



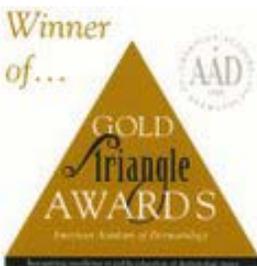
C . A . R . F .

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### Keep your subscription to CARF's newsletter up to date!

Only those who have made a donation or attended a CARF event will continue to receive this publication for the coming year.



## NIH AWARDS \$1.77 MILLION GRANT TO CARF SCIENTIFIC ADVISOR PRATIMA KARNIK, PhD

### Investigation will provide new information about the origins and development of cicatricial alopecia and may facilitate the creation of new and more effective therapies



Pratima Karnik, PhD

SAN FRANCISCO, Oct. 25, 2009 —The National Institutes of Health have awarded Principal Investigator Pratima Karnik, PhD (Assistant Professor, Department of Dermatology, Case Western Reserve University), a grant of \$1.77 million to fund a five-year study titled "PPAR-gamma Signaling in Normal Pilosebaceous Units and in Scarring Alopecia." This study will continue research already begun on linking a defect in lipid processing and peroxisome biogenesis to cicatricial alopecia.

"In preliminary studies that formed the basis of the NIH

award, we provided insight into highly complex interactions between hair follicle cells and environmental factors that may cause cicatricial alopecia," said Dr. Karnik. "This funding provides us the support necessary to aggressively test novel ideas aimed at understanding progression of these diseases and the development of novel therapeutic strategies."

In December 2008, Dr. Karnik, and her collaborators, Paradi Mirmirani, MD (Adjunct Assistant Professor, Department of Dermatology, Case Western Reserve University, and Assistant Professor, Department of Dermatology, University of California, San Francisco), and Vera Price, MD (Professor, Department of Dermatology, University of California, San Francisco), published findings that unprocessed lipids set the stage for developing scarring hair loss. The work suggests that either processed lipids are necessary for hair growth or unprocessed lipids are toxic. These clinical studies corroborate similar studies performed in mutant mice. In

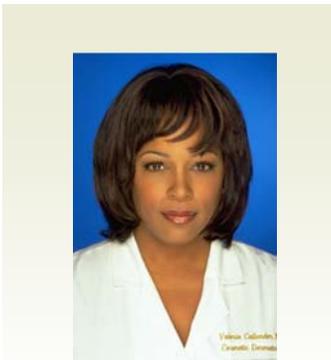
their preliminary studies, the researchers found that treating patients with drugs that enhance lipid processing relieved the clinical symptoms and signs of the disorder. See Karnik P, Tekeste Z, McCormick TS, Gilliam AC, Price VH, Cooper KD, Mirmirani P (2009) "Hair Follicle Stem Cell-Specific PPAR gamma Deletion Causes Scarring Alopecia." *J Invest Dermatol* 129: 1243-57.

According to Vera Price, MD, Co-Founder of the Cicatricial Alopecia Research Foundation (CARF), who has been treating this group of hair diseases for many years, "This grant is validation of Pratima Karnik's seminal work and will support further studies to unravel the mystery of these diverse diseases and explore new directions for their management."

This groundbreaking research by Drs. Karnik, Mirmirani and Price has been supported in part by the Cicatricial Alopecia Research Foundation (CARF).

## The Surgical Management of Cicatricial Alopecia

### Valerie D. Callender, MD



Valerie Callender, MD

Cicatricial (scarring) alopecia (CICAL) refers to a group of hair loss disorders characterized by permanent injury to the stem cell and sebaceous gland region of the hair follicle. This injury results in the permanent destruction of the hair follicle and its replacement with fibrous (scar) tissue. There are two types of CICAL: primary and secondary. Primary CICAL is a result of inflammation that specifically targets the hair follicle. Examples include lichen planopilaris (LLP), central centrifugal cicatricial alopecia (CCCA) and folliculitis decalvans. Secondary CICAL results from tissue injury that destroys the hair follicle non-specifically. Burns, severe infections, chemical injury, and neoplasms all can produce a secondary scarring process of the scalp and destroy the hair follicle as a kind of "innocent bystander."

