



C . A . R . F .

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## CARF 5<sup>th</sup> International Conference for Patients and Doctors

Friday, August 10 – Sunday, August 12, 2012  
Hilton Boston Back Bay Hotel

The CARF biennial conference is a must for patients and physicians involved with cicatricial alopecia. Attendees attest 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 invite you and your family to attend this 3-day educational conference, where infor-

mation will be presented on the diagnosis and available treatments, latest research breakthroughs and cosmetic solutions. You will meet leading physicians and researchers in the field, participate in breakout sessions, meet new friends and have an opportunity to explore a variety of attractions in the Boston area. We look forward to seeing you there. You will receive a registration packet prior to the conference.

## CARF Grant Recipient Dr. Marlon R. Schneider



Marlon Schneider, MD

CARF is pleased to announce the award of a research grant to Dr. Marlon Schneider for his work on the function of sebaceous glands and the role of lipid metabolism in normal hair follicle biology, two highly relevant topics for cicatricial alopecia research.

Dr. Marlon R. Schneider studied veterinary medicine (1990-1995) and obtained a M.Sc.

(1997) from the UFRGS University in Porto Alegre, Brazil. In 2001, he added a PhD from the Ludwig-Maximilians Universität München in Munich, Germany. After completing his postdoctoral training at Columbia University in New York City (2001-2002), he returned to Munich where he has been working as a Research Associate and Lecturer (*Wissenschaftlicher Assistent; Privatdozent*) at the Gene Center, LMU Munich.

Dr. Schneider's research focuses on the role of the epidermal growth factor system in health and disease, particularly in the skin and skin appendages such as the hair follicle. He oversees several ongoing projects related to the development and biology of sebaceous glands as well as the role of these fascinating structures in human disease. Dr. Schneider is a member of

the European Society for Dermatological Research and has published in and served as an expert reviewer for several dermatological journals, including the Journal of Investigative Dermatology, the British Journal of Dermatology, Experimental Dermatology, Journal of Dermatological Science, Dermatology, and Archives of Dermatological Research. In addition to a grant from CARF, Dr. Schneider has received financial support from the Deutsche Forschungsgemeinschaft (DFG), the Bavarian Research Foundation (BFS), the Else-Kröner-Stiftung, and the Fritz-Thyssen Stiftung. In 2010, he was awarded the Schöller-Junkmann Prize from the German Endocrinology Society. Dr. Schneider and his wife live in Munich. They have a 2-year-old daughter.



## Dr. Hiroko Hama Receives CARF Grant



Hiroko Hama, MD

Dr. Hiroko Hama obtained a PhD in Biochemistry in 1990 from Okayama University in Okayama, Japan. After completing postdoctoral training at Harvard Medical School (1991-1993) and the University of California San Diego/HHMI (1993-1995), she continued her research at the University of Texas Southwestern Medical Center at Dallas (1995-1997) and Utah State University (1998-2001). She joined the faculty at the Medical University of South Carolina in 2001, where she is currently an Associate Professor.

The main focus of Dr. Hama's group is lipid metabolism within the nervous system. Ongoing investigations include the pathogenesis of the demyelinating disorder FA2H deficiency and the development of lipid therapeutics for this disorder. Dr. Hama's group, in collaboration with CARF's Scientific Advisor Dr. John Sundberg at The Jackson Laboratory, discovered that FA2H deficient mice

develop not only a neurological disorder, but also sebaceous gland abnormalities and cicatricial alopecia. Together, Drs. Hama and Sundberg set out to explore the role of the sebaceous gland in the pathogenesis of cicatricial alopecia.

Dr. Hama is a member of the American Association for the Advancement of Science, American Society for Biochemistry and Molecular Biology, American Society of Neurochemistry, and Society for Neuroscience. She serves as a member of the NIH Biochemistry and Biophysics of Membranes Study Section and has served as a reviewer for numerous biochemistry and neuroscience journals. Her current research projects are supported by the National Institute of Neurological Disorders and Stroke and a fellowship from the North American Hair Research Society. Dr. Hama lives in Charleston, SC, and enjoys gardening, hiking and dancing.

