



C . A . R . F .

Cicatricial Alopecia Research Foundation

CARF Communiqué

Fall 2006

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CARF Communiqué — Inaugural Issue

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This inaugural edition of CARF's newsletter, CARF Communiqué, complements other efforts used to fulfill CARF's mission:

- ◆ To provide funds for research to find effective treatments and a cure;
- ◆ To support education and advocacy; and
- ◆ To raise public awareness.

CARF's website provides up-to-date news about patient conferences, colloquia, research, fundraising, and other collaborative efforts for patients and their families, members of the medical and scientific communities, donors, and interested others.

And now, CARF Communiqué on an ongoing basis will focus on informing readers about:

- ◆ "Friends of CARF" (including profiles of patients, scientific advisors, and donors);
- ◆ Promising research dealing with causes and treatments of cicatricial alopecia;
- ◆ Special events (such as conferences, colloquia, and fundraisers);
- ◆ CARF in the news;
- ◆ "Tips and Tricks" relating to personal grooming and helpful products and services;
- ◆ Suggestions and support concerning the emotions relating to scarring, inflammatory hair loss; and
- ◆ Ways in which each of us can support CARF and its efforts.

It is our hope that everyone (patient, family member, physician, researcher, or donor) reading a CARF Communiqué (or looking at CARF's website or attending a CARF-sponsored event) knows that they are NOT alone in dealing with these rare diseases.

CARF is an organization committed to offering support, creating an informative resource, and providing the impetus and ongoing financial backing for groundbreaking research on treatments and a cure for cicatricial alopecia.

In this spirit, with this inaugural edition of CARF Communiqué, let's collaborate and see the positive outcomes we can generate!

Mark Your Calendar!

You won't want to miss CARF's "Diamond Affair," July 21, 2007, Beverly Hills, CA! (See preliminary details on page 5.)

American Academy of Dermatology Honors CARF With Two Gold Triangle Awards

The American Academy of Dermatology established its Gold Triangle Awards to recognize media, industry, health community, public service, and individual accomplishments that further the understanding of dermatologic issues and encourage healthy behavior in the care of skin, hair and nails. At its 10th Annual Gold Triangle Awards ceremony, held in San Diego on July 27th, 2006, CARF received two of these prestigious awards. "We are honored and delighted to receive these two esteemed

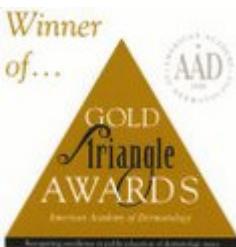
awards," said Sheila Belkin, who co-founded CARF with Vera Price MD.

One award was for the 1st Cicatricial Alopecia Patient Conference, held in San Francisco in August 2005, where the lives of 60 individuals were changed forever as the result of participating in this historic event. Cicatricial (scarring) alopecia includes a group of rare disorders that are difficult to treat and cause permanent hair loss, often with much



Actor Robert Wagner presents CARF's Amanda Roth and CARF Co-Founders Vera Price MD and Sheila Belkin with Gold Triangle Awards

(continued on page 9)



"In clinic now we are seeing many of the patients that participated in the CARF conference. Patients have more questions and are seeing the cicatricial alopecias through a different set of eyes. The experience was good for all - patients, physicians, students."

Regards,
Maria Hordinsky MD,
University of MN, co-host of MN Conference
and speaker at both
Conferences

"We both thoroughly enjoyed the weekend; the doctor's morning was very enlightening, the small groups added the bit of personal touch we all need, but meeting others who are experiencing the same hair and scalp problems and learning their ways of dealing was the best."

The Housers,
Modesto, CA



Dr. Anita Arnstein-Dunsay,
CARF Conference Speaker/
Facilitator and Richard
Dunsay, CARF Board
Member, Emcee and
Auctioneer

CARF Patient Conferences — A Patient's Perspective by Donna Dreher Weaver

I've been lucky enough to attend both the first and second CARF Conferences, the first time (in San Francisco) as an organizer and breakout session facilitator, the second (in Minneapolis) largely as a participant. I can't say enough positive things about the Conferences, both in terms of my personal experiences and what I observed and heard from other participants.