#### Medical and Surgical Therapy for CICAL

There are medical and surgical treatments available for CICAL. Medical therapy includes anti-inflammatory or antimicrobial treatments, such as immunomodulating drugs and oral antibiotics. This

treatment addresses the symptoms and signs of inflammation and the progression of hair loss. Surgical intervention is an option only for patients treated successfully by medicine and who have biopsy-proven absence of scalp inflammation. The two main surgical treatments include hair transplantation and scalp reduction. Both procedures can provide excellent aesthetic results.

#### Hair Transplantation

Hair transplantation (HT) is based on the principle of donor dominance in which healthy follicles taken from one area of the scalp and transplanted into an area of hair loss will grow normally in the damaged area of the scalp. Follicular unit transplantation (FUT) involves transplanting hairs from one area of the scalp, usually the occipital region (donor site), to the area of hair loss (recipient site) in the naturally occurring hair groupings called follicular units. This newer technique produces better aesthetic results compared to procedures performed in the past. Typically, FUT is performed in male patients with male pattern baldness, which is a non-scarring type of hair loss characterized by miniaturization of genetically determined hair follicles on the scalp. Hair transplant surgery is performed less frequently in women and in patients with CICAL. According to the International Society of Hair Restoration Surgeons (ISHRS) 2007 practice survey, there were approximately 225,779 hair transplant procedures performed worldwide in 2006. Of these, less than half were performed in the United States and only 14% were performed on women. It is unclear from this survey how many of

these HT surgeries were in patients with CICAL.

#### Scalp Reduction

Scalp reduction involves surgically removing a small or large area of affected scalp skin and then closing the area with stitches. Generally, scalp reduction is recommended for small areas of hair loss where the entire area can be removed, or for larger areas that can be reduced in size by this procedure and then amended with hair transplantation.

#### Hair Transplantation into Scar Tissue

There are no scientific studies comparing survival rates of grafts in patients with non-scarring alopecia and CICAL. What we do know is that, although the blood supply is low in scar tissue, the transplanted grafts *can* survive but tend to grow more slowly than the normal rate of growth. In many cases, a physician will perform a test session so that she and the patient can determine the possible outcome of a full HT procedure. In addition, other test sessions are usually required. Therefore, it may take several months to years before the patient sees the final results of the procedure.

#### Risks and Complications

There are always risks involved with any surgical procedure. HT surgery complications are usually rare and, if they do occur, are minimal. These include postoperative swelling, bleeding, infection and scar formation at the donor site. In patients with cicatricial alopecia, the risk of HT surgery or scalp reduction includes the possible recurrence of inflammation after the procedure.

## “Dr. Kevin Cooper: A Doctor of Many Accomplishments — and Much More”

Interview by Nancy West



Kevin Cooper, MD

*“The intelligent man is one who has successfully fulfilled many accomplishments, and is yet willing to learn more.”—Edward Parker*

It took my computer four minutes just to download his resume. So naturally, I was a little intimidated when I picked up the phone to interview Dr. Kevin Cooper. It turns out that I had nothing to worry about. Dr. Cooper—Chair of the Department of Dermatology at Case Western Reserve University and University Hospitals Case Medical Center, and holder of at least four other academic appointments—is a remarkably easygoing man.

A native resident of both New York and the Sunshine State, Cooper attended the University of Florida for both his undergraduate and medical degrees. While in medical school, he was drawn to dermatology because of its unexplored links to immunology. “Immunology affects many of our diseases,” Cooper told me with notable fervor in his voice. “And we can visualize it; we can see the process at work.” One important branch of immunology is the study of autoimmunity. In autoimmune diseases, the immune system attacks its own host’s body. While in medical school, Cooper soon realized that very little was known about autoimmune skin diseases, and he was thrilled by the abundance of opportunities for discovery.

Now, three decades later, after further training and working at Oregon

Health Sciences University, the National Institutes of Health, and the University of Michigan, he has shaped a remarkable career from helping to make such discoveries. A professor of Oncology and Pathology as well as Dermatology, Cooper spends part of his time caring for patients who suffer from melanoma, skin lymphoma, and skin inflammations, as well as practicing general dermatology at the VA Medical Center, while residents and medical students accompany him. He also runs a research lab dedicated to skin inflammation; here, he oversees collaborators, technicians, and lab assistants. And he also directs the NIAMS Skin Diseases Research Center, one of only six such centers in the country

Both the research lab and center devote much of their energy to “translational research.” To my layman’s ears, translational research is exactly what patients suffering from cicatricial alopecia want to hear about, for it involves “translating what you do in a laboratory into tangible benefits, such as possible new tests or therapeutic treatments.” Conducting this kind of research involves working closely with clinicians, individual patients, and developing patents. It also means “exploring a wide range of possible targets and drugs—many more than you ultimately get,” according to Cooper. “But we’re good at it,” he says with a charming combination of pride and matter-of-factness.

