

June 2015  
Issue XVIII

# CARF Communiqué

## A Dermatologist's Experience of Going Natural

By Yolanda M. Lenzy, MD, Medical Director, Lenzy Dermatology & Hair Loss Center

After a recent Facebook post about my decision to stop straightening my hair and “go natural” this summer, I was asked to share with the CARF family about my decision and my journey. First, a little back story. Three years ago, we relocated from Boston to a small town in western Massachusetts. With all relocations comes finding new favorite places to shop, do your dry cleaning, go out to eat and for me a major source of angst was figuring out where I would get my hair done. For the past 25 years, every 8 weeks, like clock-work, I got my hair chemically relaxed. I relaxed my hair to achieve greater manageability and allow flexibility in my hair styling options. For those of you who don't know, a chemical relaxer is a method of permanently straightening naturally curly hair. When I relocated, I was quite nervous to find a stylist to perform this service since chemical relaxers in some instances have been associated in several studies with various forms of hair loss. Throughout the long duration of relaxing my hair, my hair had been relatively issue free. I did go through a period of breakage in one small portion of my scalp when I was applying to Dermatology residency, but I chalked it up to stress as the hair regrew without problems. After speaking with several friends, I found a stylist to relax my hair. After the treatment, I had multiple sore, scabbed areas throughout my scalp likely due to her much slower application technique than my prior stylists used.

After this experience, I made the decision to stop chemically relaxing my hair. The decision was a relatively easy one for me for several reasons. First, I did not want to go through the experience of trying out new stylists to find one who could relax my hair without causing scalp burns. I knew that I did not want to ever experience scalp burns again because I knew that it could increase my chances of developing scalp damage. Second, and most importantly, I have several family members including my mother, sister, grandmothers and aunts with central centrifugal cicatricial alopecia (CCCA), which is the most common form of hair loss in African American women. Several small studies have suggested a possible relationship between relaxers and CCCA, but this association has not been confirmed in larger trials. Larger studies are being conducted that will hopefully bring further clarity into the range of risk factors for CCCA. Because of this still unknown variable, I often counsel my patients, “When in DOUBT, leave it OUT.” Third, I was excited about a new way of caring for my hair.

For the past two and a half years, I have been chemical relaxer free and I have been getting my hair blow dried and flat-ironed. After a rough New England winter, I decided to take on a running program as means to improve my cardiovascular fitness and drop a few added winter pounds. With temperatures over 90 degrees and running outside, my hair becomes damp or sometimes drenched with sweat. A few weeks ago, I decided



Flat ironed natural hair (picture on left) and natural perm rod set (pictures on right).

[www.CARFintl.org](http://www.CARFintl.org)

**In this issue:**

- Support Group News
  - London..... 4
  - South Louisiana..... 5
- Patient Corner ..... 6-9
- Meetings, Advocacy & Awareness..... 10-18
- Clinical Trials & Research Studies—Recruiting Patients..... 19
- 2014 Donor Acknowledgment ..... 20
- Support Group List ..... 21



Skin Advocate

<http://www.skinadvocateapp.com/>

continued on page 3

---

**CARF COMMUNIQUÉ  
EDITORIAL TEAM**


---

Physician Editor: Nicole E. Rogers, MD  
 Managing Editor: Cheryl Duckler  
 Contributing Editor: Carol Kotrocz  
 Contributing Editor: Victoria Ceh, MPA  
 Medical Editor: Jennifer Fu, MD

---

**BOARD OF DIRECTORS**


---

Rita Wanser, Chairman  
 Andrew Alexis, MD, MPH  
 Wilma Bergfeld, MD, FACP  
 Mary Clay, MS  
 Donna Coulson, MS, PCC  
 Jim Heerwagen  
 Maria K. Hordinsky, MD  
 Jim O'Connell  
 Sharon Potter  
 Ken Washenik, MD, PhD

---

**SCIENTIFIC ADVISORS**


---

John P. Sundberg, DVM, PhD, Chairman  
 The Jackson Laboratory  
 Victoria H. Barbosa, MD, MPH, MBA  
 Rush University Medical Center  
 Valerie D. Callender, MD  
 Howard University  
 Lynne J. Goldberg, MD  
 Boston University  
 Lloyd E. King, Jr, MD, PhD  
 Vanderbilt University  
 Amy McMichael, MD  
 Wake Forest University  
 Paradi Mirmirani, MD  
 University of California, San Francisco  
 Elise A. Olsen, MD  
 Duke University  
 Apostolos Pappas, PhD  
 Johnson & Johnson (Lipid Biology Team Leader)  
 Ralf Paus, MD  
 University of Luebeck, Germany  
 University of Manchester, UK  
 Vera H. Price, MD, FRCPC, Founder  
 University of California, SF  
 Michael D. Rosenblum, MD, PhD  
 University of California San Francisco  
 Jerry Shapiro, MD FRCPC  
 University of British Columbia  
 Leonard C. Sperling, MD  
 Uniformed Services University

---

**STAFF**

Victoria Ceh, MPA  
 Executive Director, [vceh@carfintl.org](mailto:vceh@carfintl.org)  
 Melanie Stancampiano  
 Associate Executive Director,  
[mstancampiano@carfintl.org](mailto:mstancampiano@carfintl.org)  
 Kimberly Miller  
 HQ & Administrative Manager,  
[kmiller@carfintl.org](mailto:kmiller@carfintl.org)  
 Sue Reed & Katie Masini  
 Administrative Assistants, [info@carfintl.org](mailto:info@carfintl.org)

## New! CARF Physician Referral List— Online for CARF Subscribers

Includes physicians who treat hair loss and are accepting new patients. Available to CARF Subscribers.

### CARF Subscriber Database

Subscribers may log in and access all past issues of the *Communiqué* newsletter, make donations, sign up for CARF Support Groups, and more! You may log in by visiting the CARF website, clicking on “Join CARF,” and then logging into the “Subscriber Area.”

If you received this newsletter directly from CARF, then your username and password were included in your personalized email.

#### How to Sign Up as a CARF Subscriber

Go to <http://www.registration123.com/carf/main/> and enter your information. Once completed and submitted you will receive an immediate email with your Subscriber Number.

#### How to Access Past Issues of CARF Communiqué Newsletter:

Go to <http://www.registration123.com/carf/main/> and click on “Subscriber Area.” Enter your last name and Subscriber Number. When the site opens, click on “Newsletter” heading.

#### How to Access Physician Referral List

Same as above, but click “Physician Referral” heading.

## Would you like to be a part of the newsletter?

Please consider sharing your experience with cicatricial alopecia and/or attending a support group. Send your write-up to [info@carfintl.org](mailto:info@carfintl.org).

## Cicatricial Alopecia Research Foundation

303 West State Street  
 Geneva, IL 60134 USA

Tel: 1-310-801-3450 • Fax: 1-630-262-1520

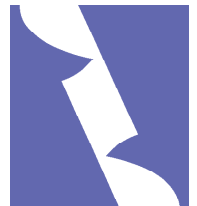
[info@carfintl.org](mailto:info@carfintl.org)

#### Mission Statement:

To provide education and patient support, raise public awareness, and advance and promote research.

#### Vision:

To improve the care of patients with inflammatory, scarring hair disorders.



C . A . R . F .

*On fire for research and a cure!*

The *Communiqué* is published bi-annually by the Cicatricial Alopecia Research Foundation. Copyright ©2015 by the Cicatricial Alopecia Research Foundation, 303 West State Street, Geneva, IL 60134, USA. The views expressed herein are those of the individual author and are not necessarily those of the Cicatricial Alopecia Research Foundation (CARF), its officers, directors, or staff. Its contents are solely the opinions of the authors and are not formally “peer reviewed” before publication. Information included herein is not medical advice and is not intended to replace the considered judgment of a practitioner with respect to particular patients, procedures, or practices. CARF makes no warranty, guarantee, or other representation, express or implied, with respect to the accuracy or sufficiency of any information provided. To the extent permissible under applicable laws, CARF specifically disclaims responsibility for any injury and/or damage to persons or property as a result of an author’s statements or materials or the use or operation of any ideas, instructions, procedures, products, methods or dosages contained herein.

**Going Natural** *continued from page 1*

that heat straightening my hair was no longer a viable option, as I knew that subjecting my hair to heat 3-4 times weekly would surely lead to breakage.

With the growing momentum of the “Natural Hair Movement” over the past 5 years, I have become interested in trying several naturally curly hairstyles. After speaking to friends about hair style options and exercise, many of them confirmed the findings of CARF Scientific Advisor Dr. Amy McMichael’s study that one-third of African American women stated that concerns with hair grooming was a major barrier impacting their ability to exercise as much as they wanted to. This is a major concern especially given that, according to the Centers for Disease Control and Prevention, 4 in 5 African American women are either overweight or obese. In my health seminars, I often share my moniker: “Don’t choose HAIR over HEALTH.” I can admit that even

as a physician, I have been guilty of sometimes choosing to not exercise when I had my hair freshly straightened. So, on May 30, I started a three-month “Summer of Transitioning to a Healthier Body and Hair” challenge with over 60 of my friends! For the summer, I have decided to refrain from applying direct heat to my hair and to explore new ways of caring for my hair with the help of my trusted stylist. So stay tuned...



