

C . A . R . F .

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Review of the CARF 5th International Patient-Doctor Conference

August 10 – 12, 2012
Hilton Boston Back Bay Hotel



Conference Co-Chairs:
Doreen Karroll, MD and
Lynne Goldberg, MD



Expert Panel: Drs. Yolanda Lenzy, Victoria Barbosa, Lynne Goldberg, Vera Price, Valerie Callender, Ken Washenik, and Maria Hordinsky



NEXT CONFERENCE

The next conference is already being planned for Chicago in 2014. We hope you will be able to join us!

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THANK YOU to all who helped make the 5th International Patient-Doctor Conference a resounding success — the highest attended meeting in CARF history with 118 attendees. The efforts of the volunteer planning committee, faculty and attendees of this conference are much appreciated. We hope those who attended enjoyed their time as much as we did and left the conference with increased knowledge and new friendships.

Attendees attested to a life-changing experience after participating in a variety of lectures, Q & As, discussion and support groups, and more. Drs. Lynne Goldberg and Doreen Karoll hosted the 3-day educational conference, where information was presented on the diagnosis and available treatments, latest research breakthroughs and cosmetic solutions. Participants met leading physicians and researchers in the field, participated in breakout sessions and had an opportunity to explore a variety of wonderful attractions in the Boston area.

This issue contains excerpts from the conference as well as a special perspective from first-time patient attendee and New Orleans-based psychologist Fran Swan. We hope this newsletter is enlightening and encouraging for both newly-diagnosed patients as well as patients who have a long-standing diagnosis of cicatricial alopecia. We welcome your feedback and suggestions.

The meeting began with a warm welcome from the Boston support group physician leader Dr. Lynne Goldberg, who discussed how the study and treatment of scarring alopecias is “not a science but still an art.” Dr. Goldberg announced that the meeting had the highest attendance ever with 118 guests, and emcee Dr. Ken Washenik encouraged everyone to ask questions and learn as much as possible. Rita Wanser, the Chair of the CARF Board, discussed the formation of CARF from the zeal of one patient with the help of her doctor, Vera Price. Rita encouraged everyone to get involved in any way they can — join CARF, read the bulletin, donate toward research or organize a local fundraiser. Patients in your community can be a wealth of resources and support.

Friendship and learning coincided for a fun-filled weekend. As a clinical dermatologist in New Orleans, Louisiana, I was happy to return to my college stomping grounds and enjoy the cooler weather as well. Most of all, I felt very lucky to have three of my patients also in attendance. We had a great time at the meeting. It was terrific to catch up with old friends and to make new friendships with lovely people from across the U.S. and extending as far as Canada and Bermuda.



CARF Conference Photos



CARF 2012 Board of Directors: Melanie Stancampiano, Assoc. Executive Director, Sharon Potter, Rita Wanser, Chairman, Vera Price, MD, Victoria Ceh, Executive Director, Ken Washenik, MD, PhD. Board members not shown: Jerry Shapiro, MD and James Heerwagen



Thank you to Ken Taylor, volunteer photographer!



Anne Taylor, CARF volunteer and Rita Wanser, Chairman of the Board

CARF Conference Photos



Vera Price, MD and Mary Clay, volunteer



Registration in full swing



Vera Price, MD, Laurence Spector and Rita Wanser, Chairman of the Board



Victoria Ceh, MPA, Executive Director, and Nicole Rogers, MD

Review of 2012 Patient-Doctor Conference

Overview of Scarring Alopecias

presenter: Vera Price, MD, Professor at UCSF

Summarized by: Nicole E. Rogers, MD

Dr. Price, who founded NAAF and CARF, and is a dermatology professor at the University of California, San Francisco, gave a wonderful introduction to the cicatricial alopecias. From this, we provide a glossary to readers:

Cicatricial alopecia = scarring alopecia (this includes several forms)

Primary cicatricial alopecias: the hair follicle is the primary target of the destruction and the rest of the skin is not affected. This is what we are discussing.

Secondary cicatricial alopecias: the follicular destruction is incidental to a non-follicular process: infections, tumor, burns, radiation.

Non-cicatricial alopecias: these make up 95% of hair loss conditions and include androgenic alopecia (AGA) and alopecia areata (AA). These conditions are always potentially reversible.

Cicatricial alopecias: these comprise about 5% of hair loss conditions and are irreversible. They are not hereditary, not contagious, and may be painful, itchy, and burning. They usually occur in otherwise healthy, beautiful people.