I was first diagnosed with cicatricial alopecia over a decade ago. Like most of my fellow patients/attendees, before my involvement with CARF I'd never known of anyone else who has it. While I have supportive friends and family, no one else could relate to the physical symptoms I was experiencing, my uncertainty as to appropriate treatments (and my embarrassment over some of the messier ones!), the challenge of finding a physician who could help me, and the emotions associated with my hair loss. For someone who'd had Shirley Temple curls as a child and had been affectionately nicknamed "Moaptop" for several decades of her life, having "hair on fire" symptoms, losing some auburn curls, and facing the situation as a new, mid-life divorcee was a challenge!!

My life changed for the better when I saw Dr. Vera Price at UCSF for the first time. The treatments began to slow down my symptoms for the first time in years. She asked me to join one of her patients, Sheila Belkin, and a small group of others who were working to create a patient support, advocacy, and fund-raising organization: CARF. They'd created a brochure and were working on a website. Would I be interested in coming to a meeting?



Organizing Committee for 2nd CARF Patient Conference in Minneapolis, May 2006



**CARF Patient Conference Organizer/
Facilitator, Donna Dreher Weaver**

Not knowing anyone else with hair loss like mine, I must admit to being interested – and nervous. At the first organizing session, an afternoon meeting followed by dinner at Dr. Price's home, I joined a team of inspiring, caring, dedicated and capable people. Our leader, dynamo Sheila Belkin, planted the seeds for an inaugural patient conference and insisted that it occur within a year – a daunting task!

Collectively, we put our faith in one another and, via phone calls, emails, and just a few face-to-face meetings, we pulled it off! The inaugural Conference in San Francisco was so successful that some of the medical doctors in attendance from Minnesota asked for our planning template and materials so that they could take the initiative, work with local volunteers in Minneapolis, and conduct a second conference – less than one year later!

Seven of the organizers from the first conference were on hand in Minnesota to lend their support and share the experience with a new group of patients and physicians. We had a second resounding success!

Many of the Conference participants were newly diagnosed with scarring alopecia, and were receiving detailed information about the condition and treatments for the first time. Virtually all of us were hearing about pioneering research for the very first time. Several at each conference attended with their spouses or other family members, who were able to better understand the condition and related emotions, seeing that their loved ones were not alone or unusual in their responses to scarring hair loss. Having a disease that sometimes feels like "hair on fire, with "no known cause, no known cure,"

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Profile in Giving: An Interview With Betty Ruth Tanzey

by Laurence Spector

About her:

Betty Ruth Tanzey is a former United States Naval officer who was stationed at Treasure Island Naval Base off the coast of San Francisco. She specialized in encrypted communications, encoding and decoding secret messages for the United States Military. After retiring from the Navy, Betty worked as a court reporter in California, and now resides in San Francisco.

Her cause: empowering CARF to underwrite the research projects necessary to find a cure for cicatricial alopecia.

Betty learned about CARF on the Internet; however, she did not realize that her diagnosis of lichen planopilaris was a form of cicatricial alopecia until she checked with her physician. She thinks there are other patients who have this condition, but don't know that they have it because they have not seen a specialist who can make a proper diagnosis. She realized her hair was disappearing slowly, and she knew something had to be done.

At this year's CARF patient conference in Minneapolis, Betty enjoyed meeting other

patients with cicatricial alopecia, but she was frustrated because there aren't answers to many questions surrounding the mystery of her disease. Betty believes CARF is challenged with promoting awareness among doctors, patients, and research scientists.

When asked if there was anything good about having cicatricial alopecia, Betty commented that, "I suppose if you have to be cursed with something, this is not as bad as many other things. And if the patients unite, together we can find a cure by supporting CARF."

Why she gives to CARF:

"I want to help fund a cure. CARF is a great candidate for my charitable contributions because I know the money will be used for research. This is one of the main goals of CARF — to fund research. I can only say to others that investing in CARF is in their own best interest. If anyone's going to find an answer, it's going to involve the patients working together. This year, after attending CARF's patient conference to learn more about the disease, I left feeling determined to help find better treatments, as well as a cure."



CARF Donor and Patient Conference Attendee, Betty Ruth Tanzey

"I can only say to others that investing in CARF is in their own best interest. If anyone's going to find an answer, it's going to involve the patients working together."

—Betty Ruth Tanzey

CARF Scientific Advisor Profile: Kurt Stenn MD

Kurt Stenn is Chairman of the CARF Scientific Advisors, and has been a member of the CARF team since the inception of the organization. He has had a long term interest in the hair follicle: its formation, cycling and diseases. Trained as a physician within the University of Chicago and University of Rochester Medical Schools, he did his hospital training within the Harvard Medical School system.