## Meet New CARF Scientific Advisor Ralf Paus



Ralf Paus, MD

Ralf was born in 1960 in Münster, Germany. He is married, has three kids, and currently lives in Hamburg. Since 2005, he has served as Professor and Head of Experimental Dermatology in the Department of Dermatology at the neighboring University of Lübeck on the Baltic Sea. He holds a secondary appointment in the UK as Professor of Cutaneous Medicine at the School of Translational Medicine, University of Manchester, and is Editor of *Experimental Dermatology*.

Following medical school at the Universities of Wuerzburg (Bavaria), Berlin, and Vienna and subsequent to his internship in Switzerland, he worked as a post-doc in the Department of Dermatology at Yale University, New Haven, CT, where he became addicted to hair biology under the supreme mentorship of Kurt Stenn, one of our own CARF Scientific Advisors.

During his residency in Dermatology in Berlin, he worked primarily on hair follicle immunology (with emphasis on its relevance for alopecia areata) and on the molecular controls of hair follicle development. Since moving to Hamburg, first as Professor and Vice-Chair of Dermatology at the University, he became intrigued by the skin as a source and target of multiple neurohormones and neuropeptides; and he is still trying to find out the need our skin and hair follicles have for all these neuromolecules.

With regard to cicatricial alopecia research, Dr. Paus' current major interest is to better understand how hair follicle epithelial stem cells are normally protected from an autoaggressive inflammation and what goes wrong when this protection collapses, leading to scarring hair loss.

## CARF Contributes at Society of Investigative Dermatology Meeting

Scientific Advisors and patients Sheila Belkin and Annemarie Hartman-Charness were in high gear networking at the May 2011 Society of Investigative Dermatology (SID) Annual Meeting in Phoenix, which attracted over 1400 attendees from around the world. The SID is committed to the advancement and promotion of the sciences relevant to skin health and disease through education, advocacy and scholarly exchange of scientific information.

The SID is committed to fostering scientific careers for young researchers, increasing public and government awareness about the need to support skin research, working with industry in the development of new technologies and cooperative ventures, and encouraging scientific collaborations among researchers worldwide. Founded in 1937, the

SID has a worldwide membership of 1700 and publishes *The Journal of Investigative Dermatology (JID)*—the premier journal dedicated to research in cutaneous biology.

Highlights of the SID meeting:

CARF Scientific Advisor Pratima Karnik, PhD and her laboratory staff presented three research posters on cicatricial alopecia and gave a talk at the Hair and Cutaneous Development session. These research studies were supported in part by CARF.

The SID and the JID honored members of the Coalition of Skin Disease (CSD) for their advocacy on behalf of patients.

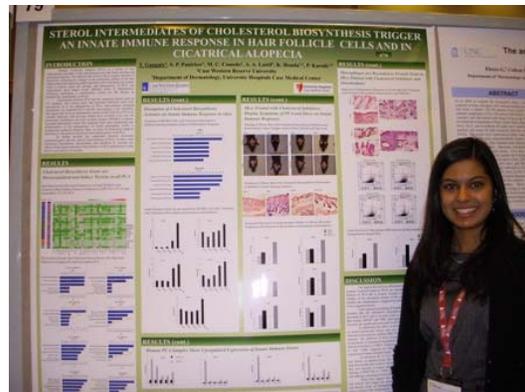
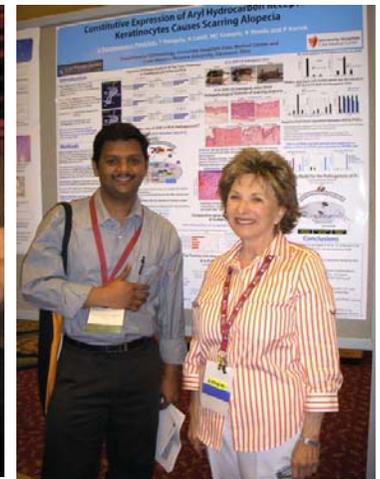
CARF manned a display booth and

gave out materials highlighting and promoting research grant opportunities.

Scientific Advisor Chair Dr. Kurt Stenn and CARF CEO Sheila Belkin participated in a CSD Collaborative Research Initiative for a new Itch Study as it relates to cicatricial alopecia, cutaneous lymphoma, ichthyosis, eczema and ectodermal dysplasias.