Bantu knots before exercise (*left*) and after (*right*).



**Message from the Program Chair**

Nicole Rogers, MD

**Get Jazzed for the next CARF Patient-Doctor Conference!**

We are excited to announce that the 7th Patient-Doctor CARF Conference will be in New Orleans, Louisiana, June 3-5, 2016. Nearly all of the weekend events will be held at the Hampton Inn Hotel, near the Convention Center and a short 5-minute ride to the historic French Quarter. Attendees can expect informative lectures by physicians specializing in hair loss, members of the hair care and wellness industry, and a live demonstration by a local cosmetic tattoo artist. Most important of all, they can look forward to connecting with other patients who are affected by cicatricial alopecia. Attendees can enjoy delicious local seafood, creole cuisine, 'po-boy' sandwiches, a brass band performance, and optional walking ghost or voodoo tours of the French Quarter.

**C. A. R. F.**  
CICATRICAL ALOPECIA RESEARCH FOUNDATION

**7th International Patient-Doctor Conference**

New Orleans, Louisiana  
Friday-Sunday, **June 3-5, 2016**  
Host: Dr. Nicole Rogers

**NOOLA**

[www.carfintl.org](http://www.carfintl.org)



# SUPPORT GROUP NEWS

## Report from London

By Jacquelyn Adams (Patient Support Group Leader)

CARF London held their second event on Saturday, November 14, 2014, at the British Association of Dermatologists in London.

Dr. Dadzie opened the session providing an update on scarring hair loss. This was followed by Dr. Tziotzios speaking about his ongoing research into the genetics of frontal fibrosing alopecia (FFA). The research requires blood samples from participants. Anyone who is willing to be a research participant can contact Dr. Tziotzios at [christos.tziotzios@kcl.ac.uk](mailto:christos.tziotzios@kcl.ac.uk). (See page 18 for more information about U.K. FFA Research Study.)

Dr. Wong gave an overview of scarring alopecia in men and Dr. Nilofer Farjo spoke on hair transplantation.

Thanks again to Dawn Forshaw, Director of Finishing Touches Group, who attended for the second time, for providing information on available hair loss solutions for men and women.

The event ended with Dr. Mizara talking about the psychological aspects of hair loss, emphasizing the importance of a holistic approach to hair loss.

Attendees said:



“I would like to thank sincerely everybody involved in planning and implementing today’s conference. I found it exhilarating, empowering and very informative. It was so good to meet with other people with similar conditions and to discuss our hopes and fears. My thanks to the health professionals who gave up their time to address the meeting to talk and give advice, where possible.”

“I found the meeting enjoyable and was glad to meet other people with my condition—I just wish I could have stayed longer.”

“Thank you so much for today’s group.”

The time and location for the next event is to be confirmed.



Patient Support Group Leaders (left to right): Dr. Ophelia E. Dadzie, Marva Holder, Gita Kothari, Jacquelyn Adams, and Dr. Sharon Wong



15 delegates attended (including surprise visitors from Glasgow and Ireland).

# SUPPORT GROUP NEWS

## Report from South Louisiana, USA

By Nicole Rogers, MD (Support Group Physician)

On April 19, 2015, the South Louisiana Support Group heard from a wonderful speaker on the subject of stress management. Dr. Kendall Genre, a New Orleans–based female psychiatrist, spoke to the CARF attendees about techniques to better manage stress in their lives. She spoke on the subjects of sleep, mindfulness, and exercise.

**SLEEP:** Dr. Genre explained that most people need between 7-9 hours of sleep per night. She encouraged everyone to make bedtime the most important appointment of the day. She discouraged drinking alcohol before bed, because it can interfere with deep sleep. She also recommended no coffee or cokes after lunch. Melatonin may be helpful for some individuals.

**MINDFULNESS:** Dr. Genre encouraged the support group members to take 10 minutes daily over a 10-day period to stop, breathe, and think. She discussed using words like “peace” and “omm” during each breathe in moment. She also explained how phone applications like Buddhify and Insight Timer can help guide relaxation and create flow. She discussed how gratitude journaling can reduce stress. She asks many of her patients to write down three things daily that they are thankful for. When they do this, they tend to start looking for positives and feeling more optimistic. She encouraged everyone to find their sources of happiness and include more of such, whether it be spending time with a pet or eating good sushi.

**EXERCISE:** She mentioned that the new device called Fitbit® can be used to push oneself to walk more regularly. She said this has helped even in her own life to park farther from the sidewalk, to take the stairs, and to be more aware of any way she can increase her steps during the day. She also mentioned the Johnson & Johnson 7-minute workout application that does not require equipment and can be done 2 times per day, spread out.

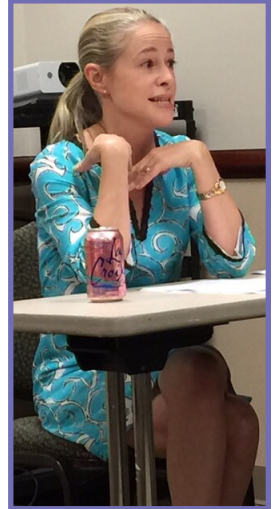
Specific books provided by Dr. Genre were the following:

- *Thrive* by Arianna Huffington
- Jon Kabat Zinn (all of his works on mindfulness are helpful)
- *The Feeling Good Handbook* by David Burns

Dr. Genre covered a specific section of the Feeling Good Handbook, which included the 10 forms of twisted thinking. These included: all or nothing thinking (seeing things in black or white), overgeneralization (using words like always and never), mental filter (dwelling on a single negative detail), discounting the positive (rejecting positive experiences because they don't count), jumping to conclusions, magnification (exaggerating the importance of problems or shortcomings), emotional reasoning, and “should” statements (when directed against yourself can lead to guilt and frustration). She then described a few ways for the group to untwist such thinking, namely: 1) identify the distortion (write down negative thoughts, so you can see what has truth to it), 2) examine the evidence, 3) talk to yourself as you would a friend (compassionately), 4) think in shades of gray (not all or nothing), and 5) use the survey method to see if your attitudes are realistic.

The talk was quite fascinating because she also discussed how technology can be implemented to manage stress. Specific phone/computer applications were:

- Johnson & Johnson 7-minute workout
- Stop/Breathe and Think
- Buddhify
- Insight Timer
- Headspace: Take 10



Dr. Kendall Genre speaking to the South Louisiana CARF support group.



Front row (left to right): Marilyn Hammond, Gerry Ward, and Dr. Kendall Genre. Back row (left to right): Dr. Nicole Rogers, Dr. Marcelo Pitchon (visiting hair transplant surgeon from Brazil), Kristina Johnson, Kristina Rees, and Vonda Kovacevich.

*At the time of the photo, all attendees agreed to have their faces and names included in the newsletter.*

## PATIENT CORNER

### What is a CARF POV?

By Nancy, Fellow CICAL Patient & POV

Just like all of us, I never imagined I would acquire something as strange as Cicatricial Alopecia (CICAL). Gosh, my condition even has a strange name! Could they not just call it scarring hair loss?

POV stands for Patient Outreach Volunteer. So, of course, I never dreamed I would also become one. Late last year the position was offered to me by an awesome POV that has now moved to another volunteer position. When someone with CICAL contacts CARF, CARF then asks if they would like a POV to call them. If so, I call the person, find out if they have been diagnosed via biopsy, find out how they are dealing with their diagnosis, determine if they have a healthcare provider knowledgeable about CICAL, ask if they are getting treatment and what kind of treatment, and connect them with CARF support resources if they wish. Then we usually have a compassionate discussion about CICAL and ways to deal with it.

As a nurse, I think the POV position fits me quite nicely. However, how does one help people deal with a devastating condition that currently has no cure? I was hoping that nursing background would help me out.

Most people with CICAL actually grieve over their loss of hair. There are 5 generally accepted stages of grief as termed by Swiss Psychiatrist, Elizabeth Kubler-Ross: 1) **Denial**, 2) **Anger**, 3) **Bargaining**, 4) **Depression**, 5) **Acceptance**.

Because I have CICAL, I too have passed through these stages of grief, sometimes even bouncing back to start all over again! Though I must say the second or third time around that each stage is less traumatic than when I was initially diagnosed 6 years ago.

Because I also have CICAL and have experienced the stages of grief, I feel I can empathize with others that are afflicted. And by combining my own basic knowledge of hair physiology and that which I have researched about CICAL along with the wealth of information and resources CARF provides, I feel I am turning out to be a pretty good POV. Of course, there is always room to improve and expand, so I am always open for suggestions.

I hope to see you at the 2016 CARF conference in New Orleans!