The Department of Dermatology at Case Western—which Cooper has chaired since 1995—currently ranks as one of the best in the country when it comes to treating and researching skin cancer, inflammation, psoriasis, infectious diseases, and photo medicine. According to Cooper, the department is unique in how it has brought together people in different research and clinical areas working with different technologies in what he calls a “matrix environment.” For example, the department has on board a consulting psychiatrist who offers guidance and

support to patients suffering from diseases like cicatricial alopecia. “We try to take a humane, holistic approach to patient care,” Cooper assures me. Given the department’s emphasis on translational research and collaboration, it makes perfect sense that Dr. Pratima Karnik—recently awarded an NIH \$1.77 million grant to work on cicatricial alopecia—is one of the department’s leading members and a close colleague of Dr. Cooper’s. “This grant will enable her to create new potential therapies for cicatricial alopecia as she discovers what the mechanisms are that produce these rare diseases. She has worked with many patients, technicians, clinicians, and researchers to get to this point. It’s very exciting and very important.”

Dr. Cooper holds many additional titles and positions, such as consultant to a wide range of companies, board member for his hospital and faculty practice corporation, and volunteer for skin disease patient advocacy organizations and dermatology professional organizations. He has patented several inventions, founded a number of organizations, and hosted a gazillion conferences. What took me by surprise was his insistence that despite his teeming schedule and myriad commitments, he finds time to relax. “Really?” I asked incredulously. And expressing the same enthusiasm he showed in talking about dermatology, he proceeded to tell me about his love of surfing, snowboarding, his family, and his dog.

Commenting on the work CARF has done since its inception in 2004, Cooper enthuses, “[the organization is] incredibly dedicated to benefiting patients with cicatricial alopecia and has tremendous energy. ... The amount they accomplish relative to their resources is phenomenal.” CARF is honored to have Dr. Cooper’s counsel on its panel of Scientific Advisors.

## Dr. Weil's Anti-Inflammatory Food Pyramid

This diet by Dr. Andrew Weil, a Harvard-trained physician specializing in the navigation between traditional medicine and alternate practices, has been recommended by many doctors—and patients—for helping to control inflammation.

### HEALTHY SWEETS

**How much:** Sparingly

**Healthy choices:** Unsweetened dried fruit, dark chocolate, fruit sorbet

**Why:** Dark chocolate provides polyphenols with antioxidant activity. Choose dark chocolate with at least 70 percent pure cocoa and have an ounce a few times a week. Fruit sorbet is a better option than other frozen desserts.

### RED WINE

**How much:** Optional, no more than 1-2 glasses per day

**Healthy choices:** Organic red wine

**Why:** Red wine has beneficial antioxidant activity. Limit intake to no more than 1-2 servings per day. If you do not drink alcohol, do not start.

### TEA

**How much:** 2-4 cups per day

**Healthy choices:** White, green, oolong teas

**Why:** Tea is rich in catechins, antioxidant compounds that reduce inflammation. Purchase high-quality tea and learn how to correctly brew it for maximum taste and health benefits.

### HEALTHY HERBS & SPICES

**How much:** Unlimited amounts

**Healthy choices:** Turmeric, curry powder (which contains turmeric), ginger and garlic (dried and fresh), chili peppers, basil, cinnamon, rosemary, thyme

**Why:** Use these herbs and spices generously to season foods. Turmeric and ginger are powerful, natural anti-inflammatory agents.