CARF Logo: Dr. Price explained how the CARF logo was inspired by a sculpture she has of two foxes. (see photo next page) The word 'alopecia' comes from *alopex*, the Greek word for fox mange. Foxes get mange, a spotty form of hair loss.

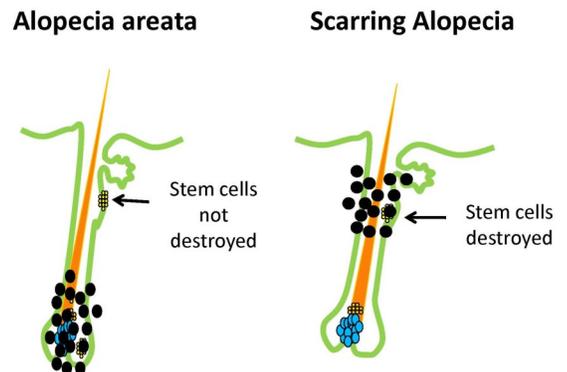
It is not life threatening but life altering. This simple statement turned out to be a major theme of the weekend. Patients and doctors alike discussed the guilt that is often felt by patients with cicatricial alopecias due to the fact that they are so affected by a condition that is not life-threatening. Many people chimed in, reflecting on how the permanent nature of this hair loss affects them so much.

Image Courtesy of Jeffrey Donovan, MD, PhD

Cicatricial alopecia begins in adults 20-65 years old and is rare in children. It occurs in all races, worldwide. There is seldom a family history of the same condition, except in CCCA.

The cicatricial alopecias are challenging because they are rare. Lichen planopilaris (LPP) for example, made up about 1.2-7% of all new hair loss referrals in four tertiary hair centers. There are about 200,000 patients with LPP in the U.S., and the average excellent dermatologist may have only 1 or 2 such patients in his/her practice. In contrast, androgenetic alopecia (AGA) affects about half the population, and about 5 million persons have alopecia areata (AA).

Dr. Price went on to show an excellent diagram by Dr. Jeffrey Donovan (above right) showing that in cicatricial alopecia, the inflammation is around the upper third of the hair follicle where it destroys the stem cells and oil (sebaceous) gland. In contrast, in AA the inflammation is around the hair bulb or lower portion of the follicle and the stem cells and oil gland are not destroyed.



Review of 2012 Patient-Doctor Conference



Overview of Scarring Alopecias by Vera Price, MD, continued

Dr. Price explained that clinically, a loss of follicular markings is an important clue to the presence of a scarring alopecia and is an indication for a scalp biopsy. If pore markings are still present, the hair loss is not likely due to a scarring alopecia. Biopsies should be done along the edge of early active, but still hair-bearing areas. There are no relevant lab tests for diagnosing cicatricial alopecia. Pustules, crusting or oozing should be cultured. The scalp biopsy indicates whether the inflammation is mainly lymphocytic or neutrophilic or mixed and guides the treatment that will be used.

Dr. Price then showed images of lymphocytic cicatricial alopecias:

- Lichen planopilaris (LPP) **causes patchy hair loss and often is accompanied by itching, pain, burning, and redness and scaling of the scalp.**
- Frontal fibrosing alopecia (FFA) was described approximately 20 years ago in Australia. It was originally thought to occur primarily in postmenopausal women. However, it occurs in younger women as well, and occasionally in men. An increase in FFA has been noted worldwide.
- Central centrifugal cicatricial alopecia affects mainly women of African ancestry and results in a symmetric expansion of hair loss that starts over the central scalp. It is the one scarring alopecia that may occur in several family members.
- Pseudopelade of Brocq is similar to lichen planopilaris except that patients have no symptoms or signs, that is, no itching, pain, burning, and no redness or scaling of the scalp.

Neutrophilic cicatricial alopecias include folliculitis decalvans and tufted folliculitis. The latter does not result in as much hair loss as folliculitis decalvans, which is why Dr. Price separates the two.

Mixed cicatricial alopecias include dissecting cellulitis and folliculitis keloidalis. They are not true primary scarring alopecias, and the inflammation is secondary to the rupture of hair follicles

Dr. Price then discussed the end-stage of scarring alopecia and how in the late stages all the primary scarring alopecias look alike. Finally, she mentioned the recently published book written for dermatologists and dermatology residents, *Cicatricial Alopecia, An Approach to Diagnosis and Management*, which can be purchased on Amazon or by e-mailing the account manager at Springer Publishers: Jamie.Goldstein@springer.com.