After four years of research in biochemistry and biophysics at the Armed Forces Institute of Pathology and Harvard Medical School, he joined the faculties of Yale School of Medicine where he eventually became Professor in the departments of dermatology and pathology. After 20 years at Yale he became Director of Skin Biology in the large healthcare company, Johnson and Johnson. Currently he is one of the founders of a new biotechnology company developing cell-based products for new hair follicle formation.

Scientific work from his laboratory has contributed to the fields of blood coagulation, cell motility, wound closure, epithelial-mesenchymal interactions, hair cycling, hair shedding, and hair shaft egression. Findings concerning the genetic basis of a form of mouse cicatricial alopecia described by his group serve, currently, as one of the models for the human forms of primary cicatricial alopecia.

Dr. Stenn is a reviewer for multiple dermatology and basic science journals and has been an advisor and officer of various hair-related organizations, including the Board of Directors of the National Alopecia Areata Foundation. Dr. Stenn lives in Princeton, New Jersey, with his physician-gardener-musician wife. He and his wife play Celtic music, he on the pennywhistle and she on the accordion. He has two children and five exceptionally beautiful grandchildren.



**Kurt Stenn MD, Chairman
CARF Scientific Advisors**



Colloquium Organizers, Doctors Kurt Stenn, Paradi Mirmirani, Vera Price and George Cotsarelis



Sheila Belkin and Doctors Terry Headington, Vera Price and Jurgen Schweizer

The Alchemist
Matheus Van Helmont
(Antwerp 1623-1679 Brussels)
Oil on canvas
Fisher Collection
00.01.277
Chemical Heritage Foundation Collections
Philadelphia, PA USA

Photo by Will Brown
Courtesy of the Chemical Heritage Foundation Image Archives

www.chemheritage.org

CARF Spearheads Cicatricial Alopecia Research Colloquium

CARF recognized the vital importance of having a one-day conference on cicatricial alopecia, particularly given the lack of relevant epidemiological, clinical, and laboratory studies of these follicular diseases.

CARF spearheaded a Cicatricial Alopecia Research Colloquium on the NIH campus, held in Bethesda, in October 2005 and attended by seventy scientists from all over the world.

After discussion of the current human and animal models relating to inflammatory hair disorders, researchers and attendees examined the causes, the pathology, and the underlying dis-

ease processes of inflammatory hair disorders, and identified possible future directions for research and treatment.

The Summary of the Colloquium, published in the Journal of Investigative Dermatology (2006;126:539-41) may be viewed in its entirety, free-of-charge, by going to the following website: <http://www.nature.com/jid/journal/v126/n3/full/5700148a.html>.

Elizabeth Blalock, of the JID, wrote to CARF: "We are pleased to make the meeting report free to all users who may click through your site, so it will be easy for them to access the materials."

Pairing Art and Science



The Chemical Heritage Foundation has one of the largest collections of alchemy art and seeks to advance understanding of the chemical and molecular sciences. CARF-sponsored research encourages discovery and the dissemination of information to create better public understanding. This exquisite masterpiece exemplifies the pairing of art and science.

Description: At center a bald, bearded, seated alchemist faces forward, looks up slightly to right at a flask in his left hand; at left a table with many books, a skull viewed from neck end, an écorche model showing musculature, a celestial globe, and snuffed candle. In left foreground a young man applies bellows to a small furnace. Above alchemist leaves blow through an open window, and in right background are six workers: one at a furnace, four in a huddle, one holding (a book?).

Mark Your Calendars: Don't Miss CARF's Summer 2007 "Diamond Affair" in Beverly Hills!

Plans are currently underway for a gala Summer 2007 CARF fundraising and awareness-building event, to be held at the boutique Luxe Hotel on Rodeo Drive in Beverly Hills, CA.

Scheduled for Saturday, July 21, 2007, the event will honor Vera Price MD for her life's work on the hair follicle and hair disorders.

Organizers promise this will NOT be another speech-filled, ho-hum event; it will be filled with fun and pizzazz! Admission for the Saturday evening gala is \$100 per person, and attendees will include those who wish to honor Dr. Price — friends, patients, celebrities, the dermatologic community of Los Angeles (and throughout the nation), and others in related medical and pharmaceutical fields.