### OTHER SOURCES OF PROTEIN

**How much:** 1-2 servings a week

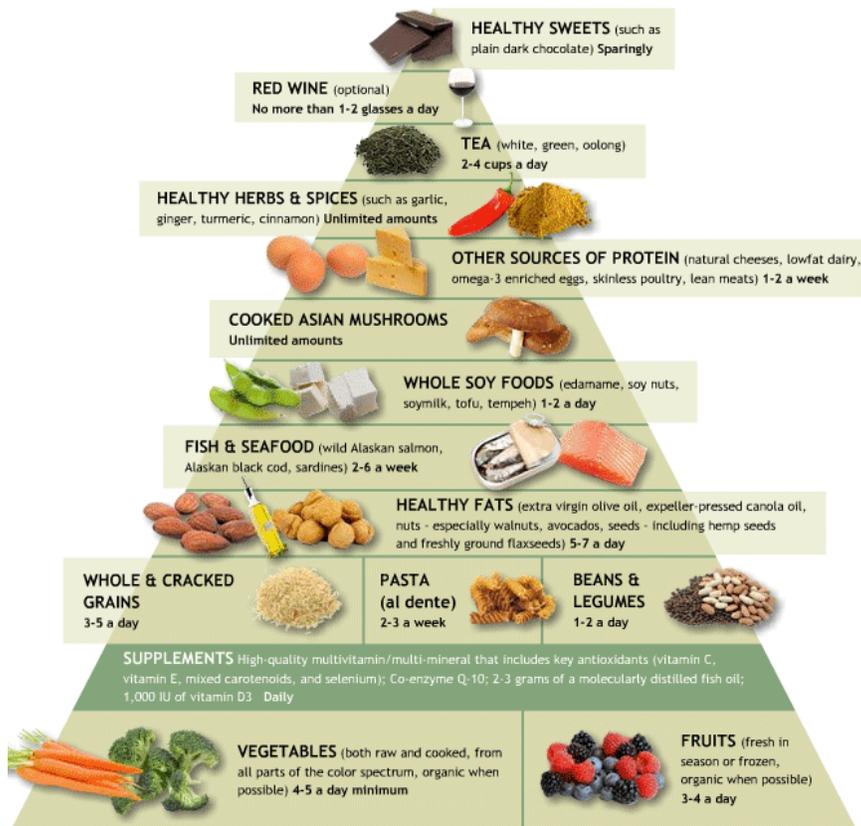
**Healthy choices:** Natural cheeses, lowfat dairy, omega-3 enriched eggs, skinless poultry, lean meats

**Why:** In general, try to reduce consumption of animal foods. If you eat chicken, choose organic, cage-free chicken and remove the skin and associated fat. Use organic, reduced-fat dairy products moderately, especially yogurt and natural cheeses such as Emmental (Swiss), Jarlsberg and true Parmesan. If you eat eggs, choose omega-3 enriched eggs (made by feeding hens a flax-meal-enriched diet), or eggs from free-range chickens.

### COOKED ASIAN MUSHROOMS

**How much:** Unlimited amounts

**Healthy choices:** Shiitake, enokidake, maitake, oyster



mushrooms (and wild mushrooms if available)

**Why:** These mushrooms contain compounds that enhance immune function. Never eat mushrooms raw, and minimize consumption of common commercial button mushrooms (including crimini and portobello).

### WHOLE SOY FOODS

**How much:** 1-2 servings per day

**Healthy choices:** Tofu, tempeh, edamame, soy nuts, soy-milk

**Why:** Soy foods contain isoflavones that have antioxidant activity and are protective against cancer. Choose whole soy foods over fractionated foods like isolated soy protein powders and imitation meats made with soy isolate.

### FISH & SEAFOOD

**How much:** 2-6 servings per week

**Healthy choices:** Wild Alaskan salmon (especially sock-eye), herring, sardines, and black cod (sablefish)

**Why:** These fish are rich in omega-3 fats, which are strongly anti-inflammatory. If you choose not to eat fish, take a molecularly distilled fish oil supplement, 2-3 grams per day.

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## Dr. Weil's Anti-Inflammatory Food Pyramid

(continued from page 4)

### HEALTHY FATS

**How much:** 5-7 servings per day

**Healthy choices:** For cooking, use extra virgin olive oil and expeller-pressed organic canola oil. Other sources of healthy fats include nuts (especially walnuts), avocados, and seeds, including hemp seeds and freshly ground flaxseed. Omega-3 fats are also found in cold water fish, omega-3 enriched eggs, and whole soy foods. High-oleic sunflower or safflower oils may also be used, as well as walnut and hazelnut oils in salads and dark roasted sesame oil as a flavoring for soups and stir-fries

**Why:** Healthy fats are those rich in either monounsaturated or omega-3 fats. Extra-virgin olive oil is rich in polyphenols with antioxidant activity and canola oil contains a small fraction of omega-3 fatty acids.