Highlights of the North American Hair Research Society (NAHRS) meeting:

CARF Scientific Advisors were elected into key posts. Wilma Bergfeld, MD was elected President, replacing Ken Washenik, MD, PhD. Maria Hordinsky, MD was elected Secretary Treasurer replacing Amy McMichael, MD. These physicians are dedicated leaders and volunteer as CARF's Scientific Advisors.



## CARF Presence at Dermatology Nurses' Convention

by Elizabeth Froman, RN

It was a pleasure to represent CARF at the Dermatology Nurses' Association convention in San Diego on March 16-17. More than 970 participants attended the event, including 200 exhibitors. Working alongside Judy Jones, President of the Cutaneous Lymphoma Foundation (at a booth sponsored by the Coalition for Skin Diseases), gave me the opportunity to distribute literature about all types of skin disease. I was also able to answer questions, instill interest in the more rare skin disorders, and educate participants about cicatricial alopecia while also promoting the work of CARF.

A highlight of working at the Coalition's booth was becoming acquainted with Vicki Kalabokes, President of the National Alopecia Areata Foundation, as well as the group's Vice President, Jeanne Rappaport. It was a pleasure to meet the officers of the Dermatology Nurses Association, including Barbara Starr, who edits the organization's journal.

Many attendees came by the booth to

inquire about CARF's own Sheila Belkin (who is also on the board of the Coalition of Skin Diseases) and to convey their warmest greetings to her. The hall buzzed with presentations, and there were offers of free products from various exhibitors, particularly those in the realm of cosmetics and anti-aging products. Our "non-product" booth offered information to professionals seeking further knowledge about specific disorders. We also took the opportunity to inform them about the lesser-known disorders, such as the rare alopecias.



I particularly enjoyed introducing nurse

practitioner students to CARF and sharing the story of my personal quest for someone who could accurately diagnose my hair loss. As a nurse, I know that nurses are often the first to be asked about the sensitive subject of hair loss, particularly when they are encountered in a non-clinical setting. Helping nurses answer these questions will hopefully be of benefit to those with hair loss.

A special feature of the Dermatology Nurses Association meetings came on the opening day when Dr. Vera Price addressed the Nurse Practitioner Forum with her "Update on Managing Hair Disorders." Dr. Price's clear and eloquent PowerPoint presentation gave the participants a useful overview of how to navigate the various types of hair disorders. The audience showered her with praise and there were numerous thoughtful follow-up questions.

I found representing CARF to be very rewarding both professionally and personally. Wearing the hats of both



The Coalition of Skin Diseases (CSD) is a voluntary coalition of patient advocacy groups addressing the needs and concerns of millions of people whose lives are affected by skin disease

a Registered Nurse and a patient with lichen planopilaris (LPP), I felt proud to be of service to CARF and to current and future hair-loss patients by disseminating information. Having a representative from our organization attend professional meetings gives medical professionals and patient attendees the opportunity to learn about us and receive printed and website information. In this way, we are able to contribute to furthering the understanding of hair disorders.

As a member of the Coalition of Skin

Diseases (CSD), I represent their mission to advocate and educate on behalf of individuals with skin disease by:

- ◇ supporting basic science and clinical research
- ◇ fostering physician and patient education
- ◇ generating awareness of skin disease
- ◇ supporting the growth of member organizations through the sharing of mutual concerns which may increase the pace of discovery of a cure while improving the quality of life

of those affected.

The CSD also works closely with the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) to coordinate research efforts for all skin diseases. Members of the Coalition meet annually with members of Congress and testify when selected, before the appropriations committees to educate Congress and the public on the seriousness of skin diseases while stressing the need for increased medical funding.

## Patient Support Group News!

CARF has 10 patient support groups around the country and in the UK, each with a physician advisor in attendance. Latest groups will soon convene in Detroit, Metairie and London. Please check our website [www.carfintl.org](http://www.carfintl.org) for locations and meeting dates in your area. In the following articles, read about the topics of interest discussed at the recent meetings held in Boston, Chicago and Los Angeles.

