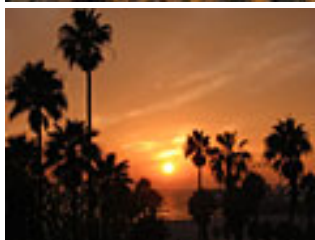




Inside this issue:

Conference Hosts Dr. L. Kakita and Dr. P. Grimes	2
CARF Sponsors Cicatricial Alopecia Symposium Dermatology Nurses Association Conference	3
Lichen Planopilaris Treatment With Peroxisome Proliferator - Activated Receptor Gamma Agonist	4
Interview with Cathy Boeck, RN	5
CARF Support Groups in Washington DC, San Francisco, Chicago and Boston	6
Dancing in the Rain	7
Margaret Sachs	
Options for Covering Hair Loss	8
Raffle Winner Enjoys a Super Vacation	9
Jana FitzGerald - Volunteer PR Coordinator World Map	10
CARF Donors for 2009	11
CARF Website Has a Makeover	12

Don't Miss Out on the Event of the Year!



Patients have described CARF's Patient Doctor Conferences as life changing. Be sure to register soon for this year's Conference in Beverly Hills, California. It is an extraordinary opportunity to meet and converse in an informal setting with leading physicians and researchers who are dedicated to helping patients with cicatricial alopecia. Meeting other patients with this rare disorder is also a wonderful way to share con-

cerns and learn new ways to cope. Many patients form new friendships that provide mutual support for years to come. And on top of all that, we have fun! Family and friends are welcome, too.

To register for the September 24-26, 2010, Conference, visit our website at www.carfintl.org.

CARF Founders Are Winners!



At the recognition luncheon of the 2010 American Academy of Dermatology Annual Meeting held in Miami Beach, Florida, Sheila Belkin and Dr. Vera Price were presented with a Gold Triangle Award for having founded the Cicatricial Alopecia Research Foundation. Members of the CARF team - Dr.

Wilma Bergfeld, Dr. Suzanne Connolly, Nancy FitzGerald and Sharon Potter - cheered them on.

"CARF has reached a group of patients who were very much alone with a rare permanent hair loss problem that few could diagnose or manage," stated Vera Price. "They now have a resource for information, support, camaraderie, and a means to increase awareness and research."

Sheila Belkin added, "As a patient, I know what CARF means to those who previously felt isolated and had no place to turn. I am appreciative of the Academy's ac-

knowledge of the vital role CARF serves."

The American Academy of Dermatology (AAD), founded in 1938, is the largest, most influential and most representative of all dermatologic associations. With a membership of more than 20,000 physicians worldwide, the Academy is committed to advancing the diagnosis and medical, surgical and cosmetic treatment of the skin, hair and nails; advocating high standards in clinical practice, education and research in dermatology; and supporting and enhancing patient care for a lifetime of healthier skin, hair and nails.





Conference Co-Host
Lenore S. Kakita, MD

Dr. Lenore Kakita, a dermatologist in the Glendale/Pasadena area of Los Angeles, works in multiple areas of dermatology. She has been President of the California Dermatology Society, Chair of the Advisory Board of the American Academy of Dermatology (AAD), a member of the Board of Directors of the AAD, and Chair of the Reimbursement

LENORE S. KAKITA, MD

Committee of the AAD. She received the Practitioner of the Year award - a national honor - from her colleagues at the Dermatology Foundation.

Much of her passion for the past fifteen years has been focused on the Women's Dermatologic Society (WDS), for which she served as President. WDS offers great networking opportunities and mentoring, provides research support, encourages leadership development, and sponsors outreach programs (including international ones) in golf and tennis with an emphasis on "Play Safe in the Sun."

When asked about her involvement with CARF, Dr. Kakita has this to say: "Sheila Belkin entered my life as a patient. As you all know, her

friendliness and passion is infectious. She soon became a great friend. She had me commit to supporting CARF. I have watched CARF grow with the help of many of you. It has been impressive and stimulating to see the involvement of physicians, researchers and patients working together for the common good of those with cicatricial alopecia."

Dr Kakita has three sons (including twins), three grandchildren and a 160 lb Akita dog. Her home is in Las Vegas, but she works in Pasadena four days a week. Her late husband, Hon. Edward Y. Kakita (a Superior Court Judge in California), was a strong supporter of all her activities in dermatology.



Conference Co-Host
Pearl E. Grimes, MD

Dr. Grimes is the Director of the Vitiligo and Pigmentation Institute of Southern California. She is also a Clinical Professor of Dermatology at the University of California, Los Angeles. Dr. Grimes graduated from Washington University in St. Louis, Missouri in 1974 and completed her Dermatology residency at the Howard University Hospital in Washington, DC, in 1979. She is nationally and internationally recognized for her work on pigmentary disorders.

