

November 2014  
Issue XVII

# CARF Communiqué

## Review of the CARF 6th International

### Patient-Doctor Conference—Chicago, April 2014: Part 2

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

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**Surgical Treatment of Cicatricial Alopecia**

Dr. Carlos Puig, president of the International Society of Hair Restoration Surgery (ISHRS), spoke about strategies for surgical correction of scarring alopecias. He pointed out that the primary function of hair is for thermoregulation, which is the retention of heat or the cooling of the scalp by protecting from the sun; however, it has evolved into much more of a beauty accessory. He discussed how in persons of darker skin (Afrocentric origin) there is lower density of hair follicles (number of follicular units per square centimeter). This may occur because persons with darker skin do not need the same density of hair follicles to cover and protect from UV radiation.

From a historical perspective, Dr. Puig discussed how cosmetic procedures in general were not possible until the invention of anesthesia. He described how during the Spanish American War and in World War I surgeons began doing the first advanced rotation flaps. They were also using advanced techniques to treat leprosy scars.

That being said, the transplantation of scar tissue can be more challenging than transplanting into virgin skin. This is because normal scalp has excellent vascularity and the scalp is very thick. In scarred tissue, the skin may be more stretched or thin, less elastic, and with little or no flexibility and a compromised blood supply. It is imperative that the inflammation be under control, through medical therapy first.

Audience members asked about the cost of hair transplant surgery, and Dr. Puig noted it ranges from approximately \$8,000-\$12,000 USD per session. (*Editor’s note:* Many doctors recommend doing a small “test” transplant first that would spare the patient the expense of a larger procedure if the grafts fail to grow.) The cost of hair transplantation also varies widely in different parts of the country and among various countries. Another audience member asked: “When can the condition be transplanted?” Dr. Puig explained how it is best to wait until the disease is fully stabilized, usually over a 12-24 month period, by when there should be no evidence of redness or scaling. He also mentioned the problem of sampling error. As doctors, we may biopsy one scalp area and find no inflammation, but there may be inflammation lurking in other areas of the scalp that could adversely affect the growth later.



Dr. Carlos Puig presents strategies for surgical correction of scarring alopecias.

**Expert Panel Q&A**

*Expert Panel:* Lynne J. Goldberg, MD, Moderator; Victoria H. Barbosa, MD, MPH, MBA; Maria Colavincenzo, MD; Lady Dy, MD; Ingrid Roseborough, MD; Jerry Shapiro, MD

*The following was transcribed by Victoria Ceb and then reviewed and edited for clarity by the Expert Panel. Questions were grouped together in themes in order to answer the numerous questions submitted to the panel.*

**I. SIGNS & SYMPTOMS**

**Burn Out: What is it? Is it permanent?**

MC: We don’t understand nerve involvement (sensation). If things are calm, we also think it may be burned out.

VB: We usually mean two things by burn out: 1) Clinical Burnout—no signs or symptoms, no further shedding, things seem calm; versus 2) Pathological Burnout—no active inflammation.



Skin Advocate

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

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## 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

CARF has migrated to a new and improved 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 CARE,” and then logging into the “Subscriber Area.”

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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

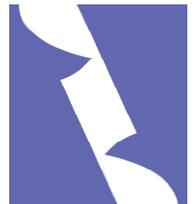
Tel: 1-310-801-3450 • Fax: 1-630-262-1520

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

### Mission Statement

The mission of the Cicatricial Alopecia Research Foundation (CARF) is:

- to provide funds for research to find effective treatments and a cure
- to support education and advocacy
- to raise public awareness



C . A . R . F .

*On fire for research and a cure!*

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**Conference Review: Part 2** *continued from page 1***Do you biopsy to determine burn out?**

JS: I don't biopsy, but I do trichoscopy.

VB: No.

LD: Yes. I am a dermatopathologist.

LG: No, unless the patient is inquiring about a hair transplant, and then I will consider biopsy.

**Sweating: Going to the gym (and sweating) as a trigger.**

JS: I don't think we know the triggers. But sometimes surgery (such as a face lift) triggers FFA.

VB: Stress is a trigger; there can be an increase in shedding.

**The role of diet: Are there any triggers or help?**

LD: We don't know what triggers cicatricial alopecia. I'm not a proponent of dictating diet.

VB: Tomorrow's talks focus on diet. A lot of patients ask about this.

**Supplements: What works?**

LG: I'm not a believer in it. There is not a lot of data on it. There is some research about iron. Although a lot of patients take biotin, most of us have enough biotin in our bodies. We don't need more.

JS: No evidence that supplements work in cicatricial alopecia (CICAL) patients, in my practice.

MC: I have a lot of patients that do strict diets. Sometimes one supplement can be in toxic amounts and patient may be unaware, so they must be careful.

VB: I check levels for biotin, Vitamin D, ferritin, and iron.

**Eyebrow loss: If I don't have it now, will I get it later?**

LD: LPP and FAA can have eyebrow loss and body hair loss.

MC: Loss of arm hair may be an early predictor. Usually eyebrow loss happens early in the disease, in my experience.

LG: Over 50% of patients will lose their eyebrows (from the literature). Even if you have scalp loss initially, you can still lose your eyebrows. Men can have facial hair (beard) loss.

**II. TREATMENTS****What are your first tier and second tier treatments?**

LD: The primary goal is to control inflammation, plus nutrition. My first level is vitamin D, iron if ferritin is low, oral antibiotics, topical steroids, and intralesional injection of steroids. If that fails, then, second tier is hydroxychloroquine (Plaquenil). Some patients may come in more severe, so I might go straight to the second tier.

JS: I have an algorithmic approach also. How aggressive are the symptoms? Age of the patient? Post-menopausal women also are treated differently. What I do: FFA: injections behind the hairline, Kenalog 2.5/cc, 32 injections total. Plus, eyebrows 2.5/cc for .5cc total. I don't use strong topicals around the face. I'll use minoxidil and tacrolimus on top of one another. If it's really progressive and painful, I'll even do doxycycline and Plaquenil. If I need to be even more aggressive: methotrexate (same doses as psoriasis) or cyclosporine (but more side effects).

VB: Mine is similar to Vera's tiers (referenced in an earlier talk). I always start with an oral medicine and topicals.

**Actos (diabetes drug, used off-label): How long do you use it?**

IR: 1 year. I see patients in 3 month blocks.

JS: 1 year, but some really want to use it longer.

VB: 4-6 months. Partly because of the long-term use warning, and that's about as long as it seems to work.

MC: Remember, every doctor is different. There is no perfect protocol and all are individualized to the patient.

