

May 2013
Issue XIV

CARF Communiqué

CARF 5th International Patient-Doctor Conference— Boston, Expert Panel Q&A (August 2012)

Expert Panel: Yolanda Lenzy, MD, MPH, Victoria Barbosa, MD, MPH, MBA, Lynne Goldberg, MD, Vera Price, MD, Valerie Callender, MD, Ken Washenik, MD, PhD, and Maria Hordinsky, MD

The following was transcribed by Marilyn Ey and then slightly modified and approved by Dr. Vera Price. All members of the Expert Panel gave consent to the recording. We wish to extend our gratitude to Marilyn Ey for her hard work and effort in putting together this transcription!

Questions were grouped together in themes in order to answer the numerous questions submitted to the panel.

Q. If you have scarring alopecia can you have a hair transplant?

Dr. Ken Washenik

Transplants work great if you don't have inflammation. If you have inflammation and the disease is active, it is likely the hair transplanted will die or not be productive. Dr. Callender talked about how in her practice she uses test areas to see whether or not that area is quiet or inactive enough for grafts to take. Some use a number for inactivity of one year or two years, but Dr. Callender's approach of a test session is helpful and the best way to go.

The way hair transplantation works is donor dominance. When you take the hair from a donor dominant area, it thinks it's still there. So when you move it, it grows like the area you took it from. However, if the ground you put it in is inflamed, the chances for the transplantation taking are not good or very slim. The one scarring alopecia that I feel is a little different than the other scarring alopecias is central centrifugal cicatricial alopecia (CCCA). CCCA will often do better even though the disease is progressing outside the area. I find the disease in the burned out center in CCCA to be a little more permissive than in lichen planopilaris (LPP).

The other twist is that out of thousands of hair transplants, there have been a couple reports where, after the transplant, LPP became more apparent. In the past two years there were a couple reports in the very, very rare category where patients developed LPP around the transplanted hair. They may not have noticed it prior to the transplant, but afterwards it became more apparent. Because it is so rare and difficult to diagnose, in our business alone with 12,000 transplants we're not clear if LPP was present before the transplant or if it developed after the transplant. This is a question we're still wrestling with so we don't have a complete clear answer for that right now.

Q. Are there any ongoing studies we can be a part of?

Dr. Maria Hordinsky

If you are interested in a clinical trial, the best thing to do is go online to clinicaltrials.gov because any clinical trial in the United States needs to be registered. On this site you'll find all the authorized clinical trials going on in the United States. At the same time you are going to hear about studies in your own area that doctors are doing. For example, Dr. Ethan Lerner from Boston has studied four patients and developed data about a device that appears to work well. So there is an opportunity now to develop a clinical trial.



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Save the date!



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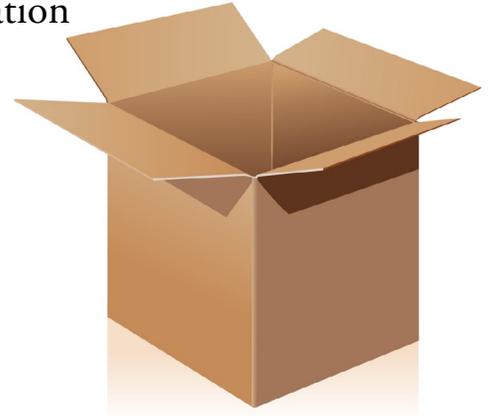


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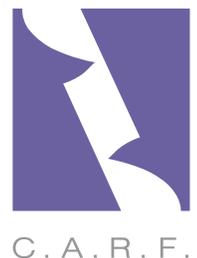
If you would like previous issues of our newsletter, please email info@carfintl.org.

Want to be part of the newsletter? Just write about your experience with cicatricial alopecia and/or attending a support group meeting.

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



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On fire for research and a cure!

Expert Panel Q&A *continued from page 1***Q. What are holistic treatment approaches?***Dr. Lynne Goldberg*

There is a whole other field of treatment that does not come down to a prescription pad. Some of us are better versed in this than others. Generally, most of us are not super-well-versed in holistic medicine, but there definitely are things that are helpful (for example, hypnosis). It is best to discuss holistic questions with your doctor.

Q. When do you know if oral medications or injections are needed?*Dr. Valerie Callender*

I believe in the assumption that three is better than one, so I like to start my patients on combination therapy. Whether I do systemic or topical, most of my patients are on both systemic and topical because I like to hit it from all angles. There is some controversy whether one is even beneficial or if topical even works.

Dr. Victoria Barbosa

We all have our favorite approach, and I agree with Dr. Callender that essentially early in first diagnosing someone to treat from both the outside and from the inside. I am a big fan of both topical plus orals to begin with. I don't use injections as frequently as it depends on which disease we are talking about and the amount of surface area we're talking about. A lot of my patients have been to three or four doctors before getting to me, and they have large areas of scalp where injections just aren't feasible for that amount of surface every four weeks. It really depends on how active the disease is. If it is progressing rapidly, Dr. Price talks about trying to form a wall around the advancing edge. For me, this is a very individualized issue.

Dr. Lynne Goldberg

I would add that I am at the opposite end of the spectrum. I have a lot of patients with scarring alopecia and this includes a wide variety of diseases; some are extremely limited and some are very, very widespread. I agree that for widespread involvement we are concerned that the topical isn't going to get everywhere, so I think systemic treatment is very reasonable. I have a lot of patients that don't want to take systemic medications for their hair loss because they are worried about the side effects. Not all patients have to take doxycycline or Plaquenil. We can start with a topical steroid and if that helps, fine. If it doesn't help, we can add injections. I have a patient who is doing very well on topical treatments alone, so I guess I am in the minority on this one.

Q. What is the injection technique?*Dr. Lynne Goldberg*

My injection technique for LPP is very similar to alopecia areata, very superficial.

Dr. Vera Price

I think the depth should not be too superficial: you don't want to inject in the epidermis or you will get atrophy; at the same time, if you inject too deeply into the subcutaneous tissue, you will also get atrophy. So you want to inject in the upper mid dermis. The other most important thing is to inject a tiny amount in each site. Atrophy occurs if you inject too much per site. I keep the injections 1 centimeter or more apart, and I don't inject more frequently than every 4 to 6 to 8 weeks. I always use full-strength Kenalog, 10 milligrams per cc, which many of my colleagues don't, and this is another aspect in which our technique varies. With tiny amounts per site, we don't get much atrophy.

Dr. Victoria Barbosa

What is important is for you to ask your physician if injections are right for you. We all have justifications for what we do. Each doctor has different opinions and techniques regarding injections.

Dr. Vera Price

I think some physicians are not comfortable giving injections and if you start with such a physician, you will be given many reasons why you shouldn't have them. You need a physician who is experienced with injections and who is comfortable giving them.

Q. What is dermoscopy and what are its uses in scarring and non-scarring alopecia?*Dr. Yolanda Lenzy*

A dermoscope is a handheld tool that has a light attached to it that basically allows you to see the tiny pore markings on your scalp magnified approximately 500 times. I look through a small lens that magnifies what is on the surface. This is helpful when patients have very early scarring alopecia, and I can see the loss of pore markings on the scalp. It also makes it easier to see scaling and redness and helps to distinguish cicatricial alopecia from other conditions. A dermoscope is primarily used for looking at moles on the skin and for melanoma. We've incorporated it in the workup of a scalp problem.

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Expert Panel Q&A *continued from page 3**Dr. Lynne Goldberg*

A recent article on the use of a dermoscope stated that it can help choose the biopsy site. When I look at a patient's scalp, I'm not sure if the redness is from dilated blood vessels from treatment or if the redness is truly inflammatory in nature. A dermoscope can help me decide if the erythema is a sign of treatment or of disease activity.

Q. Central Centrifugal Cicatricial Alopecia is found in family members. Should I get my daughter tested even if she doesn't show any signs?

Dr. Victoria Barbosa

Most of the scarring alopecias are uncommon. CCCA is fairly common, and I think most of us who treat African American women feel it is more common than anyone knows. We know that about half of the patients report a similar form of hair loss in a family member, so we know that there is some genetic or hereditary component. There is a lot of debate and discussion about the additional role of hair grooming and care, things such as the use of relaxers and the use of heated styling appliances, etc. I would say absolutely that the daughter of a woman with CCCA should be examined starting in the late teens or early 20s as we usually don't see it in patients before their 20s and even 20 is early for the disease, and after that about every year or so thereafter. For many of these women, itching or tingling is an early sign of the disease. If someone has itching out of proportion to anything the naked eye can see, then it is time to get an evaluation.