PEARL E. GRIMES, MD

Grimes lectures worldwide on many areas of dermatology, including vitiligo, melasma and other disorders of pigmentation, as well as ethnic skin and hair disorders. She also lectures on cosmetic procedures for darker racial ethnic groups, including resurfacing procedures and tissue augmentation.

An author of over 100 publications and abstracts, Dr. Grimes is also a member of the American Academy of Dermatology, the American Society of Dermatologic Surgery, the American Dermatological Association, Society of Investigative Dermatology, Dermatology Foundation, International Pigment Cell Society and the Women's Dermatologic Society. She has remained on "The Best Doctors of America" list for the past nine years. She is a past Assistant Editor and Editorial Board Member of the *Journal of the Ameri-*

can Academy of Dermatology and has served on the editorial board of the *Journal of Clinical Dermatology*, *Practical Cases in Dermatology*, and *Skin and Allergy News*. Grimes is also a contributing editor to *Cosmetic Dermatology*.

In addition to these positions and responsibilities, Dr. Grimes is a Scientific Advisor for the Cicatricial Alopecia Research Foundation (CARF). She will soon launch a new institute devoted exclusively to the diagnosis and treatment of hair disorders, where the focus will be on developing new treatments for hair disorders. She is particularly interested in hair-grooming practices and their consequences for ethnic women, as well as the pathogenesis and treatment of central centrifugal cicatricial alopecia.

16 – 19 June 2010 | Cairns Convention Centre | Cairns, Australia

6th WORLD CONGRESS FOR HAIR RESEARCH



CARF Sponsors Cicatricial Alopecia Symposium at World Congress

The Cicatricial Alopecia Symposium will be held on Wednesday, June 16, 2010, at the 6th World Congress for Hair Research in Cairns, Australia. It will be chaired by Dr. Vera Price and co-chaired by Drs. Rod Sinclair and Kurt Stenn. CARF is supporting the symposium to promote collaboration with researchers around the world.

Symposium Topics:

“Stem cells, Environmental Factors and Lipid Metabolism in Cicatricial Alopecia:

a Riddle Wrapped in a Mystery Inside an Enigma.”

Speaker: Dr. Pratima Karnik

“Possible Pathogenic Factors in Primary Cicatricial Alopecia: New Lessons from Lichen Planopilaris.”

Speaker: Dr. Matthew Harries

“Treatment of Lichen Planopilaris with Hydroxychloroquine, Mycophenolate Mofetil and PPAR γ Agonists.”

Speaker: Dr. Vera Price

CARF on the Move: Dermatology Nurses Association Conference March 25 28, 2010



Judy Jones, Vicky Kalabokes and Gwen Todd manning the booth at the Dermatology Nurses Association Conference

Interested. Inquisitive. Attentive listeners. These are words that describe the dermatology nurses at the Dermatology Nurses Association (DNA) 28th Annual National Convention. Gwendolyn Powell Todd, EdD, CARF patient, former board member and advocate, attended the DNA convention on behalf of CARF and worked in the Coalition of Skin Diseases (CSD) booth with Judy Jones, Executive Director of the Cutaneous Lymphoma Foundation. While working the booth, Gwen also had the opportunity to share information about CARF and the cicatricial alopecias.

Nurses and nurse practitioners attended the conference and appeared very interested in learning about our disorder. They asked questions, shared information about their roles and responsibilities, and recounted their experiences with our patients. Typically, dermatology nurses only have a few patients with cicatricial alopecia in their practice. But they took literature, and listened carefully to all the information we shared. The only disappointment was that there was a noticeable lack of hair and scalp education sessions, which only means. . . another opportunity for CARF!

[Arch Dermatol.](#) 2009 Dec;145(12):1363-6.

“Lichen Planopilaris Treated with a Peroxisome Proliferator-Activated Receptor *Gamma* Agonist”

P. Mirimarani, MD, P. Karnik, PhD

This report was published in the “Cutting Edge” section of the *Archives of Dermatology*, which is intended to provide clinicians with “solutions” to challenging cases. In this case we reported on a patient with lichen planopilaris who had failed multiple treatments including topical and intralesional corticosteroids, oral and topical antibiotics and oral immunosuppressive medications. The therapeutic challenge was to find a treatment that was effective in controlling or halting the patient’s symptoms, inflammation and the progression of hair loss with an acceptable side-effect profile.

Our “solution” was built on our prior research that suggested the initial trigger of inflammation in LPP is abnormal functioning of the peroxisome proliferator-activated receptor *gamma* (PPAR *gamma*) in the sebaceous gland of the hair follicle. This malfunction then leads to an abnormal “processing” of lipids, leading to a toxic buildup, and a

subsequent inflammatory response.

The patient was started on oral PPAR *gamma* agonist, pioglitazone 15 mg orally daily. He tolerated the oral medication without side effects and reported almost no scalp itching in the first month of treatment. A follow-up after two months revealed a decrease in the patient’s recorded treatment outcomes of symptoms and clinical exam. A scalp biopsy was done after six months of therapy and showed dramatic decrease in the inflammatory infiltrate. The patient continued taking oral pioglitazone for eight months, after which he stopped all treatment. One year later he remained symptom-free and without evidence of inflammation or further hair loss on examination.