The gala event will feature:

- Live and silent auctions, filled with amazing items from Beverly Hills merchants;

- A "diamond martini" raffle;
- Hollywood celebrities and entertainment;
- A video on cicatricial alopecia;
- A Saturday lunch for cicatricial alopecia patients and the doctors; and
- Food, drinks and valet parking included.

The intimate 88 room Luxe Hotel is giving CARF a super rate of \$165 per night. The hotel's newly refurbished rooms, the chef's creations, and other hotel amenities are fabulous. It will be necessary to reserve rooms early. A list of other hotels in the area will be available for those traveling from out-of-town.

Don't miss this memorable event and the wonderful opportunity to support CARF — and to explore and stroll the lovely streets of Rodeo Drive and Beverly Hills!



Promising New Research on LPP at Case Western Reserve

Researchers at the Department of Dermatology, University Hospitals of Cleveland/Case Western Reserve University conducted a study to better understand lichen planopilaris (LPP), a type of cicatricial alopecia causing permanent hair follicle scarring. Looking at scalp biopsies of both LPP patients and normal controls, researchers found that LPP patients lack normally functioning peroxisomes, an important enzyme found in all cells, including the sebaceous glands.

Peroxisomal genes are involved in cholesterol biosynthesis and lipid metabolism, and a peroxisome deficiency can cause an accumulation of unmetabolized lipids in the hair follicles of LPP patients. The researchers proposed that it is the lipid accumulation in the hair follicle which then leads to inflammation, tissue damage and cell death, causing permanent hair loss in LPP patients.

The research abstract appeared in the April 2006 issue of Abstracts from the 2006 Annual Meeting

of the Society for Investigative Dermatology, held in Philadelphia. With the permission of the Journal of Investigative Dermatology (JID), the abstract follows.

Research Abstract: Peroxisomes and Lipid Metabolism in the Pathogenesis of Primary Cicatricial Alopecia – Lichen Planopilaris P Karnik, M Smetanick, TS McCormick, KD Cooper and P Mirmirani
Department of Dermatology, University Hospitals of Cleveland/Case Western Reserve University, Cleveland, OH.

Primary cicatricial alopecias (CA) are a poorly understood group of disorders characterized by the permanent destruction of hair follicles. To understand the molecular pathogenesis, we analyzed gene expression profiles of scalp biopsies from patients with lichen planopilaris (LPP) ($n=10$, pooled) and normal controls ($n=10$, pooled) using Affymetrix Human

Would you like to enroll in a Cicatricial Alopecia research study?

See the article on page 8 for more information.



Cicatricial Alopecia Researchers: CARF Scientific Advisor Paradi Mirmirani MD and Pratima Karnik PhD

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Tips and Tricks for Cicatricial Alopecia Patients: Learning How to Care For Your Hairpiece



**Lisa Ciancio,
“Tips and Tricks”
Contributor**

NOTE: These “tips and tricks” articles were written by Lisa Ciancio, Denver, Colorado, and are reprinted (with our thanks!) with permission of the National Alopecia Areata Foundation (NAAF).

Learning How to Care for Your Hairpiece

First Things First

Find a professional hair stylist and cosmetologist that you trust and can communicate with. Consult with several different people until you are comfortable. Don’t leave yourself without options. There are many wig companies and many professional hair stylists. Don’t be talked into a purchase that you are not comfortable with. Sometimes it is helpful to take this first step with the help of a friend. They can be lifesavers.

If possible, gather old pictures of yourself and different hairstyles that you like. Take them with you to the consultant. If you want a new look, search magazines and hairstyle books. With the help of your professional hair stylist there may be a hairpiece that will look like the desired style you want, or one that can be cut and styled to suit you.

Be sure to find a person that will treat you with dignity and honor. You need this person to care about how you are going to feel and how you look when you leave. You want someone you will feel comfortable going back to.

Prior to purchasing a hairpiece, decide what you are able and willing to spend. Hairpieces can range from \$65 to \$5,000. Buyer Beware! Do your research! When considering your purchase, you may want to think about purchasing two hairpieces. Like shoes, one hairpiece will get worn out faster. It is also helpful to have a backup in case one is dirty.

When you are considering human vs. synthetic hair, keep a few things in mind. Decide what you want. If you want easy, wash-n-go hair, consider purchasing a synthetic wig. Synthetic wigs are made of a plastic-type fiber. They typically will last about six months. They are easy to wash and will go back to their original style when washed, fluffed and dried.