Dr. Yolanda Lenzy

Early diagnosis is important. Right now as clinicians we rely on two different ways to diagnose patients in the very early stages. One is symptoms. We know a patient will come into the office if there is itching, pain, or tenderness. The other is we rely a lot on hair stylists and the salon person who is washing your hair, styling your hair, and is seeing the top of your hair on a regular basis. Sometimes stylists don't pick it up until it is quite advanced. So if you have a daughter and you have CCCA, why not look at her scalp? Why not ask her if she is having symptoms? She might think it is normal, think it is hereditary, runs in the family. So you might want to examine her as we need to see these patients in the office early on.

Q. Is a receding hairline curable or is it all due to styling?

Dr. Victoria Barbosa

A receding hairline can be caused by a number of conditions. One we see most commonly is traction alopecia from tight braids, tight weaves, ponytails, and other styles that pull on the hair. All these can cause a receding hairline. Early on, traction is reversible. But if the traction continues for many years, it can permanently damage hair follicles and cause permanent hair loss. It is important when styling your or your daughter's hair, and you start to notice thinning at the interior hairline, that you realize it is time to switch styles. If you notice thinning when wearing cornrows, braids, or weaves, it is time to change the style. There are other things that can do it. Most women with CCCA start with involvement at the crown, but I've actually seen it start at the temples as well. Pattern alopecia as well as frontal fibrosing alopecia can cause receding at the hairline. The first issue is to find the right diagnosis so you can then move on to the appropriate treatment and make the appropriate adjustment to your styling.

Dr. Vera Price

The key thing to know first is the diagnosis. If it is cicatricial alopecia and it is frontal fibrosing alopecia, then you want to seek help early. Our treatments will try to slow the progression, but they won't grow back any hair that you've lost. However, even with the best of treatments started early, we can't always prevent the progression.

Dr. Lynne Goldberg

I recently published a paper on cicatricial marginal alopecia, a pretty severe band loss that I've seen where the sebaceous glands were normal, just no hair. It's probably a form of secondary scarring alopecia as opposed to primary scarring alopecia. The hairs along the frontal hairline are targeted because of the pull on the hairs in the front. I asked a series of patients with traction alopecia whether they had done a lot of straightening in terms of relaxing or with the use of heat. It was pointed out to me that all those patients wore ponytails, or just pulled their hair straight back. When we talk about traction, we aren't just talking about relaxing or straightening. I thought of gymnasts in the Olympics and how tightly their hair is pulled back. Oh, my goodness, I'm glad it's only every four years.

Q. I have noticed hair loss on other parts of my body. How does this relate to my diagnosis of frontal fibrosing alopecia and or menopause? (There also were many questions regarding loss of eyebrows and sideburns.)

Dr. Vera Price

The question of hair loss on the body usually comes up with someone diagnosed with frontal fibrosing alopecia. Often when patients notice their hairline receding and thinning of the eyebrows, they will also notice the loss of hair in their armpits, on their arms, or pubic area. This is difficult to access in women in their 50s and 60s or older, because we all have a little less hair in those areas as a natural phenomenon. We have done biopsies on some of those areas and some do show scarring alopecia. We usually don't biopsy arms and legs. If we did, we'd probably find that in some older patients there are signs of some scarring. So the loss of hair on the limbs and underarms in this older group may not be related to frontal fibrosing alopecia but may be part of the changes with aging.

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Expert Panel Q&A *continued from page 4***Dr. Lynn Goldberg**

I recently had a paper accepted, but not published yet, on hair loss in men in the sideburns. I had three male patients who lost their sideburns. I had one male patient who had loss of hair in the eyebrows and one or two male patients showing erythema on the scalp. The hypothesis is the loss of sideburns in men is almost the equivalent to frontal fibrosing in women. There are several reports of frontal fibrosing alopecia in men.

Dr. Ken Washenik

The number one cause for eyebrow loss is shaping and refining until there is nothing left to reshape or refine. If you yank a hair, it will grow back. At some point with repetitive injury or repetitive pulling, there is some damage to the hair follicle that sometimes leads to some miniaturization. Sometimes there are some little fuzzy ones left, but with many people there is nothing left, just scarring. This is not a scarring alopecia due to an inflammatory process, but due to the trauma of repetitive plucking. Occasionally, someone will come in and want their eyebrows rebuilt. This works very well if from plucking or threading – there is just normal skin that doesn't have hair follicles. The one drawback is donor dominance. If you take hair from the back of the head and move it to the eyebrow area, the hair still thinks it is on the head so you have to actively trim it.

Dr. Yolanda Lenzy

I'm also seeing a lot more eyebrow loss due to the new phenomenon of threading. Threading is a technique that I believe first started in India using two threads in a sliding motion to thin eyebrows. It produces a very pretty, refined line, but it produces a lot of trauma.

Dr. Valerie Callender

I'd like to address the widening of the part on the scalp. The first thing we dermatologists think of when we see widening of the part on the scalp is hereditary thinning, female pattern hair loss, or androgenetic alopecia. A few years ago there was a scale that was validated for central hair loss and the widened midline part. It was published by Dr. Elise Olsen and is an actual clinical scale from 1 to 5 for assessing female hair loss.

Q. Local stylists are not educated in CCCA. What can be done or is being done to educate hair stylists?**Dr. Lynne Goldberg**

When Yolanda Lenzy was a resident at Boston University, she decided to do an outreach program at salons in Boston. Yolanda will explain what she did so dermatologists can take this information to their locations.

Dr. Yolanda Lenzy

One of the ways I got interested in this is after I studied cosmetology in high school. I realized hair stylists were on the front line because they see you and your hair frequently. They often know what is going on before you do. When I was a second year resident, I started a program at my local salon where I gave lectures to fifteen stylists. I discussed the many forms of alopecia. Many of them when they saw the slides said, "Oh my goodness! I have someone with this." They just didn't know what it was called. After that I started to track the people with CCCA who came from the salon. The people from the salon whose stylists had heard the lectures were diagnosed at an earlier stage compared to people who were diagnosed after seeing a doctor. This started my passion about an outreach program to stylists. The clients trust stylists, and many clients who might have been thinking about seeing a dermatologist finally go because their stylist recommends it. I encourage stylists to continue to be informed and to keep this going.

Dr. Victoria Barbosa

When first starting a practice, you are very busy and it is difficult to start an outreach program. Since I have a fairly new practice, I keep track of the stylists who send clients in early because I know these stylists are paying attention. I send them notes periodically saying, "I'm seeing clients you are sending me and I appreciate your due diligence." I'll call them and have conversations. Then, when other patients ask me for a stylist, that is when the list comes out.

Dr. Lynne Goldberg

Can I see a show of hands about how many of you have discussed your hair loss with your stylist? (most audience members raised their hands) Most of you. How many of you have educated your stylist on what you have? (many hands raised) Excellent. How many of you have asked your stylist to tell other patients who they may see about seeing a dermatologist? (many hands raised) Excellent. So now I ask all of you to go back and tell your stylists what you have and encourage them so they send other clients with a similar problem to your doctor. Have them do it tactfully, but emphasize that perhaps they should see a dermatologist for their problem. Education and spreading the word is one of CARF's missions.

Dr. Vera Price

I think this is really one of the most important outcomes of this conference: this advice coming from you, the patients, with no ulterior motive. Coming from you is powerful.—Patients are a powerful group— and you can make a big difference.

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Expert Panel Q&A *continued from page 5***Dr. Ken Washenik**

This grass roots, local effort is commendable. One of the things we've done on a bigger basis is another group called the Hair Foundation. Its educational mission is to try to get out information about hair loss and treatment. For the last few years, we have given presentations at the meetings of the American Association of Cosmetology Schools. We're trying to get to the point where we are invited to or allowed to write a chapter on hair loss for the cosmetology schools. Whenever we go to their meetings and present a talk, we are very well received. Cosmetologists are hungry for information, so I think you'll find the reception is warm.

Dr. Lynne Goldberg

We are fortunate to have an exhibitor here, Pat Rickson, who has a salon in Boston. She is very active in educating patients about hairpieces. I went to her salon to educate myself on what she did and had to offer.

Q. How can I tell if the treatments are working if the sensation never goes away? (Sensations: crawling, tingling, itching, pins and needles) How do these sensations relate to disease activity both in the scalp as well as other parts of the body (eyebrows, eyelids) as part of the disease?