### Los Angeles Support Group

The CARF Los Angeles support group met for the first time on April 9th. Twenty-two attendees gathered at the office of Pearl Grimes, MD, the physician leader of the group and the head of the AnCaTel Hair Spa, a cutting-edge, newly-built hair clinic located in the heart of LA. In attendance were three other dermatologists, including Ken Washenik, MD, PhD, of Bosley, Adriana Schmidt, MD, of Santa Monica Dermatology, and Carolyn Goh, MD, of UCLA, as well as Andrea Marcus, PhD, (psychologist and patient); Nancy FitzGerald, CARF Strategic Advisor, and Sheila Belkin, CEO of CARF.



At the heart of the meeting was a question and answer session that evolved into an informative and dynamic discussion. Some of the questions covered:

◇ *What role does diet play in alopecia? Does gluten affect hair loss?*

The physicians suggested that you speak with your dermatologist about this, which may lead to blood tests for vitamin deficiencies or gluten intolerance. They also suggested checking with your dermatologist before taking over-the-counter vitamin and herbal supplements. Some of these may upregulate (ramp up) our immune response and therefore worsen hair loss.

◇ *What role does stress play in alopecia?*

The physicians suggested that there is an “immunogenetic” predisposition to scarring and non-scarring alopecias that may be triggered by stress, but that stress alone is unlikely to cause hair loss. Managing stress in a variety of ways is likely to be helpful in many inflammatory disorders.

◇ *How do dermatologists know that they are making the right diagnosis based on pathology?*

The physicians responded that clinicopathologic correlation is important such that while the pathology report is not always definitive, discussion between pathologists and dermatologists is essential to making an accurate diagnosis in hair loss disorders.

◇ *When is it feasible to perform a hair transplant on a patient with scarring alopecia?#*

Dr. Ken Washenik (Medical Director of Bosley Hair Restoration) responded that there must be no disease activity for 1-2 years. He emphasized that hair transplants are improving tremendously and new research supported by CARF is pointing to exciting future possibilities, such as the ability to direct one’s own cells to grow hair. He encourages patients to stay on top of research, through the CARF website and by reading and attending meetings, because “sometimes knowing what is going on helps to boost confidence.”

The Los Angeles Support Group meeting will continue to be held quarterly. Meeting sites and dates will be posted on the CARF website as well as by email to be sent by co-chairs, Andrea Marcus and Adriana Schmidt. Please join us!

## Chicago Support Group

May 14th was a very exciting day for patients with cicatricial alopecia in the Chicagoland area. It was the inaugural CARF Chicago chapter support group meeting. The meeting was planned by support group leaders Joe Lazara and Beverley Robin with Dr. Victoria Barbosa, medical advisor to the group. Fliers were sent to the area dermatologists, area patients and patients on CARF's list. The three planners hoped for at least a handful of attendees at the first meeting. The turnout far surpassed their expectations; eight patients and their loved ones



attended! People came from as far as Urbana -- a two hour drive. A lovely breakfast was generously provided by the pharmaceutical company Warner Chilcott.

Patients courageously shared their stories,

experiences and ways of coping with the effects of scarring alopecia and there was often a knowing glance or nod from other participants in the room. There were laughs and tears, but the sense of support and community was felt by all. Dr. Barbosa monitored the discussion for medical accuracy and also explained the difference between lichen planopilaris and central centrifugal cicatricial alopecia. Participants agreed that the meeting was beneficial and that they were looking forward to meeting again in the near future.

## Boston Support Group

On May 1<sup>st</sup>, the Boston support group met at the Brigham and Women's Hospital medical building in Chestnut Hill. It was the group's sixth meeting, with a full complement of patients, spouses, friends, and the medical supervisory team present. The meeting began with an informal exchange of helpful information. For example, [keratin.com](http://keratin.com) is a useful website which discusses LPP and other cicatricial alopecias, and the [NAHRS](http://NAHRS.org) website is a good source of information as well.

Always of interest, there was an exchange about wigs, clips, and partial hairpieces. It was pointed out that when getting a first hairpiece or wig, it is important to find someone you can work with. One patient recommended a provider in Wakefield who is creative with hairpieces and has successfully fitted her with a partial hairpiece that has mesh, is comfortable, and rests on her hair. Another patient recommended Hair Replacement Specialists in Hyannis, which



does hairpieces and wigs -- synthetic or human hair. They are "wonderful, very compassionate," she said. Other tips given included what is best for diffuse hair loss, such as creamy eye shadow to cover bare spots and Top-pik to give fullness. A paste, Couvre, was also recommended.