Review of 2012 Patient-Doctor Conference

Role of Scalp Biopsy in Hair Loss

Presenter: Lynne Goldberg, MD, Professor of Dermatology at Boston University

Summarized by: Kathy Huang, MD, Instructor, Harvard Medical School

Dr. Lynne Goldberg, professor of Dermatology and Pathology & Laboratory Medicine, Boston University School of Medicine, gave a seminar on the role of biopsy in patients with alopecia. She discussed that reasons for biopsy in cases of alopecia include the following: 1) if the diagnosis is uncertain, 2) if the prognosis of the condition is uncertain, 3) if help is needed for management of the condition, and 4) reassurance for the patient with further studies. After a biopsy is obtained, the specimen is reviewed in order to determine what cell type is causing the inflammation. This information can help the clinician diagnose the cause for hair loss. The diagnosis is typically determined using clinical signs of the hair and scalp in combination with microscopic findings of the biopsy specimen. Biopsy can also help determine how much inflammation is active under the surface of the skin, if the process is early or late, and if the treatment is causing any improvement of the hair loss condition.



Dr. Goldberg then described the steps of a scalp biopsy. Typically, a punch biopsy is performed, where a device is used to take out a round small core of the skin. A core of tissue is needed in order to examine if the process causing hair loss is superficial in the skin or if it extends deep below the hair follicle. Risks of biopsy include pain – which is minimized by local anesthesia, bleeding of the scalp, infection (which is generally low risk), and scar. The position of the biopsy is selected to minimize the appearance of the scar.

Sometimes, more than one biopsy is required during the course of diagnosis and treatment. With biopsy, there can be sampling error (since some conditions only affect focal areas of the scalp), lab error, inconclusive findings, or misinterpretation of the findings when there is a poor correlation between biopsy results and the clinical physical exam. Another reason for error is if the biopsy is too shallow, which is why a deep core biopsy is needed.

After the sample is taken from the scalp, it is processed by cutting the specimen into transverse sections in order to allow visualization of all the follicles in the same section. This requires careful grossing and embedding of the specimen. When examining the specimen, histologic clues such as marked inflammation, loss of sebaceous glands, thinning of hair follicles or asymmetry of hair follicles, loss of follicular epithelium, or fibrosis can help lead to certain diagnoses. Sometimes it is difficult to tell what type of inflammation is the cause of the hair loss, especially when the specimen reveals only destroyed hair follicles and scar.

Dr. Goldberg concluded with future goals of hair loss diagnosis and management stating that we hope to elucidate what causes the hair follicles to be targeted, determine the mechanism of destruction of hair follicles, and develop medications for treatment that are both safe and effective.

Review of 2012 Patient-Doctor Conference

Medical and Surgical Treatment of Cicatricial Alopecia

Presenter: Valerie Callender, MD, Private Practice Glenn Dale, Maryland

Summarized by: Deborah Scott, MD

Dermatologist Dr. Valerie Callender discussed medical and surgical treatment of cicatricial alopecias, including CCCA, LPP, FFA, chronic cutaneous lupus, folliculitis decalvans, acne keloidalis and dissecting cellulitis. She reviewed treatment goals for cicatricial alopecia, which include determining the diagnosis and beginning treatment as early as possible in order to improve and minimize scarring. She also emphasized the importance of performing a biopsy of the involved area of the scalp in order to better determine the cause of the alopecia. She reminded us that there is very little evidence-based information on treatment of the scarring alopecias. Therefore, it is very important to monitor the patient's response to assist determining the success of various treatment modalities. Patient response is monitored by serial photographs, clinical exam, and evaluation of the patient's symptoms.

She then reviewed specific treatments for the various cicatricial alopecias. The treatment for lymphocytic cicatricial alopecias includes topical and intralesional corticosteroids, topical immunomodulators such as tacrolimus ointment (Protopic), oral anti-inflammatory agents such as hydroxychloroquine (Plaquenil) and certain antibiotics (doxycycline). The treatment for neutrophilic cicatricial alopecias includes culture-specific oral antibiotics, topical antibiotics, antibacterial cleansers, topical/oral dapsone, and oral and intralesional corticosteroids.

Dr. Callender emphasized the need to discuss hairstyling techniques with patients and reviewed the potential negative impact of excessive heat or application of chemicals to the scalp on these conditions.