### A Trove of Treasures

By Sistah D.

This is the trove of “treasures” that have become part of my life in a year of living with cicatricial alopecia. From topicals and medications to hairpieces, headbands, and hats, I approach my disease from many angles. In addition to success calming inflammation and slowing down hair loss with medications, I’ve had some regrowth from minoxidil on areas that were affected by androgenic loss, not scarred from cicatricial alopecia. Headbands and hairpieces help with my public appearance and let me stop focusing on every hair I lose. Most invaluable though are the many friends I met through CARF who help me accept the unknown outcome of this mysterious condition.



### Sistatrical Support

By Sistatrical Tamara

*“Sistatrical” is a coined word combining “sister” and “cicatricial.” The following email was shared between friends who met at the Chicago Conference:*

“I think when we take control of other ways to love ourselves, enjoy ourselves, feel beautiful, and change our way of dressing, style of hair, makeup or no makeup (that’s me because everything is toxic), it creates a focus on another part of us that are just as valuable as our hair. Like, eating healthier, creating a new look, trying new ways of eating, share with friends, love hair pieces and embrace our new beauty like both ME and D are doing!! WE have choices and we can embrace our balding and give it love...acceptance. Okay, today I’m okay...we’ll see my attitude later on.”

“Today, I’m blessed beyond the imaginable to have each of you in my life. I get love and support by some for my disorder, but it’s not the same that I get from each and every one of you.”

*continued on page 7*



# PATIENT CORNER

## Cicatricial Sisters Speak

We met at the Chicago Patient-Doctor Conference, shared contact information, and have supported each other's ups and downs (Cicatricial or otherwise) ever since. We are now "Cicatricial Sisters." Here are some of our suggestions you might find helpful. We'd love to hear yours. Please share your tips, tricks, and suggestions via email (subject: "Tips & Tricks") to [info@carfintl.org](mailto:info@carfintl.org).

1. Hair Salon: Exposing hair loss in public can be uncomfortable. Thus, some hair stylists offer private styling areas. Others offer scheduling appointments before or after normal operating hours.
2. I use a product called At Ease for my eyebrows, and some camouflage at the hairline. It is like a mascara tube and brush, normally used as a temporary cover-up areas of gray hair. It is waterproof, so my eyebrows stay on, even in sweat or wet. It comes in several colors. I get mine from [hairdirect.com](http://hairdirect.com).
3. Use an atomizer when applying Toppik®.
4. My dermatologist advised me to use Tacrolimus on eyebrows for inflammation.
5. I keep a "hair" diary to help me understand patterns, triggers, and effects of my meds. I note my level of pain on my scalp from 1-10 and what areas are affected. I also note if I'm under stress, changing shampoos, treatments, or anything else of significance.
6. Just before my doctor's appointment, my "close and honest" friend exams my scalp. She tells me the good news or the bad news. I emotionally deal with bad news before hearing it from my doctor. Doing my mourning beforehand helps me hear everything my doctor says at my appointment.
7. Sources for beautiful headbands and buffs:  
U.S.: <http://www.buffusa.com>  
International: [http://www.buff.eu/es\\_en/](http://www.buff.eu/es_en/)  
Freepeople headbands: <http://www.freepeople.com/soft-headbands/>
8. One of my biggest tips is using Couvre (online or Amazon). It helps when you have an area of complete hair loss that you're trying to cover with other hair—particularly when your hair is dark and your scalp is not! After I dry my hair I apply it with my fingers. Just dab on to mostly cover areas without hair, and then keep styling. Just find a shade that matches your hair and it helps diminish any bright, shiny scalp from peeking through.
9. Find a local dermatologist that understands the necessary treatment for Cicatricial.
10. Be connected and stay with Patient Advocates.
11. Get immediate support by joining a group (in person and or via phone/email), find a therapist, and surround yourself with a tribe of family and friends that offer immediate and ongoing support.
12. Don't minimize the sadness you experience with hair loss and the dramatic change in your life. It's normal to cry, feel sad for your loss, and to feel different.
13. Find healthy ways to cope as soon as possible. Learn how to accept change, practice faith, continue on your spiritual path. help others (which can be very cathartic), find new hobbies that bring daily joy, work out, journal, learn how to accept loss and the tools that are necessary to support your healing.
14. Find a hairdresser that really understands the trauma one feels when losing hair and who is super sensitive to the evolution of CICAL.
15. Celebrate the "NEW NORMAL YOU." This does take time. Embrace you, have fun with scarfs, headbands, hats, hair clips, hairpieces, hair fillers, and wigs. Learn to celebrate yourself with new looks instead of holding on to what your hair used to looked like.
16. Remember, most people don't notice our hair loss because we become very creative in disguising it. We perceive the loss as much bigger than it is.
17. Even though our culture is all about hair, we are not our hair. We are more than our hair and we live in a world today that has many solutions to our challenge.

# PATIENT CORNER

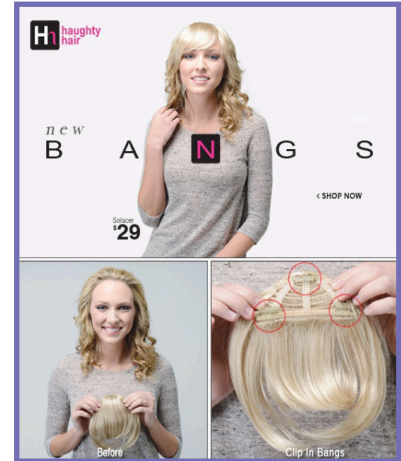
## Clip-in-Bang-Solace

By Nicole Rogers, MD

A Louisiana CARF support group member recently found some interesting “Solacer Clip-in Bangs,” which may be a big styling help to patients with frontal fibrosing alopecia.

These new glamorous bangs are available with three pressure sensitive clips that keep it securely in place. The company claims that they are easy to apply and won't damage existing hair. Visit their website for 3 free color swatches and then measure your head using their online help center. The company information is:

Beautytrends  
10725 Midwest Industrial Blvd.  
St. Louis, MO 63132, USA  
[www.beautytrends.com](http://www.beautytrends.com)  
1-800-268-7210



## Hair Piece = Peace

By Lori Bertella

My hair loss over several years started above my ears and was never diagnosed. I wear a bob style haircut so it was “out of sight, out of mind” as I could cover the bare patches with existing hair. Then, in January 2015, when I got an official diagnosis, what seemed easy to hide one day seemed impossible the next. Nothing changed except the knowledge and absolute confirmation that what was gone was gone forever. It was all mental at first. I immediately began my mission to find anything from a wig to a hairpiece to a buff to actually shaving my head! It was all a matter of panic. My sudden shift in mind-set went from “No biggie, I can hide this” to “Oh my goodness, I am bald and these spots are impossible to hide.” Crazy, I know, but maybe not. Maybe others had a similar mental and emotional journey.

During my 4-month “obsession” with finding something to hide these “boulder size” bald patches (again, my sudden perception, but not so much reality), I found a man who owns a salon/wig shop. I went in for a custom wig because I was “going bald” overnight. We shared an honest exchange of what I really needed now. He ordered a lace backing that matched my blonde hair. A week later, I went in for my first “arts and crafts” session! He made templates of the areas above my ears and cut the pieces to fit. He used surgical grade glue on the scalp, several layers, and placed those pieces over the very smooth surface, bare, no hair areas. It made a good bonding site. The pieces were longer than my hair. He fit them to my style and texture before thinning them. VOILA! Hair. I walked out uncertain because of this foreign feeling of having hair after living without it for 4 years. I couldn't feel the pieces, but I felt a hole was filled both physically and emotionally. Was this a perfect solution? No, but is there really such a thing? This option gave me a boost of confidence and a sense of peace.

My hairpieces stay in about 8 days. I then clean the pieces and my scalp before gluing back in place. While wearing the pieces I shower and do normal activities including a recent marathon relay! I don't wear them all of the time as I've finally accept I do not “need” anything just yet. I feel good with or without them. It is nice to know my little pieces are there for me when I need them.

Maybe this idea could work for you. It could provide a sense of peace knowing there ARE options allowing us to take control over cicatricial alopecia.

*Editor's note:* Please confer with your dermatologist as to whether it is appropriate for you to have any glue applied to your scalp. Some glues may cause an allergic contact dermatitis in the area where they are applied. They may also make it difficult to apply topical steroid creams or solutions.





# PATIENT CORNER

## Tips from an FFA/LPP “Cover” Girl

By Curle Temple

A couple of months ago I was in Sephora, a beauty supply chain, buying some lipstick when an attractive woman 20 years my junior came up to me from across the crowded store. She told me she loved my curly hair and wanted to know what products I used. I barely held back from laughing. I wanted to say “Plaquenil, steroid injections, minoxidil, finasteride, doxycycline, tacrolimus, clobetasol, ...and A HAIR TOPPER!!!” Instead, I told her I use Deva Curl (the stuff of my yester-years). I smiled (to myself) knowing I can walk through this world with a freedom I haven’t experienced in years. In fact, my hair never looked so good—odd that CICAL would have an upside!

