



C . A . R . F .

Cicatricial Alopecia International Research Foundation

CARF Communiqué

May, 2012
Issue XIII

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Introducing the CARF Management Team

CARF is pleased to welcome our new executive team: Victoria Ceh, Melanie Stancampiano, Carol Kotroczo, and Mike Andre. Due to our enormous growth, we are restructuring and enhancing our services to patients and physicians. We are receiving three times the number of daily patients requests for information and physician referrals. We continue to provide grants and support for research and education of cicatricial alopecia.

We wish to thank our co-founder Sheila Belkin for all she did to create a vital and caring organization. We wish her all the best in her new endeavors.

Victoria Ceh brings special and extensive expertise to CARF administration with her experience in the management of hair research societies such as North American Hair Research Society, The Hair Foundation, and the International Society of Hair Restoration Surgery, along with other non-profit medical societies such as International Society for Cutaneous Lymphomas. Victoria will oversee

management and administration of CARF activities and governance and will manage the execution of CARF's strategic plan and Board initiatives. Under Victoria's expertise and guidance, Melanie Stancampiano will lead our projects and programs. We are very pleased that Carol Kotroczo will lead the day-to-day support for CARF, utilizing her expert familiarity in CARF's activities and home office administration needs, and will also now assume the role of contact person for our patient and physician support and inquiries. Mike Andre will continue in his important role as webmaster.

Each staff member brings a wealth of education and experience to CARF. Victoria received her Master's in Public Administration Degree in Health Services Management from Roosevelt University, Chicago, and her Bachelor's Degree in Health Planning and Administration from University of Illinois, Champaign-Urbana, Illinois. She has managed and consulted for many non-profit medical and dermatological associations that have ranged in size and scope from county and state-level to international. For the past ten years, she has been the President of her own company, Medical Society Management, Inc. She is a successful entrepreneur who adds another dimension and appreciation for the values and success of small organizations.

Melanie received her Bachelor's Degree from Naperville College in International Studies with minors in Spanish and Professional Conflict Resolution, as well as a certificate in Nonprofit Business Excellence from the University of Notre Dame. She has nine years of non-profit and volunteer management experience including American Red Cross, Girl Scouts of Greater Chicago and Northwest Indiana, and International Society of Hair Restoration Surgery. In addition, she has taught health and safety courses to underserved populations as part of AmeriCorps USA.

Carol received her PhD from UCLA in fine arts. Following a university teaching career, she entered Public Relations including a position at Bosley Hair Restoration. She also has a background in medical office and non-profit management, writing and editing. Mike Andre is a patient and for the past year has served as CARF's website administrator and technical resource.



Victoria Ceh
Executive Director



Melanie Stancampiano
Associate Executive Director



Mike Andre
Website Administrator



Carol Kotroczo
Administrative Executive



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CARF 5th International Patient-Doctor Conference

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

Register on line at www.carfintl.org
We need volunteers!

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 information 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.

What is a Patient-Doctor Conference?

The conference is a place for patients and doctors to come together in a safe and supportive environment. It's a place where you can learn about cicatricial alopecia and the latest medical research in finding a cure, a place where you can meet others with cicatricial alopecia and share your stories, a place where you can discover products and lifestyle changes to better manage your disease, a place where you will become empowered and given hope, and a place where you can be yourself. Our patient conferences have changed

people's lives and we hope they can change yours as well. What past attendees have said:

The 2010 conference was overall a great experience just to see the enthusiasm of the doctors and I got goose bumps when Dr. Vera Price talked about the new research and conveyed her excitement about wanting to find a cure. Knowing that the people who are in the forefront of finding a cure are just as excited about doing it as the patients are about receiving it – that was thrilling for me as a patient.

Sandra Dubose Gibson, patient



BOSTON

The conference in 2010 was just incredible. You had a network of support and it gave you the opportunity to really talk with people, get information, and get the education you need. It allowed you to develop a sense of self-confidence and self-esteem about your disorder and to know that you don't walk alone.

Mary Clay, patient

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

Benefits of the CARF Patient-Doctor Conference

Our conferences can change people's lives and inspire hope in various ways:

Medical Education

Patients become educated about their disorders and learn the latest medical and research updates from the world's leading authorities.
Patients meet and talk in an informal setting with members of the medical community, including dermatologists, dermatology nurses, and dermatology physicians assistants.
Patients are encouraged by learning that our doctors are dedicated to finding better treatments and a cure.