Finally, she discussed the role of surgical correction of stable, inactive scarring alopecia. She emphasized the need to ensure that the alopecia was no longer active prior to contemplating any surgical procedures because any residual active inflammation will likely involve transplanted hairs as well. The surgical techniques she reviewed included hair transplantation and scalp reduction.

How to Maximize your Office Visit

Presenter: Barbara Starr, MSN, NP, Dermatology Nurse Practitioner, Kuchnir Dermatology and Dermatologic Surgery, Marlborough, MA

Summarized by: Nicole E. Rogers, MD

Barbara Starr, dermatology nurse practitioner and former editor of the *Journal of the Dermatology Nurses' Association*, addressed several important factors that make appointments that *work*. This, she explained, involves both the physician and the patient having a great interaction, understanding what needs to get accomplished, and how best to facilitate it. With enthusiasm, she called these "appointments that sing!"

First, they are never one-sided. A doctor should be able to learn not just the facts but how the patient feels about their condition since the last appointment. Patients should leave the appointment knowing the doctor is working for them, that they are in this together. Barbara emphasized that given the limited appointment time, in order to have time for the issues that are important to them, patients should be prepared in advance and ready to answer the questions they can count on to be part of almost any medical visit, such as:

continued

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How to Maximize your Office Visit, continued

- HOW are you doing? Are your symptoms (burning, itch, etc.) better? Or worse? No different?
- WHAT are you doing (meds, etc.)? How are you tolerating your existing medications? Do you think they are working? What are your goals for the visit?
- If possible, arrange to bring any relevant previous blood work or biopsy results with you. This will enhance the efficacy of your interaction and maximize the understanding of your doctor.
- Jot down questions between visits and prioritize them.
- Be sure your doctor knows what other medications you are taking, especially in case there are possible contraindications. Provide a copy of your medication list, to save time. Don't leave out the topical medications.
- Bring your medications and have them out for easy reference and discussion. Be honest, if you aren't using the drug, tell your doctor, and explain why! If they sting, smell, make you sick, are too expensive, or you don't think they help, tell your doctor!
- Help your medical team by providing feedback about your interest or lack of enthusiasm for a plan they might be proposing, so appointment time is well spent.
- For your appointment, be on time – even though your doctor almost never is. If the wait is ridiculous – ask if you can call in advance to see how the wait is running.
- Consider enlisting friends or family members to provide childcare so you won't feel distracted.
- Call sooner for an appointment if your condition is really flaring! Don't wait 2 months for the next appointment time.

Finally, Barbara offered a tip for doctors: have the patient review the plan in their own words. This lets all parties know that they are on the same page!

Dermatology Resident Experience

**By Emily M. Wise, MD, Chief Dermatology Resident, Boston Medical Center,
Boston University Department of Dermatology**

It was such an honor to participate in my first CARF Patient-Doctor conference in Boston in August. As a senior dermatology resident, I have had the privilege of working alongside my mentor, Dr. Lynne Goldberg, in her hair loss specialty clinic for the past three years and have seen first-hand the challenges that alopecia patients face. Scarring alopecia is, as Dr. Vera Price so eloquently put it, "not life threatening, but life altering". The meaning of this quote became very real for me as I was graciously allowed to participate in several breakout sessions during the conference.

I went to the conference thinking that I had a wealth of knowledge regarding alopecia and was hoping to answer patient questions about clinical presentations, prognosis, and treatment options. What I did not expect was that I would be the one who had the most learning to do, and that the patients were going to teach me. As I listened to these brave women and men share their stories about receiving their diagnoses, battling with medications and side effects, and developing coping strategies, I was

Review of 2012 Patient-Doctor Conference

Dermatology Resident Experience, continued

struck by the courage and strength of every single patient in the room spanning the spectrum from those who have only begun on their journey to those who have already lost most of their hair, the uplifting feeling generated by the CARF family was palpable.

When my first CARF conference came to a close, the message was clear: as I continue working with the spectrum of scarring alopecia patients, my role as a doctor extends far beyond purely the science and medicine. I will use the information that the patients taught me to be more compassionate and more aware of the emotional impact that this diagnosis carries, and without a doubt, will urge all of my patients to join CARF.

A Patient's Experience

By Patient Fran Swan, Clinical Psychologist in New Orleans

I had been struggling with frontal fibrosing alopecia for more than a year when I received a letter from my doctor, Nicole Rogers, stating that there was a national meeting of CARF and encouraging me to attend. I did not know what to expect but welcomed the opportunity to learn more about my condition. The fact that the meeting included both doctors (16 dermatologists!) and patients impressed me. As a first-time attendee, I was amazed. The amount of information presented was impressive covering aspects of treatment and the latest research. The doctors were available in a personal way to answer questions and to explore common issues that we were struggling with.