### Did I “need” a hairpiece?

I had thinning hair since my mid-forties and tried always to disguise my scalp with comb-overs. When I was diagnosed in 2014 with FFA, LLP, and Androgenic Alopecia, my hair’s future looked dim. I imagined three states of being: 1) loss of well-being, 2) coping (meds, support groups), and 3) forgetting about “it” My loss was moderate and some would say I looked “okay” without a hair addition: “A lot of women have thin hair...” “You look nice in a headband.” It’s how we feel about ourselves that matters though, and I knew finding a viable lasting way to disguise my loss would make it much easier for me to accept CICAL and its unknown progression. I want to stay in the “forget about it” state as much as possible.

### Finding a Solution

I educated myself through online research learning about the world of hair solutions so I could have a set of criteria when I evaluated systems. I wanted a hairpiece (rather than a full wig) that matched my natural hair as close as possible. Most of all, it had to be comfortable and compatible with my medical needs and hair loss pattern. Once I had my wish list, I researched hair specialists and then interviewed them on the phone. I chose two to visit for a free consultation. I went with the one I felt most comfortable with (based on her aesthetics, level of knowledge, understanding of my needs, and ability to communicate her process). I ended up going with a custom integrated hair system that is undetectable and easy to care for. At first, it felt weird to wear it. I felt like someone else, but after wearing it a few times (and several compliments later), I’m thrilled to have my life back after many years.

### Are you ready to explore solutions for yourself?

Acknowledging that a hair addition might be part of your life is a big step, so be patient, methodical, and most of all have compassion for yourself even if you ultimately decide not to pursue getting one. Here are the steps I found that worked best for me:

- **Get educated:** Do online research. Learn the pros and cons of types of hair (cyber-hair vs. real human hair) and attachments (comfort of clips vs. tape), bases (breathability and durability of various materials), Quality vs. cost, etc.
- **Identify your needs and expectations:** Hair loss pattern? Inflammation or other medical needs? Wear it every day or occasionally? Match your hair type or covered up? Style? Budget? Time frame?
- **Find a hair specialist:** Ask for referrals from dermatologists in your area or alopecia support groups. Do online research (keywords: medical hair prosthesis, custom medical hair and wig solutions).
- **Screen the specialists via phone:** Ask questions! Do they use off-the-shelf solutions or customize? How much experience do they have? What is their process? Work with someone who listens to your needs and who you feel confident in.
- **Meet with a few specialists for free consultation:** See their shop, photos of their work, and actual hair systems. Do you like their approach? Think long-term. Is this someone who understands your needs and can guide you? Are they patient, kind, and compassionate? Bring a close friend and get their feedback.
- **Once you choose someone:** Find examples of hairdos you like and share with specialist so they give you the look you’re after. Bring a friend, because friends tell the truth. The specialist should explain care of your hairpiece in detail.

### Resources

[Alopeciaworld.com](http://Alopeciaworld.com)

[Wigsupport.com](http://Wigsupport.com)

[Women’shairlossproject.com](http://Women’shairlossproject.com)

# MEETINGS, ADVOCACY & AWARENESS

## NEWS FROM THE CHAIRMAN OF THE BOARD

By Rita Wanser

Welcome to 2015! It's hard to believe it is almost half over already! On behalf of the Board of Directors of CARF, I offer wishes that your year go off to as good a start as CARF did and that you continue to enjoy.

During the weekend of January 11, 2015, the Board members gathered for a strategic planning meeting—a full day of introduction and deliberation on CARF plans for the next three to five years. The members flew (and one member drove!) from eight states to meet in St. Louis, Missouri, USA.

Before I go any further, I would be remiss if I didn't thank the Board members for giving up their weekend, and freely giving of their time, travel, and associated meeting attendance costs to gather together for this meeting.

Now for the meeting. As with the prior two CARF strategic planning meetings, held in 2006 and 2010, the Board met to review CARF's performance against the business plan and, overall, to understand if the plan had performed against our mission. In addition to understanding our progress, we also used this time to focus our priorities for the next three to five years, with the objective of ensuring CARF's continued success.

We began the meeting by looking back at accomplishments. It wasn't easy to capture all that has been accomplished over the past five years by such a small group of volunteers and small part-time staff that supports the efforts of CARF. However, after much team input, the list is long and should be celebrated:

- An organizational re-structure that:
  - o Established a new and efficient accounting structure suited for non-profit reporting. This has allowed us to gain a strong understanding of our finances, how and where we spend, and what our income needs are versus the income raised.
  - o Streamlined previous cumbersome processes and volunteer overburden.
  - o Finalized a new working subscriber database and new physician referral database.
  - o Gained website efficiencies, initiated by a dedicated volunteer.
  - o Gained access to discounted administrative assistance.
- Extensive research into our patient support groups that resulted in:
  - o Identifying new patient support groups leader.
  - o Increased patient support group activities.
  - o Establishing practices for startup.
  - o Establishing practices for providing assistance as needed.
  - o Understanding how groups might interact with each other.
- Activities to increase patient, physician, and general public awareness that have come about due to:
  - o Increased activities with other organizations (which has also led to best practices).
  - o Increased presence at professional meetings, including open-style satellite physician/advisor meetings.
  - o Increased digital presence with email blast capabilities, patient news, newsletter dissemination and Facebook presence/participation—efforts that also include volunteer contributors.
  - o Strengthened and new relationships with other hair loss-related organizations increasing physician outreach and interest.
  - o Patient conferences that continue to grow in attendance by patients and physicians alike, with amazing speakers and interesting activities and patient support ideas
- Formalized the engagement of the scientific community for research proposals by more widely publicizing the availability of seed grant research funding opportunities and increasing outreach by previous scientific advisors, all resulting in increased proposal submissions.
- Fundraising practices have been modified slightly with new approaches to outreach.



Rita Wanser



The CARF Board of Directors at the 2015 Strategic Planning Meeting (left to right): Wilma Bergfeld, MD, Mary Clay, MS, Andrew Alexis, MD, MPH, Victoria Ceh, MPA (Executive Director), Ken Washenik, MD, PhD, Maria Hordinsky, MD, Rita Wanser (Chairman), Sharon Potter, Donna Coulson, Kurt S. Stenn, MD, and Jim O'Connell

Kudos and many thanks to all the individuals who have contributed to these vast accomplishments. None of it can be accomplished without the volunteers and staff!

Accomplishments notwithstanding, the Board also took a long look at the challenges that affect CARF. Four major issues became apparent: 1) our fundraising efforts have resulted in less than robust results, 2) our "staff" size is part-time and small, 3) there is heavy dependence on volunteer efforts and time, and 4) we are facing new challenges in the external environment.

All of these issues affect us in a circular way, and if any one of them changes, the others can

*continued on page 11*

# MEETINGS, ADVOCACY & AWARENESS

News from the Chairman *continued from page 10*

be adversely affected. Inversely, with a change in one, the others could be positively affected. Inevitably though, during our discussions we came back to the same issue: that fundraising dollars need to change, as this has the biggest impact on how we develop our business plan moving forward.

The Board has assured that CARF spending stays true to its mission of patient advocacy and research funding and has taken aggressive measures to keep administrative costs as practical as possible. Achieving this has certainly been one of the biggest challenges, as there has been a significant change in our annual contributions with significantly less industry support. This shift is a result of the many new industry compliance constraints and budgetary disbursement policies. The acceptable donation policies of years ago no longer exist and with constant change within the pharmaceutical industry, many of our contacts are no longer in roles or with companies that have been CARF supporters. And, while we were certainly fortunate to have received donations from industry, and will always be grateful, CARF had an atypical ratio of industry to private donors, with about 35-65% coming from industry. Many other organizations receive 85-95% of their contributions from private (individual) donations, with only 5-15% from industry support. As you can imagine, this leaves a big gap for CARF. (See budget on page 12.)

We are grateful to the continued support of all of our private donors, whether small or large dollar amounts. We know our donors give what they can with generosity that comes from the heart.

Given the financial constraints, the Board is committed to increasing our donor population and seeking new avenues to fill the gap of the industry dollar support. I can share with you at this time that part of the plan is to continue to provide educational and support materials to new patients and physicians treating cicatricial alopecia, and doing an outreach initiative to make more dermatologists and hair loss professionals aware of CARF. Not only will this spread awareness about cicatricial alopecia and CARF, but it will hopefully increase our subscriber database and, potentially, this will result in additional donors. We will also seek physician help in creating CARF awareness with their cicatricial alopecia patients.

**CICATRICIAL ALOPECIA Education and Outreach Project**

**Short-term goals of this project:**

- Educate patients on this group of diseases
- Inform patients of the next CARF Patient-Doctor Conference
- Assist dermatologists with information on these diseases to provide to their patients
- Increase awareness of CARF and the support it provides to patients

**Long term goals:**

- Expand our database
- Initiate a patient registry

The right graphic also features a screenshot of the CARF website with a yellow arrow pointing to the 'Click here to join CARF' link.

