, 2009 - A breakthrough discovery in understanding hair biology paves the way for developing better treatments for cicatricial alopecia (scarring hair loss), an inflammatory permanent hair loss. The unprecedented findings link a defect in lipid processing to these rare and painful hair loss disorders.

In collaborative scientific re-

search, Principal Investigator Pratima Karnik, PhD (Case Western Reserve University), Paradi Mirmirani, MD (Case Western Reserve University and University of California, San Francisco) and Vera Price, MD (University of California, San Francisco), found that unprocessed lipids set the stage for developing scarring hair loss. The work suggests that either processed lipids are necessary for hair growth or unprocessed lipids are toxic.

These clinical studies corroborate similar studies performed in mutant mice. In preliminary studies, the researchers found that treating patients with drugs that enhance lipid processing relieved the clinical symptoms and signs of the disorder.

Karnik P, Tekeste Z, McCormick TS, Gilliam AC, Price VH, Cooper KD, Mir-

mirani P. Hair Follicle Stem Cell-Specific PPAR gamma Deletion Causes Scarring Alopecia. *J Invest Dermatol* 29:1243-1257, 2009.

According to George Cotzarelis, MD, director of the University of Pennsylvania Hair and Scalp Clinic, who has been treating this group of hair diseases for more than fifteen years, "This research represents a great leap forward in the field of scarring hair loss. The study may lead to more effective treatments and, one day, possibly prevention of scarring hair loss, now an extremely difficult problem for both patient and physician. This work may also provide insights into other skin diseases."

This groundbreaking work was supported in part by the Cicatricial Alopecia Research Foundation (CARF). Visit: www.carfintl.org.

CARF Does It Again!

CARF wins a 2009 Gold Triangle Award for our newsletter, CARF Communiqué. The American Academy of Dermatology, at its Annual Meeting in San Francisco in March, recognized CARF as a health organization for excellence in furthering public understanding of derma-

tologic issues and encouraging healthy behavior in the care of hair. "As a patient afflicted with this previously neglected group of rare diseases, I accept this tribute on behalf of our patients, our volunteers and our dedicated dermatologists", said CARF CEO, Sheila Belkin.



AAD President C. William Hanke, MD, FAAD, presents award to CARF.



CARF Research Update: CARF AWARDS RESEARCH GRANT TO DRS. HARRIES and PAUS



Dr. Ralf Paus

A \$20,000 research grant was awarded by CARF to Drs. Harries and Paus for their project, “*Characterization of hair follicle bulge immune privilege status in lichen planopilaris.*”

They have shown the bulge region of normal human hair follicles to be a site of relative immune privilege (Meyer K et al. *Br J Dermatol* 2008; 159: 1077-85) and propose that these mechanisms protect the epithelial hair follicle stem cell niche from immune-mediated damage and potential follicular destruction. In cicatricial alopecias it is likely that the regenerative potential of the hair follicle is exhausted by inflammation-based loss of epithelial hair follicle stem cells from the bulge region. Therefore, loss of bulge immune privilege may play a central role in this process. They will study and characterize the role of human hair follicle immune privilege status in lichen planopilaris. If successful, their

findings will significantly contribute to our knowledge of the mechanisms underlying cicatricial alopecia. The work will be carried out at the University of Manchester United Kingdom.

Dr. Ralf Paus is professor of dermatology and experimental dermatology at the University of Lübeck, Germany, where he has served as head of experimental dermatology since 2005. He has also held the position of professor of cutaneous medicine at the School of Translational Medicine, The University of Manchester, since 2008. His main research interests are biology and pathology of the hair follicle, neuroendocrinology of the skin, and immune privilege. His clinical interests focus on disorders of hair growth and hair pigmentation.

In addition, Dr. Paus is editor of the journal *Experimental Dermatology* and section editor of the *Journal of Investigative Dermatology*.