Dr. Yolanda Lenzy

In addition to inflammation caused by lymphocytes and neutrophils that can cause these symptoms in a cicatricial alopecia, there is also a different kind of inflammation called neurogenic inflammation. Around the stem cell region of a hair follicle, there are nerve fibers. These nerve fibers produce neuropeptides that release factors that can influence the immune system and may cause similar symptoms. Researchers are studying the neuropeptides and trying to figure out how to modulate or change their expression to see if that makes any difference to the symptoms and to the disease. For example, patients with neuropathy may feel pain and burning like someone with diabetes. At our center and other centers, we are evaluating topical gabapentin to see if modulating symptoms like tingling, burning, or itching makes any difference to these symptoms and to the disease itself. In addition, you have to take a good look at the scalp. If the scalp shows any redness or scale, consider the products that are being applied to the skin that might be irritating the skin. Sometimes you have to think about what you are putting on the scalp that could be aggravating the nerves.

Dr. Valerie Callender

I'd like to comment on that. I had a patient with CCCA who every time she came in, despite being on combination therapy, her scalp was always itching and burning. I thought about another patient who was misdiagnosed and actually had a fungal infection. So I wondered whether this patient with CCCA wasn't getting better because she also had a fungus infection. In fact, she did prove to also have a fungal infection. So if you are still having symptoms, other causes have to be considered. A fungal culture can make sure there isn't a fungal infection present. Another patient was allergic to some of the ingredients in her shampoo and conditioner, which we established with patch testing. So with persistent symptoms, think about other things that could be irritating the scalp externally and may not be part of the disease.

Dr. Vera Price

It is interesting you mentioned your patient with CCCA and a fungal infection. I had a similar experience with a patient with scarring alopecia who was under good control and then developed severe scalp itching. It was out of character with what we could see. It turned out her little granddaughter had a fungus infection of the scalp. We then looked for fungus and in fact the grandmother had a fungus infection on her scalp as well. So it is important to keep other things in mind.

Dr. Lynne Goldberg

I had a similar story with a patient with scarring alopecia. A colleague asked me, "Why are you doing a biopsy? It looks neutrophilic." Even though the patient had a neutrophilic process, the slide showed a fungus, which is curable.

Dr. Ethan Lerner—from the audience

Ultraviolet light is used to treat psoriasis. Many patients with psoriasis have itching. When phototherapy is used for psoriasis, the first thing that gets better is the itching. That is also what we've noticed in using phototherapy to treat several patients who have LPP and one patient with folliculitis decalvans. The symptoms of pain, itch, and burning improve. (Some of these patients say that their hair has come back in some areas that were not completely scarred and two of them stopped wearing hairpieces.)

Cicatricial Alopecia “Tips and Tricks”

Patients’ Suggestions

These ideas were generated by participants and volunteers at previous CARF conferences (held in San Francisco, Minneapolis, Washington, D.C., and Los Angeles) and from emails to CARF. While CARF is not advocating the use of any specific products, we support patients helping and learning from each other.

Use Topical Treatments and Shampoos to Address Itching, Scaling, and Inflammation

Limit the itching often associated with cicatricial alopecia via the use of products such as Moroccan Oil, Emu Oil, Tea Tree Oil, Sarna Ultra Anti-Itch Lotion (Stiefel), and Jason Aloe Vera Conditioner. Neutrogena’s T/Sal Shampoo can help limit scaling, as can the use of scalp brushes and vigorous shampooing, though some don’t tolerate this. Head and Shoulders Intensive Solutions (with 2% Pyrithione Zinc) was recommended by a CARF volunteer because it is very slippery so there’s hardly any friction to pull out hair; plus, it helps with itching and helps control dry scalp itching. Others recommended shampoos with dimethicone for conditioning hair.

One patient likes Nature’s Gate Tea Tree Calming Shampoo (available online at www.natures-gate.com). She has also had significant success for more than 8 years in limiting her hair loss and other cicatricial alopecia symptoms. She attributes this, in large part, to daily topical applications of the prescription Tacrolimus 0.1%, compounded in Cetaphil Moisturizing Lotion, and dispensed in plastic dropper bottles capped with a soft, smooth rounded tip with a small opening.

Look Stylish and Cover Hair Loss

One patient recommended a styling iron she uses to style her hair to cover areas where she’s experienced hair loss: Infiniti by Conair® You Style Multi-Functional Styling Iron (available at www.conair.com). Also, check out the National Alopecia Areata Foundation (NAAF) website (www.naaf.org), which includes links to almost 20 headwear sites. One of the sites listed is www.4women.com. Alopecia patient Susan Beausang, who has alopecia universalis, founded the site, on which she sells a variety of products, including patented headscarfs (the “BeauBeau”), designed for women coping with hair loss. Another of the NAAF “marketplace” sites, recommended by a CARF conference attendee, is Doma Designs. During online checkout at any of the sites found via NAAF’s marketplace, make sure to type “NAAF” in the code box, so that NAAF will receive a 10% donation from vendors.

Consider “Cosmetic Options” for Covering Hair Loss

A variety of products exist that help in “camouflaging” hair loss, including keratin protein “hair-thickening” products, hair powders, and concealing color products (in both cream and “crayon” form). See CARF’s “Cosmetic Options” handout.

Enhance Your Eyebrows and Eyelashes

We have several patients’ recommendations to fill in—or create—eyebrows. One patient recommended Smashbox’s “Brow Tech” product to fill in brows, a combination of brow wax and brow powder (www.smashbox.com). Another patient at the Washington, D.C. conference demonstrated the use of Ditzzy Cosmetics press-on stencils and fiber-infused powders to create a water-resistant “fix” (www.ditzycosmetics.com). A Boston patient recommends a Stila eyebrow pen (2 shades, medium and light). It has a fine, soft tip that allows hair-like brushstrokes that give a more natural appearance than tattoos. It stays on well and is smudge-resistant. It is available at Ann Taylor and on several websites including www.sephora.com. Many patients have had eyebrows tattooed with success. But they stress it is essential to have it done by an individual with experience tattooing someone with little or no brows.

The NAAF website (www.naaf.org) includes about a half dozen links to solutions for patients who have lost their eyebrows, among them:

- Beauti-Full Brows temporary eyebrow tattoos (www.beauti-full-brows.com)
- Stamp Me Fabulous® Eyebrow Stamps (with 13 designs and 5 colors) (www.stampmefabulous.com)
- The Brow Creator® press-on eyebrow stencils, which are used with the Natural Effect Brow Palette (brow powders infused with micronized fibers to stimulate hair) (www.ditzycosmetics.com).

NAAF also provides recommendations for those who have sparse (or no) eyelashes (www.lashcard.com and www.cheryn.com). Patients recommended Revitalash eyelash conditioner, IT Cosmetics Hello Lashes 5-in-1 Volumizing Mascara, and Illegal Length Maybelline fiber extension containing mascara.

Cover Up with Hair Extensions or Weaves

Several sources were recommended by CARF conference attendees for hair “additions” to cover sparse or bald areas. One is www.extensions-plus.com, located in Reseda, California, with ready-made and custom extensions available in various colors and textures. Another is “Aspen Additions’ Hidden Circle,” available at various online sites. About 15" long and with 3 clips, the piece can be cut and additional clips added—and the hair used to supplement/camouflage as needed. Ken Paves and Jessica Simpson have collaborated on “Clip-In Bangs” and layered hair extensions, a low-price option using synthetic hair, available via www.amazon.com and www.qvc.com. The [NAAF.com](http://www.naaf.com) site includes about 10 additional sources of wigs, hairpieces and/or extensions.

Another patient covers the area of her hair loss through the use of a hair “weave.” A hair weave is a wiglet custom shaped to the area that needs coverage and kept in place by being sewn into the existing hair. The “weaver” must be skilled in how to choose the anchoring hairs and the angle at which the hairpiece

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Tips & Tricks *continued from page 7*

will “pull” on those hairs. If not done skillfully, more hair loss will occur from tension. Since the weave is attached to your normal hair, it loosens in 3-5 weeks, depending on the rate at which your hair grows. At that time, it is removed and washed. The underlying hair is also washed and cut. Sometimes the weave can be a bit itchy, since the netting sits on naked/scarred scalp. When it is first put back on, there can be tension on the surrounding hairs, which improves in hours to a day. The circle of hair, where it is attached, can be uncomfortable to sleep on at first. A weave is only for an inactive scalp. One can apply liquid medication through the mesh, but the scalp cannot be easily accessed otherwise. Weaves cost ~\$2,400 for the unit and then \$85/visit to have it washed and reapplied. If made of human hair, and colored, it and the person’s natural hair will need color every other visit at an additional charge of ~\$40.

A patient has been successful at having wigs and weaves covered by insurance by providing a copy of the *What you should know about CICATRICAL ALOPECIA* pamphlet from CARF with her insurance claim, and offering her telephone number if there are further questions.