**When do you start tapering?**

?? If getting better, then maybe go from every month injections to every other.

?? I try to find the lowest maintenance dose.

**How soon do you taper?**

VB: After 4 months for antibiotics, then I back off. And 6 months for Plaquenil. CCCA is easier to control.

LD: FFA: I am cautious of backing down. They must be inactive for 6 months before I consider backing down.

LG: We have neglected the neutrophilic scarring alopecias. Folliculitis decalvans is typically treated with an oral antibiotic. Second tier is a combination of rifampin, a medication for tuberculosis, in combination with another antibiotic. I usually do this for at least 3 months, often longer. For dissecting cellulitis, first tier therapy for many physicians is isotretinoin (Accutane).



*continued on page 4*

**Expert Panel Q&A** *continued from page 3***Eyebrows: Do you use Latisse and/or minoxidil?**

IR: Latisse—eyebrow growth. And minoxidil.

JS: I definitely use minoxidil if there is something (existing hair/miniaturized hairs) there, in the majority of my patients; 2 drops on a Q-Tip, twice a day. It thickens existing hair.

LD: I always have every patient (scarring and non-scarring) use minoxidil.

**5-alpha reductase inhibitors (5aRI, finasteride, and dutasteride): Do you use them? Tier 1 or tier 2?**

JS: I do use them. They are tier 2 for me. There are reports that they help. Dutasteride—we do not use in pre-menopausal women [even if using birth control] because of the long half-life. For post-menopausal, I use 0.5mg dutasteride. For pre-menopausal, I use 2.5mg finasteride.

LG: It is important to note that the 5aRIs are used “off label” for scarring alopecia and for women in general. Physicians must explain this to the patient—that they have not been studied—and document it in the medical record.

?: They are class X drugs.

**III. MISCELLANEOUS****How important is it to have a diagnosis that is inconclusive?**

VB: It is preferable to have a diagnosis. We can then predict (somewhat) what to expect, and for treatment options.

NEXT ISSUE: Part 3—Hair Care & Styling, Wigs & Hairpieces, Research Update, and Integrative Medicine



# Message from the Program Chair

Nicole Rogers, MD (New Orleans, Louisiana)

## 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.



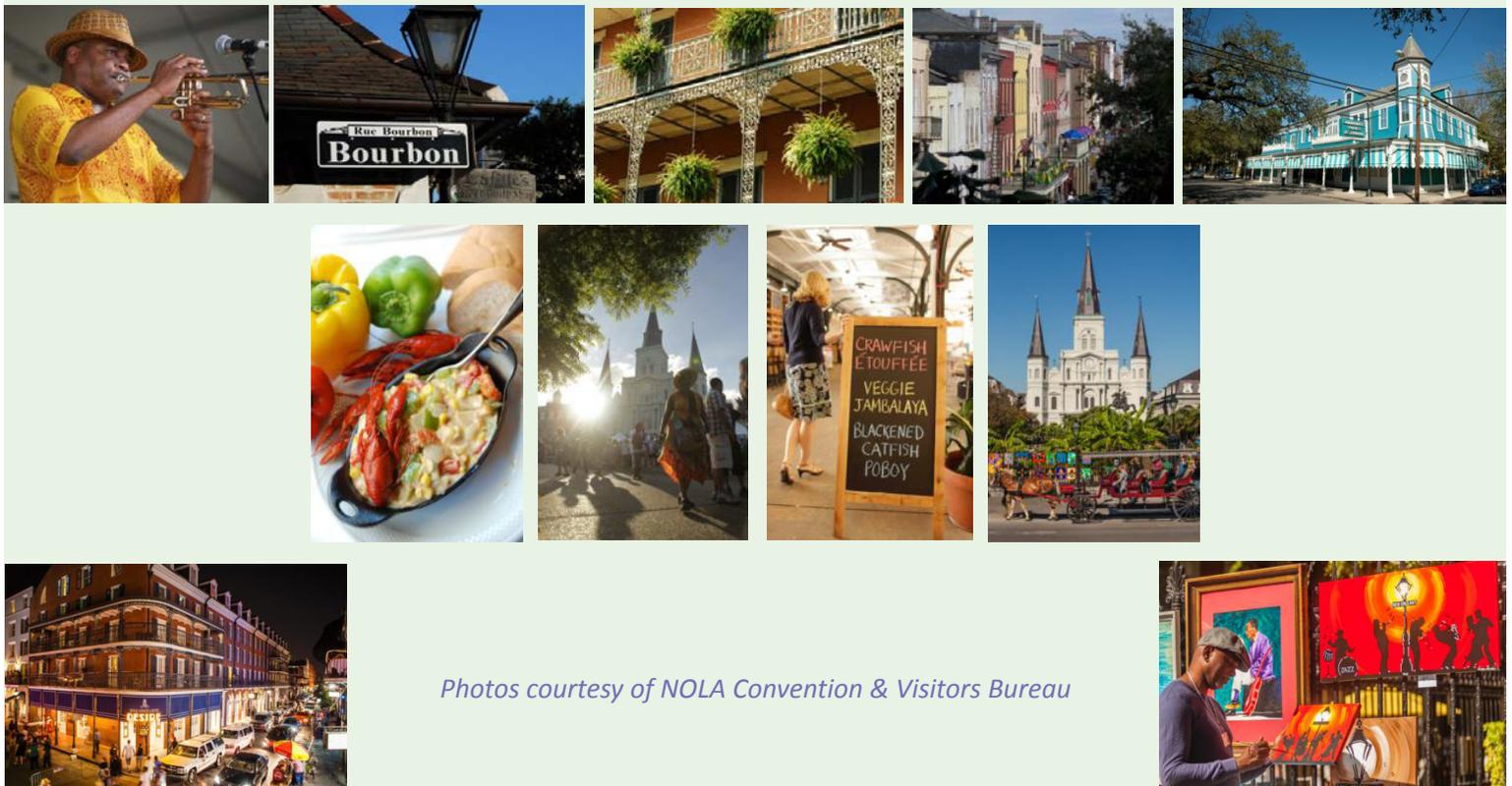
### CICATRICAL ALOPECIA RESEARCH FOUNDATION

### 7th International Patient-Doctor Conference

June 3-5, 2016

Hampton Inn & Suites New Orleans Convention Center Hotel

New Orleans, Louisiana, USA



*Photos courtesy of NOLA Convention & Visitors Bureau*

## Miracle Drugs for Hair Loss?

Lynne J. Goldberg, MD (Boston, Massachusetts) & Nicole E. Rogers, MD (New Orleans, Louisiana)

Two drugs have recently been touted by the media as miracle cures for hair loss. They are both members of the class called “janus kinase inhibitors” or “JAK inhibitors.” They work against various inflammatory diseases by blocking cytokine receptors. The first drug to appear in the news was Xeljanz® (tofacitinib citrate), which is only FDA approved for the treatment of rheumatoid arthritis. It was used to treat a young man with psoriatic arthritis, who also happened to have alopecia areata. After living for 7 years with no hair, he miraculously regrew all his hair between 2 and 5 months. The second drug to appear in the news was Jakafi® (ruxolitinib), which is FDA approved for myelofibrosis, a bone marrow disorder. It was used to treat three patients with alopecia areata, and all of them regrew hair in 2-5 months. All patients continue to be on the drugs, and it is unknown what will happen when they discontinue the drugs.