Dr Matthew Harries MRCP (UK) received his medical degree from the University of Leeds, UK. Upon graduation, he worked as a junior doctor in various medical specialties and thus gained broad experience in all aspects of adult internal medicine. In 2001, he gained membership in the Royal College of Physicians of London (UK) and in January 2003 took a post as a Resident in Dermatology in Manchester. Currently, he works as a research fellow in dermatological sciences at The University of Manchester, where he studies the hair immune system in cicatricial alopecias.

Dr. Harries has also been a visiting Research Fellow in Experimental Dermatology at the University of Lübeck, Germany, following his award of the Geoffrey Dowling Fellowship from the British Association of Dermatologists. In addition to his research commitments, he heads a monthly hair clinic in Manchester.



Dr. Matthew Harries

Can You Recognize This Skin Disease?



Lichen planopilaris

The Coalition of Skin Diseases (CSD) recently produced a 4-color poster, which was mailed to more than 4,000 dermatologists nationwide to hang in their examination rooms.

The poster features photographs of the 16 different skin diseases - including cicatricial alopecia - that CSD represents. Bullet points describing the cicatricial alopecias, a photo of an affected patient, and CARF's website are all on the poster.

This poster is a wonderful tool for generating public and medical awareness of cicatricial alopecia, and was funded by the Vaseline Skin Fund. CARF wishes to express gratitude to this organization for its generosity.

Following are speech summaries by Drs. Len Sperling and Ken Washenik from CARF's 2008 Third International Patient Doctor Conference in Washington DC:

“Clinical Aspects of Cicatricial Alopecia: A Quick Overview”

Len Sperling, MD



Len Sperling, MD

Cicatricial alopecia is separated into primary cicatricial alopecia, in which the hair follicles are the *targets* of the disease, and secondary cicatricial alopecia, where the hair follicles are “innocent bystanders,” (as seen in severe burns, scalp infections, etc.). This discussion will focus on just the primary cicatricial alopecias.

The list of names assigned to these diseases is fairly lengthy and a bit confusing because some authors have assigned different meanings to the same terms. The North American Hair Research Society developed a “working” (tentative) classification of primary cicatricial alopecia based on biopsy findings. Since biopsy findings are not a subject for this article, I will instead explore a simplified classification of cicatricial alopecia. This includes five fairly well-defined entities and a sixth category that we will call non-specific cicatricial alopecia. The first entity (central, centrifugal cicatricial alopecia = CCCA) will be discussed elsewhere during the meeting.

In *lichen planopilaris* (LPP), inflam-

mation is clearly directed against the hair follicles. LPP is felt to be an immune-mediated disease, but the cause is unknown. With this disease, there are distinctive biopsy changes and, sometimes, associated skin lesions. Indisputable cases demonstrate cicatricial alopecia, typical lichen planus lesions, and the expected biopsy features. Many cases present themselves just as a cicatricial alopecia of the scalp, requiring good biopsy correlation to make a diagnosis. LPP may be mild or severe, slowly or rapidly progressive, chronic or just fairly short-lived. The pattern of hair loss is quite variable. Therefore, when LPP just involves the scalp, the diagnosis cannot be made from clinical features alone, and we need a biopsy. Frontal fibrosing alopecia is felt to be a variant of LPP that predominantly affects hair in the frontal scalp and often the eyebrows as well.

Chronic, cutaneous lupus erythematosus is also known as discoid lupus erythematosus, or just DLE. It can be a feature of systemic lupus erythematosus, but often it is a disease confined to the scalp. Scalp lesions may resemble typical DLE on the skin, but the hair loss pattern can be quite variable. Therefore, when DLE involves the scalp the diagnosis cannot be made from clinical features alone.

Folliculitis keloidalis is also known as acne keloidalis or acne keloidalis nuchae. There are many misconceptions about this disease, even among dermatologists, but the truth is that the condition can affect both men and women of all races. It usu-

ally occurs on the lower, posterior scalp (nuchal region), but it can also extend up the scalp. It is a primary form of cicatricial alopecia, and it is unrelated to pseudofolliculitis barbae (shaving bumps). Its pathogenesis is unknown. Clinically, the basic lesion is a small bump, which either heals or results in a spot of alopecia. It can result in hypertrophic scars (not keloids) in a minority of those affected.