Look into Non-Surgical Hair Replacement

One patient recommended searching online for “non-surgical hair replacement” or “hair replacement skin systems” and the city nearest you. Stylists work with suppliers such as “American Hairlines” (www.americanhairlines.com), which produce hair replacement products (in various colors and textures) on skin-like surfaces that adhere to your scalp, typically using 2-sided tape. Pieces are cut to fit the area(s) where you have lost hair.

Depending on the shampoos and hair products you use (and/or your topical treatments for cicatricial alopecia), your hairpiece may adhere to your scalp for weeks at a time. (Oily treatments cause adhesion problems, and Salex shampoo may cause hairpiece texture problems.) Pieces may be colored to match your hair color, and your hair may be colored while you’re wearing your hairpiece. You may be required to buy a piece of the hair replacement “fabric” that is larger than what you need for the initial hairpiece. This is beneficial if additional/larger hairpieces become necessary. Some individual salons provide these services as do companies such as the HairClub (www.hairclubofficialsite.com), which requires club membership.

Investigate Hair Transplantation and/or Scalp Reduction

In limited cases, cicatricial alopecia patients whose hair loss has been dormant for two to three years may be candidates for hair transplantation and/or excision of the scar tissue. Possible transplantation candidates must have normal, healthy hair in the donor area(s) and, possibly, surgery to reduce or eliminate the scarred area(s) prior to transplantation of follicular units. In other cases, surgery is performed to remove the scarred scalp tissue and transplantation is not necessary.

Insurance companies may be resistant to covering the cost of scalp reduction and/or transplantation surgery, and may require documentation from a physician that the surgery is for reconstructive, rather than cosmetic, purposes. Even if covered by insurance, out-of-pocket costs may still be significant (e.g., thousands of dollars for scalp reduction surgery alone, performed on an out-patient basis). Ongoing hair loss may occur in cicatricial alopecia patients after the surgery and/or transplantation.

If you believe that you are a candidate for hair transplantation and/or scalp reduction surgery, speak with a dermatologist who specializes in hair loss for his or her opinion as to your suitability and (perhaps) for a referral to a qualified specialist who is experienced in performing surgery and/or transplantation on cicatricial alopecia patients.

Limit Inflammation

At present, we know that cicatricial alopecia is an inflammatory condition; however, we don’t know its cause(s) and there is no known cure. Providing you with this information is NOT meant to convey that, by following these dietary and lifestyle suggestions, your cicatricial alopecia symptoms/hair loss will be reduced. While it is not certain that an “anti-inflammatory diet” has ANY effect on the body’s ability to fight inflammation, the suggested changes may improve your overall health!

- Don’t Smoke. Cigarette smoking contributes to chronic inflammation.
- Exercise. Regular, moderate to intense exercise can have long-term anti-inflammatory effects.
- Reduce Stress. “High levels of stress hormones can lead to the release of excess inflammatory chemicals.” (www.mercola.com) Regular exercise, yoga, tai chi, visualization exercises, progressive relaxation, meditation, and biofeedback may be helpful in lowering stress.
- Get Enough Sleep. “...Research has shown that both too little and too much sleep increases inflammation. The American Academy of Sleep Medicine says most adults need between seven and eight hours of sleep each night.” (www.mercola.com)
- Watch Your Weight and Eat “Anti-Inflammatory Foods.” Realize: Excess fat is pro-inflammatory and so are many foods.

Among “anti-inflammatory foods” are (www.dlife.com):

- Coldwater fish (e.g., salmon—especially wild salmon—sardines, tuna)
- Grass-fed beef and other animal foods
- Olive oil, especially EVOO
- Salads
- Cruciferous vegetables (e.g., broccoli, cauliflower, Brussels sprouts, kale)
- Cherries
- Blueberries
- Turmeric (also included as part of curry spice blends)
- Ginger
- Garlic
- Green tea
- Consider the benefits of a “Mediterranean-style” diet, based on fruits, vegetables, nuts, and olive oil, boosting anti-inflammatory omega-3 fats. (www.mercola.com)

continued on page 9

Tips & Tricks *continued from page 8*

Consider Supplements and Herbs/Spices That May Help to Fight Inflammation

- Zyflamend, from New Chapter, is the #1 selling natural supplement and contains a combination of herbs found to be beneficial in combating inflammation: rosemary, turmeric, ginger, holy basil, green tea, hu zhang, Chinese Goldthread, barberry, oregano and Baikal skullcap.
- Other supplements including Omega-3 fatty acids, Vitamin A, Vitamin C plus bioflavonoids, Vitamin D, Vitamin E, and Grape Seed Extract are thought to have anti-inflammatory properties. Other herbs that may help address inflammation (in addition to those mentioned above) include curcumin, boswelia, oregano, ginger, cayenne, basil, marjoram, and cinnamon.

Seek Support and Inspiration

Attend a CARF support group meeting in your area. Check the CARF website for upcoming meeting dates and locations (www.CARFintl.org). There are groups throughout the United States, Canada, and England. If there is no Support Group in your area, call CARF and START ONE! Allow yourself to be inspired by fellow alopecia patients: “Crowned Regal” (Annette Moore)—check her videos on www.youtube.com—and Sandra DuBose-Gibson (www.myalopeciaexperience.com), the 2011 Mrs. Black North Carolina and a former CARF conference inspirational speaker.

One Last Tip

And if none of these suggestions seems appropriate for you (or even if they do), you might want to infuse your life with a little humor. This magnet says it all: “You can’t control everything. Your hair was put on your head to remind you of that.” (<http://minalestudio.com/products/magnets/cant-control-everything>).

And, Love the hair you’re with!



Save the date!



CICATRICIAL ALOPECIA RESEARCH FOUNDATION

6th International Patient-Doctor Conference

Embassy Suites Chicago Downtown Lakefront Hotel

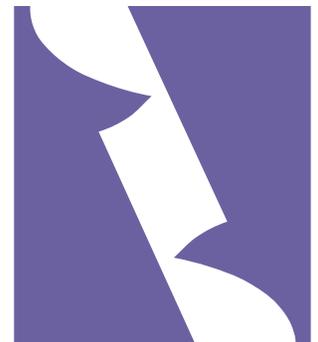
Chicago, IL, USA

Friday-Sunday, April 4-6, 2014



Please mark your calendars and plan to attend the CARF Patient-Doctor Conference scheduled for April 4-6, 2014, in the magnificent city of Chicago! Additional details will be forthcoming later in the year on the website and in e-blasts, including how to register, hotel information, program topics and speakers, and social activities being planned. We found an excellent hotel in a great location in the heart of the City—next to the Chicago River, restaurants, and shopping. We negotiated a fantastic rate for our attendees!

The CARF Chicago Patient Support Group, CARF staff and volunteers and Board of Directors are all eager to welcome you. We hope you plan to attend.



C . A . R . F .

