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CARF Dazzles Sheila Belkin



Diamonds in the sky, wishes on a star, but, most of all, hope of a cure for cicatricial alopecia—also known as *scalp on fire*.

The CARF Diamond Affair was held in Beverly Hills, California, on July 21, 2007. Attendees from eleven states and Canada honored Dr. Vera Price with CARF's first fundraiser, which raised over \$95,000. Honorary Committee members included Speaker of the House Nancy Pelosi, Senator Dianne Feinstein, Senator Barbara Boxer and Olympian Carl Lewis.

The CARF Diamond Affair began with a luncheon at which

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Research Update George Cotsarelis MD



Penn Researchers Discover that Hair Follicles Regenerate by Re-awakening Fetal Gene Programs

PHILADELPHIA – Dr George Cotsarelis and researchers at the University of Pennsylvania School of Medicine have found that hair-follicle regrowth in adult animals follows the same pattern as development of hair follicles in embryos.

These findings provide evidence that, like other animals such as newts and salamanders, mammals have the power to regenerate after injury. These findings are published in the May 17 issue of

Nature.

In this study mice healed wounds by re-awakening primitive developmental pathways that led to the regeneration of hair follicles. A better understanding of this process could lead to novel treatments for wounds, hair loss, and other degenerative disorders by taking advantage of molecular pathways involved in wound healing in the skin.

“We were able to trigger these embryonic pathways that already exist in the body by blocking or activating wnt proteins,” says senior author George Cotsarelis, MD, Associate Professor of Dermatology. “The wnts are a network of proteins implicated in devel-

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Mark your calendars for the next Patient Conference in Washington, DC

September 26-28, 2008 at the Hyatt Regency Crystal City. Join us with other patients and doctors.



It may seem heretical for the newsletter editor to admit but, I have to say, I was on the fence about attending CARF's most recent Diamond Affair. *Why not just send a donation?* I thought to myself. After all, it would be cheaper than traveling all the way from Washington, DC, to Beverly Hills, California. Plus I'd just moved to DC and, as the event approached, I wondered if it would be better to back out and run a number of

CARF Events Give Patients Hope Laurence Spector

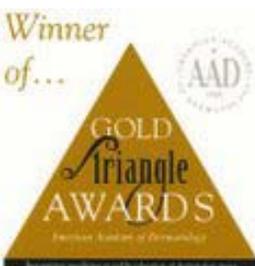
much needed errands—such as buying furniture for my very empty apartment.

As I weighed my options, I thought about the opportunity before me: a chance to spend a weekend connecting with patients and physicians, with the goal of advancing the study of a poorly understood disease. I had spent many weekends alone, contemplating cicatricial alopecia. Now I had a rare opportunity to spend a weekend learning and benefiting from the experiences of others, while raising funds for

research. I felt compelled to attend, inspired by the thought of meeting others in my same situation and helping CARF to achieve its mission.

I couldn't have known, however, how much I would gain personally from attending this conference. Upon arrival at the Luxe Hotel on Rodeo Drive, I felt proud to be affiliated with an organization as caring and effective as CARF. My first glimpse of the hotel made me excited both to be staying in one of the hottest destinations in Beverley Hills and to be

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Diamond Affair CARF Committee Brunch Suzanne and Ed Vasgerdsian

“New friendships are made and old ones are rekindled each time a CARF event is held, and the Diamond Affair was no exception.”



The CARF committee ended a wonderful weekend with a delicious brunch hosted by Francine and John Leipsic.

Their home is a combination of Southwestern architecture fused with Asian decor and is worthy of a spread in *Architectural Digest*.

In this beautiful setting, all had a chance to share their thoughts on the success of the Diamond Affair.

New friendships are made and old ones are rekindled each time a CARF event is held, and the Diamond Affair was no exception.

We have also learned that coming to CARF functions should not be limited to attending meetings or sessions. Everyone is encour-

aged to be involved by serving on a committee or becoming a volunteer.

One comes away from these special weekends with encouragement and appreciation for all the effort being made to finding answers.

We are looking forward to next year's CARF Conference in Washington, DC. We hope to see everyone there.

So Much More Than A Meal: Lunch With the Docs Nancy Gates

“We had the honor of sharing a table with Dr. Vera Price, who has a well-deserved reputation for listening carefully to feedback from her patients...”



Imagine this: you climb into a limousine and find yourself seated between two of the world's leading scalp specialists—dermatologists who have devoted their entire careers to the study of hair loss disorders. At your destination, you enter a large, lovely room filled with more of the same!