If you decide that you want human hair, understand what that means. Human hair is real hair.

You have more styling options, but like real hair, if your hairpiece does not have a curl or permanent wave and you get rained on, it will go flat and you will need to restyle it.

After you decide the type of hairpiece that you are going to purchase or order, you may be asked if you want to have your wig pre-cut or pre-styled. DON’T DO IT! Remember that every person’s head and face shape is unique, and a wig should be cut and styled to fit you exactly. Wait for the wig to come to you. Then carefully examine it before you do anything to it. Make sure the hair color is the color you ordered. Look at the construction of the hairpiece. Is it what you ordered? Make sure you are satisfied with your purchase before doing anything to it. And educate yourself about return policies. You want a company that will take care of you and guarantee their product.

Don’t Panic

When the wig comes in, it may look a little different than what the picture or example looked like. A little cut and a little texture and shaping will make all the difference in the world. Wigs tend to have about two times more hair than you are going to want. Don’t be afraid; this is where the professional hair stylist comes in. Remember be “in” the wig when it is cut and styled. You must communicate what you want. Even the best professionally trained stylists can’t read your mind.

You’re Home, Now What

First, don’t be afraid of your hair. The hair will not fall out. Play with it. If, after the first cut and shaping, you think it is too long on the top or sides, go back and have it shaped again. Remember, wig hair does not grow, so take it easy.

When is it time to wash your wig? There are a few ways to tell if your hairpiece needs washing. One certain way to determine whether or not it needs washing is to smell it. Wigs, like hair, pick up odors and pollution, and dirty wigs can look dull and sometimes frizzy. That’s the time to bathe them.

Don’t be afraid to work with your wig, play with it, and restyle it. HAVE FUN !!!! Remember that it’s your hair; you purchased it!

Tips and Tricks for Cicatricial Alopecia Patients: Learning How to Care For Your Hairpiece —

Synthetic Hairpieces

1. Brush and detangle hair, prior to washing it.
2. Fill a sink or bucket with tepid water and synthetic wig shampoo or a water softener like Calgon. The water softener will help remove the residue. Let soak in a bucket for a few minutes. Gently swish hair back and forth in the water while holding it by the bangs. After a few minutes, empty the dirty water and rinse water and rinse with cool water. Rinse until water is clear.
3. Take the wig out of the clear rinse and gently squish hair so that the bulk of the water is out of it. Then, take a towel and gently wring the hair to dry it. Of course, it won't be completely dry.
4. With a wide tooth plastic comb, gently comb through the hairpiece to remove the tangles. It is advisable to let it air dry on a wig stand or a large can, covered with a towel. Don't lay it on the towel to dry, as it will be flat on the side that it is laying on.
5. Once your hairpiece is dry, remove it from the form. Using a chinstrap to secure it to your head, use a brush or pick to set your style. Your fingers are your best styling tools. A three-way mirror is helpful when doing the final style; you can see all sides and back. If you see holes or can see your scalp, you can tease or back comb at the area to cover any holes that may still be there.
6. *No patting.*
7. Please remember, while wearing your wig, if you constantly have your fingers or hands patting and smoothing, it will make your hair look like a wig. You want to look natural, so less is best.

Human Hair Wigs

1. Brush and detangle hair prior to washing it.
2. Fill a sink or bucket with tepid water. Not too hot, not too cold.
3. Put about a quarter-sized dollop of shampoo in water. Use a professional shampoo product. Your hair stylist can make a recommendation for you. Rub your hands together with the shampoo. Hold the wig by the front of the bangs and with one hand apply the shampoo in a downward motion. Do this several times.
4. Rinse the soap out of the wig and empty the sink or bucket.
5. Fill the sink or bucket with clear water and put your conditioner in the bucket. Place the hairpiece in the water with the conditioner. Let soak for a few minutes.
6. Take hair out of the bucket and rinse with cool water. This will help close the cuticle and make the hair shine. Rinse until water is clear. Do not put baking soda or use a clarifying shampoo on your wig. If a clarifier needs to be applied, ask your professional to assist you with that. You may want to consider taking your hairpiece to a professional if you need extreme conditioning.
7. Remove hairpiece from water and gently wring. Then, using a towel, gently wring again.
8. Comb through wet hair with a wide-tooth, plastic comb.
9. Next, with a hair dryer, using medium heat, dry the inside for comfort. It also starts to dry the wefts, or the base of the wig.
10. If you only style from the outside and the weft or base of the wig is still damp, your hairstyle will not hold. If you have permanent wave in your human hair, dry minimally, without combing to avoid frizz.
11. Next, flip the hair over at the nape (or back of the head area) and continue to dry it all the way. Drying it partially upside down will

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Promising New Research on LPP at Case Western Reserve (Continued from Page 5)

The researchers proposed that it is the lipid accumulation in the hair follicle, which then leads to inflammation, tissue damage and cell death, leading to permanent hair loss in LPP patients.