Dissecting cellulitis of the scalp (perifolliculitis abscedens et suffodiens) is a relative of hidradenitis suppurativa and acne conglobata. It is most common in dark-skinned men. It presents itself as fluctuant nodules scattered over the scalp. The nodules interconnect with one another via sinus tracts. This condition can be difficult to treat, but fortunately it is an uncommon disease.

Folliculitis decalvans is a term used for any inflammatory cicatricial alopecia with pustules and when there is no other well-defined cause. *Tufted folliculitis* is usually a milder variant. “Tufting” itself is not specific and can be seen in other inflammatory scalp disorders.

The *non-specific forms of alopecia* include *Brocq's alopecia*. This is also known as “pseudopelade of Brocq,” which is a pattern of hair loss. It presents itself as a few discrete zones of cicatricial alopecia whose underlying cause cannot be determined by clinical features or biopsy findings. Most other cases of non-specific cicatricial alopecia are termed “end-stage.”

Are We Close to Cloning Hair? Will it Help?

Ken Washenik, MD, Ph.D



Ken Washenik, MD, Ph.D

The biotechnology field of tissue-engineered hair growth has attracted a lot of attention over the past few years. The general concept involves developing a way to produce the growth of new hair follicles, or follicular neogenesis. This process of hair multiplication is often erroneously referred to as “hair cloning.”

The principal limitation of current hair restoration technology is actually not a limitation of the technique. Rather it is one of a finite, limited donor supply of hair available for transplantation. This limitation is particularly glaring for patients with one of the cicatricial alopecias where hair in the potential donor areas, as well as in the desired recipient areas, is being killed by their disease. In order to address the unmet clinical need for increasing the amount of hair available to restore the lost follicles in balding areas, scientists have

begun to apply the principles of organ regeneration to the hair follicle. Bioengineering follicular cells and follicle progenitors to create new follicles is an active area of basic and applied research that has reached the level of clinical trials.

The technology involves isolating trichogenic (hair forming) cells from a patient’s scalp, expanding them *in vitro* and then injecting these multiplied cells into the patient’s scalp where they are responsible for producing new hair growth. Two differing ways of accomplishing this task are currently being evaluated. The first involves using a one-cell-type (dermal inducer cells) construction where the inductive cells are injected into the scalp and exert a trichogenic effect on endogenous responder cells within the patient’s skin. The second approach requires a two-cell-type construct. In this method,

(continued on page 6)

Scientific Advisor Profile: Valerie Dawn Callender, MD



Valerie Callender, MD

Dr. Callender is an internationally recognized, board certified dermatologist who is known for her expertise in the surgical treatment of hair and scalp disorders as well as pigmentary disorders. She received her medical degree from Howard University, where she also did her dermatology residency. She is currently a clinical assistant professor of dermatology there.

Dr. Callender is dedicated to volunteerism. As co-host of the 3rd CARF International Patient/Doctor Conference in Washington, DC in September 2008, she devoted numerous hours to making sure that the conference was a triumphant success.

She has conducted and participated in more than twenty research studies and clinical trials for both therapeutic and cosmetic products. She is also a consultant to many cosmetic and pharmaceutical companies. The author of seven textbook chapters and many articles for academic journals, Dr. Callender has been a visiting professor of dermatology at Brown University, University of Maryland, University of Florida, State University of New York, and the Henry Ford Hospital.

Dr. Callender serves on the boards of the Women’s Dermatologic Society Foundation, and the Skin of Color Society where she is a founding member

(continued on page 7)

Bald Woman is “Crowned Regal” for Accepting What She Looks Like

Annette Moore



Alopecia comes in many forms and can stem from numerous causes, including autoimmune disorders and unhealthy hair care practices. Many mistakenly associate alopecia with the effects of cancer treatment or other diseases. To the contrary, most people with alopecia are otherwise healthy individuals. But in a society that views hair as a sign of health, beauty, and status, alopecia or hair loss can be emotionally and socially devastating, particularly for women.