These amazing professionals have flown in from far and wide, donated their time and expertise, and are ready and willing to sit down with you, share a meal, chat informally and answer your questions. This was the scene for “Lunch with the Doctors” at the Cicatricial Alopecia Research Foundation's Diamond Affair in Beverly Hills last August.

Beginning with the very first

CARF 2005 Patient Conference in San Francisco and continuing through the 2006 Minneapolis Conference, CARF has perfected its traditional “dining with the docs” experience into a much-anticipated, always memorable and uniquely helpful affair.

My husband and I, along with a group of patients who are painfully familiar with the symptoms and angst associated with scarring hair loss, enjoyed the rare opportunity to ask our questions and learn about the latest treatments in a relaxed, informal, congenial, non-threatening setting devoid of waiting rooms, co-payments and rushed clinic schedules.

We had the honor of sharing a table with Dr. Vera Price, who has a well-deserved reputation for listening carefully to feedback from her patients and passing along helpful tips and tricks, cou-

pled with her expertise and guidance.

Vera told me about a particular prescription shampoo she thought I might like to try, which I have since used with wonderful results. This is just one example of the wealth of information that was shared over the course of a delicious meal—with the doctors rotating to other tables at dessert time to enable patients to spend some time with a different pair of specialists.

The helpful information, the opportunity to see the familiar friendly faces of folks who attended past conferences and to meet new folks with a common interest, a tasty lunch, and the knowledge that the money we paid for the event will go into CARF's funds for research toward a cure, all served to make CARF's Lunch with the Docs an outstanding experience. I'm looking forward to the next one!



CARF Scientific Advisor Profile: George Cotsarelis MD



George Cotsarelis, is Associate Professor of Dermatology at the University of Pennsylvania and a member of the CARF Scientific Advisor board since the inception of the or-

ganization. His clinical practice is devoted to hair and scalp disorders. He is an eminent figure in the field of cutaneous research with most of his time dedicated to basic research in epithelial stem cells, hair follicle biology, wound healing and skin regeneration.

After attending the University of Pennsylvania for both his undergraduate and medical school degrees, Dr. Cotsarelis received numerous fellowships and awards. He is an organizer and leader in professional and scientific

societies and since 2005 he has been President of the North American Hair Research Society. He continues to be active in the medical community and has served as editorial reviewer on a variety of medical publications, has written over 50 articles for various journals and lectures at meetings and universities throughout the world.

Dr. Cotsarelis first localized cutaneous stem cells to the hair follicle bulge while he was training to be a dermatologist. He then spent the next 15 years studying these cells. He developed methods for isolating and targeting hair follicle stem cells. Using powerful mouse models, he showed that these cells are necessary for continual hair follicle growth. Destruction of the stem cells in the hair follicle bulge resulted in scarring of the hair follicle and permanent hair loss, similar to

what is seen in cicatricial alopecias. Recently, his laboratory demonstrated that adult mice have the ability to regenerate hair follicles in response to wounding.

This challenged the dogma that no new hair follicles form after birth. The laboratory then showed that genes called "Wnts" were necessary for the hair follicles to regenerate. Blocking Wnt activity completely blocked new hair follicle formation. Remarkably, the over production of Wnts during wound healing resulted in a doubling in the number of new hair follicles. These findings may lead to novel ways to treat hair loss, including cicatricial alopecias. A company has licensed the intellectual property around these findings from Penn and is in the process of trying to develop treatments for hair loss.

Research Update

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opment of the embryo and cancer."

Researchers previously believed that adult mammal skin could not regenerate hair if it had already lost its hair follicles. In fact, investigators generally believe that mammals had no regenerative qualities at all.

In this study, researchers found that wound healing in a mouse model created an "embryonic window" of opportunity. The wound reignited dormant embryonic molecular pathways, sending stem cells to the area of injury. Unexpectedly, the regenerated hair follicles originated from non-hair-follicle stem cells.

"We've found that we can manipulate the wounds with wnts or other proteins that allow the skin to heal in a way that has less scarring and includes all the normal structures of the skin, such as hair follicles, subcutaneous glands, and oil glands, rather than just a scar," explains Cotsarelis.

By controlling wnt pathways to introduce more wnt proteins to the wound, the researchers found that they could take advantage of the embryonic program to promote hair-follicle growth, thus making the skin regenerate instead of just repair.

Conversely by decreasing the level of wnt proteins, they also found that they

could stop the production of hair follicles in regenerated skin.