Neither drug is presently approved for any form of alopecia, nor do we expect them to be covered by insurance until larger clinical trials have been done. We are also doubtful that these drugs can be used in the context of cicatricial alopecia, because it is a scarring disease that in most cases does not regrow. Nonetheless, more research will help understand whether these drugs could fit into the cicatricial alopecia treatment regimen. Below are complete descriptions of what is presently known about each of these drugs.



Dr. Lynne Goldberg



Dr. Nicole Rogers

### Xeljanz (tofacitinib) Fact Sheet

Prepared by Lynne J. Goldberg, MD on June 27, 2014; modified July 7, 2014

**INDICATIONS:** Xeljanz is approved for the treatment of moderate to severe rheumatoid arthritis in patients who have not responded to other medications. It is being tested and used for psoriasis. There is only a single report of successful use in a patient with both psoriasis and alopecia areata universalis. It is not approved for alopecia and its use will be off label.

**WARNINGS:** Xeljanz is a potent immunosuppressant. There is a boxed warning on serious infections and malignancy: “Serious infections leading to hospitalization and death, including tuberculosis and bacterial, invasive fungal, viral, and other opportunistic infections have occurred in patients receiving Xeljanz... Lymphoma and other malignancies have been observed in patients treated with Xeljanz.” This drug may cause increased risk of gastrointestinal perforations, which is important for patients with peptic ulcer disease or diverticulitis. Patients should not receive live vaccines while on this medication.

**DRUG INTERACTIONS:** There are several important drug interactions. Please make sure to inform your physician if you are taking other medications.

**LAB MONITORING:** Patients wishing to start Xeljanz need to have baseline lab work and a skin test for tuberculosis. Periodic lab monitoring is necessary (1 month, 2 months, and then every 3 months thereafter). Xeljanz can lower blood counts, inflame the liver, affect the kidney, and increase cholesterol.

**SIDE EFFECTS:** Xeljanz has multiple side effects. The most common are diarrhea, nasopharyngitis, upper respiratory tract infections, headache, and high blood pressure. There are numerous others that have been reported. In the study on Xeljanz for rheumatoid arthritis, up to 84% of patients taking Xeljanz had adverse events, and 11% had serious adverse events. Approximately 11% of patients discontinued the drug due to adverse effects. Five cases of lymphoma or cancer occurred during the study. Four patients died either during or after the study. Laboratory tests showed a decrease in kidney function in 10% of patients, and all patients had a decrease in their white blood cell counts.

**DOSAGE AND USE IN ALOPECIA:** The standard dose for rheumatoid arthritis is 5mg twice a day. The alopecia areata patient had a long-standing history of alopecia areata, which progressed to universalis 7 years before therapy. The dose that the alopecia patient was treated with was 5mg twice a day for 2 months, then 10mg in the morning and 5mg in the evening. He was on it for a total of 8 months at the time of the case report, with partial hair regrowth noted after 2 months, complete regrowth of scalp hair (with significant regrowth of eyebrows, eyelashes, facial hair, axillary hair, and pubic hair) at 5 months, and full regrowth of hair at all body sites after 8 months. It is unclear how long he will stay on the medication, and whether or not his hair growth will persist when he comes off of it.

**INSURANCE ISSUES:** Xeljanz is very expensive. Because it is not approved for alopecia, your insurer might not be willing to pay for its use. While prices vary, without insurance one estimate for the standard 5mg twice daily dose ranged from USD \$2,635 to \$3,100 per month. There are no guidelines as to how long the medication needs to be administered.

#### References:

Lee, E.B., et al. Tofacitinib vs. methotrexate in rheumatoid arthritis. *N Engl J Med.* 2014; 370:2377-2386.

Craiglow, B.G., and King, B.A. Killing two birds with one stone: oral tofacitinib reverses alopecia universalis in a patient with plaque psoriasis. 18 June 2014; doi:10.1038/jid.2014.260. (Accepted article preview online.)

**Jakafi (ruxolitinib) Fact Sheet**  
**Prepared by Lynne J. Goldberg, MD on August 28, 2014**

**INDICATIONS:** Jakafi is approved for the treatment of intermediate to high-risk myelofibrosis, a disorder of the bone marrow. It is not approved for alopecia and its use will be off label.

**WARNINGS:** This drug needs to be used with caution in patients with a history of cardiac disease, and can cause lowering of blood counts. Serious infections (bacterial, mycobacterial [tuberculosis], fungal, and viral infections) have occurred in patients taking this medication.

**DRUG INTERACTIONS:** There are numerous drug interactions, particularly with, but not limited to, azole antifungals, clarithromycin, conivaptin, grapefruit juice, mibefradil, nefazodone, protease inhibitors, telithromycin, and fluconazole. Please make sure to inform your physician if you are taking other medications.

**LAB MONITORING:** Patients wishing to start Jakafi need to have baseline lab work and a skin test for tuberculosis. Periodic lab monitoring is necessary (1 month, 2 months, and then every 3 months thereafter).

**SIDE EFFECTS: Greater than 10%.** Cardiovascular: Peripheral swelling (22%); Central nervous system: dizziness (15%-18%), headache (10%-15%), insomnia (12%); Dermatologic: bruises (19%-23%); Endocrine & metabolic: increased serum cholesterol (17%; grade 2: <1%); Gastrointestinal: diarrhea (23%), constipation (13%), nausea (13%), vomiting (12%); Hematologic & oncologic: anemia (96%; grade 3, 34%; grade 4, 11%), thrombocytopenia (70%; grade 3, 9%; grade 4, 4%), neutropenia (19%; grade 3, 5%; grade 4, 2%); Hepatic: increased serum ALT (25%; grades 2/3, 1%-2%), increased serum AST (17%; grade 2, <1%); Respiratory: shortness of breath (16%), nasopharyngitis (16%).