Annette Moore - aka “Crowned Regal” of Philadelphia - is a 47-year-old professional woman who was diagnosed last year with two forms of alopecia: CCCA (Central Centrifugal Cicatricial Alopecia) and AAT (alopecia areata totalis). As a result, she is bald. Her story is one of tribulations, severe depression, and ultimately a rediscovery of self. Her mission now, in addition to being a wife, mother, and grandmother, is to help others deal with

this loss. Her focus is on increasing awareness, sharing information, and networking.

Please visit <http://www.crownedregal.com>, Annette's content-rich website (receiving nearly 1,500 hits per month since it was launched) for her complete and candid story, photos, online video journals, and links to helpful resources on alopecia. In addition, you will find links to her YouTube videos, which have received more than 85,000 hits in the last few months. Since the launching of her Crowned Regal website, Annette has continued to help spread awareness of not only the more commonly seen types of alopecia (non-scarring types), but also of CCCA (a scarring type).

“My family and friends thought I had lost my ever-loving mind by exposing to the world what my scarring alopecia looked like.”

Annette Moore's first hint of hair loss was a decade ago. At first, she didn't think much of it. She chalked it up to getting older or not eating right. She was told initially that she had seborrhea dermatitis and later was diagnosed as having lichen planopilaris, another form of cicatricial alopecia. After years of unsuccessful treatments in the form of topical ointments, shampoos, and antibiotics, she decided to camouflage the bald spots with hair weaves, hair wraps, and wigs. Then one day in June of 2007, while in the shower, she realized the problem was worse than she thought. She noticed a lot of hair going down the drain.

Annette says, “I panicked. I went to the mirror to lift my weave, and from the front of my hair line all the

way to the crown of my head, the hair was gone. What used to be large areas of diffusely thinned hair was now attached to the unattached hair weave and my scalp was bald and irritated. I didn't know what was happening to me. I felt alone, ashamed, and isolated. I sought medical attention right away from my dermatologist, and that's when he decided to do a biopsy. He knew during the very first visit that I had cicatricial alopecia and alopecia areata totalis. He also told me that there were large areas of my scalp where my hair follicles were permanently destroyed. At that time, he offered to give me injections. Confused and devastated, I refused and cried all the way home.

“After breaking the news to my family, who were very supportive, I still felt isolated and alone. That's when I decided to google the word ‘alopecia.’ At first, I kept coming up with results of the more common types of non-scarring alopecia. I desperately needed to know what CCCA was and why I had it. So I typed in ‘cicatricial’ and there it was! The Cicatricial Alopecia Research Foundation! I felt like I had struck gold. I couldn't believe that someone had put her time and energy into creating a website for this rare form of hair loss, but, more importantly, I couldn't believe that there were others just like me.

The thing I remember most about the day I found CARF's website was that my tears began to flow down my face like a faucet - particularly, when I saw the photos of the various types of cicatricial alopecia. One of the photos looked like it had been taken of the top of my crown. I read the website from start to finish and this was the be-

(continued on page 7)

Why Am I Involved in CARF?

Rita Wanser



Rita Wanser

I am not a physician. I am not a patient. Nor do I have any relatives who have any of the cicatricial alopecias. So why would I be involved in CARF?

Many people ask me this question; I have never hesitated in my response. By nature, I am a volunteer. This is probably not a good thing to admit to in print, but, yes, it's true. I've been that way most of my life. But whereas I used to volunteer indiscriminately, I'm now very careful about where and how I direct this energy.