The Board is excited that the Scientific Advisors are as engaged in the Board's efforts to build upon CARF's successes. They are adopting a work group structure that includes participation from other dermatologists with an interest in cicatricial alopecia who may not be on the Scientific Advisors. Work groups will focus on specific initiatives and projects. An example of a few work group projects are: 1) educating hair stylists about cicatricial alopecia, 2) enhancing the website with more photos of examples of the various cicatricial alopecias and basic search engine optimization (SEO) efforts, and 3) assembling a proposal to initiate a patient registry. As these get established, we will share more news.

Further, the Scientific Advisors are supporting the Board as we look to focus the research efforts given the limited grant dollars CARF can make available. To have the biggest impact, the Board and Scientific Advisors believe we should concentrate our support to one effort in future years. After vetting ideas with the Scientific Advisors, we will draw up a formal plan and share it with you. Additionally, in the past, we could give multiple small "seed" grants of \$4,000-\$6,000 to help investigators explore our conditions and potential treatments; however, seed grants are not as helpful to most investigators. With external changes in their university practices, seed grant funding is not sufficient for their work.

As we were concluding the strategic planning meeting, the Board members decided that due to our limited funds we needed to focus on and prioritize against the things we could deliver upon with the limited people and financial resources available to us, ensuring no overburden in any area within the organization. In doing so, we also realized that this approach would affect our mission. Therefore, we modified the mission as follows and created a vision:

**Mission:** To provide education and patient support, raise public awareness, and advance and promote research.

**Vision:** To improve the care of patients with inflammatory, scarring hair disorders.

Coming out of this meeting, we felt that we were leaving with a strong outline of ideas that could be implemented in a timely manner with measurable progress and accountability. Accordingly, we have adopted the annual budget and, as highlighted above, already worked on two awareness initiatives and one fundraising opportunity. You have our commitment to hard work and follow through, and we look forward to keeping you informed on the progress.

Wishing you all the best for the rest of the year.

Warmest regards, Rita

*continued on page 12*



## MEETINGS, ADVOCACY & AWARENESS

### 2015 BUDGET (non-conference year)

#### Income (anticipated)

\$45K – Individual Donor Contributions

\$10K – Corporate Contributions

---

\$55K Total

#### Expenses

##### Operating/Administrative Expenses

\$50K – Administrative Management

\$ 2K – Board of Directors and Scientific Advisor Meetings (conference calls, room rental, refreshments)

\$ 2K – Insurance

##### Patient/Physician Awareness

\$20K – Outreach & Awareness campaign

\$ 2K – Staff Travel (SA Meetings, CSD, NORD)

\$10K – Research Grants

\$ 6K – Website

#### Fundraising

\$ 3K – Fundraising annual mailer

---

\$95K Total

#### Anticipated Loss\*

\$(40K)

*\*Net Income or Loss at year-end is added to the Net Assets, which are \$108,000 as of 12/31/14.*

## Celebrate Rare Disease Day—The Rarest Day of the Year

The Cicatricial Alopecia Research Foundation will again be joining the National Organization for Rare Disorders (NORD) and others around the world in observing World Rare Disease Day on February 29, 2016. On this day, millions of patients and their families will share their stories to focus a spotlight on rare diseases as an important global public health concern.

Many of the cicatricial alopecias are rare disorders, which are defined by the U.S. FDA as those with <200,000 patients.

Watch your email for further information on this important celebration. For those who live in the U.S., please visit: <http://rarediseaseday.us/>. For those who live outside the U.S., please visit <http://www.rarediseaseday.org/> to find local events in your area.

This will be a wonderful opportunity for people with rare diseases from around the world to promote awareness of the challenges of living with a rare disease, on the rarest day of the year. We hope you will join us in this awareness campaign!



Rare Disease Day®

## MEETINGS, ADVOCACY & AWARENESS

### 2015 American Academy of Dermatology (AAD) Annual Meeting March 20-24, 2015 • San Francisco, California, USA

By Victoria Ceh, MPA



### CARF Meeting

An open meeting of CARF Scientific Advisors, CARF Board members, and other dermatologists with an interest in cicatricial alopecia was held on March 20, 2015, with 21 participants. Introductions were provided and updates were given. Ms. Rita Wanser announced that Dr. Kurt Stenn would be stepping down as Interim Chair of the Scientific Advisors at the May 2015 meeting, and Dr. John Sundberg would begin his term as Chair. Dr. Lloyd King would also assist Dr. John Sundberg as required. Dr. Stenn was thanked for his leadership over the past two years in this role.

Ms. Victoria Ceh explained about the patient outreach project with the initial goal to contact 800 dermatologists with information about CARF, patient pamphlets, and “save the date” cards for the 2016 CARF Patient-Doctor Conference—with a call to action to “Join CARF.”

Dr. Nicole Rogers, Program Chair, reported on the next CARF Patient-Doctor Conference to be held in New Orleans in June 2016. The group discussed the possible next Cicatricial Alopecia Research Symposium.

Discussion occurred about various research projects being led by investigators and ideas for new projects. The idea for a patient registry came up again and it was noted that this is very much needed. Challenges around a patient registry were noted. CARF research grants were discussed. Ideas were proposed such as putting all grant monies towards one concerted effort instead of smaller seed grants.

Ms. Wanser provided updates including a review of the ideas from the last open meeting, such as educating and working with hair dressers and contributing to an app for physicians to use when diagnosing patients. She reviewed the Strategic Planning Meeting of the BOD earlier this year in January. She noted the key initiatives identified continued to be patient advocacy, education and support, and encouraging research. Ms. Wanser reviewed organizational updates such as instituting work groups under the Scientific Advisors to execute initiatives such as the hair dressers project, website improvements (more patient photos of early phase and late phases of the various cicatricial alopecias, search engine optimization on CICAL keywords), fundraising/development, and creating a physician reference guide.

Discussion occurred around the quality of life (QoL) issues with hair loss—chronicity, no cure, lack of control. Dr. Kim Salkey noted there is QoL data published on CCCA.

In summary, the meeting was a productive review and think tank of dermatologists interested in cicatricial alopecia treatment and research.



Participants of CARF Open Meeting (*back row, left to right*): Ken Washenik, Apostolos Pappas, Lloyd King, Paradi Mirmirani, Melissa Piliang, Rita Wanser, Kim Salkey, Yolanda Lenzy, Nicole Rogers, Victoria Ceh. (*front row, left to right*): Vera Price, Lynne Goldberg, Carolyn Goh, Jerry Shapiro, Nisha Desai, Janet Roberts. Not pictured: Wilma Bergfeld, Amy McMichael, Tracy Novosel, Jim O’Connell, William Parsley.

*continued on page 14*

# MEETINGS, ADVOCACY & AWARENESS

## NAHRS Meeting



Drs. Julian Mackay-Wiggan and Jerry Shapiro, keynote speakers at the NAHRS Scientific Session at the American Academy of Dermatology 2015 Annual Meeting in San Francisco.



Ms. Rita Wanser describing CARF's Cicatricial Alopecia Education and Outreach Project.

The North American Hair Research Society (NAHRS) held its annual scientific meeting and luncheon at the AAD on March 20, 2015. Ms. Rita Wanser presented updates from CARE, including the Cicatricial Alopecia Education and Outreach Project, an effort to reach out to 800 dermatologists this year who see hair loss patients to provide materials on cicatricial alopecia, CARE, and CARF's Patient-Doctor Conference. Updates from the National Alopecia Areata Foundation were provided by Ms. Dory Kranz, and updates on the upcoming 9th World Congress for Hair Research (Nov. 18-21, 2015) were provided by Dr. Maria Hordinsky. In addition, NAHRS presented 11 mentorship awards to young investigators.

One of the two keynote lectures, "What is New in the Pipeline for Androgenetic Hair Loss: Stem Cell Therapy," was given by Dr. Jerry Shapiro. The other keynote lecture, "Update on Clinical Trials Exploring the Efficacy of Rationally Selected Therapies," was given by Dr. Julian Mackay-Wiggan.