Fran Swan and Sharon Potter

The presentations were impressive and informative. I was left speechless by Dr. Goldberg's slides that graphically displayed the death of my dear hair follicles. No wonder I am left with a shiny forehead that will probably not even fill in with a hair transplant. Dr. Price, who is a legend in the field, spoke of her research in San Francisco and requested more biopsies for her research. Learning of the latest treatment technologies was very enlightening and gave me a sense of understanding that I had not had previously.

The camaraderie was an important part of my experience. Both doctors and patients spoke of ways to cope with the cicatricial alopecias and covered a wide range of topics from dealing with the emotional aspects of a diagnosis that is "not life-threatening but life-altering" to practical aspects of dealing with hair loss. We had a chance to discuss everything from wigs to special colored powders for cover-up.

Not only did I gain a wealth of information, but I also had fun. This was highlighted by the playing of "Liar's Club" on Saturday night. I thought I had a good vocabulary until I encountered this game. Amid laughter and jokes, we tried to guess the real meaning of these difficult words. It was not easy! Sharing experiences with other women and men dealing with this condition was very enlightening. Some had been dealing with this condition over time and others were newly diagnosed. The challenge of dealing with cicatricial alopecias requires courage, creativity, and humor. I learned how to use these skills and treasure what I learned at the conference. I will definitely be at the next national meeting in Chicago and encourage other fellow patients to share in this rich and meaningful experience.

Stay posted for the next CARF Newsletter as we cover other exciting topics featured in the 5th Patient Doctor Conference. Please feel free to submit your patient perspectives, fundraising experiences, research, and photos to physician editor Dr. Nicole Rogers. She and the entire CARF team want to hear from YOU! E-mail: nicolerogers11@yahoo.com Office phone in Louisiana is 504-836-2050.

Meet Our Scientific Advisor Wilma F. Bergfeld, MD



Wilma F. Bergfeld, MD

With this article, we begin a series of articles introducing our CARF Scientific Advisors, who are among the most accomplished and acclaimed doctors and scientists in the field of cicatricial alopecia.

Wilma F. Bergfeld, MD

CARF is proud to have Wilma F. Bergfeld, MD, FACP as a Scientific Advisor. She is a prominent dermatologist and dermatopathologist known worldwide. She was the first woman president of the American Academy of Dermatology and the Women's Dermatologic Society. She is currently the President of NAHRS, the North American Hair Research Society.

Dr. Bergfeld's credentials are extensive. She is Co-Director of Dermatopathology Departments of Dermatology and Pathology and senior Staff Dermatologist and Past Head of the Section of Dermatological Research in the Department of Dermatology at the Cleveland Clinic. She is also the Director of the Cleveland Clinic's Dermatopathology Fellowship and Professor of Dermatology and Pathology, The Cleveland Clinic Educational Foundation and Associate Clinical Professor, Department of Dermatology, Case Western Reserve University. Dr. Bergfeld's specialty interests include clinical dermatology (hair disorders, androgen excess, photoaging, and cosmetic dermatology) and dermatopathology. As such, she remains a vital consultant for CARF.

Dr Bergfeld completed her undergraduate work at the College of William and Mary in Williamsburg, VA, and is a graduate of Temple University School of Medicine in Philadelphia. She joined the Cleveland Clinic in 1969 and since 1977, she has been a member and the Chair (1990-current) of the Cosmetic Ingredient Expert Panel, an expert panel that determines the safety of cosmetic ingredients.

It is not surprising that Dr. Bergfeld has received numerous awards and honors. In 1996, she received the Women's Dermatological Association Rose Hirschler Award honoring an outstanding physician who has contributed to medicine and dermatology while enhancing the role of women in the Dermatology. She received the American Academy of Dermatology's prestigious Marion B. Sulzberger Award in 1997 and was the recipient of the AAD Golden Triangle Award 2000 for Community Service. In 2000, she was the first recipient of the Wilma F Bergfeld MD Leadership Award, presented by the Women's Dermatology Society.

In 2005, the Cleveland Academy of Medicine awarded her the John Budd, MD, Distinguished Member Award. The American Society Dermatopathology in 2007 awarded her the prestigious "Founders Award" and she was elected 2009 President of the American Society of Dermatopathology. In 2008 she was awarded Maria Duran leadership award and medal by the International Society of Dermatology.