The group leader, Dr. Doreen Karoll, introduced Kubler-Ross' stages of mourning – denial, anger, bargaining, grief and acceptance – as pertinent to

our reactions to hair loss. Seated in a circle, we introduced ourselves, named our specific diagnosis, and gave some details about our "journey." We exchanged information about symptoms, concerns, medications, and experiences with doctors. There was general agreement that, because there are so few patients with these cicatricial alopecias, and because hair loss is so challenging, it is difficult to find dermatologists who can provide a balance of expertise and support. We all benefited from the discussion, both emotional and practical, with input from Drs. Lynne Goldberg, Deborah Scott and Kathie Huang.

Dr. Goldberg updated the group on selected studies from the recent literature. An article published in April 2011 from London and Cardiff, UK reports on studies with mice with defective sebaceous glands that develop scarring alopecia and helps to explain the mechanism of follicle destruction. This study did not find evidence of an autoimmune basis, but did find that stem cells were deplet-

## Wig Buying: the Agony and the Ecstasy by Irine Onciano



Irine Onciano

Just five years ago, I never thought in my wildest dreams that I would go wig shopping. Not that I have distaste for wigs, mind you. I was simply thoroughly pleased with my own hair and my signature cut. I have worn my hair in a short, stylish cut, by choice, for more years than I care to acknowledge. I have honored this choice despite having had long, dark, curly hair – an inheritance from my father. Several years ago, however, following my initial cicatricial alopecia diagnosis and followed by a second alopecia areata diagnosis last year, my choices were narrowed to two options: 1) a scarce head of hair from some alien being that I didn't recognize when I looked into the mirror, or 2) a perfectly coiffed prosthesis so as not to appear as if in radiation therapy.

I first started on a wig buying "test drive" some three years ago. When I first tried on a wig, tears began to run down my face right there in the store. I felt like I was trying on hats in a public setting and none of them looked becoming. They all felt odd and I was reminded why I never wore hats -- they soon felt annoying. They gave me a headache even when they looked amazing. More importantly, it was my first moment of confronting the fact that before long, a hair prosthesis would likely be a necessity and I wasn't prepared for that reality.

I was shaken to my core and simply

left the store without making a purchase. Since my bald spots were small and on top of my head, a friend recommended that I begin to get hair weaves. This worked well for a year with a geometric cut that I grew fond of, especially when I realized that the weave gave additional styling options to my always fine hair that went limp in humid weather. There was no hat-on-the-head feeling with the weave and from the back, my own hair was visible and still looked great. I had dodged the hat-on-the-head bullet and grew satisfied with this solution --but it would not last.

Continued hair thinning and increased patchy balding took a toll on me. I'd gone through two terrible wig purchases and felt really despondent when I wrote to the CARF San Francisco Support Group for help. I'd never done much to keep my hair well coiffed – pretty much wash and wear and a quick curling iron here and there. I had no idea how to style or care for a wig or where to get help in making a better purchase decision that fit my skill level and addressed my rather large emotional needs. I received the following reply:

*Oh, Irine, I dearly wish that I could be of help because by solving your problem, I would be solving mine. You would think that the style-conscious San Francisco Bay Area would be overflowing with beauticians and wig specialists, but while I have searched and found plenty of businesses willing to sell fright wigs and even better quality very expensive wigs, I have never found someone who would or could offer individualized, quality personal service to help select, style and care for wigs, even though I would be willing to pay for such services.*

I became determined to solve my problem then and there and not to be defined by my illness, my balding appearance, or sympathetic looks from family and friends who never seemed to know what to say about my ever changing look. So, I next contacted a hair transplant/restoration specialist and immediately informed him that I didn't want a surgical procedure, scalp and hair anal-

ysis, etc. I said simply:

*Here's my dilemma. I am an alopecia patient in need of purchasing a new wig, as my hair loss has accelerated and is affecting my ability to present a professional appearance in a consulting practice with constant public contact. Wearing a wig is relatively new to me, and I have thus far made two bad choices as I don't know how to judge the hair for quality and ease of styling. I'm wondering if you know of a resource for patients in the greater Bay Area, particularly the East Bay, one that you would be willing to recommend to get the kind of quality and selection assistance that would mean so much to me. I really need your help.*