**Reflect, Rejuvenate, and REGENERATE**

**November 18-21, 2015**

## 9th World Congress for Hair Research

Miami • Florida • USA

A Comprehensive, International Hair Research Meeting for the Advancement of Knowledge In Hair Growth, Hair and Scalp Disease, and Clinical Care

Plan to Attend

FOR INFORMATION AND REGISTRATION GO TO:

[www.hair2015.org](http://www.hair2015.org)

For all inquiries, please contact  
NAHRS Administrator, Victoria Ceh, MPA  
info@nahrs.org

Hosted by

*Join us in MIAMI*

**INVITATION**

*Wilma F. Bergfeld, MD*  
Wilma F. Bergfeld, MD  
CONGRESS CO-CHAIR  
Cleveland Clinic Foundation

*Angela Christiano, PhD*  
Angela Christiano, PhD  
CONGRESS CO-CHAIR  
Columbia University

*Maria K. Hordinsky, MD*  
Maria K. Hordinsky, MD  
CONGRESS ASSOCIATE CHAIR  
University of Minnesota

*Victoria H. Barbosa, MD, MPH, MBA*  
Victoria H. Barbosa, MD, MPH, MBA  
Rush University

*Valerie D. Callender, MD*  
Valerie D. Callender, MD  
Howard University

*Luis Garza, MD, PhD*  
Luis Garza, MD, PhD  
Johns Hopkins University

*Antonella Tosti, MD*  
Antonella Tosti, MD  
University of Miami

*Ken Washenik, MD, PhD*  
Ken Washenik, MD, PhD  
New York University/ Bosley

The North American Hair Research Society (NAHRS), with participation from the Australasian Hair & Wool Research Society, the European Society for Hair Research, the Hair Research Society of India, the Japanese Society for Hair Research, and the Korean Hair Research Society, will host the **9th World Congress for Hair Research**, which will bring together hair biologists, dermatologists, cosmetic scientists and hair transplantation surgeons for this three and a half day comprehensive hair research meeting. International colleagues will present new research, share experiences, and discuss new directions for the advancement of knowledge in hair growth, hair and scalp disease, and clinical care.

The Congress will include general sessions, scientific posters, pre-Congress workshops, networking opportunities, a full exhibits program, company sponsored satellite symposia, and more. **We invite you to attend!**

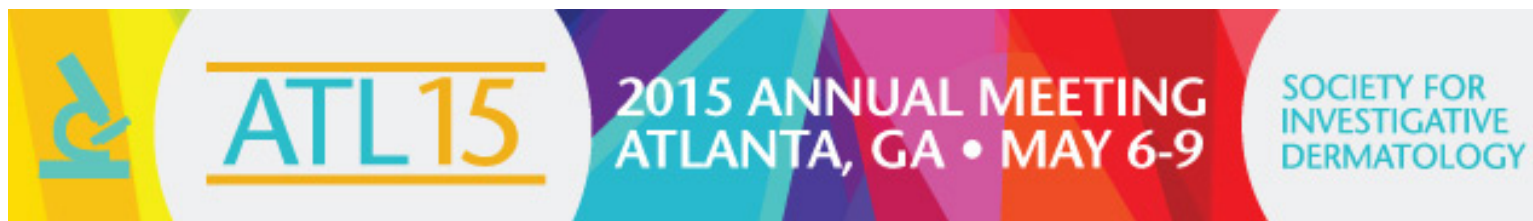
Sincerely yours,  
Congress Scientific Planning Committee



# MEETINGS, ADVOCACY & AWARENESS

## 2015 Society for Investigative Dermatology Annual Meeting May 6-9, 2015 – Atlanta, Georgia, USA

By Victoria Ceh, MPA



### CARF Scientific Advisors Meeting

The CARF Scientific Advisors met on May 9, 2015, and had a lively discussion about current research, research visioning, and how to bring together efforts. Three action items came out of the meeting including: 1) to set-up a meeting to determine global response score (Dr. Olsen to lead), 2) to outline steps and needs for patient registry (Dr. Hordinsky to lead), and 3) to set up a mini research meeting next year in conjunction with the SID with specifically selected presentations and directed discussion following to determine research direction in cicatricial alopecia (Dr. Sundberg to lead). It was suggested each presentation should answer the following: “What are the most important open questions?”



Participants of CARF Scientific Advisors Meeting (left to right): Apostolos Pappas, Wilma Bergfeld, John Sundberg, Ralf Paus, Lloyd King, Kurt Stenn. Not pictured: Maria Hordinsky, Elise Olsen, Victoria Ceh.

### NAHRS Scientific Annual Meeting

The North American Hair Research Society (NAHRS) held its annual scientific meeting at the SID on May 8, 2015, chaired by program committee chair Dr. John Seykora. Over 100 dermatologists and researchers attended the meeting, which included a poster session reception followed by 2 keynote presentations and 5 oral abstract presentations. A variety of hair research was presented including topics on cicatricial alopecia, alopecia areata, androgenetic alopecia, chemotherapy-induced alopecia, and hair biology.

There were two keynote lectures: “Wnt/Beta-catenin Signaling Regulates Proliferation but Not Survival of Hair Follicle Progenitor cells,” presented by Sarah E. Millar, PhD, Professor, Departments of Dermatology and Cell & Developmental Biology, Director of Research, Department of Dermatology, University of Pennsylvania, and “Genetics and Immunology of Alopecia Areata,” presented by Angela M. Christiano, PhD, Professor of Dermatology and Genetics & Development, Columbia University.

In addition, CARF presented research poster awards which are described later in the newsletter.



Dr. Ralf Paus

# MEETINGS, ADVOCACY & AWARENESS

## 23rd World Congress of Dermatology June 8-13, 2015 • Vancouver, BC, Canada

By Victoria Ceh, MPA



### NAHRS Hair Research Symposium

A hair research symposium took place on Monday, June 8, 2015, at the 23rd World Congress of Dermatology in Vancouver and hosted by the North American Hair Research Society. There were three keynote presentations: “Stem Cells, Skin Appendages and Evolution: A Multi-disciplinary Journey,” by Cheng-Ming Chuong, MD, PhD, Professor of Pathology, Chair, Graduate Committee, Univ. Southern California, “Dynamic Intrinsic and Extrinsic Mechanisms of Hair Follicle Regeneration,” by Peggy Myung, MD, PhD, Instructor, Department of Dermatology, Yale University, and “Genetics and Immunology of Alopecia Areata,” by Ali Jabbari, MD, PhD, Assistant Professor of Dermatology at CUMC, Department of Dermatology, Columbia University, NYC.



Panel discussion on Hot Topics in Alopecia.



Dr. Cheng-Ming Chuong

Following the presentations, there was a lively panel entitled “Hot Topics in Alopecia” moderated by Dr. John Seykora that included panelists, Wilma Bergfeld, Cheng-Ming Chuong, Peggy Myung, and Ali Jabbari. The audience also provided comments that led to interesting discussions. Questions posed to the panelists included:

- What do you think is the most promising approach to potentially treat androgenetic alopecia?
- What do you think is the etiological cause of frontal fibrosing alopecia?
- What do you think will be the breakthrough treatment for alopecia?

With regard to the question of interest for the CARF audience, “What do you think is the etiological cause of frontal fibrosing alopecia (FFA)?”, many dermatologists report seeing an increase in these cases, yet we do not know what is causing FFA. Some dermatologists noted geographic pattern of incidence may be helpful for identifying the causes of FFA. Dr. Seykora noted that nanoparticles may promote FFA. Drs. Seykora, Bergfeld, and Thompson suggested that cosmetics or hair care products could also play a role in FFA. One thing all agreed upon is that further research and understanding of this condition is necessary. Currently, there is a major epidemiologic questionnaire study taking place in the United States. Data will be analyzed as soon as the first 500 participants are enrolled. The results of this will focus further research and better define the direction whether it be towards exploring cosmetics, sunscreens, nanoparticles, or other yet to be defined culprits. Dr. Elise Olsen is leading this study.

# MEETINGS, ADVOCACY & AWARENESS

## CARF Research Poster Awards



Dr. Kurt Stenn describing the CARF Research Poster Awards.



Dr. Ralf Paus (for Dr. Hisayoshi Imanishi) (left) and Dr. Liye Suo (right) accept CARF Research Poster Awards from Dr. Kurt Stenn (center).

Dr. Kurt Stenn, on behalf of the CARF Scientific Advisors and Board of Directors, presented Drs. Hisayoshi Imanishi and Liye Suo with certificates of recognition for their research at the recent Society for Investigative Dermatology Meeting that took place May 6-9, 2015, in Atlanta, Georgia, USA.

Dr. Hisayoshi Imanishi presented research titled, “Human Hair Follicle Epithelial Stem Cells Undergo Epithelial-Mesenchymal Transition (EMT) in Primary Cicatricial Alopecia: Lessons from Lichen Planopilaris.”

Dr. Liye Suo presented research titled, “Alterations of Vitamin A Metabolism and Signaling in Central, Centrifugal, Cicatricial Alopecia Patients.”

Dr. Imanishi was unable to attend the meeting and his certificate was accepted on his behalf by Dr. Ralf Paus.