Increased wnt signaling doubled the number of new hair follicles. This suggests that the embryonic window created by wounding the skin can be used to manipulate hair follicle regeneration, leading to novel ways to treat hair loss and hair overgrowth.

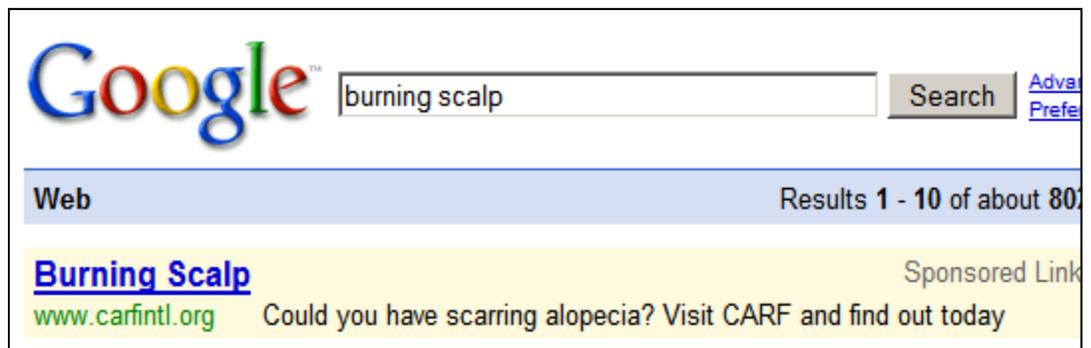
These findings go beyond just a possible treatment for male-pattern baldness. If researchers can effectively control hair growth, then they could potentially find cures for people with hair and scalp disorders, such as scarring alopecia where the skin scars itself, destroys hair growth.

Google Grant Extends CARF's Reach

Make a difference for yourself and other patients by supporting CARF today! Visit www.carfintl.org for more information.

Thanks to Google's generosity, patients searching for information about any of the cicatricial alopecia's will now be directed to the CARF web site. Today, patients from across the globe can easily find CARF and access the most current information, because CARF appears first in all Google search results.

The screen capture below demonstrates how CARF has been able to leverage Google's widely used search-word features to reach more patients worldwide.



A Google search for any term associated with cicatricial alopecia directs patients to CARF's web site, helping CARF to reach more patients world-wide.

Ways you Can Help CARF

- ◆ If you are over the age of 70½, you're eligible for a special IRA donation that can help you and the Cicatricial Alopecia Foundation. For this tax year, you can roll over up to \$100,000 from your IRA to charity.
- ◆ These gifts can be made tax-free and may help you meet your minimum required IRA distribution levels. And, as always, a gift to CARF will go far in helping us continue to meet the needs of patients in communities everywhere.
- ◆ Simply direct your custodian to transfer a portion of your required minimum distribution on or before December 31, 2007, directly to CARF.



CARF Quick Facts

- ◆ Since its inception in 2005, CARF has raised more than \$250,000 towards valuable research and resources for patients suffering from cicatricial alopecia.
- ◆ Recognized by the American Academy of Dermatology with two Gold Triangle Awards for excellence in public education of dermatologic issues, CARF has spearheaded a research colloquium and several patient conferences, as well as creating the sole educational Web site serving individuals with cicatricial alopecia worldwide.
- ◆ In 2007, CARF co-founders Dr. Vera Price and Sheila Belkin received special Congressional recognition for their outstanding and invaluable service to the community in raising awareness of cicatricial alopecia.

A Message from Speaker Nancy Pelosi



Nancy Pelosi
Speaker of the House

July 21, 2007

The Cicatricial Alopecia Research Foundation
PO Box 64158
Los Angeles, California 90064

Dear Friends,

I am delighted to send my congratulations to the Cicatricial Alopecia Research Foundation and honored to serve on the Honorary Committee for your CARF Diamond Affair.

Thank you for this opportunity to honor CARF's co-founders, Sheila Belkin and Dr. Vera Price, for their dedication to and support of those suffering from this physically and emotionally devastating disorder.

I applaud CARF'S commitment to research and education, as well as to providing valuable resources to individuals living with Alopecia and their families. Raising the public's awareness and providing information and education helps minimize the psychologically devastating effects of this disease.

Please accept my appreciation and best wishes as you continue your outstanding work.