Cosmetic Options for Covering Hair Loss

Toppik	<ul style="list-style-type: none"> • Hair-thickening, color-matched, organic keratin protein fibers intertwine with your own hair to conceal hair loss. • Atomizer available for applying for a more natural appearance. • Available in 7 colors (Auburn, Black, Blond, Dark Brown, Light Brown, Medium Brown, Gray) and White. • Needs surrounding hairs to keep in place. • Comes in 3 sizes: 1 month, \$20; 75 days, \$40; 150 days \$70. 	www.toppik.com
Nanogen	<ul style="list-style-type: none"> • Similar to Toppik: Needs surrounding hairs to keep in place. • Available in 9 colors (Black, Dark Brown, Medium Brown, Light Brown, Auburn, Cinnamon, Dark Blonde, Blonde, Grey) and White. • \$20 for 1 month supply; cheaper in bulk. 	www.nanogenhair.com
Organin	<ul style="list-style-type: none"> • Similar to Toppik: Needs surrounding hairs to keep in place. • Available in 8 colors (Black, Brown, Light Brown, Medium Brown, Dark Brown, Ash Blonde, Dark Blonde, Light Gray). • \$20 for 90 day supply. 	www.folica.com
DermMatch	<ul style="list-style-type: none"> • DermMatch colors your scalp to match your hair color. • Rub the product on, then brush it through. • You can rub it into completely bare areas. • Also coats and thickens thin hairs, making them stand up and spread out for maximum fullness. • Available in 7 blendable colors (Platinum Blonde, Silver-Grey, Red, Light Brown, Medium Brown, Dark Brown, Black) and White. • Stays on when swimming, sweating, raining (per website & reviews). • Can use in conjunction with Toppik or Nanogen. • \$30 for 1 disk; lasts 4–6 months. 	www.DermMatch.com
CRC Concealing Color	<ul style="list-style-type: none"> • Colored cream you rub into bare or thinning areas. • Can buy brush applicator for fading effects. • Available in 6 blendable colors you paint or rub in: Grey, Beautiful Blonde, Ravishing Red, Rich Brown, Golden Brown, Deep Black/Brown. • Also comes as Quick Touch applicator, available in all colors above, except Grey. • Water-resistant, but washes out with shampoo. • \$28.50 for 1.5 oz; lasts 2–3 months. 	www.crclabnyc.com
Shapley's Show Touch-Up	<ul style="list-style-type: none"> • Aerosol spray used on show horses to hide imperfections. • Will not rub off, stays on in rain and water (per users). • Available in 8 colors (Black, White, Sorrel, Chestnut, Medium Brown, Dark Brown, Palomino, Gray). • \$10 for 12 oz can. 	www.smartpakequine.com
Bumble and Bumble Hair Powder	<ul style="list-style-type: none"> • Adds volume to surrounding hair. • Can be used on areas with no hair. • Available in 4 colors (Black, Brown, Red, Blondish) and White. • Can be messy when applying (apply before dressing!). • Can be expensive (\$20 for 1 oz, \$35 for 4 oz) 	www.folica.com
Salon Grafix Powder Shampoo	<ul style="list-style-type: none"> • Similar to Bumble and Bumble Hair Powder. • Available in 4 colors (Brunette, Blonde, Black, Silver). • Less expensive: \$8 for 4 oz. 	www.salongrafix.com
Tween Time Haircolor Touch-up Stick	<ul style="list-style-type: none"> • Hair "crayons" made by Roux, available in various colors (Auburn, Ash Blonde, Ash Brown, Black, Blonde, Light Brown, Medium Brown, Dark Brown). • Shampoos out. • Available at beauty supply stores and at various online sites. • Approximately \$6.50–\$7 per touch-up stick. 	www.amazon.com
Streaks 'N Tips Hair Color	<ul style="list-style-type: none"> • Temporary hair spray. • Available in Black, Brown, White, Blonde. • Available online and at beauty supply stores. • \$5 for a 3.5 oz can. 	www.store.hello-gorgeous.net

Resources on the Impacts of Inflammation—and Strategies to Reduce It*

Donna Dreher Weaver

The Anti-Inflammation Zone: Reversing the Silent Epidemic That's Destroying Our Health by Barry Sears, PhD (2005). From Amazon.com, “Dr. Barry Sears is recognized as one of the world’s leading medical researchers on the hormonal effects of food.” From www.a1nutrition.com, “Dr. Sears was a research scientist ... Boston University School of Medicine as well as the Massachusetts Institute of Technology. His primary focus of study has been lipids.”

The Inflammation Revolution: A Natural Solution for Arthritis, Asthma & Other Inflammatory Disorders by Dr. Georges M. Halpern (2005). According to online sources, Georges Halpern, MD, PhD, DSc, is Professor Emeritus of Medicine and Nutrition, University of California, Davis, and is/was a Visiting Professor in the School of Traditional Chinese Medicine, University of Hong Kong. He is the author of many books.

The Complete Idiot’s Guide to the Anti-Inflammation Diet by Christopher P. Cannon, MD, and Elizabeth Vierck (2006). From Amazon.com, “Christopher P. Cannon, MD, is an associate professor of medicine at Harvard Medical School. In addition to being a frequent lecturer, Dr. Cannon has published more than 500 articles, reviews, editorials, book chapters, and electronic publications in the field of acute coronary syndromes. Elizabeth Vierck is a well-known, widely published author on aging, health and related topics, with 16 books and numerous other publications to her credit. (See also *The Complete Idiot’s Guide to Anti-Inflammation Cookbook* by Elizabeth Vierck and Lucy Beale.)

***Please note:** This list of books was created by Cicatricial Alopecia Research Foundation (CARF) patient and volunteer, Donna Dreher Weaver, to serve as a preliminary resource for those wanting to learn more about the issue of inflammation. Providing you with this list is not meant to convey that, by following the dietary and lifestyle suggestions in these books, your cicatricial alopecia symptoms will be reduced. At present, we know that cicatricial alopecia is an inflammatory condition; however, we don’t know its cause(s) and there is no known cure.

REPRINT REPRINT

14 Ingredients to Avoid

Tuesday, April 21, 2009 at 6:32AM Dr. Weil

Retrieved from Natural Health Information <http://www.drweilblog.com/>

The Anti-Inflammatory Diet: Tape This List to Your Fridge!

An important step in creating a healthy kitchen is to read and understand food labels. When you begin restocking your pantry, food labels are your best resource to assess what to keep and what to toss. This practice will also give you an overview of your choices in the supermarket, and is a good starting point to modify your shopping habits. Use the list below to determine which items to discard. Many of these ingredients are considered pro-inflammatory and therefore unfavorable to healthy aging. If the list of ingredients contains one or more of these undesirables, toss and don’t buy again!

- Animal fat, such as lard
- Artificial sweeteners or non-nutritive sweeteners
- Coconut oil
- Corn oil
- Cottonseed oil
- Fractionated oil
- High fructose corn syrup (HFCS)
- Hydrogenated or partially hydrogenated oil or vegetable shortening
- Margarine
- Palm or palm kernel oil
- Blended vegetable oils
- Safflower oil
- Soybean oil
- Sunflower oil

Note: High-oleic versions of sunflower or safflower oils are acceptable, as they have fatty acid profiles closer to that of olive oil.

REPRINT REPRINT

Review of Women of Color Hair Loss Symposium—March 18, 2013

Achiamah Osei-Tutu, MD *Brooklyn, New York, USA*

Overview

The 1st Annual Women of Color Hair loss symposium was held March 18, 2013, at the Wellington Hair Spa in New York. The purpose of this symposium was to discuss and educate women of color about the various causes of alopecia and to provide tips about proper care and hair loss prevention. There were approximately 40 patrons in attendance including patients with hair loss, hair stylists, and physicians.

After attendees had a chance to mingle and socialize, Drs. Achiamah Osei-Tutu and Naana Boakye began the symposium with scientific lectures and a discussion of non-scarring and scarring alopecias. Next, a talented group of hair stylist from New York City and Brooklyn shared tips for healthy scalp and hair. They focused on hair grooming practices and styles that can help to avoid hair breakage and alopecia. They also discussed hair styling options once a patient starts losing her hair. There were many questions from the audience for the dermatologists and the stylists, and many myths were dispelled. There were several questions regarding naturopathic approach to hair loss (essential oils, effects of diet, etc.), and a lot of concern was displayed as to the paucity of more definitive answers to the etiology and management options for alopecia, particularly for Central Centrifugal Cicatricial Alopecia (CCCA).

At the symposium, attendees learned that it is estimated that hair loss affects over 20 million women. Because hair is considered one of the most important and defining aspects of the human experience, hair loss or alopecia often has adverse psycho-social effects on self-esteem and identity. There are many types of hair loss, some of which disproportionately affect women of color. Many studies have suggested that hair-grooming practices may contribute to and exacerbate various kinds of hair loss in women of color. The physicians noted that they see many patients with alopecia, but often they find it difficult to convince a patient to adjust her hairstyle in order to save her hair and treat her scalp. In addition, many patients are unaware of the impact that their lifetime grooming practices, among other factors, have on their hair loss.

There are looming questions surrounding the causes and treatments of alopecia. Unfortunately, there are limited research funds allocated to this area. Donations to the Cicatricial Alopecia Research Foundation and the North American Hair Research Society were encouraged. These are the organizations dedicated to hair loss research and education.

Symposium Speakers

At the symposium, attendees were able to listen to the following speakers:

- Dr. Achiamah Osei-Tutu, Owner of Osei-Tutu Dermatology, Brooklyn, New York; Co-Owner Bergen Dermatology, Englewood Cliffs, New Jersey
 - Discussed the basics of hair biology and scarring alopecias including current evidence based understanding of pathophysiology and treatments with focus on CCCA.
- Dr. Naana Boakye, Co-Owner Bergen Dermatology, Englewood Cliffs, New Jersey
 - Discussed non-scarring alopecia including current evidence based understanding of etiology and treatments.
- Patrick Wellington, Owner of Wellington Hair Spa, New York, New York
 - Discussed the importance of a good hair cut.
- Sophia Emmanuel, Crown worthy Trichology Studio, New York, New York
 - Discussed tips for keeping hair healthy while relaxed, including how and when to use heat on chemically processed hair. She is also a trichologist and explained her field and how she works with the dermatologist.
- Natasha Paul, Owner of Evolution Green Room Salon, Brooklyn, New York
 - Discussed tips for keeping hair healthy while transitioning from relaxed hair to natural curls. She also discussed options for styling naturally curly hair to maintain scalp and hair health.
- Sabine B, Owner of Sabine's Hallway, Brooklyn New York
 - Discussed tips for those interested in wearing locks and braids; including how to create and maintain styles with decreased levels of tension.
- Tish Celestine, Owner of LaBelle Boutique, Brooklyn, New York
 - Discussed tips for those interested in wearing weaves, including how to create and maintain styles with decreased levels of tension and the importance of limiting the time that hair is weaved.
- Penny James, Owner of Penny James Hair, Brooklyn, New York
 - Discussed wig options for patients who have significant hair loss.