### ABSTRACT

**Human Hair Follicle Epithelial Stem Cells Undergo Epithelial-Mesenchymal Transition (EMT) in Primary Cicatricial Alopecia: Lessons from Lichen Planopilaris**

#### AUTHORS (FIRST NAME, LAST NAME)

Hisayoshi Imanishi<sup>1</sup>, David Ansell<sup>1</sup>, Matthew Harries<sup>1</sup>, Norbert Sepp<sup>2</sup>, Tamas Biro<sup>4</sup>, Daisuke Tsuruta<sup>3</sup>, Christopher M. Ward<sup>1</sup>, Ralf Paus<sup>1</sup>

#### INSTITUTIONS (ALL)

1. Univ of Manchester, Manchester, United Kingdom
2. Innsbruck Med Univ, Innsbruck, Austria
3. Osaka City Univ, Osaka, Japan
4. Univ of Debrecen, Debrecen, Hungary

#### ABSTRACT BODY

Primary cicatricial alopecias (PCA) like lichen planopilaris (LPP) result in permanent hair loss due to irreversible damage to hair follicle (HF) epithelial stem cells in the bulge. However, stem cell loss does not explain why PCAs typically show scarring. We hypothesized that this may result from epithelial-mesenchymal transition (EMT) of HF epithelial stem cells. During EMT epithelial cells gradually lose their epithelial characteristics and acquire a mesenchymal phenotype. By quantitative immunohistomorphometry, the bulge region of lesional LPP HFs showed a significant increase in the EMT marker proteins, vimentin, and fibronectin, and the EMT-regulative transcription factors, SNAIL, SLUG and TWIST1, compared to healthy HFs. On the other hand, the epithelial marker, E-cadherin, was decreased in the LPP bulge epithelium. Using qRT-PCR, analysis of bulge gene expression (RNA extracts obtained by laser capture microdissection) showed that fibronectin and alpha smooth muscle actin transcription were significantly up-regulated, while E-cadherin expression was down-regulated in the bulge of lesional LPP HFs. In healthy organ-cultured human scalp HFs, a cocktail of agents known to promote EMT (interferon- $\gamma$ , TGF $\beta$ 1, EGF, peptide A) substantially reduced bulge E-cadherin protein expression, while increasing that of vimentin and SLUG (IHC/IF) after 3-6 days. Moreover, the PPAR- $\gamma$  agonist, pioglitazone, was capable to prevent experimentally induced EMT development in organ-cultured humans HFs. Taken together, these observations suggest that human HF epithelial stem cells undergo EMT in situ during LPP, that EMT can be stimulated even in the bulge of healthy human HFs, and that PPAR- $\gamma$  agonists counteract bulge EMT. Thus, EMT may explain at least in part the extensive scarring associated with PCAs, and PCA management strategies are needed that inhibit EMT.

*continued on page 18*



# MEETINGS, ADVOCACY & AWARENESS

## ABSTRACT

### Alterations of Vitamin A Metabolism and Signaling in Central, Centrifugal, Cicatricial Alopecia Patients

AUTHORS (FIRST NAME, LAST NAME)

Liye Suo<sup>2</sup>, Wilma F. Bergfeld<sup>1</sup>, Natasha Mesinkovska<sup>1</sup>, Helen B. Everts<sup>2</sup>

INSTITUTIONS (ALL)

1. Dermatology, Cleveland Clinic, Cleveland, OH, United States
2. Nutrition, Ohio State University, Columbus, OH, United States

## ABSTRACT BODY

Central, centrifugal, cicatricial alopecia, or CCCA, is the most common scarring hair loss (alopecia) among African American women. Although the pathogenesis of CCCA is unknown, vitamin A plays an important role in the development of CCCA. Previously, in mice we found that many key components in vitamin A metabolism and signaling were altered in CCCA including: DHRS9 (dehydrogenase reductase member 9); ALDH1A1 (retinal dehydrogenase 1); CYP26A1 (cytochrome P450 26A1); and RARB (retinoic acid receptor beta). Their expression increased in mild disease and decreased in severe disease. The purpose of this study was to examine the possible alteration of those proteins among CCCA patients. Reviewed were African American women diagnosed with CCCA at Cleveland Clinic in the past eight years. These patients were initially clinically evaluated with a standardized central scalp alopecia photographic grading scale that graded the disease severity. The diagnosis of CCCA and severity was confirmed histologically. The control subjects were African American women diagnosed with pilar cyst. Totally, we had 11 mild disease, 11 moderate disease, 5 severe disease, and 12 controls. Immunohistochemistry (IHC) on all the scalp biopsy samples using antibodies against DHRS9, ALDH1A1, CYP26A1, and RARB were examined. The results were a decrease of all four proteins ( $p < 0.01$ ) in the basal layer of the severe group as compared to controls. Also found was a decrease of RARB expression ( $p < 0.01$ ) in sweat glands and dermis in the severe group as compared to the mild group. These findings suggest that the expression of important vitamin A metabolism and signaling components in the skin decreases as severity increased. These findings expand the knowledge of pathogenesis of CCCA and emphasize the importance of vitamin A metabolism and signaling in the health of skin and hair.

# CLINICAL TRIALS & RESEARCH STUDIES— RECRUITING PATIENTS

## U.S. Frontal Fibrosing Alopecia (FFA) Study

Frontal fibrosing alopecia (FFA) is a type of scarring or permanent hair loss that was first described in 1994. It typically occurs in post-menopausal women of European descent but has been reported in men, premenopausal women, and other races and ethnicities. It typically involves recession of the frontal hairline, redness of the involved scalp, and eyebrow loss. There is no known cause and no established treatment.

A multicenter, data collection research study is now going on at 9 different sites across the U.S. If you, or your dermatologist, feel that you may have this condition, please either contact one of the sites directly or ask your dermatologist to contact the site on your behalf. The study doctors first request that you be seen in their clinics for a routine visit for hair loss, and then if your diagnosis is confirmed to be FFA, you would be consented to participate in the study. The study would allow the study doctors to collect further information on your hair loss condition and for you to fill out an online questionnaire that may help to lead to information about what is causing this disorder. There is no treatment or compensation related to the study.

If you are interested in participating in this study, please contact or have your dermatologist contact one of the following sites closest to your home. The sites will set up an appointment for you to see the study doctor:

Duke University (central site)  
Durham, North Carolina  
Investigator: Elise A. Olsen, MD  
Contact: [joan.wilson@dm.duke.edu](mailto:joan.wilson@dm.duke.edu)

The (Kaiser) Permanente Group  
Orinda, California  
Investigator: Paradi Mirmirani, MD  
Contact: 707-651-2552

University of Minnesota  
Minneapolis, Minnesota  
Investigator: Maria Hordinsky, MD  
Contact: 612-624-5721

Callender Center for Clinical Research  
Glenn Dale, Maryland  
Investigator: Valerie Callender, MD  
Contact: [FTitanwa@CallenderSkin.com](mailto:FTitanwa@CallenderSkin.com) or 301-352-1520

Northwest Dermatology and Research Center  
Portland, Oregon  
Investigator: Janet Roberts, MD  
Contact: 503-223-1933

University of Pennsylvania  
Philadelphia, Pennsylvania  
Investigator: George Cotsarelis, MD  
Contact: 215-662-2737

Cleveland Clinic  
Cleveland, Ohio  
Investigator: Wilma Bergfeld, MD  
Contact: 216-444-5722 or 216-445-9110

University of Miami  
Miami, Florida  
Investigator: Antonella Tosti, MD  
Contact: [CKittles@med.miami.edu](mailto:CKittles@med.miami.edu)

Wake Forest University  
Winston-Salem, North Carolina  
Investigator: Amy McMichael, MD  
Contact: [amcmicha@wake.health.edu](mailto:amcmicha@wake.health.edu)

## U.K. Frontal Fibrosing Alopecia (FFA) Research Study

Dr. Christos Tziotzios, an academic specialist registrar in Dermatology, is working with John McGrath, Professor of Molecular Dermatology, Michael Simpson, Professor of Genomic Medicine, and Dr. David Fenton, Consultant Dermatologist and Expert in Hair Disorders, at St. John's Institute of Dermatology in London on genetic aspects of frontal fibrosing alopecia (FFA).

The team of researchers is collecting DNA samples from individuals affected by FFA and would be delighted to see you in their Research Clinic, which takes place at Guy's Hospital in London. A number of clinicians in other UK cities and towns are registered collaborators and it may be possible for you to be seen locally. The research appointment involves taking a blood sample for extracting your genetic material (DNA) and a focused clinical history, and it lasts 20-30 minutes on average. The research study is supported by a Fellowship award to Dr. Tziotzios by the National Institute for Health Research (NIHR), has been ethically approved, and adheres to Good Clinical Practice guidelines. The aim is to understand the genetic basis of this distressing condition with the hope to better direct future treatments. To participate in the research or for any questions or clarification please email [christos.tziotzios@kcl.ac.uk](mailto:christos.tziotzios@kcl.ac.uk).

## Gabapentin Study

Do you have pain, burning, or itching associated with scarring alopecia?

The Department of Dermatology at the University of Minnesota, Twin Cities (USA) is currently recruiting participants for a clinical trial to assess the efficacy of a topical Gabapentin 6% solution at treating the discomfort associated with scarring alopecia. Study entails applying a topical solution to the affected scalp twice daily over the course of 12 weeks. Biopsies and blood work will be used to assess effectiveness along with questionnaires and photographs. You will be compensated \$25 for each skin biopsy that is taken, and the study drug will be provided to you free of charge.