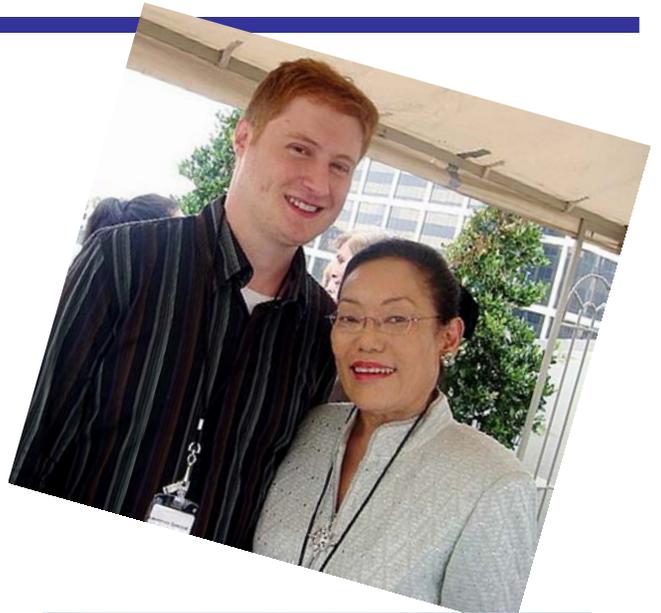
Best regards,

A handwritten signature in blue ink that reads "Nancy Pelosi".

NANCY PELOSI
Democratic Leader

CARF's Diamond Affair—Truly An Event to Remember!





CARF Dazzles

(continued from page 1)

nine expert dermatologists talked informally with patients about cicatricial alopecia and answered their questions.

Following the luncheon, a dazzling evening on the rooftop of the chic Beverly Hills Luxe Hotel was filled with entertainment and impressive silent and live auctions.

The celebration continued on Sunday with a special thank-you brunch for out-of-town guests at a private, art-filled home.

"I applaud CARF's commitment to research and education," commended Nancy Pelosi, speaker of the House and Honorary Committee member. "Raising the public's awareness and providing information and education helps minimize the psychologically devastating effects of this disease."



CARF Events Give Patients Hope

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"Now I had a rare opportunity to spend a weekend learning and benefiting from the experiences of others, while raising funds for research."

meeting and socializing with the other attendees. Like many patients with cicatricial alopecia, I haven't had the chance to spend much time with other patients, so these events are always a therapeutic opportunity for me to relate to others.

As evening approached, I was excited to see what the Diamond Affair itself would bring. And when I arrived on the rooftop deck of the Luxe Hotel that evening, I couldn't believe how enjoyable and lively the event was, with its live music, delicious hors d'oeuvres, all the wine one could drink, and a huge turnout. CARF really outdid itself—even presenting a professional video about cicatricial alopecia that played in the auction room.

The auction itself is always a highlight for me because it's an incredible chance to pick up a number of one-of-a-kind items and the money paid really makes a difference for our organization. I even bought

a tremendous children's movie, "Spooky House," made by one of our members, Margaret Sachs, and her husband and it was an honor for me to get a chance to meet and speak with the creators.

Overall, my experience with CARF has really helped me feel better and worry less—by meeting and speaking with other patients to whom I can relate, getting expert and up to date referrals and information about treatments, and mostly by giving me peace of mind that our organization will lay the foundation for effective treatment. Even my condition has improved because I am under significantly less stress and personally feel much better. I hope that everyone reading this makes certain to attend CARF's next event, the CARF Patient Event on September 26-28, 2008, in Washington, DC.



Lights, Camera, Action

Sheila Belkin



Hollywood came to San Francisco this summer when veteran documentary filmmaker Frank Zamacona and his talented crew shot a first-ever documentary about cicatricial alopecia.

Eight patients of Vera Price assembled for an intensive, daylong shoot that included various indoor and outdoor sequences with integrated, impromptu interviews, examination of scalps, and a support group session.

Emotions loomed high between laughter and tears, and ended on a hopeful note. The result was three hours of informative footage that was then expertly edited down to eight minutes.

The documentary, which pre-

sents an honest, inspirational and supportive look into the world of scarring alopecia, was well received at its premiere at the Diamond Affair in Beverly Hills.

The video can be viewed by going to www.youtube.com and searching for "CARF VIDEO."

If you would like to purchase a copy of the video, please mail a check for \$25 to:

CARF; PO Box 64158; Los Angeles, CA 90064

"The result was three hours of informative footage that was then expertly edited down to eight minutes."

Cicatricial Alopecia

RUNNING TIME
8 minutes

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www.carfiatl.org



C. A. R. F.

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

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ADDRESS CORRECTION REQUESTED

CARF Receives Congressional Honors