Support

Patients make new friends who share their disease so they no longer feel isolated and alone.
Patients receive a wealth of support from their peers and hair doctors that empowers them and gives them hope.
Patients are encouraged to feel free to be themselves, tell their stories, and share with others.
Patients learn to find humor in their situation by sharing laughter.
Patients can be helped with depression and feelings of low self esteem so that they can heal, turn their situation around, and go on to lead normal lives.
Patients are invited to bring family members and friends who learn how to give additional support.

Lifestyle and Product Education

Patients share common lifestyle changes and adjustments to better understand and manage their diseases.
Patients learn that cicatricial alopecia patients do not lose all their hair and do not always need various types of hair pieces and wigs. They do often need creative hair styling and camouflage.
Patients gain knowledge about products helpful to patients.

CARF Resources for Patients

- ◇ referral program of doctors
- ◇ telephone support
- ◇ newsletter
- ◇ informative website
- ◇ regional support groups

Bulletin

**Watch for information on
the door prize to take place
at our August
Patient-Doctor Conference:**

**Vacation for Two:
Airfare and Hotel**

CARF Meeting News



Cicatricial Alopecia

Research Symposium

took place on October 27-28, 2011

Bethesda, Maryland

The 2011 Cicatricial Alopecia Research Symposium featured 90 world-class experts presenting the latest research from the scientific community representing academia, industry, and government. Hair biologists, immunologists, dermatologists, environmental toxicologists, and hair transplant surgeons met in their common pursuit of a deeper understanding of the etiology and pathogenesis of the disease. The symposium facilitated the exchange of ideas and information between laboratory and clinical researchers to accelerate the translation of basic scientific discoveries into clinical applications. Participants included Pratima Karnik, PhD; Stephen Katz, MD, PhD, NIAMS Director (National Institute of Arthritis and Musculoskeletal and Skin Diseases); keynote speaker Kevin D. Cooper, MD; panel moderators Thomas McCormick, PhD; Lloyd King, Jr., MD, PhD and the following presenters:

Inflammatory Alopecia with a Focus on Cicatricial Alopecia: David A. Norris, MD

UV Radiation and Autoimmune Disease in Women: Frederick W. Miller, MD, PhD

NK and NKT Cells: Bridging the Innate and Adaptive Immune Systems: John R. Ortaldo, PhD

Role of Environmental Factors in T Cell Differentiation and in Autoimmune Disease: Francisco J. Quintana, PhD

Hair Follicle Immune Privilege and Immune-mediated Attack in PCA: Matt Harries, MB ChB, MRCP (UK)

Autoimmune Mechanisms in Cicatricial Alopecia: John E. Harris, MD, PhD

Disease Presentation and Epidemiology: Paradi Mirmirani, MD and Vera H. Price MD

Clinical Aspects of Cicatricial Alopecia: Vera H. Price, MD

Histopathological Aspects of Cicatricial Alopecia: Len Sperling, MD

Dramatic progress has been made in the field since the last colloquium. Looking to the future, we hope more new projects will be tackled. Much needs to be done, but the future looks brighter because of greater understanding of these

Acknowledgements:

Support for the symposium was provided by the National Institute of Arthritis and Musculoskeletal and Skin Diseases (R13 AR061259 to PK), Skin Diseases Research Center (SDRC) at Case Western Reserve University, Cicatricial Alopecia Research Foundation (CARF), Johnson & Johnson Healthcare Products, The Procter and Gamble Company, Skin Medica, North American Hair Research Society (NAHRS), Follica, Warner Chilcott, Leiter's Compounding Pharmacy, Aderans Research institute, Bosley, Hill Dermaceuticals, L'Oreal USA, The L'Oreal Institute for Ethnic Hair and Skin Research, and Fisher Scientific.

CARF News

Join the Escrip Program to Help Fund CARF Research

CARF has enrolled in the eScrip fundraising program. You can benefit CARF without any out-of-pocket expense. Shop for groceries, airline tickets, personal purchases, and/or dine out — it's simple and free!. Participating merchants contribute a percentage of your purchases made on your credit or debit/ATM card to CARF. Invite your extended family and friends to support CARF by joining eScrip and designating CARF as the organization they wish to benefit. Check out the eScrip website for participating merchants. Shop retail or online.

To select CARF, go to www.eScrip.com and select us as your beneficiary. CARF's Group ID # is **500020699**. Funds generated with your purchases will be deposited directly into CARF's bank account each month and will support CARF's ongoing patient support, patient education, and research to find better treatments and a cure for cicatricial alopecia.