My involvement with CARF has evolved over the years. Through work, I became associated with Dr. Vera Price. A couple of years later, Dr. Price introduced me to Sheila Belkin. I should have realized at that very first meeting that I would join CARF because Sheila's

dedication to this organization is highly contagious (to this day, I don't know where her energy comes from!). Sheila was just beginning her quest to get CARF started. Over the next few years, she, Dr. Price, and I would talk from time to time about CARF. My interest in it grew, professionally and personally, due to these two women.

I then attended my first patient conference. What an experience for me! As I stated earlier, I am not a patient nor did I know of anyone with any of the cicatricial alopecias before meeting Sheila. Now, I was amongst a spirited group of people who were willing to share their stories about how they've coped with their disease. At this point, I decided to become more actively involved in CARF.

Fortunately for me, a board position became available. Sheila and Dr. Price asked if I would like to be an official member of the board. I readily accepted.

I have since been to another patient conference and had other opportunities to speak with patients. I am humbled by the dedication of the dermatologists and by the courage and strength of the patients as they await new information and drugs to help their conditions.

While I cannot offer patient care, I am committed to helping in other ways to support the efforts of the board of directors, the scientific advisers, and patients.

I am On Fire for Research and a Cure!

We Need You!

Do you have data entry skills?

Want to help with patient support, patient registry, and clinical trials?

Become part of the CARF database team.

Let's hear from you at info@carfinl.org

autologous cultured dermal inducer cells are combined with exogenous responder epidermal cells (isolated and grown in a separate culture system). The mechanisms whereby these techniques can lead to folliculoneogenesis or to the regeneration of terminal hair growth from existing miniaturized follicles will be illustrated, as will how these can translate into clinical applications.

Another very exciting, approach is to allow the trichogenic cells in culture to form aggregates and early structures that resemble hairlike shapes. These may have potential for implantation into the area of the scalp affected by the cicatricial process. This approach is still in an early research stage. Unfortunately, none of these approaches will be useful if inflammation is still present.

Very recently, groundbreaking research revealed that during the wound healing process entirely new hair follicles could form in the scarred area. This work has been demonstrated only in the laboratory so far, but the implications are particularly exciting for conditions like the cicatricial types of hair loss since wound healing can be considered part of the condition itself.

Are We Close to Cloning Hair? Will it Help?

(continued from page 4)

Scientific Advisor Profile: Valerie Dawn Callender, MD

(continued from page 4)



Los Angeles,
California,
will be the site of
CARF's 2010
Patient Doctor
Conference.

Stay tuned!

and treasurer. Dr. Callender, is a past chairman of the National Medical Association's Dermatology Section and has received the Alpha Omega Alpha Honor Medical Society's Clinical Faculty Award. She is active in the American Academy of Dermatology and has participated in the Forum for Future Leaders in Dermatology, Women's Health Task Force, Diversity Task Force (chair) and Healthcare Delivery Committee.

A frequently invited speaker to national

and international meetings, Dr. Callendar has given presentations in cities around the world, including Buenos Aires, Sydney, Berlin, London, Mexico City, San Juan, and Port of Spain.

Dr. Callender is founder of the Callender Skin and Laser Center, which is located in the Washington, DC, metropolitan region. She lives in Mitchellville, Maryland, with her husband and son, and she enjoys playing golf with her son and traveling to Jamaica to visit family.

Bald Woman is "Crowned Regal" for Accepting What She Looks Like

(continued from page 5)

ginning of my journey to acceptance. From that point onward, I was hungry to know more - and not just about the medical and research side to this disease. I wanted to know more about the psychological side of having CCCA, up to and including tips and tricks for covering up bald spots with the latest in wig fashions. I was so thankful for the existence of CARF."

Annette felt that CARF was the beginning of her journey to self-acceptance. "Through CARF's existence, I became more educated about cicatricial alopecia and through education comes self-acceptance and ultimately self-empowerment. When you reach that level of self-acceptance, doors of opportunities begin to open that you never knew even existed."