The specialist heard me and what I said mattered to him. He gave me the name of a wig salon in another city and suggested that I inform them that he had referred me. I immediately called the salon and talked to the owner of Valley Rags and Wigs in Dublin, California. I found that she had other clients with my condition and she offered empathy before education -- which was very important to me. I drove there within the hour, was met by a very pleasant young employee who listened to my plight and guided me through the process of making a wig purchase that met my needs – from fit to checking the color by viewing it outside in different lights and other such tips. She also provided information on how to care for my new wig, and offered to cut it then or after I'd worn it a while and perhaps decided on shortening the bangs. She and other staff made what had started out for me as an agonizing experience into an ecstatic one. I left the salon, wig on head, smile on face. To use a golf metaphor, "sometimes you have to play the ball from where it lies..."

*(Irine Onciano is an organizational development consultant, trainer and coach in Walnut Creek, California, and principal of Onciano Consulting, [www.oincianoconsulting.com](http://www.oincianoconsulting.com). She enjoys playing golf in her spare time. Feel free to contact her at [irine@oincianoconsulting.com](mailto:irine@oincianoconsulting.com) or (925) 942-1059.)*

## How to Care for Synthetic Hair

### by Marty Monroe and Patty Reinhardt

#### Washing

- ◇ Gently remove tangles using a wide-tooth comb and turn inside out.
- ◇ Use a mild shampoo (or shampoo formulated to clean synthetic hair).
- ◇ In a sink or basin, mix a capful of shampoo in cool water and immerse your hairpiece.
- ◇ Let soak for five minutes. Gently swish and rinse the hairpiece in cool water until shampoo is removed.
- ◇ Do not rub/scrub the wig; just swish from side to side and dunk up and down.
- ◇ Rinse thoroughly.

#### Conditioning

- ◇ Using conditioner is highly recommended to reduce tangling.
- ◇ Refill the sink or basin with clean, cool water and add a capful of conditioner.
- ◇ Immerse hairpiece and agitate gently. **DO NOT RINSE OUT CONDITIONER.**
- ◇ Blot dry in a towel and then gently shake.
- ◇ You can also use a "spray-in" conditioner. Simply spray your wig thoroughly after washing and blot dry with a towel to remove excess water.

#### Drying

- ◇ To avoid damage, be sure not to rub, wring or twist, brush or comb wig when wet.
- ◇ Allow your hairpiece to air dry on a wig stand or on top of a hair spray canister. Avoid using a styrofoam head form. It may damage your wig when drying.
- ◇ **DO NOT BRUSH OR COMB THE HAIRPIECE UNTIL IT IS COMPLETELY DRY.**
- ◇ Once dry, spray sheen or detangling spray onto the wig and comb or brush, depending upon the type of wig you have.

*Editor's note: We wish to thank NAAF (National Alopecia Areata Foundation) and the authors of this article for allowing us to reprint it in our newsletter.*

## We are grateful to our corporate donors who have continued to support our diverse programs that are central to our mission.

Johnson & Johnson Consumer Products, The Procter & Gamble Company, Nestle Waters Canada, SkinMedica, Spencer Forrest, Stiefel, an GSK Company, Allergan, North American Hair Research Society, Aderans Research Institute, Bosley, L'Oreal USA, Warner Chilcott, Wells Fargo, Follica, Galderma Laboratories, L.P., Leiter's Pharmacy, Medicis Pharmaceutical Corporation, Corn Products US.

## Boston Support Group

(continued from page 6)

ed and that there was faulty communication between the dermis and the epidermis. In addition, while PPAR gamma was lost in these mice, there was no increase in arachidonic acid or prostaglandins, suggesting LPP may have several mechanisms.

Two other studies were mentioned: one from the Cleveland Clinic also published in April 2011 studied risk factors for the development of central centrifugal cicatricial alopecia

(CCCA) using a questionnaire at a church fair. The average age of onset was 44.9 years and 16% of women had high grade, presumably scarring hair loss (28% had loss overall, but not confirmed to be CCCA). Those with high-grade loss had a significant increase in the use of traction styles (braids and weaves), but not hot combs. A study from China on treatment of folliculitis decalvans, published in the *International Journal of Trichology*, discussed the authors' experi-

ence using minocycline, acitretin, clarithromycin and rifampin, with 7 out of 13 patients improving on minocycline.