Until Next Year

Adding some excitement to the event, raffle prizes were awarded and gift bags given that included beauty bags, makeup sessions, and discounts on hair salon sessions. On completion of the program, many attendees requested additional similar events, connections were made, and all parties learned a great deal from each other.



more photos on page 13

*From the camera's eye:
March 18, 2013
Women of Color Hair Loss Symposium*



NAHRS Scientific Session in Miami during 2013 American Academy of Dermatology Annual Meeting

Nicole Rogers, MD *Metairie, Louisiana*

In March, members of the North American Hair Research Society gathered to have their business meeting and update each other on various hair-related research projects during the American Academy of Dermatology meeting in Miami. Recipients of the 2013 NAHRS Mentorship Grants were announced, including Dr. Yolanda Lenzy, who will study with Dr. Antonella Tosti at the University of Miami about techniques in hair and scalp dermoscopy as well as dermoscopy for cicatricial alopecia. Eight other awards were given to study other non-cicatricial hair loss disorders. Dr. Vera Price was recognized for her Lifetime Achievement Award to be recognized through the Dermatology Foundation Annual Meeting the next day.

Dr. Rox Anderson, Professor of Dermatology at Harvard Medical School, the Director for the Wellman Center for Photomedicine, Massachusetts General Hospital, and Adjunct Professor at M.I.T., spoke about the use of low level light therapy (LLLT) for treating various hair diseases. The mechanism of action of LLLT is still unknown exactly. However, Dr. Anderson discussed how LLLT can potentially rescue cells from hypoxia, ischemia, oxidative stress, and apoptosis. Light appears to release nitric oxide from surrounding cells, which can result in vasodilation of the nearby arteries, according to Furchgott's phenomenon (published in the journal *Nature* in 1963). This may possibly explain the mechanism by which hair growth seems to improve with LLLT. (Topical minoxidil is also a local vasodilator.) Although one device (the HairMax Laser-Comb®) has obtained 510K FDA clearance for treatment of male and female pattern hair loss, Dr. Anderson discussed how the technology has probably still not been fully optimized. Variations in wavelength, exposure time, and pulsing of the light may offer even better results than are presently being shown.

Dr. Angela Christiano, Professor of Dermatology and Genetics & Development at Columbia University, described her latest research in alopecia areata in a lecture entitled, "Translational Genomics in Alopecia Areata." She presented exciting results from her work with the Genome Wide Association Study (GWAS) showing a strong link to the NKG2D-activating ligand. These NKG2D+CD8+ T-cells were found to be the dominant phenotype in active alopecia areata cells. She demonstrated that these cells were necessary and sufficient, producing large amounts of interferon- γ to cause the disease in mouse models. She also identified two different medications (tofacitinib, a JAK-3 inhibitor, and ruxolitinib, a JAK-1 and -2 inhibitor) that were able to prevent alopecia areata in mouse models, as well as to reverse disease in mice with long-standing alopecia areata.



Drs. Rox Anderson and Angela Christiano

CONGRATULATIONS!

We are proud to announce that at its
2013 Annual Meeting on March 2, 2013,
the Dermatology Foundation presented:

Vera H. Price, MD

LIFETIME CAREER
EDUCATOR AWARD



Scientific Advisors Report on CARF Happenings

Rita Wanser, Chairman of the Board; Victoria Ceh, MPA, Executive Director; Melanie Stancampiano, Associate Executive Director

As a result of her ground-breaking research, Pratima Karnik, PhD, CARF Scientific Advisors Chairman, has been added to the “Rare Disease Research Hall of Fame” through the National Organization of Rare Disorders (NORD). Congratulations to Dr. Karnik on this honor!

In other exciting scientific news, in early March, over 20,000 medical and industry professionals gathered in Miami for the American Academy of Dermatology (AAD) Annual Meeting. At this time the brightest minds met to learn about the latest research and innovations in the field of dermatology, including hair loss disorders.

In attendance was a special group of medical professionals, the CARF Scientific Advisors, who met and reported back on two very important items:



Pratima Karnik, PhD

1. CARF has an interest in funding studies aimed at determining the prevalence, incidence and natural history of cicatricial alopecia.

A rare disease is defined as any disease or condition that affects less than 200,000 persons in the United States, or about 1 in 1,500 people.

Cicatricial alopecia is often referred to as a rare disease however there are no published studies on the prevalence (a measure of the total number of cases of disease in a population), incidence (a measure of the number of new cases per population per year), or the natural history of disease (description of the uninterrupted progression of a disease in an individual).

The Scientific Advisors agreed that these are important areas of research and should be funded by the CARF pilot grant program.

2. TEACH & OUTREACH PROGRAM: How to educate dermatologists to better diagnose cicatricial alopecia.

At the last patient conference, patients expressed concern about having to go to three or four dermatologists before they were accurately diagnosed. Discussion at the Scientific Advisors meeting focused on how to better teach or do outreach to dermatologists about diagnosing cicatricial alopecia. CARF will be exploring options to partner with larger dermatology-focused organizations, such as the AAD, as well as community partners, such as churches and salons, to spread information about cicatricial alopecia.

We look forward to bringing you continued updates on these important projects.

Help Fund Cicatricial Alopecia Research Today!

We are thrilled to report that CARF has received a recordbreaking number of research proposals for 2013. The Scientific Advisors are busy reviewing these proposals and selecting those most worthy of CARF funding. We need your help so that we can increase the number of research projects we fund this year!

Please consider making a donation, of any size, to help us fund additional proposals in 2013. By May 31st, we hope to raise an additional \$70,000 for research; we have a good start, but a long way to go.

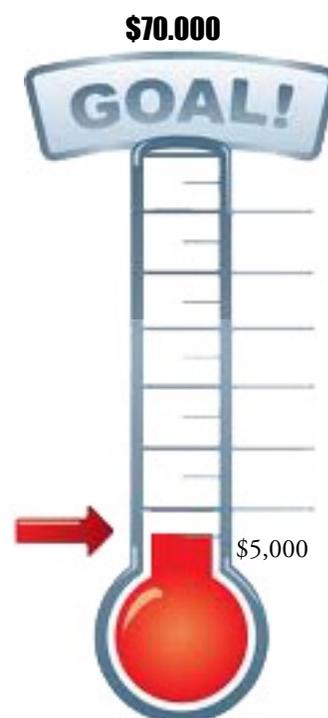
We hope that each of our CARF subscribers, including you, will make a donation to this special cause. Don't have much extra money to donate? Know that even the smallest of donations can make a difference. Every single dollar counts, and will be put toward this year's research grants. Here are a few ideas on how you can contribute:

- Skip your morning coffee stop, or pack a lunch, and donate the money you would have spent that day.
- Ask friends and family to make a contribution in your honor, for your birthday, etc.
- Host a dinner party and ask guests to donate in lieu of going to a restaurant for dinner.

You can donate by visiting <http://www.carfintl.org/donations.html> or by sending a check to:

Cicatricial Alopecia Research Foundation
 c/o Technical Registration Experts
 303 West State Street
 Geneva, IL 60134, USA

If sending a check, please write “Research Funding” in the memo line. **THANK YOU!**



Volunteer Focus: Laurence Spector

Nicole Rogers, MD *Metairie, Louisiana*

Laurence is 32 years old and lives in Manhattan where he specializes in real estate development. I caught up with him while he was at the gym (take the hint, the guy is smart—and in shape!) and we talked for almost 45 minutes. He works for an apartment real estate development company called Archstone. Interestingly, he has lived in Washington, D.C., Chicago, and Philadelphia, where he went to school. He has degrees from Northwestern (college) and Wharton (business school). Laurence is a CARF leader, donor, and volunteer, but he began his involvement just as a patient. He was initially diagnosed with cicatricial alopecia at age 25. From here we begin the interview:



Q: How did you initially handle your own diagnosis?