Annette decided to take a chance and call CARF to talk to someone about her diagnosis. At first, she thought she'd get a customer service representative on the line and be told to leave a message. Instead she got one of CARF's founders, Sheila Belkin, on the phone. Sheila engaged Annette in a warm and welcoming conversation, filled with detailed information about the disease and the work CARF has been undertaking. At that point, An-

nette offered to volunteer for CARF. And now, she is donating her time and technical skills as a website programmer and graphics design specialist. Annette is thrilled to be associated with Vera Price, Sheila Belkin, and all the wonderful researchers and volunteers of CARF.

Because of the information and support she has received from CARF, Annette is able to continue to spread her message of self-acceptance through her motivational speaking engagements, support groups, and, most recently, the launch of her very own social network, "Accept Me As I Am."

"Gaining knowledge of things that we don't understand - like cicatricial alopecia - is truly empowering. I no longer look at the fact that I have this disease as a curse but as a gift of opportunity to empower others who may not know of the wonderful work CARF is doing. In my personal journey to self-acceptance, I tell others about CARF every chance I can get. "

"I have been hereby 'Crowned Regal,'" says Annette.

For more information about Annette visit: www.crownedregal.com

CARF Launches Its First Wine and Cheese Fundraiser

Read about **CARF's successful fundraiser** as it appeared in the Chico Enterprise-Record:

Thank you to those who attended the Cicatricial Alopecia Research Foundation's recent fundraiser at Vino 100. The fundraiser was to support our organization's mission: educating and supporting patients and funding research to find treatments and a cure for this condition.

Thanks to our donors: Soroptimist International of Chico; Dr. Donald Richey, Rejuvené; Dr. James Nagel, Quality of Life Institute and Q Spa; Wakefield and Son's Glass; Marilyn Whittle Photography; Olde Gold Estate Jewelry; Chico Certified Farmers' Market; John Peters, Stone Circle Arts; Vicki Lea Eggen, CMT; Laura's Wig and Beauty Supply/Salon;

Soxies with Moxie; Costco; Sicilian Café; Postal Plus; La Hacienda; ABC Books and Bidwell Perk.

Thanks also to Vino 100 for donating a portion of the evening's proceeds and to the Chico Enterprise-Record for publicizing our event.

Cicatricial (or scarring) alopecia encompasses a group of rare inflammatory conditions, with no known cause or cure. Patients experience permanent, generally progressive, hair loss and, often, intense itching and painful "hair on fire" symptoms, plus accompanying emotions.

CARF is a nonprofit organization, founded about five years ago by a patient and her physician. Supported entirely by donations and run by volunteers, CARF has been awarded three prestigious Gold Triangle Awards by the American Academy of Dermatology. Go to www.carfintl.org to learn more about this organization and cicatricial alopecia.

We challenge supporters of CARF worldwide to host similar grassroots fundraising events — and we will provide a "how-to" planning template. Together, we are making a difference for cicatricial alopecia patients.

- Donna Dreher Weaver, Marilyn Ey, Chico



Become inspired; advocate for CARF!
Have your own community fundraiser and benefit fellow patients.
If you are interested in having a fundraiser, contact info@carfintl.org

CARF Donor Contributions 2008

CARF wishes to recognize the outstanding generosity of our donors.

Because of your support, our patient services and research funding became possible.

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

CARF Communiqué Editor: Nancy West, PhD
Layout Editor: Margit McPhillips

E-MAIL CORRECTION REQUESTED

SAVE THE DATE! CARF's 5th ANNIVERSARY Bay Area Fundraiser



You are cordially invited to attend a splendid reception and buffet supper in observance of CARF's 5th Anniversary at 6 pm, Saturday, October 17, 2009 at the University of California Faculty-Alumni House 745 Parnassus Avenue, San Francisco

The evening will be a gathering of patients, doctors, families, and friends with entertainment and a silent auction
Watch your inbox for more details and registration information

Meanwhile, mark your calendar and save the date for this very special get-together!

If you are interested in helping or have any questions, please e-mail SFevent@carfintl.org



CARF team plans event