### WHOLE & CRACKED GRAINS

**How much:** 3-5 servings a day

**Healthy choices:** Brown rice, basmati rice, wild rice, buckwheat, groats, barley, quinoa, steel-cut oats

**Why:** Whole grains digest slowly, reducing frequency of spikes in blood sugar that promote inflammation. "Whole grains" means grains that are intact or in a few large pieces, not whole wheat bread or other products made from flour.

### PASTA (al dente)

**How much:** 2-3 servings per week

**Healthy choices:** Organic pasta, rice noodles, bean thread noodles, and part whole wheat and buckwheat noodles like Japanese udon and soba

**Why:** Pasta cooked al dente (when it has "tooth" to it) has a lower glycemic index than fully-cooked pasta. Low-glycemic-load carbohydrates should be the bulk of your carbohydrate intake to help minimize spikes in blood glucose levels.

### BEANS & LEGUMES

**How much:** 1-2 servings per day

**Healthy choices:** Beans like Anasazi, adzuki and black, as well as chickpeas, black-eyed peas and lentils

**Why:** Beans are rich in folic acid, magnesium, potassium and soluble fiber. They are a low-glycemic-load food. Eat them well-cooked either whole or pureed into spreads like hummus.

### SUPPLEMENTS

**How much:** Daily

**Healthy choices:** High quality multivitamin/multimineral that includes key antioxidants (vitamin C, vitamin E, mixed carotenoids, and selenium); co-enzyme Q10; 2-3 grams of a molecularly distilled fish oil; 1,000 IU of vitamin D3

**Why:** Supplements help fill any gaps in your diet when you are unable to get your daily requirement of micronutrients.

### VEGETABLES

**How much:** 4-5 servings per day minimum

**Healthy Choices:** Lightly cooked dark leafy greens (spinach, collard greens, kale, Swiss chard), cruciferous vegetables (broccoli, cabbage, Brussels sprouts, kale, bok choy and cauliflower), carrots, beets, onions, peas, squashes, sea vegetables and washed raw salad greens

**Why:** Vegetables are rich in flavonoids and carotenoids with both antioxidant and anti-inflammatory activity. Go for a wide range of colors, eat them both raw and cooked, and choose organic when possible.

### FRUITS

**How much:** 3-4 servings per day

**Healthy choices:** Raspberries, blueberries, strawberries, peaches, nectarines, oranges, pink grapefruit, red grapes, plums, pomegranates, blackberries, cherries, apples, and pears—all lower in glycemic load than most tropical fruits

**Why:** Fruits are rich in flavonoids and carotenoids with both antioxidant and anti-inflammatory activity. Go for a wide range of colors, choose fruit that is fresh in season or frozen, and buy organic when possible.

### Additional Item: WATER

**How much:** Throughout the day

**Healthy choices:** Use purified water or beverages made with purified water, such as unsweetened tea, sparkling water, or water with a small amount of fruit juice for flavor

**Why:** Water is vital for overall functioning of the body.

## CARF's 2009 5<sup>th</sup> Anniversary Fundraiser Event - October 17, 2009

On a sunny Saturday in San Francisco at the stately UCSF Faculty-Alumni House, CARF celebrated its 5th anniversary with a gathering of 80 patients, physicians, families and friends for a sumptuous buffet luncheon, silent auction, and the camaraderie of old friends and new acquaintances.



Display artists extraordinaire, Nicole Vasgerdsian and Suzanne Vasgerdsian, transformed the main room into a showcase of enticing items donated by CARF supporters. On the silent auction tables, participants eager to support a good cause could bid on such items as jewelry, orchids, and enticing weekend-vacation packages. Auctioneer Dr. Ken Washenik presided over the energetic bidding and added to everyone's enjoyment of a lovely afternoon.





## Zumba Dancers Zumba for CARF

Would you like to dance for CARF? That's exactly what fitness instructor Cristiane Machado's students did. To help celebrate Cris's birthday in honor of CARF, Gainesville Health & Fitness Center director Ann Raulerson and her staff enthusiastically pitched in. The result: a festive community event with live music and exuberant dancing to the rhythms of the zumba beat.