Dr. Bergfeld has received many AAD Presidential citations that have included Leadership in AAD Communications and the Volunteer Circle. Since 1995, she has been cited in "Best Doctors in America," "Top Doctors," "Top Pathologist," and in numerous Who's Who publications. Dr. Bergfeld is the author of over 600 publications, 3 books and 72 book chapters. She has served on many editorial journal boards and has been a reviewer in the both her professional fields of clinical dermatology and dermatopathology. Other activities include consultant/scientific adviser to many pharmaceutical companies.

Dr. Bergfeld is married to John A Bergfeld MD, an internationally known Sports Medicine Orthopedic Surgeon at Cleveland Clinic. She is the mother of two daughters, Onee Bergfeld Lowe (deceased) and Sigrid Bergfeld Grieco. She has five granddaughters.

Wilma Bergfeld, MD, answered questions on alopecia in the *New York Times*, December 2010:

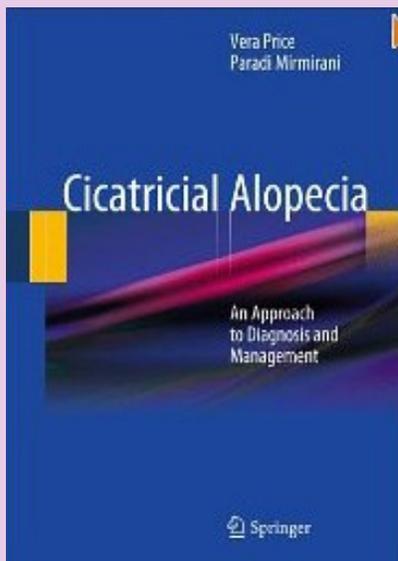
<http://consults.blogs.nytimes.com/2010/12/27/expert-answers-on-alopecia/?emc=eta1>

Information

Join the eScrip Program to Help Fund CARF Research

CARF has enrolled in the eScrip fundraising program. You can benefit CARF without any out-of-pocket expense. Shop for groceries, airline tickets, personal purchases, and/or dine out — it's simple and free! 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 for participating merchants. Shop retail or online.

To select CARF, go to www.eScrip.com and indicate us as your beneficiary. (CARF's Group ID # is [500020699](https://www.eScrip.com/group/500020699).) Funds generated with your purchases will support CARF's ongoing patient support, patient education, and research to find better treatments and a cure for cicatricial alopecia.



Cicatricial Alopecia: An Approach to Diagnosis and Management

Vera Price, MD and Paradi Mirmirani, MD, acknowledged world experts on the cicatricial alopecias, have written the first book devoted to these disorders. Written for dermatologists and dermatology residents and fellows, it is a supremely practical and authoritative guide to the scarring alopecias. "Each disease chapter is introduced with a clinical scenario of a patient, along with relevant clues for making the diagnosis. The discussion section follows and includes multiple photographs and take-away pearls..... A final chapter contains contributions by patients that highlight the frustration...in finding a physician who can accurately diagnose and treat their disorder."

Many patients have also found the book helpful as a useful over-

Please consider making a donation to CARF. Go to: www.carfintl.org and click "Donate Now". Thank you!

Information

**SPECIAL OFFER FOR CARF
from GR&M Celebrity Wig Warehouse**

www.wigwarehouse.webs.com

live on-line chat and free-consultations

GRM Celebrity Wig Warehouse specializes in designing **Full Lace Wigs, Lace Front Wigs and Men's Toupee's, Non-Slip Cap Wigs for Women and Men, Lace Eyebrows and Eyelashes**. Custom Full Lace Wigs and In-Stock.

This company offers well-priced wigs for those patients (men, women, teens) who would like to have a hair alternative. A human hair cranial prosthesis is \$500. They offer a donation to CARF for each 3 units purchased. They also offer a complimentary human hair men's lace replacement for every three purchased. Let us know if you are interested. Carol@carfintl.org.