Pioglitazone and rosiglitazone are medications widely used for the treatment of type 2 diabetes but can also be safely used in non-diabetics. The main side effects include weight gain,

leg swelling and fluid retention.

In summary, treatment with a PPAR *gamma* agonist - instead of the standard anti-inflammatory medication - may be a promising therapy that warrants further study.

An possible analogy: the build up of toxic lipids in the sebaceous glands of the hair acts like “gasoline,” “igniting” the body’s inflammatory responses and leading to destruction of the hair follicle. Anti-inflammatory medications may “put out” the “fire” but may not always succeed, or the “fire” may “re-ignite” as long as the “gasoline” or toxic lipids are present. Treatment with a PPAR *gamma* agonist (pioglitazone) may allow the follicular sebaceous glands to “clean up” or properly metabolize these toxic lipids.

CARF Advocates on Behalf of Patients

Every year, CARF representatives participate in medical events to advocate on behalf of cicatricial alopecia patients and spread awareness of the disease within the medical community. Many beneficial relationships with other patient organizations and medical professionals are fostered in the course of this networking.

In October of last year, Sheila Belkin and CARF Scientific Advisor Pratima Karnik, PhD, attended the NIAMS Coalition meeting of the National Institute of Arthritis and Musculoskeletal and Skin Diseases in Bethesda, Maryland. At this event, Dr. Karnik - who had recently been awarded a \$1.77 million NIH grant to study cicatricial alopecia -

became acquainted with the key NIAMS members.

This March, Sheila and Board Member Sharon Potter attended the annual meetings of the American Academy of Dermatology (AAD), the CARF Scientific Advisors, and the Coalition of Skin Diseases (CSD). CARF’s accomplishments at these meetings include:

- lecturing and holding forums about cicatricial alopecia to educate other physicians;
- updating consumer and pharmaceutical companies about CARF’s activities and accomplishments;
- advocating successfully for the

Coalition of Skin Diseases’ inclusion of cicatricial alopecia as one of 16 skin conditions featured on a poster and a tear-off pad for use in doctors’ offices. The tear-off pad includes CARF contact information for patients.

CARF Strategic Advisor Gwen Powell Todd, EdD, attended the Annual Convention of the Dermatology Nurses’ Association (DNA) in Lake Buena Vista, Florida, to further our partnership with dermatology nurses, who are often the frontline contacts with patients. Gwen was invited to write an article for the DNA Journal to educate them from a patient’s perspective.

Cathy Boeck, RN



Cathy Boeck, RN

The feature article in the May/June issue of the *Journal of the Dermatology Nurses' Association*, Volume 2, Issue No. 3, is "Cicatricial Alopecia Research Foundation: Patients' Perspectives and Recommendations for Dermatology Nurses" by Sheila Belkin. It is accompanied by the article "Cicatricial Alopecia" by Drs. Jenny Fu and Vera Price.

In a book on health care and spirituality, William Osler writes that "The trained nurse has become one of the great blessings of humanity, taking a place beside the physician and the priest." I would suggest that the nurse takes her place alongside three figures, not two: physician, priest and therapist. Like all good therapists, a nurse performs daily what Gandhi once identified as the most important of all human acts: to listen well to others.

The nurse's role is especially important for patients with cicatricial alopecia, since this is a disease that, while it doesn't threaten lives, does threaten self-esteem. And self-esteem can be a hard topic to discuss with a doctor, sometimes even with a loved one. A nurse—trained in the science of medicine and the art of compassion—can often be just the person to talk to.

Cathy Boeck, currently the Clinical Manager at the Clinical and Translational Institute at the University of Minnesota, is a firm believer in the role of nurses as listeners. For nearly fifteen years, she worked closely with Dr. Maria Hordinsky, a specialist in hair loss, at the University of Minnesota. Boeck helped conduct clinical research trials and met one-on-one with both scarring and non-scarring alopecia patients. She prepared patients for their examinations and assisted in procedures such as scalp biopsies. Once CARF and NAAF were established, she also became a liaison between patients and these foundations, directing those she saw to seek additional help from people like Sheila Belkin.

"The difficulty with hair diseases is that there aren't always clear-cut answers," Cathy observes. "You can get an idea of what is contributing to the problem. . . but you can't predict what is going to happen in the future. It's frustrating, unpredictable and very difficult for people and their families to deal with. "Cathy

Interview by Nancy West

tries, then, to help patients come to terms with the disease. "We give patients tools to help themselves and others. . . to better understand their condition and realize that there are other people who are dealing with the same problems they are dealing with."