"I am celebrating my 40th birthday totally healthy and thankful for my life," said Cris, who has a friend in California diagnosed with cicatricial alopecia. Folks with cicatricial alopecia are also healthy but have a form of permanent hair loss. "I decided to share the knowledge about cicatricial alopecia with all the people who have helped me, in one way or another, to be where I am. Zumba at Gainesville Health & Fitness Center gives me the chance to do that, so, to give some of that happiness back, I chose to fundraise for the Cicatricial Alopecia Research Foundation."

This generous act of kindness and collective spirit in a city where there are no known cicatricial alopecia patients brings further awareness to our rare group of diseases. It shows the world what can be accomplished when everyone works as a united entity.



## CARF Goes to the NIH



Lily Talakoub, MD

In September, 2009, Dr. Lily Talakoub represented CARF at a meeting of the National Institutes of Health (NIH) with new director Dr. Francis Collins.

Dr. Talakoub reported that the auditorium was packed with representatives from more than 300 organizations. Dr. Collins reviewed the five goals of the NIH, which include the following:

- To apply unprecedented opportunities in genomics and other high-throughput technologies in order to understand fundamental biology and uncover the causes of specific diseases.
- To translate basic scientific discoveries into new and better treatments, including ones for rare diseases.
- To put science to work for the benefit of healthcare reform in areas that include comparative effectiveness research, pharmacogenomics, and healthcare research economics.
- To encourage greater focus on

global health including nutrition and disease prevention.

- To foster better communication within the biomedical research community.

Dr. Collins invited all patient organizations and healthcare agencies to write him an email that summarizes the issues they feel need to be addressed by the NIH, along with suggestions on how to address these issues in a timely and effective manner. He assured those present that he would read and respond to each email message individually. CARF is following up on his suggestion.

Dr. Talakoub recently completed her dermatology residency at the University of California, San Francisco, and is now practicing dermatology in the DC area. She has a special interest in CARF and hair problems, has past experience at the NIH, and a special talent in media and public education. Dr. Talakoub will be attending future meetings and will serve as CARF's liaison with the NIH.

## NORD Recognizes CARF For Partnering in Rare Disease Day



**NORD Salutes Our Rare Disease Day Partners!**



*Rare Disease Day*

More than 220 organizations, agencies, and companies signed on as Rare Disease Day Partners to promote awareness of rare diseases as a public health issue for World Rare Disease Day on Feb. 28th. They did a fantastic job, and we extend our heartfelt gratitude to them! Through their efforts—such as special events, letters to the editor, videos, news stories, and state proclamations—many people across the nation now have a better understanding of some of these diseases.

**Cicatricial Alopecia Research Foundation**



## An Easy Way to Help CARF... Just Go Shopping!

Some people love to shop. Some people live to shop. And some people use their shopping as a way to help CARF...

No matter how you feel about shopping, now there's an easy way to raise cash for CARF, just by going to your store or buying from your favorite online merchant. How does it work? It's easy. You register your existing credit cards, supermarket loyalty cards, and debit cards, and CARF earns a percentage of your purchases.

You don't have to use a special credit card—the cards you have are just fine. If your cards earn reward points or airline miles, you'll still receive them. Nothing changes from your end. The program is funded by merchants—from major retailers like Macy's to small regional grocers.

More than 1,000 online merchants also participate, such as:

**Apparel and Shoes – men:** Bloomingdales, Brooks Brothers, Gap, Nordstrom, Men's Warehouse...  
**Apparel and Shoes – women:** Banana Republic, DSW, Victoria's Secret, Wilson's Leather...  
**Auto and Travel:** Enterprise Rent a Car, Virgin Atlantic Airways, Travelocity, Jet Blue, Marriott...  
**Baby and Maternity:** Babies R Us, Diapers.com, Kids Foot Locker, MyStrollers, Walmart...  
**Books, Music and Movies:** Amazon, iTunes, eBay, Guitar Center, Kaplan Test Prep, Netflix...  
**Computers and Software:** Apple Store, Adobe, HP, Microsoft, Quickbooks, Toshiba, CompUSA...  
**Electronics and Photos:** Best Buy, Bose, Circuit City, Fuji Film, Kodak, TiVo, Radio Shack...  
**Financial Services:** Allstate Insurance Company, Lifelock, Turbo Tax, stamps.com, H&R Block...  
**Flowers and Gifts:** 1-800-Flowers, Crabtree & Evelyn, FineStationery.com, Lenox, Pottery Barn...  
**Gourmet and Grocery:** Godiva Chocolatier, My Wines Direct, Harry and David, Starbucks Coffee...  
**Health and Beauty:** The Vitamin Shoppe, Clinique, Lenscrafters.com, Sephora, Walgreens, QVC...  
**Home and Garden:** Home Depot, Linens 'N Things, Williams Sonoma, Gardener's Supply...  
**Jewelry and Watches:** Zales, Fossil, Hammacher Schlemmer, HSN, Adorn Brides, The Watchery...  
**Office and School Supplies:** Staples, Office Depot, Vistaprint, 123Inkjets.com, Monster.com...  
**Pet Supplies:** PetSmart, PETCO, Live Aquaria, 1-800-PetMeds, Pet Food Direct...  
**Sports and Outdoors:** REI, Six Flags, ProGolf.com, TicketsNow, U.S.OlympicShop.com...  
**Toys and Hobbies:** Toys R Us, Batteries.com, DisneyStore, Scholastic Store, Blick Art Materials...  
**Wireless and Internet Services:** Verizon Wireless, Verizon Broadband, eFax, Skype, eBay...