**1% to 10%.** Endocrine & metabolic: weight gain (7%); Gastrointestinal: flatulence (5%); Genitourinary: urinary tract infection (9%); Infection: herpes zoster (2%).

**<1% (limited to important or life-threatening).** Edema, heart murmur, peripheral neuropathy, tuberculosis, withdrawal syndrome (acute relapse of myelofibrosis symptoms, splenomegaly, severe cytopenia, and septic shock).

**DOSAGE AND USE IN ALOPECIA:** Three alopecia areata patients have been treated with Jakafi at a dose of 20mg twice daily. All exhibited near complete regrowth within 3-5 months of treatment. It is unclear how long they will stay on the medication, and whether or not their hair growth will persist when they come off of it.

**INSURANCE ISSUES:** Jakafi is very expensive. While prices vary, without insurance, one estimate for a 20mg dose twice daily is \$11,550 per month. There are no guidelines as to how long the medication needs to be administered.

**References:**

Xing, L., et al. Alopecia areata is driven by cytotoxic T lymphocytes and is reversed by JAK inhibition. Nature Medicine Advance Online Publication. 17 August 2014. doi:10.1038/nm.364.

<http://www.uptodate.com/home>

## Welcome to the New CARF Board of Directors Members & Scientific Advisors

CARF is pleased to welcome new members to both the Board of Directors and Scientific Advisors!

Wilma Bergfeld, MD, FACP, Maria Hordinsky, MD, and Jim O'Connell are newly appointed members of the CARF Board of Directors. Dr. Bergfeld is the Director of Cleveland Clinic's Dermatopathology Fellowship and Professor of Dermatology and Pathology at the Cleveland Clinic Educational Foundation. She is also an Associate Clinical Professor in the Department of Dermatology at Case Western Reserve University. She serves as a consultant to the Department of Sports Medicine at Cleveland Clinic. Dr. Bergfeld is the current President of the North American Hair Research Society, and Co-Chair of the 9th World Congress for Hair Research taking place November 18-21, 2015, in Miami.



Dr. Wilma Bergfeld



Dr. Maria Hordinsky



Jim O'Connell

Dr. Hordinsky is Professor and Chair of the Department of Dermatology at the University of Minnesota, Twin Cities campus. Dr. Hordinsky is recognized for her expertise and research in hair diseases and the peripheral nervous system as it relates to hair follicle biology. Dr. Hordinsky also serves as the Secretary/Treasurer for the North American Hair Research Society as well as Associate Chair of the 9th World Congress for Hair Research.

Drs. Bergfeld and Hordinsky have previously served as CARF Scientific Advisors and bring their extensive experience with many dermatological organizations into their roles on the Board.

Mr. Jim O'Connell has over 30 years of experience with Proctor & Gamble, and recently started a Dermatology consulting business. Throughout his career, his main area of concentration was in consumer and trade cause marketing, working with a number of important and well-known causes such as Special Olympics, the American Heart Association, the Juvenile Diabetes Research Foundation, Big Brothers/Big Sisters, the Susan G. Komen Foundation, and Give Kids The World. His interest in causes and charities extends beyond pure cause marketing, as he serves on the Women's Derm Society Marketing Committee and as Past-President of the Board of Trustees of Hamilton County (Ohio) Special Olympics.

CARF is also pleased to welcome five new members to the Scientific Advisors. Our scientific advisors are highly esteemed clinicians and researchers with expertise in hair loss disorders. These volunteers meet regularly to seek out and review the most worthy research grant submissions for funding by CARF. Their oversight is critical to achieving CARF's mission to find effective treatments and a cure.

Lynne J. Goldberg, MD, Boston University; Elise A. Olsen, MD, Duke University; and Apostolos Pappas, PhD, of Johnson & Johnson (Lipid Biology Team Leader) have all come on as newly appointed CARF Scientific Advisors, where they will review research grant proposals and maintain other important responsibilities. After completing their tenure on the Board of Directors, both Vera H. Price, MD, FRCPC, CARF Founder, University of California, San Francisco, and Jerry Shapiro, MD, FRCPC, University of British Columbia, have also formally joined the Scientific Advisors.

We would like to welcome all into their new roles, and thank them for giving their time and expertise to CARF!



Dr. Lynne Goldberg



Dr. Elise Olsen



Dr. Apostolos Pappas

# SUPPORT GROUP NEWS

## Report from London

Patient Support Group Leaders: Jacquelyn Adams, Marva Holder & Gita Kothari

Physicians: Drs. Ophelia E. Dadzie & Sharon Wong

CARF London held their inaugural event on Saturday, November 16, 2013, at the British Dermatology Association in London. There were 20 people in attendance, listening to a cross mix of speakers.

The session commenced with Drs. Ophelia Dadzie and Sharon Wong giving an overview of scarring hair loss and medical therapies and Dr. Reena Shah speaking on the psychological aspects of hair loss.

Patient contributors were Ms. Davis, who spoke about living with hair loss, and Ms. Holder who explained how to navigate the National Health Service to obtain a wig prescription.

Thanks to Lucinda Ellery, Hair Management Consultancy and Dawn Forshaw, Director of Finishing Touches Group, who attended and provided information on treatments available to patients, including cosmetic and medical tattooing.

The event ended with Dr. Christos Tziotzios, who shared his research: "Focus on the scarred alopecia: new insights into scarring alopecia."

Attendees said:

"I learned a lot. I felt better finding out that I can get support."

"The speakers gave such useful information in a friendly, interesting, and easy to understand way. Also, the group and hospital staff who attended were such lovely people, it made the event an even better experience."

"The chance to hear from industry experts on developments, but also to meet others who suffer with cicatricial alopecia, share information and show support."

"The degree and quality of information covering different aspects of the subject was great."

"What I liked best: all the different presentations and the discussion, meeting other patients, hearing about the research and how we may be able to contribute to it."

"There was a wealth of information and practical support from a number of different specialists and lay people within the field. I am extremely pleased with the level of information provided and the question and answer session was most useful as well."

The second annual event is planned for Friday, November 14, 2014, 10:00AM, British Association of Dermatologists (BAD), Willan House, 4 Fitzroy Square, London W1T 5HQ.