I have red hair. People always called me “Red.” I’m the redhead in a crowd, which made it easy to find people and meet people. Part of the challenge of dealing with this condition was that I didn’t know where I began and my hair color ended. [Laurence stated that he developed the condition when he was under severe emotional stress. This experience was not unlike others patient experiences he had heard about.] I think stress can play a major role in the onset or the exacerbation of this condition. A friend recommended yoga. I was initially against it but found the breathing techniques to be relaxing. I also encourage others to explore the benefits of therapy or talking about one’s condition in a CARF support group. I was once inspired by a panelist at a CARF conference in 2006 (Minneapolis), who told us: “Your hair is very important, but you are not your hair. It is a part of you, but the hair does not define you.”

Q: When did you first get involved with CARE?

I found out about CARF on the Internet because I was a patient and there was no information about the condition except for on the website. I went to see Dr. Vera Price in San Francisco and she encouraged me to attend the CARF Patient-Doctor conference. My first one was in Minneapolis in 2006, and it made a big difference. When I first found out I had CA, I was a total wreck and couldn’t process the information. I feel like CARF helped me approach it in a healthier way.

Q: Can you tell me about your role as a support group leader?

I run the New York support group, and we have had two meetings since August 2012. I started the group after I had lived in several places around the country, working in real estate development. New York City is an interesting place for a support group because it is so close to patients in New York State, New Jersey, Connecticut, and Pennsylvania. Dr. Jerry Shapiro agreed to serve as medical advisor and NYU Langone provided a conference room at the Department of Dermatology. The thing I really like about the support group is that patients just want to talk, and this gives them an outlet. They want to be heard. By splitting the group into teams of 3 people, everyone has more “air time.” I write down questions to challenge people, and they take turns answering them. For instance: Is it possible for me to have a positive self-outlook, even with cicatricial alopecia? I then let them talk, say 5 minutes each. Then we switch people so everyone has their turn. Soon we will be doing a program sponsored by Spencer Forrest, so everyone will be able to try Toppik samples to camouflage their hair loss.

Q: At what point did you make the leap from a member to a leading volunteer?

I want to be the person that sees a need for something and is willing to jump in and address it. If I can create the momentum then hopefully other people will create their own support groups and participate. I see how much it helps the newly diagnosed. I was once one of them! Helping other patients made me feel better. I also think that helping other people is a natural human path to fulfillment. I liked creating a platform for people to express themselves. I knew I was helping them find access to resources and improve their emotional health.

And, as I learned more and went to more meetings, I realized this was a tricky problem and there weren’t a lot of answers.

Q: How have you kept up your motivation as a volunteer over the years?

Seeing other people benefit from my work, and knowing I am helping to grow CARE, because I know that is helpful to other people. I have also been motivated by the physicians and patients involved with CARF who I have worked with over the years.

Q: How did you decide to make your generous donation for the door prize of hotel room nights for the Boston Patient-Doctor meeting?

I donated 2 nights in San Francisco, California, or Key West, Florida. These hotel rooms were part of a package that also included two flights. I have an MBA degree, so I see a lot of value in something that costs \$700 but brings in added revenue of \$4,000-\$5,000 for the organization. Dr. Ken Washenik of Bosley provided the flights that went with my donated the hotel room.

Q: What would you say to other patients who are considering getting involved with CARE?

Definitely do it. It will really benefit them in ways that they cannot imagine! I hope people reading this will start a support group in their area. We have a lot of resources, and people might be surprised how much interest there is. We have 15 members so far in New York (while the weather is cold) and I expect our numbers to grow as the weather warms up. The CARF website will list the support group and CARF can do mailings to patients in their database in the support group’s target area. We send a reminder every 2 weeks up until the day of the event.

I think about ways to improve the meeting, make it efficient, and also about what people want to get out of it. I do a survey afterward and make a summary of the discussion to send to patients afterward. Because we only have limited time, it’s important that the support group provides the maximum benefit. We also have Dr. Achiamah Osei-Tutu, a dermatologist in Brooklyn who sees a lot of African Americans in her practice, attending our meetings. We ask patients to submit questions for the physicians in advance. The doctors can then prepare and answer comprehensively.

We wrapped up the interview with a promise to meet up either in New York (for one of his support meetings) or here in New Orleans (for one of our support meetings). I was glad to hear he likes New Orleans and hope we can share a po’ boy or some raw oysters next time he is in town!

SUPPORT GROUP NEWS

Report from New York City

Laurence Spector, Patient Support Group Co-Leader

We had a very successful 2nd meeting of the CARF New York City Patient Group, which was held on February 20, 2013. We are fortunate to have Dr. Jerry Shapiro of NYU Langone Medical Center as advisor to our group! Dr. Shapiro also serves as Director of the University of British Columbia Hair Clinic and is a member of CARF's Board of Scientific Advisors. (Our meetings are held at NYU Langone Medical Center in Manhattan.)

I am happy to report the tremendous reach of our group, with patients traveling from four surrounding states—New York, Pennsylvania, New Jersey, and Connecticut—to attend our meeting. We look forward to seeing you at CARF's next patient support meeting in the New York area! Please email newyorksupportgroup@carfintl.org if you have any inquiries about future meetings or would like to get involved with our New York patient program.

Our meeting began with a 45-minute-long Q&A with Dr. Shapiro, who covered a lot of ground with a list of questions submitted by attendees in advance. The remaining time was spent on several patient discussion topics. I have learned that it's helpful for patients to talk about their feelings with each other so we split into smaller groups to allow for more discussion time. We talked about the possibility of a positive outlook with cicatricial alopecia and asked participants about the effect on their self-esteem. There was also 15 minutes of patient one-on-one discussion time.

We were also fortunate to have Dr. Achiamah Osei-Tutu, a dermatologist based in Brooklyn, New York, who treats many patients with cicatricial alopecia, with an especially large concentration of patients with central centrifugal cicatricial alopecia. Dr. Osei-Tutu organized the "Women of Color Hair Loss Symposium," which met on March 18, 2013 in New York and is reviewed on page 12. For more information, please visit her website, www.osei22derm.com.

Also in attendance was hair stylist Penny James, who provided input on hairstyles and cosmetic products. In future meetings, we will have more product samples and provide additional cosmetic resources for patients.

A special thank-you...

Thank you to Spencer Forrest for supporting CARF by supplying samples of Toppik for our support groups. The NYC Patient Support Group on June 12, 2013, at the NYU Langone Dermatology Department, will focus on "Hair Products Discussion for Patients with Cicatricial Alopecia." Toppik samples will be provided to patients to take home along with other selected hair products. I personally use the light brown and I find it to be very effective as well as match my hair color.



CARF needs your help...

PATIENT SUPPORT CONTACTS

Are you interested in speaking with patients and helping others? We need a group of volunteers who can speak with newly diagnosed patients who call or email headquarters requesting to speak with someone who has cicatricial alopecia. Marilyn Ey has accepted the position of Coordinator for the Patient Support Contacts workgroup, and she will be orientating and assisting new volunteers with the activities of this workgroup, which focus on providing emotional support to these new patients.

We are looking for volunteers who have a sense of understanding and acceptance about the challenges of their own disease, have developed their own supportive coping strategies and skills, and have a general understanding about the different types of cicatricial alopecia. The frequency of the calls can vary between 1 or 2 per month to 1 or 2 per week. If you can share some of your time and experience to help these patients cope with and work through their emotional circumstances, please contact (need to insert the contact information here for the Admin Center). We need you and the patients need you!

If you are interested, contact info@carfintl.org.

SUPPORT GROUP NEWS

Reports from New Orleans

Debbie Shaver

Louisiana Support Group Paints the Night Away!

The CARF Louisiana Support Group met in January at the home of local artist and group member, Elayne Kuehler. After a busy and stressful holiday season, the group decided to have a fun and relaxing break, and started the New Year with their own version of a “Corks N Canvas” meeting. For those of you not familiar, Corks N Canvas is fast becoming a nationwide rage as friends and co-workers gather to paint together under the guidance of a group art leader. The fun is often enhanced with a little wine or spirits that patrons can bring from home and enjoy while in the studio!

Each member started with a blank canvas, brush in hand, and dabs of bright, primary colored paint. Elayne provided beginning words of instruction, and then encouraged all to have fun and be creative! The image she selected for us to paint was a beautiful sunset over the water. It was interesting to watch how each novice painter started—timidly mixing colors, stroking, dabbing, questioning—and how each progressed as the afternoon passed. Painting and creating art can be a good way of distracting our thoughts from stressful situations; and although it won't solve problems we are dealing with, it can help put them into perspective and reduce anxiety.