Meet our Scientific Advisors

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

Good news for United Health Care Insureds

from Doreen Karoll, MD

I had my \$2600 wig covered under our UHC "Durable Medical Goods" benefit. They at first said they only covered wigs for those with cancer/or on chemotherapy (or a diagnosis on a short list of other disorders, which they didn't share). I explained that lichen planopilaris is a Cicatricial Alopecia meaning it causes scarring alopecia - unlike after chemotherapy, my hair will not grow back. I asked that they have a physician reviewer look at the CARF website for more information to render an opinion on the claim. I also faxed them the 1st page of the article (page 125) of the Dermatology Nurses Association Journal, 2010. They agreed to cover it as being from an out-of-plan provider and applied the whole cost to our deductible. If you have had success with another insurance company, please share your story!

Generous Patient Donates Wigs: My name is Tiffany and I am the founder of a new non-profit organization called Hair Peace of Mind. I have been living with trichotillomania and hair loss for 21 years and recently decided to start a non-profit to donate human hairpieces to women of ALL ages." Thank you Tiffany!

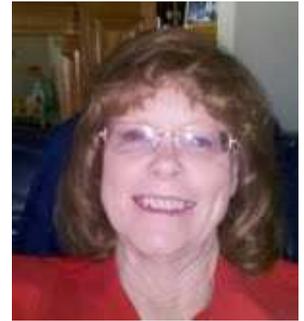
To apply for a complimentary wig: <http://www.hairpeaceofmind.org>.



Patient Support Groups

CARF has 5 patient support groups, 3 pending, and 5 new locations in the works, each with a physician advisor in attendance. Please see www.carfintl.org for meeting dates in your area. Note: in some locations we are looking for patient co-leaders.

News from San Francisco Patient Support Group: Marilyn Ey and Joe Hahner are the co-leaders. "We have great participants and the meetings are always fun and informative," says Marilyn who is honored to work with the group and has attended almost all of the meetings since the historical inaugural cicatricial alopecia support group meeting on October 22, 2007. At each meeting, she has learned something new and is happy to share her knowledge with new people who are always welcome.



Marilyn Ey

As for Joe, he has been attending the meetings for about two years and has high praise for physician advisor, Dr. Vera Price. "She is so caring and informative. Dr. Price invites the young doctors who are in training with her to attend as well. They contribute to whatever is being discussed and the two-hour meetings go by very quickly. Marilyn has been doing a great job of coordinating and leading the meetings. I am a 57-year-old retired peace officer, diagnosed with lichen planopilaris in 2008. I enjoy the meetings which give me an opportunity to meet others with cicatricial alopecia from whom I can learn. At our last meeting, the subject of shampoos came up. Several of us had been using Head & Shoulders 'clinical strength,' and have enjoyed success with it (little or no itching). The active ingredient is selenium sulfide. Dr. Price suggested we try a shampoo with zinc as the active ingredient, which is less harsh.

I also have celiac disease. Others at the meeting also commented that they either have gluten sensitivities or it has been suggested that they avoid gluten, as it may be an inflammatory factor. One of the interns in attendance also commented that he has celiac disease, and we spent some extra time on that topic."

Join Our Support Groups

CALIFORNIA (2 active)

Los Angeles: losangelessupportgroup@carfintl.org

San Francisco: Contact Marilyn and Joe at:

sanfranciscosupportgroup@carfintl.org

ILLINOIS (active)

Chicago: Contact Joe and Bev at:

chicagosupportgroup@carfintl.org

LOUISIANA (pending)

New Orleans/Baton Rouge: Contact Debbie and Elayne at:

neworleanssupport@carfintl.org

MARYLAND, WASHINGTON DC, VIRGINIA (active)

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

MASSACHUSETTS (active)

Boston: Contact Melody at: bostonsupportgroup@carfintl.org

MICHIGAN (pending)

Detroit: Contact Virdell at: detroitssupportgroup@carfintl.org

MINNESOTA (pending)

Minneapolis: Contact Maggie at:

minneapolisupportgroup@carfintl.org

New Groups Forming

New York: newyorksupportgroup@carfintl.org

Portland: portlandsupportgroup@carfintl.org

Salt Lake City: saltlakecitysupportgroup@carfintl.org

London: directorsupport@carfintl.org.

Manchester, UK: manchesteruksupportgroup@carfintl.org

Drugs in Dermatology

by Vera H. Price, MD and Adriana N. Schmidt, MD

The treatment guidelines that follow are from the University of California, San Francisco (UCSF) and in other parts of the country, different guidelines may be used.

Primary cicatricial alopecias are a group of rare disorders that lead to permanent hair loss. The first step in managing a patient with a suspected scarring alopecia is to perform a biopsy. The absence of scalp follicular orifices is the clinical sign that suggests a scarring alopecia and the need for a biopsy.