# SUPPORT GROUP NEWS

## Report from San Francisco

Marilyn Ey, Patient Support Group Leader

There are some wonderful custom-made hairpieces for Frontal Fibrosing Alopecia:

**FFA Bangs Band:** The bangs band is made from synthetic hair styled and dyed to match your own hair. Velcro attaches to the underside of both the bangs and the band. This allows bang attachment to various colored hair bands. This works great for when the doorbell rings and there's no time to style your hair. The Bangs hairband can use either synthetic or dyed hair. (*See photos.*)



**FFA Custom Hairpiece:** Another styling option is an FFA “custom hairpiece.” From emailed photos and simple measurements, one member had Kathy Ricci ([AdvancedHair4U.com](http://AdvancedHair4U.com)) design a forehead pattern to cover ONLY the area of permanent hair loss. Using a special double-sided tape, the hairpiece attaches comfortably to the forehead. It NEVER touches the existing hair. This provides a cooler option from wearing a full wig. (*See photos.*)



If you would like to wear a hairpiece that just addresses the hair loss along your frontal hairline, Ms. Ricci can help you to create a custom adhesive design. Her phone contact information is:

Kathy Ricci  
Advanced Hair Alternatives  
549-C Merrimon Ave  
Asheville, NC 28804

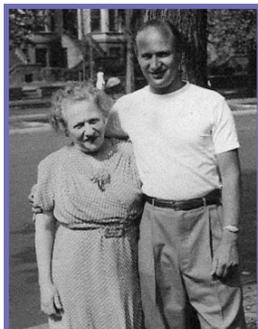
Telephone: 1-828-281-9088  
[www.advancedhair4u@aol.com](mailto:www.advancedhair4u@aol.com)

Give her a call and she can tell you what specific dimensions she needs from you and you're on your way!

# PATIENT CORNER: PERSONAL STORIES

## Living the Life: Newly Diagnosed and Coping

Sistah D. (California)



My father and grandma.



A girl so proud of her pigtails.



The disease is like being on a roller coaster.

There's an old photo of my father and his mother that stands out in my mind. She was younger than I am now, balding with very fine frizzy hair. My father was 28 years old and almost completely bald. As many girls growing up in the 50s, I took pride in my long ponytail. Little did I know that I would someday look like my grandmother...and then some.

In my 20s and 30s, I can't say anything was remarkable about my hair except that I had to deal with common frizz. By my late 40s, it began to get a little thin in the front and approaching my mid-50s, my hair was getting somewhat thinner on top too. Four years ago (at age 58), I noticed my temples and sideburns began thinning. Women and men my age and older seemed to have more hair than me, and so I started to get self-conscious but assumed it was just androgenetic alopecia, inherited from my father's side. The hair loss pattern was unusual though, so finally I went to a dermatologist in February 2014 who noted inflammation around my follicles and opted for a biopsy. The diagnosis was unsurprisingly androgenetic alopecia but also coupled with scarring alopecia (LPP and FFA). I was told it was a rare, difficult to treat, incurable condition, and that they would provide me with medical support for many years. It was so real that it was unreal, and I was devastated.

I did endless research to better understand my condition and take charge of my health. Serendipitously, I came across the CARF website in time to attend a support group. They met every three months and suggested I take part in an upcoming CARF Doctor-Patient Conference. The speakers answered my many questions about the disease. As a new patient, it served as a quick start for my personal CICAL (Cicatricial Alopecia) journey. Equally invaluable was being able to connect with other patients at the event. Having a rare condition is very lonely, and only other patients can truly appreciate the nuances of living with scarring alopecia along with its emotional and physical impact.

After the conference, I was in shock after being with others like myself for the first time. I could no longer be in denial about this new challenge to my sense of well-being. I "toughed it out" for a few days, but finally allowed myself to cry my heart out and continued to do so for three full days. No words can describe my feelings other than total loss blended with complete compassion for self. Letting down my guard and embracing those raw emotions gave me the strength I needed to nurture myself and move forward with my life.

My dermatologist had said the hardest thing about this disease is "not knowing" (how much hair we will lose, if a treatment will work, for how long, etc.). She wasn't kidding—it's like being on a roller coaster! I take an arsenal of tier 1 treatments. Sometimes I feel symptom-free and overjoyed, thinking I'm on the mend, but then the next day I get a painful flare-up and fear the worst extreme outcome possible. Most likely, it's something in-between that I will learn to live with and accept while I take the best care of my health as I can.

Baldness is one of a woman's greatest primal fears. After I have a (heavier than normal) shedding episode, I find myself imagining the loss will be endless and I panic. I then look in the mirror at the new unfamiliar me and have a talk with her. It is still me and I will love and be proud of her no matter what. I think of what brings real meaning to my life: my family, friends, the health and beauty I still have, and the joy of being alive in the moment—including enjoying the hair I still do have while I have it.

The first time I wore a headband I felt I could relax wind or shine. They're now my failure-proof public disguise. I'm excited to be getting a lovely hairpiece soon, so I'll be less obsessed with the progression of losing hair and have something in my hair future to look forward to.

After 8 months, I'm reaching a level of comfort with my disease that I couldn't imagine was possible. No longer mortified, I've shared my condition with several friends who are nothing but supportive. I opt for a lifestyle that includes more sleep, less stress, exercise, and balanced nutrition. I'm excited to say the time-consuming arsenal of medications and topicals I am using seem to be slowing down the disease and helping with inflammation. I've had some regrowth in non-scarred areas but am preparing myself to live a happy, hairless life regardless. I'm intent on enjoying the moment, the life and hair I have now.

Probably what has given me the most courage of all are the other patients I've met through CARE. Some have been on the CICAL journey a long time and others are just beginning. We share our experiences, resources, and tips. We allow each other to whine and, most of all, we laugh together.

Personal Stories *continue on page 13*

# PATIENT CORNER: PERSONAL STORIES

## Easy Going: One Man's Perspective

Frederick Lewis (New Orleans, Louisiana)

My name is Frederick and I have lichen planopilaris alopecia. The confirmation came from a scalp biopsy that my doctor performed about 5 months ago. To be truthful, I knew in the broad sense what alopecia was, but not until I had googled “cicatricial alopecia” did I understand how little I knew and how devastating this disease could be.

It started around 10 months ago as an itch. No big deal. A few days later, it was itching more and I decided it had to be dandruff. No big deal again. I got some heavy-duty dandruff shampoo and it seemed to help and actually went away for a couple of weeks. This happened for months until I could feel sores that burned when you touched them. Suddenly it was a big deal.

I was very lucky to have found my dermatologist, as this is one of her passions and she is also one of the leaders in combatting this disease. She started an aggressive treatment from the get-go and this has proven to be the right course for me. Today, she gave me a thumbs-up and said that the inflammation seems to have calmed down. This is wonderful news, but I know this is not over. I can still laugh, I'm not dead, and with my doctor's help, I will overcome this.