This need for psychological and emotional counseling applies to patients suffering from a variety of dermatological diseases. Nurses trained in dermatology must be prepared to help patients with the non-medical difficulties of their disease because, as Cathy remarks, "Skin and hair are so visible." A patient with missing hair, or extensive psoriasis, needs to learn how to adapt to changes in her self-image. And—in the case of cicatricial alopecia—she must learn how to cope with uncertainty. This is where the nurse can help. "The nurse is more accessible to the patient than the doctor is," observes Cathy. "We can sit longer with them, listen to them, refer them to CARF and other places that will help them further with the psycho-social dimensions of their diseases. . . . There aren't a lot of things we can do to help them regrow their hair. But we can give them an opportunity to lead a better quality of life and adapt better to any changes in their self image."

Cathy clocks in 10 hour days, five days a week. Her commitment to dermatology extends well beyond her employment, however. A past president of the Nurses Dermatological Association, she has also done extensive volunteering for CARF and other agencies. For example, Cathy served on the Steering Committee of CARF's 2nd International Patient Doctor Conference in 2006, helping to plan the event and make attendees feel welcome to the Twin Cities. Graced with a lovely sense of humor, and an obvious gift for compassion, Cathy is the kind of nurse we all hope to see in a waiting room: a medical specialist, spiritual healer and counselor all in one.

New Support Group in the Washington, DC, Area



Chicago Support Group leaders: Angelia Robinson, Alissa Parker and Beth Critchley

We are thrilled to announce the formation of our fourth patient support group in the Washington, DC, Maryland and Virginia area. Patients Alissa Parker, Beth Critchley and Angelia Robinson have volunteered to be co-leaders, while CARF Scientific Advisor Dr. Valerie Callender has graciously agreed to be in attendance at meetings to answer any medical questions. Information about when and where the group will be holding their first meeting will be posted soon on the Patient Support page of our website at www.carfintl.org. If you need further information, please contact Beth at bethdc@att.net.

CARF now has support groups in four areas. The other three are in San Francisco, Chicago and Boston. For upcoming meetings, please check the CARF website.

If you are interested in forming a support group in your area, please contact Betty Tanzey at directorsupport@carfintl.org. Betty can provide you with a support group start-up kit and help guide you through the process.

Supporting Each Other in New England Holly Whitlegde



On Sunday, January 31, 2010, the Boston-area CARF support group met at the Cary Memorial Library in Lexington, Massachusetts, for its second (ever) session. Fourteen people came to meet in this informal setting to hear Dr. Lynne J. Goldberg (Associate Professor of Dermatology and Pathology at Boston University School of Medicine, and Director of the Hair Clinic at Boston Medical Center) speak about cicatricial alopecias, ask questions, share their experiences, and

provide support to one another.

After sign-in and a warm welcome, Doreen Karoll got the ball rolling by introducing Dr. Goldberg and then asking everyone else to introduce themselves, describe their condition, and explain the reasons for their being at the meeting. After a question and answer period, Dr. Goldberg made her PowerPoint presentation, which included an overview of the various kinds of scarring alopecias, a brief look at current investigations into their causes, and an update on cutting-edge research for better treatments and a cure.

Participants broke briefly for refreshments and conversation at the conclusion of Dr. Goldberg's presentation. Refreshments were followed by a lengthy discussion period in which Dr. Goldberg answered more questions and participants shared their concerns, experiences, tips and coping strategies.

The next meeting for the Boston-area CARF support group is scheduled for Sunday, October 3, from 2:30 - 4:30 p.m., at the Lexington Cary Library. For more information, please email bostonsupportgroup@carfintl.org.

Dancing in the Rain

Margaret Sachs



Margaret Sachs

I sat in my local Los Angeles dermatologist's office three years ago, listening in stunned silence as he told me that my hair was going to fall out and there really was nothing much to be done about it. He gave me cortisone shots in my scalp, handed me tubes of antifungal cream, and sent me on my way. The terror I felt left no room for rational thought. When I arrived home, my husband, Bill, asked me what the doctor had said. All I could remember were the words "permanent hair loss" and "scarring alopecia." Bill and I are writers, so our house is filled with books we use for research. After we had looked through all our medical texts, I called the doctor back with questions. He made it clear he was annoyed and told me he would answer any questions at my next appointment. I was devastated. I pictured myself with no hair on my head. I had always been proud of my thick, strong hair. Although I had never thought of myself as a vain person, I was taking this news badly.

Bill went online and found the CARF website. I immediately contacted Sheila Belkin, who helped me get an appointment with Dr. Vera Price in San Francisco. As rational thought slowly came back to me, I remembered a best friend who had succumbed to cancer, leaving her daughter motherless. I thought of

children with disfiguring facial deformities and other ailments, and I kept telling myself that my reaction was extreme. After all, hair loss is not fatal, and it's not even disabling. But the emotional part of my brain refused to listen.