National Organizations Providing Free Wigs for Children

Name of Organization	Website
Wigs for Kids	www.wigsforkids.org
Locks of Love	www.locksoflove.org
Hair Club for Kids	www.hairclub.com/hc_for_kids.php

News from CARF Patient Support Groups

BOSTON Support Group

We had a terrific meeting. Attendees received a copy of "What you should know about Cicatricial Alopecias" provided at the August conference. It is a great way to communicate basic information about our disease to primary care providers, to beauticians and to insurance companies when asking for wig/hairpiece coverage. They also received Dr. Vera Price's UCSF Cicatricial Alopecia Management; Cicatricial Alopecia "Tips and Tricks;" Patients' Suggestions; Hypnosis and the Body Mind Connection: Tools for coping with stress by Drs. Johnston and Devaney; and Cosmetic Options for Covering Hair Loss and Resources on the Impacts of Inflammation and Strategies to Reduce it" by Donna Weaver. Our topics for the next meeting will include a presentation on wigs and make-up and a guest from the Right Questions Institute to help us learn how to ask better questions.

Howard Shepard, Jr., Boston Support Group Member, writes: "it was nice to see everyone and to help out where I can. My site: <http://dissectingcellulitisofthescalp.blogspot.com/>

Dissecting Cellulitis of the Scalp — Welcome to the Forum

Here is a place for adults with Dissecting Cellulitis of the scalp to share there life stories, pictures and medical treatments. In this world, we have the ability to treat all sorts of disorders and there is all this research and funding to help people. But our disorder has nothing -- no research, no medical doctors that specialize in DCS. We are left with great doctors who try, but we suffer for lack of an effective treatment. This forum will be the start some day of a charity with the hope of funding research. Please join in!

SAN FRANCISCO Support Group



NEW YORK Support Group

We had our inaugural meeting on October 23. We are fortunate to have Jerry Shapiro MD of NYU Langone Medical Center as advisor to our group! Dr. Shapiro also serves as Director of the University of British Columbia Hair Clinic and is a member of CARF's Scientific Advisors. We look forward to seeing our New York/New jersey patients in the near future at upcoming meetings.

Laurence Spector, Patient Co-Leader

CARF Support Groups

See www.carfintl.org for meeting dates in your area. Note: in some locations, we are looking for patient co-leaders and physician advisors.

CALIFORNIA (2 active)

Los Angeles: losangelessupportgroup@carfintl.org

San Francisco: Contact Marilyn and Joe at: sanfranciscosupportgroup@carfintl.org

ILLINOIS (active)

Chicago: Contact Joe & Bev: chicagosupportgroup@carfintl.org

LOUISIANA (active)

New Orleans/Baton Rouge: Contact Debbie and Elayne at: neworleanssupport@carfintl.org

MARYLAND, WASHINGTON DC, VIRGINIA (active)

Contact Beth at: md-dc-va-supportgroup@carfintl.org

MASSACHUSETTS (active)

Boston: Contact Melody at: bostonsupportgroup@carfintl.org

MICHIGAN (pending)

Detroit: Contact Virdell at: detroitssupportgroup@carfintl.org

MINNESOTA (pending)

Minneapolis: Contact Maggie at: minneapolisupportgroup@carfintl.org

New Groups Forming

New York: newyorksupportgroup@carfintl.org

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Scalp Micro-Pigmentation (SMP) for Men excerpt from www.scalpmicropigmentation.com

Scalp MicroPigmentation (SMP) is a permanent cosmetic 'tattoo' that mimics the very short hairs of a closely shaved scalp. It is a new and innovative technique that offers an alternative styling option for men who do not want, or are not candidates for, hair transplant surgery.

With the entire head shaved, Scalp Micro Pigmentation looks natural even under close scrutiny. It creates the appearance of a close shave or a short buzz cut over the entire scalp with a natural looking hair line. It is a permanent 'concealer' medically tattooed on the scalp with special pigments and is an alternative to the topical daily applications of powders, fibers and other cosmetic concealers. It may eliminate the hassle of frequent applications, messy transfer of product onto clothing, sheets or pillow cases and the anxiety of being in close contact with people.

SMP can be used for a variety of scalp conditions that include: genetic androgenic alopecia (AGA) otherwise known as male pattern balding (MPB), scarring alopecias from a variety of autoimmune diseases of the scalp (e.g. alopecia areata, alopecia totalis), and scarring from neurosurgical procedures or burns. Almost any size scar can be treated. It is also used to manage the unnatural appearance that is associated with outdated hair transplant procedures. SMP is an adjunct to hair transplant surgery by creating a thicker look to the transplanted area. Today's hair transplant surgery can create a completely natural appearance using your own hair to provide fullness in thinning areas. This process adds to the look of fullness by reducing the contrast between your scalp and your hair color. It can also camouflage scars found on the scalp including those that form from 'strip harvesting'. The technique is dependent on highly specialized and artistic skills. It requires a clinical understanding which professionally blends the process with the problem being addressed. Specialized instruments and pigments are used. This is a non-surgical procedure by experienced hair restoration surgeons and qualified staff and trained cosmetic tattoo artists.