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## Confessions of a CARF Volunteer

Marilyn Ey (Chico, California)

In 2007, when diagnosed with FFA (Frontal Fibrosing Alopecia), the lymphocytic form of cicatricial (sick ah trish ul) alopecia, I was emotionally devastated. Feeling like a freak, I wanted to hide from the world. One day, a CARF volunteer called and CHANGED MY WORLD. I no longer was alone. What a relief. By attending support group meetings and Patient-Doctor Conferences, I not only learned about Cicatricial Alopecia (CICAL), but I learned how to deal with its emotional aspect.

How could I repay what CARF had helped me through? How could I help others? The answer was becoming a CARF volunteer. It started when two of us CICAL patients hosted a Wine Tasting fundraiser that netted CARF over \$1,000. Volunteering at a conference was next. Being a “greeter” was a unique experience. I still remember standing in the hotel lobby holding a CARF sign as a couple approached me. The husband said, “She's never met anyone else with this disease.” I smiled, told her I had FFA, and welcomed her to the CARF family with a hug. Now we always hug at conferences. Whether leading a support group, writing a CARF newsletter article, or helping at a conference... I LOVE what I do!

Years ago, CARF asked if I'd be willing to speak with another patient. Never having done this before, I was quite nervous. What if I did it wrong? What if I said the wrong thing? Would I make it worse for her? Knowing how a volunteer helped me, I took a deep breath and agreed to help. This lady and I emailed and spoke on the phone. When meeting at the conference, we hugged. Her life had changed and I was a small part of that change. I felt wonderful. CARF received more patient-to-patient contact requests, so I became a Patient Outreach Volunteer (POV). Now, a wonderful lady in Wyoming is the CARF POV and I am her assistant. My role with CARF changed again. Now my focus is on creating support groups and helping volunteers find their CARF niche.

So, I must confess: by helping CICAL patients I've discovered my PASSION in life. Interested in learning about volunteer opportunities? Just email me at [sanfranciscosupportgroup@carfintl.org](mailto:sanfranciscosupportgroup@carfintl.org) so we can discuss your interests. Together, we'll discover what you'd ENJOY doing. Maybe you too will find... your passion in life.

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**Personal Stories** *continue on page 14*

# PATIENT CORNER: PERSONAL STORIES

## My FFA Journey

Susan Huffman (Harrisonburg, Virginia)

In February of 2013, at age 54, I went to my dermatologist for my routine annual mole check. Her PA performed the check and as she finished up, she told me she wanted me to have a biopsy of my scalp. When I asked why, I could tell she was very uncomfortable when she told me she suspected I had a disease called Frontal Fibrosing Alopecia (FFA). I was a little skeptical, because at that point, I had no symptoms other than a slight redness at the front of my scalp, which I had not noticed but that she pointed out to me. So, first let me say, kudos to her for catching this at such an early stage. But that's where the kudos end. When I asked her for more information on FFA, she told me there was very little information available on it and printed out a half-page description from the internet and gave it to me. She then asked me if I had noticed the woman who came out to the waiting room while I was still there. "She has FFA and see how much her hairline has receded?" REALLY—I couldn't believe she was delivering this diagnosis in so callous a manner. Of course, I went back to work, googled FFA and was devastated by the pictures I saw. But other than the pictures and just a little information, the only thing I found were blogs by women who were frustrated by the lack of information on this disease, complaining about the side effects of the drugs they were using, etc.

Just a week before my FFA diagnosis, I had been diagnosed with breast cancer. Needless to say, I was a little overwhelmed at that point. Once I got through my surgery and treatment for breast cancer, I focused on the FFA. I switched dermatology practices and found a doctor who had much more empathy for my diagnosis. The more questions I asked, however, the more I discovered that this doctor, also, had very few answers. With my cancer diagnosis, I was given a complete book of information before I even left the doctor's office and recommendations of websites to browse for answers to any of my questions. My doctor gave me her home and cell phone numbers in case I had any questions before my surgery. I do realize that breast cancer is life threatening and FFA is not, so there is a difference. BUT...FFA is most definitely life altering. Battling breast cancer, I had an incredible support network and more information than I could possibly read. Not so with FFA. I was literally lost and felt that there was nowhere to turn.

One sleepless night in mid-February 2014, I prayed for God to give me peace in dealing with this condition. In my inbox the next morning, out of the blue, was an email from a counselor I had seen six months prior in my quest to find a positive way to deal with FFA. Her email led me to the CARF website, and what a difference that one email has made in my ability to deal with this disease. By the end of the month, my husband and I had made all the arrangements to attend the 2014 CARF conference in Chicago. That conference was a game changer for me. Not only did we receive more information in a weekend than I had been able to obtain for an entire year, but we were surrounded with such positive energy! Finally, I was no longer lost in dealing with this disease. All of the doctors who spoke at the conference were both interesting and compassionate. It was obvious that they have dedicated their lives to researching Cicatricial Alopecias, and that they are passionate about their work. Finally, I had all the information that was available regarding FFA. Last, but certainly not least, it was awesome to meet so many wonderful women who were dealing with the same challenges I was facing with this disease. We shared stories, coping mechanisms, fears, concerns, etc. I look forward to seeing many of these women again at the 2016 CARF Conference in New Orleans!

During the weekend, all conference attendees had the opportunity to buy raffle tickets to support CARF's research of Cicatricial Alopecias. The prize for the raffle was a trip to San Francisco, California, or Key West, Florida, that was made possible by the generous donations of hotel points and air miles by Laurence Spector and Dr. Ken Washenik. My husband and I were lucky enough to win this raffle and just returned from a wonderful trip to San Francisco where we stayed in the historic Westin Hotel in the heart of Union Square. We are so grateful to Mr. Spector and Dr. Washenik not only for making this trip possible for us, but for everything they do to help find treatments and cures for Cicatricial Alopecia.

If you are coping with a Cicatricial Alopecia, consider attending the 2016 CARF Conference in New Orleans. The information and support you will receive there can be as much of a game changer for you as it was for me. In addition, if you or someone you know is dealing with one of these diseases, please consider donating to the CARF organization to help fund the research that is so desperately needed to find treatments and cures.

# MEETINGS, ADVOCACY & AWARENESS

## NEWS FROM THE CHAIRMAN OF THE BOARD

Rita Wanser (South Amboy, New Jersey)

We welcome new board members to the team: Dr. Wilma Bergfeld, Dr. Maria Hordinsky, and Jim O'Connell (see Welcome on page 8). Each of these individuals brings many years of valuable experience to the Board through their disease expertise and years of experience as leaders on several other boards.