Elayne proved to be a gracious and patient teacher, and at the end of the afternoon, everyone came away with their own original painting and a satisfying feeling of accomplishment. Group members enjoyed the friendship and support and look forward to their next meeting in April, which will be about relaxation techniques and will be led by a local yoga instructor and therapist.

Dr. Nicole Rogers, physician advisor to the group, was available to answer questions and provide medical updates.



Fran Swan



Elayne Kuehler assists Debbie Shaver



Geraldine Ward

Elayne Kuehler, Patient Support Group Co-Leader

We had a really wonderful meeting on Sunday, April 14, 2013. We had many new members at the meeting. Our program included Suzanne McCann who gave us exercises and information on relaxation. Suzanne and her husband own Insights of New Orleans and they are located in Metairie, Louisiana. She concentrates on Focus, Balance, and Wellness. Some of us may have actually fallen asleep during the exercise itself, she was so effective. Suzanne is a registered Yoga teacher and therapist as well as an Ayurvedic Practitioner, among other accreditations. We are all very grateful to her for her suggestions and enjoyed her presentation very much.

Our next program—Cosmetic Tips and Tricks—is scheduled for Sunday, July 14, 2013, at 3:00PM, so mark your calendars. The location is yet to be determined, so watch for more information to follow.

It was a wonderful event and I look forward to getting to know everyone better and seeing you all at future meetings.

SUPPORT GROUP NEWS

Report from San Francisco

Marilyn Ey, Patient Support Group Leader

Participants

At the April 2, 2013, Bay Area Support Group meeting, Drs. Ingrid Roseborough and Vera Price joined 18 patients for a lively and informative discussion. The patients represented both lymphocytic and neutropilic cicatricial alopecia. Seventeen patients had either FFA, CCCA, or LPP; 1 woman with cicatricial alopecia also had alopecia areata, an unrelated hair disorder; and 1 patient had tufted folliculitis, one of the neutrophilic cicatricial alopecias.

Every person introduced herself or himself and shared with the group. Emotions ranged from tear-filled eyes to laughter. After the meeting, one new attendee said she felt connected to the group, especially with the patient who shared her hairpiece experience. The new attendee was warmed by a patient's brother who donated to CARF every Christmas. Donations such as this one allow CARF to help thousands of patients worldwide. For such a rare disease, it is vital to provide accurate information. Please consider making copies of the CARF newsletter articles to share with your doctors and hair stylists. Your effort will make a difference.



Stress

Patients reported that stress management was key to limiting flare-ups. A patient with tufted folliculitis shared how quickly stress seemed to flare the scalp. As Dr. Price reminded us, "Stress doesn't help any disease." So put a smile on your face, find happiness, exercise, do yoga, relax... or do whatever reduces your stress. Enjoy life and kick stress out the door.

Wigs

One patient recommended trying on wigs in stores before purchasing. For good advice, take a friend along who values you. Once you decide on a wig, check to see if it is available online for less money. Make sure the online version is the same length of hair as the store wig. Before buying, learn about the store's return policy or lack of one. To prevent your wig from being ruined while exercising, use a wig liner to absorb sweat. Each liner is good for about 7 days, and costs around \$25 for a pack of 10.

Soothing Suggestions

To reduce itching or that "on fire" feeling, apply an ice bag. Sometimes taking an antihistamine reduces itching. Alternating two or three shampoos may be helpful. Some found tea tree oil shampoo soothing, others did not.

Appreciation

Dr. Price thanked several attendees who donated scalp biopsies for research. Those who volunteered biopsies told the group they didn't feel any pain! Dr. Price hopes other patients will volunteer to donate scalp biopsies. As a direct result of molecular studies done by Dr. Pratima Karnik on previously donated biopsies, a deficiency of PPAR-gamma was found in some of the lymphocytic cicatricial alopecias. This has led to using an FDA-approved PPAR-gamma agonist in treating lymphocytic cicatricial alopecias, which has been a major contribution to our available treatments.

In addition, several women present at the Support Group were given special recognition because they had attended the world's first cicatricial alopecia support group in San Francisco, as well as the first Patient-Doctor Conference.

Spotlight On... Marilyn Ey



Marilyn Ey is our valued CARF patient liaison. CARF receives daily emails from patients who are newly diagnosed and need help adjusting to their symptoms and individual treatment. A long-time CARF volunteer, Marilyn calls patients referred to her and shares her insights so they no longer feel alone. Her goal is to help them accept their disease of cicatricial alopecia so they can begin the emotional healing process.

Marilyn knows the importance of reducing stress, citing the important advice of Dr. Vera Price: "Stress doesn't help any disease." Wise words indeed, especially for this challenging condition. It is crucial to let patients know that this isn't a life-threatening situation, but it is their unique disease and it's normal to be angry and ask, "Why me?" However, it's not okay to stay this way and let the disease win.

Marilyn has helped hundreds of patients with her counseling and shared first-hand experience. She is the co-leader of the San Francisco Support Group and you can look forward to meeting her at our CARF patient-doctor conferences.

Letters to the Editor

I have been styling hair for 30 years and sadly over the last 10 years, I have seen more and more of my younger clients with hair loss. This led me to undertake a two-year training program to become a Trichologist to have a better understanding of what causes hair loss and how, as a hairstylist, I can help my clients with hair care treatment or recommendations for a CARF dermatologist.

I was shocked to learn how dismissive hairstylists are to the words “hair loss” when I attended the New York CARF Support Group meeting. My goal is to be able to offer a private environment at my salon for conciliation and hairstyling ideas that hide thinning hair, including wigs and hairpiece options that clients can easily maintain at home.

Penny James
30 E 60th Street
New York
pennyjameshair@gmail.com

Dear Friends,

Great news: Earlier this week the Skin Advocate app hit the milestone of having been used over 10,000 times.

That's right—the app has now been used over 10,000 times to refer patients to your organizations.

I am preparing to post about this on social media including Facebook and Twitter, and if you all respond to this, we can amplify the publicity for all of your organizations.

So please make sure of the following:

1. **Your organization is following the Skin Advocate app on Twitter. Search for @SkinAdvocate.**

Then, when I tweet about the 10,000 referrals, you will be ready to Re-Tweet this to your followers and increase publicity to get others to refer people your organizations.

For those of you who are on Twitter, Please feel free to personally follow @SkinAdvocate and ask your members to do the same!

2. **You join the Skin Advocate Facebook group.**

Then, when I post the 10,000 referral news on Facebook, your organization can “Like” it and repost on your Facebook pages.

If we all can be ready to take action in concert, we can really amplify the effect!

Please let me know if you have any questions,

Best,
Shadi

A. Shadi Kourosh, MD
Department of Dermatology
UT Southwestern Medical Center
Dallas, Texas
Phone: 972-672-0726



Join the eScrip Program to Help Fund CARF Research

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



To select CARF, go to www.eScrip.com and indicate us as your beneficiary. (CARF's Group ID # is 500020699.) Funds generated with your purchases will support CARF's ongoing patient support, patient education, and research to find better treatments and a cure for cicatricial alopecia.

CARF is a proud participant of Rare Disease Day
(<http://rarediseaseday.us/>)



RARE DISEASE DAY USA
ALONE WE ARE RARE. TOGETHER WE ARE STRONG.

Rare Disease Day is the last day of February each year, so the 28th—or the 29th, coming from when it lands on leap year being a "Rare Day."

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 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: Contact losangelessupportgroup@carfintl.org

San Francisco: Contact Marilyn at sanfranciscosupportgroup@carfintl.org

ILLINOIS

Chicago: Contact Joe and Bev at chicagosupportgroup@carfintl.org

LOUISIANA

New Orleans/Baton Rouge: Contact Debbie & Elayne at neworleanssupportgroup@carfintl.org

MARYLAND, WASHINGTON DC, VIRGINIA

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

MASSACHUSETTS

Boston: Contact Melody, Doreen, & Joyce at bostonsupportgroup@carfintl.org

MICHIGAN

Detroit: Contact Virdell at detroitssupportgroup@carfintl.org

MINNESOTA

Minneapolis: Contact Maggie at minneapolisupportgroup@carfintl.org

NEW YORK CITY

Contact Laurence and Ilene at newyorksupportgroup@carfintl.org

International Support Groups

CANADA

Toronto, Ontario: For more information on this group, contact info@carfintl.org

UK

London: For more information on this group, contact info@carfintl.org

Manchester: Contact Annete at manchesteruksupportgroup@carfintl.org