U133B chips. A significant decrease ($p<0.00001$, $FC<2.0$) in expression of peroxisomal genes involved in cholesterol biosynthesis and lipid metabolism (fatty acid β -oxidation and desaturation) was observed in LPP. Indirect immunofluorescence staining of the peroxisomal membrane protein PMP-70 showed an abundant staining of peroxisomes in the sebaceous glands and in the inner (IRS) and outer (ORS) root sheaths of the hair follicles in normal tissue. In stark contrast, there was a complete absence of peroxisomal staining in LPP tissue. Nuclear staining with DAPI confirmed that the lack of PMP70 staining in LPP is due to lack of peroxisomes and not due to the absence of sebaceous glands. Our microarray data confirmed the downregulation of peroxin genes PEX3, PEX16 and PMP22 that are necessary for peroxisome

biogenesis. Peroxisomal deficiency should cause an accumulation of unmetabolized lipids in LPP tissue. Indeed, Nile Red staining showed large lipid droplets in the perifolliculum of LPP tissue. In contrast, normal tissue showed no lipid droplets in the perifollicular region. Lipid analysis confirmed a 110% increase in triacylglycerols and a significant increase in long chain fatty acids (linoleic and arachidonic acids) in LPP. There was also a 50% decrease in cholesterol esters in LPP compared to normal tissue. We propose that peroxisomes are a crucial determinant of lipid homeostasis in the hair follicle and that increased lipid accumulation causes tissue damage (lipotoxicity), triggers inflammation and activates a lipid-mediated programmed cell death (lipoapoptosis) causing destruction of hair follicle stem cells and permanent hair loss in LPP.

Cicatricial Alopecia Research Study Now Enrolling Patients



Paradi Mirmirani MD, Kaiser Permanente, Vallejo, CA and Vera Price MD, UCSF, San Francisco, CA

Dr. Paradi Mirmirani and Dr. Vera Price are now enrolling patients with cicatricial (scarring) alopecia in a research protocol that is being conducted in collaboration with the Department of Dermatology at Case Western Reserve University.

This study expands on the initial Case Western research by providing scalp biopsies from fifty additional patients and including all types of cicatricial alopecia. CARF funds are supporting this important research.

Patients over the age of 18 with active cicatricial alopecia (any variant, treated or untreated) are eligible for enrollment. Participation includes filling out a hair loss questionnaire, scalp photographs, and two scalp biopsies. Scalp biopsies will be evaluated for changes in enzymes of the sebaceous glands (peroxisomes) which may lead to

lipid accumulation and then destruction of the hair follicle. There is no compensation for participation in the study.

For patients requesting further information or patients interested in participating in the study, please contact:

Dr. Paradi Mirmirani at Kaiser Vallejo:
Phone: (707) 651-2552
e-mail: Paradi.Mirmirani@kp.org

Or

Dr. Vera Price or Dr. Blanca Ochoa at UCSF:
Phone: (415) 353-9529
email: hair@derm.ucsf.edu.

Tips and Tricks for Cicatricial Alopecia Patients: Caring For Human Hair Wigs (Continued from Page 7)

help to give it volume. If you want a straighter, sleeker look, don't blow dry upside down. A flat wig that doesn't have movement will tend to look really fake, therefore giving you that "wiggy" look.

12. Attach your wig to a head block, which is best because you can work with it three-dimensionally. Brush it into a semi-style and finish drying with a roll brush or blow dryer brush. You can back comb or tease to cover holes, create height, and finish styling.



CARF Celebrates Two Gold Triangle Awards



Vera Price MD Makes Acceptance Speech



Speakers at CARF Conference in Minnesota, May 2006



CARF Conference Attendees and Speakers Enjoy Casual Meal in Minnesota, May 2006



Organizers of 2005 CARF Conference (CA) Help With Silent Auction at 2006 CARF Conference

My husband and I spent a very productive weekend in Minn. at the CARF conference on May 26-28. This conference was so well organized and informative. The people were friendly and willing to share their ups and downs. The physicians were very down to earth and sympathetic to our plight. Sheila Belkin and her many helpers should be congratulated on a job extremely well done. I look forward to seeing them all again.