We send our many thanks to Drs. Vera Price and Jerry Shapiro who have stepped down from the Board of Directors as their terms have come to an end. There are not enough thank you's for their continued years of service on the Board and their contributions to the vision and mission of CARF. Both will be joining the Scientific Advisors.

It is perfect timing for the new Board members to come aboard! In January, the Board will be holding a Strategic Planning Meeting as we continue to build upon the growth of CARF. The last planning meeting resulted in the strengthening of our structure, enhanced patient support, and continued interactions with other non-profits and patient groups, and it further developed the team of volunteers who so willingly give of their time to sustain the daily operations of the organization. I look forward to sharing the outcomes of the meeting in a newsletter next year.

CARF continues to associate with key organizations as part of our patient advocacy and public awareness efforts. We attended the annual Coalition of Skin Diseases (CSD) Development Day. The meeting was both informative and educational. The CSD is working with the Patient Advocacy Task Force of the American Academy of Dermatology (AAD) to explore ways of increasing awareness of our conditions within the dermatology community and to increase dermatologist support of the CSD activities. Further, we heard from speakers on Non-Profit Board Management and Organizational Best Practices for Fiscal Management.

In that same weekend, and in collaboration with the Coalition of Skin Diseases (CSD), CARF attended the 2014 American Academy of Dermatology Association Legislative Conference. We joined dermatologists from across the nation to present a united voice to Congress on current, pressing issues facing dermatology. This was an especially important year, as two of three important issues involved insurance provider networks; within Medicare Advantage, thousands of dermatologists and other specialists are being dropped from Medicare Advantage provider networks. This limits access to care and coverage. In addition, funding for research continues to experience cuts. Under the current budget, the National Institutes of Health was cut by \$1.03 billion; further cuts in 2016 and beyond are expected. Imagine the impact to rare diseases such as ours when these cuts are being done to cancer and other life-threatening disease research. The last issue, while not related to our disease specifically, is important to each one of us and our families: skin cancer prevention. Congressional support is vital to develop innovative solutions to an alarmingly increasing incidence of melanoma. We look to a creation of a Skin Cancer Caucus in the Senate and increased membership by House members to the Congressional Skin Cancer Caucus to promote prevention and create awareness.

In October, we also attended the Rare Disease and Orphan Product Symposia through the National Organization of Rare Diseases. CARF was awarded a scholarship that covered registration fees and a travel stipend. The two-day symposia brought industry, physicians, patients, and patient advocate organizations together to discuss and learn about rare diseases. The topics highlighted the recognition of patient organizations to furthering research and promoting work for cures. In her talk, Dr. Janet Woodcock, current Director of FDA's Center for Drug Evaluation and Research, highlighted the importance of patients in helping scientists better understand the thousands of rare diseases that currently have no FDA-approved therapy. Other major topics discussed were widening industry support of rare disease research and the FDA's increased flexibility in the development of orphan products.

We continue to explore partnerships and collaborations with other organizations to increase our learning from governmental and other external influences on non-profit health organizations, while creating increased awareness of our disease and of our organization. We will highlight these meetings in future newsletters.



Rita Wanser

### Celebrate Rare Disease Day – February 28, 2015

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 28, 2015. 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.

No matter where you are, you can participate virtually in the Handprints Across America project. It's easy!

- Print a flyer of the overlaying hands.
- Take a photo of yourself with the flyer.
- Submit it with your personal story about cicatricial alopecia at <http://rarediseaseday.us/take-action-now/handprints-across-america/>.

Please also consider contacting your local newspaper or television station to raise awareness. We have a press release and sample letter to the editor that we are happy to provide you. If you are interested, please contact Melanie at [mstancampiano@carfintl.org](mailto:mstancampiano@carfintl.org).

For those who live outside of the U.S., please visit <http://www.rarediseaseday.org/> to find local events in your area.

This is a wonderful opportunity for people with rare diseases around the world to promote awareness of the challenges of living with a rare disease. We hope you will join us in this awareness campaign!



Rare Disease Day®

## Funded 2014 Research Grants

Kurt Stenn, MD (Philadelphia, Pennsylvania), Chair, CARF Scientific Advisors

Although we know that all the cicatricial alopecias involve hair follicle inflammation and scarring, we do not yet know why some people and some hair follicles are affected and others are not. To that end, CARF has a program of granting monies to gifted researchers who study the problem. Although the grants are small, we hope the grants will generate new insights and stimulate more scientists to help us find treatments and a cure. This year CARF awarded two projects.

The first project will be carried out in the laboratory of **Professor Kehinde Ross**, Department of Biomolecular Science, University of Liverpool, England. During the past decade, scientists discovered a group of natural chemicals called microRNAs, which regulate genes. The microRNAs are like stoplights: sometime giving a green signal—for cells to grow—and, other times, a red signal—for cells to stop growing. Professor Ross and her team will study if these regulatory molecules play any role in the hair follicle of patients with one form (LPP) of cicatricial alopecia. If Ross finds that microRNAs play a role in the disease, she postulates we will be able to use that microRNA to treat patients.

The second project will be executed by **Professor Raja Sivamani**, Department of Dermatology, University of California Davis, California. Dr. Sivamani notes that all forms of cicatricial alopecias start with destruction of sebaceous glands and in her research project she asks why. In this project, Sivamani and her team will test if the biochemistry of sebaceous glands from people with LPP is different from normal. She argues if any biochemical defect is identified, researchers could use it to identify preventive, if not curative, treatment.

At the end of the research period, these investigators will share with us their findings. Although we don't expect a major result in one year, we hope for promising leads. The best results for CARF, and for any of us in the cicatricial alopecia community, is for these very gifted researchers to continue their work on this very difficult medical condition.