Bill understood how I felt. He insisted on going with me to my appointment. The 350-mile drive to San Francisco was tense. I was miserable. Inside Dr. Price's waiting room, I remember telling Bill, "I know this is really silly, but I feel like I'm awaiting execution." When she examined me, Dr. Price turned out to be an angel. She understood my fears and immediately calmed me down. She helped me to understand the situation was not as bad as I had made it out to be and that there was indeed hope. I realized how important knowledge was to attitude.

The mood on our drive back to Los Angeles was completely different from the dread-filled one to San Francisco. Bill believes in transforming every problem into an advantage, so we turned the trip into a mini-vacation. We joked and laughed. We took the coastal route, stopped at some scenic spots, and spent time watching a crowd of sea lions resting on a boat dock only five feet away from us.

Not long after that first trip to San Francisco, I started helping Sheila by answering emails from patients, sending out doctor referrals, and assisting with the maintenance of the CARF database. I began to wonder, however, if this was a good move. I wanted to help Sheila because she had been so kind to me, but the problem was that all too often when I focused on my volunteer work for CARF, the pain, itching and burning in my scalp seemed to act up. I couldn't help wondering if thinking about cica-

tricial alopecia was going to make the condition worse. I decided to bite the bullet, however, and focus on the patients we were helping instead of my fears.

Last year, I assumed more duties, assisting Sheila in a variety of areas. In spite of my early reservations, I have found the work both fulfilling and healing. I have never agreed with the saying, "Ignorance is bliss." In this case, the more I learn about cicatricial alopecia and the work done by CARF's exceptional team of dedicated volunteers, the more optimistic I become. I rarely give a thought to my own symptoms, which have progressed much more slowly than I had feared that day in the L.A. dermatologist's office. I've learned that cicatricial alopecia does not mean total hair loss. Bill and I look on our trips to Dr. Price's office as enjoyable breaks from our everyday routine. Helping CARF brings me great pleasure. I've made wonderful new friends. And most importantly, I experience the satisfaction of helping newly diagnosed patients who, without CARF, would have nowhere to turn for the kind of support, information and education we offer.

Ordell McLendon, medical affairs coordinator at Stiefel—one of CARF's corporate donors—has this tag after her email signature: "Life isn't about how to survive the storm, but how to dance in the rain. "Everyone experiences periods of rain and sunshine in their lives." As members of the CARF family, we can learn to dance together even when it pours.

Options for Covering Hair Loss

Cosmetic Options for Covering Hair Loss

At previous CARF Patient Doctor Conferences, patients have shared information about cosmetic items they have found helpful in their daily lives. Below is a list of some of them.

Do you use something that works for you? Would you like to share information about a product with others? If so, please send your suggestions to Margaret@carfintl.org.

Please note that CARF does not endorse any particular product. Items listed on this page are for informational purposes only.

Product	Description	Where It Can Be Purchased
Toppik	<ul style="list-style-type: none"> Hair-thickening, color-matched, organic keratin protein fibers intertwine with your own hair to conceal hair loss Spray Applicator for more even applications (\$18.95) Hairline Optimizer to eliminate straight lines (\$5.95) Fiberhold Spray to strengthen bond (\$8.95) Available in 7 colors (Auburn, Black, Blond, Dark Brown, Light Brown, Medium Brown, Gray, White) Needs surrounding hairs to keep in place. Sizes: Travel \$6.50; Regular \$21.95; Economy \$43.95; Giant \$76.95 	www.toppik.com
Bumble and Bumble Hair Powder	<ul style="list-style-type: none"> Adds volume to surrounding hair Can be used on areas with no hair Available in 5 colors (Black, Brown, Red, Blondish, White) Can be messy when applying (apply before dressing!) Expensive (\$19 for 1 oz, \$35 for 4 oz) 	www.bumbleandbumble.com (type "hair powder" in search box in upper right hand corner)
Salon Grafix Powder Shampoo	<ul style="list-style-type: none"> Similar to Bumble and Bumble Hair Powder Available in 4 colors (Brunette, Blonde, Black, Silver) Less expensive (\$8 for 4 oz) 	www.salongrafix.com
CRC Concealing Color	<ul style="list-style-type: none"> Colored cream you rub into bare or thinning areas Can buy brush applicator for fading effects Available in 6 blendable colors you paint or rub in (Grey, Beautiful Blonde, Ravishing Red, Rich Brown, Golden Brown, Deep Black/Brown) Also comes as Quick Touch applicator, available in all colors above, except Grey Water resistant, but washes out with shampoo \$28.50 for 1.25 oz, lasts 2-3 months 	www.crclabnyc.com
DermMatch	<ul style="list-style-type: none"> DermMatch colors your scalp to match your hair color Rub the product on, then brush it through You can rub it into completely bare areas It also coats and thickens thin hairs, making them stand up and spread out for maximum fullness. Available in 7 blendable colors (Platinum Blonde, Silver-Grey, Red, Light Brown, Medium Brown, Dark Brown, Black, White) Stays on during rain and while swimming or sweating (per website and reviews) Can use in conjunction with Toppik or Nanogen \$30 for 1 disk, lasts 4-6 months 	www.DermMatch.com