At our next meeting in September, recommendations for good providers of wigs, eyebrow/lash tattoos, etc. will be compiled. Some group members volunteered to serve as "wig buddies" to accompany any group member who wishes to have an unbiased opinion while selecting a wig to purchase.

## We Get Letters

My Dear Sheila:

Well, I think it's time I tell my Cicatricial Alopecia story. My name is Lisa Carter, I'm 43 years of age and I've been losing my hair for over 23 years. I write to you now because I've finally accepted my condition – I'm no longer ashamed of who I am or what I look like. Hallelujah!

I have two sisters who also share this same hair-loss disease: Pamela, my oldest sister, and Veronica, the middle sister. It's important to note that Pamela is 6 years older than I am and Veronica is 5 years older.

The first I heard of hair loss was from Veronica when she turned twenty. She would stand in front of the mirror for hours and complain that her hair was falling out. Of course, everyone thought she was

crazy/obsessed with her hair because we couldn't tell. As the years went by, Veronica continued to complain. Later, it would be Pamela who would start to complain of hair loss. By this time, Veronica had been diagnosed with nonspecific alopecia.

For each of us, the onset of this disease materialized around the age of 20, the time when I began to notice slight hair loss myself. At this point, Veronica had visited many dermatologists and was given various shampoos, monthly steroid scalp injections, etc. We all were able to cope with it as long as we had enough hair to cover the crown area, but as many alopecia patients can attest, at some point you can't naturally camouflage it any longer. Each of us began to take separate journeys to deal with our hair loss when we could no longer hide it naturally.

Pamela decided to shave it all off and now wears it bald. Veronica continues to treat her hair tenderly but wears wigs daily. As for me, I've worn partial weaves, full weaves, and wigs for about 7 years continuously, and now I've shaved and have been wearing beautiful scarves and matching outfits.

I just wanted to let you know that I'm free! I am free from worrying about what's gone and what people think about my looks. I am way more comfortable with the scarves than the wigs. This is me – and I'm fine with that!

All my love and best to you and the organization! Hoping to be an inspiration,

Lisa Carter



My mother and me (with my full head of hair) at age 25



Lisa (full wig), age 36



Lisa age 43

Share your cicatricial alopecia story to give hope and help others. Please send to [carol@carfintl.org](mailto:carol@carfintl.org).



Pamela, Lisa (partial weave, age 40), and Veronica

# Fundraising: My Cloth, My Way!

by Gwen Todd Powell, EdD  
Patient and CARF Strategic Advisor



A fundraiser I am not. Can I talk with someone and end the conversation with receiving a \$5,000 donation? No. Do I like calling people and asking them for money for a worthy cause? Definitely not. We're not all cut from the same cloth.



I can, however, contribute in a way that I like...out of my cloth. For me that is personal donations and, recently, a dinner party. My husband and I were celebrating our 25<sup>th</sup> anniversary in June. We decided to have friends over for a dinner party. We asked them to contribute to CARF in lieu of gifts. Most made the contributions as we asked. We raised over a thousand dollars from nine couples! Now it's not much, but just imagine if we all found "our way, our cloth" and collected as much as we could. Ten people celebrating anniversaries, birthdays, or holidays can make a difference. How about making cards or knitting hats for the winter and selling them with proceeds to CARF? I see \$10,000 in the making from CARF supporters...doing it your way!



Be creative. Help benefit CARF.

## CARF Volunteers 2011

**CARF wishes to recognize the extraordinary dedication and commitment of our volunteers**

Our research and patient support programs are possible because of the kind and generous donation of their time and talent

Jim Aleveras	Andrea Marcus, PhD
Armando Alvarez	Amy McMichael, MD
Mike Andre	Margit McPhillips
Victoria Barbosa, MD, MPH, MBA	Paradi Mirmirani, MD
Tara Belkin	Karen Morgan
Wilma Bergfeld, MD	Annete Njue
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