Like any tattoo process, the technique involves placing a special pigment into the skin of the scalp to mimic 'hair follicles' almost to the size of a closely cropped head of hair. Think 5 o'clock shadow or stubble. We have been using Scalp Micro-Pigmentation (SMP) for two purposes: As an alternative style for making a balding person look full headed with the placement of pigment into the scalp and to camouflage the scars from a strip procedure or anywhere on the scalp.

What does it look like?

The patient likes his hair cut close, so follicular unit extraction (FUE) would have been a reasonable way to achieve it without a detectable linear scar that traditional strip surgery might produce. The problem is that he needed somewhere between 4000-6000 grafts to cover the balding area. This means that he could have been looking at 2-5 FUE surgeries to obtain the final look he wanted; and as he continued to bald, he might run out of donor hair. This patient was heading towards a Norwood class 7 pattern, and eventually he might need 6000-8000 grafts to follow the hair loss he would experience over time when/if his Propecia would stop producing the benefits he is now getting from the drug. (*continued*)

Scalp Micro-Pigmentation, continued

BEFORE Scalp Micro-Pigmentation



AFTER Scalp Micro-Pigmentation



This patient will have to maintain this short-clipped look unless he elects to have a hair transplant. The upside of this technique beyond what you see is the low maintenance — just trimming his head about every other day. If he is against medication use (like Propecia,) this style allows this choice, but as balding progresses as it inevitably will, a few touch-ups of the SMP technique may be needed (also because the pigmentation tends to fade a bit. The downsides is that the pigment is considered permanent, so the style must be acceptable and it is a lifetime decision.

He is thrilled with the initial results. His comments reflect upon the freedom his new look gives him and how much he loved rubbing his bald head. No more styling gels and repetitive worries about going bald have made him a happy man. He also knows that when hair cloning or hair multiplication become available (fingers crossed), he can just add the value these breakthroughs will give him, and maybe get him the hair that he wanted at some appropriate time in the future.

For more information on this technique, go to www.scalpmicropigmentation.com.



C . A . R . F .

Our CARF Mission and Accomplishments

The Cicatricial Alopecia Research Foundation (CARF) is an authoritative source for those with cicatricial alopecia. The Foundation's mission is to provide funds for research to find effective treatments and a cure, to support education and advocacy, and to raise public awareness.

- CARF represents patients who feel isolated and alone and who have a rare disease that causes permanent hair loss that few physicians can diagnose or manage. There is no known cure and few treatments. We provide an important resource for information, support, and camaraderie and a means to increase public awareness.
- CARF funded seed grants for groundbreaking research on the cause of cicatricial alopecia, which resulted in a \$1.77 million NIH grant in 2009 that was awarded to CARF Scientific Advisor Pratima Karnik. Her research is the first to describe a deficiency in the transcription factor PPAR gamma, which results in a defect in lipid processing and peroxisome biogenesis in lichen planopilaris and frontal fibrosing alopecia. This grant is a milestone and is the first large grant devoted solely to the study of cicatricial alopecia.
- CARF, with its focus on research, has funded or participated in 19 research projects that are at the cutting edge of new insights into cicatricial alopecia.
- CARF's team of Scientific Advisors is comprised of 15 world-renowned researchers and clinicians committed to hair loss disorders: Pratima Karnik, PhD, Victoria Holloway Barbosa, MD, Wilma Bergfeld, MD, Valerie Callender, MD, Kevin Cooper, MD, George Cotsarelis, MD, MPH, Maria Hordinsky, MD, Lloyd King Jr, MD, PhD, Amy McMichael, MD, Paradi Mirmirani, MD, Ralph Paus, MD, Michael Rosenblum, MD, PhD, Leonard Sperling, Kurt Stenn, MD, John Sundberg, DVM, MD.
- CARF has received four Gold Triangle Awards from the American Academy of Dermatology for excellence in public education about dermatologic issues and CARF's founders have been honored with the individual achievement award. CARF's founders were also recognized with Special Congressional Commendations for Outstanding and Valuable Service to the Community.

Please consider supporting CARF so that it can continue to expand its unique and vital work: funding cicatricial alopecia research, educating patients and doctors, and advocating on behalf of patients. Please see our award-winning website: www.carfintl.org.

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Send CARF your new e-mail address:
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