Current treatment selection is based on the predominant cell type (lymphocytic or neutrophilic) seen with light microscopy. It is essential to explain that current treatments relieve symptoms (itching, pain, burning) and signs (erythema, scaling, crusting, pustules), but may not halt progression of hair loss, and hair re-growth is not possible.

Lymphocyte-predominant disorders include lichen planopilaris, frontal fibrosing alopecia, central centrifugal alopecia and pseudopelade (Brocq). Systemic agents are indicated if patients are symptomatic or have clinically active disease, and hair loss is progressive.

First tier treatments include hydroxychloroquine (200mg twice daily) or doxycycline (100mg twice daily).

If signs and symptoms persist, then second tier agents include mycophenolate mofetil (0.5gm twice daily for the first month, then 1gm twice daily for five months) or cyclosporine (3 to 5mg/kg per day or 300mg/day for three to five months) or pioglitazone (15 mg daily for three to six months).

Topical treatments include high-potency topical corticosteroids, topical tacrolimus or pimecrolimus, Dermasmoothe FS oil, and intralesional triamcinolone acetonide injections at the



active margins of disease.

Neutrophil-predominant disorders include folliculitis decalvans and tufted folliculitis. Repeat culture and sensitivity of pustules or pulled-out hair bulbs or a small scalp biopsy is essential to selecting the optimal oral antibiotic. For staph aureus, we use cephalexin (500mg four times daily for ten weeks) with oral rifampin (600mg daily for ten days). Substitutions include clindamycin (300mg twice daily), trimethoprim-sulfamethoxazole DS (twice daily), ciprofloxacin (750mg twice daily), or doxycycline (100mg twice daily), all given for 10 weeks with rifampin (600mg for ten days).

It is helpful to culture the nostrils to determine whether the patient is a staph carrier in which case topical mupirocin ointment is applied daily to the nostrils for one week, then repeated for one day each month. For dissecting cellulitis and folliculitis keloidalis, cultures often do not grow a pathogen, and isotretinoin (small doses) or infliximab may be helpful.

The above treatments are usually effective in controlling signs and symptoms but may not halt progression of the hair loss since they do not address the underlying pathophysiology. In a recent landmark report, molecular studies of scalp tissue from patients with lichen planopilaris (LPP) revealed a loss of peroxisome proliferator-activated receptor gamma (PPARγ), a protein that regulates inflammation and lipid metabolism in the pilosebaceous unit.

This loss leads to a buildup of toxic lipids that generates inflammation and eventual destruction of the hair follicle and sebaceous gland. A similar PPARγ deficiency has been found in frontal fibrosing alopecia.*

Further study is still needed in central centrifugal cicatricial alopecia and the neutrophilic cicatricial alopecias. The role of PPARγ in cicatricial alopecia is supported in mice in which a targeted deletion of PPARγ in follicular stem cells causes scarring alopecia.

These findings suggested that treatment with PPARγ agonists may provide a new upstream treatment strategy for patients with LPP and frontal fibrosing alopecia. Pioglitazone and rosiglitazone are glitazones and PPARγ agonists that are FDA-approved and used widely to treat type 2 diabetes mellitus as well as atopic dermatitis. Pioglitazone was successful in a 47 year-old male patient with active and symptomatic LPP who had failed all treatments.**

The most common side effect of the glitazones is dosage dependent weight gain as a result of fluid retention and edema. Other reported adverse reactions include an increased risk of myocardial infarction with rosiglitazone, CYP P450 drug interactions with pioglitazone.

* Karnik P, Tekeste Z, McCormick et al. Hair follicle stem cell-specific PPARγ deletion causes scarring alopecia. *J Invest Dermatol* 129: 1243-57, 2009

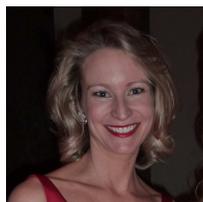
**Mirmirani P and Karnik P. Lichen plano-pilaris treated with a peroxisome proliferator-activated receptor gamma agonist. *Arch Dermatol* 145: 1363-66, 2009

Drugs in Dermatology, continued

About the Authors



Vera H. Price, MD has served as a Director of the American Academy of Dermatology (AAD) and is a consultant to the Academy. She is the co-founder of the National Alopecia Areata Foundation and the Cicatricial Alopecia Research Foundation. She is also founding member and past President of the North American Hair Research Society. The years she spent at the Western Regional Research Laboratory studying human hair with the wool chemists led her to her expertise and subspecialty in hair. She has described several new hair disorders.