(continued on page 9)

Options for Covering Hair Loss

(continued from page 8)

Product	Description	Where It Can Be Purchased
Great Looking Hair	<ul style="list-style-type: none"> • Temporary hair spray • Available in 8 colors (Black, Dark Brown, Medium Brown, Light Brown, Auburn, Silver Brown, Silver Black, White) • \$10 for 1 can 	www.ronco.com (type "GLH" in search box in upper left corner)
Nanogen	<ul style="list-style-type: none"> • Similar to Toppik: Needs surrounding hairs to keep in place • Available in 9 colors (Black, Dark Brown, Medium Brown, Light Brown, Auburn, Cinnamon, Dark Blonde, Blonde, Grey, White) • \$25 for 1 month supply; cheaper in bulk 	www.nanogenhair.com
Organin	<ul style="list-style-type: none"> • Similar to Toppik: Needs surrounding hairs to keep in place • Available in 8 colors (Black, Brown, Light Brown, Medium Brown, Dark Brown, Ash Blonde, Dark Blonde, Light Gray) • \$30 for 90 day supply; cheaper in bulk 	www.folica.com (type "Organin" in search box in upper left corner)
Shapley's Show Touch-Up	<ul style="list-style-type: none"> • Aerosol spray used on show horses to hide imperfections • Will not rub off, stays on in rain and water (per users) • Available in 8 colors (Black, White, Sorrel, Chestnut, Medium Brown, Dark Brown, Palomino, Gray) • \$10 for 12 oz can 	www.smartpakequine.com (type "Shapley's Show Touch-Up" in search box in upper left corner)
Streaks 'N Tips Hair Color	<ul style="list-style-type: none"> • Temporary hair spray • Available in Golden Blonde, Icy White, Burnt Brown, Platinum, Mid-night Black, Pale Blonde • Available online and at beauty supply stores • \$4 for a 3.5 oz can 	www.folica.com (type "Streaks 'N Tips" in search box in upper left corner)
Tween Time Haircolor Touch-up Stick	<ul style="list-style-type: none"> • Hair "crayons" made by Roux, available in 7 colors (Auburn, Black, Light Brown, Medium Brown, Dark Brown, Violet Blaze, Wildfire) • Shampoos out • \$7 per touch-up stick 	www.sleekhair.com (type "Tween Time" in search box in top right hand corner)

Prepared by the Cicatricial Alopecia Research Foundation (CARF) from information shared by patients about cosmetic items they have found helpful in their daily lives. Please note that CARF does not endorse any particular product. Items listed on this page are for informational purposes only.
Updated April 14, 2010.

Raffle Winner Enjoys a Super Vacation!



Porcia Bradford, MD, and JC Love

"We want to thank the Cicatricial Alopecia Research Foundation for this amazing trip. Key West is such a beautiful place during the Christmas season. Our vacation was so wonderful and relaxing, that we will be returning in June!"