—The Kritemans,
Middleton, MA

CARF Receives Two Gold Triangle Awards

(Continued from Page 1)

pain, itching and burning. Patients describe their symptoms as "hair on fire."

At the Conference, patients from across the United States, their families, doctors and nurses had the opportunity to meet one another, learn about the latest treatments and cosmetic solutions, ask questions of expert clinicians and researchers, participate in small group discussions, share experiences, make friends, and offer support.

"Rave reviews were given by all those who attended. The successful first conference led to the second patient conference, held in Minneapolis in May 2006," reported Ms. Belkin, CARF's Chief Executive Officer.

A second Gold Triangle was awarded for CARF's website, www.carfintl.org, which is the sole educational forum in the world dedicated to serving individuals with cicatricial alopecia, the medical community and the general public. The unique website provides easy access to important current information, including Frequently Asked Questions answered by CARF's Scientific Advisors, all leading clinicians and researchers.

The website also contains photographic illustrations, up-to-date references, and information about opportunities to meet other people with an interest in hair and these rare disorders.

CARF Conference — A Patient's Perspective

(Continued from Page 2)

can be challenging; yet, I now feel I have access to the most up-to-date research information. I have met physicians who are committed to collaborating with one another and to helping patients like me.

The CARF Conference breakout sessions that we attended provided us with information and an opportunity to express frustration, uncertainty, concern, sadness – and resolve and hope. We shared our experiences and ideas – and often unexpected humor and laughter, bonding while sharing meals, checking out hairpieces, and bidding on silent auction items to raise funds for cicatricial alopecia research.

Attending CARF Conferences helps me to

be proactive in dealing with this disease – by getting information from "the best;" by thanking physicians who spend their time treating and supporting scarring alopecia patients; by sharing my experiences and perspective with physicians; by providing support for – and receiving understanding and nurture from – other patients; and by helping to raise funds.

I think of CARF and my experiences in Minnesota every time I wear the beautiful pearl necklace, just as I think of San Francisco when I look at the watercolor painting that hangs in my home – both won at CARF silent auctions! And I look forward to attending the next CARF patient conference — and to meeting some of you there!



C. A. R. F.

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

Contact CARF:

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Donations	donations@carfintl.org
Press Releases	media@carfintl.org
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Volunteers	volunteers@carfintl.org
Diamond Affair 2007	events@carfintl.org

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

ADDRESS CORRECTION REQUESTED

CARF Communiqué Guest Editor: Donna Dreher Weaver



CARF Co-Founder and CEO Sheila Belkin, with 2006 Gold Triangle Award



CARF Board Member and Conference Speaker Ken Washenik MD PhD with Sheila

CARF Needs Your Help! Join Us.... Our Award-Winning Organization Is Just Getting Started!

CARF depends on its volunteers! We're just getting started — and we've already had a big impact!

CARF volunteers are patients and "friends," men and women of all ages, from all parts of the country, of diverse ethnic and educational backgrounds.

What we have in common is a desire to support one another, learn about cicatricial alopecia, manage our symptoms, and live our lives well. We also share a hope that researchers and clinicians will soon determine the causes of this disease, will devise more effective treatment protocols — and will ultimately find a cure for cicatricial alopecia.

Please contact us and tell us of your interests and talents. It's thanks to CARF volunteers that:

- ◆ Funds are raised to support research and the costs of educating patients and the medical and scientific communities;
- ◆ Patient conferences, research colloquia, and special events are planned and conducted;
- ◆ Meetings of members of the scientific community are held and their results published;
- ◆ Strategic and operating plans are devised;

- ◆ Photos are taken and graphics are designed; and
- ◆ CARF's website, conference materials, brochures, newsletters, press releases, and other promotional materials are written, edited, printed, and reach people worldwide.

If you've benefited from CARF's efforts — even just in the course of reading this newsletter — you have volunteers to thank!

We want to hear from you. Join us and share your expertise. Collaborating with CARF volunteers (face-to-face, or across the miles via phone, email and conference call) provides numerous personal benefits — and you'll be working with others committed to conquering this disease!