Adriana N. Schmidt, MD is a board-certified dermatologist working in private practice in Santa Monica, California. She completed her medical doctorate and advanced dermatology residency training at Vanderbilt University after receiving her Bachelors of Arts degree at Brown University, where she graduated magna cum laude. Dr. Schmidt is a member of the American Academy of Dermatology, the Womens Dermatologic Society, and the North American Hair Research Society.

Topical tacrolimus for relief of symptoms and signs

Tacrolimus is the active drug in the topical ointment called Protopic. Protopic Ointment is an FDA-approved formulation for the treatment of atopic dermatitis (eczema) for relief of itching and skin inflammation. Topical tacrolimus is a good alternative to potent topical corticosteroid preparations, especially for long-term use, because it does not have the side effects of long-term topical corticosteroids such as thinning of the skin (atrophy) or malfunction of the adrenal glands. The disadvantage of Protopic Ointment is that it is very greasy and not always acceptable or suitable for the scalp (this is not a problem for the scalp of most African-American patients).

One of our patients originated the idea of compounding tacrolimus in Cetaphil Moisturizing Lotion, an over-the-counter, fragrance-free, non-comedogenic lotion made by Galderma, and compounding it with the same strength of tacrolimus as in Protopic Ointment 0.1%.

Many times, physicians recommend the use of therapies for alternative uses. Topical tacrolimus is an effective drug and is a popular alternative to potent topical corticosteroids for the relief of symptoms and signs such as itching, burning, pain, redness and scaling in many of our patients with cicatricial alopecia. Ask your doctor for a prescription to have tacrolimus compounded in the non-greasy Cetaphil Moisturizing Lotion for easy and effective application on the scalp.

As with all treatments, compounded tacrolimus 0.1% does not bring relief to all patients. It is not reimbursed by all insurance companies because it is not the FDA-approved preparation. We refer to the compounded formulation as C-Tacro 0.1%, and a compounding pharmacy is needed to prepare it.

C-Tacro 0.1% is not a cure, and regular daily application to the active areas of the scalp is needed for the relief of symptoms and signs.

Pronunciation Tips

Some of our readers have expressed an interest in learning the abbreviations and correct pronunciation of the cicatricial alopecias. Cicatricial alopecia is a diverse group of rare disorders that destroy the hair follicle, replace it with scar tissue, and cause permanent hair loss. The hair loss may be accompanied with severe itching, pain and burning, and progress rapidly. In other cases the hair loss is gradual, without symptoms, and is unnoticed for long periods.

Cicatricial alopecia, also known as scarring alopecia, occurs in otherwise healthy men and women of all ages and is seen worldwide. Cicatricial comes from the Greek word “cicatrix” for scar. In this case, the scar is under the skin.

Please refer to www.CARFintl.org Frequently Asked Questions for more information:

Cicatricial alopecia: (sickatrishal alōpēshă)

LPP: lichen planopilaris (lykin plănōpīllarīs)

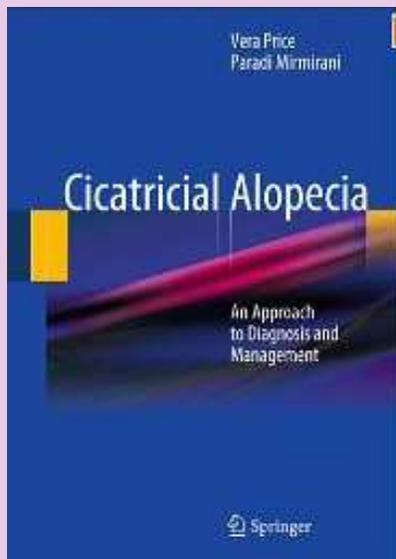
FFA: frontal fibrosing alopecia (alōpēshă)

CCCA: central centrifugal cicatricial alopecia (sentrifewgle alōpēshă)

Pseudopelade (Brocq): (sudōpēlad brock)

Folliculitis decalvans: (follickulytis dēkălvăns)

Tufted folliculitis: (tufted follickulytis)



Cicatricial Alopecia: An Approach to Diagnosis and Management available on Amazon.com.

This is the first and only book on the diagnosis and treatment of cicatricial alopecia, written by Vera H. Price, MD and Paradi Mirmirani, MD. This highly illustrated and practical text helps residents and practicing dermatologists to accurately diagnose and treat the scarring alopecias.



Our CARF Mission and Accomplishments

C . A . R . F .

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

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

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

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CARF wishes to recognize the outstanding generosity of our donors. Because of your support, our patient services and research funding continue to be possible

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