The program is called **eScrip**. It's been around for ten years and accredited by the Better Business Bureau since 2001. The firm behind eScrip is ESI, based in San Mateo, California. They point out: "The best reference we can put forward is the caliber of retailers that ESI is enrolling in the program. These retailers are entrusting ESI to run a quality, safe, and very visible program using their names and their donations."

Ready to try? Great! I'll walk you through the process.

First, go to: [www.escrip.com](http://www.escrip.com)



# An Easy Way to Help CARF... Just Go Shopping!

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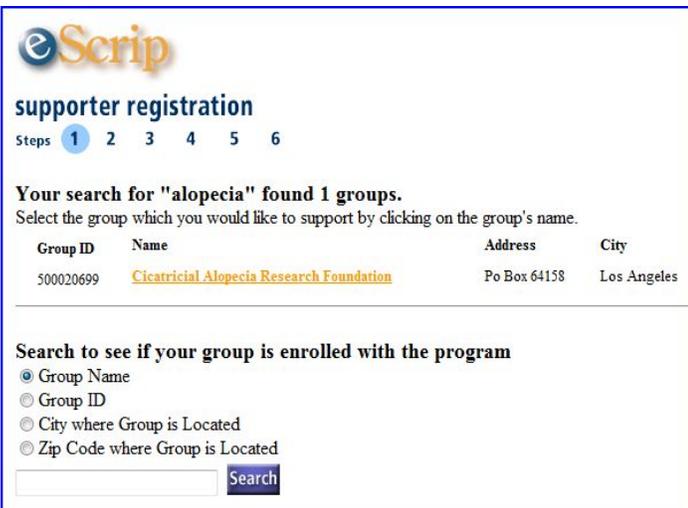


## Step 1: Find CARF

Click on "Sign up now" and search by "Group Name" for the Cicatricial Alopecia Research Foundation by entering "alopecia" in the box.



You could also use "cicatricial," if you like spelling that! (Typing "CARF" will not work, since acronyms aren't used.) Then you'll see Cicatricial Alopecia Research Foundation. Click on that...



## Step 2: Identify Yourself

Next, enter your name and address. Note that this and all other pages are secure ("https...")



## Step 3: Enter Grocery Cards If You Have Any

In the third step, you'll be asked for a grocery card. If you don't have a Safeway Club Card or something similar for another participating grocer, just skip this step and click "Next."



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## An Easy Way to Help CARF... Just Go Shopping!

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### **Step 4: Enter Your Credit Cards**

Step 4 is the important part. Enter your credit and debit cards. Again, your browser will show this is an encrypted, secure page.



### **Step 5: If You're a Macy's Cardholder**

The fifth step is only if you have a Macy's credit card right now. If not, just click on "Next."



### **Step 6: Confirmation and You're Ready to Go**

The final step just summarizes what you entered. If it looks OK, just hit "Confirm." Otherwise, you have a chance to edit what you entered.

That's it! You'll automatically earn CARF from 1-5% or more of each purchase you make at participating retailers. As mentioned above, if you receive reward points or airline miles on your credit cards, you'll still get them from your bank. The contributions that CARF receives are from the merchants.

Have a look around the site and you'll see that companies in all categories and all parts of the country are represented. And thanks for taking the time to help CARF!