Porcia Bradford

Volunteer PR Coordinator Jana FitzGerald

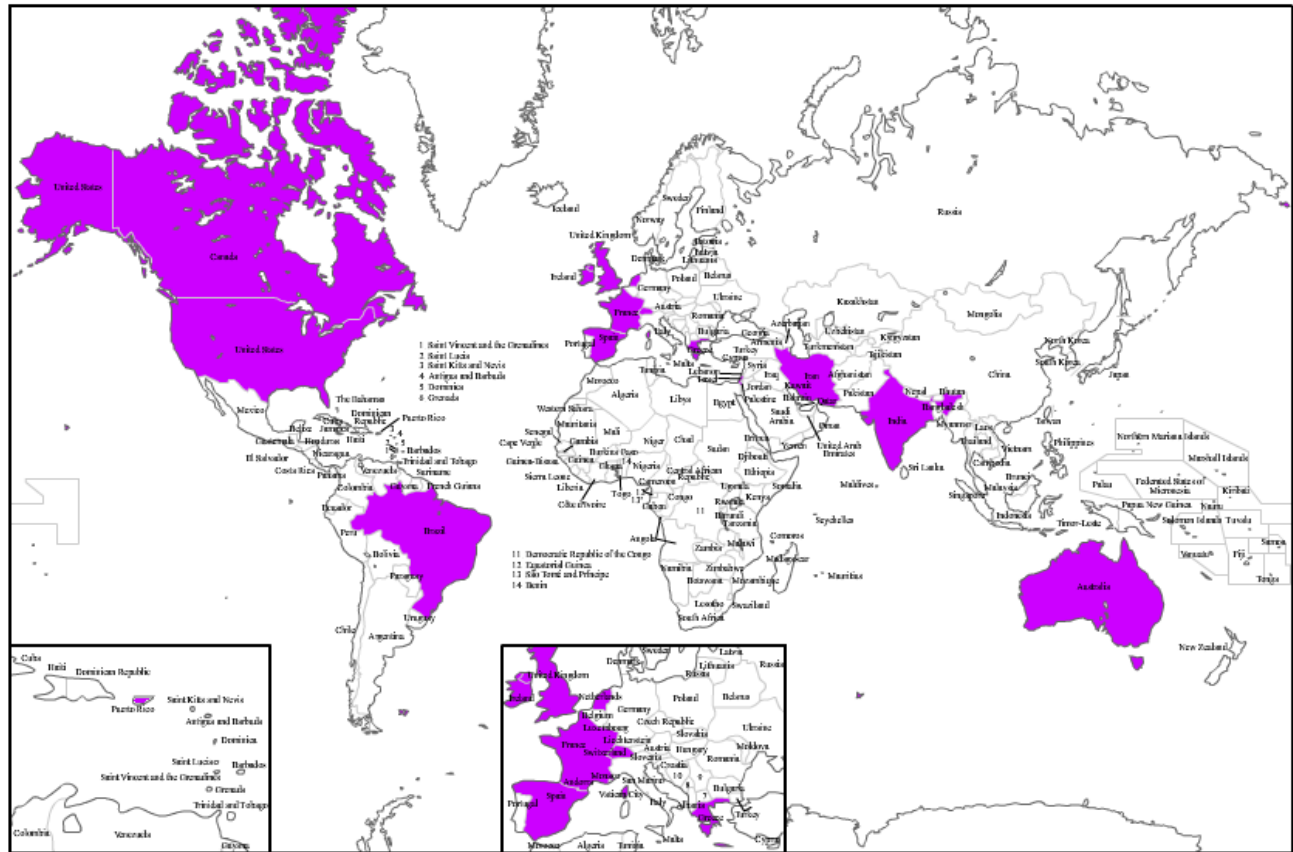


Jana Balik FitzGerald

Jana Balik FitzGerald is a new addition to the CARF team. A graduate of the University of California, Berkeley, with a degree in comparative literature, she also studied art history in Florence, Italy, and literature in Cambridge, England. She brings three years of experience in the field of communications, marketing and public relations. Jana is excited to work with CARF because of the passion, dedication and drive of its members and staff. And she welcomes the opportunity to be involved in such meaningful work.

Jana currently resides in San Francisco. She is an avid ocean enthusiast and is passionate about yoga, health and wellness, art, music, cooking and travel. She attributes the last of these passions to growing up in a family that took the opportunity to visit new places whenever possible. Always ready for the next adventure, Jana is eager to become a part of the CARF community.

CARF now represents 1,013 patients in 19 countries



CARF's reach has expanded dramatically over the past five years. Virtually every day, patients contact CARF via email, newsletter requests, forms filled out in doctors' offices and registration on the CARF website. These connections with individuals throughout the world increase CARF's ability to educate, support, conduct research and advocate for cicatricial alopecia (CICAL) patients.

CARF Donor Contributions 2009

CARF wishes to recognize the outstanding generosity of our donors.

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

Some donors raised all or a portion of their donation by fundraising.