Dr. Kurt Stenn

## CARF 10-Year History

Elaine Hansen, Mariposa, California

*Note: This information was assembled from all past newsletters.*

Date	Event	Notes
10/01/04	First CARF planning Luncheon	Home of Dr. Vera Price
08/12/05	1st Cicatricial Alopecia Patient-Doctor Conference	San Francisco, CA. Emcee: Ed Vasgerdsian
10/01/05	Cicatricial Alopecia Research Colloquium	NIH <a href="http://www.nature.com/jid/journal/v126/n3/full/5700148a.html">http://www.nature.com/jid/journal/v126/n3/full/5700148a.html</a> .
05/26/06	2nd Cicatricial Alopecia Patient Conference	Minneapolis, MN. Emcee: Richard Dunsay, JD. Host: Maria Hordinsky, MD
07/27/06	American Academy of Dermatology Golden Triangle Awards	Vera Price, MD and Sheila Belkin
10/01/06	First CARF Communiqué	
05/01/07	Society of Investigative Dermatology Annual Meeting	Century City, CA
07/21/07	Diamond Affair	Beverly Hills, CA
10/22/07	First CARF Support Group Meeting	Kaiser Medical Center, San Francisco Patient Group Leaders: Betty Tanzey and Linda Assalino Physician Advisor: Vera Price, MD
02/01/08	American Academy of Dermatology Annual Meeting	
01/01/08	NIAMS Coalition Outreach Day ( <i>exact date not known</i> )	Bethesda, MD. Sheila Belkin, Laurence Spector
04/09/08	Fifth International Skin Disease Research Day	Kevin Wang, MD, PhD
09/26/08	3rd International Patient-Doctor Conference	Hyatt Regency Crystal City, Washington, DC. Host: Valerie Callender, MD
10/01/08	Donations to CARF	Chico Soroptomist International, and others
09/01/09	NIH meeting, Lily Talakoub, MD. Liaison with NIH	Washington, DC
03/12/09	Breakthrough Discovery in Hair Biology	Drs. Karnik, Mirmirani, and Price
10/17/09	CARF's 5th Anniversary Celebration	San Francisco, CA. Emcee: Ed Vasgerdsian. UCSF Faculty-Alumni House
10/25/09	NIH grant to Pratima Karnik, PhD of 1.77 million	5-Year Study PPAR Gamma Signaling in Normal Pilosebaceous Units and in Scarring Alopecia

CARF 10-Year History *continued on page 17*

**CARF 10-Year History** *continued from page 16*

Date	Event	Notes
01/31/10	Boston Area Support Group holds 2nd meeting	Lexington Cary Library
03/25/10	Dermatology Nurses Association Conference	
06/16/10	Cicatricial Alopecia Symposium at World Congress for Hair Research	Cairns, Australia
08/24/10	Baltimore Health Fair	Shakia Gullette
09/24/10	4th International Patient-Doctor Conference	Beverly Hills, CA. Hosts: Pearl Grimes, MD and Lenore Kakita, MD
01/01/11	CARF Research Grant Award	Hiroko Hama, PhD
01/01/11	CARF Research Grant Award	Marlon R. Schneider, DVM, PhD, MSc
01/01/11	CARF Research Grant Award	Professor Thomas Franz, University of Bonn, Germany
03/26/11	Sandra Dubose-Gibson Crowned Mrs. Black North Carolina	
04/09/11	Los Angeles Support Group formed	Pearl Grimes, MD
02/04/11	American Academy of Dermatology Annual Meeting	New Orleans, LA
05/14/11	Chicago Support Group formed	Victoria Barbosa, MD
08/15/11	New Orleans Support Group formed	Nicole Rogers, MD
10/27/11	Cicatricial Alopecia Research Symposium	Bethesda, MD
03/16/12	American Academy of Dermatology Annual Meeting	San Diego, CA
08/10/12	5th CARF Patient-Doctor Conference	Boston, MA, Host: Lynne Goldberg, MD
01/01/13	CARF Research Grant Award	Dr. Helen Everts & Dr. Wilma Bergfeld
01/01/13	CARF Research Grant Award	Dr. Matthew Harries, Dr. Iain Haslam & Professor Ralf Paus
01/01/13	CARF Research Grant Award	Dr. Christopher S. Potter
02/20/13	New York Support Group Meeting	Jerry Shapiro, MD
03/01/13	American Academy of Dermatology Meeting	Miami Beach, FL
03/02/13	Lifetime Career Educator Award to Vera H. Price, MD	Dermatology Foundation
03/18/13	Women of Color Hair Loss Symposium	New York, NY. Host: Achiamah Osei-Tutu, MD
04/01/13	BIO Orphan Disease Forum, and National Organization for Rare Disorders	Chicago, IL. Victoria Ceh, MPA & Melanie Stancampiano
04/02/13	San Francisco Support Group Meeting	Drs. Price and Roseborough
05/01/13	CARF Headquarters moves	303 W. State St., Geneva, IL 60134, USA
05/01/13	@SkinAdvocate app on Twitter and Skin Advocate Facebook Group	
05/04/13	7th World Congress for Hair Research	Edinburgh, Scotland
09/01/13	AADA 2013 Legislative Conference in Washington DC	Melanie Stancampiano & Rita Wanser
10/23/13	International Society of Hair Restoration Surgery's 21st Annual Scientific Meeting	San Francisco, CA. Session on CICAL. Vera Price, MD, Rita Wanser, Victoria Ceh, MPA, Melanie Stancampiano, Nicole Rogers, MD, & Jeffrey Donovan, MD, PhD
02/28/14	Rare Disease Day	
03/22/14	NAHRS Scientific Session, American Academy of Dermatology Meeting	Denver, CO. Dr. Elise Olsen provides update on the Frontal Fibrosing Alopecia Project. She also described her research using dutasteride and finasteride as off-label treatment options for FFA.
04/04/14	6th International Patient-Doctor Conference	Chicago, IL. Host: Victoria Barbosa, MD
05/30/14	CARF Research Grant Award	Dr. Kehinde Ross
05/30/14	CARF Research Grant Award	Dr. Raja Sivamani
09/07/14	AADA 2014 Legislative Conference in Washington DC	Rita Wanser
10/20/14	National Organization for Rare Disorders (NORD) Summit, Alexandria, VA	Rita Wanser

## CARF's Hair Raising Challenge!

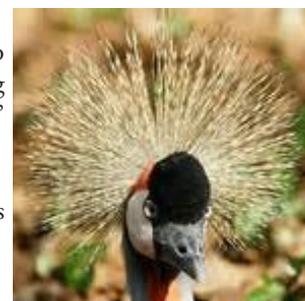
It has been an interesting year for raising funds and awareness for diseases. How many of you were challenged to dump a bucket of ice water on your head or make a donation? As a not for profit organization dedicated to improving the lives of those suffering from the cicatricial alopecias, we are encouraged by how effective this "viral fundraising" proved to be.

We would now like to issue you, our CARF Family, a challenge of our own.

**CHALLENGE:** By year's end, meet CARF's "Hair Raising" challenge and recruit five friends or family members to make a \$5 donation in your honor, or donate \$25 yourself.

It's easy to make a donation: <http://www.carfintl.org/donations.php>.

Good luck with the challenge!



## 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>



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

### International Support Groups

#### CANADA

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