If you are over the age of 18 and interested in participating, please contact the Dermatology Department at [derm@umn.edu](mailto:derm@umn.edu) or 1-612-624-5721 for further information.

# THANK YOU TO OUR 2014 DONORS

CARF would like to give a heartfelt THANK YOU to each of the individuals and corporations below who have supported the mission of CARF through their generous financial support.

## DIAMOND BENEFACTORS \$10,000 +

Anonymous Husband  
International Society of Hair Restoration Surgery

## SILVER BENEFACTORS \$2,500 to \$4,999

Janet and Tom Hough  
Johnson & Johnson  
Proctor & Gamble Company

## BENEFACTOR \$1,000 TO \$2,499

Anonymous  
Bosley  
Mary Clay  
Millennium Park Dermatology  
Susan Miner  
Sharon S. Potter  
Nicole E. Rogers, MD  
Nancy Scott

## SPONSORS \$500 to \$999

Jovita Brantley  
Catherine B. Combs  
Beatrice Daniel  
Kenneth Dorsey  
Marilyn Ey  
Joseph Lazara  
Achiamah Osei-Tutu, MD  
Ellen Pedersen/AT&T United Way  
Betsy Sullivan  
Shubha Tuljapurkar  
Suzanne & Ed Vasgerdsian  
Rita Wanser

## GRAND PATRONS \$101 to \$499

Kenneth Alpern  
Teresa Anderson  
Anonymous  
Patricia Baldwin  
Victoria Holloway Barbosa MD, MPH  
Karen Bliss  
Diane Butler  
Lenune Chrispin  
Holly Conrad  
Donna Coulson  
Josephine & Paul Currie  
Alice Gianni Charitable Fund  
Joseph Hahner  
Michelle Hajek  
Barbara Hall  
Iltefat Hamzavi, MD  
Diane Johnson  
Doreen Karoll  
Melody Kriteaman  
Lorraine Lester  
Susan Mikowski  
Dennis Morgan  
Beverly Nicbols  
Jayne Nordstrom  
Jim O'Connell

Stavonnie Patterson  
Christopher Polizzi  
Carlos Puig, MD  
Caroline J. Saucer  
Gloria Scherman  
Jerry Shapiro, MD  
Elaine Sheidlower  
Diana Toomajian  
Linda Turner  
Jaslynn Vesuvio  
Elizabeth Wannemacher

## PATRONS up to \$100

Beatrice Abrams  
Laurel Anderson  
Anonymous  
Linda Assalino  
Deborah Barnes  
Lorna Bell-Knight  
Esther Bendik  
Faith Brown  
Sherry Carroll  
Martha Carter  
Joan Chasen  
Dianne Cormier  
Christine Costley  
Deborah Covell  
Amy Curran  
Jackie & Ronald Davies  
Dianna Day  
Rosa Del Valle-Cabrera  
Anne Devereaux  
Lynne Dotson  
Shirley Dresch  
Laurie Ellison  
Carmel Engel  
Alison Erickson  
Rhonda Everett  
Ronald & Dorothy Falcione  
Eimear Fitzpatrick  
William Fleharty  
Susan French  
Wendy Gare  
Peter Goldman, MD  
Faye Guarienti  
Marybeth Guiney  
Mary Halitzer  
Caroline Halverstam  
Mary Hansen  
Mary Hanson  
LaVonne Hendricks  
Catherine Hirsch  
Melissa Hogle  
Maria Hordinsky, MD  
Susan Huffman  
Marrissa Hutton  
Irene Johan  
Megan Jones  
Jennifer June  
Shelby Keiser

Nima Khiabani  
Diane Kimmel  
Joyce Krall  
Elayne Kuehler  
Susan Leihy  
Frederick Lewis  
Judith Lewis  
Suzanne Little  
Carl Lovio  
Brenda Mack  
Fernando & Adreane Maestrini  
Patrick Malie  
George Mantikas  
Laura Marconi  
Lillian Martinian  
Linda Matsumoto  
Linda McDonough  
Tanya McKay  
Debra McVey  
Elaine Meadows  
Mette Menotti

Marylyn Morin  
Joanne Nicholson  
Vicki O'Meara  
Jane Papacostas  
Rodrigo Pirmez, MD  
Monique Pouliot  
Barbara Raimondi  
Eileen Recher  
Lillian Resnik  
Patricia Rheaume  
Valerie Ritter  
Anna Roca  
Tamra Roloff  
Ayn Romaine  
Elizabeth Ruhland  
Maureen & John Saar  
Kenneth Sanchez  
Huntley Sanders  
Elise Schmidt  
David Schwartz  
Francell Shade

Nadine Smedshammer  
Carol M. Smith  
Erika Spieldoch  
Donelle Staley  
Amy Stark  
Sharon Stein  
Debra Steinhagen  
Joylene Sutherland  
Josephine Taylor  
Marianne Tinagero  
Susan Tosk  
Ellen Vandenburg  
Helle Voldbaek  
Judith Walsh  
Geraldine Ward  
Nancy West  
Nancy White  
Yvelin Yang  
Raye Ziring  
Jody Zolli  
Pamela Zupo

## Proceeds from textbook donated to CARF



Samuel M. Lam, MD



Ken L. Williams, Jr., DO

### In Support of the Cicatricial Alopecia Research Foundation

*This textbook is dedicated to our patients who have experienced hair loss because as hair-restoration surgeons we understand all too well the emotional and painful embarrassment of hair loss that our patients undergo. When we began this journey to share the collective experiences of international experts in FUE, we never believed financial remuneration should be personally received but instead should be shared with the hair-loss community. As the two editors, we are so pleased to dedicate all proceeds from this textbook to the Cicatricial Alopecia Research Foundation (CARF).*

CARF acknowledges the kind dedication of future proceeds of  
*Hair Transplant 360: FUE* textbook  
edited by Drs. Samuel M. Lam and Kenneth L. Williams, Jr.



## Help Fund CARF

Amazon will donate 0.5% of the price of your eligible AmazonSmile purchases to CARF when you shop using the following link: <http://smile.amazon.com/ch/20-2049037>

Thank you to those who are already participating in this program, CARF has begun receiving donations through this program!



Member of Coalition of Skin Disorders  
(<http://www.coalitionofskindiseases.org/>)



Member of National Organization of Rare Diseases  
(<http://www.rarediseases.org/>)



## CARF Support Groups

See [www.carfintl.org](http://www.carfintl.org) for meeting dates in your area. Note: In some locations, we are looking for patient co-leaders and physician advisors.

### USA Support Groups

#### CALIFORNIA

Los Angeles: For more information, contact [losangelessupportgroup@carfintl.org](mailto:losangelessupportgroup@carfintl.org)

San Francisco: For more information, contact Marilyn at [sanfranciscosupportgroup@carfintl.org](mailto:sanfranciscosupportgroup@carfintl.org)

#### ILLINOIS

Chicago: For more information, contact Joe and Bev at [chicagosupportgroup@carfintl.org](mailto:chicagosupportgroup@carfintl.org)

#### LOUISIANA

New Orleans/Baton Rouge: For more information, contact Debbie and Elayne at [neworleanssupportgroup@carfintl.org](mailto:neworleanssupportgroup@carfintl.org)

#### MARYLAND, WASHINGTON DC, VIRGINIA

For more information, contact Beth at [md-dc-va-supportgroup@carfintl.org](mailto:md-dc-va-supportgroup@carfintl.org)

#### MASSACHUSETTS

Boston: For more information, contact Melody, Doreen, and Joyce at [bos-tionsupportgroup@carfintl.org](mailto:bos-tionsupportgroup@carfintl.org)

#### MICHIGAN

Detroit: Contact Virdell at [detroitssupportgroup@carfintl.org](mailto:detroitssupportgroup@carfintl.org)

#### NEW YORK

New York City Area: For more information, contact Ilene at [newyorksupportgroup@carfintl.org](mailto:newyorksupportgroup@carfintl.org)

#### NORTH CAROLINA

Winton/Salem: For more information, contact Travis at [winston-salem-sg@carfintl.org](mailto:winston-salem-sg@carfintl.org)

#### PENNSYLVANIA

Pittsburgh: For more information, contact Lori at [Pittsburghsupportgroup@carfintl.org](mailto:Pittsburghsupportgroup@carfintl.org)

### International Support Groups

#### CANADA

Toronto, Ontario: For more information, contact Shirley at [torontosupportgroup@carfintl.org](mailto:torontosupportgroup@carfintl.org)

#### UK

London: For more information, contact Marva at [londonsupportgroup@carfintl.org](mailto:londonsupportgroup@carfintl.org)

Check online for up-to-date schedule of Support Group meeting dates and locations!

<http://www.carfintl.org/support-groups.php>