*As with any time you enter your credit card or other personal information online, use caution if the computer is shared with others. Typical precautions include closing the window, and following the browser's process to "clear the cache" or "delete cookies."*

Please encourage your friends and family members to register their credit cards, supermarket loyalty cards, and debit cards to help raise money for CARF.

## Putting Patients First

Sheila Belkin and Marilyn Ey



Sheila Belkin

At CARF we never lose sight of our patients, who are at the center of everything we do. Our goal is to educate patients, their families, their physicians and nurses by providing them with the most current information about cicatricial alopecia. The CARF volunteer Board of Directors, whose members come from the United States and Canada, convene regularly and plan exceptional strategies on behalf of patients. Our Scientific Advisors are doctors who are dedicated to furthering the advancement of research and patient care. Truly, we have a passionate team!

CARF is unique. Unlike other organizations, we do not rent office space, nor do we have a large paid staff. Instead, our office is donated and our corps of committed, talented volunteers performs a potpourri of tasks—anything and everything that comes their way. Our success is attributed to this amazing grassroots effort of folks who come together and get the job done, no matter what is asked of them.

As we continue to grow and seek answers about our disease, more than ever we need to recruit volunteers. CARF is always available to give you, our patients, supportive and encouraging words by email, telephone or in person, including times when you are depressed, have doubts, or questions, or simply want to know more about your disease. Once you contact us, you become part of a larger family and no longer feel isolated. You are referred to a specialist and provided with information to help you embark on a healing path. CARF becomes your golden resource. The time is now ripe to reach out, give back

and help other fellow patients in need.

Our Volunteer Coordinator, Marilyn Ey, is a patient from Chico, California. She will facilitate finding the ideal assignment that suits your schedule and allows you to have fun. Please contact her at:

[volunteer@carfintl.org](mailto:volunteer@carfintl.org)

Would you like to lend a helping hand and change lives through commitment? Let us know what you do and how you would like to help out. We need assistance with:

**Data entry** – aid in updating database

**Events** – plan patient conferences, awareness campaigns

**Fundraising** – solicit funds, services or donated items; have a local fundraiser

**Graphics** – design flyers, posters, invitations, stationery

**Grants** – look for grant prospects; write proposals

**Marketing** – raise awareness; search for partnering opportunities

**Newsletter** – help write, edit or format layout

**Patient support** – give email or telephone support

**PR** – send out press releases and follow up

**Special Projects**

**Support Group Leader**

**Video** – video events

**Website** – assist the updating and enhancement team

**Writer** – submit awareness articles for newspapers and magazines, award entries, CARF newsletter, thank you notes.

We invite you to become a part of our winning team of volunteers and to enjoy the rewards of an enriching and gratifying experience!



Marilyn Ey

## Layout Editor Extraordinaire:

Margit McPhillips



Margit McPhillips

Earlier this year, Dr. Vera Price asked me if I was interested in working on the layout for CARF's newsletter. Although I do not have very much experience in desktop publishing, I agreed to give it a try, and to my relief we published a successful spring newsletter.

Working with Sheila and the other volunteers has been a very rewarding experience. As a cicatricial alopecia patient it is uplifting to be involved with an organization that works so hard toward finding a cure for what can be a very frustrating condition.

Working on the newsletter, which is more on a project basis, fits my current schedule well, and I look forward to getting more involved with CARF next year.



C. A. R. F.

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Check out CARF's award-winning website: [www.carfintl.org](http://www.carfintl.org)

**CARF Communiqué** Editor: Nancy West, PhD  
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## SAVE THE DATE!

### CARF's 4th International Patient Doctor Conference

Friday – Sunday, September 24 – 26, 2010

Beverly Hills, CA



We invite you to attend an exciting conference for those who have cicatricial alopecia, their families, friends, physicians and nurses. This event will provide the latest medical and research information to help you understand cicatricial alopecia.

The CARF Conference will be held at the Crowne Plaza Hotel, Beverly Hills, at a special room rate of \$99 per night. Plan your 2010 family vacation to coincide with the Conference.

Check our website [www.carfintl.org](http://www.carfintl.org) in 2010 for more details. If you wish to receive a conference registration brochure in February 2010, please **email** a request to [conference2010@carfintl.org](mailto:conference2010@carfintl.org), and include your home address and phone number.

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