GOLD BENEFACTORS

\$20,000 to \$29,999

Eva and Douglas LeBon

SILVER BENEFACTORS

\$10,000 to \$19,999

Anonymous

James Aleveras

Anonymous from Patient's Spouse

Sheila Belkin

DIAMOND BENEFACTORS

\$5,000 to \$9,999

Johnson & Johnson

Consumer Healthcare Products

Vera Price MD

Stiefel, a GSK Company

Rita Wanser

MAJOR BENEFACTORS

\$2,500 to \$4,999

Bosley

Chevron Humankind

Chevron USA Inc

Merck & Co Inc

Ken Washenik MD, PhD

Wells Fargo Bank

BENEFACTORS

\$1,000 to \$2,499

Valerie Callender MD

Mary Clay

Follica

Galderma USA

Sherie Hickman

Anonymous

Janet & Thomas Hough

Kaiser Permanente

L'Oreal USA, Inc

Sharon & Henry Potter

SkinMedica Inc

Gwen & Don Todd

Warner Chilcott

SPONSORS

\$500 to \$999

Linda Assalino

Jeff Callen MD

Lisa Carter

Elizabeth Critchley

Marilyn Ey

Nancy Gates

Pearl Grimes MD

Leiter's Pharmacy

Carl Martin

Bhupinder & Satwant Samrao MD

Nancy Scott

Jerry Shapiro MD

Betsy & Robert Sullivan

Betty Tanzey

Suzanne & Ed Vasgerdsian

Michael & Julie Zimmer

GRAND PATRONS

\$200 to \$499

BCN Advisors LLC

Victoria Barbosa MD

Bruce & Elizabeth Cassayre

Joan Chasen

Amy and Neil Corley

Joseph Catalano

Sally & Donald Duggan

Betty Fairly

Nancy Gates

Anita Geleyne

Denise & Ray Gilbert

Joseph Hahner

Linda Jimerson

Kaiser Permanente

Community Giving

Lloyd King Jr., MD, PhD

Francine & John Leipsic

George Mantikas DMD

Leslie Mark MD & Ken Gross

Debra & Charles McVey

Lois O'Grady

Catherine & Christopher Polizzi

Douglas Robins MD

Elizabeth Ross MD

Ray & Ruth Stankowski

Kurt Stenn MD & Judit Stenn MD

Matt Vasgerdsian

Elizabeth & Felix Wannemacher

Rita Wanser

PATRONS

Up to \$199

Beatrice Abrams

Linda Abrams

Beth and Peter Adeson

Susan Anacker

Laurel Anderson

Marilyn & Gerald Anderson

Nita Andrews

Gary Arnstein

Carol Ashmore

Kylie Barbara

Karol Berger

Wilma Bergfeld MD

Cleveland Clinic Foundation,

Department of Dermatology

Liz Bilbro

Martha & Richard Bittikofer

Diane & Dr. Russell Blaylock

Karen Bliss

Gary Brauner MD

Diane Butler

Lisa Carlomagno

Carmen Chalek

Marrietta & Douglas Cobb

Judy Corrado

Howard Darvey

Jackie & Ronald Davies

Ellen & Glenn Davis

Alma De Bisschop

Shirley Dresch

Patsy DeSimone

Drs. Andrea & Jeff Donovan

Marilyn & Frank Dorsa

Donna Dreher Weaver

Laurie and Ron Ellison

Patricia Engasser MD

Carmel & Stanley Engelle

Christel Emy

Loretta Foster

Caryn Friedman

Jennifer Fu MD

Nancy FitzGerald

Cheryl Fuller

Cheryl Gallagher

Penny & Dr. Martin Grubin

Joyce Gruenberg

Mary Halitzer

Linda Haro

Joseph Hahner

Sandra Hauprich

Dorothy Imai PhD

Joan Johnson

Beverly Jones PhD

Rosalie & Jeffrey Jones

Patricia Keane

Patrice Kelly

Mary and Peter Klabunde

Florence & Dr. Martin Klein

Ashley Kneidel

Joann & Maurice Knox

Carol & Ray Kotroczo

Melody & Dr. Jacob Kriteman

Elayne Kuehler

Liz and Steve Lang

Joseph Lazara

Shirlee and Ronald Lee

Joseph Leone

Carl Lovio

Fernando & Adreane Maestrini

Sandra & Peter Mancus

Jon Marcus

Carol McGovern

Margit McPhillips

Susan & James Mikowski

Andrea Miller

Lillian Miller

Dennis Morgan

Joan Moxley

Marni Murti

Olde Gold Estate Jewelry

Sharon & James Olson

Sue Paget

Patricia & William Pequignot

Lyla Graham Pober

Francine Powell

Bruce Rauch

Laura Rickards

Nusrath & Waheed Roomi

Ray Rosenman MD

Elizabeth Ross MD

Amanda Roth

Manfred Rothstein MD

Elizabeth Ruhland

Ruth & Y. H. Rutenberg PhD

Arlene & Stephen Sakatos

Derek Schug

Marilyn and John Seely

Wendy Sellers

Francella Shade

Mary Sheehy

Jo Ann Silverstein

Dustan Skidmore

Sandra & Robert Slusher

Carol Smith

Laurence Spector

Len Sperling MD

Tamara Stephenson

Irene Stradcutter

Joy Sutherland

Gail Taboada

Diana Toomajian

Lisa & William Warren

Jack Wicks

Lisa White

Karen Williams

Stacy Yost



C. A. R. F.

Cicatricial Alopecia Research Foundation
P.O. Box 60158 , Los Angeles, 90064

Contact CARF:

Information	info@carfintl.org
Donations	donations@carfintl.org
Press Releases	media@carfintl.org
Newsletter	newsletter@carfintl.org
Volunteers	volunteer@carfintl.org
Support Groups	directorsupport@carfintl.org

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

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

EMAIL CORRECTION REQUESTED
[Send CARF your new email address](#)

CARF Website Has a Makeover!

When you log on to <http://www.carfintl.org>, you will see some significant changes in our website. Originally produced for under \$100, the site was designed by volunteer web administrator Amanda Roth and Sheila Belkin, using software provided by Tech Soup. Over the years, it has been edited by Margaret Sachs. We wish to thank the Google Grants program for helping to promote the site through Adwords, which provides search engine optimization tools and merchant tools.

CARF shares a solid commitment to making sure the website delivers the information you want. If you are interested in submitting an article for the Living with Cicatricial Alopecia page, please send it to Margaret@carfintl.org.

We hope you enjoy the exciting changes to our website.

For address changes, removals and misdeliveries, please notify us at info@carfintl.org